



SOCIAL CARE SYSTEM IN CRISIS

The human story in Ealing

Ealing Reclaim Social Care Action Group (ERSCAG) has brought together a series of anonymised case-studies (of real people living in the Borough of Ealing) which highlights a very wide range of problems that need to be addressed urgently by Ealing Council.

“After a jump of 45% in my social care costs, I am running into debt”

“My husband with dementia has had to be admitted to full time residential care but this could have been avoided with affordable & good daycare provision and some carer support”

“I sense staff are concentrating primarily on cutting costs, and it makes me feel very vulnerable”

“I am 28 years old; I was told I could use pads rather than have carers visit to help with my transfer to the loo”

We are told that the social care system is in crisis: what does this mean in human terms in Ealing?

Most Ealing residents know little about 'social care'. They may not know much about medical care either, but they do 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. Our taxation system means that everyone contributes (according to their ability) to ensure that everyone gets the medical treatment they need, and that it is free for the person concerned. The same is not true for social care.

"Social care" is care provided by local Councils to promote people's well-being and facilitate their control over their day to day lives. For example, you or other family members may be quite elderly and in need of support (one of the case-studies here refers to a woman of 103). Maybe you look after someone suffering from dementia and unable to be left alone safely? Alternatively, you might be a young disabled person and need support with basic tasks in order to pursue independent living and feeding, toileting, or dressing? Maybe you are a full-time family carer for someone who needs companionship and support but feel that your health is at risk because of the responsibilities you have taken on for a loved one? If you fit into any of these categories, you can - by law - ask the Council to assess your care needs, but your financial circumstances will determine what support will be provided. Councils have had their budgets decimated in recent years and, despite the good intentions of Council staff, people's well-being, physical and mental, is being seriously compromised.

The confusing division of labour between the NHS and local Council budgets; the pressure on local Councils to reduce their expenditures; and the impact that this is having on residents in the Borough of Ealing is largely an invisible, or hidden, problem. Ealing Reclaim Social Care Action Group (ERSCAG) has brought together a series of anonymised case-studies (of real people living in the Borough of Ealing) which highlights a very wide range of problems that need to be addressed urgently by Ealing Council. These case-histories were gathered together between the end of October 2019 and January 2020; they are therefore current as of early February 2020. Some reflect past experiences, some are being actively pursued with the Council at the time of writing; some are written in the 1st person, others are summarised from interviews carried out by ERSCAG. ERSCAG is not in a position to verify all the claims made, but we believe that they raise concerns which merit careful study by decision makers in Ealing. Moreover, we cannot claim that the case-studies provide a comprehensive picture of all the problems facing the provision of social care in Ealing, but ERSCAG believes that, in combination, they reflect a wide variety of the challenges faced.

At the end of this report, Ealing Reclaim Social Care Action Group brings together some of the conclusions we draw from these human stories, and what we intend to campaign on in coming months and years.

Case Study One – extracts from letter to local Councillor on 24 November 2019

“I fail to see why I should have to live with the anxiety and confusion that this situation causes me”.

“The concern I have is about charging as I find the charge is going up and I am running into debt. I am basically very confused and do not understand the calculations. I appear to be paying much more than somebody who I know who gets the same income as myself. Also my disability related expenses are not being taken into account. I have to pay about £500 a month and this is too much from my income of £1,371 per 4 weeks. The charge was £344 until last year.¹ I received no notification of the increase to £499 and now it seems I am in arrears. This charge is too high and now I simply cannot make ends meet. I am experiencing a great deal of anxiety about this situation and I hope you can help me get to the bottom of what is happening to me. All in all, I fail to see why I should have to live with the anxiety and confusion that this situation causes me. A further issue is my need to give my workers a pay rise. Ealing Reclaim Social Care Action Group has raised the issue of the need to pay the London Living Wage to all support workers. We need to get a successful outcome with this soon, or disabled people will be unable to retain or recruit workers. This is simply not acceptable and is also a considerable anomaly given that Ealing is vocal in its policy of championing the London Living Wage.”

Case Study Two: ERSCAG interview dated 13th November 2019

A family struggling with multiple disabilities, carer fatigue and high care charges with no clear solutions being offered.

A 79 year old man who uses a wheelchair due to left leg amputee has memory problems/dementia; and his wife provides all his personal care, as well as all cooking, shopping and cleaning. The only support they received was his attendance at the Michael Flanders Centre 3 days a week but this they cancelled in October due to increased charges (charges of £163 per week or £652 per month). A new financial assessment has been completed but the family have been awaiting details of new charges for several weeks (note: they receive Housing Benefit). No services have been received for over 4 weeks and no sitting service or other respite care offer has been made for the wife, even though he could not be left alone as he had gone wandering previously.²

Case Study Three: ERSCAG interview dated 31 October 2019

“It is difficult to be told that you have an ‘expensive’ care package – it makes you feel very vulnerable. The impression is that social care staff are looking to make cuts”

¹ This amounts to a 45% increase in one year.

² Since the interview, the person concerned has been admitted to residential care. Whilst the family thinks that this is the ‘least-worst’ option, they also believe it was avoidable if preventive action had been taken earlier.

The interviewee believes that the assessment process is problematic. For example:

- Staff give the impression that they like to report that a need is being “well managed” and there is an implication that this means ‘all is well’. However, from the client’s perspective, the good management of need does not mean that there is no need and therefore no action is required by them - the need is still there. On the contrary, the assessment should address how it is being well managed and what is needed to maintain that situation.
- It is difficult as a client to be told by staff that you have an ‘expensive’ care package – it makes you feel very vulnerable.
- The impression is that social care staff are looking to make cuts and are also eager to note what care is being provided by family and informal carers if that can help lessen the need for Council support.
- Having reached the criteria to be moved from Council to Clinical Commissioning Group (ie from the Council budget to NHS budgets) responsibility in terms of a “continuing healthcare need” status, the feeling of pressure has diminished, but there is an abiding sense that this is a matter of negotiating over costs between the two budget holders, rather than a response to her situation as such.
- Sometimes the assessment visits are organised at short notice, and occasionally this gives the client the impression of the staff being ‘sneaky’. Are staff distrustful of the clients they are assessing: they sometimes give the impression that they are trying to catch out the client/family?

Case Study Four: Letter to Cllr Rai dated 24 November 2019

“So far, the threat (of cutting my care package) has not been carried out, but I am still living in fear.”

“Briefly, I have had two very frightening recent experiences with social services. I am a wheelchair user with 24-hour support needs. However, I am not in receipt of support for the full 24 hours, and I increasingly need the 3 ½ hours that I am missing. I was reassessed last November for this and during the reassessment interview was told, I would not get any extra funding, but I would actually lose a substantial chunk of my daytime hours, and also lose the extra cover I am given for a holiday. Given that I was, and still am, in serious need of increased cover, this threat seemed to me the most astonishing turn of events and I was seriously shaken. So far, the threat has not been carried out, but I am still living in fear.

Another experience I had was in 2017 when social services, without warning, or explanation, withheld a chunk of, about £3000, which I owed to my workers. Again, this caused huge worry. I got the money back after fighting the decision for about 6 months.

I am currently in confusion about how my Package works out and **I am disinclined to discuss this with Social Services in case they start again on a plan to cut my Package**. I am in the fortunate position of having an accountant friend who is helping me understand the finances of my package. The information sent out by LBE is impossible to interpret without some finance experience. All in all, I fail to see why I should have to live with the anxiety and uncertainty that this situation causes me.

Finally, I need to give my workers a pay rise. The issue of London Living Wage being payable to all support workers, has been raised by ERSCAG at a recent meeting with the Council. I already pay my workers £10.50, so this would not help me much, but the shortfall obviously increases each year. Disabled people need to be able to give pay rises to our workers when appropriate, or we will find it increasingly difficult/impossible to retain or recruit loyal high calibre workers. I have received no

increase in the rate I can pay support workers since my current package began in 2014. This is simply not acceptable and is also a considerable anomaly given that Ealing is vocal in its policy of championing the London Living Wage.”³

Case Study Five: – testimony submitted in writing to ERSCAG email dated 13 February 2020
“Under the Care Act 2014, the fact that a local authority has financial problems or is using a Resource Allocation System (RAS) is not a lawful reason to cut care”

The Care Act of 2014 requires that local authorities promote the wellbeing of adults in need and carers, and to do this in a way that satisfies underpinning principles – these include 1) the assumption that the individual (and/or their representative) is best placed to judge their wellbeing and 2) the duty to promote their control over their day to day life, including over the care and support that they receive (As detailed in section 1 Care Act 2014 and sections 2,6, and 7 of the Social Services and Well-Being Act 2014). Under the Care Act 2014 - the fact that a local authority has financial problems or is using a Resource Allocation System (RAS) is not a lawful reason to cut care.

Mrs S’s previous assessments were carried out in line with The Care Act 2014 in a “*collaborative and appropriate way*” together with her daughter and paid carers. They concluded that “*overall the existing package of care is working well and meeting the needs of Mrs S.*” The teams agreed the following categorically: “*Due to the advancement of her dementia and restricted mobility, Mrs S. requires 24 hour care and supervision to sustain her health, care, and safety in her community home and to achieve her “wellbeing and quality of life” as defined by the CARE ACT 2014.*”

The recent meeting in early November arranged to cut Mrs S. care hours could not have been in starker contrast to previous person centred and collaborative assessments. **Without warning or reassessment, a staff member declared that because Mrs S’s care was costing more for the Council than putting her in a care home, her care package had to be cut back by 7 hours.** This was determined beforehand and proposed by someone who had never met Mrs S. These cuts were not put in writing before or even at the meeting and were based not on any change in my mother’s proven needs, but, solely on the council’s financial needs.

Previous care plans had not been read,⁴ for example, it was suggested that Mrs S. could attend a day care centre if carer provision was cut. The conclusion of the 2016 assessment was “*Mrs S. was unable to make use of necessary facilities or services in the local community as she has limited mobility and is unable to participate in communal activities*”. Mrs S. is now 103 years old, she cannot walk and has hoisted transfers, has impaired hearing and vision and her skin is increasingly fragile. She has not been in any transport in the past 5 years as the last time she used it to go to hospital day appointments in 2014 - she was terrified, violently sick and had diarrhoea.

Her needs have increased with age and not decreased. **Mrs S. has not been left alone in the house in the past 16 years.** To do so now, at the age of 103 and with her advanced dementia would be nothing less than cruel and neglectful. Mrs S. is as limited in her ability to be left alone as an infant, for whom it is illegal to be left alone at home.

³ Since the date of this letter, the person concerned has been notified (11.12.19) that she will be re- assessed but is worried that this is not necessarily going to end positively for her.

⁴ This complaint about over-stretched workers, or a constant change in personnel, leading to people not being aware of previously-agreed care plans is something that others have noted also.

Her day to day care plan has been developed over many years. It stresses, for example, the need to take vigilant preventative action to protect her increasingly frail skin. This means that she requires regular use of the commode at least 4 times a day and a pad change and if necessary a change of clothes. To prevent urine infections she requires regular hydration and is patiently given a drink five times a day. Her eating and drinking cannot be completed in a stressful 30 minutes, and would represent a damaging change in routine for her.

All agencies compliment the well-established and evolved system of care that Mrs S. has, to meet her needs, after 21 years with dementia. She has a team of experienced carers who have been working together for some years and who make her feel safe and protected, clean and comfortable and who, most importantly she is familiar with and are a key to maintaining her emotional and physical wellbeing.

They have stayed at Mrs S's, over the years, despite the lack of the *updated* London Living Wage (still not forthcoming from Ealing Council since 2017/18 despite numerous requests) and despite other much higher paid offers as carers. To destroy Mrs S's existing care plan, that they have helped to develop, and to fragment and pressurise their whole relationship with her and to reduce their hours and wages, would seriously risk losing some, if not all, of the team. This would have a disastrous impact on the care provision and well-being and put her at risk and is directly contrary the legal requirements of the Care Act of 2014.

Mrs S. pays over £990 a month towards her care package, despite being on pension credit and also incurs sole costs for those who stay in the house at night to ensure her safety and that she is not left alone at any time, day or night. She is clearly not in a position to fund the cut hours, nor should she, as they have been substantially evidenced as needed in line with the 2014 Care Act and in all previous proper assessments.

Two weeks later a following "reassessment" held with the senior social worker who had come with the original staff member, proposed a reduced cut of 3, not 7 hours, from the support plan of the hours allocated to shopping and housework. These 3 hours have, also, been integrated for years into the daily care plan to ensure that she is not left alone. If these 3 hours are cut Mrs S WILL BE LEFT ALONE, and this is contrary to her assessed needs, specifically failing her wellbeing needs under the CARE ACT 2014, as assessed in all previous assessments.

If these shopping and cleaning hours are cut, then how is Mrs S supposed to order her shopping and get her food and supplies and have her house kept clean? Her daughter is at her absolute limit with the huge amount of time spent co-ordinating and organising to fulfil Mrs S's wishes to stay at home, employing and coordinating her team of carers, maintaining the repairs to the house etc, etc. She is NOT able or willing to compensate for cuts in Mrs S's care plan and simply cannot and will not take on the full, essential responsibility of shopping and housework.

It is NOT LEGAL that she is expected to do so: *"Authorities must not assume a carer is willing or able to provide any care - including additional care arising from a reduction in a care package. IT WILL BE MALADMINISTRATION FOR SUCH A REDUCTION TO OCCUR WITHOUT ASSESSING THE CARER AND EXPLICITLY CLARIFYING (AND RECORDING) WHETHER SHE/HE IS "ABLE AND WILLING" TO PROVIDE THE ADDITIONAL CARE. (Complaint no. 15 020384 against London Borough of Bromley 7th September 2016 and see also complaint not 15 006 613 against Sheffield City Council 17th March 2016) Luke Clements – Challenging reductions in Care Services*

Mrs S. will **not** have essential shopping done and nor her housework to live in a hygienic, clean home. *"Eligible needs must be met and the support cannot be cut unless there is convincing evidence*

as to why the previous support is no longer required..... The fact that a local authority has financial problems is not a lawful reason"- Luke Clements.

This relentless agenda on cutting hours of vital care provision of those with a high level of need must be taking place across the borough, on behalf of a panel with a given mission to cut care costs in the face of disastrous government austerity policies on council funding. **Vulnerable people who do not know their rights under the Care Act 2014 are being misled into thinking these cuts are legal and unavoidable** and think they have to somehow cope with them or go into residential care.⁵ Can you imagine the distress, despair and dangers that these cuts cause to people who most need the support?

Case Study Six: ERSCAG interview dated 6 December 2019

This client believes that the council has chosen to punish her by cutting her package from 80 to 28 hours a week as she had not been the best at organising her care package

An interviewee, who has cerebral palsy and epilepsy, is an electric wheelchair user living alone. She is having serious problems with the care package she receives from Ealing Council. She is 28 and freely admits she has not been the best at organising her package in the past. She believes that the Council has chosen to punish her for this by cutting her package from 80 hours to 28 hours a week.

Her care package included hours during the day as a Direct Payment User, which the Council was calling "companionship" hours, though no reason was given for this description. The interviewee says that she didn't use this allocation very sensibly; she got ripped off by people; and was also abused by a neighbour. Hence, the Council withdrew that funding. Nevertheless, she needs this money. Without it she cannot go out at all on her own or manage to do anything indoors – such as going to the loo, cooking or getting a drink. The reason she is unable to go out alone is intercranial hyper-tension, which causes random sight loss. This condition is getting worse and she is often hospitalized with it. She also has difficulty positioning herself comfortably in her chair.

She was told by the Council that she should get help from voluntary groups for companionship and she should go for counselling. She has made it clear to the Council, that neither suggestion is useful. She is becoming increasingly frustrated and miserable at not being able to go out or get the support she needs. Previously, she also received an extra 20hrs a year for her to go to Birmingham, to maintain her relationship with her foster parents, but this has also been cut.

It seemed to the ERSCAG interviewer that the Council are taking the moral high ground because, in the past, the interviewee did not use her money efficiently, but she did, at least, get the cover she needed. She now receives all her support via short agency visits and she has a friend who gives her some cover, for which he receives Carers Allowance. However, neither of these are long-term solutions. Currently the client is working with a lawyer to get some redress on this matter: she needs her original package restored and comprehensive training on how to manage a package successfully.

Case Study Seven: Personal testimony submitted to ERSCAG dated 14 January 2020 *Detailed account of one person's experience of trying to arrange a care package*

⁵ Other case-studies here give examples of people going into residential care: while this option may be right for some people, ERSCAG would argue that this option must never be chosen because it is a 'cheaper' option than providing a more person-centred care package.

and the administrative difficulties encountered.

“I suspended my package on 23rd September 2019; I simply couldn't afford to pay £99 p/wk.

I had moved from my previous home in January 2018 and my financial situation had changed (and notified the financial services team accordingly). Before moving home, I had been paying £72.27 per week. I had already had a very difficult time getting the assessment completed in the first instance. I eventually had to see my local Councillor to expedite this. (In response to request in late May/June 2018 to complete assessment forms) the Duty Social Worker sent me the form by e-mail and I printed it out, filled it in and submitted with three months bank statements as required. I also took out Careline (following an assessment by the occupational therapist) and assured that the additional expenditure would be taken into account within my overall contribution. My contribution then went up to just over £79 per week in April 2018, and after 6 weeks I was then charged just over £58 quarterly. These changes were confusing, but I didn't worry too much as I believed I would be notified of the new contribution rate in due course. I tried to call the team numerous times for a progress update with no success, and despite leaving messages as requested by the recorded message. Throughout the time I had a package, particularly in early months after moving to my new address, when I had a new kitchen and bathroom put in, I suspended numerous calls on a daily basis for lunch, morning and evening. My contribution remained the same.

Yet by April 2019, my contribution had increased to over £99 per week and I was struggling to meet my commitments and accrued a large debt on my credit card.

I also cancelled several full weeks' care with the required notice but money was still taken as I had opted to pay by direct debit. Social Services knew of this since they would contact me whenever I cancelled a full week's care; I also know that the Care Agency did not charge for those periods. In July 2019 I was away for 3 weeks but cancelled care for 4 weeks. I'd written to Social services on a couple of occasions previously to request a change to my package because I wanted a reduction to try to save some money. I had also e-mailed the duty Social Worker on several occasions to request a review of my care package, as I felt I did not need the level of care and was unhappy with elements particularly when my usual carer was on leave. In my last message I requested a response by the time I returned from holiday. **When I returned, I still hadn't had contact from Social Services regarding a review of my package and the Financial services team had continued taking money.** My account was seriously overdrawn. I cancelled the direct debit for Care Charges to avoid incurring further bank charges.

I made a formal complaint to Social Services including the fact that I'd been charged for care I hadn't received. I then suspended my care package because I simply couldn't afford the cost which, with Careline was more than my mortgage. I have my pension, a token amount of ESA and higher rate PIP but have to pay my Mortgage, Service Charge, Council Tax, utilities, food and transport costs. I don't get help with any of these costs.

Following the complaint, I was visited by a senior social worker and we agreed a reduced package. I explained about the incorrect assessment and she requested a visit from the Community benefit team to ensure forms would be received and actioned. She contacted the Care Agency to verify the cancelled periods I had provided. I received a response to my complaint which addressed the package review but not the inaccurate or inappropriate care charges.

I was visited, eventually, on 16th December, by someone from the Community benefits team who took the details of my outgoings and income and asked for the last 3 months bank statements. She advised that I would need to provide the statements early in the following week or nothing would be

done before Christmas. I wasn't able to do this before she went off on leave for Christmas but sent them by email in early January.

However, in the meantime, I received an invoice in mid December for a negative amount which included charges for care for another 4 week period in which I had received no such care. I called the invoice team for an explanation. They couldn't tell me anything but referred me back to the assessment team. I finally managed to speak the officer who originally did the assessment and advised that I hadn't had care for the period charged. It was late afternoon on the Friday before Christmas. He was very dismissive: said he couldn't deal with the issue without reviewing my file and was about to go on holiday for Christmas and wouldn't be back until 6th January and would look into it then. I requested a call on 6th January.

I called on 6th as I had had no contact and left a message with someone who was just covering because the officer had not returned to work because of a "family emergency". He was expected back the following day. I asked for a call back on his return. Once again I didn't get a call, so called again and asked to speak to his manager. I was told his manager would call back, but no one called. I called again the next day and was told the officer had not returned to work and his manager had had a "hard day" so left early. The manager did call me back on the 8th January but at a time when I had an appointment with my mortgage lender. His message said he would call me back after 3 pm or I could call back. I called and left messages on his voicemail on Thursday and Friday but have yet to speak to anyone.

I have had no care since 23rd September, no new assessment and no refund of charges for care not received. I am writing this testimony on the 14th January: I have called every day this week and message is the same "high call volumes". No-one has returned my calls."⁶

Case-study Eight: testimony originally prepared in March 2019 and updated Jan 2020
"I am a disabled woman of 74 with Motor Neurone Disease...unable to do anything for myself. I need 24hr care ...it is now being seriously threatened"

"I am a disabled woman of 74 with Motor Neurone Disease that began with slurred speech in 1989. The illness has progressed slowly and now I am almost completely paralysed, unable to do anything for myself. I need 24hr care, which has been provided by the London Borough of Ealing for the last 20 years. However, it is now being seriously threatened.

In 2018 I was allocated a new social worker to review the care plan that has been in place, successfully, since 2016. This social worker appeared friendly, if not very experienced in independent living and arranged a series of meetings with other professionals over the summer of 2018. It was explained to me that the review was a 'holistic' view of my needs. During these meetings the OT/Physio etc seemed very helpful and there was no mention of cutting my care.

In November 2018, the social worker together with a support planner, arrived at my home and informed me that my care plan was being cut and I was being supplied with technology in place of

⁶ Given the urgency and the long-standing nature of this case, ERSCAG alerted Council staff to this testimony on 20 January; the person concerned has also reached out to Council Leader Julian Bell and, as of early February, is still awaiting action.

human carers. This amounted to a mattress turner at night and a Community Alarm system to enable me to be left on my own during the day between visits from outside carers.

This news didn't sink in for a few days: **my care was to be cut by two thirds**. It was too awful to contemplate. I had no support from the local Centre for Independent Living because its advocacy funding has been cut by the Council. I was left feeling very anxious and depressed.

By Christmas (2018) my usual good health had deteriorated so badly that I developed double pneumonia, pleurisy and sepsis and was admitted to hospital. Prior to this, I'd hardly ever had a cold, let alone a chest infection.

It has taken months to recover but, with the help of friends, I sent an appeal letter to the Council in early March requesting that they reverse the new assessment of 2018 back to the previous assessment of 2016. I have received no response from them.

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."

Postscript early 2020: "In December 2019 I was assessed for a transfer for Community Health Care funding and January 2020 I heard that I have been turned down for this. I am appealing accordingly."

Case Study Nine: Testimony from unpaid carer writing in (7th May 2019)

"Basically, we do everything for her (sister). I care for her 20 to 21 hours a day, and had to give up my highly paid, high profile, job 20 years ago to take on this responsibility."

"I am 68, my sister is 66. My sister has early onset dementia which was finally diagnosed in 2010. She is now at an advanced stage and needs constant care and supervision. She is nonverbal, partially blind and doubly incontinent. She has no self-control, or self-awareness and we have to assume she is thirsty and hungry. She has pushed me when I was cooking, swallowed random objects – such as dice, and fallen when my back was turned. Basically, we do everything for her. I care for her 20 to 21 hours a day and had to give up my highly paid, high profile job 20 years ago to take on this responsibility.

My sister lives with her husband and son. Her husband, who has depression and OCD, is in denial about his wife's illness. Her son became a young carer initially, but this badly affected his studies, so I took on the responsibility of looking after my sister.

My sister has been investigated for Huntington Disease. She jerks and shakes in her sleep, which means she could fall and injure herself. She needs 2 people every night, so I stay with her along with a paid carer. This means I do not really sleep. Basically, I am always at her house except for when I am doing my 6 hours of voluntary work a week. I need this break just to have my own life for a few hours and stay mentally stable – otherwise I would have no life. I pay two carers during this time from my own money, so that my sister is not left alone. I don't just care for her, I do all her paperwork, I am her appointee for DWP, I liaise with the GP and organise hospital appointments.

I am an unpaid carer and am not claiming the Carers Allowance. The small amount wouldn't help and claiming would be too stressful. Luckily, I had savings after quitting my job and was careful, so didn't need to claim any benefits. In 2016/17 I got help to fill in the local authority Carers Assessment form, but have yet to hear back about this. I have contacted them, and it seems they lost the 40 page form.

My sister's Care Package is now in place provided by the Clinical Commissioning Group (CCG), but after the long struggle to get it, it is now under threat. She currently gets 4 short doubled up visits during the day and 11 hours care every night. I double up with this night worker, so I get no sleep. I am then left with 9 hours per day where I am left on my own as the sole carer to look after my sister. As she now needs 1 to 1 with 2 people constantly, this is too risky for me. Therefore, I asked for an additional 35 hours a week to provide full 24 hour care, which is not asking for 2 carers 24/7, just one as I can do the doubling up myself. This would not reduce my unpaid workload - I would still be working the same hours, but with less stress, meaning, for example, that I could go to the toilet without my sister being placed in danger; it is a compromise.

On the 28th of February (2019) we had a reassessment from the CCG. This was also to discuss an increase in pay for the carers, four of which have left because they were offered better pay elsewhere. During a meeting on the 13th of March, the Social Worker said that I should not worry and that they will sort it out. In mid-April, I got an email saying they intended to slash my sister's Care Budget by 23 hours a week – from 161 a week to 138 hours. The battle is not over yet. I requested a review on the 29th April. I reiterated my request for 24/7 care and **they said that she is better off in a Care Home. However, this is simply not an appropriate solution.** Where do I go from here?"

Postscript "Since this was written, the Care Package has been adjusted. My sister now receives 2 nights double-up, but has lost the short visits in the day apart from 1 double up in the morning. In order to go out I pay for two people to work with my sister as and when during the day. This enables me to go out for about 15hrs per week. I have been so isolated in this situation I now find it very difficult to socialise with people. My sister is now deemed to be palliative and I am thinking about the future. I find it hard to imagine how I will fit in anywhere after this very long period of very intense care giving."

Case-study Ten: testimony provided by care-worker in December 2019

The value of good admin systems and the need for good carer/client relations

Elderly lady (97) partially blind and hard of hearing has visits from care workers from private care company. A care worker is booked for the same time on two consecutive days. On the first day the carer does not arrive. On the second day the carer comes and, when questioned about the previous day, she persistently attempts to persuade the client that she was there describing in detail what work she had done. A witness who was present on both occasions has confirmed that the care worker did not attend on the first day. Should there not be appropriate admin systems that protect the client from being defrauded (and made to feel as though she has dementia) and which also protect care workers from unfounded criticisms?

Case Study Eleven: testimony provided by care worker in December 2019.

The importance of good and early diagnosis of needs

Nineteen year old left special needs school where he was placed following a diagnosis of epilepsy. He was subsequently placed into special need further education. After three days the Principal of the College contacted the parent carer to ask why his severe autism was not mentioned on his application papers. This was the first time anyone has identified his autism. He was re-assessed and severe autism was confirmed. He has not returned to education. A support worker was hired and seizures become a rarity! Why was this autism not diagnosed earlier, and how much better for the

19-year old, for his family, and for the community if appropriate action had been taken much earlier?

Case-study Twelve email from assistant for people both deaf and blind (29 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 time to collate all the information for you but here are a few comments”⁷

The national charity DeafBlind UK and indeed the UK Government Website, both give clear information about the law and duties concerning Local Authorities and people who are affected by dual sensory impairments.⁸

Unfortunately, no department of Ealing Council will answer to this law and Social Services operate in a way that is very blatantly against the law and it leaves (my client) at risk. (My client) is now 64, he lives completely alone and is socially isolated, he has additional social and emotional difficulties on top of the issues which often accompany severe dual sensory loss. 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 giving alerts to Social Services.

The usual arrangements for direct payments and buying of agency hours is not enough to keep my client well or safe. He has 11 hours support, granted in June 2018, and these were gained after a 18 month fight. It was very difficult to get this reviewed, as it should be done annually. I have now finally got him a review of his hours for tomorrow. However there is no DeafBlind specialist involved.

My client also must have a coordinator for his needs, to work with Housing, Health and provide support for his mental & emotional wellbeing. He cannot leave the house alone and his Council owned home is dilapidated. Ealing Council does not do coordination, in fact communications with Ealing Council and between departments within Ealing Council are astonishingly confused and dangerously inefficient for people with vulnerabilities or urgent needs, such as my client. The Health Authority has started to explore the situation but they have difficulty getting cooperation from Ealing Council. Council workers generally fail to answer calls, messages or email. This issue is systemic and by now almost accepted as normal.

Ealing Council are happy to keep giving me extra voluntary jobs, to deal with complex issues for (my client), but will not take on board the fact that I will be retiring from support work and will not be able to volunteer anymore after this March. Social Services seem to now think that the Independent Living Alternatives agency will volunteer to do all the support that is not funded, after I have gone, yet that is not the role of an hourly paid contractor who is given funds for very specific tasks. The overall responsibility surely belongs to the Local Authority. Ealing Council never pays for anything extra - even emergency help!

Suitable housing for my client would make a huge difference to his life but Ealing Council gives low priority to single individuals with dual sensory impairments. The method of bidding and viewing also discriminates against a person with these disabilities.

⁷ ERSCAG note: This comment reflects the difficulty faced by many when trying to secure the care they need.

⁸ The link to DeafBlind UK information is at <https://deafblind.org.uk/information-advice/deafblind-assessments/understanding-your-legal-rights-the-care-act-2014/>

Concluding Remarks

Ealing Reclaim Social Care Action Group (ERSCAG) asked to hear directly about the experience of people in receipt of care, and their care-givers (paid and unpaid). As noted at the outset, we cannot guarantee the accuracy of all these accounts, but they give an insight into the lived experiences of people in receipt of social care. Ealing Council is under a legal obligation to meet all eligible assessed need yet does not appear to keep records of people who argue either that their needs have not been properly assessed, or that all their eligible needs have not been met. Several of the case-studies raise issues common to more than one person and these will be issues that ERSCAG will be campaigning around in coming weeks and months.

Charging: Several case-studies refer to the financial fears that arise at the time of assessment and/or re-assessment of care packages and the risk of cuts to care. There appears to be a general feeling that the Council wants to use assessment processes to reduce the costs of care packages, and there is a long period of uncertainty and fear facing those in need of care. There appears to be little warning of significant cost increases, and some of the case-studies refer to the risk of going into debt because of increased charges. Obviously, people are going to be extra anxious in such situations. One person complained that she has not been reimbursed for payments that had been made when the care was not provided. One case-study even talks of a sense in which the Council seems to be trying to 'catch people out': whilst the Council must check that Council taxes are being properly spent, surely this should not lead to a breakdown in trust between staff and those seeking support?

Assessment Procedures: Several case-studies refer to delays in getting an assessment or re-assessment, and financial assessments which are incomplete or not explained thoroughly to those concerned. Several also talk about the difficulties of dealing with the bureaucracy involved and nearly all comment on the complexity of completing the necessary forms, and some suggest that applicants need advice from independent financial experts. Is there enough transparency in the system; are staff adequately trained given the very different needs that require assessment (see deafblind case-study); and can anything be done to make this whole experience less demeaning and demanding?

Carers paid or unpaid: Several people raised issues regarding their paid carers – they must be paid at least the London Living Wage (in line with Ealing Council's policy for its direct employees), but Council financial assessments and Direct Payment arrangements do not take this into account. Apart from being unfair, if carers are not paid proper salaries, it will be impossible to retain them, and yet continuity of care is often an important part of care arrangements. When family and friends provide care, different problems may arise. People need to be reminded routinely of their right to request a carer's assessment; to be told what benefits are available to them; and how to ensure that their needs are reviewed alongside the needs of the person wanting support. Do they need signposting towards useful training? How do they help in providing care whilst also ensuring that the person concerned can live as independently as possible?

Advocacy: Sometimes during the process of assessment, an independent third-party advocate might be useful, as an honest broker accepted by all parties. But funding for this seems like an unattainable luxury when funds for advocacy as a whole are being reduced. Local voluntary groups are having their Council funding cut, so are having to cancel, or charge much more, for respite, day-care, and advisory services, leading to serious consequences for carers and those in receipt of care.

Institutionalisation: Clearly some people might benefit from being supported in some form of residential setting outside their own homes, but any such a decision should only be taken with the full inclusion of the disabled person in the decision making process and, ultimately, their full support. In the case of people with impaired decision making, the decision should be taken because it is felt to be the best solution for that person's well-being and has the fully informed support from their advocate(s). Institutionalisation should never be seen as the appropriate answer because day-care provision has been cut or because it is a cheaper option than providing them and their carers (paid or unpaid) with adequate support. Another problem is "compartmentalisation". The case-studies highlight that there is almost an audible sigh of relief when clients move from Council-funded care packages to the NHS (via something called 'Continuing Healthcare'), which, like all NHS provision, is not means tested. But is this division between healthcare (free at the point of need via the NHS) and social care (subject to financial assessment and the pressure on Council budgets) a logical one?

Legal situation: The Care Act makes provision for most of the issues raised by the case-studies, and it is always open to people or their carers to take legal action to ensure that Ealing Council lives up to its responsibilities. Why are care assessments making many feel that financial constraints at Council level are leading to a reduction in care packages, even sometimes when more care is needed not less? Are assessments being carried out in a "*collaborative and appropriate way*" as laid down in the Care Act; are they being carried out together with formal and informal carers (involving a carer's assessment when appropriate); are they based on an understanding of previous care plans; why are preventative actions not given sufficient priority in determination of needs; and how can teams of experienced paid carers who "*are a key to maintaining (a client's) emotional and physical wellbeing*" being underpaid/under-respected in the planning process. Some of the people in the case-studies above are indeed pursuing legal actions, though the restrictions introduced for legal aid creates further obstacles to people remedying their concerns. Some are pursuing complaints preparatory to considering legal action, though not everyone was aware of how best to start such a complaint process. This route – of complaints and legal action - however should be a last resort as it is wasteful of limited Council resources and detrimental to the well-being of all concerned.

Ealing Reclaim Social Care Action Group, is a non-partisan, politically independent group, working for improvements in the provision and monitoring of social care in Ealing. We work with others to campaign for a national social care system, well-funded from general taxation, free at the point of delivery and without means testing.

ERSCAG is committed to working to promote equality and non-discrimination.

Please join us in our efforts; contact -
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