



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

Date: February 2017

NNPCF Response to the Department for Transport

Blue Badge scheme: Consultation on eligibility

The National Network of Parent Carer Forums (NNPCF) is made up of local Parent Carer Forums from across the 152 Local Authority Areas of England, and has a steering group which consists of 10 Parent Carer Representatives from each of the nine regions in England, and the Co-chairs of the Network. We represent children and young people (birth-25 years) and are pan disability. Our current membership is in excess of 85,000 parent carers. These parent carers representatives link into the regional Parent Carer Forum Networks,

The NNPCF Steering Group has where possible worked within their regions to gather evidence to support our response to this green paper. We believe that our response helps to identify the most common experiences and views of Parent Carers of children and young people SEND (birth-25).

Question 1.

The NNPCF welcomes the government decision to look at how the Blue Badge scheme can work for children, young people and adults with hidden disabilities to ensure that those with the greatest needs have access to a Blue Badge. Our members have told us how difficult it is to access a blue badge if your child had autism or a learning disability even though their condition causes them very significant difficulties when undertaking a journey. This in turn leads to social exclusion and isolation and impacts upon the family and primary carer.

Parents from across the nine regions that make up the NNPCF have told us that the current regulations and guidance are not clearly understood by their local authorities and this is leading to a disparity of offer/experience across England. The NNPCF believes that the Blue Badge scheme should be fair and equitable and not discriminate in principle between physical and non-physical disabilities or depend upon the practice of the Local Authority in which you live.

The NNPCF agree with the proposed new criterion which focuses on the difficulties experienced when making a journey rather than the physical act of walking. The NNPCF welcomes the change from 'permanent' to 'enduring' when describing the nature of the disability and the addition of 'when' in the eligibility 'undertake any journey without it causing very considerable difficulty *when* walking'.

However, the NNPCF would welcome clear guidance to illustrate what the government means by these changes to ensure that they are allied consistently by local authorities.

Question 2.

The NNPCF agrees that where an expert opinion is required it should be provided by an eligibility assessor, however, many of our members have told the NNPCF about the number of appointments they are required to attend with their child/young person and the amount of time required to complete forms to access the support their child/young person needs. Families tell us about having to repeat their story over and over again which can be emotionally draining and difficult to do.

The NNPCF would like to ask the government to consider using professional advice that has already been requested, for example, as part of the child/young person's EHC Needs assessment to inform the decision making process for a Blue Badge rather than presenting families with yet another hurdle to overcome.

Question 3.

The NNPCF agree that there should be automatic badge eligibility for young people and adults with non-physical disabilities who score 12 points under the PIP activity 'Planning and Following Journeys'. However, we are concerned that the government are not proposing a similar eligibility for children and young people under the age of 16 who are in receipt of Disability Living Allowance (Mobility component – Higher rate).

Currently, there are two ways that a child with a learning disability or autism spectrum disorder may qualify for higher rate mobility component. If they can be classed as:

- having 'a severe mental impairment and behavioural problems', or
- being 'virtually unable to walk'.

Some children qualify for the higher rate of the mobility component of Disability Living Allowance (DLA) because they can be classed as having a 'severe mental impairment' and exhibit behavioural problems. To qualify under this rule, parents must show that their child needs a lot of watching over whether they are indoors, in the car, walking outdoors or playing in the garden. Their ability to walk is not important under these rules – it is all about their behaviour.

To be entitled to the higher rate mobility component on this basis the child/young person must meet all of the five tests listed below:

Test 1 the child/young person must be entitled to the higher rate care component of DLA.

Test 2 the child/young person must suffer from 'an incomplete physical development of the brain or a state of arrested development which results in severe impairment of intelligence and social functioning'. 'Incomplete physical development of the brain' is where a person's brain has not grown or developed properly, and this can be seen or assessed. 'Arrested development' can mean any sort of emotional or functional delay or lack of development, whether or not the brain is fully developed, as long as there is a physical cause. Disability Living Allowance case law has accepted that because autism is a disorder of brain development, children with a diagnosis of autism or autism spectrum

disorder will satisfy the condition of 'arrested development' or 'incomplete physical development of the brain'. Global development delay could also be accepted as being 'arrested development or incomplete physical development of the brain'.

Test 3 the child/young person must 'exhibit disruptive behaviour' which 'is extreme' – the sorts of behaviour that may count includes: running into the road, making loud noises, hitting out at people, throwing or breaking things, getting very upset, refusing to move. The word 'extreme' in the DLA rules means 'out of the ordinary', so that other behaviour that could be dangerous may also be taken into account, such as touching hot or sharp objects, putting harmful objects in their mouth, scratching or biting themselves repeatedly, banging their head or harming themselves in other ways.

Test 4 the child/young person must regularly require another person 'to intervene and physically restrain the child to prevent them causing physical injury to themselves or another, or damage to property.' 'Physical restraint' means physically stopping your child from doing something that would cause injury to themselves or others or damage to property. Physical restraint does not necessarily have to involve the use of force and the level of restraint required to meet this test can vary depending on the individual child. Sadly for many families regular restraint is part of everyday life to avoid any risk of danger for their child and makes accessing the local community extremely challenging.

Test 5 the child/young person's behaviour must be 'so unpredictable that your child requires another person to be present and watching over them whenever they are awake.' Many of our members' children need to be watched over whenever they are awake to prevent them from causing harm to themselves or to other people or any damage to objects, for example, furniture, clothing, and household appliances. Often the child's actions are unpredictable.

The NNPCF therefore strongly requests that the government introduces eligibility for children and young people 'without further assessment' which is in line with the proposals for young people and adults so that the system is equitable and fair.

Question 4.

The National Network of Parent Carer Forums (NNPCF) is made up made up of local Parent Carer Forums from across the 152 Local Authority Areas of England, and has a steering group which consists of 10 Parent Carer Representatives from each of the nine regions in England, and the Co-chairs of the Network. We represent children and young people (birth-25 years) and are pan disability. Our current membership is in excess of 85,000 parent carers. It is not possible to provide the government with accurate information from our membership on the number of disabled children and young people that the NNPCF might consider would become eligible under the new proposed criteria. However, the report by the Council For Disabled Children and The True Colours Trust which looks at what we can learn from national data on the numbers of children with complex needs or life-limiting conditions, estimates that numbers have increased dramatically by over 50% since 2004, from 49,300 to 73,000 children and young people. The primary area of needs are as follows; 10,900 children with profound and multiple learning difficulties; 32,300 children with severe learning difficulties; 27,500 children with autistic spectrum disorders in special schools and 2,300 children with multi-sensory impairments.

Question 5

Under the proposals being consulted upon, children and young people in receipt of higher rate DLA would lose an automatic entitlement to a blue badge (see previous comments Question 3).

Question 6

The vision of the Children and Families Act 2014 is “ *for children and young people with special needs is the same as for all children and young people – that they achieve well in early years, at school and in college; lead happy and fulfilled lives; and have choice and control.*”

Department for Education

The SEND Code of Practice describes supporting children and young people to prepare for adulthood from the earliest years in order for them to access education and training, have good health and wellbeing, develop independence and have friends and access to their communities. The NNPCF would encourage the Department for Transport to share the vision of colleagues from the Department for Education and give children and young people with hidden disabilities the opportunity to lead happy and fulfilled lives. Many children and young people would benefit from access to a blue badge to enable them to be part of their local community, to be safe and to achieve better life outcomes.

The NNPCF would welcome the opportunity to work with the Department for Transport to support the development of better life outcomes for children and young people affected by disability. As parent carers we are experienced individuals who have been working with the Department for Education and Department of Health for many years and have a wealth of knowledge and experience to share in a spirit of coproduction.

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