



The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 27 October 2015

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PUBLIC PETITIONS COMMITTEE
17th Meeting 2015, Session 4

CONVENER

*Michael McMahon (Uddingston and Bellshill) (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:

David Birrell
Freda Birrell (UK Association of HPV Vaccine Injured Daughters)
Chic Brodie (South Scotland) (SNP)
Jordan Daly (Time for Inclusive Education)
Murdo Fraser (Mid Scotland and Fife) (Con)
Stephanie Fraser (Bobath Scotland)
John Naples-Campbell
Liam Stevenson (Time for Inclusive Education)
Rachael Wallace

CLERK TO THE COMMITTEE

Catherine Fergusson

LOCATION

The Robert Burns Room (CR1)

Scottish Parliament

Public Petitions Committee

Tuesday 27 October 2015

[The Convener opened the meeting at 10:00]

New Petitions

LGBTI+ Issues (Teaching) (PE1573)

The Convener (Michael McMahon): Good morning, everyone. Welcome to the 17th meeting of the Public Petitions Committee in 2015. I remind all those present, including members of the committee, that mobile phones and any BlackBerrys or other electronic equipment should be completely turned off as they interfere with the sound system even when they are on silent.

The first item of business is consideration of three new petitions. As previously agreed, the committee will take evidence from the petitioner in each case. The first new petition, PE1573, is by Jordan Daly, on behalf of Time for Inclusive Education, on statutory teaching of lesbian, gay, bisexual, transgender/transsexual and intersex plus—LGBTI+—issues. Members have a note from the clerk, the petition and a Scottish Parliament information centre briefing to help us with our consideration of the petition.

I welcome the petitioner, Jordan Daly, to the meeting. He is accompanied by Liam Stevenson from TIE and John Naples-Campbell from Knightswood secondary school, Glasgow. I invite Mr Daly to speak to his petition for no more than five minutes and to explain what it seeks to do, after which the committee will begin to ask questions.

Jordan Daly (Time for Inclusive Education): Thank you. Section 28 was repealed 15 years ago, yet many of our schools in Scotland are still not teaching topics and issues relating to the LGBT community. LGBT phobia remains a massive issue within our schools and we believe that that can only be addressed with a widespread commitment to tackle it, from a legislative level right down to the schools and teachers themselves. In the petition, we are calling for a statutory inclusion of LGBT issues and topics within Scottish schools. We are aware that that is contentious and we have come here with several angles that we can use to address the issues that we have raised throughout the time that we have been campaigning.

Currently individual institutions can choose not to acknowledge the LGBT community and their

contributions to society, both within the school environment and within schools' learning programmes. We feel that by refusing to acknowledge or teach LGBT issues, such institutions are essentially candidly ostracising LGBT pupils and telling them, "You are not included here". It is the responsibility of our schools and the teaching staff within them to ensure that every pupil has an equal opportunity to achieve a high-quality education and feel supported and encouraged while doing so. However, currently a large section of our youth is being denied that right.

We have statistics from Stonewall Scotland which found, in 2012, that one in four LGBT pupils in Scottish schools right now is attempting suicide as a result of homophobic bullying. Further, 54 per cent are deliberately and regularly self-harming; 99 per cent of LGBT pupils in Scotland hear phrases such as "That's so gay" in school and as a result 49 per cent do not feel that they are achieving their best at school and 54 per cent do not feel part of their school community. As far as we are concerned, that is a national disgrace and it is something that should be tackled seriously. All children deserve to grow up in an environment free from prejudice and discrimination and to be loved, valued and cared for regardless of their sexual orientation or gender identity.

Although the LGBT community has made progress, serious issues are still holding us back, the situation in the education system being one of the largest. I am gay myself and when I was in school, I struggled with my sexuality. At my lowest point, there was no support or pastoral care available for me within my school. I was reminded repeatedly that if anyone was bullied on the grounds of religion or race, we had someone to speak to, but I had no idea what to do if I was being bullied because of my sexuality.

Homophobia was a term that was largely ignored in the school—and when I say "ignored", I really do mean ignored; I did not hear the term at all in my school. It certainly was not in my school's bullying policy either. That is despite the use of homophobic language and the derogatory treatment of kids who appear to be gay being two of the biggest problems that plague the hallways. In many schools—primarily faith schools—the social education being provided is abysmal and LGBT kids are being excluded. We feel that the Scottish Government has to do a lot more when it comes to this issue.

We were recently considered top of the league for LGBT rights and although a lot of progress has happened in Scotland, the lived experiences of LGBT youth are very different from what seems to be portrayed, as various new reports that have come out in the past few years show. Social

progress is still not reflected in the school environment. I believe that we are failing future generations and we really risk the problems carrying over if we do not start tackling the issue and taking it seriously.

One of the important things for us about the petition and the campaign that we have been running is that this is not a gay issue. We really want to stress that. It is not just about LGBT kids. It is a humanitarian issue; it is about human rights.

We feel that all kids would benefit from having that sort of education. I have a personal example. One of my best friends knew that I was struggling and had no idea how to tackle it and she has since recently said, "I wish that I had known. I could maybe have helped you when you were feeling suicidal."

Essentially, we believe that both the contributions of the LGBT community and the issues affecting LGBT pupils should be recognised and taught in school environments, with the ultimate goal of LGBT inclusion in all school curricula and pastoral care resources. Not only would statutory inclusion allow us to bypass many of the hurdles in our way and to begin improving the lives of all LGBT youth, regardless of which school they attend, but an LGBT-inclusive education will benefit all youth, as I have already said.

Thank you for inviting us to speak with you today. We welcome any of your questions.

The Convener: Thank you very much, Mr Daly. I do not know whether you are aware that there have been a number of petitions where organisations have felt that the Government should go further in forcing something into the curriculum in relation to the area that they are interested in. That has been resisted because the Scottish Government takes the view that we should not put things in the curriculum through statute. Short of doing that, what do you think could be done to take the issue forward?

Jordan Daly: I point out that religious education is a statutory part of the school curriculum.

Short of statutory LGBT education, teacher training is the best route that we can go down to tackle the issue. We have consistently highlighted in our campaign that we feel that a realistic aim is to have at least one teacher fully trained on LGBT issues in every school in Scotland. There are training programmes available, such as Stonewall Scotland's train the trainer initiative.

We recently met Colin Macfarlane, the director of Stonewall Scotland, who gave us a rough estimate. It would cost the Scottish Government about £300,000 to ensure that at least one teacher from every school could attend that training

programme. Currently, only 70 schools are signed up to the programme, which works out at about 16 per cent of teachers in all schools who have been trained in how to deal with LGBT-phobic bullying, which is not good at all. You can see where these issues are coming from: 88 per cent of secondary school staff say that pupils in their schools have experienced direct homophobic bullying, yet only 16 per cent know how to tackle it.

I will pass over to John Naples-Campbell. He is a teacher so he will be able to give you a better outline of where we should look to address the issue.

John Naples-Campbell: It is very clear that the health and wellbeing outcomes in the new curriculum for excellence are the responsibility of all teachers in Scotland, but when it comes to LGBT issues, a lot of teachers do not have the confidence—and it is about that word "confidence". They do not know how to tackle some of the language that they hear within the classroom. They do not know how to tackle questions that may be raised by young people. I agree with Liam Stevenson and Jordan Daly that it is about training staff.

Staff in schools do not have equality training. It is not something that schools do. I have worked in secondary and further education and it is something that we have to do regularly in FE. Therefore, telling schools that they have to do mandatory equality and diversity training might be a way of bringing it into schools.

It is also very clear that although all schools have pastoral care teams, the personal and social education programmes are taught by a wide range of staff. They could be normal teaching staff, they could be deputy heads, or they could be pastoral care staff. As someone who has a background in human rights, I am very passionate about this area. My colleagues who teach technical studies, mathematics or English, for example, might not have done the same research or have the same knowledge about human rights and therefore they would need training to deliver that education. If we had one member of staff in each school who followed the train the trainer programme from Stonewall, they would be able to go into the school and train the staff on how to deal with the issue, and I think that the health and wellbeing of all students, including LGBTI students, would benefit greatly.

The Convener: I did not want to assume that you were a teacher but you mentioned there that you were.

John Naples-Campbell: Yes, I am a teacher.

The Convener: Can you give us examples from your personal experience or from speaking to colleagues of when teachers are being prevented

from intervening? I think that both you and Mr Daly have said that teachers do not have the confidence because of a lack of training.

John Naples-Campbell: Yes. They do not have the confidence to tackle the issue.

The Convener: Are there instances when teachers who wanted to engage with and discuss these issues have been prevented from doing that?

John Naples-Campbell: Section 28 still plays a large part within schools. I am an openly gay teacher. I came out on my very first day of teaching. I came out because I felt that I had to be authentic to who I was and also to be a role model for young people, which I never really had at school. There are a lot of gay teachers who do not know whether they can come out at school. They do not know whether they feel that they should come out. A lot of that is fear; it is fear not really from the kids but fear from the public, from religious groups, from repercussions from the headteacher. There is not really an open dialogue in schools.

The only cases that I have heard about of people being prevented from speaking have been in faith schools. That is about the boundaries and where they lie, but all teachers have a responsibility for health and wellbeing—the experiences and outcomes are there and teachers must address issues that arise in the health and wellbeing curriculum.

Jordan Daly: Throughout the campaign, we have been speaking to teachers and we have collected quite a lot of experiences and stories from them. I do not know whether you know of the Vale of Leven academy in Dumbarton. That school is a benchmark for what should be happening, but it is massively in the minority. It has an excellent LGBT committee that consistently campaigns in the school and ensures that the pupils who are LGBT are included and welcomed.

You asked for an example. We visited the Vale of Leven academy—we have been quite a few times. We spoke to the teacher who runs the LGBT committee, who told us that they have a young transgender boy who came out as transgender after the summer between the second year and third year. The school and the senior management team freaked out straight away, thinking, “How on earth do we deal with this? This has never happened before. We don’t know what to do”.

If any of you are in tune with issues affecting the transgender community just now, you will know that it is a very sensitive topic and you have to be very, very careful, especially in how you deal with young transgender children. What we were told was that the teacher who runs the LGBT

committee, who had been trained by Stonewall, guided the staff through how to deal with it. Basically, she told them to do whatever the child wanted them to do. Had it not been for that teacher being in that school, the school would have had absolutely no idea how to tackle or address the issues. That is one example that highlights what we are essentially saying—that teacher training, which can improve the lives of LGBT youth, should be prioritised.

There are cases going on all across the country. Just two weeks ago, we had what is probably one of the worst cases that we have heard. It was about a transgender boy once again, in an unnamed high school in Glasgow, who was stood on his desk in front of other pupils, with the teacher pointing out, “You have boobs, you have curves, you have a bum; you are not a boy—you’re a girl.” This is a serious issue and I want to stress that it is happening en masse across Scotland.

John Naples-Campbell will talk about some of the good work that is going on that we feel should be used as a benchmark and to highlight the issues. However, in our experience of speaking to and hearing from teachers, they do not know what to do because they are very scared. They do not know what to say. One of the most worrying things is that a couple of people we spoke to who are training to be teachers say the exact same thing. An LGBT pupil might come to them and say, “I am transgender. I am gay. I am bi. I don’t know what to do. Can you help me?”, and we have heard point blank from these teachers that they would have no idea how to tackle that and would just go on their personal life experiences.

The Convener: Mr Stevenson, I want to come to you. Being part of the campaign, you must have an idea of your capacity for engaging with teacher training colleges and local authorities. What resistance have you been encountering?

Liam Stevenson (Time for Inclusive Education): So far, the TIE campaign has received very little resistance. I understand that the committee received a letter from a religious group asking it to throw out the petition but the general reaction has been very positive. I believe that we live in a pretty progressive Scotland.

I am a parent myself; I am not part of the LGBT community. I have a four-year-old child and that is my motivation. I will not know my wee girl’s sexuality for eight to 10 years and I want to make sure that she gets a good, inclusive education at home, but she is in the minority among her friends; that is a fact. I want to make sure that the systems and protection are there at school to look after her if she struggles with these issues.

10:15

Not having had contact with the LGBT community before the end of last year, the issues did not register on my Richter scale, even as a parent. When I was introduced to those statistics, however, became friends with people such as Jordan and John and understood their struggles and the places that they had been in, I realised that problems over LGBT issues need to end in our country and are not something that I want for my daughter.

To answer your question, we have had really great responses from other teachers. We have had a lot of folk contacting us online, and it has all been very positive. There seems to be a thirst out there among the vast majority of people we have spoken to. Teachers want to be doing this because they understand that they are shaping future generations. A lot of them also understand that, given the way we are going, we will continue to churn out damaged adults with mental health issues and so on. Lots of people are scarred so badly by their experiences of school and growing up that they do not fully recover.

I have learned from my experience of being introduced to the LGBT community that there is an internal struggle and an external struggle. The internal struggle is when a young person realises, "I don't fancy kids of the opposite sex; I fancy my peers of the same sex". The child has that emotional turmoil to deal with. After that, they have an external battle to fight to find out where they stand in their peer group. A lot of times, because they feel so low and bad, they end up moving to a different peer group completely. Jordan had good friends but he moved away from his peer group.

If we can introduce such things in our schools, future generations will not feel that they have to break off friendships with those they have played football with or gone to football with all their lives, because there will not be a social stigma over whether a kid is gay. It will become inconsequential.

During my time with my wee girl introducing her to the issues and to the fact that Jordan is gay, I have seen that opportunities for homophobic thoughts or behaviours completely disappear because there are no barriers that can be put in my daughter's mind. She is very fortunate—she has a friend who stays in our street who has two mums.

The evidence is there: I have seen it with my own kid and I have seen it with all the kids in our area. When they are introduced to these things and are taught that they are not wrong, evil or bad, we can make changes that will benefit the whole of society, from top to bottom.

There is another side issue. The Scottish Government would recoup the £300,000 that Stonewall reckons it would cost to train one teacher from every school, because there would be savings for the national health service from the reduction in damaged adults with serious mental health issues as a result of their experiences.

It would be better not only for society but for the Government, because the Government should be representative of all the people. If we can make the better, fairer, more progressive Scotland that I hope everyone in this room wants to see, we all prosper and benefit.

The Convener: I am going to ask another question. I have not had an indication from colleagues that they want to ask a question yet.

You have given us examples of good practice. You have told us that local authorities are willing to engage and talk about these issues and how to promote them. I come back to my original question: if these things can happen at present with good direction and support, and if £300,000 would train enough staff to go into our schools and be more aware of the subject, why do we need to put that in statute to make it happen? There does not appear to be anything in statute to prevent it from happening, so why would putting it in statute make it happen?

Jordan Daly: We called for a statutory approach to bypass the obvious hurdles that are going to come up if we try to do this through teacher training.

Stonewall has been running its programme for years now, and it is very well promoted, but only 70 schools are taking it up. We found that many schools are saying, "We don't have the budget for this. We can't do this. We don't have the time for this". In addition, I went to a faith school, and a lot of faith schools are just point blank refusing to teach about the issues. We put the petition in and called for statutory inclusion to bypass those hurdles.

You need to remember that this fight has been going on for a very long time. Stonewall Scotland, LGBT Youth Scotland and the Equality Network have been trying for years to get inclusion into the education system. On the side, everyone says that a statutory requirement would help us get past a lot of the problems and break down a lot of walls.

We are aware that statutory inclusion is very contentious, and that is why we have come today prepared with other solutions. If it cannot be made statutory, we have to have a serious commitment. Currently, there are teacher training programmes on offer. However, a lot of schools are using the cop-out that their continuous professional development budget does not allow staff to go on

the training or that they do not have enough money to send teachers on it.

There has to be some resolution whereby the Government says, "Here is £100 to send one teacher. That money is only for this course and if you do not do it we will maybe carry out a review to find out why you do not want your teachers trained in these issues".

If it cannot be made statutory, there has to be some other commitment to highlighting the problems, because the way things are now is just not good enough. There are several options—I will hand over to John Naples-Campbell.

John Naples-Campbell: We have done amazing work within schools on getting it right for every child, but we are failing because we are trying to do that in a blanket way.

My headteacher said to me yesterday, "We can give every child a pair of shoes but we have to give every child a pair of shoes that fits", and we are not doing that.

As Jordan says, schools have really tight budgets. Sometimes they cannot afford to pay the £150 to send a teacher out.

Amazing work is happening across Scotland: we have a brilliant group here today from a school in Edinburgh that formed its own LGBT group; Braes academy in Falkirk has set one up; St Joseph's college, a faith school in the south-west of Scotland, is trying to get its LGBT charter mark from LGBT Youth; there is great work within Glasgow; and Highlands and Islands took a whole local authority look at what is happening within its schools.

Those are random examples of where work is happening. However, it should not depend on which school your child goes to; it should be happening across the whole of Scotland.

This should not be a lottery. We need the Government to fund teachers to be trained, even if it is just one teacher from each high school, so that schools do not have to worry about budgets, because this is about getting it right for every child.

Jackson Carlaw (West Scotland) (Con): Good morning. Can I ask what TIE is?

Jordan Daly: TIE is a campaign that we founded around the time when we put the petition in. TIE stands for Time for Inclusive Education. While the petition has been sitting in the Parliament and we have been waiting to come to speak to you guys, we have been campaigning on the side. Nationally, we have been going to schools and taking assemblies, and we have just published a booklet, which most of you have received—every MSP in Scotland should have received one.

Jackson Carlaw: Who is "we", just so that I understand?

Jordan Daly: TIE. It was co-founded by Liam and myself, John Naples-Campbell works with us and we have Niall, who is in the audience. A few people work with us.

Jackson Carlaw: So it is a relatively small campaign organisation that you have initiated.

Jordan Daly: Yes.

Jackson Carlaw: That is fine. Can I ask a question just to help my own understanding? I am 56. I have two sons who have now left school and gone to university. I suppose I might as well say that admission of homosexuality would have been regarded as a capital offence when I was at school—people were simply expelled and cast out of society. I have friends for whom that led to a very tragic outcome.

My own impression had been that today's generation was far more enlightened than mine, or at least than the generation that presided over schools when I was at school. My sons' experience seemed to have been a more positive one than my own. I had imagined that there was a natural evolution in the understanding of the issues in Scotland, and some of the narrative that you detailed in the petition takes me quite by surprise.

I am not so naive as to suppose that none of this ever goes on, but you paint rather a bleak picture. Is it universal? I note that Jordan was at a faith-based school. Is there a prevalence of discrimination in faith-based schools, or is that a generalisation?

You talk about the transgender community. I felt that the school my son was at handled such an issue very well. In fact, the big surprise to me was that absolutely nothing came out of it. I was tremendously encouraged that that was so.

What is your understanding and impression? Am I, at 56, hopelessly out of touch with how things are? Perhaps Mr Naples-Campbell could answer, because he looks slightly older than you do, Jordan, and his perspective must go past your immediate experience. Have things improved or have they not?

John Naples-Campbell: Things have changed. We need to remember that we just got equal marriage at the end of last year. We still have a lot of staff members of a similar age to you who are teaching; they have not been retrained since section 28 was repealed in 2002. We have an epidemic in our schools of the daily use of the term "That's so gay".

I go back to the point about there being a lottery. There are wonderful staff—there is a teacher here

who had the drive and the passion to set up a LGBT group in her own school—but those people are not in every single high school. What your son experienced within school is amazing. That is the benchmark we want, but it is not happening. There are children who, as Jordan has said, are attempting suicide, self-harming and leaving school early because they cannot attain and be authentic to who they are. Although young people make mistakes and can learn from them, staff are very unconfident in dealing with certain issues, especially when staff who teach personal and social education have not been given the proper training in it.

I have also witnessed homophobia within the staffroom. When I first came out at a school in the south-west of Scotland, it was as if I was this monster. There were lots of questions.

I am an Edinburgh boy. I was sent to a small village for my first year of teaching. That was pretty scary, but I embraced it and stayed for two years. However, on a daily basis, I had to listen to conversations about Elton John getting married and how he was a poof. That is not the type of conversation I want to hear in my work environment. That is just one story I heard among numerous others.

Jackson Carlaw: Mr Daly, I would not give up on your petition yet because, from what you are suggesting, there is a casual disregard of all the best practice instructions and framework documents that have been put in place. In the petition, your argument is that in those circumstances something more directive is required. I know that you have said that you have come with other solutions, but I would not encourage you to lose sight of your petition yet. If what you are saying is so, I find myself quite drawn to the petition. The experiences you detail are not encouraging at all.

In the event that a more statutory type of approach was taken, how would that manifest itself within a school? What would you like to see happen? Be careful not to give me a huge, long shopping list. Tell me specifically how you would see such an approach impacting in a school to neutralise the prejudice of others or the casual disregard that is shown when, if there is an option on how to spend money, other areas are prioritised.

Jordan Daly: The number 1 priority for me would be pastoral care.

On the curriculum, one of the main gripes that I have is that the LGBT community's history and contributions to society are largely disregarded within school. Education is a vital tool to tackle that.

We have taken a couple of assemblies. We always ask the kids, "How many of you know about the Stonewall riots? How many of you know about Harvey Milk?", and maybe one or two people put their hand up. When we ask, "How many know about Martin Luther King?", everyone in the room puts their hand up.

We need to educate kids about the struggles of the LGBT community and the persecution that many of us faced not long ago in Scotland—it was illegal to be gay here until 20-odd years ago. If we can teach kids about that it will give them the understanding and the empathy that they need. A kid in school would never leave a history lesson about the Ku Klux Klan, how black Americans were treated in the south and the race movement and see a black—

10:30

Jackson Carlaw: You have identified two strands. We are almost coming on to the narrative of the curriculum. You started off by talking about pastoral care. How would you see that working? Would that be provided by a designated teacher who is already in a school?

Jordan Daly: It would tie in with what we said about having one fully trained teacher. Stonewall's train the trainer programme, which we are going to do, trains teachers how to deal with the issues. They get taught, for example, how to deal with a trans kid saying, "I'm a girl but I'm actually a boy; I'm in the wrong body. How do I deal with this?" They get taught what to do and where to signpost to. We have said—this is what VOLA does—that schools should have one teacher who all pupils know about, who is fully trained in the issues and who is available to speak to kids, based on the guidance teacher model.

Jackson Carlaw: And empowered to some extent, I imagine.

Jordan Daly: Yes. We need simple things as well. At my school we had anti-racism posters everywhere. Changing school policies to include LGBT-phobic bullying would be good.

Hanzala Malik (Glasgow) (Lab): Good morning. John Naples-Campbell mentioned a few things that I can relate to from my experience as a youngster at school. Coming from a mixed background, I was subject to bullying, harassment, discrimination and all sorts—from not being included in games to being physically hit by items in the classroom. The teachers were totally unable to deal with the issue. Because I can relate to that, I am not particularly convinced that statutory activity would enhance the situation in any way. A better way of moving forward would be to deal with all the issues at teacher training centres from the very start. Having one teacher or lecturer

responsible for a whole school or a whole college would be impractical; if that member of staff was not available for long periods, nobody would be available in the school, college or university. A broader training course at source would be more practical.

Also on statutory activity, as you say, last year we had the vote on same-sex marriage. Most people were supportive because a lot of religious organisations' rights were protected. However, if we were to try to legislate on this matter in schools, we would almost challenge that protection, particularly in relation to faith schools, and I am not sure that we would get all the support that is needed. To be successful, you need people to come on board voluntarily and willingly. You need to win hearts and minds. If you try to go down the statutory route you may find more hurdles, and people might not be willing to engage fully. Believe me, I can understand the issues because, as I say, I have been there myself and I know what it is like. However, unless you win hearts and minds, it will be an uphill struggle. To win hearts and minds you have to do things in a way in which other people's human rights are respected and protected. I just wanted to share that.

The Convener: There was no question there, but do you want to comment on anything that Hanzala said?

Liam Stevenson: I will pick up on Hanzala Malik's first point. As we said, we have investigated different routes to tackle the issues. One of the things we have focused on, helped by John Naples-Campbell's input, is the fact that we would like to see these things fully included as part of teachers' university training. That is something that we have looked at. I fully agree with Hanzala Malik's point and I would definitely like to see such training implemented. We have thought about that and it is a route that we quite fancy.

John Naples-Campbell: I mentioned that secondary and primary school teachers do not have compulsory equality training, but lecturers have that in FE and higher education. We might have to go down that route as well—that would cover all the protected characteristics. I ran a staff training day at Knightswood secondary school, where I am from, because of my qualification and background. The feedback was excellent. It was something that staff needed and wanted. It covered all areas and it tied in with the hate crimes work that is currently being done in Scotland.

Angus MacDonald (Falkirk East) (SNP): Good morning, everyone. You have certainly presented a good case and I have to say that the figures from Jordan came as quite a surprise. I was astonished to hear, for example, that only 16 per cent of teachers have been fully trained in LGBT

issues and that only 70 schools are signed up to the programme that you mentioned. However, I was interested and pleased to hear that there is a good example at Vale of Leven. Braes academy in Falkirk leads the way in many ways, so it is good to hear that one of my schools is heavily involved.

Can you give some more detail on the programme that you mentioned? Can you embellish a bit more exactly what is involved? You seem to be indicating that if your request to make LGBT training statutory is not successful you would be content, though perhaps not entirely happy, with proper equality training. Is that the case?

John Naples-Campbell: Would you like me to go through what happens at Stonewall's train the trainer day?

Angus MacDonald: That would be helpful.

John Naples-Campbell: Train the trainer is a day's training led by Stonewall Scotland. Sophie Bridger normally leads it. She goes through the skill set that a teacher or someone who works with young people needs to support and help a young person who comes to them with any issues that they may be facing. She gives you case studies of various incidents that could happen and how to approach them, and the training builds up confidence to tackle them. It also shows where to seek help if a teacher feels that something might be out of their depth: it signposts various organisations that could help. Teachers leave with a pack that they can take into a school and use to train other staff to help them. It is a brilliant training programme and we should definitely be looking at the model in this economic environment. It is about training trainers. It trains up one person who can then go out and train more people. We have used the model in Knightswood and it has worked incredibly well.

Jordan Daly: On whether we would be content if the statutory approach got thrown out, we would be happy with full equality teacher training as long as there was a commitment at the Government level to prioritise the issues and start taking them seriously. Angus MacDonald is not alone in being surprised at the statistics and the situation that is going on. Most people we encounter are gobsmacked. We have put together a little booklet that highlights all the scenarios. Most people seem to think, "Hey, we just got marriage equality; surely things are better," but they are not. We would be happy as long as there was a serious commitment to tackle the issues.

We also believe that institutional reviews should be carried out. If we prioritise teacher training and tell schools to prioritise it, we need to follow up on that to ensure that schools go through with it, the trainers who come back from Stonewall's training

programme are training other staff and things are improving in schools. It is a long process, but we would be content as long as there was a commitment to prioritise the issues.

Angus MacDonald: You mentioned the booklet that you produced. Obviously you are a small group with limited resources. Have you managed to get that booklet out to the other however many schools in the country that have not signed up?

Jordan Daly: This booklet has not gone to any of the schools yet. It cost us £400 just to get 200. The booklet was delivered to all MSPs at Holyrood and we have 80-odd left that will be given out to schools. We are trying to find out whether we can get it to some local authorities as well. We have the PDF, so we will definitely get more published and get them into schools.

Angus MacDonald: I think that it was Liam Stevenson who mentioned the submission from the Free Church of Scotland. Before I talk about the submission I should declare an interest, in that I am currently undertaking a financial transaction to purchase a Free Church property. However, that has no bearing on my position with regard to the petition and I have no direct contact with the Free Church, I hasten to add. The purchase is being conducted through agents.

The Free Church highlights in its submission the United Kingdom's Human Rights Act 1998, which states:

"In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions."

The Free Church submission says:

"We believe that the real object of the petition is to indoctrinate school pupils with one particular perspective on moral and sexual ethics and one which is contrary to mainstream Christianity. We believe this is a Trojan horse to impose an ideological perspective on all pupils, whether they want it or not."

What is your view on the church's stance?

John Naples-Campbell: The United Nations Convention on the Rights of the Child states that children should have an education and that it is a up to them, not their parents, what that education is. In all my years of teaching LGBT education I have never come across what the Free Church is talking about. The UN Convention on the Rights of the Child is something that we teach in schools and something that all young people are aware of at an early age. If they have an issue with LGBT education, we address it in class time as openly as we can. The word to use is respect: we need to respect people regarding their opinions and their beliefs. I always go by the UN Convention on the Rights of the Child more than anything else.

Angus MacDonald: It is good to have that on the record.

John Wilson (Central Scotland) (Ind): Good morning. On that last point about the Free Church's position about indoctrination, some of us would argue that indoctrination takes place in many different guises, particularly in the present educational environment, so we need to be careful when we talk about indoctrination.

Who participates in the training? Is there an indication that particular local authorities are encouraging schools to participate in the training? Are there particular schools in particular areas? It would be useful to find out, given Stonewall's findings and percentages, whether there was discussion with local education authorities to determine whether action should be taken in particular areas. The percentages are horrendous in terms of bullying and it would be useful to find out whether, when the survey was carried out, particular local authority areas highlighted issues of direct discrimination.

John Naples-Campbell: I am not aware of how Stonewall carried out its research. I am aware that it took a sample from across Scotland, so I would hope that it heard from a number of regions.

Whether people sign up for the train the trainer programme very much depends on the headteacher and their CPD plan. If schools highlight it in their forward plan for the year, normally they will fund it to happen. It depends on the budgets, as well—£100-odd for a training event is a lot of money. It depends on a number of different things, including whether the person wants to be trained and whether there is an open conversation with the headteacher or the head of CPD for the school.

10:45

John Wilson: That is interesting. No doubt as we go on to investigate the matter further, convener, we can write to Stonewall and ask some further questions.

Are you aware of any individual teachers who have been willing to fund a train the trainer day but have had their request refused by the headteacher? You might not be able to give me an answer on that this morning. I will leave it there. We will write to Stonewall and ask that question.

The SPICe briefing on the petition says that in 2009 the Scottish Government funded a toolkit for teachers on dealing with homophobic bullying. The toolkit was supposed to have been distributed to all schools during that year. Are you aware of whether it was distributed and whether it is being used?

Mr Daly, your time in education might have overlapped with the period in which the toolkit was supposed to have been distributed to schools. Do you have any experience of the toolkit being used?

Jordan Daly: I am not aware of whether it was used en masse, but I was in school in 2009, and that was around the time when I heard from some teachers that I was an abomination, and that God clearly does not like gays and that is why we got AIDS. I can speak only from my personal experience, but that is what was happening in my school in 2009, and I had absolutely no idea that a toolkit was being given out. As I said, not once did I ever hear homophobia mentioned in my school. I am sorry that I can give you only one example, but in my personal experience there was no reference to or mention of such a toolkit at all in my school.

John Wilson: We are told that a toolkit was distributed in 2009, and we are now six years on from that. The experience of many of the school students who were interviewed as part of the Stonewall survey shows that, if the toolkit is out there, it is not being used by schools or education authorities to hinder or stop homophobic bullying that is taking place, irrespective of whether it is happening in the playground or in the classroom or is being carried out by teaching staff themselves.

John Naples-Campbell: You can send out any number of toolkits to schools, but staff need to be trained on how to use them. If a toolkit comes to my desk and I am not comfortable dealing with it, I will not use it because I do not want to do more damage. As well as sending out toolkits, you often need to train the teacher to use the toolkit.

Kenny MacAskill (Edinburgh Eastern) (SNP): I have some qualms about the statutory approach, but you raise a significant issue.

I am perhaps a year or so older than Jackson Carlaw, but I think that the progress that has been made in education in dealing with bullying, violence and racism has been extraordinary and quite remarkable. It is clear, however, that that has come about not by accident but by design. Presumably the reason for that is an increase in awareness, resources and guidance. That is where you are seeking to make progress to address the issue that you are focusing on. You have already commented on that aspect, but I wonder whether you would agree with that, or whether there are other issues that require to be taken on board.

John Naples-Campbell: No. Everything that you have said is completely right.

We need training and guidance, and we need money behind that. We all know how schools work: you give local authorities the money and

they give it to the school. If the training is not a priority for a school, it will not put money towards it.

I am very lucky in that all three schools in which I have worked—in Dumfries and Galloway, at Knox academy in Haddington and at Knightswood—have been incredibly supportive. If a school does not have any openly gay students, the headteacher might say, “Well, why do we need to train if we don’t have any issues here?” However, they do not know that that is the case. There might be a young person in that school who is gay but does not want to come out because they hear “That’s so gay” on a daily basis in the classroom or the playground.

I completely agree that we need to focus on the elements that you mention, such as guidance and money.

The Convener: We appear to have exhausted questions from the committee. Do members have any suggestions for how we take the petition forward? I think that we need to get some clarification from the Government on a number of the issues that have been raised regarding toolkits and the work that it has done.

Hanzala Malik: I would be interested to know what the universities are doing to include the issue as part of their teacher training programmes. Is it in the syllabus at present? If not, do they intend to put it in the syllabus? That would indicate how things are moving and perhaps encourage universities to do that if they are not doing so already. Training all teachers is important; I do not think that isolating one teacher in a school is the solution.

Kenny MacAskill: We have to write to the Government, which is the principal body involved. I am not necessarily persuaded of the need for a statutory requirement, but it seems that we must have a strategy. Simply sending out a toolkit in 2009 may have been worthy, but it has clearly not been successful.

We know that such an approach has worked on other issues—such as violence, bullying and racism—on which we have wanted societal change. We have seen that happen over generations. We recognise that resources are tight, but much of this is not about huge amounts of money; it is about knowing what you want and getting the information out because you already have it. I would be for asking the Scottish Government whether it is going to develop a strategy to address the issue.

Jackson Carlaw: Specifically on that point, we might ask the Scottish Government if it would be prepared to engage with the petitioners and with others who have clearly amassed a certain amount of best practice experience. That might

underpin the programme that the Government launched and ensure that it had a greater reach than it would appear the previous heartfelt effort in 2009 had, given the suggested response that it met.

I would be interested to know a bit more about Vale of Leven academy's best practice model. Perhaps we can write directly to the school, although there may be some other process by which we could get that knowledge.

The Convener: We can certainly write to the education authority if you want an answer on behalf of the school. We can take that further.

I would like to know the view of the Convention of Scottish Local Authorities, given that it has responsibility for all education authorities, so I urge that we write to COSLA as well as to the specific local authority concerned.

John Wilson: I agree that we should write to COSLA, but I also suggest that we write to the local authority education department that covers Vale of Leven academy and to the headteacher at the school. I am interested to see the overall education policy of the local authority as opposed to the decisions that are made by an individual headteacher. Many headteachers have a level of autonomy in dealing with issues in their own educational establishments, so it would be useful to see if there were any contradictions between the two approaches.

One issue that we should examine is that, although individual headteachers and teachers are keen to deliver and participate in that type of training, the question is whether teachers can be blocked at headteacher level or whether there is a diktat from the local authority education department that guides schools in how they react to such requests.

On that basis, I suggest that we write to Stonewall Scotland, given that most of the information that we are using comes from the results of the survey that it carried out, to ask what engagement it has had with the education authorities throughout Scotland in relation to those results, and whether it has found that there has been any movement by local authority education departments to try to address the issues that have been raised.

We have done a lot to address racial and other bullying, but we do not seem to have tackled other aspects. Society has moved on since section 28, and equal marriage legislation has been introduced. It would be useful to find out whether some of the local authorities, as well as COSLA and other bodies, are moving ahead at the same pace. We should ensure that they do.

I suggest that we write to the Educational Institute of Scotland to find out whether it has identified any particular issues regarding the ability of teachers to engage in the train the trainers programme or the delivery of pastoral care to students who feel that they require that support.

The Convener: I think that the committee is agreed on that.

Angus MacDonald: I do not disagree with any of the comments from John Wilson or other members. However, at the risk of being accused of being parochial, I ask that we also write to Falkirk Council and the headteacher at Braes academy, given that the school was highlighted as an example.

The Convener: I was going to make that point too, because some good examples were given of schools whose representatives have attended the committee this morning. Writing to Braes academy in Falkirk and Vale of Leven academy and their respective education authorities would give us an understanding of how things developed in those areas and those specific schools.

We have had a wide-ranging examination of the issue from colleagues. I thank the petitioners for coming this morning. We will write to all the organisations, collate that information and get back to you when we have received the responses.

Do you want to make a final comment?

Jordan Daly: Yes, just briefly. I thank all of you, because we expected to come in here and have the petition thrown out. We did not expect that it was going to—

The Convener: Oh ye of little faith—did you learn that at school?

Jordan Daly: Seriously, I thank you—on behalf of the LGBT community in Scotland and LGBT youth across the country, you are seriously going to do a lot to improve things.

The Convener: Thank you very much. I will suspend the meeting for a couple of minutes for a change of witnesses.

10:56

Meeting suspended.

11:00

On resuming—

Human Papillomavirus Vaccine (Safety) (PE1574)

The Convener: The next petition is PE1574, by Freda Birrell on behalf of the UK Association of

HPV Vaccine Injured Daughters on human papillomavirus vaccine safety. Members have received briefings, and I welcome to the meeting Chic Brodie MSP, who has indicated an interest in this petition.

I welcome the petitioner, Freda Birrell. She was to be accompanied by Steve Hinks from AHVID, but as far as I understand it, he is unfortunately unwell and is not able to join Mrs Birrell this morning.

Freda Birrell (UK Association of HPV Vaccine Injured Daughters): His daughter has had a relapse.

The Convener: I am sorry to hear that. Please pass on our regards.

I will hand over to you, Mrs Birrell. You have five minutes or so to introduce the subject, and then we will interrogate it a bit further.

Freda Birrell: Thank you. On the off-chance, convener, I have brought a one-page summary relating to Lucy Hinks, copies of which are available if members would like to take them and read them at their leisure.

The Convener: Thank you. We will have a look at that.

Freda Birrell: I thank the committee for allowing me to provide additional information relating to my request for a round-table discussion to be held in Edinburgh between scientists and medical professionals from both sides of the HPV vaccine safety debate.

I speak today on behalf of not only the UK Association of HPV Vaccine Injured Daughters, whose lives have been turned upside down after HPV vaccine administration, but each of the 2,019 people from 55 countries who have signed the petition because they are having similar experiences and support open scientific discussion. Our association, which was organised at the beginning of this year when it became apparent that we needed to co-ordinate everyone's individual efforts as a group, represents families from Scotland, England, Wales and Northern Ireland and operates under the banner of the UK Association of HPV Vaccine Injured Daughters.

As a group, we have been able to receive greater publicity, and increased awareness has caused our membership to grow by leaps and bounds. Our initial group of 60 members has expanded to 208 and rising. Despite the fact that Scotland accounts for only 8 per cent of the UK population, 15 per cent of the association's members come from it. We do not know how many others are out there, but for now there appears to be no end in sight. A senior politician in Ireland, Paschal Mooney, recently made an

impassioned plea to Irish Government officials regarding the Irish HPV vaccination programme, the lack of informed consent and the devastating effects on young girls around the country. Specifically, he mentioned Irish girls being admitted to psychiatric hospitals following HPV vaccinations.

Japan has rescinded the Government recommendations for HPV vaccines and has initiated studies to determine whether there is a causal relationship between HPV vaccines and adverse outcomes as well as a 21-year study to determine whether HPV vaccines have an impact on cervical cancer diagnosis rates. On 31 October, the national association of HPV-adverse sufferers in Denmark is hosting an HPV vaccine information symposium to bring families together with medical professionals, health authorities and legal professionals to explore treatment options and potential legal remedies. Denmark has recently made the decision to change from Gardasil to Cervarix as the HPV vaccine of choice. In the past week, at the urging of Liselott Blixt, a Danish politician with a Gardasil-injured daughter, the Danish Government has set aside 7 million krone to conduct an independent investigation into the HPV vaccine and its side effects.

Our association is in the process of compiling information for the European Medicines Agency's consideration in its safety assessment of HPV vaccines. Of the 88 family reports analysed to date, 68 per cent reported that their daughters experienced health problems serious enough to interfere with their education; 24 per cent reported symptoms so severe that their daughters could no longer participate in educational activities; 70 per cent required help with daily care; and a full 91 per cent reported being told that their daughters' medical conditions were psychological in origin.

On that last point, it is interesting to note that national health authorities in Denmark, Norway, Japan, France, Spain and many other countries have led doctors and other vaccine administrators to believe that any new medical conditions experienced after HPV vaccine administration are most likely psychosomatic. Consequently, as many UK families have experienced, the average medical health professional faced with a patient exhibiting symptoms that they have never seen before and which do not fit neatly into any current diagnostic criteria naturally assumes that they are psychological problems.

I put forward the following facts for the committee's consideration. According to the insert in the package for Merck's Gardasil 9, which is the new vaccine that is coming in, 3.3 per cent of participants who were given Gardasil, which was used as the control during the most recent clinical trials, experienced new medical conditions

potentially indicative of auto-immune disorders. That works out at 3,300 per 100,000 recipients. According to a press release from Sanofi Pasteur MSD dated 17 June 2015, 183 million doses of Gardasil have been distributed worldwide. If we use Merck's own clinical trial percentage, we see that there could be as many as 6,000,039 girls around the world suffering autoimmune conditions, which could very well influence their health for the rest of their lives.

According to the World Cancer Research Foundation, 528,000 cases of cervical cancer were diagnosed worldwide in 2012. Is this worth the risk? I am very much aware that HPV vaccines are controversial and that this information puts Scotland at a crossroads with a very difficult decision to make. Do we accept what the manufacturer and its list of experts are saying and assume that HPV vaccines are safe and effective and that there just happens to be an epidemic of psychosomatic disorders spreading around the world, affecting certain young people who have one thing in common: they were injected with the HPV vaccine? Do we listen to experts from both sides, try to discover exactly what the situation is and make every effort we can to get the problem solved? Do we sweep all these families under the proverbial psychological disorder carpet and ignore their misery, or do we treat them with the dignity and respect that they deserve by using every means at our disposal to identify those at risk of serious adverse reactions and to develop successful treatment protocols for those who are already suffering?

Please demonstrate to the world that Scotland is still a country that does not ignore the suffering of innocents, and show the world Scotland is not afraid to hold open and honest scientific discussions, no matter how controversial the subject might be.

The Convener: Thank you very much. Chic, do you want to come in at this point?

Chic Brodie (South Scotland) (SNP): Thank you, convener. In the past two-and-a-half years since I initially met Freda Birrell and others who are involved, I have done some personal research on this matter, and I ask the committee to ask the appropriate questions, given the ramifications that it has beyond Scotland. Clearly there is an issue here that needs to be resolved and, on that basis, I ask the committee to interrogate the petition thoroughly but, I hope, decide on the appropriate recommendation to allow us to take a further step on this journey.

The Convener: Thanks very much.

I want to ask a direct question, Mrs Birrell. Who should call the round-table together? Whose

responsibility should it be to invite people to sit around that table?

Freda Birrell: I would like to think that, after listening to what I have said and perhaps asking many more questions and getting more evidence, the committee will be influenced enough to conclude that this is a very serious problem. It is neither a Scottish problem nor an English problem; it is a worldwide problem, and it is happening in those countries where the vaccines are being administered. We certainly have many medical professionals and scientists who would be willing to come and debate with scientists and medical professionals from the pharmaceutical companies, Government or wherever, and we also have witnesses who would be able to say, "This is what has happened to our children."

In the end, these girls need to be healed. After all, they are still very ill. Given that these things have been happening since 2008 or 2009, something has to be done to get someone to look at and find out what has happened, why these girls are so ill and why they have had such a serious adverse reaction to either Gardasil or Cervarix. The two sides need to get together, sit down and say genuinely, openly and honestly, "These children need help—let's look at this seriously." We need to try to find a way forward, come to some solution to get these girls healed and discuss the matter in an open debate.

Chic Brodie: When I had the privilege of being a member of this committee, we dealt more widely with the issue of mesh implants. After what Freda Birrell has said, it might behove the Health and Sport Committee to encourage the Cabinet Secretary for Health and Wellbeing to embrace the notion that we in Scotland can lead in this discussion and facilitate such a gathering of experts.

Angus MacDonald: Good morning, Mrs Birrell. The committee quite recently considered a petition from Jamie Rae on behalf of the Throat Cancer Foundation that called on the Scottish Government to extend the HPV immunisation programme to include boys in Scotland. Your petition deals specifically with girls, but are you aware of specific research on adverse outcomes in countries where boys have been routinely included in an HPV immunisation programme?

Freda Birrell: In Australia and America, boys are included on the programme. I am not quite sure, but there is a possibility of it happening in New Zealand, and I am aware that the proposal has been discussed here in Scotland as well as down south. Boys, too, have become sick or have died following HPV vaccination. I cannot say whether the vaccination caused their death, but they died suddenly shortly afterwards. Boys are being vaccinated overseas and it is causing

problems for them just as it is for girls. However, there are not as many boys getting vaccinated overseas as there are girls.

Angus MacDonald: But there is evidence.

Freda Birrell: Yes. I know of one particular family in America whose twin son and daughter were vaccinated at the same time. Both of them were taken seriously ill and developed seizures. I know that family personally and I could talk about what happened if you wished, but there are other families where boys have been harmed.

Angus MacDonald: Thank you.

Jackson Carlaw: Good morning. Mrs Birrell and I have met on a number of occasions over the years, and I applaud her for the focus that she has brought to this issue.

It is fair to say that, over that period, you have through your own perseverance had a very considerable opportunity to meet politicians and ministers in the UK Department of Health, in Scotland and, indeed, internationally. You have been very persistent in the case that you have made, and it is not one that has not been brought to the attention of politicians along that path. Ultimately, however, ministers have responded that they do not take political decisions on these issues; instead, their decisions are based on the recommendations of the chief medical officer and the scientists who advise the Government on the value and merits of the various vaccinations programmes that are employed.

Cervical cancer has been one of the most common killers of young women under the age of 35 in the UK. According to the briefing that we have received, mortality rates have declined some 44 per cent, coincident with the vaccine having been introduced, which is a very considerable reduction. *[Interruption.]* Well, from the figures that I have, it looks as if there has been a significant reduction in the number of women dying of cervical cancer, and it seems to coincide with the period that the vaccine has been there. I imagine that that is what is informing the advice that Government ministers are considering.

11:15

You ask that a round-table discussion be convened between those who are knowingly opposed to the vaccine and those who are knowingly for it, whose debate, I imagine, is already informing the decision that ministers will ultimately take. I want to understand the purpose of the round-table discussion that you would like to see convened. What do you imagine it would contribute to ministers' understanding that has not already—given the considerable representations that have been made and the concerns that have

been expressed—been factored into the thinking that has led them to continue to recommend that the vaccine be offered?

Freda Birrell: In February 2014, Japan held a round-table discussion over two-and-a-half days. There was a symposium to begin with and then scientists and doctors from both sides met in the Japanese Parliament and had an open, honest debate on the subject. Our Dr Lee, who I know has sent in representations on my behalf, was there. At that time, Japan was seeing what was happening to young Japanese girls as psychosomatic. That word was used.

Dr Lee, who has been a pathologist for more than 50 years, had carried out an analysis of the post-mortem results for a young New Zealand girl who died six months after she was last vaccinated, and what he discovered in her blood and spleen tissues was the HPV DNA. He said, "You are all saying that this is psychosomatic. Will all of you who regard these results as being psychosomatic put up your hands?" Not one hand could go up.

In Japan, the politicians who were for the vaccine and those who were very concerned about it discussed it at length, and they put the young Japanese girls first. Scientific papers have come out on what they believe to be a neurological condition that has come from the vaccine, and they have set up the 21-year study. That is their way of trying to find out the truth. That is what came from Tokyo.

In France the following May, there was a similar open discussion, and the people there concentrated a lot on aluminium. There is a difference between aluminium being eaten, which can happen through the use of pots and through the environment, and aluminium being injected into the body. Professor Chris Exley, who has also given me support, is the top expert on aluminium in the United Kingdom. In France, they discussed having vaccines that contain no aluminium.

Something has to happen. We now have an Irish politician who is very concerned. He has met Irish families and heard their stories, and he has spoken out and said that something has to be done. The families want to meet the Irish health minister—that is their request.

Jackson Carlaw: Sorry, but may I interrupt? I think that I get the drift. Presumably, however, the fact that those discussions have taken place in those other legislatures will be part of the review that the Scottish Government will undertake in relation to the recommendations to ministers.

It seems to me that you would hope that the outcome of a round-table discussion would be that a compelling argument would arise from it for a change of policy in Scotland. If such a round-table discussion took place and the outcome was

contrary to that, would you be content with that decision?

Freda Birrell: I would not be happy if there was no progress. The reason why I say that is that somebody has to realise that young girls worldwide—in Scotland as well—are ill, and they became ill following the vaccine. Prior to vaccination, their medical records were perfect, or almost perfect. They were normal young girls with no serious medical issues, and certainly no psychological issues. That does not come in straight away; there is a progression to it. I would be disappointed if nobody was asking, “What has happened to these girls?” or “What has happened to the boys overseas who are becoming sick?”

If I may quote,

“Professor Yehuda Schoenfeld, director of the Zabłudowicz Centre for autoimmune diseases and international specialist on immunity, pointed out that certain individuals have a genetic predisposition to much greater and more serious reaction to immune system stimulation in the form of aluminium salt-containing vaccines.”

He also informed the meeting that he was speaking to that we already have

“genetic ‘tests’ which can determine, before any vaccine is administered, whether an individual’s genetic makeup is such that he may be susceptible in the long term to a potentially very serious auto-immune reaction.”

Jackson Carlaw: I understand the perseverance with which you have approached the issue, Ms Birrell. You are convinced, from the body of evidence to which you have been exposed or which you have been involved in unearthing, that the vaccine is unsafe and that there should be a change of policy in Scotland as to its application. Essentially, that is what you want. You see a round-table discussion as a means to that end, but that is what you want to get to. Is that correct?

Freda Birrell: Yes.

Jackson Carlaw: So the issue at hand is really the Scottish Government’s attitude to the vaccine.

David Birrell: The real issue is to get these girls properly treated.

Freda Birrell: Yes—I have said that. As David says, my main issue is to get these girls properly treated. One of the things that I and many of my colleagues have discovered is that girls who are very active and are into sports, dance and so on seem to be the ones who get hit very hard. I am not saying that that is the case 100 per cent, but it is true of a good 90 per cent, and the same with boys.

Jackson Carlaw: As I recall, you had the father of one of these girls present in the Parliament at a cross-party round-table discussion that took place.

Freda Birrell: That is correct.

Jackson Carlaw: So that is the secondary thing. Your concern is the attitude to the vaccine and also the appropriate treatment of those people who have been adversely affected by it.

Freda Birrell: It is, and it is to ask why this is happening. It may not be happening to all, but why is this happening to a good portion of the young people in this country? Unfortunately, the medical professionals do not seem to recognise what is happening, what the symptoms are or what is being developed, and that is when they go down the road of saying that it is a psychological problem.

Many of the young people are eventually diagnosed with medical conditions such as postural orthostatic tachycardia syndrome. The EMA is looking at that. These young girls may originally be diagnosed with chronic fatigue syndrome and then, because of their mother’s perseverance, they will carry on down the road until they find out about POTS. They go and get a tilt table test and they get an official diagnosis.

The doctor might say to the young person and the family, “It’s all in your daughter’s head.” Once they have used that expression, the damage has been done to that young person. She believes that her doctor knows more than she does, so is the doctor right? They then find out that she does have a medical condition.

May I pick up on one little point? I might have picked this up incorrectly, but I think that you commented that the vaccine has prevented a number of cases of cervical cancer since its introduction.

Jackson Carlaw: No. I said that, coincident with the time since the vaccine was introduced, there has been a fall in the number of people who have cervical cancer. I was not necessarily attributing that to the vaccine.

Freda Birrell: Right. Our young girls were vaccinated at 12, and in Scotland papillomavirus screening is done from the age of 20, so I do not think that many of these young girls will have gone to be screened to see whether the vaccine has prevented a problem. In America, which started earlier than us in 2006, Gardasil-vaccinated girls are now displaying HPV infection or cervical dysplasia or cervical cancer. That comes through the American vaccine adverse event reporting system, which is similar to our Medicines and Healthcare products Regulatory Agency.

David Birrell: May I add some figures to the percentages that were mentioned, to make sense of the figures? According to Cancer Research UK, about three deaths per 100,000 are due to cervical cancer and there are about eight or nine cases of cervical cancer a year. In 1970, the rate of deaths due to cervical cancer was about eight

per 100,000, but that dropped before the programme started to just under three per 100,000.

If we are talking about 44 per cent of three, we are talking about one per 100,000, yet if we look at the data from the pharmaceuticals on the serious adverse events, they quote 2.5 per cent, or 2,500 serious adverse events per 100,000. Those are the figures that we are talking about. We know that the girls are there, but we are just starting to find them.

John Wilson: Good morning, Ms Birrell. Like Jackson Carlaw, I want to get to the point of the petition that you have submitted to us. You are asking the Scottish Government to convene a round-table discussion between those who are in favour of continuing with the vaccination and those who are opposed to it or have reservations about it. Will you clarify exactly what you are looking for? Are you looking for the proper support to be put in place for those who have suffered an adverse effect from the vaccination or for a moratorium or a ban on the HPV vaccine programme?

Freda Birrell: I have never asked, to the best of my knowledge, for a ban on the HPV vaccines. I know that that would be a huge thing. I am asking, if possible, for a moratorium so that a proper investigation can take place to determine why certain young people are having serious adverse reactions that are lasting for many years. We are not talking about something that is there for a month or six weeks and then goes away. That is the opposite of what the MHRA says, which is usually that the side effects do not last long but go away in a matter of weeks. That is not the case.

I know every single one of the families in the UK association. I have spoken and written to them, and we have been on the telephone or Skype or whatever, so I know their background. I know exactly what is going on and what has happened to them. The one thing that I always say to them, because MPs are not the first place that they would naturally go to, is, "Please go and discuss what's happening in your house with your member of Parliament, because that's the only way to raise awareness."

11:30

Somebody somewhere has to say, "This is not right." Somebody has to ask why all these young people are becoming sick and point out that the thing that links them together is the HPV vaccine. Somebody has to ask why this is happening to these young people. They cannot be ignored and swept under the carpet. I have heard many times that it is just a coincidence. Well, that word means "by chance" but, when we have thousands of cases around the world, that is not by chance.

There is something unusual and something not good happening, which is why I submitted the petition. I have worked on the issue since 2008, but I felt that this is the time to raise the petition, as Denmark is looking seriously at the issue and is putting money into investigating it and having an independent study.

I urge the committee to make contact with the Danish politician—I have her details—and the Irish senator who I have mentioned. I urge you to speak with others who are at your level and on your wavelength and ask them what they think. I urge you to find out the facts and information from others, and not just from me, about what is happening in Ireland, Denmark, Colombia and many other countries. I believe that the vaccine has harmed these girls, and boys overseas. I have been involved for too long now not to realise that that is what is happening. Something is not right and, I hope, somebody has to recognise that.

John Wilson: Thank you for your response. You mentioned the MHRA, and my colleague Mr Brodie raised the issue of mesh implants. The committee certainly has experience of dealing with the MHRA decision-making process in allowing things to go forward.

Are you aware of any research that has been carried out by the chief medical officer or any Government department regarding the effects of the vaccine on the females who receive it? From what I am picking up from you, we know that some adverse effects have occurred but, apart from the reporting mechanisms that are in place at present, are you aware of any follow-up research being carried out to determine the long-term impact? You said that we do not know how long term the impact may be on females who have received the vaccination. Are you aware of any follow-through research being done in the UK?

Freda Birrell: Dr Lee discovered the contamination in the Gardasil vaccine, and work was done by Dr Lucija Tomljenovic from the University of British Columbia in Canada. She analysed brain samples of three young girls who died following HPV vaccination with Gardasil and discovered that the antigen 16, which is part of Gardasil, had crossed the blood-brain barrier. There is scientific evidence of that. I believe that it was sent to the Joint Committee on Vaccination and Immunisation, the MHRA and the Government departments down south, but they all just dismissed it. We asked for specific scientific articles and evidence from the pharmaceutical company Merck, the Department of Health or anyone who could show that what we were saying on, for example, the contamination in the Gardasil vaccine, was incorrect.

To begin with, when the information came out, the pharmaceuticals and the Department of Health

always said that there was no virus in the vaccine but, when we discovered that there was contamination, they accepted that—they did not deny it. Then we asked them for the evidence that they had to show that it will not harm any of the girls. We were talking about a serious contamination in the Gardasil vaccine, and GlaxoSmithKline has now had to say that there is the possibility of insect residue in the Cervarix vaccine. We have asked for the evidence that proves that that will not harm any of the girls and we have never got it. We never ever get any science. We provide science all the time from respected scientists and professionals, but we never get any science back.

Hanzala Malik: You clearly have a strong and passionate view on the issue. I am surprised about the NHS's position on the issue. I would have thought that chief executives in the NHS are looking to save money and that, if there was any danger or if any vaccination was harmful, they would be keen to take it off the list rather than keep it on that list. Perhaps we could ask the chief executives in the various regions in Scotland to advise us on what action, if any, they have taken to look into the matter. That would help us to determine why they are continuing to use the vaccination given the evidence that has been provided. We should also ask whether they have any evidence to prove that in fact the vaccination is safe. Unless we get professionals giving us advice, it will be difficult for us as laypeople to come to a decision.

That is important because, although you have collected evidence internationally, we have professionals in the UK who could look into the matter for us. It might be quicker for them to come back to us with the relevant evidence and, of course, it would be strongly backed by professionals. It would be helpful to have that evidence before we go into a round-table discussion. Before we take the issue any further, it is important to get the NHS to clarify its position on the evidence that you have collated and any evidence that it has that perhaps counterbalances that.

Chic Brodie: As usual, Mr Wilson asks a very pertinent question on the analysis. I think that Freda Birrell has made it clear that what is being sought is not a moratorium on the drugs. We can write to the experts all day long and, at the end of the day, they may or may not have a view; certainly, the drug companies that are involved will have a view. The issue is that one death or one serious illness is one too many. We should look at the process of prescribing through which girls and boys who apparently have had no major illness or who have nothing wrong with them are then injected. We need to know what check takes place before that happens and what the medical

implications are. Therefore, we need to create a forum by which we can at least have a meaningful look at the processes, the prescriptive method of inoculation injection and indeed the consequences. Drawing on international information is essential. As I say, one death or one serious illness is one too many.

David Torrance (Kirkcaldy) (SNP): The European Medicines Agency is carrying out a review of the HPV vaccine, which started in July this year and will report back to the European Commission. The agency's decisions will be legally binding on all European member states. Is it not better to wait for the EMA's findings on the safety of the vaccine?

Freda Birrell: A good proportion of the members of the committee that is advising the EMA are very pro-vaccine—it is not an independent group. One of them is Professor Pollard, who is connected with the Joint Committee on Vaccination and Immunisation. Our association has been getting families to complete questionnaires, and we have been sending that information to the EMA, but what is disturbing—I spoke to my MEP about this because he is on the European Parliament's health committee—is that, if the review is open, honest and genuine, we should not be hearing from the EMA or from the Department of Health at Westminster that the vaccine is safe and effective. It was Denmark that originally brought the issue to the attention of the EMA. If the EMA is looking at individual illnesses that are affecting girls, it should be taking it from the base and saying zero. It should look at the issue objectively and consider what it gets from Spain, Denmark and other countries in Europe, including the United Kingdom, and then assess whether there are serious side effects following vaccination.

However, that is not what we are hearing—we are hearing the opposite. Sadly, we are hearing from the minister at Westminster that the vaccine is safe and effective and that they do not see that there will be any problem. We should not have to listen to that when we are genuinely trying to help the EMA to come to a resolution. David Torrance is right that, whatever the EMA comes up with, that will be it—it will be law. However, it is not fair on those who are trying their best to help the EMA when they hear such comments. That is wrong and it should be stopped. The people involved should say, "We're going to do this properly and professionally and, if there's something wrong, let's look at it." They should not say, "This vaccine is okay."

There possibly will not be any serious issues with the two health conditions that are being investigated, but more than two need to be investigated. There are many auto-immune

disorders that young girls suddenly develop and other health conditions. That is my greatest worry. David Torrance is correct that the EMA's answer will be definitive, but is it right for it to express an opposite view and not to start from the status quo and look at the issue objectively and honestly? I am not sure that it is doing that, although I would like to think that it is.

The Convener: The committee will now discuss what we do with the petition.

I have to be honest and say that I am genuinely concerned about whether there is any merit in doing what the petition asks for. It is very specific in asking for a round-table discussion, but I am puzzled as to what that would achieve. The petitioner has raised a lot of very important issues and I am sure that they are being discussed in the scientific and medical establishments, but I do not know how they would be resolved by a round-table discussion.

I have spoken to clinicians and experts in the field of cancer and the majority of them argue strongly that screening for breast cancer, prostate cancer or bowel cancer is effective and that there is merit and value in that but, equally, I have spoken to clinicians who do not believe that that makes an impact on the treatment of the conditions. If we got people from both sides of that argument round a table, we could pretty much establish before we went in what the outcome would be: they would each come out saying, "We think it's good," or, "We think it's bad."

I am not sure how we can take forward the petition on the basis that all that we are asking for is a round-table discussion, because I do not know that that would achieve anything. At the same time, I am really concerned by the evidence that you have produced about the impact on girls and women and the fact that there is not a consensus on whether there is a causal link with certain medical conditions. Those things have to be investigated. However, that is not what the petition asks for, so I am in a bind as to what we do with it.

Do members have any considerations on how we can take this forward?

Jackson Carlaw: We should certainly ask the Scottish Government about its attitude to the petition. However, given that the issues raised by the petition have come before ministers and that they will have responded previously, it might be interesting to explore some of the evidentiary issues that were raised in any on-going review that the Scottish—[*Interruption.*]

The Convener: The fire alarm that we are hearing is not a test.

Jackson Carlaw: It says that we have to stay where we are. Do I carry on trying to speak?

David Torrance: No, just wait, for the sake of the recording.

Jackson Carlaw: It has stopped. We have to stay where we are, so I will take that as licence to finish my point.

The Convener: I think so. We should stay here until we hear otherwise.

Jackson Carlaw: I reassure people in the gallery that this happens from time to time, so they should not panic.

On the issue of whether there has been any on-going review by the Scottish Government—[*Interruption.*]

The Convener: I will suspend for a couple of minutes until the notifications stop.

11:46

Meeting suspended.

11:50

On resuming—

The Convener: I am assured that we can go ahead without further interruption, unless the security staff need to evacuate us. We should not be interrupted by an announcement, though. We go back to you, Jackson.

Jackson Carlaw: Thank you, convener. I am clearly a candidate for North Korean brainwashing. All I can think at the moment is, "Attention, please. Attention, please. A fire has been reported in the building. Please stay where you are."

Given that these issues have been raised with the Scottish Government before, it would be a bit pointless simply to write to the Government asking it about its attitude to the issue. We know that it will say that it acts on the advice of the chief medical officer and the best scientific evidence. It would be better, in exploring the issues with the Scottish Government, to try to tease out whether any review is being conducted in Scotland into the implications and experience since the vaccine was introduced. We could also ask whether the Scottish Government has received any briefing on the more recent experience that we were advised of in Ireland, Denmark, Japan and France.

Finally, we could ask to what extent the Government acts on the advice of the MHRA. As Mr Wilson said, we have had cause to be underwhelmed by that advice on a previous occasion. Indeed, the cabinet secretary herself, in the evidence session that we had when that was raised, expressed concerns about the weight that had been placed on that particular study. Until we examined the study in some detail and discovered

that it was perhaps not all that it had purported to be, it had seemed to carry the day.

Those things might bring out more of the issue. I suspect, a bit like you, convener, that enthusiasm for the round-table discussion will be lacking unless a clear outcome is being sought as a consequence. *[Interruption.]*

John Wilson: It is not quite North Korean brainwashing but, in Jackson Carlaw's case, it is something that may have to be investigated.

The Scottish Parliament information centre briefing refers to the Countess of Mar's question in the House of Lords and the response from Lord Prior of Brampton. The response contains some details of the reporting mechanism that has been taking place, which claims to be UK-wide. If we are writing to the Scottish Government, I suggest that we try to get some Scottish figures for the reporting of any adverse effects. Questions need to be raised about the figures that we have in front of us and it would be useful to get some Scottish figures.

It would also be useful to find out—given our experience in the mesh implant debate and petition that we have had before us—what advice is currently given to general practitioners about any mechanism for the reporting of adverse effects from the vaccine. One of the things that were highlighted with mesh implants is that many GPs did not know how to report or who to report to about adverse effects of the operations and procedures that were carried out.

It would also be useful to find out from the Scottish Government whether any guidance is currently provided to GPs to help them to identify what may be an adverse event arising from the HPV vaccine, because that would indicate whether there is underreporting of adverse events. It would be useful to try to get as true a figure as possible of the number of adverse events as a result of the HPV vaccine.

The Convener: That all sounds very sensible. There are a few areas that we want to investigate.

Freda Birrell: Mr Wilson's point is 100 per cent correct. I always say to the families who we find now, "Have you reported through the yellow card system?" That is the system that goes direct to the MHRA, which then divides it into Ireland, Scotland, England and Wales. Very few have reported their adverse reactions to the MHRA. Not enough education is being given at the point of contact; the school nurse may not be giving the girls any information or saying, "If you feel unwell, make sure mum gets in touch." They expect them to have seen the information that is sent out at the time of consent, which is very little. That information says that the side effects are mild. What the child or the mother does not get at that

time is the patient information leaflet, which describes more serious adverse reactions, such as Guillain-Barré syndrome. That is identified on the Gardasil.

The convener mentioned the round-table discussion and someone mentioned the science. I would like to have the scientists at the round-table discussion because the committee can ask them to prove that what we are saying is not correct, for example the contamination, or the possibility that the Cervarix vaccine contains insect DNA. Where is the science from GlaxoSmithKline that shows that there is no harm to the child? DNA, no matter how miniscule, is going into the body. We asked for a round-table discussion so that such questions could be asked openly and the witnesses could be asked for that science. They will ignore us, but they would not ignore you.

On the issue of the yellow card, you are right—there is a huge rate of underreporting.

The Convener: As you have heard, we have agreed that we will write to the Scottish Government to ask for its views on holding such a round-table discussion.

Freda Birrell: Thank you.

The Convener: Once we have received responses from the Government and others who we have agreed to contact, we will be in touch with you and take the petition forward from that point. Thank you for giving us evidence this morning.

Freda Birrell: Thank you.

Chic Brodie: Thank you for allowing me to participate, convener.

11:57

Meeting suspended.

11:59

On resuming—

Adult Cerebral Palsy Services (PE1577)

The Convener: Our final new petition is PE1577, by Rachael Wallace, on adult cerebral palsy services. Members have notes from the clerk on the petition and the SPICe briefing. I welcome to the meeting Murdo Fraser MSP, who has indicated that he has an interest in the petition.

It remains for me to welcome the petitioner, Rachael Wallace, to the meeting. She is accompanied by Stephanie Fraser from Bobath Scotland. I invite Ms Wallace to make some introductory comments, after which I will open it up to discussion.

Rachael Wallace: I have cerebral palsy. As you can see, I am a full-time wheelchair user, and I am on numerous pain and tone-reducing medications for my condition. Cerebral palsy is recognised in childhood and treated by a multidisciplinary team that is there to minimise any suffering and treat any medical problems that arise. The moment I became an adult, all that support stopped, but I did not stop having cerebral palsy. There is no co-ordinated clinical pathway such as there is with other neurological conditions. Cerebral palsy is not treated as a lifelong condition by the NHS. Medical professionals treat it as a static condition, but my body would disagree.

All the benefits of childhood input are wasted. There is not a professional who specialises in cerebral palsy whom I can go to. Instead, I rely on the good will of health professionals who try, on top of their own workload, to help me—that is if I can find anyone. I pay a paediatric physiotherapist to help me with my stretching exercise, as there is no specialist adult physiotherapist.

I developed severe pain in my back and leg nine months ago, and my first appointment with the local NHS physio is next week. In the past when I have seen a physio about an injury, they have given me exercises that are designed for non-disabled people, which they have tried to adapt. It is not possible to separate my cerebral palsy from a localised injury, but unless the physio has treated cerebral palsy, they do not understand that and can do more harm than good.

I am fortunate that I can voice my pain and am able to navigate a piecemeal system, but there are many who cannot. That is why I have raised the petition. Cerebral palsy is not a local health board issue; it is a national issue. I cannot even call the present situation a postcode lottery, as there are no NHS services across Scotland. There is a need for a national clinical pathway and trained adult physiotherapists and other allied health professionals in cerebral palsy to provide on-going therapy services.

The Convener: Thank you very much.

Murdo, do you want to make some comments at the outset?

Murdo Fraser (Mid Scotland and Fife) (Con): Thank you, convener. Thank you for the opportunity to speak to the committee.

I have been trying to assist my constituent Rachael Wallace on the issue for several months at least, since she first came to me. Rachael makes her own case extremely well and very eloquently, if I may say so. The key point that she made in her presentation is that, although there is provision in the NHS for children with cerebral palsy, unfortunately when children get to the age of 18 and become adults, that provision all but

disappears. The point that Rachael's petition makes is that we need a clear clinical pathway to be established for adults with the condition.

We have been in correspondence with the Scottish Government on the matter. We have had several unsuccessful attempts to have a meeting with the Minister for Sport, Health Improvement and Mental Health through correspondence. We have raised the issue in correspondence and have had what I would characterise as brush-off responses in the usual civil service language that have not really got to the nub of the issue.

I encouraged Rachael to take the issue to the Public Petitions Committee to try to get the committee's backing to take the issue to the Scottish Government and perhaps get it taken more seriously than it has been to date.

The Convener: Thanks very much, Murdo.

I will kick off by asking for clarification. The documentation that we have in support of the petition says that 15,000 adults have cerebral palsy. Does that cover the whole spectrum of cerebral palsy?

Stephanie Fraser (Bobath Scotland): Yes, it does. It is a best guess. There is no formal record in Scotland or in the United Kingdom of how many people are living with cerebral palsy, but we know that about one in 500 births will result in a diagnosis. That covers the whole spectrum.

The Convener: I suspected that that might be the case, which is why I thought that I would put on record the fact that I have a daughter who has cerebral palsy. She is well known to my colleagues on the committee—she is one of our colleagues. Because of that, I understand exactly what the petition is directed at. My daughter received support all the way through school. Sometimes we had to fight hard to get it, but she received physiotherapy support and NHS support. That stopped when she became an adult, so I understand exactly where the petition is coming from. If she now requires any support or assistance because of the condition that she has, she has to start from scratch as an adult. She has to argue for her situation to be addressed as an adult, rather than as someone with cerebral palsy. Therefore, I completely understand why we have this petition in front of us.

I open up the discussion to colleagues who might want to ask additional questions.

Jackson Carlaw: Is the approach of the Department of Health in England different or is the deficiency that the petition identifies one that is just as much of a deficiency across the whole of the United Kingdom? I do not flag that up as a tribute to it, but are there different approaches or are we following the same path?

Stephanie Fraser: No—sadly, there is not a difference in England. Recently, the Westminster Government conducted an inquiry into children's services. Bobath Scotland made a representation in which we asked, "Why are you stopping with children's services?" Sadly, I am afraid that there are not any services that we can look at.

Rachael Wallace: I run a website called "Living Positively with Cerebral Palsy", which is a support group for adults with cerebral palsy. I have many members throughout the UK, and I am afraid that the responses that they give are the same.

Jackson Carlaw: Okay.

Bobath Scotland has been very effective in the job that it does. It is well known in the Parliament and I have visited the premises. It is a singularly impressive organisation. I understand that Bobath's focus is children, but I presume that it will have raised with ministers the issues to do with cerebral palsy in adults. Murdo Fraser referred to the civil service speak of the responses that he has received. Beyond that, do you have a sense of why nothing more appears to have been forthcoming by way of adult care?

Stephanie Fraser: Bobath Scotland started an adult service in 2012 and we got private funding for a two-year project, which was evaluated by the University of Glasgow. Until then, we were not really in a position to understand what the solution could be. It is all very well identifying that there is a problem, but we wanted to be able to say, "Here's a possible solution."

We are not the only game in town. Bobath Scotland is a very small organisation. There are representatives here today from Capability Scotland, for example, and there are other providers, including private providers such as Neuro Physio Scotland and so on. Over the past three years, we have all been able to come together to work to identify the problems and to approach Government.

You might be aware that a review of neurological services that the minister asked for is going on. The problem for cerebral palsy is that it does not fit very easily under the neurological umbrella. It is not the same as epilepsy, Parkinson's, motor neurone disease or any of those other conditions. One of the things that we have to fight for is understanding and acceptance that cerebral palsy is not a static condition. Traditionally, cerebral palsy has been seen as a static childhood condition, so all services are concentrated in paediatric services. That understanding is the key to unlocking a pathway for adults.

Rachael Wallace: I have had problems over the past few months whereby I am losing mobility because I do not have the same physio input as I

did when I was a child. I go to my doctor and he says, "I'm not sure what to do with you. I can't put you into a hospital because you're not ill, and I'm not even sure whether you would get the rehabilitation support you need." The condition is treated in the community, but there is no specialist physio to whom I can go or other specialist support. Someone with multiple sclerosis will have an MS consultant and an MS nurse who will give advice on the condition.

The provision is very piecemeal. I had to go through paediatric services and ask my neural paediatrician who was the best neurologist to go to. I was referred to an acquired brain injury specialist, who is very good but cerebral palsy is not her main workload. She will advise on medication and stuff like that, but her remit is elsewhere.

Stephanie Fraser: To pick up on Jackson Carlaw's point, because CP does not fit, it has become challenging, let us say, for ministers to understand where to put us. Rachael mentioned specialist nursing. A review of neurological services is going on; as you are probably aware, there is also a review of specialist nurse funding. The minister, Jamie Hepburn, suggested that we might like to be involved in that in some way.

I will quote from some correspondence that we received from the chief nursing officer, which said that the review had been put towards the health boards and that Bobath Scotland or anybody who was interested in adult services for CP should liaise with the individual health boards, on whom it was incumbent to liaise with third sector organisations. I wrote back to say that I was not entirely clear where we would liaise. If we look at services at an individual health board level, there is no clear pathway for liaison. A child with cerebral palsy would go to the paediatricians and the consultant paediatricians. My question was, "As an adult talking about CP services, where would I go?"

The letter that I got back said:

"The Scottish Government's aim is to ensure that people living with conditions such as cerebral palsy have access to the best possible care and support. Being told you have a condition for which there may be no cure can be devastating and individuals respond to this in different ways."

I am afraid that, to me, that sentence clearly demonstrates a lack of understanding of the condition of cerebral palsy. People are born with it. To receive a letter that is cut and pasted with that kind of sentence in it from the chief nursing officer directorate illustrates the problem that we have.

Jackson Carlaw: I am aware that we have a growing community of young men with Duchenne's disease who are surviving well into

adulthood. In some ways, their problem seems similar, in that they have previously had respite in children's hospices—that is where any of the experience lay, because it was usually children who experienced the condition—but they are now in their 30s and 40s, and some of them still go to children's hospices for respite because the wider health service has no broader experience of a larger community surviving into adulthood.

Is there a parallel there, in that we now have a community who can expect a much longer lifespan with cerebral palsy than might once have been the case, and the health service has not necessarily understood that and addressed the issue of adult care specifically?

Stephanie Fraser: People with cerebral palsy are expected to live a normal lifespan, in most cases.

Jackson Carlaw: Has that always been the case?

12:15

Stephanie Fraser: No, it has improved. However, what is more significant is the move from providing residential care for people with complex needs to providing more personalised care. That has helped with the increased lifespan. It is a great thing.

We are up against a situation in which people such as Rachael are told to put up with things because they are part of CP. For example, somebody who is having difficulty walking might go to social services and say, "I have CP. I have difficulty walking. What can you do to help me?" and, instead of social services realising that the person might be helped to walk again, they might give them a wheelchair. That is where we are.

Rachael Wallace: I was not expected to still be walking by the time I was in my teens. However, I was walking until my early 20s, and then I had a hip replacement. I want to retain my mobility. My mobility is really important to me. If I am wheelchair bound, my health will deteriorate, I will get a chest infection or something quite serious and it will develop into an acute problem.

Along the spectrum of cerebral palsy there is something called secondary ageing. University of Glasgow research on secondary ageing has shown that mobility is affected and there are more muscle contractures that have to be sorted out by surgery, if they are acute. Usually, that is the route that is taken by orthopaedic surgeons and so on because by the time that someone sees the orthopaedic surgeon, they are past the point of rehabilitation and they need that surgery. Sometimes, that is not the right decision, because the situation could have been sorted out earlier

with physiotherapy or input from neurological services.

The Convener: Do our colleagues want to make a contribution?

Hanzala Malik: I will wait until your summing-up comments.

The Convener: The fact that we do not have a lot of questions is not indicative of a lack of interest. The petition is so cut and dried that it is obvious what we need to do with it. I am happy to take suggestions from the committee, but I think that the course of action that we need to pursue is pretty clear.

Hanzala Malik: Jackson Carlaw and Murdo Fraser are quite right: Rachael Wallace has given us a clear picture of exactly where she stands just now. I do not want to use the word "ludicrous", but I am quite surprised that someone is given treatment until they reach adulthood and then it is stopped, even though the symptoms remain. Rachael is quite right in saying that her symptoms are going to get worse, not better. Therefore, I am with the petitioner all the way in saying that we need to urge the Scottish Government to look at this issue and ensure that we find the resources to take the proposals on board and deal with the condition from the cradle to the grave. It is quite right that we do that. I do not think we have any other options.

Jackson Carlaw: We have been advised that the Scottish Parliament has not specifically addressed this issue in the past and that no other committee has addressed it, although I know that there have been members' business debates on the matter—one led, of course, by your daughter, convener. Therefore, there is an opportunity for this committee to give some focus to the issue and to take matters forward. In the first instance, we can write to ministers, but I can see the value in having an evidence-taking session following on from that.

The Convener: Yes, I think so. For the purpose of getting as much evidence as possible, we should contact Capability Scotland and Bobath so that they can tell us exactly what we need to hear.

I am extremely curious about the response that you had from the chief nursing officer, Ms Fraser. Could you liaise with our clerks and provide that response? I would like to question where that response came from, because it sits very ill with me.

Stephanie Fraser: The minister has been made aware that that letter was not particularly acceptable.

The Convener: The committee would like to make the Government aware of that as well. If you

could co-ordinate that with our clerks, I think that it would be useful to pursue that specific point.

John Wilson: The submission states that a meeting had been requested with Jamie Hepburn, the Minister for Sport, Health Improvement and Mental Health, but that no meeting has been held yet. Could either Mr Fraser or Ms Wallace give an indication of when that request was made? It is important that we ask the minister why he has failed to date to arrange a meeting to discuss the issues that are raised in the petition.

Rachael Wallace: Murdo Fraser will be able to give you the date. However—Stephanie, when was the Bobath conference?

Stephanie Fraser: We had a conference on world cerebral palsy day, which was 7 October.

Rachael Wallace: I approached the minister at that conference. He was one of the keynote speakers. He took my details and said, “I will get back to you.” I have not heard anything since. I told the minister that I would not be giving up on this issue and that I really want to work with the Scottish Government to put something in place. However, that was a very brief discussion and I do not think that he was expecting to be cornered, as he was by me.

John Wilson: As the convener has tried to assure you, I do not think that the committee will be giving up on this petition either. As the convener indicated, it is an issue that is very dear to his heart and, given what we have heard this morning, I think that the committee, to a person, will be keen to investigate this further and ensure that we get the services that individuals with cerebral palsy deserve and require.

There is an issue about people having to wait nine months for a physiotherapy appointment. If somebody who is in a wheelchair complains about a back injury, that should trigger a faster response. There is also the point about the need for a specialist physiotherapist who can tackle and deal with the issues concerned rather than, as you indicated, do more damage than good.

Murdo Fraser: I am happy to respond to Mr Wilson’s point about dates. On 15 December 2014, I wrote to the Scottish Government asking for a meeting between the Scottish Government and Rachael Wallace. I got a reply from Mr Hepburn, the Minister for Sport, Health Improvement and Mental Health, on 29 January. It did not make any direct reference to my request for a meeting but made some more general points. I wrote again on 6 February reiterating my specific request for a meeting. I received a reply dated—if I can decipher the minister’s handwriting—4 March 2015, which again did not specifically address the request for a meeting. I took that as a brush-off, on two occasions.

John Wilson: Convener, can we agree to write to the minister asking why he has not met Mr Fraser and Ms Wallace to discuss the issues that were raised in the initial correspondence with Mr Fraser? After waiting 10 months, Mr Fraser has received only what he described as a brush-off from the minister. If we put the weight of the committee behind that request, we might get the minister to see reason and have a meeting as soon as possible with Ms Wallace and Mr Fraser to discuss not only the issues that are raised in the petition but other issues relating to services for individuals who suffer from cerebral palsy.

Jackson Carlaw: We should take the most constructive approach possible and not make it sound like a savage admonition of the minister. We want to progress this petition. I am sure that that is Mr Wilson’s intention.

John Wilson: I find that a strange response from Mr Carlaw, given his previous interventions in this committee, but I take it on board.

The Convener: I thank the petitioners for giving evidence. We have given you a firm commitment on how supportive we are of the petition, and we will continue to take it forward as constructively and aggressively as we can.

I suspend the meeting for a couple of minutes while the witnesses leave.

12:25

Meeting suspended.

12:28

On resuming—

The Convener: Before we move to agenda item 2, the Deputy Convener has thought of another suggestion on PE1573, which was the first petition that we considered this morning. He would like to get the committee’s agreement on that point.

David Torrance: Thank you, convener. I apologise for not thinking of it earlier, but can we write to the YMCA and the Scout Association? They have hundreds of thousands of members across the UK and they have good policies and training in place for LGBT issues. Let us see what they are doing to be inclusive of the membership that they have.

The Convener: Does the committee agree to that?

Members indicated agreement.

Continued Petitions

12:28

A83 (Rest and Be Thankful) (PE1540)

The Convener: Our next item of business is consideration of five continued petitions. The first continued petition is PE1540 by Douglas Philand on a permanent solution for the A83. Members have a note by the clerk and a submission from Transport Scotland that sets out the response to the questions. We had asked for more information, including future mitigation works that are planned and more details on the economic impacts of road closures. Transport Scotland has indicated that it expects to write again to the committee in the new year.

David Torrance: Can we keep the petition open until we get that response in the new year from Transport Scotland?

Hanzala Malik: I agree with that, but a year is a long time, so we should also ask Transport Scotland when in the new year we can expect that response.

The Convener: Do we agree with those suggestions?

Members *indicated agreement.*

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

12:30

The Convener: The next petition is PE1545, by Ann Maxwell, on behalf of the Muir Maxwell Trust, on residential care provision for the severely learning disabled. The last time that we considered this petition, we agreed to seek further information on issues including improving data on people with profound and multiple learning disabilities and the adequacy of guidance issued to social workers on assessing need. The petitioner's submission notes the differences in service provided to people under 18 and those over 18 and she suggests that one option could be to expand the services provided for under-18s at Donaldson's College. Colleagues, do you have any views?

Kenny MacAskill: We should ask whether that option is realistic, given that it is a solution that has been raised. It may be impractical for a variety of reasons but it would be remiss of us not to at least venture down one possible route to see whether it is feasible.

The Convener: Yes. Do members agree?

John Wilson: If we write to the Scottish Government, I suggest that we refer it to the Muir Maxwell Trust submission. A couple of issues were raised in the submission on which I want to seek further guidance from the Scottish Government or a further indication of its views. Those issues relate to the independent care needs assessments being conducted by local authorities and whether the Scottish Government has considered an appeals process.

A number of individuals have raised concerns about care needs assessments being done by local authorities, the right of appeal against those decisions, and whether the local authorities are making the best judgments in relation to care needs assessments at a local level. The services that are being asked for in the petition are decided by local authorities, and local authorities then determine whether they will fund placements in establishments such as Donaldson's. It would be useful to find out whether the Scottish Government is considering a review or has reviewed the current procedures for care assessments.

The Convener: Members do not seem to be opposed to that idea, so we will take the petition forward on that basis.

Electric Shock and Vibration Collars (PE1555)

The Convener: Our next petition is PE1555, by Siobhan Garrahy, on electric shock and vibration collars for animals. The Scottish Government's response indicates that it intends to carry out a consultation on the regulation of the use of e-collars. I invite contributions.

David Torrance: I would be quite happy to close the petition, given that we are getting a guarantee from the Government that it will consult on the use of the collars.

The Convener: I am more minded to wait and see what the consultation arrives at. We could then decide whether the issues that the petition raises have been addressed.

John Wilson: I am of the same mind as the convener. I would like details from the Scottish Government about the consultation time period—when the Government expects to consult, when the consultation will be concluded and when any reports arising from that consultation will be produced. The Government says that it will consult, but that does not provide specific answers on a timetable. If we close the petition, the petitioner could resubmit the petition at a later date. However, I would rather get some details now from the Scottish Government about the consultation timescales and procedure.

The Convener: Yes. I am sure that everyone welcomes the consultation, but that is not the end of the matter.

Jackson Carlaw: I endorse all that. The petition called for a ban on the collars, not a consultation on their use. I would like to know more about the scale and breadth of the consultation before we decide what to do.

The Convener: We have a consensus. David?

David Torrance: I am happy to go along with the committee.

The Convener: We will keep the petition open on that basis and take it forward.

Hanzala Malik: Convener, I think that the committee hopes that you will write to the Scottish Government asking it when exactly the consultation will take place and how long it will run for.

Jackson Carlaw: And with whom it will consult.

The Convener: Yes. I think that that is what we have agreed to do. Thank you.

National Parks Strategy (PE1556)

The Convener: The next petition is PE1556, by John Mayhew, on behalf of the Scottish Campaign for National Parks and the Association for the Protection of Rural Scotland, on a national parks strategy for Scotland. The Government's response sets out its view on the petition and answers questions that we asked. Our questions covered assessment of future sustainability of existing national park authorities, governance models and the creation of a national park strategy group. Have colleagues had a chance to look at this?

Angus MacDonald: The letter from the minister is encouraging. There is clearly on-going dialogue between the Scottish ministers and the SCNP and the APRS, although the minister highlights the issue of cost as possibly being a temporary barrier, so it is not that this is unfinished business, as the SCNP report suggests.

However, as there seems to be a lack of consensus among the stakeholders on the petitioner's aims, I think that there needs to be a greater meeting of minds to ensure that the protection and enhancing of Scotland's wild landscapes is progressed. I suggest that we close the petition in the hope that the petitioner's good work will continue. I certainly encourage him to work with the stakeholders identified in the unfinished business report. The Government has clearly not closed the door on the issue either. There is more work to be done, but the door is still open.

The Convener: Thank you. Do members agree?

Members indicated agreement.

Animal Welfare (Rabbits) (PE1561)

The Convener: The final continued petition is PE1561, by Karen Gray, on behalf of Rabbits Require Rights Scotland, on pet rabbit welfare. The submissions from animal welfare groups concur on there being a general issue about rabbit welfare and the Scottish Government's response addresses each of the points that are identified in the petition. It also notes that the welfare of pet rabbits will be considered as part of its wider review of pet welfare legislation. Are colleagues happy with that or are we in the same position as with the previous petition—do we want to wait and see what the outcome of that review will be?

John Wilson: Once again, it is a question of the timescale. We need to know what the Government intends to do and how quickly it intends to do it. That will either indicate when the Government will introduce improved legislation or give us a clear steer on how the Government intends to move forward on animal welfare legislation.

Kenny MacAskill: To some extent, the situation is the same as it was for the previous petition. I welcome the Government's position in its response. The petitioner having raised the issue, the committee having written to the Government and indeed the other animal welfare agencies having indicated that there seems to be an issue, some clarity from the Government would be welcome as to timescale, whether the review will include this issue and whether the Government will engage, at least to some extent, with the petitioner.

Jackson Carlaw: As on the previous occasion, although people who are looking casually at our deliberations might wonder about the issue of rabbit or pet welfare—indeed, I see that there is a submission from a Best4Bunny.com website—when we took evidence, the detail of the issue underpinning the welfare of animals was—

The Convener: A very serious one.

Jackson Carlaw: —and very robustly made. Until we see the scope of that consultation, we should keep the issue alive.

The Convener: That seems to be agreed by everyone. I close the meeting at that point.

Meeting closed at 12:38.

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