

EHRC Social Care Inquiry – evidence gathering session with Inclusion London members 29 September 1-2pm

What people know about their rights – to social care, to challenge and to advocacy – and how do they know?

In February 2020 (prior to covid) Ealing Reclaim Social Care Action Group (ERSCAG) produced a series of some dozen local case-studies about people's experiences of social care (Social Care System in crisis: the human story in Ealing). It is clear from even a cursory review of these case-studies (attached) that people know relatively little about their rights or how to effectively challenge care decisions. The following paper draws on some of those specifics.

In purely statistical terms, our Local Council (London Borough of Ealing) reported "Twenty formal complaints received about charging" (for year 2017/2018); "0" for 2018/2019.; and 14 for 2019/2020. The last statistics were only received at the time of writing, and we have not yet received any information about the situation in 2020/2021.

What are the main types of decisions that people want to challenge?

ERSCAG is aware of people wanting to challenge issues such as:

- **The assessment process itself:** are all needs (beyond the basic ones of washing and eating) effectively considered (see case study six); are staff trained properly in assessing different kinds of needs (see case-study 12); the very strong sense that assessments are primarily driven by financial considerations (several inc. case study 3) ; the fear that a request for re-assessments, even when health has deteriorated, will lead to either a diminution of care/increase in costs (several); the fear of humiliating or demeaning experiences or the lived reality of not being listened to (several); the issue of negotiating opaque bureaucracies (case study 10) etc. Recently, ERSCAG learnt that there is meant to be a note in every user's file about their "preferred means of communication" but this does not seem to be regularly referred to by all Council staff, leading to frequent problems of mis-, poor, or failed communications.
- **The financial assessment process:** what sums are taken into account; what items are disregarded; the handling of increases in charges and any debts that arise; updating of costs (such as annual increments); the apparent complexity of some of the forms to be filled out; the very fact that the assessment process is tied into financial decision making which distorts the whole process and makes the Local Authority both judge and jury. One Direct Payment user (see case study 8) has written to say that the Council has a cap of £30pw towards wheelchair costs, whereas the rental costs for her adapted chair is £189 a month, and she fears that these shortfalls that have built up will be treated as debt, and clawed back from sale of her home (despite the needs of her daughters who currently live with her and help with care). The same user has not had a holiday for four years since she needs two carers and is not allowed to claim expenses for the PAs when on holiday. Another Direct Payment user reported that her required contribution jumped from £150 a month to £550 a month at one assessment.

Specifically on complaints processes, one person said in a recent email "*No, I didn't complain to the Council, there seemed no point*". In yet another case, a Direct Payment user had her care agency

changed (presumably to save money) and friends now report that her previous interest in socialising and IT connection with others is not being catered to, leaving her extremely isolated. While respecting the person's confidentiality, how do others pursue this concern, and who do they complain to if appropriate? Case study 9 has a carer reporting that she is not claiming Carers Allowance on the grounds that "*the small amount would not help and claiming would be too stressful*".

How accessible and effective are processes for challenging?

The case studies suggest that people do not know who to contact to challenge decisions and, for the most part, have not accessed such processes. Some went to their locally elected Councillors (and/or the Council Leader), others to other staff teams, and one mentions a formal complaint to 'Social Services' but this did not resolve the problem. Some users also refer to the reduction of support for advocacy groups (locally), and the cutting of legal aid (nationally), as disincentives for pursuing formal complaints. In retrospect, ERSCAG's conclusion in the case-study paper (p13) may also be off-putting in that we refer to complaints and legal action as a "last resort". Given how few people report using the formal complaints process, it might have been more appropriate for us to encourage people to actively challenge decisions that they believe to be unfair?

What support is available to challenge effectively?

Our local Council has produced two useful documents relating to Direct Payments "Independence, Choice & Well Being: Your Guide to Direct Payments" and "Determining your financial contribution: information for all adult social care customers in Ealing" (the latter dated April 2019). However, on checking what they say about complaints, the former merely offers "*the department's Customer Care Team*" with an email address (complaints_adults_services@ealing.gov.uk) and telephone/postal address. The Financial Circumstances document notes "*If you are dissatisfied with the Income Manager's review of your assessed charge, you can make a formal complaint. The response letter to your appeal will have details of the complaints procedure*". These do not seem adequate routes given some of the fear that many users have of the whole assessment process.

Who does and doesn't challenge and why?

The case studies suggest that people who have been long involved in disability rights work are more likely to seek possible remedies. It may be that people whose need for care arises fairly suddenly, or who are seeking social care provision for others (perhaps older family members and/or neighbours) are less aware of the options available? Several case studies definitely imply that most people are afraid to 'put their head above the parapet' to seek assessments/re-assessments, still less start a formal complaint process, as they fear that this might leave them in a worse situation than they are already.

What are the impacts on people wanting to challenge – good and bad?

Nothing special to add but see several of the case studies which highlight the serious emotional and other problems created for people who are unhappy about their situation and unable to get their problems addressed effectively.

How are Deaf and Disabled Peoples Organisations using insight to influence and improve local authority processes?

This answer should be prefaced by the comment that ERSCAG is not a DDPO, though our focus on social care means that many of our supporters are people with disabilities.

We try to assist people in receipt of social care in two ways. Firstly, we draw social care users together regularly (in person/virtually and by way of newsletters) to exchange information, develop shared agendas and show solidarity with each other. Indeed, we know of at least one of our members who responded to the EHRC online form because we publicised its existence in our July newsletter. Secondly, we try to improve local authority processes by drawing problems to their attention (eg developing the attached case-study paper) and by attending relevant Council meetings on a regular basis. However, we are not convinced that these efforts are always seen – as intended – as helpful interventions. There is rarely a sense that Council staff or elected Councillors reach out to get this kind of feedback from their users, or at least, not with a view to reviewing or changing their practices.

To give a very practical example: we asked the Council some time ago about the extent of “unmet need” in our Local Authority area. Senior staff replied by pointing out that all Councils are obliged by law to meet all “eligible need” and therefore there is no monitoring of “unmet” need. The answer implies that no-one in the Council is checking what is not being done properly, on the grounds that if they found any unmet need they would be opening themselves up to legal challenge. This question, and worrying answer, has been raised with elected Councillors to little effect.

The existence of this EHRC inquiry has alerted us to the fact that ERSCAG should become more aware of the complaints mechanisms that exist and publicise them more. Currently we use our monthly newsletter to alert people to independent legal centres/advice centres of assistance but could be doing more to publicise formal complaints systems too.

What changes would most people most like to see on this issue?

We think that social care needs to be radically reformed and, as a minimum, social care needs to be free at the point of need which would remove many of the problems created by the financial assessment process. Social care users and their Local Authority need to be able to benefit from a mutually supportive relationship, but this is difficult to secure when funding is an integral part of the relationship. See case study 3 for reference to “*the feeling of pressure has diminished*” when her funding arrangements moved from Local Authority to NHS arrangements.

Specifically, on complaints, there needs to be more information about the complaints processes available to people. It would be particularly important to understand and better advertise the INDEPENDENT complaint systems that are available to people.

At the same time, 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.

**Ealing Reclaim Social Care Action Group
27 September 2021
For more info, contact ERCAG Secretary**