

**Response from the Nystagmus Network, registered UK charity 803440, to PIP consultation process, January 2012.**

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

These are too narrow and basic. Most people with sensory loss, such as nystagmus, have the mental ability to do these tasks and much more. However, they are often prevented from doing these tasks – and social engagement – for complex reasons not captured by the simplistic PIP approach. For instance, many people with nystagmus use DLA to fund special equipment for accessing information online and in other situations. Without DLA/PIP, they stand to lose this already limited access, resulting in lower economic and social participation in life, reduced health and higher costs to the state. At the very least Daily Living activities should include accessing online information and using a mobile phone.

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

See above

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

Most people with nystagmus can move around. The question these definitions ignore is safety. Can they move around safely on their own? In many cases the answer for people with nystagmus is No. Again, we worry that people with nystagmus will be unfairly and unwisely excluded from PIP by these definitions.

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

See above

**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?**

The sentence “The Government therefore does not believe that support needs arising from short, acute periods of impairment should be met by this benefit.” Is a major cause for concern. Nystagmus is a complex, fluctuating condition. We are concerned that assessors – including most general medical staff such as GPs – could misuse (inadvertently or otherwise) this wording to deny applicants access to PIP.

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

## **Q8 – What are your views on the definitions in the regulations?**

As indicated above, the definitions do not take account of complex sensory disability such as nystagmus.

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

The only references to sight loss concern two people who are blind. These regulations risk perpetuating the widely held yet inaccurate belief that someone is either blind or not blind. Visual impairment, especially nystagmus, is far more complex than this. A growing number of optometrists recognise that standard measures of visual acuity (such as Snellen eye test charts) are inadequate for assessing a complex visual disorder such as nystagmus and invariably underestimate the impact of this condition. We will provide academic, peer reviewed evidence to support this view in “The challenge of nystagmus” to be published September 2012. In the meantime, here is a brief summary of some impacts of nystagmus on vision:

- Poor distance vision, not correctable by glasses or contact lenses.
- Vision fluctuates during the day depending on factors such as stress, fatigue, anxiety, illness, lighting. This is measurable, as the involuntary eye movements characteristic of nystagmus increase under adverse conditions. The greater and faster the movement, the worse the vision.
- Time. People with nystagmus need more time to see even within our limited visual range.
- The null point. Most of us with nystagmus have our “best” vision (which is considerable worse than normal) in one limited direction only. This fact is not captured by current eye tests. Effectively it means that people with nystagmus are “blinkered” and therefore at greater risk than others – regardless of their visual acuity score.
- Clutter/crowds/confusion. The poor overall quality of vision resulting from nystagmus means that people with nystagmus struggle in busy environments – shops, stations, crowds, schools, some workplaces and crossing roads. Once again, our functional vision in these situations is much poorer than a simple visual acuity test would suggest. Consequently, people with nystagmus are at much greater risk than average in many daily situations and need help with mobility.

Finally, the overwhelming impression left by the draft proposals and the consultation process to date is that the Government’s aim is simply to reduce spending on disabled people. Nowhere is it apparent that the aim is to genuinely help more disabled people lead healthier, more productive and happier lives. It may be useful

for all politicians involved in this process to look back at their party manifestos from 2010 and remind themselves of the promises they made then.

END