

## 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.

Autism is a serious, lifelong disabling condition that affects the way a person communicates with, and relates to, other people. It is a spectrum disorder which affects each individual in different ways. Around 1 in 100 people have autism, which equates to over 50,000 people in Scotland.

Autism is not itself a mental health problem but is classified as a developmental disorder in the DSM and ICD manuals. It is perfectly possible to have autism and very good mental health. However many people with autism will experience co-morbid conditions such as problems with mental health. As many as 71% of children with autism can have a mental health problem such as anxiety disorders, depression and obsessive compulsive disorder. Around 40% of children with autism will have two or more mental health problems.

This has a wider impact on families and carers, on their health, wellbeing, income and relationships.

NAS Scotland very strongly welcomes the questions raised by the consultation document on the impact developmental disorders are having on mental health services, and how these services can best meet the needs of people with conditions such as autism. We agree that this is an area of significant challenge – 42% of people affected by autism rate the understanding of the condition by care professionals as poor or very poor (NAS 'We Exist' report 2010).

It is the view of NAS Scotland that strategic direction is urgently needed but that this is not fully addressed by either the mental health or the autism strategies. 'Developmental disorder' isn't defined in the consultation document, and there is very little information on what progress is felt to have been made.

A strategic view should address the priority areas highlighted on pages 5 and 6. The provision of appropriate psychological therapies and the accessibility of 'low-intensity treatments' are both areas of concern and where there is little available information. This problem is also closely connected to the provision of community based services as many adults with autism may not be diagnosed or identified within services.

The problem of identification is a key one and of huge significance given the prevalence of autism and the nature of the impact it has on an individual.

### 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.

NAS Scotland is concerned that amongst clinicians and professionals it is not always clear how they should be addressing autism. Concerns remain that misdiagnosis is still possible and that many professionals do not fully understand the communication needs of people with autism.

To address this clear clinical guidance is required. The Scottish Government will be aware that there is SIGN guidance for children with autism and that NICE is developing guidance for both children and adults. The provision of guidance in Scotland is needed if we are to truly say 'we know where we are trying to get to' as we do not feel this is the case for people with autism.

## 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.

Improving services for people with autism, which is a form of developmental disorder, requires services to be able to identify people with the condition. NAS Scotland highlighted within the consultation on the Scottish Government's autism strategy our concerns that so few people with autism are accurately identified within services. Poor identification of people with autism has led to service providers and commissioners ignoring the condition.

The provision of adult autism diagnosis is absent in many areas of Scotland and where it is available waiting times can take years. It is not yet clear from the autism strategy when, or how, this will be fully addressed. This will impact on the HEAT target for the availability of psychological therapies for adults if they require an autism diagnosis.

Cross-agency working and information sharing is also needed because the need of an individual is often not addressed within the one service. Autism specific input is also required to ensure that a range of services are appropriately addressing need.

The training needs of professionals at all levels need to be understood. Autism presents complex challenges when it co-occurs with mental health problems that can lead to poor treatment.

**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

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

Many children and adults with autism are experiencing bullying, harassment and discrimination related to their condition. There has never been a national campaign to address these attitudes but the experience of these negative attitudes often contributes to stress and the difficulties with social interaction all on the autism spectrum experience.

People with autism also need to know their own rights, and what responsibilities they have.

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?

Many people with autism and other conditions have communication support needs. These can be a barrier to recognising the development of a mental health problem as well as a cause for their development due to stress and anxiety.

Support with communication and adjustments in both the means of delivering services and of providing support information are required. Measures of outcomes should address the success of communication methods used, for example those developed for the Public Service Improvement Framework.

**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?

Children with autism need to be properly identified in the balanced scorecard. It is not clear to us how those children with a learning disability and autism are identified and if this extends to cover the whole autism spectrum.

NAS surveyed parents on their experiences of CAMHS in England and Wales in 2010 and discovered that just one third of parents believed that CAMHS had improved their child's mental health. Less than half thought CAMHS staff knew how to communicate to their child and 44% found it difficult to get a referral. We do not believe these experiences are substantially different for parents in Scotland.

The Scottish Government can ensure that those who plan and commission services meet the need of children with autism and mental health problems. This would reflect the national priority stated by Ministers in the Autism Strategy.

At present it is not known how many CAMHS teams support children with

autism, and how many teams provide targeted support.

We strongly recommend that government should review its definition of emergency CAMHS provision to better meet the needs of children and families and that local CAMHS are funded to provide 24-hour support to children and families who need it.

We also recommend that guidance for transitions involving mental health services be drawn up. There are substantial differences between child and adult psychiatry practice which do not support the concept of services designed around people.

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

NHS Boards would benefit from clear guidance on what is expected in terms of providing services to people with autism who have a mental health condition. NAS Scotland is concerned that children and adults with autism may not be considered to qualify for services in some areas and the issue of unaddressed diagnosis may also be a barrier 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?

People with disabilities or conditions that affect how they communicate can experience difficulties explaining how they feel. NAS Scotland believes this requires a more specialist approach than that which would be used with the general population. Given the strong connections between disabilities and poor mental health this is an area that would benefit from a focus on action.

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

NAS Scotland has found that supporting families and carers to understand what good mental health is and how to spot the signs of poor mental health is of particular benefit. When working directly with someone who has autism, communicating in a way they understand is also essential to effectively supporting them but often in services this set of skills is not available.

**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?

The 26 week target for referral to specialist CAMHS is an improvement on waiting times but still represents a 6 month wait for what to many people is a critically important service.

There is enough medical based evidence to show that children or adults with autism, and indeed other disabilities and conditions, are more likely to need access to mental health services but there is little information available to say how easily or difficult it is for people with autism to access services.

A clearer picture of how services are being matched to need is therefore required.

**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?**

It is not clear in this consultation as to what 'non-value adding activities' relates to.

Page 18 highlights the evidence base for effective treatment and it would appear that one of the key interventions highlighted in the evidence base – employment – has not been addressed. This has been promoted within other sections of the Scottish Government, for example in relation to the Supported Employment Framework and the work pioneered on mental health and social care at the University of Nottingham. A more joined up approach would incorporate employment support within the mental health strategy.

**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

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

Comments

**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?**

**Comments**

**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

**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?**

NAS Scotland welcomes the development in CAMHS of the balanced scorecard and the balanced scorecard for learning disability. This should be extended to cover other groups.

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?

NAS Scotland welcomes the identification of the significant gaps in service provision to people with developmental disorders. It is important for those in the Scottish Government responsible for the mental health strategy to connect with those responsible for the autism strategy and the Autism Reference Group.

**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?

There is considerable overlap in CAMHS between children with learning disability and children with autism. NAS Scotland is concerned that children with autism who do not have a learning disability will be excluded from the developing framework.

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?

As previously highlighted, the use of communication support, for example Speech & Language Therapists, is essential for many people to be able to access support in institutional and other settings. Often this specialism is absent along with the specialist knowledge required on more complex conditions.

Multi-disciplinary teams are often highlighted as the most cost-effective way of delivering services in this context and we would agree that this is most likely the required shape for services in Scotland.

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

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

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?

NAS Scotland is concerned that adult autism diagnosis isn't available in many parts of Scotland and that many clinicians do not have up-to-date skills. The Autism Reference Group is in the process of commissioning some work on this but at this point it is unclear what outcomes can be expected.

The evidence-based competence framework covers learning disability but should also cover autism.

**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?

The performance and outcomes of services provided to people with autism urgently needs to be addressed given the concerns expressed by many professionals that capacity does not exist to adequately support people with autism.

**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?**

Comments

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

Comments

**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?**

NAS Scotland has for a long time been concerned about the lack of understanding and inappropriate support for people with autism in mental health services. We are also concerned about the impact of legislation on the rights of people who are on the autism spectrum and who do not have a mental health condition.

As we have stated, autism is not a mental illness. It is perfectly possible to have autism and very good mental health. Yet people with autism often face a lack of appropriate services to meet their needs, and this can lead to a breakdown in mental health.

We are aware that many mental health professionals lack training in autism. This makes it difficult to diagnose an additional mental health problem or determine mental capacity. Further confusion can arise when behaviours which are a direct result of a person having autism are mistaken as signs of mental illness. Equally, mental health problems can be neglected at the assessment stage when problems are put down solely to an individual's autism. These uncertainties can often lead to inappropriate intervention, which may fail to help or even make things worse.

In terms of the legal framework, the Millan Report clearly recommended that the inclusion of learning disability and autism within the provisions of the Mental Health Act should be reviewed in the medium to long-term. This implies to us the need to fully review the impact of the legislation. The Mental Health Act has been in place since 2003 and this current consultation on mental health is an ideal time to call for such a review.