National Care Service Consultation
Edinburgh Community Voices October 2021

(Easy Read version of consultation paper)

Edinburgh Community Voices is a collective advocacy group for people in Edinburgh with lived experience of mental health issues. ECV is supported by AdvoCard who supported their participation in this consultation and collated the response.

Feedback on consultation itself

It's badly designed, long and complicated. There is no way an individual with the kinds of support needs talked about here would be able to respond to this consultation without help from an organisation – even using the Easy Read version. It was a shame they could not have asked things in a more easily digestible way.

Question 1 - Do you think a National Care Service will help make sure good practice in services is shared across Scotland?

Mix of views - YES / NOT SURE

It could but this is not automatically guaranteed.

There has been a history of cutbacks since 2007.

Social care couldn't be a whole lot worse than it is at present. The social care system is broken and does need to be fixed. The current system does not respond to need. You shouldn't have to fight to get the absolute basic care that you need. They weren't sure if a National Care Service was the best way of doing this.

It's important to have free access to care no matter where it is – for instance care in the home or in the community. It should be universal. You're not asked if you have a house or how much money you have if you get treatment for your heart, you shouldn't be asked these things when you are accessing care.

The report is aspirational - it's good that they're talking about good practice. They would also want to see information about how to prevent breaches of rights and abuse of the system.

You need a model of good practice and training, underpinned by principles.

People with Lived Experience should get to say - this is what good practice looks like. Professionals also have a good idea. There should be collaboration.

It's good to see that they are talking about working in a person centred-way. Self-directed support is important. It increases choice which is a good thing, it means the patient is in the driving seat.

Are there any risks that we need to consider?

There are horror stories of how people have been treated in care homes. It could go wrong if it's not done carefully - 'the road to hell is paved with good intentions'. It depends on human input and human input is fallible.

It might be more difficult to implement in rural areas. Places where people have long bus journeys. A blanket approach could mean that some areas lose out, particularly if they need particular expenditure.

But there should be the same standards. A strong set of standards, with flexibility as to how those standards are met so services can still respond to individual needs in their areas.

There is a high level of aspiration here – a great deal of money is required to make it work. They would be worried that if the money was not put behind it the good intentions would just be that – good intentions.

Access to care and support

(Feedback)

Early intervention is important. It's not something that has to be expensive, in fact it can save money – early support in the community can mean that expensive intervention in a hospital is not required.

Support should be proactive not reactive

When doing a care assessment, they need to think about the danger of diagnostic overshadowing.

Professionals can be difficult to communicate with. Sometimes they say to people 'you can cope', when they're not coping.

Nobody is geared up in hospitals to think about social care.

You need a system that does not stigmatise against people for being in need.

Each area has to have good lines of communication with everything else.

Question 2: If you or someone you know needed to access care and support, would you contact these places? Please tick the ones you would contact.

- GP or another health professional
- Voluntary sector organisation, like a Carer centre
- Public sector organisation
- Drop in service in your community
- Council contact centre
- Contacting council by email or through their website Website or online
- A national helpline that can be contacted 7 days a week

ALL OF THEM – It would be good to have the option of all of them.

There would need to be a range of face to face options.

Some people have good relationships with their GP and would want to be able to speak to their GP about accessing care and support. One person has a good relationship with their GP and went to them for information about social care and was given the wrong information. GPs need to be better informed - although this is difficult when they are under a lot of pressure.

One person has had bad experiences with their GP and would want other options as they feel that their GP would only focus on the health side of things – a voluntary sector organisation would be better. Some GPs don’t consider mental health as part of their job. Workers at voluntary sector organisations in the community tend to be good listeners.

Question 3: How can we better coordinate care and support? This means how we will bring all parts together. Tick all that you think.

- Have one professional who co-ordinates everything for you
- Have one professional who talks to you, and then tells other people involved in your care and support what you have said
- Have local community or voluntary organisations who can talk to people involved in your care and support for you, when you want

ALL OF THEM

They would want to be involved in the decision making.

It would be good to have a key worker co-ordinating support.

You should get to choose or nominate your key worker. Or choose from a list of key workers. You should be able to reject a key worker if you don't like them, they don't come up to standards or you don't get on with them.

You should know that there will be somebody who can step in who has all the necessary knowledge if your key worker is off sick or on holiday.

It's important that if a professional or organisation is talking to other professionals or organisations, this is only when you want them to.

Question 4: Tell us how you think support planning should work? Tick all that apply.

- Me, my family and my unpaid carers should be involved in support planning – YES
- If I want to, I should be able to get help from a community or voluntary sector organisation to plan my support. - YES
- A professional working with me should decide what support I need, taking my views into account – MIX OF VIEWS, Some YES, some NO, some NOT SURE
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- My support should focus on the tasks I need to carry out each day to be able to take care of myself and live a full life – YES

- My support should focus on the things I want to live a full life – YES
- There should be a light touch process for people who need a little bit of support or should everyone have the same support planning - NOT SURE.

Comments:

You need to recognise that not everyone has family or unpaid carers.

Community/voluntary sector organisations helping with support planning should be independent from other services and should not pass on information without consent.

If a professional is deciding support they must take the person's views into account.

Another person said a professional would just tell them what they needed and make a decision based on their budget

Light touch process - This is difficult. They would want equality and everyone to have the same process, but if you only need a little support you should have light touch process. / Others thought that if only a small amount of support was needed you should be able to have a more simple process not the same process for planning for complex support needs

Question 7: Do you think information about your health and care needs should be shared across the different services you use?

YES with conditions.

Yes, but you should be able to have a level of control over it.

You should be able to stop people people accessing your records if you don't want them to.

It would be good for you to know what it's in your records so you can add a correction where there are any inaccuracies.

Question 8: What changes do you think would make a new system of complaints work better? Tick all that apply

- Charter of rights and responsibilities that says what people can expect from the service - YES

- Single point of access for feedback and complaints about all of the system – MIX OF VIEWS - NOT SURE / YES

- Clear information about advocacy services - YES

- The same model for handling complaints for all services YES

- Addressing complaints initially with the body the complaint is about NO

- Clear information about next steps if a complainant is not happy YES absolutely

- A commissioner to protect the rights of people who receive care and support – MIX OF VIEWS – NOT SURE / YES

Single Point of access for feedback and complaints about all of the system – the system could be overwhelmed

Advocacy is important.

‘A commissioner to protect the rights of people who receive care and support’ - They don’t have enough information about the role. It would need to be fully independent of services, ‘without fear or favour’. There should be a human rights agenda. It would be helpful (though not essential) if they had some kind of lived experience of the care system.

‘Addressing complaints initially with the body the complaint is about’- We weren’t sure exactly what this means

It’s good if you can take issues to the organisation early on with advocacy support to help, to help you avoid having to make a complaint.

Other – please explain below:

A charter for whistleblowing.

A proper recording and reporting system.

Question 10: Do you agree the Scottish Government should be responsible for the delivery of social care?

YES

It should be accountable to the Scottish Government.

Question 11: Should this be through a National Care Service?

YES

The National Care Service / Community Health and Social Care Boards should be bottom up not top down. If it's top down, with everything decided at the top by the NCS and with the NCS not listening to people in local areas about their needs and involving them in decisions about their services, you could end up with a blanket approach which suits some areas but not others.

They like that accountability would be changing and line of authority changing to Community Health and Social Care Boards > National Care Service > Scottish Government.

They would want people with lived experience to have a place on Community Health and Social Care Boards and to have a vote. That doesn't currently happen on Integration Joint Boards – they are sometimes given places, but not given support and not given a vote.

People with Lived Experience taking part in CHSCBs should have support to take part.

Question 13: What parts of mental health care should be delivered in a National Care Service? (Tick all that apply)

- Primary mental health services,
- Child and Adolescent Mental Health Services,
- Community mental health teams,
- Crisis services,
- Mental health officers
- Mental health link workers
- Other – please explain below

ALL OF THEM

All of the above should come under National Care Service, including CAMHS

Question 14: Should Community Health and Social Care Boards cover the same area as local councils?

YES

Question 15: The Community Health and Social Care Boards will have members that represent local people. Who else should be on these boards?

People with lived experience of mental health issues. Carers.

Question 24: What other support might help personal assistants and people wanting to employ personal assistants? (Please tick all that apply)

Feedback from one person about personal assistants:

They would want basic training and standards for personal assistants. There is a local organisation which helps people with self-directed supported advice and payroll services, but not everybody is told about this. This is a problem because the self-directed support / payroll process is confusing. Their friend has been going without support because they had been told they would have to get their care through self-directed support and they had not been told that this payroll support was available.