CAPS Independent Advocacy – Mental Health and Wellbeing strategy for Scotland 2022

The comments below represent responses, gathered from CAPS collective advocacy groups, from people who identify as having lived experience of mental health issues. The group chose to answer the questions in a way accessible to them by discussing the categories and expressing their opinions in less formal way.

This document represents the results of these discussions;

When the group discussed Part 1 of the consultation looking at definitions and how reference should be made there were several comments which considered the language of the terms and the need for any definition;

It seems there is no difference between Mental Health and Mental Wellbeing

It is confusing having 3 descriptions. Would be better if Mental Health described people's mental health when they are well and Mental Health conditions described when people are less well

Don't like Mental Illness, feels like there is too much stigma attached to this.

I think it's useful to distinguish mental 'illness' from times when people will generally feel low/sad/worried (low wellbeing/health) Sometimes MH awareness glosses over what it's like to be seriously unwell so there's a misrepresentation about what it looks like. However – giving psychiatrists sole power in this domain by having the right to diagnose (or not) needs to be challenged

In **Part 2** most people agreed that the **overall vision of 'better mental health for all'** is a good vision and a positive goal to aspire to. The comments here both reflect a major question that people feel would need to be answered to achieve such a vision, along with what they believe it should look like if the vision was achieved.

Hard to know what this means?...who defines what is better?

It would mean no more suicides

There would be less people in hospital for Mental Health issues

More joined up services – not being pushed from pillar to post

There would be help available when you need it

Access to benefits that you are entitled to – not having to go through lengthy stigmatising processes to get them.

Access to healthy, affordable housing

Invitations to ask for help not feeling like you don't deserve it.

Better community contribution – helping others makes everything more sustainable.

Personality disorder would be explicitly included as this is often excluded not defined as a 'mental illness'

In **Part 3 thinking about what the strategy's key areas of focus** should be, the group spent time considering what the proposed areas of focus were and how these might help to achieve their thoughts on what success would look like. They provided thoughts on these as well as making many suggestions of their own. Much of the discussion surrounded the practicalities of the world that we are living in where **funding, resources etc are often being reduced** and the **cost of living crisis** means that accessing many services has become harder. They also discussed the things that they felt were missing from the priorities around communication

People who have mental health issues are really aware of how these could be achieved and could be helpful with these messages they need to included more

Agree that providing accessible signposting to help, advice and support is important but investment in services PROVIDING help, advice and support is needed first.

It will be important that decisions on conditions for good mental health and wellbeing come from people with their own lived experience

There needs to be equal focus and priority given to early interventions

A priority for good mental health and wellbeing needs to be that everybody has the right to GOOD quality housing, food and shelter

A priority should be around more choice for services in recovery

There should be more in priorities about co-operation between services, particularly the benefits systems….there is a real need to work more closely with services to avoid people being excluded for example for drug and alcohol, learning disabilities and neurodiversity.

Models of capitalism need to be reformed when dealing with people who have mental health issues. There are proportions of people being treated as less than because they do not contribute to 'productivity'.

For **Part 4 of the strategy looking at outcomes,** the group considered each question in turn. For Question 5 on **whether the Mental Health and Wellbeing Strategy should influence the social factors that affect mental health** and wellbeing. The group felt that this was vitally important.

We discussed each priority suggested in question 6 for the outcomes for the Mental Health and Wellbeing strategy. **The priorities that had the most support from the group was that people should be involved in the decisions that affect their health, treatment and lives.**
Several comments were made on the language and implication that people would need support to understand what makes them sad and felt that language around empathy and belonging would be more appropriate.

General education in society [on what is meant by mental health and wellbeing and mental health conditions] would be helpful

How will we know these are working? Not all people have the same definition of what is helpful

What about education society /communities on supporting some experiencing a significant life event?

[The outcome suggesting people need more support to recognise what affects mental health] seem pitying, I would like to see belonging, welcoming, empathy

Not all people have the same understanding of life

Recovery is really important but not the same for everyone

[The strategy should aim to support people with physical health issues to have as good mental health as possible] - but this shouldn't come from mental health budgets. it should see ups killing of others, like mental health services had to do when they started upping their game on physical health

[The priority aiming to help people recognise natural things that affect their mental health] feels condescending!

Rights respecting systems and services must be paramount

People need to feel that they will be believed

Diagnostic overshadowing needs to be addressed

Advocacy is really important and must be available

When discussing question 7 on **whether the Mental Health and Wellbeing strategy should aim to achieve certain outcomes for communities**, the group felt that it was indeed important for communities to provide access to a range of activities for enjoyment and learning and that support for this in a national strategy would be helpful.

Outlook project is great -it has all sorts of classes to provide different opportunities for people with mental health issues

Enjoyment is part of good mental wellbeing so this strategy should definitely strive to support this

Each geographical location can have very different facilities and communities should be supported to provide access to their residents in a range of ways

It is important that the strategy helps to provide opportunities for marginalised communities in the same way as geographical ones, i.e. Transgender communities

Looking at **what the strategy should aim to achieve for populations,** people had further suggestions on what should be included here and how this could be more catered to a national arena.

There should be ageless services, false age transitions make accessing any support harder

A positive thing for the strategy to support would be businesses to implement more flexible working options, like the 4 day week and support schemes like universal basic income as these all affect mental wellbeing.

Create schemes for knowledge and experience sharing. Schemes bringing together different parts of communities e.g. young and old.

It is important to support activities that are positive for communities as a whole and are accessible and inviting to all. When people came together during the pandemic community spirit was an important factor to success

There should be more initiatives to bring focus to good treatment for all. Less focus on what not to be and more good conversations about how to treat people with kindness and compassion as a statutory part of children's education

When the group discussed the section on **"Creating the conditions for Good Mental health and Wellbeing"**, we took the conversation around the members of the group asking individually **what positively and what negatively impacts their mental health.** A number of things were suggested as having positive impacts on mental health was suggested, including **safe housing and socialising**. When looking to the things that negatively impact on mental health there was a universal feeling that **money worries**, particularly in our current economic climate, were are at the top of these. Surrounding this, but linked in many ways, were the **reduction of services** and **social inequity**.

Mixing with other people

Reading books and playing computer games

Work - purposeful activity

Housing - safe, secure and provides companionship

Being involved - trying to make a change/difference

Peer groups - like at CAPS - the chat here is very understanding

Laughing!

Work! Although purposeful activity is good this is not work for everyone.

Cost of living

Lack of diverse groups that are available for my needs or choice

We explored question 14 on what stopped people from being able to do the things that have positive impacts on their mental health. Money, time, and services being shut down were the main barriers that people brought up.

Services being shut down or only there for limited time, when you find something that works it is frustrating when local or national priorities change and things are closed or restricted to fit new priorities that you had no involvement in setting!

opportunities for connecting - it is hard if you don't even know what's available

Life Admin! Everything seems to require more time and work to organise just living and having your affairs in order.

MONEY!! - The cost of living crisis

geography - rural areas or poor public transport links to things you would like to be involved in

Library closures/reduced facilities/opening hours

Societal inequalities

Time! Needing to work full time to pay bills - basic survival leaves no time to be able to pursue things that positively impact my mental health

Access to libraries is getting harder, reduced mobile library facilities lately is challenging for people with access needs

Digital exclusion - everything moved online during the pandemic and for people unable to access things in this way it has made it harder

For **question 15,** we talked about **what support would help with money worries.** This was a question the group found quite hard to answer as it felt like the **only way to get rid of money worries would be to have enough money.**

Universal living wage

It's not budgeting that's the problem - there is just not enough money. Every service you access for help pretty much audits you and suggest where you could cut down...there is nothing left to cut!

Extend schemes such as insulation, double glazing, air source heating pumps to private lets and council houses. Lots for home owners but low income housing relies on local authorities fulfilling these things which they don't always do.

More effective national policies on wealth re-distribution

Better benefits assessment process for people with Mental Health problems

In the next section **"Access to Advice and Support for Mental Wellbeing"** we discussed where people would go if they wanted to improve their mental health and wellbeing. When answering this question, people mentioned third sector support, google, and peer support services before considering NHS options like going to your GP, as people felt they already knew what their GP would recommend, and often hadn't found their GPs suggestions in the past very helpful.

Crisis services

Private psychotherapist

Google! Would be my first call for groups in my area, services etc.

GP

Counselling

Voluntary organisations

Connections that I already had, so groups or classes I attended, work colleagues etc

Royal Ed emergency team

Peers....where I could be confident of no judgement

Peer group

Psychiatrist

Crisis phonelines

As a group we discussed **what makes a positive experience with a mental health service.** Being **seen, valued and listened to** were incredibly important for a positive experience with a mental health service. Other important things that made for a positive experience was when **staff followed through with actions** they had agreed to, and when staff had the time to **build trusting relationships**. People told us that these were things that still needed considerable work and that the emphasis on trust still did not seem to be paramount in services. **Authenticity in interactions** often felt missing and a feeling of dismissal was still present all too often.

Only being prescribed treatment by someone who has actually met you

Working with you – valuing your lived experience and giving you a say over your own treatment

In-person meetings being arranged when this suits someone's needs

Being listened to

Specific services to treat you for exactly what you are dealing with

When they have the time to build a trusting relationship

When the staff follow through on their actions promptly

Finding someone what they need/asked for

Where it doesn't feel like the staff hold all the power

Being acknowledged

Next, we discussed what makes a negative experience with a mental health service.

Long waits for assessments

Being given treatment by someone who doesn't know you

Having to retell stories to multiple people/services (which can be retraumatising)

Services not following through on actions

Not ensuring the safety of people getting home afterwards [from a crisis situation]

Not having your human rights met

Receiving rushed letters with mistakes

Being arrested by police instead of being offered mental health help

Do consultations and then not listen to the feedback

Services changing without consulting their patients

Only being listened to when an MSP/MP gets involved

Feeling not believed

Lack of communication between services

Feeling people don't care

Limited kinds of services you can access e.g. only CBT or counselling

Opening up about your trauma, and then not being offered any support

Asking for help and it not being available or provided

Appointments being cancelled and not rearranged

Sending letters that need to be responded to within 7 days, that only arrive 2 days or longer after being written, giving you even less time! Unnecessary pressure

Fear that if you decline a service (due to not being relevant or useful for you) you will have to wait a long time to get offered alternative help

The group brainstormed ideas to answer Question 19 about how mental health services can improve. Much of what was suggested were clear, practical suggestions to counteract the things that make experiences negative. There are so many parts of the system where human interaction, language and attitude are what make the difference between a good experience and a bad one. The group wanted to point out how these things can be considered in services.

Keep thorough notes and read them!

Be more understanding

Not diagnostic overshadowing

Communication and listen – make it a conversation

Acknowledge and place value on your lived experience

Avoid cancelling appointment, and offer quick alternatives if this happens

Have an overall understanding of the person that are trying to support

Follow up on actions

Keep everyone involved in the person's care informed – including the person accessing support themselves!

Take your duty of care seriously

Make it clear you can decline treatment

Non psychiatric options!

Show empathy

Treat people as humans

It is a matter of significant resourcing in the system. Tinkering at the edges and moving the deckchairs will not achieve anything in a system that is chronically underfunded and under researched compared to other health conditions

Deal with feedback and complaints appropriately

Take a holistic approach

If services can't help, they should be signposting – and actively referring you to other services which can

Part 8 asked specifically about Traumatic life experiences. The group felt that this was a particularly important area for the strategy to highlight. Over the past 10 years the treatment of trauma has been aligned more with Mental Health services and this is still in it's infancy in many ways. **The involvement of people with lived experience is once again paramount in this area**... Length of time for access to services for trauma was highlighted as an important feature of priority in this area.

Not having a limited amount of help you can access e.g. 5 sessions

Not being able to form long term, trusting relationships is also a challenge when recovering form trauma

Offering time and resources to longer therapies instead of just offering medication

Not being believed is a barrier to recovery from trauma

Work on the effects of trauma within the mental health services still feels relatively new and it is important to listen to lived experience about how it affects people.

Collective advocacy can fill a gap of how to I move forward/engage in life?

When looking at "Children, Young People and Families' Mental Health" the group felt that high quality evidence based interdisciplinary approaches for child and family separately and together should be a strategic priority when supporting children/young people and their families. They felt that any interventions in the environments around the child should ensure the child/young person is included in the decision making.

The group also discussed what they felt has the biggest impact on children's Mental Health and Wellbeing:

Excessive pressure to conform to the current social and economic models that attribute their worth to their productivity - when in reality the job market is unstable and ever changing.

Needing to move around and being dislocated from robust family support networks (where they are health)

Excessive pressure from social media to be happy/pretty/extroverted

The group talked about what could be done to address mental health inequalities for a particular group of people. The most common suggestions were having gender specific services and training staff appropriately.

Training for staff about inequalities to get them to understand/empathise/adapt their practice

Services need to better consider the contemporary pressures for both men and women, there is little consideration of what it is like to be a modern man or woman in services

reduce barriers between communities

Having ethnicity specific services

Having gender specific services, including trans and non-binary

Talk about equity rather than equality – so we all get an equal outcome, not equal support

giving everyone the same access to treatment regardless of their location

In Part 12 – Funding, the group discussed how mental health funded could be better used, but found it very hard to answer the question when it is often unclear how mental health funding is currently used in their area. Transparency is an area that needs work in all authorities.

Campaigns to break stigma of mental health, make services more noticeable and inviting break taboos of mental health

More available opening hours to make appointments and contacts with staff supporting mental health and wellbeing

Look at other services - e.g. those in the third sector, or examples from other countries - that have had more success working with minority groups and learn from them

Need to give staff the skills to be comfortable with those with different life experience/those facing barriers

Suggestions for areas that need more funding included hiring more staff and having more buildings local to people to access help in.

More buildings/places to meet/areas that support groups getting together - these have been reduced

It's been said before but more staff are needed

It is important to have transparency with funding - where does the money go? Support people to find out about decisions on funding and offer REAL invitations and opportunities to make suggestions.

Investment into making sure that information is current and available so that people are aware of what is out there

More signposting - better signposting

Getting back to facilitating face to face appointments - this requires more staff and resources

Addressing the section of the consultation on **Our Vision and Outcomes for the Mental Health and Wellbeing workforce,** the group discussed what the strategy should achieve in the **next 1-2 years** for the Mental Health Workforce. The group felt that the burden on staff should be reduced by hiring more staff, giving existing staff more manageable workloads, and giving staff the time and ability to changes the systems that they work within.

Investment into making sure that information is current and available so that people are aware of what is out there

Big part of the workforce has their own lived experience of mental health - their should be opportunities created to harness this experience. Inclusion for staff who have mental health needs - greater flexibility

Staff should have manageable workloads and be supported themselves - staff are being worked to capacity and are having to make impossible resource allocation choices. Need to make sure that change in systems is well managed as this can be hard on staff

Build More diversity in the workforce

Don't agree that the staff should be giving/pushing self-care/online ideas
o   What about people who can't use technology?
o   What does online tools mean?
o   Will they check if people have access to the technology, teach them how to use them/ give them the technology?

Ensure workforce are knowledgeable about the local community they are working in

But you also need to think about what you want them to provide. More nurses providing poor care is no use to anyone.

Giving staff the time to suggest changes in their area - be involved in planning - this relies on manageable workload and support from management welcoming input

Peer led services as an alternative - think about who we want professions to be and what their values should be, Attitudes in MH nursing and psychiatry can be appalling.

Increase lived experience in development, and delivery of mental health services

Be more open to feedback/constructive criticism. Have better complaints systems. Be more accountable to the people accessing the services

Increase the inclusion of lived experience training as part of the curriculum to train mental health professionals. It is valuable for all areas of mental health training (e.g. nursing, medical students, psychology, social work, occupational therapy, third sector) to have a lived experiences perspective in their core training

You will need more people - so it's worth deciding if you are willing to actually resource what your assessment shows.

Thinking **over the longer term** the group thought that real time and investment into culture change for people with specific issues such as alcohol and substance use would be a good idea. Working on **sustainable models of evaluation** was also important to the group.

New models constantly should be developed to stay up to date with what works.

Work on changing cultural perspectives of people with substance use issues – educate people on issues around choice/ fault. Blame culture

Peer workers are part of the workforce at every level - Peer support workers need better support and supervision

Ongoing development to better understand gaps in services/capacity/supply
Links to idea of working at capacity and needing to develop services all the time
People's hands are so tied
More money required
Service time limited -leaving gaps

Not convinced by some current degree programmes. They are enormous and seem to let very poor quality applicants through

In **Part 16** the group focussed particularly around the question dealing with **how to grow the workforce in particular around the area of early intervention and prevention**. Adequate **value driven pay** was high on the list of suggestions, although the group also commented on the need to **define roles within services**, ensuring that people were doing jobs that gave them energy rather than drained it and that skills were used to their best ability within systems.

Pay them better!

Less paperwork so people have time to spend with people – think about role definitions – whose job is it to write reports? Who prescribes medication – are the right people being given the right support to do what they do best? Expecting one person to do everything/three different roles is unrealistic and leads to staff burnout.

Stop burning out staff – everyone I know burnt out because they cannot practice how they should and know is right because of bureaucratic expectations, poor attitudes amongst colleagues and a pressure to discharge people asap

Greater presence in primary care of CMHT of non-medics and eliminate the culture and training models that mean the medic always sits at the top of the hierarchy. More staff delivering specialist interventions – often staff that are much more affordable than consultant psychiatrists.

Don't redesign for the sake of it. Redesigning services rarely leads to any improvements in actual outcomes.

Allow them to focus on what is unique about their role and reduce management and administrative responsibilities that do not require a professional specialism or clinical expertise. E.g. occupational therapists as care co-ordinators cannot deliver occupational therapy full time.

Look at how you can reduce waiting times to acute care, not just signposting people round in circles.

When thinking about **immediate actions that should be considered in the area of workforce planning** the group considered the suggestions and many liked the idea of **different options for entry into the sector**. It was also important to people, as noted throughout this response, that **transparency over how budgets** are spent and how these can be better used with insights from people with their own lived experience is a crucial step in planning for the future.

Like the idea of having different routes into mental health – university is not always the best path for people although they may have skills that would be good in these jobs. Maybe apprenticeships but is it also possible to look at options to offer promotions opportunities through peer support workers? This might help to create a more diverse workforce?

An evaluation of how successful money has been spent in the past would be good. What have the positive outcomes been? How do people know this? Who has benefited.

Deliver treatment that enables someone to live despite mental illness and progress to participation in the activities they value

Make sure your current workforce feel valued. Identify good evidence based and values based practice and make sure this is available nationally. Clapping is nice but what really counts is being able to deliver the care that you want to ad seeing people getting to where they want to go.

There is an assumption here that is problematic that quality equates to professional status. This is what needs to be challenged amongst the existing workforce as it stops new roles being welcomed and valued. However there also needs to be recognition of what professionalism means in terms of expertise and knowledge, and that this is not devalued as people can become polarised.

Throughout the discussions that we had in the groups there were **several other comments that were voiced and issues raised that people felt either had not been addressed or there were not sections that dealt with them.** The following comments are other ideas and issues that felt important for the group to record.

Equitable access to expertise – the patchwork available in Scotland around certain issues e.g. Personality Disorder is appalling. These services are miles behind other countries.

Make specialists available nationally where expertise is lacking using digital technology – none should be denied personality disorder services just because they are in an area that lacks specialist services.

People need to be supported in their choice over gender/sexuality etc

Real thought needs to be given when integrating people with lived experience into the NHS to ensure they are not further harmed. There are many examples of good and appalling practices in England of people with experience basically being treated as assistants, not being supported with the emotional demands of the role, and staff being unpleasant when the feel threatened by the success of peer worker. There is also a valuable consideration as to whether the true recovery model should sit within mental health services at all, and whether Scottish Government should fund lived experience services such as the crisis support, recovery cafes and other initiatives that are separate and distinct, but also inspected like the NHS

Don't lose your heart – this is about all people being part of Scotland. Let's see a shift in political discourse about what is important – life should not be about the individual striving to get ahead, but about what we can do so that our communities all thrive.

CAPS Lothian Voices collective advocacy group look forward to seeing how their voice will be included in the final strategy and are keen to continue to feed into any further consultation.