

The Children's Society response to Personal Independence Payments: assessment thresholds and consultation

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Introduction

The Children's Society welcomes this opportunity to respond to the Department for Work and Pension's consultation 'Personal Independence Payments (PIP) assessment thresholds and consultation'. We are concerned that the proposed assessment thresholds may not adequately reflect the support needs of disabled young people aged 16 to 24 associated with their disability and related to the changes that they experience in different areas of their lives during their transition to adulthood.

The Children's Society supports over 48,000 children and young people every year through our specialist services and children's centres. We believe in achieving a better childhood for every child but have a particular focus on vulnerable children such as disabled children and those with special educational needs (SEN). We seek to give a voice to children and young people, deliver direct practice and influence policy so they have a better chance in life. Our response is informed by our direct work with disabled children and young people, our research into issues related to disability and special educational needs, and the views of the disabled children and young people we work with.

We also support the Every Disabled Child Matters campaign's submission to this consultation and have contributed our views to their response.

Summary

Our key messages are:

- The Children's Society is concerned that young people 16 and over who are considered children under other legislation¹ are treated as adults under PIP and that the thresholds and assessments designed with adults in mind are going to be applicable to them. This may result in young people not being adequately assessed to receive this important benefit or not getting it at the right level which may have long-term impact on their future life chances and well-being.

¹ For the purposes of child benefit, childhood continues until the child is 19 or 20 in some circumstances; the Education and Skills Act 2008 placed a duty on young people to participate in education and training up to the age of 18; and the special educational needs and disability Green Paper recognises that transition to adulthood for disabled young people continues up to age 25.

- We believe that the assessment thresholds and assessment process for PIP should reflect the additional needs of disabled young people between the ages of 16 and 25. This will be in line with the government's position outlined in the Green Paper '*Support and aspiration: A new approach to special educational needs and disability*' which recognised that disabled children and their families need more support than other families and that transition to adulthood for disabled young people is a more complex process that requires additional planning and joint working across the range of services. To this end, it proposes to introduce a single 'Education, Health and Care Plan' which will identify support needed from birth until the age of 25.
- We are concerned that the draft assessment criteria are based on a medical model of disability and do not take into account the wide range of social and environmental factors that have a huge impact on the lives of young people. We believe that social and environmental factors, as well as the changing nature of these factors in the lives of young people, should be reflected in the PIP assessment and thresholds for this age group.
- To enable disabled young people to participate in PIP assessments effectively, the assessment process itself should take into account the information and support needs as well as experiences of this age group. It should recognise that for young people this will be their first experience of applying for this benefit in their own right and that they are in the process of developing the skills and knowledge to enable them to live independently. It is important that good quality accessible information is provided to young people about PIP assessment; that young people are offered advocacy support to prepare for assessments and attend face to face consultations; and, that assessments and scheduling of face to face consultations are flexible to meet the educational needs of young people.
- To ensure consistency and good quality assessments for young people we would like to see PIP assessments delivered by a group of professionals who are trained to work with this age group and have a good understating of the additional needs of disabled young people.
- We support the recommendation made by EDCM that additional activity 'Preparing for Adulthood' is considered in assessments for this age group to better reflect the experiences and additional needs of disabled young people.

Questions 1-4 on activities and thresholds.

We believe that the experiences and opportunities that disabled young people have as they transition to adulthood lay the foundations for their future life chances and their well-being. Therefore, it is critical that PIP is available to disabled young people at this important time and that the assessment for PIP adequately reflects the needs of children and young people which are very different to those of adults as recognised by the government².

² The Government's response to the consultation on Disability Living Allowance reform. Department for Work and Pensions, April 2011.

Disabled young people are also more likely to incur higher costs associated with establishing independent living for the first time. We believe that the weighting during PIP assessments should reflect the higher costs that disabled young people face as they move from childhood to adulthood.

We have expressed our concerns in responses to previous consultations on changes to DLA that the reform is driven by the need to make savings³⁴⁵. We are concerned that the current assessment process may result in young people not getting the right level of support as the assessment does not adequately take into account their experiences.

- **Experiences of independent living**

Young people at the age of 16 are beginning their journey to independence.

The proposed assessment for activities seems to rely too heavily on assistance from family or carers that young people can use in daily living and mobility activities. This can undermine their ability to learn new skills and establish independent living and explore their options for the future. It is not clear how the availability of such assistance or lack of it is going to be taken into account in assessments and whether as a young person prepares/ moves to live independently it will be possible to reflect these changes in the assessment process.

We also believe that case studies used to model the assessment criteria do not adequately present the process of changes that young people experience when they turn 16. Many of them at this age may be going to colleges or universities, moving into training and employment, relocating to new residential placements and experiencing a variety of other changes relevant to this age group in particular. They will also be learning for the first time skills needed for independent living such as cooking and dealing with finances and using public transport, exploring new social situations outside their familiar environments or communicating with people who are not familiar to them.

Critically, although undertaking activities outlined in the PIP assessment may not pose a risk or be difficult to perform for a young person in familiar situations, in new situations and unfamiliar environments these activities may be more difficult to perform. The PIP assessment should reflect this and support young people to develop the skills they need.

- **Importance of independent social life**

We welcome the introduction of Activity 8 'Engaging Socially' in the assessment for PIP. Disabled young people find it hard to have an independent social life and develop friendships⁶, even though having friends and opportunities to spend time with their friends is one of the factors determining the well-being of a young person⁷⁸.

³ See: www.ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation/

⁴ See: <http://www.dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf>

⁵ the Minister for Disabled People in December shortly after the consultation on DLA was launched: "we are looking at saving 20% of the Disability Living Allowance expenditure in line with the Chancellor's commitment."

⁶ Heslop, P, et al (2002) Bridging the Divide at Transition. What Happens for Young People with Learning Difficulties and their Families? Kidderminster: British Institute of Learning Disabilities.

⁷ Smyth, M. & McConkey, R. (2003) 'Future aspirations of students with severe learning disabilities and of their parents on leaving special schooling', British Journal of Learning Disabilities, 31, pp. 54-59.

The Children's Society's project in York has been running a new scheme funded by Children in Need's Fun and Friendship Initiative. The overall aim of the scheme is for workers and volunteers to play a facilitation role to support 60 disabled young people to identify and meet up with their chosen friends in their homes and in local community settings. The feedback from the parents and young people involved in this scheme is that independent social life is very important for young people but they do not always have opportunities to develop friendships and make friends as other young people of their age do.

'Parents don't want the responsibility of taking disabled young people out, and I don't like to impose on other people to have to take him out. This project prevents me holding back in this way, or over protecting him'

'He is more enthusiastic about trying new things now whereas he used to be scared it 's easier for him going along with his friends instead of just a carer'

Young people involved in the project said:

'Before I joined the scheme I never got to see my friends apart from at school'

'If I wasn't at PACT I wouldn't have as much time with my friends'

'Sometimes I get upset about stuff and seeing friends help me'

'Grown ups sometimes keep things to themselves so I like being with friends my own age'

'I never used to see my friends during holidays and now we go out for pizza and go bowling which I love'

Considering that disabled young people do not have many opportunities for engaging socially and are more likely to experience bullying and therefore have more negative experiences of engaging socially, we are concerned that 'a matter of preference' will be taken into consideration when assessment for this activity is conducted. We believe that young people at this age should be supported to explore new social situations and widen their social networks and that PIP should play an enabling role in making it happen.

Recommendations:

- **We believe that the assessment process and thresholds for PIP should reflect the additional needs of disabled young people between the ages of 16 and 25. This would be in line with the Government's position outlined in the Green Paper 'Support and aspiration: A new approach to special educational needs and disability', which recognised that disabled children and their families need more support than other families and that transition to adulthood for disabled young people is a more complex process that requires additional planning and joint working across the range of services.**

⁸ Gwyther Rees, Jonathan Bradshaw, Haridhan Goswami and Antonia Keung. Understanding children's well-being: the national survey of young people's well-being. The Children's Society, 2010

- **We believe that social and environmental factors as well as the changing nature of these factors in the lives of young people should be reflected in the PIP assessment and thresholds for this age group.**
- **We support the recommendation made by EDCM that additional activity 'Preparing for Adulthood' is considered in assessments for this age group to better reflect the experiences and additional needs of disabled young people.**

Questions 4-7 on assessment process

- **Experiences of transitions**

Young people's experiences of moving into adulthood as well as financial and other forms of support they receive during that time determines their ability to establish independent living and become successful adults who can fulfil their potential.

Disabled children and young people we work with tell us that transition to adulthood can be an extremely stressful experience for them and their families. There is considerable research indicating the difficulties they face including poorly coordinated services, a lack of accessible, comprehensive information about their options for the future⁹ and a lack of experiences for young people to have a say in decisions about their lives¹⁰.

Many disabled young people face considerable difficulties continuing into further education and training, and experience barriers to entering paid employment. As a result, an estimated 30% of young people who had a statement of special educational needs when they were in Year 11, and 22% of young people with a declared disability, were not in any form of education, employment or training at the age of 18 compared with 13% of their peers¹¹. Research has also found that disabled young people at the age of 16 and 25 were four times more likely not to be in employment as their non-disabled peers¹².

Overall the research highlights the anxiety and uncertainty when a young person turns 16 and has to reapply for DLA. Transition workers who are meant to support disabled young people and their families through transition processes also perceive welfare benefits for young people in transition as a complex issue, particularly when young people are living in supported or residential accommodation.¹³

Considering the importance of this period in any person's life but particularly in the lives of disabled young people we believe it is vital that young people can receive adequate PIP support. We are concerned that as a result of the proposed changes many young people who are entitled to DLA will not get PIP as they turn 16.

⁹ Morris, J. (2002) Young disabled people moving into adulthood Foundations. York, Joseph Rowntree Foundation

¹⁰ Ibid 1.

¹¹ Progression post-16 for learners with learning difficulties and/or disabilities; Ofsted, August 2011

¹² Burchardt, T (2005) *Frustrated Ambition: The Education and Employment of Disabled Young People*. Joseph Rowntree Foundation, York, UK.

¹³ Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and costs. <http://php.york.ac.uk/inst/spru/pubs/child.php>

It is also important to ensure that the assessment process itself is carried out in an appropriate way for this younger age group; the process must not result in increased anxiety for the family at a time when many families are already under a huge amount of stress.

- **Shared understanding of language used**

It is important that terms used to assess a young person's ability to undertake activities have clear explanations that are applied consistently by all assessors. For example, using 'reliably' which is explained as 'to a reasonable standard' may be open to interpretation and may result in different levels of PIP awards across the country. It is important that there is consistency and shared understanding of terminology used by professionals assessing young people.

It is also important that the assessment process and thresholds are explained to young people appropriately. Information needs to be produced in accessible formats to enable young people to adequately prepare for assessments.

Young people may require help preparing for assessments. Many young people have family and carers who can support them but for some young people, particularly those in care of the local authority, this help may need to be provided in the form of independent advocacy.

We support the recommendations made by EDCM in their submission that assessments of young people should be undertaken by a group of professionals who only assess this age group and who have been specifically trained to understand the needs and experiences of disabled young people.

- **Flexibility in the way the assessment is conducted.**

The assessment process and regulations governing how it is going to be conducted need to reflect the young people's experiences of everyday life. For example, a face to face assessment which requires a person to participate in a consultation at a place, date and time determined under the regulations may be inappropriate for children who will need additional support and preparation to explain their level of needs to the assessor or may find it upsetting to talk about their circumstances and experiences with a stranger.

Young people may also need a different schedule of assessments that will not interfere with their participation in education and training. Negative determination can be made if a person fails without a good reason to participate in assessment. As the age of participation in education and training rises¹⁴ assessments for children will have to be scheduled around times that the child participates in education and training, which may lead to delays with decisions, missed assessments and even negative determinations on the basis of a failure to turn up for an assessment.

¹⁴ The Education and Skills Act 2008 increased the minimum age at which young people in England can leave learning, thus requiring them to continue in education or training to the age of 17 from 2013 and to the age of 18 from 2015. This is a fundamental change and also means that young people are less likely to be earning a wage from the age of 16, as before.

Recommendations:

- To enable disabled young people to participate in PIP assessments effectively the assessment process itself should take into account the information and support needs as well as experiences of this age group. It should recognise that for young people this would be their first experience of applying for this benefit in their own right, that they are in the process of establishing their independence. It is important that good quality accessible information is provided to young people about PIP and assessments, that young people are offered advocacy support to prepare for assessments and attendance at face to face consultations, and that assessments and scheduling of face to face consultations is flexible to meet the educational needs of young people.
- To ensure consistency and good quality assessments for young people we would like to see PIP assessments delivered by a group of professionals who are trained to work with this age group and have a good understanding of the additional needs of disabled young people.

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