

Cross-Party Group on Health Inequalities

18:00 – 19:30 Wednesday 14 December 2022

Minute

Present

MSPs

Donald Cameron MSP

Emma Harper MSP

Invited guests

Richard Meade, Carers Scotland and Northern Ireland

Non-MSP Group Members

Salena Begley, Family Fund

Lauren Blair, Voluntary Health Scotland

Sophie Bridger, Chest Heart and Stroke Scotland

Shelly Ann Brown, Edinburgh Voluntary Organisations Council

Megan Burt, Edinburgh Voluntary Organisations Council

Christine Carlin, Home-Start UK

Susan Chambers, Pasda

Judith Connell, Kidney Care UK

Alison Crofts, Voluntary Health Scotland

Andrew Cromwell, Kidney Care UK

Helen Forrest, Children's Health Scotland

Paula Fraser, VOX Scotland

Susan Fullerton, PLUS (Forth Valley) Ltd

Edward Giles, EVOC

Rob Gowans, Health and Social Care Alliance Scotland (the ALLIANCE)

Toni Groundwater, Families Outside

Jen Hardy, Cancer Card

Una MacFadyen, PLUS Forth Valley and Children's Health Scotland

Angus Maclean, Befriending Networks

David Main, Voluntary Health Scotland

Catriona Melville, Age Scotland

Justina Murray, Scottish Families Affected By Alcohol and Drugs

Daniel O'Malley, Diabetes Scotland

Fiona Partington, The Health Agency

Bushra Riaz, Kidney Research UK

Tilly Robinson-Miles, Food Train
Kimberley Somerside, Voluntary Health Scotland
Claire Stevens, Voluntary Health Scotland
Nicola Watson, Shared Lives Plus
Hugo Whitaker, Edinburgh Voluntary Organisations Council
Tom Wightman, Pasda
Laura Wilson, Royal Pharmaceutical Society

Non Members

Margaret Brown, NHS Highland
Christine Farquhar, Edinburgh Integration Joint Board
Zephania Hartojo, UN House Scotland
Gary Meek, GCA
Naomi Watson, NHS Highland

1 Welcome and apologies

No apologies were received.

Claire Stevens welcomed everyone to the meeting and suggested Donald Cameron MSP chair the meeting until Emma Harper MSP could attend.

2 Minutes of last meeting

Paula Fraser, VOX Scotland, approved the minutes of the last meeting held on Wednesday 19 October and Rob Gowans, The Health and Social Care Alliance Scotland, seconded them.

3 Previous Matters Arising

No matters arising.

4 Applications to join the CPG

The following applications to join the CPG were agreed:

- [Obesity Action Scotland](#)
- [Families Outside](#)
- [Shared Lives Plus](#)
- [Kidney Care UK](#)
- [Cancer Card](#)

5 Topic for discussion: understanding and addressing the health inequalities experienced by unpaid carers in Scotland

Presentation by Richard Meade, Director, Carers Scotland and Northern Ireland.

Carers Scotland is a charity with a vision to create a society that recognises values and supports carers. They do this through policy, public affairs, training and development, providing information and support, along with running the Carers Positive scheme which helps organisations become carer friendly organisations.

Richard explained an unpaid carer is an unpaid family member, partner or friend who helps a person with daily activities who wouldn't be able to manage if they didn't have help. This could be someone who is seriously ill, disabled or who needs extra help as they grow older.

We heard 17.5% of the adult population were carrying out an unpaid caring role in Scotland, including 30,000 children and young people. To replace that care would cost £43m each day, without unpaid carers the care system would collapse.

Richard made the case for caring to be recognised as a social determinant of health, an idea first floated in a Public Health England report last year. Carers experience greater risk of stress, anxiety, depression, physical health problems, multimorbidity, severe disease and premature death. These issues are likely exacerbated by social isolation and loneliness, financial constraints and lack of support. Many carers are forced to give up work, put their career on hold and a number live in poverty. There is also a gendered element to unpaid care in that carers are more likely to be women.

The pandemic exacerbated many of these issues for carers, 70% of carers did not get a break or any respite. Richard drew on Carers Scotland's most recent report on The State of Caring in Scotland, it found one fifth of carers reported bad or very bad physical health, which rose to 25% for those who care for 35+ hours. Furthermore, 27% of carers reported bad or very bad mental health, rising to one third of those caring 35+ hours. In terms of the cost of living a quarter of carers are struggling to make ends meet and this survey was taken in the summer before the cost of living had really started to bite this winter.

Richard highlighted that unpaid carers contribute £11bn a year to the health and social care system. He felt that we as a society had largely abandoned them, especially during the pandemic. He noted that interventions to support carers were effective in reducing inequalities.

He emphasised that the crisis in care was only going to get worse with the ageing population. Without support, inequalities will massively increase for carers and this will have a spiralling impact the health and social care system.

Richard felt we needed to better understand the Scottish context of health inequalities for unpaid carers and called on the government to invest in this. He set out the current policy context on unpaid care in Scotland. The Health, Social Care & Sport Committee took on some of the calls Richard made while giving evidence to the health inequalities inquiry with regards to unpaid care. Including creating an unpaid carers' poverty strategy, which could help with things like tackling the high cost of running medical equipment. He highlighted the recent [story of Carolynne](#) who was having to source £17,000 to cover the energy costs of running her child's life support equipment at home. He described this as a shift in the burden of care from the state to people, noting we wouldn't be sent home from hospital with an electricity bill.

In terms of upcoming policy he noted:

- A Carers Strategy is due to be published but is very delayed.
- The National Care Service (Scotland) Bill includes a provision of breaks for all carers, but he questioned what we mean by a breaks, for how long and will it be outcome focused. He felt the bill could make a difference and fill the gap carers are currently experiencing in respite support.
- He felt Carers Assistance was genuinely making a difference but it doesn't go far enough in terms of the carers who are entitled to it.
- At a UK level Carers Scotland are calling for unpaid carers to be a protected characteristic.

Questions:

Donald Cameron MSP felt this was one of these issues we were not gripping as a country and that unpaid care played into so many issues in wider society.

Autism: Susan Chambers, Pasda, spoke about the invisibility of autism and the importance of respite care. She raised concerns about what happens to autistic adults when their older unpaid carers can no longer support them or when they pass away. Susan felt this wasn't on anyone's radar. She noted that respite often meant leaving family members in a care home, which was not an option for many parents of autistic children. She emphasised that people need to be able to trust those caring for their loved one, which was not possible if they don't know the carer. She asked about plans for respite care. Tom Wightman, Pasda, said carers of someone with autism weren't recognised as carers because autism doesn't receive a formal diagnosis. He echoed a point made by Susan Chambers about what happens when older parents can't care for their child with autism anymore. Richard recognised these concerns especially with regards to the fear families feel about who will care for their loved one when they are gone. It adds to their anxiety and mental health issues. He felt the National Care Service needed to provide wraparound support so that families weren't left with these worries. Emma Harper MSP said she would put this to the Minister next week.

Holistic Approach: Angus Maclean, Befriending Networks, felt unpaid caring was a massive issue that crossed so many areas, he asked how we best take a holistic approach with support.

Cost of Caring: Selena Begley, Family Fund, emphasised that families were struggling to meet support needs due to the cost of living and explained that caring responsibilities impact significantly on people's ability to work. She explained these issues were avoidable if the right support was in place. She drew on a recent cost of caring report by the Family Fund.

Hidden Carers: Justina Murray, Scottish Families Affected by Alcohol and Drugs, noted some of the families they support don't recognise themselves as carers despite the fact they are. This means they miss out on support. She asked about the implementation gap and how we uphold carers' rights. Richard noted Carers Scotland wasn't an advocacy service but recognised how much legislation there is on carers' rights. He felt recognising unpaid caring as a social determinant of health could make a difference. He agreed many people don't recognise themselves as carers, they see themselves as parents, partners, and people. He felt there was a disconnect between what people were entitled to and what they get. He said there had been a bit of traction recently on carers' rights and hoped there might be a government debate on this when the carers strategy emerges. He underlined it's in governments' interests to make sure carers are supported as it reduces unplanned hospital admissions and acute interventions. He stressed the importance of the preventative action in unpaid caring.

Protected Characterises: Rob Gowans, Health and Social Care Alliance Scotland, asked about the campaign for unpaid carers to be recognised as a protected characteristic and how this could benefit data analysis and intersectionality. He also raised concerns about opening up the equality act and what might happen if it was amended. Richard said they were gathering evidence about how carers were discriminated against in the workplace and he was happy to speak to organisations individually about the [campaign](#).

Respite Support: Nicola Watson, Shared Lives, highlighted the value of their work as an organisation and how it can provide families with respite they can trust and get to know. She explained it's a flexible, responsive service depending on people's needs. She underlined the importance of trust in delivering these respite services. Richard felt respite needed to be outcome focused as one size does not fit all, he emphasised this would be really important as part of the National Care Service. Hugo Whitaker, EVOC, highlighted research being undertaken by EVOC about respite services and carers, noting the research was going to be very far reaching. He also highlighted the Shared Care Scotland project to roll out tests for change of respite care. Richard agreed services that support carers don't need to be badged as carers' services. Emma Harper MSP noted the committee had been discussing what

“sufficient breaks” meant in terms of the National Care Service. She also spoke about social prescribing and the role the third sector has in supporting carers.

CPG Action: Claire Stevens, Voluntary Health Scotland, asked what this CPG could do to support Carers Scotland’s work. Richard Meade said VHS had been very helpful in getting him in front of the Health, Social Care & Sport Committee during the health inequalities inquiry. He encouraged the CPG to take forward the committee’s report and hold some ownership of it in our work going forward. Emma Harper MSP encouraged CPG members to get in touch with MSP members of the group with parliamentary questions and responses to debates.

Unmet Need: Tom Wightman, Pasda, asked about whether local authorities could record “unmet need” when services were not available so they could easily identify gaps when resources became available. Emma Harper MSP noted unmet need and data also came up during the debate in parliament on health inequalities which would be available through the official report. Christine Farquhar, carer representative on an IJB, noted that a recording of unmet need was going to be part of adult carers’ support plans when they were implemented. She had concerns about adding bureaucracy to the system while the implementation gap persists.

Mental Health: On community mental health support, Salena Begley, Families Fund, felt a lack of support for people with long term health conditions would have an impact on their informal support. She noted unpaid carers often carry the burden when formal support is not available.

6 Any other competent business

Committee Inquiry: Claire Stevens, Voluntary Health Scotland, provided a brief update on the Health, Social Care & Sport Committee Inquiry on Tackling Health Inequalities in Scotland as a parliamentary debate on the findings had taken place that day. Emma Harper MSP noted the challenge of speaking for five minutes on such a big inquiry on such an important issue. During her speech she focused on Gerry McCartney’s and David Walsh’s contributions on how poverty impacted health inequalities. She noted multiple committees were considering health inequalities now and every Minister had to be a Health Minister going forward. She highlighted the committee finding that there was no overall strategy to tackle health inequalities. She suggested individual findings from the inquiry should be picked up for future CPG discussions.

Long-term Residential Care: Susan Chambers, Pasda, commented briefly on autistic adults in long term residential care. She drew attention to a BBC Disclosure programme on long term residential care of autistic adults. She raised concerns about the government’s response to this programme. She noted reports and strategies which had been published which found people should not be spending long amounts of time in hospital. She raised concerns that many adults were in secure units with no plans for discharge, adding that each person in a secure unit costs a quarter of a million pounds a year. She asked what the plan was for those

adults with a delayed discharge. Emma Harper MSP endeavoured to be in touch with Susan on this.

Actions:

- Emma Harper MSP said she would ask the Minister in committee next week about plans for respite for carers as part of the National Care Service along with care plans for older carers who are worried about who will care for their loved one when they are gone.
- Emma Harper MSP encouraged CPG members to get in touch with MSP members of the group with parliamentary questions and responses to debates in relation to health inequalities.
- Susan Chamber spoke about mental health support for unpaid carers, she asked if Emma Harper MSP could ask in parliament about access to community mental health nurses in general practice. Susan felt there was a post code lottery in terms of mental health support in primary care currently. Emma Harper noted this was something Alex Cole-Hamilton MSP brought up in the chamber during the debate on health inequalities. She agreed to speak to Susan about the issues she had raised during the meeting.
- Emma Harper MSP suggested the CPG take forward individual findings from the Health, Social Care and Sport Committee inquiry on health inequalities in its work next year.

7 Date and topic of next meeting

The next meeting will take place in the Scottish Parliament, in person only, on Tuesday 7th February 2023 in Committee Room 2. This meeting will be chaired by co-convenor Brian Whittle MSP and will explore the topic of Health inequalities in Scottish Prisons.