



Afasic's response to the consultation on the *Personal Independence Payment: Assessment Thresholds*

Afasic is the UK-wide parent-led charity representing children and young people with speech language and communication impairments (SLCI).

It is still often thought that SLCI is primarily a problem affecting young children which resolves itself over time. However, this is not always the case. Approximately 1 in 500 children has a severe long-term disorder which persists into adulthood. The impact on those young people who are affected cannot be over-estimated. Speech, language and communication are fundamental skills underlying most aspects of adult life and a young person who struggles with these skills has a significant disability. In particular, the young people we represent find it difficult to:

- Access learning opportunities within school and college.
- Develop independent living skills and cope with the demands of adult life.
- Cope with the social demands of teenage and adult life.

All of these demand increasingly sophisticated language skills that young people with SLCI do not have. During adolescence, they usually become increasingly aware that they are 'different' from other people they know of the same age, but generally find it hard to discern in what way exactly. This seriously affects their self-confidence.

It should also be stressed that young people with SLCI often have associated cognitive impairments affecting their memory and ability to organise and plan their thoughts, which, in themselves, can constitute significant additional disabilities.

Regrettably, young people with SLCI rarely receive the support and consideration they are entitled to for various reasons. These include:

- A general lack of awareness of SLCI and its implications, particularly as it affects teenagers and adults.
- The 'hidden' nature of SLCI. Because it is not immediately obvious that young people have a disability, people assume that they do not and treat them accordingly.

The lack of recognition and support for SLCI can have severe consequences for the young people we represent. At best they often feel marginalised from mainstream society. Many face even worse consequences. They are often unable to cope with college or work placements that have been arranged for them and become NEET. Some drift into crime and anti-social behaviour (there is evidence that 60% of young people in young offender

institutions have speech, language and communication difficulties¹) or the mental health system.

Afasic welcomes the opportunity to respond to this consultation.

General Points

As explained above, young people with ongoing severe SLCI are potentially capable of functioning at age appropriate levels but will be prevented from doing so by the impact of their disability, and they can often face additional costs as a result. For example, some young people are so afraid of arriving late for college or university that they will pay for a taxi rather than risking something going wrong with a bus journey. As explored further below, this is not just about the possibility the bus might be late but fear of how to cope in the event of something completely unexpected happening. To take another example, some young people instead of struggling to operate a washing machine – because of their difficulties with memory, planning and sequencing a series of actions (pressing the right buttons on the machine in the right order) – will simply buy new clothes to wear, in itself indicative of difficulties handling money. While it may be argued that this sort of behaviour is not untypical of many young people anyway, in the case of young people with SLCI it results directly from their disabilities and so should entitle them to PIP.

It is important to understand that while most young people with SLCI can, with training, learn to handle most predictable situations, for example a regular journey, or meeting someone for the first time, it is not always possible to prepare them adequately to cope with the unpredictable or unexpected. As by definition, it is impossible to know when these are likely to arise, young people with SLCI may either spend most of their life in a state of heightened anxiety, or alternatively seek to avoid situations in which they might find themselves out of their depth. This can severely limit their lives, compared to their peers.

Understandably, young people with SLCI want to be like anyone else and, although they are usually aware they find some things more difficult than their peers, they lack insight into their disability. This will, of course, severely impact on their ability to complete an application form for PIP, or give accurate responses to an assessment interview. This will be compounded by their disability, given that, by definition, it affects their ability to understand questions and respond appropriately. Some young people will not even know that they are supposed to give accurate information, and will just give whatever answer is easiest, or will say what they think the interviewer wants to hear. This means young people with SLCI will be unable to apply for PIP without appropriate help. It will be essential for them to be supported by someone they trust with expertise in their condition.

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

Being able to live independently involves a number of tasks, including doing household chores, organising and planning your time, and handling correspondence as well as basic personal care. Somebody who could get themselves up and dressed in the morning but who could not, and did not have any help to, clean the house, wash and iron their clothes, book and get to a doctor's appointment etc. would not be able to manage on their own. Yet the draft criteria fail to acknowledge any of these things adequately.

Specific comments on individual activities:

¹ K. Bryan *Speech and language therapy for young people in prison* (2004) submitted to HM Prison Service and Helen Hamlyn Trust

Preparing Food and Drink: We are concerned that the proposed criteria do not adequately take account of:

- someone who is able to cook one particular meal, but would not be able to cook anything else without considerable training or assistance. For instance, we are aware of one young man with language and communication difficulties who knows how to cook spaghetti bolognese, but that is all. Due to his sequencing difficulties he would not simply be able to find another recipe and follow it without help.
- Whether or not an individual could plan a weekly menu, ensuring a balanced and healthy diet. This would be difficult for many young people with SLCI.
- Issues around safety. Some young people with SLCI have very poor memories and often forget to turn the cooker off, or, worse, forget they have left food cooking on a grill. They might then not be able to cope with a fire, if one resulted, as anything unpredictable can be very difficult for young people with SLCI.

Communicating: Most of the criteria appear to apply to very basic levels of communication, which are barely adequate, on their own, for adult independent living. Increasingly, modern life requires complex levels of language, but this is only mentioned in criterion E, with a tariff of 4 points, which barely seems adequate acknowledgement of the fundamental role it plays. Young people with SLCI will have difficulty with this skill, and, as a result, may struggle to participate fully in society.

Engaging Socially: The criteria in this section do not appear to take sufficient account of the vulnerability of some disabled people. Some young people with SLCI, even if they have been trained to manage most straightforward social situations reasonably well, may be unable to cope if confronted by, for example, a stranger coming to the door or speaking to them on the street. They may also be unable to distinguish between a friendly overture and something potentially more sinister and thus risk getting into situations that might be at best tricky and at worst, threatening or exploitative. Even the fear of being unable to cope, based perhaps on an upsetting previous experience, might deter some young people from trying to engage socially any more than is necessary, depriving them of an important part of most people's lives.

Making Financial Decisions: It is important to be aware that the ability to purchase items in a shop, open a bank account and write cheques do not necessarily mean that an individual really understands the concept of money. Some young people with SLCI might be able to do some or all of these things, in a mechanical way, but not really know where money comes from, what the coins in their pocket or bank balance actually mean in terms of what they are able to buy, and thus be quite unable to budget or plan their expenditure.

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

We are concerned that they do not take sufficient account of the impact of cognitive impairments, such as those related to speech, language and communication. Their impact is significant, seriously affecting young people's ability to cope with the demands of adult life in ways that cannot be readily addressed with a mechanical or electronic aid. They really need personal support, at a much higher level than it is reasonable to expect families to provide, and this costs money.

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

Planning and following a journey: This section needs to take account of:

- an individual's ability (or inability) to cope with the unexpected eg cancellation of trains, alteration of bus routes due to roadworks etc.

- whether the individual concerned would be able to cope with any social interaction that might be necessary, whether predictable (such as buying a ticket from a bus driver) or unpredictable (such as being spoken to by another passenger, and not understanding either what they are saying or how to react).

We do not have any other specific comments on the questions in this consultation. However, we feel it important to stress the impact of the 'what if' factor on the young people we represent. The fear of not being able to cope should anything unexpected happen (based often on previous negative experiences) can be ever present in their lives seriously affecting their ability to engage in everyday activities in the way that their peers do.

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