Written evidence from Action for M.E. (DEG0031)

1. Executive summary

1.1 Several key points have emerged from this consultation:
- Integrated employment and health support can make a positive difference to disabled and ill people with employment goals.
- Employment support for disabled people must be personalised and tailored to their needs.
- Specialist disability employment advisers need to be trained in a wide range of disability and health matters, including chronic, fluctuating, long-term conditions such as M.E.
- New services must offer a much greater level of job retention support, not just job-seeking support, to reflect real needs.
- Awareness about support available through Access to Work needs to be increased.
- The Disability Confident campaign is not perceived as having been a success.
- The abolition of the Employment and Support Allowance Work Related Activity component is likely to cause financial hardship and stress for many people with M.E., potentially leading to a worsening of symptoms and therefore moving people with M.E. further away from work.
- Some people are simply too ill to work, regardless of the support made available to them.

2. Introduction

2.1 Action for M.E. is responding to this call for evidence as the UK’s leading charity for people affected by the disabling neurological condition Myalgic Encephalomyelitis (M.E.), which affects an estimated 250,000 men, women and children in the UK.

2.2 Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or CFS/M.E. is often given. M.E. is also sometimes diagnosed as Post-Viral Fatigue Syndrome (PVFS).

2.3 The economic impact of M.E. on the UK is £6.4 billion per year.\(^1\) Lost earnings are estimated at £102 million per year.\(^2\)

2.4 To inform our response to this inquiry, we have used expertise and evidence gathered through our SEE M.E. (Support, Empower and Employ people with M.E.) pilot project.

2.5 SEE M.E. launched in January 2015 and is for people with M.E./CFS who live in Bristol, Gloucestershire, South Gloucestershire and North Somerset. Its aim is to support people with M.E. to stay in work, return to work or meet other employment

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\(^2\) Collin S et al, The impact of CFS/ME on employment and productivity in the UK: a cross-sectional study based on CFS/ME National Outcomes Database (2011)
goals, or to leave work well, if their state of health prevents them working. The project employs specialist staff with experience of both M.E. and employment support.

2.6 In addition, we have also taken into account:
- the experience and expertise of our staff and volunteers
- the views of people with M.E./CFS who responded to our 2015 survey of key proposals in the Welfare Reform and Work Bill
- \textit{M.E. Time to deliver}, our large-scale consultation with more than 2,000 people with M.E. in 2014
- the feedback we receive from people with M.E. who contact our Welfare Advice and Support Service and our Information and Support Officers
- the views of people we engage with via our membership magazine, social media and Online M.E. Centre.

3. Action for M.E.'s submission

3.1 To what extent are the current range of proposed measures likely to achieve the Government's ambition of closing the disability employment gap?

3.2 Action for M.E. understands that the measures include: a new Work and Health Programme; a real terms increase in spending on the Access to Work Programme; a White Paper to be published this year.

3.3 The Work and Health Programme

3.4 Interim evaluation\textsuperscript{3} of our SEE M.E. project indicates that integrated employment and health support can make a positive difference to disabled and ill people with employment goals.

3.5 Our SEE M.E. project has shown that:
- Existing employment support providers lack sufficient understanding of M.E. to make their services accessible and effective for people with M.E.
- Existing employment support provision is delivered at too great a distance from existing specialist M.E. healthcare services. This reduces access and collaborative working.
- The majority of people with M.E. have needs relating to job retention rather than job seeking (60% of all referrals received by SEE M.E. and 68% of referrals from our partner NHS Specialist M.E. Service). New services must offer a much greater level of job retention support.
- Prioritising expertise and capacity for job retention case management allows for more positive, solution-focused work with employers, to enable them to retain experienced employees.
- Job retention case management has the potential to offer the government a better return on investment, when one takes into account:
  - people not moving onto welfare benefits (remaining in work)
  - reduction in statutory sick pay

\textsuperscript{3} The final Project Evaluation will be available in June 2016
prevention of escalation of health problems relating to work stress and job loss
the collaborative working approach serves to increase specialist knowledge throughout all parties involved (healthcare, employment support, employer, Occupational Health, Union, Access to Work advisers and assessors).

- The focus of existing Work Programme and Work Choice provision on job outcomes of over 16 hours per week, effectively discriminates against people who are unable to work this much, due to the holistic reduction in their functioning caused by their specific condition. M.E. is a clear example of this, but the principle applies to many other fluctuating long-term health conditions.
- The combination of ‘payment on outcome’ and top-line numerical targets (halving the gap) will naturally lead to ‘cherry picking’ and therefore further discrimination against people with conditions that:
  - are less well understood by staff in services
  - have less well developed pathways between health (and social) care services and employment support provision
  - have lower perceived likelihood of ‘sustained outcomes.’ For example, many people with M.E. choose to work in ways which allow them to not work when their symptoms are worse – eg. self-employment which does not require consistently working a certain level/generating a certain level of income per week). Therefore, all targets and contractual service level agreements will need to address the potential discrimination that can occur for a wide range of conditions, and has been demonstrably the case for M.E. to date.
- We recommend the funding of capacity building projects, such as SEE M.E., which focus on building integration between healthcare and employment services. By mobilising specialist condition/impairment expertise (such as that held by organisations such as Action for M.E.) it addresses the specific barriers and needs of people with that condition in ways which reduce cost over time. We recommend that such projects take a form that understands the barriers and needs; addresses them through integration; addresses them through training and supervision; and reviews and reports.

3.6 Access to Work

3.7 Action for M.E. strongly supports the recommendation made by the Halving the gap? report to “expand Access to Work to allow more people to benefit from the support offered, and make the administration of claims more accessible.”

3.8 To ensure that increased government spending on Access to Work actually achieves its aims, specific actions need to be taken to ensure that it is accessed and effectively utilised by people with conditions/impairments that are currently relatively under-represented by Access to Work funding recipients.

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4 Mencap (2015) Having the gap? A review into the Government’s proposed reduction to Employment and Support Allowance and its impact on halving the disability employment gap.
3.9 Action for M.E.’s SEE M.E. employment advisers help clients access the support they are entitled to. Through the project we have enhanced Access to Work assessments by working directly with independent workplace assessors on site.

3.10 Assessment support provided by SEE M.E. has been welcomed by employers, employees and assessors, due to the additional challenges, needs and solutions raised by our own expert advisers.

3.11 In one case a patient’s eligibility for Access to Work funding was confirmed and he was helped to apply. This enabled him to get a taxi to work, rather than two buses or lifts. As a result he had more energy to devote to his work.

3.12 Again, we recommend integration/capacity building projects such as SEE M.E., which can provide value for money for the government in terms of enabling Access to Work to more fully achieve its purpose and aims.

3.13 Based on our experience we believe people with M.E. would also benefit from:
- earlier access to Access to Work
- more effective integration of Access to Work within health and social care
- a wider range of expert input to the Access to Work advice and assessment process.

3.14 The White Paper

3.15 The White Paper can be viewed as a response to the Government’s decision to cut £30 a week for new claimants in the Work Related Activity Group (WRAG) of Employment and Support Allowance (ESA), which Action for M.E. campaigned hard against.

3.16 Action for M.E. disagrees with the rationale used to underpin this cut – that increasing poverty will incentivise sick and disabled people to move into work. In our experience people with M.E. are highly motivated to work but either face a lack of support in terms of reasonable adjustments from employers (or help from the Access to Work programme), or are simply too ill to have any capacity for work. Cutting benefits will move people with M.E. further away from work (see paragraph 9.1).

3.17 Action for M.E. agrees that tailored support (ie. that meets the employment needs of people with M.E.) will be vital to help disabled people get back into work. Approximately two thirds of people who engaged with support from our SEE M.E. project had goals and needs relating to remaining in work (same job, same employer/different job, different employer, leaving work but remaining close to the labour market).

3.18 Also, of those who accessed SEE M.E. and were seeking employment or aspiring to work in the future, none were looking for work of 16 hours or more per week. Therefore we are concerned that any future provision which starts with an ‘off benefits’ outcome driven remit will not provide a service tailored to individuals’ needs.
4. Should the Government set interim targets along the way to meet the commitment to halve the disability employment gap? What should they be?

4.1 Yes, the Government should set interim targets along the way to meet the commitment to halve the disability employment gap.

4.2 An example might be that disabled people are better able to access volunteering and participation in the community (as this can be an indicator of moving closer to the labour market).

4.3 However, the Government should ensure that all targets serve the true overall purpose and do not drive discrimination or other undesired outcomes, especially when coupled with other aspects of the model.

4.4 Any targets set should include driving provider behaviour which counteracts a ‘cherry picking’ culture. We recommend that a thorough equality impact assessment is carried out, which informs the setting of appropriate targets for access and levels of service provision, including satisfaction with service provided.

4.5 In addition, if the government intends that the new service be delivered closer to health and social care provision and is more integrated with it, then targets around achieving this and demonstrating it should be set. The Statutory Referral Organisation (SRO) mechanism was very helpful for linking up Work Choice provision with health and social services, but this needs to go further.

4.6 For example, via SRO status it was possible for healthcare services to support access to Work Choice directly for job seekers. But for job retention cases a referral had to be made to see the Disability Employment Adviser at Jobcentre Plus first. This creates an additional barrier and sometimes time delay before support is put in place. These are precisely the kinds of barriers which make a crucial difference for people with M.E., and which led to the needs and gaps in provision which our SEE M.E. project was set up to address.

5. How effective is the Disability Confident campaign in reducing barriers to employment and educating employers?

6. What more could be done to support employers?

6.1 Action for M.E.’s SEE M.E. project works with employers to support the employment goals of people with M.E. The approach offered is impartial and seeks to input independent specialist expertise to enhance the knowledge and support which the employer may already have in place, to help facilitate a best case scenario outcome for both the employee (or prospective employee) and the employer.

6.2 SEE M.E. staff have been trained in the Job Retention Case Management model (developed by Roger Butterworth) which has been used effectively within a mental
health services context. This provides a holistic, biopsychosocial approach to facilitating a sustainable job retention outcome, as well as furnishing practitioners with a toolkit of knowledge, skills and resources for using in lighter touch models of support.

6.3 One client with M.E. told us that Action for M.E.’s SEE M.E. employment adviser: “has been instrumental in helping me plan my return to work and consider how to work this in to my energy and symptom management. Having him at my last work meeting was great. His expertise was very helpful in negotiating what I needed from my work management in order to facilitate my return to work. He helped negotiate a much longer phased return and backed up my request to initially do some of my work from home.”

6.4 An employer has fed back how helpful it has been to work with SEE M.E. staff alongside their employee, particularly in relation to understanding the issues for people with M.E. The employer has appreciated advice on how best to respond in order to meet their employee’s needs within the law and in terms of best practice.

6.5 SEE M.E. staff have a professional approach to their employer advocacy work and feedback from partners and employers is that this approach is highly beneficial.

6.6 Clinical staff have cited the fact that they often felt themselves to be in conflict with employers due to their relationship and loyalty to their patients, and they have appreciated the non-conflict approach that the SEE M.E. staff have adopted in working with employers.

7. What should support for people with health conditions and disabilities in the proposed Work and Health programme look like?

7.1 Interim evaluation of our SEE M.E. project indicates that it provides an effective model to work from in terms of identifying appropriate support for people with health conditions and disabilities.

7.2 The SEE M.E. service involves careful coaching of clients over time. Partner organisations and clients have cited this as an essential element of the work leading to increased knowledge, skills and the ability of clients to take control and work towards achieving their own self-identified employment goals.

7.3 The service has been adapted well to meet the needs of the client. For example, telephone work is particularly successful because it is more accessible and less onerous for clients. In contrast, clients say that they suffer anxiety and stress during visits to the Jobcentre which can be exhausting, and can compound their condition.

7.4 Where face-to-face meetings have taken place with the SEE M.E. staff, these have largely been at the clinic, with clinical staff reporting that patients see the clinic as a safe and trusted environment, with a very different feel to the Jobcentre.

7.5 The specialist knowledge of the SEE M.E. advisers means that clients are getting the right advice and the right referrals earlier than they would have previously. Whilst it is difficult to measure what “didn’t happen” as a result of this early intervention
work, feedback from clinical staff is that getting the right support early prevents a spiral of decline both in terms of patient’s employment status and their health and wellbeing.

7.6 Clients report that it has been incredibly beneficial to have support and advocacy in interactions with their employers. One client commented: “I feel for the first time that I have somebody on my side, somebody to advocate on my behalf […] I thought that a return to work was never on the cards, but now I have hope that we can find a way.”

7.7 People with M.E. who have participated in the pilot have been supported to:

- achieve their employment goals
- become more confident and better able to navigate and secure the support and benefits available to them
- be better informed of their rights and entitlements.

7.8 As a result of this support, participants also reported measurable improvements in their sense of wellbeing.

7.9 Examples of support offered have included: increasing employer awareness and understanding of M.E.; negotiating successful, thorough and carefully planned phased returns to work; identification and implementation of a wide range of effective reasonable adjustments; facilitating greater numbers of and more effective Access to Work applications; negotiating temporary and permanent changes to contracts of employment.

7.10 In summary, a model for effective employment support for disabled people is as follows:

- Provision closely integrated with health and social care, with strategic goals and targets designed to drive the necessary provider behaviours to underpin this.
- Thorough, holistic and individual needs assessments, with a clear feedback mechanism for national gathering of this vital planning information.
- Individual support tailored to individual need, goals and aspirations. This is vital to ensure that individual personal motivation is supported as a critical underpinning element of both action and outcome.
- Elements of provision (and associated funding) proportionate to individuals’ needs (ie. increased focus on expert job retention support).

8. What are the likely impacts on disability employment of the abolition of the Employment and Support Allowance Work Related Activity component?

8.1 In our submission to the House of Commons Public Bill Committee on the Welfare Reform and Work Bill\(^5\), we made it clear that removing part of the payment for people in the WRAG of ESA is likely to cause financial hardship and stress for many people with M.E., potentially leading to a worsening of symptoms – therefore moving people with M.E. further away from work.

\(^5\) www.publications.parliament.uk/pa/cm201516/cmpublic/welfarereform/memo/wrw16.htm
8.2 One person with M.E. told us: “If someone is ill and trying their best to get prepared to return to work, reducing their ESA is obviously not going to help that and the stress of it could cause people to become more ill.”

8.3 Another said: “If you are not fit for work then you are not fit for work and cutting benefit payments won't change that, it will just make an already difficult life even harder.”

8.4 A survey of 550 people by the charity Mind found that only 6% of people with M.E. had moved into full or part time work as a result of being in the WRAG.6

8.5 Linked to this, our M.E. Time to deliver survey in 2014 asked more than 2,000 people with M.E. about the impact of their symptoms. 87% told us they had stopped or reduced paid work because of the illness.

9. What evidence is there that it will promote positive behavioural change? What evidence is there that it will have unintended consequences, and how could these be mitigated?

9.1 Action for M.E. has seen no evidence that the abolition of ESA work-related activity component will promote positive behavioural change. There is also no evidence that people with M.E. lack the incentive to work, or that ESA premiums act as a disincentive to work.

9.2 Action for M.E. takes issue with the implication that the disability employment gap is due to the behavioural traits of ESA recipients. Instead, the DWP should focus on behavioural change among large employers.

9.3 It is essential to remember, however, that some people are simply too ill to work, regardless of the support made available to them.

9.4 One person with M.E. told us: “My job was my life. I honestly loved what I did as a veterinary nurse. My employers did try to make things easier but there’s nothing that can inject a person with energy. Sure, they can provide chairs and more breaks but it's not enough. I had to give up after a year of trying; it was just too much and I collapsed.”

9.5 Another told us: “Around seven months after I initially had to give up work, I went back to the same job, working with people I knew, in the same environment. I was only asked to do two hours on Monday, Wednesday and Friday. I lasted three weeks and became so ill I had to be signed off permanently. I haven't been able to return to work since. Even when your work is understanding, even when they make what adjustments they can, you are still effectively doing the same job. Which means everyone you work with thinks you are back at work and ok again. Even with the best of intentions, the pressure is no less.”

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9.6 Action for M.E.’s volunteer Policy and Research Officer, Catherine Hale, who has M.E., says: “The emphasis should be on better employment support that disabled people would actually want to engage with. Disabled people who don’t want to work usually have valid reasons, like being simply too unwell. Most want to work and would engage with support if it were effective.”

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