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**Choice: What, when and why? Exploring the  
importance of choice to disabled people**

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## Introduction

Extending choice and control for disabled and older people over public services is central to current policies in England. The overall government vision is to create a high quality personalised system which would enable people to live their own lives as they wish, and be responsive to their individual requirements for independence, well being and dignity (Putting People First, 2007; Department of Health, 2008). To this effect, Government proposals published in three policy documents during 2005 (Cabinet Office, 2005; Department of Health, 2005; Department for Work and Pensions, 2005) and the White Paper 'Our health, Our care, Our say' published in 2006 were introduced to foster a major transformation in public services in the community.

The emphasis on recent policy objectives around personalisation and nurturing greater self-directed support is not a new idea. It is occurring in a policy context initiated by demands of the disability movement for increased independence and control (Barnes, 1993; Campbell and Oliver, 1996; Priestley, 1999) and influenced by long-term demographic factors, particularly population ageing; and economic pressures to meet increased public expectations and contain the costs of long-term care by maximising value for money from public expenditure on services.

Measures to increase choice include extending take-up of direct payments to people with parental responsibility for disabled children, disabled people aged 16 or over and to carers aged 16 or over; and Individual Budgets, first piloted in 13 local authorities between 2005 and 2007 and rolled out as personal budgets across all English local authorities between 2008 and 2011. In addition, personal health budgets are planned to be piloted in the NHS in summer 2009. Building on what works with direct payments, Individual Budgets were introduced to give the individual more choice and control over resources by bringing a number of income streams together and create a more joined up package of support. The principle underlying such policies is that the greater the choice public service users have, the more empowered they become and that in turn encourages better quality services and maximises welfare gains.

There is a body of literature that criticises consumerist approaches to public services, as they may result in inequitable outcomes for some newly empowered individuals (Lent and Ardent, 2004; Clark *et al.*, 2005; Schwartz, 2004). Nevertheless, in relation to social care and personal support, there are strong arguments that giving people choices leads to enhanced well being and therefore is the way forward. Choice is important in enabling disabled people to achieve their desired outcomes from services (Vernon and Qureshi, 2000;

Rabiee *et al.*, 2005); it is central to conceptions of independence among older people (Parry *et al.*, 2004); and it is intrinsically linked to other key principles of citizenship and human rights. As Morris (2006) points out 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.

However, it is still not clear whether choice works the way the government expects and indeed whether everybody would want to exercise it once they are given the opportunities. Moreover, choice may be highly problematic and have distinct significance for certain groups of disabled and older people, for example, people with on-going, complex and multiple changing needs for support and people whose condition is unpredictable and fluctuating. Within the context of interdependency that characterises many disabled and older people (Morris, 1991; Shakespeare, 2000; Lloyd, 2003; Fine and Glendinning, 2005), one person's choice may have implications for other people around them (Arksey and Glendinning, 2007) influencing the choices they make. In addition, where resources are limited, 'choice' may be perceived to be simply a question of accepting the 'least bad' option (Boeije *et al.*, 2003). Therefore, while in principle maximising opportunities for choice sounds like a sensible idea, translating this new vision into reality is challenging and would require a good understanding of what choices are important, for which groups of people and in what areas of their life. Without this knowledge such policies may not live up to their potential to achieve welfare gains.

This paper reports from an ongoing qualitative longitudinal study to investigate the realities of exercising choice about support and other related services in the context of changing circumstances, as experienced by disabled and older people and their families. The paper presents findings from our first round of interviews with respect to the priorities and importance that those participating in this study attach to specific choices in different areas of their lives and their reasons for it.

## **Research methods**

Ethics approval was obtained from an NHS research ethics committee. Three groups of people, all likely to experience changes over time in their circumstances and/or support needs were recruited to the study. This included: 27 young people with degenerative/progressive conditions (between the ages of 13 and 21), 34 parents, 50 adults and older people (age 25 and above) - 30 with fluctuating support needs and 20 experiencing the sudden onset of health

deterioration. In a number of cases parents were interviewed but they did not want their son/daughter to participate. In one case parents declined to take part but the young person did participate. There is considerable diversity within each of these groups of participants in terms of gender, ethnicity and household composition.

Participants were recruited from a wide range of organisations, including: specialist/condition-specific voluntary organisations and support groups; hospitals, local authority adult care services departments; minority ethnic community groups; an independent recruitment agency; children's hospices, the Family Fund Trust and 'snowballing' from other study participants.

Qualitative data were collected through semi-structured interviews with the participants. Nine of the young people and one of the adult participants had limited speech and were interviewed using 'talking mats' (Murphy, 1998), a visual framework using symbols to help people with communication difficulties to communicate. Data from these interviews was more general and focused on specific choices people had made and is not reported here. Interviews were tape 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 subsample 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 were then used to draw the data together and identify overarching themes and conclusions. Conclusions were verified by checking with transcripts and through ongoing discussions within the research team.

## **Key findings**

We asked the study participants whether or not choice was important to them, over which services and why. This was not an easy question for some participants, firstly because of the abstract nature of the question and secondly because not everyone in our sample had a great deal of relevant experiences to draw on. While we had detailed responses from adults, older people and parents, the disabled children themselves found the questions harder to answer.

Many interviewees across all groups felt it was important for them to make choices in all areas of their life. Just as healthy people could aspire to all choices relating to them, disabled and chronically ill people should also be given the opportunity to make their own choices, rather than being presented with a

'fait accompli'. However, they felt that in reality there was an assumption that because someone is disabled he/she is unable to make choices. A few people felt more disabled by not being able to take control of their daily activities (i.e. making decisions) than by not being able to do everything for themselves (i.e. executing decisions):

I don't see me as sick, I see me as disabled, and there are some places where I'm disabled that I can't affect, but there are some places where I'm disabled and I can affect it, like whether or not I'm clean. I may not, I may be disabled in that I can't wash myself, but the only real disability is if I don't get washed.

[AS 125]

A number of participants whose health had deteriorated suddenly said they were shocked to find out how limited their choices had become since they first became unwell. It seemed to them like there was an expectation that by becoming disabled, people had to give up their choices and adjust constantly to fit into the services. However, they felt that their life had become difficult enough without them having to change who they are. A number of parents said the choices they were able to make over services was often no more than 'taking or leaving' the only option available. Many interviewees said having control over choices surrounding them made them feel healthier and more independent.

Among parents many were concerned that as their child got older they would become side lined in decisions made for their disabled child. However, they felt that even when their son or daughter looked mature, they would still need a lot of support to communicate their preferences especially where the child had learning difficulties and communication problems. A number of parents felt it was more important for their disabled child to have choice than for parents because it affected the child's daily life:

'She relies on someone for all her personal care and to take her wherever ... so I think it is quite important from her point of view to at least have a choice of where she's going or who's taking her or what they're gonna do. I think it gives her that little bit of ... it's part of her dignity I think. It's, it's her dignity's quite important to her.'

[YP 019 P]

The findings show that while many interviewees highlighted the importance of being able to make choices in all areas of life, the way they prioritised different aspects of choices differed between different age groups and also depended on the nature and severity of their condition, their previous experiences with services, and their family circumstances. The following sections summarise the

service domains where having a choice was considered important and the reasons why.

## **Healthcare**

Healthcare was the service area that adults, older people and parents of disabled children identified most frequently as being important to exercise choice and control in. In general, being able to choose one's doctor, to change the doctor if not happy with the service and to maintain continuity with a doctor were important to most participants. Parents felt this was particularly the case as it can take a child a long time to build up a relationship with people. While there were some common feelings among the participants as to what outcomes they would want to achieve from their health care, and in the case of parents, the health care of their disabled child, namely to be healthy, there were a wide range of views in the choices participants wanted to exercise in relation to where to have treatments and what treatments to have.

### **Where to have treatments**

Ideally most study participants across all groups wanted to have a good hospital close by, but they felt having good quality health care services was more important than having a choice about the location of their healthcare. However, with regards to some health services most people wanted choice over facilities that were physically accessible. For example, a few older interviewees talked about the importance of using a GP surgery either near their home or somewhere on a bus route. Others felt the choice of a local respite/rehabilitation unit would be important for the benefit of other people visiting the person. One person said he would prefer to go to a specialist hospital for major treatments but he would be happier to have physiotherapy at a place easy to get to as he felt they all provided the same standard of care.

The choice of having healthcare delivered at home was important to a number of interviewees, particularly older people who wanted to have their family around them. An Asian lady explained that what made it uncomfortable for her to go into hospital were communication problems caused by language and cultural barriers, e.g. staff not understanding her religious needs of wanting to pray. A few people who had to be hospitalised quite regularly because their condition made it difficult for them to cope with infection, did not like to go into hospital because of the fear of picking up more serious infections in the hospital

wards. Loosing choices in the hospital environment was another reason why some interviewees wanted to avoid going into hospital:

'... I hate going in to hospital ... and my consultant obviously agrees with me to some extent, because he knows if I go in I'm likely to pick up something worse, because there are all these cross-infections on the respiratory ward ... I just hate losing my choice. Cos if I'm in hospital I can't choose when I eat and when I sleep and when I go and walk round and when I don't, I hate the fact that I lose my choices when I go into hospital, and although I'm very sick, I still want to make my own choices.'

[OF-200]

One person who had refused to go into hospital when she had pneumonia, also because of the fear of infection, felt that she was saving money in the long run, yet she received no visit from nurses to check on her. A number of participants with chronic respiratory conditions thought hospitals should have an early release service to allow patients to receive as much of their treatment as possible from a specialist team of nurses in their own home.

Study participants who had experienced a sudden onset of a disabling condition, in particular, prioritised a good quality service and a shorter waiting list over hospital location. A few people said living in the 'wrong' NHS Trust area sometimes meant having to wait for weeks before they could see a doctor. They would be much happier if they were given a choice of seeing a doctor more urgently but had to travel to get there. Interviewees' personal experiences and the information they had about hospital performances influenced their choice of hospital. A stroke patient, who was conscious when taken to hospital by ambulance, was given a choice of two hospitals he could go to, the local general hospital or the specialist hospital which was further away. He decided to go to the specialist hospital he had known about:

'... If I'd have been unconscious they'd have taken me to [local hospital] but because I was conscious they took me to [specialist hospital further away] ... I don't think I would have got as far as I have if it hadn't have been for the places I went to ... everybody there had been trained specifically for stroke patients ...'

[AS-130]

For parents of children who used multiple services the important choice was having all the care delivered to their child in one place. They thought this would facilitate communication between the health professionals and lead to a better quality of care for the child.

## What treatments to have

In general, most interviewees with fluctuating conditions who had lived with their condition for years felt that their experiences with making previous choices had made them expert patients who knew how to make good decisions for themselves. While they all valued having professional advice, informing them of the possible options and side effects, they also wanted to be able to use their previous experience in making similar choices about their health. For example, one person who had suffered from the side effects of standard drugs for many years talked about how the use of the complementary health care helped her not only to control these side effects but also substantially reduce the number of drugs she used to take. Another person who had experienced repeated operations said she would prefer, wherever possible, to have a local anaesthetic to a general one in order to minimise the risk of after effects she had experienced in her previous operations. These findings suggest that people with long standing conditions may be able to acquire a wider range of personal and experiential information to support choice:

'... I had the choice of three medications to start with and ... they told me which one would probably be beneficial to me the most. ... But no that wasn't the way I saw it ...it's my body, I'm going to decide what I'm going to do ... So I did and I had a bad reaction to the other two as well, so.'  
[AF 101]

Evidence from this study also suggests that choice is conditional and circumstance specific, that is the way people weigh up their options about what treatments to have is very much coloured by their own circumstances at the time. So, for example, a drug that is seen to be too risky at one time may be considered as a risk worth taking at another time if the condition becomes very uncomfortable for the person to tolerate and/or if the person feels more informed about the possible risks. For example, one parent delayed the decision to go on a drug which would relieve her pain but made her very drowsy until her children started full time school. For some participants reducing the risk of ending up in hospital was the overriding factor that led them to choose to go on a drug which they would otherwise consider too risky.

In contrast, interviewees who had experienced a sudden deterioration of their health were more likely to say that they simply wanted 'the best' and would be happy to accept less choice in areas they did not know enough about and/or when they were not well enough to make decisions for themselves. They felt professionals were in better positions to make choices for them:

'[I am] not in favour of all this choice business ... when you're ill you need people to make choices for you ...I simply want the best. I don't want ... to make choices where I don't have the information myself as to how to make a decision ... that's up to the experts, to decide, not me ... the only reason why you'd want a choice would be if you weren't satisfied with, with what you were getting, you would like to have a choice to change it ....'  
[OS-214]

Not many children and young people talked about the importance of choice in relation to their healthcare. Those who did said that the decisions about their healthcare were taken by the hospital and their family members. They were happy with the decisions made for them but they wanted to have more of a say in their healthcare when they got older.

## **Equipment**

Equipment was the second biggest area of services that adults and older people identified as being important to exercise choices in.

### **Concerns for independence**

Almost all adults and older study participants said that their illnesses removed many choices from them (for example, having to use a wheelchair) but there were still choices they wanted to make with regards to the type of equipment they used. First and foremost, they wanted equipment to be suitable for them and responsive to their demands for independence. There were examples where people were given equipment that they could not use independently.

Eligibility criteria sometimes limited interviewees' choices about what equipment to use and when to use them. For example, one person said she could still manage at home without a wheelchair but did not feel safe to go out without one. She asked for an assessment but felt this did not accommodate her circumstances as she could not easily be categorised as 'dependent' or 'independent', as defined by the eligibility criteria:

'I've already had people just give me things that didn't work or tell me I can't have, they said "You fit the criteria for a wheelchair so we'll give you a self-propelled chair, but physically you cannot self-propel a chair because it's your thoracic spine, but you don't meet the criteria for an electric wheelchair which means we can't give you one. So 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".'

[AS-125]

## Concerns for identity and self-esteem

The findings also showed a clear link between choice and identity. Adults and older participants wanted to avoid stigma felt to be associated with being labelled 'disabled' and 'old'. A number of people noted that occupational therapists were only concerned about what equipment people needed with no due regards for how they felt their lives would be affected by it. For example, one person said that she decided to buy a commode from eBay because the ones provided by the NHS 'makes your house look like a hospital'. Some preferred a stair lift to a ceiling lift, as they felt the latter would make the house look like a disability house.

Adults whose support needs fluctuated particularly valued choices that enabled retention of their identity as a non-disabled person as long as possible. One person explained how at first she was very resistant to the idea of using a wheelchair because she thought it would reduce her self-esteem, make other people see her differently, and possibly make her even more dependent:

'... when she [OT] first mentioned me having a wheelchair I was absolutely furious because, you know, I was saying to her "Don't you realise I'm trying to do as much as I can for myself, if I get a wheelchair I might as well give up" ... the important thing that swayed me was her saying it was about choice ... I don't have to use it all the time but it would be here for when I needed it, and this fits in with my fluctuating condition ... when I'm fit and able I don't have to use it.'

[AF-105]

For many interviewees the timing of when to have the equipment was a crucial factor. Those who had experienced a sudden onset of a condition in particular wanted to have the equipment as and when they needed it rather than having to wait weeks, months and sometimes a year for something to happen. There were a few examples where OTs had advised older people to apply for equipment they did not yet need on the grounds that they would need it by the time it was delivered. Not everybody was happy with the idea. This is how one person responded to applying for a stair lift before she needed one:

'I ... said no, only because of ... pride I think, for a better word. ... The layout of the house, I felt I'll be an old woman, just, a stair lift, you can't get

away from it no matter where you, well sitting here you don't see it, but any other time it's there all the time, and I just said no.'

[AF 100]

Lack of choice, either because people could not have what they wanted when they needed it or they did not like what social services offered them, often made people purchase equipment privately.

## **Housing and adaptations**

Most adults and older interviewees argued that choice was important in relation to their housing and home environment because it could lessen their need to ask for help on a daily basis. Living in a bungalow or a ground floor flat; having wide doors and corridors; having accessible kitchen and bathrooms were desired options for most people. A few older participants said that their family felt they would be better off going into a residential home, but they preferred to live independently as long as they could manage. In general, living in the centre of town where people could access facilities easily and living near relatives were the desired options identified by some older interviewees. For a number of parents what was important was to live in an area where their child had access to a social life.

Planning ahead for future housing needs was particularly important to interviewees with fluctuating support needs like MS who wanted to be prepared before their condition deteriorated more. Many felt that housing choices were often constrained because of professionals' lack of understanding of the unusual way certain conditions present themselves. For example, one person with MS living in rented accommodation had asked for a ground floor flat as she knew she would soon find steps difficult to manage. She said that her application was not accepted because at the time she did not appear to have had any problem with managing the steps. She had to provide medical information about her condition, before her application was reconsidered.

Interviewees who owned the property they lived in said that their choice of housing had been affected by their current or future anticipated needs. Other interviewees wanted to be able to make similar choices before they became more frail. Many people valued having adaptations that not only enabled them to live more independently, but also took into account their preferences. Several interviewees felt that there was a big expectation that disabled people would compromise when using services. Someone who had recently started using a wheelchair said she needed a kitchen where she could get under the units. She

said social services had designed her a 'disability' kitchen which was only suitable for someone who lived on pre-cooked food which only needed warming. She felt that was not the style she had been used to, neither did she feel eating like that was good for her Crohn's Disease. She decided to have her kitchen converted privately in the way she wanted. Others were concerned about having their house turned into a 'disability' house they would find difficult to sell.

## **Education/training**

Parents talked about the importance of being able to make choices about their child's education. Having a choice over their child's education was not so much about the choice of mainstream versus special school but whether it was the 'right' school - one that was best suited for the child in the long term. Concerns about safety and physical accessibility, access to health care support, inclusion in school activities and staff attitude were among the key factors parents talked about when making choices about schools. Parents of children with deteriorating physical conditions felt that their child's choice of school was often restricted to a special needs school because of child's need for adapted environment, even though it would not meet the child's academic potential. The 'right' choice would be for the child to be in a mainstream school which had all the adaptations needed. On the other hand a few parents felt they were pressurised to put their child in a mainstream setting. With hindsight, they regretted the decision because it appeared that it was not in the long term interest of the child and their child's needs were not met there. They had to move the child a few years later. All parents highlighted the importance of being able to make informed choices but felt that they often did not know what options were available for them.

Most parents felt that having limited choices in the education system for their disabled children made families either accept what they were offered, or pay for an alternative. One parent reported that bullying was a big issue in her child's school but the child did not have the choice of going elsewhere because there was no other suitable school available:

'I think life's hard enough for him and going to school's is hard enough ... and then if that [bullying]'s going in school, it puts him off, from going really'  
[YP 013 -P]

Parents with dependent children felt that their choice of training was limited by the lack of affordable child care support. A single mother suffering from MS,

with caring responsibilities for a child who also had an unpredictable condition, said that she had to give up her training and with that her desired career option after her mother passed away because she could not afford the specialised child care support that was available. She felt the only way she could do the training she felt so passionate about, and which would also enable her provide a better future for her children, was if she had access to a network of support both for herself and for her son's needs. This is what she said:

'... they say that university is adult learning so you're going in there, you should have made your choice already, so if you forfeit whatever you're supposed to do, that, that's your fault because you knew when you were coming in what was expected of you ... there was no support for adult learning ... you'll always need support as long as you're learning, but university doesn't see it that way'.

[AF 122]

For adults with fluctuating conditions having access to part time training was said to be a key factor in supporting their education. A number of adults felt that more than one realistic option was needed for there to be a choice. So where, for example, education was the only option available, the desired choice could well be not to take it. As one person put it:

'where I go, what kind of advancement I have, what kind of a salary I have depends on that, so of course I want to have a choice ... I don't want to be told you can only take education if that's not what I want to do'.

[AS 125]

## **Social care**

Not all the people interviewed received social care services. However, in principle having choice and control over flexibility, timing and who delivers the support were important to most interviewees. A few people reported that this was only possible when social care was provided by private agencies rather than local authority in house services:

'... they [social services] sent us a list of ten people and said "You can't choose whether or not you have a male or female carer ... they had to send whoever came. They wouldn't give me the specific hours ... there really was no choice, well there was a choice to make, ... the choice was either take what you're given, no matter what it is .. or adapt.'

[AS 125]

Study participants also valued having some choice and flexibility in the tasks the carers were able to undertake. Quite a few people mentioned their carer was only allowed to do things they were quite capable of doing themselves like making a drink, warming up food and washing up. Instead they wanted their carer to vacuum and give them a bath or shower rather than a wash.

The lack of choice had led some people to give up the home care service allocated to them either entirely or for part of the day. Many said the timing they were allocated for the carer to visit them did not suit them. This was either because they were early risers and they were up, dressed, and had breakfast (though with great difficulties) by the time their carers arrived, or they had carers to put them to bed but sometimes they were not ready to go to bed when their carers turned up, or the carers arrived couple of hours after they had gone to bed.

The lack of flexible options had led a few interviewees to turn to their partners for social care support. While this often gave people the flexibility they required, a number of people said they made the choice unwillingly because they were concerned about the likely impact this would have, both on their family life in general (e.g. by the partner having to give up their job) and on their personal relationship with their partner. One person said she had lost certain choices since her husband became her carer:

'I used to take a shower every day, I don't get to take a shower every day now ... I had to amend those expectations ... like he said "I like washing your hair but I don't like going to work smelling like fruit salad, could we use a different shampoo?" because, you know, so there were lots of things that we had to look at as part of that decision making process.

[AS 125]

Many wanted to be able to built up a relationship with their carers but felt this was not possible because they were getting different carers. For some people being able to stay with the same carer was even more important than having a choice about who the carer was. This was particularly important for interviewees who had acquired a sudden health condition, who were going through a new learning experience. They needed continuity to help them adjust to a situation they were not familiar with:

'... everything is new to me and it's adjusting, and for them, of course for them to adjust to my needs. They don't know what I need, I don't know what I need. So it's trial and error and it has been, and it has been, and I've been supported by my social workers and every avenue I, I can't, I'll not say it's been easy for either of us.'

[AS 117]

Both children and parents felt maintaining continuity with the carer was important as it often takes a long time for the child to feel comfortable with a carer.

'... It's mainly my everyday cleansing and things like that, cos I'm very particular about how I do things and that's why I only have carers that I've known for a while because they know how I do things, so obviously like my mum's done me for like all my life and I've known my Carer No.1 [college] for, well she used to be at my High School as well, so I've known ... her for about six years, so. But other than that I just tend to make decisions for myself, as many as I can, to give me independence, so.'

[YP 006 Y]

Evidence from this study also suggests that there are often tensions between choices involving a trade off between adapting to new circumstances and maintaining identity. For example, an adult with a fluctuating condition explained how difficult it was becoming for her to wash her long hair. She approached an OT for help and this is what happened:

'... "My hair is heavy and thick, I struggle to wash it" she [OT] said "well cut it, make it short" I said "I've always had long hair" and she said "Yeah, but it'll be easy to take care of it if it's short" I said "Yeah, but that's not me, why do I have to be somebody other than me?" It's like when you're sick they take away who you are and it's not right ... I can't cut it, you know, cos then it would just make me more depressed about what I've lost ... I didn't want to be any more disabled than I already was, I didn't want to feel like I need to cut my hair or become somebody else, I wanted to stay me. ... Nobody said "Do you have trouble getting that done".'

[AS 125]

## Employment

The importance of having choice in relation to employment was raised by the working age adults. They associated employment with their financial security and were concerned that having to take time off work would threaten that security. Ideally, they wanted to be able to choose flexible jobs and work for employers who understood their conditions and were sympathetic to their needs. Interviewees with fluctuating conditions such as MS were particularly anxious about their employer's lack of understanding of their condition and how it affected them. Some people reported they had to change their hours from full time to part time and sometimes tried different jobs, but it was still not working

for them so they 'chose to give up work'. Quite a few participants felt that doing a voluntary job or doing a job 'you would not dream of doing' otherwise, were their only real options.

The interviewees who had experienced a sudden onset of a condition and had to take a long time off work were quite anxious about losing their jobs, either because their employers would not have them back or because of difficulties in adjusting to the work environment. A few people felt it was the support they had from their employers that enabled them to return to work. One person who had lost a leg in an amputation said:

'... My company were always saying, your job is there for you when you want to come back, as and when, and they were still saying this, this is not up to you, you know, you come back for a couple of days and then you decide that it's too much, we will still support you on long-term sick ... so there is absolutely no pressure and, you know "If you're tired, go home, don't sit there and, you know, so you can't get yourself home."  
[AS127]

## **Leisure and transport**

The importance of having a choice over what leisure facilities to use and where to go was raised by the participants from all the study groups. Interviewees with dependent children felt keeping up such activities would contribute to the well being of their whole family. However, they thought choices were often limited by lack of accessible, suitable and affordable facilities. People who had more recently become dependent on using equipment such as a wheelchair or oxygen concentrator felt they had lost choice in pursuing some of the activities they previously enjoyed because they could not access the same places. For example, an older person who had to use oxygen told us she was prevented from staying at a hotel because the hotel considered her oxygen concentrator a fire risk. She thought that would not have been more risky than using it at home and so she decided to take it there without letting them know:

'... I'm not going to be prevented from going on my holiday to the hotel that I've always gone to just because, but you shouldn't have this. I mean some, a lesser person would say "Oh well I just won't go any more" and that's sad, you shouldn't be discriminated against because my oxygen, of course it's not dangerous, it's, and it's not going to bother any of the other guests.'  
[OF 200]

Another person who had recently started using a wheelchair described her new experience:

'... you have to adapt constantly, you have to be really flexible and if you get put into a position where you can't adapt or can't be flexible and you've got no option ... [it] just destroys you emotionally ... we went to the theatre ... the only disabled seating they had required the wheelchair to face the row rather than the stage. So I had to turn my body, which I don't do well, to watch the show, which meant that by the time I got home I couldn't move ... so I just had to be hurt, and when you face that all the time you become very hostile and angry or you become apathetic and you just cease to engage and people have value and if they start being apathetic, what value is there...'

[AS 125]

Participants' leisure choices were restricted further by the availability of the transport system they had access to (e.g. Dial-a-Ride). A few people mentioned that the transport they used was reluctant to take them to places that were not local but had more facilities. People also wanted to have control over the timing of transport. Older interviewees wanted to get out more but for many this was only possible if they had access to door to door transport. Parents of disabled children felt quite restricted in where they could go and what they could do as a family. Lack of disabled toilet facilities was said to be one of the main restrictions. Parents also wanted to have access to respite centres that had nursing cover. Without that it did not feel like a break for parents.

## **Discussion and conclusion**

Almost all respondents interviewed in this study supported the principles of choice, control and flexibility. They felt that having choice is important because it helps improve health and maintain independence. It also helps to retain a chosen identity and life style. Last but not least, respondents thought choice is important because it helps maintain interdependent relationships within the context of care giving situations.

In principle, participants highly valued having choice – but only so long as choices were real and able to deliver desired outcomes, that is give people what they want. So, if someone, for example, wants a bungalow and he/she is offered a first floor flat this is not true choice. Or if someone has to eat early when he/she is not hungry but has to do so because the carer has to go somewhere else that is not a choice. Evidence from this study reveals that choices are either not available or are highly restricted and do not include the

options that meet individual preferences and circumstances. Many, therefore, do not count as a real choice.

The findings suggest that while, for many people, exercising choice is important in all areas of life, such as health care, education and housing, the priorities given to choices in different domains vary according to age, the nature and severity of conditions, previous experiences of services and family circumstances. So while, for example, choices in relation to employment are particularly important to working age adults, older people value having choices in transport, and parents of disabled children prioritise choices in education.

The findings highlight the importance of learning over time. Some people can become better at making 'informed' choices over time as they acquire experience of their condition and knowledge of service options. For example, interviewees with fluctuating conditions were particularly keen to exercise choice in the context of their repeated and on going experiences with services. So they wanted to be able to go to the hospital of their choice, even if many miles away from their family and friends, to be treated by the doctor of their choice and have the treatment of their choice. In contrast, among interviewees with sudden onset of disabling conditions, some were more willing to accept less choice in areas they did not know much about or when they were too ill to make their own decisions. In those circumstances, they preferred to rely on 'the experts' to make some of those decisions for them. Further rounds of interviews in this longitudinal study will enable us to track whether the priorities attached to choices in different domains change over time and the factors that shape those changing priorities.

Since 2008, patients have been expected to have the right to choose hospitals. This idea was supported by most participants across all groups. However, the choice of hospital was not necessarily the most desired choice that interviewees involved in this study wanted to make in relation to their health care. Some people wanted to be able to choose complementary care instead of medication. Among the older interviewees, many prioritised receiving treatment at home over going to hospital. Parents of children with long-term conditions wanted to be more in control of how their child's healthcare was managed.

Moreover, the choices people want to exercise are not just about their health care. For example, interviewees with fluctuating conditions felt they had become expert 'choosers', able to make choices over their future housing needs in anticipation of a possible time when their independence might be further reduced. Adults were particularly interested in having access to flexible

employment, whereas for parents having access to a suitable school, one that could meet all their child's needs, was considered to be very important.

The findings also show that more often than not choices are made in the context of care giving and family relationships where the outcomes for more than one person are considered. For example, participants with dependent children strongly felt that having choice over personal care tasks was important, but such choices needed to take into account other family responsibilities as well. As other research has also shown (Beresford *et al.*, 2006), this study revealed a strong link between the parents' own well-being and their children's well-being. Thus, parents need to be well before they can care for their children and equally children's needs have to be met before parents can begin to think about their own well-being. Adults and older interviewees also felt that their circumstances were affecting their partners in many ways and they were concerned about the long term effect this would have both on their partners and on their relationships. Therefore, they felt that whatever choices they had should be extended to other family members who care for them or are being cared for by them.

The findings reported in this paper have important implications for policy and practice and in particular the role of services in addressing the key factors constraining choices. They suggest that current policy mechanisms to increase choice (e.g. hospital choice or direct payments/personal budgets) are relatively crude and may not cover all the areas where choices are important such as housing, leisure, employment and equipment.

Reinforcing the argument for personalisation, the examples provided above give a clear picture of how important and complex 'choice' is. In the practical context, they highlight the importance of identifying mechanisms for capturing choice when commissioning a service as well as illuminating the need for adopting a whole family approach, flexibility to accommodate changing needs and opportunities for planning ahead for anticipated needs. So, while the potential of the personalisation agenda is immense, evidence from this study suggest that for the change to be effective it will need rigorous organisational changes and a cultural shift in developing outcomes focused practices with a clear commitment for user involvement, workforce development and partnership working.

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