

## **Personal Independence Payment: second draft of Assessment criteria- Response.**

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22<sup>nd</sup> April 2012

I have greatly welcomed the opportunity to further comment of the assessment criteria for Personal Independence Payment on behalf of the UK charity Tourettes Action <http://www.tourettes-action.org.uk/>. Within the initial draft there were indeed problems both from my perspective as a person with Tourette's Syndrome (TS) and from the general perspective as a person with a disability. I was very please also to note that our point that people with disabilities, should like any other person, be entitled to a varied and healthy diet that includes fresh ingredients, rather than cold snacks such as sandwiches and microwavable food. (Activity 2 – Preparing Food and Drink).

This lapse in time since the opening of the consultation period for this particular document has enabled me to discuss with other affected by TS their thoughts and opinions on both the proposed assessment criteria and my own thoughts about it and how it may affect them.

I still hold the opinion that we do need to reform our current system of Disability Living Allowance, but although fully aware that the Welfare Reform Bill has now become law I would still like to reiterate that I very much feel that given the current economic climate now wouldn't be a good time to make such big changes given the expense required to implement the systems required to process and assess PIP claims.

TS is a complex neurological condition that usually starts in childhood, it is characterised by the presence of tics (uncontrollable movements or sounds), in severe cases the tics can be quite disabling making many everyday tasks that most would take for granted very difficult or impossible. Many people with TS also suffer from co-morbid conditions such as ADHD, OCD (obsessive compulsive disorder) Asperger's Syndrome, Autism and depression or anxiety. These additional invisible disabilities also need to be taken into account as well as the disabling effect of the attitude of the general public towards people with TS particularly the minority of people with TS (approx 10%) who have coprolalia, the much stereotyped involuntary use of obscenities.

I do have some major concerns with regards to the change from DLA to PIP, first of all the speed that is being undertaken to facilitate these changes, already some people are taking part in trials to assess the assessment process and the private company that will be doing the face-to-face assessments has already started to design the software. Secondly, I find it quite unacceptable that a private company will be carrying out the face-to-face assessment and that will override information provided by the claimant's own GP, consultant or social worker. The removal of the lowest care component will leave many people with, what seem like minor needs being unable to access vital support to sustain independent living.

### **Consultation Questions**

#### **\* Q1 What are your views on the latest draft Daily Living Activities?**

I am pleased that "Activity 1 – Planning and buying food and drink" has been moved to "Making Financial decisions" as purchasing groceries wouldn't be the only activity of this nature that a person would need to undertake within the course of their daily lives, such as shopping for clothes or other

items. Unfortunately this task doesn't take into account the additional difficulties that a person with TS would have to face whilst shopping that I outlined in my response to the first draft.

*Just planning what to eat and drink can be a huge task for people with TS. Many adults tell us that the supermarket trip is the most difficult thing they do or can imagine doing. For those with noticeable tics the social stigma of being pointed at or stared at or indeed being personally abused is huge. For those with expansive motor tics the problems are even worse. The risk of knocking things off the shelves, dropping breakable items and even striking someone make shopping trips in general a nightmare.*

*"As a person with TS shopping can be a very stressful occasion, I need someone to help me stay on task and not be distracted by other things and get the items on the list. Coupled with this is the fact that many people find the outward symptoms of TS (motor tics and vocal tics) quite strange so there is added stress and anxiety added to the activity and often the reactions from strangers can be abusive and deeply upsetting."*

*When you take into consideration co-morbidities, especially bouts of debilitating depression, planning and buying food is impossible due to lack of motivation and often you have to rely on others to do this. There isn't a descriptor for people who fit this category. Many people with TS also suffer from crippling anxiety and so would have to rely on others to get their shopping for them.*

"Preparing food and drink" is now Activity 1 – I am very pleased that some of our suggestions have been taken on board and a "simple meal" now contains only fresh ingredients and if supervision is required to enable a person to prepare or cook. However for myself and many other who suffer from depression the suggestion that some may lack the motivation to cook a meal and would require help to either cook for them or to encourage them to do so hasn't been taken account of in the second draft. This is disappointing. These are the suggestions I made in response to the first draft for this particular activity.

*This depends very much on the severity of the claimant's tic and other co-morbidities, whilst some with TS may be able to cook quite easily, for others this would be a very dangerous activity.*

*"For myself cooking can be dangerous, particularly chopping and using hot pans and I am constantly at risk of stabbing myself due to hitting tics, dropping items due to another tic or burning myself due to a tic where I need to tap surfaces, hot cooker included."*

*"Taking co-morbidities into consideration when I'm suffering a depressive episode it would be impossible for me to be able to cook."*

*We are concerned that the descriptor states 'can prepare a simple snack only with continual assistance' undermines the right to have a healthy diet and appears to be in opposition to the Dept of Health who are working to promote fresh food, freshly cooked. The implication that a continued diet of*

*cold food such as sandwiches and pastry products would suffice for someone with a disability*

Again from my perspective, our suggestions with regards to those with depression who lack motivation to eat, our points haven't been considered.

*This could be problematic for those with severe motor tics. Tipping over or throwing hot drinks can cause injury to themselves or indeed other people.*

*We spoke to young man on the helpline last week who had burnt his flat and all his possessions due a an incident with oil whilst cooking.*

*"I have on occasion spilt hot drinks on myself due to tics or spilt my food on the floor due to my table banging tic knocking items off the table. This does in turn often create extra laundry as I frequently spill food on my clothes due to tics. Although I don't myself use any special eating implements, I have heard of other's with TS that need special non-spill cups or plastic plates."*

*Additionally none of the descriptors allows for those who have depression or eating disorders*

"Managing medication and monitoring health conditions" (Activity 4) has been merged with "Managing prescribed therapies other than medication" (Activity 5). This step does make sense to me but again it's very much concerned about a person's physical ability to take medication rather than due to memory problems (that many with TS experience) it's more likely to be supervision that is required, also, since writing my previous response I would like to consider those that suffer from depression or mood disorders (like myself) who have needed monitoring to prevent an overdose been taken deliberately.

I would also like to mention at this point that a new psychological treatment for TS is becoming more commonly used, Habit Reversal Training. This new treatment does require support to monitor the patient's tics and help undergo some of the prescribed activities to do at home. I would be happy if my original suggestions and these recent additions could be again looked at for the next draft as they don't just apply to people with TS but to those that have any mental health problem.

These were my original thoughts on the first draft -

#### ***Activity 4 – Managing medication and monitoring health conditions***

*This again is very much dependant on the individual and their tics and co-morbidities.*

*Both from the practical stand point of preparing the medication and the ability to take it successfully.*

*"I find it quite difficult to get into a new routine of taking meds when they've been changed or altered, when I'm in my depressed state I frequently need prompting to take my medication. I often find it quite difficult at the time to be able to judge if I've had a good day or bad day with regards to my tics and sometimes I'm unaware of how my moods can quickly alter."*

#### ***Activity 5 – Managing prescribed therapies other than medication***

*Assuming that this includes appointments with both the hospital and GPs, much the same problems occur as in section 1.*

*Public transport and sitting in crowded waiting rooms is so stressful as to be almost unbearable in terms of tics. Loud vocal tics draw attention to oneself*

*and for those unfortunate enough to coprolalia (swearing or other inappropriate words) likely to cause huge offence to other patients.*

Bathing and Grooming is now Activity 4, It remains very much the same as it was in the first draft and the exclusion of washing below the waist has been explained away as being assessed as part of the next activity - "Managing toilet needs or incontinence" This still seems somewhat "odd" to me as any disabled person is entitled to the dignity of being able to maintain a level of cleanliness and personal grooming that any non-disabled person would expect. I am pleased that "a level of self-neglect" has been removed as I would like point out is that many current DLA claimants have paid employment and like to dress appropriately for their job – so therefore if I was in paid employment I would like to dress smartly and be appropriately well groomed, including make-up. It is also within most people's nature to make the best of themselves and enjoy a certain standard of hygiene and dress regardless of their circumstances. I am disappointed that the points I made in response to the original draft haven't been considered as part of this latest draft. Here's what I stated previously.

*Again severe tics make this activity very difficult mainly in terms of safety, especially in the shower or bath. However, what is almost incomprehensible is why help with washing and personal care should focus on 'above the waist'. Common sense would dictate that this is not the most problematic area! Other types of care such as shaving or maybe applying make up are equally important to levels of self esteem. Personal grooming is an integral part of self worth*

*"The high standard of personal hygiene I do have can be lost when I am in a depressive state, and although I can wash myself I would need to be encouraged to do so. This could also apply to those that have autism or Asperger's."*

Managing toilet needs or incontinence. I originally stated that -

*In most cases this probably wouldn't be applicable.*

But since the closing of the last consultation I have been approached by individuals who have experienced tics involving the bladder that have caused periods of bladder incontinence that have caused much embarrassment as well as extra laundry, in convenience and of course caused immense anxiety away from the home.

Dressing and undressing (Activity 6) I'm please to see that "prompting" to dress or undress has been added as this point very much applies to those who have ASD or motivational issues coming from depression. I would also like to add that for some people with TS who suffer from particularly violent tics, protective clothing (as often used in sports such as rugby or skateboarding) needs to be worn to help minimise damage from tics that involve hitting oneself or if a person frequently falls due to their tics. But due to the sensory problems that many with TS experience clothing in general can be an issue. Here's what I said in my response to the first draft.

*On the whole this would only affect those with very severe tics, but many people with TS do have sensitivities to certain fabrics and textures so would need to be very selective when buying clothes, things like seams or labels can aggravate the skin and create new tics or make existing tics worse. Taking into account co-morbidities namely autism and depression, sometimes help may need to be given to help choose an appropriate outfit to wear and that it is worn correctly, not worn inside out for example.*

Communicating with others has now been split into two categories "Communicating" (Activity 7) and "Engaging

Socially" (activity 8) I welcome that more detail has been added to this area as this is something that effects those people with TS who experience coprolalia (involuntary use of obscenities) and NOSI (non obscene and socially inappropriate behaviours) such as myself. This my original response to the original single activity -

*The notes state "Engage socially means to interact with others in a contextually and socially appropriate manner"*

*However this takes no account of TS at all despite this being often the biggest issue for some with TS.*

*Descriptor D states "Cannot engage socially with other people due to such engagement causing either –*

- i. overwhelming psychological distress to the claimant, or*
- ii. the claimant to exhibit uncontrollable episodes of behaviour that would result in substantial risk of significant distress to the claimant or another person."*

*Although not mentioned TS would neatly fit into this descriptor.*

*" both my motor tics (which attract attention from strangers) and my range of vocal tics (which again attracts unwanted attention from strangers) which also includes coprolalia (the involuntary use of obscene words) and non-obscene social inappropriate behaviours which include shouting personal remarks at strangers. These elements can make communicating with strangers very problematic. When I've needed help, for example directions, I have been often avoided or insulted and although I'm an outgoing and articulate person some people don't take in what I have said as they are distracted by my tics. Apart from asking people directions this has also led to me been asked to leave pubs and refused custom in shops."*

*There are many people with TS who also suffer from anxiety and who would experience great distress if they had to leave their home and communicate with strangers.*

*"Apart from these particular vocal tics I did have a period of time where I had a tic which involved poking people in the back which some people didn't take kindly to."*

*This activity would apply also to those with TS who also have autism or Asperger's.*

I think what is overlooked in the descriptors for these activities is that those people with TS who aren't affected by Asperger's syndrome or Autism are fully aware of what behaviours are acceptable and are often highly intelligent and articulate individuals, but due to their TS find it extremely difficult or impossible not to exhibit behaviours that most people would find wholly inappropriate. I imagine for many seeing a person with severe TS accompanied by coprolalia would be startling and to initiate a conversation with such a stranger can be traumatic both for the person with TS and for the other person. Rather than support or prompting to help us understand social cues what is required is a person to perhaps intervene if it is particularly difficult for the person with TS to be understood or misinterpreted and be there as emotional support as people with TS are often the target of verbal attacks from strangers. Frequently people move away from me in queues in shops or sitting on buses or trains. The descriptors still unfortunately refer to "overwhelming psychological distress caused by an enduring mental health or an

intellectual or cognitive impairment” This descriptor in my opinion definitely needs to be re-worded to cover the problems and distress that frequently occurs due to the social effects of tics.

Q2 What are your views on the weightings and entitlement thresholds for the daily living activities?

I was pleased to discover that “communicating with others” carries the highest weighting as the problems that arise from this area of our lives can be far-reaching affecting our self esteem, job prospects and safety whilst out and about. Whilst talking to others with TS about this particular consultation paper men with coprolalia were particularly happy with this outcome as they often come into direct conflict with the police due to their tics and are either often perceived as more “frightening” by passers by or seen to be inciting violence by others when the opposite could be said to describe the individual. Having coprolalia is frequently a major barrier to the work place for many.

Q3 What are your views on the latest draft mobility activities?

Again, with planning and following a journey the descriptors refer to “overwhelming psychological distress caused by an enduring mental health or an intellectual or cognitive impairment” would apply to many with TS, although TS is a neurological condition. I know of many with TS who would never consider using public transport due to the anxiety levels that journey would induce. I am quite unusual in the fact that I regularly use public transport, but for me it does cause anxiety but that is due to the unpredictability of doing so, a journey to a certain place maybe smooth and uneventful one day yet another day I may meet hostility and verbal abuse (and as a result abandon my journey and go home distressed) or may have difficulty boarding a bus, due to the driver not letting me on. In itself this unpredictability causes a lot of distress. This is my original statement regarding planning and following a journey –

*It states “The descriptors take account of the impact of psychological distress and reflect whether support from another person is required to enable an individual to follow a journey.”*

*The descriptors don’t take into account the variability of the main problem for people with TS when travelling on public transport and that’s the attitudes of your fellow travellers and the bus driver or train conductor. Although in a good state of mental health people with TS can quite easily plan and follow a journey, getting to their destination without some incident involving a stranger who doesn’t understand TS is almost impossible.*

*“It is only a matter of time until I find that I’ve been physically attacked by a fellow passenger or not allowed on the bus or train due to my TS.”*

*“I am an outgoing person who enjoys meeting new people but, I am seriously at risk travelling alone on public transport, particularly being a petite female with a disability, and there being a frightening increase in crimes committed against people with disabilities. Many of my friends with TS very rarely use public transport for these reasons and also the anxiety brought on by being in such environments.”*

*Activity 11 – Moving Around -This applies to those claimants with TS that have tics that involve the feet and legs whilst walking that can affect the way that they can effectively move. Although unusual there are still a considerable number of people with TS whose tics impact greatly on their mobility.*

*“A friend of mine with TS has injured herself on numerous occasions due to a tic that involves her ankle twisting whilst she walks. This has caused her great*

*pain and she has frequently fallen whilst out in public. She now almost most of the time has to use a wheelchair whilst outdoors"*

Unfortunately, this current draft again hasn't taken into account the different environments a wheelchair user may need to go; different pavement surfaces or heights can be problematic as can crowded shopping areas or shops and restaurants with furniture.

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

From the point of view of many, the reasoning behind the assessment criteria for the mobility activities, particularly moving around were a contentious issue due to the fact it's being assessed using the person's wheelchair or walking aid. Like any other piece of equipment a person may have and use, it may break or may be replaced thus altering the person's ability to get around. However, I'm pleased that "planning and making a journey" has been recognised as being problematic for many and given appropriate weighting.

Q5 What are your views on how the regulations work regarding benefit entitlement?

Q6 What are your views on how we are dealing with fluctuating conditions?

It's good to see that fluctuating conditions have been recognised. However the fluctuating nature of TS is extremely unpredictable and TS is forever changing, the severity of the tics wax and wane, tics come and tics go, sometimes on a weekly basis. Unlike MS (which is the condition used as an example) One can never tell how long a person with TS will have a "good" period and won't need the same level of support. I think using the approach of whether or not a descriptor applies for 50% of day within a period is a fair approach and practices common sense, but what I would like to see is a system in place to "revisit" a claimant's application if they find that their TS has worsened and is having an affect on how they carry out any of the daily living activities and mobility activities without too much undue bureaucracy.

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

All these definitions in principal I agree with, though "repeatedly" would often be quite difficult for many with TS due to the unpredictability of individual tics and of course the fluctuating character of TS itself. As well as TS other movement disorders (such as Parkinson's disease) may need to be addressed when defining such definitions.

Q8 what are your views on the definitions in the regulations?

Q9 Do you have any other comments on the draft regulations?

There are many issues surrounding PIP that I still have grave concerns about. When assessing the needs of a person with TS it is important to note that TS is a spectrum disorder and it affects each person in different ways. TS is also a very complex condition that many people understand very little about. This is a major concern with the proposal that the assessment is done by a representative of a private company. I am not happy about using private for-profit companies to carry out work relating to people's disability benefits. I have concerns also with regards to the assessment procedures. I would feel much more comfortable if PIP was solely assessed on the information given by the claimant and of course the healthcare professionals involved in their care as DLA currently is.

*"I feel that my consultant would have of course a far greater insight to both my condition and how it affects my day-to-day living."*

I like many others are nervous about this approach due to the experiences that many have faced whilst being assessed for Employment and Support Allowance and would hope that the DWP would consider the findings from Professor Harrington's report and take them on board when designing the face-to-face assessments

To me in the first draft PIP seemed to be designed just too merely help with a person's existence rather than having a meaningful life. Like DLA PIP should help people living with TS to lead an almost normal life, enjoying work, being able to access the same services that non-disabled people do, and have a quality of life. If the assessment criteria were to remain as proposed I believe the quality of life for many people with disabilities would deteriorate greatly and many would effectively become prisoners in their own homes.