

Cross-Party Group on Visual Impairment

Tuesday 16 May 2023, 18.00-19.30

Committee Room 3, Scottish Parliament and via Teams

Minutes

Present – attending in person

MSPs

1. Stuart McMillan MSP
2. Colin Smyth MSP

Invited guests

1. Anna Kynaston, National Care Service Division, Scottish Government
2. Carla Marchbank, North East Sensory Services (online)

Observers

1. Ingrid Roberts, National Care Service Division, Scottish Government

Non-MSP Group Members

1. Catriona Burness, RNIB Scotland
2. Eileen Clarkson, RNIB Scotland
3. Gillian Hallard, RNIB Scotland
4. Morag Innes (Kirin's support worker)
5. Matthew Leitch, Office of Stuart McMillan MSP
6. Fiona McDonald, Sight Scotland and Sight Scotland Veterans
7. Nicoletta Primo, Sight Scotland and Sight Scotland Veterans
8. Kirin Saeed
9. Davina Sheill, Sight Scotland and Sight Scotland Veterans
10. Alan Stewart
11. Jacquie Winning, Forth Valley Sensory Centre

Present – attending online

MSPs

1. Nick Bibby MSP

Invited guests

1. Carla Marchbank, North East Sensory Services

Observers – attending online

1. Karen Mowat, Scottish Government
2. Mike Stewart, Scottish Government

Non-MSP Group Members – attending online

1. James Adams, RNIB Scotland
2. Deirdre Aitken, Sight Action
3. Jordon Anderson
4. Liz Bates, MACS
5. Claire Black, NHS Education for Scotland
6. Steve Brown, Roche Products Ltd
7. Lesley Carcary, seescape
8. Bruce Christie, RNIB Scotland Advisory Group
9. Elizabeth Docherty, Optometry Scotland
10. Claire Forde, RNIB Scotland Advisory Group
11. Laura Gray, Macular Society
12. Sheila Hands, NHS Tayside
13. Kirstie Henderson, RNIB Scotland
14. Colin Hilditch, Sight Scotland
15. Thelma Ingram
16. Joan Kerr
17. Jo MacQueen, RNIB Scotland
18. Hazel McFarlane, Scottish Sensory Hub
19. Iona McLean, Macular Society
20. Gillian Mitchell, Sight Action
21. Mary Rasmussen
22. Professor John Ravenscroft, Scottish Sensory Centre,
University of Edinburgh
23. Susan Robinson
24. Allan Russell, Connect Radio
25. Angus Scott, NHS Forth Valley
26. Brenda Smart, Sight Action
27. Danny Sweeney, North Ayrshire Council
28. Laura Walker, Visibility Scotland
29. Sandra Wilson

Apologies

1. Paul Bartley, Optelec
2. Salena Begley, Family Fund
3. Miles Briggs MSP
4. Jacqueline Cowan, Police Scotland
5. John Donaldson, Scottish Braille Press

6. Graham Findlay, NESS
7. Niall Foley, Guide Dogs Scotland
8. Mairi Graham
9. Gillian Heavie, Scottish Government
10. Margaret Jackson, RNIB Scotland
11. Lisa Kelly, SAVIE
12. Sheila Mackenzie, Scottish Sensory Centre, University of Edinburgh
13. Maureen McAllister
14. Mike Moore, Guide Dogs Scotland
15. Rod Murchison
16. Sally Paterson, Vision Support Service, Aberdeen City Council
17. Hussein Patwa
18. Alison Rae, Dundee Blind & Partially Sighted Society
19. Ken Reid
20. Terry Robinson
21. Lee Shennan, Scottish Government
22. Susan Shippey, Scottish Government
23. Tess White MSP

Agenda item 1 - Welcome, introductions and apologies

Stuart McMillan, MSP, welcomed everyone to the meeting. The meeting was hybrid, bringing people together face to face in the Scottish Parliament for the first time since February 2020, as well as online. Introductions and apologies were acknowledged, and the General Data Protection Regulation (GDPR) statement was read out. Individuals who do not want to be named in the minutes were asked to inform the Secretary.

Agenda item 2 - Approval of minutes of meeting of 1 February 2023

The minutes from the previous meeting were proposed, seconded and agreed.

Proposer: Gillian Hallard (RNIB Scotland)

Seconded: Eileen Clarkson (RNIB Scotland)

Agenda item 3 - Matters arising and Action Points report

The Action Points were read out.

Agenda item 4 - National Care Service Scotland activities and how people can become involved in co-design

- Anna Kynaston, National Care Service Division, Scottish Government
Anna provided an update on the National Care Service (NCS) and what is going to be happening over the coming months. The National Care Service (NCS) Bill remains at Stage 1 following a request from Scottish Government for additional time to consider it further. This includes considering improvements and what new legislation may be required as part of the process of establishing a National Care Service (NCS).

An example of new legislation is whether the NCS Bill will include an explicit clause so that Inclusive Communication is embedded within it. This would mirror the position of Scottish Social Security legislation which has Inclusive Communications and Accessible Information enshrined.

Another consideration is defining what is meant by 'Co-Design' - for example, how do we work together to develop solutions and agree a system moving forward?

Five broad areas were outlined:

- Information sharing to improve social care support:
This includes finding ways to share data across health and social care systems as well as others.
- Keeping social care support local:
The needs of people living in rural areas will diverge from those in urban areas. Therefore, areas should be able to decide how best to use resources to respond to local needs. It is hoped that the standard of care will be the same across the country, reducing geographical disparities.
- Realising rights and responsibilities:
This includes ensuring people can raise concerns in a meaningful way with practitioners, and that there are tools to help people realise these including a Charter of Rights.
- Making sure your voice is heard.
- Valuing the workforce.

Over the summer there will be a series of Co-Design regional events, online and in person.

Q & A

Question (Q)1: On data sharing, how can it be made easier for information to be transferred between agencies without individuals having to repeat their story to various professionals?

Answer (A)1: There is ongoing work to identify what platform could work best in Scotland, and how to get a system in place which could share pertinent information about individual's needs.

It is also hoped that the NCS will provide an opportunity to ensure that people are genuinely involved in developing their own care plan. Self-Directed Support (SDS) was a trailblazing piece of legislation to enable this. However, it is recognised that the accompanying guidance should be revised so that its application is consistent across Scotland.

Q2: Disabled people, including blind and partially sighted people, have been involved in training social workers about SDS, to assist in getting a care plan right for the individual from the start. In addition to this, other notable points included:

- Some visually impaired people do not see themselves as being eligible for a care package. There needs to be greater recognition that a care plan is also about gaining independence.
- The right people must be in the room at the same time, who have experience.
- Inclusive communication and accessible information must be provided from the outset, at the earliest possible stage. People should not have to wait six-eight weeks to get a letter in their preferred format.
- The process of co-design must include an open and honest conversation about what resources are available from the start, so that a person is not set up to fail. Resource allocations often involve setting up hours of support as opposed to the outcomes people want to achieve.

A2: NCS is looking at establishing a national social work agency, with national leadership to look at Continuous Professional Development (CPD) requirements. This includes using the experience of users, and how to get care right first time. It is also about recognising the cultural change required to get this right and leadership to take it forward.

The Convener also highlighted the need for accessible information, citing the example of the Scottish Social Security legislation.

Q3: How will the NCS ensure the voice of young people is included in the Co-Design Process? There must also be a requirement to align the NCS with the UNCRDP (United Nations Convention on the Rights of Persons with Disabilities) to ensure human rights are recognised.

A3: The Scottish Government is currently thinking about how the NCS Bill can align with UNCRPD in its commitments to realising human rights. This includes the Charter of Rights for the NCS. The Government wants to speak to young people and hear their opinions on whether the NCS should be an all-age service or just focus on adults. It is important to engage children and young people. They do not always want to share views freely in a co-design process with adults, so there must be ways of gathering views and experiences separately, including via the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill.

Q4: The experience of care and support varies widely. The definition of care should be extended so that it is easier for VI people of all ages to seek support at all ages. This may also consider looking beyond a traditional medical view so that care can be understood as enabling inclusion and independence. What definition of 'care' is being used in the NCS?

A: There is an unmet need – people do not always come forward where there are wider system pressures. Many who could access care and support who do not do so at present.

Evidence is being collated on the disparity amongst the cohort of people who find their support falls away once they reach 18 years of age. Further research is needed to quantify this gap and to better understand what type of support is required. This includes looking at models of good practice that can be replicated elsewhere in Scotland.

Q5: Data and information systems form the backbone of any care service. Is there scope for the integrated care record to store information about a person's preferred format, so this information is available from the outset? In addition, the register for blind and partially sighted people is held on a local authority basis and there are various arrangements for this across Scotland. Is there scope within the NCS to maintain and update a national CVI (Certificate of Visual Impairment) record?

A: The care record must hold information on what a person's preferred format is. The Scottish Government is encouraging people to attend co-design sessions to help shape what a future record could look like. This

is also about reaching out to the people responsible for the sight loss registers at local levels and exploring what a national CVI could entail.

The Convener mentioned that during COVID vaccination letters were sent out in each health board, using information from GP practice records. However, when vaccination letters first went out, many people did not receive their letter because GP records were out of date. It is crucial that if there is an integrated care record, it is kept up to date and maintained so it is dependable and accurate. The Convener indicated that this problem greatly reduced with every new round of vaccinations.

Q6: Integrated care records should include the needs of everyone in a household. Many people with VI are also carers for other members of their family. If this is not recorded somewhere it results in misunderstandings when contacting services such as NHS 24 or emergency services.

Q7: Social Security Scotland is designing an Inclusive Communication Standard with third sector organisations. This could be a useful model of joined up working for Scottish Government NCS colleagues to learn from in terms of implemented Inclusive Communications within the NCS.

Q8: The last time Scotland publicised national statistics of numbers of people with a CVI (or registered as severely sight impaired (SSI) or sight impaired (SI)) was in 2010. Are there plans to transfer this to NCS or publish up to date figures at a national level soon?

Answer to points 6, 7 and 8 above – We need to discuss the merits of NCS holding a national CVI register. We are also keen to learn from other Scottish Government colleagues on models of best practice, including speaking to those involved with Social Security Scotland and its inclusive communications work.

Q9: Professor John Ravenscroft referred to the national register for Children with Visual Impairment in Scotland (VINCYP), currently held by NHS Scotland. He chairs the group which oversees this and the existing system for children works well. He offered to share his contact details with Scottish Government NCS colleagues.

Q10: At present the CVI registration process is voluntary - people can opt out if they do not want to register as Severely sight impaired (SS) or Sight impaired (SI). Yet people who have opted out or who do not meet the registration criteria may still have functional difficulty with vision and

benefit from local services. Rehabilitation and facilitation are key to enable independence.

A: There are various understandings of what care means for different people and we recognise there is a need to build on a shared understanding of care, including encapsulating other aspects of care such as prevention, enablement and rehabilitation.

The Convener thanked Anna Kynaston and Ingrid Roberts and invited them to give a further update on NCS progress to a future meeting, ideally before the end of the year.

Action Points:

1. To share John Ravenscroft details with NCS colleagues.
2. To invite Anna Kynaston and Ingrid Roberts to return to the CPGVI to give an update on NCS progress.

Agenda item 5 - Domestic abuse and violence experienced by visually impaired people – The Unseen Report and future Scottish research

Carla Marchbank, Statutory Services Manager, North East Sensory Services (NESS) presented.

The Unseen Report focussed on the unique experiences of people affected by visual impairment affected by domestic violence and abuse. It published information at a UK level. However, it was unable to disaggregate information across different geographies, including those from Scotland. The report highlighted that people with visual impairment are three times more likely to experience domestic abuse than non-disabled people and that having a visual impairment adds a unique dimension to abuse. This last includes coercive control and lack of confidentiality when contacting services.

A working group has been set up to scope whether further research can be carried out which may help inform service provision in Scotland, for those affected by VI and experiencing domestic abuse.

At present the working group consists of representatives from the Sensory Hub, Sight Scotland and Sight Scotland Veterans, RNIB Scotland and Guide Dogs Scotland. The group hopes the CPGVI membership, whether as organisations or individuals, might be able to support their work. This includes identifying existing provisions which

support visually impaired people in avoiding or getting out of domestic abuse situations. It is also about finding out what is required to equip domestic abuse organisations with the tools to support people with sight loss and sensory loss, such as accessible communication.

Q & A

Q1: Will the research include children affected by VI as well as adults? Children with VI can be at higher risk of domestic abuse so the working group should include children and young people with VI in its remit.

A1: We are not sure. The group is still working on the research proposal, although we recognise the unique experiences of VI children and young people.

Q2: Encourage group overseeing this to include people with VI from ethnic minorities, as this adds another facet to abuse experienced, including, for example, coercive control and financial abuse.

A2: Yes – the research must examine intersectionality, including recognising where further research is required within groups of people with VI.

Q3: It is also necessary for the research to recognise/examine the presence of other disabilities or long-term conditions amongst people with VI.

A3: These are all helpful points. With the help of CPG members, we hope to identify and approach agencies who can support the research and gain further information.

Q4: Does the working group have someone from the Equally Safe Strategy represented on it? The proposed work sounds like what they are doing. This also involves health and social care partnerships, and those working in adult and child protection also. Contacts within NHS Tayside can be shared.

Action point:

1. Sheila Hands to provide contact details to Carla Marchbank of those she knows doing similar work in Tayside.

Agenda item 6 - Any other competent business

1. NCS presentation – the Convener suggested writing a letter to the Minister about recognising the importance of accessible information, the possibility of national statistics being published from CVI data, and in general ensuring the NCS offers a fresh opportunity to consider sharing data across health, social care and other independent providers.
2. James Adams asked to have information about RNIB Scotland's technology conference circulated to the wider CPGVI group. The programme is taking shape and will include key speakers on inclusive design and sustainability from across the globe, such as the Head of Disability and Inclusion from Google and a keynote speech from Richard Lochhead, Minister for Small Business, Innovation and Trade.
3. Gillian Mitchell of Sight Action announced she is retiring in June 2023, after 18 years working in the sight loss sector. She also introduced Deirdre Aitken who will be taking over her representation on the group.

Deirdre asked whether anyone on the CPGVI had come across a gap in service provision, specifically, home eye tests when someone is unable to leave their home. There seems to be no provision of this service in Caithness and the surrounding area. Is this a common issue/gap felt elsewhere in Scotland, for example in rural locations?

CPG members were not aware of this gap in service provision. Claire Black suggested Optometry Scotland may be able to give information on domestic/home-based services. She also suggested contacting local community optometrist services who may be able to provide information or support for a home visit. There may also be further information on Eye.Scot.

4. Kirin Saeed asked for details of a VI theatre production to be circulated to members of CPGVI and others.

Action points:

1. Letter on the NCS to go to the Scottish Government from the CPGVI.

2. Details of RNIB Scotland's technology conference to be circulated to the CPG and the Convener will send to all MSPs.
3. Deirdre Aitken to send on further information on home eye tests to the Secretariat of CPGVI.
4. Details of the VI theatre production to be circulated to CPGVI members and to MSPs.

Agenda item 7 - Date of next meeting

To be confirmed. The next meeting will take place after the Scottish Parliament's summer recess.