

Personal Independence Payment: assessment thresholds and consultation

About Contact a Family

Contact a Family is the only UK-wide charity providing practical and emotional support and information to families with disabled children and young people – regardless of disability or health condition (0-19 years). We deliver this through local, regional and nation offices plus family workers and volunteer parent representatives. We enable parents to get in contact with other families through a family linking service, our network of parent support groups and online resources. We pioneered and continue to support the development of parent participation, promoting partnership working between parent carers and decision makers and services.

Our freephone helpline offers a one stop shop advice service to families on any aspect of caring for a disabled child including welfare rights, community care issues, education needs and housing issues with access to interpreters. Last year we supported more than 340,000 families through our range of services. We give families with disabled children the skills and confidence to live the lives they want to lead.

Background

Families with a disabled child face two specific financial challenges in addition to those faced by all families. Firstly they incur considerable additional and ongoing costs caring for their child - it costs three times as much to raise a disabled child¹. Research by Contact a Family² has shown that many families with a disabled child already struggle financially - almost a quarter are going without heating, more than half have borrowed money from family or friends to keep financially afloat or pay for essentials, and more than a third have fallen behind with repayments on debts such as credit cards. In addition parents with a disabled child will face specific difficulties in sustaining employment due to the demands of juggling work and caring. Consequently disabled children, young people and their families are at greater risk of living in poverty³.

Disability Living Allowance plays an essential role in helping to mitigate the financial pressures that families with disabled children and young person commonly face. It provides a pool of income that a family can use to meet a whole range of disability related costs, helping them to participate in everyday activities and acts as a

¹Paying to Care: the costs of childhood disability by Barbara Dobson and Sue Middleton

²Counting the Costs 2010, Contact a Family

³Department of Work and Pensions 2006/07 Households Below Average Income showed the risk of relative poverty for families with a disabled child but no disabled adult family member has increased from 20% to 25%, meaning disabled children are now at greater risk of living in relative poverty than non-disabled children.

gateway to a range of other forms of financial help for disabled children and young people.

The transition from childhood to adulthood is a notoriously difficult time for many disabled young people, with many parents describing it as like 'standing on the edge of a cliff, about to fall into a black hole'⁴. This transition period is difficult for a range of reasons but largely due to the large amount of changes in support that take place as someone reaches 16. As someone moves from child to adult health and social care services this can often lead to breaks in support. It is also the point at which many disabled young people leave school and can find themselves not in employment, education or training.

Contact a Family welcomes the government's determination to make the process of claiming DLA simpler and more transparent. We also welcome the fact that the government's proposals for the Personal Independence Payment (PIP) make clear that the benefit will be non means-tested, will retain special rules for the terminally ill and will continue to provide help with the extra costs of a disability. However we continue to question the assumption that Disability Living Allowance is no longer fit for the purpose and in need of the scale of reforms proposed.

Contact a Family welcomes the Government's decision not to extend PIP to disabled children under 16 and would urge the government to consider delaying the extension to 16-25 year olds until the new system has been fully evaluated.

The last two years have seen the government announce a number of planned changes to the benefits system. Taken together these changes will amount to the biggest shake-up of the welfare system in generations. The cumulative impact on families with disabled children and young people is huge, ensuring they have access to specialist information, advice and advocacy is vital.

We are concerned that disabled young people and their families will need targeted support as they move between the two benefits. Additionally due to the higher costs associated with someone establishing independent living for the first time we believe that the weighting during PIP assessments need to reflect the higher costs that disabled young people face as they move from childhood to adulthood. Contact a Family is concerned that this targeted support needs to be in place prior to the introduction of PIP.

From October 2013, all disabled young people who want to continue to receive support through PIP will be assessed when they turn 16. This trigger for reassessment means that disabled 16 year olds will be one of the biggest groups moving onto PIP when it is first introduced in 2013. We are concerned this makes them very vulnerable to any glitches in the new system which are a risk when a new benefit and accompanying IT system are launched.

Concerns have been discussed in Parliament and the Minister for Disabled People, Maria Miller stated: *"I urge the hon. Lady not to make the assumption, at this stage,*

⁴ House of Commons (2006) Parliamentary hearings on services for disabled children

that 16-year-olds would be the first to go through the new assessment, because that may or may not be the case. We want to look at it in great detail.⁵ The Minister for Welfare Reform, Lord Freud, also said *“We have the power and flexibility to treat 16 year-olds differently. This includes different assessment processes during the migration period. We are working actively now with children's groups to make sure that we have the right migration strategy for youngsters and to finalise it. We will publish that approach.”⁶*

For many disabled young people their support needs relating to transition run until the age of 25. It is vital that as PIP is introduced there is adequate support in the system to meet the needs of the 16 - 25 age group, that the assessment process is carried out in an appropriate way for this younger age group, and, fundamentally this process does not result in increased stress for the family at a time when many families are under a huge amount of stress.

Contact a Family's research Counting the Costs 2012 due for launch in May 2012 will provide additional information about how families with disabled children/young people are feeling about the changes to the benefits system.

Contact a Family attended the Every Disabled Child Matters (EDCM) consultation workshop on the 20th April 2012. Contact a Family is a leading member of EDCM. This response is based on the EDCM submission but also reflects views from Scotland, Wales and Northern Ireland.

The principles that underpin the design of the assessment criteria for disabled 16 – 25 year olds should be:

Consultation

Contact a Family is part of the Specialist Young Person Panel, which is a subgroup of the PIP Implementation Development Group. The Specialist Young Person Panel has been developed to look at the ways that PIP can be designed to help meet the needs of disabled young people aged 16 - 25. However we are concerned that as of yet we have seen limited evidence that the Government has sufficiently consulted with disabled young people and their families on PIP, or with the wide range of organisations that work with disabled young people.

We believe it is vital that the Government works directly with disabled young people and the organisations that support them to ensure the design of a benefit and assessment process that works for them. Whilst we value the opportunity to be part of the Specialist Young Person Panel, we would be very concerned if the consultation through the Specialist Young Person Panel was the main consultation that the DWP undertook on how PIP will be designed for 16 – 25 year olds.

Adequate financial support

⁵<http://www.publications.parliament.uk/pa/cm201011/cmpublic/welfare/110512/pm/110512s01.htm#Column913>

⁶ Hansard Citation: HL Deb, 17 January 2012, c481

Disabled young people are more likely to have grown up in poverty than their non-disabled peers. They are also more likely to go on to live in poverty as adults; largely this is due to greater barriers to the work place resulting in disabled young people being disproportionately likely to be Not in Education, Employment or Training.

The National Youth Agency in 2009 found that young people dependent on benefits such as Job Seeker's Allowance could not meet essential costs such as rent, food and utility bills, let alone engage in positive activities or go out with friends, and that this resulted in social isolation and depression. This level of hardship also made it very difficult to obtain suitable clothing or meet travel costs to work or training, creating a vicious circle⁷. Costs are particularly high when people are moving towards living independently for the first time.

A recent study found that DLA is especially important for disabled people seeking employment, because it is secure income and therefore provides some cover for the risks they face in coming off other benefits⁸.

Smooth transition process

The transition from childhood to adulthood is a notoriously difficult time for many. Whilst we welcome the Government's decision to only move working age adults onto PIP at this time we are concerned about the impact that having two benefit systems may have on disabled young people as they turn 16 in 2013 and beyond. Contact a Family has been worried that because all disabled young people who want to continue to receive support through PIP will be assessed when they turn 16, that disabled 16 year olds will be one of the biggest groups moving onto PIP when it is first introduced in 2013. Our concern is this will make them very vulnerable to any glitches in the new system.

Contact a Family welcomes the Government's commitment that disabled young people will continue to receive DLA until the outcome of the PIP assessment has been made. However we recommend that to safeguard against disabled young people being disadvantaged by being one of the first groups to be moved onto PIP and so risk unfairly losing their benefits that if a young person wants to appeal the decision made on their PIP award that they are able to continue to receive DLA until the outcome of this appeal. We recommend this protection is put in place until at least 2016 by when all working age adults will have been contacted about moving onto PIP⁹.

Appropriate assessment

It is vital that the DWP considers how the specific needs of disabled young people are taken into account when designing the assessment process for PIP, and in particular face to face assessments. The Consultation document, *Personal Independence Payment: assessment thresholds and consultation* gives details about the trial assessments that have taken place to assist the DWP in designing an

⁷ The National Youth Agency (2008/9) Young people, economic wellbeing and financial capability

⁸ Hendey and Pascall (2001) Disability and Transition to adulthood: Achieving Independent Living

⁹ DWP (2012) Personal Independence Payment, Frequently asked questions

appropriate assessment. We know this is an area that the Government is already looking into. There have been statements from the Government that they are piloting the use of the single Education, Health and Care assessment in making PIP and DLA awards. The Work and Pensions select committee has also made recommendations on assessment for 16 – 25 year olds. We detail our thoughts on these ideas below as well as other important factors that need to be taken into account when designing assessments for this age group.

Face to face assessments

The Government has indicated that it intends that most people being assessed for PIP will have a face to face assessment¹⁰. Contact a Family has heard from many parents that feel face to face assessments can be very stressful for disabled young people and can cause great harm to the self esteem. It is unrealistic to expect most children and young people under 25, and particularly under 18, to present accurate information on the impact of their disability to an unfamiliar professional.

The SEND single assessment in England

The Green Paper, *Support and Aspiration: A new approach to special educational needs and disability*¹¹ proposes that: *'In order to reduce the number of assessments a family has to undergo, we will use learning from these assessments and plan pathfinders in local areas to explore whether the single assessment process might also be used to support claims for the Disability Living Allowance and Personal Independence Payment.'*

Contact a Family is deeply concerned by the risks that using the single assessment process for making decisions about DLA and PIP awards presents. We would not support moves to incorporate the assessment for PIP with assessment for wider services. Eligibility for services and eligibility for benefits and financial support are based on different criteria. While we welcome any move to make applications for financial support simpler, it is crucial that direct financial support is not conflated with budgets to fund the procurement of services. It is also vitally important that decisions about benefits are not based on the opinions of professionals who have only a snapshot view of a child or young person's life in a particular context – e.g. a teacher would only see a child in a school context and would have no knowledge of night time care needs.

Additionally the pathfinders who are looking at the single assessment will not have had sufficient time to test out the whether using the single assessment process is appropriate by the time that PIP is introduced – the findings from pathfinders are expected in 2015. As we have said previously we think it is vital that the Government implements a support structure for 16 year olds moving onto PIP upon its introduction in 2013.

Assistance of a school or college

¹⁰ DWP (2012) Personal Independence Payment, Frequently asked questions

¹¹ Department for Education (2011) *Support and Aspiration: A new approach to special educational needs and disability*

Contact a Family also notes the report by the Work and Pensions Select Committee inquiry on *Government support towards the additional living costs of working-age disabled people*. We strongly welcome the Report's recommendation that "*We recommend that this cohort [16 – 25 year olds] should be the last to be migrated to the new benefit.*" This would enable the Government to undertake sufficient consultation with disabled young people to facilitate the design of a benefits system that is supportive and enables people to have independent lives. Additionally it would remove concerns that the large group of 16 year olds that will be amongst the first people to be assessed for PIP will bear the brunt of any glitches that may accompany the rolling out of a new benefit system.

However we are deeply concerned about a further recommendation the report makes that "*One option which should be explored is for the reassessment at the time of the migration to PIP to take place in, and with the assistance of, the young person's school or college.*" We believe it would be deeply inappropriate for a young person to require the assistance of staff at their school, such as their teacher, for a PIP assessment to take place. This would be an activity outside of a teachers remit and they will therefore not have received sufficient training to provide adequate support to their disabled pupil. Furthermore there are very personal issues discussed during an assessment for DLA and will be for PIP – such as personal care needs that would not be appropriate for a teacher to hear about. We fear that including school staff in an assessment could result in the young person underplaying the significance of the issues that they face because they are embarrassed.

The Government has signalled that disabled people will be able to choose to have someone attend their face to face assessment with them, and for some people they may chose to be supported by their teacher or someone who works at their school. This should remain a choice for those for whom it is appropriate but should be recognised for many people having a staff member from their school attend their assessment would not be appropriate.

Assessment thresholds and consultation

Q1 – What are your views on the latest draft Daily Living activities?

*"You can't just say, 'Do you want to go shopping?' I have to say, 'Do you want to go shopping next... whenever' I can't just say to my mum, 'I'm going out now' like a normal teenager. I have to say, 'I'm going out on Saturday' so she can help me sort things out."*¹² Bex, aged 17

On April 20th 2012, EDCM held an expert consultation event with representatives from 20 organisations with an interest in issues relating to disabled children. We also received written submissions from two further organisations. Our consultation with the disabled children's sector has allowed us to look at the proposals put together under *Personal Independence Payment: assessment thresholds and consultation* to see how they would work for disabled young people. As well as to see how the

¹² EDCM (2008) Going Places!

proposed assessment thresholds may need to be altered to meet disabled young people's needs. Our consultation response outlines the views we collected at this event.

Assessment for the daily living element of PIP

At EDCM's expert workshop we established nine principles of assessment. These reflect things that should both be taken into account when reviewing the activities and descriptors, and by assessors carrying out assessments.

Establishing independent living

Whether disabled young people would be able to establish independent living as a result of the proposed PIP assessment is of crucial importance. However concerns have been raised that at the moment the proposed PIP assessment will not enable young people to achieve independent living.

We are concerned that assistance from families is relied upon too heavily in the proposed assessment and that this will create a vicious circle that will prevent disabled young people from establishing independent living. The proposed thresholds require a significant level of 'assistance', 'prompting' or 'supervision' in a number of activities before eligibility for the standard rate of daily living could be achieved. Given that reduced local authority budgets are leading to raised eligibility criteria for social care services. We queried how people with significant supervision needs in everyday activities would be able to move away from living with their family if they didn't qualify for the standard rate of PIP.

Questions that we seek responses to include:

- How will assistance from family members be taken into account when assessing for PIP?
- What happens when someone has an identified need that isn't being met e.g. can do an activity with assistance but that assistance is not available?
- If someone wants to **prepare** to leave home and will have less support available to them following this, will this be taken into account in their assessment?

Dealing with change

Concerns were raised that the PIP assessment criteria as it stands takes a static approach to people's lives. However to take a 'real life' approach we think it is vital to look at how people can cope with change in their everyday routine. It was felt that this would be particularly important in the assessment of activities 10 and 11 for the mobility element, but also applied to the daily living assessment. For example when assessing activity 7, Communicating, who you are communicating with will have a huge impact on your ability both to understand and convey information. An example would be someone who lip reads – their experience of understanding their

immediate family will be very different to understanding someone they are not familiar with who may use a different dialect.

Coping with change is a particularly important factor when assessing young people as they begin to live their lives independently for the first time and have to navigate themselves through changing circumstances, ensuring they have the right level of support to enable them to do this is key.

Geographical factors

We would like more information from the Government on whether the PIP assessment will take into account your geographical situation and your home environment. Both of these factors can have significant impacts on the challenges you may face, as well as the costs you encounter. Again this was raised most frequently in discussion around the assessment for the mobility element of PIP. Young people between the ages of 16 – 25 are going through many life changes – changing schools, going to college, starting employment. Every time they change environment they will have different levels of need depending on how accessible the environment they are entering is and whether sufficient support is available.

Self esteem

Questions were raised over the extent to which proposed thresholds allow for quality of life, dignity and therefore self esteem. This is an issue that is particularly important to disabled young people as they develop their sense of self for the first time. Negative self esteem during someone's adolescence and early adult years can have life long implications on mental health and therefore inevitable impacts on local health services and budgets.

One example where issues around this were raised was in relation to Activity 5 – managing toilet needs and incontinence. There was a huge amount of concern that this activity only awarded points if you needed assistance to manage toilet needs and incontinence. There was a particular concern on this from parent carers who have reported for many years on the high costs of nappies and continence products. We are concerned that these costs are not acknowledged in the proposed thresholds. For an incontinent young person at college they are going to want to frequently change their incontinence pads and if they are unable to change this as much as they would like to due to the financial costs their self esteem and associated independence is likely to suffer significantly. It is vital these costs are acknowledged in the assessment.

We are also concerned that due to embarrassment disabled young people may be more likely to underplay the impact of their disability during a face-to-face assessment meaning that their assessment will not accurately reflect their abilities.

Risk

Worries were raised about the proposed PIP assessment criteria and their interaction with risk. In terms of both the evidence that will be required to prove risk

and the level of risk that is seen as acceptable prior to someone becoming eligible for the daily living component of PIP.

We have concerns about whether disabled young people would have enough experience to establish how risky an activity is for them. For example under Activity 10 there is the requirement for 'evidence that overwhelming distress has/would occur, not just that it might'. We are worried that many disabled young people at the age of 16 with high level needs will have had little opportunity to go out without their parents on a journey. It is unlikely there will be the level of evidence needed to accurately assess young people against this activity. This could result in many young people being assessed incorrectly and receiving less support than they to help them establish independent living.

We are additionally concerned that because disabled young people have less life experience they are less able to assess an activity as 'risky' for them. At a life stage when many people want to push the boundaries of what they are able to do, this is likely to be a particular issue.

Reduced financial support

There are significant concerns about the impact of the increased eligibility criteria for the standard rate of PIP compared to low rate care component of DLA. Due to DLA continuing for under 16s this will mean a big increase, or loss of, disability related financial support for many young people as they move to adulthood. This will create significant barriers in establishing independent living.

We are also very concerned about the lack of recognition within PIP of night time care needs. When assessing for DLA, night time care needs are recognised through allocation of the high rate care component of DLA. Substantial night time care needs are likely to make entering employment significantly more difficult as people will not be able to focus during the day time hours. We have significant concern, for example, about families who give a huge amount of care at night, for example because their child is epileptic, but do not have significant care needs at other times of the day.

Many of these families will have to cope from receiving high rate care DLA to potentially no, or a significant reduction in financial support. Additionally, if they receive no PIP award then their family will also lose their eligibility to Carer's Allowance. We are concerned that this could lead to many families quickly entering crisis as a young person turns 16. This could lead to higher numbers of young people entering residential care at significant cost to the state.

Fluctuating conditions

We share the concerns of the Disability Benefits Consortium (DBC) that requiring someone to prove they have a level of need 50% of the time is going to be difficult for individuals to calculate. In addition, we support the DBC's concerns that those who experience severe fluctuations which result in considerable costs for significant amounts of time that amount to less than 50% of days are unlikely to score any points and that this is unsatisfactory.

Language

There was a lot of concern and confusion over the terminology used in the proposed assessment criteria. The biggest fears were that some of these terms would be open to wide interpretation and this could lead to different awards across the country, such as 'overwhelming psychological distress', 'a matter of preference' and 'appropriate'. We feel that much more guidance needs to be given to assessors on these terms. We go into more detail on our concerns on these terms in the rest of our response.

Preparing for adulthood

It is clear that there are a wide range of additional factors that need to be taken into account in assessing disabled young people as opposed to the rest of the adult working age population. In particular the need to take into account the impact that providing sufficient financial support at this crucial age can have on the life chances of that individual. This in turn has long term implications on the funding the state provides to support that young person.

In the Green Paper, *Support and Aspiration: A new approach to special educational needs and disability*, the Government identifies the value of targeting support on this age group. We therefore call on the Government to consider looking at creating a separate activity 'Preparing for adulthood' to be included in PIP assessments for 16 – 25 year olds. This activity would assess what level of support disabled young people need in these transition years to develop the skills and support needed for independent living. For example assessing whether someone was developing their independent travel skills for the first time because they were just about to receive guide dog training, or, whether someone was looking to move out of home and is developing the skills needed to employ a Personal Assistant. If this additional activity was able to provide disabled young people with 2 additional points in either the mobility assessment, daily living assessment or both we believe this would be beneficial to young people and their families, and to the Government both in reducing the long term benefits bill of this group and in achieving its aims to support disabled young people in their move to adulthood¹³.

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

At the expert workshop EDCM held there was broad concern about some of the low scores that will be awarded to people who need supervision or support to do activities that are necessary for living independently and leading an ordinary life. We are particularly worried for example about the impact on someone similar to 'Pete' as described in case study 4. Pete is likely to currently be able to access the low rate care component of DLA. Pete has support needs that will mean he cannot live independently unless he is able to access daily support so that he can bathe and prepare a meal. We are concerned that if he does not meet the LA eligibility criteria for social care then he will struggle to ever live independently. This is something that is of growing concern as LAs operate in tighter budgets and are raising their

¹³ Department for Education (2011) *Support and aspiration: A new approach to special educational needs and disability - A consultation*

community care eligibility – with many areas only providing assistance to disabled people with ‘critical’ or ‘substantial’ care needs.

The Convention on Rights of People with Disabilities is the newest of the UN Human Rights Treaties ratified by the UK in June 2009. Article 19 recognises the equal right of disabled people to live in the community with choices equal to others. In particular there is a duty on states to ensure that “Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.” We are concerned that if financial support is withdrawn from people like ‘Pete’ then the opportunities for choosing places of residence is significantly reduces, as he will have to remain at home to access support from his family.

“Everyone should be treated as an individual, with the same rights of access to leisure, education, health, support, transport, personal development and appropriate housing as everyone else. Even if that means they need much more support and input to achieve equality. We are not asking for more rights, just the right to equality.” Roger¹⁴

There are benefits to the state to be gained from supporting disabled young people to live independently. “Independent Living” means that disabled people have access to the same life opportunities and the same choices in every day life that their non-disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, being educated in the local neighbourhood school, using the same public transport, getting employment that is in line with their education and skills, having equal access to the same public goods and services. Most importantly, just like everyone else, disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others¹⁵.

A report by the Office for Disability Issues (ODI) states that Independent Living options are often more cost effective than conventional systems of support¹⁶. Work by the British Association for Supported Employment (BASE) found that the benefits of commissioning high quality, outcome-focused supported employment for disabled people, indicate to average annual savings of £1290 to councils and over £3500 to the taxpayer for every disabled person in work. The study considered changes to welfare benefit entitlements, the cost of services received and tax and national insurance payments before and after employment¹⁷.

Despite the benefits of supporting disabled people to live independently disabled young people are less likely than their non-disabled peers to live independently of their parents¹⁸. By the age of 26, disabled young people are nearly four times as likely to be unemployed or economically inactive, as non-disabled young people¹⁹.

¹⁴ EDCM (2009) Disabled children’s manifesto for change

¹⁵ Jane Campbell (2004) quoted in Office for Disability Issues, (2007) *The costs and benefits of independent living: Executive Summary*

¹⁶ Office for Disability Issues, (2007) *The costs and benefits of independent living: Executive Summary*

¹⁷ British Association for Supported Employment

¹⁸ Hirst, M. & Baldwin, S. (1994) *Unequal Opportunities: Growing up Disabled*. London: HMSO.

Contact a Family strongly believes that for the state to reap the cost savings from Independent Living, it is vital that disabled young people are able to access sufficient financial support through PIP. Even with current levels of financial support through DLA, disabled people aged 16–35 are the most likely of all age groups to say that they had severe financial difficulties²⁰. Limited financial resources reduce the possibility of ‘Independent Living’ for disabled people, with 23% of disabled people already citing lack of money or cost as one of the main barriers to them participating in more social activities²¹. Through investing in disabled young people at a time when they are developing the skills, support network and organising support to enable ‘Independent Living’ there will be long term financial benefits to the state.

We have the following specific comments on how we believe the activities that will be assessed to establish eligibility for the daily living component should be altered to support young people to establish independent living:

Activity 1: Preparing food and drink

Preparing food and drink is one of the main ways that young people are recognised as different from children in the current DLA assessment. It is therefore already established that it is only as children turn 16 that they will begin to cook independently for the first time.

Given the potential hazards of the kitchen and the lack of life experience that young people will have in cooking we think it is vital that when assessing young people assessors take into account whether people can react to the dangerous risks of the kitchen, such as small fires, spitting oils etc.

Disabled young people may also for the first time be given the freedom to start to choose their own diet. However, again due to lack of life experience they may struggle to be able to achieve a nutritious diet. For disabled young people with poor health this could have particularly negative impacts on their health condition. We therefore think it is also important to take into account a young person’s ability to choose a nutritious diet.

Activity 2: Taking nutrition:

In the assessment of a young person’s ability to manage a therapeutic source to take nutrition we think it is vital that assessors take into account additional support a young person may need to learn how to manage their therapeutic source independently. For example learning about the care and cleaning of equipment as well as how to prepare food appropriately for the therapeutic source. Learning how to do this independently will significantly increase a young person’s independence but will require a high level of input from others to safely learn how.

¹⁸ Office for Disability Issues, (2007) *The costs and benefits of independent living: Executive Summary*

¹⁹ ODI (year) *Independent Living: A cross-government strategy about independent living for disabled people*

²⁰ ODI (2008) *Experiences and Expectations of Disabled People*

²¹ ODI (2008) *Experiences and Expectations of Disabled People*

Concern was also raised about disabled young people who have the physical ability to feed themselves but to do so uses up so much energy that they will lose weight. Given the reduced opportunities that a young person has had to manage eating on their own, queries were raised around how the young person would be able to prove the detrimental impacts to their health of undertaking this activity alone.

Activity 3: Managing therapy or monitoring a health condition:

We support the DBC's concerns that 'managing therapy or monitoring a health condition' has unacceptably low scoring. We are also very concerned about the lack of overt recognition of night time care needs for people managing a complex health condition. In DLA the additional strain of night time care needs are recognised through allocation of the high rate care component of DLA. It is already well recognised that substantial night time care needs are likely to make entering employment significantly more difficult as people will not be able to focus during the day time hours.

However under the proposed changes families who give a huge amount of care at night, for example because their child is epileptic, but do not have significant care needs at other times of the day, will have to cope with the drop from receiving high rate care DLA to potentially no, or a significant reduction in financial support. We are concerned that this could lead to many families quickly entering crisis as a young person turns 16. This could lead to higher numbers of young people entering residential care at significant cost to the state.

Activity 4: Bathing and grooming:

We fear that compared to the rest of the working age population, disabled young people are more likely to become embarrassed of the assistance they require when discussing personal care such as bathing and may underplay the level of support they require.

Concern was also raised at our expert workshop that the working definition of 'grooming' is very narrow. For instance ability to cut toe nails, apply make up, do your hair as you want to will be very important to disabled young people and their self esteem, but are not included in the assessment. Again we believe that ensuring people are able to develop a good level of self esteem in these adolescent years has long term implications on independent living for young people.

Activity 5: Managing toilet needs or incontinence:

We are confused as to why being incontinent doesn't score any points by itself if it is 'managed'. There is a significant wealth of evidence on the additional costs relating to incontinence such as buying additional clothes, extra washing and buying incontinence products as there is evidence that some PCTs place limits on the number of continence products that people can receive²². It is vital these extra costs are taken into account when scoring for PIP awards.

²² See: <http://www.edcm.org.uk/campaigns-and-policy/health/nappies-campaign.aspx>

As we mentioned in our response to Question 1, we are additionally concerned of the impact of this omission on the self esteem of young people. For an incontinent young person at college they are going to want to frequently change their incontinence pads and if they are unable to change this as much as they would like to due to the financial costs their self esteem and associated independence is likely to suffer significantly. It is vital these costs are acknowledged in the assessment.

We are also concerned that due to embarrassment disabled young people may be more likely to underplay the impact of their disability during a face-to-face assessment meaning that their assessment will not accurately reflect their abilities.

Disabled young women aged 16 – 25 are also likely than other age groups to have to begin managing their menstruation for the first time and it was felt that dealing with this activity for the first time should be recognised in the assessment for PIP. Disabled young women with learning disabilities can require particular assistance with this.

Activity 6: Dressing and undressing:

The clothing we wear helps to define us as individuals. For young people in particular this is an important way of expressing personality and individuality. There was some confusion on the scoring of descriptors D and E as there was concern if someone needed assistance for both their lower and upper body what descriptor they would be awarded. It was therefore felt these two descriptors should be amalgamated into one 'Needs assistance to dress' and that they score on this should be increased above 4 to recognise the level of assistance needed.

Activity 7: Communicating

Contact a Family believes that no-one 'cannot communicate at all', children have may be non-verbal but still develop communication in other ways. It is therefore unclear as to whom would be assessed as meeting descriptor G – is this intended to be for people who are non-verbal? There needs to be much clearer guidance on this point.

In addition other things that we think need to be taken into account when assessing young people is that young people will for the first time be developing the skills and confidence to communicate in unfamiliar situations and environments. This may mean that they will not be able to accurately know the challenges they will face when doing these things on their own.

Assessment of young people with speech, communication and language needs is something we are particularly concerned about due to the 'false environment' of an assessment centre. By this we mean that assessors will have difficulty in gauging how people are able to interact in real life situations with background noise, and without a parent or carer who is likely to have attended the face-to-face assessment with them.

Activity 8: Engaging Socially

Contact a Family welcomes the inclusion of the new activity 'engaging socially' in the assessment for PIP. One of the biggest challenges that disabled young people face is becoming socially isolated as they are unable to participate in activities with their peers due to lack of support. With this in mind we think it is vital that when the activity 'engaging socially' is being assessed that assessors take into account whether the social activities a person is able to participate in are age appropriate. The activities and risks that we undertake as teenagers enable us to build the skills to live independently throughout life. Providing support to disabled young people to engage socially also means that they are much more likely to have a friendship group of both disabled and non-disabled friends, which is something disabled young people repeatedly tell us they want.

Queries were raised at the expert workshop EDCM ran on the inclusion of the statement 'a matter of preference'. We believe that it will be extremely challenging when assessing disabled young people whether this really is a matter of preference or something they feel unable to do due to lack of support or confidence issues. Disabled young people are more likely to be bullied than non-disabled young people - 80 per cent of young people with a statement of educational need or a disability have been bullied, compared with under two thirds for other young people²³. Given the impact of bullying on self esteem and the courage then needed to build new friendships we believe it will be particularly difficult for disabled young people themselves to establish whether they do not engage socially as a matter of preference or not.

Additionally concerns were raised around why descriptor (d) (i) has been limited to those with a mental health condition, intellectual impairment or cognitive impairments. It was felt that this could be discriminatory against people with physical disabilities and does not recognise the issues of anxiety and panic attacks when socially engaging for many disabled people if they do not have sufficient support.

Activity 9: Making Financial Decisions

The inclusion of a descriptor on *making financial decisions* is very welcome for disabled young people. This is again another activity that marks a disabled young person's move to adulthood. Upon turning 16, for example, a disabled young person will be able to receive their PIP directly into their bank account for the first time. Providing sufficient support to make financial decisions at this stage in their journey to establishing independent living is therefore particularly important.

However it was felt that descriptors at the moment are too limited as there is no ability to award someone points who needs support and/or assistance to make financial decisions to recognise the additional support the needs to be put in place in this scenario. There currently seems an extremely big jump between needing prompting to not being able to make any financial decisions at all. Disabled young people would significantly benefit from a wider range of descriptors under this activity.

²³ Reference to be added

Q3 – What are your views on the latest draft Mobility activities?

As with the daily living component, we again established some key principles to both reform and assessment:

Establishing independent living

Being able to get out and about is a key stepping stone to establishing independent living. We therefore believe that there should be capacity within the assessment criteria to reflect the additional support and costs involved as disabled young people develop mobility skills for the first time. Helping young people establish independent use of travel at this time will help them throughout their life, will enable them to gain vital life experience and access education and employment. 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 not in education, employment or training (NEET), compared to only 7% of non-disabled people²⁴. 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.

Dealing with change

We believe it is vitally important that the assessment for the mobility element of PIP takes into account how people can cope with change in their everyday routine. Taking account of dealing with change would make the assessment much more 'real life' based and provide people with the right level of support. Things such as coping with change to public transport routes when things go wrong such as a tube line is closed, or a bus terminates early or is diverted. It would also be helpful to think about how young people can navigate a familiar route with changes such as bin day, or if it is icy or has snowed.

Geographical factors

Concerns were raised about how assessments will take into account your geographical situation, as this will have a significant impact on your ability to get to places, as well as the costs you face. Concerns were particularly raised about someone who lives in a rural or suburban area where local shops and public transport hubs are more than 200meters away. These people will be disabled by their surroundings and will find it much more difficult to achieve independent living without significant support.

The Motability Scheme:

Contact a Family of disabled young people is concerned about the impact of the changes to the entitlement thresholds for mobility activities and the impact that this will have on disabled young people being able to access a Motability vehicle.

²⁴ Add reference

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 buses²⁵. These difficulties accessing transport mean that disabled people travel a third less often than the general public²⁶. 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."²⁷ Kim

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."²⁸ Becky aged 21

Contact a Family is concerned that the new weightings and entitlement thresholds will reduce the number of people able to access the Motability scheme. 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.

It is currently proposed that if someone is able to independently plan a journey, they will only be able to access the higher rate of the mobility payment if they are a wheelchair user. We would be concerned that this would significantly impact on the ability of disabled young people with impairments that restrict their mobility but don't cause them to need to use a wheelchair from leading an independent life.

We would be particularly worried that people who 'cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device' will not be entitled to the higher rate mobility component of PIP. These young people, will have significant mobility needs that will not be met. Many of the young people currently in this category will get a mobility vehicle as a child but will lose it as they move to adulthood. Additionally along with the loss of the ability to access a mobility

²⁵ DWP (2002) 'Disabled for life?' attitudes towards and experiences of disability in Britain. (cited from improving the lives of disabled people, 2004, PMSU)

²⁶ Disabled Persons' Transport Advisory Committee (2002) Attitudes of disabled people towards public transport, DPTAC (cited from improving the lives of disabled people, 2004, PMSU)

²⁷ EDCM (2008) Going Places!

²⁸ Council for Disabled Children (2011) Young, Disabled and In Control

car, these young people will also have more difficulty in accessing a blue badge.

Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

Contact a Family would welcome a more joined up approach in the assessment of activities 10 and 11. It feels that people with physical impairments are very much excluded from activity 10. This separation risks missing the full spectrum of disabilities and not providing disabled young people with the right level of support they need to establish independent living.

For young people establishing the skills needed to get out and about for the first time they are going to have different abilities to identify risk, respond to challenges in the environment, solve problems and overcome obstacles than the rest of the adult population as they will be establishing this experience and knowledge for the first time. How a young person will need to be taught these and increase their confidence in getting out and about will be vital to establishing independent living. However it may be that additional support is initially needed to enable them to do this.

Activity 10: Planning and following a journey

Concerns were raised over the use of the term 'overwhelming psychological distress'. This was seen to be inappropriate, reflecting a very medicalised view of disability. It was also seen as vague and open to interpretation by assessors. We are also concerned about what evidence would be needed to prove there would be 'overwhelming psychological distress'. This is the point in someone's life when they will be going out and about independently for the first time, they therefore are unlikely to be able to know the impact of doing so independently. We are concerned that having to provide this level of evidence may lead to someone undertaking undue risks and then being reassessed when it becomes clear the impact of taking those risks.

Concern was also raised at the expert workshop EDCM held, that providing that you need prompting to complete a journey only due to 'overwhelming psychological distress' is too limiting and that people may need prompting because of behaviour such as sitting down in the street or refusing to get off the bus. It was also highlighted that many young people need support to undertake journeys for example so they can process what announcements mean and talking to the bus driver but it was unclear if this was covered at the moment.

Again as young people will be establishing mobility skills for the first time the support needed to establish mobility skills need to be taken into account such as problem solving, staying safe, responding to changes (e.g bus cancelled).

Finally it was felt that descriptor D was scored too low and that disabled young people with this level of need would require the higher level of mobility support otherwise they have a high risk of becoming house bound. To limit financial support for this group of young people would have a significant impact on their life changes.

Activity 11: Moving around

There is a general level of concern over the distances that have been picked under Activity 11 and the impact this will have on independent living. A 'whole life' approach needs to be taken that considers people's ability to undertake an activity once they have completed their journey e.g. how someone copes with both getting to college, supermarket etc and then moving around once they have arrived.

Whilst we recognise that there will be some level of financial support available to people who are entitled to the lower mobility component of PIP we are concerned that this does not fully meet the cost of the barriers to transportation that the people in this group will face. For example if someone can move up to 50 meters unaided and then no further, but needs to travel on public transport to get to the shops. It is very unlikely they will be able to shop independently and will require taxi's and assistance in the shop. We are also concerned for young people who are attending college who will now need to get taxi's everywhere because they cannot move more than 50 meters unaided. Their costs for transport will quickly rise and they will also be limited in the number of 'ordinary life' activities they can take part in with their friends outside of college.

We are similarly concerned that disabled young people, who can walk more than 50 meters but less than 200 meters unaided or using an aid or adaptation other than a wheelchair or a motorised device, will have no financial support at all to recognise the additional costs of getting around. This is likely to severely impact on the ability of these young people to live independently.

Q7 – What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?

The definitions of safely, timely, repeatedly and 'in a timely manner' will be of crucial important to how well the PIP assessment criteria and thresholds meet young people's needs.

However, we have some concerns over the definition of 'reliably' which we are told to interpret as 'to a reasonable standard'. The definition of a reasonable standard is going to be very open to interpretation and may mean a level of variation in awards across the country. We are therefore calling for assessments of young people to be undertaken by a group of professionals who only assess this age group and have been specially trained to understand the needs of disabled young people, that we have referred to throughout this consultation response. This would help to establish a benchmark amongst assessors of what 'reasonable standards' are in the real lives of disabled young people.

We also think that how 'safety' will be taken into account in assessments is unclear – for example under 'preparing food and drink' it appears a high level of health and safety risk is allowed before a young person would be deemed to have sufficient needs qualify for the daily living component of PIP. For example someone who would qualify for descriptor F would be at significant risk if they were left to cook alone but score only 4 points.

