

DHA REFORM TEAM
SWI H QAA

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Dear Sirs

PLEASE FIND ENCLOSED MY RESPONSE TO THE
CONSULTATION PAPER ON DHA REFORM.

PLEASE EXCUSE THE PRESENTATION - AGE AND
TECHNOLOGY DO NOT ALWAYS BLEND.

I HAVE MADE ON LINE RESPONSES, BUT HAVE NOT YET
CONSIDERED CUTTING AND PASTING AND ATTACHING,
AND MADE SERIOUS ERRORS WITH WORDS THAT I COULD NOT
RECTIFY, I TYPE AT ABOUT A PAGE AN HOUR, SO FEEL
QUITE EXHAUSTED, AN EXHAUSTION DESERVED BY AN
DOCTOR GENERAL.

I FEEL I HAVE PROBABLY INADEQUATELY
SHOWN THE FEARS OF MY GENERATION FOR THEIR CHARGES
WHEN THEY CAN NO LONGER SUPPORT THEM.

YOURS FAITHFULLY

RESPONSE TO THE CONSULTATION PAPER – DISABILITY LIVING ALLOWANCE REFORM

Introduction : I am one of the "Old Guard" who fought forty years and more for recognition of the disabled person, particularly children, often with multiple handicaps, many of them still not adequately understood. I was involved with every aspect of Special Education, usually as a parent, although I sometimes held office in NCSE, and in a number of local parent groups.

I myself have a multi-handicapped daughter (now in her forties), burdened with Cerebral Palsy and Epilepsy and countless other problems, which led me to read Neurosciences (mainly psychology but Exploring the whole field) for some six years, following extensive research in the field of Handicap, of all kinds – involved in the concepts of integration/segregation, accommodation and protest, etc, with no particular emphasis.

I fear we may have to gird our loins for battle again on behalf of such of our children who still live.

The Background : It is difficult to see the enormous changes that are everywhere being rushed through and the future reduction of services as non-political. There seems to have been some very basic econometric modelling which produced a formula of "Slash at 20%", irrespective of the subject involved. I think this creates a philosophy that encourages considerations of change voicing a mantra of immediate and wholesale destruction of well established practice for the implementation of the new (improvements ?)

Forward to the Document : The whole idea is wrong and the timing is also wrong. The current system has been formulated by experience and it is complex because the people who may benefit have complex problems. There can be no such thing as a Personal Independence Payment that is all encompassing. When any law is promulgated, it seeks clarity, only to be overwhelmed by subsequent case law – Read any guide to any governmental system. A clearer more straightforward assessment process – one that can cater for a hundred or more forms of disability – the idea can be seen as insulting, for example, to the congenitally disabled. What individual could be found to make even the simplest assessment of all the handicaps. Certainly not someone armed with some yardstick, but possibly someone with a micrometer. The document is not considering the problems of the disabled person – phrases like the cycle of dependency echoes much earlier cycles – of deprivation, for example, which may be a different pole of the spectrum. The nonsense that social attitudes have really changed belongs to Cloud Cuckoo Land, apart from quota systems, which might favour a coloured lady in a wheelchair "ticking several boxes", and that phrase seems to suggest what some new assessment that is universal might well be.

Executive Summary : DLA is not confusing – it was introduced to bring the disabled person up to something like his/her able bodied counterpart. Considering the impact an individual's impairment has on their daily life is a nonsense catch-all phrase. What is not mentioned is what the government or the department might define as normal daily life. Somewhere in the document is the suggestion that the ability to use a wheelchair greatly enhances their mobility, which seems to mean that a disabled person is mobile if they can use an aid to take them to the corner shop – so much for changing attitudes. What does it mean to get around – in a universal sense. What does it mean to members of government or to executive civil servants – I think they would prefer (vide above) the yardstick to the micrometer. What does mobility mean? Would making one's way to the local station, travelling to London (with any attendant changes of train), hopping onto the Tube (understanding how to do it), down to the river to have tea with their MP on the terrace – is that reasonable. Any reason for anyone in the Provinces to the Capital could well define what a normal able-bodied person expects as a definition for mobility – in these days of air travel, the field is widened. What does daily living mean? – trips to the zoo, a quick pint at the pub, the use of mobile phones, MP3s, etc., etc. – as well as eating, again with or without aids, watching TV (Sky, HD – what is normal?) – paying board in the home situation (or am I living too much in the past?) There is much said about employment – a lot of wishful thinking – assumptions that there is no longer discrimination, just because there is now the act, but the disabled remain at the bottom the pile, behind even female workers, coloured workers, the large elements of unemployed able-bodied, increasing daily.

The New Assessment : The document talks of some kind of universal assessment, with periodic reviews. They have always been there and multiply-handicapped children were assessed annually even when their condition was obviously permanent – some of us had hoped that wasteful exercise was gone forever, but at least, it was a medical assessment (of sorts). Just what kind of independent (of the NHS ?) healthcare professional will give an in-depth analysis of an individual's circumstances. There will be few, if any, who will be aware to all the problems a handicapped person might have. For the multi-handicapped, a multi-disciplinary board would have difficulty in making an adequate assessment of all the factors involved. Different types of disability make different demands upon the individual and some disabilities may be involved in some indefinable cycle of remission and further outbreak, often more serious. Will this undefined professional be acquainted with the "mental" problems of many disabilities. How long will the assessment take and will there be sufficient time to understand the individual (who, by definition, is already seen as a client, an object who will not be subjectively assessed – on the other hand, the subjective assessment of a disabled person will often militate against the client, whose problems have been defined by a first impression assessment, when time could be taken from ticking the boxes on some universal form for only a short period of time. The definition of "passports" to other assistance are surely only applicable to the well defined disabled person – the whole vocabulary within the document is not that of people acquainted with the wide (or indeed and specific) problems the

Handicapped face. The document has overall the flavour of the text book, sadly composed by people remote from the serious difficulties faced by the disabled – people whose first reaction to my comments might be "he blends impairment, disability and handicapped together where we would establish separate definitions" – is only a question of degree, but the multi-handicapped may have all compounded.

Such conflation is a natural thing — the document points to an apparently high incidence of fraudulent claims, blown out of proportion by media reiteration — it fails to distinguish unacceptable Big F frauds from possible (perhaps misconstrued) small f fraud — there is a precedent before the legislators — how many MPs have been charged with fraud over their expenses — and how small a proportion is this of MPs whose expense claims have been criticised — these legislators claim to suffer from Draconian now (universal ?) supervision. They can speak for themselves, where many handicapped people could not meet the challenge.

The document suggests that applicants in the past have not understood what they are claiming, but does not observe that the majority of such claims have been made with the guidance of a professional, often filling in the 30+ page forms — and possibly even by the as yet undetermined professional who may be assessing in the future. These will be perhaps Healthcare professionals, whatever that means, but the word Care is a word about which many disabled and elderly people recoil in horror — there can be marvellous care (like that old TLC), but there can also be absolutely disastrous care, which leaves a lifetime mark — the percentage of the incidence of this poor care may be higher than either of the two suggested in the paragraph above. It is not only physical and/or mental damage that is caused, but there may be considerable misdiagnosis — made by lower grade professionals who do not and cannot contemplate the difficulties of their client. Cases are legion.

This is why a "face to face" interview with a professional is a matter of concern. Disabled people are often seen to be capable of performing tasks which are, in fact, beyond them, but able bodied expectations lead to the disabled (under interrogation) to exaggerate their capabilities. The simplest example is that of the disabled reader, who does not comprehend; at it's simplest dyslexic people may not admit their problems but seek to "pass." Passing is a very common phenomena in the world of handicap — will the professional busy with his/her questionnaire identify such a problem? If we only had some idea of who that might be, and what kind of specialist training he/she might have undergone.

This proposed interview system is dogged by many concerns. First of all, disabled people, anxious to conform, may mislead their interviewer; on the other hand, there may very well be professionals whose authoritative manner may well intimidate their client — few interviews will have an egalitarian aura. There are a great many handicapped people who will have no understanding of what is going on. Executive Summary: DLA is not confusing — it was introduced to bring the disabled person up to something like his/her able bodied counterpart. Considering the impact an individual's impairment has on their daily life is a nonsense catch-all phrase. What is not mentioned is what the government or the department might define as normal daily life. Somewhere in the document is the suggestion that the ability to use a wheelchair greatly enhances their mobility, which seems to mean that a disabled person is mobile if they can use an aid to take them to the corner shop — so much for changing attitudes. What does it mean to get around — in a universal sense. What does it mean to members of government or to executive civil servants — I think they would prefer (vide above) the yardstick to the micrometer. What does mobility mean? Would making one's way to the local station, travelling to London (with any attendant changes of train), hopping onto the Tube

STETS - NOT ON/COLES

This type of situation leads to the conclusion that "face to face" interviewing may not always be possible; clearly there are a great number of cases where a parent, an appointee, an agent should clearly be in attendance – and there arises the "Social Services problem" – can the unidentified professional believe the parent, etc., and what challenge might be made. There is also the semi-professional or indeed professional advocate who perhaps should accompany the disabled – after all there are in most families these days a doctor or a lawyer or otherwise intelligent relative. Older people often have the guidance of their current Healthcare or Social Care professional assisting them. The matter of a witness to "face to face" interrogation is a protection for both parties and hopefully of such character to at least seem to be "independent".

There next arises the question of reviews – who would undertake the review and how often would they be made, bearing in mind that the as yet undetermined professional may not have made a proper assessment and it may well have been challenged – how far up the scale of appeal will the matter have progressed – what system of appeal is envisaged to what would be the constitution of any appeal tribunal and how well versed would those members in the world of handicap?

There will be appeals; there will be successful appeals and changes will be made to the initial structure – there are already grades of disability envisaged in the document. It may start with as little as six, but what will rapidly follow will be the Clauses (a to X) and sub-clauses (i to VIII and beyond) – it is inevitable and the new system will become as complex as the old – because it needs to be. Handicapped people have enough problems without being forced into some Procustean bed of universality, which may well be hi-jacked by the Treasury or whatever.

The writer has already made on line responses to 22 Questions, some of which elaborate upon the concerns herein raised.

One final comment: the writer is mainly concerned with the multi-handicapped person in society and in particular the congenitally handicapped. His fears may be unrealistic but they have to be expressed – every one becomes ^{involved} – parents, siblings, children (if there are any). Everyone struggles to see their relative independent, but often this can never be totally achieved. Massive steps have been made in the past forty years and an adequate working structure has emerged, which may well be in danger in this period of change all round – to what purpose.

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APPOLOGIES FOR MY INEFFICIENT USE OF WORDS / PLEASE FOLLOW MANUSCRIPT
ATTACHMENT