

## Carers Scotland (Carers Parliament) response to: “A National Care Service for Scotland: Consultation”

This response from Carers Scotland brings together the views of the 239 carers who attended the Carers Parliament. The Carers Parliament is organised by Carers Scotland with the national carer organisations, supported by the Scottish Government. It is an annual event for carers from across Scotland to discuss key issues directly with politicians and policymakers.

We hosted 18 discussion groups on 4<sup>th</sup> and 5<sup>th</sup> October 2021 and a main event which included a panel discussion and contributions from Scottish Ministers on 7<sup>th</sup> October. Carers were also encouraged to submit any questions they had about the proposed development of a national care service.

This response summarises responses from carers in key areas of the consultation. We have appended summary notes from discussion groups (combined where there was more than one session on the topic) together with discussion and questions raised in advance and on the day. The films of the main event and panel discussion can be found at: <https://bit.ly/3CBPXrY>

Whilst carers delved into the consultation at the Carers Parliament, discussions did not address all the questions but rather sought to enable carers to consider what mattered to them. For ease of analysis, we have sought to bring together this response into sections and, where we have undertaken polls<sup>1</sup> or asked questions, we have provided statistics or commentary.

However, the remainder of the response focuses on this key question of how changes to social care, including a national care service can better meet the needs of carers and those they care for.

*“Go back to Christie – build services around people”*

*“... a system that helps carers to thrive not just survive”*

*“Must be rights based on the ground, in reality, not just in fine words in the air.”*

### Access to support and improving care

Carers identified that one of the biggest problems they faced was what *“where to go”*. They often did not know how to access social care, did not know their rights and, for many carers, did not recognise themselves as carers. This creates significant barriers to support.

Therefore, a clear pathway to support is needed so that whether or not a carer has knowledge of social care, they can access support as quickly as possible.

*“Even as a professional working in care field I can resonate with this and think about my mum as my dad’s main carer who is so unassuming and just wouldn’t know where to start”*

*“Clear path of support needed; not every carer knows where to start”*

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<sup>1</sup> Not all carers were asked questions within polls and where this is the case and each discussion topic report details what was polled in each session/across combined sessions.

Across many of the discussion sessions, carers identified the need for more independent advocacy services to can help them work their way through this pathway to get the support they and the person they care for needs.

*“Carers need more advocacy and help to navigate through health & social care system. A carer’s knowledge and experience of health/care system can make journey easier – knowing the right language, phrases to use, etc. But not every carer has this experience or confidence.”*

Equally the bureaucracy of the system needs to be reduced as does the need to fight for even a little support. This causes significant stress to carers. Services need to be more coordinated, consistent and responsive to carers’ needs.

*“Biggest stress is dealing with bureaucracy; everything is so bureaucratic and complicated”*

*“The biggest stresses on carers are often not the caring but dealing with bureaucracy.”*

*“The weight of local bureaucracy saps the energy of carers”*

Carers at the Carers Parliament also described having to fight or battle for support and expressed their hopes that a national care services and plans for “Getting it right for everyone” would make an appreciable difference to their lives.

*“Self-Directed Support was/is a nightmare. Getting support set up for my dad (during a pandemic) took about 7 months. I still don't have anything in place for mum as social work are completely snowed under”*

*“Having to fight for basic care for loved one is kind of what causes carer stress.”*

*“Listen. Don’t dictate to families”*

Carers also noted the need to develop a diversity of services and support to truly deliver human rights so that social care enables both individuals and their carers to have live the lives they want. Too often what carers or the person they care for want and need is not available. It feels disjointed and even where carers identify what could help, they or the person they care for may lose out because of eligibility criteria. More of the same, under a National Care Service will not deliver the change that carers want to see.

*“And the assumption that all elderly people are interested in is bingo and Vera Lynn”*

*“Happy to pay to go away but funding for what I do day in day out in addition to working should be covered”*

*“All the social work can suggest is a day care centre which my mum would not really be interested in.”*

*“I have organised a 'network' of extra carers for my parents, a cleaning company and a couple who do some shopping for them, which means that I can spend more time batch cooking and taking care of ancillary tasks for them both either during the week, which happens a lot as well as at weekends.*

*The pandemic is being blamed for so much, but why haven't the various bodies 'thought out of the box' to put procedures in place remotely?”*

*“The support my mum \*needs\* is help with hoarding issues but that is very thin on the ground. Provider in Edinburgh are not registered with my local authority so self-directed support will not apply to them even if I go to them directly”*

*“Services are not joined up – no one stop place a carer can go to.  
Carer services/centres don’t have the links to create a full care package.  
Eligibility criteria makes things worse.”*

There was also a range of comments from carers on ensuring that both assessment and the underpinning services met carers own human rights. Carers felt that recognition of the impact of caring on every aspect of their lives – relationships, careers, education, health – should underpin the National Care Service.

*“I had to give up senior nurse career and PhD and when I became a full-time unpaid family carer I became: vexatious, and a nuisance with a voice. I met someone recently at an NHS AGM... who had worse experience than me. Carer's voice is invisible in all services.”*

*“My own career took a hit so I could care for my son.”*

*“Need to give back some of what they have taken from people when they become carers  
– health, financial, pensions, work”*

Carers also suggested that a Carers Charter within the workplace and educational settings would be beneficial and this reflects discussions that a national care service and the development of policy in other areas must link together to make a difference to carers’ lives

## **A National Care Service**

Carers at the Carers Parliament were asked whether accountability should move from local councils/partnerships to Scottish Ministers. There was broad support for this, with an average of 64% of participants in discussions agreeing that this was a positive idea. Participants were even more strongly supportive of the establishment of a National Care Service, with 91.67% of carers in favour.

Carers were emphatic that something has to change and that the current system is not working at the moment. This reflects the experience outlined in previous sections and indeed the experience of carers over many years. Carers felt that the pandemic had shone a light on issues with social care that were long standing, and ignored.

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

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

*“I agree, it doesn't work at present and devolving to local areas could make the difference”*

*“Need flexible support, individualised. What the system is doing for you and not to you.”*

All respondents agreed that establishing such a National Care Service would help make sure good practice in services was shared across Scotland and the majority (84.62%) agreed that it would benefit people if complex and specialist services are managed nationally by the National Care Service.

However, there were some cautions and concerns raised by participants.

### Funding

Many carers specifically mentioned the lack of funding in social care and some felt that this, rather than local or national accountability, was the critical issue. Others noted that they were in favour of a National Care Service but only if it was *well funded*.

*“The main issue is not planning it's the lack of resources”*

Carers also talked about the need to raise awareness of social care and to ensure that funding is sustainable for the future. This reflects what the National Carer Organisations noted in our response to the Independent Review of Adult Social Care, highlighting that it will take all of us to deliver the change that is needed. It will require long-term commitment - in adequate and sustainable funding and in political and public support

*“Changing the mindset of society about what ‘social care’ is needs to happen. It is not just for an ageing population. We also need the discussion to begin as to how we fund it and where it comes from.”*

### Bureaucracy

There were some concerns that it may create yet another layer of bureaucracy that carers would have to tackle.

*“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!”*

### Will it bring about the intended change?

Others questioned whether it would indeed make the changes that the Scottish Government intends, citing previous good legislation that had been implemented poorly

*“We have excellent legislation under SDS but the delivery of this is so diverse across Scotland. Under a National framework will the same thing happen?”*

### Will a national approach be inclusive to all communities and responsive to all areas?

Carers noted that all developments and policy must be tested against diversity and inclusion and planned in such a way to be responsive to the needs of all communities.

### **Carers with protected characteristics**

A specific discussion was held with carers on improving care for people with protected characteristics. This highlighted that there was a need for more data and information on carers and cared for people with protected characteristics and that this would be essential for the effective planning and delivery of services under the National Care Service. Current gaps in information were highlighted as a critical barrier to effective planning and delivery.

Carers also stated that it was vitally important that cultural differences were considered within services and assessment and that good communication was essential to carers being able to access the services when they needed or wanted to.

It is also important that in developing a national care service, that it is understood that individuals had many different aspects of identity and that intersectionality should be recognised.

Specific mention was made of the gendered nature of care, both unpaid and paid and the need to recognise and respond to this in planning, funding and delivering a national care service.

The issue of no recourse to public funds was raised on national contracts for people with complex or specialised needs who have NRPF but who require access to services. The emphasis was on the carers to fight for an assessment through human rights legislation with little or no support or information.

## Rural and Island Communities

There was significant feedback on ensuring that any national care service, and the commissioning and delivery of care and support was responsive to the needs of rural, remote and island communities. Carers noted that there were practical issues that carers in these areas faced e.g., having no phone signal or living *“off the beaten track”*. Added to this are the challenges of recruiting. Carers noted the need to ensure that they are fully involved in the planning of services in these areas to ensure it works for them.

*“What happens in the Central Belt doesn’t work in rural and island areas”*

*“Conflicted – no doubt that things have to change but have major concerns over it being centralised into the hands of people who don’t understand rural areas.”*

## A right to a break from caring

*“If we agree that care should be a human right, I would say everybody should be able to “apply for” the right to a break.*

Almost 73% of carers attending the Carers Parliament think that there should be a right to respite. The majority (64.71%) believing that this should be a universal right for all carers, with a third (33%) thinking that this should be only for some carers who meet qualifying thresholds.

There were concerns raised that applying thresholds based on hours of caring would not take account of other key factors that can intensify the impact of caring on carers. For example, the need to balance work and caring, or the carers own health and resilience which may mean even small amounts of caring can be difficult to sustain.

*“Breaks are not just for having time for yourself for going out for lunch etc. They are also needed as carers to meet our medical needs. It can be impossible to attend medical appointments/hospital care for ourselves without carer support. This can be at short notice.”*

*“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.”*

Views were split on the approaches to deliver a right to a break from caring. With just over a third (37.5%) thinking it should be decided on an individual basis depending on needs, a quarter (25%) thinking it should be a gradual scale with increasing amounts of breaks as intensity of caring increases and just over a third thinking all carers should receive a minimum entitlement but with more to those with intensive caring roles.

While it was generally agreed that the right to a break should be a universal right, there was agreement that a right based on providing a flat-rate entitlement would risk leaving many carers far short of what they needed to have sufficient, regular breaks from caring. This assumed that the resource available would have to be spread very thinly due to the large number of carers concerned.

A personalised approach was thought to be a better way forward, but people were concerned about how this would work in practice given the current bureaucratic system of assessment, inconsistencies of practice, and their experience of this not leading to good outcomes in practice.

*“The main issue in Highland currently is the lack of social care workers, meaning carers*

*who want a break have zero option to take one and are, in fact, undertaking far more care work than they would wish to do.”*

*“Criteria (be they high or low) need to be consistent across Scotland: Aberdeen set the criteria impossibly high. There is also a risk that when the offer becomes a flexible one that that flexibility pushes the provision downwards.”*

A combination of a personalised approach - with a guaranteed minimum entitlement as a backstop - was more positively received. This could provide the reassurance of a guaranteed minimum but also access to further breaks to those who needed them via a reformed support plan process.

*“I have picked both [a mixed approach and tailored to the individual] because everyone deserves a level of support but then some people may need more support than others and that should be considered too”*

During the discussion, concerns were expressed about the complexity of the current system of assessment and use of eligibility criteria which created an immediate barrier to people seeking support for a break. The lack of availability of suitable provision was another concern. Having a right to a break is rather meaningless if there isn't the support or services available to enable people to claim this right.

*“We also need to learn lessons from rollout of SDS and ensure that any budgets provided to carers for respite doesn't include the red tape and bureaucracy that currently surrounds SDS budgets”*

*“Nationwide consistency, simple framework and easy to get the support they need”*

Making universal (mainstream) leisure and recreation opportunities more inclusive and accessible was also raised as a way of increasing the range of options available – potentially reducing the pressure on more targeted or specialist services.

## **Using data to support care**

Carers were in support of a single electronic health and social care record with 86.21% of those taking part in the discussion at the Carers Parliament agreeing that this was a good idea. It was noted however that it was important that the relevant information was actually read!

*“Constantly need to repeat your story to everyone”*

*“Lots of things to be done to put this in place as no systems talk to each other but one system will help improve health & social care”*

*“Sharing the information makes sense with complex conditions makes it safer when in an emergency.”*

*“We have a shared record in maternity services patient held notes and now in app for via BadgerNet. you can have all the info in one place the drawback will be does the medic/care professional in front of you have the time and capacity to read it”*

*“If the loved one has complex needs and are discharged from mental health services it can lead to services not being fully informed of a situation.”*

However, carers noted that there should be clear protocols around what could be shared and with whom and that they should have a right to limit access to information.

*“Sounds good but with a right to limit access to information to the purpose they wish”  
“My view is it would be fine, but if you have the right to limit the access  
the information to the purposes you wish.”*

Carers strongly agreed that information about their health and care needs, and that of the person they care for, should be shared across services. 93.75% taking part in the discussion at the Carers Parliament agreeing that this was a good idea. Carers highlighted that this could also be a positive development to support planning to improve their own health needs.

However, questions arose about aligning information where the carer cares for more than one person and also about the record of the person they care for and who would be permitted access to it.

*“What about if you are caring for 2 people with 2 GPs – nightmare coordinating it all”  
“I’m caring for two separate people, in two separate locations, with very different needs and conditions. Just managing my own notes and diary is a nightmare!”*

*“Will there be challenges for carers to access cared for records if that person has capacity or if no Power of Attorney set up?”*

There were also a range of comments about earlier intervention, with most noting that support was not provided until a crisis occurred. Carers identified the opportunity with a national care service to effectively measure intervention and its impact. It will be crucial to gather the right data consistently across Scotland and use it effectively.

*“Resources are too often provided at crisis despite mantra of early intervention and prevention. Need to intervene sooner rather than later and allocate resources at a much earlier stage. However, with target and evidence driven reports, it’s more difficult to measure early intervention and impact - but it is the key.”*

## **Complaints and putting things right**

Carers had mixed views on what elements would be most important in a new system for complaints about social care services. 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 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 carer specific advocacy services was highlighted as a particular concern.

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 on-line as this could prove off-putting and mean an additional barrier for people who were digitally excluded.

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 carer to be responsible for this.

The time taken to resolve complaints was also specifically highlighted by carers. 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.

One carer raised a particular question on a complaints system enabling group complaints. They said *“in hope of getting a quicker response, some carers in Edinburgh had suggested putting their complaints in as a group. This was refused on the basis that the system could not deal with group complaints, even although it would speed things up.”* It is our experience that with some issues there may be a number of carers with similar or the same complaint so this may could be an area for consideration within a new system for complaints.

On the question of whether a model of complaints handling be underpinned by a commissioner for community health and care, there was little support for a Care Commissioner. 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, 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.”*

## Scope of the National Care Service

In general, the majority of carers (70%) agreed that the areas outlined within the consultation should be included in the National Care Service. However, the discussions focused primarily around mental health services, children’s services and healthcare and did not consider wider services such as justice, alcohol and drugs services and prison services.

### Mental Health Services

Carers were asked what they thought about proposals for mental health services to be included within the National Care Service. In the dedicated session around this, it would be fair to say that views were mixed. Whilst the majority of carers (62.5%) agreed that primary mental health services should be included, there was less support for Child and Adolescent Mental Health Services, Community Mental Health teams and Mental Health Officers being included.

Carers said that, as with other services, it is at the moment *“too fragmented”* and that it is a *“postcode lottery”*. There were questions if whether consistency and a more coordinated service could have a benefit of *“quicker referral”*. They noted however, that whether within the national care service or not, communication needs to improve between support providers.

*“Improving communication between different support options is so important whether that be GPs, CAMHS, community mental health etc but having everyone on the same page training and knowledge wise is also so important because in my experience different sectors have different levels of knowledge and that is such a barrier and can lead people round and round when they need the correct support as fast as possible.”*

*“In an ideal world I would like to get mental health support in my own locality”*

*“I agree - back to consistency and quality”*

*“My dad was diagnosed with dementia via local Old Peoples Mental Health team.  
It was a bit disconnected and we had to wait nearly a year for Post Diagnostic Support”*

Carers also noted that they were not treated as equal partners in care and a move to improved care and support and a new National Care Service must change this.

*“My new care Manager has proclaimed she has the last say. The person should have last say. If impossible, next of kin. Care manager should be way down pecking order.”*

*“My sons had the Human rights assessment and the Care Manager still says she has the last say.  
We've had a psychiatrist GP and MHO agree my son needs services and the care manager says it's up to her to decide if my son meets the eligibility.”*

However, participants were concerned that, to include mental health services in the national care service would take work, particularly in training and enhancing knowledge amongst a range of professionals. There were also questions as to whether or not moving services away from the NHS would be beneficial.

*“Even if it is all brought together, there is so much difference from each social area with the knowledge of GPs and the support offered so the first thing that needs to happen is everybody on the same page with training and knowledge etc”*

*“Also having everybody on the same training and knowledge level because there is a huge difference in knowledge between different professionals.”*

*“I find that as well, a lot of comorbidity between conditions are not understood very well”*

*“I am not sure if bringing the service under the government away from NHS would help that or make it worse”*

*“It has been my experience that so many professionals do not understand the link between mental health and how it impacts autistic individuals. Autism Awareness training needs to be looked at.”*

There were some strong views expressed about Scottish Government priorities for delivering better mental health care.

*“Yes, but the government need to change their priorities... to focused on saving money and improving other areas instead of the really important aspects like mental health support.”*

*“Yes, with mental health it is not about recovery it is about healthy management and support but the government don't see it that way”*

*“I think the government making constant changes does not help things at all. I have a Masters degree in Forensic Psychology and half way through my degree, the government changed things. They now send Mental Health Nurses into prisons instead of forensic psychologists which takes them away from the hospitals and community... creating a longer wait time for those individuals. All of this in an attempt to save money which doesn't work in the long run when more than a mental health nurse is needed.”*

## Children's Services

Carers expressed general support for children's services to be included in the National Care Service. The majority (80%) were in favour with the remainder being unsure which perhaps reflects the need for more detail as further proposals emerge following the consultation.

They noted that there was fragmentation and families would benefit from a joined-up service from childhood right into adulthood. Carers talked about services stopping when moving from the children's team and having to fight to get adult services in place. They noted there are huge barriers to a smooth transition and some noted that families often faced this transition within social care **and** health care at the same time.

*"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"*

*"I am a carer to a child with severe mental health difficulties and there is currently little or no support under the age of 16"*

*"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. Having to deal with transition in both health and social care."*

However, some 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; as social work may utilise a child protection approach to services. It was also noted within the young carers discussion that it there is a risk it may create a less personalised service. It is important that incorporating Children's Services into a National Care Service does not create unintended barriers.

*"Hopefully raise standards for adult services rather than lose standards of children's services"*

*"Could this possibly de-personalise young carers experiences?"*

*"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 understand it would potentially bring more to areas that don't have a lot of thing but for others it could do the opposite. 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?"*

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."*

*“I think it would be determined by the scope of services covered e.g. CAMHS is not fit for purpose”*

Portability of care was noted as a benefit. Individuals and their carers should have a right to move in Scotland and still receive the same level of service.

*“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.”  
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 holding up GIRFEC as an 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”*

### Healthcare

We used the opportunity of questions around including community health and care services within Community Health and Care Boards to explore with carers the impact of caring on their health and what would help better support them.

The role of general practice is seen as critical by participants to identifying and supporting carers but importantly to referring them to relevant services to support their health and their caring role.

A better integrated service offers the opportunity to develop clear pathways for carers, with community health care being equally responsible for offering carers an adult carer support plan and ensuring they can access the support they need.

*“All carers to be offered an adult carer support plan - any professional they encounter to ensure carer is aware.”*

Carers noted that improving availability of social care services – both carer support and support for the person they care for - would have a direct benefit to carers' own health and wellbeing. There is a key opportunity to reduce the impact of caring on carers' health and crucially to improve their health.

*“There is a lack of services for those who care and a huge lack of support for the person they care for. If you ask most carers, they will tell you that their health would be improved if the person they provided support for had more.”*

*“Carers too busy caring to deal with their own health – need to look after themselves more but have to fight for social care. Carers' health would improve if loved one had more support.”*

## **Reformed Integration Joint Boards: Community Health and Social Care Boards**

The majority of carers (83.33%) agreed with the reform of integrated joint boards into Community Health and Social Care Boards.

Carers agreed that there should be strong representation of people with lived experience and carers. All carers in the discussion groups agreed that carers should be voting members. However, within the discussion carers felt that there should be more than one carer representative, as is the case on current IJBs.

*“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?”*

*“Needs more public representatives – carers reps/citizens reps”*

Carers also noted the need to ensure that there is greater diversity and inclusion within Boards, noting Board members are often *“middle class, white professional, often male”*

Carers said that there is a mixed picture of involvement in IJBs, with an imbalance of power. Some talked about being excluded or being seen as a problem when difficult issues arose. One carer noted that they have pre meetings to have difficult conversations with carer/service user representatives *“out of public view”*

*“Involvement comes and goes depending on “urgency of budget cuts”.  
On these occasions feel there is an irritation with lay members”*

*“Reps are kept well away from procurement”*

In terms of equality with professional members of Boards who are paid in their respective roles, we asked if carers thought there should be a payment made to carer representatives and more than a quarter (76.92%) agreed that this should be the case.

Carers noted that, within IJBs, it is a very mixed picture

*“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”*

## Voluntary Sector

Throughout the discussions carers raised the crucial role of the voluntary sector and the need to ensure that they are fully involved in the Boards and that commissioning and delivery of services within a new National Care Service fully recognises their integral role in supporting carers and disabled and older people in their own communities. Participants noted that funding should be provided equitably across sectors.

*“Prevention is mostly done in the community by 3rd sector organisations. Yet their purse strings are held by local authorities and NHS Boards who look at the lowest price rather than the value of what these organisations provide locally which prevents the person going into hospital.”*

*“Not just carer centres, there are so many smaller carer charities providing specialist support.”*

*“Some funding should go to third sector. So many carer charities have been the ones to support carers at grass roots.”*

*“Better collaboration with 3<sup>rd</sup> sector and health & social care. Equality between all services.”*

*“My 88-year-old mother-in-law who is going blind cares for her 84-year-old husband. She has support from 3rd sector Sight Action who have provided free of charge equipment to help her remain as independently as she can with family support. Like many organisations no uplift in funding for years to provide a fundamental service. They helped develop the SG See Hear Strategy and work in collaboration with others. Yet NHS Highland have made little attempt to implement policy into practice.”*

## Valuing people who work in social care

### Fair Work

Carers were strongly in favour of taking action to improve pay, working conditions, training and development for social care workers. Over 90% of participants agreed that this was important. Carers felt that improving this would be of benefit in recruiting and retaining care workers and in social care, in all its forms, being seen as a valuable and important role that people want to join... and want to stay in.

*“Care workers should be a profession with appropriate training, proper pay and career structures”*

*“To make a NCS work efficiently, it needs good quality trained staff, they deserve a professional standard of pay, job description must be enticing to attract the thousands of vacancies there is at present. How do you plan to attract people to the profession (and it is a profession)?”*

*“Will paid carers be more valued, have more autonomy, better terms and conditions and opportunities to build a career in caring?”*

Carers living in rural and remote areas specifically questioned whether support would be provided to ensure that they can recruit and retain staff and, as noted earlier in “Access to support and improving care” there is a clear need for plans to be tested regularly to ensure that they meet the diverse needs of communities across Scotland.

*“Given the lack of staffing that is being featured regularly in the news at the moment, I am not hopeful for more rural areas to receive the same kind of support as more built-up areas. Is this something that would be considered?”*

### Personal Assistants

Some carers have concerns over proposals to register personal assistants centrally, particularly where this requires SSSC registration. Carers managing SDS and PAs can face even greater recruitment challenges as

budgets often only allow for payment of the minimum wage and care workers can be paid at a higher level by other providers including in the local authority or NHS.

*“We are always concerned about the retention of our PA support for our son, as we live in Shetland where there is currently a shortage of social care staff overall, and where that work is well paid, as the local authority directly delivers the service. We think this will be exacerbated by the proposal that all PA staff will require SSSC registration. ”*

Some carers also highlighted that if the national care service is to be a service that responds in a personalised way to meeting the human rights of individuals, they should have the *ability to choose* to able to employ family members as paid care workers/personal assistants.

*“We should also look at ways in which family members can be employed as paid carers (without the current red tape)”*

Self-directed support budgets should, through a new national care service, be sufficient to enable those who choose to employ personal assistants or family members to offer pay and conditions that are equitable with the public sector. This includes enabling workers to be able to access training and professional development. Carers often manage a budget on behalf of the person they care for but often there is little support and significant bureaucracy which makes this challenging. Individuals managing a budget should have access to advice, payroll and other services to support their staff recruitment, management and support.

*“There’s a need for more guidance and training around SDS – guidance for carers and training for staff”*

## Conclusion

Carers welcomed the opportunity to discuss their views on the consultation and, within this response and its appendices, are broadly supportive of plans to develop a national care service and to improve care and support.

However, we conclude this response with two key pleas from carers.

The first, strongly emphasised by carers, is that their voice is heard, that they are treated as full and equal partners in care, and that they are fully involved in developments both nationally and locally.

Secondly, and most importantly, we cannot do justice to what carers told us at the Carers Parliament, without asking *“what about right now?”*. The developments proposed are some years away from being a reality. Carers have told us that they are *“on their knees”*, *“exhausted and worn out and beaten down”*. It is therefore vital that the Scottish Government sets out how it will improve support in the coming months and years and to sustain carers and help them to recover from the huge demands the pandemic has placed upon them.

*“Unpaid Carers are on their knees!  
We can’t wait for the implementation of the national care service”*

## Contact

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# APPENDICES

## Appendix 1

Discussion on main Carers Parliament event 7 October 2021 and questions submitted by carers about the national care service

## Appendix 2

Summary reports from discussion workshops – 4<sup>th</sup> and 5<sup>th</sup> October 2021

# Appendix 1

## Carers Parliament

Main Session – 7 October 2021

Carers were offered the opportunity to submit questions they had about the consultation and about a national care service. Some of these questions were able to be answered in the event panel discussion but we have included the remainder as key questions to ask of the consultation within the response. We have also included questions and discussion raised on the day via the chat function.

*“The government have to be clear, there is no point making more empty promises, expectation and reality have to be very clear. “*

## What will a national care service look like? How will carers be fully involved in designing it?

*“1.1 million unpaid carers equal to another NHS workforce.  
We need more of our voices round the table being listened to and have a meaning place not a token gesture place in decision making.”*

*“Nothing about us without us!!! Why is this so difficult to treat carers as valued and equal”*

- How will you win over COSLA?
- What will the national care service actually mean? More private companies being given money?
- Will these services be local authority run or private?
- Will the recommendation of the Adult Social Care Review to have people with lived experience of caring at decision-making levels be fully implemented?
- There are 57 Third Sector Carer Centres who support over one million Unpaid Carers in Scotland, who in turn are looking after that same number of Cared For. That represents one third of the entire population engaged in preventative care, delivered free at the point of delivery; not for profit being a cost effective and highly efficient delivery model. It follows that Carer Centres should play a central role in the NCS and be fully resourced.
- If we have a National Care Service going forward, what would your vision be in real terms for all Carers in Scotland in terms of equal local improvement to the services provided?
- Any care organisation requires a strong foundation. Millions of pounds have been spent collectively amongst all health disciplines and charities unanimously agreeing with certain requirements that are essential. Our strong foundation is the increase in numbers of Care Workers, having received proper training and education to reach an agreed benchmark. This would alleviate stress & distress, allow people with disabilities (PWD) to remain at home for longer and also free up hospital beds. Many PWD are kept in hospital unnecessarily due to this shortage. Once that has been put in place standards of care should improve with people living for longer and enjoying a better lifestyle for longer.
- What can carers do support the development?
- How will unpaid care integrate within the service?
- The principles are right but the task is enormous. How do you plan to achieve introduction of a Bill by 2022 with short a short consultation period?
- Government should: 1. resource Carer Centres to support unpaid carers within the NCS; 2 For the Scottish NCS to be world leading, we shall need to adjust our education curriculum to introduce care to the next

generation as being both an aspirational and well remunerated career; and 3. Why are unpaid carers so seldom given any consideration when health & social care nationally would crumble without our unstinting efforts?

- In what way do you think carers will benefit most from a National Care Service?
- 1 carer rep? .... from the biggest workforce. Surely multiple carers from different scenarios giving a better interpretation of what we do and the challenges we face every single day
- What is the government's position on eligibility criteria? Is there an intention to move away from it to enable a more preventative, human rights approach, or will it still exist in some form?
- How will the National Care Service help improve the experience of SDS for carers and people with care needs?
- What provisions will be made for those with PMLD and their family carers, especially with respect to those with Legal Guardianship under AWIA 2000?
- How do you think the development of a national care service will support unpaid carers?
- I've just come off a Carer HSCP meeting, has the Price Waterhouse Coopers elephant in the room been addressed yet? Was PWC the only one to tender for the national care service? What does that say to the SG?
- Is centralisation the answer, is my question?
- We are experts by experience
- Nothing about us without us!!! Why is this so difficult to treat carers as valued and equal
- There has been consultation after consultation, we should all be very aware of needs of carers. action is needed and needed now
- Sat around many tables talking but nothing seems to change. Very slow train
- Why do we need to create another expensive behemoth - surely not just parity of esteem between health and social care??? Why not spend the money on equitable advocacy and legal representation
- Why? is it something to do with implementation, budget control and accountability - lack of it
- I have a no size fits all approach within my LA
- If people haven't read it InControl Scotland and Strathclyde University produced an excellent report on accountability
- The framework around SDS is there! We need standardised practice and accountability. SW should be separate from LA control!
- Accountability?
- If councils were capable of implementing SDS they would have done it by now. They have had 10 years.
- Why wait to make improvements when carers are very clear about what needs improved now!
- That's why the control should be taken from LA
- COSLA also agreed to back door charging in Children Services delivery of self-directed support, allowing authorities to claw back transport costs in SDS budgets linked to the level of DLA the child receives! Despite the promises in law that in children services it should be about need and not financial assessment I am certain it will cost more to administrate this than is saved. Again, more time and energy spent saying NO than allows lives to be lived
- But you still only 1 carer on your board?

## When will there be a national care service?

*“Realistically how long will this take to implement and what will be done in the meantime, to support carers at this time of crisis?”*

- What date will it actually be implemented?

- What's the expected timeline to introduce a NCS for Scotland?
- In 2014 there was a referendum on Scottish Independence. Why can we not have the same approach to a National Care Service. For example, every household is given a white paper which explains exactly what it is.
- Is there a timescale for implementation of the NCS and how do you see it improving care in the future?

## How will it be funded and will funding of third sector be equitable?

*“Funding is essential across the board, postcode lottery at best at the moment and down to luck.”*

- What will happen if the final bill is more than the £800m presently proposed? Will we then get a watered-down version which will not result in the improvements required to improve social care?
- What funding is going to be made available following COVID?
- How will the NCS be funded and will the funding be protected from cuts in the future?
- Where will the money and staff come from to resource this?
- How much of money promised to Social care and Health will reach Social care, none or very little I suspect?
- Where is the funding for a National Carer Service coming from?
- As an unpaid carer and working full time, I have great interest in all that is proposed. My question is this, given the staggering amount of money involved, and rightly so, how is it envisaged this will be funded?
- Funding is essential across the board, postcode lottery at best at the moment and down to luck. More recognition of what we do every single day 24 hours a day 7 days a week. Communication is essential too. For organisations to actually talk to each other.
- One size can never fit all and this needs to be clearly understood. All local authority areas must be told to give same standards of service. I already employ privately a number of trusted people who assist me with various household chores, paid for by my parents through Attendance Allowance. Money for Social Care must be 'ring fenced' and spent on this alone.
- Totally agree money it should be ring fenced.
- Some funding should go to Third Sector. So many Carer Charities have been the ones to support carers at grass roots.
- Presently the NHS is always at the front when the money is dished out and Social Care at the end. I hope that a NCS will put Social Care up alongside the NHS in respect to the allocation of finances.
- Instead of talking large figures, please be realistic and talk figures per person.
- We need to fund, not free up!
- Prevention is mostly done in the community by 3rd sector organisations. Yet their purse strings are held by LA's and NHS Boards who look at the lowest price rather than the value of what these organisations provide locally which prevents the person going into hospital.
- Not just Carer Centres, there are so many smaller Carer Charities providing specialist support.
- Funding is not the same as resources!! if there are no alternative care providers, PA's, services, carers and disabled people are left sitting on budgets that the LA will happily claw back to shore up their budgets blasted my profiteering in health and social care
- My 88-year-old mother-in-law who is going blind cares for her 84-year-old husband. She has support from 3rd sector Sight Action who have provided free of charge equipment to help her remain as independently as she can with family support. Like many organisations no uplift in funding for years to provide a fundamental service. They helped develop the SG See Hear Strategy and work in collaboration with others. Yet NHS Highland have made little attempt to implement policy into practice.

## How will a national care service improve outcomes and deliver human rights for carers and service users?

*"... a system that helps carers to thrive not just survive"*

*"Must be rights based on the ground, in reality, not just in fine words in the air."*

- How will this new strategy change the outcomes for carers and the services they and the person requiring care receive.
- What are the best models of human-centred design (including co-design) to use when developing new social service policy? Which organisations are world-leading in doing co-design or collaboration with carers well?
- What would you do to ensure that funds meant for the benefit of carers and those they care for are not simply swallowed up by the care industry like presently?
- Charges for Carers were waived years ago. When will the charges be abolished for those we care for as stated during the election campaigns?
- Better to work from the ground up, with communities and what is in place there
- Good aspirations, hope the reality is the same
- Why is it that Carers don't have a Right to Privacy and Family Life - why is it deemed acceptable we have to share all in a Carers Assessment or Statement which is then shared with all and a dog on the off chance that it meets eligibility criteria?
- I don't believe this new national approach will work.
- Stop accepting that carers don't have a Right to life outside caring - get the narrative changed from " A right to life alongside caring". It's not about hours of alternative care it's about having what works to have a life at the right time at the right place and with the right people
- I am an unpaid carer for my dad and my in-laws plus I work. I am exhausted retelling their story over and over to health professionals who either don't have the time or the inclination to read their case notes. We had a case conference on Tuesday for my dad who is back in hospital. The doctor turned up 10 mins late and kept calling him the wrong name. My sister and I left the meeting saying dad wasn't recognised as an individual but treated as a commodity to be moved on! Person-centered approach!
- I'm not accessing support because of the intrusive nature of that process. Can't cope with it any more.
- Sadly, very sadly you are far from the only carer that has no more energy to deal with any more intrusion, more meetings and more paperwork on the off chance of support. Why are local authorities not requested to provide Performance reports regarding Carers. Nobody seems to question why in some LA's there is a 2% up take of assessments and an abysmal 0.03% rate of delivery of SDS support packages.
- Standards and frameworks are all very well but if you do not have allies, advocates or a clear system for accountability, including equal access to advocacy and legal representation we are back to conversations of "warm words"
- Independent advocacy is needed badly for carers
- We have the right to a carer's assessment, the right to assessment for self-directed support. How many carers do you know who ACTUALLY get access to either of these?
- So many times, I hear that as Carers we often don't know what services we can access for those we care for - but what about the Carers who care for family members where care just isn't available e.g., under 16 young people with severe mental health problems. It's widely known that CAMHS is underfunded and not currently 'fit for purpose' they are unable to provide support to young people who don't respond to one type of therapy.
- Regard for ECHR Art 8 is a constant problem
- Support is only often provided to carers when there is a real crisis (even then it often doesn't happen) there has to be a much more proactive approach

- I very much welcome a more consistent approach particularly around eligibility criteria for care packages and respite care and also in terms of quality and breadth of carer support available regardless of postcode.
- It becomes available we know what needs to be targeted.
- Autonomy is key!
- Look at what we do - we are well able to decide what we actually need, without massive intrusion by professionals.
- We must have uniformity to stop this going from 'pillar to post' to get something actioned, including 'free personal care'!
- If adopting a human rights approach then unmet need does not fit in with that approach and certainly not with Convention on Rights of Persons with Disabilities
- Rights are all very well. We need to be recording unmet needs though. So that if money if and when
- Why are we being told Daycentres for older people are a thing of the past and not being opened up again?
- Why do local authorities decide who should get 2-1 in the community as my son requires 2-1 but local authority won't pay it. They wanted to put him in a care home at 25 but instead I have become 2nd carer unpaid.
- Largest workforce is a valuable point
- it is awful on the ground just now - something needs to happen.
- "Outcomes" - once upon a time this meant Hopes, dreams and aspirations. The language needs to change. The transactional nature and risk adverse culture of social work (and other professionals) needs broken
- Outcomes an awful term.
- We need to give staff time to ask such questions and have time to really listen to what carers are saying it's what person-centred support should be all about
- Eligibility criteria is the biggest stumbling block to carers at present.
- It's very concerning to hear Fiona say earlier that she doesn't feel optimistic that the NCS will produce the solutions needed. I'm sure other carers feel the same that expectations have been raised in the past but not met. What can we do to give carers hope that this is going to be different?
- Eligibility and the horrible intrusion involved in accessing things.
- So how will this be monitored to ensure equity throughout Scotland as no one in NHS takes responsibility
- I obviously had to rein my talk in but some concerns I also have are consultation fatigue that we have, and also now tentative conversations I'm having with my oldest daughter about her becoming her brother's full-time carer should my husband and I not manage to care. This goes against every fibre of my being as we did not ever want our girls to be their brother's keeper. "May we last one breath longer than the folk we care for"
- It's not all about money, its looking why carers are not able to access their communities and the services that are there. The abstract term "Governance" should not be used as a noose to stop opportunities. More time and money are spent saying no rather than supporting from the outset
- Partnership working is KEY!
- Why is there a policy that every local authority can't implement properly?
- Again, tailoring packages. Communities will need to look more to coming together for that community's needs. Again, if you get a chance, do look up the very workable model of Braemar Care. Hard work but we got there
- Postcode lottery comes up in every carer parliament and discussion.
- Self-directed support needs to be person centred the most important part of the assessment is the "good conversations" and following this through most people are not asking for the moon they only want flexibility to live a good life
- It's the individual not a centre or service that has Rights, why are we still talking about there always being a need for an intermediary - shock horror, in the Carers Act (well written poorly implemented) there is

scope for Carers writing their own assessments but they have no means to directly access their needs - bonkers

- About all agency's working together
- Fundamentally, one size doesn't fit all. Can I ask the panel, now that we have more information after the vaccine rollout, about who unpaid Carers are and not those just on CA.? Can I ask can we commission, a demographic study to see exactly what 'type of Carers' there are and then we can target the help more specifically so the help needed is based on evidence and not just those on CA. There are after all 1.1m unpaid Carers in Scotland.
- And it's still a mess!
- It should be working right now.
- Sadly, SDS has not developed as the ethos of the legislation initially suggests we can't turn the clock back but opportunities are now there to make the changes. In Highland we are proactively support carers through SDS Option 1 to receive short breaks by making the process as light touch as possible
- Again, culture and power need to shift if taking a human rights approach otherwise it will not work and nothing will change
- It is actually discriminatory under convention of rights of person with disability that carers are being asked to go through hoops because they are a carer when someone not a carer does not have to do
- Mr Stewart you are frustrated? This is how we feel every day when we are not being listened to
- Ensuring choice and availability of support provision is also key to success of SDS. Giving people a budget (no matter how insufficient) is of no value if there isn't support available to purchase.
- Many people were not allowed to use the powers of the Covid legislation (flexibility in SDS)
- SDS can work and we need to look at it differently to support carers well
- Every day I have to tell Carers who have already spoken to their LA what SDS is and their entitlement
- It is a gendered issue. No-one should be being demeaned like that.
- Enabling carers and cared for people to live their best life, fulfilled with the optimum level of wellbeing is not achieved provision of one type of service. It requires much more.
- About mental health wellbeing: A person is not treated for mental health problems if they have an addiction, e.g. alcohol and they have to have that addiction dealt with first. Should this be changed? As surely the addiction would be the result of poor mental health
- Why is there not a legal time limit in which Care Managers must respond to calls and emails, and when will we see one?
- How will it be ensured provisions for carers are rights-based. Assessments often involve revealing details of family life, and can be off-putting for some people, who may decide not to access support.
- My concern is how much is being taken into consideration for unrecognised carers from the BME community, that are not able to speak English.

## Right to a break

*How can it be right that there are carers (like myself) that have not had a break of even a few hours for more than 3 years.*

- For many carers the right for a break from caring is essential for their wellbeing, their capacity to sustain carer role and their relationships with their cared for person and others. Will this right include access to free replacement care for cared for person? as without this many carers will be denied a break.
- Existing problems need sorted now regarding respite - so who would ensure all the policies were delivered and delivered correctly and fairly

- How will the development of a National Care Service and improving social care help myself and so many other carers to have the right to access respite, out health is suffering as a result of failing to provide this at present? How will you turn empty promises into reality?
- I am unpaid carer for my mum who has Dementia and other illnesses. I care for her 24/7 and like everyone else is on my knees. In Aberdeen they've closed all Daycentres except one and we've been repeatedly told they are a thing of the past won't open up again. My mum has deteriorated since this has happened. I like other carers are begging you to rethink this
- Local Authority day centre in Glasgow opened again a few weeks ago so why not in Aberdeen - not right!
- That's the reality - many of us don't access things like nights out because of the hassle
- I was told my respite hadn't rolled over because of Covid legislation
- We definitely need local respite facilities
- Unpaid Carers should have total flexibility about respite
- There is a stereotypical view of what respite should be! Carers need autonomy
- Short break opportunities need to be flexible and bespoke to each individual not carers and/or cared for people fitting into existing services
- Welcome the comments from Cllr Currie, but we are hearing from many carers that local authorities/HSCPs are closing day services removing vitally important support to carers and supported people who have had to deal with so much this past year.
- Day care services are vital and need to open
- When will suitable local residential respite be available in all areas?

## What about carers in employment?

*“How can we improve employment prospects for Carers?”*

*There is currently a huge breadth of talent that is not in the workforce due to the demands of their caring role. I had to leave a well-paid, big management role 10 years ago, to care for my disabled son. I have been unable work since as I cannot find appropriate care for him, after school and during the holidays, that would allow me to return.”*

- I am an unpaid carer for my parents who live in Fife and am acting Attorney for both who are living at home with mixed Dementia. As I live in East Lothian, I am constantly juggling work commitments, meetings at their home and telephone calls. All I can say is thank heaven for flexi time! I can be tearful sometimes, as I know their time with us will be limited no doubt, but throughout the pandemic have continued juggling their care with the shared home-schooling for my middle granddaughter too.
- We work longest hours in UK compared to other EU countries
- Registers of Scotland has recently acquired a Carers Positive Accreditation through the hard work from our Carers Network.
- My employer North Lanarkshire Carers Together are Carer Positive Exemplary - cannot fault their support to the workforce some of whom are carers
- Carer Positive is an excellent approach to support carers it does take time to develop process here at NHS Highland we secured our established status and are striving to ensure all staff managers and frontline workers appreciate the importance of carer positive status and what it means to the individual
- Many carers have skills that can transfer and be beneficial in the workplace.
- Carers should be able to gain a qualification to work and recognise their abilities and skills
- Carers have so many skills to offer society.
- Staff have on carers not just now but well into the future.
- Have to say support from my employer, Carers Trust Scotland, has been fantastic and kept me going as a full-time worker and carer

- Sometimes worker will not appreciate the huge impact that outcomes reached by adult social care
- Forget Carer Positive, forget the jargon - just see people asking for help and do something about it when they ask
- How will the government ensure support for carers in employment?
- As a manager it is important that I support staff to keep them in work and manage their caring responsibilities flexibility and home working (where possible) assist greatly with this
- And many of the care managers and health care staff stressed with the pandemic also have caring responsibilities when they go home at the end of a shift
- Are there any plans to compel employers to provide people caring for adults and in full time employment rights to time off for their caring responsibilities in line with the rights afforded to parents of children?

## How will the national care service support young carers?

*“Schools need to do a lot more to raise awareness around this and get hidden [young] carers the support they need. Could every school not have a named contact person for young carers who could provide information about supports available?”*

- I think fundamentally its catastrophic that as a society there sadly are young people in this position!
- I care for my husband who has bipolar and I find it hard and I understand is illness. I cannot imagine what it would be like to do that and be under 16 and it being a parent or sibling.
- I hope the policy and decision makers will listen and make the change young carers not only need but are entitled to because they give up so much to support those, they care for
- Great video. Thank you for making. I was also a young carer and got no help or support throughout school. Unfortunately, a lot of young carers don't even realise they are a carer because it's the norm for them and they don't know any different. Schools need to do a lot more to raise awareness around this and get hidden carers the support they need. Could every school not have a named contact person for young carers who could provide information about supports available?
- Young carers may well meet the definition of 'additional support needs' in their own right due to their caring role. This puts responsibilities on education authorities to ensure adequate supports are in place.

## Staffing of social care

*“Care workers should be a profession with appropriate training, proper pay and career structures”*

- We are always concerned about the retention of our PA support for our son, as we live in Shetland where there is currently a shortage of social care staff overall, and where that work is well paid, as the local authority directly delivers the service. We think this will be exacerbated by the proposal that all P A staff will require SSSC registration. Discuss.
- Given the lack of staffing that is being featured regularly in the news at the moment, I am not hopeful for more rural areas to receive the same kind of support as more built-up areas. Is this something that would be considered?
- How can we retain workers?
- To make a NCS work efficiently, it needs good quality trained staff, they deserve a professional standard of pay, job description must be enticing to attract the thousands of vacancies there is at present. How do you plan to attract people to the profession (and it is a profession)?

- Will paid carers be more valued, have more autonomy, better terms and conditions and opportunities to build a career in caring?
- Pay carers a decent wage as there's a shortage.
- I understand the extra funding recently announced will not improve pay and conditions for those people working in frontline children and YP services. I fear this is sending the wrong message about how much this work is valued.
- No mention of pension and decent pay to employ PAs. Can't get breaks
- Poor management and lack of proper training are some of the problems not only with SDS but also with the proper implementation of the Carers Act.
- We need to think more than just about caring staff. Better outcomes come from support that is unique to the individual person
- We should also look at ways in which family members can be employed as paid carers (without the current red tape)

## Carers can't wait

*"Unpaid Carers are on their knees!  
We can't wait for the implementation of the national care service"*

- Communications and contacts via regional hubs
- Do you have any real idea of how exhausted and worn out and beaten down carers are just now? An extra carers bonus payment just doesn't cover the exhaustion we feel after the continued closure of services.
- It was disappointing that support for carers wasn't specifically mentioned in the launch of the winter funding package for health and social care. Will there be measures to support carers in the full plan?
- When is this Government going to fully support Carers?
- Really disappointed Scot Gov didn't mention unpaid carers in covid recovery plan
- Carers need emergency support and help now!
- I've been on this caring nightmare for 21 years
- We need help NOW!
- Amongst the search for the solution to current problems is the fact that there is still covid going round the population. Until Scotland screws the head and lowers the R number significantly and permanently it doesn't matter what social care support is available, I won't trust it not to cause covid into our family by sending my son into the unknown.
- Don't think it going to get any better - they need to look at why it not working currently
- There's much talk of Social Care managers leaving their positions, because of the stress and mental health. Those managers go home at the end of the day. An unpaid Carers work day does not end.
- What will be done to help Unpaid carers NOW who are on their knees?!?!?

## Thinking more widely, how will the national care service link with wider policy on social security and reducing poverty for carers

*"Inspiring words, hope they become inspiring actions Ben McPherson"*

- Its #ChallengePovertyWeek so what is actually going to be done? Why is it still acceptable that over 30% of families with disabled members are living in poverty? The otherwise excellent Joseph Rowntree foundation report also failed to mention Carers - says it all

- We need more than just a bus pass.
- No free dental care, access to leisure, bus passes etc. It's a life we are asking for. Anyone want judicial review?
- But buses need to be accessible and reliable.
- It is not acceptable that anyone lives in poverty not just people with disabilities
- In our household we are lucky not to be living in poverty, but it's all down to my husband's 40 hours a week labour, not my 168 hours a week labour
- Will the national carers allowance still give NI credit?
- Unpaid Carers should be paid for the work and myriad of skills we have and use looking after in my case my 21 yr. son. I pay PAs ££8.91 hour to do much less to what I do BUT I only get CA!
- Also, only 10% of Unpaid Carers get CA!
- Or the new CA benefit. What happens for the 90% not eligible?
- Extending the eligibility of Carers Allowance.
- Why do the Government treat the State Pension as a benefit, resulting in the loss of the Carers Allowance as soon as you receive your first Pension payment?
- When are they going to lift the carers earnings threshold? Why was it not increased during the pandemic when many unpaid carers also work as a paid carer. Shocking!!! Feel not valued and worked all the way through the pandemic.
- Will there be an increase in earnings concerning carers allowance
- Are there any suggestions for providing more accessible social care or education to young carers of mentally ill parents in schools?
- How much do you think Unpaid care workers should be paid per hour?
- How can we as carers influence and assist the development of the Scottish Carers Allowance benefit
- Support for unpaid carers, who do not receive carers allowance yet still provide care to adult children with protected characteristics - no recognition
- I'm a full-time student and also care for my mum I'm not eligible for carers allowance what's the reason for this?
- That's not enough how can we afford to pay for the increase in costs for fuel and food as an unpaid carer (Carers Allowance Supplement)
- Will eligibility for the new equivalent for Carers Allowance change?
- is it not only 10% of carers that are eligible for Carers Allowance?
- I think it's kind of a wasted exercise to do so much work into a Scottish carer's allowance when UBI is also on the horizon.
- Caring is a full-time commitment and trying to base allowances on hours is totally the wrong approach.
- Anyone know what the ETA for the new payment (not the supplement but the whole thing) is?
- What are those unpaid Carers to do when they can't get Carers Allowance (or any of the Covid funds,) because their cared person, is prevented from receiving benefits or public funds of any sort; despite Social Care Lawyers, declaring that the "Cared for" persons' Human Rights are being violated, under article 8, after those same lawyers doing a Human Rights Assessment?

# Appendix 1

## Carers Parliament

Discussion Sessions – 4 and 5 October 2021

### 1. Carers Parliament Workshop: Complaints and Getting Things Right

A brief overview of issues raised by carers with regard to the current issues regarding the making and resolution of complaints was given as an introduction at the start of the work to set the context.

The workshop discussion focused on the following questions:

#### What elements would be most important in a new system for complaints about social care services?

- Charter of Rights & Responsibilities that says what people can expect from the service
- Single point of access for feedback & complaints about all of the system
- Clear information about advocacy services
- The same model for handling complaints for all services
- Addressing complaints initially with the body the complaint is about
- Clear information about next steps if the complainant is not happy
- A Commissioner to protect the rights of people who receive care and support
- Other

#### Should there be a Commissioner for Social Care?

- *I have often seen the role of a commissioner being suggested but I'm unsure exactly what someone in that role would do.*
- *There would have to be a clearly defined job description for that role.*
- *Discussion on this role would go to the Social Covenant Group*
- *Wondering where the money for that person's salary would come from? Would not want it to come from money otherwise meant to go towards caring services.*
- *I think we need more information on exactly what this commissioner would do...*
- *I think it may depend also on what powers a commissioner would have*

#### Should a National Care Service use a measure of experience of those receiving care and support, their families and carers as a key outcome measure?

The above suggestions taken were polled during the workshop and the results as part of the notes at the session. This a summary of the discussion that took place in addition to the notes in the chatbox during the workshop ((see section 2 of this paper):

- Workshop participants felt strongly that more could be done to reassure complainants that complaints would not be held against them and that they would be treated as an opportunity for improvement.
- There was agreement that a national single body to deal with complaints would be useful as it would ensure consistency of approach and response.
- Participants felt that the word 'complaint' was very negative and that it would be helpful to change the language. A suggestion was made to refer instead to feedback so that it became a much more constructive approach.

- Participants felt it would be useful if individuals providing feedback set out the terms of their concerns clearly stating grounds and what they wanted resolved.
- A suggestion was made to learn from, and implement, the Care Opinion model used by the NHS. As a public platform, this would support public accountability which was felt to be crucial. Carers felt there was a lack of transparency and an unwillingness to take responsibility when things did not go well.
- Participants felt 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 carer to be responsible for this.
- Participants highlighted that 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 were mixed opinions about moving any complaints process on-line as this could prove off-putting and mean an additional barrier for people who were digitally excluded.
- 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. Suggestions were made that the role and remit of a Care Commissioner should be consulted on and the final role/remit should be widely publicized.
- Participants called for wider and more vocal support from MSP's in support of carers.
- A suggestion was also made to remove the 'time bar' placed on the complaints process as carers were not always in a position to meet deadlines.
- There was support for a Charter on Rights and Responsibilities and access to clear information on any complaints process and advocacy agencies which could assist. The lack of carer specific advocacy services was highlighted as a particular concern.
- All participants agreed that the lived experience of carers should be valued and reflected in an outcome.

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

*"Definitely agree as many people making these reports can come in without much lived experience of caring and specific requirements of those being cared for."*

*"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."*

*"Instead of creating a further layer to plough through together with ancillary costs, the entire outdated systems should be excised with a minimum acceptable standard set and individuals held to be truly accountable. Fed up being sent from pillar to post."*

*"We should have specially trained police officers who will charge professionals who provided criminally bad care e.g. patient has bruises etc"*

*"We have to remember that we can also complain directly to the care commission. If you read the report and object to it, they can do a surprise inspection. I had very positive results from doing this."*

#### Comments

- General comments on complaints
- Advocacy is irrelevant to complaints.

- Re: advocacy there have been some issues herein highland with belief not available to carers a new tender came into being on 1st October and seems to have been advertised widely
- There is often no system in place for people to challenge a decision without having to go to complaints...if councils were better at facilitating these discussion
- Refusal to accept group complaints
- complaints are rejected for timebar reasons
- One issue I have encountered re complaints is people being unsure/wary of the process - they perhaps think it might be held against them if they do follow the complaints process.
- People have a fear that they 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.
- Having a National Care Service may help reassure people and provide a more consistent response across Scotland.
- The NHS says that it welcomes feedback of all kinds: good & bad. Maybe this ethos is one that should be reflected into the NCS.
- I agree - a bit like the Care Opinion model perhaps...? Care Opinion model is one that could maybe be used by the NCS?
- People need to be clear when they make a complaint what the issue is but also what would resolve the issue. Many people just make a complaint but just have a rant. The need to vent is understandable but this is not also helpful to resolve the issue.
- Both the care provider and the carer have a responsibility to resolve issues.
- Care Opinion is used to give both positive and negative feedback to the NHS. This avoids the use of the word complaint which has negative connotations.
- 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.
- I have never used this platform - a useful tool by all accounts.
- Carers can find the process of complaining a very time intensive process. Many don't have the time or mental energy to pursue complaints unfortunately...
- There appears to be a lack of understanding as to how stressful all of these things are and a resistance to solve issues.
- Complaints often require or encourage online engagement - which again can be a barrier for some people. Any complaints system should allow for a really clear way for people to raise concerns in whatever way they are able.
- We need leadership from MSPs. The bad care professional will escape censure. Look at other cases e.g. Jimmy Saville. They can go over 50 years undiscovered.

## 2. National Care service – improving care for people and overview

### How can we better co-ordinate care and support?

- Implement serial legislation
- Listen. Don't dictate to families
- The Independent Living Fund needs to have a greater role
- The weight of local bureaucracy saps the energy of carers
- Carers are best placed. Should be brokers in care
- We need to prioritise
- To avoid differences in delivery, there should be a national training model
- Better career advancement for those taking up social care. They currently have to train outside work in their own time, unlike NHS employees.
- More personalized care
- Flexibility
- Ambitious
- The implications on women mainly, who have to give up work must be recognized. A level playing field.
- A national minimum wage for carers
- It must oversee all age groups.
- A National Social Work agency should be established
- There needs to be more support for people with mobility issues in rural areas
- The time allowed for social workers and other professionals to get back to you should be time limited (between request and care package in place), not dependent on LA as it is at the moment

### Better resolution of complaints

- There must be a complaint mechanism in place
- In the hope of getting a quicker response, some carers in Edinburgh had suggested that they put their complaints in as a group. This was refused on the basis that the system couldn't deal with group complaints, even although it would speed things up.

### Accountability and better assessment of impact

- There needs to be more accountability
- Community impact assessments. The same cuts are being made to the same families. How are they supposed to cope?

### In Summary

- There is a need for adult training on adult carer support plans
- Time limited responses
- Accountability
- Listen, don't dictate
- Less local bureaucracy
- More support for rural carers with mobility issues

## Polls

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

- 75% agreed
- 0% were against the proposal
- 25% were unsure

Do you agree with setting up a National Care Service?

- Yes: 100%
- No: 0%
- Unsure: 0%

Do you agree with plans to reform IJBs?

- Yes: 100%
- No: 0%
- Unsure: 0%

Do you agree with carer representatives on the Health and Social Care Boards being paid?

- Yes: 50%
- No: 0%
- Unsure: 50%

Do you agree with carers being voting members on the new Health and Social Care Boards?

- Everyone taking part in the poll agreed that carers should be voting members on the new Board

Do you agree that children's services should be covered in the National Care Service?

- Yes: 100%
- No: 0%
- Unsure: 0%

### 3. National Care Service - Improving Mental Health Support

Benefits or drawbacks of mental health services within a national care service

- In an ideal world I would like to get mental health support in my own locality
- Even if it is all brought together, there is so much difference from each social area with the knowledge of GPs and the support offered so the first thing that needs to happen is everybody on the same page with training and knowledge etc
- Possibility quicker referral?
- Wider range of available medications under NHS, shorter waiting time to get to see a psychiatrist, shorter wait time for talk therapy
- I saw my gp for stress a few months ago and got referred for counselling which came fairly quickly and also for an autism assessment which was much slower
- Improving communication between different support options is so important whether that be GPs, CAMHS, community mental health etc but having everyone on the same page training and knowledge wise is also so important because in my experience different sectors have different levels of knowledge and that is such a barrier and can lead people round and round when they need the correct support as fast as possible
- Yes I think so, because just now things are too fragmented
- Yes, but the government need to change their priorities... to focused on saving money and improving other areas instead of the really important aspects like mental health support.
- I agree - back to consistency and quality.
- Yes with mental health it is not about recovery it is about healthy management and support but the government don't see it that way.
- And again, it's a postcode lottery at the moment.
- I got counselling v quickly as there is provision in my area.
- Unfortunately, I think we are a long way away from that but it is not due to the care providers.... it is purely the government holding the progress back and limiting the care than can be provided.
- I find that as well, a lot of comorbidity between conditions are not understood very well
- Not sure if bringing the service under the government away from NHS would help that or make it worse.
- They government could stop focusing on saving money and focus on providing the support people need. Also having everybody on the same training and knowledge level because there is a huge difference in knowledge between different professionals.
- I don't think MHOs add anything to MH treatment.
- I think the government making constant changes does not help things at all. I have a Masters degree in Forensic Psychology and half way through my degree, the government changed things. They now send Mental Health Nurses into prisons instead of forensic psychologists which takes them away from the hospitals and community... creating a longer wait time for those individuals. All of this in an attempt to save money which doesn't work in the long run when more than a mental health nurse is needed

#### Dementia

My dad was diagnosed with dementia via local Old Peoples MH team. It was a bit disconnected and we had to wait nearly a year for Post Diagnostic Support

#### Autism

It has been my experience that so many professionals do not understand the link between mental health and how it impacts autistic individuals. Autism Awareness training needs to be looked at.

### Community Health and Care Boards

- It's a change in name - but also aims to be a redistribution of power (in theory) so that all members of that board have equal power and voting rights rather than the hierarchy of IJBs at the moment.
- Do carers feel valued as equal partners? From the responses "No"
- My new care Manager has proclaimed she has the last say.
- The person should have last say. If impossible, next of kin. Care manager should be way down pecking order.
- My sons had the Human rights assessment and the CM still says she has the last say.
- We've had a psychiatrist GP and MHO agree my son needs services and the care manager says its up to her to decide if my son meets the eligibility.
- I should add the caveat that my son has been transferred from Elder CM -who were just authorising a package under the HR article 8,- to an LD CM who's-denied him twice- saying she going to start again. (despite what the council lawyers have decided)

### The role of the third sector is important and needs to be recognised in the proposals

- Knowing what support is available locally should be something any source of support should have to hand... whether that is about local charities or more formal support. I volunteer with a charity and we provide so much outreach work for our service users, we have great knowledge and communication with all organisations in our area so we can best support the people who need us.
- Better links to Third Sector orgs for support
- I think the way funding is dished out needs to be totally changed.
- The Third sector get a raw deal here.

### Is the use of digital support helpful?

- I think so but each individual circumstance needs to be considered and then a lot of providers won't provide the support online which is an issue.
- Not always accessible for some communities ( both in terms of IT infrastructure and also non English speakers)
- I think on line where possible could be a benefit for people on an individual basis
- Before COVID my brothers partner had 8 different counsellor options to find a good fit for her and during COVID she was given the option of 2 because the others didn't want to do the support online.
- Huge accessibility issues with tech only solutions.
- Accessibility needs to be as flexible as possible.
- I've found all of these very useful.

### Polls

Carers at the session were asked if about which of the mental health services proposed to be included, they agreed with the national care service scope to include: Primary mental health services 62.50%, Child and Adolescent Mental Health Services 12.50%, Community mental health teams 12.50% and Mental health officers 12.50%.

#### 4. Making it work for carers in employment

- I am so grateful for Carer Positive and the support I get from my line manager as a carer. It makes a huge difference and gives me real peace of mind to know that my employer supports me and understands what I am going through as a carer in full time employment
- You would think so, wouldn't you! I sometimes feel not all managers fully understand what we have to deal with on an ongoing basis.
- Caring responsibilities never end
- Good to hear there are some really supportive employers out there the importance of flexibility and home working where possible can make the real difference and allow people to remain in employment
- Not everyone has a job that can be changed to work from home mine is impossible
- Within NHS Highland we have variable times for our virtual groups for working carers within the organisation this is very much at an early stage (first evening session being tomorrow night)
- Views on a national care service
- Having Care as a government responsibility would at least reduce the reliance on the LA SW depts
- But it could be yet another level of bureaucracy
- I do so long as it's well funded
- My gut feeling is positive
- Scottish Government should not make these decisions on their own, carers are experts
- but only cos I've had nightmares dealing with my local authority
- It's a huge piece of transformational time and will take time to do well
- Some councils are terrible and are so inept they can cause harm and duly dismiss family unpaid carers
- If SG took responsibility away from LA's, 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!
- I put unsure, most of the time I would be in favour. The problem is when disputes arise.
- It's important we all feedback to the consultation to ensure voice of carers is heard
- We have excellent legislation under SDS but the delivery of this is so diverse across Scotland. Under a National framework will the same thing happen?
- I am fearful that different Health Boards will allocate their cash to services differently, so surely we will never have a unified system?
- My sister, who works for the NHS as an OT and works in the Community with her clients says that a unified system will never happen unless told to do so by the Scottish Government.
- All the SW can suggest is a day care centre which my mum would not really be interested in.
- Changing the mindset of society about what 'social care is needs to happen. It is not just for an ageing population. We also need the discussion to begin as to how we fund it and where it comes from.
- I have organised a 'network' of extra carers for my parents, a cleaning company and a couple who do some shopping for them, which means that I can spend more time batch cooking and taking care of ancillary tasks for them both either during the week, which happens a lot as well as at weekends. The pandemic is being blamed for so much, but why haven't the various bodies 'thought out of the box' to put procedures in place remotely?
- And the assumption that all elderly people are interested in is bingo and Vera Lynn
- Would SG do it any better?
- I have no voice but my experience as a senior nurse, community carer, one to one carer in AD, worked in a variety of areas and 30 years almost supporting alcoholic partner with related brain damage to sobriety with my excellent skills but no aftercare just complete helplessness and unchecked meds. I see mostly 'evidence-based practice' that is just too judgemental text book way of working.
- Anything that brings about a good level of consistency would be good.
- I have been working for an organisation that provides care by commissioned services. Every time the commission comes up for renewal the local authority wants more services but are prepared to pay less for them. They have signed up to be a living wage employer, we are unable to as the commission

only allows us to pay minimum wages. We're struggling to recruit and when employees are recruited and trained, they leave to join the NHS where they can get living wage. Will a NCS help address this problem

- Happy to pay to go away but funding for what I do day in day out in addition to working should be covered
- Especially for rare and complex needs
- Oban has a frailty group which I am a member of as the manager of a respite service for unpaid carers. It is made up of GPs, Nurses, Physios, OTs, Social Work, Pharmacists and the local carers centre
- The support my mum \*needs\* is help with hoarding issues but that is very thin on the ground. Provider in Edinburgh are not registered with my local authority so SDS will not apply to them even if I go to them directly

Being recognised as a carer and having a clear pathway to support

- My GP recognised me as a carer.
- My GP has also noted that I have caring responsibilities.
- Having a clear pathway to support available rather than a carer having to search for it.
- All carers to be offered an adult carer support plan - any professional they encounter to ensure carer is aware.
- Carers need a higher profile and be valued and understood.

Must be less bureaucratic and ensure carers do not have to fight for support

- The biggest stresses on carers is often not the caring but dealing with bureaucracy.
- It can be a minefield to get through to the right person with consistency. I now have a fantastic relationship with our Social Worker, who has been providing fantastic support to me.
- 'Battered about' - that is how it can feel.
- Bureaucracy is one of the most stressful parts of being a carer. Just for info, at Age Scotland we run workshops for unpaid carers of people living with dementia to learn more about their rights.
- And a variety of social workers etc/ Comedy moment when my mum's OT called me to discuss my dad and was really really confused
- Having to fight for basic care for loved one is kind of what causes carer stress.
- SDS was/ is a nightmare. Getting support set up for my dad (during a pandemic) took about 7 months. I still don't have anything in place for mum as SW are completely snowed under

Needs to be better information sharing

- I'd agree, there's a lot of repeating your story continually
- Share information there would need to be better valuing of a family carer.
- Sharing the information makes sense with complex conditions makes it safer when in an emergency.
- If the loved one has complex needs and are discharged from mental health services it can lead to services not being fully informed of a situation.
- I'm caring for two separate people, in two separate locations, with very different needs and conditions. Just managing my own notes and diary is a nightmare
- And I'm dealing with two different GPs (though one of them is also my own which does help)
- My view is it would be fine, but if you have the right to limit the access the information to the purposes you wish

Impact on carers' own health and wellbeing – what could help?

- Yes caring has impacted my physical and mental health.

- The impact on anyone who cares cannot be underestimated.
- It can be difficult when juggling responsibilities for my parents with my work, so I have learned to Meditate and have regular acupuncture at my own expense to help relieve the stresses I encounter
- There is a lack of services for those who care and a huge lack of support for the person they care for. If you ask most carers they will tell you that their health would be improved if the person they provided support for had more.

### Juggling Work and Care

- I had to give up senior nurse career and PhD and when I became a full time unpaid family carer I became: vexatious, and a nuisance with a voice. I met someone recently at an NHS AGM and it was so fluffy with all the managers a little talk that were boring but I met someone who had worse experience than me. Carer's voice is invisible in all services.
- I will say that having flexi time is invaluable, but I have had a big issue with blood pressure earlier in the year and now work with my GP to monitor this regularly.
- My own career took a hit so I could care for my son.
- My current job has let me speak with families all over the country and mainly parents of teens finding it difficult to get care for youngsters with mental health conditions and getting a diagnosis for autism.

### Consistency

- My dad's dementia makes communication difficult and I have "the knack" that his daily carers don't always get.
- The problem can be allowing a new face into mum and dad's house without a 'responsible adult' being there. I am terrified that mum would let anyone into their house, which she did recently, although the organisation concerned knew that I had to be present and an appointment made to accommodate my work, allowing for at least an hour or more driving!

### Other comments

- Most of what I do for my parents can't really be done by a respite carer. It's almost entirely communication and emotional support rather than functional
- My loved one often says to me 'my carer what do you do?' I am still on the emergency register and he said the other day you were never a nurse, hahahaha, I showed him my details and he believed me.
- As a dementia researcher I see the Mental Capacity Acts never addressed unless against the person.
- I think the police need better training.
- Re CAMHS it is true there is a wait list and a teen can take overdose to get that help. Having been a senior mental health nurse, the feedback re CALMS can be mixed.
- I have written to Sadiq Khan last week re my planned birthday trip to London tomorrow about supporting unpaid family carers of adults with complex needs. He was busy at the Labour party conference but transferred to TFL who said they admired some of my vignettes of previous trips on how I kept a sense of humour. I am documenting this trip, Theatre needs evidence of jabs or test and masks!! I am documenting the trip.
- In Edinburgh my adult son was told by mental health services that he was a wee bit stressed. I paid for him to go private in discussion with GP to see a psychiatrist trained in caring for people with my sons long term conditions. They took more time and diagnosed him with being on the Autistic Spectrum as well as being Dyslexic.
- There are independent advocacy organisations throughout Scotland who can help with navigating the Social Care system. Details can be found on <https://www.sdsscotland.org.uk/>
- Social care and all services need to know about the situation what is written can be wrong.

- Having them at IJB but silent needs to change!
- Carer IJB reps need the right to vote at IJB
- All services must be aware of mental health issues, delusions and so on. I have met excellent social workers and very corrupt who cause harm because of their inadequacy and out of their depth.
- We need a person to contact at the outset when things go wrong for clarity especially no mental health services can be attained.

### Polls

As part of plans for a National Care Service, the Scottish Govt would like responsibility for social care to shift from local authorities to Scottish Ministers. Do you agree with this proposal?

- Yes 53.85%
- NO 15.38%
- Unsure 30.77%

Do you agree with establishing a National Care Service?

- Yes 92.85%
- No 0%
- Unsure 7.25%

Do you agree all the areas should be in the National Care Service?

- Yes 70%
- No 10%
- Unsure 20%

Do you agree there should be a right to respite?

- Yes 91%
- No 9%

Should it be universal?

- 33% said yes and the remainder were unsure

Should it be available to some carers e.g. those in greatest need?

- 58% disagreed with this with a 33% saying they agreed, the remainder were unsure.

## 5. Making it work for parent carers – Salena Begley, Family Fund and Susan Walls, CONTACT

Two sessions for parent carers were held.

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

*"We had to start all over when moving to adult services"*

*"Is setting up the NCS as big as setting up the NHS was back in the 1940s 50s?"*

Should the National Care Service include both adults and children's social work and social care services?

- What I find baffling is that no-one seems to understand that a child with disabilities becomes an adult with those exact same disabilities
- Absolutely, The fragmentation within children services, then into the transition phase and then into adult services is a minefield for many families. There needs to be as much consistency as possible.
- Plus, children with disabilities are not functioning at their birth age, i.e delayed development.
- All services stop when moving from the children's team, then you have to fight to get anything at all after that
- There also needs to be more consistency in ability to access services across the country: the criteria to access services vary across the country - support may be available to individuals in some areas but not available to individuals with the same level of need in another area.

Do you think that locating children's social work and social care services within the National Care Service will reduce complexity for children and their families in accessing services? For disabled children?

- All the same sounds worth exploring as so much planning for their future has to be done well in advance.
- The roles of many professionals have changed over the years or no longer exist. This has a profound impact on many families for preschool children, especially at a time when answers are few and far between and waiting lists are long for potential assessments.
- Very useful comments about the principles of delivery and culture as well as the structures through which services are delivered
- I am not sure shifting children's social work services entirely under the National Care Service banner would help. I think care services for disabled children need to be considered separately from other social work roles.
- A study in England found 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 approach (even if not considering the children having a child protection need)

Do you think that locating children's social work services within the National Care Service will improve alignment with community child health services including primary care, and paediatric health services?

- Community based healthcare services in Scotland cover a wide range of services provided by registered nurses, midwives, and allied health professionals. This includes, for example, community nurses (district nursing, general practice nurses, prison health nurses, care home nurses, community mental health and learning disability nurses, clinical nurse specialists, health visitors, family nurses, school nurses, and community children's nurses) and allied health professionals such as physiotherapists, occupational therapists, podiatrists, dieticians, and speech and language therapists. They should allow people to know what services are available. It would be helpful if there was a time limit that social workers must reply to parents, as well as telling parents what the criteria for eligibility for services
- It has the potential to be more supportive.
- 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.
- Good to hear what people want - this is a time to be aspirational and ask for what is needed and wanted
- The big service misses from that list is Education.
- Yes, some concerns about community health services that are provided within education settings

Do you think there are any risks in including children's services within the National Care Service?

- Will it have the right amount of funding? Avoid short cuts
- We already have issues with COSLA and the recommendations in the report.
- 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.
- Regards planning the consultation proposes a Getting it Right for Everyone approach, based on the success of Getting it Right for Every Child - I am not sure everyone would agree that GIRFEC is successful!
- I think the main risk is children mature at different rates and ages. Maturity levels range massively but I do believe enough training and support from other organisations can solve that.
- 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

Other comments

- Social work act as the gate keepers to support and services, if don't meet the threshold, no service or support
- Some areas experience no choice with SDS
- Integrated joint boards – 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. 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.

- More funding definitely, more information and consistency but also more promotion/recognition. I watch television programmes who have storylines featuring sensitive issues like carers or featuring victims of crime and in the numbers listed at the end of the episode... victim support scotland is never there and I don't recall any Scottish carer organisations or charities either. A lot of English based charities or just one main big one which is not enough and does not reach nearly enough people. I just think that a huge volume of people watch television and identify with the characters and storylines but they aren't offered the support or information they should be. The first thing i did was take a huge number of leaflets from carers centre and put them in our victim support office to improve that connection
- I think one of the main reasons we are able to provide the amount of support we do to service users is because in Inverclyde, we make sure we know of all the services available within and outwith the area. If we are presented with a situation, we aren't sure of or a particularly unique situation, we research and connect with other organisations to find out to be able to provide the best support for individuals. This kind of initiative can improve everything discussed today.

## 6. National Care Service Overview

- Thoughts around national care service proposals
  - We need it – proved over last 18 months
  - Needs closer work and working better together
  - Need to recognise the hard work of care workers
  - It is not working at the moment
  - Something has to change
  - The main issue is not planning it's the lack of resources

*"I agree, it doesn't work at present and devolving to local areas could make the difference"*

- You could have a centrally funded but decentralised NCS under local control
- **Rural carers**
  - Rural carers need to be involved in working groups
  - What happens in the Central Belt doesn't work in rural and island areas
  - Examples of differences – support systems, no phone signals, carers living "off the beaten track".
  - Difficulty in availability of local care workforce in rural areas
  - Noted drops in care visits from 4 to 2 per day and some smaller care companies pulling out.
  - Conflicted – no doubt that things have to change but have major concerns over it being centralised into the hands of people who don't understand rural areas.
- Have to do things differently – even in a city the size of Edinburgh, it has been a struggle to get care workers just now.
- Lots of challenges – the system doesn't work. Changes over the years have made little difference.
- Go back to Christie – build services around people
- There is great urgency on delivery which hasn't been achieved so far
  - Noted women largely
  - Noted unpaid care workforce
  - Need to give back some of what they have taken from people when they become carers – health, financial, pensions, work
- European carer attending was astonished at Carers Parliament and accessibility of Ministers and policymakers. Scotland has more developed services and resources than Spain.
- Transitions – what is very important. There are huge barriers to smooth transition and this includes in NHS. 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. Having to deal with transition in both health and social care.
- **Having a voice**
  - It is a mixed picture for carer reps on IJBs
  - Involvement comes and goes depending on "urgency of budget cuts". On these occasions 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 reps out of public view
  - Reps are "kept well away from procurement"
  - Need parity in resources with NHS if we are to get social care right (Less people will end up in hospital and reduce inequalities)
  - Having a voting right won't make things easier
  - Needs more public representatives – carers reps/citizens reps
  - There is a power imbalance

- Noted “board think”
- Noted lack of diversity and inclusion – middle class, white professional, often male
- “People recruit the people who are like them”
- Lay members – not insured for their decisions? Is there a potential for legal comeback?

*“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?”*

*“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”*

- **Children’s Services**

Hopefully raise standards for adult services rather than lose standards of children's services

*“I think it would be determined by the scope of services covered e.g. CAMHS is not fit for purpose”*

*“I am a carer to a child with severe mental health difficulties and there is currently little or no support under the age of 16”*

### **Polls**

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

- 44.44% agreed
- 22.22% were against the proposal
- 33.33% were unsure

Do you agree with setting up a National Care Service?

- Yes: 85.71%
- No: 0%
- Unsure: 14.29%

Do you agree with plans to reform IJBs?

- Yes: 75%
- No: 0%
- Unsure: 25%

Do you agree with carer representatives on the Health and Social Care Boards being paid?

- Yes: 88.88%
- No: 0%
- Unsure 22.22%

Do you agree with carers being voting members on the new Health and Social Care Boards?

- Everyone taking part in the poll agreed that carers should be voting members on the new Board

Do you agree that children’s services should be covered in the National Care Service?

- Yes: 55.55%
- No: 0%
- Unsure: 45.45%

## 7. National Care Service - Making health and social care work better for carers

Two sessions on this topic were held.

### How could health & care work better together for carers? Current experiences?

- Biggest problem is where to go – how does a carer get into the system when they don't know their rights and don't recognise themselves as carers which creates barriers. Clear path of support needed; not every carer knows where to start
- Services are not joined up – no one stop place a carer can go to. Carer services/centres don't have the links to create a full care package. Eligibility criteria makes things worse.
- Getting everything coordinated is hard; minefield to get to the right person, no consistency.
- Carers need more advocacy and help to navigate through health & social care system. A carer's knowledge and experience of health/care system can make journey easier – knowing the right language, phrases to use, etc. But not every carer has this experience or confidence.
- (More) Independent advocacy organisations can/could help with navigating the social care system and getting help for carers
- One parent carer had issues with the vaccine. Had to go through an HSCP Pathway to get community nurses. Why couldn't the GP coordinate it all - why have to go through an HSCP Pathway?
- Better link to community care is needed
- Policies needs to be tested against diversity and inclusion – need to make health & social care more inclusive
- Biggest stress is dealing with bureaucracy; everything is so bureaucratic and complicated
- Constantly need to repeat your story to everyone
- Covid has meant face-to-face appointments are difficult to get. Phone calls and Zoom are not suitable for everyone
- Why haven't services thought 'out the box' during pandemic to put procedures in remotely? – eg one carer has organised a network of extra carers for her mum – cleaning company, shoppers, etc which frees up her time to do other caring tasks.

### Self Directed Support

- Legislation good but delivery of it is too diverse and inconsistent. Will it be the same under a National Framework?
- Will different boards allocate cash to different services?
- Is a unified system possible, unless run by SG
- There's a need for more guidance and training around SDS – guidance for carers and training for staff
- Need flexible support, individualised. What the system is doing for you and not to you.
- What does an individual need and want – budgets sometimes determine only need and not want.
- Not all 'old' people want or like the same thing
- No consistency with workers/teams even in same area - and what a carer is.

### Power of Attorney

- Increasingly some carers feel legal powers within POA are not fit for purpose
- Too expensive – cost to register, cost of solicitor - cost not practical, solicitor costs vary. Need to be free service
- Can no longer get POA templates from Office of the Public Guardian so have to go through more expensive route of solicitors.
- Some solicitors can do it through legal aid, but this is rare and eligibility issues.

- Carers need help to find right solicitor to do POA, eg through Citizens Advice or another service.
- Carers need to ensure they are getting right kind of POA, eg continuing & welfare
- Need to take into account your digital information - hard to control with POA

Carers comments in chat

*"I think that's a major issue, many carers say that the legal powers they have through POA isn't worth the paper it's written on"*

*"I agree, the legal powers through guardianship isn't worth the paper it's written on either"*

*"All depends on the type of Attorney set up. I did mine and my parents directly through The Office of The Public Guardian. Watertight no solicitor fee"*

*"I've had to go through an attorney, the office of the public guardian, and the welfare, and there was attorney costs, despite financial help , however I was very lucky the GP and psychiatrist didn't charge for the reports"*

*"I have activated my parents financial POA without any problems also registered my own last year too"*

*"My attorney told me I should get POA for both my kids and myself- (all disabled)-because its cheaper than when the POA is "needed"*

*"However, we all must remember that 'cheapest' is not always best! In my current job, I am finding an increasing number of 'qualified solicitors' who don't fully understand their responsibilities."*

*"My husband and I were about £700 last year to set ours up opted to use a solicitor to ensure wording was correct as Marc said the templates don't seem to be available now"*

*"You will need to arrange for your own PoA document to be drafted. This is not something we can help with as our role is to provide a registration service. from the OPG Website"*

*"The costs-too high now as it is"*

*"Solicitors for Older People Scotland are a great organisation. I've used this organisation for referrals for elderly carers in order they are given the correct advice / information around POA etc. Different lawyers have different costs and in the voluntary sector we do not give or promote lawyers in North Lanarkshire as this is classed as a business, who all operative differently with different costs."*

### **Happy for information to be shared more easily between health and care services? A single electronic health and social care record?**

- Unsure – what happens when disputes arise?
- Would be good to have more coordinated approach involving the carer. Carers voice is invisible in all services
- Makes sense with complex conditions; safer in an emergency
- If all of someone's information is in one place, does a medic or any other professional have time or capacity to read through it all?
- Sounds good but with a right to limit access to information to the purpose they wish
- Lots of things to be done to put this in place as no systems talk to each other but 1 system will help improve health & social care
- Will there be challenges for carers to access cared for's records if that person has capacity or if no POA set up?
- What about if you are caring for 2 people with 2 GPs – nightmare coordinating it all
- Carers too busy caring to deal with their own health – need to look after themselves more but have to fight for social care. Carers' health would improve if loved one had more support.

- Lack of services for those who care and lack of support for cared for person
- Govt. needs to look at CAHMS system – key player. Feedback mixed. People not being listened to.
- Govt. has it wrong on mental health. It's not just about money. Need to train more people to provide services. Shortage of professionals. How can you encourage people to join?
- Needs to be huge investment in training and maintaining staff in social care. Morale low in social care staff – lack of recognition of their role.
- Police need better training

#### Carers comments

*"We have a shared record in maternity services patient held notes and now in app for via badgerNet. you can have all the info in one place the drawback will be does the medic/care professional in front of you have the time and capacity to read it"*

#### The one thing you would change to make things better for carers?

- Need a clear pathway to support
  - *"Even as a professional working in care field I can resonate with this and think about my mum as my dad's main carer who is so unassuming and just wouldn't know where to start"*
- Carers need higher profile, be valued and better understood
- Better collaboration with 3<sup>rd</sup> sector and health & social care. Equality between all services.
- Clear pathway for when families are not in agreement with services they've been given – need a resolution process and better carer rights on disagreeing with something. Something similar to a children's tribunal?
- Need to change mindset of society around what social care is – eg it's not just for old people
- Carers on IJBs need the right to vote
- All services need to be better aware of mental health issues – better training of staff
- Where do we get the manpower to change things when currently struggling to keep status quo? Need to invest in people (training, etc) to make services better - in mental health, doctors, nurses, etc
- More advocacy for carers
- Carers should not have to fight to get services
- Adult carer support plans should be offered by any health/care professional.
- Resources are too often provided at crisis despite mantra of early intervention and prevention. Need to intervene sooner rather than later and allocate resources at a much earlier stage. However with target and evidence driven reports, it's more difficult to measure early intervention and impact - but it is the key.
- Anticipatory Care Planning and Advance Statement helpful around medicine, treatments, etc.
  - *"Even things like Anticipatory care Planning and Advance Statements can be helpful in the discussion around realistic medicine , treatments etc"*
- Counter intuitive to try and make savings when we have an ageing population. Lot of ageing population is still earning or paying taxes.
  - *"Please remember that a lot of 'the ageing population' is still earning or paying tax on their 'earnings!'"*
- Need a real discussion around funding of health & social care and where it comes from.

#### Issues highlighted in chat

*I find that my local medical practice is quite carer friendly. However, the pandemic has meant getting appropriate appointments for my autistic adult son has been difficult. Telephone calls and Zoom meetings are no good for him. He needs face to face appointments.*

*I work in health promotion / health improvement, (also have multiple caring roles) where our mantra is early intervention and prevention. Sadly, the resources don't often align with that mantra and as someone mentioned above the resources are provided at crisis intervention ... too late*

*Do you not also agree that sometimes good 'old fashioned' perseverance pays off, particularly where 'free personal care' provision is concerned? I feel at times that I am continually challenging those who do a review re my dad without recourse to me as his acting Attorney & not just once I have had to remind whoever it is, I am talking to of their legal responsibilities! My dad's carers have told me on several occasions that they are grateful for my presence and 'dog with a bone' attitude.*

### **Polls carried out**

**Would you be happy for information to be shared more easily between health and care services?**

- Yes: 93.75%
- No: 0%
- Unsure: 6.45%

**Would you be in favour of a single electronic health and social care record**

- Yes: 86.2%
- No: 0%
- Unsure: 13.8%

## 8. Improving Care for People with Protected Characteristics

A brief overview of available data on carers with protected characteristics was given as an introduction at the start of the work to set the context.

The workshop discussion focused on the following 3 questions:

- Do you agree the Scottish Government should be responsible for the delivery of social care? Should this be through National Care Service?
- It is proposed that national contracts for people with complex or specialist needs are commissioned and managed nationally. Will it benefit people if complex and specialist services are managed by the National Care Service?
- Do you think there should be a right to respite? For all carers? For some carers? If so, what would that look like for you?

This is a summary of the discussion that took place to during the workshop:

- There was agreement that the Scottish Government should be responsible for the delivery of social care in Scotland.
- On the question of national contracts for people with complex or specialist needs, a specific issue was raised for cared for people living in Scotland with no recourse to public funds but who required access to services. The emphasis was on the carer – a UK citizen - to fight for an assessment of need through human rights legislation. The carer highlighted that there was little or no support or information to utilize this route, that practitioners were unaware of it and subsequent delays once the assessment was transferred to local teams for action (a second assessment has had to take place).
- Workshop participants agreed that more data and information on carers and cared for people with protected characteristics would be essential for the effective planning and delivery of services under the National Care Service. Current gaps in information were highlighted as a barrier to effective planning and delivery.
- Workshop participants felt that ‘good communication’ was essential to be able to access services when they needed or wanted to.
- Workshop participants also felt it was important to recognize that individuals had many different aspects of identity and that inter-sectionality should be recognized.
- Workshop participants stated that it was vitally important that cultural differences were considered within services.
- Workshop participants agreed that all carers should have a right to respite. There was a difference of opinion as to whether this should be a guaranteed minimum entitlement or whether it should be based on individual circumstances. It was agreed that it was the quality of the service that mattered and not the quantity. There was too much inconsistency across services and it felt like a ‘postcode lottery’.
- Carers felt that recognition of the impact of caring on every aspect of their lives – relationships, careers, education, health – should underpin the National Care Service. One carer stated that there needed to be much more clarity about what constituted a break from caring. For example, it is not considered respite if you have to work to put food on the table. Carers also suggested that a Carers Charter within the workplace and educational settings would be beneficial.

## 9. Right to a break from caring

2 sessions were held on this topic

	<p><b><u>QUESTION 1 – Who should the right to a break apply to? (KATE)</u></b></p> <p>Question is on slide.</p> <p><b>Should the right to a break be a universal right for all carers, or one that is only available to carers who meet qualifying thresholds? For example, those caring above a certain number of hours</b></p> <p><i>“The consultation sets out different ways a right to breaks could be introduced and we’ll take a little time to go through each of the options so we can hear what you have to say.</i></p> <p><i>Firstly, should the right to a break be a universal right for all carers, or one that is only available to carers with more intensive caring roles? For example, those caring above a certain number of hours.”</i></p>												
<p><b>POLL QUESTION</b></p>	<p><i>Who should be entitled to the 'right to a break from caring'?</i></p> <ul style="list-style-type: none"> <li>• All carers</li> <li>• Only carers with a more intensive caring role</li> <li>• Not sure</li> <li>• Other</li> </ul> <p>Should this be for all carers? (ie a universal entitlement but may be spread more 'thinly')</p> <table data-bbox="874 1160 1085 1317"> <tr> <td>Yes</td> <td>64.71%</td> </tr> <tr> <td>No</td> <td>5.88%</td> </tr> <tr> <td>Unsure</td> <td>29.41%</td> </tr> </table> <p>Should this be for some carers? (eg above a certain threshold based on hours caring or intensity – less carers but a greater level of support )</p> <table data-bbox="874 1532 1085 1688"> <tr> <td>Yes</td> <td>33.33%</td> </tr> <tr> <td>No</td> <td>58.33%</td> </tr> <tr> <td>Unsure</td> <td>8.33%</td> </tr> </table>	Yes	64.71%	No	5.88%	Unsure	29.41%	Yes	33.33%	No	58.33%	Unsure	8.33%
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	<p><b><u>QUESTION 2 – What form should the right take? (KATE)</u></b></p> <p>Question is on slide.</p> <p><i>“The second option that we need to consider is how the right might be made available to carers -</i></p>												

	<ul style="list-style-type: none"> <li>- as a <b>flat-rate or graded entitlement</b> – expressed in hours, weeks or as a financial amount – OR</li> <li>- should it be based on a review of individual needs and therefore there is no set amount – meaning all carers would get <b>personalised support</b> based on their identified needs and circumstances – OR</li> <li>- <b>should it be a combination</b> of flat rate entitlement, plus a personalised amount as necessary, based on individual needs</li> </ul>
<b>POLL QUESTION</b>	<p>What form should the right take?</p> <ul style="list-style-type: none"> <li>• All carers should be entitled to the same amount <b>37.50%</b></li> <li>• It should be decided on an individual basis, depending on needs <b>25%</b></li> <li>• There should be a gradual scale, with increasing amounts as intensity of caring increases <b>37.50%</b></li> <li>• All carers should receive a minimum entitlement but with more to those with intensive caring roles <b>0%</b></li> </ul>

#### DISCUSSION FEEDBACK FORM

<b>Discussion 1</b>	<p><u>Who should a right to a break apply to</u></p> <p><u>Key points from this conversation</u></p> <p>A range of views were expressed in relation to this question but mainly in favour of the right to a break being a universal right that is available to all carers.</p> <p>There were concerns raised that applying thresholds based on hours of caring would not take account of other key factors that can intensify the impact of caring on carers. For example, the need to balance work and caring, or the carers own health and resilience which may mean even small amounts of caring can be difficult to sustain.</p>
<b>Discussion 2</b>	<p><u>What form should the right take? Key points from this conversation</u></p> <p>While it was generally agreed that the right to a break should be a universal right, there was agreement that a right based on providing a flat-rate entitlement would risk leaving many carers far short of what they needed to have sufficient, regular breaks from caring. This assumed</p>

	<p>that the resource available would have to be spread very thinly due to the large number of carers concerned.</p> <p>Within the on-screen group, a personalised approach was thought to be a better way forward, but people were concerned about how this would work in practice given the current bureaucratic system of assessment, inconsistencies of practice, and their experience of this not leading to good outcomes in practice.</p> <p>A combination of a personalised approach - with a guaranteed minimum entitlement as a backstop - was more positively received. This could provide the reassurance of a guaranteed minimum but also access to further breaks to those who needed them via a reformed support plan process. There was not enough time to discuss this hybrid model in detail, or take views on who should have the right to the minimum guarantee and how this should be set.</p>
<p><b>Discussion 3</b></p>	<p><u>Three key points from this conversation</u></p> <p>During the discussion, concerns were expressed about the complexity of the current system of assessment and use of eligibility criteria which created an immediate barrier to people seeking support for a break. The lack of availability of suitable provision was another concern. Having a right to a break is rather meaningless if there isn't the support or services available to enable people to claim this right.</p> <p>Making universal (mainstream) leisure and recreation opportunities more inclusive and accessible was also raised as a way of increasing the range of options available – potentially reducing the pressure on more targeted or specialist services.</p>

<p>Comments from Chat</p>	<ul style="list-style-type: none"> <li>• Should the right to a break be a universal right for all carers, or one that is only available to carers who meet qualifying thresholds?</li> <li>• Everyone should have access to a break. Could what that break consist of be assessed during the ACSP process?</li> <li>• Criteria (be they high or low) need to be consistent across Scotland: Aberdeen set the criteria impossibly high. There is also a risk that when the offer becomes a flexible one that that flexibility pushes the provision downwards.</li> <li>• The main issue in Highland currently is the lack of social care workers, meaning Carers who want a break have zero option to take one and are, in fact, undertaking far more care work than they would wish to do.</li> <li>• One thing they need to get right is consistency of provision</li> <li>• Breaks are not just for having time for yourself for going out for lunch etc. They are also needed as carers to meet our medical needs. It can be impossible to attend medical appointments/hospital care for ourselves without carer support. This can be at short notice.</li> <li>• I confess to not having a Carer Support Plan. However, I do have a wonderful Social Worker on board.</li> <li>• Instead of 'all carers should receive' I think it should be 'all carers should be entitled to'</li> <li>• There will be multiple providers in the local area and nationwide who can provide support for the people that we care for.</li> <li>• Nationwide consistency, simple framework and easy to get the support they need</li> <li>• There will be accessible leisure and community facilities so that we don't need to be setting up 'separate' services for supported people. Our communities will be inclusive</li> <li>• It should be 'must'. 'should' allows authorities not to do it.</li> <li>• We also need to learn lessons from rollout of SDS and ensure that any budgets provided to carers for respite doesn't include the red tape and bureaucracy that currently surrounds SDS budgets</li> <li>• "If we agree that Care should be a Human Right, I would say everybody should be able to ""apply for"" the right to a break.</li> <li>• Depending on the resources it may be ""assessed"", but most preferable ""advised"</li> </ul>
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## 10. Young carers and young adult carers

### Introduction

- I think that wouldn't allow for more consistency as I can go to my GP with a problem and be given some advice and my friend could go to hers, 3 miles away and be given different advice. I think a huge problem is the volume of inconsistency and differences in knowledge and training levels for various conditions and situations among medical professionals
- I am a slightly negative person so I do apologise for that but I think a National Care Service is a good idea but I just think the government are too focused on saving money rather than helping people so they would cut corners where they could, like that do with the NHS

### Right to Respite: what would work for you?

- 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 CFP is safe and being looked after by someone.
- How would it work if someone has more than one carer?
- I have picked both [a mixed approach and tailored to the individual] because everyone deserves a level of support but then as well said by Paul, some people may need more support than others and that should be considered too 😊

### Valuing people who work in social care

What would better support social care workers?

- Better communication and joint communication with other local services (3 thumbs up)
- Yeah, I still don't have an official contract written up which is a little stressful because I don't know my boundaries or structure of my role yet but it is because my line manager is also new to the job so he is learning it too but, in that case, I feel someone higher up should have stepped up in that case

### Should the National Care Service take action to make pay, working condition, and training and development for social care workers better?

Yes • 88.9% 8 Votes



No • 0.0% 0 Votes



No preference • 11.1% 1 Votes

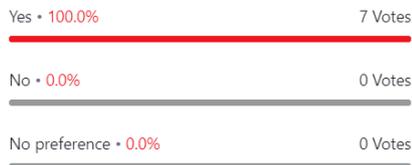


## Incorporation of Children's Services (Nicola)

- Could this possibly de-personalise young carers experiences?
- Similar to [ANONYMISED], each local area having their own things to offer young carers. I wouldn't be able to comment on what could become a barrier without further thought though sorry.
- 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 understand it would potentially bring more to areas that don't have a lot of thing but for others it could do the opposite. With what [ANONYMISED] said, 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.

Do you agree that children's services should be covered in the National Care Service?

 Hannah Martin • 2 minutes ago



1. Do you think the Scottish Government should be responsible for the delivery of social care?



Should this be through a National Care Service?

