Joint Committee on Human Rights (JCHR) Inquiry: Protecting Human Rights in care settings

Introduction

Ealing Reclaim Social Care Action Group (ERSCAG) works to transform the social care system both locally and nationally to benefit the lives of older people and people with physical, mental or learning disabilities. In February 2020, we developed a series of case-studies of local people in receipt of social care and the problems faced,¹ and - with our experiences since - those case studies inform our responses to the four questions your Inquiry is addressing.

What issues need to be addressed in care settings?

People in care settings, like all human beings, have the right to be treated as "free and equal in dignity and rights".² Rights such as those to life & liberty, the right not to be subjected to cruel, inhuman or degrading treatment, and rights to privacy, family life, community participation, etc.³ are all essential to one's dignity. Yet people in care settings are often less able (by reason of infirmity, disability or other long-term condition) to fully assert their rights.

- An obvious concern is for those who might be 'institutionalised' inappropriately. ERSCAG
 knows of people with disabilities kept in residential care settings long after they should have
 been provided with independent accommodation (due to delays in Council provision of
 adapted housing; inertia on the part of the largely privatised residential care sector not
 wishing to 'lose' paying clients; and/or limited challenge from the disabled person/carers
 unaware of their rights).
- More generally, ERSCAG's case-studies (mainly focused on domiciliary care settings) highlight the assault on the right to independent living⁴ when (a) social care is seen as an 'add on' rather than essential; (b) vital services are cut purely on financial grounds; (c) disability related expenditures are treated as a matter for 'negotiation'; and (d) those in receipt of care packages (and any carers) are not engaged in the 'collaborative and appropriate' manner required by the Care Act 2014. Individuals report poignantly the human distress, and lack of dignity caused by some of these practices.⁵

How effective are providers at respecting human rights of people under their care?

ERSCAG has little direct knowledge about the *privately run residential care sector* but, in studying extensive media coverage during covid, wonders to what extent residential care providers are aware of the human rights framework within which they (and their staff) are expected to operate? ERSCAG believes that care staff (both residential and domiciliary) are often poorly paid and/or trained, and so the extent to which they are helped understand their own human rights or those of people in their charge, is also questionable. In *local authority provision*, ERSCAG has raised issues of consultation and human rights training (specifically disability equality). The British Institute for Human Rights is now carrying out a study about government consultative processes, and provides advice to local Councils, but ERSCAG is unaware of the extent to which such resources are routinely used by local authorities.

 $^{^{1}}$ Attached as Appendix One: Social Care System in Crisis – the human story in Ealing, February 2020

² Article 1 of the Universal Declaration of Human Rights (UDHR)

³ See for example Articles 3, 5, 12, 18, 25 and 27 of the UDHR

⁴ Set out in detail in Article 19 of the UN Convention of the Rights of People with Disabilities (UNCRPD)

⁵ Appendix Two is a short personal testimony highlighting the human rights implications of failings in a mother's care arrangements

How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

The review of complaints by the Local Government and Social Care Ombudsman (September 2021) is informative about many problems in social care, but it is not clear that the Ombudsman considers that their Office should address the human rights framework in their regulatory efforts? ERSCAG has separately made a submission⁶ to the current inquiry into complaints being carried out by the Equality and Human Rights Commission. We conclude: "it would be particularly important to understand and better advertise the independent complaint systems that are available to people.it is difficult to conceive of a situation where people will find it easy to pursue formal complaints as long as they feel 'dependent' on the goodwill of the Local Authority to cater to their social care needs. Yet without a willingness to pursue formal complaints, much-needed changes in Local Authority practices and procedures may not be openly discussed and addressed". Indeed, even when complaints are brought to court and are upheld,⁷ it is difficult for local activists to monitor implementation.⁸

What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in future?

Firstly, all emergency legislation must be temporary and time-limited in nature. Our rights as citizens were extensively curtailed during the various lockdowns – and however justifiable - emergency provisions must always be carefully scrutinised by parliamentary and other bodies to avoid the 'routinisation' of extraordinary measures.

Secondly, communication is vital. In a Review of Covid Learning, ERSCAG commended the efforts made to communicate effectively with people in different social care settings — and requiring different communication methods - and also made a number of recommendations for improvements. Concerns about communicating effectively and in a timely fashion with people of different disabilities, ages, and ethnicities go to the heart of treating everyone with dignity and respect.

Thirdly, in the same Review, ERSCAG found that there was "a need for a clearer division of responsibilities and/or better coordination between national and local government decision making; clearer division of responsibilities and/or better coordination between the NHS/local Council's public health services; and better, and more timely, disaggregated and localised data". In Ealing - local knowledge and language skills, the deployment of strong community and faith networks, and excellent working relations between Council staff/the NHS/and the private care sector proved crucial to the public health response. Many positive measures were introduced (eg emergency contact numbers, PPE supplies, priority shopping options) – but for some people dependent on social care provision, many of these improvements should be put on a permanent basis. Moreover, the more localised the response, the more likely it is to be adapted to real needs. This in turn also allows for more effective local scrutiny, which is surely in the interests of the human rights of social care users.

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⁶ Appendix Three: ERSCAG submission to EHRC Social Care Inquiry, evidence gathering session with Inclusion London, September 2021

⁷ See SH v Norfolk County Council (2020) EWHC 3436 (Admin)

⁸ Cuts to the funding of advocacy groups and legal aid have reduced local scrutiny options

⁹ Appendix Four: Updated Review of Covid Learning, July 2021, ERSCAG