

D.L.A. REFORM TEAM
1st Floor, Caxton House,
Tottenham Court Road,
London W1H 9NA.

Rec'd
18/2/11

14.2.11.

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Dear Sir or Madam,

Enclosed is a submission on the D.L.A. changes. My M.P.'s Senior researcher has assured me that the consultation period has been extended to Friday 18.2.11. My enclosed submission is four pages (sides).

I have a particular concern with the growing number of pensioners who undertake this most difficult of all caring roles - being responsible for physically and/or mentally disabled adults as their ageing parents, with all parties becoming frailer over time.

I serve on the committee of the [redacted] Pensioners Action Group, and it is in this capacity that I write to you, as it seems that such people have little, if any, group-representation. Ultimately I shall report back to committee, and at our general meetings, but in the first instance, should you contact me, please write to my above address, but please do not just generally pass on my contact details without first asking me! - Thankyou. It is my hope that your office will let those of us who write know what will happen next, and when.

A copy of this submission will go off to my M.P.'s office, as requested, for additional information for them. As a point of information for you, I should like to say that it cost me over £10 (a great deal) in mobile 'phone calls to establish WHICH office, WHERE, WHEN, etcetera, to send a written contribution to you. There were no library-leaflets or any other references for those of us devoid of computers - I looked in the preceding weeks, and suddenly saw that I would soon miss you, so had to do it that way. (My mobility is compromised.)

The parent-pensioners of this focus have similar problems and more, and so it may be that far fewer of them are able to make contact with you than should have had the opportunity, with better advertising.

Will you be recording how many people contact you, and groups, to give all interested parties a picture of the numbers involved and whether the consultation is deemed successful/useful etcetera? This would be so useful, as it is an arena of great difficulty for the clients and carers themselves, -getting heard, getting feedback, and getting their needs met.

Yours faithfully, [redacted]

This submission refers to adult carers (often elderly) and their adult children with disabilities, many of whom broadly categorise as having "special needs", often with accompanying physical disabilities.

Assessment is now tied into a system where a budget is being allotted to the 'special needs client', yet, contrary to this, it seems the family will now be means tested on this budget which actually only belongs to the client in their own right. Furthermore, new assessments have new criteria - in other words, the goal posts have been moved to achieve new ends for the relevant authorities, focused on juggling their budgets. These new reassessments 'make lighter' of the clients' disabilities, cutting funding - entitlements as a direct result of this change.

One example cited is of an elderly parent whose adult special needs 'child' has had his varied paid help slashed, in hours per week, by almost two thirds - a staggering reduction. It has thrown their entire lives as local authority client and his parent-carer into disarray, and the pensioner parent is now failing to cope with the withdrawn support and subsequent increasing demand (and distress) laid upon this mother, by her own child, who is equally distressed.

It should be borne in mind that the client lacks even the dubious benefit of understanding the cause of the sudden and catastrophic collapse of their joint life as they had lived it, containing as it once did established elements of physical, mental and emotional respite, in the form of practical support-systems, for both family members.

Such parents are being forced into mediating budgets which they don't want, which they experience as being calculated with bias unconnected to disability guidelines and client needs. In the past, up until now, Direct Payment systems were used by the parents to pay small discrete amounts for varied required help, and many say it was better for being done at source. Nor do many parents agree with the so-called "Modernisation of Services", given that what they feel it really means, by all appearances, is the "Whittling Down and Withdrawal of Services".

An added worry, of proportions which can only be understood by the ageing parents affected, is that their care is suddenly deemed to be devoid of economic relevance when they reach retirement age, and their carers' allowance is then stopped. This happens as they themselves enter their most vulnerable, worrying and frail years, descending into old age, yet with just as much need placed upon them by their ageing offspring as when a sum existed for the carer also, to ameliorate the problems of stretched circumstances and old age itself.

Often the demands upon them increase around this time, as the already compromised physical strength of their grown child begins to deteriorate also, the health of all parties having been worn away by the unusual and unremitting physical and mental demands of a lifetime.

Even pro-active parent carers with high levels of awareness of how to engage positively on their child's behalf, can be quite damaged as they are sidelined throughout the processes meant to have been set up on their families' behalf and in their interests.

One such mother was invited to attend a conference apparently setting out the so-called "Modernisation of Services". With no prior warning, the bombshell was dropped that she and parents like her would no longer have respite access for their adult children's facility, as it was closing. It provided a valuable social link between the users, among other things.

Notes were made professing to be recording what the parents were saying. These were re-worded with meanings entirely changed. A council employee charged with contacting all families affected was told there were seven, when in reality there were forty. So, many people were left out. This was never fully rectified.

The parent referred to wrote to one set of parents whose child also used this facility, to try to pool information and opinions. In order to keep everyone in the picture, she told a council employee of her efforts. This employee then visited the elderly couple. The husband is a very ill man. She tried to remove the letter (not addressed to her, or maligning her or anyone) but, though very frightened, they refused. She described their friend to be "scaremongering" (in merely describing the

truth of events.) The couple then became frightened that they were causing problems for her, as well, because the letter had been read by this employee meant to help them all, and again, paid to do so.

This woman then complained to her own manager, (about the letter which she'd made the elderly couple show her, which was not addressed to her or meant for her eyes.) It was not a serious missive yet she denounced its author to the couple and then her Senior as though speaking of a criminal. By now, all the put-upon parties subjected to this treatment were terrified of what might come next.

Yet when the conference had been announced, the parents had asked for two rooms at the conference: one in which the discussions would go on, and one in which the adult children should be, nearby, but overseen by some familiar staff members so that conferencing activities were actually, genuinely, possible.

The request was ignored and no such practical aid was made available. As a consequence, many of the parents were eliminated at the first hurdle - simply unable to attend the conference, which was meant to be FOR them, at all.

A parent submitted questions to the relevant party employed by the authority. Despite polite re-requests, they were never answered. The person paid to do so later said that she could not answer them until the relevant consultation period attaching to this matter was over! (By which time answers would be useless.)

Her Senior colleagues had the questions sent to them. They have never answered the questions either, thus ensuring that the authority's obligations to the parents were left undisturbed and unchallenged: and unfulfilled.

One of the worrying developments of direction is this: That in the enforced reassessments of these vulnerable adult clients, the nursing needs are being focused on more, declared more to be a requirement. It is suggested that therefore nursing homes may be used more for this group of people, even where unsuitable for their types of disabilities, because

there are ring-fenced budgets available which can be drawn down through these facilities. It will thus look as though NHS funds are being made available even though (a) the facilities are not suitable and (b) it will block future access of the people for whom the nursing homes are designed, along with the trained staff. This possibility is worrying all concerned, and has not been addressed when asked about, - like other questions referred to, in P. 3, para. 5.

To invite interested parties to either attend meetings, engage with paid workers or contribute to a period of "consultation" is to believe that they are in full knowledge of all the facts in good time to discuss the implications with one another, get questions asked and fully answered. All without the presence of any feeling or form of intimidation. It seems quite possible that a cynical process of "bundling people through" the changing events of their own lives, in the realms of the disabled, may well be taking place in other parts of the country. How many affected people may feel "frightened into silence"? And are those inviting consultation-contributions aware of those kinds of problems being existent in "the real disabled world"? These questions should be acknowledged, and answered, alongside the reality of 'needs of attendance': if it is not ^{made} possible for the parents to take part in conferencing, it is not a conference, even though funds will have been made available to its organisers as if it fulfilled applicable requirements and criteria.

In closing, the contention is made that all of the information here is relevant and germane to "Disability Living Allowance Reform" becoming "Personal Independence Payment", because it maps the near-impossible terrain which claimants have to try to familiarise with (until it changes) and then negotiate, - all separated by hostile means from helping one another - over long periods of time. Their desperate voices often go unheard along the way, as here described.

