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070. Con. Res. Wr


DLA Reform Team

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Dear Team

DLA Reform: answers to Chapter 6 of consultation paper

We are the parents of a 32 year old daughter with Down's syndrome. The experience of seeing the distress of similar adult children when bereaved decided us to look for residential living for our daughter where she is now very happy in a protected environment with the company of good friends.

There are some 60 parents who made similar decisions with children in the same community, all retired and many in their eighties and older.

Our local council are seeking economies which are gradually affecting our children's lives.

The present financial support for people like our daughter allows the government to reduce financial help, telling the county council that such needs should be met by them. At the same time government has drastically reduced support to councils and cuts have to be made somewhere.

The needs of disabled people are an easy target – as a group they lack public attention and an articulate voice. They are caught between the government and the county councils – all of whom should be protecting them.

Meanwhile families of disabled adults all over England view the changes to DLA and the shape PIP may take along with council cuts with great apprehension. We are hoping that the lives of our disabled children are not to be made unviable.

After reading the consultation paper we were struck by variety of needs of the group the Disabled Living Allowance seeks to assist. For those born with a disability to be placed in a group whose needs and motives are so startlingly different seems unlikely to produce a satisfactory result. Those with a learning disability alone already cover a vast spectrum and few of them are easy to assess.

I hope above all that the vulnerable are not to be thrown into the pool of 'opportunity' (independent living) from which they will be thought to be waving when they are drowning.

Thank you for your attention.

Yours sincerely



Question 1

For our daughter who has Down's syndrome the problems or barriers that prevent her participating in society and leading an independent, full and active life are not always apparent.

She appears articulate, is overweight but has no obvious physical disability. On the other hand her understanding is limited since she has no conception of the implications of what she is being asked and little grasp of reality outside the narrow world of her intelligence and often misguided imagination. Her main motive is to give answers that please.

Because she cannot understand the concept of what work involves and what would be expected of her in a work place she cannot realistically assess what she may be capable of.

If she could be found appropriate work she would need patient, informed and disciplined support for a long time, possibly always, if she were to have any success.

She would need help in travelling to and from work safely.

It would be important that she was not placed in a situation where temptations such as food or money were readily accessible.

She would need to be protected from exploitation of all kinds. She is vulnerable.

It is difficult to divide where the needs of DLA end and benefit support begin. It would be easier if both were dealt with in one place.

Question 2

The financial support given by the DLA (or PIP as it may be) needs to be realistically adequate to provide for this support.

Question 3

The main extra costs our daughter would have would be in paying for support in daily living such as cooking, shopping, maintaining an appropriate level of cleanliness in her environment, travelling and in personal hygiene. She would also need support in any unexpected situation e.g. unknown caller, understanding and dealing with official letters, contact with people. These are in the main covered by benefit support.

She would find it very difficult to live without support constantly on hand. She could not do so safely.

Question 4

The current DLA attempts to cover such a multiplicity of needs that it is hard to understand how the new PIP, dividing this varied group into 2, will operate.

Question 5

If it is possible to consider all claims fairly so that needs are adequately met and circumstances understood, then that would be ideal.

My experience of the disabled is that they are a diverse section of society and considering their claims fairly will not be a 'box-ticking' exercise.

Question 6

It is very difficult to prioritise those people least able to live full and active lives or which activities are essential to everyday life. My knowledge is of those with a learning disability who show some understanding and often some verbal facility and in a familiar supported environment can function quite well. Beyond that, in an unfamiliar environment, e.g. a workplace, can only function satisfactorily with fulltime and continued support.

Question 7

For assessing the needs of those with a learning disability only someone with expert knowledge and experience can monitor changes, improvements or deteriorations, and assess accordingly.

Question 8

For those with a learning disability but no physical disability, only the help of a more able person can provide the support needed.

Question 9

However simply the claim form is worded and however appropriate the font, our daughter will not be capable of understanding without help.

- Carers, often elderly parents, need a simplified form in larger print.

Question 10

There is no easy tickbox method of assessing ability. A GP can confirm a medical syndrome but only a range of daily contacts can give a rounded picture of capability.

Question 11

In face-to-face discussion with a health professional our daughter still needs support. She finds it hard to follow discussion and to understand its implications is impossible for her.

With support a face-to-face discussion in a sympathetic location would be helpful – certainly more so than a written response.

Question 12

It is to be hoped that any change in our daughter's condition would be noticed, in which case it would be reported.

Question 13

I have no experience of people who deliberately do not report changes in their needs.

Question 14

Our daughter is unable to claim unaided.

As parents the current system has not always been transparent. More detailed advice and information in accessible language is vital.

Questions 15 and 16

The implications of these questions are beyond my experience.

Question 17

As parents of 4 children, we can only say that the needs of our disabled child were at least double those of our other children and frequently much more than that.

As a mother meeting the needs of my disabled child meant that I was out of employment for many years and thereafter could only work part-time. This meant that I could not try to look for promotion. This has affected my teachers' pension enormously. The needs of our disabled child constantly affected our income and will continue to do so.

I don't suppose the State can compensate for that.

Question 18

We have not received help in getting access to other services or entitlements for our disabled daughter. We have found trying to do so stressful. Caring for our daughter has been difficult but rewarding. Worrying about what happens to her when we die is stressful.

Question 19

At present we have had no experience of this passport and its help in accessing other benefits and services.

Our daughter, now aged 32, has only ever had a social worker for a few weeks at a time so advice from that quarter has not been available. For a very short period of time some years ago we had the help of a wonderful social worker who found our daughter's current placement.