



Women and Equalities Committee

Oral evidence: National Disability Strategy, HC 241

Wednesday 5 July 2023

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Members present: Caroline Nokes (Chair); Elliot Colburn; Jackie Doyle-Price; Kim Johnson; Ms Anum Qaisar.

Questions 114 - 182

Witnesses

I: Tom Pursglove MP, Minister for Disabled People, Health and Work, Department for Work & Pensions; Maria Caulfield MP, Minister for Mental Health and Women's Health Strategy, Department of Health and Social Care; Marcus Bell, Director of the Equality Hub, Cabinet Office; David Nuttall, Deputy Director of Neurodiversity, Diversity and Learning Disability, DHSC; Jennifer Heigham, Deputy Director for Strategy and Briefing, Work and Health Unit, DWP.



Examination of witnesses

Witnesses: Tom Pursglove, Maria Caulfield, Marcus Bell, David Nuttall and Jennifer Heigham.

Q114 **Chair:** Good afternoon and welcome to this meeting of the Women and Equalities Committee and our oral evidence session on the National Disability Strategy. Can I thank our witnesses, Tom Pursglove, Minister for Disabled People, Health and Work, Maria Caulfield, Parliamentary Under Secretary of State, Minister for Mental Health and Women's Health Strategy at the DHSC, Marcus Bell, Director of the Equality Hub at the Cabinet Office, Jennifer Heigham, Deputy Director for Strategy and Briefing at the DWP and DHSC, Joint Work and Health Directorate and David Nuttall, Deputy Director of Neurodiversity, Diversity and Learning and Disability at the Department for Health and Social Care. Are you all happy that we refer to you by your first names?

All witnesses indicated assent.

Chair: Thank you very much.

Before we begin, in consultation with the Speaker, I have waived the rule on legal cases in relation to the Government's appeal to the High Court judgment on unlawful consultations on the National Disability Strategy. I would encourage witnesses to refer to the case only if strictly necessary.

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I am going to start straight away with a question to the two Ministers. The Government paused 14 policies that were directly connected with the National Disability Strategy due to this litigation. What assessment have you made of the impact of that pause? Tom, I will start with you.

Tom Pursglove: The National Disability Strategy is a really important part of the work that the Government want to take forward to make our society more inclusive, to expand opportunity and deliver on a full range of day-to-day life issues that we know are important to disabled people. I am very disappointed and frustrated that the policies in the strategy have had to be paused and that we have had to adopt this approach, but it was right that we acted with caution and in accordance with the Court ruling. It is also disappointing to the stakeholder groups I work with; I know, for example, that there is a lot of interest in the Disability Confident review, which is one of the policies that has been paused. That is not to say, however, that we have not continued to strive to make improvements in the disability space. I have no doubt that during the course of this session we will get into the detail of those.

Q115 **Chair:** Are there any measurables that you have looked at over the period of the pause to ascertain what might not have been done that otherwise would have been done?



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Tom Pursglove: The approach taken by Ministers prior to my time in this role was to act with caution and to act in accordance with the Court ruling. We have appealed against it; the appeal was heard last week, and we now await the outcome. The principle of the strategy, and the delivery of the strategy, has had to be paused, but in the meantime, the Government are still continuing to deliver in the disability and inclusion space.

Q116 **Chair:** This Committee has heard very specifically about the additional costs disabled people face. In a cost of living crisis, where energy bills have risen, what are your concerns about the pause of the Extra Costs taskforce, and should that area be picked up on as a priority?

Tom Pursglove: I do not want to get drawn into the outcome of the appeal process. Obviously, we will take stock when we are in a position to know the decision of the Court and how we are going to move forward from there. It is fair to say however, that, as Ministers, particularly in the Department for Work and Pensions, but also across Government, we are exercised about the cost of living challenges that people are experiencing. We want to understand more about what those challenges and those costs look like, and we are taking that work forward in a number of ways, for example, through an evaluation of the cost of living payments that we have committed to conduct in the autumn.

We are also working through the Disability Unit to understand more about the costs that people are experiencing and seeing how those are best met, while also thinking about how we can future-proof people against some of those costs, for example, through the work that the Department for Energy Security and Net Zero are doing on delivering a social tariff. Although we have not been able to take forward the particular initiative that was talked about in the National Disability Strategy at this point in time, we are able to do other pieces of work that we have commissioned since that are helping to build a better evidence base.

Once we are in a position to know the decision of the Court, we will say more.

Q117 **Chair:** Maria, from the DHSC's perspective, do you have anything to add about the impact of the pause in the strategy?

Maria Caulfield: Not really. We are still getting on with our programme of work, including, for instance, getting the annual health checks rolled out. The target for those is 75% by March next year, and we are already at 78%. We have some progress to make on building the right support, but the pause is not having a detrimental effect. We are still able to get on with our health and social care programme of work for people with learning disabilities and autism.

Q118 **Chair:** Can I just clarify that statistic? Seventy eight per cent of people who are eligible for an annual health check are receiving—



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Maria Caulfield: Seventy eight per cent of annual health checks are happening. Our target is that 75% have to be done on an annual basis by March of the following year.

Q119 **Chair:** Thank you. Are those statistics broken down by integrated care board?

Maria Caulfield: I think they are available, but David will be able to confirm that.

David Nuttall: They are collected by the integrated care boards. I do not know if the breakdowns are routinely published; we can see if those are available.

Q120 **Chair:** Yesterday the Committee was in Billericay talking to people with lived experience of disability. One of the questions they raised was whether people were receiving their annual health check, so it would be really interesting to have that broken down by ICB.

Tom, can you share with the Committee how much your Department spent on appealing the High Court's ruling?

Tom Pursglove: I do not have a figure to hand that I am able to share with the Committee today, but you would expect that there would be costs associated with ongoing proceedings. I can certainly take away that request and see whether we are able to provide an update.

Q121 **Chair:** Thank you. I think you have said that you do not centrally track the different departmental commitments in the National Disability Strategy. They are left to the individual Departments, and you are not collating those figures. How can you assess the extent to which they are fulfilling their commitments? Is anyone collating that information?

Tom Pursglove: One of the key ways that we track progress and bring some accountability is through the appointment of ministerial disability champions in each of the Whitehall Departments. MDCs look at everything their respective Departments do through the lens of disability, championing disability and inclusion within the workstream. The Prime Minister appoints them, and I chair the MDC network. We bring the MDCs together to talk about key pieces of work that we are taking forward. The disability action plan is a good example of that, with different Departments providing a stocktake around that work.

I am pleased that, in response to your written question, we have been able to provide the Committee with an update on the respective Departments and their work. We will continue to look at how we can better report on the performance of individual Departments in delivering policies that are relevant to disability, and also where the Disability Unit can help us work across Government to grip problems and challenges and issues that affect disabled people. That is the ethos behind the disability action plan.

Q122 **Chair:** As you chair the ministerial disability champions, does that mean



that you sit with overall responsibility for the National Disability Strategy in Government?

Tom Pursglove: I do not have any direct ability to compel individual Government Departments to act in a particular way. There are manifesto commitments that Departments want to see through, and they have their own workstreams. My role is to make sure that all in Government are pulling in the same direction when it comes to disability, providing grip where there are challenges or where we need to work collectively together to make progress.

To answer your specific question, I would say ownership of the National Disability Strategy and the disability action plan would sit with my responsibilities quite neatly.

Q123 **Ms Qaisar:** The Norwegian Government are carrying out specific projects to raise awareness of, and implement, the UN convention on the rights of persons with disabilities. What practical steps are you and your Government taking to ensure that Departments and other public bodies comply with the CRPD?

Tom Pursglove: That is a really good question. I had a bilateral meeting with the Minister of Culture and Equality at COSP16 in New York a few weeks ago when we talked about the work that is going on in their country to drive forward the inclusion and disability agenda. The work we are doing is similar in many respects. Their action plan is focused on driving the inclusion agenda across Government, with a cross-Government grip and responsibility approach. The principles they are working to are also very applicable to our work. In fact, our ministerial disability champions were of interest to many of the Governments I met there.

When you think about delivering universal solutions and special measures, working for self-determination, participation, involvement, inclusion, better organisational co-ordination at all levels, about areas of focus such as education, employment, health and social care and culture and leisure, all of that mirrors the National Disability Strategy and the long-term work we are seeking to take forward. I suspect that the disability action plan will also capture some of these areas.

That is the work that I understand Norway are doing to try and live up to their UNCRPD requirements and obligations, and I would argue we are doing that in a similar way. Everything that we do as a Government is trying to act in accordance with the UNCRPD, not just in letter but also in spirit. Of course, we do not enshrine the treaty directly in our domestic law, but through our actions and our policies and our lawmaking, we seek to incorporate its principles.

Q124 **Ms Qaisar:** Just towards the end there, you said that you are not going to incorporate the CRPD into domestic law. Why not?



Tom Pursglove: Broadly speaking, that is not the way we go about doing these things. We have had many debates in this House about interpreting our treaty obligations. We think the best way of achieving the outcomes required of us through the UNCRPD is to implement them on an ongoing basis, with the Equality Act as the cornerstone upholding the requirements on public bodies and organisations in day-to-day life, while making sure that we consistently evolve our policy offer in response to requirements.

I would argue that things like the Access to Work scheme, the Disability Confident scheme and the White Paper reforms that I am seeking to deliver in the Department for Work and Pensions, the Down Syndrome Act, the British Sign Language Act, are all good examples in practical terms of how we are living up to those expectations.

Q125 **Ms Qaisar:** Could it not be argued that, if the UK Government were to incorporate the CRPD, it would send a message to disabled people that you are taking their rights seriously?

Tom Pursglove: I think people can see a firm commitment to those principles and expectations in our ongoing work.

Ms Qaisar: I would slightly disagree.

Tom Pursglove: We perhaps disagree on that point.

Q126 **Kim Johnson:** Good afternoon, panel. My first question, Tom, is on the disability action plan. You said that it will set out the actions you will take in 2023-24. Can you tell us why you are only setting out actions for one year? Given that we are several months into 2023-24, is it a bit late to be producing a plan, and what actions are you expecting to deliver by the end of this Parliament?

Tom Pursglove: There seems to have been a bit of confusion about this in some of the proceedings that we have had in the House. It is very much in addition to the National Disability Strategy. The National Disability Strategy is a long-term piece of work that addresses a range of issues to improve the day-to-day lives of disabled people. The disability action plan is focused on short-term changes, short-term improvements in response to feedback from disabled people and the issues they are raising. It is a really focused piece of work, harnessing all of Government to deliver on those areas.

We are indeed committed to a fully accessible consultation, provided in fully accessible versions with engagement and opportunities for people to feed in their views. I very much want to commence that consultation work, quickly evaluate the feedback from it and then concentrate on delivery. We do not want to waste any time in delivering on areas where, in the short term, we can make real progress for disabled people informed by their lived experiences, their views and ambitions and their asks of Government and society more generally.



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We will focus on delivering on those areas in the short term, whilst in the long term, hopefully having the National Disability Strategy once the legal proceedings are resolved.

Q127 **Kim Johnson:** Thank you. It will be interesting to see how the strategy is produced and developed.

Maria, Tom has just mentioned ministerial disability champions. I wanted to know how you have ensured that disability inclusion is a priority in the work of your Department.

Maria Caulfield: There is obviously a natural link with health because many people with a learning disability or autism have close contact with health and social care services. As I touched on earlier, we have to do annual health checks for people with a learning disability and we are above the target for that. However, there are real opportunities for people who may not readily engage with health and social care services to be assessed overall and to be given an opportunity, every year, for services to be put in place.

We are embedding that not just in our Department but across the health and social care piece. Every integrated care board—there are 42 in England—now has to have a lead executive member for learning disability, autism, and Down syndrome, so we are embedding that at a local level. Every Member of Parliament should be able to go to their ICB and ask them who their lead executive member is and their plan for their autistic and learning-disabled communities.

We also have pieces of work separate to Tom's: we obviously have the Down Syndrome Act, and we are now working to develop the guidance after that was made into law. We are also rolling out a consultation on the Oliver McGowan draft code of practice. Oliver McGowan was a young lad with autism and a physical illness, who sadly died as a result of poor care. His parents felt that occurred predominantly because the wider health and social care network did not have training on autism. The code of practice is out to consultation as we speak, and it will be in consultation over the summer, so I would encourage everyone to respond to that. However, the Oliver McGowan Mandatory Training on Learning and Disability is already available, and we have had over 400,000 people take part in that training.

That is just one example of where we are trying to embed disability inclusion, whether at a local level through our ICBs, or nationally across health and social care, so that people with lived experience feel that at any point of entry into health and social care services, staff are well trained in their needs, and appreciate that they have specific needs that other members of the population do not have.

Q128 **Kim Johnson:** Thanks, Maria. Can you say a little about how you and the other champions are inputting into the action plan, if at all?



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Maria Caulfield: We meet regularly. Tom chairs the meetings, and we feed in what we are doing from our various Departments. The DHSC is probably a very active Department as it is a natural fit.

Tom also feeds back to us if there are things that he would like Departments to be doing more widely, for instance staff training. In the DFE, there is a lot of work going on to provide teachers with information and support about learning disabilities, particularly in mainstream education. Likewise, we have a responsibility for our health and social care staff.

It is really a two-way conversation. We set out what we are doing so that it feeds into Tom and his team about what is happening to support people with learning disabilities. Likewise, if there are pieces of work he needs us to do, he will then feed that to us to drive that change forward.

Q129 **Kim Johnson:** You have just said your Department is a natural fit. What about the other ministerial champions? How often have they met and what has been the outcome of those meetings?

Tom Pursglove: We have had our most recent meeting in the last couple of weeks. At the moment we are collectively working towards the disability action plan consultation. It will provide a really good opportunity to have a stocktake of the work of individual Departments and bring that together as a whole, to update people and to talk about some of those achievements and the progress we have made.

Work is also ongoing in Government to deliver on the policies of individual Departments that are of benefit to disabled people and that help drive inclusion, opportunity, and everything you would want to see. There are areas where there are particular challenges and problems, and we can make progress with some cross-Government work and some cross-Government grip.

I regularly meet with individuals or collectives of ministerial disability champions to talk about specific issues, and I do a lot of stakeholder engagement with disabled people's organisations, with charities, and with our disability and access ambassadors to hear views, opinions and ideas.

I try to make sure those are properly heard across Government, and I concentrate on bringing people together to engage still further in discussion and, hopefully, action.

Maria Caulfield: The Down Syndrome Act is a perfect example. We are just developing the guidance at the moment, and Tom has been engaging with our stakeholders. We had a brilliant event in Westminster not that long ago.

Part of the guidance is that wherever someone with Down syndrome interacts with public bodies, for instance in the workplace, education, or with the DWP—it is not health and social care specific—they should not have to navigate all the various agencies. That should be facilitated for



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them. For example, if they go to see someone in the DWP and they have a health care need, the DWP should be able to help them navigate that if they are struggling to do so.

We can only do that with Tom's help, and the action plan, so that it is embedded in every part of Government. That is just one example of where we are working closely together to make that happen.

Tom Pursglove: Another good example is the meeting we had only last week with Baroness Vere in the Department for Transport. She is not actually the MDC but is doing very good work helping to respond to the "Rights on Flights" campaign and the issues it has raised, particularly about broken equipment and broken wheelchairs, but also the general experience of air travel for disabled people. A policy announcement was made around that last week, informed by those experiences and conversations. We were also able to bring a lot of interested relevant parties together to talk about how we move to an implementation stage and deliver on those policies.

As I said earlier, our international counterparts at COSP16 were interested in MDCs because they could see the opportunity to have accountability within Departments, as well as having that disability lens, looking at everything individual Departments are doing and then bringing that back together as a whole.

Q130 **Kim Johnson:** Thanks, Tom. I have a question for Marcus on the Disability Unit: what barriers do your unit typically face when trying to get Departments to pay attention to the disability agenda, and how do you overcome them?

Marcus Bell: The main barrier to Departments taking disability seriously is feeling, or not feeling, from the top that it is a priority for their Department.

In that connection, what the Minister has been saying about the role of ministerial disability champions is really important, because officials and Departments know that they have a Minister who really cares about the issues, wants them to be taken seriously and for progress to be made. I will say—mirroring what the Minister was saying at official level—that there are lots of enthusiasts in other Departments who really care about disability policy and really want to make a difference. Part of our role, as well as overcoming barriers, is to find allies we can work with constructively. We have been quite successful at that.

Q131 **Chair:** Is there someone in every Department who is passionate?

Marcus Bell: There are certainly people that we talk to in every Department who are helpful in taking the agenda forward. Whether all of them are passionate about the issues, I could not say. Many of them are.

An additional point to make is that disability policy is an area that attracts enthusiasts and people who really want to make a difference. One thing



we have always done in the Disability Unit, since it was set up, is to have people on secondment from other Departments, often on a free basis because they are willing to lend us people.

That has been very helpful, both in terms of expanding our capacity but also in building on knowledge, because obviously it is helpful from our point of view to have people who are experts in transport, health or education policy, actually working in the Disability Unit.

Tom Pursglove: That is a very live point. I am really encouraging MDCs to try and identify people in their respective Departments who could come and lend a hand with the disability action plan over the course of the coming months. It is a really good opportunity for them to have a learning experience and to help us champion the work in Whitehall Departments and across Government. I hope that MDCs will respond to that call and hopefully provide some keen and willing individuals to come and help us to take this forward.

Q132 **Kim Johnson:** The Disability Unit has lost 18% of its staff. Has that reduction in resources affected your ability to co-ordinate the successful delivery of the disability strategy and the action plan?

Marcus Bell: The Chair has recently written to the Minister for Women and Equalities about that issue, and the Minister will be replying very soon. I will make a couple of comments now. There have been some small reductions in the Disability Unit, we are talking about two or three posts overall. Those are part of wider reductions in the Cabinet Office. We did not single out the Disability Unit, but there were some overall reductions and that was their share. I do not think it has impacted on the ability of the Disability Unit to support the Minister in what he is doing. We have a number of different teams within the Equality Hub, so as pressures wax and wane, we can move people from one area to the other. Obviously, as resources have reduced overall we are having to do that to some extent. The point that I have already made about borrowing people from other Departments with particular expertise has also been helpful in mitigating the impact of that change.

Q133 **Kim Johnson:** So you are not expecting any more reductions?

Marcus Bell: No.

Q134 **Kim Johnson:** Okay. My next question is about the evidence base. In which areas do you need a better evidence base, and what steps are you taking to address any gaps and weaknesses in evidence?

Marcus Bell: There are two main areas I would mention in relation to evidence around disability. A lot of the data that the Government collect about people, whether we are talking about the Labour Force survey or other areas, has quite a lot of detailed information about sex, gender, and ethnicity. It is less likely to include detail about disability, so that is a long-term thing. Data which is collected about some characteristics is often not collected about disability. We have been talking to the ONS



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about whether we might be able to influence that in the longer term. There is also room for better qualitative evidence about disabled people and their views and experiences. We have tried to improve our understanding through the Disability Unit, but on both the quantitative and qualitative side, there is a case for more and better data, and we are working on that.

Q135 Kim Johnson: The PCS union has raised some concerns about the Equality Hub's restructure. I want to know if you can give us an update in terms of where those discussions are.

Marcus Bell: We have involved the PCS in the restructure throughout. I have had a number of conversations with them, and we are in an ongoing exchange of correspondence, but I hope they feel, even if they do not agree with everything that has been done, that they have been fully involved and consulted.

Q136 Chair: The Disability Discrimination Act was passed in 1995. In 2023, nearly 30 years on—we can all do the maths—we are still talking about not having enough data on people with disabilities. Is that evidence of the unit not doing its job?

Marcus Bell: I did not say no data.

Chair: You said not enough.

Marcus Bell: We will probably always want more data about disability, but there is not enough. One of the benefits in the Equality Hub of having a team of analysts who look at data around ethnicity and socioeconomic issues and geography is that, because they look at all those issues together, if they feel there is a particular lack of clear data on disability then that is something that needs addressing.

Q137 Chair: Is it good enough that you are only now having conversations with the ONS as opposed to having any concrete plans to make sure that more, better quality, disaggregated, granular data is collected?

Marcus Bell: It would have been good to make more progress. There was an action in the National Disability Strategy around evidence and data.

Chair: We are back to that, which is paused.

Marcus Bell: That has hampered progress, but there is definitely a case for more.

Q138 Jackie Doyle-Price: Tom, what discussions have you had with disabled people's groups, including user-led organisations, prior to developing the draft disability action plan?

Tom Pursglove: We meet regularly, both at an official and ministerial level, with a whole range of stakeholders, for example, the regional stakeholder network. We have regular meetings with them, a number of



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those in my time since coming to this role in October. We continue to have regular engagement with the Disability Charities Consortium and DPO Forum England, who I met with just a few days ago. Hearing that real, lived experience is incredibly important in terms of policy development and thinking about the issues that we ought to be concentrating on.

Our network of disability and access ambassadors also spend a lot of time doing fantastic work with Government and with individual industries about how we can improve access and see tangible improvements, working particularly with the business community in all its forms to see change come about in the way that all of us would wish to see.

The disability action plan is an opportunity to respond to many of the issues, suggestions and priorities that people raise with us through that regular engagement, but there has to be thorough ongoing consultation over a period of time in order to take stock of our achievements so far, to be able to give thought to ongoing workstreams, and to those areas where the Government, with some cross-Government collaboration can deliver on the priorities that people have. I think we will see quite a lot of people want to engage with that.

Q139 Jackie Doyle-Price: That all sounds very nice, but it is not consistent with the feedback we are getting from the disabled sector.

Fazilet Hadi from Disability Rights UK has said that the trouble with the disability action plan is that, "It is not coming from disabled people." The Disability Unit, with colleagues, has come forward with a list of actions and had some roundtables but it is not our list of actions.

The message we are getting is that disability organisations do not feel that they own this agenda. They do not feel they have had strategic input. What you are articulating to us this afternoon is that there are some very established structures for dialogue, but they are not really delivering the policy input that the disability organisations would expect.

Tom Pursglove: It is slightly premature to say that. The consultation is not yet out there and available for people to see. At the moment, I am reflecting on the finer details of what that consultation process will look like. I want it to be fully accessible—which it will be—I want it to be inclusive, I want to hear people's views as part of it. If there are things that are not included in the disability action plan and it comes through in feedback from disabled people's organisations, from charities, from individual disabled people, then we will look at that and seek to incorporate what we can before we reach a final product for delivery.

Q140 Jackie Doyle-Price: Minister, can I ask you to go away and reflect? We need to encourage a culture of dialogue here. These organisations need to feel that there is ownership and genuine collaboration or else we are not going to get anywhere. This is a set of people that are used to being patted on the head and, if we are really going to deliver a marked



improvement and a cultural change to empower people with disabilities, that is not going to be a very helpful starting place. That is what comes out to me from these submissions. Perhaps I could turn to—

Tom Pursglove: Sorry, can I just say that I take this really seriously and I would hope that disabled people, the charities, and disabled people's organisations feel, since I have come into this role, that I have been very available and very accessible. I have been very committed to engaging regularly. In fact, I met with Fazilet only this week, along with DPO Forum England members which was the latest of our regular engagement with them.

Q141 **Jackie Doyle-Price:** You have outlined today that there is a whole hierarchy of consultation. I believe you when you say you take this very seriously, but from my perspective it is a cultural thing and it is reflecting a history of dialogue, so there is a need to make sure that that is pushed all the way through.

Tom Pursglove: I think it would be of benefit to the Committee if we set out a couple of practical examples of where that sort of co-production piece is really happening, and that people can relate to it. The British Sign Language Act got the recognition for BSL in England, Wales and Scotland, which is a really important step forward. We have now established the British Sign Language Advisory Board, which is co-chaired by Craig Crowley. All the members of the BSL Advisory Board have lived experience of BSL and are associated very strongly with the deaf community. They are helping us to work through the commitments that were made as part of the BSL Act.

I am absolutely clear that I want Government communications to lead by example and be the very best that they can be when it comes to BSL. Beyond that, we would all want very high-quality Government communications, but the focus is on BSL in relation to the BSL Act. We are moving that forward together and we will also be looking at the issues that the deaf community is raising around, for example, the availability of interpreters.

We have a commitment to the BSL GCSE and how we deliver that, which is a really important move forward. In policy terms and delivery of that policy, there is a real bringing together of Government and partners, and disabled people, including people with lived experience, to deliver on that. For example, when it comes to the White Paper reforms that I am seeking to deliver around employment, we also have workstreams that are now moving the reforms forward.

Q142 **Jackie Doyle-Price:** That is fine, Minister; that is absolutely fine. You have talked about process, but what we are saying is our feedback from stakeholders is not being shown in delivery, but I think we need to move on.

We had very much the same feedback in respect of the White Paper on social care, and are very much feeling that, again, they did not feel they



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had the input in terms of those proposals. It certainly reflects something, from my perspective, where the needs of working age adults, in particular, have been lost because of the focus in terms of the politics on elderly social care. Maria, do you have any reflections on that that you would like to share with the Committee?

Maria Caulfield: Yes. In our autism strategy, for example, we have an implementation—

Jackie Doyle-Price: Talk specifically about the engagement on the social care White Paper.

Maria Caulfield: I was not a Minister at the time, so it is difficult for me to reflect on the engagement.

Q143 **Jackie Doyle-Price:** David, perhaps you could give us some observations because you have been dealing with these issues for many years and you probably know your way around this community better than anyone else in Government.

David Nuttall: My understanding is that there is an attempt to involve people in all the different elements of the policy development. Similarly, I was not directly involved in that process around the social care White Paper, but we do have various forums and groups that we use to engage with people directly and get their views on the different stages of the policy development as they are going through. As I say, I do not know the details of the precise engagement around the social care White Paper, but we do have, for example, fora for people with lived experience in terms of specific policy areas, whether that is learning disability, autism, etc.

Q144 **Jackie Doyle-Price:** It does not feel very joined up. We are looking at this whole issue of social care based on how much it is costing the taxpayer but because the politics is all about the elderly, again, it seems we end up with people with disabilities having things done to them rather than having been given ownership.

When we went to Norway, we were very impressed to see that there were some very good models of care where you had working-age adults actually involved in the delivery of their care. That is something that has been missing from this. It feels very disappointing because it feels like we really have not moved on in about five years in terms of talking about this.

Maria, coming back to what you started to speak about in terms of autism, the Department has been committed to an autism public standing initiative, which was promised by autumn 2021. We are now in June 2023, and we do not have it. Why is that?

Maria Caulfield: We are working with stakeholders and people with lived experience in our work around autism. We meet with our implementation group on a regular basis.



Q145 **Jackie Doyle-Price:** We had a promise of an initiative by 2021. It is now June 2023. We do not have it. Why?

Maria Caulfield: I do not have the particular information on that; I am happy to write to the Committee about it.

Q146 **Jackie Doyle-Price:** You answered a parliamentary question to the Chair where she specifically asked this, and you revealed that it was not ready. Surely that work has been done. There must be an explanation within the Department of Health and Social Care.

Maria Caulfield: We do not have a date for that, so I am happy to write to the Committee with an update on the date.

Q147 **Jackie Doyle-Price:** The question is why has that commitment not been delivered?

Maria Caulfield: We are working through that.

Jackie Doyle-Price: You do not know; that is the answer.

Maria Caulfield: We do not have a date. You asked me—

Q148 **Jackie Doyle-Price:** The question is, “Why do we not have it yet?” The answer to that question is not that we do not have a date; it is why. You do not know why, so let us move on.

What work have you done to better understand how autism particularly impacts women and girls?

Maria Caulfield: We are doing a lot of work in the Women's Health Strategy, and autism is one of our priority areas. We know that young girls, in particular, are often underdiagnosed because they present very differently to boys. One of the things I was trying to explain in my previous answer is that we are working across Government on that. I am working with Minister Coutinho in the Department for Education around SEND provision, and we have stakeholders, young people with lived experience—

Jackie Doyle-Price: This is all process.

Maria Caulfield: It is not process. We are listening—

Q149 **Jackie Doyle-Price:** This is all process, and we have known for a long time about underdiagnosis in women and girls.

Maria Caulfield: If you let me answer the question, what I am trying to say is that we are working with young people to find out which measures are making a difference to them. One of the practical things we are doing is we have teams going into schools that are able to support teachers to identify those pupils that may have been missed in the past. Those mental health support teams are then able to refer in to specialist provision to try to get those diagnoses, not just for autism but for ADHD.



We know there is a link between autism and eating disorders in young girls, and so there is a huge piece of work between us and DFE to try to get into the ground, into the schools where those young people are, and try to get those assessments done earlier and start interventions earlier. In our implementation group, which is co-chaired between me and Minister Coutinho, we ask young people, "Are these interventions making a difference? If they're not, what can we do better?" So we are learning from the experience of those young people. That is just one example of how we are using people's experience to shape our policy and intervention.

Q150 Jackie Doyle-Price: It is not going well, is it? Specifically, what work are you doing to better understand how autism presents in women and girls? You are correct to link that to eating disorders. Can I ask you whether there is any examination as to the links between autism and gender dysphoria?

Maria Caulfield: There is work being undertaken on that and we are supporting research into it as well because the evidence is sparse in nature. We have a number of academic groups that want to do this research to try to gather the evidence base so that we can shape policy around it. There is an indication that there is a link between gender dysphoria and autism, and it is fair to say, in young women and girls, we are learning more about it.

One of the things we are trying to do—in terms of when we are looking at the assessment process and speeding up getting an assessment diagnosis—is to integrate ADHD and autism assessments. The feedback we are getting, particularly from young women and girls, is that they go through the whole process of waiting to be assessed for autism and then they are either diagnosed with it or not, but then they may also have ADHD and they have to start the whole process again. So, we are trying to build the assessment around the individual rather than going through the process—

Q151 Jackie Doyle-Price: How does someone access an assessment?

Maria Caulfield: There is a range of ways. Some people can go through their GP; other times it is through schools or local authorities. Part of the issue is that it is not joined up at the moment.

Q152 Jackie Doyle-Price: It should really all go through the GP. If it is being routed through schools, that is because there is, clearly, some kind of assessment as to a learning need which is leading to a referral—and similarly with local authorities. Ultimately, it should be down to, "We will tackle a backlog of people waiting if we have a simpler route to an assessment."

Maria Caulfield: Part of the work we are doing by embedding mental health support teams in schools is to try to identify those people that, perhaps, will not go to their GP or maybe have been to their GP and the symptoms, particularly in young girls, have not been identified,



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potentially, as autism. By having those teams that will be able to either link back to the GP or directly refer themselves means that we should be able to pick up those who need assessment much more quickly than happens at the moment.

Q153 **Jackie Doyle-Price:** What is the backlog?

Chair: Do you have a target?

Maria Caulfield: In terms of?

Chair: If I am a parent and I suspect that my child has autism, what would your target be for how quickly a diagnosis should be available?

Maria Caulfield: We have not set that target yet.

Q154 **Chair:** Are you going to set a target?

David Nuttall: The National Institute for Health and Social Care Excellence clinical guideline suggests that the quality standard is to have your first appointment for assessment within 13 weeks of a referral. New guidance was issued in April by NHS England which is intended to standardise assessment processes. At the moment, there is a wide range of different ways in which assessments and diagnostic pathways work.

Q155 **Chair:** So, if the target is 13 weeks what—

Maria Caulfield: It is not a target. That is the guidance.

Q156 **Chair:** Okay. So, if the guidance is 13 weeks, what is the current waiting time?

Maria Caulfield: It depends where you are in the country. Some parts of the country are almost there, and some parts are a long way off. NHS England recently published its strategy on this; it set out what it expects of each individual ICB. Up until now, there has been no national pathway for that. What we are trying to do is establish that across all ICBs in England. Also, there has not been great joined-up working between health and education. It is fair to say that education has done some of the heavy lifting on this, and we are trying to change that. We will get to a place where we want to set a target.

Q157 **Chair:** Will we get to 13 weeks?

Maria Caulfield: We would like to get to 13 weeks; I do not think we are there yet.

Q158 **Chair:** What level of recruitment is there in the NHS workforce plan that will enable you to get there?

Maria Caulfield: It is not so much about the recruitment of staff; it is also about the types of assessments that are done. That is part of the evidence base I was talking about that we need to develop. There are so many ways of assessing for autism and sometimes people, often parents—and I know in my own constituency—will pay to get a private



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diagnosis because they have been waiting so long and some of those private assessments are not always accurate in terms of assessing autism. That is why we are trying to standardise this.

We are going from a very low base where there has been virtually no guidance and no consistency across the country, and that is what we are trying to do. We want to get to 13 weeks, but that is going to take time to develop. Workforce is one issue, but standardising the assessment process in the first place would be the first hurdle we want to get over.

Q159 Chair: I am conscious we are short on time, and I do not want to grandstand, but yesterday the Committee was at the Hamelin Trust in Billericay, Essex, where we heard from one parent who had been trying to get an autism diagnosis for their child the whole time their child was at primary school. The whole time. We are not talking 13 weeks, are we? We are talking six years. We need progress, and what those parents want—taking it back to Tom's point—is to be listened to, and I hope this Committee can do a job of reflecting the concerns that were raised with us yesterday. Jackie, sorry, back to you. Expect to hear more of the Hamelin Trust later.

Q160 Jackie Doyle-Price: Yes, exactly. I totally endorse the point you have made, Chair, and, frankly, there is nothing new in any of this. It does feel a bit like groundhog day. We are hearing lots of words about processes and standardisation. Let us just listen to parents and be properly responsive to children. This is all words; it is all nonsense.

Can I ask you about the in-patient detention of people with autism and learning disabilities? Every 18 months we have a cause célèbre of somebody who has been incarcerated for a number of years and it suddenly shines a light on the fact that we are still treating vulnerable people very badly by locking them up. What progress has been made in tackling that in-patient detention?

Maria Caulfield: For people with learning disabilities and autistic people, we have a target to reduce those numbers by 50%. We are at 30% at the moment.

Q161 Jackie Doyle-Price: That 50% is from when to when?

Maria Caulfield: It should be 50% by March 2024.

Q162 Jackie Doyle-Price: When did you set that target of 50%?

Maria Caulfield: In 2019.

Q163 Jackie Doyle-Price: In 2019, and we have reduced it by 30%.

Maria Caulfield: Yes.

Q164 Jackie Doyle-Price: Okay. What conversations do you have with NHS England about fast-tracking that progress? What tools do you think are needed?



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Maria Caulfield: What we are doing now is breaking it down by ICB. Some ICBs—

Jackie Doyle-Price: But a lot of these people are detained away from their—

Maria Caulfield: Absolutely, but the ICB retains responsibility. Even if someone is out of area it retains responsibility.

Jackie Doyle-Price: It pays the cheque.

Maria Caulfield: But it still retains—

Q165 **Jackie Doyle-Price:** Once that person has gone from the area, it does not really care about them.

Maria Caulfield: It still has the legal duty to look after that person. What we are doing is going ICB by ICB to look at those specific people who are being detained and finding out what it is that is stopping them from being discharged. We are meeting with every single ICB, with the worst performers first. Some are in a good place, but others are very much behind. What we are finding at the moment is that it is not necessarily about packages of care in terms of getting people out of wherever they are placed; it is often about housing.

Q166 **Jackie Doyle-Price:** It is, and it has always been about housing. We have known it has been about housing for years. What conversations are you having with NHS England to properly manage that removal from detention?

Maria Caulfield: I am personally having meetings with the ICBs to go through their patient lists to find out what the plan is for each individual patient. We are working through that data at the moment because I am not happy with it being at 30%. I want it to get to 50%, but we do have to work with those ICBs to ask what the challenges are, and what are the resources needed for each individual patient so that each one has a plan to enable them to get to that discharge. I am personally meeting with the ICBs to do that.

Q167 **Chair:** Can I just check that? You are personally meeting with ICBs to go through their lists of patients?

Maria Caulfield: Yes, because I want to be sure that there is a plan in place for every single one because progress has been too slow. We are working through the data ICB by ICB to find out what the challenges are. Some of them are long term and we may not be able to fix those immediately. Quite recently, I met a young lady at an event here in Parliament. She had been detained for 12 years and she needed very little support to get out and live a normal life. She is now a mum, and she is absolutely thriving. If there are cases like that, we need to address them quickly, and that is why I take this so seriously.

Jackie Doyle-Price: You are doing it personally.



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Maria Caulfield: I am meeting with the ICBs individually to go through their figures. We have asked them to send in the data and we will be working with them to make sure they know how much of a priority this is for Government.

Q168 **Jackie Doyle-Price:** The real trick to end long-term detention—whether it is involuntary or voluntary, whether it is for learning disabilities, autism or mental health—always comes back to the housing solution and supported housing. How does that play out in your discussions with ICBs?

Maria Caulfield: I chair the “Building the Right Support” meetings and we know, from talking to local government leads, that there is capital funding for housing programmes for supported housing. Revenue may be slightly different, but there is capital funding available. What we are not seeing is that capital funding being used to build the supported housing.

There are often multiple tiers of Government, so what we are trying to do is join up the county councils that have responsibility for social care with the district councils that have responsibility for housing and try to get them to work together. If they know they have 20 people who need supported housing in the local area, what are they doing to find that housing if there is none available? Is it about building new housing? Is it about commissioning new housing from housing associations?

Q169 **Jackie Doyle-Price:** It is, and we have known this for more than six years.

Maria Caulfield: Yes, and that is the responsibility of each local ICB. It is not the responsibility of Government to do that.

Q170 **Jackie Doyle-Price:** It predates ICBs. Again, this is all talk and no delivery. This is why disability organisations have no confidence in this and do not feel that there is any interest in it.

Maria Caulfield: You were a Minister in the Department of Health and Social Care, so you know that in your—

Jackie Doyle-Price: Yes, that is why I know what I am talking about. It has not moved on, and we are not going to tackle systemic issues just by setting up more talking shops.

Maria Caulfield: It is not a talking shop. If I am meeting with the ICBs to go through their lists of patients who are not yet discharged and finding out what those challenges are, that is not a talking shop. That is looking practically at what the solutions are that we can deliver for each of those individual people.

Q171 **Jackie Doyle-Price:** But we are still not making the progress we want. What we found before, actually, is that as quickly as we were moving people out, we were backfilling with people with serious autism anyway.

Maria Caulfield: That is not necessarily the case now. We have a much more robust system where we are not admitting people in the first place.



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Many of the people who we are trying to discharge right now have been in a placement for many years. They have complex needs; it is not as simple as just being able to discharge them. We are actively looking at those individual cases, but we do not want to be in a place where we are admitting new people as soon as those people are discharged.

Jackie Doyle-Price: Because the longer they are in, the more harm is done.

Maria Caulfield: Of course. Absolutely.

Q172 **Jackie Doyle-Price:** Can I ask you why you decided not to proceed with the 10-year mental health strategy?

Maria Caulfield: The Major Conditions Strategy includes mental health. Obviously, we collected the evidence, and all the evidence submitted by stakeholders and organisations is being used in the Major Conditions Strategy, but what we have seen is that those people suffering with their mental health have significantly worse physical outcomes, both in terms of morbidity and life expectancy. Also, people with major conditions—such as cancer and heart disease—often have poor mental health. If we are serious about putting mental health on a level playing field—a parity of esteem—then we need to look at an individual as a whole and not just label someone as someone with a mental health problem or a physical health problem but jointly treat them and look after them holistically.

We have to ensure that people with mental health problems are getting the right physical healthcare as well, and that is the same for people with learning disabilities. That is why the annual health checks are there. That is why we are driving those forward—we are at 78% of those checks happening—because it is so important that their physical health needs are assessed and looked after as well as the other additional needs they have.

Q173 **Jackie Doyle-Price:** Did you consult with mental health organisations before deciding that?

Maria Caulfield: I have been meeting with mental health organisations because we are also, at the same time, doing our Suicide Prevention Strategy, and so I am heavily engaged with stakeholders.

Q174 **Jackie Doyle-Price:** That is not the answer to the same question, is it? Did you discuss incorporating them in the major conditions specifically, rather than attending a mental health assessment?

Maria Caulfield: Yes. I met with various stakeholders. We have regular meetings with a range of stakeholders, organisations, and charities. First, we went through why we were changing it. Secondly, we reassured them that the evidence they gave for the call for evidence was still going to be used and that we were not going to do a new call for evidence because we had had such a huge response. We are going to use all that for the work in mental health and the Major Conditions Strategy.



Q175 **Jackie Doyle-Price:** Okay. Final question from me: you talked earlier about the health checks for people with a learning disability, but we are told that many people who should be on the GP learning disability register are not currently on it. Do you have a target for getting eligible people on to the register?

Maria Caulfield: Dave, I think you can come on to that one.

David Nuttall: Yes. The way the GP learning disability register works is that anyone who considers themselves to have a learning disability can put themselves forward to be added to it. Ultimately, it is a matter for the GP to exercise clinical discretion about whether they feel the person meets the criteria or not, and so there will inevitably be some variation from area to area.

NHS England has issued guidance which includes a list of specific diagnostic codes. If you do have one of those particular diagnoses, you should be added to the register. There is also a second list which comprises codes which may indicate a learning disability and that is where there would be some clinical judgment applied. A third point is that you do not have to have a formal diagnosis of any of those codes to be added. It could be a judgment for the GP based on somebody's social interactions or ability to take on board new information, for example.

If somebody does feel they should be on the register and they are not being allowed, then our advice would always be to pick it up with the practice in the first instance. There is the option to go to the integrated care board and raise a complaint if they feel they are not being treated appropriately, but that is the way we would usually see it working.

Jackie Doyle-Price: That is if they feel empowered to do so.

Q176 **Chair:** Shall I tell you how a young man from Colchester got himself on the disability register at his practice? He took Minister Quince with him to his GP surgery because they would not let him on the register. You have just told us that GPs should have discretion. It really should not take a young man with learning difficulties having to take his own MP to the surgery to achieve that. Can we please try to issue better guidance to GPs?

I only have nine minutes left and Elliot has still not asked any questions, but I want to say that yesterday we went to the Hamelin Trust in Billericay where I met the young man in question. We heard a range of things, and the most important point the parents and carers made to us was lack of a voice, which is why I am using their voice today.

I have a question on Court of Protection orders. I am not sure, but I think this could be for Maria. If somebody has capacity, it is relatively easy to get a power of attorney; it is relatively inexpensive. If they do not have capacity, then it can take six to nine months to get a Court of Protection order and it can cost in the region of £3,000. I quote, "It is easier to get a financial order than a health and wellbeing order." What is the DHSC



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doing to look at the difficulties parents and carers of young people with learning difficulties are having in getting those sort of protection orders?

Maria Caulfield: I am not sure that comes under us. I think that is cross-Department in terms of justice, but I am happy to take it away.

Q177 **Chair:** I am sure it is, but it may be for Minister Pursglove, who is shouldering the responsibility for being the Government champion on this, to take it up with the MOJ.

Tom Pursglove: My understanding is that the Ministry of Justice largely leads on those matters, but we will very happily take that on.

Chair: You have your MDCs.

Tom Pursglove: In my capacity as chairman of the MDCs, I will gladly take that point away and raise it with Mike Freer, who is the Ministry of Justice's MDC.

Q178 **Chair:** Thank you. I am going to give Elliot five minutes but, before that, I am coming back to you, Tom. Why has Disability Confident failed?

Tom Pursglove: Disability Confident has not failed. It has been an amazing vehicle to engage more employers in providing good quality work for disabled people around the country, and that is reflected in the achievements we have had in recent times.

Q179 **Chair:** Why is it being relaunched or rebooted yet again?

Tom Pursglove: One of the things that I most definitely want to see happen is the Disability Confident review because I want to understand what more we can do to deepen commitment to Disability Confident, what more we can do to get more businesses signed up to be Disability Confident, particularly smaller businesses, and I want it to interact with, for example, Access to Work more effectively.

I want to look at what we can do around our new universal support offer and how we get the links to that right. For example, the information and advice service that we have launched is all about trying to provide good quality information for businesses around employment and health. We need to have a look at this in the holistic sense to see how we bring all that together.

As a brand, Disability Confident is very strong. It has delivered a lot, particularly when you look at the achievement of a million more disabled people in work and the goal being met five years early, and we are currently thinking about where we go from here in terms of that employment goal. For me, Disability Confident played an important part in that in engaging a lot of businesses to support more people into good quality work.

Q180 **Elliot Colburn:** Tom, very briefly, given the time constraints, could you outline some of the work that Government are doing to boost



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employment prospects for people with learning disabilities and autism?

Tom Pursglove: Yes. This is an important question and one that I feel really passionately about. To take autism as an example, it is just not acceptable that fewer than three in 10 autistic people are accessing work opportunities. That is why we are bringing forward our White Paper reforms, which are all about re-tilting the benefits system and getting rid of that jeopardy that people feel.

At the moment, someone who has a desire to work and is ambitious about trying work seeks to do so. Perhaps they identify a role that is suitable for them but think about it a little because the jeopardy of trying that and it not working out, then having to reapply and be reassessed to get that benefit entitlement back is just too much. It gets in the way and people step back from it.

We need primary legislation to change it, and we have a commitment from this Government that in the next Parliament we will deliver that—if we are re-elected at the general election, which I obviously hope we are. That is a fundamental systemic reform that needs to happen. In the meantime, we are not being complacent about this. We are working that up and moving forward with the workstreams around implementation. We also have, for example, the commitments the Chancellor made at the spring Budget around universal support, which is a supported employment model where we want to help people to identify what their aspirations are, find a role that is right for them and support them into it. We are rolling that out in the early stages with individual placement and support in primary care—which we know works—and that is our pioneer activity.

Having evaluated the trial of Access to Work Plus, we have just gone live with it. Where there is an employer that is keen to employ a disabled person, it is all about crafting the role with them and the individual to make sure it is the best that it can be to support that individual into it and to retain it.

Then, we have things like the WorkWell Partnerships Programme that we are working up at the moment too, which was also announced at the spring Budget. What we are seeking to achieve through that is greater wellness within work, helping support our colleagues in health by building greater capacity alongside local health systems, working with integrated care boards, understanding local landscapes, understanding what the needs are, and trying to help build some greater capacity to support more people into work. There are lots of things and, perhaps, I could write to the Committee with a little more detail about everything we do.

Elliot Colburn: Please.

Tom Pursglove: There is a lot of extra energy, impetus and support going into this because, as a Government, we are absolutely clear that



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we can do better on disability employment, building on the successes we have had so far.

Elliot Colburn: That would be helpful. I have three minutes—

Tom Pursglove: I did not want to eat all your time.

Q181 **Elliot Colburn:** Not at all. There are just some very important things that I wanted to quickly go through. Did you consult with disability groups when the change was made to remove the work capability assessment and replace the work element with the health element? What consultations did you have with disability groups that this would address their concerns before that decision was made?

Tom Pursglove: Over the years—and it probably predates my time in the House—there has been a lot of debate back and forth about the work capability assessment. We have decided that the best thing to do is to scrap it because we do not think it is the right approach and it has all the negative connotations about having to prove that you are unfit to work in order to receive your benefits entitlement. We want the system to focus on what people can do rather than overly focus on what they cannot. Obviously, there will always be a safety net and, where work is not appropriate, we must provide that support and we will continue to.

Historically, people have wanted to see reform in the space of the work capability assessment, and we think we can do this more effectively through the reform model that we are taking forward and, of course, there was a thorough Green Paper consultation that took place where many consultation events were held. Over 4,500 responses came in to the Green Paper and the feedback from that was reflected in our final White Paper proposals.

Q182 **Elliot Colburn:** Quickly on PIP, I have to admit I hear so much from people saying they have been told to, frankly, almost make stuff up or hype stuff up or say stuff a certain way on a PIP application because people are battling the PIP system. Do you have any plans to review the way that assessments for PIP are done?

Tom Pursglove: There are a few things. Again, in response to the Green Paper, there was some really clear feedback that came through, and some of that was around right decision first time. One of the things we are piloting is how we match expert assessors to people's primary conditions or disabilities so that claimants have a greater confidence that the individual who is conducting the assessment has a greater understanding of their condition or disability, which will help us get more decisions right. We want to test that, and we will come forward with more detail.

The Severe Disability Group is concentrating on trying to reduce the assessment burden on individuals where their condition is unlikely to improve and is only likely to deteriorate. We also want to more effectively structure and capture where people have fluctuating conditions which can



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vary from day to day, week to week or month to month to ensure that they get their entitlement right and that we support them most effectively.

All that speaks to your question around PIP decision making and disability benefit decision making more generally, and how we want to improve the quality of decision making. Sometimes the numbers that are touted around overturn rates do not accurately reflect the picture, but I always want us to do better in terms of getting more decisions right first time to give people confidence.

Elliot Colburn: I am sure you must have it in your postbag as much as we do. There is a lot more we could ask; we will follow up in writing.

Tom Pursglove: I would be very happy to meet with you to run through anything that you would be keen to talk about.

Chair: Thank you very much. Can I thank the witnesses for their evidence this afternoon? It has been hugely appreciated. If there is anything that we need to follow up in writing, I trust it will be okay to do so, and I will call the meeting to a close.