



The Scottish Parliament
Pàrlamaid na h-Alba

PUBLIC PETITIONS COMMITTEE

AGENDA

3rd Meeting, 2021 (Session 5)

Wednesday 10 February 2021

The Committee will meet at 9.30 am in a virtual meeting and will be broadcast on www.scottishparliament.tv.

1. **Consideration of continued petitions:** The Committee will consider the following continued petitions—

PE1517: Polypropylene Mesh Medical Devices;
PE1707: Public Access Defibrillators;
PE1722: Parking charges at island lifeline ferry ports;
PE1775: Introduce statutory allergy care legislation in nurseries and schools;
PE1780: Consultation on the closure of large shops on New Year's Day;
PE1789: Learning difficulties and disability qualifications;
PE1820: Compulsory bereavement education in schools;
PE1836: Expand the remit of the Care Inspectorate to investigate individual child protection complaints;
PE1837: Provide clear direction and investment for autism support;
PE1839: Review maternity models in remote and rural areas;
PE1840: Addressing racism in Scottish education; and
PE1841: Allow a designated visitor into care homes.

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The papers for this meeting are as follows—

Agenda item 1

Note by the Clerk	PPC/S5/21/3/1
Note by the Clerk	PPC/S5/21/3/2
Note by the Clerk	PPC/S5/21/3/3
Note by the Clerk	PPC/S5/21/3/4
Note by the Clerk	PPC/S5/21/3/5
Note by the Clerk	PPC/S5/21/3/6
Note by the Clerk	PPC/S5/21/3/7
Note by the Clerk	PPC/S5/21/3/8
Note by the Clerk	PPC/S5/21/3/9
Note by the Clerk	PPC/S5/21/3/10
Note by the Clerk	PPC/S5/21/3/11
Note by the Clerk	PPC/S5/21/3/12

Public Petitions Committee

3rd Meeting, 2021 (Session 5)

Wednesday 10 February 2021

PE1517: Polypropylene Mesh Medical Devices

Note by the Clerk

Petitioner	Elaine Holmes and Olive McIlroy on behalf of Scottish Mesh Survivors - "Hear Our Voice" campaign
Petition summary	<p>Calling on the Scottish Parliament to urge the Scottish Government to:</p> <ol style="list-style-type: none">1. Suspend use of polypropylene Transvaginal Mesh (TVM) procedures;2. Initiate a Public Inquiry and/or comprehensive independent research to evaluate the safety of mesh devices using all evidence available, including that from across the world;3. Introduce mandatory reporting of all adverse incidents by health professionals;4. Set up a Scottish Transvaginal Mesh implant register with view to linking this up with national and international registers;5. Introduce fully Informed Consent with uniformity throughout Scotland's Health Boards; and6. Write to the MHRA and ask that they reclassify TVM devices to heightened alert status to reflect ongoing concerns worldwide.
Webpage	parliament.scot/GettingInvolved/Petitions/scottishmeshsurvivors

Introduction

1. This is a continued petition, last considered by the Committee at its meeting on 22 October 2020.
2. At that meeting, the Committee agreed to write to the Cabinet Secretary for Health and Sport. It also agreed to write to the petitioners, Dr Wael Agur, the Chief Medical Officer and other relevant professional bodies.
3. The Committee has since received written submissions from the Cabinet Secretary for Health and Sport, the then Interim Chief Medical Officer and the Royal College of Obstetricians and Gynaecologists. A submission has also been received from the petitioners.
4. The Committee is invited to consider what action it wishes to take.

Committee Consideration

Cabinet Secretary for Health and Sport's submission

5. In her most recent written submission, of 27 November 2020, the Cabinet Secretary for Health and Sport responded to questions in respect of the Patient Safety Commissioner, engagement with the petitioners, engagement with Dr Veronikis and the future care of women with mesh complications.

Patient Safety Commissioner

6. The Cabinet Secretary states that proposals are being developed for a Patient Safety Commissioner (PSC). These proposals will be informed by a patient reference group and another, running in parallel, to provide expert input.
7. The patient reference group includes members with lived experience of the issues arising from the use of mesh implants, Sodium Valporate and Primodos. The Cabinet Secretary envisages that the other group will comprise organisations that currently have a role in the patient safety landscape in Scotland.
8. It is the Cabinet Secretary's intention that these groups will help to shape the draft remit of the PSC, which will then be subject to a wider audience through a public consultation.
9. Although unable to provide a definitive timetable, the Cabinet Secretary stresses that she intends for this work to be taken forward as quickly as possible.

Patient engagement

10. The Cabinet Secretary states that the Scottish Government recognises the importance of lived experience and patient engagement, highlighting its work with the Health and Social Care Alliance ("the Alliance") to draw on the experience of those with lived experience to inform its work.
11. The Cabinet Secretary notes that further work from the Alliance has been commissioned. This is to understand what the specialist service mesh removal is doing well, what could be done better, the concerns that women have about the service at present, and what can be done to allay those concerns and ensure that women can access appropriate treatment that they have confidence in.
12. The work with the Alliance is intended to capture the views both of women who have recent experience of the specialist service, and also of those with mesh complications more generally.
13. The Cabinet Secretary states that she is disappointed to note that the petitioners' feel let down with their engagement with Scottish Government groups. Although its work with the Alliance is highlighted, the Cabinet Secretary

explains that the Scottish Government is committed to doing more to ensure that women know their views are being listened to, and to ensure that they get the services they need.

14. The Cabinet Secretary highlights a recent meeting with one of the petitioners to discuss the future engagement work that the Scottish Government intends to take forward. She further highlights that the petitioners could be involved with the work on the specialist service, should they wish.

Engagement with Dr Veronikis

15. In her submission, the Cabinet Secretary sets out the Scottish Government's position in regard to Dr Veronikis, explaining that the Chief Medical Officer confirmed, in writing, that NHS Scotland would be able to offer him a contract, subject to detailed discussions during a proposed observational visit in February 2020, and agreement on processes and working within the NHS Scotland environment.
16. The Cabinet Secretary states that the process being asked of Dr Veronikis is the same as would be asked of any visiting clinician.

Future care of women with mesh complications

17. In her submission, the Cabinet Secretary highlights the establishment of the nationally designated specialist service, explaining how it will operate. She acknowledges, however, that there may remain some women who continue to feel reluctant to have treatment in Scotland.
18. As a consequence, since planning for the new national service began, the Cabinet Secretary explains there has been an intention to establish close working relationships with the equivalent services being developed by NHS England. It is envisaged that this working relationship will allow referral to NHS England services, as a further choice, where necessary and clinically appropriate.
19. These close working relationships will also allow Scottish clinicians to work with their peers in England to establish consensus around the risks, benefits, techniques and processes associated with full and partial mesh removal, as recommended by Baroness Cumberlege in her report.¹
20. The Cabinet Secretary explains that officials are now also considering what further steps can be taken to provide additional options for patients, including possible referral outside of the NHS.
21. The submission highlights, however, that the referral of patients for treatment outwith NHS Scotland, particularly where it involves foreign travel, is a complex

¹ The Independent Medicines and Medical Devices Safety (IMMDS) Review, led by Baroness Cumberlege published its [report](#) on 8 July 2020.

issue. This is particularly so in terms of ensuring the safety and wellbeing of patients.

22. The Cabinet Secretary states that the Scottish Government must therefore be assured regarding the quality and safety of care available and that, in each case, any proposed treatment is in the patient's best interests. Treatment must also take account of, and be integrated with, pre and post-operative care.

Interim Chief Medical Officer's submission

23. In his written submission, the then Interim Chief Medical Officer (CMO) states that he has taken careful note of the concerns that women have raised, where they believed that they were to undergo full mesh removal, only to later discover they had had partial removal surgery.
24. The submission states that the lack of clarity over terminology is a serious issue in Scotland, as well as in the rest of the UK, as noted in the Cumberlege review, and possibly further afield.
25. Although the ultimate responsibility – and therefore accountability – for the accuracy of the information given to patients, and the content of patient notes, lies with the health board concerned, the First Minister and the former Chief Medical Officer, recognised the seriousness of these concerns when raised by the mesh injured women in November 2019.
26. As a result, the Cabinet Secretary instigated a Case Record Review. The review will give the women who attended the meetings, in the first instance, the opportunity to set out their concerns about their mesh removal, and have their records reviewed by clinicians.
27. The submission explains that the Review will be undertaken by a Panel led by a Moderator with a team of three clinicians and an administrator. It will be independent of Scottish Ministers and each member will be expected to make a contemporary and full declaration of their interests, which will be made available for scrutiny by the women whose cases are being considered and by other review group members. It will also be placed in the public domain.
28. Regarding skills and training for surgeons, the then Interim CMO explains that on completion of their training, following a curriculum that is approved by the General Medical Council (GMC), surgeons are awarded a Certificate of Completion of Training (CCT). A CCT in the relevant discipline is required before being appointed to a consultant post in NHS Scotland.
29. All doctors who treat patients are required by law to hold a Licence to Practice and, for the past seven years, doctors have been required to show that they are “up to date and fit to practice” by participating in the mandatory process called Revalidation.
30. Doctors will also, on occasion, be required to undertake new or innovative techniques after they have achieved a CCT. This issue has been recognised

and considered by the UK Shape of Training Steering Group. A process for post-CCT GMC approved credentials is now being developed.

31. GMC approved credentials are significant elements of training that are required to rapidly upskill the medical workforce to enable the service to respond to innovation or changing patient need, where there is a legitimate public concern or the need for governance. The Interim CMO states, given the concerns that have been expressed in relation to mesh removal surgery, the Scottish Government is firmly of the view that a GMC credential requires to be developed in this area.
32. The Scottish Government will therefore, in due course, take a proposal to the UK Medical Education Reference Group, which is the first step in the current process for submitting proposals for GMC regulated credentials.

Royal College of Obstetricians and Gynaecologists' submission

33. In its submission, the Royal College of Obstetricians and Gynaecologists (RCOG) explains that it has gathered feedback from key stakeholders on the action called for in the petition, including the British Society of Urogynaecology (BSUG) and the RCOG's Scottish Committee.
34. The RCOG states that it agrees with the Scottish Government's interim report of its ['Transvaginal mesh implants independent review'](#) which states—

“Many women have experienced a positive outcome following a transvaginal mesh implant procedure. No procedure is without risk and therefore many people, including the broad clinical community consider that polypropylene mesh should continue to be used in these procedures as it presents an acceptable level of risk, supported by a number of studies, including research by the UK regulator for medical devices, the Medicines and Healthcare product Regulatory Agency (MHRA).”
35. The Royal College states that it is committed to patient safety and is constantly assessing how it can improve care to make it safer and reduce the risks associated. It also agrees that work to improve clinical governance of these procedures is required, including improving the informed consent process, work of which is underway by the College and BSUG.
36. It states, however, that the suspension of vaginal mesh completely could adversely impact upon some women who suffer from incontinence and require surgery and treatment, in the form of polypropylene Transvaginal Mesh (TVT-retropubic), in order to treat this debilitating condition.
37. In respect of the petition's call for a Public Inquiry and/or comprehensive independent research to evaluate the safety of mesh devices, the RCOG states that it agrees with comprehensive independent research forming the basis of future recommendations and practice.

38. The RCOG highlights work being undertaken by the London School of Hygiene & Tropical Medicine (LSHTM) independently to investigate what the impact of transvaginal mesh procedures are on autoimmune disease compared to non-mesh procedures as well as studying the differences in long term outcomes of mesh versus non-mesh continence procedures.
39. The Royal College argues that the implemented recommendations of the Scottish Government's 'Transvaginal mesh implants independent review' should be reviewed and evaluated and that any recommendations which are yet to be implemented are done so without delay.
40. Furthermore, it urges the Scottish Government to consider the findings of the Cumberlege Review so that its "valuable learnings" can be applied in Scotland.
41. On the call for the establishment of a Scottish Transvaginal Mesh implant register with view to linking this up with national and international registers, the RCOG highlights the [BSUG database](#), which was established in 2004.
42. The RCOG explains that it, along with BSUG, continue to call for mandatory prospective data collection through the BSUG database. The organisation states that this would provide more accurate information regarding outcomes, including both success and complication rates, and provide comprehensive data to inform women and healthcare professionals about the benefits and risks of all urogynaecological procedures, including those that use mesh.
43. The RCOG also highlights the National Registry being set up by NHS Digital which is expected to be functional by March 2021. As the register is to be made available across the devolved nations and patients move freely between the devolved nations, the RCOG strongly recommends that this National Registry is also implemented in Scotland so that there is a consistent approach to data recording across the UK.
44. On the petition's call for fully informed consent, RCOG believes that consent is a fundamental part of clinical practice.
45. In its submission, the Royal College details the information and guidance that it provides to its members within its [consent hub](#) and guidance as well as the resources it provides for healthcare professionals and women/the public on mesh, to support evidence-based care and shared, informed decision making.
46. The organisation states that it will work with NHS England, the Royal College of Surgeons, BSUG, the British Association of Urological Surgeons and the Pelvic Floor Society to produce an England-wide mesh removal service.
47. The RCOG further states that its aim is for this to be a world-leading, patient centred NHS service, which will provide safe, high-quality care with full consent and where women will have easy access to robust patient information.
48. The Royal College highly recommends that NHS Scotland and the Scottish Government collaborate with NHS England on this project and with its Complex

Mesh Removal Surgical Service delivered by NHS Greater Glasgow & Clyde so that learning can be shared across the UK and care improved for all women requiring this service.

Petitioners' submission

49. In their most recent written submission, the petitioners express their disappointment that they do not feel that the Scottish Government is listening to mesh injured women.
50. The petitioners acknowledge that the Scottish Government is investing millions in the development of its national specialist mesh removal service. They highlight, however, that the service will be staffed by surgeons, some of whom inserted implants into mesh injured women, and others who have repeatedly told the petitioners that they could not safely and fully remove “so many of the implants favoured by Scottish hospitals.”
51. The petitioners note that some women have been offered the opportunity to see surgeons in England. They explain that this is not a solution, however, as, for some, concerns also persist over the ability of these surgeons.
52. As the petitioners do not believe there is a safe and proven treatment route here, they believe that the Scottish Government should fund women able to travel to the US to be treated by the surgeon they trust and choose, if that is their wish. The petitioners suggest that the cost of surgery in the US, including flights and accommodation, is less than the cost of such surgery in Scotland.
53. The petitioners also call for the Scottish Government to refund the small number of women who have already paid life savings to attend surgeons in the US.
54. In their submission, the petitioners state that—

“Mesh injured women have already suffered and waited too long, each one of us at risk of deadly infection and antibiotic resistance at any time. We fought hard over the last nine years to ensure no other women are subjected to the harm that destroyed our lives...This is the first time we have asked anything for ourselves.”

55. In correspondence with the clerks, the petitioners have confirmed that the written submissions from the Cabinet Secretary, the Interim Chief Medical Officer and the Royal College of Obstetricians and Gynaecologists, which were received after their submission of 26 November 2020, do not amend the substantive points they wish to raise to the Committee. In this correspondence, the petitioners also express their frustration as they feel that they are going around in circles.

Action

56. The Committee is invited to consider what action it wishes to take. Options include —

- To close the petition under Rule 15.7 of Standing Orders on the basis that the Scottish Government has accepted and will implement the recommendations of the Independent Review of Transvaginal Mesh Implants which will address the actions called for in the petition; and is—
 - committed to working with the petitioners on the development of the national specialist service;
 - developing proposals for the remit for a Patient Safety Commissioner, which will be subject to public consultation;
 - working with the Health and Social Care Alliance to ensure its work is being informed by people with lived experience, and is committed to doing more to ensure that women know their views are being listened to, and to ensure that they get the services they need;
 - establishing close working relationships with the equivalent services being developed by NHS England, which will allow referral to NHS England services, as a further choice, where necessary and clinically appropriate;
 - considering what further steps can be taken to provide additional options for patients, including in terms of referral outside of the NHS; and
 - taking a proposal to the UK Medical Education Reference Group, which is the first step in the current process for submitting proposals for a GMC regulated credential with respect to mesh removal surgery.
- In closing the petition, the Committee could—
 - Write to the Cabinet Secretary for Health and Sport to consider the calls made by the Royal College to—
 - review and evaluate outstanding recommendations from the ‘Transvaginal mesh implants independent review’;
 - consider the findings of the Cumberlege Review so that learning can be applied in Scotland; and
 - collaborate with NHS England on the project and with its Complex Mesh Removal Surgical Service delivered by NHS Greater Glasgow & Clyde so that learning can be

shared across the UK and care improved for all women requiring this service.

- Write to the petitioners to ask them to note that they would be able to submit a new petition in the future, specifically focussed on their call for the Scottish Government to fund women able to travel to the US to be treated by the surgeon they trust and choose, if that is their wish, and to refund the small number of women who have already paid life savings to attend Dr Veronikis in the US.
- To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1517/NNNN: Royal College of Obstetricians and Gynaecologists submission of 20 November 2020 \(171KB pdf\)](#)
- [PE1517/OOOO: Petitioners' Submission of 26 November 2020 \(80KB pdf\)](#)
- [PE1517/PPPP: Interim Chief Medical Officer submission of 27 November 2020 \(66KB pdf\)](#)
- [PE1517/QQQQ: Cabinet Secretary for Health and Sport submission of 27 November 2020 \(55KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#)

PE1517/NNNN

Royal College of Obstetricians and Gynaecologists submission of 20 November 2020

The Royal College of Obstetricians and Gynaecologists (RCOG) has gathered feedback from key stakeholders on petition PE1517, including the British Society of Urogynaecology (BSUG) and the RCOG's Scottish Committee. Please see below our views on the calls of the petition.

Following the initial suspension of all vaginal mesh for both prolapse and incontinence, there is now evidence to show that there is no benefit to the use of vaginal mesh for prolapse and the RCOG support the NICE '[Transvaginal mesh repair of anterior or posterior vaginal wall prolapse, Interventional procedures guidance](#)' (IPG599) which notes that the evidence on the safety of transvaginal mesh repair of anterior or posterior vaginal wall prolapse shows this procedure should only be used in the context of research.

The views expressed here are therefore in relation to transvaginal mesh for stress urinary incontinence (Retropubic TVT) which has been shown by NICE to be equivalent to the native tissue procedures.¹

Views on the suggested suspended use of polypropylene Transvaginal Mesh (TVM) procedures.

The RCOG is in agreement with the following statement in the Scottish Government's interim report of its 'Transvaginal mesh implants independent review':

"Many women have experienced a positive outcome following a transvaginal mesh implant procedure. No procedure is without risk and therefore many people, including the broad clinical community consider that polypropylene mesh should continue to be used in these procedures as it presents an acceptable level of risk, supported by a number of studies, including research by the UK regulator for medical devices, the Medicines and Healthcare product Regulatory Agency (MHRA)."²

The RCOG is committed to patient safety and is constantly assessing how it can improve care to make it safer and reduce the risks associated. We agree that work to improve clinical governance of these procedures is required, including improving the informed consent process, work of which is underway by the College and BSUG, as outlined below.

The RCOG supported the implementation of high vigilance restrictions on use of vaginal mesh in 2018, which is still in place. However, the suspension of vaginal mesh completely could adversely impact upon some women who suffer from incontinence and require surgery and treatment, in the form of polypropylene Transvaginal Mesh (TVT-retropubic), in order to treat this debilitating condition.

¹ NICE, [Urinary incontinence and pelvic organ prolapse in women: management NICE guideline](#) [NG123] (2019)

² Scottish Government, [Transvaginal mesh implants independent review: interim report](#) (2015)

Views on the suggested initiation of a Public Inquiry and/or comprehensive independent research to evaluate the safety of mesh devices using all evidence available, including that from across the world.

We agree with comprehensive independent research forming the basis of future recommendations and practice. This is being undertaken by the London School of Hygiene & Tropical Medicine (LSHTM) independently to investigate what the impact of transvaginal mesh procedures are on autoimmune disease compared to non-mesh procedures as well as studying the differences in long term outcomes of mesh versus non mesh continence procedures. Reviewing mesh procedures in isolation however is not beneficial as informed choices are based on the comparison to other procedures undertaken for the same clinical condition. This is why we feel that any research should be into the use of mesh as well as its comparators.

Furthermore, the RCOG considers that the implemented recommendations of the Scottish Government's 'Transvaginal mesh implants independent review' should be reviewed and evaluated and that any recommendations which are yet to be implemented are done so without delay.³

The Scottish Government should also consider the findings of The Independent Medicines and Medical Devices Safety (IMMDS) Review. Although the remit of the Review was to consider how the healthcare system in England responds to reports from patients about harmful side effects from medicines and medical devices, valuable learnings can be taken from that report in Scotland and the other devolved nations, where similar systems are in place. The RCOG recommends a coordinated approach and plan to address the findings of the IMMDS Review across England, Scotland, Wales and Northern Ireland would be beneficial so that women can receive the same quality of care, treatment and support irrespective of their location.

Views on the suggested establishment of a Scottish Transvaginal Mesh implant register with view to linking this up with national and international registers.

The British Society for Urogynaecology (BSUG) runs the [BSUG database](#) which was established in 2004. BSUG and the RCOG continue to call for mandatory prospective data collection through the BSUG database. This would provide more accurate information regarding outcomes, including both success and complication rates, and provide comprehensive data to inform women and healthcare professionals about the benefits and risks of all urogynaecological procedures, including those that use mesh. The RCOG and BSUG also strongly encourage reporting of all complications related to all medical procedures to the Medicines and Healthcare products Regulatory Agency (MHRA).

NHS Digital has the responsibility of setting up the National Registry, a project which is underway. NHS Digital has started piloting data entry and we expect the Registry to be functional by March 2021. This is to be made available to the devolved nations as well. It would be more appropriate to collect data in a UK registry as patients move freely between the devolved nations hence to have separate Registries would not be logical.

³ Scottish Government, [Transvaginal mesh implants independent review: final report](#) (2017)

We therefore strongly recommend that this National Registry is also implemented in Scotland so that there is a consistent approach to data recording across the UK.

Views on the suggested introduction of fully Informed Consent with uniformity throughout Scotland's Health Boards.

The RCOG believes that consent is a fundamental part of clinical practice.

Since 2004, the College has produced an '[Obtaining Valid Consent](#)' guideline, which has been updated three times, most recently in 2015, and is currently being updated in line with the new GMC guidance on '[Decision making and consent](#)' (September 2020). The purpose of the advice is to provide a good practice framework for obtaining valid consent in obstetrics and gynaecology. The College also has a [Consent Advice series](#), which promotes good practice in this area focusing on specific procedures.

All of this information is brought together on our [consent hub](#), setting out how to apply these resources and also referencing the Montgomery ruling. These resources have been highlighted to our members on a number of occasions via our regular member communications.

The RCOG also has a dedicated page on its website bringing together [resources for healthcare professionals and women/the public on mesh](#), to support evidence-based care and shared, informed decision making.

Additionally, the College provides patient facing information to ensure that women receive consistent, high-quality information about risk, including Clinical Governance Advice on '[Presenting Information on Risk](#)' and patient information on '[Understanding how risk is discussed in healthcare](#)'. The College has a [patient information leaflet on pelvic organ prolapse](#), which is currently being updated, as well as patient resources on [incontinence and bladder problems](#). BSUG have a range of patient information leaflets on [prolapse and incontinence](#) and we are also working with BSUG to co-produce a Shared Decision Aid for stress urinary incontinence. The aid will help women to consider their surgical options after non-surgical options have been exhausted, guiding their thinking around the outcomes that are important to them to help make decisions.

BSUG are planning to incorporate training for obtaining informed consent to clinicians in forthcoming meetings and workshops and the RCOG is collaborating with BSUG and other Specialist Societies to develop Patient information leaflets and Patient Decision Aids for mesh removal.

The experiences of women and the issues raised in reports, parliamentary questions and debates, and the media stress the importance of ensuring consent and an understanding of risk are central to issues of patient safety. The RCOG and BSUG therefore remain committed to improving informed consent processes to all our membership, within and without of Scotland.

We consider that the recently published [NICE Patient Decision Aids](#) go a long way to ensuring patients give informed consent and encourage all clinicians performing prolapse and incontinence surgery to use these.

Write to the MHRA and ask that they reclassify TVM devices to heightened alert status to reflect ongoing concerns worldwide.

This is not within the remit of the RCOG.

Views on the evidence presented at the Public Petitions Committee's meeting on 22 October 2020.

The College is unable to comment on the information presented by Dr Veronikis as published data is not available on the outcomes of the mesh removal surgeries that he has performed.

The RCOG will work with NHS England, the Royal College of Surgeons, BSUG, the British Association of Urological Surgeons and the Pelvic Floor Society to produce an England-wide mesh removal service. Our aim is that this will be a world-leading, patient centred NHS service, which will provide safe, high-quality care with full consent and where women will have easy access to robust patient information. These centres will share learning and outcomes data so that we can continue to improve the service provided to women. We highly recommend that NHS Scotland and the Scottish Government collaborate with NHS England on this project and with its Complex Mesh Removal Surgical Service delivered by NHS Greater Glasgow & Clyde so that learning can be shared across the UK and care improved for all women requiring this service.

PE1517/0000

Petitioners' Submission of 26 November 2020

Scottish Mesh Survivors wish to thank the Public Petitions Committee for inviting Dr Veronikis to address them directly. His testimony was powerful and informative, highlighting the urgent need for the Scottish government to find a way of enabling mesh injured women to travel to see him in the US for safe, full, mesh implant removal.

Disturbingly, in the time he spent trying to find a way of fulfilling his promise to the women whose lives have been utterly destroyed by mesh, instead being thwarted by those who seem to have a vested interest in keeping him at arm's length so their own inadequacies are kept from the spotlight, this world class surgeon could have operated on 50 women and given them the only opportunity they will possibly ever have to regain some of the life they have each lost. It seems that Scottish government officials have pandered to surgeons who we believe repeatedly misled patients and abused their position of trust, seemingly in a bid to deflect blame and preserve egos. The very last thing being considered was the desperate needs of the patients whose lives were destroyed.

Following years of denial, patients were told their pain was 'all in their head', women were sent to psychiatric units, many were left suicidal, bedridden and in wheelchairs, when all along the surgeons who implanted these devices knew mesh implants were the problem. These same surgeons actively sought to undermine Dr Veronikis, a professional with a track record of the safe and full removal of thousands of mesh implants of all kinds, as well as do everything in their power to prevent him coming to Scotland.

Many women we have spoken to would rather continue suffering in pain than allow any of these implanting surgeons near them again. Others talk about using life savings to fund seeing Dr Veronikis in America.

Despite many face to face meetings with injured women, letters, emails and newspaper stories clearly setting out why mesh injured women lost all trust in Scottish surgeons, the government invested £millions and persist with developing a mesh removal centre staffed by some of those same implanting clinicians. Some of those same surgeons sat on working groups with us, and repeatedly told us they could not safely and fully remove so many of the implants favoured by Scottish hospitals, implants which have repeatedly been found to be defective in courts around the world.

But, suddenly, with no apparent obvious new training route, they are operating on women and telling them they 'can remove mesh'. There has been no evidence of their success, no evidence of how they suddenly acquired the skills to perform such highly specialised surgery. What there has been, however, is disturbing evidence of patients told they have had a full mesh removal when they have had anything but and patients suffering further injury while undergoing mesh removal.

Complaints have been lodged with the General Medical Council.

A number of women have been offered the opportunity to see surgeons in England, but for some, concern persists over their skills too.

In the absence of a safe and proven treatment route here, we believe the Scottish government should follow other countries and fund women able to travel to the US to be treated by the surgeon they trust and choose, if that is their wish. The cost of surgery in the US and including flights and accommodation is less than the cost of such surgery in Scotland.

Mesh implants caused the biggest medical scandal of modern times. The NHS chose to use these devices to save around £200 per patient without properly assessing if they were safe or adequately tested – they put us in harm's way. The harm caused was completely avoidable. We are victims of a failed system which was supposed to protect us. The very least we should now expect is to be treated by a surgeon of our choice, one with a proven track record.

We respectfully ask you to support our call to the Scottish government and to refund the small number of women who have already paid life savings to attend Dr Veronikis in the US. We cannot understand why they do not consider making a claim to recover the costs of our treatment from the medical manufacturers or their insurers.

Mesh injured women have already suffered and waited too long, each one of us at risk of deadly infection and antibiotic resistance at any time. We fought hard over the last nine years to ensure no other women are subjected to the harm that destroyed our lives. As a result, we believe thousands have been 'saved' from devastating injury. This is the first time we have asked anything for ourselves. We cannot undo the damage done to us but we hope the committee will support us in our plea to get the medical help we need, as soon as possible, so we can have the best possible chance of getting back what we can of our shattered lives.

PE1517/PPPP

Interim Chief Medical Officer submission of 27 November 2020

Thank you for your letter of 29 October 2020 concerning petition PE1517, polypropylene mesh medical devices.

I am aware that you have also written to the Cabinet Secretary for Health and Sport in relation to this matter, and she will therefore more fully set out the Scottish Government's response to the evidence that Dr Dionysios Veronikis gave to your committee on 22 October. However, I will address the specific questions you raise about mesh removal surgery.

I have taken careful note of the concerns that women have raised, where they believed that they were to undergo full mesh removal, only to later discover they had had partial removal surgery. This issue became particularly apparent here in Scotland after the First Minister, the Cabinet Secretary for Health and Sport, and my predecessor met mesh injured women in November of last year.

However, it is important to note that this matter was also raised in *First Do No Harm*, the July 2020 report of the Independent Medicines and Medical Devices Safety Review. In the report, Baroness Cumberlege makes reference to the terminology used to describe mesh removal, and it is therefore apparent that this is a serious issue not only in Scotland, but across the UK and possibly further afield:

"We have had reports from some women about confusing terminology used by clinicians when discussing removals. Women have been offered a 'full vaginal removal' and understood that this operation would remove all their mesh. A 'full vaginal removal' is the removal of the vaginal portion of the mesh, leaving the rest of the mesh in situ."

I should explain that ultimate responsibility – and therefore accountability – for the accuracy of the information given to patients, and the content of patient notes, lies with the Health Board concerned. However, in light of the concerns expressed in last November's meetings, the Cabinet Secretary agreed to instigate a Case Record Review. The review will give women the opportunity to set out their concerns about their mesh removal, and have their records reviewed by clinicians.

The Review will be undertaken by a Panel led by a Moderator with a team of three clinicians and an administrator. The work of the Panel will be independent of Scottish Ministers and each member will be expected to make a contemporary and full declaration of their interests. These will be made available for scrutiny by the women whose cases are being considered and by other review group members, and will be placed in the public domain.

In the first instance, the Review will be offered to women who attended the meetings last November. This is to ensure that the review is purposeful, however, after careful evaluation, we will consider whether it would be beneficial for more women to be offered a similar review. I will very soon be in touch with all those who attended the meetings last November with further details.

With respect to skills and training, mesh removal is highly specialised and can involve input from more than one specialty (uro-gynecology, urology, colorectal surgery). The extant position for surgeons is that they undertake training by following a curriculum that is approved by the GMC. At the completion of training they are awarded a Certificate of

Completion of Training (CCT) by the General Medical Council. For all practical purposes doctors must hold a CCT (or equivalent) in the relevant discipline before being appointed to a consultant post in NHS Scotland.

All doctors who treat patients are required by Law to hold a Licence to Practice. For the past seven years doctors have been required to show that they are “up to date and fit to practice” by participating in the mandatory process called Revalidation. For this purpose a doctor relates to a responsible officer (usually a senior doctor appointed by the organisation where the doctor works) who makes a recommendation to the GMC every five years based on annual appraisal as to whether the Licence to Practice is renewed. Over the five year cycle the doctor is required to submit evidence to support their practice. This will include feedback from peers and other colleagues, as well as patients. The evidence will testify that their practice is contemporary and competent. Audit and other data detailing outcomes will be reviewed. They will be required to reflect upon their entire clinical practice.

It is also important to note, however, that doctors will, on occasion, be required to undertake new or innovative techniques after they have achieved a CCT. This has been recognised and considered by the UK Shape of Training Steering Group (led by Scottish Government) and addressed in their final report. The recommendations were accepted by all four UK Ministers. The recommended solution was to develop a process for post-CCT GMC approved credentials. This is an emerging process of governance that is being developed.

GMC approved credentials are significant elements of training that are required to rapidly upskill the medical workforce to enable the service to respond to innovation or changing patient need, where there is a legitimate public concern or the need for governance. The current process for submitting proposals for GMC regulated credentials is that they are considered in the first instance by the UK Medical Education Reference Group. This group comprises members of the four UK Governments and the four Statutory Education Bodies.

Given the concerns that have been expressed in relation to mesh removal surgery, the Scottish Government is firmly of the view that a GMC credential requires to be developed in this area. This is with the intention of ensuring formal recognition of the technical skills possessed by the surgeons working in this field, and thereby building public confidence that both the surgeons and the institution are approved by the independent UK Regulator.

In light of the above, the Scottish Government will, in due course, take a proposal to the aforementioned Referenced Group.

I hope this is helpful.

Thank you for your letters of 16 September and 29 October concerning polypropylene mesh medical devices, and please accept my apologies for the delay in replying to the former.

Patient Safety Commissioner

The development of proposals for a Patient Safety Commissioner (PSC) is being informed by meaningful engagement with those with lived experience of the issues covered in Baroness Cumberlege's Independent Medicines and Medical Devices Safety Review. The Scottish Government has now set up a patient reference group, which includes members with lived experience of the issues arising from the use of mesh implants, Sodium Valporate and Primodos. The group had its first meeting on 29 October 2020. This was well attended with good engagement levels from the members who gave some positive feedback afterwards. The group has agreed to meet regularly to progress this work as quickly as possible.

In addition, the Scottish Government is in the process of forming a group to run parallel to the patient group. I envisage that this group will be made up of organisations that currently have a role in the patient safety landscape in Scotland and will provide expert input to help shape and guide this work as it progresses. Officials intend to publish all papers from both groups on the Scottish Government website in due course.

I intend that this engagement will begin to shape the draft remit of the Patient Safety Commissioner and that this draft will then be open to a wider audience in a public consultation.

At this stage, I cannot give a definitive timetable but please be assured that I intend that this will be taken forward as quickly as possible, whilst still allowing time for meaningful engagement. I will update the Committee as soon as I am able to.

Patient Engagement

It is disappointing to note that the petitioners feel let down by the Scottish Government groups that they have participated in. This is unacceptable and I am sorry that this is the case. I can confirm that I have recently met with one of the petitioners and discussed with her the future engagement work that we intend to take forward.

To date, we have sought to work with the Health and Social Care Alliance ("the Alliance") to draw on the experience of those with lived experience and inform our work on the mesh fund, case record review and the new specialist service. We are, however, committed to doing more to ensure that women know their views are being listened to, and to ensure that they get the services they need.

We recognise the importance of lived experience and patient engagement, and we have therefore commissioned the Alliance to undertake further work that will build on their 'My Life, My Experience' report. The precise detail of how this work will be undertaken is presently being finalised. However, it is intended to capture the views both of women who have recent experience of the specialist service, and also of those with mesh complications more generally, including the petitioners, should they wish to take part. This is with a view to understanding what the service is doing well, what could be done better, the concerns that

women have about the service at present, and what can be done to allay those concerns and ensure that women can access appropriate treatment that they have confidence in.

I will announce further detail of this engagement work shortly.

Dr Veronikis

I noted the evidence given to your Committee by Dr Dionysios Veronikis on 22 October. The Scottish Government was grateful to Dr Veronikis for his offer to come to Scotland and I am, of course, disappointed that he appears to have decided against this option now. The Scottish Government has remained ready to welcome him here for an observational visit, as he discussed with the Chief Medical Officer in February 2020.

After those discussions the Chief Medical Officer subsequently confirmed, in writing, that NHS Scotland would be able to offer a contract, subject to detailed discussions during that visit and agreement on processes and working within the NHS Scotland environment. The visit would have allowed Dr Veronikis to see the clinical arrangements here, meet NHS staff, review our facilities in order to determine if there is more that he needs, consider the cases and patients he would deal with, familiarise himself with our multi-disciplinary team process and, from all of that, agree the contractual basis on which he would then come back to Scotland. General Medical Council approval would have been sought after the award of a contract, given that the approval process requires confirmation of employment in the UK, as well as a letter of introduction from a Royal College.

The process set out above, which I also explained during the debate on Baroness Cumberlege's recommendations on 8 September, as linked to in your letter, is with patient safety and wellbeing in mind, and is the same as would be asked of any visiting clinician. I am sure you will appreciate that a surgeon cannot simply operate on a woman with whom he has had no prior contact, and will also appreciate the importance of ensuring that appropriate pre- and post-operative care is in place.

It is unfortunate that Dr Veronikis did not feel able to agree to an observational visit. However, the action taken by the Scottish Government indicates a clear intent to welcome him here, and to engage purposefully and constructively with him.

Future Care of Women with Mesh Complications

NHS Scotland is establishing a nationally designated specialist service, and it is being introduced on a gradual basis, in line with wider remobilisation plans, as we continue to manage the pandemic. The national service will be delivered by a multi-disciplinary team located within NHS Greater Glasgow and Clyde (NHS GGC). This service will assess all of a woman's relevant health needs and, subject to a fully informed agreement, offer vaginal mesh surgery for those who are suffering mesh complications from mesh insertion (vaginally or abdominally) for stress urinary incontinence and pelvic organ prolapse.

The Scottish Government supported Jackson Carlaw's amendment to the motion that I tabled in the Parliament on 8 September, which stated that women affected by complications arising from mesh should have "the early prospect of full transvaginal mesh removal surgery being undertaken by surgeons who enjoy the full confidence of the women affected, fully funded by the NHS". We do hope that this confidence can be secured by the national specialist mesh removal service at NHS GGC, and the aforementioned engagement work is being undertaken by the Alliance with this in mind.

Despite the foregoing, and as you rightly point out, there may remain some women who continue to feel reluctant to have treatment in Scotland. It is for this reason that, since planning for the new national service began, there has been an intention to establish close working relationships with the equivalent services being developed by NHS England. It is envisaged that this working relationship will allow referral to NHS England services, as a further choice, where necessary and clinically appropriate. In addition, those relationships will allow Scottish clinicians to work with their peers in England to establish consensus around the risks, benefits, techniques and processes associated with full and partial mesh removal, as recommended by Baroness Cumberlege in her report:

“A consensus needs to be reached on whether it is better to carry out full or partial removals. This is a clinical matter, and it must be done collaboratively. This consensus should be validated by carrying out follow up on those who have removals at the specialist centres. We strongly recommend that NICE actively monitor the situation and update their guidance promptly once a consensus has been reached.”

Officials are now also considering what further steps can be taken to provide additional options for patients, including in terms of referral outside of the NHS. Any service commissioned by the NHS would, of course, be provided free of charge to any patient. However, it is important to note that the referral of patients for treatment outwith NHS Scotland, particularly where it involves foreign travel, is a complex issue. This is particularly so in terms of ensuring the safety and wellbeing of patients. We must be assured regarding the quality and safety of care available and that, in each case, any proposed treatment is in the patient's best interests. Treatment must also take account of, and be integrated with, pre- and post-operative care.

I would take this opportunity to reassure the Committee that we are absolutely committed to ensuring women get the services they want and need, and continue to work at pace to deliver improved services.

JEANE FREEMAN

Public Petitions Committee**3rd Meeting, 2021 (Session 5)****Wednesday 10 February 2021****PE1707: Public Access Defibrillators****Note by the Clerk****Petitioner** Kathleen Orr

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to introduce a requirement for all new build or newly renovated or re-purposed buildings with a floorspace of over 7500m² to have a public access defibrillator (PAD) fitted to the exterior of the building, for public use, and for the PADs to be officially registered.

Webpage parliament.scot/GettingInvolved/Petitions/PE1707**Introduction**

1. This is a continued petition, last considered by the committee on 25 November 2020. At this meeting, the Committee took evidence virtually from:
 - Steven Short, Clinical Effectiveness Lead for Out of Hospital Cardiac arrest (OHCA), Scottish Ambulance Service;
 - David McColgan, Senior Policy and Public Affairs Manager, British Heart Foundation Scotland;
 - Dr Gareth Clegg, Senior Clinical Lecturer, Resuscitation Research Group Edinburgh.
2. Following the evidence session, the Committee agreed to write to the Minister for Public Health, Sport and Wellbeing. Responses have now been received from the Scottish Government and the petitioner.
3. The Committee is invited to consider what action it wishes to take.

Committee consideration

4. During the evidence session on 25 November 2020, witnesses explained while they did not all agree that PADs should be placed in all new or newly renovated buildings with a floorspace of 7500m², they were all clear that more needs to be done to provide access to public access defibrillators (PADs).
5. It was also highlighted that many members of the public did not have the confidence to use a PAD if the need arose. Witnesses agreed more needs to be done to train members of the public in how to use a PAD.
6. A variety of ways these outcomes could be achieved were discussed, including:

- increased funding to Save a Life Scotland;
 - improved lifesaving skills taught in schools (this can currently be taught as part of various classes or not at all but it is already mandatory in England);
 - making the provision of PADs in non-residential buildings compulsory;
 - include CPR and PAD training in compulsory health and safety training (as with fire extinguishers); and
 - issue national guidance on the placement of PADs
7. Local projects that acquire and train people in the use of PADs were commended and noted as being successful on a small scale. Witnesses agreed however, the balance of responsibility for this must move towards the Scottish Government to demonstrate leadership in this important area of public health. It was felt only the Scottish Government has the power and resources to ensure this happens on a large scale.
 8. The Committee highlighted the above in a letter to the Minister for Public Health, Sport and Wellbeing and asked for a response to the suggestions and any others raised in the evidence session.
 9. The Scottish Government advises that within the lifetime of the current out of hospital cardiac arrest strategy, it has provided over £725,000 of funding to the Save a Life for Scotland partnership, including £50,000 a year for operational costs.
 10. The submission notes Scottish Government officials met with Education Scotland, St. Andrew's First Aid and the British Red Cross at the start of 2020 to explore ways in which first aid education could be taught more widely in schools. These discussions will reconvene as soon as it is appropriate to do so following the pandemic.
 11. Although building standards are a reserved matter, the Building (Scotland) Act 2003 section 1 allows Scottish Ministers to make regulations regarding the construction of buildings, their fittings and equipment for the purpose of securing the health, safety and welfare of persons in or about those buildings.
 12. The Scottish Government is currently considering permitted development rights for defibrillators on public buildings, which would remove the need to apply for planning permission to place a PAD in an external area of a building. It aims to provide an update in Summer 2021.
 13. Health and Safety at work is also a reserved matter. However, the Scottish Government intends to liaise with the Health and Safety Executive in Scotland to explore CPR and PAD training options within health and safety training.
 14. The submission highlights that as part of the aims of the Out of Hospital Cardiac Arrest Strategy it published [OHCA: A Guide to PADs](#) in March 2018.

The guide provides practical advice to those considering a purchase and installation of a PAD for their local community.

15. The Scottish Government states it does not have a direct role in the PAD/CPR training of members of the public, so this is the decision of the independent organisations and charities who deliver the training. However, it notes discussion on what steps it can take to support PAD placement continues at leadership level.

Petitioner submission

16. The petitioner highlights that since submitting the petition a lot of work has been undertaken in her local area to provide PADs. Via her charity, Jayden's Rainbow, she has been able to purchase a good number of defibrillators and place them about Inverclyde. St Andrew's First Aid also gifted the charity 30 defibrillators that they were replacing.
17. The petitioner notes she feels "safer living in Inverclyde as a result of these defibrillators being place in the community, on hand to help local people if they are ever in need".

Member's Bill

18. On 3rd of March 2020, Anas Sarwar MSP lodged a draft proposal for the [Proposed Mandatory Registration of Automated External Defibrillators \(Scotland\) Bill](#). This is a proposal for a Members' Bill to require the registration of existing and newly acquired automated external defibrillators (AEDs) in Scotland. In launching the consultation Anas Sarwar MSP advised:

"Registration would support the ambulance service to identify the nearest available working AED, potentially significantly reducing the time involved in getting a defibrillator to the scene and, in turn, improving survival rates. The Bill would also have the advantage of allowing for AEDs to be placed in a more strategic way than at present across Scotland. By locating and mapping current AEDs, we can identify areas which lack them within an accessible distance."

19. The consultation on the proposed Bill closed on 26 June 2020. The Member in charge of the Bill has indicated they wish to lodge a final proposal.

Action

20. The Committee is invited to consider what action it wishes to take on the petition. Options include—
 - To close the petition under Rule 15.7 of Standing Orders on the basis that:
 - the majority of the witnesses the Committee heard from during the evidence session did not agree with the aim of the petition to

place public access defibrillators in all new or newly renovated buildings with a floorspace of 7500m²;

- a Members' Bill seeking the mandatory registration of automated external defibrillators has been lodged in Parliament.
- To take any other action the Committee wishes to take.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1707/G: Scottish Government submission of 21 January 2021 \(65KB pdf\)](#)
- [PE1707/H: Petitioner submission of 2 February 2021 \(55KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

PE1707/G

Scottish Government submission of 21 January 2021

Thank you for your letter of 1 December 2020 on behalf of the Public Petitions Committee regarding consideration of further questions in relation to Petition PE1707 – Public Access Defibrillators. We welcome the opportunity to reply to the Petitions Committee.

We thank Mrs Orr for raising the petition, and commend the work of Jayden's Rainbow Campaign in raising funds to have defibrillators placed in schools and public places. We also fully encourage the Campaign's work in ensuring that PADs provided in local communities are registered with the Scottish Ambulance Service (SAS). They have set an excellent example that we would encourage others to follow. This debate is an important one and one which should include voices from across Scotland.

It may help if I respond to the committee's queries in the order they have raised them.

1. Increased funding to Save a Life for Scotland;

Within the lifetime of the current out of hospital cardiac arrest strategy, the Scottish Government has provided over £725,000 of funding to the Save a Life for Scotland (SALFS) partnership, including £50,000 a year for operational costs. All members have a key role to play in the sustainability of SALFS and we actively encourage other partners to financially contribute to the work of the partnership.

2. Improved life saving skills taught in schools (this can currently be taught as part of various classes or not at all but it is already mandatory in England);

Scottish Government officials met with Education Scotland, St. Andrew's First Aid and the British Red Cross at the start of 2020 to explore ways in which first aid education could be taught more widely in schools. However, the ongoing COVID-19 pandemic has since stalled progress. We will reconvene these discussions as soon as it is appropriate to do so. Under the provisions of Curriculum for Excellence, the Scottish Government does not mandate on any aspects of the Scottish curriculum. Education authorities and schools have the flexibility to decide upon the content of their own lessons at the local level, including whether to offer first aid education at school.

3. making the provision of PADs in non-residential buildings compulsory;

Building standards are a reserved matter for the Westminster Parliament. However, the Building (Scotland) Act 2003 section 1 allows Scottish Ministers to make regulations regarding the construction of buildings, their fittings and equipment for the purpose of securing the health, safety and welfare of persons in or about those buildings.

The Scottish Government is currently considering permitted development rights for defibrillators on public buildings, which would remove the need to apply for planning

permission to place a PAD in an external area of a building. We aim to provide an update in Summer 2021.

4. Include CPR and PAD training in compulsory health and safety training (as with fire extinguishers);

Health and safety at work is a reserved matter for the Westminster Parliament. Unfortunately the Scottish Government could not take action to legally require that employers include these topics in their health and safety training. However, the Scottish Government will liaise with the Health and Safety Executive in Scotland to further explore CPR and PAD training options within health and safety training.

5. Issue national guidance on the placement of PADs

As part of the aims of the Out of Hospital Cardiac Arrest Strategy the Scottish Government published OHCA: A Guide to PADs in March 2018. The guide provides practical advice to those considering a purchase and installation of a PAD for their local community.

6. Local projects that acquire and train people in the use of PADs were commended and noted as being successful on a small scale. Witnesses, however, agreed that the balance of responsibility for this must move towards the Scottish Government to demonstrate leadership in this important area of public health. It was felt that only the Scottish Government has the power and resources to ensure this happens on a large scale.

The Scottish Government does not have a direct role in the PAD/CPR training of members of the public, so this is the decision of the independent organisations and charities who deliver the training. Discussion on what steps the Scottish Government can take to support PAD placement continues at leadership level.

I hope this reply is helpful to the petitioner and the PPC.

PE1707/H

Petitioner submission of 2 February 2021

Thank you for taking the time to again consider my petition.

Since submitting the petition, a lot has happened in my local area. I fundraise via my charity, Jayden's Rainbow and have been able to purchase a good number of defibrillators and place them about Inverclyde. Further, St Andrew's First Aid gifted the charity 30 defibrillators that they were replacing. I had begun to place these across the community before covid-19 hit.

I know that I feel safer living in Inverclyde as a result of these defibrillators being place in the community, on hand to help local people if they are ever in need. So far, four of the defibrillators placed by Jayden's Rainbow have been used. One time the use of the defibrillator was successful, unfortunately the other three occasions were not successful, but I would argue that they still gave the person in need a greater chance of survival having a defibrillator close to hand.

I also wanted to make the point again that the 7500 square foot size that I refer to in my initial petition was just a starting point. This could either be increased or reduced based upon the evidence gathered by this committee.

Public Petitions Committee

3rd Meeting, 2021 (Session 5)

Wednesday 10 February 2021

PE1722: Parking charges at island lifeline ferry ports

Note by the Clerk

Petitioner Dr Shiona Ruhe mann on behalf of Iona and Mull Community Councils and others

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to island-proof transport infrastructure to ensure that public bodies do not charge for parking in car parks at island ferry ports, which are essential lifeline services, and any proposed island parking charges are subject to rigorous impact assessment.

Webpage parliament.scot/GettingInvolved/Petitions/PE01722

Introduction

1. This is a continued petition, last considered by the Committee on 12 November 2020. At that meeting, the Committee took evidence from the Minister for Energy, Connectivity and the Islands.
2. Since this meeting, the Committee has received written evidence from the Minister for Energy, Connectivity and the Islands and the petitioner.
3. The Committee has also previously considered extensive written evidence from a range of interested parties including local authorities, CalMac Ferries, local MSPs, the Scottish Government and the petitioner.
4. The Committee is invited to consider what action it wishes to take.

Committee consideration

5. With regard to the specific case highlighted by the petitioner, the Scottish Government commented that it would have expected an impact assessment and stakeholder consultation to be carried out as part of the implementation of a Traffic Regulation Order (TRO). The Scottish Government also highlighted that local authorities are independent corporate bodies and as such, Scottish Ministers have no remit to intervene in their day to day duties or how they allocate funding.
6. Argyll and Bute Council acknowledged in its response to the Committee that the TRO process referred to by the petitioner did not fully comply with the statutory and regulatory requirements and in particular, failed to properly consult with Iona Community Council in accordance with the statutory

requirements. The Council has apologised publicly to Mull and Iona Community Councils.

7. The petitioners' response of 3 November 2020 requested that the Committee focus on the core issue of their petition (which is for all island lifeline ferry car parks to be free of charge, as a lifeline service), as the petitioners were concerned that the Committee has focussed its consideration on the commencement of ICIAs .

Oral evidence from the Minister on 12 November 2020

8. The Minister told the Committee on 12 November 2020 that the commencement and review of decisions regulations to instigate ICIA's would come into force on 23 December 2020 (having being delayed from spring 2020). He said that the guidance associated with ICIA's had been consulted on, with a closing date of 9 November 2020. That guidance will be in place for when the ICIA duties are brought into force.
9. The Minister also said that he accepted that ferries were a lifeline service for islanders and that he would prefer that there was no parking charges, but that as local authorities were independent bodies, their decision should be respected. His intention was that ICIAs would assist in future, and that local authorities would use them as a robust impact assessment to ensure proportionality and fairness and to avoid causing hardship for islanders.
10. The Committee asked the Minister how the Scottish Government could assist local authorities to avoid introducing parking charges in the future, as Argyll and Bute Council were forced in this case to explore parking charges in the face of the challenging financial situation.
11. The Minister said that the Scottish Government had committed additional resources of approximately £1 billion, including £382 million to local authorities in response specifically to the Covid-19 pandemic, and a package of financial flexibilities for Scotland's local authorities that could be worth up to £600 million over the next two years. Additionally, Scottish ministers and Cosla were working jointly on a lost-income scheme worth an estimated £90 million.
12. The Committee also asked the Minister whether the Scottish Government could instigate a national policy on making lifeline car parks free of charge, similar to the policy of bridge tolls. Scottish Government officials responded that car parks were in the control of local authorities so this proposal would not be possible, unlike bridge tolls which were in the remit of Scottish ministers.
13. The Committee asked the Minister about the petitioner's concerns that ICIAs would not work in the way he intended. The Minister and his officials said that with the new ICIA system, a review could be applied retrospectively, even in cases where an ICIA was not carried out. In this case, the applicant could request a review at any time after the decision has been made. There is no time limit, so as not to prejudice an applicant in those circumstances.

14. The Minister also said that it was his intention that the Scottish Government's wider strategic work on transport would also improve the kind of case raised by the petitioner in future. He highlighted specifically the islands connectivity plan, which will succeed the Scottish ferries plan, which ends in 2022. The islands connectivity plan will be closely linked to the Strategic Transport Projects Review 2, and aims to create a broader view of island connectivity and transport types, with a particular focus on active, public and shared transport, and the Scottish Government's commitments to achieve net carbon neutrality.
15. The Minister told the Committee that he would discuss the issues raised by this petition within wider discussions on the islands connectivity plan and STPR2. He agreed to keep the committee informed on the results of any positive discussions that the Scottish Government had with the relevant local authority officials and Transport Scotland, as well as with wider local authorities that have an interest, such as Shetland Islands Council. He said that the Scottish Government position was that, in practice, where it is practical, CalMac does not impose parking charges.
16. The Committee asked whether the Scottish Government would consider Shetland Islands Council's proposal to island proof transport infrastructure through fair funding for ferry services, on the basis that if fair funding had been delivered previously, difficult decisions about car parking charges might not have arisen.
17. The Minister said that the Scottish Government had provided £11.5 million of additional support to local authorities to operate ferry services. He acknowledged that did not meet the full cost, but said the money had increased annually. He also described his ongoing dialogue with the relevant councils, in advance of the draft budget being published, regarding their requirements for the next financial year.

Written responses received for meeting of 10 February

18. The Minister provided correspondence of 8 December 2020 in follow up to the 12 November session, to provide a list of Island Communities Impact Assessment (ICIA) work carried out "in the spirit of the 2018 Act" before they were formally introduced, as requested by the Committee.
19. He also said that parking charges at lifeline ferry ports would be discussed at the Islands Strategic Group with islands authorities' leaders and Chief Executives on 9 December 2020, and that he would provide an update on this. Despite repeated requests by the clerks for this information, it has not been forthcoming.
20. The petitioners have responded on 11 January 2021 reiterating their views in the petition that public bodies should not charge for parking in car parks at island ferry ports, repeating their concerns that ICIA's will not improve the issues, and detailing their ongoing concerns as regards the local authority's handling of their specific case.

Action

21. The Committee is invited to consider what action it wishes to take. Options include—

- To write to the Minister for Energy, Connectivity and the Islands seeking an update on the discussions that took place at the Islands Strategic Group on 9 December 2020.
- To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1722/N: Minister for Energy, Connectivity and the Islands submission of 8 December 2020 \(74KB pdf\)](#)
- [PE1722/O: Petitioner submission of 11 January 2021 \(179KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

PE1722/N

Minister for Energy, Connectivity and the Islands submission of 8 December 2020

Island Lifeline Ferry Ports (Parking Charges) (PE1722)

At the Committee for the above Petition on Thursday 12 November, I gave two commitments:

- To provide a list of Island Communities Impact Assessment (ICIA) work carried out “in the spirit of the 2018 Act” before they were formally introduced; and
- to revert to the Committee with the results of any positive discussions that we have with the local authority (Argyll and Bute Council) and with colleagues in Transport Scotland, as well as with wider local authorities that have an interest.

My officials have produced a list as requested (annexed to this letter), detailing examples of where advice has been given in regard to the preparation of ICIA's. This list augments the examples already given to Committee, being:

- On-going work on the Strategic Transport Projects Review, which will be completed in two phases. The first phase will look at Active Travel and locking in the good behaviours that have resulted from the Covid-19 pandemic. The second phase will look at the investment opportunities.
- Phase 3 of the Covid Route Map.
- Deposit Return Scheme.
- Producer responsibility for recycling and packaging.
- The Covid-19 Vaccination Strategy.

I can also confirm that parking charges at lifeline ferry ports is an agenda item at the forthcoming Islands Strategic Group where the matter will be discussed with islands authorities' leaders and Chief Executives on 9 December. I can confirm that I will write to you further regarding progress of these imminent discussions.

Advice given on the preparation of Island Communities Impact Assessments:

1. The United Nations Convention on the Rights of the Child Incorporation Bill
2. Sport Scotland's Review of Cumbrae National Watersports Centre
3. Regulations relating to the Scottish Nursery Milk Scheme
4. Internal Review of Scottish Government Impact Assessments
5. Scotland's Environment Strategy - screening report
6. Burial regulations
7. Future Fisheries Management
8. HIAL - Proposal for Remote Air traffic Control screening document
9. Good Food Nation Bill Screening assessment
10. Bioenergy Action Plan
11. Scottish Crown Estate Strategic Management Plan
12. Early Learning and Childcare Recovery
13. Age of Criminal Responsibility - ChIRPs Regulations
14. St Andrews University (Medical Degrees) Bill
15. Transport Transition Plan
16. Events Sectoral Guidance - ICIA Screening Report
17. Construction guidance
18. National Development Plan for Crofting
19. SSI to align with a recast of EU legislation on PCBs (polychlorinated biphenyls)
20. Winter Heating Benefits
21. Scottish Government's Cleaner Air for Scotland Strategy
22. SSI is to extend the "relevant period" specified in schedule 14 of the Corporate Insolvency and Governance Act 2020
23. Single-Use Plastics Directive - Islands Screening Assessment
24. Housing to 2040 Route Map
25. Food Waste Consultation
26. Travel Restrictions - regulations
27. NTS2 Delivery Plan
28. ICIA National Transport Strategy (NTS2)
29. ICIA Scotland's Census 2021
30. Motor Sport on Public Roads (Scotland) Regulations 2019
31. Outer Hebrides Community Planning Partnership's Guidance on ICIAs
32. ICIA for the Fuel Poverty (Targets, Definition and Strategy) (Scotland) Bill

Joint Petitioners' Response: Iona and Mull Community Councils, South West Mull and Iona Development, Mull and Iona Community Trust, and Mull and Iona Ferry Committee

We enormously appreciate the consistent views expressed by all members of the Committee at its last meeting (12.11.20). We also greatly appreciate the participation of the Minister for Energy, Connectivity and the Islands and his support for the principle of our Petition. We remain convinced of the Minister's strong personal commitment to the Islands Act and to sustaining island communities.

In line with the Committee's clear arguments, **we very strongly request that the Committee and the Minister now jointly secure a positive, meaningful outcome for island communities** through:

- Accepting it is necessary for Scottish Government to ***act directly*** on the agreed principle, that all lifeline car parks should be free of charge;
- Using Scottish Government's ***equally principled policy of no charges on 'fixed links' (bridges)*** as an excellent comparator and precedent to guide that action;
- Recognising that the purpose of our Petition is to ***address principles of equity and fairness for all island residents*** that have been demonstrated and accepted, that are enshrined in Scottish law and policy, and with which all public bodies are obliged to comply; whereas Island Community Impact Assessments (ICIAs) are in no way an alternative to supporting this Petition – their purpose is to identify ***whether*** there are significant impacts.

In December 2020, we wrote to the Minister – as Iona and Mull Community Councils and Dr John Holliday from Tiree – to explain our very serious concerns that the draft guidance for ICIAs does not fulfil the intentions of the Islands Act, and cannot address the needs of this Petition. We explained why, as island communities, we sincerely need him as our Island Minister to act in the terms above. We cited what is, to us, a particularly alarming and urgent example:

Argyll & Bute Council carried out a Community Engagement Review (March 2020) of the Mull Traffic Regulation Order process. The Mull TRO was so disastrous that it was revoked by the Council on legal advice and catalyzed our Petition on behalf of all island communities. We declined to participate in the Council's Review because it was led and overseen by the people who had themselves imposed the TRO, who could not possibly assess their own actions with any objectivity. The review was not shared with us as the communities directly affected, and we only came across it by chance last month (December 2020). The review concludes that: *"while car parks are integral components of island lifeline ferry services, whether charges should be imposed should be considered on a case by case basis"*.

The participants in this internal review entirely exonerated themselves of any wrongdoing in relation to the TRO, only admitting to a narrow technical failure. They produced recommendations for generating *more* consultation responses, whilst ignoring the fact that they failed to listen or respond in any way to the mountains of consultation responses that were actually submitted to them. We have absolutely no confidence whatsoever that our Council understands why we fought so hard to prevent the imposition of charges, nor that the draft guidance for ICIAs would shift the current power imbalance between the Council and its island communities, or

prevent imposition of another damaging *fait accompli*; the ICIA guidance would in fact give an additional veneer of legitimacy to exactly the same behaviour and outcome.

We explained to the Minister that the **draft Island Community Impact Assessment guidance entrenches and *further worsens* the disadvantages and dangers for island communities**. The Islands Act must move from good words to meaningful actions if it is to ‘island proof’ and protect – let alone – empower island communities, i.e.:

- Allowing island communities to express views after off-island “experts” have been consulted and off-island “evidence” gathered does not redress the enormous power imbalances between Relevant Authorities and island communities and does not allow meaningful impact assessments to be carried out.
- Island communities are already subjected to outdated processes that are more ‘consultative’ than the approach of the draft ICIA guidance, e.g., as in the TRO process, that require notification of island statutory bodies at the outset, and allow plenty of views to be expressed – but ***our recurring experience is that no attention is paid to consultation with us***.
- **Off-island evidence will produce very little of meaning or value**: to fulfil the intention, purpose and spirit of the Islands Act, island communities must be **full partners** in the process **from the first step** and recognised as the primary stakeholder, and holder and interpreter of evidence regarding their community and any impacts on it. We have proposed a critical and proportionate way to manage this requirement through ‘live’ Island Profiles.
- **We fear it may soon become impossible for island communities to engage effectively with official bodies**, because – *even more than currently* – we will *constantly* have to expend scarce volunteer resources rowing back on bad processes and decisions, whilst (completely contrary to the Islands Act) having no power or ‘teeth’ in these processes. We stress this in the context of shared fatigue at the extent of demands put on Community Councils to respond to enquiries, surveys, notices etc, and to put our case to official bodies *who do not listen*.
- **The intention behind a review mechanism is certainly positive, but we do not agree that this ‘empowers an island community’**. By not producing consultative, sound ICiAs *in the first place*, the review mechanism creates an unbalanced contest between un-resourced powerless island communities and **heavily-resourced powerful Relevant Authorities**, able to dismiss any challenge and assert that they followed the guidance.
- As above in our direct experience, ICiAs will bring a veneer of legitimacy and authority to decisions that – accidentally or intentionally – risk endorsing and enabling harmful actions without having genuinely assessed their impacts.

We could not be more supportive of the intentions of the Islands Act and of ICiAs, or more appreciative of the Minister’s own commitment, and we are very keen to support him in delivering on these intentions in any way we can. However, ICiAs are separate from and no solution to our Petition. We again urge the Committee and the Minister to act directly in support of our Petition, by appropriately balancing consideration of local authority autonomy with the fundamental responsibility to take *principled action* consistent with Scottish Government’s own legal and policy priorities. **Acting on our Petition, before the conclusion of the current Parliamentary session, would have great significance for island communities and minimal real-world implications for local authority budgets.**

Public Petitions Committee
3rd Meeting, 2021 (Session 5)
Wednesday 10 February 2021

PE1775: Introduce statutory allergy care legislation in nurseries and schools

Note by the Clerk

Petitioner	Catrina Drummond
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to pass legislation that will make an allergy care policy statutory for every nursery and school and to establish appropriate standards for nursery and school staff of medical training, education and care for children with anaphylaxis.
Webpage	parliament.scot/GettingInvolved/Petitions/allergyprovisioninschools

Introduction

1. This is a continued petition, last considered on 1 October 2020. At that meeting, the Committee agreed to write to the Scottish Government. A response has been received from the Deputy First Minister and Cabinet Secretary for Education and Skills and the petitioner.
2. The Committee is invited to consider any action it wishes to take in relation to the petition.

Committee Consideration

3. At its meeting on 1 October, the Committee noted concerns raised by the petitioner that Scottish Government and local authority guidance and procedures did not appear to be followed in every case due to various factors including a lack of training or different levels of training, which has led to inconsistency across local authorities, or at worst, a life and death situation. The Committee also noted concerns raised by the petitioner that school and nurse staff did not have sufficient confidence overall in the care for children with anaphylaxis.
4. The Deputy First Minister and Cabinet Secretary for Education and Skills' response reiterates that the Scottish Government recognises the importance of schools and early learning and childcare (ELC) settings having robust procedures in place to deal with allergic reactions, including anaphylaxis.
5. In response to the petitioner's concerns regarding implementation of the [guidance on supporting children and young people with healthcare needs in schools](#) ('the guidance'), the Deputy First Minister explains:

"...under the National Health Service (Scotland) Act 1978, securing the medical inspection, medical supervision and treatment of children and young

people at school is the statutory responsibility of NHS boards. NHS boards, education authorities, schools and other partners must work collaboratively to implement the guidance and put in place a policy framework to ensure adequate and efficient provision for children and young people with healthcare needs in schools. The day-to-day management and support of their medical needs should be met by staff in schools and ELC settings.”

6. With regard to training on the use of adrenaline auto-injectors, the Deputy First Minister refers to the guidance which states that any member of school staff can volunteer to take on this responsibility and that schools must arrange specialist anaphylaxis training to support staff in fulfilling this role. The Deputy First Minister explains that NHS Boards and education authorities are responsible for working collaboratively to ensure that all staff receive an appropriate level of training. The Deputy First Minister also advises that training requirements are best decided at a local level and driven by the individual needs of children and young people in the schools within the relevant area.
7. In terms of the funding available for adrenaline auto-injector devices, the submission reaffirms that the Human Medicines Regulations 2012 allows all schools in the UK, including independent and grant-aided schools, to buy adrenaline auto-injector devices without the need for a prescription for use in emergency situations on children who are at risk of anaphylaxis. The submission explains that whilst there is no specific funding set aside, local authorities can purchase these devices using money allocated through the Scottish Government's existing grant funding settlement.
8. For care providers in ELC settings, the Deputy First Minister refers to the Care Inspectorate guidance on [management of medication in daycare of children and childminding settings](#) which recognises the need to consider training for staff who manage medicines. The Professional Development Award (PDA) in Health and Social Care: Administration of Medicine at SCQF level 7 has been designed to meet the requirements of social service workers who are in a job role where they assist or administer medication to individuals. The 2019 Care Inspectorate data shows 97.3% of ELC settings reported that they have at least one member of staff with a current first aid certificate or a current paediatric first aid certificate (or multiple staff with a combination of both types of certificate). The administration of medication in ELC settings is also something that the Care Inspectorate review during their inspections.
9. The Deputy First Minister concludes by explaining that taking into consideration the legislative framework around this issue, as well as the substantive guidance available to practitioners, his position remains that there are sufficient provisions already in place to make clear to education authorities, schools, ELC settings, and NHS Boards their respective responsibilities in relation to this matter.
10. In her response, the petitioner agrees that the current legislation and guidance is appropriate, however she remains concerned about how this is implemented. The petitioner is of the view that there are no available resources or implementation guidance to help schools implement the Scottish Government advice. She feels mandatory training or a step-by-step manual for the implementation of an allergy

policy should be introduced. She also believes school competence should be measured annually and given constructive feedback on areas of practice that need improvement.

11. The petitioner closes by asking the Deputy First Minister to meet with stakeholders directly to discuss and share information regarding the issues raised which would mean for a more effective dialogue than written communication.

Action

12. The Committee is invited to consider what action it wishes to take on the petition. Options include—

- To close the petition under Rule 15.7 of Standing Orders on the basis that the Scottish Government and COSLA have stated that there are sufficient standards, provision and guidance for local authorities, schools, early learning and childcare settings and NHS Boards, and therefore statutory requirements are not necessary.
- In closing the petition, the Committee could write to the Deputy First Minister and Cabinet Secretary for Education and Skills to ask that the Scottish Government engages in the work being conducted by the University of Glasgow and NHS Greater Glasgow and Clyde, which has initiated a pilot scheme working with schools to advise on management of pupils with allergic disease, if it has not already done so.
- Any other action the Committee wishes to take.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1775/D: Deputy First Minister and Cabinet Secretary for Education and Skills submission of 26 January 2021 \(72KB pdf\)](#)
- [PE1775/E: Petitioner submission of 1 February 2021 \(53KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

PE1775/D

Deputy First Minister and Cabinet Secretary for Education and Skills submission of 26 January 2021

Thank you for your letter of 6 October 2020 regarding petition PE1775 calling on the Scottish Government to pass legislation that will make an allergy care policy statutory for every nursery and school, and to establish appropriate standards of medical training, education and care for children with anaphylaxis for nursery and school staff. I am sorry for the delay in responding you.

As set out in my previous submission to the Committee, the Scottish Government recognises the importance of schools and early learning and childcare (ELC) settings having robust procedures in place to deal with allergic reactions, including anaphylaxis. I was extremely saddened to hear about the tragic incident leading to the inquest that the petitioner refers to; every child in Scotland has the right to safe, good quality, compassionate care in education including schools and ELC settings and I would like to convey my deepest condolences to Karanbir Cheema's family.

In response to the petitioner's concerns regarding implementation of the [guidance on supporting children and young people with healthcare needs in schools](#) ('the guidance'), under the National Health Service (Scotland) Act 1978, securing the medical inspection, medical supervision and treatment of children and young people at school is the statutory responsibility of NHS boards. NHS boards, education authorities, schools and other partners must work collaboratively to implement the guidance and put in place a policy framework to ensure adequate and efficient provision for children and young people with healthcare needs in schools. The day-to-day management and support of their medical needs should be met by staff in schools and ELC settings.

Regarding training on the use of adrenaline auto-injectors, the guidance states that any member of staff can volunteer to take on the responsibility for administering adrenaline to children and young people, although they are not obligated to do so. Where school staff choose to take on this responsibility schools must arrange specialist anaphylaxis training. This training should include practical instruction on how to use the different adrenaline auto-injector devices available.

NHS Boards and education authorities are responsible for working collaboratively to ensure that all staff receive an appropriate level of training to understand the needs of the children for whom they are responsible, including the provision of refresher courses to update competencies relating to their roles. Training requirements should be planned for and driven by the individual needs of children and young people in the schools within the relevant area. Therefore this is best decided at a local level given the better understanding of the needs and circumstances of the children and young people in attendance in each school.

In addition, the guidance recommends that general awareness training of common conditions including anaphylaxis should be provided to ensure that staff in schools have a basic understanding, can recognise symptoms, and know where to seek appropriate support. Education authorities should ensure that their

insurance/indemnification arrangements provide full cover for their staff who meet healthcare needs or administer medication within the scope of their employment. At the school level, the school management team and the school health team should both be aware of the arrangements in place for staff training and ensure that the training provided gives staff sufficient levels of knowledge, understanding, confidence and competence appropriate to their roles.

Regarding availability and funding for resources, the Human Medicines Regulations 2012 allows all schools in the UK, including independent and grant-aided schools, to buy adrenaline auto-injector devices without the need for a prescription for use in emergency situations on children who are at risk of anaphylaxis, if they wish to do so. This school-held device can then be used on children and young people where both medical authorisation and written parental consent has been provided to do so, including in instances where a child or young person is at risk of anaphylaxis and been provided with a medical plan confirming this, but has not been prescribed with an adrenaline auto-injector device of their own. Whilst there is no specific funding set aside for this purpose, local authorities can purchase these devices using money allocated through the Scottish Government's existing grant funding settlement.

In relation to ELC settings, the Care Inspectorate guidance on [management of medication in daycare of children and childminding settings](#) recognises the need for care providers to consider any training and qualifications required for staff who manage medicines. The Professional Development Award (PDA) in Health and Social Care: Administration of Medicine at SCQF level 7 has been designed to meet the requirements of social service workers who are in a job role where they assist or administer medication to individuals. The PDA is also designed to provide Continuing Professional Development for employees who are currently in a role where they administer medicine.

Continuous professional learning also includes regular first aid/paediatric first aid training that includes training on the relevant skills to understand and respond to a child suffering from an allergic reaction. The 2019 Care Inspectorate data shows 97.3% of ELC settings reported that they have at least one member of staff with a current first aid certificate or a current paediatric first aid certificate (or multiple staff with a combination of both types of certificate). This demonstrates that there continues to be a high commitment from registered ELC services in supporting staff development in relation to paediatric first aid training.

The administration of medication in ELC settings is also something that the Care Inspectorate review during their inspections. Each ELC settings has responsibility to meet every child's medication needs and ELC providers must make proper provision for the health, welfare and safety of all children in their care. Additional guidance for ELC providers on management and treatment of allergies is contained within the [setting the table](#) guidance, which states that all relevant details relating to food allergy, symptoms, emergency procedures and contacts should be recorded in the child's personal care plan in discussion with the child's parent/guardian. When a child has a severe allergy to a particular food the guidance provides information on how to minimise the risk of exposure. It is the individual ELC setting's responsibility to decide whether particular foods will be removed from their menus/setting. This should be communicated with parents, and form part of the setting's food policy.

It is the responsibility of the individual ELC setting to ensure that each member of staff is adequately trained. For ELC settings delivering the funded hours, training and development of staff is supported by the National Standard for ELC, which promotes continuous professional learning for the ELC workforce. As part of our programme to expand funded hours from 600 to 1140 hours, all settings delivering this entitlement will be required to meet a minimum National Standard, which requires them to achieve good or better in Care Inspectorate inspections on quality themes including quality of staffing and quality of care and support.

Taking into consideration the legislative framework around this issue, as well as the substantive guidance available to practitioners, my position remains that there are sufficient provisions already in place to make clear to education authorities, schools, ELC settings, and NHS Boards their respective responsibilities in relation to this matter. Therefore, we do not plan to introduce a further statutory requirement upon school and ELC staff in respect of an allergy care policy.

Finally, I would like to thank the petitioner for bringing the University of Glasgow and NHS Greater Glasgow and Clyde research study and pilot scheme to my attention, and for bringing forward these important issues for discussion.

I hope the above information is helpful in response to the petition PE1775.

JOHN SWINNEY

PE1775/E

Petitioner submission of 1 February 2021

Many thanks for your response. We understand the pressure that everyone is under during this pandemic and especially the members of the Government who need to coordinate all different strategic actions.

We do feel that the current legislation and guidance is appropriate and sufficient, however we have identified issues in their implementation. All the interested parties involved are very keen to put in place measures to improve school preparedness in the management of the severely allergic child but up to now, there are no available resources and implementation guidance to help schools implement Scottish Government advice.

A clear step by step 'manual' that guides school staff and offers troubleshooting if an issue arises, along with face-to-face training for the implementation of an allergy policy and emergency protocol are required. This should be generated centrally and be made available to all schools for mandatory implementation. Schools should be able to prove their competency towards a safer environment for pupils with allergies; their performance in this area should be measured yearly and they should receive constructive feedback along with recommendations for those areas of practice that require improvement.

We feel email/letter communication is not adequate to give a real dimension of the issue. We propose instead a stakeholder meeting that could bring together patients and parents/carers, schools, councils, NHS, academia and Scottish Government. We will be happy to share with all involved current data and challenges in school preparedness along with solutions which we feel that would not have an impact on other services. Please let us know if you would be open to a meeting with us.

Public Petitions Committee

3rd Meeting, 2021 (Session 5)

Wednesday, 10 February 2021

PE1780: Consultation on the closure of large shops on New Year's Day

Note by the Clerk

Petitioner	Stewart Forrest on behalf of USDAW
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to launch a consultation on implementing legislation already in place to ban large shops from opening on New Year's Day.
Webpage	parliament.scot/GettingInvolved/Petitions/PE1780

Introduction

1. This is a continued petition, last considered by the Committee on 16 December 2020.
2. At that meeting, the Committee agreed to write to the Minister for Business, Fair Work and Skills. Two submissions have since been received from the Minister in addition to a submission from the petitioner.
3. The Committee is invited to consider what action it wishes to take.

Committee consideration

4. In his submission of 17 December 2020, the Minister for Business, Fair Work and Skills stresses that the Scottish Government is not opposed to exercising the power under Section 2 of the Christmas Day and New Year's Day (Trading) (Scotland) Act 2007.
5. The Minister advises that he has continued to engage with unions and retailers to seek further views on the issue, meeting with representatives from Usdaw, the Scottish Retail Consortium and a few of their larger members. A meeting was also held with Neil Bibby MSP and representatives of the GMB union, specifically on the issue of implementing the provisions of the Act in time for 1 January 2021.
6. The submission explains that the specific provisions of the Act require—
 - consultation with local authorities, retail sector representatives and others who may be affected.
 - Reports on the economic impact of the proposal and of the impact on family life to be prepared, which must then be submitted to the Parliament

along with a formal statement of the Scottish Government's findings and recommendation.

- once the order to put into effect the closure of large retailers on New Year's Day is laid, Standing Orders requires a minimum period of 40 days for it to proceed through the committee process, plenary session and voting process.
7. The Minister states that it would therefore not be possible to implement the provisions for 1 January 2021, in the timescales available, as called for by the Committee at its meeting of 16 December 2020.
 8. Although the Minister highlights that the implementation of the Act would not guarantee that workers would receive a day off, only that those shops would not be able to open to the public, he states that he has a great deal of sympathy with the objective of the petition and is continuing to actively engage with unions and retailers about its proposition. The Minister commits to write to the Committee again, once he has reached a definitive conclusion on both scope and timing of a possible formal consultation.
 9. In its most recent submission, while accepting that implementing the legislation for 1 January 2021 was not possible owing to the timescales required by parliamentary procedure, the petitioner is keen that "such delays are not allowed to negate the possibility of the ban coming into force ahead of New Year's Day 2022."
 10. The petitioner is therefore calling on the Scottish Government to bring forward a timetable for formal consultation on the possibility of enacting Section 2 of the Christmas Day and New Year's Day Trading (Scotland) Act 2007, to ensure that it can be completed within the current parliament.

Action

11. The Committee is invited to consider what action it wishes to take on this petition. Options include—
 - To close the petition under Rule 15.7 of Standing Orders on the basis that the Scottish Government is actively engage with unions and retailers about the action called for in the petition.
 - To take any other action members consider appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1780/G: Minister for Business, Fair Work and Skills submission of 17 December 2020 \(65KB pdf\)](#)
- [PE1780/H: Minister for Business, Fair Work and Skills submission of 23 December 2020 \(59KB pdf\)](#)
- [PE1780/I: Petitioner submission of 29 January 2021 \(140KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

I am writing in response to your letter of 16 December in regards to the above mentioned petition. I am sorry that I wasn't able to respond by your requested time of the end of yesterday, but I am sure you will appreciate that was a tight timescale.

Before I respond in detail to the specific points set out in your letter I would like to set out that I am, like all of us, hugely appreciative of the efforts of our retail workers who have been extremely diligent throughout the pandemic. This has been a year like no other and no one should underestimate the impact of those circumstances on those working on the front line of retail. I agree that employers should show their appreciation to their staff in a way that acknowledges their endeavours, including through allowing those that want to be able to take time off to spend with their families over the coming holiday period and considering the necessity of opening on New Year's Day.

On the matters detailed in your letter, in the first instance I want to respond to what I felt was a sense from some on the committee that the Scottish Government is opposed to exercising the power under Section 2 of the Christmas Day and New Year's Day (Trading) (Scotland) Act 2007. I want to reassure you that this is not the case. I greatly appreciate the time that Usdaw has taken in petitioning the Parliament on this matter and the deliberations of your Committee in considering it.

When I last wrote to you on 6 November I provided a commitment that I was seeking further views and opinions from unions and retailers on the issue and would advise the committee of my findings. I note that Usdaw's submission to the committee of 3 December welcomed that response.

I have continued that process of engagement – which has included meeting with representatives from Usdaw, the Scottish Retail Consortium and a few of their larger members. This latter meeting was to help understand the operational approach taken by retailers in terms of staffing arrangements on New Year's Day – primarily whether they were achieved through compulsory or voluntary means. I have a further meeting with Usdaw and the Scottish Retail Consortium scheduled for 21 December.

In addition I met with Neil Bibby MSP and representatives of the GMB union on Friday 11 December with a particular focus on implementing the provisions of the Act in time for 1 January 2021. This was of course a feature of your deliberations yesterday as set out in your letter. It may be helpful if I set out some of the issues around that matter.

As I believe you acknowledged during your discussion on Wednesday, there are indeed a number of challenges in the limited time left before 1st January 2021 to enable the law to be enacted. To say the least, this would be an exacting timescale in any circumstance, but there are specific provisions in the Act that essentially render it impossible to use it as a vehicle to close large retailers on that date.

As mentioned above Section 2 of the Christmas Day and New Year's Day Trading (Scotland) Act (the Act) contains provisions enabling the Parliament to prohibit New Year's Day trading. As you discussed, the Act states that before the statutory instrument can be laid there must be a consultation, involving local authorities, retail sector representatives and others who may be affected. Part of your discussion yesterday focussed on the ability of undertaking such a process in a very short timeframe as the Act doesn't specify any period for this.

Whilst that is technically correct, given we are less than a week away from the end of the Parliamentary session, I do not believe that any serious consultation could be done. That of course could be subject to a matter of opinion, but even allowing for that, the process involved is not as simple as consulting on the matter and then determining to implement any measure.

In addition to the process of consultation the Act prescribes that there must also be reports prepared on the economic impact of closing large retailers on New Year's Day and of the impact on family life of the proposal. These reports must be submitted to the Parliament along with a formal statement of the Scottish Government's findings and recommendation. That simply would not be possible in the timescale we have.

Again though, even allowing for that to be a possibility, as unlikely as I consider it, the Act also prescribes that once the order to put into effect the closure of large retailers on New Year's Day is laid, Standing Orders requires a minimum period of 40 days for it to proceed through the committee process, plenary session and voting process.

We are of course only a fortnight away from the end of the year. On the basis of the above, utilising the Act as a means by which to put in place the closure of large retailers on New Year's Day is I am afraid to say not possible.

It is also important that I highlight the limitations within the Act of achieving what has been the central thrust of the argument for the closure of large retailers; that being that all shop workers would receive a day off. The legislation would only stop those shops from opening to the public. Whilst I of course recognise that this would reduce demand for employees to be required to work on New Year's Day, a retailer could still require them to be at work. By way of example this could include those involved in restocking, warehousing and fulfilment and transportation of online orders may still be required to work by their employer. And it is of course the case that smaller retailers would, of course, not be required to close and their workforce could still be required to work.

Nevertheless I would reiterate that I do have a great deal of sympathy with the objective of the petition. I am continuing to actively engage with unions and retailers about the proposition in the petition and will give the matter full consideration with what I can assure you is an open mind. I am conscious that undertaking a consultation doesn't necessarily commit the Scottish Government to a specific course of action but could serve to better inform any such decision. I do believe that speaking with those in the sector to be properly informed on what any such consultation exercise might look like, should that be the course of action determined, is important. Once I have reached a definitive conclusion on both scope and timing of a possible formal consultation, I will write to the Committee again.

I hope that this has been helpful in setting out not only some of the challenges with moving at pace but also in providing you with assurance of my intent.

I am of course happy to offer further clarity on any of these points if that is helpful.

JAMIE HEPBURN

PE1780/H

Minister for Business, Fair Work and Skills submission of 23 December 2020

When I wrote to the Committee on 17 December I undertook to write again once I had deliberated further.

I would like to reiterate again the Scottish Government's recognition of the work that retailers and their workforce have undertaken over the last year which has been an exacting period. They have helped the country keep going and I am extraordinarily grateful for the efforts they have made.

Since issuing my letter to you I have had the opportunity for further discussion on the issue. On 18 December I had a call with Jackie Baillie and Maurice Golden in their capacity as party spokespeople. Other party representatives were invited but did not attend. I was grateful to both Ms Baillie and Mr Golden for the chance to speak with them.

As I indicated in my last letter I also had a call on 21 December with Stewart Forrest and Tracy Gilbert of Usdaw and David Lonsdale of the Scottish Retail Consortium. This was a helpful opportunity to build on the engagement I have had previously to discuss in detail the proposition in petition PE1780 that your Committee continues to consider.

In addition, I asked my officials to thoroughly examine and reconsider all possible vehicles that could be used to enact legislation by 1 January 2021. That detailed assessment has led me to conclude that the position set out in my letter – that utilising legislative means to put in place the closure of large retailers on New Year's Day on 1 January 2021 in a robust and legally defensible way in the time available is I am afraid to say not possible.

We have of course moved into a different phase of responding to the pandemic since we exchanged correspondence that sees us now heading into a period of further measures which will see mainland Scotland moving into level 4 and bringing further restrictions in regulations to the list of essential retail sector that will require a larger cohort of retail businesses to close from 26 December. This itself greatly reduces the number of large retailers as defined in the Christmas Day and New Year's Day (Trading) (Scotland) Act 2007 which will be able to open on 1 January 2021.

On the matter set out in the petition I want to signal my intent to continue to give this matter very careful consideration and to revisit this early in 2021 based on the helpful dialogue I have had with unions and retailers. I will therefore write to the Committee again as early into the New Year as I possibly can.

I will of course also be informed by any recommendations that the Committee makes.

I trust the details I have laid out here are helpful but please do not hesitate to revert back to me as necessary.

PE1780/I

Petitioner submission of 29 January 2020

Usdaw is writing in response to comments made by the Minister for Business, Fair Work and Skills in relation to petition PE1780.

When this issue was last discussed by the Petitions Committee, Usdaw was delighted to see the Committee's willingness to investigate the possibility of introducing a ban ahead of New Year's Day 2021. As outlined in the correspondence from the Minister, unfortunately, this was not possible as a result of the relevant timescales required within the parliamentary procedure.

Usdaw is now keen to ensure that such delays are not allowed to negate the possibility of the ban coming into force ahead of New Year's Day 2022. As such, we are calling on the Scottish Government to bring forward a timetable for formal consultation on the possibility of enacting S.2 of the Christmas Day and New Year's Day Trading (Scotland) Act 2007. Such a timetable should ensure that the consultation can be completed within the current parliament.

We note the Minister's comments to the Committee that, "I want to signal my intent to continue to give this matter very careful consideration and to revisit this early in 2021..." Usdaw believes that the discussions towards the end of last year showed a significant amount of work on the issue has already been completed and it should now be ready to progress to the next stage.

Usdaw firmly believes that, based on the positive work and engagement of the Committee on this issue, as well as the results from our own survey, that it is now clearly time for the Government to launch the required consultation.

Public Petitions Committee**3rd Meeting, 2021 (Session 5)****Wednesday 10 February 2021****PE1789: Learning difficulties and disability qualifications****Note by the Clerk**

Petitioner	James A Mackie on behalf of the 1673 Network
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to increase the number of professionals such as speech and language therapists, educational psychologists, physiotherapists, psychiatrists and occupational therapists qualified to assess children and parents with learning disabilities/difficulties and other behavioural problems, to reduce the number of children taken into care.
Webpage	parliament.scot/GettingInvolved/Petitions/LDDqualifications

Introduction

1. This is a continued petition, last considered by the Committee on 9 December 2020. At that meeting, the Committee agreed to write to the Minister for Mental Health.
2. A response has now been received in addition to a written submission from the petitioner.
3. The Committee has previously considered responses from the Minister for Mental Health, the Association of Scottish Principal Educational Psychologists (ASPEP), the Royal College of Psychiatrists in Scotland (RCPS), the Education Institute of Scotland (EIS), and the petitioner.
4. The Committee is invited to consider what action it wishes to take on the petition.

Committee consideration*Previous Committee consideration*

5. In a previous response from the Minister for Mental Health, the Minister stated that the Scottish Government does not believe that the petitioner's proposal of increasing the health workforce is the only answer, but that the way forward is through early intervention and the more holistic approach outlined in the independent care review, The Promise.
6. Responses from the professional bodies listed above highlighted substantial concerns (such as a significant increase in young people with additional needs, insufficient staff and resources, and the substantial resources and increased staff that would be required), as well as proposals on how resources should be

handled, focussed and ringfenced, and data on which staff are under resourced and understaffed.

7. The RCPS highlighted the importance of early intervention, and said that families should be able to access support when the need is first identified to avoid a crisis. The RCPS also said there was a need for more joined up working; more co-location of paediatrics, specialised social workers and multi-disciplinary LD Child and Adolescent Mental Health Services (CAMHS), and a joined-up IT platform across Scotland as sharing information is currently difficult and time consuming.

Current Committee consideration

8. At its meeting on 9 December 2020, the Committee agreed to write to the Minister for Mental Health to ask for:
 - A response to the concerns raised in the written submissions received;
 - To outline how these concerns will be addressed by The Promise and any other relevant strategies and;
 - To outline the timescales for implementing the findings of The Promise, recognising the petitioner's concern that the approaches identified may take too long.
9. The Minister's response describes how The Promise will operate in further detail and also work being undertaken on additional support needs, in response to the Committee's queries.
10. In relation to the Committee's specific questions on stakeholders' concerns, the Minister explains that the first stage of implementing The Promise between April 2021 and March 2024 will—

“allow for early intervention and prevention will become standard helping to lead to an obsolescence of crisis services...A practice and culture change programme will be embedded and the next stages will focus on consolidation and then continuous improvement. The workforce is key to delivering the work of The Plan and we acknowledge the concerns raised around providing vital support and training as a priority”.
11. As regards structure, approach and staffing, the Minister states that The Promise will facilitate “redesign of whole system approaches to care and support”. An Oversight Board is being established to monitor processes. A dedicated, independent Promise Team will be established, including investing £4 million in the Promise Partnership Fund “that will help embed and scale up holistic family support”.
12. On additional support needs, the Minister states that the Scottish Government has accepted and will implement the recommendations in the [review of implementation of additional support for learning](#) which was led by Angela Morgan and published in June 2020.
13. In response to the petitioner's concerns on timescales, the Minister says—

“Please be assured that we are committed to continue to work with relevant statutory bodies and third sector partners to ensure that the inequalities children with learning disabilities/difficulties face daily are addressed across all sectors including education, health and social care”.

14. In his response to the Minister’s written submission, the petitioner states that The Promise is a delaying tactic, as its first remit will not be published until 2024. He says that the Scottish Government is aware that the current unsatisfactory situation (as outlined by the professional bodies to the Committee), but that insufficient action has been taken due to lack of local authority funding and subsequently lack of relevant staff.

Action

15. The Committee is invited to consider what action it wishes to take. Options include—
- To close the petition under Rule 15.7 of Standing Orders on the basis that the Minister has outlined Scottish Government strategies for addressing the issues associated with children and parents with learning disabilities/difficulties and other behavioural problems;
 - To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting-

- [PE1789/F: Minister for Mental Health submission of 18 January 2021 \(90KB pdf\)](#)
- [PE1789/G: Petitioner submission of 18 January 2021 \(10KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

Thank you for your request dated 21 December 2020 requesting a response to the concerns raised in the written submissions received by the Committee. I hope my response reassures the petitioner and the Committee that strategies are in place and work is underway that will do much to address these concerns.

The Promise

The Promise highlights the importance of providing support for all families caring for disabled children and those with additional support needs. If families require intensive support they must get it and not be required to fight for it. We know that some families caring for children with learning disabilities/difficulties will require long term support that goes beyond what is currently provided.

We know that children who have learning disabilities/difficulties may express themselves in a way that is perceived as trauma. It is therefore vitally important that trauma informed support therapies act as a cushion to all those that require it, regardless of diagnosis. A key theme throughout The Promise was the importance of listening to children and families and allowing them to be involved in shaping decisions that impact them, and the support that is provided.

Creating a structure that can facilitate the re design of whole system approaches to care and support is a substantial and significant piece of work. It is therefore important that the plan is developed and changes are made in collaboration with those that it impacts. This will include engagement with the workforce and delivery partners, and the voice of lived experience.

However the timeframe for The Plan has to reflect the urgency for change and The Plan published in February 2020 sets out a ten year phased approach for implementation which includes three stages.

The first stage between April 2021 and March 2024 will allow for early intervention and prevention will become standard helping to lead to an obsolescence of crisis services. The necessary legislative reform will be undertaken to make sure The Rules are enabling. A practice and culture change programme will be embedded and the next stages will focus on consolidation and then continuous improvement.

The workforce is key to delivering the work of The Plan and we acknowledge the concerns raised around providing vital support and training as a priority. Our dedication to developing and nurturing the workforce and working with children and families means this will happen in the first stage, as we have committed to ensure early intervention and prevention becomes standard.

During this time the work of the Scottish Government will not stand still and the 2020/21 Programme for Government illustrates our unwavering commitment to delivering The Promise, highlighting three early steps:

- Firstly, we are committed to creating a structure that can facilitate the re design of whole system approaches to care and support. This begins with embedding the commitments that have already been made to care experienced people into policy and delivery, with significant and intensive work across the entirety of government policy;
- Secondly, an Oversight Board is being established to hold us all to account, with Fiona Duncan – Chair of the Care Review – appointed to lead it. At least half of the members of the Oversight Board will be care experienced, because we cannot build a new approach without having those with lived experience at the heart of accountability;
- Finally, we are also supporting the establishment of a dedicated, independent Promise Team, including investing £4 million in the Promise Partnership Fund that will help embed and scale up holistic family support.

Additional support needs

The Scottish Government is determined to improve the educational experiences of children and young people with additional support needs, ensuring that they get the support that they need with their learning to reach their fullest potential.

As you will be aware, education authorities have duties under the Additional Support for Learning Act 2004 (as amended) to identify, provide for and review the additional support needs of their pupils. They can also ask for help from appropriate agencies, including Health Boards and others to carry out their duties under the Act.

The review of implementation of additional support for learning which was led by Angela Morgan and published in June 2020, suggested several areas for improvement in how children and young people can be best supported to flourish in their learning and beyond.

The Scottish Government, COSLA and the Association of Directors of Education in Scotland (ADES) carefully considered the report and accepted the recommendations that it made. Our joint response was published on 21 October 2020. This response sets out the range of actions we will take, in collaboration with key partners, to address the recommendations from the review and enhance the experiences of children and young people with additional support needs. These actions will inform and help us to build on work that is already being taken forward to support children and young people with additional support needs, their families and those who support them at school to ensure that those children and young people are fully supported to reach their fullest potential.

Whilst we recognise the petitioner's concern that the approaches identified may take too long. Please be assured that we are committed to continue to work with relevant statutory bodies and third sector partners to ensure that the inequalities children with learning disabilities/difficulties face daily are addressed across all sectors including education, health and social care.

I hope the Committee find this response helpful.

Clare Haughey

PE1789/G

Petitioner submission of 18 January 2021

Thanks for forwarding me the Government response. My response is that this is a positional statement by the Government. It obviously is clearly aware of the current diabolical situation but is doing nothing about it. To make reference to "The Promise" is a delaying tactic. "The Promise" is charged with, looking at improving child protection procedures and outcomes in Scotland. Its first remit will not be published until 2024 - 3 years down the line. The situation has been well known to Government for a long period of time, yet nothing done. There is legislation in place that gives Local Authorities the power to put in place such resources but lack of funding to them prevents the necessary number of trained staff in place. The net result is that far too many children and their families are traumatised and unable to fulfil their potential because of lack of Government funding to train and put in place sufficient fully trained staff to help. By failing to put resources in place now, it is breaching everything it pushes in GIRFEC and will leave a generation or more of children with little or no education and severe problems that will affect them all their lives. The Government response is just "kicking the can down the road" for a further number of years rather than address a serious problem identified by both professionals and families.

Public Petitions Committee
3rd Meeting, 2021 (Session 5)
Wednesday 10 February 2021

PE1820: Compulsory bereavement education in schools

Note by the Clerk

Petitioner	Sameena Javid
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to introduce compulsory bereavement education into the school curriculum.
Webpage	parliament.scot/GettingInvolved/Petitions/bereavementeducation

Introduction

1. This is a continued petition last considered by the Committee on 9 December 2020. At that meeting, the Committee agreed to write to the Scottish Government.
2. Submissions have now been received from the Scottish Government and the petitioner.
3. The Committee is invited to consider its next steps.

Committee consideration

4. At its last consideration of the petition on 9 December, the Committee agreed to write to the Scottish Government to seek its views on the submissions from Young Scot and CHAS, in particular the view that there must be more information on the subject, appropriate support, and more conversations on the topic in schools and that death, dying and bereavement be formally included in teachers' training and education.

Scottish Government submission

5. The Scottish Government's previous written submission of [3 September 2020](#) stated that in March 2020, a contract for a National Childhood Bereavement Coordinator for Scotland was awarded to Includem. The role of the coordinator is to have strategic oversight of childhood bereavement support services in Scotland and act as a national champion to improve the capacity and capability of families and the children's sector workforce to respond appropriately to children and young people's needs.
6. The Scottish Government's submission of 20 January 2021 advises the key priorities for the National Bereavement Coordinator are:

- Work with partners to develop an action plan, developing a vision for support for those children who have experienced bereavement;
 - Develop a framework of support;
 - Promote an understanding of bereavement across Scotland; and,
 - Work with schools to develop the curriculum around bereavement
7. It highlights that in a recent report, the National Coordinator noted the work with schools to develop a curriculum around bereavement, their Key Deliverable 8, was 40% complete as the Project has engaged with Seasons for Growth trainers and coordinators across Scotland; Education Psychologists in several local authorities; teachers in primary and secondary schools; and, with the individuals involved in the petition.
 8. The National Coordinator will be building on this initial engagement through their roundtable discussions to formulate recommendations on how to develop a proposal for a curriculum around bereavement. The roundtables are planned to commence in January 2021.
 9. The submission notes the Scottish curriculum is designed to allow schools flexibility to decide what to study against the experiences and outcomes. The Scottish Government is reassured to hear schools are using their flexibility to bring in organisations like CHAS.
 10. The Scottish Government notes the comments in the CHAS submission about teacher confidence around dealing with bereavement as well as inclusion of education and training around death, dying and bereavement. It advises this may be taken forward as part of the work delivering and implementing the recommendations of the PSE review.
 11. In relation to counsellors in schools, the submission advises education authorities and other agencies have duties under the Additional Support for Learning Act 2004 (as amended) to identify, provide for and review the additional support needs of their pupils. An additional support need would include children and young people who have experienced a bereavement.
 12. The submission notes the British Association for Counselling and Psychotherapy and Counselling and Psychotherapy in Scotland advised that the training required to work with children under the age of 10 is very different and more complex to that for children aged 11-18, which is why the Scottish Government commitment is only for children and young people aged 10 and over.
 13. It advises however that schools and education authorities have the capacity to identify specific measures to support children in primary schools under the age of 10 and draw on a number of resources provided by Education Scotland.
 14. The Scottish Government also highlights that Education Scotland have a number of resources which raise awareness of early adversity and trauma and

develop approaches to prevent and mitigate the impact of Adverse Childhood Experience's.

15. The submission also highlights that some councils have support policies in place for bereavement. For example, the City of Edinburgh Council's policy¹ is based in wider family policy areas whereas Comhairle nan Eilean Siar's policy² sits within their Education and Children's Services Department.

Petitioner submission

16. The petitioner notes the Scottish Government submission states the curriculum is flexible and schools are encouraged to "do their own thing". However, the petitioner is of the view that many schools and councils are still choosing not to teach children about death and bereavement.
17. She highlights that schools teach children many things they may never use after school, so finds it surprising they are not taught something that will definitely affect them at some point. As such, she strongly urges the Scottish Government to reconsider this flexible approach and make it mandatory for all schools to teach about death and bereavement.
18. The petitioner highlights [research published by Strathclyde University](#) that found that by 7.8 years, 50.8% of children had suffered bereavement with the figure rising to 62% by age 10. The research notes age appropriate education on bereavement and death in early years and primary education could help to engage with children on these issues.
19. As mentioned above, the Scottish Government submission states that "training required to work with children under 10 is more complex...". The petitioner notes if a child under the age of 10 needs help, then it should be readily available for them, highlighting the research mentioned above advises intervention in early years can make all the difference to a bereaved child.
20. The petitioner highlights that Child Bereavement UK believe that having a bereavement policy in every school would be a great help. The submission notes the "flexible" policy appears to show that death and bereavement isn't dealt with unless we have to, and sadly, schools are a reflection of this.

Action

21. The Committee is invited to consider what action it wishes to take. Options include—
 - To close the petition under Rule 15.7 of Standing Orders on the basis that:
 - the Curriculum for Excellence is not a statutory curriculum prescribed to the level of individual courses that must be

¹ <https://www.edinburgh.gov.uk/support-families/supporting-children-young-people-loss-change-bereavement/1>

² <https://www.cne-siar.gov.uk/media/4802/support-for-bereavement-policy.pdf>

followed by each individual school, schools are encouraged to apply their own judgement;

- the National Bereavement Coordinator is undertaking work with schools and with the petitioner directly to develop a curriculum around bereavement, with roundtable evidence sessions due to begin in January 2021;
- education and training around death, dying and bereavement may be taken forward as part of the work delivering and implementing the recommendations of the personal and social education review;
- To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1820/G: Scottish Government submission of 20 January 2021 \(72KB pdf\)](#)
- [PE1820/H: Petitioner submission of 30 January 2021 \(75KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

PE1820/G

Scottish Government submission of 20 January 2021

Thank you for your recent letter regarding the petition on Compulsory Bereavement Education in Schools where you sought the Scottish Government's views on the submissions made by Young Scot and CHAS.

With regard to the Young Scot submission, the Committee may be interested to know the key priorities for the National Bereavement Coordinator I mentioned in my previous letter are:

- Work with partners to develop an action plan, developing a vision for support for those children who have experienced bereavement;
- Develop a framework of support;
- Promote an understanding of bereavement across Scotland; and,
- Work with schools to develop the curriculum around bereavement.

In a recent report, the National Coordinator noted the work with schools to develop a curriculum around bereavement, their Key Deliverable 8, was 40% complete as the Project has engaged with Seasons for Growth trainers and coordinators across Scotland; Education Psychologists in several local authorities; teachers in primary and secondary schools; and, with the individuals involved in the petition. They will be building on this initial engagement through their roundtable discussions to formulate recommendations on how to develop a proposal for a curriculum around bereavement. The roundtables are planned to commence in January 2021.

With regard to the CHAS submission on the petition itself, the Scottish curriculum is designed to allow schools flexibility to decide what to study against the experiences and outcomes. Schools are encouraged to do their own thing, using people and places in their local area, or the individual interests of classes and pupils to choose topics to focus on. The idea is this will make lessons more relevant and therefore more rewarding for children. It is reassuring to hear schools are using their flexibility to bring in organisations like CHAS.

The Scottish Government notes the comments in the CHAS submission about teacher confidence around dealing with bereavement as well as inclusion of education and training around death, dying and bereavement. This may be taken forward as part of the work delivering and implementing the recommendations of the PSE review mentioned in the previous submission.

On the subject of counsellors in schools, education authorities and other agencies have duties under the Additional Support for Learning Act 2004 (as amended) to identify, provide for and review the additional support needs of their pupils. An additional support need would include children and young people who have experienced a bereavement. Education authorities and all those working in our schools have a responsibility to support and develop the mental wellbeing of pupils, with decisions on how to provide that support taken on the basis of local circumstances and needs.

During the planning and implementation of the commitment to provide access to a counsellor in schools, BACP and COSCA advised that the training required to work with children under the age of 10 is very different and more complex to that for children aged 11-18, which is why our commitment is only for children and young people aged 10 and over. Schools and education authorities have the capacity to identify specific measures to support children in primary schools under the age of 10 and draw on a number of resources provided by Education Scotland.

Some local authorities may have staff trained to deliver 'Seasons for Growth', a programme widely used in primary, secondary and special sectors across Scotland to support children and young people suffering from loss and grief. The core element of the programme is the promotion of social and emotional wellbeing and the development of resilience for young people who have experienced significant loss due to death or family breakdown.

Education Scotland also have a number of resources which raise awareness of early adversity and trauma and develop approaches to prevent and mitigate the impact of Adverse Childhood Experiences (ACEs). These include: professional learning materials on nurturing approaches and Adverse Childhood Experiences; the Applying Nurture as a whole school approach self-evaluation framework and 'The Compassionate and Connected Community' professional learning resource delivered by local authority staff. Education, health and the Scottish Government are working closely together to ensure that these key resources form part of the delivery of the Trauma Training Plan. Almost all authorities have now received the two day 'Compassionate and Connected Community' coaching session.

Finally, the Committee will wish to be aware some councils have support policies in place for bereavement. For example, the City of Edinburgh Council's policy¹ is based in wider family policy areas whereas Comhairle nan Eilean Siar's policy² sits within their Education and Children's Services Department. Both policy documents are designed to help adults support children and young people who have experienced bereavement.

I hope the Committee finds the additional information contained in this letter helpful.

¹ <https://www.edinburgh.gov.uk/support-families/supporting-children-young-people-loss-change-bereavement/1>

² <https://www.cne-siar.gov.uk/media/4802/support-for-bereavement-policy.pdf>

PE1820/H

Petitioner submission of 30 January 2021

I would like to provide this written submission in response to the Scottish Government submission of 20th January 2021.

The Scottish Government states that the curriculum is flexible and schools are encouraged to “do their own thing”. However, it appears that many schools and councils are still choosing not to teach children about death and bereavement. As mentioned in previous submissions, death will affect everyone at some point, so why is this education not made compulsory? I strongly urge the Scottish Government to reconsider this flexible approach and make it mandatory for all schools to teach about death and bereavement. We teach our children many things they may never use after school, so it is very surprising that we don't teach them about something that will definitely affect them at some point.

Research published by Strathclyde University in the journal “ Palliative Care and Social Practice “ found that by 7.8 years, 50.8% of children had suffered bereavement. This figure rises to 62% by age 10. Bereavement can make children vulnerable to depression and anxiety, self-harm, suicide, underachievement at school, unemployment and crime. It was found that a lack of social support from schools contributes to this. Furthermore, age appropriate education on bereavement and death in early years and primary education could help to engage with children on these issues. So why is bereavement education not compulsory in our schools? I will only benefit our children in the future. These children are our future and we must do all we can to help and nurture them into adulthood.

www.strath.ac.uk/whystrathclyde/news/studyrevealsmorethanhalfscottishchildrenexperiencebereavementbytheageofeight

In relation to this, the Scottish Government states that “training required to work with children under 10 is more complex...” and that is why their commitment is for children aged 11 to 18. As mentioned in the above research paper, intervention in early years can make all the difference to a bereaved child, so why is it not available for children under 10? If anything, this age group need it more. If a bereaved child is not given the appropriate help when needed, this will impact on their mental development into adulthood. If a child under the age of 10 needs help, then it should be readily available for them. We can't just ignore them because the “training required to work with children under 10 is very different and more complex“. Agreed, some local authorities do have “Seasons For Growth”, but not all of them. In addition, this programme is only offered to children who have suffered bereavement. A compulsory bereavement education policy should be in place that is delivered to all children so that those not affected by bereavement can understand the feelings of those who have suffered loss. This will teach our children to be more understanding and empathetic.

Child Bereavement UK believe that having a bereavement policy in every school would be a great help. Unfortunately, just now this “flexible” policy appears to be that we don't deal with death and bereavement unless we have to, and sadly, schools are a reflection of this.

In an interview with “Holyrood” magazine on 24th November 2020, the National Bereavement Coordinator agreed that if bereavement education is a part of the school curriculum, then we can better support our children to understand and prepare for grief and death.

(www.holyrood.com/inside-politics/view,a-lesson-in-death-why-bereavement-should-be-on-the-school-curriculum)

If all these experts and organisations agree that bereavement education should be part of the school curriculum, then why is the Scottish Government reluctant to listen to these experts and ignore the research findings?

In conclusion, I would once again strongly urge the Scottish Government to make bereavement education a compulsory part of the school curriculum. As mentioned earlier, death is something that will definitely affect everybody at some point, so why are we not teaching our children about this? We teach them about things they may never use again after school, so why not about this? If teachers don't feel comfortable teaching about death and bereavement, then make it a compulsory part of teacher training. Bereavement education should be mandatory in every school, and not something that teachers can choose to teach if they wish. Research also indicates that our children would definitely benefit from compulsory bereavement education, and there should be counsellors in our schools for children under 10 as well. If children under 10 are not given the appropriate help at the appropriate time, then the consequences can be dire.

Our children are our future. We need to equip them with the necessary life skills they need to be successful, especially in these difficult times. Please make bereavement education compulsory in our schools.

Public Petitions Committee

3rd Meeting, 2021 (Session 5)

Wednesday, 10 February 2021

PE1836: Expand the remit of the Care Inspectorate to investigate individual child protection complaints

Note by the Clerk

Petitioner	James A Mackie
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to expand the remit of the Care Inspectorate to investigate individual child protection complaints.
Webpage	parliament.scot/gettinginvolved/petitions/PE01836

Introduction

1. This is a continued petition, last considered by the Committee on 9 December 2020. At that meeting, the Committee agreed to write to Children's Hearings Scotland, the Promise, the Scottish Children's Reporter Administration, the Scottish Child Law Centre, the Scottish Public Service Ombudsman and Who Cares? Scotland.
2. Submissions have been received from the Promise and the Scottish Public Service Ombudsman. A submission has also been received from the petitioner.
3. The Committee is invited to consider what action it wishes to take.

Committee consideration

4. In its submission, the Promise explains that it was established in July 2020 to take forward the final [conclusions](#) of the Independent Care Review, which had heard the stories of more than 5,500 people with experience of Scotland's care system.
5. The Promise states that a transformation of the care system is required, to fundamentally change the way services are designed, delivered and scrutinised.
6. A key part of the transformational, whole system change is a fundamental alteration of the way Scotland inspects services for children and the way it regulates and supports its workforce.
7. The submission goes on to state that if Scotland is to shift its practice to support, prioritise and nurture relationships, then Scotland must shift its accountability

structures. It notes, however, making only this change and adding it onto the existing ineffective system is insufficient.

8. The Promise believes that a multiagency approach is needed and outlines a shift that involves all those who have a role in inspection and regulation, including the Care Inspectorate and the Scottish Social Services Council (SSSC) working together to drive changes in the care system shaped around a new framework that values what children and families value.
9. The Promise highlights that an effective framework would include—
 - Prioritising the quality of relationships experienced by children, with the rights and voices of children at the heart;
 - Consistency across all inspectors and regulators to align and avoid duplication; and
 - High quality inspectors who value and understand relationship-based practice. Support and training should be provided for less experienced inspectors.
10. The submission concludes that as the care system operates within a series of complex interdependencies, beyond granting additional powers and small amendments, changes must be considered in the wider context of change that is required throughout the 'care system' to maximise efficacy and impact.
11. In its written submission, the Scottish Public Services Ombudsman (SPSO) explains that social work is under its jurisdiction. It can therefore investigate and make findings and recommendations about service delivery of processes and procedures.
12. Since being given additional powers from 1 April 2017, the SPSO can also challenge the merits of professional decisions made by social workers and others exercising social work functions.
13. Since this change, the SPSO has seen a rise in the number of substantive complaints being submitted. It states that this is a result of simplified complaint processes which are now easier for people to access and complete.
14. The SPSO notes that there has also been a reduction in the number of premature complaints¹ it receives concerning social work, explaining that this is a general indicator that local complaint processes are being accessed and completed timeously.
15. The SPSO also explains that it publishes anonymised summaries or full reports of cases investigated, enabling the organisation to share the critical detail of its findings and recommendations. It states that its "casework, while not definitive on

¹ Premature complaints are complaints made before local, internal processes have been completed.

the concerns expressed in the petition provides some support for concerns about the quality of social work decision-making relating to children.”

16. The SPSO states that while its casework contains some indications that, suggest that at times, social work decision-making is not of the required standard, it does not consider it to be sufficient to warrant supporting the solution by the petition.
17. Although the SPSO considers that there are improvements that could be made, it does not believe that these lie in increasing the complexity of the accountability structure but improving and adequately resourcing existing systems to ensure timely, good quality support is available for children and families and that agencies collectively improve our approach to information sharing to support systemic improvements.
18. With regard to the specific references to children’s hearings and looked-after children within the petition’s background information, the SPSO notes that anything put to a children’s hearing can be challenged at that hearing and decisions of children’s hearings can be further appealed to a Sheriff.
19. The SPSO further notes that neither it, nor any other organisation which was responsible for investigating complaints, could question the judgement of a children’s hearing as it is not appropriate for a complaints handling process to intervene in a legal process.

Petitioner submission

20. In his most recent written submission, of 25 January 2021, the petitioner states that while neither the Promise nor the SPSO is incorrect about the current appeal process, in his experience, the system does not work in practice.
21. He states that his petition asks for the remit of the Care Commission to be expanded so that the organisation can step in early, prepare and investigate the complaints about the contents and allegations of documents submitted to Children’s Hearings and resolve disputes quickly for the sake of the children and their families.

Action

22. The Committee is invited to consider what action it wishes to take on this petition. Options include—
 - To close the petition under Rule 15.7 of Standing Orders on the basis that—
 - the Scottish Government does not support the action called for in the petition as it believes it would pose a risk to local accountability and multi-agency working; would undermine legal processes; and that there are existing powers and duties in place to investigate such complaints; and

- key stakeholders also do not support the action called for in the petition.
- To take any other action members consider appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1836/A: Scottish Government submission of 24 November 2020 \(65KB pdf\)](#)
- [PE1836/C: Scottish Public Services Ombudsman submission of 14 January 2021 \(157KB pdf\)](#)
- [PE1836/D: The Promise submission of 15 January 2021 \(69KB pdf\)](#)
- [PE1836/E: Petitioner submission of 25 January 2021 \(86KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

In response to the Committee's invitation for the Scottish Government's views on the action called for in the above petition, and following consultation with the Care Inspectorate, the Scottish Government can offer the following.

As you will be aware, the Public Services Reform (Scotland) Act 2010 ("the 2010 Act") enables the Care Inspectorate to investigate specific complaints in relation to the provision of care in a care service, as defined in Schedule 12. This does not extend to investigating specific complaints about non-registered services such as intervention by social workers working in children and families teams, assessment and care management teams (adults) or criminal justice social work teams.

In respect of investigating individual child protection complaints as suggested in the petition, there would be several challenges. These relate to:

Definitions

Clarity would be required about what is meant by a 'child protection complaint'. Child protection processes in Scotland sit within the framework of Getting it Right for Every Child. This is recognised in the National Guidance for Child Protection in Scotland 2014. It would be important that barriers were not introduced which might inhibit professionals in raising and sharing concerns about the wellbeing of a child, nor that might inhibit the further exploration or investigation of concerns.

Risk to local accountability and multi-agency working

The Care Inspectorate has a general duty of furthering improvement in the quality of social work services. Child protection is not a matter wholly for social work services, however. Under the Children (Scotland) Act 1995, certain responsibilities in terms of child protection are given to the local authority, generally discharged through the social work service. These include key actions such as deciding on how to investigate concerns when it is suspected that a child is suffering, or is likely to suffer, significant harm; making application for a court order authorising action to protect or assess the child; and referring the case to the Principal Reporter where compulsory measures of supervision may be required. The actions of social workers in protecting children are informed and influenced by the decisions and actions of a range of other professionals. National Guidance for Child Protection 2014 places a clear emphasis on the importance of multi-agency working to keep children safe.

Strong child protection practice and decision making is achieved through the embedding of tripartite discussions involving social work, health and police around the timing and process of investigation of concerns; joint assessment of risk and need; and collaborative planning to ensure safety and meet the child's needs through multi-agency child protection case conferences and core groups. Where children require multi-agency input such as where there are child protection concerns, the role of the Lead Professional will typically be taken by the local authority social worker, but in no way detracts from the multi-agency and collective nature of ensuring that children are kept safe.

The importance of collective responsibility for child protection is reflected in the fact that inspections of child protection activity in Scotland are undertaken under Section 115 of the 2010 Act jointly by scrutiny bodies covering social work, police, health and education

services. Inspections are led by the Care Inspectorate but must involve scrutiny partners in order to properly reflect the multi-disciplinary nature of child protection practice.

Investigating complaints involving child protection activity would require a similar approach. Implementing a new duty would result in having to navigate a complex network of different complaints processes which are relevant for each agency. There could be a risk of duplication or confusion with the functions of the Public Services Ombudsman and the Police Investigation and Review Commissioner.

Risk of undermining legal processes

Critical steps to ensuring children's safety are taken by professionals in the context of decisions by Sheriffs, Courts and Children's Hearings. Children's Reporters and Children's Hearings play a significant role for children who require support and protection on an ongoing basis, whether while living with their families or in alternative provision such as foster care or residential homes. This makes investigation of complaints about the actions of social workers working in the area of child protection different and significantly more complex in many respects than the investigation of complaints about care services.

Existing powers and duties

Finally, the routes to raise and address complaints are already well established. Scottish Government invites the Committee to note that the Scottish Social Services Council (SSSC) already has the power to investigate and take action where it is suspected that a social worker has acted improperly. Furthermore, complaints about social work practitioners can, and are often, made to their employer who has a duty to investigate, or can be directed to investigate by the Scottish Public Services Ombudsman.

Sections 55(1)(b) of the 2010 Act gives Scottish Ministers the power to direct the Care Inspectorate to undertake an inspection into the organisation or co-ordination of any social services that they may specify. They may specify purposes for any inspection under this section. Section 55(4)(c) allows the Care Inspectorate to investigate a specific matter, such as a complex complaint, at the direction of Ministers where Ministers judged it to be a matter of sufficient importance. The 2010 Act does not prescribe what activities constitute an inspection, only that an inspection should result in a published report.

In summary, the Scottish Government recommends that the matters above are considered by Committee. In addition, it would be problematic to extend the Care Inspectorate's duties to include only those aspects of social workers' responsibilities related to the protection of children, while excluding all other aspects of social work practice including the protection of vulnerable adults, and could potentially undermine local accountability and existing multi-agency working.

Thank you to the Committee for giving me an opportunity to submit the SPSO's views on this petition.

The petitioner has outlined a problem; concerns about difficulties in challenging social work reports, particularly where a child is in care (a looked-after child), and proposed a solution; providing the Care Inspectorate with the power to investigate individual complaints.

Having reflected carefully on the petition, the evidence given and the comments of the committee on 16 December 2020, I am responding by looking at those two points separately.

I will first comment on the evidence we hold about the quality of social work provision and then on whether the proposed solution would be the best approach to resolving the concerns raised by the petitioner.

SPSO experience

As the final stage for complaints about local authorities, social work is under my jurisdiction. The jurisdiction is wide and enables me to investigate and make findings and recommendations about service delivery of processes and procedures, **and** the merits of professional decisions made by social workers and others exercising social work functions.

The powers relating to being able to challenge professional decisions were conferred on the Ombudsman following concerns being raised about the previous complaints scheme (Complaints Review Committees) which required complainers to attend an internal complaints review committee hearing. This resulted in the Scottish Government abolishing the previous statutory scheme and we were given additional powers from 1 April 2017.

Volume and key figures¹

Since the 2017 change we have seen a rise in the number of substantive complaints made to us. This is what we would have expected given the change simplified the process and reflects what we have seen in other areas when complaints processes are made easier for people to access and complete.

A significant change has been the reduction in the number of premature complaints. Premature complaints are complaints made to us before they have completed the local, internal process. We use this as an indicator of people's experience in navigating and accessing local procedures. Put simply, a lower proportion of premature complaints is a general indicator that local complaint processes are being accessed and completed timeously.

¹ These figures are for all social work but the trends are consistent across all subjects.

Social work historically had one of the highest premature rates and it is encouraging that the service is now in line with the average for local authority complaints. This suggests that service users are able to use and access complaints procedures, and that organisations are responding to them (although we recognise there is always scope for all of us to develop and refine our approach).

Another indicator of the benefits of the change is the number of complaints we receive that we can now investigate. This has significantly increased because we can look at the merits of the decisions. This means we have been able to look closely at more complaints, resulting in a significant increase in the number of decisions where we have upheld and supported the position of the complainer.

The uphold rate is now similar to health where we also have this extended jurisdiction (to look at both process and merits).

	2016/2017	2017/2018	2018/2019	2019/2020
Volume of SW complaints received	219	340	361	329
Premature rate	53%	25%	22%	20%

Number investigated	9	21	51	54
Uphold rate	37%	66%	66%	65%

Our findings

We publish anonymised summaries or full reports of cases investigated, enabling us to share the critical detail of our findings and recommendations. Relevant themes from our published casework across child protection include: failure to listen to and take the views of children into account²; and failure to gather all relevant evidence and provide a clear rationale for key child protection decisions³. Our casework, while not definitive on the concerns expressed in the petition provides some support for concerns about the quality of social work decision-making relating to children.

While our work can provide some general evidence, it is important to note that the petition specifically references children's hearings and looked-after children. Anything put to a children's hearing can be challenged at that hearing and decisions of children's hearings

² <https://www.spsso.org.uk/decision-reports/2020/november/decision-report-201900885-201900885>; and

³ <https://www.spsso.org.uk/decision-reports/2020/october/decision-report-201806908-201806908> and; <https://www.spsso.org.uk/decision-reports/2020/august/decision-report-201903373-201903373>; and <https://www.spsso.org.uk/decision-reports/2019/october/decision-report-201804660-201804660>

can be further appealed to a Sheriff. My legislation says that I should not normally consider matters that could be appealed to a court and SPSO is not able to question the judgement of a children's hearing, this means our role in relation to reports put to children's hearings is more limited and so we have less direct evidence. **It is important to note** that this would remain the case whatever organisation was involved in complaints as it is not appropriate for a complaints handling process to intervene in a legal process.

I note the concerns in the petition that the process for legal challenges is not accessible and return to that point in the comments below.

While we receive complaints on behalf of children who are or have been taken into care, these are few in number and complaints tend to come from families where the parents (or legal guardians) are better able to navigate the system or have good advocacy support. This means, while we can extrapolate from our general evidence around child protection, there is less direct evidence about the experience of looked-after children in the complaints system.

The proposed solution

While SPSO casework contains some indications that, suggest that at times, social work decision-making is not of the required standard, I do not consider it to be sufficient to warrant supporting the proposed solution. As the evidence from the Scottish Government shows, this is already a complex area in terms of the numbers of agencies involved and their roles. Introducing further complexity into the system is unlikely to produce benefits and runs counter to developments over many years to simplify the complaints processes across Scotland. It also would have limited impact on the specific situation referenced by the petitioner as the decisions of children's hearings would remain subject to court appeal and outside the remit of a complaints process.

I refer back also to my earlier point about the change in complaint volumes when the current, simpler complaint process was introduced. What that suggests to me is that making the system and landscape more complex runs the risk of restricting access and deterring people from using, not encouraging them.

This does not mean there are no improvement changes that could be made that would improve the complainer's journey through the complaints process from local level to regulation at a national level. Indeed, one of the requirements of the model complaints handling process is a focus on learning and improvement. We monitor complaints handling performance and through our Support and Intervention Policy actively pursue improvement

where need is identified. We have also updated the model complaint handling process in light of learning and experience recently.

In addition to the focus on making the current systems more effective, there are national initiatives which should impact positively on complaints from or concerning children. One of the welcome outcomes of the proposed incorporation of the UN Charter for Children's Right is recognition of the requirement for child-friendly and, I would argue, child-focussed complaints processes. As a stakeholder with a significant interest in this area, I will be participating actively in the development of the incorporation, for example I will be participating in a webinar on this in February, chaired by the Children and Young Person's Commissioner for Scotland. I am keen to see Scotland lead in this area.

Improvements to make complaints more accessible to looked-after children about their care do not require legislative reform. But it is the case that looked-after children will remain a vulnerable group who will be reluctant to complain. The Scottish Children and Young Person's Commissioner will, if the current bill is passed, take on the power to initiate court action when no individual child is able to do so.

Many Ombudsmen have a parallel power which allows them to take complaints even when no one has complained and this is a matter which I have raised with both this Parliament and the Scottish Government and I intend to pursue the need for reform of our legislation within the next parliament. This is a significant omission in my powers as it means I cannot investigate matters I identify which are in the public interest, even if they are significant, if I don't receive a complaint about them. This means that there are likely to be issues that impact on vulnerable individuals and groups that go unaddressed simply because they don't complain.

These are general improvements and despite the comments made about the inability of the complaints process to intervene in a legal process, I would suggest there are two areas that could help support and improve the positions for families and children.

- improved advocacy support for children and families and
- the ability to more constructively share information amongst key agencies.

A key factor when we identify good practice, is access to good advocacy support for children and families. There have already been positive recent developments with the recent legislation (Children (Scotland) Act 2020) that focused on listening to children, including younger children and the launch of the hearings advocacy website. For individual children and their families, access to good, supportive information and advocacy at key

points in their involvement with social work may well be the most effective route to preventing problems and resolving issues in the hearings and courts system.

It is also important that we take a systems approach to early detection of problems and to prevent problems recurring. We publish our findings and recommendations to encourage others learn from individual complaints. We are also a member of the Sharing Intelligence in Health and Care Group which brings together agencies on a monthly basis to share information about trends and themes. To date this has focussed on the NHS but we would argue a similar model would be of benefit for social work and would help us collectively drive systemic change.

In closing, while I consider there are improvements that could be made, these do not lie in increasing the complexity of the accountability structure but improving and adequately resourcing existing systems to ensure timely, good quality support is available for children and families and that agencies collectively improve our approach to information sharing to support systemic improvements.

PE1836/D

The Promise submission of 15 January 2021

In response to the Committee's invitation, The Promise can offer the following:

The Promise was established in July 2020 to take forward the final [conclusions](#) of the Independent Care Review (the Care Review). With three years of careful listening as its foundation, the conclusions of the Care Review - published on 5th February 2020 - set the steps Scotland must take to embed transformational change in the 'care system'.

The Care Review heard the [stories](#) of more than 5,500 people with experience of Scotland's 'care system'. The [methodology](#) used ensured the Care Review focused on the human experience of moving through the 'care system' and took a wide angled approach to consider the impacts of the system on care experienced infants, children, young people, adults and their families. Many of these stories and experiences were about when things went wrong. The picture of the 'care system' uncovered by the Care Review was complex, fragmented and system rather than person focused at every level.

At times, these stories told of experiences of services, interactions with those who were employed to provide support and protection, and the impact of the behaviours and actions of the workforce. Where the issue of complaints arose, the overall message was one of frustration as it was felt that complaints were not handled in a serious manner and procedures were not correctly followed.

Some people expressed anger towards professionals that had made mistakes or done something wrong which had negatively impacted their lives. They spoke of the need for the 'system' to acknowledge the suffering that had been caused by any mistakes or wrongdoing that occurred whilst being cared for by the state. Specifically, some spoke passionately about the importance of making sure the same mistakes were not made again and that nobody else had to go through what they experienced.

The Care Review recognised that many services operate in a risk averse environment with an overt focus on risk assessment, management and the reduction of risk which maximises the sense of safety but does not always support families in the way they need. Nor do these risk frameworks support the development and nurturing of safe, kind and loving relationships between the workforce and children and young people. Too often, the workforce is placed in positions where they must focus on protecting themselves and their colleagues above the children and young people in their care.

The evidence gathered by the Care Review identifies 'risk aversion' as one of the professional barriers prohibiting the positive health and well-being for children and young people in care. This is not about tolerating more risk or having a culture that does not consider risk, it is about ensuring that the workforce and Scotland's services broaden their understanding of risk to include a more holistic approach that recognises the risk of not having safe, kind relationships with the workforce.

Moreover, there must be active encouragement of a supportive and collaborative culture when making decisions about children and their families. Transforming the 'care system' will fundamentally change the way services are designed, delivered and scrutinised.

A key part of the transformational, whole system change is a fundamental alteration of the way Scotland inspects services for children and the way it regulates and supports its workforce. Accountability and what is measured has a profound impact on the way professionals behave and services are run.

If Scotland is to shift its practice to support, prioritise and nurture relationships, then Scotland must shift its accountability structures. However, making only this change and adding it onto the existing ineffective system is insufficient.

As acknowledged by the committee members, a multiagency approach is needed. The Promise outlines a shift that involves all those who have a role in inspection and regulation, including the Care Inspectorate, the Scottish Social Services Council (SSSC), working together to drive changes in the 'care system' shaped around a new framework that values what children and families value. This work needs to significantly declutter and streamline professional codes, procedures, and processes with a clear focus on enabling relationships – above anything else.

An effective framework is one totally focused on children's experiences. This would include:

- Prioritising the quality of relationships experienced by children, with the rights and voices of children at the heart;
- Consistency across all inspectors and regulators to align and avoid duplication;
- High quality inspectors who value and understand relationship-based practice. Support and training should be provided for less experienced inspectors.

To conclude, the premise of The Promise is that the entire system needs to be re-designed to be fit for purpose. As the 'care system' operates within a series of complex interdependencies, beyond granting additional powers and small amendments, changes must be considered in the wider context of change that is required throughout the 'care system' to maximise efficacy and impact.

PE1836/E

Petitioner submission of 25 January 2021

I have read the submissions by SPSO and The Promise. Neither is incorrect about the current appeal process. However, in my experience, the system does not work in practice and, I believe, the current system assumes that the mother is guilty as charged.

Agreed that many different agencies/organisations (NHS, schools, police, foster carers, charities and others) are involved in preparing a case. All information is collated by social workers who condense these reports into one for submission to a Sheriff or a Children's Hearing. I believe that these reports are based predominantly on opinion, supposition and assumptions and all information collected is to prove those opinions, assumptions and suppositions.

This Petition asks that the Care Commission be empowered to investigate at very early stages in proceedings. The Care Commission does that with other sectors that involve multi agencies. Care Commission supervises childcare and protection matters but will not look at individual cases. It monitors files, procedures and protocols.

As I understand it, it is rare for a mother/parents to be informed in advance of an application to a Sheriff. Within 48 hours (excluding weekend days and public holidays) of the Sheriff's decision the case appears before a Children's Hearing. Panel members are laymen with, what I believe, is very limited experience. A Hearing is not a trial – it is, to my mind, an expression of thoughts against the mother who does not have the resources within a Hearing to counter them. Any decision a Hearing reaches can be appealed to the Sheriff by mother, child and other relevant persons. A Children's Hearing is scheduled to last no more than 1 hour for each child. Only the mother and relevant persons plus the social workers appear in the Children's Hearing. Children do not always appear, especially if they have been taken into care.

An appeal to the Sheriff must be made within 7 days including weekend days and public holidays. There is no assistance from Scottish Children's Reporter Administrator (SCRA) to lodge an appeal. The family do it on their own or try to engage a solicitor. If an Appeal is not lodged within 7 days, a another cannot be lodged for 3 months.

At an appeal, the Sheriff can only make judgement on the decision of the Children's Hearing. If a Sheriff does uphold the Appeal, the case is referred back to the Children's Hearing for them to review their original decision and the cycle restarts.

Complaints are from children, mothers and other relevant persons and are often about reports submitted by social workers. A complaint against a social worker must be made direct to the Social Worker involved. If the complainer is not happy with the

response, then a further complaint is made to the social workers manager and so on up the line. That can take months, meantime the children continue in care.

Social workers do not have powers to investigate other agencies where complaints are made about the information they have supplied. The child, mother or other relevant person must make individual complaints to these different agencies. In my experience, complaints are not taken seriously and eventually whitewashed or ignored. This process can take months. The engagement of legal advisers is very expensive, and beyond the reach of many families

Complaints that are made to Scottish Public Services Ombudsman (SPSO) and Scottish Social Services Council (SSSC) can only be lodged once the full complaints procedure has been exhausted through the various agencies. The SPSO can only investigate the process followed by the authority complained about. The SPSO does not have the powers to force a reinvestigation of the complaint. SPSO can take up to 4 years to complete an investigation and come up with findings. The SPSO can only investigate some of the bodies/agencies. They cannot investigate complaints involving charities (who provide commercial services to local authorities in child care).

Complaints can be made against social workers to SSSC. Again, SSSC will only accept complaints after the social workers employers' complaints procedure has been finalised.

Both SPSO and SSSC require copies of all files and correspondence that form the complaint. Files must be obtained by way of a Subject Access Request. Despite the legislation it can take 6 months and often a year to obtain full files and only then with the involvement of the Information Commissioner's Office. It can take both SPSO and SSSC at least 18 months and, in my experience, more often up to 4 years to investigate and take any action on a complaint. Meantime children are in care away from their families. Through three different FOIs, SSSC admit that they take no action in 99.7% of complaints from the public.

Taking civil action through the Courts is extremely expensive and takes years to resolve if ever. One case is reported to have cost over £2 million in legal aid and after 7 years it is not fully resolved.

The proposal from the Petition asks for the remit of the Care Commission to be expanded so that it can step in early, prepare and investigate the complaints about the contents and allegations of documents submitted to Children's Hearings and resolve disputes quickly for the sake of the children and their families. It would bring accountability to child protection in Scotland as, I believe, there is none currently.

Public Petitions Committee
3rd Meeting, 2021 (Session 5)
Wednesday 10 February 2021

PE1837: Provide clear direction and investment for autism support

Note by the Clerk

Petitioner	Stephen Leighton
Petition summary	<p>Calling on the Scottish Parliament to urge the Scottish Government to:</p> <ul style="list-style-type: none">• clarify how autistic people, who do not have a learning disability and/or mental disorder, can access support and;• allocate investment for autism support teams in every local authority or health and social care partnership in Scotland
Webpage	parliament.scot/GettingInvolved/Petitions/supportingautism

Introduction

1. This is a continued petition last considered by the Committee on 16 December 2020. At that meeting, the Committee agreed to write to the National Autistic Society and Scottish Autism.
2. Submissions have now been received from the National Autistic Society Scotland, Autism Resources Co-ordination Hub - South Lanarkshire (ARCH), Autistic Network Scotland, Scottish Autism and three from the petitioner.
3. Additional responses have been sent from various individuals and organisations who support the petition. These submissions have made similar points, so only points unique to each submission are highlighted in this paper.
4. The Committee is invited to consider what action it wishes to take in relation to the petition.

Committee Consideration

The National Autistic Society Scotland (NASS) submission

5. The NASS broadly welcomes the call for more resources to be made available by the Scottish Government to provide support for autistic people, not just across local authorities and health and social care partnerships in Scotland, but also across the third sector and autistic people's organisations.
6. It also welcomes the recent resourcing of the national autism post diagnostic support service but advises "there continues to be an absence of consistent

and accessible support services for autistic people throughout their lifespan in a number of local authority areas across Scotland, creating something of a postcode lottery”.

7. The submission notes this issue requires further action by the Scottish Government and COSLA to ensure that the human rights of all autistic people are recognised in Scotland.
8. The NASS highlight that it is often simplistic to automatically attribute failings at local authority level solely to a lack of investment, whilst not understating the importance of increased investment.
9. The NASS note there is a lack of accountability and consistency across local authority areas that continues to be a serious barrier to providing adequate and accessible support. Therefore, it would suggest that work should be undertaken to identify best practice at a local level with the aim of then sharing this widely to ensure greater consistency across Scotland, alongside a commitment to additional funds.
10. The Scottish Parliament Cross Party Working Group (CPWG) for Autism in their Report [‘The accountability gap’](#) recommended a new role of Commissioner. It is the NASS’s view that such a role would be in a position to undertake work such as investigating and sharing best practice, and orchestrating collaborative work between the Scottish Government, local authorities, health and social care partnerships, third sector organisations, and APOs.
11. The NASS advises it mirrors the views of the Cross Party Group on Autism that a new fully funded Autism Strategy and the establishment of a Commission or Commissioner role are both required to ensure consistency and accountability is implemented across every local authority area. It notes *“This would be a crucial first step to lifting the barriers currently preventing adequate support being made available to all autistic people in Scotland.”*

Autism Resources Co-ordination HUB – South Lanarkshire (ARCH) submission

12. ARCH notes that as part of the review of the Scottish Strategy for Autism (SSfA), the National Autism Implementation Team (NAIT), Scottish Autism and the National Autistic Society Scotland has only selected nine Local Authorities to input. It advises this means the remaining 23 Authorities have been excluded from the consultation which will leave the vast majority of the autistic community without any representation from locality resources who are much better acquainted with local need on the ground.
13. ARCH is concerned that the narrative relating to the Transition and Recovery plan is becoming increasingly centralised with only a few stakeholder organisations views being given prominence.
14. ARCH advise the revised outcome consultation undertaken by Autism Network Scotland (ANS) in 2017/18 was carried out in several key locations in Scotland. As such this process was inclusive and participatory and resulted in actions and

revised outcomes which were subsequently incorporated into the 'Scottish Strategy for Autism - Revised Outcomes' document in 2018.

15. ARCH highlights it has drafted and had approved the South Lanarkshire Local Autism Action Plan 2018-2023, which echoes much of the Transitions and Recovery plan published by the Cross Party Group on Autism (CPGA). However ARCH advises it has had no part in any consultation events despite its presence being known by principle CPGA contributors.
16. ARCH states it has been embodying the Asset Based Community Development (ABCD) approach to service design and delivery for nearly 5 years. It advises that in spite of this, there has been no formal or informal approaches made to it by the pilot participants of the Autism Post Diagnostic Pilot recently announced by NAIT.
17. The collective lived experience of the Scottish Strategy for Autism is, in ARCH's opinion, that all of its stated outcomes (original as revised) have in no way been met. ARCH remains clear that workforce and community development/capacity building must be a priority if even a basic 'autism-informed' level of understanding is to be realised.
18. The submission advises it has also seen nothing by way of additional funding from the Scottish Government, and all costs have been met from existing Health and Social Care Partnership budgets. By contrast, it notes, all additional funding announced had been focused on a handful of autism organisations.
19. ARCH notes it remains concerned that third sector organisations are being used by NHS Scotland to provide adult autism diagnostic services, which are already provisioned for by the NHS within Children and Families services, CAMHS and Neurodevelopmental services. ARCH believes this has resulted in a piecemeal and inconsistent provision for crucial adult diagnostics for those who do not have mental health conditions or an intellectual disability.
20. The submission states the recent [Neurodevelopmental Service Specification draft](#) issued by the Children and Young People's Mental Health and Wellbeing Programme Board appears to have focused on applying a highly 'medicalised' model of service delivery for the autism community which directly contradicts all Autism/LD related policies published by the Scottish Government since the Christie Commission in 2011.
21. In closing, ARCH states it *"is gravely concerned that Autism Network Scotland has been informed it will no longer receive Scottish Government funding from 2021, with the result that Autism Lead Officers from all of Scotland's 32 Local Authorities will be excluded from the development of autism policies and practice throughout the country."*

Autism Network Scotland (ANS) submission

22. ANS states that the challenges that autistic people have in accessing the right support and have not improved significantly during the life of the Scottish Strategy for Autism and gaps in what people need still exist.

23. The submission advises those without a learning disability/mental health disorder still fall between the gaps in responsibilities of health and social care services. It notes most of the supports that autistic people receive come from various support and health organisations and not from the specialist autism agencies who support a minority of autistic people in Scotland.
24. ANS note that although improvement in diagnosis has been a focus of the strategy from the beginning, it continues to hear of difficult experiences of the process, length of time taken and people without a learning disability of mental health disorder not able to access diagnostic services.
25. A positive change ANS has seen is that how to diagnose autism is now largely understood however it states the challenge now is about carrying out the diagnostic process. As such it believes it is a systems, organisation and resource challenge and therefore resources and effort should be channelled appropriately.
26. The Scottish Government continues to fund the NAIT to lead on this work. The submission highlights this work has not been evaluated and it believes it misses the importance of a Scotland wide approach inclusive of investigating the areas that have made huge practical improvements in diagnosis and waiting times.
27. In relation to the National Mapping project, ANS notes this was completed some years ago and unless the individual local authority has committed to maintaining their local service maps, they will be out of date. ANS engages with the local authorities/HSCP's across Scotland and it is not aware of these local maps being used or providing useful information.
28. ANS facilitates the network of Local Authority autism lead officers and states this is an easy and practical way in understanding the local context for autistic people as well as sharing best practice nationally. It further advises *"The gap between national strategy and local implementation, highlighted in the Autism CPG 'Accountability Gap' report, needs to be resolved before any national strategy can have a significant local impact."*
29. In relation to funding ANS advises:

"Given the role that ANS can take in delivering the priorities of autistic people in Scotland, some of which is described above, the Scottish Government's recent decision to end the funding to ANS (whilst funding to other key strategy delivery partners continues) is short sighted and flawed."

Scottish Autism submission

30. Scottish Autism advise they agree that too many people do not receive adequate services and are too often excluded from society. This is why it is campaigning for a commissioner to champion and uphold the rights of autistic people as well as people with a learning disability.

31. The submission notes the work of such a commissioner should include advocating for autistic people who do not have a learning disability, who often do not receive support from their local authority.
32. Scottish Autism highlights it aims to support autistic people with a wide array of needs, however its service provision is limited by what local authorities or government will commission.
33. The submission notes it regularly seek funds for new services in response to what the autistic community advises it needs. Where peer-support and advice is most appropriate, Scottish Autism state it regularly refers people to Autistic People's Organisations.

Thom Kirkwood submission

34. Mr Kirkwood's submission notes that neurodevelopmental conditions, for example autism, ADHD and learning disability, are "not in a societal context a mental health disorder, yet currently in diagnostic and clinical terms they are out of kilter". Mr Kirkwood advises this was highlighted in the recent [Independent Review of Mental Health \(Care and Treatment\) Scotland Act 2003, Autism, Learning Disabilities](#).
35. Mr Kirkwood highlights that in a previous role as an Engagement and Participation Officer at Autism Network Scotland, he saw some wonderful practice and partnership working in action but also unfortunately saw disenfranchisement from inclusion at various levels.
36. He advises the majority of smaller organisations feel left out and ignored but they deliver valuable service often at very little costs to society. The submission highlights the Scottish Government's [Microsegmentation Report](#)¹ and notes it is "perceiving it was predominantly geared to organisational sustainability of the few, not the many."

Deborah McKenna submission

37. Ms McKenna advises she has witnessed first-hand the difficulties that a lack of support can create for individuals with autism and their families. She notes the issues raised in this petition rightly describe many of the challenges that autistic people and their families face and there is "currently a distinct lack of appropriate provision for autistic people across Scotland, despite the Scottish Strategy for Autism coming to an end".
38. The findings of the 2018 Microsegmentation Report recommend that investing in specialist services for autistic people can result in the tangible improvement of outcomes and reduction in overall economic cost. For many of the people that Ms McKenna has worked with, there are clear points at which appropriate support would have made a difference – difficulties at work, a relationship change, a transition from education. She notes that unfortunately there is

¹ Economic research on autism and the implications for Scotland, including how the economic cost of autism can inform strategy and planning.

simply no relevant support on offer and often the situation that these people are in deteriorates and results in the support needed being far more substantial.

39. The submission highlights that in many instances there are individuals who are in contact with Community Mental Health Teams, who have poor mental health due to the lack of appropriate support and therefore opportunity. She notes these people are ultimately discharged, often as it has been determined that their difficulties are associated to the core characteristics of autism and as such are not “treatable” under mental health teams. As such, she believes the development of autism support teams could give clinicians a referral route and ensure that people are not simply left with nothing.
40. Ms McKenna notes the real difficulty lies after a diagnosis has been given, advising many people she has worked with have described their diagnosis as “pointless”, as there is no tangible support available for autistic people. She states, “Reducing diagnosis waiting times will not make this situation better”.
41. In closing Ms McKenna advises:

“There is no quick-fix which will make it easier, there needs to be a whole-system change in the approach that is taken to autism support. I believe that the creation of autism support teams could not only prevent many of the difficult situations that have been created by the current system but could make a tangible and practical difference in the lives of autistic people and their families.”

Professor Jean MacLennan submission

42. Professor MacLennan advises that in the early 2000s, Scotland was regarded as a world leader in creating an autism needs assessment targeted at improving the commissioning of services. She notes the national Scottish Strategy for Autism followed in 2011 which created change to some degree but, as it draws to a close, there is a sense of disappointment.
43. The submission notes the Strategy is ending eight months early and a COVID related Transition and Recovery Group that considers the needs of those with autism and learning disability has widened its remit to consider how best to taper current activity and to consider the possibility of a new Strategy.
44. Professor MacLennan notes “It is unfortunate that a Group created for one purpose has had its remit extended in this way without broader consultation with autistic individuals and families”.

Petitioner submissions

45. In his submission of [23 December 2020](#) the petitioner advises the support highlighted by the Scottish Government in its submission of [2 December 2020](#) is not enough. He advises the one-to-one support is from volunteer support, usually one hour every two weeks and the online support is accessed by only 200 people.

46. As already explained in the petition, the petitioner highlights the difficulty for autistic people accessing support is due to the confusion within the Mental Health (Care and Treatment) (Scotland) Act 2003.
47. The petitioner notes the Scottish Government highlight the National Autism Implementation Team (NAIT) in their submission. NAIT explain that autism is not a mental disorder and the petitioner highlights this contradicts what the Scottish Government states.
48. The petitioner explains the Scottish Government defines autism as a mental disorder, however:

“Mental health (MH) services decline to support because they claim autism is not a mental disorder, they will signpost autistic people to either learning development (LD) services or social work services – yet most social work services decline to support because they work towards the definition the Scottish Government has set, that autism is a mental disorder. LD services will only support autistic people with a dual diagnosis of autism and LD. This is why autistic people without a LD or MH can’t access support”.
49. The petitioner highlights the fact the Scottish Government has not considered the CPWG on Autism Accountability Gap report in its submission and – questions why statutory services not available for autistic people.
50. The petitioner notes the Scottish Government states it is engaging with Health and Social Care Partnerships. He advises this engagement is facilitated through ANS who received their funding through the Scottish Government, but the Scottish Government has just informed ANS that their funding is to be stopped as of March 2021.
51. In relation to the new Post Diagnostic Pilot (PDP) mentioned by the Scottish Government, the petitioner advises the Scottish Government have paid £250,000 to organisations *“who were already providing the support they are claiming is part of the ‘new pilot’ but have no record of how decisions were made for this allocation (FOI request). These organisations were doing this support before the money was paid and will continue to provide this support once the Pilot is concluded.”*
52. In closing the petitioner notes the Scottish Government claim support is available but he would challenge the Scottish Government to evidence how each of the 10 recommendations of the Microsegmentation Report are available in each Health and Social Care Partnership.
53. The petitioner’s submission of [19 January 2021](#) notes the Scottish Government state they established the NAIT to *“support Health and Social Care Partnerships to consider best practice”*. When asked by the petitioner if autism was a mental disorder, he advised NAIT said *“Autism is not a mental disorder. Although Autism is diagnosed through the DSM – statistical manual of mental disorders, it is clearly described as a neurodevelopmental disorder, and not a mental disorder”*.

54. *Following a FOI request, the petitioner advised the Scottish Government confirmed "As autism is in the DSM, autism is indeed included under MHA s.328(1)" – yet, within the same reply they said, "autism on its own, does not qualify as a mental disorder under the 2003 Act".*
55. The petitioner believes the Scottish Government are not listening to concerns and this is evident from the proposed 'Learning/Intellectual Disability and Autism Recovery Plan. The petitioner notes the Scottish Government have said this plan will align the closure of the autism strategy with the LD plan in 2023. However the petitioner advises *"this is alarming the autistic community as they have long been in the shadow of learning disability."*
56. The submission advises the concern from the autistic community is that this transition plan is just the start of a super LD policy to follow in 2023. The autistic population will have major difficulty highlighting their challenges if their narrative is shared with LD.
57. The petitioner submission of [1 February 2021](#) highlights there is a pattern emerging from the petition submissions – that is it seems to take years for people to be diagnosed, only to then struggle to access any meaningful support across the lifespan. He believes this proves the 10-year autism strategy has been a failure.
58. The submission notes The National Autistic Society and Scottish Autism were instrumental in producing the Cross Party Working Group for autism report 'The Accountability Gap' which highlighted that autistic people are not being supported at a local level and that investment is needed.
59. The new Post Diagnostic Support is only a 6-month pilot. The petitioner questions what happens after this period, and when does Post Diagnostic Support stop and ongoing support start. The petitioner believes the need to develop a post diagnostic support toolkit highlights that there is no tangible ongoing support for autistic people, and that if there was, a post diagnostic toolkit would not be needed.
60. In relation to the joint Learning Disability and Autism Plan, the petitioner notes this is a major concern for the autistic community, for all the reasons made in various submissions.
61. By joining the two groups together the petitioner feels this gives the public the perception that learning disability services support autism needs. However, he advises these services will only support people with a learning disability who are autistic, but not autistic people who do not have a learning disability.
62. The petitioner also highlights the concerns raised in submissions that autism charities do not speak for autistic people. He believes this is as a result of charities becoming Scottish Government stakeholders which mean they have access to funding, the Scottish Government then claim, "they are getting 'the consent of the autism community' because these charities say so".

Action

63. The Committee is invited to consider what action it wishes to take. Options include—

- To continue this petition and include it in its legacy paper for its successor Committee, along with a suggestion to take evidence from the Cabinet Secretary for Health and Sport on the various concerns raised in written submissions received on the petition;
- To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1837/A: Scottish Government submission of 2 December 2020 \(76KB pdf\)](#)
- [PE1837/B: Petitioner submission of 23 December 2020 \(89KB pdf\)](#)
- [PE1837/C: Autism Resources Co-ordination Hub \(ARCH\) - South Lanarkshire submission of 24 December 2020 \(74KB pdf\)](#)
- [PE1837/D: Gary Ballantyne submission of 1 January 2021 \(62KB pdf\)](#)
- [PE1837/E: Autism Network Scotland submission of 5 January 2021 \(84KB pdf\)](#)
- [PE1837/F: Thom Kirkwood submission of 5 January 2021 \(112KB pdf\)](#)
- [PE1837/G: Deborah McKenna submission of 5 January 2021 \(84KB pdf\)](#)
- [PE1837/H: Professor Jean MacLellan OBE submission of 13 January 2021 \(60KB pdf\)](#)
- [PE1837/I: Patricia Hewitt submission of 10 January 2021 \(69KB pdf\)](#)
- [PE1837/J: Petitioner submission of 19 January 2021 \(122KB pdf\)](#)
- [PE1837/K: Anonymous submission of 20 January 2021 \(59KB pdf\)](#)
- [PE1837/L: The National Autistic Society submission of 21 January 2021 \(86KB pdf\)](#)
- [PE1837/M: Wendy Ferguson submission of 22 January 2021 \(81KB pdf\)](#)
- [PE1837/N: Jean McNally submission of 26 January 2021 \(80KB pdf\)](#)
- [PE1837/O: Patsy Quinn submission of 26 January 2021 \(83KB pdf\)](#)
- [PE1837/P: DIFFERabled Scotland submission of 26 January 2021 \(90KB pdf\)](#)
- [PE1837/Q: Jane Hook submission of 26 January 2021 \(38KB pdf\)](#)
- [PE1837/R: Petitioner submission of 2 February 2021 \(84KB pdf\)](#)
- [PE1837/S: Deborah Best submission of 2 February 2021 \(63KB pdf\)](#)
- [PE1837/T: Scottish Autism submission dated 4 February 2021 \(52KB pdf\)](#)

All written submissions received on the petition can be viewed on the [petition webpage](#).

PE1837/A

Scottish Government submission of 2 December 2020

Thank you for your email of 4 November seeking advance views on the above petition. Please see below.

Clarify how autistic people, who do not have a learning disability and/or mental disorder, can access support.

Support for autistic people is available from a wide range of sources, including health and social care partnerships, national organisations like Scottish Autism and the National Autistic Society for Scotland and local organisations including autistic led organisations. They provide a range of support including social groups, 1:1 counselling and post diagnostic support.

Following our Programme for Government commitment in September 2019, the Scottish Government is working collaboratively with the national autism charities and autistic led organisations to deliver a national autism post diagnostic support service for people diagnosed within the past two years. Following a diagnosis of autism, individuals, parents and carers living across Scotland will be routed to appropriate support. That support will enable individuals to understand, embrace and develop their identity as an autistic person. It will also aim to ensure that parents and carers will have access to information, support and advice to enable them to support their child's development and personal growth. We also want to make sure that those with a late diagnosis can access support, including peer support.

This is a pilot project running from December 2020 – May 2021, with the pilot then being independently evaluated and decisions being made on the further development of the service.

The Scottish Government established the [National Autism Implementation Team](#), in partnership with Queen Margaret University, to support Health and Social Care Partnerships to consider best practice and improve service in the redesigning of autism diagnostic services. The National Implementation Team is supporting NHS Boards to examine diagnostic pathways for autism and establish regional experts to assist with improving tiered autism specialisms across health boards. This will, by extension, allow for utilisation by individual health and social care partnerships.

Concurrently, we are engaging with local health and social care partnerships across Scotland about why it is so important for them to increase capacity for autism diagnostic services and for them to redesign services which are sustainable.

Allocate investment for autism support teams in every local authority or health and social care partnership in Scotland

Following the publication of the Scottish Strategy for Autism in 2011, a national mapping exercise was undertaken and each local authority was provided with their own map of local services. Local authorities were asked to consider the strategy in each of their local areas and develop local strategies and action plans to support the needs of their local population.

£1.2 m of funding was provided to support this work. The strategy also commissioned research into the economic costs of autism - this report was published in March 2018 - *The microsegmentation of the autism spectrum: research project*. This report provides evidence of the economic costs of autism and makes recommendations for Health and Social Care Partnerships to consider when commissioning autism services.

The Scottish Government provides the policies, frameworks and resources to allow Integration Authorities, along with their partners, to deliver services that meet the needs of their local populations. When preparing their strategic commissioning plans, Integration Authorities are required to take into account the integration planning and delivery principles and the national health and wellbeing outcomes which are set out in the legislation that underpins integration. This approach is designed to ensure that outcomes are at the heart of planning for the local population's needs, and to embed a person centred approach alongside anticipatory and preventative care planning.

All Integration Authorities are expected to ensure that resources are spent in a way that improves the health and wellbeing of their community and delivers best value for taxpayers. Integration Authorities are also expected to work with colleagues more widely across the public sector to improve outcomes for local people. Integration Authorities are rightly required to continually assess their expenditure of public funds to ensure the delivery of best value and make the most effective use of funding for the benefit of patients, other service users and their families.

- There are 31 integration authorities in Scotland who are now responsible for over £9 billion of funding for local services.
- This year, we are delivering £811 million of additional direct investment in social care and integration. This is an increase of 14% - up from £711 million in 2019/20.
- These authorities are required to work with their local communities and providers of care to ensure care is responsive to people's needs.
- The Scottish Government is committed to ensuring our health and social care services get the support they need during these unprecedented times. We are working closely with COSLA, Integration Authorities, Local Authorities and Health Boards to provide the necessary funding across the sector in recognition of costs incurred to date and to support the remobilisation of services, ensuring that safety remains the top priority at all times.
- The Adult Social Care Winter Preparedness Plan includes additional investment of £112 million to further support the social care sector, this is on top of £150 million already announced, bringing the total to £262 million.

I hope this information is helpful.

PE1837/B

Petitioner submission of 23 December 2020

I am requesting to give oral evidence to the committee due to the complexity of the petition.

The support highlighted by the SG is not enough. For example, the one-to-one support highlighted is from volunteer support, usually one hour every two weeks. The online support is accessed by only 200 people, what about the other 50,000 autistic people in Scotland?

The support highlighted by the SG is not enough to deal with complexity. Most people would then say, "*social work or mental health services should support*". As already explained in the petition, the difficulty for autistic people accessing support is due to the confusion within the Mental Health Act (MHA) 2003. This is fully explained in the original petition, but a summary can be quickly watched over a couple of minutes with my video: <https://www.youtube.com/watch?v=SQaTozSDTlc>

The SG highlight the National Autism Implementation Team (NAIT) in their submission. NAIT explain that autism is not a mental disorder. This contradicts what the SG state. The SG state that autism is a mental disorder defined within the MHA (as was disclosed to me via a FOIR). Most people in Scotland assume that autism is a mental disorder/learning disability due to the MHA defining autism as a learning disability.

The SG state autism is a mental disorder. Therefore, requests for support are sent to mental health. Mental health services decline to support because they claim autism is not a mental disorder, they will signpost autistic people to either LD services or social work services – yet most social work services decline to support because they work towards the definition the SG has set, that autism is a mental disorder. LD services will only support autistic people with a dual diagnosis of autism and LD. This is why autistic people without a LD or MH can't access support.

There is no accountability and people are falling into chaos. This is what the Cross Party Working Group (CPWG) for autism described in their Report 'The accountability gap' - there is a lack of support, yet the SG have not even considered this report in their submission. This begs the question – why are statutory services not available for autistic people? Services should be provided by statutes: Children's Scotland Act s.23 & 24 for children, Social Work Scotland Act s.12 for adults, Mental Health Act 2003 – s.25 for people with a mental disorder.

Why are autistic people denied access to support? Here is a summary why: People refer to mental health, mental health signpost the autistic person to LD or social work, but LD and/or social work will re-refer back to mental health – a vicious cycle.

It creates a perfect storm for autistic people who do not have a LD or MH need – they can't hold any statutory service accountable and therefore can't access to support. This is why there is an accountability gap.

The SG said they are engaging with HSCPS. This engagement is facilitated through Autism Network Scotland (ANS). ANS receive their funding through the SG, yet the

SG has informed ANS that their funding is to be stopped as of March 2021 – an opportunity lost.

The SG are giving the public the perception that a new Post Diagnostic Pilot (PDP) is being developed- this is misleading. They have paid £250k to organisations who were already providing the support they are claiming is part of the ‘new pilot’ but have no record of how decisions were made for this allocation (FOIR). These organisations were doing this support before the money was paid and will continue to provide this support once the Pilot is concluded.

The SG state they engage with HSCPS. Why wasn’t there any HSCPS asked to be part of this Pilot, especially considering PDS could be defined as a statutory service? Apparently, the SG had to spend the money on the Pilot before the end of this financial year, hence why they approached services in the third sector who would obviously accept money, which helps the SG give the impression they are doing something new. The money originally allocated for developing a PDP has been wasted and we have lost the opportunity to look at developing anything new. This concern was raised at various ANS meetings. I would ask the Committee to seek the views of the CEO of ANS, Richard Ibbotson on the petition and the claims I’ve made.

Just by even talking about developing post diagnostic support (PDS) evidences there is not enough support! PDS deviates from the real subject – access to ongoing support. If the right support was available at the time of need, we wouldn’t need to develop any post diagnostic models.

When does post diagnostic support stop and ongoing support start? Is it after 4 days, 4 weeks, 4 months, 4 years, 14 years or 24 years? What about the boy diagnosed at 4, what happens when he turns 14, 24 or 44 years old? You see, PDS stops discussion about ongoing support.

The SG highlighted the Mapping Project - this information is out of date. Hardly any local authorities have a specific autism plan. This is down to the confusion of the MHA – no specific accountability on services.

The SG gave a breakdown of investment for HSCPS in Scotland but did not highlight any specific areas for autistic support. The SG submission clearly puts the accountability on how money is spent onto HSCPS, hence why we need direction from the Scottish Parliament on who provides autism support, that way accountability can be placed within local budgets. The SG have highlighted the Microsegmentation Report. I have heavily referenced this report in the original petition and summary video. It explains that 10 recommendations will provide best outcomes for autistic people. If implemented with 10% efficacy it would save £223 million each year.

The SG claim that support is out there and has asked for the petition to be closed. I would ask the SG to evidence how each of the 10 recommendations of the Microsegmentation Report are available in each HSCP before considering the petition be closed? This can’t be done until we have clarity on who supports autism – hence the petition.

PE1837/C

Autism Resources Co-ordination Hub (ARCH) - South Lanarkshire submission of 24 December 2020

With respect to the current Learning Disability and Autism Transition and Recovery Plans ARCH South Lanarkshire would respectfully submit the following for the committee's consideration;

- The current review of the 10 year Scottish Strategy for Autism has been commissioned from Blake Stevenson research. A total of 9 Local Authorities have been selected by the National Autism Implementation Team (NAIT), Scottish Autism and National Autistic Society Scotland with the result that the remaining 23 Authorities have been excluded from the substantive consultation – leaving the vast majority of the autistic community within the rest of Scotland without any representation from locality resources who are much better acquainted with local need on the ground. The concerns are that it seems the narrative relating to the Transition and Recovery plan is becoming increasingly centralised with only a few stakeholder organisations views being given prominence.
- ARCH would like to draw the committee's attention to the revised outcome consultation undertaken by Autism Network Scotland (ANS) in 2017/2018 throughout several key locations in Scotland. This process was inclusive and participatory and resulted in actions and revised outcomes which were subsequently incorporated into the 'Scottish Strategy for Autism - Revised Outcomes' document in 2018. ARCH was then invited by ANS to take part in the Advocacy Roundtable Collaborative meetings with the Scottish Independent Advocacy Alliance and a range of other stakeholders tasked with developing more comprehensive advocacy services at local level alongside Professional Independent Advocacy provision. This roundtable seems to have been abandoned in spite of the Scottish Government commitment to fulfilling the clear message conveyed by all stakeholders during the revised outcomes events.
- The fact that ARCH South Lanarkshire have represented a unique alternative to third sector provision means we have influenced Local Authority policy and practice in a manner inconceivable by third sector organisations. ARCH has drafted and had approved the South Lanarkshire Local Autism Action Plan 2018-2023, which in many respects is echoed in much of the Transitions and Recovery plan published by the Cross Party Group on Autism (CPGA). However ARCH has had no part in any consultation events in spite of our presence being known by principle CPGA contributors.
- ARCH has been embodying the Asset Based Community Development (ABCD) approach to service design and delivery for nearly 5 years. In spite of the Autism Post Diagnostic Pilot recently announced by NAIT , there has been no formal or informal approaches made to us by the pilot participants to consult on our experience of such provision or our ongoing collaboration with stakeholders in all sectors in identifying unmet autism support needs , then setting about collaborating,

designing and co-delivering supports and services with all these partners in the private, statutory, third and peer led sectors in what has become a 'bottom up' as opposed to 'top-down' model.

- The fact that the Learning Disability and Autism Transition and Recovery Plans mentions community based approaches; it is unclear why ARCH's experience in this area has not been sought.
- The collective lived experience of the 10 year long Scottish Strategy for Autism is that all of its stated outcomes (original as revised) have in no way been met. ARCH remains clear that workforce and community development/capacity building must be a priority if even a basic 'autism-informed' level of understanding is to be realised. This is in line with the NES Optimising Outcomes Training Framework document published in 2014 and which remains the best 'benchmark' of autism levels of training; Informed, Skilled Enhanced and Expertise.
- ARCH has also seen nothing by way of additional funding from the Scottish Government, and all costs have been met from existing HSCP budgets. By contrast all additional funding announced had been focused on a handful of autism organisations.
- ARCH remains concerned that third sector organisations are being used by NHS Scotland to provide adult autism diagnostic services, which are already provisioned by NHS within Children and Families services CAMHS and Neurodevelopmental services This has resulted in piecemeal and inconsistent provision for crucial adult diagnostics for those who do not have Mental Health conditions or an Intellectual Disability - 66% of all Scotland's Autistic people do not have a learning disability as articulated in the Microsegmentation report 2018.
- The recent Neurodevelopmental Service Specification draft issued by the Children and Young People's Mental Health and Wellbeing Programme Board appears to have focused on applying a highly 'medicalised' model of service delivery for the autism community which directly contradicts all Autism/LD related policies published by the Scottish Government since the Christie commission in 2011.
- ARCH is gravely concerned that Autism Network Scotland has been informed it will no longer receive Scottish Government funding from 2021, with the result that Autism Lead Officers from all of Scotland's 32 Local Authorities will be excluded from the development of autism policies and practice throughout the country. This matter has already been raised by ARCH South Lanarkshire with COSLA and Social Work Scotland as a particular area of concern.

PE1837/D

Gary Ballantyne submission of 1 January 2021

As an autistic adult, one of thousands who have fallen between through the allocation gap of the Scottish Government's autistic policy created by the grey zoning of fallacy clinical and local care support errors Scottish wide by Scottish Government policy.

The Scottish Government autism policy has created harm, is harming the autistic community at large and creating a bias discriminatory policy against the core of the autistic community.

The divide between clinical and supportive networks is so wide, non-existence and is at principle in error leads me and others to believe the policy officers in the Scottish Government are totally out of touch or running a deliberate policy of discrimination which is in nefarious political nature. 10 years of Autism Strategy, a get Scottish Government out Autism Act clause has delivered nothing as it was probably designed to, shameful.

Autism is not a mental health disorder. I have a rational logical mind.
Autism is not a learning disability. I have above average IQ as with 70% of my autistic peers. Why are we labelled incorrectly and stereotyped as such?

Just because I am intelligent does not mean I am coping social environmentally in society due to sensory and pure communication needs (logical rational reasoning), however this does not mean I have a learning disability nor have an insane mind.

There is a desperate need for the Scottish Government to give clarity to medical world, care organisations and autistic stakeholders if autistic people are categorically labelled born innately retarded, insane or both as the law is using the mental health act to apply so resulting in unlawful acts of state and gross harm by disenfranchisement and malfeasance by MWC, courts and doctors.

Because that is the current cognitive dissonance which is running the autistic policy foundation of the Scottish Governments which is a negative construct bias and cruel to say the least. It is a position of gross error, which needs to be redressed.

This is not a question for autistic charities which run Scottish Government funded inconsistent drop and go schemes and defraud the public using a sympathy aggressive donation model technique which delivers nothing in real terms for the whole autistic community but spins a revenue plate game to nowhere which is at best just a pseudo money making laundering and tax evasion business model.

Can I ask the MSPs to review the following in the spirit of the petition.

Clarity on autism, not as a mental health disorder nor learning disability.

Why is autism centrally promoted as learning disability or mental health disorder, the autism Scottish Government policy, medical and care lie.

1. Local care specialist autism support assistance at the point of need at local authority care partnership level. Why are the autistic community refused statutory care support?
2. Review of autism charities operating and failing in Scotland. What do they really do?
3. Review of what the autism strategy has delivered in real terms in the last 10 years and to hold Chair to account. What have they really done?
4. Hold the Scottish Government autism policy officers to account for the harm they have caused to the 50,000 autistic persons in Scotland for a gross failure of role, duty and obligations. Why is the reality on the ground not changed in the last 10 years it has got worse?
5. Clare Haughey Health Minister ?
6. Rewrite Autism Policy review with real lived experts/ specialist in tandem with autism community, not with the current false proxy third party actors.

Thank you for your considerations and apologies for any affective wording, but it is real issue for autistic people in an unfair Scotland.

Clarify how autistic people, who do not have a learning disability and/or mental disorder, can access support.

Autism Network Scotland (ANS) hears of the challenges that autistic people have in accessing the right support. This has not improved significantly during the life of the Scottish Strategy for Autism and gaps in what people need still exist. For those with a learning disability or mental health disorder the gaps in accessing the right support, delivered by well-informed professionals. As described in the petition, those without a learning disability/mental health disorder still fall between the gaps in responsibilities of health and social care services.

Most of the supports that autistic people receive come from various support and health organisations and not from the specialist autism agencies who support a minority of autistic people in Scotland. ANS engages with a wide audience of autistic people and their families and also connect with autistic people's organisations. Having been involved in networking across Scotland throughout and before the Strategy, ANS would be delighted to provide further evidence with a solutions focus to the petitions committee in response to the issues.

In the Petitions Committee (16.12.20), Alexander Burnett MSP rightly referred to diagnosis as being the first important step to enabling the autistic person to lead their best life. Improvement in diagnosis has been a focus of the strategy from the beginning. However we continue to hear of difficult experiences of the process, length of time taken and people without a learning disability or mental health disorder not able to access diagnostic services. It would appear that despite the focus on diagnosis and funds allocated to this, the experience for many has not improved.

A positive change is that how to diagnose is now largely understood. As evidenced in the recent Autism Strategy conference organised by ANS, the challenge is now about carrying out the diagnostic process. As such it is a systems, organisation and resource challenge, not a lack of knowledge. Therefore resources and effort should be channelled appropriately. Scottish Government continues to fund the National Autism Implementation Team (NAIT) to lead on this work. This has not been evaluated and misses the importance of a Scotland wide approach inclusive of investigating the areas that have made huge practical improvements in diagnosis and waiting times (e.g. the Glasgow Adult Diagnostic Team).

Mr Burnett suggested inviting National Autistic Society and Autism Scotland to input into the debate. Whilst both have much to offer, ANS is willing to contribute their Scotland and organisation wide network perspective.

Allocate investment for autism support teams in every local authority or health and social care partnership in Scotland

The Scottish Government provides the policies, frameworks and resources that allows services to meet the needs of the entire population. However at times, autism specific knowledge, resources, and interventions are needed to enable autistic people to be equally served.

The petitioner's proposal may be one such time when resources need to be redirected to allow autistic people equality of service. ANS is similarly placed to engage with a range of statutory and third sector partners to support existing services to be better informed and enabled to meet the needs of autistic people and their families.

Mr Burnett also referred to the National Mapping project. This was completed some years ago and unless the individual Local Authority has committed to maintaining their local service maps, they will be out of date. ANS engages with the Local Authorities/HSCP's across Scotland and we are not aware of these local maps being used or providing useful information. ASN facilitates the network of Local Authority autism lead officers and this is an easy and practical way in understanding the local context for autistic people as well as sharing best practice nationally. The gap between national strategy and local implementation, highlighted in the Autism CPG 'Accountability Gap' report, needs to be resolved before any national strategy can have a significant local impact.

The most positive action of the Autism Strategy over the last 10 years is the very recent launch of the Autism Understanding campaign 'Different Minds, One Scotland'. Autistic people and families recognise that the biggest improvement in the lives of autistic people occurs when there is better, wider understanding, not just from professionals but within the general public. The daily interactions with the bus driver, the hospital nurse, the shopkeeper are where a real difference to the quality of life and human rights of an autistic person are made.

Given the role that ANS can take in delivering the priorities of autistic people in Scotland, some of which is described above, the Scottish Government's recent decision to end the funding to ANS (whilst funding to other key strategy delivery partners continues) is short sighted and flawed.

PE1837/F

Thom Kirkwood submission of 5 January 2021

Neurodiversity, a topic difficult to cover, as many people do not understand it and many feel uncomfortable with it. Many don't understand the world of mental health and like those within that world need a label to give them a peg. That peg can be round or square. Square pegs do not always fit into round holes and vice versa. Pegs or labels can be right wrong or completely misleading. With society's obsession with labelling in a modern complex world, and, the [United Nations 2030 Agenda for Autism, Inclusion and Neurodiversity](#), which most, if not all countries have signed up to. It's time we had a meaningful grown up societal discussion on what this means. Associated to a component contributions to 2030 Agenda for Sustainable Development, which includes [17 Sustainable Development Goals \(SDGs\)](#) and 169 targets that promise to "leave no one behind." In 2016 the World Autism Awareness Day focused on Inclusion and Neurodiversity.

A discussion, not just about those with minimal support needs, but those with high levels of support. Does neurodiversity directly correlate in the modern world to a neurodevelopment condition? Does diagnostic context genuinely mirror societal context?

In a societal context does neurodiversity matter? In my mind it does. Big caveat, as a society we must not use 'umbrella labelling' for the sake of short-termism in either policy or political sense, nor for the sake of the variances within neurodevelopment conditions, that require both diagnostic and supportive specialisms and associated knowledge and understanding.

Neurodevelopmental conditions, for example Autism, ADHD, Learning Disability, are not in a societal context a mental health disorder, yet currently in diagnostic and clinical terms they are out of kilter. This was highlighted in the recent Independent Review of Mental Health (Care and Treatment) Scotland Act 2003, Autism, Learning Disabilities.

Until recently, I worked as the Engagement and Participation Officer at Autism Network Scotland covering Scotland. I saw some wonderful practice and partnership working in action.

Unfortunately I also saw disenfranchisement from inclusion at various levels. With sadly too much assumption that big two speak for all. How can one have active citizenship, choice and control, when their voices are not heard? This could be argued and equally applicable to the Cross Party Group and the Evaluation of the Scottish Strategy for Autism.

Lots of smaller organisations at local levels some constituted some not, some attached to schools and other larger charities as family support groups, the majority of whom feel left out ignored. The majority, if not all, deliver valuable service often at very little costs to society. Meaningful provision that have direct impact on people's lives.

There are also local authority operations that are central to service integration and delivery of post diagnostic support at the right time, by the right person in the right

place, yet I know have little direct input on the wider arena when it comes to positive practice.

Both of those have significant potential in addressing some of the components of the Scottish Government's Microsegmentation Report, Mar 2018. A report that seemed never ending in arriving, yet when it did, with some perceiving it was predominantly geared to organisational sustainability of the few, not the many. Perhaps this is reflective in both the discussions associated to what next and to who is spoken to in the evaluation of the Scottish Strategy for Autism. Centralist predetermined outcomes.

I like many of my associates and colleagues across Scotland, when ANS were achieving improvement at local level via key officer collaboratives and my 'keeping it real' input from a balanced objective advocacy and parental perspective, encompassing the sharing of positive practice, incorporating reflective learning, this work stopped. Why? It never stated that it had to stop when we had our monitoring meetings. This was a regular decision, taken by I presume by government as it was seen as no longer a priority, it was like, - 'making a difference, lets stop it', with focus moving to aspects of issues whilst important, but often further away than the reality of the time dictated – tactical avoidance perhaps?

We must all recognise the lack of accountability is not directly a result of the Scottish Strategy for Autism nor will an Autism Commissioner reasonable address those matters. The accountability or lack of, which is not universal across Scotland neither for families, or by authority area. This unaccountability exists, because of centralist control, not clear if this is political or their civil servant driven, seeking to control a greater percentage of the decisions at all levels.

Such approach does not bode well with families, practitioners, or local councillors. Indeed it is repressive and suppressive, stifling imaginative innovation, inclusion and regressive ignoring the fantastic opportunity for grounded theory learning, refer back to my point re the cohesive work of ANS. This is an essential component to strive re our contributions to the aforementioned UN Agenda.

May I remind the committee, if I recall correctly, a cabinet minister for finance said in the chamber this government would fund public services so as not to leave provision behind or word to that effect.

PE1837/G

Deborah McKenna submission of 5 January 2021

I write to you in support of petition PE01837: Provide clear direction and investment for autism support.

I support this petition for several reasons. I have worked with autistic people for ten years, specialising exclusively in the field of autism for the past four years, and have recently achieved my M.Ed Autism with the University of Strathclyde. However, most importantly, I have personal family experience of autism and have witnessed first-hand the difficulties that a lack of support can create for individuals and their families. The issues raised in this petition rightly describe many of the challenges that autistic people and their families face. There is currently a distinct lack of appropriate provision for autistic people across Scotland, despite the Scottish Strategy for Autism coming to an end.

At this moment in time there is an opportunity for meaningful support to be developed which could improve the lives of autistic people. The findings of the 2018 Microsegmentation Report (commissioned by Scottish Government) recommend that investing in specialist services for autistic people can result in the tangible improvement of outcomes and reduction in overall economic cost. For many of the people that I work with, there are clear points at which appropriate support would have made a difference – difficulties at work, a relationship change, a transition from education. Unfortunately, there is simply no relevant support on offer and often the situation that these people are in deteriorates and results in the support needed being far more substantial.

This has been the case time and time again across my professional experience. In many instances there are individuals who are in contact with Community Mental Health Teams (CMHTs), who have poor mental health due to the lack of appropriate support and therefore opportunity. These people are ultimately discharged, often as it has been determined that their difficulties are associated to the core characteristics of autism – differences and difficulties in communication and interaction, with flexibility of thought and repetitive and restricted behaviours or interests, and sensory processing – and as such are not “treatable” under mental health teams. This is not only a huge waste of money and time for both parties, but often results in further deterioration in mental health. The support detailed within the petition could end this cycle and produce real results for autistic people. In instances where an intervention is applicable, for example such as the delivery of psychological support for anxiety or depression, once the intervention is completed the clinician discharging will recognise that continuous social support is needed, however this is not available. The development of autism support teams could give these clinicians a referral route and ensure that people are not simply left with nothing.

Waiting times for diagnostic assessment can be difficult, however I feel that the real difficulty lies after a diagnosis has been given. Many of the people that I have worked with have described their diagnosis as “pointless”, as there is no tangible support available for autistic people. For some people who receive a diagnosis, such as those who were accessing mental health services, this means that this support is no longer appropriate (as you cannot “treat” the characteristics of autism) and they are discharged. Those who have tried to approach social work to have their needs

assessed are often referred to community mental health teams. Those who do have their needs assessed are often still left in the same situation as there are no suitable or appropriate services to spend their budget on. Reducing diagnosis waiting times will not make this situation better. Many people are slipping through the cracks whilst their difficulties are growing greater and greater. Autism support teams could fill this gap and could work in partnership across services to deliver the holistic approach that is required to adequately address the needs of people with autism.

Although the development of a post-diagnostic support pathway would be a big improvement on the 'leaflets in an envelope' support offered to my family at time of diagnosis, there is still no support for the day-to-day difficulties that many autistic people can experience. There is no quick-fix which will make it easier, there needs to be a whole-system change in the approach that is taken to autism support. I believe that the creation of autism support teams could not only prevent many of the difficult situations that have been created by the current system but could make a tangible and practical difference in the lives of autistic people and their families.

PE1837/H

Professor Jean MacLellan OBE submission of 13 January 2021

As a former civil servant involved in national autism policy and a former Director of Autism Network Scotland, I am writing in support of this Petition.

I have listened carefully to the deliberations of the Committee and would like to make some broader contextual observations prior to commenting on the two specific asks.

In the early 2000s Scotland was regarded as a world leader in creating an autism needs assessment targeted at improving the commissioning of services. This was thought to be a global first and was focused on research and training as well as endeavouring to improve practice. The national Scottish Strategy for Autism followed in 2011 which many have invested in and which has created change to some degree but, as it draws to a close, there is a sense of disappointment.

The ten year programme is ending eight months early. A Covid related Transition and Recovery Group that considers the needs of those with autism and learning disability has seemingly widened its remit to consider how best to taper current activity and to consider the possibility of a new Strategy. It is unfortunate that a Group created for one purpose has had its remit extended in this way without broader consultation with autistic individuals and families.

There is considerable uncertainty about the future support that may be available. Autistic individuals and families are exhausted by simply surviving day to day. This can mean that those who would like to participate in policy development are too tired so imaginative person centred outreach is what is needed to assist in articulating what the needs are. There is good practice out there which is not always costly.

Moving to the two specific asks in the Petition, Recommendation 11 of the Scottish Strategy states that it should 'consider the specific supports needed for more able individuals with ASD.' The main way in which this was addressed was the creation of six one stop shops across Scotland where individuals could drop in and be supported. This lessened social isolation for many as well as managing anxiety and depression whilst also providing information, advice and support in terms of issues like employment. The Scottish Government funded this provision on a pilot basis but the lack of funding to sustain them when finances were withdrawn meant that some survived and others did not. The one stop shops were highly valued by many autistic individuals and families. In some areas, alternative models have emerged which are very effective, most notably in South Lanarkshire.

What is at the heart of this Petition is the lack of consistent support. What happens is that those with autism and no learning disability will not necessarily meet stringent eligibility criteria because they fall below thresholds and so are reliant on broader based support in the community (if it exists and if they can access it). When such support is given, lives can be transformed and individuals are able to live those lives as equal citizens.

If the Committee is so minded, I would respectfully suggest that it seeks views beyond those of Scottish Autism and the National Autistic Society. Whilst these organisations are integral to service provision, there are others that would widen the range of perspectives. The National Autistic People's organisations, the local autism societies, and HSCPs will all offer further depth of understanding the complexities here. Additionally, I would suggest contacting No. 6 which is an Edinburgh based service run by Autism Initiatives which runs support groups for those with autism alone.

To conclude, I would reiterate the point that MSP Burnett makes about diagnosis. We know how to do this now but systems need to match that understanding to reach people who can wait for years. Without diagnosis, post diagnosis support has little relevance.

We need a clear Vision for the future and a pathway to get there.

I support the Petition and would be happy to provide further information if that would be helpful.

PE1837/I

Patricia Hewitt submission of 10 January 2021

I have experience of caring for people in their early twenties on the autistic spectrum who have been failed by numerous professionals including CAMHS, educational psychologists, education and the NHS.

The lack of understanding of the autism spectrum in Scotland and beyond is jaw dropping. My experience of a first significant diagnosis of Asperger's was at seventeen and eighteen years of age so much for early intervention yet numerous "red flag" pointers were missed over years. They have been denied a childhood and an education suitable for their needs . They have been left with mental health issues that were totally preventable, humiliated, degraded including one being handcuffed by the police, and discriminated against over the years due to lack of recognition.

They fit the profile of pathological demand avoidance. I was refused an out of area referral and I have had to pay thousands of pounds for a number of private assessments. We can't access the type of support required because PDA is not recognised in the Scottish Borders which surely breaches human rights . One of them was expected to attend a first class University. Tragically they will spend their life on benefits due to the lack of early intervention and recognition of PDA. Not one person will accept any responsibility. Being fobbed off to Enquire and Govan Law Centre after the event isn't an acceptable response from Cabinet Ministers.

The other person was written off as "lazy and winging it " and never referred which happens to be a legal requirement. Due to an inspirational tutor and ongoing support from Lead Scotland against all the odds they have zig zagged through college and completed a degree . I have had to fight for years for support. Without the in depth knowledge from Lead Scotland one of them would have dropped out at the first hurdle. We have never had one transition yet! They have had illegal 5 month exclusions and numerous education laws breached over the years with no accountability whatsoever. GIRFEC is a joke.

We need alternative education settings as many can't cope with mainstreaming which leads to school refusal and a downward spiral of issues many lasting a lifetime. Although one has a PTSD diagnosis we all fit the diagnostic criteria after years of battling the system. If it wasn't for my GP believing it wasn't me at fault I believe one would be in prison and one in a homeless unit.

I have petitioned Scottish Ministers twice with the support of the Lib Dem's and the PDA Society to spread the awareness of the PDA Profile. I hear on a daily basis families in total crisis and beyond desperation who are passed from pillar to post. I am now a member of the Disability, Dyslexia and Autism Cross Party Groups. The first Scottish PDA case was recognised in 1998 and from my research first discussed in a public petition in 2006. NAS in recent years has recognised PDA. Even with a diagnosis getting appropriate support is really challenging. Can anyone enlighten me why something wasn't done years ago and this was left to

parents to campaign? It was press articles that led me to PDA and my “lightbulb moment”.

We have education laws not worth the paper they are written on and a Autism Strategy to match. Neither are fit for purpose. “Refreshed” isn’t good enough it’s shameful .

I would take Mr Leighton’s submission further by suggesting autism spectrum assessments are removed from CAMHS and adult mental health, it is not a mental health issue, and specific ASD Multi-Disciplinary Teams set up to assess and diagnosis ASD including the PDA Profile with ongoing support from childhood right through to adulthood. I am quite aware how challenging it is to get an accurate diagnosis as a child and as an adult yet this is essential for the correct support. These teams could also be utilised for in-house training of other Professionals and families.

Mental health services were at crisis point before the pandemic and will be for many years to come. Through FOI requests for my last petition we found out there are no statistics for PDA therefore no long term planning. That would be a starting point plus a specific working party to follow through.

I believe the only effective system that works in Scotland is the system to cover up the truth. I found that out the hard way after I dared to complain. We don’t want political spin and broken promises we need a cost effective efficient support system that will benefit ALL not just a few.

The Scottish Government is in total denial and needs to wake up. You just need to look at the Public Petitions website how many petitions are relevant to the autism spectrum. As far as I am concerned the autistic community have been sold down the river for years and it’s about time there was accountability with the added proposal of an Autism Care Commissioner. The only answer the Scottish Government has is consultation after consultation and nothing ever changes. We don’t need any more consultations it’s a delaying strategy on their behalf we need a completely new approach that works not tinkering at the edges.

I include a link to a support statement released by South Lanarkshire Council which I feel is a real step forward that other local authorities certainly need to take onboard:

https://www.southlanarkshire.gov.uk/downloads/file/14113/extreme_demand_avoidance

PE1837/J

Petitioner submission of 19 January 2021

Due to the complexity of the issue, I am keen to provide oral evidence to the committee at the earliest opportunity. It is clear from the submissions that there is a lack of support for autistic people.

The Cross Party Working Group for autism (supported by the National Autistic Society (NAS) and Scottish Autism) published 'The Accountability Gap', highlighting the autism strategy has failed. Their report found that: 72% do not have enough support, and 78% saying they can't access support locally. It also highlighted a lack of accountability at a local level. Why is there an accountability gap when there are statutory supports available such as the Children's Act s.23&24, Social Work (Adults) s.12 and Mental Health Act s.25?

The Scottish Government state they established the National Autism Implementation Team (NAIT) to "*support Health and Social Care Partnerships to consider best practice*". I asked NAIT if autism was a mental disorder, they said "*Autism is not a mental disorder. Although Autism is diagnosed through the DSM – statistical manual of mental disorders, it is clearly described as a neurodevelopmental disorder, and not a mental disorder*".

Yet, when I sent a freedom of information request (FOIR) to the Scottish Government asking if autism is a mental disorder they said "*As autism is in the DSM, autism is indeed included under MHA s.328(1)*" – yet, within the same reply they said "*autism on its own, does not qualify as a mental disorder under the 2003 Act*". Why is this an issue? How does this relate to 'The Accountability Gap Report' and why does having a diagnosis of autism prevent autistic people accessing support?

The following narrative happens across Scotland ... people think autism is a mental disorder and will refer to mental health services, but mental health services usually decline to support solely autistic needs, they reject or re-refer to social work. Social work will generally decline to support because they claim autism is a mental disorder. This is why autistic people without a learning disability (LD) or mental health issue can't access support. This is at the root of the problem in Scotland. Until we have direction from the Scottish Government, there will always be an accountability gap ... even an autistic commissioner wouldn't help until this is resolved. People wait for years to be diagnosed, only to find no support once diagnosed.

The Scottish Government state it is Health and Social Care Partnerships (HSCP's) who determine autistic support. Often the only way an autistic person will be able to access support will come down to a professional's decision on whether or not they think autism is a mental disorder. This is why there are some examples of social work supporting autistic people, but other areas are not.

Autism Network Scotland (ANS) are funded by the Scottish Government to be the host organisation for the strategy. The idea is for all local autism leads of HSCP's to come together to feedback to the Scottish Government. The Scottish Government have not mentioned any of this in their submission? Local autism leads have

continued to raise concerns to ANS that the Scottish Government are not consulting this network.

The previous Director of ANS, and ANS as an organisation, have both made submissions supporting this petition. How can the Scottish Government claim that autistic people are being supported when the host organisation claim otherwise? I would ask the committee to engage with ANS to give an overview of what is happening in Scotland.

The Scottish Government are not listening to concerns. This is evident in the proposed 'Learning/Intellectual Disability and Autism Recovery Plan. The Scottish Government have said this plan will align the closure of the autism strategy with the LD plan in 2023. This is alarming the autistic community as they have long been in the shadow of learning disability. For example, the Milan Report for the Mental Health Act recommended autism be covered in the Act under an LD definition.

The Scottish Government claim the issues faced by autistic people and LD population are very similar, hence the joint plan, yet the challenges are not the same. I sent a FOIR to the Scottish Government about the joint plan, yet they can't provide any information as to who made the decision to join LD and autism together. ANS claim they haven't been consulted either?

The worry from the autistic community is that this transition plan is just the start of a super LD policy to follow in 2023. The autistic population will have major difficulty highlighting their challenges if their narrative is shared with LD. As one autistic person's submission explains "I have above average IQ as with 70% of my autistic peers. Why are we labelled incorrectly and stereotyped as such?".

If the Scottish Government had engaged with ANS network they would have been told this is not the way to conclude the autism strategy, ... that the reason there is an accountability gap is because autism has always had to co-exist with other dispositions such as LD & mental health and until there is clarity from the Scottish Government, there will always be an accountability gap for autistic people.

PE1837/K

Anonymous submission of 20 January 2021

I fully support the petitioner's views on the subject of autism support.

When the original Scottish Strategy for Autism was published the autistic community were promised a roll-out based on best practice. No money was made available for this. It was simply assumed that local authorities would fund the one-stop shops.

Autism Initiatives and Scottish Autism then surveyed their existing users, and carried on as normal. No provision was made to survey people like me, so Scottish Autism can now claim that their service users are satisfied. I believe this is grossly misleading.

Their recent publication on the Accountability Gap is concerned only with holding local authorities accountable, while dodging any criticism of their own failures.

When I approached the one-stop shop in Fife I was turned away, in effect because I do not have an intellectual disability. When, in desperation, I turned to the one in Edinburgh, I was also turned away because I do not have £1800 a year, the cost to buy in, to throw around.

I understand that Number 6 in Edinburgh provide the exemplary service that might be considered best practice, the best practice we were promised ten years ago. Promises the Scottish Government, the big charities and the local authorities proceeded to renege upon.

I would like to note that I consider the big charities to be part of the problem. Scottish Autism appears to be only interested in autistic people if they have intellectual disabilities and have families to advocate for them. The National Autistic Society Scotland holds an annual Autism Hour which only serves to reminds us that we are expected to do all our annual shopping on one day a year, at someone else's convenience, and otherwise stay out of the way of real people. I find the annual Autism Hour extremely hurtful. I understand that these are the people behind a campaign for an autism commissioner whose role will continue to conflate autism with intellectual disability.

I dislike these organisations, just as much as I believe they hate me, and do not consider them fit to run autism services for people like me.

The petitioner correctly notes the savings involved in providing proper support to autistic people. The actual cost of rolling out best practice is a fraction of this. The figure I was given was £150,000 per local authority, per year, a pittance in government terms. I was told to my face (noting the guidelines for this type of submission I will refrain from naming this person) that the Scottish Government considers this too expensive.

Autistic people are disproportionately unemployed. I feel your society

(neurotypicals) threw me away shortly after I left university. Many of us are desperately isolated. Autistic people are disproportionately homeless, and yet when I approached the one-stop shop in Kirkcaldy they told me they did not provide any relevant services, and referred me to Shelter, who know nothing about autism. Autistic people have much shorter life expectancies than do real humans. I am approaching my life expectancy, my early fifties, with growing bitterness.

This is an outrage, and Scottish society appears utterly indifferent.

According to the Scottish Government our lives are not collectively worth £150,000 a year.

The post-diagnostic support pilot might have been of great value to me ten years ago when I first learned I am autistic. It is useless now.

To be clear, there are no meaningful services in Fife and almost certainly in many other areas of Scotland, and I am extremely upset that the response from the Scottish Government to this petition looks like an attempt to cover this up. The local authorities clearly won't act unless they are forced to – my emails to Fife Council went unanswered, as did those from my MSP. It feels they hold the likes of me in nothing but contempt. Fife Council have a strategy, which the Scottish Government, it is true, paid for. It has not been proofread, never mind implemented.

The Scottish Government failure to implement the Scottish strategy has utterly failed the majority of autistic people in Scotland.

The Scottish Government are spending substantial sums of money on social care, but it's clear autistic people only count if they have intellectual disabilities and have families to advocate on their behalf.

I hope the Scottish Government and the local authorities will choose to prove me wrong and keep the promises they made ten years ago.

If you do not, I would like to understand why.

PE1837/L

The National Autistic Society Scotland submission of 21 January 2021

About us

The National Autistic Society Scotland is a leading charity for autistic people in Scotland and their families. There are around 56,000 autistic people in Scotland, both children and adults, plus their more than 174,000 family members and carers. We provide local specialist help, information and care across Scotland to autistic children, adults and families. We offer a wide range of personalised quality support at home and in the community, both in groups and one-to-one. Our branches in Scotland offer families and autistic people help and mutual support, and our employment team support autistic people in work and their employers.

Petition PE1837

The National Autistic Society Scotland welcomes the recent resourcing of the national autism post diagnostic support service for people diagnosed within the last two years and is currently working in collaboration with the Scottish Government to ensure that our charity can play a positive, high impact role in this new service. However, it is our charity's view that there continues to be an absence of consistent and accessible support services for autistic people throughout their lifespan in a number of local authority areas across Scotland, creating something of a postcode lottery. This issue requires further action by the Scottish Government and COSLA to ensure that the human rights of all autistic people are recognised in Scotland.

Our charity, therefore, broadly welcomes the call for more resources to be made available by the Scottish Government in order to provide support for autistic people, not just across local authorities and health and social care partnerships in Scotland, but also across the third sector and autistic people's organisations. As the collaborative work around the post diagnostic support service, and services which resulted from the Scottish Strategy for Autism such as the One Stop Shops, shows, it is only by involving third sector organisations and APOs in this work that tangible, long-term success can be achieved.

In terms of investment, we recognise that a lack of funding is currently a concerning issue and greater resources are required in order to support autistic people through services at a local authority level. However, we would also wish to highlight that it is often simplistic to automatically attribute failings at local authority level solely to a lack of investment, whilst not understating the importance of increased investment. As the Cross Party Group on Autism's recent review of the Scottish Strategy for Autism found, as detailed in the resulting *The Accountability Gap* report¹, there is a lack of accountability and consistency across local authority areas that continues to be a serious barrier to providing adequate and accessible support. Therefore, we would suggest that work should be undertaken to identify best practice at a local level with the aim of then sharing this widely to ensure greater consistency across Scotland, alongside a commitment to additional funds.

¹ Cross Party Group on Autism (2020) *The Accountability Gap*. Available to download at: <https://www.autism.org.uk/what-we-do/news/scotland-cross-party-group-on-autism-report>

The aforementioned Cross Party Group report, *The Accountability Gap*, sets out an array of findings and lists a number of recommendations that would help to ensure greater consistency and availability of efficient support services for autistic people in Scotland. The primary recommendations identified are the creation of a new fully funded Autism Strategy, and the foundation of a Commission or Commissioner role. It is our charity's view that such a role would subsequently be in a position to undertake some of the work mentioned above, such as investigating and sharing best practice, and orchestrating collaborative work between the Scottish Government, local authorities, health and social care partnerships, third sector organisations, and APOs.

Conclusion

The National Autistic Society Scotland acknowledges the Scottish Government's response to this petition, including highlighting the recently established national post diagnostic support service. We welcome the resources that have been made available for this service and our charity is committed to making it a success. However, we do recognise that further support is still required for autistic people throughout the lifespan and we do agree that more resource is required within the system to support autistic people at a local level. Our charity mirrors the views of the Cross Party Group on Autism that a new fully funded Autism Strategy and the establishment of a Commission or Commissioner role are both required to ensure consistency and accountability is implemented across every local authority area. This would be a crucial first step to lifting the barriers currently preventing adequate support being made available to all autistic people in Scotland.

PE1837/M

Wendy Ferguson submission of 22 January 2021

I feel strongly about the content of the above petition which is why I have decided to write this document, despite the significant difficulty this involves for me.

Imagine having various tests done at hospital, over several years and then the health practitioner confirming that you need surgery but there are no services available to deliver this. And any that do exist you don't qualify for since you are not ill enough. Imagine the absurdity of this just for a moment.

Because this is what happens to an autistic adult at diagnosis. It happened to me. After years of waiting lists and appointments, all the while suffering for reasons I did not understand. I expected that receiving diagnosis would open the door to the support I so desperately needed. But it didn't. Because there wasn't any.

Since we live with a medical model where we seek medical assistance and it is there, unconditionally. Why should this be different with autism? Despite it being something I find difficult and overwhelming, I have tried to engage with some of the large autistic societies in Scotland – National Autistic Society and Scottish Autism. At various times in the last few years, I have asked for help to access any available local support through charities etc. I was surprised to find that neither of these societies provide direct support to people like me. In my last contact with Scottish Autism the person who promised to email me with information didn't. I had wasted the energy on the call, for nothing.

In November 2019 I engaged with an organisation called RAMH. It had taken me months to make the initial call to try to arrange an appointment to get help. I attended an in depth session which was exhausting due to the content. I wanted to try to deal with my lifelong anxiety and the detrimental impact it was having on my daily life. The person I saw knew nothing about autism. This meant I had to explain a lot of things in depth, adding to the exhaustion. I attended session one of the Anxiety Management course suggested and was so significantly anxious because of the facilitator style that I did not go back. I was supposed to receive an invite for another course with a different facilitator, this didn't happen.

By February 2021 I was experiencing such significant daily challenges that I saw my GP. I had come to a point where significant self-management was not working. I was mentally unwell. I believe this happened as a result of years of no support following my autism diagnosis in 2017. Referrals were to be made to social work, mental health services. I had no one to advocate for me and found myself having to call social work and mental health services while I was mentally unwell to try to establish support. Sadly what was evident was that I didn't fit in, anywhere. Social work seemed surprised that I was referred to them as I didn't "qualify". The mental health professionals typically do not understand autism and therefore do not understand me, my life, perspectives and ultimately what will help me most. I have received no support at all to help me with autism and the effect it has on my daily life. I have been unable to work for almost a year. I had to stop because it was making me increasingly unwell.

What I have learned about autism has all been through my own investigation, personal reflection and expense. Until very recently, I qualified for no financial support to assist me. It has been an exhausting journey. Not at all what I was expecting when I decided to seek a diagnosis. I have grown up with the medical model where you consult the health professional and they give you the help you need. Except, it seems, when you are an autistic adult and do not have a learning disability.

Imagine that scenario again of being ill and in need of life changing surgery. And the health professional saying they couldn't help, almost turning their back on you. Your GP offering a "sticking plaster" to see if it made any difference. And you then watching a Youtube video or two and doing a DIY job for yourself. I wonder how the end result would compare to that of a suitably qualified surgeon with all the necessary resources at their fingertips?

As an autistic adult, I need easy access to well informed, empathetic people with premises, resources and solutions to help me in daily life. I did not choose this diagnosis, I was born with it and lived into my forties managing it (or not) by myself. I just thought there was something wrong with me. Now I know different.

As I see support readily available, it seems to focus on children. It's as if the world has forgotten that autistic children grow into autistic adults. The daily challenges never go away, they are inherent, intrinsic to who we are and need specialised support which can easily be accessed, without a fight about whether we qualify or not, are unwell/disabled enough or not.

PE1837/N

Jean McNally submission of 26 January 2021

I am in support of the petition reference number PE01837.

I have experience of caring for a 20 year old that has Asperger's but not a learning disability or mental disorder. As a result, we have not been able to access support in the areas of occupational therapy as occupational therapy in Glasgow is based in either the learning disability or mental health teams which the person does not meet the criteria for. We have been unable to access sleep support because sleep support like Sleep Scotland only goes up to 18 and there are not similar services for adults. Sleep disorders are very common among people with an autism spectrum disorder (ASD). As much as 80% of them suffer from one or more sleep disorders.

When the person was at college we tried to get support from the National Autistic Society (NAS) and South Ayrshire Autistic Society (SAAS) would have paid for this service but NAS could not provide a worker and they were left with no support for one year. Services like the Autism Resource Centre (ARC) have had services cut and were unable to offer any support. In Glasgow the ARC no longer provides the service it was set up for and no longer meets the needs of people in Glasgow who have ASD. We have been left with no services or support because they do not have a learning disability or mental disorder. They have received no support from health or social work as an adult.

My uncle also had a diagnosis of Asperger's. He was diagnosed with Asperger's at twenty-eight. My gran got dementia and could no longer care for him and he went into residential care. He was sectioned shortly after around twenty-five years ago. He stayed in residential hospital institutions until he died a few months ago. For the last nine years he stayed in a small community hospital. He continued to live there because there was nowhere in Scotland which could meet his needs. They have talked about closing this hospital in line with government guidelines for the past three years but they are unable to because there is nowhere which can meet their needs. Care in the community has not worked for this group and the majority of people in this hospital will never be able to return to the community.

He is not the only person with ASD who died well before he should have. Autistic people have been found to have an overall risk of early mortality more than double that of the general population. Schendel, D.E. et al. (2016). Autistic people die on average 16 years earlier than the general population. For those with autism and learning disabilities, the outlook is even more appalling, with this group dying more than 30 years before their time. Hirvikoski, T. et al. (2015).

People with autism are at increased risk for experiencing mental health problems, particularly anxiety and depression. People with ASD are more likely to experience mental health problems than the general population. This can be because there are fewer resources and support to help develop coping skills. Also, they can experience more negative life events, and face stigma and discrimination from people and services.

The support provided in psychiatric hospitals is not geared towards people with ASD, the staff do not have enough ASD training or understanding. People with ASD need

the right support at the right time. There needs to be specialised services for those with ASD which does not depend on having a learning disability or mental health problem to access the service.

PE1837/O

Patsy Quinn submission of 26 January 2021

I am in support of the petition PE1837.

I was the carer of a young man aged 19 who was failed by the system. All his life I had to fight to get him support because his disabilities were not visible. When I asked for support all the services said it was just bad behaviour. He was given a late diagnosis of Asperger's Syndrome.

Education was difficult for him as main stream education did not meet his needs. We had tried when he was 14 to get him into a school that met his needs. They could support him on a 2 to 1 basis but I had to get education and social work to refer him. He had agreed to go, said it looked great, but education said no his mainstream school was best. Then 4 weeks later they said there's no point him being here and he stopped attending school. Due to lack of support, he ended up in the criminal justice system.

He received a diagnosis of ADHD when at a young offenders institute. It took him going to prison to get some help and medication for his ADHD but he received no support once he was out. When he got out of the young offender's institute, he was put in housing support that did not meet his needs. This service was not geared towards a teenager with ASD and ADHD. He was not in employment or training and had a lack of support from social work.

He was depressed and became suicidal and was saying he was going to kill himself. This was made worse when his best friend overdosed and had died in front of him 5 weeks before. He and another friend tried to revive him but couldn't. He was told on the Tuesday that his friends funeral was on the Friday and he just couldn't cope.

He had been trying to get help from his social worker but could not get support as an adult. He received support as a child because I was his Kinship carer and he had a residence order until he was 16. He had a children and family's social worker but we could not get him support as an adult.

He was living in a hostel and he overdosed. He went out and a member of staff found him in the street passed out she called an ambulance and did CPR on him and she managed to restart his heart. He was taken to hospital and treated but then he was able to walk out of the hospital. He was brought back to hospital and walked out again.

I got a call at 7.30PM and I went to the hospital. Unknown to me he had been there twice that day. He told the staff and his family that he was going to finish the job.

In the hospital he started to wake up and he asked me why I was there then he said oh no I'm still here. Despite him saying this they still would not section him. The staff told me he would be lucky to survive the night and in the unlikely scenario he did survive he would have had severe brain damage, yet they let him walk out again. The services did not think he was at immediate danger and sent him home each time. When at home he took another fatal over dose.

All agencies failed him and he did not receive support for his ASD and ADHD. The suicide rate among those with ASD was 9 times higher than the general population. Between 30% and 50% of autistic people have considered committing suicide. Balfe, M, Tantam, D (2010). Raja, M (2014) Segers, M &, Rawana, J (2014).

His carer made the point that she had received good support from her carers centre but the carers centre had been put out to tender and she was no longer receiving suitable support to meet her needs as a carer from the new centre.

I currently support a twenty-one year old and I cannot get adequate support for them. They have been refused self-directed support and are currently receiving no support from social work. They are another young person who is getting failed by the system which provides poor support to young adults with ASD and which fails to move many young people from child services into adult services.

PE1837/P

DIFFERabled Scotland submission of 26 January 2021

We are a Charity set up, (by parents/carers of children on the Autism Spectrum & co-existing diagnosis') specifically to support, highlight and unite the needs of (fellow) families with children/young people and adults on the Autism Spectrum – to share information, signpost, create awareness & understanding within our own families & our communities. To create meaningful, vital support & services for the benefit & value of our individuals on the Autism Spectrum. In addition to supporting our families & community members; we are also an Autistic led organisation. We provide real-time-1:1 peer support, online sessions for families to come together, Autism & Neuro-Diversity Sensory training workshops; for parents/carers & family members, who would like to create awareness & understanding. Creating further support for their individuals on the Autism Spectrum.

DIFFERabled Scotland are placing our submission in full support of this Petition.

There is an immense feeling of disappointment shared within our 'neuro-diverse families,' and our community, particularly around the complexity of 'Autism/ASD.'

There appears to be confounded interpretations of the legal and clinical approval of Autism Spectrum Disorder.

As families, many of our individuals do not have a Learning Disability – 67% **do not.**

We would like to highlight issues that present themselves to DIFFERabled on a weekly, if not daily basis. Many of which create further barriers and impacts for our ASD individuals, as well as their families:

- 1) Many of the children/young people can be on 'The diagnosis process,' for up to 3.6yrs. NICE(2017) recommends that an ASD diagnostic assessment begin within 3mths of first referral – for both children and adults.
- 2) Receiving diagnosis, they are then given handouts and sent on their way (lack of post-diagnosis support/lack of emotional support throughout the process).
- 3) CAMHS support? Difficult to receive support due to complex nature of the ASD diagnosis – Mental Health – postcode lottery on who receives and who does not! (ICD-11/DSM-5 (328.0 Meaning of 'mental Disorder.' In this Act 'Mental Disorder,' is as:
 - a) Mental illness
 - b) personality disorder
 - c) learning disability

Autism on its own, is not covered within this Act. Therefore, this 'lack of Autism direction within any manual specifically defining what Autism is or is not, prevents accessing support. Attempting to create support for their child/young person within CAMHS, is very often met with, "We are not an Autism service. Autism is not a Mental health issue. Anxiety experienced with your child is based on specific Autism associated behaviours. The inability to understand or make sense of the environment is not a mental health issue, but a behavioural issue"

- 4) Lack of support around Asperger's (pre-post) Diagnosis
- 5) Lack of understanding/support within Education
- 6) Lack of Carers support
- 7) Lack of appropriate housing support/accommodation toward ASD individuals
- 8) Lack of appropriate understanding/awareness/training Employment support toward ASD individuals (& potential employees)
- 9) Alarming rates of individuals on the Autism Spectrum being sectioned (specifically young people). Once sectioned many of our young people/adults are very often placed in residential settings/units far from their own homes and communities. There is no specific ASD supported/setting or unit for young people In Scotland.
- 10) Lack of services to support transitions/funding - E.g., Social work/Children with disability assessment. Without Social work assessment, the application for SDS cannot be submitted. Access to Adults services become increasingly difficult without one service supporting/communicating with the other. Breakdowns in these vital links or 'collaborating/multi service support, results in further impacts & barriers to our individuals' journey.

There is a persistent financial failure toward the Social Care Support for our individuals with ASD. Third sector organisations are stepping in to provide this shortage of inconsistent provision. Autistic individuals and their families are unfortunately becoming the resource! Becoming ever more exhausted/depleted, by an unmet provision toward their individuals. Resulting in services needed for the entire family. Furthermore, services that require acknowledging and supporting autistic individuals with co-existing conditions; NICE(2017) estimates that on average 70% of ASD individuals present with these 'additional conditions,' such as, ADD, ADHD, Sleep Disorders, Tourette's, Anxiety based Disorders, Gender identity Issues, Ritualistic & Repetitive behaviours; and/or OCD etc. All of these can/may also be present with or without an intellectual Disability.

- We require positive outcomes, provision and services for the ASD individual and their families and interventions that will lead to and sustain positive impacts for our ASD individuals.
- We require clarity on how autistic people, who do not have a learning disability and/or mental disorder, where/can access support.

PE1837/Q

Jane Hook submission of 26 January 2021

I wish to support this petition lodged by Stephen Leighton in which he asks for clear direction and investment for Autism Support.

I am deeply saddened that the Scottish Strategy for Autism is due to finish at the end of March 2021. It promised much for people with Autism but significant issues have not been addressed.

The Petition 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;
- allocate investment for autism support teams in every local authority or health and social care partnership in Scotland.

It is a disgrace that people with Autism who do not have a learning disability should not be able to access appropriate support services. This is of course partly due to the fact that people with Autism and have a learning disability still find the main focus of their service delivery is around their learning disability and not their Autism. This means many services do not address their actual needs.

Until the focus is on people's autism and the individual needs this brings service provision will not improve. it also does ill service to the many who have a learning disability but not Autism. Their needs are very different. It is therefore important that service provision for people with Autism should be appropriate to the individual's needs as dictated by their Autism and not whether they have or have not got a learning disability.

This of course should be done on the basis of 'Think National but act at local level'.

The Scottish Parliament already has a mass of information on Autism at all levels and surely by now should realise that urgent action is required for the massive number of people with Autism who are simply being lost due to lack of appropriate support.

I highly recommend that The Scottish Parliament should act on this Petition.

PE1837/R

Petitioner submission of 1 February 2021

There is a pattern emerging from the submissions. It seems to take years for people to be diagnosed, only to then struggle to access any meaningful support across the lifespan. This proves the 10-year autism strategy has been a failure.

The National Autistic Society and Scottish Autism were instrumental in producing the Cross Party Working Group for autism report 'The Accountability Gap' – highlighting that autistic people are not being supported at a local level and that investment is needed. The Petitions Committee asked The National Autistic Society Scotland and Scottish Autism to provide submissions.

Scottish Autism did not make any submission.

The Scottish Government gave £200,000 to the National Autistic Society Scotland and Scottish Autism to support autistic people in relation to the pandemic. Out of the £250,000 allocated for the Post Diagnostic Pilot, £110,000 was given to the two charities. That is a combined £360,000 in the last 8 months.

The Scottish Government seem to highlight two main outcomes to the closure of the strategy:

- The new Post Diagnostic Pilot
- The new 2 year 'Learning/Intellectual Disability and Autism Recovery Plan 2021' – to bridge the gap between the closure of the autism strategy in 2021 with the learning disability policy (The Keys to Life) that will close in 2023.

The new Post Diagnostic Support is only a 6-month pilot, what happens after this? When does Post Diagnostic Support stop and ongoing support start? The need to develop a post diagnostic support toolkit highlights that there is no tangible ongoing support for autistic people across the lifespan - if there was ongoing support, you wouldn't need to develop a post diagnostic toolkit! The charities that are involved in this Pilot were already providing this support, they have been collectively paid £250,000 to more or less be reviewed as to what they were already doing. The money was initially procured to develop an alternative model, not just review what was already being provided. I sent a Freedom of Information Request to the Scottish Government asking for the minutes/contract/tendering process of how this money was allocated. The Scottish Government said they don't have any information to provide. How can they allocate a quarter of a million of pounds of public money with no record of how that decision was made?

The joint 'Learning Disability and Autism Plan' is a major concern for the autistic community, for all the reasons made in various submissions. By joining the two groups together (autism & learning disability) gives the public

the perception that learning disability services support autism needs. So, it will look as if there will be support for autistic people, but these services will only support people with a learning disability who are autistic, but not autistic people who do not have a learning disability. As the narrative is now shared with learning disability, it will be even harder for autistic people to 'close the accountability gap'.

The Scottish Government claim the issues faced by autistic people and the learning disability population are similar, hence the joint plan, yet they are not the same. I sent a Freedom of Information Request to the Scottish Government asking who made the decision to join learning disability and autism, they said they have no information they can provide me as to who made the decision to join learning disability and autism together. Instead they said the stakeholders agreed, the stakeholders being The National Autistic Society and Scottish Autism. How can they have no record/minute of such a big policy decision? Also, why did they make this decision before the closure of the autism strategy? It is clear that policy officers are designing policy without reflecting what the autistic community are saying, and are therefore giving the Scottish Government the wrong information to act on.

There seems to be a pattern emerging from the Scottish Government – the charities get to be a 'stakeholder' and get access to funding, then the Scottish Government claim they are getting 'the consent of the autism community' because these charities say so. As other submissions have highlighted, the charities do not have a mandate to represent the autistic community.

This is why the autistic community feel let down by some of the charities, as they seem to be 'willing to go along' with joining learning disability and autism. How can these charities claim to be advocating for autistic people, asking for people to fundraise for autism, by agreeing to policies that merge autism with learning disability, especially considering 67% of autistic people do not have a learning disability?

PE1837/S

Deborah Best submission of 2 February 2021

I strongly agree with petition PE01837 .

I was diagnosed autistic myself in February 2020. I sought this diagnosis to bring closure and fully identify with my Neurodiversity. In the weeks, months that followed, I wanted the diagnosis retracted. I didn't feel different, but many in the world who had accepted me as I was, changed their behaviour towards me. Many speak of the euphoria of diagnosis, the closure, but for me all the 'stuff' which was brought up was left unsupported. My clinician suggested I was referred for counselling but I had to follow through this option on my own. I was on a waiting list at the adult autism team for a post diagnostic group support group, but early into lockdown, I received a letter to say it had been cancelled and signposted me once again, but to nowhere really.

I've tried to access some services but 'I don't quite fit'. I've been described 'as being a pendulum which swings between the neurotypical and neurodiverse worlds'. I would like to fit somewhere, but since my diagnosis I don't. It has been damaging to my mental health with no suitable post diagnostic support. I can't imagine what service could be offered to me where I could feel supported ' invisibly'. I don't want to stand on a rooftop celebrating my diagnosis. I want support to reconnect with that 'lost little girl' and help me understand my life's difficulties and my vulnerabilities. I try to navigate the invisible daily difficulties I experience, which will continue to challenge me without any suitable support. My anxiety is debilitating.

I care for a 20 year old autistic person whom I've had to fight for since early years. No appropriate support at nursery or school, no childcare which would 'tolerate ' their autistic behaviours, no social activities which would include them. They were even asked to leave an arts project aimed at young people on the spectrum because they 'wern't autistic enough'. They had SDS and a personal assistant for 6 years but wasn't disabled enough for SDS as an adult. They fell off the 'cliff edge' on leaving School with their mental health irreversibly damaged, attempting to fit into a system which didn't understand them nor even want to. Exclusion, isolation and inequality are what being autistic means to them. A damaged child reaching an adult world where even less people care about their rights and needs.

We are NOT 'disabled enough' .

PE1837/T

Scottish Autism submission dated 4 February 2021

Scottish Autism are sorry to learn that the commenter here feels ill-served by autism services. We agree that too many people do not receive adequate services and are too often excluded from society, which is why we are campaigning for a commissioner to champion and uphold the rights of autistic people as well as people with a learning disability. We are extremely clear that the work of such a commissioner should include advocating for people autistic who do not have a learning disability, who too often do not receive support from their local authority.

Scottish Autism aims to support autistic people with a wide array of needs. Our outreach services, one-stop-shop, advice line, as well as our post diagnostic support and Affinity services all support autistic people who do not have a learning disability. Our service provision is necessarily limited by what local authorities or government will commission, but we regularly seek funds for new services in response to what the autistic community tell us they need. Where peer-support and advice is most appropriate, we regularly refer people to Autistic People's Organisations. Scottish Autism will continue to campaign for better service provision and social inclusion for autistic people in partnership with others.

Public Petitions Committee**3rd Meeting, 2021 (Session 5)****Wednesday 10 February 2021****PE1839: Review maternity models in remote and rural areas****Note by the Clerk**

Petitioner	Maria Aitken on behalf of Caithness Health Action Team
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to ask all relevant health boards to review their maternity model to ensure that it meets the needs of remote and rural communities.
Webpage	parliament.scot/GettingInvolved/Petitions/reviewmaternitymodels

Introduction

1. This is a continued petition, last considered on 16 December 2020. At that meeting, the Committee agreed to write to the Scottish Government. The Committee has written a response from the Scottish Government. The petitioner was invited to respond however, a submission has not been provided to date.
2. The Committee is invited to consider what action it wishes to take.

Committee consideration

3. At its meeting on 16 December, the Committee noted a number of workstreams currently underway by the Scottish Government including discussions with regards to changes in rural service provision and arrangements for obstetric transfers across Scotland and the development of an in-utero transfer risk assessment tool to assist clinicians in their decision to transfer pregnant woman who are threatened with pre-term labour. The Committee therefore agreed to ask the Scottish Government what the timescale was for the conclusion of these respective workstreams.
4. The Scottish Government's response states that the current priority for health boards is on the delivery of essential maternity services and managing the impact of COVID-19. Work on implementing and reporting progress on many aspects of Best Start has paused, or proceeded at a slower pace, however some areas have accelerated to meet COVID-19 service requirements.
5. The Scottish Government explains that it continues to work with health boards to support them and gauge their readiness to re-start Best Start implementation during the course of 2021.

6. The submission explains that a number of innovative approaches to delivery of maternity and neonatal services have been tested by health boards and, although fast-tracked as a response to COVID-19, the ethos of care delivered by these new approaches supports the Best Start aims of keeping mothers and babies together, individualising care and delivering care closer to home.
7. The Scottish Government's submission confirms that the development of an in-utero transfer (IUT) risk assessment tool, which has a specific focus on supporting midwives in remote and rural areas in their decision-making capacity to transfer women threatened with pre-term labour, has continued throughout the pandemic. It assumes that an underpinning protocol will be developed, which will bring an obstetrician and ScotSTAR into the decision-making process when required.
8. The Scottish Government advises, however, that whilst development of the tool has made progress in recent weeks, the work on care pathways and protocols which the Maternity Transport Group was considering before the pandemic has been unable to progress. The submission explains that its priority is in tackling the pandemic and it therefore can't commit to any firm timescales for this specific piece of work. It does, however, see it being a deliverable within overall implementation timescales for Best Start.
9. During its meeting on 16 December, the Committee also noted the Scottish Ambulance Service SCOTSTAR Paediatric Retrieval Service and whether this service could be extended to obstetricians, in remote and rural areas, where needed. In response, the Scottish Government explains that ScotSTAR is fundamentally a retrieval service for critically ill patients to transport them to a higher level of facility. The submission highlights concern regarding the time for the assembly and arrival of the 'obstetric flying squad', which might delay the care that women need. The Scottish Government is of the view that a balance must be struck between the small number of transfers from remote and rural areas that involve an obstetric emergency, against the importance of ensuring processes are in place for midwives managing such emergencies.
10. The Scottish Government's submission concludes by explaining that the Maternity Transport Group has been set up to develop the aforementioned tool, pathways and protocol in order to ensure that remote and rural staff are supported in their decision to transfer pregnant women and that the right medical expertise is involved in that decision.

Action

11. The Committee is invited to consider what action it wishes to take. Options include—
 - To close the petition under Rule 15.7 of Standing Orders on the basis that the Scottish Government has confirmed a number of work streams, relevant to the petition, are currently underway including—

- discussions with regards to changes in rural service provision and arrangements for obstetric transfers across Scotland;
 - the development of an in-utero transfer risk assessment tool which has a specific focus on supporting midwives in remote and rural areas in their decision-making capacity to transfer women who are threatened with pre-term labour and;
 - work to establish and expand specialist perinatal services in all health boards.
- To take any other action members consider appropriate.

Clerk to the Committee

Annexe

The following submission is circulated in connection with consideration of the petition at this meeting—

- [PE1839/C: Scottish Government submission of 28 January 2021 \(62KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

Thank you for your letter of 17 December, asking the Scottish Government to advise on timescales for the conclusion of various workstreams in relation to the transfer of pregnant women in remote and rural areas, following the Committee's consideration of the above petition.

As the Committee have noted, as part of The Best Start five year forward plan for maternity and neonatal services, discussions are ongoing with regards to changes in rural service provision and arrangements for obstetric transfers across Scotland. With Boards focussing on delivery of essential maternity services and managing the impact of COVID-19, work on implementing and reporting progress on many aspects of Best Start has paused, or proceeded at a slower pace, whilst other parts have accelerated to meet COVID-19 service requirements. The nature of any change in rural service provision and arrangements for obstetric transfers within rural areas is inevitably part of the whole scale change in maternity and neonatal models recommended in Best Start which has slowed in the effort to tackle the pandemic.

It is however clear that a number of innovative approaches to delivery of maternity and neonatal services have been tested by Boards and, although fast-tracked as a response to COVID-19, the ethos of care delivered by these new approaches supports the Best Start aims of keeping mothers and babies together, individualising care and delivering care closer to home. These innovations will put Boards in a good position to continue to deliver Best Start and bring care closer to home which is essential for remote and rural areas.

The Scottish Government continues to work with Boards to support them where possible and gauge their readiness to re-start Best Start implementation during the course of 2021.

As noted, some aspects of Best Start have continued throughout the pandemic, where led by the Scottish Government and where there is capacity for NHS staff to engage. That includes the development of an in-utero transfer (IUT) risk assessment tool to assist clinicians in their decision to transfer pregnant woman who are threatened with pre-term labour, as part of the Maternity Transport Group.

The tool has been developed with a specific focus on supporting midwives in remote and rural areas in their decision making capacity to transfer women. It is based on the assumption that an underpinning protocol will be developed, which will bring an obstetrician and ScotSTAR into the decision making process when required. The development of this tool has made excellent progress in recent weeks and further work to refine it will continue, however, putting in place the formal protocol to support implementation will be dependant upon the involvement of frontline staff being able to contribute and agree such a protocol. Work on care pathways and protocols were being considered by the Maternity Transport Group before the pandemic but it hasn't been possible to progress that aspect of the work since. We recognise that tackling the pandemic is the priority and the Scottish Government are therefore not committed to any firm timescales for this specific piece of work at this time, but do see it being deliverable within overall implementation timescales for Best Start.

Finally, the Committee has asked for the Scottish Government's view on whether the ScotSTAR Pediatric Retrieval Service could be extended to obstetricians, in remote and rural areas where needed. ScotSTAR is fundamentally a retrieval service, sending out a team including the relevant critical care specialists (adult, paediatric or neonatal) to retrieve a critically ill patient and transfer them to a centre providing a higher level of facility, in order to

receive the care that they require, by the most appropriate mode of transport. It is important to note that women are transported to expedite access to obstetric care which includes theatre and other interventions that would not be appropriate in a rural setting without the wider anesthetic, monitoring and neonatal services required. The time taken waiting for an 'obstetric flying squad' would delay that care.

The Scottish Government recognises that a balance must be struck between the small number of transfers from remote and rural areas that involve an obstetric emergency, against the importance of ensuring processes are in place for midwives managing such emergencies. That is why the Maternity Transport Group has been set up to develop the aforementioned tool, pathways and protocol in order to ensure that remote and rural staff are supported in their decision to transfer and that the right medical expertise is involved in that decision.

I hope you find this response helpful.

Public Petitions Committee
3rd Meeting, 2021 (Session 5)
Wednesday 10 February 2021

PE1840: Addressing racism in Scottish education

Note by the Clerk

Petitioner	Debora Kayembe on behalf of The Freedom Walk
Petition summary	<p>Calling on the Scottish Parliament to urge the Scottish Government to urgently address racism in the Scottish education system by—</p> <ul style="list-style-type: none">• implementing anti-racist education in the classroom;• delivering anti-racist training to all school staff and;• record, monitor and address racist incidents in schools
Webpage	parliament.scot/GettingInvolved/Petitions/PE01840

Introduction

1. This is a continued petition last considered on 16 December 2020. At that meeting, the Committee agreed to write to the Scottish Government.
2. Written submissions have been received from the Scottish Government and the petitioner.
3. The Committee is invited to consider what action it wishes to take.

Committee consideration

4. At its meeting on 16 December, the Committee agreed to write to the Scottish Government asking it to respond to a number of questions raised by the petitioner in their written submission of [8 December 2020](#). The Scottish Government's response addresses each of the petitioner's questions as well as confirming that the petitioner has received a further separate response in reply to a letter sent to the Deputy First Minister and Cabinet Secretary for Education and Skills.

Tackling racism in Scottish Education

5. With regard to the question of how Scottish teachers are developing their practice in response to tackling racism in Scottish education, the Scottish Government advises that Education Scotland delivers training at all levels of teaching that supports the development of anti-racist practice. It also signposts teachers to places of further learning. The submission breaks down in

detail, the type of training available at all levels of teaching and can be summarised as follows—

- **Teachers** - The Teacher Leadership Programme (TLP) workshops on Critical Race Theory and Decolonising the Curriculum Education Scotland and the General Teaching Council for Scotland working with SAMEE to provide a range of learning for BME educators.
 - **Middle Leaders** - The Middle Leaders Leading Change programme encourages self-reflection, reading and planning how to take the leadership of cultural intelligence and anti-racism forward in future.
 - **Aspiring school leaders** - A revision of the Into Headship programme in 2020/21 to include intercultural and anti-racist professional learning.
 - **School Leaders** - The Excellence in Headship Programme offers 'Learn' sessions for headteachers on Socially Just Leadership. From the 2021/22, a cultural identity element will be developed.
 - **System Leaders** - The Evolving Systems Thinking Programme has the core focus of leadership for school and System improvement, includes principles of equity, diversity and inclusion and an emphasis on school and system leaders as advocates for every child, young person and their families.
6. The petitioner also questioned how the status quo was being challenged in order to hear the voice of those who are marginalised and often forgotten about. The Scottish Government highlights that the issues raised by the petition cannot be tackled in isolation and that a new programme of work has been initiated to make progress in this area and will focus on:
- curriculum reform;
 - diversity in the teaching profession;
 - racism and racist bullying;
 - professional learning and leadership.
7. To ensure the Scottish Government fully understands how these issues are best tackled, it has engaged with a number of race equality and education stakeholders, Black and Minority Ethnic groups and young people. Some sessions have also been attended by Ministers so that they can hear directly from those affected by racism.
8. The submission explains that the programme will be aligned with work being taken forward by the Human Rights Taskforce and the recommendations made by the Covid Expert Group in Ethnicity. The work will also be aligned with the Scottish Government's Race Equality Action Plan (REAP) as its 2021-25 iteration enters the development stage.
9. With regard to the question on whether every school has a policy or strategy to tackle racism or an equalities policy, the Scottish Government explains that

all schools and local authorities have a policy which outlines their commitment to inclusion, diversity and equality and this forms part of local authorities' obligations under the Public Sector Equality Duty. These policies link to school improvement planning, are regularly reviewed and are overseen by Quality Improvement Officers within Local Authorities. Local Authorities are obliged to review policies in line with their legal obligations.

10. The petitioner asked for an explanation of how the whole school community is involved in tackling racism in Scottish schools. The Scottish Government's submission explains that a number of initiatives are in place including:

- All educators must follow 'Responsibility of All' to ensure the mental, emotional, social and physical wellbeing of the children and young people in their care;
- The Scottish Government provided funding to produce the 'Addressing Inclusion: Effectively Challenging Racism In Schools' resource;
- The Scottish Schools (Parental Involvement) Act, 2006, provides a statutory framework for ensuring that parents and families from all backgrounds and communities are fully engaged with their children's schools;
- The Scottish Government's 'Learning Together' equalities and equities fund is providing £350,000 to eight projects aimed at developing best practice and recourses across a range of equalities and equities categories in the fields of parental involvement and engagement and learning at home;
- The Mentors in Violence Prevention (MVP) programme empowers young people to challenge gender-based violence, bullying, abusive and violent behaviour;
- UNICEF's Rights Respecting Schools Award - Rights Respecting is available to schools across the UK and provides a framework through which schools can embed the UN Convention on the Rights of the Child at the heart of their practice;
- All accusations of racist incidents must be recorded, monitored and responded to by schools and escalated to Police Scotland if needed.

The Difference Between Racism and Bullying – Ensuring Effective Recording

11. The Scottish Government's submission explains that school are expected to record racist incidents and on the school management system SEEMIS and escalated to Police Scotland if appropriate. The submission explains that the presumption should always be against criminalising children and young people wherever possible.
12. It further explains that no national guidance is available on the procedures for recording racist incidents as these will vary across schools and local authorities. As a result, there is no central monitoring of this data. The submission explains however that guidance is in place to assist educators in identifying if an incident is bullying or racism and which category of offense would be appropriate for consideration by the Procurator Fiscal or Children's Reporter.

13. In their response, the petitioner highlights that the Scottish Government's submission does not mention training for school communities in anti-racist education nor implementing anti-racist education in the classroom. The petitioner also states that there has been no evaluation of the effectiveness of the range of programmes the Scottish Government refer to in their written submission.
14. The petitioner also raises the issue of accountability for those who commit racism in the classroom as a hate crime. The petitioner's submission refers to an FOI request regarding the number of instances of racism in schools (at least 2551 between 17/18 and 19/20) but notes as reporting is not mandatory, some local authorities did not report their numbers.

Action

15. The Committee is invited to consider what action it wishes to take. Options include—
- To close the petition under Rule 15.7 of Standing Orders on the basis that —
 - the Scottish Government has initiated a new programme of work focussed on curriculum reform, diversity in the teaching profession, racism and racist bullying and professional learning and leadership which will explore the issues raised by the petition;
 - Education Scotland delivers training at all levels of teaching that supports the development of anti-racist practice and;
 - schools and local authorities have their own procedures for recording racist incidents, either through their own systems or SEEMIS, the school management information system.
 - In closing the petition, the Committee could write to the Cabinet Secretary to request that training for school communities in anti-racist education is a top priority as part of its new programme of work on curriculum reform, in line with the petitioner's concerns.
 - To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1840/C: Scottish Government submission of 26 January 2021 \(198KB pdf\)](#)
- [PE1840/D: Petitioner submission of 26 January 2021 \(80KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

PE1840/C

Scottish Government submission of 26 January 2021

Further to your letter of 17 December about the following petition:

PE01840: Addressing racism in Scottish education, Debora Kayembe on behalf of The Freedom Walk

Calling on the Scottish Parliament to urge the Scottish Government to urgently address racism in the Scottish education system by:

- *implementing anti-racist education in the classroom*
- *delivering anti-racist training to all school staff and*
- *record, monitor and address racist incidents in schools*

We submitted our initial response to the petition on 7 December 2020, and a further separate response was also issued to Ms Kayembe on 8 January 2021, in reply to a letter she sent to Mr John Swinney, Deputy First Minister and Cabinet Secretary for Education and Skills.

We have now been asked by the Committee to respond to a number of questions from the petitioner based on our initial reply. Please now find attached this further response.

I hope the Committee and the petitioner find the information helpful.

Tackling Racism in Scottish Education

1. How are all Scottish Teachers developing their practice in response to tackling racism in Scottish Education?

Education Scotland offer professional learning that supports the development of anti-racist practice at all levels of teaching, works with partners to deliver this professional learning and also signposts further learning across the system.

Teachers

The Teacher Leadership Programme (TLP) offers anti-racist workshops to participants on Critical Race Theory and Decolonising the Curriculum with these sessions taking place in December 2020 and then recorded and available to watch anytime. Sessions were led by members of SAMEE (Scottish Association of Minority Ethnic Educators). A TedTalk on Cultural Intelligence is now part of the TLP 20/21 Pre-programme reading.

As part of the Covid-19 Education Recovery Group (CERG) Workstream 6 coaching and mentoring offer, Education Scotland and the General Teaching Council for Scotland are working with SAMEE in three ways. The first, to deliver their bespoke Leadership and Mentoring Programme for Black and Minority Ethnic (BME) educators. This programme provides safe, positive spaces for BME educators to acknowledge their experiences, affirm their skills and competencies, define actions to support career progression and develop into race-cognisant advocates. The second area of this work includes peer-to-peer-mentoring. The aim of this is to prepare and support BME teachers who have undertaken the Leadership and Mentoring programme to mentor fellow teachers, building capacity within the profession. This work involves working closely with BME educators and white senior leaders to support their learning in the area of race equality and professional equity. The third area involves working with BME teachers in mentoring through preparation for promotion to leadership roles.

Post Probationers

The Stepping Stones programme, part of the same CERG package of support and aimed at teachers in their first four years post-probation, includes a workshop on culturally-responsive pedagogy.

Middle leaders

Participants in the Middle Leaders Leading Change programme engage in self-reflection around cultural intelligence, exploring work by Julia Middleton, a noted expert and campaigner for the progression of diverse leaders in a civil society. Participants also engage in reading around the importance of diversity from a leadership perspective and plan how they are going to take the leadership of cultural intelligence and anti-racism forward in future.

Aspiring school leaders

A revision and refresh of core learning modules of the Into Headship programme in 2020/21 will be undertaken with BME educators to ensure it cover intercultural and anti-racist professional learning. This means from 2021/22 all practitioners obtaining the Standard for Headship will have undergone anti-racist professional learning.

Professor Rowena Arshad provides an annual lecture to new Into Headship participants at their conference on race and 'Leading for Equality.'

School leaders

The Excellence in Headship Programme offers 'Learn' sessions for headteachers on Socially Just Leadership, designed and delivered by Khadija Mohammed, Chair of SAMEE. One session was delivered in 2020 with the remaining two sessions planned for 2021.

A new extension of the Excellence in Headship programme (EIH Stretch) facilitates headteachers to undertake collaborative enquiry. Six headteachers have elected to focus on equalities and diversity.

From the 2021/22 academic session, Excellence in Headship will be developing a new core element of the programme around cultural identity.

System leaders

The Evolving Systems Thinking Programme has the core focus of Leadership for school and System improvement. This work is based on and encompasses the principles of equity, diversity and inclusion with a strong focus on the ethical stance of school and system leaders as advocates for every child, young person and their families in our system.

Specific aspects of the work covered include:

- exploring the roles of school and system leaders in terms of processes, providing and aligning resources, developing leadership capacity and ensuring productive relationships
- understanding effective practices at school and system level
- exploring in-depth the concepts of emotional and cultural intelligence
- through the online professional learning resource that sits on the Education Scotland website we have recently posted a guest blog from the Anti-Racist Educator site and signposted further reading.

The Education Scotland [Race Equality Wakelet](#) pulls together a wide range of resources for professional learning for all staff, including those supporting learners.

Other organisations offer anti-racist professional learning for teachers, for example professional associations, General Teaching Council for Scotland and third sector organisations.

2. How is the status quo being challenged in order to hear the voice of those who are marginalised and often forgotten about?

The Scottish Government recognises that the issues raised in this Petition are not new. We also know that they are intrinsically linked and cannot be tackled successfully in isolation. We have initiated a new programme of work to help focus our efforts and make progress in this area. The programme will focus on

- i. curriculum reform
- ii. diversity in the teaching profession
- iii. racism and racist bullying
- iv. professional learning and leadership

In order to better understand how these issues need to be tackled, we have carried out a number of engagement sessions with race equality and education stakeholders, Black and Minority Ethnic groups and individuals and young people. Some of those sessions have been with Ministers in order that they get to directly hear the voices of people who have experienced racism in the education system.

Throughout the lifetime of this programme, engagement with Black and Minority Ethnic groups and individuals, including young people, will continue in order that solutions and ensuing actions can be identified in collaboration. As part of the programme we will work with existing and establish new networks and opportunities for engagement and consultation to ensure that a diverse range of communities and voices are heard.

However, we know that tackling the education system in isolation is short sighted, and we will therefore align this programme with the Scottish Government's Race Equality Action Plan (REAP) as its 2021-25 iteration enters the development stage. This will ensure that any actions we develop dovetail with the Scottish Government's overarching ambitions on race equality. The next version of the REAP will also be developed in conjunction with race equality groups and Minority Ethnic groups and individuals to ensure that voices who are marginalised are included.

Similarly, this programme will also align with work being taken forward by the Human Rights Taskforce and the recommendations made by the Covid Expert Group in Ethnicity to ensure consistency and optimum delivery of outcomes.

3. Does every school and local authority have a specific published policy and strategy to tackle racism in the educational environment?

All schools and local authorities have a policy which outlines their commitment to inclusion, diversity and equality, embedding the values inherent in the Equality Act. This forms part of local authorities obligations under the Public Sector Equality Duty and tackling racism is a key component of this. Local authorities understand the benefit of taking an intersectional approach and any policies which tackle racism will consider the other protected characteristics as set out in the Equality Act as well.

These policies will link to school improvement planning, and are reviewed in line with identified improvement priorities. Quality Improvement Officers within Local Authorities have oversight of these school improvement plans.

4. What does the anti-racist training to teachers and school support staff look like – how long is it, who delivers it, is it deemed effective?

The professional learning offered to practitioners by Education Scotland is outlined in the response to question 1. Sessions are offered regularly throughout the academic year as part of the programme delivery. The offer is co-constructed and co-delivered by partners across the Scottish education system. Evaluations of anti-racist sessions by participants form part of the ongoing programme evaluation and used cyclically to plan each iteration of the programme for the next academic session.

Evaluative comments from participants on the Excellence in Headship 'Socially Just Leaders' session reveal the impact on headteachers' planning and practice.

I found the session grounding, interesting and inspiring. We are down the line with some of this work in school but really needed a refresh on some of my thoughts. In particular the frustration at the process of change. I think Khadija is honest in her approach and is excellent at creating a safe space for discussion.

Hearing from an expert in the subject of racism, like Khadija, gave me a better perspective of the reality for BME children and adults. I was aware of our white privilege but unsure how

best to tackle it, without causing offense to minority groups. I realise that the best way to do this is to be explicit and open.

Aspiring school leaders on the Into Headship programme shared their evolving understanding in light of the Professor Arshad conference session on 'Leading for Equality'.

Rowena Arshad made me think that I need to consider how diversity impacts my setting, my practice and the practice of others.

Rowena Arshad lecture was very relevant. I really liked how she gave lots of examples of what she was talking about and I could relate to the issues of equality she was discussing and only yesterday in school had to discuss racial issue with a class.

Professor Arshad has made me consider the depth to which we address equality within school.

5. How is the whole school community being involved in tackling racism in Scottish Education?

Every child has the right to grow up fully included in their learning experience and to be treated with respect. We want all children and young people to be included fully in their learning and for all children and young people to learn tolerance, respect, equality and good citizenship to address and prevent prejudice.

Each local authority is responsible for the care, safety and welfare of pupils in school in the authority area. All adults who work in schools have a responsibility to ensure the mental, emotional, social and physical wellbeing of the children and young people in their care. This is something referred to as the 'Responsibility of All', which is in place to ensure each practitioner fulfils their role in promoting open, positive, supportive relationships across the school community.

The Scottish Government expect all schools to be safe, inclusive and welcoming environments for all children, parents and families. In order to create this environment for effective learning and teaching there should be a shared understanding of wellbeing, underpinned by children's rights, and a focus on positive relationships across the whole school community. In order to create this environment for effective learning and teaching, the four fundamental capacities of CfE should reflect and recognise the lifelong nature of education and learning, understanding the need for all children and young people to know themselves as individuals and to develop their relationships with others, in families and in communities. In addition, the four contexts recognise the knowledge, skills and attributes that children and young people need to acquire to thrive in our interconnected, digital and rapidly-changing world to enable children and young people to be democratic citizens.

We provided funding to the Coalition of Racial Equality and Rights (CRER) to publish a resource on racist bullying in line with Respect for All: The National Approach to Anti-bullying for Scotland's Children and Young People. 'Addressing Inclusion: Effectively Challenging Racism In Schools' was published in January 2019. This guidance is clear about the difference between racial bullying and racism and reinforces the importance developing a school environment where the values of inclusion and respect are uniformly applied to all students and their families. It is this inclusive ethos that addresses the root cause of prejudice-based bullying and contributes to its prevention.

Involving and engaging the whole school community

We know that when parents, carers and families are involved in the life and work of our school communities it leads to better outcomes for all children and young people. We also know that, through their work to involve parents and families from a range of backgrounds and from all parts of the school community, schools can often become a central point for community integration and for building shared understanding.

The Scottish Schools (Parental Involvement) Act, 2006, provides schools and local authorities with a statutory framework for ensuring that parents and families from all backgrounds and communities are fully involved in the life and work of their children's schools and engaged in their learning. It also sets out the importance of building effective two-way communication between schools, parents and families, taking account of any specific needs that individual parents and families may have. Additionally the Act places duties on school Parent Councils to take account of the needs of the whole school community, ensuring that it is adequately representing all members of the school's parent forum; including black and minority ethnic parents and families and parents and families for whom English is an additional language.

The Scottish Government's 'Learning Together' equalities and equities fund is providing £350,000, over two financial years, to eight projects aimed at developing best practice and recourses across a range of equalities and equities categories in the fields of parental involvement, parental engagement, family learning and learning at home. The fund, which is a key part of the Scottish Government's 'learning together' national action plan includes projects aimed at supporting parent's, families and building cohesion in areas where there are a high proportion of black and minority ethnic learners. Each of the eight projects are currently expected to conclude by December 2021 when final project reports, resources and materials will be published and shared with the wider system.

Mentors in Violence Prevention Programme

The Mentors in Violence Prevention (MVP) programme, is a bystander programme which empowers young people to safely challenge and speak out against gender-based violence, bullying, abusive and violent behaviour. In partnership with Education Scotland, this programme is delivered throughout schools across Scotland.

During the pandemic, the programme messages are being delivered online as and when schools and young people can engage. This has included monthly information wakelets for young people, and for the month of October, the focus was standing up against bullying and hate crime.

The MVP programme encourages young people to become leaders amongst their peers, speaking and standing up against harmful behaviours such as bullying and hate crimes. The programme also encourages young people to explore different scenarios around Insults and Words and the harm that language can cause which provides a useful basis for understanding some forms of hate crimes.

School Community Police Officers

Police Scotland school community based officers, form part of a whole school community approach to fostering good relationships and helping young people feel safe. They play a vital role in helping to build positive relationships with young people to prevent and reduce the harm from all forms of violence, including verbal, physical and/or emotional threats,

abuse and violence. They provide a positive interaction between young people, the police and the community in order to promote the wellbeing and reputation of young people within that community, addressing any disorder associated and the community perception of crime, particularly that which relates to young people. Their role with young people will be varied and subject to local issues arising within each community.

UNICEF's Rights Respecting Schools Award

Rights Respecting is available to schools across the UK and provides a framework through which schools can embed the UN Convention on the Rights of the Child at the heart of their practice. To obtain accreditation as a UN Rights Respecting School, an establishment must display evidence that it has delivered outcomes in three areas:

- teaching and learning about rights;
- teaching and learning through rights (ethos and relationships);
- teaching and learning for rights (participation, empowerment and action)

As the duty to deliver education sits with local authorities Scottish Government do not prescribe or formally endorse approaches at national level. This includes initiatives such as the UN's Rights Respecting Schools, although the positive outcomes of these initiatives are widely recognised and used in Scottish schools.

6. Who is being held accountable for tackling racism in Scottish education?

Everyone involved in Scottish education is accountable for tackling racism. Accountability for the programme of work designed to tackle racism in Scottish schools ultimately rests with the Cabinet Secretary for Education and Skills.

Curriculum for Excellence is based on four values - wisdom, compassion, justice and integrity - which everyone in the Scottish education system is responsible for upholding. On a day-to-day basis, teachers must respond to any accusations of racism which are made, using the recording and monitoring process as set out in SEEMIS. However, responding to and recording to racist incidents is only a small part of the picture and teachers and the Senior Leadership Teams in schools are responsible for establishing and maintaining a culture which demonstrates zero tolerance for racism.

The Difference Between Racism and Bullying – Ensuring Effective Recording

1. As racism is a hate crime, are schools recording and reporting racist incidents to Police Scotland to record as hate crime?

We all need to be vigilant in challenging any racist and abusive behaviour in our schools. Where it occurs, it must be challenged through educating children about all faiths and belief systems, and ensuring they learn tolerance, respect and equality as well as healthy relationships. Promoting the principles of inclusion amongst children and young people is key to preventing hate crime.

We expect schools to record any racist incidents. Schools and local authorities may use their own systems for recording such incidents or can use SEEMIS, the school management information system which enables schools to record and incidents appropriately and refer to Police Scotland as necessary. However, the presumption should always be against criminalising children and young people wherever possible unless it is in the public interest.

Building environments where racial stereotypes and prejudice-based views can be challenged constructively by everyone can help to create inclusive learning environments. Promoting respectful relationships and ensuring we respond to all forms of prejudice will help create these environments. We need to challenge prejudice and offer the opportunity to learn and change behaviour.

In November 2017, the Scottish Government updated its anti-bullying guidance 'Respect for All: The National Approach to Anti-bullying for Scotland's Children and Young People'. The guidance is clear that some behaviours can be perceived as or assumed to be bullying.

However, certain incidents can often be more serious and, in fact, criminal in nature. Understanding the individual circumstances is important to ensure that there is a clear distinction between bullying and criminal offences such as hate crime. There are laws to protect children and young people from this very serious type of behaviour.

The Lord Advocate has issued guidelines about which category of offence will be reported to the Procurator Fiscal for consideration of prosecution. Children who do not come within these guidelines may be referred to the Children's Reporter or made subject to Police direct measures, depending on the circumstances. The Procurator Fiscal and the Children's Reporter discuss cases which are subject to joint referral and the Procurator Fiscal will decide where the case is best dealt with. The presumption should be against criminalising children and young people wherever possible unless it is in the public interest. Adults and children and young people can seek appropriate advice and guidance from Police Scotland if they feel a crime may have taken place.

2. Does every school and local authority in Scotland use the SEEMiS System to record and report racism? The Freedom Walk campaign has heard evidence from practitioners that states this is not the actual case.

Schools do have the facility to record racist incidents through a specific module on the SEEMIS system. However, there is no national guidance on this and procedures for recording racist incidents will vary across schools and local authorities.

3. How effective is the recording and reporting of racist incidents on the SEEMiS system? The Freedom Walk campaign has heard evidence from practitioners and parents that there are gaps with how different schools and local authorities are reporting which contradicts the guidance provided by the Scottish Government as mentioned in its response to committee.

As outlined above, schools and local authorities will have their own procedures for recording racist incidents. This is not monitored centrally.

The Freedom Walk campaign may be referring to guidance produced for schools to record and monitor bullying incidents in schools which is a different approach to recording racist incidents. An evaluation will be undertaken in 2021 to assess how successfully the new system to recording and monitoring bullying incidents in schools has been embedded.

The guidance published by Coalition of Racial Equality and Rights (CRER) is clear that if a bullying incident is serious in nature, with clear criminal aspects, it must be reported to Police Scotland. Adults and children and young people can also seek appropriate advice and guidance from relevant authorities if they feel a crime may have taken place.

4. Do all schools and local authorities have A) a Tackling Racism policy B) an Equalities Policy that reflect latest legislation and guidance?

As stated in response to an earlier question, all schools and local authorities have policies which outline their commitment to inclusion, diversity and equality, embedding the values inherent in the Equality Act. This forms part of local authorities obligations under the Public Sector Equality Duty and tackling racism is a key component of this. Local authorities understand the benefit of taking an intersectional approach and any policies which tackle racism will consider the other protected characteristics as set out in the Equality Act as well.

These policies link to school improvement planning, and are reviewed in line with the identified improvement priorities. Quality Improvement Officers within Local Authorities have oversight of these plans.

‘How Good is Our School 4’ (HGIOS4) is designed to promote effective self-evaluation as the first important stage in a process of achieving self-improvement. This includes quality illustrations, features of highly-effective practice and challenge questions for a range of quality indicators including one specifically linked to ensuring wellbeing, equality and inclusion to support schools policies and practices to be well grounded in current legislation and a shared understanding of the value of every individual.

The quality illustration in HGIOS4 for inclusion and equality states – *We ensure inclusion and equality leads to improved outcomes for all learners. All learners are included, engaged and involved in the life of the school. All children and young people feel very well supported to do their best. Learners, parents and carers, staff and partners feel that they are treated with respect and in a fair and just manner. We understand, value and celebrate diversity and challenge discrimination. In our school age, disability, gender reassignment, marriage and civil partnership, pregnancy, race, religion or belief, sex and sexual orientation are not barriers to participation and achievement. We have effective strategies in place which are improving attainment and achievement for children and young people facing challenges such as those from our most deprived areas, young carers, those who are looked after and those with additional support needs.*

During school inspections, schools are required to submit evidence in relation to safeguarding. Inspectors subsequently engage in discussion with the school leadership team regarding how well the school meets its equality duties and supports learners from all protected characteristics groups.

The Equality Act 2010 (section 149) places a duty all public authorities to: eliminate discrimination, harassment and victimisation; advance equality of opportunity; and to foster good relations between persons who share a protected characteristic and those who do not. This is known as the public sector equality duty.

Although the Equality Act is largely reserved, the Scottish Government introduced regulations in the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012 to help public authorities implement the public sector equality duty. Under these regulations Local Authorities have duties in their role as Education Authorities, which include a requirement to report on the work to mainstream equality and to publish equality outcomes and report progress on them.

Local Authority and school policies including inclusion/diversity/equality and anti-bullying policies should directly reference the Equality Act 2010 and include an explicit commitment to challenge all types of prejudice based bullying and language and should reflect the underlying principles of a race equality approach. These policies should be available to pupils, staff and the wider school community, and be easily understood by all.

5. When were these policies published or recently revised? The Freedom Walk Campaign has heard that local authorities such as Falkirk do not have a Tackling Racism Policy and its Equalities Policy was last revised in 2006.

Local Authorities will review policies in line with their legal obligations.

PE1840/D

Petitioner submission of 26 January 2021

Introduction

On 27 January 2021, the Freedom Walk campaign was made aware that the Scottish Government issued a response in relation to our petition currently being considered by the Scottish Parliament. As such, we are submitting correspondence to Committee for consideration considering the Scottish Government's response to Committee. We are also calling on the Committee to call witnesses to ensure the full evidence has been identified and considered before a final decision is reached.

Tackling Racism in Scottish Education

Noting the issues raised by the Scottish Government in relation to racism in Scottish education, the following issues are still not tackled by the Government.

1. The Scottish Government does not mention any training for schools communities in term anti-racist education and implementing anti-racist education in the classroom.
2. The Scottish Government has presented a range of programmes that are currently available in Scottish schools but has not presented any evaluation of these programmes and initiatives to demonstrate effectiveness. It is also necessary to clarify that all these policies and programmes are not mandatory.
3. The Scottish government does not mention accountability for those who commit racism in the classroom as a hate crime.
4. A freedom of information request made by the Scottish Liberal Democrat found at least 2251 instances of racism in schools between the 2017-18 and 2019-20 academic years; some local authorities did report their numbers but some did not wish to report; simply because reporting is not mandatory.

Recommendation

The Freedom Walk Campaigns call on the Scottish Parliament's Public Petitions Committee to call for any witness who wants to testify about their experiences on the issues raised by the Scottish Government, or anyone who wishes to submit additional evidence in support of this petition.

Public Petitions Committee
3rd Meeting, 2021 (Session 5)
Wednesday, 10 February 2021

PE1841: Allow a designated visitor into care homes

Note by the Clerk

Petitioner	Natasha Hamilton on behalf of Care Home Relatives Scotland
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to allow a designated visitor into care homes to support loved ones.
Webpage	parliament.scot/gettinginvolved/petitions/designatedcarehomevisitors

Introduction

1. This is a continued petition, last considered by the Committee on 16 December 2020. At that meeting, the Committee agreed to write to Scottish Government, the Coalition of Care and Support Providers in Scotland (CCPS), Scottish Care and the COVID-19 Committee.
2. Responses have been received from the Coalition of Care and Support Providers in Scotland, the Scottish Care, Anas Sarwar MSP and the petitioner. At the time of writing this note, a submission had not been received from the Scottish Government.
3. The Committee is invited to consider what action it wishes to take.

Committee consideration

4. In its submission of 22 January 2021, the CCPS explains that its position statement on supporting family contact in care homes was shared with the Scottish Government in October 2020. The CCPS confirms that the statement has been acknowledged but no substantive response has been received. The submission acknowledges that care homes have worked hard to ensure face to face contact continues and where this is not possible, digital contact has been introduced. It notes that care homes will require support from the Scottish Government and statutory partners to implement the guidance safely.
5. The submission highlights that neither the CCPS or the wider care sector were consulted prior to the guidance being issued. As a result, care homes are finding it challenging to respond to requests from families seeking clarification on how they can take advantage of the new and expanded permissions set out in the guidance. The CCPS calls for support in staffing and resources, risk management and testing.

6. With regard to vaccinations, the CCPS advise that the guidance requires that current arrangements for infection control remain in place irrespective of vaccination status. It therefore believes that vaccination does not change the issues currently being faced.
7. In its submission of 22 January 2021, Scottish Care's view is that legislation alone rarely achieves desired improvements. It stresses the importance of all stakeholders engaging in consensual dialogue to achieve the outcomes to suit all needs. It is pleased to note such discussions are underway.
8. Scottish Care highlights that the health and wellbeing of care home residents has deteriorated as a result of the Coronavirus pandemic lockdown. Scottish Care supports the view that family members are an essential part of someone's care and should be recognised as such. It does note however that not everyone agrees that visiting should be opened extensively, given the challenges of high infection and death rates currently being faced.
9. Scottish Care advises that it continues to work collaboratively with the Scottish Government to improve the guidance to ensure clarity and flexibility to suit local circumstances. It is of the opinion that a combination of approaches such as PPE use, vaccinations, testing and social distancing remain the best approach to balancing the need for protective measures and care home visits. It does not support 'blanket approach' policies and feels more legislation would be a distraction from the positive work underway.
10. In her written submission, the petitioner advises that although guidance was issued on 12 October 2020 allowing for up to 4 hours of visiting with touch, the reality is that few relatives are getting any meaningful indoor visits. She highlights results from a survey undertaken by Care Home Relatives Scotland which shows that many respondents have had no meaningful interaction with loved ones at all, and that the few care homes that are following guidelines tend to be charity run or not for profit.
11. The submission highlights that many care home companies have their own rules and have cited a number of reasons for refusing contact. As a result, loved ones are not being allowed visits with touch, video calls, or access to their relative's room. Some care homes have cited difficulties in being able to discuss their requirements with "public health". The petitioner also explains that relatives are being asked to dress in full PPE and to sit behind a screen 2 metres away from their relative in order to facilitate a visit, which can be difficult for hard of hearing and non-verbal residents.
12. The petitioner makes the point that—

"Care home residents have never had the freedom that the general public have but, yet they are the first to suffer because of the freedom the general public has been granted"

13. The petitioner goes on to explain that some care companies have indicated that even with the introduction of testing, they will not be changing their rules around visiting. The petitioner explains that the emotional distress is unimaginable for families and residents being kept apart, even when loved ones are dying.
14. The petitioner states that in their opinion, if the guidance was working, the petition would not have been required. The petitioner closes her submission by asking for changes to be made now so that current and future residents know they will never be isolated from families.

Action

15. The Committee is invited to consider what action it wishes to take on this petition. Options include—

- To close the petition under Rule 15.7 of Standing Orders on the basis that:
 - the Scottish Government is actively considering how it can best support visiting in care homes; is regularly updating its advice on to reflect the evolving evidence base; and is working with the petitioner and others to support further opportunities for visiting in care homes.
 - In closing this petition, the Committee could write to the Scottish Government to highlight the inconsistencies in how the guidance is being applied and ask that it provides further clarity and support to people working in the care sector.
- To take any other action members consider appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- [PE1841/C: CCPS - Coalition of Care and support Providers in Scotland of 22 January 2021 \(56KB pdf\)](#)
- [PE1841/D: Scottish Care submission of 22 January 2021 \(73KB pdf\)](#)
- [PE1841/E: Petitioner submission of 1 February 2021 \(65KB pdf\)](#)
- [PE1841/F: Anas Sarwar MSP submission of 3 February \(9KB pdf\)](#)

All written submissions received on the petition can be viewed on the petition [webpage](#).

PE1841/C

CCPS – Coalition of Care and support Providers in Scotland submission of
22 January 2021

Many thanks indeed for the invitation to comment on this petition.

CCPS has produced a [position statement](#) on supporting family contact in care homes, which was shared with the Scottish Government in October. Although our statement has been acknowledged, and we have been advised that it has been taken into account, we have had no substantive response to the issues raised.

Broadly, the statement recognises the importance of supporting family contact in care homes and makes it clear that third sector care home providers have worked hard to ensure the continuation of in-person contact wherever possible, with appropriate social distancing safeguards and within the scope of Scottish Government guidance, and to introduce virtual contact through digital connectivity where in-person contact has not been possible.

The statement is equally clear that in order to support the enhanced permissions set out in guidance in a safe and balanced way, care home providers will in turn need strong support both from Scottish Government and from their local statutory partners with responsibility for public health, social care and clinical services.

The statement notes that with regret, no CCPS members were invited to be involved in drafting the guidance, nor was there any consultation with us or with the wider sector before the guidance was published. Consequently, whilst families are perfectly understandably now seeking urgent clarification as to when and how they may be able to take advantage of the new and expanded permissions set out in the guidance, many care homes are finding it a huge challenge to respond.

The statement calls for support in three key areas:

1. Staff and resources
2. Risk management
3. Testing

On the matter of vaccination, please be advised that current guidance requires that existing arrangements for infection prevention & control remain in place irrespective of vaccination status, so in practice, at this stage vaccination does not alter the position. As we understand it, this may change when it becomes clearer how effective vaccination is in reducing transmission, as well as what level of protection it gives. We await further guidance on these matters.

Thank you for inviting us to comment. We would be pleased to assist the committee further as required.

PE1841/D

Scottish Care submission of 22 January 2021

It is Scottish Care's position that we do not formally respond to petitions. However, we are happy to provide some general comment in relation to this particular petition.

In our view, legislation very rarely achieves the desired improvements in situations of sensitivity and nuance, such as the balancing of risk versus access in relation to care home visiting.

What is important is that all parties – in this instance care homes, relatives, Public Health officials and Scottish Government – work consensually to achieve outcomes which both protect health and promote wellbeing. We are pleased that this collaborative work is underway, with regular meetings organised between these parties to address concerns and progress our shared ambition to support and enable more care home visiting in a safe way.

Scottish Care is very aware of the deterioration of residents' health and wellbeing as a result of the Coronavirus pandemic lockdown and other restrictive measures, as reported by both relatives and care home staff. We are also very clear that family members are not merely visitors to care homes but are an essential part of someone's care and support network and should be recognised as such. We fully support the need for and realisation of care home visiting wherever possible and our engagement with members has highlighted that those who operate and work in care homes want this to happen as quickly and safely as possible too.

However, it is important to note that not everyone – including care homes, relatives and other stakeholders – agrees that visiting to care homes should be opened extensively, particularly at a point in the pandemic when health and social care services are facing unprecedented challenges, infection and death rates are particularly high and the country is dealing with an extremely infectious strain of the virus.

We continue to work collectively with the Scottish Government to inform the development and improvement of guidance to ensure that visiting measures are clear, consistent and flexible to local and individual service circumstances. We do not support a blanket approach to the severe restriction or prevention of care home visits.

It is our view that the combination of approaches currently available including the rollout of Coronavirus vaccines, testing, use of PPE and social distancing can provide the positive protective measures required to support care home visits to take place more consistently and frequently. It is therefore essential that all continue to be prioritised and utilised effectively together.

At the current time, therefore, we consider additional legislation to be an unhelpful distraction from the crucial work already underway on the ground to support care home visits.

I trust you find the above of some assistance.

PE1841/E

Petitioner submission of 1 February 2021

Guidance was issued 12th October 2020 which allowed for up to 4 hours of visiting with touch. Initially, we thought that this was a reasonable compromise however the reality is that very few relatives are getting any meaningful visits indoors.

The Government has provided care homes with PPE, lateral flow testing, funds for care home staff to self-isolate, funds to purchase iPads and funds to allow extra staff to be recruited to facilitate visits and yet we are only seeing a handful of care homes follow the guidelines from October. From our survey results, we see that the few care homes that are following the guidelines tend to be charity run or are not for profit organisations.

It is evident from the experiences from the members of Care Home Relatives Scotland (CHRS) that the majority of people in care are not having any kind of meaningful interaction between residents and their loved ones. Every time progress is made with residents and families benefiting, another obstacle appears. Members of CHRS have been refused contact because the care homes can't—

- follow guidance because our company has its own rules,
- allow visits with touch,
- facilitate video calls,
- have Christmas decorations,
- allow you access to your relative's room,
- trust you to use PPE.
- get through to public health,
- allow indoor visits because public health haven't approved them,
- accept Christmas presents,
- have hairdressers,
- alternate visitors,
- give you an extra visit even though visits are going unused,
- let visitors push a wheelchair,
- facilitate outside visits as we haven't bought any heaters for winter,
- give you an essential visit as we'd have to give everyone them,
- let you see your dying relative for more than 15 minutes a day,

Many members of CHRS have been told

- We don't trust test results,
- Public health say no,

Sadly the default is to dress relatives in PPE and sit them behind a screen 2 metres away from your hard of hearing, non-verbal relative. We have been given no exit plan to resume meaningful family contact.

Even with the introduction of testing and vaccines, we are hearing from care companies that there still won't be any changes to visiting which begs the question, what will it take?

Care home residents have never had the freedom that the general public have but yet they are the first to suffer because of the freedom the general public has been granted whilst at the same time being denied face to face medical assessments from GPs & wider multidisciplinary teams.

We have heard from many organisation and groups about what can and can't be done, what the guidelines say or don't say, who can make decisions and who doesn't have to follow these but yet nearly 11 months on, no one has ever asked what is important to the residents. Over 35,000 citizens of this country have had their voice and rights stripped away. If this was children or animals there would be a national outcry.

For example,

- Non-cohabiting couples across the country can visit each other, not applicable if you live in a care home.
- People living alone are allowed to create bubbles for their mental health, not applicable if you live in a care home.
- The general public are encouraged to get outside and connect with others for their mental health, not applicable if you live in a care home. Many have spent days, weeks and months alone in their room.
- Provisions are in place to allow access to someone's home to provide care, not applicable if you live in a care home. The love and care that families offer, which differs from what staff offer has been deemed irrelevant.
- Christmas bubbles were allowed for one day, not applicable for those living in a care home. They were lucky to see one person for 30 minutes.

We hear constantly restrictions are in place to protect residents yet residents are dying daily of non-covid related reasons and at times still being kept from families, sometimes until their last few hours. How is this fair or humane? The emotional distress this is leaving on the families left behind is unimaginable, does our mental health not matter?

No-one should be living out their final days alone in a place that they call home.

Once again, we would like to finish by reiterating that if guidance was working then this petition would never have been needed. We cannot emphasise enough the pain that is being caused throughout the country for residents that have been isolated the past 11 months and the families watching them suffer.

We have the power to make this change for residents living today, and it can be done safely, but also for future residents to know they will never be isolated from families for what could become years.

PE1841/F

Anas Sarwar MSP submission of 3 February 2021

I am writing in support of Petition PE01841 and in support of constituents who have contacted me since last March, seeking help on this issue.

The situation care home residents and their families have found themselves in since the start of the pandemic is tragic. Many family members have not been able to spend time with a loved one for almost a year. This is unacceptable and unforgivable.

I fully understand the initial caution as care home operators, be they private or public, came to terms with the impact of Covid-19 and what this meant for the safe operation of their care homes. Almost one year on it is unacceptable that a safe solution has still not been found to allow loved ones to spend precious time together in a safe environment.

This situation cannot be allowed to go on. A solution has to be found and I would urge you and your committee to do all it can to support the petitioners.