



Response from the National Carer Organisations: Quality Standards for Adult Secondary Mental Health Services

Introduction

The National Carer Organisations (NCOs) welcome the introduction of these quality standards. For too long we have heard from local carer organisations and directly from unpaid carers, that one of the missing pieces within mental health services has been a set of standards. They are essential to enable those who use services, their unpaid carers and those who work in mental health services can recognise, challenge, if need be, and be assured of progress towards such standards.

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

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

The following is our collective response to the consultation.

Access Standards

The NCOs agree that standards in this section will make mental health services better for people who use them. However, it is stressed that adequate resources will need to be put in place to ensure that improved standards of service are met, especially in light of the findings from Scottish Mental Health Law Review. In particular, there has to be a system for monitoring what is needed across mental health services to ensure the human rights of those accessing services are maintained.¹ Only through public scrutiny can we be assured that the standards set down for access are fully adhered to.

¹ Scottish Mental Health Law Review; September 2022 pg 79 Summary and Recommendations

1.2 If I seek support, I will be supported to get the help that is right for me regardless of where I first made contact

People experiencing mental health problems may first seek support from a range of health or community settings. Indeed, it may also be the case that the people seeking such support are the unpaid carers who have noticed a change in the person's presentation. For support to be effective, meaningful attention has to be paid to concerns raised by unpaid carers. Even where no consent has been given by the service user, or where the mental health service does not know the individual or unpaid carer, there is nothing to stop services hearing the concerns of an unpaid carer regarding a deterioration in the cared-for person's mental health. Similarly, such support must be appropriate and take into account the way in which mental health is viewed in ethnically diverse communities and how problems can be conveyed. It is not good enough to have a 'one fix for all' approach.

1.3. After I am referred to a service, I will be contacted with an estimate of the time I will have to wait to be seen. I will receive regular updates if the time I have to wait is longer than this.

This will be important for many people accessing services, but especially those accessing for the first time. In the situation where the person is possibly presenting with a first episode of psychosis, prompt attention is vital in order to reduce the duration of the psychosis and improve eventual outcomes. It will also be important for unpaid carers to have the person they care for seen promptly as this can aid their (the unpaid carer's) understanding and education in how to best support the person during their care, treatment and recovery. It also allows the unpaid carer to make plans regarding any employment leave they may need to take, arrangements for care of others (childcare etc) and can help them reassure the person waiting to be seen. With permission, regular updates about waiting times should also be shared with unpaid carers.

Information should be provided to the person waiting to use the service and unpaid carers about alternative places of support they can access whilst waiting.

Notification of when individuals can expect to be seen should be communicated to them in a format that is accessible to their specific and identified communication requirements.

1.6 I will get care and support at a time that suits my needs.

We agree that this is important, but it is also important that consideration is given to the needs of unpaid carers who may be accompanying the person. Very often we are told that appointments are made when it least suits unpaid carers, during working hours or school hours. Care must be taken not to overlook input of young carers here and to minimise disruption to their schooling routines.

"Given plenty of notice I can arrange time away from work, but quite often I don't get told about the appointment and need to rely on xxxx and he often forgets until the day before." (Unpaid Carer, Glasgow)

2. Assessment, Care Planning, Treatment and Support

Services need to be able to recognise how distress and difficulties may appear in different people, such as those who are neurodivergent, those who experienced trauma and people from diverse cultural and ethnic communities. This is also the same for the involvement of unpaid carers and the needs that unpaid carers may have which may affect their level of involvement or engagement. The Triangle of Care resource is one way of ensuring that services get such information about needs of unpaid carers and can therefore make reasonable adjustments to ensure their involvement as much as possible.

2.2 I will be asked what is important to me and this will be part of my mental health assessment, care planning, treatment and support. My carer or family can be involved if I want them to be.

We welcome this inclusion here. It is essential that where, with permission, unpaid carers are involved. Their engagement must be reflected in the person's care planning and support. Unpaid carers play a huge part in the recovery of someone experiencing mental health problems and that input should be accurately recorded and acknowledged to enable the unpaid carer to have the assurance that they are providing the best informal care they can. Also, the information held by the unpaid carer can prove valuable to services in establishing what the person is like when unwell and what techniques can be tried to encourage recovery.

2.4 The care and support I receive will be centred around my personal circumstances. This care and support will take into account my cultural and social needs and will be trauma informed.

The NCOs welcome the person-centred approach, as it should be an important component of any intervention. The recent Scottish Mental Health Law Review set out recommendations to Scottish Government concerning the establishment of core obligations on public bodies to meet economic, social, and cultural needs.² These are ambitious recommendations, but if the Scottish Government is determined to set down quality standards which reflect cultural and social needs, then these have to be seen within the context of social and cultural rights. By working towards these rights, the realisation of system changes in culture and the way services are commissioned and organised can only be of benefit to all the population.

2.5. Based on my needs and safety, my mental health care and support will be delivered in the community whenever possible.

The NCOs agree that individuals should be supported to remain in the community, including rural areas, with their families, unpaid carers, and friends. It is essential though that for this to happen effectively that unpaid carers must also be supported to continue to provide the level of unpaid care required. This means taking account of their needs through Adult Carer Support Plans and the use of the resource Triangle of Care.

² Scottish Mental Health Law Review 2022; Summary and Recommendations, pgs. 32-36

Gaps in services must also be identified to improve the commissioning and development of services going forward.

2.8 If I am having a crisis, I will be able to get information, care and support when I need it, in an accessible and safe space. I will be treated well by the people who provide my support.

The NCOs would like to see this standard strengthened to include unpaid carers' needs for support when they identify that the person being cared for is entering a crisis and needs additional support. The promotion of local carer organisations is also important as they can have a vital role in supporting the unpaid carer.

In a case where consent for involvement of an unpaid carer has been given, then it is essential this is shared with all involved, or likely to be involved with the service user. Too often we hear situations like this:

"They tell you to call the crisis team if you need help. You call and they (crisis team) won't deal with you [the unpaid carer] as they say they don't have consent. There is consent, my daughter has given it. NHS 24 are no better." (parent carer, East Renfrewshire).

The above highlights how information is not shared between services. Even when consent is not given, services can still, and should listen to an unpaid carer, especially when it looks like a crisis situation is developing. Very often the unpaid carer is in a precarious situation as a crisis deepens, and they can find themselves vulnerable and unsure on what to do. Turning to crisis services to help can be a way of relieving such stress for unpaid carers.

Further, it is essential that crisis responses are culturally appropriate and accessible to non-English speakers. A person's probability to experience a crisis will tend to be influenced by having one or more protected characteristics, and the NCOs believe that the standards should reflect that.

3. Moving between and out of services

Joined up options for care to be transferred within and between services and regions is essential to make such moves seamless and to reduce need for people to repeat their story to every different service encountered. Using a resource such as Triangle of Care throughout mental health services across Scotland could lead to a standardised approach to identifying and engaging with unpaid carers and this can 'travel' with them as the person they care for moves between services.

The ability to make a seamless move is especially relevant for the Gypsy/Traveller community, where moving between regions is common practice. Mental health issues are often viewed as a taboo in Gypsy/Traveller communities, which leads to difficulties in speaking up about mental health issues and approaching relevant support services. Hence, training of service providers should include a culturally competent approach.

3.1 I will have one written care plan which is made by me and the professionals supporting me. If I move between different services, this will include clear information which helps me make the move.

Having one written care plan, which also includes information about their unpaid carer/s and level of consent, would transform many people's experiences and make it easier for unpaid carers to play their role in the care, treatment, and recovery of the person they care for. However, the NCOs believe that it should be explicitly mentioned that the information will be translated and culturally competent.

3.4 If I am discharged from mental health services, I will understand how to get care and will easily get support if I still need it.

The NCOs believe this should be strengthened to reflect the duty on health boards under s28 of Carers (Scotland) Act 2016 to involve unpaid carers in discharge discussions and plans. The discharge process needs to be fully explained to unpaid carers so that they are aware of when someone is being discharged and can have the time for their (unpaid carer's) questions can be answered.

Unpaid carers also need to be aware of where to get further help, not only for themselves, but for the person they care for. Accessing such support and help should be made easy for unpaid carers who very often are the first people to notice a change in a person's illness or behaviour.

Are there any other areas of mental health services in which you think these standards could apply outside of adult secondary services?

These could also apply to third sector organisations providing support to people experiencing mental health problems and unpaid carers. Standards should also apply to transition services and times, such as CAMHS and older people mental health services to ensure smooth transition between services.

Please share with us any of your thinking on your answers above and give us your views on the standards overall.

The National Carer Organisations welcome the development of these ambitious Standards and hope to see many of them extended to include unpaid carers and what the standard of service they can expect when engaging with mental health services. It is to be hoped that the ambitions of these Standards translate into real-life benefits for those who use secondary mental health services and those who provide unpaid care to such persons, to maximally benefit recovery.

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
- Sune Skaarup, MECOPP: sune@mecopp.org.uk

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