Submission to the Scottish Government consultation on a National Care Service for Scotland

coalition
of carers in scotland
from recognition to rights

COALITION OF CARERS IN SCOTLAND
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The Coalition of Carers in Scotland

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1. Introduction

We welcome this opportunity to respond to the consultation on a National Care Service for Scotland. We hope that this will lead to radical change in how we think about, design and deliver social care in Scotland. We, and our members, would like to see an approach to social care that is progressive, ambitious and will ultimately improve the lives of supported people and unpaid carers.

As a country we need to re-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. Social care should enable supported people and unpaid carers to access the same rights and opportunities in life as everyone else. 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.

In our discussions with carers, they have been clear that new systems alone will not deliver the radical change that is needed to develop a new approach to social care that is fit for purpose. People told us of a system that is broken and that increasingly relies on the labour of unpaid carers. Carers told us that they had not had a break for years, that they are exhausted, that their mental and physical health had been severely affected. *"We are preventing a tsunami of need from overwhelming public services. That comes with costs to us, to our families"*[2]

Our members expressed concerns that the government's consultation is focused more on structures and processes and does not adequately reflect the vision set out in the Independent Review of Adult Social Care.

Carers at our meetings envisaged an approach to social care where people are able to move with ease through the system, a system which is preventative and based on human rights, supported by navigators, rather than gatekeepers. Where people do not have to 'battle' or 'fight' to access support. As one carer expressed it '*We need **rights** not **fights***'

They also called for a change to the current framework for funding social care A framework which 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.

We have a once in a lifetime opportunity to transform social care. To value and invest in people with care needs and unpaid carers and to expand the role of social care as a key part of reducing both health and income inequalities. As the Independent Review of Adult Social Care says 'If not now, when?'

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[2] All the quotes in this document are from our engagement events and surveys

2. How we consulted

Engagement Events

Between August and October we facilitated a series of engagement events with carers and other key stakeholders. Approximately 130 people participated in our discussions, the majority of which were unpaid carers. Engagement event were held with the following groups of people:

1. Carers Collaborative Forum for carer representatives on IJBs
2. Carers Collective, a group of carers involved in local campaigning
3. Rural and Island Carers Group, carer support staff working in rural and island communities
4. Mental Health Workers Forum, carer support staff supporting mental health carers
5. Carers Centres Managers Network
6. PASDA – An organisation supporting families of adults with Autism, based in Edinburgh
7. COCIS member meeting, comprising carers and carer support staff

Surveys

We hosted two surveys to ensure we heard from as wide a range of carers as possible. In advance of the survey, in partnership with the National Carer Organisations, we developed a range of briefing papers for carers, providing accessible information on different elements of the consultation.

1. Survey on the government's proposals to a right to breaks from caring. We received 997 responses to our survey, all responses were from carers and we received responses from all local authority areas in Scotland. Evidence from the survey can be found in Section 4 and analysis of the comments can be found in Appendix One
2. Survey on the proposal to develop a National Care Service. We received 424 responses from all local authority areas in Scotland. Evidence from the survey can be found in Section 6 and analysis of the comments can be found in Appendix Two

3. Summary of Key Messages

As the largest providers of health and social care in Scotland, unpaid carers have an intimate knowledge of the strengths and deficiencies of the current system. As well as addressing the consultation questions, our discussions were much broader, looking at the social care system as a whole and people's ambitions for it.

Following our engagement events and the analysis of our survey results we presented the key findings to our members at a meeting on the 20th of October. Our members voted on the key messages to submit to the consultation. These were passed by a majority, with additional points agreed by consensus.

Principles and Key Messages

Principles	**Key Messages from Carers**
Principles and Key Messages in relation to the purpose and value of social care *"We need a system that is controlled nationally, that delivers locally, has the person at the centre, that does not cost the earth"*[3]	
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	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. 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 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 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 ○ 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 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
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	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

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- Participation - Accountability - Non-discrimination - Empowerment - Legality	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. 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 ‘*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.’*
Resources should be determined by need, rather than need being determined by resources. Any unmet need should be recorded Eligibility Criteria should be removed and there should be a preventative approach to the provision of social care and carer support	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’ The government’s position on eligibility criteria is unclear and a human rights, preventative approach is unworkable if eligibility criteria remains in place. 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
Principles and Key Messages in relation to 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”*	
Carers must be viewed as equal partners in care	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. 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 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 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.
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	The value of unpaid care in Scotland is estimated at over £36billion a year (The NHS cost £13.4billion in 2019) 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.** 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.
All carers who require a short break should be able to access one	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 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
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	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. 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 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 Carers should also be able to choose how they access their break, including through a payment, similar to a direct payment 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. 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 Further evidence to support this approach can be found in Section 4
Carers must have access to training to support them in their caring role and to protect their health and wellbeing. For example, moving and handling and managing medication	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. We believe that carers should also be able to access appropriate training, either locally, or through the NCS to support them in their caring role and protect their health and wellbeing 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.

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.	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 disproportionally impacts women. With females making up 78% of carers of working age[4] 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 population[5]. Carers have repeatedly told us they are exhausted from combining work and care without any external support. 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.
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 renumeration should be explored	We welcome the government's proposals to include carers on the Board of the Community Health and Social Care Partnerships. 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. It is our view that they should receive renumeration in the form of a payment or fee, similar to the approach recently taken with the Social Covenant Group. 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. 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

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[4] Carers Census https://www.gov.scot/publications/carers-census-scotland-2018-19/pages/4/

[5] An unequal crisis, Citizens Advice, August 2020

	Further information can be found in Section 7 of this submission
Principles and Key Messages in relation to all social care recipients *“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”*	
Equal Access to social care support for all caring communities	We must acknowledge the unequal impact that some communities experience when accessing social care, particularly in relation to the current pandemic. 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. More information can be found in Section 4
People must know their rights and be able to access them	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: ○ 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
People should have the right to rapid recourse and redress when rights are not met	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. We believe a national, independent, single body to deal with complaints would provide greater transparency and clarity Carers must also have access to advocacy services to support them in seeking redress when they are unable to access their rights
Needs of rural and island communities must be given specific consideration	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. 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
Needs of BaME communities must be specific consideration	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. 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 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, 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)	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 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

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)	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 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
Good transitions from Child to Adult services must be an integral part of any system	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. 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
Principles and Key Messages in relation to the system as a whole *"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"*	
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 favour of responsibility shifting away from local authorities. We provide further information in Section 6
Processes should be simple, fair, timely and transparent with clear timescales set out.	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. 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

Localism must not be lost to centralisation. Decisions must be taken as close to the person and their community as possible	This was felt strongly across several engagement events, involving both carers and carer support staff. It was particularly relevant to carers from rural and island communities. More information can be found in Section 4
Decision making in the new structures should be bottom-up and community-led, not top down and with a centralised viewpoint	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. 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 Decisions must be rooted in communities and reflect the views of people with lived experience and their carers.
The government must ensure full implementation of existing legislation, including SDS and the Carers Act	Any changes arising from these proposals must be fully implemented and the organisations responsible for implementing changes must be held accountable for doing so. 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
Any new legislation must be fully funded and implemented	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.
Principles and Key Messages in relation to 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”*	
While standards and data collection are inconsistent and a national	Concerns have been expressed about over-reach by the Care Inspectorate and the burden of enhanced standards

approach and standards are welcomed, this must not be too burdensome for small grass-roots organisations.	and data collection on small organisations. There are fears that this may stifle innovation. 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
Principles and Key Messages in relation to 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."*	
The pay and conditions of the third sector must be improved as part of the Fair Work programme Pay, conditions and training should be more consistent across the third sector Any costs associated with improving pay and conditions must be part of core costs and factored into service level agreements	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. 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 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
Principles and Key Messages in relation to the 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"*	
A Collaborative and ethical approach should be taken to commissioning, as outlined in the Feeley report	The government proposals mention ethical commissioning and do not reflect the recommendations set out in the Feely 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. 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. 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

4. A right to breaks from caring

"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"

This section addresses the government's proposals on a right to breaks from caring and addresses the consultation questions 9 and 10, looking at the key factors carers consider important in establishing a right to breaks from caring and setting out carers preferred approach to implementation.

It will not be surprising to note that of all the government proposals, the proposal for carers to have a right to breaks from caring was the one which carers were most in support of and engaged with during our consultation sessions.

We received nearly 1,000 responses from carers to our survey on a right to breaks from caring and as well as answering polling questions, 462 carers shared their views with us on breaks from caring by providing additional comments. A full analysis of these responses can be found in Appendix One. The top messages were as follows:

1. *"Respite must be suitable for the person being cared for. There's no point in allocating respite hours or weeks if the appropriate care cannot be provided. Having a 'right' and having 'access' to care are two completely separate things."*

   110 carers said there needs to be a mix of respite options, providing adequate provision and catering for different needs.

   This includes:
   - Catering for the needs of people with autism/attachment disorders who may not be able to access building based services, or support from people they don't know
   - Support for children with disabilities (this was mentioned multiple times)
   - Accessible breaks for carers with mobility issues, or their own health needs
   - More flexible support such as help with shopping
   - Support which enables carers to stay in their own home
   - Being able to employ a relative

- Taking a holiday with the person you care for with additional support
- Having freedom to use the service that best meets your needs, without local authority intervention
- Day Care provision
- Breaks that are culturally sensitive
- Support with other domestic or household tasks
- Accessible childminders for children with disabilities
- Overnight support to allow carers to sleep
- Breaks which are of benefit to both the carer and the cared-for person

2. *"We have had 2 hours off caring in the last 3 years. As carers this is very hard but we have been turned down by the local council for any support. A car can only run on fumes for so long."*
   84 carers reported that social care is inadequate and does not meet people's needs. Many carers have budgets they cannot spend, due to lack of provision. The deficits in the system will need to be addressed before a right to a break can be become law

3. *"I think it's vital that carers have a legally protected right to respite . We don't get to leave our place of "work" but we absolutely need time to recharge ourselves mentally and physically"*
   43 carers said that breaks need to be regular and consistent. Carers need breaks from caring in the same way the paid workforce requires regular breaks

4. *"Carer's tend to put everyone before themselves until they are so unwell they fall apart. We hide our feelings and our exhaustion so not to let people think we can't cope Authorities don't want to see the strains so they don't have to do anything to help and even when they have to help it's a battle carers are not fit to fight"*
   41 Carers report that they are exhausted and at breaking point. Their health and wellbeing has been impacted. This was the case pre-Covid and has been exacerbated by the pandemic

5. *"The amount of forms we need to fill in put us off asking. We constantly need to fight. We are tired. We don't have the energy to prove our existence"*
   27 carers said the process for accessing a break must be simple, fair and transparent. Lengthy assessments and form filling will dissuade some carers from accessing support. Carers must not have to 'fight' and 'challenge' to get breaks from caring

6. *I'm sitting here with tears in my eyes hoping that this can bring about real change. …I am utterly exhausted and no longer feel I'm giving my best because I'm just so worn down with never getting a break."*
   Other key messages included:
   - The right to breaks from caring would enable and encourage carers to take regular breaks and this will have a positive impact on their health and wellbeing
   - Carers indicated that they felt the right to a break from caring should be universal, but the level of support should be linked to an individual's needs
   - Many carers can't afford a break. Charges should not be applied to either the carer or the person they are caring for

  - Carers need a holiday – holiday provision should be part of the right to a break, both with and without the cared-for person
  - If a right to short breaks is introduced, there needs to be access to information, with carers proactively informed of their rights. Alongside this, there needs to be accountability and monitoring around information provision, access to breaks and reviews
  - The right to a break needs to take account of people with multiple caring roles who may have different requirements in relation to their different caring roles
  - Carers are isolated, regular breaks are needed to ensure they have access to a social life and to build and maintain relationships
  - The right to short breaks needs to consider the needs of all caring communities, including working carers who require a break in addition to any support they require to enable them to work, carers from BaME communities, young carers and carers from rural and island communities

Survey Polling Results

In both our survey and engagement events we held several polls to ascertain people's views on the government's proposals. Below are the results:

The Scottish Government would like to introduce a 'Right to Respite' for carers. Who do you think should be entitled to this Right to Respite?

	Percentage	Number
All carers	79.94%	747
Only carers with a more intensive caring role	14.24%	142
Not sure	3.61%	36
Other	2.21%	22
TOTAL		997

How should the amount of respite a carer receives be decided?

	Percentage	Number
All carers should be entitled to the same amount of respite	15.55%	155
The amount of respite a carer receives should be decided on an individual basis, depending on needs of carer	24.27%	242
All carers should receive a minimum entitlement, with carers who have a more intensive caring role receiving an additional amount, according to need	38.82%	387
The amount of respite a carer receives should be on a scale, so that carers with a more intensive caring role receive more respite, with the amount clearly being set out	19.26%	192
Not sure	1.40%	14
Other	0.70%	7
TOTAL		997

What should a Right to Respite look like for carers?

	Percentage	Number
It should be a payment directly to the carer	37.85%	377
It should be an allocation of respite hours	24.90%	248

It should be an allocation of respite weeks	16.27%	162
Not sure	12.65%	126
Other	8.33%	83
TOTAL		997

Polling and discussion at our Engagement Events

Across our other engagement events our polls remained consistent with our survey results, indicating that the majority of carers, with an average of 78% believe that all carers should be entitled to a break.

However, in relation to how the amount of respite should be decided, there was more variation. In the survey the most popular response was the hybrid option described as 'All carers should receive a minimum entitlement, with carers who have a more intensive role, receiving an additional amount, according to need' with 39% of carers voting for this option. The next popular option was 'The amount of respite should be decided on an individual basis, depending on need' which received 24% of the vote.

These results were broadly similar to the polling results we held with staff from local carers centres, with an average of 40% voting for the hybrid option. However, at the engagement events we held with carers the percentage was much higher at an average of 78%.

This difference possibly reflects the opportunity carers had through engagement sessions to explore the different options in more detail and debate their pros and cons with other carers. At the beginning of the session there was often a split with some people favouring a consistent approach with the amount of respite a carer receives being a set entitlement, whereas others thought it should vary according to need. The hybrid option fulfilled the joint requirements for consistency and personalisation. It was also attractive to carers who specified that they did not want to have to go through an additional assessment process and would therefore prefer a minimum entitlement

Specific needs of different caring communities

In order for the right to breaks from caring to be delivered equally across all caring communities, we believe the following requires consideration:

Carers from rural and island communities

The needs of carers from rural and island communities require specific consideration. In discussion at our rural and island carers working group, members 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. One solution they promoted was the employment of family members to provide carers with breaks from caring. We also recommend that targeted resources are directed to rural and island communities to help address these additional challenges.

Carers from BaME communities

The needs of BaME carers have been highlighted through our BaME carers forum. Members have said that in order to support the equalities agenda and ensure carers from BaME communities have equal access to breaks, investment is required to develop accessible information and support within mainstream services and community venues, alongside specialist support where required

Working carers

The needs of working carers was highlighted in both our survey and engagement events and must be considered within the social care system. 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. We heard from many carers who are struggling to juggle work and care through the pandemic with no access to external support.

"One of the biggest stumbling blocks for me is finding help with care so I can work. Work is respite for me and I don't want to give up a career I love because I have a child who needs care. I am constantly told I cannot have respite hours so me to work. I think it should be entirely up to me how I use the hours of respite"

Working carers are often given Hobson's choice being told they cannot use their respite allocation to enable them to work, but are not provided with access to adequate replacement care. Both forms of support need to be considered within the new system, being able to work and to rest are both basic human rights.

Carers of Children and Adults with a Learning Disability

We heard about the specific challenges which parent carers face both in our survey and in our engagement event with PASDA, a carers support organisation for parents of adults with autism.. The overwhelming message was that carers felt that had been let down, that there was a lack of understanding of the needs of adults with autism and a need for specialist services. Many parent carers who meet eligibility criteria are not able to access a service because providers do not meet their child's needs, or there is simply too much demand to meet local need.

> *"If I was given a million pounds today, I still couldn't get a service"*

Other carers talked about the long waiting times for diagnosis and being unable to access support for several years until a diagnosis was finally received.

Conclusions in relation to a right to breaks from caring

- Carers are providers of services and must be viewed as such with legislation extended to provide a right to breaks from caring
- All carers who need a break should be able to access one
- We support the Hybrid option put forward in the consultation option. This was favoured by the majority of carers and staff and allows for both consistency, with all carers receiving a minimum entitlement, whilst recognising that carers with a more intensive caring role will require more substantial support
- The Covid-19 SDS Guidance should be introduced as regulations and implemented consistently across Scotland. Both social care recipients and carers should be trusted to have choice and control over the support they access.

- Options for support should include being able to employ a relative. The Scottish Government should explore the Burgenland pilot project in Austria which has been underway since 2019 and will be evaluated over the coming months.
- There needs to be a range of short break services to ensure all carers have equal access to breaks from caring. As well as short break services this should include investment to make mainstream community support more accessible. This diverse marketplace needs to be in place before a right is enacted
- There is clear evidence of the impact a lack of breaks has had on carers' health and wellbeing and the ongoing impact is has on their ability to access basic human rights. This situation needs to be addressed now, we cannot wait for legislation, but must begin to invest now and move towards a right incrementally
- A right to short breaks will require significant funding. . We need to value the role unpaid carers play and recognise that both social care and health service would be in crisis without their contribution., We need to move towards targeted investment so that commitments made nationally are properly funded. To quote Derek Feeley *"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"*
- The right to breaks from caring cannot be delivered unless other deficits in the social care system are addressed, including valuing and increasing the care workforce and commissioning services which meet people's needs.

7. Access to Care and Support

"I have dealt with scores of agencies and individual professionals. It's exhausting and actually, traumatising. Forced to relieve difficulties over and over again in return for help that doesn't quite fit"

This section addresses the government's proposals on Access to Care and Support and addresses the consultation questions 6 and 7 looking at application of the GIRFEC model in adult services

While we discussed support planning at our engagement events, we did not address the consultation questions, as we found them to be too lengthy and not always relevant to the experience of carers.

The Carers (Scotland) Act 2016 enhances the duty on local authorities to involve carers in the support planning of the person they care for. It is essential that this principle is integral to any reform of support planning arrangements. Both because carers have a contribution to make in relation to the preferences and needs of the person they care for, particularly where they lack capacity and because the support plan needs to reflect the carer's role in the provision of care and how much care they are willing and able to provide.

In relation to support planning for carers, the Carers Act and the new duties in relation to Adult Carers Support Plans has led to some excellent, outcomes focus practice in Scotland, although the duty has not been consistently applied across the country.

In most areas local authorities have devolved the responsibility for undertaking ACSPs to carers centres, a model which works well, drawing on the expertise and specialist nature of third sector organisations and the good conversations approach. It is therefore our view that this model should be retained and built on, particularly when it comes to support planning in relation to a right to breaks from caring.

Survey Polling Results

In our survey we included a poll to ascertain people's views on the government's proposals in relation to GIRFEC. Below are the results

The 'Getting it Right for Everyone' national approach will be a way to plan support for you or the person you are caring for. It will bring together everyone who is involved in supporting you and your family to produce a single plan. This would be supported by a social care and health record so that your information moves through care and support services with you. Do you agree with this approach?

	Percentage	Number
Yes I agree with this approach	73.58%	312
I'm not sure	14.39%	61
No, I don't agree with this approach	7.55%	32
Other	4.48%	19
TOTAL		424

The majority of people agree with the GIRFEC approach at 74%. However, in discussions with parent carers, both at the PASDA meeting and our Carers Collaborative meeting, some said they felt let down by the GIRFEC model and that it has not achieved its potential. This was reflected by 7 people who commented on our survey in relation to GIRFEC, with one carer saying *"We have used an integrated service under GIRFEC and it was counterproductive and judgemental. There was overstepping by professionals into areas they were not qualified to address"*

Eligibility criteria

The position of the government in relation to eligibility criteria is unclear stating that

"We will remove eligibility criteria in their current form by moving away from a focus on risk and instead focusing on enabling people to access the care and support that they need to lead a full life. This will mean significantly changing the way care and support services are designed, so that prevention and early intervention is prioritised and people can move easily between different types of care and support as their needs change."

It is not clear from this whether the government intends to remove eligibility criteria entirely, remove eligibility thresholds, or simply change the process and parameters for applying eligibility criteria.

Despite the government consultation not including any questions on eligibility criteria, we asked the Carers Collaborative for their views on the government proposals

Do you agree with the Scottish Government's proposals for eligibility criteria?

Event	Yes	No	Don’t Know
Carers Collaborative	29		71

The majority at 71% said they don’t know, which perhaps reflects the opaque nature of the government’s position.

It is our view that a human rights approach is not consistent with the use of eligibility criteria. 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

Conclusions in relation to Access to Support

- Support planning should build on outcomes focused best practice, including the good conversation model
- The work of carers centres in undertaking Adult Carer Support Plans should be retained and built on. The government should consider devolving responsibility to the third sector for other forms of support planning
- The process for support planning in relation accessing a right to breaks from caring must be simple, fair and transparent. Lengthy assessments and form filling will dissuade some carers from accessing support.
- It is our view that the use of eligibility criteria is not compatible with a preventative or human rights based approach. The government should consider other methods to facilitate access to social care to ensure people do not have to focus on deficits and risks and are supported to live their best lives

8. Proposals for 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”

This section addresses the government’s proposals on the National Care Service and the Scope of the National Care Service. It addresses the consultation questions 20 to 22 asking for views on the responsibility for social care shifting to national government and the proposed functions of the National Care Service

It also addresses consultation questions 23 to 26, 52 and 53 looking at the scope of the National Care Service

We discussed the government’s proposals for a National Care Service in all our engagement events, both with carers and staff. We also received 424 responses to our survey on the National Care Service. A full analysis of these responses can be found in Appendix Two.

Many participants found it difficult to engage with the consultation questions, as they felt that the proposals lacked detail. They also found it challenging to relate to how structural changes can deliver real progress, ultimately improving their lives and the lives of the people they care for.

To provide an analogy, when people think of the National Health Service, they don't tend to picture a monolithic structure or a system, instead they think of doctors, nurses and other health care workers who deliver a service to them. Many carers struggled to imagine what tangible difference setting up a National Care Service would make to their lives and preferred to focus on changes that need to happen at a local level in relation to direct service provision.

That said, the majority of people who took part in our polls indicated that they were in favour of the development of a National Care Service. However, at our engagement events this support was more nuanced and included many caveats for which more detailed information on the proposals was required.

The top messages from our survey were as follows:

1. "I support a National Care Service because my local authority has failed me and no one is willing to accept accountability"
   55 respondents said they would prefer that responsibility for social care shift to national government. The reasons given for this include:
   - More consistent standards and an end to the postcode lottery (recorded separately)
   - The view that the system is 'not fit for purpose'
   - A desire for change and to 'overhaul the system'
   - Greater accountability
   - Portability of care
   - Better integration between health and social care
   - Hope that a National Care Service would raise standards for care homes

2. *"I think the social care works better and is more accountable and accessible at a local level. National services are too remote and do not reflect local needs"*
   25 respondents said Would prefer that responsibility for social care remain with local authorities. The reasons given for this include:
   - Services are more responsive to local needs if they are locally based
   - Lack of trust in the government to oversee social care
   - Concerns that this is a cost cutting exercise
   - Concerns that national strategies lack flexibility
   - Concerns that a central approach will not be responsive to the needs of people in rural and island communities (recorded separately)

3. *"At the moment it's a postcode lottery within a locality never mind the various local authorities, hopefully this will ensure consistency, transparency and equality"*
   14 respondents said they believed that a National Care Service would ensure more consistent standards and help to end the 'postcode lottery'

4. *"Any NCS needs to be properly funded, informed by people who will use it and have compassion , good relationships and rights at its heart"*
   Other key messages include:
   - Some respondents said they were unsure if the establishment of a NCS would result in better outcomes for carers and care recipients

- Carers felt strongly that they must be viewed as equal partners within the new structures
- Several people said they agreed with the proposal to have a single health record
- Many held the view that there was not enough information to give an informed view of the proposals
- People were of the opinion that there needs to be a balance between centralisation and localism and there were concerns that a NCS would not be responsive to the needs of people in rural and island communities
- There was a strong view that the proposals will require significant funding and will not be successful without this
- Several people felt that the scope of the NCS was too broad and that is should be developed incrementally

Survey Polling Results

In both our survey and engagement events we held several polls to ascertain people's views on the government's proposals. Below are the results:

As part of the plans for a National Care Service, the Scottish Government would like responsibility for social care to shift from local authorities to Scottish Ministers. What do you think about this proposal?

Yes, I think this is a good idea	52.12%	221
I don't know	21.93%	93
No. I don't think it is a good idea	21.23%	90
Other	4.72%	20
TOTAL		424

Do you think that the National Care Service should have responsibility for the following areas?

	Yes	No	Don't Know	Total
Adult social care and social work	77.12%	13.21%	9.67%	424
Children's services; children's social work and social care services	71.6%	14.32%	14.08%	412
Alcohol and drug services	61.65%	17.96%	20.39%	412

Scottish Government are proposing that the National Care Service have responsibility for some mental health services. What elements of mental health care do you think the National Care Service should have responsibility for?

	Yes	No	Don't Know	Total
Primary mental health services	64.35%	16.99%	18.66%	418
Child and Adolescent Mental Health Services	66.18%	16.91%	16.91%	414
Community mental health teams	59.57%	22.49%	17.94%	418
Crisis services	59.95%	20.14%	19.90%	417
Mental health Officers	62.08%	17.87%	20.05%	414
Mental health link workers	59.71%	18.47%	21.82%	417

Polling and discussion at our Engagement Events

Across our engagement events the support for the government taking responsibility for social care and appointing a Minister was much higher than in the survey. Only a slim majority of respondents to our survey (52%) agreed with this proposal, compared to an average of 87% at our carer engagement events and a unanimous 100% at two of our engagement events with staff.

A significant percentage (22%) of respondents to our survey answered ‘Don’t know’ which supports our view that people felt they did not have enough information to express an opinion and the subject matter is too complex to determine without more informed discussion.

Children’s Services

In relation to the scope of the National Care Service and the inclusion of Children’s services in the NCS, support for this proposal was higher at engagement events, with an average of 84% of carers and 92% of staff voting in agreement, compared with 72% in our survey. However if we look at the poll results from our engagement event with PASDA, only 58% of carers were in favour of this proposal.

There are several reasons for this. PASDA members are all carers of adults with autism and in discussion they expressed the view that they were more satisfied with the service they received from children’s services and in general found the service they currently receive through adult services as challenging and inadequate. They also had concerns that as children’s services and education work closely together at present, this relationship may be undermined if children’s services became the responsibility of the NCS

They were concerned that by integrating both services through the NCS children’s services would level down, lose their specialism and be less responsive to the needs of children with autism. In particular they made the points that

- There isn’t an understanding of the needs of adults with autism in adult social care
- Getting the views of people with autism requires specialism
- Carers feel under-represented and not listened to
- There needs to be better training of practitioners around autism
- Decision makers don’t recognise the specific needs of people with autism

In contrast, respondents at other engagement events were hopeful that by including both services within the NCS would support transitions from child to adult services and lead to more consistent standards

Mental Health Services

This was discussed at two of our engagement events, our Carers Collaborative forum for carer reps on IJBs and our Mental Health Forum for staff who support mental health carers. 93% of carer reps agreed with the government proposal to include some mental health services within the NCS.

In relation to details of what services should be included, members of our Mental Health Forum differed slightly from the views of people who completed the survey. They had stronger support for Primary Mental Health (80%) CAHMS (90%) and Community Mental Health Teams (80%) being part of the NCS, but had less support for crisis services being part of the NCS with only 50% agreeing versus 60% in the survey.

In discussion members of the forum felt that some mental health services relate more closely to social care than health care and early intervention could be strengthened by moving some services into an NCS. For example, CAHMS does not have the capacity to deal with issues such as anxiety and could be split into people with a diagnosis requiring specialist services from the NHS, and those requiring support for their mental wellbeing

Conclusions in relation to a National Care Service

- We are concerned that the government's proposals are too focused on structures and processes and not human rights and enabling people to live their best lives.
- The involvement of carers and people with lived experience as equal partners in the new structures and processes, both nationally and locally is a prerequisite to improving social care
- A balance must be struck between centralisation and localism. While national standards and accountability can drive improvements, decisions must be made as close to people and communities as possible
- The development of a NCS will require considerable investment. However, our members were keen to emphasise that they wished to see the majority of additional resources made available for the reform of social care being directed to frontline services
- The proposed scope of the NCS is very broad and goes far beyond the remit and recommendations of the Feeley report. We agree with our members that the government should consider developing the NCS on an incremental basis, starting with adult social care and then including other areas once more consideration has been given to the implications of widening the scope.
- Given the proposed relationship between the NHS and the proposed NCS, while we welcome a greater drive towards integration at a national level, the NCS must not follow the medical model, but must have human rights as its heart.

9. Reform of IJBs

"A National Care Service sounds good but I wonder if it will change the existing systems in place. It also has to be devolved to local areas and staff who know the area"

This section addresses the government's proposals on Reformed IJBs: Community Health and Social Care Boards and addresses the consultation questions 58 and 59, looking at the models and boundaries of Community Health and Social Care Boards and questions 63 and 64 looking at the membership of the new Boards

Polling and discussion at our Engagement Events

We discussed the review of Integration Joint Boards (IJBs) and the formation of Community Health and Social Care Boards (CHSCBs) at our meeting with Carers Centre Managers and our meeting with the Carers Collaborative forum for carer reps on IJBs.

Centre Manager were asked ‘Do you agree with the establishment of Community Health and Social Care Boards and them having a more enhanced role than IJBs’ and 100% agreed with this proposal. The majority of Carers Collaborative members also agreed at a slightly lower rate of 93%

Because of the specific role members of the Carers Collaborative play as members of local IJBs, we spent more time discussing these proposals with them than with participants at our other engagement events. We held a series of polls and the results were as follows:

Do you agree that Community Health and Social Care Boards should be the only model for the local delivery of health and social care in Scotland?

Event	Yes	No	Don’t Know
Carers Collaborative	71		29

Do you agree that Community Health and Social Care Boards should be aligned with local authority boundaries unless agreed otherwise at a local level?

Event	Yes	No	Don’t Know
Carers Collaborative	57	21	21

Do you agree with Community Health and Social Care Boards receiving their funding directly from the Scottish Government?

Event	Yes	No	Don’t Know
Carers Collaborative	93		7

Do you agree with carers being voting members on the new Boards?

Event	Yes	No	Don’t Know
Carers Collaborative	100		

Overall it was felt that the proposals lack detail, so it was difficult for people to have an informed discussion. Carer reps wanted to know - Are they just IJBs by another name?

They also raised the following points and questions:

- The membership of the Boards is vitally important, there needs to be representation from a range of people with lived experience and carers, one person cannot understand and represent the diverse range of experiences
- Who will chair the new Boards?
- How involved will Local Authorities and Health be?
- How much involvement will the NCS have locally?
- There was disappointment expressed at the lack of information provided by IJBs on how Carers Act Funding was allocated and the question was raised – Will this change with new Boards? Will there be more transparency and financial accountability?
- Will they be too large, making it difficult to make decisions?
- Will everyone be a voting member?
- What will happen to strategic planning structures where the real discussion takes place?

- Will the Boards be equitably funded? Some have greater needs. There were concerns that the budgets of smaller areas would all be used up by staff costs to implement structures and processes

In addition to the proposals outlined in the consultation we had a discussion with the Carers Collaborative on paying carer representatives on CHSCBs and providing them with a clearer remit and more support in their role. 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

While the experience of carer reps has largely improved over the last 5 years, recommendations for improvement are still outstanding or have been implemented inconsistently, including providing full expenses, induction training, ongoing support and succession planning.

Being a carer rep on an IJB is equivalent to a full time occupation, once you factor in reading the papers and attending the additional strategic planning groups, sub-groups and local carer forums that carer reps attend to ensure they are a representative voice for local carers. The proposals to give carers a vote on the new Boards, while welcomed, further extends their role and responsibilities. The majority of carer reps therefore believe that they should receive some form of renumeration for their time.

Do you agree with carers being paid?

Event	Yes	No	Don’t Know
Carers Collaborative	71	7	21

There is precedent for providing renumeration of this kind. People with lived experience on some Health Boards receive a payment and we understand that the members of the Social Care Covenant Group have also received renumeration for their time.

Careful consideration would need to be given to the form of payment, in case it had financial consequences for those in receipt of social security benefits. We also believe that the role and remit of carer reps in these circumstances should be clearly established, so that although they may receive a payment, this should not conflict with their role in representing the views and needs of local caring communities without censure and they should not be restricted in doing so as a result of receiving a payment or renumeration

Since carer reps are currently subsidising their role within IJBs, not just through their unpaid labour, but also as many do not receive full expenses, by addressing this financial discrepancy the role would be more inclusive and accessible to those on a lower income

10. Commissioning of Services

“Money is useless if there’s nothing to spend it on. The same as hours, you can legislate entitlements, but entitlements are useless without actual service provision”

This section addresses the government's proposals the Commissioning of Services and addresses the consultation questions 67to 69 on the structure of standards and processes

Commissioning is an area of concern for unpaid carers and the staff that support them. In Section 4 of our submission we go into detail of how there must be a range of providers and options for short break services in order for carers to be able to realise a right to breaks from caring. Commissioning is therefore a key element of improving social care. We were disappointed that the government's proposals did not include the recommendations around collaborative commissioning set out in the Feeley report. We believe that a collaborative approach, particularly involving people with lived experience and unpaid carers goes to the heart of the changes that are required to improve the process of commissioning

In addition, local carers centres who are members of COCIS have told us over many years that the current commissioning processes rarely contribute to good outcomes for social care recipients and unpaid carers. They are not collaborative or focused on the needs of the local population and are time-consuming and bureaucratic, requiring small grass-roots organisations to take valuable time away from service provision with little benefit for the end user.

Polling and discussion at our Engagement Events

We discussed the commissioning of services at our meeting with carers centre managers and at our member meeting, which was attended by a representative of the Coalition of Care Providers Scotland. Only one poll was used during our discussions which asked about the development of structures and standards for commissioning

Do agree that the National Care Service should be responsible for the development of a structure of Standards and Processes for commissioning?

Event	Yes	No	Don't Know
Managers Network	91	9	

In discussion the following points were raised:

- Following a vote with our membership there was agreement to support the proposals from the Coalition of Care Providers in relation to improving commissioning, including making the practice more collaborative
- There are good examples of outcomes focused commissioning. We should be drawing on best practice.
- We support the principle of subsidiarity as defined in Article 5 of the Treaty on European Union. This aims to ensure that decisions are taken as closely as possible to the citizen and that constant checks are made to verify that action at EU level is justified in light of the possibilities available at national, regional or local level.
- While we support the development of a structure of standards and processes for commissioning, there were concerns that these could become too onerous for small community-led organisations. Our ambition must be to support grass-roots services and ensure they are able to work collaboratively with local people in developing local solutions for support

11. Valuing People who work in social care

"Difficulty with this is staffing. Already receive SDS which is used for activities to allow us respite, but have not received this for several weeks due to staffing issues. Adequate pay and conditions for social care sector is essential to retain staff as we have had numerous workers introduced then leave within the last few years."

This section addresses the government's proposals on valuing people who work in social care and addresses the consultation questions 87 on the Fair Work Accreditation Scheme and Q88 on what would make social care workers feel more valued

As with the previous section on commissioning, it is imperative that the social care workforce is valued and is viewed as an attractive career, with good terms and conditions and opportunities for advancement. The current pandemic has exposed how far away we are from this as a reality and shortages in the workforce have increased to the level that social care provision is now almost unsustainable.

As we write this submission in early November, we have just learnt that several local authorities have written to unpaid carers to tell them they will have to increase their caring hours even further due to ongoing shortages in the social care workforce. As with other inadequacies in the social care system carers have been given no choice but to step in and account for the deficit.

In our discussions in relation to a right to breaks from caring we heard many examples of how carers with an agreed package were unable to use it due to the shortage of social care staff. If social care is to improve and expand, workforce issues must be addressed. At the moment it is failing to meet even people's basic human rights

Polling and discussion at our Engagement Events

We discussed valuing the workforce at our meeting with Carers Centre Managers, where the following poll was used:

Do you think a 'Fair Work Accreditation Scheme' would encourage providers to improve social care workforce terms and conditions?

Event	Yes	No	Don't Know
Managers Network	93		7

We then asked 'What do you think would make social care workers feel more valued in their role?' and received a variety of responses across all of the options, with the most popular response at 100% being: Improved terms and conditions, including issues such as improvements to sick pay, annual leave, maternity/paternity pay, pensions, and development/learning time

The key message that came through our discussions was the importance of valuing the third sector and understanding the expertise of staff and the specialist nature of third sector organisations.

During the pandemic local carers centres provided uninterrupted and enhanced support to carers, while many statutory services were reduced or ceased altogether. Despite this staff were disappointed not to receive the £500 government payment given to health and social care staff and felt unrecognised and undervalued as a result.

The third sector must be viewed as equal partners to statutory partners with access to long-term, sustainable and adequate funding to enable them to continue to play their vital role in the delivery of social care support.

12. Conclusion

We welcome the government's focus on social care and the promise of radical change and improvement, alongside greater investment. However, we have struggled with the consultation process and being able to involve carers and carer support staff in contributing to the proposals.

The consultation covers so many areas and is very complex in nature, with most of the critical details yet to be decided. This has meant that we have not been able to fully address many of the key areas that could potentially have a profound impact on carers' lives. For example, we were not able to address the regulation of services, or the workforce and commissioning in any detail.

In addition, while the current pandemic has exposed many of the failings of the social care system and we appreciate the government wanting to move swiftly to rectify these deficiencies, the last eighteen months have been incredibly challenging for unpaid carers and many have not had the energy or means to contribute to these important discussions

We hope that this will be just the start of the discussion and that there will be a greater effort to engage carers and people with lived experience before important decisions are made and set in legislation. We would urge the government not to rush this and to establish a collaborative process with organisations like ourselves in the next stage of developing their proposals. Carers are not fully won over yet by the government's plans for social care. When we asked carers "Do you think these proposals will make a difference to the lives of people with care needs and unpaid carers?" only 7% answered 'Yes', with 43% answering 'Partly' and half answering 'Don't know'

Finally, while we absolutely agree that the government needs to take a long term view of social care, the radical reform required will take years. We want to make the point that carers can't wait for legislation to be enacted.   As came across very strongly in our discussions with carers, they report that they are exhausted, that many have not had a break since the start of the pandemic or even before and their health and wellbeing is at breaking point. We need sustained investment in social care and carer support as a matter of urgency, or the cost to individuals, society as a whole and the economy will only increase.

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.

Since its inception in 1998 the Coalition has played a fundamental role in advancing carer recognition and support and more recently in establishing a Carers Rights agenda in Scotland.

It is our vision that carers in Scotland will achieve full recognition as equal partners in care. Carers will have the right to quality services and access to personalised support at every stage in their caring role to ensure they enjoy good health and a life outside of caring.

Through our membership we connect with carers and carer-led organisations from all local authority areas, from urban, rural and island regions and many individual carer members, ensuring that carers from the Borders to the Shetlands have the opportunity to have their views heard.

Further information

Claire Cairns, Network Coordinator
Email: coalition@carersnet.org
Telephone Number: 01786 850247
www.carersnet.org
Address: PO Box 21624, STIRLING, FK7 1EF

Appendix One – Analysis of Comments
Survey of carers on the proposal for right to breaks from caring

Theme – Messages from carers	Number of Comments	Quotes
There needs to be a mix of respite options, providing adequate provision and catering for different needs. This includes: • Catering for the needs of people with autism/attachment disorders who may not be able to access building based services, or support from people they don't know • Support for children with disabilities (this was mentioned multiple times) • Accessible breaks for carers with mobility issues, or their own health needs • More flexible support such as help with shopping • Support which enables carers to stay in their own home • Being able to employ a relative • Taking a holiday with the person you care for with additional support • Having freedom to use the service that best meets your needs, without local authority intervention • Day Care provision • Breaks that are culturally sensitive	110	• Respite should be appropriate to each situation. With two autistic children it is difficult to find an adult they will allow me to leave them return. Respite for my mother might mean someone else being available to help her get her shopping or change batteries or a lightbulb for her. At the moment I am constantly on call for her, but also for my children who are struggling so much since covid that they are no longer able to attend school. • One of the biggest issues I have with any respite is it never seems to cover families like mine - carers are usually able-bodied, elderly, or kids. Nothing is tailored for my lower energy or mobility, lack of transport, etc. • Respite should not mean the cared for person is put out of their home to somewhere else. That's not respite for either them or the carer, it only introduces additional problems. • Consideration given to carers of young children with attachment disorders - my daughter has intensive care needs but finding any respite for myself is extremely difficult due to her extreme separation anxiety. Respite hours alone would not work for us as she would not be able to enter a respite service with strangers. In our case an allocation of funds would allow me to employ someone known to her, or for them to accompany us, as help for me. • The local authority shouldn't dictate to carers about what they do with the money. Ok, you shouldn't spend the money on anything illegal (that really goes without saying), but all carers are different and what one would like to do, others might not ! • There needs to be consideration for other responsibilities: EG disabled wife needs care but also have to look after young children.

• Support with other domestic or household tasks • Accessible childminders for children with disabilities • Overnight support to allow carers to sleep • Respite which is of benefit to both the carer and the cared-for person		Respite from wife's care is no use unless there is also support for the children. • Respite is an individual thing. What suits one person won’t suit another. My budget at present allows me to purchase a break for my son and whilst he is away having fun a break is purchased for my husband and I to coincide with his . Both are paid from the Carers budget. • Carers should be able to decide what they regard as respite to suit their needs based on their personal circumstances and their caring role. One shoe does not fit all. • Carers often need a break from the domestic / household demands stemming from being a carer. Support to pay for help with domestic tasks (as well as the more traditional forms of support offered to carers) would give carers time to themselves and valuable time to spend with their cared for person • West Lothian had a type of respite called flexible respite. Money was held by council department and could be accessed by carer to pay for a variety of respite. That included the booking of hours a care company could look after cared person, a holiday for carer, additional hours in day centres so carer had free time. Worked well. • Respite has been difficult because my child is comfortable with so few people. TRAINING on all conditions, including PDA, is sorely needed. • Respite must be suitable for the person being cared for. There's no point in allocating respite hours or weeks if the appropriate care cannot be provided. Having a 'right' and having 'access' to care are two completely separate things. • I think the councils need to look into having more suitable respite available for very challenging children. Although my son is entitled to Saturday club / or other means of support, he cannot access it because his needs are so challenging. I think more support for challenging children or adults is required when accessing respite. • Overnight care is crucial for carers to enable them to rest properly

			• Respite should be individualised to the needs of the Carer and their cared for. It should be up to the Carer what they need and what they would benefit the most from. Total autonomy & flexibility
Carers report that social care is inadequate and does not meet people's needs. Many carers have budgets they cannot spend, due to lack of provision. The deficits in the system will need to be addressed before a right to a break can be become law	84		• Just look at social care it's so upsetting the lack of care we have absolutely been forgotten about • There isn't enough care providers to allocate hours so this would need to be looked at as well. it's great for it to be proposed but not if the system wouldn't cope • I have had a respite budget of approx. £7k per year for past 3 years and have been unable to use it as yet. Obviously covid has made this difficult but it would be useful to know other ways that it can be used • When carers ask for emergency respite they must be listened to, not fobbed off with lack of funds or places Most of the time we are on our knees before something is done • Money is useless if there's nothing to spend it on. The same as hours, you can legislate entitlements, but entitlements are useless without actual service provision. • When you have only had 5 weeks total respite in 9 years caring I think something should be done • Waiting lists for respite are an insane length of time. • There is a shortage of respite services . My son used to attend Scottish Autism's service at Clannalba. It closed 3 years ago . Now there are no suitable services for people with autism, learning disabilities and challenging behaviour. I cannot go on holiday . I work and care for my adult son and have always cared for him at home. I am a single parent. There is nowhere for him to go for a holiday from me and nowhere safe for me to leave him so that I can go in a holiday with friends • Difficulty with this is staffing. Already receive SDS which is used for activities to allow us respite, but have not received this for several weeks due to staffing issues. 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.

			• There is a dire lack of respite for carers. My free time currently exists when I’m in the loo or in the shower. • We have had 2 hours off caring in the last 3 years. As carers this is very hard but we have been turned down by the local council for any support. A car can only run on fumes for so long. • Some carers are at the end of their tether. But there are no available carers to help. Two friends who were carers have recently died because they were exhausted and at the end of their tether and couldn't get the help they needed. • I have over £80,000 sitting in my SDS fund but nowhere available to send my loved one as there is zero provision available for complex needs. So there’s no point talking about increasing the right to rest if there is nowhere to send them!
Breaks need to be regular and consistent. Carers need breaks in the same way the paid workforce requires regular breaks	43		• We are both full time key workers with a son with ASD. Our only respite support is our 75yrs+ parents who already have our son every day after school to allow us to work. We need more, consistent help to relieve the burden on our family. • Please educate the Social Work departments of each Council with the same information as there are too many differences depending on what LA you are in • This should be equal and fair. I have never been offered respite and have no family help. I work only the hours my child is at school and so don't qualify for carers allowance. Things should be fairer • All we would like access to is regular, consistent hours each week where our children can be supported by caring adults in accessing something of interest to them outwith of the family home. • Unpaid carers have the right to be acknowledged as unpaid professionals • Unpaid carers should be regarded as employees of the state particularly since their caring role is recognised through a payment of carers allowance acknowledging a relationship between state and carer which at the moment given no entitlement to employee rights

			- I think it's vital that carers have a legally protected right to respite . We don't get to leave our place of "work" but we absolutely need time to recharge ourselves mentally and physically - Carers need better, more consistent support to carry out their caring role well and to take a break from caring with regular access to quality respite provision. - This would need to be understood and implemented the same way across all councils otherwise it ends up like SDS, a postcode lottery of support which is largely misunderstood by SW and unfairly allocated.
Carers report that they are exhausted and at breaking point. Their health and wellbeing has been impacted. This was the case pre-Covid and has been exacerbated by the pandemic	41		- Carer’s tend to put everyone before themselves until they are so unwell they fall apart. We hide our feelings and our exhaustion so not to let people think we can’t cope Authorities don’t want to see the strains so they don’t have to do anything to help and even when they have to help it’s a battle carers are not fit to fight - Carers deserve a break, it's the hardest job in the world and it's exhausting. - As a single parent with two autistic sons plus my mental health I'm at the brink of nervous breakdown social work couldn't care less - Caring is exhausting and we deserve respite to recharge our batteries - We have cared for 9 years along with covid its caused o lot of stress and mental strain with no help last year at all - So many carers experience burnout from their caring role. This would be great to get so much needed respite - Children with autism are often missed if they are higher functioning and good at masking therefore no one really sees how exhausted parent carers are - I care for my son and long term adult friend and it’s hard work on a day to day basis keeping up beat keep moving so everything till bed time some Days I’m absolutely shattered cry myself to sleep no one Else to help me !!!!

			• Without regular respite, I would never be able to continue in my caring role. Everyone needs something to look forward to. During Covid, I felt totally abandoned and had no support whatsoever. My caring role includes night time care too and I was totally exhausted. I then was diagnosed with breast cancer and had emergency respite cover for 8 nights. It really wasn't enough as my caring role is very physical but I just had to get on with it • Caring is draining, it becomes an existence instead of living. My mum gets up about 4 to 5 times every night as she can't sleep that disturbs me even when she doesn't deliberately waken me, my temper is so short due to lack of sleep. • I'm sitting here with tears in my eyes hoping that this can bring about real change. …I am utterly exhausted and no longer feel I'm giving my best because I'm just so worn down with never getting a break.
A focus on outcomes is needed. The process for accessing a break must be simple, fair and transparent. Lengthy assessments and form filling will dissuade some carers from accessing support. Carers must not have to 'fight' and 'challenge' to get breaks from caring	27		• A very simple form to be completed as and when needed would suit me best • The amount of forms we need to fill in put us off asking. We constantly need to fight. We are tired. We don't have the energy to prove our existence • Allocation of respite should be clear and transparent • It should be offered "as standard" by local authorities without the need for the carer to ask. You are too busy caring, working, raising a family, seeing to personal tasks carers do not have the energy to waste trying to track down the right person to ask • The needs and outcomes of the individual being cared for must absolutely be separated from the carers needs and outcomes. These are too often confused • When applying for short break grants you're made to jump through hoops to justify getting a break. The new system should be less stressful and much fairer on already burnt out carers. • Not everyone has the energy or drive depending if their own levels of stress are at an all-time high but energy levels are at an all-time low . To start fighting in order to get what you should deserve .

			• I have dealt with scores of agencies and individual professionals. It’s exhausting and actually, traumatising. Forced to relieve difficulties over and over again in return for help that doesn’t quite fit. • The guidelines for allocation of respite should be transparent. The differing quantities to people in very similar situations has always been a great frustration. So often those requiring most support are those getting least respite • It should be fair, transparent and easy to administer. Not another thing that you need to fight for.
A right to short breaks would enable and encourage carers to take regular breaks and this will have a positive impact on their health and wellbeing	26		• I have never used respite as I always feel that there are those who are more in need than me, if this proposal is passed I would use it and not feel guilty, knowing that other Carers all have the same rights and options too • This could change carers mental health and physical health • Each family is unique. Some cope remarkably well then crash. Respite should be an option before carer reaches anywhere near burnout. • Respite by right would make such a difference to the lives of carers and in turn would benefit the cared for, by improving the quality of the care their carers are able to give. Better quality of life all round. • Every unpaid carer deserves some sort of respite, unpaid carers are going without vital respite which ultimately puts our caring role at risk, from personal experience it got too much for me so I attempted suicide as I just couldn’t cope anymore and no matter who I approached there was just no help or respite so this is service that is more than needed to stop anyone else feeling the way I did. • Having an amount clearly set out might have taken a bit of guilt away from considering respite, not having to justify why respite would be a benefit, feelings of not being able to cope add to stress/anxiety of caring. Confidence that the right to respite is recognised as beneficial and actually improves ability to care. • It is the utmost importance that all carers have some sort of respite, through caring my health has deteriorated. I’ve had 6

		slipped discs, twisted spine which I have had to pay a chiropractor to help me out of pain, I ended up with several prolapses by lifting my girl so much,
Carers indicated that they felt the right to a break from caring should be universal, but the level of support should be linked to an individual's needs	23	• I would like to have a general right to respite for unpaid carers according to their needs, if this were easy to put into practice. • Individual circumstances need to be taken into account as there a massive scale between intensity of carers. Some carers receive no break from caring and are unable to even leave their house where as some carers provide a few hours a day
Many carers can't afford a break. Eligibility must not be linked to Carers Allowance or a person's income and charges should not be applied to either the carer or the person they are caring for	19	• It should not be dependent on the amount people earn but on the physical and mental health. • Must not be based on carers allowance. I do not claim this but often miss out in things as a result. Just because someone works shouldn't mean they are not entitled to essential respite. • How are we expected to afford a break, at the moment I'm struggling to afford a pair of shoes!! • Right to respite must not be a means tested situation, disability is disability no matter what you have in bank. Assessment of carer feels like a judgement and takes time which frankly most carers can't afford to spare or endure • Would want this right to respite for all unpaid Carers not just ones in receipt of Carers allowance
Carers need a holiday – holiday provision should be part of the right to a break, both with and without the cared-for person	18	• The carer should be able to "get away on holiday" like every other normal person and not just be treated like they are less relevant than others. It's discriminatory. • Respite with the card for person is just as important. Spending time in other environment is just as beneficial as a break from each other
If a right to short breaks is introduced, there needs to be access to information, with carers proactively informed of their rights. Alongside this, there needs to be accountability and	18	• Council's don't follow up what respite you are entitled to • If this is to become a thing the Scottish government need to make sure each council is providing what ever the government decide is the way forward.

monitoring around information provision, access to breaks and reviews		• If successful in achieving respite for carers it must be made well advertised and communicated to allow no carers to fall through the net
The break must benefit the cared-for person as well as the carer. Otherwise the carer will not be able to relax and enjoy their break	16	• Respite is also an opportunity for the person being cared for to see a fresh face/have a new relationship so, when possible, continuity should be built in to the care being delivered during respite for the main carer. • The provision of safe stimulating care for the cared for person to allow the carer to relax in their respite time
The right to a break needs to take account of people with multiple caring roles who may have different requirements in relation to their different caring roles	14	• They should take into account those that care for multiple people (I care for both disabled children & my elderly disabled mum) • While every family is different we all need help and a break especially if you are caring for more than one person • Family situation and responsibilities are complex. I am a carer for my severely disabled son 24/7 & for my parents as my mother has dementia. Respite is required for more than one family member.
Carers are isolated, regular breaks are needed to ensure they have access to a social life and to build and maintain relationships	10	• Respite is necessary if carers are expected to continue caring, sometimes carers like myself don't have friends because they are too busy looking after other people so don't have a social life outside my caring roles • We give up our social life, hobbies, and spend less time with other family members and friends to provide this care. It’s not just the carers who lose out it’s their extended family and friends who the carers can’t dedicate the same amount of time to. • More support. It’s lonely being a carer • Relationships deteriorate for couples in a caring role so a break to regroup is essential to keep carers happy to care • Not all carers are retired, some of us work and the support generally is during the day. This can lead to a feeling of isolation for some carers • Caring has isolated me and the heavy burden of care and the insane never ending stress, has also left me with ME, so I need him now to help me. No one gets it.

The right to short breaks needs to consider the needs of working carers who require a break in addition to any support they require to enable them to work	9	• Carers who work full time are continually left behind. We have to be heard in this new Parliament. We have to be recognised and financially awarded for the work we do. Many of us are not in a position to give up work and are exhausting ourselves to care and work. Please help us. • Over the many years I have tried to get respite, I have been told so many times it is 'not to be used' for work. As a full time professional, my biggest source of actual respite that makes a difference to my life and my very being, is being able to work. It gives me an identity, a purpose beyond being a carer, and takes my mind off my caring role. It is the only thing that does that in my life • One of the biggest stumbling blocks for me is finding help with care so I can work. Work is respite for me and I don’t want to give up a career I love because I have a child who needs care. I am constantly told I cannot have respite hours so me to work. I think it should be entirely up to me how I use the hours of respite. • Many unpaid carers are exhausted trying to fulfil their caring role and hold down employment with little support and understanding from professionals They can’t afford to give up employment as carers allowance would not cover their living costs
The right to breaks from caring needs to include young carers	2	• How do Young Carers get recognised too? My son helps with his disabled father and gets no recognition for the adjustments he has to make as being part of the family dynamics. • I think young carers should be included as well as adults
The needs of carers from BaME communities must be considered	2	• As an immigrant, I am still a resident of the UK....but according to my Visa I am not eligible for public funds. In this one case, however, I believe that myself, and any other who cares for their disabled spouse /children /family members should still receive Right to Respite should also be culturally sensitive and meet carer's own needs.

Appendix Two – Analysis of Comments
Survey on the proposal for a National Care Service

	Theme – Messages from carers	Number of Comments	Quotes
1.	Would prefer that responsibility for social care shift to national government. The reasons given for this include: • More consistent standards and an end to the postcode lottery (recorded separately) • The view that the system is 'not fit for purpose' • A desire for change and to 'overhaul the system' • Greater accountability • Portability of care • Better integration between health and social care • Hope that a National Care Service would raise standards for care homes	55	• I think a National care Service is a wonderful idea. It means Scottish people can have the same standard of care across the whole country, not just according to which Council area they live in. It will be as good as NHS Scotland too and give social care staff more status • The current approach doesn't work. The whole thing needs an overhaul • We should have Scottish minister for social care to whom all councils account • Will be good to stop Scottish Government shifting blame for under-funding local authorities • I think the principle is absolutely correct, in terms of removing barriers to mobility in Scotland • I support a National Care Service because my local authority has failed me and no one is willing to accept accountability • I would welcome this, the discrepancies between local councils is unfair, I would also welcome accountability • I think that local authorities have failed in local services such as this, making it a lottery postcode and dependent on the priorities of the local council. It needs to be focused back on the individual and accountable to government ministers. • LA's have had ample to time to address issues in social care, part of the issue is lack of funding but I do believe that it's time social care was removed from their remit. As funding for this is not ringfenced I believe the only reason they are fighting so hard to retain this is because it's their go to pot of cash to siphon off to other projects. • The removal of responsibility for social work and social care from the local authority is vital in ensuring vital funding is targeted and spent

			on resources, staffing and services which meets the needs of clients rather than the gatekeeping approach of local authorities
2.	Would prefer that responsibility for social care remains with local authorities. The reasons given for this include: • Services are more responsive to local needs if they are locally based • Lack of trust in the government to oversee social care • Concerns that this is a cost cutting exercise • Concerns that national strategies lack flexibility • Concerns that a central approach will not be responsive to the needs of people in rural and island communities (recorded separately)	25	• Scottish ministers are too far removed from the basics in society. Local authority need more funding for resources. Social workers need less paperwork. • I am worried that by centralising everything, that the government will cut or close care places in local authorities as they deem them as not being financially viable/unsuitable even though they provide excellent and necessary care to the people who need it in the local community • Local services and local authority is best. It's so much better for professionals to have close relationships with the community, rather than a national, remote approach. Do not nationalise this, I beg you! • No I don’t agree. It won’t work. These things are best left to local health boards or councils. Central government will just spend more money and mess it up more than it is now. • I don't believe care can be organised for all the diverse cases by a government based service. Local authority services better understand the needs of clients in a more personal level. • It’s hard to get a council to listen to you when you need support. Nationally I think this would be worse • I think the social care works better and is more accountable and accessible at a local level. National services are too remote and do not reflect local needs • Can’t believe that a ‘national’ service, organised by government, will be any good at all. They can’t organise the NHS so highly unlikely to be able to organise a care system. • It my experience when services move away from local authorities to a central service, the service is diluted. Is this a cost saving initiative or designed to improve the lives of carers and the people they care for? I fervently hope it is the latter. • I know that the care my mum is getting just now is supportive and organised, I'm not sure this would be the case if it was run centrally

			as I have no faith in the present Scottish government to organise anything. • National strategies do not allow flexibility in local arrangements and are far removed from reality at times. • The National care service should be publicly run and democratically accountable locally. It should not be the responsibility of one Governement minister who is not elected to do the role. • It is an attack on local democracy and a move further away for real accountability.
3.	A belief that a National Care Service would ensure more consistent standards and help to end the ‘postcode lottery’	14	• The care service in Scotland is a postcode lottery, there is little to no support in the Highlands. Families are desperate it takes years jumping through hoops being passed from pillar to post with no support at the end of it . It can’t get any worse up here something needs to change • 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 • 32 local authorities in Scotland who please themselves what rules and laws they choose to follow is a joke, making it one set of regs across the board can only simplify and be more cost effective • At the moment it’s a postcode lottery within a locality never mind the various local authorities, hopefully this will ensure consistency, transparency and equality • I think having one ‘unit’ dealing with all aspects of care, would allow all citizens in Scotland to be able to access the same standards of care thought out the country, do away with ‘postcode lottery care’.
4.	Unsure if the establishment of a National Care Service will change things or result in better outcomes for care recipients or unpaid carers / concerned about the role of politics in the social care system	5	• I'm not sure I understand how the proposals will change outcomes for carers. • Wary about care being centralised as becomes a ‘political football’ with arguments between Central and Local government on funding, implementation etc

			- I don’t care who is in charge at the top I just need to know the person supporting us is immediately available. - I have real concerns about this strategy. We have had Integrated Health & Social Care services for the last 7 years or so, and this approach does not seem to have made any difference to services. We have a national Dementia Strategy which is largely being ignored by Local Authorities, and there is no accountability at all in the system. Too many 'Transformational Strategists' who seem to have little knowledge of what it is like at the coal face. Similarly for the Carers' Act. Unless there is total accountability and effective monitoring in place, I have doubts that a National Care Service will make any difference, unfortunately.
5.	Agree with the proposal to have a single social care and health record	4	- There should be one file for medical, police and care record, social care set up should be in house affair and not big companies like PWC!! If we get this right it will be amazing get it wrong and millions will suffer! - 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 - I do however like the idea of a single plan and would like to see people having access to their own data so that they have control over which services and organisations can see that data. - Having a single plan for someone with multiple disabilities would be beneficial but so would having a single carers support plan for someone caring for more than one person
6.	Do not believe the GIRFEC model is a good model to replicate for adults	7	- We have used an integrated service under GIRFEC and it was counterproductive and judgemental. There was overstepping by professionals into areas they were not qualified to address - GIRFEC hasn't been implemented fully and now they want to use a similar model for adults. - GIRFEC wasn't much help to my son as a child, so I have little faith in GIRFEC

			• GIRFEC hasn't really worked in the way that it was intended. Children still don't have a seamless pathway and access to support, so I'm a bit wary of us replicating that model for adults.
7.	Do not feel they have enough information to give an informed opinion on the proposals	10	• More information is needed on how it will actually work for people • Implementation without knowledge and funding will always be a problem. Having worked in social care at various levels have struggled to do my job without being swamped with ridiculous policies set by people who have no idea about the real struggles that people experience. I spent more time on paperwork than on the people under my care. • I think without balanced or nuanced pros and cons descriptions of why services should be run by one or another body, the average unpaid carer is not equipped to know how to respond to these questions in a balanced or nuanced way. I resent making a judgement on something I do not understand well. • I would like to know more about this service before committing to an answer • I think I would like to see great detail and information on how a National Care Service will work in practice there's not enough information yet on the finer details of how it will work on how it will work in practice to make an informed opinion
8.	There needs to be a balance between centralisation and local decision making	6	• A National Care Service sounds good but I wonder if it will change the existing systems in place. It also has to be devolved to local areas and staff who know the area • If this model would improve current provision I would be supportive of the change, however, concerned re the recruitment difficulties, how the change would impact on care at a local level, and what support would look like for me at a local level. It's so demanding being a carer and having to fight for the help needed
9.	Concerns that a central approach will not be responsive to the needs of people in rural and island communities	5	• Need to ensure services are responsive to differences in rural and city settings

			• Must be properly funded! Must have capacity to be flexible in different authorities - what is good for central belt may not be appropriate for remote islands • Centralising of responsibility should work well in a fairly small country such as Scotland, so I have supported the move, but I am concerned that local knowledge will be sacrificed, especially in remote areas such as Kintyre. Some statements emanating from the Central belt make one wonder if we inhabit the same country! • By keeping it local I feel authorities could respond to local needs. This is especially important in rural areas. • Having a centralised service sounds excellent on paper but I worry that patients will be forced out of their locality due to service provision. The National Care Service might have a glut of staff in the central belt and very few in rural areas - how will that be fair on those rural patients requiring care?
10.	The proposals require significant funding and will not be successful without this	13	• Any NCS needs to be properly funded, informed by people who will use it and have compassion , good relationships and rights at its heart • I support the National Care Service in Scotland if it has enough funding to reach out to all those in need. Funding to bring all local services under one roof would seem a good idea, in cooperation with the local authority in the local area. • I think it’s a great idea in theory. However put into practise is another story , and where is all the funding coming from to do this? • Budgets are not well monitored at LA hence increasingly overspent . More funding is needed and better management is required • How will these proposals be funded, and will all services be moved on mass taking the funding from Local Authorities at the same time • I just hope this gets the resources necessary to carry out all that is required • The only way services improve is by allocating more funding. It’s irrelevant who it is under without this commitment

			• There's no doubt an overhaul is needed but until Carers (paid or unpaid) are valued and services are adequately resourced then there's no point in moving forward.
11.	Carers must be treated as equal partners in care within the new structures and systems	7	• Ensure that carers voices are heard first before professionals. We are the main professionals regarding our children • Voices from people like myself who both have caring responsibilities on a personal level and also work in the Social Care Sector need to be sought and listened to. • Carers must be viewed as equal partners
12.	The proposed scope of the NCS is too broad	5	• The proposed structure is already overloaded by including adult and children' services, mental health and social work. • Whist supporting an eventual all-inclusive National Service involving all population categories, my pragmatic preference would be to roll out Adult Services first as a template for further development.. it is too much without testing the principles and practices on a template category which will advise and inform a further roll out. • I think the consultation proposals overstep the Feeley review. I think that the govt is trying to do too much too soon, when adult social care is so completely broken. Let's fix that first. • I have concerns regarding the use of the National Care Service to cover drugs and alcohol when these services may be better served by health professionals. • I think the remit is too large and should be done it incremental stages