The Health and Sport Committee has launched its inquiry into child and adolescent mental health services (CAHMS) and would like to invite you to submit your views to the inquiry.

After making a number of informal visits to child and adolescent mental health projects around Scotland earlier this year, where they spoke to service users, the Committee has decided to focus its inquiry on the younger generation’s needs.

The Committee is particularly interested in how children and adolescents at risk of developing mental health problems are identified by the medical and other professions. It is also keen to learn more about access to services and ongoing support for this group of children and any improvements that could be made in the transition from children’s mental health services to adult mental health services.

The Committee’s inquiry will be structured around a number of key questions that arose from members’ discussions with young service users. The Committee would be grateful if your response could focus on these questions.

How children and adolescents potentially at risk of developing mental health problems are identified and how those problems should be prevented?

The risk factors for emotional and mental health problems in children and young people include their circumstances and experiences. Reducing these risks involves effective interagency action on a wide front. NHS Lothian has programmes in place to reduce smoking, especially amongst teenagers and expectant mothers; it is working with its partners on the Drug and Alcohol Teams to encourage pregnant women not to drink or take drugs or at least reduce their intake to safe levels before birth; it is addressing the need to reduce teenage pregnancies; and it is working with local authority children’s services to encourage and support a range of parenting programmes, further details below.

The early recognition of children and young people at high risk of developing significant mental health problems depends on the awareness and recognition of problems in frontline staff, health visitors, social care workers, school nurses, teachers, youth and community workers, etc. We know that especially in the early development of complex and pervasive mental health problems young people often withdraw from regular structures such as school and community groups, which makes the recognition of their difficulties trickier. This is particularly pertinent for mental health difficulties such as psychosis, bipolar disorder, severe eating difficulties and recurrent depression.

1 Communities That Care, Edinburgh Risk and Protective Audit, a survey of 17,000 school pupils. Nov. 2006
In order to improve the early recognition of these significant and severe difficulties we need to increase public awareness, and improve the specific knowledge base of those working with vulnerable groups. Where this has been targeted, e.g. in Norway, through a public health and national service initiative and in the UK in services designed for ultra high mental states, the recognition and appropriate treatment of vulnerable young people could be significantly increased by 30 to 50%.

The Community Health Partnerships have worked with each of the four local authorities within the Board area to develop Parenting Strategies which fit well with the Scottish Government’s recently published Early Years Framework and its 10 elements. Each of these Strategies recognise and reflect that the mental health and wellbeing of children and young people is, in varying degrees, the responsibility of everyone who works with them and comes into contact with them all of whom need to be suitably prepared and trained.

At the next level up the Child and Adolescent Mental Health Services is highly committed to delivering evidence based parenting interventions such as the Webster-Stratton model, a comprehensive programme for parents and teachers of children with conduct and emotional problems aiming to present these problems from developing into more serious disorders, and runs training for staff across Scotland as well as delivering clinical programmes of intervention locally. This intervention is suitable for children with disruptive behaviour disorders who, if untreated run a high risk of developing later academic problems, school exclusion, substance abuse, delinquency and violence.

At a specialist level all CAMHS out-patient teams offer consultation so that early discussion can take place around children at risk of developing mental health problems. Each team also has community mental health workers who have 50% of their time dedicated to building the capacity of education, and other partners providing universal services to promote well-being and recognise the signs of common mental health problems in children and young people. This early intervention works well in areas where there are sufficient staff to link in an effective way with schools but less well in areas such as Edinburgh where community mental health workers are trying to link with too many schools. The department has also developed resources for schools such as the depression in teenagers DVD which has been sent out to all Scottish schools and has developed web-based resources suitable for young people and parents about stress and depression in teenagers. (www.stressandanxietyinteenager.co.uk & www.depressioninteenagers.co.uk) all aimed at improving early recognition of difficulties and sign posting to effective self-help and other treatment options.

There are also specialist teams working with high risk groups:-
- Paediatric Psychology and Liaison team at the Children's Hospital working with children impacted by physical ill health,
- Child Sexual Abuse Team.
- Early-onset Psychosis Support Service
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- Look After and Accommodated Children’s team in Edinburgh offers in depth consultation to residential care staff and foster carers and input into all the systems that feed into LAAC in order to identify early in the care process existing and emerging mental health problems
- ADHD team in N-West and S-West Edinburgh.

Each of these teams is linked in to the relevant part of the universal services to advise on and, if appropriate, see children and young people suspected of having a serious mental health problem. There are capacity issues for these teams in relation to the assessed need and expressed demand for their services.

More work is needed with both universal and targeted groups of children but this will require an increase in capacity as well as any improvements which can be achieved through more effective joint working.

Learning Disabilities and Autistic Spectrum Disorders – there is a consultant and a clinical psychologist for people with learning disabilities who have mental health problems. Within their limited capacity they can offer the following pathways for identifying those at risk:

- Consultation between CAMHS-LD with nursing, paediatrics, social work
- Regular consultation with schools at behaviour forums
- Child development centre assessment / Community Child Health reviews
- Referral to community mental health nursing who then may refer on to CAMHS LD after assessment

With a larger team they could also offer :-

- a screening assessment to the Early Years services identifying the support needs of the child and family, including the potential risks of developing behavioural / mental health difficulties.
- Provision of support and advice to parents in the early years.
- Consultation clinics with Early Years staff and parents to offer practical advice with behaviour / developmental difficulties.

Outreach:

- Intensive outreach for those families where a young person’s behavioural and emotional difficulties are extremely challenging.
- A potential development would be a CAMHS –LD link worker into the special schools and nurseries to work with staff on identifying / assessing difficulties early and developing helpful approaches.

What obstacles are there in identifying children and adolescents with mental health problems and how they might be overcome?
Stigma around mental health problems which exists within the general population and especially within the teenage population which may inhibit young people and families seeking help for their problems.

Waiting times which prevent children and young people being seen as soon as the problem is identified and impact on the amount of training, consultation and liaison CAMH teams can offer. Progress is being made in reducing waiting times through better organisation but there are capacity issues as well given the level of referrals and the complexity of the children and young people being seen by CAMHS. The out-patient teams have 7-8 whole time equivalent staff per 100,000 population, this is below the levels recommended by the national strategy ‘Getting the Workforce Right, Getting the Right Workforce’. This is an area where we need further development.

An under-recognition of ADHD\(^2\). This is probably due to a number of reasons including a lack of awareness and knowledge among referring agencies and perhaps continuing uncertainty about the nature of the condition. A group has been convened in Lothian to consider how the recommendations from QIS can be implemented.

There are gaps in provision which we are working towards closing with a combination of redesign and development. Looked After and Accommodated Children (LAAC), who have a high (45%) incidence of significant mental health problems, have specialist mental health workers in Edinburgh and West Lothian while Midlothian and East Lothian can only offer consultation and limited training. Children who are ‘Looked After at Home’ and those in foster care also have no dedicated service.

Single young homeless, offenders and early school leavers are all vulnerable groups who need to be targeted more specifically given the high incidence of mental health problems amongst these groups.

People with Learning Disabilities have a higher risk of experiencing mental health problems. They may face a number of obstacles:

- Diagnostic overshadowing – a young person’s behaviour may be attributed to the learning disability rather than an underlying mental health or emotional difficulty.
- The referral pathways for children and young people with learning disabilities need to be clarified as they can fall between the mental health services and those for learning disabilities.
- Skills in adapting general therapeutic approaches / assessments for young people with LD/ASD
- The need for inpatient services for children and young people with learning disabilities for assessing more significant mental health difficulties. Admissions into adolescent in-patient unit are not always safe or appropriate, nor is admission into the adult learning disabilities wards. Some very challenging young people with learning disabilities

\(^2\) QIS ADHD Services Over Scotland report (2008)
What action is being taken to facilitate early intervention and what else can be done?

Early intervention has already been referred to above. In addition the Community Mental Health Workers and other members of the CAMHS teams provide early intervention via consultation and training to primary and secondary schools.

There are opportunities to support parenting training and other evidence based programmes such as “Friends for Life” which have been rolled out successfully in schools internationally.

Many schools have sessional counselling services and NHS Lothian jointly funds services in a number of schools.

Health Visitors in Early Years and School Nurses in primary and secondary schools are alert to the mental health and well-being of the children and young people they see. They can seek advice and support from CAMHS or refer children and young people to the service.

For children and young people with learning disabilities community learning disability nurses will offer advice and input on behaviour if a child is referred to this service. But there is a need to develop a co-ordinated, multidisciplinary early years service, linked into the child development service, with clear referral pathways to CAMHS. By identifying potential emotional and behavioural difficulties early parents can be helped to develop strategies for supporting their children. A pilot parenting group in West Lothian was well received by parents and a service evaluation found that parents welcomed input at this early stage. Also advice, support and supervision could be offered to nursing colleagues working with clients.

A proposal has been drawn up to develop an intensive outreach service for young people, almost all with learning disabilities, who present with severe behavioural and emotional challenges. The aim would be to prevent difficulties escalating to the point of requiring admission. The CAMHS Learning Disabilities service is working jointly with Education and Capability Scotland on a new initiative to support young people presenting challenges to schools and home to the extent that a breakdown of either placement is likely.

How access to services and how ongoing support can be improved?

- The CAMHS out-patient teams have all introduced the Choice and Partnership Mode (CAPA) which is an established model of managing patient flow and so minimising waiting times in CAMH teams.
The Community Mental Health Workers work directly with schools to facilitate the link between the specialist CAMH teams and schools. This works most effectively in areas where there are sufficient Community Mental health workers to provide an effective link between schools and specialist CAMHS.

CAMHS has a 24/7 out of hours cover and all teams offer consultation and prioritise urgent cases.

Recent surveys of users and staff indicate that improved community accommodation, parking and good public transport to these facilities would also help families access more easily the help they need.

Access is being improved via the use of ‘phone text reminders to families to attend appointments with CAMHS. Where there are circumstances which may have proved to be barriers to a family accessing the service referrers are contacted and plans devised by which a family are supported to make a choice re attending.

There is a need for increased support to tiers 1&2 (community and primary care) to provide support and intervention for children and young people who have a mild mental health problem and for those who have been treated by specialist CAMHS and need non-specialist ongoing support.

As well as improving the efficiency of the existing service increasing its overall capacity will improve access given the level of expressed need now being referred to CAMHS.

Access is helped via the use of consultation clinics offered to schools, and respite services on a regular basis.

Respite care is a vital service for families with a child or young person with complex needs and/or challenging behaviour. NHS Lothian jointly funds with all four Local Authorities a specialist respite care service provided by a national voluntary organisation for this group. This service is very highly valued by relatives.

The provision of Day Programmes provides an accessible and very effective alternative to in-patient care, helping to maintain the child or young person’s links with home and peers whilst receiving specialist treatment. Lothian provides Day Programmes in Edinburgh and West Lothian for children and adolescents.

The development of intensive community treatment and support for young people with severe mental health problems living at home or in the community. Lothian has drawn up proposals with its regional partners for this service.

Providing appropriate training and skills development for staff through programmes such as ‘New To CAMHS’.

What problems are there around transition from CAMHS to adult mental health services and how a smoother transition may be achieved?
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- Transition to adult services can be difficult for care leavers aged 16-18 as the adult services offer a different level and range of support to patients and these young people are often difficult to engage with.
- CAMH teams work closely with families, schools, and colleges etc. This does not always continue once a young person accesses adult services even though they may still be needing significant support from parents and education etc.
- There is a transition team within the adult services but it's focus is on patients with complex packages of care.
- CAMHS plans to develop a range of intensive treatment options available to families. This augmented team will have a role in helping to plan for transition to adult services for young people who need ongoing support beyond their 18th birthday.
- We would wish to devise individual plans for patients moving from CAMHS outpatient to adult outpatients making the process as smooth and supported as is possible. Our experience shows that success with this is variable. The differing waiting times, referral and initial assessment procedures in each of the adult teams make this, at times, very complex.
- We have a specialist early psychosis service which works with young people for up to three years after their first psychotic episode. This means young people can be seen up to their 21st birthday. This service works very closely with adult services but transition and ongoing support for these young people is variable. Essential differences in service models between the CAMHS early intervention service and general adult mental health services and differences in provisions and the number and level of interventions available make a seamless transition difficult to achieve.
- For ADHD, NHS Lothian has convened a group from CAMHS and adult mental health to look at the development of services for adults with ADHD, including improving transition of young people from CAMHS. The has been complicated by GPs’ concerns about reviewing arrangements for adults on medication for ADHD.

For young people with learning disabilities and mental health problems and young people with Autistic Spectrum Disorder there are some additional issues:

- Young people seen by the CAMHS LD service transfer to the adult LD services at 16, unlike other CAMHS patients who transfer at 18.
- The CAMHS LD service sees young people who may have a diagnosis of ASD but no learning disability. Adult LD services do not at present work with young people who do not have a learning disability (IQ less than 70 and significant impairment in adaptive functioning). Services for these young people are very limited and it is not clear which Adult service can best meet their needs.
- When young people are subject to parts of the Mental Health Act prior to 16 yrs and up to 18yrs, they remain under the care of the Consultant Child Psychiatrist in CAMHS LD, rather than being transferred over to
Adult Psychiatry. This can pose practical and logistical difficulties at the age of transition as it may be more appropriate, due to the nature of the risks for support to be accessed via adult services.

- We need to develop clearer pathways between CAMHS LD and Adult LD in to facilitate a smoother transition.
- Early identification of young people with LD / ASD reaching 14 yrs and beginning the transition process in terms of outlining their support needs would be useful.

Additional Comments – Services for Children and Young People with Severe Illness.

The in-patient places in Edinburgh are planned to serve the South-East of Scotland comprising Borders, Fife and Lothian, a catchment population of about 1.2 million people, a level of provision slightly higher than that provided for by the 24 places in the West of Scotland serving a catchment population of 2.6 million. At present, however, these 12 in-patient places are also providing care for some referrals from the north of Scotland.

The South-East of Scotland Regional Planning Group recently reviewed the use of in-patient care, including admissions of young people to adult psychiatric beds, by the CAMH services in Borders, Fife and Lothian. The review also took into account the difficulties Borders and Fife currently experience in getting emergency and urgent admissions into the unit in Edinburgh.

From this work it became clear that all admissions to adult beds and emergency and urgent admissions from Fife and Borders could have been accommodated in the existing in-patient unit if three conditions were met -:

- that the 12 places were used primarily for South-East of Scotland patients with out-of-region patients only using places on an emergency, short-stay basis.
- that Lothian used the available bed days proportionate to its population.
- that long-stays beyond 3 months were largely eliminated.

It was recognised that to achieve the first condition depended on the completion of additional in-patient provision in the North of Scotland; to achieve the second and third condition would depend on the development of an alternative model of care in Lothian in particular but also in Fife and Borders which had occasionally experienced patients with long-stays in the in-patient unit.

The alternative model is develop an Intensive Community Treatment and Support Service for young people with serious mental health problems providing them and their families with specialist care and support at home and through the Day Programmes which would be extended to 7 days a week and evenings. This will enable in-patient care to focus on its core acute functions for those who need to be admitted including emergency and urgent
admissions. Also it will enable patients to be discharged when clinically ready to go home with intensive care and support in the community if necessary. Most of the long stays beyond 100 days are for non-clinical reasons.

This model of intensive community treatment and support is very similar to models developed in many CAMH Services elsewhere in the UK.

The Intensive Community Treatment and Support Service would be part of a comprehensive care pathway for children and young people with serious mental health problems. The pathway offers a continuum of treatment and support from

- Early Identification at Tier 1 or 2,
- through the specialist Tier 3 locality CAMHS teams
- to Intensive Community Treatment and Care, including attending a Day Programme,
- and to In-Patient Care if necessary and appropriate

This is set out in its simplest form below :-

<table>
<thead>
<tr>
<th>Tier 1/2</th>
<th>Tier 3</th>
<th>Tier 3/4</th>
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<tbody>
<tr>
<td>Prevention, Early Identification &amp; Early Intervention in :- Early Years, 1^o School 2^o School Training for all staff in basic mental health &amp; wellbeing of children &amp; young people. Advice &amp; Counselling Community MH Wrkrs.</td>
<td>Multi-disciplinary Specialist locality CAMHS Teams</td>
<td>Specialist out-patient teams :- Early Onset Psychosis (14 – 21 year olds) Child Sexual Abuse Looked After and Accommodated (Edinburgh Connect) Learning Disabilities/Mental Health ADHD</td>
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<tr>
<td></td>
<td>Tier 4</td>
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<td></td>
<td>Intensive Community Treatment &amp; Care. Day Programmes (7 day availability) In-patient Care.</td>
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--------------------- Patients being supported by different services --------------------- along the pathway in both directions according to their needs

The alternative to the intensive community treatment model of care was to plan the provision of an additional 4 in-patient places. These would have cost as much to provide as the community service but would have increased activity by only 20 extra admissions across the region compared to many more patients expected to use the intensive community model of care.

John Thomas
Strategic Programme Manager
21 January 2009