

**The revolution in
equipment supply and
what it **means** for
information**

Research report



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Introduction

A systematic review of social care systems in England was published in 2007 '*Putting People First*'¹. This led to developments that have been described as "the biggest change to the provision of social care in England in 60 years"². It set the direction for transforming adult social care over the next 10 years, including a shift in the way statutory services supply equipment. It is expected that these changes will bring about changes in private systems of equipment supply as well as those operated by health and social services.

The term *disability* embraces a huge diversity of impairments. They may be congenital or acquired, due to a traumatic incident, a medical condition or simply be a consequence of ageing. Impairments can be physical, sensory or intellectual, or any combination of these. The equipment any disabled person needs depends on the nature and complexity of their impairments. It follows that a very wide range of equipment is available along with different strategies for meeting individual needs. The system of equipment supply spans private purchase for example by 'self funders' and several different local systems of statutory supply. Discussions and reviews of these systems of supply have been held at regular intervals³ and almost all have criticised them as being complicated.

The transformation of adult social care services has great implications for information on equipment and its provision. Individuals will have more involvement in decision making and in some cases be expected to make decisions more independently. There will therefore be a greater need for high quality information for consumers. And as the roles of professionals involved in the supply of equipment changes, the nature of the information they need will also change.

This report looks at information on equipment and its provision in this changing environment. It is based on the literature and on original Ricability research carried out for this project. It describes what will be needed and makes practical recommendations for ways in which information can be improved.

¹ *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, 10 December 2007

² *Evaluation of the Self-Directed Support Network, A Review of Progress up to 31st March 2007*

³ *Improving the life chances of disabled people*, Office of the Deputy Prime Minister, 2005; *Independence, Well Being and Choice: Our Vision for the Future of Social Care for Adults in England*, March 2005; *Commissioning for Personalisation: A Framework for Local Authority Commissioners* Department of Health, May 2008 *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, 10 December 2007

Summary and recommendations

Information is needed to support change

This is a time of profound change in relation to the way services, including equipment, are provided. This change can be confusing and unsettling to existing organisations, to people who have received equipment before, and to new service users who need equipment for the first time.

A variety of different names – personalisation, direct payments, individual budgets, the retail model – are used to describe different but overlapping services. Most are being developed simultaneously and there can be some confusion about how they relate to each other.

These new services have been well evaluated and their development has been well documented. This body of evidence is remarkably consistent in its underlining of the need for good information and identifying what this consists of. Indeed it can be claimed that all these schemes depend on good information for their success and further development. High quality information is needed by service users and those professionally involved with the supply of equipment.

The wider social care context – see page 20

For more than ten years, reviews, consultations and legislation have contributed to the progressive development of the social care system towards what has come to be called *self directed support*. These various initiatives have at their heart the idea that social care service users know what support they need, and should be able to choose what services they want and who should supply them. They have echoed and followed work pioneered by disabled people and the organisations that represent them.

The literature and its implications for information – see page 24

Self Directed Support (SDS) is a radical new method of social care provision. Reviews and evaluations have shown that service users, carers and families could feel anxious about the responsibilities and procedures they needed to master to get the services and equipment they needed. Service providers could also find the cultural shift, new systems and their new responsibilities quite demanding.

Professional staff

The changes in the nature of their work, has meant that some staff worried that their skills and experience would be undervalued in the new system. Reviews pointed to the need for an effective information system for staff, This was likely to include a sustained information flow, training and

mentoring. Staff needed to understand and support the system and to be its advocates.

Apart from clear leadership, particular techniques recommended in the literature to achieve this included

- internal communication channelled via a 'guru' who had responsibility for cascading of information to other staff
- support for staff
- sharing of information and experiences, including feedback from the field and other projects. Evaluations of any effective information providing enterprises needed to be shared.

Particular information included

- ways of involving disabled people as part of everyday working practices
- information on how to approach particular groups in the population traditionally assumed to have difficulty with SDS. These included people 'who are isolated, without capacity or exhausted'.

Consumers

For consumers there have been new responsibilities. Finding their way through new systems has been daunting for some. Success has sometimes depended on the way new systems have been introduced and explained – often by stressing potential benefits, explaining the practicalities of participation and providing reassurance. And the literature stressed that disabled people needed to be involved in the introduction and operation of any SDS scheme.

- Detailed practical information is needed to guide service users through the stages of choosing, acquiring and using equipment. More tangible support (advice, assistance) may be needed at any point in the process for some. This may in practice be provided by a broker, advocate, family or friends. This network of people will themselves need access to information.
- Some consumers are likely to have to make fairly complex equipment choices. They need to have enough information to weigh up the pros and cons of alternative solutions to a problem - different ways of meeting needs. For example there are different ways of overcoming the difficulties of getting into a bath, each with different pros and cons and costs.
- Information needs to be presented and targeted in appropriate ways to different groups of disabled people, for example those with visual

impairments or learning disabilities. This may involve differences in content as well as methods of publication and dissemination.

Pilot schemes found that SDS did throw up particular problems for the supply of equipment. Some of them could have been alleviated by better information. Examples were

- providing consumers with a clear directory of where to go for information.
- information about the circumstances when professional advice should be sought, along with details of where to get such advice
- information about comparative prices
- information about availability, affordability, suitability, quality and safety

More generally it was recognised that information needed to be targeted and delivered more effectively to those who needed it. It also needed to be produced in a variety of formats so that it was accessible by everybody – this would include both high and lower-tech solutions.

Risk. As far as equipment is concerned the main risks are involved in choosing equipment, maintaining it and using it correctly. Information should help people decide if professional advice is needed, for example on more complex equipment and explain how to get it.

Ricability surveys

Local Authority interviews – see page 38

Interviews carried out with seven local authorities who had experience of direct payments for equipment revealed somewhat mixed enthusiasm. All acknowledged its potential advantages for some consumers but had concerns for others. They also noted that information (backed up by enhanced services) could have a greater and pivotal role in making the system work more effectively.

Most respondents agreed that direct payments opened the door to a greater **choice** of equipment. In fact consumers opted for cash only when they could use it to get items not available directly from the council. Opinions about **value for money** were less clear – some thought that cost saving solutions could be found on the open market while others considered that individuals could not match low prices achieved by local authority bulk purchase. Direct payments sometimes meant equipment could be acquired **quickly**, since once the money had been received there were no more procedures or paperwork to hold things up. This was sometimes negated by lengthy waiting times for assessments. Direct payments also brought with them the gains in **autonomy** and self esteem

associated with being able to buy products in a shop in the ordinary way, in contrast to the stigmatised process of statutory supply.

Respondents describe the disadvantages of direct payments. There were concerns that it might disproportionately benefit those who could afford to top up the payment, resulting in a **two-tier** service. The lack of provision for the **refurbishment and reissue** of equipment no longer needed, was seen by many as wasteful. Many respondents had concerns about **suppliers**, particularly as the success of direct payments would largely depend on the calibre of retailers. In some areas they were too thin on the ground to provide easy access or adequate competition. Some people considered that a commercial retail environment was not well suited to the provision of advice.

Many believed a transaction that ended with the receipt of money might cut people off from **essential support** – checks that the equipment was appropriate, instructions and demonstration of its use, continuing monitoring and maintenance and repair.

Take up for direct payments was low. Some thought certain groups of people would be at a disadvantage with direct payments – older people, those who needed a high level of support, people in crisis, people with learning disabilities and some younger people. Suggestions for improving take up including increasing and targeting promotion so that it stressed the specific advantages that it would have for defined groups in the population, and would overcome any cynicism there might be about new services. Sometimes front line staff did not pass on information about the scheme, either because they felt it was not appropriate for an individual client or because of their own uncertainties about its merits. They needed to be convinced that the new system had advantages and that their clients could negotiate the challenges it provided.

Interviews with prescription users – see page 45

Nearly 100 recipients of prescriptions were interviewed or completed questionnaires about their experiences.

Respondents were pleased with the equipment they received on prescription and in many cases described how it had made a great difference to their lives. This tended to influence their opinions of the service. Indeed, for most respondents the method of supply (prescription or stores) was not of great interest – any system that provided them with the equipment they needed with little fuss would have been applauded.

Information about equipment

Most respondents had not actively sought information about the equipment they needed; nor did they voice a great demand for better information. Assistive technology was not a topic that was greatly discussed. Few people knew much about it, and it only became an issue of interest when it became obvious that some sort of equipment was needed. Even then, it appeared to be a 'distress purchase' – something that was acquired out of necessity rather than being actively desired. For these reasons, and because the equipment was not usually seen in high street outlets, it was widely assumed that information would have to be sought from health and social care staff – it was seen as technical equipment rather than as a consumer product.

For these reasons few people had a realistic idea of where to go for information about equipment. This lack of knowledge, coupled with the assumption that information was not always necessary, puts great responsibility on the assessor and others involved in the supply of equipment.

The assessment

Nearly everyone was impressed by the standard of the assessment, which they saw as being perceptive, thorough, friendly and helpful. Most respondents were not daunted and took the assessment process in their stride. However many were passive recipients rather than active partners in the process. No one claimed to have prepared for the assessment and it did not appear to be seen as an opportunity to discuss anything other than respondent's most immediate needs. Everyone treated the outcome of the assessment as being definitive, because they viewed the assessor as an expert.

The prescription system

Nearly everybody first heard of the prescription system when they were assessed. They accepted the idea fairly readily, and understood how to set about exchanging their prescriptions. Most people said that they thought prescriptions were a good idea when the system was first explained. Despite the revolutionary nature of prescriptions as a means of getting equipment, most people saw the process as a simple exchange, just like those used for medicines. The advantages of wider choice or the possibility of topping up was not mentioned by many people, either because they were not aware of them or because they considered that the equipment described on the prescription would meet their needs.

Exchanging the prescription

Most people found suppliers helpful and rated the different aspects of the service they provided positively. However few respondents demanded

much of them - most aimed to simply exchange the prescription for the product specified without further discussion.

Most people did not fully understand that accreditation brought with it a set standard of service, although they did know that prescriptions could only be exchanged in the shops listed. Most people simply chose the nearest shop since they had little other information to go on. Topping up the prescription was unusual, because few people realised they could do this. Where a prescription was topped up, it appeared to be in cases where the retailer had taken the initiative and shown the respondent something of the range of equipment available. Few people took the opportunity of browsing in the shop to find other equipment that might be useful, and only a few said that they might do this in future. Some suppliers did not have the equipment prescribed in stock, which caused some irritation. It appeared that suppliers were not consistent or assiduous in offering to deliver or fit equipment.

Stores vs prescriptions

Generally respondents took prescriptions in their stride. They were not concerned about them as a development – they just accepted that they represented the way things were done nowadays. Many did not see the new system as having particular advantages or disadvantages over previous arrangements. This was mainly because the features of the scheme had not been fully explained or appreciated. Otherwise the main advantages were seen to be choice and (in some cases) speed. The main disadvantages were the need to go to a shop rather than wait for a delivery and potential waste if equipment that was no longer needed was just discarded.

Information

In general respondents were not concerned about the lack of information they had about equipment, since they relied on OTs and others to provide what they needed. However they were aware of the gaps in their knowledge particularly when they were faced with a situation where they did not know what to do. Consequently when asked to say how important particular kinds of information were to them, a high proportion of people rated all of them as being useful. There was a widespread demand for information about what the Community Equipment Service could provide.

Survey of disability organisations and others – see page 64

This part of the research consisted of consultation with organisations and individuals with a direct interest in equipment. Its aim was to get an expert opinion and practical view of how the changes in supply system would affect consumers. The sample included local and national organisations, individuals concerned with policy and with delivery in the field.

The survey showed that the majority were in favour of direct payments and considered that they would bring significant benefits to consumers and service providers, and improve retail services along the way. Respondents were particularly eloquent about the enhanced choice and consumer empowerment direct payments would bring.

However they were not entirely uncritical. Many of their concerns echoed those expressed in other parts of this report. The most widespread concern was the potential loss of guidance and information currently provided by local authorities. Some people also felt that the loss of bulk purchasing power would mean an increase in costs. There was also a concern that some of the ongoing costs of maintenance, repairs and insurance would fall to the consumer.

It was also felt that the advantages of the new system might not be relevant to those people who just wanted a simple piece of equipment with minimum fuss. Some people pointed out that the choice of accessible suppliers may be limited in some areas.

Questions about the reuse of equipment came up frequently in interviews.

The success of the scheme was said to be largely dependent on the availability of good information. This not only needed to be of high quality, but well disseminated. Some respondents suspected that the information-providing role of local authorities would diminish, particularly as providing good quality information is expensive. Many did not believe that this gap would be filled adequately by suppliers or manufacturers.

Information in a new environment – see page 71

Greater choice brings with it a need for more and better information. Surveys consistently reveal that disabled and older people do not have the information they need. Many attempts have been made to repair this deficit but there will never be an easy means of getting through to everybody. There is no generic “type” of disabled person, and so there can be no generic “type” of information that will suit all disabled people. Information needs to be available in a range of formats, a range of accessible places, and in a range of different styles, of presentation and content.

While some recipients of direct payments or budgets for equipment, are easily able to find and collect the information they need, many others are faced with the problems of coming to terms with their new situation without clear signposts to help.

Various organisations have set out broad principles for information provision, which apply irrespective of subject. Chief among these is the need to involve potential users at every stage.

Beyond this, there appears to be a consensus that information is at its most effective when it is targeted. Our consultations identified several groups whose needs should be considered separately. These included different types of service user, family and friends and others who pass on information informally and various categories of 'professionals', including GPs.

Different kinds of information about equipment were needed at different times. People need to know about the wide variety of equipment available, where they can go to get it, and the different ways of accessing what they need. They need to know how to go through the statutory equipment provision routes, as well as how to confidently buy equipment privately. Information needed about equipment includes:

Basic information

- *Different approaches and strategies for solving a problem.* Information needs to emphasise that there is often more than one way to solve a problem. Finding a solution can involve knowing about the different types of equipment available.
- *The range of equipment available.* There is a need for a clear guide to the types of equipment available. Few people are aware of what information is already available, particularly those who fall through the social services net or who muddle through after acquiring a disability.
- *How to get equipment from private and statutory sources.* This information needs to be locally based to include local contacts and an explanation of the systems of supply that operate in the area. Different ways of acquiring equipment need to be explained.
- *Comparative retail price guide.*

Assessments

- *What is involved and how to prepare for an assessment.* Information about what to expect and how to get the best from an assessment is essential. It needs to encourage people to get an assessment and allay any fears.

Choosing equipment

- *Comparative information on suitability and performance.* There was widespread uncertainty about how well individual products performed,

reflecting the lack of independent evaluative information available (e.g. 'best buy', 'recommended'). Funding is needed for this research.

- *Consumer feedback on the quality of equipment, services and support.* Peer groups are a powerful and important source of information. Personal advice is persuasive and has high credibility and more information is needed of this type. Ricability has launched a pilot website which provides a channel through which disabled people can record experiences and views of the products they use. .

In use

- *Delivery and fitting*
- *Instructions for use*

Follow up

- *Maintenance and after sales service*
- *Information and advice about changing needs.* People do not always seek help when their circumstances change, particularly if this happens gradually.
- *Refurbishment and recycling.* Information about what local resources exist for the refurbishment and reissue of equipment and for its recycling.

General

- *Sources of information and advice.* Information about local, regional and national organisations, including disability-specific organisations, information and advice organisations and specialist services.

As we have shown, information is complex and is acquired in different ways. Many people build up a picture from several sources. For this reason a proliferation of sources of information is to be welcomed. We support CSED's contention that a set of basic information should be available from a wide variety of sources to maximise reach and ensure that a consistent message is conveyed. However this needs to be augmented by more specialised and detailed information. However we consider that some organisations have particular responsibilities:

Manufacturers: Manufacturers should provide performance and descriptive specifications of their equipment, details of key features and clear exposition of what the equipment will and will not do. Factual information needs to be separated from promotional copy, and be clearly given. So that products can be compared this information needs to provide consistently by each manufacturer. Standards and guidelines need to be developed for each product group to make this possible.

Retailers. The introduction of prescriptions has meant that retailers have a greater responsibility for providing information. This includes about the comparative merits of different strategies for solving a given problem; details of the performance and features of individual products; value for money advice and information about after sales and follow up support. It would also be useful if they provided information about rights of return and of any complaints procedures.

Local authority and health authority equipment services. Consumers need: details of their services and of the equipment they supply. This should include details of the assessment process, with clear indications of timescales involved, information on the financial contributions required from service users, if any, description and contact details of relevant support services and a directory of sources of additional information and advice.

Peer group support organisations: Support groups run by consumers have high credibility and considerable appeal to service users. In addition to general information these groups would be a natural source of practical help and encouragement. The information they provide should be comprehensive – their particular strength is that they can provide practical guidance by drawing information from all sources and combing it with their own first hand experiences.

Independent information providing organisations: Information providing charities have a particular role as their information is independent and trusted. Many provide information directly for consumers and some provide information that can be adapted by others for local use.

Recommendations

Retailers

The introduction of the retail model of equipment looks to change suppliers' relationship with their customers and their enhanced information-providing role brings with it new responsibilities.

While it can be assumed that they have a basic knowledge of the products they supply, retail staff need to be knowledgeable and trained to give information in an effective way.

While they cannot be expected to carry out formal assessments, they need to know enough about the equipment to know if it is likely to be suitable for a given individual and the circumstances in which it will be used. They

need to recognise situations where a particular customer is likely to need a formal assessment, and advise accordingly.

As a matter of routine, staff need to be able to

- provide basic information about equipment. It should be up to the retailer to ensure customers are fully informed, particularly in cases where customers are not aware of what they need to know
- know about alternative solutions to common problems
- demonstrate equipment on their premises and, where appropriate make arrangements for demonstrations at customers' homes
- give details about able be able to make arrangements for the fitting of equipment
- advise about routine maintenance and after sales service

They should have access to printed information about equipment and its use. On line access to available information sources would be an advantage.

Suppliers' premises need to be organised so that products can be inspected and tried out with reasonable ease. If possible, advice and information should be provided in a reasonably private environment.

Community equipment providers

General

The changes in equipment supply will mean a greater mix of supply from commercial and statutory sources. Local authorities and health authorities must take responsibility for funding the provision and delivery of up to date, free, independent *local* guidance about getting equipment. The community equipment service should provide information for both private purchasers and their own clients. Such guides need to prepare people realistically for what to expect. They should include

- sources of information about equipment
- sources of equipment
- realistic details of waiting times
- the assessment process, to encourage people to seek an assessment and prepare them for it
- likely costs (such as charges for delivery and fitting)
- sources of finance to those who are not eligible for LA services
- arrangements for maintenance and servicing.

Initial information on equipment and its provision

The primary source of information about prescriptions for equipment is the Community equipment service. Take up of direct payments for equipment

schemes may have been low because service users were not provided with sufficient information or because the idea had not been fully endorsed by the equipment service. Information at this critical stage needs to be clear and described in very practical terms. Information provided needs to stress the positive features of greater choice and empowerment if people are to be effectively persuaded.

More publicity about the prescription scheme would give potential users more time to consider its benefits and how to get the best from the system. A short clear leaflet, left with *all* prescription users, would be likely to help.

Broad brush information about the range of equipment available needs to be actively delivered to those who are likely to need it. It should be geared to providing information to people who are new to the subject. It needs to be well illustrated and explain clearly what each item of equipment does.

Follow up support

Some local authorities provide continuing support even when equipment had been bought with a direct payment or exchanged for a prescription. Where support cannot be provided, information needs to fill the gap as far as possible. This may include:

- everyday maintenance
- repairs and local after sales service facilities. It needs to direct people to appropriate sources of help and advice should the equipment fall short in any way.
- identifying wear and tear or other potential safety hazards
- guidance on how to recycle equipment and resources for its refurbishment
- how the equipment might be offered for resale or reuse including details of brokers for second-hand equipment and opportunities for private sale.

Assessments

A clear, realistic and detailed exposition of the assessment process is required. This needs to encourage people to seek an assessment and prepare them for it. Information should cover:

- details of the assessment itself (where, when, what is involved how long it takes)
- eligibility for local and health authority assessments; private assessments
- likely costs
- what happens following an assessment

- rights and responsibilities of the assessor and the person being assessed.
- complaints procedures

Government departments

Concerns that the information landscape was changing were widespread. There was a suspicion that some gaps might not be filled, particularly as information was an expense rather than income producing activity. Agreement needs to be reached on what core information is required *nationally* and how it might be provided for use by local organisations.

Duplication of research is a waste of resources. Where there is existing, high quality, third sector expertise and information this provision should be funded centrally and provided as a resource to local authorities to reduce the cost and improve the quality of their local guidance.

Some important elements include:

- Independent evaluative information (e.g. 'best buy' and 'recommended') on assistive technology is thin on the ground, and does not begin to meet the need for it. Organisations such as Ricability exist to provide such information, but the main problem is funding. Ricability is experimenting with techniques based on cheaper expert assessment rather than full scale user or technical laboratory tests.
- consumer advice on buying and legal rights
- evaluative information on key products
- instructions provided with equipment can be poor. Products that are persistently supplied with poor instructions should be withdrawn from the national catalogue.
- standard template designs for information guides

A system of independent inspection and feedback is necessary to monitor retailer standards and develop benchmarks for accreditation.

Local information points are needed to act as focus points for information that can both pass on nationally collected information and local intelligence. These should include opportunities for getting face to face advice. Local authorities and health authorities should consider jointly funding local third sector agencies to fulfil this role.

Voluntary organisations

Voluntary organisations, with government or other external funding, are increasingly providing direct service to the community. Many have strong community roots, high local credibility and a reputation for independence. They often have expertise in the provision of information and developed delivery networks. Local and health authorities should seek partnerships with these organisations in order to devise and implement information services.

Local 'one stop shops' should be established as a focus for this information, perhaps based on existing Disabled or Independent Living Centres.

Support is needed to guide some people through SDS. Over the past five years highly successful techniques have been developed, particularly by voluntary organisations. These techniques need to be adapted by voluntary organisations for the provision of information on equipment, an area that has so far been comparatively neglected.

Consumer feedback on all aspects of equipment services are vital. Meetings, electronic and other facilities for information exchange should be set up along with a process of feeding back the information collected to service providers. Ways need to be found of linking these with the new Ricability website that allows consumers to record their opinion of experiences of the assistive technology equipment they use.

Definitions

New terms develop to describe new systems and the equipment revolution is no exception. Unfortunately some terms have come to be used almost interchangeably:

There is a degree of confusion on the ground about whether Direct Payments, In Control, Individual Budgets, Self-Directed Support, and personalisation are all part and parcel of the same thing, or if they are different... It might be helpful to simplify the number of different terms in use and to promote wider recognition of personalisation as an umbrella term⁴

Below we define the terms we have used in this report. These are based on our understanding of the most common uses of these terms.

Direct payments. These are payments made to service users to enable them to choose and buy products or services. Direct payments can be in cash or in the form of a voucher or prescription. They have to be spent in a way that achieves agreed outcomes. We use the term *Direct payments for equipment* whenever they are used exclusively for equipment.

Individual budgets. These are funds given to an individual after an assessment. The budget is intended to be large enough to meet all the needs covered by the assessment. Recipients can either take their budget as a direct payment, or choose to have services provided in kind. Or they can have some combination of the two. So far, individual budgets have been funded by combining six different sources:

- Access to Work
- Council-provided Social Care services for adults
- Disabled Facilities Grant
- Independent Living Fund
- Integrated Community Equipment Services (ICES)
- Supporting People for housing related support

There is also flexibility in how funds can be provided - directly to an individual or held or administered by a third party or service provider.

⁴ *Here to Stay? Self-directed support: Aspiration and Implementation* A review for the Department of Health By Melanie Henwood & Bob Hudson June 2007
P 82

Personal budgets. This term is often used interchangeably with Individual budgets. However the term is used by some local authorities to cover funding for equipment only, by combining the budget streams that can be used to buy equipment. Recipients can choose a direct payment or to have equipment provided by the Council.

Personalisation. This term is often used interchangeably with 'self directed support'. It describes a philosophy in which service users make decisions about the social care services they require and systems of support which are geared to individual needs. A good description of this is in *Personalisation, a rough guide*:

Personalisation means starting with the individual as a person with strengths and preferences who may have a network of support and resources, which can include family and friends. They may have their own funding sources or be eligible for state funding. Personalisation reinforces the idea the individual is best placed to know what they need and how those needs can be best met. It means that people can be responsible for themselves and can make their own decisions about what they require, but that they should also have information and support to enable them to do so. In this way services should respond to the individual instead of the person having to fit with the service. This traditional service led approach has often meant that people have not received the right support for their circumstances or been able to help shape the kind of help they need. Personalisation is about giving people much more choice and control over their lives⁵.

We have used it to describe programmes that use the term, but otherwise use 'self directed support.'

Self directed support. This covers any way in which people are given a degree of personal control over their choice of products or social care services and is often used interchangeably with personalisation. The term originated with the *In Control* project and shares many features with personalisation:

- The support is controlled by the individual.
- The level of support is agreed in a fair, open and flexible way.
- Any additional help needed to plan, specify and find support should be provided by people who are as close to the individual as possible.

⁵ Sarah Carr, *Personalisation: a rough guide*, Social Care Institute for Excellence, p3

- The individual should control the financial resources for their support in a way they choose
- All of the practices should be carried out in accordance with an agreed set of ethical principles⁶.

We use it as an umbrella term to include developed systems of direct payments, individual and personal budgets.

Retail model. This is a system of supplying assistive technology equipment. People who are assessed by their local authority as needing equipment are provided with a voucher or prescription in place of the equipment itself. This voucher or prescription can be exchanged at an accredited retailer for equipment that has been agreed to meet the assessed need. The consumer can top up this prescription or voucher with his or her own money to buy a different piece of equipment with extra features. Consumers choose which retailer to go to from a list of accredited outlets.

The equipment which can be provided in this way is listed in the national catalogue⁷. A national tariff fixes the face value of the prescription.

Local authorities are not obliged to adopt this system, although it is argued that in the long term it will create a way of providing equipment more efficiently and cheaply.

⁶ *Ibid* p5

⁷ The national catalogue provides details of simple aids to daily living (the most common items of equipment issued by community equipment stores in England) that can be provided on prescription. It is reviewed and updated regularly. The National tariff shows the value of Information on the catalogues is available at www.dhcarenetworks.org.uk

Part I – research

The context

The 25 years that separate the Chronically Sick and Disabled Persons' Act (1970) and the Disability Discrimination Act (1995) have witnessed a seismic change in attitudes.

In the 1970s, organisations of disabled people began to appear. One of them - the Union of the Physically Impaired Against Segregation – published *Fundamental Principles of Disability*⁸ in 1974. It marked the beginning⁹ of the development of a social model of disability.

Up to then, the dominant medical model described disability as a collection of medical symptoms that either needed correction or cure. Disabled people were seen as passive recipients of services supplied by non-disabled professionals. In contrast the social model saw disability as something that was created by an *environment* that did not cater for impaired people. It argued that disabled people should control their own lives and exercise personal choice over everyday matters.

As far as health and social services are concerned the social model of disability has now largely eclipsed the medical model. In turn this has led or contributed to a reassessment of how services should be provided and recently to a greater *personalisation* of services, which are shaped by individuals to meet their own needs.

Several overlapping and parallel initiatives are underway, evidence of an idea whose time has come. In chronological order, legislation that has contributed to this change has included:

The Community Care (Direct Payments) Act, 1996

Since 1996 recipients of care services have been able to select cash payments instead of directly provided services or equipment¹⁰. These payments have to be spent on the services and equipment agreed at an assessment. This legislation opened the way for greater individual choice of equipment models and suppliers.

⁸ Union Of The Physically Impaired Against Segregation *Policy Statement* , Adopted 3/12/74, Amended 1976

<http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/UPIAS.pdf>

⁹ Shakespeare, T, *Disability rights and wrongs* Routledge, London, 2006

¹⁰ The Community Care (Direct Payments) Act (1996)

http://www.opsi.gov.uk/acts/acts1996/ukpga_19960030_en_1

Improving the life chances of disabled people, 2005

In January 2005 the Cabinet office published *Improving the Life Chances of Disabled People*. This strategy paper described how equality for disabled people would be achieved over a 25 year period¹¹. Equipment was central to this strategy:

There is evidence that providing appropriate equipment and adaptations increases independence reduces the need for personal assistance and prevents or reduces health problems.

Life Chances recognised that the traditional systems of supply for equipment fell well short of what was needed to achieve maximum effectiveness:¹²

- support was not tailored to the individual; assessments focused on services rather than individual needs
- existing models of support encouraging dependence because they were not geared to helping disabled people help themselves
- the fragmentation of services resulting in needs not being met
- resources were duplicated through repeated spending on assessment, delivery and monitoring by different agencies.

The paper proposed a radical solution - the progressive introduction of individual budgets for disabled people¹³. Rather than a series of assessments for equipment and services, a single assessment would culminate in the award of a budget, set at a level to cover all needs:

including personal care; family roles and responsibilities; access to the community, employment, voluntary work, training and education, and leisure activities; and include equipment, personal assistance, transport, adaptations and advocacy¹⁴

Individuals would have considerable freedom about how this budget was spent as long as it achieved agreed outcomes. Products and services could be bought from statutory or private sources. The recipients of individual budgets would have the autonomy to make far reaching strategic and practical personal decisions for themselves.

¹¹ *Improving the life chances of disabled people*, Office of the Deputy Prime Minister, 2005 p74

¹² *Ibid.* p74

¹³ *Ibid.* p7

¹⁴ *Ibid.* p93

Social Care papers

Self Directed Support (**SDS**) was described in the Green Paper, *Independence, Well Being and Choice: Our Vision for the Future of Social Care for Adults in England* in March 2005¹⁵, and was further developed in the Health and Social Care White Paper, *Our Health, Our Care, Our Say* in 2006¹⁶. This set out the Government's intentions to change the way support services were delivered.

It supported the idea of personalisation, and saw it as part of an integrated package that included an 'information prescription' service¹⁷ - 'to get the service they need, people want more information about where it is best for them to go'¹⁸:

*We plan to do this by giving everyone better information and signposting services better, putting people at the centre of the assessment process, increasing the take-up of direct payments, and introducing individual budgets that will give people greater freedom to select the type of care or support they want*¹⁹

Putting People First, 2007

Following extensive public consultation the Comprehensive Spending Review (CSR) the key issues and options for the reform of care services were announced in 'Putting People First' :

*...there is now an urgent need to begin the development of a new adult care system. A personalised system which can meet the challenges described earlier and is on the side of the people needing services and their carers. While acknowledging the Community Care legislation of the 1990s was well intentioned, it has led to a system which can be over complex and too often fails to respond to people's needs and expectations*²⁰

¹⁵ *Independence, Well Being and Choice: Our Vision for the Future of Social Care for Adults in England*, March 2005

¹⁶ *Our Health, Our Care Our Say A New Direction for Community Service*, Department of Health, January, 2006.

¹⁷ *Ibid* p8

¹⁸ *Ibid* p15

¹⁹ *Our health, our care, our say* p81

²⁰ *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, 10 December 2007, p 1

Putting People First proposed radical reform. Notable features included collaboration between central and local government and service providers²¹ and the participation of users and carers at every stage:

- people who used social care services and their families would shape and commission their own services
- personal budgets would allow people to choose their own support services
- people, irrespective of illness or disability, would be supported to live independently, stay healthy and recover quickly from illness. They would exercise maximum control over their own lives
- 'A transformed community equipment service, consistent with the retail market model'

Summary

For more than ten years, reviews, consultations and legislation has contributed to the progressive development of a social care system of what has come to be called *self directed support*. They have echoed and followed work pioneered by disabled people and the organisations that represent them. These various initiatives have at their heart the idea that services users know what support they need, and should be able to choose those they want and who should supply them.

The revolutionary changes these ideas have brought about have made great demands on those responsible for the organisation and supply of services and equipment.

The literature has underlined the scale of the cultural change needed if these changes are to be successful. It also emphasised the support that will be necessary if individuals are to get due benefits from the new system.

²¹ *Ibid* p1

The literature and its implications for information

Several reviews have looked at developments in self directed support. They have covered three overlapping areas - self directed support, individual budgets and payments for assistants. Most have not addressed information directly, although they all have had clear implications for its provision. In this respect, their conclusions were remarkably similar, despite the different focus of each review and the point in the development of SDS at which they were written. These are summarised below.

Cultural change

Most reviews have emphasised the extent to which cultural change will be needed if SDS is to flourish. New ways of doing things have challenged the nature of existing jobs and demanded a more imaginative approach at every stage – in how needs might be met, in the way services would be provided and in the respective roles of all involved. New ventures involved some degree of risk, since success could not be guaranteed. This has challenged existing beliefs and practices.

Making change has not always been straightforward. *Here to Stay* reported that difficulties were caused when agencies were too conservative in their approach or, conversely, were over zealous in their eagerness to embrace change. As might be expected, front line staff were particularly apprehensive about the ways in which their roles would change under the new system. Concerns that were particularly relevant to equipment included:

- loss of the 'giving and doing tradition', where staff do as much as they can *for* their clients
- the idea that personalisation would cater for extravagant desires rather than needs
- a suspicion that service users would try to get as much out of the new system as they could.

These reviews pointed to the need for an effective information system for staff. Staff at all levels needed to buy into to it – they needed to be convinced and motivated. They needed to understand the principles behind these new ideas, be clear about objectives and take responsibility for some of its development. There needed to be good communication between front line workers and management staff, with frequent information exchanges between them. This process needed to be participatory in that all made a contribution rather than have a new system imposed on them.

The attitudes of front line staff were particularly important. A Joseph Rowntree Foundation evaluation²² examined a direct payment scheme for assistants in a rural area, focusing on what the new system would mean for social workers in particular. This was important since they were the effective gatekeepers to the service and most people were told about direct payments by them. They found, perhaps not surprisingly, that it was necessary for social workers to *believe* that disabled people were sufficiently competent to manage payments if they were to be able to promote the system. They had to explain the scheme to service users in a compelling way, and sometimes make the judgement about who shall be offered direct payments.

IBSEN²³ recommended:

Clear, comprehensive and sustained information, training and on-going mentoring for staff at all levels were perceived to be vital. Ring-fenced resources for training will be needed if IBs or personal budgets are introduced gradually alongside existing patterns of assessment and care management over a transitional period, otherwise it may be difficult to divert funding from established training programmes. Training and capacity-building with external brokerage and support organisations, including those run by user and carer groups, are also essential²⁴.

- Allocation of named members of staff to act as a “guru” for IB, and to cascade information to other staff as needed²⁵

Good quality information to care managers to encourage involvement and the support of staff, including case coordinators and social workers²⁶

Clear **leadership and support for staff** is needed. Information for these staff may include:

²² Dawson, Carol *Independent successes: Implementing direct payments*, YPS for the JRF 1997; www.jrf.org.uk/knowledge/findings/socialcare/n.asp

²³ The IB Pilot project. A pilot was carried out to test how well individual budgets worked. It began in April 2006 and ended in December 2007. The pilot included older people, people with learning disabilities, people with physical or sensory impairments and people with mental health needs. 13 Local Authorities from around the UK took part. This pilot was evaluated by the Individual Budgets Evaluation Network (IBSEN) in October 2008.

²⁴ IBSEN p248 (Glendinning et al, Evaluation of the Individual Budgets Pilot Programme, Final Report, Individual Budgets Evaluation Network, Social Policy Research Unit, University of York, October 2008)

²⁵ IBSEN p21

²⁶ IBSEN p22, p197

- The reasoning behind the changes
- Experience from the field – case histories and findings of the research
- An understanding of how information works in practice

Involvement of disabled people

Many reviews point out that SDS was only likely to be practical and workable if disabled people were involved in its introduction and operation. While this should not be news as it has long been one of the guiding principles of the social model of disability information may be necessary to show how this could be incorporated formally into everyday working practices.

Objectives

Although the literature outlined the practical difficulties experienced by many SDS projects, it reported widespread endorsement of their objectives. Thus people interviewed for *Here to Stay*²⁷ were fully supportive of the idea that SDS would give service users more control, choice and flexibility over how their needs were met.

Similarly the ISBEN evaluation described several advantages of including the equipment services into individual budgets²⁸. They included:

- *Increased choice.* In principle the inclusion of community equipment was thought to provide more flexible solutions and choice of a greater range of equipment than was traditionally offered through health or social services' equipment stores. This could be particularly beneficial for those who wanted *bespoke* equipment, and for people with sensory impairments who might prefer equipment in different colours or textures.
- *Avoidance of delays.* In some areas people had to wait for assessments and for the delivery of equipment. IBs for equipment was a way of cutting down waiting time:

... our equipment budget was traditionally always overspent. People had to wait a long time to get access to it, and what's happened is some people have been kept prisoner for things like ramps for 300 quid.

²⁷ Henwood Melanie & Hudson Bob, *Here to Stay? Self-directed support: Aspiration and Implementation* A review for the Department of Health, June 2007. It examined how self directed support (SDS) schemes had worked in practice. It was based on interviews carried out with staff, service users and carers in three local authorities that were chosen because they represented different points in the SDS continuum.

²⁸ IBSEN p133-134

Despite these levels of support, many reviews recorded particular difficulties in introducing these changes. Many of these were due to the experimental nature of the work; some procedures were being introduced for the first time. It was therefore important that teething problems and their knock on effects did not eclipse the support for the project's overall objectives. The key to this appeared to be in the **sharing of information and experiences** between projects, areas and disciplines.

The various Department of Health initiatives have provided examples of how this can be done effectively. For assistive technology this has included the Care Services Improvement Partnership (CSIP) and the Care Services Efficiency Delivery (CSED) programme, which was set up in 2004 to help councils develop more efficient ways of delivering adult social care. It has focused on supporting the policy direction set out in 'Putting People First'. CSED offers advice, guidance and coaching to councils across the country through a network of local managers. Latterly much of the practical guidance and sharing of experiences has been channelled through the DH Care Networks (www.dhcarenetworks.org.uk) which now has responsibility for the People First initiatives and associated reforms.

Excluded groups

There were concerns that one size would not fit all and that some groups would not be able to cope with SDS.

For example, *Wider Options* reported on using direct payments as a way of making it possible for disabled people to employ personal assistants²⁹. Among other things the research revealed that some local authorities had been reluctant to offer direct payments to some people because they considered that it was too difficult to involve, engage and support them. These groups were:

- people with learning disabilities
- older people
- users of mental health services
- BME groups
- people with complex needs
- younger disabled people

Although IBSEN reported that extending the pilot to include older people had been easier than expected³⁰ the authors suggested that independent budgets may be a cause of anxiety for them:

²⁹ *Wider Options*. Report of a research project into intensive support schemes for direct payment. Luckhurst, L NCIL 2005

³⁰ IBSEN p20

A very important message for rolling out IBs for older people is that they may have a negative impact on psychological well-being, at least in the ways these new arrangements were introduced and implemented during the pilot³¹.

The literature is inconclusive on how far these preliminary findings would hold true. IBSEN itself reported that

for working age people with physical or sensory impairments, IBs had positive effects on all dimensions of social care outcomes, although these did not reach statistical significance this group has most experience of and enthusiasm for taking control of their support arrangements³²

Here to Stay maintained that doubts about how far different groups could cope with SDS tended to be expressed by those who had a limited understanding of the different forms it could take or were not familiar with the support and brokerage that existed to overcome these problems for service users³³. Similarly subsequent feedback received by the DoH suggested that some IBSEN pilots later achieved more positive developments with older people³⁴. *Wider Options* found that, rather than being incapable of dealing with direct payments, these groups may just have needed better information and more reassurance:

The views of a range of groups who have been marginalised in relation to Direct Payments, are clearly favourable toward Direct Payments, but are remarkably consistent in their concern about aspects of the financial management and administration, and in calling for intensive support which is both reliable and flexible³⁵

Support for particular groups

Good support planning was a key element in success. Essential elements appeared to be the quality of 'information and communication', providing clear signposting (knowing who to contact) and the way the system was explained. The choice of equipment can be complicated, but this points to the need for better information, rather than the exclusion of people from complex decisions.

³¹ *Ibid* p87

³² IBSEN p235

³³ *Ibid.* p ii

³⁴ *Moving Forward: Using the Learning from the Individual Budget Pilots.* Response to the IBSEN evaluation from the Department of Health, DoH, October 2008 p7

³⁵ Luckhurst L. *Wider Options.* Report of a research project into intensive support schemes for direct payment. NCIL 2005, p12

The SDS network evaluation³⁶ recognised that support was needed for people who used SDS. Some had misinterpreted SDS to mean that people were just left to 'get on with it' while in fact practical guidance was needed on how to use budgets and how to organise services. In fact this support needed to be tailored to particular groups including older people, people with learning disabilities, and younger people with physical impairments, and needed to continue throughout the SDS process.

Equipment issues

IBSEN reported on the *disadvantages* of providing equipment through an IB scheme as described by the managers interviewed during the project³⁷. Some respondents not see any advantages for consumers:

... the equipment that you're going to buy yourself isn't always that much better. It's a lot more difficult to get hold of. You've got to do the research for yourself, all of that sort of stuff. It's much easier to get the local authority on with it and we're not bad at it either. (IB lead officer, metropolitan district)³⁸

Loss of specialist information. Most managers argued that there was a risk that users would not be given any advice or would be given inappropriate information, since OTs were unlikely to be involved. There were also concerns about health and safety risks if inappropriate or poorly fitted equipment was supplied without professional guidance or if it was used without proper instruction. Also lost would be the expertise of equipment store staff, who currently offered advice or responded to user queries.

Increased costs. ICES were able to purchase standard pieces of equipment at low cost and both IB and ICES managers argued that users would not be able to buy at such low prices:

If we buy 1000 .. raised toilet seats, and they cost £1 each ... Now if we say 'Well, it's cost us £1, so that's what we'll give you', they actually can't go to the High Street and get one for £1. They've got to spend 15 quid. So ... we could be under pressure to pay people the market price, despite the fact that

³⁶ Henwood Melanie & Hudson Bob, *Evaluation of the self-directed support network: an overview of key messages*. A review for the Department of Health. June 2007

³⁷ IBSEN p134

³⁸ *Ibid* p135

it's very much more cost effective for us to supply equipment ourselves³⁹

Fitting, delivery and maintenance. Equipment provided by ICES was fitted and maintained at no cost to users who might have to pay for the installation and maintenance of privately bought items. ICES stores were usually able to deliver stock items in seven days; some respondents argued that people who lived in rural areas would be hard pressed to find a supplier who could deliver as quickly. It was also argued that some vulnerable people would not want to shop around for equipment that the local authority could provide, fit quickly and maintain free of charge:

... for people to buy a piece of equipment, if that's what they identify they need, they're not really going to want to go and buy one down the road that's three times more expensive and doesn't come with maintenance and cover and all the rest of it⁴⁰

Delays. A number of respondents argued that assessments were carried out at short notice in urgent cases, and were not confident that this could happen in an integrated system.

... if you need a zimmer frame, you need it now. If you need a bar to get you in and out of the bath, you need it now. Why bother aligning/ integrating assessments? ICES assess before IB assess because that need is pressing, so, you know, you just do it⁴¹

Clearly all these points represented real experience. In many cases some of the concerns can at least be partly addressed by providing better information. SDS need not involve the loss of professional advice from OTs – indeed the principles of the system recognise that consumers will draw on expertise whenever they need it. Procedures could be developed to ensure that people get the advice they need. If not information needs to be provided about the merits of getting it, either from a free or low cost local authority source or privately.

The realities of the loss of bulk order discounts have been hotly debated at NAEP conferences and elsewhere. The actual size of any cost savings made by local authorities has been challenged. It has been argued that the development of a retail market will bring prices down, although we have not been able to find any conclusive evidence of this happening yet. It may be

³⁹ *Ibid* p135

⁴⁰ *Ibid.* p136

⁴¹ *Ibid* p136

that some form of cooperative movement develops that will encourage competitive prices. While IBSEN accepted that the benefits of bulk purchase might be lost, it was considered that this would not be serious since most people bought relatively minor items of equipment. And higher prices had to be weighed against the possibility of acquiring equipment more quickly. They concluded:

All these considerations suggest that tackling any remaining barriers to the integration of ICES within IBs is a high priority that may have both budgetary and user-level benefits⁴²

Information issues

Importance of information

The literature, either explicitly or implicitly, recognised the importance of information.

Access to information, advice and advocacy examined in some depth the ways in which information was distributed by seven local authorities⁴³. All had corporate websites and contact centres for social care information, supplemented by networks of one stop shops, libraries, health centres and other outlets. Although these information sources had often developed piecemeal and were not 'strategically ordered or coherent', new services were developing rapidly to fill gaps. There was:

- Recognition of the fact that high quality information was necessary if people were to choose appropriately and have control over their lives. Good information was an integral part of personalisation and information needed to be personalised just as the services were.
- For equipment, the information needed included availability, affordability, suitability, quality and safety.
- Meeting the needs of different groups including 'those who are articulate and energetic and who want maximum involvement in the management of their services AND those who are isolated, without capacity or exhausted.

Our health, our care, our say also recognised the importance of information. Chapter 8 described how it was the key to managing health and well-being. It needed to be provided in a way that was not confined by

⁴² *Ibid.* p244

⁴³ *Transforming adult social care: access to information, advice and advocacy*, Improvement and Development Agency, April 2009, p4

organisational boundaries. Distribution needed to embrace both electronic technologies and the kind of 'face to face' information people preferred.

IBSEN made several references to the need for information. They included:

- The need for targeted, accessible information for different client groups, including people with learning disabilities⁴⁴
- The need for equipment suppliers to provide clear information on prices to consumers⁴⁵
- The most common source of information about IBs was social services, although IBSEN found that this was supplemented by a wide variety of other sources. The majority of people did not have a clear understanding of the system⁴⁶. There is clearly a need to provide information about IBs to the range of individuals and organisations who may be asked for information about it.
- Involvement of other agencies, including health providers in information dissemination⁴⁷.

Personalisation toolkit

The toolkit⁴⁸ included templates to help plan the transformation of services, financial modeling, resource allocation, equal access and commissioning. It was backed up by examples and opportunities for information exchange. In April 2009 the site added a link to *Transforming Adult Social Care: Access to information, advice and advocacy*⁴⁹. A literature review carried out for the project led to eight recommendations about information: ⁵⁰

- ensure the strategic significance of providing good quality information is understood by all stakeholders
- provide information at the points in people's lives when it is needed
- ensure information is available in a range of formats and channels, and is accessible by all groups

⁴⁴ *Ibid*, p20

⁴⁵ *Ibid* p135

⁴⁶ *Ibid* p144

⁴⁷ *Ibid* p223

⁴⁸ In recognition of the scale of transformation of council services, the Department of Health produced a toolkit – practical on-line materials to help guide them through the change⁴⁸.

⁴⁹ *Transforming adult social care: access to information, advice and advocacy*, Improvement and Development Agency, April 2009

⁵⁰ *Ibid*, executive summary, p2

- ensure that information needs for all groups are met and where possible, ensure that support is tailored to individual needs and preferences
- improve co-ordination and signposting between information providers across professional/ governmental boundaries, and remove unhelpful boundaries to information provision
- involve people who use information, advice and advocacy in the design, implementation and evaluation of those services
- provide support to organisations so that their information, advice and advocacy services can be maintained at the required standard
- undertake research into 'what works' in relation to information, advice and advocacy

A survey of the directors of adult social services carried out for the project found that information, advice and advocacy were seen as priority activities in transforming adult social care, with information being the most important. The most significant gaps were⁵¹

- Use of standards and quality assurance
- Marketing existing information
- Meeting the needs of socially excluded people
- In sharing information and effective referrals
- Use of technology

Outreach and delivery

Managing knowledge was important – information needed to be managed as did awareness of it and its delivery. There was more information around than people were aware of and all potential sources of information needed to know what exists. And

- information needed to be delivered in a variety of ways, using the range of local organisations and networks
- There seemed to be agreement that information needed to be delivered locally while drawing on national resources. Face to face advice, outreach and personal information and advice about local services needed to be done locally
- Information needed to reflect what is actually available, rather than what theoretically might be possible

⁵¹ *Ibid* p3

- It made sense to build on existing resources such as the DirectGov and local authority websites.

Self assessment

One of the more controversial features of SDS was self-assessment. As the name implies, this is a process that enables service users to be largely responsible for assessing their own needs. Methods and tools for doing this have been developed by In Control (see page 86) and others. *Here to Stay?* reported that some local authorities had used self assessment for individual budgets although, as far as we can tell, it has not yet played a part in direct payment schemes for equipment. Even so, *Here to Stay?* stated that:

Self-assessment lies at the heart of SDS. The principle that people should be supported to identify their own needs is the starting point for self-directed support, and this is a fundamental principle which gives practical effect to the idea of transferring power from the professional to the service user and their carers.⁵²

It reported that there was sometimes an unjustified suspicion that self-assessment would lead to frivolous or excessive demands - there were fears that service users might just see the scheme as a 'piggy bank'⁵³. Although some service providers considered that the reverse was true - people might set their expectations too low⁵⁴ – caution appeared to rule the day:

There is no doubt that moving to a system of personalisation and supporting people in assessing their own needs and making appropriate support plans is very challenging for many social services staff. Making decisions about what is and is not legitimate use of social services funding requires people to think much more flexibly and laterally than they have been trained to do⁵⁵

More significantly as far as information was concerned, the report recognised that an enhanced system of support was needed if self assessment was to work. They envisaged that this would need to come from many sources:

The SDS model is clear that many users will need support in using their resource allocation and

⁵² *Ibid.* p 37

⁵³ *Ibid.* p38

⁵⁴ *Ibid.* p39

⁵⁵ *Ibid.* p40

planning their lives. This support may come from professional staff currently providing the assessment and care management functions, from existing direct payments support staff or from user-led community groups such as Centres for Independent Living. An important feature of SDS implementation is therefore the extent to which localities have robust arrangements in place or in the planning stage to support the early users of SDS⁵⁶

Despite the number of practical disadvantages described the evaluation reported that:

Sites found ways of managing the apparently contradictory pressures of conducting specialist assessments where these were needed, in the context of wider use of self-assessment processes.

Risk

In 2007 the Department of Health published *Independence, choice and risk: a guide to best practice in supported decision making*⁵⁷. They found that disabled people wanted to be able make real choices about services, and particularly to have control over the sorts of things that others take for granted⁵⁸. The Department recognised that:

. a culture of choice ... entails responsible, supported decision-making⁵⁹

This document argued for a documented approach to decision making, which recorded the nature of risk and discussions about potential consequences⁶⁰. Safeguards for people with reduced capacity were discussed⁶¹ with an outline of how these risks could be evaluated and weighed against the increased quality of life that taking these risks might achieve⁶².

In arguing the case for a mature and reasonable approach to risk, the document discussed many of the perceptions that have led to an

⁵⁶ *Ibid* p71

⁵⁷

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773

⁵⁸ *Independence, choice and risk: a guide to best practice in supported decision making*, DoH, May 2007

⁵⁹ *Ibid.* p1

⁶⁰ *Ibid.* p5

⁶¹ *Ibid.* p5

⁶² *Ibid.* p26

overcautious approach. In support of their case the authors record that the Health and Safety Executive endorsed 'a sensible approach to risk'⁶³, and the Mental Capacity Act 2005 asserted 'that people must be assumed to have capacity unless it is established that they do not'⁶⁴.

As far as equipment is concerned the main risks are involved in choosing equipment, maintaining it and using it correctly. The more complex the equipment the more risk factors there are. Information needs to be provided about the nature of risk, particularly where any inherent dangers are not obvious. It particularly needs to help people decide if professional advice is needed, and explain where to get it and what might be involved.

Exchange of information and support

The development of SDS has been marked by an impressive number of evaluations, conferences, discussions and meetings. Until April 2009 information about its development and practical tools for its successful implementation had been available from the CSIP website. It had been recognised from the start that information needed to be shared as experience grew.

One example of this was the Self directed support network, made up of the various authorities, agencies and individuals who worked together on SDS scheme:

*The Self-directed support network is a community of people who want disabled people, older people and their families to get more control over their support and services. It's a place where you can make connections with other people who are involved in changing service systems and practices, and get information to understand what these changes might mean for you, too*⁶⁵

This network provides information and mutual support. It

*.... has provided an extensive programme of conferences, papers posted on web sites, specialist and regional workshops, regional coordinators, consultants and advisors, and an academy for training people in receipt of individual budgets to provide 'peer support' to others*⁶⁶

⁶³ *Independence, choice and risk: a guide to best practice in supported decision making*, DoH, May 2007, p26

⁶⁴ *Ibid.* p27

⁶⁵ <http://kc.csip.org.uk/about.php?grp=36>

⁶⁶ *Evaluation of the Self-Directed Support Network, A Review of Progress up to 31st March 2007* p1

Many of the practical problems and those that arise of the consequence of the cultural shift organisations are being required to make are common from area to area and agency to agency. The evaluation recognised the importance and strengths of peer support and the need to share information. It asserted that the timely establishment of support networks, both for consumers and local authorities, was crucial to the success of SDS nationally. *Here to Stay?* found that the knowledge community was not sufficiently well known and not always helpful⁶⁷, although improvements were in hand.

*Those respondents who had used the Knowledge Community expressed a wish for something more timely and accessible such as contact details for colleagues and peers in other authorities, web links to relevant sources of information and a proactive approach to encourage use, such as emails announcing new features and information.*⁶⁸

It was clear that experiences need to be pooled and solutions to problems shared. Agencies that has enlisted the help of more experienced organisations such as *In Control* found their help and experience useful.

All who provide information, whether internally to staff members or to the wider public need to monitor effectiveness and make their experiences available to others. This will eliminate duplication, eliminate repeated trials of ineffective methods and allow the building up of a systematic body of knowledge.

⁶⁷ Henwood Melanie & Hudson Bob, *Here to Stay? Self-directed support: Aspiration and Implementation* A review for the Department of Health, June 2007 pv

⁶⁸ *Ibid* p66

Ricability surveys

Ricability carried out three pieces of research into equipment direct payments for this project. The first research consisted of interviews with local authorities who have used equipment direct payment schemes; the second comprised interviews with 94 service users who had been provided with a prescription for equipment; while the third research project was with voluntary organisations of and for disabled people and others with an interest in equipment. The broad aim of all three surveys was to investigate the kinds of information that will be needed by consumers if they are to have greater control over what equipment is provided for them.

Local Authority Interviews

Ricability interviewed seven local authorities that had provided direct payments for equipment to find out what they thought of the process and how well it worked in practice. Their experience was confined to cases where service users had opted for cash instead of equipment, rather than the full retail model. We have identified implications for information provision for the retail model type schemes and for the more limited budgets for equipment.

Opinions were mixed, perhaps because all seven local authorities reported that relatively few people had opted for cash rather than equipment. In some areas direct payments were a new venture and the system may have not fully bedded down. Something of their ambivalence is expressed in the following quote:

Everyone agrees that the introduction of direct payments for the provision of care has transformed lives, but [I am] not sure that the argument for equipment has been sufficiently made

Overall three out of the seven local authorities thought that providing equipment through the loan system was better, although even this group saw that there were advantages and disadvantages to both systems. Indeed most considered that the two methods of supply should continue side by side.

Advantages

Choice

Direct payments were intended to provide more choice for consumers.

Some local authorities supplied a limited range of equipment through their stores and some had a restricted choice of models in each range. Most

respondents reported that direct payments did provide more choice and provided access to equipment that would not have been available otherwise.

Consumers opted for cash when they wanted a better product. Take up may have been low because they many did not know what was available. Better information about the range of products available may have resulted in greater take up. In other words the success of direct payment schemes may be related to the quality of information provided about what equipment is available

Value for money and budgets

One respondent pointed out that with the internet, clients were not restricted to what was on offer locally and could find cheaper products and negotiate favourable deals for insurance and maintenance. Another claimed that the products bought directly could offer better value for money than those provided in-house.

However this was not always the case. For example, in one area direct payments had not been taken up widely because budgets were set at what it cost the local authority to supply a given item of equipment. Generally this was too low to be viable (£7 for an adapted toilet seat which would cost £30 on the open market, for example). There were wide differences in take up between councils that gave consumers a realistic budget for equipment and those that based the budget on their internal costs.

The DH and the Chartered Institute of Public Finance and Accountancy published guidance on this in 2004⁶⁹. This stated that direct payments should reflect the 'true cost to the individual of acquiring the service'. However at the same time also it also said that direct payments should be no more than the cost to the LA of securing the equivalent service.

Speed

Direct payments sometimes meant that equipment was acquired more quickly:

. there was a man who needed a hoist, he would have had to go into care for the time it would have taken the Council to order one. He was able to receive a direct payment for the equipment, which meant that he could receive the hoist without having to wait, so he was able to remain at home.

⁶⁹ *Community care direct payments: accounting and financial management guidelines*, Department of Health CIPFA 2004

Independence.

Some respondents argued that being able to go out and buy equipment removed the stigma that had attached itself to statutory supply:

It's about self-esteem, it makes them feel better if they are buying it for themselves

Throughout this project, autonomy and control were cited as being major benefits of self directed support. It follows that information provided about the system should stress the empowerment aspect of the service and try to neutralise any negative associations that surround equipment and its supply.

Disadvantages

Some thought there were no disadvantages to direct payments. Otherwise the potential disadvantages were described as:

Two tier system

There were anxieties about the development of a two-tier system in which those who could afford it got better equipment than those with more limited means. One respondent said that 'as the system stands' it was only attractive to those who wanted and could afford more expensive equipment than was offered by the council.

Recycling of equipment

A frequently mentioned drawback was that there was no system of refurbishment and reissue for equipment bought with a direct payment. This was not only wasteful of resources but was said to overturn the economics of the system of supply. Most local authorities claimed to make large savings through the reissue of equipment. One authority calculated that they spent £1.7 million on equipment annually, but recycled equipment to a value of £2 million each year.

This was a classic case of the benefits a DP can bring; it was immeasurably preferable for both the man and his family that he could be cared for at home – where he then died - than for him to be taken into hospital or a care home. This option also saved the Council a great deal of money. But when he died his family was faced with the problem of what to do with the hoist. It was distressing for his wife to have the equipment in the house – a constant reminder of the final stage of her husband's illness. And following her husband's death she didn't want to have the extra worry of finding a way of getting rid of the hoist.

Time

Although, as we have seen, direct payments could eliminate delays in the supply of equipment, waiting times for assessment could run into 'a number of months'. Many people faced with delays simply went out and bought equipment for themselves. It is important that such hold ups do not eliminate the potential time savings of direct payments.

Suppliers

While some local authorities considered that the internet provided access to a wide choice of suppliers, others said that there were too few local outlets to provide adequate choice. An added problem was that many people found it difficult to get to these outlets, and that a commercial retail environment was not well suited to the provision of advice. Some of these objections have been overcome with the development of the full retail model with its system of accredited suppliers. It was clear, however, that the successful use of direct payments largely depended on the calibre of retailers.

Maintenance

Calculations for the size of a direct payment usually involved an allowance for repairs or servicing costs. However one authority felt it would be administratively simpler (and possibly more effective) if the council retained responsibility for this. It was difficult to predict maintenance costs and it was considered to be easier for clients to contact the Council for repairs than negotiate these through commercial suppliers. Another authority considered that their own technicians had greater experience and skills than their commercial counterparts, particularly when they had installed the equipment themselves.

Follow-up and support

Some respondents considered that direct payments meant that less support was provided for their clients. Individuals did not get advice from OTs 'right the way through the process', there was no help buying equipment, and no follow up after the equipment arrived. One local authority did not provide any kind of aftercare to direct payment clients unless social workers did so 'unofficially'.

*they have their assessment, receive their money
and that is the end of Council involvement, apart
from social workers reviewing the situation if a
person's needs change*

However some respondents considered that direct payments did not absolve them from continuing responsibility. For example, monitoring may be required to ensure that people did not buy inappropriate equipment and

in one area social workers checked that equipment was suitable when it arrived. They also had procedures to ensure that equipment was insured and maintained.

Some local authorities provided support after equipment had been bought with a direct payment. Some did not. Where support is not given, information needs to fill the gap as far as possible. For example, it needs to include practical advice about maintenance and repairs, checks that need to be carried out to identify wear and tear or other potential safety hazards. It needs to direct people to appropriate sources of help and advice should the equipment fall short in any way.

Take up

Take up of direct payments was generally low. Even the most enthusiastic council had only provided payments for 40 people at the time of our research. In other areas only handfuls of people had opted for a direct payment. This may be because few service users were told about the cash alternative to equipment. It could also be the case that consumers saw little advantage in what was offered:

The Council conducted a survey which showed that OTs were offering patients direct payments to buy the equipment they needed, but that they could acquire this equipment at no cost through the Council, no one was interested ... it is the more vulnerable people who use Council services in the first place – the well off simply purchase the equipment they need without going through the social services

The councils interviewed acknowledged that their strategies had not yet taken into account the development of individual and personal budgets which one person predicted were going to be “massive”. Another pointed out that the DoH set targets for social care direct payments but did not do so for payments for equipment. If this was done service managers would take the scheme more seriously. And one respondent pointed out that direct payment had more advantages in paying for care than it did for equipment, since it could be used in more creative ways and offer greater choice than was possible with equipment.

It is to be expected that take up of a new scheme will depend on how much potential users know about it. Information needed to be clear about potential benefits, and these needed to be described in very practical terms. Consumers needed to know what is in it for them.

Potential users

Many respondents said that direct payments were not suitable for everybody. For example, some older people

... don't expect to be offered choice on this sort of issue, and are often quite happy for the council simply to take charge of providing them with any special equipment they need. Many aspects of the direct payment challenge their expectations (eg being given money, and being expected to shop around for equipment which is essentially functional)

There was also some agreement that those who needed the 'full support' of the council would not find direct payments useful. Also

People who are in a crisis don't want the additional involvement and responsibility of having to deal with the money side of a direct payment, and having to choose and order equipment, and organise its installation and maintenance

People who are too ill, for whom there is a consent issue, or who don't want to use the system don't use it. Some people prefer to get bespoke equipment, and to pay the extra; others just want the equipment as soon as possible and for the Council to take responsibility for purchase, installation and maintenance

Other groups who might find direct payments difficult were those who lacked the ability to manage the payment (although one authority reported that 'quite a few' people with intellectual impairments had successfully used direct payments to pay for equipment). Some said that success depended on when the payments were offered:

When the patient is discharged from hospital they take whatever equipment is provided for them; but over time, once they have got used to living with their disability, their expectations and needs become more complex. This is the moment when the direct payment option might become more attractive to them

It was also claimed said that younger people, coming to terms with disability, found direct payments attractive – older people 'have often come to rely on social services, and find the direct payment quite off-putting'.

it was younger people with disabilities who campaigned for the scheme to be introduced, and this is reflected in take up

Younger people often had greater expectations and so were more at home in this commercial environment. However this was not a unanimous view. One local authority reported that some of the people who had managed direct payments best had been older people who had never had a bank account until they opened one to receive the payment.

There was some agreement and some disagreement about who might find direct payments for equipment useful. Information about them needs to be targeted and tailored to individual groups in the population, and needs to stress the advantages that are important to each group.

How could take up be improved?

Increase Promotion. First of all clients needed to be persuaded that the new system offered them significant advantages. In some areas take up was low because direct payments did not appear to offer any tangible benefits.

For example, in one area the loan store was said to offer all the equipment that people wanted and the process of acquiring it was simple – the implication was that most clients did not want to take responsibility for purchasing and maintaining equipment themselves. Most equipment was delivered within five days while the administration involved with direct payments took longer.

... they are more concerned with receiving the required apparatus in a swift and efficient way than they are about having a choice of model

Information also needed to convince service users that direct payments were not a cost cutting measure, but a means of increasing choice and meeting needs more effectively. In doing so it needs to overcome some cynicism about government and local authority initiatives.

Provide follow-up support. One area reported that some people were put off by the lack of back up behind the new system, and were unwilling to take on extra responsibility themselves.

Provide Comprehensive Information. Information was clearly an issue that directly affected take up.

People tend to be nervous about purchasing para-medical equipment themselves – when the apparatus is supplied through the Council then they have a professional arranging everything. Good

advice needs to be provided throughout the process – as is the case when direct payments are used for social care. Advice needs to be offered about where to go to find suitable equipment, and what exactly is needed.

Local authorities varied in the way they publicised direct payments. This was often done by using leaflets and face to face explanation by front line staff. One had used a local magazine and another had made a promotional film with the support of the Department of Health.

Some staff had limited enthusiasm for the scheme. One respondent claimed that front line staff did not fully understand the system as it applied to equipment, which meant that they did not recommend it to their clients. A certain amount of informal filtering went on. Some staff did not provide information about direct payments to those they felt would not be up to using it. Some were concerned that it would leave patients open to exploitation from suppliers.

OTs were said to be more enthusiastic than social workers, but were in a minority. One local authority stipulated that OTs reported back after each assessment to explain why direct payments had not been taken up – it was not clear if this was a disciplinary measure or an attempt to explain low take up.

There were signs that attitudes were changing. For example in one area all social workers, OTs, and community psychiatric nurses were given mandatory training on direct payments and in consequence even staff who were sceptical about consumers' ability to use the system had begun to be persuaded otherwise.

Interviews with prescription users

Method

To find out how prescriptions worked in practice we carried out a survey of people who had been given a prescription between January and December 2008 in one local authority area.

The first group (120 people) were interviewed by telephone. An explanatory letter was sent by the local authority to seek permission for names and telephone numbers to be passed on to RICA. Successful interviews were achieved with 37 of them.

The second group were sent a self completion questionnaire by post. It did not collect names or personal details so full anonymity was assured. 57 usable replies received.

The topic guide used for the telephone interviews and the self completion questionnaire are attached as Appendix A and B. This report is based on both surveys, and so reports on the experiences of 94 people.

Information about equipment generally

Little is known

Most people readily admitted that they did not know enough about equipment generally. As one person put it 'when you had been independent all your life you have no idea what exists':

I have not got a clue what they have and have not got. It is only the last few years I have got very disabled , and it is only when you go to the doctor he comes up with something, the doctor seems to know who to get in touch with and it is the hospital (M, 74)

I don't know what's available (F, 87)

I would not have known about most of it, only from the OT telling me these were available (F, 50)

Don't know enough but until you need something you don't really know it exists (F, 88)

Don't know anything about it, never thought about it (F, age unknown)

Not really because this is the first time I have ever had anything, so know nothing about it, did not even know that I could have a walking stick until the physiotherapist gave me a prescription ... should have more information (F, 68)

A few people did claim to be well informed. In a few cases this was because they had been living with a disability or had used equipment for some time and so 'knew something about it'.

I know quite a lot about equipment having had both knees done in the past (F, 76)

Otherwise people who claimed to know enough about equipment did so because of unusual circumstances – for example 'because my sister helps at the Red Cross station'.

It was clear that clients did not ask for more information (primarily because they trusted their assessor – see below). Only two people reported that they had been told where to go to find out more about equipment – in one case a physiotherapist gave the respondent ‘a few books’ about equipment and in another:

The physiotherapist gave me a good website to use - physioroom.com. It was very useful. For information I would go to the web or ring the occupational therapist (M, 71)

The information needed is underestimated

In some cases those who claimed to know ‘all’ about equipment clearly underestimated what they needed to know. For example a casual conversation with an OT was considered to be a full briefing:

Yes, I do. No gaps. I got an update from the OT and he gave me all the information (F, 50)

Sometimes they felt they knew enough because their own needs were simple:

Yes, because I only needed the toilet seats raised (F, 82)

As it was basic equipment [2 walking sticks] I felt I did not need further information (M, 50)

This lack of knowledge coupled with the assumption that information is not always necessary puts great responsibility on the assessor and other involved in the supply of equipment.

Faith in assessments

The overwhelming majority (94%) claimed to know enough about the equipment they needed after having had an assessment. The assessment meant that they would not have to seek further information. Most had an absolute faith that they would be provided with any equipment or information necessary:

I am happy that equipment has been recommended by someone else (M, 81)

Would not have been able to choose it for myself. Happy for it be provided by the hospital, they knew what I needed and they did a good job. They are the experts (M, age unknown)

They, the hospital should be the ones to explain about various pieces of equipment (M, 50)

No, certainly would not be able to choose, the lady who comes, we talk and you describe what you want and they tell you what is the best thing to do, would not have a clue, the girls or ladies from St Cath's have been very helpful (M, 74)

Information is seen as being provided by specialist staff

While most people could think of someone they would approach if they needed information about equipment, in the overwhelming majority of cases these were professionals they had seen or who had provided them with equipment previously. Those mentioned included occupational therapists, doctors, social services and nurses:

I would normally go to the doctors or to the hospital (M, 74)

I do not know what is available for me and feel the doctor should be the one to know (M, 66)

Not sure, I rang up the people who supplied me with my wooden stick

Through my doctor .. I was told it was all changed and I needed a prescription, before that I got it from hospital (M, 56)

Some respondents were aware of 'mobility shops' but mentions of them were few and, understandably enough, confined to those who had used them. However it was clear that most people would go back to a mobility shop once they had discovered them and had no hesitation in including them as a potential source of information. A large number of people considered that doctors would be a good source of information about equipment. We suspect that this is not realistic, although doctors may be a good place to start when trying to obtain equipment from a statutory source.

The assessment

Arranging for an assessment

It appeared that most assessments were arranged by hospitals or other agencies rather than being asked for directly:

I don't understand as all I know is that when I needed something like the walking stick a lady comes from St Catherine's hospital and gave me the walking stick, and then my disability got worse and they have given me a specially adapted toilet (M, 74)

There was no question about it, the hospital gave me the prescription before they let you out, particularly living on my own. I stayed in an extra day and you go into the kitchen to make sure you can cope with the kettle and that sort of thing (F, 82)

A few people reported problems arranging for assessments quickly.

Yes he had an assessment done, but I had an issue with someone on social services, they said he was not priority, he has half a lung, has lost the use of his left arm, has had two heart attacks and has kidney failure and we have had to wait 12 months to get the work done. (M, age unknown)

The process

Most people accepted what followed without question. Indeed there was no call for greater participation; respondents were more concerned with what the assessment delivered in terms of equipment than the process itself:

Did not make much of it, but it was fine and I was very satisfied (M, 74)

Had a telephone call and they said the way I would be assessed (M, 56)

The girl came and had a look round and asked me to go up the stairs. She wanted to see me in and out of bed and see the grab rails. She said I would get the trolley and gave me the booklet with all the addresses in (F, 90)

They come from St Catherine's a sort of assessment, they got someone to come and put things under my settee which made it higher and easier to get out of (M, 74)

It was OK, thorough. Found the best solutions and was quite helpful (F, 29)

Most respondents were bemused by our questions about preparing for an assessment – being prepared was for them just a matter of knowing when the assessor would call:

They explained what they would do when they came. I had a phone call (F, 29)

Was told, she said when she was coming (F, 90)

Assessments seen as successful

Most people were very happy indeed with the assessment. As one person put it 'she knew more about me than I knew myself'.

He was brilliant and went through everything to see what I needed and got me what I did need. He was phoning to make sure everything was OK ... I was pleased, he found the best solution (F, age unknown)

Thorough, and they found the best solution (F, age unknown)

Many were impressed with the care, attention and expertise they received:

Over the phone I did not sound as confident as the physio would have liked, and she came and told me where all the possible dangers were in the house. When I said [name] leant on me when he got out of the bath she nearly had a fit and said I had to have carers coming in; you don't know what you will be like after an operation (F, 82)

Only one person complained:

I felt it was not adequate; too quick (F, 66)

Most answers implied that respondents had a great faith in the assessment, and no one questioned the judgements made.

I would certainly recommend the assessment process and I would recommend this way to friends. The assessment was adequate for my needs and I got the best as it was done at home by the occupational therapist (M, 71)

The assessments clearly were a source of reassurance, particularly as many people felt that they could maintain contact:

..at least they are keeping in touch and if one was desperate I would ask the doctor first, and she left me her number (F, 90)

Had I needed any more it would have been there for me, she checked everything (F, 82)

The prescription system

Hardly anyone had heard about prescriptions *before* they were told about them at the assessment. This is not surprising since the scheme is very new and has received little general publicity. Most people accepted the new system without demur:

I just assumed it was part and parcel of the community service thing (M, 74)

Don't know what to compare it with, but very happy with it (F, 29)

I had not heard about prescriptions until the assessment for two walking sticks (M, 50)

Nearly nine out of ten people were told why they were getting a prescription at the assessment. They claimed to know how the prescription system worked even if they were not aware of the theoretical benefits it might bring. Nearly everybody understood that they could choose which shop to go to.

A handful of people were not given any information at all. Areas of uncertainty for them were where to go to get the equipment, what to do if they were in hospital and doubts about the precise nature of the equipment that had been prescribed.

Leaflets

About two fifths of the sample remembered being given a leaflet about prescriptions. Nearly all of them said the leaflet was useful and no one made any suggestions for ways it could be improved.

Topping up and choice of retailer

Only about one person in five remembered being told about the possibility of topping up the prescription. Around nine out of ten people remembered being told that they could choose which shop to go to.

Mainly favourable opinion

Most people were favourably disposed towards the scheme when it was explained to them. Just under two thirds of those in the postal survey said they had thought it to be a 'good idea' when it was explained to them at the assessment. In the telephone interviews, respondents were more positive. However in discussion it appeared that their gratitude for the equipment coloured their opinions of the system that provided it:

I think so, it is good, I have been very lucky, things like raising the settee make a hell of a difference to your life (M, 74)

A super idea because the equipment is very expensive and it is nice to know you can get it on prescription (M, 71)

Some saw the immediate benefit of going to a shop:

I like to see the items that are available so really prefer to go to a shop (F, 84)

For most people the process of exchanging the prescription was seen a simple transaction. Nearly all respondents saw the system in these very simple terms of exchange. The benefits of topping up or of being able to get additional information from the supplier was not mentioned by many people, either because they were not aware of these possibilities or because their needs were fairly simple.

A few people described the additional advantages the prescription system would bring - more choice, quicker delivery, new equipment:

I think it is a good idea. Very good, because you can see what you are getting yourself, whereas before you get commodes and all second hand stuff, where you know if you get new stuff it is better, at least you know. You have your own choice of what you want. Because you are not waiting you can go straight to the shop once you get the form or the voucher, you might get it the same day or wait, it is up to you (M, age unknown)

In practice, very few people did more than exchange the prescription for the product described on the form, and when they did they looked for mainly cosmetic differences. For example when getting a perching stool:

I could have a white or a grey one – I chose grey (F, 66)

Critical points were few. There were a few examples of absolute failure:

I telephoned in the first place to the shop, this was soon after I left hospital. They said they could not get the equipment. I also phoned the physiotherapist at the hospital but she did not comment. I expect it was because I was no longer a patient at the hospital. I phoned again to the shop and again they could not get hold of the equipment. The shop is the only one in the local area. I destroyed the prescription after many calls to the shop and I am managing (F, 73)

Some people believed felt there was potential waste because equipment would not be reissued once it was no longer needed:

A good idea in that you get nice new equipment, but don't know whether it is a good use of resources, leaving the people who have got them to dispose of them. Two toilet seats are not a huge expense, but you multiply that by the number of people who have had their knees done The whole system is very efficient and if the admin people find it is economical to do it this way, rather than scrubbing and washing and disinfecting everything, then that is OK. (F, 82)

All I know is that you had to take it to one of the places on the list of where you get it from but we don't have a car so it is not that easy. My daughter has a car and in the week she would have been at work, so it was lucky it was on the weekend, but in the end they did not have it (F, age unknown)

In two extreme cases, difficulty getting equipment meant that respondents tried to cope without it:

..they gave me a certificate for the commode to pick it up from Wallasey but did not take it up, because it is awkward for me to get there; no transport and could not ask anyone to take me there ... I did explain when someone phoned why I never used the certificate (F, 82)

Was supposed to use it, came out of hospital on Saturday afternoon and went down to Brombrough for the frame that goes over the loo and they did not have it, so had to go round looking for it, everywhere was shutting because it was a Saturday afternoon, and it turned out that I did not need it, as I found a way of coping without it (F, age unknown)

However when postal survey respondents were asked which system they preferred only around one in five (18%) said they preferred prescriptions over direct supply. Over half (56%) said that they would prefer to get equipment directly while just over a quarter (27%) had no strong feelings either way. Their reasons for this were entirely practical and were mainly based on the difficulty of arranging transport or getting to the retailer. This was borne out by comments made by those who were interviewed by telephone:

I think the older way was in preference, because if you did not have anyone to run round to see about

the trolley. I would have had to give it to my son and it might not have been the right thing. It must be harder for anyone without family or anyone to run them around. Parking is difficult and we had to look up where to go (F, 90)

I did not go for the stuff, the OT rang me and asked me if I wanted to go for it but I could not get a van so they got it delivered for me (F, 29)

I was given a prescription and given various addresses, which was the hard part for me, as have no transport of my own, and the nearest place was quite a long way away, have to have transport for it. None of them very close to home (F, 88)

Exchanging the prescription

Accreditation

A few people were not aware of accreditation at all:

Not aware of accredited Mobility shops. Went to the only one near my home – knew the shop was a chosen one on a list (M, 71)

Understanding of what accreditation meant was not widespread. Even those who claimed to know something about it were somewhat vague:

It is approved by the NHS for the different appliances people would need, rather than someone walking into a shop and saying I need a stick, they knew what I needed, so someone must have been out to check over them (M, 56)

Accredited shop means a shop particular for certain things (F, 87)

I assume because they are suitable for mobility and disability purposes (F, 50)

Choosing the supplier

Half of the prescriptions were exchanged at the shop by the person who would use the equipment and half were exchanged by someone on their behalf - usually because the recipient had difficulty travelling or was in hospital:

My son took the prescription to the mobility shop for me whilst I was in hospital, possible the day before I left (F, 76)

Overwhelmingly the shops chosen were the nearest or the easiest to get to ('was passing anyway').

I thought we would have to go to Timbuktoo to get them. And have no car, so I was worried, but it turned out okay (F, 82)

Was just given a list of shops for the disabled, and went around until we found it (F, 90)

However over one in ten chose a shop that had been recommended and a few chose an outlet they had visited before. It may be that shop loyalties will build up as the prescription system becomes more widely used. Most respondents knew little about the shops in the area, so had little to go on other than proximity.

Some assessors or therapists also exchanged the prescription on behalf of clients who were unable to do so – a service that was much appreciated.

The exchange

Most people simply did what was easiest and exchanged the prescription for the item described:

My wife took the prescription to the mobility shop. She handed over the prescription and the walking sticks were handed to her ... it took about 5 minutes (M, 50)

I was shown the ones that I could have bought but just used the prescription (F, 88)

In fact, a process that was easy and straightforward was what most people wanted, particularly if they were getting equipment for someone else:

I understand, and am happy with the system, you want to get on and do it and get the person comfy. The more I can get things done for my husband the easier it is for me (M, age unknown)

Topping up

No one in the telephone sample topped up the prescription and only four respondents to the postal survey did so. This was usually because they assumed that the prescription (having been identified by an expert) was for the optimum equipment ('why would you' top up?) but over a quarter of the sample said that they did not know they could top up. It was clear that many people did not have a practical idea of what extra qualities alternative equipment might provide.

One person who had been prescribed a chair did not like the look of the one specified on the prescription – ‘I could not have put it in the house’. She considered paying for an alternative which had a more acceptable design but decided it was too expensive. She ended up not getting a chair at all.

All four respondents to the postal survey who had topped up based their decision on what they were *shown* in the shop. This suggests that retailers need to be more assiduous about demonstrating equipment and providing information about alternatives. In one of these cases the respondent was surprised at the level of knowledge that was needed to choose equipment:

I did not realise they took such detail of the length that you needed it in accordance with your height, would have randomly chosen one (F, 88)

This shows that it is vital that suppliers are able to advise customers competently if they do decide to top up the prescription. When this does not happen it is easy to end up with the wrong equipment because customers may not know what to choose and only find out too late that the equipment is unsuitable: From an interviewer’s notes:

Despite the fact the one she chose was not appropriate (the stool it had no arms on it) the assistant exchanged it for the prescription (‘I just handed the prescription over and he said ‘This is it’ (F, age unknown)

Looking around

Few customers took the opportunity to look around the suppliers premises while they were there. Comments such as

My son remarked that there was some wonderful equipment at the shop

Yes a few things, which I might be tempted to buy in the future (F, 50)

were fairly rare. One respondent in our sample chose a particular retailer because it was bigger and therefore likely to have a wider choice and a small number had been back to the shop or intended to go back:

I would like to go to the accredited shops to look at the equipment ... I do want to go and have a look at some of the bath things that are on offer. I saw a catalogue which had some of the things that I am looking for in and this place also sells loads of other things for disabled people (F, 87)

Another said:

We have been back since and have looked at ideas for jug kettles, stands for kettles, but up to now have not found out any more information about how to get hold of these things, as they are so expensive, so will have to wait and see when social services come out over the other things we need, like a chair lift (F, 36)

However it appeared that most people did not think they needed anything else, so did not look ('No, I had no need to look at other mobility equipment'), although whether they missed seeing things that might have helped is unknown.

Quality of service

Shops were rated as good by over three fifths of postal respondents for being a pleasant place to shop, having well informed and helpful staff and being generally welcoming.

The service was ideal (M, 56)

Fewer rated that as food for the number of products on show and for the amount of information provided.

A minority of respondents (19%) said that they were shown a choice of products and in over a third of cases they were just *given* the product named on the prescription. When customers were given more explanation than this, they were highly impressed:

The staff were lovely. She showed me others. But I thought they looked like big buckets (M, age unknown)

Went there because it was the nearest one to my area. I just went to see what the choice was and to talk to them about what I could have and was pleased with what there was and chose what I liked ... They were more forthcoming with conversation and they came forward with all the conversation and the answers, if I was not too sure they explained everything before we even asked any questions (F, 36)

Conversely:

The staff weren't interested or helpful. They just said they didn't have it and that I'd have to go somewhere else (F, age unknown)

For all these reasons, overall experience of going to the shop was nearly always positive and in consequence most respondents would trust them enough to go back if they needed more information:

My wife felt the shop was very trustworthy and has she needed further help they were there to give it (M, 50)

Demonstration

Accredited suppliers are required to be able to demonstrate equipment. Over two thirds of the postal sample said that the retailer explained how to use the equipment and some said they 'told me all I needed to know'. However nearly a third of suppliers did not give any explanation at all. In some cases this was perhaps because the equipment was too simple for this to be appropriate. In other cases responsibility for this appeared to have been retained by social or health care staff:

Not necessary, the OT girl came a couple of weeks after to do it for height, and to show me how it could be heightened or lowered (F, 90)

Stock levels

Five respondents to the postal survey (9%) said that the equipment they wanted had to be ordered and a handful of telephone respondents reported problems. However this situation caused a disproportionate amount of inconvenience and was one of the main reasons why some became disillusioned with the prescription system. One OT told a disgruntled client that the system was 'flaky'. Another respondent pointed out that

There is not a lot of liaison because the shop said the equipment she prescribed was obsolete, but we found it eventually (F, 90)

There could be problems when more than one item appeared on the prescription.

One respondent pointed out that the four items on the list took ten days to assemble; a process that 'was not easy'. Several people pointed out that an overriding disadvantage was that you could not take individual items if the other items on the prescription were not available:

I needed three pieces of equipment .. none of the shops had a perching stool. Eventually I had to go to the hospital and wait for two hours while they got me one from there. I guess it is because no one takes these things back when they've finished with them, so there aren't enough to go round (F, age unknown)

Delivery and fitting

Few postal survey respondents reported that retailers offered to deliver. Of the few that accepted, only one reported that they were charged for this service.

In the postal survey, fifteen items of equipment were of a type that needed fitting. Only in five cases did the retailer offer to fit this equipment, and this was taken up in four cases. No charges were made.

Ownership

Over half (57%) of the postal survey respondents understood that the equipment exchanged with a prescription belonged to them. However approaching a third (27%) said that it belonged to the community equipment service (the remaining 15% were not sure who owned it).

Suggestions for improvement

There were very few suggestions for the way the service could be improved.

The only other criticism, made of one shop, was:

Entrance to the shop should have had a ramp or rails (M, 52)

Stores vs prescriptions

Respondents that had used both system of supply were asked to describe the relative merits of each. The comparative strengths and weaknesses of the two systems came across clearly and echoed comments described elsewhere in this report.

Respondents did not have any objections *in principle* to either system of supply – their ideas were based on their own individual personal experiences. Thus many of the reasons given for liking prescriptions were general votes of approval – the system was seen to a good one because it supplied equipment easily and without effort.

I would recommend the prescription to friends as it will help them to get better and to have more quality of life (M, 66)

For many the fact that one could go and collect equipment from a shop was a key advantage. Only three people specifically mentioned the fact that the system made it possible to shop around for equipment and discuss this choice with the supplier – perhaps because some were not aware of this possibility or because it was not a matter of great concern to them because they assumed the items on prescription would be suitable.

Oh yes I think they should be able to go and see, maybe if you went and saw you could say I don't like this thing, so it would give you choice, and that is quite a big thing to go and see what it is they are offering you (F, age unknown)

I think you do have that choice, you can choose to upgrade if you want to and you did not have that when they used to just bring it to you. No disadvantages, if you have a car it is not a problem (F, 50)

When you find out where to go, you don't have to wait for social services to come up with equipment. You can go and pick it up yourself. And you can choose yourself what you like. No disadvantages, there needs to be more widespread knowledge of how to get hold of these prescriptions (F, 36)

I think it is a quick and easy way to get hold of things you need, if you desperately need that equipment it is a much easier way of getting hold of it and a quicker way rather than waiting for it to come through from the department (F, 36)

Their main criticisms of prescriptions were almost entirely focused on the need to collect equipment. Even so, only eight people mentioned this, three of them because they had experienced problems finding a shop which had the equipment they needed in stock.

Why can you not go to the hospital direct? People have to find the shops and travel to collect them. I would prefer to receive equipment when I leave the hospital (M, 71)

Was a bit worried when I could not find anyone who could collect it, but they [OTs] kept phoning me to check how I was getting on, and then said they would organise it for me (F, 29)

There is no problem for us to get to the shop, but perhaps for an older person it would not be so easy and they would need it delivered (M, 50)

I don't go out much. To go and collect equipment – I'm not fit to lift it into and out of the car. It should come from a central point – there's too much fiddle (F, age unknown)

Two people were concerned about the lack of any arrangements by which equipment could be recycled once it was no longer needed.

Just concerned now when I see them in my garage, and we are all talking about money and so how I dispose of them, that is my only query. Should there be some system of having them picked up because there must be an awful lot of equipment lying around. We live in a throw away society who would say put it on the skip. We don't put things on the skip very easily. People are not going to bother, toilet seats you might not want to use again, but other things you would use again (F, 82)

When we had things from St Caths, you could return it, and let someone else use it. Useful if you could take it back. If people could do that and not use it, what would you do with it all, once you no longer wanted it. We are at an age where you don't like wasting anything, or being extravagant (F, 82)

Another concern was that equipment, once collected, could not be returned. This appeared to be true even when inappropriate equipment had been supplied. From an interviewers notes:

A neighbour helped get it into the house for me. It was only then she noticed it was not what she needed (it had no arms, and she says she needs arms to help her get onto it). The council told her that there was nothing they could do – she now owned it, and had to keep it. She asked if she could give it to a neighbour who would be able to use it, but the council told her not to. She is now stuck with a perch stool in her garage that she does not want and cannot use - "I just wish someone would come and take it away" (F, age unknown)

The strengths of direct supply were equally obvious. Fifteen people considered that automatic delivery was an overriding advantage. Nearly as many people were in favour of the old system because they felt it had worked well in the past – it provided a good and friendly service and did not require the recipient of equipment to do anything. Many people considered it to be quicker and easier for these reasons.

There were seem to be few disadvantages, and most of them were anecdotes – a toilet seat that was not clean and accidental damage caused to a bathroom, for example.

Information

.Ignorance of sources of information

As we have shown, most people assumed that the professionals involved in the supply of equipment would provide them with sufficient information about it. Apart from what they are told by these professionals, little is known. Some information is stumbled upon by chance:

Her daughter then took Sylvia out of the house shopping, or to go for a walk. On one of these walks they passed a shop selling aids to daily living where Sylvia saw detachable bathroom grab rails, and she bought 2, to help her to get into and out of the bath. She says she finds these really useful, and still uses them (F, 70)

It is therefore not surprising that some respondents said that they had ‘no idea’ about where to go for information. Others just hazarded a guess about where information might be obtained – these answers were hopeful rather than realistic:

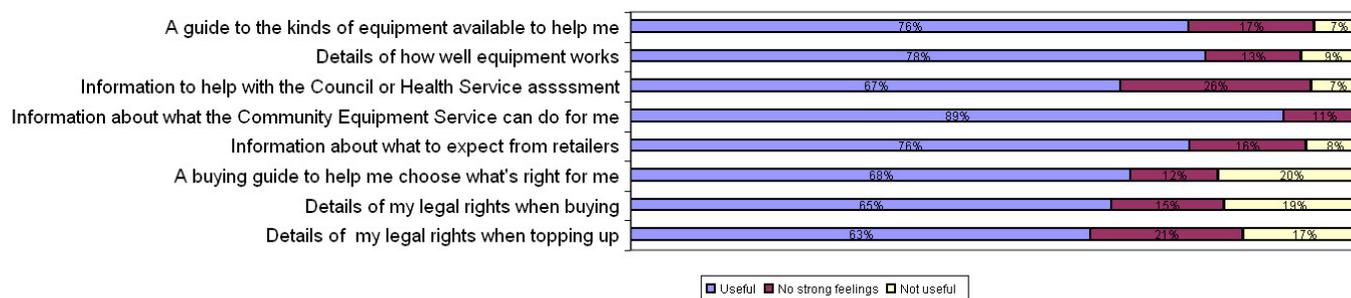
No, I don't really know enough about available equipment. I possibly would pick up information at the surgery. Possibly in the local papers or by chatting to people (F, 79)

Perceptions of need

Even so, over a third of respondents to the postal survey said they would like to have more information about equipment *generally* and a similar proportion were open to having more information, although they had no strong feelings about it. The remaining third did not consider they needed any information.

All respondents were asked to rate the usefulness off various type of information. There was a high level of demand for most types. Although numbers are small the greatest demand was for more information about what the community equipment services had to offer, and a guide to the general kinds of equipment available.

Information required



Since respondents to the survey all had been provided with prescriptions and therefore could be expected to know more than most for this reason, it can be assumed that ignorance is even more widespread among the wider population.

How information might be provided

The combination of uncertainty about equipment and faith that the hospital or social services would advise respondents meant that there was considerable uncertainty about how information might be provided. However many people interviewed by telephone expressed a need for a general guide:

I would like to get information about the different types of equipment that are available and to be kept in touch. A little booklet with some colour would be a nice way (F, 76)

A booklet would be useful, through the doctor's surgery ... do not know what you are entitled to

It should be provided on an NHS list ... a mailing list and every so often send out a pamphlet ... rather than being told go back to your doctor

Don't know, have not thought about it, social services I suppose. Bit if it was something expensive like a stairlift, unless the bank loses its money would go and find one for myself .. for minor equipment would go myself. There are shops around .. if financial circumstances change would go to social services (F, 82)

Would like a booklet with a number you could ring and they could come and see you or you could go and see them, it is easier to talk to someone and find out, as when you get older, you don't remember things and in hospital you do not have pen and paper to hand. I might have an idea about what I

wanted, if I was shown what they had got I could work out what was best for me (F, age unknown)

Doctors don't give you any help in that respect although that would be the best place to find information from because that is where you go to, or they could have leaflets available in the surgeries (F, 50)

These answers suggest that information is seen as being provided primarily by medical and social care staff. This may change as customers become familiar with retailers and continue to be impressed by the standard of service provided by them:

In the future I would always go back to the mobility shop if I needed equipment (F, 'elderly')

However it is clear from these surveys that information will be needed in greater quantities as the prescription system grows. Most people will not ask for it since they are not likely to recognise in advance what they need. The survey suggests that it is unrealistic for the responsibility for this to fall exclusively on suppliers. Their record on this appears to be patchy and they are likely to consider that the provision of generic information lies outside their remit or competence. This suggests:

- the responsibility for providing information is likely to remain with health and social care services
- this needs to be done proactively since few people know what information they need
- it needs to exploit the high standard of service provided by assessment staff

Further

- discussions need to be held to determine what kind of information retailers need to provide if the retail model is to work effectively.

Survey of disability organisations and others

The part of the research consisted of consultation with organisations and individuals with a direct interest in equipment. Its aim was to get an expert and practical view of the changes in supply system covered by this report. The sample included local and national organisations, individuals concerned with policy and with delivery in the field. Within each organisation the person who knew most about direct payments was interviewed. Some respondents consulted members of their organisation before the interview. The organisations interviewed were:

Cornwall Friends Mobility Centre
 DIAL Cornwall
 Disability Alliance
 Disability North
 The Disabled Parents Network
 DRC Bedfordshire
 Folk.US
 MENCAP
 National MS Society
 National College of OT's
 RADAR
 Spinal Injuries Association
 Two independent OT's.
 West of England Centre for Independent Living

General Findings

Positive responses

Respondents had thought about direct payments in detail and their comments were both perceptive and wide ranging. There was general recognition that the new system brought with it substantial advantages. Central to these were gains in consumer choice, empowerment and control – entirely consistent with other findings of this research described above.

You could also buy more exciting stuff than the standard equipment offered by the LA, e.g. coloured rails to match the colour scheme in the house

If they can top the vouchers up they'll get more choice - to choose a more comfortable seat, a better colour, something that matches their house more, etc. This choice is enhanced if they can put the vouchers towards buying new equipment - can they put a voucher for a raised toilet seat towards buying a new, larger toilet, which will look better in their house? These advantages only exist if they are built into the scheme, when they will result in greater choice and autonomy.

Several people commented that the new system allowed individuals to choose equipment that better suited their personal situation - sometimes saving money in the process:

You can buy exactly what you need, you could buy equipment more cheaply if you can shop around, e.g. my friend was assessed as needing a ramp to

her house. The LA wanted to put in a concrete ramp with a rail, which would have meant she could not use her garage. She was also planning to move house in a year or so. She found a plastic modular ramp that she could fit exactly where she needed it to go, and which she could take with her when she moved. This saved her time and money, and was a more practical solution to the problems she was having

One person described how budgets meant choice was not restricted by local authority procedures and regulations – for example in relation to safety:

What the LA deems as “safe” equipment might not be suitable for the individual, e.g. I was assessed as needing an electric wheelchair to use in my house. This would have meant I would not have been able to use my kitchen or work surfaces, as the foot rests would have been in the way. I use an office chair to do this instead, which is fine, as I’m careful

Some considered that more consumer choice would affect on the market in time:

The user can choose ... e.g. LA raised toilet seat is a white plastic toilet seat with no lid. Many people don’t want this, because it has no lid, and therefore ... select another one

Disability equipment is often over 20 years old, with few design changes from when it was first created. If this demand changes, with disabled people making choices over what they do or do not buy, then products will change and evolve more quickly. The voucher system could help move disability products away from the medical world where they are located right now. For example B&Q, or Mothercare might start doing more of it to respond to demand. This will help normalise disability equipment, moving it away from a purely medical field

Disability equipment shouldn’t be any different from other products ... Consumer demand will change products and also ideas about disability

The standard of retailing services was also expected to improve because of the requirements of the accreditation scheme and because retailers would need to develop services appropriate to consumers:

Retailer accreditation will mean that individuals don't have advantage taken of them

The individual can create a better relationship between the supplier and the individual. The relationship between a provider and an individual is different to that between a consumer and a supplier

Several respondents pointed out that if all these advantages were to be gained, individuals needed support to make informed decisions.

Negative Responses

Most people interviewed recognised that there were potential downsides to direct payments. The most widespread concerned the loss of guidance and information currently provided by local authorities::

if LA staff see their role as merely assessing people and giving vouchers and nothing more. For example someone who has had a stroke and doesn't know what is available might need assistance to get what they want. Relatives might also not know - for people who are new to the field this scheme might prove more problematic than for those who are not

One respondent hoped this would not represent an opportunity for a local council to "fob off" their responsibilities, while another said:

In general the statutory services provision of equipment is getting less and less. They seem to be taking less of a role in this area as time goes on

There was some scepticism about what was driving these changes:

... this could be a way of diluting the amount of money an individual receives, e.g. if an individual is encouraged to pay additional equipment costs the authority could reduce overall budgets

And some thought the overall cost of providing equipment would rise because of the loss of discounts available to bulk purchasers:

The NHS has bigger purchasing power and can consequently get far better value than an individual could, and this would therefore mean a far lower cost for the NHS than a scheme like this. The NHS buying 5,000 wheelchairs would be better value than 5,000 individuals buying one wheelchair each

The next most common worry was that consumers might be harassed by sales staff “pressure selling and encouraging people to top up”. There was also a danger that they might end up with the wrong equipment. One OT said:

If shops don't have the right training for staff then they may sell people the wrong products, therefore the individual may spend their money badly, therefore who is liable? Is it the LA, the seller, or the individual? At present anyone can set up as a disability equipment seller, therefore people might be taken advantage of, and they might buy the wrong equipment. As an OT I see up to 80% of the equipment purchased as being wrong and therefore returned

Other critical points included:

- too much choice could confuse people with simple requirements (‘all they want is a simple piece of equipment to help them do something’) or who did not want the extra bother of purchasing products
- equipment suppliers may be inaccessible
- choice would be limited by the proximity and number of accredited outlets, particularly if internet shopping is not possible with a prescription
- some people would be excluded because of the nature of their impairment

Some people - for example because of their impairment or illness, including ME, MS, people with severe impairments - are not able to go shopping

Ownership

Under direct payment and prescription systems, products are owned by their users rather than by the local authority. Respondents considered that this had a number of consequences.

Maintenance costs. The ongoing costs of maintenance, repairs and insurance would fall to the consumer. This might mean that people might not maintain their equipment properly, and might not be aware if its deterioration, or their changing condition, meant that it was no longer suitable.

Equipment recycling. Questions about the reuse of equipment came up frequently in interviews. Local authorities claim to make savings by reconditioning and reissuing used equipment, although it was claimed that not all of them did this:

Equipment is not often recycled now! There has always been a big issue around second hand equipment - LA and Health do not often give out second hand equipment, so this scheme probably won't make much difference. Most old equipment is just thrown away - you can go to any public rubbish dump in the country and there will be items of disability equipment there

Several participants said that owners of equipment might be less willing to pass it to the LA for recycling and some considered that they might sell it. This raised questions about the information buyers would need in these circumstances. Some people pointed out that equipment for children had great potential for reuse:

Equipment should be recycled - I'm amazed this doesn't happen much already, especially equipment for disabled parents, where there can be a high turnover, and it can be expensive

Childcare equipment is not used much because it's quickly redundant as the child grows

One person was more cynical about how effective recycling was;

Have there been any studies about how much it costs to recycle equipment? Is it really cost effective, or financially viable for smaller pieces of equipment?

Other comments

All respondents were asked if they had any other comments about direct payments. Most showed widespread support for them, and many thought they would lead to tangible benefits for consumers and to LAs:

I feel passionate that this is a good way forward. With changing demographics this will hopefully open the market and change products, making the retail sector meet the needs of the client

This should/could work well. It could save money for the LA - people will find innovative/inexpensive solutions. Less equipment will be wasted - inappropriate purchases will be less common. It's empowering to go and do things for yourself

This is very overdue - it's needed and important. It will be a difficult and rocky road to open up the institutionalisation of equipment provision, which has been administered by the LA for the last 30 or 40 years

I think it's probably a good development. It all depends on how the LA and equipment providers make it work. The LA are well placed to make this happen, but they assess according to budgets, not according to individual need, which is bad. This is why we need more independent OTs

A few were doubtful about the benefits of the scheme. They gave a variety of reasons for their views. One person thought the problems of distance in rural areas might be difficult for those buying their own equipment:

Is there an urban/rural split? There are specific problems in rural areas, including how to get to the right place at the right time?

Another thought that regional variations would make the whole system unfair:

As far as I'm concerned it's still a hung jury on this one. There will be benefits to service users if the scheme is well managed and funded properly, and therefore helps facilitate independent living. But will it result in a postcode lottery, like so much other social care provision? Disability benefits, such as DLA, are administered within national guidelines, and a national framework, which seems much fairer

A number of comments underlined the contention already noted that the success of the scheme would depend on the information provided to consumers. Not only did the quality of information need to be high, but it needed to be made available as widely as possible - at GP's, advice services, community care outlets and so on.

Part II – Information in a new environment

In this part of the report we look specifically at the need for information about equipment.

Common sense, as well as the findings of this research, suggests that greater choice brings with it a need for more and better information. This has been the experience of the consumer movement whose success and influence has been based on the provision of accurate independent information. Indeed the National Consumer Council in 1977⁷⁰ declared that information was the ‘fourth right of citizenship’.

Yet surveys consistently reveal that disabled and older people do not have the information they need. Many attempts have been made to repair this deficit, from the 1981 International Year of Disabled People, which set up a working group to look at information, to the National Disability Information Project, set up by the Department of Health in the 1990s. Even more recently *Improving the life chances of disabled people*⁷¹ acknowledged the central role played by information for disabled people.

We have drawn on these sources, our own experience, research carried out for this project and on the wider literature on self directed support to identify what information should be provided and what characteristics this information needs to have. Our conclusions are outlined below. However information is not a simple commodity that can be simply distributed. There will never be an easy means of getting through to everybody, given the diversity of the audience and the complexity of what needs to be communicated. There will always be room for innovation and experiment, particularly as advancing technologies and new social networks develop.

Generic principles of information provision

The National Information Forum, the National Disability Information Project and the Office of Disability Issues have all produced criteria for information services (See Appendix 1). These are standards and practices that apply to all information for disabled people, irrespective of content. Those which we have identified as being particularly important to the provision of information about equipment are:

⁷⁰ *The fourth right of citizenship: A review of local advice services* (Discussion paper) National Consumer Council, 1977

⁷¹ *Improving the life chances of disabled people*, Final Report, Prime Minister’s Strategy Unit, January 2005, P88

Process

- Disabled people should be involved from the start to ensure that the information meets their needs
- Consultation should take place with statutory and voluntary information providers to optimise resources
- Effectiveness of information should be monitored regularly

Standards

- Information should be current and timely
- Information should be accurate and relevant

Dissemination

- Information should be provided through a range of channels and formats
- There should be no physical or bureaucratic barriers to access
- Necessary information should be free at the point of delivery
- Information should be widely publicised

Presentation

- Presentation and delivery methods should be the result of consultation with a representative selection of potential users
- Information should be available in formats and media to suit users' needs
- At no time should the content, format or method of delivery be determined solely by the availability of a particular technology.

Target groups

Our interviews, consultation and work carried out by other organisations during the development of self directed support within social; care services all point to the need for better targeted information. What is required is neither uniform nor simple. Different information is required at specific points in the equipment provision process. Different groups need different information. And whatever is provided has to keep pace with changes in equipment, systems of supply or other changes in the equipment environment.

Particular groups identified in our discussions as having distinctive needs included:

Service users

- young and older people
- people with physical, sensory or intellectual impairments
- people from different religious, ethnic, and cultural backgrounds
- people with acquired or congenital impairments.
- people in regular contact with social and other caring services
- those who have little or no contact with social and other caring services
- people who prefer and choose to buy equipment privately.

Family and friends

Many surveys have shown that the main source of information for disabled people are family and friends. It follows that there is a need for information to reach those who pass it on informally.

Professional staff

It is essential that the professionals who are seen as key sources of information are provided with it in a form they can assimilate and pass on. GPs, who are widely trusted and sometimes the only professionals people see regularly, are particularly important as a conduit of information, although they may be reluctant to provide non medical information directly.

The information needed

All of the people we interviewed recognised the importance of information. They were also aware that a broad range of information was needed. Put at its most simple this was:

Anything to help the individual make an informed choice

But as respondents discussed the scope of what might be required, they became more aware of its volume and complexity, and many reeled off lists of specific requirements:

All of the following would be useful, especially information about the maintenance of equipment - managing budgets, alternative strategies for meeting certain situations, Which? type report on equipment, comparative price guides, sources of supply, legal information - rights, guarantees, faulty products etc, source of follow up support, maintenance

In doing so many acknowledged the complexity and open-ended nature of the information required. The main topics they identified as important for equipment are listed and discussed below.

Basic information – see page 74

- Different approaches and strategies for solving a problem
- The range of equipment available
- How to get equipment from private and statutory sources
- Comparative retail price guide

Assessments – see page 77

- What is involved
- Preparation for assessment

Choosing equipment – see page 80

- Comparative information on suitability and performance
- Consumer feedback on the quality of equipment, services and support

In use – see page 81

- Delivery and fitting
- Instructions for use

Follow up – see page 81

- Maintenance and after sales service
- Information and advice about changing needs
- Refurbishment and recycling

General – see page 83

- Sources of information and advice
- Information about an individual's responsibilities within the scheme.

Basic information

Different approaches and strategies to solving a problem

It is important to provide consumers with information about the different ways they can solve their individual problems. Those who get a statutory assessment may be provided with alternative strategies and be advised on how to choose between them. Those who devise their own solution may base it on partial knowledge or an incomplete understanding of the kinds of equipment available to help. Finding an appropriate solution involves knowing about the range and types of equipment available, about comparative prices and exactly what different items of equipment can and cannot do.

Information needs to

- emphasise that there is often more than one way to solve a problem – this may not have been appreciated. It may be helpful to give examples of how people have solved the same problem in different ways. Our research found examples of imaginative ways in which the prescription scheme enabled people to find new ways to solve their problems. For example:

One man, who was assessed as needing a therapeutic mattress for his back, was given a

prescription for a single mattress. This would have meant he would have been unable to share a bed with his wife. Consequently he topped up the voucher with his own money to buy a double, rather than a single mattress.

A new wheelchair user was assessed as needing a ramp to get into and out of her house. She was hoping to move house in the near future, and so did not want to make major adaptations to her home before moving. Added to this, her local authority had a long waiting list for home adaptations. With her voucher she bought a plastic removable ramp system, which could be installed very quickly. When she moved house she took the ramps with her.

The equipment prescription scheme can give people the freedom to find innovative, individually tailored solutions to their own situation. To be able to exploit this opportunity they need information on a wider range of possibilities than has been necessary before.

The range of equipment available

Our survey of prescription users showed that a surprising number of people were unaware of the range of equipment available before they actually needed it. For the most part they relied on being told what might be useful by the professionals they were in touch with ('doctors', 'the nurse'). In some cases their faith in these professionals was misplaced. Some people had visited a specialist retailer ('a mobility shop') and said they would visit it again if they felt they needed anything. However this only worked if they knew such shops existed, and believed that it stocked products that might help. Hardly anyone said that they visited such shops speculatively.

Information about equipment is already available. The Disabled Living Foundation produces comprehensive descriptions, and is progressively publishing guides that focus on particular activities such as bathing or telecare. Other disability organisations (such as the RNIB, RNID, SIA) have information on products appropriate to their client group. Some disability organisations sell equipment. All major suppliers have their own online or paper catalogues. Ricability has in depth information about products it has tested, and consumer orientated reports on others. The new Department of Health national catalogue is a new additional source of information.

Few are aware of this proliferation of sources. Those who fall through the social services net or who just muddle through after acquiring a disability,

are particularly unlikely to be aware of them. When they hear of something by chance they opt for it, often without further investigation.

- There is a need for a clear guide to the types of equipment available. This guide would alert people who know little about the subject to the range of possibilities. Such a guide needs to be accessible in the sense that it should not have a lot of distracting detail. It needs to be engaging. It needs to be illustrated. And it needs to be freely available at places where those who might find it useful congregate.

Such a guide would encourage people to arrange for an assessment by convincing them that potential solutions exist for the problems they have. It would be particularly valuable in areas where opportunities to see equipment are few and far between:

There will be areas within cities like London where it might be hard to get to equipment stores or suppliers, which can be located in suburbs or away from the city centre.

How to get equipment from private and statutory sources

Different ways of acquiring equipment need to be explained. This information needs to be locally based to include local contacts and an explanation of the systems of supply that operate in the area. It needs to include local eligibility requirements:

At the LA level an individual has to meet the new Fair Access to Care Services (FACS) Criteria. The people who meet this criteria are people with long term disabilities, including people with sensory or physical impairments, and learning disabilities. People leaving general or specialist hospitals or hospices have access to equipment to help them to return home.

It should also include information for those who buy privately.

Children and young people who don't meet LA assessment criteria ... might buy equipment themselves ... [as might] disabled people who are not ill, or people who don't meet the FACS criteria

Information needs to cover the situation of people with severe impairments and more complex systems of supply as well as those with less severe needs, who may simply go to a shop and buy what appears to meet their needs. It needs to include information about allowing for changing needs and the need for follow up support.

Comparative retail price guides

These are needed to enable consumers to find products at a fair price. The disability organisations consulted recognised that this information was difficult to keep up to date but suggested that recipients of prescriptions should at least be able to search the web for information on prices.

The Disabled Living Foundation's website now lists the prices charged for selected products from a national range of suppliers. The availability of this information needs to be highlighted in other guides as it allows some scope for 'shopping around' electronically.

Since price is important to private buyers, other guides need at least to give a guide to prices of categories of equipment. This is particularly helpful for those who are considering alternative strategies for solving a problem.

The national tariff. Prescribers who use the retail model prescribe products from the national catalogue. The DoH has set a price for all the products in it, based on prices paid by local authorities and on consultation with retailers. These prices should be a fairly realistic guide for private purchasers, and could be incorporated into any consumer guide.

Extract from the national catalogue and tariff

Mobility MO26 Caddy Walking Frame	£20.00
Mobility MO27 Wooden Stick	£3.00
Personal Care / Living Aids PL01 Pick Up and Reaching Aid Standard	£4.00
Personal Care / Living Aids PL02 Personal Hygiene Device	£10.76
Personal Care / Living Aids PL03 Leg Lifting Strap	£4.76
Personal Care / Living Aids PL04 Long Handled Shoe Horn	£1.75
Personal Care / Living Aids PL05 Sock / Stocking Aid	£3.88
Personal Care / Living Aids PL06 Tights Aid	£2.50
Personal Care / Living Aids PL07 Key Safe	£39.47

Assessments**What is involved?**

Assessments are key to the provision of equipment through statutory services and determine what equipment or services will be provided by them. The disability organisations we interviewed all stressed the importance of assessments – they strongly believed assessments to be the single most important factor in obtaining appropriate equipment. They needed to be wide ranging, thorough and perceptive:

*It all comes down to the quality of the assessment.
The person doing the assessment should help you
to think around situations and problems, to reach*

informed decisions. They should be able to give you good advice.

The assessment should be a process of teasing out priorities for the individual. The assessment process needs to be wide ranging over many subjects.

Despite their importance, many service users are unclear about what assessments are and what they involve. Some people are daunted by the prospect and some are apprehensive about what they may be asked to divulge about their financial and other circumstances. In our survey of prescription users very few prepared for the assessment in any way. Many feel the assessment is something that happens to them rather than something they participate in:

Disabled people often discuss how disempowered they feel within this process, and how they feel talked at or about, rather than talked to. There needs to be an increased level of engagement in the process for disabled people.

Information about what to expect and how to get the best from an assessment was almost universally regarded by the disability organisations consulted as being critical. Information is needed to encourage people to get an assessment, allay fears, and provide the understanding needed to ensure the assessment is as effective as possible. It also needs to be clear about what an assessment will not do, to avoid unrealistic expectations. These quotes illustrate something of the scope required:

A first timer needs to know the procedure and how it works - who will do it, what they will do, what they are looking for/at, what professionals might tell/give them, etc. Especially people with traumatically acquired impairments, who have no knowledge prior to this time in relation to this whole field/process. The individual needs to know that they need to be prepared to express how they feel.

The types of question that will be asked. Where will the assessment be held? Do you want/need support during the assessment? Would a home visit be useful? Background information about the assessment process - your rights, responsibilities, what to expect, etc.

The individual needs to know their rights and responsibilities, as well as what it might be reasonable to expect from this assessment - e.g. they should know that if they have a housing need

this will not address this need, but that the assessor might know how to go about addressing this need. Part of the assessment process relates to equipment, but other things may crop up, e.g. housing. The individual needs to know the limits of assessment and the assessor needs to be able to provide contacts for other identified needs.

All this sets an ambitious target for information. Although the dangers were recognised:

However you don't want to overload people with too much information

Preparation for assessment

Information can make a critical difference to the success of an assessment. Those being assessed sometimes need to be given the confidence to express their views. They need to be prepared and sometimes be provided with a structured way of considering their situation and aspirations:

The service user needs to think about his or her individual life - what do you do, and how long for? E.g. I was assessed for a certain type of wheelchair but no-one asked me in the assessment how I used it or how long I spent sitting in it. At conferences I might be sitting still in my wheelchair for up to fourteen or fifteen hours in a day, and it was not suitable for that. An individual needs to assess his or her own needs and requirements before the assessment. The individual needs to know that any equipment provided is there to help you do what you want to do in your life - it is a facilitator. The equipment is there to assist and help you, not vice versa. The individual could keep a self assessment diary form based on what they do, not based on the assessment criteria

While some people advocated a formal set of questions to help people think about different areas of their lives – home, work, social, personal relationships, etc – others thought a diary would be less restrictive. However this assessment preparation is organised, those being assessed need to consider what they can and cannot do, and what they would like to be able to do. One participant put this succinctly:

You need to think about it from the point of view of a person who is about to go through this process. They are probably at a crisis point in their life. They need to think about the situation they want to address, what they can and cannot do, what they need help with, and what could help them. They

could use bullet points and guidelines about “You, your health, how it affects you, the situations you need to address, what you might need, etc.”

The assessment process needs to be a service to help people live independently, not an attempt to shoehorn people into the services that are available.

Choosing equipment

Comparative information on suitability and performance

There was widespread uncertainty about how well individual products performed. This reflected the lack of evaluative information available. There are few sources – Ricability specialises in the evaluation of equipment but funding for full scale laboratory and user testing falls short of what is required. PASA’s (the NHS Purchasing and Supply Agency) programme of testing is almost entirely confined to medical equipment of use in hospitals. From time to time ad hoc evaluations are carried out by OTs, universities and others but these do not add up to anything like a comprehensive coverage of the market.

The lack of information does not mean that there is no demand for it.

This type of guide would be useful now. Ricability do some already ...there is a need for this kind of information.

Ricability is developing systems of expert assessments which can provide some of the information needed more economically than other forms of evaluation.

Evaluation information needs to be provided in context so that the performance of individual items of equipment can be seen in relation to alternative strategies, as well as the performance of competing brands.

The main problem is lack of funding for such research.

Consumer feedback on the quality of equipment, services and support
Peer groups are a powerful and important source of information. Personal advice is persuasive and has high credibility. However it can be difficult to find people with similar needs and similar circumstances to exchange information with.

Opportunities are provided through various forums run by disability and other organisations on the internet. A few local authorities arrange events for their clients to provide an opportunity to discuss equipment and services.

Ricability has launched a pilot website which provides a channel through which disabled people can record experiences and views of the products they use. We are exploring the possibility of encouraging use through local authorities' equipment services. If enough people participate, this should become a useful reference point for those thinking about what equipment might suit them.

In use

Delivery and fitting

Consumers need to know what to expect from retailers and information needs to be provided about standards of service, codes of practice and any other yardstick by which quality of service can be measured. The survey of prescription users found that very few consumers discussed equipment with the retailer and generally their awareness of the services that retailers could provide was low. For their part, retailers did not appear to volunteer much information about their services.

Delivery and fitting costs are paid by private purchasers and by prescriptions users when these costs have not been included in the value of the prescription. Consumers need to be provided with clear information about the circumstances in which charges are levied, along with an indication of what these costs might be.

Instructions for use

Instructions supplied with products are notoriously badly written, poorly laid out and sometimes ambiguous. Clear instructions are necessary to ensure that users understand the capabilities and limits of the products they use and know how to get the best from them. Safety information needs to be particularly clear.

Instructions are normally produced by manufacturers, although accredited retailers have responsibility for ensuring that purchasers understand how to use what they have bought. Given that close after sales monitoring may not be provided under the retail model, clear instructions are vital.

Follow up

Maintenance and after sales service

The need for information does not cease once a product has been bought. Some concerns were expressed in our survey of organisations that the periodic checks made by statutory agencies would stop if equipment was bought like any other product. Various, the disability organisations consulted considered that consumers need:

- need information on their rights when products are faulty
- information about what kind of maintenance is required ‘... especially for bigger pieces of equipment’
- need to know where to go for servicing, repairs and insurance
- need information to help them judge if maintenance contracts (service agreements) are good value.

Information and advice about changing needs

People do not always seek help when their circumstances change, particularly if this happens gradually. They need to know when a new assessment should be sought and to recognise the point at which a different product might be more appropriate than the one they are using:

Advice on the need for regular re-assessments, and the need to stay up to date with new products and information as they become available

Some respondents hoped that retailers would provide a follow up service:

This might be a legal requirement of relevant codes of practice to provide this. If the suppliers are approved they should have a follow-up system

Others suggested that some kind of local support be set up. This might consist of a telephone helpline, a drop in centre or regular group meetings. Whatever form it took, it would provide a contact point for users of equipment and a way of getting in touch with people in similar situations.

Refurbishment and recycling

Equipment provided on loan is often refurbished and reissued, and some local authorities claim that, in addition to ecological advantages, the financial savings they make by doing this are considerable. Even when equipment cannot be reissued, its materials can be recycled.

Our survey suggests that prescription users were concerned about the potential waste if equipment that is no longer needed is discarded. Several organisations exist that arrange for equipment exchanges, although they do not arrange for its decontamination, safety checks or refurbishment. Information needs to be provided about what local resources exist for the refurbishment and reissue of equipment and for its recycling.

General

Sources of information and advice

As a matter of course information provided to consumers should include sources of further information and advice for those who need more detail or more personal guidance. This should include local, regional and national organisations, including disability-specific organisations, information and advice organisations, and relevant specialist services.

Information about an individual's responsibilities within the scheme

The retail model gives the consumer more choice and autonomy. Clarity is needed about what this means in terms of responsibility. Recipients of equipment have not always understood that they are responsible for repairs and maintenance, equipment insurance, as well as making sure they fully understand how the product works and how to get the best out of it safely.

Who should provide information?

A consumer led market can only work if good information is freely available. The Care Services Efficiency Delivery (CSED) website states –

Only informed users and their carers/personal assistants can make choices and take control over decisions affecting their lifestyle and their care⁷².

CSED proposed that a *minimum set* of information should be available from any source likely to be approached for it, including GPs, local councils, health services and third sector organisations. CSED envisaged that additional information would be available from a variety of sources, including the internet, such as that provided via the portal developed by the Disabled Living Foundation.

A proliferation of sources of information is to be welcomed. Different organisations reach different audiences, and may communicate in a style that best suits them. Information is more likely to be remembered if it comes from several sources.

Survey evidence shows consistently that when people are asked how they get information, most say they get it by word of mouth from family and friends, often by chance. It is therefore important that essential information is provided by a variety of organisations to increase the chances of it getting through to these information providers.

⁷² <http://www.csed.csip.org.uk/solutions/solutions/transforming-community-equipment/the-retail-model-for-users-and-their-carerspersonal-assistants.html>

We support CSED's contention that a set of basic information should be available from a wide variety of sources to maximise reach and ensure that a consistent message is conveyed. However this needs to be augmented by more specialised and detailed information. Organisations involved in the supply of equipment have different responsibilities for providing it:

Manufacturers. Many of the disability organisations consulted considered that information from commercial sources had limited reliability and need to be tempered with information from other sources:

*Impartial information is of benefit to the client.
Commercial information is of benefit to the
provider/company*

*Many people will not trust this (commercially
provided information) as their sole information
source.*

*Commercial suppliers only provide their own
information. Each must stick to the codes of
practice within their fields. Information needs to be
as accessible/jargon free as possible. Many people
will not trust this as their sole information source,
and therefore there needs to be individual
organisational views from e.g. Ricability, DLF,
professional organisations such as OTs, etc*

Manufacturers need to provide performance and descriptive specifications of their equipment, details of key features and clear exposition of what the equipment will and will not do. Factual information needs to be separated from promotional copy, and be clearly given. So that products can be compared this information needs to be provided consistently by each manufacturer. Standards and guidelines need to be developed for each product group to make this possible.

Retailers. The introduction of prescriptions has meant that retailers have a greater responsibility for providing information. This includes about the comparative merits of different strategies for solving a given problem; details of the performance and features of individual products; value for money advice and information about after sales and follow up support. It would also be useful if they provided information about rights of return and of any complaints procedures.

Local authority and health authority equipment services. Consumers need: details of their services and of the equipment they supply. This should include details of the assessment process, with clear indications of timescales involved, information on the financial contributions required from

service users, if any, description and contact details of relevant support services and a directory of sources of additional information and advice.

Councils should help individuals who may wish to approach them for support by publishing and disseminating information about access, eligibility and services, in a range of languages and formats. The information should also say what usually happens during assessment and care management processes, related time-scales, and how individuals might access direct payments. Local "Better Care, Higher Standards" charters will be the means for providing this information and for setting standards and targets. Councils should promote the development of services that provide interpreters, translators, advocates, and supporters to help individuals access and make best use of the assessment process.⁷³

Peer group support organisations: Support groups run by consumers have high credibility and considerable appeal to service users. In addition to general information these groups would be a natural source of practical help and encouragement. The information they provide should be as comprehensive as possible – their particular strength is that they can provide practical guidance by drawing information from all sources and combining it with their own first hand experiences⁷⁴.

One stop shops: Putting People First proposed the establishment of centres that would act as a focus for information.

A universal information, advice and advocacy service for people needing services and their carers irrespective of their eligibility for public funding. A 'first shop stop', which could be accessed by phone, letter, e-mail, internet or at accessible community locations⁷⁵

A centre that can act as a focal point for information and services has the obvious advantages of convenience and a real possibility of becoming a natural first point of call. Several organisations interviewed as part of this

⁷³ *Fair Access To Care Services: Guidance On Eligibility Criteria For Adult Social Care* 2002, p7

⁷⁴ Although peer support groups are often small voluntary groups of enthusiasts, this is not always the case. In one area, funds were secured to develop a social enterprise, run by budget users to provide information and to help individuals develop their own support plans. It aimed to increase consumers' negotiating and purchasing power by organising collective activities and influence the quality of the services themselves.

⁷⁵ *Putting People First*, A shared vision and commitment to the transformation of Adult Social Care, 2007 p3

project considered that Disabled or Independent Living Centres should take on this role as they were independent, already specialised in equipment and could provide assessment services:

It would be helpful to the individual to have a one stop place for assessment, information, advice. This would help produce a holistic picture of what a person needs. A place like a DLC, or Independent Living Centre.

Voluntary organisations and social enterprises: These organisations have high credibility and are independent. In recent years many have developed professional support services of a high calibre on behalf of central and local government. For example *In Control* has been developing services to support the Individual Budgets programme since 2003 and offers information, advice, support and other resources to help individuals and local authorities manage the process:

In 2003 In Control started working with six authorities on services for people with learning disabilities. By the end of 2006/07 the organisation was providing support to 92 authorities out of 150, and was increasingly branching out to cover services for other groups of disabled people.

... In Control Total – will help authorities to move to a position where they deliver self-directed support to everyone. In Control is supported and receives substantial funding from the Care Services Improvement Partnership (CSIP) of the Department of Health⁷⁶

The disability organisations interviewed considered that clear, appropriate provision of information was a particular strength of the voluntary sector:

The independent sector is better at explaining things to disabled people than government departments. For example one of our main customers is the Department for Work and Pensions, who buy copies of our (guide) to explain all their benefits to their own staff! However we should be properly financed to provide this information

Voluntary organisations and social enterprises are seen as able to produce guides to the system from the service users' point of view. They can also

⁷⁶ *Evaluation of the Self-Directed Support Network, A Review of Progress up to 31st March 2007 p7*

provide advice, support and advocacy throughout the process as appropriate.

Local and national information

Some information about equipment is available from national sources (DLF, Ricability, manufacturers' brochures, for example). The advantages of compiling information at a national level are obvious. However consumers need this information in conjunction with local intelligence.

Consultation with local authorities carried out for this project showed that the equipment supplied, eligibility requirements, the process of assessment, local support, local suppliers and follow up services differed significantly and would limit any nationally produced information to very broad generalities.

Respondents to our survey of disability organisations were accordingly sceptical about how nationally produced information alone could meet local consumers' needs. People need practical details of how things work in their own area:

Where are the centres? Who is in charge; does the individual need an appointment, or can they just turn up? What is available at the centre, and what help is available? Will there be professional advice at the point of purchase, eg. to make sure the bath seats are appropriate, will fit, will work, etc? Assistance from the supplier vs. home visits

Information guides need to be tailored to the specific needs of a locality in order to be the greatest possible use, to reduce confusion, and increase confidence. For this reason national information providers need to gear information so that it is compatible with, and complementary to, local information. Templates containing national information need to be prepared so that they can be edited and adapted to apply locally. An example of this has been provided by Ricability at www.ricability.org.uk

Charges for information

The majority of respondents in our survey of disability organisations maintained that information should be free to individuals:

If commercial information is free, and it is, then independent information also needs to be free, to provide individuals with choice.

Yes, it should be free

Absolutely this information should be free, though maybe the information can be distributed through a variety of means, e.g. in disability magazines and publications, such as Disability Now. It needs to be available to an individual at no additional cost - if they buy Disability Now they will get the information anyway, but they should not be expected to buy Disability Now to get the information. Information on the web should be free. But also this depends on the cost of the equipment - it should not cost £6 to buy a guide for toilet seats, which only cost £10 themselves.

It's our right to have free information - of course!

However some thought that information that was paid for may be more highly valued because it has a price, or that it might be possible to charge for information if the product being considered was expensive:

Information is valuable, therefore if people pay for it do they value it more?

Information should be free, but advice has a price (e.g. legal or financial advice).

if someone wanted to spend a lot of money on a super-wheelchair then they might be willing to pay for information.

people might buy a guide for more expensive equipment, for example an electric wheelchair that costs £3,500.

Formats

When asked, nearly all respondents said information should be available in any format, to suit the needs of everyone who might use the scheme:

This depends on the needs of the voucher recipient. The information needs to be accessible to the voucher users - printed, on the net, audio, etc

You need to avoid the "one size fits all" ethos, and provide different formats for different people to help those people relate to and understand the information

On a demand basis - we offer everything in a standard format, but the individual can choose to have it in any format they want

This information should be available in as many ways as possible

It should be available wherever and whenever possible.

Examples given included:

Printed: booklets and leaflets; posters; large print

Tactile: Braille

Audio: CD and tape; on the Internet

Electronic: in digital formats for Digital Readers; as a download;

There is a wealth of literature about the various formats used and preferred by people with different impairments. It is generally accepted that simultaneous publication in print, large print, audio and electronic forms should be the norm. There are a number of guidelines about the effective use of all these formats. For this reason this did not emerge as a particular problem in our survey apart from the fact that some organisations failed to comply with guidelines.

Appendix 1 - Principles of good information

The Office of Disability Information has developed five core information principles⁷⁷:

- Ensure that disabled people are involved from the start
- Provide information through a range of channels and formats
- Ensure your information meets users' needs
- Clearly signpost other services
- Always define responsibility for information provision

Principles compiled by the National Information Forum⁷⁸

- Information should be accurate and relevant.
- Information should be current and timely.
- There should be no physical or bureaucratic barriers to accessing information and it should be locally available to all.
- Information should include relevant local, regional and national content.
- Content, presentation and delivery methods of information should be the result of consultation with representative end users. Consultation should also be sought with statutory and voluntary information providers so as to optimise the benefits of available resources.
- As far as is possible, information should be available in format and media to suit the user's needs, eg in print, by telephone, in Braille, on cassette etc. It should be suitable for face-to-face and telephone advice and available in appropriate minority languages. At no time should the content, format or method of delivery be determined solely or primarily by the availability of a particular technology.
- Unless unavoidable, no charge for information should be made to users.
- Matters relating to effective information provision, as suggested above, should be included in the induction, education, awareness training and retraining of all relevant and concerned professionals and service providers at national, regional and local levels.

⁷⁷ <http://www.officefordisability.gov.uk/working/improvinginformation.asp>

⁷⁸ National Information Forum, Newsletter No 4, 2008

- The effectiveness and value of information provision should be monitored on a planned and regular basis. The monitoring process should include independent assessment by means of direct user feedback.
- Information services should be widely publicised, by whatever means may be suitable, with regard to availability and accessibility.

Quality objectives from NDIP⁷⁹

National information providers should:

- Be needs led and accountable to users
- Be well publicised
- Be accessible
- Be responsive
- Be accurate
- Be appropriate
- Be confidential
- Be independent and impartial
- Operate an equal opportunities policy
- Provide users with means of feedback and redress

⁷⁹ Improving the provision of national disability information, Nick Moore, Jane Steele, Carolin Boswell, Policy Studies Institute 1994