



## **Consultation on the “Moving around” criteria for PIP**

### **Submission by Contact a Family and the Every Disabled Child Matters (EDCM) campaign**

#### **About us**

Contact a Family is the only UK-wide charity providing advice, support and information to families with disabled children – regardless of disability or health condition.

Every Disabled Child Matters (EDCM) is the campaign for rights and resources for disabled children and their families. The campaign has over 34,000 supporters and partners represent over 770,000 disabled children and young people in the UK. Our Campaign Network is made up of 75 organisations from across the disabled children’s sector.

Contact a Family and EDCM are members of the Disability Benefits Consortium (DBC). We whole heartedly support the evidence and views outlined in their submission to this consultation. We have based our response on the issues raised in their submission.

#### **Summary**

Contact a Family and EDCM welcomes the decision to consult again on the mobility criteria for Personal Independence Payment (PIP) and the opportunity to respond to this consultation.

This response outlines our concerns regarding the distance used in Descriptor E for people to qualify for the enhanced rate of the benefit i.e. 20 metres and how this will impact on disabled young people (16-25 year olds) and their families in particular their parent carers.

We are pleased that regulations now include consideration about whether claimants can perform activities, ‘safely, to an acceptable standard, repeatedly and in a reasonable time period’. We think this will ensure a fairer approach to assessing whether claimants can mobilise.

We are also disappointed that the consultation period has been limited to just 6 weeks, which also partly covered the school and college holiday. This has proved a barrier in enabling families with disabled young people to respond and for us to produce robust evidence to support our case.

Contact a Family and EDCM believe that the negative impact of the 20 metre qualifying distance will include:

- Disabled young people and their parents dropping out of work, education or volunteering activities. It will also act as an additional barrier to entering employment.
- Increased poverty and isolation of disabled young people and their families, with the associated risk of worsening health.
- Act as an additional barrier to establishing independent living for disabled young people for the first time
- Reduce opportunities for disabled youngsters to socialize and maintain friendships with their disabled and non-disabled peers.
- Increase costs to the taxpayer and move costs elsewhere, such as unemployment benefits, the Access to Work Scheme, social care and NHS
- Increased pressure and strain on family carers.

Many disabled young people and their parent carers have also told us of the potentially devastating consequences of losing access the Motability scheme/car. For disabled young people just starting to live their adult life, to have this lifeline taken away will undoubtedly have long term implications on the ability of disabled young people to live independent lives.

### **Our recommendation**

We strongly urge the government to reinstate the 50 metre qualifying distance for the enhanced rate mobility component of PIP. We hold that the use of a 20 metre qualifying distance is flawed and will leave those with greatest needs without vital support. We believe that Descriptor E should be amended to read:

*"Can stand and then move more than 1 metre but no more than 50 metres, either aided or unaided."*

### **Our evidence**

Our response is based on the direct feedback we have received from over 200 parent carers, disabled young people and parent carers groups or forums. It is also based on our experience are working alongside families with disabled children and young people through our helpline, networks, partners and offices.

*"My daughter is 23 years old and has complex health needs and she loves to walk. She has her good days and her bad days. On her good days she can walk beyond even 50 metres but on her bad days which are usually seizure related it is tough. She will always be supported when going out into the community and we encourage her to live a full and active life as much as possible. The financial support she receives currently through the DLA and in future through PIP enables her to be less isolated and part of her local area. Since she first started*

*walking at 7 years old we have valued this financial assistance and would be shocked if this were to change because she can actually walk beyond 20 metres. We should be celebrating her achievement not penalising her."*

Contact a Family and EDCM support the position set out by the Disability Benefits Consortium in that it will always be extremely challenging to use a set distance to assess the impact of different individuals' ability to mobilise. Factors such as where people live have a substantial bearing on the extra costs they face to maintain a reasonable level of independence. For disabled young people they will also face additional costs associated with established independence living for the first time.

However, we recognise that the department must find a workable solution in the context of the current assessment. For this reason, we urge the government to reinstate the use of 50 metres to identify those in the greatest need.

While this is not a perfect solution it is based on a degree of evidence to suggest that 50 metres is a realistic measure to gauge whether a person is 'virtually unable to walk'. The distance of 20 metres is an arbitrary figure that lacks an evidence base and automatically discounts thousands of disabled people who really do need the benefit the most.

We are also concerned that the distance of 20 metres may have been set to restrict the size of the group deemed to be 'in greatest need' and keep costs down as a result. We strongly reject this approach and call on the government to introduce criteria that realistically identify those that fit into this group based on a realistic assessment of the extra costs and barriers they face, not simply the amount of money deemed to be available.

#### **Impact of 20 metre measure on disabled young people gaining independence**

To our knowledge, no specific modelling or research has been carried out how the 20 metre rule will impact on disabled young people's (16 – 25 years) ability to become independent for the first time.

Being able to get out and about is a key stepping stone to establishing independent living. And will opening up more opportunities to education and employment will have long term financial benefits to the state, as well as being beneficial to the young person. In 2009 17% of disabled young people were NEET, compared to only 7% of non-disabled people<sup>1</sup>. Supporting disabled young people to be able to get out and about will help tackle the disproportionate number of disabled young people who are NEET.

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<sup>1</sup> Department for Children, Schools and Families and National Statistics (2009) Youth Cohort Study & Longitudinal Study of Young People in England: The Activities and Experiences of 17 year olds: England 2008. (cited from New Philanthropy Capital (2009) Rights of Passage)

### **Accessing education and after school/college activities**

It is vital that disabled young people's links with education and social activities are not limited by the 20 metre rules. Of those that contacted us in response to the consultation, 75% raised concerns about the impact on opportunities to do 'ordinary' teenage things with disabled and non-disabled peers.

■■■■ is 20 years old with complex health needs, he said:

*"Will this mean I can't go out for a pint and a curry with my mates, I could walk to the pub but not to the Indian too and back again home. I get a taxi home, I guess I could ask my mum but I would feel like a kid – not very cool."*

■■■■ is a disabled teenager with cerebral palsy. He is studying at further education college about 20 miles away from home, his mum told us:

*"The local FE college couldn't meet his needs. He can walk 20 to 30 metres fairly confidently around the house but at college the environment and busyness means this becomes more difficult. Doug uses his DLA to pay for a taxi as we live in a coastal town in Norfolk and the public transport is a bit hit and miss. The taxi gives him independence and flexibility especially if he needs to stay late at college or go out with friends."*

■■■■ is 18 years old and has a rare condition which makes her limbs and joints sore, she told us:

*I get quite lonely after college has finished as the other students go off and do a lot of sports, go to the pub and hang out at each other's house, it's not easy getting my wheelchair to those places...but when we have parties and do crafty things at the youth hub it's brilliant. I use my DLA to get a taxi home, it's only 3 miles away but I like to stay late to make the most of the time there."*

### **Motability**

EDCM and Contact a Family are concerned about the impact of the changes on disabled young people being able to access the Motability scheme.

Motability vehicles are crucial to many young people's independence. For many young people across the country being able to access and drive a car for the first time is a big step towards adulthood and independent living. This is particularly true for young people living in rural areas.

It is well recognised that disabled people have more difficulty in accessing public transport. Over a third of disabled people who travel experience difficulties the most common being getting on or off trains or buses<sup>2</sup>. These difficulties accessing transport mean that disabled people travel a third less often than the general public<sup>3</sup>. Disabled young people have told us about the impact that this has on their ability to live an 'ordinary teenage life' and to maintain friendships.

*"You can't get to places, like if you want to go and meet your friends in town but the buses aren't accessible then you won't be able to do it independently. It's good if you can do it independently cause you learn independence skills and confidence."<sup>4</sup>*

Disabled young people have told us about the positive impact that being able to access a Motability car has had on enabling them to live independently. It allows them to get to places that may otherwise be inaccessible even if public transport runs there. It also means that where disabled young need to have a car with adaptations then they are able to access a car that meets their needs.

*"It's fantastic (my mobility car) provides me with all the independence I need to go and live my life really, going to university and playing sports."<sup>5</sup>*

The loss of access to the Motability scheme as a result of the 20 metre rule is a particularly disturbing prospect for many disabled young people and their parent carers.

Many families with disabled young people see the Motability vehicle as a 'lifeline', and the primary means by which they take part in everyday life. Motability vehicles are often the only way that disabled people can get to work, socialise with friends and family, or maintain the mobility they need to remain healthy. Removing access to the scheme is very likely to incur costs to the Exchequer in other ways, primarily in losses to tax revenues and increased spending on the NHS.

### ***Isolation, ill health and impact on carers***

We feel that that the DWP's own impact assessment dramatically underestimates the impact on disabled people's and their carers health from increased poverty and isolation that is likely to occur as a result of the tightening of the mobility criteria for PIP.

in addition, we are deeply concerned about the impact of the loss of DLA upper rate mobility on family carers. Many will be forced to bear the financial cost, as well as the

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<sup>2</sup> DWP (2002) 'Disabled for life?' attitudes towards and experiences of disability in Britain. (cited from Improving the lives of disabled people, 2004, PMSU)

<sup>3</sup> Disabled Persons' Transport Advisory Committee (2002) Attitudes of disabled people towards public transport, DPTAC (cited from Improving the lives of disabled people, 2004, PMSU)

<sup>4</sup> EDCM (2008) Going Places!

<sup>5</sup> Council for Disabled Children (2011) Young, Disabled and In Control

impact on their own health and wellbeing from the additional stress that the loss of a vehicle or covering additional costs like petrol, taxis, aids and adaptations will bring. If families become more isolated the knock on costs to the NHS and care services are very likely to increase.

In Contact a Family's study<sup>6</sup> the charity found that 65% of parent carers of disabled young people feel isolated all or most of the time. The study found isolation causes almost three quarters (72%) to experience poor mental health such as anxiety, depression or breakdown, with one in five (21%) saying isolation due to a lack of services had led to the break up of their family or marriage. The cost of mental ill health and family breakdown alone is in the order of billions (£126 billion<sup>7</sup> and upwards of £20<sup>8</sup> billion) yet the proposals are set to make these issues worse.

*"[redacted] receives the higher rate of DLA but I'm unsure about whether we'll get it under PIP as he can walk 40 metres or so most of the time. I have contacted motability and they don't know if we'll lose the car. The council say they won't provide his transport because of cuts. I will probably be able to get a loan for another car but [redacted] won't be able to drive it. I'm not sure how I'll manage as need to take my younger son to school and then take [redacted] to school but it's 25 miles away. Plus I would have to pay the petrol to cover the journey there and back twice a day. It seem so unfair."*

For more information about this submission please contact:

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<sup>6</sup> Forgotten Families 2011. Contact a Family.

<sup>7</sup> *No health without mental health: a cross-government mental health outcomes strategy for people of all ages* (2011) Department of Health and Centre for Mental Health, £105 billion for England, Scotland £10.7 billion, Wales £7.2 billion, Northern Ireland £3 billion.

<sup>8</sup> Centre for Social Justice (2007) and The Relationships Foundation's annual index of the cost of family failure (2011).



