

National Carer Organisations response to: Scottish Mental Health Law Review Consultation

Introduction

The National Carer Organisations welcome the opportunity to submit a response to the Scottish Mental Health Law Review consultation. In our response we use the term mental disorder/disability in much the same way as in the review, in other words to mean mental illness, learning disability, dementia, neurodevelopmental conditions and cognitive issues.

We have chosen to only respond to those parts of the review which concern the population we work with, namely unpaid carers of all ages.

Purpose of Law

On the purpose and principles being proposed, we are broadly in favour of them and wholeheartedly agree that there needs to be a minimum obligation for economic, social and cultural rights in the area of mental capacity legislation and the principles which underpin it. Without this there can be few meaningful routes to recovery and wellbeing for large parts of the Scottish population.

We agree with the approach being taken. Moving away from laws which are protective and possibly risk averse to a more enabling and human rights based legislative approach encourages recovery and places the person at the centre of what that recovery means for them.

However, we are concerned about the removal of the principle of “Respect for Views of Carers”, which is currently in 2003 Mental Health Act. This was widely welcomed when that Act was introduced, along with the Adults with Incapacity (Scotland) Act principle “Consultation with Relevant Others” which includes the wording of primary carer, as these were key pieces of legislation which acknowledged the existence and extensive role played by unpaid carers in the lives of people affected by these laws. To have that removed is an unacceptable step backwards and de-values the role of unpaid carers at a time when society is placing more and more emphasis on unpaid carers and families to look after relatives and friends.¹

We would welcome it if you would reconsider, as you suggest in the consultation, a return to the Millan principle of Respect for Carers as a specific principle thus giving value to unpaid carers and the role they play. We would also welcome a specific principle relating to children and young people as also mentioned in consultation.

¹ BBC Scotland, July 2021 <https://www.bbc.co.uk/news/uk-scotland-glasgow-west-57947825>

In our discussions with over 100 unpaid carers as part of this review, the overwhelming majority, across all ages, agreed that there needs to be a specific principle relating to unpaid carers. Without this it was felt that those working under the auspices of the pieces of law being discussed could simply overlook unpaid carers and have no regard to their views. One comment provided but echoed throughout our consultation exercises was: *“without recognition at the outset of the law we are just consigned to the background. This would be a disastrous step back at a time when we are, to some extent, given a voice when the person being cared for is under the Act.”* [MHA]. Unpaid carer response, 2022.

The four principles being suggested are welcomed as they do fit with the human rights based approach being discussed in the overall consultation. However, we would argue that they could be strengthened by the addition of Respect for Carers of all ages, their rights and views. This would also bring these pieces of legislation in line with Carers (Scotland) Act 2016², which places a statutory duty on local authorities, NHS and other agencies to involve unpaid carers and respect their views. The addition of the wording carers of all ages, highlights the importance of including young carers in this principle. Young carers are very often overlooked when it comes to services and we are told by young carers that this can have a detrimental impact not only to them but also the person they are caring for. One young carer commented: *“I know my sister so well and I am the only person she can really talk to. She really relies on me at home and to do things for her when she is too anxious to go out. So I would have thought I would have some useful things to add. Plus what the doctors decide affects me!”* Sibling carer³. This is an important point. As well as knowing the person, carers need to be involved in any treatment and care plans as there may be assumptions about the support they are able and willing to provide.

It is stated in the consultation that *“Our proposals seek to strike a balance – ensuring that everyone has a right to appropriate care and support within the context of the core human rights obligations”*. However, by not specifically stating a Respect for Carers as a core principle that balance is, once again, tipped away from those who - in most cases - play a pivotal role in the life of someone experiencing mental disorder or disability.

The National Carer Organisations welcomes the proposals on adequate income, housing and independent living, inclusion in society and accessible information. We have long advocated for adequate income which truly reflects and values the work and role of unpaid carers. Having the aforementioned income, adequate housing etc are necessary for all people’s mental health and wellbeing and so we are heartened to see this reflected throughout the review and endorse the system-wide change which the review is setting out to achieve. Moving away from the current paternalistic approach taken around mental disorder/disability can only be a good thing and moves Scotland into new era of human rights based services which enable rather than disable people. Taking such approach can be of great benefit to unpaid carers, as it puts them as part of the team around the person that they care for, rather than

² Carers (Scotland) Act, 2016, Scottish Government <https://www.gov.scot/publications/carers-scotland-act-2016>

³ Triangle of Care: Guide to Best Practice in Involving Carers in CAMHS in Scotland, Carers Trust Scotland, 2019.

someone who picks up the pieces once services withdraw or when the cared for person is discharged from a service.

Unpaid carers own mental health can be greatly impacted upon due to the nature of their caring role. The majority of unpaid carers are female and can find themselves caring for more than one person, usually an older relative and either a child or partner. The stress of this carries the real risk of developing mental health problems and the nature of caring means that unpaid carers usually put their own needs to back of their minds. Poor job security or having to give up paid employment is a reality for many unpaid carers, further adding to stress and anxiety. A recent Carers UK study found that the use of foodbanks during the pandemic had increased in families where there was an unpaid carer.⁴

The State of Caring survey⁵ in 2021 reported findings around unpaid carer health and wellbeing. It found that unpaid carers reported their mental health as worse than physical health with 30% stating their mental health is either bad or very bad and just 25% as good or very good. This highlights a worrying move towards poorer mental health, especially given that this figure has increased from 27% in just two years since 2019. For those caring for more than 35 hours per week the picture is even worse (as is the case with physical health).

The National Carer Organisations particularly welcomes the inclusion of unpaid carers as part of the lived experience and in particular wholeheartedly support your view that *“best practice should be defined by and with people with lived experience of mental disorder or unpaid care.”*

Supported Decision Making

This concept is one which unpaid carers are broadly in agreement with, but there are some concerns over undue influence and accountability of those providing the support to someone. Many of the unpaid carers we consulted with felt that this could be a role that a lot of unpaid carers do already, but also concede that sometimes it is easier for them to make a decision which they think is in the best interests of the person they care for. This shift away from that approach could see a change in the relationship between unpaid carers and the people receiving care, so this would need to be handled in a sensitive way. Other unpaid carers see it as a welcome assistance in the recovery and move to independent living for the person receiving care as one commented: *“Our daughter can make some decisions for herself and getting support to make other types of decisions, like where she lives, would be great for her self esteem and her view of herself as an adult.”*

The barriers to Supported Decision Making could be the reluctance of some professionals to give up their perceived power, this could also be a barrier for families as well. A cultural change is needed to ensure that people with mental disorder/disability are viewed as being capable of making decisions, no matter how small or large they may be, and that with support that can happen. Too often much is

⁴ Carers Week Research, Carers UK 2020 <https://www.carersuk.org/for-professionals/policy/policy-library/carers-week-2020-research-report#:~:text=Read%20the%20full%20report%20here>

⁵ State of Caring Survey 2021. Carers UK

https://www.carersuk.org/images/Research/CUK_State_of_Caring_2021_report_web.pdf?_ga=2.98637406.1135050592.1652276850-1462604597.1652276850

relied on a professional's diagnosis of incapacity, and it causes real concern with unpaid carer and families as to how this incapacity is determined. For example, someone deemed incapacitated and needing compulsory care and treatment is then able to consent or not to have their unpaid carer involved. For many unpaid carers, this seems like a contradiction and one which is never fully explained or explored with them or the person being cared for. By using Supported Decision Making, some unpaid carers feel this could be avoided and the true wishes of the person can be brought to the fore, as one unpaid carer stated: *"I just think it's easier for the staff to say he doesn't want you involved, rather than taking the time to find out if he actually means that."*

To mitigate against undue influence there would need to be some kind of training in place for people who wanted to be supporters, as well as information or training for those wishing to be supported. By giving information and/or training then the risks of undue influence can be minimised. The World Health Organisation states: *"It is important to train the following people on strategies to prevent and deal with potential exploitation from supporters:*

- *people with psychosocial, intellectual or cognitive disabilities*
- *families, care partners and other supporters*
- *mental health and other practitioners*
 - *peer workers and advocates*
- *legal professionals*
- *other relevant people from the community.*

*The training should address the social factors and processes that might make exploitation more likely to occur – such as power dynamics and discrimination across gender, age or disability."*⁶

This is not to suggest that this will be an easy or inexpensive option, but that should not deter Scotland in moving towards creating a Centre of Excellence to ensure that best practice is developed and shared worldwide.

Named Person

We were at the forefront in the 2015 review of the Mental Health Act in raising concerns from unpaid carers about the status of default named person. However, we did not want that replaced by Listed Initiator which we think is not understood and little used, certainly by unpaid carers.

The role of Named Person has great responsibility and can be onerous, but it is one that many unpaid carers want to take on. To enable them to do that however needs them to be trained in exactly what is expected of them and what their rights are. Currently this is not happening or is only happening if the unpaid carer asks the right questions to the right person. There needs to be accessible information campaigns around role of Named Person and what that might mean for an unpaid carer if they accept that role.

Where a person has not nominated a Named Person due to lack of capacity, the Tribunal, as the judicial body with powers to appoint or remove a Named Person should be able to approach an unpaid carer - if there is one - and ask them about

⁶ Legal capacity and the right to decide WHO QualityRights Core training: mental health & social services

taking on that role. This should not be forced onto the unpaid carer and they should not feel coerced into the role.

The Role and Rights of Unpaid Carers: Information Sharing

Information sharing is consistently an issue for unpaid carers, particularly with regard to mental health services. The issue of patient confidentiality is seen by some to be used as a barrier to providing even the basic of information to unpaid carers. Research tells us that family involvement is strongly recommended in clinical guidelines but suffers from poor implementation⁷. In further research, families and unpaid carers were seen as a resource in a number of ways. They were often seen as “potentially competent partners” in the stabilisation phase of the patient and in adherence to clinical procedures. They were also perceived as a source of information about the patient’s situation – whether directly or by observation.⁸

When viewed and treated in this light, unpaid carers can play a pivotal role in the care and recovery of someone experiencing mental disorder or disability. The reality however is very different, and we have heard from many unpaid carers (of all ages) how difficult it can be to share information or even be identified as an unpaid carer. This can be particularly the case for young carers. In Carers Trust Scotland’s document *Triangle of Care*, it was noted that young carers are particularly likely to not be acknowledged by mental health services and professionals. Young carers often have a wealth of hidden insight and information into the mental wellbeing and illness of the people they care for.⁹

The National Carer Organisations support the idea of a framework for identifying and working with unpaid carers of all ages. Such a framework can be found in our resource *Triangle of Care* but there appears little appetite within services to use this approach. Other approaches could be looked at and would include the Somerset model, which is a service-wide approach, developed to address policy and advocacy led calls for more family/unpaid carer inclusive services. All families/unpaid carers are offered an initial needs assessment and information about the service and may be referred to more intensive provision, such as local carer services¹⁰. Another model seen mainly in early intervention in psychosis service in Glasgow is family psychoeducation model. This has been developed from research into the role of family communication in relapse. Specialist teams provide a package of support, including at least an education component about the patient’s diagnosis and the recommended treatment; problem solving and/or communication training to simplify communication and emotional support for the family.

It is vital that the transcultural awareness of mental health is also at the heart of any engagement with unpaid carers and families. Different ethnic groups construct mental disorder differently and it is important that mental health practitioners pay due regard to this in order to ensure the best care and treatment for the individual. This is an instance also where it is vitally important that information is sought from family

⁷ Why Involve families in mental Health care, a collaborative conceptual review, BMJ, 2017

⁸ As in no. 5

⁹ Triangle of Care: Guide to Best Practice in CAMHS in Scotland, 2019

¹⁰ As in No. 5

members to enable mental health practitioners to better understand their construct of mental disorder.

We would be fully supportive of any of these models being recommended by the review team as ways of identifying and engaging with unpaid carers across mental health services.

Another area of concern for unpaid carers is that of involvement, or not, in discharge planning. We have heard of people being discharged in the middle of the night with family/unpaid carer having no notice of this happening. This cannot be allowed to happen and does not bode well for recovery of the person or trust in the service. Unpaid carers have also told us of not being ready for the person to be discharged. This can especially be true where an admission to psychiatric hospital has followed a crisis situation. Usually, unpaid carers have tried to safeguard the individual, and in some cases, tried to get services involved earlier. By the time admission takes place the unpaid carer is usually exhausted and worn out. Services need to be aware of the rights of unpaid carers to state their views about the discharge of someone they care for and whether they are ready to take that person home. Unpaid carers should not be forced into accepting someone back home. The Carers (Scotland) Act 2016 has placed a duty on health boards to involve unpaid carers in discharge planning, where practicable, and steps must be taken to ensure this is achieved within mental health services on as equal a footing as in physical health settings. Having a framework in place which includes unpaid carer involvement in discharge would be welcomed by the National Carer Organisations.

We support the recommendation of mandatory Carer Awareness Training for all mental health staff. This training should be for everyone who may come into contact with carers of someone with a mental disorder/disability and not just for nursing staff. It is our experience that it is primarily nursing staff who attend any Carer Awareness Training, but this training must be for the whole team, including consultants. How to make that mandatory is quite a feat but one way may be to have it as part of registration process or accreditation for professional body. Another way may be to include Carer Awareness Training as part of the academic training programme of professionals. This currently takes place, again for nursing students, at University of West of Scotland via Carers Trust Scotland's Mental Health Coordinator and proves to be very welcome and successful.

We would support any recommendation made by the review for mandatory Carer Awareness Training but would caveat that by stating that this training needs to be developed and delivered jointly between unpaid carers of all ages and local or national carer services. Currently there is online Carer Awareness Training developed by NHS Education for Scotland with unpaid carer involvement, but this needs to be strengthened as it is not compulsory for staff and it is not hearing directly from unpaid carers. It provides key messages to staff but misses out on a lot which can be gained from training developed and delivered by the experts, that is the unpaid carers and carer support services.

The involvement of local carer services and unpaid carers would require an injection of funding to help with roll out of such training and so any recommendation being

made by the review around accompanying funding for mandatory Carer Awareness Training would be supported by the National Carer Organisations.

Accountability

In this section of the review, we are especially welcoming of the recommendations for changing the system of how complaints are dealt with. Unpaid carers often talk about their fear of repercussions for the person they care for if the unpaid carer raises a complaint. Although these fears may in many instances be unfounded, many carers would rather not risk upsetting the care team or being seen as 'challenging' so would not raise legitimate concerns. This is not a helpful situation and invokes the question of how services can change and learn from mistakes. We agree wholeheartedly that complaints systems need to be designed around the needs of the complainant and not for the purpose of safeguarding the service which is how a lot of unpaid carers perceive the current complaints system, one unpaid carer stated: *"the system is made so complex so you just give up, that suits the service but doesn't change anything for us."*

Greater transparency is needed when complaints are being handled and a clear understanding of any learning must be noted and shown to be effective. By doing this, greater trust can be placed in the complaint handler and the service.

An issue which would help unpaid carers in the area of complaints - or even just raising a concern - is the lack of specific advocacy for unpaid carers. To date there are only a few unpaid carer advocacy services with one example being Edinburgh Carers Council. Other local carer services try and provide as much support as possible and Carers Scotland offers free carer advocacy training to unpaid carers. But many unpaid carers tell us that they would like to have access to carer specific advocacy. This can be especially true when engaging with mental health services and not just around making complaints. For many unpaid carers the mental health system is complex and daunting, full of language and terminology that can be disarming and alarmist. Having a dedicated advocacy service to help an unpaid carer cope with this would be very welcome and we would endorse any recommendation the review proposed around this type of service.

Children and Young People

The National Carer Organisations supports the reviews recommendation that there should be a specific principle which reflects the needs and rights of children. However, this should go hand in hand with a specific principle about respecting the needs and rights of unpaid carers, many of whom will be parents of children exposed to mental health services or be young carers (therefore children and young people).

Parent/unpaid carers tell us that sometimes they feel unheard when it comes to child and adolescent mental health services, with one parent stating: *"Not sure the consultant really 'gets it'. Much of the discussion was trial and error- which was OK as he was being honest – but would have felt better if he had been dealing with me as an expert on my child."*¹¹

¹¹ Triangle of Care: Best Practice Guide for CAMHS in Scotland, 2019, Carers Trust Scotland

We would agree that more needs to be done to ensure that services understand Article 5 of UNCRC stating that families have the right to support their child. However, this is not to suggest that a child under 16 who has capacity should not be allowed to make decisions for themselves. Many parent/unpaid carers are accepting of this provided there is information shared, with consent of child, that can help the parent/carer, or at least an explanation as to why the service is accepting the child's decision making. Too often parent/unpaid carers are simply told your child has that right without any further explanation. This can then lead to resentment and conflict within parent/child relationship.

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

Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The National Carers 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.