

Joint Committee on Human Rights

Submission from The Residents & Relatives Association (R&RA)



1. The Relatives & Residents Association (R&RA)

1.1 The Relatives & Residents Association (R&RA) is a national charity that exists to promote the rights and well-being of care home residents by providing information, advice and support to them and their relatives, especially at times of crisis.

1.2 It is the only national charity concentrating wholly on the complex needs of older people who live in residential care homes because of frailty, ill-health, dependency and, often, dementia. We do this by operating a telephone advice line, campaigning on key issues of concern (currently, the human rights of care home residents in general, the specific needs of self funders whose interests are not safeguarded by the statutory authorities, the position of residents with neither kith nor kin to champion them and general issues of quality of care), undertaking project work (e.g. developing training materials for care assistants in the prevention of abuse) and building relationships between care home providers and relatives and residents.

2. Human rights: the basis of R&RA's knowledge of the issues

2.1 Our knowledge and understanding of human rights in relation to older people is drawn directly from the evidence we gather from the real life experience of callers to our advice line. Last year we dealt with nearly 3,000 issues – of which 9% were concerned with possible breaches of human rights and abuse, and roughly a third around poor quality of care and other complaints.

Issues	Number of times raised	% of total
Financial (e.g. funding rules)	764	28
Standards of care	669	24
Admission to/eviction from care homes	418	15
Legal (e.g. Enduring power of attorney, deprivation of assets)	314	12
Human rights/abuse	239	9
Care home management	92	3
General incl R&RA info	95	3
Daily life (food, meals, social activity, environment)	35	1
Inspection	31	1
Interpersonal (guilt, worry)	82	2
Total	2739	98% (rounded up to 100%)

2.2 On this basis we are pleased to be able to submit evidence to the Joint Committee, in anticipation that it will be accepted as an authentic picture of the problems encountered by older people entering and living in the care system today. Several pen-pictures of cases helped by our advice service are appended to this submission [Appendix 1], providing detailed illustrations of the issues raised in the call for evidence published by the Joint Committee.

3. R&RA's response to the questions raised in the Joint Committee's call for evidence

3.1 We note that the Committee on this occasion is considering neither the meaning of 'public authority' nor the issues arising in relation to palliative care and decisions about withdrawal of treatment and other end of life concerns. While accepting this, we would, nevertheless, like to stress that we regard consideration of them as essential in any comprehensive inquiry into human rights issues. We regard the situation of self funders (those who by reason of either their capital or weekly income do not qualify for state support to meet the cost or management of their care) with particular concern. We look forward to the outcome of the Joint Committee's deliberations on these areas of concern.

3.2 Our evidence is wholly concerned with the experience of older people living in care homes. We are not able to address breaches of Convention rights in hospitals or other health settings (except insofar as they may be related to processes that span both health and residential care settings: for example, discharge from hospital into a care home, or difficulties gaining access to primary care services for patients living in residential care settings).

4. Specific points raised in the call for evidence:

4.1 Removal from care homes:

i) Precipitate closures of care homes without preparation or consultation with residents and their families undoubtedly threaten the wellbeing (and, in the worst cases, the lives) of residents and pose potential breaches of Convention rights. While residential care is a cornerstone of social care in this country (although sadly undervalued), ninety percent of it is owned and run by the independent (mostly private) sector. The interests of residents are not necessarily the first priority when the business case deteriorates and closure is seen as the only option. Government policy over the last thirty years has deliberately fostered the ceding of responsibility for vulnerable people to the independent sector with insufficient accompanying protective measures to ensure the interests of those vulnerable people are safeguarded.

ii) Some of the most serious cases reported to our advice line relate to individual cases of eviction, rather than the closure of care homes en bloc. Too often it happens because of the 'difficult behaviour' of the resident – even though the home is required to undertake an assessment of the resident before admission and should therefore be aware of the resident's condition. Indeed, national minimum standards state that a home should only admit a resident if it is able to meet the individual's

needs (including behaviour management). The other cases of eviction usually result from relatives making a complaint on behalf of the resident about the quality of care or other concerns. This makes residents and their families afraid of complaining for fear of victimisation. Our penpictures in Appendix 1 illustrate this.

4.2 Medication

We are aware of cases where poor medication practice has developed in homes. This may be as a result of malpractice or negligence by care home staff in the administration of medication properly prescribed by a general practitioner or it may be as a result of poor working/or slipshod relationships between a home and local primary care services. One of our penpictures describes a case where the local GP was willing to prescribe medication at the behest of the home for its convenience without seeing the patient concerned. This is not an unusual example.

4.3 Lack of privacy and dignity

A substantial number of cases reported to our advice line relate to the compromising of residents' privacy and dignity. Bathroom and toilet doors are left open, staff talk over the heads of residents when providing intimate personal care, residents are left in a state of undress, residents' own clothes are lost and insufficient care is paid to maintaining continence – as distinct from dealing with incontinence. Staff are heard referring to residents with dementia as 'the babies'.

5. Broader issues

i) The Joint Committee asks whether there are differences in the challenges to the human rights of older people in hospital and residential settings. One key difference is that care homes are people's 'own homes'. With the disappearance of long-stay hospital wards, hospitals are mostly transitory places. Poor care and, at worst, breaches of human rights may take place there but at least there is the hope that the individual will eventually move on. For a care home resident, there is no such expectation unless extraordinary action is taken to move on (either through eviction, dissatisfaction or substantial decline in health). However, in both settings, many of the causes of poor treatment have the same roots – arguably, poor training of staff, inadequate leadership and shortage of resources. Staff are too rushed and have no time to focus on the individual needs of the older person. There is a danger of this turning into a lack of concern and negligence – a downward spiral. Managers provide poor leadership and fail to halt this.

ii) In response to the question about discriminatory restrictions, the whole subject of access to NHS continuing care must be raised. We are concerned that older people as a generation are being treated unfairly. The conditions associated with old age are unfairly classified as 'social' or 'personal' and so those suffering them are excluded from NHS funding. A good example is someone with advanced Alzheimer's disease being denied NHS continuing care.

iii) We are also concerned that some residents in care homes are denied access to

other NHS care (primary and community health care services) that is theirs by right – either through failures of homes to put them in touch with those services or because those services are reluctant to get involved. There are also other rights that are denied – e.g. exercising the right to vote in local and parliamentary elections. A resident can only exercise the right to vote if someone has taken responsibility for ensuring that her/his name is entered on the Register of Electors.

iii) The Joint Committee asks what are the main practical, management and resource considerations facing providers in seeking to protect the human rights of residents. On the basis of our experience, drawn from real life cases, we believe that many of the problems that older people encounter and which threaten their human rights are caused by three major factors: lack of training, poor leadership and failures of regulation.

Lack of training – Care staff tend to be under-valued, under-paid and under-trained. We also have concerns about the adequacy of the training that is available. Competencies in the practical elements of caring are important but just as important is training in the humane, personal aspects of caring. We are currently developing training for care staff in the prevention of abuse and we hope to take account of this need in our current work.

Leadership – Managers set the tone and develop the ethos of a care home. Unless they are attuned to the needs of residents and are fiercely committed to observing the human rights of those they are responsible for, their staff will also fail. This leadership role needs to take account of the attitude towards older people that some staff may bring with them from their experiences elsewhere in society.

Regulation – The regulator, the Commission for Social Care Inspection (CSCI), ought to play a leading role in ensuring that the human rights of all those using registered services are observed. We are concerned that this obligation is being compromised in three ways:

- Inspectors have not, it appears, been trained in adopting this approach. It seems to us that too much time has been devoted to changing the structural aspects of the inspection regime, as a result, embedding fundamental human rights values may have moved at a slower pace.
- CSCI is pulling back from playing a direct role in hearing and resolving complaints. The main thrust of its approach now is to refer complainants back to a care home's own complaints procedure even though many complainants are fearful of victimisation if they do so.
- Moreover, under changes to inspection procedures introduced by CSCI this year, homes are no longer inspected twice a year. A new, flexible procedure has been introduced where the only mandatory requirement is that homes will be inspected once every three years. We feel that this not only gives out the wrong message regarding the role of the regulator, it also runs the real risk of compromising residents' safety and further undermining the fragile confidence that characterises public perceptions of the care sector and the inspection regimes overseeing performance.

6. Conclusion

We endorse the approach advocated by the British Institute of Human Rights which calls for the adoption of a human rights framework for all organisations working in the field of social care. This would mean a transformation in the way that providers (owners, managers, staff) view and care for their residents. We would welcome the extension of that principle to those regulating both health and social care services – the Healthcare Commission and CSCI.

This last point raises important questions about the role of regulation with regard to health and social care – as distinct from the regulation of business, industry and commerce. Over the last few years, government has been concerned to lift the ‘burden’ of regulation from all these sectors and has included health and care in this. We think that health and social care is substantively different from the other sectors. The first priority in the regulation of these latter two sectors must be the protection of the vulnerable people who use the services rather than reducing ‘red tape’. This fits very well into a human rights framework. Pulling back from regulation does not. We urge the Joint Committee to consider and take account of this view.

Dr Gillian Dalley
Chief Executive
R&RA
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