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.

Comments

There is no mention of advocacy in this document. The right to *independent* advocacy for people with a 'mental disorder' should not be assumed. Advocacy in mental health arose out of a human rights movement and historically in Scotland was grassroots and community in nature.

With the introduction of tendering in advocacy, we are seeing a challenge to the user led advocacy provision. The aim of the funders (statutory organisations) might be to improve the advocacy provision, regarding outcomes and targets. But the cost to the service user and carer could be much greater. If advocacy becomes like any other mental health service then it has lost its independence and autonomy.

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.

Comments

As a carer and past user of psychiatric/mental health services I would like to see each and every health board area being accountable to the customers and carers in their own areas, as well as to the government, in terms of implementing the required

changes. For those of us working locally to see improvements in psychiatric and mental health services, it is not always apparent that there have been positive changes made.

The government says that the user carer experience is at the heart of mental health improvement. And yet in the localities it can be difficult to 'have a voice' and to 'make a difference'. We can be excluded from decision making and disempowered through lack of information or recompense. Some of us live in areas that have a lack of real meaningful mental health user carer involvement. Where the grassroots user led mental health groups have disbanded or lost funding and now cease to exist.

I would like the government to support user carer participation and leadership in the localities, not leaving it up to the statutory agencies in the local health board areas who might have contributed to the diminishing of the user carer voice.

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.

Comments

Ask the people who use mental health and psychiatric services, and their carers/family members. Hold focus groups in the localities and don't expect the local statutory agencies to lead on this for they are likely to bring in the 'usual suspects' and you should be reaching a wider group than usual. Use a range of ways and means to reach people on the ground.

Speak to people who have recovered from serious mental ill health, despite being labelled, medicated and given a poor prognosis. Speak to those who live with mental health problems but have managed to avoid the psychiatric system. Speak to others who might only access their GP when in mental distress but are on anti-depressants, and may have been on them for a long time. Ask them what would have helped them recover and get back on with their lives.

Enlist the help of local mental health activists, in engaging with a variety of consumers, community members and citizens. Be creative in your engagement. Do it differently in different areas. For urban and rural require different strategies. Some of us in rural situations, squeezed between urban sprawls are disadvantaged, not always because of our geography but because of the lack of imaginative management of the resources available.

[Eg in Fife we have 3 acute wards in 3 geographic areas. Regardless of your mental health needs you are admitted to the ward in your area. Male and female together. A mixture. Substance misuse, depression, criminal record, psychosis, domestic abuse, mania. Younger or older. Student, housewife, unemployed, breach of the peace, ex-veteran, 'revolving door' patient, drug addict, beginnings of dementia or medication side affects. Everyone flung in together and medicated. No psychology or OT, for these therapies are 'in the community'.]

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?

Comments

I'd rather there was a focus on promoting wellbeing and providing choices for people in crisis. Wellbeing centres where people could just drop by for information, therapies, peer support, group work, physical activities/sport, advocacy, guidance and a chat. A place that was for anyone and everyone, not just the 'severe and enduring' but open to all, with paid workers and volunteers, peer led and recovery focused.

The government should put resources into the voluntary sector and community groups to lead, along with people with lived experience, on local wellbeing initiatives. The HEAT target of reducing waiting times for psychological therapies to 18 weeks does not address the needs of people in crisis, who are suicidal or who self harm to survive.

Question 4: What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

Comments

A fresh campaign and strapline to challenge stigma would be helpful. Something that doesn't focus on labels or diagnoses but raises awareness that mental ill health can affect anyone and is no respecter of persons. We are all in this together so campaigning should reflect this.

The psychiatric system has served to separate people with mental ill health from the general public. And yet GPs are treating many people with mental health problems, prescribing anti-depressants and/or counselling, referring to anxiety or stress management groups or to services that might alleviate the problems. Except for the 'severe and enduring' who are compelled, persuaded or are resigned to seeing a psychiatrist where they are kept under control by psychotropic drugs. Whose side effects reduce their life span and cause serious side effects and physical disability.

Reducing stigma and discrimination is of vital importance in changing and improving the psychiatric system and mental health services. In Fife we still have 94 people in long/medium stay psychiatric wards, 45 of whom are coming out 'into the community'. I'm hearing that other areas of Scotland do not have any patients still living long term in psychiatric wards. What does this tell us about the Fife psychiatric system and mental health services?

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?

Comments

As in previous answer, changing the focus and strapline of See Me's campaign. The 'see me not the label' message has been on the go for 10 years, time for a moving on to focusing on the community and their attitudes to 'mental illness' or a preferred description 'mental health problems'.

I'd like to see a challenging of the 'severe and enduring' label. For many of us given that label have recovered, got off all the drugs and got back on with our lives. Being given that label can be very negative for service users and carers, who might think that they are unable to recover. I and many other family members were put into that category but didn't believe it, took charge of our own mental health and recovered. However this personal challenging of the system and self management takes resilience and strength of mind which many people using services and on drugs will find difficult.

In Fife there are community mental health teams that only work with the 'severe and enduring', similarly day centres funded by NHS Fife that only take people with that label, psychologists who only work with this client group and CPNs also. I went to a day hospital in 2002/3 and was never encouraged to consider recovery. It was more about maintenance and management of the patient. I think this reinforces stigma and discrimination. People who attend do not expect recovery or any change in their circumstances. The staff are institutionalised and pass this on to the patients/service users.

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

Comments

Wellbeing centres for anyone and everyone in the community, with access to psychological therapies, peer support, advocacy, sport/physical activities, employability skills, crisis support out of hours and suicide prevention. An information hub and phone helpline run by trained volunteers, supervised by paid staff. Managed by partnerships with leadership of users and carers. Funding made available by government. Priority given to areas that are more in need, where the user carer voice has been diminished, where there are no 24/7 home treatment teams or out-of-hours crisis support. Start with Fife.

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?

Comments

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

Comments

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.

Comments

Fund peer led initiatives and peer support projects, independently run by people with 'lived experience' of mental ill health and recovery. Let's hear from survivors of mental ill health, people who have recovered despite a negative diagnosis or poor prognosis. The narrative research project by SRN enabled people to tell their 'stories. This could have been the beginning of an initiative and not an end in itself.

More strengths training/workshops and a focus on building resilience. These are the attributes that will enable a person to recover from mental ill health, to resist dependence and to take charge of their own mental wellbeing. Less prescribing of psychotropic drugs and more activities, therapies, choices for recovery.

Respect activism and alternative approaches in the mental health world. Create opportunities for innovation by enabling the 'experts by experience' to share ideas, not just their story of recovery. Recognise carers and family members by providing resources nationally and locally so that they can have a say in the development of services.

Comments

More information in the places where people go. Bring services and information into the community and social areas eg pubs, community centres, local shops. Campaigns highlighting that mental distress is common to humanity, anyone can be in crisis, it's a normal reaction to major upheavals in life.

Let's shift mental distress away from medical professionals and into the community. More community peer support projects led by users, survivors and carers. Provide resources for peer led initiatives – funding, shared use of buildings, training. Involve the voluntary sector who have many resources, volunteers and expertise.

Bring together the folk who are doing grassroots peer support work in communities, changing lives and making a difference. The people we don't often hear about but who are working away, getting alongside others and helping them along the recovery road.

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?

Comments

The problem is in calling it 'mental illness and disorder'. For you've started off by labelling people and medicalising their distress. Then they are in the psychiatric system which can be difficult to get out of. Easier for people to go to their GPs, get a pill or referral to therapy, less stigmatising and they already have a relationship with their GP.

The previous questions focused on self management and self directed help whereas this question implies that the onus is on psychiatry to manage and control. Providing a variety of options for mental distress would be useful. Talking therapies at the point of need. Alternatives to psychiatric drugs. Someone to speak to and signpost to services.

Involve the voluntary sector who provide a range of mental health services. Support the participation and leadership of service users, survivors and carers, in mental health service design and delivery.

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?

Comments

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

Comments

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?

Comments

Remuneration for user involvement, recognition of the time taken and expertise given. Interview, select and engage service users and survivors in proper posts that put them on a par with professionals. Encourage them to speak out and from their personal experience. Train and prepare the 'professionals' to engage with these 'experts by experience'.

For some of us in localities there is still tokenistic involvement. We are disadvantaged by lack of information about the task or process and lack of respect for our position. It seems that statutory managers prefer conformist attitudes and beliefs, involvement from users who agree with their decisions. This has resulted in apathy and burnout from previous user activists who have given up on being heard. This has been exacerbated by the advocacy tendering and loss of user led advocacy projects.

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

Comments

Training for staff in user carer participation and leadership. Involving service users, carers and family in creating and facilitating the training and have a mixture of people taking part – users, survivors, carers, family members, statutory and voluntary sector workers.

Extra resources, money, put into this activity, otherwise it is likely to be an 'add-on' in an otherwise tight budget.

Scottish areas where partnerships are working well could be visited by other areas where things are not so well developed. There could be 'roadshows' or events where good practice is shared. Make videos of teams and projects that demonstrate this. Use the internet to share experiences and bring people together remotely. Promote exchanges where staff can work in other areas geographically, to learn and to share. Enable service users experienced in participation to travel to other areas and share what has worked, and what hasn't.

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?

Comments

I am concerned that these outcomes haven't been 'embedded' in every local area to the same extent. For it is a cultural shift that is required in some areas where there is tokenistic involvement of users and carers. I'm not sure that staff in these areas really understand what person-centred practice is.

For example many of the psychiatric nursing staff in Fife were trained in the Tidal Model of Recovery but when I have visited acute wards, to hand out posters about Peer Support Fife events, and asked about Tidal the staff say that they haven't got the time to do it all but take 'bits' out of it. Not sure what 'bits' they are doing but think it's likely to be the bits that don't require a change of culture or practice. Others say that they have done the training and read the manual but are not doing it in their ward.

I have delivered training for over 30yrs and have attended many training courses. Staff may have undertaken the Ten Essential Shared Capabilities' courses and other recovery training but are not willing to, or are unable to practice what they have learnt. Feedback from patients, service users and carers would demonstrate that the care was person-centred and the treatment was value-based. As a carer I have never been asked to feedback on the service provided to the person I care for. That hasn't stopped me feeding back anyway. The psychiatric services should be accountable to patients, carers and family members, as well as funders.

This will mean listening to negative as well as positive feedback. In fact the negative feedback is more likely to be the implement of positive change in service redesign and delivery.

Comments

Comments

I am not sure that SRN has been effective in embedding recovery approaches across groups and in different areas. That's not to say they haven't been effective in some areas but maybe not in the areas they should have been concentrating on, so as to make a real change.

For example with GPs and psychiatrists, the people who prescribe the psychiatric drugs and make the diagnoses. These are the professionals with the power over the lives of people with mental health problems. Not always in a positive way, which has been my experience, in terms of psychiatrists. However I have found that if there is an opportunity to build up a relationship with a psychiatrist then they are more likely to listen and to be person-centred. The recovery approach is a different matter and my experience is of them talking about 'remission' rather than recovery.

My GP was always supportive, having known me over a number of years, mostly in good mental health, so she believed my story and listened to my point of view. Meeting with the psychiatrist was mostly problematic and to recover I had to not listen to their advice. For their mantra is 'medication', 'mental illness' and a life in mental health service land. They seem to have no other tools to hand. Time for a rethink and restructure of psychiatry and the psychiatric system. To make may for alternatives and choices for people in distress.

I think that SRN will need to change its focus and tackle the challenging areas where recovery isn't embedded, where there is still institutionalisation and tokenistic involvement of users and carers. They shouldn't worry about being popular or populist but be engaging with psychiatrists and doctors in primary care, both of whom are using psychiatric drugs as a frontline treatment. Drugs can be useful as a short-term measure but the side

effects can be debilitating and if long-term disabling physical health can result.

Coming off psychiatric drugs is not easy and we need more support for this. When I came off them I had to do it myself, against the advice of psychiatrists, except in 1984 in Lanarkshire when a community psychiatrist recommended how to taper the withdrawal and was happy to leave me to manage the process. In 2003, in Fife after a psychotic episode, hospitalisation and a cocktail of psychiatric drugs, I had to manage my own mental health and work out a plan of reducing then coming off the anti-depressant (given to counteract the depression which happened from taking the anti-psychotic) and lastly the lithium. I was on my own but fortunately had the prior experience of recovery, in 1978 and 1984, after 2 bouts of postpartum psychosis.

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?

Comments

This is a good question that needs consideration. As a carer I have found it difficult to participate meaningfully in the care and treatment of the person I care for. If I agreed with the psychiatric professionals then it could mean disagreeing with the person I care for. Meaningful participation should take into account the person's preferences and hopes. It will also require that the carer and family has all the appropriate information available, about the choices available treatment wise, the range of services available in the community, waiting times for therapies, opportunities to engage with the team involved in the person's care. Not much of this was/is my experience in Fife. My 3 sons have been 'in' the psychiatric system and I have supported them in their treatment and recovery, as an advocate, peer supporter and carer.

A national organisation for carers and family members of people with mental health problems could be useful. With dedicated workers to collate information and disseminate, to provide training for carers/family and staff, to promote advocacy for carers/family, to represent the voices and needs of carers/family.

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?

Comments

Involve families and carers in creating and delivering training to the staff
who work in psychiatric care and mental health services. Enable the carers
and family to share their experience(s) so as to help the staff to have insight
into what it's like to look after and support a family member with mental
health problems and in crisis.

Some staff may themselves be carers/family members of people with
mental health problems. Encourage them to share their experiences and to
see this as a strength in their work. For it shouldn't be about *them and us*
but about *us*.

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?

Comments

Share the information, knowledge and experience around. Create
communities of interest around this, actual and virtual. Welcome positive
and critical comments so that learning can occur. If it hasn't worked well
that's OK. Share the learning from this. Without the taking of risks we will
have no innovation and real improvements in mental health.

Above all, let's hear from the people who are now using these 'redesigned
services' to see if they are happy with the developments. And from others
linked to these people. Ask the community where the service is based, if
they have noticed and heard that things are better.

What are good outcomes? I'm hoping they are not just financial or about
systems but about the recovery and wellbeing of the service users and all
those connected. It will be about the *soft* indicators too – increased self
confidence, strengths, resilience, personal development, happiness and
better physical health. Keep the customer satisfied.

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?

Comments

Improving accessibility to services that are person-centred makes sense. The HEAT target of reducing waiting times for psychological therapies, although useful, is not good enough for people in crisis who need to be listened to at the point of their need. Prescribing psychiatric drugs to people with mental distress without any other option is more about management and control rather than person-centred practice.

We need crisis alternatives, preferably led by peers, so that the label of 'mental illness' isn't an easy option and entry into a lifetime of psychiatric drugs. It will be more cost effective in the long term to provide a range of crisis supports to people in distress and to help them develop inner resources and strengths to work through the episode. Psychiatric acute wards are traumatic places, I speak from experience - a mixture of people, male and female, in dormitory accommodate, some single rooms, drugs offered 4 times a day, nurses describing their work as "fighting fires" and "like watching paint dry" (latter about 24/7 obs).

I can understand why people might not want to 'access services'. But some of us have had no choice and were detained in these mixed wards, depending on nurses to protect us from other patients while on occasion forcibly injecting us with psychiatric drugs. There must be a better way. We're not criminals to be detained against our will, drugged involuntarily and put at risk.

Comments

Comments

Services particularly for women and the mental health issues they face eg postnatal, postpartum psychosis, menopausal mental health problems. We shouldn't be hospitalised with men in the same ward. This is scary when we are unwell. Some women could be vulnerable in this position, doing things they wouldn't usually do eg forming relationships with men that are unsuitable.

Acute psychiatric wards now have people in them with drug and alcohol problems, people in for a breach of the peace or with prison records. Why should I, a mother and grandmother, a responsible citizen and community worker, be expected to sleep in a bed in a dormitory beside other women who are addicts and have broken the law. Would you like to do this?

As a carer I have seen women in these mixed wards in states of undress walking about, because they are unwell and because the psychiatric drugs have sedated them. This is a loss of dignity for women and unacceptable in my opinion. Why should psychiatric treatment mean that women are not respected? As a visitor to a Fife acute ward in 2010 I witnessed a young female student from St Andrews University who wouldn't keep her clothes on. If I could see this then no doubt the male patients walking up and down the ward corridors could also see this. The nurse who was doing 24/7 obs on this young woman drew attention to the fact she wasn't keeping her clothes on, announcing it to the ward.

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.

think we should be doing nationally to support NHS Boards and their key partners to work together to deliver person centred care?

Comments

Question 26: In addition to the proposed work in acute hospitals around people with dementia and the work identified above with female prisoners, are there any other actions that you think should be national priorities over the next 4 years to meet the challenge of providing an integrated approach to mental health service delivery?

Comments

Crisis service alternatives to hospitalisation and psychiatric drugs. The biomedical model has been to the fore in psychiatric care. Let's have more psychosocial and psychoeducational programmes. Alternatives to popping a pill for mental health issues like stress, anxiety, depression.

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?

Comments

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?

Comments

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

Comments

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

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.

Comments

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

Comments

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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?

Comments

A more thorough monitoring and evaluation of the real improvements in mental health and psychiatric services from the user and carer perspective in the local areas. Engage locally with users and carers to find out from them if the improvements are happening on the ground:

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

Comments

Effective communication of information to, and representation from all stakeholders.

I attended a national mental health collaborative event in August 2009 for users and carers, the only person from Fife to take part. I only found out about it through other networks, not in Fife, and it was subsequently difficult to engage with the statutory agencies and decision makers working in mental health in Fife so as to disseminate information.

It's only because of my persistence that I managed to eventually get a carer representative position on the Fife MH collaborative group towards the end of 2010 shortly before the group disbanded in March 2011. I have tried for nearly a year to be a carer representative on the Fife Acute Inpatient Forum as there is no carer rep on the group. I'm still waiting to hear about this. It seems that the NHS Fife managers are trying to find another carer that might be interested. Meanwhile I have joined the national crisis and acute care network steering group and appreciate participating in this group where my opinions are valued and I am treated like a peer.

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?

Comments