



National Care Service consultation response

Introduction

About See Me

See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is for a fair and inclusive Scotland, free from mental health stigma and discrimination. We are working to change negative attitudes, behaviours and cultures towards mental health by growing the See Us movement, bringing people together across Scotland who are passionate about tackling stigma to work as one.

Our strategy, *With Fairness in Mind*, outlines our plans for tackling mental health stigma and discrimination, helping to achieve the Scottish Government's aim of creating a society "where people can get the right help at the right time, expect recovery, and fully enjoy their rights, free from stigma and discrimination."

We influence change in behaviours, cultures and systems so that people with experience of mental health problems are respected, valued and empowered to achieve the outcomes important to them. We do this through a blend of influencing and protest work, education and capacity building, and social contact.

Mental health stigma in social care and community health

See Me believes that addressing stigma and discrimination must be seen as foundational to all work to improve people's health. To achieve the best outcomes, mental health inclusion should be considered in all action to improve people's health. Unfortunately, mental health stigma remains a significant issue in social care and community health settings, and this can have profoundly negative effects on people's experiences of services and on their mental health.

People thinking about disclosing mental health problems in these contexts may worry about how their concerns are met. They may also lack the mental health literacy to describe their own condition. Being able to describe what you are experiencing can be especially difficult for young people.

People may experience stigmatising and discriminatory behaviour from social care and community health workers. People with lived experience of mental health problems have spoken about being treated as weak, attention seeking or inadequate. They can feel locked out of decision making, worry about things not being kept private, or being seen as a burden.

They might also face indirect and structural forms of discrimination such as a lack of professional knowledge of their condition, especially ongoing, complex conditions. They can find services inaccessible and overly complex. Many people describe the mental

health stigma and discrimination that they receive through systems such as social care as harder to deal with than their mental health condition itself. Covid and the outcomes of lockdown may well have exacerbated the situation by increasing demand on services, reducing access, and straining professional and care-giving relationships.

At the same time, See Me is mindful of the excellent job that so many carers do, and the extent to which they can also experience stigma, including self-stigma—often because they might feel unable to acknowledge their own mental health whilst caring for others.

Our work towards this submission

See Me has spent four years working closely with health and social care partners to improve their internal policies, workforce learning and development around mental health, embedding an anti-stigma culture in their organisations. We played a key role in the development of training for Distress Brief Intervention and we have supported better community mental health at a local level through our work with Moray Wellbeing Hub, our funding of Stigma Free Lanarkshire, and other initiatives.

Over the last year we have conducted research including working with See Me volunteers – who have lived experience-based expertise on mental health stigma – to develop a set of positions and perspectives on social care. In preparation for this submission, in September 2021, a group of See Me Policy Champions – volunteers with particular interests in social care and policy development – explored key themes for the submission.

Summary, general points and feedback

Ensuring mental health literacy and reducing stigma across social care

Reducing mental health stigma and discrimination across social care – for service users, their carers and staff – is vital to achieving a more person-centred, right-based system, where the needs of all three groups are properly acknowledged. Our response to this consultation is therefore not so much focused on the merits of developing a National Care Service as such – although we broadly support the idea (see Q20) – as on how that service, or any equivalent service, should account for mental health stigma and discrimination and seek to reduce them.

A National Care Service

We see the idea of a national service as a positive if it is able to provide overarching and enforceable standards of care and terms of employment. This is because nationally applied principles would offer a chance to embed mental health literacy , mental health inclusion and an anti-stigma agenda more evenly across Scotland’s social care and community health sector.

We acknowledge and support the findings of the Independent Review of Adult Social Care, in particular its findings around ensuring person-centred and human rights-based care, nurturing and strengthening the workforce, and offering greater recognition and support for unpaid carers. We believe that plans to create a National Care Service, making ministers responsible for the delivery of social care support and evolving

Integration Joint Boards into the delivery arm of the service (alongside third-sector organisations), should be geared towards achieving those outcomes.

During development sessions and focus groups with our community and policy champions we gathered qualitative evidence of stigmatising treatment through assessments for social care and community health care, including a tendency for social care workers to associate mental health conditions with weakness, attention seeking, and inadequacy. We also heard that people with mental health conditions can feel locked out of decisions about their care, including decisions around self-directed support, and that the people working with them often lack detailed knowledge of mental health problems, particularly more “severe and enduring” conditions. We also heard stories of inaccessible care.

At the same time, we heard many positive stories about social care and community health care, and valuable evidence from volunteers who worked in a community health or social care setting, or as unpaid carers. They often experienced a good deal of self-stigma around their own mental health, connected to a sense that it should be placed below the needs of the people they were caring for – in addition to stressors such as low pay and poor working conditions.

These issues are often contingent on policies and practices within individual local authorities, under the jurisdiction of particular integration joint boards. In general, the setting of consistent and enforceable standards across all Scotland’s local authorities, and across a range of services, will be positive if it allows a broad reduction of instances of mental health stigma and discrimination for health and social care users and staff like those outlined above. This could happen, for example, through setting core principles for regulation and scrutiny, ethical commissioning principles through the proposed Structure of Standards and Processes, strengthening codes of practice for employers, and ensuring Fair Work conditions for workers at a national level. We strongly encourage those with responsibility for setting out the standards of care for the National Care Service to meaningfully involve people with lived experience in developing those standards.

Themes from Policy Champions development session, September 2021

Views from our Policy Champions on the idea of a National Care Service in relation to mental health stigma and discrimination underpin many of our answers to questions below. Some of the themes discussed can be summarised as follows

POSITIVES

- There was broad though not unqualified support for the idea of a national care service
- There is a need for social care and community health services to be subject to a national standard; this might help particularly with reducing instances of stigma and discrimination experienced by service users with mental health problems

- It is difficult to see how exceptions to the idea of national standard for social care and community health users could be defined or justified
- The lack of mental health services in certain local authority areas may be seen as an inequality issue
- Communication and data sharing between services through a NCS could reduce the stigmatising effects of having to repeat traumatic or personal information to different services. People should not have to share their story every time they are trying to access support or services.
- Better communication and data sharing could create more efficient and appropriate services
- Many social care and community health staff need to be more mental health-literate: more confident and able to have conversations about the mental health needs of service users and signpost them to appropriate services.
- In some local authorities, assessment of social care and community health needs can be overly siloed and effectively discriminate against service users. For example, a mental health-oriented care assessment may not provide financial support physical health and support needs, hence writing discrimination into assessment processes.¹

POINTS OF CONCERN

- People with mental health problems have lived experience as social care and community health workers as well as users, and mental health stigma and discrimination within social care must also be reduced for and amongst this group
- Confidentiality and accuracy must be ensured in data-sharing between services to avoid stigmatising circulation of misinformation or private information about service users
- Service standards need to be defined in ways that recognise the demographic needs of different local authority areas, with a particular focus on distinctions between urban and rural or remote locations; this was connected to questions around the difficulty of defining quality of service. One issue of structural mental health stigma for people in rural communities is that there is not always the choice of service which best suits their personal need, or the service may not be easily physically accessible. A NCS should ensure that the availability of person centred mental health support is considered as important as physical health services.
- A national service should not risk cutting service users' links to local services that may fall outside the remit of its delivery. Inspection and registration regimes, for

¹ For example, we heard of a situation where the majority of someone's social support could be defined as "essential needs" (covered by free social care for working age adults). But they were told that, having been assessed by a mental health team, they would have to pay full costs for the same support. Any national service needs to ensure that discrimination of this kind is not written into policy.

example, need to be flexible to recognise how different models work in different places.

- From a care provider's perspective there were concerns about the practical difficulty of signing up to new, and potentially multiple, standards regimes and the effects on wellbeing and morale of this. Any new standards must take into account people's mental health and ensure it is supported.

Structure and wording of consultation

It was difficult to present on overall organisational perspective within the framework provided, which opts respondents into brief answers on a large number of specific points without providing much space to expand on more broadly relevant views, evidence, and ideas. We have chosen not to answer a number of questions – for example, most sections of “Scope of the National Care Service (54-88) – because they would have obliged us to repeat positions. We have instead outlined them above.

The above point, along with the length and density of the consultation, may have put organisations and – crucially – people with lived experience of social care and other relevant services off from responding. We accept the complexity of the themes involved and that this consultation was accompanied by a number of opportunities to respond to proposals orally. But the amount of preparatory information required to take part in these oral sessions might have made participation harder.

We suggest, as a point of constructive feedback, that consultations of this type are presented in more accessible language and that more space is provided for respondents to talk through themes in general terms from their own point of view and expertise, in their own language; rather than – or as well as – being invited to offer short responses on a large number of very specific and technical points.

Responses to questions

Improving care for people

Question 1: What would be the benefits of the National Care Service taking responsibility for improvement across community health and care services?

- Better co-ordination of work across different improvement organisations
- Effective sharing of learning across Scotland Intelligence from regulatory work fed back into a cycle of continuous improvement
- More consistent outcomes for people accessing care and support across Scotland

Question 5. How should support planning take place in the National Care Service? For each of the elements below, please select to what extent you agree or disagree with each option

a. How you tell people about your support needs :

Support planning should include the opportunity for me and/or my family and unpaid carers to contribute.

Strongly agree

If I want to, I should be able to get support from a voluntary sector organisation or an organisation in my community, to help me set out what I want as part of my support planning.

Strongly agree

NB. Many people with mental health problems find that meetings to determine their social care needs can be alienating, pressuring, and isolating. They can often experience a power imbalance with the professionals in the room—some report being talked over or ignored. One way of reducing experiences of stigma within social care settings would be to ensure that Community Care Assessments do not feel pressurising, judgemental, or too “high-stakes.” This can partly be achieved by allowing family, friends, or advocates to contribute assessment meetings; anecdotal evidence highlights that often advocates and carers are allowed to “be there” but not participate, which limits service users’ right to participation and decision-making. We also suggest providing options around location and form of contact (face-to-face, phone, online, etcetera), and not making decisions based on single meetings.

Question 6: The Getting It Right For Everyone National Practice model would use the same language across all services and professionals to describe and assess your strengths and needs.

Do you agree or disagree with this approach?

- Agree

Please say why.

With a more consistent approach to language being proposed there is an opportunity to ensure that language is mental health-inclusive and non-stigmatising across the board, as well as simple and accessible. It is important that co-production in the design and development of the model includes people with lived experience.

This approach could support with the transition between CAMHS services and adult mental health services for young people. Young people have highlighted how challenging it can be to transition to adult mental health services as a young adult, partly due to losing long-standing relationships built over time, but also because of the lack of information and guidance about processes and procedures in the adult settings to they're transferred.

Young people have also highlighted the inaccessible jargon and administrative processes they face when accessing support, as well as stigma around their age and presumed lack of capacity, which disempowers them further. This could be minimised by a more consistent approach to language. However, it is critical that people and young adults with lived experience are involved in the development of the GIRFE model, co-designing these with relevant stakeholders.

Question 7. The Getting It Right for Everyone National Practice model would be a single planning process involving everyone who is involved with your care and support, with a single plan that involves me in agreeing the support I require. This would be supported by an integrated social care and health record, so that my information moves through care and support services with me.

Do you agree or disagree with this approach?

Agree

Please say why

A single planning process could allow a more holistic and person-centred approach. However it is critical that this works in practice. The GIRFEC model, for example, has been challenging to implement in many areas and aspects such as the named person element.

The approach could also help to embed a rights-based approach that will reduce discrimination, focusing on what support people need rather than a choice between receiving or not receiving support. A GIRFE model would be geared towards including people in the decisions that affect their care and support rather than excluding them.

The approach presents more of an opportunity for community-based and early-intervention support, of a type that is significantly lacking within the current provision of mental health services. In theory, the model could also mean that service users do not have to share their story every time they are trying to access support or services.

Using data to support care

Question 11. To what extent do you agree or disagree with the following statements?

There should be a nationally-consistent, integrated and accessible electronic social care and health record.

Agree

Information about your health and care needs should be shared across the services that support you.

Agree

Question 12. Should legislation be used to require all care services and other relevant parties to provide data as specified by a National Care Service, and include the requirement to meet common data standards and definitions for that data collection?

Yes

Please say why

Our work with Community and Policy Champions suggests broad support for better integration and sharing of data. Data sharing has the capacity to reduce the stigmatising effects of having to re-share information. We agree with the assertion that “consistent, good quality and portable information would help people achieve their own goals and desired outcomes by ensuring those providing services have a better understanding of people’s care and support needs.”

At the same time, there is a need to ensure appropriate and respectful use of personal data, with controls in place that maintain data confidentiality and trust. Many of our volunteers raised concerns around security, in particular the stigmatising effects of confidentiality breaches and the spread of misinformation, which can be particularly traumatising for people with mental health problems.

National Care Service

Question 20. Do you agree that Scottish Ministers should be accountable for the delivery of social care, through a National Care Service?

Yes

NB. As noted above, we support the idea of a National Care Service if it ensures consistency of standards in a way that reduces mental health stigma and discrimination and tackles the “postcode lottery” effect in relation to social care and community health care. We also support consistent and better mental health learning and development and working conditions for social and community health care staff, which would help to reduce mental health stigma for both care providers and service users. People with lived experience should be at the heart of ensuring that this accountability is met.

Mental Health

Q52. What elements of mental health care should be delivered from within 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

Q53. How should we ensure that whatever mental health care elements are in a National Care Service link effectively to other services e.g. NHS services?

We note the finding of the Independent Review of Adult Social Care that integrated arrangements work especially well where the widest range of functions is delegated to integration authorities. We believe that this point holds in relation to mental health, particularly with regards to ensuring consistency of care standards and training principles and allowing data sharing and communication that could help to minimise mental health stigma and discrimination.

Effective linkages with NHS services could be achieved through maximum synchronisation between relevant NHS standards and regulations and the various models for ensuring consistency of care outlined in this consultation, including: core principles for regulation and scrutiny; ethical commissioning principles through the proposed Structure of Standards and Processes; strengthened codes of practice for employers; and measures to ensure Fair Work conditions for workers at a national level such as the Fair Work Accreditation Scheme.

Another challenge may be the clash between the medical and social models of health and disability that the two systems are likely to use. For the systems to synchronise they will have to find common language as well as effective data sharing systems, and workforces will have to be onboard with the process.

Membership of Community Health and Social Care Boards

Question 62. The Community Health and Social Care Boards will have members that will represent the local population, including people with lived and living experience and carers, and will include professional group representatives as well as local elected members. Who else should be represented on the Community Health and Social Care Boards (CHSCBs)?

See Me believes that CHSCBs should include care providers from across sectors and service users with lived experience of mental health issues and carers to be involved in the co-design and redesign of services, as well as monitoring of support and services. Research shows that a lack of mental health literacy within social care and community

health culture can still lead to diagnostic overshadowing of mental health conditions – and of the physical health of people with mental health problems. It can also prevent parity of esteem being established between mental and physical health. Achieving such parity of esteem is a key aim of the mental health strategy for 2017-27, and one that should be carried forwards into plans for mental health transition and recovery following Covid.

See Me works on the basis that social contact – meaning ongoing equal status co-production involving people with and without mental health problems – is vital to achieving outcomes such as the above, and the overarching aim of tackling mental health stigma and discrimination. For that reason, we would advocate for specific provision of regulation or guidance to ensure the inclusion of people with lived experience of mental health problems and those who care for them – on a paid and unpaid basis – in CHSCBs.

Commissioning of Services

Q67. Do you agree that the National Care Service should be responsible for the development of a Structure of Standards and Processes?

Yes. Within this we believe that there should be universal learning and development on mental health stigma and discrimination to social care and community health workers.

Q68. Do you think this Structure of Standards and Processes will help to provide services that support people to meet their individual outcomes?

Yes

Q69. Do you think this Structure of Standards and Processes will contribute to better outcomes for social care staff?

Yes

Q70. Would you remove or include anything else in the Structure of Standards and Processes

We welcome the idea of a Structure of Standards and Processes to ensure ethical commissioning and procurement processes nationally and locally. We believe in a compassionate, human rights-based approach driven by care quality and listening to expressed needs. All ethical commissioning guidelines and practices adopted by the National Care Service should be geared towards achieving these outcomes and that these criteria could be more clearly emphasised in the Structure.

We believe that stakeholders in the commissioning of services, including, crucially people with mental health problems who use social care and community health care, must be engaged in the co-production of those services. We would therefore request that the Structure makes clear that where commissioning involves mental health oriented social care and community health services, the stakeholders engaged as part

of the co-production process (see bullet point 5) must include people with lived experience of mental health problems and those who care for them. For example, a panel of service users including people with lived experience of mental health problems could be involved in the commissioning process.

The consultation also refers to a professional development programme “to ensure all commissioning and procurement professionals working with social care have the appropriate skills to effectively implement ethical commissioning and procurement.” It is crucial that this development programme includes adequate provision of training to ensure mental health literacy and reducing stigmatising and discriminatory behaviour towards people with mental health problems, including service users and other staff.

Regulation

We propose the following core principles. We have numbered these to make it easier when answering the questions, but they are all equally important.

- 1. Scrutiny and assurance should support human rights-based care, focus on outcomes for people, and the positive impact community health and social care services are making to their lives, including the relationships staff have with them.**
- 2. Activity should be targeted, proportionate, intelligence-led, and risk-based. This approach will allow the regulator to choose different types of scrutiny, assurance, or quality improvement intervention relative to the individual service and how it is performing.**
- 3. The NCS should generally seek to review, update, and improve standards and practices as an organisation and across the care sector on a regular and ongoing basis (this is a separate role and process from any improvements which those who have responsibility for delivering social care services (or overseeing those) may be required to make arising from enforcement or other action by the regulator).**
- 4. There should be a strong link between the regulation of the workforce and their professional standards and the inspection and scrutiny of the services they work in.**
- 5. Overall national scrutiny should involve the regulator working collaboratively, where possible, with other professions and agencies and continue to be informed by lessons learnt and good practice arising from the experience of the pandemic.**
- 6. Regulation is fundamental to ensure a qualified and skilled social care workforce which enables employers to deliver high quality, responsive care and support.**
- 7. Regulation is a key element in ensuring the safety of vulnerable people, ensuring high standards for practice, conduct, training and education across the workforce.**
- 8. Scrutiny and assurance should aim to reduce inequalities with an emphasis on people, prevention, partnership and performance.**

9. Where possible, regulators should involve people in the development and delivery of scrutiny approaches and amplify the voice of people experiencing care.

10. Where appropriate, scrutiny and assurance should take account of legislative requirements, Scottish Government policy, national standards, and codes of practice.

Q73. Is there anything you would add to these core principles?

We agree with the consultation's assertion that people-centred and human rights-based approaches should be at heart of core principles for regulation, and that arrangements should ensure consistent and high standards of care and support. It is important that core principles ensure consistently high standards of mental health literacy across the services administered through the National Care Service, and work to reduce instances of mental health stigma and discrimination. See Me believes that there needs to be a stronger emphasis on accountability around inspection and improvement within the core principles.

With regards to the first principle, we agree with the ideas of human rights-based care and a focus on personal outcomes, and on the positive impact of community health and social care on service users' lives. This principle could incorporate an explicit emphasis on discrimination to ensure that the rights of people with protected characteristics, including and overlapping with people with mental health problems, are guaranteed. The right to freedom from discrimination is a key human right, enshrined in the CRPD, CEDAW, and other international human rights regulation, and should be front and centre of National Care Service principles.

Under principle 9, we agree that where possible regulators should involve people in the development and delivery of scrutiny approaches. We believe that as a whole the principles could be strengthened on the point of involvement of lived experience, social contact, and co-production: not only in the scrutiny of services, but in their design and delivery. The principles should work to uphold a service which involves those who use it in its design, delivery, and assessment, through ongoing, equal-status co-production wherever possible. Where the service in question is mental health-oriented this should involve people with mental health problems and those who work with them on a paid and unpaid basis.

Q83. Would the regulator's role be improved by strengthening the codes of practice to compel employers to adhere to the codes of practice, and to implement sanctions resulting from fitness to practise hearings?

We believe the regulator's role would be improved by strengthening codes of practice to compel employers to adhere to the codes of practice and to implement sanctions resulting from fitness to practise hearings. We note, for example, that Scottish Social Services Council regulation obliges workers to meet certain standards for registration,

but does not place an onus on employers to ensure that their workforce are meeting these standards. We also note that some social services workforce are not regulated through SSSC, such as health care assistants, day care of adult services, and personal assistants. Employers are required to adhere to the SSSC code of practice but there are limits of the SSSC's power to enforce this, and there are no statutory obligations on organisation to ensure that staff attain qualifications required for regulation.

If a more binding regulatory framework included provision for a minimum level of mental health literacy that minimised instances of mental health stigma and discrimination, this would be beneficial for both staff and service users across the areas administered by the National Care Service. For example, employers would be obliged to assist with and enforce SSSC decisions on fitness to practice based on instances of stigmatising behaviour with regards to mental health or disability.

84. Do you agree that stakeholders should legally be required to provide information to the regulator to support their fitness to practise investigations?

Yes, for the same reasons.

Valuing people who work in social care

Q87. Do you think a 'Fair Work Accreditation Scheme' would encourage providers to improve social care workforce terms and conditions?

Yes

Please say why

We note that there is currently no ability to set minimum standards for workforce conditions within individual providers, and this leads to variety of workforce conditions across the sector; we also note the findings of a 2020 labour report, cited in the consultation, that many workers wanted to leave the social care sector to due to low pay and the difficulties of the role.

Our own qualitative research towards this consultation response highlighted that people with mental health problems are employed in the social and community health care sectors as well as benefiting from its services. There is grounds for arguing that poor pay and unreasonable workloads constitute a form of structural discrimination against employees with mental health problems if they make it impossible to fulfil the role effectively. Recommendation 44 of Independent Review of Adult Social Care is particularly supported in this sense: on putting in place national minimum terms and conditions as a key component of new requirements for commissioning and procurement by Integration Joint Boards.

We would therefore support the National Care Service in taking a lead in developing and administering national Fair Work principles. We would be keen to learn more details of an "accreditation scheme" approach to this end. For example, we would hope that this will prove sufficiently binding for employers to make decisions in the best

interests of their staff's mental health and broader wellbeing rather than an "opt in" system with minimal impact.

Q88. What do you think would make social care workers feel more valued in their role? (Please rank as many as you want of the following in order of importance, e.g. 1, 2, 3...)

1. Better access to training and development opportunities
2. Better access to information about matters that affect the workforce or people who access support

NB All the points noted are important and supported but we have focused on those geared around allowing social care and community health care workers to gain better mental health literacy.

Training and development

Question 92. Do you agree that the National Care Service should set training and development requirements for the social care workforce?

Yes

Please say why

The National Care Service should have many of the values driving its strategic decision making that See Me seeks (human rights, compassion, person centred approach, involvement of lived experience, consistent and high quality care, etc.). Given that the organisation will be starting out with these motivations across leadership, policy, communications, operations and other areas, it makes sense to be consistent and translate this into learning and development decision-making as well.

Learning and development should have mental health literacy and the reduction of mental health stigma and discrimination at its heart. Too many of the people See Me works with encounter uninformed attitudes to mental health in the social care and community health care system, and there is a sense that the quality of care received is often contingent on local authority area. This must be remedied through universal learning and development allowing social care and community health care workers to recognise the signs of a range of mental health symptoms, and to take steps to reduce direct and indirectly stigmatising behaviour and language in their interactions with clients.

Staff dealing with care users with more persistently stigmatised mental health conditions, including those described as severe and enduring, should have specific training on the condition in question. This should result in people with mental health problems being more meaningfully involved in decisions about their own care, with more participating in self-directed support.

Social contact on equal terms is key to reducing stigma and discrimination towards people with mental health conditions. Interaction with, and learning from, people with mental health problems must be central to all staff learning and development. It should therefore include face-to-face learning from people with lived experience wherever possible.

At the same time, it is not appropriate only to focus on training and development. Any new service must also create supportive conditions in which staff are able to apply their learning and skills. NCS should lead by example as a mentally healthy workplace, creating mental health-inclusive cultures, systems and processes within its services. Our [See Me In Work](#) programme can assist with this process.

The COVID-19 pandemic has laid bare the mental health impact of providing social care, and self-stigma continues to be a major issue for people providing social care, often because of a sense that the needs of the care recipient must come first. Mental health learning and development must include a focus on recognising the mental health needs of social care staff, including recognising signs of self-stigma and mental health struggles amongst colleagues.

The aim should be to have staff with the knowledge, ability and confidence to open conversations about mental health and signpost to support where needed. They should also be able to support each other as peers.

Question 93. Do you agree that the National Care Service should be able to provide and/or secure the provision of training and development for the social care workforce?

Yes