



The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 3 March 2015

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PUBLIC PETITIONS COMMITTEE
6th Meeting 2015, Session 4

CONVENER

*John Pentland (Motherwell and Wishaw) (Lab)

DEPUTY CONVENER

*David Torrance (Kirkcaldy) (SNP)

COMMITTEE MEMBERS

Jackson Carlaw (West Scotland) (Con)

*Kenny MacAskill (Edinburgh Eastern) (SNP)

*Angus MacDonald (Falkirk East) (SNP)

*Hanzala Malik (Glasgow) (Lab)

*John Wilson (Central Scotland) (Ind)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Peter Adams

Peter Campbell

Iain Gray (East Lothian) (Lab)

Akri Jones

Ann Maxwell

Gil Paterson (Clydebank and Milngavie) (SNP)

CLERK TO THE COMMITTEE

Anne Peat

LOCATION

The Adam Smith Room (CR5)

Scottish Parliament

Public Petitions Committee

Tuesday 3 March 2015

[The Convener opened the meeting at 10:00]

Current Petitions

St Margaret of Scotland Hospice (PE1105)

The Convener (John Pentland): Good morning. I welcome everyone to the Public Petitions Committee and remind you to switch off mobile phones and electronic devices, as they interfere with the sound system. Apologies have been received from Jackson Carlaw.

Agenda item 1 is consideration of current petitions, the first of which is PE1105, by Marjorie McCance, on St Margaret of Scotland Hospice. Members will recall that consideration of the petition was deferred from our meeting in Dumfries to enable Gil Paterson to attend and to feed in any comments on behalf of the hospice. This morning, members have received an email from the petitioner; they also have a note by the clerk and two Scottish Government letters. I welcome Gil Paterson, who has a constituency interest in the petition.

I invite contributions from members.

John Wilson (Central Scotland) (Ind): I am rather concerned by the submission that we received this morning, which is dated 2 March. I understand that agreement was reached between Greater Glasgow and Clyde NHS Board and St Margaret's hospice to carry out an impartial review of the funding, but from the submission that we have received, it is clear that actions are being taken behind the scenes that are having a severely detrimental impact on the ability to make an honest and impartial assessment of the funding to St Margaret's hospice. I refer, in particular, to the comment at the top of page 2 of the email, where it is alleged that Catriona Renfrew of Greater Glasgow and Clyde NHS Board indicated that the board should not share the information regarding the funding of other hospices in the health board area.

I think that that goes to the heart of the matter that the committee has been considering over the past eight years, which is about the fairness and equity of funding for hospices in the health board area. Greater Glasgow and Clyde NHS Board has repeatedly procrastinated in giving an honest answer to St Margaret's hospice. If the statements that are made in the submission that we have

received today are true, as a committee we should write to the board to seek clarification of the comments that are made in the submission to find out whether a fair and honest assessment is being made of the funding for St Margaret's in comparison with the funding for other hospices in the area. Unless we get that comparison, which must be open to review, we will find that St Margaret's will still be being dealt with unfairly and unjustly by the board.

David Torrance (Kirkcaldy) (SNP): I am quite happy to support John Wilson's comments.

Angus MacDonald (Falkirk East) (SNP): I am inclined to agree with John Wilson. Judging from the submission that we have received, it would certainly be a good idea to seek clarification from Greater Glasgow and Clyde NHS Board with a view to the issue of funding being dealt with on a more equal basis.

Gil Paterson (Clydebank and Milngavie) (SNP): I thank the committee for deferring the petition as it did. The hospice and I are very grateful for that and commend the committee for the way in which it handled the matter.

John Wilson has highlighted one of the two main issues that the hospice and the letter have raised, which I do not think are insurmountable. First, on the sharing of information, how can a third party work out what the formula is if it does not have all the information? It is entirely right that a third party is looking at the issue and measuring what each hospice gets from Greater Glasgow and Clyde NHS Board, and it is a must that the formula and the numbers be provided. That is an easy fix.

The second issue might be slightly more difficult to address. The petitioner talks about Grant Thornton and impartiality. Grant Thornton has carried out work on behalf of both the Scottish Government and Greater Glasgow and Clyde NHS Board, whereas we were hoping that someone would be appointed who had no connection to either party. That issue might be a bit more difficult to address, but I hope that it is not insurmountable.

I draw the committee's attention to the comments in the letter that are attributed to the chief executive, Sister Rita, whose work in the hospice is renowned. The work of the hospice itself is renowned, as it has a terrific record and every inspection produces impeccable results. Sister Rita recognises that, through good hard work on the part of different people, the gap has closed over the past year, and the hospice appreciates the work that has been done. I believe that we are close to a final conclusion. I do not think that I am speaking out of turn in saying that there is not far to go before the issue is resolved.

I appreciate and welcome the point that John Wilson makes. What he suggests might bring

clarity about where the main blockages are. Maybe I have faith in what has happened so far, but I think that there is a willingness among all parties to come to a conclusion on the matter. The committee's assistance has played a big part in that and I ask that, besides what John Wilson has asked for, the petition be kept open.

The Convener: My understanding is that the parties agreed to Grant Thornton undertaking the review—is that correct?

Gil Paterson: I do not think that that is quite correct. The parties agreed that a chartered accountancy firm would look at the issues, but I do not think that the hospice ever accepted that that firm would be Grant Thornton. If you look at the history of the relationship between Greater Glasgow and Clyde NHS Board and the hospice, you will see that the hospice has always taken a cautious approach.

I might be wrong, but I think that the hospice never agreed to Grant Thornton being used. However, it did what I would call its due diligence to ascertain what Grant Thornton was and so on. The process was not simple or straightforward and there was no yes/no answer—I have seen the correspondence. In my view, if Grant Thornton had answered in the affirmative, in the way that it did in the last email, there might not have been a problem. However, it had to be asked several times whether there had been a conflict of interest in relation not to the Government but to NHS Greater Glasgow and Clyde, and that is the element that is more difficult to solve.

I am fairly certain that the hospice never agreed to Grant Thornton.

Hanzala Malik (Glasgow) (Lab): I am quite clear that we should continue this petition. However, I am puzzled about what the agreement of the committee is in relation to certain instructions. If you are looking for a third party to resolve an issue, who will instruct that third party? Who will pick up the cost for the third party to do that? How long will it take? I would like someone to answer those questions for me.

The Convener: I believe that the committee has the right to write to Greater Glasgow and Clyde NHS Board to ask for that information. I would also like to find out whether the hospice raised in writing its concerns about Grant Thornton being part of the review committee.

Gil Paterson: I think that we can provide that information. I can also answer the question that Mr Malik raised. Money has been set aside for the third party to conduct the work. There is no question but that it will be paid for. The money is already allocated.

Hanzala Malik: That is helpful. However, I would still like to see an end date on this petition. The situation seems to have been going on for a long time, and I think that it is unhealthy to allow it to fester. That will affect people's employment and, of course, service delivery. I am keen for this to come to an early conclusion. Can we do something to speed up the process?

John Wilson: I have sat on the committee throughout its consideration of the petition. The last time that we talked about it, the committee was clear about its wish to seek an early resolution. As I said earlier, the difficulty is that Greater Glasgow and Clyde NHS Board seems to have procrastinated. First, it talked about provision at Blowerhill, and then there were other issues. In the papers that are before us today, there are two letters from two different cabinet secretaries for health that are dated almost exactly a year apart—one is from 17 February 2015 and one is from 19 February 2014. Both letters say that the cabinet secretaries are moving forward with the investigation and the review of the funding.

To add to the question that has been asked about the Grant Thornton issue, if we write to Greater Glasgow and Clyde NHS Board, could we ask it how many companies it put forward to act as investigators into this matter and whether Grant Thornton was the only company that was presented to St Margaret's hospice for consideration? That would be useful. Part of the difficulty with calling for someone impartial to do the review is that there will be very few companies that will be completely impartial, because it is likely that they will have worked for either the health board or the Government. We should find out whether the hospice was provided with a list of organisations so that it could, as Gil Paterson said, do its due diligence and decide which organisation it believed would conduct a genuinely impartial review of the services that were being delivered and the funding that was being made available.

10:15

The Convener: We will consider the action that we will take on the petition. Do we agree to write to Greater Glasgow and Clyde NHS Board about the latest email and the issues in it? We will also ask whether it alone appointed Grant Thornton, or whether the Scottish Government did that. The third point was that we could write to the hospice to ask whether, at any given time, it raised concerns about Grant Thornton with Greater Glasgow and Clyde NHS Board or the Scottish Government.

Hanzala Malik: I want to draw the health board's attention to the fact that we really want a conclusion. I do not like all this ping-ponging; I want a result. We have had enough ping-ponging.

We need to bring the petition to a conclusion and we should be looking to suggest a closing date. It is important for us to have a benchmark now. We cannot just keep going on endlessly.

The Convener: I know that the petition has been going since 2007 but other issues have been raised today and it is only right that we do what is requested. When that information comes back, there will be recommendations and we can then decide whether to continue the petition or close it.

Hanzala Malik: What timeframe do you suggest for that to happen?

The Convener: If we write to any organisation, we expect to get a reply within 20 days. If that happens this month, the petition will no doubt be back before the committee sometime in April.

Hanzala Malik: I simply stress my point that we need to bring the petition to a conclusion. We need to suggest to the health board that we want to draw the petition to an end rather than go through another set of correspondence.

The Convener: In reaching that conclusion, the committee has to be made aware of all the facts. If we write to the organisations that we have identified, we will expect a response that will allow us to bring the petition back to the committee in April. Are we agreed?

Members *indicated agreement.*

Proposed Cockenzie Energy Park (PE1537)

The Convener: The next petition is PE1537, by Shona Brash on behalf of the Coastal Regeneration Alliance, on the proposed energy park at Cockenzie. Members have a note by the clerk and the submissions.

I welcome Iain Gray to the meeting. He has a constituency interest in the petition.

Iain Gray (East Lothian) (Lab): Thank you, convener. I appreciate the opportunity to speak briefly to the petition once again.

The committee will see that the marine energy park project is continuing. That is clear from a number of the submissions from stakeholders, not least that from Scottish Enterprise, which makes it clear that it is deciding on the next steps based on an assessment of market interest, the outcome of on-going technical feasibility work and so on. It is clear that the project continues.

The submissions also make it clear that the petitioners do not feel that they have received the assurances that they sought—or assurances that they can accept—regarding consultation in the future. A lot of the submissions try to suggest that consultation has taken place, in spite of the fact

that the petitioners and the petition have made it clear to the committee that the community does not accept that.

It is also clear that the petitioners do not believe that there are indications that proper regard will be given to the community's aspirations for the site— aspirations that are quite well developed and were presented to the committee when it considered the petition at an earlier stage. The truth is that the community around the site, in Cockenzie and Port Seton, remains very much in the dark as to what is happening. That is what led to the campaign and support for the petition in the first place.

I therefore suggest that the committee continues the petition and further interrogates the situation. The committee could help to provide some clarity for the local community by either continuing the petition and seeking evidence or referring the petition to an appropriate committee. My preference is for the former, but obviously it is for members of the committee to decide. However, I strongly request that the committee considers continuing the petition, as the situation has not resolved itself.

Angus MacDonald: The issue of energy supply has been in the news agenda for a number of days recently, not least because of the possible need for a large combined cycle gas turbine somewhere in Scotland. The major obstacle to that is the transmission charging regime, which discriminates against new electricity generation in Scotland.

The national planning framework 3 is basically a Government wish list, for want of a better term. There are quite a number of projects in my constituency on that wish list that may or may not come to fruition. I take on board Iain Gray's point that the Cockenzie energy park project seems to be continuing as far as Scottish Power is concerned, and it is clear that the Coastal Regeneration Alliance is not taking any chances regarding NPF3 not moving the project forward.

Given that the issue of energy generation is hotting up, to coin a phrase, it might be an idea to refer the petition to the Economy, Energy and Tourism Committee. I am not definite about this, but I imagine that it will be doing some significant work on energy supply in the future.

David Torrance: I am happy to support Angus MacDonald's recommendation, mainly because the issue is in the remit of the Economy, Energy and Tourism Committee. It involves the aspects of energy, the local economy, tourism, historic value and environmental impact. I think that that committee could do a far better job than we could, because the petition falls within its remit.

Hanzala Malik: Because the issue is of such high significance and people are still working on

the project and we do not have the full package, it may be premature to send the petition to another committee. I would rather get all the facts before we make that decision. I am minded perhaps to continue the petition at this early stage and wait to see the final case for what we are trying to achieve before we refer the petition on. There is a lot of information still to come—tasks are still going on—and I would like to see the results first so that we can see what the best way forward is. I am happy to continue the petition.

Kenny MacAskill (Edinburgh Eastern) (SNP):

I think that there is a way between the two options. It seems to be a fluid situation. Iain Gray is quite correct that there has been almost a democratic deficit, and the Government does appear to have a wish list. It seems that Scottish Power and Scottish Enterprise are operating at a level that is perhaps not taking on board the clear views of the local people. Equally, however, I understand that this is a moveable feast.

Am I correct to say that, if it is not today, it will be any day now that the towers are due to be demolished? I think that I saw that somewhere in my constituency, as it affects the vista.

Iain Gray: It is the towers, not the chimneys.

Kenny MacAskill: Yes. Things are moving there.

It seems to me that to refer the petition to the Economy, Energy and Tourism Committee would be more appropriate, assuming that it would accept it—it could be remitted back. I do not know whether there is a way of satisfying Hanzala Malik's concern that the petition be kept alive by giving it to a committee that might be more appropriate, given that it is part of a wider issue, as Angus MacDonald correctly said. However, the petition has highlighted that there is a local democratic deficit that needs to be addressed.

The Convener: The consensus seems to be that we should refer the petition to the Economy, Energy and Tourism Committee. My understanding is that, even though we are referring it, the petition remains open. Is that right?

John Wilson: For clarification, if we refer the petition to the Economy, Energy and Tourism Committee, it will then rest with that committee to make deliberations on it, and the only information that we will get back from that committee will be about what action it has taken. If the Economy, Energy and Tourism Committee decides to close the petition, we will have no further jurisdiction over it.

Hanzala Malik: That is why I suggested that, initially, we should keep it open to see what new information comes in before we decide to send it on. I do not think that the time is right for it to be

sent on as it stands. Local concerns need to be addressed. Let us allow that to happen. It will not do any harm to keep it open at this stage.

Iain Gray: I appreciate that there is a consensus among committee members that the petition should not be closed but should be continued. That is welcome. I said that it is, of course, for the committee to decide how to deal with the petition, but I also said that my preference would be for the committee to take evidence. Perhaps it is worth while for me to explain my reason for that.

The thrust of the petition is about the reluctance of the local community to have an industrial development of such a scale foisted upon them. That is how it feels to them. It is more about what happens to the site and to their community than about the potential importance for Scotland's energy strategy of an energy park at that site or another site. There seems to be some merit in continuing to explore the nature of the consultation and how things have been taken forward before the petition is referred on. However, I defer to the committee. It is the committee's decision.

The Convener: Okay. What action do we want to take, colleagues?

Angus MacDonald: Given the comments by the local member, if there is concern about referring the petition to the Economy, Energy and Tourism Committee immediately, I would be content to seek further information from Scottish Enterprise and East Lothian Council and to request that the public consultations on the development be extended. However, that would be with the proviso that, ultimately, the petition will be referred to the Economy, Energy and Tourism Committee for further investigation.

Kenny MacAskill: We might be able to take some informal soundings from the Economy, Energy and Tourism Committee. Notwithstanding the legitimate comments that Iain Gray made, it appears to me that consideration by that committee would be more appropriate because, although the petition is site specific, it is likely to have more general relevance. We need to balance projects on the Government's wish list and consider not just the site that concerns the petitioners but other sites in Angus MacDonald's constituency and elsewhere, so the Economy, Energy and Tourism committee would be more effective than we would.

However, I understand John Wilson's point that there is no point in us remitting the petition to that committee if it then says that it is too busy to do anything. The worst situation for Iain Gray's constituents would be for nothing to happen because we had got rid of the petition but the other committee did not accept it.

As Angus MacDonald said, we could seek further information and make some discreet inquiries about the Economy, Energy and Tourism Committee. I tend to agree with him that that committee is likely to be looking at energy in the round, and it could consider the petition as a factor within that wider remit, which would be more appropriate than a standalone investigation by us. If we keep the petition going for a few weeks pending a letter to Scottish Enterprise and some informal discussions, that would be a suitable course of action.

10:30

John Wilson: I agree with Kenny MacAskill that we should keep the petition open and write to East Lothian Council and Scottish Enterprise to find out what is happening.

As Angus MacDonald pointed out, NPF3 is, like NPF1 and NPF2, a wish list developed by the Scottish Government. It has allocated no actual funding to the proposals, and whether they go ahead is down to local circumstances and arrangements. It would therefore be useful to write to those two agencies to get some clarification about exactly where they are in the process. After all, although Scottish Power is the main operator of Cockenzie, it has indicated in its response that it has had no negotiations or discussions about taking forward the power plant in any shape or form or about being involved in the energy park.

In seeking clarification from those two agencies, however, we also need to ask for a clear outline of the consultations that they intend to undertake with the local community in relation to any proposals for the site and to ensure that there are guarantees that the community has the right that it has always had to object to any proposals. I hope that, if the Community Empowerment (Scotland) Bill goes through in the first half of the year, the community will have greater powers under that legislation to challenge any such proposals and, indeed, to come up with its own, as it did at the end of last year.

I therefore propose that we write to those two agencies. As Kenny MacAskill suggested, our committee clerks could have an informal word with the clerks to the Economy, Energy and Tourism Committee to find out whether that committee has time in its calendar to devote to what we think should be considerable consideration of the petition.

The Convener: Do we agree to write to Scottish Enterprise and East Lothian Council to request that public consultation on the proposed development be extended and to take into account the points that committee members have raised?

Members indicated agreement.

New Petitions

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

10:33

The Convener: Agenda item 2 is consideration of three new petitions. The committee previously agreed to hear from the petitioners on all three.

PE1545 by Ann Maxwell on behalf of the Muir Maxwell Trust is on residential care provision for the severely learning disabled. Members have a note by the clerk, a Scottish Parliament information centre briefing paper and the petition.

I welcome Ann Maxwell to the meeting and ask her to set out the context of her petition and what she is looking for, after which we will move to questions.

Ann Maxwell: Thank you, gentlemen, for giving me the opportunity to speak to you this morning.

I ask the committee to walk with me in my shoes for a moment. I am the mother of Muir, who has a severe form of epilepsy called Dravet syndrome. Muir had his first seizure when he was just four months old and, as we rushed him in to hospital, we did not know that the legacy of the seizures that would follow would leave him profoundly brain damaged and would dramatically alter the course of not just his life but the life of his family for ever.

My husband and I are now Muir's legal guardians. For more than 18 years, we have been his voice. He cannot read, he cannot write and he can barely colour in between the lines. He will never work or marry or have children of his own. He requires care 24/7, including all aspects of personal care. However, he is a speaking child and he has an amazing personality and sense of humour. His behaviours are at times challenging, but there is still much to celebrate.

Muir has been a pupil at Donaldson's college since he was five years old. At his most challenging, around the age of 12, we fought for him to become resident at Donaldson's lodge. Since that day, Muir has positively thrived, with lots of friends and a very fulfilled life, but now that he is 18, what the future holds for him is extremely uncertain.

Along with my husband, I am co-founder of the Muir Maxwell Trust, a charity established 12 years ago in Muir's name to support children like Muir throughout the United Kingdom, as well as their families, who are struggling to cope. Epilepsy, in all its forms, is just one condition, but the Scottish Government's policy review identifies that 66 per cent of people with profound and multiple learning disabilities have epilepsy. Therefore, without

doubt, the Muir Maxwell Trust represents the most needy group among the learning disabled.

It is glaringly obvious from our research that the Scottish Government, by its own admission, lacks factual data on people with learning disabilities, especially those with profound disabilities and who may require residential care as an option. We should remember that they have no voice. The Government relies on data that is provided by local authorities and social work services, which often comes through charities such as the Scottish Consortium for Learning Disability. I know from first-hand experience that both are failing to properly assess the needs of the group, because of their lack of understanding of profound disabilities and their lack of proper application of the assessment process. Senior members of my council have admitted to those failings. The group's needs are therefore not being recognised, understood or met.

That includes the desperate need for sophisticated long-term residential care, by which I do not mean long-stay hospitals as we had in the past—nobody wants those. I have fought a relentless battle for our son to receive the very best of care, including residential care, and it has worked for him. It would work for many others, too, but sadly other families have not won their battles as I have and their children have been denied the same care. That will all come to an end shortly for Muir because, at great cost to his local authority, he will be in an out-of-area—in fact, out-of-country—placement. There is nothing appropriate by way of sophisticated residential care in Scotland for young people such as Muir, and that must be urgently addressed.

Recommendations 51 and 52 of the Scottish Government's review of services, "The keys to life—Improving quality of life for people with learning disabilities", suggest that changes are in progress, but we fear that the review will fail to recognise—and, importantly, find—the substantial funding that is required to meet those needs, in particular for residential care. We fear that the homecoming of our learning disabled from out-of-country placements that the Scottish Government plans for June 2018 will amount to no more than saying, "Sorry, please adapt to fit to what we have to offer, because we cannot meet the need." That will then become unmet need.

The Mansell report says that early intervention and

"sophisticated long-term arrangements for management, treatment and support"

will prevent problems from arising in the first place. In the absence of long-term arrangements such as residential care, the cost to Government will be

high, as needs fail to be met and families therefore fall apart.

Only proper assessment of need will lead to recognition and understanding of this most severe and complex group, which will then lead to service delivery in the essential form of sophisticated long-term residential care, which does not yet exist in Scotland, other than in much underused and remote areas of child services such as Donaldson's college.

I urge the Scottish Government to support schools such as Donaldson's with significant public sector investment and to encourage local authority placements for children and young people at the school and in residence, and then to go one step further and replicate the service in adult services, in partnership with organisations such as Donaldson's, which are already delivering. In turn, they will be the feeder for the long-term residential care, with respite for those families who desperately need it.

The Convener: Thank you, Ann. Do members have any questions?

John Wilson: Thank you, Mrs Maxwell, for that powerful presentation outlining the case for your petition.

You referred to your local authority. Can you expand on the support that you have—or have not—had from your local authority to deal with your son's condition?

Ann Maxwell: That dates back probably more than a decade. Initially, we received no support from social services. After that, we received poor support from social services. We have had engagement from educational psychology, which has always been good. However, in pursuing support for my son Muir, I sought something called a section 23 assessment, which is made under section 23 of the Children (Scotland) Act 1995. It took me 18 months to have that assessment carried out—it really was passed from pillar to post. In the end, I asked a student who was working for the charity Epilepsy Scotland to help me with that report. It was then passed from pillar to post within the council. It is interesting to note that it was the same person, who chaired a number of committees, who was passing it from pillar to post. Eventually, through 18 months of fighting, we got the support that we needed to have a residential placement within Donaldson's college.

The social worker then had a statutory obligation to review Muir regularly, but she was not doing that. I had deep concerns, knowing that the future would require an on-going fight and that, if there was nothing on record to evidence his needs, the fight would become harder. Therefore, we approached the council and asked it to find us

another social worker, which it did. We are told that we now have the best social worker that it has in children's disability services.

The looked-after child review meetings have been poor in their quality and administration. Very often, nobody has been given the notice that they need to prepare for those meetings and submit reports, and the paperwork often does not arrive on time. The meetings are poor at the level of basic administration, never mind the time that is required to understand the complex and profound needs of my son. That warranted meetings at a senior level in the council at which officials literally held their hands up and said that I was right about all the issues and that I needed their help to correct them. Within social services, there is a fundamental problem with understanding the complex needs of children with disabilities.

John Wilson: Thank you. I have a couple more questions arising from that.

In your opening comments, you referred to 2018 and used the phrase "out-of-country care". Would you care to expand on that?

Ann Maxwell: We have spent considerable time looking around our local area and around Scotland for long-term care for our son Muir once he reaches the age of 19—he will not leave school until he is 19. We have investigated everything with social services, and the conclusion is that there is nothing that can support his needs in Scotland. However, he is likely to get a placement at Young Epilepsy in Lingfield, Surrey.

John Wilson: I assume that that will mean uprooting the family.

Ann Maxwell: No, because I have two other children and it is really not appropriate to do that. What it will do is put enormous distance between ourselves and Muir.

The facility is fantastic—it is exactly what he needs. However, he has been at Donaldson's since he was five years old and he has had the same peer group and carers throughout. Therefore, for him, as someone who is very fragile emotionally—and he is just an example of many—the change is devastating. Furthermore, the placement is for three to five years only; after that, we will have to find somewhere else.

10:45

John Wilson: You indicated that you have been fortunate. You have fought hard to get the services that you have received. Despite that, you have had to continue to fight to ensure that the services were being delivered consistently. You gave examples of assessments and reviews by social work staff and you have been told that you have the best social worker on the case. How would you

want your petition to be widened out to ensure that parents of other children who have the same condition are supported? You have, I hope, resolved all the issues in your local authority area, but I am sure that, as you have indicated, there are parents throughout Scotland who may be facing similar if not the same problems in getting the social work department and the local authority to sit up and take notice of their child's condition.

Ann Maxwell: Without wanting to sound arrogant, I am unique, in as much as I have fought a hard and furious battle for my son. I have also anticipated the future throughout the journey, which has enabled me to consider what might be required ahead. A lot of parents do not do that; a lot of parents live day to day and are still living with the hope that, somewhere in the course of their journey, there will be a cure. Therefore, the forward thinking by parents is not there. To some extent, I regard myself as their voice.

There are parents who are fighting with their social worker and their social work department on a daily basis in the same way that I did with mine. They do that with the support of the schools that they would like their children to attend—the schools will attend meetings, for example.

At the end of the day, even with the support of a social worker, you must still convince the local authority behind that social worker to fund the request. There are times when it is difficult to know whether the social worker is representing the local authority or the child and the family. That black hole often results in a negative decision.

First of all, a cultural change is required, so that social workers clearly recognise that they are responsible for the family. That is about identifying need. Meeting the needs has an associated cost, but that is not the concern of the social worker. It might be the concern of the local authority, but there needs to be a definite loyalty on behalf of social workers to the families.

Additionally, we must broaden our horizons. Local authorities must be much more supportive of schools such as Donaldson's and the blind school. There are not many of them—very few facilities operate at the high end that I am talking about, particularly where residential care is concerned. Fundamentally, the schools are not being supported by local authorities in honouring the funding packages. If we could get that support, that would be the best way of supporting the families.

John Wilson: Thank you very much.

The Convener: Mrs Maxwell, you said that you had a concern about the lack of data held by the Scottish Government. Some of the data that we have seen suggests that the demand for residential care is on the decrease, because of

independent living. Could you expand on your concerns?

Ann Maxwell: First of all, we must be clear that there is no clear definition of “residential care”. The phrase is used a lot; it conjures up images of the long-stay hospitals of the past, which no one wants, and images of—shall we say—care homes, of which we have a number in the community. However, what we do not have, certainly in adult services, is residential care similar to that which supports a school. The example that I use is Donaldson’s and the residential lodge that is attached to the school. That is unique residential care.

A decline in interest in residential care is inevitable. Historically, there were many people in long-stay hospitals. That had to come to an end, and I fully support the strategy that was recommended in 2000. There is no doubt that a lot of those patients, including people with learning disabilities, have been and will continue to be well supported in the community.

I am talking about the very small number of profoundly learning-disabled people who are not capable of living independently in the community and whose needs are greater than those that a traditional care home can support. Those needs can be so profound that 24/7 care is required, and such care must engage fully with the person to avoid all the problems that might otherwise arise if they were to become unmanageable behaviourally, health-wise or otherwise.

The statistics are wrong, because they are obtained from local authorities and social services. I know from first-hand experience of the way in which those bodies have gathered our information that the information that they feed back to the Scottish Government via charities and so on is incorrect. They do not understand the disabilities. In fact, when I met representatives from my local authority, they said, “We need someone like you to speak to social workers and educate them about these profound disabilities and how difficult they are to manage in order to help them identify them.”

The data is not coming to the Government from the ground up. The people who know the children best are the families, and the information and assessment process is not happening on the front line to give the Scottish Government the proper information.

The Convener: You said in response to John Wilson that dealing with social workers has sometimes been a bit of a fight. Is that because of a lack of understanding among social workers?

Ann Maxwell: Social workers are failing to identify the small group of profoundly learning-disabled children who are distinct from those who are learning disabled. That group is a small

minority, but their disabilities are severe and complex and social workers do not, in the main, understand their needs. Because of their lack of understanding, they do not recognise the need to apply the assessment process rigorously in order to get a grasp of the needs.

The Convener: Have you ever been in touch with any other organisation about your petition? I am thinking in particular of SCLD.

Ann Maxwell: I have been campaigning on various issues on behalf of the Muir Maxwell Trust for some time now. I know that SCLD campaigns as well, but it does not campaign for the same group of people. We represent a very small group of people who are profoundly learning disabled, whereas SCLD tends to represent the majority of learning disabled people as distinct from that small group. I have always felt that, if we were to become part of that coalition, there would be a risk that our voice on behalf of those who are profoundly learning disabled would be diminished. I am aware of what SCLD is doing, and I think that it is aware of what I am doing, but we do not campaign together.

The Convener: As there are no further questions, I invite the committee to consider what action it wishes to take in relation to the petition.

Kenny MacAskill: I think that we should write to the Scottish Government to ask for its position. There is clearly a gap here. I know from dealing with a constituent’s issue, which did not involve the same disability from which Mrs Maxwell’s son is suffering, that there is a lack of facilities for young adults who leave the care provision that is available for children. Tragically, people are on occasion dealt with in adult mental health facilities when they are clearly not suffering from a mental health impediment. To some extent, the wrong thing is done for the right reasons. Those people should not be in mental health institutions in the city of Edinburgh, but I can understand the pressures on a council at a time when care in the community accounts for a quarter of a million people.

Something has to be done. I understand that there are restrictions and limitations in a smaller jurisdiction and, as I have noticed in dealing with specialist criminal justice matters, many institutions go south, because apparently we do not have the numbers here. However, I am not necessarily convinced that there is not a need here and that we do not have the numbers. The Scottish Government will be the organisation with a general overview of the situation in which young people like Muir Maxwell and my own constituent leave care facilities for children to go into the big wide world and are not provided for.

The Convener: I suggest that, given that this is a new petition and that we are already writing to the Scottish Government, we could also write to the Learning Disability Alliance Scotland, SCLD and Scotland Excel to seek their views.

John Wilson: We could also ask whether the Scottish Government collects data on the number of young adults or adults who have profound learning needs and would benefit from residential care.

I am concerned that, as Mrs Maxwell has outlined, the only residential care that might be available for Muir Maxwell is in Surrey. I would like to understand whether the Scottish Government has assessed the need for provision in Scotland to give parents that option. After all, moving someone to Surrey would break family links. If we can get accurate figures from the local authorities and health boards on the number of young adults and adults who have profound learning needs, a case might be made for delivering in Scotland a service for those individuals that is similar to the service offered by Donaldson's lodge or the Donaldson's school, so that a person can keep their family links instead of completely losing their relationship with not only their family but potentially their wider family. Some of those young adults and adults have not only close family but, as Mrs Maxwell has indicated, peer group support, and it is frightening to think that they could be completely separated from the links that have been created in their lives.

Kenny MacAskill: I know that we are proposing to write to an extensive list of people, but Mrs Maxwell also mentioned social workers. Perhaps we could write to Alan Baird, the chief social work adviser, because it seems that some of the issues might relate to training and the level of understanding among undoubtedly hard-pressed social workers.

Epilepsy is a very specialist condition. I remember having to go through the same process with the police, as people's perceptions of epilepsy are usually about someone having a fit in a room. They do not realise that the condition manifests in a variety of ways. Some understanding of what the chief social work adviser expects and whether he thinks that any improvement in training is needed might be helpful.

The Convener: Does the committee agree to action the points that have been raised?

Members indicated agreement.

The Convener: I thank you for your attendance, Mrs Maxwell—it is much appreciated. I suspend the meeting for a couple of minutes.

10:58

Meeting suspended.

11:00

On resuming—

Adultery (Definition) (PE1536)

The Convener: The next new petition is PE1536, by Akri Jones, on the definition of adultery. Members have the petition, a note by the clerk, the SPICe briefing and a submission from the Free Church of Scotland. I welcome to the meeting the petitioner, Akri Jones, and invite her to speak to her petition for about five minutes. We will then move to questions.

Akri Jones: Thank you for giving me the opportunity to speak about my petition. Through my petition, I seek an amendment to the definition of adultery so that it also applies to spouses who have been unfaithful through involvement in same-sex extramarital relationships. My intention is not to have the adultery laws abolished.

I am a Christian and I am proud to call myself a Christian. I recognise the importance of safeguarding the adultery laws for people such as me, who follow a faith, and for non-religious people who value the principle of faithfulness in a marriage and see adultery as wrong.

As the definition of adultery stands under current law, it is discriminatory, as one section of society is treated differently from another. That makes the law unequal. The marriage legislation should treat people equally. The use of "unreasonable behaviour" as an alternative ground does not quite address the issue, which is that marriage equality should mean equality in all respects, and that fundamental principle should not be violated. Furthermore, unreasonable behaviour can be defined widely. It does not apply only to infidelity but has been used as the common ground for divorce in UK divorce law because of incidents of antisocial behaviour, domestic violence, substance misuse et cetera.

The right to equality is a basic human right that the Government has a duty to protect, respect and fulfil. It is enshrined in law and respected in practice, in all aspects. As the definition of adultery stands, it is in direct breach of legislation. For example, article 1 of the Universal Declaration of Human Rights states:

"All human beings are born free and equal in dignity and rights."

Article 5 of protocol 7 to the Convention for the Protection of Human Rights and Fundamental Freedoms, which promotes equality between spouses, states:

“Spouses shall enjoy equality of rights ... during marriage and in the event of its dissolution.”

The Human Rights Act 1998 safeguards existing human rights and places a duty on the Government, the courts and other public bodies to respect them.

The definition is also in breach of the Equality Act 2010. It is an example of direct discrimination under section 13(1), as it treats one person less favourably; it is a form of victimisation under section 27(5), as it involves

“committing a breach of an equality clause or rule”;

and it is a form of indirect discrimination under section 19, as it places one person at a disadvantage.

As I stated, my intention is not to have the adultery laws abolished. We live in a world where morals are on the decline and a world that has become a bitter place, with more social problems, more division and more hostility. We are living in a world that needs to safeguard our morals more than ever. Marriage is one of the most important institutions in our society. Faithfulness is an essential part of marriage and the adultery laws uphold that belief.

The law, our morals and social and spiritual behaviours are steeped in biblical principles—do not steal, do not commit adultery, love one another, be a good Samaritan et cetera. Adultery is not just a personal offence against the injured spouse; it is an offence against morality laws that has enormous consequences for the rest of society. It is a clear violation of the contractual obligation between those in a married couple.

In the UK, we treat adultery as a civil and personal matter. We seem to forget that, in many parts of the world—such as Saudi Arabia, the Philippines, North Korea, Taiwan, Pakistan and 26 states of the United States of America—adultery remains an offence in law and is punishable by fines and imprisonment.

This Parliament needs to leave as a legacy to future generations a “powerful moral compass” that informs us of what is and is not acceptable and a “set of values” that treats everyone equally and recognises and protects basic human rights. We need to leave this world a better place than we found it. Moral fibres bind the nation together, and removing the adultery laws would affect our society’s moral fibres, contribute to the decline of morals, create more social problems and leave a legacy to future generations that unfaithfulness is acceptable. It would devalue the importance of faithfulness within a marriage and send out the message that adultery does not matter and does not harm the injured party. That might lead to an increase in divorce rates, which would place further pressure on existing services, and divorce

law would eventually slide towards a fully no-fault system.

Parliament cannot remove the adultery laws without breaching other legislation. For example, under the Equality Act 2010, religion, its characteristics and beliefs are protected for people who follow a faith, and removing the adultery laws would breach that law. In fact, such removal would be a form of discrimination against those who follow the fundamental principle that marriage is based on exclusive sexual fidelity.

Religion decrees that, when unfaithfulness is cited, the ground of adultery needs to be used to petition for divorce, regardless of gender status. A sexual relationship, whether it be heterosexual or homosexual, is an equivalent betrayal to the injured spouse, causes deep distress to the betrayed partner and, as has been seen, rips the fabric of society as it tears marriages and families apart. It is important for an individual to be able to dissolve a marriage in a manner that does not compromise their faith and integrity. If people have the right to marry how they choose, they should also be able to choose how to divorce.

It is within the scope of the Parliament’s powers to change the definition of adultery without removing the adultery laws. In the UK, adultery is defined as “voluntary sexual intercourse with a member of the opposite sex who is not the person’s spouse”; in the USA, it is defined as “voluntary sexual relations between an individual who is married and someone who is not the individual’s spouse”; and the Bible defines it as “consensual sexual union”. As we can see, many terminologies are available to the Parliament in redefining adultery.

Scotland is a nation wealthy in culture, history, natural beauty, creativity, forward thinkers and leaders in academia, science, research and politics. It has produced Prime Ministers and so on. Let us not become a nation poor in morals. Removing the adultery laws would divide a nation on moral grounds. Mark, chapter 3, verse 24 puts it well when it says:

“if a kingdom be divided against itself, that kingdom cannot stand.”

The Convener: Thank you, Ms Jones. Do members have any questions?

John Wilson: Ms Jones, you asked on several occasions in your statement for the current adultery legislation not to be removed, but your petition is fairly straightforward and consists of one sentence asking for the adultery laws to apply to all forms of marriage. Are you concerned that pressing forward with the petition would mean that the legislation would be changed to take adultery out of the legislative framework?

Akri Jones: I am very concerned about the issue. Since last October, I have been reading in the papers of concerns that, if my petition goes through, the adultery laws will be abolished. That is not the intention behind my petition—I am simply seeking a change in the definition of adultery—and I highlight the importance of the consequences of removing the adultery laws. The Parliament has the option of redefining adultery without removing the adultery laws.

John Wilson: I am just wondering where your concern comes from. You are concerned that an unintended consequence of your petition would be that the current adultery legislation was dropped. The Scottish Government or other agencies might decide that this is the time to review the adultery legislation and either widen the definition or, as you have pointed out, decide that the legislation is antiquated and no longer fit for the 21st century.

Akri Jones: I have also raised my concerns after reading the SPICe briefing and seeing the recommendation about abolishing the adultery laws. That was the other reason why I felt it important to highlight the matter; I did not want to cause any confusion about what I am trying to achieve with my petition.

The Convener: If there are no more questions, I ask the committee to discuss the action that it is prepared to take on the petition.

Kenny MacAskill: I think that we should close the petition. The petitioner has made her point, although I do not necessarily agree with her. I tend to take the position that the concept of adultery is past its time and that divorce should be on the basis of irretrievable breakdown.

In any case, the Government clearly has no plans to do anything about this. We have had the programme for government; we are now in the spring of 2015; and the Government is not going to legislate on this or any other such matter between now and the end of the parliamentary session in 2016. It would be up to an incoming Administration, whatever that might be, to decide its priorities.

Ultimately, this is more a matter for the Scottish Law Commission, and I know informally that, after recent discussions, it has no plans to do anything about the subject. Those discussions have recently taken place; the Government has no plans to deal with the issue; there is nothing on the legislative timetable; and the timescales are against us. It will be for future Administrations—or the Scottish Law Commission—after 2016 to consider the matter, if it is decided that there should be a review of divorce law or, as is more likely, wider family law.

The Convener: Do members agree with the action point suggested by Kenny MacAskill?

Hanzala Malik: Yes, but we need to let the petitioner know that, even if we decide to close the petition today, she has the right to bring it back after a year.

The Convener: Okay. Do we agree the action point?

Members indicated agreement.

The Convener: I thank Ms Jones for attending the meeting.

11:12

Meeting suspended.

11:17

On resuming—

Cancer Treatment (PE1552)

The Convener: The third new petition is PE1552, by Peter Campbell, on choice of treatment for cancer patients. Members have a note by the clerk and a SPICe briefing as well as the petition. I welcome Peter Campbell and Peter Adams to the meeting. I invite Mr Campbell to speak to his petition for around five minutes, after which we will move to questions.

I understand that the two of you wish to share your presentation. It is over to you first, Mr Campbell.

Peter Campbell: I am a deaf person, a war pensioner and a former member of the 51st Highland division. I sustained an injury while I was in the Argylls, so I would like you all to speak up—shout at me—so that I can hear. I would be grateful for that. In fact, I am always getting shouted at—the sergeant major said that.

I have come here having watched my family die in front of me. No parent should ever witness what I have witnessed, especially as far as my daughter Barbara is concerned. I will read a short statement.

Barbara worked in a hospice for eight years, so she knew all about cancer. I will never forget the day that Barbara came in with my daughter-in-law and they sat down. I knew there was something coming. I said, “What’s wrong with you, Barbara?” She said, “Dad, look, I’ve got a wee lump in my breast.” I said, “Well, you’re a nurse, Barbara. You will deal with that. You work in a hospice and you know what cancer’s all about, darling, don’t you?” She took off. That was in 2006. By 2010, I was to witness my daughter being butchered—that is the only word that I can use for it. She had one breast taken off, and then the next breast came off. In 2010, I just had to stomach it. I thought, “God, I’m a war pensioner but I’ve never seen so much

cruelty in all my life,” and it was the health service that was doing it. I could not take it all in—I just knew it was not right. Time went on, and Barbara succumbed to death. That is my statement.

When I think about it now, I feel so angry knowing that what was happening was legal mass murder—in my eyes, anyway. Barbara and I surfed the net and we found all sorts of communications from people who are helping to cure cancer through other means—for example, through electric medicine. I have brought an example of that with me today. The machine costs £4,000 and is called a Photon Genie, and I am on it every day. My wife has Alzheimer’s, and she is on it every night and is responding, treating her dementia with this electric medicine.

That and other good things are all coming to me. I am a reborn Christian, and I was cured of cancer in Međugorje in 1994.

The Convener: Thank you for your part of the presentation, Mr Campbell. Let us now move to Mr Adams.

Peter Adams: Thank you for allowing me to speak in support of Peter Campbell’s petition. We believe that, since the passing of the Cancer Act 1939, cancer sufferers have been failed by the British medical system, which offers only the three-pronged treatments of chemotherapy, radiation and surgery. I believe that it was Albert Einstein who said that the definition of madness is

“doing the same thing over and over again and expecting different results.”

I suggest that this madness is evident in our cancer treatments. In fact, a report that came out recently said that breast cancer patients who reject all conventional treatments survive four times longer than women who follow the system.

Cancer statistics show that, in the UK and especially in Scotland, we have among the lowest survival rates in the European Union. One of the countries far above us is Germany, where the system allows cancer patients to use other forms of treatment if the first round of conventional treatment does not work. Here, if patients ask about or suggest other treatments, some of them are belittled and threatened with ostracism and not getting any further treatment.

Outside Europe, there is a beacon of light at Dr Contreras’s Oasis of Hope clinic in Mexico. The survival rate there is, on average, double the survival rate at the five-year point in our cancer units, yet the majority of patients attending that clinic present with stage 4 cancer having already gone through conventional treatment and having been told, “We can do nothing further for you.” The question is, how come Dr Contreras’s patients have a much better survival rate than ours here in

Scotland? Would it not be a good idea to find out why?

A large number of treatments, including the protocol that Peter has mentioned, are used in various parts of the world and are successfully treating patients. They include intravenous vitamin C, laetrile, Essiac, ozone therapy and immunotherapy, to name but a few. Because they use products that cannot be patented, there is no incentive for the pharmaceutical industry to produce them or for anyone to spend money on testing them against the so-called gold standard. Therefore, they will never be accepted or even trialled because of the restrictions in our health system under the Cancer Act 1939.

With our devolved health system here in Scotland, we have the opportunity to look outside the conventional cancer treatment box and to encourage treatment that is already used in other parts of the world for the benefit of our citizens. That would not only result in better outcomes for the patient; it would also reduce the costs to the health budget—we all know how much we are struggling with ever-increasing numbers and costs.

There is a whole world of information out there. Please be open minded and find out more about what is working across the world instead of paying for the ever-increasing and exorbitantly expensive magic bullets that are promised by some research labs and pharmaceutical companies. If we do not take steps to incorporate successful treatments that are already available to others, we will continue having to fund the ever-increasing costs of cancer treatments, which we all know this country cannot afford.

The Convener: Thank you. I invite questions from members.

Mr Adams, did you at any time pass the information that you have just provided to the committee to the Scottish Government and the Scottish task force for their attention?

Peter Adams: I have passed on the information previously. The first time, I passed it to Nicola Sturgeon at a conference up in Stirling when she was the health minister. There have been a couple of other times when I have passed on similar information. Also, for a number of years, I was part of a pilot project with the Fife NHS board. I was one of the elected health board members and I raised the issue a couple of times within its system. One time, for our board’s information, we had the cancer people in and we were allowed to have a question-and-answer session with them, but when I asked questions I was given the treatment that I just mentioned. They look down their noses and attempt to belittle you because

what you suggest is not within the standardised treatment.

Peter Campbell: I tried to approach Nicola Sturgeon when my daughter was alive, to tell her that my daughter was going through a terrible time. I did not get to see Nicola Sturgeon but I gave all the information to her secretary. That was about two years after my daughter was diagnosed. I was shouting, “Wolf!” to everybody in Scotland about what was happening, but it was going in one ear and out the other.

Kenny MacAskill: What position do the cancer charities such as Cancer Research UK, Macmillan Cancer Support and the Breast Cancer Campaign take on the issue?

Peter Adams: The cancer charity that I am involved in is CANCERactive. It is now one of the best holistic cancer charities out there. I have brought a copy of its *icon*—integrative cancer and oncology news—magazine along. I will leave the magazine with you so that people can have a look through it.

In my opinion, Cancer Research UK is part of the problem because it is too tied in with the pharmaceutical companies and, in a lot of ways, it is subsidising the shareholders of those companies by putting a lot of money into research, which the pharmaceutical companies should be doing.

Peter Campbell: The pharmaceutical companies think that they can walk on water, but it is time that they were confronted. That is what it is all about for them—it is all about money.

The Convener: We are here to talk about alternative treatments, Mr Campbell; we are not here to disparage some of the companies. Can you keep to your line?

Are there any other questions from members?

Angus MacDonald: You have referred to what you say is working abroad. What research have you done on that? Is there any research that you can point us towards?

Peter Adams: I do not have the details here, but there is a lot of research. In the *icon* magazine there is a section about current research—both conventional and non-conventional—around the world. It has references to the different research that is going on. I am not one of those people who can keep things in their heads about all the different research, but there is a lot of evidence out there and I am quite happy to pass that on to the committee so that it can dig further.

I mentioned Dr Contreras. His clinic has been running for 50 years and was started by his father. The success rate there is twice the rate that we have here, so they must be doing something right

that we are not doing here. Just go and have a look at it.

Angus MacDonald: Where is it?

Peter Adams: That particular clinic is in Mexico.

Peter Campbell: I would like to come in on that. My wife has Alzheimer’s and I am flying her out to the Mayo clinic in Florida to get her cured—

The Convener: Mr Campbell, can you let Mr Adams answer the question, please?

Angus MacDonald: It would be helpful if we could get some information on the clinic so that we could look at it.

The Convener: As there are no further questions, the committee needs to decide what action it will take on the petition. I suggest that we write to the Scottish Government, the Scottish cancer task force and Cancer Research UK, asking about the extent to which choice of treatment exists for cancer patients and for views on what the petition seeks.

Members indicated agreement.

Angus MacDonald: I suggest that we also contact the General Medical Council to seek its views.

The Convener: Okay.

Angus MacDonald: We need to take on board what Mr Adams has alleged with regard to Cancer Research UK, given that it is one of the charities that we intend to write to.

Hanzala Malik: Is it possible to wait until we get the information from Mr Adams on the evidence from around the world that he suggests is available? That might be helpful.

The Convener: That would be helpful but, in the meantime, we should probably go ahead with the action that we have just agreed. When we get all the information back, we can make a decision on the petition.

Peter Adams: That is why I would prefer the committee to choose option 2 in the clerk’s paper rather than option 1.

The Convener: Well, we have agreed to go for option 1.

I thank Mr Adams and Mr Campbell for attending.

Meeting closed at 11:30.

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