



CARERS UK
the voice of carers

THE EQUALITY BILL AND CARERS

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This briefing considers the impact of the reforms proposed in the Equality Bill, on carers. It has been developed by Professor Luke Clements through a discussion with representatives of Carers UK, IDeA, and staff from Hertfordshire and Surrey County Councils.

The paper commences by considering the wider policy context in which these reforms will rest. It is a policy context containing a number of countervailing challenges: a context where an undue focus on the Equality Bill's reforms risks obscuring more pressing and present changes that could undermine the rights of carers to equal treatment. The paper briefly considers the scope for combining some of the new obligations on public bodies, created by the Bill, with other existing functions – for example the obligation to gather information for the Outcomes and Performance Characteristics framework and Equality Impact Assessments as part of a council's auditing and inspection responsibilities in relation to the Care Quality Commission. The paper concludes by arguing that policy developments that may impact on carers, need to be evaluated before they become established

Policy context

The European Court of Justice's judgment in *Coleman v Attridge Law* (2008)¹ was an historic moment for carers. The Court ruled that adverse treatment of a carer could constitute unlawful discrimination. The judgement came less than 5 years after Dr Hywel Francis MP proposed (in the first draft of his Carers (Equal Opportunities) Bill)) that the Disability Discrimination Act 1995 be amended, to make it unlawful, not only to discriminate against disabled people, but also to discriminate against people 'associated' with disabled people – ie carers.² Although such a provision did not survive the 2004 Act's Parliamentary process, the identification of this injustice (now referred to as 'associative discrimination') meant that pressure would continue building for it to be addressed – as the title of the 2004 Act forewarned – Carers and the Equality agenda was to be a new front in the fight by carers to be treated fairly.

Whilst the reforms consequent on Equality Bill do not prohibit all forms of discrimination against carers – they do take the law a considerable way to creating a 7th strand to the equality framework³ and most probably compel public authorities, when undertaking 'impact assessments' for any new policy of initiative, to consider whether these are likely to have an adverse affect on carers. The combination of this development, with the implementation of the Carers (Equal Opportunities) Act 2004 means that a major cultural shift is occurring, in the way carers are viewed: a shift in seeing carers not so much as unpaid providers of care services for disabled people, but as people in their own right: people with the right to work, like everyone else: people who have too often been

¹ *Coleman v Attridge Law* (C-303/06) (2008) All ER (EC) 1105 ECJ (Grand Chamber) Judgment 17 July 2008 accessible at <http://curia.europa.eu/juris/cgi-bin/form.pl?lang=EN&Submit=rechercher&numaff=C-303/06>

² The prohibition of discrimination 'by association' is found in other legislation – for example the Race Relations Act 1976.

³ The law currently makes unlawful discrimination in relation to six 'protected characteristics' – namely on grounds of sex, race, disability, age, sexual orientation, and religion – albeit that these are expressed as 8 distinct categories in the Equality Bill, clause 18(3), namely age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex and sexual orientation.

socially excluded and (like the disabled people for whom they care) often denied the life chances that are available to other people.

Important as the development of a legal anti-discrimination dimension is, to the campaign by carers for equal treatment, two caveats need be born in mind when looking at the likely overall impact of such an initiative:

- (1) the first, is that equality legislation in itself is unlikely to make radical changes to the deep structural barriers that carers face in their everyday lives. An authoritative review of the impact of the disability anti-discrimination legislation in the USA has concluded⁴ that initiatives aimed at challenging such inequalities require Governments, in addition, to adopt direct and sustained interventions across all areas of their influence including the use of public funds and the provision of benefits; and
- (2) the obverse of the first point – namely that actions by Governments have not only the potential to make radical improvements to the lives of carers – they also have the potential to be regressive and harmful.

Carers and social exclusion

The depth of the social exclusion experienced by carers stands in stark contrast to these new 'inclusive' obligations: a disparity noted by the Commission for Social Care Inspection in the following terms:⁵

there are major tensions for councils in their policies to support carers. They are charged with improving efficiency and targeting resources effectively and are consequently restricting eligibility to services. But at the same time they are looking to support carers, recognising the risk that without support many carers own health and well-being may suffer and they, too, will need help in their own right. The danger, as ever, is that carers are only seen as a 'resource' and some carers continue to be socially excluded and barred from the opportunities others would expect.

The difficulties experienced by carers can be highlighted by three simple statistics:

- Carers lose an average of £11,050 pa by taking on significant caring responsibilities.⁶
- Over half of all carers have a caring related health condition.⁷
- Carers represent one of the most socially excluded groups of people – for whom the Government's inclusion policy appears (to date) to have failed.⁸

Carers & the law: 20 years of incremental progress

The struggle by disabled people for political and legal recognition has been mirrored by that waged by carers. The two campaigns are linked⁹ albeit that disabled people have, in the last 20

⁴ Samuel R. Bagenstos, S. A., (2004) *The future of disability law* Yale Law Journal 114.1 Oct 2004 pp 1 – 84.

⁵ Commission for Social Care Inspection (2006) *The state of social care in England 2005-06*. London: CSCI at para 7.106

⁶ *Out of Pocket, the financial impact of caring*, Carers UK, 2007

⁷ Carers UK, *Missed Opportunities: the impact of new rights for carers*, Carers UK June 2003.

⁸ *Breaking the Cycle: Taking stock of progress and priorities for the future. A report by the Social Exclusion Unit* Sept 2004, Office of the Deputy Prime Minister, London: para 6.17.

years, achieved many of their legal goals. Disabled people are now seen as ‘rights holders’ and it is generally accepted that their marginalisation and social exclusion is the product of social and political factors and not the inevitable consequence of their physical or mental impairments. Carers are still some way from achieving a similar recognition, even though they experience similar levels of social exclusion. The support carers receive is still viewed as evidence of the state’s beneficence rather than as compensation for the discrimination they experience from the non-carer majority, and in consequence they are still not seen as ‘rights holders’.

Carers have, however, achieved a great deal in the last 15 years, and it is essential that these gains are not lost – or traded away in any new legal or policy initiative.

One way of charting these achievements is to plot them against the evolutionary scale propounded by Twigg and Atkin in 1994.¹⁰ In their opinion carers could be conceptualised in four distinct ways, namely:

1. where the carer is viewed as a resource valued only in terms of their ability to provide support for the disabled / older person;
2. where the carer is viewed as a co-worker whose well-being is addressed solely to ensure that the caring role remains sustainable;
3. where the carer is viewed as a co-client entitled to support in their own right;
4. the superseded carer model – where the care planning process for the disabled person aims to dispense with the need for informal care.

It is arguable that the NHS and Community Care 1990 treated carers as a resource valued only in terms of their ability to provide support (level 1 on the above scale). The Act made no reference to the rights for carers, relying instead on the rhetoric of the guidance to deliver the message that they were valued. It was the lack of recognition that promoted Carers National Association (now known as Carers UK) and Malcolm Wicks MP to engineer the passage of the Bill that became the Carers (Recognition and Services) Act 1995. The Act provides recognition by entitling carers to an assessment of their needs – albeit that this assessment is directed at sustaining their caring role – and so placing this at stage 2 of the scale. Accompanying the Act was important guidance that stressed (amongst other things) that the voluntary basis of the caring role and that carers assessments should in general take place in private – ie in the absence of the looked after person. The 1995 Act, by its single focus on sustaining the caring role, was seen as problematic as was its requirement that the carer’s assessment could only arise when the disabled person was ‘being’ assessed: not least that the disabled person had the power to negate the right by refusing to be assessed. The Carers and Disabled Children Act 2000, again a Private Members Bill supported by Carers UK, addressed these shortcomings by providing for a freestanding right of carers to an assessment of their needs and for services in their own right – and thereby conceptualising the carer as a co-client entitled to support in their own right. This was further strengthened by the Carers (Equal Opportunities) Act 2004 (the third Private Members Bill, engineered by Carers UK and Dr Hywel Francis MP). This provided for carers to have support in accessing (or retaining) employment, education training and leisure opportunities.

⁹ Carers cannot however attain full freedom – to have access to life chances and opportunities on an equal footing to those who do not have caring responsibilities – until disabled people have the unconditional right to high quality support.

¹⁰ Twigg, J and Atkin, K (1994) *Carers Perceived: Policy and Practice in Informal Care*. Open University Press, Buckingham

Incremental as the above gains may have been, they have each been contested and have proved to be highly valued by individual carers. The right to a freestanding, separate and private assessment; the recognition that caring is not a legal obligation but only to be done by those 'willing and able'; the recognition that carers have a right to work, to participate in education, training and leisure activities on an equal footing to non-carers and that the promotion of these aims is a public responsibility are - in their way – no less important than the rights gained by disabled people during the same period, notwithstanding that carers have yet to achieve the broad based entitlement delivered by the Disability Discrimination Act 1995.

These gains are of core importance and any new development – legal (ie the enactment of the Equality Bill) or policy (ie the personalisation agenda) must secure and then build on these gains and must in no way, be seen as compromising them.

The Equality Bill and carers

The Equality Bill introduces four important new opportunities for carers:

- **Socio-economic disadvantage**
Clause 1 requires public authorities to have due regard to socio- economic disadvantage when exercising strategic planning functions.
- **Associative discrimination**
The Bill recognises the concept of 'associative' discrimination in relation to disabled people – and widens the impact of the *Coleman* decision (clause 13 of the Bill) to make unlawful such discrimination, not only in relation to a person's employment, but also in relation to goods, services, housing and other fields.
- **Indirect discrimination**
The Bill contains an explicit provision relating to indirect discrimination and disabled people (clause 19) – which is not found in the Disability Discrimination Act 1995. Indirect discrimination occurs where an apparently neutral provision, criterion or practice puts, or would put, people with a protected characteristic (ie due to disability or sex or race etc) at a particular disadvantage compared with other people, unless that provision, criterion or practice can be objectively justified as being a proportionate means of achieving a legitimate aim. A problem with this formulation is that there is a need to establish a comparator – ie a person who has not got the protected characteristic, and would not be adversely affected. An example is a height restriction for people wanting to enter the police force. This was neutral (ie it affected men and women alike) but because women are generally shorter than men, this provision adversely affected more of them than men.
- **Impact assessments**
The Bill (clause 145) extends the current duty on public bodies – such as local authorities and the NHS – to ensure that their policies and practices do not have an adverse impact on disabled (and other) persons. This duty is not merely negative: it includes an obligation to ensure that policies and practices are designed to eliminate discrimination, harassment and victimisation and to advance equality of opportunity and foster good relations. This includes an obligation to consider the impact of their policies and practices because of the concept of 'associative' discrimination.

Speculating on the potential impact of the above provisions, one could suggest:

Socio-economic discrimination

Whenever a government department, local authority, health body etc, is 'making a decision of a strategic nature' it will be obliged to have 'due regard to the desirability of exercising them in a way that is designed to reduce the inequalities of outcome which result from socio-economic disadvantage'. Since the economic disadvantage of caring is well established, the clause 1 obligation will require public bodies to assess the 'carers impact' of all such initiatives. This obligation may affect central government most – for example the initial formulation of the personalisation programme was largely silent on its impacts on carers and it is arguable that this was also the case with the reform of pension law – where the current law places carers at a severe economic disadvantage and results in significantly impaired pension rights

Associative discrimination

This arises where a policy or practice aimed at someone associated with a protected characteristic (ie due to disability or sex or race etc) disadvantages the person with the protected characteristic. In relation to carers, it is probably best understood where a disadvantage can be expressed in the following simple statement – *'but for my relationship with the disabled person, this would not have happened'*.

Examples of responses could be:

- *'I would not have been forced to leave my job'*. Sharon Coleman claimed that her employer refused to allow her to return to the same job after maternity leave, accused her of being 'lazy' when she needed to take time off to care for her child and threatened her with disciplinary action. The Tribunal that considered her case said it was unclear whether the law protected her because she wasn't disabled herself. The European Court of Justice ruled that she should be protected by the law because she is associated with disability: that because of disability (albeit not her own) it was arguable that she had been subjected to this treatment.
- *'I would have got the bank loan'*; John, a carer who runs a small business, was denied a bank loan because he has a disabled son who lives with him. This change would mean that he could challenge the bank's decision and make an application to a County Court to seek damages for his distress and any loss – because of disability (albeit not his own) he has been denied a loan.

Indirect disability discrimination

As noted above, this arises when an apparently neutral provision puts a disabled person at a particular disadvantage compared with other people (unless the provision can be objectively justified). The extent to which this provision will benefit carers – is unclear. An example might relate to a GP practice that has inflexible appointments arrangements. This would affect all people but have a disproportionately adverse impact on carers, whose caring responsibilities make it particularly difficult to fit into such rigid arrangements. If as a result a carer was unable to see her GP and her health was compromised, such that the disabled person's care or wellbeing was jeopardized, then a claim of indirect discrimination could arise. If such a policy

was being promoted by a hospital or other public body, then in addition there would be a duty, prior to its implementation, to have undertaken an Equality Impact Assessment (see below).

Disability discrimination can arise, when a difference of treatment exists between different categories of disabled person and this in turn may impact on the carer. In such a case it could be understood by the response to the following statement: *'but for the specific characteristics of the disabled person, I would have been treated in a different way'*. An example could be if the services provided to physically disabled older people are materially inferior to those for (say) learning disabled younger people. If this lack of support put a carer at a disadvantage such that the disabled person's care or wellbeing was jeopardized, then a claim of indirect discrimination could arise.

Impact assessments

Equality Impact Assessments are likely to provide an important mechanism for increasing awareness of carers' needs and carers' rights through large parts of the public sector. They may prove to be valuable tools for Carers organisations to challenge in circumstances where carers feel that their needs have been overlooked.

This may become more effective if public bodies can combine implementation with the discharge of other functions – eg the preparation of Local Authority Self Assessment Survey reports. The Care Quality Commissions 'Outcome and Performance Characteristics' used for evaluating local authority performance already have carers issues referenced throughout. There may be important opportunities to extend this approach to the equivalent criteria for assessing the performance of Health and Mental Health Services by CQC and Children's Services (by Ofsted).

Conclusions

1. There is a need for the Equality legislative reforms to be integrated into the other reforms affecting social care – particularly the personalisation and modernisation agendas. Without this overview, it is possible that some of the rights that carers have succeeded in gaining over the last 20 years may be lost.
2. Public bodies need to consider a training and education programme of their employees and members to alert all to the impact of the new reforms and the particular responsibilities in the four areas listed above – namely (1) strategic socio-economic assessments; (2) associative discrimination and the rights of carers; (3) indirect disability discrimination and carers; and (4) disability/carer impact assessments.
3. Consideration should be given to combining Equality Impact Assessments with other local authority and health body planning functions – so that they are not seen as an additional bureaucratic requirement – but a core element in discharging all such responsibilities;
4. Policy developments that may impact on carers, need to be evaluated before they become established. It may follow, for example, that if the current personalisation agenda (in England) had been subjected to a carers impact assessment (as will be required when the Equality Act is in force) it is possible that it would have been implemented in a very different way.

About Carers UK

Carers UK is a membership organisation of carers, led by carers for carers. We improve carers' lives by:

- Campaigning for changes that make a real difference for carers.
- Providing information and advice to carers about their rights and how to get support.
- Training professionals who work with carers.
- Mobilising carers and supporters to influence decision-makers.
- Transforming the understanding of caring so that carers are valued and not discriminated against.

Carers UK

20 Great Dover Street
London SE1 4LX
020 7378 4999
info@carersuk.org
www.carersuk.org

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