

3rd February 2005

Re: Progress on a Bill of Rights for Northern Ireland: Issues for Carers

Thank you for the opportunity to respond to this consultation document. Overall we welcome the document. We are pleased to attach our response.

Yours sincerely



Helen Ferguson
Director
Carers Northern Ireland

Progress on a Bill of Rights for Northern Ireland Issues for Carers

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination. There are approximately 185,000 carers in Northern Ireland.

Carers Northern Ireland, a nation office of Carers UK, is an organisation of carers which is here to improve carers' lives.

- We fight for equality for carers. We want carers to have the same right as everyone else to an ordinary life – a fair level of income, access to support to protect their health and well being and access to the world of work, leisure and education
- We seek to empower carers. We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of health and social care services.

Carers Northern Ireland, and Carers UK, achieve this by

- campaigning for the changes that make a real difference for carers
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision-makers
- gathering hard evidence about what needs to change
- transforming the understanding of caring so that carers are valued and not discriminated against

**Progress on a Bill of Rights for Northern Ireland
Issues for Carers**

Introduction

Carers Northern Ireland is concerned that the current proposals for a Bill of Rights will not adequately protect the human rights of carers, particularly where those rights conflict with the needs and desires of the person that they care for, or with the interests of the State.

Definitions

Carers Northern Ireland uses the term 'carer' to refer to "those who look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid."

They may sometimes be described as 'family carers' or 'informal carers', although neither description is completely accurate.

In discussion with carers, there has been a strong feeling that a 'catch-all' heading of 'marital or family status/dependents' should not be used. It is not helpful, as it confuses different issues that are not related or relevant to each other. The question of marital status is irrelevant to the difficulties associated with having responsibility for the care and well being of another person who could not manage without that assistance. For one thing, marital status implies reciprocal responsibility, while the impact of caring is due to a responsibility that falls on just one person - the carer. Confusing the two could have unforeseen adverse effects.

A recent Carers Northern Ireland meeting considered the definition of Family Status included within the Single Equality Bill consultation document, based on the definition included in the Republic of Ireland's Employment Equality Act 1998:

"Responsibility as a parent or in loco parentis in relation to a person who has not attained 18 years; or as a parent or *the primary resident* carer in relation to a person with a disability which gives rise to the need for continuing, regular or frequent care or support".

If this definition was to be used as a basis for a definition for the purposes of legislation, the words "primary" and "resident" should be removed from the definition.

It is clear that more than one person can be actively and substantially involved in caring for a disabled individual. If someone's human rights are disregarded on the basis of their caring responsibilities, then it is irrelevant whether they are the sole, primary or 'secondary' carer - it is enough that they are a carer.

The residency requirement in the Republic of Ireland definition may have been inserted to be consistent with definitions used within their benefits system. The same argument as above applies - every carer would need the same protection from a Bill of Rights, whether or not they live with the person they care for.

There was some discussion about the terms 'continuing, regular and frequent care or support'. The consensus is that they were reasonable. The Commission may like to note that the definition of a carer within the Carers and Direct Payments (Northern Ireland) Act 2002 refers to persons providing care on a 'regular and substantial' basis.

'Mainstreaming' and Visibility

We understand from 'Progressing a Bill of Rights: an update' that the Commission is still undecided about whether to include detailed provisions for each disadvantaged or vulnerable group, or whether to 'mainstream' rights for all. We would certainly agree that it is 'unsatisfactory and invidious to include detailed provision for some but not all groups of this kind.'

Our main concern with regard to this is the invisibility of carers. Carers are living in situations where they are indeed vulnerable, by virtue of their caring responsibilities. Without adequate recognition and support, carers cannot assert their right to a normal, everyday life: to pursue the concerns and interests of their own lives, outside caring - to work, to relax, to pursue other relationships, to rest and leisure, to protect their own health and well-being. They are responsible, in most cases, for protecting the life, the well-being and the rights of two people - themselves and the person for whom they care. Compared with parents, the other group of people who care for dependants, they have an open-ended commitment that may last many, many years, and is likely to increase rather than decrease over time. Parent carers, by definition, have more onerous caring responsibility in that the term applies to those whose children, by virtue of their disability, require[s] more than the levels of care that would normally be required for a child of that age. Additionally, whereas disabled people and older people increasingly have public recognition and legal protection for their civil and human rights, those who care for them are in many cases invisible.

There is within Northern Ireland strong cultural pressures to take on caring responsibilities. Although there is no research base to prove this, there is a widespread view that this does appear to be a particular circumstance for Northern Ireland. Also it is a fact that the vast majority of what is referred to as community care, is in fact provided not by public bodies, but by carers - unpaid, unsupported and unrecognised. The state could not afford to replace this care, should carers choose not to continue (replacement cost estimated at £1.9 Billion in Northern Ireland in 2003). It is clearly in the State's interest that carers are encouraged to take on caring responsibilities, and there is a danger that this is experienced as an undue pressure to do so. Carers, and public bodies, need to understand that they do have rights to choose not to provide care.

It is particularly important that if an issue arises where the human rights of a carer conflict with the human rights of an older person or disabled person, the rights of the carer are recognised to be an equally valid consideration.

We do not seek a separate section on the rights of carers. However we would wish the commissioners to consider making specific reference to carers at a number of key points throughout the Bill of Rights and the accompanying commentary.

Right to equality and non-discrimination

As regards the Commission's new proposals for Section 4, we do not believe that the current proposed wording of section 4(3) will adequately serve to protect carers rights. The wording 'marital or family status', as discussed above, does not convey the unique nature of the caring relationship. The final catch-all of 'other status' does not resolve the problems currently caused by the invisibility and/or lack of recognition of carers.

This is vital to carers, because if it is clear that carers are included in the statement of rights to equality and non-discrimination, then it becomes evident that all other provisions of the Human Rights Bill do, indeed, apply to them.

We would therefore request that the Commission consider making carers manifest in the wording of Section 4 (3) by including an additional phrase, such as 'status as a carer'.

Social and Economic Rights

Many of the concerns about human rights that carers expressed related to their exercise of social and economic rights. We would support very strongly the inclusion of Social and Economic Rights within a strong and inclusive Bill of Rights. We would still endorse the comments made in our previous submission (December 2002) on the Bill of Rights.

Additionally, we would like to make the following points.

Section 15 (2) - the Right to Health Care is a huge issue for carers, who commonly neglect their own emotional and physical health and well-being in order to preserve the well-being of the person they are caring for. Although we accept that the wording in Section 15 (2), which offers protection to 'everyone' is sufficient to protect carers, we would like to see the commentary amended to make it clear that the obligations on the state include a specific duty to promote good health for those who have others dependent on them for their health and well-being.

We have a particular concern that carers are not being given access they need to proper information that would enable them to care effectively and to preserve their own health and well-being. We feel strongly that the information provisions contained within the current proposals are too specific. There would be rights to information held about you, to information about sexual or reproductive matters and to matters which concern the environment, but not to information you need to make an informed choice on any other matters.

Such a right may be regarded as a generalisation of *informed consent* in the consumer or medical domains. More basically, it may be regarded as grounded in human dignity. Students of human rights frequently rely on a concept of human dignity to ground rights, for example referring to conditions of economic deprivation, inhumane physical or psychological treatment. More fundamentally, however, human dignity arises from reflective human action, i.e., taking responsibility for the consequences of one's actions.

Considering action, individuals are vulnerable when they do not know the available range of options. Their choice of option may be less than optimal on that account. Articulating a right to be informed of available options is a warning to those who take advantage of such vulnerability by failing to ensure that choosing is informed. Consultations are a case in point. While consultees are able to describe conditions they find onerous, they do not necessarily know how best to deal with the conditions. Presented with what is in fact one of a number of "solutions," they may indicate acceptance, yet had they been informed of the range of available solutions their choice may have been different. Absent a human right to information relevant to decisions an individual must take highlights a condition where reflective human action is open to abuse.

Therefore we suggest that some form of wording be inserted into the Bill of Rights such as:

"Everyone has the right of access to information held by public bodies, or held by another person, and that is required for the exercise or protection of rights, or for informed decision making."

Because this is such a broad and far-reaching issue, we are not suggesting that Section 15 (2) is necessarily the best place to reflect this concern. Perhaps Section 9, on Civil and Administrative Justice, would be the best place to address the issue. We would ask the Commission to reflect on how and where best to make such a provision within the Bill.

Section 15 (3) - the Right to Social Care and support in accordance with their needs. We note a comparison with proposals under the Children's chapter. We note with approval Section 12 (5) which describes in positive terms the rights that we should expect for children with disabilities. We note, also, that Section 12 (3)a makes clear the obligation on the state to 'provide adequate support and assistance to parents and other primary carers ...'

We would encourage the Commission to consider including a similar clause under section 15 (3) with regard to those caring for adults. The wording of this should refer simply to 'carers', not to 'primary carers', for the reasons stated previously.

This is particularly important given carers' views on a Right to Leisure. In this regard, we quote from our 2002 submission:

"For carers, a right to leisure, enshrined within a Bill of Rights, could transform their lives, and their treatment by health and social services, because it would require the availability of adequate levels of high-quality, appropriate respite care, to enable carers to avail of leisure time.

A right to leisure may seem like a frivolous demand. However, essentially, it refers to the right for time off from doing what is necessary to maintain life and quality of life. For carers, of course, it refers to the carer's right to time off from doing what is necessary to maintain life and quality of life not just for themselves, but also for the person being cared for. Accordingly, for carers, what it means is a right to be educated, a right to be a friend, a spouse, a lover or a parent as well as a carer, a right to be stress-free and healthy. At its basic level it means having the right to a day off sick, which at the moment is a luxury that many carers cannot experience. We agree wholeheartedly that a right to leisure is central to ensuring access to and protection for a full and valued life."

Clearly, carers cannot access leisure, or indeed any life of their own unless the social care and support they receive is based on a clear understanding that they have a right to *respite from their caring*. Therefore, we propose that the Commission actively considers including a clause 15 (3)c.

Carers have a right to appropriate respite from their caring responsibilities.

In Conclusion

We offer this paper as an indication of the carer perspective on Human Rights and on the Bill of Rights. We appreciate the opportunity to discuss these and other issues with the Commission, and look forward to working together to forward the cause of Human Rights for carers in Northern Ireland