

# The need for Law Reform

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## **Introduction**

I have been asked to prepare an outline paper addressing the following question – “is new legislation needed to deliver independent living for disabled people of all ages?” Happily – or unhappily – as may be the case, I was involved in much the same task 10 years ago and what was written then seems equally relevant today<sup>1</sup>:

Community care law is, beyond peradventure, in a mess. The primary statutes contradict each other, give different rights to different service users and have been so amended as to contain many quite incomprehensible provisions. The product of this mess is that service users have little idea as to their service entitlement and social services departments are generally acting outside the law. The NHS & Community Care Act 1990 deceived much of the population into believing that the principles expounded in the White Paper “Caring for People” had been enacted into law; the Act is however silent on the rights of carers, the right of individual choice, and the “seamless service” with the NHS.

The problem goes beyond the mere fact that the legislation is riddled with inconsistencies and beyond the public policy ‘resource issue’ so prominent in the present *Gloucestershire* litigation. At its heart is the problem that we are dealing with a body of legislation enacted over a period of 50 years embodying differing philosophical attitudes and economic expectations.

If the law was in a mess in 1997, then it is in a dreadful mess today. In the intervening 10 years there have been volumes of amending statutes<sup>2</sup>, devolution, the Human Rights Act 1998, the restructuring of social services departments (to create yet another fault line for disabled children in transition) and many important and a few landmark judgments – all adding

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<sup>1</sup> L. Clements (1997) ‘Community Care: Towards a Workable Statute’ in Liverpool Law Review Vol. XIX(2) [1997] p181-191

<sup>2</sup> See for instance – the Community Care (Residential Accommodation) Act 1998; the Health Act 1999; the Care Standards Act 2000; the Carers and Disabled Children Act 2000; the Carers (Equal Opportunities) Act 2004; the Health and Social Care Act 2001; the Community Care (Delayed Discharges etc) Act 2003; the Children Act 2004; the Disability Discrimination Act 2005; the Mental Capacity Act 2005.

to the complexity (some might say incomprehensibility) of the statutory scheme.

### **The poor law legacy**

When Sir William Beveridge declared war on the famous five – the five giants of evil – he had in mind Giant Want; Giant Disease; Giant Ignorance; Giant Squalor and Giant Idleness<sup>3</sup>. At the end of WWII legislation was brought forward with the purpose of slaying these monsters – principally the Education Act 1944, the NHS Act 1946 and the National Assistance Act 1948.

The neglect of disabled, elderly and ill people living in the community was in many respects the forgotten sixth Giant. Part III of the 1948 Act did however make passing reference to their needs – albeit in the context of an institutional model – the provision of residential accommodation and workshops.

Over the succeeding 60 years the 1948 Act has been sustained by a mishmash of statutory patches – such that today it is the only ‘Beveridge statute’ that remains in force. It is an Act whose material provision describes disability in medical terms (‘handicapped by illness, injury, or congenital deformity’) and bears a cross heading referring to ‘*crippled persons, etc*’ – an Act whose unmistakable context is of a big State fixing the lives of the unproductive and helpless. It is an Act that purported to abolish the poor law (section 1) but in reality merely created a less austere 20<sup>th</sup> Century regime incorporating much of the old architecture – a regime designed for the poor (being means tested); a regime predicated on the parish (the ‘ordinary residence’ and post code entitlements); a regime with an institutional mindset and one that talks of carers in the language of ‘liable relatives’.

In every other branch of social welfare law, there has been radical reform and codification. The statutes regulating housing, education, mental health, children’s rights, health and social security have all been the subject of fundamental reform to reflect the socio-economic, political and philosophical changes that have occurred since the war – particularly to accommodate the changing relationship between the citizen and the modern state. Alone of all these discrete social welfare legal systems, community care remains unformed – much tinkered with – but fundamentally unreformed. The 1948 Act forms the legislative foundation and the philosophical context for our community care rights: it is the statute which regulates 95% of all adult social services care support (residential and non-residential).

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<sup>3</sup> See for instance N Timmins (1995) *The Five Giants: A Biography of the Welfare State*, Harper Collins, London.

## The disabling complexity

*We cannot conclude this judgment without expressing our dismay at the complexity and labyrinthine nature of the relevant legislation and guidance, as well as (in some respects) its obscurity.*

Crofton v. NHS Litigation Authority (2007)<sup>4</sup>

*Some of the worst, if indeed not the worst-drafted and most confusing subordinate legislation it has ever been my misfortune to encounter.*

Ryan v. Liverpool Health Authority (2002)<sup>5</sup>

The need for reform stems, not only from the National Assistance Act's anachronistic and increasingly objectionable premises – it also springs from the extraordinary complexity of the current legislative regime: time and time it reduces senior lawyers and judges to a state of consternation – as the above *cris de cœur* by the Court of Appeal and Munby J illustrate. If the law is obscure to our cleverest legal minds – then how does it fare with the poorly informed, the unassertive, the fearful, the exhausted, the distracted and those with intellectual impairments? Its very complexity constitutes a profoundly disabling barrier to disabled people accessing their civil and statutory rights – a point that has been made repeatedly – see for instance Camilla Parker (2006) 'the policy and legislative framework for the provision of health and social care is an area of particular concern, creating significant barriers to independent living'.<sup>6</sup>

The complexity also creates inertia and hesitancy (and opportunities for obfuscation) in the public bodies that are required to administer the system – expending considerable time and resources instructing lawyers to advise on all manner of questions. Some of those I have currently waiting in my 'in tray' give a flavour of the fundamental nature of this problem – concerning as they do:

- whether it is lawful to reduce disabled people's services to the point that only those in the most critical of need are supported – and even in such cases whether they can be placed on waiting lists for essential services;
- whether it is lawful, on cost grounds to institutionalise disabled people (notwithstanding that community based solutions are available)

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<sup>4</sup> Per Dyson LJ, [2007] EWCA Civ 71 § 111: (2007) 10 CCLR 123 at 148.

<sup>5</sup> Per Munby J (2002) [2002] Lloyds Rep Med 23, para 5.

<sup>6</sup> Parker, C (2006) Independent Living and the Commission for Equality and Human Rights: *Background paper prepared on behalf of the Disability Rights Commission* August 2006.

- whether it is lawful to pay direct payments to people entitled to NHS Continuing Care funding or provide them with disabled facilities grants or support their carers;
- whether a PCT can refuse dialysis to a person with dementia, not for clinical reasons, but purely because they have no carer available to sit with them during the 'dialysis at home' process – the effect of which policy is, of course, death; and so on and on and on.

These questions touch upon fundamental human rights. Take for instance the first issue. Despite the rhetoric of 'zero tolerance of abuse' and 'Dignity in Care' the binding guidance to English social services departments on when community care support should be given to disabled people specifically allows local authorities to limit their services to people whose need is 'critical'<sup>7</sup> (ie in the most severe need). The evidence suggests that increasing numbers of English local authorities are following this advice and considering restricting their services to people whose need falls into this band<sup>8</sup>. The same guidance, states that an adult who is experiencing abuse is not in 'critical need': that abuse is only critical if it is 'serious abuse'. Whilst it is highly likely that the courts would rule such a policy as unlawful – it is a measure of the confusion that in England at least the government is prepared to sanction such a policy. There is a positive obligation on the state to take steps to protect everyone from degrading treatment / a violation of article 3 European Convention on Human Rights / abuse – call it what one may.

The second question (above) – namely whether it is a legitimate policy to institutionalise disabled people because it is less expensive than enabling them to live independently – is no less fundamental. It may seem abhorrent that such a cost benefit analysis can be undertaken in the 21<sup>st</sup> Century – but it is a calculation that lies at the heart of virtually every local authority and NHS body's approach to service provision. Such authorities operate policies which mean that if a person's care needs exceed a particular sum, then there is a presumption that s/he will be institutionalised, being the cheaper option. Government guidance encourages the use of 'costs ceilings'<sup>9</sup> although it does not state explicitly that they can be used to make institutional vs independent living decisions. Nevertheless the guidance has been taken by many public

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<sup>7</sup> Fair Access to Care Services, Practice Guidance Q.3.9 A (page 5).

<sup>8</sup> The Commission for Social Care Inspection in 2006 noted that 'the thresholds for accessing services are high'; that nearly two thirds of councils' threshold for services was set at 'substantial' and that a number of these councils are expecting to raise their eligibility thresholds: CSCI (2006) *Performance Ratings for Adults' Social Services (England) 2006* p1.

<sup>9</sup> Department of Health Fair Access to Care Services 2003 practice guidance (Q6.4)

bodies as a green light to adopt such policies. Jenny Morris<sup>10</sup> has referred to the widespread use of such ceilings and their discriminatory impact. In her paper she cites a London Borough's policy that if a person's needs could not be met:

fully and safely at home within the level of funding that we have decided is reasonable ... then the Department will ... make arrangements for the service user's needs to be met through the provision of an appropriate residential or nursing home placement`

For reasons I explain below, it is likely that such a policy is unlawful – but once again it is a measure of the confused nature of the law that local authorities believe they can adopt such a policy. It is almost certainly the case that the right to independent living has developed to the extent that it could be termed a 'fundamental human right' and yet nowhere in the community care legislative or policy framework is there any acknowledgment of this fact.

Examples of community care policies that ignore fundamental principles of dignity, autonomy and indeed human rights recognised by the European Convention on Human Rights are common. These policies exist because there are no clear underpinning principles in the legislation that alert the policy maker – that set alarm bells ringing – when such ideas are being mooted. No local authority officer would propose a general policy of institutionalising children rather than meeting the costs of supporting them in their family – because it is would be in obvious conflict with the principles in s1 Children Act 1989 as would a policy of refusing (on costs grounds) to protect a child from abuse – unless it could be ascertained that the abuse was sufficiently 'serious. There is therefore an urgent need for a clear legislative expression of the underpinning principles in this domain of the law.

### **The need for underpinning principles**

Increasingly, contemporary social welfare statutes kick off with a set of underpinning principles – witness the Children Act 1989 and the Mental Capacity Act 2005. A modern community care statute would presumably draw considerable inspiration from the 'General Principles' in section 1 of the Disabled Persons (Independent Living) Bill – and in particular the core principle in s1(1), namely the right to 'enjoy the same choice, freedom, dignity, control and substantive opportunities as person who are not disabled at home, at work, and as members of the community'.

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<sup>10</sup> Morris, J (2004) *'Independent living and community care: a disempowering framework'*, *Disability & Society*, Vol. 19 No, 5, August 2004, 427, at 429.

The explicit acknowledgment of guiding principles in a modern community care statute should not be seen as a new innovation: as an expensive new obligation on public bodies. Arguably many of these principles are already recognised and protected by the legal system. The problem, however is that the very complexity of the system has meant that these rights are not 'universally acknowledged' as such. Take for example, the right to independent living.

Such a right can be discerned from the Government's broad policy documents and from the English and Welsh community care policy guidance. The 1989 community care White Paper '*Caring for People*'<sup>11</sup> (at para 1.8) declares that 'promoting choice and independence underlies all the Government's proposals'. Neither devolution<sup>12</sup> nor electoral changes have altered these objectives, a point manifest in the title of the 2005 English Green Paper '*Independence, Well-being and Choice: our vision for the future of social care for adults in England*'<sup>13</sup>. The 2006 White Paper<sup>14</sup> that followed sought to encapsulate this 'vision' in three key 'themes' namely

- Putting people more in control of their own health and care;
- Enabling and supporting health, independence and well-being;
- Rapid and convenient access to high-quality, cost-effective care.

### **The organic development of the right to independent living**

The promotion of independent living is a core – perhaps the core – principle underpinning the community care legislation. References to independence litter the policy documents of the last 20 years and have been given quasi-statutory force by policy guidance<sup>15</sup>. The 1990 Policy Guidance<sup>16</sup> states:

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<sup>11</sup> *Caring for People: community care in the next decade and beyond*. Secretaries of State for Health, Social Security, Wales and Scotland, HMSO, London November 1989 Cm 849.

<sup>12</sup> See for example the Unified and Fair System for Assessing and Managing Care (in Wales) (UFSAMC) 2002 policy guidance which at page 6 gives as the first two 'key aims' Social Inclusion and Independence.

<sup>13</sup> Department of Health March 2005: which at page 9 gave as its vision the promotion of certain principles, of which the first was the development of services 'to help maintain the independence of the individual by giving them greater choice and control over the way in which their needs are met'..

<sup>14</sup> *Our health, our care, our say: a new direction for community services* (2006) Secretary of State for Health January 2006 Cm 6737, p 13

<sup>15</sup> Guidance issued under s7(1) Local Authority Social Services Act 1970 – see *R v Islington LBC ex p Rixon* (1997) 1 CCLR 119.

<sup>16</sup> *Community Care in the Next Decade and Beyond: policy guidance* (1990): London, HMSO; and see also the 2002 FACS policy guidance which at para 15 provides further emphasis, stressing the importance of maintaining an individual's independence over time; and the UFSAMC

## CARE PLANS

3.24. Once needs have been assessed, the services to be provided or arranged and the objectives of any intervention should be agreed in the form of a care plan. The objective of ensuring that service provision should, as far as possible, preserve or restore normal living implies the following order of preference in constructing care packages which may include health provision, both primary and specialist, housing provision and social services provision:

- support for the user in his or her own home including day and domiciliary care, respite care, the provision of disability equipment and adaptations to accommodation as necessary;
- a move to more suitable accommodation, which might be sheltered or very sheltered housing, together with the provision of social services support;
- a move to another private household i.e. to live with relatives or friends or as part of an adult fostering scheme;
- residential care;
- nursing home care;
- long-stay care in hospital.

The courts have placed considerable reliance upon this requirement<sup>17</sup> thus in *R v Sutton LBC ex p. Tucker* (1996)<sup>18</sup> the fact that there was an 'effective option' for the service user's discharge from long-stay care in hospital was treated as creating an obligation to act purposefully to progress this objective.

Domestically s49A Disability Discrimination Act 1995<sup>19</sup> places a duty on all public bodies to have due regard to the need to promote equality of opportunity between disabled persons and other persons. In furtherance of this duty public bodies must develop Disability Equality Schemes<sup>20</sup> that (amongst other things) encourage participation by disabled people in public life. Disability Rights Commission Guidance for social services authorities concerning such schemes<sup>21</sup> gives as its first 'Action Point' (page 30) the objective of increasing 'the proportion of disabled people who are enabled to live independently'.

Internationally, the UN Convention on the Rights of Persons with Disabilities article 19 declares:

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2002 policy guidance in Wales which lists at page 6 as a key aim Social Inclusion and Independence.

<sup>17</sup> See for example *R v Islington LBC ex p Rixon* (1998) 1 CCLR 119, at p128.

<sup>18</sup> (1998) 1 CCLR 251 at 255H and 274H.

<sup>19</sup> Inserted by s3 Disability Discrimination Act 2005.

<sup>20</sup> Disability Discrimination (Public Authorities)(Statutory Duties) Regulations 2005 SI No. 2966.

<sup>21</sup> The Social Care sector and the Disability Equality Duty: A guide to the Disability Equality Duty and Disability Discrimination Act 2005 for social care organisations.

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

A powerful argument can be made that the inappropriate institutionalisation of elderly and disabled people may be contrary to the European Convention on Human Rights – contrary to article 8 alone or in combination with Article 14. This is particularly the case given that the UK has accepted the right in the UN Convention (which it signed in March 2007) and is effectively estopped from denying that such a right can be read into analogous binding Conventions such as the European Convention on Human Rights (article 8)<sup>22</sup>.

As yet there is no decided case that addresses this question directly, although there is relevant authority for this proposition in the form of a US Supreme Court decision, *Olmstead v. L.C.* (1999)<sup>23</sup>. *Olmstead* concerned the Americans with Disabilities Act 1990 which (amongst other things) proscribes discrimination in the provision of public services. Whilst there is no exactly equivalent legislation in England and Wales, Part III of the Disability Discrimination Act 1995 (goods, facilities and services) is sufficiently similar to permit comparison. *Olmstead* concerned a care planning regime in the State of Georgia, which skewed funding arrangements to favour institutional placements, rather than community based independent living placements. The applicants alleged that this constituted unlawful discrimination and the majority of the Supreme Court agreed. Whilst the Court emphasised that the financial resources of States' were relevant factors in determining their policies, it stressed the importance of policies being rational and fair and of

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<sup>22</sup> For an analysis of the enhancement effect of such interconnected Convention provisions, see Clements L & Read J (forthcoming, 2007) *Disabled People and the Right to Life*, Routledge, Oxford and see article 53 European Convention on Human Rights.

<sup>23</sup> 527 U.S. 581 (1999).

the basic principle that “unnecessary institutionalization” should be avoided if possible. In the view of the majority:

The identification of unjustified segregation as discrimination reflects two evident judgments: Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, ...;

and

confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

The Supreme Court’s acknowledgement that financial resources were of relevance in determining the extent of the independent living obligation raises the question of how these two community care principles ‘independence’ and ‘cost effectiveness’ should be balanced. The issue was addressed tangentially by the court of Appeal in *R v Southwark LBC ex p Khana and Karim* (2001)<sup>24</sup> where the applicants, an elderly couple, sought judicial review of the council’s decision to meet their care needs by provision of a placement in a residential care home. The applicants wanted, for personal and cultural reasons, to live in the community independently in a home of their own with the support of their relatives and the statutory services. Mance LJ giving judgment of the Court of Appeal held that:

... section 47 of the 1990 Act contemplate[s] an assessment by the local authority of a person’s accommodation needs, which takes very full account of their wishes, including the very fundamental aim of preserving the independence of elderly people in the community and in their own homes for as long and as fully as possible. A certain degree of risk-taking is often acceptable, rather than compromise independence and break family or home links. But, where a local authority concludes, as Southwark did here, that ‘the only way in which Mrs Khana’s needs can properly be met is for her to go into a full time residential home’, and makes a corresponding offer, and where this assessment and the reasonableness of the offer made cannot be challenged as such, then the local authority has in my judgment satisfied its duties under the legislation.<sup>25</sup>

The judgment confirms that the default position for any community care intervention must be the promotion of independent living and that only where the social care authority concludes for professional (ie not solely

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<sup>24</sup> (2001) 4 CCLR 267 (CA).

<sup>25</sup> (2001) 4 CCLR 267 at 281K.

financial) reasons that independent living is not viable, is it reasonable for it to propound an institutional care plan.

The principles recognised in *ex p Khana and Karim* are not unique to the statutory regime regulating the social services community care responsibilities. *Gunter v SW Staffordshire PCT* (2005)<sup>26</sup> concerned a disabled person who wished to remain in her own home rather than be placed in an institutional setting by the PCT (which accepted NHS continuing care responsibility for her). Collins J considered these considerations engaged article 8 of the European Convention on Human Rights and had to be given considerable weight. In respect of the PCT's argument that it would be less expensive to provide the care in an institutional setting, the judge referred to this as an obvious interference with family life and observed:

I do not regard evidence of what benefits could accrue from the expenditure of sums which could be saved in providing a less costly package for Rachel as helpful. It is obvious that Health Authorities never have enough money to provide the level of services which would be ideal, but that cannot mean that someone such as Rachel should receive care which does not properly meet her needs.

The strong presumption in favour of independent living (over and above financial considerations) comes additionally from the Strasbourg Court's comments upon the positive obligations imposed by article 8: to take action to 'the greatest extent feasible to ensure that they have access to essential economic and social activities and to an appropriate range of recreational and cultural activities' to ensure that their lives are not 'so circumscribed and so isolated as to be deprived of the possibility of developing [their] personality'<sup>27</sup>. Such compensatory measures, as Judge Greve observed in *Price v. UK* (2001)<sup>28</sup> are fundamental to disabled people's article 8 rights.

The above extended analysis suggests that we have, in the UK, reached a stage where it is not hopelessly optimistic to argue that the principle of a right to independent living is firmly entrenched in our domestic law. If this is the case, it is of fundamental importance that this right receives statutory recognition – rather than reliance upon the rhetoric of policy guidance and White Papers and convoluted legal argument.

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<sup>26</sup> [2005] EWHC 1894 (Admin) 26/08/05; (2005) 86 BMLR 60.

<sup>27</sup> Per Commissioner Bratza (as he then was) in *Botta v Italy* [1998] 26 EHRR 241 and cited by Munby J in *R (A & B, X & Y) v. East Sussex County Council* [2003] EWHC 167 (2003) 6 C.C.L. R. 194 at para 102 and see also *R (T, D & B) v Haringey LBC* [2005] EWHC 2235 (Admin) 21st October 2005

<sup>28</sup> Times 13 August: 34 E.H.R.R. 1285.

## The issue of access

A fundamental – possibly ‘the’ fundamental – problem concerning the human rights of disabled people is the question of access<sup>29</sup>. Rights without remedies are hypothetical and illusory. For rights, such as a right to independently living, to be a concrete reality in the lives of disabled people, they must be accompanied by accessible and effective enforcement mechanisms.

In practice, however, legal remedies are anything but accessible to disabled people. Major obstacles to access include the lack of adequate advocacy support and the imposition of particular rules for people considered to lack mental capacity – effectively frustrating the possibility of self advocacy. For many disabled people, however, their access to justice is not so much frustrated by the imposition of an unwanted representative, but rather by the absence of any support or assistance.

The rhetoric of government support for advocacy permeates official community care utterances – in policy documents concerning the NHS, learning disability support services, the rights of older people and mental health service users and so on. Incrementally these high sounding references are finding expression in modest statutory obligations – in relation to NHS complaints procedures, children’s complaints, in relation to major decisions concerning ‘unbefriended people’ deemed to lack mental capacity to determine certain major decisions and so on. .

Over 20 years ago, however, Parliament approved the right of disabled persons to advocacy support via sections 1 and 2 of the Disabled Persons (Services, Consultation and Representation) Act 1986. Successive governments have frustrated the will of Parliament by declining to implement the relevant provisions of the 1986 Act. The advent of the Human Rights Act 1998 and the requirement in article 6 (the right to a ‘fair hearing’ and the concept of effective ‘access to court’<sup>30</sup>) has changed the debate – from one of state beneficence to one of state obligation. Nevertheless for a disproportionately large number of disabled people, the right of access to justice is purely hypothetical and illusory. Such a state of affairs is unquestionably contrary to the Convention, and therefore, contrary to our domestic law. The right in article 6:

necessitates some positive action on the part of the State; in such circumstances, the State cannot simply remain passive ... The obligation to secure an effective right of access to the courts falls into this category of duty<sup>31</sup>.

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<sup>29</sup> See L. Clements & J. Read (2003) *Disabled People and European Human Rights*; Bristol: Policy Press

<sup>30</sup> See for instance *Golder v. UK* (1975) 1 E.H.R.R. 524.

<sup>31</sup> *Airey v. Ireland* (1979) 2 E.H.R.R. 305; 9 February 1979.

A modern community care statute would take steps to ensure that the will of Parliament in 1986 and the obligations adopted by the Parliament in 1998 are made a concrete reality for disabled people and include a statutory right to advocacy support.

### **The need for a unified multi-agency obligation**

A further, and compelling reason, for requiring a modern community care legislative regime concerns the many areas where the responsibility for delivering community care support rests with different agencies or is the collective overlapping responsibility of several such bodies. In such cases the need for shared goals and collaborative working are of course essential. The response to this difficulty has been decades of government exhortations to organisations, professionals and other service providers to work together more closely and effectively. In practice however the reality is all too often a jumble of services fractionalised by professional culture and organisational boundaries and by tiers of governance.

Disabled people are frequently negotiating transitions (particularly disabled children) between social services, education, housing, the NHS – transitions exacerbated by organisational reform – the division of social services into adult and children’s services – the merger or demerger of Care Trusts – the endless reconfiguration of NHS bodies and so on. In such a reality shared duties are essential if the disabled people are not to be overwhelmed, exhausted and disempowered. The inevitable inter-organisational friction is exacerbated by the differing legislative obligations in relation to the goal of independent living. The duty under the Children Act 1989 to promote the welfare of disabled children, under s17, is only a ‘target duty’ and so a resource dependent duty (not unlike a mere ‘power’) that provides no enforceable right to support. On reaching 18 however the disabled person gains specific and enforceable rights. There can be no logic whatsoever for such a distinction. Likewise if a disabled adult’s condition deteriorates to the extent that they are assessed as being entitled to NHS Continuing Care, then their specific and enforceable rights, instead of strengthening, also deteriorate – becoming mere ‘target’ resource dependent rights.

Such absurdities litter the community care landscape and are not confined to the different authorities responsible for delivering community care. They also discriminate against different service users – for example, the right of a physically disabled person is generally ‘specifically enforceable’; whereas the right of a person with identical needs, which has arisen merely because old age has made her frail (eg through muscle wastage) is only a ‘target’ resource dependent duty. Both individuals are disabled for the purposes of the

Disability Discrimination Act 1995 and it should therefore be unlawful to treat them differently, and yet that is exactly what is done by the statutory regimes.

## **Additional grounds for reform**

For reasons of time – this briefing paper has been prepared ‘on the hoof’ – I flag up (albeit briefly) two additional and compelling reasons for reform of the law in this field.

### *The assessment process*

The first concerns the assessment process at the heart of the statutory regime. In practice all support needs are dependent upon a community care assessment – a determination that is predicated upon entitlement to ‘services’ (section 47(1) NHS and Community Care Act 1990). The assessment process is council led, not ‘user led’ (notwithstanding the rhetoric of government guidance to the contrary) and generally conforms more to a ‘risk of harm’ assessment than a ‘potential for independent living’ assessment. The conceptual basis of the assessment process is, no matter how enlightened the assessor, one of disempowerment. In her analysis of ‘independent living and community care’ Jenny Morris<sup>32</sup> has highlighted this question, noting that:

assessments commonly measure dependency levels: they thus often ask ‘what is wrong with this person?’ rather than ‘what is wrong for this person?’ A medical model of disability therefore continues to underpin much of the contact between social services professionals and disabled people.

The base line for ‘eligibility’ for support is primarily a determination based upon the resources a local authority is prepared to put into the social services budget. The constant references in the community care guidance to the resource decision inherent in the eligibility criteria banding, colours the debate. It is at least arguable that as a society we count the cost of that which we do not value. That by constantly stressing the cost impact of supporting disabled people, the government is articulating and advancing a deeply offensive question – namely whether we can afford to allow disabled people to live independently – whether indeed the sum total of disabled people’s experiences can be expressed in financial terms.

### *The ordinary residence disincentive to ‘independent living*

The duties under the community care regime are local – not national – duties. Local obligations require rules about local connection, habitual residence and (in the case of community care law) ‘ordinary residence’. These can have a chilling effect on the actuality of independent living. Two examples suffice.

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<sup>32</sup> Morris, J (2004) ‘Independent living and community care: a disempowering framework’, *Disability & Society*, Vol. 19 No, 5, August 2004, 427, at 432.

If a person is receiving community care support to live independently, s/he may well be fearful of moving to another authority – because the entitlement cannot be guaranteed. The new authority may have different procedures, different priorities and different eligibility criteria. The disabled person would not know whether s/he would be better or worse off, until s/he had actually moved and been assessed. In organisational terms the new authority is likely to be reluctant to encourage the disabled person into its area since this will be seen as an additional burden and not surprisingly may appear less than welcoming if such a move is mooted.

On the other hand, if a disabled person is in a care home, then the ordinary residence rules mean that s/he is the responsibility of the local authority that placed him or her in that home – which may not be the authority in which the care home is situated. Indeed 19% of care home residents are placed outside their funding local authority area – of which over half of these are adults with physical disabilities. In inner and outer London the figures are even more dramatic – with 55% and 37% of their residents respectively being placed in care homes outside of their boundaries.<sup>33</sup> If such a resident wishes to move out of the care home and live independently in the authority area in which they have been living (ie the council area in which the care home is situated) then this has a major economic impact on that authority – since on leaving the care home the disabled person becomes ordinarily resident in that authority and hence its financial responsibility. In effect therefore the rules financially penalise such authorities if they assist a disabled person to live independently and (again) in organisational terms act as a significant disincentive to authorities supporting a disabled person to make such a choice.

## Conclusions

For reasons of time – and of course deference – I leave these to the meeting on the 2<sup>nd</sup> May.

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<sup>33</sup> Statistical Bulletin Community Care Statistics 2006 Supported Residents (Adults), England.