



Response from Carers Trust Scotland on behalf of unpaid adult carers to the National Collaborative on the Draft Charter of Rights for People Affected by Substance Use.

Introduction

Carers Trust Scotland welcomes the opportunity to submit a response on behalf of unpaid carers that we consulted with on the Draft Charter of Rights for People Affected by Substance Use. To inform this response, we undertook a focus group with seven participants and two individual interviews with unpaid carers caring for a person affected by substance use.

Carers Trust in Scotland works to transform the lives of unpaid carers.

We partner with our network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes and raise awareness and influence policy.

Carers Trust's vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

An unpaid carer is anyone who cares unpaid for a friend, family member or neighbour who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support.

1. Does the content of the draft Charter apply to you and/or the communities you are involved in?

Many family members and friends who are affected by someone's substance use will be unpaid carers, whether they have identified themselves as an unpaid carer or not. This type of caring role is still heavily stigmatised for some and unpaid carer identification still poses as a challenge for those who care for someone affected by substance use.

The Starter Checklist for Families section of the draft Charter is of particular interest for our organisation, as it highlights how meaningful participation from unpaid carers can influence outcomes in healthcare decisions about the person they care for, and how this can be achieved.

2. What could improve the content of this draft? Is there anything you would like to add?

As part of our consultation response to the draft Charter, we spoke one-on-one with two unpaid carers, as well as co-hosted a focus group alongside SFAD (Scottish Families Affected by Alcohol & Drugs) with seven participants.

Overall, the feedback from the draft Charter was very positive. Unpaid carers we spoke to were pleased to see progress not just for their rights, but for the person they care for. There was optimism that this Charter could be a positive step in changing the stigma over drug and alcohol addiction, which they felt still very much exists in society and can be barrier to accessing support (for both the person affected by substance use and their unpaid carer/s).

There was general agreement that the seven rights included in the draft Charter are needed and were welcomed by those we consulted with. However, there were some hesitations over the content and language in the draft.

Some of the unpaid carers who we engaged with highlighted their concern over some of the language featuring in the draft Charter, which left them confused as to the actual meaning of some of the rights. Such as "Freedom from torture and other cruel inhuman or degrading treatment", "Freedom from arbitrary arrest or detention" were examples noted through our conversations. One unpaid carer continued that they often do not have the time, due to their caring role, to research and look up on what their rights are. Language which is unclear leaves them feeling confused and results in them having to undertake more research to try understand what the right specifically means, and how it will relate to them and the person they care for in their everyday life.

One unpaid carer we spoke to one-to-one agreed that the seven rights were extremely important for their husband who they care for. However, from their perspective, the draft Charter has been written through the lens of someone affected by substance use and not of the family member/unpaid carer lens.

"My husband has access to all those seven rights, as I am caring for him and ensuring those rights. However, in order to maintain his rights, mine are denied and that has come at a cost to me."

This unpaid carer expressed how when situations at home can be volatile due to her husband's addiction, she feels she is at risk of having some of the rights included in the draft Charter broken, for example the right to a healthy environment. The unpaid carer felt as though they would not know what steps to take if they felt their rights were being breached by someone being protected by the Charter.

From our organisation's perspective, an improvement to the draft Charter would be to include the term 'unpaid carer' when referring to family members. Often family members for people affected by substance use are undertaking a caring role unknowingly. They could know they are an unpaid carer, but due to stigma

they are reluctant to come forward to access support and advice. By including the term 'unpaid carer' it could have a positive impact on encouraging family members to identify as unpaid carers and enable them to reach out for support if needed.

3. What would support you to use the Charter in practice? (e.g. training, resources, guidance, different formats)

As mentioned above, concern around the language throughout the Charter was highlighted. There was agreement amongst the group that this subject matter can be difficult to understand, but that more could be done in the draft to make the content clearer and easier to understand. A suggestion was given for an easy-read version to be created so that family members and unpaid carers wouldn't need to read the full 28 page document, and a summary sheet would be helpful.

It was also suggested to include real-life scenarios in the draft Charter. Participants that we consulted with agreed that it can be difficult to fully understand each right and what it means on an everyday basis for people affected by substance use and their family/unpaid carers. However, if examples could be provided of scenarios when rights could be breached for each right, it could be understood better and people would be more likely to come forward with a complaint over a rights breach. This could also be helpful with unpaid carer identification too.

Training was also highlighted as extremely important when putting this draft Charter in practice. Questions in the focus group were also raised about who the Charter will be shared with, and who will be determined as 'duty bearers'. Some unpaid carers expressed that they would like the Charter to be shared beyond health and social care services, with organisations such as the police, prison services, housing and social security services as some examples. This was raised as often unpaid carers will have to engage with numerous services on behalf of the person they are caring for, and ensuring each service has the same level of training and understanding of the Charter could help prevent breaches of rights.

4. Can you foresee any challenges or barriers to implementing the draft Charter? How might these be overcome?

The main challenge to implementing the draft Charter identified by our engagement was ensuring that different organisations value and implement it to a similar level. As mentioned above, concern was highlighted that this draft Charter could only be implemented by health and social services. Whilst that it is needed and would be valued, if family members and unpaid carers caring for someone affected by substance use have to engage with other services - such as the police or a house association - and receive conflicting advice or support, there is fear that it could lead to confusion, frustration and the potential for rights breaches.

Some unpaid carers in the group discussed how their trust in services over the years had declined, due to poor communication and lack of support. A participant who previously was a young carer for their parent highlighted how as a child they were fearful of social services and the police in case they separated the family due to the nature of their parent's caring role.

Through this discussion about the breakdown of trust between services and family members who care for someone affected by substance use, there is a real opportunity for relationship building between services and service users if implemented well.

However, despite the concerns flagged on some issues on content, overall the draft Charter was met with positivity. If this Charter is fully implemented across services and with transparency, there was a belief amongst the group that it would help people affected by substance use.

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