PUBLIC PETITIONS COMMITTEE

AGENDA

10th Meeting, 2018 (Session 5)

Thursday 7 June 2018

The Committee will meet at 9.45 am in the David Livingstone Room (CR6).

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

   - [PE1545](#) by Ann Maxwell on behalf of Muir Maxwell Trust on Residential care provision for the severely learning disabled;
   - [PE1591](#) by Catriona MacDonald on behalf of SOS-NHS on Major redesign of healthcare services in Skye, Lochalsh and South West Ross;
   - [PE1627](#) by Annette McKenzie on Consent for mental health treatment for people under 18 years of age; and
   - [PE1631](#) by Maureen McVey on Child Welfare Hearings.

2. **Consideration of new petitions:** The Committee will consider the following new petitions—

   - [PE1690](#) by Emma Shorter on behalf of ME Action in Scotland on Review treatment of people with ME in Scotland; and will take evidence from—Emma Shorter and Janet Sylvester, volunteers with ME Action in Scotland, and Prof. Chris Ponting, Chair of Medical Bioinformatics at Edinburgh University and Deputy Chair of the UK CFS/ME Research Collaborative;
   - [PE1695](#) by Ben and Evelyn Mundell on Access to justice in Scotland.

3. **Consideration of a continued petition (in private):** The Committee will consider a draft report on petition [PE1517](#) by Elaine Holmes and Olive McIlroy on behalf of Scottish Mesh Survivors - "Hear Our Voice" on Polypropylene Mesh Medical Devices.
The papers for this meeting are as follows—

**Agenda item 1**

Note by the Clerk  
PPC/S5/18/10/1
Note by the Clerk  
PPC/S5/18/10/2
Note by the Clerk  
PPC/S5/18/10/3
Note by the Clerk  
PPC/S5/18/10/4

**Agenda item 2**

PRIVATE PAPER  
PPC/S5/18/10/5 (P)
Note by the Clerk  
PPC/S5/18/10/6
Note by the Clerk  
PPC/S5/18/10/7

**Agenda item 3**

PRIVATE PAPER  
PPC/S5/18/10/8 (P)
Public Petitions Committee  
10th Meeting, 2018 (Session 5)  
Thursday 7 June 2018  

PE1545: Residential care provision for the severely learning disabled

Note by the Clerk

Petitioner  
Ann Maxwell on behalf of Muir Maxwell Trust

Petition summary  
Calling on the Scottish Parliament to urge the Scottish Government to recognise residential care as a way severely learning disabled children, young people and adults can lead happy and fulfilled lives and provide the resources to local authorities to establish residential care options for families in Scotland.

Webpage  
Parliament.scot/GettingInvolved/Petitions/PE01545

Introduction

1. This is a continued petition that the Committee last considered at its meeting on 15 March 2018. At that meeting, the Committee agreed to invite the petitioner to make a written submission in response to the Scottish Government’s written submission and to write to the Scottish Learning Disabilities Observatory.

2. Responses have now been received and the Committee is invited to consider what action it wishes to take.

Committee consideration

3. As Members will recall, the Scottish Government has commissioned work to address the data visibility of people with learning disabilities in Scotland which includes projects by the Scottish Learning Disabilities Observatory (SLDO).

4. The petitioner’s written submission of 16 October 2017 raised concerns that the focus of this work is on the prescription and effect of antipsychotic drugs which do not represent the group of people she is petitioning on behalf of. The Committee therefore agreed to write to the Scottish Government asking for a response to the concerns raised by the petitioner.

5. The Scottish Government’s written submission of 27 November 2017 stated—

“…the Observatory’s work streams commissioned to address the data visibility of people with learning disabilities in Scotland are not largely focused on the prescription and effect of antipsychotic drugs, as this is only one of many projects within a much larger programme of work, aimed at addressing the diverse needs of people with learning disabilities in Scotland”.

6. The Scottish Government’s submission also stated that the SLDO could provide further information about its work. The Committee therefore agreed to ask the SLDO for further information about its work programme and for its views more generally in relation to the specific action being called for in the petition at its meeting on 15 March 2018.

7. The SLDO’s written submission of 17 April 2018 provides an outline of its work programme, established in 2015, with funding from the Scottish Government to “understand more about the health inequalities faced by people with learning disabilities and to make those needs more overtly visible”.

8. The work programme sets out 33 projects the SLDO is currently progressing on areas such as the management of long term conditions, the general health status of people with learning disabilities and the health conditions in people with autism and down syndrome.

9. The SLDO’s written submission states that its views in relation to the specific action being called for in the petition can be found in the Director of the SLDO’s written submission of 31 July 2015. This submission stated that—

“Local Authorities need to be able to provide or commission a range of services, supports, and accommodations to suit every person with learning disabilities in their area…It is important that people have choices”.

10. The petitioner’s written submission of 30 May 2018 states that the SLDO’s response—

“…confirms that they are not addressing the specific points raised in PE1545 but rather reporting on a work programme agreed with Scottish Government (the funder) and aligned to Government policy outlined in Keys to Life¹”.

11. The petitioner is of the view that the SLDO’s programme of research highlights a number of problems that support the issues identified in the petition. This includes people with learning disabilities in Scotland receiving poorer primary health care, having poorer physical and mental health than the general population and experiencing issues with hate crimes.

12. The petitioner also highlights that “much mention is made in the research of autism and also Down’s syndrome and the comorbidities of these conditions, which in a large number of cases will include epilepsy”. However, she raises concerns that there are limited references in the work programme to epilepsy,

¹ The keys to life’ is Scotland’s learning disability strategy - [https://keystolife.info/](https://keystolife.info/)
Despite Keys to Life stating that 60 per cent of people with profound learning disabilities having this condition.

13. The petitioner accepts that while residential care for severely learning disabled people may not necessarily be a “perfect place”, it would better meet their needs by “providing a safe haven…supported by the right level of experienced staff as well as round the clock medical and nursing support”.

14. It is the petitioner’s view that residential care would resolve many of the issues the SLDO are currently researching and suggests that the financial consequences of inadequate care for the profoundly learning disabled should be a focus of their work.

Conclusion

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

- To ask the Scottish Learning Disabilities Observatory—
  - What work it is undertaking to understand the links between people with profound learning disabilities and epilepsy
  - Whether it would consider exploring the financial consequences of inadequate care for the profoundly learning disabled as part of its work programme.

- 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—

- PE1545/W: Scottish Learning Disabilities Observatory submission of 17 April 2018 (281KB pdf)
- PE1545/X: Petitioner submission of 30 May 2018 (83KB pdf)

All written submissions received on the petition can be viewed on the petition webpage.
PE01545: RESIDENTIAL CARE PROVISION FOR THE SEVERELY LEARNING DISABLED

<table>
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<tr>
<th>Petitioner</th>
<th>Ann Maxwell</th>
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<tbody>
<tr>
<td>Date Lodged</td>
<td>03 December 2014</td>
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<tr>
<td>Petition summary</td>
<td>Calling on the Scottish Parliament to urge the Scottish Government to recognise residential care as a way severely learning disabled children, young people and adults can lead happy and fulfilled lives and provide the resources to local authorities to establish residential care options for families in Scotland.</td>
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<tr>
<td>Previous action</td>
<td>I met with Cabinet Secretary for Health Alex Neil to discuss this issue in May 2013 but no Scottish Government action was taken forward as a result. I later sent him an open letter calling for more residential care options in Scotland but, again, the Scottish Government didn’t commit to taking a fresh look at this issue. In addition, I have brought up the issue of long-term residential care in formal written evidence submissions to Scottish Parliament consultations and have raised the issue in the local and national media. As the lack of suitable residential care options is a problem affecting the whole of the UK, I also met with UK Minister of State for Care and Support Norman Lamb MP to bring the issue to his attention.</td>
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<tr>
<td>Background information</td>
<td>The profoundly learning disabled have a range of complex physical and mental disabilities which leave them in need of 24 hour-a-day care and with no hope of living independently. The Scottish Government has placed a great emphasis on ensuring the disabled can live independently within the community, but for those with profound learning disabilities, even supported living in community settings is simply not appropriate. Right across the UK, it is recognised that access to appropriate residential care for profoundly learning disabled children is an issue, especially for those leaving school and unable to pursue further education or employment. The normal world in which we live is not a world in which the profoundly learning disabled can relate to; indeed, they must be protected from it while at the same time being given the opportunity to live a happy and fulfilled life. The fear of many is that the profoundly learning disabled will be forced to live unseen behind closed doors</td>
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with families who may struggle to cope with their needs or who may have to put up with an endless stream of visiting carers.

There are many loving mums and dads who give up everything for their children but for some, the condition their child may suffer from is so extreme that the only way they can hope to lead a happy and fulfilled life is in the specialised environment offered by residential care.

Right now, there are no suitable long-term residential care options for families in Scotland. My own son Muir suffers from Dravet Syndrome, which has left him with a range of complex physical and mental disabilities. He needs residential care, but the only suitable facility for him is in Surrey, in the very south of England.

The reason for the lack of long-term adult residential care in Scotland is because the Scottish Government currently measures the demand for long-term residential care in part on the current number of children and young people currently in residential care. This is a wholly flawed way of measuring demand and fails to capture the true need that currently exists in Scotland.

Moreover, the Scottish Government have admitted that the statistics they hold are not fit for purpose and are far too generalised to form a meaningful basis for any policy decisions regarding profoundly the profoundly learning disabled. It will be 2015/16 before this data on disabilities is reassessed, meaning families will have even longer to wait before policy catches up with their needs.

In addition, many parents believe they can cope or are wrongly stigmatised for putting their children into what may be perceived by others as ‘institutions’. Add to this the fact that the needs of profoundly learning disabled children can evolve greatly as they get older and many parents don’t realise they need residential care until it is too late.

The Scottish Government should not wish to limit the profoundly learning disabled’s interaction with the world to a succession of visiting carers and a few hours respite away from home each week.

More community care is not the answer for this group. Scotland needs long-term residential care options for this vulnerable group and the Scottish Government should provide the funding in which to make this a reality.
Thank you for your correspondence dated 20.3.18 which asked the Scottish Learning Disabilities Observatory:

1. To provide more information about its work programme aimed at addressing the diverse needs of people with learning disabilities in Scotland, and
2. To provide the views of the Observatory in relation to the specific action being called for in petition PE145.

In response, I attach an outline of the Observatory work programme. This was established in 2015 with funding from the Scottish Government to “understand more about the health inequalities faced by people with learning disabilities and to make those needs more overtly visible.” This programme was agreed with the funder, and is shaped by the Scottish Learning Disabilities Observatory Steering Committee (membership shown below). Its ongoing development will be aligned to future implementation priorities in The Keys to Life strategy.

In relation to the second point I request that the Committee refers to my previous correspondence on this, dated 31.7.15.

Scottish Learning Disabilities Observatory Steering Committee membership

Associate Professor Linda Allan, Strategic Clinical Lead/Professional Advisor-Learning Disabilities Policy, Health and Social Care Integration Directorate, Scottish Government

Professor Sir Kenneth Calman, The Chancellor, University of Glasgow (Chair of the Steering Committee)

Mr Chris Creegan, Chief Executive, Scottish Commission for Learning Disability

Dr Colin Fischbacher, Clinical Director for Information Services, Information Services Division, NHS National Services Scotland

Dr Andrew Fraser, Director of Public Health Science, NHS Health Scotland

Ms Rona Laskowski, Strategic Programme Manager-Learning Disabilities, NHS Lothian

Dr Phil Mackie, Lead Consultant in Public Health, Scottish Public Health Network

Dr Gerry McCartney, Scottish Public Health Observatory, NHS Health Scotland

Mr Duncan McIntyre, Chair of Learning Disabilities Practice Network, Social Work Scotland

Mr Neil Mellon, Primary Care Division, NHS Ayrshire and Arran

Professor Craig Melville, Professor of Intellectual Disabilities Psychiatry, University of Glasgow

Ms Jenny Miller, Chief Executive Officer, Profound and Multiple Impairments Service (for people with profound learning disabilities)

Professor Chris Philo, Professor of Geography, University of Glasgow

Ms Pandora Summerfield, Chief Executive Officer, Down's Syndrome Scotland
Professor Carol Tannahill, Chief Social Policy Advisor, Scottish Government

Ms Fiona Wallace, Member, People First Scotland

Professor Nicholas Watson, Professor of Disability Studies, University of Glasgow
## Work Programme

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<th>METHOD</th>
<th>RELEVANCE TO POLICY &amp; PRACTICE</th>
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| Management of long-term conditions in primary health care for adults with learning disabilities  
https://www.sldo.ac.uk/projects/primary-health-care/long-term-health-conditions-management-and-learning-disabilities/ | Cohort study from 2007-2014. Completion on health care indicators compared with the general population in NHS Greater Glasgow and Clyde | Good health care and health promotion is a pathway to health improvement. We found people with learning disabilities receive poorer primary health care than the general population, but crucially, following health checks and learning disabilities-primary care liaison within NHS Greater Glasgow and Clyde, we have demonstrated a narrowing of the health care inequality gap over time. This is good practice to share across Scotland, and suggests the need for policy consideration regarding national provision of health checks for adults with learning disabilities. |
| Prevalence and general health status of children, young people and adults with learning disabilities  
https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities | Analysis of general health data from people with learning disabilities compared with the general population using Scotland’s Census, 2011 | We found substantially lower general health ratings and a greater limiting effect on daily activities. This was across the lifespan for people with learning disabilities, including in early childhood. Specialist learning disabilities services have traditionally had a focus on skill development, mental health, challenging behaviours and epilepsy. This study demonstrates the need to raise professional awareness to pay greater consideration and time on general health needs of people with learning disabilities. |
| Prevalence of mental health conditions and relationship with general health in children, young people and adults with learning disabilities  
https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities/ | Analysis of mental health data from people with learning disabilities compared with the general population using Scotland’s Census, 2011 | Mental health conditions were more prevalent across the lifespan for people with learning disabilities, and were associated with poorer general health. A combination of poor mental and general health is associated with negative health outcomes, such as premature death. This study demonstrates a need to improve understanding of the relationship with mental and general health in the population with learning disabilities to help influence the development of appropriate interventions, and health and social care policy. |
<p>| 4 | Health conditions in people with autism | Systematic review of systematic reviews and meta-analyses | There is emerging evidence that people with autism have a different pattern of health conditions compared with the general population, and may be at higher risk of suicide. This review identified what we know on this topic and where knowledge gaps remain. Professionals need this information to develop guidelines and training for improved detection and interventions aimed at improving quality of life for people with autism. This is closely aligned to values at the core of the Scottish Strategy for Autism recommendations. |
| 5 | Prevalence of long-term health conditions in a whole country population of 25,063 children and young people known to have autism | Analysis of comorbid conditions data for children and young people aged 0-24 with autism compared with the general population using Scotland’s Census 2011 | We found that children and young people with autism were 11 times more likely to report poor general health, 50 times more likely to report intellectual disabilities and 16 times more likely to report mental health conditions. Females with autism had more of each comorbid condition than males, including intellectual disabilities, suggesting they may have more severe autism than the males. It is important to raise clinicians’ awareness of this extent of comorbidity, and to have accurate prevalence data to plan appropriate prevention and intervention measures, and to follow health inequality trends. |
| 6 | Prevalence of long-term health conditions in a whole country population of adults known to have autism | Analysis of comorbid conditions data for adults aged 25+ with autism compared with the general population using Scotland’s Census 2011 | The likelihood of having sensory impairments, intellectual disabilities, mental health conditions, physical disabilities, and other conditions was between 3 and 95 times higher in the population with autism than the general population. Within the population with autism, females were more likely than males to have intellectual and physical disabilities and other conditions, more so than in the whole population. Clinicians need heightened awareness of comorbidities in autism to provide suitable care and support, especially given the added complexity of assessment in this population and the hearing and visual impairments, which may impact on reciprocal communication and exacerbate underlying difficulties in autism. |</p>
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<td>Prevalence, age at identification, and general health status of children and young people known to have autism - a whole country population cross-sectional study</td>
<td>Analysis of general health of children aged 0-24 with autism compared with the general population using Scotland's Census 2011</td>
<td>Children and young people known to have autism (n=25,063) comprised 1.6% of the total population of 0-24-year olds in Scotland (n=1,548,819). There were 19,880 (79.3%) males and 5,183 (20.7%) females with autism. 21.9% of children and young people with autism, and 1.9% without autism reported poor health. Children and young people with autism were 11 times more likely to report poor general health, especially females. Their poorer general health is prevalent at all ages, meriting attention across the full lifecourse, from the point of autism diagnosis.</td>
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<td>8</td>
<td>Prevalence, age at identification, and general health status of adults known to have autism - a whole country population cross-sectional study</td>
<td>Analysis of general health status data for adults aged 25+ with autism compared with the general population using Scotland's Census 2011</td>
<td>Adults known to have autism (n=6,649) comprised 0.2% of the total population of people aged 25+ in Scotland (n=3,746,584). There were 4,610 (69.3%) males and 2,039 (30.7%) females known to have autism. 46.8% of adults with autism, and 23.7% without autism reported poor health. Adults with autism were 5 times more likely to report poor general health, especially females and older people aged 65+. Existing evidence is limited, yet very much needed to accurately plan for appropriate prevention and intervention measures and service provision.</td>
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<td>Mental ill-health and its determinants in mothers caring for a son or daughter with learning disabilities across and beyond the caregiving trajectory: secondary data analysis and data linkage of administrative and health records in Scotland</td>
<td>Cross-sectional case controlled cohort study of an estimated 9,250 mothers of a son or daughter with learning disabilities</td>
<td>Little is known about the prevalence of mental ill-health of maternal carers of a son/daughter with learning disabilities across the caregiving trajectory, including post caregiving, and the factors that compound or mitigate against it. This study will provide unique insights into the multiple social determinants of health that impact on health outcomes of maternal carers. This research will answer important and overdue questions on mental ill-health which will subsequently identify gaps in current services and provide evidence to inform professional support for mothers at pivotal points in the caregiving trajectory including post caregiving.</td>
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<td>10</td>
<td>The prevalence and types of</td>
<td>Cross-sectional study of 1,023</td>
<td>Failure to identify health conditions and diagnostic</td>
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<td>11</td>
<td>Prevalence, types, and associations of medically unexplained symptoms in adults with learning disabilities</td>
<td>Cross-sectional study of 1,023 adults with learning disabilities</td>
<td>This study found that people with learning disabilities have substantial additional unexplained symptoms and signs, some of which are painful or disabling. These findings can be used to develop the content of health checks, which should not just focus on management of long term conditions and health promotion (which has tended to be the focus in England).</td>
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<td>12</td>
<td>Oral health of adults with learning disabilities and its determinants</td>
<td>Longitudinal cohort study of adults with learning disabilities</td>
<td>We found very poor oral health in this population, and high levels of toothlessness. Oral problems are painful, impede eating and nutrition, and impact on quality of life. We are investigating the causes of this, which appear to be more complex than just poor daily care and access to services for check-ups and treatment.</td>
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<td>13</td>
<td>Understanding the levels and inter-relationships of dental and medical complexity in adults with learning disabilities</td>
<td>Secondary analysis and record linkage using GP records, Management Information &amp; Dental Accounting system, and Prescribing Information System, in 4,000 adults with learning disabilities</td>
<td>We will study the role of anticholinergic burden and sugared liquid medicines in oral health problems. There is thought to be over-prescribing of drugs with these effects in people with learning disabilities (e.g. antipsychotic drugs), and lack of awareness of dental consequences in prescribers. If relationships are found, this will give further evidence to prescribers to avoid unnecessary repeat prescriptions, and to</td>
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<td>Project Title</td>
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<td>A decade of psychotropic prescribing for adults with learning disabilities</td>
<td>Analysis of 10 year trends in psycho-tropic prescribing in a cohort of adults with learning disabilities, with record linkage to Prescribing Information System, and GP clinical data</td>
<td>People with learning disabilities are prescribed antipsychotics at rates higher than reported rates of mental ill-health. These drugs can have significant health side-effects, including sudden death; NICE guidelines recommend regularly review and reduction. We found a slight decline in newly prescribed antipsychotic medications and a marked increase in antidepressant prescribing. Supporting appropriate prescribing is aligned with the strategic direction of <em>The Keys To Life</em>. This study will feedback trends to prescribers, helping them to meet good practice targets.</td>
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<td>Prescribing trends in children and young people with learning disabilities, and with autism</td>
<td>Record linkage of Scotland’s Pupil Census with Prescribing Information System</td>
<td>This study will find out if antipsychotic prescribing is increasing over time for these groups, and the variability of this across Scotland. This will enable good practice recommendations and targeted actions to be made for prescribers.</td>
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<td>Children and young people with learning disabilities, and with autism in Scottish schools</td>
<td>Secondary analysis of Scotland’s Pupil Census data</td>
<td>This study provides information about schooling trends for children and young people with learning disabilities and autism in Scotland. This information is important to support Scottish learning disabilities policy, given the drive to supporting learning in mainstream schools for children and young people with additional support needs.</td>
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<td>Hospital admissions for physical conditions for people with learning disabilities</td>
<td>Systematic review</td>
<td>We found that people with learning disabilities have more admissions in medical and dental, but not surgical specialities than the general population, but there is a shortage of evidence as to whether this relates to their higher level of morbidity compared with the general population, and whether admissions are higher for ambulatory care-sensitive conditions (conditions that do not lead to admission if managed well in primary care). It highlights where to prioritise training of secondary care staff.</td>
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Health care quality for children and young people with learning disabilities, and with autism
https://www.sldo.ac.uk/projects/secondary-healthcare/hospital-admissions/

Record linkage of Scotland's Pupil Census with Scottish Morbidity Record 01
This study will determine if rates of admissions for ambulatory-care sensitive conditions – specifically diabetes, asthma, and epilepsy – are higher than for children and young people with these conditions who do not have additional support needs. This is a marker of health care quality, so will raise awareness with practitioners and carers of any problems identified, and can be used as an indicator of trends in health care quality over time for policy-makers.

Life expectancy and causes of death of people with learning disabilities
https://www.sldo.ac.uk/projects/mortality/life-expectancy/
Systematic review
This study found that people with learning disabilities die on average 20-25 years earlier than the general population, and identified the high risk groups. Causes of death differ to the general population and about 40% of deaths are potentially amenable to health care. Standardized mortality rates are higher for women than for men for reasons that we don’t yet know (women with learning disabilities have a greater health inequality with the general population). This requires further study, and work to support policy-makers.

Causes of death in children and young people with learning disabilities and with autism
https://www.sldo.ac.uk/projects/mortality/life-expectancy/
Record linkage of Scotland’s Pupil Census with National Records of Scotland death records
It is important to understand causes of death, as a proportion will be preventable and/or amenable to health care. The causes of death in children and young people are likely to differ from those in adults, and from the general population. This study will find out about this, and could therefore identify what further interventions and/or policies are needed to reduce inequalities.

Life expectancy and causes of death of people with Down syndrome
https://www.sldo.ac.uk/projects/mortality/life-expectancy/
Systematic review
This study will provide information on life expectancy and causes of death of people with Down syndrome compared to the general population, and trends over time. Changes in lifespan are important to quantify. This will help in planning services and resources to support this ageing population.
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<td>22</td>
<td>Trends in infant mortality and childhood survival in children with Down syndrome</td>
<td>Regional genetics unit data linked to NRS death records, and Scottish Morbidity Record 01</td>
<td>Historically, deaths of children with Down syndrome are most common in the first year of life, due to congenital heart disease and respiratory problems. We will determine trends in mortality and survival, given access to and advances in surgery. We will also investigate patterns in hospital admissions for children and young people with Down syndrome. Parents need information on outcomes to help with difficult decisions at the time of foetal diagnosis, and to help them plan to support their child. Access to surgery should be equal for all children who need it.</td>
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<td>23</td>
<td>The physical and mental health of people with comorbid autism and learning disabilities</td>
<td>Analysis of health data from people with learning disabilities and autism compared with the general population using Scotland’s Census, 2011</td>
<td>About 20% of people with learning disabilities have autism, and about 20% of people with autism have learning disabilities. This study examines whether their needs differ from people with just one of these conditions, and the extent of difference from the general population. This may have implications for service planning and for policy, dependent upon the study findings.</td>
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<td>Prevalence of long-term health conditions in a whole country population of people with comorbid autism and learning disabilities</td>
<td>Analysis of comorbid conditions data for people with comorbid autism and learning disabilities compared with the general population using Scotland’s Census 2011</td>
<td>About 20% of people with learning disabilities have autism, and about 20% of people with autism have learning disabilities. This study examines whether the prevalence rates of long-term health conditions differ for this group when compared with the general population. This may have implications for service planning and for policy, dependent upon the study findings.</td>
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<td>Trends and variation in per capita spending on services for adults with learning disabilities by individual Health Boards and Local Authorities for 2012/13, 2013/14 and 2014/15</td>
<td>Secondary analysis of data from Information Services Division and NHS National Services Scotland</td>
<td>Our study shows that austerity has impacted on Scotland’s expenditure on adult intellectual disabilities services, by not keeping abreast of rises in living costs, and with much variation across areas. This suggests that health and social care are not equitable across the country for adults with intellectual disabilities. This information will help guide service planning and design across Scotland. We now have baseline</td>
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<td>#</td>
<td>Mental health admissions for adults with learning disabilities in 2014 &amp; 2016</td>
<td>Analysis of Scotland’s Mental Health and Learning Disabilities Census 2014 and 2016 (within area and out of area beds)</td>
<td>Patients with learning disabilities are considerably more likely to be admitted under the mental health act, and to experience delayed discharge compared with other people. This suggests they are more severely ill at the point of admission, and there is a need for concerted action and greater flexibility in planning discharge supports and service redesign. The Census analysis allows progress over time to be assessed.</td>
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<td>26</td>
<td>What is the effect of transition from school to adulthood on health and wellbeing in young people with learning disabilities?</td>
<td>Systematic review</td>
<td>We found issues related to obesity, sexual health and social conflict over transition. However, the evidence base was small and had considerable gaps, despite parental concerns on transition having been expressed for many years. The study findings have identified areas for further work to build upon what is already known, and to address gaps.</td>
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<td>The impact of transition from school to adulthood on health and wellbeing in young people with learning disabilities</td>
<td>Secondary analysis of data from Scotland’s Census 2011, and a qualitative study</td>
<td>Both physical and mental health are poorer in young people with learning disabilities aged 16-24 than those without learning disabilities. Among the population with learning disabilities, those aged 19-24 (who have transitioned from school) are more likely to have mental health conditions than those aged 13-18 (who are still in school). Themes identified were emerging mental health problems including anxiety and challenging behaviours, with lack of support during transition and limited appropriate options for post-school activities contributing. Support for families during the transitional period is essential.</td>
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<td>28</td>
<td>Impact of hate crimes and targeted</td>
<td>Narrative review and qualitative</td>
<td>Issues with police coding of hate crimes have been identified</td>
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<td></td>
<td>violence on health and wellbeing of people with learning disabilities</td>
<td>study with people with learning disabilities, their families, carers, representatives from disabled people’s organisations, and Police Scotland</td>
<td>and reported. Themes will be identified and drawn together to identify the extent and impact of hate crimes. All data has been transcribed and is now currently being coded and analysed by thematic analysis using NVivo11 qualitative data analysis software. Emergent themes thus far (from participants with LD) are centred around fear, anxiety, depression and wellbeing in relation to violence and hate crime.</td>
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<tr>
<td>30</td>
<td>Reproductive health of women with learning disabilities</td>
<td>Qualitative study (focus groups and interviews with women with learning disabilities) with Engender Scotland, exploring the reproductive health journeys of women with learning disabilities</td>
<td>Commencing 2018, this project is investigating women with learning disabilities’ experiences of accessing reproductive health care (sexual health care, pre/anti/post-natal care, menstruation and menopause).</td>
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<tr>
<td>31</td>
<td>The relationship between physical ill-health and mental ill-health in adults with learning disabilities</td>
<td>Cross-sectional study of 1,023 adults with learning disabilities</td>
<td>This project found that the extent of physical multi-morbidity in the population with learning disabilities is overwhelming, such that associations are not found with mental ill-health. Mental health interventions and preventative measures are essential for the entire population with learning disabilities and should not be focussed on subgroups based on overall health burden.</td>
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<tr>
<td>32</td>
<td>Older parent carers health and its reciprocal effect on their ageing offspring with learning disabilities: a record linkage study</td>
<td>Observational study of all older parent carers (n = 3000+) and their offspring with learning disabilities living in Scotland</td>
<td>Parents caring over a prolonged period of time for their offspring with learning disabilities may be at particular risk of poor health, and both mental and physical health may deteriorate the longer the carer has been caring. Little attention has been paid to the health of older parent carers and the health of their ageing offspring with learning disabilities, including how poor health in one affects the other, and the factors that increase or decrease the risk of poor health. We will link health databases to investigate the extent of physical and mental ill-health of ageing parent carers and their ageing offspring, compared with the general population and what determines this ill-health.</td>
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<tr>
<td>33</td>
<td>SPIRE Learning disabilities primary care data project</td>
<td>Development of a bespoke extraction of learning disabilities and autism data from GP systems using the national SPIRE system to understand comorbidity profile and psychotropic drugs prescribed for learning disability population and compare with that of general population.</td>
<td>This project will support the delivery of a central aim of Scottish Government learning disabilities policy which is to increase understanding the health and health needs of this population in order to improve policy and practice. This project will also act as a pathfinder for the development of future bespoke data extractions from GP held data for the purposes of service audit and research.</td>
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SLDO’s response to the committee confirms that they are not addressing the specific points raised in PE1545 but rather reporting on a work programme agreed with Scottish Government (the funder) and aligned to Government policy outlined in Keys to Life.

PE1545 has been addressed separately with a copy of SLDO’s historic response dated 31.7.15. This response states that:

1. There are approximately 3,177 adults with profound learning disabilities in Scotland. (Keys to Life estimates 4,000)

2. In terms of care provision, there is a move away from institutionalised care for people with learning disabilities, in favour of person-centred care in the community. (PE1545 acknowledges this shift and argues that there is a still a place for residential care amongst these options.)

3. The response acknowledges that person-centred care is not the answer for all families and local authorities must provide a range of services, support and accommodation in order to provide choice. (PE1545 is asking for exactly this.)

SLDO’s comprehensive programme of research which is still in progress, highlights a number of problems that we believe support the issues raised in PE1545 for some families.

1. Those with learning disabilities in Scotland receive poorer primary health care - we believe this is because doctors are not as accessible in the community as they are in a residential care setting where there is medical support on site. This is particularly relevant for profound epilepsies where the need for specialist epilepsy care is paramount. Much mention is made in the research of autism and also Down’s syndrome and the comorbidities of these conditions, which in a large number of cases will include epilepsy - but there is barely any reference to epilepsy, although Keys to Life refers to 60% of those with profound learning disabilities having epilepsy.

2. Poor primary health care leads to lower general health ratings for people with learning disabilities - the day to day health care needs of this group are far greater than in the general population because of compromised immunity due to their health condition and possibly prescription medication. Minor ailments such as skin and eye conditions can be over looked or ignored because of the absence of immediate access to a doctor. These minor ailments badly need attention as they can be a sign of compromised general health, including mental health. Health issues in the profoundly learning disabled should not be considered in isolation but as part of a ‘whole health’ picture. This requires a
much higher level of medical care than that of the general population that for the
most part, cannot be accessed by people with profound learning disabilities who
are living in the community.

3. Mental health conditions are more prevalent amongst those with learning
disabilities than in the general population - care in the community doesn’t always
meet the needs of those with profound learning disabilities, failing to consistently
provide the right skill set to keep them safe and well and a lack of engagement in
fulfilling activities that can lead to boredom and frustration. Mental health is
therefore compromised and can lead to difficult behaviours. Families who are
dependent on self-directed support to provide care themselves for their learning
disabled child or young person often find that financial support to be inadequate
and sometimes the care resource is unavailable. Many profoundly learning
disabled people living at home, cared for by family members are therefore
leading unfulfilled lives.

4. Clinicians need a heightened awareness of comorbidities in autism - this begs the
question what about epilepsy? Understanding and awareness of comorbidities in
epilepsy and autism and indeed all cases of profound learning disabilities is
paramount for good physical and mental health; but only a specialist skill set will
enable an understanding of the ‘whole picture’ in these patients, not generally
available from within the community.

5. The impact on mental-health of maternal carers is an extremely important area
of research in terms of PE1545. Mental health can be devastating and totally
debilitating for maternal carers, particularly if their learning disabled child or
young person is cared for at home or even in a local community setting. Many
simply cannot cope and this in turn impacts on the health of the learning disabled
off-spring.

6. Poor oral health. The importance of routine dental health care in this group is
underestimated, many of whom are affected by their medication and/or poor oral
or dental hygiene. Amongst the profoundly learning disabled dental treatment is
more often required under sedation and therefore regular dental check-ups and
easy access to specialist dental care is as vital as easy access to medical care. A
residential setting where medical care is on site is better placed to provide this
vital support in dental care. Those with learning disabilities are not necessarily
able to communicate tooth pain. An undiagnosed abscess can lead to sickness,
difficult behaviours and even death.

7. Antipsychotics are reportedly prescribed to those with learning disabilities at rates
higher than rates of mental-health patients - this is most alarming and begs the
question why? If we are treating behaviours that are the consequence of
frustration or depression or general unhappiness then we are treating the
symptoms and we are failing to address the underlying cause. Behaviours in
profound learning disabilities are often a form of protest in the absence of the
ability to express feelings and emotions and communicate in any other way. It is
important to ensure that we are meeting the needs of the profoundly learning
disabled person and that they are living a fulfilled life, often more easily facilitated
by more structured residential care.
8. Hospital admissions are higher and mortality is 20-25 years earlier and 40% of deaths are due to amenable health care - amongst the profoundly learning disabled better access to primary health care and also specialist health care as described above is vital. This is not facilitated in the community to the same extent as residential care with medical provision on site.

9. About 20% of people with learning disabilities have autism. About 20% of people with autism have learning disabilities. Do those with comorbidities in autism and learning disabilities have different health needs? A reference to epilepsy is essential in this too and YES THEY DO HAVE DIFFERENT HEALTH AND SOCIAL CARE NEEDS, particularly if they have profound learning disabilities. But to this end there simply isn't enough choice.

10. Transition issues include poor physical and mental health in transition, including anxiety and challenging behaviour, limited appropriate options for post school activities and lack of support for families (including the absence of any residential care options as discussed in PE1514).

11. Issues with hate crimes - such issues raise the question of whether the profoundly learning disabled should live in the community or whether they should be cared for in a more protected environment, more compatible with their needs and one that shields them from a population that for the most part, cannot understand their health issues and may not be sensitive to their needs.

12. Physical multi morbidity can result in mental health issues for those with learning disabilities - in particular where the learning disabilities are profound, which in turn supports the argument in favour of protecting them from the general population who cannot be expected to understand their health issues and their resultant needs. A more appropriate environment can perhaps better support their mental health.

13. Ageing parent carers bring risks to the health of off-spring - what happens to a profoundly learning disabled adult cared for by an ageing parent who can no longer cope or who dies? At the best of times these grown up children can't cope with change, never mind in the event of a aged parent who has been their life-long carer dying. Better to establish that learning disabled person at an early stage in life in an independent setting where they will have the time and youth to adapt.

Whilst PE1545 is asking the committee to consider the issue of the absence of any residential accommodation in Scotland for the profoundly learning disabled, we accept that residential care would not be the preference of all parents but only of some. We also accept that residential care may not always be perfect and indeed, at times, may face some of the same challenges presented to local authorities in terms of providing care in the community. But whilst residential care may not necessarily be a ‘perfect place’ for those with profound learning disabilities, it should better meet their needs by providing a safe haven and where routine is their refuge, supported
by the right level of experienced staff, as well as round the clock medical and nursing support.

For parents who prefer this option, they believe they know what they are dealing with and do not trust that the alternative care in the community will be safer or that the extensive services required for their son or daughter will be available. These parents believe that not everyone can live well in the community, they also are concerned about their off-spring's long term future taking in to account their own inevitable mortality. They are seeking a sanctuary, a calm and perhaps semi-enclosed environment that enables leisurely walks and a connection with nature without exposure to risk or the population at large. They want recreational activities and structure and routine with dedicated staff and residential living in an appropriate environment that can also meet their specific health and social care needs. Ideally this place would be in reasonable proximity to their own homes to enable regular visits by family members. And they want a relationship with the care providers that will involve the family in every plan. Such a place for some families will resolve many of the issues raised by SLDO’s on-going programme of research and which so far remain unresolved for too many Scottish families caring for a profoundly learning disabled.

This level of care is undoubtedly more costly which doubtless is a factor that has influenced the shift in favour of care in the community away from residential care but the financial consequences of inadequate care for the profoundly learning disabled are increasingly evident and should perhaps be an additional focus of research by SLDO on behalf of the funder, Scottish Government.
Public Petitions Committee  
10th Meeting, 2018 (Session 5)  
Thursday 7 June 2018  

PE1591: Major redesign of healthcare services in Skye, Lochalsh and South West Ross  

Note by the Clerk  

Petitioner: Catriona MacDonald on behalf of SOS-NHS  

Petition summary: The petition calls on the Scottish Parliament to urge the Scottish Government to reverse its approval of the major service change to healthcare services in Skye, Lochalsh and South West Ross.  

Webpage: parliament.scot/GettingInvolved/Petitions/skyelochalshsouthwestross  

Introduction  

1. This is a continued petition, which was last considered by the Committee at its meeting on 29 March 2018. At that meeting, the Committee agreed to defer further consideration of the petition until Sir Lewis Ritchie's review of Out of Hours Urgent Care & Minor Injury clinical services in Skye, Lochalsh & South West Ross (SLSWR) had reported.  

2. The final report of the review was published on 25 May, and is included in the annex to this paper. Members are invited to note the findings of the review and to consider what further action they may wish to take on the petition.  

The review and its findings  

3. The remit of the review was “to assess the resilience of urgent primary out-of-hours provision.” The terms of reference for the review clarified that the remit would not “cover the redesign of wider health and social care services currently underway, with Ministerial approval, which will progress to an Outline Business Case for a Hub and Spoke model incorporating a new-build facility in Broadford as part of a wider redesign.”  

4. Members may, however, wish to note that the sixth key message of the report states—  

“Our terms of reference specifically excluded us from reviewing the major service SLSWR redesign programme presently underway. However, the availability and location of community beds and other hospital services clearly impact on the resilience of OOH [out-of-hours] services. We have endeavoured to take that into account, in our findings and recommendations.”  

5. In respect of future community bed provision, the report notes that the current provision of four beds reflects a decline from the twelve bed provision in 2009 and needs to be seen in light of the decline in nursing and care home provision
in the area, particularly North Skye. The report makes five recommendations, including that "In-patient bed availability at Portree Hospital must continue until sufficient alternative resilient provision is provided in North Skye" and that a "rapid review of care at-home and community bed provision for SLSWR should be undertaken."

6. The recommendations also comment on difficulties experience in recruiting nurses and support staff to work in Portree Hospital which "may be exacerbated by ongoing service redesign uncertainties and the offer of short term contracts in the recent past for prospective staff in a facility that is perceived to be closing."

7. Members will recall that issues regarding transport have also previously been raised during the Committee’s consideration of the petition. A Transport Group has been convened as part of the major service redesign and the report recommends the “Terms of Reference and membership of the SLSWR Service Redesign transport Group should be reviewed in the light of wider inter-agency considerations and the recommendations from this External View.”

8. Members may wish to note that a clear thread running throughout the report is one that has been highlighted in previous consideration of the petition: the need for NHS Highland and local communities to work together. In that connection, members may wish to note key messages seven and eight—

“Whatever the antecedents, it is evident that in parts of SLSWR, the relationships between NHS Highland and the public are now crucially compromised. This particularly applies to the North of Skye and in some local communities, such as Glenelg & Arnisdale and Raasay. NHS Highland should carefully reflect on why this has happened and respond accordingly. This has materialized, despite ongoing efforts and engagement by the NHS Highland management team and the very evident and clear commitment of local communities to actively collaborate to realise and improve the resilience of local services. This pressing issue of public confidence needs to be addressed four-square and resolved together, with dispatch.”

9. These key messages are expanded in recommendation 15 of the report, which is set out in full below—

“Making it Happen: Major service redesign and transformation is complex and challenging as will be implementation of the recommendations in this report. Transformation and translation will neither be easy nor quick. Some recommendations will bear fruit in the short term but others will take longer to come to fruition - flexibility and understanding will be required.

These recommendations can only be delivered by the combined endeavours of NHS Highland working intimately, fully and continuously with the public and with other care agencies in a genuine partnership to shape and deliver services – by truly pulling together. High quality leadership and ongoing commitment will be required, at all times.
We recommend that:

a) All future service development and delivery must be done in partnership with the people of SLWRS with a focus on co-production.

b) The National Standards for Community Engagement must be observed by all.

c) All relevant partners should participate, including all emergency services, the third sector and those that control wider infrastructure.

d) An implementation plan with realistic timescales, adequately resourced, making best use of public funds and robustly governed - with clear accountability, reporting to the Highland Health and Social Care Committee.

e) Independent external third party facilitation should be deployed as required and agreed.

f) In view of the aspiration in these recommendations and the Major Service Redesign Programme underway, Scottish Government should seek regular and robust assurance that satisfactory progress is being made."

Submission from the petitioners

10. The petitioners’ submission of 31 May highlights some of the recommendations noted above regarding out of hours services and community bed provision. The petitioners contend that “Sir Lewis’ statement about the need for out of hours services based on his assessment of the population and geography is equally pertinent to the whole range of health services being redesigned by NHS Highland.”

11. In respect of the call made in the report for communities and NHS Highland to work together, the petitioners state—

“We are embracing the opportunity to work in ‘co-production’ with NHS Highland, the emergency services and others to develop the health and social services which these areas require, and are in the process of choosing an external facilitator to make sure this happens quickly and smoothly.”

12. The petitioners conclude by asking the Committee to keep the petition open until at least 6 months’ time and this is the period within which Sir Lewis intends to assess progress made on the findings of his report.

Action

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

- Close the petition under Rule 15.7 of Standing Orders on the basis that the Cabinet Secretary has indicated that she does not intend to reconsider her decision to approve the major service redesign, which is the action called for in the petition, and that the petitioners have
indicated that they are embracing the opportunity to work with NHS Highland and other partners and are in the process of choosing an external facilitator.

- Inviting the Scottish Government to provide its views on the findings of the review, particularly with regard to recommendation that it “should seek regular and robust assurance that satisfactory progress is being made.”

- Any other action the Committee wishes to take.

Clerk to the Committee
# PE01591: MAJOR REDESIGN OF HEALTHCARE SERVICES IN SKYE, LOCHALSH AND SOUTH WEST ROSS

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<tr>
<th>Petitioner</th>
<th>Catriona MacDonald on behalf of SOS-NHS</th>
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<tr>
<td>Date Lodged</td>
<td>30 October 2015</td>
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<tr>
<td>Petition summary</td>
<td>Calling on the Scottish Parliament to urge the Scottish Government to reverse its approval of the major service change to healthcare services in Skye, Lochalsh and South West Ross.</td>
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<td>Previous action</td>
<td>We participated at every possible opportunity in NHS Highland’s consultation on the proposed service changes and campaigned against these changes. We highlighted issues with the consultation and design process to Dave Thompson MSP in December 2014 and sought to explore concerns with senior NHS Highland representatives at a meeting in January 2015 that was chaired by Mr Thompson. We held public meetings in March and June 2015, each attended by several hundred people, to raise awareness and demonstrate support for our campaign to have an Independent Scrutiny Panel (ISP) examine NHS Highland’s major service change proposals. Over 4500 signatures have been collected on a petition calling on the Cabinet Secretary for Health to establish an Independent Scrutiny Panel (ISP) to examine the NHS Highland proposals. We sought to engage the support of all the May 2015 General Election local parliamentary candidates for an ISP, and spoke with the First Minister during her pre-election visit to Portree to raise our concerns. We met with Mary Scanlon MSP who raised a parliamentary question on our behalf on 10 June 2015. We are seeking reversal of the Scottish Government’s approval of NHS Highland’s major service change proposals for hospital and healthcare services in Skye, Lochalsh and South West Ross, because we are extremely concerned about the potential impact of the proposed service changes on our remote and rural population.</td>
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<td>Background information</td>
<td>NHS Highland has decided to close two hospitals and build a single new one for the area without assessing the medical, health and social care needs of the Skye, Lochalsh and South West Ross population. We have evidence that the design process and the public consultation that sought to justify its outcome are both deeply flawed. We believe that the proposed major service change will lead to deterioration in the safety and efficiency of, and equitable access to, essential health services and will have a significant impact on the sustainability of living in the North of Skye. We therefore urge the Scottish Government to reverse its</td>
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authorisation of the proposed major service change and to establish an Independent Scrutiny Panel, which would be charged with determining the medical, health and social care needs of the communities of Skye, Lochalsh & South West Ross. The Panel would then require NHS Highland to respond and amend the design based on the findings of the Panel.
INDEPENDENT EXTERNAL VIEW OF
SKYE, LOCHALSH AND SOUTH WEST ROSS
OUT OF HOURS SERVICES

May 2018
Chair’s Foreword

This independent external view report has been prepared in response to a request from Dr David Alston, Chair of NHS Highland, to review the sustainability of Out-of-Hours (OOH) services in Skye, Lochalsh and South West Ross (SLSWR) - particularly North Skye. Our terms of Reference are listed in Annex 1. An independent External Panel was assembled, including health professional and public representation drawn from across Scotland (Annex 2). The process of the review is described in Annex 3.

As part of the external view, we were privileged to meet and talk with many health and social care colleagues, colleagues working for other agencies, including charities, individual members of the public and public representatives (Annex 3). We also received numerous written submissions from members of the public, health professionals, NHS Highland and other agencies. We are immensely grateful for the time, commitment and courtesy of all those we met with and for the submissions received.

We also witnessed and were encouraged by the dedication and exemplary work of clinical, social care and support workers, delivering urgent and emergency care services on a 24/7 basis.

We found that current OOH services were not sufficiently sustainable, nor equitable. We offer 15 Key Messages and have made a number of recommendations under 15 issues.

It is now time to move forward at pace, in joint endeavour. To secure success, leadership and partnership working of a very high order will be required, with the full engagement of the public of SLSWR, its public representatives and other agencies.

Getting urgent and emergency care right is of paramount importance for the people of SLSWR and for those who provide care for them. This will need to be done well, done with resolve, and done together.

In closing, I wish to record my personal appreciation to my fellow External Panel members and support colleagues for their sterling professionalism and commitment throughout.

Lewis D Ritchie
Chair, Independent External View Panel
A view of Portree Bay, including *RNLB Stanley Watson Barker*, taken from Portree Hospital
Expert Panel’s View

Key Messages

- We were tasked to assess the sustainability of out-of-hours (OOH) services in Skye, Lochalsh and South West Ross (SLSWR), with a specific emphasis on North Skye.

- During this external view, we witnessed the dedicated commitment and exemplary work of clinical, social care and support workers, delivering urgent and emergency care services on a 24/7 basis.

- Future delivery of high quality sustainable urgent and emergency care services with and for the people of SLSWR requires a shared vision and co-production. Clinical leadership, multi-agency collaboration and meaningful engagement with the public, will be essential to realise this.

- Recruitment and retention difficulties for clinical and support staff are seriously impacting on the resilience of OOH services. This issue is not confined to SLSWR, nor to remote and rural Scotland.

- Individual members of the public and public representatives of North Skye have vociferously expressed their stark opposition to the removal of overnight OOH services in the Minor Injury Unit at Portree Hospital, the recent and substantial diminution of available in-patient beds therein and the threat of closure.

- Our Terms of Reference specifically excluded us from reviewing the major service SLSWR redesign programme presently underway. However, the availability and location of community beds and other hospital services clearly impact on the resilience of OOH services. We have endeavoured to take that into account, in our findings and recommendations. We also took into account the Independent Review of Primary Care Out of Hours Services: Pulling Together: Transforming Urgent Care for the People of Scotland.¹

- Whatever the antecedents, it is evident that in parts of SLSWR, the relationships between NHS Highland and the public are now crucially compromised. This particularly applies to the North of Skye and in some local communities, such as Glenelg & Arnisdale and Raasay. NHS Highland should carefully reflect on why this has happened and respond accordingly.

¹ http://www.gov.scot/Publications/2015/11/9014
• This has materialized, despite ongoing efforts and engagement by the NHS Highland management team and the very evident and clear commitment of local communities to actively collaborate to realise and improve resilient local services. This pressing issue of public confidence needs to be addressed four-square and resolved together, with dispatch.

• We regard current and future planned service provision by NHS Highland for OOH services in SLSWR as neither sufficiently sustainable nor equitable, and have framed our recommendations, in that light.

• Some of the recommendations here will take some time to fully implement and flexibility and understanding will be required.

• These recommendations can only be delivered by the combined endeavour of NHS Highland working intimately, fully and continuously with the public and with other care agencies in a genuine partnership to shape and deliver services – pulling together.

• We hope that the recommendations will not only support OOH services but will also promote 24/7 sustainability of urgent and emergency care. Getting this right will be of paramount importance not only for those who receive care but for those who provide care.

• We recommend that a shared and agreed implementation plan should be developed with robust governance and accountability, to assure delivery of these recommendations.

• SLSWR has the potential to become a centre of excellence for developing and evaluating new models of 24/7 remote and rural health care, including digital innovation.

• Multidisciplinary and multiagency learning and training opportunities should be also maximized and will further reinforce sustainability of services. If realised well, this will bring enduring benefits not only for the people in SLSWR, but also for the whole of Scotland and beyond.
Key Issues and Recommendations

Models of Care

1. **Portree Hospital Out of Hours Service and Minor Injury Unit**: We heard or received numerous submissions from individual members of the public, Save Our Services NHS (SOS-NHS), local councillors, community council members from the North of Skye, the three local MSPs and the local MP. They consistently expressed serious concerns about Out of Hours (OOH) Service and Minor Injury Unit at Portree Hospital not being open overnight and frequent closure at short notice, the significant recent diminution of in-patient bed numbers and the threat of closure of all in-patient beds there.

We visited both Broadford and Portree Hospitals and observed excellent and compassionate person-centred care provided by clinical and support staff.

We were made aware of misunderstandings and differences in perception between the public and NHS Highland about what services are presently provided at Broadford and Portree Community Hospitals. They both work together to deliver high quality urgent and emergency care for the people of SLSWR. According to clinical need, timely transfer of acutely and critically ill patients may be required to secure secondary or tertiary care, consultant-led services. This is primarily, but not confined, to Emergency Departments (EDs) and acute services at Raigmore Hospital, Inverness or the Belford Hospital, Fort William and mental health care services at New Craigs Psychiatric Hospital, Inverness. Broadford Hospital operates 24/7 but Portree Hospital presently is designated as a part-time unit, closing between the hours of 2300 and 0800. In reality, it is normal practice for the small numbers who present directly to Portree Hospital seeking urgent help between 2300-0800, to be allowed access and for assistance to be offered. This is therefore regarded as a 24/7 service by some, if not all the public.

After careful consideration, we take the view that the proposal to provide all OOH urgent and emergency care services at one community hospital site in Broadford, are neither sufficiently accessible nor equitable, for all the population served. The proposed closure of OOH services at Portree Hospital overnight is disadvantageous to the people of north Skye, with its larger population, socioeconomic and geographic hinterland, growing tourist numbers, travel costs burden and volume of service requirement.

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\(^2\) [http://www.sosnhsskye.co.uk/who-we-are](http://www.sosnhsskye.co.uk/who-we-are)
We recommend that:

a) Out-of-hours urgent care access at Portree Hospital should be provided 24/7 -- there should be no closure of Portree Hospital in the out-of-hours period.

b) Enhanced, and sustainable models of urgent care should continue to be developed and delivered in the Minor Injury Unit at Portree Hospital, involving combined teams and other agencies (see also Recommendations 3-6 below).

c) The services at both Broadford and Portree Hospitals should continue to work synergistically together to add resilience and to provide optimal services, provided by multidisciplinary teams for the whole of SLSWR.

d) It is essential that in the event of acute illness, services are used properly – dial 999 in the event of an emergency 24/7 (time-critical, immediate response required). If urgent OOH care is required (care that requires a response that cannot wait until the next routine service is available), contact NHS 24 by phone – dial 111 or via their website: [https://www.nhs24.scot/](https://www.nhs24.scot/). Only in this way will the safest and most effective care be delivered and received. This must be clearly understood by the public of SLSWR (see also Recommendation 14).

e) The excellent care provided by clinical and support staff at both sites must continue to be nurtured and supported.

f) Possible confusion about the nature and level of urgent and emergency care services provided at Minor Injury Units and Community Hospitals is unlikely to be confined to SLSWR. We offer a supplementary recommendation here for consideration by Scottish Government to review nomenclature, service definitions and signage of Minor Injury Units, throughout Scotland.

2. **Future community bed provision:** During the ongoing SLSWR major service re-design process, in-patient service provision at Portree hospital has declined from a peak of 12 beds in 2009 to four beds currently. This also needs to be seen in the context of a significant and rapid decline in nursing and care home provision in SLSWR, particularly in North Skye. Maintaining and caring for people at home where appropriate is essential to avoid unnecessary hospital or institutional care. This is already NHS Highland policy and should be reflected in the sufficient provision of urgent health and care at-home services during both in-hours and OOH periods. Such provision needs to be buttressed by adequate community bed provision for

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3 NHS 24 is a 24/7 hour service. In hours/daytime urgent care needs are normally provided by local GP services and community pharmacies. Community pharmacy opening hours extend beyond hours when GP services may be closed.
ongoing nursing and care requirements, including rehabilitation and palliative/end of life care needs.

We recommend that:

a) In-patient bed availability at Portree Hospital must continue until sufficient alternative resilient provision is provided in North Skye. This transition, which will take time, must be informed and shaped through co-production with the community.

b) Difficulty in recruiting nurses and support staff to work in Portree Hospital may be exacerbated by ongoing service redesign uncertainties and the offer of short term contracts in the recent past for prospective staff in a facility that is perceived to be closing. We understand that for the last 12 months or so contracts have been offered on a substantive basis. This latter policy should be maintained, and we note that with greater certainty recruitment may become easier.

c) A rapid review of care at-home and community bed provision for SLSWR should be undertaken, taking account of present requirements, transfer activity to out-of-area secondary care facilities and future socio-demographic factors. Such a review should also take account of current and potential partnership developments, including statutory and voluntary provision such as contributed by the Howard Doris Centre in Lochcarron and Skye Cancer Care.

d) NHS Highland has already committed to procure additional services in the form of a new ten-bedded community unit in the Portree area. We understand that negotiations are underway to deliver on this commitment. This should be progressed at pace, with any bed capacity and capability revision informed by the above community bed review.

e) NHS Highland plans to co-locate Portree Medical Centre into the present Portree Hospital premises. The timing of this must be subject to the above recommendation about in-patient beds retention. Such a combined Unit might be renamed Portree Community Hospital and Medical Centre, or similar, to signify its dual and complementary role.

3. **Closer Inter-agency and public participation:** Service provision must meet the changing and growing 24/7 care needs of SLSWR and take full account of projected demographics and population density, socio-economic factors, transport constraints and expanding tourist/visitor numbers. To realise a shared vision for co-production of sustainable services in the years ahead:

We recommend that:
a) NHS Highland must collaborate much more closely on an ongoing, agreed basis with members of the public, public representatives, front line staff and other emergency and urgent care providers. Those who receive and those who deliver services are entitled to shape them. This is a joint endeavour with joint obligations - all must rise to the occasion.

4. **Collaboration with the Scottish Ambulance Service (SAS):** We heard and received written evidence about increased ambulance journey travel times and utilisation with current OOH services mostly provided in Broadford. Ambulance availability may also be compromised by vehicle(s) being retained in the Inverness area for other local emergencies, following transfer of patients from SLSWR. As part of the External View process, we have instigated positive discussions with SAS to develop and evaluate new models of care for SLSWR.

We recommend that:

a) The Scottish Ambulance Service (SAS) should increase its paramedical staff (paramedic) capacity and capability in SLSWR, in line with its present strategy: *Towards 2020: Taking Care to the Patient*.4 This is particularly relevant for North Skye where SAS staff should be co-located at Portree Hospital as part of the wider Rural Support Team, jointly working within multidisciplinary teams, including the Rural Practitioners based at Broadford.

b) SAS should review the availability, capacity and capability of all units in SLSWR, including fast response vehicle (FRV) provision.

c) SAS paramedics should be deployed on-shift rather than present on-call arrangements.

These proposals encapsulate the role of ambulances as mobile urgent care centres, as mooted in the National Review of Primary Care OOH Services: *Pulling Together: Transforming Urgent Care for the People of Scotland*.5 We envisage that the recommendations made here will buttress SAS support not only for OOH services but also daytime primary care.

5. **Collaboration with NHS 24:** An issue for staff working in remote and rural areas is the maintenance and development of clinical skills, where workload volume might be low during OOH periods, set against the need for continuous availability for urgent and emergency cases.

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We recommend that:

a) To optimise utility for staff on OOH shift patterns, dual roles should be considered and developed with NHS 24. The involvement of SAS paramedics, should also be explored and evaluated.

b) NHS 24 should work with NHS Highland to develop a hybrid staffing role, based at Portree Hospital.

By working in this way, appropriately trained staff based in SLSWR could be contributing to the resilience and service provision of NHS 24, helping the urgent care needs of people on a Scotland-wide basis.

As part of the External View process we have instigated positive discussions with NHS 24, to take this forward.

6. First Responders: A number of community voluntary first responder schemes are already in place in SLSWR. We commend this approach, but difficulties have been experienced including provision of equipment, ongoing support/training, communication and co-response issues. These voluntary schemes can augment but must not supplant statutory urgent and emergency care provision. We recognise that first responder schemes may not be feasible in some communities, owing to lack of individuals prepared or available to act as first responders. This will also be adversely impacted by the ageing demographic and sparsity of the population. In addition, the Scottish Fire and Rescue Service (SFRS) has recently aspired to take on a first responder care support role, assisting the Scottish Ambulance Service (SAS), when available, and are already engaged in responding to out-of-hospital cardiac arrest (OHCA) events in some locations in Scotland.

We recommend that:

a) A review of all present first responder schemes in SLSWR to identify deficiencies, remedies and support requirements.

b) That the feasibility of a systematic development plan should be explored for all statutory and voluntary first responders, with a view to ongoing collaborative working and mutual support. This would involve NHS Highland, SAS, SFRS, Police Scotland, HM Coastguard, the RNLI, Mountain Rescue Scotland, other third sector organisations, including Lucky2BHere and local community representatives.


Workforce Planning

7. **Workforce capacity and capability**: Sustainability of 24/7 urgent care and emergency services is predicated on a high-morale and well-led staff, of sufficient capacity and capability. Present capacity deficiencies have adversely affected continuity of OOH care provision, including intermittent closure of the Minor Injury Unit at Portree Hospital and the suspension of community midwifery services.

We discussed OOH workforce issues with colleagues including nurse practitioner members of the Rural Support Team, Rural Practitioners, General Practitioners, community and hospital nurses, midwives, social care support staff and SAS personnel. We heard of concerns with on-call arrangements, contractual issues, high turnover rates in some cases and serious accommodation difficulties. Workforce planning was a key recommendation in the National Review of Primary Care Out-of-Hours Services, and a National Health and Social Care Workforce Plan (Part 3) - *Improving Workforce Planning for Primary Care in Scotland*, was recently published.

We recommend that:

a) The capacity of the Rural Support Team and the numbers of Rural Practitioners should be reviewed and fully staffed, accounting for new models of joint working with SAS paramedics and NHS 24, to support 24/7 urgent care, as described above.

b) Going forward, ongoing clinical leadership and engagement will be essential for the development and delivery of future service provision, including a sustainable OOH service. We are encouraged that clinical colleagues recognise this imperative and NHS Highland must facilitate and support that.

c) As indicated for SAS, we suggest that shift working should supplant on-call working for members of the Rural Support Team.

d) While this External view was asked to focus on OOH services, we recommend that a comprehensive 24/7 Urgent and Emergency Care Workforce Plan should be developed, including inter-agency working and contractual arrangements which promote recruitment and retention of staff - with sufficient capacity and capability.

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Accommodation

8. **Housing solutions:** We heard clear and recurring concerns and recognition by healthcare staff, the public and public representatives of refractory accommodation issues. Accommodation constraints undermine recruitment and retention of staff.

We recommend that:

a) Novel staff accommodation solutions should be sought with Highland Council (lead agency for housing), public representatives, housing associations, the independent sector and local communities.

This is a pressing matter, which should also take account of temporary accommodation for undergraduate and postgraduate health care worker training, which requires flexibility (see Recommendation 13). Such training accommodation, when not in use for training purposes, might be re-deployed to give temporary accommodation to growing numbers of visitors and tourists, particularly in Skye. These accommodation solutions are also relevant for the resilience of other public sector organisations and should be pursued in common endeavour.

Infrastructure, Transport and Digital Innovation

9. **Road issues:** We heard concerns expressed about road surface issues and significant potholing on many single-track roads but also on the single carriageway A road system throughout Skye. This makes urgent and emergency patient transport more hazardous and may result in more lengthy journey times for patients, whether by ambulance transport or by private vehicles. The tourist season has recently been rapidly expanding both in duration and number of visitors. Single track roads can become temporarily blocked because of volume of vehicle numbers. The main A87 road between the North of Skye and Broadford can occasionally be blocked by snow or road traffic accident (RTA) for extended periods - we took this into account as part of our conclusions for Recommendation 1.

We are conscious that significant road surface issues and repair requirements are not confined to healthcare transport needs nor to the SLSWR area alone.

We recommend that:

a) Expressed concerns about adverse road surfaces and congestion issues should be shared with Transport Scotland and other relevant agencies with transport responsibilities. This should help to inform key road maintenance priorities.
10. **Transport and accessibility**: Ready accessibility to 24/7 urgent and emergency care services should be equitable. This is particularly telling for all remote and rural areas whether by private, public or Scottish Ambulance Service transport. Transport is not confined to road accessibility alone. Air evacuation of urgent/emergency cases is normally undertaken by SAS via fixed wing aircraft from Broadford Airfield or by SAS helicopter, including the charity-funded dedicated helipad at Portree. Air evacuation of critically ill patients is also undertaken by Scotland’s Emergency Medical Retrieval Service (EMRS). Air evacuation procedures may be compromised at times by severe weather conditions. The UK Search and Rescue (SAR) Helicopter Service deployed by HM Coastguard has nearby bases in Stornoway and Inverness, which may be of assistance to augment response resilience.

Sea evacuation of patients from Raasay is undertaken via CalMac ferry to Sconser, during its year-round timetabled services. During OOH periods and during adverse weather conditions when the ferry might not be running, the crew of the Portree RNLI Lifeboat, *RNLB Stanley Watson Barker*, willingly and unfailingly assists, when requested to do so. This is voluntary and like other third sector organisations, provides distinguished service to the community. The remote community of Glenelg and Arnisdale is serviced by part-time ferry from Glenelg to Kylerhea during summer months only and when timetabled. Approach roads from the mainland to Glenelg and on Skye to Kylerhea are single track and treacherous in adverse weather conditions and subject to blocking by snow. This renders impractical and difficult ferry evacuation by sea to Skye and onwards to Broadford Hospital and is unlikely to be feasible. However, this and other options merit consideration.

NHS Highland has convened a Transport Group, as part of its Major Service Redesign Programme. Consideration of the latter was placed outwith our remit.

We recommend that:

a) The Terms of Reference and membership of the SLSWR Service Redesign Transport Group should be reviewed in the light of wider inter-agency considerations and the recommendations from this External View.

b) A review of air evacuation services of patients should be considered, involving inter-agency discussions between NHS Highland, SAS, EMRS and HM Coastguard, to determine whether any improvements can be made.

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10 [https://www.emrsscotland.org/](https://www.emrsscotland.org/)
c) A review of sea evacuation procedures should be undertaken, involving inter-agency discussions between NHS Highland, SAS, CalMac and the RNLI.

d) The Memorandum of Understanding between SAS, HM Coastguard and the RNLI, recommended in the National Primary Care Out-of-Hours Review,\textsuperscript{12} should be finalised and implemented.

11. \textbf{Digital Innovation}: Looking to the future, digital innovation will be increasingly important for the delivery of healthcare, including OOH and 24/7 urgent and emergency Care. This aspiration has been underpinned by the recently published: \textit{Scotland’s Digital Health & Care Strategy – Enabling, Connecting and Empowering}.\textsuperscript{13} This will be underpinned by superfast broadband being implemented via Digital Scotland Superfast Broadband.\textsuperscript{14} Coverage is expanding rapidly, and is presently available, for example on Skye, in the communities of Ardvasar, Broadford, Dunvegan, Portree, Raasay and Staffin. In Kyle and South West Ross superfast broadband is presently available, for example, in the communities of Applecross, Lochcarron, Kyle of Lochalsh and is due to become available in Glenelg and Arnisdale soon. As for other places in both rural and urban Scotland, technical difficulties are delaying short term comprehensive superfast broadband coverage for SLSWR.

Digital innovation has the potential to revolutionise healthcare provision, including: remote monitoring of frail older and vulnerable people, maintaining people at home, avoiding unnecessary hospital and residential/nursing home admission, and assisting earlier hospital discharge. In new build homes, NHS Highland and Highland Council are working with the Digital Health & Care Institute (DHI), Albyn Housing Society and academic partners on the \textit{Fit Home} project\textsuperscript{15}. Further work is being considered for retrofitting sensing technology to existing homes.

Digital technology also offers the potential to avoid unnecessary travel for clinical assessment, through video-linking. DHI are developing a videoconference service into people’s homes called: \textit{Attend Anywhere},\textsuperscript{16} which is being rolled out across Scotland by the NHS 24 based Scottish Centre for Telehealth and Telecare. NHS

\textsuperscript{12} \url{http://www.gov.scot/Resource/0047/00474154.pdf}
\textsuperscript{14} \url{https://www.scotlandsuperfast.com/}
\textsuperscript{15} \url{http://www.audit-scotland.gov.uk/uploads/docs/report/2016/nr_160818_broadband_update.pdf}
\textsuperscript{16} \url{http://news.hie.co.uk/all-news/fibre-broadband-for-skye/}
\textsuperscript{15} \url{http://news.hie.co.uk/all-news/fibre-broadband-for-skye/}
\textsuperscript{16} \url{http://news.hie.co.uk/all-news/fibre-broadband-for-skye/}
\textsuperscript{17} \url{http://www.attendanywhere.com/}
\textsuperscript{18} \url{https://sctt.org.uk/programmes/video-enabled-health-and-care/attendanywhere/}
Highland are supporting adoption of this technology – the *NHS Near Me* programme.\(^{17}\)

Effective deployment of digital technology will help to underpin 24/7 urgent and emergency care, particularly for remote and rural communities. As part of this External View we have had positive discussions with the Digital Health & Care Institute (DHI) to promote further collaboration.

Reliable video-linking is essential between care sites within SLSWR and with secondary care facilities elsewhere, particularly Raigmore Hospital, Inverness and the Belford Hospital, Fort William. This will facilitate optimal professional-to-professional communications and enable specialist medical advice to be rapidly provided to remote and rural locations, when required.

We recommend that:

a) Ongoing collaboration with the Digital Health & Care Institute should continue to explore and evaluate emerging digital technology to enable remote monitoring and video consultations from people’s homes.

b) A review of video-conferencing facilities at all relevant care sites should be undertaken to provide reliable 24/7 professional-to-professional communications.

**Specific Localities**

12. During the External View process, we received submissions and held discussions about the needs of specific communities within SLSWR. We are conscious that all local communities are unique with a need for tailored requirements. Two local communities in particular: Glenelg & Arnisdale and Raasay, expressed much dissatisfaction about their current emergency and urgent care, which they regarded as a significant deterioration from former provision. Extensive discussions between NHS Highland and each of these communities, expectations have not been met and have not yet led to shared and meaningful agreed outcomes for the wellbeing of either. The present situation in both communities is unsatisfactory and must be remedied, by mutual agreement.

We also discussed ongoing excellent care provision at the Howard Doris Centre in Lochcarron,\(^{18}\) a voluntary-statutory care collaboration.

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\(^{17}\) [www.nhshighland.scot.nhs.uk/Services/Pages/NHSNearMe.aspx](http://www.nhshighland.scot.nhs.uk/Services/Pages/NHSNearMe.aspx)

\(^{18}\) [http://ionalister.co.uk/HowardDoris/home.htm](http://ionalister.co.uk/HowardDoris/home.htm)
Glenelg & Arnisdale: This community until four years ago, was served by two general medical practitioners (GPs), providing 24/7 in-situ cover from Glenelg Health Centre. One GP left in October 2011. Since then, until end July 2017 that post was covered by locums to preserve 24/7 cover. From August 2017, part-time daytime cover has been provided by the remaining GP, with advanced nurse practitioner cover one day a week, and Broadford Medical Practice covering one day a week from Broadford with no capacity to make home visits, or to consult in Glenelg. OOH cover is presently provided by the remaining GP part-time, and by clinical staff based at Broadford Hospital for the remainder. Fears were expressed that NHS Highland was intent on further downgrading the service by failing to provide adequate support for the remaining GP. Community representatives were also adamant that a downgrading of services provided a threat to the safety and future viability of the community itself. NHS Highland has since confirmed that there is no intention to undermine - but rather to shore up and support - existing GP provision. We were informed that present air evacuation methods were unreliable in severe weather conditions. We have sought to address this in Recommendation 10. The community of Glenelg and Arnisdale continue to press for the reinstatement of another GP, to restore the former complement to two GPs.

Recently, a constructive pre-Christmas (2017) desk top exercise took place, involving partner agencies, to rehearse care scenarios and solutions for the community. We consider that the present care provision for Glenelg and Arnisdale to be unsatisfactory and should be improved.

We recommend that:

a) NHS Highland should continue to work with the Glenelg and Arnisdale community to agree jointly and rapidly a solution which is not only desirable, but feasible and sustainable. Independent external third party facilitation should be considered to help achieve this.

b) The present GP led service at Glenelg should continue to be underpinned by adequate multidisciplinary support via the Rural Support Team and SAS, on a 24/7 basis.

c) Air and sea evacuation procedures for Glenelg and Arnisdale should be kept under review on a multi-agency basis, given the vagaries of road access in adverse weather conditions - see recommendation 10.

d) The Scottish Fire and Rescue Service (SFRS) have a unit based at Glenelg. Statutory first responder status should be pursued, in concert with the additional potential of a voluntary first responder scheme - see Recommendation 6.

e) The imminent availability of superfast broadband should be exploited for the succour of the Glenelg & Arnisdale community. This community should be
considered as a potential development site for digital innovation - see Recommendation 11.

**Raasay:** This island community until recently has been served for many years by a resident district nurse, which lapsed on retirement of the former incumbent. The Raasay community had expectations that this post would be maintained. This did not materialise. After a protracted delay and a number of meetings with NHS Highland, the Raasay community agreed to compromise on their initial expectation when a support worker was offered instead. Understandably the Raasay community representatives were anxious to be assured that this role had the required skill set. NHS Highland agreed to share and agree the job description but this did not happen before the appointment was made, after significant delay. This and other failed expectations has led Raasay community representatives to lose confidence on the management of NHS Highland. We would ask NHS Highland to reflect carefully about this and respond accordingly. We understand after significant delay an appointment of a support worker has been made. A part time vacancy (22.5 hours) presently remains. The job description used for this vacancy includes First Responder and on call duties. NHS Highland have made a commitment to develop the support worker to an enhanced level with the assistance of SAS. SAS are currently reviewing this level of enhanced service which is impacting on the resilience of workers on Raasay as well as on Eigg. In the interim, NHS Highland has made available daytime nursing cover on a Monday to Friday basis. OOH cover is provided through the NHS 24 (phone 111) service for urgent care or by 999 calls for emergency care.

Raasay residents with urgent or emergency care needs requiring sea evacuation to the Skye mainland can only do so by timetabled year-round ferry transfer to Sconser when operational. When the ferry is not operational and during OOH periods, the crew of the Portree RNLI lifeboat invariably respond. We have discussed this in Recommendation 10 above. Raasay presently has access to superfast broadband.

We recommend that:

- **e)** NHS Highland and other partners should continue to engage with the residents of Raasay in a meaningful way and to rapidly develop an agreed and sustainable service on the island that provides safe and resilient care 24/7. Independent external third party facilitation should be considered to help achieve this.

- **f)** As part of the review of sea evacuation procedures in Recommendation 10, Raasay is a key priority. Discussions should take place with CalMac whether the Raasay-Sconser ferry can be deployed on demand for urgent/emergency
care transfers. Irrespective of these discussions and possible agreements, the ongoing role of the crew of the RNLI Portree Lifeboat is respected and appreciated.

g) The Scottish Fire and Rescue Service (SFRS) have a unit based at Raasay. Statutory first responder status should be pursued, in concert with the additional potential of a voluntary first responder scheme - see Recommendation 6.

h) The present availability of superfast broadband should be exploited for the support of the community. Raasay should be considered as a potential development site for digital innovation - see Recommendation 11.

Lochcarron: We also discussed ongoing excellent care provision at the Howard Doris Centre in Lochcarron, a voluntary-statutory care collaboration.

We recommend that:

i) The Lochcarron Centre should continue to be nurtured and supported.

Learning, Education and Training

13. Centre of Excellence for Learning, Education and Training: SLSWR has the potential to become a centre for excellence for multidisciplinary undergraduate and postgraduate learning and training. The National Review of Primary Care Out of Hours Services recommended that OOH and Urgent Care Services should be regarded as important venues for learning and training, as well as for service delivery and this is supported by other publication/presentation including: Remote & Rural Education and Training. This should help future recruitment and retention of care staff to the area, aiding sustainability. International research confirms that local training provision encourages recruitment and retention of health care workers.

A number of education and training providers are relevant here: including: NHS Education (NES), SAS, NHS24, Medical Schools and relevant academic partners, for example, the University of the Highlands and Islands (UHI). UHI has growing

19 http://ionalister.co.uk/HowardDoris/home.htm
21 MacVicar R, Mckerrow W. Remote & Rural Education and Training
http://www.nes.scot.nhs.uk/media/2681823/1145macvicar_carrick.pdf
MacVicar R, Nicoll P. Supporting Remote & Rural Health Care, NES Board Paper 2013
22 Strasser R. Rural health around the world: challenges and solutions.
ambitions for Remote and Rural Healthcare learning, teaching and research, and wishes to promote more distributed learning opportunities, including at the West Highlands College UHI, Portree. Highlands and Islands Enterprise (HIE) is also be a key partner in this endeavour.

Increased based-community training for medical undergraduates and postgraduates and other healthcare professionals is a high priority for Scottish Government.

Optimised training and learning opportunities within SLSWR should also foster future workforce capability and capacity for the remainder of NHS Highland and for other remote and rural areas throughout Scotland.

We recommend that:

a) NHS Highland should engage closely with education and training providers and including: NHS Education (NES), Scottish Ambulance Service (SAS), NHS24, Medical Schools and relevant academic partners, for example, the University of the Highlands and Islands (UHI). Highlands and Islands Enterprise (HIE) should also be included.

Making Best Use of Services – Know Who to Turn To

14. Best use of services: It is imperative that whatever services are provided they should be used responsibly and appropriately. NHS Highland has already conducted developed and distributed materials to the public of SLSWR23 and have in place a Know Who to Turn To website:

http://www.nhshighland.scot.nhs.uk/Services/KWTTT/Pages/welcome.aspx

NHS 24 website resources may also be helpful:

http://knowwhototurnto.org/ and accessing services through NHS 24’s national directory which is accessed through NHS Inform:

https://www.nhsinform.scot/national-service-directory

We recommend that:

a) A programme of assisting the public to make best use of available services should be developed and implemented, including Know Who to Turn To. This will need to be done on a systematic and advocacy basis, with the full engagement of and advocacy by local communities and their representatives. Social media may be helpful.

23 http://www.nhshighland.scot.nhs.uk/Publications/Pages/KnowwhototurntoSLSWR.aspx
Making it Happen – Pulling Together

15. Making it Happen: Major service redesign and transformation is complex and challenging as will be implementation of the recommendations in this report. Transformation and translation will neither be easy nor quick. Some recommendations will bear fruit in the short term but others will take longer to come to fruition - flexibility and understanding will be required.

These recommendations can only be delivered by the combined endeavours of NHS Highland working intimately, fully and continuously with the public and with other care agencies in a genuine partnership to shape and deliver services – by truly pulling together. High quality leadership and ongoing commitment will be required, at all times.

We recommend that:

a) All future service development and delivery must be done in partnership with the people of SLWRS with a focus on co-production.
b) The National Standards for Community Engagement\(^{24}\) must be observed by all.
c) All relevant partners should participate, including all emergency services, the third sector and those that control wider infrastructure.
d) An implementation plan with realistic timescales, adequately resourced, making best use of public funds and robustly governed - with clear accountability, reporting to the Highland Health and Social Care Committee.
e) Independent external third party facilitation should be deployed as required and agreed.
f) In view of the aspiration in these recommendations and the Major Service Redesign Programme underway, Scottish Government should seek regular and robust assurance that satisfactory progress is being made.

Expanded Footnotes from within the Report

1. Pulling Together Transforming Urgent Services for the People of Scotland. Main Report of the National Review of Primary Care Out of Hours Services:  
   Summary Report of the National Review of Primary Care Out of Hours Services  
2. Save Our Services NHS (SOS NHS)  
   http://www.sosnhsskye.co.uk/who-we-are
3. NHS 24 is a 24/7 service. In hours/daytime urgent care needs are normally provided by local GP services and community pharmacies. Community pharmacy opening hours extend beyond hours when GP services may be closed.  
   https://www.nhs24.scot
5. See Reference 1.
7. Out of Hospital Cardiac Arrest: A strategy for Scotland  
8. See Reference 1.
10. Emergency Medical Retrieval Service  
    https://www.emrsscotland.org/
11. Bristow operates from 10 coastguard helicopter bases around the UK on behalf of Her Majesty’s Coastguard to respond to all Search and Rescue incidents for the whole of the UK.  
    http://www.bristowgroup.com/uk-sar/
12. Preparing Scotland - Scottish Guidance On Resilience - Philosophy, Principles, Structures And Regulatory Duties  
13. Out-Of-Hospital Cardiac Arrest - A Strategy For Scotland  
14. Scotland's Digital Health & Care Strategy  
15. Digital Broadband – Where and When  
    https://www.scotlandsuperfast.com/Superfast broadband for Scotland - A progress update – Audit Scotland  
    Fibre broadband for Skye - The roll-out of high-speed broadband on Skye has started, and more than 3,000 more homes and businesses are the next to be drawn into the new fibre network as work continues on the island.  
    http://news.hie.co.uk/all-news/fibre-broadband-for-skye/
16. The vision for Fit Homes is to create a new way of living which has potential to transform the way health and social care services are delivered. The concept supports residents to take charge of their own wellbeing as well as having access to an enhanced, more personalised level of support at home. The model is aimed at creating a viable, lower cost alternative to full-time residential care and prolonged stays in hospital, designed in partnership with service users, that can be replicated throughout Scotland.  
    http://www.in0v8.scot.nhs.uk/fit-homes/
17. Attend Anywhere provide a suite of services and solutions that enable 'business-as-usual' video call access to existing health services.  
    https://www.attendanywhere.com/ and a link
to Scottish Centre for Telehealth & Telecare [https://sctt.org.uk/programmes/video-enabled-health-and-care/attendanywhere/]

18. Attend Anywhere in NHS Highland is there NHS Near Me programme. [http://www.nhshighland.scot.nhs.uk/News/Pages/Newservicewillprovideeasieraccesstoointments.aspx]

19. The Strathcarron Project is the company that manages The Howard Doris Centre which provides supported accommodation. [http://jonalister.co.uk/HowardDoris/about.htm]


Annex 1 – Terms of Reference

Context

Primary Care out of hours and urgent care is of key importance to the board of NHS Highland. It has been continuously evolving following the GMS contract in 2004. Most recently, NHS Highland Board agreed an approach and direction of travel for out of hours and urgent care services in 2015. This was considered to be in line with the multi-disciplinary approach and recommendations set out in the report Pulling Together - Transforming Urgent Care for the People of Scotland.

A more detailed paper was presented and agreed at the NHS Board meeting in September 2016. Work to implement the recommendations continues. Specifically, in Skye, Lochalsh and South West Ross, work on building a sustainable model has most recently been ongoing since 2014. Significant effort has gone into developing Advanced Practitioners to be part of a multi-disciplinary service (including Rural Practitioners and GPs) to address these challenges. Nevertheless, some significant concerns remain from members of the public, NHS Save Our Services – NHS and elected members, particularly in North Skye. In particular these concerns relate to aspects of delivery, and access to, emergency care, urgent primary care out of hours care, minor injuries and illness. Taking these concerns into account, the Chair of NHS Highland has invited a team, led by Sir Lewis Ritchie to provide an external professional view of the urgent care services in the area.

Remit

The specific remit is to assess the resilience of urgent primary care out-of-hours provision.

Out of scope

The remit will not cover the redesign of wider health and social care services currently underway, with Ministerial approval, which will progress to an Outline Business Case for a Hub and Spoke model incorporating a new-build facility in Broadford as part of a wider redesign.

Objective

To ensure that the present and planned delivery of urgent primary care out-of-hours provision is in line with the recommendations set out in the report Pulling Together - Transforming Urgent Care for the People of Scotland.

Governance

Sir Lewis Ritchie, assisted by a small team of independent colleagues, including representation from NHS 24 and the Scottish Ambulance Service, will report to the Chair of NHS Highland, David Alston, and the Chair of the Highland Health and Social Care Partnership, Melanie Newdick.
A work plan will be created for the external view including meetings with:

- representatives of the local community including action group, SOS-NHS
- local clinical staff who provide the service, service managers and any other staff as deemed necessary.
- with local GPs and other clinicians in the area,
- As part of the work plan, meetings will be arranged with service users and providers including political representatives.

The external view team will be asked to provide peer opinion on the safety, sustainability and organisation of the service and be invited to make recommendations if necessary for further action or developments.

**Deliverables**

A report of the external view will be produced by Sir Lewis Ritchie for NHS Highland by the end of April 2018.
Annex 2 - External View – Panel Members

**Margaret Anderson** is from Ayr and has been volunteering with NHS Ayrshire & Arran since 2003 and NHS 24’s Public Participation Forum since 2008. Margaret has been involved in some key projects as a public representative during this time, including the creation of NHS Inform and the 111 number change. Margaret recently completed a three year term of office as Vice-chair of the NHS 24 PPF, having served as Chair for the preceding three years. She was the Public Representative on the Public Holiday Review published in December 2017. Margaret joined the Board of NHS Ayrshire & Arran as a Non-Executive Director and she also serves on her local Integrated Joint Board in that capacity. Margaret takes a very keen interest in how services are delivered ensuring that ‘person-centeredness’ is at the heart of all discussions.

**Kate Bell** is Head of Service Change & Transformation at NHS Lanarkshire. Kate has worked in the public sector for many years, starting out in voluntary organisations, local authorities and now in the National Health Service. Kate is passionate about engaging the public in designing and shaping the services they receive. Kate’s work is system wide and includes working with the Scottish Government, other NHS Boards, and Health & Social Partnerships in large scale, often complex service change, service redesign, systems and process improvement which involves working at a national, regional and local level with a range of people and across a mix of organisations.

**Garry Fraser** joined the ambulance service in 1997 as an ambulance care assistant moving to Technician and becoming a Paramedic in 2001 which he has maintained. Garry worked as an air ambulance Paramedic out of Glasgow serving remote and rural communities around Scotland. He became an Area Service Manager for Clyde, Head of Service for Argyll and Clyde and onto General Manager for South West Scotland. Garry is now undertaking the role of Regional Director for the West of Scotland and is a member of SAS’s executive team.

**Linda Harper** has worked in the community for many years, firstly as a district nurse, midwife and health visitor. Linda then became a practice nurse progressing to an Advanced Nurse Practitioner. In 2000 Linda took up the post of Associate Nurse Director for Practice Nursing and the lead for Non-Medical Prescribing in NHS Grampian whilst maintaining a clinical role. In 2004 Linda was asked to develop a team of practitioners to work in the Out of Hours service, she started with 5 nurse and paramedic practitioners. Linda now has a team of 23 substantive staff and 14 bank staff working OOH across NHS Grampian alongside the GP’s. Linda is now lead nurse for the Moray Health & Social Care Partnership. Linda has enjoyed secondments with the Scottish Government and the Royal College of Nursing.

**Dr Angus McKellar** completed his GP training in Stornoway, then worked in Nepal for eight years, involved in service development and clinical leadership. He became a GP partner in North Harris in 2002, delivering GP training, chaired the AMC and served on the Area Clinical Forum, taking up the post of NHS Western Isles Medical Director in 2014. He does
occasional GP sessions, retains an interest in overseas work, and serves on a number of Regional and National committees.

_Fergus Millan_ joined the civil service in 1997 following a career as a scientist. He has held a number of posts across education, local government and health. He recently moved from Public Health Division in the SG where he had responsibility for policy on a wide range of subjects including national screening programmes, obesity and health inequalities. In his current role he leads one of three teams in the Primary Care Division with responsibility for the sponsorship of the Scottish Ambulance Service and NHS 24. In addition, he is responsible for policy on Out of Hours and optometry.

_Dr David Pedley_ is a consultant in Emergency Medicine and Clinical Director of emergency care in Dumfries and Galloway. Training as a registrar in Tayside and Grampian, David spent a year working as a rural fellow helping to establish one of the UK’s first telemedicine networks. He represents Emergency medicine to the Royal College of Physicians of Edinburgh and, until recently was a member of the Scottish board of the Royal College of Emergency Medicine representing the rural district general hospitals.

_Sir Lewis Ritchie_ is presently James Mackenzie Professor of General Practice, University of Aberdeen and Honorary Professor of Primary Care and Public Health, University of the Highlands and Islands, Honorary Professor of General Practice, University of Edinburgh and Honorary Consultant in Public Health, NHS Grampian. He is a former Principal General Practitioner, Peterhead Health Centre and Community Hospital. He has also held posts as Director of Public Health, NHS Grampian and Consultant in Public Health Medicine, Grampian Health Board.

_Dr Laura Ryan_ has been a doctor for 20 years. She has worked in Scotland since 2001. She is the Medical Director for NHS 24 and works in the Out of Hours Service in NHS Borders. She was the Clinical Lead for OOH in NHS Borders for 7 years and is well versed in the challenges of covering a large area of diverse geography. She chaired the National OOH Operational Group for three years and was part of Professor Sir Lewis Ritchie’s reviews of Urgent care OOH and covering OOH during the Public Holiday period. Recognizing the need for joint working to best serve our communities, as part of her OOH work in Borders she developed a professional to professional line for SAS staff (supporting a safe alternative to admission in 85% of cases) and also developed the OOH nursing staff to allow them to carry out home visiting.

_Dr Charlie Siderfin_ is the Lead GP for NHS Orkney and has lived and worked there, with his family, for the last 17 years. As part of the role, he works as a 24/7 single-handed GP on the outer island of Westray for 3 out of 9 weeks and 6 weeks in Kirkwall. In 2009 he was involved in redesigning the delivery of services to the outer islands of Orkney, working with individual island communities to develop and refine systems of care. He has worked closely with the island communities to recruit and retain staff to the islands. Prior to taking up his
current role, he worked for 14 years in the Balfour Hospital providing A&E and acute medical inpatient care, in combination with General Practice work in the community. He has a particular interest in the development of systems to support the recruitment and retention of practitioners to challenging remote and rural practice.

**Dr Sian Tucker** is a GP; she has been Clinical Director of Lothian Unscheduled care service for the last 5 years. Other roles include National Clinical Lead Urgent Care program for NHS Health Improvement Scotland. Sian is co-chair of the National Operations Group for OOH and RCGP Scotland’s executive officer for OOHs and interface. She works clinically one session a week in OOHs.
Annex 3 - Process and meetings

During the process of the review, Sir Lewis visited Skye on 5 occasions, supported by members of the Scottish Government Primary Care Transformation team and Expert Panel. The programme of engagement developed as issues were brought to the review team’s attention and resulted in around 70 meetings with staff from NHS Highland, other public agencies and third sector organisations, local representatives, clinicians and local residents (including phone discussions). In addition to meetings the review team received many documents and letters from a wide range of organisations and individuals. The expert panel was convened with members drawn from across Scotland Boards with a wide range of knowledge and expertise in remote and rural medicine, OOHs and emergency and urgent care as well as public representation. A timeline of meetings is noted in the table below.

<table>
<thead>
<tr>
<th>Day</th>
<th>Attendees</th>
<th>Location</th>
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<tbody>
<tr>
<td>Friday 2 February</td>
<td>NHS Highland Managers, Councillors and SOS-NHS Secretary, Portree Medical Practice Staff, NHS Highland Clinicians and Managers</td>
<td>Portree Hospital, Council Offices, Portree, Portree Medical Practice, Dr MacKinnon Memorial Hospital</td>
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<tr>
<td>Monday 26 February</td>
<td>NHS Highland Managers, NHS Highland – Non Exec Board Member, SFRS and SAS Managers, NHS Highland Managers, Councillor</td>
<td>Assynt House, Inverness, Teleconference, Assynt House, Inverness</td>
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<tr>
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<td>Raasay Community Council, Councillors, Lucky2bhere, NHS Highland Nurses and SAS Paramedics, SOS-NHS Skye Representatives</td>
<td>Raasay Community Centre, Council Offices, Portree, Lucky2bhere office, Portree, Portree Hospital</td>
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<tr>
<td>Wednesday 28 February</td>
<td>Members of Rural Support Team, Portree Medical Practice Staff, Police, Scottish Fire and Rescue Service, Scottish Ambulance Service, Royal National Lifeboat Institution and Third Sector, Dunvegan Medical Practice Staff, Working Group Health</td>
<td>Portree Hospital, Portree Medical Practice, Portree Fire Station, Dunvegan, Aros Centre</td>
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<tr>
<td>Thursday 1 March</td>
<td>Broadford Clinical Team, NHS Highland Chair, Parliamentarians, Community representatives South Skye and Lochalsh, Glenelg Patient Representatives and GP</td>
<td>Dr MacKinnon Memorial Hospital, Teleconference, Teleconference, Dr MacKinnon Memorial Hospital, Glenelg Health Centre</td>
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<tr>
<td>Wednesday 7 March</td>
<td>NHS Highland Chair</td>
<td>Telephone</td>
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<td>Wednesday 21 March</td>
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<td>HM Coastguard</td>
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<tr>
<td>Mountain Rescue Team (MRT) Medical Director</td>
<td>MRT base at Sligachan</td>
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<td>GPs and RPs from across SLWRS</td>
<td>Broadford Medical Practice</td>
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<td>Strathcarron Project Representative</td>
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<td>Member of the Public</td>
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<td>Community Nurses</td>
<td>Portree Hospital</td>
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<td>Parliamentarian</td>
<td>Teleconference</td>
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<td>Members of the Public</td>
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<td>North Skye Community Councils</td>
<td>Council Chamber, Portree</td>
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<tr>
<td>Councillors</td>
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<td>Midwives</td>
<td>Dr Mackinnon Memorial Hospital</td>
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<td>Members of Public</td>
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<td>Chief Executive, NHS Highland</td>
<td>AROS Centre</td>
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<td>Parliamentarian</td>
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<th>Saturday 24 March</th>
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<tr>
<td>NHS Services</td>
<td>Portree and Broadford Hospitals</td>
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<th>Wednesday 28 March</th>
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<tbody>
<tr>
<td>Parliamentarians</td>
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<tr>
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<td>South Skye and Kyle Community Councils</td>
<td>Kyle Health Centre</td>
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<tr>
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<td>SOS-NHS Skye representatives</td>
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<td>Glenelg &amp; Arnisdale representatives</td>
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<td>NHS Highland clinical staff</td>
<td>Jans Centre, Portree</td>
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<td>Raasay representatives</td>
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<td>Community Councils</td>
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<td>Emergency Services</td>
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<td>NHS Highland Senior Management Team</td>
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<tr>
<td>Members of the Public</td>
<td>Dunollie Hotel, Broadford</td>
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<td>Skye Cancer Care</td>
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<tr>
<td>Friday 20 April</td>
<td>NHS Highland Chief Executive and Team Teleconference</td>
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<tr>
<td>Monday 30 April</td>
<td>Chair and Chief Executive NHS Highland and senior staff St Andrew’s House Edinburgh</td>
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<td>Tuesday 7 May</td>
<td>Councillors</td>
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<td>Glenelg &amp; Arnisdale Representatives</td>
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<td>Chair, NHS Highland and Senior Team</td>
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<td>Jans Centre, Portree</td>
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A view from the A87 between Broadford and Portree, near Sligachan
We are pleased that Sir Lewis Ritchie’s report Independent External View of Skye, Lochalsh and South West Ross Out of Hours Services has now been published and makes recommendations about health services in our area that recognise the issues and realities that we have been presenting to the Committee since this petition was lodged.

The report makes these crucial statements:

Under heading 1 ‘Portree Hospital out of hours service and minor injury unit’ “After careful consideration, we take the view that the proposal to provide all OOH urgent and emergency care services at one community hospital site in Broadford, are neither sufficiently accessible nor equitable, for all the population served. The proposed closure of OOH services at Portree Hospital overnight is disadvantageous to the people of north Skye, with its larger population, socioeconomic and geographic hinterland, growing tourist numbers, travel costs burden and volume of service requirement.” (page 6)

And under heading 2 ‘Future community bed provision’: ‘…sufficient provision of urgent health and social care at home services during both in hours and OOH periods. Such provision needs to be buttressed by adequate community bed provision for ongoing nursing and care requirements, including rehabilitation and palliative/end of life care needs.’ (page 7)

2 key recommendations follow:

**Recommendation 1a:** “Out of hours urgent care access at Portree Hospital should be provided 24/7-there should be no closure of Portree Hospital in the out of hours period.”

**Recommendation 2a:** “In-patient bed availability at Portree Hospital must continue until sufficient alternative resilient provision is provided in North Skye. This transition, which will take time, must be informed and shaped through co-production with the community.”

While the external view remit did not include the redesign which we are petitioning the Committee about, Sir Lewis’ statement about the need for out of hours services based on his assessment of the population and geography is equally pertinent to the whole range of health services being redesigned by NHS Highland. These details are in our previous submissions to the Committee where we contend that NHS Highland has not given these facts sufficient weight in the redesign to date.

The Ritchie report has brought hope to those who use and provide health and social services in north Skye, Raasay and the parts of South West Ross where 24/7 out of

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hours service provision has become unacceptable. We are embracing the opportunity to work in ‘co-production’ with NHS Highland, the emergency services and others to develop the health and social services which these areas require, and are in the process of choosing an external facilitator to make sure this happens quickly and smoothly.

We continue to assert that the redesign should be subject to an independent and expert view/review process such as that used by Sir Lewis and the panel who concluded that the elements of the service they examined were ‘not sufficiently sustainable, nor equitable’. If there is not to be such a review of the redesign proposals to address the other issues outwith the purview of his work, but to which his findings clearly apply in terms of inequitable provision due to ignored issues of geography and population, then we would expect a further resource input so that quality and equitable health and social care services may be available to all in the redesign area.

Sir Lewis stressed the need for this work to proceed ‘at pace’ and intends to assess progress in 6 months’ time. We respectfully request that the Committee keeps this petition open until at least then, since the support and scrutiny provided by our elected representatives has been pivotal in reaching this stage, and should not be withdrawn until there is evidence of real improvement in service provision.
Public Petitions Committee
10th Meeting, 2018 (Session 5)
Thursday 7 June 2018

PE1627: Consent for mental health treatment for people under 18 years of age

Note by the Clerk

Petitioner  Annette McKenzie

Petition summary  Calling on the Scottish Parliament to urge the Scottish Government to provide for consultation with and consent from a parent or guardian before prescribing medication to treat mental ill health if the patient is under 18 years of age.

Webpage  Parliament.scot/GettingInvolved/Petitions/PE01627

Introduction

1. This is a continued petition that the Committee last considered at its meeting in public on 29 March 2018 and then subsequently in private on 10 May 2018. The Committee is invited to consider what action it wishes to take.

Committee consideration

Written consent forms

2. At its meeting on 29 March 2018, the Committee reflected on the evidence it heard from the Minister for Mental Health on 18 January 2018, as well as written submissions received from the petitioner and other respondents with an interest in the petition.

3. The Committee noted a suggestion made by the petitioner to introduce the use of written consent forms for young people who have been prescribed antidepressants and agreed to ask the Minister for Mental Health for her view on this suggestion.

4. The Minister for Mental Health’s written submission of 10 May 2018 states that she does not support the introduction of written consent forms and is of the view that the use of such forms—

“…would undermine the whole concept of capacity and confidentiality…and capacity to give consent is one of the core ethical foundations on which the clinician-patient relationship is based.”

5. The Minister’s submission also expresses concern that written consent forms for young people being prescribed mental health medication could be considered discriminatory towards young people and that the use of such forms could create issues of parity between mental and physical health.
6. The Committee also discussed the Scottish Association for Mental Health survey, published in March 2014, which found that almost three quarters of GP’s would like more information about non-pharmaceutical treatment options for common mental health problems and almost half of GPs are not aware of, or not sure if they are aware of, the Scottish Intercollegiate Guidelines Network (SIGN) guideline on non-pharmaceutical treatments for depression.

7. The Committee therefore agreed to ask the Minister for Mental Health to reflect on the findings of this survey and how it intends to promote the SIGN guideline to all GP practices in Scotland.

8. In response, the Minister’s written submission states that having reflected on the findings of the survey, she has asked officials to work with the Royal College of GPs, the Royal College of Psychiatrists and the British Medical Association to —

   “…provide information to general practitioners reflecting on the issues and learning raised by this petition, to inform them of where they can find more information and training about non-pharmaceutical treatment options for common mental health problems and to promote the relevant SIGN Guidelines”.

9. This information is expected to be sent to general practitioners by the end of June 2018 and members of the Committee will be provided with a copy.

**Youth Commission on Mental Health Services**

10. At its meeting on 29 March 2018, the Committee noted the work currently underway by the youth commission, led by Young Scot, to explore the potential for people aged 18 to 25 to continue their care within Child and Adolescent Mental Health Services. The Committee therefore agreed to ask Young Scot for an update on how this work is progressing.

11. Young Scot’s written submission of 16 May 2018 explains that the Youth Commission on Mental Health Services, launched on 26 April 2018, has been established in response to the Mental Health Strategy 2017-27. Over the next 15 months, the Commission will—

   “gather evidence, encourage debate and conversation and develop a set of solutions and recommendations from young people to the Scottish Government and other service providers on how child and adolescent mental health services can be developed and improved for young people in Scotland both now and in the future”.

12. The key outcomes anticipated for the project are as follows—

   - The Scottish Government and service providers better understand young people’s experiences of mental health and service delivery in response to mental health needs
• Young people have opportunities to propose and influence changes that would improve mental health service delivery and outcomes for young people


*Healthcare Improvement Scotland*

14. The Committee also noted at its meeting on 29 March 2018 the work currently being progressed by Healthcare Improvement Scotland to improve Child and Adolescent Mental Health Services redesign with individual NHS boards as referenced by the Minister for Mental Health during the evidence session on 18 January 2018. The Committee therefore agreed to ask Healthcare improvement Scotland for further information about this work.

15. Healthcare Improvement Scotland’s written submission of 9 May 2018 states that the ihub (Healthcare Improvement Scotland’s improvement directorate) manages a mental health portfolio which leads national improvement work for CAMHS services. The work is split across the Scottish Patient Safety Programme for Mental Health which is focussed on improving safety and quality of care and the Mental Health Access Improvement Support Team (MHAIST), focussed on improving access and waiting times.

16. The written submission explains that the MHAIST have identified improvement opportunities specific to the different CAMHS and Psychological Therapies communities as well as opportunities for shared learning across communities. In order to realise these opportunities, MHAIST is running a collaborative which consists of two workstreams as follows—

• Neurodevelopmental Pathways for CAMHS
• Increasing access for Psychological Therapies and CAMHS.

17. The collaborative will run from May 2018 to October 2019 and will consist of events open to teams from across NHS Scotland to share ideas, learning and progress.

*Consideration of petition in private*

18. At its meeting on 10 May 2018, the Committee reflected on all of the evidence it had received in relation to the petition in private, including 33 written submissions from a range of stakeholders and interested parties as well as oral evidence from the petitioner, young people’s mental health charities and the Minister for Mental Health.

19. Members discussed the primary action called for in the petition to change the process for allowing under-18s to consent to treatment for themselves and the evidence it had received to date in relation to the support available to young people to access mental health services in Scotland.
Conclusion

20. The Committee is invited to consider what action it wishes to take. Options members may wish to discuss include—

- To hold an inquiry on how young people can access mental health services and treatments
- To consider a scoping paper in relation to the inquiry in private at a future meeting
- Any other action the Committee wishes to take.

Annexe

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

- PE1627/HH: Minister for Mental Health submission of 10 May 2018 (121KB pdf)
- PE1627/II: Healthcare Improvement Scotland submission of 9 May 2018 (235KB pdf)
- PE1627/JJ: Young Scot submission of 16 May 2018 (731KB pdf)

All written submissions received on the petition can be viewed on the petition webpage
**PE1627: CONSENT FOR MENTAL HEALTH TREATMENT FOR PEOPLE UNDER 18 YEARS OF AGE**

<table>
<thead>
<tr>
<th><strong>Petitioner</strong></th>
<th>Annette McKenzie</th>
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<tr>
<td><strong>Date Lodged</strong></td>
<td>21 December 2016</td>
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**Petition Summary**

Calling on the Scottish Parliament to urge the Scottish Government to provide for consultation with and consent from a parent or guardian before prescribing medication to treat mental ill health if the patient is under 18 years of age.

**Previous Action**

Contacted local Member of UK Parliament regarding dispensing regulations and legislation.

Contacted media outlets including Daily Record, Sunday Post, and Scottish Daily Mail to draw attention and highlight issues relating to prescribing to under-18s, resulting in a number of similar cases coming to attention in the media.

**Background Information**

My 16-year-old daughter Britney made an appointment with her local GP without my knowledge or consent. She explained to the GP that she was a self-harmer and was having night terrors and suffering from depression and anxiety, and having suicidal impulses. Britney was 16 years old at the time of the appointment.

The GP subsequently prescribed 40mg of Propanol to be taken three times a day and this prescription was duly filled by the local pharmacist with 84 tablets issued – a month’s supply at once.

At no stage was I aware of the consultation with the GP or that Britney had been prescribed this medication or the quantity of medication prescribed, because the law currently allows GPs to prescribe young persons under-18 medication without the knowledge or consent of the parents or guardians.

Sixteen days later, Britney overdosed on Propanol. The police confirmed there were no suspicious circumstances. This was the first I know of my daughter’s prescription and consultation with her GP, despite the fact she express to her GP that she had mental health concerns. I was not made aware of this until after my daughter’s death.

I believe that the type of medication and care required specifically related to mental health issues requires a particular approach when diagnosing and treating these kinds of conditions in younger people.

The strength and effect of some mental health medications make it important that parents and guardians are fully involved and aware of the circumstances, allowing them to support treatment and ensure
that pathways of care are most appropriate for their children.

The quantity and strength of medications prescribed to Britney represented a danger to herself, and I believe that my daughter may still be with us if I had been privy to the information that was vital to her care and health issues.

There are undoubtedly cases where young people with mental health issues require prescription medication, in addition to other forms of care. However this should only be done in the case of under-18s with the involvement, knowledge and consent of the parents or guardians.

I ask the Petitions Committee to investigate this issue fully to try and ensure no more parents have to go through what I have gone through in recent months.
Thank you for your letter dated 9 April 2018 regarding the above petition, and for inviting me to give evidence on this matter. Consideration has been given to the suggestions in that letter, and I outline the Scottish Government’s proposed action below:

1. Consent Forms

Firstly, the petitioner suggested introducing the use of written consent forms for young people who have been prescribed antidepressants, and you asked for the Scottish Government’s view on this suggestion.

Having given this suggestion due consideration, my position is that this would undermine the whole concept of capacity and confidentiality. Effective partnerships between people receiving care, their families and healthcare services are central to this and capacity to give consent is one of the core ethical foundations on which the clinician-patient relationship is based.

GPs and other medical practitioners already have very clear duties in this regard and the capacity of all patients to consent to treatment must be considered by the prescriber in every treatment situation, not just in cases of anti-depressants and young people. Requiring written consent forms for young people being prescribed mental health medication is potentially discriminatory towards children and young people as well as creating issues of parity between mental and physical health.

In addition, as I stated when I appeared in front of the Committee, I agree with the Scottish Youth Parliament and others, that young people have a right to confidentiality when seeking medical advice and to make informed decisions about consent. To change the current system may deter children and young people from seeking help from doctors and other professionals, and may make them less likely to disclose the full facts of how they are feeling and their symptoms. This is the case across the range of physical as well as mental health conditions.

The General Medical Council guidance on capacity is comprehensive, and states:

“You must decide whether a young person is able to understand the nature, purpose and possible consequences of investigations or treatments you propose, as well as the consequences of not having treatment. Only if they are able to understand, retain, use and weigh this information, and communicate their decision to others can they consent to that investigation or treatment. That means you must make sure that all relevant information has been provided and thoroughly discussed before deciding whether or not a child or young person has the capacity to consent.”
The capacity to consent depends more on young people’s ability to understand and weigh up options than on age. When assessing a young person’s capacity to consent, you should bear in mind that:

i. at 16 a young person can be presumed to have the capacity to consent

ii. a young person under 16 may have the capacity to consent, depending on their maturity and ability to understand what is involved.

It is important that you assess maturity and understanding on an individual basis and with regard to the complexity and importance of the decision to be made. You should remember that a young person who has the capacity to consent to straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences. The capacity to consent can also be affected by their physical and emotional development and by changes in their health and treatment.”

The Health and Social Care Delivery Plan sets out that people should be ‘regularly involved in, and responsible for, their own health and wellbeing’. In the plan, the Scottish Government committed to reviewing the capacity and consent process for patients in Scotland with the General Medical Council and Academy of Medical Royal Colleges. That work is now underway.

There is also a growing recognition that shared decision making can lead to more effective healthcare. In her first annual report, Realistic Medicine, the Chief Medical Officer (CMO) Catherine Calderwood sets out a new approach based on ‘realistic medicine’ that will support people through informed, shared decision-making to better reflect their preferences and what matters most to them. She said: “You should expect the doctor (or other health professional) to explore and understand what matters to you personally and what are your goals, to explain to you the possible treatments or interventions available with a realistic explanation of their potential benefits and risks for you as an individual, and to discuss the option and implications of doing nothing. You should expect to be given enough information and time to make up your mind. You should consider carefully the value to you of anything that is being proposed whether it be a treatment, consultation or diagnostic investigation and be prepared to offer challenge if you feel it appropriate.”

Realistic Medicine and the CMO’s subsequent reports give examples of work already underway to support the change in culture described, including the development of decision support tools and techniques such as ‘Teachback’. The Health Literacy Place (www.healthliteracyplace.org) is another online resource for practitioners that provides case studies, tools and techniques to support shared decision making.
In ‘Realising Realistic Medicine’, the CMO committed to commissioning a citizens’ jury, to provide an opportunity for members of the public to consider realistic medicine in greater depth. The jury will be held later this year and its conclusions will provide insight into what members of the public, with the benefit of evidence from experts, consider could be done to foster shared decision making across Scotland.

2. **Medicine information leaflets**

In relation to the petitioner’s suggestion of a printed medicine information leaflet to be given to a young person and then potentially them to a parent or guardian, every prescribed medicine already has a patient information leaflet already printed and folded inside the medication pack. Any patient can read this and share with anyone else in their family or support network should they so wish.

3. **SAMH survey and GP awareness**

I have also reflected on the findings of the SAMH survey published in March 2014 and have asked officials to work with the Royal College of GPs, the Royal College of Psychiatrists and the British Medical Association to provide information to general practitioners reflecting on the issues and learning raised by this petition, to inform them of where they can find more information and training about non-pharmaceutical treatment options for common mental health problems and to promote the relevant SIGN Guidelines. We will ensure this is sent out to general practitioners by the end of June 2018. We will also ensure a copy is sent to the Committee.

4. **Support at consultations**

Finally, the Petitioner mentions in her response of 19 February that patients have the right to have a supporter with them for their appointment, if they so wish, and suggests that GPs may not always be informing children and young people of this possibility. I would like to reassure the Committee that all practitioners will be familiar with the benefits of involving relevant others in the care of patients of all ages and with both physical and mental health conditions. Most practitioners, if not all, will be inviting some of their patients to consider and agree to involve a family member or other supporter in their care and treatment as part of their day to day practice. The GMC’s guidance for doctors includes discussion of situations when patients may need extra support in their care and how this might be applied.
Healthcare Improvement Scotland’s work in Children and Adolescent Mental Health Services (CAMHS)

Background

The ihub (Healthcare Improvement Scotland’s improvement directorate) manages a Mental Health portfolio which leads national improvement work for CAMHS services. This work is split across the Scottish Patient Safety Programme for Mental Health (SPSP-MH) and the Mental Health Access Improvement Support Team (MHAIST). SPSP-MH, part of the national SPSP programme, has been operational for 5 years with a focus on improving the safety and quality of care. MHAIST is a newer offering that has a specific focus on improving access and waiting times.

Summary of MHAIST activity

Introduction

The Mental Health Access Improvement Support Team (MHAIST) was operational from summer 2016. The team initially worked with specific Boards, offering responsive improvement support tailored to localised need. This included providing practical advice and support to:

- Analyse current service provision to identify the key opportunities for making better use of existing resources. This has included supporting systems to apply quality improvement approaches such as:
  - mapping current processes to understand where there is duplication, waste and fragmentation;
  - analysing demand and capacity data to understand the scale of the mismatch and where there are opportunities for reducing demand and/or making better use of current capacity, and
  - making systematic use of clinical outcomes to track the impact of the treatment provided.

- Develop targeted improvement plans.

- develop the local quality improvement capability so that staff working within CAMHS and psychological therapies services have the knowledge and skills in how to systematically test improvements to processes, assess if the change has led to an improvement and, where it has, embed the change into routine practice.

Through the support noted above, the team has identified that there are improvement opportunities specific to the different CAMHS and Psychological Therapies communities, as well as opportunities where learning and sharing across communities would be beneficial.
To ensure those opportunities are realised, and to maximise the impact of the national support, MHAIST is now running a joint CAMHS and PT Mental Health Access Improvement Collaborative which consists of two workstreams:

1) Neurodevelopmental Pathways for CAMHS (Neurodevelopmental Pathways provide treatment for children with Neurodevelopmental Disorders, which may include Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorders, Learning Disabilities and Speech and Language Disorders)

**Aim:** The aim of this workstream is to support services to develop and implement an effective neurodevelopmental pathway enabling

- 50% of children and young people presenting to CAMHS across Scotland with a neurodevelopmental condition to be assessed and diagnosed within 18 weeks of referral by December 2018.
- 95% of children and young people presenting to CAMHS across Scotland with a neurodevelopmental condition will be assessed and diagnosed within 18 weeks of referral by June 2019.

2) Increasing access for Psychological Therapies and CAMHS

**Aim:** The aim of this workstream is to improve access to CAMHS and PT services in Scotland to deliver better experiences for people who require this support. The work will support services to achieve the target of 90% of people requiring CAMHS and PT services receiving treatment within 18 weeks of referral to the service.

**The collaborative process**

The collaborative will run from May 2018 to October 2019 and will follow the Breakthrough Series Collaborative model developed by the Institute of Healthcare Improvement (IHI). This approach formed the basis of the initial SPSP-MH work. Collaborative events will be open to teams from across NHSScotland who have joined the collaborative following the application process. The process (see figure 1) consists of 2 learning sets a year where teams come together to share ideas, learning and progress. In between learning sets, teams are supported by MHAIST WebEx sessions to use quality improvement methodology to develop change ideas to test in the ‘action learning’ period between events.
Following the success of the first four years of the Scottish Patient Safety Programme for Mental Health (SPSP-MH), there was an ask from the Scottish Government to extend the reach of programme. The team encouraged NHS boards to continue to build on the success to date, while at the same time, identifying local priorities across health and social care partnerships, including how best SPSP-MH could extent into the CAMHS environment.

Working in partnership with the Mental Health Access Improvement Support Team (MHAIST), SPSP-MH co-hosted two events in 2017 which helped to identify where the two teams can work together in the CAMHS environment. The following priority areas were identified as areas which SPSP-MH and MHAIST will initially concentrate on:

- Developing the Patient Safety Climate Tool (PSCT) within CAMHS. (SPSP-MH)
- Supporting Carers Trust Scotland in expanding the use of the Triangle of Care Carers Included: A Guide to Best Practice in Mental Health Care in Scotland (MHAIST/SPSP-MH)
- Reviewing the possibility of adapting SPSP-MH Safety Principles from an adult inpatient to a CAMHS environment; work is at an early stage around this and which is ongoing in 2018-19. (SPSP-MH)
- Updating the ‘Essential CAMHS’ toolkit, which is used by all staff in the CAMHS environment with NHS Education for Scotland (NES) and the Carers Trust (SPSP-MH).
- Hosting a range of national, regional and community specific events to understand local systems and priority areas for CAMHS.
- Collaborating with a range of partners from across the UK to learn and share new knowledge and ideas (MHAIST).
Please find attached our response to your request for an update on the Young Scot/SAMH “Youth Commission on Mental Health”, which launched at the end of April. I hope the information in the attached briefing is helpful and please do not hesitate to contact me if you have any further questions.
Youth Commission on Mental Health Services

Young Scot are currently working in partnership with SAMH and Scottish Government to develop a 15-month Youth Commission on Mental Health Services in response to the Mental Health Strategy 2017-27 and the ambition for people to ask once, get help fast, expect recovery and fully enjoy their rights, free from discrimination and stigma. To achieve the best mental health outcomes possible, a key action in the strategy is to take a whole system approach to reviewing child and adolescent mental health services (CAMHS) and deliver services for young people with a key focus on prevention and early intervention.

Over the next 15 months, the Commission will gather evidence, encourage debate and conversation and develop a set of solutions and recommendations from young people to the Scottish Government and other service providers on how child and adolescent mental health services can be developed and improved for young people in Scotland both now and in the future.

STATUS

We have recently recruited 22 young people aged 13-22 from all over Scotland and from a variety of socio-economic backgrounds. The Commission represents a diverse range of young people including care experienced, LGBT+ young people, those from BAME communities and those with extensive experience of using mental health services and others with little or no experience of using services.
CO-DESIGN: EXPLORE OPPORTUNITIES AND DEVELOP IDEAS AND SOLUTIONS FOR IMPLEMENTATION

The overall timeframe for the Youth Commission is 15 months, 12 months of which will see the Youth Commission undertaking a wide range of activity with both their peers and key stakeholders from across the country, including research, expert witness events, evidence gathering sessions, attending relevant events and conferences to increase knowledge and gather insights, developing and testing ideas and solutions, creating recommendations and contributing to the Mental Health Biannual Forum in December 2018. The Youth Commission will follow the Young Scot co-design methodology which enables young people and experts or stakeholders to explore insights and experiences and develop ideas together. The table below provides an outline of each of the five stages of the co-design process and the activity/outputs that will be undertaken during each stage.

<table>
<thead>
<tr>
<th>CO-DESIGN STAGE</th>
<th>RATIONALE</th>
<th>ACTIVITY</th>
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<tbody>
<tr>
<td>Explore</td>
<td>Define by uncovering the issues through gathering insights and experiences from experts, stakeholders and young people.</td>
<td>Understanding perspectives/awareness Understanding “the system” Building capacity Desk research Commissioning new research, where gaps are identified from desk research, involving online and offline engagement Expert Witness Events – special events to hear and gather evidence from experts Local events, to promote and stimulate debate and gather views</td>
</tr>
<tr>
<td>Create</td>
<td>Generate ideas and co-produce solutions with/by young people.</td>
<td>Increasing awareness with young people Challenging “the system” through wider ideas and recommendations Defining / prototyping ideas and solutions Strategic relationships – building further</td>
</tr>
<tr>
<td>Reflect</td>
<td>Consider the future impact and sustainability of the ideas / solutions produced.</td>
<td>Strategic relationships – sharing preliminary findings with peers &amp; experts Testing models for ideas and solutions Survey for feedback from peers</td>
</tr>
<tr>
<td>Recommend</td>
<td>Produce influential ideas / solutions with young people.</td>
<td>Reporting and Presenting – consolidating insights, finalising recommendations/ideas and presenting these to Scottish Government and key stakeholders/decision-makers. Presentation of work at the Mental Health Biannual Forum</td>
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Young Scot’s tried and tested co-design approach, to support the young people to develop informed insights, ideas, recommendations and solutions for policy and practice in relation to child and adolescent mental health services. This model will provide opportunities for the Youth Commissioners to engage with key stakeholders, experts and young people from across Scotland and potentially further afield.
We see this as a 15-month-long study with appropriate milestones into mental health services for young people – fully led by young people, resulting in both recommendations and solutions. In addition, based on Young Scot and SAMH experience, it is recommended an Advisory Group of stakeholders be established to provide guidance, a sounding board and possible mentoring to the Youth Commissioners.

‘I am excited to have an opportunity to make real change to improve the quality of care for young people struggling with their mental health’ (Commissioner, 17)

‘I’m excited to meet people just as passionate as I am and to be part of a positive change to current services’ (Commissioner, 15)

‘Young people are often made to feel like their feelings are invalid just because they are young, this negatively impacts on individuals’ mental health and needs to change.’ (Commissioner, 19)

All young people involved will have the opportunity to receive formal accreditation for their involvement, primarily through the Youth Achievement Awards and the Saltire Awards for volunteering.

The independence of the Commission is vital to ensure credibility therefore Young Scot and SAMH would simply facilitate and support the group. Training in research, facilitation, media and presentation skills for the group will also be co-ordinated by Young Scot and SAMH, paying particular attention to the specific capacity building approaches required for those with lived experience of mental health problems.

**LAUNCH**

We officially launched the Commission on Thursday 26th of April in the Royal Botanic Gardens Edinburgh. The Minister for Mental Health, Maureen Watt, met with our Commissioners and discussed their hopes and ambitions for the year ahead on the Commission.
SHARING LEARNING

Sharing the learning with other young people and relevant organisations / individuals across Scotland will be a key strand of activity. We will therefore develop a simple digital platform to allow progress and learning to be shared as the programme develops.

In addition, the following parallel activities will also require to be engaged and where possible, aspects of coordination and synchronisation should be considered:

- Audit Scotland review of Children and Young People’s Mental Health
- Scottish Government / SAMH / ISD audit of rejected CAMHS referrals in Scotland
- Education Scotland review of PSE
- Scottish Youth Parliament – Work in relation to ‘Our Generation’s Epidemic’ report, and consultation with young people on Anticipatory Care Plans and transitions from children’s mental health services into adult mental health services
- Youth Forum Renfrewshire

As part of the overall Youth Commission process, we will ensure that relevant on-going work being undertaken by other organisations is considered and where appropriate, used to inform the Youth Commission’s investigation and evidence gathering. In addition, we will seek opportunities to involve the Permanent Secretary in the work of the Youth Commission given her interest in children and young people’s mental health as a key theme of the Year of Young People 2018.

REPORTING

During the Recommend phase of the Co-design process, the Youth Commissioners will compile a final report for the Minister and the Scottish Government. In December 2018, there will be an opportunity for the Youth Commission to present their work and test out their findings so far at the Mental Health Biannual Forum before producing their final report and set of recommendations. We would also hold an event in March 2019 at the end of the process for the Youth Commissioners to formally report to the Minister and Scottish Government.

OUTCOMES

Evaluation of both the process and impact will be embedded throughout the programme, including working with the Youth Commissioners and Evaluation Support Scotland to develop a theory of change. We will be seeking to monitor and evaluate the key outcomes for the project, namely:

- The Scottish Government and service providers better understand young people’s experiences of mental health and service delivery in response to mental health needs
- Young people have opportunities to propose and influence changes that would improve mental health service delivery and outcomes for young people

The programme should also evaluate the personal outcomes for young people involved in the Youth Commission, including:

- Increased confidence, a sense of empowerment and raised aspirations
- Development of new skills, experiences, qualifications and accreditation
- Greater awareness and understanding of decision-making processes
- Increased employability
FURTHER INFORMATION
For more information please contact:

Louise Macdonald OBE | CEO | Young Scot | Louisem@young.scot | @Louisemac
Public Petitions Committee
10th Meeting, 2018 (Session 5)
Thursday 7 June 2018

PE1631: Child Welfare Hearings

Note by the Clerk

Petitioner Maureen McVey

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to change the laws that govern the recording of discussions at Child Welfare Hearings (CWH) in Scotland so that presiding Sheriffs have access to such records.

Webpage Parliament.scot/GettingInvolved/Petitions/PE01631

Introduction

1. This is a continued petition that the Committee last considered at its meeting on 15 March 2018. At that meeting, the Committee agreed to write to the Scottish Government and charities providing advocacy and support to children.

2. Responses have now been received from the Scottish Government, the Scottish Child Law Centre and the petitioner and the Committee is invited to consider what action it wishes to take.

Committee Consideration

Fixed specialised family law courts

3. At the last consideration of this petition on 15 March 2018, the Committee noted a suggestion made by the petitioner to use fixed specialised family law courts for Child Welfare Hearings as an alternative to the current arrangement of holding them in local courts across Scotland. The Committee sought the Scottish Government’s view in relation to this suggestion.

4. The Scottish Government’s written submission of 27 March 2018 explains that the Courts Reform (Scotland) Act 2014 (the Act) gives powers to the Lord President to determine that family cases be heard by specialist family sheriffs. The Scottish Government highlights that there are a number of matters which the Lord President would need to consider before determining that family cases be heard by specialist sheriffs including the number of expected cases, the time they are expected to take and how many sheriffs might be required.

5. The petitioner’s written submission of 30 May 2018 states that she recognises that the Lord President can determine what family cases are heard in family courts and questions—
“Is there then a criteria for the Lord President to determine when and in what child contact cases this happens? At present some child contact cases are held in peripheral courts for example Ayr, Dumbarton, Inverness etc., as Child Welfare Hearings. Are these courts deemed as family courts or are the family courts only within Glasgow and Edinburgh where Specialised Sheriffs hear family cases?”

6. The petitioner states that it is her understanding that the Lord President can make the decision regarding Sheriff specialisms within the court system, but that the Act “does not delineate and specify that the family court/child Welfare Hearings could be heard within this specialism”.

Current practice of recording discussions at Child Welfare Hearings

7. At its meeting on 15 March 2018, the Committee considered a recommendation made to the Scottish Civil Justice Council from independent research it had commissioned as follows —

“Use note sheets to ensure information flowed between sheriffs in situations where scheduling meant the same sheriff was not able to remain with the case”.

8. The Committee agreed to write to charities providing advocacy and support to children including Young Scot, Barnardo’s, Children 1st, the Scottish Child Law Centre, Children in Scotland and Who Cares? Scotland for views in relation to the current practice of recording discussions at Child Welfare Hearings.

9. Young Scot responded by stating that it does not speak on young people’s behalf and had nothing to submit on this occasion in relation to the petition. Who Cares? Scotland explained that as Child Welfare Hearings are a forum where custody issues are disputed between two separated biological parents, this is not something that “crosses their world”.

10. The Scottish Child Law Centre submission of 16 April 2018 is supportive of the idea of note sheets stating—

“…it would be beneficial to sheriffs to have sight of notes from previous presiding sheriffs of Child Welfare Hearings in order that the current presiding sheriff has all sufficient and relevant information before them, not only information from the parties, to enable the sheriff to conduct the Welfare Hearing”.

11. While supportive of the use of the note sheet system, the Scottish Child Law Centre highlights that this should only be used to facilitate information flow between sheriffs and should not attach a presumption that a previous decision be continued. In other words, it is their view that note sheets should not compromise judicial impartiality.

12. It is also the Law Centre’s view, that note sheets would improve the quality of decision making, promote and safeguard the best interest of the child, promote
consistency and therefore improve the experience of a Child Welfare Hearing for the child.

13. In striking the appropriate balance between recording discussions at Child Welfare Hearings without it being overly burdensome, the Law Centre suggests that—

“...it would improve the Child Welfare Hearing process for sheriffs to provide a written account of the basis on which their decision in the Child Welfare Hearing to form in the form of a “Child Welfare Hearing Decision Note” for future presiding sheriffs to have sight of. We suggest that the written decision include the discussions which the sheriff was presented with during the Child Welfare Hearing, what weight was given to submissions and any determination as to the child’s best interests. We would suggest that a written decision confirms that the presiding sheriff has considered the note(s) from the previous hearing(s)”.

14. In response, the petitioner states that the use of a decision note “is a welcome addition to the basic interlocutor using prescriptive terms relating to contact times in the main”.

Planned consultation by the Scottish Civil Justice Council

15. Members will recall that the Scottish Civil Justice Council have agreed to carry out a consultation on a report by the sub-committee on case management of family actions. The consultation opened on 30 May 2018 and will close on 22 August 2018 and seeks—

“…views on recommendations to improve how family and civil partnership actions are dealt with in the sheriff court, particularly in order to prevent undue delay in proceedings relating to the welfare of children”.

16. A final report on the consultation will be published on the Scottish Civil Justice Council’s website.

Review of part 1 of the Children (Scotland) Act 1995

17. The Scottish Government’s most recent written submission highlights that it also intends to issue a consultation on a review of part 1 of the Children (Scotland) Act 1995. The consultation opened on 15 May 2018 and seeks views on a wide range of areas in order to reform part 1 of the 1995 Act which covers parental responsibilities and rights and on creating a Family Justice Modernisation Strategy. The consultation also covers other matters related to family law, such as aspects of the Children’s Hearings System.

18. In response, the petitioner states—
“It does seem that the Lord President has in his future plan the needs of a specialism within the family court system and hopefully this comes to fruition for our children and families sake.”

Conclusion

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

- To ask the Lord President’s Office what, if any, criteria are used to determine what family cases are heard in family courts and in what child contact cases this happens.
- To ask the Scottish Government to respond to the suggestion made by the Scottish Child Law Centre with regard to the use of Child Welfare Hearing Decision Note.
- To defer further consideration of the petition until the outcome of the consultations by the Scottish Civil Justice Council and the Scottish Government have been published.
- 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—

- PE1631/L: Scottish Government submission of 27 March 2018 (84KB pdf)
- PE1631/M: Scottish Child Law Centre submission of 16 April 2018 (175KB pdf)
- PE1631/N: Petitioner submission of 30 May 2018 (72KB pdf)

All written submissions received on the petition can be viewed on the petition [webpage](#)
## PE01631: Child Welfare Hearings

<table>
<thead>
<tr>
<th><strong>Petitioner</strong></th>
<th>Maureen McVey</th>
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<tr>
<td><strong>Date Lodged</strong></td>
<td>23 November 2016</td>
</tr>
<tr>
<td><strong>Petition summary</strong></td>
<td>Calling on the Scottish Parliament to urge the Scottish Government to change the laws that govern the recording of discussions at Child Welfare Hearings (CWH) in Scotland so that presiding Sheriffs have access to such records.</td>
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| **Previous action** | 1. I have met with my local MSP, Mr John Scott, to discuss my petition. I also contacted Ms Aileen Campbell, then Minister for Children, to see if there is any intention to update CWH. Her office emailed to say that verbatim recording of criminal cases in Scotland is currently very restricted and bound by legislation set out in section 93 of the Criminal Procedure (Scotland) Act 1995. There is no comparable section in relation to CWH.  

2. I have also written under the auspices of Grandparents Apart UK to the Scottish Civil Justice Council (SCJC) in January 2016 relating to the recording of what is discussed during CWH. (Also contained within my letter were issues around specialised Sheriffs, judicial training, case management and mental health issues, however these were for the Lord President and SCJC Family Law Committee to consider.)  

I received a reply from the SCJC Secretariat advising that I contact the Scottish Government on recording discussions at CWH. The letter states:  

- The recording of what is discussed at Child Welfare Hearings (CWH) is presently that there are no rules of court providing for a “verbatim” recording of these discussions. They state that recording of such hearings would require a policy decision by the Scottish Government  

- Disclosure of personal data, Chapter 28, Rule 28.8 the Sheriff Court Ordinary Cause Rules makes a specific provision on confidentiality.  

However, SCJC suggests I may seek an update from the Scottish Government on the current position regarding confidentiality. |
| **Background information** | It states in the UN Convention on the Rights of the Child, Article 3. “The best interests of the child must be a top priority in all decisions and actions that affect children.”  

Also within the Family Law (Scotland) Act 2006 it can be noted that the welfare test (also known as the “best interests” test) which is used by courts to make decisions about parental rights and responsibilities – usually decisions about residence and contact – has been |
amended.

The court time spent in some CWH is detrimental to both parents and the child involved.

The Sheriffs presiding in CWH try and resolve issues surrounding contact as best they can. However, it is sometimes impossible when a few CWH become adversarial and protracted which is not in the best interest of the child.

The modernisation of Scotland’s civil justice system was undertaken by Lord Gill. Lord Gill recommended substantial changes to modernise and improve the structure and operation of the courts, which he described as “slow, inefficient and expensive”.

Lord Gill and his Project Board delivered the report on the review of Scottish Civil Courts in 2009. On 6 February 2014 the Courts Reform (Scotland) Bill was formally introduced in Parliament by Kenny MacAskill and the Royal Assent was received on 10 November 2014.

I noted also with interest that within the Scottish Civil Courts Review Bill 2014, family courts were to be looked at. However, it is not clear if the term family courts encompasses both Children’s Hearing System and the Child Welfare Hearings.

I therefore feel if the Child Welfare Hearings are not included within the changes then they should be.

I have highlighted some changes/recommendations which I feel would be of benefit to all court users using Child Welfare Hearings.

My recommendations regarding procedures which should happen during CWH are:-

- Minute taking or recording what is said at CWH’s and made available to each Sheriff who presides over a particular case. This would fit in with what Lord Gill’s review proposed, regarding the development of the modern methods of communication and case management.

- Recording or Minute taking may lessen the need for numerous CWH going over old ground again and again. It would also assist Sheriffs who are not familiar with the case to have a background on what has gone on before during CWH, rather than an interlocutor detailing only the outcome of the CWH. This is even more important since this would also have particular regard to the cost of litigation to parties and to the public purse.
Thank you for your letter of 19 March 2018 to my officials.

The Courts Reform (Scotland) Act 2014 gives powers to the Lord President of the Court of Session and to the Sheriffs Principal in relation to judicial specialisation. Under section 34 of the 2014 Act, the Lord President may determine categories of sheriff court case which the Lord President considers to be suited to being dealt with by judicial officers who specialise in that category of case. Therefore, the Lord President could determine that family cases be heard by specialist family sheriffs.

Once categories of cases for specialist treatment have been determined by the Lord President under section 34, section 35 permits Sheriffs Principal to designate one or more sheriffs or summary sheriffs as specialists in one or more of those categories.

Decisions on specialist sheriffs are, therefore, a matter for the Lord President and the Sheriffs Principal rather than for the Scottish Government.

However, it appears to the Scottish Government that there are a number of matters which the Lord President would need to consider before determining that family cases be heard by specialist sheriffs. These include:

- Careful consideration of the number of expected cases that might arise; the time they are expected to take and how many sheriffs might be required to deal with those cases.
- Whether there would be sufficient specialist judiciary across Scotland, bearing in mind that Scotland has courts in large urban areas and courts in more rural areas.
- Exactly what would be treated as family cases. These can be quite varied and include, for example, divorce, financial provision on divorce, contact and residence and applications for civil protection orders against domestic abuse.
- The judicial training requirements.

The Scottish Government is aware that in some parts of Scotland, such as Glasgow and Edinburgh, there are sheriffs who spend most of their judicial time dealing with family cases.

You also asked about the planned consultation by the Scottish Civil Justice Council (SCJC) on the report by the sub-committee on case management of family actions. The timings of that consultation are for the SCJC, rather than for the Scottish Government. In line with usual practice, the consultation will need to be cleared by the SCJC and its Family Law Committee. I understand a draft of the consultation may be put before the Family Law Committee for its meeting on 30 April 2018.

Finally, the Public Petitions Committee and the Petitioner may be interested to know that the Scottish Government will shortly be issuing a consultation on a review of part 1 of the Children (Scotland) Act 1995. This will seek views on a wide range of areas including:

- How best to obtain the voice of the child in contact and residence cases and how best to feedback the outcome of the case to the child.
- The regulation of Child Welfare Reporters.
- The regulation of Child Contact Centres (which, of course, is directly relevant to Public Petition PE 1635).
- Child contact with grandparents and siblings.
• Complying with contact orders.
• Cross-UK border family cases and jurisdictional issues.
• Aspects of the law on parentage.
• Parental Responsibilities and Rights.
• Joint birth registration.
• Shared parenting.
• The role and involvement of non-resident parents.
• Child abduction by parents.
• Domestic abuse.
• Alternatives to court, such as mediation.
• Guidance.
• Aspects of birth registration.
• Aspects of the children’s hearings system.

I will ensure the Committee is sent the Scottish Government consultation when it is issued.
Thank you for your letter dated 19th March 2018 in which we were invited to comment on petition PE1631 seeking reform of the way in which the discussions in Children’s Hearings are recorded. Please find the views of the Scottish Child Law Centre below:

- **Current practice** - The rules governing Child Welfare Hearings are found within the Ordinary Cause Rules (OCR), Chapter 33.22A. It provides that the sheriff shall “seek to secure the expeditious resolution of disputes in relation to the child by ascertaining from the parties the matters in dispute and any information relevant to that dispute” (OCR 33.22A(4)). There is no provision requiring the recording of discussions or the recording of reasons for a Sheriff's decision for consideration by any future presiding Sheriff. There exists an explicit duty on parties to “provide the sheriff with sufficient information to enable him to conduct the Child Welfare Hearing.” (OCR 33.22A(6)).

  **Our comments** – in pursuance of securing the expeditious resolution of disputes in relation to the child we suggest that it would also be beneficial to sheriffs to have sight of notes from previous presiding sheriffs of Child Welfare Hearings in order that the current presiding sheriff has all sufficient and relevant information before them, not only information from the parties, to enable the sheriff to conduct the Welfare Hearing.

  **Concerns** – We respectfully suggest that the purpose of a note sheet system should be to ensure information flow to enable the presiding sheriff the opportunity to consider the reasoning of a previous decision but not to attach a presumption that such previous decision should be continued/followed. The importance of judicial impartiality should not be compromised by an information flow system.

- **Improving quality of decision making** – we support information flow between sheriffs in the form of written reasons for decisions made to ensure that all relevant information is before the presiding sheriff. We consider that this will improve the quality of decision making and promote and safeguard the best interest of the child.

- **Improving the experience for the child** – It is suggested that information flow from previous Child Welfare Hearings will promote consistency thus improving the experience for the child.

  In order to ensure the child’s views are taken into account in sheriffs’ decision making it may be appropriate for the presiding sheriff to include in the note details of any view expressed by the child or reasons for not obtaining the child’s views.

- **Experience from the Scottish Child Law Centre** – We have received calls to our advice line which reflect concern from parents and young people when there have been different sheriffs presiding over a Child Welfare Hearing. We
believe that if parents and children knew and could be informed that any decisions made were based on fully informed and relevant information from previous hearings, then this would give assurance to children and families that the principles of natural justice and fair process underpin all decisions and the element of “unfairness” felt by parties would lessen.

- **Striking the right balance** – We suggest that it would improve the Child Welfare Hearing process for sheriffs to provide a written account of the basis on which their decision in the Child Welfare Hearing to form in the form of a “Child Welfare Hearing Decision Note” for future presiding sheriffs to have sight of. We suggest that the written decision include the discussions which the sheriff was presented with during the Child Welfare Hearing, what weight was given to submissions and any determination as to the child’s best interests. We would suggest that a written decision confirms that the presiding sheriff has considered the note(s) from the previous hearing(s).

We hope the above is of assistance. Should you have any questions are require any clarification on the points above please do not hesitate to contact our office.
REPLY TO SCOTTISH GOVERNMENT’S SUBMISSION

I thank the Scottish Government for their reply to Petition PE 1631/L and wish to comment on some points of their reply. I do appreciate and note in Section 34 of the Courts Reform (Scotland) Act 2014 “that it is down to the Lord President or the Sheriff Principle of a sheriffdom to designate particular members of the sheriff court judiciary as specialist in one or more area”.

It states that the Lord President could determine what family cases are heard in family courts.

Is there then a criteria for the Lord President to determine when and in what child contact cases this happens? At present some child contact cases are held in peripheral courts for example Ayr, Dumbarton, Inverness etc., as Child Welfare Hearings. Are these courts deemed as family courts or are the family courts only within Glasgow and Edinburgh where Specialised Sheriffs hear family cases?

Contained within Section 34 and 35 of the Court Reform Scotland Act 2014 it states as I understand it, that the Lord President makes the decision regarding Sheriff Specialisms within the Court system. It does not delineate and specify that the family court/ Child Welfare Hearings could be heard within this specialism.

It is my understanding that children are paramount in any decision made by the family law courts, and as stated within them that their benchmark should always be “in the best interests of the child”. This is at its heart, and at present it tries to make the focal part of CWH system the child, however due in some part to the adversarial nature of some CWH, the child’s welfare sometimes gets lost due to the protracted nature of some CWH. Within these cases there can be a wealth of knowledge about the child heard within the court however there is no continuity in that, no documentation or note taking is held within court and this could be one reason for child contact cases lasting for years, which is not in the child’s best interest. These delays give the opportunity in some cases, for the resident parent to put the child under pressure to reject the other parent. This can be detrimental to the child/children involved.

Surely then a specialist court/sheriff is a must for these type of cases to prevent children being subjected in some cases to the above behaviour. Lord Carloway, Lord President has said in the past that “Specialised Sheriffs are being looked at in family law cases”. He also stated that as part of his remit for the Judiciary that he wanted “a fairer and effective justice system.”
The figure which seems to be mentioned regarding **protracted child contact cases** which are heard in court is about 5%. Surely then it would be commensurate that within the Scottish Judiciary that these type of cases which are problematic could be held within a specialised family court system. Only when it becomes evident that a case is becoming problematic and protracted then could the Lord President, be made aware of this and the case then could be heard at the Specialised Family Courts within Glasgow, Edinburgh for example?

It would assume that this type of family court has the knowledge base within it to deal with these more protracted cases and get to the heart of why they are protracted in the first instance.

Maybe a more detailed fact finding system at the outset with both parents, regarding child contact could take place prior to going into the courtroom. This would expedite or negate the need for protracted CWH.

Since there is a modernisation strategy of the family court system ongoing, and the use of **case management** within the family court setting is being looked at, then it will negate the need for long drawn out contact cases involving parents and their child/children.

Children deserve better.

It does seem that the Lord President has in his future plan the needs of a specialism within the family court system and hopefully this comes to fruition for our children and families sake.

**REPLY TO SCOTTISH LAW CENTRE SUBMISSION**

I thank the Scottish Law Centre for their submission and wholehearted agree with the contents therein.

Any means used to expedite a Child Welfare Hearing for the benefit of all concerned but especially the children who are at the heart of discussions is welcomed. Thus ensuring that the child’s best interests are at the forefront of all decisions made.

Using as suggested a Child Welfare Hearing Decision note is a welcome addition to the basic interlocutor using prescriptive terms relating to contact times in the main.

Continuity for all concerned seems the way forward, and I do hope that the soon to be updated Children (Scotland) Act 1995, will contain some changes, which will enhance the outcomes of future issues regarding family law for all concerned especially the children.
Public Petitions Committee

10th Meeting, 2018 (Session 5)

Thursday 7 June 2018

PE1690: Review treatment of people with ME in Scotland

Note by the Clerk

Petitioner Emma Shorter on behalf of ME Action in Scotland

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to review the level of support for people with Myalgic Encephalomyelitis (ME) in Scotland with a view to:

- Investing in biomedical research and creating a centre of excellence for ME
- Ensuring healthcare professionals' training and education materials reflect the latest scientific evidence
- Providing specialist care for patients and discontinuing the harmful treatments graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

Webpage parliament.scot/GettingInvolved/Petitions/PE01690

Introduction

1. This is a new petition that collected 5,765 signatures of support online (with a further 1,274 collected offline, as of 30 May 2018) and 453 comments.

Background (taken from the SPICE briefing)

2. ME stands for myalgic encephalomyelitis. It is also sometimes referred to as chronic fatigue syndrome (CFS). However, there is some debate about the term used for the condition\(^1\) and it is often referred to as ME-CFS.

3. ME-CFS is a long-term illness with a wide range of symptoms. The most common symptom is extreme tiredness\(^1,2\). ME-CFS is more common in women and in patients aged from 35-55 years. However, it can affect men and women of any age and any ethnic group. Epidemiological evidence is lacking in Scotland but a population prevalence of at least 0.2-0.4% is widely accepted and it is thought that over 20,000 people in Scotland may be affected\(^3\).

4. The diagnosis of ME-CFS is clinical, based on recognising specific symptom patterns. Currently, there are no specific tests available to confirm the presence of the illness. Prognosis is extremely variable. Most patients have a fluctuating

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\(^1\) NHS Choices website.

\(^2\) The petitioners note that this statement stems from criteria developed in 1991 and that post-exertional malaise is now considered the key criteria for diagnosis, in line with Canadian guidelines.

\(^3\) Scottish Good Practice Statement on ME-CFS.
course of illness with some people recovering, or improving significantly, in less than two years, while others remain ill for several decades.

Guidelines

5. In 2010, the Scottish Government produced the Scottish Good Practice Statement on ME-CFS as a guide for health professionals on the diagnosis and management of ME-CFS. This was supported by two other pieces of guidance: A quick reference clinical guide and a patient guide.

6. NICE (The National Institute for Health and Care Excellence) has produced a clinical guideline chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management. This is currently being updated and a new guideline is due to be published in 2020.

7. The Scottish Government has indicated that any decision on reviewing the Scottish Good Practice Statement will be taken after the updated NICE guidelines are published, to ensure any changes are based on the most up to date clinical evidence available.

Health care needs assessment of services

8. Also in 2010, the Scottish Government commissioned the Scottish Public Health Network to undertake a formal health care needs assessment of services for those people who are living with ME–CFS. This assessment made 26 recommendations (see Annex A) including recommendations on the development of:

- the research strategy and the establishment of a centre for research excellence and dissemination.
- a specific tiered ME–CFS service.
- managed clinical networks in order to ensure that there are effective and clinical services to meet the healthcare needs of people with ME–CFS.
- education packages, by NHS Education Scotland and independent organisations, to feed into undergraduate, foundation and professional training of healthcare staff across Scotland.

Research

9. ME Research UK is a charity which aims to commission and fund scientific (biomedical) investigation into the causes, consequences and treatment ME/CFS. They note that much of the existing research into ME has

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4 It should be noted that these documents provide guidance to aid health professionals and clinicians, and are not statutory.
5 Scottish Government personal correspondence – May 2018
6 NHS Education for Scotland offers a wide range of education and training support for both clinical and non-clinical staff in NHSScotland.
concentrated on psychological interventions designed to ‘manage’ the illness and comment that a programme of biomedical research is needed.

10. The Scottish Government’s Chief Scientist Office and Action for M.E. have recently announced a joint funding call for Scottish Universities to host a Ph.D. studentship in biomedical research into the underlying aetiology, diagnosis or treatment of M.E. In May 2018, it was announced that the successful application is to be led by Professor Chris Ponting from the University of Edinburgh. The PhD. student funded through this initiative will use cutting edge techniques to analyse cells from the immune systems of M.E patients compared to healthy controls. While not a clinical trial, this research has the potential to increase the understanding of the underlying causes of M.E.

Treatment

11. The Scottish Good Practice Statement on ME-CFS provides information on interventions, management and rehabilitation. In relation to graded exercise therapy (GET) it notes that:

“it is intended to redress decline in physical fitness due to inactivity. GET has proved to be a particularly controversial form of treatment about which many patients have concerns and some patients have indicated that GET has worsened their symptoms. GET makes use of an exercise programme involving a gradual increase in exercise/activity. It must be delivered by a suitably trained GET therapist with experience in M.E-CFS, ideally on a one-to-one basis. Where fibromyalgia is also present, supervised aerobic exercise therapy may help physical capacity and relieve pain symptoms”.

12. In relation to cognitive behavioural therapy (CBT) it notes that:

“…it can be used, as in other chronic physical medical conditions, as a tool to aid people develop better ways of coping with symptoms such as fatigue, pain and sleep disturbance. CBT may be of particular value to patients when their symptoms have led to a psychological response that has compounded their problems”.

Scottish Parliament and Scottish Government Action

13. As part of its recent Inquiry into Clinical Governance, the Health and Sport Committee took oral evidence from Clare Ogden (Action for M.E) on 14 November 2017. The Committee heard that:

“The “Scottish Good Practice Statement on ME-CFS” was published in 2010: when GPs were surveyed four years later, two thirds said that they were not aware of that statement....That is reflected in the patient experience, too—many patients say that their GP does not understand ME and gives them bad advice that does not help.”

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7 ME Research UK
8 Written evidence was also received – page 8 of Committee papers.
14. They also heard that in relation to ME:

“lots of recommendations that are made do not then become standards—in 2002 there was a short-life working group on ME, in 2007 cross-party group reports identified areas for action, and in 2010 there was a healthcare needs assessment. Lots of elements from all of those pieces of work have still not been put into practice.”

15. A Members’ Business debate was held on the 11 May 2017 on International ME Day (S5M-05038). The Minister for Public Health and Sport commented on the Scottish Government’s work with Action for ME. The Scottish Government has provided funding to the organisation to support project work aimed at making improvements in care for people with ME through increasing knowledge of the condition among health professionals and working to raise awareness, and promote self-management solutions. Action for ME were also awarded funding from the Transforming Self-Management Fund for a project which aims to build confidence and reduce isolation of people, and their carers, affected by ME and the development of a peer-mentoring, self-management support network in Scotland.

Action

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

- Writing to the Scottish Government to seek its views on the action called for in the petition

- Writing to a range of stakeholders to seek their views on the action called for in the petition. Stakeholders might include—
  
  - Action for M.E.
  - Scottish Public Health Network
  - ME Research UK

- Any other action the Committee wishes to take.

SPICe/Clerk to the Committee
**Annex A:** Recommendations from the Scottish Public Health Network’s formal health care needs assessment of services for those people who are living with ME–CFS.

1. It is recommended that the clinical, symptomatic definition of ME outlined in the Canadian guideline be adopted in Scotland.

2. It is further recommended that a symptomatic definition of CFS, based on that proposed in the NICE guideline, be adopted in Scotland.

3. a) There is an urgent need for a sound epidemiological study of ME and CFS in Scotland; in which regard consideration should be given to including ME and CFS within the Scottish Health Survey.

   b) Routine reporting of ME and CFS should be considered within the context of developing information systems for long-term conditions monitoring under the Quality and Outcomes Framework (QOF).

4. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist’s Office and a new strategy developed, aimed at broadening the evidence base for ME–CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a centre for research excellence and dissemination. It is recommended that to meet these expressed needs, health boards in Scotland should develop a specific tiered ME–CFS service that provides:
   - rapid and accurate diagnosis and assessment
   - supportive care and treatment of presenting symptoms
   - access to wider social and economic support.

5. It is recommended that the characteristics of such services would include a local management of care, provided by the primary care team at its heart and supported by a specialist team that can assist in the progress of diagnosis and assessment, and plan care on both a clinic and outreach basis.

6. At the present time there is insufficient research evidence on which to base a SIGN ME–CFS guideline for Scotland. However, a clinical guideline which supports effective diagnosis, signposts people with ME–CFS towards appropriate medical and therapeutic assessment and service, and provides the basis for ongoing care management is desirable. It is suggested that this is in keeping with the Scottish Good Practice Statement on ME–CFS.

7. It is recommended that the tiered model for services proposed by the CMO’s Short-Life Working Group be used as a basis for ME–CFS service development in Scotland.
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<th>8.</th>
<th>It is recommended that a dedicated helpline and website to provide information and support for people with ME–CFS and those who care for them be established in Scotland.</th>
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</table>
| 9. | A broadly constituted stakeholder group should be established to:  
   a) create a national, core information set which can be used for people with ME–CFS and their carers  
   b) create a national, core information set which can be used for health and social care professionals to explore appropriate ways of making such information widely available. |
| 10. | NHS Boards in Scotland should develop formal, care pathways for the diagnosis, assessment and management of people with ME–CFS as outlined in the report of the CMO’s Short Life Working Group. These local pathways should be compatible with the Scottish Good Practice Statement on ME–CFS. |
| 11. | NHS Boards in Scotland should formally identify ME–CFS within their long-term conditions plan or strategy. Management of ME–CFS should be carried out in line with local arrangements for other long-term conditions, where appropriate. |
| 12. | When developing local approaches to long-term conditions management, NHS Boards should ensure that:  
   a) assessment and review mechanisms are in place for people with ME–CFS, including domiciliary assessments/reviews where needed  
   b) appropriate referral mechanisms are in place so that people with ME–CFS can receive appropriate supportive therapies  
   c) appropriate referral mechanisms are in place so that people with ME–CFS can access services that can meet specific, symptomatic needs. |
| 13. | When developing local approaches to long-term conditions management, NHS Boards should ensure that both rehabilitation services and specialist, symptom-specific services have sufficient capacity to support people with ME or CFS in addition to the many other people with long-term conditions for whom they will be providing care. |
| 14. | Local arrangements for transition to adulthood should be extended to cover the needs of young people with ME–CFS. These arrangements should be included in local care pathways. |
| 15. | NHS Boards in Scotland should develop, or assist the development of, self-management programmes to support people with ME–CFS. These programmes should be subject to appropriate quality assurance:  
   a) for the NHS, such quality assurance should be provided by NHS Quality Improvement Scotland  
   b) for the independent or third sectors, guidance on quality assurance should be developed on a wide, partnership basis. |
16. Consideration should be given to developing an appropriate regulatory framework for the provision of self-management programmes by independent or voluntary sector providers as for independent healthcare providers.

17. Consideration should be given as to how best to assist the development of consultant posts for ME–CFS at NHS Board or NHS Regional Planning Group level across Scotland. These consultants should lead multidisciplinary teams to provide services at Tier 3.

18. Consideration should be given as to how best to provide an appropriate skill-mix in medical provision as part of the multidisciplinary teams to provide services at Tier 3.

19. NHS Boards or NHS Regional Planning Groups should prioritise the development of consultant-led services, supported by a Tier 3 multidisciplinary team for ME–CFS. Consideration should be given to a more detailed workforce plan in the medium term. In establishing multidisciplinary teams, the NHS Boards or NHS Regional Planning Groups should:

a) ensure that once staff are appointed, an appropriate period of staff training is funded to allow an effective service to be established
b) ensure that multidisciplinary teams have a suitable lead in time to develop effective collaborative working arrangements with local services at Tier 2.

20. NHS Boards and NHS Regional Planning Groups should develop managed clinical networks in order to ensure that there are effective clinical services to meet the healthcare needs of people with ME–CFS

21. NHS Boards and NHS Regional Planning Groups, working with key stakeholders, should decide how best to ensure the development of such clinical networks for ME–CFS both regionally and across Scotland.

22. NHS Boards should ensure that services which operate at Tier 2 for ME–CFS should have the opportunity and capacity to participate in the development and operation of the clinical networks at regional and national level.

23. NHS Quality Improvement Scotland should work with all interested parties to develop service standards for ME–CFS services in Scotland. Consideration should also be given to developing specific standards for clinical networks as part of this development.
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<tr>
<th>24. NHS Education Scotland should work with independent ME–CFS organisations to develop solutions to ME–CFS issues which would be included within education packages. These should be fed into undergraduate, foundation and professional training of healthcare staff across Scotland.</th>
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<td>25. The third sector and independent sector agencies that work with and for people with ME–CFS should explore how best they can develop educational support for healthcare providers modelled on the approaches of similar agencies.</td>
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<tr>
<td>26. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist’s Office and a new strategy developed, aimed at broadening the evidence base for ME–CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a centre for research excellence and dissemination.</td>
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PE1690: Review treatment of people with ME in Scotland

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<th><strong>Petitioner</strong></th>
<th>Emma Shorter on behalf of ME Action in Scotland</th>
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<td><strong>Date Lodged</strong></td>
<td>1 June 2018</td>
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**Petition summary**

Calling on the Scottish Parliament to urge the Scottish Government to review the level of support for people with Myalgic Encephalomyelitis (ME) in Scotland with a view to:

- Investing in biomedical research and creating a centre of excellence for ME
- Ensuring healthcare professionals' training and education materials reflect the latest scientific evidence
- Providing specialist care for patients and discontinuing the harmful treatments graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

**Previous action**

Contacted MSPs and the Health Minister.

**Background information**

ME is a devastating disease that affects 21,000 people in Scotland and causes profound and disabling ill-health – one in four patients is home or bedbound, and quality of life is some of the lowest recorded of any chronic disease.

ME is defined by the World Health Organisation as a neurological disease (ICD 10 G93.3) but, following recent research, is often called a neuro-immune or multi system disease. It is estimated to affect more than 21,000 people in Scotland (see endnote 1), which is more than the number of people affected by Multiple Sclerosis (MS) and Parkinson’s Disease combined. Due to decades of under-investment in biomedical ME research, there are currently no effective treatments available on the NHS and there are no ME specialist consultants in Scotland. Care is the responsibility of GPs, who do not receive training into how best to diagnose and treat ME, and have often been badly misinformed about the disease.

ME causes profound neurological (2), immunological (3) and endocrinological dysfunction. Research shows that people with ME score lower on health-related quality of life scores than people with most other chronic illnesses, including lung disease, heart disease and MS (4). It is estimated that 25% of ME patients, some of whom have been bed bound for decades, are severely affected unable to sit up, speak or feed themselves.

The estimated cost of ME to the UK economy is £8.8 billion per annum (5, 6), while the human costs are far higher. A recent survey of patients showed that over 65% of people with severe ME had been ill
for 10 years or more. In Scotland, less than 10% of people with ME are in full-time paid work, education or training and only a further 24% are in part-time work, education or training (7).

Issues we would like to see raised by the review:

Research
Commitment to a programme of investment in biomedical research by the Scottish Chief Scientist Office, proportional to disease burden. Creation of a Scottish Centre of Excellence for ME.

Education
Ensure that NHS Education for Scotland (NES) is complying with the classification of ME as neurological disease by WHO and updates its training material based on the latest scientific evidence, and ensuring that there are no conflicts of interest in the development and review of NES materials, with reference to previous studies, such as the PACE trial. Concerns about the PACE trial have recently been raised and, in a recent Westminster debate, Carol Monaghan MP said "When the full details of the [PACE] trial become known, it will be considered one of the biggest medical scandals of the 21st century"(8)

Care
Increased access to and investment in care for patients. Access for patients to physician-led services to provide appropriate advice along with recognition by GPs and medical practices that many people with ME require home visits due to the debilitating nature of the illness. Removal of Graded Exercise Therapy and Cognitive Behavioural Therapy from the Scottish Good Practise Statement. Ensure that no healthcare services in Scotland offer Graded Exercise Therapy and Cognitive Behavioural Therapy. These therapies are based on the outdated bio-psychological model, there is a lack of evidence of efficacy for both CBT and GET and the majority of patients report adverse reactions.

Please support this petition. 21,000 people with ME in Scotland are in desperate need of better care and treatment. Some have been waiting for decades, for others it is too late.

ENDNOTES
2. Nakatomi Y et al. Neuroinflammation in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: An C-(R)-PK11195 PET study 10.2967/jnumed.113.131045
4. HvidBerg M.F et al. The health-related quality of life for patients
with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS)  
PLos One. 2015; 10(7): e0132421:  
http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0132421  

5. Kershaw BJ. How much is M.E. costing the country? Report  
prepared by the Survey & Statistical Research Centre. Sheffield  
Hallam University, 2006. [Estimated annual cost at £6.4 billion in  
2006.]  

6. £6.4 billion in 2006 equates to £8.8 billion in 2017 using the Bank  
of England Inflation Calculator  

7. Action for ME (2016) Time to deliver in Scotland:  
https://www.actionforme.org.uk/uploads/pdfs/me-time-to-deliver- 
survey-report.pdf  

https://hansard.parliament.uk/commons/2018-02- 
20/debates/990746C7-9010-4566-940D- 
249F5026FF73/PACETrialPeopleWithME

| Unique Web Addresses / Related Information | http://www.parliament.scot/GettingInvolved/Petitions/PE01690 |
Public Petitions Committee
10th Meeting, 2018 (Session 5)
Thursday 7 June 2018
PE1695: Access to justice in Scotland

Note by the Clerk

Petitioner  Ben and Evelyn Mundell

Petition summary  Calling on the Scottish Parliament to urge the Scottish Government to take action to ensure that access to justice, including access to legal advice from appropriately trained lawyers and financial support through legal aid, is available to enable people in Scotland to pursue cases where they consider a human rights breach has occurred.

Webpage  parliament.scot/GettingInvolved/Petitions/PE01695

Introduction

1. This is a new petition that was lodged directly rather than being open to collect signatures and comments.

Background to the petition

2. The petition is linked to EU milk quotas. In the UK, farmers were permitted to trade their quotas. However, in a small number of ring-fenced Scottish areas, free trade in quotas was not permitted. One aim behind ring-fencing was to support dairy producers and processors in peripheral parts of the country.

3. The petitioners have claimed in previous public petitions (PE1263 from August 2009 and PE01542 from November 2014) that the Scottish ring-fencing mechanism breached human rights legislation, specifically property rights in the quotas protected by Article 1 of Protocol No. 1 to the European Convention on Human Rights (the Convention).¹

4. Their general argument was that the ring-fencing mechanism was implemented in an arbitrary way which did not correctly balance the right to property and the public interest. The previous petitions also argue that the policy was economically damaging due a paucity of buyers of raw milk in ring-fenced areas as well as farm gate prices which were below production costs. Farmers were therefore unable to sell milk economically in the ring-fenced areas, and also could not trade their milk quotas to fund diversification into other areas of agriculture.

5. More details on milk quotas and ring-fencing can be found in the SPICe Briefing for Petition PE01542.

¹ The Convention is an international treaty which can be relied on in the UK by means of provisions in the Human Rights Act 1998 and the Scotland Act 1998
6. The current petition is focused on access to legal advice and support on human rights law, rather than the human rights impact of the ring-fencing policy itself. Specifically, it argues that:

- The Law Society of Scotland’s list of firms undertaking human rights cases is out of date
- There is a lack of lawyers in Scotland who are willing to take on human rights cases
- The law firms that are willing to take on human rights work will only do so if paid large sums up front and will not consider such work on a legal aid basis

7. According to the petitioners, these issues mean that it is difficult for individuals such as themselves to bring human rights cases in Scotland.

*Access to justice – human rights*

8. The court system is divided into civil and criminal. Criminal courts deal with criminal matters, whereas the civil courts deal with disputes about legal rights and obligations between people or organisations. The human rights issues raised by the petitioner relate to property rights – a civil matter.

9. An individual can represent themselves in any court (in which case they are known as a “party litigant”). However, in all but the simplest of cases, it is normal to be represented by a solicitor who will often begin by providing his/her client with legal advice on the strength of the case and options which would be available.

10. Where a civil case is heard by the Court of Session (Scotland’s highest civil court), it is necessary to engage an advocate\(^2\) (also referred to as “counsel”) as well as a solicitor to present a case. Advocates specialise in presenting arguments to the Court of Session.

*Lawyers undertaking human rights work in Scotland*

11. SPICe does not have information on the numbers of Scottish solicitors or advocates with experience of human rights law.

12. There are, however, certain online sources of information (in addition to the Law Society of Scotland’s find a solicitor service). For example:

- The Legal 500’s index of advocates with experience in human rights
- Chambers and Partners guide to Scottish human rights and civil liberties solicitors

*Bringing human rights cases in Scotland – legal fees*

\(^2\) It is also possible to be represented by a “solicitor-advocate” or one of a limited number of other specialists who have “rights of audience” in the Court of Session.
13. A key issue for anyone considering taking legal action is how much it is going to cost. A party must consider their own legal costs in taking an action (which can include the costs of legal advice, expert evidence, fees for using the courts and using an advocate if necessary. In addition, there also the risk that they may have to pay the other side’s expenses if they lose as the general rule is that “expenses follow success”.

14. Like other professionals, solicitors charge fees to cover the work they do. Clients can be charged an hourly rate, a set rate for the whole job, or in various other ways. Different solicitors charge different fees - and clients can negotiate over the price or the way the work is charged for.

15. In addition, solicitors may also agree to work on a “no win no fee basis” which means that their fees will only require payment if the case is won. Solicitors will usually only be prepared to take on cases on a no win no fee basis where there is a good prospect of success.

16. Solicitors can also choose to work for free (known as “pro bono” work).

17. Further details on solicitors’ fees can be found on the website of the Law Society of Scotland

18. It is possible to agree on fees in advance with an advocate. In addition, advocates can also act on a speculative “no win no fee” basis. If fees are not agreed in advance, it is possible to challenge an advocate’s fee in the Auditor of the Court of Session, an independent public official, who will determine whether the fee is reasonable in the circumstances.

19. Further details on advocates’ fees can be found on the website of the Faculty of Advocates.

Bringing human rights cases in Scotland – legal aid

20. Legal aid is financial help towards the cost of legal advice and representation so that people on low and moderate incomes can gain access to the legal system. It is paid for out of public funds and administered by the Scottish Legal Aid Board.

21. Civil Legal Aid is a form of legal aid which is available to pay for advice and representation in court from a solicitor on a civil law matter. It can cover judicial review actions – i.e. challenging government decisions - including actions based on human rights grounds.

22. The qualifying criteria for Civil Legal Aid are:
   - that there is a plausible legal basis for the claim;
   - that it is reasonable in the particular circumstances of the case that legal aid is granted; and
   - that the applicant meets the financial eligibility criteria.
23. The financial eligibility criteria for qualifying for Civil Legal Aid are disposable income of up to £26,239 and disposable capital of up to £13,017 (in some cases, it can be more).

24. Another form of legal aid is “Advice and Assistance”. This can pay for advice, but not representation, in court.

25. The legal aid rates paid to lawyers are set by statute and can be less than the market rates which lawyers charge for certain types of work.

26. For more general information on the funding of legal actions in Scotland and legal aid see the SPICe briefing on the Civil Litigation (Expenses and Group Proceedings) (Scotland) Bill. See also the SPICe Briefing on Legal Aid.

Scottish Government Action

27. The scope of human rights in Scotland is currently being examined by an expert advisory group set up by the Scottish Government - the First Minister’s Advisory Group on Human Rights Leadership. The first meeting of this group took place on January 17 and 18. It is set to make recommendations by the end of 2018.

Scottish Parliament Action

28. The Equalities and Human Rights Committee is currently carrying out an inquiry into how the Scottish Parliament could enhance its approach to promoting and protecting human rights.

Action

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

- Writing to the Scottish Government and the Law Society of Scotland to seek their views on the actions called for in the petition
- Any other action the Committee wishes to take.

Clerk to the Committee/SPICe
**Petitioner**  Ben and Evelyn Mundell

**Date Lodged**  11 May 2018

**Petition summary**  Calling on the Scottish Parliament to urge the Scottish Government to take action to ensure that access to justice, including access to legal advice from appropriately trained lawyers and financial support through legal aid, is available to enable people in Scotland to pursue cases where they consider a human rights breach has occurred.

**Previous action**  Most recently we have raised this issue with David Stewart MSP.

Before this we have taken a range of steps to try and access justice. These include:

- Asking the Law Society of Scotland for a list of firms undertaking human rights cases and a list of firms undertaking legal aid work. Lists were provided but were out of date.

- Contacted over 50 law firms. The majority of these did not take on human rights cases and most of those that did indicated they would only take on human rights cases involving ‘prisoners or immigrants’ (their words, not ours).

- Being told by the few firms that may take on human rights cases that they would only do so providing they were paid a fairly considerable amount of money in advance of any work. (Including comments such as needing to pay £25,000 before even reading the papers on our case or not taking on the case on a legal aid basis as they would receive only £27 per hour compared to the £175 per hour they charge.)

**Background information**  This petition stems from our own experiences in relation to the application of ring fencing of milk quotas in the Southern Isles of Scotland both before and after devolution.

Milk quotas and ring fencing

Milk Quotas were introduced throughout Europe in 1984. “Ring Fencing” of milk quota was introduced, in Scotland, at the same time.

On the 1st November 1994, the UK Government, in the name of the “free” market, forced the Milk Marketing Boards to disband, removing the statutory duty that boards had to uplift farmers milk, regardless of size or location. After that, there was no longer a “guaranteed” market for any farmer’s milk. Milk buyers could and did impose whatever terms they wished. One of their first actions was to get rid of their smaller and outlying milk producers.
The Secretary of State for Scotland removed the ring fences from Scotland, other than the Scottish Islands.

This meant milk quota, owned by individual dairy farmers, could be sold or leased UK wide. There were over 36,000 dairy farmers in the UK who were allowed to sell, buy or lease their milk quota on the open UK market, whatever suited their individual business. For example, in 2000, over 6,000 dairy farmers in the UK leased out all of their milk quota, because that suited their individual business.

The retained milk quota ring fences in the Scottish Island areas, denied the Island area dairy farmers access to the full UK milk quota market. They could only sell or lease their quota on the limited island market – in fact, sometimes there was no market at all. This was particularly devastating post 1996 when the BSE crisis escalated, meaning there was virtually no market for dairy cattle over 30 months old, no market for dairy calves and the price of milk was unviable for most dairy farmers. Government did, at different times, remove The Western Isles, Islay and Shetland from the ring fences. Dairy farmers in the Southern Isles, who were having to give up or reduce production, were therefore not treated equally with the rest of dairy farmers in the Scottish Island areas, let alone the rest of the UK, and were denied the ability to use their own property to run their own business.

The original aim of the milk quota ring fence had been 3-fold - to ensure a supply of milk to the Island creameries, to ensure the survival of dairy farmers in the Island areas and to ensure a supply of liquid milk to the Island consumer. Unfortunately, the end result was 2 out of 4 creameries closed, only about 20% of dairy farmers left producing milk and little liquid milk from the Island areas going to Island consumers. Latterly Government appeared to say the only aim was to keep the creameries in business, because they were important to the local economy.

Dairy farming is very capital intensive, and requires hundreds of thousands of pounds to be invested in land, stock, buildings and machinery. Thus the vast majority of dairy farms have a substantial overdraft. The ring fence put an enormous burden on any dairy farmer in the Southern Isles of Scotland who was either, having to give up production, or cut back production. This could be for various reasons, illness, financial pressure from their milk buyer etc. For example, small producers were charged 10p/litre for haulage, despite only being paid 17p/litre for their milk. Conditions, such as requiring the construction of second access roads (to separate cows from tankers), were put in place by dairy companies and put some farmers in an impossible situation. With no market for their milk, these farmers obviously needed the full value of their quota to go towards their overdraft and/or diversify either within or out with agriculture. The result was catastrophic for some, many farmers were struggling to
survive, some were forced into impoverished retirement and some were forced out of their farms.

As Jamie McGrigor MSP said to the PPC on 15/02/11:

“My view remains that retaining the Southern Isles ring fence negatively and disproportionately affects the individuals concerned. It is disproportionate to the extent that it seems to have been considered acceptable for my constituents to bankrupt themselves to support the wider community, I struggle to find other examples of the Government, through its direct actions, forcing individuals or businesses to make serious financial sacrifices for the greater good of an area or sector – at least in peacetime.”

Some consultations were carried out by Government but none were done according to Government’s own criteria and sometimes the wording of the consultation pre-empted the result. 64 organisations were consulted, but not the individual farmers who owned the milk quota. Sometimes farmers did not know the consultations were taking place. None of the “consultations” even explained to those being consulted who actually owned the quota. SAC carried out three (as far as we are aware) “reviews” on behalf of Government. Again, the ownership and the rights of the individual owners were ignored.

In our opinion, to be correct, the Consultations on Southern Isles Ring Fencing of Milk Quota should have been worded similarly to Government’s Consultation on the Trading of Single Farm Payment Entitlements, which was as follows:

“It would be possible to restrict the transfer of entitlements by ring-fencing within Scotland. Regions would need to be defined at an appropriate territorial level in accordance with objective criteria and in such a way as to ensure equal treatment between farmers and to avoid market and competition distortion.”

Jim Mather MSP, saying “any normal person can see this situation is unfair” advised us to complain to the Ombudsman, which we did. At first, the Ombudsman’s office said they dealt with human rights, months later they said they did not. At first, they said they could deal with our case as it was an ongoing issue – again it was some time before they said they could not deal with our case as it was not an ongoing issue. (That was untrue, it was an ongoing issue.) They gave no ruling, whatsoever, on Government’s handling of the issue.

We spoke to a Human Rights Lawyer who said “This was a Political decision. Go back to the Politicians, they should sort it out. You should not have to.”

We submitted, supported by others in the Southern Islands who had suffered similar catastrophic discrimination re the ring fencing of their
milk quota, 2 previous Petitions (PE1263 and PE1542) to the Scottish Parliament.

In response to the PPC, Government did accept that the milk quota was the property of the individual farmer and that the Human Rights Act was invoked (having previously not accepted that this was a human rights issue), but said they had acted in the “public interest”. We contend that if Government does something in the “Public Interest”, a fair balance has to be struck between the right of the individual and that of the state. As the SHRC stated in a letter to the PPC, dated 05/01/10 “a fair balance will not have been struck where the individual property owner is made to bear an individual and excessive burden.”

Peter Peacock MSP described how we felt when we submitted our first Petition and we quote “To say that the Mundells feel grievously offended by what has happened to them or that they feel upset, angry, dismayed, victimised, unfairly treated, discriminated against and impoverished as a result of their experience would be grossly to understake what they feel”. Nothing has happened since to improve that situation.

Human rights and access to justice

We hear Government continually profess to support Human Rights and the Single Market.

On 12 May 2015, Alex Neil, then Cabinet Secretary for Social Justice, Communities and Pensioners Rights said in the Chamber “On human rights we are all vulnerable, irrespective of our social or economic status, human rights are a fundamental which affects every individual in our society.”

Alex Salmond told the Leveson Inquiry:

“The Human Rights Act applies mostly, you might argue, to Scotland, because it is embodied in the Act which established the Scottish Parliament, which means that the Parliament and indeed Ministers have to act at all times in accordance with the Human Rights Act. It is, if you like, a written constitution in that sense.”

Nicola Sturgeon, First Minister said on 20 April 2017 “We will oppose, vigorously, any attempt to scrap the 1998 Act. One of the worst things that the UK could do and the worst message it could send internationally is to be seen to roll back on human rights. The SNP will always oppose that and will always stand up for human rights.”

However, it is meaningless if people are denied access.

At the European and External Relations Committee on 28 May 2015,
in response to a question from Jamie McGrigor MSP and supplementary questions from Hanzala Malik MSP, Bruce Adamson, Law Officer with the Human Rights Commission, commented, specifically, on access to justice as follows:

“The State is required to set up a legal framework to ensure that people can access justice and get a remedy for breaches of their human rights.

There is also a wider point about legal education, alternative dispute resolution methods and the way in which we provide for remedies through the court system. There is significant work to be done on each of these aspects.

On legal education, the experience of Mr McGrigor’s constituent, in being unable to find a lawyer to take on their case, is not unique. The legal community needs to do more to improve legal education in Scotland.

There is also scope to look at alternative ways of resolving disputes. All those things form part of the solution.

There are not enough lawyers in Scotland trained in human rights issues. The pool of people you can ask to take on your case is smaller than it should be. We can do a lot to improve legal education and lawyers understanding of human rights, which would allow individuals to approach more lawyers than they currently can. At the moment very few lawyers take on that type of case.

In order to best protect human rights, you need to have in place good law, policy and practice. By the time you need a lawyer, something has gone wrong. Given the legislative competence of the Scottish Parliament and the Scottish Government there is a requirement on them to put in place laws that protect people’s human rights.

A lot of positive things can be done to ensure that people do not end up being forced to go to the courts to enforce their rights. There is a problem when you get to that stage, particularly with some types of cases.

The most recent high level conference in Brussels focused on what Parliaments should be doing to ensure that human rights are respected through their roles as legislators and in serving constituents.

There are massive concerns, domestically, about sending a message that some people or issues do not matter in terms of human rights.”

Speaking at the same meeting, the now former MSP Roderick Campbell said “The Parliament, the Justice Committee and others
have been looking at alternative dispute resolutions and ways of funding that. The essential point is that if you cannot access your human rights they are of lesser value.”

It is very clear from the foregoing that some cases involving Human Rights find it impossible to achieve justice in Scotland. We ask for action to be taken to change this.

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