

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.

fSDC is a coalition of a wide range of voluntary organisations from across Scotland working together with parents/ carers of disabled children and young people working to ensure rights and justice for disabled children and young people in Scotland. We aim to see the good intentions of government policy and strategy turned into better lives for disabled children and their families.

fSDC is broadly happy with the overall structure of the Strategy but would ask for the distinct yet variable needs of all disabled children to be recognised and prioritised as an area of challenge.

Disabled children face exceptional pressures that can lead to the development of mental health conditions, but they often do not have the same emotional support resources available to them as other children. This can be linked to social isolation or problems with communication.

Disabled children are more at risk of social isolation due to discriminatory practices and a lack of resources (especially in as families of disabled children are more likely to be living in poverty and to experience the relationship breakdown). There are often barriers which limit opportunities for meaningful social inclusion, to develop an appropriate level of independence, to access education and employment and to make a contribution to one's community.

Disabled children are also at greater risk of experiencing abuse and bullying and the impact both in childhood and in later life can be substantial (BMJ 2001, Bond et al, *Does bullying cause emotional problems? A prospective study of young teenagers*). A strategy for Scotland's Mental Health should include a focus on anti-bullying work.

The coalition welcomes the fact that investment and increased targets for CAMHS are included in the strategy but questions why CAMHS has not been made one of the priority areas for the strategy. We strongly recommend that the MH Strategy include CAMHS and psychological services for CYP as one of the priority areas.

Key facts

- Social and economic costs of mental health problems in Scotland are £10.7 billion per year. (SAMH, What's it worth now? 2011)
- One in ten 5 – 15 year olds experiences a significant mental health problem (The Mental Health of Children and Young People in Great Britain, Office for National Statistics 2004) and that this risk increases with factors which include amongst others disability, abuse, family mental health problems. Therefore investment in the health of children and YP must go beyond the CAMHS, to incorporate mental health in early years' education, early intervention programmes for parents and early years health visitors trained in mental health. In addition, disabled children and young people who do develop mental health problems must have equality of access to specialists who can help them, particularly if they have complex needs.
- Children in Scotland aged 5-10 who are looked after at home or accommodated are 6 times more likely to have a mental health disorder than those in families in the community (52% compared with 8%) The coalition would remind the government that when more and more children are becoming **looked after** by virtue of their disability, this is a factor which needs to be given priority within any mental health strategy.

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.

The Scottish Government should consider how best it can produce evidence of effective change. fSDC members believe that many of the initiatives highlighted could not demonstrate any impact on local service improvement.

Members also question the evidence base used by clinicians and medical professionals for making change was at a 'higher' or more scientific level than is required for providing social care, and if therefore service changes were not being made where it appears necessary to service users, families

and carers.

Local authorities and health boards should also be able to demonstrate in a way that is accountable what partnership arrangements they have in place and how they are addressing local need, joined-up working, commissioning, training and service user participation. With greater budget restrictions, over the life time of the Strategy, we need to ensure maximum return for expenditure so the Strategy must incentivise joint work between the NHS, local authorities, justice services and the voluntary sector and relate this clearly to other systems such as GIRFEC and the ASL framework.

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.

fSDC members believe that definitions sometimes act as a barrier to accessing appropriate support or services, for example 'learning disability' can have a broad or a narrow definition.

From the point of view of services, clear clinical guidance needs to be available and the development of multi-disciplinary teams is believed to provide the best type of service. Many families feel mental health services are not well integrated into, for example, family support or school.

From the point of view of families or carers the impact of a mental health condition also affects them. Some have expressed the view that they are treated as being a problem.

We welcome the recognition given to children with developmental disorders and would point out that there are many forms of disability that rely on addressing communication support needs. Not all children think about or understand their feelings in the same way and communication support is vital for many with a disability to be able to access services. Increased opportunities to identify one's strengths and abilities, to have skilled intervention to better understand the nature of one's difference and to realize one's potential should be made available to disabled children and young people. Adequate provision of speech and language therapy for children and young people and training in augmentative forms of communication for families and those working with disabled children is also vital.

Those supporting disabled children and young people within education, care and social settings should be aware of the mental health needs of disabled children and be equipped to facilitate early identification of concerns, to offer

appropriate support or signpost relevant services to children, young people and families.

The coalition is very concerned that with the increase in understanding around the impact of early adverse experiences e.g. trauma on the mental health of very young children, there is no CAMHS service for the under 5s. We would recommend that the Strategy prioritises this both in scope and range.

Access to CAMHS should not be determined by whether there is a diagnosed mental health disorder as psychology input may be essential for some children and young people e.g. those with long term conditions or disability but who may not need the input of full psychiatric services.

Improved provision of accessible and appropriate post diagnostic support and support to parents and carers in relation to behavioural concerns, including sleep problems and relevant and appropriate would deliver better long term outcomes. Support in the form of mutually beneficial short breaks for disabled children and their families would also improve outcomes in the longer term.

The national strategy also needs to consider how it relates to other key policy areas for children, such as GIRFEC or Additional Support for Learning.

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?

Many children and young people do not have positive self-awareness and can suffer from serious bullying. Services or programmes for tackling self-harm and suicide should be accessible and not just in a physical sense. Sometimes self-harming is related to communication issues and an intervention to address depression may not be appropriate.

The Strategy needs to promote ways that children and young people with disabilities can develop a positive sense of themselves.

Stats – In Scotland, 781 people died by suicide in 2010. As the SG Choose Life Strategy ends in 2013, the MH Strategy should give priority to continuing suicide prevention work beyond 2013. This can and should include counselling and other forms of support to reduce self-harm amongst CYP and those with ASN (e.g. the Place2be in schools)

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

fSDC members felt the use of multi-disciplinary teams can reduce the

stigma attached to mental health services and that more work should be done with children and young people directly to challenge discrimination.

Children and young people may also face indirect discrimination if their parents have a condition and we would support more work to help them.

The sharing of information on parents' mental health is part of the GIRFEC system and a vital component for the children's well-being.

Education should have a different view of mental health and rather see it as a part of the global health of the individual. It is unfortunate that MH has a separate referral system and we would recommend integrating it within mainstream health which would help to remove the stigma and otherness that is often associated with MH.

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?

There is not enough understanding of the issues facing people with mental health problems especially amongst children and young people and especially amongst those who are affected by disability and chronic conditions. The Strategy should continue to promote and prioritise work streams to raise awareness and fight stigma e.g. the See Me Campaign and Respect me are excellent examples of best practice.

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

Befriending schemes and social groups are highly valued as both a form of support and of early intervention. Despite the number of studies that highlight their cost-effectiveness these schemes are not made available widely enough.

We would highlight the effectiveness of programmes such as the Place 2 Be (at present in 18 schools across Scotland) which embedded in schools and local communities will enable greater access to CYP with mental health needs. Many of these programmes, if not cost neutral, carry minimal costs e.g. Seasons for Growth.

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?

It is not always clear who CAMHS services are expected to provide a service to, often children with co-morbid conditions are not properly supported especially if they have communication support needs. The purpose of CAMHS needs to be more clearly defined as some parents and carers have been refused support because their child has a disability and

not solely a mental health or behavioural problem.

The CAMHS service needs to be made more widely available and in particular not rely on the formal diagnosis of a mental health disorder which may exclude children who have mental health issues allied to their disability or long term condition.

Some fSDC members have highly valued CAMHS input and support but had to wait exceptionally long times to get help. They do not believe the HEAT target fully addresses the needs of families. Many parents and carers simply don't know that the service exists or what they should be telling professionals about their child's mental health. Families and carers need to be much better equipped with advice and information and supported much sooner.

We know from families that CAMHS is very inequitable across the country and that waiting times can vary enormously. A 26-week waiting time is just too long for a child or young person. We would recommend that the strategy promotes best practice and sets an 18-week waiting time for all referrals and not just for those who will require CAMHS i.e. following initial assessment, children will be signposted to the most appropriate treatment or service for them and their family.

Nor should access to CAMHS be time-limited as we know that CYP affected by disability and long term conditions will need support on an ongoing and recurring basis.

Members welcomed the development of the 'balanced scorecard' system but would like to see it extended to include information on a range of conditions so information more would be available on disability and mental health across the country.

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?

Information on mental health and supporting services need to be accessible, especially for those with communication support needs. This covers not only different formats but also the ways in which someone may conceptualise feelings differently.

There is a need to build mental health promotion in to GIRFEC as part of

the child plan.

There should also be work undertaken to raise awareness and of services such as Hands on Scotland www.handsonscotland.co.uk (HOS). The strategy needs more emphasis on the promotion of good and preventative mental health and better coping mechanisms within families and in the community through resources like HOS and others. If this can be achieved, then we will reduce the need for crises management.

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

For a child or a young person with a disability their needs should be addressed through the GIRFEC approach and this should include their mental health needs.

The support for family or carers is also very important but members are concerned that this is an area not likely to be prioritised in funding.

If direct service support is not likely, then priority should be given to promoting resources like Hands on Scotland which will not only help front-line workers make a difference to CYP lives, but also enable their families and carers to benefit from the information, support, advice and techniques. Hands on Scotland have recently developed an early year's portal to their website.

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?

Around a third of GP appointments are about mental health problems yet research suggests that GPs do not feel confident in providing information on mental health (Scottish Executive Health in Scotland; report of the CMO, 2003)

Members would like to see GPs develop a much better understanding of mental health problems to better help families.

The Strategy should offer GPs regular CPD opportunities in positive mental health and common mental health problems especially when relating to children

Parents, family members and carers also need to know a lot more about mental health and what they should be looking out for.

This applies equally to all practitioners and Staff training in MH should be available not just for those working in the field of MH e.g. LTCs specialist nurses, teachers etc so that they can inform, signpost and support families.

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?

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

The impact of the evidence for the effectiveness of early intervention has not been fully measured; it appears that many areas of the country experience very different standards and outcomes.

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?

Many members were concerned that engagement did not make good use of appropriate adaptations for communication support.

Outcome 6 mentions the **whole person** and their capability for growth, self-management and recovery – it should be noted that any consideration of the whole person must include the wider family and the person's carers particularly in regard to CYP affected by disability.

It is very important to harness the participation of the users in service design and delivery through existing opportunities such as a Service Users' Group within the relevant Managed Clinical Networks and family support groups for different condition e.g. Autism, ADHD, Tourette's etc. In addition; service user involvement in service design and delivery could be improved by investment in the development of a forum for disabled children and young people and/or a service which aims to improve opportunities for Disabled children and young people to be consulted upon with regard to those things which matter to them most. Too often there is an expectation that consultation is happening without the required investment in the resource required to undertake this in a meaningful way.

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

Communication support is now a part of the national outcomes measuring framework and should be used as a measure of effective change. Along with communication support it would be very important to include easily accessible advocacy services.
Interventions such as Family Group Conferencing to facilitate

communication within the partnerships and ensure the best possible outcomes for all concerned

It will be vital to provide ongoing help when needed as CYP, affected by disability and LTCs do not **recover** in the conventional sense and will need treatment and support possibly for the whole of their lives.

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?

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

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

The SRN should also develop services to cover for the needs of children and young people and in particular, those with a disability.

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?

fSDC is aware that families often feel that they are not listened to and in fact some have had very poor experiences of mental health services. A good assessment should not only take on board their views but also relate to any support family or carers may need.

It is also often unrecognised the importance short-breaks can provide a family.

In thinking about the whole family, it will be important to recognise the impact that a child's condition can have on their sibling(s) whose mental and emotional wellbeing can often go un-noticed when the focus is on the affected child.

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?

Again fSDC would highlight the need for training in communication support needs.

There will be a need to facilitate the provision of information sources for staff such as a one stop shop. All staff should also be aware of the support

voluntary agencies can offer in terms of advice, support and information not only on specific disorders but also on welfare benefits and other resources.

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?

Members considered the information collected and commented upon by the Mental Welfare Commission. They thought it may be beneficial if health boards or CHPs should be required to respond to the MWC, if they do not already do so, on what they intend to do to address issues identified in the MWC Annual Report.

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?

fSDC would be interested to know if the 'balanced scorecard' could be developed to build a more detailed picture, including outcomes with those who have protected characteristics under the Equality Act.

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

We need to harness the power of systems like the Curriculum for Excellence and make sure that the principles of any Mental Health Strategy are firmly embedded within CfE.

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

Members felt that all those who come under a 'protected characteristic' should be monitored to see if they are experiencing any significant barriers to mental health services.

There needs to be more focus on early intervention and support in order to promote good infant mental health and reduce the negative impact of poor parental mental health on very young children.

Within hospital settings mental health liaison for CYP plays a very important role i.e. the provision of a paediatric psychologist.

When an increasing number of children are becoming *looked after away from home* by virtue of their disability and looked after children are 6 times

more likely to have a mental disorder than those living with their families, it follows that adequately resourcing mental health provision in this area will be an urgent priority for the Scottish Government.

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?

fSDC members welcome the work being done on learning disability and would like to see this extended to cover a more comprehensive range of complex needs and children and young people with communication support needs.

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?

The strategy should demonstrate it has a clear understanding of what barriers exist for children and young people with disabilities and how these will be overcome.

The knowledge and understanding around Early Years attachment psychology is an area of immense importance in the positive life outcomes for children and young people and one which needs to be universally recognised and understood across all service providers.

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?

Policies and initiatives such as the SG's recent *Common core of skills, knowledge and understanding and values for the children's work force in Scotland* along with the current *Improving Advocacy for Children and young people: Principles and minimum standards* will be crucial in the implementation of *Promoting Excellence* across all health and social care settings.

Clinical supervision and support for professionals will be just as critical as support for carers.

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?

fSDC members would like to see more information on who is accessing services and what outcomes they are experiencing.

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

In addition to improving understanding of communication support needs, fSDC believes the impact of co-morbid conditions needs to be much better understood.

An increase in CAMHS provision in general along with a widening of the service to include provision for CYP who may require psychological input but who do not necessarily have a diagnosed mental health disorder or need a psychiatric service.

This should also as a matter of priority include infant mental health.

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?

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

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?

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?

CYP should not be treated within adult mental health wards. The European Association for Children in Hospital (EACH) charter <http://www.ascscotland.org.uk/default.asp?page=66> states clearly that they have a right to be treated along with others of the same age and stage and the right to access Education while there. GIRFEC principles and the protection the system offers should be extended to all YP up to 18 (25 with a disability) admitted to adult mental health wards.

There is a wide-spread misunderstanding and misapplication of the law around consent and confidentiality with regards to children and young people. The giving of consent has nothing to do with age and rests on the capacity of the child to understand the treatment and consequences of it.