



Parliamentary Debate on the Independent Review of Adult Social Care 16th February 2021

Briefing on the Review in relation to **unpaid carers**

The National Carer Organisations welcome the bold and ambitious vision set out by the review and believe that if fully implemented it has the potential to be transformative in improving the lives of people with social care needs and unpaid carers

As a country we need to be clear about how we define social care, recognising its value and purpose. Social care should not be viewed as a 'service', but as an investment in supported people and unpaid carers, recognising the rights and capabilities of supported people and the contribution unpaid carers make to the lives of supported people and the economy.

The review recognises that unpaid carers are 'the cornerstone of social care support.' This has never been more starkly illustrated as during the current pandemic. As a result of Covid-19, there are an additional 392,000 new unpaid carers, bringing the total number in Scotland to 1.1million.¹

Since March 2020 many social care services have been reduced or have ceased altogether, resulting in 87% of unpaid carers having no choice but to provide more care. Almost two thirds of unpaid carers have been unable to take a break from their caring role since the start of the pandemic¹

However, it is clear that the issues the pandemic has uncovered and brought to public attention are long standing: social care has become increasingly fragmented, rationed and lacking in choice. Self-directed support has failed to live up to its promise and many people are left with little or no support – or support that is not the right fit for them. Too often unpaid carers are left exhausted and in poverty while trying to fill the gaps that exist

Unpaid carers say that they feel 'broken' or 'worn down' and are worried about how they will make it through the Winter. The pandemic will leave behind it a significant legacy of

¹ Caring behind closed doors: 6 months on, Carers UK, October 2020

damaged physical and mental health, poverty and inequality which will need sustained action to improve.

This review is needed now more than ever. The recommendations it sets out are finely balanced, with all parts contributing to the whole. For unpaid carers it is essential that we see a whole system change with a new narrative and new delivery system, alongside specific measures to support unpaid carers, to sustain them in their caring role and ensure they have a fulfilling life alongside caring. Because, as the review recognises, without support unpaid carers cannot access their basic human rights.

Breaks from caring

The review recommends that unpaid carers be given a right to respite, enshrined in law, through an amendment to the Carers (Scotland) Act 2016. In order to deliver this, it says a range of options for respite and short breaks should be developed.

Unpaid carers currently do not have a right to breaks from caring. While some short breaks are available, there is no minimum entitlement and unpaid carers struggled to access regular time off from their caring responsibilities, even before the pandemic. During the pandemic 65% of unpaid carers have not had a break from caring and 77% have reported feeling exhausted and worn out.²

The review has rightly drawn attention to the need to invest in the paid care workforce. But we cannot discuss investment in paid care work without also underlining the crucial need to invest in unpaid carers as equal partners in care. The value of care provided by unpaid carers in Scotland is greater than that of the health and social care workforce combined.

Investing properly in unpaid carers is an essential part of preventative support. This includes short break and replacement care services that enable unpaid carers to work, study, access leisure and wellbeing opportunities and maintain social connections alongside their caring role. Caring should not drive people into isolation, poverty and poor health.

The right to short breaks set out in the review must take a preventative approach to supporting unpaid carers and must not be linked to strict eligibility criteria, with only those already reaching crisis being able to access a break

As Derek Feeley said at a meeting with unpaid carers in November “Not only are carers indispensable, they are also human beings and need time off like the rest of us. That’s an investment I think we ought to make”

Carers and employment

² Caring behind closed doors: 6 months on, Carers UK, October 2020

The review acknowledges the impact caring has on a person's employment status, particularly when unpaid carers struggle to access support, such as replacement care, to enable them to combine caring with paid work. It recommends that consideration of a carer's access to employment should be a routine part of assessment for support.

One in five unpaid carers give up work to care, meaning they are no longer economically active, pushing them into poverty, which can impact into retirement and later years. In many cases this is because they are not able to access replacement care to enable them to combine caring with employment.

During the pandemic the employment status of unpaid carers has been particularly vulnerable. Research from Citizens Advice found that two in five people with caring responsibilities were facing redundancy, more than double that of the average working population.³

While we support the recommendation in the review we think it needs to go further. **In order for unpaid carers to be able to combine caring with paid employment there needs to be an investment in replacement care services and employment support for carers.** The government has invested in childcare to enable parents to remain economically active, the same economic arguments apply to enabling unpaid carers to remain in and return to employment.

Carers as Equal Partners in Care

The review sets out the need for a 'relentless focus' on involving people who use social care services and unpaid carers in developing new approaches and implementing the recommendations in the review.

Despite the duties relating to carer involvement in The Carers (Scotland) Act 2016 and unpaid carers previously being recognised as 'Partners in Care' in the Community Care and Health (Scotland) Act 2002, this has yet to translate into carers being viewed as equal partners in care. As a carer representative on an Integration Joint Board commented "Carers are meant to be equal partners. However, the reality so often is that we are given all the responsibility without the support, resources or recognition. It's so often far from being a real partnership"

We welcome the recommendation in the review that unpaid carers should be represented as full partners on Integration Joint Boards, with voting rights and on the Board of the National Care Service. **Unpaid carers have been clear that unless they have a seat at the top table, there will not be the required impetus or expertise that comes with lived experience to drive the radical change and improvements that are needed at a local and national level**

³ [An unequal crisis, Citizens Advice, August 2020](#)

Young Carers

The review does not include any specific recommendations in relation to young carers and young adult carers. However, the needs of young people caring for adults with support needs must not be overlooked or become a casualty of the often artificial silos between children's and adult services. **Young carers and young adult carers have specific needs and challenges that require their own solutions.**

Key to supporting young carers and young adult carers is ensuring that age appropriate services are readily available when they need them and are designed to meet their needs and outcomes. Young carers and young adult carers often have little choice but to take on care because services and support is simply not available, particularly at the start of their caring journey

The urgency for action has been heightened by the pandemic and its impact on young people, and without action the impact on young carers and young adult carers may be felt well into their future

Carers from Black and Minority Ethnic Communities

The focus on human rights and equalities within the Review of Adult Social Care is to be welcomed but this commitment has not been underpinned and strengthened by a specific recommendation which acknowledges and seeks to address the specific challenges faced by unpaid carers from Black and Minority Ethnic communities. Existing equalities legislation has been limited, at best, in its impact on the delivery of health and social care services leaving already marginalized communities struggling to cope with little or no support. The impact of COVID-19 has amplified existing structural inequalities.

Black and Minority Ethnic (BME) carers are represented in every strata of the caring population, from the very young to the very old and face a specific set of challenges which require specific solutions. Research highlights that BME carers are least likely to be aware of their rights and entitlements, have significantly lower uptake of services and experience overall poorer health.

We ask that equity of opportunity and resources be considered as a key means of achieving equality of outcomes.

About the National Carer Organisations

The National Carer Organisations are brought together by a shared vision that all Scotland's unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Trust Scotland, the Scottish Young Carers Services Alliance, Carers Scotland, the Coalition of Carers in Scotland, Shared Care Scotland and Minority Ethnic Carers of People Project (MECOPP)

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