Barriers to Independent Living: A scoping paper prepared for the
Disability Rights Commission

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"This report has been produced for the Disability Rights Commission
to examine evidence on disabled people's access to independent
living and to inform development of the Commissions work in this
area. It is not a statement of Disability Rights Commission policy."

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Introduction

In 2002, the Disability Rights Commission (DRC) adopted the formal policy aim that:

> There should be a basic enforceable right to independent living for all disabled people. (Disability Rights Commission, 2002)

This paper has been written to assist the DRC to identify what measures are necessary in order to deliver this right to independent living. It is important that we start from a clear understanding about what independent living means and this is therefore the focus of Part 1 of the paper. The main emphasis of the paper is on the social care system as it is in this area of legislation and service delivery that there is considerable potential for improving access to independent living, and a key role for the Disability Rights Commission, as the DRC's own policy statement recognises. Part 2 of the paper, therefore, looks in some detail at the barriers within the social care system.

However, disabled people's needs for support do not exist in a vacuum. Neither do attempts to meet their needs through the social care system. The final part of the paper, Part 3, therefore briefly addresses the wider societal barriers that can result in a denial of independent living.

Throughout the paper, an attempt has been made to identify some possible indicators for measuring independent living. Some of these indicators concern experiences that could be measured by gathering quantitative data. Others are criteria by which legislation or services should be evaluated. All the measures suggested could be used by the DRC, government departments, and disability organisations as a basis for monitoring progress on enabling independent living for all disabled people.

It should be stressed that this is a 'scoping' paper. That is, it aims to identify the scope of future work that will be necessary in order to deliver an entitlement to independent living. It does not attempt to provide a comprehensive analysis of either existing research or the legislative framework.

Part 1: What do we mean by 'independent living'?

The DRC's policy statement sets out a general definition of independent living:

> The term independent living refers to all disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.

There are three elements to this definition, which are also to be found in most other discussions of what independent living means. Firstly, there is an assertion that disabled people should have the same opportunities for choice and control in their lives as non-disabled people; secondly there is a challenge to the usual interpretation of the words 'independent' and 'independence'; and finally, the aspiration that any assistance required should be under the control of disabled individuals themselves. As Simon Brisenden, an early pioneer of independent living, wrote 'Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it' (Brisenden, 1989, p.9).

While this definition is useful for identifying the changes required in the social care system in order to deliver independent living, the underlying philosophy of independent living also needs to be made clear in order to make the case for such changes. As Adolf Ratzka, one of independent living movement's pioneers, has stated 'Independent Living is a philosophy and a movement of people…who work for self-determination, equal opportunities and self respect' (Ratzka, n.d.). Independent living is essentially a challenge to the place of disabled people in society.

The goal of independent living is motivated by three fundamental ideas:

- That disabled people should have access to the same human and civil rights as non-disabled people
- That, historically, society's reaction to impairment, and the failure to meet needs relating to impairment, have undermined disabled people's human and civil rights
- That this is not inevitable; in other words that impairment does not have to determine life chances. Our biology is not our destiny.

The relationship between independent living and human and civil rights

Independent living itself is a means to an end: it is a way of people accessing their human and civil rights.

Disabled people should have the same human and civil rights as non-disabled people. However, disabled people are different from non-disabled people in that they have <u>additional requirements</u>, such as mobility needs, communication assistance, personal assistance, accessible information, and so on. These additional requirements stem from both experiences of impairment *and* from the disabling barriers of negative attitudes and unequal access. If these additional requirements are not met, disabled people's human and civil rights will be denied. A legislative and constitutional framework which confers human and civil rights will not, therefore, be effective for disabled people unless they also have entitlements to these additional requirements.

Looking at it another way, additional requirements are necessary in order to enable disabled people to have equality of opportunity with non-disabled people. There are social and economic factors which may threaten both non-disabled *and* disabled people's human and civil rights, and these are not the subject of this paper. Rather, the 'right to independent living' argument rests on the contention that disabled people have additional requirements, which must be met if they are to experience a level playing field in terms of their access to human and civil rights.

Additional requirements are usually called needs in the context of social care. They are related to both impairment and to disabling barriers. If needs (additional requirements) are not met then human and civil rights are denied. For example, a person's human right to a family life and to privacy can be denied if resources are only available to support them in a residential setting. Moreover, impairment can be made more significant by a denial of human rights, and indeed can be created by a denial of human rights (the day to day experience of discrimination and exclusion can create mental health difficulties, for example).

Choice and control are key aspects of independent living

The International Summit Conference on Independent Living in 1999 adopted what is known as the Washington Declaration. This states that, '…… all human life has value and ….every human being should have meaningful options to make choices about issues that affect our lives'. 'Independent living' is therefore closely associated with the words 'choice and control' and is usually applied to both the environment in which someone lives and the assistance they might need in order to go about their daily lives. The disability movement identified first seven (Davis, 1990) and then 12 'basic needs' which are central to achieving independent living. These are:

- 'Full access to our environment
- A fully accessible transport system
- Technical aids – equipment
- Accessible adapted housing
- Personal assistance
- Inclusive education and training
- An adequate income
- Equal opportunities for employment
- Appropriate and accessible information
- Advocacy (towards self-advocacy)
- Counselling

- Appropriate and accessible health care provision

(Southampton Centre for Independent Living, n.d.)

These are areas in which disabled people have requirements/needs, over and above those of non-disabled people, which must be met if they are to experience equal access to human and civil rights. However, the philosophy of independent living also emphasises that the *way* in which these additional requirements are met is crucial to whether this level playing field is achieved: responses to need must be characterised by giving the disabled person choice and control over how those needs are met.

Thus, independent living is achieved if a disabled person:
- Lives in an environment where they:
- have a legal entitlement to live there
- can choose who comes into the home
- can choose who they share their home with.

- Receives assistance and/or has access to equipment, transport and/or environments which enable the individual to:
- carry out tasks of daily living
- engage in relationships of choice
- engage in activities of choice, including work, leisure, political, and voluntary activities.

The following are some of the things that might make independent living, as defined above, possible – i.e. they are the means to the end, not the end in themselves. They are all characterised by enabling choice and control, thus meeting additional requirements/needs in a way which gives the disabled person equal access to human and civil rights:

- personal assistance over which the individual has choice and control, for example by using direct payments to recruit and employ personal assistants
- advocacy and peer support
- circles of support made up of people who use their knowledge of the individual to ascertain his/her wishes and put in place the support needed to achieve these aspirations
- emotional support which enables the individual to live safely in their own home
- involvement in decisions about treatment or equipment directed at needs arising from impairment or disabling barriers
- one-to-one support with communication (e.g. speech facilitator, sign language interpreter)
- equipment to meet mobility and/or communication needs
- easy access to public transport, including any support needed to use it
- use of a car
- tenancy of a self-contained flat, with the support needed to maintain the tenancy
- financial assistance to adapt an owner-occupied property
- affordable rented housing adapted/designed to suit the individual's needs.

Barriers to independent living

There are a number of barriers to independent living. Some of these operate at a societal level, and some are to be found in the legislative framework for, and delivery of, additional requirements. The main focus of this paper is the barriers that exist in the field of social care. Part 2 therefore examines the legislation and services which have been developed in order to address the needs/additional requirements of disabled people, but which either do this inadequately or themselves have also created barriers to a level playing field. However, in order to identify the barriers posed by the social care legislative framework, it is necessary to place these in the context of a more general understanding of the barriers to independent living. Part 3 of the paper briefly identifies the factors

operating at a societal level which prevent disabled people experiencing a level playing field in terms of their access to human and civil rights.

Part 2: The social care system - Barriers to independent living

This section considers the legislative framework and systems of service delivery which are intended to meet disabled people's need for support. This is the most detailed part of this paper, dealing as it does with an area which the DRC has identified as both crucial to the experience of independent living and where there is potential for change. By 'support' we mean the assistance that people require in order to go about their daily lives and this may take the form of personal assistance and/or equipment. People may need assistance with personal care, running a home, looking after others, with mobility and transport, with paid employment, voluntary and leisure activities. They may also need assistance with communication and/or to advocate their needs.

The main piece of legislation under which people access support is the NHS and Community Care Act, 1990. This built on the Chronically Sick and Disabled Persons Act 1970 and was subsequently extended by the Disabled Persons (Services, Consultation & Representation) Act 1986 and the Community Care (Direct Payments) Act 1996. There are five fundamental problems with this legislative framework:

- It places duties on local authorities to provide services, rather than gives rights to individuals to receive support
- There is no entitlement to live at home rather than in residential or nursing care
- Its coverage is limited to 'community care services'. In particular, the legislation does not adequately covers assistance to enable a person to participate in leisure activities, to work, to have relationships, or to look after children or other family members
- There is no entitlement to advocacy
- Enforcement of existing entitlements involves negotiating an inaccessible legal system with inadequate sources of support.

A large number of barriers to independent living can also be identified in the way the legislation is implemented. This section attempts to list them, but it will be evident that there is often overlap between the various barriers. It is also clear that the lack of a right to independent living allows other factors to dominate and thereby creates situations where choice and control (and human and civil rights) are denied. Some case study examples (which are based on real situations) are used to illustrate how this happens.

Financial incentives to provide residential care rather than to support independent living

It has long been recognised that there are strong financial incentives for local authorities to place people in residential care rather than to support them to live in their own home (Audit Commission 1996).

The way in which this happens has recently been made explicit by the imposition of cost ceilings placed on the amount of support available to support an individual in their own home. The London Borough of Tower Hamlets attracted much negative publicity when a policy was adopted which stated that, should it not be possible to meet an individual's 'eligible needs fully and safely at home within the level of funding that we have decided is reasonable…. then the Department will give reasonable notice (in the case of an existing care package) of the withdrawal of that care package, and will make arrangements for the service user's needs to be met through the provision of an appropriate residential or nursing home placement' (London Borough of Tower Hamlets, 2002).

The practice of imposing cost ceilings on supporting people to live in their own homes has, in fact, been in place for many years - although it is usually operated in a more subtle fashion than in the Tower Hamlets case. Local authorities – required by the government to use their resources in the most cost effective way - set cost ceilings on care packages to support people in their own homes and these limits are usually set in relation to the relative local costs of residential

care. In 2001, the average gross weekly expenditure in England on residential care was £323 for an older person; £622 for a working age adult with a learning disability; £391 for a working age adult with mental illness and £528 for a working age adult with a physical and/or sensory impairment (Department of Health, 2003a).

This practice, of setting cost ceilings on 'home care' in relation to comparative costs of residential care, is not just a barrier to independent living. It also creates discrimination against older people. Social service departments will commonly spend less on supporting an older disabled person at home than they will spend to support someone below retirement age, because costs of residential care are lower for older people. This means that older disabled people are forced into residential care at lower levels of support needs. There is similar discrimination against people of working age with a diagnosis of mental illness, in comparison with people of working age who have physical/sensory impairments or learning disabilities.

Example

Mrs Barry is 82 and lives with her son, who is in his 50s. Mrs Barry has had a stroke and is currently in hospital. She has impaired mobility which means she would not be able to use the stairs in her house and needs assistance at night in order to use the toilet. Her son says he cannot provide assistance to his mother at night, and indeed his mother does not want him to. The cost of providing waking night cover would take her care package above the cost limits set by the local authority.

Mrs Barry has no choice or control over:
- whether she returns home
- how her personal assistance needs are met.

Mrs Barry will be unable to return home and will have to enter a residential home. She will have little or no say over the quality of care provided, who she shares the home with, or where it is.

The following human and civil rights are threatened:
- right to a private life
- right to a family life
- her right to occupy the home she owns.

This is a result of Mrs Barry having no entitlements to:
- return and remain living in her own home
- the assistance and/or adaptations required in order to do this.

There are other financial incentives to provide residential care. For example, while the cost ceilings for supporting people with learning disabilities to live in their home are generally higher than for other service user groups, the historical pattern of expenditure means that current resources are overwhelmingly tied up in residential provision. Although *Valuing People,* the national learning disability strategy, aims to increase the numbers of people with learning disabilities living in the community, the lack of an entitlement to independent living allows financial structures to act as a barrier to this. This is because, in many areas, current resources are overwhelmingly tied up in institutional provision. For example, in one local authority area, only 4% of learning disability revenue funding supports people with learning difficulties living in their own home. The other 96% pays for people to live in residential care services, with 60% of this allocated to large residential services (South Down Housing Association, 2002, pp.36-37).

A survey of services for people with learning difficulties in 24 local authority areas found that, although local health and social services agencies subscribed to 'principles of social inclusion, citizenship and ordinary community living….congregate [residential] forms of care still predominated, with two thirds

of people accommodated in some form of congregate living arrangement...'
(Department of Health 1999a, p.3) People with high levels of needs were
particularly unlikely to be catered for by community services. Although most of
the authorities surveyed expected to increase the number of people in individual
supported accommodation, half of the authorities also expected to increase the
number of placements in residential homes.

The way in which the Independent Living Fund operates also creates financial
pressures towards residential provision. There are two points to be made here.
The first point concerns the way in which the funding conditions for Independent
Living Fund (ILF) grants discriminate against those with the highest support
needs. People whose total weekly support costs are over £665 are not eligible for
an Independent Living Fund (ILF) grant. In these circumstances, instead of the
local authority paying £270 per week and the ILF paying any costs over and
above this, the local authority would have to fund the entire cost of supporting
them to live at home. There are wide variations in the experiences of people with
high levels of support needs, depending on how much their local social services
is prepared to pay. However, there is clear evidence that some people are
forced into residential care as a direct result of the cost ceilings imposed both by
the ILF and by social services departments (Kestenbaum, 1999).

The second point concerns one group of people with learning disabilities. Since
1999, the ILF has refused to consider applications from people with learning
disabilities who previously lived in long-stay hospitals. The reasoning behind this
is that Section 28a of the 1977 Health Act already makes provision for transfer of
funds from health to social services. 'Health Act flexibilities' should therefore be
used to pay for such support rather than local authorities seeking a contribution
from the ILF. This practice does, however, discriminate against one group of
people with learning disabilities in comparision with others in terms of their
access to ILF grants.

The funding structure of the community care system generally creates a financial incentive for local authorities to use residential care. It could be argued that this contravenes disabled people's rights under the Human Rights Act to a private and family life. In the United States, funding arrangements which favour institutional placements over independent living placements have been held by the Supreme Court to result in 'unnecessary institutionalisation' and therefore to be unlawful discrimination (see Clements and Read, 2002, p.66).

In addition, there is evidence that, while the costs of residential provision are increasing, the quality of care provided is sometimes very poor. A significant proportion of the current overspend on social services authorities' budgets comes from the rising costs of residential care (Local Government Association, 2002). At the same time, some residential care provision clearly does not represent value for money. A recent report by the Commission for Health Improvement, for example, catalogued the poor quality residential care purchased by the Bedfordshire and Luton Community NHS Trust (Commission for Health Improvement, 2003).

Measuring independent living:
- *What proportion of people, in different service user groups and different age groups, live in residential settings?*
- *In how many cases are people forced into residential care as a result of cost ceilings?*
- *What would be the average unit cost and what would be the gross cost of enabling people, currently affected by cost ceilings, to live in their own home?*

Attitudes which undermine choice and control

Negative attitudes about disabled people are one of the key barriers faced in daily life, and the impact of some of these are discussed in Part 3 of the paper. In the context of the community care system, however, there are some specific ways in which attitudes act as important barriers to independent living. In

particular, assessments and service delivery are sometimes dominated by attitudes held by professionals and support workers that get in the way of promoting choice and control. One important way in which this can happen is in attitudes towards 'capacity' and 'risk'. (Other examples of negative attitudes are to be found under some later headings.)

Assumptions about 'capacity'

Negative attitudes about 'capacity' are commonly applied to anyone identified as 'vulnerable' in some way. There is currently no legal definition of capacity: professionals make decisions based on their judgements, which could be legally challenged using case law, but rarely are.

The Making Decisions Alliance argues that people should be 'presumed to be capable of making their own decisions in the absence of evidence to the contrary', and if decisions are made on behalf of someone they should 'have proper legal authority and be enforced by legislation' (Making Decisions Alliance, 2002). It should be noted, however, that Values into Action – an organisation with a strong track record of campaigning for the rights of people with learning difficulties – is not a member of the Making Decisions Alliance. The government intends to introduce legislation in the near future which will provide a legal definition of 'capacity' – a move supported by the Making Decisions Alliance - but people with learning difficulties, and the DRC's Learning Disability Action Group, have expressed concern about the implications of this for self-advocacy. In any event, this new legislation will need to be examined for its implications for access to independent living.

Advance directives are an important way for people to exert choice and control in the event that they lose 'capacity' or are detained under the Mental Health Act. Currently advance directives have no legal status. Mind and other organisations have campaigned for legal status to be given to advance directives in the forthcoming Mental Health Bill.

Many people's ability to have choice and control is curtailed by assumptions about their 'incapacity'. Older people in particular often have decisions made for them about whether they can remain living at home or have to enter residential or nursing care. Although common law assumes that everyone is capable of making decisions for themselves, unless proved otherwise, in many situations this is reversed and disabled people are required to prove they are capable of making decisions. This is particularly the case for people with learning difficulties: 'They are presumed to be incapable of making their own decision until they pass some unspecified 'test' to prove that they can' (Edge, 2001, p.30). Research carried out by Values into Action concluded that: 'People with higher support needs may find themselves labelled as 'mentally incapable' of making their own decisions and subject to decisions made 'in their best interests' by others, often without guidance, monitoring or the opportunity to effectively challenge those substitute decisions' (Edge, 2001, p.11).

There has been a very low take-up of direct payments by people with learning difficulties and an important reason for this is that individuals are often assumed to be not capable of giving consent. Moreover, some social services professionals have been reluctant to work with local advocacy groups to enable people with learning difficulties to use direct payments. This situation may change with the government's encouragement, through the national learning disability strategy, of direct payments for people with learning difficulties.

Example

Jo is 35 and two years ago moved out of a long-stay hospital to live in a group home for people with learning disabilities. The organisation that runs the home provides support workers to assist the residents in daily living activities.

Jo has met a man, Rory, at the local college which she goes to twice a week and has started to go out with him. Rory lives with his parents. Rory and Jo want to start a sexual relationship but neither the support workers nor Rory's parents think this is a good idea. The support workers feel that Jo does not have the capacity to consent. They, and Rory's parents, will not allow Jo and Rory to spend time alone together in either his house or Jo's group home.

Jo has no choice and control over:
- what she does in the home in which she lives
- whether she has a sexual relationship.

Jo has been deemed to be incapable of consenting to a sexual relationship without a proper assessment of whether she does have 'capacity' in a legal sense. She has no recourse to challenge this decision, unless she can access independent advocacy.

The following human rights are denied:
- the right to privacy
- the right to a family life.

This is a result of Jo having no entitlements to:
- choice and control over the support she needs to go about her daily life
- a secure tenancy
- information and support to make decisions and take risks.

Measuring independent living:
➢ *Is the legal framework in place to protect people from unjustified and unexamined assumptions of 'incapacity'?*

> *Is the legal framework in place to enable people to influence future decisions about their care at a point in the future when they may be deemed 'incapable'?*

> *What services are in place to enable access to independent advocacy and to information?*

> *What mechanisms are in place to enable challenges to assumptions of 'incapacity'?*

Concerns about 'risk'

Concerns about risk to the welfare of a disabled person are closely tied up with assumptions about an individual's capacity to make decisions. The tendency to see disabled people as uniquely vulnerable means that, even when professionals and service providers talk of 'empowerment' concerns about safety and/or liability can get in the way. Much research, for example, on services for people with learning disabilities finds that, even within services which have stated philosophies concerning the empowerment of people with learning difficulties, there is evidence that concerns about safety tend to override the desire to empower service users (Alaszewski et al, 1999).

Risk is also an issue in terms of the welfare of professionals and service providers and this is most clearly seen in the recent development of regulations on 'lifting and handling' (see Cunningham 2000). In recent years, a number of local authorities and service providers developed very restrictive policies on when a disabled person could be lifted without the use of hoist. These policies, which sometimes took the form of a blanket ban against lifting a person over a certain weight, or in certain circumstances, have resulted in the following types of restrictions on independent living:

- lack of choice over where to live
- being confined to bed, or to the home
- being unable to participate in particular activities.

The development of restrictive practices stemmed from the Royal College of Nursing's (RCN) Code of Practice on Patient Handling which states: '....the manual lifting of patients is eliminated in all but exceptional or life threatening situations' (Royal College of Nursing, 1996). This was then confirmed in 1999 by Health and Safety Executive guidance which, as required by EC Directive 89/391/EEC, placed greater emphasis than previously on preventive and protective measures to protect staff. A number of local authorities and service providers adopted a complete ban on the manual lifting of disabled adults and children over a certain weight, while others insisted on the use of hoists and/or no lifting outside the home.

Following pressure from the DRC and the National Centre for Independent Living (NCIL), the Health and Safety Executive issued further guidance that is not so restrictive. This guidance, rather than the RCN's Code of Practice, has been upheld by the High Court in a recent ruling concerning two women whose local authority refused to allow support workers to lift them (R v East Sussex County Council, 2003). The ruling recognised that, when decisions are made about lifting, the disabled person's human rights (including their right to participate in the community) and their wishes and feelings should be taken into account.

Nevertheless, many services are still operating significant restrictions on lifting and will require challenging in order to uphold disabled people's rights. Moreover, the RCN's Code of Practice still operates in hospital settings. People with significant physical impairments are more likely to require lifting and a ban on this in a hospital setting impacts on their experience of health services, and in some cases can actually put their health at risk

Measuring independent living:
➤ *How many people who require lifting are assisted to use community facilities, such as local shops, cinemas, leisure centres?*

➢ *How many people who require lifting are in employment or education/training?*

Assessments of need are service-led and not needs-led

The likelihood of someone being able to achieve independent living is very dependent on the quality of the assessment they receive. Assessments (and care plans and reviews) are potentially mechanisms for identifying what barriers there are to a disabled person accessing their human and civil rights, and how to address these barriers. However, because there is no entitlement to independent living, assessments are commonly dominated by other concerns.

Although guidance issued on the implementation of the NHS and Community Care Act stressed that assessments should be needs-led, in practice they are more usually a method of determining whether someone is eligible for a service. This is because the process of assessing need is usually carried out at the same time as the process of rationing scarce resources. Assessments, therefore, commonly measure dependency levels in order to determine eligibility: they thus often ask 'what is wrong *with* this person?' rather than 'what is wrong *for* this person?' New guidance issued last year does not provide a sufficiently strong message about needs-led assessments to make it likely that this situation will change (Department of Health, 2002a).

Example: An assessment which identifies needs and disabling barriers

A 55 year old woman, Mrs Davies, with sickle cell anaemia, was referred for assessment having experienced a crisis in her condition. The referral form said 'This lady requires an assessment for home care', that her crises were becoming more frequent, and that she was increasingly isolated.

An assessment identified the following needs:

- to see members of her family, particularly her grown up sons, more frequently

- to eat food which she likes regularly

- to have help with housework when she's having a crisis

- to have control over pain relief

- to not go into hospital so often

- to not feel isolated

- to be able to move around her flat more easily.

This list of needs is in fact closely related to her human rights.

The following barriers were identified as getting in the way of meeting the needs assessed:

- she feels reluctant to invite her sons and other members of her family into her home when she hasn't been able to keep up her usual high standards of housekeeping

- she finds it increasingly difficult to go out shopping, difficult to cook when she is having a crisis and the meals on wheels service does not provide the kind of food she likes

- the pain associated with a crisis in her condition makes it impossible for her to do any housework at all when she is having a crisis

- she does not have much confidence in her GP and has not seen a specialist in sickle cell anaemia for many years

- she does not know whether or how it might be possible to take medication or other action which would reduce either the frequency of her crises or the need for hospital admission

- she has been losing touch with her friends because she has felt too unwell and in too much pain to socialise much

- her flat, although on the ground floor, has four steps down to the kitchen and she sometimes finds these difficult to negotiate.

This list of barriers is helpful in determining the appropriate responses to the needs identified.

The next stage would therefore be to:

- identify what service responses are available to meet the needs and address the barriers identified-
- whether Mrs Davies qualifies for the available service responses.

The process also enables an identification of needs which remain unmet – either because resources are not sufficient to meet them (and therefore Mrs Davies does not meet the eligibility criteria) or because the particular service response is not in place.

If the community care system was driven by assessments which were about needs and disabling barriers (rather than dependency levels and eligibility criteria), local authorities would not only be more likely to deliver independent living for individual disabled people. They would also be more likely to clearly identify what level of resources are required to meet the needs of their local populations, *and* to identify what types of service response are most likely to effectively meet those needs and represent good value for money.

Measuring independent living:

➢ *How many care managers have received disability equality training?*
➢ *Is assessment practice evaluated by service user organisations?*
➢ *How is unmet need recorded and analysed?*
➢ *Does information about unmet need inform decisions about service development?*

Some support needs are unmet, or inadequately met.

As there is no entitlement to independent living, and resources are always scarce, local authorities devise eligibility criteria which can mean that some

disabled people's needs for support are unmet, or inadequately met. Moreover, custom and practice has grown up whereby some types of support needs are not usually considered in community care assessments and/or are inadequately responded to (the importance of custom and practice is also discussed separately later). This can undermine independent living and human and civil rights.

Low level or preventative support

Since the early 1990s, it has been the policy of central and local government to increase the numbers of people receiving intensive support to enable them to remain living in their own homes. However, this has been achieved at the cost of a decrease in the numbers of people receiving lower levels of support and has, in fact, resulted in a decrease in the overall numbers of people receiving support. Between 1997 and 2002, the number of home care hours provided has increased by 14% while the number of households receiving services has decreased by 23% (Department of Health 2003c). Although new policy guidance on eligibility criteria, *Fair Access to Care Services* (FACS)*,* stresses the importance of preventative support this is more about short-term rehabilitative support. Moreover, although assessments are supposed to be based on the level of risk to independence, both the FACS guidance itself and the way it is being implemented still gives much greater weight to risks to 'life and limb' rather than the risk of exclusion. Again, this inhibits rather than promotes independent living.

People with mental health difficulties may be particularly affected by the denial of support services to people with lower level needs as a failure to meet such needs can lead to a deterioration in mental health. Service users have identified how difficult it is to access support before they reach a crisis. Even then, it is harder for someone who is only a danger to themselves to access support than it is for someone who is considered to be a danger to others. A person's state of mental health may be a barrier to their achieving independent living but if, for example, the manifestation of their mental health takes the form of self-harming, they are

less likely to get access to services than someone whose state of mental health harms others.

Example

Raj (24) has a long history of using psychiatric services. He says that he has no friends. He gets very lonely at times. He likes Bhangra music and sometimes goes to club and dances, though generally he does not go out very much and spends most of his time reading. His family are devout Hindus and he has become increasingly interested in religion. He loves to debate and discuss religious issues and he regularly attends the local temple.

Raj does not claim any kind of social security benefits and is dependent on money from his parents. Both he and his parents want him to remain in the family home but there are times when Raj gets violent. His parents fear there may come a time when they cannot cope with him. Raj feels he needs one to one support from someone independent from the family but who would be able to help him stay at home. However, the only service for which he is eligible was a local day centre. He was the only Asian service user there and he attended only once. He said that the people at the centre made jokes about his accent and called him names.

Raj has not worked yet, although he has good educational qualifications and he is very interested in information technology. He has not been well enough to take up training or employment opportunities through the employment service.

Raj has no choice or control over:
- his financial income
- the type of support he receives
- what he does in his daily life.

Raj cannot access support services that would enable him to claim the benefits he is entitled to or help him to get work or training. Neither can he get the support he needs to enable him to develop leisure interests and find friends, or to help him remain at home in spite of his mental health crises.

The following human and civil rights are at risk of being denied:

- the right to a family life
- to use services without experiencing racial discrimination
- the opportunity to earn a living.

This is because Raj has no entitlements to:

- support to enable him to have more control over his life (e.g. help with applying for benefits, with developing preventative strategies to avoid a deterioration in his mental health)
- support which is geared towards his specific interests
- be free from racial harassment.

Even when people with mental health difficulties have accessed appropriate support, they often live with the fear that a reduction in symptoms of distress can lead to a withdrawal of services – without consideration being given to what level of service would prevent future crises. In particular, some people with mental health support needs have expressed the fear that, if they are able to manage direct payments they would 'be seen as "getting better" at reviews [and] direct payments might be withdrawn' (Davidson and Luckhurst, 2002, p.14).

Measuring independent living:

➢ *What local services are in place which have low eligibility thresholds and the aim of preventing a deterioration in mental health?*

➢ *How many people with mental health difficulties use direct payments?*

> *How many people with low levels of personal assistance needs use direct payments?*

Disabled people living with their parents

Disabled adults who live with their parents commonly experience difficulties in meeting eligibility criteria for housing and support (Morris, 1999). This applies across all service user groups. According to Mencap, 'as high a proportion of (now more severely disabled) people with a learning disability are living with their families, by necessity rather than choice, as were living with their families thirty years ago.' (Mencap, 2000, p.1)

Measuring independent living:

> *What proportion of disabled people, over the age of 25, are living with their parents (in comparison with the proportion of non-disabled people)?*

Needs for 'invasive procedures'

Some disabled people require assistance which involves particular expertise: for example, if someone requires tube-feeding, or uses a ventilator or requires rectal valium. Many people with such needs find that they are excluded from leisure, education and employment opportunities because the support available does not meet these needs (there has been more research concerning this issue for disabled children and young people than for adults: see, for example, Noyes, 2000; Lenehan, 2001). This is usually because the service provider has not been able to sort out training, insurance and any additional costs associated with the assistance required.

Measuring independent living:

> *How many people who require 'invasive procedures' are assisted to use community facilities, such as local shops, cinemas, leisure centres?*
> *How many people who require 'invasive procedures' are in employment or education/training?*

<u>Support for disabled adults in their parenting role</u>

A failure to recognise that many disabled adults are also parents has resulted in a common assumption that assistance with parenting tasks is not covered by the community care legislative framework – although this has not been tested in the courts. The ILF's Trust Deed specifically excludes funding for assistance with parenting tasks. Custom and practice has developed whereby, if disabled parents require assistance with parenting tasks they generally have to access this through the Children Act.

The Department of Health's Social Services Inspectorate found significant gaps in services to support disabled parents, with 'a lack of co-ordination of services provided, time delays and limited appreciation of the necessity for services to meet the needs of the whole family' (Social Services Inspectorate 2000, p.5). Inspectors expressed particular concern about responses to the needs of parents with learning difficulties. In some councils, they found:

- 'eligibility criteria for receiving a service were very restrictive and did not take parenting into account
- staff who did not have the necessary skills undertook assessments of parenting skills and parenting courses;
- critical decisions about the children of learning disabled parents (being placed on or remaining on, the child protection register and/or being removed from the family) could be made on inappropriate or inadequate information'.

(Social Services Inspectorate, 2000, p.6)

During the years 2001 and 2002, the Joseph Rowntree Foundation supported a Task Force on Supporting Disabled Adults in their Parenting Role which considered a range of issues affecting disabled parents (see Morris, forthcoming). One key issue identified was whether disabled parents can access the assistance they need without their parenting capabilities being called into question, or their children being considered to be at risk. In other words: Can

assistance with parenting tasks be accessed through disabled people's entitlements under community care legislation? Or is assistance with parenting tasks only available through the Children Act?

In order to access assistance under the Children Act, a child has to be considered to be 'in need'. Many parents feel that there is a stigma attached to this: there is an association with 'child protection', with children being at risk of harm, and with social workers' role of assessing parenting capability.

Parents with mild to moderate learning disabilities find it particularly difficult to get help in their parenting role under community care legislation, as they commonly do not meet the eligibility criteria of Adult Learning Disability Teams. In addition, the Task Force were told by disabled parents that it is much easier to access funds for 'young carers' services than support for them in their parenting role. Moreover, parents are likely to be charged if they access support from adult services but will not be charged for 'young carers' services. There is therefore a perverse incentive to identity the children of disabled parents as being 'in need'. Yet, disabled parents say there is a stigma attached to this and many are reluctant to ask for help if this is the consequence.

It had been hoped that new government guidance on 'adult social care' would have made clear that help with parenting tasks was included under community care services. However, although 'family and other social roles and responsibilities' were included in the eligibility criteria laid out by the guidance (Department of Health, 2002a), it remains unclear as to whether assistance with parenting could be accessed *entirely* under community care legislation or whether the need for such assistance would inevitably trigger an assessment under the Children Act.

When the Department of Health then issued Practice Guidance in the form of questions and answers, the situation remained unsatisfactory. The emphasis is

still on the need for adults' and children's social work teams to work together and reinforces the impression that, if a disabled parent requires assistance with parenting tasks, this will trigger a Children Act assessment (Department of Health, 2002b). It is, however, to be welcomed that disabled parents can receive direct payments to meet needs identified under Children Act assessments.

Other government initiatives intended to address support needs in more empowering ways have failed to make specific provision for disabled parents. The National Service Framework on Mental Health has very little on how people with mental health support needs can be assisted to fulfil their parenting role and joint working with children's services is only mentioned in a child protection context (Department of Health 1999b). *Valuing People*, the national strategy on learning disability launched in 2001, contained a commitment to support parents with learning disabilities (Sub-objective 7.4). However, this is not an issue which has, so far, been tackled in the implementation of the strategy. For example, maternity services are not mentioned in the good practice guidance on health action plans (Department of Health, 2002c); support to parents with learning difficulties is not mentioned in the guidance for Learning Disability Partnership Boards on implementing Person Centre Planning (Department of Health, 2002d); and parenting is not mentioned at all in the guidance on Person Centred Planning (Department of Health, 2002e).

Example

Alison has a physical impairment and is expecting a baby in three months' time. Her partner has mild learning difficulties. Alison currently does not require any personal assistance to meet her own needs and does not receive any services; her partner does not meet the eligibility criteria for services from the Adult Learning Disability Team.

Alison has identified that, once the baby is born, she will need some adaptations to her flat and also to standard baby equipment (such as a cot and changing table).

When she contacts the local adult community care team she is told that she does not currently meet their eligibility criteria and that she should contact the Children and Families Team. She does not do this as she feels that this service is associated with 'problem families'.

Six months after the baby is born, Alison contacts social services again because she is struggling to safely look after her child without the necessary adaptations and support. She also feels that her partner needs some advice and support in his parenting role. Following a referral from the health visitor, adult community care services arrange a joint visit with the Children and Families Team to assess Alison's needs and those of her child.

Because of the failure to provide an early response to their needs, Alison and her partner are having to expose themselves to an assessment of their parenting capacities. They are vulnerable to negative attitudes about disabled people as parents. Their human rights, and those of their child, are at risk.

Measuring independent living:

➤ *How many disabled parents are provided with practical assistance (including equipment and adaptations) in their parenting role?*

➤ *How many disabled parents receive direct payments?*

➤ *Can disabled parents access such support through the adult social care system?*

<u>Support to take up, or continue, paid employment</u>

Although new guidance on charging for local authority services, and new regulations adopted by the ILF, have removed the main financial disincentive for personal assistance users to employment, other barriers remain. It is very uncommon for support needs relating to employment to be covered in community care assessments. In 2001, only 1% of ILF recipients were in employment and it is estimated that somewhere between 6 and 18% of all personal assistance users are in employment (Howard, 2002, pp.30-31). A review of welfare to work by the Department of Health's Social Services Inspectorate found that social services generally:

- Saw their main focus to be on people with 'high dependency needs' who were not perceived to be seeking work
- Organised support services in such a way that, for example, they could not be relied on to get someone up in time to go to work
- Did not promote direct payments as a way of enabling disabled people to work

(Griffiths, 2001).

There is also anecdotal evidence that, if a disabled person takes up employment, they are often considered to have reduced support needs.

If someone requires support or equipment specific to getting to work or carrying out tasks at work, they must look to another system of funding for this – the Access to Work scheme. This requires people to compartmentalise their needs, which can sometimes be difficult. It also means dealing with different rules and accounting systems. Moreover, if someone moves from one area to another they have to re-apply to Access to Work and also be re-assessed by their new local social services, which may apply different eligibility criteria. The fact that assistance at work is discretionary only adds to the obstacles to social and economic mobility, thereby maintaining dependency rather than promoting independence. These issues are also discussed below.

Measuring independent living:

> *How many disabled people, who receive support or direct payments from social services departments, or ILF grants, are in employment?*

Communication support

There is no entitlement to what is perhaps the most basic human right – to communicate. This discriminates against anyone who needs communication support. For example, Deaf people require access to BSL interpretation in all areas of their lives but the community care system, as currently constituted and funded, does not provide this.

Partly as a result of negative attitudes, and partly as a result of custom and practice, people who do not use speech to communicate have often not received either a proper assessment of their communication needs nor a comprehensive response to those needs (Morris, 1991, 2001). While developments within the education system, including an increased level of funding for communication needs, may better address these needs in the future, there are many adults who are denied access to independent living as a result of past failures.

Example

Jo has lived in residential care since she was 5. At age 16 she was put in a residential home where it was assumed she would stay long term. However a new speech therapist worked out a communication system with her, and it was then discovered she did not actually have learning difficulties although a poor education had left her with poor literacy skills.

She is now 26 and has moved to a council flat in a low rise block where there are a few other wheelchair users. Only the flats used by the wheelchair users are fully accessible.

Her parents live nearby and are opposed to Jo living independently because she may not be properly looked after - an anxiety that they express all the time.

Jo receives direct payments, and has the usual problems in recruiting and keeping Personal Assistants. She particularly needs Personal Assistants who are good at interpreting her speech when she is out and about and also on the phone. She also needs PAs with skills and experience in the software and hardware of the system she uses to communicate.

Recently she has begun to get to know a few people of her age range in the flats but she cannot join in their spontaneous social activities because their flats are inaccessible to her. She has begun to form a particular attachment to one of them, something that has further upset her parents. Her PAs are also unwilling to assist her in her communication in a more private settings.

Jo has restricted choice and control over:
- her literacy skills and educational development
- communication
- leisure activities.

The following human rights are in danger of being compromised or blocked:
- the right to communicate, and to freedom of expression
- the right to privacy and a private life

The barriers to independent living are even greater for someone who experiences cognitive as well as communication impairment. People with high

levels of cognitive impairment are particularly likely to be assumed to be unable to assert choice and control in their lives. That this is not necessarily true is illustrated by the experience of recent developments such as the Choice Initiatives (see Foundation for People with Learning Disabilities, 2000) and the work of people like Phoebe Caldwell (e.g. Caldwell, 1998). Person Centred Planning, promoted by the new learning disability strategy, also has great potential for delivering independent living through establishing how someone communicates their preferences. Indeed, Person Centred Planning can illustrate how someone's human rights have been denied in the past, through a denial of communication. For example, it was only after Person Centred Planning was introduced for one man, that staff realised how he communicated that he needed to go to the toilet. Prior to this he had been 'incontinent' (Social Services Inspectorate, 1996, p.11).

Measuring independent living:
➢ *How many people living in residential settings or group homes have received an assessment of their communication needs in the last year?*
➢ *How many people have received new or upgraded communication systems in the last year?*
➢ *How many people who have communication impairments receive direct payments?*
➢ *How many people with significant learning disabilities have been assisted to use direct payments?*
➢ *Do community care assessments routinely consider communication needs? Do care plans routinely include communication support?*
➢ *How many Deaf people have access to BSL interpretation in all areas of their lives?*

Denial of independent living by default
A failure to assess and adequately meet communication needs can result in a denial of independent living without this even being recognised as such. This is

possible because a lack of entitlement to independent living allows other factors to determine the outcome. Examples of where independent living is denied by default include situations where the combination of rationing and a lack of entitlements have the result that a decision to place someone in residential care seems to be the only option. For older people this commonly happens when either their home is no longer physically suitable for them and/or they require assistance during the night. When someone who has been identified as a 'carer' says they can no longer carry on providing assistance, this can further increase the pressure for a denial of independent living. In such situations disabled people themselves often perceive there to be only one option open to them and 'accept' that they cannot expect their families to carry on supporting them.

The Community Care (Discharge) Bill currently going through Parliament will make things worse because there will be greater pressure to move people out of hospital quickly, thus less time to explore and put in place alternatives to residential care.

A number of young people are denied access to independent living, by default, when they make the transition from full-time education, particularly those who have been in residential secondary or further education settings.   Some disabled people present this as their own 'choice'. As one person said, 'I chose to go into residential care….it is just that it was the only choice there was….' (Brown and Croft-White, 2000, p.25). This is the kind of situation where the cost ceilings referred to above are implicitly applied with the result that there is no option other than residential care.

There are many situations where decisions are taken by default – that is, without either the decision or the reasons for it being made explicit. For example, people who are, often unknown to themselves, deemed to be 'incapable' of taking decisions, or too 'vulnerable' to risk certain situations, find that their access to independent living is curtailed without proper assessments of either capacity or

risk. This is particularly common for people with significant learning difficulties (see above discussion). People who are long-term users of mental health services are also vulnerable to these decisions 'by default', which, moreover, can be based on assumptions about 'capacity' based on a person's past behaviour rather than their current situation.

Measuring independent living:

➢ *What mechanisms are in place to ensure that all options are considered when determining how to meet an individual's support needs?*

➢ *Do disabled people have access to information and advice concerning all options for meeting their support needs, including access to peer support and advice?*

'Custom and practice' take precedence over entitlements laid down in legislation and guidance

A similar situation is where 'custom and practice' grows up without much consideration of what people's actual entitlements are under existing legislation. One example is the way in which people living in residential care are rarely able to access direct payments. Direct payments cannot be used to pay for residential care but this does not mean they cannot be used by people living in residential care to give them more choice and control in their lives. However, as Ken Simons pointed out:

> A number of authorities appear to have developed policies which specifically preclude the option of applying for a direct payment if the individual lives in residential care, even if the direct payment is specifically intended to support activities outside the home (the legislation precludes the use of direct payments to pay *for* residential care). It is worth remembering that, at a stroke this excludes three-quarters of people with learning difficulties…The reason given for this is usually that residential care is funded as a '24 hour' global service.' (Simons, n.d.).

Another common 'custom and practice' is that once a person has entered residential care, this is usually treated as a final decision and no consideration is given to possibilities for moving out. As one study of disabled women in residential settings concluded, 'Residential care often becomes the final option for women; there is no plan for progress to anywhere else' (Smith, n.d. p.4). This is also the attitude taken towards young people who have high levels of support needs and have moved into residential or nursing care in their late teens or early 20s (Morris, 2001). One of the reasons that this can happen is that statutory reviews of such placements are often not carried out and, even when they are, there is usually no consideration of whether needs could be better met by community-based provision. The women in Angela Smith's study, for example, often had no contact with the social services department who funded their placement and did not know how to contact a social worker, should they need to. People in residential care generally have very little access to independent advocacy.

Measuring independent living:

➢ *How many disabled people have moved out of residential care over the last year?*

➢ *How many people in residential care have access to independent advocacy?*

Access to independent living depends on where you live

A lack of individual entitlement to independent living means that local authorities have the discretion to vary levels and types of support with the result that there is a 'postcode' lottery in terms of access to independent living. It also means that moving from one part of the country to another can have more impact on access to independent living than the actual needs of the individual. Access to independent living can vary according to local variations in:

- allocation of local social services budgets
- charging policies
- availability of direct payments and personal assistance support schemes

- continuing care policies.

This latter factor has great significance for people with the highest support needs. Some areas have continuing care criteria which enable people with high levels of support needs to access health authority provision in a way which keeps their total 'care package' within the ILF's cost ceiling (see discussion above). Others, in contrast, are 'so tight that hardly anyone who isn't in a nursing home or dying can get help' (Kestenbaum, 1999).

Government guidance, *Fair Access to Care Services,* was intended to create greater consistency across the country, as was guidance on local authority charging policies. However, local authorities are still able to determine what level of need is 'eligible' for a service. Local variations are inevitable unless there is a universal entitlement to a certain level of support. When a person moves from one part of the country to another, the new authority is only required to take into consideration the previous support package when assessing eligibility and there is no guarantee of continuing support, even for a transitional period.

There have also been quite complex disputes about who is responsible for funding the support needs of someone who is placed by their local authority in another part of the country. If someone is placed 'out of authority' they usually remain 'ordinarily resident' in that authority, who therefore retains responsibility for funding their placement. However, if a person moves out of that placement, say into ordinary or supported housing, a dispute often arises as to whether the local authority who funded an original residential placement out of area still has a responsibility to fund the individual's support needs. Such disputes can create disincentives to moving out of a securely funded residential placement. They can also create difficulties in getting responses to changing needs when someone has moved on from a residential placement (Chinery, 2003).

Local variations pose a particular barrier for people with high levels of support needs who are the most likely to be placed in institutions outside their local community area. One county, for example, has placed 220 people with complex needs outside the area because there is 'very limited or no housing and support available' within the area (South Downs Housing Association, 2002, p.10).

Measuring independent living:
- ➢ *Are disabled people able to move from one area to another without interruption in the funding of their support needs, or changes in the level of funding?*
- ➢ *What services are available, within a locality, for people with complex and high levels of support needs?*

The various sources of funding responsibilities for support needs can get in the way of independent living

Individuals may have to look to a number of different sources of funding their support needs. Support needs in an education context may be met by a Disabled Students Allowance; in a work context by Access to Work; within the home by adult community care services and/or by health services; in the context of parenting tasks by children's services. Needs for equipment may also be met by any of these sources. Variations in sources of support can pose a particular barrier for Deaf people (i.e. people who use BSL): they need to communicate in all areas of their lives yet may have to look to different funding and assessment systems to achieve this.

Government encouragement of joint working and pooled budgets may help bridge some of these gaps but the lack of a universal individual entitlement to independent living means that disabled people continue to struggle with different assessment systems, eligibility criteria, funding mechanisms and monitoring processes.

Measuring independent living:

➢ *Is the system for funding support needs simple and accessible? Does it cover all forms of support or do people have to look to different systems for different types of support?*

Poor quality services undermine independent living

There may be many different causes of poor quality services. The consequences for disabled people are a denial of choice and control in their lives. In some cases, this can be manifested in abusive practices, for example, in the way many older people (particularly those with dementia) are controlled by neuroleptic drugs (Stokoe, 2001). One recent study found that 25% of older people in a sample of nursing homes were given drugs such as thorazine, haloperidol and chlorpromazine and over 80% of these were considered to be inappropriately prescribed (Oborne, et al, 2003). One of the reasons for such a 'chemical cosh' (as the Alzheimer's Society calls it) is that nursing homes are often short of trained staff.

People living in their own homes can also be denied choice and control because of poor quality staff and little understanding of the principles of independent living. These are issues which have to be tackled by training, working conditions and by inspection and monitoring.

While there has been an increase in regulation and monitoring of services in recent years, performance targets and standards have not focussed on measuring disabled people's access to independent living. Perhaps this is not surprising as, generally, targets and standards have not been developed in consultation with disabled people and their organisations.

Measuring independent living:

➢ *Do social care inspections include standards related to independent living principles?*

- *Do national minimum standards for services promote independent living principles?*
- *Does education and training (qualifying and post-qualifying) of social care workers include disability equality training and also cover the principles and practice of independent living?*
- *How do pay and working conditions for support workers compare with local labour market rates?*

Barriers to the effective use of direct payments and ILF grants

The *Personal Assistance Users' Newsletter,* published by the National Centre for Independent Living, contains a wealth of information from disabled people about the difficulties they experience with recruiting and employing personal assistants. Two particular issues can be identified which could be addressed by the community care system.

Support to use direct payments

Appropriate support to use direct payments is not always available, particularly for people who have been under-represented amongst direct payments users: older people, people with learning difficulties, mental health service users, young people. Although disabled people are now entitled to receive direct payments to meet assessed and eligible needs, they have to meet certain criteria in terms of 'capacity'. We have already seen how negative attitudes can affect whether someone is considered capable of making safe decisions. There needs to be specific resources put into developing support systems for people who are vulnerable to these attitudes.

Although there is now a statutory duty for local authorities to offer direct payments to people who are 'willing and able to manage direct payments, with assistance if necessary', there is no parallel duty to provide such assistance. Unless assistance to use direct payments is available as an entitlement, many

disabled people will be denied the choice and control which can be achieved through the use of direct payments.

At the same time, disabled people, especially those who pioneered independent living, have expressed concern that some personal assistance support services are being set up by organisations who have little understanding of the principles of independent living. This can mean that direct payments are used in ways which do not give the disabled person choice and control. This may be particularly the case as direct payments start to be made available for older people and to carers.

Measuring independent living:
➢ *What support services are available to enable people to use direct payments?*
➢ *What personal assistance support services are available geared towards older people, people with learning difficulties, mental health service users, young people?*
➢ *Do personal assistance support services promote independent living principles?*
➢ *Are personal assistance support services accountable to personal assistance service users?*

Pay and conditions for personal assistants
People who use direct payments consistently report difficulties in recruiting personal assistants. Poor rates of pay create situations where disabled people are sometimes forced to take on personal assistants who cannot provide them with a good service. If support needs are not properly funded, personal assistance service users find they cannot provide good working conditions for their workers (holiday, sick and maternity pay, overtime for unsocial hours etc.).

Measuring independent living:

➢ *How do pay and working conditions for personal assistants compare with local labour market rates?*

Access to information, advice and support; involvement in decision-making

Choice and control cannot be achieved unless information relevant to the decision to be made is available in an accessible form. The advice and support of others must also be available to assist people to make choices and this may be from peers, advocates and/or professionals. Decision-making processes must involve the people who are affected, whether this is on an individual level (for example, assessments and care plans) or on a collective level (for example, commissioning and delivering services).

While progress has been made in making information available and accessible, providing advice and support, and encouraging involvement in decision-making, continuing inadequacies in these areas create blocks to independent living. This is evident across all 'service user groups'. For example, research carried out ten years ago found that three out of four mental health service users say that they are not given enough information about the treatments they are prescribed (Rogers, Pilgrim and Lacey, 1993) and more recent research confirms the difficulties created by a lack of information about, and involvement, in treatment decisions (Faulkner, 1997). Long-term users of mental health services stress the importance of professionals working with them, for example, to decide when increased support might become necessary and how to manage that support (Crepaz-Keay, 1998; Campbell, 1998). Unless services are planned and delivered with service users there is little prospect of them either meeting people's needs effectively, or providing the choice and control which is essential to achieve independent living.

The disability and survivors' movements have long argued that user-led organisations are the most effective way of developing appropriate and

empowering services. This also applies to the development of services to meet the needs of particular population groups. For example, the Sainsbury Centre for Mental Health's work concerning African and African-Caribbean mental health service users argues for greater support and funding to services led by the Black community (Sainsbury Centre for Mental Health, 2002).

Measuring independent living:

➢ *Do disabled people have easy access to information, advice, advocacy and peer support services?*

➢ *Do social care organisations fulfil their duties under the DDA in terms of making information accessible to disabled people?*

➢ *How many user-led organisations are funded to develop and deliver services?*

➢ *How do assessors and care managers demonstrate that disabled individuals have been fully involved in the assessment and care management process?*

Part 3: Barriers operating at a societal level

This section of the paper considers some of the wider social and economic barriers that can have an impact on disabled people's opportunities for independent living and, consequently, the level of support they are likely to need from both social care and other public services.

For example, financial resources (both individual and public) will have a major impact on disabled people's ability to secure adequate support to meet their practical needs. The fact that many people have a range of additional disability-related costs only adds to the pressure on their own financial resources and, therefore, the likelihood of their having to turn to public finance and services.

The availability of accessible housing and transport also impacts on opportunities for independent living and there is a knock-on effect on other civil and human rights. Rights to protection against discrimination in employment, for example, become academic if people are not able to get out to work because of a lack of accessible transport. As with other social and economic barriers, this will also increase disabled people's dependency on public services such as special transport provision.

Similarly, access to appropriate health care is of critical importance, not only to general health and well-being, but also in terms of supporting independent living and enabling people to maintain choice and control over how they live their lives.

Finally, in addition to economic and material barriers, attitudinal barriers among both services professionals and the general public also influence disabled people's opportunities for independent living. In particular, as discussed in the final part of this section of the report, negative or restrictive attitudes can have a significant impact on the creation of dependency.

It is not possible to discuss all of these wider social and economic barriers in detail in this report which, as stated earlier, is intended to focus mainly on the social care system. A brief discussion of these barriers has nevertheless been included in the report in order to illustrate some of the ways in which they can be just as important in promoting or restricting opportunities for independent living.

Economic barriers to independent living

Disabled people are disadvantaged in terms of purchasing power

Disabled people generally do not acquire, through the labour market, enough purchasing power to meet their needs/additional requirements relating to independent living. There are two dimensions to this

a. Both impairment and disabling barriers mean that disabled people are less likely to be in paid employment, and less likely, if in employment, to be earning average or above average wages. They are also less likely to have savings, to be owner occupiers, or to have an occupational pension.

b. It is more expensive to be disabled – i.e. impairment creates needs which can be costly to meet; and disabling barriers of unequal access and negative attitudes can also lead to additional costs.

The combination of these two factors creates a vicious circle of disadvantage. Reduced employment opportunities mean that disabled people are *less likely* to have sufficient resources to meet the additional support needs which they are *more likely* to experience than non-disabled people. The impact of this tends to be cumulative, so that disadvantage and dependency increase over time (Zarb and Oliver, 1993; Zarb, 1999). Moreover, the recent guidance on charging for services has created a situation where older disabled people are placed at a relative disadvantage as income from pensions and savings are not disregarded in the same way as earnings from employment. This exacerbates the cumulative

effect of economic disadvantage and is effectively a tax on older disabled people's support needs.

Measuring independent living:
- *Incomes (earned and pension) of disabled people relative to non-disabled people*
- *Savings held by disabled people relative to non-disabled people*
- *Additional costs of impairment/disability.*

Insufficient resources are provided, through the social security system and funding for social care, to meet the additional requirements/needs of disabled people.

Political decisions taken about the distribution of money raised through the taxation system have implications for the level of income provided through the benefit system, and the availability of support services, transport, housing, equipment and adaptations. If disabled people cannot rely on purchasing power acquired through their activity in the labour market to meet their additional costs, these political decisions have particular importance. Decisions have been taken in all these areas which influence whether disabled people will be able to meet their additional costs and requirements through the state's redistribution of public resources.

It has long been recognised that benefit levels are not sufficient to cover the additional costs of impairment and disability (Thompson, 1988; Berthoud et al 1993). A recent analysis of the standard of living of disabled people, taking into account both extra costs and disability related benefits, indicated high rates of poverty amongst disabled people which are not reflected in official statistics (Zaidi and Burchardt, 2003). In addition, this analysis found that 'a worryingly high proportion of those who face extra costs receive no extra costs benefits at all: 9 per cent of non-pensioners and almost one-third (30 per cent) of pensioners. The particularly large gap for pensioners may be related to the fact

that there is no help with mobility-related costs for those who become disabled over the age of 65.' (Ibid. p.48)

Reductions in the comparative values of benefits undermine disabled people's relative standard of living. While benefit levels have increased in real terms, all types of income support benefit (retirement pensions, incapacity benefit, income support and so on) have been declining as a percentage of average earnings over the last 20 years. For example, invalidity/incapacity benefit for a single person has declined from 23% of average earnings in 1982 to 15.3% in 2002 (Department for Work and Pensions, 2003).

This is also the case with Disability Living Allowance: for example, while the real value of the highest care component has increased from £54.87 p.w. in 1992 to £56.25 p.w. in 2002, as a percentage of average earnings it has declined from 14.2% to 12.1%. The equivalent figures for the higher mobility component are: £38.36 to £39.30; and 9.9% to 8.5% (Department for Work and Pensions, personal communication).

If independent living includes participating in society it is difficult to see how anyone who has to rely on benefits can achieve this when the value of their income, relative to those with a waged income, reduces each year.

The pattern of funding of 'social care' has never been sufficient to deliver full independent living. In the last few years, decisions about levels of public spending have led to cuts in services, increases in charges and revision of eligibility criteria so that people with lower support needs are no longer eligible. While expenditure on public services is set to increase in real terms over the current three year spending cycle (2001/2-2004/5), this is happening against a backdrop of an increase in the numbers of people, particularly older people, who require assistance in their daily lives.

Moreover, while there are compelling arguments for increasing resources for social care, there is also evidence that current levels of resources are used in ways which create dependency rather than promote independent living. The Audit Commission noted that resources continue to be wasted on inappropriate aids and equipment (Audit Commission, 2000); inaccessible and unadapted housing increases dependency and the need for support (Esmond and Stewart, 1996; Esmond et al, 1998); and, as we have already discussed, significant resources are still tied up in dependency-creating services rather than being diverted to direct payments or services based on independent living principles.

Measuring independent living:
➢ *relative values of benefits over time*
➢ *expenditure on social care, equipment and adaptations over time, measured against demographic changes*
➢ *relative incomes of disabled people, in comparison with non-disabled people, after taking account of disability/impairment related costs, charges and benefits*
➢ *expenditure on types of social care, equipment and adaptations that have been demonstrated to increase opportunities for independent living, in comparision with expenditure on services which have been shown to create dependency.*

Housing

The way the housing market operates, and associated political decisions, create disadvantages for disabled people. A combination of factors has led to a spiralling of house prices and disabled people's economic disadvantage means that they are particularly likely to be priced out of the housing market. At the same time, the supply of social housing has been depleted by over 1.5 million dwellings by the right to buy (Office of the Deputy Prime Minister, 2002a), and new building in the social housing sector has fallen dramatically over the last 20 years and continues to fall (Office of the Deputy Prime Minister, 2002b). Recent

announcements of increased investment in social housing may improve the situation in coming years.

Historically, the physical design of housing has created considerable barriers for people with physical impairments (see, amongst others Esmond and Stewart, 1996; Esmond et al, 1998).   While progress has been made in recent years in terms of the Part M Building Regulations and the adoption by some housing providers of 'lifetime homes' standards, there is still a signficant shortage of accessible homes. Moreover, standards and regulations are only of use if they are properly implemented and there needs to be much more effective monitoring of housing developments than in the past.

The way the Disabled Facilities Grant system operates also creates barriers:
- the means test creates an economic disadvantage for disabled people who require adaptations or equipment. This means they do not experience a level playing field in comparison with non-disabled people in similar households.
- The ceiling on funding available for adaptations discriminates against those with the highest needs and/or living in properties which are more expensive to adapt
- A national shortage of occupational therapists, and in some areas poor administration of the DFG system, means that many disabled people spend a long time in accommodation which limits their access to independent living.

Supporting People is a positive move in terms of breaking the dependency-creating linkage between support and housing, and extending choice about where to live. It may also open up options for people with lower levels of support needs, who do not meet the eligibility criteria for community care services. However, there are concerns about the very limited level of personal allowances and the anomalies created by different charging regimes. There also remain concerns that there are insufficient financial incentives to create flexible support to respond to individual needs (Simons, 2001).

Measuring independent living:

➢ *proportion of disabled people who are: owner occupiers; secure tenants; in comparison with non-disabled people in same age groups*

➢ *proportion of properties in the private and social housing sectors which are built to, or adapted to: wheelchair standard; 'lifetime homes' standard.*

➢ *Average length of time that disabled people have to wait for adaptations to be completed*

➢ *Numbers of people who do not obtain the adaptations they have been assessed as needing*

➢ *Extent to which existing policies, such as Supporting People, enable disabled people to live in their own homes with support tailored to individual need.*

Transport

Disabled people travel a third less often than the general public (Disabled Persons' Transport Advisory Committee, 2002). Almost half of disabled people use some initiative for disabled people to make travel easier. There is evidence that some groups of people who are entitled to concessionary fares do not get access to them and that, in the case of mental health service users the existing legislation is framed in such a way as to make it especially difficult for them to access this benefit (Mind, 2002).

An affordable, accessible public transport system is particularly important for disabled people because of their experiences of economic disadvantages. Yet, public transport in itself creates barriers to independent living.

People with physical and/or sensory impairments experience an unequal access to public transport as a result of a failure in the past to take their access needs into account when designing and building current provision. While progress has been, and is being, made to rectify this, significant physical barriers remain. Moreover, those who require one-to-one assistance to use public transport

(which includes some people with learning disabilities or mental health difficulties, as well as some people with physical and/or sensory impairments) are also disadvantaged if price systems do not take this into account and/or the social care system or DLA levels do not meet these costs.

Although disabled people do not use the car as frequently as the general public and the majority have no car in their household, many consider private cars to be the only form of transport that is convenient and accessible. Private cars provide choice and control in terms of timing, venues and the ability to go from door to door. Such features are particularly important for disabled people but they are less likely to have access to a private car – for economic as well as impairment related reasons. This type of choice and control can be promoted by (a) subsidising car ownership and use by disabled people; (b) subsidising the use of taxis; (c) providing an individual transport service as part of a public transport system.

When Dial-a-ride was first developed the intention was that a disabled individual would be able to book transport to make a specific journey and that eventually Dial-a-ride would be part of the public transport system. Current Dial-a-ride schemes fall short of this aspiration.

While disabled people drive far less often than non-disabled people, they use taxis/minicabs and buses more often. The most frequently used mode of transport overall is a car driven by someone else (DPTAC, 2002). Taxi use is subsidised by Taxi-card schemes but people who use taxis commonly report (a) difficulties in getting wheelchair accessible taxis and (b) poor attitudes amongst some taxi drivers. Both these barriers will potentially be tackled by regulations concerning new taxis and by training of newly qualified taxi drivers. However, problems remain in terms of both the limitations of the application of the Disability Discrimination Act to the taxi trade, and the practice on the ground of taxi-drivers and companies.

Generally, policies to address disabled people's access to transport have focussed on the barriers faced by people with physical impairments. The transport barriers faced by people who have other types of impairment or need have often not been acknowledged or addressed within existing policies. One key area of discrimination is the way that the eligibility criteria for the mobility component of DLA do not take into account the needs of people who require assistance with going out on the grounds of fear and anxiety (Disability Rights Commission, 2001).

Measuring independent living:
➢ *surveys of disabled people's use of transport and levels of satisfaction*
➢ *proportion of buses, underground and over-ground trains which are accessible to people with mobility impairments*
➢ *proportion of taxis which are accessible to people with different mobility impairments (recognising that a range of access features are required)*
➢ *quality of customer service (to cover, for example, booked assistance, information services, assistance available at stations and on buses and trains, etc.)*
➢ *costs of using public transport measured over time and in relation to benefit levels*
➢ *purchasing power of DLA mobility component in relation to costs of using public transport, taxis and the cost of purchasing and running a car*
➢ *extent to which additional costs of using transport (including personal assistance costs) are included in provision of support services and direct payments/Independent Living Fund (ILF) grants*
➢ *provision of disability equality training amongst different transport providers*
➢ *extent to which inclusive design is part of the training of all occupations concerned with transport and the built environment (see DPTAC's Charter on training and education in accessibility).*

Access to health care

Access to, and the quality of, health care can be an important part of independent living. If health care is unavailable, inadequate or inappropriate then this can constitute a major barrier to independent living.

Access to primary health care

Access to primary health care is known to be poor for people with learning difficulties (Kerr, 1998). This can mean that, as one worker put it, 'people aren't well enough to live ordinary lives' (Morris, 1999, p.98). In one survey 60% of deaf people reported that GP surgeries were inaccessible to them (Heaven et al, 2002). There is also evidence that people who use mental health services have poor access to health care in terms of their physical health (Stansfield, 2002) and have an increased risk of physical ill health (Phelan et al, 2001).

A recent survey of Primary Care Trusts found that disabled people face significantly greater difficulties in accessing primary health care services than the general population. Many of these difficulties arise from inadequate communication, inflexible service delivery patterns and negative attitudes towards disabled people. Only half of the PCTs surveyed had consulted disabled people about access to their services and only one in 10 provided mandatory disability equality training for their staff (Campion, 2003).

Some groups of disabled people experience direct or indirect discrimination in terms of their access to health care. The Department of Health's audit of NHS policies found age discrimination in a number of areas, including, amongst others, management of coronary heart disease, resuscitation, breast screening, referral to palliative care, rehabilitation stroke services, mental health, alcohol dependency services, transplant policy (Department of Health, 2002f, p.5). In addition, the audit found older people's access to services is affected by 'implicit

or unintended discriminatory practices' in 12 areas including, access to rehabilitation, identification and treatment for depression, waiting times, hip/knee replacement, cataract removal, misdiagnosis of abuse (Ibid, p.7).

Access to specialist services

Inadequate access to specialist advice, services and equipment can mean that impairments are more significant than they need to be. Sometimes this may be life-threatening. For example, the commonest cause of death amongst people with cerebral palsy is chest infection (Strauss and Shavelle, 1998) and some people have argued that the risk of chest infection can be alleviated by physiotherapy and better posture brought about by good seating. Research carried out in the early 1990s emphasised the important of specialist and multi-disciplinary health for people with conditions such as epilepsy, referring to evidence that:

> treatment delivered by a multidisciplinary team is effective in reducing
> frequency of seizures and rationalised therapy results'. (Chamberlain,
> 1993, p.30).

As she went on to point out, reduced seizures through effective treatment can mean an increased chance of employment and the person may also be able to drive. The Department of Health has itself recently carried out an audit of the quality of care received by people with epilepsy in general practice and in hosptials and found that '54% of adults had inadequate care, leading to the conclusion that 39% of adult deaths were considered potentially or probably avoidable' (Department of Health, 2003b). People with conditions such as epilepsy require high quality specialist health services over a long period of time in order to maximise their ability to live independently. Findings concerning the experiences of people with epilepsy may well be replicated amongst other groups of people with long-term conditions. Although this is an issue which should start to be tackled by the National Service Framework for People with Long-Term

Conditions, concern has been expressed that this particular NSF covers a limited number of conditions.

Medication can, in itself, inhibit independent living. The older anti-psychotic drugs are associated with disabling side effects (such as tardive dyskinesia) and the newer ones are not without their problems. Anti-depressants have been shown to effect some people in ways which profoundly limit their lives. There is evidence that people whose behaviour is difficult for others to cope with are mis-prescribed drugs: one study of people with learning disabilities and challenging behaviour found that, 'despite relatively low levels of mental illness, just over half…were taking antipsychotic drugs' (Qureshi, 1994, p.31). Many people find that they have to take – over a long period of time - medication which has a disabling effect on their lives. Their choices over this are often limited, sometimes because of the severity of withdrawal symptoms and sometimes because they are pressured by professionals into continuing with medication. People who are compulsorily detained in hospital can be forced to take medication and Compulsory Treatment Orders, as proposed by the government, will mean that some people living in the community will lose their right to refuse treatment.

Measuring independent living:
➤ *Numbers of health care providers who provide mandatory disability equality training for their staff*
➤ *Access audits of all forms of health care*
➤ *Surveys of use of health care by disabled people and satisfaction levels*
➤ *Monitoring of access to treatment and equipment by age and impairment.*

Cultural values

The negative values ascribed to any experience of depending on others and the associated meaning of 'care' have the result that the lives of people who need assistance are devalued. There are a number of different aspects to these

negative attitudes, which are explored below. The impact of these attitudes on opportunities for independent living should not be underestimated, particularly in terms of how they influence the ways in which disabled people's support needs are met. Most support services are based on the belief that disabled people are 'vulnerable people' who need to be protected and 'cared for'. This is extremely damaging to the development of independent living as it only serves to reinforce perceptions of disabled people as passive 'recipients of care', rather than active citizens facing practical barriers to participation in the social and economic life of the community. By refusing to acknowledge any other legitimate role for disabled people in society, such beliefs are also discriminatory.

The social construction of 'carers and their dependents'
Carers as a pressure group started off as a self-help, grass roots organisation with the aim of giving women the support and confidence to refuse to act as unpaid helpers. It became a national organisation whose aim is the establishment of informal caring as a career, with a carers' income, protection of pension and other benefits. This fits in with the government's (both Labour and Conservative) position that public resources will never be adequate to provide the support needed by older and disabled people and the acceptance that, to quote a government white paper published twenty years ago, 'Care *in* the community must increasingly mean care *by* the community' (Department of Health, 1981, para. 1.9).

The social meaning of 'dependency
Dependency is associated with being helpless, powerless, and vulnerable. Independence, in contrast, is associated with being in control, in charge and capable. Crucially, independence is associated with *doing things for yourself.*

The social meaning of dependency underpins the government's policies on combating social exclusion. The assumption is that paid employment is the path out of poverty and will bring about an experience of social inclusion. The

promotion of these kinds of cultural values undermines the challenge to the meaning of independence which is central to the philosophy of independent living; namely that independence is not about doing things yourself but having choice and control. The negative attitudes associated with the need for assistance are particularly damaging of older people's social status.

<u>The recognition of difference is accompanied by negative attitudes about that difference.</u>

Human and civil rights are undermined, rather than promoted, by the way disabled people's additional requirements are responded to. Responses to difference have come in the form of segregation and separation from the wider society. The people and organisations giving assistance have choice and control rather than the person receiving it. The very process of the recognition of difference can be disabling. For example, for people with mental health difficulties, a diagnosis can, in itself, be a barrier to independent living in that label of mental illness commonly results in social stigma and discrimination, particularly in the context of employment (Dunn, 1999). People who use mental health services face particular barriers in terms of how their 'difference' is perceived: in the tabloid press especially they have been identified as a 'public safety issue' and increased control of them is urged on the government. Such attitudes are in conflict with attempts to deliver support in a way which increases the choice and control of services users over their lives (Beresford, 1999).

Within general categories of service users, particular groups are especially affected by discriminatory attitudes. For example, African and African-Caribbean people who have mental health difficulties are particularly vulnerable to negative attitudes about difference. Research on their experience of services makes a link between negative attitudes amongst professionals and the general public and this group's experiences of services: African and African-Caribbean adults with mental health difficulties are more likely to be subjected to force or restraint

and less likely to be offered talking treatments than white service users (Sainsbury Centre for Mental Health, 2002).

The knowledge that negative attitudes about disabled people are commonplace can have a significant impact on disabled individuals' self-esteem and self-confidence. Disabled people have reported that their interaction with non-disabled people is dominated by being patronised, ignored, mocked, and assumed to be stupid (Knight and Brent, 1998, p.6). Such experiences are inhibiting in terms of participation in the community and hardly conducive to independent living.

Measuring independent living:
➢ *Attitudes to disabled people amongst non-disabled people.*
➢ *Disabled people's perception of how they are viewed by the general public and by professionals and service providers*
➢ *Attitudes amongst professionals and service providers to 'risk' and 'capacity'*
➢ *Attitudes amongst professionals towards particular service user groups (e.g. people with significant learning disabilities; older people) and particular population groups (e.g. African and African-Caribbean men).*

Conclusion

This paper has attempted to provide:

- An understanding of independent living and its relationship to human and civil rights

- A detailed examination of the social care system and the barriers it poses to independent living

- A brief summary of some of the barriers to independent living which exist on a wider societal level.

It can be seen that there is much scope for improving disabled people's access to independent living. Some progress could be made if the DRC used its formal investigation powers to address some of the barriers identified within the social care system. For example, the geographical variations in access to direct payments and personal assistance support schemes; the differential access to direct payments and personal assistance support schemes across different service user groups.

There are other barriers which require changes in legislation or government guidance. That some of these barriers have grown up almost unintentionally (for example, the failure of the community care system to adequately address personal assistance needs in the context of parenting) would tend to indicate that change may be possible. Tackling other barriers may mean more resources but we do not have evidence of how much more resources would be required, for example, to lift the cost ceilings imposed by the Independent Living Fund and local authorities.

There therefore seems to be plenty of scope for the DRC to promote better and more equal access to independent living for disabled people.

Jenny Morris
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