



Parkinson's Disease Society response to DWP public consultation

No one written off Green Paper

Introduction

The Parkinson's Disease Society welcomes this opportunity to comment on the proposals made in the Green Paper, 'No one written off: reforming welfare to reward responsibility'.

1. About Parkinson's

It is estimated that 120,000 people in the UK have Parkinson's and approximately 10,000 people are newly diagnosed with Parkinson's each year in the UK. It is a progressive fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'.

Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in 20 will be diagnosed before the age of 40.

Parkinson's is a degenerative condition, although the speed of deterioration varies between individuals. One person may experience only slow and slight deterioration over years, while another person may report rapid decline in dexterity and mobility despite drug treatment. Symptom management is generally handled through prescribed medication and this can enable those in work to maintain their employment.

The results of a 2004 research project *Parkinson's disease and Employment*¹ revealed that people with early stage Parkinson's who are unable to work need tailored, personalised support. Many younger people with Parkinson's find that work makes a key contribution to their health and well-being.

It is beneficial for people with Parkinson's to be given detailed support in looking for work, especially if they have been out of the workforce for a number of years. It is clear that re-entering the labour market requires effective support, understanding and encouragement. The fluctuating nature of the condition means that some people can only work intermittently and the benefits system needs to be flexible enough to accommodate these needs.

However, many people with Parkinson's are not able to remain in or return to work, and it is important that these people are correctly identified and not placed under any inappropriate pressure to seek work.

Parkinson's and Incapacity Benefit / Employment Support Allowance

A high proportion of people with Parkinson's of working age rely on Incapacity Benefit. In our 2008 members' survey, which was completed by more than

13,000 members of the PDS, 47% of those aged 40 under 45 were on Incapacity Benefit and 39% of those aged 45 to 54².

2. General Comments on the consultation

The Society welcomes this consultation as an important opportunity to review and improve the support provided to disabled people seeking to return to, or remain in, employment and welcome many elements of the proposals, in particular:

- The commitment to double the budget of Access to Work and the commitment to explore ways to make Access to Work more responsive to the needs of claimants with fluctuating conditions. The majority of employment-related calls to our Helpline concern people with Parkinson's needing support to remain in work.

We are, however, disappointed that the date for doubling the budget is 2014, we would like to see this additional funding introduced immediately, so that the support is available for those assisted back to work by the other reforms in the Green Paper.

- Offering those aged 60 to 64 the opportunity to attend Work Focussed Interviews. It is important that older disabled people are able to access available support, though it is essential that this remains non-compulsory.
- The promise to explore the effectiveness of Employment Retention Assessments
- The commitment to pilot a Fit to Work service to help those in early stages of sickness to stay in touch with work
- Plans to expand the supported employment budget.

All of these measures to support disabled people to remain, in or return to, work where they are able are most welcome. However, it is disappointing that there is not a stronger focus within the Green Paper on engaging with employers and on supporting disabled people to remain in work.

We also have a number of concerns relating to the proposed reforms to Employment Support Allowance / Incapacity Benefit and would like to highlight the following areas for particular attention:

(i) Poor understanding of Parkinson's by professionals

Poor understanding of Parkinson's Disease may lead to people being mistakenly placed in the Work Related Activity Group of ESA and placed under inappropriate pressure to seek work.

- The fluctuating nature of the condition means that people with Parkinson's are at risk of being wrongly categorised as being fit for work, particularly if these decisions are made by a health professional without appropriate and recent training in Parkinson's. There is a danger of someone having a "good day" at interview and the

interviewer not understanding that this is not typical of the person's condition.

- This problem is reinforced by poor understanding of the non motor-symptoms of Parkinson's and the difficulty people with Parkinson's have expressing these symptoms. A third of respondents to a training needs analysis of healthcare professionals identified that they were not confident in identifying the mental health symptoms of Parkinson's. There was also uncertainty about the side effects of both mental health and anti-Parkinson's drugs³.
- There are various communication issues that a personal advisor should be aware of in dealing with a claimant with Parkinson's that may be misunderstood as being uncooperative if the advisor has not had training about the condition. These include the 'on/off' syndrome, fluctuations in functionality where a person can change from reasonable mobility to absolute immobility in the space of a few minutes, and limited facial expression due to muscle rigidity, which can make people appear anxious, hostile or bored.
- Parkinson's is also a degenerative condition. It is important that any people with Parkinson's on the Work Related Activity Group are able to be reassessed as their condition deteriorates.
- It is important that any decision relating to a person with Parkinson's takes into account the formal medical history of the person with Parkinson's provided by the person's specialist or Parkinson's Disease Specialist Nurse. Symptoms vary from individual to individual and decisions should reflect the views of the professional with the best possible knowledge of the claimant's health. For conditions such as Parkinson's this type of evidence is essential to ensuring an accurate decision and would reduce the number of mistakes and subsequent costly appeals.

ii) Increased compulsion and sanctions

The Parkinson's Disease Society is concerned by proposals to require all ESA claimants in the WRAG to undergo "work related activity". Given the fluctuating nature of the condition and often unrecognised mental health problems people with Parkinson's may face, many people could be wrongly placed in the Work Related Activity group and put under inappropriate pressure to find work and the consequent risk of 'sanctions'.

We are concerned, for example, that people with Parkinson's may have difficulty attending interviews and appointments due to the fluctuating nature of the condition. A person with Parkinson's may also have communication difficulties that may be misunderstood as being 'difficult' or uncooperative. Unless the individuals enforcing the conditionality have had training in Parkinson's their symptoms may be misinterpreted as non-compliance. We would be very concerned at any form of sanction being used in this scenario.

Given that ESA does not commence until 27 October we would urge that increased conditionality be resisted at this stage, until the new system has been properly assessed and reviewed, i.e. that further reform reflects needs identified under the new approach.

iii) The aim to reassess all 2.6 million Incapacity Benefit claimants within five years

The Parkinson's Disease Society is also concerned by proposals to reassess all existing Incapacity Benefit claimants by 2013. The Work Capability Assessment is not put into practice until 27 October and to put an additional 2.6 million people through the system before any opportunity to review how the new system is working is likely to result in large numbers of mistakes and consequent appeals. This might in turn result in the appeals system being overrun. The Government already estimates an increase of more than 20,000 appeals when ESA is introduced.⁴

This is a particular concern to the Society given the complex nature of Parkinson's and poor understanding of the condition amongst healthcare professionals, discussed above.

iii) The economic climate

We are concerned that the proposals in the Green Paper do not take into account the current economic climate. The focus on compulsion seems inappropriate at a time when there are fewer jobs available. We are also concerned that the proposals for back-to-work support rely on the private sector being able to raise upfront the money required for provision of support services and would be interested to learn what plans the has to ensure that this does not impact on those in need of back-to-work support.

iv) The impact of the proposals on carers in receipt of ESA / IB

It is worrying that the proposals relating to ESA / IB make no mention of taking into account any caring role the client may have. DWP statistics indicate that one in five current Incapacity Benefit claimants are themselves carers.⁵ The proposed use of compulsion is extremely worrying in this context and disappointing in light of the recent National Carers Strategy."⁶

There needs to be an holistic assessment of the client's capacity to work that takes into account caring roles and the support needed to enable carers to combine work with their caring role. The definition of a 'reasonable job' as applied to carers needs to reflect the limitations that their caring role places on their ability to work, in addition to the impact of their health condition, especially for carers of a person with a fluctuating condition such as Parkinson's.

The likely impact of these reforms in their current form is to force carers with a disability onto lower rate benefits - which is surely not the intention.

v) Plans to review the qualifying period for contributory ESA

The Society is concerned at proposals to change the qualifying period for ESA to a minimum of six months work within the last two years. This may exclude some people with Parkinson's who have left work and not claimed benefits, for example because of a delay in diagnosis of the condition, or because they were unaware of the benefits they might be able to claim, or because they took a few months to come to terms with their diagnosis and decide on their next steps. Extending the qualifying period to six months work in the last five years would avoid this problem.

vi) Use of Voice Recognition Analysis

The PDS has concerns over the roll-out of, and reliance on, Voice Risk Analysis as an anti-fraud measure. Voice Risk Analysis systems have not been properly tested with people with Parkinson's, many of whom have complex communication problems, and may consequently discriminate against people with the condition and lead to incorrect denial of claims.

vii) Plans to freeze current Incapacity Benefit rates

The PDS is concerned with the proposal that existing Incapacity Benefit claimants on higher rates of benefit because of age additions will have their benefit rate "brought into line with" those on ESA – in other words the rate of benefit will be 'frozen' at the existing level, consequently losing out in real terms. This goes against the spirit of the government's commitment that nobody would lose out from the welfare reforms⁷ at a time when the level of relative poverty for disabled working age adults is increasing⁸.

Consultation Questions

Q.2. How could capacity and capability to provide full-time work experience in the community sector be provided and incentivised to produce the best employment outcomes for participants?

Volunteering should be encouraged amongst ESA / IB claimants and amongst disabled people, not only as a means back to work but as an important factor in maintaining their health and well being.

However, volunteering shouldn't be compulsory, or restricted to those able to commit to a minimum number of hours, or to those roles that have a clear linkage with work. Many people are already doing voluntary work (for example as organisers of their local Parkinson's branch), and the Department might consider producing advice and guidance on how to turn existing experience into job-seeking advantage. There also needs to be a clear guarantee that entitlement to benefits will not be affected by volunteering.

Q.4 What penalties do you think would be most effective to deter more people from committing benefit fraud?

The PDS would support measures to reduce benefit fraud, though, as detailed in paragraph 2.23 of the Green Paper, existing measures have been successful in reducing fraud. The PDS are concerned that the wording of paragraphs 2.24 and 2.25 confuses the definition of fraud: non compliance

with back to work activities, such as missing appointments, is different from fraud and should not be treated as criminal behaviour.

Q.6. Do you agree with the proposed approach for identifying problem drug use? How should it be implemented? Do you think that everyone claiming a working-age benefit should be required to make a declaration of whether or not they use certain specified drugs?

The PDS are concerned at the reference to a long-term plan to widen this approach to those with alcohol addiction, and that these judgements would be made by JobCentre Plus staff. People with Parkinson's frequently tell us that people often confuse their symptoms with drunkenness. This reinforces the need for front-line JobCentre Plus staff to have Parkinson's awareness training.

Q.8. When is the right time to require ESA claimants to take a skills health check?

Priority should be given to those who believe they would benefit from such a check, i.e. getting one when they want.

A skills health check should build on information gathered during the work-focussed health-related assessment (where applicable) and incorporate any relevant report from the client's medical specialist.

Q.9 Should ESA customers be required to attend training in order to gain the identified skills they need to enter work?

Many people with Parkinson's could benefit from training, but compulsion is not the best way to address this need and will not necessarily give people the skills they need to return to work.

The priority should be ensuring that the benefits system provides greater flexibility for those claimants wanting to undertake study and education. An approach such as that outlined in the Work Skills command paper⁹, which proposes a Skills Account providing a guaranteed amount towards an individual's chosen form of training, would seem the most beneficial approach. This should take into account the individual's skills and experience, any restrictions imposed by the condition, and other factors such as accessibility and any caring roles and the type of jobs available to them locally. People must be able to choose training that is appropriate to their circumstances.

Greater integration between the social security system and the education and skills systems is also essential if benefit claimants are to be able to access the training they need to return to work.

Q.12 Are there any other circumstances where customers cannot get the skills they need to enter employment under present and planned arrangements?

Many existing training programmes are focussed at younger workers and those lacking basic skills. Paragraph 2.57 of the Green Paper, for example, refers to the needs of "low skilled individuals". People with Parkinson's tend to

be both older and are more likely to have worked at a relatively high skill level. It is essential that people with Parkinson's are able to access training that is relevant to their skills needs and not be forced onto inappropriate basic skills courses.

Before any form of compulsion is introduced, serious consideration needs to be given to those factors that make accessing skills training difficult. For example, those living in rural areas, who may have difficulty accessing courses because of the timing/location of courses and lack of accessible public transport. Many carers experience difficulty accessing formal courses because the timing of the courses does not fit in with their caring responsibilities. In such cases home learning packages may offer the best opportunity to gain the skills they need, rather than formal courses at which attendance can be recorded. For example, the City and Guilds Learning for Living course might be a suitable first step for many carers.

It is important that the focus on compulsion doesn't lead to people being forced onto inappropriate courses, or being discouraged from accessing courses that would benefit them.

Q.15. What expectations should there be of people undertaking the personalised support we will now be offering in the Work Related Activity Group? Could this include specific job search?

It is important that the system isn't used to force claimants to meet inappropriate goals, for example to apply for jobs that would leave them worse off, or which do not reflect the limitations placed by their disability or condition. Assessments should be holistic, taking into account all of the needs and abilities of the claimants, including their condition, their age, skills and experience and any caring role.

Q.16 How can we make Access to Work more responsive to the needs of claimants with fluctuating conditions – including mental health conditions?

It is important to ensure that healthcare professionals and personal advisers are aware of the availability of the Access to Work scheme, as well as the availability of suitable equipment, aids, adaptations and other support services. Those carrying out work capability assessments, for example, should be able to highlight potential entitlement to Access to Work support for those who may be eligible. It is also important that those frontline staff have a basic understanding of key groups of claimants, such as people with Parkinson's, so that they are aware of the type of support they are likely to need and might be able to access through the scheme.

The Department should work with local social services departments to address the long waiting lists for aids and adaptations that exist in some areas and which prevent many of those on those waiting lists from returning to work.

There also needs to be greater flexibility within the scheme, to facilitate portability of equipment between jobs.

Q.17 What additional flexibilities in the system or forms of support would claimants with multiple and complex problems need to enable them to meet the new work-focussed requirements proposed in this Green Paper?

Parkinson's is a degenerative condition, and it is important that any person with Parkinson's in the Work Related Activity Group is able to be quickly reassessed in light of any deterioration in their condition, both to ensure that they receive appropriate financial support and to avoid inappropriate compulsion to continue to engage in work related activity.

We would like to see better monitoring of the different impairment groups, including people with Parkinson's, particularly in relation to sanctions, appeals and numbers supported back to work, to ensure that the reforms are not having a negative impact on people with a particular condition. This is particularly important in relation to people with Parkinson's, given the poor understanding of the condition described in section 2:1 above.

Q.18 What are the key features of an action planning approach that would best support employees and employers to take the steps for the employee to make a swifter return to work?

It is disappointing that there is not a stronger focus within the Green Paper on engaging with employers, it should be the number one priority if low employment rates of disabled people are to be addressed. Many of those people with Parkinson's who contact our Helpline in relation to employment do so because they are not being properly supported by their employer and are at risk of losing their job. We would like to see a much stronger focus on employment retention, rather than focussing support on those that have already fallen out of work.

There is a need to actively engage employers, both to highlight the benefits of supporting their employees with a long-term condition to remain in work and to remind them of their duties under the Disability Discrimination Act. It is equally essential that employees and employers are able to access information about the support that might be available, including examples of best practice (perhaps covering a wide range of conditions, including Parkinson's).

We would also like to see government explore ways to ensure that disability discrimination legislation can be effectively actioned by disabled people who do experience discrimination from employers.

Q.20 What approach might be suitable to assist partners of benefit claimants who can work into employment?

The PDS are concerned that the proposal for partners of Incapacity Benefit / Employment Support Allowance recipients to be required to look for work may discriminate against carers of people with Parkinson's who do not qualify for Carer's Allowance.

There are a number of problems with relying on Carer's Allowance as evidence that a person is a full time carer. People may not qualify for Carer's Allowance for a wide variety of reasons, for example:

- Where two or more people are caring for the same person only one of these can receive the Allowance.
- Many people may not qualify for CA because they are caring for two or more moderately disabled people, though the collective impact of their caring roles mean that they are unable to work
- The low take-up of DLA means that many carers are consequently unable to claim Carer's Allowance
- Attendance Allowance and the higher two rates of DLA (Care) both have a qualifying period for which care must be required. Until those qualifying periods have elapsed, a carer cannot access Carer's Allowance, which means some carers face a 3 to 6 month period during which they are ineligible for CA.

In addition to the problems associated with using Carer's Allowance as a mechanism to identify carers, compulsion seems an inappropriate mechanism in relation to carers.

Q. 21: What are the next steps in enabling disabled people, reliably and easily, to access an individual budget if they want one? Should they include legislation to give people a right to ask for a budget or will the other levers the Government has got prove sufficient? What are the safeguards that should be built in? How can this be done?

Many disabled people would be able to return to work if appropriate support was in place and the development of individual budgets could offer claimants an opportunity to obtain services which meet their needs and choices, such as an employment support budget that they can spend on support services of their choice. It is also important that the opportunity is taken to link better with social services and other systems, to share information and support that might help a claimant return to work.

However, it is worth commenting that other elements of the Green Paper appear to run counter to the notion of choice and control for disabled people. For example, the proposal that ESA claimants be required to undertake work-related activity or face financial sanctions.

Q. 22: Is a system based on a single overarching benefit the right long-term aspiration? How could a simpler system be structured so as to meet varying needs and responsibilities?

No. The needs of disabled people and carers will always need to be addressed differently from the needs of other job seekers. Though there would be benefits to simplifying the benefits system, bundling together all income-replacement benefits under the JSA banner is not an appropriate solution.

Q. 23: Would moving carers currently on IS onto JSA be a suitable way of helping them to access the support available to help combine caring with paid work or preparing for paid work?

No. The Parkinson's Disease Society has real concerns about plans to move carers from Income Support to JobSeeker's Allowance.

Proposals to abolish Income Support and require carers to claim Jobseeker's Allowance are bound to cause anxiety to significant numbers of carers claiming these benefits and may discourage uptake of the benefit.

Whilst we strongly support efforts to improve the support available to enable carers that are able to return to work to do so, we do not believe that JSA would provide a suitable framework. JSA is based on a strong element of conditionality on claimants to find a job. To date the system has not been sensitive to carers needs and the threat of conditionality resulting from such a change would be entirely inappropriate and against the spirit of supporting carers contained in the National Carers Strategy¹⁰.

Q.26: What information would providers need to make the Right to Bid effective? How would the evaluation process need to work to give providers confidence that their ideas would be evaluated fairly and effectively? How do we get the balance right between rewarding those who come up with new ideas and the obligation to tender projects?

The PDS welcomes proposals to pilot ways to improve back to work support for disabled people through use of private sector and third sector providers. It is important that the contracts do not enable providers to 'cherry pick' clients that are likely to need less support to return to work and reward appropriately those providers that support those with complex needs. Regular evaluation and monitoring of contracts is essential to ensure that they are delivering the right support to all client groups, including any people with Parkinson's.

The recent National Carers Strategy¹¹ recognized that many professionals do not understand the needs of carers and included a commitment to provide carer-awareness training for a range of professionals, including JobCentre Plus staff, in light of the high proportion of Incapacity Benefit claimants who are carers. It is important that this training is extended to any private and voluntary sector providers used as a result of these proposals.

References

¹ Parkinson's Disease and Employment Paper published in May 2004, by the Parkinson's Disease Society of the United Kingdom.

² *Life with Parkinson's today – room for improvement*, Parkinson's Disease Society, 2008

³ Results from Parkinson's Disease Society training needs analysis, 2008.

⁴ Explanatory memorandum to The Employment and Support Allowance Regulations 2008 No. 794

⁵ Cited in *Valuing and Supporting Carers*, Work and Pensions Select Committee Fourth Report, July 2008

⁶ *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, Department of Health, June 2008

⁷ "the Government's commitment is about protecting rates for existing claimants and putting future customers on a higher [ESA] rate than the current long-term IB rate" – Jim Murphy, Committee debate on the Welfare Reform Act, 17 October 2006, column 56, Hansard

⁸ Disabled adults are twice as likely to live in low-income households as non-disabled adults, and the gap is bigger than a decade ago - Monitoring poverty and social exclusion 2007, Guy Palmer, Tom MacInnes and Peter Kenway New Policy Institute, Joseph Rowntree Foundation December 2007

⁹ Work Skills, Department for Work and Pensions and Department for Innovation, Universities and Skills, 2008.

¹⁰ *Carers at the heart of 21st century families and communities*, op cit

¹¹ *Carers at the heart of 21st century families and communities*, op cit