

Rec'd 31/1/11

26 January 2011

I am diagnosed with the degenerative neuro-muscular disorder, Muscular Atrophy (MA) that has resulted in the severe wasting of all the muscles of my arms, wrists, hands, legs and feet. As a very young child, MA nullified the effects of corrective surgery to certain deformities of my feet and a little later took away my voluntary ability to open my hands. No amount of money could ever compensate for that, but receiving DLA certainly helps me lead a full and active life at home and in my voluntary roles in the charities I help to run. I can only attempt to answer the following questions asked in the consultation on Personal Independence Payment.

1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

Feelings of inadequacy connected with me not being physically quick enough to keep up with the pace that others can do things.

Feelings of anxiety connected with the dangers caused by the carelessness of others being less easy for me to avoid.

Feelings of embarrassment connected with the awkward looking ways I do certain things.

Being comparatively poorer than most folk.

Difficulties encountered negotiating the natural and built environment safely.

Feelings of anxiety due to my inability to walk safely outdoors

Feelings of frustration at being unable to use a wheelchair

Pain and physical & nervous exhaustion I experience planning, during and after activities both at home and away from home.

2. What are the main extra costs that disabled people face?

The costs of having someone else assist me with many of the tasks of everyday life as I have very limited use of my hands and feet and am very unsteady when on my feet and easily overbalance.

Paying for help with meals preparation and for deliveries

Paying for taxis etc or for someone to hold onto me and to help me get out and about safely.

Paying for someone else to go on holiday with me to assist me and keep me safe.

Paying to have clothing altered so that I can wear it safely and manageably.

Paying for laundry services.

Paying for chiropody and manicures as impossible to do myself.

Paying for hair to be regularly cut short, as I can't look after it.

Paying for extra visits to dental hygienist as I have difficulty manoeuvring toothbrushes of all sorts

6. How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

I believe that everyone has their own unique understanding of what a full and active life is, and that everyone's level of satisfaction with the extent of their achievement of such a life is subjective. If you are too objective, you will deny that and risk superimposing a prejudiced understanding and arriving at faulty priorities. I would offer the following as most essential for my everyday life.

Washing, bathing, cleaning teeth and maintaining a healthy level of personal care

Comfortable sleep

Getting dressed and undressed

Preparing, cooking and eating meals and washing-up

Maintaining a clean and safe home

Washing clothes

Maintaining clear communication with others

To be able to get out and about safely to appointments and meetings and for relaxation, recreation and holidays

Obtaining all items needed per above.

10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

The people who already provide services to me and have known me for a long time are best placed to provide supporting evidence.

14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

All questions to be asked in interviews should be made available well in advance and the purpose of each question should be clear, after all it's not a job interview or quiz game. There should be no second-guessing or undeclared extrapolations taking place.

16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

Most of my aids and adaptations are provided free because of my low income. However it is more common now to be directed to places that retail appliances. I think there should be no limit on what PIP can be spent.

18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?

The Mobility component has been particularly very helpful in obtaining parking permits and reduced fares for train travel

19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

Any change due to it not being possible to use PIP as a passport to other benefits and services would have to be fully mitigated via other arrangements between people with disabilities and the providers of those benefits and services.

