HEALTH COMMITTEE

Tuesday 26 April 2005

Session 2

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HEALTH COMMITTEE
12th Meeting 2005, Session 2

CONVENER

*Roseanna Cunningham (Perth) (SNP)

DEPUTY CONVENER

*Janis Hughes (Glasgow Rutherglen) (Lab)

COMMITTEE MEMBERS

*Helen Eadie (Dunfermline East) (Lab)
*Kate Maclean (Dundee West) (Lab)
*Mr Duncan McNeil (Greenock and Inverclyde) (Lab)
*Mrs Nanette Milne (North East Scotland) (Con)
*Shona Robison (Dundee East) (SNP)
*Mike Rumbles (West Aberdeenshire and Kincardine) (LD)
*Dr Jean Turner (Strathkelvin and Bearsden) (Ind)

COMMITTEE SUBSTITUTES

Robert Brown (Glasgow) (LD)
Paul Martin (Glasgow Springburn) (Lab)
Mr Stewart Maxwell (West of Scotland) (SNP)
Mary Scanlon (Highlands and Islands) (Con)

*attended

THE FOLLOWING ALSO ATTENDED:

Rhona Brankin (Deputy Minister for Health and Community Care)
Alex Fergusson (Galloway and Upper Nithsdale) (Con)
Carolyn Leckie (Central Scotland) (SSP)
Mike Watson (Glasgow Cathcart) (Lab)

THE FOLLOWING GAVE EVIDENCE:

Dr Michael Cornbleet (Scottish Executive Health Department)
Dr Arthur Johnston (Scottish Executive Health Department)
Joe Logan (Scottish Executive Health Department)
Jean MacLellan (Scottish Executive Health Department)

CLERK TO THE COMMITTEE

Simon Watkins

SENIOR ASSISTANT CLERK

Tracey White

ASSISTANT CLERK

Roz Wheeler

LOCATION

Committee Room 6

Scottish Parliament

Health Committee

Tuesday 26 April 2005

[THE CONVENER *opened the meeting at 14:00*]

Item in Private

The Convener (Roseanna Cunningham): Under agenda item 1, the committee is asked to agree to take item 5, which is consideration of options for its forward work programme, in private. It is normal procedure for committees to discuss future work programmes in private. Does the committee agree to take item 5 in private?

Members *indicated agreement.*

Subordinate Legislation

National Health Service (Travelling Expenses and Remission of Charges) (Scotland) Amendment (No 2) Regulations 2005 (SSI 2005/179)

Miscellaneous Food Additives Amendment (Scotland) Regulations 2005 (SSI 2005/214)

Smoke Flavourings (Scotland) Regulations 2005 (SSI 2005/215)

14:01

The Convener: Under agenda item 2, there are three Scottish statutory instruments to be considered under the negative procedure: SSI 2005/179, SSI 2005/214 and SSI 2005/215. The Subordinate Legislation Committee, which considered SSI 2005/214 and SSI 2005/215 at its meeting this morning, has comments to make on the instruments but it has not formally reported to us. On that basis, I suggest that we consider those two instruments at our next scheduled meeting, on 10 May. Is that agreed?

Members *indicated agreement.*

The Convener: The Subordinate Legislation Committee previously considered and commented on SSI 2005/179. That committee's report has been circulated to members and no comments have been received. Is it agreed that the committee does not wish to make any recommendation on the instrument?

Members *indicated agreement.*

Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No 3) (Scotland) Order 2005 (SSI 2005/208)

The Convener: Under agenda item 3, we are asked to consider an instrument that is subject to the affirmative procedure—SSI 2005/208—on amnesic shellfish poisoning. I welcome to the committee Rhona Brankin, the Deputy Minister for Health and Community Care. The Subordinate Legislation Committee had no comment to make on the instrument. Does any member wish to seek clarification from the minister?

Mrs Nanette Milne (North East Scotland) (Con): I do not seek clarification, but I wish to say that I will take the same stance as before.

The Convener: Do you want to make the point?

Mrs Milne: Given that we are looking for end-product testing—which is, I understand, not too far off—I will maintain the stance that has been taken by the Conservative party previously and oppose the instrument.

The Convener: Minister, do you wish to say anything in response to that?

The Deputy Minister for Health and Community Care (Rhona Brankin): As the committee knows, we feel strongly that the orders on amnesic shellfish poisoning are necessary to protect public health in Scotland. We think that they should be seen as part of our continued efforts to protect public health and the consumer, but also to protect the good name of the Scottish shellfish industry.

The Convener: Does any member wish to debate the instrument?

Members: No.

Motion moved,

That the Health Committee recommends that the Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No.3) (Scotland) Order 2005 (SSI 2005/208) be approved.—*[Rhona Brankin.]*

The Convener: The question is, that motion S2M-2685, in the name of Rhona Brankin, be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

FOR

Eadie, Helen (Dunfermline East) (Lab)
Hughes, Janis (Glasgow Rutherglen) (Lab)
Maclean, Kate (Dundee West) (Lab)
McNeil, Mr Duncan (Greenock and Inverclyde) (Lab)
Rumbles, Mike (West Aberdeenshire and Kincardine) (LD)
Turner, Dr Jean (Strathkelvin and Bearsden) (Ind)

AGAINST

Milne, Mrs Nanette (North East Scotland) (Con)

ABSTENTIONS

Robison, Shona (Dundee East) (SNP)

The Convener: The result of the division is: For 6, Against 1, Abstentions 1.

Motion agreed to.

Petitions

Epilepsy Service Provision (PE247)

Myalgic Encephalomyelitis (PE398)

Autistic Spectrum Disorder (PE452)

Psychiatric Services (PE538)

Autism (Treatment) (PE577)

Heavy Metal Poisoning (PE474)

Aphasia (PE475)

14:05

The Convener: The minister is staying with us for item 3, which is consideration of petitions; we will hear evidence from her on a number of outstanding petitions. From the Scottish Executive Health Department, I welcome to the committee Joe Logan, of the public health division, and Dr Michael Cornbleet, the senior medical officer.

The petitions have been under consideration by the committee for a considerable time, and have been the subject of extended correspondence with a variety of ministers over the years. Today's session will focus on the outstanding questions and issues that have been raised with the committee in recent submissions from the petitioners. As agreed at the committee's meeting on 1 February, consideration of the petitions will be closed on the basis of today's session.

I welcome to the committee's proceedings Alex Fergusson MSP, who has a particular interest in one of the petitions.

The minister will give an overview of the petitions before we deal with them one by one.

Rhona Brankin: Do you want an overview of all the petitions now, or would you prefer me to provide an overview of each petition as we come to it?

The Convener: We can deal with the overview of all the petitions first, then we will ask questions on each one.

Rhona Brankin: I will start with epilepsy service provision. We have developed single shared assessment for all client groups in Scotland. We have funded the development of four epilepsy managed clinical networks: three between them cover Lothian NHS Board, Fife NHS Board, Borders NHS Board, Forth Valley NHS Board, Greater Glasgow NHS Board, Ayrshire and Arran NHS Board and Tayside NHS Board, and there is a national paediatric managed clinical network. We have guidelines from the Scottish intercollegiate guidelines network on adult and paediatric epilepsy. The work on managed clinical networks is on-going.

The centre for change and innovation is about to consult on neurology patient pathways as part of out-patient redesign; that will include two pathways on epilepsy. NHS Quality Improvement Scotland will begin work soon on a project to improve standards of care for people with all neurological conditions.

We have set up a short-life working group on chronic fatigue syndrome and myalgic encephalomyelitis. We asked NHS boards to advise us of progress on the planning of services for people with CFS and ME; in particular, we asked whether they had carried out needs assessments. If so, a copy of the conclusions was requested. We also asked whether it had been possible to identify any sources of expertise in their areas, what contact had been made with the voluntary sector, and what proposals the boards had for the future planning of CFS and ME services.

I believe that the boards have given that information to the committee. We have made the responses available. As part of the service change framework, we are setting up a working group to consider how best to manage all chronic conditions. We have just given grant funding to the voluntary organisation Action for ME to develop information for general practitioners. We will arrange for an assessment of need as soon as possible. We will also fund NHS Quality Improvement Scotland to produce a best practice statement on ME as part of its current work programme. We will ensure that the good practice clinical guidelines on CFS and ME, which are being developed by the National Institute for Clinical Excellence, are made available to the NHS in Scotland.

On autistic spectrum disorder, the learning disability review includes ASD, with or without co-existing learning disability. Work on implementation also has relevance to that particular client group. In addition, ministers commissioned a Scottish needs assessment programme report, which was published in 2002.

We set up an autistic spectrum disorder reference group in 2003 to take forward the recommendations of the SNAP report. Members of the group include an individual with ASD, family, carers and professionals in psychiatry, psychology, speech and language therapy, education and social work. An Action Against Autism director is also a member of the reference group.

An autistic spectrum disorder service audit that was carried out in 2003 in the health, social care and education sectors showed that there was poor data collection and variation in practice. A follow-up is being done by monitoring of partnership in practice agreements through learning disability agreements.

In March 2004, we held a national event for 70 lead clinicians who are involved in ASD diagnosis. That resulted in a network of clinicians in adult services now meeting to share knowledge.

There are numerous strands of activity in taking forward the needs assessment recommendations. First, diagnosis training pilots are under development to assess the use of specific diagnostic tools for both children and adults. Those pilots aim to increase the knowledge of autism among professionals at tiers 2 and 3, thus reducing waiting lists and the need for referral to specialists at tier 4.

Work is being done with the Scottish Social Services Council on ASD skills sets—that is, qualifications—for social care staff at levels 3 and 4. Level 3 is now available and level 4 is being evaluated this spring. NHS Education for Scotland has been funded to develop ASD training and information for general practitioners and primary care staff. A national ASD training framework project is funded by the Education Department, and some work will be delivered by the National Centre for Autism Studies in taking forward the national service network. The reference group is examining ways to influence continuing professional development training across agencies.

Following recent consultation, we are publishing a quality service standard for diagnostic services for children and adults, which provides a framework for diagnostic services that encourages clear communication with individuals and families. The standard includes identification of other needs and onward referral for medical or other assessment. It also sets timeframes from referral to assessment and on to service delivery.

The SIGN council agreed to develop a guideline on ASD assessment, diagnosis and interventions for children and young people aged from nought to 18. Work to develop that guideline involves individuals with ASD and family carers.

We are planning a national conference in the autumn, which will look at meeting the health needs of people who have autistic spectrum disorder and co-morbid conditions and it will consider non-invasive interventions that improve their quality of life. That will include addressing mental health issues for individuals and for family carers.

The reference group will consider the need for and the shape of tier 4 diagnostic services in Scotland and how those services fit in with community health partnership developments and managed clinical networks.

I will move on to heavy metal poisoning. On the issues surrounding the placement or removal of dental amalgam, it is now common practice not to use amalgam on pregnant women. That is highlighted through student education. Specific alternative materials are available and claims for these alternatives can be made by NHS dentists. However where there is specific need to use a stronger material such as amalgam, temporary fillings are recommended subject to replacement with amalgam at a later date.

14:15

On the issue of lead in water, the Executive is taking action on several fronts to tackle the illegal use of lead solder. That action includes providing information and advice to the public on the safe use of drinking water, for example through the "Be Water Wise" leaflet; working with building and plumbing trade representative bodies, for example the Scottish and Northern Ireland Plumbing Employers Federation, to reiterate that the use of leaded solder on drinking water plumbing is illegal and to discourage the practice; working with Scottish Water to strengthen the byelaws that enforce the ban on the use of lead solder in all buildings that are supplied by the public water supply through stiffer penalties and an improved monitoring regime; and looking at how the new building standards system that is proposed for 2005 might also encourage proper plumbing practice through the Building (Scotland) Act 2003.

A number of measures are in place to control the level of exposure for people of all ages. Those measures include legislation to curtail severely the use of lead in paints; legislation to curtail severely the availability of leaded petrol; legislation for recording and control of emissions of heavy metals from industrial operations; legislation on the levels of heavy metals in food; legislation on the levels of heavy metals in drinking water; the banning of the use of lead solder under byelaw 7, made under section 70 of the Water (Scotland) Act 1980; and the removal of lead plumbing under local authority grant schemes. I can provide the committee with more detailed information about those measures if it is required.

In relation to aphasia, we are providing funding as part of the national workforce strategy to train and recruit 1,500 more allied health professionals by 2007. Allied health professionals include speech and language therapists, who provide treatment for aphasia. Given that stroke is the most common cause of aphasia, we have funded the development of stroke managed clinical networks in every NHS board area. We give a grant of £5,000 to Speakability to help in its work.

We will consider an approach to the development group that is working on the national stroke dataset to ask whether a separate question on aphasia should be included. That would give us more information on the condition.

The Convener: Petition PE247 on epilepsy service provision, which was submitted by Epilepsy Action Scotland, calls for co-ordinated health and social services for people with epilepsy. I invite Duncan McNeil to begin the questioning.

Mr Duncan McNeil (Greenock and Inverclyde) (Lab): I thank the minister for giving us the opportunity to ask questions on the petitions. The petitioning body recognises that we have excellent SIGN guidelines for the care and treatment of people with epilepsy, but it is concerned that those standards are not being met. It also recognises that while the diagnosis of epilepsy should be made only by epilepsy specialists, there is a clear shortage of neurologists in Scotland. Some boards have no neurology services while others buy in services from Edinburgh and Glasgow, and there are vacant consultant neurologist posts throughout Scotland, which increases the pressure on the specialists who work in the area. What strategy does the Health Department have to increase the number of neurologists to a satisfactory level? How can the recruitment of neurologists be made more proactive?

Rhona Brankin: You are right to state that there is a United Kingdom-wide shortage of neurologists at present. That affects people with all neurological conditions and there is not a quick-fix solution.

Through the centre for change and innovation, we have been working on the neurology outpatients redesign project, which is intended to maximise the resources that we have. The draft patient pathways, which will go out for consultation by the end of the month, include epilepsy pathways. Epilepsy Scotland has been involved in the development of the patient pathways. Joe Logan might say something about the broader workforce issue.

Joe Logan (Scottish Executive Health Department): I do not have exact numbers for the committee, but I understand that considerable effort is being made to recruit and train additional neurologists. However, as the minister said, results cannot be achieved overnight, because of the fairly lengthy training period. As she said, there is a recognised shortage of neurologists throughout the UK.

Mr McNeil: We look forward to receiving additional information from you about the numbers and about the efforts to recruit—I presume that they are going on worldwide.

Joe Logan: I cannot say with certainty that efforts are going on worldwide, but we can certainly provide the committee with more information.

Mr McNeil: Why are efforts not being made to recruit worldwide, if that is the case and there is a recognised shortage of neurologists?

Dr Michael Cornbleet (Scottish Executive Health Department): The advertising process is international, in that adverts in the *British Medical Journal* are on the BMJ website and are visible to everyone who is looking for a post in neurology anywhere in the world.

Mr McNeil: Is that the normal practice?

Dr Cornbleet: Yes. The BMJ—

Mr McNeil: We know of health boards that go further and actively recruit through agencies, for example. Is that approach being taken in the recruitment of neurologists?

Dr Cornbleet: I am not aware that that approach is being taken specifically in relation to neurologists. As we said, there is an international shortage. However, I think that the number of consultant neurologists in Scotland has increased from 40 to 47 in the past few years, as part of the general increase that is required for the treatment not only of epilepsy but of multiple sclerosis and other neurological conditions. However, neurology remains a shortage area and, given the length of training that is required and the difficulties of ensuring that people remain part of the workforce after completing their training, there are no simple answers to the shortage. Recruitment is going on wherever we can find people who are suitably qualified.

Mr McNeil: Will we get further detail on the matter?

Rhona Brankin: I am happy to provide the committee with more detailed information on your specific point.

Mr McNeil: You referred to managed clinical networks, which would help to support professionals in the field. You also mentioned that networks are at different stages of development. Some networks are auditing epilepsy services, some are managing patient pathways and some are producing quality assurance frameworks or information technology. All that is well and good, but how can we ensure that the good practice and ideas that emerge from the networks can be developed and funded, so that we can improve services?

Rhona Brankin: One of our key jobs is to ensure that the best practice of managed clinical networks is shared between NHS boards throughout Scotland. It is our intention to do that. We are keen to promote the development of more managed clinical networks for epilepsy and other chronic conditions, because such networks offer an important way of working. We need to be able to ensure that we can monitor and measure improvements, to ensure that NHS boards are prepared to continue to fund managed clinical networks that are making such improvements. It is hugely important to be able to disseminate information from the networks, which are an important tool. We are strongly committed to the development of more managed clinical networks.

Mr McNeil: The Health Department has provided limited pump-priming funding for managed clinical networks for two years, but how will the work be taken forward when that funding runs out?

Rhona Brankin: Current improvements in services have not necessarily come at a high cost. We are confident that those improvements will continue, because they have provided huge benefits to health boards. It is important that the boards, as they are asked to, evaluate the improvements that the networks bring.

The Minister for Health and Community Care and I will want feedback on the success of managed clinical networks. We believe them to be a hugely important tool in improving standards of care for patients.

Mr McNeil: We all acknowledge that good work is going on, as is shown in the correspondence from the Minister for Health and Community Care dated 19 January, which we have among our papers. Future funding is a regional planning issue. How can the Scottish Executive Health Department ensure that budget allocations support that good work and develop good practice?

Rhona Brankin: Under the current system, health boards are encouraged to develop managed clinical networks. We also have SIGN guidelines. Through both of those means, we believe that boards receive adequate guidance and support to enable them to improve services.

Through the performance assessment framework or through other means, ministers can ensure that services for people with chronic conditions such as epilepsy continue to improve. You will know that Professor Kerr has been looking into work on chronic conditions; we will consider his recommendations carefully.

Mr McNeil: We are talking about guidelines that are implemented region by region and health board by health board, but the petitioners would like central direction in the development of good work.

Rhona Brankin: There are more than 80 SIGN guidelines. Some of the most important work will be done in the development of community health partnerships. In the work that will have to be done across local agencies—involving colleagues in social work, community care and education—community health partnerships will be hugely important in managing services.

Mr McNeil: The petitioners acknowledge that epilepsy services could be developed at that local level, as could asthma services and many others. To ensure that work is developed locally, does the minister support the principle that each community health partnership should have, for example, a nurse who is an epilepsy specialist? Would she consider pilot projects along those lines?

Rhona Brankin: Community health partnerships will have to make their own decisions based on what they feel is best for them. Where that happens, I would be interested in receiving feedback. That would be valuable. However, I cannot determine what CHPs do locally.

Mr McNeil: Would you encourage them in that kind of local work?

Rhona Brankin: Absolutely. I would encourage them very much.

Mr McNeil: Another area that interested the petitioners was the need for information for people with epilepsy. The amount of information that is available differs in different parts of the country. A lot of information about the condition—relating to medication, side effects, safety, driving regulations, women of child-bearing age, and so on—has been collated by epilepsy groups, but it is not always available to people who have been diagnosed with the condition.

Is there an opportunity for the minister to give some direction to the boards to allocate funding for patient information from their budgets? Alternatively, will the Health Department fund and support Epilepsy Scotland to provide free literature to all clinics in Scotland that are attended by people with epilepsy?

14:30

Rhona Brankin: I would certainly be keen to work with Epilepsy Scotland to consider the issue. I agree that we need to ensure that people have access to information. It may be that we could work with Epilepsy Scotland, or that Epilepsy Scotland could approach Voluntary Health Scotland, which is an organisation that the Scottish Executive set up to disseminate best practice and to get information out to patients. I am happy to look into that.

Mr McNeil: Thank you.

Shona Robison (Dundee East) (SNP): I return to something that you said earlier about the performance assessment framework. As you rightly said, the framework is a way of monitoring the performance of health boards, but, as I understand it, performance indicators for epilepsy are not included. How is the performance of health boards truly monitored if we do not have performance indicators for epilepsy? Will you ask the performance assessment framework steering group to consider developing performance indicators for epilepsy?

Rhona Brankin: There are different ways of monitoring what is going on at health board level. The performance assessment framework is one way of monitoring the on-going work, but it is also important to be able to monitor what is happening through the national service framework for epilepsy and NHS Quality Improvement Scotland on the development of standards for patients with neurological conditions. That will become a more integral part of the work that NHS QIS does in the future.

Dr Cornbleet: There are a couple of indicators on epilepsy care in the new general medical services contract, which will allow community health partnerships to monitor prescribing and other aspects of care. However, that information will not start coming through until the CHPs have been up and running for enough time to make the data meaningful.

Mike Rumbles (West Aberdeenshire and Kincardine) (LD): My question relates to all the petitions. In your opening remarks, minister, you commented on the working group that was set up to advise the Executive on how best to manage all sorts of chronic conditions. Will you give a little more detail on that? We have been in the same situation in relation to eating disorders: we had the policy and guidelines, but our inquiry found that health boards were not coming up to scratch. In relation to all the petitions—not just the one on epilepsy—it strikes me that there is something missing. It is not good enough to say, “This is the responsibility of each health board.” I detect that we are now saying, “It will be the responsibility of community health partnerships,” but I do not think that we should go down that line. When can we expect the working group’s recommendations?

Rhona Brankin: Work is being done through Professor Kerr’s committee, which will report in the summer. I cannot give any detail on the date on which that work will be taken forward.

Mike Rumbles: It is all part of the Kerr report.

Rhona Brankin: Yes. As you know, the difficulty is that, if we were to include every long-term chronic condition in the current performance assessment framework, the framework would become a very unwieldy tool. However, we recognise that there are certain chronic, long-term conditions for which effective ways of working—clinical networks and care pathways—have been developed. We must ensure that health boards have access to that information and provide the highest quality of service to patients with chronic conditions. We are well aware of the need to develop a system for ensuring that best practice is followed in all the health boards, as that is the key. Ensuring that that happens without making the performance assessment framework hugely unwieldy is a challenge for us.

The Convener: Thank you, minister. You have addressed a number of issues, including the shortage of neurologists and the training and recruitment problems that are associated with that. You have also talked about the sharing of best practice in the managed clinical networks and the need to monitor and measure the outcomes. The committee notes the difficulty of making the health boards do something that they do not necessarily want to do, although we acknowledge your reassurance that the outcomes will be such that the health boards will want to continue to do such things. At the moment, there are no guarantees about any of that. Professor Kerr has a sub-group dealing with chronic ailments—recommendations for handling such matters will, no doubt, arise out of his report. However, the petitioners will be heartened by the general invitation to talk to them about patient information distribution. That will, perhaps, result in some movement, at least on that score.

We now move on to petition PE398, on ME and chronic fatigue syndrome, which was submitted by Helen McDade and others. The petition calls for a strategic needs review on ME and CFS and for action on research and treatment of the conditions. I invite Janis Hughes to begin our questioning.

Janis Hughes (Glasgow Rutherglen) (Lab): In 2002, the then minister for Health and Community Care stated that the short-life working group had been set up, effectively as a result of campaigning by the cross-party group on ME. He explained that he felt that it would be better to set up that group than to undertake a needs assessment, which he reckoned would take about two years. However, two and a half years later, the then Deputy Minister for Health and Community Care said that funding could not be given to pump-prime ME services because no needs assessment had been done. The petitioner suggests—and I hope that you can understand the confusion, minister—that patient groups that participated in the short-life working group in good faith have been misled.

We have since seen the reports back from health boards that were initiated following previous consideration of the petition by the committee. Those reports show that provision across health boards is patchy, to say the least. What is your view on the facts that no needs assessment was done and that the short-life working group has not led to the results that the petitioners hoped for?

Rhona Brankin: The information that we have received from the short-life working group and, subsequently, from NHS boards shows that provision is patchy—there is no doubt about that. In a sense, that links into the questions about, and the broader issue of, how health boards are supported and encouraged and how they are accountable for providing the best quality of service for patients with a range of conditions.

We must now move to assessment of need in order to take the issue forward; we will make arrangements for an assessment of need to take place as soon as possible. As I have said, we will also fund NHS QIS to produce a best practice statement on ME as part of its current work programme. In addition, we will ensure that the good practice clinical guidelines that are being developed by NICE are made available to the NHS in Scotland.

Health boards were asked for information on ME/CFS because it is necessary to have some clarity on the scale and scope of the problem to inform our work in future. We need to obtain that baseline information, although we must acknowledge that different health boards started from different positions.

Janis Hughes: I welcome your commitment to moving towards a strategic needs assessment. You cannot be held responsible for the decisions of previous ministers, but it is a shame that we have wasted so much time—petition PE398 has been on the go for a long time. If such an assessment had been carried out in the first place, we would have been much further down the line by now. However, we are where we are and I welcome the direction in which you are moving and the fact that NHS QIS will be involved. Will you clarify what you said about the NICE guidelines? Would they be adopted in Scotland in the form of SIGN guidelines?

Rhona Brankin: When the NICE guidelines are developed, we will consider them in a Scottish context, with a view to advising practitioners to follow them.

Joe Logan: The NICE guidelines will cover only England and Wales.

Rhona Brankin: That is right.

Janis Hughes: You mentioned that, when the health boards were asked what they were doing locally, they were coming from different positions. It is clear that that was the case. One of the most important consequences of that is that we do not appear to have any estimates on the number of ME and CFS sufferers in Scotland. How could that be addressed? As well as assessing the numbers of people involved, we need to research the nature of the illnesses. How do you suggest that we make progress in that regard?

Dr Cornbleet: The chief scientist office has said that it would be more than happy to consider supporting research in that area. Indeed, it is supporting such research as part of the PACE—pacing, activity and cognitive behaviour therapy: a randomised evaluation—trial, which is a wider

Medical Research Council study. Any research proposals that are produced must be subject to the same competitive situation that all research that is funded by the CSO is subject to, because there are always more challenging topics to be investigated than the office can fund. In principle, however, the CSO has committed to being highly interested in supporting such research.

The prevalence of the condition should emerge from the assessment process. As part of its response to the questionnaire, Fife NHS Board was able to produce a figure for the number of patients affected. That can be done by using questionnaires. I do not know how reliable the information obtained will be or how uniform the diagnostic criteria will have been, but some idea of prevalence should emerge from that process.

Janis Hughes: What GPs use to diagnose the condition has been an issue. Do you have any thoughts on that? There are papers from around the world in which people have come up with various diagnostic criteria. Have you considered any of those and are there any that you think might be useful? As GPs have not always received specific training on identifying ME, the provision of some diagnostic criteria might help us to work out the prevalence of the condition.

Dr Cornbleet: That is not work that the Executive would undertake; it would have to come out as part of the NICE process—

14:44

Temporary loss of sound.

14:45

Janis Hughes:—as a neurological illness. Most neurologists will not see patients with ME. What steps are the Executive and health boards taking to improve specialist training in ME among undergraduates and existing neurologists? Notwithstanding the fact that, as has been mentioned in the context of epilepsy, there is a shortage of neurologists, it is important that current and future neurologists should be trained in identifying and working with ME patients.

Dr Cornbleet: I would refer back to NICE the question of the World Health Organisation definition. Professor Sharpe in Edinburgh has written extensively on the condition and might take a different view. The condition has enjoyed a variety of names over time and its aetiology—what causes it—and how it should best be managed remain controversial issues. Where patients are referred is part of that debate, but most of the management will need to be done in primary care, which will involve information and support for primary care practitioners. The issue will be part of all undergraduate medical curricula, but it will not be possible to give it an enormous amount of time because of competing pressures on the timetable.

Janis Hughes: I accept what you are saying, but we have reports from several health boards on the issue. Forth Valley NHS Board, for example, has set up a working group that includes local psychiatrists. It says that a

> "protocol for primary care which was developed by psychiatrists in the area"

has been drawn up. There are obviously differences of opinion among health boards about how best to assess and treat ME. That concerns me. If the guidance offered a more level playing field, that might be more beneficial to sufferers.

Dr Cornbleet: Those differences of opinion go right up to the working group of the chief medical officer in England—there were a large number of resignations from the group, because its members could not agree on the best definition and the best treatment. I do not see how we can resolve those dilemmas at the moment. The treatments that clinical trials have verified as being of benefit are those that lie within the province of the psychologist and psychiatrist rather than the neurologist. That is one reason for using that referral mechanism and why such treatments are the most common therapy. However, many other forms of therapy have been advocated, although they have not been subject to that kind of scrutiny—or, if they have, they have not survived it. At the moment, the most appropriate referrals are to psychologists or psychiatrists.

Janis Hughes: I have a final question; I am conscious that other people want to come in on the debate. The petition suggests that there is a pressing need for a specialist Scottish ME clinic. What are your views on that?

Rhona Brankin: When we receive the report on the management of chronic conditions, we will have to consider such possibilities, but at the moment there are no specific plans for such a clinic in Scotland. Because there has been no assessment of need, it is difficult for me to give a firm indication of our plans. The fundamental issue is that we get an assessment of need, consider what comes out of the NICE guidelines, look at the NHS QIS best practice statement and look for the best configuration of services for people with ME/CFS.

Janis Hughes: That demonstrates how important it is that we have the assessment. How long do you envisage it taking?

Rhona Brankin: At the moment, I can say only that we will make arrangements for an assessment of need as quickly as possible. I am happy to keep in touch with the committee on that, because I know that it has a significant interest in the matter, as does the cross-party group, which I am meeting in June. I undertake to keep in touch with the committee and the cross-party group on the timescales.

Shona Robison: Will you consider ways of ensuring that the needs assessment does not take as long as two years, as has been suggested? If it takes two years, that will be a five-year delay from when the short-life working group was first mooted in 2002—such a delay would be unacceptable to all the patient groups and individuals who are hoping and waiting for an assessment of needs. I urge you to speed up the process as much as possible.

Rhona Brankin: It is not the case that nothing has happened: progress in local health boards is somewhat patchy, but we have made progress. I would certainly want the needs assessment to be undertaken as quickly as possible.

Alex Fergusson (Galloway and Upper Nithsdale) (Con): I thank committee members for putting those relevant questions to the minister. I also warmly welcome the minister's announcement of a needs assessment and the fact that NICE guidelines will be made available to practitioners. However, I hope that I will be forgiven for saying that patient groups will regard that as a distinct possibility of yet another two-year delay. Every step that has been taken so far has led to delay—the short-life working group took 18 months to report and it took the health boards 18 months to compile and return their responses. However, I will look on the announcement in the best possible light and hope that "as quickly as possible" really means what it says and that some results will come from the announcement straight away. I also welcome the recognition that the response from health boards is patchy at best and that the assessment is needed urgently.

Dr Cornbleet's last sentence was something along the lines of "The psychiatric approach is the most appropriate," but that attitude is why ME patient groups the length and breadth of Scotland feel that no improvement has been made in their treatment in the three and a half years since the petition was lodged. At that time, Linda McLean, the mother of a child with ME, said to the Public Petitions Committee:

> "As Heather said to me, young people could not lie in bed as she lies in bed even if they were paid £1 million. They could not stay still in a dark room, unable to watch television, talk to people or see friends. There are no words to describe how terrible the condition is and how little it is understood."—[*Official Report*, *Public Petitions Committee*, 2 October 2001; c 1305.]

I hear what the minister said about the shortage of neurologists. I agree with her on that, but I wonder whether she is aware that the only neurologist for adults who supported ME patient groups was refused the leading post at the Glasgow ME clinic, even though he had tremendous backing from the patient groups and no other clinician had expressed any interest in running the clinic. The minister might also be unaware that that neurologist has now left Scotland, which means that his expertise is no longer available to ME sufferers in this country. I am sure that she agrees that that is totally unacceptable, but the fact is that the psychiatric lobby—I hate to call it that; perhaps I should say "the psychiatric branch of medicine"—has a complete grip on the throttle of treatment for ME. That grip needs to be loosened, but nothing that the minister has said today points towards such a loosening. Will she comment on that?

I also ask the minister to comment on the desperate need for a more balanced approach to research on ME. The way to address all the problems that she has admitted today was suggested in the original petition's demand for a national centre of excellence. Will she comment on that proposal? We are not talking about a fancy hospital or even one that is designed by a Spanish architect; we are talking about ensuring that there is a meeting of like minds to discuss the best way forward for the people who suffer from this dreadful disease.

Rhona Brankin: As a former teacher and lecturer, I am conscious of the issues relating to pupils with special educational needs. Indeed, I have worked with children with ME and chronic fatigue syndrome and am aware of the current debate around psychiatric and neurological approaches. I have an open mind on the issue and would be concerned if you were to interpret what has been said today as being an endorsement of a purely psychiatric approach. I would want us to be open minded about the issue. Having worked with young people in schools, I am aware that the condition can be explained in many different ways. We must not close our minds. We need to be confident that we have the very best information, which is why we have to examine closely the NICE guidelines and ensure that we have access to the research that is being done around the world.

I am certainly keen to work closely with the various representative bodies on chronic fatigue syndrome and ME. Ministers and other politicians have a huge amount to learn from people who have had those conditions and from the experience of the families of those people. I am happy to do that.

Alex Fergusson: I am delighted to hear that the Scottish Executive is not taking a purely psychiatric approach, minister. When you visit the cross-party group on ME, you can expand on that point. Do you acknowledge that ME is a different disease from CFS? Do you recognise it as being a neurological disease? Do you recognise it as being a chronic condition, which will be considered by the relevant care sub-group? You might have already answered the last question, but I would like you to clarify your position.

Rhona Brankin: As I said, I am aware that there are various schools of thought on the issue. I think that there are strong grounds for viewing ME as a neurological condition, but I would not want to say to you that my mind is closed to other views. I know that there is considerable debate and discussion about the issue, but my professional experience of contact with people who suffer from ME suggests to me that it is a neurological condition. Clearly, however, I am not an expert and must be guided by what people say to me. I will therefore take guidance from medical advisers, but I also need to listen to what I am told by people who have had experience of the conditions and by their families.

Alex Fergusson: Are you aware of a report by the charity Action for ME, which commissioned the research two years ago, showing that the cost of ME in Scotland is some £299 million? If that is accepted, does the minister agree that the health board by health board response that you have admitted is patchy does not compare favourably with the situation south of the border, where £8.6 million has been given by central Government on a regional basis to bring about a national response to the problem? If the strategic needs review throws up a better way forward for ME sufferers, will the Executive pursue that way forward with vigour?

15:00

Rhona Brankin: I cannot predict what the review will come up with, but I have said that ensuring that there is an accurate assessment of needs is important. As the Deputy Minister for Health and Community Care, I will look closely at what the review throws up. We must ensure that there are the highest-possible standards of treatment and the best advice for people who suffer from ME and chronic fatigue syndrome.

The Convener: I welcome Mike Watson to the meeting and gather that he wants to ask a question.

Mike Watson (Glasgow Cathcart) (Lab): I will be brief. In my six years as a member of the Scottish Parliament, this is the first time that I have asked to come to a meeting of a committee of which I am not a member to ask questions. I hope that that shows how seriously I take the need to get adequate acceptance of ME and CFS and to put in place structures to ensure that people who suffer from those conditions are properly treated.

I am encouraged by the minister's response on the strategic needs assessment and, other than echoing comments by others that things should be done as soon as possible, will say nothing further on that matter. I am also encouraged by her saying that there will be no presumption that the psychiatric route will be followed in respect of that needs assessment. Dr Cornbleet seemed to echo what the chief medical officer, Mac Armstrong, said about that being the way forward when he spoke to the cross-party group on ME at the end of last year. People with the condition will emphatically say that that is not the way forward.

I want to pick up on a point that the minister made earlier when she talked about epilepsy. She said that she wants to ensure that best practice is followed in all health boards, as that is the key to providing treatment for epilepsy. Whatever comes out of the strategic needs assessment—obviously, I do not ask the minister to anticipate that—does she envisage that the aim will be equality of treatment as far as possible throughout Scotland for sufferers of ME and CFS?

Rhona Brankin: One reason for the Kerr review considering the management of chronic disease is to ensure that there is the best-quality treatment throughout Scotland for chronic conditions. Obviously, ministers will carefully consider Professor Kerr's hugely important report and, following the needs assessment, I intend to consider how we can ensure that the best-quality assessment, treatment and support are provided throughout Scotland.

Mike Watson: Will Dr Cornbleet elaborate on what he said in response to Janis Hughes about training for medical students including sessions on ME and CFS? The information that ME and CFS sufferers and I have received is that medical students do not receive any such training. Many people will be pleased to know about any developments in that respect.

Dr Cornbleet: I cannot speak about the curriculum of each medical school, but ME and CFS will be in the range of conditions with which all medical students are expected to have some familiarity. They will not receive a fortnight or a month of nothing but such training, but I would expect them to have some awareness of ME and CFS as part of their neurology or psychiatry education—given the uncertainties that are involved, training on those conditions will probably be part of both. The undergraduate curriculum is extremely congested and I would expect it to be insufficient for them to be confident in making a diagnosis, but they will make diagnoses as they go through their postgraduate training for whatever discipline they want to end up in.

Rhona Brankin: Perhaps we could also consider the development of services at the general practitioner level, for example where GPs are looking to develop a specialist interest, as they are increasingly looking to do. There is no doubt that the curriculum is crowded and it is sometimes difficult for all GPs to have access to the most up-to-date information on every condition that is known to man. That is undoubtedly a challenge for them. I hope that the development of specialist GPs will help in that regard.

Mike Watson: That is helpful. I thank the minister for her comments, although that is not to pre-empt her decision. A great deal of progress has been made today. Whether the minister decides to continue with that progress is up to her.

The Convener: Some progress has been made today. Everybody, including the petitioners, will welcome the strategic needs assessment. However, the history of this process has been very unedifying. The petitioners first asked for a needs assessment, and that was followed by the announcement of a short-life working group, which was presumably to progress matters faster and

"provide suggestions for improvements … more rapidly".

Sometime later, however, there was a turnaround and it was decided that, because there was no needs assessment, nothing further would happen.

In a sense, we are right back where we were at the start of the petition. The set of events in the intervening years has been unfortunate. Although I appreciate that the minister is at the sticky end of the lollipop and that the matter had nothing to do with her in the first place, I ask her to suggest to her department that that is no way to proceed. It now looks as if the short-life working group was nothing more than a delaying mechanism, which is unfortunate and not a very sensible way to proceed. That is not what the group was meant to be but, as a result, we have lost time.

Rhona Brankin: Let me say something in defence of the department. I do not take the view that there has been no progress. However, when one considers the reports coming back from the boards, one can see that, although the boards were starting from different places, progress has been very patchy. Given that, an assessment of need will allow us to take things forward.

The Convener: We move on to the three petitions dealing with autistic spectrum disorder. I welcome Jean MacLellan, head of the vulnerable adults unit. Two of the petitions, PE452 and PE538, were submitted by James Mackie and relate to methods of diagnosis and treatment of adults with autistic spectrum disorder. They call for the setting up of an advisory committee. PE577 was submitted by Steve Law and calls for the establishment of an autism-specific medical treatment facility in a Scottish hospital. I invite Nanette Milne to begin the questioning.

Mrs Milne: To some extent, a common thread runs through the chronic conditions that we are discussing. Autistic spectrum disorder seems to be reaching epidemic proportions in the country, particularly among children, who are being diagnosed in increasing numbers. Although the increased diagnosis of children is welcome, it is increasingly understood that significant numbers of adults have not been diagnosed. Many have experienced significant difficulties throughout their lives, perhaps in mental hospitals or other institutions, simply because they have not been picked up as being on the autistic spectrum.

The minister dealt with a number of issues in her overview. I hope that she will forgive me if I ask her to repeat herself, but it was difficult to pick up all she said. The petitioner has a number of concerns. He is of the view that GPs and psychiatrists in particular have very little training on autism and, as a result, often misdiagnose the condition. People might end up being sectioned under the Mental Health (Scotland) Act 1984 when in fact they do not have a mental illness but have a developmental disorder that affects them throughout their life. What undergraduate and postgraduate training on autism exists? I would welcome your repeating what you said about future training.

Rhona Brankin: We have under development training pilots to assess the use of specific diagnostic tools for children and adults. The aim is to increase knowledge of autism in professionals at tiers 2 and 3. I hope that by doing that we will reduce waiting lists and the need to refer people to specialists at tier 4. We are conscious of the challenges in diagnosis. There will be a quality service standard for diagnostic services for children and adults. Jean MacLellan can say a bit more about diagnosis.

Jean MacLellan (Scottish Executive Health Department): As the minister said, in 2003 we conducted an audit that covered education, social care and health. For the first time in Scotland we got partners to sit in the same room and compare their data. The audit was a baseline study on which to build. It suggested that the prevalence rates in Scotland were lower than had been suggested in the special needs assessment on autism that we conducted previously. We acknowledge that those figures are not entirely accurate and might be an underestimate.

We also asked about the tools that are used for diagnosing autism and more than 20 such tools were described to us. That led us to conclude that we needed to do something about ensuring that the diagnostic tools were fit for purpose, which is why we set up the training pilots to which the minister has just referred. There are four in total, which are using different tools that link with the "Diagnostic and Statistical Manual of Mental Health Disorders", fourth edition, and the

"International Classification of Diseases", 10th revision—some relate to children and some relate to adults. The pilots will be conducted in four areas of Scotland. We will take each into account and, on the back of that, issue guidance to clinicians on what we believe to be best practice in diagnosis.

Mrs Milne: Thank you. That is helpful.

Probably because of misdiagnosis, treatment is often inappropriate. A number of patients find themselves sedated on psychiatric drugs, which is not the most appropriate treatment for dealing with their behaviour. What work is being undertaken to research what is the best treatment for people who suffer from autism?

Jean MacLellan: The Mental Health (Care and Treatment) (Scotland) Act 2003 will have a part to play in reviewing cases of those who are compulsorily detained. It is possible that those who are on the spectrum have co-morbid conditions. I ask Dr Cornbleet to talk more about that, because it is a clinician's area rather than mine. Co-morbidity is accepted—[*Interruption.*]

The Convener: I remind everybody that we have members of the public present. When members are asking questions and witnesses are answering them, they should remember that members of the public are listening to them and will have a great many concerns about the issues that are raised. I ask members of the public not to make any further noise; otherwise I will clear the room—I mean that.

Jean MacLellan: I am respectful of the person who has just left the room. The Public Health Institute of Scotland report identifies early intervention as being critical. We are mindful of that in other areas of the implementation of the report. As I understood it, the question related to adult care.

Mrs Milne: It did.

Rhona Brankin: Work is under way to develop the services that are provided by allied health professionals and speech and language therapists. We recognise the importance of those services and the need for them to be provided.

15:15

Mrs Milne: I should stress that the questions concern adults, as the first two petitions on autism that we are considering relate to adults.

Rhona Brankin: I want to address the issue of detention in psychiatric wards and possible treatment with inappropriate medication. The Mental Health (Scotland) Act 1984 is relevant here. Information on people who are detained under the 1984 act is recorded on the basis of mental impairment or severe mental impairment. The Mental Welfare Commission for Scotland has a role in visiting individuals who are detained. Those powers were strengthened by the Mental Health (Care and Treatment) (Scotland) Act 2003. The work that we are doing to develop a framework for children's and young people's mental health, which spans promotion, prevention and cure, should assist service delivery to children with ASD who also have mental health problems.

Mrs Milne: The Scottish Executive's recent review of therapy services found that there are gaps in provision for adults with autism and that services are sometimes poorly designed. Are steps being taken to remedy that problem?

Jean MacLellan: Yes. As you know, the review of therapy services identified a need to develop integrated approaches to the provision of therapy and a systematic approach to workforce analysis. An AHP officer for Scotland is supporting implementation of the review. An AHP secondee is working with education colleagues, with a specific focus on the Education (Additional Support for Learning) (Scotland) Act 2004. Those working on the review recognise that further work will be needed to determine how other recommendations relating to adult services can be progressed. The AHP strategy is developing initiatives, principally on recruitment and retention. An AHP project manager is involved in the national workforce planning aspects of the issue. That is the point that has been reached to date.

Mrs Milne: My next question concerns the number of adults who have been diagnosed with autism. Following the PHIS report on autism, health boards were asked to publish a register of all those who have been diagnosed with ASD. Has that information been forthcoming from all health boards, or is it patchy?

Jean MacLellan: Are you referring to the number of adults who have been diagnosed in Scotland?

Mrs Milne: Yes.

Jean MacLellan: The 2003 audit revealed that information is extremely patchy. Some areas, such as Lothian, which did a manual trawl of all its case files, were able to give us very accurate figures. The figures from the west of Scotland were based on rates of prevalence in the population. There was huge variation.

We are beginning to address some of the dearth of provision. As you know, there are two one-stop shops that are designed to provide adults on the autistic spectrum with social skills and interventions of different types, depending on individual need. One is based in Glasgow and the other is based in Edinburgh. We will use the findings of the one-stop shops to disseminate good practice more widely. They are currently in year 2 of a three-year programme.

Mrs Milne: I know that the National Autistic Society is concerned about the three-year funding plan for the one-stop shops. Is funding likely to continue? There is concern that funding will stop suddenly in year 3. What will happen after that?

Jean MacLellan: The intention was to pump prime to enable the services to be set up. The expectation was that those who were given the moneys would continue to provide the services in the future. Although that was a condition of the tendering arrangement in Lothian, I do not think that that was the case in Glasgow. We in the Executive have regular meetings with the Glasgow partnership and with local authority and health board representatives there with a view to considering how the initiative can be developed on a more permanent basis.

Mrs Milne: Is it likely that the one-stop shops will be expected to continue to operate using existing funding, or will funding be forthcoming from the Executive?

Rhona Brankin: That will be for health boards to consider. Health boards have been getting consistently increased amounts of funding.

You asked about the audit of health boards. Not only did the audit show variations in the ability of boards to produce accurate up-to-date data, it showed variation in practice. That is why the follow-up is being done through the monitoring of the partnership in practice agreements for learning disability and autistic spectrum disorder. Active monitoring and valuable work are going on in the area.

Jean MacLellan: The original audit was done in 2003. Obviously, we do not want to overburden local authorities and health boards with yet another demand. There is an existing mechanism through the learning disability review whereby partnership in practice agreements are submitted to the Executive on a three-year cycle. After our baseline audit, we went to the partnership in practice agreements and asked for updates on what was going on in autism. Those have just come in and we received the last one about two or three weeks ago. We will collate the responses and establish what the trends have been since we did that baseline study.

Mrs Milne: I note that the Royal College of Psychiatrists is interested in co-operating with the Executive to help to set up a national register. Is that part of your planning?

Jean MacLellan: We are aware of that and we have some representatives from the Royal College of Psychiatrists in the ASD reference group.

Mrs Milne: Action Against Autism has a number of concerns about the causes of ASD in children and cites deficiencies in essential minerals, a dysfunctional immune system and the measles virus as possible causes. Action Against Autism asks the Executive to instigate an examination of children on the spectrum for those conditions and to identify treatments from the findings. What is your view on that proposal?

Jean MacLellan: I will defer to my medical colleague but, by way of introduction, I note that one of the measures that we have funded is a representative sample of all the cases that were referred for diagnosis to the Scottish centre for autism at Yorkhill hospital, where all the second opinions are given. We are currently funding a researcher there to go over a representative sample of cases from the past 15 years, to look at what was going on with all those children and what is happening to them as they make the transition into adult life. There will be a report in the next six to nine months, so that is one step towards addressing what Action Against Autism is interested in.

We have committed to holding a conference in the autumn on different medical interventions and one of the directors of Action Against Autism is involved in the planning group for that. The conference will cover dietary aspects and many other aspects in which AAA has a particular interest.

Dr Cornbleet: A number of pieces of research are under way that are jointly funded by the MRC and the CSO. They address some of the areas that you mentioned, including dietary interventions and environmental risks in particular. The CSO is also awaiting a proposal on omega 3 fatty acids, which will undergo peer review in the competitive process for awarding funds. Many interventions and investigations could be used—I was going to say “inflicted”—on a child, and the people who make the assessment must use their expertise to determine the investigations that are the most appropriate and the most likely to produce a useful and meaningful yield in relation to the treatment that might be possible.

Mrs Milne: Action Against Autism thinks—

The Convener: I think that the minister wants to comment. It would be quite useful to let her in when she wants to say something.

Mrs Milne: I am sorry, minister.

Rhona Brankin: Have we moved on to a different petition?

The Convener: Yes; we are discussing PE577.

Rhona Brankin: With the convener’s permission, I will make a final point on PE452 and PE538. I am very aware of the possibility of misdiagnosis of people who have autistic spectrum disorders and of the potential for inappropriate treatment of adults in psychiatric wards. We need to take the issue seriously and I hope that the national conference that will take place in the autumn, which was mentioned, will consider such matters.

The Convener: I ask everyone to be a little briefer with their questions and answers, so that we can move on.

Mrs Milne: I have a brief question, which I should have asked when we were considering PE452 and PE538. SIGN guidelines on children who are on the autistic spectrum are in place. Are there plans to extend the guidelines to adults?

Dr Cornbleet: I do not think that such plans feature in SIGN's current work programme.

Jean MacLellan: I am an observer on the SIGN group, which will report in the next 12 to 18 months. The guidelines currently cover the nought-to-18 age group, but some of the material that relates to the late teens might be helpful for adults. However, that is not clear at this stage.

Mrs Milne: There is clearly a desire for an extension of the guidelines.

PE577 calls for the establishment of an autism-specific medical treatment facility, so that some of the innovative techniques that are used elsewhere might be introduced to this country. Has the Scottish Executive explored the merits of treatments that might be taken forward?

Dr Cornbleet: The Executive has not done so. The secondary referral centre would form the basis of an opportunity to contribute to studies in the area, if such studies were thought to be appropriate.

Rhona Brankin: I hope that members find this useful. It would be useful if the Executive were to fund a piece of work that would follow on from the current information project, which would consider practice beyond diagnosis and the service models that provide the best response to the need for medical, dietary and other interventions. Such a piece of work would be informed by the current work on developing the SIGN guidelines and the retrospective study that we funded, which will analyse a representative sample of diagnoses made at Yorkhill hospital during the past 15 years. It would also test the application of the quality service standard that we are about to publish and its impact on onward referral and follow-up. I am happy to take forward and fund a piece of work in that area.

Mrs Milne: That would be helpful.

Shona Robison: During some of the discussion, it has felt as if we were wading through treacle. I have a simple question, which is asked by many of my constituents. They tell me that the system breaks down when a child with autism leaves their special needs school to go into adult services. In relation to some of the matters that the petition raises, I ask the minister to say in simple terms what she will do to improve the move from children's services to adult services. That is the point at which people feel that they lose services and support that they have had for many years.

Rhona Brankin: There is no doubt that when youngsters leave school, a gap in service provision often occurs. You will be aware of the Education (Additional Support for Learning) (Scotland) Act 2004. Such support was highlighted as a major issue, and the 2004 act places a duty on health boards to collaborate with schools and education authorities to put in place a plan for youngsters on leaving school. That is the way forward.

15:30

Shona Robison: When will those plans have to be in place? Are they mandatory?

Rhona Brankin: They are mandatory. Following assessment of a pupil's additional support needs, a decision is made about whether they require a co-ordinated support plan or an individualised education programme. Part of a support plan or education programme is a system of regular reviews. A co-ordinated support plan will be reviewed annually.

The 2004 act requires a review to take place at a specified time before a youngster leaves secondary school. I do not remember the detail, but I understand that, as a minimum, a year before a youngster is due to leave school is when a plan is set out for provision after a youngster leaves a school setting—whether that is a special or mainstream school—and goes into adult services.

As I said, the act places a duty on health boards—

Shona Robison: When does that start? If you cannot say now, will you advise us later?

Rhona Brankin: I will advise you.

The Convener: That would be helpful.

I ask Carolyn Leckie to make her questions as brief as possible, because we are running late.

Carolyn Leckie (Central Scotland) (SSP): Sure—of course.

I have two short questions. Ms MacLellan talked about co-morbidity in relation to petition PE452. It struck me as a wee bit strange that when misdiagnosis and the Executive's inability to provide statistics on the number of adults who have autism are acknowledged, the Executive can be confident about the diagnosis of co-morbidity in connection with mental health. How many cases can the Executive cite of a formal diagnosis of co-morbidity?

My final question is on the Action Against Autism petition. I am sure that, like me, the minister is aware of much research that has been produced on medical diagnosis and treatment for a cohort of people with autism who have achieved recovery. What will the Executive do to try to replicate those findings and to make medical diagnosis available to children—particularly those who present with physical symptoms, who tend to encounter a barrier at their GP and do not even receive treatment for those symptoms? Does the minister agree that if a cohort of children with autism responds to medical treatment, everyone should have a right to that treatment on the NHS, if it is appropriate for them?

Rhona Brankin: First, we need to be sure that we have access to the best research information about treatment. It is important that the conference that we are funding discusses that, as a vehicle for ensuring that we have the information.

Every child has a right to the best treatment. We must ensure agreement about and recognition of what constitutes the best treatment. I want to ensure that we have consensus about that.

Carolyn Leckie: You referred—

The Convener: I will not allow the discussion to continue. We have talked about what we need to deal with on the petitions. There are probably still some outstanding issues but I thank the minister for her comments and I particularly thank Ms MacLellan for her assistance during this part of the process.

Petition PE474 was submitted by James Mackie and calls for the establishment of a review group to study heavy metal poisoning and any link to childhood conditions. We are joined by John Frogatt from the public health division and Dr Arthur Johnston, the scientific adviser at the Scottish Executive Health Department. I remind members that we are running behind our scheduled time. Members of the committee who wish to ask questions should indicate that clearly and should keep their questions as brief as possible.

Helen Eadie (Dunfermline East) (Lab): The petition concerns the impact on health of heavy metal poisoning, particularly its link to childhood conditions. One of the petitioner's objectives is to ascertain whether any component of any vaccine creates symptoms similar to heavy metal poisoning. Is the minister aware of that issue? What research has been undertaken in that area?

Rhona Brankin: It is my understanding that the World Health Organisation’s global advisory committee on vaccine safety has concluded that there is no evidence of toxicity in infants, children or adults exposed to thiomersal, which contains ethyl mercury, in vaccines. Advice from the WHO makes it clear that the risk of death and complications from vaccine-preventable illnesses is real, in comparison with the theoretical risk from the side effects of vaccines.

Dr Arthur Johnston (Scottish Executive Health Department): Some of the symptoms are shared, but that does not necessarily mean that there is a shared cause. Some symptoms of heavy metal poisoning, particularly from mercury, influence neurodevelopment in children. Our current position is that there is no clear evidence of a link between thiomersal in vaccines and the development of neurodevelopment diseases.

Rhona Brankin: To reduce avoidable exposure to mercury in general it has been agreed Europe-wide that, even if there is no evidence of toxicity, as a precautionary measure thiomersal should be substituted or reduced as soon as safe and effective thiomersal-free alternatives become available and licensed. Work is under way to that end.

Helen Eadie: The petitioner is of the view that many of the symptoms of childhood conditions resemble symptoms of heavy metal poisoning. He is calling for a scientific review group to investigate that link. Are you aware of that issue, and are you prepared to consider that proposal?

Dr Johnston: We are aware of the petitioner’s call. The Food Standards Agency and the Department of Health jointly sponsor the Committee on the Toxicity of Chemicals in Food, Consumer Products and the Environment. That would be the appropriate body to advise the UK on the issue. Anything that we set up in Scotland would be duplication and would probably be unwarranted.

Helen Eadie: The petitioner holds the view that certain individuals accumulate toxic build-up of heavy metals. Consequently, he is calling on Executive to instigate a programme of testing in a large cohort of children with autism to check whether mercury and other toxic metals are present at abnormal levels. What is your view on that suggestion?

Rhona Brankin: Some studies have indicated that hair samples from autistic children contain levels of mercury that are lower than expected. The implications that might be drawn from that include: first, that the uptake of mercury from food is restricted; secondly, that the ability to excrete mercury is inhibited; and thirdly, that the ability to metabolise all metals, including those central to neurological development such as iron, is inhibited. We need to consider the importance of such implications as evidence becomes available.

Dr Johnston: There is no clear evidence of an association between autism and heavy metal poisoning. It is doubtful whether a large-scale screening programme would achieve anything. Individual diagnoses and treatments are probably the better alternative.

Helen Eadie: The petitioners say that the NHS does not screen for heavy metal toxicity and that it is left to individuals to fund such tests privately. Why is that?

Rhona Brankin: The Scottish Executive Health Department feels that it would not be appropriate for the NHS in Scotland to devote resources to routine screening for heavy metal toxicity. If an individual suspected diagnosis of heavy metal toxicity arose, appropriate laboratory investigation would be carried out at NHS expense.

Regular surveys of public exposure to mercury in food and to mercury generally have consistently indicated that, for most people in the United Kingdom, exposure has been well within current guidelines. For example, in March 2002 a report from the Medical Research Council collaborative centre for human nutrition research showed that, among 1,320 adults aged between 19 and 64 who were participating in the national diet and nutritional survey, 97.5 per cent had blood mercury levels that showed that their mercury intakes were within the provisional tolerable weekly intake recommended by the Joint Expert Committee on Food Additives. The recommended figure is 1.6 micrograms of mercury per kilogram of body weight per week.

Helen Eadie: This is my last-but-one question. The Minister for Health and Community Care wrote to us on 19 January and kindly laid out progress on the issue of lead solder in new housing developments in Scotland. The letter highlighted the fact that the illegal use of lead solder in such developments was widespread. It also mentioned a report by the Scottish centre for infection and environmental health. Stage 2 of that report recommended that surveys be carried out that could be monitored to see whether compliance within the building industry is happening. The letter says that that "is currently being considered."

Will you update us on progress? It appears from the letter that the Scottish centre for infection and environmental health has considerable concerns.

Dr Johnston: We have asked Health Protection Scotland—as SCIEH is now called—to provide us with a further project proposal for that work. We await that proposal. I spoke to people at HPS recently and they assured me that they were preparing the proposal and that we would have it soon. In the meantime, HPS has done further work on method development in this area. That work has been sponsored by the Scottish Executive Environment and Rural Affairs Department.

Helen Eadie: I think that the minister will agree that there is concern about the illegal use of lead solder. I therefore welcome that update.

Finally, can you update the committee on the Executive's progress in ensuring that the limits on emissions that are set in the European directive are met in Scotland?

Dr Johnston: Again, we are talking about emission limits for specific pollutants, particularly in Scottish cities. The cities with problems are the largest ones—Edinburgh, Glasgow and Aberdeen. There are indications that those cities will have difficulty in meeting some of the targets. The requirement then is to declare air quality management areas, and such areas have been declared. Work is going on in controlling emissions from vehicles—for example, in stopping the idling of buses and taxis in streets.

Helen Eadie: I thank you for that answer, which highlights the need for heavy metals to be taken in the round. It seems that the argument on heavy metal poisoning must not be narrowed down to just one aspect; a host of factors can cause heavy metal poisoning.

15:45

The Convener: I will let in Carolyn Leckie, but only if her question is brief and does not turn into three questions.

Carolyn Leckie: I return to the minister's comment on guidelines for safe levels of mercury in the atmosphere. If the Executive does not believe that there is a link between mercury levels and autism, how is it possible to establish a safe threshold? I ask Dr Johnston to clarify why, although advice was issued in 1998 to dentists not to give women mercury fillings, babies are still being injected with mercury eight years later?

Dr Johnston: For clarity, we are not still injecting babies with mercury; the last of the mercury-containing vaccines was phased out last year. I am referring to the four-component vaccines that are contained—

Carolyn Leckie: So, we were injecting babies with mercury six years after that advice was given to dentists.

Dr Johnston: Again, the general advice from the World Health Organisation is that if mercury exposure can be avoided, it should be avoided. The programme to phase out the use of mercury in vaccines was introduced for that reason. Clearly, in pregnant women, mercury exposure can be avoided by the simple expedient of giving a non-mercury-based amalgam. That is exactly what dentists are guided to do.

Carolyn Leckie: So why were non-mercury vaccines not made available at the same time?

Dr Johnston: Because, until recently, it was not possible to produce a wholesale pertussis vaccine without using a mercury preservative. Following the completion of that work, a mercury-free vaccine is now in place.

Carolyn Leckie: Why was that not possible until recently?

Dr Johnston: As this is not my area, it is difficult for me to say how that research developed. Clearly, these things take time.

Carolyn Leckie: Could we get that evidence?

The Convener: Could you forward an explanation to the committee, or it is something that is completely outwith your knowledge?

Dr Johnston: The speed of development of the non-thiomersal-containing vaccine is completely outwith my knowledge. That said, I could look into the matter.

The Convener: If it is possible to forward an explanation to the committee, we would appreciate that.

We move on petition PE475 on aphasia. John Froggatt, Jean MacLellan and Arthur Johnston will leave the table and Joe Logan and Dr Michael Cornbleet will return. The petition, which was submitted by Speakability, calls on the Scottish Parliament to take a number of steps in respect of the measurement of and provision of services for people with aphasia. Dr Jean Turner will open our questioning on the petition.

Dr Jean Turner (Strathkelvin and Bearsden) (Ind): Time is short and I will try to be brief, although I want to pick out the salient points that Speakability raises in its petition. I understand from what the minister said earlier that the Executive plans to include a question on aphasia in the Scottish stroke care audit system. Although Speakability would like that to happen, the audit system deals only with stroke patients and does not apply to others on whom aphasia has an impact.

The most important factor is communication: aphasia can cause speech loss, which in turn causes difficulties in understanding. We understand the time that is required to make an early diagnosis of aphasia and to decide on the correct treatment for each patient. Earlier, the minister said that the Executive aims to put in place a system of allied health professionals. How many of those professionals will be speech therapists? I am aware that you may not have the information with you today, minister.

Rhona Brankin: I do not have with me information on the number of speech therapists out of the 1,500 AHPs. I will see whether I can provide the committee with the figure.

Dr Turner: That would be great. It is important that patients feel that they are getting the right treatment at the right time.

Another issue that stands out is the short-term nature of the connection with speech and language therapists in the acute phase and in the rehabilitation stages. If patients are lucky, their speech therapy will last for months, yet it should be offered for longer.

Speakability is also concerned about how the Executive intends to address the on-going social needs of people who live with aphasia, because aphasia is a lifelong disabling condition. Can you tell us what is in the Executive's mind? The Executive needs to know who suffers from aphasia, so that it can know how many people will be needed to treat the condition, from diagnosis onwards, throughout sufferers' lives.

Rhona Brankin: As I said, I have agreed to approach the development group that is working on the national stroke data set to enquire whether a separate question on aphasia could be included. If that were to happen, we would have more information. As part of the national workforce strategy we are recruiting and training 1,500 more allied health professionals, which is hugely important. I am cognisant of the central role that speech therapists play in working with adults who suffer from aphasia. I hope that in future, every adult who suffers from aphasia will have a care plan that includes a number of measures that will ensure that the person receives the treatment and support that they need. I am conscious that we still have some way to go in developing our speech therapy workforce and I need to address that central issue.

Dr Turner: The numbers could be gleaned from GPs, because every GP cares for a number of people with aphasia. Information about many of the matters that have been raised could be gathered through community health partnerships and then transferred to the centre, if there was a mind to do that. That might help. Perhaps the Executive has considered such an approach.

Rhona Brankin: We need access to information about the incidence of the condition. However, probably the most effective way of getting that information would be for the development group that is considering the national stroke data set to include a question on the matter.

On the provision of care and support for people with aphasia, work is being done on joint assessment between health and social work services. Joint assessment provides an important tool whereby a programme can be designed to ensure that people's needs are met. I hope that a care plan would not only include information about access to speech therapy, for example, but consider broader social needs, because people can be severely isolated as a result of the condition.

Dr Turner: Nothing is more frightening than having a stroke and not being able to communicate. Sometimes a person understands what is going on but is unable to speak; other patients forget the word for a table, for example. The previous Minister for Health and Community Care suggested that Speakability join the neurological alliance of Scotland. I think that Speakability welcomed that participation, but said that the alliance's documents are such that communication with it is not aphasia-friendly, given that communication is very difficult for people with aphasia. Will you address that situation to make communication easier? There is also a problem with the complaints procedure. The documents are wordy, difficult and, as I said, not aphasia-friendly.

Rhona Brankin: Perhaps Speakability might want to work through Voluntary Health Scotland, which was set up specifically to help in the interface between NHS boards, community health partnerships and the voluntary sector. We want to address the issue that has been raised and support the petitioners' efforts in that regard. I am happy to work closely with Speakability because I recognise the value of the work that it does in this area. Although it is only a small amount, we are currently—

Dr Turner: Earlier, you mentioned a figure of £5,000 for Speakability. What was that money for, specifically?

Rhona Brankin: It was to help Speakability in its work.

Joe Logan: It was to help Speakability run support groups for aphasia sufferers.

Dr Turner: People can have an accident and suffer brain damage at any stage of life. If they live in a remote area, they will perhaps be taken to Glasgow to access specialist neurological science services. However, what procedures are in place to accommodate the needs of those people when they return home? We all know that we have a workforce problem in the NHS. I know that that has not come about as a result of the doings of those who are on this particular watch, but it will take a while to sort out the problem. Do we have any plans for dealing with the situation better? Even in the city, someone who has problems arising from a head injury can feel isolated as, towards the end of their treatment, they will have only short sessions with the professionals.

Rhona Brankin: I understand that the way in which support is provided through the stroke managed clinical networks is consistent with the needs of rural areas. Clearly, when a person is discharged from hospital following a stroke, there is a need for a clear plan to be developed by the health board, in conjunction with the local authority, so that appropriate support for the patient is provided when they are back out in the community.

On top of that, I recognise that there are particular issues in relation to the provision of services in rural areas. On the issue of workforce planning, we need to monitor closely where we are in the provision of allied health professionals such as speech therapists in rural areas.

Dr Turner: Would you allocate a speech therapist to an area if it did not have one?

Rhona Brankin: That is an issue for health boards to consider when they think about the way in which they provide speech therapy. Clearly, we expect the more rural health boards to make provision for speech therapy based on local needs.

Mike Rumbles: In response to Jean Turner's question on speech and language specialists, you said that you would let the committee know how many of the 1,500 posts for allied health professionals would be allocated to that profession. When you do that, could you also tell us the figures for the other eight professions? That would be helpful.

The Convener: It would be useful, from a broader perspective, if we knew how the 1,500 extra allied health professionals that are in the partnership agreement break down into the various professions. We do not know that at the moment.

Rhona Brankin: I am happy to do that.

The Convener: That concludes this afternoon's consideration of petitions. We will probably send a final summing-up letter to the minister but, as a consequence of today's meeting, the petitions are being closed.

16:00

Meeting continued in private until 16:19.

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