HOUSE OF COMMONS

Women and Equalities Committee

Oral evidence: National Disability Strategy, HC 241

Wednesday 29 March 2023

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Watch the meeting

Members present: Caroline Nokes (Chair); Elliot Colburn; Dame Caroline Dinenage; Kate Osborne.

Questions 1-32

Witnesses

I: Fazilet Hadi, Head of Policy, Disability Rights UK; Svetlana Kotova, Director of Campaigns and Justice, Inclusion London; and Lord Shinkwin, Chair (2020-2021), The Centre for Social Justice Disability Commission.

II: Martin McLean, Senior Policy Advisor, National Deaf Children's Society; Fran Springfield, Co-Chair, Chronic Illness Inclusion; and Nil Güzelgün, Policy and Campaigns Manager, Mind.

Written evidence from witnesses:

Disability Rights UK [NDS0021]

Inclusion London [NDS0030]

National Deaf Children's Society [NDS0036]

Examination of witnesses

Witnesses: Fazilet Hadi, Svetlana Kotova and Lord Shinkwin.

Q1 **Chair:** Good afternoon, and welcome to this afternoon's meeting of the Women and Equalities Committee and our inquiry into the National Disability Strategy. I thank our witnesses for coming along this afternoon: Fazilet Hadi, Head of Policy at Disability Rights UK; Svetlana Kotova, Director of Campaigns and Justice at Inclusion London; and Lord Shinkwin, who between 2020 and 2021 was Chair of the Centre for Social Justice Disability Commission.

As is our usual procedure, we will ask questions of you in turn. If at any point, any of you wish to come in on a question or add to something that one of the other panellists has said, please indicate by raising your hand. I will try to bring you in at an appropriate moment.

In addition, before we begin properly, in consultation with Mr Speaker, I have waived the rule on legal cases in relation to the Government's appeal against the High Court judgment on unlawful consultations on the National Disability Strategy, but I encourage witnesses to make reference to the case only if it is strictly necessary, please.

A British Sign Language interpretation of this evidence session will be available for viewers on parliamentlive.tv after the meeting. Subtitles will also be made available, for the recorded version; apologies for that.

Fazilet, may I start with you? What were your expectations of the National Disability Strategy? How does the Government's vision compare with what you had expected?

Fazilet Hadi: We were really pleased that the Government were committed to creating a National Disability Strategy. It was a manifesto commitment, and that was really positive. But when we got to the strategy that was published in July 2021—and even before that, because we didn't feel that disabled people were properly engaged in the development of the strategy—we were disappointed.

I just want to cover three areas that were disappointing. Actually, the ambition in the strategy is very big: the language used by Government is about transformation. It was clear that the evidence on the systemic inequality that disabled people were facing was set out very coherently, and it was no holds barred. It was very clear that disabled people fared worse in terms of education and employment. We experience more crime. Some of us experience more domestic violence. We experience more loneliness and worse wellbeing. So, absolutely, the evidence was there and the vision was grand, but the actions contained in the strategy didn't live up to that very grand vision of transforming society.

A lot of the actions were reviews, audits and consultations—they were maybes, not actions. There were some good actions, but they were few and far between. There wasn't the kind of systemic challenge that was

needed to the inequality that the strategy had set out quite clearly. In fact, it's debatable whether it was a strategy in the sense of, "We want to do this over the next 10 years, and this is how we are going to start it in year 1." It was actually a grand ambition with a one-year action plan.

To add to that, the starting point was not the lived experience of disabled people, or the evidence. It felt like the starting point was what Departments had committed to doing in their own departmental silos—that was very much how the document read. Also, massive areas were left out. Social care was left out. Education was left out. Benefit reform was left out. Of course Departments are going to take forward those issues, but for a Government strategy, which should have joined up things, to leave out those huge issues, which are fundamental to the life chances of disabled people, was very strange.

Q2 **Chair:** Thank you. Kevin, may I turn to you? I will come to you in a moment, Svetlana. Kevin, you were certainly very outspoken in your criticism of the lack of strategic thinking, and we have just heard from Fazilet that there was no systemic challenge. Why do you think that was the case, and what is the solution?

Lord Shinkwin: I think the root cause lies in the culture of the DWP in particular. I think they have a culture of low aspiration. I think that they are stuck in a time warp. For example, I chaired a commission for the IOD last year. One of the commissioners was a wheelchair user who also happened to be the chief executive of a FTSE 250 firm that was going from strength to strength—PageGroup—and thrived during the pandemic. That is anathema to the DWP. They simply can't get their head around that end of the spectrum of disability, where people are really achieving and realising their potential.

I think there is a major drag factor, to go back to Fazilet's comment that it is debatable whether there even is a strategy. I don't think the DWP were capable of computing the problems that Fazilet said they outlined in the strategy with the solutions. In fact, what mystifies us all—we were having a chat outside the room before this session—was why they needed to have yet another big consultation on a national disability plan when there are so many recommendations out there that they could pick up and run with and say, "Well, you've suggested this. What do you think of this?" Just one example is mandatory workforce reporting on disability by the end of this Parliament, which the IOD commission recommended, so business is signed up to it, but the DWP is nowhere.

Svetlana Kotova: I want to build on what Fazilet said. From our perspective, Government policy in relation to disabled people was largely framed within two spheres. The first is reduction in public spending, as disabled people are largely perceived as a burden on the public purse. I am not questioning the purpose of balancing the books, but when it comes to achieving equality for disabled people, there needs to be a recognition that there are entrenched barriers in society that require investment action and Government support. For some disabled people, to do things that non-disabled people do requires support, which requires funding.

The second sphere, which we see a lot, is protecting the most vulnerable. There are many questions and problems with that, because we don't know who is most vulnerable: people with higher support needs, or maybe people who cannot get diagnosis and support anywhere. Again, it just reaffirms the stereotypes and patronising attitude. Our expectation was that a disability strategy would look at disability equality from a social model point of view—that we are disabled not by our impairments, but by society—and look at all the fundamental barriers we face that the Government could help to address in a co-ordinated way, because you cannot tackle separate issues in silos. You can't tackle the problem of disability employment without looking at social care, because people need support even to get out of their house or do basic things—otherwise they will not start thinking about employment. If public transport is the way it is and you are late for work several times a month because you can't get assistance to get you off the train, for example, there are problems there too. It needs a co-ordinated approach, and we did not really see that.

Q3 **Kate Osborne:** I want to direct my question to Lord Shinkwin. Kevin, you raised concerns with the Government about how it was engaging with disabled people on the National Disability Strategy. Can you tell us a bit about the response you received, please?

Lord Shinkwin: The response was mixed. The Chair asked about expectations of the strategy. The Prime Minister at the time, to be fair, was very ambitious. He talked about "transformative" and about "the most ambitious disability plan in a generation." But I am not sure—to go back to the problem that I identified earlier in terms of a cultural, systemic issue with the DWP—that the DWP was then able to step up and deliver. In fact, I wouldn't be surprised if there were officials in the DWP who felt distinctly uncomfortable at the Prime Minister's language.

To go back to your question, this was reflected in the response. I wrote twice to the Secretary of State for Work and Pensions at the time, Thérèse Coffey, and eventually I received a really quite curt and perfunctory response to a letter that had been perfectly warm and had asked for further information about the engagement process. I cannot help thinking that this was symptomatic of the DWP's defensiveness and inability to engage with disabled people as equals—as equal partners.

For example, in another part of the UK, co-production is the approach that has been adopted in terms of developing strategies. I think that would be completely undesirable as far as the DWP is concerned; they are still treating disabled people as maybe people from ethnic minority backgrounds would have been treated, or even women would have been treated by men, 50 years ago.

Q4 **Kate Osborne:** Thank you very much. Svetlana, since the High Court ruled the National Disability Strategy to be unlawful, have you seen any improvement in how the Government engages and communicates with disabled people?

Svetlana Kotova: The background to this is that the Government established the DPO forum. That was one of their ways to engage in the development of a strategy, but that did not work well. The meetings were not even minuted. There were no agendas, and no information was given. But after that, those organisations invited to take part worked together. After the High Court ruling—we are part of this—we requested face time with the Minister for Disabled People and better engagement with the unit. Our assessment, I guess, is this: we do now have regular face time with the Minister, and they are committed to listening to us. We have a relationship with the Disability Unit, but we are still not really involved in strategic engagement, so some of it feels a bit ad hoc. We are not, for example, involved in any engagement around the disability White Paper that was published a few weeks ago. We were not engaged in the development of social care reform. So, although we have face time, it does not necessarily always lead to real change.

Q5 **Kate Osborne:** Can you tell me a bit more? You mentioned face time, but what does meaningful engagement with disabled people look like?

Svetlana Kotova: Engagement on issues that are priorities for us. Engagement where we are given enough information at the stage when policies are developed so that we could have a meaningful input. We are grown-up people. We understand that a Government has limits and there are certain objectives. We understand that, but we want trust and an open conversation about possible solutions, instead of brief two-minute verbal updates about a very general approach and very open questions along the lines of, "What do you think we should do to address the problem of the disability employment gap?", for example. I guess we need engagement at the right stage and enough information so that we can have intelligent and meaningful input.

Q6 **Dame Caroline Dinenage:** Welcome to all of you. What sort of impact is this delay and pause having on the ground in real life? We know the Government has paused several of the policies in the National Disability Strategy while it appeals the High Court ruling. Fazilet—am I saying your name correctly?

Fazilet Hadi: Don't worry. It's pronounced Faz-ee-lay.

Q7 **Dame Caroline Dinenage:** Fabulous; that is much more glamorous. I would like to get an understanding from you. While the Government appeal the High Court's ruling that the strategy is unlawful, what kind of effect is that having on the daily lives of disabled people while that is going on?

Fazilet Hadi: The first thing to say is that there have been some very big moves from Government, such as the special educational needs and disabilities plan from DFE, the Health and Disability White Paper that came out a couple of weeks ago, and the White Paper on social care. These things were never in the strategy. As Svetlana said, we have not been round those tables.

Coming back to the strategy, we heard towards the end of last year, in the autumn, that 14 action areas had been paused because of the High Court ruling, and we were told that the areas that had been paused were the areas that were only there because of the strategy. That, to me, says that the other 100-plus areas were going to be in departmental action plans anyway. It's great that they were pulled together in a document and made visible, but, essentially, they were already in train.

We understand that the legal advice has paused eight areas, some of which are quite important—producing harmonisation of data, a dashboard and an annual report, looking at the extra costs of disabled people and supporting disabled people who want to be self-employed. Those significant areas have been paused completely, but we have not heard anything about the other 100 actions. Some have not been delivered, we know; some have been delayed and some delivered in part, and we have had no reports back. There is no reason why we should not be hearing what Departments are doing on the actions they committed to. Why have we not had reports back? It feels like the High Court ruling has been used as an overarching pause when that is not really needed.

Q8 **Dame Caroline Dinenage:** Given the inaction on some of the measures and the fact that other good measures across Government were not included in the first place, is there any value in the Government scrapping or dropping the appeal and starting the whole disability strategy again from scratch?

Fazilet Hadi: Absolutely. I do not really know why the decision to appeal was taken. Given the urgency of the situation set out in the July 2021 strategy, there would have been ways of coming together with disabled people. Even though it was a strategy in terms of its ambition, it was essentially a one-year action plan that was going to be reported on in July 2022. There would have been a lot more merit in talking to disabled people about how to move forward. As I understand it, the High Court issued its ruling basically because a survey the Government conducted was called a consultation. It was not a consultation; it was a survey. Really, I think we could have got round a table and thought about how to move forward in a more productive way than a High Court appeal, which apparently is not even going to be heard until this summer. Fifteen months of energy and impetus have been wasted, and it is taking a toll on disabled people.

The actions are many and varied. I do not know whether the audit of 2,500 railway stations has been done, but the strategy admits that only a proportion of stations are step-free. The proposal that new-build housing should be accessible rather than inaccessible has not been implemented. There are some good things that we could have moved forward with and seen some changes—things like improving how we spend the disabled facilities grant. Let's do that; why can't we get on with it? What's going on? I feel that the High Court ruling, in some senses, was used as a pause on the strategy actions more widely, even those that were not impacted by it.

Q9 **Dame Caroline Dinenage:** Your answer neatly leads me to the next thrust of my question. I get a bit confused about the difference between a strategy and an action plan. I am more attracted to an action plan because it seems a bit more "doing", a bit more active, but we have now heard Tom Pursglove say that there is going to be a disability action plan, completely separate from the National Disability Strategy. Fazilet, what is your thinking on how that should look? What do you want to see in the action plan?

Fazilet Hadi: For me, a strategy will have annual action plans, but it will set out things like: this is where you want to be in five years' time, or in 10 years' time; this is how you want to shift the dial. Think of the NHS 10-year plan: they are taking actions every year, but this is where you want to end up. That is all I have to say about a strategy: it gives a notion of how you want the world to change, and you can see whether your actions are taking you there.

On the proposed disability action plan, I think Tom Pursglove probably wanted to do something after the Government found itself on hiatus, challenging the High Court ruling. The trouble is that, again, it is not coming from disabled people. The Disability Unit, with colleagues, is to come forward with a list of actions and have some roundtables. It is not our list of actions; it is theirs, or Government's, so we are starting in the wrong place. The issues have not been finalised yet, but we are not clear why the issues on the draft list we have been shown are there. The idea is that there will be pre-consultation roundtables, then a three-month consultation on the action plan, which we are told is about quick wins, not systemic change, because with a general election next year, how can it be about systemic change?

It appears that we are to have a Rolls-Royce consultation—excellent—but a quick-wins action plan. If there are quick wins, I don't know what they are—even the quick wins in the 2021 National Disability Strategy have not been delivered, as far as I can see. It is quite hard to feel optimistic about this process. I think it is done with good intentions, but it is quite hard to feel positive about it.

Q10 **Dame Caroline Dinenage:** I can understand that. Has the Minister for Disabled People asked for your input into the disability action plan?

Fazilet Hadi: He has not asked for our input into what the areas of focus should be. He has asked that the DPO—disabled people's organisations—Forum find two people for each of the roundtables. That is as far as it goes.

Q11 **Dame Caroline Dinenage:** I have completely monopolised Fazilet. Does anyone else want to come in on any of the questions I have asked about how the action plan should look?

Lord Shinkwin: My key question is just how much taxpayers' money has the DWP burnt by employing high-charging barristers to lodge an appeal and then pursue it in the Court of Appeal? I totally agree with Fazilet and with you that it might be a good idea to draw a line and move on.

On what I would like to see in the disability action plan, action would be a good start.

Dame Caroline Dinenage: The clue is in the name.

Lord Shinkwin: Yes. I agree with Fazilet that we are starting in the wrong place. There are so many recommendations. I mentioned one of them—mandatory workforce reporting on disability—but there is another from the Institute of Directors' commission, which I chaired, about strengthening the Disability Confident scheme by requiring members to report on workforce and pay gaps. At the moment, they are marking their own homework, either as individuals or among the top level, in which still, after five years, there are fewer than 500 organisations out of 1.2 million UK employers. They are marking each other's homework and are not required to be transparent on workforce and the pay gap. There are specific concrete measures that the Government could put into a disability action plan and say, "They have already recommended this—and by the way, business is behind them—so what do you think? How are [the Government] going to take this forward?"

Svetlana Kotova: The situation is very serious for disabled people. There is lots of evidence of regression in rights. I will not cite all the stats, but 4 million people are living in poverty and there are 400,000 people living in inaccessible homes. There are no quick wins, but we want to see real commitment to disability equality. We want to see a proper engagement mechanism put in place, so that our experiences are listened to, not denied—at least that's how we feel it was.

In terms of really quick wins, we want to see accessibility standards for new build homes, and more than what was promised. We want to see full implementation of the Equality Act. This Committee recommended some measures that the Government could put in place to make the Equality Act work better. That could include, for example, looking at how licensing and other frameworks could be used to improve accessibility. But first we definitely want a good working engagement mechanism in place.

Q12 **Dame Caroline Dinenage:** Just before the Chair slaps my wrist for taking up too much of the Committee's time and your time, I would like a quick answer from all of you. Do we think that appointing ministerial disability champions would be the right approach to developing disability-inclusive policies? Lord Shinkwin, I am going to start with you

Lord Shinkwin: At a senior level, I think it should be Secretaries of State, who would then cascade it down to a Minister of State on the basis that there would be a report upwards.

Fazilet Hadi: There are disability champions, as I understand it, that are Ministers—certainly in the National Disability Strategy—but I am not clear what they have been doing to champion disability.

Dame Caroline Dinenage: So you would want a better understanding of what that means.

Fazilet Hadi: They can be acting now. There may not be a strategy, but there is nothing to stop them driving forward disability equality in their Departments.

Svetlana Kotova: I have many questions about this. I think a better approach would be to give more power, resource and expertise to the Disability Unit and make it a driver of policies. The Disability Unit would come and question Departments and challenge them, as opposed to what happens now. I think that would be a more sustainable and strategic approach and would not depend on individuals.

Dame Caroline Dinenage: Thank you.

Q13 **Chair:** I turn to the proposals in the health and disability White Paper, specifically around how the Government is going to encourage and foster more disabled people into work. Fazilet, can I start by asking you whether you think this is ambitious enough, whether it's going to work, and what is good and what is not?

Fazilet Hadi: We are of the view that this is going to make life very, very difficult for disabled people. It feels like disabled people need sanctions and conditionality if we are to work, but other people need incentives, and that is not right. The reason I say that is because the Government has really lauded the fact that it proposes to get rid of the work capability assessment. While that assessment has no friends among disabled people, it does give some disabled people who have limited capability for work—those who either cannot work at all or can only work limited hours—some protection from sanctions and conditionality, and that is really, really important.

Scrap the work capability assessment, but the current plan is not to replace it with an assessment that works better. That was always the ask: let us have an assessment that really looks at my capability to work, looks at the employer and the sort of circumstances around me, as Svetlana was saying earlier, looks at transport, and looks at my social care. Let us have a proper assessment that looks at my circumstances and the barriers for me in getting into employment.

Let us have assessors who understand how to deliver that assessment, because we need a consistent way of working out who are the disabled people who do need protection or some additional support. Leaving it to individual work coaches up and down the country to decide individually what should happen, through a health and work conversation, leaves disabled people extremely exposed to bad practice. That is one point.

Secondly, the Government sought to introduce a link in the White Paper between the personal independence payment, which is a benefit to meet the extra costs of being disabled, and a health component of universal credit. That is dangerous because there are people who do not have a long-term disability, so they do not qualify for PIP and could find themselves without the health component of universal credit.

There could be lots of disabled people who are regularly assessed for PIP who live in fear of losing it, because if they do so they will then lose the health component of universal credit. We know that 50% of claims for PIP are rejected first time. That puts additional pressure on people. The linking of PIP and the extra costs benefit with access to a higher rate of universal credit is problematic. If you combine the greater imposition of sanctions, the failure to understand consistently across the service the fitness for work of disabled people and the link to PIP, that is a very scary prospect.

On the day the White Paper was published the phones were hot with disabled people ringing because they were anxious about what was happening. The proposals need primary legislation, which would be introduced after the next general election. They will not affect current claimants, and they will be implemented from 2026, so we can quell people's fears, but the direction of travel is all bad.

The only good thing is that there seemed to be more money for employment support, which is really welcome, because there are disabled people who want to work. I am not sure how those employment support programmes will be delivered. I think they should be delivered by disabled people's organisations and impairment-specific organisations. We understand the barriers and what gets people into work, and I do not think those programmes should be delivered by the DWP.

Chair: Thank you very much. Kevin, would you like to add anything?

Lord Shinkwin: Only that I think that the Centre for Social Justice has done a wonderful job in persuading the Chancellor and the Government to adopt universal support. I know that Iain Duncan Smith wanted to see that when universal credit was initially introduced, so all credit to them. I agree with Fazilet that, in effect, it is one step forward, two steps back, creating concern and anxiety among disabled people, particularly on the PIP assessment point which she explained so eloquently. I do not think that, as designed, PIP is fit for purpose for what it is now proposed it be used for.

Svetlana Kotova: A couple of points. First, we have not seen evidence that sanctions work in relation to disabled people, and it is disappointing to see, again and again, that that is the main focus of policies to help as many of us as possible to get into work. There is still very little about improving the workplace itself. If you wanted people to go to the beach you would clean it and make it nice so that people would go there. It does not feel like that that is what Government are doing on making the workplace better and more attractive to disabled people. There are things we had to fight for. For example, promoting the message that employers could treat disabled people better and create specific programmes to help them to progress and so on; or specific recruitment to reserve posts for disabled people; or using procurement powers to improve opportunities. We want people in good jobs. We do not believe that work in itself—any kind of work—would improve people's lives. We think that people need good jobs.

Secondly, to echo the points that have been made about PIP, there are about 600,000 people who get the work capability element, but not PIP. There is a question as to why that is. Obviously, they will be big losers, and many of them will be in real trouble. We think it is important to completely detach the money element from the employment support element.

We are also quite worried about work progression. Work progression is really important and necessary for disabled people. We know that the higher you go in organisations, the fewer disabled people there are, but it looks like the work progression offer would be about making people work more hours or apply for higher paid jobs. There are some people who cannot work more hours; part-time work is the only way for them to work and to manage their impairment and health conditions. We are really worried that people will be pushed to work more, with detriment to their health.

Q14 **Kate Osborne:** Svetlana, in written evidence submitted to this inquiry, Inclusion London said that the UK's compliance with the United Nations convention on the rights of persons with disabilities shows "significant retrogression" in many rights for disabled people. Can you tell us what your main concerns are around that, please?

Svetlana Kotova: First, this is not us saying this; this is the UN disability committee saying this. In 2016, it found that welfare policies and reductions to public services had led to gross and systematic violations of disabled people's rights to independent living, employment, work, and an adequate standard of living; then, in 2017, the UN committee again issued quite critical recommendations to the UK Government. What was shocking to us was that this was completely dismissed; there was no attempt from the Government to engage with this. They might disagree, they might think that the UN got it wrong, but they should at least hear and look at this in a grown-up, serious way.

Also, in its general obligations, the UN convention requires Governments, when developing policies, to engage with disabled people through their representative organisations. In its general comment, the UN clarified these are organisations led and directed by disabled people. Obviously, there was a clear breach of that.

We collected evidence last year to submit to the UN about progress, and the evidence is shocking. The disability strategy included some of this evidence, and you could find some of it as well. People feel that their situation has got worse since 2017. That is about all rights, but especially the right to independent living, because institutionalisation is going on. Resources are going to segregated settings, where people are not necessarily supported well and they are definitely not supported to live independently and be included in the community. The convention talks about inclusive education, but there is more segregation in education. Mental health reform doesn't really look at the fundamental issue of human rights and why only people in mental distress are detained on the basis of risk. And so it continues—the list could go on, unfortunately.

We talk about the UN convention a lot, and that is not just because we want to challenge the Government. This is a document that was developed together with disabled people. It sets international standards for what Governments should do to promote the rights of disabled people. This is why we think it is important. It should be like a blueprint for any Government: if they want to develop disability policies, they should start with what the UN convention says.

Chair: I thank all three of our witnesses for their contributions this afternoon. It has been hugely appreciated. If at any point you wish to add anything to what you have told us, please feel free to contact us in writing. I am going to suspend the meeting for a short while so that we can swap panels of witnesses.

Examination of Witnesses

Witnesses: Martin McLean, Fran Springfield and Nil Güzelgün.

Chair: Good afternoon and welcome to the second panel of this meeting of the Women and Equalities Committee as part of our inquiry into the disability strategy. Can I check that all our witnesses are content that we use your first names when addressing you? I have had nods all round—thank you. I welcome Martin McLean, senior policy adviser at the National Deaf Children's Society; Fran Springfield, co-chair of Chronic Illness Inclusion; and Nil Güzelgün, policy and campaigns manager at Mind. Members of the Committee will ask witnesses questions in turn, and if at any point you wish to add anything or contribute when one of the other panellists is speaking, please raise your hand or indicate to me and I will bring you in. We will start with questions from Elliot Colburn.

Q15 **Elliot Colburn:** Fran, from your perspective, to what extent do the Government recognise the experiences of people with invisible disabilities and chronic illnesses, and what is the typical attitude of society towards people with non-visible conditions?

Fran Springfield: Because our conditions are invisible, we are very often invisible. People can see very obviously if somebody has a broken leg or is using a wheelchair, yet if you have a low energy condition such as ME or CFS, people cannot see what that is, so they do not believe it. I have had this—I have been accused of exaggerating my symptoms. I have been accused of putting it on, and that is by a healthcare professional. That is my own professional background, so that was utterly horrendous as a personal experience.

People just do not understand. They do not recognise how difficult our lives can be. We often measure our activity levels by spoons. You will have got up today, had a shower, come into Parliament to work and probably not thought about the energy that that will have used up for you. For me, that is half my energy—half my spoons for a day. If I carried on and tried to do anything else, I would be utterly exhausted and probably in bed for

the rest of the week. One of the reasons why I have chosen to give evidence virtually today is to enable me to do other things tomorrow and Friday, which I would not have been able to do had I travelled only a very short distance to the House. I live just south of the river, so practically I could have come, but it would have been too much for me to do so.

Q16 **Elliot Colburn:** Thank you for that, Fran. I am thinking particularly about the intersection of disability and other protected characteristics, with views not just from my own postbag as an MP but from friends of mine. How much does that intersection affect the lives of disabled people? I am thinking particularly of the impact on women. Many of my female friends, for example, suffer from either fibromyalgia or other endometriosis-related conditions. They report to me that they have very similar experiences to what you have just laid out in terms of not being believed and having exacerbated symptoms. Could you talk to us a bit more about where disability meets other protected characteristics, and the impact that has?

Fran Springfield: Yes, certainly. Can I chime in by also talking about the problems we have getting diagnoses? For most women who are seeking a diagnosis for one of their conditions, it can take up to 10 years to get one. Some of us were unfortunate enough to become unwell with other things during the covid pandemic. I did and I needed to seek a second diagnosis for something, and I couldn't get one. I ended up having to pay privately, which is the last thing I wanted to do. There is a major problem with that.

Women's problems are nearly always trivialised until somebody goes through something and understands what it is. "Oh, you've only got a heavy period. Oh, come on; it can't be that bad." The medical profession and others allied to it don't get it. I would say there needs to be a huge amount more teaching on this. Teaching and resources need to be in hospitals, surgeries and workplaces for professionals, and they need to be delivered by people who have invisible illnesses.

Q17 **Elliot Colburn:** Thank you for that, Fran. Nil, may I ask you the same question about intersectionality, where disability meets other protected characteristics and the difficulties that presents?

Nil Güzelgün: Absolutely. This is a really important topic for Mind. As part of our new strategy, we focus on race equity, poverty and young people. We acknowledge that people who are racialised—from racialised backgrounds—are disproportionately affected by mental health problems. Similarly, there is a two-way link between poverty and mental health problems. We see a greater prevalence of mental health problems in areas with higher levels of deprivation. Similarly, people with mental health problems are more at risk of slipping into poverty.

The focus on young people is there because we have acknowledged that younger people have been struggling to access mental health support since the pandemic, and the need for support has increased. These intersections are critical. One in four of us will experience a mental health problem in any given year, but too many of us are made to feel isolated or

ashamed because of that. We think that needs to be addressed urgently through a cross-Government mental health strategy and the National Disability Strategy.

Elliot Colburn: Thank you. I may have some more questions a bit later, but for now I will hand back to the Chair.

Q18 **Chair:** Thank you very much. I will turn my questions to Martin. I want to talk about the challenges that young people face when they have hearing loss, and how that impacts their education. We know that the pandemic highlighted the ability of deaf people to communicate more widely and to receive information. Can you tell us a bit more about how significantly it affects children in schools?

Martin McLean: Certainly. The National Deaf Children's Society is particularly focused on barriers to education. There is an issue around deaf awareness in schools. In a young people's survey that we carried out, 31% of children and young people said that most or all of their teachers did not have good awareness of their needs. That is a pretty significant figure when you think about it; almost one third of deaf young people are saying that the majority of their classes are difficult to access.

An important factor enabling them to overcome some of the barriers they face around a lack of awareness in the classroom is the role of teachers of the deaf—teachers who have an additional postgraduate qualification in deafness. They work in a range of roles and settings, including visiting deaf children in mainstream schools and colleges. Unfortunately, we have seen a 19% decrease in the number of teachers of the deaf since 2011. That means that, particularly for teachers of the deaf in peripatetic roles, who visit schools and families in their homes, the case loads are increasing. That unfortunately makes them less able to carry out work that could be very impactful—for example, supporting two-year-old development checks carried out by health visitors, or supporting the provision of tailored careers guidance for deaf young people so they are better prepared to move into work.

It is not just in schools where we see barriers to education; it is also in colleges and universities. We know of a number of deaf students, particularly those who use BSL as their first language, who are not getting the support they need in higher education. That is partly due to a rigid regulatory system, which makes it harder to source BSL interpreters and other specialist support for deaf students.

Q19 **Chair:** Can you explain why the regulatory regime makes it harder for students to access the support they need?

Martin McLean: Since 2016, there has been the quality assurance framework, which applies to any support worker funded through disabled students' allowance. To fund the use of a BSL interpreter in higher education through DSA, they need to be on a register of providers and follow terms and conditions that the Government sets out to be on that register. Many interpreters are freelancers, and they find that there is just too much bureaucracy around being on the register. There are agencies

that are registered and have a core of BSL interpreters that they use, but we have an issue with agencies not having enough people on their books. That results in the agencies saying that they are able to supply interpreters, but when it comes down to it—

Chair: They don't appear.

Martin McLean: The interpreters are not turning up at lectures, and the students are left unable to access the lecture or seminar, which is really bad.

Q20 **Chair:** Is the problem around the regulatory regime the bureaucracy or the cost, or both?

Martin McLean: There is a cost that comes with bureaucracy; there are a lot of terms and conditions that are required to be followed. What we have asked the Department for Education to consider is introducing more flexibility into the system, because there is already a national register of communication support providers. Most BSL interpreters are on that register, and there is quality assurance of that register. So we have asked the Government to consider whether, when an agency is unable to provide a BSL interpreter, it is possible to use DSA to fund an interpreter—or it could be a palantypist—from that national register. It is just about introducing a little bit more flexibility into the system. That proposal has been put to the Department for Education, and we are waiting to hear back from them.

Q21 **Chair:** Thank you. Do you think that the SEND improvement plan is going to help? Will it make it more inclusive for deaf children?

Martin McLean: There is the potential, but there is still a lot of detail to be worked out. In the improvement plan, the Government has committed to developing new national standards, and these aim to ensure more consistency in the experiences of children with SEND. We certainly support that aim, but it really is important that the Government creates deaf-specific national standards that will set out expectations around early identification of deafness, involvement of teachers of the deaf, deaf awareness in education settings, and access to assistive technology and sign language. So a lot depends on the actual content of these standards.

Within the improvement plan, there is a workforce development plan, and we were pleased to see that teachers of the deaf were referenced in that plan and the Government is committed to signing off an apprenticeship pathway for people to become teachers of the deaf—to do an apprenticeship. That could help overcome some of the issues around the cost of training people up to become teachers of the deaf. But it is not until 2025 that that apprenticeship will get launched, and we wouldn't be looking at new teachers of the deaf until 2026 or 2027. In the meantime, we are asking for the Government to consider a training fund to boost the number of teachers of the deaf in the short term so that we can get the numbers back, or towards where they were back in 2011.

We also think that the improvement plan could be a lot bolder around young people preparing for adulthood and employment. There is reference to an adjustments passport that the DWP is piloting for young people. This has the potential to help ensure that deaf and disabled young people are made aware of the Access to Work scheme, which is very important in enabling deaf people to sustain work. It could also have them consider what adjustments they might need in the workplace. However, a lot depends on the knowledge of the professionals who are introducing that passport to young people, their ability to talk about reasonable adjustments, and whether they know what support is available in the right place for deaf people. Unless you consider the professional practice around that passport, it will effectively be a glorified PDF sitting on the Government website. It will be a shame if it does not have an impact.

Q22 **Chair:** Do you think the Government have a better understanding now of the needs of deaf children?

Martin McLean: That remains to be seen. There have been some positive steps; for example, there is recognition of the role of teachers of the deaf in the SEND improvement plan. We also recently saw the BSL Act passed, and the establishment of a BSL advisory board. That board can certainly help shine a spotlight on issues that deaf children and young people face, and on the difficulty that parents of deaf children have in learning sign language and finding a sign language course, because courses are very expensive.

Additionally, a BSL GCSE is expected to launch in 2025. We hope that the Government can support the roll-out of that GCSE, for example by ensuring that sufficient numbers of people are qualified to teach it. Those are certainly positive developments, but we also need to see action on the ground in terms of the services that deaf children and young people can access.

Q23 **Dame Caroline Dinenage:** Nil, I would like to talk to you about mental health. In January, the Government announced that they would be publishing a major conditions strategy, and that mental health would be a component of it. What are your aspirations for what it might look like?

Nil Güzelgün: I think it is fair to say that at Mind, we were disappointed to see the Government drop the cross-Government plan on mental health, and to propose instead a major conditions strategy. We think that there needs to be a cross-Government plan on mental health, with a long-term, 10-year vision, as previously proposed.

On the major conditions strategy, we welcomed the principle that mental health conditions would be there alongside other health conditions, so that there would be an integrated approach to these issues, but we worry that the focus on mental health will be diluted.

We think that there needs to be a focus on the social determinants of health, such as poverty, education, employment and housing, and we also need to look outside the NHS system. That is why a cross-Government plan is critical. We also think that the strategy needs to target

interventions at the people most at risk of having mental health problems. According to our analysis, those are people who are more likely to experience poverty, people from racialised backgrounds, and younger people.

Mental health needs to be considered alongside all policies and to become a reality. Our key concern around the strategy is that younger people and children might be excluded because they are less likely to have long-term, chronic health conditions, albeit that they are the group that might benefit most from early interventions. The other risk is that the major conditions strategy has a five-year timeline, which does not offer the same stability and focus on long-term conditions that the cross-Government plan on mental health would have offered.

Q24 **Dame Caroline Dinenage:** Has Mind had the opportunity to feed into the construction of the strategy? Were you asked what you thought about it?

Nil Güzelgün: We have obviously fed into the cross-Government plan, and I want to highlight that 23,000 people with lived experience of mental health problems fed into that. When it comes to this plan, I do not think we have been consulted to the same level.

Q25 **Elliot Colburn:** I would like to start with you, Nil, but this is for every panellist. We were talking about strategies, and I would like to look at the health and disability White Paper in a bit more detail. From your perspective, how will the proposals in that White Paper affect people with non-visible conditions?

Nil Güzelgün: I can obviously only talk about the effect on people with mental health problems. There were two major proposals that I want to focus on: the scrapping of the work capability assessment and then the implementation of more rigorous sanctions, which were announced as part of the White Paper.

We welcome the scrapping of the work capability assessment, because they were perceived by people with mental health problems as difficult and oftentimes humiliating. Equally, I think it also means that assessments will be separated from financial support, and it will also hopefully reduce the number of assessments.

We are concerned, however, that they will be replaced by PIP assessments, as there are some critical challenges linked to that. Indeed, in our report, "Reassessing assessments", which we published only at the beginning of this month and which we are happy to share with the Committee, we have seen a number of issues. In a poll of more than 1,000 people with mental health problems, we found the following issues with regard to PIP assessments. Almost one in two people who participated in the poll did not agree with their PIP assessment, and that compared with one in three people disagreeing with their work capability assessment for universal credit and ESA.

Similarly, nearly one in seven people who went through a PIP assessment were left feeling that their mental health deteriorated following this

assessment. Again, a lower percentage of people had a similarly negative experience on their mental health for work capability assessments. Nearly half of all respondents felt that their PIP assessor did not understand mental health problems, and that compared to 36% of people who went through a work capability assessment.

I think our report highlighted that PIP criteria and assessments are not suitable for people with mental health problems, and this is due to the fluctuations and shorter-term nature of mental health problems. We think that the Government really needs to review urgently and improve PIP assessments, so that they can be more appropriate for the people that go through them. The way to do that, we think, is by establishing a committee and a commission led by disabled people with experience of the benefits system who can review the criteria and who can meaningfully input into what this looks like.

Q26 **Elliot Colburn:** Thank you very much, Nil. Martin, I will put the same question to you.

Martin McLean: I looked at the White Paper from the perspective of what it was offering young people in terms of employment support. Overall, it was very disappointing in relation to young people. In the Green Paper, there had been questions around the support that young people may need specifically to move into work, but when you looked at the White Paper, that seems to be absent. There was no recognition that young people may need more tailored support. I suppose there is an assumption that whatever is going to work for older adults and people with acquired disability looking to get back into work is going to be effective for young people as well.

At the moment, the DWP has a network of youth hubs that it funds and the White Paper is a missed opportunity because there is no reference to the role that these youth hubs could play, potentially, in supporting disabled young people into work, through things such as drop-in centres where young people could find out opportunities to improve their skills or to find work experience. It is just frustrating that disabled young people have not been considered within that, because they can face some of the biggest barriers in moving into work.

Our insight has found that young people in general have little awareness of what support is offered through DWP, such as the Work and Health programme, the Access to Work scheme and Disability Confident. They are not aware of those programmes, and that increases the risk of disabled young people leaving education and falling into long-term unemployment. Some of the programmes could make a big difference to the lives of young disabled people, but the Government need to do a lot more to make sure that they are informed about them.

Q27 **Elliot Colburn:** Thank you, Martin. Fran, over to you for my final question on that issue. From your perspective, how might the health and disability White Paper affect people with non-visible conditions and, crucially, what was missing from it?

Fran Springfield: First, can I start by saying that I very much agree with what the representative of Mind has said? This will have a huge impact on people with disabilities. As much as they can't be seen, these conditions are fluctuating and some days are better than others. There is no movement in the system at all. Taking away the work capability assessment and not replacing it with something else does not make any sense to me. I cannot see how you can move PIP into parts of universal credit, either, because PIP is a completely different system.

From our perspective, we do not think that this has been properly thought out at all. I do not think there has been any input into this from disabled people and it is going to make life much more difficult for those of us with invisible disabilities. Indeed, only today the PCS union has come out and called this "a massive attack on claimants" that will usher in a "computer says no" system. That is the last thing we need from the DWP. As we have heard already, the DWP does not have a reputation for listening to us. It does not have a reputation for understanding our conditions. People's mental health will deteriorate during appointments—I have seen this, graphically—or indeed after appointments with the DWP. We have to find a system that is compassionate and encourages people if they are well enough to go into work, but which accepts that there are some people who will never be well enough to go into work, and those people deserve support and help.

Q28 **Elliot Colburn:** Thank you very much, Fran. One final question to all our panellists; Fran, I will start with you this time. Notwithstanding everything that you have said so far, are there any further recommendations to Government that you would suggest that would help to address the challenges you have discussed today? I will start with you and then I will come to the panellists in the room.

Fran Springfield: Thank you. I would certainly start by ending DWP sanctions. They actually don't achieve anything; they don't help people into work. All they do is push people further down into poverty. We certainly need a fairer benefit system, one that looks at people's holistic needs, not just at whether they can move a book from there to there or whether they can walk 20 yards, or whatever it is—20 metres these days.

It needs to be a system that looks at how people manage, how they live and how they interact with people, rather than being focused just on physical things. Again, that is really difficult for our people—it is much more difficult to get that across to DWP staff. We believe that there should be an end to charging for social care because at the moment so many of us have to make a decision between whether we eat, whether we heat or whether we pay for our care. It is that bad. It is awful to have to make those decisions, and we shouldn't have to. We need to restore the legal aid system for DWP cases; it would make a lot of difference if people could get the right help.

The other thing that comes out of charging for social care is that there should be much more co-production with disabled people on social care. Hammersmith Council has done a good job, and Tower Hamlets is just

about to start. There are lots of opportunities that people can see and lots of ways of actually getting this right.

We have wanted a disability rights commission because at the moment the Equality and Human Rights Commission does not seem to have a disability committee; it has not met for almost two years, I think. We certainly need to strengthen the Equality Act and give it some teeth, so that if there are ways in which people are being discriminated against but they cannot get legal help to sort that out, there will be a role for the EHRC to come in and deliver training, support or whatever is needed as far as that is concerned. We need to have the UNCRPD enshrined in UK law.

My final worry is about transport. The Department for Transport needs to work with disabled people to ensure greater access for us on trains, buses and aeroplanes—plane journeys particularly are a total nightmare if you are in a wheelchair. There should be more contact with organisations like the Disability Unit. I am glad we have two places on that committee, but frankly we need a great deal more than two. We are the disabled people, so we know what it is like every day. We need more representation.

Q29 **Elliot Colburn:** Thank you very much for that, Fran. Martin, may I come to you next on that same question? Are there any other recommendations that you have not gone through so far that you think the Government should be listening to?

Martin McLean: We probably have three recommendations for a disability action plan. One is a recognition of the need for specialist support and actions to address shortages, which I have already described: boosting the number of teachers for deaf people and addressing access and specialist support in higher education.

Secondly, we would like to see improved cross-departmental working. It would be particularly helpful for deaf and disabled education leavers if there was more cross-working between the Department for Education and the Department for Work and Pensions. That would help them avoid that cliff edge that many young people face when coming up to the end of their education.

Thirdly, we need more data. We welcomed the commitment in the original disability strategy to improving the availability of Government disability data. There is a lot that we do not know or are not monitoring around deaf children and young people. For example, we know very little about the education and employment outcomes of 19 to 25-year-olds. We would like the outcomes to be published with a breakdown by type of disability.

There is also the attainment and progress of deaf children, who are not recorded as having special educational needs—that significant group are not captured in Government data at all. Also, there should be quality metrics on early identification and intervention—it is obviously really crucial for deaf children's early development for there to be a referral from the NHS to specialist educational services, but there is no data around that.

Q30 **Elliot Colburn:** Thank you very much. Finally, I put the same question to Nil.

Nil Güzelgün: With regard to the sanctions regime and the health and disability White Paper, we are concerned that people with mental health problems might be disproportionately affected by a toughening or more rigorous sanctions regime.

As other panellists have previously highlighted, there is no evidence base that sanctions help people to move into work. With this new approach, we are concerned that people with mental health problems could face a risk of sanctions because work coaches will be able to set mandatory work-related requirements for anyone with a health condition or disability. Given that our research has highlighted that work coaches and assessors have a fairly limited understanding of mental health problems, people could then be pushed into those activities even though they are too unwell to engage in them.

When it comes to the National Disability Strategy, we wanted to highlight some other points. One is about the definition of disability in the Equality Act. In a survey we conducted in 2019, people with mental health problems struggled to understand whether they would fall under the definition of disability, and the element that presented the biggest challenge for people with mental health problems was around the requirement for the issue to be long term. As mental health problems fluctuate and the issues can be short to medium term, that element of the definition was particularly difficult for people with mental health problems. We think that needs to be reviewed and changed.

Q31 **Chair:** I have two questions. One is for Fran about transport accessibility. You made a comment about wheelchair users and planes. I think it was Fazilet earlier—I hope you heard her evidence—who spoke about an audit of railway stations. Why is there still a problem with accessibility of railway stations? I speak with some level of interest, in that one side of the track at Swaythling station in my constituency is still completely inaccessible to wheelchair users. Is there a quicker, easier way of highlighting where there are still problems than a full audit of every railway station in the country?

Fran Springfield: I am sure there are quite a number of disabled people who would willingly help with that audit, certainly if you follow @Doug_Paulley on Twitter. He is the expert on trains and what goes wrong at train stations.

I suspect the bottom line on this is money. It is all very well people saying that we need to be active in the jobcentres and active in the world of employment if we cannot actually get to work. That is a bigger problem, and I do not know—other than the suggestion of a wide audit—how we solve that one. I am sure there will be disabled people willing to help with that.

Q32 **Chair:** Thank you. I just think that when it comes to engagement with disabled people and accessibility issues, they are the absolute experts on

where they can and cannot get access to.

Martin, can I ask you a question about technology and how that might help young deaf children in particular? There are some amazing advances in technology, including apps such as Signly, which can overlay BSL on every website. Why do you think there is still such a blockage to them being rolled out more widely?

Martin McLean: That is a good question. There is not always that understanding of what is out there. There are various different apps, but whose role is it to sit down with families and talk about what is available? Many teachers of the deaf would acknowledge that they would like to be more informed and upskilled in terms of what technology is available.

We have certainly seen during the pandemic a lot more use of automatic captions, on platforms such as Teams and Zoom. However, there is still work to do in ensuring that those captions are as accurate as possible. We have seen higher education students who are deaf having to rely on various captioners for online lecturers, but then complaining about the number of errors. They are not yet quite at the level of a human captioner. More could be done there.

We would also like to see better access to radio aids, which are supplementary to hearing aids and cochlear implants, which can help a lot in situations with a lot of background noise because they transmit the sound of someone's voice clearly. They tend to be used in schools, but less so outside schools. They could be used more in the workplace and also in the home with families of deaf children in early years to help to support language development. A lot more technology could certainly be utilised.

Chair: Thank you. I make the same offer to this panel: if there is anything that you feel we have not covered that you would like to raise with us, please get in touch with us in writing after this session. I thank you all for taking part. It has been hugely appreciated and very helpful.