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Personal Independence Payment consultations April 2012

Thank you for inviting Cardiff & the Vale Parents' Federation to comment upon the latest proposals for the new Personal Independent Payment (PIP) benefit entitlement. The following comments have come out of consultation with some of our 800 family members who are all lifelong unpaid carers for their children (and adults) with a variety and scope of disabilities, including learning disability.

As unpaid family carers who know our 'children' and their needs more than anyone else, we are concerned that people with learning disabilities may lose out under the new PIP system unless special allowance is given to such individuals. A learning disability is for life and while we strive and focus our efforts on helping our relatives to live 'ordinary' lives and overcome the many barriers they face, for most people their disability will be a constant and limiting factor.

The present proposals seem reasonable at first but we fear that they could be used as a means to deny vulnerable adults from accessing essential support that currently promotes and sustain their independence. The weighting and interpretation of the criteria used for assessments is too vague and could lead to many genuine claimants either having their needs underestimated or worse still, ignored altogether.

We suggest that a person with a recognized learning disability (e.g. either a medically diagnosed condition or a history of 'special needs') should automatically have some form of weighting to recognize that they have a lifelong expectation of their 'condition' remaining. This may enable a small number of inappropriate successful claims but on balance this 'cost' would be acceptable since the cost of denying a vulnerable adult assistance could have dire (and expensive) consequences. This would be of especial relevance to the many individuals who, while undeniably vulnerable and disabled, are deemed insufficiently at risk to receive a local authority care package. These individuals

are often the very people that stand most chance of living a full and independent life if they remain able to access low levels of support!

In the past, receipt of even the lowest levels of DLA has been vital to many such people as it serves as a means for them to be signposted to appropriate assistance and support and also allows them to access benefits and entitlements that enable them to work and live independently and with dignity e.g. working tax credits, priority in housing etc.

If we consider the various 'domains' (descriptors) used to measure a person's abilities we must stress and recognize the importance and risks of overestimating a person's **actual** ability in **real life** situations. The suggested new system calls upon an arbitrary and subjective weighting or scoring and while the examples included in the appendix seem logical for many 'typical' people, the subtle nuances of cognitive and learning disabilities are not taken into account.

Certainly, an individual that 'presents' with the out and out classic 'symptoms' of autism or some other learning disabilities ought to have their core needs recognized using the assessment criteria suggested- although they may lose points if being supported effectively, due to their being able to demonstrate a growing range of independent skills. A slightly more able person may lose out altogether!

The individual completing an assessment claim (or monitoring it) will have to make a subjective judgement based on the level of abilities of an individual without reference to benefits of any holistic outcomes for that person.

For example, an individual when asked, may agree that they can attend to their personal care independently yet in reality not appreciate what a 'normal' standard of appearance and hygiene is; nor appreciate the consequences to their social independence and relationships of appearing unkempt and generally displaying a poor standard of hygiene.

Neither would the assessment necessarily pick up on a person's real needs if they agree that they can 'cook food and prepare a simple meal' - if that meal is oven chips and pie washed down with cola! Many people with a learning disability, coping on meagre incomes, are at even more risk than the mainstream population with regard to health, diet and obesity- take away basic DLA(PIP) and this will be even more of a danger! Judging whether food is fresh enough to cook and eat, properly cooked, basic hygiene standards met and the like are all essential questions that must be addressed along with an understanding of what nourishment means!

Being able to eat unaided is more than being able to cram down food as quickly (or messily) as possible – in a social setting it is also important that a person doesn't attract undesired attention through behavior that would disadvantage them, their safety and independence.

Similarly, the ability to take one's own medication may mask the need for a person to have low level support offered to ensure that their medication is both appropriate and actually being used correctly.

Therefore it is imperative that during the assessment process that the individual with a disability completely understands how that disability impacts upon themselves socially, physically and emotionally; or that the person's representative (typically the parent) has that understanding.

With regard to mobility issues we again need clarification and understanding of the uniqueness of many people with a learning disability. Clearly someone that is permanently unambulant will score highly but many individuals need encouragement to be remain independently mobile. This may be in order to maintain muscle tone and balance yet at times they may be too weak or lack the confidence to walk unaided and rely upon assistance/wheelchairs. This could be episodic and inconsistent in its nature so difficult to 'prove' on the day of assessment. Such people are not 'faking it' for the benefits (indeed they will probably not understand the complexity of the system), but any assessment must take this into account and 'scoring' needs to recognize this. A crude measure of CAN you walk 200 metres is not the same as WILL you! Individuals are different and we must respect that. Square pegs will not fit into round holes however much we would wish!

People with a learning disability are no different to any other 'group' of citizens yet they are more often the subject of bullying, abuse, vilification and exclusion than almost any other sector of society. For many, a simply low level of informal support is enough to live a fulfilling life and it is essential that support is accessible and available when needed. Maintaining basic skills and abilities is often an achievement and ongoing goal and an end in itself and the existing DLA system has encouraged appropriate low level and non invasive support structures to evolve by recognizing these lifelong abilities (and limitations).

Being in receipt of DLA currently helps individuals to access support as and when needed without a constant need to be assessed and 'prove' their disability. Getting DLA, contrary to the media image, is not easy and many find the entire process humiliating and demeaning – for families it is also a depressing reminder of their 'child's' shortcomings.

We constantly strive to push for better and more inclusive lifestyles for our relatives and yet, if they dare demonstrate that as a result of appropriate (and often informal (invisible)) support,; that they are 'improving', or can prepare a simple meal, bathe themselves or travel to a part time job or daytime activity alone - they risk losing an essential lifeline!

In conclusion it is imperative that the stated aim of the reform to DLA "...the introduction of the Personal Independence Payment to meet the needs of disabled people today" does actually meet their needs and not cause extra stress and difficulty

to vulnerable people who are already dealing with complex mental and physical disabilities.

Please contact us if you would like any additional information of views from parents and carers that we represent.

Yours sincerely,

John Cushen
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