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

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

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.

More trained support in the community for people with developmental disorders and learning difficulties - especially those with autism spectrum disorders.
Respite for parents who care at home for people who have autism spectrum disorders. Ardlui in Helensburgh is an excellent idea. Every sizeable town should have one.
http://bit.ly/w22O6n
NHS Residential homes for profoundly affected autistic persons should be considered. At the moment these are in the private sector and costs to local authorities are crippling.

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?

Quality support in the community is needed.
At the moment people have to pay £20 an hour from their benefits for support in the community – unless they are under a CTO. Many opt to do without that support, as they can't afford it and consequently are becoming ill.

Educate all medical staff in the dangers of antidepressants especially SSRIs – which have been shown in some cases to worsen depression and even to cause an increase in self-harm and suicidal feelings.
http://www.mhra.gov.uk/home/groups/pl-p/documents/drugsafetymessage/con019472.pdf
[Pg 181]
Patients prescribed this class of drug should be very closely monitored.

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

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

If required or desired, provide FREE trained support for these individuals within the community.

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?

Behavioural, dietary and medical interventions for autistic children should be researched and instigated as will be recommended in the new NICE guidelines for ASD in England. In clinical management, the diagnostic components are to include biomedical investigations, genetic assessments, neuroimaging, EEGs and metabolic testing. Hopefully SIGN guidelines for Autism will also include these components.

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

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?

Access to counselling could be helpful.

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

Comments

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

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?

Professionals should be made more aware of the dangers of drug side effects. Patients should be constantly monitored. The recent study by Dr Alex Mitchell from Leicester University found that deaths from inadequately monitored / treated drug side effects accounted for deaths at four times the rate of suicides. If professionals feel too far removed from their GP training to safely address these side effects, [as Dr Mitchell's study suggested] then GPs should be permitted to be included 'in the team'.
http://www2.le.ac.uk/offices/press/press-releases/2011/august/psychiatrists-failing-to-adequately-monitor-patients-for-metabolic-side-effects-of-prescribed-drugs

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?

Consult with, and include the patient when appropriate.
They should be told about Advance Statements and be encouraged to have one prepared.
However, where patients with learning disabilities and / or an autism spectrum disorder are concerned, the subject of Advanced Statements needs reappraisal, in my opinion.
Without some kind of advance statement these patients are in a very vulnerable position – left with no protection from the lack of knowledge and understanding in psychiatry, of the unusual drug reactions and metabolism problems in ASDs. If permanently placed within a residential unit, psychiatrists can prescribe psychotropic drugs to the client without consulting parents - once the client reaches 18 that is.
Harry Horne-Roberts' parents welcome probe by police into autistic son's death while in care home.
http://www.islingtontribune.com/news/2010/apr/harry-horne-roberts-parents-welcome-probe-police-autistic-son%E2%80%99s-death-while-care-home

All patients with an ASAD should be tested first to see if they can tolerate psychoactive drugs.
http://www.healthanddna.com/drug-safety-dna-testing/dna-drug-reaction-testing.html
In fact with poor metabolisers occurring at 1 in 10 of the general population, ALL patients should receive this test.

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

A JCB? – to knock down the barrier of 'patient confidentiality' - with agreement of the patient of course. So much remains undisclosed behind this wall.
And to knock down the barrier of the territorial mind-set within psychiatry. The study by Dr Mitchell emphasises the need for this.
Inclusion of other disciplines should be encouraged. Especially where autism and asperger syndrome are concerned. Input from neurologists and psychologists should be sought, welcomed and heeded.

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

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?

By treating them with respect courtesy, and including them in discussions and decisions – with the permission of the patient. All too often family members are deliberately excluded on the grounds of 'patient confidentiality' or on premise that the 'professionals know best'. Families and carers and ultimately the patient would benefit for example, on advice on how to handle difficult situations. 'Talking down' to parents and carers in a patronising fashion, benefits no one and can create a communication barrier, which could adversely affect the well being of the patient. With the agreement of the patient, inclusion at hospital review meetings. All too often hospitals actively discourage the presence of relatives. This stance is encouraging exclusion and isolation.

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?

Education and training in autism spectrum disorders.

This must include an awareness that people with an ASD are sensitive to psychiatric drugs and can react badly to them. They have metabolic differences and sometimes, multiple chemical allergies.

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?

Adults with Asperger syndrome. Desperately need informed professionals and trained, educated support workers. Within psychiatry there is a frightening ignorance of the condition and how it can affect individuals.

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?

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?

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?

Workforce should be trained and educated in autism spectrum disorders especially in adults with Asperger syndrome who can display behavioural differences, challenging behaviour and apparent social deficits. Authoritative and bullying attitudes can result in a crisis in a person with an ASD – or a 'meltdown' as it is sometimes called. This can lead to disastrous outcomes for adults on the spectrum, within the mental health system.

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?

It would be useful to carry out a survey to ascertain the number of adults with Autism and Asperger syndrome within the mental health system.

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

Diagnosis and treatment of people with Autism Spectrum Disorders should be a priority.
It seems the professionals not only lack expertise and education in diagnosis and treatment of Autism spectrum disorders, but also in the dangers of prescribing psychotropic drugs to patients with these disorders. Often the drugs given to people on the autism spectrum start with Ritalin or SSRI antidepressants, both of which can result in psychosis. These prescription drug-induced states seem to be poorly recognised within the profession and inevitably lead to the prescribing of antipsychotics, which can also cause or worsen psychosis. This problem is not new – it has been around for decades, but as the present tsunami of people on the Autism spectrum hit adult psychiatry, it could now rapidly worsen unless something is done to prevent it. Apart from the obvious rising cost of care and treatment, inappropriate drugging is causing untold suffering to patients and their families.

http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/ASDRef/ASD24Jan11
Agenda Item 10: Criminal and forensic issues and ASD - Brief introduction - Dr Iain McClure
10.2 It is vital that people are not misdiagnosed. A significant number of people may be being criminalised (i.e. their ASD is not picked up in criminal investigations of aberrant behaviour) and / or possibly admitted to forensic psychiatry units such as Carstairs and medicated for possible 'false positive' diagnoses e.g. for schizophrenia (which has many symptoms and

signs on mental state examination that overlap with ASD) when they are in fact undiagnosed autism. Such scenarios may lead to possible miscarriages of justice, as well as inappropriate clinical management approaches.
With the emergence of drug-induced psychosis – or a psychotic episode resulting from stress and anxiety, patients are mistakenly being labelled and treated as schizophrenic, or as having bipolar or some other affective disorder.

Paul Shattock in Autism File Magazine Issue 31 -
[He is now president of World Autism Organisation]

Adolescents and Adults with Asperger's Syndrome
"Personally, I have come across literally hundreds of adults who have been diagnosed late in life and so many of them have been misdiagnosed as suffering from bipolar or dyspraxia or Tourette's syndrome, the features of which constitute parts of the tapestry of Asperger's. Worse still, many are diagnosed at some stage as having schizophrenia and have consequently been treated with powerful drugs which are completely inappropriate for Asperger's and which can clearly make some of the symptoms worse. [And this is seen as evidence that higher doses should be given and so on...]"

A quote from Tony Attwood –
http://www.tonyattwood.com.au/index.php?option=com_content&view=article&id=120:adults-with-asperger-disorder-misdiagnosed-as-schizophrenic&catid=48:diagnosis-and-assessment&Itemid=473
"Individuals who were not diagnosed with pervasive developmental disorders in childhood may subsequently be misdiagnosed as chronic, undifferentiated schizophrenics."

There is little evidence that SSRIs can help and children may suffer serious adverse effects as a result of taking the drugs.

http://www.physorg.com/news200226527.html

Benzodiazepines are effective in the short term but cannot or should not be used long-term.

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

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?

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

Again – in people with an ASD – a multidisciplinary approach should be accessible. And psychiatrists should be able to seek advice from experts – and follow that advice – without feeling their 'authority is being questioned or threatened'.
As in NICE Guideline for ASDs -

"The autism team should either include or have regular access to the following professionals if they are not already in the team:

- paediatrician or paediatric neurologist
- child and adolescent psychiatrist
- educational psychologist
- clinical psychologist
- occupational therapist.

The autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including:

- coexisting conditions such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders
- looked-after children and young people.

Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others.
Psychiatry seems to be far too territorial. It is imperative that ASD persons have access to input from other disciplines.

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?