

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.

On the consultation paper and the strategy:

- difficult to navigate, far too much text for any but the most dedicated
- no clear logical progression
- too much jargon: 'appreciate it's for the professions, but extremely off-putting for 'service-users' – presumably you want to hear from them too?
- too many objectives, too many questions, real purport of questions often isn't clear, several questions overlap
- despite the welcome attempt to address root and branch, and develop an effective strategy, there is in some of the language, in the 'what we have done', in the use of statistics, a sense of complacency.

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.

Change involves 'redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.'

- Yes, it does require integration of the services provided, but an even more fundamental re-orientation of service-providers' thinking is required (I have addressed this further below, but it bears repeating): the lead service-provider is usually the family/carers of the person who is ill; and if the person is not an inpatient, it is the family/carers

who are on the front line 24/7. The 'services' provided by the family/carers are the hub around which the externally provided services need to be organised, integrated and deployed. That is the fundamental 'redesign' that is required.

- 'Significant challenges' – for sure. But is that a euphemism for 'impossible'?

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 (see above Q1)

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?

We contribute to this consultation as parents whose son committed suicide in 2011; he was diagnosed with bipolar disorder and was severely depressed. Over a period of 5 years he was an inpatient and outpatient in CAMHS services in England, and an outpatient in Scotland.

- We welcome the repeated references in the strategy to the families, carers, and communities who are the principal source of care, therapy and healing for people who are ill. However, the references need to move beyond rhetoric, and fully commit to supporting (and so getting the best out of) the principal carers.
- We also welcome the emphasis in Outcome 1 on promoting good mental health further upstream, rather than trying to spot and prevent imminent suicides at the last moment, by which time it is probably too late: suicide watch 24/7 isn't possible for an indefinite length of time. However, it is not clear to me that the publicly funded mental health services understand very well what generates good (and poor) mental health: a broader understanding of mental health within a much wider cultural, social and philosophical context is essential.
- Suicide and self-harm are not purely medical phenomena, there are major cultural and social factors – as evidenced for example by all the studies showing variability over time, geography, social class etc. Indeed, these factors are so important that marginal improvements to NHS and local authority services are unlikely to have a significant impact on suicide rates.

- To repeat, then: each service must look outside its own boundaries and area of expertise; learn from the others; and work harder to understand the much bigger societal and cultural issues (specific examples of these latter below).

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

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

(The young people's *see me* site <http://www.justlikeme.org.uk/> says it's down for maintenance and will be back online Aug 2010)

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

As above and below.

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?

CAMHS & Schools

A major contributor to mental ill-health is our current system of schooling which, notwithstanding the positive aspirations of Curriculum for Excellence, remains tightly focused on getting young people to pass exams, which require them to recapitulate subject-content which the educational system has deemed important. Schools function to provide tickets to the next stage of life, be that university, college, work, or unemployment and failure; and they provide a screening service for employers, colleges and universities (who frequently complain nevertheless about the quality of their recruits' literacy, capacity for independent thought etc). The 'content' schools offer to young people is increasingly irrelevant to their lived experience; the transmission model of pedagogy still predominates over collaborative learning, especially in secondary schools (after all, they have to learn stuff to pass exams); bullying remains a serious problem; and, when youth unemployment is climbing inexorably, and massive structural change is occurring across employment 'markets', the gap between what schools provide and what young people need grows ever larger. (This critique is

developed further at <http://www.youtube.com/watch?v=zDZFcDGpL4U>)

Of course, this strategy cannot address the dysfunctions of the school system, but it is important for CAMHS services to recognise and fully comprehend the damage that schools can do to some young people, and how that damage contributes to young peoples' mental illnesses. In a residential CAMHS service I experienced in England, the aim of its education unit was to help the young people (those who were judged able to cope with it) to 'catch up' with school subjects, so they didn't get too far behind. I believe this aim is entirely wrong-headed, merely adding fuel to the fire, piling on the pressure. Where education services are provided within a CAMHS service, the sole aim should be therapeutic, and bespoke to the needs of the young person. Whatever it is – be it learning skills or learning about things, be it creative work (gardening? art/music/film/photography appreciation or making? cooking?), working with others or singly – the sole object should be to help the young person to develop confidence, self-awareness, self-management, coping strategies etc, and to find constructive things they can enjoy. (I have no experience of CAMHS in Scotland, perhaps this latter is already the norm in Scotland.)

On young people in particular: the transition from CAMHS to adult services can be extremely difficult and stressful, and apparently arbitrary. A young person may be just getting used to the professional carers, then at 18 have to undergo re-assessment, new staff, a new regime, and new responsibilities. If they have been ill for a period before they are 18, they will still be extremely vulnerable at that age, will still be just beginning to learn about their illness and how to cope with it. The 18-25 age group needs a more appropriately targeted approach.

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.

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

We all trust most the information and advice we get from our peers. This is true for people who suffer from mental health problems too, yet it is very difficult for a young person with depression, for example, to meet or learn from other people who have suffered from depression. It is true that there are, for example, voluntary bipolar support groups in some locations, but referral from medical services doesn't seem to be the norm; and a young person in the grip of depression will need more than a referral to get them to take part. Medical (and other public) services should take a much more proactive and persistent role in helping sufferers find support networks,

information etc.

Why was it, for example, that it was Ruby Wax who created opportunities for people who suffer from mental illness to talk to and support each other (as part of her 2011 'Losing It' show):

After each show, Ruby invited the audience to talk freely about their own experiences with mental illness and was overwhelmed with the response. Ruby says: "It was like the floodgates opening, people were desperate to speak, to get the chance to talk about what they were going through with people who are dealing with the same issues.

"It was clear there was a huge, unmet demand from people to be able to talk to others in the same predicament about mental illness. Nina came one night and I told her about my frustration that we couldn't meet the demand out there just through the shows. She suggested creating a social networking site and the seed was sown for Black Dog Tribe."

Users of the site (<http://www.blackdogtribebeta.com/> currently in beta test mode) are encouraged to create communities with like minded people - to form 'tribes' - and start things off. Seven of these tribes have been set up, based around themes that kept coming up during the theatre tour. <http://www.femalefirst.co.uk/health/Ruby+Wax-2250.html>

There are other good sources of information from 'peers' of all kinds, especially online, but, again, referral to them does not seem to be the norm. We found them too late, after the death of our son, and they might have made all the difference. This one, for example, has many *filmed* interviews with carers that would have been extremely helpful for us; and interviews with sufferers that might have helped our son:
http://www.healthtalkonline.org/mental_health/

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

It is often when people become (very) ill that they cannot or will not seek help, especially if they have no confidence in the efficacy of the services that are provided. So: work much more closely with family/carers so that carers are better able to bring sufferer and services together.

Also: some sufferers may become more self-aware and willing to self-refer if they benefit from the kind of 'peer-reviewed' advice and insight available through resources exemplified in Q9.

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?

As above Q10

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?

As indicated in the strategy, dig deep into the Suicide/Critical Incident Reviews already carried out by NHS Boards on hundreds of suicides, to pull out the learning that these can provide – yes, of course, review, improve and harmonise the CIR processes across all NHS Boards for the future – but surely there is a huge amount of epidemiological evidence in what's already there? The NHS QIS Suicide Mapping Exercise Report (Jack 2010) only reviewed the *review process*: the hundreds of CIR's already on file (notwithstanding their non-uniformity) and the collective experience of some of the professionals involved must surely yield some valuable lessons worth promoting.

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?

Provide a complete picture of the kinds of services that the 'service user' may find helpful; make the effort to educate yourselves as to the full range of help and opportunities that s/he/they might find helpful (see eg Q9), beyond the standard medical/care services, so that you can make s/he/them aware of them and they can choose for themselves. If they don't know they can't choose.

As the strategy says: 'People with a lived experience bring a unique and valued contribution and are well placed to support recovery education and learning...' Dig into what 'service users' themselves say eg:

<http://purplepersuasion.wordpress.com/>

<http://juliesmum.blogspot.com/>

<http://www.blackdogtribebeta.com/>

http://www.healthtalkonline.org/mental_health/

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

- Much better, and more frequent and substantial communication,

among all parties.

- To that end, thought and effort is required to engineer interactive communication among the various parties, and to address the inevitable legal issues.

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?

As above: recognise and acknowledge at the outset that in many cases the family/carer/s are the LEAD partner in the care, and all the other services are there to *support* them in their care for the person who is ill.

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

Comments

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

Comments

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?

'The Carers Strategy promotes a vision of a society in which carers are recognised and valued as equal partners in care.'

I find this patronising. As stated above, family/carers are often on the front line, providing care 24/7; society – and, crucially, the care/medical professionals – need to recognise and acknowledge that family/carers are more often than not the LEAD partners; they should not be partners struggling to gain recognition as *equals*. Further, it should be recognised and acknowledged that the family/carers have so much more to lose than the professionals, up to and including the death of their loved one. *Equal partners?*

The confidentiality rule presents a huge barrier to integrating family/carers' care with the professional services. Sometimes when people are extremely ill – eg extremely depressed and contemplating suicide – they withdraw consent for their carers to be involved. The problems caused by confidentiality are raised time and time again by carers whose care has been compromised by the lack of communication with the professionals. No-one wants to erode patients' rights, but couldn't we find a solution

somewhere between the extremes of complete confidentiality and sectioning or power of attorney?

Simply put: much better communication: see eg Q14 & Q15

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?

- A more complete and holistic understanding of the illness, its cultural and social causes and operation as well as the medical
- Greater awareness and understanding of families' and carers' lived experiences, and greater sensitivity to these: there's a wealth of information online (see eg Q14)
- Communication skills of the highest order: listening and responding, not just transmitting.

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

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

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

Comments

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

Comments

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?

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

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?

Our experience of mental health services indicates that a narrow, predominantly medical conception of mental ill health prevails. Of course the medical aspects are critical, but a much broader understanding of cultural, social and philosophical perspectives needs to be developed and promoted urgently.

By way of illustration: the extreme myopia and silo-thinking of mental health services is evident in many ways. At the CAMHS unit in England (where our son was both in- and out-patient) we were amazed to see the waiting room and the day room liberally strewn with foul celebrity and gossip magazines: vindictive trash, obsessed with cellulite and women's weight, celebrating fame for its own sake; this in a place where the young people's self esteem and identity were desperately fragile and vulnerable, and where fully half of them suffered from anorexia! It was as if the professionals were completely blind to the world outside, blind to its agency in bringing the young people to this state of terrible confusion in the first place: as if they assumed the world was just fine, and had no bearing on the young people's ill health. They just needed fixing, no need to address how they related to and understood the world out there. The very same trash mags were on the coffee table in the waiting room in the out-patient unit in Scotland at which our son was seen.

Despite an attractive new building, the same thoughtlessness was evident in the hospital waiting room in Scotland, where our son and I waited one evening to see the consultant psychiatrist. A TV was on, blaring out rapid-fire aggressive nonsense at a deafening volume, there was no escape from it. How can that possibly be therapeutic? Why the default assumption that a barrage of TV is what people want, and that it's good for them?

These observations greatly undermine my confidence in the medical professions, indicating as they do an extraordinarily limited critical awareness of the world at large, a complacent and unquestioning outlook, and an inability to relate their specialist knowledge to the wider world.

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?

- As above Q27.
- Attitude and behaviour change: welcome learning and collaboration with other service providers and primary carers, rather than staying within particular service boundaries, and patrolling those boundaries.
- Empower senior managers to address the logistic and territorial challenges of greater collaboration
- Embrace even broader cross-sectoral and inter-disciplinary learning

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

Comments

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

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?

As above Q29

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

As above Q29

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?

As above Q19. The confidentiality rule is a major problem.