



OFFICIAL REPORT
AITHISG OIFIGEIL

Equalities, Human Rights and Civil Justice Committee

Tuesday 8 March 2022

Session 6



The Scottish Parliament
Pàrlamaid na h-Alba

© Parliamentary copyright. Scottish Parliamentary Corporate Body

Information on the Scottish Parliament's copyright policy can be found on the website - www.parliament.scot or by contacting Public Information on 0131 348 5000

Tuesday 8 March 2022

CONTENTS

	Col.
DECISION ON TAKING BUSINESS IN PRIVATE	1
WOMEN'S UNFAIR RESPONSIBILITY FOR UNPAID CARE AND DOMESTIC WORK.....	2

EQUALITIES, HUMAN RIGHTS AND CIVIL JUSTICE COMMITTEE

7th Meeting 2022, Session 6

CONVENER

*Joe FitzPatrick (Dundee City West) (SNP)

DEPUTY CONVENER

*Maggie Chapman (North East Scotland) (Green)

COMMITTEE MEMBERS

*Karen Adam (Banffshire and Buchan Coast) (SNP)

*Pam Duncan-Glancy (Glasgow) (Lab)

*Pam Gosal (West Scotland) (Con)

*Fulton MacGregor (Coatbridge and Chryston) (SNP)

*Alexander Stewart (Mid Scotland and Fife) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Jenny Miller (PAMIS, Promoting a More Inclusive Society)

Dr Pauline Nolan (Inclusion Scotland)

CLERK TO THE COMMITTEE

Lynn Russell

LOCATION

Committee Room 4

Scottish Parliament
Equalities, Human Rights and
Civil Justice Committee

Tuesday 8 March 2022

[The Convener opened the meeting at 10:00]

Decision on Taking Business in
Private

The Convener (Joe FitzPatrick): Good morning, and welcome to the seventh meeting in 2022 of the Equalities, Human Rights and Civil Justice Committee.

The first agenda item is a decision on whether to take in private item 3, which is consideration of today's evidence. Do members agree to take item 3 in private?

Members indicated agreement.

Women's Unfair Responsibility
for Unpaid Care and Domestic
Work

10:00

The Convener: The next agenda item is to continue taking evidence on women's unfair responsibility for unpaid care and domestic work. The evidence session will have an intersectional focus on disability. We have two witnesses, who join us remotely. I welcome Dr Pauline Nolan, head of leadership and civic partnership with Inclusion Scotland; and Jenny Miller, chief executive of PAMIS, Promoting a More Inclusive Society.

I refer members to papers 1 and 2. I invite both of our witnesses to make brief opening statements, starting with Dr Pauline Nolan.

Dr Pauline Nolan (Inclusion Scotland): Thank you. Without wanting to correct you, I am head of leadership and civic participation.

The Convener: Apologies.

Dr Nolan: Thank you for the introduction.

Inclusion Scotland and I welcome the opportunity to contribute evidence to the Equalities, Human Rights and Civil Justice Committee about disabled women's unfair responsibility for unpaid care and domestic work. I am particularly glad to join you on international women's day, to highlight some of the intersectional challenges that have been experienced over the past two years by disabled women and women who are affected by disabilities.

I will briefly say a little about Inclusion Scotland. We are a disabled people's organisation that is led by disabled people. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout Scottish society as equal citizens. We do that by influencing decision makers, supporting disabled people to be decision makers themselves, and developing the capacity, awareness and engagement of disabled people.

We have a network of 50 disabled people's organisation members across Scotland, and many partners; and we have a large reach through things such as our newsletter. We have built up a strong reputation as an independent and non-party-political representative organisation of disabled people across Scotland.

Rather than go over the opening statement that my colleague Susie Fitton gave at a previous meeting—I prepared a very similar opening statement—I will open with the words of a disabled

woman for whom I had, and still have, the utmost respect. The quotation is taken from Glasgow Disability Alliance, one of our largest disabled people's organisation members. It is from Susan McKinstery, who was its policy and participation officer and who, sadly, died at the beginning of February. For a long time, she was a very active intersectional disabled activist. These are her words and thoughts about disabled women:

"We are individuals with skills, talents and life experiences filled with the kinds of ingenuity and adaptability which are essential attributes when living ... in a still inaccessible world. Our human rights to safety, stability and the choice over how we live our lives are more than dry and burdensome obligations which must be grudgingly met; they are an opportunity to bring a richness of talent and expertise to bear in meeting the challenges we face nationally and globally. Until disability is seen as a rich and useful facet of human experience and not as an individual deficiency, this cannot happen. The person with the insight into how to tackle some of the critical social or environmental issues today may already exist but be trapped in a system which deprives them of the choice over when to use the toilet let alone share their knowledge."

That is a powerful statement to begin with. I will close my opening statement by saying that all the evidence that I present today, both from our own surveys and from the GDA's, during the pandemic, and from the Fawcett Society, the Women's Budget Group, and Sisters of Frida, which is a United Kingdom-wide disabled women's organisation, shows that disabled women, including those who care for a disabled person, have been hit harder by Covid-19. That is not only because they may have been at a greater risk of severe illness but, equally or more so, because Covid-19 has supercharged the existing inequality that they already face and has made new inequality likely.

Jenny Miller (PAMIS, Promoting a More Inclusive Society): Good morning. On international women's day, PAMIS welcomes the opportunity to #BreakTheBias and provide evidence to the committee about women's unfair responsibility for unpaid care and domestic work.

We are a charity that, for 30 years, has supported children, young people and adults with profound learning and multiple disabilities, and their families, to lead healthy, valued and inclusive lives. Through our family support service, and from academic research, we know that the main unpaid carers of that group of people are women and, in many cases, women who are lone parents. Their caring role is intense and complex, and that has been even more the case during the pandemic.

Evidence tells us that a high proportion of those unpaid carers face deterioration in their physical and mental wellbeing. Their caring role is particularly prolonged, demanding and complex. Along with the many challenges that parallel care of a loved one with complex medical needs, carers

of children and adults with profound learning and multiple disabilities present unique challenges for support services.

First, while they may be the most medically skilled group of unpaid carers, their experience is that their knowledge and skills often go unrecognised among health and social care professionals. Secondly, there is an indication that this group includes a high percentage of women who are single parents, who often care for other children, some of whom also have additional support needs. Thirdly, the overwhelming emotional experience of having a child diagnosed with life-limiting disabilities may be felt as unresolved trauma for many families, which can lead to further triggering and difficulties, especially in relation to the care of their child. However, there are no specialist support services to support and emotionally resource that group of family carers, which those who manage such complex care particularly need.

People with profound learning and multiple disabilities require 24/7 care, and many carers provide between eight and 16 hours a day of that care. At worst, during the pandemic, we saw unpaid carers providing round-the-clock support.

Recent research by the Fraser of Allander Institute provides invaluable evidence on the role of that unique group of unpaid carers, which is a role for life that is unlike that of many other carer groups. The research highlights the savings to the taxpayer of that unpaid care. It would cost £114,000 per person per year to deliver the equivalent care. Their caring commitments restrict the family carer's ability to work, and many carers are living below the poverty line.

We know that many women wish to return to work or enter employment, but the expectation, and the norm, is that they will fulfil that full-time carer role. We have heard from carers who have been told that they are the person's mother and therefore are required to care for their child with complex disabilities, that they must co-ordinate the care of that child and that it is not the duty of the statutory bodies to support them to return to work by providing adequate care packages.

One mother highlighted that her right to be a mother is overtaken by the demand for her to be the physio, the nurse, the teacher, the occupational therapist, the speech and language therapist and the care assistant, which leaves no time for her to be a mum to that child or, indeed, to her other children.

That mum also highlighted the desire to remove herself from the poverty line, to provide for her family and to seek appropriate housing where she can afford her rising fuel bills. She has recently been supported to take up a part-time role in our

charity, but the barriers that she faced in accessing that opportunity, alongside the prejudices from statutory services that should be supporting her, were enormous. Remarkably, she has navigated the benefits trap and the care package issues, and—with our flexibility on her working hours—has been able to work. She asked whether her daughter's dad would have faced the same challenge. This week, when there was an issue with her daughter's care, who was the first port of call? It was not the daughter's dad, but her, as the mother.

We feel that we need to challenge the widespread belief that the role of family caregiver should be reserved for women, while men are not required to make the same level of commitment, and to uphold the rights of such women to have a liveable standard of living, a right to health and a right to work.

The Convener: Thank you very much for your opening statements. We have a smaller panel than we have been used to of late, so there should be time for us to ask both witnesses each of our questions. I guess that there might also be a bit of time for supplementary questions. If members can indicate that they want to ask a supplementary on the same topic before we move on, that would be helpful. Members might also want to indicate who they want to hear from first.

If either of the witnesses feels that they have not been brought in on something that they are keen to contribute to, please type R in the chat, but I have a feeling that we will want to hear from both of you on each of the topics.

We now move to questions, and I will start with Maggie Chapman.

Maggie Chapman (North East Scotland) (Green): Good morning, Pauline and Jenny, and thank you very much for joining us and for your opening remarks. The statements and testimonies that you have given us are very powerful.

Jenny, I will come to you first. I am interested in exploring some of the physical and mental consequences of the pandemic for people's wellbeing. You talked about deterioration in physical and mental wellbeing. Can you say a bit more about the health impacts that you saw in the carers whom you support?

Jenny Miller: Absolutely. Those quotes were made prior to the pandemic, but the pandemic put a real spotlight on them. Families talked to us about feeling abandoned, isolated and invisible. They were affected by having no support coming in, and they are still receiving no support because day services are still limited in a lot of areas. People who had five days a week care now have nothing or have two days a week. Families are therefore absolutely exhausted.

The most awful impact of the pandemic is seen in the families who have been left with suicidal tendencies because they just do not know where to go. They have children who they really love but they are now having to think about putting them into residential care because they are exhausted, and they cannot cope.

We know that there is a shortage of care providers and that there is a national crisis in social care provision, so people's emotional wellbeing has really deteriorated. Alongside that, we have also noted a lot of physical deterioration because families are suddenly having to do all the moving, handling, and lifting, and by midway through the pandemic, relatives had put on weight and there was no upgrading of equipment. The pandemic therefore had an enormous impact.

UK Covid research highlighted the percentage of families that felt that their health and physical wellbeing had declined, as had their children's. One of the really awful things is that families saw their children's skills and health deteriorating, along with the things that they could do before the pandemic, because they were just not doing them. The effect was dramatic, and it is still going on.

Maggie Chapman: Pauline, could I bring you in to answer the question on the physical and mental consequences for disabled people and for the people around them?

Dr Nolan: Ours and other's surveys show that the mental and physical health of disabled women has deteriorated sharply since the pandemic, and the two have had an impact on each other. As Jenny Miller outlined, those who had key responsibilities felt undersupported or unsupported. In addition, many disabled queer people and shielders felt abandoned and experienced extreme loneliness, isolation and depression. That was backed up by Sisters of Frida, the disabled women's organisation, and by our own survey. It was a big theme in the April 2020 survey that we did.

The Fawcett Society and the Women's Budget Group found that 56 per cent of disabled women reported finding social isolation difficult to cope with, compared to 41.6 per cent of non-disabled women.

Anxiety was highest among women overall, but particularly among disabled women: more than half of disabled women report high anxiety. Sisters of Frida say that disabled women feel let down by the public attitudes to social distancing and mask wearing, which has impacted on their access to community and green spaces.

10:15

It is a long-term issue that continues to affect disabled women and women impacted by disability. At the beginning of the pandemic, disabled women did not access preventative health care treatments or other treatment necessary for their health conditions—they either considered that they might be a burden on the NHS and wanted to put others before themselves or they had concerns and fears that they would catch Covid. We have heard from disabled women that some of the unofficial health treatments that are important to women that they access via health and beauty shops and hairdressers were also shut to them. That meant that pain management techniques that disabled women had found worked for them were no longer available.

There has been a huge impact on families. In a previous meeting, my colleague Susie Fitton talked about disabled women and women carers of disabled children who suddenly had to look after disabled children and support their mental health, which was worsening because they were not able to get outside or get to their usual supports. The women did not have support to look after the children, and respite services were not available.

One carer said:

“My youngest child not being at school is proving difficult for my health as I’m now struggling to care for her 24 hours a day. I normally have 2 nights respite per week and one weekend daytime respite to rest in order to help me pace and cope. The stress and extra required activity is making my symptoms worse.”

The additional struggles, such as difficulties getting shopping and accessing medication, have all had an impact.

Maggie Chapman: Thank you—that is really helpful.

Pam Duncan-Glancy (Glasgow) (Lab): I thank the witnesses for the evidence that they gave us in advance and for joining us today. On international women’s day, it is particularly special that we are taking evidence on disabled women because, in order to break the bias for women in general, we have to look at us in all our glorious shapes and sizes. I am delighted to be joined by all the witnesses.

I point members to my entry in the register of members’ interests, which shows that I was an employee of Inclusion Scotland from 2009 to 2015.

I would also like to take a moment to remember Susan McKinstery. I thank Pauline Nolan for reading out a quote from Susan, who was an absolute powerhouse of the disability movement and a woman who shall be sorely missed.

The evidence that you have already given this morning has been moving and stark. I have a couple of questions. My first question is for Pauline Nolan—it is lovely to see you again, Pauline. I want to ask about the “Rights at Risk” report and the fact that you have highlighted that many disabled people’s human rights were breached and that we could be seeing a regression in disabled women’s rights. Will you tell us a bit about what you think needs to be done to address that?

In that context, will you set out your aspirations for the new disability equality plan? What is the scale of the challenge and what do we need to do to improve circumstances and reverse regression?

Dr Nolan: It is good to see you, too, Pam. That is a big question. We are just starting to work on the asks from the new disability equality plan with the Scottish Government and other disabled people’s organisations in the Scottish independent living coalition.

Our “Rights at Risk” report was based on a survey that we conducted in April 2020 with more than 800 disabled people. It really showed the mental health impacts that I was just talking about. It also showed that there was an impact on rights to independent living under article 19 of the United Nations Convention on the Rights of Persons with Disabilities. For example, women were having their social care support removed overnight with no discussion, and a further survey carried out later that year showed that some people were still being charged for that social care support. Furthermore, some women could no longer access their housing, because they had no support in their own house and so had to go to live with family, increasing those reliance and dependency relationships.

If we are to tackle gender inequality in relation to social care support, we need sustained public investment in a nationwide modern infrastructure of social care support to protect, promote and ensure human rights and to tackle inequalities for disabled people. Eligibility criteria and care charges need to be removed.

Disabled people need to be involved in setting any ambitions for the new disability equality plan. It needs to be realistic and not go over things that are already happening or that have been done before. It needs to have ambitions that are achievable and can be implemented and co-designed with disabled women and their supporters.

As well as setting out the rights to dignity and access to services to meet rights to independent living that all disabled people have, the UNCRPD, which has been brought into Scottish law, recognises that disabled women are “subject to

multiple discrimination". The Sisters of Frida report states:

"measures need be undertaken to ensure that our rights are protected and advanced in society."

We would like to know how policies and legislation such as the national care service bill will align with the incorporation of the UNCRPD article 19 right to independent living and article 6 right to non-discrimination against disabled women and girls.

An immediate method of easing the strain of the caring responsibility of women impacted by disability would be for the Scottish Government to reopen the independent living fund—that seemed to be on the table, but it is nowhere to be seen in the national care service proposals—to new applications from people who need it and extending what funds can be used for. The independent living fund enables disabled people to pay for care so that they can be supported in their homes and local communities. However, it was closed to new applications in 2010. The reopening of the ILF could be done immediately and could provide much-needed support to people with high support needs and their carers. That urgently needs to be added to the work on the national care service, while work is done on other ways to improve social care support.

Pam Duncan-Glancy: Thank you. Convener, may I ask two further questions?

The Convener: Yes, if they are in the same area.

Pam Duncan-Glancy: Pauline, have you carried out any analysis of the impact of shielding on disabled people's ability to continue to work during the pandemic? What support has been provided by employers to enable that to happen?

Dr Nolan: We looked at shielding and did an additional survey of more than 150 disabled people on their experiences of shielding. We found that disabled people, including disabled women, were really concerned that they would lose their job. Around one in 10 respondents—11 per cent—were concerned that they could lose their job as a result of the pandemic. According to Sisters of Frida:

"Discriminatory work practises and the government's failure to implement fair employment regulations led to unemployment, reduced work hours and reduced pay."

A big failure has been in not adapting to home working for disabled women, particularly those who have caring responsibilities or who look after children and older people. That has been particularly the case in low-paid and public-facing jobs.

Was that helpful, Pam?

Pam Duncan-Glancy: It was. Thank you.

I have other questions, convener, but not on this theme.

Alexander Stewart (Mid Scotland and Fife) (Con): I welcome Pauline Nolan and Jenny Miller to the meeting and thank them for their opening statements.

You mentioned the concerns that women have about their financial security now and in the future. We are well aware that, during the pandemic and even prior to it, disabled women were having to deal with cost of living issues, and the situation has only been exacerbated in recent times. It would therefore be good to hear your views on issues in that respect that are specific to disabled women. However, I note that other factors come into it, too, including age—in other words, how old women are and what they are having to deal with—ethnic background, whether someone is a lone parent and the impact of that on their financial security and stability. We have heard a lot about individuals having to make choices, one of which might be between eating or heating, and how they have managed such circumstances.

It would be good to hear from Jenny Miller, to begin with, and then from Pauline Nolan about their experiences in that regard. Do you feel that women from a certain individual background are more susceptible to or more in crisis because of the challenge to their financial security and because of the situation in which they find themselves every day—having to manage their family, their lifestyle and their opportunities?

Jenny Miller: Last week, we had a case involving a mum who is a lone parent who lives with her two children in an incredibly cold and draughty house. Her daughter requires 24/7 care and to have the heating on in her room at all times, there is a variety of electrical equipment that needs to be run, and she has to run the washing machine three or four times a day. Her fuel costs have just gone up from £286 to £874 a month, and she does not know how she is going to pay that.

At the moment, she is heating her disabled daughter's room while she and her other daughter are sitting with six jumpers on and no heating on. She is making the types of decision that you referred to about what food she buys to ensure that she can pay for the heating, but the fact is that she cannot pay for it. She wants to get out of the poverty trap and has been trying to get into employment, but there is still an expectation that she will be the person who delivers the care.

These lone parent women who are caring for children with really complex needs are those who are also in the poverty trap, and they cannot see a way out of it.

Alexander Stewart: Have you had similar experiences, Pauline, or are there other areas that you want to comment on?

Dr Nolan: You are right to suggest that the intersections of disability, gender, race and class compound women's income poverty, increase their time poverty and impact on their health, but there is not really enough data on those intersections with regard to disabled women. What we do know is that nearly half of all those living in poverty in the UK are either disabled or living in a household that contains a disabled person. That said, the official measure of poverty—that is, households living on less than 60 per cent of the median income—fails to take into account the additional costs associated with disability, which Jenny Miller just highlighted.

10:30

In 2018, Scope found that disabled people in Scotland spent an average of £632 a month on disability-related expenses such as additional heating, washing, taxis, special equipment and care costs. Those are the highest excess costs in the UK. On average, disabled people have £108,000 less in savings than non-disabled people have. Once those costs are fully taken into account, half a million Scottish disabled people and their families are living in poverty. In total, that is 48 per cent of all people who are living in poverty in Scotland, despite the fact that they make up only 22 per cent of the population.

That is backed up by other research. Sisters of Frida found that

“The cost of living for Disabled women increased however income decreased. Many Disabled women were not eligible to access the government's £20 uplift of Universal Credit.”

Other issues have been brought to the fore during the pandemic, such as a lack of access to technology, which was vital for the switch to home working and home schooling for children. That has been a particular problem for disabled women. A report by the Women's Budget Group, the Fawcett Society and others stated that almost 40 per cent

“of disabled mothers reported that their children did not have access to the equipment they needed to study at home, such as a computer or printer, compared to 24.2% of non-disabled mothers.”

Pam Gosal (West Scotland) (Con): Good morning. I thank Jenny Miller and Pauline Nolan for coming to the meeting and for their opening statements, especially on international women's day.

We have heard that the rates of domestic abuse and violence against women increased throughout the pandemic. Was that the case for disabled women, too? If so, were there specific impacts on them? If so, how could we have addressed that?

Jenny Miller: We have seen the intensity of the caring role from family support directors feeding back on the lack of support. A couple of weeks ago, there was a case in which a father absolutely lost it because of the stress and strain in the household. The family support director then spent a whole week trying to find appropriate support services that could go in and alleviate that stress.

We have not collected specific evidence, but we are picking up case studies. We know that family relationships break down in families with children who have really complex needs. A child with complex needs who communicates in a challenging way causes even more issues. People not having any social support or any respite has definitely heightened the issues that families face.

There have been a few cases in which families have had to leave the family home. Mothers have had to leave because of a breakdown in relationships and it has been really difficult for them to get any support. Some of those families are now thinking about their child going into residential care because they cannot cope any more.

I am sorry—that is not a very good answer. We do not have specific evidence, but those are just some of the cases that our family support directors are tackling. Parents have been left to home school more than one child on top of the complex caring role, so tensions have been incredibly high.

Pam Gosal: You say that tensions have been high. Could anything more have been done to address the situation, and are there any examples of that?

Jenny Miller: I have said that families have felt invisible. They have felt completely out on a limb. Some families said that the only support that they had was the telephone calls from PAMIS. Sometimes, people just wanted somebody to phone them up to see how they were doing. We are talking about people whose children experience complex communication issues and who are growing and transitioning into adulthood. For a small lady who is looking after a very large son, it is incredibly difficult, particularly if she does not get any phone calls.

Families get really tired. I have heard families say that they need their child to go into residential care because they are so tired that they do not even know what they are doing any more, so there needs to be more support. People also need an opportunity to get out of the house. Living in small accommodation, with nowhere to have private conversations, is incredibly difficult.

Dr Nolan: I back up what Jenny Miller said about those experiences. I have spoken about the research that Sisters of Frida did, and I have said that disabled people felt as though they had to

depend on others during the pandemic. That put a strain on families. Sisters of Frida pointed to

“a dramatic increase in calls to domestic violence helplines and support services”,

and said that many disabled women

“will find it much harder to flee dangerous situations, or to find the refuges and services they need”.

That includes accessible refuges—which there were not enough of in the first place—that allow disabled women to make the decision to leave.

The care-dependency relationship is often a factor. The forms of domestic abuse that disabled women face diverge slightly from what we might call usual domestic abuse. For example, there could be abuse of medication, financial abuse and so on. Some of those issues were exacerbated for women with learning difficulties or with other communication barriers, because there was no access to advocates who provide one-to-one support during the pandemic. That was a huge issue.

Over many years, a lot has needed to be done to improve access to domestic abuse services for disabled women, and the issue has been exacerbated by families being stuck in the home.

The Convener: Pam Duncan-Glancy would like to ask a wee supplementary question.

Pam Duncan-Glancy: I want to ask about the care-dependency relationship, but Pauline Nolan has just outlined the situation, so I do not need to ask my question because it has already been covered.

Karen Adam (Banffshire and Buchan Coast) (SNP): I thank Pauline Nolan and Jenny Miller for coming along to give evidence. You have spoken about disabled people facing additional restrictions on their activities and freedoms due to being at higher risk of more severe impacts from the coronavirus. Some disabled people needed to shield completely and felt more vulnerable to being exposed to the virus. Overall, disabled people, especially women and those receiving unpaid care, were more likely to spend extended periods without leaving their home during the pandemic.

Research shows that 16.6 per cent of people said that they had not left their house the previous week to go for a walk, to exercise or to go shopping, but the figure for disabled women rose to 25.5 per cent. Ensuring that clinically vulnerable people isolated at home was an essential part of the response to the coronavirus, but going for extended periods of time without leaving the house could have significant impacts on mental and physical health. Data suggests that that will have particularly impacted disabled people, including disabled women.

What are the witnesses' views on that? Could lessons be learned about such scenarios that would help us in the future? I ask Pauline Nolan to come in first.

Dr Nolan: Disabled women, and disabled people in general, need to be involved. Under article 11 of the United Nations Convention on the Rights of Persons with Disabilities, disabled people have the right to be involved in any measures that are put in place in emergency situations.

It would have potentially put them at less risk from the virus and the measures to control it if we had been involved in emergency planning. However, as the pandemic came on and emergency planning was happening at such a fast rate, there was no involvement of disabled people's organisations or disabled people in that. We believe that that put disabled people, and disabled women in particular, at more risk from the pandemic and the restrictions that were put in place because of it.

Jenny Miller: I absolutely agree with you, Karen. One of our arguments all along was that getting access to the outdoors was important, particularly for our group of people. You mentioned the tensions that arose in houses where people were not getting out, because they needed activity. I think that a blanket risk assessment was done. For some people who were living in shared accommodation and care homes, there was absolutely no opportunity to get out, and we know that that had, is having and will continue to have an impact on the health and wellbeing of people with complex needs and their family carers. The damage has been done, and it will never be undone.

The other day, one mum told me that she wanted to take her daughter out and was told categorically that she could not. However, she said that, in reality, when she goes to the park with her daughter, nobody rushes up to chat to them anyway. It would have been far safer to go to a park or open space and give her daughter the opportunity to be out and to exercise than it was to keep her locked up indoors.

As Pauline Nolan said, we would have really appreciated it if there had been more personalised risk assessments. There were recommendations from the Government that said, “Please do risk assessments with individuals.” When we did risk assessments with families, we found that they absolutely understood the needs of their children and wanted to keep them safe. The families' risk assessments minimised risk, although there was no way to get rid of every risk. I just wish that there had been more collaboration with organisations, as Pauline highlighted.

The damage has been done, however. If we are ever in the same situation again, we need to remember just how important physical activity is for the wellbeing of everybody. It would have made a huge difference if we had enabled people to get out and about, particularly in the first lockdown, when the weather was reasonable. The group of people we deal with were far more discriminated against and were not able to do things. As we all started going to the pub, they were still locked down.

Thank you for that question.

Karen Adam: Thank you, Jenny. I think that Pauline would like to come back in.

Dr Nolan: In fact, a lot of disabled women are still locked down. We need to ask those disabled women and other disabled people what the solutions are and what can be done to prevent them from catching Covid. That is still an issue for many disabled people. As Jenny said, we also need decision makers and service providers to understand that disabled women's lives are complex, because of their intersections with other protected characteristics and because of where they live in the country, the supports that they have or do not have and the poverty that they face. That all needs to be included in the mix when we look at solutions and carry out future planning.

Karen Adam: That is really helpful. Thank you very much.

Maggie Chapman: I want to follow up on the topic that you both started to explore with Alexander Stewart—financial security—but from the point of view of education and training. Jenny Miller spoke about the poverty trap and people not having access to a range of employment options or having to curtail their paid work because of caring responsibilities. There is also the issue of people curtailing other opportunities, such as skills development, training and education opportunities. I ask Jenny Miller and then Pauline Nolan to say a little more about the impacts on access to education, skills and training that carers and disabled people experienced during the pandemic.

10:45

Jenny Miller: Many of the families we support have given up prestigious and well-paid jobs to take on their full-time caring role. It has been depressing to see the lack of confidence that they have when they start applying for roles, because they feel that they have lost so many skills. We are interested in providing a family carer job description because we are pretty sure that it would map to a Scottish vocational qualification level 5 in supervisory management because of all the jobs that they take part in, such as care

management and financial management. There is a huge range of skills involved.

It is difficult for family carers to find the time to attend training, further their education and think about jobs. It has to be flexible. We are finding that the flexibility of courses and employment is not appropriate for people who have to take a child to hospital at the drop of a hat or provide emergency support. Real consideration needs to be given to empathetic employment. At the moment, we are putting in a funding application for routes into empathetic employment, providing support and buddying for families who have managed to manoeuvre their way around the benefits system and the barriers so that they can support each other back into employment.

As I highlighted, the group of families we support are probably some of the most skilled carers we have. We need to consider how we translate the skills that they have developed into accredited vocational qualifications. With the Scottish Clinical Skills Network, we have been talking about accrediting some of the invasive procedures that some of those families have learned on the job. They are a highly skilled workforce and, sadly, many of them lose their children earlier in life, so they have a wealth of skills that then goes untapped because they have not been given the possibilities and support to think about employment.

As employers, we need to consider how we support that group of people, who are an absolute asset if we provide the right conditions. Flexibility is key.

I am sorry, Maggie, did I go off on a tangent? I am a bit passionate about that.

Maggie Chapman: No, Jenny, that is really helpful. Thank you. You mentioned empathetic employment and the adaptations that employers need to think about. Inclusion is good for everybody, not just the people for whom it is designed.

Pauline, do you want to comment on the question as well? You talked earlier about the need for people to feel fulfilled and feel that they are able to do something that they want to do and not just be stuck indoors at home. How have the people you work with and you support felt through the pandemic?

Dr Nolan: I spoke earlier about lack of digital support and accessible equipment for getting involved in education. To use the phrase that the Glasgow Disability Allowance uses, the situation has supercharged existing, pre-pandemic inequalities in access to work and qualifications. The cost of broadband has also been a barrier to disabled women. The juggling of work, social care support and childcare or caring for relatives is

discussed in our evidence. There were also issues with the inflexibility of the system requiring wet signatures to endorse claims for access to work, which has been a big problem.

Inclusion Scotland provides employment opportunities for disabled graduates and disabled people who have been out of work via paid internships in the Parliament, the Scottish Government and other parts of the public sector. Those are highly successful because we couple them with training for employers. We need to look at the employability of employers rather than at disabled individuals' own deficiencies regarding work and education. Employability programmes that tell people what they need to access work do not always help when workplaces are physically inaccessible and also often inaccessible in terms of attitudes to disabled people.

Disabled women are, of course, victims of the dual intersectional bias against them in workplaces. Then we have the intersections of impairment; employers and also educational establishments will have their own biases around mental ill health. Not enough is being done to address the barriers and to train people. We do some training, but we think that more needs to be done to train employers to become accessible.

Maggie Chapman: We have got a lot of work to do, and a lot of culture change to get on with. Thank you, convener; I will leave it there.

Pam Duncan-Glancy: I will stick with employment for my first question, if that is okay, and then I have a question on social security.

You have highlighted some of the significant barriers to employment that disabled women experience in general. What specifically do we need to do as a result of what we have seen during the pandemic and the rolling back of rights that it caused? Can you also talk a little bit about the inclusion of disabled people and unpaid carers in the Government's main initiatives on employment, such as the no one left behind approach, the parental employability fund, green jobs, the women in business centre and modern apprenticeships, and about what it would need in order for those initiatives to take account of disabled people's needs?

Jenny Miller: Pauline Nolan talked earlier about engagement with the people themselves. Our empathetic route to employment project was brought forward and is totally led by family carers who have a passion and drive to make sure that they can get back into the market. They have come up with the most amazing and creative ways of getting over the barriers and managing their complex lives.

We need to engage far more with the people themselves who require the services. Families will

often say to us that they are not asking for the earth; they are asking for someone to work with them so that they can look at solutions.

The situation is complicated, so our other ask is often why not spend a day in those people's shoes, and have a day in the life of their experience so that we can really understand what they have to cope with. Carolynne, who works with us, has done a detailed step-by-step account of the barriers that she had to overcome so that she could get into employment. One of the biggest ones—and this might feed into your next question—was how she makes sure that she earns enough money to look after her child and come off benefits, because she knows that, once she has come off them, it will be difficult and complicated to get back on them. She had to have many conversations with the benefits agencies to work out how she could do that in a way that meant that she would not be destitute before she started working.

It is about engagement with the people themselves. What gets me up and going to work is the fact that I am inspired by families and people who have disabilities who absolutely know what the solutions are, but we maybe need to think about how we make those into a reality.

Dr Nolan: Workplaces and educational establishments need to be more flexible in their approach to including disabled people, particularly disabled women. There is a need for social care support to be properly in place and for people's needs to be met. If somebody cannot leave their house in the morning or cannot get on public transport, they may have no opportunities to be involved in the programmes that Pam Duncan-Glancy mentioned. The employability programmes need to be more flexible and accessible.

A lot of disabled women work in jobs that were formerly seen as unskilled. Those jobs became key work during the pandemic, and those key roles need to be fully recognised. They include unpaid care and support work, which is predominantly feminised, and all the low-paid roles in the public sector. Disabled women had to go out and work in shops, where they were put at increased risk. They were probably due danger money because of that increased risk of Covid-19.

On the point about benefits, disabled people and families need benefits to be uplifted to a point at which they can afford to meet their additional costs. It is as simple as that. For the past 10 years, we have had a benefits system that has focused on deficiency and seen disabled people as scroungers. We need to turn that round in order to give disabled people, including disabled women, opportunities to work and take part in society and their communities. It is an investment.

The Convener: That brings us to another area that Pam Duncan-Glancy is looking to go into.

Pam Duncan-Glancy: I am keen to understand the financial impact of the pandemic, particularly on disabled women but also on unpaid carers. In her opening remarks, Jenny Miller made a point about families being expected to pick things up and someone being told, “You’re their mum—you should just do it.” I recall, and I thought that it would be nice to put it on the record, that when I finally got the social care and support that I needed, my mum said—I remember this very specifically—“I can now be your mum and not your carer.” I was 18, incidentally, so she had done that for 18 years. It is very important that we do not make assumptions about unpaid care.

Will you both say a little about the financial impact of the pandemic and how helpful the support that was put in place, such as the doubling of the carers allowance supplement, has been?

Dr Nolan: I have already mentioned some of the financial impacts on disabled women. I believe that the uplift to the carers allowance supplement still placed the benefit below the standard rate that can put people into poverty. Although it was welcomed, more needed to be done. There should be a focus on that in the upcoming carers strategy. However, I have already talked about the impacts of poverty, so I will allow Jenny Miller to come in on that.

Jenny Miller: There was nowhere for some of the families we have supported to spend their care packages, because no services were open. The biggest issue at the moment is the total clawback, whereby somebody is told on a Monday that, by the Friday, all the unclaimed money will be taken back. That money would be so useful if people can now find opportunities to have respite from their caring roles.

The impact for families was vast. As we have talked about, people’s heating bills went through the roof. Many were unable to go back to work because they were caring five days a week—or indeed seven days a week—and there was no possibility for them to do home working. I am amazed that some families managed to juggle home working, which was really difficult. Some families had to consider giving up their work, particularly as some employers were demanding that people work set hours, which was almost impossible.

For people to be able to work, they need to have the right care. Not having access to appropriate care and not wanting to hand over the care to someone they are not convinced will deliver it in the same way that they do is a barrier to supporting people to get back into employment.

11:00

With the fuel crisis, the poverty will be stark. We have families who just do not know what to do. I feel awful because, as an organisation, we are not sure how to support them. This week, we are having an emergency meeting with our board to talk about what to do to provide support. We might get in touch with Pauline Nolan to discuss what we can do as organisations. Trebling people’s monthly bills is a recipe for disaster. I am sorry—I am waffling.

Dr Nolan: You are not; I absolutely agree. I hope that it is okay for me to come back in, convener.

The Convener: Yes, that is fine.

Dr Nolan: We have a lived experience poverty group at Inclusion Scotland. I am so aware that so many people face stark decisions about what to do. Many disabled people and families of disabled people face additional costs when it comes to heating and use of fuel. That needs to be looked at in a policy context, because the war in Ukraine is adding to the existing fuel crisis. There are also the on-costs of accessing paid-for services, which are increasing their prices because of increased bills.

There will be disabled women who are unable to access the paid-for beauty services that they need in order to manage pain. Last year, we were told that they could not do that because those services were closed; now, they cannot do that because they cannot afford to.

Pam Gosal: I want to go back to the issue of apprenticeships, which my colleague Pam Duncan-Glancy mentioned. This week is also apprenticeship week. I want to ask about take-up of and access to apprenticeships for disabled people. Do you have any links with organisations such as Skills Development Scotland and Apprenticeships Scotland? How is that working? Is that an area that you are looking at?

The Convener: That was a very timely question, Pam.

Jenny Miller: I have made a note of those organisations. In our project on how to get family carers back into employment, we are keen to look at how we work with organisations in order to get the skills that people in such families have developed recognised and accredited, so that they can think about where they can work. Again, our conversations will be about the need for flexibility in supporting people into apprenticeships and skills training so that they can carry on with their caring role.

It would be fantastic if the wealth of skills that family carers have developed through their caring role could be recognised and accredited, as that

would affirm their value. We hope to develop such links in the future.

Dr Nolan: At the end of the week, Glasgow Disability Alliance will publish its report on the triple whammy of impacts from being a woman, being disabled and being affected by the Covid pandemic, in which it will talk about how employment opportunities have dried up for disabled women jobseekers as the job market has become more competitive.

We are currently working with Skills Development Scotland on delivering our employerability training to the hotel and tourism industry. That is a short-term project that will, I hope, have a big impact. A lot of disabled people are employed in that industry, but the number who face barriers in the sector or in gaining employment in it is probably hidden.

In the past, a lot of the work of disabled people has been segregated. We do not want to see that. We provide the employerability training and internships to ensure that they are included in mainstream work. Many past projects were valuable to disabled people but segregated them from society; they also did not let mainstream employers know what barriers disabled people were facing.

Pam Gosal: You mentioned that you are working with Skills Development Scotland. Does more need to be done to promote apprenticeships and to make people aware that they are accessible to all, including disabled people?

Dr Nolan: Yes, more needs to be done to make apprenticeships more accessible. We are working on that, although that is being done by someone else, so I cannot go into much detail. However, I would be very happy to follow up on that via my colleagues who work in that area, if that would be helpful, Pam.

Pam Gosal: Yes, it would—thank you, Pauline.

The Convener: As there are no further questions from members, I thank Jenny Miller and Pauline Nolan for their time and helpful input. The committee will want to consider further a number of the areas that you have mentioned, to try to get movement on them. It was good that we were able to have a more in-depth discussion around the topics, rather than feeling that we were chasing our tails.

That brings the public part of our meeting to a close. The next meeting will be on Tuesday 15 March.

11:07

Meeting continued in private until 12:28.

This is the final edition of the *Official Report* of this meeting. It is part of the Scottish Parliament *Official Report* archive and has been sent for legal deposit.

Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

All documents are available on
the Scottish Parliament website at:

www.parliament.scot

Information on non-endorsed print suppliers
is available here:

www.parliament.scot/documents

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000

Textphone: 0800 092 7100

Email: sp.info@parliament.scot



The Scottish Parliament
Pàrlamaid na h-Alba