King's Fund

Autonomy for disabled people

Mutual problems, mutual solutions

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Foreword

Everyone has the occasional experience of being prevented from doing things that we want to do and that we are capable of doing. But whilst it is relatively rare for most of us, for around 14% of the population significant disabilities *regularly* interfere with their functional activities (Martin, 1988).

Impairments can restrict people's ability to carry on their day to day lives independently. As a result, they must rely on help from others – they are *dependent* on them.

Dependence survives so well because our attitude towards it rests on several insecure and all-too-rarely challenged assumptions. Firstly, it is quietly accepted as unavoidable. This is certainly not true. The authors have yet to meet a dependent consumer who could not do more of what she wanted for herself if she had the right environment, equipment, products and appropriate supporting services.

It is also assumed that allowing dependence to persist costs society little or nothing. This is highly questionable. It is difficult to work out the costs of, for example, giving up work or study to look after a member of the family. As a result, the sums are hardly ever done. If they were, the costs might well turn out to be very high.

There is a further assumption that service-providing agencies must either cope by themselves or else pass responsibility on to another agency. For a clear example of fragmented services, one need look no further than the provision of services for disabled people. Provision is mostly a patchwork of well-meaning individuals struggling to make an unplanned, and incoherent system work.

Recently, a number of influential papers and reports have highlighted the need to address dependence squarely. These include the Disabled Living Centres Council (1999), SCOPE (1998), RICAbility (in press), the King's Fund (1998a, and in press) and the Audit Commission (2000). Each has highlighted existing problems – in terms of how consumers see things themselves; ineffective service planning; the lack of essential information for consumers; and the inefficient use of resources.

This report takes these studies as the starting point for analysing the problems, suggesting how they are caused and suggesting a new, mutual approach to overcoming them. It is a very serious piece of work, and policy makers, service providers and voluntary agencies alike should read it carefully.

If the government is truly committed to 'joined up service provision,' here is a clear place to start.

Rabbi Julia Neuberger, Chief Executive, King's Fund

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For policy makers

Around 14% of the population are thought to have significant disabilities that interfere with their functional activities (Martin, 1988). There is a rising aging population in the UK suggesting that this percentage will continue to increase over the next 20 years. In addition to this there is evidence that the levels of current informal care (the majority of which is currently provided by female relatives) will be difficult to maintain in the future due to changes in demographics and the rise in female employment.

These combined factors point to the need for an urgent review of policy to address the issues of dependence in the 21st century.

Dependence degrades the quality of life for disabled, elderly and sick consumers, and also places heavy demands on carers and support agencies.

The assessment of dependent consumers' needs are not been designed to be compatible with each other and their data cannot be put together or analysed. As a result, it is not possible to:

- amalgamate and analyse individual's assessments
- generate a comprehensive picture of consumer needs
- reveal and quantify potential new markets
- estimate the actual costs of consumer dependence
- compare the effectiveness of equipment and services.

All of the above information is essential if services are to provide cost-effective and streamlined responses to consumers' needs. In addition, it would provide policy makers with the evidence they need in order to develop an informed approach to measures to tackle the problem of dependence.

Suggested action

Although these problems are widespread and severe, they are nevertheless likely to respond to straightforward and available remedies.

It is unlikely that the mutual problems of dependence could be overcome by any one stakeholder working in isolation. The King's Fund therefore recommends the establishment of the Forum for Autonomy, Choice and Innovation to establish new partnerships, new approaches and to develop better methods of gathering and analysing the evidence they need to use their resources to best effect.

The Forum's three initial programmes would gather evidence on:

- Consumer dependence (its nature, scale and patterns)

- Responses to dependence (the availability and effectiveness of equipment, products services and policies for restoring autonomy)
- Human and economic effects of dependence (the penalties for the stakeholders when consumers remain dependent instead of regaining their autonomy)

Addressing the issue of dependence requires widespread cross-sectoral collaboration in a field that is currently so fragmented that it provides an ideal example of an area in which 'joined-up services' are urgently required.

For service providers

Dependence degrades the quality of life for disabled, elderly and ill consumers, and also places heavy demands on carers and support agencies.

The assessments of dependent consumers' needs made by different agencies have not been designed to be compatible with each other, and the data cannot therefore be put together or analysed. As a result, it is not possible to:

- amalgamate and analyse individual's assessments
- generate a comprehensive picture of consumer needs
- reveal and quantify potential new markets
- estimate the actual costs of consumer dependence
- compare the effectiveness of equipment and services.

Service providers must respond to the needs of dependent consumers within tight, pre-determined budgets.

Only relatively minor levels of dependence can be resolved by any one agency working in isolation. More commonly a combined response is required from health, social support, benefit, housing and other agencies. These essential partnerships are impeded not so much by the existence of different agencies but by their lack of common, integrated, mutually agreed methods of revealing, costing and responding to dependence.

In order to respond effectively to the issue of dependence, and the needs of individual consumers, service providers need reliable information on the :

- nature, extent, and penalties of dependence
- actions that were taken
- effectiveness of the actions in restoring autonomy
- needs that remained unaddressed.

Suggested action

In response to these needs the King's Fund 1998 report *Better Beds for Health Care* recommended the establishment of the Forum for Autonomy, Choice and Innovation to establish new partnerships, new approaches and to develop better methods of gathering and analysing the evidence they need to use their resources to best effect.

The Forum's three initial programmes will be aimed at ensuring that service providers and the other stakeholders have the information they require to use their resources to best effect by gathering evidence on:

- Consumer dependence (its nature, scale and patterns)
- Responses to dependence (the availability and effectiveness of equipment, products services and policies for restoring autonomy)
- Human and economic effects of dependence (the penalties for the stakeholders when consumers remain dependent instead of regaining their autonomy)

The establishment of the Forum, underpinned by an IT system that would network the stakeholders and gather information to provide a cumulative evidence-base, would benefit all aspects of service provision.

Dependence: a hidden and mutual problem

This section provides working definitions for key terms, examines the nature and effects of dependence, discusses its causes, outlines who attempts to deal with it and the methods they use. We include a 'case-study' to show how dependence can affect a middle-aged man and his family. Using this case-study as an example, the penalties of dependence are analysed.

There follows a discussion of the effectiveness of existing methods of responding to dependence, together with the lack of evidence on the nature, causes, extent and costs of dependence and the effectiveness of different forms of intervention.

We then move on to discussing the effectiveness of existing methods of responding to dependence. In particular the lack of evidence on the nature, causes, patterns,extent and its costs of dependence and on the effectiveness of different forms of intervention.

The conclusion is that it is in nobody's interest to continue with ad-hoc responses to what is likely to be a major national problem.

Autonomy and its loss

Personal autonomy is highly prized in our society. It means that we can decide what we want to do, when, how and with whom. It enables us to match our lives to our own individual preferences and to develop our lifestyle as we wish.

Our autonomy and the quality of our lives can be restricted or lost in several ways - for example, through heavy commitments to caring for children or dependent family members, through straitened financial circumstances or through age, illness or disability. Alhough these factors can all affect a particular individual at a particular time, in this paper our focus is on the latter - dependence through age, illness or disability.

Consumers themselves frequently resent dependence and would much prefer ways of restoring their own autonomy. Dependence can also place heavy restrictions on the lives, activities and resources of those who are helping and providing care.

Consumers may require high levels of support that is provided informally (by family or friends) or formally (by statutory services or privately employed assistants). There is evidence that the levels of current informal care (the majority of which is currently provided by female relatives) will be difficult to maintain in the future due to changes in demographics and the rise in female employment (Allen et al, 1995).

What is dependence?

As a result of age, illness or trauma, people can find themselves unable to move or get about easily, use their hands, see, hear, communicate or understand precisely what is happening.

These problems can prevent them from going where they wish or doing what they choose and can disrupt almost every area of their lives.

Table 1: Working definitions of key terms

Consumers	People who are impaired by disability, age or illness, whose needs are responded to by services and retailers in the sectors of health, housing, transport, education, employment and social services
Stakeholders	Individuals or organisations who use or provide wheelchairs or support services for consumers
Function	Whatever is done by consumers
Mobility	The process of moving between functional settings
Autonomy	Mobility or function without help from other people
Dependence	Mobility or function which is either impossible or which can only be undertaken with help from others
Needs	Requirements of the disabled person to carry out activities of daily living
Wants	Extra things that the consumer would like to do, such as hobbies, recreation etc
Revealing need	Exposing the factors that are necessary in order for the consumer to carry out their required activities
Responding to need	The action that is taken to address the need, in the form of services, equipment or adaptations
Systems	Areas that the consumer interacts with eg products, environments, services

Consumers often find that parts of their lives that they had previously taken for granted have suddenly become difficult, dangerous or impossible for them.

For example, a good cook's meals may deteriorate, or even become dangerous, when their sight begins to fail and they cannot read their labels or watch their pots closely. People who are used to climbing stairs, carrying heavy loads and getting things out of hard-to-reach cupboards will find their activities are restricted if they can no longer stand, walk, bend or stretch.

How is dependence caused?

Many products or environments appear to have been designed on the assumption that all their users can see, hear, speak, stand, walk, climb stairs, manoeuvre in confined spaces, reach and use their hands freely. Such assumptions take a heavy toll by excluding those who lack these capacities.

Making choices, accepting responsibility and taking opportunities are essential and desirable parts of life and its activities. However, people can only do this if they can use the systems (including facilities and products) they require.

Unless systems are designed and chosen to match their users' requirements and capacities, some will be unable to use them fully, effectively, easily, safely or comfortably. Some individuals can make up for problems that are 'designed-in' to products and prevent them being user-friendly. To do this they must compensate for the product's problems, for example by using greater strength to open an awkward jar, or scrutinising a video or audio tape to find out how to remove the wrapper. However, these problems 'filter out' many elderly and disabled people who may not have these capacities.

The user-population represents the full spectrum of physical, sensory and cognitive capacities in the United Kingdom and includes those with high and low capacity. The effect of systems such as town centres, supermarkets, photocopiers or computer programmes that impose demands on their users is to reduce the percentage of the total population that can use each system. Highly demanding systems impede or exclude large numbers of their potential users. Those that place low demands on their users, on the other hand, can be safely and effectively used by virtually the entire population (Mitchell et al, in press a).

Case study

The consequences of illness and products and environments that are difficult and demanding to use can be seen in these examples which have been taken from a study of wheelchair consumers.

Mr A was a building contractor until he lost both his legs shortly before retiring two years ago. Otherwise he is a strong and capable man in his late fifties. If he had suitable wheelchairs he would have plenty to do around his home in maintaining and decorating it, looking after his garden and helping his wife. Outside the home he would go for walks with his twenty-five year old son who has learning disabilities, go shopping with his family and play snooker or bowls.

His present self-propelled wheelchair does not enable him to do any of these things. All he can do is to get into his bedroom, bathroom and living room and the seat is so uncomfortable for his short stumps that he spends all day on the sofa. If he propels up his steep drive, the wheelchair tips over backwards.

Instead of being able to spend his time helping his family, Mr A and his son are now entirely dependent on his wife. The housing department has installed a lift to his bedroom and community health services have provided a special bed. Social services will not be faced with the potentially very heavy costs of supporting the family for as long as his wife's health holds out.

This consumer is not unusual. Each of the 143 people who took part in the survey (Ohras et al, 1997) believed that given the right equipment and settings, they could have regained much of their autonomy and improved the quality of their lives and those of their households.

Stakeholders in autonomy

A number of different agencies have an important 'stake' in restoring autonomy to disabled people. Each is penalised when disabled people remain dependent.

Table 2: Stakeholders

Stakeholding group	*Who they comprise*
Consumers	Consumers and Carers
Local Employers	Organisations seeking consumers' skills & productivity
Commerce	Manufacturers, Leasers and Retailers of equipment
Statutory Services:	
NHS	Hospital and Community Health Services providing care, treatment, rehabilitation, nursing home care and the supply or loan of wheelchairs, health care beds and other equipment
Employment Services	Service providing support and adaptations to support disabled people in work
Local Authorities	Social Services providing support and care in the community and residential care
	Housing departments providing housing, rehousing and adaptations
	Education, providing school and tertiary education and linking with Further and Higher Education
Benefits Agency	Providing benefit for those who cannot work or care independently for themselves or their dependents
Local and National Exchequers	Who lose Council Tax, PAYE, NI and VAT when disabled people cannot fully support themselves or their households

Penalties of dependence

If consumers cannot regain their autonomy they may have to give up valued activities or parts of their lives, or depend on help from either friends or family, or from support services. In a survey of wheelchair consumers that was conducted for the Wheelchair Lifemap project (Ohras et al, 1997) none of the respondents were content to lose their autonomy. They all wished to do more than was possible at present.

Costs of dependence

As a result of hostile living and working environments many disabled people find their choices and opportunities can be severely restricted, even in their own homes. Instead of being able to go where they wish and do what they want, they find that they are confined to the places and activities that are accessible rather than those that they would personally prefer. They often lose their autonomy and must depend on other people either to help them or even to replace them when they can no longer undertake their key roles and responsibilities.

McNamee et al (1998) carried out a study to establish the costs of the support of frail, older people. As they state, there is currently little information around the health and social care costs of dependency in the community setting. They compared the costs of those with high functional ability in activities of daily living (ADL), those with low functional ability and those with changing conditions. The study showed that the main impact on costs was when someone was admitted to some type of institutional care. The implication was that keeping people within the community through prolonging functional ability would show cost benefits.

Research has shown that suitable housing and adaptations can result in a decrease in the amount of personal assistance that disabled people require, which can therefore offset some of the money spent on adaptations (Nocon, 1998).

In a survey of wheelchair consumers conducted for the Wheelchair Lifemap project (Ohras) none of the respondents were content to lose their autonomy. They all wished to do more than was possible at present. People from a wide range of ages and backgrounds reported that their lives were spoilt and diminished by not being able to visit their friends, do their shopping, look after their children, go to work or go on holiday.

The survey respondents believed that, given the right equipment and settings, they could have regained much of their autonomy and improved the quality of their lives and those of their households. Instead, they felt that environmental barriers and inadequate wheelchairs prevented them from doing what they wanted and kept them dependent on help from others.

Stakeholders can face financial losses in a number of ways if dependence is not relieved. Although equipment suppliers benefit from helping to overcome consumer dependence, each of the other stakeholders is directly penalised when consumers become dependent and unproductive.

Table 3: Financial losses as a result of dependence

Costs are incurred when:	
consumers can no longer	• maintain their work or businesses profitably • contribute to local productivity and profitability • care for dependent members of their families • look after and maintain their homes • undertake their own self-care
carers have to give up	• their work • other productive activities
consumers, health trusts, local authorities or social security must provide	• house adaptations • special or residential care or accommodation • short or long-term support • support from sickness or incapacity benefits
the National Exchequer loses consumers' contributions as a result of a reduction in their payments of	• PAYE • NI • VAT

The balance between the care of disabled people in hospitals and the community has changed in recent years. (Mitchell et al, 1998a). While formerly, many elderly or disabled people might have remained in hospital during their periods of greater dependence, a higher proportion are now being discharged into the community. The responsibility for supporting these dependent consumers falls upon their families and upon community and social services.

The Clinical Standards Advisory Group (CSAG) (1998) have reported that district nurses are suffering from high stress levels and low morale (Cohen, 1998) due to having to take on extra duties that are now carried out in the community because of earlier hospital discharges, and rising dependency levels within the community. The CSAG (1998) describes community health services for elderly people as being fragmented and over concerned with cost-shunting. This resulted in people being inappropriately placed in residential care homes rather than nursing homes or hospitals, purely as a cost-saving measure. This then puts further pressure on district nurses who care for those in these homes.

To date, attempts to address these problems have been largely initiated by the different stakeholders acting in isolation from each other and without full consultation with consumers themselves. It is obviously difficult for any one agency to ask other to use its own methods as a model for their own. However, such problems have less impact when consumer-centred approaches are used since each agency focuses its efforts on revealing and meeting these needs.

Assessments have not been designed to be compatible with each other and their data cannot be put together or analysed. As a result, it is not possible to:

- amalgamate and analyse individual's assessments
- generate a comprehensive picture of consumer needs
- reveal and quantify potential new markets
- estimate the actual costs of consumer dependence
- compare the effectiveness of equipment and services.

The statutory, voluntary and manufacturing sectors all have a responsibility and a role to play in breaking down these barriers and opening things up so that the stakeholders can work together in a productive way to help to reduce the overlap and wastage that can result from fragmented working methods and develop better ways of working that will benefit both consumers and themselves.

Shaping policy

This section examines the way that services for dependence have developed during the twentieth century and the growing emphasis on involving consumers in their own care and choices. It outlines the types of support that governmental and other agencies provide at present for disabled consumers and points out that the various agencies can only use their resources effectively and efficiently if they have found out properly what consumers need. Using examples from the areas of healthcare beds and wheelchairs the process of assessment and choice is analysed, concluding that consumers needs cannot be fully revealed by current methods.

The problems of age, disability and dependence are universal and enduring. Nevertheless, society has chosen to address them in a number of different ways over the previous century.

Until the 1970s attention was largely focused on providing care and support for disabled people, either within their homes or in institutional settings. It was within this context that Beveridge (1951) drew up the plans for establishing the 'welfare state' which included a 'benefits system' to provide support for disabled people. However, it did not provide them with the means of regaining their autonomy.

From the 1970s there has been an increased emphasis on identifying and meeting individual needs and on increased user involvement in services, and towards an attempt to increase the empowerment and autonomy of disabled people.

Citizenship

The issue of citizenship developed out of the New Liberalism in the early 20th century. It was founded on the belief that 'citizens' should possess legal, political and social 'rights'. In turn they would contribute to that society. This idea was based around a patriarchal family-based system, assuming a working father, a mother looking after the home, children and dependent relatives. It took little account of anyone who fell outside that model, for example through disability. Women were automatically assumed to be the 'carers' of their disabled relatives, thus imposing dependence on both the disabled person and the carer. However, the idea of citizenship has developed over the century into strong user movements with an increasing call for user involvement, particularly within health and social services.

The development of the welfare state provided disabled people with benefits that enabled them to live, but assumed that they were dependent people who did not have the capacity to work or support themselves. Consequently the 'support' which was given to disabled people did little to help them to become independent working people.

Oliver (1996) says:

> *''Benefits' which are not carefully related to the struggle for integrated employment and active social participation will constantly be used to justify our dependence and exclusion from the mainstream of life – the very opposite of what is intended... What we really need is to be helped to make our maximum active contribution to society as full members... '*

> *'the struggle to achieve integration into ordinary employment is the most vital part of the struggle to change the organisation of society so that physically impaired people are no longer impoverished through exclusion from full participation. Only when all physically impaired people of working age are as a matter of course helped to make whatever contribution they can in ordinary work situations, will secure foundations for full integration in society as a whole be laid.'*

Social model versus individual/medical model of disability

The social model of disability approach looks at disability with a view to identifying disabling barriers and finding ways of dismantling them; disability is viewed as a social construct and a social responsibility (Oliver, 1990; Marks, 1999; Moore et al, 1998). There has been a great deal of literature produced around this model, which developed in opposition to medical and individual models of disability which regard the individual's impairment as the 'problem', rather than the disabling environments and systems that surround them.

The impact of the disability movement

The development of models of disability has gone hand in hand with the rise of the disability movement. This rose in profile with the Independence for Life movement in the late 1960s and developed with the set up of the Union of the Physically Impaired Against Segregation in 1974 (Morris, 1997). This movement is part of the increase in consumer awareness and the rise of the user movement in general. This movement centred around the issue of direct payments for personal assistance and the right to live independently. This has developed into a strong disability movement today which continues to fight for the right of disabled people to live autonomously.

User participation

Documents published by the NHS Executive and the Department of Health throughout the 1990s were concerned with increasing user input into services (NHS Executive, 1996; Department of Health 1997; NHS Executive, 1999) and in involving consumers at the research commissioning level (Morris, 1996). There has been a move in terminology from calling people 'patients' to referring to them as 'consumers' and 'users' which is seen as an empowering change. A Standing Advisory Group on Consumer Involvement in the NHS R&D Programme has been set up, and there is a growing body of literature about consumer involvement in health services and health research.

The concept of consumer choice gives the consumer power rather than a passive role, but the issue of how much real power this transfers remains. The market approach which was adopted by the NHS in the 1990s, following the NHS and Community Care Act in 1989, set up of a system of quasi markets of 'purchasers' and 'providers', and encouraged a more consultative and empowering approaching, involving consumers and eliciting their views.

However, there are, as yet, few means of ensuring that service users' views are implemented, or that services are developed in direct connection with consumer views on the need for services (Alcock, 1996). In an analysis of the introduction of health panels in the NHS, Harrison et al (1998) found that

> *'Despite the engagement of a significant number of HAs in public consultation through health panels, none agreed to be bound by their decisions... all were careful to leave themselves with the ammunition to ignore the outcomes of user involvement and many were able to use it for their own internal political purposes'.*

They noted that the 'user card' was often used by practitioners and officials to back up a policy that they wished to implement when they were aware that consumers are in agreement with them.

There is now a need to move on from developing policy around consulting consumers to developing policy for implementing their views within the services.

Bloor (1997) poses the question of who is the 'expert' in a practice setting. As has been claimed over and over again in disability literature, the user is the real expert and the results of able-bodied researchers may often be viewed with suspicion by disabled people. Oliver (1996) states that

> *'Few of those who seek to speak for us or write about our lives take seriously the need to represent our views, our lives and our struggles accurately'.*

The Charter for Disabled People Using Hospitals (1992) defines as one of its key principles that 'A person who has learned to live with a disability is usually much better informed about it and the way to live with it than anyone else'.

In addition to the policies for user involvement in general within the NHS, specific measures have been introduced to involve disabled consumers.

In 1989 the Department of Health set out a framework for user participation in assessment in *Caring for People*, which laid down a statutory requirement to consult on community care planning.

Recommendations have also been made to increase the input of consumer organisations in the development of services. The Charter for Disabled People Using Hospitals (1992) was produced 'in partnership' with disability organisations. It stresses the necessity of consumer involvement and acknowledges consumer as being expert in the field. The document states that:

> *'it cannot be stressed too strongly that by consultation with disabled people, taking heed of what they say (and frequently of their key assistants also), nearly all unnecessary unhappiness and calamity can be avoided.'*

Change is needed from both the bottom and the top of the NHS structure. At the management level there is a need to give consumers a real input into policy initiatives:

> *'if quality policies are to be serious tools for effecting patient empowerment, they will have to pay much greater attention to the patient's view of clinical aspects of care'* (Gilbert, 1995)

Inevitably one of the major barriers cited is funding. Gilbert (1995) concludes from a review of literature on patient empowerment that *'It falls to providers to ensure that their services* *meet the needs and expectations of their patients'*, but admits that in the implementation of the ideas around increasing the quality of healthcare

> *'the best-intentioned purchasers can only invest small change in the pursuit of quality for its own sake, and without that investment many providers are unable to implement even the most obviously-needed improvements in process or access'.*

The NHS has produced document after document advocating user involvement and collaborative working strategies, but without the funds to invest in these issues there is a limit to what can be achieved. There must be financial backing to these proposals, and a commitment to implementation.

As Gilbert (1995) says:

> *'So far, the NHS has acquired the language of quality, but efficiency targets and short-term performance goals mean that effective action and genuine commitment rarely keep pace with the rhetoric.'*

Policy influences on disability services

The Chronically Sick and Disabled Persons Act of 1970 and the Disabled Persons Act in 1986 established statutory requirements for services for disabled people. Care in the 1990s has been split between health and social services, with a considerable grey area around the provision of some equipment and services.

Disabled people now have rights to need assessment and the creation of a care plan by social services, as a result of the policy shift towards user involvement. Alcock (1996) states that this development was an attempt to move towards creating collaboration between the services that provide care for disabled people but that it failed to meet the needs of disabled people as a result of resource cuts and that consequently more pressure came to bear on informal carers, a trend which has already pointed to earlier in the century in the discussion of the concept of citizenship.

The wheelchair voucher scheme was introduced in 1997, in response to the policy shift towards giving the consumer more choice. The consumer was now given the choice between being provided with an NHS funded wheelchair, or contributing to the cost of a more expensive chair, with a voucher being provided by the NHS for the equivalent value to the price of the NHS chair they would have been provided with. A number of other funding schemes also exist which can be accessed by those eligible for them, these include funding or provision of chairs for use to enable access to educational or employment settings. The consumer is now, in theory at least, given some choice over what wheelchair they have. However, choice is obviously restricted to those who can afford to contribute, and it must be remembered that disabled people are more likely to be unemployed, and have additional costs due to their disability needs than the able-bodied population (Alcock, 1996)).

The increasing focus on consumer involvement may well reflect the recognition among consumers and providers that this is an effective way of restoring life quality. In view of the penalties of dependence, it may prove to be a highly effective way of reducing these for the stakeholders.

Revealing and responding to dependence

This section brings together the themes of the previous discussions on dependence and the development of the response to this by examining the ways in which consumer needs are revealed and addressed. At present services are widely fragmented and have yet to develop common methods and measures. The process of 'joining-up' services needs a clear focus and objectives if it is to be successful. Consumers and their needs can provide not only the obvious focus but can also contribute considerable experience and expertise.

This section considers:

- present methods of revealing needs
- new holistic, consumer-centred methods
- the process of choice and innovation
- the evidence needed by stakeholders
- how evidence from consumers could be used to improve future choice and innovation.

How can autonomy be increased?

A number of studies have been carried out to develop methods of provision in conjunction with, and centring around, the consumer.

The Wheelchair Lifemap system was developed for the NHS Executive and user trials for the Department of Health concluded in March 2000 (Mitchell et al, 1998 and in press). The Wheelchair Lifemap is a holistic consumer-centred approach to wheelchair assessment. It comprises a series of questionnaires to be completed by consumers and assessors that aim to find out: what consumers want to do from their wheelchair; what improvements they want over any previous chairs; and what the main barriers are that impede them.

The system aims to provide information not only for consumers and assessors, but also for manufacturers for the future development of wheelchairs in the form of consumer feedback. It has the potential to be used as a model for developing assessment methods for other types of equipment.

Kasper, Mulley & Wennberg (1992) developed Interactive video shared decision-making programs in USA. Each addresses a particular condition and presents treatment options, personalised information on risks and advantages, and interviews with previous patients. This provides an excellent model for empowering patients in the context of individual care.

A study in Italy (Bernabei et al, 1998) conducted a trial on the impact of introducing integrated health and social care and case management to one group of consumers and compared them to a control group, using the outcome measures of admission to institutional care, use and costs of health services and changes in functional ability. The case managers were given intensive training and referral of consumers to services was through a community-based setting. There was close collaboration between the professionals involved in the consumers' care.

The consumers receiving the integrated care package showed lower rates of admission to institutions, fewer home visits by GPs, improved physical function and a lower rate of cognitive decline than the control group. They concluded that

> *'Integrated social and medical care with case management programmes may provide a cost effective approach to reduce admission to institutions and functional decline in older people living in the community'.*

They cited the key messages from their research as being that: the responsibility of care management of older people in the community is ill-defined; an integrated care management programme approach would improve the level of care; the results of reduced institutional admissions and slower rates of functional decline would result in reduced costs.

It would be possible for projects such as these to provide the basis for models of consumer-based involvement, choice and information around the full range of health and social care equipment and services for disabled people.

Responding to dependence

Dependence is caused by unsuccessful interaction between consumers and the systems they wish to use. Stakeholders have therefore attempted to restore autonomy by increasing consumers' capacities and making systems easier to use.

Rehabilitation is aimed at improving consumers' power, flexibility and control so that they can cope with demanding systems, such as bathrooms. However, there have been criticisms of the rehabilitation process by disabled people, who believe that it is sometimes an unnecessary intervention and following the medical model of disability that seeks to change the person rather than the environment that impedes them (Oliver, 1990).

Assistive technology is focused on the interface between consumers and systems. It uses products, such as hoists or wheelchairs, to effectively increase their capacities. Aids and adaptations, such as raised toilet seats and ramps, are also used to reduce the demands of 'unfriendly' systems to a point at which consumers can manage independently.

Inclusive design is an approach to development that can be used in both healthcare and mainstream products. It ensures that products are developed around user-friendly designs and enable the maximum number of consumers to use the system easily and effectively.

Two contrasting responses can be made to dependence which consist in either providing support for the individuals concerned without addressing their dependence or, alternatively, by challenging their dependence and attempting to restore their autonomy. These approaches are often used in combination by restoring autonomy for some activities and providing support for other, more intractable problems.

Supporting dependence

When people can no longer do what they want the obvious response is to step in and help them. A range of formal and informal support is used such as benefit and support services.

This approach has the important advantages of simplicity and flexibility. However the costs of long-term support may be high. The use of able-bodied helpers to meet the demands of difficult products and facilities also has two disadvantages. Firstly, helpers are may be exposed to the risks of handling heavy loads in difficult conditions. Secondly, no attempt is made to find out how the problems are caused or whether they could be avoided by better design.

Challenging dependence

Dependence is rarely welcome. Even if people need help urgently, they may still find it very difficult to hand over control to other people. Consumers prize their autonomy highly. Autonomy is also potentially very desirable for providers as well because it can reduce the costs of long-term support and enable some consumers to become economically active once more and resume their contributions to local and national taxation.

The two components of dependence are the people themselves and the demands of the products and facilities that they are attempting to use. Poor quality products and facilities place heavy demands on their users and, as a result, only those who are fully able-bodied can function relatively easily. High quality, 'user-friendly' facilities, on the other hand, place much smaller demands on their users. As a result, they can be used independently by people who would require substantial help in more demanding facilities.

For example, kerbs and steps are difficult to negotiate for people who use wheelchairs, prams or buggies. This may explain why so few of these users can be seen in inaccessible high street shops and pavements while many more use accessible hypermarkets, particularly if they have well planned public and private transport facilities.

Again, few blind people attempt to use 'hole-in-the-wall' cash machines because information is only provided for people who can see and read it. As a result, blind people can only choose the 'dependence option' and seek help from sighted cashiers.

Current support for dependent consumers

Service providers

Various national and local agencies address the needs of consumers who are dependent in the following ways:

Table 4: Service providers for dependent people

Organisation making provision	*What is provided?*
NHS	• treatment in hospitals and the community for illness or trauma to avoid or minimise subsequent dependence • rehabilitation to maximise remaining capacities • 'assistive technology' such as wheelchairs, to maximise autonomy
Department for Education and Employment	Support and assistive technology to enable: • disabled students to study in schools, colleges and universities • disabled people to get and keep employment
Benefits Agency	Various forms of financial support for consumers who are unable to support themselves financially or carry out essential living activities without help.
Local Authorities via departments of education, housing, social services and in some cases, equipment loan stores	variety of support services for disabled and dependent consumers including: • home adaptations • residential and sheltered homes • assistive technology
Commerce	Private sector: • support services • home adaptations • assistive technology
Voluntary and Charitable agencies, such as Disabled Living Centres, the Red Cross and Equipment Loan Stores	Equipment • demonstrations • loans and in some cases contributions towards the costs of: • support services • home adaptations • assistive technology

Assessment of need

As the King's Fund have pointed out (1998a), 'one-off' surveys of consumer needs can be highly influential and effective. Nevertheless, at the end of such projects the link between consumers and developers is severed. User problems cease to be exposed and innovation can slow down or even go into a 'time-warp'.

Systematic, routine feedback is needed to find out how particular products and services are performing. The marketplace, and needs assessments, are the two main potential sources of this evidence.

The most obvious way for consumers to influence the quality of their products and services is through the market place. Products will generally thrive when consumers buy it in preference to competing products. However, the healthcare market is not so straightforward (Mitchell et al, 1996). Responses are often chosen and paid for by a third party, they may only be used in very small volume and choices are often made with or by intermediaries who may not be aware either of the full range of options or of their relative advantages and disadvantages.

It can be particularly difficult for dependent consumers to find out about and compare different responses so as to choose the option that will suit them best. In consequence, consumers currently cannot expect their decisions and purchases to have much more than an marginal effect on the products and services they use.

Evidence from 'needs assessments'

Both consumers and providers must decide what is needed before they decide what action to take and how their available resources can be used to best effect.

Simple, everyday needs may require little conscious effort. However, the needs of dependent consumers are often both complex and demanding. If so, they need careful thought and assessment. Although consumers' needs are constantly assessed by a many different agencies, no attempt is yet being made to harness this rich source of evidence. There are a variety of reasons for this failure.

At present methods of assessment are in transition between standardized assessments for standard responses such as wheelchairs (Mitchell et al, in press), which do not require full and detailed assessment of needs, towards a more individualised market in which consumer preferences and circumstances have a much higher priority.

Before planners and designers can help to restore autonomy by developing 'user-friendly', inclusive designs, they must become aware of what is wrong with those that are already in use. Unfortunately, there is little evidence about the usability of either products or facilities by disabled people at present.

Facilities in the built environment are rarely evaluated by their users, either able-bodied or disabled. Access surveys have recently become more widespread, often in connection with applications to the National Lotteries Charities Board. However, few of the findings are placed in the public domain. As a result, there is little accessible documentary evidence of the problems that disabled people face in using even recently designed buildings and facilities.

Some specialised and 'mainstream' products have been tested by the Consumer's Association, RICAbility and the Medical Devices Agency for many years. Despite this work, only a small range of products have been tested and disabled consumers often have no evidence to guide them in choosing the products that would be most suitable for their purposes.

Feedback from disabled people who had used particular products or facilities could provide an excellent source of expertise to help other disabled people to choose the product that would suit them best. Though the internet would provide an excellent way of sharing these insights, so far there is little activity in the field.

Equipment retailers and health and social service staff regularly assess consumers' needs for products such as wheelchairs, for support services or for benefit. These assessments could provide valuable evidence about:

- consumers' profiles of need and dependence
- the effectiveness of chosen responses
- the costs of dependence and autonomy.

Unfortunately, since the assessments were not designed for this purpose the emerging data cannot be pooled, analysed, costed or used to help develop better responses.

Current methods of revealing needs

A large number of statutory, commercial and voluntary organisations have a stake in promoting better health care through improved choice and innovation of equipment and services. None of these agencies can use their resources effectively used unless consumer needs have been fully and effectively revealed. At present, each of the stakeholder agencies uses its own methods for assessing the entitlement to equipment, benefit, services and the liability for tax. These methods are intended to assess individual cirumstances rather than to describe and analyse the overall position.

The result is a multitude of systems that are unable to reveal and respond to individual needs because assessment methods don't collect users' needs properly. These methods are ineffective and fragmented: no routine feedback is collected from consumers; there is no evidence about the effectiveness of products, services or facilities; information about products is fragmented, inconsistent, unreliable, out-of-date and difficult to assess and use. The Audit Commission (in press) describe the organisation of disability equipment services as *'ramshackle'* and being *'more reminiscent of a feudal state than a modern, co-ordinated, user-focused service'*.

Focusing on consumers and assessing their needs

Effective, well-chosen healthcare products and services can help to restore autonomy and quality of life to dependent consumers. All the stakeholders would benefit if these choices and responses were improved still further. The essential factor to underpin these improvements is the involvement of the consumer.

The central stakeholders in these improvements are consumers themselves for a number of reasons. Consumers are the only stakeholders who can speak with authority about:

- their own needs and priorities
- whether a product or service met their needs.

Their needs are the common target for all forms of response to dependence. The needs are also the ultimate measure of the success of these responses because providers can only be sure they have hit the target by examining it carefully.

The analogy of a common target might also suggest how the present patchwork of fragmented services could work together more closely and effectively as the government has suggested (Department of Health, 1997; NHS Executive, 1999). It might be difficult for any one provider such as the NHS, social services, the Benefits Agency or commerce to persuade the others to subscribe to its own priorities and strategies for restoring autonomy. Since consumer needs are the common target for each provider they could be used to enable the stakeholders to develop common approaches and strategies.

Consumers must be an active catalyst to enable providers to use their resources more effectively. The inclusion of consumers in the process is such a simple and obvious step that it is difficult to imagine why they are not already there.

All providers use some form of assessment to decide what action to take and whether the consumer is eligible for any form of assistance. However, assessment need not be used solely for taking decisions on immediate action. It could be used to provide the missing feedback between consumers and providers and be used to evaluate the effectiveness of the actions that were taken. Further, they could begin to assemble the ‘evidence-base’ that is needed to improve choice and innovation in the future.

Before assessments could provide this rich source of evidence they would have to be capable of revealing and recording in detail the nature of consumers’ dependence, the actions that were taken and whether or not it was successful. It is likely that the emerging profiles of dependence could also be costed. It would then be possible to assess the likely human and economic consequences of restoring autonomy instead of simply supporting dependence.

However, wheelchairs and other healthcare products can only provide autonomy if the consumer’s needs have been thoroughly revealed and matched up with products that have the necessary performance.

The essential starting point for both effective choice and innovation is that consumers’ needs have been fully and accurately revealed and recorded. Evidence from consumers is fundamental to improving the choice and innovation of responses to dependence. It will provide the basis for stakeholders to phase out responses that have little effect on dependence, to promote those that perform better, and to suggest how better responses could be developed in the future.

Analysing the process of choice

When the King's Fund was analysing the factors which affect the choice and innovation of healthcare beds (1998a) they identified a predictable process underlying the choice and innovation of all kinds of healthcare products. The process falls into four stages, each of which has specific goals and requires certain information to enable these goals to be met. The information generated about consumers' needs and about the quality and performance of the various responses to dependence can provide a sound 'evidence-base' for improving both choice and innovation in the future.

The same process also emerged from Mitchell and Bennington's analysis of wheelchair assessment forms. Each assessment and its components fitted readily into the sequence shown in Table 5 below.

Table 5: Stages in the process of choosing a wheelchair

1	Revealing consumers' priorities and problems	• e.g. arising from their lifestyle and responsibilities, their health needs, the functional and environmental barriers they face and their social and recreational requirements
2	Choosing a suitable TYPE of wheelchair	• having suitable performance for consumer's needs
3	Choosing a suitable MAKE and MODEL	• meeting the required performance, cost-effectively and including necessary fittings and adaptations
4	Evaluating the chosen wheelchair	• in terms of restored autonomy, matching the consumer's priorities and problems and reliability and low maintenance

Stages 1 and 4 focus on consumers. Stage 1 is used to reveal their needs and priorities while Stage 4 reccords their evaluations of their chosen wheelchairs.

Stages 2 and 3 are concerned with the responses that can be made to these needs. Stage 2 is concerned with finding suitable types of wheelchairs whose performance specifications could match consumers' profiles of need. If a suitable type of wheelchair can be found, Stage 3 is concerned with finding the best available make and model.

Linking the processes of choice and innovation

In view of the interdependence of choice and innovation, it important to find out if there are any similarities between the emerging process of choice and the widely accepted accounts of the process of innovation (Archer, 1967; Richardson et al 1996; Urban and Hauser, 1993; and Wheelwright and Clark, 1992).

These authors agree that innovation should be based on an understanding of consumers' needs and their evaluations of existing and prototype solutions. This suggests that information from Stages 1 and 4 of the process of choice would therefore provide a valuable source of evidence for innovators.

There is divergence between the two processes at Stages 2 and 3. While choice is concerned with products that are immediately available, innovation is concerned with the development, testing and refinement of prototypes.

What information do stakeholders need?

None of the stakeholders has all the information they need to use their resources to best effect. The information they need is available from one or other of the remaining stakeholders.

All the stakeholders require accurate information in order to enable them to make informed and cost-effective decisions. The information the different stakeholders need may vary, but it is inter-connected, and the needs could all be met through a cohesive information provision system hosted by a cross-sectoral Forum.

Table 6: Information needs of stakeholders

Stakeholders	*Aims*	*Information needed*
Consumers	To obtain equipment and services that meet their needs	Up-to-date, reliable information on available products and services
Providers	To meet the needs of consumers within their budget limitations	Accurate information on available equipment; feedback from consumers on the effectiveness of what was supplied
Manufacturers	To increase their standing in the market and develop successful new products	Feedback from consumers on existing products and what needs to be developed

For example, providers and innovators both require good quality information from consumers about their needs and problems covering the:

- nature, extent, and penalties of dependence
- actions that were taken
- their effectiveness in restoring autonomy
- the needs that remained unaddressed.

Choosers and providers need to find out from consumers, providers and innovators/suppliers:

- what consumers need
- what is available to restore their autonomy
- the human and economic costs of their dependence
- how the chosen response is likely to perform.

Once the consumer has used the chosen product or service, all stakeholders need to find out how well it performed so that they can weigh up its human and economic effects for future planning and provision.

Information from consumers and from providers is also needed by regulators, information providers and innovators to enable them to prioritise and focus their activities.

Integrating choice and innovation

From the above it is clear that all stakeholders could benefit from much clearer evidence on:

- consumers' priorities and problems
- the responses made
- their effectiveness in restoring autonomy
- the human and economic effects of dependence.

Routine assessment of consumers needs by themselves and by the other agencies involved could provide this evidence. The problems which prevent its collection at present could be overcome by developing common methods for revealing, analysing and responding to consumer need through the development of consumer-centred, holistic 'tool-kits' using currently available IT methods.

The evidence from these 'tool-kits' could then be fed into and analysed within a an IT system in order to generate a unique 'evidence-base' to promote the choice and innovation of responses to dependence.

Current fragmentation

Although all providers use some form of assessment in an attempt to find out what their consumers need, their methods are not always compatible. This section examines the variety of different methods that are used and the consequent impossibility of amalgamating the data to produce a coherent evidence-base on dependence.

Consumers' needs can be assessed by a wide variety of different agencies. Tables 7 and 8 below show some of the agencies in England that can assess consumers' mobility and related needs.

Table 7: Assessments of mobility and health

Statutory	NHS Wheelchair Centres (approximately 150)
	Community Health Care Teams
	Special Seating and Support Clinics
	NHS Equipment Loan Stores
	DfEE Disabled Students' Allowance
	DfEE Access to Work Scheme
Commercial	Wheelchair Retailers (approximately 200)
Voluntary	Disabled Living Centres (40)
	Transport and Mobility Centres (11)
	Charitable Trusts (eg the Red Cross)

Table 8: State agencies addressing related needs

National	***Local***
Department of Health	Social Services
Benefits Agency	Housing
Further and Higher Education	Equipment Loan Stores
	Other Local Authority Departments
	Schools

Inter-agency collaboration

A large number of statutory, commercial and voluntary organisations have a stake in promoting better health care through improved choice and innovation of equipment and services. At present, each of the stakeholder agencies uses its own methods for assessing the entitlement to equipment, benefit, services and the liability for tax. These methods are intended to assess individual circumstances rather than to describe and analyse the overall position. Support, guidance and home trials are fragmented and disorgansed. Assessments have not been designed to be compatible with each other and their data cannot be put together or analysed. As a result, it is not possible to:

- amalgamate and analyse individual's assessments
- generate a comprehensive picture of consumer needs
- reveal and quantify potential new markets
- estimate the actual costs of consumer dependence
- compare the effectiveness of wheelchairs or other equipment or services for disabled people.

These problems are shared by all the stakeholders and they cannot be resolved by individuals or organisations working in isolation. Without agreeing coherent working methods, existing efforts and resources are dissipated and unproductive. These stakeholders have no established forum where they can meet to express and pursue their mutual interests in choosing and developing better products. This absence limits and impoverishes their opportunities for joint planning to identify and meet their common priorities.

A Disabled Living Centres Council (DLCC) project which aimed to develop good practice guidance for disability equipment services found that the low level of user involvement and limited collaboration between services were hampering the provision of equipment. Winchcombe (1998) states as one of the main findings of the project that

> *'Collaboration at strategic, as well as operational levels, is essential to ensure that all the service components work effectively together.'*

This research that was carried out by the DLCC in a two year project. It aimed to develop good practice for the planning and review of disability equipment services, collaboration with other agencies involved in the care of disabled people, and improving the efficiency of the services.

The study revealed a number of issues that need to addressed urgently in these services:

- Lack of inter-agency collaboration. This is of particular importance in the sphere of disability services because of the high percentage of people who are assessed by more than one agency, as has been shown in the outline of the Lifemap project above.
- Lack of follow-up assessments for equipment and of feedback about how effective the equipment is.
- User involvement in the planning, implementation and on-going monitoring and evaluation of services.

The main findings of the project were a need for:

- collaboration at strategic and operational levels between different areas of the service through consultation with users about service planning and about feedback about equipment in use

- better information for users and practitioners
- better use of resources.

The case study introduced in section 'Dependence: a hidden and mutual problem' shows how someone's activities can be considerably diminished through lack of equipment provision. The future costs in terms of support from social services could easily exceed the cost of providing better equipment at an earlier stage. This would extend the period of the consumer's autonomy and avoid or diminish the pressures that could come to bear on carers and services in the future.

Section 29 of the Health Act 1999 offered a major opportunity for taking this collaboration forward by inserting into section 28A of the NHS Act 1977 the authority to enable the transfer of funds from the NHS to local authorities for health related activities, where this transfer will improve the health of local people more effectively than its use by the NHS. A reciprocal arrangement allowing transfer of funds in the other direction (from local government to the NHS) will come on line from April 2000.

Marks (1998) also recommends that partnerships be set up between stakeholders in the equipment provision sector in her report for SCOPE, and that consumers should be consulted throughout the processes of developing and providing equipment.

Some wheelchair services and social services departments are now beginning to set up collaborative working practices in order to try to address the lack of collaboration in the service provision for wheelchair consumers (Mitchell et al, in press). One of the problems is the fact that stakeholders can view the same problem from different perspectives, and that the barriers this creates can cause confusion and problems for both users and practitioners, and lack of communication between the agencies only serves to augment this. However, this move is far from universal and there remains a level of fragmentation between the services that results in a reduction in efficiency and a waste of resources.

Quality of evidence from assessments

Not all data from assessment is necessarily of good quality. All of the wheelchair consumers survey about their priorities and problems in 1996 for the Wheelchair Lifemap project (Ohras, 1997) reported that some of their needs had not been identified during assessment. As a result they felt that they remained dependent in parts of their lives in which, given a suitable wheelchair, they might well have regained their autonomy.

Mitchell and Bennington (in press) analysed some fifty of the assessment forms used to reveal consumers needs for wheelchairs and related equipment. They found that they were not consumer-centred or holistic and did not identify needs that could not readily be met from the available stock of wheelchairs. Furthermore, none of the assessments studied asked consumers to rate the quality of their new wheelchair and none suggested involving 'linked services' such as housing or social services in joint planning to address the consumer's problems.

The King's Fund reported in 1998 that, at the time, there were no methods for revealing users' requirements from healthcare beds (King's Fund 1998a).

In a study of the housing needs of disabled people in Shropshire, Nocon (1998) stressed the fragmentation between the agencies involved in the provision of housing and adaptations for disabled people. Some of the problems can be seen as stemming from a lack of specialist knowledge of disabled people's needs and of the issues of disabling environments among professionals, such as OTs, in these sectors (Abberley, 1995).

Nocon says that:

> *'The lack of clear definition in community care policy means that individual SSDs, practitioners or their professional bodies will interpret independence in different ways – and, in the process, often fail to acknowledge or respond to disabled people's own experiences and needs.'*

The findings of the study highlighted the fact that disabled people have *'needs that can only be identified by allowing people to specify what barriers they encounter in their daily lives'*. The findings also showed the necessity of involving disabled people at all stages of service planning and provision:

> *'Whether in assessing needs, identifying the services required, selecting the location of alternative accommodation, designing new properties or installing adaptations, disabled people called for the right to be treated as partners in the way their needs are met... this could save resources, for instance by not having to replace inappropriate adaptations.'*

Integrating and upgrading evidence from assessments

None of these problems are insoluble. It is perfectly possible to develop tool-kits for revealing consumers' needs that can be used by the full range of stakeholders. It is also possible to develop holistic, consumer-centred assessments. For example, the Wheelchair Lifemap was developed jointly by an R&D team from Sheffield Hallam and Loughborough Universities, commerce, the NHS, the Spinal Injuries Association and RICAbility. The King's Fund's developed its guides to choosing healthcare beds in collaboration with consumer, commercial and NHS stakeholders.

The problems are dissemination, collection and analysis. It is costly and time-consuming to analyse information on consumer priorities and problems when these are collected on paper forms and consequently this is rarely done at present. However, when IT is used for this process it will be simple and cheap to disseminate assessments on-line and to collect and analyse the resulting data. This can be achieved through the gradual introduction of compatible IT systems into the industry.

Inadequate information flow

Methods for sharing information about disability equipment between purchasers, providers, users, evaluators and developers are, as yet, poorly planned and set up. There is no system which provides the up-to-date, comprehensive and reliable information which is required to ensure that human resources in health and social care are not wasted on poorly chosen or poor quality equipment or adaptations.

Neuberger (1998) stresses the importance of providing good information for consumers in a variety of formats, and highlights the use of IT initiatives as a means of both providing consumers with information and gaining their feedback on services that they have used.

Information provision is the starting point for increasing user input into service provision. This in turn can lead to a better inter-professional dialogue. As Neuberger (1998) states:

> *'by making the patients take more responsibility for decisions, it allows the health professionals to talk to each other in a different way. That is really important in engendering a different sort of debate about how patients and users of services think about life and illness.'*

In a report produced by SCOPE around equipment provision, Marks (1998) highlights the lack of good quality information provision in this area:

> *'Respondents highlighted numerous difficulties with information: not knowing where to turn for information; professional staff who gave biased or inaccurate information as a result of their concern over budgets; bureaucracy and poor communication between statutory departments and agencies; the lack of places to try out products.'*

Nocon (1998) found that information provision around housing provision was poor and that people often did not know what options were available to them. He links this to the failure of services to identify or meet people's needs or to record this information. He believes that

> *'If disabled people's needs are to be fully and appropriately met, it is vital that agencies should obtain information about the nature of those needs and design appropriate policies for meeting them.'*

Much of this information is already available. It is often a matter of co-ordinating and distributing, rather than producing information from scratch. The Charter for disabled people using hospitals (1992) states that:

> *'National support groups for specific medical conditions remain insufficiently recognised and promoted within hospitals. Many of them provide informative literature and their regional workers can be invaluable sources of advice and support.'*

All providers need to understand fully the nature of the problems that they are addressing, the effectiveness of their present responses and the roles of other providers. At present because of the poor quality of assessments, and the impossibility of combining them to produce a multi-sectoral evidence-base on dependence, they cannot achieve this essential goal.

Systematic choice and innovation*

Proposals and suggestions

Routine collaboration can enable each stakeholder to get the information they need to use their resources to best effect. At present, this is not possible, since the necessary information is not collected, analysed or passed on.

The two components of dependence suggest two approaches to challenging it. Rehabilitation and training services are well-established ways of enabling consumers to cope with such 'hostile' situations. However, there is no reason why the products and facilities which place such high demands on their users should not also be rehabilitated, have their barriers removed and become more 'user-friendly'. Indeed, many disabled people feel that the removal of such barriers is an essential step towards autonomy and full participation in society.

This 'inclusive' approach would need to focus not only on specialised healthcare products, such as wheelchairs, beds and hoists but also on 'mainstream' items such as buildings and consumer products.

This approach has the advantage of maximising choice and quality of life for disabled people and their carers and of minimising their long-term support costs.

The task of 'remodelling the world' should not be underestimated. Many familiar mainstream and healthcare products and facilities place heavy demands on their users. Earlier producers may well not have recognised that disabled people form a substantial part of the population and the markets for at which they are aiming

Present arrangements are fragmented and lack a 'common thread'. This cannot be resolved by any one agency working in isolation. All stakeholders should be encouraged to work together to decide how to improve the system as a whole.

Effective links are needed between those who choose, use, evaluate and develop products and services. User needs have been revealed, analysed and responded to effectively on many occasions by 'one-off' developments. However, if user-innovator links are severed at the end of such projects, subsequent user problems can remain undetected and unaddressed.

The need for links betwen users and innovators has been recognised for many years. The science of ergonomics is concerned with the quality of the interface between users and their equipment, facilities and systems. A number of design/development methods have been proposed to ensure that effective consultation takes place between users and innovators.

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* Much of this section has been abridged. with permission, from Ricability's report *Report of the Wheelchair Lifemap User Trials* (Mitchell 2000).

These have been described by a number of authors (Archer, 1965; Urban and Hauser, 1993; TIDE; Wheelwright and Clarke, 1992).

These methods are intended for use in single, 'one-off' projects, such as the development of the King's Fund's specification for acute hospital beds' during the 1960s, and lack the necessary aspects of feedback and ongoing evaluation. Though this project was an outstanding success, opportunities for routine user feedback were not taken up (Mitchell et al, 1998). As a result, problems which were familiar to bed users remained undetected and unaddressed. Instead of developing specifications for more advanced beds to match the changing conditions of modern health care, few changes occurred.

Good routine feedback between users and innovators can be readily established by linking the routine functions that each undertakes. A 'common tool' is needed for universal use in equipment provision. A tool such as the Wheelchair Lifemap is well placed to begin the integration of mobility and functional assessment within the health and welfare services and generate comprehensive, up-to-date information as a matter of routine, and could be extended to other areas of equipment provision. This would meet the recommendations of the Audit Commission (in press) who stress the need for assessment to be addressed in a holistic way, based on the needs of consumers and including evaluation and feedback.

The remodelling of products and facilities requires firm evidence of the functional problems that disabled consumers face, the costs of their resulting dependence and the effectiveness and of different ways of addressing this dependence.

If it is to be successful this approach requires effective methods for:

- revealing consumers' profiles of need and dependence
- matching their needs to suitable products and facilities
- establishing the human and economic benefits of different responses
- innovating better products, services and facilities when required.

Because so many agencies are involved in assessing consumers' needs and providing information about possible responses, very little useful evidence is available at present to guide choice and innovation.

The nature of individual dependence is not collected at present. As a result, the overal extent of dependence, its responsiveness to different forms of intervention and its costs are impossible to estimate accurately.

Partnerships for autonomy

One way of beginning to address the needs of disabled people and establish a coherent approach to addressing dependence would be to establish an entirely new body, the Forum for Autonomy, Choice and Innovation. This new body would bring together representatives of all those who have an interest in reducing the burdens of dependence and maxmimising autonomy for disabled, elderly and sick consumers.

The Forum would do this by developing systematic, consumer-centred methods to find out precisely what consumers need, what actions were taken and if autonomy was restored or not.

To achieve this, the Forum needs the following three R&D programmes to reveal:

1. Consumers' needs and dependence
2. What products and services are available, and how effective they are
3. The costs (human and economic) of dependence.

Programme 1 is the most fundamental. Without a clear benchmark of individual consumer's needs and priorities it is impossible to choose responses or to evaluate them effectively.

Programme 2 would be concerned with developing accessible information about products and services that can be used to restore autonomy, and evaluating their effectiveness.

Programme 3 will use the information gathered by programmes 1 and 2 to calculate the costs of dependence and evaluate the human and economic effects of available responses.

Stakeholders will control these programmes through the Forum, which will develop mutual policies and strategies for restoring autonomy and oversee the R&D work under the various programmes.

Outline of proposed R&D programmes

The following proposed programme of work comprises:

Three inter-related research programmes which involve: finding out what consumers need (programme 1); matching these needs to the products and services available and evaluating these responses (programme 2); and establishing the costs and effectiveness of different measures of addressing dependence (programme 3).

Each of these programmes contains a number of sub-projects that could be carried out either in parallel or as a series of independent projects. However, programme 1 would need to be set up first to provide evidence on need as a basis for the subsequent work. It would be essential that the work on programmes 1 and 2 was carried out before the analysis of costs and effects in programme 3 could begin.

R&D Programme 1: Revealing consumer needs and dependence

Programme 1 aims to reveal the profiles of need, priorities and dependence of individual consumers by using holistic, consumer-centred assessments.

It is envisaged that the Wheelchair Lifemap and the King's Fund's Guides to choosing healthcare beds will be further developed and that IT versions will be produced and tested. If these prove to provide the essential data on consumer needs they will be used as the starting point for developing a series of 'tool kits' or even a 'universal tool kit' for revealing consumers' priorities and problems in all areas of dependence.

Programme 1 will develop these methods in conjunction with consumers and providers involved in this sector.

R&D Programme 2: Choosing and evaluating responses to dependence

Before effective responses to dependence can be chosen, consumers and/or providers need to know:

- what the consumer's needs are
- what products and services are available
- how effectively they address consumer's needs

Users currently face major difficulties in accessing and using information on available responses. This information is widely fragmented and there is no common system that brings together all the information that is needed. Information about products is often inconsistent because there are no standard methods for describing them or their performance. Product information is also frequently out-of-date. Information is generally intended for use by professionals and is not presented in ways that are easy for consumers to understand and use.

The effectiveness of the responses will be evaluated by their consumers and providers in terms of meeting consumer's needs and restoring their autonomy.

Programme 2 will work with information providers to develop, evaluate and implement improved methods of providing this information. Quality standards will be developed to define the accessibility, ease of use, content, reliability, consistency and recency of the information provided.

R&D Programme 3: The human and economic effects of dependence

The establishment of methods for costing dependence is essentially the lever for encouraging stakeholders to develop more effective systems. If it was shown that dependence is expensive and a poor use of stakeholders' resources, considerable pressure would be generated for introducing more updated responses.

There are currently no systems for establishing the costs of individual dependence and pooling these to producing an accurate analysis of the overall costs. The profiles of need emerging from the work in programme 1 will provide the starting point for developing this system.

Programme 3 will develop and test methods of estimating the costs of dependence so as to provide planners and innovators with the information they need to evaluate and improve their responses to dependence. This will be achieved by analysing data from consumers and other sources about:

- their profiles of need and dependence
- the costs of dependence for consumers, carers and services

- the cost and effectiveness of different responses

Supporting frameworks for autonomy

IT communication system

An IT system underlying the three programmes will:

- carry assessment formats for revealing consumers' needs
- collect and collate profiles of need
- carry product and service information
- collect feedback from consumers on action taken
- evaluate the effectiveness of the responses on the basis of feedback from consumers and providers
- analyse the costs of responses to dependence.

Evidence base

As these methods are developed, they will be analysed to produce a unique 'evidence-base' on the patterns, effects, costs and responsiveness of dependence.

What the benefits would be

This system should mean that, if they choose, consumers could complete some of the selection process themselves. This would not only give consumers more control, but would cut the workload for practitioners involved in assessment and equipment provision.

Better feedback on barriers to function and mobility in buildings will enable architects and planners to increase the effectiveness, productivity and profitability of their buildings.

Initially, a clearer picture of consumer needs will reveal needs that are unrecognized and unrecorded at present. However, the more precisely needs are identified, the better the choice of equipment. Better analyses of dependence and its penalties will galvanise stakeholders to develop better methods of meeting needs. Better market intelligence on consumer needs and markets will also galvanise manufacturers to move rapidly into the more productive and profitable areas and other potential investors.

Conclusion

Addressing the issue of dependence requires widespread cross-sectoral collaboration in a field that is currently so fragmented that it provides an ideal example of an area in which ' joined-up services' are urgently required.

Major stakeholders are beginning to recognize the scale of the problems that they face at present and the need for working together to develop mutual solutions. We have already found widespread support for a Forum for Autonomy, Choice and Innovation to support this process. Establishing the Forum and its R&D programmes needs money and other resources.

We urge policymaking and other stakeholders alike to review realistically the likely effectiveness of their existing approaches, and the advantages that should accrue from adopting the mutual approaches outlined above.

Many of the stakeholders themselves are already willing to contribute 'in kind' with their time and effort to set up the Forum and oversee its programmes. However, core funding and R&D funds need to be secured to set up the Forum and develop and test the programmes themselves, and their supporting frameworks.

At present the research team are looking for stakeholder collaborators to take these ideas forward, especially those in charge of policy and planning of the major service areas and also service providers at local level to join in developing plans and putting forward joint bids for funding in this area.

From a small core team funded at roughly £120-150,000 pa, bids to funding agencies for a range of contributory projects could be developed. Individual projects would be on a range of scales, from tens to hundreds of thousands of pounds per project. They would progressively build into coherent programmes of research, development and implementation., to reduce the toll of disability, dependence, individual and societal costs, as outlined elsewhere in this paper.

Major research sponsors in the field are invited to direct their funding policies towards finding more effective ways of reducing the effects of dependency in the ways suggested here.

Expression of interest, and offers of funding from potential funding agencies, are invited, addressed to:

Forum for Autonomy, Choice and Innovation
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References

Abberley, P. (1995) Disabling ideology in health and welfare – the case of occupational therapy. *Disability and Society*, 10 (2), 221-232

Alcock, P. (1996) *Social Policy in Britain*. London: Macmillan

Allen, I, Perkins, El (1995) *The future of family care for older people*. London: HMSO

Archer, BL (1965), *Systematic Method for Designers*, Council of Industrial Design, London

Audit Commission (in press) *Promoting Independence: The provision of disability equipment by NHS trusts and social services departments in England and Wales. Draft 3*

Bernabei, R., Landi, F., Gambassi, G., Sgadari, A., Zuccala, G., Mor, V., Rubenstein, L.Z., Carbonin, P. (1998) Randomised trail of impact of model of integrated care and case management for older people living in the community, *BMJ*, 316, 1348-51

Beveridge, W. (1951) *From the cradle to the grave*. London: HMSO

Bloor, M. (1997) Addressing Social Problems through Qualitative Research, in Silverman, D. [Ed.] *Qualitative Research: Theory, Method and Practice*, London: Sage, 221-237

Clinical Standards Advisory Group (1998) *Community Health Care for Elderly People*. London: HMSO

Cohen, P. (1998) Rising dependency, *Community Practitioner*, 71 (31), 89

Department of Health (1989) *Caring for people*. London: HMSO

Department of Health (1997) *The New NHS: Modern and Dependable*, London: HMSO

Gilbert, H. (1995) *Redressing the balance: a brief survey of literature on patient empowerment*. London: The King's Fund

Harrison, S., Mort, M. (1998) Which Champions, Which People? Public and User Involvement in Health Care as a Technology of Legitimation, *Social policy and Administration*, 32(1), 60-70

Jones, J., McNair, B. and Mitchell, J. (1998) *Choosing Beds for Hospitals*. London: King's Fund

Kasper, J.F., Mulley, A.G., Wennberg, J.E. (1992) Developing shared decision-making programs to improve the qulity of health care, *Quality Review Bulletin*, vol 18 (6), 182-190

Laurie, L., Macfarlane, A. (1995) *The Effect of Community Care on Housing for Disabled People*. York: Joseph Rowntree Foundation

Marks, D. (1999) *Disability: controversial debates and psychosocial perspectives*. London: Routledge

Marks, O. (1998) *Equipped for Equality*, London: Scope

Martin, J., Meltzer, H. and Elliott, V. (1988) *The Prevalence of Disability Among Adults*. London: OPCS

McNair, B., Jones, J., and Mitchell, J. (1998), *Choosing Beds for Nursing and Residential Homes*. London: King's Fund

McNamee, P., Gregson, B.A., Wright, K., Buck, D., Bamford, C.H., Bond, J. (1998) Estimation of a multiproduct cost function for physically frail older people, *Health Economics*, 7, 701-10

Mitchell, J. and Bennington, J. (1998) *Mapping the Mobility and Functional Needs of Consumers in Wheelchairs*, Sheffield: Health Research Institute, Sheffield Hallam University

Mitchell, J., Bennington, J. (in press a) Autonomy for Disabled Consumers: the need for systematic choice and innovation, *Ergonomics Society Conference Proceedings 2000*

Mitchell, J., Bennington, J., Yelding, D. (2000) *Report of the Wheelchair Lifemap User Trials*, London: RICAbility

Mitchell, J., Jones, J., McNair, B. and McClenahan, J. (1998a) *Better Beds for Health Care*. London: King's Fund

Mitchell, J., McNair, B. and Jones, J. (1998c) *Choosing Health Care Beds for Use at Home*. London: King's Fund

Moore, M., Beazley, S. and Maezler, J. (1998) *Researching Disability Issues*, Buckingham: Open University Press

Morris, J. (1996) *Encouraging User Involvement in Commissioning. A Resource for Commissioners*. Leeds: Department of Health/NHS Executive

Morris, J. (1997) Care or Empowerment? A Disability Rights Perspective, *Social Policy and Administration*, 31(1), 54-60

Neuberger, J. (1998) Information for health: whose information is it? *Journal of Information Science*, 24 (2) pp67-73

NHS Executive (1996) *Patient Partnership: Building a Collaborative Strategy*. London: Department of Health

NHS Executive (1999) *Working together: Securing a quality workforce for the* Posted on internet

NHS Executive (1999) *Involvement works: the second report of the Standing Group on Consumers in NHS Research*. London: Department of Health

Nocon, A. (1998) The housing needs of disabled people, *Health and Social Care in the Community,* 6(5), 361-369

Ohras A, Yelding, D, Mitchell, J (1997) *Consumers and their Wheelchairs*, London: RICA and Sheffield Hallam University

Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan

Oliver, M. (1996) *Understanding disability: from theory to practice*, Basingstoke: MacMillan

Royal College of Physicans and Prince of Wales Advisory Group on Disability (1992) *A Charter for Disabled People Using Hospitals*. London: Royal College of Physicians

TIDE European Commission (1996) *User Fit: A practical handbook on user-centred design for assistive technology*. Brussels: European Commission

Urban, G. and Hauser, J. R. (1993) *Design and Marketing of New Products*, 2nd Edition, Englewood Cliffs, New Jersey: Prentice Hall Inc

Wheelwright, Steve and Clarke, Kim (1992) *Revolutionising Product Development*, London: MacMillan

Winchcombe, M. (1998) *Community equipment services... why should we care?* London: DLCC