

Tackling Health Inequalities in Scotland

Response to Health, Social Care and Sport Committee, Scottish Government

Some good work has taken place around trying to incorporate certain aspects of United Nations Conventions, such as United Convention on Rights of Child and United Nations Convention on Rights of Persons with Disabilities. Although in very early stages of incorporation, the intent behind Scottish Government's approach to these conventions shows the desire to use human rights-based approaches to tackle health inequalities.

However, much work remains to be done in recognising the health inequalities faced by unpaid carers of all ages across Scotland. A common theme emerging from unpaid carers can be summed up in the quote below,

*"Carers tend to put everyone before themselves until they are so unwell, they fall apart. We hide our feelings and our exhaustion so not to let people think we can't cope"*¹

Part of feeling this way can be a direct result of unpaid carers not feeling supported or taken seriously when the extent of caring gets too much. Accessing health services can be difficult as these tend to operate traditional 9-5pm workdays and during the working week. For many unpaid carers these are the times when they can be required to provide caring, or attend school, further education, or work. It can be hard to get time away for their own healthcare needs and much is dependent on schools/colleges/employers understanding the needs of unpaid carers.

The adverse health effects of providing care informally are primarily psychological and often manifest themselves as symptoms of anxiety, depression and social dysfunction. Michael Hirst, in his final report, Health Inequalities and Informal Care² noted that *"caring related inequalities in psychological well-being are quantifiable and significant; they are most pronounced at key turning points in the caring trajectory*

¹ COCIS carer survey on the National Care Service

² Hirst, M, Inequalities and Informal Care: End of Project Report, 2004, University of York

and in the more demanding care situations. Caregiving is associated with an increased risk of both onset and recurrent distress, and legacies of poor health persist beyond the end of caregiving”.

Unpaid carers who provide over 20 hours per week of care are often at increased risk of poor health and adverse health changes because of their caring responsibilities.³ It is important to recognise the links between the mental wellbeing of unpaid carers and access to regular breaks from caring, emotional support, financial wellbeing and supportive employment, amongst other things. The majority of unpaid carers are female and tend to work in the type of services damaged by pandemic and lockdown.⁴ Specific measures are required to support unpaid carers where their health has deteriorated as a result of caring. Such measures include the recognition of unpaid carers as a protected characteristic within equality legislation. The current situation recognises the cared for belonging to a protected characteristic group, but this discriminates against those who provide that person with informal care as it does not recognise them or the role they perform. By gaining protected characteristic status, unpaid carers can exercise certain rights, and organisations - such as healthcare - would be expected to comply with equality laws in respect of unpaid carers.

Various stressors are associated with providing informal care. Nolan et al, and Schulz et al,⁵ noted some of these as being physical (e.g. sleep disturbance, fatigue, back injury), emotional (e.g. absence of rewards in providing care, quality or history of relationships with cared-for person, guilt), social (e.g. motivations to care, marital or family conflict, isolation, lack of support), or economic (e.g. loss of income from giving up paid employment, costs of providing informal care). Another issue facing unpaid carers is the impact of the illness or impairment of the cared for person which may be stressful for unpaid carers (e.g., challenging behaviours, incontinence, cognitive impairment, uncertainty about prognosis.)

Despite the body of research evidence that unpaid care is associated with adverse health effects, critical appraisals of the literature have highlighted methodological weaknesses in studies that attempt to quantify the health impacts of providing informal care. This may explain why in the 2015 Tackling Health Inequalities Report (Scottish Government) only scant mention is made regarding unpaid carers. Although since then it is acknowledged that there has been more Scottish Government awareness of the impact of providing unpaid care on carer health and wellbeing. This needs to be built upon and developed both locally and nationally.

Another measure which could be pursued is the inclusion of unpaid carers within upcoming health strategies, such as mental health strategy. In the past, only young

³ As no. 2

⁴ Carers Week Research, Carers UK 2020 <https://www.carersuk.org/for-professionals/policy/policy-library/carers-week-2020-research-report#:~:text=Read%20the%20full%20report%20here>

⁵ Nolan et al., 1996, Schultz et al, 1995

carers have been included in such a strategy. But the pandemic has raised the issue of adult carers, including older adult carers', mental health. Even before the pandemic, there has been clear evidence that caring often has an impact on peoples' mental health and wellbeing. The 2019/2020 Health and Care Experience Survey found that only 38% of unpaid carers said that caring had **not** had a negative impact on their health and wellbeing. This survey has consistently shown a decline in the health and wellbeing of the unpaid carer population since its inception.

Similarly, Carers UK State of Caring Report evidences the impact of caring on people's mental health and wellbeing. Its 2019 report found that 27% of unpaid carers said their mental health was 'bad' or 'very bad'.

The 2021 State of Caring report found that the pandemic had contributed to a further decline in the wellbeing of the carer population, with 31% of carers describing their mental health as 'bad' or 'very bad'.

Further, the above report also found that, across the UK 1.76% of unpaid carers had to use a foodbank during April 2020. The use of foodbanks varied by sex and caring duties. Female carers were more likely to live in a household which had used a foodbank than women and men without caring responsibilities. As mental wellbeing is affected by many factors, including socio-economic ones, the impact onto wellbeing would have resulted in increased anxiety and worry.

In addition, VOCAL Carers Hub, which provides support to unpaid carers in Edinburgh and Midlothian, received 1,286 responses to their unpaid carer survey in 2021. 79% of respondents agreed that "being a carer has affected my mental health", with 39% agreeing strongly. This compares with 57% in 2017 who agreed with the statement "being a carer has made my health worse."

A review of national and international literature⁶ relating to impact of COVID on mental health in populations noted that families/carers of patients who survive critical illness can also be adversely affected with estimates that up to 30% may experience stress, anxiety, depression or complicated grief. Risk factors for family/carers to develop such outcomes include:

- poor communication.
- having a decision-making role.
- lower educational attainment.
- and the severity of the relative's condition such as being close to death or dying.

The most common problems experienced by family members providing care and support include sleep deprivation, anxiety, depression, complicated grief, and PTSD." ([Rawal et al. 2017](#))

⁶ Mental Health Effects of the COVID 19 Pandemic in Scotland, Dr John Mitchell, PMO Mental Health Directorate – 12.06.20

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In moving forward, the Scottish Government should look at commissioning research into refining Government's understanding of the health effects of providing informal care, not least because the demands on unpaid carers are changing and their responses and expectations are likely to evolve. Further research is needed to evaluate the mechanisms for providing care and health outcomes and how adverse effects are modified by the coping skills and expectations of unpaid carers.

The importance of psychological well-being for public health has seen a great stride forward in prominence since 2015, through programmes around good practice in the workplace and support and help at particular stages of the life course. Explicit consideration of the role of unpaid carers could increase the effectiveness and acceptability of health improvement programmes.

Identification of unpaid carers has to be a priority for all involved with health and social care. The Carers (Scotland) Act 2016 sets this out as a key duty expected from services. It is only by identifying unpaid carers that Scottish Government, and others, can start to address the health inequalities faced by many unpaid carers as a result (whether directly or indirectly) of providing informal care.

Our ask is:

- Providing unpaid care should be recognised as a public health issue. This would assist in releasing additional health care resources for developing carer support and encourage a more thoroughgoing approach to policies that promote carers' health and prevent ill health.
- Providing unpaid care should become part of the health inequalities agenda. This would ensure that providing unpaid care is given consideration alongside other social determinants when tackling health inequalities. Another benefit of this would be to ensure that key Scottish Government departments, (social security, education, finance, and skills development) assess the health impacts of their policies and programmes on unpaid carers, and to consider whether and how they can reduce caring-related health inequalities.

Continuation of the joint approach between health, social care and the third sector to support carer specific services needs to be a priority to enable such services to promote unpaid carer health and wellbeing activities and interventions in settings which unpaid carers are more likely to access and gain benefit from. Working in partnership with third sector unpaid carer support services is a first step in helping health and social care agencies identify unpaid carers and to start to address some of the health and wellbeing issues faced by unpaid carers.

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