

## National Care Service: Call for evidence response

### 1 Introduction

This response has been jointly prepared and submitted by the following National Carer Organisations, collectively referred to within this document as the NCOs: 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 may be supplemented by individual responses submitted by the above organisations.

We welcome the opportunity to submit our views, informed by unpaid carers, to the Committee. Whilst our response has not addressed all the questions posed, we have sought to lay out the discussions we have had with unpaid carers in a way that highlights views on the National Care Service (NCS) and Bill, and areas we feel need strengthened or further articulation.

#### 1.1 Lack of detail

We start by noting that our key criticism of the Bill is that the proposals lack detail, and it is impossible to articulate an informed response on their merits or deficits while they are in an amorphous state. Given the importance of the parliamentary process in scrutinising draft legislation and mitigating against unintended consequences, there are real concerns that the legislation may not deliver its stated aims.

This lack of detail is also hampering local discussion. Many carer representatives on Integrated Joint Boards (IJBs) are reporting that discussions at a local level are being hindered by the lack of detail in the Bill. This is concerning, as there will be a lack of preparation for involvement at local level if IJBs are waiting until regulations are produced.

##### 1.1.1 Lack of detail: ethical commissioning

We note that the Bill contains no definition of 'ethical commissioning' and this should be more clearly defined. In particular ethical commissioning should be seen as an opportunity for local Care Boards to require services to set out how they will meet equality and human rights obligations (as a principle on the face of the Bill) and also consider social/community investment. While this has relevance across all areas, it is of particular note for the successful delivery of a Right to a Break from caring.

### 2 Support for a National Care Service

Throughout the review of adult social care and the consultation on a national care service, unpaid carers have been emphatic that something must change and that the current system is not working. This reflects not only the experience of unpaid carers throughout the pandemic, including the

current challenges they face, but their experiences over many years. Unpaid carers felt that the pandemic had shone a light on issues with social care that were long-standing, and often ignored.

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*“We need it – proved over last 18 months.”*

*“Some councils are terrible and are so inept they can cause harm and unduly dismiss family unpaid carers.”*

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In September and October 2021, NCO partners held a series of engagement events with adult unpaid carers and hosted a survey and online polls. We have also held further discussions with unpaid carers including on the Bill itself. The majority of unpaid carers<sup>1</sup> voiced their support for the development of the national care service. Over half (52%) supported the responsibility for social care transferring to Scottish Ministers.

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

The predominant reason for supporting this shift was the perceived failures in the current system and a call for a radical shift in the way social care is resourced valued, alongside the desire improved processes, services, and pathways to support.

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*“I support a National Care Service because my local authority has failed me and no-one is willing to accept accountability”*

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Notwithstanding the overall support for a national care service and fundamental change in the delivery of social care, we remain concerned that the Scottish Government's proposals are too focused on structures and processes and not human rights and enabling people to live their best lives.

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*“The Bill focuses on structures; how can we know how this will deliver real change?”*

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<sup>1</sup> For example, over 90% of carers at the Carers Parliament in October 2021 supported the establishment of a national care service

We would further argue that whilst the focus of the realisation of human rights is paramount to enabling individuals to live their best life, much more weight needs to be given to the enactment of Equalities legislation as the primary level for supporting people with protected characteristics. A human rights-based approach treats equality as a matter of non-discrimination, whereas in contrast, the General Duty of the Equality Act 2010 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. It is our contention that the National Care Service will not lead to transformational change without acknowledging and addressing the existing structural and systemic barriers that actively disadvantage people with one or more protected characteristics. The progression of equality and human rights within the National Care Service must go hand in hand.

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*"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)*

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## **2.1 National care service terminology**

Social care is about people who need care *and support* to live independently or to have a life outside of caring. Carers have told us that this distinction is important because often people don't need what might traditionally be called 'care' but they do need support and that can include a range of services and people. Based on what carers have told us, it would perhaps be more accurate to call this a National Care and Support service.

## **2.2 Young carer support for a national care service**

In autumn 2021, we held engagement events with young carers and undertook a survey and online polling. The majority of young carers that participated supported the development of a National Care Service. Young people can see the potential for a National Care Service to improve the support available both to unpaid carers of all ages, 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 models differ across Scotland's local authorities. Young carers expressed their view that a National Care Service could have a role in standardising the support available, ensuring high-quality provision regardless of location.

Young carer respondents also told us that 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.

### **2.3 BME carer support for a national care service**

We note from our consultation activities with BME carers, inclusive of Gypsy/Traveller carers, that whilst there was majority support for a National Care Service, this was partly motivated by the failure of local authorities to date to recognise and respond appropriately to their specific needs. Evidence of this lack of progress was evident in the findings of a recent internal review undertaken by MECOPP of local authority Carer Strategies and Action Plans to identify whether they contained any strategic action, outcome and measure aimed at BME carers. Of the 27 documents we could locate on local authority websites, 15 contained a statement of values or principles setting out their commitment to equality, diversity and human rights. Of these 15, only 7 contained specific strategic outcomes underpinned by actions and measures in the main limited to: information gathering, accessible information and training/resources for practitioners.

Respondents indicated that stronger leadership and direction from National Government was necessary to change the status quo. Whilst we actively welcome the commitment within the principles of the Bill to “advance equality and non-discrimination” we would argue that there is insufficient detail to see how this will transpire in practice.

### **2.4 Balancing local and national responsibility and accountability**

The results of our consultation work showed that of those carers who did not support the transfer of responsibilities to Scottish Ministers, or who were unsure (43%), the most common reason was a preference for retaining local accountability and a concern that a national service would not reflect local needs.

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*“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.”*

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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.

### **2.5 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, including young 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.
- A human rights-based approach must be underpinned by a targeted focus on improving equality. The relationship between the two must be made explicit. There must also be greater recognition that each of the constituent parts of the National Care Service have a role to play and a duty to promote and achieve equality for people with one or more protected characteristics.
- Require Care Boards to set equality outcomes to be monitored and accountable to the National Body

### 3 Translating principles and codesigning real change

Whilst we welcome the fact that the principles are set out on the face of the Bill and, importantly, that it is clearly articulated by the Scottish Government that this is an investment in society, it is not yet clear how this will be translated into action.

There are already examples of good legislation, such as the Social Care (Self-Directed Support) Scotland Act 2013 and supporting strategies, which have failed to deliver on their intention. The reality for unpaid carers is that, when they come up against bureaucracy, rationing, lack of trust and an unwillingness to cede control, they are too often on the losing side; left exhausted, demoralised and with unsustainable caring responsibilities.

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*“If Scottish Government took responsibility away from local authorities, would that make any real difference to us as carers, or would it merely be another level of bureaucracy for us to tackle? I get exhausted at times trying to get folk to really listen to what I am saying or asking!”*

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From the outset, every decision nationally and locally must be measured against how it will ‘contribute to the realisation of human rights’, how it will ‘enable people to thrive and reach their potential’ and how it will ‘enable communities to flourish and prosper’. This includes setting out and addressing existing inequalities within the social care sector to ensure that all those who require support receive the support that is right for them. True choice and control for individuals and their unpaid carers, trust, eliminating bureaucracy and giving more autonomy to frontline workers will be key elements of making this happen – but this will not happen simply by creating a new structure.

Moreover, to realise the principles, the full involvement of unpaid carers and people who use services **as equal partners** in the codesign of the national care service is a pre-requisite for improving social care and we welcome the initial commitment by the Scottish Government on co-design. This must extend to all aspects including equal involvement in local care boards. We cover this in more detail in 4, Unpaid carers as equal partners in care, however it is important to highlight in the context of co-design that unpaid carers have raised concerns about how stakeholders' contributions be weighted.

Individual representatives often feel that their views are not given the same standing as that of larger organisations and public sector representatives. Managing competing interests and ensuring that people who use services and their unpaid carers are heard equally and their views and experiences given the weight they deserve will be a key measure of successful codesign. Consideration must also be given to how young carers are represented and heard through co-design processes and through unpaid carer representation.

Concerted and explicit efforts are also required to ensure those who are 'distant' from services as they are currently planned, commissioned and delivered have a voice. As a starting point, we would argue that the Equality Impact Assessment process should be much more robust and, as a minimum, be much more inclusive of equality organisations.

It is also important to note that, whilst welcoming a greater drive towards integration, given the proposed relationship between the NHS and the National Care Service nationally, the National Care Service must not follow inadvertently the medical model but must ensure that it not only has the stated principles as its heart but delivers them.

***To deliver this fundamental change in provision and in principles, we are keen to reiterate our position and that of carers that the majority of funding must be directed to frontline services and support. It is vital that the funding available is used to its best effect and does not end up swallowed up in bureaucratic structural change.***

### 3.1 Children's Services: preventing detriment

As recognised with the policy memorandum, the proposed scope of the National Care Service is very broad and goes far beyond the remit and recommendations of the Independent Review of Adult Social Care (Feeley report), and beyond what is delegated consistently to Integration Authorities. We therefore welcome the intention to gather further evidence before transferring children and justice social work services and reiterate that we believe consideration should be given to developing the National Care Service on an incremental basis. However, we would note that consideration is needed on the key aspects of ensuring that young carers and parent carers do not face detriment from this decision – either individually or in the quantum of funding available for the services that support children and young people. At a minimum, early attention should be paid in particular to how local Care Boards and local authority children's services can be funded and guided to work together to:

- improve work during transitions between child and adult services.
- expand accessible childcare and activity services to support parent carers.
- expand support for young carers in school, communities and for their mental health.

## 4 Unpaid carers as equal partners in care

Unpaid carers have expressed concern that the Bill does not explicitly mention the role that unpaid carers will play in the design and delivery of the National Care Service. While we understand that this is a framework bill and there will be more details provided in regulations and guidance, the role of statutory stakeholders is mentioned throughout the Bill, leading unpaid carers to the conclusion that they will still not be viewed as equal partners in the new structures.

Unpaid carers have expressed the following views in relation to their role as equal partners in care in the design of the National Care Service:

- Unpaid carer involvement in local and national strategic planning has shown some improvement, but remains an area which requires greater investment is required. In particular this investment is needed to support unpaid carers from harder to reach communities in order to better represent the diversity of the unpaid carer population.
- Support has been expressed for the role of an equality and diversity champion or lead both on the National Care Service Board and on local Care Boards. This would strengthen accountability and, if properly integrated within work streams, could support the setting of equality outcomes (as suggested in our submission) and reporting.
- They welcome the principle that ‘Services provided by the National Care Service are to be designed collaboratively with the people to whom they are provided and their unpaid carers’ but note that this requires investment to ensure equity and enable all unpaid carers to have the opportunity to contribute.
- Many unpaid carers have expressed the view that unpaid carers must be full members of the local Care Boards and the National Care Service Board, with voting rights. This should be included on the face of the Bill.
- We understand that the process for the appointment of members to Care Boards may take a public appointment approach. This is concerning as our report Equal, Expert and Valued shows that Integrated Joint Boards (IJBs) already struggle to appoint unpaid carers, so making this a more challenging process will have an impact on unpaid carer involvement. *‘We presently lack proper representation of member of the public on boards. This may result in further problems as people won’t want to go through the process’.*
- If the codesign process is how key decisions will be made this has to be robust and transparent and allow equal involvement of unpaid carers. The right people need to be around the table and there needs to be a true balance of power, where unpaid carers and members of the public have an equal say. Consideration must also be given to how young carers are represented and heard through co-design processes and through unpaid carer representation.
- As well as unpaid carers being represented at Board level, there needs to be more accessible opportunities for unpaid carers to become involved in the design of the National Care Service. Due to intense caring roles, many do not have the time, energy, resources, and access to replacement care to attend meetings. For example, social media should also be used as a route to engage unpaid carers in a more accessible way.
- The Bill allows for Care Board members to receive recompense for their involvement. We welcome this development. Many unpaid carer representatives on IJBs undertake the equivalent of a full-time job, with no financial payment. In fact, many have to subsidise this role as they don’t receive full expenses such as replacement care, or they lose out on earned income when they attend meetings. A poll was held at the Carers Parliament in 2021 asking about this issue and the following responses were received.

***Recompense for involvement: 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, to ensure it would not have negative financial consequences for those in receipt of social security benefits. We also believe that the role and remit of unpaid carer representatives in these circumstances should be clearly defined, so that although they may receive a payment, this should not conflict with their role. They should not be restricted from representing the views and needs of local caring communities without censure as a result of receiving a payment or remuneration.

#### 4.1 Recommendations from the Equal, expert and valued report and conclusions

Strengthening unpaid carer involvement must be an early priority if unpaid carers are to equal and expert partners in both the design and delivery of the National Care Service.

The Carers Collaborative Forum for unpaid carer representatives on IJBs was established six years ago and has produced four scoping reports looking at the experience of unpaid carer reps on IJBs, making recommendations for strengthening carer engagement and involvement in health and social care. The latest report was published in April 2022 [and can be downloaded here](#).

The key recommendations from the report are:

- An investment needs to be made in the recruitment and retention of unpaid carer representatives.
- Succession planning needs to be put in place in all areas.
- Support needs to be put in place for unpaid carer representatives, including induction, training, mentoring and a buddying system for new reps.
- In most areas there are only one or two unpaid carers who are the 'Go-To' people and who are undertaking the equivalent of a full-time role. The development of the National Care Service is placing even more pressure on them and this is not sustainable.
- It was noted by the Carers Collaborative that there is a lack of diversity and inclusion in relation to unpaid carer representatives. Representatives are often middle class, white professional, often male. One unpaid carer commented "*People recruit the people who are like them.*" There is less representation from working carers, unpaid carers from harder to reach communities, such as BME unpaid carers and unpaid carers from areas of multiple deprivation.
- Not all areas have an expenses policy for unpaid carer representatives and those that do, do not always include full costs, such as replacement care, or the costs of printing. The Carers Collaborative have produced a best practice expenses policy and this should be adopted nationally to provide greater consistency and ensure no unpaid carer is out of pocket.
- Over many years unpaid carer representatives have reported that they have less involvement in financial planning and commissioning. It was noted from an unpaid carer representative in one area that they were "*kept well away from procurement*". If unpaid carers are to be viewed as equal partners in care in the new structures they must have equal status in decision making and agenda setting, particularly in relation to budgetary

decisions. As one unpaid carer remarked *“it feels there is an irritation with lay members”*. Another said *“Involvement comes and goes depending on the urgency of budget cuts”*.

- Consideration must be given to allow young carers to meaningfully participate in local planning. This involvement must be age appropriate, at times that doesn't impact on their education and delivered through engaging methods.

## 5 Transitioning from Integrated Joint Boards to Care Boards

We held two meetings with the Carers Collaborative forum for unpaid carer representatives on IJBs to discuss the Bill. Much of the discussion focused on the establishment of Care Boards and what this will mean to the current structures, including IJBs.

The carer representatives were frustrated by the lack of detail regarding IJBs and the transition to Care Boards. It does not explicitly state that Care Boards will replace IJBs, although this is clearly the intention and there is no information on the transition period, including timescales, transfer of functions and membership. For example, will the carer representatives on IJBs transfer to become members of the Care Boards? This uncertainty and anticipated additional workload has added further pressure to the role and, as a result, some unpaid carers are considering stepping down.

The unpaid carer representatives had the following questions and conclusions in relation to the establishment of Care Boards:

- What powers and duties, relating to social work and care will be retained by Health and Social Care Partnerships and local authorities, and how will the new structures impact their service provider role?
- What will happen to IJB membership? Will unpaid carer representatives transition or will there be a new recruitment process? How will young carers be engaged and heard?
- Given the current challenges in relation to the recruitment and retention of unpaid carer representatives, there is potential for this to leave a further deficit and the loss of unpaid carers with a great deal of experience and expertise.
- A common concern from carers has been balancing national consistency and local responsiveness. What will the process and scope be for local decision-making and responsiveness?
- There are challenges for some rural areas in terms of boundaries for the new Care Boards. For example, in Argyll some services provided by Greater Glasgow, as well as NHS Highland.
- The Bill states that Care Boards and the NCS must consult on their Strategic plans, however there is no specific mention of unpaid carers. Unpaid carers expressed a preference for this to be included on the face of the Bill, rather than in regulations
- The Bill does not mention how housing will fit into the National Care Service plans. Will local care boards include representation from housing services? The lack of suitable housing is a huge barrier to independent living for many older and disabled people. If local care boards don't work in partnership with housing, these issues will not be addressed.

We also reiterate our call for meaningful consideration to be given to the role of an equality and diversity champion or lead within each local Care Board to ensure the views of marginalised communities are actively sought and acted upon.

## 6 Eligibility criteria and assessment

### 6.1 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 unpaid 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' 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.

Our evidence shows us that there is a great deal of cynicism about assessments and adult carer support plans amongst BAME carers, inclusive of Gypsy/Travellers as very often, conversations do not lead to the provision of services. We would argue that there needs to be a renewed focus on the outcomes of assessments/conversations being used to inform future commissioning processes.

We welcome the introduction of a right to breaks from caring and the removal of eligibility criteria in relation to providing unpaid carers with 'sufficient' breaks. With the removal of eligibility criteria, having a meaningful conversation with unpaid carers, rather than a focus on the assessment process will be even more essential to prevent Adult Carer Support Plans and Young Carer Statements being used as a gatekeeping or rationing device to manage resources, as an alternative to eligibility criteria

### 6.2 Eligibility criteria

In terms of the reform or removal of eligibility criteria, the government has not made their intentions clear. The Feeley report (Independent Review of Adult Social Care) included as one of its recommendations that:

*“ People must be able to access support at the point they feel they need it, including for advice and signposting to local community-based resources and help, and for barriers to this, such as the current eligibility criteria and charging regime, to be fundamentally reformed and removed, to allow a greater emphasis on prevention and early intervention”*

In their consultation on the National Care Service in 2021 the government committed to the following:

*“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.”*

We asked unpaid carers if they agreed with the Scottish Government’s proposals for eligibility criteria and they responded as follows

Yes	No	Don’t Know
29%		71%

The majority at 71% said they don’t know, which perhaps reflects the opaque nature of the government’s position. They have not included any further reference to eligibility criteria in the Bill and have not specified what they mean by ‘removing eligibility criteria in their current form’.

It is our view the use of eligibility criteria is not consistent with a human rights based approach. Eligibility criteria is used as a form of gatekeeping: it promotes a deficit model, which undermines the principles of independent living and preventative support and is a significant factor in people ending up in crisis. We support the position put forward by the Independent Review of Adult Social Care that eligibility criteria should be removed.

We are part of a collaborative project involving multiple stakeholders who are looking at alternatives to eligibility criteria. Over 100 stakeholders met in June 2022, with representatives including unpaid carers, supported people, front-line social workers, third sector organisations and policy makers. Participants heard from a range of speakers who have taken a different approach to eligibility criteria, both in Scotland and other parts of the UK. One of the conclusions from this project was the need for carefully constructed tests of change to enable comparisons to be made, while opening possibilities for change in a managed way, within a learning system approach.

### 6.3 Eligibility and 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 Adult Carer Support Plans/Young Carer Statements should be retained and built on. The government should consider devolving responsibility to the third sector for other forms of support planning.
- We welcome the removal of eligibility criteria for short breaks. The process for support planning in relation to 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. Support planning must not be used as a method of gatekeeping or rationing resources.
- 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 -such as example from eligibility meeting – test of change.
- Meaningful support planning and the identification of personal outcomes does not, and cannot, exist in isolation from what is available locally to support BME unpaid carers and unpaid carers more generally. The two are inextricably interlinked. There needs to be greater recognition that BAME carers and carers with other protected characteristics may prefer different forms of support, which may be unfamiliar to practitioners, but which should not influence their decision making.

## 7 Complaints

Whilst we welcome the Scottish Government's intention to seek to improve the complaints procedure, it is hard to see how much different this system would be once a complaint is passed to the relevant person. Whilst it is important to make the system as smooth as possible, unpaid carers have said that the current system lacks both trust and transparency and leaves them with issues unresolved. To bring about a trusted complaints procedure, we recommend a new complaints process should be developed to enable complaints to be assessed against the principles of the National Care Service Bill.

- Has the decision/issue negatively impacted about the realisation of human rights for the individual or their unpaid carer?
- Has the decision resulted in a detriment to carers with one or more protected characteristics?
- Has the decision/issue impacted upon an individual or their carer's ability to thrive and/or reach their potential?

This includes individuals and their unpaid carers having the ability to complain about the allocation of social care resources, how any assessment of eligibility is decided upon and whether they have been able to have the choice and control they wish over how their needs and outcomes are met. The SPSO, as we presume the final arbiter of individual complaints, should be able to review such decisions and instruct further work to be undertaken to provide a suitable resolution.

We accept and understand the role of professional judgement but too often unpaid carers are mystified and indeed frustrated by decisions that appear to align with neither assessments and guidance nor in enabling people to have choice and control over what best meets their needs and outcomes.

We also feel that it is appropriate for the key elements of whether decisions impact upon the realisation of human rights, ability to thrive or reaching potential to be extended to both the NCS and NHS complaints processes. Equally, consideration should be given to providing the same principles framework and one door approach for complaints about commissioned services (local or national) in the third and independent sector service. Although there may be a different body that undertakes investigation such as the Care Inspectorate, the SPSO should have oversight of the resolution provided.

Finally, the SPSO should identify where themes of complaints emerge and undertake investigations of these themes. It is important to proactively act to resolve problems that are impacting on the realisation of the human rights.

To support the development of a trusted complaints system, we would also like to see consideration of a statutory entitlement to advocacy services and a review of timescales in which complaints can be submitted.

## 8 Data and integrated record keeping

We welcome proposal to improve data quality, establish consistent standards and consider the development of a single electronic health and care record.

We have made some broad recommendations on this within the recent Data Strategy for Health and Social Care which we believe would be relevant to the proposals within the Bill.

In the first instances, there is an assumption that shared record keeping will only be between the local authority and health staff. There is need for developing shared data across the relevant public, third and independent sectors and indeed with community providers. There are often more providers outside the public sector than within it and in order to have a full understanding of provision and gaps, workforce and investment planning, and importantly of impact on achieving the principles of the Bill, this wider pool is needed.

### **8.1 Data and integrated record keeping: BAME carers**

We are aware that Scottish Government is currently consulting on its Equality Evidence Strategy 2023–2025, that this is directly relevant to improving data collection to inform the development and implementation of the constituent parts of the National Care Service and would strongly advocate that Public Bodies be supported to improve data collection across all protected characteristics.

For example, we note from the accompanying Equalities Impact Assessment that continual reference is made to the limitations of data which prevent any conclusions being drawn on the use of health and social care services by ethnic minority groups. Public bodies are required to collect equalities monitoring data as part of the General Equality Duty. Guidance produced by the Equality and Human Rights Commission explicitly states that “having due regard to the aims of the General Equality Duty requires....an adequate evidence base for ... decision-making”. The lack of robust data will severely compromise decision-making processes going forward.

### **8.2 Single electronic health and care records**

It is important that, from development, that health and care records should belong to the individual, and they should:

- have full access to their own health and social care records with a mechanism for providing summary data for ease of access.
- be able to update their own records, for example, to add information about changes or increased needs.
- be able to set informed limits on who can access their records and what information can be shared. This could include providing independent advocacy and ad.

Any system should be able to provide translated records for those whose first language is not English and consider how it provides data in a way that is easily accessible for people who have, for example, a learning disability or who have difficulties with literacy.

### **8.3 Accessibility for unpaid carers**

In developing such a record it is also vital that there is recognition of the need for information to be provided to and from unpaid carer. This enables unpaid carers, as key partners in the provision of health and social care services, to be able to provide the right support to the person they care for and receive and provide relevant information to paid health and social care staff.

Suitable safeguards must be in place, including where an individual is unable to provide consent. Where an individual is unable to give consent and a power of attorney or guardianship is not in

place, there should be a clear process for enabling the sharing of relevant information and for unpaid carers to provide information.

Where consent is not given or where consent is given to sharing only certain information, it is worth considering the development of a summary health and care record similar to that which ambulance or out of hours staff can currently access to enable individuals providing care to be able to access information that is relevant to the provision of care - for example, medication and side effects, what services will be provided etc.

At a minimum, carers should be able to share information with those who provide health and care support.

## 9 Right to a break from caring

The National Carer Organisations in Scotland welcome the inclusion of the Right to Break within the National Care Service. This new right represents a huge step forward in recognition of the importance of regular breaks in supporting Scotland's unpaid carers to have a life outside of caring and good health and well-being.

Our response has been influenced by the evidence we have drawn from initial consultation events on the National Care Service and by wider research into breaks from caring. We have also taken into consideration our response to the initial consultation on the National Care Service in which we outlined certain conditions that we see as necessary to ensure a right to a break will make a meaningful difference. These can be summarised as:

- A more developed market in short breaks provision that offers greater choice and flexibility and is sensitive and responsive locally to considerations such as geography, age of population and support needs. This also covers the role of community development, mainstream leisure providers, and volunteering in supporting the expansion of universally available breaks.
- Unpaid carers having confidence in the quality and availability of replacement care when it is required.
- Adequate provision of what is often regarded as the more expensive or difficult options such as overnight or weekend respite.
- An understanding that the break must be delivered sensitively and in a person-centred way that benefits both the unpaid carer and cared-for person without adding to stress.
- Much simpler and clearer access to breaks, including making assessments to access breaks less time-consuming and intrusive.
- An embedded human right based approach, with equalities and diversity at the heart of decision-making and implementation.

We have restated these points here in the belief that they are fundamental to a Bill which will successfully deliver a Right to a Break from caring. Some aspects of these have been addressed within the Bill however there are others where we feel meeting these conditions will be more challenging with the current provisions, or it is unclear how they will be met. We cover these points below.

It is also important to emphasise that while research consistently tells us that having access to planned, regular good-quality breaks is vital to unpaid carers' health, and there is an existing duty on local authorities to consider them as part of an Adult Carer Support Plan, only a small proportion of unpaid carers receive regular and meaningful breaks from their caring role. According to government data as few as 3% of unpaid carers currently receive support for breaks from caring and there is significant variation in the availability of breaks, and unpaid carers' experience will be different due to a variety of factors, including where they live.

### 9.1 Right to a break: Young carers

Young carers were asked their views about a Right to Breaks during this summer's Scottish Young Carers Festival. They voiced that a Right to Breaks needs to be fully resourced and a range of age appropriate short break services must be available that meets their varied needs to ensure this right is implemented and upheld:

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*"There is never enough funding or breaks. No respite – I've been laughed at from social workers for suggesting I need respite" Young Carer, Scottish Young Carers Festival, 2022.*

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Young carers have repeatedly told us that it is important that they get regular breaks from caring. 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:

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*"It helps us in so many ways not just our mental health it helps physically, speaking to new people, making fun, being in the outdoors, having not to panic every two minutes, no cares, no worries, no one to judge us or to even be so not free, we can just be ourselves and just be free that's a small word but big difference" Young Carer, Scottish Young Carers Festival, 2022.*

*"It allows me to relax and have time to myself meaning I can sleep and just generally function better" Young Carer, Scottish Young Carers Festival, 2022.*

*“If I could have time from my role it would be great to go and meet friends without worrying and maybe do some sports” Young Carer, Scottish Young Carers Festival, 2022.*

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Opportunities for breaks are important to all unpaid carers, including young carers. It is important to young people that 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:

*“I want to spend more time 1:1 with my mum and dad ... 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.” Young Carer, Survey 2021.*

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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 unpaid carers. All unpaid carers, including young carers, should have regular access to personalised short breaks which meet their needs. The process for young carers accessing short breaks must be simple, consistent and fair. There needs to be flexibility on how short break budgets are used to meet the diverse needs of young carers.

## 9.2 Right to a break: Framework approach

We welcome the greater level of detail which is contained within the Right to A Break section of the National Care Service Bill, however, the framework approach used throughout the Bill makes it difficult to assess the potential effectiveness of the legislation as a whole, because of the omission of key detail on specific issues.

For a right to breaks from caring this causes particular challenges in respect of the approach to workforce development, fair work, and ethical commissioning. Each of these components has a crucial role in developing and delivering a sustainable short breaks infrastructure on which the new Right to a Break is entirely contingent.

For BAME carers and carers with other protected characteristics, the right to a break is only as good as their ability to exercise that right. The points raised above – workforce development, fair work and ethical commissioning – are paramount from both an equalities and human rights perspective in supporting carers who are currently excluded for a variety of reasons from mainstream provision.

### **9.3 Right to a Break: Workforce development**

A [recent report by the Equality and Human Rights Commission](#) and a supplementary Policy Paper (Scotland specific) highlights the following on the treatment and experience of BME workers in the health and social care sector:

- incomplete data on lower-paid ethnic minority workers, particularly in adult social care
- different treatment and experiences at work
- commissioning and outsourcing leading to poor pay and insecure work
- low awareness of employment rights
- fear of raising concerns and a lack of mechanisms to do so

Having previously alluded to systemic inequalities within health and social care in our submission, the development of the National Care Service and the wider reform agenda in Scotland provides an opportunity to address the above.

### **9.4 Right to a break: Human rights based approach**

The Independent Review of Adult Social Care was unequivocal in the need to take a human rights based approach, and while we recognise that this is partly included in the Bill we would like to see a stronger commitment to human rights throughout the Bill and particularly around the sections on unpaid carers.

We believe there are opportunities throughout the Bill to define more specifically what human rights apply and where they are built in, rather than as a vague guiding principle. The lack of specificity on human rights does not serve rights holders well, as it gives little opportunity for scrutiny, accountability, and redress when things go wrong.

We also feel that with potential changes to the Human Rights Act and the Bill of Rights, it is crucial that this is explicit within the Bill.

### **9.5 Terminology**

#### **9.5.1 Sufficient**

One area where the application of human rights should be more clearly defined is the use of the term 'sufficient' as it relates to the right to breaks from caring. (Part 3, Section 2(1) of the Bill).

The lack of definition gives us cause for concern as, with the removal of the application of eligibility criteria on breaks from caring, the term 'sufficient' is pivotal to how this right will be experienced by unpaid carers. As a key standard in the Bill, it is vital that 'sufficient' is clearly defined within the legislation and we would like to see a great deal more detail on this within the regulations.

We believe that clearly defining 'sufficient' strengthens the position of rights holders, gives a level of accountability and scrutiny to the term. We also believe that a failure to define 'sufficient' would disproportionately impact on carers with one or more protected characteristics who are currently and significantly underserved by existing short breaks provision.

We would like to see changes made to link sufficiency to Articles 24 of the International Declaration of Human Rights, and acknowledgement of the link to the Right to Health. For example "sufficient breaks to enable them to realise their human right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay."

We would also like to see reference to the fact that the UN Committee on Economic Social and Cultural Rights has stated that health is a fundamental human right indispensable for the exercise of other human rights. We know that having access to regular breaks from caring is a key to unpaid carers being able to look after their own health and well-being, and linking the right to a break to these standards reduces ambiguity, increases measurability and firmly places it within a human rights framework.

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*"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." NCO Right to a Break Survey 2021*

*"The break allowed me not only to relax physically but I also recognised that I was able to take a rest and that it was important to do so when I needed it" "It has also been a comfort knowing that there are people able to help and that I am not alone" – Jennifer, a carer who accessed a Time to Live grant*

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There also needs to be clarity on what "sufficient breaks" means specifically for young carers and a person-centred approach adopted to meet the individual needs of young carers.

### 9.5.2 Providing care

Section 38 2, 1 of the Bill makes reference to "the outcome that the adult carer is able to take sufficient breaks from providing care for the cared-for person." We are concerned that by using this definition of 'sufficient breaks from providing care', the terminology may exclude the possibility of the carer and cared-for person having a break from routine together.

With reference to the Carers Act Statutory Guidance Annex C, we would again like to see the inclusion of the Short Breaks definition produced by Shared Care Scotland and particularly would reference Part 3 that a break from caring may 'take the form of the carer and the person they care for having a break together, with assistance if necessary, providing a break from the demands of their daily caring routines.

This point is particularly relevant to BAME carers on two counts: the lack of appropriate and accessible replacement care as a significant barrier to enabling carers to have a break; and, a preference to take breaks with the person they are caring for.

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*"Before the break, I was very tired and run down. Being told about the break had me looking forward to something...The hotel itself and the staff plus good food all made for a relaxing time. It felt as though you left all your worries behind for that one night and just chill. Even though I took my husband who I care for with me, we both relaxed." – Carer on Respite break at Crieff Hydro.*

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## 9.6 Eligibility criteria

The removal of the application of eligibility criteria to the duty to provide breaks from caring is a very welcome inclusion in the Bill. However, in addition to our recommendations on the definition of sufficient, we would also like to highlight the potential for unintended consequences to derail the effective delivery of the Right to Break, particularly for those who have a higher level of need.

Resources are finite and – even with significant and sustained investment – it is likely that demand will continue to outstrip supply. We will refer to this in more detail in Section 9.7, Short breaks infrastructure however, it is important to address the potential bottleneck or ‘rationing’ of services that could be put in place through an assessment process which largely remains the same.

If the means to access more personalised, high levels of breaks, such as replacement care, is through the production of an Adult Carer Support Plan or Young Carers Statement, then unpaid carers could be subject to lengthy waiting lists which are applied as a means of managing demand.

We are also concerned that finite resources may be used as an excuse not to invest in additional services which support BAME carers and carers with other protected characteristics.

## 9.7 Right to a Break: Hybrid model

The initial National Care Service consultation made specific reference to a hybrid model of delivery for the Right to a Break from caring. This was suggested to be made up of a guaranteed flat rate of entitlement coupled with enhanced provision for those who had more significant needs, met through an assessment.

The Bill as it is set out does not meet this hybrid model and there needs to be greater clarity on the Government’s intention around ‘easy access’ and how they can be guaranteed. As it stands, the easy access breaks will be scaled up as part of the increased investment in the voluntary Short Breaks Fund, rather than a statutory provision. While this is not in itself problematic, it is not clear if ‘easy access’ breaks can be guaranteed for every unpaid carer who needs one, and, as these fall outwith the statutory sector, there is no provision for how this will be contested if an unpaid carer is refused a break. The position and intention on easy access breaks therefore needs to be much more strongly identified.

Scrutiny of the financial memorandum as carried out by Social Work Scotland identifies a shortfall in the figures allocated to this and therefore it is difficult to see how a Right to a Break on an easy access break could be guaranteed as it would inevitably be subject to funding and demand.

This potentially places the delivery partner within the voluntary sector – currently Carers Centres – within the position of gatekeeper. Our routine meetings with the Centre Manager’s Network have consistently highlighted that carers centres are operating at the limits of, or beyond, their capacity and further investment in staff and infrastructure would be required if this role was to further expand.

## **9.8 Short breaks infrastructure**

### **9.8.1 Variety and sufficiency**

The Independent Review of Adult Social Care stated that a range of options for short breaks and respite should be developed and the Bill makes an inclusion within the Carers Act under development of local carers strategy that there must be “plans to promote a variety of providers of support to relevant carers and to promote the variety of support provided.”

The promotion of options is also referenced in the Carers Act in relation to Self Directed Support.

While variety is without doubt vitally important to ensuring unpaid carers can access the type of break that is right for them and the person they care for, having provisions for a variety of short break services does not address the crucial fact that there are not *enough* short break services to meet the level of needs: and by this we mean both enough services, but also enough capacity within existing services. Concerns about the lack of availability of short breaks were raised repeatedly during the National Care Service engagement events and in survey responses. This is supported by Scottish Government figures themselves which demonstrate that only 3% of carers are accessing short breaks through statutory support.

We feel it is important to highlight that whilst a pre-existing lack of variety and sufficiency impacts on all carers, some groups of carers, i.e. those with one or more protected characteristics are disproportionately impacted. There is little to suggest in the Bill that current providers will be encouraged to develop a range of provision for carers with protected characteristics and we would therefore advocate that more active consideration be given to micro-commissioning as a key plank within guidance and regulations.

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*“As part of its focus on improving support for unpaid carers, the National Care Service should also increase investment in a range of respite provision including options for non-residential respite, and for short breaks.”*

*- The Independent Review of Adult Social Care*

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We are concerned that much of the focus of the Bill is on developing variety, however we would like to see both variety and sufficiency included with clearer parameters on how the development of a

short breaks infrastructure will be supported. Without this it will be impossible for carers to fully realise their right to a break.

Carers and the people they support want the opportunity to participate in community life in a way that is supportive and accessible. This must be considered in the context of community planning and development, access to leisure and the skill set for volunteers and volunteering roles.

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*“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.”*

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There are clear comparisons that can be made with the extension of childcare provision within Scotland and the sustained investment that this required in order to meet the level of need.

The Early Education and Childcare Expansion policy states:

*Local authorities are responsible for ensuring that funded entitlement is available for all eligible children in their area. We are supporting them to build the capacity needed in their communities to phase in extended entitlement. We have a multi-year capital and revenue funding agreement in place with the Convention of Scottish Local Authorities (COSLA) which is fully funding the expansion*

While we welcome and recognise the upscaling of short breaks through existing powers, as detailed in the Financial Memorandum, increased investment in the Short Breaks Fund does not, in itself, address the need to invest in capacity building.

There are clear links between the upscaling of short breaks and respite services and ethical commissioning, and workforce development, however owing to the framework nature of these sections of the Bill it is difficult to gain perspective on how this will work in practice.

### 9.8.2 Pre-pandemic levels

It is important to note in any discussion on short breaks infrastructure, the significant impact that the COVID-19 pandemic had on short break services and their capacity.

We understand that a recent Scottish Government survey through COSLA indicated that less than 50% of adult day services are open at pre-pandemic levels. It also showed that 12% remain closed. Pre-pandemic levels of provision did not fully meet the short breaks and respite needs of cared-for people in Scotland and their unpaid carers. Prior to the implementation of a right to short breaks and respite we would like to see a thorough review of the capacity, viability and sustainability of the short breaks and respite sector: giving a comprehensive understanding of where gaps are, where

investment is needed, and where need is not being met, in order that investment in infrastructure can be prioritised accordingly.

### **9.9 Right to a break: data challenges**

As detailed above, the lack of comprehensive data on short breaks infrastructure makes it difficult to understand how a right to respite will be experienced by carers.

It is important to note our concerns with the data used throughout the Bill and the Financial Memorandum and the heavy caveats that apply. Our concerns can be summarised as follows:

Much of the data is based on pre-pandemic levels of service. In many cases these have not resumed so the baseline measurement that is being used is higher than reality;

The estimated costing on short breaks in the financial memorandum is based on historic figures and does not account for current inflationary pressures. With this escalating and continued unpredictability the current figures included in the Bill look increasingly unlikely to meet the levels of need.

We endorse the work of Social Work Scotland in scrutinising the financial memorandum and highlight that the implied intention is to increase the percentage of those accessing statutory support from 3% to circa 26%. This requires greater clarity as 26% is far removed from a universal right.

We have concerns that these figures are also based on funding allocated as part of the Carers Act, but which in many cases was not spent locally on improving carer support. A Freedom of Information request to local authorities in the first year of the Carers Act found a shortfall of over £5million from the £19.4million allocated to implement the Act. We know that in subsequent years there has continued to be a shortfall in the funding allocated directly to support carers from this resource, although information on this is incomplete

### **9.10 Right to a break: costs**

Many of our concerns regarding the costs of the Right to a Break have been touched upon in earlier sections however we feel it is useful to summarise this in this section:

The paucity of data and accurate information on the current picture of short breaks and respite provision across Scotland makes it difficult to make accurate predictions on the scale and nature of investment required, and therefore to predict accurate costs;

Many of the assumptions in the Financial Memorandum are based on old datasets. This applies across the range of figures including the number of adult carers which is estimated to have increased from the figures that were used within the Bill and the financial memorandum.

This also applies to young carers. The financial memorandum for the Bill has used an estimation of 30,000 young carers in Scotland, with the Scottish Health Survey as the only source. This figure is generally regarded as an underestimation, some studies estimate as many as 1 in 5 to 1 in 10 child or young person in a class has a caring role, bringing this possible estimation to over 100,000. Scottish

Government acknowledges there is an underestimation: *“the number of young carers is likely to be an underestimate as young carers in particular may not identify themselves as such in a survey”*<sup>2</sup>. As the number of unpaid carers in Scotland has estimated to have increased and forecasted to continue to increase, 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. We are concerned that estimates produced on a Right to Breaks for young carers has significantly underestimated the actual number of young carers that will be entitled.

We are also very concerned that there is lack of any replacement care for young carers listed in the financial memorandum and we urge that this is reconsidered. We appreciate that many young carers will be part of a family network providing unpaid care and other family members may be available to step-in to allow the young carer to have a break. However, this is not exclusive and there are many young carers who are the primary unpaid carer or have significant caring roles. Therefore, replacement care must be available for young carers so that this right can be upheld:

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*“I definitely need to know there is someone there to look after them before I go out anywhere” Young Carer, Scottish Young Carers Festival, 2022.*

*“I feel guilty to take a break as it puts a lot more pressure on my mum to do the full caring role and I feel bad for putting myself first as I know things need done and I should be prioritising those” Young Carer, Scottish Young Carers Festival, 2022.*

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Further investment is needed in young carer services across Scotland. These services are extremely valued and provide vital support for the many young carers accessing them, and allows these children and young people to take short breaks from caring. We hope that the National Care Service recognises this and takes actions to ensure adequate young carer support provision is available across Scotland:

The uprating for inflation has not been included in the figures and the impact of increases across both running costs and salary costs will cause significant variance.

There is not enough transparency in the financial memorandum on which costs are based on which data sets, which have been uprated and which are based on fixed figures. This makes discussions at local level about short breaks infrastructure extremely challenging.

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<sup>2</sup> [https://archive2021.parliament.scot/S4\\_Bills/Carers%20\(Scotland\)%20Bill/b61s4-introd-en.pdf](https://archive2021.parliament.scot/S4_Bills/Carers%20(Scotland)%20Bill/b61s4-introd-en.pdf), page 26.

We would like to see priority given to investment in recovering from COVID to reach pre-pandemic levels as many unpaid carers remain unable to access lifeline short break services;

The stated intention of the Right to a Break is to form part of the focus on prevention. In order for this to be successful – to ensure demand is brought down by preventative measures being successful – there needs to be overlapping investment in services over the initial period: giving parity to preventative support and to crisis/business as usual support.

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