The implications for social care of the Disability Equality Duty
A paper prepared for the Disability Rights Commission

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The paper is organised under the headings set out in the contract
commissioning the work.

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1. Public authorities In England, Scotland and Wales concerned with arranging social care support and what the disability equality duty means for them

1.1 <u>The meaning of 'social care'</u>
Before listing the public bodies concerned with social care support it is necessary to identify what is meant by this term. The main formal sources of defining 'social care' are the statutes, guidance, legal judgements and local protocols that, in England and Wales, distinguish 'social care' from 'health care', and, in Scotland, distinguish 'social care' from 'personal care'. The distinction is necessary because, in England 'health care' is free at the point of delivery whereas 'social care' is not. In Scotland, 'personal care' is free – like health – at the point of delivery, but 'social care' is not. In Wales, a manifesto commitment to abolish charging for social care has been followed by wrangling over definitions of 'social care', and attempts to follow the Scottish route of only making 'personal care' free at the point of delivery.

Traditionally, health and social services authorities across all three countries have also used distinctions between health and social care in attempts to limit demands on their budgets. The later discussion in this paper on continuing care criteria is relevant here. However, increasingly organisations responsible for services in the community (both health and social care) are forming organisational partnerships[1]: in England and Wales this has mainly happened in terms of community services for people with mental health problems and people with learning disabilities (although there are also some partnerships covering services to older people); in Scotland Community Health and Social Care Partnerships are being set up by Health Boards and Social Work Departments.

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[1] What is meant here is more than the joint strategies which, for example, are written by Local Strategic Partnerships in England or the Health, Social Care and Well Being strategies by the 22 Local Health Boards and local authorities in Wales. The Health Act 1999 made it possible for local health and social services in England and Wales to work together in three different ways (all of which had previously been hampered by existing legislative and regulatory frameworks): pooled budgets – where health and social services pool local budgets to meet needs; lead commissioning – where one organization delegates its responsibilities and funding to another organization to meet needs; integrated provision – where two organizations jointly provide a service. Subsequent legislation (the Health and Social Care Act 2001) set up Primary Care Trusts to commission local health services and increased the opportunities for joint funding and joint working. In Scotland, *Community Care: A Joint Future*, published in 2000, set out the framework for joint working, followed by *Reinvigorating the Joint Future Agenda* in 2004.

In another context, attempts have also traditionally been made to distinguish 'social care needs' from 'education needs' when parents or professionals make the case for out of authority and/or residential placements for disabled children and young people. In these cases, the primary motivation is to reduce the call on education or social services budgets (see Abbott et al, 2000). There have also been disputes between health and education services as to the funding responsibilities for services such as physiotherapy when delivered in a school setting. However, recent developments in children's services[2] are also leading to organisational partnerships across health, social care and education. These developments include, in England, the shift in responsibility for children's social care from the Department of Health to the Department for Education and Skills; Children's Trusts and the appointment of Directors of Children's Services; Sure Start; the policies on extended schools and children's centres.

The DRC's Policy Statement on Social Care and Independent Living states that "The term 'social care' covers all practical support provided in community and residential settings". However, the lines between practical support which is 'health care' and that which is 'social care' can become blurred when delivered in a non-hospital setting: for example, cleaning a wound can be designated as 'health care' but dressing it can be designated as 'social care' – the issue in contention is which organisation pays for these tasks and (sometimes) which type of worker has the relevant skills. For disabled children and young people in education settings, the distinction between 'practical support' (social care) and 'learning support' (education) can also be contentious.

'Social care' is not necessarily a term that makes sense either to individual disabled people or within an independent living perspective. Caroline Glendinning's research, for example, found that disabled people using direct payments did not distinguish between 'health' and 'social care', but saw both as part of their overall 'personal care' needs (Glendinning, 2000). 'Personal care' is not an appropriate way of defining 'social care' however, as it does not include the 'practical support' that takes the form of equipment or adaptations. Neither does it include advocacy or

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[2] Following *Every Child Matters* and the Children Act 2004 in England, *Children and Young People: A Framework for Action* in Wales and *For Scotland's Children*, in Scotland.

self-advocacy support, or communication support. Such 'practical support' is key to independent living for many disabled people.

For the purposes of this paper, the DRC's definition of social care will be used, encompassing both 'personal care' and other forms of practical support. However, the mechanisms which make a formal distinction between health and social care, and social care and education support, are part of the context to the implementation of the Disability Equality Duty, and will therefore be discussed at relevant points in this paper.

If the DRC was to take a wider definition of social care than that commonly found within the disability agenda, we would need to also include services such as Supporting People, which – although they are key to some disabled people's opportunities for accessing independent living – are mainly used by people who do not come under the DDA definition. We might also include services, such as accommodation and support services to people fleeing domestic violence, which are focussed primarily on needs that have nothing to do with the experience of impairment or mental health, but which may be important sources of 'practical support provided in community and residential settings' to disabled (and non-disabled) people.

This broader definition of social care has been used when listing the public authorities, and relevant policy areas, below.

1.2 <u>List of Public Authorities</u>

The following public authorities are concerned with social care support:

1.2.1 <u>England</u>

<u>Government departments</u>
Department of Health
Relevant policy areas:
- National Service Frameworks: older people; mental health; children; long-term conditions
- Adult Social Care Green Paper
- Health and Social Care White Paper (forthcoming)

- Improving Life Chances of Disabled People (cross departmental)
- Community care, including direct payments
- Fair Access to Care Services: Policy and Practice Guidance
- Continuing Care guidance and forthcoming National Framework
- Protection of Vulnerable Adults
- National Carers Strategy
- Fairer Charging policy
- National Care Standards
- Sure Start (cross departmental)
- National Drugs Strategy
- Domestic violence

Office of the Deputy Prime Minister
Relevant policy areas:
- Supporting People
- Housing renewal and adaptations
- Local authorities - targets, equality standard, etc
- Sustainable Communities – national homelessness strategy
- Domestic violence.

Department for Education and Skills
Relevant policy areas:
- Every Child Matters
- National Service Framework for Children, Young People and Maternity Services
- Sure Start (cross departmental)
- Improving Life Chances of Disabled People (cross departmental)
Children's Commissioner for England.

Home Office
Relevant policy areas:
- substance abuse: Drugs Strategy – Tackling Drugs to Build a Better Britain
- domestic violence: Safety and Justice.

National agencies
NHS National Treatment Agency for Substance Misuse

Care Services Improvement Partnership (previously within DH, now commissioned by DH)

- Valuing People (the National Learning Disability Strategy)
- National Institute for Mental Health in England
- Change for Children
- Health and Social Care Change Agent Team
- Integrated Care Network
- Integrating Community Equipment Services
- The National CAMHS Support Service (NCSS)
- Health in Criminal Justice.

?Independent Living Funds

?Social Care Institute for Excellence

Regulation and Inspection bodies
Audit Commission
Commission for Healthcare Audit and Inspection
Commission for Social Care Inspection
National Audit Office
Ofsted (leads on the new Framework for the inspection of children's services)

?General Social Care Council

Ombudsman
Local Government Ombudsman

Local public bodies
Councils with social services responsibilities (CSSRs)[3]
- Adults' services
- Children's services
Children's Trusts
Care Trusts
Primary Care Trusts (see discussion re overlaps with health care responsibilities).

Training and Qualification bodies
?Skills for Care[4]

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[3] Councils with Social Services Responsibilities is a legal term – relating to the Local Authority Social Services Act 1970 – and is not a term used colloquially. It refers to local authorities across the United Kingdom who have social services responsibilities (for children and/or adults). It is used in this paper as a convenient term to cover a range of local authorities which may be called different things (Social Work Departments in Scotland, Children's Services Authorities in England for example) but which all have the same legal status.
[4] Skills for Care and the Children's Workforce Council were previously known as TOPSS

?Children's Workforce Council

Voluntary and private sector organisations delivering services commissioned by public bodies.

1.2.2 Scotland

Scottish Executive
Health and Community Care Department
Education Department
Environment and Rural Affairs Department
Communities Scotland
Children and Young People's Commissioner
Relevant policy areas:
- Fair Care for Older People
- The Same as You (National Learning Disability Strategy)
- Joint Future Agenda
- For Scotland's Children
- Direct Payments Scotland
- Improving Life Chances of Disabled People
- National Care Standards
- Protecting Vulnerable Adults
- Supporting People
- Homelessness Task Force Agenda
- National Drugs Strategy/Getting Our Priorities Right
- Preventing domestic abuse: a national strategy
- Sure Start Scotland

Regulation and Inspection
Scottish Social Services Council
Care Commission
Social Work Services Inspectorate
Audit Scotland

Social Work Inspection Agency
HM Inspectorate of Education, Services for Children Unit (has child protection responsibility)

Ombudsman
Public Services Ombudsman

Local bodies
Councils with Social Services Responsibilities[5]
Health Boards[6]
NHS Trusts

Training and Qualification bodies
Scottish Social Services Council
?Scottish Institute for Excellence in Social Work Education

Voluntary and private sector organisations delivering services commissioned by public bodies

1.2.3 Wales

National Assembly for Wales/Welsh Assembly Government:
Health and Social Services Department
Children and Families Directorate
Children's Commissioner for Wales

Relevant policy areas:
- Wales: A Better Country
- Designed for Life – 10 year strategic plan for health and social care.
- Fulfilling the Promises (National Learning Disability Strategy)
- A Strategy for Older People in Wales
- National Service Frameworks: older people; mental health; children
- Children and Young People: A Framework for Partnership
- Children and Young People: Rights to Action
- Fair Access to Care Services
- Fairer Charging policy
- Improving Life Chances of Disabled People
- National Care Standards
- Protection of Vulnerable Adults
- Housing renewal and adaptations
- National Homelessness Strategy
- Supporting People

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[5] Councils with Social Services Responsibilities is a legal term – relating to the Local Government Act 1970 – and is not a term used colloquially. It refers to local authorities across the United Kingdom who have social services responsibilities (for children and/or adults).
[6] Health Boards and CSSRs (Social Work Departments) are currently setting up Community Health and Social Care Partnerships.

- National Housing Strategy
- National Drugs Strategy
- Tackling Domestic Abuse: The All Wales National Strategy
- Cymorth: the Children and Youth Support Fund (incorporating Sure Start Wales)

National agencies

Wales Office for Research and Development for Health and Social Care (WORD)

Local Government Data Unit

Regulation and Inspection bodies
Care Council for Wales
Audit Commission in Wales
Care Standards Inspectorate for Wales
Social Services Inspectorate for Wales

Ombudsman
Public Services Ombudsman for Wales

Local bodies
Councils with Social Services Responsibilities[7]
Health Boards
(NB CSSRs and Health Boards are developing Health, Social Care and Well-Being Strategies.)
NHS Trusts

Training and Qualification bodies
?Skills for Care
?Children's Workforce Council
? Health Professions Wales

Voluntary and private sector organisations delivering services commissioned by public bodies

1.2.4 England, Scotland and Wales

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[7] Councils with Social Services Responsibilities is a legal term – relating to the Local Government Act 1970 – and is not a term used colloquially. It refers to local authorities across the United Kingdom who have social services responsibilities (for children and/or adults).

HM Treasury
Relevant policy areas:
- spending reviews
- Public Service Agreements and Performance Targets.

DWP
Relevant (cross-departmental) policy areas:
- Opportunity Age (Older People's Strategy)
- Improving Life Chances of Disabled People.

Home Office
- asylum seekers and refugees.

National Asylum Support Service
- provision of accommodation and support to asylum seekers who would otherwise be destitute.

Skills for Care and Development: UK wide Sector Skills Council for Social Care

Health and Safety Commission
Health and Safety Executive

1.3 What does the DED mean for these public authorities?

The focus of this paper is on public authorities as policy makers and providers of social care, rather than as employers. Obviously they will have responsibilities as employers to fulfil the disability equality duty. These duties are not included in this paper.

The duty "requires authorities to proactively eliminate discriminatory practices, policies and procedures, to eliminate barriers and to ensure equal access to and participation in society of disabled people" (DRC 2004, para 1.7). For example, a local authority might find that take-up of direct payments – which have been shown to be a more effective way of enabling people to participate in society[8] than community care services - is particularly low among mental health system users or disabled people from ethnic minority communities. Effective strategies to increase take-up on a par with other groups could be achieved by working

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[8] This is to leave unanswered for the moment the question of what 'participation in society' looks like. It is nevertheless a question which will need to be addressed in the development of the Guidance.

together with mental health teams in NHS Trusts and community groups to increase awareness of the purpose and availability of direct payments and how to access this resource.[9]

Social care services have a particular importance in promoting equality of opportunity for disabled people as many people require personal assistance, equipment, communication support and/or advocacy in order to have equal access to employment, education and training, family and community life, leisure activities and to society in general. This importance is reflected in the DRC's Policy Statement on Social Care and Independent Living:

> The Disability Rights Commission believes that social care services can help secure equality and participation of disabled people by providing support that promotes independence and social inclusion and enables choice and control for all disabled people.

Social care services also have a role in protecting children and vulnerable adults from harm, and this role would also be covered by the DED. In respect of this role, a key question will be to what extent 'protection' becomes limitation of opportunities. Guidance could assist social care organisations to take a more empowering approach to this aspect of their role than is often currently the case.

Social care support services for people experiencing domestic violence, homeless people, drug treatment or asylum support services will also play a key role in enabling some disabled people to experience equality of opportunity.

The DED applies to public authorities involved in social care in two main ways:
- equality of access to social care services, particularly to those that enable independent living: i.e. public bodies should "proactively eliminate discriminatory practices, policies and procedures" to ensure equal access to services
- the role of social care services in enabling equal access to and participation in society: here the issue is more what kind of outcome for disabled individuals (and groups of individuals) is achieved by the services provided.

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[9] This example was given by Gerry Zarb in his comments on the draft paper.

1.3.1 <u>Equality of access to social care services</u>

There are three elements to this aspect of the DED that can be identified as relevant to social care services.

a. Equality of access in comparison with non-disabled people

There are some social care services used both by people who do not come within the DDA definition of disabled person and by those who do. They are:

- Supporting People services are mainly targeted at people who have relatively low levels of social care needs, most of whom therefore would not come within the DDA definition. There is some evidence that the implementation of *Supporting People* is not meeting the needs of people with the most complex needs (Watson et al 2003). Amongst these will be people who come within the DDA definition of disabled person.

- Services for carers: An important section of social care services are aimed at supporting people who provide significant amounts of support to a disabled friend, family member or neighbour. The 2001 Census found that, of the nearly 2 million people aged 16-74 who were recorded as 'permanently sick or disabled', almost 273,000 provide some unpaid care for other people (this is 5% of all carers) and 105,000 provide 50 or more hours care (10% of all carers). Social care policies and services concerned with carers will need to address the access requirements of disabled carers.

- Children and families support services are intended to assist parents to look after their children. There is some evidence that such services do not adequately support and are not appropriately accessible to parents with learning disabilities. The children of parents with learning disabilities are over-represented amongst children subject to care orders and other child protection proceedings. For example, a study on care orders found that 25% of the children involved had a parent with a learning disability (Harwin et al, 2001). Another study on child protection applications to family courts found that 15% involved a mother and/or father with learning disabilities (Booth et al, 2003). Only 2.5% of the population

have mild to moderate learning disabilities (Department of Health, 2001, p.15). Apart from possible discriminatory practices within the family court system, here the issue is whether children and families support services discriminate against parents with learning disabilities.

- Sure Start, a government programme which runs in England, Wales and Scotland. It brings together early education, child care, health and family support to "deliver the best start in life for every child". It funds local programmes and Children's Centres throughout each country: for example there is a commitment to provide 3,500 children's centres in England by 2010. The government has recognised that there is a need to evaluate whether the programme is adequately addressing the needs of disabled children and their families (Prime Minister's Strategy Unit, 2005, Recommendations 5.2 and 5.3).

- Substance abuse services: although there is limited UK evidence, a US study found drug and alcohol abuse to be higher amongst disabled people than non-disabled people (Substance Abuse Resources and Disability Issues, n.d.). Yet a literature review carried out for the National Treatment Agency (in England) found some indication that substance abuse services are not always accessible to people who have physical and/or sensory impairments and/or learning disabilities (Dyter and Mitchell, 2003). The Scottish Executive's recent publication, *Getting Our Priorities Right*, which sets out policy and practice guidelines for working with families affected by problem drug use, mentions the particular needs of disabled children whose parents use drugs. However, it contains no acknowledgement that some drug-using parents may also have physical and/or sensory impairments and/or learning disabilities, although there is recognition of the overlap with mental health.

- National Asylum Support Service: this service provides accommodation and support for asylum seekers (previously the responsibility of local authorities). There is currently very little information about how many asylum seekers are disabled and whether the NASS is meeting their needs (see later).

- Homelessness services: although the majority of people who use homelessness services are not DDA disabled, there is evidence that disabled people are becoming more vulnerable to homelessness. In England, between 1997 and 2003, there was "a 44% increase in the number of homeless households in priority need because a household member has a physical [impairment] and a 77% increase in the number of households where the priority need is a household member with a mental illness. The overall increase in the number of households in priority need over the period was 35%" (DWP, 2005)[10].

- A Women's Aid Federation (England) survey reported that disabled women make up 2.4% and disabled children make up just 0.7% of the total women and children accommodated in refuges (Toren, 2005). Yet the Women's Aid Federation also refers to a Home Office study, carried out in the 1990s, which found that disabled women were more likely than non-disabled women to experience domestic violence (Abrahams 2001). There is currently very little information to enable us to judge whether disabled women and children have equal access to domestic violence services. While the Welsh Assembly Government's and the Scottish Executive's national strategies on domestic violence have a specific commitment to ensure that services meet the needs of disabled people, there is not a similar commitment in the equivalent English policy.

b. Equality of access between different groups of disabled people.

Amongst the services usually referred to as 'community care services', most users come within the DDA definition of disabled person. Therefore, the 'equality of access' issue is not usually comparative with non-disabled people but between different groups of disabled people. For example:
- there is evidence that mental health services are not always accessible to people with physical and/or sensory impairments (Morris, 2004), Deaf people (Department of Health, 2002) , or people with learning disabilities (Mental Health Foundation, 2002). Here, the discriminatory practice

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[10] Please note this quote comes from a DWP document provided in confidence and should not be quoted publicly without permission.

affects people who have an impairment additional to the condition which the service is focussed on.

- In a survey carried out by the Council for Disabled Children, 75% of CSSRs in England and Wales responded that there are disabled children who are eligible for services but whom they think their services either cannot help or have nothing to offer. Some of these are children who are deemed 'too disabled' for services because of the complexity of their needs (Council for Disabled Children 2004). Here, the discriminatory practice is focussed on level of impairment.

- Some services for older people have eligibility criteria which exclude people with learning disabilities or mental health needs.

- Black and minority ethnic disabled adults and children experience unequal access to social care services in comparison with white disabled adults and children (Mir, 2001; Chamba et al, 1999). With examples such as this, public authorities will need to consider possible overlaps with the Race Equality Duty. These overlaps also pose a challenge for the DRC, as discussed later.

- Asylum seeking disabled people may experience unequal access to mental health services (and indeed to other health and social care services). The British Medical Association highlighted in 2001 that, not only did the physical health of many asylum seekers get worse after they entered Britain but those with mental health support needs are not getting access to relevant support services. For example those suffering from psychological affects of torture are not always referred to specialist centres (BMA, 2001). Here, the discriminatory practice concerns immigration status.

c. Equality of access to policies and services that promote independent living.

Some social care policies and services are more important than others in terms of enabling participation in society and promoting independent living (see later discussion about how to judge which policies and services promote independent living). It will be important therefore for national and local public authorities to

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monitor the implementation and take up of these policies and services. Some groups of disabled people may experience unequal access to such policies and services and this would be something that could be picked up by the implementation of the Specific Duty.

If it appears that some groups are under-represented amongst those benefiting from policies and services which promote independent living, this might be for a number of reasons:

- the policy itself may not be an appropriate way of delivering independent living for that particular group

- additional action and/resources may be required in order to implement the policy for that particular group

- CSSRs may be discriminating against this particular group, albeit unintentionally, in the way they implement the policy. For example, in the implementation of direct payments, social workers working with people with mental health problems may not have the information or confidence to promote direct payments to the people they are working with; the personal assistance support scheme contracted to assist direct payment users may not have the necessary expertise to work with people with learning disabilities.

1.3.2 <u>The role of social care services in enabling equal access to and participation in society</u>
It is not just a question of ensuring equality of access to social care services, but of looking at the role of social care in enabling "equal access to and participation in society of disabled people" (*The Duty to Promote Disability Equality: Statutory Code of Practice, Draft for consultation*, Para 1.7: this paragraph is in the draft Codes for both England and Wales, and Scotland).

The Specific Duty requires public bodies responsible for social care to examine the extent to which social care policies and practices promote equality of opportunity for disabled people.   The requirement to gather information on services and functions and to assess the impact of policies and practices on equality for disabled people has particular implications.

The DWP envisages that "certain Secretaries of State should report on progress towards equality for disabled people across

their sphere of influence" (DWP, 2004, para. 6.8). As we can see from the list of government departments given above, there are a number of Secretaries of State, Scottish Ministers and Assembly Ministers who are concerned with social care in England, Scotland and Wales.

The DED applies not only to current and future policies and practices but public bodies will also need to look at the impact of past decisions: "Not only must authorities have due regard to disability equality when making decisions in the future, but they will also need to take action to tackle the consequences of poor quality decisions in the past" (*Draft Code of Practice*, para 1.9). This has particular implications for social care organisations. For example, past decisions about how to respond to people who have high levels of, and/or multiple, needs mean that a lot of existing resources are tied up in institutional care. CSSRs are often unable to develop local services to meet the needs of children and adults with high levels of needs because they would require additional funding and they cannot easily free up resources tied up in existing placements. Some English local authorities have pressed the DH and Dfes for additional short-term funding to enable the development of local services. Redressing the impact of past decisions may well require central and local government to work together on agreed priorities: this will therefore need to be reflected in both government departments' and local authorities' Disability Equality Schemes.

In some cases, past decisions have created unintended inequalities which require changes to policy or regulation to address them. For example:

- While earned income is not taken into account when charging for community care services, direct payments or ILF grants received by disabled people living in their own homes, this is not the case for people living in residential care. This means that those living in residential care experience a major financial disincentive to taking up paid employment. Such inequality is an unintended consequence of an assumption that people in residential homes are unlikely to be engaged in paid employment. While this is generally true the Prime Minister's Strategy Unit received evidence – when carrying out its work for *Improving Life Chances of Disabled*

People - that there are some people in residential homes who do wish to work.

- Assistance with carrying out parenting tasks is specifically excluded from the remit of the Independent Living Fund (which operates across the United Kingdom) by its Trust Deed. This is an anomaly which, it has been argued, creates unequal opportunities for disabled parents with high level support needs.

2. Identify how the duties can complement and build on gaps in current legislation, policy and guidance in England, Scotland and Wales relevant to the provision of social care support, to deliver on promoting disability equality and Independent Living for disabled people.

2.1 Disability equality, independent living and social inclusion
The goals of disability equality and independent living are integrally linked to definitions of social inclusion and social exclusion. Social exclusion has been defined as follows:

> An individual is socially excluded if (a) he or she is geographically resident in a society and (b) he or she does not participate in the normal activities of citizens in that society.
> (Burchardt et al 1999, p.230).

If disability equality and independent living were to be achieved, disabled people would experience equality of opportunity in terms of access to the 'normal activities' referred to above. These 'normal activities' are:

> to have a reasonable standard of living, to possess a degree of security, to be engaged in an activity which is valued by others, to have some decision-making power, and to be able to draw support from immediate family, friends and a wider community
> (Burchardt et al, 1999, p. 231).

For some, though not all, disabled people, social care services are key to bringing about equality of access to these 'normal activities'. It is against this that social care services must therefore be measured.

2.2 <u>In what ways does the social care system currently fall short in terms of delivering disability equality and independent living?</u>

A number of factors mean that social care resources are often used, not to access 'normal activities' but to maintain and create dependency. Needs are therefore met in ways that result in social exclusion. These factors can be summarised as:

- An inadequate legislative and policy framework, which:
    - places duties on CSSRs to provide services, rather than gives rights to support or to live in one's own home
    - does not adequately cover the full range of assistance to engage in 'normal activities'
    - contains no entitlement to advocacy or supported decision-making[11].

- Financial pressures: current resources are often tied up in service provision that creates and maintains dependency. For example, local education and social services authorities in England find it difficult to develop local services to meet the needs of disabled children with high levels of support needs because large sums of money are tied up in out of authority placements (see Abbott et al, 2003). It is unclear as to whether an overall increase in resources is required but existing financial structures make it difficult to invest in independent/inclusive living.

- Attitudes: "Policy and practice on social care is often based on negative assumptions about risk and capacity, which work against the principles of extending choice and control. Basically, disabled people who use support services are seen as 'vulnerable people' needing to be 'cared for', rather than citizens facing practical barriers to participation and inclusion" (Zarb, 2004). Such attitudes are particularly apparent in the consultation paper recently issued by the Scottish Executive which defines anyone in receipt of community care services as 'vulnerable'

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[11] There is some limited entitlement to advocacy in certain situations across England, Wales and Scotland but disability organisations have argued that a more comprehensive entitlement is required, as set out in the Disabled Persons Act 1986 but not implemented.

(Scottish Executive 2005) and by the renaming of the Community Care Unit as the Vulnerable Adults Unit.

For a full discussion of the barriers to independent living within the current social care system, please see my earlier report for the DRC, *Barriers to Independent Living: A scoping paper*, written in June 2003, and also Chapter 4 of *Improving Life Chances*. Apart from the main three issues listed above, some of the detailed barriers are:

- Assessments which are service-led rather than needs-led
- Some support needs remain unmet, or inadequately met, in particular: low level or preventative support needs; communication needs; support to take up or remain in employment; support to carry out parenting tasks; needs associated with 'invasive procedures'; support for young disabled people to leave the parental home
- 'Custom and practice' leads to denial of independent living by default: e.g. where a move into residential care is seen as final and permanent decision
- Local variations in policies and practices which support independent living, particularly in the take-up of, and support to use, direct payments and ILF grants
- Fragmentation of support needs across different sources of funding
- Poor quality services which institutionalise people
- The pay and conditions of support workers
- Inadequate access to information, advice and advocacy.

2.3 How could the DED complement and build on the gaps in the current social care framework

The underlying problem is that, within the existing framework, there is no requirement that public bodies use their resources to promote 'normal activities' which are key to independent living and social inclusion. The Disability Equality Duty could potentially redress this situation.

If policies and practices are to promote independent living they need to be informed and underpinned by a clear understanding of the social model of disability and its implications for social care. The DRC has a clear role in promoting such an understanding in the context of the implementation of the Disability Equality Duty.

Key to the application of social model of disability to social care is the recognition that:

- Disabled people have additional requirements which stem both from experiences of impairment and from the disabling barriers of negative attitudes and unequal access
- If disabled people are to have equality of opportunity with non-disabled people these additional requirements must be met in ways that deliver choice and control.

The organisations and professions involved in social care do not have a good track record in terms of promoting independent living. Instead, independent living has been struggled for by disabled people and their allies by, for example:
- Demonstrating that direct payments work
- Developing and delivering training programmes for social care staff which promote the social model of disability and independent living
- Campaigning for mental health resources to be used in ways which are more flexible and personalised, and less coercive and institutionalised
- Developing new ways of using resources to promote self-directed support with people with learning disabilities.

Older people have been less active in terms of influencing change in the social care system (their resources have tended to be more focussed in other areas such as pensions). However, older people give similar importance to choice and control over the support needed as younger disabled people do:

> "…choice, control and self sufficiency were central to older people's perceptions of independence. Although good health, the ability to maintain personal mobility and being able to live in your own home were commonly associated with being independent, independence was only felt to have been lost if you were unable to exercise control and choice over key aspects of daily living" (Parry et al, 2004, p.1)

In assisting public bodies responsible for social care to carry out their Disability Equality Duty, therefore, the DRC will need to ask three fundamental questions of their policies, procedures and practices:

- Have disabled people been involved in the formulation of policies and procedures (including those policies and procedures not specifically aimed at disabled people)? Are they involved in monitoring practice?
- Do policies, procedures and practices deliver choice and control for disabled people?
- Do policies, procedures and practices enable disabled people to engage in 'normal activities' (as defined above)?

Some examples of how the DRC might assist public bodies to address these barriers are given in both the next and in the final section of this paper (Section 6), when we discuss some priority areas for the DRC to focus on.

3. Identify positive examples of what the duties might mean in practice for different public authorities and Local Authorities with Social Services responsibilities in particular.

A few local authorities in England have developed Disability Action Plans as part of implementing the Equality Standard for Local Government and sometimes this covers social care services. For example, Manchester City Council's Children, Families and Social Care Department published a Disability Action Plan 2004-5 and have also recently published details re progress (see http://www.manchester.gov.uk/ssd/disabilityplan/). Such initiatives may provide a starting point for Disability Equality Schemes (although see Section 5.1 below for caveat).

3.1. Duty to "Proactively eliminate discriminatory practices, policies and procedures"
(see also examples under 3.3 and 3.6 below)

Equal access to safeguarding services
There is a great deal of evidence that disabled children are not provided with equal access to safeguarding – from the recognition of abuse all the way through to investigation and prosecution of perpetrators (see NSPCC, 2003).

One Area Child Protection Committee found that an investigation involving Deaf[12] children was hampered by a lack of clarity about

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[12] The term Deaf is used here to cultural/linguistic status.

who would be responsible for paying BSL interpreters. There was also uncertainty about the children's levels of understanding. Subsequently, a protocol was drawn up and agreed by the members of ACPC on responsibilities for funding and provision of communication advice and assistance. Some work was also done on identifying experienced interpreters who could assist with investigations in the future. (NB ACPCs are multi-agency bodies, with Councils with Social Services Responsibilities having lead responsibility. ACPCs are to be replaced in April 2006 by Local Safeguarding Children Boards but CSSRs will retain lead responsibility).

Unequal access to Child and Adolescent Mental Health Services
Children with learning disabilities are more likely to experience mental health problems than children without learning disabilities (about 40% have a "diagnosable mental disorder") yet only a third of NHS Child and Adolescent Mental Health Services (CAMHS) provide specific services for children and adolescents with learning disabilities (Dfes, 2004, para 7.6). A survey in Manchester, for example, found significant levels of unmet mental health needs amongst children with learning disabilities, particularly those who also had communication difficulties and/or visual impairments. Specialised services only reached a minority of these children (Emerson and Robertson 2002).

The Department for Education and Skills, and the Welsh Assembly, have recognised that "the low level of resources available to children and their families represents serious inequity and a significant challenge for the development of appropriate services" (Department for Education and Skills, 2004, para 7.6; Welsh Assembly Government 2004, p.86).

The English NSF recognised that children and young people with learning disabilities need to have access to appropriate mental health services to ensure "that they are not disadvantaged because of their disability" (Dfes, 2004, para. 7.7). The Welsh NSF stated that "It is not acceptable to exclude any child from receiving a service because of their IQ" (Welsh Assembly Government, 2004, p.87).

This is an example of government departments attempting to address unequal access to services, through their function of setting the national framework and standards for service delivery.

Unequal equal access to day services
The example given below relates to unequal access experienced by black and minority ethnic disabled people. Again, there is a lot of evidence of this but the example does raise the issue of the overlap between the DED and Race Equality Duty.

Liverpool's Supported Living service – aware that there was a very low take up of its day services by black and minority ethnic people with learning disabilities – appointed outreach workers to make contact with potential users of day services within these communities, draw up a Person Centred Plan, and broker a package to meet their need.
Contact: Natalie Markham, Project Manager, Integrated Services in Neighbourhoods – Supported Living Portfolio.
Natalie.Markham@liverpool.gov.uk

Increasing access to domestic violence services
Leeds Inter-Agency Project "has been working with agencies in Leeds for over 6 years to improve the services and community support offered to disabled women who are experiencing violence from the men they know". The partner agencies are Leeds Community Safety Partnership, Leeds Drug Action Team and Leeds Youth Offending Service. The project delivers education programmes, one to one support, and accessible information, and has produced a video and training pack (www.liap.org.uk).

3.2. Duty "to ensure equal access to and participation in society of disabled people"

See also 3.3 and 3.6 below.

Developing social care strategies to promote independent living
Essex Social Services' Equal Lives Strategy was written following a two-stage wide-ranging consultation with people with physical and/or sensory impairments, voluntary organisations and carers.

"The strategy supports the concept of independent living in which choice and control rests with the disabled person…..By implementing this strategy, Essex Social Services will:
- Work to the principles outlined in the social model of disability
- Transfer control and choice to disabled people

- Offer our expertise
- Change the assumption that impairment means the automatic need for care by seeking alternative means of maintaining people's independence."

The Strategy has been evaluated and is currently being updated, involving wide consultation with disabled people.
Contact: Nanette Wright, County Manager, Services for Independent Living. nanette.wright@essexcc.gov.uk

Supporting parents with mental health difficulties
Kent Social Services and South West Kent Primary Care Trust fund the Family Welfare Association to work with parents with mental health problems, bridging the gap between adult mental health services and child and family services. The project, Building Bridges, aims to 'help people to control their own lives and so achieve their full potential'.
Contact: Rose de Paeztron, Development Manager, Family Welfare Association. rose.depaeztron@fwaprojects.org.uk

Reducing the number of children with severe learning disabilities and/or autistic spectrum disorders who are placed out of authority
Bristol City Council set up a service whose aim was to reduce the number of out of authority placements of children with severe learning disabilities and/or ASD by:
- providing an intensive, locally based, multi-agency assessment and intervention service
- enabling these children, through intensive co-ordinated intervention and support, to access local service provision.
The service includes specialist residential and community placements, individually tailored therapeutic and support packages for families, and school support packages.

Contact: Ian MacDowell, Service Manager, Bristol Social Services. ian_mcdowall@bristol-city.gov.uk

Taking a proactive approach to enabling people with learning disabilities to have a home of their own
People with learning disabilities often have to move into congregate forms of provision because of a shortage of housing opportunities in the privately rented, social housing and owner occupied sector. Essex Social Services has appointed a Project Worker for two years to identify and promote housing opportunities

for people with learning disabilities with the aim of increasing the number who have a home of their own.
Jenny Owen, Director, Adult Social Care, Essex County Council.
jenny.owen@essexcc.gov.uk

Supporting parents with learning disabilities to look after their children
Parents with learning disabilities are more likely to have their children taken into care than parents who don't have learning disabilities. A study on care orders found that one in four (25%) of the children involved had a parent with a learning disability (Harwin et al, 2001). Another study on child protection applications to family courts found that 15% involved a mother and/or father with learning disabilities (Booth et al, 2003). Only 2.5% of the population have mild to moderate learning disabilities (Department of Health, 2001, p.15)

The Truro Special Parenting Service was set up in 1988 and aims to work positively with parents with learning disabilities. It has developed a Parental Assessment tool which focuses on parents' capacity and what support and training would assist them to parent effectively. It offers both home-based and group-based programmes and also runs courses for parents with learning disabilities with Truro College.
Contact: Sue McGaw - Sue.McGaw@cpt.cornwall.nhs.uk or
Debbie Valentine – parenting@cht.swest.nhs.uk.

3.3. Increasing take up of direct payments amongst under-represented groups

On the assumption that direct payments in themselves promote choice and control (although see later discussion) then addressing unequal access to direct payments both "eliminates discriminatory policies practices and procedures" and promotes "equal access to and participation in society of disabled people".

Information about direct payments for people with learning disabilities
The Department of Health funded Swindon People First and Real Voice Media to produce *An easy guide to direct payments*
http://www.dh.gov.uk/assetRoot/04/09/73/98/04097398.pdf

Using Local PSA targets to increase take-up of direct payments
Cheshire County Council has set a Local PSA target to enhance
the take-up of direct payments, supported by a pump-priming grant
of £72,000. This is expected to result in an increase of 150 people
using direct payments (over and above the increase which would
have been expected without the enhancement).
Contact: jane.colville@cheshire.gov.uk;
www.cheshire.gov.uk/psa/target4.htm

*Funding personal assistance support services to support young
disabled people to use personal assistants*
The West of England Centre for Inclusive Living's Youth PASS is
funded by Bristol Disabled Children's Service, the Bristol
Regeneration Partnership, Neighbourhood Support Fund and the
New Deal for Communities. The project:

- Offers young disabled people the opportunity to experience
  using personal assistance
- Provides support and training on using Personal Assistants
- Provides Personal Assistants to young disabled people on
  work experience organised by schools and colleges
- Offers support to parents whose children are participating in
  the project.

Contact: reception@wecil.co.uk; www.wecil.co.uk

*Enabling people with significant learning disabilities to use direct
payments*
A recent report published by the National Centre for Independent
Living, looked at ways in which Personal Assistance Support
Schemes have enabled access to direct payments for people who
are currently under-represented amongst direct payment users.
For example, some Personal Assistance Support Schemes have
assisted in the setting up of Independent Living Trusts for direct
payments to people who have significant learning impairments:

"In all cases, the Direct Payment was used entirely for employing
staff to work with the young disabled person. The workers were
employed to enable the young people to take part in a range of
activities which improved their health, social contacts and quality of
life, such as:

- Going to concerts
- Playing computer games
- Music
- Art

- Swimming
- Trips to the zoo

Crucially, the staff employed were chosen either because they were already known to, and liked by, the young person; or observed to work well with and be liked by the young person over a period of time following recruitment.

The staff also provided respite care for the young people, which meant that they stayed in their own homes whilst their parents took a break, and avoided going into respite facilities which two parents had experienced as 'totally unsuitable'" (Luckhurst, L. 2005).

Enabling disabled children and their families to use direct payments
Choices and Rights Disability Coalition in Hull has a Service Level Agreement with Hull City Council to employ 2 full-time direct payments support workers, and part-time administrative support. One worker is designated to enable disabled children and their families to use direct payments.
Information provided by Mark Baggley:
mbaggley@habinteg.org.uk; www.choicesandrights.org.uk

Promoting direct payments amongst older people from minority ethnic communities
A Direct Payments Support Service worked with Somali community workers to enable older people within the Somali community to gain access to direct payments. The accountancy service provided by the Support Service to deal with banking and administrative requirements was essential in overcoming the language and literacy barriers faced by older Somali women (Clark, H. Gough, H. and Macfarlane, A. 2004).

3.4. Involving disabled people in the development and implementation of policy

It will be important that the involvement of disabled people actually results in changes to policy and service delivery and this will need to be a key criterion in determining good practice in this area.

Involving young disabled people in providing information to other young disabled people

Suffolk health and social care services and Connexions involved young disabled people in developing an information resource on transition to adulthood. The young people produced a DVD and website which gives up-to-date information about services and opportunities and helps young people to find out how to plan their future (www.nolimits.org.uk). This is also an example of moving beyond 'consultation' to actual involvement.

Contracts for providing support to people to use direct payments are given to organizations of disabled people
There are a number of Centres for Independent Living and other local user-led organisations which have had such contracts for the last few years (although recently some CILs have been losing this work). Glasgow Centre for Inclusive Living has just been awarded such a contract.
Contact: Etienne d'Aboville; etienne@gcil.org.uk

Methods of consultation and involvement can sometimes exclude people
[negative example: this is an actual example but I haven't named the social services department] One Social Services Department used the *Aspiring to Inclusion* materials to consult with users of a Vocational Training Centre about their experience of the Centre and what improvements they wanted to the service. This consultation was lacking however in respect of:
- the methods chosen (questionnaire and workshops) were not used in ways which adequately addressed the access needs of the service users
- potential service users were not consulted.

3.5. Involving disabled people in the regulation and inspection of social care

Seeking the views of service users' about CSCI inspections led by CSCI
The Children's Rights Director (based at CSCI) has a duty to seek the views of children about the way CSCI carries out inspections of children's services. In the first 'Children's Audit' report (http://www.rights4me.org.uk/childrens_views_of_inspection.pdf), there was no indication as to whether disabled children had been amongst those using services that had been inspected, or if so

how they had been consulted. However, this duty to carry out children's audits is an important mechanism for promoting disability equality and the DRC could assist the Children's Rights Director to ensure that audits are carried out in the most inclusive way.

Involving users of services in inspections
CSCI's predecessor, the Social Services Inspectorate, had developed a practice of including 'lay inspectors' (people who use services) in their inspections of services. CSCI has announced their intention of extending the use of lay inspectors, for example, to enable them to more effectively gather information from people living in care homes about their experiences (http://www.csci.org.uk/media/press_releases/joint_response_elder_abuse.pdf). CSCI has also appointed a Director of User Involvement and new initiatives are being developed to involve people who use services in inspections, including enabling service users to be fully participating (and remunerated) members of important working groups and Inspection Teams.
Contact: Frances Hasler - Frances.Hasler@csci.gsi.gov.uk

3.6. Impact assessments and social care

Impact assessments in the field of social care are likely to involve an assessment of whether one particular group of disabled people is disadvantaged in comparison with other disabled people, as a result of a particular policy or practice, *and* an assessment of the extent to which policies and practices are promoting equal access to and participation in society.

Access to minor aids and equipment
Many Adult Social Care services are increasing the type of minor aids and equipment that people can access without an Occupational Therapist's assessment. The intention is to recognize disabled and older people's own expertise about their needs, to make it easier for people to access what they need, reduce waiting times for aids and equipment, and to ensure that Occupational Therapists are deployed where their skills are most needed.

An impact assessment should consider whether this policy may disadvantage disabled people who face barriers to information about the availability of aids and equipment, self-assessing their

need and/or requesting the equipment or aids they need. For example, people with a cognitive impairment may face such barriers; as may socially isolated disabled or older people.

Measures which might mitigate such an adverse impact could include:
- funding a local advocacy organization to support people with a cognitive impairment (e.g. people with learning disabilities or people with acquired brain injury) to access minor aids and equipment
- funding a local older people's organization to disseminate information about the new system and advise older people about what aids/equipment might meet their needs.

One Stop Shops
Many local authorities are establishing 'one stop shops', i.e. one place where people can access the range of services provided by a local authority and, sometimes, other local statutory agencies. This is usually both a building (e.g. a shop front in the local high street) and a telephone number and a website/email.

An impact assessment should consider whether some disabled people may experience barriers to accessing the 'one stop shop' or telephone/internet contact point. For example, a person with a mobility impairment, living in a rural area with little access to public transport, would find it difficult to access the one stop shop. Telephone access may provide a reasonable alternative, as long as they have access to a telephone. Email access may provide access to someone with a communication impairment, as long as they have access to the internet and a PC.

Measures which might mitigate an adverse impact may therefore include:
- ensuring that people with mobility impairments in isolated areas receive priority for assistance with providing a telephone (under Section 2 (h) of the Chronically Sick and Disabled Persons Act 1970).
- Working with the voluntary and private sector, as well as the local authority library services, to increase the number of internet access points in areas of particular socio-economic deprivation.

Are there particular groups of disabled people who services are not reaching?
The Scottish Executive Health Department Community Care Division commissioned the Public Health Institute of Scotland to provide information about the incidence of autistic spectrum disorders and current service provision in Scotland. The report found that current service provision across Scotland:

> is inconsistent and inadequate for the number of individuals with ASD requiring support. Health care, education and social services vary depending on local resources and there are marked differences in ease of access to services due to limited facilities in some geographical areas. Although there are some examples of good, innovative and multi-agency practice across Scotland, some areas and some client groups, particularly adults, and their families experience delays and inconsistencies in the delivery of services and inadequate support after diagnosis (Scottish Executive, 2003, para. 4).

The Scottish Executive then required local authorities and Health Boards to carry out a joint audit of current service provision and relevant training, identify the gaps and develop plans for services (Scottish Executive, 2003, para 9).

An impact assessment could look at service development following these audits, and could also assess the extent to which people with ASD and their families were involved in service planning.

Monitoring access to social care services

There is very little information about how many asylum seekers are disabled and whether the current system of support to asylum seekers is providing equal access and equal outcomes for disabled people. A research project on disabled asylum seekers (Roberts and Harris, 2002) pointed out that:

> There is no official source of data on the prevalence of impairment amongst refugees and asylum seekers living in Britain. Estimates range from 3 per cent to 10 per cent of the total population of refugees and asylum seekers. An initial survey responded to by 101 refugee community groups and

disabled people's organisations identified 5,312 disabled refugees and asylum seekers known to 44 organisations.

This research questioned whether the National Asylum Support Service is adequately meeting the needs of disabled asylum seekers but there is currently no information available to assess this. The National Audit Office pointed out that the NASS does not always provide information to accommodation providers about whether service users are disabled or what their particular needs might be (National Audit Office, 2005). The Disability Equality Duty could provide an opportunity for NASS to proactively address this issue.

The Home Office states that it wants "to ensure that disabled people have the same access to information and services relating to drug misuse as non-disabled people". Accordingly, it commissioned two reviews of what is known about drug use and access to services amongst disabled people (Dyer and Mitchell, 2003) and people with hearing impairments (COI Communications, 2004). However, both reviews highlighted that very little is known about either. The Disability Equality Duty could provide an important impetus to both research and action in this area.

Do social care services promote independent living?
CSSRs should assess to what extent their practices promote choice and control for disabled people and whether there is equal access for all groups of disabled people to provision which enables independent living.

"Andrew has severe learning difficulties and complex uncontrolled epilepsy. He requires one-to-one support wherever he goes and also needs lots of help in explaining tasks or new situations."
Person Centred Planning was done to establish what Andrew wanted to do with his life. Now he uses direct payments: "Andrew currently has a full week, having three jobs which offer 2 hrs per session on a farm, a garden project and a small Co-op Supermarket. He also goes riding, swimming and attends college, all with a PA."
Example taken from Direct Payments Scotland, 2005. *Direct Payments Case Studies* www.dpscotland.org.uk/

Government departments with responsibility for social care should assess whether their policies promote choice and control for disabled people.

The right to, and availability of, independent advocacy is an important part of independent living for many disabled people. The Mental Health (Care and Treatment) Scotland Act 2003 gives people with mental health problems a right to independent advocacy. Also, guidance on the implementation of direct payments states that "Local authorities must ensure that independent advocacy plays a role in the successful operation of direct payments." The Scottish Executive Health Department has a policy that everyone who needs it should have access to good quality independent advocacy. It funds the Advocacy Safeguards Agency to promote independent advocacy, evaluate services and provide information to those looking for advocacy services. The Agency has mapped the availability of advocacy services. An impact assessment could include this type of information about the availability of independent advocacy services, in order to assess whether there is equal access to advocacy – both in geographical terms and in advocacy services for particular groups.

4. Illustrate how the relevant public authorities might measure their performance on delivering improved outcomes for disabled people in relation to independent living.

Some practical examples of measuring performance are given in the previous section. This section will consider in more general terms how public authorities might measure their performance on delivering improved outcomes in relation to independent living. Outcomes are more likely to be measured if they can be incorporated into existing performance measurement frameworks. This section starts, therefore, by setting out these existing frameworks, before identifying some of the issues that the DRC will need to address when seeking to help public authorities measure disability equality. This description needs to be prefaced with a recognition that there is often confusion between outcomes, indicators and targets (see later).

4.1 Cross governmental aims and outcome measures

Earlier this year (2005), the government set out an over-arching aim for improving the life chances of disabled people, articulated as "By 2025, disabled people in Britain should have full

opportunities and choices to improve their quality of life and will be respected and included as equal members of society" (Prime Minister's Strategy Unit, 2005, p.7). Annual reports on progress towards this aim will be presented to the Prime Minister and published. Although the report covered disabled children and disabled adults of working age, it also stated that "Implementation of these measures should take account of the needs of older people who are disabled or who have care requirements" (Ibid., p.8). The report, and its aims, includes the devolved administrations but details of the implementation will be the responsibility of the Welsh Assembly Government and Scottish Executive.

Improving Life Chances does not cover the detail of how progress towards the over-arching aim will be measured but it is likely to be similar to the current work by the DWP in England on outcomes and indicators (DWP, 2005)[13]. This uses a combination of sources to bring together information about disabled people's opportunities. While wide-ranging in its scope, it is limited by what information is currently gathered by government departments (such as employment and benefit data, Performance Indicators, etc). While it also draws on some government-sponsored surveys that produce relevant data (such as the Family Resources Survey. Survey of English Housing and Citizenship Survey), this is limited because outcome measures for disabled people are not integrated into the design of such surveys.

The section on 'health and social care' has five measures:
- Life expectancy
- Children in need
- Permanent admissions to care homes
- Adults helped to live at home
- Waiting times for social services assessment/care package.

There is also a section on 'Living Arrangements' with two measures:
- Living in suitable accommodation
- Statutory homelessness.

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[13] Please note this is a DWP document provided in confidence and should not be quoted publicly without permission.

These, together with the measures concerning transport, community participation, work, and other issues, provide useful indicators of disabled people's experiences but will not provide either a comprehensive way of measuring access to independent living or public authorities' role in bring this about unless some influence is brought to bear on what information government departments are gathering. The virtue of this approach, however, is that it can take advantage of whatever information is available: it could indeed spread its net wider than currently by, for example, including whatever information results from the Neighbourhood Renewal Unit's work on indicators of community involvement (Chanan, 2004) and making more use of the Performance Indicators in the Performance Assessment Framework (see below). Another advantage is that, although the DWP's report only sets out the national statistics, most of the primary sources of the data can be disaggregated to local authority areas.

4.2 Social Justice Indicators of Progress (Scotland)

In Scotland, there are overarching goals set out as Social Justice Indicators of Progress (Scottish Executive 2003). These include goals relating to increasing the proportion of people with learning disabilities "able to live at home or in a 'homely' environment" and the proportion of older people "able to live independently by doubling the proportion of older people receiving respite care at home and increasing home care opportunities" (Ibid). There is much scope for working with the Scottish Executive to improve and expand on its Social Justice Indicators of Progress.

4.3 Public Service Agreements and Local Public Service Agreements (England)

Public Service Agreements are agreements entered into between government departments in England and the Treasury, which reflect government priorities and set goals for achieving improvements in public services. There are about 130 PSA targets in all: the Department of Health has 12, four of which have particular relevance to social care services:

- Target 7: Improve life outcomes of adults and children with mental health problems through year on year improvements in access to crisis and CAMHS services, and reduce the mortality rate from suicide and undetermined injury by at least 20% by 2010.

- Target 8: Improve the quality of life and independence of older people so that they can live at home wherever possible, by increasing by March 2006 the number of those supported intensively to live at home to 30 % of the total being supported by social services at home or in residential care.
- Target 9: Improve life chances for children, including by reducing the under-18 conception rate by 50% by 2010. Joint target with DFES.
- Target 10: Increase the participation of problem drug users in drug treatment programmes by 55% by 2004 and by 100% by 2008, and increase year on year the proportion of users successfully sustaining or completing treatment programmes.

In addition, Performance Target 12 is:

- Value for money in the NHS and personal social services will improve by at least 2% per annum, with annual improvements of 1% in both cost efficiency and service effectiveness.

The Department for Work and Pensions has a specific Performance Target relating to disabled people:

- In the three years to 2006, increase the employment rate of people with disabilities, taking account of the economic cycle, and significantly reduce the difference between their employment rate and the overall rate. Work to improve the rights of disabled people and to remove barriers to their participation in society.

Each Performance Target has a series of Indicators used for measuring progress towards the target. So, for example, the Department of Health's Target 7 (on life outcomes for adults and children with mental health problems – see above) has three Indicators:
Indicator one: Death rate from suicide and undetermined injury (per 100,000 population)
Indicator two: Number of people receiving crisis resolution services
Indicator three: Percentage increase in Children and Adolescents Mental Health Services (CAMHS).

Current Performance Targets and their indicators are of some but limited use in measuring progress towards disability equality. However, they are the outcomes that are taken the most seriously by government departments. Moreover, the setting of Performance Targets is of course an activity covered by the Disability Equality Duty and there is therefore scope to work on developing more useful Targets.

Local Public Service Agreements are agreements entered into between individual local authorities and the government, to bring about improvements in services over and above the PSA targets. They involve a reward element for the local authority if it achieves the target. Current outcome indicators for older and disabled people (announced in 2004 http://www.dh.gov.uk/assetRoot/04/09/97/43/04099743.pdf are designed to address two outcomes based on research evidence:

> Outcome a) That people's quality of life is enhanced if they live "independently" rather than in care homes, and
> Outcome b) That the quality of life of people who need support is better if they determine what support they get, rather than having what providers will give them.

Three 'outcome-based indicators' have been nominated to measure these outcomes:

Outcome a)
> Indicator 1 – Movements out of institutional care; and
> Indicator 2 – Movements into institutional residential care

Outcome b)
> Indicator 3 – An independent survey of "quality/control of daily life and quality of support". The survey will be based on research evidence that identifies how local services (directly provided or not) can deliver the outcomes that enhanced recipients' quality and control of life.

It would be useful if the DRC put some resources into working with the Department of Health and CSSRs to develop local PSAs that promote independent living and disability equality.

4.4.   The Performance Assessment Framework (England)

The Performance Assessment Framework is the responsibility of the Commission for Social Care Inspection in England. The Framework consists of 50 performance indicators, and is used to measure how well local authorities are serving their local populations. There are three sections to the Framework:

- Children and families
- Adults and older people
- Management and resources.

Within each section there are five domains or standards:

- National priorities and strategic objectives
- Cost and efficiency
- Effectiveness of service delivery and outcomes
- Quality of services for users and carers
- Fair access.

The Performance Indicators are used – together with service inspections and Delivery and Improvement Statements – to give each council a star rating. The Performance Indicators of particular relevance to this paper are:

CF/C63 Participation of looked after children in reviews
CD/D35 Long term stability of children looked after
CF/D65/D66 User experience survey
CF/E67 Children in need with disabilities
AO/C27 Admissions of supported residents aged 18-64 to residential/nursing care
AO/C28 Intensive home care
AO/C29 Adults with physical disabilities helped to live at home
AOC30 Adults with learning disabilities helped to live at home
AO/C31 Adults with mental health problems helped to live at home
AO/C32 Older people helped to live at home.
AO/C51 Direct payments
AO/C62 Services for carers.

Each Performance Indicator has a Definition and a Numerator to measure how the local authority is doing. So, for example:

Indicator: CF/E67 Children in need with disabilities
Definition: The number of disabled children supported in their families or living independently, receiving services in the census

week, as percentage of the estimated total population of disabled children in the council area.
Numerator: The number of disabled children in need under 18 who are not looked after but who receive some form of service from their Local Authority Social Services Department during the children in need census week, plus any disabled children receiving services under a series of short term breaks.

These Performance Indicators have a similar advantage to the Treasury's Performance Targets for government departments in that they are taken seriously by CSSRs, each of whom is keen to be a 'three star authority'. They are also more detailed than the central government Targets and contain more measures of direct relevance to disabled people and social care. However, they are not adequate measures of disability equality and social care (see also discussion below), and there is limited scope for adding to them as there are political pressures to reduce the number of targets.

Nevertheless, like the Treasury's Performance Targets, the setting of Performance Indicators by CSCI is an activity covered by the Disability Equality Duty and there is therefore scope for the DRC to assist CSCI to develop useful outcome measures.

4.5 <u>National Outcomes and Local Improvement Targets for the Joint Future Agenda (Scotland)</u>
This is a framework of outcomes and targets set out by the Scottish Executive, COSLA and NHS Scotland as part of the 'reinvigorating the Joint Future Agenda' initiative. Four national outcomes have been set initially:

- Supporting more people at home as an alternative to residential and nursing care
- Assisting people to lead independent lives through reducing inappropriate admission to hospital, reducing time spent inappropriately in hospital and enabling supported and faster discharge from hospital
- Ensuring people received an improved quality of care through faster access to services and better quality services
- Better involvement of carers.

(Scottish Executive/COSLA/NHS Scotland, 2004).

Local improvement targets to achieve, and measure, these outcomes have been proposed, such as "Increased number of people receiving intensive home care or care at home packages.

4.6 Policy Agreements and the Performance Measurement Framework (Wales)

Individual local authorities have Policy Agreements with the Welsh Assembly Government which set out what the local authority aims to achieve over a three year period. In return for making and delivering upon the agreement, the Welsh Assembly Government makes a Performance Incentive Grant to the authority which the authority can deploy as it sees fit. The aims relate to the WAG's National Strategic Indicators (see below): an example is that of Cardiff local authority which has targets for (a) reducing the numbers of people over the age of 65 who are supported in residential or nursing homes; and (b) increasing the numbers of people over the age of 65 who are supported to live at home (Welsh Assembly Government and City and County of Cardiff, 2004).

The Performance Measurement Framework is being established in Wales in two stages, the first stage of which has been completed. Guidance has been published setting out Performance Indicators for local government (Local Government Data Unit, 2005). These fall into two: National Strategic Indicators and service specific Core Indicator Sets. Adult Social Care has two National Strategic Indicators:

- The rate of delayed transfers of care for social care reasons per 1,000 population aged 75 or over
- The rate of older people (aged 65 or over):
a)Helped to live at home per 1,000 population aged 65 or over
b)Whom the authority supports in care homes per 1,000 population aged 65 or over.

National Performance Indicators for Adult Social Care are the above two Strategic Indicators, with a third:

- The percentage of clients who are supported in the community during the year, who are:
a) Aged 18-64
b) Aged 65+.

4.7 <u>Best Value Performance Indicators</u>
Best Value Performance Indicators are the responsibility of the
Office of the Deputy Prime Minister in England and Wales and in
Scotland of the Scottish Executive.   In Scotland, guidance issued
under the Local Government in Scotland Act 2003 lays down some
fairly general best value aims for local authorities. A duty of 'best
value' was imposed on local councils in England and Wales by the
Local Government Act 1999, which required local authorities "to
seek to achieve continuous improvement by having regard to the
efficiency, effectiveness and economy of their service delivery".
However, in England Best Value Indicators have also been
developed which provide more detailed ways of measuring
outcomes and some of these correlate with the Performance
Indicators referred to above. For example, for 2004/5 Best Value
Indicator 201 is: "The number of adults and older people receiving
direct payments at 31 March per 100,000 population aged 18
years or over (age standardised by age groups)".

As with some other Indicators however this raises the question as
to whether the numbers of people in receipt of direct payments is
an accurate way of measuring independent living (see discussion
below).

4.8 <u>Service standards</u>
The inspection and regulation organisations in England, Scotland
and Wales all use standards which are based on assumptions
about the relationship between certain service characteristics and
the quality of life of service users. For example, the Scottish
Commission for the Regulation of Care has set standards for Care
Homes for people with learning disabilities which include Core
Standards of "expressing your views" and "making choices". The
implementation of the DED should encourage (a) the involvement
of service users in the setting and inspection of standards and (b)
the adoption of standards which promote disability equality and
independent living.

4.9 <u>Broad outcomes set by social care organisations</u>

The Local Government Association and the Association of
Directors of Social Services (in England and Wales) have already
adopted outcomes for older people which are compatible with
disability equality and independent living. These are:

- living longer and healthier lives
- better quality of life, enhanced lifestyles
- reduced poverty
- more involvement in decision making
- better informed
- greater control and choice
- more independence and interdependence
- no discrimination
- greater opportunities for employment and flexible retirement policies.

(See www.idea-knowledge.gov.uk/idk/core/page.do?pageId=262757)

These outcomes are similar to the five outcomes set out by the recent English Green Paper *Independence, Well-Being and Choice*, which are:
- improved health
- improved quality of life
- making a positive contribution
- exercise of choice and control
- freedom from discrimination or harassment
- economic well-being
- personal dignity

(Department of Health, 2005a, p.26).

In England and Wales, outcomes to be aimed for in relation to children have been given statutory status by the Children Act 2004.   They are that children should be able to:

• stay safe

• be healthy

• enjoy and achieve

• make a positive contribution

• achieve economic well-being.

These types of outcomes are useful in that the focus is on people's actual experiences. However, it is necessary to identify concrete ways of measuring these experiences (see discussion below).

4.10 What type of outcome measures would enable public authorities to assess progress on independent living?

Although all the above methods and frameworks provide potentially useful information, none of them comprehensively attempts to measure progress towards independent living. One of the main barriers to measuring outcomes is that the large-scale surveys (such as the General Household Survey) and censuses (the decennial population census and annual children in need census) do not always:

- use a consistent definition of disabled person
- enable analysis across and within different groups of disabled people
- measure the types of experiences which would enable us to assess the extent of disabled people's access to and participation in society.

If the DRC is to assist public authorities to do this, there are various resources which can be drawn upon:

4.10.1 Research on independent living
There is a significant amount of research on independent living which both tells us what independent living means to disabled people and the barriers that get in the way (see summary in Morris, 2003a). As outlined above, the Department of Health in England has already started to use research evidence on older and disabled people's experiences and aspirations in order to develop outcome measures for Local Public Service Agreements.

Further work could be done on developing outcome measures to assess public authorities' performance in promoting independent living. For example:

- Young disabled people want to have the same experience as their non-disabled peers in terms of leaving their parents' home in early adulthood and moving into a home of their own. Yet they often find it difficult to move out of the parental home unless it is into a residential or group home.
Potential Indicator: What proportion of disabled people, between the ages of 25 and 35, are living with their parents (in comparison with the proportion of non-disabled people)?
NB: this is an example of an outcome measure which will require housing and social services authorities to work together.

It is also the type of outcome measure which would be easier to assess if the variables involved could be incorporated into large surveys such as the Family Resources Survey and General Household Survey.

- Disabled people who need to be lifted are particularly at risk of social exclusion.

Potential Indicator: How many disabled people in a local authority area who need to be lifted are given practical assistance to enable them to participate in leisure activities? This is the kind of indicator that would probably best be measured by local surveys of this specific group. The large datasets provided by the FRS and GHS would then provide a comparison with equivalent groups of non-disabled people (by age and socio-economic status, for example).

The main point here is that it is research on the actual experiences of disabled people which points us in the direction of both what outcomes should be aimed for and how to measure them.

4.10.2 Current work by public authorities on promoting disability equality and independent living
Some CSSRs in England have adopted disability equality goals as part of implementing the Equality Standard for Local Government and/or as part of their strategic planning. For example, Manchester City Council's Disability Action Plan includes the goal and measurement of increasing the amount of social housing available for people with acquired brain injury. A more comprehensive example is that of Essex County Council's Equal Lives Strategy which set out in 2001 with the aim of:
- Enabling people to express and exercise choice and control throughout their lives, and
- Increasing disabled people's ability to be more socially included.

The measurable outcomes related to both process and outputs, including:
- Increase in accessible information
- Adoption of the social model of disability as the basis for assessment
- Increase in advocacy services
- Increase in numbers of people receiving direct payments.

4.10.3 Consultations with service users about what they want from social care services

Over the last twenty years there has been a significant amount of research and consultation concerning what service users want from services. Such material tells us a lot about what types of social care services promote disability equality and independent living. Recent work by the Social Policy Research Unit, for example, gives a clear picture of what older people want from home care services (Patmore, 2002; Patmore and McNulty, 2005).

4.11 <u>Implications of the DED for the methodologies of performance measurement, inspection and regulation</u>

More detailed work is needed on the implications of the DED for current methodologies of measuring how social care organisations are doing. However, a number of implications can be identified at this point:

4.11.1 Close attention needs to be given to whether current indicators are appropriate and adequate measures of independent living.

For example, there are real question marks over two current important indicators used in England. Firstly, an increase in the supply of extra care housing for older people, as promoted by current ODPM and DH policy, is generally taken to be a measurement of increased access to 'independence' for older people. Yet some local authorities are resisting this policy on the grounds that extra care housing is just the latest version of institutionalised provision and would prefer to put their resources into supporting people to stay in their own homes. Secondly, while direct payments may have been a good proxy indicator of independent living in the early days (because of the circumstances of the individuals who were the pioneers of direct payments), this may be less true as the policy becomes more 'owned' by social services departments who have less understanding that they are merely a means to an end. The current Performance Indicator – and its aggressive promotion by the DH – may have the unintended consequence of making direct payments a less satisfactory proxy indicator of access to independent living.

4.11.2. The involvement of disabled people in the development of outcomes, indicators and targets, and in the development and

inspection of standards, will be crucial to fulfilling the DED in the context of social care.

For example, it is generally accepted that the views of people who use services should be sought and form a key part of inspections of services. There are some groups of service users who face barriers to their views being heard however. These barriers include: negative attitudes about methods of communication which do not involve ordinary speech; lack of relevant skills and experience available to inspectors; inadequate communication support or equipment available to the service user. Such barriers will need to be addressed if there is to be equality of access in terms of service user views being sought and treated seriously. There may also need to be revisions to the framework and principles of inspection: for example the recently published *Framework for the Inspection of Children's Services* does not recognise the barriers which will have to be addressed in order to gather the views of children with significant communication and/or cognitive impairments. Instead of recognising children's right to communicate and the Inspectors' obligations to address barriers, the issue is posed in terms of children's "preferences" and the aim is only that these "preferences" will be met "where practicable" (Ofsted, 2005, p.5).

It will also be important to measure whether disabled people's involvement in setting standards and outcome measures has had any actual impact on the way services and outcomes are assessed.

4.11.3 Information will need to be gathered which enables comparisons between disabled and non-disabled people and amongst groups of disabled people.

We need to look at whether current statistics provide enough information in order to make comparisons. For example, the Department of Health in England doesn't do a breakdown of different groups using direct payments although CSCI does.   In order to determine whether different groups of disabled people experience equal access to various social care services, the organisations concerned will need to monitor their services in a way which is not currently widespread., For example, it is not known how many people with physical and/or sensory impairments use mental health services so it would be difficult to measure whether there is equality of access to such services.

In Wales, for example, the Local Government Data Unit will be covered by the DED (as an organisation wholly owned by local government). The Duty will provide an opportunity to look at whether current data, and the support it gives to local government, provide enough information in order to measure disability equality. The Unit would be well placed to recommend action in order to fill any gaps in information.

Indicators will be needed which:
- Compare disabled people's experiences with the non-disabled population
- Measure the delivery of services to specific groups
- Measure the types of services provided.

Some indicators can be identified which more or less measure outcomes (such as numbers of young disabled adults living in their own homes), while other outcomes can only be measured by proxy indicators (e.g. receipt of direct payments – the assumption being that direct payments are more likely to enable choice and control) or research (survey of whether people who use home care services feel they have choice and control over the service they receive).

5. Outline particular challenges which the DRC may need to address when producing guidance for relevant public authorities.

There are a number of challenges that the DRC will face when writing guidance concerning the implementation of the DED for social care.

5.1 <u>Organisations which have already written diversity or equality strategies and/or disability action plans may feel they have already covered disability equality</u>

The Equality Standard for Local Government provides a framework for local authority action plans to tackle inequality in four areas: disability, gender, race and ethnicity, and lesbians and gay men. Large numbers of public authorities already have diversity or equality strategies and most of these pay at least some attention to disability equality. Busy senior managers may feel that they can

adapt existing Disability Action Plans in order to fulfil the Specific Duty.[14]

5.2 <u>The 'invisibility' of social care</u>
In England, Scotland and Wales, social care suffers from being very much the junior partner to the NHS in terms of the government's and the public's priorities. In England, for example, the Department of Health's current Race Equality Scheme has very little on social care and this could be replicated in its Disability Equality Scheme. It is likely that local authorities will include social care in a 'corporate' Disability Equality Scheme and there may be insufficient attention paid to this area of activity.

5.3 <u>Outcome measures are not easily available</u>
Outcome measures will need to be compatible with and preferably overlap with measures that local authorities already have to gather. The Government is currently cutting back on targets and performance indicators and it may be difficult to try to persuade local authorities to introduce new ones.

Social care outcomes are notoriously difficult to measure. Currently contracts primarily focus on 'deliverables' such as number of home care visits made; and DH targets concern measurements such as numbers of direct payments and numbers of people supported to live at home. These types of measures are not necessarily indicative of independent living.

The DWP's consultation document on the DED stated that:

> In monitoring disabled people's experiences of service provision it will be important to consider not only whether disabled people are able to access services, but also whether the services provided actually meet the needs of disabled people. For example, a disabled person might find it admirably easy to access their county council's social services provision – but that is not a guarantee that the assistance the council was offering actually met the disabled person's needs.
> (DWP, 2004, p.39)

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[14] Two senior managers in two different social services departments have told me that they will just "dust down" their existing plans/strategies rather than devote any resources to any significant work on fulfilling the specific duty.

The word 'need' has a formal meaning within the social care context, based on the legislative framework and case law (in particular R v Gloucestershire County Council ex parte Barry). Local authorities are allowed to take their level of resources into account when determining need (with a few exceptions). In contrast, the DRC may have a different view of the concept of 'need' in the context of the duty to promote equal access and participation in society. There may be a tension therefore in setting outcomes to be monitored.

Another challenge will be posed, in England, by the fact that CSCI – having not long been established as an independent inspection body – is facing yet more change with the reduction in the number of inspection agencies. In addition, CSCI is assuming that its budget will reduce significantly, following the Gershon review on public sector efficiency. The next two to three years may be a difficult time in which to work with the organisation on developing ways of measuring disability equality in social care.

5.4 <u>There are some social care policy areas which are not generally included when discussing disability policies and yet which have important implications for some disabled people's lives</u>

There is some evidence that experiences such as domestic violence, homelessness and substance abuse are more common amongst disabled people than non-disabled people (see 1.3.1a above). Yet there has been an historic failure to recognise this amongst services aimed at addressing such difficulties, exacerbated by a tendency to categorise people into one 'service user' group rather than recognising that one individual may have a range of experiences.

The Disability Equality Duty could provide an opportunity to redress these failings but the DRC will need to make the case for research in order to fill the gaps in our knowledge about disabled people's experiences of these issues (see also 5.5 below).

It is also the case that services in these areas are less likely to be familiar with the social model of disability.

5.5 <u>The consequences of social care organisations failing disabled people can be devastating but it may not be easy to prove a causal relationship</u>

Failures of social care organisations to fulfil their disability equality duty (either in terms of ensuring equal access to services or in terms of promoting equal access to and participation in society) may only be apparent if other agencies carry out disability monitoring and even then the causal relationships may be difficult to prove.

One example is the controversy over Anti-Social Behavioural Orders and children and adults identified as having behavioural difficulties that are said to be the result of (sometimes undiagnosed) impairments such as autistic spectrum disorder, attention deficit hyperactivity disorder, learning disabilities, brain injuries, or mental health problems. A failure to adequately assess and meet needs relating to such impairments or mental health problems can result in behaviour which other people find difficult and which may be misinterpreted and misunderstood.

Anti-Social Behaviour Orders aim "to protect the public from behaviour that causes or is likely to cause harassment, alarm or distress". They are civil orders which can be granted on the basis of hearsay or professional evidence (i.e. a lower level of proof operates than in the criminal courts) but breach of an ASBO can incur a custodial sentence. (See www.homeoffice.gov.uk/crime/antisocialbehaviour)
Recent statistics indicate that 43% of ASBOs are breached (Home Affairs Committee, 2004a). Figures for those given custodial sentences as a result of breaching an ASBO are only available for 2000 and 2001, when about 50% were jailed or detained in a young offenders unit (NAPO, 2005).

Newspapers have reported anecdotal evidence of children and young people with ASD or other impairments being the subject of an ASBO which they have great difficulty in complying with (*The Observer*, 22 May 2005). There have also been anecdotal reports of adults with mental health problems being issued with ASBO's. Statewatch and NAPO collect case studies of ASBOs being issued (most of them based on newspaper reports), a small number of which concern children and adults who may be disabled (see www.statewatch.org/asbo/ASBOwatch-extreme.htm and NAPO, 2005). Asbo Concern also collect case studies (see www.asboconcern.org.uk/) The British Institute for Brain Injured Children launched a campaign in February 2005, called 'Ain't Misbehaving' aimed at educating politicians, professionals and the

public that some children (and their families) labelled as anti-social are in fact living with communication and/or cognitive impairments (see http://www.bibic.org.uk/newsite/general/campaigns.htm). The BIBIC is concerned not just about the inappropriate use of ASBOs but also of initiatives – such as parenting classes - which assume that it is poor parenting skills which account for children's behaviour.

To put the argument at its starkest, it could be that a combination of government policy on ASBOs, and a failure of social care organisations to adequately assess and respond to the needs of children and adults with ASD, ADHD, communication and/or cognitive impairments, and/or mental health problems, is resulting in these groups facing restrictions and a risk of being locked up (and, moreover, being locked up on lower standards of evidence than that normally required in a criminal court). However, the only evidence of this so far is anecdotal and mainly reliant on newspaper reports (which are notoriously unreliable on this type of issue). The Home Affairs Select Committee received very little evidence which might support such an argument: one organisation – NCH – referred in its evidence to one newspaper report about a child with ASD and autism being issued with an ASBO; and the Crime and Society Foundation referred to anecdotal evidence of a use of ASBOs to evict older people from sheltered housing – "the behaviours giving rise to these evictions are the result of diminishing health, such as the onset of dementia or other mental health problems associated with the aging process" (House of Commons Home Affairs Committee 2004, Evidence 31, para. 11).

There is some research evidence that adults with mental health problems may be more at risk of receiving an ASBO – homeless people are at risk of receiving an ASBO, particularly those who beg, and some research shows a very high level of mental health problems and drug dependency amongst homeless people.

It is also relevant that the Home Affairs Select Committee, while broadly supporting the government's policies on anti-social behaviour, concluded that while resources are available for preventative work, the "funding streams are complex and we are not confident that the resources are always targeted on those most in need of support". The Committee went on to say that key agencies such as social services and Child and Adolescent Mental

Health Services "do not always seem to have access to additional funding" (Home Affairs Committee, 2004b, para 370).

This is a complicated issue, therefore, both in terms of establishing evidence, and of causation and responsibility. However, the disabled children and adults concerned are amongst the most vulnerable and the consequences of a failure to assess and meet needs relating to impairment or mental health are very significant. It is an issue therefore which deserves investigation in the context of the Disability Equality Duty: social care organisations may well be failing in their duties to provide equal access to services and to promote equal access to and participation in society. It is likely, however, that primary research would be required to make the case for such a breach of the Duty.

A similar issue concerns the disproportionate numbers of people with learning disabilities and/or mental health problems amongst the prison population. About two thirds of people in prisons have mental health problems (Davies, 2004; Singleton et al, 1997) and about 60% of those referred to Youth Offending Teams have special educational needs (NACRO, 2003). A case could be made that people with mental health problems and/or learning disabilities are more likely to enter the criminal justice system if their health and social care needs are not properly assessed and met. Again, however, while there is a strong case for investigating such a possible breach of the Duty, primary research would be required to establish both incidence and causation (see Section 6.5 below).

5.6 <u>Social care organisations are likely to be dependent on the actions of other bodies to deliver some of their equality targets</u>
The draft Code of Practice envisages that there will be a separate action plan covering social care within a local authority's generic Disability Equality Scheme. However, the delivery of equality targets is likely to depend on more than one local authority department, and can also depend on other public authorities. One obvious example is the reliance by social services authorities on housing authorities in terms of enabling disabled people to live independently in their own homes. Another is the widespread evidence that even when schools, children's services and Connexions assist young disabled people to make choices, the lack of appropriate local provision in adult services makes transition to independent living very difficult (Social Care Institute for Excellence, 2005).

5.7 <u>Definitions</u>
The social care framework – in England, Wales and Scotland – uses a different definition of disabled person than the Disability Equality Duty. In the context of social care the definition used is that contained within the National Assistance Act 1948, namely someone who is "blind, deaf or dumb, or who suffers from mental disorder of any description and other persons who are substantially and permanently handicapped by illness, injury or congenital deformity" (National Assistance Act 1948, Section 29(1)). This is the basis for entitlement to assessments. Someone may also qualify for assessment if they 'appear to be in need of community care services' even if they do not meet the definition of disabled person.

5.8 <u>The health and social care divide</u>
In issuing guidance on the disability equality duty and social care, the DRC will face difficulties caused by the distinction between health and social care. As the House of Commons Health Committee recently pointed out. "In nearly every enquiry undertaken in recent years, the absence of a unified health and social care structure has been identified as a serious stumbling block to the effective provision of care" (House of Commons Health Committee, 2005, para. 24). The Committee referred to the "artificial distinction" between health and social care and there was unanimous agreement amongst those giving evidence to the Committee (the Minister, senior health and local authority officials, nurses, carers) that it was not possible to give a clear definition of the difference between health care and social care. Whereas there are organisational and budgetary distinctions between health and social care, it is less easy to distinguish between the impact of health care and social care when measuring outcomes for disabled people.

5.9 <u>Organisationally it is becoming more difficult to separate out responsibility for social care.</u>
This is particular the case in the context of mental health services, and learning disability services in England, where the joint pooling of budgets and responsibilities between health and social care is further advanced. But even within older people and physical and sensory impairment services this may increasingly become difficult – particularly with the advent of individual budgets which are

intended to reduce the current fragmentation of people's needs into different budget categories and organisational responsibilities.

There are also moves to bring together the administrative systems of the pension service and local authority services for older people. In England, there are currently 39 Joint Teams with responsibility for providing services for older people, bringing together local authority services and The Pension Service local services. The intention is that there will be Joint Teams in all English local CSSR areas by June 2006. The Joint Teams have both operational and strategic responsibility.

In Scotland, area-based Community Health and Social Care Partnerships are in the process of being set up and there are also plans to bring together older people's and 'physical disability' services. In Glasgow, for example, a joint management group will have responsibility for "health and social care services for older people (including older peoples mental health services), physical disability, and rehabilitation". Organisational arrangements between the Community Health and Social Care Partnerships and the Health Board's Acute Services Division are intended, as an NHS Greater Glasgow Committee Report put it, "to ensure there is a properly integrated system of care across NHS community and hospital and social care services".

The setting up of Community Mental Health Trusts and Learning Disability Partnerships in England and Wales means that it can be difficult to separate out organisational responsibilities for social care from community-based health care. Social care services for people with mental health problems are delivered by mental health trusts, accountable to Strategic Health Authorities. Services are commissioned by local authorities and Primary Care Trusts. For example, Manchester City Council's Disability Action Plan does not cover mental health service users because the Children, Families and Social Care Department does not provide a service for people with mental health problems. Instead the City Council commissions the local mental health trust to provide such a service.

Mental health trusts have written Race Equality Schemes which cover both health and social care services and it would make sense for them to do this also for their Disability Equality Schemes.

The DRC may need therefore to combine its guidance on health and social care.

There has been a similar development of joint health and social care Partnership Boards in the field of learning disabilities.

5.10 <u>Tensions between promoting disability equality and rationing of scarce resources</u>

Following the Gershon Review, local authorities in England are under considerable pressure to make savings. Front-line services are one of the three areas being focussed on to identify efficiencies: the three areas are 'client facing'. 'back office' and 'procurement strategy and supply chain' (Department of Health 2005b). In fact efficiency savings in all three areas could have an impact on service users.

If the Guidance is to be applicable to charging policies, some difficult issues may need to be grasped. For example:
- when the DH in England comes to review its guidance on charging, it should address the disability equality consequences of the differential treatment of earned and unearned income. Currently, earned income is disallowed when carrying out means tests to determine charges for social care. This means that disabled people in receipt of pensions (which many see as deferred income) are more at risk of social exclusion than disabled people in receipt of earned income.
- The Welsh Assembly Government is currently considering how to implement its commitment to abolish charges for social care but is likely to limit this to 'personal care'. This could create unequal treatment and unequal opportunities for people who require other forms of 'practical support in community or residential settings'.
- The Scottish Executive already makes a distinction between 'personal care' and 'social care' when deciding which services should be free at the point of delivery. This may well have opened up inequalities between different groups of disabled people and created further barriers to independent living.

5.11 <u>Identifying what social care policies and practices promote independent living can be quite complex</u>

For example, direct payments per se do not promote choice and control. There is anecdotal evidence that, in some situations, CSSRs offer people direct payments in order to divest themselves of the problems of, for example, recruiting support workers in rural areas or to work with children and young people who have autistic spectrum disorder. This achieves little more than passing on recruitment problems to the disabled person and their family.

The extension of direct payments to people who need support to use them is welcome but an increase in such payments cannot be taken as a measure of an increase in choice and control. As recent research points out, in the case of Independent Living Trusts, set up to enable young disabled people who do not meet the 'able and willing' criteria to have access to direct payments, "the extent to which the young people were able to influence decisions was almost completely dependent upon their parents commitment to them. It was not clear that there was anything guaranteeing this inherent in the structure of the IL Trust. It appeared that the reality was that the parent acted as they thought in their son/daughter's best interests, with little or no reference to any other Trust members" (Luckhurst, 2005).

It will be important that the Guidance encourages public authorities, especially the Department of Health, to develop outcome measures which can truly assess the extent to which policies and practices "ensure equal access to and participation in society of disabled people".

5.12 <u>The goal of 'choice and control' is vulnerable to being hijacked by the political agenda on 'choice' in public services</u>

A focus on 'choice and control' – key concepts in the aim of independent living – is sometimes confused with the aim of creating 'choice' in public services (and particularly in the health service). This is problematic because the latter policy is criticised as undermining public services (and particularly the NHS). For example, there is a strong argument that the Conservative government's enactment of direct payments in the 1990s was more a result of their desire to privatise public services than an espousal of the ideals of the disability movement. Current policies

associated with promoting independent living – in particular *Improving Life Chances*' proposals on individual budgets – are vulnerable to a similar criticism. This will be especially so if the piloting and implementation of individual budgets encompasses health care as well as social care services. The promotion of independent living could, at least in terms of the policy implications, be politically contentious.

5.13 <u>Some key organisations are 'arms length' bodies</u>

One example is the Improvement and Development Agency, a "local government's improvement agency, set up by and for the local government community" (<u>www.idea.gov.uk</u>). It is a company wholly owned by the Local Government Association so is not a public body. However, its activities are potentially influential in terms of whether social care services promote disability equality. It aims to improve service delivery in adult social care, as well as children's services. Amongst its activities is the Beacon Awards scheme, which it runs on behalf of government. It is therefore an organisation which to a large extent defines what is good practice as well as being closely involved in promoting what it perceives as good practice.

The equivalent organisation in Wales is Syniad and in Scotland the Improvement Service.

6. Recommendations on priority areas for the DRC to focus its influencing and promotion work on the DED in the social care sector.

In terms of achieving maximum impact upon the sector, it is undoubtedly the case that a focus on social care services for older people should be a priority – as they are the largest group of social care users. However, there are also other aspects of the social care framework that have important consequences for some disabled people's experiences of inequality. In all, five priority areas have been identified.

6.1 <u>Social care and older people</u>
As a great deal of the DRC's activity has been specifically relevant to disabled people of working age, work on the DED in the social

care sector would be a good opportunity to focus on disabled older people.

All the aspects of the DED as applied to social care (identified in 1.3.1a, b, c and 1.3.2 above) are relevant to older people's experiences, that is:

- Equality of access to social care services
  - Equality of access in comparison with non-disabled people: not all older people using social care services come within the DDA definition of disabled person
  - Equality of access between different groups of disabled people: some services for older people have eligibility criteria which exclude, e.g. people with personal care needs
  - Equality of access to policies and services that promote independent living: e.g. the take up of direct payments amongst older people has been slow.

- Assessing whether social care policies and practice promote equal access to and participation in society: e.g. home care delivered in '15 minute slots' can create dependency and result in social isolation; the personal expenses allowance for people in residential care is £18.80 per week which makes it difficult for people living in residential care to have any kind of social life or to enjoy leisure activities or participate in their local community.

The two areas where the DED could potentially make the biggest impact on social care policy and services for older people are:

- Equality of access to policies and services that promote independent living; and
- Assessing whether social care policies and practice promote equal access to and participation in society.

The National Service Framework for Older People has as its first Standard: "NHS and social services should be provided regardless of age and on the basis of need alone". This provides an important mechanism for "rooting out age discrimination" (although such discrimination undoubtedly still exists) but is not an adequate mechanism for changing the whole culture of the way older people's support needs are met. The DED provides an exciting

opportunity for applying the social model of disability and the principles of independent living to this largest group of disabled people.

The DRC would be able to draw on the work of a number of different organisations, for example:

- Help the Aged has been focussing on human rights and older people over the last five years and have recently published a paper on the implications of the Human Rights Act for older people (Harding, 2005).
- Action on Elder Abuse seeks to raise awareness about, and campaigns against, the abuse of older people. Their work raises important issues about the balance to be struck between 'protection' and 'independence', as illustrated in the following extract from their response to *Independence, Well-Being and Choice*:

  "Experience from our helpline suggests that choice and independence must be seen and promoted within a context of security and protection if it is to encompass issues of abuse. Although the current national data on prevalence of abuse is insufficiently robust, it is beyond question that older people experience a range of different types of abuse from a variety of potential abusers - including members of their immediate family and care staff (both social care and health). We would not wish to see any weakening of the commitment to protect vulnerable adults as part of a general drive towards promoting greater independence, and indeed would strongly argue that a desire for choice/control should not equate to a loss of protection. Older people are citizens with rights, and one of the rights that must be promoted and enshrined within any system of care is protection from harassment, abuse and discrimination."
  Action on Elder Abuse, 2005.

- The Joseph Rowntree Foundation has funded an Older People's research programme. Developed by and with older people themselves, the programme examines the priorities that older people defined as important for 'living well in later life'. There are 27 projects funded within the programme. One of the projects due to finish in September 2005

concerns developing new approaches to supporting frail older people at home.   The aim of the project is to:

"develop some new approaches to commissioning and providing services. It aims to review what is currently happening in the light of the identified barriers, and to devise alternative ways of commissioning and providing home care services which older people need and want. We will work with local older people and staff from public sector and independent services on two sites - Darlington and Dorset."
http://www.jrf.org.uk/knowledge/wip/record.asp?ID=801594

Work such as this may provide useful pointers as to how social care organisations can promote equal access to and participation in society for some of the most socially excluded groups of older people.

- The Scottish Executive published a review of research on older people and community care in 2004 which provides a useful starting point for assessing the experiences of older people in Scotland (McDonald, 2004).

6.2 Disabled children with significant additional needs

Again, because much of the DRC's work to date has focussed on disabled adults of working age, the disability equality duty provides an opportunity to focus on a different age group, in this instance children, but particularly those who have the most significant impairments.

In recent years, there have been increases in the numbers of children in contact with social services who have:
- Autistic spectrum disorder and learning disabilities
- Continuing health care needs
- A combination of physical and sensory impairments, and learning disabilities.

There is a danger that disabled children who have significant additional needs are losing out in current developments in children's services. Much of the emphasis has been on 'mainstreaming' and this has undoubtedly benefited many disabled children. However, the needs of those with significant and sometimes complex needs are harder to meet within mainstream settings unless additional requirements are met and/or services

change the way they do things. At the same time, an in-principle commitment to inclusion (in its many forms), combined with a desire to reduce costly residential placements can have negative consequences for some children's life chances if local services are unable to meet their particular needs.

The Disability Equality Duty provides an opportunity to produce guidance and assist public authorities to pay detailed attention to how disability equality can be achieved for children with the most significant needs. For example, in England, the government has adopted the following outcomes for all children:

- Being healthy – enjoying good physical and mental health and living a healthy lifestyle
- Staying safe – being protected from harm and neglect.
- Enjoying and achieving – getting the most out of life and developing the skills for adulthood.
- Making a positive contribution – being involved with the community and society and not engaging in anti social or offending behaviour.
- Economic wellbeing – not being prevented by economic disadvantage from achieving their full potential in life.

It will be important to ensure that the measurement of progress towards achieving these outcomes enables an identification of progress for disabled children with significant additional needs. Social care organisations would also benefit from dissemination of information about good practice in achieving the same outcomes for children with significant needs as for non-disabled children.

6.3 Implementation of *Improving Life Chances* and the forthcoming Joint White Paper

Improving Life Chances made a specific commitment to bringing about a transformation in social care to enable disabled people to be full citizens. It did this by building on the independent living principles espoused by both organisations of disabled people and by the DRC and proposed that individual budgets would be an appropriate way of delivering self-directed support.   At the same time, the role of the disability equality duty was identified as an important mechanism for delivering the government's aims for social care as set out in the report (in Chapters 4, 5 and 6).

Improving Life Chances also committed the government to ensuring that government departments modelled good practice in user involvement and that local authorities developed user involvement protocols. The report referred, in this context, to the DRC's task of assisting public authorities to involve disabled people (Prime Minister's Strategy Unit, 2005, pp.75-76).

This paper has already identified some of the political tensions that may result from the commitment to introduce individual budgets (see 5.12 above). The disability equality duty could play a key role in ensuring that this commitment does not get hi-jacked by other political agendas. It will also be an important mechanism for ensuring that self-directed support (in the form of individual budgets and the support needed to use them) is available to all groups of disabled people: individual budgets have been piloted with people with learning disabilities, while people with physical impairments pioneered direct payments. It will be important to focus on whether older people and people who use mental health services have access to individual budgets and that these are delivered in ways which promote choice and control.

6.4 <u>Social care services which are predominantly used by non-disabled people</u>

This is a relatively neglected area in terms of disability equality but there are a number of social care services where more attention needs to be paid to whether disabled people have equal access to services. There are four particular services which merit closer attention:

6.4.1 Children and family support services. There is evidence that disabled parents are being poorly served by children and families support services delivered by CSSRs (Morris, 2003b; Wates, 2003). In addition, the national evaluation of Sure Start has not, so far, enabled an assessment of whether this very important programme of support to families with young children has addressed the needs of disabled parents or disabled children. There is concern that, in the implementation of the new policy of Extended Schools, disabled parents and disabled children will be similarly invisible. The Social Care Institute for Excellence has commissioned a Practice Review of support to disabled parents and intends to develop good practice guidance. There has also been talk recently within the Department of Health about producing

good practice guidance on supporting parents with learning disabilities. It will be important that the work of SCIE and the DH is informed by the disability equality duty.

6.4.2 Support services to asylum seekers. As already mentioned, there is a lack of information about how many asylum seekers (adults and children) are disabled although estimates range between 3% and 10%. Moreover, existing monitoring systems of the services provided do not include data that would enable an assessment of whether services are making the reasonable adjustments required to meet the needs of disabled asylum seekers.   There is also concern that disabled asylum seekers are not accessing their entitlements – as disabled adults and children – to services under community care and children's legislation. Research carried out by the Refugee Council and the University of York (Roberts and Harris, 2002) found that:

- Unmet personal care needs, unsuitable housing and a lack of aids and equipment were common amongst the disabled refugees interviewed
- Disabled refugees often had little knowledge about their entitlements or how to get a community care assessment.
- Communication difficulties and extreme isolation were also common
- Most workers in 'reception assistant' organisations lacked knowledge about the disability-related entitlements and needs of refugees and asylum seekers.

The research also found an acute need for improved joint working between reception assistant organisations, local authority social services departments and the National Asylum Support Service (NASS). With few exceptions, relations between these key agencies seemed very strained, arising from**:**

- unclear policies and procedures and lack of named contacts equipped to handle enquiries about disabled asylum seekers, especially in NASS
- considerable confusion in and across agencies about responsibilities for financing community care packages and suitable housing
- overstretched social services resources, which sometimes meant the needs of disabled refugees and asylum seekers were seen as less pressing than those of other disabled people in the locality.

6.4.3 Domestic violence services

As already mentioned, it would appear that disabled women and children are under-represented amongst users of refuges (Toren 2005).   However, there is not sufficient monitoring of these and other services to people experiencing domestic violence to properly assess whether disabled adults and children have equal access to such services. This seems to be an issue – at a strategic level - which is better recognised in Wales and Scotland than in England. The DRC could however usefully promote the disability equality duty in the context of domestic violence services in all three countries, paying particular attention to the need to monitor the use of services by disabled adults and children. It would also be useful to identify good practice, such as the Leeds Inter-Agency project referred to in 3.1 above, in order to encourage service providers to take a proactive approach to ensuring equal access.

6.4.4 Drug and alcohol treatment services

These services are another area where there is a lack of monitoring of take up by disabled people. At the same time there is some evidence (although mostly from the United States) that drug and alcohol abuse is more common amongst disabled people. None of the national drug strategies adopted in England, Wales or Scotland identify access to services by disabled people as an issue. There is real scope therefore for the Disability Rights Commission to encourage the relevant government departments and agencies to take a proactive approach to ensuring equal access for disabled people to these important services - services that can make a significant difference to people's life chances.

6.5 The social care needs of disabled people in the criminal justice system

As mentioned above (para 5.5), about two thirds of people in prisons have mental health problems (Davies, 2004; Singleton et al, 1997) and about 60% of those referred to Youth Offending Teams have special educational needs (NACRO, 2003). There is also anecdotal evidence that some children and adults with ASD, ADHD and/or mental health problems are at risk of receiving ASBOs. Research is needed on whether these experiences are the result of a failure of social care agencies to assess and adequately meet the needs of these groups of disabled people.

However, the disability equality duty provides an opportunity for both investigating and putting right a significant injustice.

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