

Personal Independence Payment: assessment thresholds and consultation

The transition from childhood to adulthood is a notoriously difficult time for many disabled children, with many parents describing it as like 'standing on the edge of a cliff, about to fall into a black hole'¹. 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.

Given the difficulties this period can throw up we have some concerns that there will now be two different forms of disability related financial support – Disability Living Allowance (DLA) for under 16s, and Personal Independence Payments (PIP) for over 16s. Whilst we welcome the Government's decision to have a different commencement date for children and working age adults for PIP we are concerned that disabled young people 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.

EDCM 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 automatic 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.

Our 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, 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."*² 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."*³

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,

¹ House of Commons (2006) Parliamentary hearings on services for disabled children

² <http://www.publications.parliament.uk/pa/cm201011/cmpublic/welfare/110512/pm/110512s01.htm#Column913>

³ Hansard Citation: HL Deb, 17 January 2012, c481

fundamentally this process does not result in increased stress for the family at this stressful time.

On April 20th 2012, EDCM held an expert consultation event with representatives from 22 organisations with an interest in issues relating to disabled children. We also received written submissions from two further organisations. Our consultation 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 and how the 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.

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

Consultation

*"I will vote for your party if you promise to do your job properly and actually listen and consider what people actually want and feel need to be sorted."*⁴

EDCM 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 only limited evidence that the Government has sufficiently consulted with disabled young people 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 them⁵. 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.

The UK Government ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2009. Article 7 of the UNCRPD on children with disabilities states that 'states parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.' To ensure the Government is fulfilling its commitments under the UNCRPD we think that it is crucial that the Government ensures meaningful consultation takes place with disabled young people on the development of PIP.

⁴ EDCM (2009) Disabled children's manifesto for change

⁵ See Making Ourselves Heard (2009) Exploring disabled children's participation...

Adequate financial support

*"A young disabled person needs more help when looking for a career because, as I said before, it is so much harder for disabled people to get a job."*⁶

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 workplace resulting in disabled young people being disproportionately likely to be Not in Education, Employment or Training (NEET).

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

*"I have often heard Transition described by other parents as like 'standing on the edge of a cliff, about to fall into a black hole'. I can now confirm that this is exactly what it feels like!"*⁹

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. EDCM 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.

EDCM welcomes the Government's commitment that disabled young people will continue to receive DLA until the outcome of a 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 that if a young person wants to appeal the decision made on their PIP award that they

⁶ EDCM (2007) If I could change one thing...

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 Parliamentary hearings on services for disabled children: Full report (2006)

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 PIP¹⁰.

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. *Personal Independence Payment: assessment thresholds and consultation* gives details about the trial assessments that have taken place to assist the DWP in designing an appropriate assessment, however only a limited number have looked specifically at 16 – 25 year olds.

We detail our thoughts on the ideas that have been muted on supporting 16 – 25 year olds, as well as what we believe are 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 assessment¹¹. There is a fundamental problem with the proposed PIP assessment in that it fails to address the criticisms raised by disabled people about current DLA assessment that they focus on what cannot be done and are very medicalised. This damages self esteem, and is particularly harmful for young people who are developing their sense of self for the first time.

EDCM supports the concerns of the National Deaf Children Society's (NDCS) that face to face assessments can be very stressful and can cause great harm to the self esteem of children and young people. It is unrealistic to expect most children and young people under 25, and particularly under 18s, to present accurate information on the impact of their disability to an unfamiliar professional. For example, an NDCS Family Officer attended an annual review meeting with a family where the child had previously completed a questionnaire face to face with a professional to represent their views. Within this they had answered "yes" when asked "are you able to go out on your own to the shops?". The child's mother had to point out that this was not true, and that her child would not be able to safely go out alone to the shops – clearly the child in question was not comfortable with revealing the impact their disability has on them¹².

The SEND single assessment

The Green Paper, *Support and Aspiration: A new approach to special educational*

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

¹¹ DWP (2012) Personal Independence Payment, Frequently asked questions

¹² Case study provided by the National Deaf Children's Society

*needs and disability*¹³ 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.'

EDCM 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 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

EDCM 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 16 year olds that will be amongst the first people to be assessed for PIP and may 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

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

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.

Disclosing a disability or mental health problem to school staff could have a negative consequence for young people pursuing a college course or job. Young people have told stories of being approached in the street by teachers from their school not directly involved in their education, who nevertheless asked if they were 'feeling better'. They were most unhappy to think that they and their problems were being talked about in the staff room¹⁴.

"Children and young people don't seem to be able to get involved in discussions that affect us"¹⁵

Transition is a time when many families can experience problematic relationships as roles and finances change. 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. However, trained independent advocates should also be available for those who want them – this is particularly important for disabled young people to help them through this time of change.

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."¹⁶

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 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:

¹⁴ Developing Connexions – Foundation for People with Learning Disabilities (2004)
Young people with disabilities, mental health needs or autistic spectrum disorders

¹⁵ EDCM (2009) Disabled children's manifesto for change

¹⁶ EDCM (2008) Going Places!

Establishing Independent Living

At the expert workshop 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 community care eligibility – with many areas only providing assistance to disabled people with 'critical' or 'substantial' care needs.

Article 19 of the UNCRPD recognises the equal right of disabled people to live in the community with choices equal to others. In particular by ratifying the Convention states have committed 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 reduced, 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."¹⁷

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 others¹⁸.

A report by the Office for Disability Issues (ODI) states that Independent Living options are often more cost effective than conventional systems of support¹⁹. Work by the British Association for Supported Employment (BASE) found that

¹⁷ EDCM (2009) Disabled children's manifesto for change

¹⁸ Jane Campbell (2004) quoted in Office for Disability Issues, (2007) *The costs and benefits of independent living: Executive Summary*

¹⁹ Office for Disability Issues, (2007) *The costs and benefits of independent living: Executive Summary*

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 employment²⁰.

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 parents²¹. By the age of 26, disabled young people are nearly four times as likely to be unemployed or economically inactive, as non-disabled young people²².

EDCM 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 difficulties²³. 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 activities²⁴. 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.

"I have to rely on my mum to take me everywhere. (I feel like)... saying I'm not coming with you, politely saying "no thank you!"²⁵"

However, we are concerned that assistance from families is relied upon too heavily in the proposed PIP 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:

²⁰ British Association for Supported Employment

²¹ Hirst, M. & Baldwin, S. (1994) *Unequal Opportunities: Growing up Disabled*. London: HMSO.

²¹ Office for Disability Issues, (2007) *The costs and benefits of independent living: Executive Summary*

²² ODI (2008) *Independent Living: A cross-government strategy about independent living for disabled people*

²³ ODI (2008) *Experiences and Expectations of Disabled People*

²⁴ ODI (2008) *Experiences and Expectations of Disabled People*

²⁵ EDCM (2008) *Going Places!*

- 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?

Establishing Independent Living– a new activity

"I would vote for your party if you promise to give more chances for people with disabilities to do the things they want to do and reach the goals they have themselves²⁶"

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. For this reason, we believe that the DWP should introduce an additional Activity – Activity 12 – ‘*Establishing Independent Living*’ 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 adulthood²⁷.

There might be many approaches to creating descriptors and points weightings under this activity, but below is an example of one option:

Recommended Activity 12: Establishing Independent Living

Daily Living Activities

Can establish independent living in terms of daily living activities unaided = 0

²⁶ EDCM (2009) Disabled children's manifesto for change

²⁷ Department for Education (2011) Support and aspiration: A new approach to special educational needs and disability - A consultation

Needs prompting, assistance or support to establish independent living in terms of daily living activities = 2

Mobility

Can establish independent living in terms of daily living activities unaided = 0

Needs prompting, assistance or support to establish independent living in terms of mobility activities = 2

Dealing with change

It appears that the PIP assessment criteria as it stands takes a static approach to people's lives. To take a 'real life' approach we think it is vital to look at how people can cope with change in their everyday routine. 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

"Yeah. 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"²⁸

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. 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

"I don't want to feel like I'm a nuisance or somebody different... I just want to do everything that everyone else does"²⁹

²⁸ EDCM (2008) Going Places!

²⁹ EDCM (2008) Going Places!

We are concerned about the extent to which proposed thresholds allow for quality of life, dignity and 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.

For example we are very concerned that *Activity 5 – managing toilet needs and incontinence* only awards points if you need assistance to manage toilet needs and incontinence. Particular concerns on this were raised by 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 are 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

We are worried 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 significant 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 need 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'. 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

We have 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 variation in 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 eligibility 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 require 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 is a lot of concern and confusion over the terminology used in the proposed assessment criteria. We fear that some of these terms would be open to wide interpretation such as 'overwhelming psychological distress', 'a matter of preference' and 'appropriate' and that this could lead to different awards across the country. 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.

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

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.

Concern was also raised in the EDCM expert workshop 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:

"If he's having fits in the night sometimes I'm so tired I'll sleep though them. There's other times I wake up and he's sleeping in vomit and I haven't woken up."³⁰

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,

³⁰ EDCM (2011) Raised Expectations: Parental experiences of short breaks

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:

"I love my sink, because if it weren't for my sink I wouldn't be able to get myself a drink, I wouldn't be able to do my teeth, and I wouldn't be able to wash my hands or anything like that."³¹

We fear that compared to the rest of the working age population, disabled young people are more likely to be embarrassed of the assistance they require and therefore 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:

"Although nappies are provided and delivered by the NHS we still use disposable bed mats as changing mats when we are out as most places only provide changing tables suitable for babies and toddlers and endless amounts of baby wipes for all his personal use. This also impacts on extra bedding as changes are more frequent due to nappies leaking in bed and more mattresses."³²

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 receive³³. It is vital these extra costs are taken into account when scoring for PIP awards.

"My daughter's allowed 6 nappies a day. But when she got older and I said she needed a higher absorbency nappy, they said, 'Oh well, in that case, we'll drop you down to 4.' It made no sense."³⁴

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

³¹ EDCM (2009) Disabled children's manifesto for change

³² Quote provided by the National Network of Parent Carer Forums

³³ See: <http://www.edcm.org.uk/campaigns-and-policy/health/nappies-campaign.aspx>

³⁴ EDCM (2011) Disabled Children and Health Reform: Questions, Challenges and Opportunities

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. We are confused about the scoring of descriptors D and E, it is unclear that 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

"I may not have speech, but I have a voice. I can give opinions, I can even argue!"³⁵

EDCM believes that no-one 'cannot communicate at all', disabled young people 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 it should be taken into account 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.

³⁵ EDCM (2009) Disabled children's manifesto for change

We are also concerned that unless someone needs a sign language interpreter to express or understand basic verbal information, that they will not be eligible for the standard rate of PIP. This is going to mean a loss of financial support for many young disabled people as they turn 16. Most notably for deaf young people who do not rely on sign language but still require communication support.

Activity 8: Engaging Socially

"I have Aspergers Syndrome and my brother has dyspraxia. Our parents are okay but most of the time we have to go out with them... I would like to go to places with young people who might be a bit older than me, who would be okay with looking out for me, because I am not street safe. It would be exciting and would feel like we had mates to go out with. I want to go to places like museums, cinema, bowling, for pizzas, and to do those things with friends not just my parents..³⁶"

EDCM 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. This would reflect the Government's commitment under Article 7 of the UNCRPD which reads "*States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.*"

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.

"I don't like the street, I don't like the park, I don't like the swimming pool because of bullies.³⁷"

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 people³⁸. Given the impact of bullying on self esteem and the courage then needed to build new friendships we believe it will be

³⁶ EDCM (2008) Going Places!

³⁷ EDCM (2008) Going Places!

³⁸ Department For Children, Schools And Families (2007/08) Youth cohort study and longitudinal study of young people in England: the activities and experiences of 16 year olds

particularly difficult for disabled young people themselves to establish whether they do not engage socially as a matter of preference or not.

"When I was at primary school, these kids that bullied found out how to put my chair onto manual and one day they went behind me and put it onto manual and wheeled me into a bush and the teachers knew about it and none of them did anything about it they said it would have to have been an accident. One of them said 'oh it can't have happened'. I told my teacher and my head teacher and they didn't believe me and the only one that did believe me said that it must have been an accident"³⁹

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

"[I] can't go to town on my own, I have to go with mum because I can't deal with money yet"⁴⁰

The inclusion of an activity 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 the proposed descriptors 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 that 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.

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

The key principles to both reform and assessment that we have identified are:

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

³⁹ EDCM (2008) Going Places!

⁴⁰ EDCM (2008) Going Places!

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 NEET, compared to only 7% of non-disabled people⁴¹. 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 changes 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

"Where I live there's only one bus service, and you have to book a week in advance and sometimes they're fully booked 'cos they do stuff for the over 60's as well and if I want to get on the train I have to book in advance as well and sometimes they forget I'm on the train so they forget to have the ramp."⁴²

Concerns were raised in the EDCM expert workshop 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. There were particular concerns about when someone 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:

EDCM 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. 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

⁴¹ 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)

⁴² EDCM (2008) Going Places

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 buses⁴³. These difficulties accessing transport mean that disabled people travel a third less often than the general public⁴⁴. 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."⁴⁵

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."⁴⁶

EDCM 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 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 are 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 are 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 car, these young people will also have more difficulty

⁴³ DWP (2002) 'Disabled for life?' attitudes towards and experiences of disability in Britain. (cited from improving the lives of disabled people, 2004, PMSU)

⁴⁴ Disabled Persons' Transport Advisory Committee (2002) Attitudes of disabled people towards public transport, DPTAC (cited from improving the lives of disabled people, 2004, PMSU)

⁴⁵ EDCM (2008) Going Places!

⁴⁶ Council for Disabled Children (2011) Young, Disabled and In Control

in accessing a blue badge.

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

EDCM 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 to develop their skills to identify risk, respond to challenges in the environment, solve problems and overcome obstacles. 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

"I've had incidences where a driver have been rude to me just because I've had a pass or something different to someone else. If I'm feeling bad about it, what is someone else going to feel?"⁴⁷

At EDCM's expert workshop, 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 un-due 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

⁴⁷ EDCM (2008) Going Places!

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

"If I can't get there by car I can't get there because I can't get on public transport, I can get on public transport it's when I got on public transport, nobody else can get on the bus... the bus needs to be bigger to accommodate these wheelchairs and I need to have somebody else... they can't get the electric wheelchair and other people on at the same time. They got the access onto the bus right – they got that but they haven't thought out when I get on the bus, where I'm going to sit⁴⁸"

We are concerned about 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.

We would also like more information on how 'timely' will be assessed for this activity and whether the impact of wider factors will be taken into account, if they occur on a regular basis. For example, many disabled young people report to us the challenges of getting on a bus due to over crowding, accessibility ramps not working and even bus drivers refusing to stop to let disabled passengers onto the bus.

⁴⁸ EDCM (2008) Going places!

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 importance 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.

Organisations that attended EDCM’s expert workshop:

Ambitious About Autism
Babcock Enterprise
The Council for Disabled Children
Contact a Family
Down's Syndrome Association
Family Carer Support Service at HFT
Family Fund
Hackney Ark
Kids
Mencap
Muscular Dystrophy Campaign
National Deaf Children’s Society
National Network of Parent Carer Forums
Sense
Standing Commission on Carers
Surrey County Council
The Children's Society
Wandsworth, Contact a Family
Whizz Kidz
Working Families

About EDCM:

Every Disabled Child Matters (EDCM) is the campaign for rights and resources for disabled children and their families. EDCM is a consortium campaign run by four of the leading organisations working with disabled children and their families: Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. The campaign has over 34,000 supporters, the campaign partners represent over 770,000 disabled children and young people in the UK, and our Campaign Network is made up of 75 organisations from across the disabled children's sector. EDCM is also a member of the Disability Benefits Consortium.

For more information:

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