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By email to:  
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30 March 2011

Dear Sir or Madam,

**Healthy Lives, Healthy People: Transparency in outcomes. Proposals for a Public Health Outcomes Framework**

Parkinson's UK welcomes the opportunity to respond to this consultation.

It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. Parkinson's affects people from all social and ethnic backgrounds and age groups.

Preventative and wellbeing services play an important part for those affected by Parkinson's to manage their symptoms, maintain quality of life and maximise their independence. While much of this is delivered through NHS and adult social care services locally, a reinvigorated approach to public health could help deliver improved outcomes for both people with Parkinson's and carers.

**Question 6: Have we missed out on any indicators that you think we should include?**

Domain 2 focuses on the wider determinants of ill health: tackling factors which affect health and wellbeing.

We note that children in poverty is included as an indicator. We also believe that **disability poverty** should be an indicator. Disabled people are twice as likely to live in poverty as other citizens.<sup>1</sup> This will include people with long term conditions such as Parkinson's. While disability poverty is not measured uniquely or in terms of the extra costs that someone with a disability has, there is current data collected on Households Below Average Income dataset that makes comparisons between households that have a disabled person and those that do not, so is easy to collate and publish.<sup>2</sup>

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<sup>1</sup> Disability Alliance. Tacking Disability Poverty, Disability Alliance manifesto (2009).  
[www.disabilityalliance.org/damanifesto.htm](http://www.disabilityalliance.org/damanifesto.htm)

<sup>2</sup> Department of Work and Pensions. Households Below Average Income, Department of Work and Pensions dataset. See: <http://research.dwp.gov.uk/asd/index.php?page=hbai>

We also note that **access to suitable housing and adaptations for disabled, disadvantaged and vulnerable people** is not included in the list of indicators. Appropriate housing when you are an older person or living with a disabling condition can contribute massively to a person's wellbeing. The retention of Supporting People and the Disabled Facilities Grant for use by councils justifies the inclusion of an indicator that allows for reporting on these outcomes, as the data is collected and reported upon at a local population level.

There should be an indicator that measures **enabling those with caring responsibilities to fulfil their educational and employment potential**. Our members survey, *Life with Parkinson's today*<sup>3</sup> found more than one in five carers has had to give up or reduce their employment since starting to look after the person with Parkinson's. National surveys of carers, such as for Carers UK<sup>4</sup> has found that three out of four (72%) carers are worse off as a result of caring, rising to four out of five (83%) among those aged 45-54.

Under Domain 4, Prevention of ill health: Reducing the number of people living with preventable ill health, it is important to include indicators that relate to national objectives of the Carers Strategy<sup>5</sup> and **address the need to prevent carers falling into ill-health from the stress of their responsibilities**.

In our members survey, previously referenced, we found just over half of carers felt that their own physical or mental health had deteriorated since living with or caring for someone with Parkinson's. Nearly nine out of ten of these reported stress or fatigue. Our findings are corroborated by national data<sup>6</sup> which found two-thirds (67%) of carers reported feeling tired in the last 12 months, 54 per cent had suffered from disturbed sleep, 52 per cent had experienced a general feeling of stress and 37 per cent had felt depressed. Only 14 per cent did not report any effects.

We therefore believe there should be indicators that measure:

- **proportion of carers receiving a respite break through health and social care services** and
- **proportion of carers who have been identified and offered support by their GP**

This would aid reporting on government objectives to "support carers to remain physically and mentally well".<sup>7</sup> It would enable carers and those who support them to clearly identify how the new £6m for training to support GPs to identify and support carers is being used. It would also aid identification of how the £400m over four years

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<sup>3</sup> Parkinson's UK. Life with Parkinson's today – room for improvement (2008).

[www.parkinsons.org.uk/about\\_us/results\\_of\\_the\\_members\\_survey.aspx](http://www.parkinsons.org.uk/about_us/results_of_the_members_survey.aspx)

<sup>4</sup> Carers UK. Carers in crisis - A survey of carers finances in 2008. (2008).

[www.carersuk.org/Newsandcampaigns/Shortchanged/Hardevidence](http://www.carersuk.org/Newsandcampaigns/Shortchanged/Hardevidence)

<sup>5</sup> Department of Health. Carers at the heart of 21<sup>st</sup> century families and communities (2008)

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085345](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345)

<sup>6</sup> NHS information centre. Personal Social Services Survey of Adult Carers in England 2009 2010 (2010)

[www.ic.nhs.uk/webfiles/publications/Social%20Care/psscscarersurvey0910/Personal\\_Social\\_Services\\_Survey\\_of\\_Adult\\_Carers\\_in\\_England\\_2009\\_10\\_v1.2.pdf](http://www.ic.nhs.uk/webfiles/publications/Social%20Care/psscscarersurvey0910/Personal_Social_Services_Survey_of_Adult_Carers_in_England_2009_10_v1.2.pdf)

<sup>7</sup> Department of Health. Recognised, valued and supported. Next steps for the Carers Strategy (2010).

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/D\\_122077](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/D_122077)

to PCTs to specifically fund carers breaks<sup>8</sup>, is being used, as well as assessing the reach of the existing carers grant through local councils.

**Question 9: How can we improve indicators we have proposed here?**

Domain 2 also contains two indicators:

*Proportion of people with mental illness and or disability in employment.*

*Employment of people with long-term conditions*

Neither of these indicators appear appropriately worded at present.

We agree focussing minds on improving work and vocational opportunities for disabled people are one area where the public health outcomes framework could improve matters. Ensuring people with Parkinson's can access these opportunities is a national policy objective in the National Service Framework for Long-Term conditions,<sup>9</sup> which states:

Quality Requirement 6

People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.

In our membership survey<sup>10</sup> we found only a third of working age people with Parkinson's are in employment; just 12% of women are in full time work and 20% part-time, with 25% of men in full-time work and 7% part-time.

The indicator *employment of people with long-term conditions* needs to have proportionality to show how many people within the long term condition population is in employment, and we suggest that there should be a **separate indicator** that more fully recognises the numbers of people with disabilities and long term conditions that are accessing vocational training or education.

We hope that these observations and suggestions are of interest.

Yours sincerely,

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<sup>8</sup> Department of Health. Recognised, valued and supported. Next steps for the Carers Strategy (2010).  
[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/D\\_122077](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/D_122077)

<sup>9</sup> Department of Health. National Service Framework for long term neurological conditions (2005)  
[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4105361](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361)

<sup>10</sup> Parkinson's UK. Life with Parkinson's today – room for improvement (2008).  
[www.parkinsons.org.uk/about\\_us/results\\_of\\_the\\_members\\_survey.aspx](http://www.parkinsons.org.uk/about_us/results_of_the_members_survey.aspx)