
**The use of information by disabled people in making
choices about care and support**

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Abstract

The current policy trend is to encourage greater choice in the use of welfare services. To make informed choices, people need information. The process of finding and using information has costs for individuals in terms of effort, time and material resources. These costs are different for different people and for different support services.

With a growing emphasis on choice, it is important to understand whether or not people have access to information, whether they are presented with relevant information or have to search for it themselves and, indeed, what information people want to help make an informed choice. In social care, for example, personalisation necessitates quite detailed choices being made by service users about the content and nature of appropriate support arrangements as well as the way in which support should be purchased. In other areas, such as housing and employment, people make choices routinely, but for those who are disabled or older, the options can be limited and the accessibility of information more complex.

We have explored individual's use of information in making choices as part of the longitudinal qualitative study 'Choice and Change'. This study is exploring the realities for disabled people of making choices in changing circumstances. Data are being collected over three years through annual semi-structured interviews with up to 100 participants. These participants fall into the following groups: young people with progressive conditions; their parents; adults and older people with fluctuating support needs or a sudden deterioration in health.

This paper uses data from the first round of interviews to consider differences between the study groups in terms of the sources of information used in making choices, the processes of obtaining information, and information that was desired but not available. The reasons why different people accessed different types of information are also explored. The paper concludes by discussing the ways in which service providers need to make information available in order to facilitate choice and how different opportunities for accessing information might affect outcomes.

Introduction

This paper considers the use of information by disabled people in making choices about their care and support. Considering the use of information by different people and across different services is complex due to the enormous range of issues that people want information about and the equally wide range of methods by which they source information (Sykes *et al.*, 2008). However, there is a growing emphasis on encouraging choice in the use of welfare services and, to make informed choices, people need information. Information may also expand and make transparent the options available to individuals and thus act as a stimulus for access to services (Thiede, 2005).

Accessing information for making choices, and indeed choice itself, may be highly problematic for people who are disadvantaged; who may not be knowledgeable or articulate; or who have multiple or on-going needs for support. In social care, for example, personalisation necessitates quite detailed choices being made by service users about the content and nature of appropriate support arrangements as well as the way in which support should be purchased. To find relevant information, people need to be determined (Glendinning *et al.*, 2008). In other areas, such as housing and employment, people make choices routinely, but for those who are disabled or older, the options can be limited and the accessibility of information more complex.

In health care, patients are more likely to make use of information and exercise choice if they are better educated (Fotaki *et al.*, 2008). Patients who access health-related information on the internet have been shown to feel more prepared and able better to participate in decision-making about treatments than those who do not (Dolan *et al.*, 2004). Inequalities such as these could be exacerbated unless information and help for making choices is provided specifically for less advantaged populations (Lent and Arend, 2004; Fotaki *et al.*, 2008).

Fotaki *et al.* continue that, while information provision is a key element of choice, people appear to use published information only in certain circumstances; these include instances where there are single outcomes of major importance, where the data can be understood easily, or where there is no trusted doctor–patient relationship. Age may also affect which types and sources of information are used and when. Reed, Mikels and Simon (2008) studied older and younger adults' preferences for choice making. They presented evidence that older adults seek less information to inform decision making than younger adults; they are also more selective in their information searching, tending to recall more positive than negative information and to set emotional, rather than knowledge-based, goals. Children, on the other hand, may not always be given the opportunity to consider information; in health care decisions, for example, time pressures in consultations can mean insufficient time is devoted to a children's understanding (Coyne, 2008).

Regardless of age, targeted or personalised information is preferred to routine, non-specific information (Baxter *et al.*, 2008; Grime *et al.*, 2007). It is a challenge to provide this information without overwhelming those receiving it. One solution might be to offer expert advice or help in navigating information and support systems. However, fragmentation between the multiple services used by many disabled

people means that professionals may be poorly informed about services outside their immediate remit and therefore poorly equipped to offer relevant information and advice (Grewal *et al.*, 2004). Individual budget holders have made a similar point; they felt insufficient information was available from local authorities to enable them to make choices about home care agencies (Glendinning *et al.*, 2008), indicating that even where professionals might be expected to be able to offer appropriate information, this may not happen systematically (Swain *et al.*, 2007). Alternatively, professionals with appropriate knowledge may choose not to pass it on; evidence suggests that clinicians may do this as they underestimate patients' desire for information but overestimate their desire to make decisions (Lewin *et al.*, 2004).

Thus it is important, in the context of increasing emphasis on choice, to understand whether or not disabled people have access to information, whether they are presented with relevant information or have to search for it themselves and, indeed, what information people want to help make an informed choice. The literature raises further questions which we attempted to explore in our data: do disabled people in different age groups access and use information differently; are differences related to people's support needs or the service areas in which they make choices; how might existing inequalities impact on access to information; and how do complex choices or those that cross service boundaries affect information needs and its accessibility?

This paper presents work in progress. It is based on analysis from an ongoing longitudinal qualitative study 'Choice and Change' which is exploring the realities for disabled people of making choices about welfare support in changing circumstances. The main aim of this paper is to illustrate the kinds of information participants in the Choice and Change study use and to explore some of the reasons why and how information is obtained. After describing the methods of the Choice and Change study and presenting relevant findings, the paper highlights some areas for discussion and others that have been included in a subsequent round of data collection and currently are being analysed.

Methods

Three groups of people likely to experience changes over time in their circumstances or support needs were recruited to the study. They included: 27 young people (between the ages of 13 and 21) with degenerative/progressive conditions; 34 parents; and 50 adults and older people (age 25 and above). Of the adults and older people, 30 had fluctuating support needs and 20 had experienced the sudden onset of health deterioration. In a number of cases parents were interviewed but they did not want their son or 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 *et al.*, 2005), a visual framework using symbols to help people with communication difficulties to communicate. Data from these interviews were more general and are 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. Data were coded with the aid of a computer-assisted qualitative package (MAXqda). 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.

Findings

Study participants selected which choices they wished to discuss. As a result, some topic areas were discussed more frequently than others. Information issues were discussed by participants most frequently in relation to choices about health, education, social care and housing. Information was discussed less often in relation to choices about respite care, employment and equipment; and only occasionally in relation to leisure, transport and diet.

Information around education choices was discussed almost solely by young people and their parents. Adults and older people discussed information issues related mainly to housing choices. Information for respite care choices was discussed only by parents and one young person. Information for employment choices was discussed only by adults and one young person. Within the groups of people with fluctuating or sudden onset of support needs, those with the sudden onset of needs talked more often about information issues around social care choices whereas those with fluctuating needs spoke more commonly about information for health choices.

The similarities and differences in the types of choices being made and the groups of people making the choices are drawn out throughout the remainder of this paper.

Sources of information used in making choices

The main sources of information that participants reported using can be categorised as written, verbal and experiential.

The internet was an important source of written information, in part because it was easily accessible from home and thus removed some of the transport or other mobility difficulties encountered in accessing information from elsewhere, for example, job centres. In addition, it enabled people to check information obtained elsewhere, to look for best and worst case scenarios related to a particular choice, or to get a good grounding in a topic area before talking to professionals. Leaflets were considered useful sources of information but participants felt they were not usually provided soon enough; more often they were made available in response to a

request or after an application for support had been made. Some written information, especially in the form of leaflets or brochures, was considered useful as a point of reference, compensating for the fact that sometimes the amount of information could be overwhelming. A common concern about information from the internet was that sites were not always reliable and there could be too much information to digest, making it difficult to disentangle the good from the poor quality.

Verbal information was obtained usually from professionals, friends and informal experts, and voluntary organisations. The most common professional sources of information included nurses and doctors, social workers, occupational therapists, teachers and the Connexions service. Verbal information was considered hard to remember and participants preferred to have written information as well. Poor communication skills were felt to be unhelpful, but an advantage of seeing someone in person was being able to ask questions at the time, whereas for information given in a leaflet, the effort of finding out further information could be off-putting.

Committed professionals such as specialist nurses were valued highly.

Professionals who contradicted each other, or gave advice that was inconsistent with written information, were not considered useful. Friends or acquaintances who worked in health or social care roles were called upon for informal but expert advice. Many national organisations and help lines, often run by voluntary organisations or the government, were accessed. Help lines were particularly useful for people who found it hard to get out of the house. Participants felt voluntary organisations found relevant information very quickly, but some of the condition-specific information they provided could be hard to digest.

A mixture of written and verbal information was helpful:

I like hearing what people have to say, then I also like reading the facts, you know. There's like, you can have people's opinions but in the end it's their opinions. I also like having the facts in front of me going, you know, this is what's going to happen blah-blah-blah-blah, this isn't, you know, this is what's wrong bang-bang-bang.

[Young person - YP-006]

Experiential information was important also for all study groups. This could be derived from personal or other people's experiences. Some information came from previous experiences that could be drawn upon; others were new experiences created specifically to find out relevant information, such as overnight stays in residential schools or testing equipment. Previous experiences were related often to work, especially for those people who had (or still) worked in health or social care, or to using schemes before, for example Access to Work. Other people, often friends, peers or support groups, were a source of information through sharing their experiences. Sons and daughters were key sources of information for older people. Some information was passed through a third party, for example, nurses describing the experiences of other patients. Similarly, other people's experiences were obtained also from magazines or the internet. Occasionally, hearing about others' experiences was completely opportunistic. For example, a man considering whether or not to have a lung transplant did not know anyone he could talk to who had made a similar choice until an electrician, doing some work in his house, put him in touch with a friend who had had a transplant.

Processes of obtaining information

Participants obtained information through combinations of active and passive means. These were: pro-active searching; chance; prior knowledge; and being provided with information.

Pro-active information searching is about hunting for information. This might be through asking people for information or by searching for other sources of information. Some people created opportunities to gain experiential information. One reason for hunting for information was a belief by some people that they could never have too much information for making an informed choice. These people felt driven by their desire to know more. Others felt equally driven, but by a lack of trust in the information they already had, or in the source of that information. For example, a working age female searched the internet for information about the risks associated with taking a certain drug because she didn't entirely trust the information she'd been given about it from her doctors who she felt were "working with" the drug. Some people felt forced to search for additional information if, for example in a crisis, they were given very little information. Suggestions from other people to think about alternatives or to plan ahead prompted additional searching for information; one example is a teacher suggesting to the parents of a young person that they begin to look two years in advance at their son's post-school options.

Chance information refers to all information discovered unexpectedly. Sometimes, new sources of information were discovered. For example, a working age female found a copy of Disability Times when she was in hospital as an inpatient; she used the magazine's web pages later in her hunt for jobs. At other times, information was discovered and stored for later use, as these parents of a young person explain about their idle chat to other parents at a children's hospice:

Mother: ... it's like a jumble sale of information.

Father: It is really, it's just chit-chat.

Mother: You might not need it that time but then later on you think oh so-and-so, isn't it?

[Parents of young person - YP-036]

Participants with prior knowledge about a subject area or system felt they had an advantage over others in terms of information collection. Prior knowledge usually came from participants' own job-related knowledge or from knowing other people with appropriate jobs or knowledge. Participants who used to work in, for example, benefits offices or as nurses, felt they knew the right questions to ask and the right people to ask. Others had friends who were GPs or nurses who were able to give health-related information, or knew young people who already attended a particular college.

Being provided with information is about being given information without having to ask for it. Often, this is information given by health or social care professionals or is given at a time of crisis. Schools and organisations such as Connexions commonly provided information to parents and young people making choices about education.

Gaps in information

Participants expressed concern that sufficiently detailed information, for example, age-related survival rates after an operation or funding options for young people to attend college, was not readily available. Information was often standardised whereas the preference was for personalised information. A woman in her thirties with arthritis would have liked help with searching for appropriate work:

[The Job Centre] have got enough people that are watching for those that are saying they're unemployed and they're actually moonlighting and getting money from, you know, illegal sources, but what about people like me that do want to work but would like good advice? Not an eighteen year old like pumping into a computer saying oh well this is what you could do. Try and understand me as an individual, you know, that would be lovely, I would feel so relieved if that person came to the door and understood where we were at.

[Adult with fluctuating needs - AF-107]

Similarly, a woman in her fifties who found herself disabled very suddenly felt there was a gap in information about adjusting to being a person with different abilities; she would like to see mentors to help newly disabled people adjust to their circumstances.

Another common concern was that knowledgeable and helpful professionals with the time and communication skills to impart information were not available. Parents of young people in particular felt that they were more knowledgeable than the professionals. In some cases, time pressures and lack of communication can lead to sub-optimal decisions being made. For example, an older man had a stroke. The paramedics gave him a choice of being taken to one of two hospitals. He chose the one he had been an inpatient in previously because his experience there was a good one. The hospital did not have a specialist stroke unit but the alternative did; the participant did not know this and the paramedics did not tell him.

Frequently, participants felt that information was not available soon enough. Participants wanted the reassurance that information was available and they could access it before they actually needed it; the stress at the time of making decisions, particularly where decisions had to be taken quickly, could lead to people not thinking clearly. One woman gave up a university course after her mother died and her disabled son became ill; she did not know about the university's bereavement facilities and was not thinking clearly enough to ask, but had she known about them before the event, she may have gone to them for help. Another had set up a voluntary group to help provide information on the current and future needs of people with MS. She felt that even though people newly diagnosed would not be ready mentally to access information, the fact that they knew where to go when they were ready would be a comfort. Even where events were more predictable, for example being discharged home from hospital and transition across organisations (for example, from health to social care or from children's to adult's services), sufficient information was not always available soon enough. One suggestion was that disabled young people should be encouraged to start making post-schooling choices a year before their non-disabled peers; the reason for this was the time taken to visit each potential college and to arrange the necessary financial and other support was far longer for disabled young people.

Other gaps in information included failures to provide information in appropriate languages and a lack of information relating to specific tasks (such as reputable builders). Even where people did not feel that there were any gaps in the information they had for making their choices, they would have liked reassurance that they had found all the information available.

Trust in information

Different sources and types of information were trusted to different degrees.

Dedicated professionals or experts in an area were trusted because participants felt it was their job to do the best for the patient or service user. However, some professionals might be trusted to do one thing but not another; for example, a consultant surgeon was trusted with carrying out an operation but not trusted to give information to help make a choice about having the operation. Furthermore, the detailed knowledge by doctors of people as patients rather than individuals lead to them not always being trusted to give more holistic advice and information.

Neighbours and friends with relevant experience or other people who were well known to the participants were trusted. For example, a young female expressed her view that doctors concentrated on the medical side of things, her parents concentrated on her well-being, but to find out what an operation was really like, she spoke to other young people who had been through the same experience.

Information was not trusted if it was provided by people or organisations who were believed to put their own interests first, including local authorities that might be trying to save money. Other examples of information sources perceived to provide biased information were architects, estate agents, employers and some colleges, especially if they were developing new services:

I don't know whether they were touting for another possible candidate (laughs) but that some would anyway, because they were trying to sell it to me you see as a residential kind of ... provision. But as I said I wouldn't touch anything that was a pilot with a bargepole anyway (laughing) so that answered that one.

[Parent of young person - YP-023]

Information that filtered down through different people or was confusing and contradictory was not trusted. In an example of information being passed through different people, a parent had been trying to use direct payments (DPs) to employ a care team for her daughter but had received contradictory, and possibly incorrect, information from social services:

After all she'd [the social worker] been given the job of telling me the details in the first place, and they [the managers] kept giving her the bullets to fire and then, you know, not taking ... any responsibility for what had been said. It got very, very messy in fact. ... I've since found out that probably I wasn't being told the whole truth.

[Parent of young person - YP-030]

There was some concern that websites, especially those originating from the USA, contained untrustworthy and anecdotal information that was not true, such as stories

of people recovering from diseases like MS. Information displayed on the websites of UK-based organisations such as the MS Trust, the MS Society and Directgov was trusted.

Participants tended to be cautious about trusting information that appeared either unduly negative or unduly positive. Examples included doctors who painted bleak pictures of potential outcomes, other people’s stories about problems with social services, and what was considered to be a “positive spin” given by local authorities about using DPs.

Information and different types of choices

We looked at the data according to the most common types of choices made, to try and shed some light on how different support needs, choices and ages of the participants were related to their use of information. These choices were: decisions about schools, colleges and going to university; major housing-related choices such as moving house or having extensions and major adaptations; social care and DPs; decisions about having major operations: and choices about employment. The table below shows the different age groups of the study participants making these types of choices. It illustrates how (in this sample) the age of the participants is related to some extent to the type of choices they are making. The findings may therefore be related in part to the choice and in part to the age of the participant.

Topic area of choice	Participants making choices about this topic
Schools, colleges and going to university	Young people and parents (two adults)
Major housing-related choices	Half older people, rest all age groups
Social care and direct payments	Parents and adults (one older person)
Major operations	Half young people, rest adults and older people
Employment	Adults only

Choices about schools, colleges and universities

Choices about education were discussed almost exclusively by young people or their parents. Choices included choosing new schools or colleges, opting to live at home or attend residential college, and choices about universities and university courses. Generally, information was provided by teachers, education offices, SENCO, Connexions and sometimes social workers or support groups. The internet was a popular choice for accessing information and those young people considering universities and university courses sent off for appropriate prospectuses. Although a lot of information was searched for on the internet, talking to friends or other parents was important also and could lead to alternative options being identified.

What was notable about this group was the amount of experiential information they collected. Visits were arranged to colleges and universities on specially arranged days but also on general open days; there were concerns that seeing universities only on specially arranged visits could give a false picture of facilities and opportunities. Collecting experiential information, however, was not just about visiting organisations on open days, but entailed far more detailed and extensive research to determine exactly how appropriate to their needs many institutions were.

It was common for the young people to arrange overnight stays to test out accommodation and care facilities or to have trial runs to find out more about travel times.

For example, parents described how their son had attended a potential new school on a temporary basis to test out the journey times. After two days the decision was made that the school was not appropriate as he was worn out after having to leave home at 7.30am and not get back until 5.30pm. The next step was to try out a closer school for two weeks the following term to check on facilities such as lifts and classroom and canteen space, and to check again on problems with locked fire doors and unsuitable toilet facilities that the parents had identified on an earlier visit.

Visits to colleges might highlight also important issues that had not been considered previously. For example, a mother realised after many visits to residential schools across the country that the distance from home to school was more important than the school itself.

And it was very difficult because, because [disabled son, aged 18]'s got ... an illness where he can be taken ill very quickly, the geographical location then became an issue, which originally it wasn't, it was about where's the best place and how, you know, which one best meets his needs, and then as we started to get into it, it was well is that, is that too far away for [disabled son, aged 18] because, you know, we felt we needed to be quite near and, and that, that didn't, wasn't something we just realised on a certain day, it was kind of as we got into it and we started to think about it. Because when you start to consider something you don't consider all the things to do with it, all the elements immediately, it's as you, you kind of think of another thing as you go along ...

[Parent of young person - YP-023]

Young people and their parents appeared to be given at least some information to help them begin thinking about their options. However, it was not always in an appropriate format (for example more information in Braille or on tape would be helpful) and was often supplemented through a lot of additional effort from the young people and parents themselves.

Young people and their parents did not talk often about trusting or not trusting the information they were given. However, some did allude to issues of trust or, at least, not believing the information available. Some information on websites, the Learning and Skills Council was mentioned, suggests options are available when experience shows that they are not. Organisations promoting their own pilot schemes were not trusted and 'flashy' college prospectuses could be found to be disappointing. Visiting organisations during term time or on standard open days helped to allay fears of being shown an overly positive picture.

Major housing-related choices

Although discussed by all age groups, half of the participants who opted to talk about major housing-related choices were older people. The choices that were discussed were extensions and adaptations to existing homes, and decisions to move house, often into a bungalow or sheltered accommodation.

Information was not usually provided spontaneously; people had to ask. This may be because the timings of decisions of this nature were driven most often by the desires of the participants. For example, people regularly described making decisions to have wet rooms or adapted kitchens installed after seeing them in friends' houses, and decisions to move house were gradual rather than sudden developments. This meant that external organisations or professionals reacted to requests about, rather than initiated the provision of, information. Exceptions occurred when professionals became involved after an event such as hospital discharge.

Generally, for decisions relating to extensions and adaptations to existing homes, people knew that the first point of contact should be social services or, if they had one, their social worker or occupational therapist. These professionals were approached often with specific questions about adaptations, for advice about where to go to purchase adaptations and for information about financial assistance. Social care staff could also put people in touch with the housing department or arrange appropriate housing assessments. Initial queries to social care professionals were followed up with further information searching, often from friends and families. Other people, frequently friends, families and estate agents, were important especially to people who opted to move house. Older people and those with the sudden onset of disability relied heavily on others, often sons or daughters, to find information about housing-related choices. Those with fluctuating conditions commonly took the lead role themselves. Most people felt that they had sufficient information, but there were cases where people had unanswered questions or where they felt they had not researched the issue thoroughly enough.

Where professionals gave information, some were trusted and some not. Occupational therapists tended to be trusted, as were friends and family, especially those with relevant experience, such as builders. Trust in estate agents was mixed.

Social care and direct payments

Choices about social care and DPs were discussed almost exclusively by parents of young people and by adults; one older person discussed her choice to end her home care service. Choices centred around deciding on whether or not to receive help at home, who should deliver that support, and whether or not to opt for DPs. A handful of people were given information about home care or DPs from their social worker or GP. Events such as regular social services reviews or discharge from hospital acted as opportunities for these professionals to provide information about home care. In the main, however, people had to ask for information or find it by chance.

People had often taken a long time to realise, and sometimes come to terms with the fact that, they needed help at home. These people were not given any information unless they asked for it. Generally, they asked social services, work colleagues, friends or voluntary organisations. Having a relevant job such as a nurse or working for a care-related organisation was helpful in providing easy access to information. Having worked previously for a social services department of any sort also appeared advantageous; people knew that support was available and knew where to call as a first point of contact.

In contrast, people who did not receive information after experiencing an event and who did not have the advantage of work-related knowledge, did not know they were entitled to support and so did not search for associated information. These people found out about home care or DPs by accident, through friends or in looking for information about different things:

Adult: ... we felt there was a lack of information ... we stumbled upon the information that we could have direct payments ...

Interviewer: When, when you say we, you and [partner]?

Adult: My partner and I, yeah. We kind of stumbled upon the idea that we could have direct payments and nobody was able to tell us what services were available to us as a disabled person and her carer and had we not done some research ourselves, I don't know if we would have realised that there was quite a lot of support available ...

[Adult with sudden onset of disabling condition - AS-120]

Experiential information was important in choosing home care services in particular. Personal experiences were important but sometimes the experiences of others weighed heavily in people's decisions; one adult male heard very poor experiences from his fellow inpatients about the unreliability of independent home care agencies so, after a weekend trial, opted to be supported by his local authority in-house team instead, even though he felt embarrassed by knowing some of the carers socially as they were his wife's ex-colleagues.

There were mixed views on trust, especially in relation to information about DPs. Friends and family were trusted, as were support groups, voluntary organisations and people with experience of DPs. Local authorities were less trusted; a common view was that they often put a positive spin on DPs but their staff did not know much about them. Some conflicting advice about DPs was given by different organisations or from different sources of information within social services.

If information was trusted, people took that advice but also searched for additional information. Sometimes this was because people liked to check information themselves; sometimes they were concerned they had missed something, for example an innovative way of using DPs. Where information was not trusted or was contradictory, people also carried out their own searches before making a decision.

Major operations

Half of the participants who discussed choices about major operations were young people (one was a parent of a young person), with the remainder being adults and older people. For adults and older people, the choices considered here were major operations such as lung transplants, bowel resection and joint replacement. For the young people and the parent, the choices were all about gastronomies or the fitting of spinal rods.

Common sources of information were health care staff, support groups and friends. In general, people were given information by health care staff, however, one young person felt they had to shout at their doctor to get any information from them.

Information given by health care professionals was trusted and people had confidence in their doctors, although there were concerns that they could ‘dress up’ information to give quite a black picture. Despite this level of trust, second opinions were sought, especially from people able to give different viewpoints:

Young person: ... two years before I had my surgery my friend had the same surgery. So, you know, I got her opinion on it and she was like, you know ...

Interviewer: Did you find that useful having her opinion?

Young person: Yeah, because she understood me, she understood where I was coming from, where the doctors thought purely the medical side, mum and dad thought purely about me and I was just thinking well can somebody just tell me what the operation's like, you know.

[Young person - YP-006]

Experiences of other patients or nurses also helped to build up the overall picture for making an informed choice.

Work-related choices

Six adults talked about information to help make work-related choices. Three spoke about their choices around getting back to work, one about unexpectedly having to stop work, one was reducing her hours and wanting advice on associated benefits, and the other had to make an important career choice shortly after a serious injury.

None was provided with information; they had to ask for it or do their own searching for information on the internet or in newspapers and magazines. In looking for information to help decisions about getting back to work after an extended period of time off, people used the same sources of information as anyone else looking for work, namely job centres and newspapers. However, their experiences with the job centres were poor. There was little understanding from staff in job centres about the particular needs of disabled people. One female with a fluctuating medical condition which meant she needed to work flexible hours and have access to toilet facilities felt that she received very helpful information from a job centre adviser who herself was disabled but much poorer information from her able-bodied replacement. Another female with fluctuating needs felt afraid to ask the job centre for help in case they forced her into an inappropriate job that could make her health deteriorate.

Friends were trusted if they had experienced similar situations or if they had relevant expertise. One woman had a GP friend who regularly compared her state of health with those of patients who were off work sick; this provided information to the study participant about her readiness for work. In contrast, some friends' advice was taken with a pinch of salt as they could over estimate people's capabilities.

Discussion

This paper has described the sources of information that disabled people access in making choices about their welfare and other support, how they obtain that information and any gaps where they feel information is not readily available. It then illustrated some differences in the use of information in specific service areas.

Study participants were asked to select the choices they wished to discuss. What is apparent from this using this method is that the range of choices that are important to disabled people is extremely varied, even for those people with similar needs or of similar ages. Our original intention to explore the use of information by need and age was not productive given the diverse nature of people's choices within these groups. It was therefore dropped in favour of looking instead at the use of information for different choices. There were, however, some links between choices and ages, for example, work-related choices were discussed only by adults of working age and choices about education were discussed mainly by parents and young people. Nevertheless, the diverse range of people wanting information about specific service areas makes it a challenge for providers of those services to offer information at appropriate times and in appropriate formats for everyone.

The findings presented have confirmed those from previous studies (Sykes *et al.*, 2008; Baxter *et al.*, 2008) that timing is essential but people do not wish to be overwhelmed with information. At times of crisis or when decisions have to be made quickly, people do not necessarily have the time or the inclination to search for information and process it effectively. (Strategies for processing information were explored in the subsequent round of interviews, but are not yet analysed.) For disabled people, uncertainties arise not only from everyday events but also from the unpredictable nature of many health conditions. In some circumstances, however, even though the timing can be unpredictable, the occurrence of events can be anticipated and information gathered in advance. For example, many voluntary organisations offer information about the main events and choices that people with certain conditions or facing certain life events may have to make. Choices around education for young people can be anticipated and there are opportunities for service providers to help families prepare in advance. However for choices around housing, social care and to some extent employment, if there is no ongoing contact with a professional who might act on behalf of or predict someone's information needs, people can be left feeling very isolated. It is these people, who do not realise they are eligible for help or do not know where to turn for advice, who need most support in finding information.

The findings reiterate also the importance of personalised information. People felt that they were faced too often with standard information designed to meet the basic needs of all people but the specific needs of none. The difficulty with personalised information is that it cannot be presented in pre-designed leaflets; it must be provided interactively, either face to face with an expert or through some form of decision-support software. It is likely that such systems will be more expensive to design and administer than standardised information, meaning that providers of services and service information need to make judgements about the cost-effectiveness of developing such systems. Nevertheless, many services already have professionals who undertake this role face to face (for example, Connexions, specialist nurses, social workers, job centre advisers), but our evidence suggests some people still feel their personal needs are not understood or catered for.

Another important finding is that people appreciate receiving coherent messages from knowledgeable people but, instead, they can receive conflicting information. Conflicting information might come from different sources (for example, a university disability officer and an actual visit to test out facilities) or in different formats from

the same source (for example, a discussion with a social worker and a local authority leaflet on DPs). We know that people sought second opinions and searched for additional information even where they trusted the information they had been given. What we do not know is how people reconciled differences of opinion or conflicting information. We asked questions about these issues, along with views about professionals being uncertain about a topic or lacking experience, in the subsequent round of interviews which have not yet been analysed.

Experiential information has emerged as a significant source of information for choices about education, social care, major operations and, to a lesser extent, housing. For education choices in particular, young people's own experiences, rather than second hand experiences from others, were especially important. One advantage of experiencing something first hand was that the information it provided could trigger the recognition that other factors not considered previously were in fact important. Opportunities for people to test out different options for support at home might prove beneficial, particularly as more people begin to use personal budgets to arrange their own support. For some choices such as major operations, however, where it is not possible to gain first hand experience, information about other patients' experiences was drawn upon instead. There were some instances where people were disappointed that they were offered the opportunity to talk to other patients but these meetings never materialised. It may be that the Expert Patient Programme (Department of Health, 2001), by offering lay-led support for people in the self-management of long-term conditions, has a role to play, or that a related system for putting people in touch pre- and post-operatively could be considered.

These findings have shown also that, from the perspective of people making choices, it is important that the providers of information are impartial. Organisations providing information about their own services and support were likely not to be trusted. Local authorities encouraging people to use DPs were not exempt from this lack of trust; doctors generally were. Friends and relatives were usually trusted but are not necessarily impartial and do not necessarily offer the best advice. We cannot tell which information was most accurate for participants in this study, but there is other evidence that anecdotal or informal sources of information can weigh more heavily in people's decisions than official and non-biased information (Schwartz, 2004; Rosen *et al.*, 2005). Ultimately, different people place different emphasis on different sorts of information (Reed *et al.*, 2008) and there is no guarantee that the "right" advice will be followed.

A number of key issues have been highlighted by this research. First, accessing information at the right time is difficult, particularly for choices resulting from unexpected events or where people are not already engaged with the welfare system. Second, it is important for people to be able to access multiple sources of information: official information; information from friends and family; and, especially important, information gained from their own or others' experiences. Third, information is needed to enable choices to be made by people with diverse information and support needs, and providing it can be costly. Together, these issues raise concerns about the appropriateness of placing such emphasis on choice when the infrastructure for enabling informed choices by disabled people is not well developed. As Hudson (2008) points out, if social policies based on market-type

models are to be effective, potential service users need information about what options are available and which would suit their needs best.

The next steps in this research are to explore any relationships between information and outcomes, and to analyse the data that have been collected about: the strategies disabled people use to process information, and how these strategies might differ from making everyday choices; how people reconcile receipt of conflicting information; and how able they are to question professionals they feel lack appropriate knowledge. We are also interviewing professionals and informal carers to explore their views about, amongst other things, providing information to people making choices.

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