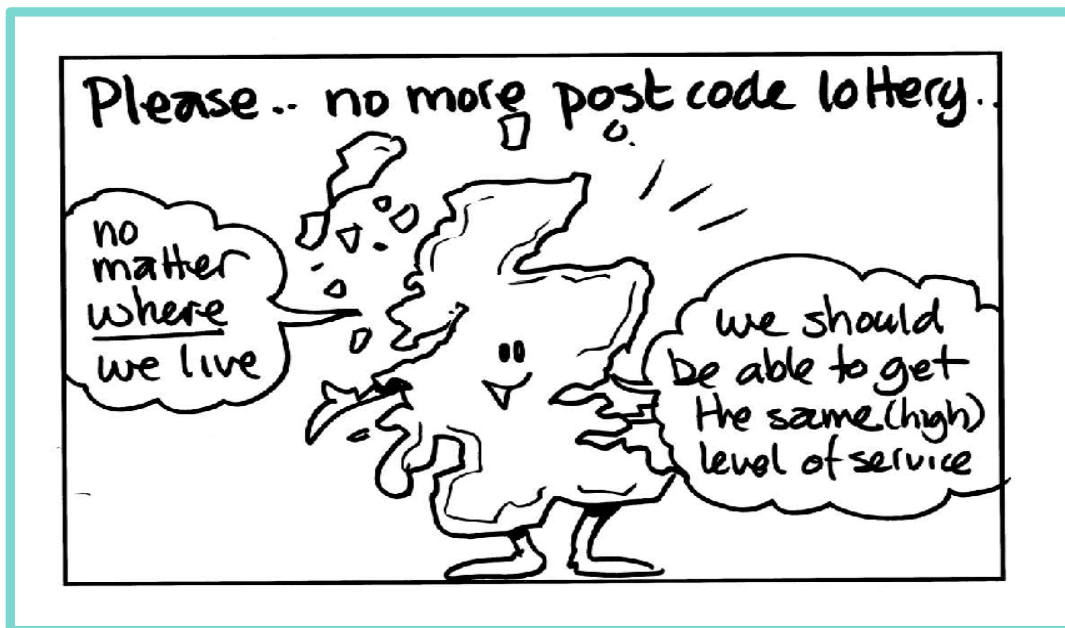




## VOX Scotland Response

### The Scottish Government's National Care Service Consultation

1<sup>ST</sup> November 2021



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# National Care Service Consultation

## VOX Members' Response

### Who we are

VOX is a national charity run by people with lived experience for people with lived experience. We represent our members' views to Scotland's politicians and health professionals to ensure our laws and mental health services reflect our members' needs and interests.

VOX welcomes the opportunity to present our members' views on the National Care Service consultation and we hope to positively influence the way in which these plans are taken forward with particular regard to the impact on mental health services and support, informed by a lived experience perspective.

### Who we engaged with

During August, September and October 2021 we engaged with 41 participants\*<sup>1</sup> from different areas of Scotland, including Argyll & Bute, Lanarkshire, Greater Glasgow, Lothian and Highlands. Due to the pandemic, the majority of the discussions were held online, though one session took place in person with individuals at a Simon Community residence.

Participants were diverse in terms of their mental health problems, and, also in terms of age, gender, LGBT status, ethnic identity and socio-economic circumstances.

Engagement with our VOX group members also took place, including:

- CAPS Advocacy
- Acumen
- Mental Health Network Greater Glasgow
- Time and Space
- Lanarkshire Links
- Advocard

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<sup>1</sup> \*Participant refers to either an individual VOX member, or another person with lived experience (e.g. VOX group member or another mental health group member).

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VOX also participated in the Scottish Government's Consultation online events and the event hosted by the Alliance. We sought clarification through questions to facilitators and contributed our members' views and concerns.

### **Methods for engaging with our members**

Right from the start of the consultation process, we found that participants were reporting difficulty engaging with the consultation information and questions on both a practical (initial lack of easy-read options, lack of BSL) and content-based level.

As people were finding it hard to relate the questions to their own experiences of mental health, and of social care needs and experiences, we looked to start discussions from a more approachable basis. For participants to engage more meaningfully with the consultation, we gave an explanation of the proposals and principles the Scottish Government put forward for a National Care Service and we prompted discussion by asking them:

- Whether people with mental health problems currently have their needs met (physical, emotional and social support).
- What needs to be focused on to ensure people have the social care they need to live independently, be active citizens, participate and contribute to society and maintain their dignity and human rights.
- What sort of service is required to address the needs of people with mental health problems.
- Whether they thought a National Care Service could help to make this work.
- What pros and cons could be identified about a National Care Service.

Due to the issues of accessibility and relatability, as well as pandemic circumstances, a mixed-methods approach was taken. VOX facilitated focus groups and individual sessions directly (online and in person) with participants who have lived experience while we also arranged for group members to consult and provide feedback from individuals in their groups, where this was more appropriate.

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## Background

Mental health problems remain a significant issue for people in Scotland. Approximately 1 in 4 people experience a mental health problem at some point in their lifetime, and at any *one* time around 1 in 6 people have a mental health problem.<sup>2</sup> Approximately 1 in 6 people in Scotland who are receiving social care currently, do so due to a mental health problem.<sup>3</sup> In 2017, 67% of those receiving social care due to a mental health problem were aged under 65. This is akin to the percentage of those receiving social care due to a learning disability, of whom 85% are aged under 65, whereas the majority in the other adult groups receiving social care were aged over 65.<sup>4</sup> The young and working-age cohort that so many of those experiencing mental health problems are in is an important factor to consider in the types of interventions and social care services and support that they may need.

As part of the Scottish Government's 2017-27 Mental Health Strategy, mental health is championed as equally important as physical health. The strategy therefore calls for a preventative, early interventionist approach, with acknowledgement that a broad range of factors influence mental health and contribute to mental health problems.<sup>5</sup> The development of integration between health and social care was seen as a crucial element in this strategy. It was legislated for in the Public Bodies (Joint Working) (Scotland) Act 2014 and work began on the integration in 2016, creating significant change to the model of working. The Health & Social Care Integration Review in 2019, agreed with the Audit Scotland report, that there was good practice developing, both in terms of how Integration Joint Boards (IJBs) were operating, and in how services were being planned and delivered to ensure better outcomes. Both the Review and the Audit Scotland report acknowledged that this was not yet the case in all areas of Scotland though and that work was needed to extend that good practice across Scotland.<sup>6</sup>

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<sup>2</sup> Public Health Scotland, Overview of Mental Health & Wellbeing, Key Facts

<sup>3</sup> Scottish Government, National Care Service Consultation, August 2021, Pg. 7

<sup>4</sup> Scottish Government Social Care Survey 2017, Figure 8

<sup>5</sup> Scottish Government Priorities, 2017 Mental Health Statistics, Priority 3

<sup>6</sup> Scottish Government, Health & Social Care Integration Review - Integration Review Leadership Group, 4 FEBRUARY 2019, Point 4

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The Independent Review of Adult Social Care has highlighted the geographical differences in access to support and services across social care. The review recommended the creation of a National Care Service in order to develop and maintain consistent high standards of delivery and practice throughout Scotland with clear accountability. The review also highlighted the importance of a human rights-based and person-centred approach.<sup>7</sup>

## Our Findings

### 1) The Consultation itself:

While participants expressed their clear desire for mental health support and services to improve, they reported being unsure if the creation of a National Care Service would necessarily achieve this improvement. Our participants reported finding it hard to understand *how* the proposed National Care Service would impact (positively or negatively) on the actual *delivery* of mental health support and services on the ground.

Those who had tried to engage with the consultation documents stated that the information and scope was quite overwhelming and that it felt far removed from their experiences. Participants also stated that many of the questions were complicated and seemed to require in-depth knowledge of how the yet-to-exist system would work before being able to answer them. ***“It’s badly designed, long and complicated – even using the Easy Read version.”*** (Participant)

Participants also described feeling that the consultation was ***“too rushed”***<sup>8</sup> to understand, consider and contribute to properly. In combination with these barriers to meaningful engagement, members expressed the concern that mental health support and services seemed to be an aside in the consultation, with little attention or clarity.

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<sup>7</sup> Scottish Government, Independent Review of Adult Social Care 2021

<sup>8</sup> Participant

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In exploring the questions detailed in our methodology, some other key themes emerged.

## **2) Impact on support, personalisation, equitability, and eligibility:**

Participants were concerned about what a National Care Service would mean for the practical delivery of the individual mental health services and support they need and rely on.

***“How is my support going to change? Will it be personalised and will I be seen as eligible for what I need?” (Participant)***

This theme divided into several issues that participants identified.

- a. Everyone agreed that access to the most appropriate and well-delivered mental health services and support for individuals is currently extremely inconsistent geographically. There is a postcode lottery at work. Participants in some rural and island areas felt they had a distinct lack of support and choice due to their location. Participants agreed that people should have equal access to the services and support they need no matter where they live, but there were concerns about whether, and how, a National Care Service would be more able to achieve this standardisation and consistency of quality and access of delivery than the current structures.

***“Having another new structure won’t automatically mean that there are staff and services in places that don’t have them at the moment or that delivery will suddenly be better quality.” (Participant)***

***“A strong set of standards (is needed), with flexibility as to how those standards are met so services can still respond to individual needs in their areas.” (Participant)***

- b. Some people were concerned that many of the local services, run by third sector organisations, for example, where the delivery standard is currently high and is

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appropriate for their individual needs, may be lost completely or **“dumbed down”**<sup>9</sup> if the system becomes more centralised and standardised. They stated that in areas where provision is lacking they want services and support to be **“leveled up”**<sup>10</sup> to meet the quality and access levels in areas where provision is better. Participants also want standards development to be based on the needs of people with lived experience rather than driven by clinical or financial criteria.

- c. Participants raised concerns regarding equitability and eligibility and what that would mean for the services and support they will be able to receive. Individuals expressed concern that in trying to make delivery equitable, the National Care Service may in fact further de-individualise care, assuming each person within certain criteria deserves and needs the exact same number of hours of support, or type of service, when in fact needs vary enormously from person to person. They confirmed that a person-centred approach was the right one but that the services, eligibility criteria and needs assessments must actually be guided by that principle in practice.

***“The current system does not respond to need. You shouldn’t have to fight to get the absolute basic care that you need. We are not sure if a NCS is the best way to fix this.”***  
**(Participant)**

- d. Our participants agreed with the preventative and early intervention approach which is proposed, and expressed their hope that this could be borne out in practice to prevent some mental health problems from escalating and reaching crisis point. At present, participants and our wider membership report that eligibility criteria often mean access to services is only achieved when need is severe and that opportunities for early intervention are routinely missed. The participants acknowledged the levels of investment this would require to be successful but would argue that this investment was absolutely worth it in terms of the benefits to people, but also in saving money spent dealing with crisis situations which are so much more expensive.

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<sup>9</sup> Participant

<sup>10</sup> Participant

***“Support should be proactive not only reactive.” (Participant)***



- e. A significant issue which participants raised on this topic was around the need for the system to allow for varying levels and types of support *one* individual may need at different points in time. Many mental health conditions see needs fluctuating and changing over time rather than remaining constant. Participants explained that individuals can need high levels of support at some times when they are very unwell, and lower levels of support at other times when they are well (or at what they feel is an acceptable level of functioning/quality of life).

***“Those lower levels of support are still very important in helping to maintain wellness or ‘recovery’, but how can needs be assessed properly to account for these changes, and how quickly could changes in support be made?”***

***(Participant)***

As research conducted on Self-Directed Support in Mental Health in Scotland found in 2013, ***“...many people using the services provided by third sector providers fall between two extremes, with periods of good functioning, and periods of very poor functioning. A person might require very little support one month, and extremely intensive support the next and their level of need for care services may vary... Participants were concerned that assessment and review systems may not be sensitive or accessible enough to plan for***



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***fluctuating needs.***<sup>11</sup> This is still a concern for our participants, who described the need for a flexible and adaptable system. The Independent Review of Adult Social Care also recognises that commissioning using generic frameworks based on hourly rates does not work well for people in this context.<sup>12</sup>

### **3) Developing and sharing good practice, integration and communication:**

- a. Participants talked about how good practice should be shared across Scotland to improve services and achieve the best outcomes for people wherever they lived. They acknowledged this would be beneficial but that it is something that can already happen within the current system and just requires a better system of communication between different providers.

***“A National Care Service could help this to happen but this is not automatically guaranteed. You need a model of good practice and principles behind it.”***  
***(Participant)***

Some participants spoke about how the Integration Joint Boards work at the moment and the worry that just as they are beginning to succeed they will be overhauled again. The development of IJBs has been a lengthy and difficult process in almost all parts of Scotland, and members worry that this is not the time for yet another major reorganisation. Some participants also expressed the view that people with lived experience should be involved in the new Community Health and Social Care boards as full voting members, but that people may need support to *play a full role*.

***“People with lived experience should get a say.”*** ***(Participant)***

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<sup>11</sup> Mental Health Foundation & Scottish Mental Health Cooperative - Self-Directed Support in Mental Health: Capacity Building for Third Sector Providers, Summary Findings, April 2013

<sup>12</sup> Scottish Government, Independent Review of Adult Social Care, 2021, Pg. 11

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***“People with lived experience taking part in CHSCBs should have support to take part.” (Participant)***

Some participants also spoke about the structure of the National Care Service and the CHSC Boards proposed.

***“The National Care Service and the 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 National Care Service, and with the National Care Service 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.” (Participant)***

- b. Most participants could see the benefit of better communication and record/information-sharing amongst different health and social care providers on individuals, their needs, support plans and care. However frustration was also voiced about how often this has been discussed and included in strategies, yet has failed to work even at a local level due to different IT systems, misplaced paper work, and data sharing laws. There was some doubt that it would be actionable without changing every service to the one IT system. People were in favour of having particular named contacts, and for information to be passed on where appropriate but with the proviso that consent was given by the individual concerned and that there was transparency so they also had access to their own health and social care records.

***“It would be good to have a named individual (e.g. officer or member of staff) coordinating support. But you would want to have choice in that, and know that if they were on holiday, someone else would be able to access information needed about you, but only if you wanted them to.” (Participant)***

***“It would be good to know yourself what is in your record so you can identify any inaccuracies and make sure things are updated. It would be good if records and plans were shared but only with your consent.” (Participant)***

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#### 4) The role of the third sector, contactable services, and resources:

- a. As mentioned with regards to the concern about local services being cut or “dumbed down” due to standardisation or centralization (Finding 2b), participants voiced concern about how smaller local third sector organisations would fare in a National Care Service environment, and whether they would be able to take on the burden of national regulations and standards, and the implications on resources for these organisations and services they provide. In particular, the burden of annual commissioning rounds and the need for voluntary organisations to have longer term contracts and financial settlements to enable development, staff retention and security. The importance of the role of third sector providers, and the wide range of innovative services they can offer, when considering mental health services in Scotland is easily demonstrated. ***“Third sector providers were at the forefront of developing and promoting person-centred, recovery oriented mental health services, and they continue to innovate and develop tools and approaches to support emerging service models such as peer support.”***<sup>13</sup>
- b. When discussing who people would want to be able to contact when in need of support, many participants said they would want a range of options, covering health and social care, and including third sector organisations.

***“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.”***

***(Participant)***

They also discussed the importance, coming out of the Covid pandemic, for there to be a range of options that included face-to-face services, voicing the impact that the isolation and lack of in-person contact and care from services has had on their mental health.

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<sup>13</sup> Mental Health Foundation & the Scottish Mental Health Cooperative - Self-Directed Support in Mental Health: Capacity Building for Third Sector Providers, Summary Findings, April 2013

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***“I don’t get to see my CPN in person now, it’s just phone appointments which I don’t find helpful.” (Participant)***

***“I feel like with the telephone appointments for my GP, there isn’t the same connection and they just prescribe me more pills that I don’t want, instead of seeing me and listening to what I really need.” (Participant)***

Participants talked about the services that matter to them and how things like mental health community hubs with drop-in support are a really important resource that everyone should have access to. This is something echoed by previous research, where individuals with mental health problems ***“pointed to the value of group sessions and drop-in services as being important to them, reflecting that Self Directed Support seemed to be very focused on individual services rather than group activities.”***<sup>14</sup> Participants also brought up the inconsistency in referring and signposting people to relevant support that is available and the action they think should be taken on this ***“if people are now not physically in GP surgeries, for example, to see a poster or leaflet advertising a service”***<sup>15</sup>.

Individuals also voiced frustration at the lack of out-of-hours service and support available, and the need for those services.

***“I’ve been feeding back for years now that we need more than just a service that stops at 8pm. We need an out of hours service that we can access for mental health problems, not just resorting to A & E or the police.”***  
***(Participant)***

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<sup>14</sup> Mental Health Foundation & Scottish Mental Health Cooperative - Self-Directed Support in Mental Health: Capacity Building for Third Sector Providers, Summary Findings, April 2013

<sup>15</sup> Participant



- c. Participants conveyed their concerns about the need to resource mental health services and support properly, through the National Care Service or otherwise. Participants expressed worry that resources given to services, including the third sector, had been cut or were only for limited time periods. As previously mentioned, (Finding 2d), the value of investing in proactive, consistent services and support to avert avoidable crises is clear and is less expensive than the alternative of paying for more acute and emergency provision.
- d. Some participants voiced their view that access to care should be free of charge wherever it is provided (community/home, geographically) in the same way that it is for a physical health concern.

***“It’s important to have free access to care. It should be universal.”***

***(Participant)***

Participants expressed concern that a great deal of investment (both in terms of time and money) would be diverted to setting up new governance systems and bureaucracy that could otherwise be spent directly on the more effective delivery of services and support.

Participants also stated the worry that the set up of the National Care Service ***“will be driven by cost-cutting (lack of resources) rather than a motivation to***

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*achieve the best possible system for individuals despite the resource implications”.<sup>16</sup>*

*“ (I) worry if the money is not put behind it the good intentions will be just that – good intentions.” (Participant)*

### **5) Workforce value and conditions:**

During discussions, participants talked about the importance of valuing the social care workforce, and how recruitment of experienced, caring and skilled staff would be enhanced by assigning the same value to social care staff as NHS staff. Participants spoke about how better pay and conditions to make it fair and attractive for people to join the social care workforce could help to some extent with providing quality services across different areas, and again alluded to the need to allocate the resources for this. It is also important to highlight the fact that remote and rural areas have additional challenges in attracting skilled staff, and that this must be considered.

### **6) Regulation and Complaints**

Regulation and complaints were areas where consultation questions were found to be quite confusing and difficult to answer without first knowing details of the National Care Service scope. Participants did say that ministers should be accountable for a National Care Service, and that they felt strongly about the attention paid to how human rights could be upheld.

*“We want to see information about how breaches of rights will be prevented.”  
(Participant)*

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<sup>16</sup> Participant

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## Summary

VOX hopes that our contributions from people with lived experience on the National Care Service consultation can genuinely help to inform and influence the proposals and plans going forward. We also hope some consideration will go into improving how future consultation around this topic and others will be expressed, taking on board accessibility and relatability issues raised at the start of this submission.

Our participants' responses highlight that the most important need is for improvement in access to and quality of mental health services and support across Scotland. But the responses do not necessarily share the view that the proposed National Care Service is the best way to make that improvement. Their comments also demonstrate significant concerns that an overhaul of the whole system, following many other changes in recent years, may have a negative impact on services in the short and longer term, with resources diverted to create new structures, which many fear will not in fact automatically produce better outcomes in terms of delivery on the ground.

Our participants support the need for significant investment in the social care sector and mental health services and support in particular, and want to ensure that good local services and third sector providers do not have to reduce their offer due to an inability to meet standardisation or regulation criteria or due to a lack of resources allocated to them.

Participants want to see clarity on how creating 'equitable' support will work, and how eligibility criteria can allow them to access the support they need, when they need it. Finally, our participants want communication amongst services to improve, and to be involved in decisions about services overall and choices about their own care, as is continually highlighted by our members at VOX.

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## ***Acknowledgements***

Graphics by Graham Ogilvie, Ogilvie Design Ltd.

Our sincere thanks to all participants, and to CAPS Advocacy, Time and Space, Acumen, Lanarkshire Links, Mental Health Network Greater Glasgow and Advocard, for their time and contributions.