



Action for M.E.'s response to the *Improving Lives: Work, Health and Disability* green paper consultation

Executive Summary

In our February 2017 response, we set out how people with M.E. could be affected by the proposals set out in the UK government's recent green paper, *Improving lives: work, health and disability*. In order to focus on the areas where we had the most evidence and expertise, we have not answered all questions from the consultation document.

For the quantitative data from Action for M.E.'s survey, please see Appendix 1.

We put forward a number of key points:

There needs to be an improvement in understanding of complex, fluctuating conditions such as M.E. among employers and Jobcentre Plus staff.

A number of our survey respondents highlighted how misunderstanding from employers and Jobcentre Plus staff about M.E. had resulted in inappropriate suggestions regarding their employment.

Jobcentre Plus staff must have the information, or support from a Disability Employment Advisor, available to ensure that they can support claimants appropriately.

Employers need to be supported in understanding how a condition affects their employee, so that they know how to accommodate the employee's needs.

Practical measures were the most effective way to support people with M.E. in employment, such as communication between clinicians and employers.

Action for M.E.'s SEE M.E. employment project¹ secured outcomes through working with clients and their employers and clinicians to secure practical solutions to problems.

Our survey found that people with M.E. preferred this practical intervention, compared to having access information and advice services.

We recommend that the government's employment support includes practical solution brokering in order to assist people with a disability or health condition in achieving their employment outcomes.

¹ Action for M.E., *SEE M.E. project*, accessed 16 February 2017, <https://www.actionforme.org.uk/living-with-me/managing-work/see-me-project/>

Early, targeted intervention can prevent people from leaving employment.

Where a person with M.E. is struggling to maintain their current employment arrangements, early intervention can help them make adjustments and retain their current role. This benefits not only the employee but also the employer, who is able to retain a skilled and valuable member of staff.

The SEE M.E. employment project provided an opportunity for professionals to communicate early and intervene where appropriate to dress the clients' employment needs, offering an independent employment advisor who could liaise and encourage cooperation between employers and clinicians.

There needs to be recognition of the fact that some people with a disability or health condition are not able to work, for example the 25% of people with M.E. who are severely affected.

People with severe M.E. are often housebound and bedbound, and find that work is not possible. Not only would they be unable to accept employment, but the exertion required to take part in employment support programmes could cause their symptoms to increase and their condition to deteriorate over the long-term.

This group, and others who are severely ill and unable to work, must be made exempt from the Government's employment support offer.

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Introduction

Action for M.E. is responding to this call for evidence as the UK's leading charity for people affected by Myalgic Encephalomyelitis (M.E.), which affects an estimated 250,000 men, women and children in the UK.² Symptoms include post-exertional malaise (a period of intense exhaustion brought on by any mental or physical activity) and chronic pain.

M.E. affects different people in different ways and symptoms can fluctuate and change over time.

25% of people with M.E. are severely affected.³ Severely affected people may be confined to bed or unable to leave the house except for very short periods using a wheelchair. Typically, severely affected people will be unable to hold themselves upright, sitting or standing, and will experience a wide range of cognitive difficulties (eg. unable to process conversation, unable to read, unable to concentrate for more than a few minutes) and extreme sensitivity to light and sound.⁴ For this group, work is not possible.

Even those more moderately affected may need a period of some months, or more likely years, to recover to the point where limited part time work may be possible.⁵

However, for those who are mildly affected, or who have been more severely affected but have made significant recovery, returning to work is an important aspiration for many, but a process which is often beset with barriers.

Our response is based on:

- A survey conducted through December 2016 and January 2017, for people with M.E. who had experiences of employment or welfare benefits. More than 600 people responded.
- The learning we gained through running an 18-month specialist employment service, Support, Empower and Employ people with M.E. (SEE M.E.). SEE M.E. was a pilot project where specialist employment advisors worked within North Bristol NHS Trust to liaise with employees, employers and health professionals in order to assist people with M.E. in achieving their self-defined employment goals. The project increased job retention, increased returns to work, and produced savings for employers and the health service.

The responses we received from the survey and the outcomes of the employment service highlight recurring key issues and concerns. These reflect the experiences of people affected by M.E. who engage with our information and support services, including our Welfare Advice and Support Service; our ongoing consultations and surveys; our social media platforms; and our peer-support forum, M.E. Friends Online.

² Action for M.E., *Introduction*, accessed February 8 2017, <https://www.actionforme.org.uk/what-is-me/introduction/>

³ Action for M.E., *What is M.E.?*, accessed February 8 2017, <https://www.actionforme.org.uk/what-is-me/severe-me/>

⁴ Ibid.

⁵ Action for M.E. *Symptoms*, accessed February 8 2017, <https://www.actionforme.org.uk/what-is-me/symptoms/>

Chapter 1: Tackling a significant inequality

Consultation question: what innovative and evidence-based support are you already delivering to improve health and employment outcomes for people in your community which you think could be replicated at scale? What evidence sources did you draw on when making your investment decision?

The SEE M.E. employment service provided specialist support to people with M.E. and was based out of North Bristol NHS Trust. This was a pilot project and ran for 18 months until 7 October 2016.

At its conclusion, there were 102 concluded cases, with outcomes of:

- 72% of clients achieved their employment goals. A majority of these retained their job or secured appropriate work, training or volunteering. A minority also recorded a positive outcome in securing the best exit from unsustainable employment.
- 83% of employers or trade union representatives reported that the project's intervention made a positive difference to the anticipated outcome of their employee's case.
- 60% of employers considered that the service had resulted in financial savings for the employing organisation.
- 60% of clinicians said the service enabled them to use their clinical time more efficiently, with the average estimate being two hours per week saved.
- Based on increased capacity among professionals and an increase in employment, an evaluation of the service found that every £1 invested in the project produced a social return on investment of more than £5.⁶

Additional outcomes include 93% of clients reporting improved understanding of their employment rights and entitlements, 83% reporting increased access to mainstream services, and 65% reporting an improved sense of wellbeing.

As referenced above, the project also built the capacity of employers and health professionals who became involved in the service through its clients.

The project's success is unlikely to be limited to M.E., as its approach could be transferred to a range of other fluctuating, long-term health conditions. The learning is likely to be applicable to a number of patient groups.

The lessons from the project can be used to inform service design at scale are:

- Person-centred provision ensures individualised and appropriate employment goals.
- The independence of the advisor, in both perception and actuality, provides a crucial bridge between different health and employment agencies.
- Specialist employment advisors support and can build the long-term capacity employers and clinicians to help individuals to meet employment goals as outlined above.

⁶ Action for M.E., *SEE M.E. project*, accessed 16 February 2017, <https://www.actionforme.org.uk/living-with-me/managing-work/see-me-project/>

- Early, targeted intervention with channels of communication between employers, health professionals and the employment advisor meant that concerns were addressed as they arose as they arose, preventing the development of long-term barriers.

Chapter 2: Supporting people into work

Building work coach capability

Consultation question: how do we ensure that Jobcentres can support the provision of the right personal support at the right time for individuals?

Two of the most important factors are:

- The delivery of accurate assessments that succeed in capturing the actual capability of the claimant. This first step, taking place towards the beginning of the claimant's journey, determines the level of support a person receives and would result in the appropriate support being provided
- Provision of support by advisors with some understanding of the condition of the individual, the specific barriers they face and possible solutions.

A key barrier people with M.E. face in being accurately assessed is the knowledge of medical staff conducting the assessments. These staff have varying backgrounds and consequent understanding of illness groups, which can limit their understanding of how a claimant's condition impacts on capability. This could be rectified by ensuring medical professionals conducting the assessment have experience of the condition that affects the claimant, or have a resource to consult on less widely understood conditions and symptoms. An additional mechanism to ensure that the assessment is accurate is for the assessor to begin by offering the claimant an opportunity to provide any specific information on their condition that they feel is relevant to either how the assessment can be as accessible as possible, or how the claimant's condition affects their capability.

This issue recurs later in the process with the provision of employment support. A number of our survey respondents stated that Jobcentre Plus (JCP) staff failed to make appropriate and reasonable suggestions to help them into work. Our respondents said this was due to a lack of understanding about their condition, with some saying JCP staff did not believe their condition really existed. By discounting the symptoms that people with M.E. experience, staff failed to deliver the correct level of personal support and consequently failed to achieve appropriate employment goals.

Individuals who had well-informed staff spoke of the difference this made in receiving relevant advice, with one respondent stating:

“Having someone who understood M.E. and could think of things I didn't know about was really helpful, such as earphones to help with noise sensitivity, specialised chair to help with fatigue etc.”

Experiences such as this show how the lack of medical knowledge among other assessors acts as a barrier to the successful functioning of the current system.

Following on from the delivery of the SEE M.E. project, Action for M.E. has produced resources such as the *Support, empower and employ people with M.E.: a toolkit for*

professionals⁷ in order to share the learning from the project with professionals. One JCP Disability Employment Advisor (DEA) who downloaded the resource told us:

“The tool will be an invaluable source of information, providing all points to consider when offering advice and guidance to this customer group. I will be using it as a point of reference to make sure I don’t forget anything!”

Such responses evidence how specialist guidance on how to support an individual with particular health and employment needs is valued by DEAs. By supplementing their knowledge they are enabled to provide more suitable and effective advice to claimants.

The existing problem of staff and assessors having insufficient medical knowledge or awareness of specific employment barriers for people with M.E. could be further exacerbated where the capacity of JCP is reduced. The diminishing funding of disability employment programmes, and the large range of tasks required of JCP staff, as set out in the green paper, suggests that they will be dealing with people with a very wide variety of conditions. Some mechanism by which they specialise in certain sub-groups of illness, or where DEAs with a certain specialism support staff in the relevant cases, would contribute to supporting JCP staff in attaining the correct and sufficient medical knowledge to work with claimants effectively.

Consultation question: what specialist tools or support should we provide to work coaches to help them work with disabled people and people with health conditions?

As stated in answer to previous questions, a lack of medical understanding inhibits the provision of appropriate employment support for people with M.E. Therefore, specialist input in understanding conditions would lead to better support for claimants. It could also help in their work with disabled people directly, by helping them in knowing how best to structure each meeting with the claimant. For example, people with M.E. experience a worsening of symptoms after exertion and the more intense the exertion the worse those symptoms.⁸ Therefore, breaking a meeting into chunks and allowing a person time to process information would reduce those after-effects and increase the effective participation of the claimant. A person with another condition may prefer a different kind of engagement. Currently, meetings are very uniformly structured in a defined time period. Medical knowledge would ensure that the way JCP staff interact with claimants is productive and most conducive to a successful outcome.

Action for M.E.’s resource *Support, empower and employ people with M.E.: a toolkit for professionals*⁹ provides an example of how specialist advice on accommodating a person with health and employment needs can be disseminated, as well as how such resources, produced by the voluntary sector, can be of benefit to employment advisors.

⁷ Action for M.E., *SEE M.E. toolkit for professionals*, accessed 15 February 2017, <https://www.actionforme.org.uk/resources/our-publications/booklets/see-me-toolkit-for-professionals/>

⁸ Action for M.E. *Symptoms*, accessed 8 February 2017, <https://www.actionforme.org.uk/what-is-me/symptoms/>

⁹ Action for M.E., *SEE M.E. toolkit for professionals*, accessed 15 February 2017, <https://www.actionforme.org.uk/resources/our-publications/booklets/see-me-toolkit-for-professionals/>

It includes essential knowledge about the condition's impact on capability, as well as sections on practical support strategies which include among others:

- Disclosing M.E. to an employer
- Flexible working and contractual variations
- Reasonable adjustments
- Return-to-work planning
- Sustaining work

A webinar for JCP work coaches and DEAs which covered similar content to the toolkit received positive feedback, with one person stating:

“As a fresh face to the DEA role I gained valuable knowledge in the understanding of M.E. as there has been a lot of stigma around this debilitating illness.

“Having an understanding of M.E. will definitely help myself, our work coaches and our claimants journey into work. The toolkit is great, full of very useful contacts with clear steps and supporting tips.

“Definitely more awareness sessions on other illnesses would be very useful.”

Supporting people into work

Consultation question: what support should we offer to help those ‘in work’ stay in work and progress?

In the survey we conducted, people with M.E. showed a preference for higher intervention employment support. While a majority of people thought that information and advice on having discussions with their employer and on managing their condition at work were helpful for people who were already in work (66% and 51% respectively), much higher percentages felt that higher levels of ‘hands-on’ intervention would be beneficial. A notably larger majority stated that reasonable adjustments (75%), liaison between health professionals and employers (76%), and a change in working pattern (86%) would assist people with M.E. in remaining in work. These higher percentages here are statistically significant.

This is supported by the success of the SEE M.E. employment project in securing outcomes for people with M.E. by working with employers and health professionals to create a sustainable working situation for the individual using the service. The highest number of people using the service were those already in work but who couldn't sustain the current situation. Employment support at this stage is crucial in preventing a person from firstly falling out of work, and subsequently having to re-enter the workplace.

The advisors at the service would often meet either jointly with the relevant groups (ie. employer, employee, health professional), or individually as necessary, to explore long-term mutually agreed solutions.

For example, one client of the employment service was a teacher who was struggling to sustain her part-time work, working heavily for a few days a week and

then doing nothing the remaining four days. After a period of absence, the advisor worked closely with the client to look at return-to-work options, which included attending two meetings with the head teacher, HR and union representative. The advisor supported the client in negotiating an extended return to work and secure practical measures. This included a 'recharge space' in the client's workplace and a dedicated workstation, with regular reviews of progress built into the plan. The advisor said:

"I have been able to explain to the employer about the condition. The employer really tried to take everything on board. He listened and took on board information from the clinical report and put together a detailed plan."

The client highlighted the vital role of the advisor within the network of support:

"My Union Rep was able to support me but only around employment. The Doctor and clinicians only have health knowledge. [My employment advisor] brought it all together."

This evidence points to a need for more in-depth and targeted support. While information and advice services are valued by the patient community, there is a greater preference for practical solution brokering from employment support services, and there is clear evidence for the effectiveness of this approach. By investing in this approach, employment support can secure not just a return-to-work outcome, but a return-to-work that is sustainable over the longer-term due to the full consideration and accommodation of the capability of the employee.

Consultation question: what does the evidence tell us about the right type of employment support for people with mental health conditions?

M.E. is a neurological illness, not a mental health condition. However, it is common for people with M.E. to also have mental health conditions as the result of the effects of having to deal with a long term chronic illness.¹⁰ People with M.E. are often isolated, frustrated and financially worse off than they were when they were well which can result in co-morbidity of poor mental health as well as their pre-existing condition of M.E.

The approaches outlined throughout this response as suitable for people with M.E. could also be applicable to people with other health conditions including mental health. It is not immediately obvious why mental health conditions and physical health conditions need to be treated as entirely separate. As well as the co-morbidity considered above, it is also the case that neurological conditions often present with a range of physical and mental symptoms, such as chronic pain and cognitive difficulties. The current *Revised WCA handbook*¹¹ erases this through the explicit exclusion of consideration of non-physical symptoms for physical conditions, and the equivalent for mental health conditions. As financial and employment support is determined entirely by functionality, the fact of a claimant's capability is unaltered by what classification any ill health of the claimant is placed under.

¹⁰ Action for M.E. *What is the impact of M.E.?*, accessed 8 February 2017, <https://www.actionforme.org.uk/resources/questions-and-answers/what-is-the-impact-of-me/>

¹¹ Centre for Health and Disability Assessments (2016), *Revised WCA Handbook*, accessed 15 February 2017, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535065/wca-handbook-july-2016.pdf

Improving access to employment support

Consultation question: should we offer targeted health and employment support to individuals in the Support Group, and Universal Credit equivalent, where appropriate?

Greater support for those in the Support Group could be offered, but this must be voluntary and would need to be implemented in such a way that claimants are not anxious, and have no reason to be anxious, about the consequences of accepting or declining this support.

People with M.E. who are in the Support Group are likely to be more severely affected by their condition. This means that additional exertion could worsen their condition over the long-term.¹² For those who voluntarily opted in to such support, it is likely that any individual would either have to drop-out due to a later period of illness or that any positive results would only be seen in the (very) long term. This latter outcome would be due to the need for further recovery before progress towards employment became realistic. Offering this kind of support to this group would therefore be of less obvious financial benefit.

Making employment support mandatory for this group would therefore not only be ineffective in the short term but could worsen illness and significantly damage the prognosis for the individual and reduce the longer-term chances of a return to work for people who are already severely ill. This would defeat the object of providing the support in the first place.

Another potential difficulty with this proposal is that the current system creates a financial disincentive for Support Group members to take up support, on the basis that if they were consequently transferred to the Work-Related Activity Group they would face a significant drop in income. If a Support Group member decides to take up this offer of targeted health and employment support, a record of this could be taken into account at their next assessment and they could be placed in the Work-Related Activity Group. This would result in a financial loss (the differential will be increased further with the upcoming £30 weekly cut for WRAG members), and mandatory activity (with the alternative being a sanction). Any provision of support to this group would need to avoid this implication, as it would have the dual outcome of:

- disincentivising Support Group members who want support from accepting it, thus reducing the efficacy of attempts to encourage wider use of that support, and
- leading to the incorrect classification of people with needs appropriate to the Support Group, in the Work-Related Activity Group on the basis of voluntary engagement with support.

If extending voluntary support to this group, there would need to be full assurance that taking up this support would not be taken as evidence of capability in future assessments of the claimant and would not be used as a backdoor route to imposing conditionality on Employment and Support Allowance (ESA) Support Group claimants. Without this assurance, extending support to this group would be

¹² Action for M.E., *Symptoms*, accessed 8 February 2017, <https://www.actionforme.org.uk/what-is-me/symptoms/>

detrimental both to the health of claimants (and thus their future ability to return to work) and to their financial security, increasing the disadvantage experienced by those who are most severely ill.

Consultation question: what type of support might be most effective and who should provide this?

One of the issues highlighted previously is the need for this support to be voluntary. People who are placed in the Support Group are placed there because they are unable to work or to take any steps towards employment.

For people with M.E., this point is particularly crucial for the 25% of people who are severely affected. This group will either be bedbound or housebound, and have difficulties accessing benefits.¹³ One person said:

“Process very very slow and complicated and too exhausting for me to deal with. Unable to face going through appeal process.”

Another stated:

“I passed out at the assessment and was wheeled out on an office chair. I went on to be bedbound for 12 months and am still trying to recover.”

The experiences of this group demonstrate the need for some people within the Support Group to be excluded from this employment support offer, as those who are severely unwell would not only be unable to take part but could see their condition deteriorate as a result of exertion.

However, there may be people in the Support Group who are able to voluntarily take up some level of employment support.

One of the possibilities for this group would be to offer access to peer support services, rather than the professional support offered to Work-Related Activity Group members and Jobseeker’s Allowance claimants. Peer support can be an effective way of engaging a patient community by providing the assurance that the people they met will necessarily understand their situation. It has been shown to be an effective method of improving disabled people’s employment prospects [Effectiveness of peer support]. While not a necessary element of the SEE M.E. service, having an employment advisor with M.E. themselves elicited positive feedback from clients, who highlighted the value of an advisor with a realistic perspective grounded in their own experiences.

Peer support does not need to be provided by someone with the same condition to elicit this response. One person with M.E. told us about their experience:

“Before I managed to return to work, I attended a course for disabled people wanting to return to work. I think it was the thing that gave me the biggest boost in what felt like a long and lonely battle to persuade someone to look at my ability, not my illness, and give me a chance. The course was run totally

¹³ Action for M.E. (2014), *My life stopped*, accessed 15 February 2017, <https://www.actionforme.org.uk/uploads/pdfs/my-life-stopped-severe-ME-report.pdf>

independently of JCP, which I valued, and was delivered entirely by disabled people who knew about employment barriers from personal as well as professional experience.

“It was a very empowering course, partly because of those who delivered it and partly because I was introduced to the social model of disability on a very real and practical level... From then onwards, I realised that many of the barriers I would hit would not be about me but about the attitudes and inflexibility of others. I remembered what I had to offer and that actually, in the right job and with reasonable adjustments, I would be a great asset to my employer and could aspire to a rewarding job.”

Another approach to take that would ensure individualised support was tailored to each person’s needs and capability could be to make use of the claimant’s own knowledge, experience and judgement about how their condition affects them and how effective any intervention may be.

The most efficient way for the assessor to find out the capabilities of the claimant is to ask them, yet a number of respondents to our survey said that they did not feel as though they were listened to during their assessment and so their assessment was not accurate. One claimant told us that:

“[Improvements to the process] could start with the assessors reading what is written on the form/evidence and listening to what I told them. My assessor was very pleasant but it appeared that we were not in the same assessment together as the final record was so different from my recollection of it.”

This approach would mean that support provision would necessarily be kept at an appropriate level (as determined by the claimant themselves). There would be the additional benefit of using a collaborative approach between claimant and JCP staff that could improve the claimant’s attitude towards, and relationship with, benefit providers going forward.

Consultation question: how can we best maintain contact with people in the Support Group to ensure no-one is written off?

The proposals in the Green Paper and DWP statements have emphasised the intention to adopt ‘light-touch intervention’ to maintain contact with the Support Group.

This is an appropriate decision given that those in the Support Group have been assessed as both being unable to work and as being unable to take steps to move towards employment. It is important that when maintaining contact with the Support Group, it is clearly and accessibly stated that all stages of this provision are voluntary and will not impact on the provision of support that the claimant rightfully receives.

There is a large culture of distrust around the welfare and employment support process that increases anxiety for claimants and will reduce the efficacy of DWP attempts to engage with claimants in a non-threatening manner. It is a recurring statement from people with M.E., as well as other claimant groups, that communications from the DWP increase their anxiety and a concerning number of

survey respondents expressed suicidal thoughts and feelings while sharing their experience of assessments and benefits. One person said in our survey:

“All the stress involved in the assessment/appeal process makes it extremely difficult to stay positive for months on end... an endless cycle of wasting all of the energy I have on sceptical strangers trying to catch me out to save a bit of money that I'd rather be earning anyway.”

Another stated:

“I get suicidal thoughts when under threat as I feel there is no hope for my future and all I have is my benefits to live.”

Due to the severe illness of people in this group, and the very high levels of anxiety associated with DWP contact, the DWP needs to show caution in implementing any policies to increase contact with this group.

Furthermore, people with M.E. often experience significant cognitive difficulties. People with M.E. tell us they find some benefit documentation confusing; this problem is amplified for those with severe cognitive difficulties,¹⁴ which can cause a lot of extra work for the claimant and for the DWP. For example, one respondent to a survey we conducted on the Work Capability Assessment (WCA) said that:

“Last year the DWP put me into the Work-Related Activity Group for ESA (or so I subsequently gathered) in April 2013 for 365 days. Their letter was five pages long and I did not understand it then at all. So I wrote to them asking them to explain what it actually meant to me. I wrote to the name at the bottom of their letter but got no reply. After a couple of chases I used their complaints procedure to obtain a reply.”

When getting in touch with Support Group claimants, it is essential that these extra difficulties are taken into account and that all communication is clear, expressed as simply as possible and is always written in plain English. This should ensure that the nature of the support on offer is not misconstrued.

¹⁴ Action for M.E., *Symptoms*, accessed 8 February 2017, <https://www.actionforme.org.uk/what-is-me/symptoms/>

Chapter 3: Assessments for benefits for people with health conditions

Consultation question: should the assessment for the financial support an individual receives from the system be separate from the discussion a claimant has about employment or health support?

Overall, 55% of respondents expressed their distrust of the proposed changes. This was either due to speculation on what the intentions behind the changes were, or the capability of assessors to make a fair judgement. On the latter point, it has been expressed throughout this response how better medical information and knowledge would improve assessments of claimants and the approach taken by JCP staff.

In a comment that is broadly representative of these concerns, one respondent stated:

“[I am] worried that the intention is [to] impose conditions on those in the support group which they will be unable to fulfil or struggle to, and may end up being sanctioned.”

This is an understandable concern given the conditionality attached to ESA Work-Related Activity and many other benefits. In order to allay these concerns and consequently move this proposal forward in a constructive manner for those it is intended to support, it should continue to be the case that no conditionality is attached to those in the Support Group.

Such a move would also be consistent with the recent findings from the National Audit Office (NAO) that conditionality has not been sufficiently evidenced as an effective measure. Furthermore, the report states that there is evidence that sanctions may reduce claimant numbers in the short-term, but that the employment gained by the claimant is often unsustainable over the longer-term.¹⁵

Asked both how such a change would affect their own experience and how it would affect people with M.E. more widely, there was a mixed response from our survey respondents. This was largely due to a lack of information about how the change would be implemented.

When considering their own experience of claiming ESA, 11% of survey respondents felt that this change would impact them positively and 26% thought the impact would have been negative. The remainder either thought there would have been no change (22%) or that they weren't sure (42%).

When considering the general experiences of people with M.E., 22% thought the impact would be positive and 16% thought it would be negative. 17% thought there'd be no change and 45% weren't sure. These results show how the proposal in its current form is unclear and more detail would be needed to accurately determine its likely impact on people with a disability or health condition.

¹⁵ National Audit Office (2016), *Benefit Sanctions*, accessed 15 February 2017, <https://www.nao.org.uk/report/benefit-sanctions/>

Consultation question: how can we ensure that each claimant is matched to a personalised and tailored employment-related support offer?

One of the key findings from our SEE M.E. employment project evaluation was the efficacy of helping people in achieving their self-defined employment goals, rather than a rigid set of outcomes being imposed on all individuals.

The person-centred delivery of the project was delivered by:

- individuals setting their own goals and aspirations
- individuals being guided through a 'needs-based assessment' which highlights gaps in appropriate knowledge, skills and support to achieve employment objectives
- services tailored to be responsive and proportionate to individuals' needs.

Such an approach prevented clients from being limited by focussing on pre-defined job outcomes such as 'paid employment of over 16 hours per week', which may have been an unachievable goal for many and discouraged them from aiming for a lower level of employment which was more sustainable for them.

This is an approach that ensures individuals have a personalised and tailored employment-related support offer. It could be incorporated into a number of the proposals in the green paper that are designed to afford more flexibility in the system. These include the separation of financial and employment support assessment for ESA claimants, and the offer made to Support Group members to take up employment support.

However, as previously emphasised it is necessary that employment support remains a voluntary option for claimants. The NAO has shown that conditionality may not be an effective route to securing employment outcomes, and evidence elsewhere shows that an individual's volition in accepting support may be the key determinant.¹⁶

Consultation question: how might we share evidence between assessments, including between Employment and Support Allowance/Universal Credit and Personal Independence Payments to help the Department for Work and Pensions benefit decision makers and reduce burdens on claimants?

61% of those surveyed responded positively to the idea of evidence being shared by assessors on the basis that it would reduce the number of assessments they would have to attend and forms they would have to fill out, which are processes that are often detrimental to the health of people with M.E.

However, 17% of respondents reacted negatively to the suggestion of evidence being shared between assessors. There were some concerns over the power this would give one assessor. There were a number of people who claimed that they did not trust the assessors to give a fair and accurate assessment, mostly because assessors seem to have inadequate knowledge about the nature of M.E and were therefore worried about information sharing having a negative impact on multiple

¹⁶ National Audit Office (2016), *Benefit Sanctions*, accessed 15 February 2017, <https://www.nao.org.uk/report/benefit-sanctions/>

claims. There was also a concern that as M.E. is a fluctuating illness¹⁷ it is very difficult for an assessor to gauge the level of illness or barriers to employment in the space of one meeting. This is a particular concern given that assessors also use the meeting to observe the capability of the claimant: for someone with a fluctuating condition, a momentary observation is not valid evidence and can completely misrepresent their actual capability. If any such invalid assessment was then shared this would compound the problem.

Tribunal decisions must also be included to ensure that the information shared is used appropriately, as these decisions often include a successful challenge to inaccurate medical reports.

Action for M.E.'s Welfare Benefits Advisor said:

“Sharing tribunal decisions alongside medical reports may help assessors to understand the original assessment may not have been an accurate reflection of the claimant’s health condition and subsequently they may decide not to place reliance on the medical report. As a result, this could relieve the claimant’s anxiety and ensure inaccurate reports are not affecting multiple claims.

“There is a potential concern with sharing evidence claimants may feel forced to appeal a decision to ensure an accurate result is recorded on their file in case this evidence is shared. This results in a dangerous situation where claimants may feel they have no choice but to appeal as it is not just one benefit at risk, but multiple. They may push themselves to appeal decisions even when they are not well enough to go through an appeal and as a result risk deterioration in their health. In the long-run this situation can prolong recovery for the individual and lead to further long-term reliance on the welfare system.

“A way to create a safety net in the above situation would firstly be to make sure medical assessors understand the health condition the claimant has to avoid any inaccurate reports in the first place. The second way to avoid the situation described may be to ensure that all evidence is looked at by the medical assessor, including tribunal decisions. However, it should be mandatory for the assessor to ask the claimant whether they felt the assessor’s decision regarding their PIP/ESA/UC claim was accurate and if not, why they did not challenge the decision. Any answers given by the claimant should be considered when making their decision.”

A recurring suggestion from survey respondents was that assessors required a more in-depth understanding of how an illness affects the capability of a claimant. One way of addressing this difficulty would be for the assessor to have more comprehensive support from a DEA who specialised in the conditions of claimants being assessed. In cases of co-morbidity, the assessor would need to have the capacity to draw on expertise from a number of specialists.

¹⁷ Action for M.E., *Symptoms*, accessed 8 February 2017, <https://www.actionforme.org.uk/what-is-me/symptoms/>

An additional way to allay the concerns of claimants would be to only share the results of assessments with the consent of the claimant. However, this should not be used as an alternative to the desperately-needed improvement in medical education that assessors and JCP staff have, particularly with regard to fluctuating or invisible illnesses where the effects on capability can be more difficult to capture. This consent mechanism was suggested by a number of our survey respondents due to the prevalence of human error and bias in the assessments they have experienced. There were also suggestions that there should be two independent assessors for each assessment, so that the results are mediated. One respondent said that:

“Maybe needing 2 independent assessors’ reports would limit [the influence of one inaccurate assessment].”

Consultation question: building on our plans to exempt people with the most severe health conditions and disabilities from reassessment, how can we further improve the process for assessing financial support for this group?

It has been announced by the DWP that the exemption from assessment for those with severe health conditions will apply only to those with ‘minimally fluctuating care needs’.¹⁸ While M.E. is a fluctuating condition, 25% of those affected are severely ill.¹⁹ This results in them being either housebound or bedbound and dependent on others to take care of their most basic needs.

On this basis, our survey respondents shared ways in which a person with M.E. who was severely affected could be considered for this exemption. 41% believed that a person should be exempt from reassessment based on the severity of their condition. Post-exertional malaise, a hallmark of M.E., means that activity and exertion increase a person’s symptoms.²⁰ For a person with severe M.E., simple tasks like brushing teeth can leave a person with severe M.E. exhausted. Therefore, taking part in assessments is not only unnecessary (due to the enduring nature of the condition in the severely ill) but can be actively detrimental to the health of those who are required to take part.

18% of respondents said that confirmation from a doctor or medical professional that a person is unfit for work should be sufficient evidence that they are unfit for work. Assessors are unlikely to have a better understanding of the nature of M.E. than a medical professional, so doctor’s notes should take greater precedence in assessments. This is particularly the case where the medical professional is one that has been in regularly contact with the patient and therefore has an understanding of the person’s capability that is based on their condition over a longer-term period.

A number of respondents suggested that the length of time between assessments should increase depending on the severity and length of time a person has been ill for, as the longer a person has been ill for, and the more severe their illness the less likely they are to see any kind of change in their health. One respondent said:

¹⁸ Disability Rights UK (2016), *Government gives more information about ESA retesting*, accessed 15 February 2017 <https://www.disabilityrightsuk.org/news/2016/october/government-gives-more-information-about-esa-retesting>

¹⁹ Action for M.E., *Symptoms*, accessed 8 February 2017, <https://www.actionforme.org.uk/what-is-me/symptoms/>

²⁰ Ibid.

“At the very least, I would suggest these sufferers be assessed less frequently even if they cannot be exempt.”

Another person agreed, stating:

“I do feel very strongly that many M.E. patients should only be re-assessed at much longer intervals.”

Chapter 4: Supporting employers to recruit with confidence and create healthy workplaces

Embedding good practices and supportive cultures

Consultation question: what are the key barriers preventing employers of all sizes and sectors recruiting and retaining the talent of disabled people and people with health conditions?

One of the key issues highlighted both by employers and people with M.E. was a lack of understanding from employers, both of the impact of the condition and of how to accommodate the needs of employees with health conditions.

Based on our SEE M.E. employment project, a large number of employers were grateful for guidance on how to accommodate their employees. With recruitment costs and the employee's prior experience, employers were keen to retain their staff but would not have had the knowledge of how to sustainably do so without the intervention of specialist support. Many were unaware of available support such as Access to Work (AtW). The expansion of AtW is a positive step but it is essential that DWP takes action to ensure that employers are better informed about the existence of the scheme and the benefits to both individual and employer.

Through the project, we found that support and equipment funded by AtW made a crucial difference to people with M.E., enabling them to secure new jobs, work more and retain employment. People are much less likely to apply for the scheme when they are unable to identify exactly what may be funded – this compounds the issues that many people with less widely understood conditions face, and should be taken into account in the planning of the expansion of AtW.

For example, one person, who received six sessions of one-to-one coaching through AtW to assist her in adapting to new ways of working, said:

“The coaching has helped me to attend more closely and carefully to what is going on, how my body is feeling and to what I need. This can be attending to the little things like making sure I have set up my desk so I’m not constantly moving my head from left to right of the screen and back again. Or making sure I have put files close to hand, so I remember to complete tasks.

This has enabled me to understand I have a ‘new normal’ and to recognise and embrace this so I can choose how to respond to the requirements of my work and not just reach in old, overly fatiguing ways.”

People with M.E. at both SMEs and larger enterprises also reflected this in our survey. 66% of respondents at SMEs either agreed or strongly agreed that their employer “*wasn’t sure what reasonable adjustment to make to accommodate my disability or health condition*”, compared to 67% for larger enterprises (with an overall average of 67% for all respondents). However, there was a statistically significant difference between respondents’ willingness to disclose their condition, with employees at larger organisations (defined as those with over 250 employees) being less likely to expect a negative reaction. There was no corresponding difference in

how employers did treat the employee once they had disclosed their condition, which suggests this is largely down to perception.

Solutions include employers signalling that they offer a disability-positive workplace (although this has to be backed up by experience on the ground, something which can be influenced by individual managers as much as by an organisation as a whole). A number of people with M.E., when responding to our survey, said that it would help to know which employers take a positive approach. Comments made it clear that they were looking for 'M.E.-friendly workplaces' where they could expect understanding and flexibility. This concept goes beyond existing arrangements such as the two ticks scheme but could perhaps be built on it.

Consultation question: what expectation should there be on employers to recruit or retain disabled people and people with health conditions?

The minimum requirement is that employers should ensure fully accessible recruitment practices and advertise and demonstrate that they are willing to accommodate the accessibility needs of employees.

A significant number of survey respondents stated that their employer had failed to make the essential reasonable adjustments recommended by an occupational therapist to make employment sustainable. One respondent said:

“My employer consistently ignored occupational health advice.”

Another said that:

“The employer does not have to do the adjustments [the occupational therapist] suggest anyway and in my case find every way not to.”

This reluctance to adapt could be reduced with the expansion in Access to Work, and greater awareness-raising around its provision.

Consultation question: should there be a different approach for different sized organisations and different sectors?

SMEs necessarily face barriers that larger employers do not face when it comes to supporting employees with either a disability or health condition.

SMEs will have less financial resource to contribute to the adjustments required for an employee with a disability. This has already been recognised in Access to Work whereby an SME employer is granted greater financial support than a larger enterprise employer.

There can also be a difference in understanding resulting from prior experience. A large employer has a varied workforce and is likely to have had an employee with a disability previously. They are also more likely to have an in-house HR department that can support the organisation in what steps to take. SMEs may not have had any previous experience of an employee with a disability.

These differences point to a need for greater support for SMEs, both financial and in an advisory capacity.

However, the experience of people ‘on the ground’ is that, all too often, people with M.E. have not been benefiting from effective reasonable adjustments even in large employers, so there is still a significant amount of work to do to raise awareness – and in some cases to change attitudes – if people with M.E., and other disabled people, are not to continue to experience barriers and discrimination which prevent entry to employment or make it unsustainable for people with conditions such as M.E.

Consultation question: how can we best strengthen the business case for employer action?

An evaluation of the SEE M.E. employment service found that the service was cost-effective on the basis of the gains it produced for employers and health provision. Over half of employers considered that the engagement had resulted in financial savings for the employing organisation. For employers, that difference was largely due to retaining an employee, meaning they did not face the dual costs of recruitment and lost output. It has been estimated that the cost of staff turnover for an employee earning over £25,000 a year results in an average financial impact of over £35,000.²¹

The previous government has looked into how accessible venues can increase the income of businesses who are able to accommodate disabled customers.²² There may be scope to take a similar approach, emphasising – preferably with case studies – the benefits to organisations of an inclusive workforce which reflects society and is best placed to deliver services to or attract business from all parts of society, including large numbers of disabled people, with reference to the ‘purple pound’ (the spending power of disabled people).

Moving into work

Consultation question: how can existing government support be reformed to better support the recruitment and retention of disabled people and people with health conditions?

27% of people with M.E. highlighted how their employers and colleagues didn’t understand the impact of their illness, with 17% adding that they believed this was due to the invisible and fluctuating symptoms. One person stated that:

“Unfortunately a lot of people still think disability is only real if it is visible and cannot understand the difference between disabling fatigue and tiredness.”

This suggests there is a greater need to increase understanding of the impact of illness in the workplace, particularly in relation to conditions that are not widely understood. While Disability Confident offers training for recruiting managers, there is a need for resources and support that can be referred to later on in the employee’s journey. These could offer not just general advice on accessibility, but specialise in

²¹ Oxford Economics (2014), *The Cost of Brain Drain: Understanding the financial impact of staff turnover*, accessed 15 February 2017 <http://www.oxfordeconomics.com/my-oxford/projects/264283>

²² Department for Work and Pensions (2014), *High street could be boosted by £212 billion ‘purple pound’ by attracting disabled people and their families*, accessed 15 February 2017 <https://www.gov.uk/government/news/high-street-could-be-boosted-by-212-billion-purple-pound-by-attracting-disabled-people-and-their-families>

certain conditions or scenarios and thus provide employers specific guidance beyond general accessibility training.

One of the findings from the SEE M.E. employment project was that often employers did not know about existing government support. Furthermore, one trade union representative stated:

“I was not aware about Access to Work. [Since finding out through SEE M.E.] I have already used it for other cases.”

This example is worrying given the fact that one of a representative’s main responsibilities is advocating for employees in the workplace and offering guidance on how to navigate problems with an employer. Without the proper dissemination of information on government support and how to access it, the professionals who are responsible for identifying solutions to employment problems will necessarily fall below their potential output.

Staying in or returning to work

Consultation question: should Statutory Sick Pay be reformed to encourage a phased return to work? If so, how?

Reforming Statutory Sick Pay so that employees were able to receive it pro rata could facilitate a more flexible approach to both returning to work and sustaining part-time work. This would reflect the true nature of many conditions whereby the person is not able to work fully but can complete some work part-time. When someone has had a leave of absence due to illness, returning to work full-time may not be an option and could be detrimental to their recuperation. A return through part-time work can create financial difficulty as they drop from receiving the full amount of Statutory Sick pay to only being paid for the level of part-time work they can currently manage. By reforming Statutory Sick Pay in the way outlined above, employees can make a return to work without initial over-exertion and fear of financial instability.

The need for flexible working is demonstrated in our survey, where 86% of respondents stated it would be helpful for people with M.E. who were unable to sustain their current employment. One person said *“the only real help would be part time and/or home working”* while another emphasised their early morning shift patterns and how *“physically it’s making me ill.”*

It is also essential to recognise that the end goal for all employees cannot necessarily be a full return to work, where that work position is unsustainable over the longer term. As well as reforming Statutory Sick Pay to support phased returns to work, there needs to be support for employers and employees to negotiate long-term or permanent changes to working hours or working patterns that enable sustainable part-time working where appropriate. There should also be clarity on sources of financial support for people in financial hardship due to reduced working hours to a sustainable level, as a viable alternative to having to leave employment.

Chapter 5: Supporting employment through health and high quality care for all

Improving discussions about fitness to work and sickness certification

Consultation question: how can we bring about better work-focussed conversations between an individual, healthcare professional, employer and Jobcentre Plus work coach, which focus on what work an individual can do, particularly during the early stages of an illness/developing condition?

The SEE M.E. employment project bridged the gap between employment and health support. One notable outcome of the SEE M.E. employment service was that clinicians felt more able to broach employment issues. One stated that

“The project helped keep me up to date with employment issues and provided support with complex issues so that my clinical time has been used as well as possible.”

This feedback was replicated across the wider clinical staff. The direct link between health services and employment support also ensured the earliest appropriate intervention, since where clinicians were not sure what action to take there was the option of immediate consultation of or referral to the employment project.

One example given was of an individual who was in part-time work and in receipt of benefits. Their work income made them eligible for tax suggesting they would need to take on extra working hours in order to maintain income levels, which they were not capable of sustaining. Specialist advice identified that the individual was on the wrong benefits regime and the resulting change enabled them to continue working at a sustainable level.

This example suggests the importance of close co-operation between agencies. Where such communication does not take place, opportunities for finding sustainable solutions for employees are lost.

As well as having conversations between the above agencies at defined points in the individual's journey, the project found that there was great value in there being an ongoing facility for communication between individual, healthcare professional, employer and work coaches. This allows issues to be dealt with as they arise, consulting the relevant agency to consider solutions and avoiding escalation of difficulties.

Action for M.E.'s *Support, Empower and Employ people with M.E.: a toolkit for professionals*²³ resource outlines some ways in which this channel of communication can be created and maintained, based on the learning from the employment project itself:

²³ Action for M.E., *SEE M.E. toolkit for professionals*, accessed 15 February 2017, <https://www.actionforme.org.uk/resources/our-publications/booklets/see-me-toolkit-for-professionals/>

- When you first assess a person with M.E., or any other condition, determine what other forms of support they have in place which fall outside your remit
- Help your client to identify any unmet needs and how/where they can gain support to meet them
- When signposting a client to another service, or are aware that they're using one, the professional can provide the client with a brief letter of introduction or service leaflet to encourage liaison when necessary
- While specialist clinicians may not have time to communicate directly with employers to advocate for a patient, they can find out when in the process their input is needed so that evidence is available at key review and decision-making points
- If the patient belongs to a union, a clinician can send a copy of medical evidence letters to the union representative and invite them to get in touch in order to clarify the representative's understanding when they advocate for that patient

An additional advantage that the SEE M.E. service provided was the independence of the project advisor. Frequently, the parties involved with an individual will necessarily have different views of what the ideal outcome would be based on their perspective and interests. The advisor's assistance was in providing a mediator between these views. For example, the advisor met with a person's employer so that the employer could have a frank discussion about business needs as well as the concerns that arose from an employee's ill health. This mediatory role is lacking in many people's experiences of current provision. For example, a number of our survey respondents commented that their occupational health professionals mirrored the desires and needs of the employee without considering how those needs could be met in a way which best supported business delivery.

Consultation question: how can we ensure that all healthcare professionals recognise the value of work and consider work during consultations with working age patients? How can we encourage doctors in hospitals to consider fitness for work and, where appropriate, issue a fit note?

Healthcare professionals face an issue of capacity when it comes to integrating work as a health outcome into their clinical practice. While they are fully able to recognise the value work can have for someone who is capable of it, they may have to prioritise other aspects of health.

The SEE M.E. employment project was found to assist healthcare professionals in this regard, as it facilitated the consideration of work issues. It also provided the option of referring to specialist employment advisors as necessary.

This approach elicited positive feedback from clinicians, with one stating:

"The project has helped keep me up to date with employment issues and provided support with complex issues so that my clinical time has been used as well as possible."

Any measures intended to ensure that all healthcare professionals consider work during consultations must take into account their limited capacity to do so. Employment specialists can facilitate better consideration of work and health by

ensuring clinicians have up-to-date basic knowledge and by stepping in where the required knowledge goes beyond what a practising clinician could reasonably manage alongside their other work.

The employment advisors additionally increased the ability of clinicians to provide productive guidance when writing letters to employers. Previously, doctors would do this to the best of their ability, but being informed of what adjustments or interventions might be appropriate allowed this communication to suggest more proactive measures that were conducive to achieving the client's outcomes. One employer commented on how much they valued these practical recommendations, saying:

“When you come across situations like this you take medical advice and the specialist service at Cossham hospital but it only goes so far. The real practical stuff is missing and that is what makes people nervous”.

Therefore, specialist employment input could also increase the value of the fit note mechanism, by assisting clinicians in identifying what practical measures could assist a return to work.

Consultation question: are doctors best placed to provide work and health information, make a judgement on fitness for work and provide sickness certification? If not, which other healthcare professionals do you think should play a role in this process to ensure that individuals who are sick understand the positive role that work can play in their recovery and that the right level of information is provided?

Doctors are best placed for these assessments. Our *Time to deliver* report found that decision makers at the DWP and assessors who carry out face to face assessments often have limited knowledge of M.E. and are very unlikely to have the same level of understanding as a doctor.²⁴ M.E. is an invisible illness, meaning that whilst someone with M.E. may be in pain, their symptoms are not visible to an outsider. As a result of this, in order to ensure the right decision is made regarding a person's capability to work, it is important that the person carrying out the assessment properly understands the nature of the illness they're assessing, and a doctor is likely to have the best level of understanding.

A notable amount of respondents (32%) said that their GP was not helpful in providing evidence for them to help with their welfare benefit claim and it is not unusual for a person with M.E. to be misdiagnosed by their GP.²⁵ Therefore, there should not be an over-reliance on GP testimony that subsequently disregards the claimants own understanding of how their condition impacts them. Those without a supportive GP are at a huge disadvantage in their application, yet this does not completely detract from the fact that generally, doctors are in a much better position to make these kinds of assessments than someone who is not medically qualified.

²⁴ Action for M.E. (2014), *Time to deliver*, accessed 15 February 2017, <https://www.actionforme.org.uk/uploads/pdfs/me-time-to-deliver-survey-report.pdf>

²⁵ Action for M.E. (2017, February 8). What is M.E.?: Action for M.E. Retrieved from Action for M.E.: <https://www.actionforme.org.uk/what-is-me/severe-me/>

Additionally, the above question states that the role of doctors is to highlight the 'positive role that work can play in their recovery'. It is important to understand that work may not play a positive role, and the health and employment outcomes for each individual will be unique to them. Work must be appropriate, timely, and in some cases people will not be fit to work at all. Work can be incorporated as a health outcome and addressed in a clinical context, but a doctor's ultimate focus will be on the health and wellbeing of their patient. There will be cases where work would be detrimental to the health of the patient.

Transforming the landscape of work and health support

Consultation question: how can occupational health and related provision be organised so that it is accessible and tailored for all? Is this best delivered at work, through private provision, through the health system, or a combination?

Survey respondents had a mixed view of occupational health (OH) services, with 26% stating they were very useful, 33% slightly useful, 22% not very useful and 20% not at all useful.

Of those who commented on the service, 26% stated that one issue was the lack of understanding OH staff had of the impact of their condition. One person stated that the

"Assessor was unfamiliar with M.E., didn't know how to assess me, nor to support my return to work."

The high rate of people who raised this issue suggests that the standard of the OH service is largely determined by which individual administers it.

Another person, who rated the service as 'very useful', said

"I'd be in a much worse position without it! My OT [occupational therapist] has broken down every aspect of my life over the last 2 years and has helped me to learn appropriate pacing, improving sleep and hygiene and rebuild my ability to perform tasks for myself and return to work part time. My OT gave me my life back!"

A number also emphasised the role the OH services played in communicating to employers. One person said the service:

"Told my employers that what they were expecting me to do was too much for a person with M.E. They also suggested reasonable adjustments be made and made my employer aware that I was covered by the Equality Act."

Occupational health services can be a way of bridging the gap between health and employment for the individual in question. In order to be accessible for all, it needs to operate more consistently with staff being supportive of individuals and more able to recognise the needs of those with fluctuating or invisible illnesses, which at the moment a large number are failing to do.

This is best demonstrated by an individual who stated that occupational therapists need training.

“Medical professionals have to up their game... to start with, they need to start learning about M.E. and start to support us in our employment.”

Many individuals want to continue in work and currently lack the appropriate support to do so. Having effective and knowledgeable OH staff could contribute very significantly to their efforts to retain employment.

Consultation question: what has been your experience of the Fit for Work service, and how should this inform integrated provision for the future?

Our survey respondents who had used the Fit for Work service had mixed responses to it. 25% stated it was very useful, 25% slightly useful, 30% not very useful and 19% not at all useful.

These responses suggest that the provision of Fit for Work is not consistent across clients. This was largely due to the individuals involved in the process: some had doctors that did not have adequate understanding of M.E. and others had employers who did not accept the adjustments recommended by the service.

For example, one respondent stated:

“I went back to work doing reduced hours. But there was no compromise in those hours, they were chosen by my employer and that was that.”

However another stated:

“[I returned to work] on reduced hours until a diagnosis of my condition was made in the months following, allowing me time to get used to my symptoms and learning how to manage them.”

The latter example demonstrates how useful this service can be in steering employees and employers towards a mutually beneficial solution. However, feedback provided to us suggests that too many employers take part in it as a matter of process without genuinely considering alternative arrangements that would assist the employee.

Creating the right environment to join up work and health

Consultation question: what is the best way to encourage clinicians, allied health professionals and commissioners of health and other services to promote work as a health outcome?

The clinicians who were involved in the SEE M.E. employment project stated that as a result they had increased knowledge of employment support and awareness of how to integrate work outcomes into their clinical service.

Being involved in the project gave clinicians the confidence to address employment issues, and they reported that they felt upskilled in their capability to address them. 60% felt that their confidence, skills and knowledge in supporting patients with their

employment needs had increased as a result of the project. Largely they had not had time to keep abreast of welfare changes etc. and therefore did not fully broach the topic. Being in contact with the specialist employment advisors meant that they could be supported in having that knowledge, or where the issue was more complex they could refer the patient directly to the advisor.

The project also assisted in helping clinicians to know what details to include when writing letters to employers. They were therefore able to comprehensively advise employers on what adjustments or interventions would support the employee in achieving their employment goal. The advice was personalised for each case.

The project demonstrated a need for effective communication between clinicians and health professionals and the other agencies supporting people with disabilities or health conditions into employment. Clinicians must maintain a wide range of medical knowledge, and as much as they may want to support their patient holistically their capacity to tackle employment issues is ultimately limited. By providing the employment advisors to work alongside clinicians, it was possible to provide a whole health and employment package which delivered strikingly positive outcomes for clients, removing the barriers of time and expertise which clinicians usually have in supporting their patients with employment matters.

Chapter 6: Building a movement for change: taking action together

Consultation question: how can we bring about a shift in society's wider attitudes to make progress and achieve long-lasting change?

Most people with M.E. have found themselves either in the challenging situation of having to try to prove to the benefits system (which is ill equipped to assess a complex and fluctuating condition like M.E.) that they are too ill to work, or trying to persuade employers who don't want to take on 'health problems' that they are not too ill to work.

Some people – having made some recovery but still only able to work part-time and with reasonable adjustments – have found themselves having to manage these situations simultaneously as the reality is a complex mixture of the two.

One vital change is in severing the link by which many employers and wider associates assume a person's ability to work (or otherwise) on the basis of that person's disability or health condition. This needs to be replaced by the more nuanced position that some people may require more assistance in order to be capable of work and also that some people are ill to the point where they are not able to work.

Specific learning from our employment project suggest that the most effective way of changing outcomes and attitudes would include:

- properly informed assessment of people with M.E. to enable fair and honest conversations about achievable work goals and the degree of support needed to achieve them
- specialist support for employers and employees, delivered alongside healthcare by people with professional and personal experience of living and achieving with illness, assisting with barrier removal and negotiation of reasonable adjustments
- raising awareness of schemes such as Access to Work with employers and in society more generally
- promoting 'disability-friendly' employment practices, with a good understanding of reasonable adjustments
- the promotion of flexible-working arrangements to employers and more widely in society, with information and advice on benefits and implementation
- empowering disabled people, developing their confidence, and equipping them with practical tools (eg. knowledge of reasonable adjustments and Access to Work).

We suggest that the following would also assist with changing wider attitudes in society:

- The government leading by example through its employment practices
- Publicising positive examples in a variety of sectors and industries of employees whose health needs have been accommodated

- The open acceptance of the principle that some people have health needs which mean they are not capable of work at any level, and that financial support provision should continue for this group

Consultation question: what is the role of government in bringing about positive change to our attitudes to disabled people and people with health conditions?

The government is in a position, as a highly visible authority, to use its role to bring about positive change to attitudes to disabled people and people with health conditions through its impact on public discourse.

There remains a widespread problem in the UK with negative attitudes and discrimination against disabled people. For example, Scope has found that:²⁶

- 67% of the British public feel uncomfortable talking to disabled people
- 36% of people tend to think of disabled people as not as productive as everyone else
- 24% of disabled people have experienced attitudes or behaviours where other people expected less of them because of their disability

People with M.E. have expressed consistent messages, with one person telling us that the discrimination they experience has worsened since 2010:

“It has deteriorated, both in terms of employers’ rights, disability access, and negative treatment and attitude of the public perpetuated by irresponsible journalism focusing on benefit scroungers rather than genuinely ill people. It is harder to get welfare, harder to travel and a definite increase in hostility and lack of understanding towards people with a disability.”

In 2014-2015, the rate of recorded hate crimes against disabled people increased by 41% on the previous year.²⁷

Any efforts made to reinforce the relationship between health and work will ultimately be undermined by the government’s use of rhetoric such as ‘strivers vs. skivers’.²⁸ Such discourse is dually troubling in reinforcing the linear division of the population into those who do work and those who do not, and its use of derogatory language when referring to those who are not working.

²⁶ Scope (2014), *Current attitudes towards disabled people*, accessed 15 February 2017,

<http://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Current-attitudes-towards-disabled-people.pdf>

²⁷ The Independent (2015), *Hate crime against disabled people rises 41 per cent in one year*, accessed 15 February 2017, <http://www.independent.co.uk/news/uk/hate-crime-against-disabled-people-rises-41-per-cent-in-one-year-a6713546.html>

²⁸ New Statesmen (2012), *George Osborne’s speech to the Conservative conference: full text*, accessed 15 February 2017, <http://www.newstatesman.com/blogs/politics/2012/10/george-osbornes-speech-conservative-conference-full-text>

Appendix 1: Survey data

1	Where do you live?				
	North East	5%			
	North West	9%			
	Yorkshire and the Humber	9%			
	East Midlands	6%			
	West Midlands	5%			
	East of England	9%			
	London	5%			
	South East	17%			
	South West	18%			
	Scotland	10%			
	Wales	2%			
	Northern Ireland	1%			
	<i>Skipped question</i>	2%			
2	How old are you?				
	16-25 years old	7%			
	26-35 years old	16%			
	36-45 years old	32%			
	46-55 years old	25%			
	56-65 years old	18%			
	66 years and over	1%			
	<i>Skipped question</i>	1%			
3	What gender do you identify as?				
	Male	16%			
	Female	82%			
	Non-binary	1%			
	I would prefer not to say	0%			
	<i>Skipped question</i>	1%			
4	How long have you had M.E.?				
	Less than 2 years	7%			
	2-5 years	21%			
	5-10 years	24%			
	10-20 years	27%			
	Over 20 years	20%			
	<i>Skipped question</i>	1%			
5	What level of M.E. do you currently have? Please choose the option that most closely describes your experience.				
	Mild	33%			
	Moderate	54%			
	Severe	12%			
	<i>Skipped question</i>	1%			

6	What is your current employment status?					
	Unemployed - I am seeking employment but have not been able to secure suitable work	4%				
	Unemployed - I am not able to work due to ill health	48%				
	Employed - I am in a position of employment that accommodates my needs and is sustainable	22%				
	Employed - I am employed but do not feel that my needs are adequately accommodated for me to sustain the position	18%				
	Retired	6%				
	Skipped question	1%				
7	What is your current working pattern? If you are currently employed in more than one job, please select according to the sum total of your working hours per week across all roles.					
	Full-time	16%				
	Part-time	24%				
	Skipped question	60%				
8	Are you self-employed?					
	Yes	6%				
	No	35%				
	Skipped question	60%				
9	Counting all locations where your employer operates, what is the approximate number of people who work there?					
	50 employees or less	12%				
	51-250 employees	6%				
	251-1000 employees	7%				
	More than 1000 employees	15%				
10	Have you disclosed your disability or health condition to your employer?					
	Yes	67%				
	No	9%				
	Skipped question	24%				
11	Please tell us to what extent the below statements are in line with your experience of employment.					
		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
	My employer didn't want to make reasonable adjustments to accommodate my disability or health condition	19%	21%	25%	22%	11%
	My employer wasn't sure what reasonable adjustments to make to accommodate my disability or health condition	26%	41%	20%	11%	3%
	I did/do not want to disclose a disability or health condition to my employer because I expected a negative reaction	19%	24%	18%	23%	16%
	My family and friends have assumed I am fully able to work because my health condition is not visible	26%	40%	12%	16%	6%

12	Please share anything further you wish to about attitudes to disability and employment.				
	<i>We have not included qualitative data in order to ensure respondent's anonymity</i>				
13	Have you received specialist employment support in the past five years either because of your M.E. or another health condition?				
	Yes	13%			
	No	78%			
	<i>Skipped question</i>	24%			
14	What kind of specialist employment support did you receive?				
	A condition management programme to help with self-management of symptoms			6%	
	Information and advice on entering or retaining employment			4%	
	Skills workshop eg. CV writing or computer skills			1%	
	Other (please tell us more if you can)			5%	
	<i>Skipped question</i>			87%	
15	Was the support you received appropriate to your needs?				
	Very appropriate	3%			
	Quite appropriate	4%			
	Not very appropriate	3%			
	Not at all appropriate	2%			
	<i>Skipped question</i>	87%			
16	What kind of support do you think would be helpful for people with M.E. who are able to work to some extent and want to find employment?				
	A condition management programme to help with self-management of symptoms			53%	
	Information and advice on entering or retaining employment			48%	
	Skills workshop eg. CV writing or computer skills			19%	
	Other (please tell us more if you can)			36%	
	<i>Skipped question</i>			19%	
17	What kind of support do you think would be helpful for people with M.E. who are unable to sustain their current employment? This could include people who wish to find more appropriate work, or leave work altogether.				
	Information and advice on discussing issues with their employer			58%	
	Advice on managing their condition			44%	
	Liaison between health professionals and employers			66%	
	Reasonable adjustments to workplace environment			65%	
	Taking a temporary leave of absence			54%	
	A change in working pattern, which may include a reduction in working hours			75%	
	Other (please tell us more if you can)			20%	
	<i>Skipped question</i>			13%	
18	Do you claim Employment and Support Allowance (ESA)?				
	I am currently claiming ESA			33%	
	I have applied for ESA but do not know the outcome			2%	
	My claim for ESA has been refused - I am currently appealing that decision but do not know the outcome			5%	
	I used to claim ESA but do not claim it now			13%	
	I have never made any claim for ESA			38%	
	<i>Skipped question</i>			10%	

19	How long have you been claiming ESA for? If you are no longer claiming ESA, please tell us how long you were claiming it for in total.					
	6 months or less	4%				
	Between 6 months and 1 year	6%				
	1-2 years	9%				
	2-5 years	13%				
	5 years or more	11%				
	Not sure (please tell us more if you can)	6%				
	<i>Skipped question</i>	51%				
20	While claiming ESA, which Group were/are you in?					
	Support Group	26%				
	Work-Related Activity Group	7%				
	I have been in both Groups (at different times)	4%				
	Not sure	10%				
	<i>Skipped question</i>	53%				
21	Do you think the proposed change would have impacted on your personal experience of claiming ESA?					
	Yes - positively	5%				
	Yes - negatively	13%				
	No - I don't think there would be any change	11%				
	Not sure	21%				
	<i>Skipped question</i>	51%				
22	Do you think this change would improve the outcomes of benefit assessments for people with M.E. in general?					
	Yes - positively	19%				
	Yes - negatively	14%				
	No - I don't think there would be any change	15%				
	Not sure	39%				
	<i>Skipped question</i>	13%				
23	Asides from ESA, have you claimed any other benefits? Possible benefits include: Disability Living Allowance, Personal Independence Payment Disability premiums (Income Support)					
	Yes	45%				
	No	38%				
	Not sure	1%				
	<i>Skipped question</i>	16%				
24	Please tell us how you think evidence could be usefully shared between assessors. You could consider: What the appropriate purpose of sharing the evidence should be, how the assessors could effectively use this evidence, whether evidence could be shared and used in such a way that benefited people being assessed					
	<i>We have not included qualitative data in order to ensure respondent's anonymity</i>					

25	Do you think the sharing of evidence would have impacted on your personal experience as a claimant?				
	Yes - positively	24%			
	Yes - negatively	5%			
	No - I don't think there would be any change	15%			
	Not sure	31%			
	<i>Skipped question</i>	24%			
26	Do you think sharing evidence would impact on the experience for people with M.E. in general?				
	Yes - positively	34%			
	Yes - negatively	6%			
	No - I don't think there would be any change	10%			
	Not sure	30%			
	<i>Skipped question</i>	20%			
27	Please tell us under what circumstances, if any, you think a person with M.E. should be exempted from being reassessed. You could refer to your own experience or the experiences of others.				
	<i>We have not included qualitative data in order to ensure respondent's anonymity</i>				
28	Please tell us how you think people with M.E. could be appropriately assessed to determine if they qualify for this continuous support. Factors to consider could include: how long a person has had M.E.; the level of severity of their M.E.; the likely effect of the assessment on their health				
	<i>We have not included qualitative data in order to ensure respondent's anonymity</i>				
29	As an employee, have you had experience of the Fit for Work service?				
	Yes	10%			
	No	61%			
	Not sure	5%			
	<i>Skipped question</i>	24%			
30	What was your desired outcome while using the Fit for Work service?				
	Taking a leave of absence	1%			
	Returning to work	3%			
	Remaining in work	3%			
	Other (please tell us more about this if you can)	4%			
	<i>Skipped question</i>	89%			
31	What is your overall view of how Fit for Work assisted you?				
	Very useful	3%			
	Slightly useful	3%			
	Not very useful	3%			
	Not at all useful	2%			
	<i>Skipped question</i>	90%			
32	Do you have any experience of occupational health provision?				
	Yes	47%			
	No	28%			
	Not sure	2%			
	<i>Skipped question</i>	22%			

33	When did you use occupational health services?				
	6 months or less	11%			
	Between 6 months and 1 year	7%			
	1-2 years ago	7%			
	2-5 years ago	10%			
	More than 5 years ago	12%			
	<i>Skipped question</i>	53%			
34	How did you access the occupational health service?				
	Employer referral	37%			
	GP referral	2%			
	Specialist health professional referral	2%			
	Other (please tell us more about this if you can)	5%			
	<i>Skipped question</i>	53%			
35	What is your overall view of the usefulness of occupational health services?				
	Very useful	12%			
	Slightly useful	15%			
	Not very useful	10%			
	Not at all useful	9%			
	<i>Skipped question</i>	53%			