



**OFFICIAL REPORT**  
AITHISG OIFIGEIL

# Public Petitions Committee

**Thursday 10 January 2019**

**Session 5**



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](http://www.parliament.scot) or by contacting Public Information on 0131 348 5000

---

**Thursday 10 January 2019**

**CONTENTS**

	<b>Col.</b>
<b>CONTINUED PETITIONS.....</b>	<b>1</b>
Social Care (Charges) (PE1533).....	1
Residential Care (Severely Learning-disabled People) (PE1545) .....	15

---

**PUBLIC PETITIONS COMMITTEE**

**1<sup>st</sup> Meeting 2019, Session 5**

**CONVENER**

\*Johann Lamont (Glasgow) (Lab)

**DEPUTY CONVENER**

\*Angus MacDonald (Falkirk East) (SNP)

**COMMITTEE MEMBERS**

\*Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con)

\*David Torrance (Kirkcaldy) (SNP)

\*Brian Whittle (South Scotland) (Con)

\*attended

**THE FOLLOWING ALSO PARTICIPATED:**

Jackie Baillie (Dumbarton) (Lab)

Gillian Barclay (Scottish Government)

David Fotheringham (Scottish Government)

Jeane Freeman (Cabinet Secretary for Health and Sport)

**CLERK TO THE COMMITTEE**

Sarah Robertson

**LOCATION**

The Adam Smith Room (CR5)



# Scottish Parliament

## Public Petitions Committee

*Thursday 10 January 2019*

*[The Convener opened the meeting at 10:00]*

### Continued Petitions

**The Convener (Johann Lamont):** Welcome to the Public Petitions Committee's first meeting in 2019. I wish everyone a happy new year. I give a particular welcome to Dr Gabriele Andretta, President of the State Parliament of Lower Saxony, who is in the public gallery. I also welcome Jackie Baillie.

#### Social Care (Charges) (PE1533)

**The Convener:** The first petition is PE1533, by Jeff Adamson on behalf of the Scotland against the care tax campaign, on the abolition of non-residential social care charges for older and disabled people. The petition was lodged in September 2014 and was first considered by the committee in November 2014, in session 4.

When we considered the petition in October 2018, we noted the petitioner's concerns as set out in his submission of 11 September 2018 and agreed to invite the Cabinet Secretary for Health and Sport to give evidence to address his concerns and clarify the Government's approach to the delivery and implementation of the extension of the free personal care policy. We received a written update on the issue from the cabinet secretary in November 2018, and that is included in our meeting papers.

The cabinet secretary will be accompanied by officials, who will be here shortly. Cabinet secretary, I appreciate you taking the time to speak to the committee, and I hope that we will have a useful discussion. I invite you to make a brief opening statement.

**The Cabinet Secretary for Health and Sport (Jeane Freeman):** I, too, wish committee members and others a happy new year. Thank you for the opportunity to speak to you today. I apologise for the current absence of my officials. I am grateful that we have been able to start on time; I would not want to hold the committee up for that reason.

As you said, convener, on 20 November, I wrote to the committee to set out our approach to the implementation of the extension of free personal care to those who are under 65 to ensure that it is consistent with the current approach for those who are over 65. We want to ensure equality of

treatment between adults who are under 65 and adults who are over 65.

Parliament approved legislation in June 2018 to extend free personal care to all adults who are found eligible by their local authority, regardless of their age, condition, socioeconomic status or marital status. That exceeds the original remit of Amanda Kopel's petition, which focused on those with dementia only.

The extension of free personal care will be delivered on time as the legislation comes into effect on 1 April 2019. That builds on previous action to reform the charging system. In 2016, we raised income thresholds, which means that less income is taken into account. We also ensured that local authorities would disregard from financial assessments all veterans' income from war disablement pensions and the armed forces compensation scheme. Further, we worked with the Convention of Scottish Local Authorities to ensure that people who are in the last six months of a terminal illness receive free social care at home.

When I was in my previous role as the Minister for Social Security, we in the Parliament ensured that those who are clinically diagnosed with a terminal illness are fast tracked so that they receive the maximum financial support that they are entitled to quickly and with dignity, regardless of any number that is put on their terminal diagnosis as the expectation of when they might die. That ensures that people receive what they are entitled to at the right time and as smoothly as possible.

Extending free personal care to all adults is an important further step in our work to reform charging for social care, but further steps must be taken on a sustainable basis. I recognise that the latest step does not go as far as the petitioner would like it to go, because other social care charges will remain for people who do not meet the criteria that I outlined.

Any future reform to the cost of social care and how it is paid for needs to be considered as part of our wider adult social care reform programme, to ensure that our approach is sustainable now and in the future. Funding of £30 million for the extension of free personal care to people who are under 65 is part of our draft budget, which was published last month. I hope that the budget will be supported across the chamber to ensure that we have the resources to deliver this important improvement.

I am happy to deal with any questions that members might have.

**The Convener:** Thank you very much. Before we move to questions, I welcome from the Scottish Government Mike Liddle, policy manager,

and David Fotheringham, head of adult social care policy.

I think that you made this point in your statement, but I want to confirm that you expect the extension of free personal care to adults who are under 65 to be implemented by 1 April. Are your partners in delivery so confident that that can be done?

**Jeane Freeman:** Yes—I confirm that that is my expectation. We have worked extensively with COSLA. As recently as last night, I had the opportunity to discuss the readiness of local authorities to deliver the progress that needs to be made with Councillor Currie, who is COSLA's lead on social care and other matters in my portfolio. I am happy to say that we are on track.

**The Convener:** Do you accept the petitioner's argument that, for human rights reasons, there should not be care charges at all, and charges often mean that people cannot get the support that they need to access work, college and so on? Do you understand the general argument behind the petition? For someone with a disability, the issue might be not about personal care but about the provision of transport or whatever. Such provision is not within the scope of what you have suggested.

**Jeane Freeman:** I completely understand that point. During the two years that I was the Minister for Social Security, I had the benefit and the privilege of working extensively with individuals in looking at that area of the portfolio, which helped me to understand better the situation and the difficulties that people face. I am making the point that we have made stepped progress on charges for adult social care, which I outlined in my opening statement. We want to consider further progress that could be made in the work that is being done on the reform of adult social care.

Considering steps that we might take on charging is an important part of that work, but the work extends to looking at how we ensure that the correct facilities and support are available for everyone in our country to live as fulfilled a life as possible, with equal opportunities. That relates to the second petition that we will consider this morning, too.

**The Convener:** Do you accept that, if we take a human rights perspective—I think that the Scottish Parliament has done that—there is an argument to be explored about how social care is delivered? It is about levelling the playing field so that people can access what they need. The current charging policy does not comply with human rights in that regard.

**Jeane Freeman:** The legal advice that we have is that what we currently do complies with human rights and with our need as a Parliament and a

Government to meet that requirement. However, the thrust of the question was whether we should adopt a human rights approach to all this work, and I absolutely agree with that—that is an area to explore.

The reform work that we are undertaking on adult social care, which is people led, very much adopts the kind of approach that we took and are taking to social security. In establishing that area of work, we were led by those with lived experience, and we start from the premise that that is where we want to be. Not simply this Government but the Parliament has, throughout the time since it was established, taken significant steps along that road.

There is more to do, but we need to do it in a way that is sustainable financially and in other ways. We need to take the time to do the work so that we properly understand everything—including the question of charging—that needs to be done to continue to improve and reform adult social care.

**Angus MacDonald (Falkirk East) (SNP):** In response to the convener's initial question, you said that you are on track with implementation. I am curious as to whether you expect any barriers to implementation and whether everything has been fully costed and budgeted for.

**Jeane Freeman:** We believe that the extension has been fully costed and budgeted for. We undertook that work with COSLA, and we included in the draft budget an estimate of the implementation cost to local authorities of undertaking the additional work. Discussions have been had with directors of social work, directors of finance and others to ensure that people understand everything that is to be done and that we hear about anything that they think might stand in their way. We work with them to try to remove any concerns or misunderstandings that might exist.

On the basis of that significant shared work over a number of months and where we are now—including, as I said, my conversation yesterday evening—I remain confident that we are on track to deliver the extension from 1 April. I should also say, of course, that the work has been on estimating costs. The reality will be what the real costs are, which might differ from the estimates. We are therefore working with COSLA on how we monitor delivery of the policy, including its cost, in order to be sure that, year on year, we can adjust what needs to be done so that we can fully deliver the policy to all those who wish to use it.

**Brian Whittle (South Scotland) (Con):** You have acknowledged that the extension does not go as far as the petitioner would like. Will you be good enough to explain the rationale behind the

decision to do that on a consistent basis with the approach for adults who are over 65?

**Jeane Freeman:** I am sorry—do you want me to explain why we want the position to be the same for people whether they are over or under 65?

**Brian Whittle:** Yes.

**Jeane Freeman:** To go back to the convener's perfectly helpful and correct starting question, we believe that we should move progressively and increasingly towards an equality of approach. That sits—absolutely rightly—with a human rights-based approach. It seemed that, if we were to extend the approach to people who are under 65, the right thing to do was to go beyond a particular condition that individuals might suffer from and extend it to all adults under 65 who meet the criteria for having free care, as opposed to being charged for it.

**Brian Whittle:** With that in mind, I ask you to respond to the petitioner's comment that

"This ... will leave most disabled people under 65 no better off despite millions being given to local authorities for the implementation of the new system."

Is that consistent with your answer to my previous question?

10:15

**Jeane Freeman:** I disagree with the petitioner's view on that matter. What we will implement from 1 April, with our colleagues in local government, is an approach whereby every adult, regardless of their income or assets, will be eligible to receive without charge the personal care that they require. Many of those who are in receipt of social care already receive those services free, and we have provided the additional funding of £11 million that I touched on to increase the charging thresholds and support veterans, as I described.

I do not accept the petitioner's premise. I do understand and accept that there is an absolute need for us to consider whether we can go any further and, as I said, the appropriate way for us to do that is in our current overall consideration of the reform of adult social care. In the Parliament's 20th year, it is appropriate to stop and ask what more we need to do across adult social care, including on charging, but there are other matters to take into account in that regard, too.

**Brian Whittle:** Thank you for that helpful answer. You obviously do not agree with the petitioner's concerns, which is fair, but how will you monitor the situation to make sure that they are not realised?

**Jeane Freeman:** As I said in response to Mr MacDonald, we are working with COSLA to

develop a series of monitoring tools, which we will test run before 1 April to check that we are gathering all the information that we need from local authorities on implementation. That information will include impacts on individuals as well as key questions about the reality of the cost set against our current agreed estimate with COSLA.

All of that sits within the piece of work that I touched on, which is led by those with lived experience, on the reform of adult social care. We have a leadership group of individuals and stakeholders, and a panel that is doing some of that work, many of whom I had the good fortune to meet and listen to in 2018. That will provide us with feedback about any individuals or groups that appear to be being missed, even with the extension. We can consider that in the overall reform, including any further reforms on charging.

**Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con):** Good morning, cabinet secretary. I want to home in on the monitoring process. In your letter of 20 November, you state that the

"Implementation Advisory Group has considered the effects of"

additional demand

"in assessing the likely budget required".

You state that the non-personal elements of care for adults under 65 will be monitored. How will that be done and who will do it?

**Jeane Freeman:** The monitoring arrangements are shared between the Scottish Government and local authorities. As you would expect, local authorities are the primary providers of the data. Clearly, however, there are some very prominent and experienced stakeholder groups in this area of work, and our continued contact with them will feed information into the monitoring as well.

As I said earlier, we have developed, again jointly with COSLA, a series of tools for monitoring across more than just cost. We will test run those tools before 1 April just to double check that we are capturing all the data that we believe is needed in order to effectively monitor this over the years and, should it be required, we will make any adjustments or changes to how we are implementing this as we go.

That monitoring information and the data that is gathered also feed into the overall reform of adult social care that we are undertaking. That is important information that will point us towards and give us evidence of where there might be gaps or other areas that we need to take account of.

**Rachael Hamilton:** Thank you. I am interested in the system and the tools that you say you will be using for monitoring. The petitioner has the same concerns that I have about non-residential care services, whether they be something like a community alarm or other services, and how they can differ dramatically across local authorities.

I have some figures—I am just using these local authorities as examples. East Lothian charges £4 a week for a community care alarm and Aberdeen charges £1.35. We are already seeing a disparity in those care services. I do not know whether the tool that you will use is software or some sort of digital monitoring, but we are already seeing a huge disparity across local authorities.

**Jeane Freeman:** Without sight of your figures, I am not going to disagree with the central thrust of what you are saying, which is that there is a degree of disparity across local authorities.

One of the areas that we have to temper in how we look at this work is the balance between wanting to have equity across our country in what people receive, how it is charged for and how people are dealt with, with the fact that we have 32 local authorities, each of which is, in its own right, democratically elected and accountable to the population that it serves. That means a tension between what the Scottish Government wants to do and the perfectly correct position of local authorities on their democratic mandate and accountability. I know that colleagues around this table are very familiar with that tension, and with the fact that it is 20 years old. That is why it is so important for us to manage our way through the joint work with COSLA and look at where we can increase the equity of provision on the basis of local authorities being willing to agree to that—there is no suggestion that they are not—and being treated fairly in terms of the resource that they receive to do it.

I am happy to write to the committee to set out what the monitoring and tools are, so that members can see that level of detail. Following that, I can answer any further questions that members might have.

**Rachael Hamilton:** Finally, cabinet secretary, on the question of balance and equity among local authorities, what is your timescale for the monitoring? I am probably asking that too soon—it is a bit far in the future—although if the legislation comes into force on 1 April, we are on the cusp. Regardless of politics or who has been democratically elected in local authorities, how will you ensure that there is equity and balance? If we are working with COSLA, what will happen if we see that one local authority is charging extraordinary amounts and another is charging what would be considered to be fair amounts? Will there be a negotiation or a sanction?

**Jeane Freeman:** There will not be a sanction because that is not the best way to work in partnership with colleagues in local authorities. There will be continuous discussions with local authorities.

We have a bit of an example of how we might manage that and reach a shared agreement when we look at school uniforms. Local authorities have taken different approaches to the support that they offer to eligible families for the purchase of school uniforms. We managed that through discussion. At the end of the day, more or less everybody wants to do the right thing and we have to work out how we can get as close to that right thing as possible in terms of managing, in a resource-sustainable way, some of the tensions that I touched on earlier. We will do that here.

For years, the Parliament has benefited from a good-quality relationship with local authorities and COSLA, notwithstanding political differences and disagreements on matters from time to time. You just keep doing that because that is the right way to reach conclusions and move things forward step by step.

**David Torrance (Kirkcaldy) (SNP):** The petitioner has previously raised concerns that some local authority representatives are “poorly informed” about the delivery of the extension. What is your response to that?

**Jeane Freeman:** I understand that. We have done a great deal of work with local authorities to ensure that they are very well informed about the extension and what is required in the implementation, not just at the councillor level but, just as important—if not, arguably, more important in respect of implementation—at the level of their officials. I have had a number of conversations with Councillor Johnston. In July last year, we sent a joint letter in which he and I set out what was planned and required. As I touched on earlier, we have also had discussions with the chief social work officers group and local authorities’ chief finance officers, and we issued further guidance to local authorities on 21 December.

We continue to meet COSLA and, obviously, it continues to monitor local authorities’ preparedness and understanding through its network. There is no question in my mind that, if COSLA felt that there was any significant difficulty in the area, it would raise that with me and would want me to do something further.

**The Convener:** I want to go back to the Scottish Government’s role in monitoring. We are aware that the Scottish Government has a reserved power to intervene. I think that that was given in 2002, but it has not been exercised. An evaluation of guidance from COSLA has never happened. The petitioner’s evidence says:



"charges for a single hour of Home Care varied between £8.56 per hour and £23.70 in different areas."

The petitioner is very exercised by the issue of the minimum income threshold. The evidence says:

"COSLA recommends that this should be the Income Support level plus 16.5%, but local authorities across Scotland set this at different amounts. For a single person under 60 it varies from £122 per week, in East Ayrshire, to £173 per week in neighbouring North Lanarkshire—both less than the ACTUAL amount of Income Support disabled people can get."

Do you accept that there is a substantial issue there, particularly for people who are under 65, that relates to the ability to sustain education and employment because of the level of charging? The petitioner goes back to the cost to all of us as a result of folk not being able to achieve their potential and not being able to access education or work because they simply cannot afford the charging, and the variability across the country being so significant.

Do you see the issue as a matter of urgency? The urgency of the issue for many people is the strongest thing that has come from the petitioner. People are making decisions now that will deny them opportunities in the future.

**Jeane Freeman:** As I said, I understand that. I also completely share the petitioner's view that, if people are denied the opportunity to pursue what the rest of us take for granted—whether that is employment, education or simply social engagement—that is a real cost that is counted in more than financial terms to society in Scotland as a whole. I absolutely agree with that.

There is a reserved power, but I do not believe that, other than in the most extreme circumstances, any Government should ever seek to use such a thing. I do not believe that that is the right approach.

**The Convener:** With respect, the reserved power was not to come in and close down a local authority; it was to evaluate the guidance because it was not effective. I have described the funding gap, and there is the inconsistency in what is defined as the minimum income and the issue of what is caught or defined as income. A young woman campaigner who made a film about her experience told me that her student loan was counted as income, which had a massive impact on her ability to do what any other, non-disabled young person would be able to do.

10:30

Given the scale of those inconsistencies, do you not think that the Scottish Government should use its power or that we should turn the issue on its head, as the petitioner has asked, and start from the premise that having the ability to get the

support that allows a person to function in the world is a question of human rights? Would it not be much simpler and more straightforward if we took that view, instead of getting bogged down in a variety of ways of dealing with things across the board?

**Jeane Freeman:** It is absolutely the case that that is the simple and straightforward view but, ultimately, we must be able to implement it in a way that is sustainable. The inconsistency in charging and the other issues that you and the petitioner have raised constitute a significant part of the discussions that we are having as part of our work on what we need to do next as regards the overall reform of adult social care. In our discussions with the Convention of Scottish Local Authorities, we want to understand the rationale for how different local authorities approach the matter and what we need to do to bring about improved equity of charging across the piece.

**The Convener:** In those discussions, would you be open to taking a human rights approach, which involves starting from the position that, regardless of the size of the cake, people have a right to access it in a fair way, with the end point being that they will have the same economic and social opportunities as others?

**Jeane Freeman:** We have adopted that approach with under-65s. Overall, that is my answer to Mr Whittle's question about why we extended the provision for under-65s beyond those with a single condition—we wanted to ensure a degree of equality of approach, regardless of age.

As I said earlier, taking that to the next stage is part of what we should do in the reform of adult social care, and we are doing that. I have made it clear that my starting point is to consider the issue from a human rights perspective. However, as well as having the warm words of a good policy, we must be able to implement it in a way that is sustainable.

**The Convener:** Do you recognise the petitioner's frustration that, although they met the implementation group, they were allowed only to make a presentation and were not engaged in developing the policy? Will you look for them to have greater participation in that in the future?

**Jeane Freeman:** Their voice is one voice among many. I would certainly be very happy for all those voices to be heard.

**The Convener:** The petitioner felt that they got a hearing from the implementation group, but that is not the same thing as being engaged in policy development. I hope that you would recognise that.

**Jackie Baillie (Dumbarton) (Lab):** I have absolutely no doubt about the cabinet secretary's intentions, but I hope that she will forgive me, because I am slightly frustrated, as is the petitioner.

The guidance that was issued in 2002 was not evaluated and it was at least nine years ago when COSLA and the Scottish Government set up yet another working group to look at consistency of charging. I am not sure that it ever produced any guidance; if it did, that guidance has certainly not made a difference.

I hear what you say about your current work on the reform of adult social care, which is very welcome, but when will that work be concluded? Will it make any difference, given the history of what happened, both in 2002 and nine years ago under the current Government?

**Jeane Freeman:** I must start by saying that I was not the cabinet secretary in 2002 or nine years ago. I can speak only about my personal commitment to addressing the issue. The work that is under way on the overall reform of adult social care includes a number of important strands, one of which is the strand on consistency.

We will conclude elements of that work as we approach the summer. An important element of the current review is listening to lived experience and using a version of the approach that we took to social security. We are asking individuals and stakeholder groups to tell us and COSLA the priority areas that they want us to fix first. I think that it would be reasonable to expect that consistency of charging will feature in those priority areas.

As that work proceeds, my conversations with COSLA will proceed in parallel. Frankly, I do not have the time to wait for the work to conclude before I have the discussions with COSLA. There is no reason why the work and the discussions cannot run in parallel. We will look at approaches that have been taken. For example, the approach that we took to school uniforms is a good indicator to me of the way in which we can work together to reach a degree of equity.

We will be able to see whether, during this year, we can produce a better resolution to the question of social care charges than the current one. That is as much as it is fair for me to say at this point, because the discussion is taking place jointly between me, as a representative of the Scottish Government, and COSLA, which is representing local authorities.

**Jackie Baillie:** So, we can expect some change to have happened by summer. Again, I do not doubt your intention, but history tells us that, no matter the partnership or the discussion, things have not changed on the ground. I am so

exercised by the issue because charges have trebled in my constituency in West Dunbartonshire, so people are taking themselves out of their care packages because they cannot afford to contribute to them. We have very real unmet need because of the inconsistencies in care charging, and I do not think that that is what the cabinet secretary wants. If the conversations, the dialogue and the discussion get us to the same situation that we are in today, what will you do?

**Jeane Freeman:** I am not going to be pressed into saying that there will be guidance and change by the summer. I could easily say that that will be the case, but that would not be the right thing to do. As Ms Baillie would expect of me, I will put dates to things only when I am confident that I will meet them. However, I am more than willing to say that, by summer, I will be in a position to update this committee and others in Parliament on how well we are making progress in the area. There are a number of difficult issues on resources, charges and equity, some of which the committee has touched on.

One of the other big issues relates to high-cost packages. How authorities manage that high cost can have a significant impact on individuals. Some of our key third sector providers have very strong views and important propositions on how the matter could be handled, to which we need to listen. Those areas of work have been the subject of discussion with COSLA since last summer, and we will continue that discussion to see whether we can reach an improvement—I will not go as far as committing to an absolute resolution—on the current situation. That work is under way at the same time as we are looking at wider issues around adult social care.

**Jackie Baillie:** My interest is, as ever, in the numbers. Could you perhaps not now but at a later date provide the committee with the free personal care budget for the over-65s and the number of people that it covers as well as your estimates for the budget for people under 65 who will now receive free personal care and the number of people whom we are talking about? The reason that I am asking for those figures is that the petitioner contends that those under the age of 65 receive less personal care than those who are older and that, as a result, the personal care is of not as much benefit to the younger cohort—the under-65s—as we would imagine it to be, given that they receive other kinds of care support that would not be covered by this. Those figures would help us to understand the impact of the policy.

**Jeane Freeman:** I am happy to undertake to provide the committee with those figures.

**Jackie Baillie:** But is the petitioner correct in their assumptions? They are based on raw data from the Scottish Government that I think is no

longer published, but that was the analysis at the time. Do you think that the petitioner's analysis of the situation is correct?

**David Fotheringham (Scottish Government):** The Scottish Government does not always agree with the analysis that is produced by the Scotland against the care tax campaign. We sometimes see things differently. However, we are happy to provide the committee with information that is based on what we regard as reliable sources.

**Jackie Baillie:** Okay, but the figures that we are talking about come from you. It is data from the Scottish Government.

**David Fotheringham:** But data can be analysed in different ways and different assumptions can be made. The only commitment we can make is that our very skilled analysts—I am sure that the Scotland against the care tax campaign is skilled, too—will provide the information based on their modelling and assumptions.

**Jeane Freeman:** That is, partly, the critical bit; there are numbers and then there are assumptions and modelling. We will provide the committee with what we used.

**The Convener:** I should say that, when the argument was made, there was an assumption that, given the big, huge, massive sum involved, the proposal was unsustainable and therefore could not be done. However, when pressed, no one could explain how they got to that figure. It is reasonable for petitioners to expect rigour with regard to the figures as well as—and I wonder whether the Government would be interested in looking at this—a cost benefit analysis of people's ability to get to their places of work and study and not having to withdraw from care packages and so on. There is benefit that could be offset against the estimated cost of any care packages, and the committee will be very interested in seeing those figures.

**Brian Whittle:** For my own clarification, I want to go back to the inconsistency in charging approaches across local authorities, which has been mentioned several times. The Community Care and Health (Scotland) Act 2002 gave the Scottish Government the power to regulate the practice of care charging. I totally understand that there is tension between Scottish Government policy and local authorities having freedom of implementation; indeed, it is for that reason that the Government has not exercised that power to date and has preferred to support self-regulation by COSLA. That said, I note that a commitment was made to holding the power in reserve until the implementation of the COSLA guidance could be evaluated, but it is my understanding that the evaluation has not taken place. Are there any

plans for it to take place, and would that be helpful?

**Jeane Freeman:** I have to confess that I have no reason to disagree with Mr Whittle that the evaluation did not take place. I am happy to discuss with my officials the value of evaluating the guidance now, given the other work that we are undertaking, and to come back to the committee on that.

**The Convener:** You mentioned the Government's people-led policy group. Can you clarify who is in the leadership group and what lived experience they have? To what extent will the experience of those involved in this petition, which has a very broad coalition of people behind it, be engaged with, and how do you see that engagement happening? The sense from the petitioners is that, in the past, they had a hearing but were not particularly engaged with. How will you address that?

**Jeane Freeman:** The people-led policy work is hosted and led by Inclusion Scotland on our behalf—we have commissioned that organisation to undertake the work. I do not know whether we have with us a list of those involved in the leadership group, but I am happy to provide you with that information. I should say that we will make sure that you have all the additional information that I have committed to providing by next week. That will include exactly who is on the leadership panel, how the people-led policy work is progressing and the timeframe for that work.

10:45

**The Convener:** That is very helpful.

**Rachael Hamilton:** I want to put on record a small point on the petitioner's behalf. Despite what Brian Whittle has said about the original COSLA guidance being advisory, the petitioner is sceptical that COSLA will ever succeed in standardising care charges. You have mentioned your work with COSLA a lot. As Johann Lamont has said, the petitioner has concluded that care should be a human rights issue; he believes that, at the end of the day, there is no possibility of our ever getting to a position in which care charges are standardised. I simply leave you with that comment, because it is important that we communicate what the petitioner has stated.

**Jeane Freeman:** I think that the point has been clearly communicated.

**The Convener:** Thank you very much, cabinet secretary, for responding to our questions as you have done. We look forward to receiving the information that you have committed to providing.

With regards to action, I think that the most important thing is to get a response from the

petitioner on what we have heard today and hear from others who might want to respond. We can reflect on any further submissions and see what we wish to do subsequent to that and once we have received the information from the cabinet secretary, which will be useful. The petitioner's response is probably most important in that respect.

As members have nothing else to add, we conclude our consideration of the petition. I thank the cabinet secretary and suspend the meeting briefly for a changeover of officials.

10:46

*Meeting suspended.*

10:48

*On resuming—*

### **Residential Care (Severely Learning-disabled People) (PE1545)**

**The Convener:** The second petition for consideration is PE1545 by Ann Maxwell on behalf of the Muir Maxwell Trust, on residential care provision for the severely learning disabled. This petition has also been under consideration for a number of years. It was lodged in December 2014, and was first considered by the session 4 Public Petitions Committee in March 2015.

At our meeting on 25 October 2018, we noted the petitioner's anger and disappointment with the lack of progress on the action that she is calling for. Of particular concern to her is the data visibility of learning-disabled children and young people around Scotland, together with the lack of suitably high-quality and appropriately resourced residential care homes. We agreed to take evidence from the cabinet secretary to respond to the petitioner's concerns.

For this session, the cabinet secretary is accompanied by Gillian Barclay, strategic lead for dementia, learning disabilities and autism, and Pauline MacDonald, policy officer on autism and learning disabilities.

I invite the cabinet secretary to provide a brief opening statement, after which we will move to questions.

**Jeane Freeman:** I thank the committee for the opportunity to speak briefly on the important matter of residential care for severely learning-disabled people.

I record my respect for and appreciation of the Maxwell family for all the significant work of the Muir Maxwell Trust in providing practical support to families raising children who have epilepsy and for widening understanding and awareness of that

condition. That significant work is valued by everyone who benefits from it.

It has been a consistent policy priority across different Governments of different political parties since the 1980s that all adults with learning disabilities, including those with complex needs, should experience meaningful and fulfilled lives. That applies to where individuals live and the services that they receive. The closure of large-scale hospitals is widely acknowledged as a major step forward for the human rights of people with learning disabilities, and I am sure that no one here wants to return to having large-scale residential institutions.

Although we have come a long way since that time, I acknowledge that it has not always been a smooth road. However, from the early days of "The same as you?" and "The keys to life", Scottish learning disabilities policy has been developed on a human rights basis and informed by listening to the views of people with learning disabilities and their families.

During that time, we have not heard a persistent call for more residential care establishments—indeed, we have heard quite the opposite. Nonetheless, finding appropriate and sustainable community placements for people with the most complex needs has proved difficult. It is true that the sector has examples of good practice in which people with complex needs are well supported and live full and active lives in their communities. However, when things have not gone so well, we find examples of individuals who have undergone multiple placement breakdowns, hospital admissions and difficult experiences and who have not received the right support at the right time in order to meet their desired outcomes.

We know that people with profound learning disabilities and the most complex health needs can be well supported with personalised care packages in their own homes and with their own tenancy agreements. In my view, that makes for better provision, and that is available around the country. All adults with severe or profound learning disabilities are entitled to that support; they do not have to live with their families unless they and their families wish that.

I will touch briefly on the recently published report that the Government commissioned from Dr Anne MacDonald. That report looked in some depth at why young people with learning disabilities end up being placed in care homes or hospital facilities that are far from their families and home communities. Dr MacDonald found that the factors influencing that are multifaceted and complex. As a consequence, solutions for young people in that situation need to be about more than individualised service changes and must instead be seen in the context of a more

transformational systems change. We agree with Dr MacDonald's conclusions and we are working with our integration authorities to take forward the report recommendations to ensure that that happens.

Support to people with learning disabilities needs to be framed in the broader context of equality and social justice and not solely in the narrower focus of service design and delivery, important though that is. Services or models of care should not be the sole focus; it is about everyone with a learning disability having access to the support that they need and, crucially, being involved in decisions.

I am committed to ensuring that we implement the recommendations of Dr MacDonald's report. Our current work with people and their families who are directly engaged in and have personal experience of these issues, which we touched on in consideration of the earlier petition on the reform of adult social care, will help us to achieve that.

**The Convener:** Thank you. How do you respond to the petitioner's concern and disappointment that, in the four years since the petition was lodged,

"nothing constructive and supportive has resulted."?

**Jeane Freeman:** I do not agree with that; I do not believe that that is an entirely fair characterisation of where we are. I certainly share what I am sure is some of the petitioner's frustration that we have not seen enough done, but I do not accept that nothing has been done. There are examples of very good practice in which people with complex needs are well supported and live full and active lives in their communities, including Beeswing in Dumfries and Galloway, Teviot Court in Midlothian and Moray Council's new homes. However, I acknowledge that there are examples that have not worked, and we need to do more, working with our integration authorities, to implement the recommendations of Dr MacDonald's report.

**The Convener:** Are you aware that one of the reasons why the committee invited you to come along is that the Scottish Government did not address the questions that the petitioner was raising and that the research mentioned was not on the issues that she had identified about the needs of people in the category of having complex needs? Perhaps you simply think that it is a policy difference, that you do not believe that there is a need for long-term care for people with complex needs and that there should always be support in the community rather than in such units.

**Jeane Freeman:** Part of what I have to do is to listen to a range of organisations. That, of course, includes the petitioner's organisation, but also

organisations such as Enable Scotland, which says:

"It is vital that we resist any temptation to revert to building more multi-bed, residential units."

Different approaches can be taken in terms of the accommodation and support packages and how those are configured. I have given some examples of that. I have had discussions with Kevin Stewart, who is, as you know, the minister for housing, on some of the approaches that we might take in terms of the Government's commitment on social housing build and the work with some registered social landlords. There is some coverage of that in our disability delivery plan, but what I do not agree with—I share Enable's view on this—a return to multibed, residential units.

**The Convener:** I suspect that that is not what the petitioner wants, either. It would be a false characterisation to present those as the only two choices. The issue is that particular needs are not being addressed. Part of that is to do with those people not being visible in the data, which is what a lot of the conversation with the Scottish Government has been about.

**Angus MacDonald:** Cabinet secretary, you mentioned your commitment to ensuring access to the support that learning-disabled children need. What assurances can you give the petitioner that the issues raised in her petition are being and will be given due consideration by the Scottish Government in order to deliver support for vulnerable and severely learning-disabled children, young adults and their families?

**Jeane Freeman:** A significant part of my answer to that is contained in the work that we commissioned from Dr MacDonald, in the recommendations of her report and in our acceptance of those recommendations and the work that we now need to do, in conjunction with the integration authorities, to ensure that we can deliver on them.

**Angus MacDonald:** Thank you.

**Brian Whittle:** The convener mentioned data. Identifying the data sets for this young group of people is necessary in order to understand what support is required to be delivered by the Scottish Government. How do you respond to the petitioner's comment that

"the Scottish Government has repeatedly deflected the matter to the Learning Disabilities Observatory (LDO) in an attempt to convince the petitioner that their research is relevant to the issues raised"?

**Jeane Freeman:** The learning disabilities observatory was set up to provide a high standard of analysis of data that is routinely collected about people with learning disabilities. It is data that we

need. Of course, that does not necessarily mean that that is all that we need to do. I am happy to look further, particularly on the basis of Dr MacDonald's report, at how we might improve not just data collection but data analysis, and at how that will inform the work that we need to undertake to improve the situation.

11:00

**Brian Whittle:** There is an apparent absence of clear data sets, so do you have an estimate of how many children and young people require long-term residential care provision? How would you respond to the petitioner's assertion that a group of young people is "invisible"?

**Jeane Freeman:** My understanding, which is based on research findings, is that there are just over 5,000 children and 21,000 adults in Scotland with learning disabilities. About 1,000 children and 4,000 adults of those have severe learning disabilities; a similar number have profound learning disabilities. Those people require significant additional support. Some of that may be particular to their residential and accommodation needs; for others, it will be a combination of that and other types of support.

**The Convener:** Are you aware that, in response to the petition, the observatory said:

"We are not aware of any existing datasets in Scotland that include a marker for profound learning disabilities."

**Gillian Barclay (Scottish Government):** The observatory figures that the cabinet secretary has quoted are an estimate.

**The Convener:** So the petitioner is right. There is no marker and we do not know what the level of need is for profound learning disabilities.

**Gillian Barclay:** That is correct.

**The Convener:** Most people here would very much support the thrust of policy on community support and inclusion, and an end to long-stay care in hospitals and so on, but the petitioner's point is that there is no visibility for the particular needs of those who have profound learning disabilities. Should there be research in that regard? Would you make a commitment to carry out such research?

**Jeane Freeman:** Yes, I would.

**Rachael Hamilton:** The petitioner states that there are no long-term residential care facilities in Scotland. She also makes the point that, although there are too few such facilities in England, there are some good-quality residential care homes, for example the David Lewis Centre in Cheshire, Home From Home Care in Lincolnshire and the St Elizabeth's Centre in Hertfordshire. There is a different position in England on residential care.

Why is England taking a different point of view from us?

**Jeane Freeman:** I cannot answer for the approach that England takes.

**Rachael Hamilton:** But the petitioner does not understand why we do not have long-term residential care facilities in Scotland and, naturally, she is looking elsewhere to find examples of that provision. Has any work been done that suggests that such provision has a benefit? Why would it be offered in the rest of the UK and not in Scotland? I am just trying to get an answer on behalf of the petitioner, if you do not mind.

**Jeane Freeman:** I understand what you are asking me. I think that a false distinction may be being made here about what is residential care and what is not residential care. The convener quite rightly made it clear that the petitioner is not looking for a return to the situation that we had in the 1980s—none of us is. Some of the examples that I gave about housing in Midlothian and elsewhere constitute a form of residential care but in individual homes.

I have not had the benefit of meeting the petitioner yet, but I would need to understand better from her exactly what she is looking for that is not represented by the examples that I am pointing to but, equally, is not a return to the situation in the 1980s. That would allow us to have a better conversation, which would be important to inform the work that we do to implement the recommendations in Dr MacDonald's report.

**Rachael Hamilton:** That is an extremely generous offer. The convener can take it to the petitioner. It would be helpful to distinguish the complex needs and services that she is talking about.

**The Convener:** Cabinet secretary, are you aware that one of the arguments that the petitioner makes is that people with learning disabilities are able to live longer now, often into quite old age—which is a blessing—and are often supported by their families, but, because there is not an appropriate residential support, they remain within their own homes, with a care package that is under pressure? Do you agree that that means that we do not know the scale of the problem? The petitioner describes this group as being invisible. Do you also agree that that means that we therefore do not know what the pressures are on the carers and the community around them? Is it the case that, under a policy that we all support, we are missing a group of people who, because we are not going to do what we did in the past, are being failed by the policy approach?

The petitioner says that we must meet the real needs of this voiceless group and their families. I am sure that your offer to meet the petitioner

would be welcomed, but do you agree that, at the heart of the issue is the fact that we are not identifying this particular group? How do we do that, and how do we shape the policy around their needs?

**Jeane Freeman:** I am grateful to you for that question and for encompassing the issues in that way. Broadly speaking, I agree. I am very conscious that we are working to try to provide the right support in the right setting for a group of people who, in the past, would not be living as long as they now are. It is very welcome that they are now living as long as they are, but that places significant strain on their families, and I absolutely know about and understand the significant worry and concern that parents and families have about what will happen to their son, daughter or whoever when they are no longer there.

I am genuinely not trying to dance on the head of a pin here, but I would not characterise that as a policy failure. I think that what we are seeing is an inadequacy in the full extent of that policy when it comes to covering everyone who should be encompassed by it.

I want to stick with the core principles of the policy but do more work now to ensure that we know the number of people we are talking about. That is what the petition calls for and what you have highlighted. I want to hear from the petitioner what they have in mind when they talk about residential care and how that might differ from what I have in mind when I talk about some of the good examples that I touched on earlier.

The issue that this petition is concerned with feeds into some of the issues that we touched on in relation to the previous petition that we discussed, and particularly the issues of overall cost and charging and how they are managed. Sense Scotland and Enable have raised with me their issues and concerns about high-cost packages not being fully met. We are giving some consideration to how we can relieve local authorities of that additional burden so that they have less of a difficult resourcing choice to make over, for example, whether they fund a number of high-cost packages and, therefore, not others. There are some complex areas to work through here, but there are some clear basics that we can do more on, a lot of which come from Dr MacDonald's report, and some of which I have touched on already.

**Jackie Baillie:** Convener, I should probably declare an interest as convener of the cross-party group on learning disability. We very much welcomed Dr MacDonald's report, and I welcome what I thought was a clear commitment from the cabinet secretary to data collection, because we count what matters to us.

I have been working with a number of families for more than three years now. They are exactly as you described—families with people who have profound and complex learning disabilities but whose local authority is not unwilling but unable to deal with some of the large-scale packages, which are very labour intensive for local authorities. I was going to ask whether the Scottish Government will co-ordinate some of that effort across local authority boundaries in order to bring a lot of the people who are cared for away from home in institutions in England and elsewhere back home with a collaborative approach that provides some of this small-scale, residential, supported, labour-intensive accommodation much more locally. However, you have partially answered that, based on your discussions with Enable and Sense Scotland. Will you unpack that a bit more and say when we should expect to see something? As I said, I have had families waiting for three or four years now.

**Jeane Freeman:** I completely understand that and I understand the degree of frustration and the impatience to see the significant improvements that people want. As Ms Baillie and others will know, I am a pretty impatient person myself.

We began discussions through COSLA in the summer around propositions on how we can look at the high-cost packages, which are high cost over a number of years, and how we can find a way through that with local authorities in terms of overall funding approaches. We have not yet reached a conclusion. We are doing some more thinking based on the responses that local authorities gave us, as are they, and we are due to come back and continue those discussions. I would not want to imply that we have not had anything since the summer. We are keeping going to refine this and see whether we can find an approach that we can afford and is therefore sustainable but which meets those needs by providing the assistance that local authorities need.

We will keep going in that direction, and that forms a significant strand in the reform of adult social care that I touched on earlier. I am keen that we reach, or get very close to, a resolution on that element by the summer, because it will then need to be something that I feed into budget negotiations for future years. We are working on that, and part of that encompasses our response to those elements of Dr MacDonald's recommendations on—I cannot recall the exact phrase that she uses—inappropriate out-of-area placements. She has helpfully produced some analysis of those out-of-area placements and what she means by that. Some of them are out of area in Scotland and others are south of the border.

The work is under way to see what we might do in a way that is financially sustainable and works with our local authorities and integration authorities in order to shift this along significantly.

**Brian Whittle:** The petitioner highlights the work that groups such as Quarriers do in providing excellent care for those who are less profoundly learning disabled, whereas we do not have adequate support for the group that we are discussing. Is the minister aware that there is a gap between that provision and the provision that is required for those with more substantial needs?

**Jeane Freeman:** Will you repeat the question?

**Brian Whittle:** The petitioner wanted to highlight that groups such as Quarriers are doing excellent work in the community but they do not work with the group that we are discussing today. We should recognise that there is a gap between what they provide and the kind of provision that we are discussing today.

11:15

**Jeane Freeman:** Yes, I think that that is fair. There are other stakeholder organisations that have a significant understanding and degree of expertise in this area, such as Sense Scotland, which has been mentioned, and Enable. It is primarily those organisations—others have done so, too—that have raised with me the point about the extent and complexity of the need and what needs to be done to meet that need, which I discussed with Ms Baillie. In practical terms, there is underprovision for those with the most complex learning disabilities and needs, but that is not necessarily because there is under-understanding of what is needed. That touches on what we are discussing and what we need to do on the basis of that understanding to improve how well we meet those needs.

**Brian Whittle:** I have a quick addendum. We often hear that many of the issues are to do with the transition from children's services to adult services. In your deliberations on delivering the policy, what consideration are you giving to that issue?

**Jeane Freeman:** That is a common area of concern across a range of levels of learning disability and needs, and it is one that I am very familiar with from the work that I did previously on the disability delivery plan. There are elements of the disability delivery plan that sit with other portfolios that look to address those transition gaps in education, employment and other areas of support. Similarly, at this more complex end, that needs to be part of the consideration that we give to how we implement the recommendations and what more we need to do.

**The Convener:** I would like to highlight something that the petitioner said, which is reflected in the conversation about the danger of viewing the situation as one in which we have a choice between what we do now and what we did in the 1980s. She said:

"many parents believe they can cope or are wrongly stigmatised for putting their children into what may be perceived by others as 'institutions' ... the needs of profoundly learning disabled children can evolve greatly as they get older".

She went on to say:

"More community care is not the answer for this group. Scotland needs long-term residential care options for this vulnerable group and the Scottish Government should provide the funding in which to make this a reality."

She suggested that, because we do not have such facilities, the support that is provided—a couple of hours in the morning and a couple of hours in the evening—is inadequate, which puts a burden on families.

Do you recognise that, in pursuing the policy that we all support, there is a danger of implying that those who believe that there is still a need for residential care feel stigmatised in asking for such help for their young people?

**Jeane Freeman:** I recognise that that might well be the case, but I go back to my point that I need to understand better what the petitioner means when she talks about residential care options and to establish whether that is what we are trying to do through some of the examples that I highlighted earlier or whether there is more that needs to be done.

**The Convener:** Do you accept that there is perhaps a parallel with the presumption in favour of inclusion in mainstream schooling, whereby we have ended up losing some specialist support? Parents would say that that presumption should not mean that such highly specialised provision is not available for some and that they should not feel that, by asking for that support, they are somehow letting down their young person. Do you think that there is a parallel here, in that we are closing down what parents understand that their young person needs because of adherence to a policy that somehow creates the impression that there should never be such supported accommodation? Is it the case that people are being left in the community with a bit of support from carers because of a very narrow interpretation of a policy that I believe is not narrow at all? Surely a wide spectrum of support should be available.

**Jeane Freeman:** I do not believe that everyone in the group is being left in the community with inadequate support. Some of the examples that I have touched on and some of the other key



stakeholder organisations would argue strongly against a generalisation of that sort. I am not suggesting that you are making that generalisation, convener, but it is important to say that for the record.

That said, I accept that there is undoubtedly more that we need to do. We need to test whether the policy—I think that we all broadly agree that it is the correct policy—has, in either its sweep or its implementation, unintentionally created a gap in provision and support that we now need to address.

**The Convener:** Thank you. That is very helpful.

I thank you again for responding to our questions and particularly for being so responsive to the issues that the petitioner has identified. We can give you the information that will allow you to follow protocol in inviting the petitioner to a meeting.

Are there suggestions about what we should do with the petition?

**Rachael Hamilton:** It is fascinating to see the possible unintended consequences of the lack of markers in the data set that might identify a hidden group of people with profound disabilities. Until the cabinet secretary has met the petitioner and understood her absolute aims in the petition and until those markers are created, I do not think that we can take the petition as far forward as we would want at the pace that we would want.

**The Convener:** My view is that we have made more progress in the past hour than the petitioner has made in quite some time, because there has been a conversation about whether the point has simply been missed—I would not say that that has been done deliberately, because that would be most unfair. The petitioner has been frustrated about that.

I think that we want to hear the petitioner's response to what has been heard and to hear from other people with an interest in the area. The cross-party group on learning disability or organisations that support individuals may have a view on something that in some ways is about individual needs but is also about the way in which policy is implemented and how we ensure that we have the right information. I hope that we can invite the petitioner to respond, that others with an interest will want to respond, and that we can get a further update at a later stage on how the matter has been progressed by the cabinet secretary and the Scottish Government. Is that acceptable?

**Members** *indicated agreement.*

**The Convener:** I again thank the cabinet secretary very much for her attendance, which has been extremely productive. Perhaps there has been an interesting lesson about the benefits of

direct conversation as opposed to correspondence. We can sometimes feel that some substantial points have been missed. I therefore thank you very much for your attendance.

**Jeane Freeman:** Not at all. Thank you.

**The Convener:** I thank everyone else, too.

*Meeting closed at 11:23.*



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](http://www.parliament.scot)

Information on non-endorsed print suppliers  
is available here:

[www.parliament.scot/documents](http://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](mailto:sp.info@parliament.scot)

---



The Scottish Parliament  
Pàrlamaid na h-Alba