

Submission to the Scottish Government consultation on a National Care Service

Principles and Key Messages



Principles and Key Messages

During the National Care Service consultation, carers and carer organisations told us what the strengths and weaknesses of the current social care system were and what the new approach to social care should be. We have summarised this information in the tables below.

THE PURPOSE AND VALUE OF SOCIAL CARE	
<i>"We need a system that is controlled nationally, that delivers locally, has the person at the centre, that does not cost the earth"¹</i>	
Principles	Key Messages from Carers
The person must be at the centre and the principles of independent living and self-directed care must be at the heart of future health and social care support	<p>Any changes to social care must not focus only on systems, processes and structures. The starting point for any change in the way social care is designed and delivered must begin with the person, their rights, capabilities, strengths and ambitions.</p> <p>While a comparison with the principles of healthcare (NHS) is helpful, a NCS must replace the medical model with a social model focused on creating the supportive environments for independent living and support for carers as the foundation principle for the National Care Service</p> <p>We heard from carers who wanted to use their Self-Directed support more flexibly and innovatively to better meet their needs and the needs of the people they care for, but have been prevented from doing so. They believe they should be trusted to have choice and control over the social care they access and that this will lead to better outcomes</p> <p>We have recently undertaken research with carers on the implementation of the SDS Covid-19 guidance, which required local authorities to take a more flexible approach to the use of direct payments. 210 carers responded. Our key findings showed</p>

	<ul style="list-style-type: none"> ○ Only 50% knew that they could use their SDS more flexibly during the pandemic. Of those that did know, only 19% were informed by their local authority ○ 1 in 3 people had been able to use their SDS more flexibly. ○ Of those who were unable to use their SDS more flexibly 28% had asked and been turned down by their local authority and 14% has not received a response to their enquiry <p>Carers have told us that the current Covid-19 guidance on the flexible use of SDS should be consistently implemented across Scotland and should be made permanent</p>
<p>A Human Rights approach must be central to the design and delivery of social care and apply both to people with social care support needs and carers</p> <ul style="list-style-type: none"> - Participation - Accountability - Non-discrimination - Empowerment - Legality 	<p>At our engagement events participants were of the view that the Feely report was much stronger and detailed in relation to embedding a human rights approach in a future social care system</p> <p>While this was referenced in the Scottish Government consultation paper, it was lacking in detail and required more specific proposals in relation to how this would be achieved.</p> <p>This human rights based approach must extend to include support for carers. Carers cannot access their human rights, such as a right to employment, training and to participate in cultural life, without access to support, including regular breaks from caring. This also reflects National Health and Wellbeing Outcome 6 <i>'People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being.'</i></p>
<p>Resources should be determined by need, rather than need being determined by resources. Any unmet need should be recorded</p> <p>Eligibility Criteria should be removed and there should be a preventative approach to the provision of social care and carer support</p>	<p>The current system uses a deficit model and is very undermining for people. People have to set out what they can't do and justify the risks if they do not receive a service, they are then often told they don't 'meet needs.' This is driven by budget, not needs and was described by one carer as 'gaslighting'</p> <p>The government's position on eligibility criteria is unclear and a human rights, preventative approach is unworkable if eligibility criteria remains in place.</p> <p>We partially support the position put forward by Colin Slasberg in his paper 'Blue print for a post eligibility social care system with human rights at its heart' We believe an outcomes focussed alternative to eligibility criteria can be developed which would enable a move away from the deficit model, based on strict and eligibility criteria and thresholds</p>

UNPAID CARERS

“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”

Principles	Key Messages from Carers
Carers must be viewed as equal partners in care	<p>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.</p> <p>Feeley talked about a ‘relentless focus on involving people with lived experience and carers’ and this sentiment was strongly supported by carers at our engagement events</p> <p>While the government proposes that carer representatives on Community Health and Social Care Boards should have voting rights, it does not specify that carers should be viewed as equal partners in care and there is little indication that the foundations have been laid to enable power to shift towards people with lived experience, carers and local communities</p> <p>Carers at our engagement events felt very strongly that unless carers play a central role in the reform of social care, from inception, at both grass root and Boards level, then it will not succeed.</p>
Carers must be viewed as providers of care, not users of services. Like paid care workers, they require the resources to support them in their caring role and protection to have a life outside of caring	<p>The value of unpaid care in Scotland is estimated at over £36billion a year (The NHS cost £13.4billion in 2019)</p> <p>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.</p> <p>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.</p>
All carers who require a short break should be able to access one	<p>The right to short breaks must take a universal, preventative approach to supporting unpaid carers and must not be linked to lengthy assessment processes and eligibility criteria, with only those most in need being able to access a break</p>

	<p>We support the Hybrid approach: a smaller guaranteed minimum entitlement for all carers with a more personalised entitlement for those with a more intensive caring role.</p>
<p>Carers must have choice and control in relation to the breaks from caring they access and breaks must be a positive experience and of mutual benefit for both carer and cared-for</p>	<p>The consultation proposals for breaks from caring are limited in scope. While they outline a set of options for determining who would be eligible for a right to a break, they do not consider what steps would need to be taken to ensure there are sufficient services in place to meet demands and that there are a range of options to fulfil the diverse needs of the carer population and the people they care for.</p> <p>In addition, the scope of the consultation does not include the level of short break provision carers would have a right to or the mechanism for carers to take-up their right. For example, a financial payment, entitlement to weeks or hours of breaks, vouchers, or a mix. These are factors that will need consideration</p> <p>Our view is that a wide range of quality short breaks services must be in place before a right is in place. This should include innovative approaches, for example, support to access universal services, such as leisure facilities. Carers should be supported to make the right choice for them through access to information and brokerage services</p> <p>Carers should also be able to choose how they access their break, including through a payment, similar to a direct payment</p> <p>The Covid-19 SDS Guidance should be retained and extended to allow people to use their resource in a flexible way, this should include through employing a relative.</p> <p>We believe the government should also explore the option of unpaid carers being offered the opportunity of being formally employed for the duration of their caring role, with safeguards for financial security, pension rights and national insurance contributions, regular breaks, training and other supports</p> <p>Further evidence to support this approach can be found in Section 4 of our response to the National Care Service consultation.</p>
<p>Carers must have access to training to support them in their caring role and to protect their health and wellbeing. For</p>	<p>The Scottish Government proposes that the NCS should oversee training by setting training and development requirements and providing or securing training for the workforce where appropriate.</p> <p>We believe that carers should also be able to access</p>

<p>example, moving and handling and managing medication</p>	<p>appropriate training, either locally, or through the NCS to support them in their caring role and protect their health and wellbeing</p> <p>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 workers present. Unpaid carers must have similar protections to the paid care workforce.</p>
<p>The needs of working carers must be considered within the right to breaks from caring. Working carers require both replacement care to enable them to combine their caring responsibilities with their employment, as well as breaks from caring.</p>	<p>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. We need to also recognise that this disproportionately impacts women. With females making up 78% of carers of working age²</p> <p>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 population³. Carers have repeatedly told us they are exhausted from combining work and care without any external support.</p> <p>The needs of working carers must be considered within any approach to social care. The government has invested in early years childcare to enable parents, predominantly women, to remain economically active. The same economic arguments apply to enabling carers to remain in employment through investment in replacement care services.</p>
<p>Carer representatives on the new Community Health and Social Care Boards and the Board of the National Care Service must receive full expenses and a form of remuneration should be explored</p>	<p>We welcome the government's proposals to include carers on the Board of the Community Health and Social Care Partnerships.</p> <p>Our position is that carer reps needs to be fully supported and the role must be strengthened if they are to become full voting members within the new structures with increased responsibilities.</p>

² Carers Census <https://www.gov.scot/publications/carers-census-scotland-2018-19/pages/4/>

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

	<p>It is our view that they should receive remuneration in the form of a payment or fee, similar to the approach recently taken with the Social Covenant Group.</p> <p>Their role as carer representatives should be clarified, building on the best practice role and remit produced by the Carers Collaborative forum for carer reps on IJBs. The principle of carers on the Boards being independent members, acting in the interests of local carers should be established.</p> <p>We have been scoping the experience of carer representatives on IJBs since 2016 and produce an annual report charting progress and making recommendations to enhance their role. The most recent ‘Equal, Expert and Valued’ report can be found here</p> <p>Further information can be found in Section 7 of our submission to the National Care Service consultation.</p>
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ACCESSING SOCIAL CARE	
<p><i>“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”</i></p>	
Principles	Key Messages from Carers
Equal Access to social care support for all caring communities	<p>We must acknowledge the unequal impact that some communities experience when accessing social care, particularly in relation to the current pandemic.</p> <p>In our engagement events we heard about the challenges carers from BAME communities, rural and island communities and many parent carers faced in accessing support.</p> <p>More information can be found in Section 4 of our response to the National Care Service consultation.</p>
People must know their rights and be able to access them	<p>This was one of the key pillars of the Feeley report, but is largely absent from the consultation paper. The following must be an integral part of any reformed social care service to ensure we close the gap between policy and practice:</p> <ul style="list-style-type: none"> ○ Investment in specialised local information services, such as carers centres ○ Carers treated as equal partners in decision making, including the design and delivery of social care support ○ Investment in national representative organisations, such as COCIS ○ Access to carer advocacy services ○ Transparent budgeting and ringfencing

<p>People should have the right to rapid recourse and redress when rights are not met</p>	<p>The government's proposals on the complaints system do not go far enough and require strengthening. People must be able to seek redress when their rights aren't met through a complaints system that is rapid, simple to navigate and independent.</p> <p>We believe a national, independent, single body to deal with complaints would provide greater transparency and clarity</p> <p>Carers must also have access to advocacy services to support them in seeking redress when they are unable to access their rights</p>
<p>Needs of rural and island communities must be given specific consideration</p>	<p>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.</p> <p>We recommend that targeted resources are directed to rural and island communities to help address these additional challenges.</p> <p>The group also raised concerns about the National Care Service potentially being informed and driven by the experience and concerns of the central belt. It is essential that there is a focus on the needs of rural and island communities through appropriate representation within the new structures</p>
<p>Needs of BaME communities must be specific consideration</p>	<p>BAME communities have suffered more through COVID-19 than most 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.</p> <p>We cannot ignore this and any new approach to social care must build equality into its foundations with accessible services and community support which is responsive to the needs of the diverse BaME communities, alongside more specialised services. For example, specific BAME carer support posts within carers centres</p> <p>We need to also ensure that current equality legislation is adhered to and that organisations who support carers are fully funded to provide any tailored support to carers from BaME communities. For example costs of interpretation, translation, community outreach workers needed to be fully costed and funded. These additional services should not be regarded as just a nice 'add on' to existing services,</p>

	they need to be seen as a legal requirement to ensure that services meet their public sector equality duty.
Social Care should be Universal, available to all and free (same as health service)	<p>Scrapping charges for non-residential charging is not mentioned in the consultation. We understand this is something the government has made a commitment to deliver, but the timescale and scope of removing charges needs to be clarified. Several carers in our survey highlighted the impact charges have had on their families</p> <p>Feeley talked about moving from risk, deficits and needs to capabilities, an asset based approach and a focus on independent living. This must form the basis for a universal system, not reliant on eligibility criteria to manage demand and resources</p>
An outcomes (not impact) approach which measures personal outcome changes achieved, needs to be embedded in the new system, with solution-focused conversations, rather than assessments (i.e. ACSP)	<p>There is very little focus on outcomes in the SG paper. The proposals around a single assessment should build on outcomes learning, such as having good conversations and the EPiC model</p> <p>In addition, we heard from Carers Centre Managers that they believe the good practice and outcomes focus which has been developed in some areas in relation to Adult Carer Support Plans must not be lost and should form the foundation for any future carers assessment process</p>
Good transitions from Child to Adult services must be an integral part of any system	<p>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.</p> <p>Carers have broadly welcomed the government's proposal to include children's services in the new structures and hope that this will lead to greater consistency and clarity in the level of support between the two services. However, some parent carers are not in agreement as they view children's services as superior to adult services and are concerned that this will lead to them levelling down rather than improving. We say more about this in Section 6 of our response to the National Care Service consultation.</p>

CHANGES TO CURRENT SOCIAL CARE SYSTEM

"There is too much variation between council areas just now. People with the same conditions or needs shouldn't be getting such vastly different care based on their postcode. Centralising the system is sensible and can only be an improvement on what is offered now"

Principles	Key Messages from Carers
National oversight and accountability leading to consistency of standards	The majority of carers who responded to our survey and attended our engagement events support the proposal for a National Care Service. However, they still expressed many concerns and a significant proportion where not in

	<p>favour of responsibility shifting away from local authorities.</p> <p>We provide further information in Section 6 of our response to the National Care Service consultation.</p>
Processes should be simple, fair, timely and transparent with clear timescales set out.	<p>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.</p> <p>One of the most predominant themes from our survey and engagement events was the trauma carers had experienced when trying to navigate their way through the system. They described it as 'exhausting' and many carers said they had given up and foregone much needed support</p>
Localism must not be lost to centralisation. Decisions must be taken as close to the person and their community as possible	<p>This was felt strongly across several engagement events, involving both carers and carer support staff.</p> <p>It was particularly relevant to carers from rural and island communities. More information can be found in Section 4 of our response to the National Care Service consultation.</p>
Decision making in the new structures should be bottom-up and community-led, not top down and with a centralised viewpoint	<p>Our members have expressed disappointment at the decision to bring in consultants, before the consultation has closed and are concerned that this signifies a hierarchical approach.</p> <p>While the role of consultants has now been clarified, this highlights the need for transparency and accountability around decisions about social care, made at a national level</p> <p>Decisions must be rooted in communities and reflect the views of people with lived experience and their carers.</p>
The government must ensure full implementation of existing legislation, including SDS and the Carers Act	<p>Any changes arising from these proposals must be fully implemented and the organisations responsible for implementing changes must be held accountable for doing so.</p> <p>Furthermore, 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.</p>
Any new legislation must be fully funded and implemented	<p>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.</p> <p>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</p>

	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.
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DATA COLLECTION

"Hopefully a single record would help supported people receive a service tailored to suit their needs at a time they need services. A coordinated approach would be beneficial"

Principles	Key Messages from Carers
While standards and data collection are inconsistent and a national approach and standards are welcomed, this must not be too burdensome for small grass-roots organisations.	<p>Concerns have been expressed about over-reach by the Care Inspectorate and the burden of enhanced standards and data collection on small organisations. There are fears that this may stifle innovation.</p> <p>The government proposes prioritising preventative support by providing increased resources to community-led organisations. Yet this seems to contrast with the primary focus on systems and processes set out in the proposals</p>

VALUING THE WORKFORCE

"Adequate pay and conditions for social care sector essential to retain staff as we have had numerous workers introduced then leave within the last few years."

Principles	Key Messages from Carers
<p>The pay and conditions of the third sector must be improved as part of the Fair Work programme</p> <p>Pay, conditions and training should be more consistent across the third sector</p> <p>Any costs associated with improving pay and conditions must be part of core costs and factored into service level agreements</p>	<p>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.</p> <p>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. Many carers reported through our engagement events and surveys that despite being eligible for support they have been unable to access this due to shortages in the care workforce</p> <p>We also held an engagement session with Carers Centre Managers who outlined the value of the third sector and the need to invest further in third sector organisations and staff who play an essential role in supporting people. More information is included in Section 9 of our response to the National Care Service consultation.</p>

COMMISSIONING OF SERVICES

“There are good examples of outcomes focused commissioning. We should be drawing on best practice. Consistent mediocre practice will do nobody any favours”

Principles	Key Messages from Carers
A Collaborative and ethical approach should be taken to commissioning, as outlined in the Feeley report	<p>The government proposals mention ethical commissioning and do not reflect the recommendations set out in the Feeley report to move towards a collaborative commissioning approach. In our engagement sessions carers and staff were adamant that successful commissioning is reliant on a collaborative approach.</p> <p>For a level playing field and a relationship of equals, the statutory sector must be subjected to the same scrutiny and accountability as the third 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.</p> <p>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. We say more about this in Section 8 of our response to the National Care Service consultation.</p>

Further information

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