

# Belfast Central Branch, Carers UK

December, 2007

Mr Chris Sidoti, Chair  
Bill of Rights Forum  
Interpoint Centre  
20 – 24 York Street  
Belfast, BT15 1AQ

Dear Chris

Re: Submission to the Bill of Rights Forum

Please find attached a submission of member views using the suggested issue format.

We suggest that these views may be relevant to the *Economic and Social Rights, including relevant Equality Issues* Working Group.

We acknowledge with gratitude a grant from Community Foundation, NI that supported a human rights membership event on October 27, 2007.

Yours sincerely,

Geraldine Fennell, Chair

## Carers

### 1 What are the issues/needs relevant to carers?

Unpaid (family) carers are disadvantaged because government/society allows the burden of caring for people who can't care for themselves to fall disproportionately on those near to them. The rest of society escapes the burden. The basic injustice is this:

It is a fact of the human condition that some proportion of the population needs care before they die—they find themselves unable to maintain their life and quality of life (QOL) because of frailty, disability, or illness. A roll of the dice chooses such individuals. The fact that they can no longer maintain life or QOL for themselves may arise from something in their genes and/or exposure to environmental hazards.

Just as the people who need care are chosen by a roll of the dice, so also a roll of dice chooses the specific individuals who come in line to be carers for such folk. Here it is the accident of propinquity—being close, physically and/or psychologically, to those in need of care. Is it fair that those singled out in this way should bear the burden, and the rest of the population escape from any part in this aspect of the human condition?

Carers take on an impossible task, i.e., shouldering double duty—maintaining life and QOL for two individuals, the caree and themselves. What gives—what is neglected—are the concerns and interests of the carer's own life, including, as research shows, the carer's own good health. Equality considerations require society to provide the support needed if carers are not to suffer the detrimental consequences of addressing an aspect of the human condition that hitherto has not been well recognized.

Justice demands that the cost of caring for those who cannot do so for themselves be regarded as a societal cost. Unequal treatment exists at present between carers and noncarers. Clearly, equal treatment demands that the cost of addressing the fact that some people need care before they die is shared equally by all in society, carers and noncarers. Unpaid carers remain, of course, on the front line in delivering care to individuals needing help. They should, however, be supported with appropriate assistance so that the cost of providing care to such individuals is shared equally by carers and noncarers alike.

### 2. What are the particular needs of carers in the NI context?

What might this “appropriate assistance” look like? Such support should address the direct, indirect and opportunity costs of caring—costs that unfairly are now borne by carers and escaped by noncarers. Elsewhere (e.g., Fennell 2005), in a submission to the recent Review of Mental Health, an answer to that question was sketched by considering some eight respects in which carers' circumstances put them in conditions in which they are vulnerable and, in respect of which,

provision for their support should be in place. Such circumstances include absence of:

- Awareness among noncarers of the multi-faceted burden that caring entails
- Informed consent, when carers take on the caring task;
- Formal preparation of carers for what they encounter during caring, leading to carers needing training as well as information, referral and advice tailored to their circumstances and accessible, via internet and helpline;
- Transparency from the health and social care system;
- Help for carers in the face of active hostility, including groundless accusations, from some professionals who prefer not to be observed as they conduct their work for the caree;

See also the submissions from Carers NI to the BOR Forum for further specific carer needs.

3. Are there barriers which might prevent the rights of victims being respected in practice and how might these be overcome?

The first barrier is lack of awareness of what it entails to be a carer. Unless one has been a carer, or known carers, one typically is unaware that some individuals, other than those who do so professionally, are devoting their time to maintaining life and QOL for another human being. Once that fact is cognized, along with awareness of the multi-faceted ensuing burden on carers, then the barrier is that society is not organized to support carers appropriately.

Moreover, the data suggest that many carers don't recognise their carer role as such. The recent census figures (2001) show 185,000 people answering the caring question affirmatively, i.e., they are looking after someone who can't do so for themselves. Nevertheless, the number of carers known to caring ngos in NI is counted in the low four digits. Accordingly, a first need is to bring awareness to such "hidden" carers of their status a carer. Beyond these two kinds of awareness deficits, the barrier to appropriate support for carers is getting arrangements in place to ensure appropriate support as discussed above including ongoing, daily, respite so that carers have time to pursue the concerns and interests of their own lives.

4. What rights for victims should be in the BOR for NI?

Right to have:

The burden of maintaining life and quality of life for those who can't do so for themselves shared equally among carers and noncarers, i.e., via appropriate support for carers. Appropriate support includes addressing multi-faceted carer burden arising from conditions that carers encounter qua carer.

## References

Carers NI (2007). Submissions to BOR Forum, December. (BOR Forum website: BS 12 – 15)

Fennell, Geraldine (2005). Carers are Vulnerable: Implications for NI Legislation. Presentation to the Legal Issues Working Group, Bamford Review of Mental Health, October 21;

<http://www.qub.ac.uk/sites/EqualitySocialInclusionInIreland-HomePage/2006InternationalConference/Presenatationsavailabletodownload/>

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