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.

Under the 14 outcomes we would like to see a greater emphasis place on early identification of mental health difficulties and further development of the concept of placing the patient at the centre of their own care plan. Those with mental health needs require improved access to evidence based support and services at primary care level.

Gaps in the key challenges identified.

Currently there are limited and insufficient adult mental health or psychological services for adults with ADHD (A-ADHD) in Scotland. This poses considerable problems for individuals who require diagnostic evaluations and treatment programmes for ADHD beyond the school years. In a few NHS Board areas, services have been established and the items completed in this response draw partly on experiences of patients who have undergone assessment for A-ADHD in Scotland, the results of our own freedom of information requests and partly on guidelines established in England and Wales. With specific reference to A-ADHD we conclude that:

1. Services are not applied consistently across Scotland, patients are frequently deigned a far assessment by a clinician familiar with the condition.

2. There is no identifiable clinical pathway

3. At local level only one NHS Board has prepared a needs assessment for adult ADHD

4. In 11 of the 14 NHS Boards there are no future plans for developing services for adults with ADHD

5. People with ADHD face substantial difficulties in accessing assessment by those with the appropriate level of skill and expertise.

6. There is substantial scepticism within health professionals who do not have experience of assessing and advising those with ADHD about the condition. This does not give a fair chance to those wanting an objective assessment.

7. Correct treatment can bring about substantial changes and facilitate people taking charge for themselves,

What are the service standards that should be expected?
Service Standard 1. An effective and accessible A-ADHD assessment and treatment service is offered across all NHS Boards.
Service Standard 2. Patients with suspected A-ADHD are assessed by clinicians with the appropriate level of skill and expertise.
Service Standard 3. A-ADHD health services provide a high quality of care that meets the needs of patients, referrers and providers.
Service Standard 4. There is an effective patient management process from the point of first referral.
Service Standards 5. Patients with severe A-ADHD have ongoing apcess to specialist services appropriate to their needs.
Service Standard 6. Patients with A-ADHD receive co-ordinated care from healthcare professionals with experience and expertise of diagnosing and management of patients with A-ADHD.

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.

In order to define a policy, the extent of the problem must first be assessed. NHS Lothian has provided some high level statistics in their response to our freedom of information enquiry and petition, but more mature established clinics, both in the UK, specifically the Maudsley and in Europe, specifically Stockholm are longer established and will be able to offer more detailed figures to identify the extent of the problem, both with transitioning yourig adults and previously undiagnosed adults.

The costs to society caused by issues which may affect ADHD adults, including family break up, prison, unemployment and misdiagnosis through the Mental Health Service need to be measured so that the potential benefits of treating adult ADHD can be realised. The desired outcome of the policy is to enable ADHD adults to align their wellbeing with the NHS Health Scotland's Outcomes Triangle.

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.

As part of the Mental Health Strategy for Scotland, there must be widespread recogriition that adult ADHD exists, understanding of the impact it can have on a person's life, their family and society and provision of appropriate interventions. Sufficient resources must be available for the number ADHD adults requiring services. The ADHD adult's environment must be inclusive, enabling them to thrive in line with NHS Scotland's Outcomes Triangle for Mental Health.

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?

National adoption of best practice initiates
A good practice example
The development of ASD (Autistic Spectrum Disorder) diagnosis for adults in the South East and Tayside (SEAT) Learning Disabilities Managed Care Network Area - Lothian, Fife, Forth Valley and Borders.
The Regional ASD Consultancy Service (RASDCS) is a Tertiary level multi disciplinary team with staff from each of the four Health Board Areas in South East Scotland and has been running sirice 2002. It is a "virtual" team with one full time member of staff and the others giving time in special interest sessions or by arrangement with their managers.
As of August 2011:

- 4 Consultant Psychiatrists
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The team receives referrals from the age of 18. Average age of referral is 38. RASDCS operates at Tertiary level; referrals are accepted from General Adult Psychiatry or Learning Disabilities Services. Direct referral or referral by GP is not possible. Referral may be for Assessment, Diagnosis or Advice. RASDCS can not take ongoing responsibility for care. The team currently receives about 8-10 referrals per month. Referrals at this level take an average of 10 hours to assess, frequently with very considerable individual variation. A key aspect is the likelihood of an extensive time commitment required by staff.
These referrals are often very complex and may be for second or even third opinion. Several members of the team may see them to ascertain different perspectives. No one test is appropriate for all and each individual referral may be assessed using a different combination of tools and psychiatrists carry out psychiatric interviews. Eariy developmental history is gathered by whatever means possible (interviews with parent if available, partner, family member, early medical

records, school reports etc).
There is a clear Diagnostic Care Pathway document which is adhered to and audited regularly so there is a consistent method of addressing an inconsistent type of referral.

Evaluation forms are completed by the referrer and the clients themselves in order to maintain quality and improve it where necessary. Clinical Governance support is provided by CGST in Lothian. Recent analysis carried out by CGST found that 100% of referrers returning evaluation forms felt that the service met their expectations. Of the people referred to the Service 100% found it useful to have been referred to the team arid 93% felt their expectations had been met. Some team members are involved in ASD research projects and may recruit from clients on the database (subject to NHS Ethics Committee approval).
From http://www.scotland.gov.uk/Publications/2011/11/01120340/4 accessed 19/01/2012

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

Continue and expand the partnering approach with third sector organisations and follow up on the good work achieved under the see-me campaign.

Questiori 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?

Engage with third sector organisations and service user involvement in the provision of mental health care, expand and develop choice and options to care by providing well informed evidence based matched care.

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

Advice and support about the following should be considered: workplace and career, college and educational matters, time management and organisation, family and relationship concerns and support groups. Specific advice may be given to partners and relatives of adults with ADHD and to people with ADHD concerning gender-specific issues.

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?

More formalised transition protocol to adult mental health services.

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

A clearly defined transition protocol to adult services.

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?

Psychological support should be available, targeted at the particular problems related to ADHD. This includes a wide range of treatments and could include psychoeducation, anger management, daily living skills and treatment of comorbid anxiety and depression. Counselling may be required particularly with emotional problems related to chronic impairment from early childhood. Adults starting on pharmacological treatment for the first time will often need advice on how best to take advantage of potential improvements in their mental state and level of functioning. ADHD coaching dr long-term support will be important in some cases where short-term psychological interventions are insufficient. For those with a high level of impairment, community healthcare provision may be required on a longer-term basis and occupational therapy will be important in some cases.

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

Under the current model
The first recourse is an appointment with the GP. Anecdotal evidence suggests that a GP who recognises and is educated in adult ADHD is rare.
SIGN
All health professionals rely on the **SIGN** Guidelines to inform them of the correct procedures to follow. Adult ADHD does not have a clinical pathway for diagnosis and treatment.
Referral
It is at the discretion of the GP whether to refer. Previously undiagnosed adults with ADHD, often first go to the GP with depression or anxiety issues. By not identifying and treating the underlying ADHD, they are being prevented from recoverlng.

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 tb treatment?

For adult ADHD there are two broad models for healthcare provision.

1. Generlc services: Trained psychiatrists and adult mental health teams have included the diagnosis and treatment of ADHD within their general adult psychiatric practice. This model is recommended, since the symptoms of adult ADHD overtap with a range of other common psychiatric disorders, and the specialist should be aware of the full range of adult

psychopathology when evaluating adults with ADHD. However this does presuppose that there are sufficient clinical professionals with understanding of the condition and experience of assessing and advising adults ADHD.

2. Specialist neuro developmental services: An alternative model is to establish a specialist service for common neuro developmental disorder in adulthood that could incorporate overlapping conditions such as autism and mild learning disability. The advantage of this model is that an expert team can be developed to optimise sensitivity to the diagnosis and care pathways, including both pharmacological and psychological treatments. Where such services have been success- fully established, they have usually incorporated transitional services in addition to the evaluation of new patients.

Outcome 5: Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently.

Question 12: What support do NHS Boards and key partners need to apply service improvement approaches to reduce the amount of time spent on non-value adding activities?

Comments
This needs consideration and assessment of evidence based matched care approaches.

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

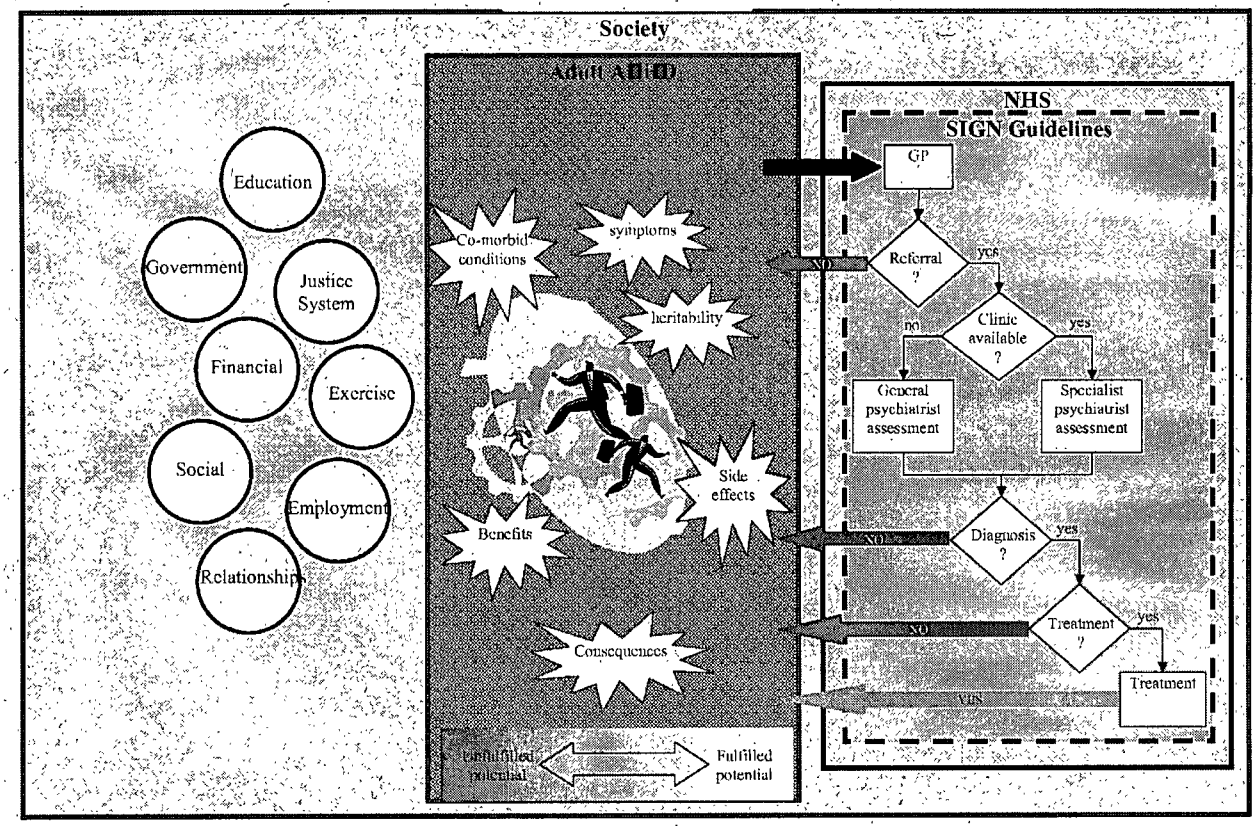
Assistance with designirig and developing service provisions in line with a quality agenda such as customer service excellence.

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?

The current model does not provide the opportunity of a fair assessment for adult ADHD.

Current model



This is a user care group with a high level of risk of a poor outcome and provision of a strategy and policy for adult ADHD in Scotland will substantially improve the outcome prospects for individuals and their families and reduce the overall cost to society for dealing with the fallout from undiagnosed adult ADHD.

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

The following services are required for adults with ADHD:

1. Drug monitoring service: For patients taking stimulant or other medication there needs to be a drug monitoring service. Any suitable trained specialist including adult psychiatrists, nurse practitioners and primary care physicians can provide this. In most cases shared-care protocols should be established in which primary care takes responsibility for routine prescribing and health checks.

2. Psychological treatment services:

3. Diagnostic services: Specialist services for the diagnosis of ADHD in adults should be available. This includes the diagnosis of adults who were and were not initially diagnosed with ADHD in childhood. There is a large population of people who went undiagnosed and untreated in childhood and present for the first time as adults.

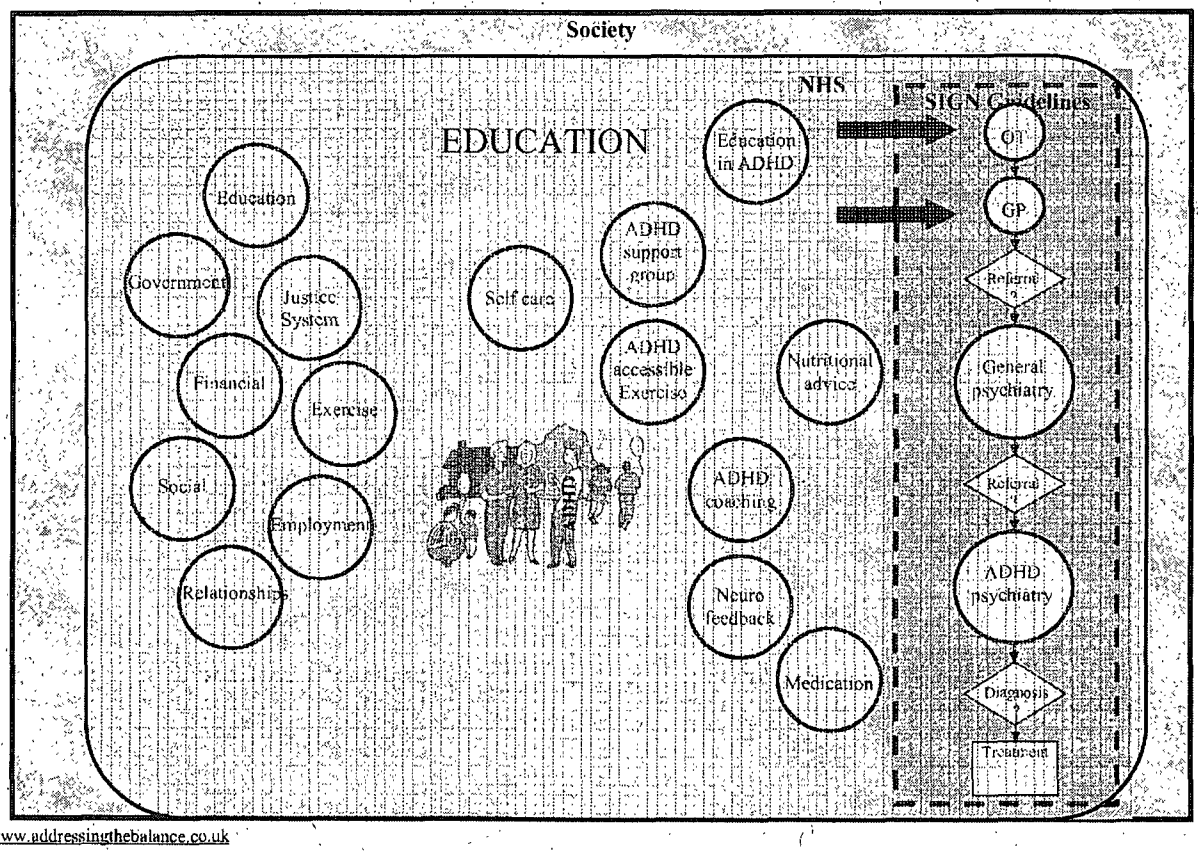
The diagnosis of ADHD should be made by a specialist with training in

general adult psychiatry, who can take account of the full range of mental health problems (usually a consultant or other trained psychiatrist, or child and adolescent psychiatrist working within an adult mental health team). Where medication is indicated, diagnostic services should initiate and monitor treatment during the titrationi phase. Prescribing during this initial phase can, however, be devolved to the primary care physician where a shared care protocol is established.

Questipn 16: How do we further embed and demonstrate the outcomes of person-centred and values-based approaches to providing care in mental health settings?

Improve the model of care, enhance education and promote self management.

Suggested model



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

Comments
Wider acceptance of the family and community health involvement and value in the recovery process.

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

Comments
Wider acceptance of the family and community health involvement and value in the recovery process.

Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.

Questibn 19: Hdw do we support families and carers to participate meaningfully in care and treatment?

Provision of facilities in community health care to encourage service users, their carers and family members to understand and be educated about the mental health condition, to accept the reality and best align their life to encourage wellbeing and resilience.

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
Training for staff and time to develop trust and appreciation of the involvement of family and carers. A more widespread adoption of advocates and user involvement in the choice of intervention or therapy.

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?

Numerous reports and assessments have been produced on mental health services in the last 12 years and these have provided direction and recommendations which have not in their entirety been accepted. Enacted developments in service provisions should be reviewed against the stated national objectives for improving wellbeing, resilience and self management, results published and initiatives for knowledge sharing encouraged.

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
Rather than rigorous data collection and benchmarking, NHS Boards should eb encouraged to adopt a knowledge sharing and collaborative approach.

This could be by more widespread adoption of the community of practice, web based forums already in use by lpcal authorities.

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

Develop mental health awareness, review and publicise innovative approaches and good practice examples such as the RASDCS initiative (see answer to Q3).

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

In considering the care pathway needs for adults with ADHD there are several categories of need that can be distinguished:

1. Currently treated group: Diagnosed and treated for ADHD in childhood (or adulthood) and still requiring treatment. This group can be further sub-divided into: (a) stably maintained on medication, no need for psychological treatment (b) stably maintained on medication, need for psychological treatment and (c) not stably maintained on medication, requires further titration of pharmaco-logical treatments and/or psychological treatment.
2. Currently untreated group: diagnosed with ADHD in childhood apd currently untreated.
3. Never diagnosed: diagnosis of ADHD not made in childhood. For people iri each of these groups, a psychiatric evaluation is required by a specialist in adult mental health with the training to diagnose and advise on treatment for ADHD.

Full psychiatric evaluations are required for all groups apart from those that are previously diagnosed and stably maintained on treatment (group 1a) and require no further intervention apart from a follow-up service for drug monitoring. The other groups require follpw-up services to monitor the current and future needs for medical and psychological interventions. The benefits and disadvantages of both pharmacological and psychological treatments for each individual case need to be considered and both should be available.

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?

More widespread understanding of neuro developmental disorders and adult ADHD in particular. Establishment of a clinical pathway for adult ADHD.

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?

Provision of a strategy and policy for adult ADHD.

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?

Reduce silo mentality and consider service provision across agencies with collaboration and integration established as a common approach rather than as an exception.

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?

A Scotland wide, needs assessment should be undertaken for adults with ADHD and a thematic review of existing services should be undertaken.

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

Comments
Improved information for staff, extend the SIGN guidelines to include adult ADHD. Development and adoption of a strategy and policy for adult ADHD. To support this it will be necessary to complete a national thematic review and needs assessment in each NHS Board.

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
See answer to Q22.

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

See answer to Q22.

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?

Target adult ADHD and the crirninal justice system.

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

Define neuro developmental disorders and explain how the strategy and policy for adult ADHD is integrated or separated frorn the autism strategy.

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.

Ouestion 35: How do we ensure that staff are supported so that care and treatment is delivered in line with legislative requirements?

1. A clearly defined and integrated clinical pathway and a programme of CPD and training in mental health conditions similar to the suicide awareness training undertaken.
2. Design and development of services in accordance with a quality agenda commitment.

THE ORGANISATION OF CARE FOR A-ADHD

Currently there are limited and insufficient adult mental health or psychological services for adults with ADHD (A-ADHD) in Scotland. This poses considerable problems for individuals who require diagnostic evaluations and treatment programmes for ADHD beyond the school years. In a few NHS Board areas, services have been established and this recommendation draws partly on experiences of patients who have undergone assessment for A-ADHD in Scotland and partly on guidelines established in England and Wales. This statement explores user expectation of service standards.

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Full psychiatric evaluations are required for all groups apart from those that are previously diagnosed and stably maintained on treatment (group 1a) and require no further intervention apart from a follow-up service for drug monitoring. The other groups require follow-up services to monitor the current and future needs for medical and psychological interventions. The benefits and disadvantages of both pharmacological and psychological treatments for each individual case need to be considered and both should be available.

The following services are required:

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Advice and support about the following should be considered: workplace and career, college and educational matters, time management and organisation, family and relationship concerns and support groups. Specific advice may be given to partners and relatives of adults with ADHD and to people with ADHD concerning gender-specific issues.

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MODELS OF CARE FOR ADULTS WITH ADHD IN ESTABLISHED SERVICES

There are two broad models for healthcare provision:

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2. Specialist neurodevelopmental services: An alternative model is to establish a specialist service for common neurodevelopmental disorder in adulthood that could incorporate overlapping conditions such as autism and mild learning disability. The advantage of this model is that an expert team can be developed to optimise sensitivity to the diagnosis and care pathways, including both pharma- cological and psychological treatments. Where such services have been success- fully established, they have usually incorporated transitional services in addition to the evaluation of new patients.

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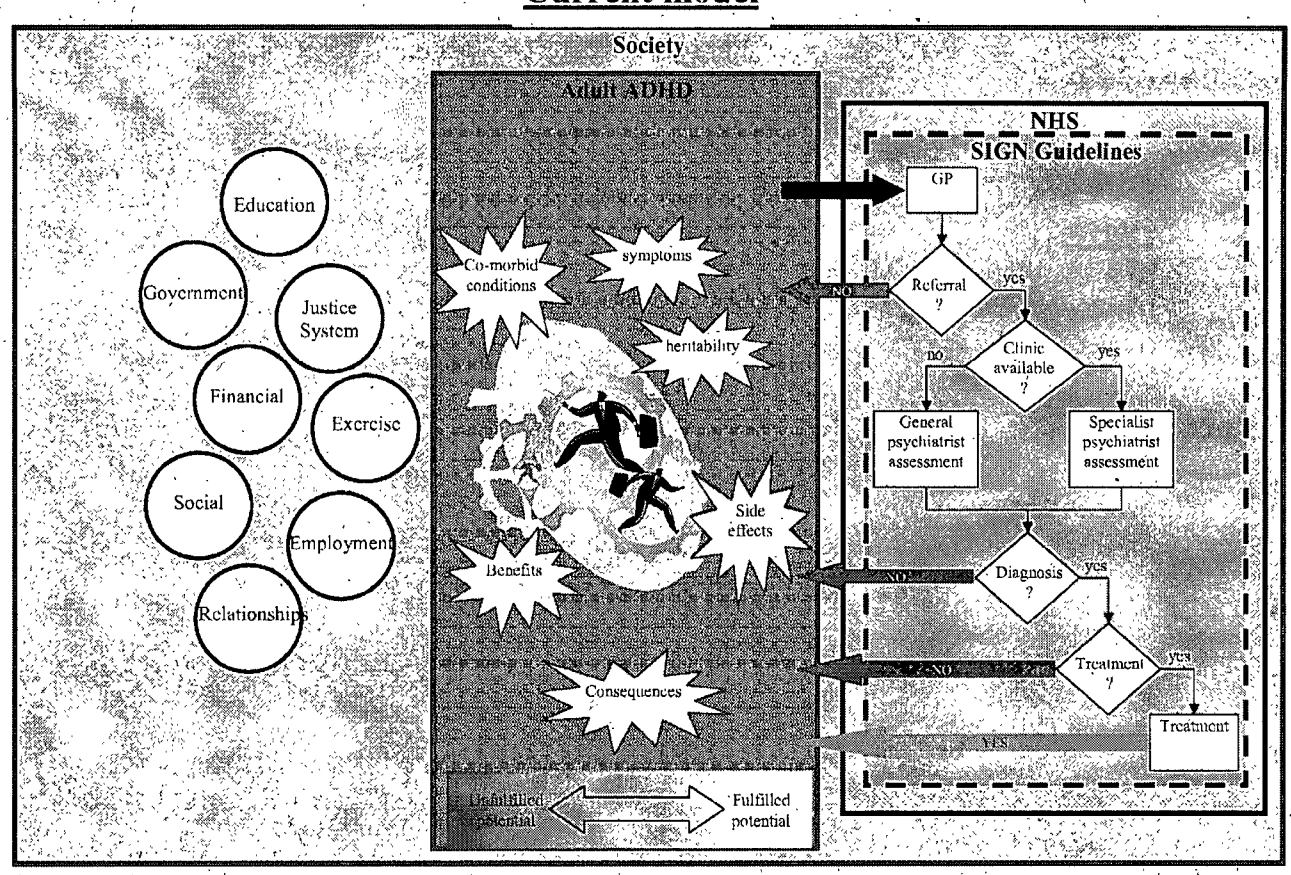
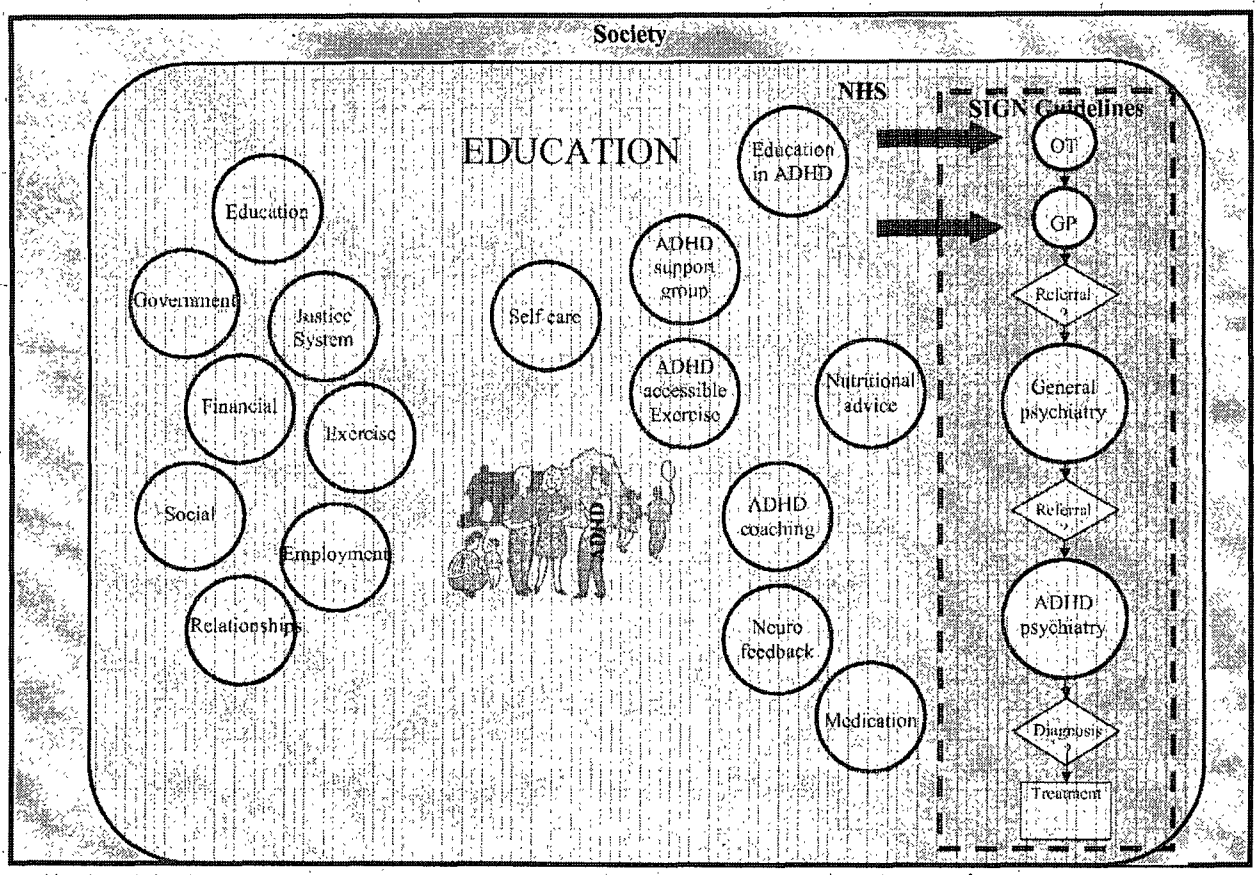
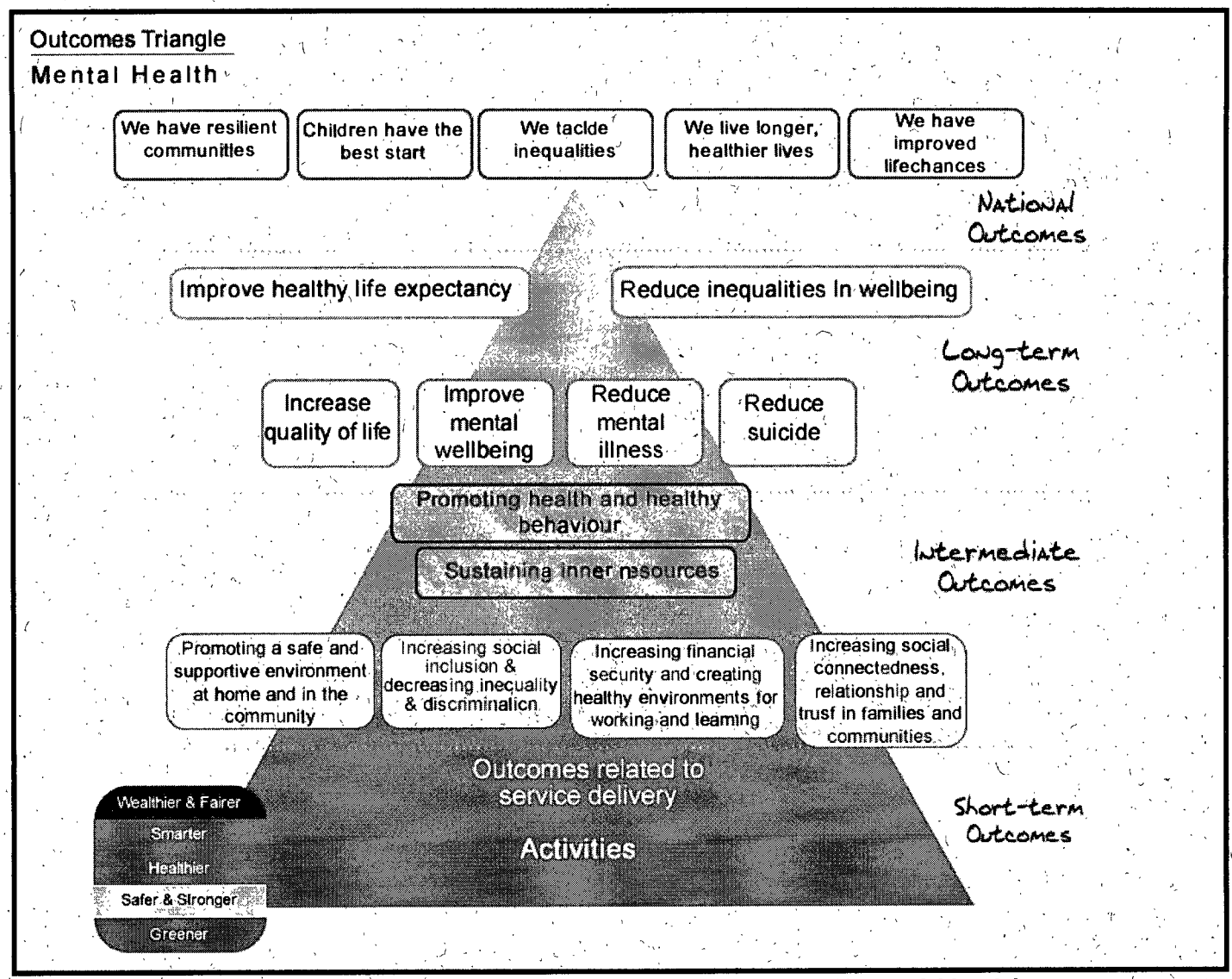


Suggested model





NHS Health Scotland - Outcomes Triangle Mental Health