

Lifting the veil: Removing the invisibility of adult social care

Submission by Ealing Reclaim Social Care Action Group (ERSCAG) to
House of Lords Adult Social Care Committee
May 2022

Ealing Reclaim Social Care Action Group (ERSCAG) is a small voluntary group working on Adult Social Care (ASC) in the London Borough of Ealing. We welcome the Inquiry established by the House of Lords ASC Committee into the invisibility of social care, particularly because we believe that it is the very ‘entrenched invisibility’ that your Call for Evidence alludes to, that delays remedial action being taken. We enclose in Appendix testimony from the ‘experts by experience’ that you wanted to hear from and we explore here some of the causes and consequences of the invisibility of Adult Social Care, as well as the positive changes needed.

Causes of the invisibility of adult social care

Adult social care is largely invisible to the public and policy makers because of factors such as:

- a. Many people in receipt of ASC are elderly and/or face significant mental or physical health challenges which requires most, if not all, of their attention to manage. This often leaves them with limited resources for advocacy or policy engagement beyond trying to cater to their own immediate needs.
- b. There are national and local campaign groups available to help those in receipt of ASC, but often they focus on specific aspects of the field - the needs of carers or care-workers, or the rights of elderly or disabled people, etc. Adult Social Care *per se*, is a vast field with few support groups working across all the needs of ASC users.
- c. The organisation of ASC provision in England is highly fragmented, largely privatised, and sometimes amounts to a ‘postcode lottery’ regarding Local Authority funding. The assessment process is difficult to navigate (see Appendix for personal testimonies) and the level of unmet need is great, but hard to quantify (see <https://www.adass.org.uk/waiting-for-care-adass-report-may-2022>)
- d. It has been described as the ‘Cinderella service’,¹ historically dependent on resourcing from personal, family, and charitable rather than statutory resources. Indeed, for much of our history, society ‘preferred’ institutionalisation or segregation of disabled people (especially those with mental or learning disabilities), so that care was provided far from support networks, and (deliberately?) away from public gaze.
- e. People often like to keep their personal care needs discrete. In social settings, and in a desire for autonomy, independence and personal dignity, Personal Assistants (PAs) may be asked to avoid drawing attention to themselves or the help provided for their clients. Social care users may – for entirely understandable reasons – ‘collude’ in rendering invisible the importance of the social care or support they receive.
- f. People only start to ‘see’ Adult Social Care when they need it (for themselves or family members) and this is exactly the time when they may be least able to negotiate its confusing maze-like systems. By the time of adulthood, most people

¹ See for example publication entitled “Goodbye Cinderella” from the National Pensioners Convention (May 2020)

have used, and know how to access, public services such as schools or the health system, but ASC is nearly always provided in non-public buildings – in one’s own home, in residential homes, or in specialist centres such as day care settings etc. As such, the provision of such services is largely hidden from, and unknown to, the general public, their elected representatives, or the media.

The experience of Covid also highlighted that this cohort of the population is indeed normally quite invisible, and it was only once some of the important oversights in their care came to public attention that their needs began to be addressed. Even then, ERSCAG would argue that it was largely the sector of those in residential care that were being addressed, not those in receipt of domiciliary care, or day-care provision.

Consequences of invisibility

The main problem with the ‘invisibility’ of the issue of Adult Social Care is that there is no concerted campaign by current or potential future stakeholders for improvements, and political parties tend to go for ‘short term fixes’.² There is a hesitation in moving from the current arrangements to a system which allows people to live the lives they want, rather than merely ‘survive’ with limited choice or control. The organisation of ASC needs to be radically overhauled. The current move towards greater integration of health and social care – whilst in some senses well-intended – may mean that the needs of ASC provision are made subservient to the needs of the NHS. Without a bespoke system of Adult Social Care provision, integration may in fact only render ASC even more invisible in future.

Funding is vital.³ Currently, the main funding for ASC is covered either privately or by an array of Local Authorities, whose potential for good policy making are increasingly constrained. The situation is in crisis now. In the future, it might only get worse with the numbers needing social care likely to be on the rise; the number of unpaid carers on the decrease (with smaller and/or geographically dispersed families and friends); and the costs of social care increasing at a time of inflation, cost-of-living crisis, and workforce shortages.

Positive changes to be made to challenge the invisibility of Adult Social Care

1. ERSCAG believes that a **National Care Support and Independent Living Service** (NaCSILS) should complement the National Health Service. Such a service would be publicly funded; free at the point of use; nationally mandated; designed and delivered locally; produced with service users and democratically accountable; underpinned by staff whose pay and conditions reflect their true value and skills; framed to meet the needs of unpaid carers; and informed by a task force on Independent Living. Like the ‘venerated’ NHS, NaCSILS would give a recognisable

² ERSCAG fears that measures by government, whilst claiming to address long term needs, are aimed merely at short term concerns (eg around capping residential care costs) – see for example, most recently [People at the Heart of Care: adult social care reform ...](#)

³ This paper has not engaged with the broader need for funding etc. but would refer the Inquiry to [House of Lords Economic Affairs Committee: Social Care Funding – Time to end a national scandal \(June 2019\)](#), and excellent research regularly carried out by specialist think-tanks like the Kings Fund (www.kingsfund.org.uk), the much-earlier Dilnot Review, and <https://www.centreforwelfarereform.org/.../fully-funded-social-care.pdf>

profile to the needs of those within society who require social care, and it would ensure that the organisation, oversight, funding, and service provision of Adult Social Care responds to the real needs of service users (see www.nacils.co.uk)

2. **For social care users**, ERSCAG believes that an efficient system of ASC would:
 - a. Promote the concept of Independent Living
 - b. Ensure the rights of ASC users are safeguarded
 - c. Render visible, and more accessible, the nature of the services needed
 - d. Promote the concept of co-production

In particular, the concept of ASC being ‘free at the point of need’ would put medical and social care on the same footing. This would remove the indignity, fear, and stigma often attached to the system of people being financially assessed and charged for their care needs (see appendix).

3. **Paid carers** need to be given greater respect for their important work – this can be done by way of improved working conditions (including pay), training opportunities, good recruitment, accreditation and support systems. Currently the reality is that most carers are poorly paid: this reality both arises from, and contributes to, the lack of respect shown carers, and the invisibility of the sector as a whole. The Inquiry will presumably be hearing from experts in the field – care managers, trade union reps etc. – and ERSCAG would urge that their practical proposals be listened to carefully.
4. **Unpaid carers** need to be supported in their efforts. They must not be seen as an alternative to paid workers but an adjunct who should be recognised and supported. They need respite care; they need to be informed of their rights (to carers assessments, emergency contact systems etc); and they need signposting help to the appropriate care arrangements for the person/s they are assisting. Much more coordination of efforts could be made between Councils/the NHS/GP surgeries etc. to signpost these carers to useful resources. Again, groups like Carers UK (www.carersuk.org), the Carers Trust (www.carers.org), and other such groups which specialise in this field will have practical and detailed policy proposals for the Inquiry.
5. **Learning from covid:** ERSCAG carried out a study⁴ of the local learning from Covid, and we concluded the following:
 - a. The rapid discharge of patients from the NHS to local care homes was in large part due to initial decisions made to ‘protect the NHS’ with insufficient consideration given to the consequences for the ASC sector. We fear that there is a risk of this problem recurring again with the ‘discharge to assess’ provisions made in the recent Health and Social Care Act.
 - b. Many new systems for coordination, quality control, and improved communications established between Local Authorities/GPs/care homes/NHS services/care agencies etc. to address urgent common problem should be maintained on a permanent basis. Some crisis support systems and signposting efforts for social care users/carers/PAs should also be

⁴ Review of Learning post-covid in Ealing (August 2020); and updated version in July 2021, by ERSCAG.

maintained. Failings in some administrative systems need improvement: are all carers recorded as such on GP records? are there mechanisms for communicating simultaneously with *all* Direct Payment users? how do we more effectively record and respond to specific needs (eg housebound unable to access vaccination centres, or the communication needs of deafblind clients etc)?

- c. The workforce is predominantly female, often non-white, and themselves vulnerable to illness, but there is limited slack in the system to reduce the movement of staff between different homes or reduce their need to have multiple jobs. The lack of pay for travel time and the introduction locally of Low Traffic Neighbourhoods (without any adaptation for disability access or ASC needs) even led to the cancellation of some ASC home visits.
- d. Daycare provision was changed to cater to the new situation, but this has left some long-term problems for providers that need to be addressed.

6. General:

- a. Any move to render more visible the provision of ASC must be pursued on a **rights basis**, respecting the autonomy and dignity of all involved, in which regard the UNCRPD and the UN Principles for Older People would be of assistance.⁵ The British Institute for Human Rights provides some very useful training and guidance to the public sector regarding a rights based approach to, amongst other issues, health and social care (www.bihhr.org.uk).
- b. There would be a value in a **public education campaign to promote a better understanding of social care**.⁶ Many members of the public assume that social care users are all elderly and are unaware of the 1/3 of social care users who are of working age with a disability. The same general public is aware of the existence of residential social care, but unaware that much care is provided in people's homes and is costly. Yet at the same time, those same members of the public are paying taxes and rates into a poor system of provision – they deserve to be better informed about how their money is being used, and to be assured that it is being used as effectively as possible. Their elected representatives cannot make appropriate policy decisions without understanding the field better. The media needs to be informed of, and report on, developments in the field to hold local and national politicians to account.
- c. The same, or a complementary, **public education campaign should promote the important and valuable work undertaken by carers**.⁷ Social care work needs to have its profile raised so that the general public (and potential recruits) realise that the work is valued and requires a complex range of skills.

⁵ See www.un.org/disabilities/documents/convention/convoptprot-e.pdf and [United Nations Principles for Older Persons | OHCHR](#) and specific reports such as the Council of Europe's Human Rights Commissioner report dated 21 April 2022 - [Addressing the invisibility of women and girls with disabilities](#)

⁶ See #socialcarefuture for further discussion

⁷ The Times (3 May 2022) reported that many "would prefer a supermarket job to the low paid care sector".

Carework is not necessarily about educational qualifications, but it does require common sense, good English/communication skills, thoughtfulness, commitment and excellent inter-personal and social skills. Potential carers and rates/tax-payers need also to be made aware of how much good, well-paid and respected social care can contribute to local economies.

- d. If anything, the move to new arrangements around health – with Integrated Care Partnerships/Integrated Care Systems etc. – have rendered even more convoluted the democratic controls that exist. It is next to impossible for care-users, or their supporters, to influence these mega-bodies. At the local level, ERSCAG can see that the representation of the care-user is diminishing in favour of ever more specialist ‘representative’ bodies like Healthwatch etc. **Only with service-users in representative roles will the needs of users become more visible and bring about the changes required.**
- e. At the same time, there are many groups who work closely with service users and which are in a position to effectively advocate with and for service users at the policy level. Yet these same groups are having their funds cut and are having to focus on service provision rather than advocacy. Covid has created new problems for the provision of adequate daycare services, and Councils are reducing their support for accessible venues etc. crucial for people with disabilities to socialise and organise. **Less advocacy means less visibility.**
- f. Until such time as the overall funding of social care is remedied by way of national policies, **Local Authorities must accord more political priority to the needs of Adult Social Care.** One Authority in London (the Borough of Hammersmith and Fulham) chose to prioritise ASC and no longer charges its residents for non-residential social care. Other Councils could similarly decide to prioritise social care in their budgetary decisions, but they have not.

Indeed, the fact that few Local Authorities have ended charging for domiciliary care, or made co-production central to their service provision, is the best proof the Committee needs of the invisibility of social care.

If the needs of this sector were more visible, and proponents of proper funding and organisation were also more visible, ERSCAG has no doubt that some of the necessary change would already be underway across the country.

**Maggie Beirne, Secretary, on behalf of:
Ealing Reclaim Social Care Action Group (ERSCAG)
May 2022**

Appendix with examples of 'lived experience'

Selected extracts from "Social Care System in Crisis: the human story in Ealing" ERSCAG, February 2020

From Introduction: "Most Ealing residents know little about 'social care'. They know that if their health ever breaks down, they can go to their local doctor and access the NHS to get the diagnosis and treatment required. No-one will assess whether or not they can afford that medical treatment.....The confusing division of labour between the NHS and local Council budgets; the pressure on local Councils to reduce expenditures; and the impact that this is having on residents in the Borough of Ealing is largely an invisible or hidden problem".

Case Study Three (interview October 2019): "It is difficult to be told that you have an 'expensive' care package – it makes you feel very vulnerable.....staff give the impression that they like to report a need is being 'well managed', but from the client's perspective the good management of need does not mean that there is no need, and no action is required....(it should be) what is needed to maintain that situation?"

Case Study Four (interview November 2019) "So far, the threat (of cutting my care package) has not been carried out, but I am still living in fear.....I am currently in confusion about how my package works out and I am disinclined to discuss with Social Services in case they start again on a plan to cut my package"

Case Study Five (written testimony submitted February 2020): "Without warning or reassessment, a staff member declared that because X's care was costing more for the Council than putting her in a care home, her care had to be cut back by 7 hours.....Vulnerable people who do not know their rights under the Care Act 2014 are being misled into thinking cuts are legal and unavoidable".

Case Study Eight (testimony from March 2019 & January 2020):....."My care was to be cut by two thirds. It was too awful to contemplate. I had no support from (local group) because its advocacy funding had been cut by the Council....I am still feeling anxious and depressed at the uncertainty of my situation and find it very difficult to make plans about my care, such as recruiting new carers, if I am not able to continue paying them should my funding cease".

Case Study Twelve (testimony from assistant for people both deaf and blind, January 2020): "I am sorry but I have spent so much time and energy on trying to get support in place for (my client) that I have not had the time to collate all the information for you but here are a few comments.....Social Services operate in a way that is very blatantly against the law and it leaves my client at risk.....There are also some practical issues of neglect to sort out, because he has been ignored by Social Services for so many years, despite charity workers trying to help and alerting Social Services. The usual arrangements are not enough to keep my client well or safe....he has 11 hour support gained after an 18month fight....".