CAPS (The Consultation and Advocacy Promotion Service) is an independent advocacy organisation for people who have lived experience of using mental health services. We are set up so that we are as free as possible from interests which may conflict with those of the people we support.

We work with individuals and groups of people to set their own agenda, to find a stronger voice, to get their point across and influence decisions which affect them. We enable service users to get their issues on the agenda in service planning and provision, as well as supporting them to respond to consultations and inform strategy.

We were established in 1991 and provide individual and collective advocacy services in Lothian. We are committed to tackling stigma and discrimination. Our work is directed by our service user-led management committee and we place people with lived experience of mental health issues at the centre of everything we do.

CONSULTATION QUESTIONS

Overall Approach

This consultation reflects a continuation and development of the Scottish Government's current approach for mental health. There is a general consensus that the broad direction is right but **we want to consult on:**

- The overall structure of the Strategy, which has been organised under 14 broad outcomes and whether these are the right outcomes;
- Whether there are any gaps in the key challenges identified;
- In addition to existing work, what further actions should be prioritised to help us to meet these challenges.

The Strategy is outcome based and CAPS believes the best outcomes for service users, service providers, planners and the wider community will be achieved through the design of services that meet the needs of the people who use them, based on what the people who use them say.

The Principles of the Mental Health Act explicitly make a commitment to the participation of service users in all aspects of their assessment, care, treatment and support. We think the Strategy should make a stronger and clearer commitment to involving service users, not just in decision making about their own care and treatment, but also in the planning and provision of services, in the education and training of staff and in the evaluation of services. We think this is a key issue and should be one of the priorities for the next 4 years!

The Mental Health (Care and Treatment) (Scotland) Act 2003 gives everyone with a 'mental disorder' the right to access independent advocacy and the more recent McManus review of the Act highlighted the benefits of independent advocacy and the need to ensure adequate funding for its delivery. McManus made a specific point about the value of and need to properly resource collective advocacy services. We believe the Strategy

should strongly state a commitment to ensuring resourcing for the provision of independent advocacy to support service users to engage in any decision making that affects their mental health and wellbeing.

CAPS also believes that the best use and targeting of services will be achieved through collaboration and effective partnership working between all stakeholders. We think that the Strategy should more explicitly place value on the contribution the voluntary sector and service user led services can make, especially in the community.

There is evidence that demonstrates strong links between mental wellbeing and housing, employment, education and deprivation. Until politicians and other influential members of society are prepared to support policies that directly challenge the way power and privilege are used to maintain inequality, it is hard to believe we will be able to do much to improve the mental health and wellbeing of the growing number of people experiencing some form of discrimination in Scotland.

Improvement Challenge Type 1

We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes. An example of this is the implementation of the Dementia Strategy. There is a consensus that services for people with dementia are often not good enough and we already know about a range of actions that will improve outcomes. However some of these changes involve redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.

Question 1: In these situations, we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes.

Better monitoring and accountability of joint planning between NHS Boards and Local Authority partners. More effort should be made to ensure the meaningful participation and influence of service users, both through their individual experiences and their collective views.

The Strategy should strongly state a commitment to ensuring adequate resourcing for the provision of independent advocacy, including collective advocacy, to support service users to engage in this process. Boards and Local Authorities should produce, evidence and resource local independent advocacy plans which should be reviewed on a regular basis.

Improvement Challenge Type 2

We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes. Supporting services to improve care for people with developmental disorders or trauma are two areas where further work is needed to identify exactly what needs to happen to deliver improved outcomes.

Question 2: In these situations we are keen to get your views on what needs to happen next to develop a better understanding of what changes would deliver better outcomes.

Better participation and influence of service users in the development, provision and evaluation of services. Service users should be encouraged and supported to take part in developing creative new ideas for service delivery.

The role of independent collective advocacy in supporting the participation of service users should be recognised and resourced.

Outcome 1: People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.

Question 3: Are there other actions we should be taking nationally to reduce self harm and suicide rates?

More services based on models service users say work best for them, for example the Edinburgh Crisis Centre.

More access to early intervention services.

Feedback we get from service users suggests that attitudes of staff, particularly at A & E need to be addressed. Dismissive and discriminatory comments and treatment do not support service users to take more control. We believe that service users can play an important part in challenging and changing staff attitudes and practice when their involvement is valued and supported.

SSRIs are prescribed to children and young people despite there being evidence that an additional effect of SSRIs is an increase in suicidal ideation and self-harm. The use of SSRI prescribing to children and young people should be further investigated.

More socially responsible policies and action by politicians. Address inequalities in education, housing, employment and health!

Support the safe participation of service users in holding difficult conversations with each other, professionals, family members and carers, and the public about mental health and well being. Platforms such as the Scottish Mental Health Arts and Film Festival can provide opportunities where people can engage with each other within the safe zone offered by 'arts spaces'.

Collective advocacy provides space for service users to come together to explore common issues, express their views and rehearse solutions to addressing the stigma and discrimination they can face.

CAPS believes that there is power in the words people use to describe their own experiences. More opportunities should be created to help people break through traditional power relationships, to cut through jargon and to develop more critical thinking and problem solving approaches to mental health issues. Service users should be given more opportunities to lead learning for staff, professionals and the public through supporting their exposure to and involvement in the experiences of service users.

Provide information to families when a family member is experiencing mental health problems.

Question 5: How do we build on the progress that *see me* has made in addressing stigma to address the challenges in engaging services to address discrimination?

See answer to Question 4.

Continue to resource *see me* to support creative ways for service users to use their own words to describe their views and lived experiences.

Question 6: What other actions should we be taking to support promotion of mental wellbeing for individuals and within communities?

Government and other public bodies should take more of a lead in employing and supporting people who have lived experience of mental health problems.

Improve education, housing and employment opportunities. Address the discrimination in the way eligibility to welfare benefits are assessed for people experiencing mental health problems.

Encourage the realistic representation in the media, arts, film, etc of the impact mental health issues, positive and negative, can have on people.

Make sure accessible information is readily available to people about mental health and wellbeing, what affects it, what you can try to do yourself, and what services are available.

Outcome 2: Action is focused on early years and childhood to respond quickly and to improve both short and long term outcomes.

Question 7: What additional actions must we take to meet these challenges and improve access to CAMHS?

The provision of independent advocacy services to children and young people should be detailed in Board Independent Advocacy Plans. Plans should be implemented and properly resourced. Adequate independent advocacy services to children and young people should be provided by properly trained and skilled staff and should not be funded at the cost of services to other age groups.

SSRIs are prescribed to children and young people despite there being evidence that an additional effect of SSRIs is an increase in suicidal ideation and self-harm. The use of SSRI prescribing should be further investigated by the Scottish government.

Question 8: What additional national support do NHS Boards need to support implementation of the HEAT target on access to specialist CAMHS?

They need to be reminded that under the Mental Health Act, children and adolescents have a right to access independent advocacy services and that NHS boards have a duty to make sure these services are available.

Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.

Question 9: What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?

GPs are often the first point of contact for people when life events begin to cause stress, it is important that GPs have a good understanding of mental health and wellbeing and are able to link these with the concept of recovery.

Improve the education and training of GPs on mental health issues, including recovery. Improve information and support to GPs on self-help and early intervention services.

Support more opportunities for public exposure to stories of people's lived experiences, their journeys of recovery and the ways they have found to take back control.

Independent advocacy can enable people to identify options and access support. Make sure that advocacy services are available and positively promoted by mental health staff and professionals.

Make sure accessible information is readily available to people about mental health and wellbeing, what affects it, what you can try to do yourself, and what services are available.

Provide befriending support to people to help them engage with services and activities.

Question 10: What approaches do we need to encourage people to seek help when they need to?

People have told us about a wide range of responses they have experienced. On the one hand people have described their lives being taken over by overprotective practitioners, while at the other end of the scale the response has been to fob people off with a prescription and little or no explanation or engagement. It is easy to see why somebody would be reluctant to seek help again, quickly, if this has been their experience of approaching services for help in the past. Services need to be open, honest and reach out to people. Independent advocacy can be a powerful partner in supporting somebody to understand and explore their options and to help them feel that they can take control back over their lives and their futures.

Services need to be accessible and welcoming. The link between mental health and wellbeing and social issues such as employment, housing, poverty and discrimination needs to be more clearly linked in the

construction of social policy and the way services are planned and provided. It is difficult for people to feel it is in their power to take more control while mental health is still so strongly constructed as a medical problem.

Build a stronger and better publicised evidence base of people's lived experiences of recovery.

Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.

Question 11: What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?

We think there should be a clearer commitment to involving service users, not just in decision making about their own care and treatment, but also in the design of services and in the education and training of staff. We believe that involving service users in the design of services results in better targeted resources and more effective services.

Independent advocacy services provide support that enables individuals to more safely contribute to this process.

Mental ill health and deteriorating mental wellbeing can be the result of many different events in a persons life. There should be a wider range of public sector pathways to support people, responsibility should not just rest with specialist mental health services.

Access to services needs to be straightforward and presented in a positive way.

Outcome 5: Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently.

Question 12: What support do NHS Boards and key partners need to apply service improvement approaches to reduce the amount of time spent on non-value adding activities?

The Strategy should more strongly promote the value of service user participation in evidencing the outcomes of services for them.

Independent collective advocacy services provide support that enables individuals to more safely contribute to this process. NHS Boards should be more directly accountable to the Scottish Government regarding the development and implementation of advocacy plans. Boards should be able to identify and protect resources to adequately fund the delivery of independent advocacy services.

Boards and their partner Local Authorities should be required to evidence how they have enabled service user participation.

Question 13: What support do NHS Boards and key partners need to put Integrated Care Pathways into practice?

NHS Boards need to continue to report on the implementation and outcomes of ICPs.

Scottish Government should ensure there are funds available to evidence the use of ICPs.

Outcome 6: Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.

Question 14: How do we continue to develop service user involvement in service design and delivery and in the care provided?

Make sure NHS Boards fully implement their Independent Advocacy Plans based on evidenced needs assessments, which cover the commissioning of both individual and collective advocacy.

Boards should be asked to evidence that the advocacy services they commission meet the Principles and Standards for Independent Advocacy (SIAA 2008).

Boards and their Local Authority partners should be required to evidence and report on how they have enabled service user participation and what the outcomes have been, not just for service users but also for planners, staff delivering services and wider communities.

Boards and Local Authorities should be encouraged to commission service user led services.

Stronger links should be encouraged and supported between service user groups and academic institutions, to enable the building of a stronger evidence base for service user participation at all levels of service design, delivery and evaluation. The Scottish Government should recognise the value of and provide support for service user led research.

Question 15: What tools are needed to support service users, families, carers and staff to achieve mutually beneficial partnerships?

Develop education and training material based on the experiences of each of these interest groups and aimed at helping them explore and understand each others issues.

There is power in the words people use to describe their own experiences. More opportunities should be created to help people break through traditional power relationships, to cut through jargon and to develop more critical thinking and problem solving approaches. Service users and carers should be given more opportunities to lead learning for staff by supporting staff exposure to and involvement in the experiences of service users and carers. Tools such as Forum Theatre and Readers Theatre have been used to enable engagement in social issues, explore the use of these tools in developing new ways of working together.

Question 16: How do we further embed and demonstrate the outcomes of person-centred and values-based approaches to providing care in mental health settings?

See response to previous Question.

Support research, including service user led research, into exploring and evidencing outcomes.

Value and promote advocacy, individual and collective, as a way of creating safe spaces for service users to explore and identify the outcomes that are important for them and to reflect on their experiences of the care they have received.

Hold more local and national events to discuss practice and outcomes.

Support more service user led participation in the education and training of staff and professionals including the development of training material by service users.

Question 17: How do we encourage implementation of the new Scottish Recovery Indicator (SRI)?

Make more use of social media, film and art events, as well as training events and publicity to increase the exposure of GPs, workers and professionals in public, voluntary and private sectors, to the concept of recovery and the SRI.

Use local voluntary sector and faith networks to publicise concept of recovery.

Increase opportunities for service users to promote and provide training on recovery.

Question 18: How can the Scottish Recovery Network develop its effectiveness to support embedding recovery approaches across different professional groups?

Increase opportunities for service users to directly promote and provide training on recovery.

Ask all NHS Boards and their partner Local Authorities to establish educational and training programmes for all professional groups. Allow access to voluntary sector providers. Ask them to report back and evidence the effectiveness of their programmes.

Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.

Question 19: How do we support families and carers to participate meaningfully in care and treatment?

Make sure there are easily accessible and appropriate services available for service users so that they do not have to rely on family/carers if they don't want to.

Make sure there are easily accessible and appropriate services available to support families/carers.

Recognise there are times when carers do not want to care.

Make sure any support services understand and manage potential conflicts of interest between service users and family/carers.

Make sure NHS Board Advocacy Plans separate independent advocacy provision for service users and that for carers.

Question 20: What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?

NHS Boards should make sure independent collective advocacy is commissioned to support and enable carers to work with staff groups to identify and design relevant, appropriate and accessible information for families/carers. Carer groups can also advise and help with the distribution of information.

Service user advocacy groups should also be involved in deciding which information is appropriate and to develop protocols to make sure service users interests are respected and protected.

Outcome 8: The balance of community and inpatient services is appropriate to meet the needs of the population safely, efficiently and with good outcomes.

Question 21: How can we capitalise on the knowledge and experience developed in those areas that have redesigned services to build up a national picture of what works to deliver better outcomes?

Make use of local and national networks to circulate information on, and discuss practice.

Hold national networking events.

Require Boards to publish information on a national website.

Make sure redesigned services are evaluated by service users. Make sure this is done in a meaningful way and does not just rely on 'customer satisfaction' questionnaires.

Support the evaluation of services by independent service user led groups.

Encourage constructive, critical debate on the experiences and outcomes for all stakeholders.

Offer national acknowledgment of innovation and good practice, awarded by a panel of service users each year.

Outcome 9: The reach of mental health services is improved to give better access to minority and high risk groups and those who might not otherwise access services.

Question 22: How do we ensure that information is used to monitor who is using services and to improve the accessibility of services?

Boards should provide annual report back to Scottish Health Council on information about service usage. Data should be accompanied by a needs assessment, which includes minority and high risk groups in local populations and which is carried out in a consistent way across Boards.

Question 23: How do we disseminate learning about what is important to make services accessible?

Make use of local and national networks to circulate information on, and discuss practice.

Hold national networking events.

Require Boards to publish information on a national website.

Make sure redesigned services are evaluated by service users. Make sure this is done in a meaningful way and does not just rely on 'customer satisfaction' questionnaires.

Support the evaluation of services by independent service user led groups.

Encourage constructive, critical debate on the experiences and outcomes for all stakeholders.

Offer national acknowledgment of innovation and good practice, awarded by a panel of service users each year.

Question 24: In addition to services for older people, developmental disorders and trauma, are there other significant gaps in service provision?

Independent advocacy services, both individual and collective, for people with mental health problems who are in prison.

Independent advocacy services, both individual and collective, for children and adolescents.

Outcome 10: Mental health services work well with other services such as learning disability and substance misuse and are integrated in other settings such as prisons, care homes and general medical settings.

Question 25: In addition to the work already in place to support the National Dementia Demonstrator sites and Learning Disability CAMHS, what else do you think we should be doing nationally to support NHS Boards and their key partners to work together to deliver person centred care?

Promote the role independent advocacy, both individual and collective, can play in making sure people are able to set their own agenda, find a stronger

voice and influence decisions which affect them.

Encourage Boards to create more opportunities where different stakeholders can safely share learning spaces.

CAPS believes that the best service will be delivered when those services are designed to meet the needs of the people who use them, based on what the people who use them say.

The Principles of the Mental Health Act make a commitment to involving service users in decision making. We think the Strategy should make a stronger and clearer commitment to involving service users, not just in decision making about their own care and treatment, but also in the planning and provision of services, in the education and training of staff and in the evaluation of services. We think this is a key issue and should be one of the priorities for the next 4 years!

One way this can be achieved is through the commissioning of properly resourced independent advocacy service, collective as well as individual, across the whole of Scotland.

Outcome 11: The health and social care workforce has the skills and knowledge to undertake its duties effectively and displays appropriate attitudes and behaviours in their work with service users and carers.

Question 27: How do we support implementation of *Promoting Excellence* across all health and social care settings?

Support and meaningfully involve service users directly in the development of material and in delivering education and learning for the workforce.

Question 28: In addition to developing a survey to support NHS Boards' workforce planning around the psychological therapies HEAT target – are there any other surveys that would be helpful at a national level?

A survey on service user participation and its outcomes.

Question 29: What are the other priorities for workforce development and planning over the next 4 years? What is needed to support this?

Requirement that staff have participated in some service user led training.

Question 30: How do we ensure that we have sustainable training capacity to deliver better access to psychological therapies?

No comment

Outcome 12: We know how well the mental health system is functioning on the basis of national and local data on capacity, activity, outputs and outcomes.

Question 31: In addition to the current work to further develop national benchmarking resources, is there anything else we should be doing to enable us to meet this challenge.

Carry out and publish more service user led research into service outcomes, for them and the wider community.

Question 32: What would support services locally in their work to embed clinical outcomes reporting as a routine aspect of care delivery?

No comment.

Outcome 13: The process of improvement is supported across all health and social care settings in the knowledge that change is complex and challenging and requires leadership, expertise and investment.

Question 33: Is there any other action that should be prioritised for attention in the next 4 years that would support services to meet this challenge?

> Meaningful participation by service users in all stages of planning, providing and evaluating services.

Question 34: What specifically needs to happen nationally and locally to ensure we effectively integrate the range of improvement work in mental health?

> Better joined up working and shared values and practice between NHS Boards and Local Authorities.

Outcome 14: The legal framework promotes and supports a rights based model in respect of the treatment, care and protection of individuals with mental illness, learning disability and personality disorders.

Question 35: How do we ensure that staff are supported so that care and treatment is delivered in line with legislative requirements?

> Rolling programme of training on role of independent advocacy.
>
> Service user led training on how to make participation and involvement meaningful for them.