

Response to the adult social care review

This response has been developed by the national carer organisations. The national carer organisations are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, Crossroads Caring Scotland, MECOP, Shared Care Scotland, Scottish Young Carers Services Alliance.

The Coalition of Carers in Scotland is one of the members of the national carer organisations has already submitted this response and the national carer organisations have contributed towards this and have been involved in helping to supporting their engagement events. We have also supported the activity within the Carers Parliament in engaging with carers on their views on the future shape of social care in Scotland. We therefore support the contents of their response. However, rather than repeating this, the following are some key elements we believe should be included within the review. We have appended the Coalition response to this.

Quotes within the response are from Carers Parliament 2020, State of Caring in Scotland¹ survey and the Caring Behind Closed Doors Reports.²

A new social care system?

The COVID-19 pandemic has laid bare many of the issues that have long dominated discussions between carers, service users, service providers and national and local government. COVID-19 brought about unique circumstances and significant challenges but whilst there are lessons that can be learned, and a groundswell of support for 'building back better', responding to these challenges should not be the primary driver, nor should it be the framework for subsequent decision-making or solutions.

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. Many people are left with little or no support – or support that is not the right fit for them – and too often carers are left exhausted and in poverty in trying to fill the gaps that exist. In State of Caring in 2019, only 28% of carers were receiving any formal social care support for the person they cared for.

"The assessment covered a lot of details but nothing happened afterwards and I feel I might as well not have had it"

"After being assessed as critical we are still waiting for respite almost a year later."

¹ <https://www.carersuk.org/scotland/policy/policy-library/state-of-caring-in-scotland-2019>

² https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf
http://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

With the pandemic carers have said they felt 'broken' or 'worn down' and worried how they will make it through the Winter. The pandemic will leave behind it a legacy of damaged physical and mental health, poverty and inequality which will need sustained action to improve.

For example, almost two thirds of carers have not been able take any breaks from their caring role during the COVID-19 pandemic. This at a time, when 8 out of 10 carers said the needs of the person they care for have increased since the pandemic began.

*"I am more anxious about going out than I have ever been in my life.
My boundaries have narrowed. It is so lonely."*

*"I have struggled hugely being with my husband 24/7, unable to have a break from caring.
There are times I think I can't go on, but of course I have to. Sometimes
I don't want to wake up in the morning."*

It appears to many carers and people that use services that, *for the first time*, a consensus is emerging across Scotland of the *value* of social care and the *need for change*. Consensus on what these changes may be has yet to emerge but what is clear is that fundamental change is needed and a clear vision for the future must be articulated and delivered.

Despite the review itself being short term, it is vital that a "new social care" model (whatever form it takes) has consensus and cross party support at national and local level because, like the NHS, it will require long-term commitment: in funding and in public support. There is unlikely to be one simple solution and the task to develop a way forward is complex – both in developing a vision and in implementing delivery.

The national carer organisations are clear that the implementation of further development of what emerges from this review must involve carers fully as key partners in care moving forward. Without their involvement and the involvement of disabled and older people, there will be a lack of expert knowledge and experience of social care. It is worth remembering a key statement in "Changing Lives: Report of the 21st Century Social Work Review", a previous review published in 2006, which says "People who use services can be both inspirational and visionary".

There is cautious support amongst unpaid carers for a national care service as it is as yet unclear what form this will take but, whatever emerges, the national carer organisations have set out, from our work with carers and carers organisations, the key outcomes and elements that will be vital.

SOCIAL CARE MUST BE FUNDED MORE EFFECTIVELY

Social care must be funded sufficiently. Social care is as important as health care and must be funded accordingly. Resourcing should also recognise the additional costs faced by remote, rural and island communities and in meeting the needs of diverse communities.

There is a need for extra investment as, without it, it is unlikely that real change will be delivered.

The current framework for funding social care has created a system fraught with inequalities, and the rationing of services through eligibility criteria consistently set to meet only the highest or critical level of

need. There is an opportunity to expand the role of social care as a key part of reducing both health and income inequalities and, as such, should be seen in the same way as corresponding policies to increase investment in targeted areas such as early years. This is as an investment in Scotland's people.

"All items were thoroughly considered and I get excellent support from Quarriers, but I am not able to seek sufficient support for my cared for or myself to actually make the right difference to juggling, breaks etc. My cared for is ineligible for social care as he is not in crisis. I am on the waiting list for social care as a carer."

EFFECTIVE IMPLEMENTATION AND MONITORING

Any change that is implemented must be monitored both locally and nationally, and organisations responsible be held accountable for doing so. There are many examples of good legislation and policy that are poorly and inconsistently implemented across Scotland. There should be oversight and the ability for the Scottish Government to require change should local areas not implement changes fairly in their area.

This was a clear point from carers across engagement activities around the review and indeed, has been one that carers have consistently raise. How can legislation be effective when national policy and local delivery vary so significantly? Carers and the people they care for fall through the cracks.

PEOPLE SHOULD BE ABLE TO EXPECT CONSISTENCY AND PARITY OF PROVISION

There should be consistency of support across Scotland. This does not mean that exactly the same services should be provided everywhere but that there should be parity to ensure that, for example, a carer knows that they have, for example, a right to a break, a right to services to support them to remain in employment or a right to training. It is essential that regardless of where in Scotland someone lives, they are confident they will be able to make choices about their support and that their needs will be met.

There is also a need to lessen bureaucracy within the system for people who use it. Carers reported that dealing with statutory services has a greater impact on their health and wellbeing than their caring role. This is also a deterrent to some carers accessing support.

"My daughter left school- she gets a budget which took a 9-month fight; my son gets no budget. I care for my mum she gets no help at all"

The review also presents an opportunity to begin to address the artificial silos between children's, adults and older people services, which create challenges and bureaucratic hurdles for carers, particularly during transitions for young people with disabilities. During the Carers Parliament, carers talked about the huge challenges they face at this time – a time in a young person's life that is clearly predictable for authorities.

WE MUST SEEK TO CHANGE LIVES NOT STRUCTURES

The focus of change must be on making a real difference to the lives of disabled people, older people and carers and not on lengthy (and often costly) structural change. We also emphasise that changing the structure of how social care is delivered must not be framed by the reaction to the COVID-19 pandemic, but must have the lives of individuals at the heart.

In the creation of something “new” it is also important not to lose what is good and supported. At the Carers Parliament there was support for self-directed support and its intention to deliver choice and control; albeit not always what was offered. For carers who were able to, for example, benefit from a direct payment, this presented opportunities to organise care in a way that suited the lives of the person and their carer. However, issues around adequate resources and availability of options remain.

SOCIAL CARE IS MORE THAN PERSONAL CARE

Carers in discussions at the Carers Parliament were clear that the core purpose of social care needs be set out as part of the review. The national carer organisations believe that social care must be focused upon the whole person, providing choice over what services and support will meet their outcomes and their aspirations. It is not enough to only offer services that meet, for example, personal care needs. We must seek to develop an approach that enables people to fulfil their potential, and to be part of their communities: to work, volunteer and study if they wish and to have strong community, family and social connections.

Social care should promote human rights and support people to exercise those rights. For carers this also includes having a real choice over whether or not they want to provide care and at what level; too often a choice never offered or denied by the rationing described earlier. As noted earlier, social care should also be recognised as having an important role in preventing inequality and as such investment in prevention should be seen as a core function not just as a “nice to have”.

“We no longer have a life outside full time work and our family home resembles a care home our bills have trebled and quality of life decreased disappeared in fact”

“Loneliness is such an integral part of caring. I no longer have a husband. I care for him. We cannot share what we used to, we rarely do things together because of my husband’s health. I’ve been to some dark and hard places over the last few years as his health has become poor...lots of long, lonely nights. Caring for your spouse brings a lot of emotional trauma that people do not appreciate or understand.”

INVESTMENT IS NEEDED IN UNPAID CARERS TO REDUCE POVERTY

There is a crucial need to invest in unpaid carers. Unpaid carers in Scotland are a larger workforce than the health and social care workforce combined. Investing properly in our unpaid carers is an essential part of preventative support. This investment in unpaid carers should include parity with the paid workforce, including access to training to support their caring role and occupational health type support to manage the impact of caring on the health.

Other key investments should include the value of Carer's Allowance matching the demands of carers alongside rights to access services that enable them to continue work, study, access leisure opportunities and maintain social connections alongside their caring role.

Caring is normal, with 3 in 5 of us becoming carers at some point in our lives. Caring should not leave carers with a legacy of poverty (often well beyond the end of their caring role and into retirement), poor health and wellbeing. The poverty that carers face is not just financial and we should seek to address the poverty of opportunity that many carers face, where their world shrinks as caring, unsupported, grows.

"I am already using my life savings and they won't last much longer so I don't know how I will survive."

If anyone had paid any attention when I asked my mental health wouldn't be broken now.

SPECIFIC INVESTMENT AND ACTION IS NEEDED TO SUPPORT YOUNG CARERS

Young carers and young adult carers have specific needs and challenges that require their own solutions. Many young carers provide care and support for an adult and as such, their needs must be considered in the review. The national carer organisations include the Scottish Young Carers Services Alliance who have supported the development of a young carers manifesto³ which outlines key areas of activity.

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.

Young carers and young adult carers must have support in place to protect them from undertaking inappropriate caring roles, to also allow them to make an active and informed choice about the level of care, if any, they are willing and able to provide. Ultimately ensuring they have a fulfilling life alongside caring.

Young carers and young adult carers should be supported first and foremost as children and young people. Significant work is needed to ensure that young people with caring responsibilities do not face exclusion or disadvantage simply because they are caring.

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 futures. Whilst the review's focus is on adult social care, the needs of those young people caring for adults cannot be lost in often artificial silos between children's and adult services.

INVESTMENT IS NEEDED TO SHOW THE VALUE OF PAID CARE WORK

Investment in social care staff is also critical. The value of social care must be reflected not only in the quality of services it provides to carers and those they care for but also in the employment conditions of staff that

³ <https://www.carersuk.org/files/section/6552/a-manifesto-for-young-carers-2021-draft.pdf>

support the delivery of care. Whilst work has been undertaken with SSSC to enhance the professional standing of social care workers, this is not yet reflected consistently in wages, terms and conditions or career development. Poor pay and conditions has an impact on the ability to recruit and retain staff, with staff turnover meaning losing valued relationships that are important to people receiving care.

At the Carers Parliament, carers highlighted the need to invest and value paid work, including investing in training and career development.

THERE MUST BE RIGHTS TO SOCIAL CARE

Social care should be framed in the principles of human rights and with tangible and enforceable rights enshrined in statute. Individuals should have a redress when their rights are not met beyond what is seen by many as a toothless complaints system or complex and expensive legal action. Particular attention should be given to how access to social care will meet the needs of those with protected characteristics.

EQUALITY OF VALUE FOR COMMUNITY AND THIRD SECTOR ORGANISATIONS

Many unpaid carers rely heavily on the services they receive from third sector organisations such as carers centres. This has never been illustrated so starkly as during the pandemic where community and third sector groups rallied across Scotland to meet the needs of disabled people, older people and carers where the public sector had stepped back services, or could not respond and innovate so quickly. Any review of social care must place equal value on our voluntary organisations and community groups as public sector bodies. Their crucial role and the trust that they have earned, not just during the pandemic, should not be lost in “the need to do something”. Giving people choice and control within a social care system also means having a sustainable market available that can deliver on the choices that they make. The role of the third sector in delivering services, for example, short break services is critical to this and how this is commissioned needs careful consideration.

In conclusion, notwithstanding the detail above, fundamental to developing a social care system that is fit for the 21st Century and beyond are three key tests.

- **Is it person centred?** Are the people who use services and their carers at the heart of decisions about social care and are their views paramount, strategically and in their day-to-day lives?
- **Is it adequately resourced?** Is our 21st Century social care system funded to a level that will truly improve the lives of people who use services and their carers? Will it meet not only their daily needs but also their ambitions and aspirations and will it reduce the inequalities they experience - or is it simply moving about the pieces?
- **Does it deliver choice?** Does any new social care service deliver choice to individuals and their carers? The choice to be independent, to care or not to care, to have services that fit around their lives not around time slots, contracts and tasks? Does it place individuals and their carers in the driving seat rather than as passengers in an unresponsive system?

Carers Parliament 2020 - Social Care and Social Care Review

The following outlines responses from carers at the Carers Parliament during a discussion with Derek Feeley. This has already been submitted.

- Review needs to set out an understanding what Social Care is – what is its core purpose?
- How can a national care service be paid for?
- How can legislation be effective? National policy v local delivery. Carers and the people they care for fall through the cracks between this.
- There is room for improvement in the Carers Act. There is a gap between the initial expectations and the reality. Lack of contingency planning and inclusion of carers even though they provide majority of care. There is no duty of care and little emergency planning. What happens when a carer can no longer care? Carers support is needed to be a dialogue – not a one off thing
- Work is needed to ensure that this aligns with services for children with complex needs on their transition to adult services. There is a lack of opportunities and we need to plan better for anticipated events.
- Charging remains an issue – and was highlighted across most of the workshops in the Carers Parliament. There is no consistency nor fairness and not a comfortable position e.g. Human Rights and consistency/fairness perspective
- Eligibility to services the same. There is a lot of bureaucracy to get care and support, with carers reporting it can take months to get support in place, and even then it is seldom at a level that provides the supports they or the person needs.
- Accountability and parity – how can there be transparent accountability and parity across local authorities. Also addressing differences in policy, practice and values.
- The review and plans developed need to recognise the gendered issue of caring – both paid and unpaid. What will the review so to ensure that gender equality and inclusion is delivered for carers and care workers?
- General support across workshops for self directed support but it is too often inconsistent, does not meet needs or outcomes (budget based) and difficult to access. Also budgets do not always provide for costs of training for those employing PAs (or for PAs themselves).
- Carers want to know the timescales for the implementation of the review and want politicians to make a commitment to a timescale.
- Work is needed to review the way in which paid carers are prepared for their role, valued for their skills and developed during their career.
- Social care assessments needs to deliver support to enable carers to return to or remain in work (or education). Carers should have a right to support for this.
- ILF policies were raised as good practice and a mechanism for going forward - One example of this is when the living wage increases then the budget increases in line with this. Not always the case with HSCP. Some of whom have still to implement the 3.3% uplift for the Living wage back in April.
- Carers who are involved in planning at a strategic or policy level need training and support to ensure that their role is meaningful. For example, carer representatives on IJBs often report a lack of input and not being listened to.
- Digital access/skills etc. should be the first consideration in social care assessments. Digital inclusion is key but there is nothing proactive. Especially important as more options emerge to be delivered online.
- Carers felt abandoned by social services during COVID

- Respite fell apart. There should be a base requirement during COVID that carers are checked in on.
- Respite – should be an entitlement. Work needs done on a definition of respite (which should not include paid work) and greater clarity in definition of rights to it.
- Human rights based approach
- What can we do to make it easier for citizens to access/express their human rights?
- How do duty bearers respond to requests?
- What about when they don't match up or work?
- Not being able to visit care homes was raised in a number of Carers Parliament events. Carers remain carers, even when their loved one has gone into a care home and the lack of contact has been devastating. Regular testing needed and support for stress.

The Coalition of Carers in Scotland



Carers as Equal Partners in Care

“Nothing is going to change radically until there is far more provision, and that will not happen until caring (both paid and unpaid) is valued in a very real, financial sense”¹

We welcome this opportunity to respond to the review of adult social care. We hope that the review will deliver radical change by creating a social care system which is progressive, ambitious and will ultimately improve the lives of supported people 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. We believe that a broader definition should be taken of what it means to be a successful country, looking not just at economic growth but at the collective wellbeing of citizens. The value of unpaid care and the contribution carers make to the economy must be viewed through this lens.

We wholeheartedly agree with the comment Derek Feeley made at our recent meeting

‘One of the challenges we have around funding is that social care is looked at through a lens of crisis and burden, it’s time to change the conversation. An investment in social care is a good investment. It makes sense in economic development terms, in citizenship terms.’

We hope this signals a new approach to how social care will be designed, delivered and funded in the future. We are committed to supporting and contributing this ongoing process and would value future involvement in the implementation of recommendations leading from the review.

⁴ All quotes are from carers and carer support staff who attended our engagement events

Section One: Engaging with carers and emerging themes

Throughout October and November we facilitated the following engagement events with carers and other key stakeholders. Over 100 carers participated in our discussions, each meeting was attended by Derek Feeley.

1. Our member meeting, which included carers and carer support staff from across Scotland
2. The Carers Collaborative Forum for carer representatives on IJBs
3. The Carers Centres Managers Network Meeting
4. The Carers Collective, a group of carers engaged in local campaigning

Some of the key themes that emerged from the participants were:

- Several people stated that they felt the ‘system is broken’ Inequalities which were in evidence before have been further exacerbated by Covid-19. (More information on how carers have been impacted by their caring role both pre-Covid and during the pandemic is included in Section Three)
- Carers highlighted the lack of consistency within the current social care system, both between areas and also within areas. Participants felt the system was unfair as it was a ‘postcode lottery’ with support depending on where you live, what services you require and how much your care manager is able to advocate on your behalf.
- The social care system is massively complex. Both process and provision vary considerably between areas and data collection is inconsistent. It is therefore difficult to identify where the deficits and inefficiencies are. For example, there is no way to calculate how much is spent on carer support in Scotland, as the information typically sits across several workstreams and is calculated differently in each area.
- The system is hugely bureaucratic. Carers reported that dealing with statutory services has a greater impact on their health and wellbeing than their caring role. This is also a deterrent to some carers accessing support
- Because of the inconsistencies within the system, the lack of portability and the bureaucratic process required to access support, people feel unable to move between local authority areas and fear transitions.
- When carers have been unable to access their rights, including their right through the Carers Act to have their eligible needs met, they are unable to challenge effectively. The complaints system is inadequate and legal recourse is not a viable option for most people.
- Caring can impact on all areas of a person’s life. This has been amplified by the current pandemic. Several carers said they felt ‘broken’ or ‘worn down’ and worried how they will make it through the Winter. Covid-19 will leave a legacy of diminished physical and mental health for many carers, which will need to be addressed.

Section Two: Key Asks

As part of our engagement meetings we asked people what they wanted to come out of the review and what their ‘Key Asks’ were, these included the following:

- The review needs to take a radical approach, several people used the phrase ‘there is no point in moving deckchairs around on the titanic’ as an analogy to the need to re-think both the current system and how it is resourced
- Participants welcomed the reviews focus on human rights. In developing its recommendations carers expressed the need to adopt a rights based approach and consider the need for additional rights, including the right to short breaks for carers.
- Social care requires significant investment, but it is essential that both existing and additional funding is maximised to achieve the best outcomes for supported people and carers. Several participants talked about how funding allocated to implement the Carers Act has been used for other purposes to the detriment of carers. **We need to move towards targeted investment so that commitments made nationally are properly funded.**
- Social care cannot be viewed in isolation, it needs to interface with other services, including housing, education, and employment support. For example, parent carers talked about the impact of education on their caring role and carers of disabled people talked about the need for accessible housing.
- Power must shift to communities, supported people and unpaid carers. Carers must be viewed as equal partners in care. There has been significant disappointment at the lack of carer representation on advisory boards across all social care review/renewal programmes. Despite carers providing the majority of care in Scotland they are still not included at the highest levels of decision making.

“Right now it comes to value and how we choose not to value disabled people and unpaid Carers. We’ve made choices as a country pre and post covid which have made our lives smaller, harder and more difficult. Until our families are at the heart of shaping these policies, nothing will change”

- The needs of all caring communities must be addressed in the review. There are already pockets of good practice across Scotland, but often groups which are considered ‘hard to reach’ experience barriers to accessing support. Social care must be accessible to all (In Section Six we look at specific groups of carers who require additional consideration)
- Transitions continue to be a very difficult and stressful process for many people, particularly for parent carers when their son or daughter transitions from children’s services to adult services. In their submission COSLA identified funding as a specific issue: *‘This is due, in part, to how parts of the system work together, and how the associated funding streams are provided. This makes it difficult to enact transition planning meaningfully and the variation in budgets that will be available for people can change drastically almost overnight’* Although this review focuses on adult social care, it should also consider the transitions from childrens services and the need for greater consistency and clarity in the level of support between the two services.

Section Three: The impacts of caring

“We are preventing a tsunami of need from overwhelming public services. That comes with costs to us, to our families”

The impacts of caring have been well researched, most notably by Carers UK annual State of Caring research.⁵ The 2019 survey, pre-Covid, evidenced the following impacts on carers:

Finances

37% of carers said they were struggling to make ends this rose to 53% of carers receiving Carers Allowance. 79% of carers regularly use their own income or savings to pay for support, equipment or products for the person they care for. 54% said they were not able to plan for their retirement

Carer Support

90% of carers worry that the support they receive might be reduced. 12% reported that their support had reduced in the last year. 21% of carers thought an emergency hospital admission could have been avoided if more support had been provided

Health and Wellbeing

90% of carers said they are not able to do as much physical exercise as they'd like. 93% of carers reported feeling lonely and isolated because of their caring role. 29% of carers reported 'bad' or 'very bad' mental health

The current pandemic has had a disproportionate impact on unpaid carers. Many social care services have ceased or been reduced during this period, meaning carers have not had access to the support they generally rely on. Carers UK have undertaken two surveys during this time, the most recent one in October 2020⁶, found that carers had been affected in the following ways:

Increase in unpaid care provided

As a result of the pandemic there are an additional 392,000 new carers bringing the number of carers in Scotland to 1.1million. 87% of carers are providing more care now than they did before the pandemic and 92% of BAME carers are providing more care.

⁵ [State of Caring, Carers UK, 2019](#)

⁶ [Caring behind closed doors: 6 months on, Carers UK, October 2020](#)

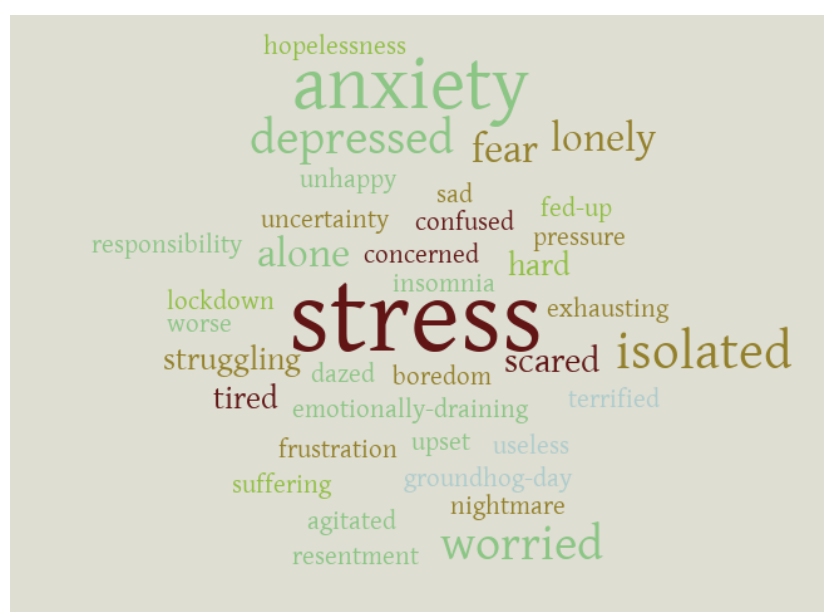
Carer Support

65% of carers have not had a break during the pandemic. 77% reported feeling exhausted and worn out

Carers Health and Wellbeing

63% of carers are feeling more stressed and 55% said it has had an impact on their health and wellbeing. 72% of BAME carers are worried about how they will manage this winter.

Angus Carers Centre undertook a survey of local carers in October 2020. The Wordcloud below provides a visual description of how respondents reported feeling during the pandemic



Section Four: The arguments for supporting carers

“For me the biggest issue is the expectation that I will sort everything. I've recently had several minor operations, but no time for me to be unwell, recover, hard enough to find time to go to hospital appointments. My daughter is 28 so this has been for years and will be for the rest of my life”

The contribution carers make is incontrovertible. Their contribution has long been recognised in national and local policy, but recognition has only recently led to legal rights for carers and services leading from those rights have been slow to materialise.

On an individual level, having a family member who is perceived as being available to provide care means that supported people are considered a lower priority and are therefore less likely to meet local eligibility criteria for support.

Human Rights

Carer support is a human rights issue in the same way that support for disabled people is. As the table below shows, lack of support often means carers are unable to access their human rights.

Participation	<ul style="list-style-type: none"> Carers are on IJB Boards – but are non-voting members and often feel ignored Without replacement care and short breaks carers cannot participate fully in society and often cannot maintain employment
Accountability	<ul style="list-style-type: none"> The Carers Act and SDS Legislation have not been fully or consistently implemented. Funding allocated to implement the Carers Act has been re-directed elsewhere
Non-discrimination	<ul style="list-style-type: none"> Carers from rural and BAME communities struggle to be heard and get support Caring disproportionately affects women 1 in 10 carers are older people Carers are not routinely included in EQIAs, despite facing discrimination by association
Empowerment	<ul style="list-style-type: none"> In our 2019 survey 46% of carers did not know about The Carers Act or their rights in it Carers are not yet equal partners in care
Legality	<ul style="list-style-type: none"> Carers have rights on paper – but they are a postcode lottery There is very little right to redress for people who have not been able to access their rights

“To date we’ve been very focused on the people who use services and their human rights and perhaps not so much on the human rights of carers” (Derek Feeley)

Carers Economic Contribution

The value of unpaid care in Scotland is estimated at over £36billion a year (The NHS cost £13.4billion in 2019)

Carers Health and safety

We have already outlined the impact of caring on people’s health and wellbeing in Section Three. However carers’ safety is rarely acknowledged or accounted for, unlike the paid work force who have substantial legal protection. In our discussions we heard from several carers who were expected to use equipment such as

hoists with no training and without support. In comparison, following risk assessments, paid care workers would only use equipment with two or three workers present. **Unpaid carers must have similar protections to the paid care workforce.**

“The rights of unpaid carers should be aligned to the rights the PAID workforce, NOT to those of people requiring care. If a carer requires care, they will have those rights, but they need the rights of PROVIDERS, not of USERS of services”

Breaks from caring

Carers currently do not have a right to breaks from caring. While some short breaks are available, there is no minimum entitlement and carers struggle to access regular breaks. We held a poll at our member meeting asking people if they felt carers should have a right to short breaks and replacement care, 100% of participants agreed that they should.

“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” (Derek Feeley)

Employment

1 in 5 carers give up work to care, meaning they are no longer economically active. 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 carers has been particularly vulnerable. Research from Citizens Advice found that 2 in 5 people with caring responsibilities were facing redundancy, more than double that of the average working population⁷. The government has invested in childcare to enable parents to remain economically active. The same economic arguments apply to enabling carers to remain in employment through investment in replacement care services.

“Access to replacement care for carers in employment should also be viewed in the same way as childcare - with the same investment”

⁷ [An unequal crisis, Citizens Advice, August 2020](#)

Section Five: The System – A National Care Service?

“We need a system that is controlled nationally, that delivers locally, has the person at the centre, that does not cost the earth”

At all our engagement meetings there were discussions on the value of a National Care Service. We introduced a poll at our member meeting and 38% of respondents thought it was a good idea, 56% said they ‘don’t know’ and 7% were not in support of it.

In general, the majority of people were cautiously positive, but this was dependent on what model the National Care Service would take. There was some hesitation around the cost in establishing and running the service, with concerns that it would result in less investment going directly to social care provision and individual support. There was also a concern that rather than supporting the integration agenda it would result in a silo effect between the National Health Service and the National Care Service.

Some of the pitfalls of the NHS would need to be avoided, such as being too bureaucratic and rigid, making it unable to evolve rapidly to changing needs. A National Care Service must not stifle innovation or lead to resources being directed to large national organisations, rather than smaller grass-roots organisations. Overall, there was agreement that in order for it to be effective it would need to come under the jurisdiction of elected members of parliament, in the same way the NHS does.

“Social care should stand alone, it is such a huge piece of work. Any new National approach to care should not be management top heavy, I would like to see majority of money going to services for the people we care for”

For it to address some of the deficits and inadequacies of the current social care system it would need to centre people with lived experience of social care, along with unpaid carers and understand and value the role of the third sector in the design and delivery of social care.

Below we have set out the key principles and features that we believe must be an intrinsic part of any National Care Service, whatever shape it might take.

Human rights approach

Social care must be framed in the principles of human rights, with tangible and enforceable rights enshrined in statute. Individuals should have redress when their rights are not met, beyond what is seen by many as a toothless complaints system or complex and expensive legal action. Particular attention should be given to how access to social care will meet the needs of those with protected characteristics.

To support people in accessing their rights **unpaid carers should have a right to advocacy in the same way as people under The Mental Health Act have a right to advocacy**

National Oversight and Consistency of standards

Across Scotland people with social care needs must experience equality of entitlement and rights. There should be consistency of provision across Scotland with support not determined by local authority resources, but by people's needs. This does not mean that exactly the same services should be provided everywhere, but that people should have an equal entitlement. For example, a carer should know that they have a right to a break or a right to services to support them to remain in employment. It is essential that regardless of where in Scotland someone lives, they are confident they will be able to make choices about how their support is delivered, and that their needs will be met.

A National Care Service should establish the framework for consistency by providing

- national standards
- national improvement programmes
- national eligibility standards
- national contracts for the workforce – pay conditions and training

“You can have all the national standards you want - we have these in the existing legislation but we have local culture which often blatantly ignores these standards and expectations. How do we challenge/change this?”

Sufficient Funding, Preventative Support & Choice

Social care must be funded sufficiently. It must have equal parity with health provision and be funded accordingly. Resourcing should also recognise the additional costs faced by remote, rural and island communities and in meeting the needs of diverse communities. Without additional investment, real change cannot be delivered.

The current framework for funding social care has created a system fraught with inequalities, and the rationing of services through eligibility criteria consistently set to meet only the highest or critical level of need. There is an opportunity to expand the role of social care as a key part of reducing both health and income inequalities and, as such, should be seen in the same way as corresponding policies to increase investment in targeted areas such as early years. This is as an investment in Scotland's people.

“Eligibility criteria is used to set the bar high in order to reduce the spend on SDS. Officers also do not fully understand the legislation. Risk also supersedes outcomes where it should be the other way around”

We need to see a shift from financial responsibility being placed on families, through charging and the provision of unpaid care, to a more equal division, with an end to social care charging and the financial burden of ill-health and disability being equally shared by the whole of society.

“Fair and equitable funding does not place the burden on individuals through charging”

Choice is one of the central tenets of Self-Directed Support. Both supported people and carers should be able to exercise choice in the type of support they access and its delivery mechanism. This means delivering SDS in a more flexible way, allowing people greater autonomy in setting their personal outcomes and deciding what support options will help them achieve them. In the case of carers this may often mean purchasing an alternative to traditional models of support, such as gym membership or a break with the person they care for.

Carers also need to be able to choose how much care they are ‘willing and able’ to provide. Pressure should not be placed on them to provide more care and assumptions should not be made about their availability, or the other responsibilities or ambitions that they are juggling alongside their caring responsibilities

“Carers aren’t able to specify what care they are able and willing to provide. This has been highlighted even more so during Covid with even more expectations put on the carer”

Inclusivity – Carers as equal partners

Despite the duties relating to carer involvement in The Carers (Scotland) Act 2016 and carers previously being recognised as ‘Partners in Care’ in the Community Care and Health (Scotland) Act 2002, carers are not yet treated as equal partners in care.

In 2018/19, two reviews of Health and Social Integration took place, one carried out by Audit Scotland and one by the Ministerial Strategic Group for Health and Community Care. Both noted the importance of involvement and collaboration for effective health and social care integration and made recommendations or proposals for improvement.

However, the Carers Collaborative, established in 2016 by the Coalition of Carers to support, evaluate and improve carer representation on Integration Joint Boards (IJBs) noted in its 2019 scoping report that there are still areas for improvement in relation to carer involvement in strategic planning. In particular:

- Recruiting and retaining new carers who are willing to undertake representative roles has become a challenge
- Most IJBs continue to require Carer Reps to subsidise their public duties, with expenses not being provided and expenses policies not being in place.
- Involvement in agenda-setting has improved in some areas, but Carer Reps are still excluded in many others.

As equal partners in care, carers must be included in the governance arrangements of any future National Care Service, as full voting members.

“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”

Changing Lives and reducing bureaucracy

Change must be focused on making a real difference to the lives of disabled people, older people and carers and not on lengthy (and often costly) structural change and process. We also emphasise that changing the structure of how social care is delivered must not be framed by the reaction to the COVID-19 pandemic, but must be focused upon the whole person, providing choice over what services and support will meet their outcomes and their aspirations. It is not enough to only offer services that meet, for example, personal care needs. We must seek to develop an approach that enables people to fulfil their potential, and to be part of their communities: to work, volunteer and study if they wish and to have strong community, family and social connections.

People should be able to move with ease through the system supported by navigators, rather than gatekeepers. People should not have to ‘battle’ or ‘fight’ to access support

“The level of bureaucracy carers are facing in order to access support or to access their rights in relation to ACSPs is diabolical. They are creating barriers rather than seeking solutions. The number of carers facing extreme mental health concerns is growing every week”

Full implementation

Any changes arising from the review must be fully implemented and the organisations responsible for implementing changes must be held accountable for doing so. There are many examples of good legislation and policy that are simply not implemented consistently across Scotland. There must be oversight and the ability for the Scottish Government to intervene where required



This graphic was developed by the Coalition of Carers in Scotland to illustrate the implementation gap, which cannot be bridged without a commitment from all partners

“We need some accountabilities in our system for how the money is spent...we need transparency about how much we are spending and simplification of some of the flows of how money is allocated. Clear accountability for every pound for social care, what are we spending that on and what’s the thought process that led us to invest in X rather than Y” (Derek Feeley)

Investment in carers

Many people have 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 our unpaid carers is an essential part of preventative support. This ranges from a Carers benefit that properly compensates carers financially for their contribution and loss of earnings, to support services that enable carers to work, study, access leisure opportunities and maintain social connections alongside their caring role. Caring should not drive carers into poverty and poor health.

“Carers have to fight for everything, or they just give up and think it’s easier just to get up in the morning, do what I have to do and then go back to bed. 100 reasons why you can’t get something rather than 1 reason why you can”

Investment in the paid work force

Investment in social care staff is also critical. The value Scotland places on social care must be reflected not only in the quality of services it provides to carers and those they care for, but also in the employment conditions of staff that support the delivery of care. Whilst work has been undertaken with SSSC to enhance the professional standing of social care workers, this is not yet reflected consistently in wages, terms and conditions or career development. Poor pay and conditions has an impact on the ability to recruit and retain staff, with staff turnover meaning the loss of valued relationships that are important to people receiving care.

“In our area there are not enough paid carers, even for personal care packages. Social care is not paid adequately and there is a really high turnover of staff, Covid has exposed these gaps”

Valuing Community and Third Sector Organisations

Many unpaid carers rely heavily on the services they receive from third sector organisations, such as carers centres. This has never been illustrated so starkly as during the pandemic where community and third sector groups rallied across Scotland to meet the needs of disabled people, older people and carers, while the public sector stepped back services, or could not respond and innovate quickly enough.

Throughout the pandemic carers centres have provided continuous, unbroken service provision. They have delivered practical and emotional support to carers, ensuring people have access to food and medication, organising PPE deliveries and keeping in regular contact by phone and online platforms to ensure carers feel safe and supported. They have also been able to support carers to access alternative forms of breaks where traditional services have been suspended.

“What we've learned absolutely from the pandemic is the significantly quicker response/adjustments possible from the third sector.”

Any review of social care must place equal value on our voluntary organisations and community groups as public sector partners. Giving people choice and control within a social care system also means having a sustainable market available that can deliver on the choices that they make. **The role of the third sector in delivering services is critical and must not be secondary to the statutory sector.**

For a level playing field and a relationship of equals, the statutory sector must be subjected to the same scrutiny and accountability as the voluntary sector. Current commissioning practice must be reformed and power must shift from the statutory services to community provision, ensuring that third sector organisations receive adequate, long-term, sustainable funding.

In order to achieve this we need to move from a market economy to a community economy. This requires a paradigm shift from investment in the profit making private sector to resources being directed to the third sector and community organisations, led by supported people and carers. With an emphasis on local community solutions to social care

Collaborative commissioning needs to be the standard model, creating the conditions to allow innovation and collaboration to flourish

This requires a turnaround to traditional commissioning relationships and a shift in the balance of power and responsibility between agencies, supported people and unpaid carers

“Carers centres should not be put out for sale. We are here to do a fundamental job to support carers in our community. We can only do the best we can if we have stability of funding. Third sector organisations should not be traded this way. The government has said often that we need to be seen on the same level as statutory partners, we are not”

Use of technology

Throughout the pandemic the prodigious use of technology has enabled people to stay connected. For many carers, particularly those in rural areas, or with very isolating caring roles, it provided them with greater opportunities to engage than they had before Covid-19. Technology has the ability to extend and customise choice and promoting and facilitating digital inclusion must be a recommendation for the review. However, digital connectivity must never be viewed as an alternative to personal, face-to-face support, but rather as an enhancement to this.

Section Six: Specific Groups that require additional consideration

BAME carers

We must acknowledge the unequal impact that some communities experience when accessing social care, particularly in relation to the current pandemic.

BAME communities have suffered more through COVID-19 than other communities. Those who were already disadvantaged are now even more marginalised because of a lack of tailored support to meet their specific needs, including the need for community languages and culturally responsive services. (Section Three provides further information on how BAME carers have been disproportionately affected by Covid-19)

We cannot ignore this and the review must make some recommendations regarding this. For example, where carers centres have specific BAME carer support posts, there is much greater uptake of services from minority ethnic communities.

Caring as a gender issue

Around the world, women spend two to ten times more time on unpaid care work than men⁸ and in Scotland twice as many female carers rely on benefits than male carers. We cannot talk about unpaid care without acknowledging the specific impact it has on women.

This unequal distribution of caring responsibilities is linked to discriminatory social institutions and

⁸ [Unpaid Work, the Missing Link, OECD Development Centre, December 2014](#)

stereotypes on gender roles. Gender inequality in unpaid and paid care work is the missing link in the analysis of gender gaps in labour outcomes, such a wages and job quality.

“The capitalist patriarchal system has found a great care solution - make the women do it for nothing. Care crisis is as much to do with women asking for more as about the ageing population”

Carers from rural and island communities

The Coalition of Carers has facilitated a working group for rural and island carers for the last 10 years. This group has consistently highlighted how carers from rural and island communities face additional challenges, including a lack of public and community transport, increased levels of poverty, additional isolation, challenges with the recruitment and retention of the social care workforce and less choice and availability of social care provision and carer support. We recommend that targeted resources are directed to rural and island communities to help address these additional challenges.

Young carers

Young carers have specific needs and challenges that require their own solutions. As an organisation. we only engage with adult carers, however our colleagues at the [Scottish Young Carers Services Alliance](#) are an excellent source of expertise on the needs of young carers.

Section Seven: Supporting Carers – Models of Support

“We need to move away from only providing support to those in critical need. We need to invest in preventative support. This is a priority to enable a healthier fairer Scotland”

In principle we believe that models of social care provision should be co-produced locally through engagement with local communities, supported people and carers. However, as part of our discussions with carers they have recommended three models of support, which if applied nationally would contribute to a preventative approach and greater consistency for carers in accessing support.

In illustrating these models we have used a human rights approach, based on the PANEL principles.

Preventative Support Budgets for Carers Centres

In 2018 The Carers Act brought in new rights for carers, including the right to support for carers who meet local eligibility criteria. However, the majority of carers still rely on local community and third sector organisations for support. We propose that local carers centres should hold a preventative budget in order to respond to the needs of carers identified through Adult Carer Support Plans in a flexible way, allowing carers to choose what support best meets their outcomes and preventing them from reaching crisis point.

Participation	This model will allow carers to choose the right support for them. It would build on the principles of SDS, extending choice and control to carers who do not meet local eligibility criteria
Accountability	Carers centres are trusted organisations with expertise in supporting carers. They already manage Time to Live which provides one-off interventions for carers and which is highly evaluated by carers
Non-Discrimination	Carers centres support carers from all caring communities, including carers with protected characteristics
Empowerment	Carers centres are carer-led orgs who involve carers at all levels of decision making and recognise carers as equal and expert partners in care. On an individual level, carers will be supported to identify the best options to meet their personal outcomes
Legality	This proposal supports the duties in The Carers (Scotland) Act 2016 and the Social Care (Self-directed Support) (Scotland) Act 2013

“Local authority bureaucracy is a huge barrier to the delivery of social care. Third Sector needs to be an equal partner in the delivery of social care and it needs to be recognised that Carers Centre are well placed to allocate budgets and access respite options for carers”

Minimum Entitlement to Short Breaks, including a right to replacement care for carers in employment

Although the Carers Act introduced new rights to carers in 2018, it did not include the right to a break from caring. Short breaks are critical to the health and wellbeing of carers and their ability to maintain a life alongside caring and remain active citizens.

In addition, investing in replacement care for carers looking after disabled people and older people should be viewed in the same way as investment in childcare. Replacement care is essential to enable carers to remain and return to employment.

Participation	This model would allow carers greater access to short breaks, choice in the type of provision they access and would enable them to participate in the workplace and in their local communities
Accountability	There are already measures in place in relation to the inspection and monitoring of short break providers. Most short break provision is carer-led and carers are involved in the design and delivery of services
Non-Discrimination	This model would be available to all carers, including those with protected characteristics. A range of providers would be required to ensure services were available to meet individuals needs and to ensure there were no barriers to people accessing support
Empowerment	Rather than relying on local provision and local eligibility criteria, all carers would have an equal entitlement to short breaks and replacement care, allowing people greater rights and autonomy
Legality	This proposal supports the duties in The Carers (Scotland) Act 2016 and the Social Care (Self-directed Support) (Scotland) Act 2013

More Choice & Control through Self-directed Support

As a response to Covid-19, the Scottish Government issued temporary guidance in July 2020 to reduce bureaucratic processes and enable Direct Payments to be used more flexibly, including for the employment of relatives. We believe this guidance should be made permanent and work should be undertaken to increase the take-up of direct payments by unpaid carers

Participation	This model would allow carers greater Choice and Control in line with the principles of SDS.
Accountability	There are already measures in place in relation to the monitoring of direct payments. This approach of reducing bureaucracy would reduce the barriers to people accessing support

Non-Discrimination	By introducing greater flexibility in the support people can access, this would enable carers from all communities to have their needs met.
Empowerment	As part of this approach carers would be supported to identify support solutions to best meet their personal outcomes
Legality	This proposal supports the duties in The Carers (Scotland) Act 2016 and the Social Care (Self-directed Support) (Scotland) Act 2013

“Simplify the SDS process and allow carers to be the commissioners of their own support

One of the outputs from the survey about changing SDS options during lockdown was 'if we can fast track it now, why not all the time?'”

Section Eight – The three tests

Finally, we believe that as a measure of success, any new system or models for delivering social care, must pass the following three tests:

1. **Is it person centred?** Are the people who use services and their carers at the heart of decisions about social care and are their views paramount, strategically and in their day-to-day lives?
2. **Is it adequately resourced?** Is our 21st Century social care system funded to a level that will truly improve the lives of people who use services and their carers? Will it meet not only their daily needs but also their ambitions and aspirations and will it reduce the inequalities they experience.
3. **Does it deliver choice to supported people and carers?** The choice to be independent, to choose how much care they are willing and able to provide, to have services that fit around their lives not around time slots, contracts and tasks? Does it place individuals and their carers in the driving seat rather than as passengers in an unresponsive system?

About the Coalition of Carers in Scotland

The Coalition of Carers in Scotland exists to advance the voice of carers by facilitating carer engagement and bringing carers and local carer organisations together with decision makers at a national and local level.