

National Carer Organisations response to: Mental Health and Wellbeing Strategy Consultation

Introduction

The National Carer Organisations welcome the opportunity to submit a response to Scottish Government's Mental Health and Wellbeing Strategy Consultation.

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

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

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

Consultation questions and response

1.1	Do you agree	with this	description of	"mental	health"?

Yes.

1.3 Do you agree with this description of "mental wellbeing"?

Yes.

1.5 Do you agree with this description of "mental health conditions" and "mental illness"?

Yes.

2.1 On page 8, we have identified a draft vision for the Mental Health and Wellbeing Strategy: "Better mental health and wellbeing for all". Do you agree with the proposed vision?

2.3 If we achieve our vision, what do you think success would look like?

- Success would see equitable access to all services for all.
- Success would also see greater understanding of trans-cultural perspectives on mental health and how these views shape the mental health and wellbeing of diverse communities. To properly achieve this adequate funding resources need to be in place to ensure equitable services for all of Scotland's communities.
- Improved access to independent advocacy and different types of advocacy services being provided which meet the needs of diverse communities as well as all of Scotland's population.
- Early intervention and prevention programmes would be set up to avoid crisis situations developing.
- Support for unpaid carers of people experiencing mental illness is routinely available.
- Unpaid carers are seen as expert partners in the care and recovery of the person experiencing mental illness.
- Unpaid carers of anyone experiencing mental health issues, learning disability, neurodiverse conditions are identified and treated as expert partners in care.
- Physical health checks for people prescribed psychiatric medication are routinely offered.
- Integration of mental health across several policy areas such as carer's strategy work, Social Security Scotland, children and young people policies.
- Mental health and wellbeing of an ageing population, and their unpaid carers, is resourced and supported.
- Stigma is eradicated.
- The impact of COVID on population's mental health is targeted and resourced, including the impact of long COVID. Further research into long COVID is required so that evidence-based treatment is available.
- Children and young people's mental health is improved with significant investment in a range of services, not just CAMHS; but third sector, social care, independent sector provision etc.
- Range of treatment options are available for people, with reduced reliance on medication.
- Economic, social and cultural rights are enshrined for all of Scotland's people to help reduce or eliminate inequalities.
- Right to a healthy environment is enshrined in human rights legislation in Scotland.
- Eradication of homelessness and provision of quality, affordable and accessible housing.
- Fairer social security system which does not demonise those who need to use
 it.
- We would be able to see clearly the impact of interventions on mental health and on mental health support.

3.1 On page 9, we have identified four key areas that we think we need to focus on. Those were:

- Promoting and supporting the conditions for good mental health and mental wellbeing at population level.
- Providing accessible signposting to help, advice and support.
- Providing a rapid and easily accessible response to those in distress.
- Ensuring safe, effective treatment and care of people living with mental illness.

Do you agree with these four areas?

Yes. We would add in the caveat here that these key areas must be extended to unpaid carers of all ages providing care and support to person experiencing mental health distress and illness.

At a population level the recognition of the role of unpaid carers and the impact caring has on mental health and wellbeing should be seen as a potential risk factor which needs to be mitigated against through provision of relevant information and support services.

4.1 Do you agree that the Mental Health and Wellbeing Strategy should aim to achieve the following outcome to address underlying social factors?

Strongly agree. Mental health and wellbeing needs to be cornerstones of all policy areas if human rights, especially economic, social and cultural rights are to be achieved.

4.2. Do you agree that the Mental Health and Wellbeing strategy should aim to achieve the following outcomes for people?

People have a shared language and understanding of mental health and wellbeing and mental health conditions	Agree. However, account must be taken of cultural understandings of mental health and wellbeing and mental health conditions. Each person has a unique experience of mental health and this will be affected by the different facets of their identity, for example, the experience of a BME person may be tightly interwoven with their experiences of being a Minority Ethnic person.
People understand the	Strongly agree.

things that can affect them own and other's mental health and wellbeing, including the importance of tolerance and compassion People recognise that it is Strongly agree. However, it needs natural for everyday education and resourcing of primary setbacks and challenging care and third sector as well as life events to affect how education services to provide they feel preventative work. We would note that caution is needed here however when we are talking about the experiences of racism and discrimination faced by BME communities and other marginalised groups. Using the term "everyday" normalises these experiences. There must be explicit recognition that some communities face additional challenges Challenging life events can mean different things to different people and so we need to accept what someone is telling us about their reaction to a life event that others may be able to deal with. Challenging life events may also have a greater impact on unpaid carers as they are combined with the existing impacts of their caring roles. For example, unpaid carers experiences of the pandemic. Children and young people, people with autism or learning disabilities may have different ways of processing challenges. People know what they Agree, but care must be taken so that can do to look after their added pressure is not put on unpaid own and other's mental carers by expecting them to take on more caring responsibilities if someone health and wellbeing, how to access help and what to develops mental health problems. expect Unpaid carers, through the Scott Review of Mental Health Law have told us in the first phase of review, that

knowing what to expect when using services is vital to reduce anxiety and

	challenging behaviour. For example, if there is to be a waiting list that needs to be explained. Unpaid carers need information to help them manage the expectations of people using mental health services, and other services too.
People have the material, social and emotional resources to enable them to cope during times of stress, or challenging life circumstances	Strongly agree. This makes the commitment in National Care Service Bill to introduce a right to short breaks for unpaid carers essential, because breaks are vital to help unpaid carers restore their emotional and social health to enable them to cope at times of stress or life challenging situations. Unpaid carers may also need access to wider support, materials and resources during times of stress, such as access to counselling services, financial advice, self-management resources etc.
People feel safe, secure, settled and supported	Strongly agree. This is especially the case for those newly arrived in Scotland, particularly asylum seekers and refugees from war torn countries. Cultural diversity must be taken into account to help someone feel secure and safe. The understanding of mental health, feeling safe, secure, settled and supported will be different based on the experiences of individuals and this is why it will be important to take account of trans-cultural needs of communities such as BME, asylum seeker, travellers and refugees. Unpaid carers can feel supported and safe if they are identified and seen as expert partners in care.
People feel a sense of hope, purpose and meaning	Strongly agree. Having hope is fundamental to positive mental health and wellbeing. Meaningful activity, whether that is paid employment, volunteering or studying are all areas which provide purpose. For unpaid carers, access to short breaks and alternative support which helps them either stop their caring role or carry on but only undertaking caring tasks they choose will all help reduce the impact of

	unpaid caring. To reduce the detriment of caring on mental health, unpaid carers should be actively empowered and supported to set limits around their caring role.
People feel valued, respected, included and accepted	Strongly agree. In particular, unpaid carers report that feeling included in decisions and plans around the person they care for helps with a sense of being valued. Minority communities, including asylum seekers and refugees, need to be accepted as citizens of Scotland with equal access to services and support.
People feel a sense of belonging and connectedness with their communities and recognise them as a source of support	Agree. However, for this to be achieved adequate, affordable housing and a healthy environment need to be available for all. Support to build cohesive communities, with adequate, affordable public transport and cycle lanes need to be in place and people need easy access to information and places of support. It is vital that unpaid carers are supported to balance caring responsibilities with regular breaks to reduce isolation and enable carers to have opportunities to be connected to their communities.
People know that it is okay to ask for help and that they have someone to talk to and listen to them	Strongly agree. The help that is provided must be appropriate for the individual and not one-size-fits-all. It requires to take into account cultural diversity and needs and be offered at the right time and for as long as the person needs it. Carer centres play a vital role in supporting unpaid carers and it is essential that these services are fully resourced to help ensure unpaid carers get the support that they need to achieve and maintain positive wellbeing.
People have the foundations that enable them to develop and maintain healthy, nurturing,	Agree. This needs to cross over into other policy areas such as education and child and family services to enable such foundations to happen. Impact of

supportive relationships throughout their lives

COVID needs to be seen as one factor affecting the mental health and wellbeing of children and young people and may have caused such foundations to falter.

Services need to be informed through

research and evidence of best way to encourage stable and supportive relationships post- COVID. Poverty is an area which needs to be addressed if people are to develop the positive relationships and supports which protect mental health and wellbeing. For young carers poverty can be a barrier to them moving on and having an opportunity to achieve their full potential in life. Providing educational opportunities for young carers can be one way out of poverty, but education needs to be aware of the real, serious issues which young carers face that may make attending school difficult.

Parent carers need support to help them maintain a familial relationship rather than purely carer one.

Parents with mental health problems need support to maintain family life and only be separated from family for as short a time as possible.

Attention must be paid to the impact of parental mental health on young carers. This can lead to difficulties in family relationships and young carers not feeling as nurtured or supported during childhood and adolescence.

People are supported and feel able to engage with and participate in their communities

Agree. However, this will need investment in communities and building this from grass roots level; ensuring that members of communities have vested interests in what is happening and can shape their communities.

For children and young people access

to play areas and services (age appropriate and accessible) must be provided as play is an essential right of all children and how they learn. Equitable access is important so that play schemes, community groups, play

	equipment or spaces do not actually further disable a child or young person but are suitable to their needs.
People with mental health conditions are supported and able to achieve what they want to achieve in their daily lives	Strongly agree. Services must be flexible and provide person centred support which is wanted and which is identified by person with mental health condition, perhaps with support from family/unpaid carer to articulate what they want. The issue of capacity to make decisions about what a person wants to achieve should be dealt with using supported decision making and only when everything is exhausted can someone else step in and make a decision on behalf of someone with capacity issues, as is outlined in United Nations Convention on Rights of Persons with Disability.
People with mental health conditions, including those with other health conditions or harmful drug and alcohol use, are supported to have as good physical health as possible	Strongly agree. There must be parity between physical and mental health.
People living with physical health conditions have as good mental health and wellbeing as possible	Strongly agree. Physical and mental health services need to communicate with each other more to ensure that this parity works. Too often people experiencing mental health problems report that physical health services seem to think the problems are due to mental health. Better understanding of side effects of some medications and the impact they can have on physical and mental health is a must between professionals, patients and families.
People experiencing long term mental health conditions are supported to self-manage their care (where appropriate and helpful) to help them maintain their recovery and prevent relapse	Strongly agree. However, this must not be done to save on using services. Unpaid carers of people experiencing long term mental health conditions also need to be supported to help them support the person and maintain recovery. With relevant consent, information needs to be shared with

unpaid carers about the part they can play to prevent relapse.
Cultural and faith sensitivities need to be considered here, recognising cultural diversity and that there is not a universal understanding of mental health conditions, and that the notion of recovery can be different for many.

People feel and are empowered to be involved as much as is possible in the decisions that affect their health, treatment and lives. Even where there may be limits on the decisions they can make (due to the setting, incapacity or illness), people feel that they are supported to make choices, and their views and rights will be respected

Strongly agree. Possible cross over here with any recommendations from Scott Review of Mental Health and Incapacity law should be made. Unpaid carers should also be empowered to be involved, with consent, in decisions which affect their life, as well as the life of the person they care for.

Supported decision making and human rights enablement should become the norm within services so that people are more aware of their rights to make choices and decisions. Investment in education and training around rights of people will be required, as will investment in access to advocacy services for both unpaid cares and the cared for person so that they are enabled to seek redress if need be.

4.2.1 Do you have any comments you would like to add on the above outcomes?

It is essential that the focus on the above is not wholly around the person experiencing mental health conditions, but is for the whole population. Where mention is made specifically about people experiencing mental health conditions, it is important that unpaid carers of all ages are also seen as expert partners and are supported to make a contribution to the care of that person. However unpaid carers should not be expected to replace any professional or service, and to continue to provide care and support only for as long as they feel able and willing to do so.

There must also be an emphasis on the mental health of unpaid carers. Caring can have positive effects on mental health, but more often than not, it can be seen as a risk factor due to the demanding nature of caring roles, isolation, loneliness, financial impact and uncertainty about the future.

4.3 Do you agree that the Mental Health and Wellbeing strategy should aim to achieve the following outcomes for communities?

This includes geographic communities, communities of interest and communities of shared characteristics

Communities are engaged with, involved in, and able to influence decisions that affect their lives and support mental wellbeing	Agree. Unpaid carers of all ages need to be provided with the right support at the right time to help with their mental wellbeing. To do this requires consistent funding of local carer services and the national services which provide them with advice, information and support. This would complement the Scottish Government's commitment in the Programme for Government to invest in local carer services.
Communities value and respect diversity, so that people, including people with mental health conditions, are able to live free from stigma and discrimination	Strongly agree. This is essential if we are to see a human rights based approach to life in Scotland. It will however take investment and cross policy working to enable education and understanding of impacts of stigma and discrimination on diverse communities, including people experiencing mental health conditions and their unpaid carers who can face stigma and discrimination.
Communities are a source of support that help people cope with challenging life events and everyday knocks to wellbeing	Agree. Again, this will take funding and investment in cross policy working. Communities should not be used as a substitute for services when they are needed. Local carer services bring communities of unpaid carers together for peer support, information and advice and these must continue and have adequate funding to enable them to provide this. As we emerge from the pandemic, this is more relevant than ever as we have seen an increase in number of unpaid carers across all areas of Scotland ¹ .

¹ Carers Week 2020, Research Report,

 $\underline{https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf}$

	Support for unpaid carers in employment needs to improve and better rights for unpaid carers to have flexible working (wherever possible) and carers leave needs to be encouraged to employers.
Communities have equitable access to a range of activities and opportunities for	Strongly agree. The range of activities must be accessible to all and not cause further exclusion to people.
enjoyment, learning, participating and connecting with others.	Learning needs to be flexible to take into account other roles people perform, such as unpaid caring.

4.3.1. Do you have any comments you would like to add on the above outcomes?

Unpaid carers of all ages and caring roles need to be seen as a community with shared characteristics in that the impact of providing unpaid care, especially during and after the pandemic, affects so many aspects of an unpaid carers' life. The inequalities faced by unpaid carers is not something that is routinely noted in the mental health and wellbeing strategy, but we feel this must be done.

The majority of unpaid carers are female and working in low paid roles or in sectors which were adversely affected by furlough and businesses closing. This must be addressed through adequate social security benefits for unpaid carers, as well as redressing employment rights, accessible and affordable social care and childcare and promoting paid work through education access for young carers. Better and more support for student carers of all ages is also essential if we are to produce the high skilled workforce of the future.

4.4 Do you agree that the Mental Health and Wellbeing strategy should aim to achieve the following outcomes for populations?

We live in a fair and compassionate society that is free from discrimination and stigma	Strongly agree. Compassion must be demonstrated, and this can be done through compassionate service provision, which is not target or resource driven, but person centred, and human rights based.
We have reduced inequalities in mental health and wellbeing and mental health conditions	Strongly agree. This is fundamental to any mental health and wellbeing strategy which aims to be human rights based. But it will take investment and cross policy working.

We need to recognise and be prepared for dealing with inequalities. This cannot be a sticking plaster approach but a meaningful act of improving communities, increasing financial power of populations, improving the lived environment and access to the things that promote and maintain mental wellbeing.

Early intervention work needs more resourcing to be effective and education is needed on preventative approaches that communities and people can take to reduce the possibility of developing mental health problems.

We have created the social conditions for people to grow up, learn, live, work and play, which support and enable people and communities to flourish and achieve the highest attainable mental health and wellbeing across the life-course

Strongly agree. Young carers need to have the opportunity to be children and young people first. To do that they need adequate support, and to know that when the person they care for asks for help they will get it.

Older adult carers need support to carry on providing care if they wish to, recognising the physical and mental impact of caring in older age. That support also needs to include a review of underlying entitlement to Carer's Allowance for many older adult carers in receipt of the State Pension, which makes them ineligible to receive Carer's Allowance. Poverty in older people and the impact of providing care needs to be properly researched and solutions/recommendations come from this.

Working unpaid carers and those in learning need support to carry on these to help them feel valued, hopeful and to continue to pursue their own aspirations in life alongside their unpaid caring role.

People living with mental health conditions experience improved quality and length of life **Strongly agree.** Regular physical health checks must be a priority for all people living with mental health conditions. Unpaid carers must be listened to if they have concerns.

Action need to be taken to support unpaid carers to improve their quality of
life. Unpaid carers of all ages report
experiencing stress and mental health
. •
problems on top of providing care.

4.4.1. Do you have any comments you would like to add on the above outcomes?

The National Carer Organisations would like to see specific mention of young carers being mental health carers and the impact that this can have on their quality of life, affecting education, right to play, right to thrive, moving on from school to higher or further education, accessing employment etc. All of these are impacted due to providing care. With fluctuating nature of many mental health conditions there is also the concern over safety of unpaid carers of all ages. This can be a worrying thing for young carers affected by parental mental health or addictions issues and needs to be recognised as an impact on their mental health and wellbeing.

Similarly adult unpaid carers and older adult unpaid carers are also impacted by being mental health carers. This impact is different from many other unpaid carers due to the unpredictability of mental health conditions, fluctuating nature, stigma and loneliness which can be felt as friends and family retreat or services withdraw.

4.5 Do you agree that the Mental Health and Wellbeing strategy should aim to achieve the following outcomes for services and support?

A strengthened community-focussed approach, which includes the third sector and community-based services and support for mental health and wellbeing, is supported by commissioning processes and adequate, sustainable funding	Strongly agree. It is essential that the third sector are enabled to be part of the options for people to choose to help them with recovery. Services need to be appropriately funded to stop the year-on-year funding faced by many third sector organisations.
Lived experience is genuinely valued and integrated in all parts of our mental health care,	Strongly agree. This must include the lived experiences of unpaid carers of all ages.
treatment and support services, and coproduction is the way of working from service design through to delivery	Mental health conditions do not just impact the person with the condition, they impact on the people around them, the family and unpaid carers who are supporting the person.

	Having unpaid carers involved in coproduction brings an alternative view of service design and delivery.
When people seek help for their mental health and wellbeing they experience a response that is person-centred and flexible,	Strongly agree. This can be a cause of worry for many unpaid carers who are trying to care and support someone experiencing a mental health condition.
supporting them to achieve their personal outcomes and recovery goals	Unpaid carers have noted that when they approach a service for help for the cared for person that they can be ignored or told the person needs to make contact. Doing this de-values the experience of the unpaid carer at a time when the cared for person may be so ill as to refuse to make contact, or lacks the capacity to do so.
	Unpaid carers need to be seen as part of the recovery and part of the team around the cared for person.
We have a service and support system that ensures there is no wrong door, with points of access and clear referral pathways that people and the workforce understand and can use	Strongly agree. This pathway must also have clear points of access for unpaid carers to raise concerns they have, and the workforce needs Unpaid Carer Awareness Training (mandatory) to keep their skills and knowledge up to date with their understanding of unpaid carers and their rights.
Everyone has equitable access to support and services in the right place, at the right time wherever they are in Scotland,	Strongly agree. This needs adequate funding to be in place and closer working with the third sector to deliver some of these supports and services.
delivered in a way that best suits the person and their needs	Peer led services can also be great forms of support and investment needs to be put in place for such services.
People are able to easily access and move between appropriate, effective, compassionate, high quality services and support (clinical and nonclinical)	Strongly agree. Information should travel with people to prevent someone from having to tell their story over and over again to different people and services.

Services and support focus on early intervention and prevention, as well as treatment, to avoid worsening of individual's mental health and wellbeing Strongly agree. Too much emphasis has been put on hospital care and treatment with early intervention and prevention being neglected. Intervening early provides better outcomes not just for the person experiencing mental health issues but the family and unpaid carer. It is also of benefit to services.

4.5.1. Do you have any comments you would like to add on the above outcomes?

The National Carer Organisations would like to see specific mention on lived experience to include that of unpaid carers and the role they can play in coproduction and design of services.

4.6 Do you agree that the Mental Health and Wellbeing strategy should aim to achieve the following outcome for information, data and evidence?

People who make	Strongly agree.
decisions about support,	
services and funding use	
high quality evidence,	
research and data to	
improve mental health and	
wellbeing and to reduce	
inequalities. They have	
access to infrastructure	
and analysis that support	
this	

4.7 Are there any other outcomes we should be working towards? Please specify:

We believe that it would be progressive to see an outcome around peer research with people with lived experience, including unpaid carers, looking into the services which impact their mental health and wellbeing the most.

Children, Young People and Families' Mental Health

- 9.1 What should our priorities be when supporting the mental health and wellbeing of children and young people, their parents and families?
 - Widening the range of services available to children, young people and families so that they do not all fall under NHS or local authority control.
 - Third sector investment is needed to provide mental health and wellbeing services in local communities and outside of schools.

- Improvement in CAMHS for those with serious mental health conditions and ensuring that across every local area there are a consistent range of services that provide early intervention and preventative support..
- Specific neurodiversity services for children, young people and families.

9.3 What things do you feel have the biggest impact on children and young people's mental health?

- Provision of dedicated young carer services for young and young adult carers are important and have a big impact onto these groups of unpaid carers who can come together and be children and young people first and foremost.
- Access to education, free school meals have big impact. Being adequately fed and hydrated improves concentration and helps educational attainment.
- Children and young people should not have to worry about finances, families should be supported adequately through paid employment or social security assistance.
- Providing breaks for young carers and financial support for all young carers would have big impact onto the mental health of young and young adult's mental health.

11.1 Do you have any further comments on what could be done to address mental health inequalities for a particular group of people? If so, what are they?

Unpaid carers are a group of people where more could be done around their mental health and wellbeing. A survey from 2021 highlighted that 79% of respondents (all unpaid carers) felt that being an unpaid carer has affected their mental health².

Similarly, Carers UK noted It is estimated that 328,000 unpaid carers in Scotland are concerned for their physical and mental health and 195,000 are worried about their ability to cope financially³.

More support for unpaid carers of all ages is required with an investment in services aimed at unpaid carers' mental health and wellbeing, as well as access to regular breaks for unpaid carers of all ages.

15.1 The mental health and wellbeing workforce includes someone who may be:

- o Employed
- o Voluntary

o A highly specialised Mental Health worker, such as a psychiatrist, psychologist, mental health nurse or counsellor

o Any health and social care or public sector worker whose role is not primarily related to mental health but contributes to public mental health and wellbeing

² Third Force News, Nov, 2021 https://tfn.scot/news/unpaid-carers-physical-and-mental-health-suffers-signicant-decline#:~:text=The%20results%20show%2066%25%20felt,treatment%20for%20their%20own%20health.

³ Carers UK, 2022 https://www.carersuk.org/scotland/news/carers-week-2022-rising-pressures-on-scotland-s-unpaid-carers-as-public-backing-for-greater-support-grows

- o A social worker or Mental Health Officer
- o Someone with experience of using mental health services, acting as a peer support worker

The National Carer Organisations would urge Scottish Government to add unpaid carers to this list. Unpaid carers provide a lot of the support to someone experiencing mental health problems and are vital in helping to contribute to the mental wellbeing of the person being cared for.

- 15.2 The mental health and wellbeing workforce includes someone who may work / volunteer for:
 - o The NHS
 - o The social care sector
 - o Social work services
 - o The third and charity sectors
 - o Wider public sector (including the police, criminal justice system, children's services, education)
 - o The private sector
 - o Other

Other

15.3 If you selected 'other', please specify:

As previously noted, we believe unpaid carer should be included in this list.

Submitted by Karen Martin and Paul Traynor, Carers Trust Scotland on behalf of the National Carer Organisations.

Contacts:

- Karen Martin, Carers Trust Scotland: kmartin@carers.org
- Paul Traynor, Carers Trust Scotland: ptraynor@carers.org
- Claire Cairns, Coalition of Carers in Scotland: coalition@carersnet.org
- Fiona Collie, Carers Scotland: fiona.collie@carerscotland.org
- Kate Hogarth, Shared Care Scotland: kate.hogarth@sharedcarescotland.com
- Suzanne Munday, MECOPP: suzanne@mecopp.org.uk