



OFFICIAL REPORT
AITHISG OIFIGEIL

Social Justice and Social Security Committee

Thursday 21 March 2024

Session 6



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SOCIAL JUSTICE AND SOCIAL SECURITY COMMITTEE

9th Meeting 2024, Session 6

CONVENER

*Collette Stevenson (East Kilbride) (SNP)

DEPUTY CONVENER

*Bob Doris (Glasgow Maryhill and Springburn) (SNP)

COMMITTEE MEMBERS

- *Jeremy Balfour (Lothian) (Con)
- *Katy Clark (West Scotland) (Lab)
- *John Mason (Glasgow Shettleston) (SNP)
- *Roz McCall (Mid Scotland and Fife) (Con)
- *Marie McNair (Clydebank and Milngavie) (SNP)
- *Paul O’Kane (West Scotland) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

- Vicki Cahill (Alzheimer Scotland)
- Fiona Collie (Carers Scotland)
- Chirsty McFadyen (University of Strathclyde)
- Dr Laura Robertson (The Poverty Alliance)

CLERK TO THE COMMITTEE

Claire Menzies

LOCATION

The Mary Fairfax Somerville Room (CR2)

Scottish Parliament

Social Justice and Social Security Committee

Thursday 21 March 2024

[The Convener opened the meeting at 09:00]

Decision on Taking Business in Private

The Convener (Collette Stevenson): A very good morning, and welcome to the ninth meeting in 2024 of the Social Justice and Social Security Committee. We have received no apologies. Our first item of business is a decision on whether to take agenda items 5 and 6 in private. Do members agree to do so?

Members *indicated agreement.*

Subordinate Legislation

Discretionary Financial Assistance (Scotland) Revocation Regulations 2024 (SSI 2024/58)

09:00

The Convener: Our next item is consideration of a Scottish statutory instrument that is subject to the negative procedure, the purpose of which is to bring the discretionary housing payments scheme under the control of the Scottish ministers and to allow them to issue Scotland-specific statutory guidance. Do members have any comments to make on the instrument?

In the absence of any comments, I invite the committee to agree that it does not wish to make any further recommendations in relation to the instrument. Are members content simply to note it?

Members *indicated agreement.*

Social Security (Amendment) (Scotland) Bill: Stage 1

09:01

The Convener: The next item is our third evidence session on the Social Security (Amendment) (Scotland) Bill at stage 1. The bill amends the Social Security (Scotland) Act 2018 to make changes to the Scottish social security system. Today, we will focus on the concerns of carers of potentially vulnerable clients and the concerns of clients who have a carer.

I welcome to the meeting Fiona Collie, head of policy and public affairs for Scotland and Northern Ireland at Carers Scotland, which is one of the national carer organisations; and Vicki Cahill, policy and public affairs lead for Alzheimer Scotland. Thank you for accepting our invitation and joining us today.

Before we start, I will mention a few points about the format of the meeting. Please wait until I or the member who has asked the question says your name before speaking. Do not feel that each of you has to answer every question—if you have nothing new to add to what has been said, that is perfectly okay. I ask everyone to keep their questions and answers as concise as possible.

Without further ado, we will move to questions, the first of which comes from Bob Doris.

Bob Doris (Glasgow Maryhill and Springburn) (SNP): Good morning, and thank you for supporting our evidence session this morning. This is a relatively straightforward—and, I think, non-contentious—question to start with. Different benefits have qualifying deadlines and cut-off dates for when people can apply. The bill seeks to repeal the Covid measures in relation to deadlines. Do the witnesses believe that, with that provision removed, there will still be sufficient flexibility for applying late or after the deadline for benefits?

Fiona Collie (Carers Scotland): We believe that there will probably still be sufficient flexibility but that clarity might be needed on when that flexibility exists. Consideration should be given to delays that have been brought about by caring duties, the illness of the carer or the cared-for person, or the limited availability of advice services to support the individual in making an application. There is a need for public clarification so that transparent, open information is available on how those flexibilities will enable individuals to make their applications on time.

Bob Doris: That is very helpful. In other words, removing the Covid qualification presents an opportunity to provide clarity on what the other

reasons for applying late might be. Do you agree with that, Vicki Cahill?

Vicki Cahill (Alzheimer Scotland): Yes. We would absolutely agree that clarity is paramount in ensuring that the processes are as transparent and simplified as possible, both for the decision maker and for people who make applications.

There are existing measures in the guidance and regulations. In practice, the granting of permission for late applications is very much part of the normal social security processes of the Department for Work and Pensions and Social Security Scotland. It is our understanding that that approach could be expanded to incorporate reasons—including reasons related to Covid-19—that would satisfy the description as it stands in the guidance that came out before the Covid-19 regulations. For example, reasons related directly to Covid-19 would satisfy the definition of good reason for a late application.

To go back to Fiona Collie's point about the need for clarification, we see the bill as an opportunity to review the rules and guidance on allowing late applications and to look at the backdating of awards and the impact that that has, particularly when deadlines are involved. It is important that those rules and guidance are of benefit to applicants whenever possible.

We recognise that claimants might make applications at a time that does not allow for a full backdate based on their entitlement, because of Social Security Scotland's current processes. For example, carers who apply for carers allowance as part of DWP processes or carers support payment as part of Social Security Scotland processes are only eligible for a 13-week backdate—three months from the date of claim—and their entitlement is conditional on the person for whom they care being in receipt of a disability benefit such as adult disability payment, attendance allowance or the personal independence payment.

It is not unreasonable that a carer might delay making a claim until such time as the person for whom they care is in receipt of a particular benefit. However, Social Security Scotland's data from January indicates that 8 per cent of claims for the adult disability payment, for example, are taking seven months or more to be processed. That would mean that, for example, a carer who had caring duties and responsibilities during that window of time might not be eligible for carers support payment or carers allowance at that time. Therefore, they would be disadvantaged if they waited until such time as everything had been signed off and the disability benefit payment had been put into place.

We therefore have an opportunity to look at how the approach to backdating and processing claims

can be made simpler to ensure that people are not disadvantaged by the current processes.

Bob Doris: That is very clear. I do not have any follow-up questions, because you have made your point eloquently. The committee will reflect on that.

The Convener: We move on to theme 2—the issue of challenging decisions, which is dealt with in part 3 of the bill.

John Mason (Glasgow Shettleston) (SNP): The proposal is that redeterminations could be made after a year if there are “exceptional circumstances”. Are you comfortable with the concept of “exceptional circumstances” and what it means?

Vicki Cahill: We need a bit of clarity on what “exceptional circumstances” are. We suggest that a broad approach be taken to defining that term. We recognise that life events such as illness, hospital stays, bereavement, grief and loss can have a significant impact on people’s ability to make an application or to challenge a decision.

Alzheimer Scotland is keen to ensure that the impact of living with a cognitive impairment is covered under the definition of “exceptional circumstances” and that it is recognised that the complex needs that arise as a result of living with conditions such as dementia might impact on people’s ability to follow processes within deadlines and timeframes. That is particularly important.

We also want to be clear that it is important that the descriptors and definitions that are used in considering “exceptional circumstances” are not overly prescriptive or too narrow in what they permit decision makers to consider. Each case should be considered on its own merits, and a determination that is made by a decision maker should be based on a broader understanding of the barriers and challenges that a claimant might face. In general, the process should allow for some level of discretion, and we would support an approach that would enable the broadest understanding of “exceptional circumstances”.

John Mason: In practice, how common would it be that, after a year, a request for redetermination would not have been made?

Vicki Cahill: For people with cognitive impairment, hospital stays can go on for particularly long periods of time. Committee members will all be aware of the challenges that have arisen as a result of people being unable to be discharged from hospital. There are delays to their ability to return to their own home and to be supported. When dementia is advanced, that makes it infinitely more difficult to provide those supports.

Although it might not be the norm to allow a year-long delay for a request to be made, we must accept that there are cases in which that might happen. When it is possible for us to make provision to allow for such cases and for individuals who fall under that category to be supported, it is important that that provision is made.

Fiona Collie: I absolutely agree. We know from the carers census that about half of carers are providing at least 50 hours of unpaid care. Someone who is dealing with circumstances such as hospital admission and discharge while trying to manage multiple caring responsibilities will sometimes need a little extra time. If we can make that clear, we should do so. That would be a positive development.

John Mason: As I understand it, the norm for requesting a redetermination is either 31 or 42 days. A year is quite a lot of extra time, is it not?

Fiona Collie: It is quite a lot of extra time. On the period being either 31 or 42 days, it is a little strange to me that we have different timescales. That makes it very unclear for individuals who are trying to make sense of the social security system. Those of us who are enmeshed in it on a daily basis sometimes do not see how complicated and off-putting it is, or how difficult it can be for individuals to make decisions about how to apply for a benefit in the first place, or about redetermination or appeal.

John Mason: Would you make 42 days the period for all the benefits, or would you suggest a different period?

Fiona Collie: Whatever the benefit, the period needs to be the same. I think that a period of 42 days is okay for a lot of people, but it would be sensible to have the flexibility to have a longer period. When it comes to public information, a consistent approach would be helpful.

John Mason: Part 3 of the bill includes measures that are aimed at reducing stress for clients, such as allowing individuals to withdraw their redetermination request. Are you supportive of that part of the bill?

Fiona Collie: Yes.

Vicki Cahill: Yes.

John Mason: Okay—that is straightforward.

Are there other measures that you think would improve the client experience in relation to redeterminations and appeals?

Vicki Cahill: There are ways to improve processes and experiences for people who go through the process of redetermination, which is quite stressful. The bill’s measures seek to reduce that level of stress, but they would not remove the

stress entirely. They would provide a bit of a buffer when it comes to managing timescales and enabling people to move the process along, but they would not remove the stress.

Swifter response times, whereby the processing could be done much more quickly, would be helpful. In that way, the process would not weigh heavily on someone while they were waiting for the outcome of a reconsideration, particularly in circumstances in which they were not in receipt of any financial recompense that recognised the level of disability that they might have.

It is important that we have simplified and easier processes. We also need to ensure that there is clarity and flexibility in the system to allow people with additional needs to be supported through the entire process from start to finish, whether that support is provided by a family member or loved one or by a professional who can provide some overarching guidance.

09:15

John Mason: You mentioned that it would help people if they got a quicker response. Is the system working at the moment? Again, there are different targets, but I assume that Social Security Scotland has different targets because some things are more complex to work out than others.

Vicki Cahill: Absolutely. There are variations in how social security benefits are operated within Social Security Scotland. It principally looks after disability benefits, which are based on a subjective determination based on the person's level of need and the requirement for other options to provide support for them. The prospect is different for other benefits, where it might be necessary to do a piece of financial decision making based on statistics and data.

Timescales vary, but it is important that processes are expedited whenever they can be. Social Security Scotland has very good turnaround times when it deals with people with terminal illnesses under special rules. In that case, it is meeting three-day target turnaround times for initial applications. However, it is important not just for people with terminal illnesses but for people with illnesses or disabilities more widely to be able to access decisions quickly. The caveat is that they must be good, high-quality decisions, so there must be an adequate time for applications to be assessed and considered appropriately. However, when we can speed up timescales, we should absolutely take steps to do that.

John Mason: Ms Collie, do you want to say a final word on that? If we speed up decisions, there is a risk that we will have poorer decisions.

Fiona Collie: There is, but we also need to consider the provision of accessible information and support. We know from the national carer organisation MECOPP—the Minority Ethnic Carers of People Project—about the support for those whose first language is not English. Around 11 per cent of the population of the United Kingdom have limited or no English skills, so it is important that practical information is available to individuals in different languages and formats, whether that is Braille, large print or British Sign Language.

The Convener: Before we move on, I will bring in Jeremy Balfour, who has a supplementary question.

Jeremy Balfour (Lothian) (Con): Good morning, and thank you for coming. My question is about representation of your clients. My understanding is that someone can tick a box and you can represent them for three months but that, after that, they must go back to Social Security Scotland. Is that causing you any problems? Would it be easier if someone could tick a box to say, for example, that they want to be represented from the start to whenever the final decision is made?

Vicki Cahill: That would make things infinitely easier, because we would not have to retread old ground. However, we would have to build into that system an opportunity for the person to step away from that arrangement, if they so desired, at a later date. The person could declare someone to be their representative or to be prepared to act on their behalf, but they may change their mind at a later date and want someone else to take on that responsibility, or they may want to do it themselves. For the system to be fair, the ability for them to do that would have to be built in.

Jeremy Balfour: We are still in the early days, so there will not have been many First-tier Tribunal hearings yet, but my understanding is that almost all of them now take place either online or by telephone. Is that a disadvantage for the people whom you work for? Would a face-to-face meeting be easier on some occasions? Should that be the norm rather than the exception?

Vicki Cahill: Given Alzheimer Scotland's dealings with people who are living with dementia, we would absolutely advocate face-to-face hearings, which are significantly easier for the vast majority of people living with dementia who might have to attend a tribunal.

Managing over the telephone or digitally can be very difficult and can act as a significant barrier for a lot of people with dementia. However, we believe that options are always really important, so, although that might be very difficult for some individuals, others might prefer to use digital or telephone opportunities. Therefore, we suggest

that those opportunities remain in place so that, if someone has such a preference, we could deliver it. Equally, face-to-face hearings would be an absolutely essential offering for people living with dementia.

Fiona Collie: I absolutely concur. Choice is fundamental for individuals and for carers. Sometimes, digital technology can make it a lot easier to support someone through the process; however, for other people, a face-to-face approach is far preferable. We need to have options, including the option of a face-to-face hearing, available—it is not optimal for only telephone and digital hearings to take place.

The Convener: Thank you. That is very helpful.

We move on to theme 3, on overpayments, which relates to part 4 of the bill.

Katy Clark (West Scotland) (Lab): Appointees and other formal representatives would be liable for overpayments only if they misused the funds; they would not be liable for honest mistakes. There is also an existing requirement to have regard to financial circumstances before seeking to recover overpayments. Do the witnesses agree with making formal representatives liable in those circumstances?

Fiona Collie: I will comment fairly briefly. On the idea of making representatives liable, there is a difficulty with overpayments. There are sometimes genuine reasons why people get things wrong when making an application or making a payment. I know that there is a provision saying that the representative should have noticed the error, but sometimes that is not the reality of individuals' lives.

There should be compassion in the system. We know that there can be significant consequences for unpaid carers if there is an overpayment, because of the nature of the benefit. In general, the liability should be not with the individual who is being represented but with the representative, but we need to be careful about that, because we do not want to discourage individuals from supporting disabled people.

We should also take account of circumstances—an individual might have significant caring responsibilities, be a power of attorney or a guardian and be trying to manage the individual's benefits and the household finances. Sometimes, it can be difficult to unpick who the benefit is for and who is getting the benefit of the benefits. We need to be clear about that. I certainly welcome the fact that the bill provides for appeal rights, which is a good step forward.

Vicki Cahill: We agree that we do not want to discourage people from acting as representatives

or appointees and that people who are prepared to step up should be supported. We should not put additional barriers in the way of that.

We have a few concerns about how the determinations as to whether funds have been misused might be made. It might be quite difficult to identify what is covered in a particular scenario when determining whether there has been misuse of funds. For example, disability benefits such as adult disability payment do not prescribe how people in receipt of those benefits, or representatives who are responsible for administering them on behalf of someone who cannot manage their own affairs, should spend the payment. It might be quite difficult to make determinations on what is misuse.

If there is no direct requirement for people to provide or purchase particular things with their benefit, who is to say that, for example, going on holiday, going out socially or purchasing a vehicle is a misuse of funds, when that could benefit the individual for whom the benefit is being claimed? In and of itself, that can be challenging.

Likewise, there might be difficulty in identifying the difference between an honest mistake and a more deliberate attempt to gain benefit. For example, how might it be determined whether an omission of information was the result of a genuine oversight, lack of knowledge or understanding of the process, or the deliberate concealment of information in order to gain some benefit?

For example, if an individual enters hospital, they are required to declare that to Social Security Scotland. At a time of great stress, when someone is juggling lots of different things, it could be quite easy for that to be an oversight. Where do we draw the line in determining the difference between a direct attempt at concealment in order to continue to benefit from that payment and what is nothing more than a genuine oversight? That can be difficult.

I reiterate the general point that fair and reasonable processes and clear and robust structures need to be in place to support carers and representatives. Equally, however, we must ensure that, as part of that process, there is ongoing support to reduce the likelihood of such an event recurring in the future. We should look not simply at a single instance but at the wider picture.

Katy Clark: That is very helpful.

The person who is being cared for can already be liable for noticeable overpayments caused by their representatives, and the bill extends that to include overpayments that a person might not necessarily have noticed were the result of an honest mistake by their representative. Do you agree with that?

Fiona Collie: I probably do not agree. If someone has a representative acting for them, that is because they require support to manage their social security, so they should not be liable for that. That seems fundamentally unfair.

Vicki Cahill: I absolutely agree with Fiona Collie's comments. It is unfair and unreasonable to expect claimants who have additional support needs—which are clearly evidenced by their need for a representative in the first instance—to take on the role and responsibility of providing checks and balances and ensuring that all the information is provided on their behalf. That would be absolutely unfair.

Roz McCall (Mid Scotland and Fife) (Con): Good morning. I thank the witnesses for coming along. On that theme, the balance has to be right, and the evidence that we have received shows that that involves very fine movements.

I will focus on what happens following a bereavement. It is possible that the deceased's benefits might be overpaid. Do you have any comments on the ability to recover benefit overpayments from the estate of an individual who has died? Obviously, that is a very specific example, but I am intrigued to know what you think about it.

Fiona Collie: I do not think that I need to tell anyone in this room that losing someone is a really difficult time. In particular, if you have lost someone whom you cared for, there are a lot of things to deal with. The list of practicalities just grows and grows—dealing with funeral arrangements, stopping care services, dealing with equipment and so on. We need to be careful to understand those circumstances and take a compassionate approach.

In general, the idea is in line with that for other benefits, such as pension credit. In such cases, people are told, fairly immediately, that they have to pay back the money, which can be really distressing. I speak as somebody who has been in that position; it is really distressing when you are trying to deal with everything else. There is a need for a bit of balance to ensure that individuals are not put under additional stress.

Estates can be very variable. Let us be honest—someone's estate could be minuscule. Given that things such as funerals and so on need to be paid for, there can be nothing left. There is a need for balance and compassion when attempts to reclaim money are made.

09:30

Vicki Cahill: We agree that there is a need for sensitivity when it comes to managing the winding-up of people's estates. As part of that,

consideration should be given to the timing of requests. A look should also be taken at the correspondence that is sent out. The correspondence that the Department for Work and Pensions and Social Security Scotland send out initially offers a degree of condolence to the individual in question who is responsible, but the next line is a demand for money. That is not the most compassionate or appropriate way in which to make a request for additional funds.

There are opportunities for people to write to debt recovery, which is responsible for taking in any overpayment that has occurred as a result of a death. However, those processes are not particularly clear and are not widely known, especially among the public, so perhaps there is an opportunity to think about what the processes might be at that point and under what circumstances someone might be able to request that an overpayment be written off by Social Security Scotland. For example, if money has been paid as a result of the payment processes that are in place—for example, some benefits are paid three weeks behind and one week ahead, which would automatically result in an overpayment—that is not a result of anyone declaring late or delaying notifying Social Security Scotland.

The system should have some flexibility built into it so that it takes account of those wider parameters and can support people at what is a really difficult time.

Roz McCall: That is very helpful. I was going to ask for a couple of suggestions about what Fiona Collie meant by "balance", but you have just given some. Thank you very much indeed.

The Convener: We move on to theme 4, which is on appointees, who are dealt with in part 5 of the bill.

Paul O'Kane (West Scotland) (Lab): Good morning. I will start with a broad question. What experience do you have of the existing appointee system under the DWP and Social Security Scotland? What has been your experience of that process?

Vicki Cahill: Given that Social Security Scotland's processes are relatively new, the access that we have had to them and the opportunities for engagement have been limited.

There is a bit more scope for us to comment on how the DWP's processes work. Broadly speaking, we have not come across significant challenges around appointeeship. We do not deal with significant numbers of people who have difficulty in being recognised as an appointee, in changing details or in performing that role. That is the extent of our experience at the current time.

Fiona Collie: I concur with that. We have had the odd inquiry about the DWP's processes, but, in the main, the system seems to work effectively.

Paul O'Kane: The bill requires DWP appointees to be authorised by Social Security Scotland

"as soon as reasonably practical".

What are your general expectations about how long it should take Social Security Scotland to authorise an appointee? We had a discussion with other witnesses about timescales and expectations, so it would be good to get your sense of that.

Fiona Collie: I do not have a particular timescale in mind. It should be within the timescale of the payment of the benefit. If the benefit is paid every three weeks or every week, it should be within that period so that, when the individual next has to make contact, they will be a Social Security Scotland appointee. I note that, in the early discussions, there was general frustration about there not being an automated way to make the change from the DWP to Social Security Scotland.

Vicki Cahill: We recognise that there is a need for due process and that that process takes a bit of time, because it is determined by Social Security Scotland's capacity to carry it out. Processes include face-to-face visits, speaking to the person who wishes to be an appointee and, in most circumstances, the person who wishes to appoint someone to act as their representative. That can take a bit of time.

In addition, we recognise that there is sometimes a requirement for additional information, such as medical reports, to help to determine whether the request for someone to act as a representative is reasonable. We believe that it would be perfectly reasonable for that process to be done within that timescale, but we are aware that the timescales are very much based on Social Security Scotland's capacity to deliver that.

It is possible to speed up the process of checks if such checks have already been carried out by the DWP. It might be worth having a look at what reciprocal arrangements can be agreed between the DWP and Social Security Scotland. Some of the checks that have been carried out by the DWP could be shared to enable Social Security Scotland to carry out a quick oversight, or vice versa, particularly if someone has had an appointeeship organised within the past six to 12 months. It does not seem unreasonable to place the administrative burden on Social Security Scotland, rather than expecting either the claimant or their representative to take on an additional burden as part of their claim. It might therefore be worth considering a memorandum of understanding or a reciprocal agreement, particularly for people who claim benefits from the

DWP or pension service, such as pensions and universal credit, and who also claim a disability benefit from Social Security Scotland.

Paul O'Kane: Those answers are helpful. On some of the practical suggestions, I am sensing frustration about blockages, if I can use that expression, in the system. The bill will create empowering opportunities, but a lot of the detail comes down to how the system operates in practice. Is Social Security Scotland engaging with some of the suggestions that Vicki Cahill made or with the conversation about a more automated process, as Fiona Collie suggested?

Vicki Cahill: My understanding is that Social Security Scotland and the DWP are engaging and looking at ways to work alongside each other to support claimants. Ultimately, that is the crux of what is needed. It is not about individual bodies and authorities overruling one another because of geography. Ultimately, the aim of the bill and, most importantly, of practice is to support claimants to get what they need as quickly as they can, without any additional barriers to those that already exist in the system.

Fiona Collie: I understand that Social Security Scotland has to carry out due diligence, but another public body has already made a decision, based on a range of information, that it is appropriate for somebody to be an appointee. I know that having a simple transfer is a challenge—it was a challenge with child disability payment—but it would be sensible to have some agreement between the DWP and Social Security Scotland, which would take the pressure off individuals. Ultimately, as Vicki Cahill said, it is a matter of ensuring that individuals get the support that they need quickly, without having to deal with additional stresses.

The Convener: We now move on to theme 5, on information for audit.

Marie McNair (Clydebank and Milngavie) (SNP): Good morning, panel. It is great to see you this morning. Do you agree with the provisions in part 6 of the bill on the ability to suspend people's benefit payments if they repeatedly fail to provide the information required to Social Security Scotland?

Fiona Collie: I could give a mixed message in response to that—yes and no. The information in that part of the bill is pretty unclear. We need a lot more information about the bill's intention and scope, and about situations in which an individual might or might not understand what is being asked of them. There might be very good reasons why a person is not engaging. If that part of the bill remains in place, we need to make sure that very good information is made available for advisers and for the public. There is good information for

individuals on the Social Security Scotland website about the benefits themselves, but not on some of the trickier aspects, and advisers have a very different and technical understanding of the social security system.

Vicki Cahill: I absolutely agree with the point that Fiona Collie has made. We reiterate the point that suspending payments does not really align with social security principles. I am sure that it is no shock that we would disagree with that approach.

There are some issues with the language and the wording that is used, and the clarity that Fiona has asked for is imperative. There is an issue around defining the term “repeatedly”. What does it mean? How many times does “repeatedly” mean? What methods will we use to establish contact with someone? Will we continue with the same practice when we do not get a response the first time? Are we going to repeat the exact same process the second time around? We require much more clarity on how things will play out from a practical point of view.

Speaking from Alzheimer Scotland’s perspective, we need a clear understanding of the needs of people living with dementia. They are often—although not always—older people and they sometimes have very difficult, complex needs. For them to engage or be part of a process of sharing and providing information takes a lot of effort on the part of the person requesting that information, not just the individual who is being asked to provide it.

We need to think about how information is communicated and how it is possible for decision makers or people who are requesting information to explore the needs of claimants, to ensure that their needs are being met and that they can be supportive in providing what they are being asked for.

We should consider alternatives. Are there other ways of obtaining the same information that do not place such a significant burden on an individual? Are there other routes to accessing that information? Generally, we suggest that there are other ways and means to look at information again. If there is any suggestion or significant evidence of particular wrongdoing, that requires a slightly different approach, but for reviews of information or in establishing conditionality based on eligibility criteria, the burden perhaps lies more with the decision maker than with the individual receiving the benefit.

09:45

Marie McNair: You have sort of answered my next question, which is about the kind of support that clients need. You have said that information is

key to enabling the client to understand the process. Could you add anything to that?

Fiona Collie: Time is also important. I cannot emphasise enough the fact that carers are very time poor. Carers consistently say to me that caring is sometimes the least stressful part of what they do and that all the bureaucracy—including social security processes—is hugely stressful and time consuming.

We also need to ensure that we have accessible information and that there are protections for those who have protected characteristics, including that information is available in the language that they need it in—a language other than English, BSL, Braille, large print and so on—if that is what is required. Individuals are well aware of what information can be provided to them in the form that they need, and they have a right to it. That includes a person with cognitive impairment being able to access information in a form that they can understand. Letters from bureaucracies are not necessarily that easy for everyone to understand.

Vicki Cahill: I reiterate that accessibility is key to encouraging participation.

Going back to the point about people having choice and options, we might provide written materials, audiovisual materials and digital and online options, but face-to-face conversations in which you speak to someone directly and give them an opportunity to discuss what information is needed and why it is needed are also important in making the information accessible and more relatable. Not everyone’s needs will be exactly the same, so it is important to explore what an individual claimant’s needs are, and all those options and choices absolutely have to be available.

The Convener: Our final theme is on social security principles. I invite Jeremy Balfour to lead on that.

Jeremy Balfour: You will be glad to hear that we are coming to the end of our questions. Do you have any comments on any other specific measures in the bill that you have not had a chance to comment on yet?

Vicki Cahill: I would raise the point about compensation recovery, which we referenced in our written response. Sometimes, people have multiple conditions or disabilities that coincide with an injury or illness that might have come about as a result of an accident for which they have been compensated, and we feel that it is important that, if an individual might otherwise be entitled to benefit, that should be taken into account, notwithstanding the compensation. For example, someone with dementia might have symptoms, whether or not they have a diagnosis, and that fact should be taken into account before any recovery

measures are put in place that might disadvantage them. That should be part of a slightly broader approach to ensuring that we are not just looking at the compensation award in isolation. We have to look beyond that and consider the wider circumstances of someone who has had a compensation award.

Fiona Collie: I concur with that. Hidden additional costs often arise from things such as adaptations and reasonable expenses. There is also the fact that some compensation payments are about support for the rest of someone's life, so we need to have a little bit of compassion in that regard.

Something that has been really important in the creation of Social Security Scotland and the benefits system is that it is about dignity, respect and compassion, and about ensuring that everything that we do, including the recovery of compensation payments, is thoughtful and compassionate and considers all the circumstances that individuals and their carers are living in.

Jeremy Balfour: Thank you. That is really helpful. I will open this up slightly wider, as this is a chance for the committee and the Parliament to review the proposed legislation. Is there anything that you would like to see in the bill that is not in it? I appreciate that you have only a few minutes and that you could go on for a long time on that subject.

Fiona Collie: We have some thoughts about the opportunity to create new support in the bill, particularly support for energy costs. It could open up an opportunity to look at what is missing from the creation of Social Security Scotland and the benefits that are being transferred. The creation of the Scottish child payment was brilliant, although we would probably argue that the eligibility for that assistance should be extended to people who have children and who receive carers allowance. There are other opportunities to have a think about what is missing and what we have learned in the past years and months from the cost of living crisis and how energy costs have gone through the roof, particularly for disabled people.

Vicki Cahill: In addition to Fiona Collie's suggestion about extending the scope for social security in Scotland, I am thinking about the supports and measures that people might need to access it and about providing a clearer and easier pathway to ensuring that people can access the professional support that they might need to navigate a system that is as complicated and challenging as social security sometimes is. We could look at how we can structure that support, which often comes from the third sector. There is also some provision in local authority arrangements, but those are hugely variable. It

might be worth considering how we can make that a much fairer and more even playing field, so that people can access the support that they need to navigate their way through the system.

Jeremy Balfour: Do you think that the bill aligns with the social security principles? That would be a good exam question.

Vicki Cahill: Broadly speaking, the bill aligns with the principles, with the exception of the provisions on information audit. I think that I was quite clear in my earlier response that suspending payments does not align with the social security principles. Otherwise, the bill broadly aligns with them.

Fiona Collie: I agree with that perspective.

Jeremy Balfour: I think that you have probably covered this issue, but I will give you one final opportunity to talk about the client experience. You have caveated your view of the bill with what you just said, but, outwith that, is there anything that you are still concerned about relating to the client experience? Are there things that need to be in the bill, or things that need to come out of it, to make the client experience easier? You have covered a lot of that already, but this is a final sweep up of any other comments that you might want to make.

Vicki Cahill: Broadly, we seek clarity and practical examples of how the bill will operate in Social Security Scotland's processes and practice. We need clarity about how particular processes will work, what safeguards will be put in place and whether they will be sufficient to meet the needs of vulnerable claimants, in particular. The move towards the new steps in the bill largely seeks to improve the experience of claimants and their representatives. However, the proof is in the pudding. That will come very much from how it is played out in practice and people's day-to-day experiences, so we will wait and see.

Fiona Collie: I agree with that. I emphasise the need for clarity and good, accessible information. We agree that social security is a human right and we need to make it a practical reality for everyone who applies for it, which includes encouraging the take-up of social security across the piece, as well as within the reserved system, and making the pathway for individuals as smooth as possible.

Jeremy Balfour: I thank you both for coming to the committee and for all the work that your organisations do. I know that you help so many people.

Bob Doris: I was impressed by our witnesses' answers to Mr Balfour's question about what more they would like to see in the bill. Ms Collie rightly called for greater financial support and greater consistency in that support across groups. Ms Cahill spoke about improved pathways, which

would have a financial implication, although not as much as direct financial support. Of course, it is not for committee witnesses to say where that money would come from, and they should champion the corner of the people they represent. I am, however, conscious that the Scottish Government spends £1.1 billion more on entitlements for those who are vulnerable and needing support than it receives from the United Kingdom Government. Clearly, there is a divergence between the funds that are available to support those who need extra help and the extra help that is required because of the UK situation. Genuinely, I am not drawing you on any of that; it is just the context to my question.

What advice would you give to the Government or the committee? With the limited budget that we have, we and the Scottish Government have a difficult job in weighing up how to determine in what area to invest any money. If £10 million were to become available—Ms Collie, I am afraid that that is not the situation—some would argue that the Scottish child payment should be further increased, others would argue that the entitlements for that benefit should be increased and some would suggest spending it on a wholly different area, such as carers. How does the committee or the Scottish Government reconcile those competing demands? You should make those demands, and I would expect you to do so—and you do it so powerfully, passionately and persuasively—but how do we reconcile those tensions?

Fiona Collie: It would be nice if there was £10 million. I could think of many ways to spend it. Some of the figures on poverty among unpaid carers, for example, and, equally, poverty among disabled people, indicate that about half of households that are in poverty have someone who has a disability. We need to think about the costs of not supporting people, which are borne elsewhere.

Talking about prevention and health inequalities—the idea that, if you spend on something that will reduce the health impact, there will be a reduction in cost elsewhere—is difficult, because it sometimes takes a while for that impact to be seen. That is where we tend to come in when we talk about balancing. The poverty that disabled people and their carers face is so huge and it has such an impact on their health and wellbeing that it is paid for elsewhere in the Scottish budget. We need to have a bit of a think about prevention and how investing can help to reduce that impact.

Bob Doris: It does not solve the quandary that the Government and the committee find ourselves in, but you have made a persuasive argument.

Vicki Cahill: Part of it is about whole-system design and looking at the general infrastructure and the areas in which you could maximise potential future cost savings. It is about hitting things further upstream, which is a preventative approach, as well as talking about early intervention, which can prevent further costs. It is a difficult challenge to lay bare and it does not have any quick or easy answers, otherwise I am sure that you would have come up with them by now. Certainly, the whole-system approach is important. I would also highlight the importance of considering lived experience and making an impact by listening to people's experiences on the ground and making those changes.

10:00

Naturally, I will advocate for people who are living with dementia and long-term complex care needs, and I am sure that others can make equally sound representations for people in other parts of society. However, we need to think about a much longer-term strategy that will ensure that each of the areas that we are all trying to push and champion can move forward from the system that exists now and that we see improvements so that the experiences on the ground are better.

It is about thinking about the impact that you can make with the money that you have. If a problem requires £100 million to solve it and you have £10 million, what advantage is there in throwing £10 million at it? It might as well be none. However, if £10 million can make a specific change or improvement, the experience for people on the ground will be very different. The success of the Scottish child payment is an example of that. You have shown that, by having a particular packet of money and targeting it at a particular group of individuals, you can create a change and have an impact that is felt acutely by those who receive the benefit. It is not a quick fix, but it is about looking at where you can maximise the impact.

Bob Doris: Thank you. I have no other questions, convener, but I put on the record my thanks to the witnesses for championing the issues so passionately. It is very helpful to the committee.

The Convener: Thank you. That concludes the evidence session. The committee very much appreciates your joining us today.

Next week, we will continue to take evidence on the bill with a panel of witnesses focusing on part 7, which concerns recovery from compensation payments.

I suspend the meeting to allow the setting up of our next item.

10:02

Meeting suspended.

10:07

On resuming—

Extra Costs of Disability

The Convener: Our next agenda item is a presentation on the additional costs of disability in Scotland. The committee commissioned a piece of research on the topic in March last year to inform its scrutiny work, and, following a call for bids, the research was awarded to a joint bid from the University of Strathclyde and the Poverty Alliance.

I welcome to the meeting two of the authors, Christy McFadyen, knowledge exchange associate, economics, Fraser of Allander Institute, University of Strathclyde; and Dr Laura Robertson, senior research officer, the Poverty Alliance. Thank you both for joining us today.

I believe that, first of all, you are going to take us through a presentation of your work and findings.

Chirsty McFadyen (University of Strathclyde): Thank you very much for having us. I will start and then pass over to Laura Robertson to talk about some of our work.

For context, I should say that I have been working more on the quantitative side of the research and Laura Robertson has been working more on the qualitative side. If you could direct your questions accordingly, it will probably make more sense for us. However, we will try to answer as well as we can on both sides of the work.

The additional costs faced by disabled people are recognised as being detrimental to quality of life. For any given income, a disabled person is not able to realise the same standard of living as a non-disabled person. Additional costs are many and varied, and they depend on individual circumstances, including type of disability, household composition and rurality. Those additional costs are concerning not only from the point of view of fairness, but because the impact of poorer living standards is also potentially significant and can lead to poorer wellbeing and health outcomes over the short and long term.

In recognition of those higher additional costs for disabled people, a system of disability benefits has long been established as part of the UK social security system, and it is now part of the devolved benefits system in Scotland. The Social Security (Scotland) Act 2018 states that Scotland's social security system will be designed

“on the basis of evidence”.

However, to our knowledge, there is no Scotland-specific baseline for the scale of additional costs that are faced by disabled people.

This report takes a step towards a better understanding of the additional costs of disability in Scotland. We have looked at the limited data that is available to analyse the scale of additional spending that disabled people in Scotland face. To contextualise and supplement our findings from the national survey data, we have also worked with six disabled Scottish residents, who, through weekly diaries and interviews over a five-week period, have provided us with information about their extra costs and their experiences of accessing support.

On definitions, we refer in the research to the core definition of disability in the Equality Act 2010, which states that a person is disabled if they have a “physical or mental impairment” that has a “substantial and long-term” negative impact on their ability to do normal activities. In that context, “long-term” refers to a condition that lasts or is expected to last 12 months or more, and “substantial” refers to the condition having a non-trivial impact on daily activities. A bit later, we will talk about severity of disability. Normally, in national surveys, people, in referring to their disability, can say that they are limited in their daily activities either a little or a lot. Therefore, when we talk about severity and a more severe disability, we are referring to the category of “a lot”.

I will give you a preview of our findings before we take you through them properly. They show that the best available data is far from perfect and cannot tell us enough at this stage. We found some evidence of additional spending on food, energy and health, and less spending by disabled households on transport. We cannot say whether the additional costs in the spending data that we used are statistically significant, because of the small sample sizes, but they are persistent over time, which gives us some trust that they are true effects. Importantly, data on spending also does not capture what needs are not being met due to a lack of income or what support is being received that might already compensate for additional costs.

We will start by going through what the data can tell us, starting with findings across all disabled households versus non-disabled households in Scotland, and Laura Robertson will take us through some of the qualitative findings. We will then go into some of the breakdowns that we have done, including for urban versus rural households, and more statistics on severe disabilities and extra spending in that respect.

I will just provide a bit of an introduction to the data that we use in the report. It comes from the living costs and food survey, which contains expenditure data for individuals and households across the whole of the UK. It is the best expenditure data that we have available for our

purposes, as it is designed to be representative of the UK population, and it indicates whether each household member has a disability and allows us to look specifically at Scotland. We have supplemented that with findings from the weekly diaries that I mentioned—that is, from six disabled people in Scotland over a five-week period between January and February 2024.

To provide some context, I would point out that the diaries are not designed to represent all disabled individuals—we would never claim that with only six diaries. Instead, they provide some context for the lived experience of additional costs related to disability, including the potential drivers of those costs and other available support and how they interact with people's lives. We also wanted to look at the impact of the continued higher costs of living in 2024, which the data that we have cannot provide, given that the latest data that we have available is from 2021-22.

If you have copies of our report available, you will see that table 1 and figure 1 show the additional spending by disabled households in Scotland compared with spending by non-disabled households across four essential categories: food, energy, transport and health. I will provide a bit of a primer in how to read those figures, because it might not be intuitive.

A positive number in a box means that disabled households are spending more on that category. For example, a non-disabled household might have spent £20 per week on health. If a disabled household had spent £21 per week—that is, £1 more—the box would show a positive number 1 to represent the difference in spending.

10:15

We then looked at mean total spending across those categories and subtracted the numbers for non-disabled households from those for disabled households to find the difference. If the result was a positive number, that meant that disabled households were spending more; if negative, it meant that non-disabled households were spending more. Our main finding was that there was slightly extra spending by disabled households on food, energy and health, and less spending on the transport category.

Actual spending is a lot more variable than the means show, due to different household incomes, which is why we split the sample into income groups. Instead of comparing, say, a disabled household on a really low income with a non-disabled one on a really high income—which we would not want to do, because their spending is probably wildly different anyway—we made our goal to compare like with like. We therefore split our sample of households into five equally sized

categories, with income group 1 the 20 per cent lowest incomes and income group 5 the 20 per cent highest incomes. We always compare disabled and non-disabled households that have similar levels of income, to understand where the differences are.

The chart in figure 1 shows the difference in mean expenditure across all the income groups, and you will see the variety across them. Table 1 shows the mean difference in expenditure. For example, the figure for food is 0; for energy, 1; for transport, -17; and for health, 2. We have therefore seen slight additional spending across food, energy and health and less spending on transport.

One point to note is that the mean of the food expenditure is 0, which means that we are not seeing additional spending once we average everything out across the five income groups. However, when we looked at previous years, we saw additional spending on food, so inflation has potentially had an effect there. All low-income households will have spent more of their income on food in 2021-22. If they have a limited amount of money to spend on food each week, the limit could be reached faster in disabled households than in non-disabled ones, due to the additional costs associated with disability. Laura Henderson will touch on this much more, but, when we looked at the data, one of our first realisations was that we were not seeing any unmet need in it. We were seeing only what people were able to spend money on, not what they were unable to.

Our data shows that disabled households spend less than non-disabled households on transport, and we believe that that effect is down to a combination of factors. First, disabled people take fewer trips on average than non-disabled people. We have evidence of that from a Department for Transport study carried out across the UK in 2017. Secondly, disabled people are more likely to have access to free transport via a free bus pass or similar. I reiterate that we have covered only spending data; we are not seeing use of services in our figures, but we will touch on that a bit later. Social support might cover expenditure that we would otherwise see in our figures if such support were not available.

Laura Robertson will now talk about one of the case studies from our diaries.

Dr Laura Robertson (The Poverty Alliance): I will give the committee a bit of context about the diaries. As Chirsty McFadyen mentioned, the diaries looked specifically at needs that were not being met for a group of six disabled people who took part in that section of our research. Of the six participants, one was in employment, one was a student, four were receiving universal credit or employment support allowance alongside personal

independence payment, and one was receiving adult disability payment.

I will start with a summary of the diary participants' experiences. Four of the six participants said that they were going without basic essentials every week of the five-week diary exercise, and five of the six participants said that they were finding it quite challenging or very difficult to manage on their incomes every week.

I will touch on a case study involving a man with a physical disability who uses a wheelchair and is in receipt of personal independence payment with high mobility and middle care. He also receives employment and support allowance. In his diaries, he mainly reported finding it very difficult to manage on his income. He had a range of additional costs for his disability such as taxis and energy, and some of the others are outlined in the briefing; I should say that the cost of energy was cited by all six participants as one of the highest costs. He also had to pay for specific treatments and hire people to help with household cleaning and other household tasks.

I will give an example of what he was sharing in his diary every week. He experienced a very cold time in January and February, and, because of the bad weather, he had to use his storage heaters frequently. He recorded in his diary that, in one week, the cost of using his storage heaters came to £100. He shared that, because of the high cost of food and heating that particular week, he had to borrow money from his family, as his income through employment and support allowance, alongside what he got through PIP, was not sufficient.

In most of his diary entries, the man reported not being able to cover the costs of basic essentials such as food and energy every week; indeed, one quote from his diary was that he often had to make difficult choices between heating and eating. Another effect of such high costs was the need to cut back on social activities outside his home, so there were obviously effects in terms of isolation and loneliness.

Chirsty McFadyen: I will talk a bit more about how we have broken down the data. First, on additional spending for those with more severe disabilities, we see similar results in the living costs and food survey data when we compare people with a severe disability to all other households, including people with less severe disabilities. The only obvious difference in the data for people with more severe disabilities is that they have less additional health spending. We think that that could be due to people with more severe disabilities being more likely to draw on national health service care for their condition instead of relying on over-the-counter options, but we cannot state the exact reason from the data alone.

We had to omit income group 5 from table 2 and figure 2, because that high-income group had a sample size of less than 10 observations for severely disabled people—highlighting, I would suggest, the limitations of the data. When we survey around 5,000 households across the UK, around 20 per cent of them are Scottish. We then cut the data by disability and severity, which gets us down to really low numbers of households. Again, it shows the limitations of the current data: it is harder to collect evidence when we want to do so, and it is harder for the data to be reliable when we have smaller sample sizes.

We also looked at differences between urban and rural areas. Figure 3 shows that urban households seem to be spending more than rural households on food, energy and transport. That might seem surprising at first glance, as we know that people living in rural areas often face additional costs compared with those living in urban areas. As I have said, sample sizes become even smaller when we split disabled households into urban and rural areas, which means that we are even less sure that we can trust those figures in comparison with the already volatile Scottish averages. It is possible that what we are seeing are the extra costs of living in a rural area overshadowing the additional costs related to having a disability. That is similar to what I said before: it might just be that, if people have a limit on the amount that they can spend on essential categories, disabled households are hitting that limit faster and are simply not able to spend more than that amount, so we are not seeing that evidence in the spending data.

However, we see evidence in figure 3 that disabled households in rural areas are spending more on the health category. We are not sure why that would be or why that is different from the food, energy and transport results. A further interesting difference is the large difference in spending on transport between urban and rural areas for disabled households in comparison with non-disabled households. We are not sure whether that is a true effect or a result of poor data, as I have mentioned previously. If it is a true effect, one factor that could contribute to that is the existence of relatively fewer public transport options in rural areas, which could act as a barrier if private transport is not an option for households.

We have gone over what the survey data can tell us. As I have said, the findings from the LCFS are variable, and small sample sizes become an issue when we analyse urban and rural areas and those with more severe disabilities. There are not extra costs in every disabled household in Scotland; that creates overlap, which means that we cannot say whether these results are statistically significant. However, they are, as I have said, persistent over time, which makes us

more confident in that regard. I have also included UK-wide results for comparison in the appendices, if the committee is interested in looking at them. They show similar trends.

It is important to point out that we have included the diaries in our research partly because data on spending cannot quantify financial difficulty. Laura Robertson will talk a bit more about the findings from them.

Dr Robertson: I will talk the committee through two of the case studies from participants. I will touch on some of the consequences for their day-to-day lives while they struggle on their incomes with the particular costs that they identified they were struggling to meet.

Across the sample, there were examples of participants who had to get financial support from family or friends or who were considering getting a loan because they were struggling. Energy-related debt was also mentioned by two of the participants.

We included a prompt for any additional forms of support that the participants might have accessed. We wanted to find out about things aside from benefits, such as social care support. One of the participants was receiving self-directed support for 10 hours a week, but the rest of the participants were not, although two of them were using their disability benefits to pay for social care.

One participant had accessed the Scottish welfare fund crisis grant one week, and another who was struggling with her energy costs had received the warm homes discount. Apart from that, no other forms of additional financial support were mentioned by any of the participants over the five weeks.

The diaries reveal, on a weekly basis, how much the participants are having to plan and make adjustments to lower their spending. High costs of living in respect of energy and food were mentioned frequently. One participant said:

"I combined all my journeys outside of the home into one combined journey, to save petrol costs, then did all my errands ... in one day, which resulted in experiencing fatigue and a day mostly in bed."

Several of the diary participants reflected that they were so used to having extra costs of living relating to their disability or their health conditions that, over time, they had succumbed to almost normalising those costs, which would become part of their routine and part of their weekly budget. When we did the interviews at the start of the project, quite a few of the participants said that it had become just normal to them that they had those costs that they had to manage every week.

I will read out a bit from Jenny's case study, which illustrates the financial difficulty that she was

experiencing and how that was impacting on her mental and physical health. Jenny has several health conditions and is in receipt of a personal independence payment. Her health conditions mean that she needs to buy more expensive food and that she is restricted and must stay inside more. In the five weeks of taking part in the diary, she frequently had to buy shopping on her credit card because she did not have enough money left after putting aside money for energy bills.

10:30

In her week 3 diary, she gave the specific example that she and her partner had had to cut showers to every few days to preserve electricity and to have enough money to put the heating on. She said:

"This will obviously cost me more in the long run, but I live from week to week hoping the next one will be better."

She noted the weekly effects on her mental health, as well as the negative effects on her relationship with her partner and her family. She said that the stress exacerbated her symptoms, writing:

"It is stressful and wearing and I often find myself on the edge of depression struggling to stay out of it."

The next case study from another participant illustrates the experience of accessing social care support. The participant had a physical disability at the highest rate for care and mobility and was using a big proportion of his income for social care assistance. He specifically said that he uses his PIP to hire personal assistants and that he also regularly has to use it for travel to and from work, as it can take months for him to receive his transport expenses from his employer.

He recorded in all his diary entries that he had gone without basic essentials. He wrote in one diary:

"It isn't unusual to use this benefit (PIP) in half the time it should cover."

He also shared that distinguishing his additional costs was difficult, as he feels that he has normalised those costs over time. Therefore, he has adapted and has to find his own solutions due to a lack of available social care support in his local area and the lack of wider recognition of the social model of disability.

Another issue that he raised when we did the interviews at the start of the project was about housing not being accessible for his needs, which means that he cannot access and manage the energy in his house by himself. He shared that, as a consequence, he often has to sit in his flat wearing a hat, thermals and layers of clothes with an electric fire in winter.

A big issue for him was the lack of personal assistants available in his local authority, which

means that he often feels that he has to call on friends and family for support, which he said that he does not want to do. He is therefore often not able to access the support that he needs.

He shared the following impacts in his diary entry. One week, his shopping and house cleaning were shelved—he was not able to get support that week—so that he could have support to go to a social event instead. In week 5, he said:

“I’d love to have greater personal assistant support and use it when I needed it rather than generally trying to fit in with the paid worker”

and their availability. He went on:

“I’d love to have access to a resource that is user led such as the service run by Glasgow Centre for Independent Living.”

I will pass back to Chirsty McFadyen for some conclusions.

Chirsty McFadyen: I will conclude by saying that data on spending from the living costs and food survey shows that disabled households in Scotland spend slightly more in essential categories such as health and energy but less on transport. However, we have seen from the diaries that disabled households could be rationing essential spending due to financial difficulty.

The LCFS data is far from perfect. Small sample sizes are a problem at the Scotland level, particularly when we start to look at severe disability in urban versus rural households. We have put some more information on sample sizes in the appendices.

Importantly, the spending data does not capture what households need but cannot afford. The diary entries show that the six participants’ incomes are not providing consistent adequate levels of income for additional costs associated with having a disability or health condition.

Although the diaries do not represent all disabled households in Scotland, other studies have shown similar findings on a wider scale. For example, in 2023, Scope looked at the difference in material deprivation levels between disabled and non-disabled households and found that disabled people’s incomes, including disability benefits, provided a lower standard of living when compared to those of non-disabled households on the same income across the UK.

The impacts of the cost of living crisis and deepening levels of poverty among disabled people have been evidenced in various pieces of qualitative and quantitative research. In particular, people with disabilities in the UK have been affected by rising energy and food prices and are more vulnerable to increases in those essential costs, as they make up a higher proportion of their budgets than they do for non-disabled people.

Recent qualitative research commissioned by the Trussell Trust found near consensus that disability payment levels were too low to cover the extra costs associated with physical and mental health conditions.

For some of the participants in the diary exercise, the lack of support from the social care system, including personal assistance, was a recurring challenge. Therefore, there are wider implications for social care support that meets the needs of people with a disability or health condition in Scotland. Getting the right social care support in place could reduce the additional costs that disabled people face. Some of the interviews also highlight the importance of having the right housing that better meets people’s needs, which is also a crucial issue.

Going forward, policy makers will need to think carefully about how to measure the additional costs of disability and the adequacy of benefits and other public services, to ensure an evidence-driven approach. We do not believe that there is an existing source of quantitative data that can provide robust enough evidence on the additional costs of disability in Scotland. Even if that was the case, the personal nature of disabilities means that costs are likely to differ markedly between different people. An effective, evidence-based policy to meet additional costs of disability will need to recognise that point rather than assume a one-size-fits-all approach.

We are happy to take questions.

The Convener: I apologise, because I introduced you as Christy when your name is actually Chirsty. My humble apologies to you, Chirsty.

The research that you have given us is really useful for providing insights into the hidden and extra costs of disabilities. Do you, as researchers, have any suggestions on the best way to approach further research on that?

Chirsty McFadyen: One of the main things that I spoke about is the point that, if we want an evidence-driven policy approach, we need more evidence. Some surveys in Scotland, such as the labour force survey and the annual population survey, have a Scottish boost that is paid for by the Scottish Government, which means that we have better sample sizes and can have better data. That is one option for improving sample sizes if we want to have more robust evidence on the matter.

However, as we said, the issue also has much to do with whether the appropriate social support is in place. In the diaries, we saw many times that a lack of social support was causing extra costs for people with disabilities. Looking more into whether social support and social care are

adequate and where barriers are to accessing that support could be useful in thinking about what additional costs of disability we can get rid of through better policies in other areas.

The Convener: Dr Robertson, would you like to comment on that?

Dr Robertson: We already referenced other qualitative research from the Glasgow Disability Alliance. Inclusion Scotland also published research last year on the impacts of increased costs of living and deepening poverty for disabled people.

I would always recommend more research on lived experiences. Ours is a short-term, small-scale project. We were not looking to have a very diverse sample, so we have not spoken to families who have a disabled child or adult, for example. Therefore, research could be done on those different experiences and how households are managing.

Also, given the on-going impacts of the cost of living crisis, more longitudinal research that followed people with a disability or a condition over time would show how people are managing at different points in the year. We were limited because we looked at a five-week period and this research was done in January, when energy costs are higher. That longitudinal research would also be a really important evidence base.

The Convener: That is helpful. I will open questions up to committee members.

Marie McNair: Thanks for your time this morning. In your conclusion, you have recommended that careful consideration be given to

“how to measure additional costs of disability and the adequacy of benefits”.

Are you aware of countries across the globe that are doing it right and that we could learn from? If you do not have notes on that today, perhaps you could come back to the committee. It would be interesting to see how other countries are doing.

Chirsty McFadyen: Yes, definitely. We have done some work on learning disabilities at the Fraser of Allander Institute, and some of the work that we have done on data has been quite useful learning from other countries. For example, New Zealand carries out its census over similar periods to us but, when it finds that people have a type of disability that it is interested in learning more about, it will do a booster survey to bring more information in on that. We can probably learn from that more generally. However, I do not know of any other countries that are doing it right. It is one of those complicated issues that everyone is trying to get better at. We are definitely keen to look at that more and maybe feed back to you later.

Marie McNair: That would be great. Thank you.

Jeremy Balfour: It is helpful to read this report in the light of the other report that the Fraser of Allander Institute did recently on disability and employment. The reports go quite well together, and I will raise questions about that. I would like to ask a number of questions, but, given the time, I will ask one long question.

The deputy convener will always tell me that we have political choices to make about how we spend our money, and he is absolutely right. However, may I put that to you and ask whether, if you had another £20 million to spend, you would create a universal benefit for disabled people? Would you increase the disability payment, or would you target that money in some way?

I think that Dr Robertson said that there is not one need—disabled people have different needs—so, if we had that money, how would we target it? Would you create a universal benefit or is there a more nuanced way to do that?

Chirsty McFadyen: That comes back to the commitment to evidence-based policy making. We have done a short-term study, but more work could be done to understand the issue better. The first thing that I would do with the money would be to gather the evidence so that we had a good understanding of exactly what the additional costs are and whether needs are not being met and then base policy and benefits on that. On the evidence that we have gathered, I could not tell you how to spend the money. I know that that makes it even harder for you guys to decide where to put things.

Therefore, for me, it is definitely about gathering more evidence first and trying to understand the issues so that we are not spending money in a way that is not evidence led and ending up having to go back and do things again.

Dr Robertson: From the Poverty Alliance’s perspective, outside this research that we have been doing, we would call for an increase in incomes for people with a disability who are living in poverty in Scotland.

In the evidence session before ours, one of the witnesses said that just over half of the people who live in relative poverty live in a household with somebody with a disability, so there is clear evidence that people with disabilities are more likely to be living in poverty. Therefore, there are decisions that could and should be made to increase incomes for people who have a disability. By what means that would be done, I am not sure, but it is clear that their income is not adequate at the moment.

10:45

Jeremy Balfour: I suppose that that is the issue that I am trying to work out, Dr Robertson. Personally, I probably fall into income group 5, but if you increase adult disability payment, I will benefit as much as somebody in income group 1. I do not have the answer, but I am trying to work out how we increase the income of groups 1, 2 and 3, maybe, but not necessarily of groups 4 and 5, because those people, although they will have extra costs, can probably meet those costs. I am looking for a way to identify those individuals. Maybe the data is not yet available, and we need to get that, but I am concerned that, if we universally increase incomes, although everyone benefits, it will not benefit enough those who need it more—if that makes sense.

Dr Robertson: Yes. The example that was discussed in the previous evidence session was the Scottish child payment and the learning from that. That is a passported benefit for families who receive universal credit and other eligible benefits. That has been successful in pulling a lot of families out of poverty, so that has been a very successful policy in Scotland and there is useful learning in that about identifying families who are already struggling.

I would caution that there are a lot of people in Scotland who are in in-work poverty and low-paid work who might not be in receipt of one of those eligible benefits, and they will have those support needs as well. Therefore, we need to think about that and ensure that certain households—particularly those in low-paid work—are not missing out.

John Mason: I was struck by figure 1 on page 4 of our briefing, which showed that transport costs, in particular, were quite starkly different, which follows on from Jeremy Balfour's point. It was very interesting that spending on transport costs in the highest income group—if I am reading it correctly; I am looking at the blue line—has fallen the most dramatically. One of your themes seems to be that disability affects a lot of different people in a lot of different ways. For example, some disabled people can still drive and some disabled people cannot. Presumably, that is a major factor because, if you have to give up your car, your costs are going to drop dramatically.

However, you also make the point that spending does not equal need. I am guessing that some disabled people who would be able to drive just cannot possibly afford a car. What is the data on transport telling me? Is it telling me that there is a great need that is not being met, or is it telling me that the concession card system is so good that people do not have a need that results in a cost?

Chirsty McFadyen: I think that it is a combination of things. The first thing that stands out to me is that we have UK-level evidence that disabled people travel less than non-disabled people. The reasons for that are potentially something to look at. Why are disabled people travelling less? Is it because they do not have access? Is it a lack of affordability? We do not know, but that could definitely be looked into more.

Then, yes, as I said before with regard to concessionary bus passes, in this data we do not know who has one of those passes. Therefore, we cannot tell whether people are travelling but are just not spending money on that. However, from the larger numbers in this research, it seems that the prevailing thing that is happening is that people are just travelling less when they are disabled. Therefore, that is something to look at with regard to disabled people having access to society and being able to travel where and when they want to. We also see that with regard to the extra costs for energy. We know that disabled people are spending more time at home and having to heat their home, which means that their energy costs can be higher. It is all tied in, but it is definitely something that could be looked at more.

John Mason: So, the message is that we need a much more in-depth and bigger survey. I think that we are all agreed on that. Who should do that? Is it best for the Government to do that, or should it be a third sector organisation?

Jeremy Balfour: The Fraser of Allander Institute. *[Laughter.]*

Chirsty McFadyen: It is difficult to say. What I always come back to is that, as long as something is well resourced, that is what is important. If a survey is well designed and well resourced, we will get the evidence that we need. If the Government wanted to do it by working in partnership with organisations that have specific in-depth knowledge about disability, poverty and incomes and so on, that could be really useful, but I guess it would be up to you.

John Mason: You said that there is a split between whether people's activities are affected a lot or a little. Is that too basic? Do we need to go into a lot more detail on that?

Chirsty McFadyen: Based on the data that we have, we should not be splitting things any further, because it is already very difficult to understand. Jeremy Balfour mentioned some of the other work that we have been doing on the disability employment gap, for example. We have seen that employment gaps among people with different types of disability are closing faster or slower. In the long term, and in an ideal world, we need more evidence on specific types of disability and who has additional costs based on their needs.

However, cutting the current data into smaller chunks would mean looking at one or two people in a sample, which is obviously not useful for us.

It goes back to the point that, if we had more resource to collect more information, we would definitely want to split it by something more. We use that definition because it is the national definition that is used for disability, but it would definitely be good to look at types of disability.

John Mason: Did you want to come in, Dr Robertson? Most of my questions were aimed at Ms McFadyen.

Dr Robertson: No. Chirsty is the expert on the questions that you asked.

The Convener: Chirsty, I believe that Jeremy Balfour was offering up your services again for further research. I now invite Bob Doris to come in.

Bob Doris: Thank you, convener, and thank you, Mr Balfour, for the namecheck. In the earlier session, I suggested an imaginary extra £10 million. It has doubled in the space of half an hour, and Mr Balfour is playing with an extra £20 million that does not exist.

I want to ask a wee bit about what is not in the survey. I get that there are data issues and massive restrictions on what you were able to collect and analyse. The Scottish child payment has been mentioned, and I had a wee look at it. The interim review of the Scottish child payment from July 2022 indicates that 16 per cent of people in receipt of or applying for—I am not sure which—the Scottish child payment at that point had a disabled person in the household. It might therefore be that we already have a benefit that supports those who live with disabilities, when there is a child in the household and the household is on benefits. In fact, that report suggested that, because 8 per cent did not want to say whether there was a physical or mental issue in the household, there could be underreporting and it could be that up to 24 per cent of Scottish child payments go to households with a disabled person.

Ms McFadyen suggested that the Scottish child payment has had an impact, but it might also have an impact on disabled families. I know that I am asking you a question about something that is not in the report, but was that on your radar at any point? It is quite a significant positive impact, but it also begs the question of what we are doing for households that are in poverty and where there is a disabled person but there are no children. I get that; it is about consistency of approach. Do you have any comments on that, Ms McFadyen?

Chirsty McFadyen: We did not look at any benefits in relation to our data. We looked at disability benefits briefly, but we did not include

that information in the final report, because we found very similar results whether or not people with disabilities were claiming benefits. We found similar extra costs. It would be interesting to look at that in relation to the Scottish child payment.

We decided to use the household unit in the research, because we recognised that the household is generally what receives the benefits, so you could have a point there, but we did not look at that specifically.

I do not know whether Dr Robertson has any thoughts on that in relation to qualitative research.

Dr Robertson: We were obviously very limited with the research. I mentioned that it did not include families, so there was nothing around the Scottish child payment. I am not sure without checking, but I think that Inclusion Scotland and the Glasgow Disability Alliance have published research in the past year—qualitative research and quantitative survey data—about the impacts on different types of households. There might be evidence there that is relevant to your question.

Bob Doris: That is helpful. My understanding is that Social Security Scotland does not routinely collect data on households with disabilities claiming the Scottish child payment. Perhaps it has to improve its data collection on that. Do we know the split between disabled households that live in poverty and have children and those that do not have children?

Chirsty McFadyen: I could not tell you the numbers off the top of my head, but they should be available in national surveys. I do not know whether that would be in the Social Security Scotland survey or in the UK Government's family resources survey. I personally do not know that figure.

Dr Robertson: I could not tell you that either. The other big source of data is the Joseph Rowntree Foundation's annual report. I am not sure whether it broke down the data in that way, but that would be the first place that I would look.

Bob Doris: I ask because of the political choices that Mr Balfour referenced. The Scottish child payment will have an impact on some households that are in poverty and have a disability, but not on others, so we would be able to see the ones that we need to focus on. I think that Mr Balfour was floating the idea of targeting an additional resource.

Ultimately, we get money to people of working age who need it, in Scotland and across the UK, through the benefits system, predominantly through universal credit. Has either of our witnesses looked at the sufficiency or otherwise of how universal credit recognises disability in households in relation to addressing poverty?

Chirsty McFadyen: We have not looked at that. As we said, this was a very limited study. We have looked only at the living costs and food survey and the six diarists, so there is definitely an opportunity for further research into that.

Bob Doris: That is very helpful. I have a final brief comment. I must reflect on the comments that both witnesses have made on pressures on social services provision and meeting the care needs of families or individuals who live with a disability. We will perhaps draw that to the attention of the lead committee, which looks at that kind of thing as a matter of course. I just wanted to reflect that I have listened to what has been said on that issue.

The Convener: Dr Robertson, did you want to come in there?

Dr Robertson: I have nothing to add, but it was very clear that, for four of the six participants, there was a lack of accessible local support, and they had to make decisions about what they used their benefits for. They also had to use their PIP for a large proportion of their additional costs, which was quite an interesting finding.

The Convener: As members have no other questions, I thank you very much for undertaking that research and presenting your findings to us. It will be very useful for the committee's on-going scrutiny of benefits in Scotland and for future inquiry work.

That concludes our public business for today. We will move into private to consider the remaining agenda items.

10:59

Meeting continued in private until 11:28.

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