OFFICIAL REPORT
AITHISG OIFIGEIL

Citizen Participation and Public Petitions Committee

Wednesday 6 October 2021

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

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CITIZEN PARTICIPATION AND PUBLIC PETITIONS COMMITTEE

5th Meeting 2021, Session 6

CONVENER

*Jackson Carlaw (Eastwood) (Con)

DEPUTY CONVENER

*David Torrance (Kirkcaldy) (SNP)

COMMITTEE MEMBERS

*Bill Kidd (Glasgow Anniesland) (SNP)
*Alexander Stewart (Mid Scotland and Fife) (Con)
*Paul Sweeney (Glasgow) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

David Bishop (Scottish Government)
Jacqueline Campbell (Scottish Government)
Terry O’Kelly (Scottish Government)
Kevin Stewart (Minister for Mental Wellbeing and Social Care)
Maree Todd (Minister for Public Health, Women’s Health and Sport)

CLERK TO THE COMMITTEE

Lynn Tullis

LOCATION

The Adam Smith Room (CR5)

Scottish Parliament

Citizen Participation and Public Petitions Committee

Wednesday 6 October 2021

[The Convener opened the meeting at 11:15]

Interests

The Convener (Jackson Carlaw): Good morning, and welcome to the fifth meeting in 2021 of the Citizen Participation and Public Petitions Committee.

Under agenda item 1, I want to welcome a new committee member who is replacing Tess White. Although she was not with us for very long, I very much thank Ms White for her contribution to the committee, and I know that she will have an on-going interest in a number of the petitions in which she was involved.

We have now been joined by Alexander Stewart. Mr Stewart, do you have any interests to declare before assuming your position?

Alexander Stewart (Mid Scotland and Fife) (Con): I am delighted to join the committee, convener, and I have no interests appropriate to this committee to declare.

The Convener: Thank you very much. At this point, I should tell the committee that we will be taking evidence from ministers at about 11.30.

New Petitions

Rape Charges and Convictions (Record of Sex) (PE1876)

11:16

The Convener: Item 2 is consideration of new petitions. First of all, for those who might be tuning in to see the progress of their petition or others who might be watching this morning, I should make it clear that, in advance of considering petitions, we seek submissions from the Scottish Government and receive submissions from other parties to ensure that we have a certain amount of information at our disposal before we proceed.

Our first new petition is PE1876, which has been lodged by Lucy Hunter Blackburn, Lisa Mackenzie and Kath Murray. It calls on the Scottish Parliament to urge the Scottish Government to require Police Scotland, the Crown Office and the Scottish Courts and Tribunals Service to accurately record the sex of people charged or convicted of rape or attempted rape.

In its submission, the Scottish Government states that the crime statistics that it publishes

> “are derived from data held on the Criminal History System ... an operational database which is used for the primary purpose of recording of information on people accused or convicted of perpetrating a criminal act.”

The submission argues that it would therefore be

> “for Police Scotland to determine how the sex of people charged or convicted of rape or attempted rape is recorded on the CHS.”

Since the publication of our meeting papers, the committee has received several written submissions, including from Fair Play For Women, Dr Shonagh Dillon, For Women Scotland, Sharon Dowey MSP and the petitioners. In their submission, the petitioners highlight that crime recording practices in Scotland are overseen by the Scottish crime recording board. The role of the board, which is chaired by the Scottish Government, is to

> “support the production of accurate and objective statistics on crime in Scotland”.

The petitioners therefore reiterate that the action that they are calling for is for the Scottish Government to require Police Scotland, the Crown Office and the Scottish Courts and Tribunals Service to accurately record the sex of people charged or convicted of rape or attempted rape.

The petitioners also highlight in their submission guidance that the Scottish Government published last month on collecting data on sex, gender identity and trans status and which cites the investigation of “a serious sexual offence” as an example where data on biological sex is required. They argue that the fact that the chief statistician chose to single out sexual offending in this guidance lends weight to the argument that the nature and gravity of such cases justify accurate recording.

After that introduction, I seek comments from members.

David Torrance (Kirkcaldy) (SNP): I would like to keep the petition open and investigate the issue. I suggest that we write to the many stakeholders that have been mentioned—Police Scotland, the Crown Office and Procurator Fiscal Service, the Equality and Human Rights Commission and the Scottish Courts and Tribunals Service—and see what they have to say.

Bill Kidd (Glasgow Anniesland) (SNP): Mr Torrance's suggestion is perfectly logical and sensible. The petition is one of a group of petitions that make a statement about an issue that is not in the public domain to a great degree. For us to be able to respond successfully to the petition, it is incumbent on us to investigate the issue and to consider it further once we have received the responses.

Alexander Stewart: I concur with Bill Kidd and David Torrance. I think that the petition raises important questions about trust in statistics and data. It gives us an opportunity to seek more views and opinions from stakeholders so that we can make progress on the matter and take a measured approach to what is a very sensitive and delicate situation. It is important that we engage in that way and try to gain as much information as we can so that a more balanced approach can be taken in the process.

Paul Sweeney (Glasgow) (Lab): I agree that an evidence-led approach is critical, and I concur with colleagues that the routes of research that have been identified and proposed are appropriate, and I support our taking those actions.

The Convener: I am going to be a bit blunt here. I was struck by the following paragraph in the Scottish Government's submission:

> "The crime of rape is committed by someone with a penis, including a surgically constructed penis. As the petition mentions, a person (male or female) can also be convicted of rape when their involvement was art and part (assisted in the perpetration of the crime)."

I note that the petitioners wonder whether, although that is technically the case, such a rape has been the subject of any subsequent prosecution. I do not think that that is entirely clear.

There are a number of people to whom we can write. I invite suggestions as to who they might be.

David Torrance: I think that we should write back to the Scottish Government to ask whether there are any recorded figures that back up the statement that it has made in its submission.

The Convener: David, you have already suggested that we write to Police Scotland, the Crown Office and Procurator Fiscal Service, the Equality and Human Rights Commission and the Scottish Courts and Tribunals Service. We agree to do that. On the back of my comment, you have suggested that we also write to the Scottish Government to ask for validation of the actual prosecutions that have taken place in such circumstances. I presume that, when the Scottish Government talks about the use of prosthetics, such a crime could be committed by a male or a female. I would like to understand the reality of the analysis, rather than just the theoretical and technical aspects of the issue.

Bill Kidd: I think that that is perfectly logical, although I note that the Scottish Government has stated in its response:

> "The Scottish Government publishes each year a statistical bulletin known as Criminal Proceedings in Scotland. The bulletin presents statistics on criminal proceedings concluded in Scottish courts, including a breakdown by sex of convicted persons by crime type."

Therefore, given that the Scottish Government has already given us that information, I think that it would be better to contact the organisations that David Torrance identified before we approach the Scottish Government again with those results.

The Convener: That is fine. I am quite happy for us to take that approach, if members are content.

Members *indicated agreement.*

The Convener: Do members have any other comments?

Paul Sweeney: I wonder whether it would be worth our seeking an opinion from the Lord Advocate on the matter.

The Convener: Yes, we can do that, too.

We will keep the petition open, as it touches on issues that require to be clarified. We will consider the petition again when we have received responses from the various parties to which we have agreed to write.

Israel and Palestine (Learning and Teaching Resource) (PE1879)

The Convener: The next new petition is PE1879, on providing an accessible and professionally developed learning and teaching resource on Israel and Palestine. Before we proceed, I should declare an interest as convener in the previous parliamentary session of the cross-party group on building bridges with Israel. The CPG has yet to be reconvened, but I hope and expect that that will happen later this month.

The petition, which has been lodged by Hugh Humphries, on behalf of Scottish Friends of Palestine, calls on the Scottish Parliament to urge the Scottish Government to acknowledge the right of Scotland's pupils to a bias-free education on the topic of Israel and Palestine by ensuring that Education Scotland hosts an accessible and professionally developed learning and teaching resource on its national intranet service and re-establishes a strategic review group to oversee any revision of the original resource developed in 2016.

In its submission, the Scottish Government states that, in 2015,

> "A working group was established to scope out appropriate materials to support practitioners to deliver learning on the conflict and issues around Israel and Palestine."

In 2017, an initial set of resources was made available on Glow, Education Scotland's national learning platform, on a pilot basis.

The Scottish Government states that, by February 2018, it was apparent following engagement with interested stakeholders that the consensus on the resources sought by Education Scotland could not be achieved. It further states that an offer by Education Scotland to develop the resource further was not agreeable to the Educational Institute of Scotland as a joint owner of the resource. However, the EIS offered to publish the resources on its own website, where they are still available. The Scottish Government states that, given

> "the lack of consensus across stakeholders, and the EIS publishing the resource on a publicly available platform, the Scottish Government and Education Scotland concluded that the matter was closed."

The committee has received several submissions, including three, I think, from the petitioner. In his response to the Scottish Government submission, the petitioner states his view that it was clear from early 2017 that

> "there would be no consensus between stakeholder groups"

on the resource. He believes that the Scottish Government has been lobbied into amending the resource and then removing it from Glow. He also highlights that Glow is promoted as

> "the destination hub for staff looking for additional learning and teaching resources"

and argues that, with a teaching resource being placed on another platform, it is effectively being consigned "to obscurity".

Since the publication of our papers, the committee has received a late submission from the Scottish Friends of Israel and a further submission from the petitioner, which provide opposing views on the development of the education resource. These have been circulated to members and published on the Scottish Parliament website.

I would be grateful for members' comments on the petition.

David Torrance: Given that the Scottish Government and Education Scotland consider the matter to be closed and given that curriculum for excellence is a matter for local authorities and individual schools, I suggest that we close the petition under rule 15.7 of standing orders. I do not think that the committee can take it any further.

Bill Kidd: That is a reasonable approach, as the committee has probably taken the matter as far as it possibly can. I note that the Scottish Parliament has cross-party groups on building bridges with Israel and on the situation in Palestine, and that shows that the Parliament is not ignoring this important issue or simply throwing it away.

I do not think that it is for us to chase this matter, but I would like the MSPs on both cross-party groups to come together at some point and speak to each other in a rational manner. That might actually help with developing a better approach in Scotland. Of course, I do not know whether we can influence such a move.

The Convener: Two suggestions have been made: first, that we close the petition and, secondly, that we draw the petition to the attention of the respective cross-party groups. I am not totally sure that it is within our competence to do so with groups that have not yet been officially recognised by the Parliament, but I think that we could do that. Indeed, I think that it would be useful for the elected members of both groups to initiate a discussion.

Do members agree to close the petition on that basis?

Members *indicated agreement.*

Wind Farms (Community Shared Ownership) (PE1885)

11:30

The Convener: The final new petition is PE1885, lodged by Karen Murphy, which calls on the Scottish Parliament to urge the Scottish Government to make community shared ownership a mandatory requirement to be offered as part of all planning proposals for wind farm development.

In its response to the petition, the Scottish Government states:

> “electricity generation is a reserved matter under the Scotland Act 1998. As such the Scottish Parliament does not have the legal competence to change the law for a purpose relating to the regulation of the control of electricity generation”,

as requested in the petition. In the absence of powers to change the law, the Scottish Government has developed best practice documents to encourage community shared ownership for onshore renewable energy developments.

The petitioner’s submission argues that without a mandate to offer community shared ownership, the Scottish Government will not meet its new target of 2GW of community and locally owned renewable energy by 2030. The petitioner suggests using existing land and buildings transaction tax powers to raise a form of tax that requires all developers who do not own the land to offer 15 per cent community shared ownership to locally impacted communities.

Do members have any comments or suggestions for action?

Paul Sweeney: I found this petition quite interesting, as it sets out an interesting interface. Although the Scottish Government’s prima facie case is that the matter is reserved, we know of cases in the past—for example, the development of atomic power stations in Scotland—where planning powers have effectively been used to direct or influence policy decisions. An element of leverage could be deployed here, and we could look at opportunities to create greater incentives for community ownership.

I therefore think that the petition is worth further exploration and evidence gathering. The Scottish land fund and other stakeholders that operate in this field might have some interesting and innovative suggestions about how policy could be developed, particularly with regard to potential changes to planning legislation in Scotland, which is a devolved matter and could lead to the introduction of incentives that are indirect but would be nonetheless effective. As I have said, the matter is worth further exploration.

Bill Kidd: That is a perfectly reasonable way to move forward on an issue that, with the 26th United Nations climate change conference of the parties—COP26—coming up in Glasgow this year, Scotland should be at the forefront of with regard to thinking about future developments. I am perfectly happy with the suggestion that has been made.

The Convener: Do members agree to keep the petition open and make inquiries along the lines suggested by Paul Sweeney and supported by Bill Kidd?

Members *indicated agreement.*

The Convener: That brings us to the end of our consideration of new petitions. We will have a short suspension to allow witnesses to join us.

11:33

Meeting suspended.

11:36

On resuming—

Continued Petitions

Surgical Mesh and Fixation Devices (PE1865)

The Convener: Welcome back. This morning we have our first evidence-gathering session, and I am delighted that we have with us Maree Todd, the Minister for Public Health, Women's Health and Sport. Online we have, from the Scottish Government, David Bishop, mesh team leader, and—trying to join us, although he has not yet managed to establish a link—Terry O'Kelly, senior medical adviser.

PE1865 is a continued petition that was lodged by Roseanna Clarkin, Lauren McDougall and Graham Robertson. It calls on the Scottish Parliament to urge the Scottish Government to suspend the use of all surgical mesh and fixation devices while a review of all surgical procedures that use polyester, polypropylene or titanium is carried out and guidelines for the surgical use of mesh are established.

At our last consideration of the petition, on 8 September, we agreed to invite the Cabinet Secretary for Health and Social Care to give evidence at a future meeting. The Scottish Government has advised that the issues raised in the petition are within the portfolio of the Minister for Public Health, Women's Health and Sport.

Having welcomed the minister to the meeting, my first job is to invite her to make a brief opening statement before we open up the floor for questioning.

The Minister for Public Health, Women's Health and Sport (Maree Todd): Thank you. I am grateful to the committee for having me here today. At the outset, I want to acknowledge the efforts of those who have brought forward the petition; I commend them for doing so.

As members know, we have taken decisive action on transvaginal mesh. That action is well documented elsewhere, so it is important today to focus on the use of mesh in other situations.

We are acutely aware that there is concern about the use of mesh in other sites, not least from those who are experiencing complications. I am very sorry to read of the impact that those have had on individuals and their families. I was sorry to read in a submission on this petition that people felt that their symptoms were "dismissed" when they presented for help. Some people did not feel that they were informed of the risks of the procedure that they underwent, and it is only natural to feel let down in those circumstances.

If I may, I will for a moment focus on the use of mesh in hernia repair, which is a very common procedure in NHS Scotland. The Scottish Government asked the Scottish health technologies group to review available evidence on the use of mesh in hernia repair, first in adult inguinal hernia and secondly in abdominal wall hernia more generally. The group published a report on adult inguinal hernia in January 2020 that concluded that, compared with non-mesh procedures, using mesh resulted in lower rates of recurrence, fewer serious adverse events and similar or lower risk of chronic pain. We await the publication of the second piece of work, which considered the more general use of mesh in hernia repair and is expected imminently.

There are, of course, other gynaecology procedures for which the use of mesh has not been halted. In those circumstances, a high-vigilance protocol is in place across the whole of NHS Scotland. It is important to remember that some of those procedures are complex and long established, with few—if any—viable alternatives. To suspend their use would leave a cohort of people with limited or no treatment options.

I know that this is a very difficult and emotive subject. I welcome being questioned on it and I want to reassure the committee and anyone watching that the Government is absolutely committed to ensuring that everyone with mesh complications gets the care and treatment that they deserve.

The Convener: Thank you, minister. I acknowledge and applaud the Government's forthcoming bill on transvaginal mesh. That is a complete and comprehensive response to an earlier petition that, in the light of the bill, we were able to close at an earlier meeting. That petition was lodged by Elaine Holmes, one of my constituents, and Olive McIlroy. Having spoken to them, I know that they are really pleased. They have had meetings with the Cabinet Secretary for Health and Social Care and have been reassured by the approach that the Government is taking.

My final point in relation to transvaginal mesh is that, at a recent meeting of the Parliament's cross-party group on chronic pain, which I attended, although there was enthusiastic recognition of the bill, one or two women were concerned that some of the problems that had been experienced some years ago, with clinicians suggesting that some of the problems were illusory, were resurfacing and that they were being encouraged to request a mesh option. I point that out to the minister. It would be helpful to ensure that, at all times, we do not lose sight of future concerns of women who might be considered for such an option, given the various actions and prohibitions that the Government has put in place. I know that redress, recovery and restitution will be at the heart of the forthcoming bill.

When we first considered transvaginal mesh, there was a claim that there was a lack of evidence to support the concerns of the original petitioners and an assertion that there was an appropriate level of informed consent. I am struck that those two phrases reappear in the submissions that we have received. There is mention of a lack of evidence of concern about the use of mesh more widely, particularly in males. We know that men can, in general, be less forthcoming about their health concerns. I know that many men watched with interest the way in which women were able to come together and represent effectively the issues relating to transvaginal mesh.

The cabinet secretary referred to the lack of evidence, and the minister referred to the Scottish Health Technologies Group's report, which says that the advice for NHS Scotland was that

> "surgical mesh should be used for elective repair of inguinal hernia in adult males, following a process of shared decision making and informed consent."

What process is in place to identify difficulties that have arisen? There was no such process for women in relation to transvaginal mesh. What is the process of giving informed consent? In the case of mesh in women, the process was published, was available in general practitioner surgeries and was very much to the fore of conversations that subsequently took place with patients. With respect to the matter that we are considering today, how are those two issues properly covered and reflected?

Maree Todd: In such situations, it is really important that we work with the evidence that is available. I know that, sometimes, the evidence is limited and the full picture is not clear, but the available evidence points to the benefits outweighing the risks in most cases, as we have said.

As well as working with the evidence, we have to work with the principle of realistic medicine. You will know that that has been an important principle in Scotland for a number of years. It was considered to be almost revolutionary when Catherine Calderwood wrote the first report on realistic medicine, and we have come some way since then. I say that we have come some way but I am confident that we are not at the point at which we can be absolutely 100 per cent sure that every patient in every case and at every time engages in a shared decision-making process. There is on-going work to ensure that surgeons are confident about raising issues and that they raise them in a manner that enables people to ask questions. There is a power imbalance in medicine that makes it difficult for patients to ask questions of surgeons, so we need to make sure that patients are empowered and that shared decision making takes place.

11:45

You mention women being more able than men to get together to create strength through numbers. That is an interesting observation. One of the reasons for the women's health plan is that there is evidence that women face inequalities in access to healthcare, and one of the reasons for those inequalities is the general power imbalance for women and the fact that they are easy to ignore, as are many other groups of people who suffer health inequalities.

We are working on the issues in many different ways. With regard to gynaecological procedures that have not been halted, there is a high-vigilance protocol in place that will systematically gather evidence over time on the issues. It is unfortunate that Terry O'Kelly is not here but, to provide a bit more information, a system of unique device identification is being worked up, which will mean that a barcode is entered on patients' electronic records to give information about the device that was used, the surgeon who did the operation and other details about the surgery. That will enable NHS Scotland to follow cases through for a number of years, and we will have good quality data available to us.

On the general thrust towards informed decision making—

The Convener: May I interrupt? Terry O'Kelly has now joined us on audio. Given that you have just addressed that point, perhaps he will elaborate on it.

Terry O'Kelly (Scottish Government): I apologise profusely for information technology issues. I am sitting in my office in Aberdeen royal infirmary and I confirm that the NHS Grampian firewall is as robust as you might wish it to be. I am very sorry that I have therefore had to join you by phone rather than by video conference.

There are two parts to the issue. What evidence do we have and how is it shared? We are waiting for the Scottish Health Technologies Group to publish its assessment, which looks again at the use of mesh in not only inguinal hernia but other abdominal hernias. The original report found that the majority of the evidence that we have refers to the use of mesh in men, when what we are looking for is evidence on use of mesh not only in other sites in the abdominal wall but in women with hernias.

My understanding of the evidence is that the use of mesh has benefits but that there are risks. I started my training in the pre-mesh era—we are going back to the 1980s. The introduction of the use of mesh for hernia repair was transformational and made hernia repair much less haphazard, particularly with reference to outcomes. Recurrence is one of the major fears for people with a hernia who are having surgery, and mesh has made a significant difference to that.

For every patient, it is important that they understand what the procedure involves and whether they are going to have mesh implanted. It is for them, with the information that they have, to balance the risks of use of mesh against the benefits, and it is important that they are empowered when meeting their surgeon or clinical team to discuss those risks, look at alternatives and consider what would happen if they had no treatment at all.

As for ensuring that informed consent occurs, I would note that there are two experts involved in such decisions—the surgeon, who informs and advises, and the patient, who is the expert on themselves and on knowing what they want—and we need to ensure as best we can that the culture in our clinical spaces is such that those meaningful discussions are allowed to take place. We need, as far as we can, to flatten hierarchies and adjust attitudes to allow those decisions to be made and those discussions to take place in as equal a fashion as possible.

We also need to collect data, and that need has been spurred by the vaginal mesh issue. Coupled with that is a unique device identification project that will allow information about the individual device—for example, the barcode associated with the products—to be captured at the time of insertion, and it will be associated with the electronic patient record. That will allow us to know who the patient was, who the surgeon was, the place where it happened, the time it happened and what the product was so that surgical and product performance can be followed over time.

The Convener: I have two brief supplementary questions, after which I will go back to the minister and then to other colleagues.

First, what is the timeline for introducing the pathway for recording information? Secondly, you referred to the transformational advance that you felt was made by the introduction of mesh. Do the skills still exist for a non-mesh surgical option to be offered?

Terry O’Kelly: Taking your second question first, I would say that, when I talk about a transformational advance, I mean that anyone who trained in the pre-mesh era would, I think, recognise—as I did and as others have—what happened with the introduction of the use of mesh, which in these circumstances is non-tension and provides a synthetic network for in-growth connective tissue to create a robust scar and hernia repair. Before mesh, native tissue was used, as it still can be in certain circumstances; however, we know that, in a number of circumstances, such tissue is not normal and therefore generates disordered connective tissue formation and weak repair. That was augmented by a lattice or framework of non-absorbable polypropylene sutures that it was hoped would strengthen the initial process of repair and also stimulate in-growth tissue. However, the creation of those lattices was not uniform, and the resulting outcome was not predictable. The use of mesh reduced recurrence substantially which, as I have said, has been transformational and an important outcome for many patients.

As for non-mesh skills, it will be necessary for individual boards to look at that matter. We are expecting, with the publication of the Scottish Health Technologies Group report, to write to medical directors and potentially chief executives and governance and medicine leads and ask what provision boards have made for non-mesh surgery, if that happens to be one of the recommendations, whether there is a skills gap in that respect and, if so, how it might be addressed. I do not think that every patient will want hernia repair without mesh, but for those who do not want mesh to be used, we need to ensure that they are provided with a service. We will need to look at that.

As for the UDI project, that work is on-going. There is a programme board, and a paper on funding is being submitted to the Government. As you will appreciate, none of this comes free of charge; indeed, we are looking at funding of a number of millions of pounds to do this work.

The Convener: Returning to the minister, I will have to put her on the spot by asking whether the funding will indeed be available for recording that information.

Maree Todd: I cannot make a decision on funding until I see the full proposal, but the committee should rest assured that the Government is willing to look very closely at any information that comes forward. We are well aware of the need for a good, solid evidence base in this area.

The Convener: I interrupted you earlier to go to Mr O’Kelly, minister. Was there anything more that you wanted to say?

Maree Todd: To be fair, I cannot recall where I left things, convener. However, I will say that, with regard to the second report that is coming, I am more than happy to offer to come back to the committee to discuss that, if required. We will certainly inform the committee when that report is published and available.

The Convener: I am aware that I have not invited the mesh team leader, Mr Bishop, to comment. Is there anything that you wish to comment on before I bring in my committee colleagues, Mr Bishop?

David Bishop (Scottish Government): No, convener. I completely agree with everything that has been said already, so that is all good.

The Convener: Thank you. I call David Torrance.

David Torrance: Good morning. My questions are about hernia and abdominal mesh, and I should put on record that I am one of the lucky ones who has had success with that procedure.

On the issue of data, which has just been mentioned, do we have information on the number of procedures that are carried out and the number of complications that have been recorded in this area?

Maree Todd: I think that we do. Perhaps Terry O’Kelly can confirm this, but my understanding is that more than 5,000 procedures a year are carried out in NHS Scotland, and I think that the rate of complications is somewhere between 0 and 5 per cent. I will ask my clinical colleague to confirm that to ensure that the committee gets the correct information.

Terry O’Kelly: The Scottish Health Technologies Group has looked at the issue and will obviously draw some conclusions on it in its report. However, my understanding of the information is that between 5,000 and 6,000 mesh hernia repairs and 20 to 30 mesh removals are performed per year. Not many meshes need to be removed, and those that are removed form a small proportion of the total number. Of course, that is still very significant for the patients involved.

As for other complications such as chronic pain and bleeding, I cannot give you a precise number per year, because that is not recorded. However, with regard to chronic pain—which we know for the individuals concerned is a devastating experience—the evidence overall suggests that that is less likely or at least no more likely to occur with the use of mesh.

David Torrance: You mentioned mesh removal, but how easy is that procedure for someone who has complications after being treated for hernia in the abdominal area?

Maree Todd: I will pass to Terry O’Kelly to go into the issue in detail, but we are certainly aware that, when women came forward with concerns about transvaginal mesh, they had to go through a long process of feeling that they were not being listened to and that their concerns were being dismissed. Again, that partly reflects the power imbalance that operates throughout healthcare, but there was a feeling that it was difficult to raise concerns.

I am sure that every MSP around the table will have received mail from constituents who feel worried about raising concerns about their medical treatment and who worry that, if they do, they will somehow suffer in their passage through healthcare. Some of the experiences that we have heard about with regard to women who had transvaginal mesh implanted will be common to that situation, but I would like to think that, since 2018, we have put procedures in place and communicated well with healthcare professionals to ensure that that is not the case any more. Moreover, as I have said, the general thrust in NHS Scotland for a number of years now has been towards realistic medicine and holistic and patient-centred care. I would like to think, therefore, that that sort of thing will be less problematic than it might have been in the past.

I will ask Mr O’Kelly to talk you through the process of presenting with complications and then accessing surgery to remove mesh.

12:00

Terry O’Kelly: The question with mesh complications when they occur is whether the complication has been caused by the mesh itself or whether the mesh is caught up in some other condition that is causing the complication. As for mesh removal, it all depends on when the mesh was put in and how soon after surgery we are talking about. If the mesh has been in for a while, there will be associated connective tissue fibrosis; indeed, that is why it is there.

The impact of removal on a patient is determined by what the problem is and what other structures are adjacent to it. Unfortunately, because a hernia is caused by protrusion of the intestine through the abdominal wall, it is possible that the bowel can be in close contact with the mesh. In such circumstances, one would probably remove the mesh from tissues instead of removing tissues from the mesh, with the intention of preserving other structures intact, if at all possible. Once the mesh is removed, the patient will potentially be left with a defect that will need to be dealt with, and what happens will be determined by the circumstances that pertain at the time.

Locally in my own centre and in a number of others, colleagues with a specific interest in mesh surgery have, following the acquisition of training certification, formed multidisciplinary teams or clinical networks. The patients involved will be discussed and a strategy will be devised prior to surgery with regard to what is going to happen and how best to achieve an outcome that ensures not only that mesh is removed, if that is necessary, but that any residual defect that is left behind is managed.

If the bowel is involved, that is a major problem. It is not common, given the total number of meshes used, but for every patient involved, the situation is very challenging. The issue will need to be discussed in the way that I have highlighted, with a focus on the intention behind the procedure, what will be required and what the risks and benefits will be, and the patient, sadly, will have to look at all of that in what are very difficult circumstances.

David Torrance: When an individual presents with complications, they will go to their GP first. How aware are GPs of the issue? How much information is the Scottish Government giving them in that regard?

Terry O'Kelly: Most GPs will have worked in the era of mesh being used for hernia repair, and if there are any issues, they will refer the patient on or make contact with clinical colleagues.

As I have said, the question is whether the complication is a mesh problem or whether there is a problem with the surgery and the mesh has been incorporated into it. If someone who has had a hernia repair has, say, an infected wound, is the mesh the cause of the infection, or has the patient simply got a wound infection but there is mesh involved? GPs are pretty quick to refer patients back. Moreover, I should make it clear that, when patients have problems, it is incumbent on my colleagues to ensure that every one of them is welcomed with sympathy and empathy every time and dealt with in the holistic way that has been discussed.

The Convener: Did you want to add anything, minister?

Maree Todd: No. That was perfect.

The Convener: I have just one follow-up question. One of the scandals that arose with transvaginal mesh related to the quality of the mesh itself. It turned out that the regime that was in place to ensure the highest standard of mesh material was really not robust and, to our shock and dismay, some of the mesh that had been fitted in some women was no different from the mesh that is found wrapped around packages that come through the post. Is a strong regime in place for the mesh procedures that we are talking about to ensure the quality of the product that is fitted in any operation?

Maree Todd: As I understand it, it is the Medicines and Healthcare products Regulatory Agency that grants licences for those products on a United Kingdom-wide basis. David Bishop might want to come in on this but, as I understand it, the transvaginal mesh situation prompted a review of all those processes. I think that on-going work is still being done on that.

Our feeling in the Scottish Government is that the MHRA's procedures should be absolutely robust and that there were lessons to be learned from that situation. We are keen to ensure that those lessons are learned.

I invite David Bishop to give some more information on that front.

The Convener: I can say to Mr Bishop that, if we were relying on the MHRA at the time, it was woefully inadequate in its explanation of its procedures and in respect of the subsequent regulation to ensure that only proper materials were used. It is clear that some products bypassed that. Can patients now proceed with greater confidence?

David Bishop: Terry O'Kelly might want to comment further on that, as he perhaps knows more about it than I do. That was taken up with the MHRA at the time of the transvaginal mesh issue. Our ministers at the time and the then chief medical officer wrote to it about that issue to query it. As the minister said, we raised concerns. My understanding is that the MHRA is reviewing procedures. It is also taking forward new medical device regulations as a result of Brexit and so on. That is all being looked at.

The Convener: In the interests of time, we will leave that question.

Bill Kidd: Is there any plan to ensure that everyone who has had a mesh procedure over a period of time to be decided is contacted to ask them about their experience since they had the treatment? I know that there are people who have been uncertain about how they can complain, who they can complain to, and whether they are wasting people's time. However, they are in discomfort, and having that material inside them is affecting their lives.

Maree Todd: That would be a challenging undertaking retrospectively. However, on the use of mesh in other sites for gynaecological procedures that was not subject to the halt, the high-vigilance protocol has a number of procedures in place that ensure that that is perfectly possible. There is documentation of all the procedures and complications and on the reporting of complications on an agreed database. Crucially, documentation is given to every single patient who is treated with mesh that details their procedure and the mesh product used, along with the name of the patient. Therefore, in future, the precise situation that you have outlined will be less likely to arise in gynaecological procedures in which mesh is used.

Bill Kidd: That is very important. I recently spoke to a man who had an abdominal hernia repair that involved mesh and who has suffered great pain and almost disability as a result. The issue has not been covered widely in the media, but there are men who do not know what to do next. They do not know who to complain to and whether they should just go back to their GP or somewhere else. There are people who have problems but who do not know what to do about them. I wonder whether everyone who has had the procedure could be contacted, because issues might then be raised that are being ignored at the moment.

Maree Todd: I am not sure how that would happen, given the scale of the procedures, with 5,000 to 6,000 per year being carried out since the 1980s. However, as Mr O'Kelly outlined, patients should first present at their GP.

People must be listened to, because the key point that has come out through all the testimonies is that people do not feel listened to. We must learn from the transvaginal mesh incident—people's concerns have to be taken seriously and acted on appropriately. In many areas, there will be a multidisciplinary team in place, as Mr O'Kelly outlined. There is a complexity in dealing with mesh complications, and the multidisciplinary team and clinical networks will together look at each individual case. However, it must be straightforward for patients to access that level of expertise when they find themselves in the situation that Mr Kidd describes.

Alexander Stewart: In your opening statement, you acknowledged that individuals have been let down and dismissed, and you talked about the risks that are associated with the complicated situation that many individuals find themselves in. You have talked about lessons being learned, which is vital. What you have said is helping me to think that that is happening as a result of this process.

Where are we with longer-term research on hernia? We have learned from the transvaginal mesh issues and gone through those, but is longer-term research being done when it comes to hernia? If there is no research, how are you taking forward some of the issues that have been raised by individuals who have suffered?

Maree Todd: Research will be on-going all the time. The Scottish Government has asked for a review of the evidence. The Scottish Health Technologies Group has already published a report of a review of evidence on primary inguinal hernia repair in men. Following that, we asked the group to examine hernia more broadly, to include men and women and to review the outcome of mesh versus non-mesh surgery in a variety of abdominal wall hernias. We have asked the group to look at the published evidence on that and to come back to us, and we are waiting for publication of that report. We expected it at the end of summer this year. That is quite a broad term, but we are hopeful that it will be published very soon and that it will give good-quality evidence. Without high-quality and well-reviewed evidence, it is not possible for patients to make an informed decision.

Alexander Stewart: Obviously, the pandemic has had huge implications for the NHS, with individuals not having the opportunity to have operations. What is the Government doing to ensure that people do not have to seek private treatment? With the mesh situation, individuals had to seek private help. Due to the waiting times and lists, they could not get an opportunity, and they felt that they had no option other than to go private to ensure that they received the care that they required.

12:15

Maree Todd: You are absolutely right—the pandemic has placed immense pressure on the NHS. We talk about that in almost every parliamentary committee and regularly in the chamber. Undoubtedly, after 18 months of impact on NHS capacity and how we work, there is pent-up demand for surgery in a number of clinical areas such as orthopaedics. Cancer surgery has been prioritised throughout the pandemic.

An NHS recovery plan is in place. Work is being done to ensure that we can tackle the pandemic and keep the number of hospitalisations at a level at which the NHS can function. There are plans in place for the NHS to recover from the pandemic. National treatment centres are being developed where surgery can take place. The process will not be instant or overnight, but there is a recovery plan in place that will benefit everyone who is waiting for treatment, not just the people whom you mentioned.

Paul Sweeney: Following on from those points, I noted that the petitioner highlighted the work of surgeons at the Shouldice hospital, who are pioneering alternative treatments in natural tissue repair. There have been interesting outcomes from that technique and the study of the technique. What is your view of it? What are we doing to train surgeons in Scotland in it? Are we developing a critical mass of knowledge, so that we can use it as an alternative means of treatment?

I am conscious of the significant inertia in the medical profession in relation to the use of mesh. The technique is long established and has been normalised in Scotland, so trying to move away from it is bound to meet with some resistance. Are there better ways to embed and build up alternative, pioneering techniques?

Maree Todd: That is a clinical decision, on which I will defer to Mr O’Kelly. Comparing the two techniques is way beyond my level of expertise. I ask Mr O’Kelly to give you some information about whether a process is under way to gather evidence on pioneering techniques and to compare them with existing techniques.

Medicine is slow to change practice. You will know that, in my past life, I was a clinical pharmacist. When I first started out in my practice, there was a gap of about 15 years between evidence and practice. The internet has speeded up the ability to obtain and review evidence from all over the world. We are faster at gathering evidence.

We have seen a brand-new virus that nothing was known about. During the pandemic, scientists and clinicians from all over the world collaborated to find a way forward in the emergency in which we found ourselves. I am very hopeful that some of that collaborative effort will survive into future practice and mean that we will solve some of the big questions. I also hope that, at the heart of that, there will be fewer commercial concerns and more altruism when it comes to solving some of the medical problems.

That was a bit of a philosophical answer. I will let Mr O’Kelly give you the clinical answer.

Terry O’Kelly: Shouldice repair, which has been popularised by the Shouldice hospital, is a non-mesh tissue repair for inguinal hernia. I think that that will be one of the treatments that one would look to if patients did not want mesh to be used. There are other non-mesh techniques.

Shouldice repair is not something that every surgeon undertaking hernia repair in Scotland would be familiar with, but there will be those who are skilled in it. We would need to do a skills assessment and address any skills gap, if one exists. However, the technique will not be applicable to non-inguinal hernias; it might also not be appropriate for patients with larger defects, or for very degenerative tissues. It is certainly a technique that we would look at.

The Convener: Thank you. Are you content, Paul?

Paul Sweeney: I think so. I just note that it is interesting that the onus seems to be on the patient to demand an alternative. That goes back to the issue about the power imbalance when it comes to knowledge and the need for people to be quite robust in their challenges. I wonder whether that is a potential concern.

Maree Todd: To be absolutely clear, the process of informed decision making is about the patient and the clinician sitting down together, understanding the condition that the patient presents with and talking over the options. It involves consideration of the elements of the acronym that is gaining popularity in realistic medicine circles, which is BRAN—the benefits, the risks, the alternatives and the effect of doing nothing. Alternatives are absolutely part of that process. That approach is becoming ingrained in medical practice—for example, the acronym appears in advertising campaigns in the virtual waiting room for NHS services in my area. The intention is to normalise that process.

The clinician should be sitting with someone and discussing alternatives. They should say, “Here’s what you’ve got and this is my understanding of the factors that are significant for you as an individual. What do you need me to understand about you as an individual? Let’s see what alternatives are on the table and make a decision together.” That is how it should be. The onus should not be on the patient to ask questions. We intend to create an atmosphere in which it is normal for the patient to ask questions. It is their body that is the subject of the process, and it is altogether more satisfactory if the patient is empowered to make a decision in such situations.

The Convener: Thank you, minister. I also thank David Bishop for his contribution and Terry O’Kelly for his audio participation.

I would like to reflect on what we have heard. I suggest that we take time to read the *Official Report* of this discussion and return to the petition at a subsequent meeting. Do members agree with that suggestion?

Members *indicated agreement.*

The Convener: We will suspend briefly to bring in the next panel.

12:22

Meeting suspended.

12:23

On resuming—

Autism Support (PE1837)

The Convener: We will now discuss PE1837, which is a continued petition that was lodged by Stephen Leighton. It calls on the Scottish Parliament to urge the Scottish Government to clarify how autistic people who do not have a learning disability and/or mental disorder can access support, and to allocate investment for autism support teams in every local authority or health and social care partnership in Scotland.

When we last considered the petition, we agreed to invite the Cabinet Secretary for Health and Social Care to give evidence at a future meeting. The Scottish Government has advised that the issues raised in the petition are within the portfolio of the Minister for Mental Wellbeing and Social Care. I am therefore delighted to welcome the relevant minister, Kevin Stewart. He is accompanied by Hugh McAloon, deputy director for mental health complex care; and Jacqueline Campbell, unit head, learning disability, autism and neurodiversity.

I invite the minister to make a brief opening statement that might help inform our discussion.

The Minister for Mental Wellbeing and Social Care (Kevin Stewart): Thank you. It is a little strange to be back in a committee room. I have participated in committee meetings over the past while, but this in-person stuff is going to take some getting used to again.

I am grateful for the opportunity to give evidence to the committee on how the Scottish Government is supporting autistic people.

The Scottish Government published its plan “Learning/Intellectual Disability and Autism: Towards Transformation” in March. The plan considers the actions that are needed to shape supports, services and attitudes to ensure that the human rights of autistic people and people with learning and intellectual disabilities are respected and protected. We are taking forward exciting new leadership and engagement plans with central roles for autistic people and people with a learning disability, putting them in the driving seat.

The Scottish Government has just published the “Evaluation of the Scottish Strategy for Autism”. The evaluation concludes that the strategy delivered valuable resources and services but that more work needs to be done to meet the Government’s ambition of allowing autistic people to be supported to live productive lives and of seeing change at the local level.

In response, I was delighted to announce £650,000 this financial year for tests of change on adult neurodevelopmental pathways for diagnosis and support. I also announced new funding of £425,000 to trial the Scottish Government’s new learning disability and autism leadership and engagement work, and £400,000 for the understanding autism project charity funding for a second year.

The Scottish Government also established the national autism implementation team, which supports health and social care partnerships to consider best practice and improved service in the redesigning of autism diagnostic services.

On Wednesday 8 September, the Scottish Government published the “National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care”, and on 14 September I announced £5.25 million for NHS boards to build professional capacity to support children and young people with neurodevelopmental support needs.

Additionally, we have listened to the calls for a commissioner and have committed to publishing a learning disability, autism and neurodiversity bill and to creating a commissioner to uphold and protect the rights of autistic people and other people with neurodevelopmental difference. We are committed to that and will commence scoping work on the bill shortly.

Let me be clear that although money is always important, this is not just about money. It is about how we treat people with neurodevelopmental difference in our communities, our workplaces and our schools. It is about innovation, focus and working together across national and local divides to provide solutions that work for the people we are here to serve. That is what our new engagement will support and, as members will be aware, I am committed to ensuring that the voices of those with lived experience are at the heart of all that we do.

I am interested to hear the views of the committee and I look forward—or maybe not—to your questions.

The Convener: I want to take a moment to acknowledge the work of Mark McDonald and other former colleagues who did a lot in the previous session to ensure that these issues were at the forefront of concern and whose work in the area has helped inform, and has probably led to, the actions that the Government is now taking.

I invite colleagues to lead the questions, starting with David Torrance.

David Torrance: Good afternoon. The independent review of the Scottish Government and Convention of Scottish Local Authorities 10-year autism strategy was published this month. What recommendations will the Scottish Government take from the strategy?

12:30

Kevin Stewart: We must look closely at all the recommendations and find a way forward to ensure that we provide better support and create better opportunities for people with autism.

I am sure that the committee will pick up on this, and I can go into further detail if required, but the fact is that, although the services provided to people with autism and learning difficulties are very good in some areas, I cannot claim the same for other parts of the country. We need to do our level best in all parts of the country to ensure that we are providing the services and help required to all folk with a neurodevelopmental condition. That will take quite a bit of work.

In all of that, and in light of the recommendations, we all have a duty to continue to listen to the voices of those with lived experience about what works and what does not work for them.

David Torrance: You talked about having services in each of the 32 different local authorities for those diagnosed as autistic. Do we have figures for the number diagnosed every year in Scotland?

Kevin Stewart: I have a figure for the number of autistic people in Scotland; I do not have a figure for the number who are diagnosed each year, but I can see whether we can provide that for the committee.

According to the Scottish Government-funded microsegmentation of the autism spectrum research project, whose report was published on 26 March 2018, there are approximately 44,133 autistic people in Scotland, with a national Scottish autism prevalence rate of 1.035 per cent. Around 32.7 per cent of autistic people also have a learning disability. As I have said, I do not have figures for diagnoses per annum to hand, but we will see what we can do to provide the committee with that information.

The Convener: If Hugh McAloon and Jacqueline Campbell want to come in at any point, they should try to catch my eye through the perspex screen between us. I can just about see you, despite the reflections.

Paul Sweeney: I thank the minister for helpfully outlining the Government's intentions. One thing that I noted in the petition and the background reading was the reference to the independent review, which reported to ministers in December 2019. A key finding of that review was that the current legislation was indirectly discriminatory towards autistic people. I welcome the fact that new legislation is in the pipeline, but in the meantime it is important that we consider what actions you as minister might take to protect the human rights of autistic people until that new legislation can kick in, given that that will obviously take quite some time.

Kevin Stewart: I am not a person who likes to stand still—there always has to be continuous improvement. Although there is no doubt that the legislation is very important, that is not to say that we should not be taking action in the here and now, where that is possible, outwith the legislative framework.

Government officials are working to consider all the recommendations from the review. I have already been provided with some advice and we have already taken some actions, as I outlined in my opening statement. We will co-ordinate a full Scottish response to the report; coronavirus has delayed some aspects of that work, but we are now getting back on track.

Work has been carried out on a number of specific recommendations. For example, we have already published new mental health standards; we have commissioned the Scottish learning disabilities observatory to carry out a study on the use of psychotropic medication; and we have committed to scoping out and introducing the bill that I mentioned in my opening remarks. As we move forward, we will continue to do all that we can outwith the legislative framework to ensure that there are improvements.

Alexander Stewart: Minister, you mentioned the role of the health and social care partnerships, but I want to tease out what part the local authorities play. Have you identified any councils that require more support in order to provide these services or in which this is a key area of concern?

Kevin Stewart: It is fair to say that when you take on a new ministerial role you have to do a wee bit of stocktaking to see what is going on out there. In my new role, I have been talking to lots and lots of folk about the various issues that I am responsible for, and the committee can be assured that that general stocktake applies right across the board.

As I said, I know of a number of health and social care partnerships and local authorities that are doing very well in this area, and I know of a number of others that are not doing as well as they should be to meet their people's needs. I will continue having the very detailed conversations that need to be had, to do that stocktake and to ascertain what is going on out there that is right and what is not going quite so well.

Mr Stewart knows me from numerous other committee appearances—we seem to cross each other's path on a regular basis—so I will probably bore him by saying something that he has heard me say many times before. We have had some success in other areas with this approach, but I am one of those folks who get very frustrated when we do not export best practice across the board. We are a small country, but sometimes people are afraid to blow their own trumpets and say what they are doing well, which means that others do not have the opportunity to pick up that good practice. Convener, I assure you, Mr Stewart and the rest of the committee that my ethos with regard to the exporting of best practice remains in place. That is what we will aspire to do.

Alexander Stewart: Has it been recommended or proposed that autism services be placed with the proposed national care service? If so, where would responsibility for scrutiny and accountability lie?

Kevin Stewart: I will not pre-empt the consultation on the national care service. We have posed a number of questions in the consultation document with regard to what should be in the service, and we will look at the views that we get back. I know that some folk think that some of the questions and proposals are a little bit controversial. No matter what, the national care service will be extremely important as we move forward, because it will set high-quality standards across the board. That is what people want from services, whether they be in or out of the national care service, and that high-quality standard is what we require across the board, including in autism and neurodevelopmental services.

Service users in the autism community and in others are often very frustrated about accountability, and we must ensure that they know who is accountable for the delivery of services. We cannot afford to have a continuation of the postcode lottery in which people who live in one place get a very high-quality service while those in the authority next door have much less of an entitlement. We need high-quality standards, no matter whether services are in or out of the national care service.

The Convener: Do you have a supplementary, Mr Sweeney?

Paul Sweeney: Yes, convener. I am pleased to hear about the minister's ethos of continuous improvement, but one of the themes that has recurred in this morning's evidence-taking is the power imbalance that service users often experience. Could there be a mechanism for people to report any good practice or exceptional activity that they have experienced? Such practice could, in turn, be fed in to the system so that it can be learned from and then introduced across the board. In short, service users could help inform this sort of thing. Perhaps it happens already, but given what we have been discussing, allowing service users to illustrate where good things are happening might be helpful as a pointer in setting standards of excellence and could be considered ahead of the new legislation being introduced.

Kevin Stewart: I will be a bit controversial and say that I agree with most of what Mr Sweeney said. However, we must also recognise that services deemed good in the minds of some folk might be deemed not so great by others.

When I was in my previous role as Minister for Local Government, Housing and Planning, vast changes, some of which are still on-going, were made in homelessness policy, regulation and legislation, and the voices of folk with lived experience of homelessness were at the very heart of what we did. I am not saying that that was absolutely perfect—it never is—but we are on a good journey and in a good place, because we listened to people and their experiences. I fully intend to do the same in this role. Whether it be in relation to autism services, social care or mental health services, I will continue to listen to the voices of lived experience.

In some of the conversations that I have had thus far in coming into this new role, I have noted that some of the assumptions that we all make, rightly or wrongly, about what we think needs to be improved first and what our priorities should be are not necessarily shared by folks with lived experience. I have talked to folk about mental health services in general, and something that has cropped up again and again and that I think is one of the top priorities for the groups that I spoke to—I know that some folk will disagree with me—is the fact that the complaints system does not work for people. We need to look at that very closely in this area and in others.

Beyond that, in those areas where there is very good practice, you will usually find that service users have helped to shape the service in question. Again, that is something that we need to push further. Some local authorities and health and social care partnerships are very good at listening to the voices of lived experience and shaping services and while others are not quite so good. We need to continue on this journey to ensure that everyone is doing that. I would also point out that one of the proposals in the national care service consultation is for community health and social care boards to have the voices of lived experience at the table, which I think is essential.

Bill Kidd: You have already addressed some of the issues that I am about to ask about, but it might not do any harm to take them from a slightly different angle. Submissions that we have received link the issue that we are discussing to a misunderstanding at service level about where individuals should be directed for appropriate autism support. Does the Scottish Government plan to review the legislation in respect of autistic people so that it is no longer assumed that they have either a mental disorder or a learning disability? If so, is there any timescale for such a review?

12:45

Kevin Stewart: The programme for government, which was published in September, committed the Government to carrying out scoping work on the remit of and powers in the learning disability, autism and neurodiversity bill in this parliamentary session. It will take time to scope all that and get it right, and we need to continue some of the conversations that we have been having. For example, there are polarised views on the proposals for a commissioner, and we have to listen to all sides if we are to get that right. That scoping work will happen and we will move on with the matter in this parliamentary session.

Concurrently with that, the Scottish mental health law review is due to report next September. As the committee will likely be aware, the review will make recommendations to give effect to the rights, will and preferences of the individual by ensuring that mental health, incapacity and adult support and protection legislation reflects people's social, economic and cultural rights, including the requirements of the United Nations Convention on the Rights of Persons with Disabilities and the European convention on human rights. That said, I think that today's Supreme Court ruling has put some difficulty in our way with regard to embedding certain UN convention rights in legislation, but that is probably a discussion for another day. You will be glad to hear, convener, that I will not go into a rant about that, but it is fair to say that, like many others, I am quite irate about it.

The Scottish mental health law review is extremely important in all this, but we need to listen to people and ensure that we embed rights in any legislative change, whether that be in the learning disability, autism and neurodiversity bill or in anything that comes from the review itself.

Bill Kidd: Without going into a rant, convener, I have to say that my follow-up question was taken away from me there.

The Convener: I observe only that fools rush in where angels fear to trend, minister, so I am grateful for your forbearance in holding back.

Kevin Stewart: It is not like me, convener—and it is not like you either, but there we go. [*Laughter*.]

The Convener: The questions that Bill Kidd asked are important and go to the heart of Stephen Leighton's petition, so I am glad that we have touched on the matter.

In her submission, Professor Jean McLellan, former director of Autism Network Scotland, highlighted the creation of one-stop shops across Scotland. She thought that the pilot had been "highly valued", that the space had "lessened social isolation" and "anxiety and depression", and that it had been informative for people, who gained useful advice and support. However, finances were withdrawn following the pilot, and only some of the spaces that the pilot had put in place had survived. Do you have a view on the success of the pilot and on future accessibility in that respect?

Kevin Stewart: I will make some general comments about the provision of one-stop shops, which I think are important. I think that the point being driven at is that provision varies from local authority to local authority, and local authorities are responsible for commissioning and delivering those local services. We have examples of really positive provision in some local authorities such as South Lanarkshire, which operates an autism resources co-ordination hub, and Edinburgh, with its Lothian one-stop shop. There is also a one-stop shop that is supported by Perth and Kinross. However, there is still work to do to ensure that other parts of the country have the right provision, because it is fair to say that some parts have very few services to meet the needs of autistic people.

The Government works with national and local autism charities, which also operate a number of services. Indeed, I was having a discussion about that very issue yesterday. Scottish Autism and the National Autistic Society have national coverage, but we also have close links with Inspiring Scotland and with effective and valued local organisations, such as the Aberdeen one-stop shop and Autism Rights Group Highland.

As I said—and I think that we have to be honest about this—provision is excellent in some places but not in others, and we need to encourage, cajole and perhaps even take further action through regulation to ensure that, in the short term, provision across the board gets better. Beyond that, we have the opportunity with the changes that we are making through the national care service and other actions around that to put in place a framework of high-quality standards that all can expect.

The Convener: Thank you for that. It leads me to wonder about the autism services that are provided to an individual who does not have a learning disability or mental disorder. How do we ensure that a properly and sustainably funded resource is available to that group of autistic individuals?

Kevin Stewart: I will ask Ms Campbell to respond and then come back in, convener.

Jacqueline Campbell (Scottish Government): Some of the work that we are doing, particularly the work that the minister announced on the development of a single adult neurodevelopmental pathway for diagnosis and support, is quite critical in that it seeks to support people in a much more holistic way, as is happening with children. Instead of being sent down a certain path that depends on someone making a decision on which of their issues is most important, people can be treated as a whole. We would like to develop that work so that, no matter whether people have a combination of things besides LD and autism, they still get the support that they want. As the minister announced, we and three or four health and social care partnerships will in the next year be embarking on some work to test out those approaches.

Kevin Stewart: Given all that we are doing at this moment, it is important to highlight that the work that we will be carrying out and the legislative change that we will be making in care in Scotland put the person at the very heart. What we need on many occasions are more person-centred approaches. That happens in many cases, but where it does not happen, it causes great difficulty for the individual, their family and often their community. We have to start looking at such approaches more and more and, indeed, at a very early stage, instead of waiting for somebody’s life to reach crisis point before the services that are required are provided. We must move to much more preventative measures and take folks’ views into account to ensure that we get this right as we move forward.

The Convener: Perhaps, as I have come to the matter as a consequence of the petition and have followed some of the work that has gone on in the Parliament, I can ask a question that will help me understand the broader issue. Do we know how many people are diagnosed as autistic in Scotland? If so, do we know whether there are any regional variations? You have mentioned the disparity of approach between local authorities, but does that influence our understanding of the number of people diagnosed with autism or is that not a by-product of the variable approach? Do we have a fairly clear idea about this?

Kevin Stewart: I gave you some numbers earlier on, convener, but I will repeat them for you. However, I do not have at my fingertips the figures that Mr Torrance asked for with regard to the number of people diagnosed each year or any statistics showing regional variation. Ms Campbell, who is the fount of all knowledge, might well have them, and if not, she will without a doubt find them. As I said earlier, there are approximately 44,133 autistic people in Scotland—I did say “approximately”, but it is quite a specific number.

On the question of regional variation, I will pass over to Ms Campbell.

Jacqueline Campbell: We do not formally collect statistics that show how many people are diagnosed each year. With autism, in particular, we are very aware of certain issues. For example, there might be not only children and young people but adults coming forward for diagnosis, and that population is growing. We can certainly look at whether we can do something that gives you a better idea of what things look like across the country.

I should point out that we support the national autism implementation team, which carries out that sort of work, but in a less formal way than actually collecting stats. It also works with leads across the country on their diagnostic pathways.

Diagnosis can be really critical for some autistic people, but not for everyone; it is very much a personal choice. Diagnosis is one aspect, but there is a wider range of people who might receive support but have not been formally diagnosed.

Kevin Stewart: That is something else that we need to take cognisance of in shaping services: waiting for a diagnosis does not mean waiting for help and support. Help should come naturally, no matter whether or not there is a diagnosis. Some places have got that service provision and help right, but that is not so much the case in other places.

The Convener: I apologise to David Torrance for not having properly understood the response to his earlier question.

As members have no further questions, I thank the minister, Hugh McAloon and Jacqueline Campbell for their incredibly helpful evidence and participation this morning. I think that I would like to reflect on the evidence that we have heard, have a chance to read the *Official Report* and then consider how we might take the issues forward at a subsequent meeting.

That brings us almost to the end of the meeting. For the benefit of everyone watching and committee colleagues, I want to place on record the committee’s thanks to our clerk Gemma Cheek, who is leaving us. Our loss is the Education, Children and Young People Committee’s gain. I am very sorry that she is leaving; she has been with the committee for the past two years and has provided us with a high quality of understanding and support. We very much wish her all the best in her new appointment.

Meeting closed at 12:58.

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