

# **TIER 4 ADOLESCENT MENTAL HEALTH NEEDS ASSESSMENT FOR THE NORTH OF SCOTLAND**

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## **1.0 Introduction**

National policy and a wide ranging literature detail the need for the commissioning of Tier 4 child and adolescent mental health services to be strategic, evidence based, needs led and outcome focused (McDougal, T et al (2008)). This needs assessment seeks to inform these component parts of commissioning for what is identified as Tier 4 CAMHS across the six NHS Boards in the North of Scotland.

The needs assessment has been commissioned by the North of Scotland Planning Group at the request of the Chief Executives through the Child and Adolescent Mental Health Project Board and from the North of Scotland Public Health Network. The needs assessment is intended to inform the strategic decision making that will be required to secure investment in and development of Tier 4 services for inpatient (specialist adolescent mental health inpatient unit or age appropriate psychiatric care in a paediatric or adult hospital) and community based adolescent mental health services across the North of Scotland Boards. The North of Scotland CAMHS Service Modelling and Workforce Planning Group acted as the reference group for the exercise and have been involved in the development of the report and the conclusions. A copy of the commissioning document can be found in Appendix 2.

This report will be presented to the North of Scotland CAMHS Project Board in June 2010 and will inform the development of the outline business case for the regional inpatient unit later in the year.

Tier 4 child and adolescent mental health services are required to meet the needs of young people with the most complex, severe or persistent mental health problems. Young people meeting the criteria of need for a Tier 4 service are profoundly unwell and very vulnerable. They have been likened to be in need of intensive care of the mind, which perhaps demonstrates in a more tangible way the intensity of service required from services. It is not unusual for services involved with young people with very poor mental health, for example young people with learning disabilities and/or those forensic needs to seek advice and care from child and adolescent mental health services. Often this group of young people are unlikely to benefit clinically from a Tier 4 service and

require intensive social support instead. This can be a source of tension and present dilemmas between integrated children's service partners.

Because Tier 4 need is by definition, complex and multi faceted and arises from within the whole population and can only be understood in the context of mental health need, illness and disorder across all the Tiers of need across the population, the epidemiology section considers the full range of mental health need in a population of 12-17 year olds. However, this needs assessment focuses on the requirements of young people aged 12-17 inclusive, whose level of need requires a level of specialist input that can only be met through what has been defined as a Tier 4 level of service where age appropriate care is available in a general psychiatric inpatient unit, paediatric or adult mental health bed or through intensive community services.

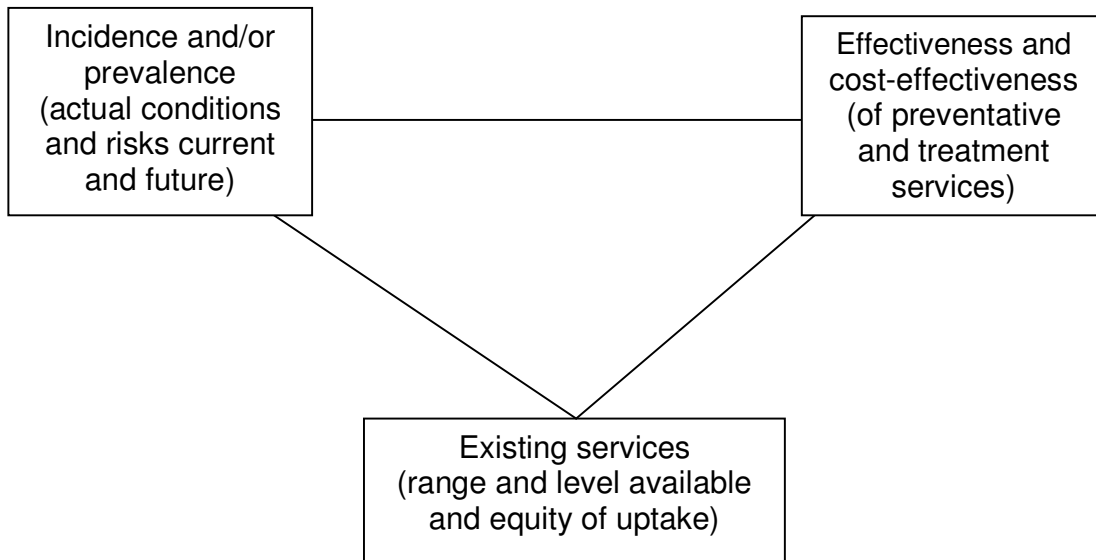
For the purposes of this report, Tier 4 mental health need (North of Scotland Planning Group (2009)) has been defined as:

Young people with mental health difficulties *and* one or more of:

- too high risk to attempt to treat with usual outpatient resources e.g. suicidal, psychotic with disorganisation, self harm or violent behaviour
- need intensive assessment or treatment (equivalent of more than weekly outpatient contact and more than one CAMHS professional)
- not responding to usual outpatient treatment – which may be because they need reassessment, or more intensive input

This exercise has sought to utilize an epidemiologically-based healthcare assessment of needs (Stevens and Raftery, 1994) and seeks to describe and quantify the level of healthcare need based on that which people, in this case young people and their families, will benefit from. The epidemiologically-based approach uses a triangulation of healthcare needs assessment (fig.1).

**Figure 1: An epidemiologically-based approach to healthcare needs assessment**



Source: adapted from Stevens and Raftery (1994)

In recognition that there is still a limited literature on the nature of and service models for Tier 4 CAMHS the needs assessment process has sought to engage in a range of approaches in recognition that using a multiplicity of measures is likely to result in a more valid appraisal of need. This has involved consideration of population epidemiology, service utilisation, a review of service models and in addition, consideration of user views.

The report covers the following key areas:

- The strategic policy context for Tier 4 CAMHS in Scotland
- Mapping CAMHS service and consideration of the human geography of the North of Scotland
- A review of the epidemiology of Tier 4 conditions
- Quantifying need for Tier 4 CAMHS across the North of Scotland
- Consideration of remote and rural issues in relation to Tier 4 CAMHS
- Reviewing the evidence for Tier 4 CAMHS service models
- A review of engaging and involving users of Tier 4 CAMHS services

The process has not included a critical examination of local service provision but assumes that the report will stimulate local discussion and inform both Board based service and regional investment decisions.



## **2.0 Developing a Strategic Framework: The Policy Context for Tier 4 CAMHS in Scotland**

A familiar theme in the literature is that the commissioning of Tier 4 services tends to be locally driven, badly planned and lacking in information about need and demand (and this was notably identified in the NHS Health Advisory Service report (1995)). All Boards in the North of Scotland are familiar with the acknowledged tensions of a regional inpatient service where all too often there is a mismatch between sporadic demand and bed availability, while Boards are challenged by the need to ensure viable, cost effective services at a specialist level either regionally or at Board level.

As summarised in the NICAPS study (O’Herlihy, A et al (2001)) ‘The relatively low volume of these services means there is a need for coordinated service planning , including the ways of achieving the optimum balance of units’.

Within the North of Scotland the establishment of a Project Board to have oversight of the commissioning of a regional Tier 4 service through the Service Modelling and Workforce Group means that the north is well placed to address these challenges.

The focus of the Government in child and adolescent mental health is evidenced in the raft of policy documents and guidance detailed in Appendix 1.

### **3.0 Mapping CAMHS services/the human geography of the North of Scotland**

#### **3.1 Introduction**

The North of Scotland NHS Boards cover 61% of the Scottish land mass and incorporate the majority of the inhabited island communities in Scotland. The populations of the island Boards and 99% of Highland residents live over a two hour drive from the central belt from where the majority of tertiary services for Scotland are accessed. This presents a particular set of issues when designing and delivering highly specialist services across the North of Scotland. These challenges of access and travel times for some of the populations in the North of Scotland are experienced wherever a specialist resource is located. Visual presentation of the issues that arise from the geography of the North of Scotland Boards through mapping can be a useful way of detailing the complexity of the human geography of the North of Scotland.

NHS Highland's Health Intelligence team supported the Needs Assessment process through undertaking a series of tasks as follows:

- Providing illustrative mapping of current Child and Adolescent Mental Health Service (CAMHS) locations across the North of Scotland
- Detailing travel times involved in attending services located in Dundee as a proxy Tayside location for the purposes of this report, using a Geographical Information System (GIS)

The technical detail and methodology involved in these tasks is detailed in Appendix 3.

#### **3.2 The population of the North of Scotland**

The population of the North of Scotland Boards, excluding Argyll and Bute CHP who are not in the scope of this report is 1,224,042 (Table 1). There are 263,282 children and young people aged 0-17, and 96,029 of these are aged 12-17 years of age. This latter age cohort is the focus of this needs assessment exercise. (Table 2) A visual presentation of where these young people live is detailed in Map A. 5% or 1 in 20 of adolescents in the North of Scotland live in island communities across Orkney, Shetland and the Western Isles.

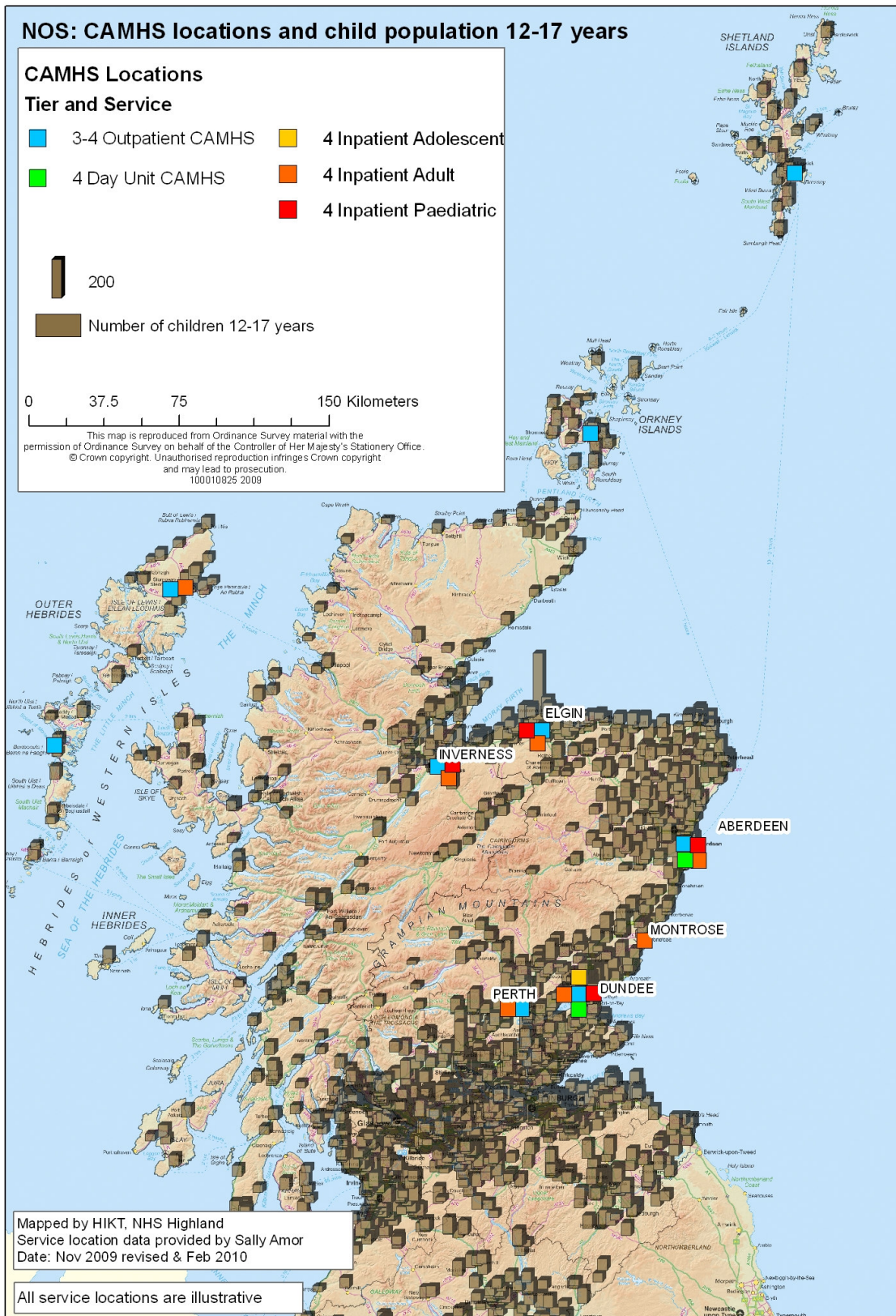
**Table 1: Data Source: GRO(S) Population Estimates for Administrative Areas 2008**

	<b>NHS Board</b>
<b>Grampian</b>	539,630
<b>Highland</b> (excluding Argyll and Bute)	219,400
<b>Orkney</b>	19,890
<b>Shetland</b>	21,980
<b>Tayside</b>	396,942
<b>Western Isles</b>	26,200
<b>Total</b>	<b>1,224,042</b>

**Table 2: Proportion of NOS child population aged 12-17 years of age within travel footprint of Dundee**

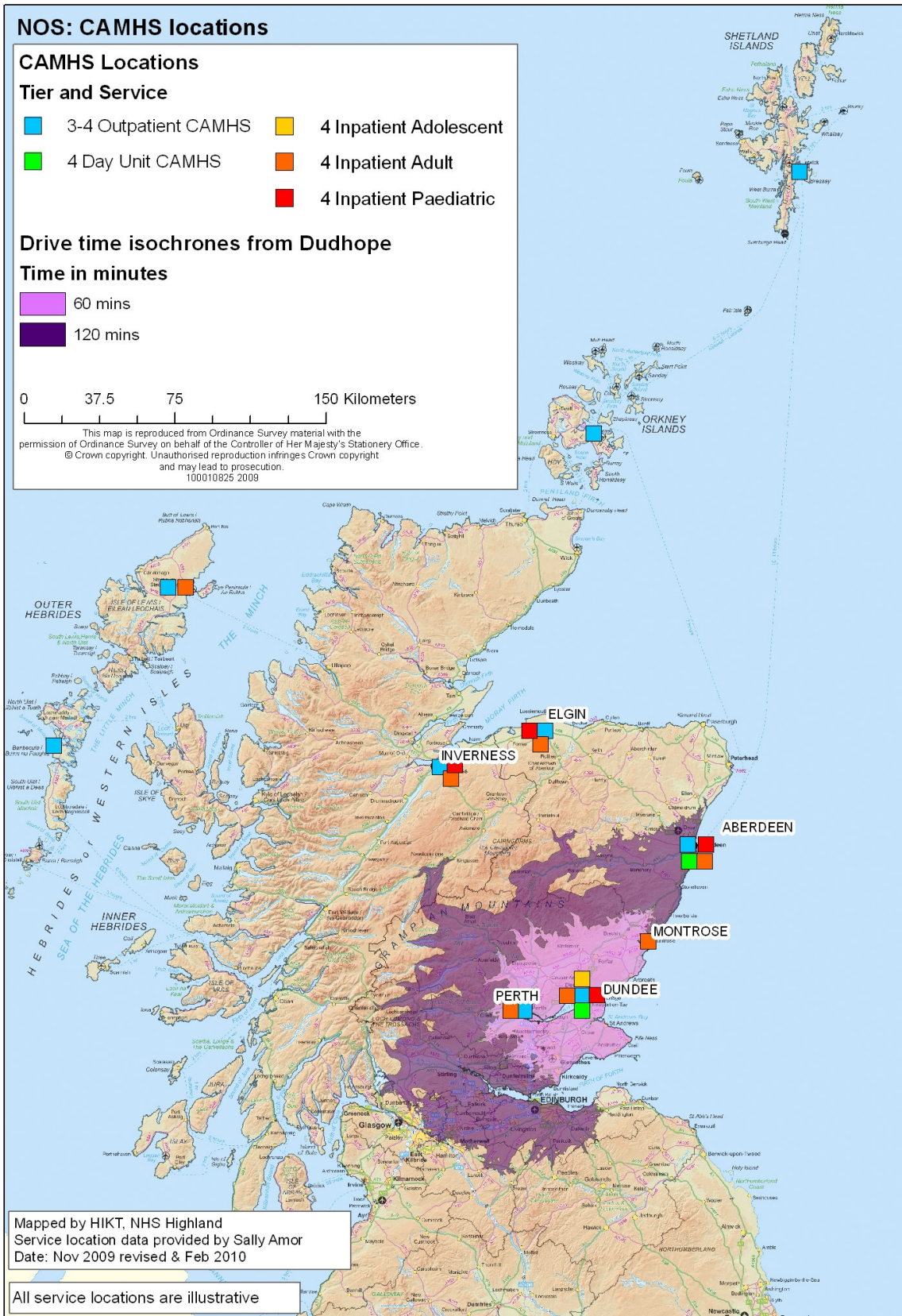
	Population aged 12-17 years	% Population within 120 minutes drive time	% Population within 60 minutes drive time
Grampian	38952	52	1
Highland	23138	<1	
Orkney	1601		
Shetland	1821		
Tayside	28548	100	94
Western Isles	1969		
<b>Total</b>	<b>96029</b>	<b>51</b>	<b>28</b>

# Map A: CAMHS locations and child population distribution aged 12-17

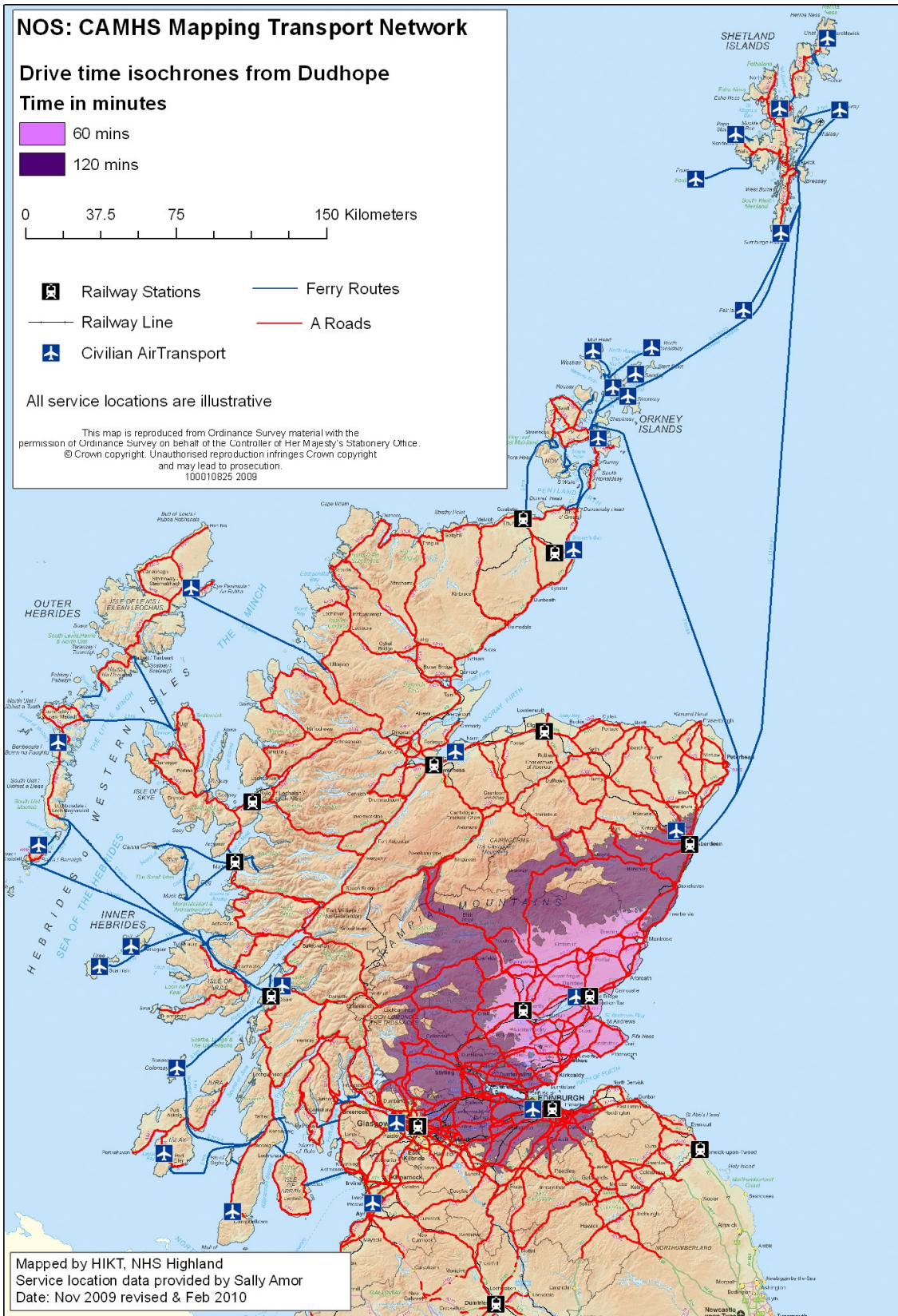




# Map B: CAMHS locations and major travel routes in the North of Scotland



# Map C: Transport links for the North of Scotland



### **3.3 CAMHS Services across the North of Scotland**

Map B details where current Tier 3 community based child and adolescent mental health services are located. All of the three island Boards have community based Tier 3 services. These are also located in Inverness and Elgin as well as in the bigger population centres in Aberdeen, Perth and Dundee.

Map B also details the two Tier 4 day patient services that are currently provided in Dundee and Aberdeen. These could provide potential for developing additional intensive service capacity as explored elsewhere in this report.

The location of the one dedicated and funded inpatient adolescent unit in Dundee sits at the proposed hub of an obligate network for Tier 4 CAMHS across the North of Scotland.

In addition Map B details where there are paediatric inpatient facilities and adult inpatient services. These locations are options for developing local age appropriate services to address Tier 4 levels of need, as explored elsewhere in this report.

### **3.4 Transport links and access to Tier 3/4 services**

Transport links across the North of Scotland and its island communities are important as they detail the links and access to professional points to receive a service. These are detailed in Map C.

Much of the populations of the North of Scotland Boards are remote from the main centres of population in the central belt of Scotland. There are no main line rail stations on the islands and limited rail lines and train journeys north and west of Inverness. Ferries and flights can be disrupted by weather. Flight times can be limited and may involve transferring at airports en route. Accessing an air link in itself may involve car, bus and or ferry journeys. There is limited trunk road infra structure on all of the islands and to the north and west of Inverness, the remainder of roads across the north and west are often single track.



It is of note that only 28% of the 12-17 population live within an hour's drive of the Dudhope inpatient unit while 51% live within a two hour drive. For just under half (49%) of the 12-17 population, an inpatient admission would require over a two hour drive to reach the unit. Whereas the need for ferries for island populations would clearly add significant travel times for island residents, less than 1% of the mainland Highland population live within a two hour drive with 48% of the Grampian population also being more than a two hour drive away. Equally, these travel challenges would also exist for some of the North of Scotland population if an inpatient unit were to be located in either Aberdeen or Inverness.

### **3.5 Key Points**

- The North of Scotland population is scattered and some communities are particularly remote which presents particular challenges for the design and delivery of highly specialised Tier 4 child and adolescent mental health services
- The transport infrastructure for the Highlands and islands has implications for access to specialist services
- The challenges of access and travel times for some of the populations in the North of Scotland will be experienced wherever a specialist resource is located.

### **3.6 Conclusions**

- The location of a range of health services across the North of Scotland presents opportunities for the development of Tier 4 services through the development of intensive community and inpatient services through a network approach.



#### **4 .0 The epidemiology of Tier 4 CAMHS**

This epidemiology section addresses the incidence and prevalence of child and adolescent mental health illness and disorders across the whole population. It is intended that the levels, distribution and trends of both the conditions and of their risk factors are described in terms of potential need in the population relevant to CAMHS. As discussed previously, a high level of mental health need does not necessarily mean that access to a Tier 4 mental health service will be appropriate or be required to address that need.

The data presented is based on published data, and each piece of research / set of data needs its own interpretation – both in the age group represented, in the population it applies to, and in the use of terms and diagnostic categories etc. The epidemiological analysis does not relate directly to bed numbers, and its interpretation in terms of service needs should be handled with caution. This point is further explored at the end of the section where the epidemiology is summarised and interpreted.

Epidemiology and the application of epidemiological methodology can inform CAMHS in a number of ways:

- Aetiology - support for the development of preventative strategies
- Quantification of the community burden of mental health disorders and problems
- Clinical assessment e.g. screening for non-mental health practitioners aiding referral to CAMHS
- Outcomes - use of observational studies to assess effectiveness of interventions

This section is principally involved in the quantification of the population burden for Tier 4 CAMHS need based on the conditions that are likely to meet the definition of Tier 4 need detailed in the introduction (p6). In order to do this, the distribution and pattern of mental health problems within populations should highlight groups of children most at risk, and where evidence is available highlight the potential for early identification and intervention. Although this needs assessment is concerned with quantifying Tier 4 need, preventive strategies for reducing the likelihood of requiring a Tier 4 level of service where possible, will undoubtedly be of interest and relevance to North of Scotland Boards.

A pre-requisite to quantifying epidemiologically-based need in relation to Tier 4 CAMHS is to define the conditions for which such services are relevant. This presents the greatest challenge to the epidemiological assessment of need as it is not represented as a mutually exclusive list of mental health conditions. Furthermore, the mental health conditions which are likely to benefit from Tier 4 services have a continuum of severity and it is only the more complex or severe manifestations that are relevant. Another consideration is the inter-relationship with Tier 3 services-referrals to Tier 4 are often determined by what Tier 3 cannot manage. It has not been possible within this piece of work to distinguish true need for Tier 4 from need as a consequence of lack of Tier 3 capacity. The regional reviews in England have recognized that the distinction between the two levels of services are unclear and are not generalisable i.e. they are dependent on regional resources and skills in the CAMH service. In other words, an assessment of the need for Tier 4 services is difficult to justify as a stand-alone exercise as it should include that of Tier 3 services at the same time (Kurtz Z, 2009). Within these limitations, the following sections describe the different conditions; the risk factors associated with them; their quantification and assessment of their future trends.

#### **4.1 Types of mental health conditions relevant to the need for Tier 4 services**

Mental health difficulties that are relevant to Tier 4 services can be related to any one or more psychiatric disorders defined by diagnostic criteria (e.g. ICD 10<sup>1</sup> or DSM IV<sup>2</sup>). Table 3 lists the disorders that are identified in childhood and adolescence using the ICD 10 criteria. These include those arising only or predominantly in childhood and are life-long disabilities e.g. mental retardation, (as defined in criteria but a term not used in current times) and others that arise in adulthood but can have earlier onset in adolescence e.g. Psychosis. Factors leading to referral to a Tier 4 CAMHS are not only based on severity and complexity, but also lack of treatment response, unusual clinical features, breakdown in therapeutic relationships, unavailability of local treatment options, increased vulnerability due to personal circumstances (i.e. in local authority care, youth justice system) and patient choice. (Specialist Services National Definitions Set 2010)

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<sup>1</sup> The [International Statistical Classification of Diseases and Related Health Problems](#) (ICD-10) is system developed by the World Health Organisation for the coding of diseases and signs, symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases.

<sup>2</sup> DSM IV codes were developed by the [American Psychiatric Association](#) (APA) and includes all currently recognized [mental health](#) disorders. The coding system utilized by the DSM-IV is designed to correspond with codes from the [International Classification of Diseases](#), commonly referred to as the ICD.

Particularly relevant to the need for Tier 4 CAMHS, is the combination of psychiatric disorders with mental health problems or a combination of mental health problems per se on the basis of severe or acute difficulties associated with emotions, behaviour or concentration (Table 4). Some people also refer to young people with severe and chronic mentally illness.

**Table 3: Child and adolescent psychiatric disorders: international classification of diseases (ICD 10) for child and adolescent mental health**

<b>F90–F98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence</b>	
F90	hyperkinetic disorders
F91	conduct disorders
F92	mixed disorders of conduct and emotions
F93	emotional disorders with onset specific to childhood
F94	disorders of social functioning with onset specific to childhood and adolescence
F95	tic disorders
F98	other behavioural and emotional disorders with onset usually occurring in childhood and adolescence
F99	mental disorder, not otherwise specified
<b>F70–F79 Mental retardation</b>	
F70	mild mental retardation
F71	moderate mental retardation
F73	severe mental retardation
F74	profound mental retardation
F78	other mental retardation
F79	unspecified mental retardation
<b>F80–F89 Disorders of psychological development</b>	
F80	specific developmental disorders of speech and language
F81	specific developmental disorders of scholastic skills
F82	specific developmental disorder of motor function
F83	mixed specific developmental disorders
F84	pervasive developmental disorders
F88	other disorders of psychological development
F89	unspecified disorder of psychological development
<b>In addition, some adult mental health diagnoses can become apparent in adolescents and younger children. The major groupings for these are:</b>	
F10–F19 mental and behavioural disorders due to psychoactive substance use	
F20–F29 schizophrenia, schizotypal and delusional disorders	
F30–F39 mood (affective) disorders	
F40–F48 neurotic, stress related and somatoform disorders	
F50–F59 behavioural syndromes associated with physiological disturbances and physical factors (includes eating disorders e.g. anorexia)	
F60–F69 disorders of adult personality behaviour	

Source: Adapted from Wallace SA et al Child and Adolescent Mental Health, Chapter 2, Series 2, Health Care needs assessment, ed. Stevens and Raftery 1997

**Table 4: Mental Health Problems relevant to CAMHS**

<ul style="list-style-type: none"> <li>• antisocial behaviour (stealing etc)</li> <li>• self-harm (injury, over-dose)</li> <li>• self-regulation (feeding, tics)</li> <li>• social relationships</li> <li>• autistic-type characteristics</li> </ul>	<ul style="list-style-type: none"> <li>• Psychosis type</li> <li>• Sexual/sex-related</li> <li>• Psychosomatic-related</li> <li>• Problems relating to school</li> </ul>
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Source: Adapted from Wallace SA et al Child and Adolescent Mental Health, Chapter 2, Series 2, Health Care needs assessment, ed. Stevens and Raftery 1997  
 For any one or more of the above disorders or problems, the severity at presentation would be assessed in terms of various dimensions (table 5).

**Table 5: Factors in assessment of the severity of presenting problems**

<ul style="list-style-type: none"> <li>• Intensity</li> <li>• Impairment</li> <li>• Duration</li> <li>• Frequency</li> </ul>	<ul style="list-style-type: none"> <li>• Age appropriateness</li> <li>• Persistence</li> <li>• Intrusiveness</li> <li>• Manageability/controllability</li> </ul>	<ul style="list-style-type: none"> <li>• Multiple presenting problems</li> <li>• Extensiveness/Pervasiveness</li> </ul>
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Source: Adapted from Wallace SA et al Child and Adolescent Mental Health, Chapter 2, Series 2, Health Care needs assessment, ed. Stevens and Raftery 1997

Other markers of severity include in addition to the problem, any associated risk factors within the individual, within the family or within social circumstances (table 6).

**Table 6: Risk factors relevant to the assessment of the severity of presenting problems**

Risk factors		
In the individual	In the family	In social circumstances
<ul style="list-style-type: none"> <li>• cognitive/academic difficulties</li> <li>• personality/temperament</li> <li>• speech and language difficulties</li> <li>• physical health problems</li> <li>• sensory problems</li> <li>• genetic conditions</li> </ul>	<ul style="list-style-type: none"> <li>• relationship (parent/carer)</li> <li>• marital difficulties</li> <li>• mental health problems</li> <li>• physical health problems</li> <li>• Abuse/neglect</li> </ul>	<ul style="list-style-type: none"> <li>• adverse (socio-economic/housing)</li> <li>• life events e.g. bereavement</li> </ul>

Source: Adapted from Wallace SA et al Child and Adolescent Mental Health, Chapter 2, Series 2, Health Care needs assessment, ed. Stevens and Raftery 1997

A recent summary of the available evidence relating to the development of Tier 4 CAMHS in England cite that children with Tier 4 needs, frequently suffer from two or more psychiatric disorders, as well as a number of factors known to increase the risk for

mental health problems (Kurtz, 2009). Furthermore, risk conditions often occur simultaneously and the number rather than the type is predictive of outcome (Rutter, 1987).

The expectation is that Tier 4 CAMHS services will be concerned with children with two or more co-morbid conditions such as a psychiatric disorder and a conduct disorder as well as a number of risk factors, where the evidence suggests they would benefit from an intervention. This does not preclude significant impairment resulting from a single severe psychiatric disorder which would also benefit from or be appropriate to the Tier 4 service.

With all this under consideration, epidemiology as a means of quantifying specific needs for a specialised CAMHS service which will mainly deal with the most acute, severe, persistent or intractable cases of conditions is challenging. As mentioned previously, using multiple sources of quantification is recommended. Thus in addition to the knowledge gained from the published literature, service utilisation provides a second source of need with the proviso that it may not necessarily reflect the epidemiological need of the population from which it occurs. A third source is the distribution of risk factors for Child and Adolescent Mental Health problems within a population which could represent a relative measure of CAMHS need. We would have to also take account of protective/ameliorating factors e.g. service provision. To give an analogy, if looking at need for intensive care for childhood asthma (a high intensity/Tier 4 type treatment), we would not just measure risk factors like rates of infections or atmospheric pollution. We would have to measure protective factors like treatment services. If there were no treatment services, many more people would end up needing Tier 4 care.

#### **4.2 Population morbidity of child and adolescent mental health conditions**

A literature search was undertaken using the e-library with the key words of:

- Child/children/childhood/adolescent/adolescence
- Mental health/disorder/problem
- Eating disorder
- Epidemiology/prevalence

In addition, the Cochrane library and the national NHS publication internet sites of the Department of Health and Scottish Government Health Department publications were searched.

As a result of this, the prevalence of general psychiatric morbidity and of selected single and co-morbid conditions was reviewed. The conditions selected as most relevant to CAMHS Tier 4 are from the categories of severe eating disorders, psychosis and major depression which are the 3 included in the Department of Health National Service Framework (Standard 9).

### **4.3 General child and adolescent mental disorder morbidity**

The main sources of data for this are derived from two British surveys commissioned by the Office of National Statistics (ONS) undertaken in 1999 and 2004 (Meltzer et al 2000; Green et al 2005). The age range was 5 to 15 years incl. in the 1999 survey and 5-16 years in the 2004 survey. Thus the morbidity relating to 17 year olds was missing from both and only the more recent survey covered those aged 16 years. Sampling was from centralised records of child benefits and was representative of children from private households in Great Britain. The sample sizes of the surveys were approximately 10,500 and 8,000 respectively.

Three main disorders were identified on the basis of ICD10 definitions which in most cases were associated with considerable distress and substantial interference with personal functions. The disorders covered were conduct, emotional and hyperkinetic. The second survey covered less common disorders namely autistic spectrum and those with multiple disorders. Reportedly, the sample size from each survey of the Scottish population was not sufficiently large enough to allow analysis without pooling the two surveys. Even on this basis, prevalence of other than conduct and emotional disorders was not possible. Since there was little difference noted in these results with those from the overall sample, this section presents rates derived from the overall sample only. Furthermore, as the results of the 2004 survey generated similar prevalence rates for any disorder (10%), measured less common disorders and included 16 year olds, this section is only concerned with the results of the 2004 survey.

For Tier 4 CAMHS, the most relevant numbers are likely to be from the group with multiple disorders. It should be noted that these numbers provide only estimates of the potential population from which need for CAMHS services arise and that there is no attempt to weight them according to risk factors that may be more prevalent in the Scottish populations. The prevalence rates and their equivalent numbers by sub-regional geography relevant to the NoS CAMHS services (Health Board areas) are presented in table 7.

**Table 7: Prevalence of Mental Health Disorders derived from the British survey of 2004 and the estimated prevalent numbers of children aged 12 to 17 years in the North of Scotland**

		Prevalence (%) <sup>1</sup>	Estimated prevalent numbers <sup>2</sup>						
			Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS
Emotional	boys	4.0%	800	333	583	31	38	40	1825
	girls	6.1%	1157	489	852	50	54	59	2661
	all	5.0%	1956	823	1435	81	91	99	4486
Conduct	boys	8.1%	1619	675	1181	63	76	81	3695
	girls	5.1%	967	409	713	42	45	50	2225
	all	6.6%	2586	1084	1893	105	121	130	5920
Hyperkinetic	boys	2.4%	480	200	350	19	23	24	1095
	girls	0.4%	76	32	56	3	4	4	175
	all	1.4%	556	232	406	22	26	28	1269
Less Common <sup>3</sup>	boys	1.6%	320	133	233	13	15	16	730
	girls	1.1%	209	88	154	9	10	11	480
	all	1.4%	528	222	387	22	25	27	1210
(multiple disorders) <sup>4</sup>	boys	2.4%	480	200	350	19	23	24	1095
	girls	0.4%	76	32	56	3	4	4	175
	all	1.4%	556	232	406	22	26	28	1269
Any disorder <sup>5</sup>	boys	12.6%	2519	1050	1837	99	118	126	5748
	girls	10.3%	1953	826	1439	84	91	100	4493
	all	11.5%	4472	1876	3276	183	209	226	10242

<sup>1</sup> prevalence in sample aged 11-16y as per 2004 British survey (Green et al 2005)

<sup>2</sup> Application of 11-16y prevalence to mid 2008 populations of 12 to 17 years old

<sup>3</sup> includes autistic spectrum, tics, eating disorders, selective mutism

<sup>4</sup> with 2 or more disorders-most common were conduct & emotional and conduct and hyperkinetic

<sup>5</sup> this is not the sum of the various types of disorders as the latter are not mutually exclusive

Source: derived from Green et al 2005

Application of the rates from the survey predicts that there could be 10,000 aged 12 to 17 years living in the North of Scotland with a clinically diagnosable mental disorder some of whom will either be taking up CAMHS services or who would potentially benefit from them (Table 7). Possibly more appropriately to Tier 4 CAMHS, around 1,269 will have multiple disorders i.e. two or more (Table 7). The morbidity from conduct and hyperactivity is greater in boys whilst emotional disorders are more prevalent in girls (Table 7). Amongst these categories of disorders, some specific types, in addition to those with multiple disorders, may be relevant to Tier 4 CAMHS. According to the survey, some 200 young people aged 12 to 17 years may have Obsessive Compulsive

Disorder (mainly boys) and 1,250 (mainly girls) may have clinical depression (Table 8). A greater number are likely to have Oppositional Defiant Disorder, 2,300 who will be mainly boys, and 700 with Autistic Spectrum Disorder (Table 8). It should be noted that none of these conditions are weighted according to severity and no adjustment has been made in respect of diagnostic criteria since 2004.

**Table 8: Prevalence of some sub-types of the main categories of Mental Health Disorders derived from the British survey of 2004 and the estimated prevalent numbers of children aged 12 to 17 years in the North of Scotland**

		Prevalence (%) <sup>1</sup>	Estimated prevalent numbers <sup>2</sup>							
			Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS	
Emotional Disorders (overall 5.0%)	Anxiety <sup>3</sup>	all % boys	4.4% 43%	1714	720	1256	70	80	87	3927
	specific phobia	all % boys	0.9% 49%	351	147	257	14	16	18	803
	OCD	all % boys	0.2% 78%	78	33	57	3	4	4	178
	generalised anxiety	all % boys	1.2% 39%	467	196	343	19	22	24	1071
	Depression	all % boys	1.4% 37%	545	229	400	22	25	28	1249
Conduct disorders (overall 6.6%)	Oppositional defiant disorder	all % boys	2.6% 70%	1013	425	742	42	47	51	2320
	Socialised conduct disorder	all % boys	2.2% 61%	857	360	628	35	40	43	1963
Less common disorders (overall 1.4%)	Autistic Spectrum	all % boys	0.8% 65%	312	131	228	13	15	16	714
	Eating disorder	all % boys	0.4% NA	156	65	114	6	7	8	357
	Mutism	all % boys	<0.1% NA	<39	<16	<29	<2	<2	<2	<89

<sup>1</sup> Prevalence in sample aged 11-16y as per 2004 British survey (Green et al 2005)

<sup>2</sup> Application of 11-16y prevalence to mid 2008 populations of 12 to 17 years old

<sup>3</sup> Includes phobias, other anxieties and Obsessive compulsive disorder

NA Not analysable-numbers too small to split demographically

Source: derived from Green et al 2005

In addition to multiple disorders, persistence of conditions is also relevant to Tier 4 CAMHS. A sample of children from the 2004 survey were followed up after 3 years (Ed. Parry-Langdon ONS 2008). The main findings have been summarised in Table 9.



**Table 9: Persistence of mental health disorders in 2007 amongst children aged 5 to 16 years in 2004:**

	Age in 2004				
	5-7y	8-10y	11-13y	14-16y	5-16y
	Percentage of those in 2004 still with a diagnosis in 2007				
Emotional	26%	[12%]	40%	21%	30%
Conduct	41%	45%	58%	28%	43%
Hyperkinetic	[18%]	[24%]	23%	[15%]	61%
Less Common <sup>1</sup>	[14%]	[29%]	[17%]	[19%]	68%
Any disorder	55%	59%	59%	36%	51%

[ ] = proportions where the base number was less than 50  
<sup>1</sup> includes autistic spectrum, tics, eating disorders, selective mutism  
 Source: Parry-Langdon (ed) 2008

Thus, overall over 50% of the full age-range (5-16 years) were found to still have a disorder after three years on. Most relevant to Tier 4 are those who would be within the age range 12 -17 years after the 3 years which includes part of the 11-13 year and the 14-16 year age groups (table 9).

#### 4.4 Specific conditions in child and adolescent Psychiatric morbidity

As detailed in the Department of Health National Service Framework (Standard 9), the conditions most relevant to Tier 4 CAMHS will include severe eating disorders, psychosis and major depression. Evidence of significant self harm with these or other psychiatric disorders would also be appropriate for Tier 4 services. Other mental health illnesses and disorders may also contribute to a Tier 4 level of need such as obsessive compulsive disorder.

#### 4.5 Severe eating disorders

Of these, anorexia nervosa is the most important in terms of life-threatening. It affects mainly females (90% of cases) and has peak incidence in adolescent and young women. It is often chronic with an average duration of 3 to 4 years hence the prevalence rate is higher than its incidence (Wakeling A, 1996). An annual incidence rate of 8 per 100,000 persons and an average prevalence of 0.1 to 0.3% in adolescents and young persons using strict criteria for diagnosis are mainly accepted (Hoek HW, 2006). The associated mortality rates measured in the 1990s, were the highest amongst all mental disorders with an SMR of 9.6 using a 6-12 year follow-up (NICE 2004) and

this reflects the severity of this disorder. It is considered that most severe cases will be in contact with specialist mental health services although overall, it has been estimated that only one third of community diagnosed cases in the Netherlands are in contact with them, (Hoek HW 2006). There are no equivalent statistics available for the UK. With the caveats of bias associated with long-term epidemiological studies (mainly ones of changing diagnostic methodology), it is likely that trends in the overall incidence of Anorexia Nervosa have stabilised in those aged 15 to 24 years in Europe since the 1970's (Hoek HW and van Hoeken D 2003). Before then there had been upward linear trends recorded in this age cohort.

Estimates of morbidity most likely to reflect population need as opposed to that estimated from service uptake are derived from a study in Rochester, Minnesota from 1935 to 1989. (Lucas AR et al 1991) and from a study based in Britain using primary care data from General Practice registers (Currin L et al 2005). The USA-based study included all health records of the resident population but as it included definite, probable and possible cases a reduced weighting (39%) has been used to estimate numbers in the North of Scotland which should reflect definite cases. A third study amongst the population of Zurich, captured incident numbers of arising severe cases of anorexia nervosa by using hospitalised case records, (Milos G et al 2004). Application of the rates from these studies to the mid year 2008 estimates of the populations in the North of Scotland are summarised in table 8. In total, the number of annual new cases arising in young females from 10 to 25 years is likely to be in the order of 20 to 25. The lower estimate reflects the estimate from the Zurich study which captured severe cases rather than those that were community wide. Prevalent numbers from USA and the various European studies reviewed by Hoek HW and van Hoeken D 2003 indicate a whole population burden of over 700 and around 150 young women aged 12 to 18 years to have anorexia nervosa in the North of Scotland (table 10). The caveat for using these numbers to reflect the need for CAMHS services is that it is a relatively low prevalence disorder in the general population and that there is a tendency for those affected to conceal their illness and avoid professional help.

**Table 10: Estimates of annual incidence and point prevalence of anorexia nervosa in the North of Scotland**

Measure	Population	Rate	Estimated numbers <sup>†</sup>						
			Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS
annual incidence	Whole <sup>1</sup>	1.17 per 100,000	6	3	5	0	0	0	14
	Females 12-25 years <sup>1</sup>	19.7 per 100,000	9	3	7	0	0	0	20
	Whole <sup>2</sup>	4.7 per 100,000	25	10	1	1	19	1	58
	Females aged 10-19 years <sup>2</sup>	34.6 per 100,000	11	4	8	0	0	1	25
point prevalence	whole, age/sex adjusted <sup>3</sup>	60 per 100,000	324	132	238	12	13	16	734
	young women, aged 12-18 y <sup>4</sup>	300 per 100,000	67	27	49	3	3	3	152

<sup>†</sup> appropriate application of rates to 2008 mid year population estimates (GROS)

From various sources:

- <sup>1</sup> Milos G et al 2003, severe cases of AN in Zurich during 1993-1995
- <sup>2</sup> Currin L et al 2005 British GP research database in 2000 (covers 5% of UK population)
- <sup>3</sup> Lucas AR et al 1991, residents of Rochester (Minnesota) in 1985 for definite cases
- <sup>4</sup> Hoek HW et al 2003 a review of several studies

## 4.6 Psychosis

When occurring in younger age it is often termed early onset Psychosis. This is a less common condition with a 3 year prevalence estimate of 5.9 per 100,000 of the general population. This measurement was based on the under 18 year old population in central Scotland (Edinburgh, Lothians, South Glasgow, Lanarkshire) during 1998 to 2001 (Boeing, L et al 2007) who at any time during or prior to the study period had been in contact with the mental health service for a psychiatric illness. It excluded psychosis of an organic aetiology (e.g. due to epilepsy) and those with learning disabilities. The average age of onset was 16 years and the age range was 10 to 18 years. The 3 year prevalence rate equated to 50 per 100,000 adolescents at risk which of course is the result of 3 year annual incidence plus the point prevalence of the condition. Over one fifth (21%) of those included in the measurement were not in contact with the mental health service i.e. inclusion was based on contact prior to the study period. Another characteristic of these young people was that 80% of them had their first hospital admission for psychosis to an adult acute ward. It is likely that this finding reflects a gap in the provision of adolescent psychiatric bed provision. As seen in table 11, nearly two thirds of the cases had a diagnosis of schizophrenia. In addition, the study reported that 20% of the cases had 5 or more unmet needs. These needs were identified using a modified version of the Cardinal Needs Schedule. Problems relating to several domains (n=21) were assessed and most of the unmet needs were problems related to psychological and social components of disability compared with more medical aspects. The equivalent numbers expected in the North of Scotland based on these findings are recorded in table 11.

**Table 11: Estimates of the 3 year prevalence of early onset psychosis in those aged under 18 years**

		Estimated numbers <sup>†</sup>						
		Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS
Whole population <sup>1</sup>	5.9 per 100,000	32	13	23	1	1	2	72
Aged 10-17 years <sup>1</sup>	50 per 100,000	26	11	19	1	1	1	58
Sub-types of early onset psychoses	65% schizophrenia	21	8	15	1	1	1	47
	11% schizoaffective	4	1	3	0	0	0	8
	3%bipolar with psychosis	1	0	1	0	0	0	2
	21% other psychotic	7	3	5	0	0	0	15

<sup>†</sup> appropriate application of rates to 2008 mid year population estimates (GROS)

<sup>1</sup> From Boeing, L et al 2007 based on population from central Scotland

An earlier study based on all case records from all Psychiatric units in Scotland over the period 1966 to 1990 (Takei N et al 1996) reported annual incidence rates of 5 per 100,000 and 10 per 100,000 of schizophrenia in 15 to 19 year old females and males respectively during the period 1985 to 1990. The equivalent numbers expected for the North of Scotland are recorded in table 12.

**Table 12: Annual incidence of schizophrenia in young people aged 15 to 19 years**

		Estimated numbers <sup>†</sup>						
		Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS
Aged 15-19 years <sup>1</sup>	5 per 100,000 females	1	0	1	0	0	0	2
	10 per 100,000 males	2	1	1	0	0	0	4
	males & females	3	1	2	0	0	0	6

<sup>†</sup> appropriate application of rates to 2008 mid year population estimates (GROS)

<sup>1</sup> From Takei N et al 1996, L based on Psychiatric unit contacts 1986 to 1990 in Scotland

To summarise the implications of these studies to the North of Scotland: during 3 years, around 70 young people under the age of 18 years are likely to have had a diagnosis of Psychosis, most of whom (n = 50), will have been one of schizophrenia. During a year there may be 6 newly arising cases of schizophrenia in those aged 15 to 19 years (two thirds of them male).

#### 4.7 Major Depression

Major depressive disorder affecting adolescents is considered to be an early onset form of adult major depression and in most cases extends into adulthood (Birmaher B et al 1996). The differences that apply between the two are in the symptoms of melancholia, psychosis, suicide attempts and impairment of functioning all of which increase with

age. Major depression in adolescence is also frequently (40-70%) associated with other psychiatric co-morbidities including Dysthymic disorder, anxiety disorders, disruptive disorders and substance abuse. With the exception of substance abuse, major depression is likely to develop after the onset of other psychiatric disorders and it has been suggested that around 70% of young people with early onset Dysthymic disorder will develop an episode of major depression where the co-existence has been termed in the literature, but not a concept used in clinical practice, as “double depression”, (Birmaher B et al 1996). In addition, those with double depression are likely to have had an earlier onset and have longer and more severe episodes of depression, are more suicidal, and have greater social impairment (Birmaher B, 1996). A high prevalence of Pervasive Development Disorders (PDD, e.g. autistic spectrum) in adolescents treated for depression (35%) has also been highlighted and a recommendation to assess PDD symptoms when treating depressed adolescents has been made (Sasayama D, 2009). There is also a gender difference with a ratio of 2:1 females to males amongst adolescents with major depression which may be attributable to genetics amongst other pre-disposing factors associated with gender. This gender difference is similar to that in adulthood. It is considered that successive cohorts of adolescents from the latter part of the 20<sup>th</sup> Century are at increased risk from developing mood disorders and that the age at onset is also decreasing. (Birmaher B et al 1996). This trend seems to apply mainly to mild and moderate depressions rather than severe depression but probably reflects the role of environmental factors on psychiatric disorders of children and adolescents. It is also reported that depressed children who experience conflict in their family lives have higher recurrence rates of depressive episodes. Follow-up studies have reported that 20-40% of adolescents who develop bipolar disorder I (major depressive disorder with mania) do so within 5 years after onset of major depression (Birmaher B et al 1996).

According to studies in western countries, the point prevalence for major depression in adolescents is 2-5% and a one year incidence of 3-5% (Olsson GI and van Knorring A.L 1999). The lower estimate in the range of prevalence rates i.e. 2% probably captures the more severe forms of major depression rather than the mild and moderate forms (Angold AI and Costello EJ 2001). If the existence of double depression is indicative of greater intensity and persistence of symptoms, then an indirect estimate of this number may be more relevant to identifying the need for Tier 4 services. Estimates of the

numbers in North of Scotland likely to be affected by Major Depression and Double Depression are recorded in table 13.

**Table 13: Estimation of the prevalence and incidence of major depression and double depression in the North of Scotland**

Measure	Population	Rate	Estimated numbers <sup>†</sup>						
			Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS
Annual incidence	12-17 y major depression	3-5% <sup>1</sup>	1,170 - 1,950	490-820	860 - 1,430	45 - 80	55 - 90	60 - 100	2,600 - 4,500
Point Prevalence	12-17 y major depression	2-5% <sup>1</sup>	780 - 1,950	330 - 820	570 - 1,430	30 - 80	35 - 90	40 - 100	1,800 - 4,500
Point Prevalence	12-17 y double depression	30-80% of major depression <sup>2</sup>	230 - 1,550	100 - 650	170 - 1,140	30 - 65	10 - 70	10 - 80	540 - 3,600

† appropriate application of rates to 2008 mid year population estimates (GROS)

<sup>1</sup> Olsson GI & van Knorring AL, 1999, review of studies in Western countries

<sup>2</sup> Birmaher B et al 1996 Review of various studies

#### 4.8 Bipolar disorder

This is another example of an adult disorder that often has an early onset in childhood and adolescence. It has some genetic aetiology as those whose parents are affected have a greater risk of developing it (Olson PM and Pacheco MR 2005). It is usually characterised by having a relapsing and remitting course throughout life. There is uncertainty regarding the prevalence of the disorder in adolescents due to the complexity in its diagnoses. This is due to the co-morbidity of other psychiatric disorders such as ADHD which makes a differential diagnosis difficult. Co-morbidity also may affect the course of the disorder (Wolf DV and Wagner, KD, 2003, Clark A, 2001). A community survey of American teenagers reported a life-time prevalence of 1% for Bipolar Disorder (Lewisohn PM et al, 1995). The same study of teenagers aged 14 to 18 years reported a point prevalence of 0.6% and an annual incidence of 0.1%. Although most of these teenagers were not demonstrating severe psychosis, the impact on functionality was very significant. Table 14 records the estimated numbers in the North of Scotland using these incidence and prevalence rates.

**Table 14: Estimated numbers developing Bipolar Disorder in the North of Scotland**

Measure	Population	Rate	Estimated numbers <sup>†</sup>						
			Grampian	Highland C.	Tayside	Orkney	Shetland	W.Isles	All NoS
Annual incidence	14-18 y	0.13% <sup>1</sup>	43	18	32	2	2	2	98
Point Prevalence	14-18 y	0.6% <sup>1</sup>	199	81	148	8	9	10	454

<sup>†</sup> appropriate application of rates to 2008 mid year population estimates (GROS)

<sup>1</sup> Lewinsohn PM et al 1996

#### 4.9 Persistent and severe self-harm

Self-harm describes a wide range of behaviours and intentions which include attempted suicide by various means to superficial cutting. The reported one year prevalence in adolescents in western countries ranges from 5 to 9% with the majority being reported by girls (Skegg K 2005). Self-harm is rare before puberty but becomes more common in adolescents with 16 years being the most common age of onset in the USA. The most likely age to present to hospital due to self-harm is 15-24 years in women and 25-34 years in men. Older people are at lower risk of self-harm but when they do, the risk of suicide later is much higher. In Scotland where the rate of suicide is high, the prevalence of self-harming measured in 15-16 year olds was similar to that in England (O'Connor RC et al 2009). Although there are many risk factors associated with self-harm (socio-economic deprivation, sexual orientation, physical illness, adverse life-events), there is a strong association with psychiatric disorders. Amongst a community sample of adolescents non-suicidal self-injurers, the most severe and persistent self-harm appeared to occur in those with a psychiatric disorder (Lloyd-Richardson EE et al 2007). The British community survey of 2004 (Green H et al 2005) recorded self-reported prevalence of attempts to self-harm or kill themselves by mental disorder (table 15).

**Table 15: Prevalence of self-reported attempts to self-harm or commit suicide in groups of young people aged 11 to 16 years with a mental disorder in Britain**

11 - 16 year old population with disorder <sup>1</sup>	Percentage of self-harm/suicide attempts <sup>1</sup>
Emotional	28%
Autistic	25%
Conduct	21%
Hyperkinetic	18%

<sup>1</sup> 2004 British survey (Green et al 2005)

A study based in England (Oxford) reported increased presentation to hospitals of young people under the age of 20 years due to deliberate self-harm between the first half of the 1980s and 1990s (Hawton K et al 2000).

In summary, overall the prevalence of deliberate self-harm is relatively common in adolescents (5-9% over one year) but there are no available prevalence rates for the most severe or persistent deliberate self-harm. Presentation to hospitals for self harm increased in the south of England but whether that trend applies to Scotland is unknown. Suicide rates do not seem to correlate with self-reported self-harm. There are numerous risk factors associated with self-harm amongst which the existence of a mental or pervasive developmental disorder appears to be important. The presence of persistent self harm with other psychiatric disorders may be indicative of a Tier 4 level of need.

#### **4.10 Distribution of mental disorders in children and adolescence**

This can be described in relation to the morbidity rates of disorders in particular groups of young people or in relation to the pattern of the known risk factors associated with particular mental health problems.



#### 4.11 Mental health problems in specific groups of young people

There are specific groups of children who are recognised to be at particularly high risk for mental health problems who are often under the care of other services such as learning disability and forensic services as listed in figure 2.

**Figure 2: Groups of children and adolescents at greater risk from mental health problems**

- Groups at higher risk than their peers for mental health problems**
- Young offenders and children from a criminal background
  - Children who are being looked after by local authorities or who have recently ended a period of public care
  - Children with learning difficulties
  - Children with emotional and behavioural difficulties
  - Children who have been sexually, physically or emotionally abused
  - Children with a chronic physical illness
  - Children with a physical disability
  - Children with sensory impairments
  - Children of parents with mental illness
  - Children of parents with a substance abuse problem
  - Children who have experienced or witnessed sudden and extreme trauma
  - Children who are refugees.

Source: Kurtz, 2009

The rates of mental disorders reported in some of these groups are summarised in table 16.

**Table 16: Groups of children and adolescents known to have higher prevalence rates of mental disorders**

Group of children & adolescents	Increase in morbidity
With Learning disabilities	> 33% have a diagnosable psychiatric disorder
In LA care	50% prevalence compared to 10% in the general population
In residential care	70% prevalence compared to 10% in the general population
In contact with youth justice system	40% prevalence compared to 10% in the general population
With physical disability or chronic illness	100% increase in prevalence (20% rate of disorders)

Source: Final report of the CAMHS Review 2008

Whilst treatment by a Tier 4 CAMHS is unlikely for some of these young people, specifically those with learning disability or within the forensic system, others should be seen as high risk for requiring access to a Tier 4 level of care from CAMH services.

The review of epidemiology has not included suicide data, suicide seen in this context as a negative outcome, but it is reasonable to note that suicide rates in young adults may well be related to limited access to services for very vulnerable young people at a younger age. This is a topic of debate within the literature.

#### **4.12 Distribution of risk factors in the population**

Risk factors are unequally distributed according to socio-economic circumstances. The most economically deprived communities generally suffer the greatest burden of mental disorders. Other risk factors associated with geography and ethnic origins have been studied but their contribution has not been clearly established. However, it is likely that the impact of geography where it is remote and rural, will limit accessibility to specialist mental health services as has been found in the USA together with possible resistance to take up services through stigma (Starr S et al 2002).

#### **4.13 Future and historical trends in the morbidity of mental health conditions in young and adolescents**

In predicting the future demand on Tier 4 CAMHS, account should be taken of the following

1. the likely projections of historical trends in morbidity of the relevant mental disorders
2. the likely changes in the level of risk factors e.g. socio-economic circumstances
3. demographic changes i.e. population structural changes (age and sex)

There is some doubt as to whether there is an upward trend in the overall mental disorder morbidity amongst this section of the population mainly due to the differences in diagnostic criteria, assessment methodologies and in reporting practices at different times in the past. A study has assessed the extent to which conduct, hyperactivity and emotional problems have become more or less common over a 25 year period in three general populations of adolescents in the UK (Collinshaw S et al 2004). The sampled populations were those from the National Child Development Study, the 1970 Birth Cohort Study and the 1999 British Child and Adolescent Mental health survey, ONS 1999. Comparable questionnaires were completed by parents of adolescents aged 15 and 16 years old at the three time points of 1974, 1986 and 1999. A comparison of outcomes was used to indicate any bias due to differences in reporting thresholds. Since 1976, the rates of conduct problems in both males and females had become significantly higher. Whilst the rates of emotional problems were also higher in 1999, the increase was mainly seen between 1986 and 1999. Changes in rates of hyperactive disorder were not conclusive of any trends.

Other sources of changes in morbidity are derived from assessments of specific disorders such as anorexia nervosa. The incidence rate of this eating disorder has been reported to have increased over the last century until the 1970s (Lucas AR et al 1991; Hoek HW and Hoeken van D 2003). A British general practice-based assessment reported stable rates over 12 years since 1988, (Currin L et al 2005). It is not clear whether this remains to be the case in the 21<sup>st</sup> century.

If it is assumed that morbidity rates remain stable, then the numbers of children and adolescents aged 12 to 17 years affected by mental disorders can be predicted by application of rates to projections of the relevant populations. On this basis the numbers predicted in 2010 and 2020 are recorded in tables 17 and 18 which apply the ONS survey of 2004 to the populations of the North of Scotland. As can be seen, numbers are predicted to decrease solely due to the expected reduction in the number of young people aged 12 to 17 years. As noted previously, review of prevalence rates measured in the UK population has indicated an increase in conduct disorders which the predictions in tables 17 and 18 do not accommodate.

**Table 17: Predicted prevalent numbers of 12-17 year olds with mental disorders in 2010, 2015 and 2020: assumes that unchanged prevalence rates apply**

		Estimated prevalent numbers by mental disorder <sup>1</sup>					
		Emotional	Conduct	Hyperkinetic	Less Common <sup>2</sup>	(multiple disorders) <sup>3</sup>	Any disorder <sup>4</sup>
Grampian	2008	1,956	2,586	556	528	556	4,472
	2010	1,887	2,506	541	512	541	4,327
	2015	1,724	2,290	494	468	494	3,954
	2020	1,801	2,380	511	486	511	4,116
Highland C	2008	823	1,084	232	222	232	1,876
	2010	800	1,058	227	216	227	1,829
	2015	744	994	216	203	216	1,713
	2020	775	1,029	222	210	222	1,777
Tayside	2008	1,435	1,893	406	387	406	3,276
	2010	1,816	1,850	396	378	396	3,200
	2015	1,294	1,714	369	350	369	2,962
	2020	1,344	1,782	384	364	384	3,078
Island Boards <sup>5</sup>	2008	272	357	76	73	76	618
	2010	258	337	72	69	72	585
	2015	224	293	62	60	62	508
	2020	224	292	62	60	62	508
NoS	2008	4,486	5,920	1,269	1,210	1,269	10,242
	2010	4,761	5,750	1,236	1,175	1,236	9,941
	2015	3,987	5,290	1,141	1,080	1,141	9,137
	2020	4,144	5,484	1,179	1,120	1,179	9,479

<sup>1</sup> Application of 11-16y prevalence\* to mid 2008 & 2008-based population projections for 2010,2015 & 2020 of 12 to 17 years old

<sup>2</sup> includes autistic spectrum, tics, eating disorders, selective mutism

<sup>3</sup> with 2 or more disorders-most common were conduct & emotional and conduct and hyperkinetic

<sup>4</sup> this is not the sum of the various types of disorders as the latter are not mutually exclusive

<sup>5</sup> Orkney, Shetland and Western Isles together

\*prevalence rates as per 2004 British survey (Green et al 2005)

**Table 18: Predicted prevalent numbers of 12-17 year olds with some sub-types of the main types of mental disorders in 2010, 2015 and 2020: assumes that unchanged prevalence rates apply**

		Estimated prevalent numbers by mental disorder <sup>1</sup>									
		Emotional disorders				Conduct Disorders			Less common disorders		
		Anxiety <sup>2</sup>	specific phobia	OCD <sup>3</sup>	generalised anxiety	Depression	Oppositional defiant disorder	Socialised conduct disorder	Autistic Spectrum	Eating disorder	Mutism
Grampian	2008	1714	351	78	467	545	1013	857	312	156	<39
	2010	1657	339	75	452	527	979	828	301	151	<38
	2015	1514	310	69	413	482	895	757	275	138	<34
	2020	1578	323	72	430	502	932	789	287	143	<36
Highland C	2008	720	147	33	196	229	425	360	131	65	<16
	2010	701	143	32	191	223	414	350	127	64	<16
	2015	655	134	30	179	208	387	328	119	60	<15
	2020	680	139	31	186	216	402	340	124	62	<16
Tayside	2008	1256	257	57	343	400	742	628	228	114	<29
	2010	1227	251	56	335	390	725	614	223	112	<28
	2015	1134	232	52	309	361	670	567	206	103	<26
	2020	1179	241	54	322	375	697	590	214	107	<27
Island Boards <sup>4</sup>	2008	237	49	11	65	75	140	119	43	22	<5
	2010	225	46	10	61	72	133	112	41	20	<5
	2015	195	40	9	53	62	115	98	36	18	<5
	2020	195	40	9	53	62	115	98	36	18	<4
NoS	2008	3927	803	178	1071	1249	2320	1963	714	357	<89
	2010	3810	779	173	1039	1212	2251	1905	693	346	<86
	2015	3499	716	159	954	1113	2067	1749	636	318	<80
	2020	3632	743	165	991	1156	2146	1816	660	330	<82

<sup>1</sup> Application of 11-16y prevalence\* to mid 2008 and 2008-based population projections for 2010, 2015 & 2020 of 12 to 17 years old

<sup>2</sup> Includes phobias, other anxieties and Obsessive compulsive disorder

<sup>3</sup> Obsessive Compulsive Disorder

<sup>4</sup> Orkney, Shetland and Western Isles together

\*prevalence rates as per 2004 British survey (Green et al 2005)

For the more specific conditions that may be more relevant to tier 4 CAMHS, viz. anorexia nervosa, early onset psychosis and bipolar disorder, the following predicted numbers apply (table 19).

**Table 19: Predicted numbers of adolescents with specific mental disorders in 2010, 2015 and 2020: assumes that unchanged morbidity rates apply**

		Anorexia Nervosa Point prevalence <sup>1</sup>	Early onset psychoses 3 year prevalence <sup>2</sup>	Bipolar disorder point prevalence <sup>3</sup>	Incidence of Schizophrenia <sup>4</sup>	Major depression point prevalence <sup>5</sup>	Double depression point prevalence <sup>6</sup>
Grampian	2008	67	26	199	3	780 - 1950	230 - 1550
	2010	65	25	195	3	750 - 1880	230 - 1510
	2015	59	23	178	2	690 - 1720	210 - 1380
	2020	61	24	172	2	720 - 1790	220 - 1430
Highland C	2008	27	11	81	1	330 - 820	100 - 650
	2010	27	10	80	1	320 - 800	100 - 640
	2015	24	10	75	1	300 - 740	90 - 600
	2020	25	10	73	1	310 - 770	90 - 620
Tayside	2008	49	19	148	2	570 - 1430	170 - 1140
	2010	49	18	144	2	560 - 1390	170 - 1120
	2015	45	17	135	2	520 - 1290	160 - 1030
	2020	46	18	132	2	540 - 1340	160 - 1070
Island Boards <sup>4</sup>	2008	9	4	27	0	110 - 270	30 - 220
	2010	9	3	25	0	100 - 260	30 - 210
	2015	8	3	22	0	90 - 220	30 - 180
	2020	8	3	21	0	90 - 220	30 - 180
NoS	2008	152	59	454	6	1800 - 4500	540 - 3600
	2010	149	57	444	6	1700 - 4300	520 - 3500
	2015	136	53	410	5	1600 - 4000	480 - 3200
	2020	139	55	398	5	1700 - 4100	500 - 3300

<sup>1</sup> Point prevalence of 300 females per 100,000 aged 12 to 18 years (Hoek HW et al 2003)

<sup>2</sup> 3 year prevalence of 50 per 100,000 in all aged 10-17 years (Boeing L et al, 2007)

<sup>3</sup> Point prevalence of 0.6% all aged 14-18 years (Lewisohn PM et al, 1996)

<sup>4</sup> Annual incidence, 5 per 100,000 and 10 per 100,000 females and males respectively aged 15-19 years (Takei N et al 1996)

<sup>5</sup> Point prevalence of major depression of 2-5% all aged 12-17 years (Olsson GI and van Knorring, 1999)

<sup>6</sup> Point prevalence of 30 to 80% of major depression in all aged 12-17 years (Birmaher B et al 1996)

As noted earlier, there is significant uncertainty in the predicted levels of morbidity of major depression and double depression due to the wide range of reported and current morbidity rates.

It is important to be aware of the limitations and caveats in the assessment of mental health need based purely on application of morbidity rates to populations. These need to be understood and acknowledged. As an illustration of this, Kurtz (2005) in Glover et al (2005) has indicated that the numbers arrived at on this basis are likely to be in the order of 7 to 10 times higher than those known to the specialist CAMHS service. The differential should not be assumed to be a measure of unmet need because of the following considerations:

- The numbers based on application of morbidity rates relate to those with a particular condition or category of problem. These are not mutually exclusive with multiple mental health disorders and problems being usual

- The natural history of these conditions can be episodic with periods of intensity between possibly long periods of remission. This means that point prevalence estimates need not reflect an actual need at that particular time
- There is a broad spectrum of severity in these conditions in which specialist services for those at the milder end are not appropriate
- There are always reasons why application of rates measured within the research environment such as from population surveys may not reflect the population of interest's true burden of morbidity. This may be because of differences in the relative susceptibility to mental health problems e.g. affluent populations versus inner city socio-economically disadvantaged populations

Conversely, the numbers known to the specialist CAMHS are likely to be underestimates in their own right as they will not include those young people who are accessing services through a different sector e.g. community mental health teams, outpatients, learning disability units, social services.

With these caveats in mind, Table 20 summarises the indicative numbers of 12-17 year olds across the North of Scotland for specific mental disorders in 2010.

**Table 20: Predicted numbers of adolescents with specific mental disorders in 2010**

	Grampian	Highland C	Tayside	Island Boards <sup>7</sup>	NoS
Anorexia Nervosa Point prevalence <sup>1</sup>	65	27	49	9	149
Early onset psychoses <sup>3</sup> year prevalence <sup>2</sup>	25	10	18	3	57
Bipolar disorder point prevalence <sup>3</sup>	195	80	144	25	444
Incidence of Schizophrenia <sup>4</sup>	3	1	2	0	6
Major depression point prevalence <sup>5</sup>	750 - 1880	320 - 800	560 - 1390	100 - 260	1700 - 4300
Double depression point prevalence <sup>6</sup>	230 - 1510	100 - 640	170 - 1120	30 - 210	520 - 3500

<sup>1</sup> Point prevalence of 300 females per 100,000 aged 12 to 18 years (Hoek HW et al 2003)

<sup>2</sup> 3 year prevalence of 50 per 100,000 in all aged 10-17 years (Boeing L et al, 2007)

<sup>3</sup> Point prevalence of 0.6% all aged 14-18 years (Lewinsohn PM et al, 1996)

<sup>4</sup> Annual incidence, 5 per 100,000 & 10 per 100,000 females & males respectively aged 15-19 years (Takei N et al 1996)

<sup>5</sup> Point prevalence of major depression of 2-5% all aged 12-17 years (Olsson GI & van Knorring, 1999)

<sup>6</sup> Point prevalence of 30 to 80% of major depression in all aged 12-17 years (Birmaher B et al 1996)

<sup>7</sup> The sum of NHS Shetland, Western Isles and Orkney

The epidemiology detailed in this section is just one of a range of approaches that are required to give an informed view of the level of service required to address Tier 4 mental health need across the North of Scotland. The limitations described above emphasise the importance of assessing unmet need by other service providers, the service itself and by users themselves.

#### 4.14 Key points

- The need for Tier 4 CAMHS is best assessed from multiple sources due to:
  - the unavailability of the population prevalence estimates of the complex, acute and persistent conditions relevant to Tier 4 services
  - multiple sources are more likely to provide an estimate of true need if also based on the views of service providers, the public and service users
- The estimates from surveys amongst the UK population have provided a context from which the need for the most specialist services will arise. Of these, the most relevant populations are likely to be those in whom multiple disorders are prevalent. The 3 year persistence of these mental disorders (up to 60%) will also be of relevance to Tier 4 need.



- The numbers imply that there will be young people in each of the six North of Scotland Boards who are likely to experience a Tier 4 level of need. Some of these will be episodic and others more enduring.
- Some of the groups with mental health needs at particularly high risk of having complex and persistent mental problems e.g. those with learning disabilities and those associated with the criminal system are not likely to form the caseload of Tier 4 inpatient services. It is therefore important that the mental health needs of these groups are incorporated within the appropriate services of the local area. In addition, local Health Boards with their partner agencies should be aware of the distribution of risk factors within their populations (which are primarily related to socio-economic circumstances) to ensure that there is proportionate uptake of services.
- Likewise there are opportunities for considering preventive strategies for young people identified at being at risk of developing intensive mental health needs
- Predictions of future need for Tier 4 CAMHS require three considerations:
  - population structural changes which are likely to reduce the need
  - trends in the risk factors e.g. socio-economic/unemployment
  - cultural and linguistic changes in identifying mental health need e.g. medicalisation of behaviour
- Of the conditions covered in the section, upward trends in the population prevalence of conduct disorders in both male and female adolescents have been reported over a 25 year period. Whilst there has also been an increase noted in the prevalence of emotional disorders, these apply mainly to the turn of the 20<sup>th</sup> century. Significant trends in the morbidity rates of other specific conditions have not been revealed and any inference from changes in rates unless undertaken as a longitudinal study, are prone to differences in diagnostic criteria as well as confounding factors (socio economic conditions, country of residence, rates of diagnosis).
- The affects of the predicted population change is generally to reduce estimated prevalent numbers of mental disorders in adolescents until 2015 and thereafter an increase is predicted. Estimates based on predicted changes in the population are prone to uncertainties, particularly the further away from a census year the projections have been based on. (e.g. age related dependency ratios, changes in employment patterns and rates and challenges arising from social/climate change).

#### 4.15 Conclusions

- The prevalence of some specific conditions most likely to be relevant to Tier 4 CAMHS have been estimated i.e. for early-onset Psychosis, major depression, double depression, anorexia nervosa, schizophrenia, bipolar disorder. The challenge lies in the assessment of the proportion of these that are likely to require a Tier 4 level of services and whether this will be best provided in an inpatient or community setting
- For those young people identified as having a Tier 4 need, access to specialist help and support should be made available in the most appropriate setting be this an adolescent inpatient bed, in an age appropriate care setting such as paediatric ward or adult mental health bed or through an intensive community service.
- There are likely to be historical and cultural changes in approaches to treatment, what is regarded as illness and what is regarded as appropriate to medicalise. These factors may be difficult to quantify but they need to be recognised particularly in CAMHS where we have different paradigms in operation – psychological, medical, social etc
- Assessment of the need for Tier 4 CAMHS using recorded estimates of the morbidity amongst adolescents in the population has proved to be very complex and challenging in terms of quantifying its actual level
- The data available and reviewed in this section informs our understanding of the level of Tier 4 need across all North of Scotland Boards. As such the data affirms the current planning assumption for 12 beds and associated investment in community/local Tier 4 services alongside other information considered in this report.

## **5.0 Quantifying need for Tier 4 CAMHS**

### **5.1 Existing Tier 4 service across the North of Scotland**

To date, the only formally commissioned Tier 4 services across the North of Scotland are the inpatient unit at Dudhope House, Dundee and its associated day unit and a day service for those up to the age of 14 in Aberdeen. There are no other designated Tier 4 funded services although all CAMHS provide a Tier 4 level of service on a regular basis through their Tier 3 community services. This is a source of considerable disquiet for clinicians. The advent of a HEAT CAMHS waiting list target, will put increasing pressure on local community Tier 3 services, when they are diverted to address Tier 4 need and potentially taken away from providing a Tier 3 service with an associated impact on the waiting list target. The reasons for this lack of investment as perceived by clinicians are potentially lack of understanding from Boards over the nature and need of Tier 4 CAMH services and/or that these services have fared less well within Board's prioritisation processes.

### **5.2 Assessment of need within North of Scotland Boards**

The most comprehensive assessment of Tier 4 need in the North of Scotland can be found in a clinical review of Tier 4 service use in Grampian over a five year timescale, 2001-2006. The 20 admissions a year if extrapolated across the North of Scotland, would suggest at least 80 admissions each year took place. This has been taken as a proxy measure of need for the North of Scotland to inform the outline business case for the development of a 12 bedded inpatient unit in NHS Tayside and associated investment in Tier 4 community and age appropriate care in hospital settings supported by an obligate network across the North of Scotland Boards. The Grampian Review is summarised in Appendix 3.

In addition, the community Child and Adolescent Service in NHS Highland have been keeping a running tally of Tier 4 need on a monthly basis for the last two years. This data suggests that within any one month period there will be between five to eight adolescents with Tier 4 need. Some of these will be in adolescent inpatient units, some in secure or residential accommodation outwith Highland but many managed on a day to day basis through Tier 3 community services.

Formal information is not available to determine whether limitations in bed numbers and therefore to admissions to the inpatient unit historically / changing patterns of length of stay / alternative management in community services has had an impact on outcomes for young people themselves.

Further information to inform the understanding of Tier 4 need was collected through the North of Scotland Inpatient CAMHS Project board in early 2008. The information collected through this process is detailed in Appendix 4. The information suggests that in the past, North of Scotland Boards have accessed inpatient beds in Dundee to differing extents. The reasons for this are not clear and it would be useful to monitor access to beds by North of Scotland Boards in the future. The data confirms the view that there is insufficient access to beds in the regional unit as young people from the mainland Boards have regularly been admitted to other regional units in Scotland, further afield in England and to independent/private units at some cost to North of Scotland Boards. In addition, young people have also been admitted to adult inpatient units where there may be concerns as to whether they have access to age appropriate care. The Mental Welfare Commission routinely monitor such admissions and are more than comfortable with admissions to adult wards provided there is input from the appropriate specialist CAMHS Service. A short term admission for a 16/17/1 year old in a local adult ward is and will continue to be the most appropriate option rather than admission to an inpatient bed

The pattern of admissions from different Boards across the north raised more questions than it answers – in terms of potential unmet need, variations dependent on provision of local services and alternatives within local community / Tier 3 services, and accessibility in terms of proximity to the unit and remote access.

What is also evident through this needs assessment process is that to date, there has not been a systematic approach to the recording and collection of Tier 4 need across North of Scotland Boards. The need to address this has been recognised and needs to be part of a wider commitment to develop robust ways of capturing data on Tier 4 need to inform service development and allow for meaningful comparisons of need and access to services across Board populations. Work is in progress at the current time to

capture Tier 4 needs across the mainland Boards for March 2010 to September 2010 to further inform the outline business case.

One of the challenges will be to reconcile a definition of Tier 4 need that is orientated around the needs of young people known to services, with the population need detailed through the epidemiology section, whilst acknowledging the influence of comprehensive Tier 3 community services on the demand for Tier 4 services.

### **5.3 What the literature tells us**

The literature affirms the view that defining Tier 4 need is challenging and that there is no clearly defined methodology for capturing need and translating this into a service model. Glover (2005) et al ( in Williams (2005)) assert that figures from national surveys do not readily translate into figures for CAMHS case loads and case mix because of the variability and mix of psychiatric diagnosis, risk factors and difficulties. This would apply to both Tier 3 and Tier 4 service needs.

The Inpatient Working Group: Psychiatric Inpatient services (Scottish Executive 2005) similarly asserted that there was no formal and accepted methodology for defining inpatient capacity required for children and young people. Gowers (2003) proposes that 'There is currently no good objective measure of unmet need for inpatient services' and details the challenges as follows:

- There are limitations in applying a purely numerical approach to assessing local needs
- Defining the purpose of inpatient services is essential
- The presence of day treatment services and intensive community services make this a more challenging task
- The emerging evidence base for community based services for some Tier 4 need adds to the challenge

As previously indicated, the literature indicates that the need for Tier 4 services should to be considered in the context of what is available in local child and adolescent mental health services, generally in community based outpatient Tier 3 services (Kurtz 2009).

On this basis, it would seem reasonable to propose that as a starting point, North of Scotland Boards work towards achieving the Royal College of Psychiatry best practice standard for a standard 0-16 Tier 3 child and adolescent mental service of 20 wte CAMHS clinicians and professionals for each 100,000 of population. (Royal College of Psychiatry 2005) More recently, advice to the Scottish Government proposed a ratio of 24 wte CAMHS clinicians for every 100,000 of population to take Tier 3 service capacity up to meet all needs to the age of 18 (Bryce 2009).

In addition, guidelines published by the Royal College of Psychiatrists in 1992 proposed 24-40 adolescent mental health beds per million. The literature suggests that these guidelines have been largely ignored and this would appear to be reflected in surveys in England, Wales and Scotland. That said, for a North of Scotland population of 1,224,042 this would equate to between 24 and 40 beds. On this basis, the proposed development of a twelve bedded unit for the North of Scotland would require parallel investment to increase the capacity of local community Tier 4 services alongside the development of inpatient capacity.

The literature suggests that relying solely on the benchmark of beds per population gives an incomplete picture of current and potential future capacity to meet the needs of children and adolescents requiring comprehensive Tier 4 services. Whilst asserting the value of inpatient units, the NICAPS study (O'Herlihy et al 2001) was of the view that it was not possible to state whether there was sufficient capacity in England at the time of the study as 'there are no current norms that command universal respect'. In addition, it was noted that 'attempts to create such norms could not reflect the diversity and development of community services... it is widely assumed that the quality of these will affect the number of beds required'.

#### **5.4 Key messages**

- To date, the only formally commissioned Tier 4 services across the North of Scotland are the inpatient unit at Dudhope, Dundee. the associated day unit and a day unit up to 14 years in Aberdeen.
- Data collected on the use of inpatient beds indicates that there is insufficient access to beds across the North of Scotland given historical patterns of usage.

- To date, there has not been a systematic approach to the recording and collection of Tier 4 need across North of Scotland Boards.
- The literature suggests that there is not a defined methodology for defining service capacity at Tier 4 for either inpatient or community based services, however guidance is available as follows:
  - Number of inpatient beds per head of population
  - Work force wte for Tier 3 0-16 and 0-18 service provision
- There is an emerging consensus on how unmet Tier 4 need can be met in both inpatient and community settings although it is not possible to determine the spread of investment across inpatient and/or community services.
- The proposed systematic recording of Tier 4 CAMHS in the mainland North of Scotland Health Boards which will be ongoing for 6 months from March to September 2010, will allow a more pragmatic assessment of the need for Tier services

## **5.5 Conclusions**

- The findings from this section justify the use of the methodology used in this needs assessment exercise whereby information from a number of sources is required to inform the commissioning of Tier 4 CAMHS services across the North of Scotland.
- Community based Tier 3/4 services are historically under funded across North of Scotland Boards
- Existing guidance on the workforce and inpatient bed numbers should inform local and regional investment decisions for Tier 4 CAMHS services
- The literature also indicates the benefits of investing across inpatient and community based services to address Tier 4 need.

## **6.0 Specialist Tier 4 CAMHS and Remote and Rural Communities**

*Access to healthcare should be as local as possible, for the whole population of Scotland, no matter where they live. (Better Health Better Care Scottish Executive 2009)*

### **6.1 Introduction**

The literature suggests that there is a growing recognition of the need to incorporate a fundamental understanding of the characteristics of rural places when designing services (Aisbett, DL et al (2007)). Whilst rural people may be physically distant they are socially proximate so that those living some distance from a neighbour may also have an intimate knowledge of each others histories, family relationships and or history in the community. This can add additional challenges and complexities to accessing specialist care for a mental health need. Work undertaken in Highland with the adult mental health user group, HUG (Highland Users Group 2009) suggested that there were a range of views over access to intensive mental health services for adolescents. Some were of the view that there should be more local specialist provision, others were of the view that those who lived remotely expected to travel to access specialist services.

### **6.2 Overview of the literature**

In reviewing policy for remote and rural health care for young people in recent years, the Remote and Rural Working Group (Better Health Better Care Scottish Executive (2005)) confirmed that key policy documents included the Kerr Report, (Building a Health Service For the Future: A National Framework for Service Change in the NHS in Scotland Scottish Executive 2005)), the Remote and Rural Areas Resource Initiative (RARARI) Paediatric Project (2005), and Delivering a Healthy Future: An Action Framework for Children and Young People's Services. These key reports identified a series of common themes as follows:

- Difficulties faced by local clinical staff in providing high quality care for children with significant acute or chronic illness given the small number involved and the lack of immediate specialist support
- A perceived lack of understanding on the part of the clinicians working in dedicated paediatric units of the particular circumstances faced by staff in remote and rural settings



- Variable quality of discharge planning after episodes of specialist care

There is no reason to assume that the experience of young people with significant mental health needs would be any different to those with physical illness and or disability where isolation and stigma may be exacerbated by distance and remoteness. Delivering for Remote and Rural Health Care (Scottish Government 2008) proposed that the solution to these challenges lay in developing network approaches linked to bigger centres.

Specific to adolescent mental health in remote and rural areas work undertaken in Australia to improve understanding over the barriers to accessing specialist mental health services (Aisbett et al 2007) found a lack of data regarding the experiences of rural adolescents who seek help for mental health problems. In the absence of data, qualitative work was undertaken with 15-17 year olds and the following key issues to accessing specialist mental health care in remote and rural areas were identified:

- Lack of transport to access services
- Lack of qualified professionals in their region
- Long waiting lists
- Lack of out of hours service
- Rural gossip networks and social visibility compound the experience of stigma and social exclusion
- These experiences impact in a negative way on the uptake of mental health services and their progress to recovery.

The stigma arising from mental health difficulties may be manifested in more overt ways:

- Low levels of support and inclusion
- Lack of confidentiality
- Social discrimination and stigma

A further smaller study in rural Australia (Boyd, CP (2006)) also found that:

- Families may move to better access a specialist service

- Users of services can feel guilty regarding the need for 'over worked' professionals to travel distance to see them
- Rural gossip networks perpetuated stigma

### 6.3 Key Messages

- It is important to understand and acknowledge what it means to live in remote and rural areas when designing services
- There are varying views amongst users of services as to whether highly specialist mental health services for adolescents should be available locally
- The development of obligate networks is an acknowledged approach to supporting the delivery of specialist services in remote and rural areas
- Barriers to mental health service utilisation affect decision to access help and their ability to engage effectively with mental health services over time
- The lack of anonymity in rural areas can make the stigma surrounding mental health need and disorder more profound
- Lack of access to services may result in extreme behaviours to enable access to a service

### 6.4 Conclusions

- There are recognised challenges in delivering specialist Tier 4 services to remote and rural communities. The development of a regional network for Tier 4 adolescent mental health services is likely to support the delivery of care across remote and rural areas in the North of Scotland by ensuring access to specialist advice and consultation on a case by case basis, developing a shared understanding of the challenges of working in these environments and by improving discharge planning and on going support
- There should be a pro active approach to seeking the views of users of Tier 4 services who live remotely across the North of Scotland regarding the design and delivery of services
- There is a need to consider how work in progress to address stigma regarding mental health need, illness and disorder can be orientated around the particular needs of remote and rural communities
- Access to the appropriate level of mental health assessment in rural communities

should be part of the pathway development process across North of Scotland  
Boards

## **7.0 A literature review of evidence informed interventions and service models for meeting CAMHS Tier 4 need for inpatient and community based services**

This section of the report provides an overview of the changing approach and emerging evidence/knowledge base regarding the provision of Tier 4 child and adolescent mental health services. It details some of the key research over the last two decades and summarises the key conclusions from two reviews, Sheppard, S et al. 2009 and Kurtz, Z 2009 on how Tier 4 services should be developed across the United Kingdom.

A literature search was undertaken using the e-library with the key words of:

- Adolescent/child
- Mental illness/disorder
- Tier 4
- Service

In addition, the Cochrane library and the national NHS publication internet sites of the Department of Health and SGHD publications were searched.

### **7.1 Introduction**

Together We Stand Report, (NHS Health Advisory Service (1995)) detailed the tiered approach to CAMHS services where by Tier 4 was seen as an inpatient service providing the necessary environment for addressing the needs of young people with the most complex needs.

In more recent years, this view has matured with O'Herlihy et al (2001). Proposing that 'For many reasons, inpatient environments have recently come to be regarded as neither necessary or the most effective for managing young people with these kind of needs'. While more recently, 'Tier 4 has more recently come to be understood as multi faceted, with multi agency services that can include in reach, outreach, intensive and community initiatives, day provision, therapeutic fostering and other services that may be described as 'wrap around'. (Highland Users Group, (2009)) or as McDougall et al (2008) assert, 'Tier 4 CAMHS refers not only to residential inpatient units but also includes a range of community, home based and out reach services .... (and) highly specialised outpatient services for specific groups of children and young people'.

Sheppard et al (2007) leading on a Cochrane Review of interventions on alternatives to inpatient mental health care for children and young people propose that 'current policy across the United Kingdom place emphasis on the provision of mental health services in the least restrictive settings whilst also recognising that some children (young people) will require inpatient care'.

Kurtz, Z (2009) goes so far as to propose that 'in recent models the therapeutic milieu as historically understood has essentially disappeared and inpatient care has returned to its root in acute hospital practice, with the emphasis on symptom stabilisation and minimum necessary change before rapid discharge'.

As previously discussed, whether accessing inpatient or community based services young people meeting the criteria of need for a Tier 4 service are profoundly unwell and very vulnerable. They have been likened to be in need of intensive care of the mind, which perhaps demonstrates in a more tangible way the intensity of service required from services.

Sheppard et al (2009) undertook a Cochrane informed review of alternatives to inpatient mental health care with the following objectives:

1. To assess effectiveness, acceptability and cost of mental health services that provide an alternative to inpatient care for children and young people
2. To identify the range and prevalence of different service models that seek to avoid inpatient care for children and young people

The methodology involved sourcing randomised control trials of mental health services providing specialist care beyond the scope of generic outpatient provision as an alternative to inpatient mental health care (5-18 years) with a serious mental health condition requiring specialist services beyond the capacity of generic outpatient provision. The control group received inpatient or equivalent care.

The review involved:

- Anxiety disorders (obsessive, compulsive, somataform)
- Conduct disorders
- Developmental disorders

- Eating disorders
- Mood disorders (depression and deliberate self harm, bi polar disorder)
- Personality disorders
- Pervasive developmental disorders
- Psychotic disorders
- Substance related disorders
- Also non specific emotional or behavioural disorders

Meanwhile, a recent review by Kurtz, Z (2009) of the evidence base for Tier 4 CAMHS was undertaken to 'guide' the development of Tier 4 CAMHS. The report details a summary of evidence that is currently available on the provision of Tier 4 CAMHS services and 'should be taken into account for the effective development of Tier 4 CAMHS'.

## **7.2 A Review of the role of Tier 4 inpatient adolescent care**

The work undertaken in child and adolescent mental health inpatient units is described in a recent presentation to the Scottish Parliament earlier this year. (Morris, J, 2009).

The core work of the Scottish inpatient units was detailed as follows:

- Assessment and formulation of complex or undiagnosed cases
- Treatment, where this requires intensive staffing or monitoring
- Assessment and management of risk, including risk of violence to self and/or others, and of suicidal impulses
- Intensive family therapy and family work
- Opportunities for very ill vulnerable young people to participate in a protected peer group and in education in our schoolrooms
- Combined medical and psychiatric management in such cases as anorexia nervosa, severe chronic fatigue, somatising disorders, co-morbid conditions (e.g. diabetes plus eating disorders)
- Training of staff
- Research

From a review of the literature, MacDougall et al, (2008) assert that a small number of children and adolescents will require inpatient care, and reasons for admission may include:

- deterioration in psychological functioning despite community treatment
- high risk to self or others, including suicidality and aggressive behaviour towards others
- family difficulties in the context of mental disorder making treatment difficult
- the need for 24 hour assessment or care

Sheppard et al (2009) confirms that the mains users of inpatient service as follows

- 25 % eating disorders
- 17% mood disorder
- 17% psychotic disorders

Numbers are small but the impact can be severe and prolonged with high use of resources with implications for services when there is a shortage of specialised beds, with young people admitted to general psychiatric wards and paediatric wards when beds are not available. The developmental needs of adolescents and the difference in disorders for which young people are admitted adds a complexity to providing appropriate and safe inpatient care.

Child and adolescent inpatient care has been shown to be effective. Findings from an increasing number of multi-centre prospective studies of adolescent psychiatric hospitalisation affirm the value and importance of inpatient care to address Tier 4 need. Wrate et al (1994), O’Herlihy et al (2001), Green et al (2007) and Tulloch et al (2008). Thus inpatient care remains a necessary part of a comprehensive child and adolescent mental health service.

Kurtz (2009) summarises the key messages regarding inpatient care as follows:

- Inpatient admission allows for detailed assessment in a controlled environment and away from the family. The individualised assessment and intensive educational input can make a major difference to young people whose social adaption within their community has broken down and who have a history of school failure.
- The individualised assessment and intensive specialist treatment in an inpatient unit can lead to more effective use of other services post discharge.

- Removal from social difficulties in the external environment and exposure to the inpatient milieu can produce rapid gains in functioning (socialisation, and academic achievement). However, young people with significant social impairments may not be able to make effective use of such a socially orientated therapeutic environment, highlighting the need for comprehensive pre admission assessment.

For acute risk assessment, in cases of self harm and risk to self and others psychiatric inpatient care may not be the best option, a safe house with highly specialist assessment may well suffice.

It has been recognised for the last two decades that there are insufficient numbers of inpatient beds across the United Kingdom. The phenomenon of reducing the numbers of inpatient beds for adolescents is not confined to the United Kingdom, but has also been the experience in the United States. Jeffrey et al (2006) summarised the key issues from a review of the decline in access to inpatient beds in the United States for adolescents with serious emotional disturbances as follows:

- Systems of care require the capacity for short, intermediate and long term inpatient care and treatment
- Psychopharmacologic interventions are becoming more sophisticated and often require close observation in closed settings for safe and effective initiation of treatment
- Professionals are becoming better at determining which adolescents require which level of service ensuring better use of resource
- Families suffer when young people with high levels of need do not access services, end up in the criminal justice system or many miles away from home.

However, inpatient care will not always be the service of choice for the individual or the provider/funding organisation on the basis of affordability. Kurtz (2009) details the disadvantages of inpatient care for the individual as follows:

- Loss of support from local environment
- Presence of adverse effects within the inpatient environment
- Effects of admission on family life



It has also been acknowledged that some young people may be challenged and threatened themselves by the behaviour, needs and vulnerabilities of other inpatients who are distressed. Indeed, hospital admission may not always confer treatment advantage over well organised outpatient care, while for some self-harming behaviour admission may be disadvantageous, especially if prolonged (as this risks 'institutionalising' self-harming behaviour (Jeffrey, L (2006))).

So, whilst there is an indisputable case for the need for inpatient care for adolescents, there is a need to be clear and explicit as to the clinical reasons for admitting young people and what the anticipated outcomes and benefits of inpatient care may be.

For those young people who require admission to a scarce inpatient resource Kurtz (2009) details key predictors of outcome for those accessing inpatient and day patient treatment:

- High levels of aggressive anti social behaviour and organic symptoms predict poor outcome and emotional disorders do better
- Intelligence measured as IQ shows a moderate positive effect but functional achievement may be more critical
- Pre treatment family functioning is a key predictor of outcome
- Longer treatment stays are in general associated with improved outcomes
- For eating disorders there are widely differing results
- For depression, suicidality and psychosis little beneficial effects of inpatient care have been shown
- For conduct disorder, multi modal day treatment for children with disruptive behaviour produced better results than a control group
- For substance misuse there are additional benefits from community treatment
- For obsessive compulsive disorder poorer outcomes are found among those needing inpatient care compared to those treated as outpatients

In summary, Kurtz (2009) proposes that 'in order to optimise effectiveness, inpatient services need to change along with the development of new forms of community based services'.

### **7.3 A Review of the role of community based Tier 4 services**

Community based Tier 4 services offer a wide range of types of intervention. They are often associated with inpatient units. Kurtz (2009) details the advantages for adolescents as follows:

- Flexibility of care
- Work with family and foster/parental care
- A focus on education

### **7.4 Out of Hospital approaches**

Kurtz (2009) further proposes that the development and evaluation of these types of services in the United Kingdom lag behind developments in the United States. Home treatment studies have found higher levels of patient and carer satisfaction for home care rather than admission to adult services. Carers find home care less burdensome and disruptive. That said, some families do not have the capacity or the resources to meet the needs of a young person with Tier 4 which may in itself prompt the need to consider inpatient care (Personal communication Dr A Morton January 2010).

‘Recent surveys show that young people and families want CAMHS to be delivered flexibly and in a variety of settings, including the home’. (Kurtz (2009)) It is worth noting that the service models may be better suited to urban environments where there are established and accessible transport networks rather than remoter and more rural or island communities of the North of Scotland.

### **7.5 Day Services for adolescents**

Day services are often associated with inpatient units and may be accessed by young people with a Tier 3/4 level of need. In the main, day services are used for the following:

- Support and transition to community services following inpatient admission
- Intensive five day per week treatment packages for children and their families
- Treatment of disruptive behaviour, using multimodal treatment strategies with a combination of individual, family and psychopharmacological interventions
- Intensive intervention aimed at improving family functioning in situations of family breakdown or child maltreatment

The approach is recognised as a service that meets the needs of children and young people with complex needs through multi-agency partnerships between health, education and social work.

## **7.6 Community based intensive services**

There is an emerging evidence base for the effectiveness of intensive community based services. MacDougall et al (2008) identify the key component parts of intensive community services as follows:

- Treatment at home or reduced length of stay in hospital
- Small caseloads
- 24 hour rapid response
- Multi modal treatment strategies
- Close involvement of partner agencies
- Individually tailored treatment
- Flexible working practices
- Systemic basis
- Strong partnership with young person and their family or carers
- Prevention of family breakdown

A summary of the differing models of community based intensive services with a summary/overview of the current evidence is detailed in Appendix 6.

The literature suggests that there are a number of factors to consider when developing community based alternative services to inpatient care. These include:

- The profile of young people in the community
- The availability of and access to inpatient services
- developing a systems approach to forge links between different agencies (social work and secure settings)
- engaging families in treatment

For information, the developing of a joined up approach to the delivery of intensive service across community and inpatient services is detailed in Case Study 1 Table 21.

**Table 21: Case Study 1**

**Learning example**

**Playfield House, Cupar**

Child and adolescent mental health services in Fife underwent considerable redesign in 2002 with the closure of the local inpatient unit. The main CAMHS service point for Fife, a region containing many rural towns and hamlets with a population of 360,000, is based in Cupar. Comparing admissions over two years to Playfield House before its inpatient unit was closed (n=77), with a three year period after its intensive-therapy nurse-led team was established, only six out-of-area admissions were necessary (the only aspect of a case-control design available to them). This example demonstrates that whilst some admission capacity is essential, assertive outreach teams can not only much reduce duration of admission, facilitate transitions between hospital and the community, and maintain benefits after discharge, but their work can frequently, but not always, substitute for the intensive treatment traditionally associated with hospital provision.

An important subsidiary key function of the Playfield team is “capacity building” in the community i.e. of the skills (and anxiety-tolerance) of “families/carers/school/social work and voluntary sector” in order that they are able to respond more effectively to their young people who have severe mental health problems.

The development of a Community Intensive Therapy Team in South Wales (Cardiff and the Vale NHS Trust) has also demonstrated how an intensive community team can meet the needs of young people with a Tier 4 level of need in a community based intensive service. (Holms, personal communication, May 2010). Of note, is the importance of access to inpatient beds if required, to support the community model of care.

In addition a case study approach (Case Study 2 and 3, Tables 22 and 23) to meeting Tier 4 need in the community from existing work in the North of Scotland indicates how Tier 4 need can be met in creative and innovative ways although at some cost to Tier 3 service provision.

## Table 22: Case Study 2

(Gilchrist personal communication 2009)

A 17 year old patient from an island Board admitted to an acute mental health bed in Royal Cornhill Hospital, Aberdeen for a two week period of admission. The service was accessed in a timely way and the service provided was considered to be clinically beneficial. The admission was considered to be straightforward.

From the perspective of the CAMHS clinicians from the island and the mainland the approach worked well and was orientated around the needs of the young person.

The CAMHS Psychiatrist acted as the RMO and the adolescent CAMH team provided care according to the agreed protocol for under 18 patients in the hospital.

### **Summary of Costs (staff time for a two week admission) (not including costs of the ward nursing team)**

Medical trainee input - 33 hours  
Consultant input - 20 hours  
Band 6 CAMHs nurse input - 5 hours  
Occupational Therapy input - 1 hour  
Pharmacy input - 1 hour  
Psychology - not required  
Social work/ MHO - not required

### **Points of note**

- The protocol to support the admission of under 18 year olds into the adult unit requires resourcing.
- This will need to involve resource transfer between the island and the mainland Boards.
- An obligate network for mental health services is being developed across Grampian, Orkney and Shetland, in addition to the development of an obligate network for Tier 4 CAMHS across the North of Scotland.
- There are no arrangements in place currently within mainland Boards to employ extra CAMHs staff, pay overtime to cover the work, or reduce the other demands on the service to free up time.
- Delivering this intervention made additional demands on staff across the child and adolescent service,
- Delivering this type of intervention may impact on care of other patients in the service

### **Conclusion**

Inpatient care can be provided closer to home and in an appropriate environment when access to a regional inpatient unit is not possible. The provision of a Tier 4 shared care service for adolescents requires explicit resource to enable clinical care and cover that is not at the detriment to staff well being and other patient's requiring a CAMH Service. There are additional complexities when a service is provided to another NHS Board and where is more than one obligate network involved.

**Table 23: Case Study 3**

A 15 year old young person accesses a visiting CAMHS clinic on a monthly basis. The young person lives with their family in a remote community on the mainland, a two and a half hour drive from the main centre of population. The young person is known to CAMH services and has an enduring and complex mental health disorder. As their condition deteriorates, an inpatient admission is considered. The young person and family are reluctant to use this service given the distance from home. Local, yet extensive service redesign enables a home based programme of care to be delivered. Over a period of eighteen months the young person makes considerable progress and is considering further education, an option that would previously have been inconceivable.

This was a local solution, made possible because the requisite clinical skills and competencies were available from within an hour and a half drive time from where the young person resided. CAMHS services located in the Community Health Partnership and the community outpatient service underwent a process of service redesign to support the delivery of this service model.

**Summary of costs**

Band 6, 2 days a week for 18 months

Backfill for substantive post Band 6 2 days a week

Administrative and management time to support redesign/recruitment/cover for substantive post

Monthly review in visiting clinic

Supervision and support for remote clinician- Consultant and Clinical Nurse Specialist

**Points of note**

- Tier 4 outreach community based services can be provided to a remote community when inpatient care is not the desired option for the young person/family
- This may be at some cost to the existing CHP and specialist CAMHS service, involving considerable service redesign
- The costs of service redesign and delivery of the model became a cost pressure for the CHP.
- There were additional costs re support and supervision for a clinician working remotely from Inverness
- This proved challenging for the outpatient service who are working under pressure to provide a core Tier 3 service.
- It is not clear how replicable this model would be across all remote locations.

**Conclusion**

Tier 4 community outreach services can be provided in remote locations when inpatient care may not be the only solution to accessing a Tier 4 service. This is not without a considerable cost to existing services that are under pressure to provide a core Tier 3 outpatient CAMHS service.

## **7.7 Achieving a balance between inpatient and community Tier 4 services for adolescents**

The literature suggests that there is clear evidence for the effectiveness of inpatient care for adolescents with Tier 4 levels of need. For Sheppard et al (2009) 'there is now research evidence supporting the use of alternatives to inpatient care for certain groups of young people with mental health problems.....the evidence suggests that treatment effects of several community models of care are of similar size to those obtained through residential treatment and may be sustained longer after follow up'. In addition, Sheppard et al (2009) conclude that alternatives to inpatient care may prevent dependency on inpatient beds and prevent and or reduce stigma. They may also facilitate the transfer of therapeutic gains to the young persons every day environment and maximise the potential for sustained health outcomes.

However, whilst there is a growing sense (not necessarily shared by all clinicians) that some community models show cost savings, there is not yet enough evidence to directly inform service commissioning as Sheppard et al (2009) conclude 'as yet there is not the evidence to decide which model is best for which group of young people'.

The literature supports the assumption that investment in Tier 4 services is not about either inpatient or community based services; McDougal et al (2008) propose that the evidence points to the need for a 'mixed economy of inpatient provision and complimentary home based and community outreach services'. For Kurtz (2009), this approach involves an integrated approach across Tier 3 and Tier 4 through a service network/pathway approach which will require a residential component.

## 7.8 Key Messages

The provision of Tier 4 services will require a mixed economy approach

- Access to inpatient psychiatric beds is a prerequisite of a comprehensive child and adolescent mental health service
- The capacity, skills and service models available in community Tier 3 services influence the demand for Tier 4 inpatient beds
- There is a growing evidence base for Tier 4 community services provided through a variety of models, in particular, for multi systemic therapy, assertive out reach and Treatment Foster Care
- The literature offers indicative options for how intensive community based services could be developed however, these tend to be based in urban areas where there are significant populations and good transport infrastructure
- Multi disciplinary comprehensive pre admission assessment is a pre requisite for the provision of a Tier 4 service as an inpatient or in the community
- The independent sector often provides a stop gap for the lack of access to inpatient beds and there may be funding diverted to these services that could offset costs to the NHS
- Tier 4 inpatient services need to be developed in conjunction with Tier 3 community based services
- There is experience in the North of Scotland in meeting Tier 4 need in creative ways but this occurs at some considerable cost to the provision of Tier 3 services
- The literature reviewed confirms the direction of travel for Tier 4 services across the North of Scotland.



## 7.9 Conclusions

- The literature is clear that there is a need for a mixed economy of investment, across a spectrum of care that includes both inpatient and community based Tier 4 services
- Whilst there is no clear view as to how the investment might be allocated across inpatient and community services the experience in Fife and South Wales suggests that an intensive community based approach with access to beds as required is a model worth replicating
- Case studies from the North of Scotland also demonstrate how community based services can address Tier 4 levels of need
- There is a need to invest in and develop Tier 4 community based services for adolescents with complex mental health needs and disorders in NHS Boards across the North of Scotland
- These two developments should be developed in tandem with the provision of outreach and consultancy with professional support and resources being available to local CAMHS teams through the proposed Tier 4 Network and the related development of an integrated care pathway and links to local Tier 3/4 community services
- These conclusions affirm the direction of travel for the North of Scotland CAMHS Tier 4 Service Modelling and Workforce Planning Group, with the proposed development of a Tier 4 CAMHS Obligate Network and related managed network for Tier 4 CAMHS

## 8.0 Engaging and involving users of CAMHS services

***'we need to develop methodologies and encourage publication and dissemination of high quality studies to inform service developments' (Heads Up Scotland 2005)***

The importance of consulting with children and young people who use services is rooted in the United Nations Convention on the Rights of the Child passed in 1989 and signed by the United Kingdom in 1989. It was an underpinning element in the development of the Scottish Needs Assessment Programme for Child and Adolescent Mental Health (Scottish Executive 2005) and the subsequent Child and Adolescent Mental Health: A Framework for Prevention, Promotion and Care (Scottish Government 2005). The need to ensure the views of children and young people was further endorsed with the publication of a discussion paper from the Heads Up National Project for Children and Young People's Mental Health (Heads Up Scotland 2005).

### 8.1 Overview of the literature:

- Claveirole, A (2004) undertook a review of issues involved in consultation research with adolescent mental health service users. Eighteen young people who were being treated in day care on inpatient units were interviewed over a period of 5-8 weeks. A series of ethical considerations were explored, when consulting with young people including issues relating to confidentiality, informed consent, mental state and distress. Key issues identified in this exercise included the importance of recognising the need to balance the respect of the voices of young people with responsibility for their best interests
- White et al (2005) undertook a consultation exercise on behalf of the Mental Welfare Commission to consult with young people about their experience of an inpatient admission, to develop good practice guidance and to consider how views could be used to inform the redesign of child and adolescent mental health services. The exercise involved 11 young people aged 12 to 18 years who had experience of inpatient admission from a few days to months to more than one admission. Their needs included significant disorders, self harm and substance misuse. Key feedback from those consulted included:
  - Inpatient admission should have taken place earlier
  - Community and outpatient services were not as intensive as was required

- Inpatient admission would not have been necessary if there had been more accessible local intensive services
- Where extensive travel was required to an inpatient unit, young people felt isolated and disadvantaged in terms of contact with friends and families
- Some inpatient environments were not appropriate and young people felt the staff did not have the skills to address their needs and that staff were fearful and judgemental. For some, this added to the distress of hallucinations and fits
- There were issues for young people who were admitted to paediatric and adult inpatient units, in both they could feel out of place either due to age or the reason for admission, resulting in poor understanding of their developmental and age appropriate needs
- Staff in the inpatient units were generally considered to have been receptive, skilled and helpful
- Some young people did not feel they had been consulted over their admission and treatment, with others having concerns over a perceived lack of information and involvement

The report drew a number of conclusions for those involved in designing and delivering care in inpatient units and used the Children's Charter to inform service thinking from a young person's perspective.

- Worrall-Davies, A et al (2008) undertook a systematic review of good practice in accessing children and young people's views on child and adolescent mental health services, to identify methods used, best practise methods and those methods that were most effective in leading to service changes. This approach identified a limited number of studies that achieved the quality criteria the authors had detailed however, 'no study reported a change in practice as a result of hearing children and young people's views'. The key conclusions from this study were as follows:
  - Many studies exploring the views of children and young people were poorly reported
  - Methods should be age appropriate and rigorous
  - Findings should be reported clearly

- There should be an explicit understanding that organisations will be willing and able to implement changes suggested by young people

Sheppard et al (2009) note that few of the studies they reviewed mentioned engagement with children and young people on service development and therefore it was not possible to establish views on the acceptability of interventions. They were of the view that this would inform an understanding of attrition and compliance rates in the delivery of mental health interventions and that the evidence base would be improved by seeking these views

## **8.2 Seeking user views across the North of Scotland**

This exercise has identified the following consultation exercises with users of CAMHS services in recent years. Further work is proposed by the Service Modelling and Workforce Planning Group into 2010 to better inform North of Scotland developments from the perspective of young people in the area. NHS Highland will also be undertaking a consultation exercise with Tier 3/4 service users in spring 2010 that will also inform the approach to Tier 4 services in the North of Scotland.

## **8.3 North of Scotland Planning Event September 2007 (Re-provision of Adolescent Mental Health Inpatient Service Report of a Planning Event, North of Scotland Planning Group (2009))**

The event aimed to engage stakeholders from across the north in the development of the overall pathway of care for young people who require access to specialist mental health services.

Participants, including over 15 young people as well as parents, who had experience of the Dudhope Unit considered a high level pathway that involved care at home through to care in an inpatient unit. Issues relating to admission and in reach and out reach were discussed.

Key points for change or improvement included:

- **Access**
  - Age barriers to different services were not patient centred
  - Referral to treatment times were too long

- Access to local services
- Distance from home:
  - Good access
  - Help to get home
  - Flexibility and choice
- **Pathway**
  - Entry and exit process from the parental and family viewpoint
  - Risk assessment of high risk patients
  - Sharing and access to notes of different professionals
  - Food/eating environment
  - Abruptness of discharge
- **Professional support**
  - Different approaches from GPs
  - Referrals from different sources were treated differently
  - Lack of clarity over roles of education and social work services when there is significant mental health need – these need to be strengthened
  - Skills and confidence to work with young people who are very unwell
- **Family Support**
  - Need to support siblings
  - Benefits of a key worker approach to support families
  - Expectations that parents will inform agencies of the needs of their child
  - Dealing with stigma
  - Address bullying

The event also asked participants to note comments for the Service Modelling and Workforce Planning Group to consider as their work evolved. These included:

### **For young people**

- Young people are people not a diagnosis, please do not label them
- Think about the 'costs' to young people and their families
- Ultimately the young person will want to draw on the skills they have learned, eg. CBT – make sure they can access this post discharge
- Patients and families should have choices at each level of intensity

### **For the family**

- Patients and families should have choice at each level of intensity
- Think about costs to young people and their families: financial/time off work , disruption to other family members, demands on parents and carers
- Travel arrangements need to be easily negotiable
- Include parents at every stage – they will be part of the solution

### **8.4 Highland User's Group NHS Highland (Highland Users Group (2008))**

Highland Users Group (HUG), established in 1997, is a network of people who use, or have used mental health services in the Highlands. There are 13 branches across Highland and over 340 members. HUG were approached by NHS Highland in early 2007 to seek a retrospective view of service users on their experience of needing specialist mental health services when they were teenagers or younger, or for views on the experience of their children or other young people requiring specialist mental health services. As HUG undertook the exercise they were able to confirm that their members had relevant experience that they were able to share. HUG also acknowledged that the report brought a particular perspective that may have limitations. The subsequent report noted the importance of families and the role of school and friends for young people with mental health difficulties.

In relation to specialist inpatient services, HUG members noted the absence of a dedicated inpatient unit in Highland and the need to travel a long way to access inpatient care. '... just because we are rural, it doesn't mean that young people don't need inpatient facilities. We need a unit that is close to home so that parents and friends can visit. This is very important when you are ill'. There was a view that young people decline admission and lose out on specialist care because of the distances that can be involved. There were also other views that saw expensive services covering a wide area as necessary and that an inpatient admission a long way from home could be a relief for some young people. There was also a recognition that accessing specialist services a long way from home was also part of 'the life we lead' in a remote rural area.

When an inpatient admission was required there were a range of views; that young people could be very vulnerable and isolated in an adult inpatient unit. At times this could involve seeing things that were not appropriate for a young person to see, re drug

and alcohol misuse and or certain behaviours. From another perspective, a short stay might be alright and even that there could be good advice from those who were older than the young person, in effect the needs of the young person needed to be matched to the environment.

There was a powerful sense that young people 'have a great need to be believed, respected and trusted ... ' and that they are 'sensitive to unjust treatment and slow to forget this when it occurred'.

'they need to know they can ask for help and we need to realise that they are young'

### **8.5 Key Messages**

- The voices and views of young people requiring specialist mental health services should be sought, valued and respected
- There have been a number of studies undertaken in Scotland that have sought to seek the views of young people who require very specialist services. There are consistent messages over timely access to appropriate care that is accessible. There are particular issues for young people and their families accessing inpatient units a long way from home
- Studies exploring the views of children and young people are not always well reported
- Methods for consultation with young people should be age appropriate and rigorous
- Findings should be reported clearly
- There should be an explicit understanding that organisations will be willing and able to implement changes suggested by young people
- Young people have a range of views regarding the benefits and disbenefits of accessing inpatient care a long way from home and support networks
- There is an interest in developing local solutions or services, be these community based or making better use of existing services such as dedicated young people's beds in adult inpatient units

## 8.6 Conclusions

- Consultation with users of services should underpin service design and delivery and there should be a clear process detailed for how this will be achieved across the North of Scotland
- There may be a difference between the views and expectations of users and what services are able to act/deliver on
- Health services need to be clear and upfront with young people as to what is possible within current resources and what the limits are from inpatient and community based services
- Where possible, young people should be given choices for where they receive Tier 4 care with consideration of the benefits and disbenefits and related issues of risk
- Health systems need to be seen to be acting on the feedback received by children and young people. Consideration should be given to the development of a continuous monitoring system, with a method of accounting for actions taken as a result of consultation with users of services
- Historical evidence from user views on CAMHS does not change the assumptions made in this report but further emphasises issues of access in remote and rural areas



## **9.0 Principle Findings and Recommendations**

Pre requisites for commissioning Tier 4 services, as detailed in the HAS Report (1995) include the need for:

- A high level of trust between partners
- Transparency in the contracting process
- Good information on service use and costs
- Adopting a medium to long term view on value for money basing decisions on robust needs assessments

It is proposed that these measures are used to bench mark and underpin the further development of Tier 4 services across the North of Scotland.

The complexity of establishing and funding Tier 4 services across the six North of Scotland Boards should not be underestimated. However, the principle findings from this needs assessment exercise detailed below should underpin and inform activity at both Board and North of Scotland levels:

### **9.1 Principle findings**

1. National policy affirms the importance of developing comprehensive CAMHS across all Tiers and that there is a need for approaches that work across the continuum of promotion, prevention and care with a focus where possible on early intervention. Services need to be provided that are age appropriate and match the level of need and intensity with appropriately qualified staff
2. The geography of the North of Scotland means that there are particular challenges in providing highly specialist services due to dispersed populations and the challenges from remote and island populations and related transport infrastructure
3. The epidemiology informs us of:
  - a. The complexity and severity of mental health disorder and illness where there is Tier 4 need
  - b. That all North of Scotland Boards can expect to have young people with a Tier 4 level of need and that therefore community based CAMHS services should be resourced to provide this level of service

4. Service utilisation information tells us that:
  - a. Not all young people requiring an inpatient bed access one can when they need it
  - b. Some young people will access care in paediatric or adult environments that may not be appropriate to their developmental needs, though appropriate use of paediatric or adult facilities can be constructed as clinically and contextually appropriate within a network approach
  - c. Others historically have required admission to private or independent facilities diverting funding away from CAMHS services
  - d. Admission out of region can mean that young people are even further away from family and peer groups if admitted
  - e. Where CAMH services are not resourced to provide Tier 4 services, when Tier 4 need arises it diverts a resource away from Tier 3 service provision. This will become an increasing pressure for community CAMHS as we move to a HEAT target for access to CAMHS over the coming years
5. The review of Tier 4 service models tells us that :
  - a. There is an indisputable need for inpatient beds and that inpatient care works for young people with a Tier 4 level of need
  - b. There is a emerging evidence and knowledge base for the provision of intensive and community based services where there is a Tier 4 level of need
  - c. The range of community services available will influence the need for and use of inpatient Tier 4 services
6. The views of young people tells us that:
  - a. They recognise that an inpatient admission may be required and may be beneficial at times
  - b. They would appreciate choice
  - c. Being away from family and friends when admitted can be challenging
  - d. Services need to be able to demonstrate that the views of young people have influenced service design delivery

In addition, the needs assessment process has affirmed much of the direction of travel of the Service Modelling and Workforce Planning Group.

This leads us to make the following recommendations. These are not listed in any order of priority:

### **Recommendation 1**

The literature is clear that there is a need for a mixed economy of investment, across a spectrum of care that includes both inpatient and community based Tier 4 services.

### **Recommendation 2**

Access to inpatient psychiatric beds is a prerequisite of a comprehensive child and adolescent mental health service. The proposal to develop the inpatient bed capacity in the North of Scotland to 12 beds is appropriate on the basis that there will be related investment by all North of Scotland Boards in local, community based Tier 4 service delivery with the development of an integrated network model of delivery equating to an investment in 16 inpatient beds as designated by the Scottish Government (2005).

### **Recommendation 3**

The use of and access to Tier 4 child and adolescent mental health services through the obligate network by different Boards should be kept under review and length of stay inpatient facilities and moves to prompt discharge when appropriate should also be reviewed. Consideration should be given to benchmarking length of stay and discharge arrangements with other inpatient services in Scotland.

### **Recommendation 4**

Thought should be given as to how the staffing for a 12 bedded unit could be used flexibly to provide expertise and consultation to community CAMHS services across the North of Scotland to support the Tier 4 network.

### **Recommendation 5**

In order to make best use of the inpatient resource there is a related need to invest in local community based Tier 3/4 services. This to be achieved by continuing to work to the Royal College of Psychiatry recommendations for Tier 3 community services (20 wte posts for 100,000 of population where CAMHS services work to the age of 16 and to 24 wte posts per 100,000 population where CAMHS services address 0-18 services) and to consider how there may be additional investment into local Tier 4 services

through the regional network and inpatient unit linked to the Dundee Unit through an obligate network.

### **Recommendation 6**

The balance of investment across the Tier 4 network (inpatient and intensive community services) should be kept under review in the coming years. It may well be that over time, different needs for inpatient and community services emerge depending on local needs, service strengths and capacity. The focus on the development of a Tier 4 network and the associated integrated care pathway will underpin this direction of travel.

### **Recommendation 7**

All North of Scotland Boards should work with local integrated children's service partners to build capacity across CAMHS services, and in particular, education, social work and the third sector, to ensure that they work preventively with young people who are known to be at particular risk of developing mental health disorder and illness.

### **Recommendation 8**

The needs assessment exercise has affirmed the direction of travel of the Service Model and Workforce Planning Group who lead on the development of Tier 4 services and related models across the North of Scotland.

This report will be presented to the North of Scotland CAMHS Project Board in June 2010 and will inform the development of the outline business case for the regional inpatient unit later in the year.

## Appendix 1

### **A Strategic Framework: The Policy Context for Tier 4 CAMHS**

#### **SNAP Needs Assessment Child and Adolescent Mental Health (2003)**

A wide ranging needs assessment of the mental health of Scotland's children and young people was commissioned by the Scottish Executive Health Department. The final SNAP report on the mental health of children and young people in Scotland informed the subsequent Child and Adolescent Mental Health a Framework for Prevention Promotion and Care (Scottish Executive 2005). The main aim of the needs assessment was to identify ways of better addressing the mental health needs of children and young people in Scotland. The report details three underlying themes/principles: that children and young people have the right to be heard and to play a full part in thinking about mental health and in influencing the arrangements that we make to improve mental health; the importance of "mainstreaming" mental health so that those with mental health problems are no longer marginalised or excluded and finally, an integrated approach across the spectrum of promotion, prevention and care.

#### **Mental Health legislation (Mental Health Care and Treatment (Scotland) Act 2003)**

The Mental Health (Scotland) Act 2003 places a duty on Health Boards to provide sufficient age appropriate services and accommodation for young people up to the age of 18, who require inpatient admission. This has implications for where, when and how young people are admitted to adult mental health inpatient units. The Act came into force on April 1 2005.

#### **Child and Adolescent Mental Health a Framework for Prevention Promotion and Care (The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care. Scottish Government (2005))**

The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care, was published by the Scottish Executive in November 2005, with a ten year timescale for implementation. The expectations of the Framework is that NHS systems and integrated children's service partners will address a range of mental health needs and difficulties for children and young people across the whole continuum of mental health, from mental health promotion, through preventing mental illness, to

supporting, treating and caring for those children and young people experiencing mental health difficulties of all ranges of complexity and severity. The Framework is to be implemented by 2015. The Framework is very clear that the primary function of specialist child and adolescent mental health services (CAMHS) is to develop and deliver services for those children and young people (and their families and carers) who are experiencing the most serious mental health problems.

The Framework details that at Board level a specialist child and adolescent mental health service should provide a comprehensive range of services addressing the full range of mental health need delivered locally through an appropriately planned and commissioned network of mental health services for children and young people. This assumption underpins the delivery of comprehensive Tier 3 services. The Framework acknowledges the need for both inpatient and intensive community Tier 4 services as part of an overall network and acknowledges that services should be provided locally where possible though some more specialised services will be more appropriately developed and delivered on a regional basis. Decisions about which services can be delivered locally and which should be delivered regionally and nationally should proceed from a presumption of local delivery, unless better care can only be made available on a regional or national basis. While such decisions will be informed by considerations of capacity within services, they should be governed primarily by considerations of quality of care.

**Child Health Support Group: Inpatient Working Group- Psychiatric Inpatient Services for Children and Young People in Scotland: A Way Forward (Scottish Executive 2004).**

In order to address the recommendations in the SNAP Needs Assessment, a short life working group was convened by the Child Health Support Group to give detailed consideration to developing a national strategic approach to the provision of psychiatric inpatient services for children and young people in Scotland. The final report made the following recommendations that inform this report:

- Phased expansion of psychiatric inpatient services for young people should be focused around the three existing sites, with ongoing review of the need for provision in the North of Scotland

- Psychiatric Inpatient services for young people should be commissioned on a regional basis with an equitable and stable funding framework, within a national context
- All psychiatric inpatient units for children and young people should be resourced sufficiently to engage in flexible and effective liaison with local community teams to plan and support admission and discharge

### **Inter Regional Working Group for the Implementation of Psychiatric Inpatient Provision for Young People (Child Health Support 2005)**

The Working Group was established with the remit to define future regional planning and commissioning arrangements for psychiatric inpatient services for young people in Scotland within a national context. For the North of Scotland the Working Group's final report recommended the development of a new unit of 16 places, through a stepped approach that was balanced with investment in community services.

### **Delivering for Health (Scottish Executive 2005)**

This report detailed a programme of action for the NHS to shift the balance of care to reduce the reliance on episodic, acute care in hospitals for treating illness, and proposed a move towards a system which emphasised a wider effort to improving health and well-being, through preventive medicine, through support for self care, and through greater targeting of resources on those at greatest risk, with a more proactive approach in the form of anticipatory care services.

With specific reference to children and young people's mental health the report acknowledged that mental health affects children and young people's behaviour, learning and physical health and recognised that services and approaches needed to be in place to promote children's mental health, prevent mental illness, and support those children and young people with mental health problems more effectively. Explicit acknowledgment was made to the need to ensure that specialist services were available and accessible for those children and young people who needed them.

Regional groups were tasked with implementing the proposal for the "expansion of adolescent psychiatric inpatient sector to at least 56 places by 2010.

### **Mental Welfare Commission**

When young people under the age of 18 require inpatient treatment the needs of each individual young person are paramount and should be central to determining the care he or she receives. It is the Commission's view that young people under 16 years should be admitted to a young person's unit. On rare occasions, the Commission recognises that it may be acceptable for a young person aged 16 or 17 to be cared for in an adult ward. This will depend on the individual circumstances of the young person, on his or her maturity, occupation, and the nature of mental health problems. However in these circumstances there should still be access to age appropriate specialist care.

### **Delivering for Mental Health (Delivering for Mental Health Scottish Government 2006)**

The report demonstrates the commitment by government to develop a national delivery plan for mental health as detailed in Better Health Better Care, based on the principles that NHS services should be delivered as locally as possible, provide systematic support for those with long term conditions, reduce health inequalities and actively manage discharge and admission to hospital. Specific to those with a Tier 4 level of need, Commitment 11 states that there will be a reduction of admissions of children and young people to adult beds by 50% by 2009.

### **Delivering a Healthy Future. An Action Framework for Children and Young People's Health in Scotland (Scottish Executive (2007)**

Developed as part of the Delivering for Health agenda, the report brings together the major policy areas and guidance for health services for children and young people. The Framework reiterates the expectation that there will be robust regional planning and commissioning arrangements to support the development of dedicated inpatient provision.

### **Better Health Better Care (Scottish Government 2005)**

The report affirms the commitment of the Scottish Government to increase the number of inpatient adolescent beds across Scotland from 44 to 56 by 2010.



### **Delivering for Remote and Rural Health Care. The Final Report of the Remote and Rural Work Stream (2007)**

The report details models of care for remote and rural communities and details the need for formal working links to be established between remote and rural areas and those in larger centres. The report develops the concept of an obligate network whereby larger centres support more local services to be sustainable and to be able to deliver more specialist care closer to a person's home and community.

### **Better Health, Better Care: Hospital Services for Young People in Scotland (Scottish Government 2009)**

This report, commissioned as a work stream of the National Steering Group for Specialist Children's Services details the need to develop age appropriate care and services for young people requiring inpatient admission to hospitals in Scotland. The report restates the importance of recognising that adolescence is a unique period of change and that these needs have often been poorly addressed in the design and delivery of hospital care across Scotland. Of particular relevance is:

- Staff caring for young people should receive training to equip them to identify and address the particular needs of this age group
- Services should be organised so as to minimize educational loss as a result of hospital care, particularly for those with chronic conditions
- The transition of patients from children's to adult services is a key element of successful care which needs to be well planned, structured and appropriately timed
- The development of services and facilities for young people should be accompanied and informed by effective engagement with young people and their families

### **Better Health Better Care National Delivery Plan for Children and Young People's Specialist Services in Scotland (Scottish Government 2009)**

The report details the action required and associated investment to improve care through networks of services working together by supporting care in specialist hospitals as well as in general hospitals and communities. Additional funding was made available for CAMHS services from 2009 to 2011 to improve quality, access, availability and the sustainability of specialist CAMHS services within NHS Boards.

### **Getting It Right for Every Child (*Girfec*)**

The principle goal of *Girfec* is that everyone has a responsibility to do the right thing for each child and that services need to work towards a unified approach, with less bureaucracy and more freedom to get on and respond to children. This will mean earlier help and the child getting the right help at the right time packaged for their particular needs.

This will be achieved through the following:

- A new duty of co-operation
- Improve joint working/communication
- Improve effectiveness through shared understanding
- Support early intervention
- Identify additional needs
- Reduce bureaucracy and duplication

### **Development of waiting list target for HEAT CAMHS**

The Scottish Government requires NHS Boards to work to a HEAT target for CAMHS waiting lists. The “Matrix of Service Components which Drive and Support Improvement” has been developed to identify and achieve focus on key aspects of the CAMH service that will promote directly or indirectly improved waiting times and maintain and enhance the level of the service. It supports the phased introduction of an overall “referral to first treatment” developmental target which recognises the different starting points of Boards. The first phase will be supported by a HEAT (Health, Efficiency, Access, Treatment) target of 26 weeks referral to treatment by March 2013.

## Appendix 2

### North of Scotland Public Health Network (NoSPHN)

#### Proposal for Work (and Health Intelligence Support if required)

(If you are requesting patient identifiable data please complete and sign the Confidentiality Statement on page 2)

	<b>Version: 2</b> <b>Date: 5<sup>th</sup> January 2009</b> <b>Prepared by: Sally Amor, Pip Farman and Sarah Taylor</b>
<b>1.</b>	<b>Project Title</b> <b>Needs assessment to inform the investment in and provision of Tier 4 CAMHS services across the North of Scotland NHS Boards</b>
<b>2.</b>	<b>Aim of Project</b> To inform a strategic approach to the development of Tier 4 CAMHS services across the North of Scotland with particular reference to the development of the outline business case for inpatient provision, investment in community based Tier 4 services and the development of a regional CAMHS network for the North of Scotland NHS Boards.
<b>3.</b>	<b>Project Objectives</b> <ol style="list-style-type: none"><li>1. To engage key stakeholders (clinicians and managers) in an interactive approach to a Tier 4 needs assessment across the North of Scotland</li><li>2. To detail the epidemiology of CAMHS Tier 4 need from a population perspective.</li><li>3. To give an indication of Tier 4 needs for North of Scotland Board populations.</li><li>4. To undertake a literature review of the nature of CAMHS Tier 4 need.</li><li>5. To undertake a literature review of evidence informed interventions and service models for meeting CAMHS Tier 4 need for inpatient and community based services.</li><li>6. To detail options for the provision of CAMHS Tier 4 services across the geography of the North of Scotland Planning Group for both inpatient and community based services. This to include indicative numbers of inpatient beds in a regional unit.</li><li>7. To inform the development and investment of Tier 4 CAMHS in North of Scotland Boards (and related opportunities for matched investment from the Scottish Government).</li></ol>

4.	<p><b>How will success of project be measured? (Do any of these issues require management?)</b></p> <ul style="list-style-type: none"> <li>• Engagement of key stakeholders (clinicians and managers)</li> <li>• Delivery of report to the proposed time scale.</li> <li>• Evidencing that the needs assessment has informed the development of the outline business case and investment in subsequent investment across North of Scotland NHS Boards.</li> </ul>	<p><b>Proposed management</b></p> <p>Management lead for the exercise: Sally Amor, Child Health Commissioner/Public Health Specialist NHS Highland (sally.amor@hnb.scot.nhs.uk), supported by wider reference group of key stakeholders from CAMHS Inpatient Board and Service Modeling Group</p> <p>Recruitment of needs assessment lead. Sally Amor as above</p>
4.	<p><b>Detailed specification of support required (please be as detailed as possible)</b></p> <p><b>Management lead</b></p> <ul style="list-style-type: none"> <li>• 6 days of time to refine specification (1), recruit needs assessment lead (1/2), influence the key stakeholders (1), support for interactive workshops (21/2) and support the needs assessment lead (1)</li> </ul> <p><b>Needs Assessment Lead</b></p> <ul style="list-style-type: none"> <li>• 1 day for population epidemiology</li> <li>• 2 days literature review</li> <li>• 2 days of time to detail service options</li> <li>• 2 1/2 days of time for consultation and feedback on the proposals with management lead and Reference Group (interactive workshops)</li> <li>• 5 days preparation of penultimate draft report for review by Management lead / others and final copy thereafter.</li> </ul>	
5.	<p><b>On what basis has the request for this piece of work been made, eg NOSP Workplan, connection to Local Health Plan, Change and Innovation Plan, etc</b></p> <p>There have been longstanding proposals to develop inpatient capacity for CAMHS in the Dudhope Young People's Unit in Dundee and the related development of a regional network to support community based services. To date, the process has not been informed by a robust needs assessment process.</p> <p>NOSPHN has been approached by the NOS Regional Director on behalf of NoSPG to undertake a needs assessment to inform the development of Tier 4 CAMHS provision across the North of Scotland. Additional impetus has been given to the exercise by the Scottish Government announcing matched funding (2 million pounds over 2009/10 and 2010/11) NHS Boards investing in Tier 4 services.</p>	
6.	<p><b>Timescales:</b></p>	<p>The process is needed to inform the development of the outline business case for the proposed NOS inpatient unit. The final report is required for the end of</p>

		September 2009
7.	<b>Project Lead/Requestor:</b>	Dr Sarah Taylor
	<b>Job Title:</b>	DPH NHS Shetland
	<b>Sector/Dept:</b>	NHS Shetland
	<b>E mail address:</b>	
	<b>Telephone Number:</b>	
	<b>Work Leads (if identified):</b>	To be confirmed
	<b>Project Team (if required):</b>	To be confirmed
	<b>Reporting mechanisms (with milestones / timescales if known):</b>	To be confirmed
8.	<b>Work required of NoSPHN Boards / others:</b>	Liaison with NOS NHS Boards  (There may be a need for later / follow on work in local boards to test out the HNA for application in local areas, ie checking out HNA against current usage to inform local redesign).
9.	<b>Risks: (the project will need to define how these will be managed)</b>	<ul style="list-style-type: none"> <li>• Required to deliver to demanding time scales: prioritise recruitment to lead for needs assessment and associated support(s).</li> <li>• Need to secure a time resource from local existing public health staff and/or identify a budget to source the needs assessment: identify internal staff resource as a priority or utilize end of year slippage to recruit external resource for the exercise.</li> <li>• Need to ensure 'buy in' and engagement with the process from NOS NHS Boards and CAMHS clinicians: ensure links with NOS CAMHS Project Board and Service Modeling Group. Meetings will need to be scheduled to achieve this within timescales.</li> </ul>

10.	<b>Further information</b> <b>e.g.</b> <b>Budget available</b>	<ul style="list-style-type: none"> <li>• Previously collated service information may be available.</li> <li>• In principle the penultimate paper should be submitted for peer review by the NoSPHN lead representative and another public health representative from outwith the North.</li> <li>• Budget available to be confirmed.</li> </ul>
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**HI Use only:**

<b>No of Days Required</b>	
<b>Specific skills required</b>	
<b>Opportunity costs</b>	
<b>External Commissioning</b>	

## NoSPHN (Health Intelligence Network) Data Request

### Confidentiality Statement

<b>User Details</b>	<b>Sponsor Details</b>
Name	See over for appropriate sponsors
Position	Only complete this section if the "User" is not the consultant responsible for each patient's care
Organisation	
Address	
	Name
	Position
Tel. No	Organisation
Name(s) of any co-user(s) * (see note 1)	Address
	Tel. No.

<b>Data Requested (See original Proposal for Health Intelligence Support form)*</b>
<b>Intended Use of Data (include publications) * (see note 5)</b>
<b>Reason Identifiable Data Required</b>

#### **User's Declaration**

I declare that I understand and undertake to abide by the rules for confidentiality, security and release of data received, as specified in paragraphs 1 - 5 on page 2 of this document.

Signature ..... Date .....

#### **Sponsor's Declaration (for appropriate sponsors see page 2)**

I declare that ..... (named as the "User" of the data), is a bona fide worker engaged in a reputable project and that the data (s)he requests can be entrusted to him/her in the knowledge that (s)he will discharge his/her obligations in regard to confidentiality, security and release of the data, as stated in paragraphs 1 - 6 on page 2 of this document. I am happy for him/her to receive the data.

Signature ..... Date .....

## Rules on Confidentiality, Security and Release of Information

1. Data received should not be divulged to any person whose name is not specified as a 'co-user of data' nor used for any purpose other than that declared on page 1 of this document.
2. Proper safeguards should be applied in keeping the data and destroying it on completion of the work/project declared on page 1, to prevent any breach of confidentiality.

### **Any misuse or loss of the data should be notified immediately to the Lead Professional NoSPHN**

Recipients should not attempt to access hospital case records using information, without the prior consent of the consultant in clinical charge of that person. This applies regardless of whether the patient is currently hospitalised or not.

3. No patient should be approached by a "User" as a result of information supplied, without the prior consent of that patient's general practitioner and the consultant who was responsible for care in the episode selected for research.
4. Any statistics or results of research based on data received should not be made available in a form which
  - . directly identifies individual data subjects
  - . is not covered by the "Intended Use of Data" clause specified on page 1
5. The use of any data for research purposes must have been approved by the relevant Research Ethics Service.

## Sponsors

- . For release of data relating to their own treated patients the relevant consultant should sign the statement.
- . For release of data relating to patients in a specific directorate the relevant Clinical Director / Lead should sign the statement.
- . For release of data relating to patients in several directorates the relevant CHP / Sector Clinical Lead should sign the statement.
- . For release of data relating patients in several sectors the Medical Director should sign the statement.
- . For releases to Health Boards of data relating to their resident population the sponsor should be the Director of Public Health.

Further advice can be obtained from and completed forms should be returned to either:

<b>Health Intelligence Support</b>		<b>General</b>
Jillian Evans	Paddy Hopkins	Pip Farman
Head of Health Intelligence	Head of Health Intelligence	NoSPHN Co-ordinator
NHS Grampian	NHS Highland	NHS Highland
Summerfield House	Assynt House	Assynt House
2 Eday Road	<b>Beechwood Park</b>	Beechwood Park
Aberdeen, AB15 6RE	<b>Inverness, IV2 3BW</b>	<b>Inverness IV2 3BW</b>
Tel: 01224 558551	Tel: 01463 704804	Tel 01463 704789



[jillian.evans@nhs.net](mailto:jillian.evans@nhs.net)    [Paddy.Hopkins@hnb.scot.nhs.uk](mailto:Paddy.Hopkins@hnb.scot.nhs.uk)

[pip.farman@hnb.scot.nhs.uk](mailto:pip.farman@hnb.scot.nhs.uk)

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**For OFFICE use only**

Ad Hoc Number .....

**Release authorised by** .....

## Appendix 3

### **NOS CAMHS: Child populations and service access**

#### **Aims:**

1. To estimate the proportion of the child population of North of Scotland Health Board areas resident within a 150 km radius of Dundee.
2. To explore potential travel times involved in attending services located in Dundee using a Geographical Information System (GIS).
3. To provide illustrative mapping of current Child and Adolescent Mental Health Service (CAMHS) locations across the North of Scotland from information provided by the NOS CAMHS network. The information received has been collated and summarised in Appendix 1

#### **GIS Method**

1. Convert service location postcodes to grid references
2. Define a 150 km zone around the location of Dudhope House in Dundee
3. Assign estimated speeds to the road network
4. Create travel isochrone 'footprints' based upon drive time intervals from Dudhope House in Dundee
5. Assign GRO(S) Small Area Population Estimate 2008 (SAE 2008) for data zones to data zone centeroids.
6. Identify population resident within the 150 km zone and drive time footprint extents using a point in polygon technique of selecting the data zone centeroids completely contained within the areas.

Two types of spatial data were used:

- Road network data (© Meridian 2: scale 100m grid) incorporating all Motorways, 'A', 'B' and minor roads covering the selected area – necessary for calculation of the travel isochrones.

- Scottish Neighbourhood Statistics data zone centeroids were used to georeference population location and to calculate total population numbers within areas.

### Data Attributes

To perform travel time analysis road speeds were applied to each of the road types in two classes (urban and rural) based upon the fastest available route. Travel times were calculated based upon the travel assumptions in table 1. The software used for the generation of the travel isochrones was ArcGIS version 9.3 with the Proterritory extension.

**Table 1: Road types and time travel speeds**

Road type	Rural (Speed - mph)	Urban (Speed – mph)
Motorway	52	34
Trunk	48	28
A Road	45	25
B Road	32	20
Unclassified	24	16
Landfill	6	4

It is recognised that journey times over the same roads may result in very different experience and will be influenced by the behaviour of the individual driver, their vehicle, the amount of traffic encountered, the incidence of road works and that driving conditions and journey times can be affected by the weather. The travel times estimated by a GIS provide no more than an average of likely journey times and the distance that it may be possible to travel within a timescale. In attempting to model regional access to a service this average picture is more useful than the range of possible extremes that may be recalled from personal experience. Other studies have shown GIS estimates of travel time to be closely correlated with actual journey times (Haynes, R et al 2006). It is also known that this association is less strong as journey distances increase and the opportunity to take alternative routes expands. A reality of looking at regional access to service is that travel times can be potentially very

long and will therefore necessarily require journey breaks. For these reasons a ceiling of 120 minutes is applied to the road network analysis.

## **Maps**

Map 1 shows the study area and the drive time footprints generated by the travel network analysis and the 150 km radius centred on Dundee. Location of outpatient and inpatient services are marked by tier classification. These can be cross-referenced against the information in Appendix 1. Map 2 provides greater detail of the travel networks in North of Scotland mainland Board areas. Map 3 provides a cartographic representation of the distribution of the child population aged 12-17 years

## Appendix 4

### **Clinical review: Tier 4 CAMHS for adolescents in Grampian (2001-2006) summarised by public health**

#### **Aim:**

Provide a clinical perspective on the range of intensive/Tier 4 adolescent mental health provision required for 12-18 year olds with mental health problems within Grampian (to include inpatient facilities and other types of intensive provision).

#### **Key issues:**

- Current CAMHS services provided within NHS Grampian do not meet the need for age appropriate intensive treatment for adolescents with severe and disabling psychiatric disorders
- *Local* psychiatric admissions of adolescents (i.e. within Grampian) mainly take place to adult psychiatric wards. Provision is not currently meeting all Mental Health Act requirements
- North of Scotland Planning Group is discussing regional commissioning and provision in the Tayside adolescent inpatient unit. This is an important facility for a relatively small number of adolescents from Grampian but at present not all patients are eligible, admissions are difficult to negotiate, and some are prolonged
- Review of admissions to adolescent units (MH division SEHD) has queried the long average length of stay and whether lack of local intensive treatment services or other factors are contributing

'Tier 4 outpatients' were defined as: outpatients requiring input from more than one team member, and contact more than once per week.

The audit considered the strengths, risks and weaknesses of Tier 4 service provision and need in relation to

- Admission into adult Psychiatric beds
- Admission to paediatric or medical wards
- Provision outwith Grampian
  - Admissions to Dudhope adolescent unit, Tayside
  - Admissions to other adolescent unit or psychiatric inpatient units
  - Private sector beds
  - Very specialist provision may also be referred to other NHS or non NHS providers in Scotland or elsewhere
- Substance misuse residential provision
- Young people with risk behaviours or offending

The audit also looked at the numbers of young people accessing the range of services with a Tier 4 level of need. From a catchment population of 26,922 13-18yr olds, between 12 and 18 teenagers were admitted each year to the Royal Cornhill Hospital, for which CAMHS has provided the RMO cover since 2005, despite a reduced capacity to do so over the last 18 months. Over a similar 5-year period, there were 23 out-of-area admissions (half from Elgin and Banff), principally to either Dudhope House in Dundee or to independent specialist providers for anorexia nervosa.

**Points of note:**

- The Grampian adolescent mental health service is not currently funded to provide a Tier 4 service
- Staff in Tier 3 services can undertake intensive work in the short term only by rescheduling or not responding to less urgent demands. In the medium to longer term, intensive work can be undertaken only by increasing the waiting times for routine patient referrals and reducing the types of other work done. There is inevitably an adverse effect on care of other patients and work with partner agencies.
- Young people with a Tier 4 level of need are likely to be accessing a level of care that falls short of what clinicians best practice would define as a good standard of therapeutic and effective care

## Appendix 5

### North of Scotland CAMHS Project – Data and Information Gathering:

#### January 2008 NHS Highland

Note: The purpose of **form 1**. Is to help gather as accurate as possible, historical information on referral and admissions of Young People (12 – 18 years\*) to either local or out of area establishments, as part of the individuals Mental Health Care and Treatment.

#### Form 1. Admissions

Number of Admissions (inc. re-referrals) to:	2003	2004	2005	2006	2007	Average per year	Average Length of Stay (per episode)
Dudhope Clinic (Dundee)	2	0	0	2	4	1.6	129 days
Other YPUs <i>It would be helpful to identify if admission was required to access a particular speciality, e.g. Eating Disorder, or whether it was on the basis of <b>NO appropriate</b> inpatient facility being available either in the local area or at Dudhope Clinic.</i>	1	1	1	1	0	0.8	503 days
Local Area – Adult Psychiatry wards**	29	28	20	32 (at least one inappropriate)	19	21.8	
Local Area – Adult Medical wards**	None identified						

	ed through SMR0 1						
Out of Area - Adult Psychiatry wards**	1	0	1	0	0	0.4	
Out of Area– Adult Medical wards**	None identified through SMR0 1						
<b><i>**If possible identify between those admissions that were considered appropriately placed in an adult facility and those inappropriately placed due to lack of availability in Dudhope or other optional YPU.</i></b>	Not Possible	Not poss	Not poss	Not poss	Not poss		
Any other comments  In the absence of access to inpatient beds Raigmore Paediatric Ward took CAMHS patients up to 2005 at which point inpatient admissions were stopped due to the ward being assessed as an inappropriate/unsafe setting							



## NHS Grampian: January 2008

Note: The purpose of **form 1**. Is to help gather as accurate as possible, historical information on referral and admissions of Young People (12 – 18 years\*) to either local or out of area establishments, as part of the individuals Mental Health Care and Treatment.

### Form 1. Admissions

Number of Admissions (inc. re-referrals) to:	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	Average per year	Average Length of Stay (per episode)
Dudhope Clinic (Dundee)	2	3	5	1	0	2.2	Estimate 12 months, but do not have the data
Other YPUs <i>It would be helpful to identify if admission was required to access a particular speciality, e.g. Eating Disorder, or whether it was on the basis of <b>NO appropriate</b> inpatient facility being available either in the local area or at Dudhope Clinic.</i>							
<i>Lothian (no Dudhope beds)</i>	1	0	1	2	1		
<i>Huntercombe specialty ED and no Dudhope beds)</i>	0	0	1	0	1		Estimate 6 months but do not have data

Local Area A : Aberdeen - (YPD CAMHs) Adult Psychiatry wards**	10	18	10	15	15		Mean length of stay was 13 days in 2005-6 No further calculated information but no reason to think practice has changed
Local Area B – : Elgin (Rowan centre CAMHs) Adult Psychiatry wards (over 16) or paediatric ward (under 16)**	5	9	12	5	0		Routinely admitted to paediatrics if under 16 and adult psychiatric of over 16 – no separate numbers are available Unsure if this is all under 18's – have asked local CAMHs team to check  No data on mean length of stay
Local Area – Adult Medical wards**							I only have data for Aberdeen local area for 3 year period 2004-2006, obtained by personal

							<p>communication with clinicians : 4 admissions to paediatrics at RACH for mental health reasons and 1 admission to ARI adult medical ward for mental health reason</p> <p>See above re Elgin - unable to provide separate data for paediatric ward admissions</p>
<p>Out of Area - Adult Psychiatry wards**</p> <p>Maudsley (not eligible for Dudhope, no beds anyway , ex patient) Priory (to access specialty ED provision 16and)</p>	0 3	0 7	1 4	1 4	0 6		<p>Priory mean length of stay 6 months 2005-6 and 2006-7</p>
Out of Area– Adult Medical wards**							None as far as I know
<b>**If possible identify between those admissions that were considered appropriately placed in an adult facility and those inappropriately placed due to lack of availability in Dudhope or other optional YPU.</b>							See notes above
Any other comments							

Middlegate lodge – specialty substance misuse (not adult psychiatry)	0	0	3	1	0		
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### NHS Tayside: January 2008

Note: The purpose of **form 1**. Is to help gather as accurate as possible, historical information on referral and admissions of Young People (12 – 18 years\*) to either local or out of area establishments, as part of the individuals Mental Health Care and Treatment.

#### Form 1. Admissions

Number of Admissions (inc. re-referrals) to:	2003	2004	2005	2006	2007	Average per year	Average Length of Stay (per episode)
Dudhope Clinic (Dundee)	10	15	12	6	9	10.4	2003 – 61.2 days 2004 – 206.3 days* 2005 – 91.5 days 2006 – 83.5 days 2007 – 82.5 days
Other YPUs <i>It would be helpful to identify if admission was required to access a particular speciality, e.g. Eating Disorder, or whether it was on the basis of <b>NO appropriate</b> inpatient facility being available either in the local area or at Dudhope Clinic.</i>					3		No beds available in YPU, Dudhope House, Dundee
Local Area – Adult Psychiatry wards**					17		

Local Area – Adult Medical wards**				2		
Out of Area - Adult Psychiatry wards**						
Out of Area– Adult Medical wards**						
<b><i>**If possible identify between those admissions that were considered appropriately placed in an adult facility and those inappropriately placed due to lack of availability in Dudhope or other optional YPU.</i></b>				2		
Any other comments				13		Intensive input from tier 3 Outpatient Service due to lack of beds in YPU.

\* One patient was admitted on 3 May 2004 and was not discharged until 23 May 2007 (1116 days) – figure not accurate due to this

Note: The purpose of **form 2**. Is to help understand the efforts made to manage TIER 4 caseloads of Young People (12 – 18 years)

**Form 2. Tier 4 Caseloads\*\*\***

Category	Estimated Number of TIER 4 patients on CURRENT CAMHS Caseload	Date of Count	Comment
Inpatient – Local Psychiatry			
Inpatient – Dudhope Clinic	Currently 6 inpatients	26.02.08	
Inpatient – Out of Region Psychiatry			

CAMHS involvement AND currently resident in Local Authority TIER 4 equivalent			
Outpatient – Requiring more than weekly appointments, by more than one CAMHS team member			
Inpatient – General Hospital and requiring more than weekly CAMHS input			

**Appendix 6**  
**Summary of Tier 4 Community Service Models**

Service model	Descriptor	Summary of Evidence
<b>Family Preservation</b>	<ul style="list-style-type: none"> <li>• A home based intensive service for families who need additional support beyond typical outpatient services.</li> <li>• It may be used as a step up or step down to inpatient admission.</li> <li>• Services are usually limited to weeks in duration as contact with therapists in intensive.</li> </ul>	<p>One study, randomised control, found that at one year follow up there were more sustained improvements in behaviour and symptom reduction than those in a residential programme. (Kurtz 2009)</p> <p>Not considered by Sheppard et al (2009)</p>
<b>Home treatment</b>	<ul style="list-style-type: none"> <li>• An intensive service for young people with mental disorders who are in crisis and are otherwise eligible for admission to a residential setting.</li> <li>• The key features are 24 hour a day, 7 days a week availability, rapid response time, and the ability to work flexibly with young people, their families and carers and a range of multi agency services.</li> <li>• Studies suggest that just 15% of young people can be safely diverted through this type of service (other than those in exclusion criteria including:               <ul style="list-style-type: none"> <li>○ severe psychosis</li> <li>○ life threatening eating disorders</li> <li>○ families living more than 30kms (20 miles) from a therapeutic unit</li> <li>○ risk taking behaviour.</li> </ul> </li> </ul>	<p>Home treatment was found to be as effective as inpatient treatment across diagnosis in reducing symptom scores and improving psycho social functioning both immediately after treatment and at three year follow up. (Kurtz 2009)</p> <p>For the Homebuilders crisis intervention model, Sheppard et (2009) noted small improvements at short term follow up for behaviour and at six month follow up improved social competency compared to the control group who displayed a greater improvement in self concept.</p>
<b>Case Management</b>	<p>A commonly used strategy for increasing access to and coordination of services within the care system. Tends to be an ongoing service that is not time limited, and endeavours to provide what is needed as it is needed, for as long as is necessary.</p>	<p>Lacks evidence of effectiveness from services in the United Kingdom. (MacDougall et al 2008)</p> <p>Sheppard et al (2009) found no difference in</p>

	<p>Unlike home based services that are time limited, case management is intended to be ongoing, providing young people with whatever they need, whenever they need it, for as long as necessary.</p> <p>The coordination and responsibility of care for an individual child or young person is assigned to an individual practitioner or team</p> <p>Case management can involve a range of different approaches including:</p> <p><b>Assertive out reach</b> Key features of this approach include round the clock/daily availability of the multi disciplinary team within the client's setting. There is an emphasis on assisting the client to manage their illness, assist with daily living, relationship building and crisis intervention. This presents another option for dual/transition services that are based around the needs of the client group rather than professional territory.</p> <p>The key features are a multidisciplinary interventions with small caseloads of young people, 24 hours a day, 7 days a week care and treatment and the availability of crisis intervention services. There is a focus on promoting life skills development, social inclusion and the principles of recovery.</p> <p><b>Intensive case management</b> This approach includes a range of models and typically works with young people with the greatest service needs. The approach focuses on family strengths and empowering families. The case manager acts as an advocate, has oversight of the plan</p>	<p>behavioural or psychological outcomes when reviewing intensive specialist outpatient services compared to those receiving no treatment , inpatient care or generic outpatient care.</p> <p><b>Assertive out reach</b> The evidence for the effectiveness of this approach comes from studies that have included adolescents and young adults (of working age).</p> <p>There is some suggestion that assertive outreach is as effective and safe as inpatient care for young adults with early onset psychosis, is valued by service users and is cost effective (Craig et al 2004; Killapsy et al 2006.)</p> <p><b>Intensive case management</b> Some models have been shown to have greater impact than others, and there is a view that this approach can lead to a revolving door approach to</p>
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	<p>and brokers between services.</p> <p><b>Wrap around</b>  Wraparound services are designed to help families develop a plan to address needs at home and at school. The services are provided through teams that implement comprehensive support plans. These aim to link children, families or carers and their support networks with health, social services, education and youth justice services.</p>	<p>inpatient and community services. Models with a full time case manager have been shown to be more satisfactory to clients with significant reductions in length of inpatient stay. (Kurtz 2009)</p> <p><b>Wrap around/therapeutic foster care</b>  Research on the effectiveness of this model is at an early stage with a range of findings on effectiveness and cost compared to other models. (Kurtz 2009)</p> <p>Some work suggests that this model of brokering services results in significant behavioural improvements, reduces time spent in hospital and may be as effective yet cheaper than treatment foster care. (MacDougall et al 2008)</p>
<p><b>Multi systemic therapy</b></p>	<p>This is protocol driven and involves an intensive family based approach to young offenders with serious anti social behaviour who were at risk of out of authority placement. The primary aims of MST are to:</p> <ul style="list-style-type: none"> <li>• reduce criminal activity</li> <li>• reduce antisocial behaviour eg. substance misuse and violence</li> <li>• decrease rates of incarceration, out of home placements and hospital admission.</li> </ul> <p>MST has also been studied as an alternative to inpatient admission for young people in psychiatric crisis.</p> <p>MST teams provide 24 hours a day, 7 days a week services for a caseload</p>	<p>There is a convincing evidence base in addressing the needs of young offenders with associated savings. (Kurtz 2009)</p> <p>Although for a significant number of young people MST is not appropriate, for some this intervention may be more effective than admission (Henggeller et al., 1999).</p> <p>Sheppard et al (2009) noted that although there were differences in outcomes the majority of these were not significant.</p>

	<p>of 4-6 young people aged between 10 and 17. Each treatment lasts 4-6 months and there is an average of 60 hours of contact during the treatment period. During this time the MST team provides a range of systemic interventions that address high risk personality traits associated with conduct disorder and antisocial personality disorder. The MST team will also provide interventions to tackle offending.</p> <p>MST does not have a unique set of intervention techniques; instead, intervention strategies are integrated from other pragmatic, problem focused treatment models including strategic family therapy, structural family therapy and cognitive behavioural therapy. MST is distinguished from other intervention approaches by its comprehensive conceptualisation of clinical problems and the multi-faceted nature of the interventions.</p>	
<p><b>Treatment foster care</b></p>	<p>This involves structured therapy within a foster family setting for young people with emotional or disruptive behaviours. Multi-dimensional treatment foster care is based on social learning theory, and comprises of structured therapy within a foster family setting and is delivered within a multi agency context.</p> <p>Treatment foster care services recruit, train, supervise and support foster families, who usually look after only one fostered child for a period of 6 to 9 months.</p> <p>Treatment foster care differs from standard foster care in several ways. This includes providing a detailed functional analysis and close monitoring of the child or young persons behaviour, providing substantial training and supervision for foster parents by case managers,</p>	<p>Treatment foster care has a relatively strong evidence base. The intervention appears to produce a reduction in symptoms and lowers rates of offending for mentally disordered and young offenders respectively compared to inpatient care groups (Chamberlain, 2002; 2003).</p>

	<p>and emphasizing therapy.</p> <p>Factors that improved the outcomes were the amount and type of supervision, consistency of parental discipline, presence of a close and confiding adult and not being closely linked with delinquent or deviant peers</p>	
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