



MS Society response to Shaping Future Support: the Health and Disability Green Paper

About the MS Society

1. The MS Society is the UK's largest charity for people living with multiple sclerosis (MS). We're here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone, and offer advice and support to help them.

About MS

2. MS can be relentless, painful and exhausting. It's a condition which damages nerves in your body, making it harder to do everyday things like walk, talk, eat and think. It is both a progressive and fluctuating condition making life unpredictable. Symptoms can include loss of balance, stiffness, spasms, speech problems, fatigue, pain, bladder and bowel, and vision problems. People with MS are recognised as disabled under the Equality Act 2010. MS affects three times as many women than men. Most people are diagnosed between the ages of 20 and 50, at pivotal times in their professional and personal lives.

About disability benefits and living with MS

3. Welfare is vital for many people with MS. It helps people manage the extra costs of the condition, stay in work for longer and participate fully in society. But our welfare system often ignores invisible symptoms like pain and fatigue and doesn't recognise how MS symptoms fluctuate. Many people with MS will reach a point where employment is no longer sustainable due to their symptoms, and a return to work may never be possible, or beneficial. This means they face hard decisions about whether to stay in work or leave. Therefore, support to transition out of work well is essential.
4. The rate of benefits is inadequate and pushes people into poverty, leaving them struggling to afford essentials such as travel and medication. Living with MS can be expensive. A person with MS may spend almost £200 a week on extra costs related to having the condition¹, for things such as help around the home and getting outside.
5. Assessments for Personal Independence Payment (PIP), Employment and Support Allowance (ESA), and Universal Credit (UC) fail to capture the difficulties people with MS face. Benefits assessors don't always take evidence provided by professionals into account, and too often people with MS are under pressure to repeatedly prove they need support. This leads to people with MS receiving inaccurate decisions leaving them without support.

6. Despite numerous government schemes for employers, and employment support programmes, the disability gap remains. People with MS have an employment rate of 41%, which is lower than the disability employment rate (52.3%)¹. The fluctuating nature of MS is a factor in people with MS leaving work early as it can limit the range of jobs and hours someone can do. The government fails to use a social model of disability when looking at solutions to employment and disabled people meaning the onus is always on the individual.
7. The COVID-19 emergency has had a profound impact on the lives of people with MS who have particular vulnerabilities. 95% of respondents to a survey by the Disability Benefits Consortium (DBC) said that they have had to spend more money than normal³. Some people with MS have been asked to shield for many months, faced higher food and delivery costs, and been refused the extra financial support offered to others.

About the response to this consultation

8. The MS Society has been campaigning for a better welfare system for people with MS for many years. We welcome the opportunity to respond to this Green Paper consultation, at a time when many disabled people need more support than ever before.
9. To inform our response, we collected evidence via a number of methods:
 1. A new survey of people with MS about their views on welfare and employment, asking specific questions related to the proposals set out in the Green Paper. This was conducted online between 9 August and 11 October. It was emailed to our campaigns community and shared to our supporters through our newsletters and social networks. We received 495 completed responses.
 2. Existing MS-Specific data and previously published MS Society reports that were likewise based on analysis and views of people with MS gathered at the times specified
 3. Collated intelligence from a small team of health professionals with expertise in MS
 4. Held 4 focus groups with people with MS who have experience of the benefits system, alongside 3 in-depth interviews whose quotes and experiences are shared anonymously throughout our response.

¹ House of Commons Library (2021) <https://commonslibrary.parliament.uk/research-briefings/cbp-7540/>

Chapter 1: Providing the Right Support

Improving reasonable adjustments

- 1.1. We welcome that the DWP are working to improve the reasonable adjustments they provide for disabled people accessing their services. However, we know there are still too many service users who do not know they can ask for reasonable adjustments. We also know there are some staff – who provide DWP services – which neither discuss what adjustments they can make, or act on their duty to provide them. This means some disabled people, including people with MS, are put in a position where they are unable to access vital services.
- 1.2. The DWP should proactively publicise that disabled people, including people with MS, have a right to ask for reasonable adjustments when accessing its services. The DWP should also inform disabled people of how they can complain about alleged failures by staff to adhere to the reasonable adjustments duty. This publicity should be done through a range of channels including advertising, at engagement events with people with MS and during phone calls with service users. Alongside this, the DWP should regularly collect and review feedback from disabled people to assess how effective the publicity has been in increasing the number of people aware of their right to ask for reasonable adjustments.
- 1.3. The DWP should also ensure staff providing services for, or on behalf of, the Department fully understand and act upon their duty to make reasonable adjustments for disabled people accessing its services. Staff should receive in-depth training on reasonable adjustments and should be regularly and effectively monitored on their adherence to the reasonable adjustments duty.
- 1.4. Many people with MS have told us their negative experiences of accessing DWP services has left them feeling that staff providing these services do not properly understand MS and how it affects people. We are concerned that too many of these staff lack sufficient knowledge of MS to enable them to understand, and effectively discuss with people with MS, the types of adjustments they may need. Staff providing services for, or on behalf of, the DWP should receive effective training to help them understand how MS affects people and to recognise the types of reasonable adjustments they may need to put in place to help people with MS access services. Disability charities and organisations should have input on the range of topics to be covered in this training.
- 1.5. People with MS have also told us they struggle with fatigue and other symptoms while making long, and sometimes unnecessary, journeys by public transport to visit DWP services in person, including Jobcentres and assessment centres. Some people in this position have even been sanctioned for being late to, or failing to attend, appointments at Jobcentres. In the first instance, all sanctions should be

scrapped. While we welcome that the DWP has established a visiting service, it is clear that the Department needs to do more to provide assistance with transport for disabled people who are asked to visit services in person. The DWP should ensure disabled people, including people with MS, are only asked to visit DWP services in person where absolutely necessary, and in these situations, assistance with transport should always be proactively offered.

- 1.6. **Recommendation:** The DWP should provide better information and support to make people aware of their rights around reasonable adjustments. This should include a pro-active campaign and regularly reviewing feedback from people using these services, as well as overall levels of awareness.
- 1.7. **Recommendation:** Frontline staff should receive training on reasonable adjustments, and how different conditions will have different requirements. There should be regularly monitoring on how staff are adhering to the reasonable adjustments duty.
- 1.8. **Recommendation:** Disabled people, including people with MS, should only be asked to visit DWP services in person where absolutely necessary. All sanctions should also be scrapped.

Improvements to forms

- 1.9. We welcome that the DWP are taking steps to improve forms, including the examples given of how the Personal Independence Payment (PIP) form will be improved. However, overall, the information provided on improvements to forms is limited. There are a number of steps the DWP should take to improve forms which are not mentioned.
- 1.10. Our previous research has shown around a third of people with MS thought four weeks was not enough time to complete the PIP form, and of these people over half were unaware that it is possible to request a two week extension from the DWP. The majority of those who were unaware said they would have asked for one if they had known. Although the DWP allows for extensions beyond six weeks on a case-by-case basis, awareness of the possibility of extensions is very low, and therefore people with MS underuse this option². The DWP should extend the deadline to submit both the PIP and ESA application forms to 8 weeks as standard to allow people to obtain evidence as well as the support they need to fill in the form. Additionally, clear information should be provided with the PIP application form which tells people about the right to request an extension to the deadline, and the circumstances under which this should be granted.

² MS Society (2019) *Pip Fails*

- 1.11. Only half of people with MS who want to know the PIP assessment criteria to help them fill in the PIP form have access to this information³. This information is available online, however not everyone has internet access or is aware they can access it online. The information is also not provided to claimants as a matter of course.
- 1.12. We know 56% of internet non-users are disabled, much higher than the proportion of disabled adults in the UK population as a whole⁴. This means that a significant number of disabled people are likely to face difficulties accessing the criteria online. And not providing claimants with the criteria is likely to be exacerbating other inequalities too. For example, households with the lowest incomes are far less likely to have internet access than households with the highest incomes⁵.
- 1.13. If all claimants were provided with information explaining the criteria and how they are scored, it would make it easier to fill out the form. This is also likely to make the claimant's information in the form better quality. This would lead to assessors being able to make more paper-based decisions, which in turn means fewer face-to-face, phone and video assessments. It would also mean that recommendations made by assessors are more likely to be correct. The DWP should therefore ensure the criteria and scoring system is provided to all applicants with all application forms.
- 1.14. Some people with MS said they often felt like they had to repeat themselves across different sections of the PIP form. We hope that the DWP's aim, as stated in the Green Paper, to simplify instructions and reduce repeated information on the PIP form is sufficient for mitigating this. If it is not, further steps should be taken to ensure people do not have to repeat themselves across forms.
- 1.15. Many people with MS have also told us the PIP form did not allow them to fully explain how their condition affects them, nor did it allow them to fully explain how their MS symptoms can fluctuate. The DWP should, in consultation with disabled people and charities, work to ensure forms allow people with progressive and fluctuating conditions, including MS, to fully explain how their condition affects them.
- 1.16. Finally, we are pleased the DWP are introducing an online PIP form. However, the DWP should ensure the application process for PIP does not become an online process only and that claimants are still provided with the option to apply by paper form or over the phone. This is important

³ Ibid.

⁴<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

⁵ MS Society (2019) *Pip Fails*

because many disabled people, including people with MS, do not have internet access and/or face barriers with accessing digital services.

- 1.17. **Recommendation:** The DWP should extend the deadline to submit both the PIP and ESA application forms to 8 weeks as standard. The DWP should also make it clear that applicants can request an extension.
- 1.18. **Recommendation:** The DWP should provide the criteria and scoring systems with all application forms.
- 1.19. **Recommendation:** The DWP should work to ensure forms allow people with progressive and fluctuating conditions, including MS, to fully explain how their condition affects them.
- 1.20. **Recommendation:** The DWP must ensure that the PIP application process does not become an online only process.

Signposting and support to help people access benefits

This section covers the following questions:

Q. What more information, advice or signposting is needed? How should this be provided?

- 1.21. People with MS have made it clear to us that the signposting, information and advice provided by the DWP in person, online and in forms is inadequate for helping them to access benefits and other support. A number of people with MS told us:
 - They were not signposted to other benefits and sources of support they could be eligible for at the time of making an initial claim for a benefit.
 - The advice on GOV.UK was not clear enough for helping them to understand which benefits and support they may be eligible for.
 - There is a lack of openness from the DWP about what benefits and support is available. In addition, we are particularly concerned that some even thought that the DWP is actively trying to hide some benefits from them so they are less likely to claim them.
 - They felt like they were left to their own devices to work out what they may be eligible for.
 - They were not provided with clear information about the right to a mandatory reconsideration and appeal when they received a decision on their benefit awards.

"They should be open... 'this is what you're entitled to, what is your living situation', and that support should be there for you, because when you come from a full-time job and you're just thrown into this world, it's like they keep it hidden from you. A person who guides you through it, they deal with it, request

the medical evidence, 'if you need help with housing we can do this for you, what medical help do you need, do you know about this charity, do you need a bus pass?' This takes the pressure off and signposts."

- 1.22. The DWP should ensure that people are able to easily initiate claims for disability benefits either online, by phone, by post or in person. At the time of, or shortly after, initiating a claim for a benefit, they should be provided with clear information outlining the other benefits and support they may be eligible for and given advice on how to apply. This should include information on benefits and support from the DWP, other government bodies, charities and support groups. This information should be provided via whichever channel is most suitable for them e.g. online, by phone, by post or in person. Every disabled person who initiates a claim for disability benefits should also be given the right to be assigned a single point of contact who can help them understand which other benefits and sources of support they may be eligible for, and support them to apply for them where necessary.
- 1.23. Clear and easily navigable advice should be available on GOV.UK on the benefits and sources of support available for disabled people and how to apply for or access them. This should be established as a 'one-stop shop' where disabled people can find out all the benefits and support they may be eligible for in one place, regardless of the Department providing them.
- 1.24. The DWP should also ensure benefit decision letters provide clear information on the right to a mandatory reconsideration and appeal. This information should also include advice on how to proceed with a mandatory reconsideration and appeal and where to go for support.
- 1.25. **Recommendation:** The DWP should provide information on all support available for an individual applying for a benefit. This should include information on other benefits, as well as wider support for example, housing, and social care.
- 1.26. **Recommendation:** Each disabled person who initiates a claim for disability benefits should be given the right to be assigned a single point of contact to help them navigate the whole process and beyond.
- 1.27. **Recommendation:** The DWP should ensure benefit letters provide clear information on rights to Mandatory Reconsiderations and Appeals.

Testing advocacy support

This section covers the following questions:

Q. Do you agree with the principles we have set out for advocacy support?

**Q. How might we identify people who would benefit from advocacy?
Q. What kinds of support do you think people would want and expect from advocacy?**

- 1.28. Many people with MS rely on advocacy services to help them more easily access the benefits and support they are entitled to. Too often this is because the system is riddled with hurdles which make it overly difficult for them to access the support they need. This includes long and overly complex forms, stressful assessments with assessors who do not understand people's conditions, and a lack of information on which benefits are available and how to apply for them.
- 1.29. We broadly welcome the Government's aim to improve advocacy support. However, attempts to improve in this area, will not be sufficient to cover up for failures to make much needed wider reforms to the disability system. For example, improving the assessment process so disabled people can more easily get the support they are entitled to while being treated with dignity and respect. We outline our recommendations for these reforms throughout the rest of this paper.
- 1.30. Time and time again people with MS have told us they do not trust services run by, or on behalf, of the DWP. Less than half of the people with MS surveyed by us in August this year answered 'yes' when asked if they would use an advocacy service independent of, but funded by, the DWP. We are concerned that many people with MS would not want to use an advocacy service seen to have links to the DWP.
- 1.31. Existing independent advocacy services are the services which already have 'on the ground' knowledge and experience of the challenges of navigating the benefits system and are best placed to be able to reach and be trusted by those who need support the most. However, these services have been hit hard by funding cuts over recent years and often struggle to provide support to all those who need it. Rather than establishing a new advocacy service, one option is for the Government to fund existing independent advocacy services. The Government could identify and map gaps in provision, and fund them to provide additional services or extend their current services to fill these gaps. If the Government decides to go with this option, it should ensure funding is sufficient to enable existing advocacy services to provide free and independent support to all disabled people who need it. By supporting organisations that are already more trusted by people who need support, it is likely the Government can go some way to achieving its stated aim of building trust with disabled people.
- 1.32. If the Government does decide to go ahead with its plan to establish its own independent advocacy service, it should ensure it is open to all, and not just those who are deemed to 'need it most'. A selective system would require processes and procedures for determining eligibility. This risks

lowering take-up by creating a two-tier system where those who are deemed to be more 'in need' could feel stigmatised and not want to use the service. It would also increase administration costs for the DWP or whichever body is to be tasked with determining eligibility for using the service.

- 1.33. Additionally, regardless of the metric used to determine eligibility (e.g. income, savings, type of disability), it is inevitable that there would be a significant number of people in need who would miss out on support. We believe the easiest way to ensure everyone in need can access support is to ensure support is available to all, free at the point of use. The DWP should also ensure people can access this support as many times as they need to, even if they have achieved their original 'outcome'.
- 1.34. According to the evidence referenced in the Green Paper at footnote 53, we know there is limited awareness about independent advocacy amongst disabled people which means that people may access advocacy late or not at all. Regardless of whether it funds existing services or sets up its own service, the DWP should ensure all relevant advocacy services are widely publicised via a range of channels to disabled people, including people with MS. It should also put in place measures to monitor whether uptake of advocacy support has increased amongst disabled people, including people with MS, and whether they have achieved their outcomes.
- 1.35. People with MS have told us the types of support they would want and expect from advocacy. This includes support with:
 - filling in forms
 - understanding how best to explain their condition on forms and in assessments
 - understanding the range of benefits on offer and the process for applying
 - applying for benefits
 - gathering evidence for benefits claims
 - attending assessments
- 1.36. They also told us they would like support to be provided by people who have experience and knowledge of both MS and the benefits system, and for it to be provided via these channels:
 - in person, including as a home visit service
 - online, by phone and by email
 - as a 'one-stop shop' where you can get everything you need in one place
- 1.37. Regardless of whether the Government decides to establish its own advocacy service or instead funds existing services, we recommend it prioritises ensuring people with MS have full and free access to the

types of support outlined above, provided via the channels outlined above.

- 1.38. **Recommendation:** The Government should review existing advocacy services before moving ahead with introducing an independent advocacy service. This should include examining the possibility of providing more support to existing trusted services rather than – or as well as – introducing a Government service.
- 1.39. **Recommendation:** Any advocacy service should be open to all disabled people, free at the point of use, and access should be provided via suitable channels.

Exploring support for mobility needs

This section covers the following questions:

Q. Are we meeting disabled people’s mobility needs? Please tell us why/why not.

- 1.40. In our response to Chapters 3 and 4, we outline the various issues with PIP assessments and decision making which lead to far too many people with MS missing out on the mobility support they’re entitled to. This often means people have to go through a stressful mandatory reconsideration, and often an appeals process, to get it. Many people with MS who need support from the Motability scheme to maintain independence have been denied this, despite not being able to carry out daily activities without the vehicle. One of the main barriers to people with MS getting the higher rate of mobility support, and access to the Motability scheme, is the 20-metre rule⁶.
- 1.41. In the first instance, the Government should follow our recommendations for reforming assessments and decision making (outlined in our response to Chapters 3 and 4) to ensure all people with MS get the appropriate level of mobility support first time. This includes scrapping the 20-metre rule for the highest rate of PIP mobility support. A review and design exercise should be carried out with disabled people, charities and healthcare professionals to design an agreed appropriate alternative. In the meantime, the 50-metre threshold should be reinstated.
- 1.42. The criteria, scope and detailed rules regarding the Motability scheme should also be reviewed by the DWP in consultation with disabled people and charities. In particular, the DWP could consider making the Motability scheme available to disabled people who are on standard mobility PIP or low mobility DLA and to disabled people not on

⁶ MS Society (2018) *PIP: A step too far*

PIP. This could be time limited to 18 months to give them time to apply for PIP.

- 1.43. Currently, disabled people can keep their Motability vehicle for 26 weeks if they are appealing against a decision not to be awarded the enhanced mobility rate. However, we know some disabled people lose their Motability vehicle while appealing as many appeals can take longer than 26 weeks. The DWP should therefore ensure any disabled person who used to get Motability who is challenging the decision not to award them the enhanced mobility rate should be able to keep using the Motability scheme for 18 months, rather than 26 weeks. This should be until their appeal is resolved.
- 1.44. **Recommendation:** The criteria, scope and detailed rules regarding the Motability scheme should also be reviewed by the DWP in consultation with disabled people and charities.
- 1.45. **Recommendation:** The Government should consider making the Motability scheme available to disabled people who are on standard mobility PIP or low mobility DLA and to disabled people not on PIP. This could be time limited to 18 months to give them time to apply for PIP.
- 1.46. **Recommendation:** The Government should ensure that people retain access to the Motability scheme while waiting for their appeal to be resolved.

Chapter Two: Improving employment support

Early intervention

This section covers the following questions:

Q. What more could we do to further support employers to improve work opportunities for disabled people through Access to Work and Disability Confident?

Access to Work

- 2.1. Many people with MS experience their first symptoms during the peak of their working lives, in their 20s and 30s. However, 8 in 10 people with MS retire within 15 years of being diagnosed, which means leaving work earlier than the state pension age and becoming economically inactive. They reach a point where employment is no longer sustainable due to their symptoms, and a return to work may never be possible or beneficial.
- 2.2. It is vital that the Government acknowledges that work is not always possible for some people, and that this is embedded and reflected in Government practice and provision of appropriate support.
- 2.3. The first two questions in this chapter approach the issue of unemployment by asking how to get people into work, but the first focus should be on how to help people **stay in** work. Surveys of our community indicate that of those who receive support to stay in work, the majority receive it from their employer. Less than a third of people who say they need support to remain in work receive it from government sources⁷. More government support is needed in order to support people with MS to remain in work.
- 2.4. People with MS often say they leave work due to the severity of their symptoms, and while the primary source of support for people with MS in employment is employers themselves, too many people with MS report unsupportive employers and a lack of understanding of MS and how it affects people individually. This means many people with MS leave work earlier than they should.
- 2.5. While many employers accommodate people with MS to the best of their ability, and are proactive in putting in place support policies and procedures, some employers fail to follow best practice or even to fulfil their legal obligations.
- 2.6. Access to Work (ATW) is a valuable source of support for people with MS. It is encouraging to see that funding for ATW has increased and there is a commitment to increasing awareness of the scheme, as well as

⁷ MS Society – My MS My Needs survey, 2019

making permanent some of the changes that were made to improve the scheme during the Covid-19 pandemic. But as good as ATW is, it still has its problems and there are a number of improvements that could be made to make it better at helping disabled people get into and stay in work.

- 2.7. People with MS do a variety of things to help them stay in work. Unfortunately, despite much evidence that support in the form of adjustments can help keep disabled people stay in work, reduce sickness absence, improve wellbeing for all employees and much more, employers are still reluctant to introduce them.
- 2.8. A lack of understanding about reasonable adjustments can be common amongst employers. They can be seen as costly and difficult. Some adjustments can be made by the individual themselves, such as writing things down, or finding ways to remember tasks, but other adjustments need support from an employer. The most common adjustment is reducing or changing hours, but other adjustments include changing job location, changing roles, or making physical adaptations.
- 2.9. Many employers are unaware that support is available through ATW funding that could help with some of the reasonable adjustments they are being asked to make. This is largely due to lack of publicity of the scheme by the government. In 2018/19 total expenditure on ATW was £129 million. The Centre for Social Justice say "it is the DWP's most expensive, yet arguably most successful, programme". However research in 2017 revealed that only 25% of employers know what ATW is and understand the help they can get from the service⁸.
- 2.10. It is only once an employee starts work that they are assessed and provided with support. Employers may therefore still be reluctant to hire a disabled employee because they are wary of the costs and difficulties that could attract.
- 2.11. The way the scheme operates should be changed to allow a preliminary three way conversation between the employer, the prospective employee, and the scheme during the recruitment process. Government proposals further on in the Green Paper around employment and health discussions, and making use of local information and expertise would also provide an opportunity for employers and prospective employees who are receiving support from the JCP to come together and have this conversation. These conversations would explore what support the employee needs, what could be provided once they start, and how soon any adjustments could be put in place. Thus mitigating any concern over cost for the employer, and a delay in starting for the employee.

⁸ Centre for Social Justice (2020) *Commissioning excellence in disability*

"My patients feel discriminated against because lots of employers don't want people who are going to take time off. There should be a support service that can help the employee and the employer to encourage and support to keep people in work."

- 2.12. We agree with the DBC that ATW could be more effective by providing more holistic assessments that look at the range of support a person needs: working hours, working practices, and addressing employers' concerns, rather than focusing narrowly on things such as equipment or travel.
- 2.13. The government has committed to providing an ATW adjustments passport for young people transitioning from education to work, and are piloting the Adjustments Passport with veterans leaving the armed forces, and freelancers and contractors moving between job roles. We believe that this should be extended to anyone who receives ATW funding reducing the need for repeat assessments, making conversations with prospective employers easier, and reducing the risk of a delay to starting a new job.
- 2.14. Employers are under no obligation to accept recommendations made by ATW regarding reasonable adjustments, even if ATW will fully fund them. To ensure better uptake, tighter legislation and enforcement of that legislation should be explored. Alongside which, other requirements around reasonable adjustments, such as providing a written response to a request, within 4 weeks, as well as a timeframe for providing the reasonable adjustment.
- 2.15. **Recommendation:** Managing the scheme should remain the remit of the DWP, but considering the scheme is not well known, there is a case for BEIS to help promote it to businesses.
- 2.16. **Recommendation:** The DWP should review the range of data collected on the scheme, to help target promotion, assess its effectiveness, and identify areas for improvement.
- 2.17. **Recommendation:** The DWP should consider changes to Access to Work that will allow disabled job seekers and prospective employers to explore what support could be available, before an employee starts work.
- 2.18. **Recommendation:** The government should extend the ATW Adjustments passport to everyone who receives ATW funding.
- 2.19. **Recommendation:** Stronger laws are required to ensure that employers are obligated to provide reasonable adjustments.

Disability Confident:

- 2.20. The Disability Confident scheme is voluntary, and doesn't have any legal powers of enforcement. A survey carried out of Disability Confident employers in 2018 showed that less than half (49%) of employers reported that as a result of joining the scheme, they had recruited one or more individuals with a disability, long-term health condition or mental health condition⁹. The Centre for Social Justice describes the scheme as "a PR stunt rather than a measure of genuine willingness to bring disabled people into the workforce."¹⁰
- 2.21. It is entirely possible for an employer to be accredited without actually employing one disabled person. People with MS have told us they consider if prospective employers are signed up to the scheme, but unfortunately they have also told us that they soon realise it means very little in reality.
- 2.22. **Recommendation:** to ensure the scheme is meaningful, the DWP should monitor employment practices of employers at all levels, and introduce mandatory reporting for organisations.

Advice and information:

- 2.23. A majority of employers, according to an IPSOS Mori poll, reported that by and large they understood their legal responsibilities (45% said very well and 48% said fairly well¹¹). But employers who had not had disabled employees had mixed interpretations of the meaning of the Equality Act 2010 and the duty to provide reasonable adjustments.
- 2.24. There is a much lower level of confidence amongst employers on where to find advice, guidance and information relating to workplace adjustments and legislation. According to the Business Disability Forum, 41% of employers they spoke to had the confidence to know where to go for advice and information outside their organisation¹².
- 2.25. This lack of understanding and information can create difficulties for people with MS in the workplace. 87% of people with MS disclosed their MS to their employer, but only 57% have discussed support in the workplace, such as reasonable adjustments¹³.
- 2.26. We were pleased to see the government's commitment to develop a national information and advice service for employers on health, work and disability.

⁹ Centre for Social Justice (2020) *Commissioning excellence in disability*

¹⁰ Ibid.

¹¹ IPSOS Mori – July 2021 <https://www.gov.uk/government/publications/sickness-absence-and-health-in-the-workplace-understanding-employer-behaviour-and-practice/sickness-absence-and-health-in-the-workplace-understanding-employer-behaviour-and-practice-summary>

¹² Business Disability Forum (2016) *Why Bother?* [online] Available at: <http://www.businessdisabilityforum.org.uk/why-bother/>

¹³ APPG for MS (2016) *Employment that works: supporting people with MS in the workplace*

- 2.27. **Recommendation:** Any information and advice service must be designed with employers and disabled people and organisations that represent them.
- 2.28. **Recommendation:** Disability Confident could provide a site of a one-stop shop style service of advice and information as committed to in the government's Health is Everyone's Business consultation response.

Statutory Sick Pay:

- 2.29. Statutory Sick Pay is an important way that the DWP can help employers to retain disabled employees and improve work opportunities for disabled people that isn't covered in the Green Paper.
- 2.30. Reform of SSP was covered in the 2019 Health is Everyone's Business consultation. However, in the response the government has made it clear that it won't be taking forward any of the reforms to SSP that were proposed, despite acknowledging how important they would be.
- 2.31. This is incredibly disappointing. A good SSP system is critical for helping people remain in work as long as is right for them. Having these policies and procedures in place creates a culture where people with MS feel they are being treated fairly and equally.
- 2.32. The proposals in Health is Everyone's Business were welcomed, but the reforms could go further. The rules around qualifying days were changed during the pandemic, and we would like to see these rules made permanent. This would help people with MS whose condition fluctuates, and provide them with the financial support needed rather than them having to take unpaid leave, or work when they aren't well enough to do so.
- 2.33. **Recommendation:** The government must commit to reforming SSP in line with the proposals set out in the Health is Everyone's Business consultation.
- 2.34. **Recommendation:** The government should make the changes to the rules made during the Covid-19 pandemic on qualifying days permanent.

Providing more support before the Work Capability Assessment

This section covers the following questions

Q. How can we support people who have fallen out of work to identify and consider suitable alternative work before their WCA?

- 2.35. We strongly agree with the DBC that a discussion with claimants, before a WCA has determined whether or not they have the capability for such

activity, should cease. The argument that such discussions are necessary to avoid people losing touch with the labour market would be redundant if Work Capability Assessments (WCA) were carried out much sooner in the process.

- 2.36. The DWP has a trust issue – a challenge that affects every chapter of the GP. Requiring people to take steps towards work too early, or that are inappropriate or unmanageable damages trust from the outset.
- 2.37. Deciding to leave work is a deeply complicated and personal decision. It has very real ramifications for people with MS, and their friends and family. It involves weighing up health needs with financial and emotional worries. A conversation about work with a work coach at this time could cause more harm. Without clear evidence on the benefits of this approach, any discussion before a WCA should be voluntary.
- 2.38. **Recommendation:** WCAs should take place within three months of a claim and before any employment support is offered.
- 2.39. **Recommendation:** Any discussion with a Work Coach about work before a WCA must be voluntary.

Ensuring Jobcentres are Welcoming, Engaging and Expert

This section covers the following questions

Q. What further support or information would help work coaches to have more effective conversations with disabled people and people with health conditions?

Q. What has been your experience of receiving employment support? What was good about the support? Are there any further improvements that could be made?

- 2.40. Please see previous question regarding conversations with work coaches prior to a WCA. Please see our responses to questions in Chapter 4 for more detailed comments on the work of work coaches more broadly.
- 2.41. Work coaches and the role they play in employment support will be covered in more detail in Chapter 4.

Conditionality and sanctions:

- 2.42. There is a short section in this Chapter on conditionality which is not linked to a question, but is important to acknowledge. While we think the Department's change in approach to conditionality is a step in the right direction – it is still conditionality. The MS Society wants all conditionality for disabled people, including people with MS in the WRAG and UC equivalent scrapped.

2.43. There is no clear evidence that conditionality and sanctions help disabled people to get into and remain in work. The National Audit Office (NAO) found that the impact of sanctions on ESA claimants is unexamined in the literature and merits further investigation, but tentatively concluded that “sanctions reduced [ESA] claimants’ time in employment, particularly part-time employment. Most of the reduction meant people spend more time claiming, suggesting sanctions may have discouraged some claimants from working¹⁴.”

“At its simplest, conditionality is based on three assumptions: that it will make claimants less selective about the jobs they are willing to take; try harder to find work; and take fuller advantage of support available to them.” Ben Baumberg Geiger¹⁵

2.44. In the year to July 2019, 91% of UC sanctions decisions occurred due to failure to attend or participate in a Work-Focused Interview¹⁶. In discussions with welfare advisors the CSJ found that many of the most vulnerable claimants struggled to keep appointments with their work coaches due to travel problems – people missing connections due to late buses or trains, having to take numerous modes of transport in rural areas. All of which are examples of asking too much of vulnerable claimants.

2.45. For many people with MS, imposing sanctions is risky and impracticable as they will not be able to comply with work-search requirements or work-related activities at any particular time due to their condition. We know that some people with MS in the Employment and Support Allowance (ESA) Work-related Activity Group (WRAG) have had inappropriate requirements applied. In a 2015 survey, over half of respondents to our survey in the WRAG (52%) said they were unable to undertake the actions asked of them to take steps towards employment¹⁷.

“There were unreasonable expectations that besides looking after my family, and managing my MS, I have the time and capacity to meet their expectations regarding weekly time spent looking for a job.”

2.46. As some of the literature points out¹⁸ conditionality and sanctions have other negative effects on disabled people: Sanctions cause people to be in ‘worse’ jobs (lower paying, unstable, part-time). It can undermine

¹⁴ National Audit Office (2016) *Department for Work and Pensions: Benefit sanctions*. p.41.

¹⁵ Ben Baumberg Geiger (2017) *Benefits Conditionality for Disabled People*

¹⁶ Department for Work and Pensions, *Benefit Sanctions Statistics* (November 2019)

¹⁷ MS Society (2015) *MS Enough: Make welfare make sense*. p.7.

¹⁸ Ben Baumberg Geiger (2017) *Benefits Conditionality for Disabled People*

claimants' relationships with their work coach who can be crucial to the employment support services people can access. Tom Pollard says in 'Pathways from Poverty' "the relationship between an individual and their coach is critical to successful employment outcomes, but the conditional nature of their interactions, and the uneven power dynamics this creates, fundamentally undermines trust and rapport¹⁹."

- 2.47. It can cause anxiety and stress, and worsen people's health conditions. There is limited, but robust evidence to suggest that sanctioning disabled people may have zero or negative impacts on work-related outcomes²⁰.
- 2.48. For people with MS who are in work, but on low pay and claiming UC, in-work conditionality must not apply. People's fluctuating ability to comply with job search requirements will make them more likely to be penalised as a result of conditionality measures. In addition, many people with MS work part-time to manage their condition, or because full-time work is unsustainable because of their MS.

"Conditionality implies that disabled people are out of work because of a lack of motivation...which ignores the real barriers they face. However, even where claimants have some work capacity and may be able to get a job, they are often uncertain about their capacity to work and require considerable support. Claimants' relationships with work coaches become critical, as does their willingness to experiment. Rather than encouraging claimants to move towards work, it can lead to fear and anxiety." Ben Baumberg Geiger²¹

- 2.49. For employment support for disabled people to be effective, it has to be free from conditionality, from fear and threats. Removing sanctions and providing high-quality, individually tailored employment support will go some way to restoring trust and a fairer benefits system for disabled people. Compulsory work-related conditionality backed up with the threat of sanctions, is a negative and uninspiring approach. High-quality employment support, backed up by the real chance of a job, is the way to inspire confidence.
- 2.50. The MS Society would like to see all work-related activity requirements made voluntary for claimants with MS on ESA WRAG or UC LCW. Current conditionality in these groups is inappropriate in many cases.
- 2.51. **Recommendation:** The DWP does not introduce any further conditionality into the disability benefits system, and removes conditionality for disabled people in the WRAG/LCW.

¹⁹ Tom Pollard (2019) *Pathways from Poverty* p.9.

²⁰ Work and Pensions Select Committee (2015) *Disability Employment Gap Inquiry*

²¹ Ben Baumberg Geiger (2017) *Benefits Conditionality for Disabled People*

- 2.52. **Recommendation:** Conditionality and sanctions must never apply to people in the SG/LCWRA groups.
- 2.53. **Recommendation:** the efficacy of current conditionality and sanction arrangements for claimants must be reviewed, with a view to removing these mechanisms which are not proved to be effective.

Personalising Employment Support

This section covers the following questions

Q. What has been your experience of receiving employment support? What was good about the support? Are there further improvements that can be made?

Q. How can we make the most of the knowledge and expertise of local organisations to support disabled people and people with health conditions into employment?

Q. What more could we do to work with other organisations and service providers, local authorities, health systems, and the devolved administrations to provide employment support in health settings and join up local support?

- 2.54. We have heard from people with MS that fear of losing benefits such as ESA if they take on work or show willingness to work, can be a barrier to seeking support. The issue of fear and mistrust in the DWP must be tackled if it is to provide employment support to any disabled person who wants it.
- 2.55. To be able to provide good employment support it is important to recognise some of the barriers that prevent this. These include a lack of understanding of the local job market, the needs of people with MS, and the perception of Jobcentres. Without tackling these good employment support can only go so far.

The Jobcentre

- 2.56. The Jobcentre shouldn't be the only place that people can get employment support, but at the moment the focus is heavily on people who claim benefits and are out of work. The Jobcentre should be there for anyone who needs it, whether at work or looking for work, whether on benefits or not. Unfortunately, Jobcentres have a bad reputation which prevents people from accessing it.

"Nothing would encourage me to do anything via the Jobcentre.

"The Jobcentre is not a suitable environment, it's hostile and intimidating."

2.57. People with MS have told us that they found the support in the Jobcentre to be less understanding of their health condition and circumstances than they expected. Some have been told to apply for jobs that are entirely unsuitable for them e.g. they are too physically demanding, or isn't appropriate for their experience and work history. The same is said when talking about taking part in work-related activity. Some people say it has even led them to avoiding claiming benefits in order to avoid having to deal with the Jobcentre, which means they could be going without the financial support they need and are entitled to.

"I knew the Jobcentre wouldn't be helpful...It's not a platform I'd use because it doesn't work for me historically. I didn't feel I needed it, I was used to getting other types of support."

"There is support but it needs to be more flexible and more individual. The people that are in front of you at the Jobcentre are trying to do their best, by following a process, but unfortunately some people don't fit."

2.58. A report by Scope agrees "Many focus group participants and interviewees highlighted their work ambitions and expressed frustration that they felt their experience and skills were being wasted...the support was too generic²²."

2.59. This aligns itself with the idea that Jobcentres are there to get you in work, any kind of work, this perception is supported by the conditionality approach as discussed in previous answers. It is also linked to work coaches and their ability to understand MS (see below section on work coaches). This does nothing to allay the perception that the Jobcentre is poor and untrustworthy.

2.60. DWP research backs this up and shows that some individuals distrust the motives behind Jobcentre offers of employment support. It shows that the main factors leading to negative perceptions of DWP and Jobcentres include:

- A perceived underlying agenda of benefits cuts and cost savings
- Past negative experiences of dealing with the DWP and Jobcentre
- A perceived understanding of poor mental health among Jobcentre staff
- Concern that Jobcentre were not sufficiently focused on finding employment appropriate to their capabilities and ambitions²³

"I was offered employment support however, as nobody at the Jobcentre or DWP had experience in offering me suitable choices – I'm a solicitor – it was a complete waste of time."

²² Scope (2021) *Time to Think Again* p18

²³ IFF (commissioned by DWP) 2020 <https://www.gov.uk/government/publications/work-aspirations-and-support-needs-of-claimants-in-the-esa-support-group-and-universal-credit-equivalent/summary-the-work-aspirations-and-support-needs-of-claimants-in-the-esa-support-group-and-universal-credit-equivalent>

2.61. It is imperative that the Jobcentre is seen as a service that can support all disabled people at all levels of employment, from entry level jobs, manual jobs, to highly specialised and professional jobs. It is also important that work coaches are able to support disabled jobseekers to find appropriate employment. So that people with MS can feel confident in their work coach is providing, the work coach must have more support from Disability Employment Advisors, particularly more condition-specific. We go into this in more detail in Chapter 4 below.

Employment support programmes

2.62. Over the years, many employment support programmes and packages have been introduced and replaced. As has been highlighted above, many are seen as not being relevant or appropriate, and they don't have a high success rate. This hasn't been helped by a reduction in investment of 76% over the last 5 years²⁴.

2.63. That said, there have been improvements as the Department moves towards a more personalised and tailored model.

2.64. Two such programmes are Individual Placement and Support (IPS) and Intensive Personalised Employment Support (IPES). We welcome the government's commitment in the Disability Strategy to increase places on IPES by 25% and to expand IPS trials. Funding levels must improve to make sure these programmes are successful, and there needs to be regular evaluations of how they are working, and how they can be improved.

Types of jobs

2.65. A lack of good quality part-time and flexible jobs is a barrier to finding work for people with MS. In the UK, 41% of people with MS who are in employment work part-time²⁵, which is significantly higher than the part-time employment rate of the general population²⁶. People with MS need this flexibility in order to manage their condition while working, but may struggle to find good quality, part-time work.

2.66. It could be argued that the Covid-19 pandemic will see the number of flexible jobs increase but according to the Timewise flexible jobs index 2020, this is not the case as they say "the dial barely moved". At the start of 2020, 9 in 10 people want to work flexibly, but only 2 in 10 jobs were advertised with options to work flexibly²⁷.

²⁴ CSJ (2020) *Commissioning excellence in disability*

²⁵ MS Society – My MS My Needs 3 survey, 2019

²⁶ ONS – Full-time, part-time, and temporary workers dataset, November 2020 (the dataset shows that out of 28,847,000 employees, 6,681,000 are working part-time)

²⁷ Timewise – The Timewise flexible jobs index, 2020

- 2.67. Additionally the pay band in which part-time jobs are readily available is for jobs paying less than £20k FTE. So part-time work is still very much associated with low pay, low quality jobs²⁸.
- 2.68. Learning lessons from the pandemic, and in order to improve disabled people's chances of finding work, BEIS and the Treasury should take charge of reshaping the UK's job market, encouraging more employers to offer flexible, part-time jobs, and allow more employees to work from home. This will mean that more good quality, and higher paid jobs will be available to disabled people. People with MS will benefit from a less rigid jobs market, as will others, and one that is less concerned with physical presence which has been a barrier for many people with MS. **However, this is heavily caveated.** In Chapter 4, later in the GP, changes in the workplace has been given as a possible reason for changes to the WCA, implying that these changes will remove barriers that should be taken into consideration when assessing someone. This is very much not the case. **The pandemic has not provided a silver-bullet to the many problems disabled people face when looking for and remaining in work.**

"My patients have used the employment service and they tell me they feel pushed into looking for work that they know they can't do or sustain. They feel discriminated against because lots of employers don't want people who are going to take time off."

- 2.69. The NAO have found that the DWP's state of knowledge over what works in supporting disabled people into work is disappointing they say "given the [DWP] has had programmes in place to support disabled people for over half a century, it's disappointing that it is not further ahead in knowing what works [to increase disability employment]²⁹."
- 2.70. With all the emphasis in the Green Paper on work, there is very little acknowledgement that many of the barriers people with MS, and disabled people more widely are down to barriers put there by employers and the rest of society. We are disappointed that still, the government chooses not to fully embrace the social model of disability, and still insists on the medical model.

Local expertise

- 2.71. The MS Society welcome the recognition in the Green Paper of the essential role that a variety of services play in the lives of people with MS. To truly improve the lives of disabled people, action is going to be needed by many different agencies. Good employment support requires a

²⁸ Ibid.

²⁹ NAO, (2019). *Supporting disabled people to work*. Available here: nao.org.uk/wpcontent/uploads/2019/03/Supporting-disabled-people-to-work.pdf

collaborative and local approach – which is why we have combined these two questions.

- 2.72. Across the country there are countless organisations offering specialised, local employment support for disabled people. A local approach to employment support, designed by and for, local people, which looks holistically at tackling the complex barriers to employment, would be better equipped to support disabled people, to find and retain employment.
- 2.73. A network of local agents, such as local authorities, charities, and disabled people’s organisations, would be better able to source personalised local support, understand the local area, and forge relationships with local employers. The involvement of disabled people in the design and delivery of these services, the connection those services have with the local areas rather than a centralised government department, will also help to build trust in the DWP.
- 2.74. Organisations that provide this support are often small, and because of that are unable to win government contracts to provide employment support due to the commissioning process. This means that disability employment support becomes dominated by a small number of national organisations, limiting the local offer, and the innovation and personalised support this can bring.

“Often the answers to challenges the government is seeking to solve have already been established at a grass-roots level by small and local Voluntary, Community and Social Enterprise (VCSEs). They are a vital resources that if effectively harnessed...When dealing with a cohort of individuals that have multiple and complex health needs, specialist knowledge and a relational approach are crucial. VCSEs function in a more relational and holistic way...meaning they often understand the very specific needs of the person they are trying to help.” Centre for Social Justice (CSJ)³⁰

- 2.75. Tom Pollard summarises it well in his report ‘This Isn’t Working’ when he says *“By addressing fundamental barriers within the current system, the shift to a community-led approach could revolutionise the support available...This is not just about employment, but the whole range of people’s interconnected needs and aspirations³¹.”*

Local organisations

- 2.76. People with MS across the UK rely heavily on services shaped and provided by a large number of government and statutory bodies such as Department of Health and Social Care, Department of Transport, Local Authorities and NHS England. As key stakeholders in the services people

³⁰ Centre for Social Justice (2020) *Commissioning excellence in disability*

³¹ Tom Pollard (2020) *This Isn’t Working: reimagining employment support for people facing complex disadvantage*

with MS rely on, their involvement will be crucial to improving employment and health outcomes. As highlighted above, a local approach to employment support is crucial, and for it to be successful, there has to be a cross-governmental approach which brings departments together to tackle barriers to employment such as, housing, transport and social care.

2.77. In order for people with MS to remain in or return to work, they don't just need employment support, but support in all areas of life. For example:

- **Social care** – in order to be able to work, some people with MS may require assistance getting ready in the morning and returning home in the evening. The DHSC and Local Authority must ensure that working-age disabled adults' care needs are provided for.
- **Housing** – people with unmet need for accessible housing are estimated to be four times more likely to be unemployed or economically inactive due to disability than disabled people without accessibility needs or whose needs are met³².
- **Transport** – the Department for Transport must work to ensure that disabled people have access to accessible public transport to get to and from work, while DWP must ensure that disabled people are able to take advantage of the Motability scheme by removing some of the barriers to participation (more details can be found in Chapter 4)
- **Financial support** – living in poverty has a significant impact on being able to find work. According to research from the Joseph Rowntree Foundation 4 million disabled people in the UK are living in poverty³³. Poverty has negative consequences across all areas of people's lives (digital access, health – physical and mental, transport issues) which can make looking for work incredibly difficult. The current rates of social security are inadequate and provide no relief and are pushing more people further into poverty.

2.78. People with MS have told us they would like more advice and information on employment at the time of their diagnosis such as support to understand their rights under the Equality Act 2010, what support is available e.g. Access to Work, but they also want their healthcare professional to be listened to by others – for example when providing medical evidence for a PIP assessment/WCA or Access to Work.

"If you're under the care of a neurologist or hospital, they will identify what kind of help and support you need, and that should go hand in hand with your job, if your healthcare professional says you need some equipment or to work fewer hours."

³² Provan, B., Burchardt, T., and Suh, E. – London School of Economics - CASereport 109 – [No place like an accessible home: quality of life and opportunity for disabled people with accessible housing needs](#), 2016

³³ Joseph Rowntree Foundation (2020) *UK Poverty report*

- 2.79. As mentioned above in the previous chapter, many people with MS want to remain in work as long as is right for them, transitioning out of work rather than leaving before they are ready. However, as we've illustrated this specific support can be difficult to find. The DWP can improve its offer and support for employers, and healthcare professionals, who can signpost and guide people with MS to the support they need.
- 2.80. **Recommendation:** The government should look at how holistic, local support could work better for disabled people. We agree with the CSJ when they recommend that the government must reassess the design of its disability employment provision and change the rules around commissioning to widen the market allowing smaller, more specialised providers to deliver local employment support.
- 2.81. **Recommendation:** The Disability Strategy is a good start to a co-ordinated cross-government approach, but it could go further. The Disability Strategy must be refreshed following the Government's response to this Green Paper.
- 2.82. **Recommendation:** The government must review current rates of social security. Benefits should be set at a sufficient level to meet the needs of people facing complex disadvantage and to live a positive, fulfilling and independent life.

Encouraging People in the Support Group or with LCWRA to take up support

This section covers the following questions:

Q. What can we offer that would encourage the Support Group or LCWRA to take up our employment support?

- 2.83. Employment is not always the best route out of poverty. While leaving employment and applying for benefits does appear to suggest that employment could be the best route. This isn't always the case. For those of our community who are unable to work – be that temporarily or longer-term, there should be adequate financial support, which recognises the difficulties of living for many years on disability benefits.
- 2.84. To justify their focus on encouraging people in the Support Group or LCWRA to take up employment support, in the Green Paper, the government states "our research with people in these groups [Support Group & LCWRA] ...showed that 1 in 5 people (20%) wanted to work and thought they would be able to work at some point in the future, if the

right job and the right support were available³⁴." However, if we delve into the detail, those figures don't paint quite as simple a picture.

2.85. What the IFF research (commissioned by the DWP) actually says:

*"1 in 5 (20%) have a **desire** to work and thought they could work at some point. Among these **4%** of claimants thought they could work now if the job was available and with the right support³⁵³⁶."*

2.86. The government's use of these figures is misleading and does not tell the whole story. Aside from the slight difference and therefore nuance behind the words 'want' and 'desire' - these figures show that the government is focused on a very small group of people percentage wise. This is particularly perplexing when such a small percentage of people in the WRAG/LCW move into work – the group that are assessed as being close to the labour market.

2.87. People in these groups only have marginally better employment outcomes than those in the Support Group or LCWRA group. Just over 1% of the WRAG and just under 1% of the Support Group move off ESA each month, but only a third of these people move into employment³⁷. Surely it makes more sense to focus on supporting the group closest to the labour market to get into work, and not the group who have been assessed as being unable to work or take part in work-related activity?

2.88. While adequate and appropriate support should be available for those who wish to access this, people with MS and other people in the Support Group must never be required to engage with employment support or work-related activity, or feel pressure to.

2.89. Employment support for the Support Group, especially with requirements, is inappropriate and could risk exacerbating symptoms, in addition to increasing stress, fear and anxiety. Many people with MS in the Support Group are unlikely to be able to re-enter employment due to the severity of their condition, regardless of the support offered.

2.90. In a survey of people with MS in 2017 79% of those were no longer working, said they had left work due to the impact of their MS symptoms. The impact was clear amongst those in the Support Group, 82% agreed or strongly agreed their MS meant they are unable to work while only 9%

³⁴ Shaping Future Support: the Health and Disability Green Paper p34

³⁵ IFF (2020) *Work aspirations and support needs of claimants in the ESA support group and Universal Credit equivalent* p.19

³⁶ It's important to note that it appears the reference in the Green Paper to these figures isn't correct. We are working on the assumption that the actual figures come from the IFFs research commissioned by the DWP and included in the evidence pack

³⁷ Tom Pollard (2020) *This isn't working* p.30

disagreed³⁸. When we asked people with MS in the Support Group what would encourage them to take up support, they told us:

"A cure, so I could physically work."

"If someone is too ill to work, nothing."

2.91. According to IFF research commissioned by the DWP, claimants' health conditions in the Support Group, were wide-ranging and the vast majority (87%) reported multiple conditions. Most (79%) expected their condition to last for the rest of their life, and most did not expect it to improve (only 9% expected an improvement). They also typically found their health difficult to predict, with two thirds (66%) reporting some fluctuation³⁹.

2.92. The government's insistence that being out of work has a negative impact on people's health and wellbeing simply isn't true for this group of people. For some people perhaps, but for a lot of people in the Support Group and LCWRA being out of work will be having a positive impact on their health and wellbeing. We have spoken to people with MS who tell us that during the pandemic, changes in their working arrangements, and in some cases being on furlough, have led them to realise that they feel much better when they're not working and that they have relief from their symptoms. What might be having a negative impact is the inadequate level of social security they may have to rely on – something we go into more detail on at the beginning of Chapter 5.

2.93. The MS Society echoes the views of other charities and organisations that, the majority of people in the Support Group will want to work but in most of those cases they won't be able to because of their health condition or disability. Disabled people in the Support Group should be trusted to know their limits, abilities, and how best to manage their condition.

"Every time I wake up, I feel great, and I think 'heck, I can do anything I want today'. Then I crawl out of bed and the world hits me with the reality that I simply cannot work. It is bad for my health. I would love to be able to work again! But if I can't, I can't. Yes, I can do a bit of gardening, and yes sometimes I can draw the occasional cartoon. But on demand? No."

2.94. An additional barrier is the labour market itself. As has been mentioned previously in this Chapter, the onus and burden to find and get into work is on the individual. In interviews and focus groups with people with MS, they have told us that even if they may feel able to work some of the time, their condition fluctuates, it can be unpredictable and finding employment that suits their needs is nigh-on impossible.

2.95. According to IFF research, when asked about barriers to employment, 72% of people agreed with the statement 'My condition fluctuates too

³⁸ MS Society (2017) *Response to Improving Lives Green Paper* p.18

³⁹ IFF (2020) *Work aspirations and support needs of claimants in the ESA support group and Universal Credit equivalent* p.18

much to work'. 73% agreed with the statement 'Worried people won't employ me because of my condition'⁴⁰. This is reflected in the conversations we have had with people with MS – as we have highlighted above.

- 2.96. Since the pandemic there have been changes to ways of working, with flexible and remote working a more likely option, but this isn't going to solve everything. People with MS know that they will struggle to find employers who will be as supportive and flexible as they need, particularly when it comes to a condition that fluctuates. This can clearly be seen in the employment figures for people with MS. No offer of support, or encouragement to work is going to change employer attitudes.
- 2.97. Trust is also very likely to play a role in shaping these views due to previous negative experiences with the DWP via the assessment process. We know that this could stem from inaccurate assessments and decisions, inappropriate work requirements or effective support.
- 2.98. According to the IFF research they identified a common concern, that showing an interest in moving towards work would trigger a Work Capability Re-assessment and cause their current benefit to end⁴¹. Something that is backed up by our own conversations with people with MS.

"The guarantee that it wouldn't leave you worse off and if we couldn't work for any reason, we wouldn't have to go back to the start to apply for support [would encourage take-up of support]."

"I would consider it [support] if it had no effect on my benefits."

- 2.99. Until this trust is restored, people are unlikely to want support from the Jobcentre.

- 2.100. Most people with MS we spoke to in the Support Group, were very clear that they did not want any support, or contact from the DWP once they had been assessed and placed into the Support Group. Any plans to increase the regularity of face-to-face contact for people in the Support Group would be of great concern. Any engagement or regular contact on an ongoing basis should only be implemented with the permission of the individual.

"Knowing there was support without pressure was really good for me."

- 2.101. We believe that appropriate and high-quality support is available on a strictly voluntary basis for those in the Support Group, for those who wish to access it. This should recognise the significant barriers to employment

⁴⁰ Ibid.

⁴¹ Ibid.

the individuals in this group will face and be able to respond to the self-defined goals they have – which may not involve paid work.

2.102.**Recommendation:** Support must continue to be made available to claimants in the Support Group on a strictly voluntary basis. We would strongly oppose any attempt to introduce conditionality to people in the Support Group or LCWRA

2.103.**Recommendation:** The government should explore how to reassure people that taking up any support, or employment will not impact their benefits. For example, by extending and improving the linking period to 12 months or changes to permitted work.

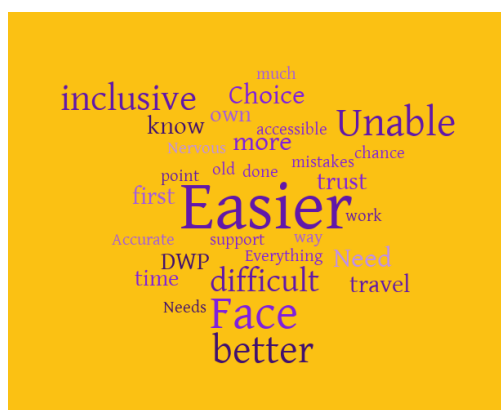
Exploring Digital Employment Support

This section covers the following questions:

Q. Would you be happy to access employment support digitally?

Q. What should we consider when developing a digital support for disabled people and people with health conditions?

2.104. In an MS Society survey for the Green Paper, out of 269 people who answered the question, 50% said they would be happy to access employment support digitally, 15% said no they wouldn't be happy, and 35% said they were unsure or didn't know. When we asked why the answers included:



2.105. Generally speaking people thought it could be easier, and better for those who might struggle with their symptoms. It was clear that people wanted a choice, and that face to face would still be the preferred option for some. Many people were concerned about access, and lack of digital skills.

2.106. All of the concerns in the previous question should be carefully considered. One of the main issues when developing any digital support is digital inequality.

2.107. There is a widening digital divide in the UK.

- 1.5 million UK households don't have access to the internet at home
- 2 million households struggle to afford internet access
- 10 million people still lack foundation-level digital skills
- 14.9 million people have very low levels of digital engagement.

2.108. Among those who are offline one of the main predictors is people with a low income and low education. We know that disabled people also, are negatively impacted by digital inequality due to other socio-economic effects.

2.109. There are many schemes across the country supporting disabled people and people with health conditions to access digital equipment and learn digital skills. One well known provider is 'The Good Things Foundation'. They partner with community organisations and work locally, in community spaces to improve digital inequality. In their recent report they call for a strategy which delivers three things: digital skills; community support; and affordable internet⁴².

2.110. To make digital support, be that employment support, or benefit application processes, the government should increase its funding in this area to reduce the digital divide and ensure that everyone who needs to access support is able to.

2.111. **Recommendation:** The government should increase funding into schemes that aim to reduce the digital divide.

2.112. **Recommendation:** The Department must learn lessons from the digital rollout of Universal Credit. No service provided by the DWP or Jobcentre for disabled people should be online only.

⁴² The Good Things Foundation (2021) *A Blueprint to Fix the Digital Divide*

Chapter 3: Improving Our Current Services

What the DWP has learned about current assessments

- 3.1. We welcome that the DWP has decided not to combine the WCA and PIP assessments into a single assessment. In our response to Chapter 5, we recommend that the DWP should ensure that, in the future, ESA and PIP are maintained as separate benefits with separate assessments. This includes ensuring PIP remains as a non-means-tested benefit.
- 3.2. While we support the two assessments not being combined into a single assessment, we also know some people with MS thought they were asked to repeat much of the same information across assessments for PIP and ESA. The DWP should take steps to ensure that information provided by a claimant in an assessment for one benefit can automatically be considered in the same claimant's assessment for another benefit, where this information is relevant to the other claim. This would ensure claimants are not asked to repeat too much of the same information across assessments for different benefits. However, it should only be done with the claimant's explicit consent.
- 3.3. **Recommendation:** ESA and PIP should be maintained as separate benefits with separate assessments.
- 3.4. **Recommendation:** The DWP should ensure that information provided by a claimant in an assessment for one benefit can automatically be considered in the same claimant's assessment for another benefit, where this information is relevant to the other claim. However, this should only be done with the claimant's explicit consent.

Introducing a new integrated health assessment service

- 3.5. We welcome the DWP's plans to roll out an integrated assessment service through the Health Transformation Programme bringing together the assessments for PIP and UC/ESA onto a single, digital system. Through discussions with DWP officials, we have also heard of some other positive developments (not mentioned in the Green Paper) regarding this programme and how it is being rolled out in the Departmental Transformation Area. This includes assessments being carried out in-house and claimants being allocated a case manager who helps them through every step of the process of claiming disability benefits e.g. helping to gather evidence and providing assistance with and arranging assessments.
- 3.6. While this service is being rolled out, the DWP should ensure that disabled people, including people with MS, and disability charities are regularly consulted on what they think could be improved about the service, and adaptations to the service should be made in response to this

feedback. We look forward to seeing how the service develops as it is tested and adapted.

- 3.7. We know that some people with MS face barriers to accessing digital services and so it is essential the DWP puts in place measures to ensure people who face these barriers are not put at a disadvantage when an integrated digital service is rolled out, and are able to access the services and support they need on an equal basis with those who face fewer barriers. In our response to Chapter 2, we make some recommendations for how the Government can close the digital divide more broadly and for how they can ensure disabled people who face barriers to digital access are not negatively impacted by the rollout of new digital services.
- 3.8. We welcome that the new integrated service aims to reduce the need for people to provide the same evidence more than once. However, as people with MS have previously told us they have significant concerns about the DWP having access to personal information, including health records, it is imperative the DWP does use information from other government sources such as the NHS and local authorities without the explicit consent of the individual concerned. Claimants should also always be asked if they want evidence held by the DWP to be used to inform other claims for financial support.
- 3.9. We are pleased that plans have been put in place to ensure assessments are audio recorded. The DWP should however go further and ensure both audio and video recordings of assessments are provided as an option to claimants, regardless of whether they were assessed face-to-face, by phone or video, and claimants should be informed of this option ahead of their assessment.
- 3.10. **Recommendation:** While the Integrated Health Assessment Service is being rolled out, the DWP should ensure that disabled people, including people with MS, and disability charities are regularly consulted on what they think could be improved about the service.
- 3.11. **Recommendation:** The DWP should not use information from other government sources such as the NHS and local authorities without the explicit consent of the individual concerned. Claimants should also always be asked if they want evidence held by the DWP to be used to inform other claims for financial support.
- 3.12. **Recommendation:** The DWP should ensure both audio and video recordings of assessments are provided as an option to claimants

Exploring different ways to conduct assessments

This section covers the following questions:

Q. During the coronavirus pandemic we introduced assessments by telephone and video call as a temporary measure. In your view, in future, what mixture of methods should we use to conduct assessments?

Q. How could we improve telephone and video assessments, including making sure they are as accurate as possible?

3.13. It is welcome that the DWP wants to make more 'paper-based' decisions to ensure people only have to go through face-to-face assessments where absolutely necessary. We recommend the DWP extends this commitment to ensuring that claimants are only asked to go through any non-paper-based type of assessment (e.g. Face-to-face, phone and video) in situations where insufficient reliable evidence has been provided and/or collected to enable a 'paper-based' decision to be made. Assessors should always exhaust all possible avenues to gather reliable evidence from the claimant, people who know them and their medical professionals to allow for a correct 'paper-based' decision to be made, first time. However, the DWP should ensure that claimants still have the choice to go through a face-to-face, phone or video assessment even if enough reliable evidence is available to make a 'paper-based' decision.

"Believe the reports of GPs, Consultants, Carers, family etc. who know the person and their problems. Assessment from a stranger with an agenda and quotas to meet is absolutely the wrong way to do it. I have felt humiliated, mistreated, judged, looked down upon, misunderstood and terrified by the assessment process. Doctors and carers know their patients/clients and have all the information about them to hand, it would be far more straightforward and less costly to use this information and certainly far less stressful for the claimant."

3.14. We have heard from many people with MS that evidence collection processes – both for assessors and claimants - fall far short of an acceptable standard and lead to too many people being asked to go through unnecessary assessments and getting the wrong decision on their claims. The DWP's commitment to increase the number of 'paper-based' decisions which work for disabled people can only be realised if these processes are greatly improved. The DWP should therefore take steps to improve evidence collection processes. We go into greater detail about the steps that should be taken in our response to Chapter 4.

3.15. We know many people with MS have experienced the same challenges with phone and video assessments as they have with face-to-face assessments, including being made to feel like they are lying, an over

reliance on informal observations, and assessors not understanding MS and the symptoms. In our response to Chapters 4 and 5 we talk about what needs to be improved about assessments more generally to ensure they work for people with MS, including how assessors need to improve. In this section, we outline some of the issues raised by people with MS which are unique to phone and video assessments, and how they should be addressed.

- 3.16. We are concerned that some assessors do not receive effective enough training for conducting phone and video assessments. The DWP should ensure all assessors receive in-depth training to help them carry out all types of assessments, accredited by an independent regulator, including to help them understand the specific differences between the different types of assessment for assessing mobility and understanding when the claimant is getting support from someone else. Assessment providers should work with people with MS, and the MS Society to help shape their training.
- 3.17. We know some people with MS who need support to take part in phone and video assessments do not always receive effective enough support to help them do so, some were not aware they could have someone supporting them during the assessment, and some thought they were not given enough time to adequately prepare. The DWP should ensure people are made aware they can have someone to support them during the call and are given enough notice so they can prepare for the call and arrange for someone to support them. If support is not available people must have the option to move the appointment without it counting towards the limited number of changes. Phone and video assessments must be carried out at the time agreed, and if support is unavailable because the call is too early or late, it should be rescheduled, and not count towards the limit.
- 3.18. A majority of people with MS have told us they would like the type of assessment people are required to go through to be decided with the input of the claimant themselves and their MS specialist medical professionals. The DWP should ensure that in situations where an assessment is necessary because a 'paper-based' decision cannot be made, or where a claimant would prefer to be assessed, the claimant themselves should be given a choice over how they will be assessed. The assessor should also seek the claimant's MS specialist medical professional's opinion on which type of assessment they think is most suitable for the claimant's needs. If this opinion differs from the claimant's choice, the claimant should be informed of their specialist's view and asked if they would like to change their choice.
- 3.19. Ultimately the decision for how a claimant is assessed should lie with the claimant themselves. However, to enable claimants to make informed choices, it should provide them with clear and in-depth guidance online, in

person and via a helpline which sets out things a claimant needs to consider before deciding which type of assessment is right for them. The DWP should consult with MS specialists and people with MS while designing this guidance. Case managers should be fully trained to understand which types of assessments are more suited to certain needs and to provide advice to claimants to help them decide the type of assessment to best suit their needs.

- 3.20. Having an assessment over the phone means that the person with MS is unable to see the assessor. Not being able to make eye contact, or read a person's body language makes the assessment difficult for some people with MS we have spoken to. Some people with MS also felt that without the assessor being able to see them, it was easy for them to make assumptions and to not understand how well (or not) they were managing with the assessment. In some cases this meant people feeling rushed, and not being given enough opportunity to explain their answers.
- 3.21. It is therefore essential that there is flexibility for claimants where a phone or video assessment is not appropriate. For some disabled people, having a phone or video assessment may not be the best option. This could be due to difficulties for some people to express themselves, or engage over the phone or by video call. It could be difficult for some to arrange for someone to support them while on the call. The DWP should ensure all claimants are offered reasonable adjustments to enable them to take part in their preferred assessment type and are offered full choice over how they are assessed. As outlined above, claimants should also be provided with clear guidance setting out things they need to consider before deciding which type of assessment is right for them.
- 3.22. It is not clear what the process is for recording phone and video assessments. A number of people with MS we have spoken to wanted to record their assessment but were unable to, others were not sure if they could. The DWP should ensure audio and video recordings of all types of assessment - face-to-face, phone and video - are provided as an option to claimants, and that claimants are informed of this ahead of their assessments. Assessors should ensure an audio or video recording of the assessment is provided to the claimant at the end of the assessment.
- 3.23. Finally, in situations where claimants are unhappy with their initial decision, and where they thought the assessment type (paper, face-to-face, phone and video) played a role in this incorrect decision, the DWP should offer them the option of being assessed via a different method to their initial assessment before being required to submit a mandatory reconsideration. If after being assessed differently they are still unhappy with their award, they should then submit a mandatory reconsideration.
- 3.24. **Recommendation:** Claimants should only be asked to go through any non-paper-based type of assessment in situations where insufficient

reliable evidence has been provided and/or collected to enable a 'paper-based' decision to be made.

- 3.25. **Recommendation:** People must have the choice of whether they would like a face-to-face, phone or video assessment, even if a paper-based assessment decision is made.
- 3.26. **Recommendation:** People must have the final decision of their type of assessment method. This should be informed by the advice of a medical professional and clear and thorough guidance.
- 3.27. **Recommendation:** Assessors must undertake appropriate training for the method of assessment they are conducting.
- 3.28. **Recommendation:** People must be given the option to have another assessment if they feel the format of original assessment impacted on their initial decision.

Reducing repeat assessments

This section covers the following questions

Q. What more could we do to reduce repeat assessments where someone has a condition that is unlikely to change?

Q. How can we make it easier for people to inform us if their condition or circumstances have changed so that a review of entitlement can be carried out at the right time? (From Chapter 4 – Reviewing Financial Support)

- 3.29. We are pleased that the government has continued to focus on reducing repeat assessments and that this remains a priority area for improvement. The government's stated intention behind repeat assessments is to ensure that people are receiving the right level of financial support. This could be that they don't need as much, or they may be entitled to more.
- 3.30. In principle we welcome this. MS is a progressive, lifelong condition. Someone who is assessed early on in their journey could be entitled to more as their condition progresses over time, and it is important they receive it. However, someone's MS is very unlikely to improve significantly, and an individual's need for support is unlikely to diminish. Therefore a reassessment to identify if someone needs less support is unnecessary, and while a reassessment to identify if someone's needs increase is important, it could be carried out in a very different, and much more appropriate way.

"You should be assessed at the beginning then asked every three years if your circumstances have changed...MS is not going to get better."

3.31. Many people with MS got in touch with us to talk about repeat assessments. There was an overwhelming sense from those we spoke to that they couldn't comprehend why anyone with MS would have to go through a repeat assessment when they knew, and their healthcare professionals knew, they would not get better. UKMSNA told us "continuous insensitive assessments on people with deteriorating conditions or whose health status is not likely to change, is a wasteful use of resources. It has a detrimental effect on the individual's health and wellbeing."

"If they [healthcare professional] said several years ago that I've got MS, they're not going to say all these years later that I haven't."

"Why do we keep reassessing people who are not going to get better?"

"The clue is in the definition of MS – progressive, neurological problem for which there is no cure."

"Once you've been granted PIP there is no need to check if you've made a miraculous recovery."

3.32. There has been progress over the last few years, with the introduction of the Severe Conditions Criteria, and 10 year light-touch review. Unfortunately there is still not much information on what a light-touch review will look like, despite reassurances that the process and guidance would be developed well in advance of the first reviews taking place, and with the involvement of stakeholders.

3.33. Also disappointing is the number of people with MS receiving an ongoing PIP award. Recent DWP data shows that there are currently 55,694 people claiming PIP with MS as their main condition and the vast majority of them have an award period of less than 5 years (78%)⁴³. Repeat assessments for people with progressive MS are unnecessary, inappropriate and are causing needless anxiety and stress for those having to go through them. We would have hoped to have seen recognition of this in these figures. What is shown is that there need to be

⁴³ DWP StatXplore (July 2021)

changes in the criteria and guidance when it comes to deciding who needs a repeat assessment and who doesn't.

- 3.34. The objective of the government should be to eliminate pointless or excessively frequent repeat assessments, which are wasteful of resources and stressful for claimants. For many people with MS, a repeat assessment is often a very distressing experience. People have told us that they feel they have to constantly prove the difficulties they face and that they find this frustrating when they know they aren't going to get any better.

"I was diagnosed 10 years ago. I've twice applied for PIP and been rejected, the second time I won on appeal and was awarded the highest rate. The thought of reassessment terrifies me."

- 3.35. The MS Society recommends that people with progressive, lifelong conditions should be given an ongoing award with the option of a light-touch review every three years for claimants not on the highest award rates. People with MS told us that they should be contacted in a way that suited them and asked if anything has changed.

"Enable us to self-assess with a simple checklist to give an idea if anything has changed enough that might lead to more help."

"It's depressing and dispiriting to fill in forms regularly focusing on what's wrong. Allow us to have a light-touch review to see if we're any worse and might qualify for more."

- 3.36. This would ensure that for those whose condition had worsened, they would have the option of a repeat assessment to see if they may be entitled to more. If their condition changes or deteriorates before the light-touch review, they can request an assessment before their review. As well as an improvement in gathering medical evidence (something which is discussed in more detail in Chapter 4) this approach would require a higher level of trust in people than the government currently has, some would say. People with MS have told us that they feel the DWP are trying to catch them out or that they are liars, and frauds.

"DLA was – you say you have this condition, how can we help you? PIP is predicated on – you say you have this condition, now you need to prove it, and

then you need to prove it again and again and again to prove you are worthy of assistance."

"My condition will never improve, PIP should be for life, unless your condition worsens and you think you could get more. The stress of reassessments and being made to feel like a liar is awful."

- 3.37. However, this change to reduce repeat assessments could mean people's trust in the DWP improves, that they see the DWP in a more positive light, and develop a better relationship with the DWP, something we know the government is keen to achieve.
- 3.38. **Recommendation:** People with progressive, lifelong conditions, such as MS, should be given an ongoing award with the option of a light-touch review every three years for claimants not on the highest award rates.
- 3.39. **Recommendation:** People with progressive, lifelong conditions should be contacted and asked if their circumstances or condition has changed since their last assessment. If the individual says no, they should be taken at their word and no reassessment should be required.

Health Impact Record

- 3.40. The introduction of a Health Impact Record could, in some cases be helpful - see above, but for many could also lead to a reduction in support, not just an increase. It might also become a source of stress for many, as they will feel like they are being constantly assessed. We agree with the DBC, that with very little detail on how it would work in practice, it's impossible to say if it's a good or a bad thing. If it is introduced, checks would need to be in place to ensure that a new assessment took place before support was reduced following the uploading of new evidence. There would need to be information and guidance on what evidence would trigger a new assessment. We also have questions around confidentiality and access.

Severe Disability Group

- 3.41. In this chapter, the Green Paper introduces the testing of a Severe Disability Group (SDG) with the intention that people who fulfil certain criteria could benefit from a simplified process where they will not have to complete a detailed application form or go through an assessment. While there are no specific questions on this, we felt we couldn't let such an important proposal pass without comment.
- 3.42. There is very little detail in the Green Paper about the SDG – how it would work, what the criteria would be etc. However, we have been fortunate enough to be invited to early conversations with the DWP team leading on this work. We do however believe that the process of developing the SDG

and the criteria should be more open and transparent – while we are grateful to be included at the initial stages of development, we would like to see more disabled people and organisations involved at an early stage to help co-produce the details of the SDG and how it will be delivered. Talking to a small number of people with MS, we can already see that this approach makes sense to them.

"There should be no need for a medical assessment if your neurologist has told them the information – it's there, it's fact. Surely that's an easier way."

- 3.43. If the SDG is to follow a similar process as SRTI – which we are led to believe it will – clinicians will have an important role to play. It is important to consider a number of things here. Firstly, managing expectation is important. It will be challenging when someone wants to apply for this group but their clinician disagrees; equally if the clinician applies and the patient isn't added to the group. There is potential here for patients to blame the clinician and create difficult relationships.
- 3.44. Secondly, there needs to be clarity of information and promotion. This reliance on a clinician with specialist knowledge puts additional pressure on them, for example MS Nurses who often support people with their benefit claims. This comes at a time when the health service is already facing strains and challenges. How much extra work is this going to be? And how will this be rolled out? This could lead the way for large numbers of people wanting to be added to this group. Thought needs to be given to the impact that this will have on clinicians.
- 3.45. Having been given sight of the criteria overall our feedback is positive, however, one of the criteria requires the patient to be declared, by a clinician, as never being able to work. The MS Society, and others feel strongly that this criterion must be reviewed to allow the SDG to be open to those who do work. It is unfair to preclude someone from this group when they are working – often against all odds. In addition, this would contravene the purposes of PIP, which can be claimed irrespective of whether someone is in employment or not. There are some people who would benefit from being placed in the SDG for PIP, who are still capable of work – even if only for short periods, or temporarily.
- 3.46. We cautiously welcome the introduction of the SDG and consequent testing – as is often the case, the devil is in the detail and there is currently very little. However, given the focus throughout the Green Paper on cutting costs, getting people in the Support Group into work, and how the number of people placed in the Support Group as higher than initially expected, it can be understood why charities and disabled people would be worried that the SDG will replace the current Support Group, but with fewer numbers of claimants due to the strict criteria. This must not

happen. We agree with the DBC that it is essential that the Support Group and LCWRA in UC in terms of financial support and conditionality should be maintained as part of any new arrangements.

- 3.47. **Recommendation:** The existing Support Group or LCWRA must remain in place with the introduction of the SDG.
- 3.48. **Recommendation:** People who are in work should be eligible for the SDG if they meet the criteria
- 3.49. **Recommendation:** The DWP must consult and engage with disabled people, charities and organisations when drafting and developing the criteria and testing of the SDG.

Improving decision making

This section covers the following questions:

Q. Decisions can be changed after an appeal has been lodged but before a tribunal hearing takes place. How can we improve the way we communicate a new decision in this situation?

Q. What other changes could we make to improve decision making?

- 3.50. We know that many people with MS who have had a decision on their PIP claim disagree with the initial decision. This suggests there is a widespread failure of assessors and Case Managers in reaching decisions that make sense for people with MS, and it is clear problems with evidence collection and the assessment do play a significant part in these inaccurate decisions. The DWP's focus should be on ensuring all disabled people get the right decision first time, so we welcome that the DWP are now using the 'holistic decision making' approach to make the first decision about entitlement following an assessment for ESA, PIP and UC, rather than just at the mandatory reconsideration stage. In our response to Chapter 4, we outline some of the issues with assessments and evidence collection and how they should be addressed to ensure as many disabled people as possible get the right decision first time.
- 3.51. However, it is not just the decisions themselves that are a problem. The way they are communicated to claimants means that many people do not fully understand how a decision has been made. Without this knowledge, many people with MS cannot effectively challenge decisions they believe to be wrong.
- 3.52. Decision letters do not specify what happened at assessments, do not provide information on the informal observations made and do not outline the evidence used to come to the decision. Our previous survey showed that 45% of people with MS who had received a PIP decision said they do not think they were given enough information with the decision letter

to explain how the decision was made. Additionally, of respondents who said they disagreed with their initial decision, only 25% said they received enough information in the decision letter to understand this outcome⁴⁴.

- 3.53. Claimants can request a copy of their assessment report, however we know many people with MS are unaware they can request it, are unclear about how to do this, or are unclear about what the benefit of doing so might be⁴⁵. Without seeing their report it may be more difficult for people to decide if the decision they received is correct, and whether they should challenge a decision.
- 3.54. We know that too many assessment reports are not of a high enough standard. While they are written by employees of the assessment providers, the responsibility for ensuring that assessment reports are of an acceptable standard lies with the DWP. It is imperative that Case Managers at the DWP, and claimants, receive accurate reports that allow for correct decision making.
- 3.55. The DWP should ensure that, as default, all decision letters outline what happened at the assessment and provide information on any informal observations made. They should also give detail on all evidence used to make the decision, including where medical evidence was overruled by the assessor and outline the reasons why this happened. The DWP should also automatically send the assessment report to every claimant along with their decision letter. The DWP should work with disabled people and disability charities to design and put in stricter quality assurance measures to ensure that assessment reports are consistently of good quality. Data related to quality of reports should be available publicly on a regular basis. By following these above recommendations, the DWP can go some way to increasing transparency in the process and giving people with MS more tools to understand the decision they get.
- 3.56. We previously found that one in ten people with MS who disagreed with the decision on their PIP claim were unaware they were able to ask for a mandatory reconsideration and only 42% of people with MS who had received a decision thought they were provided with clear information about the right to ask for a mandatory reconsideration. We also found that 49% of people with MS who disagreed with the decision on their mandatory reconsideration said they did not think they were provided with clear information about the right to appeal and how to go about it⁴⁶. These findings suggest there is a shortage of information relating to the mandatory reconsideration and appeals processes provided to disabled people, including people with MS.

⁴⁴ MS Society (2019) *PIP fails: how the PIP process betrays people with MS*

⁴⁵ Ibid.

⁴⁶ Ibid.

- 3.57. As outlined in our response to Chapter 1, the DWP should ensure benefit decision letters provide clear information on the right to a mandatory reconsideration and appeal. This information should also include advice on how to proceed with a mandatory reconsideration and appeal and where to go for support. The DWP should also ensure clearer information about the appeals process is offered to claimants when providing the outcome of a mandatory reconsideration.
- 3.58. The deadline to request a mandatory reconsideration is within a month of receiving the decision letter. For people with MS this deadline may be too restrictive, especially if going through a relapse at the time. Symptoms such as pain, fatigue and cognitive difficulties can also make it difficult to challenge the decision within this timeframe. The DWP should therefore extend the deadline for mandatory reconsideration to eight weeks, with further extensions considered due to ill health and on a case-by-case basis.
- 3.59. We cautiously welcome the DWP's intention to improve appeal lapsing to ensure that more people can get the correct decision before having to go to appeal. However, we have been very concerned by reports of disabled people, including people with MS, being called by the DWP between their mandatory reconsideration and appeal hearing and pressured into accepting a benefit award lower than what they may be entitled to⁴⁷. The DWP should ensure this never happens. In cases where a new decision does not give the claimant the award they had hoped for, but still gives them more than the previous decision, the DWP can ask if they would like to accept the new offer but should also make it explicitly clear to the claimant they do not have to accept the new offer and can continue with their appeal. The DWP should also work with disabled people, including people with MS, and charities to improve how it communicates new decisions to people.
- 3.60. **Recommendation:** Assessors reports should be send out automatically with decision letters.
- 3.61. **Recommendation:** The decision letter must include details of any informal observations undertaken by the assessor.
- 3.62. **Recommendation:** The DWP should extend the deadline to request a Mandatory Reconsideration to eight weeks, with further extensions considered due to ill health and on a case-by-case basis.
- 3.63. **Recommendation:** The DWP should work with disabled people, and charities to improve how it communicates new decisions to people.

⁴⁷ [DWP accused of offering disabled people 'take it or leave it' benefits](#) – The Guardian

Chapter 4: Re-thinking Future Assessments to Support Better Outcomes

Evidence for making changes to assessments

- 2.1. We cautiously welcome the DWP's objectives for future assessments, particularly the focus on making the assessment process more transparent and consistent, and ensuring that people do not have to repeatedly provide information or attend unnecessary repeat assessments.
- 2.2. However, we are increasingly concerned by references in this section to 'targeting support at 'people who need it most', which echo comments made by the Secretary of State for Work and Pensions at the 2021 Conservative Party conference, and others in the party⁴⁸. This rhetoric implies that the DWP sees some disabled people as undeserving of support from the state and doesn't appear to be restricted to income-replacement benefits such as ESA and UC, but also PIP which is designed to help disabled people with the extra disability-related costs. This is unacceptable. Disabled people have been the target of over 10 years of benefit cuts and austerity. The DWP must ensure that all disabled people are able to get the right amount of support they need to live independently and lead a fulfilling life. Disabled people should be treated fairly by the Government with empathy and dignity, and should never be made to feel as if they are undeserving or a drain on the system.
- 2.3. These comments and the tone of the Green Paper add to our concern that the DWP is planning to reduce the current rates of disability benefits and/or narrow the eligibility criteria for disability benefits leading to fewer disabled people being able to claim them. It is imperative the DWP ensures it does not, under any circumstances, reduce benefit rates or narrow eligibility criteria. In fact, if anything we recommend that the DWP should be looking to increase benefit rates to ensure disabled people are not plunged further into poverty. (You can see more detailed recommendations in Chapter 5). The DWP should also follow our recommendations (detailed in our response to the 'Making changes to the assessment criteria' section) for reforming the PIP and WCA assessment criteria to ensure that more people with MS, and other disabled people, can get the support they need but are currently missing out on. This includes scrapping the 20-metre rule for the highest rate of PIP mobility support. The DWP must ensure that all disabled people, including people with MS, can get the support they need and are entitled to.
- 2.4. As in Chapter 2, there continues to be an overemphasis in this section on how more people in the ESA Support Group can be supported to move

⁴⁸ [Tory DWP chief urges people who 'think they can't work' to try finding a job](#) – The Daily Mirror (online)

into work. Our evidence shows the vast majority of people with MS on ESA are placed into the Support Group and a majority of people with MS in this group are not in a position to move into work due to their condition. People have also told us that they do not want any contact from the DWP.

- 2.5. While there is no explicit mention of introducing conditionality to the Support Group in the Green Paper, we and many disabled people fear that the DWP may be planning to introduce conditionality to this group and the LCWRA group. The use of phrases such as 'make better decisions about what a person must do in return for benefit if required', a continued reference throughout the Green Paper of getting more people from the Support Group into work, and the creation of a Severe Disability Group, are deeply concerning. As mentioned previously, this, in addition to recent comments by the Secretary of State imply that this is the direction of travel.
- 2.6. We strongly oppose any move to apply conditionality and sanctions to the Support Group or LCWRA group. We would also be against tightening the eligibility criteria for the Support Group and LCWRA group. The choice to take up employment support for people in these groups should remain entirely voluntary and no-one in these groups should not be put under any pressure to move towards employment or have any contact with the DWP. As outlined in our response to Chapter 2, there is no clear evidence that conditionality and sanctions help disabled people to get into and remain in work, and can often have other negative impacts on disabled people, such as causing anxiety and stress. As such, we would also like to see the DWP remove conditionality and sanctions from the WRAG and LCW groups.
- 2.7. **Recommendation:** Disabled people should be treated fairly by the Government with empathy and dignity, and should never be made to feel as if they are undeserving or a drain on the system.
- 2.8. **Recommendation:** Conditionality and sanctions must not apply to the Support Group or LCWRA group. These should also be removed from the WRAG and LCW groups.

Separating the assessments for financial and employment support

- 2.9. The suggestion of separating out assessments for financial and employment support is not a new one. It was also included in the 2016 Green Paper 'Improving Lives'. It wasn't clear how it would work in practice then, and it's not much clearer now. We understand the intention behind splitting these two elements, but we still don't feel that the issues raised by us and other charities in 2016 have been resolved in this Green Paper. While we think there needs to be fundamental reform of the WCA, we are concerned what splitting these two elements will mean for people with MS. There needs to be more consultation and engagement with

disabled people and disabled people's organisations before any proposal to separate financial and employment support is taken forward.

Making changes to the assessment criteria

This section covers the following questions:

Q. Is there anything about the current PIP activities and descriptors that should be changed? If yes, what changes should be considered?

Q. Is there anything about the current WCA activities and descriptors that should be changed? If yes, what changes should be considered?

PIP activities and descriptors

- 2.10. In recent years, one of the changes to the disability benefits system that has affected people with MS the most, has been the introduction of the 20-metre rule to assess mobility which came into force when DLA was replaced by PIP. This has meant that people who are able to reliably walk even the smallest distance over 20-metres can no longer receive the highest rates. The introduction of this rule has had an overwhelmingly negative impact on people with MS. For example, many people with MS have lost out on access to the Motability scheme which has led to them becoming more isolated from family and friends, as well as hampering their ability to work. And for those who do not own a car, losing out on the higher rate of mobility payment has negatively affected their ability to pay for taxis when they cannot use public transport. Losing this support can also affect people's ability to be able to manage their MS, as they are unable to get to medical appointments or to other treatments and therapies that help manage symptoms⁴⁹.
- 2.11. We know a high proportion of those who have experienced a reduction in support have progressive forms of MS. For this group, it is expected that symptoms will worsen over time, meaning that a reduction in level of support is excluding those with higher need from appropriate financial support to help them cope with often debilitating symptoms. While the stated purpose of PIP was to support those most in need, it seems that it fails to do so for too many people with MS.
- 2.12. The 20-metre rule uses an arbitrary and rigid measure that is unable to consistently or reliably indicate what the mobility needs of people with MS are. In too many cases it fails to consider and capture fluctuating and hidden symptoms, particularly pain and fatigue.
- 2.13. The PIP assessment guide requires assessors to consider fluctuation of symptoms in relation to the descriptors they use during the assessment. Healthcare professionals carrying out the assessment should consider

⁴⁹ MS Society (2015) *MS Enough: Make Welfare Make Sense*

whether the ability of a claimant to carry out activities is impacted by their condition at least 50% of the days. However, since PIP was introduced, we have heard from people with MS of repeated failures by assessors to consider fluctuation. Many people with MS have told us of feeling like they were assessed on the basis of what they could do on their 'good' days and their 'bad' days were not taken into account. For example, many people with MS may be able to walk to their local corner shop one day, and the next they will not even be able to walk one metre. This is too often not taken into account by assessors.

- 2.14. Assessors must also take into account if a claimant can do an activity reliably. That means looking at whether the claimant can complete an activity safely, to an acceptable standard, repeatedly (as often as it is reasonably required) and in a reasonable time period. However, we know that too often assessors do not apply the reliability criteria when it comes to the 20-metre rule. Often this criteria is assessed by informal observation. For example, by watching a person with MS walk once from a car park to the assessment centre, the assessor assumes that individual can walk 20m. There is little consideration of how slowly they may be going, the hidden symptoms walking may be causing such as pain and fatigue, and whether the person can walk this distance again without having to rest, sometimes for prolonged periods.

"Not all our disabilities are obvious and people cope in different ways. For example: through MS I lost the sight in my left eye, I suffer severe fatigue and frequent bouts of brain fog and falling. To the observer I appear to manage fine - but I don't, it takes me days to recover from a simple trip out. I know I am not the only one."

- 2.15. Current guidance allows assessors to use informal observations and does not explicitly need them to be supported by other evidence. By using informal observations to make assessments of people's mobility, assessors can ignore the reliability guidance entirely, ignoring the complexity of MS as a condition, its fluctuating nature, and the hidden symptoms that walking can cause.
- 2.16. The issues with the 20-metre rule, as outlined above, are effectively the same as those with the daily living descriptors. This includes the descriptors being too rigid and arbitrary to properly assess people's needs and assessors making informal observations to assess whether someone can perform an activity reliably, repeatedly and in a timely manner. Too often, assessors also do not take account of people's hidden symptoms and the fluctuating nature of MS.
- 2.17. For example, one person with MS told us of scoring 0 points on the 'Preparing food' activity because they said they could prepare a simple

meal unaided. But the assessor did not take into account that they would only be able to do this on a 'good' day, or that it was very tiring to do and took a very long time. They also didn't consider that the person felt like they were putting themselves in danger as they thought they may drop sharp utensils or cause a fire.

- 2.18. The most important positive change to the PIP activities and descriptors for people with MS would be to scrap the 20-metre rule. The DWP should instead carry out a review and design exercise with disabled people, including people with MS, disability charities and healthcare professionals to develop an agreed appropriate alternative. In the meantime, the 50-metre threshold should be reinstated.
- 2.19. We would like to see the Government bring forward legislation to ensure that informal observations no longer play any role in PIP assessments. Failing this, it should be ensured that assessors explain at the beginning of an assessment that claimants are subject to informal observations which may be included in the report to decision makers. Informal observations should only be included in assessment reports where they can be backed up by evidence. Case Managers should return reports that contain unsubstantiated informal observations. Guidance should be changed to say that the reliability criteria must be applied to informal observations, and training and quality assurance should enforce this.
- 2.20. The DWP should work closely with disabled people, charities and health professionals to review and change the PIP assessment criteria to ensure they more effectively consider the fluctuating nature of MS and hidden symptoms including pain, fatigue and cognitive symptoms. The DWP should also ensure that the reliably, repeatedly, safely criteria and their definitions are embedded within the wording of each descriptor.
- 2.21. While clearly assistive technology helps people with MS move around and perform daily living activities, we do not believe that they make the level of required support lower. On the contrary, the higher level of support is required in order to purchase and maintain assistive technology, and the need to use assistive technology also points to a higher level of expenses for mobility and daily living. It is illogical to currently deny support to people with MS who use assistive technology to make their life easier. It is even more unthinkable that the DWP may be considering cutting support further for people who use assistive technology, as implied by the following phrase in the Green Paper: 'Since the assessment criteria were introduced, some of the activities referred to may have become less of a barrier to independent living and employment. For example, new assistive technology has become available.'
- 2.22. Assistive technology might bring a higher level of independence, but at the same time they also point to a high level of restriction on mobility and

ability to perform the daily living activities, which calls for a higher level of financial support. The 'aided' definition should be completely removed from the criteria for the PIP assessment, in recognition that requiring assistive technology suggests a significant restriction and impairment.

- 2.23. Finally, it is clear that one of the main reasons assessors do not adequately take into account hidden symptoms, such as pain and fatigue and the fluctuating nature of MS is because too often they have no knowledge or expertise in MS. As outlined in our response to the section 'The role of assessors in the process to decide financial support', the DWP should ensure that people with MS are only assessed by assessors who have some professional experience of neurological conditions and have received training developed in conjunction with relevant charities.
- 2.24. **Recommendation:** The Government should scrap the 20metre rule. A review and design exercise should come up with an appropriate alternative, and in the meantime, the 50-metre threshold should be reinstated.
- 2.25. **Recommendation:** Informal observations should no longer play a role in PIP assessments.
- 2.26. **Recommendation:** The DWP should change the PIP assessment criteria to ensure they more effectively consider the fluctuating nature of MS and hidden symptoms.
- 2.27. **Recommendation:** The DWP should also ensure that the reliably, repeatedly, safely criteria and their definitions are embedded within the wording of each descriptor.
- 2.28. **Recommendation:** The 'aided' definition should be removed from the criteria for the PIP assessment.
- 2.29. **Recommendation:** People with MS should be assessed by assessors who have some professional experience of neurological conditions.

WCA activities and descriptors

- 2.30. We are very concerned that the Green Paper suggests barriers to work may have reduced as a result of the increase in home and flexible working during the coronavirus pandemic. When the pandemic hit, millions of people were forced to quickly adapt to a new style of working without any choice in the matter. It is true that some people with MS have benefitted from being able to work from home and more flexibly. For example, we have heard from some people that it has allowed them to better manage their symptoms. However, many people with MS have also struggled immensely during the pandemic as they have faced increased barriers to moving into and staying in fulfilling work. This includes having to work from cramped accommodation with unsuitable equipment as well

as receiving no or inadequate support from their employers to help them adapt to new ways of working. The option to work from home should always be a choice. People with MS and other disabled people should not be assessed on the basis that remote working has become more accepted.

- 2.31. The pandemic has had far reaching negative impacts on society. There is clear evidence that shows disabled people, including people with MS, have been disproportionately negatively affected, including by facing higher energy bills, higher food costs and delivery charges, becoming more isolated from friends and family and struggling to access care and treatment. It is imperative the pandemic should not be seen as an opportunity to narrow eligibility criteria for ESA or reduce the level of support provided by this benefit.
- 2.32. The main issues with the WCA activities and descriptors are very similar to those outlined in the section above on PIP assessments. Too often the WCA results in people with MS missing out on the right level of support when they are unable to work. This includes:
- The fluctuating nature of MS is often not taken into account, including how this affects people's ability to work. People are assessed on the basis of what they can do on their 'good' days rather than their 'bad' days.
 - The hidden symptoms of MS, such as pain and fatigue, and how the impact they have on people's ability to work is often overlooked.
 - Assessors fail to consider whether people can do activities reliably, repeatedly and in a timely manner and often people's ability to do these activities is assessed by inappropriate informal observations.
- 2.33. As above, the DWP should work closely with disabled people, charities and health professionals to review and change the WCA assessment criteria. This would ensure they more effectively consider the fluctuating nature of MS and hidden symptoms including pain, fatigue and cognitive symptoms. WCAs for people with MS should only be carried out by an assessors who has some professional experience of neurological conditions. They must also have received training developed in conjunction with relevant charities.
- 2.34. The DWP should ensure that the reliably, repeatedly, safely criteria and their definitions are embedded within the wording of each descriptor and should ensure that informal observations no longer play any role in the WCA. In the meantime, it should be ensured that assessors explain at the beginning of assessments that claimants are subject to informal observations which may be included in the report to decision makers. Informal observations should only be included in assessment reports where they can be backed up by evidence. Case Managers should return reports that contain unsubstantiated informal observations. Guidance should be changed to say that the reliability criteria must be applied to

informal observations, and training and quality assurance should enforce this.

- 2.35. **Recommendation:** Changes to the world of work since the coronavirus pandemic should not be seen as an opportunity to narrow eligibility criteria for ESA or reduce the level of support provided by this benefit.
- 2.36. **Recommendation:** The DWP should work with disabled people and charities to review and change the WCA assessment criteria.
- 2.37. **Recommendation:** People with MS should only be assessed by assessors who have some professional experience of neurological conditions.
- 2.38. **Recommendation:** The reliably, repeatedly, safely criteria and their definitions should be embedded within the wording of each descriptor.
- 2.39. **Recommendation:** Informal observations no longer play any role in the WCA.

Supporting evidence for assessments

This section covers the following questions:

Q. Should we seek evidence from other people, such as other health professionals or support organisations?

Q. What type of evidence would be most useful for making decisions following a WCA or PIP assessment and should there be a standard way to collect it?

Q. How could we make sure the evidence we collect before a WCA or PIP assessment directly relates to a person's ability to do certain things?

- 2.40. Effective evidence collection processes - both for the assessor and claimant - are crucial for ensuring that as many disabled people as possible, including people with MS, get the right award decision first time. As outlined in our response to Chapter 4 we recommend that assessors should always make every effort to gather reliable evidence as early as possible in the process, including from the claimant, people who know them and their medical professionals. This will ensure that as many people as possible get the right decision first time, ideally through a 'paper-based' assessment. However, many people with MS have told us that evidence collection processes are well below an acceptable standard and lead to too many people failing to get the right support first time. This leads to too many people having to go through unnecessary face-to-face, phone or video assessments, mandatory reconsiderations and appeals.

- 2.41. Many people with MS have told us they found it difficult to gather evidence for their claim that demonstrated their support needs and the impact that MS has on their life. People with MS are not always aware that they can provide evidence, and there is lack of clarity around who they can ask for evidence from. Nearly 1 in 10 (9%) people with MS told us that they did not know there was an option to provide evidence with their PIP form and 35% said they were unclear on who could provide evidence. 28% said they did not know they were able to send evidence from family, friends and carers with their claim⁵⁰.
- 2.42. This lack of awareness of the ability to provide evidence with a claim, as well as who can provide it, shows a clear failure in guidance for claimants and points to an urgent need for simplification and clarification of the process. This will allow people with MS to submit good quality evidence from various sources when they wish to do so. The DWP should provide clear guidance online, by phone and in person to all claimants on the type of evidence they should provide, including evidence from informal sources such as friends, family and carers.
- 2.43. 59% of people with MS who applied for PIP told us it was difficult to return the form on time because the four-week deadline did not provide them with enough time to obtain evidence from healthcare professional(s)⁵¹. This is likely due to the fact that health services are often stretched and struggle to offer non-clinical support to patients, making it difficult to find time to provide evidence. 26% of MS nurses who responded to our survey said they sometimes provide evidence to people with MS and 5% said they never do. This means that some people with MS will not be able to obtain evidence from their MS nurses to support their application. Of nurses who said that they sometimes or never provide evidence for patients claiming PIP, 37% said this is because they do not have time to do so and 43% said this is because they are unable to meet the deadline given to patients⁵².
- 2.44. Some people with MS have also told us that it was difficult to gather evidence for their PIP application because their GP, neurologist and/or MS nurse wanted them to pay for evidence⁵³. The cost of paying for multiple pieces of evidence can place a huge financial strain on disabled people who are in the process of applying for the vital financial support disability benefits provide. Having the ability to pay should not determine who can and cannot submit evidence to support their claim. The DWP should pay for charges made by healthcare professionals for providing evidence to claimants.

⁵⁰ MS Society (2019) *PIP Fails: How the PIP process betrays people with MS*

⁵¹ Ibid.

⁵² Ibid.

⁵³ Ibid.

- 2.45. Providing evidence can put a strain on healthcare professionals' already precious time. It is important it is used effectively to provide evidence that is of high quality and that is relevant to the application in question. We asked nurses how confident they were in their understanding of what evidence is required to support a PIP application. Regrettably, 25% said they were not very confident, and that they are unsure of what to include in their report even though they know how their patient's condition affects them. When reporting difficulty in obtaining medical evidence to support their PIP claim, a quarter of people with MS told us this was because their healthcare professional(s) did not understand what evidence they needed to provide. While that does not necessarily mean healthcare professionals did not provide evidence, it does however suggest that whatever evidence was provided may not have been useful for the application in question⁵⁴.
- 2.46. These findings suggest a large proportion of people with MS have difficulty obtaining good quality evidence which is relevant to their application. This is concerning as it can mean they are unable to access the right level of financial support for their needs. The DWP should therefore provide clear guidance to healthcare professionals, including MS specialists and neurologists, on what evidence they should provide to support a claim. Access to support with filling in reports should also be provided to healthcare professionals who need it.
- 2.47. People MS have repeatedly told us they did not think assessors requested evidence from the healthcare professionals whose details they provided in their application⁵⁵. This is despite guidance stating that in cases of progressive or fluctuating conditions, like MS, this should always be done. We have also heard from assessment providers that when evidence is requested from healthcare professionals, return rates are low⁵⁶. Given what we have been told by nurses (outlined above), it is likely this is linked to healthcare professionals not having enough time or lacking understanding of what should be provided. Return rates from specialists are even lower than they are for GPs, so it is essential that DWP and assessment providers work to significantly increase the return rate⁵⁷.
- 2.48. The DWP should strengthen PIP assessment guidance on evidence collection to ensure that evidence is always requested by assessors when assessing claims by people with MS. Case Managers should return reports that do not comply with the guidance. Key performance indicators (KPIs) should also be introduced to assessment provider contracts, to ensure that evidence is always sought for claims by people with MS. Assessment providers' performance against the KPIs should be published regularly and if assessors regularly fail to meet these KPIs, the assessment provider

⁵⁴ Ibid.

⁵⁵ Ibid.

⁵⁶ Ibid.

⁵⁷ Ibid.

should be sanctioned. If it fails to improve it should lose its contract for delivering assessments.

- 2.49. The DWP should also work closely with assessment providers and healthcare professionals, including specialists, to achieve a significant increase in evidence return rates. This should include the DWP and assessment providers changing the way they communicate with healthcare professionals. Where required, healthcare professionals should be given more time to provide evidence both to claimants and assessors. The DWP should also work with healthcare bodies on ways to streamline evidence collection mechanisms.
- 2.50. **Recommendation:** The DWP should provide clear guidance to all claimants on the type of evidence they should provide, including evidence from informal sources.
- 2.51. **Recommendation:** The DWP should provide guidance to healthcare professionals, including MS specialists and neurologists, on what evidence they should provide to support a claim. Access to support with filling in reports should also be provided to those who need it.
- 2.52. **Recommendation:** The DWP should pay for charges made by healthcare professionals for providing evidence to claimants.
- 2.53. **Recommendation:** The DWP should strengthen assessment guidance on evidence collection for claimants, and for people providing supporting evidence, and provide extra support where needed.
- 2.54. **Recommendation:** Assessors should always request evidence when assessing claims by people with MS.

The role of assessors in the process to decide financial support

This section covers the following questions:

Q. How could we improve assessments or the specialist support available to assessors and decision makers to better understand the impact of a person's condition on their ability to work or live independently?

- 2.55. 'Fraud', 'liar', 'worthless', 'useless' and 'small'. These are just a few examples of the words used by large numbers of people with MS when asked to describe how they were made to feel by their assessor and the assessment process in our Green Paper survey. Many people with MS told us they were made to feel like they were lying about their condition by the way their assessor spoke to them and the types of questions they were asked. Some told us they felt the line of questioning used by their assessor was akin to a 'police interrogation' or 'inquisition' and many said

it felt like their assessor was trying to catch them out and spot inconsistencies in what they were telling them. Too often, people with MS have been made to feel like they are 'useless', 'worthless' and 'small' because their assessor did not treat them with empathy, dignity and respect. It is no surprise that disabled people's trust in the disability benefits system is low when they are too often made to feel like this in their interactions with the DWP and their assessors.

"They made me feel like I was scum and I was lieing (sic). They had all my proof and letters from all the NHS staff. I was reduced to tears. I never asked to get this awful disease."

- 2.56. This feedback from people with MS is incredibly concerning and suggests that the private companies contracted by the DWP to deliver assessments are falling far short of an acceptable standard. The DWP should ensure it acts now to drastically improve how assessments are carried out.
- 2.57. The DWP should work closely with disabled people, including people with MS, and disability charities to overhaul its training for assessors. We would recommend the training should make clear to assessors to always follow these key guiding principles while carrying out assessments:
- All claimants should be treated with empathy, dignity and respect by assessors before, during and after their assessment.
 - Assessors must never assume claimants are lying about their condition and how it affects them, and should never try to catch them out. What a claimant tells an assessor should be taken at face value, although of course an assessor can refer to medical evidence too.
 - Assessors must always approach the assessment on the premise that the claimant knows best about how their condition affects them and that what they are telling the assessor is a true, factual account of this.
- 2.58. The DWP should introduce KPIs to assessment provider contracts to ensure that assessors follow these principles and the training designed by disabled people and charities more broadly. Assessment providers' performance against the KPIs should be published regularly. If assessors regularly fail to meet these KPIs, the assessment provider should be sanctioned and if it fails to improve it should lose its contract for delivering assessments. The DWP should also consider bringing the delivery of assessments back in-house as the feedback from people with MS we have shared in this section shows the private providers currently delivering them have fallen far short of an acceptable standard.
- 2.59. Most people with MS told us their assessor did not have a good enough understanding of their condition. For example, nearly half (49%) of people with MS who had a WCA disagreed that the assessor understood their

MS⁵⁸. Without a good understanding of MS, assessors are unable to ask the right questions to help them understand the fluctuating nature of the condition, or how hidden symptoms affect the individual. The DWP should ensure that people with MS are only assessed by assessors who have some professional experience of neurological conditions and have received training developed in conjunction with relevant charities. This should be the case regardless of the assessment type the person chooses to go through.

2.60. People with MS have repeatedly told us they did not think their assessment report reflected what they had told their assessor during their assessment and did not give an accurate depiction of how their MS affects them. We previously asked people with MS who saw the full report of their PIP assessment whether they thought it gave an accurate reflection of how their MS affects them. 61% answered 'no' and 25% said it did, to some extent, meaning the report still had some inaccuracies or omissions. Only 12% said the report definitely gave an accurate reflection of how their MS affects them. The main reasons people gave as to why the report was not an entirely accurate reflection were:

- It did not take into account the effects of their fatigue (74%)
- It did not reflect the way in which their MS fluctuates (73%)
- It did not take into account the effect of their cognitive difficulties (60%)
- It did not take into account the effects of their pain (57%)⁵⁹

2.61. These responses demonstrate that fluctuation and hidden symptoms are not accurately reflected in assessment reports. The DWP should therefore carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.

2.62. The following responses show that the reliability criteria was also often not adequately considered in assessment reports:

- It did not reflect whether it was safe for them to do what they were observed doing in all circumstances (42%)
- It did not reflect whether they could do it again (41%)
- It did not take into account how long it took them to do it (35%)
- It did not reflect how well they did it (26%)⁶⁰

2.63. We also found that 46% of people with MS who had had a WCA for ESA disagreed that their assessment took into account whether they could do activities reliably⁶¹.

⁵⁸ [MS Society position policy paper – Statutory employment support](#) (UK-wide) - MS Society

⁵⁹ MS Society (2019) *PIP Fails: How the PIP process betrays people with MS*

⁶⁰ Ibid.

⁶¹ [MS Society position policy paper – Statutory employment support](#) (UK-wide) - MS Society

- 2.64. Although the reliability criteria is meant to apply to all activities, these responses show that the application of the criteria is inconsistent, and this leads to too many inaccurate decisions. Assessors' reports must consider the reliability criteria for each descriptor, proactively setting out evidence for why they consider that each activity can be carried out safely, to an acceptable standard, repeatedly and in a reasonable time. Case Managers should return reports that do not comply with this to the assessment provider, and no decision should be taken without fully considering the reliability criteria.
- 2.65. Many people with MS have told us they felt their assessor relied far more on informal observations in their assessment report than their medical evidence and what they had told the assessor during the assessment. We believe far more weight should be given to what the claimant tells the assessor and to supporting evidence provided by those who know the individual, than it is to informal observations. This should be the case across all types of assessments. The DWP should follow our recommendations regarding informal observations in our response to the section 'Making changes to the assessment criteria'.
- 2.66. **Recommendation:** The DWP should work closely with disabled people, including people with MS, and disability charities to overhaul its training for assessors. The DWP should introduce KPIs to assessment provider contracts to ensure that assessors follow this training and the principles outlined above.
- 2.67. **Recommendation:** The DWP should ensure that people with MS are only assessed by assessors who have some professional experience of neurological conditions and have received training developed in conjunction with relevant charities.
- 2.68. **Recommendation:** The DWP should carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.
- 2.69. **Recommendation:** Assessors' reports must consider the reliability criteria for each descriptor, proactively setting out evidence for why they consider that each activity can be carried out safely, to an acceptable standard, repeatedly and in a reasonable time. Case Managers should return reports that do not comply with this to the assessment provider, and no decision should be taken without fully considering the reliability criteria.

Reviewing financial support

- 2.70. Please see Chapter 4 under 'Reducing Repeat Assessments' for our response to the question 'How can we make it easier for people to inform

us if their condition or circumstances have changed so that a review of entitlement can be carried out at the right time?’

Testing an employment and health discussion

This section covers the following questions:

Q. What could be included in a discussion to develop a more personalised employment and health support plan?

Q. What skills and expertise should the person undertaking an employment and health discussion have?

- 4.71. Included in this section of the Green Paper (p53) the line “work may also be part of the independent living objectives of many people who claim PIP, so this support could be offered to them.” This gives us cause for alarm. PIP can be claimed by people in or out of work and is to cover the extra costs of living with a disability or long-term health condition. We are worried that the idea of PIP and work has appeared in the Green Paper more than once. We would oppose any introduction of an employability element to PIP.
- 4.72. There is some confusion around the proposal to test an employment and health discussion. When we explore the case studies provided in the Green Paper as an example of what could happen, we are surprised that this is something that needs to be tested. As far as we’re aware, these referrals from Work Coaches should already be happening and these should just be examples of best practice. Is this not the role of a Work Coach already – to ensure that the disabled person they are supporting gets the right support and is signposted to people who can provide it?
- 4.73. If we return to previous chapters of the Green Paper, we share views on cross-departmental, local, holistic health and employment support. We believe that proposals for an employment and health discussion should take the shape of those already recommended. This includes someone who understands the health condition of the person they are supporting, and their needs when it comes to employment. They should be the single point of contact and available not just at the beginning of someone’s claim, but throughout.
- 4.74. However, this emphasis on employment and health, once again demonstrates the Government’s narrow fixation on getting disabled people into work rather than focusing on the support people need to live independent and fulfilling lives, whether they can work or not. This in turn reaffirms our concerns that the Government want to narrow eligibility to the Support Group/LCWRA.

Chapter 5: Exploring Ways to Improve the Design of the Benefits System

Previous changes to benefits & why further change is needed

- 5.1. Since 2008 there has been a whole host of changes to disability benefits. Unfortunately, the culmination of these changes has had a devastating impact on disabled people, who have seen their benefits reduce by around £1,200 on average each year, compared to a reduction of around £300 for non-disabled people⁶².
- 5.2. According to research carried out by the DBC “disabled people have lost out heavily because of the changes made to the social security system since 2010. Regarding social security cuts, the individual changes with the largest negative impacts on people with disabilities are: the limits on the uprating of benefits; the benefit freeze; the replacement of DLA with PIP; and the rollout of UC⁶³.”
- 5.3. It’s little wonder then, that disabled people are anxious about the proposals in the Green Paper. History has taught them that talk of cost-cutting and getting people into work doesn’t often end well for disabled people when it comes to benefits. “Every change in the last 10 years has led disabled people further from financial security⁶⁴” We agree that further change is needed – the welfare system must be reformed so it provides greater support to disabled people so they can be free from poverty, provided with a real financial safety net that enables and empowers, and live truly independent lives.
- 5.4. To improve the current financial situation of disability benefit claimants, there are a number of things the Government could do:
 - Reintroduce the WRAG/LCW component – removed to incentivise people to work, there is no evidence to suggest this has had the desired effect
 - Introduce a disability element/Self-Care element to UC to replace the disability premiums that have been cut from the system
 - Remove the benefit cap for everyone who receives a disability-related benefit
 - Increase the Work Allowance and reduce the taper rate for disabled people
 - Remove the two-child limit

⁶² DBC (2019) *Has Welfare Become Unfair? The impact of welfare changes on disabled people* p3

⁶³ Ibid.

⁶⁴ Ibid.

- Re-instating the £20 a week uplift to UC, and extending it to legacy benefits as a stop-gap before fully reviewing the adequacy of social security
- 5.5. Above all the Government should ensure that disability benefits lift people out of poverty and cover the cost of living as well as the extra disability-related costs people face. (People with MS have average extra costs of around £200 a month⁶⁵.)
- 5.6. We are aware that the Department commissioned research on the subject 'The Uses of Health and Disability Benefits' and has been in possession of the report since before the Green Paper was published. However, it is not referred to or included in the evidence pack. This report is of direct relevance to this consultation and it's important the Department share its findings publically.
- 5.7. Independent living is not about surviving, it's not a matter of subsistence and the rates of disability benefits must reflect that. Policy on social security rates should be developed and informed by research on minimum income standards, and assessment of adequacy of disability benefits.
- 5.8. For a Green Paper titled 'Shaping future support: Health and Disability', that covers over 65 pages, to not once talk about the level of benefits needed to meet the needs and aspirations of disabled people is astonishing, and incredibly disappointing.

Should the DWP simplify the benefits system?

This section covers the following questions:

Q. How could we simplify the system for people applying for multiple health and disability benefits?

- 5.9. We believe that the Government needs to make drastic and far reaching changes to the disability benefits system and the way it provides services to ensure that all disabled people, including people with MS, can get the support they need while being treated fairly. Simplifying processes plays a role in this, but it is far from the only answer. The current system has left far too many disabled people without the support they need. Many have had profoundly negative and stressful experiences while navigating the system, including being made to feel that they are liars and frauds and that they have to prove to the 'powers that be' that they are deserving of support.
- 5.10. It is clear the DWP urgently needs a major culture change in the way it provides support and services to disabled people. DWP services should be far more transparent, accessible, easy to use and responsive to people's needs. All disabled people should be able to get the support they

⁶⁵ Scope (2019) *The Disability Price Tag*

need to live independent and fulfilled lives without being made to feel like they are a drain on the system. And everyone should be treated with empathy, dignity and respect while using DWP services. Unfortunately, the proposals suggested by the DWP in this section fall far short of what is required.

- 5.11. Firstly, we do not think it is productive to look at Switzerland, a society which is very different to the UK, and consider copying how its disability benefits system is structured. Switzerland is a small, very high-wage country, with a significantly lower poverty rate, lower unemployment rate and lower levels of tax than the UK. We similarly do not think it is productive to the other three countries referenced in this chapter, societies which are also very different to the UK. In the next section we draw particular attention to our concerns about looking to the examples of Australia and New Zealand.
- 5.12. Switzerland provides less financial support to people to help people with their extra-costs. In the UK, the support provided to disabled people to help with their extra costs is currently inadequate, so for the Government to be considering cutting this further is extremely worrying.
- 5.13. The DWP uses the Swiss approach as an example which places more emphasis on helping people to move back into work, including by making workplace adjustments and providing training. However, if the DWP wants to realise this approach, it would need to place far more onus on the changes employers need to make to help disabled people move into and stay in well paid, fair and rewarding work. Given that the emphasis in this Green Paper is focused on disabled people themselves, the shift would have to be substantial. It would require the Department moving to a social model of disability, and there is little sign of this currently.
- 5.14. We are strongly opposed to any proposals which combine PIP and ESA into a single benefit. This proposed change could lead to PIP becoming means-tested, which is extremely concerning and has led to anxiety amongst disabled people. It would mean that someone could lose all their financial support subject to one inaccurate assessment. The DWP should ensure that, in the future, ESA and PIP are maintained as separate benefits with separate assessments. It is imperative that PIP is kept as a non-means-tested benefit, and that no employability element is introduced to PIP.
- 5.15. Many of the reforms that need to take place to improve the disability benefits system are beyond the scope of what this paper can cover. Below we outline some steps which the DWP can take to improve the system for people with MS who are applying for multiple disability benefits. Many of these have been covered elsewhere in this paper.

- 5.16. Firstly, the DWP needs to go further with the changes that are currently underway to redesign forms. It is imperative that changes are made to forms so they can allow people with progressive and fluctuating conditions to fully explain how their condition affects them. The deadline to submit PIP and ESA application forms should be extended to 8 weeks and clear information should be provided with forms telling people how they can request an extension.
- 5.17. There needs to be drastic improvements made to signposting and support provided by the DWP to help people access the benefits and support they need. Too often people are missing out on support because they are not aware it exists in the first place. Changes should include providing claimants with information outlining other benefits and support they may be eligible for, including giving advice on how to apply. This should be done via a range of channels including a 'one-stop shop' on GOV.UK and by allocating a single point of contact who can advise every disabled person who applies for benefits on what else they may be entitled to.
- 5.18. Far too many people with MS are still required to go through face-to-face, phone and video assessments when there is more than enough evidence available for a correct decision to be made on their claim before this. These assessments are both completely unnecessary and often cause people a great deal of stress. They also often lead to people not getting the support they are entitled to due to poor practice by assessors. The DWP needs to ensure that claimants are only asked to go through a non-paper-based type of assessment in situations where insufficient evidence has been provided and/or collected to enable a 'paper-based' decision to be made.
- 5.19. After applying for ESA and UC, far too many people with MS are still placed into the WRAG and LCW groups. Not only is there no evidence that conditionality improves employment outcomes, but being placed into these groups also means that many people receive less support than they need and experience stress and anxiety as a result of conditionality and sanctions. The DWP should completely remove conditionality from the WRAG and LCW groups and should ensure that no conditionality is applied to the Support Group and LCWRA group.
- 5.20. Rather than the current approach of sanctions and forcing people to jump through unreasonable hoops to get their benefits, the DWP should provide disabled people with holistic employment support which is catered to their needs, and voluntary. The current system places far too much emphasis on the changes disabled people need to make to find and stay in work. Instead, the Government need to recognise that barriers to work extend beyond someone's disability or health condition. Employers should be required to play a far greater role in reducing the disability employment gap and helping more disabled people to move into and stay in fair, well

paid and rewarding work. As part of this, the Government needs to bring forward stronger regulation and enforcement of the reasonable adjustments employers need to make.

- 5.21. The DWP needs to consult with disabled people, including people with MS, and relevant charities to overhaul the PIP and WCA descriptors. The 20-metre rule has had a devastating impact on people with MS, leading to thousands losing their higher rate of mobility support which is a lifeline to an independent life for so many. The Government needs to immediately scrap the 20-metre rule and take steps to develop an appropriate alternative. The 50-metre threshold should be reinstated in the meantime.
- 5.22. The DWP also needs to change the PIP and WCA assessment criteria to ensure they more effectively consider the fluctuating nature of MS and hidden symptoms. And it should embed the reliably, repeatedly, safely criteria and their definitions within the wording of each PIP and WCA descriptor. It is also crucial that the DWP ensures that informal observations no longer play any role in the PIP assessment or WCA.
- 5.23. People with MS have repeatedly raised concerns with us that they have been assessed by people who have no knowledge of MS, let alone any expertise in MS or any neurological conditions. This has resulted in far too many people with MS being poorly assessed and missing out on the support they need and are entitled to. We do not accept the DWP's excuse that people are not assessed by experts because it is logistically difficult. If the Government wanted to, it could provide adequate funding and take the necessary steps to ensure that everyone with MS can be assessed by someone who has some professional experience of neurological conditions and has received training developed with relevant charities. The DWP should ensure it makes this happen as soon as possible.
- 5.24. The Government needs to change evidence collection processes to ensure that all disabled people are able to easily provide relevant evidence for their claim and evidence is actually collected by assessors. The DWP should pay for charges made by healthcare professionals for providing evidence to claimants and guidance should be provided to all claimants and healthcare professionals on the type of evidence they should provide. The DWP should ensure that evidence is always requested by assessors when assessing claims by people with MS and should work with assessment providers and healthcare professionals to achieve a significant increase in evidence return rates.
- 5.25. Finally, we have repeatedly heard shocking stories of people with MS being treated like liars and frauds by DWP staff and being made to feel as if they are worthless and small. This is completely unacceptable and the DWP must ensure that staff working for, and on behalf of, the Department treat all disabled people with empathy, dignity and respect at

all times. Disabled people should be believed and not assumed to be lying about their condition. It should always be accepted that disabled people are the experts in their condition and how it affects them. These standards should be strictly enforced and embedded across all DWP services. Any assessment provider that fails to meet them should lose their contract and appropriate action should be taken against individual staff who fail to meet them.

- 5.26. **Recommendation:** ESA and PIP should be maintained as separate benefits with separate assessments. PIP should be kept as a non-means-tested benefit, and no employability element is introduced to it.
- 5.27. **Recommendation:** The deadline to submit PIP and ESA application forms should be extended to 8 weeks and clear information should be provided with forms telling people how they can request an extension.
- 5.28. **Recommendation:** All claimants should be provided with information outlining other benefits and support they may be eligible for, including advice on how to apply.
- 5.29. **Recommendation:** Claimants should only go through a non-paper-based type of assessment in situations where insufficient evidence has been provided and/or collected to enable a 'paper-based' decision to be made.
- 5.30. **Recommendation:** The DWP should completely remove conditionality from the WRAG and LCW groups and should ensure that no conditionality is applied to the Support Group and LCWRA group.
- 5.31. **Recommendation:** The Government must scrap the 20-metre rule and take steps to develop an appropriate alternative. The 50-metre threshold should be reinstated in the meantime.
- 5.32. **Recommendation:** The DWP must change the PIP and WCA assessment criteria to ensure they more effectively consider the fluctuating nature of MS and hidden symptoms. The reliably, repeatedly, safely criteria and their definitions should be embedded within the wording of each PIP and WCA descriptor. Informal observations should also no longer play any role in the PIP assessment or WCA.
- 5.33. **Recommendation:** People with MS should only be assessed by someone who has some professional experience of neurological conditions and has received training developed with relevant charities.
- 5.34. **Recommendation:** The Government needs to change evidence collection processes to ensure that all disabled people are able to easily provide relevant evidence for their claim and evidence is actually collected by assessors.

- 5.35. **Recommendation:** The DWP must ensure that staff working for the Department treat all disabled people with empathy, dignity and respect at all times. Disabled people should be believed and not assumed to be lying about their condition and it should always be accepted that disabled people are the experts in their condition and how it affects them. These standards should be strictly enforced and embedded across all DWP services.

How Can We Better Support People into Work and Adjust to Changes?

This section covers the following questions:

Q. UC has many features, such as the work allowance and taper, that aim to make it easier for people to move into work. How can we ensure that disabled people and people with health conditions are aware of these features, and encourage people to try out work on UC?

Q. How could the current structure of benefits be changed to overcome people's financial concerns about moving towards employment?

Q. How could the current structure of benefits be improved so people can better manage changes in benefit entitlement?

- 5.36. The first part of this question – how to make people aware of the features of UC – have been answered in previous chapters. Recommendations around holistic support, local support, and better advocacy will all lead to better awareness of these features in UC. A good Work Coach should be having this conversation with the people they are meant to be supporting.
- 5.37. It is still however, essential that the Government recognises that not everybody can work. The Green Paper says "We want to explore whether there are better ways to target financial support at people with the highest needs so that people do not feel discouraged from trying out work." As we've pointed out throughout our response, the Government fails to recognise that not everybody can work. By continuing to push this agenda and insisting that people in the Support Group and LCWRA need encouragement because they're worried about losing financial support, over-simplifies the issue. We have shared our concerns on this and how the Department should engage with disabled people throughout our response.
- 5.38. With that said people with MS have shared their concerns of taking up work and what this means for their benefit. However, the main worry appears to be losing access to the benefit itself, rather than just the financial support it offers. People with MS have told us they are worried that they will have to face a reassessment if their job doesn't work out, or if they are in the Support Group/LCWRA and do some level of work, this will trigger a reassessment and they will be found fit for work. Of course the upshot of this is that they will lose financial support, but in the

first instance, the issue is having to fight once again for a benefit many often fought so hard for in the first place.

- That the support people require will remain in place while they try work through an effective Work Allowance and Taper Rate
 - When someone starts work, there should be no reassessment if it doesn't work out for them (a simple route back to the benefit they were receiving prior to work)
 - For people in the Support Group/LCWRA working or volunteering must not trigger a reassessment.
- 5.39. On ESA people are able to work up to 16 hours or earn up to £143 (after tax). This should be increased for example to 20 hours, or £200 a week. This would mean that claimants feel more empowered to try out part-time work and have more options open to them. A similar improvement should be made for UC, where the Work Allowance is increased to the equivalent of the permitted work threshold in ESA. This would achieve the same thing, and also mean those moving from ESA to UC wouldn't lose out as much, whilst reassuring people that they won't be worse off.
- 5.40. Disabled people should also be offered a lower taper rate, which may mean they are less worried about being worse off financially if they start work. People with MS often have part-time jobs, which tend to be lower-paid and less secure. A taper rate removes the cliff-edge and helps people transition from benefits to a wage. This would help people feel both help people with their financial concerns, and manage changes to their entitlement. An appropriate taper rate should be considered as part of the wider review of social security rates that we have previously recommended.
- 5.41. One of the greatest fears that people with MS in the Support Group have told us about is being reassessed if they carry out work or work-related activity. They worry that being seen to be able to work will trigger an assessment and they will be moved into the WRAG/LCW. There are two parts to this.
- 5.42. Firstly, people do not want to go through the process of an assessment again. If someone has been able to find work, and stay in work for 9 months, but then finds themselves unemployed, the prospect of going through a long, stressful and complex process is not appealing. The time limits for linked claims, allowing people to return to the same entitlement efficiently and easily if work is not suitable or successful should be extended. We also know that people fare better with consistency. We've welcomed the proposals in the Green Paper around reducing repeat assessments, with fewer assessments people are able to be confident in their level of entitlement, without the constant fear of it being reduced or removed entirely. This will remove the need to manage changes in benefit entitlement and allow people to gain some level of financial security.

- 5.43. Secondly, we need to understand that if someone in the Support Group/LCWRA is reassessed and finds themselves being placed in the WRAG/LCW, they will also find themselves with less financial support, and facing conditionality requirements. A way to circumnavigate this issue is to remove conditionality and sanctions from the WRAG/LCW as we have previously recommended. As the Green Paper reminds us, there are different levels of payments for people claiming benefits, which they say aim to ensure that financial support is focused towards the people who need it most. However, the differences between rates and the drop in financial support people can face if they are placed into a different group or if they work, can be devastating. The government should reintroduce the WRAG/LCW element that was removed in 2017, thus increasing the benefit rate for people in those groups, and also remove the need to manage different benefit entitlements, as well as the fear of losing financial support.
- 5.44. Being better able to manage changes in benefit entitlement requires an overall adequate level of financial security in the first instance. Something that the current benefits system does not provide. We have raised the issue of inadequate social security rates above. Providing better financial support will go some way to help people better manage those changes.

How can the DWP more effectively support people with their extra costs?

This section covers the following questions:

Q. While continuing to focus financial support on people who need it most, how could we more effectively support disabled people with their extra costs and to live independently?

Q. Should we explore options to make it easier for disabled people to access practical support such as aids, appliances, or services, and why?

Q. What particular types of practical support should we help disabled people access?

- 5.45. The main aims of PIP are to help disabled people cover their extra living costs and live independent lives. However, despite these aims, it is worrying that this section of the Green Paper makes no assessment of whether PIP is actually achieving them in its current form.
- 5.46. From what we have heard from people with MS, it is clear that PIP is failing to meet these aims. The flawed eligibility criteria for PIP, in particular the 20-metre rule, mean that many people with MS miss out on the highest rate of mobility, or in some cases any mobility support at all. We know many people with MS, in particular those on the lower rates of

PIP, are struggling to pay for their essentials, let alone their extra costs. Many have been forced to reduce their spending on things like transport, prescriptions and visiting family and friends⁶⁶. These issues are likely to be even more acute in these times of rising inflation.

- 5.47. Despite these glaring inadequacies in PIP, the DWP makes no mention of changing eligibility criteria or increasing PIP rates to ensure more people with MS can get the support they need. Instead, the DWP uses this section to look to the examples of Australia and New Zealand for how to support disabled people with their extra costs. The case studies detailed in the Green Paper suggest that the governments of these countries provide relatively little or sometimes no financial support to disabled people to help them cover their extra costs. In these countries, it would seem that disabled people are given far less control over what they spend their benefit money on.
- 5.48. As stated previously, disabled people, including people with MS, are the experts in their condition and how it affects them, and so should be given free unrestricted control over how they spend their PIP money. Disabled people themselves are the ones who are best placed to know what they need to purchase to help them live independent lives. We are concerned that the references to Australia and New Zealand could imply that the DWP is planning to reduce or even completely remove the financial support that people receive from PIP, and in its place introduce a system where disabled people are provided with non-financial support directly, such as aids, or are only provided with financial support for actual extra costs accrued.
- 5.49. Rather than taking the approach of Australia or New Zealand, the DWP should increase PIP rates to a level where all disabled people are able to cover their extra living costs. These rates should be informed by research on minimum income standards. The DWP should also follow our recommendations outlined in the section 'Making changes to the assessment criteria' for how the criteria for eligibility to PIP should be changed so that all people with MS can get the support they need and are entitled to.
- 5.50. The signposting, information and advice provided by the DWP in person, online and in forms is also inadequate for helping disabled people to find out what support they may be able to get to help with their extra costs. Some said they felt there is a lack of openness from the DWP about what support is available and they felt like they were left to their own devices to work out what they may be eligible for. The DWP should follow our recommendations as set out in the section 'Signposting and support to help people access benefits' to improve the signposting and support it provides to help disabled people access support for their extra costs.

⁶⁶ MS Society (2015) *MS Enough: Make Welfare Make Sense*

- 5.51. Many people with MS have told us they greatly value the independence they get from having access to a Motability vehicle. The DWP should ensure that disabled people continue to be offered the option of exchanging some of their PIP payment for access to a vehicle. However, some people with MS have told us they chose not to access the Motability scheme, even when they were eligible, as they were worried they might lose their vehicle if they were reassessed and received a lower award. To ensure that people with MS are not at risk of losing access to their Motability vehicle, and to help more people with MS access the scheme, the DWP should follow our recommendations for expanding access to Motability, as outlined in the section 'Exploring support for mobility needs'.
- 5.52. As outlined above, we would like to see the DWP change the eligibility criteria for PIP, in particular scrapping the 20-metre rule, and increase PIP rates so they are adequate to help all disabled people cover their extra costs. However, on top of this, the DWP should provide disabled people, including people with MS, with better access to a range of practical support and services.
- 5.53. People with MS have told us they would like more support with accessing social housing, public transport, taxis, adult education and training, and occupational therapists and physical therapists. For example, this could include more social housing being built which is ring fenced for disabled people and cards for free travel on all public transport. The DWP should work closely with disabled people, disability charities, and other relevant Departments to explore how best to provide this support. And this support should not be provided through a system where disabled people exchange their benefit money in return for access to it or in place of financial support. It should be provided in addition to the financial support disabled people receive through PIP.
- 5.54. **Recommendation:** The DWP should increase PIP rates to a level where all disabled people are able to cover their extra living costs. These rates should be informed by research on minimum income standards.
- 5.55. **Recommendation:** The DWP should provide disabled people, including people with MS, with better access to a range of practical support and services, including social housing and public transport. This should not be provided through a system where disabled people exchange their benefit money in return for access to it or in place of financial support. It should be provided in addition to the financial support disabled people receive through PIP.

Conclusion

- 6.1. The Green Paper repeatedly talks about rising spending on health and disability benefits, the higher number of people claiming PIP or placed in the Support Group than originally expected, and how work is the route to independence and better health.
- 6.2. We would have liked to have seen much more recognition of the fact that health and disability benefits are more than just out-of-work benefits, and that for some people work would be actively harmful for their health even where they would like to work.
- 6.3. The Green Paper talks about disabled people having equal access and being able to participate in society like everybody else. Participation doesn't mean work. Surely a fundamental principle of any welfare state is that a person who cannot be economically active can live as much of an independent life as that of someone who can. This principle does not seem to have guided thinking in the Green Paper.
- 6.4. The Government identifies three priorities for change at the start of the Green Paper:
 - Enable independent living
 - Improving employment outcomes
 - Improving the experience of people using our services
- 6.5. The Green Paper contains a large number of proposals, some of which we welcome. However a glaring omission is the lack of recognition that many people claiming these benefits are living in poverty- and that the only way to truly change this is by increasing the rates at which health and disability benefits are paid. Getting to a place where employment is a possibility can be challenging for some people with MS and impossible for others: this must not condemn them to a life of poverty.
- 6.6. The Government must take a long, hard look at the current inadequate rates of social security and increase them to ensure people can live the independent lives it claims it is keen to enable.
- 6.7. The Government must also urgently reform the assessment criteria so they are less of a barrier to people with MS getting support they need. This should start with scrapping the PIP 20-metre rule.
- 6.8. There are of course, some positives in this Green Paper, and we look forward to continuing to engage with the Department on developing these. However, the overall thrust of the Green Paper, when combined with the rhetoric of current Ministers, leave us concerned at the direction of travel for health and disability benefits.

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