

Response to the Scottish Government's consultation on a National Care Service



National Carer
Organisations

**NATIONAL CARER ORGANISATIONS
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Introduction

This response has been jointly prepared and submitted by the following National Carer Organisations, collectively referred to within this document as the NCO's: Carers Scotland; Carers Trust Scotland; Coalition of Carers in Scotland; MECOPP (Minority Ethnic Carers of People Project; Shared Care Scotland; and, Scottish Young Carers Services Alliance. It sets out our jointly agreed position and is supplemented by individual responses submitted by the above organisations.

The COVID-19 pandemic has laid bare many of the issues that have long dominated discussions between unpaid carers, service users, service providers and national and local government.

COVID-19 brought about unique circumstances and significant challenges but, whilst there are lessons that can be learned, and a groundswell of support for 'building back better', responding to these challenges should not be the primary driver, nor should it be the framework for subsequent decision-making or solutions.

It is very clear that the issues the pandemic has uncovered and brought to public attention are long standing: social care has become increasingly fragmented, rationed and lacking in choice. Many people are left with little or no support – or with services that are not the right fit for them and do not meet their outcomes. Too often unpaid carers are left exhausted and in poverty in trying to fill the gaps that exist.

For the very first time, it appears that there is a consensus emerging across the wider public in Scotland of the value of social care. Critically all political parties in Scotland have accepted that there is a need to change to develop a social care system that delivers real choice to meet the human rights of people who use services and their unpaid carers. We welcome this. It will take all of us to deliver the change that is needed: it will require long-term commitment, adequate and sustainable funding and political and in public support.

Therefore, this consultation on the National Care Service, which has emerged as a consequence of the Independent Review of Adult Social Care, is very welcome. Whilst it is wider than initially envisaged by the review, it is important that what develops going forward, is led and informed by people who use services and their unpaid carers. They are the experts, and their experience must be at the heart of a new social care service for Scotland.

Unpaid carers have engaged significantly in giving their views on the proposals, individually and through a range of events held by the National Carer Organisations and others.

This submission reflects what we heard from unpaid carers at our events, including the annual Carers Parliament and through surveys. A submission detailing all the responses from the Carers Parliament will be submitted separately.

Where there have been specific responses to questions from young carers and BME carers, they have been included as sub-sections within the overall response. The full responses from young carers and BME carers (as part of the NCO submission) are also included as appendices to this document.

Due to several factors, including the length of the consultation document and vast coverage of social care in the proposals, we focused our efforts to engage unpaid carers' and carer services' views on the areas of the National Care Service consultation which we identified as most pertinent to most unpaid carers. Therefore, there are some aspects of the consultation that we have been unable to respond to.

Improving Care for People

Access to care and support

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 unpaid carers.

The Carers (Scotland) Act 2016 enhances the duty on local authorities to involve unpaid 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 unpaid 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 unpaid 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 unpaid carers, the Carers Act and the new duties in relation to Adult Carers Support Plans (ACSPs)/Young Carer Statements (YCSs) has led to some excellent, outcomes focused 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/YCSs to carers centres and services, 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 'Getting it Right for Everyone' (GIRFE). 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 GIRFE approach at 74%. However, in discussions with parent carers, 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 judgmental. There was overstepping by professionals into areas they were not qualified to address”

Assessment

The Carers (Scotland) Act is supported by guidance about the Adult Carer Support Plan and Young Carers Statement being a meaningful conversation between the unpaid carer and assessor. In Scotland we have a range of resources to support good outcome-focused and strength-based conversations. We also have considerable evidence about the benefits to both unpaid carers and supported people from having the opportunity for those skilled conversations, including more effective decision-making.

However, a range of system-based requirements including excessive data requirements, performance indicators, eligibility criteria (which are deficit based and work against strengths-based practice) mean that meaningful conversations are often not supported in practice. Although there are pockets of good practice, currently the ‘assessment’ process is too often very stressful and confusing for carers, with missed opportunities to identify community resources or creative options to help unpaid carers achieve their outcomes. When done well, these conversations can immediately improve outcomes for unpaid carers.

We believe that renewed attention is required and that further clear guidance should be developed to support ‘good conversations’ with unpaid carers to ensure a personalised, responsive approach to determining the outcomes that matter to them and the people they support, leading to more effective support including more meaningful short breaks.

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 forum for carer representatives on IJBs 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 broadly support the position put forward by Colin Slasberg in his paper ‘Blueprint for a post eligibility social care system with human rights at its heart’ which we contributed to and which sets out an alternative to the use of eligibility criteria.

Black and Minority Ethnic (BME) carers

Two key issues were identified by BME unpaid carers: the value placed on being able to access community organisations who were able to support them to access social care service; and an overwhelming concern that these services were not universally available across Scotland. BME unpaid carers consistently spoke of the positive outcomes they had received as a result of having access to community organisations who were able to advocate for them or assist them to advocate for themselves:

“After [organisation A] closing, we have been blessed to have [organisation B]. All our social care needs depend on [organisation B]. We don’t have enough English and have been asking a lot of help from [organisation B] bilingual workers.” (Chinese carer for disabled adult son)

This was particularly notable in ensuring that social care practitioners had a greater understanding of the specific cultural requirements to inform support planning so that the resultant ACSP was accurate in identifying and determining need and the provision of appropriate services which flowed from this.

“I felt very angry, they weren’t taking our lifestyle into perspective, they weren’t giving it much thought. Since then I’ve had a lot of good support from carers and other members of the health team but especially the carers. The carers had more empathy for our way of life and heritage. I felt some of the social workers were looking down on us.” (Gypsy/Traveller parent carer)

In their responses, BME unpaid carers also expressed frustration that for many, the process of support planning and the identification of outcomes was a ‘paper’ exercise given the inappropriateness and inaccessibility of the majority of services available. Self-directed Support had done little to address this with unpaid carers identifying ongoing problems ranging from the lack of culturally appropriate services within the ‘mixed market’ to purchase to a reluctance on the part of some local authorities to allow them to employ family members as personal assistants.

Access to care and support conclusions

- Support planning should build on outcomes focused best practice, including the good conversation model.
- The work of carers centres/services in undertaking ACSPs/YCSs 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 unpaid 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
- Meaningful support planning and the identification of personal outcomes does not, and cannot, exist in isolation from what is available locally to support BME carers and carers more generally. The two are inextricably interlinked.

Rights to breaks from caring

Current access to breaks from caring

Research tells us that having access to planned, regular good-quality breaks is vital to carers’ health but despite the evidence of the benefits and the duty on local authorities to provide them, only a small proportion of unpaid carers receive regular and meaningful breaks from their caring role.

In 2018 only 18% of unpaid carers said they had managed to have a break from caring in the past 12 months (State of Caring 2018, Carers Scotland). And in 2019, less than a

third of unpaid carers said their need for a break was sufficiently considered as part of their Adult Carer Support Plan (State of Caring 2019, Carers Scotland¹).

According to government data as few as 3% of unpaid carers currently receive statutory support for breaks from caring.

Furthermore, across Scotland, there appears to be significant variation in the availability of breaks, and carers' experience will be different due to a variety of factors, including where they live.

COVID-19, and the suspension of many respite care services, has of course placed significant additional financial, practical, and emotional challenges on unpaid carers.

Progress in the development of unpaid carers' rights has not produced the improvements expected, particularly in relation to breaks from caring, and consequently, for carers, there is a gaping divide between policy intentions and everyday reality.

"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."

"I care for my son and long-term adult friend and it's hard work on a day to day basis keeping upbeat keep moving till bed time. Some days I'm absolutely shattered cry myself to sleep, no one else to help me."

At the heart of reform regarding a right to a break, there needs to be a human rights approach meaning that unpaid carers should have a life alongside of caring and good health and well-being, facilitated by regular breaks from caring. The emphasis too often is on crisis intervention which makes short breaks provision reactive and mechanical in planning and delivery.

We would therefore expect that a new legal right to a break will prevent unpaid carers from reaching crisis point by supporting carers to have a life alongside caring with positive opportunities for improving wellbeing without needing to be assessed as on the verge of a breakdown. A right to a break should enable unpaid carers to thrive, to live happy and fulfilled lives, and to maintain the quality of care they want to, and can, provide.

"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."

Disabled people and people with support needs must have equal rights and have access to the best quality practical support and assistance to participate in society and live a full life. The needs of unpaid carers and those they care for are often

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

interdependent and improvements in support for the cared-for person will, in many situations, provide a respite effect for the carer, and this is to be welcomed. However, we also believe unpaid carers must have sufficient access to their own flexible, carer-centred breaks that meets their personal outcomes.

“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.”

The lack of a legal entitlement to a break is not the only reason carers are unable to access the breaks they need. The diversity of caring means there are many different reasons, but carers consistently report: lack of awareness of their rights and difficulties sourcing information; complicated and stressful referral pathways; shortage of suitable and accessible provision; loss of short breaks at transition points; lack of personalisation; issues relating to the cultural sensitivity of services; and cost, as key concerns.²

While a right to a break is an important and welcome development, this must be accompanied by a commitment to address these additional barriers.

A right to a break – preferred option

From our discussions with carers, our view is that the hybrid approach is the preferred option. We believe this approach would achieve the best outcomes for carers by combining a guarantee of preventative support through a non-assessed minimum entitlement, alongside a right to additional support for those with higher levels of assessed need.

In addition, regarding the ‘assessed’ element, we would wish to see an amendment to the Carers (Scotland) Act to remove eligibility criteria to ensure all carers have a right to receive additional support if the minimum entitlement is not sufficient to meet their individual needs and outcomes. In determining the level of support to be provided, we are concerned that the proposed principle that every carer is entitled to have ‘sufficient rest’ is setting a low bar. Carers should receive sufficient breaks to be able to achieve their potential and live a full life alongside caring. In other words, sufficient breaks that support people to thrive not just survive.

Careful consideration must be given to how this will be implemented with clear guiding principles set in place around fairly and transparently determining needs. Whilst the caring role for carers intensifies with more hours of caring, this is not the only determining factor by any means. There will be a wide range of considerations including poverty, familial and community support, physical and mental health of the carer and the cared-for person. An individualised approach to determining the personalised entitlement will be key.

² [Shared Care Scotland, \(2012\) Rest assured: A study of unpaid carers’ experiences of short breaks](#)
[Shared Care Scotland, \(2020\), ‘Regular & Meaningful Breaks’, Annual General Meeting discussion](#)

Regarding the guaranteed minimum entitlement, no clear preference emerged from our discussions on how this should be specified. We appreciate the complexities of making this work and we would suggest a more detailed options appraisal is carried out with input from carers. The new Scottish Carer's Assistance grant may be an option to consider if eligibility was extended. This could provide a vehicle to deliver a minimum entitlement in the form of a short breaks payment to support break(s) from caring. Most importantly, from the carer's perspective, a new right to a break must be clear, transparent, straightforward to access and be applied fairly and consistently.

"It should be fair, transparent and easy to administer. Not another thing that you need to fight for."

"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."

More than just a right to a break

The Feeley Report whilst recommending a 'right to respite', also highlighted problems related to the availability of suitable short breaks provision and recommended, 'a range of options for respite and short breaks should be developed.' In our view, the consultation does not specifically address this recommendation but, if a new right to a break is to be effective and deliver the improvements expected, **there is an urgent need to consider the current availability and range of short breaks across Scotland**, including replacement care. A right to a break is of little value if there is insufficient availability or choice to enable unpaid carers to exercise this right.

Concerns about the lack of availability of short breaks were raised repeatedly by carers during the National Care Service engagement events and in survey responses.

"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 respite if there is nowhere to send them!"

"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."

"Waiting lists for respite are an insane length of time."

Carer engagement in short breaks planning and commissioning

Policy must continue to strongly promote the involvement of unpaid carers and those who use or who may use services in the planning and commissioning process, with the aim of providing short breaks which are more responsive, innovative, and tailored to people's requirements. Unpaid carers and service users should, for example, be involved in identifying local needs, planning, identifying, and selecting providers, formulating contracts, and evaluating the services provided.

Choice and control should be supported by the use of direct payments and individual budgets, where appropriate, but this should not limit effective collaborative commissioning, which shapes the market to ensure that sufficient provision is available that can meet current and future demand for short breaks.

Non-statutory support for breaks

As well as strengthening access to breaks through statutory measures, we believe there is also a need to expand non-statutory approaches such as the Short Breaks Fund. Time to Live has helped provide an estimated 80,000 individualised carer breaks over the past 11 years. The responsive and flexible scope of this grant funding has allowed local delivery partners to work with carers to explore alternative, personalised and cost-effective ways that breaks from caring can be achieved. Much has been learned in the process that has led to a more flexible interpretation of what a break can be. The management of this funding has also led to Carers Centres developing new capacity and skills to support unpaid carers through, for example, offering short breaks brokerage.

Similarly, the Better Breaks and Creative Breaks grants programmes have allowed third sector short break providers to work with unpaid carers and their service users to offer other flexible ways of delivering their services. Working with funded projects new tools and resources have been co-produced to help improve practice and learning exchange events have played a key role in encouraging funded projects to share ideas and transfer learning.

An expanded role for non-statutory approaches could be part of the solution of providing a more personalised entitlement but it would have to work alongside statutory provision.

Young carers

Young carers have repeatedly told us that it is important they get regular breaks from caring. As a result of the pandemic, where many statutory services were reduced or not available, many young carers spent more time caring at home while also juggling home-study and were unable to get a break. We know that breaks can be very beneficial for young carers, giving them time to recharge and do things they enjoy. It is vital that young carers are recognised as children and young people first and foremost. A Carers Trust [survey](#) undertaken during the pandemic found that 1 in 4 young carers were unable to take any break from their caring role.

Breaks from caring are essential for supporting young carers' positive wellbeing, reducing social isolation and to ensure children and young people with caring responsibilities can live a fulfilled life.

Through our consultation work with young carers, both personalised support to meet need and standardised levels were highlighted as important. The preferred approach identified by young carers is Group C – Hybrid approaches.

Young carers were asked in our survey:

It is important that unpaid carers of all ages are able to take a break. Scottish Government want to make it an unpaid carer's right to have a break. What model of breaks from caring would you prefer?

Answer Choices	Response Percent
All unpaid carers have the same support to take a break	22%
All support should be personalised to a person's needs	28%
It should be a mix of both	50%

Opportunities for respite are important to all unpaid carers, including young carers. It is important to young people that respite and breaks are available, and suitable to their needs. Each young carer has different expectations of a break; and different requirements for what makes a good break for them. This is reflected in the answers to the survey, and in the following quotes:

"I want to spend more time 1:1 with my mum and dad ... I don't feel confident enough to go with people I don't know. I want my breaks to be with my own friends and family and with people I choose ... If my mum and dad got more help with my sister this would help me too."

"For a lot of young carers – a break away is not just physical but a mental break – don't need to worry in the back of their mind about the person they care for. Even if attending a hub (physical break) there is not necessarily a mental break. Helps for them to know the cared for person is safe and being looked after by someone."

The process for young carers accessing short breaks should be simple and fair. There must be flexibility on how short break budgets are used to meet the diverse needs of young carers. It is essential that considered planning is undertaken to ensure young carers do not become an after-thought of short break provision, recognising that their needs and requirements may be different from adult carers. All unpaid carers, including young carers should have regular access to personalised short breaks which meet their needs.

Black and Minority Ethnic (BME) carers

There was universal consensus amongst BME unpaid carer respondents that having access to regular and timely short breaks was a vital support in their caring role. The emphasis was on short breaks that met their specific cultural and linguistic requirements, and this was where the biggest gap in available services was identified. Unpaid carers spoke of their lack of confidence in having the needs of the cared for

person met resulting in a reluctance to take up services and in instances where they had used services, of the detriment in the cared for person's mental and emotional health on their return.

"You could get a wee weekend away. Being a Traveller, my son is different from other kids with the same condition."

"I was offered respite when my son was seven or eight and he went to a special school. [I] didn't take it because I didn't trust anyone to look after my son."

As a result of this, there was a reliance on specialist services, which by their very nature, were very limited and not universally available across Scotland.

"What the community requires is a bilingual (Cantonese and English) organisation to arrange the trip so that the carers can have a short break once a year."

Unpaid carers from BME communities were in favour of a universal right to a short break but argued strongly that such a right was only as good as an individual's ability to exercise that right in a way which met their needs. Many carers spoke of going years without a break or not having access to a short break at all, contributing to further declines in their own health and wellbeing.

Carers also requested more flexibility in how short breaks were to be taken, arguing that for them, group breaks with other carers from the same ethnic group were preferred due to language and cultural requirements.

Using data to support care

We would strongly argue that there needs to be a renewed focus on the collection of data on unpaid carers, including equalities data within social care. Consistent failures to routinely collect data on the uptake of social care services, including unmet need, have resulted in significant data gaps which have hindered progress in the identification of services required, workforce planning and improvement activities. A recent FOI undertaken by MECOPP to quantify the number of carers' assessments and Adult Carer Support Plans by local authorities have once again highlighted incomplete or non-existent returns. The absence of robust data has implications across the whole of the social care sector at both local and national level. In order to determine and subsequently ensure that everyone in Scotland who requires social care support is benefitting equally from that support, we urge Ministers to make this a priority.

Complaints and putting things right

Unpaid carers have mixed views on the proposals put forward to improve how social care complaints are dealt with.

There was strong support for a Charter on Rights and Responsibilities and access to clear information on any complaints process and advocacy agencies which could assist. There was also support for a single point of access for feedback and complaints, as long as it was fully inclusive, clear information about advocacy services and a consistent model for handling complaints for all services were rated equally by unpaid carers. All elements detailed within the consultation as core were seen as important in developing a new system for complaints about social care services. The lack of unpaid carer specific advocacy services was highlighted as a particular concern.

Unpaid carers noted their support for a national single body to deal with complaints which would be useful as it would ensure consistency of approach and response. However, there were mixed opinions about moving any complaints process online as this could prove off-putting and mean an additional barrier for people who were digitally excluded.

Unpaid carers had a range of concerns around making a complaint and how more could be done in designing a system that reassures complainants that complaints would not be held against them and that they would be treated as an opportunity for improvement. Carers have a fear that they and/or the person they care for will be penalised for making complaints. It is important to ensure that this isn't the case but people may have had a bad experience.

They further noted that it was crucial to establish a positive working relationship with anyone dealing with their concerns but that it was incumbent on the worker and not the unpaid carer to be responsible for this.

The time taken to resolve complaints was also specifically highlighted. Unpaid carers were often exhausted by the length of time it could take to satisfactorily (or not) resolve a complaint and that very often, they did not have the energy to pursue or finish the process. They felt strongly that a quicker process would be much more helpful. There was little support for a Care Commissioner within the workshop as participants felt that there were already a number of regulatory bodies which they did not have full confidence in.

“We have had Mental Welfare Commissioner for a generation. No confidence in them”.

In discussing the potential for a Commissioner, unpaid carers were unsure, with the information available, whether this was of benefit or not. They felt that more information was needed on what exactly a Commissioner would do, what their powers would be and how this would be funded. Suggestions were made that the role and remit of a Care Commissioner should be consulted on and the final role/remit should be widely publicised.

“I have often seen the role of a commissioner being suggested but I’m unsure exactly what someone in that role would do.”

All participants in discussion were in favour of a National Care Service, collecting data on the lived experience of those receiving care and support, their families and unpaid carers to contribute to an outcome measure. Unpaid carers felt strongly that the lived experience of unpaid carers should be valued and reflected in an outcome. However, some questions arose on whether their experiences would be equally weighted.

“Does this mean this feedback should have the same value as inspection reports, etc. which currently carers have no power over?”

“It can depend on how much they value the views of carers vs those of the experts. Sometimes services can be rated very highly but the experience of using them is very different.”

The Care Opinion model was highlighted by unpaid carers as a positive way to gather both positive and negative feedback. As a public platform, this would support public accountability which was felt to be crucial. Unpaid carers felt there was a lack of transparency and an unwillingness to take responsibility when things did not go well.

“The Care Opinion format is also a public forum where everyone can see what is being said, rather than most complaints which are made privately. Action can also be taken based on positive feedback provided.”

Black and Minority Ethnic (BME) carers

In addition to the above, a number of additional issues were identified by BME unpaid carers. The primary concern expressed by BME carers was for any complaints process to be easily understood, accessible at the point of need and to have access, as a matter of course, to the necessary support mechanisms to enable them to participate fully. Access to culturally appropriate advocacy was highlighted as a specific requirement. A number of unpaid carers noted assumptions made by practitioners that younger family members could assist without recognising that whilst these family members may be fluent in English, they had limited capacity in the first and/or preferred language of their parents.

There was some support for a Charter on Rights and Responsibilities as unpaid carers felt that they would be able to refer to this if they felt they were not being listened to but that any Charter must reflect the diversity of Scotland’s caring population.

National Care Service

As part of the National Carer Organisation engagement events, we facilitated two carer discussion groups at the Carers Parliament which addressed the Scottish Government's proposals for a National Care Service and the scope of the National Care Service. We also heard from 424 people who responded to our survey on the National Care Service. 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 unpaid 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 and discussions indicated that they were in favour of the development of a National Care Service. However, at the Carers Parliament discussion groups this support was more nuanced and included many caveats for which more detailed information on the proposals was required.

Key messages

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 they 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 unpaid carers and care recipients
- Unpaid 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 it should be developed incrementally.

Polling results

In reference to Q20 we asked: *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

In reference to Q22 we asked: *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

In reference to Q52 we asked: *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

More information on the inclusion of mental health services in the National Care Service can be found in the section on the Scope of the National Care Service.

Carers Parliament workshops polling and discussion

In our discussion groups at the Carers Parliament we also used polling questions to ascertain unpaid carers' views on the proposals for a National Care Service. Firstly, we asked people their views on the government taking responsibility for social care. The results were broadly similar to our survey with 44% of unpaid carers saying they were in favour of the plans, versus 52% in our survey. 22% of people at our discussion groups disagreed with the proposal versus 21% of those surveyed. The remainder said they were unsure.

We then asked people at our discussion groups if they agreed with setting up a National Care Service. Interestingly, results were much higher with 86% saying they were in favour of this proposal. The same question was not asked in our survey. The reasons for this difference may be explained by the dual desire for greater consistency and raising of standards, while at the same time the preference was for local decision making. This is probably best summed up by one participant who suggested:

“You could have a centrally funded but decentralised NCS under local control”

The other points unpaid carers raised at the discussion groups were:

- The last 18 months has proved that the current system isn't working and things need to change
- Any approach needs to be collaborative with people working better together. It was suggested that we look at the recommendations in the Christie Report about building services around people
- The main issue is not planning it's the lack of resources
- The challenges of transitions were discussed. There are huge barriers to smooth transition. The minute someone is transferred to adult services they are discharged by their NHS consultant in children's health services rather than any attempt to a smooth transition for the young person and their family. Unpaid carers are having to deal with transitions in both health and social care

The needs of unpaid carers from rural areas was a strong theme with concerns raised about how responsive a National Care Service would be to their specific geographical challenges. The following points were made on this theme:

- Rural carers need to be involved in oversight groups and structures
- What happens in the Central Belt doesn't work in rural and island areas
- There are greater difficulties in recruiting social care workers in rural areas, which has led to reductions in care visits from 4 to 2 per day and some smaller care companies pulling out.

Young carers

The vast majority of young carers we engaged with are supportive of the introduction of a National Care Service and for Scottish Government to be responsible for the delivery of social care. The National Carer Organisations as informed by unpaid carers, young carers and carer services are therefore also supportive to the creation of a National Care Service.

A Carers Trust Scotland [survey](#) undertaken during the pandemic found that 59% of young carers and 67% of young adult carers who participated were taking on more caring hours every week. One in ten young and young adult carers surveyed have seen their caring role increase by 30 hours a week or more and 24% of young carers and 34% of young adult carers were caring for more people than they did before the pandemic. Additionally, 38% of young carers and 44% of young adult carers that participated felt less able to cope.

As the number of unpaid carers in Scotland has estimated to have increased now to over 1.1 million, it must be recognised that many of these unpaid carers are young carers. Many young carers remain hidden and unidentified and there is lack of robust data on this cohort of unpaid carers. In the creation of a National Care Service, disparity

of young carer support should be addressed. The needs of young carers should be at the fore of development to ensure these young people and their needs are recognised; they must get the support that they need and their rights as children and young people must be upheld. We know that an effective social care system should contribute to improving support for young carers and achieve better outcomes for them.

Young carers were asked in the survey:

A National Care Service would mean that the Scottish Government would become responsible for social care, like it is for health care. Do you think Scottish Government should be responsible for social care?

Answer Choices	Response Percent
Yes	86%
No	14%

Young carers could also take part in an Instagram poll to share their views in a quick response. From this poll they were asked *“Do you think Scottish Government should be responsible for social care?”*. 16 people took part in this Instagram poll, with 100% responding ‘Yes’.

Young people can see the potential for a National Care Service to improve the support available both to unpaid carers, and the person(s) they care for. Improving the support of their cared for person can often be an effective way of better supporting the young carer, where it would be expected that there would be less onus on the child or young person to provide the required social care.

Young carers noted that support available is different across Scotland’s local authorities. Young carers expressed that a National Care Service could have a role in standardising the support available, ensuring high quality provision regardless of location.

Views on this topic were also shared during the young carers’ session of the Carers Parliament, where seven out of eight participants supported that Scottish Government should be responsible for the delivery of social care. 100% of respondents to the question *“Should this be through a National Care Service?”* agreed that the delivery of social care should be through a National Care Service.

Young carers thoughts are also reflected in the following comments also:

“All care and support should be person centred. The person receiving care is the most important in all of this and should have the right to voice opinions on their care and feel listened to when they speak up.”

“I think that there should be help for everyone across the entire of the UK and extra help in rural areas.”

Black and Minority Ethnic (BME) carers

The response to this question was mainly based on how to ensure that all BME carers had equal access to social care services irrespective of where they lived in Scotland. BME carers highlighted that too often, the support they received was dependent upon the availability of other BME community organisations in their area and that the BME support infrastructure was not equally developed across the country. There were also marked disparities in the extent to which different ethnic groups were served by community organisations.

A hope was expressed that a National Care Service might be one way of addressing this imbalance ensuring that all BME unpaid carers had equal access to the services they required.

From an organisational perspective, in its' individual response, MECOPP has highlighted the potential with the National Care Service to address this issue.

National Care Service conclusions

- 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 unpaid 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. This is particularly the case for rural and island communities who must have representation within the structures of the National Care Service.
- The National Care Service must set out and address existing inequalities with the social care sector to ensure that all those who require support receive the support that is right for them
- The development of a National Care Service will require considerable investment. However, our stakeholders 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 National Care Service 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 National Care Service 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 National Care Service, while we welcome a greater drive towards integration at a national level, the National Care Service must not follow the medical model but must have human rights as its heart.

- Transitions from adult to children’s services must be considered within the work of the National Care Service, both social care transitions and health care transitions for children with ongoing medical needs. More information on parent carers views on the National Care Service can be found in the next Section.

Scope of the National Care Service

Children’s services

Carers expressed general support for children’s services to be included in the National Care Service. They noted that there was fragmentation and families would benefit from a joined-up service from childhood right into adulthood. They talked about services stopping when moving from the children’s team and having to fight to get adult services in place:

“I absolutely think this should be a joined-up service, one of the biggest issues I found was lack of passing on of information”

“What I find baffling is that no-one seems to understand that a child with disabilities becomes an adult with those exact same disabilities”

However, some unpaid carers said that whilst it was worth exploring, they were more cautious about the approach of including children’s services with one citing a study in England that found that by including disabled children under general social work introduced a bias towards parents with disabled children as social work may approach children from a child protection perspective. It is important that incorporating Children’s Services into a National Care Service does not create unintended barriers.

There were thoughts on the benefits on locating children’s social work services within the National Care Service and improving alignment with community child health services including primary care, and paediatric health services. It was noted that it does have the potential to be more supportive but needed safeguards to ensure that people did not fall through the net.

“It’s the ones who will fall through the net that concerns me. As there will undoubtedly be. I think we need to overhaul certain Acts etc and look at our use of the words ‘care needs’. Why don’t we ask what the person would like and take things from there. I know.... but I can dream.”

Portability of care was noted as a benefit.

“It would also help to have same services across Scotland, recognisable, especially when families move from one area to another, often not the same services or support and start telling story again, when paperwork could follow family.”

It was noted that this could have been possible within Integrated Joint Boards but was not often the case.

“It would make it better for children services to also be part of the NCS because in some local authority areas children’s services sit on their own apart from Integrated joint board and not enough joined up for families.”

Unpaid carers noted the role of education and ensuring that connections are maintained and but also that the experience of their child in education is improved. All parts of the system are important.

“There needs to be joined up planning between services – something like an Education Health and Care Plan that exist in England. Co-ordinated Support Plans focus too much on Education and too difficult to obtain.”

When asked about the risks of including children’s services in the National Care Service. There were a few mentioned. For example, some parents cautioned on using the GIRFEC approach for all services (Getting It Right For Everyone):

“GIRFEC hasn’t been implemented fully and now they want to use a similar model for adults.”

“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.”

Others highlighted confidentiality e.g., in one response noted a possibility of lowered confidentiality but also noted that a national care service could offer benefits too.

“I don’t know if confidentiality would potentially be lowered in anyway if everything was together? I think as long as each individual was seen as an individual it would work well rather than viewing people by their age or from assumptions made based on other experiences with people in similar situations or ages”

Young carers

Overall, the young carers that participated in our consultation exercises agreed that Children’s Services should be incorporated into a National Care Service in Scotland. However, it was also clear that young carers were cautious about whether a National Care Service could result in current good practice in specific areas not being maintained.

It is important that a National Care Service looks at good practice services across the country, adapts where required and rolls this support out to prevent a postcode lottery of quality young carer support services. It is therefore also vital to ensure that no young carer should experience a poorer quality service under a National Care Service model.

We trust that the incorporation of Children’s Services will result in a smoother transition for those young carers that will transfer from children to adult services. This transition can be a difficult time for young carers, and we hope that incorporating Children’s Services into a National Care Service will ensure an ease in this transition of support.

We did not ask young carers their views on incorporating Children’s Services into a National Care Service as part of our survey or Instagram polling. However, we did gather views through our workshop at the Carers Parliament.

Through a digital poll during the session young carers were asked *“Do you agree that Children’s Services should be covered in the National Care Service?”* and 100% of respondents agreed that it should be.

However, some young carers did have some reservations about this, particularly around the fear that a National Care Service may result in a dilution of quality services and practice that is currently operating in some areas.

Young carers thoughts are reflected in the following comments:

“I’m in two minds with that one because each local area has so many different things to offer and if we generalise, will that be lost.”

“I feel that each individual is so different even if their situation is the same. One 12-year-old may be very mature and need different levels of support than a less mature 12 year old. If support is generalized, it may not be appropriate for each person if that makes sense?”

“I see some potential benefits such as the improvement for communication between services.”

Children’s Services, Rights and Child and Adolescent Mental Health Services

The recommendations from the Children and Young People’s Mental Health Taskforce³ endorsed a whole system approach in addressing children’s mental health needs. It is good to see this reflected in the proposal for children’s services to fall under the auspices of a National Care Service. As was found by the Promise⁴, *“for Scotland to truly to be the best place in the world for children to grow up, a fundamental shift is required in how decisions are made about children and families”*.

The current proposals being put forward for a National Care Service recognises that the Independent Review of Adult Social Care did not make specific mention of children’s

³ Scottish Government (2019) Children & Young People’s Mental Health Task Force: Recommendations

⁴ Independent Review of Care (2020) The Promise.

service, out with acknowledging the need that social workers were reporting increasing concerns about fragmentation of children's services. We are pleased to see this taken forward in the proposals for a National Care Service.

The United Nations Convention on Rights of the Child⁵ (UNCRC), paradigm shift requires children to be understood and related to as rights bearing individuals who are partners in their own care, not as passive recipients of adult's decisions in a welfare-based approach. The right to be heard (Article 12, UNCRC) must be applied in a very different context to that of adults, one which works with the evolving capacities of the child, and which respects the role of parent/carers. To achieve this, investment must be made into provision of adequate independent advocacy for children and young people.

This advocacy should not be an add on to current provision but an expansion of current provision and available to all children and young people across NHS service and any proposed National Care Service. There is also a need for investment into advocacy for unpaid carers in their own right and providing that will help unpaid carers exert their rights where need be.

The Scottish Government, in its commitment to producing Human Rights Bill which includes the incorporation of various conventions, must be minded that the United Nations Convention of Rights for Child and United Nations Convention on the Rights of Persons with Disabilities require Scots law, policy and practice to reflect:

- new paradigms for understanding childhood and disability
- several principles
- a range of duties for the state
- and rights for children and young people.

Much of this may need to be included in new legislation going forward, such as new mental health legislation, but also may impact on development of comprehensive children and young people's services as envisaged by a National Care Service. If carried out, with sufficient resources and willingness on part of agencies involved in the range of children's services, there is no reason why both UNCRC and UNCRPD could not be complied with.

Q.22 In response to the question of whether children's social work and social services should be incorporated into a National Care Service, our response is yes, but with the caveat of considering the paradigm shift outlined above.

We believe that it will be provide a more human rights-based approach if children's services, especially those with disabilities, including mental disabilities, were positioned under a National Care Service which would oversee the protection of children's human rights, as set down by both UNCRC and UNCRPD.

⁵ Scottish Parliamentary Corporate Body (2020) United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill: Policy Memorandum

This is not to ignore the complexity of this task however and the cultural shift away from seeing children and young people as objects of charity or passive recipients of care, treatment, or welfare. This move, underpinned by human rights, incorporating both UNCRC and UNCRPD, moves this view to children and young people as rights bearers. This can only be a good thing in the context of ensuring equity of access to services and the right to be heard.

Q.23 & 24. In response to these questions, we think that there may be some changes needed in how we consider disability, in particular under Scottish mental health legislation ⁶when a child would be considered 'mentally disordered', under UNCRPD this would require to be changed to 'mentally disabled'.

These are fundamentally different concepts. A child's 'mental disorder' currently is understood from a medical perspective, which generally focusses on problems within the child and equates the child's disorder with impairments within the child. In contrast the UNCRPD describes those same children as having impairments, and those impairments are not the main focus for support or intervention. Those impairments, in interaction with all types of barriers in the child's environment give rise to disability. The main purpose of support and intervention is to remove barriers to the child's full and equal participation in society.

The current fragmented system of children's social work and social services stand as barriers for many of Scotland's children and increase the complexities of many of those children with disabilities. These barriers include, but are not the only ones,

- Moving between different social work and social care services/departments
- Repeating the child's and family's story over and over again
- Lack of joint communication between the various organisations supporting the child and the family
- Lack of interaction between child social work and social care services and NHS services.

All of this leads to parent/carer burn out and lack of trust with services. For the child it can add to feelings of being 'less than other children' or 'being different'. This can all deter people from seeking help and support or responding with anger and frustration at a system that is more concerned with process and policy than child centred care and support.

The inclusion of children's services within the National Care Service can only help with transitioning to adult services, an area which can be fraught with stretched relationships between young people, families and services. It also aspires to take a holistic view of the young person's needs as well as that of the family and unpaid carer. Given that for some young people transitioning into adult services may also come at a time of transition into further education or independent living, the more joined up social work and social care services can be the better the outcome for the young person.

⁶ Mental Health (Care and Treatment) (Scotland) Act, 2003, Scottish Government, 2003

The Independent Care Review⁷ identified the following 5 foundations for children and young people in Scotland to fulfil the ambitions of the Scottish Government in a Scotland which could love its most vulnerable children and give them the childhood they deserve”⁸.

Voice: Children must be listened to and meaningfully and appropriately involved in decision-making about their care, with all those involved properly listening and responding to what children want and need. There must be a compassionate, caring, decision-making culture focused on children and those they trust.

Family: Where children are safe in their families and feel loved they must stay – and families must be given support together to nurture that love and overcome the difficulties which get in the way, this has to also include support for unpaid carers within the family.

Care: Where living with their family is not possible, children must stay with their brothers and sisters where safe to do so and belong to a loving home, staying there for as long as needed. This will also require the identification and recognition of sibling young carers.

People: The children that Scotland cares for must be actively supported to develop relationships with people in the workforce and wider community, who in turn must be supported to listen and be compassionate in their decision-making and care.

Scaffolding: Children, families, unpaid carers and the workforce must be supported by a system that is there when it is needed. The scaffolding of help, support and accountability must be ready and responsive when it is required.

Q. 26. The risks of including children’s services within a National Care Service can be mitigated if there is a change in culture in line with conventions already outlined. A big risk will be lack of investment coming into the social work and social care part of a National Care Service, especially if there is also a commitment to provide Child and Adolescent Mental Health Services (CAMHS) under the same service.

A further risk may be the complexity of complying with both UNCRC and UNCRPD and how they view children with mental disabilities, this could be mitigated against by any recommendations made by the Review into Mental Health Law being undertaken, but if there are no recommendations coming from this, or if they are ignored, then fragmentation is likely to continue in CAMHS being seen as something that has no bearing on paediatric services. Education services also need to be included in the range of children’s services, as does the Children’s Hearing system.

⁷ Independent Review of Care (2020) The Promise.

⁸ As 8

Mental Health services

We agree that the current system of integration of health and social care is not fit for purpose and many people can find themselves falling between the gap. This can lead to the 'rolling door' scenario and increased use of compulsory powers to care and treat those with mental disorders.

This has a devastating impact on to the health and wellbeing of unpaid carers left in the situation of picking up the pieces and trying to support people with sometimes complex and variable mental health issues. The impact for unpaid carers can also see them losing vital income, cope with isolation and loneliness, deal with society's stigma of mental health and may even find themselves the victim of aggression or violence because of the cared for person's mental illness. All of this adds more pressure onto social work and social care services.

The attainment of economic, social and cultural rights in this context is of vital importance. Without adequate housing, meaningful activity, enjoyment, and financial stability, mental health has been shown to be poorer. Public Health Scotland states that adults living in the most deprived areas are approximately twice as likely to have common mental health problems as those in least deprived areas (22% versus 11%).⁹

The primary causes of health inequalities are rooted in the political and social decisions and priorities that result in an unequal distribution of income, power and wealth. This can lead to poverty and marginalisation of individuals and groups; this can especially be seen in unpaid carers of people experiencing mental illness as outlined above. These fundamental causes also influence the distribution of wider environmental influences on health, such as the availability of good-quality housing, green space, work, education and learning opportunities. They can also influence access to services and social and cultural opportunities in an area and in society.

If a National Care Service is to focus on health improvement and in particular mental health improvement and comply with human rights around economic social and cultural rights, then all of these need to come into play and that will take considerable investment financially and in communities and frontline staff. We acknowledge and welcome Scottish Government's vision for a future Scotland and think it is the best way to helping reduce mental health inequalities.

A human rights and recovery approach are very much aligned. Both respect people's diversity, experiences and choices and require that people be afforded the same level of dignity and respect on an equal basis with others. Also, both approaches recognise the social and structural determinants of health and promote the fundamental rights to equality, non-discrimination, legal capacity, and community inclusion, and have important implications for how mental health services are developed and delivered. Both fundamentally challenge the current status quo in this area and by delivering mental

⁹ /NHS Health Scotland; Inequality Briefing No.10, Nov 2017

health services under a National Care Service, this status quo can indeed be challenged in Scotland.

In response to Q51, it is our opinion that all the mentioned services should come under the auspices of a National Care Service. This would have the effect of improving joint working across services. The World Health Organisation¹⁰ (WHO) states that often services face substantial resource restrictions and operate with an entrenched overreliance on the biomedical model. This overreliance puts an emphasis on diagnosis, medication and symptom reduction while the full range of social determinants that impact a person's mental health are overlooked; the WHO states, "... , *all of which hinder progress toward full realization of a human rights-based approach.*"¹¹

To be successful in achieving integration, a person-centred, recovery-oriented and rights-based approach in mental health, Scotland must change mindsets, address stigma and work at reducing coercive practices. All of this is being tackled, but until we move beyond the narrow focus of biomedical model towards a more holistic approach that considers all aspects of a person's life, Scotland is not going to find it easy to comply with some of the conventions mentioned. This is why we are supportive of the move of mental health services mentioned into a National Care Service.

In response to Q52, closer working with NHS will be a crucial factor in the success, or otherwise, of this move of some mental health services into a National Care Service. Mental health research has been dominated by the biomedical paradigm in recent decades and there is a paucity of research examining human-rights based approaches in mental health. A significant increase in investment is needed in studying such approaches which can assess comparative costs of services and approaches. This could be something done in partnership with the NHS as it can only be of benefit to over-stretched health services.

The WHO sets out its ambitions for States which can lead to effective use of NHS and integration of it with a National Care Service when it says,

"A critical role for mental health services is therefore to support people to access relevant services, supports, organizations and activities of their choosing, that can help them to live and be included in the community. This includes for example, facilitating access to social welfare services and benefits, housing, employment and educational opportunities (see section 3).

*In times of crisis it is especially necessary for mental health services to respect and fulfil the right to live independently in the community, by providing support according to the person's will and preferences where they are comfortable, whether in their own home, or with friends or family, a mental health setting, or other mutually agreeable location."*¹²

¹⁰ Guidance on Community Mental Health Services, WHO 2021

¹¹ As no 11, Executive Summary

¹² As in No 12, page 10

It is hard to envisage a time when NHS mental health services will not be needed, but they should be amongst a range of services on offer and not the only one. This will need significant investment and a whole culture change but that does not mean to say we don't do it.

To help achieve the vision of mental health under a National Care Service, people with lived experience, unpaid carers and family members must be at the heart of the design process. There is a lot of talk around Equal Partners in Care and much public money spent on helping mental health services view unpaid carers as equal partners.

However, to be truly effective and meaningful the experience and expertise of unpaid carers of all ages, along with people with lived experience must be valued and given the same weight as traditional professional voices.

Overall, we think the ambitions set out in the National Care Service scope, especially those around mental health, are positive for a future Scotland. This could lead to a Scotland where all citizens can realise non-discrimination and parity regardless of age, disability, gender etc. For it to be effective and fully incorporate the recommendations of the National Taskforce for Human Rights and both the UNCRC and UNCRPD, a National Care Service will also need to be accompanied by a change in culture and attitude towards how services are designed and operate and a focus on human rights approaches to social care and health is a good starting point.

Reformed Integration Joint Boards: Community Health and Social Care Boards

We discussed the review of Integration Joint Boards (IJBs) and the formation of Community Health and Social Care Boards (CHSCBs) at a meeting with Carers Centre Managers and two discussion groups at the Carers Parliament.

Centre Managers 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 participants at the Carers Parliament meeting also agreed, although with a lower response rate of 75%, with the remaining 25% saying they were "Unsure". In reference to Q63 we asked participants at the Carers Parliament: *Do you agree with carers being voting members on the new Boards?*

Event	Yes	No	Don't Know
Carers Parliament	100		

Unpaid carers felt strongly that unless they are treated as equal partners in care within the new structures that the desired improvements will not be achieved. This was a consistent theme across all our engagement events and surveys.

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

In reference to Q64: Are there other changes that should be made to the membership of Community Health and Social Care Boards to improve the experience of service users? There was discussion at the Carers Parliament discussion groups about the role of current carer representatives on IJBs and whether or not they were able to have their voices heard through meaningful involvement as Board members. The following points were made:

- It is a mixed picture for carer representatives on IJBs in relation to being treated as equal and expert partners in care
- Involvement comes and goes depending on “urgency of budget cuts”. On these occasions one carer said *“it feel there is an irritation with lay members”*
- Often where there is a change of staff, a different focus emerges
- One area noted that they have pre meetings to have difficult conversations with carer representatives out of public view
- It was noted from a carer representative in one area that they were *“kept well away from procurement”*
- While a voting right was largely welcomed, it was felt that it won’t make things easier, in terms of their representative role
- It was felt that there needs to be more public representatives, including carer representatives and other citizen representatives. *“Will one voting carer on a big city or large rural IJB make any difference? Wouldn't it be better to devolve to local areas and give carers and users of services (and care staff) statutory rights to be represented there?”*
- There continues to be a power imbalance between the public representatives and those from statutory agencies
- It was also noted that there is a lack of diversity and inclusion – representatives are often middle class, white professional, often male. With one carer commenting *“People recruit the people who are like them”*
- The issue of insurance was raised, with one carer voicing concerns that lay members are not insured for their decisions and that there may be potential for legal comeback.

Many of the points raised reflect the findings of the Coalition of Carers in Scotland’s (COCIS) annual scoping report ‘Equal, Expert and Valued, the experience of carer reps on IJBs’. COCIS has been scoping the experience of carer representatives on IJBs

since 2016 and produces an annual report charting progress and making recommendations to enhance their role¹³.

The discussion moved on to suggestions of ways to better support carer representatives on Community Health and Social Care Boards. This included:

- Providing them with some form of remuneration for their time
- Ensuring they are compensated for all their expenses. For example, replacement care costs and the cost of printing Board papers
- Providing them with a clearer remit and more support in their role.
- Investigating the issue of insurance for non-statutory Board members to ensure they are not legally exposed.

Being a carer representative on an IJB is equivalent to a full-time occupation, once you factor in the additional strategic planning groups, sub-groups and local carer forums that carer representatives attend to ensure they are a representative voice for local carers.

The proposals to give unpaid carers a vote on the new Boards, while welcomed, further extends their role and responsibilities. The majority of unpaid carers therefore believe that carer representatives should receive some form of remuneration for their time.

"I believe it's absolutely fair to be paid [as a member of the Board]. The risk, for me, if they are ""absorbed"" by the logics of the administration"

Do you agree with carers being paid?

Event	Yes	No	Don't Know
Carers Parliament	88		22

There is precedent for providing remuneration 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 remuneration 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 representatives 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 remuneration.

Since unpaid carer representatives 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.

¹³ <https://carersnet.org/wp-content/uploads/2021/10/Equal-Expert-and-Valued-2019.pdf>

Commissioning of Services

Commissioning is an area of concern for unpaid carers and the staff that support them. In our submission we explain how there must be a range of providers and options for short break services in order for unpaid 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.

Polling and discussion at our Engagement Events

We discussed the commissioning of services at our meeting with Carer Centre Managers. 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:

- 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.

Black and Minority Ethnic (BME) carers

We would highlight the potential of more collaborative and ethical commissioning structures and processes to address the longstanding inequalities that BME unpaid carers face in accessing social care services. We would argue that the proposed National Commissioning and Procurement Structure of Standards and Processes must

explicitly set out how equality considerations will be embedded and driven forward within every component part.

We believe that this is an unmissable opportunity to go beyond the ‘identification and mitigation’ of unintended consequences or a ‘proportional’ response and to utilise commissioning and procurement to truly advance equality of opportunity within services (models of care, quality, outcomes, market shaping strategies) and the workforce (workforce planning, fair work, training and development).

Valuing People who Work in Social Care

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 unpaid 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 unpaid 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 unpaid 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.

Young carers

Young carers that we consulted strongly agreed that there should be better pay and working conditions for social care workers in Scotland.

A Carers Trust Scotland [survey](#) found that from responses received, 75% of young carers and 67% of young adult carers were accessing locally based carer services. These services can be a lifeline to many children and young people with caring responsibilities. The carer service workforce needs to be better recognised and further investment in this sector is needed for their role in social care and the valuable support they provide to unpaid carers. It is vital that young carers are given the right information at the right time and well-funded support services are available for them to access.

Young carers were asked in the survey:

Scotland's health and social care workforce provide important support to people across Scotland every day. Do you think that there should be better pay and working conditions for social care workers in Scotland?

Answer Choices	Response Percent
Yes	100%
No	0%

Young carers could also take part in an Instagram poll and share their views in a quick response. We posed the question: *“Should there be better pay and working conditions for social care staff?”* 15 people took part in this poll, with 100% responding ‘Yes’.

Young carers value the role and work of social care staff. Some of them have social care workers in their families; others who are part of a young carer project and have relationships with the workers at their carers centre, see social care workers directly benefiting their lives.

Young carers might also have social care involvement in their lives, through social care provisions for them or the person(s) they care for. Young carers value the support that this gives the person(s) they care for, and the wider family.

Young carers highlighted that social care should be connected with other local and national services, providing wrap around support. Joint working and clear communication between services is considered key in providing excellent support.

During our young carer session at the Carers Parliament, participants also had the opportunity to share their views via polls. We asked these participants *“Should the National Care Service take action to make pay, working conditions, and training and development for social care workers better?”* The majority of respondents (8 out of 9) believed that there should be better pay, working conditions and training and development for the social care workforce.

Young carers thoughts are reflected in the following comments also:

“My nana is an emergency response carer for health and social care Scotland through the night and her job is very difficult, I think she deserves to be paid well for it as it is not an easy job.”

“Both paid and unpaid carers should not be living in poverty or relying on food banks.”

“All unpaid carers should receive some money, they are seen as providing vital help, so everyone should receive something.”

“I believe the National Care Service really has to value the role of paid carers and other healthcare staff and must prioritise their wages and working conditions. This would be key to supporting unpaid carers with their role.”

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The National Carer Organisations are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance.

Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The NCOs aim to achieve this through the representation of unpaid carers and giving them a voice at a national level.

We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

Appendix 1 - Young Carers

Overview

As part of our National Carer Organisation engagement activity with unpaid carers of all ages on the National Care Service consultation, we also specifically engaged the views of young carers to inform our response. We undertook a survey, polls and delivered a bespoke young carers workshop at the Carers Parliament in October 2021 about the consultation.

Due to a number of factors, including the length of the consultation document and vast coverage of social care in the proposals, we focussed our efforts to engage young carers' views on the areas of the National Care Service consultation which we identified as most pertinent to most young carers. To assist young carers to be informed of the proposals in the National Care Service consultation, we also created a briefing paper for young carers on these key areas: <https://www.sharedcarescotland.org.uk/wp-content/uploads/2021/09/NCO-Briefing-on-NCS-for-Young-Carers-FINAL.pdf>. This briefing was circulated widely to young carers connected with us, across all carer services in Scotland and also to other youth organisations.

Information on the consultation and the briefing was also promoted widely on our social media channels – Twitter, Facebook and Instagram.

We developed and disseminated a survey for young carers to share their thoughts on the consultation, which was shared over September and received 14 responses from young carers aged 12-18, representing 12 local authority areas in Scotland. We also received 16 responses through our Instagram polls and 8 participants took part in the Carers Parliament young carers session.

Rights to breaks from caring

Young carers have repeatedly told us that it is important they get regular breaks from caring. As a result of the pandemic, where many statutory services were reduced or not available, many young carers spent more time caring at home while also juggling home-study and were unable to get a break. We know that breaks can be very beneficial for young carers, giving them time to recharge and do things they enjoy. It is vital that young carers are recognised as children and young people first and foremost. A Carers Trust [survey](#) undertaken during the pandemic found that 1 in 4 young carers were unable to take any break from their caring role.

Breaks from caring are essential for supporting young carers' positive wellbeing, reducing social isolation and to ensure children and young people with caring responsibilities can live a fulfilled life.

Through our consultation work with young carers, both personalised support to meet need and standardised levels were highlighted as important. The preferred approach identified by young carers is Group C – Hybrid approaches.

Young carers were asked in our survey:

It is important that unpaid carers of all ages are able to take a break. Scottish Government want to make it an unpaid carer's Right to have a break. What model of breaks from caring would you prefer?

Answer Choices	Response Percent
All unpaid carers have the same support to take a break	22%
All support should be personalised to a person's needs	28%
It should be a mix of both	50%

Opportunities for respite are important to all unpaid carers, including young carers. It is important to young people that respite and breaks are available, and suitable to their needs. Each young carer has different expectations of a break; and different requirements for what makes a good break for them. This is reflected in the answers to the survey, and in the following quotes:

“I want to spend more time 1:1 with my mum and dad ... I don't feel confident enough to go with people I don't know. I want my breaks to be with my own friends and family and with people I choose ... If my mum and dad got more help with my sister this would help me too.”

“For a lot of young carers – a break away is not just physical but a mental break – don't need to worry in the back of their mind about the person they care for. Even if attending a hub (physical break) there is not necessarily a mental break. Helps for them to know the cared for person is safe and being looked after by someone.”

The process for young carers accessing short breaks should be simple and fair. There must be flexibility on how short break budgets are used to meet the diverse needs of young carers. It is essential that considered planning is undertaken to ensure young carers do not become an after-thought of short break provision, recognising that their needs and requirements may be different from adult carers. All unpaid carers, including young carers should have regular access to personalised short breaks which meet their needs.

National Care Service

The vast majority of young carers we engaged with are supportive of the introduction of a National Care Service and for Scottish Government to be responsible for the delivery of social care. The National Carer Organisations as informed by unpaid carers, young carers and carer services are therefore also supportive to the creation of a National Care Service.

A Carers Trust Scotland [survey](#) undertaken during the pandemic found that 59% of young carers and 67% of young adult carers who participated were taking on more caring hours every week. One in ten young and young adult carers surveyed have seen their caring role increase by 30 hours a week or more and 24% of young carers and 34% of young adult carers were caring for more people than they did before the pandemic. Additionally, 38% of young carers and 44% of young adult carers that participated felt less able to cope.

As the number of unpaid carers in Scotland has estimated to have increased now to over 1.1 million, it must be recognised that many of these unpaid carers are young carers. Many young carers remain hidden and unidentified and there is lack of robust data on this cohort of unpaid carers. In the creation of a National Care Service, disparity of young carer support should be addressed. The needs of young carers should be at the fore of development to ensure these young people and their needs are recognised; they must get the support that they need and their rights as children and young people must be upheld. We know that an effective social care system should contribute to improving support for young carers and achieve better outcomes for them.

Young carers were asked in the survey:

A National Care Service would mean that the Scottish Government would become responsible for social care, like it is for health care. Do you think Scottish Government should be responsible for social care?

Answer Choices	Response Percent
Yes	86%
No	14%

Young carers could also take part in an Instagram poll to share their views in a quick response. From this poll they were asked “*Do you think Scottish Government should be responsible for social care?*”, 16 people took part in this Instagram poll, with 100% responding ‘Yes’.

Young people can see the potential for a National Care Service to improve the support available both to unpaid carers, and the person(s) they care for. Improving the support of their cared for person can often be an effective way of better supporting the young carer, where it would be expected that there would be less onus on the child or young person to provide the required social care.

Young carers noted that support available is different across Scotland’s local authorities. Young carers expressed that a National Care Service could have a role in standardising the support available, ensuring high quality provision regardless of location.

Views on this topic were also shared during the young carers' session of the Carers Parliament, where seven out of eight participants supported that Scottish Government should be responsible for the delivery of social care. 100% of respondents to the question *“Should this be through a National Care Service?”*, agreed that the delivery of social care should be through a National Care Service.

Young carers thoughts are also reflected in the following comments also:

“All care and support should be person centred. The person receiving care is the most important in all of this and should have the right to voice opinions on their care and feel listened to when they speak up.”

“I think that there should be help for everyone across the entire of the UK and extra help in rural areas.”

Valuing people who work in social care

Young carers that we consulted strongly agreed that there should be better pay and working conditions for social care workers in Scotland.

A Carers Trust Scotland [survey](#) found that from responses received, 75% of young carers and 67% of young adult carers were accessing locally based carer services. These services can be a lifeline to many children and young people with caring responsibilities. The carer service workforce needs to be better recognised and further investment in this sector is needed for their role in social care and the valuable support they provide to unpaid carers. It is vital that young carers are given the right information at the right time and well-funded support services are available for them to access.

Young carers were asked in the survey:

Scotland’s health and social care workforce provide important support to people across Scotland every day. Do you think that there should be better pay and working conditions for social care workers in Scotland?

Answer Choices	Response Percent
Yes	100%
No	0%

Young carers could also take part in an Instagram poll and share their views in a quick response. We posed the question: *“Should there be better pay and working conditions for social care staff?”* 15 people took part in this poll, with 100% responding ‘Yes’.

Young carers value the role and work of social care staff. Some of them have social care workers in their families; others who are part of a young carer project and have relationships with the workers at their carers centre, see social care workers directly benefiting their lives.

Young carers might also have social care involvement in their lives, through social care provisions for them or the person(s) they care for. Young carers value the support that this gives the person(s) they care for, and the wider family.

Young carers highlighted that social care should be connected with other local and national services, providing wrap around support. Joint working and clear communication between services is considered key in providing excellent support.

During our young carer session at the Carers Parliament, participants also had the opportunity to share their views via polls. We asked these participants *“Should the National Care Service take action to make pay, working conditions, and training and development for social care workers better?”* The majority of respondents (8 out of 9) believed that there should be better pay, working conditions and training and development for the social care workforce.

Young carers thoughts are reflected in the following comments also:

“My nana is an emergency response carer for health and social care Scotland through the night and her job is very difficult, I think she deserves to be paid well for it as it is not an easy job.”

“Both paid and unpaid carers should not be living in poverty or relying on food banks.”

“All unpaid carers should receive some money, they are seen as providing vital help, so everyone should receive something.”

“I believe the National Care Service really has to value the role of paid carers and other healthcare staff and must prioritise their wages and working conditions. This would be key to supporting unpaid carers with their role.”

Incorporation of Children’s Services

Overall, the young carers that participated in our consultation exercises agreed that Children’s Services should be incorporated into a National Care Service in Scotland. However, it was also clear that young carers were cautious about whether a National Care Service could result in current good practice in specific areas not being maintained. It is important that a National Care Service looks at good practice services across the country, adapts where required and rolls this support out to prevent a postcode lottery of quality young carer support services. It is therefore also vital to ensure that no young carer should experience a poorer quality service under a National Care Service model.

We trust that the incorporation of Children’s Services will result in a smoother transition for those young carers that will transfer from children to adult services. This transition can be a difficult time for young carers, and we hope that incorporating Children’s Services into a National Care Service will ensure an ease in this transition of support.

We did not ask young carers their views on incorporating Children's Services into a National Care Service as part of our survey or Instagram polling. However, we did gather views through our workshop at the Carers Parliament.

Through a digital poll during the session young carers were asked *"Do you agree that Children's Services should be covered in the National Care Service?"*, 100% of respondents agreed that it should be.

However, some young carers did have some reservations about this, particularly around the fear that a National Care Service may result in a dilution of quality services and practice that is currently operating in some areas.

Young carers thoughts are reflected in the following comments:

"I'm in two minds with that one because each local area has so many different things to offer and if we generalise, will that be lost."

"I feel that each individual is so different even if their situation is the same. One 12 year old may be very mature and need different levels of support than a less mature 12 year old. If support is generalized, it may not be appropriate for each person if that makes sense?"

"I see some potential benefits such as the improvement for communication between services."

Conclusions

Below are the key points from young carers that engaged with through our consultation exercises:

- Majority of young carers are supportive of the introduction of a National Care Service
- Young carers agree that Scottish Government should be responsible for the delivery of social care
- Most young carers thought that Children's Services should be incorporated into a National Care Service
- Young carers want to see better pay and working conditions for the social care workforce
- Young carers support for a Right to Breaks to be introduced for unpaid carers, and a hybrid approach between standardised and personalised support is their preferred option.

Appendix 2 - Black and Minority Ethnic (BME) Carers

Information from MECOPP (Minority Ethnic Carers of People Project)

MECOPP was established in January 2000 as an independent Charity. The organisation assists Black and Minority Ethnic (BME) carers access the supports and services necessary to undertake or sustain a caring role. MECOPP currently supports in excess of 750 BME carers including carers within the Gypsy/Traveller community.

MECOPP has submitted a separate organisational response. The information in this document, appended to the joint NCO response, is to inform and supplement that joint response.

General Statement

Whilst we welcome the commitment to a human rights-based approach to the planning, commissioning and delivery of care services, we are concerned that there is no specific focus on equality within the proposals set out in the consultation document. This is particularly concerning given that an Equality Impact Assessment will have to be undertaken, by law, on the creation of a National Care Service. We strongly believe that a focus on 'equity' as a means of redressing historic and ongoing discrimination within services, systems and processes will not lead to the wholesale change envisaged for the provision of social care support in Scotland. Simply put, more of 'the same' will lead to the same outcomes for individuals and communities currently disadvantaged.

*“A National Care Service will provide us with consistency, equity and fairness, and the accountability needed to deliver high quality services across Scotland.”
(Foreword to Consultation document)*

We would argue that 'equality' as a founding principle within the National Care Service is more appropriate and in keeping with a human rights-based approach.

A Human Rights based approach treats equality as a matter of non-discrimination, whereas in contrast, the General Duty of the Equality Act 2010 - which would be the focus of the statutory equality impact assessment - requires public bodies to consider how they will "advance equality of opportunity". This changes the context of the work from simply ensuring a level playing field to actively addressing the needs of people who experience discrimination on the grounds of their sex, race or disability.

“I feel like I have been treated different from others because I am a Gypsy/Traveller. I have never had any help offered and had to fight for everything.” (Gypsy/Traveller parent carer)

Equity does not have any legal standing whereas equality does.

We would advocate that 'equity' and its' relationship to achieving equality should be clearly set out recognising that it is but one mechanism amongst others to achieve the desired change.

Access to Care and Support

Two key issues were identified by BME carers: the value placed on being able to access community organisations who were able to support them to access social care service; and an overwhelming concern that these services were not universally available across Scotland. BME carers consistently spoke of the positive outcomes they had received as a result of having access to community organisations who were able to advocate for them or assist them to advocate for themselves:

“After [organisation A] closing, we have been blessed to have [organisation B]. All our social care needs depend on [organisation B]. We don't have enough English and have been asking a lot of help from [organisation B] bilingual workers.” (Chinese carer for disabled adult son)

This was particularly notable in ensuring that social care practitioners had a greater understanding of the specific cultural requirements to inform support planning so that the resultant Adult Carer Support Plan was accurate in identifying and determining need and the provision of appropriate services which flowed from this.

“I felt very angry, they weren't taking our lifestyle into perspective, they weren't giving it much thought. Since then I've had a lot of good support from carers and other members of the health team but especially the carers. The carers had more empathy for our way of life and heritage. I felt some of the social workers were looking down on us.” (Gypsy/Traveller parent carer)

In their responses, BME carers also expressed frustration that for many, the process of support planning and the identification of outcomes was a 'paper' exercise given the inappropriateness and inaccessibility of the majority of services available. Self-directed support had done little to address this with carers identifying ongoing problems ranging from the lack of culturally appropriate services within the 'mixed market' to purchase to a reluctance on the part of some local authorities to allow them to employ family members as personal assistants.

Rights to breaks from caring

There was universal consensus amongst BME carer respondents that having access to regular and timely short breaks was a vital support in their caring role. The emphasis was on short breaks that met their specific cultural and linguistic requirements and this was where the biggest gap in available services was identified. Carers spoke of their lack of confidence in having the needs of the cared for person met resulting in a reluctance to take up services and in instances where they had used services, of the detriment in the cared for person's mental and emotional health on their return.

“You could get a wee weekend away. Being a Traveller, my son is different from other kids with the same condition.”

“I was offered respite when my son was seven or eight and he went to a special school. [I] didn’t take it because I didn’t trust anyone to look after my son.”

As a result of this, there was a reliance on specialist services, which by their very nature, were very limited and not universally available across Scotland.

“What the community requires is a bilingual (Cantonese and English) organisation to arrange the trip so that the carers can have a short break once a year.”

Carers were in favour of a universal right to a short break but argued strongly that such a right was only as good as an individual’s ability to exercise that right in a way which met their needs. Many carers spoke of going years without a break or not having access to a short break at all, contributing to further declines in their own health and wellbeing. Carers also requested more flexibility in how short breaks were to be taken, arguing that for them, group breaks with other carers from the same ethnic group were preferred due to language and cultural requirements.

Using data to support care

We would strongly argue that there needs to be a renewed focus on the collection of equalities data within social care. Consistent failures to routinely collect data on the uptake of social care services, including unmet need, have resulted in significant data gaps which have hindered progress in the identification of services required, workforce planning and improvement activities. A recent FOI undertaken by MECOPP to quantify the number of carers’ assessments and Adult Carer Support Plans by local authorities have once again highlighted incomplete or non-existent returns. The absence of robust data has implications across the whole of the social care sector at both local and national level. In order to determine and subsequently ensure that everyone in Scotland who requires social care support is benefitting equally from that support, we urge Ministers to make this a priority.

Complaints and Getting things Right

In addition to the above, a number of additional issues were identified by BME carers. The primary concern expressed by BME carers was for any complaints process to be easily understood, accessible at the point of need and to have access, as a matter of course, to the necessary support mechanisms to enable them to participate fully.

Access to culturally appropriate advocacy was highlighted as a specific requirement. A number of carers noted assumptions made by practitioners that younger family members could assist without recognising that whilst these family members may be fluent in English, they had limited capacity in the first and/or preferred language of their parents.

There was some support for a Charter on Rights and Responsibilities as carers felt that they would be able to refer to this if they felt they were not being listened to but that any Charter must reflect the diversity of Scotland's caring population.

National Care Service

The response to this question was mainly based on how to ensure that all BME carers had equal access to social care services irrespective of where they lived in Scotland. BME carers highlighted that too often, the support they received was dependent upon the availability of other BME community organisations in their area and that the BME support infrastructure was not equally developed across the country. There were also marked disparities in the extent to which different ethnic groups were served by community organisations.

A hope was expressed that a National Care Service might be one way of addressing this imbalance ensuring that all BME carers had equal access to the services they required. From an organisational perspective, in its' individual response, MECOPP has highlighted the potential with the National Care Service to address this issue.

Commissioning of services

We would highlight the potential of more collaborative and ethical commissioning structures and processes to address the longstanding inequalities that BME carers face in accessing social care services. We would argue that the proposed National Commissioning and Procurement Structure of Standards and Processes must explicitly set out how equality considerations will be embedded and driven forward within every component part.

We believe that this is an unmissable opportunity to go beyond the 'identification and mitigation' of unintended consequences or a 'proportional' response and to utilise commissioning and procurement to truly advance equality of opportunity within services (models of care, quality, outcomes, market shaping strategies) and the workforce (workforce planning, fair work, training and development).