

The point of the report although well stricken on most points missed again the chance to improve the life of the severe disabled people.

Severe disabled people: definition, disabled people who by no fault of their own are in such way disabled that they either cannot do certain actions on their own or miss the audibility to express themselves, this include cognitive and other communication problems.

It is presumed by Government, Social Services and medical Consultants, that this kind of disabled should simply stay in bed or tied to a special wheelchair and stay there, that way they do not need much help and keeps the cost low. (we are told so by all three.)

The depression which this creates for the disabled is enough to help him or her to die quickly and of for the authorities, Medical or otherwise, the problem is solved.

The fact that direct payment is only for disabled people who can handle it themselves making them in fact not disabled but handicapped, is proof enough that Government feels that the severe disabled are just a nuisance which should go away soon as possible.

Let us however look at the facts;

Severe disabled handicapped by lack of use of the extremities or lack of audible speaking or ability to think or act for themselves are still people, they did not choose to fall ill or be a victim of failure (our case) of the NHS, they are real life people, to deny them the help they need is not only cruel and outdated but also is financial waste.

An severe disabled person cared for at home still needs as in special homes 24 hours a day care, which means two persons a day caring for them, or 80 hours a week if we include the help of family to fill on the rest of the hours of carers or two people in employment who pay taxes. This would benefit the Government, the people in employment the family of the disabled person and the disabled person self.

With other words benefits for everybody instead of the doom and gloom now given to them.

According they are able to help now, but only if they pay for it.

But also the direct payment in the condition as it is now does not add up, example; 500 pounds a week direct payment which is then deducted by the forced pay back of the carers allowance of the DLA. Case example; carers allowance is now used to buy Neuro Physio once a week, by handing in the carers allowance to compensate the 500 direct payment leaving them with 450 pounds a week out of which then the Neuro Physio has to be paid leaves it to 400 and after tax and NI just enough for 20 hours care well short of the minimal 40 hours needed.

Leaving it with the Social services in Local Councils sounds rational, practise however demonstrate a different picture.

Example; A severe disabled person not able verbally to communicate with strangers although understandable by the daily carer is denied any help, as the carer would not understand what the disabled person is saying, which is correct as in practise the carers come from agencies and every time an different one (experience) so that no time is found or created to understand the disabled person.

The social services then simple write the disabled person off the list of services as no help is possible, which is incorrect but that way Social Inspections will not discover that there is an section of the disabled where id not catered for, making them(the councils) look good as that way only the cared for disabled show up. Complaining is not possible as the complain has to be made against the council how is the offender in the first place, a case of a offender has to investigate himself, and naturally he is then clean as a possible.

To enable an fair and successful approach to the severe disabled not the Social Services but an medical authority could set the standard to which the Social Services has to adapt, on this moment disabled people are standardised in four groups, 1; children 2; disabled. 3; Severe disabled 5; old people who are disabled. The fist one get all the attention, the second most of the attention, 3 and 4 are simple ignored unless circumstances forces an attitude change, which sometimes does happen.

In our case , my wife was given as maybe one or two years but mostly in bed, the fact is that now many years later she is mostly out of bed enjoys her grandchildren and her short holidays with them, it also keeps the grandchildren in line as they understand the seriousness of the situation making them more responsible . She is denied three times direct payment although at all occasions the Social worker admitted that she needed it and that extra help was urgent, but it was denied the first time under Borough rules as to much savings, second time as she could not clearly audible tell the carers what she wanted(incorrect) third time because we had a debt of 2000.00(stand-up Wheelchair).

In all cases we were informed that no direct payment was available and that as no help could be given she would be no longer on the list carers assessments were ignored, but in future we could apply again.

That is why to give Social Services an frontline duty is wrong, they lack medical experience and generalise every case(we are not the only one) as is done all over the country.

The solution is an simple one, give the direct payment in dual control by the disabled and the main carer who has to sign an responsibility clause and is not in paid employment by the disabled, (family member) if no such person is available the social services could appoint such a person, it would give more life possibilities to the disabled , an less stressful life, which otherwise later would have to apply for help, carer and the employment for one or two people who would then pay taxes.

That way no other mechanism has to be developed as on your page 96 of the report, just an added function.

I hope that this a-mail can be of any help as it done from pure experienced caring for disabled over more then twenty years.

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