

## CHAPTER 6

### SERVICES FOR PEOPLE WITH SPECIAL NEEDS

6.1 The Review recognises that most people with mental health problems receive services exclusively at the Primary Care level. For people with more complex and more enduring mental health needs Mental Health Services are required. There are, however, a number of specific mental health problems which cannot be fully addressed at either the primary or secondary care levels, usually because interventions are necessary which require specialist skills and specialist services. In this section of the Framework, the needs of people requiring such specialist services are addressed. We have identified seven specific areas:

- People with eating disorders
- People with brain disease or injury
- Deaf people with mental health needs
- People with mental health needs arising from psychological trauma
- People with personality disorders
- Able adults with Autistic Spectrum Disorders
- People with disorders of gender and sexuality

6.2 While recognising that forensic services and services for people with substance misuse or alcohol related health problems are also specialist services, these are established and are the subject of specific independent reviews, to be reported on separately. The interface between community and primary care and secondary care services with these services are dealt with in Chapters 3, 4 and 5.

6.3 Some of the services being considered, for example eating disorder services, are currently the subject of DHSSPS initiatives. In others, for example services for people with brain disease or injury, aspects of service development are already in progress. Nevertheless, the needs of people with more severe and often protracted mental health problems still require to be addressed.

- 6.4 A common aspect to the service requirements of people with special needs is a tiered approach to provision. That is, there are needs that can be met at a local level, whether community or primary care (tier 1). Other needs can be met within local community mental health services (tier 2). However for some individuals, some or all of their needs can only be met through highly specialised services (tier 3 and 4).

## **SERVICES FOR PEOPLE WITH EATING DISORDERS**

### **The Nature and Extent of the Issues**

- 6.5 The National Service Framework for Mental Health recognises the potentially serious nature of eating disorders.<sup>1</sup> Nevertheless service provision in many parts of the UK remains inadequate.<sup>2,3</sup> and the National Institute of Clinical Excellence (NICE) has recently prepared draft treatment guidelines.<sup>4</sup>
- 6.6 Within Northern Ireland there have been new initiatives to develop eating disorders services.<sup>5,6</sup> and service development is part of the Department's Priorities for Action for 2003/4<sup>7</sup>. A Regional Eating Disorders Working Group (REDWG) has been established to oversee implementation. The Review of Mental Health and Learning Disability (Northern Ireland) and the REDWG is being coordinated towards the common goal of establishing adequate eating disorders services.
- 6.7 Eating disorders include anorexia nervosa (AN), bulimia nervosa (BN) and the atypical eating disorders which incorporates binge-eating disorder. Obesity can be an associated condition. There is significant overlap between the main categories<sup>8</sup> and on the whole, current classificatory systems should be seen as continually evolving.
- 6.8 Major physical complications can arise from extreme low weight as well as bingeing/purging behaviour.<sup>9</sup> Anorexia nervosa has the highest mortality of any psychiatric illness.<sup>10</sup> Most deaths result from direct medical complications or suicide.<sup>11</sup> Other mental health problems often co-exist especially depression, anxiety disorders, substance misuse and personality disturbance.<sup>12,13,14</sup> Social consequences include impaired interpersonal, educational and occupational functioning and whole families can come under intense pressure. Overall, the eating disorders and their complications pose considerable challenges<sup>15</sup> and proper assessment and management

involves a multidimensional, multidisciplinary approach which takes into account all aspects of the condition.

- 6.9 **Distribution.** The estimated prevalence of anorexia nervosa is 10-30 per 100,000 total population (0.7% in teenage girls) and of bulimia nervosa is 100 per 100,000 total population (1-2% in 16-35 year old females). Incidence of anorexia nervosa is around 4-20 per 100,000 total population per year and of bulimia nervosa, 10-30 per 100,000 total population per year.<sup>8,16</sup> About 90% of anorexia nervosa sufferers are female; the clear female preponderance in bulimia nervosa is of less certain proportion.
- 6.10 The distribution of the atypical eating disorders is largely unknown although there is a suggestion that it is the most frequently encountered eating disorder in clinical practice.<sup>8</sup> There is a general view that eating disorders have become more prevalent over recent decades. This may be true for bulimia nervosa<sup>17</sup> but there may be alternative explanations for the apparent increase in anorexia nervosa such as greater help-seeking and improved detection.<sup>18, 19</sup>
- 6.11 **Local Needs Assessment.** There is a lack of information regarding the distribution and service needs of people with eating disorders in Northern Ireland. This has been recognised and the REDWG has commissioned a Needs Assessment to address this issue. In general, services in Northern Ireland were found to be lacking in the Royal College of Psychiatrists' survey.<sup>3</sup>
- 6.12 The following is an estimation of the number of sufferers within the Province using indicative figures and some survey findings: new cases per year – anorexia nervosa: 68-140; bulimia nervosa: 170-510; existing cases at any one time – anorexia nervosa: 170-510; bulimia nervosa: ~1700.
- 6.13 From a hospital admission/discharge survey for the period 1996/7-1998/9, the average number of admissions was approximately 100/year with an inpatient demand of about 9.5 places/year. Twenty-six patients were referred to specialist units outside Northern Ireland, on average accounting for approximately 2 places/year.<sup>5</sup> The Eating Disorders Clinic in Belfast (serving mainly the Greater Belfast Area) has

approximately 175 patients on the team (3 members) caseload and there is currently a 6 month new patient waiting list. Over the past year, there have been on average 13 new referrals/month. In a small primary care survey, 15% of the sample population were found to be at high risk of suffering from an eating disorder.<sup>20</sup> The Eating Disorders Association (EDA) in Belfast reports high rates of contact with enquirers, a significant number seeking therapy which they themselves are unable to provide. In their first year of operation (2002/3), the EDA received 373 phone calls from sufferers and had 322 visits; only 25% of these cases were already receiving treatment (EDA, personal communication).

- 6.14 **Current Services.** Local service provision was reviewed by DHSSPS.<sup>5,6</sup> The lack of services was recognised (e.g. no inpatient or daypatient facilities) as well as the geographical imbalance of services. This has led to over-reliance on costly extra-contractual referrals to England (for example, in the Eastern Health and Social Services Board, the estimated cost of such referrals for the financial year 2003/4 is in excess of £600,000). The ability to provide training is limited. Services in general can be uncoordinated.
- 6.15 The Eating Disorders Clinic based at the Department of Psychotherapy in Belfast has had to restrict its catchment area to Greater Belfast, and some second opinions, due to service demand. It is currently supervised by a Consultant Psychotherapist and has 1 H grade Clinical Nurse Specialist, 1 Senior House Officer in Psychiatry and 1 Secretary providing administrative back-up. There is limited support and training to voluntary organisations. In the Western Board, an interagency partnership known as Eating Disorders West is endeavouring to realise the development of specialist services in that region.
- 6.16 The majority of sufferers are currently treated in non-specialised services including child and adolescent services, generic mental health teams, acute inpatient settings and at primary care level. Within these settings, there may be practitioners who have a particular interest in working with patients with eating disorders. There can be difficulty managing acute medical complications as there is no designated physician with a particular interest/responsibility in this area. There are several independent organisations (EDA, ADAPT Eating Distress Association (based in Lurgan) and

Derry Well Woman) who have an important part to play in terms of support, education, early detection and prevention. Parents/carers have a crucial role in the process of aiding recovery.

### **A Vision for Services**

6.17 **Treatment Guidelines.** There are now several evidence-based treatment guidelines informing what should be provided by a local service.<sup>4, 21, 22, 23</sup> Some general principles underpin the management of eating disorders:

- comprehensive assessment embracing medical and psychosocial aspects (including risk assessment of self-harm and suicide);
- individualised treatment plans tailored to the nature and severity of the condition;
- given the nature of eating disorders and their tendency to a long and fluctuating course, the level of medical and psychological risk requires to be monitored throughout treatment;
- whilst the majority of service users can be satisfactorily treated as outpatients, inpatient care is essential at times of medical crisis or if there is a significant risk of suicide; admission should be viewed as a preliminary to subsequent outpatient treatment; and
- the service user's willingness to seek help and work towards change is essential; initial motivational work may be required before further therapy can be effective.

6.18 In anorexia nervosa, there is a paucity of research-supported interventions. Nutritional rehabilitation is a clear priority; where and how this is conducted depends somewhat on the level and rate of weight loss, physical complications and the service user's level of motivation. There is some evidence for a family-based intervention that seems to be of most help to younger service users.<sup>24</sup>

6.19 Other structured psychological therapies that have been recommended include cognitive-behavioural therapy (CBT), interpersonal therapy (IPT), cognitive analytical therapy and psychodynamic therapy. Pharmacological interventions appear to have little direct benefit although there are preliminary reports of fluoxetine helping to reduce risk of relapse in service users whose weight has recently been restored.<sup>25</sup> Psychotropic medication may be necessary when other mental health

problems are present although there needs to be caution with their use due to the physical vulnerability of this patient group.

6.20 There is much more research evidence for treatment interventions in bulimia nervosa. As before, physical stabilisation may be the immediate concern, particularly management of electrolyte disturbance. A specific form of CBT (CBT-BN)<sup>26</sup>,<sup>27</sup> appears to be the clear treatment choice<sup>28</sup> although the availability of trained therapists can be a limiting factor in its delivery. Modified, self-help versions of this can be useful in less severe cases.<sup>29, 30</sup> There is some evidence that ITP could be as effective as CBT-BN but may take considerably longer to work.<sup>31, 32</sup> Antidepressant drugs (particularly higher-dose fluoxetine) seems to have a rapid antibulimic effect although apparently not as great as CBT-BN and possibly not sustained.<sup>21</sup> Combining CBT-BN with antidepressant drugs does not appear to lead to the kind of enhanced efficacy that might be instinctively expected.<sup>33</sup>

6.21 There is little research to guide decisions in the treatment of the atypical eating disorders; the general advice is to treat according to which of the above conditions the presentation most resembles. The treatment of binge eating disorder appears to be developing along the lines of treatment for BN with CBT-based approaches and the use of SSRIs.

6.22 Recent work has looked at the common mechanisms underpinning the maintenance of the various eating disorders and how an extended form of CBT may be more broadly effective. This approach may lead to clearer formulation of the eating disorders and to a modular form of CBT becoming the central psychotherapeutic intervention.<sup>34</sup>

6.23 **Principles of Service Provision.** An Eating Disorders Service must provide comprehensive care in terms of:

- adequate multidisciplinary staffing with good skill mix;
- treatment across the age range, with co-operation between Child & Adolescent and Adult services;
- range of conditions at different severities being treated within appropriate settings;

- range of treatment modalities offered: physical (medical/dietetic), psychosocial; individual/group/ family approaches; and
  - interventions at various stages of the illness (from prevention to management of chronicity) with overall accessibility at an appropriate level.
- 6.24 Whilst there should be clear boundaries of responsibility between different components of the service, there needs to be effective communication and interagency coordination. This includes good training, supervision and advice from specialist services. In many instances, there will be shared care between two or more parties.
- 6.25 An efficient service has a dynamic character: patients can change in terms of their illness profile and will move across different domains of the service according to their needs and there is flexibility among staff as regards their roles and responsibilities. The system itself must be able to respond to the changing needs and to evolve as improved methods of service delivery become evident.
- 6.26 **A Model for Service Provision.** A model for service delivery was proposed in the 2002 Consultation paper following discussion and review of models elsewhere; feedback was summarised in the DHSSPS response in 2003.<sup>5,6</sup> The model then suggested was that of a ‘hub and spoke’ specialist service well supported by local initiatives. The service is a tiered structure that is able to provide a stepped level of care according to patient need:
- 6.27 a. **Tiers 1 & 2. Community/Primary Care & Generic Secondary Mental Health Services.** Many patients can be managed at these levels where health promotion and early detection and intervention become key areas of focus. Levels of intervention include psychoeducation, guided self-help and basic psychological interventions. GPs have an important role in monitoring the physical state of service users. Mental Health Services may be necessary if other significant mental disorders co-exist. The voluntary agencies have an important role to play in providing information, support and advocacy as well

as being an avenue through which families and carers can contribute effectively.

- 6.28 **b. Tiers 3 & 4: Specialist Community/Outpatient/Day Hospital Provision and Specialist Inpatient Services.** The main roles of this service would include the assessment and management of more severe and complex cases; the provision of structured specialised therapies; teaching, training and supervision (supporting and building up Tiers 1 & 2); taking a lead in audit and research; overseeing the function and development of the overall service.
- 6.29 The proposed future structure of specialist services is to have locally accessible services linking with a single regional outpatient/day patient service.
- 6.30 In the longer term consideration is currently being given to the option of establishing local inpatient services. The cost of such a unit may be prohibitive both in absolute terms and in relation to its effect on other levels of the service. There is currently a lack of experienced professionals who could staff the unit. Nevertheless, the longer term view is that there needs to be a phased approach towards developing local inpatient services. Until then, specialist inpatient services could continue to be provided by units outside the Province, with a preferred provider being identified. Even so, there is still a need to have local access to general medical wards where medical complications can be managed and to acute psychiatric units when this is necessary.

### **Supporting Change**

- 6.31 The establishment of eating disorders services in Northern Ireland is a major task. However, the current lack of services may well provide the opportunity to develop new services in a planned, coordinated way, drawing upon the experience of others and recognised treatment guidelines. The proposed service has been presented in outline; there is much developmental work still to be done.
- 6.32 There are major implementation issues related to funding, manpower and training and the development of infrastructure. Clear management protocols and referral pathways

need to be produced that will clarify the roles and responsibilities of the various components of the service.

- 6.33 The responsibility for developing services rests with many stakeholders including service planners and purchasers, clinicians and voluntary agencies. It is important to emphasise that the creation of specialist services needs to be accompanied by the development of local and community services.

### **Recommendations**

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| <p>183. A network of people interested in and committed to developing services must be established – this is already underway through the formation of the REDWG.</p> <p>184. Service planning must involve clinical leaders, users and carers and clinical managers.</p> <p>185. Assessment of need must be undertaken with the specific goal of informing service development.</p> <p>186. Further work needs to be done to develop the proposed service model. This should include further consideration of good practice models elsewhere and advice from experts on service level interventions.</p> <p>187. The recruitment, training and retention of qualified staff to work within the service should be taken forward as a matter of urgency.</p> <p>188. A core specialist team should be trained to provide a specialist service and support and train non-specialist practitioners; the creation of specialist posts must be prioritised.</p> <p>189. Tiers 1 &amp; 2 of the service should to be strengthened in tandem with any specialist services; the development of locally-agreed management protocols and referral pathways must be established.</p> <p>190. The development of regional inpatient services, although a longer-term goal, should be planned for in a strategic and coordinated manner.</p> |
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## SERVICES FOR PEOPLE WITH BRAIN DISEASE OR INJURY

### The Nature and Extent of the Issues

- 6.34 There is growing recognition of the mental health needs of adults with neurological conditions affecting higher cerebral functions, including acquired brain injury (arising from trauma, haemorrhage, anoxia, infections, toxins, nutritional deficiency, epilepsy) and brain disease (eg Multiple Sclerosis, Parkinsons Disease, Huntington's Disease, early onset dementias).
- 6.35 Such neurological conditions can lead to a range of impairments in physical functioning (eg spasticity, disturbance of gait, sensory impairment), cognitive functioning (eg attention, language, memory, planning, judgement) and emotional and behavioural functioning (eg anxiety, depression, personality change, irritability).<sup>35</sup> Impairments in functioning can result in reduced independence in personal care and activities of daily living (eg hygiene, dressing, cooking, cleaning). They frequently impact negatively on social and family relationships and upon the individuals ability to return to work or engage in socially meaningful activity.<sup>36 37 38 39</sup>
- 6.36 A significant number of those with neurological condition will have significant and continuing health care needs over a long period of time.<sup>40</sup> It is difficult to obtain reliable estimates of prevalence of disability, following these disorders. Such information is vital in planning healthcare and the community support/services required. Local research estimates the prevalence of people with moderate and severe psychological and physical disability following traumatic brain injury and subarachnoid haemorrhage to be 66 per 100,000 and suggests that the presence of moderate and severe psychological impairment is the best predictor of long term social disability.<sup>41</sup>
- 6.37 Cognitive, emotional and behavioural deficits post injury are key predictors of negative outcome in terms of recovery, rehabilitation and community reintegration. These determine the extent to which an individual is able to adapt to their changed functioning and develop a positive quality of life.<sup>42</sup>

- 6.38 People with neurological conditions are at greater risk of mental health problems, particularly depression, anxiety and psychosis. These can go undiagnosed and untreated, impacting negatively on morbidity and mortality. Estimates of incidence and prevalence of various mental health conditions varies widely, reflecting differing definitions adopted in studies.<sup>41-48</sup> Families of people with brain injury suffer considerable emotional distress and burden which can have a considerable impact on their own mental health. They are at greater risk of mental health problems than the general population. Family stress is associated with coping with personality and behavioural change rather than in coping with physical and cognitive impairments in a relative.<sup>49--53</sup>
- 6.39 A biopsychosocial approach to understanding and managing the emotional and mental health problems associated with neurological conditions is essential.<sup>54</sup> A range of treatment options, both pharmacological and psychological are developing to address mental health needs.<sup>55-58</sup>

### **Service Provision**

- 6.40 At present there is limited specialist service provision dedicated to addressing the mental health needs of people with neurological conditions. Two services operate at a Board/Regional level but are currently underdeveloped.
- 6.41 A Regional Neuropsychiatry Service based at Belfast City Hospital. This is mainly an outpatient service, providing both new patient assessment and review clinics. A liaison service is also provided, receiving tertiary referrals, predominantly from psychiatry, neurology and neurosurgery.
- 6.42 Maine Neurobehavioural Unit, based in Knockbracken Healthcare Park, South & East Belfast Trust. This unit has developed to address the needs of people with acquired brain injury or disease who have severe and persistent behaviour problems. The unit provides short term admissions for assessment, slow stream rehabilitation/recovery and long term care for those whose behaviour cannot be met in other settings. The unit has provided a focus on this subgroup of those with acquired brain injury who present with severe challenging behaviours. It has demonstrated the utility of a

multidisciplinary approach in providing a therapeutic milieu, individual behavioural management and skills development programmes.

- 6.43 The majority of mental health needs following brain injury are addressed through: mainstream brain injury rehabilitation services (e.g., Royal Victoria Hospital Neurosurgical Unit, Forster Green Hospital, Joss Cardwell Centre, Community Brain Injury Teams in NHSSB/WHSSB/SHSSB/Down & Lisburn Trust); local community services (e.g., Primary Care Services, Social Services and local Mental Health Teams)
- 6.44 A number of non-statutory services provide support to carers, social reintegration programmes, prevocational and vocational skills training and supported living. The work of these organisations involves attention to the emotional and mental health needs of their clients.
- 6.45 Consultation with service users and carers, local service providers and individual professionals, highlights a number of problems with current service provision in addressing mental health needs. Local experience is consistent with reports concerning service provision and mental health needs throughout the United Kingdom.<sup>59 60</sup>
- 6.46 A number of common issues arise:
- **Service Requirements.** There is a lack of appropriate residential and supported living options with appropriate expertise and levels of staffing. There is also a lack of ability within services to respond rapidly to crisis situations in the community. Lack of support for families and carers.
  - **Specialist Support to Local Services.** There is presently a lack of adequate levels of specialist expertise to support local services dealing with emotional and behavioural problems.
  - **Training Needs of Staff.** There is a need for greater education of staff with regard to the emotional, cognitive, behavioural and mental health needs of people with neurological disorders affecting higher cerebral function. Lack of awareness of patient vulnerability can lead to poor care planning, inappropriate placements, lack of adequate support, crisis situations and poorly managed risk.

- **Services Responsibility.** Situations can arise where there is lack of clarity regarding responsibility in terms of local vs specialist services, or where there is co-morbidity or where an individual's needs cut across programmes of care.

### **Proposals**

6.47 It is proposed that a tiered approach as delineated by the HAS<sup>60</sup> be adopted as a model for understanding and planning service responses to meet the mental health needs of people with acquired brain injury. Adopting this framework, the key service elements required to address the mental health needs of people with neurological disorders are:

6.48 **Tiers 1 and 2: Local Primary Care Services and Local Mental Health Services.**

The majority of mental health needs of people are dealt with by local primary care services, and local mental health services and day care services, with specialist input where appropriate, from neuropsychiatry and community brain injury teams.

6.49 **Tier 3: Community Based Specialist Services Brain Injury Teams.** These teams focus on community based services promoting recovery and community reintegration and have demonstrated effectiveness in this area.<sup>61</sup>(Type 2 evidence). They work directly with the patient and family and in collaboration with local statutory and non-statutory services.

*Good Practice Example*

***Down and Lisburn Trust Community Brain Injury Team.** This team comprises a group of professionals who adopt an interdisciplinary approach in addressing the community based services promoting recovery and reintegration needs of people with acquired brain injury. The team works with the person with brain injury, their families and carers. (Contact: 028 92663572)*

### **Services to Support Community Living**

6.50 Specialist residential and supported living facilities are required to address the needs of those with neurological conditions, who present with emotional, cognitive, behavioural and mental health problems in order to enable and sustain community living.

*Good Practice Example*

**Redford Court, Toxteth, Liverpool.** *This is a supported living facility for people with ongoing emotional and behavioural problems, who require intensive support to maintain community living. The facility is run by the Brain Injury Rehabilitation Trust. The Trust offers a range of services for people with brain injury, including residential assessment, rehabilitation and training, transitional living units, individual outreach options and long term care. Each of these services is supported by a specialist multidisciplinary clinical team. (Contact: 0151 2808181).*

- 6.51 **Tier 4: Regional Specialist Services - Regional Brain Injury Services.** The majority of mental health needs arising for people during recovery are dealt with directly by the rehabilitation team in the context of a specialist rehabilitation unit. Services promoting recovery aims to optimise functioning across physical and cognitive domains. Teams have expertise in the assessment and management of problems in the individual and in managing family stress, coping and adjustment. Sessional input to the team from neuropsychiatry is required to address mental illness, e.g., depression, psychosis or complex behaviour problems, e.g., irritability and aggression.

*Good Practice Example*

**Forster Green Hospital Ward / Joss Cardwell Unit.** *Provides multidisciplinary inpatient and outpatient brain injury rehabilitation. Plans are ongoing for the development of a purpose built 25 bed unit on the Musgrave Park Hospital site. (Contact: 028 90793681).*

- 6.52 **Promoting Neurobehavioural Recovery.** These services are required by people whose behaviour difficulties are so severe that they cannot be managed in a conventional unit. Services offer multidisciplinary mental health support, assessment, treatment, services promoting recovery of function and role, respite and crisis care. They focus on reducing the behaviour deficits that impede community placement. Teams generally comprise neuropsychiatry, neuropsychology, specialist occupational therapy, physiotherapy, speech and language therapy, social work and RMN trained nursing staff.

*Good Practice Examples*

**York House, Brain Injury Rehabilitation Trust, York.** *A neurobehavioural service for acquired brain injury. York House is a 14 bedded neurobehavioural rehabilitation unit which provides an intensive neurobehavioural assessment and rehabilitation service for individuals with severe mood disturbance and challenging behaviour following acquired brain injury. The unit specialises in the management of people with challenging behaviour and is able to take referrals for people detained under the Mental Health Act. All clients have access to an intensive programme of rehabilitation and recreational activity, which seeks to restore independence as far as possible. Staffing levels are high and for some people a programme of one to one support is available. (Contact: 01904 412666).*

**Robert Ferguson Unit, Royal Edinburgh Hospital, Edinburgh Healthcare NHS Trust.** *This unit is the National Neurobehavioural Rehabilitation Unit for Scotland. It addresses the needs of those people who suffer severe behavioural complications after acquired brain injury. It operates on the basis of a multidisciplinary team, which a high staff-patient ratio and provides slow stream rehabilitation in preparation for community reintegration and continuing care. (Contact: 0131537 6214).*

**The Kemsley Unit, St Andrews Hospital, Northampton.** *Provides specialised rehabilitation for adults with non-progressive acquired brain injury, with challenging behaviours, including physical aggression, who are excluded from conventional rehabilitation settings. In addition, physical, emotional and cognitive and other behaviour problems may be present. The service offers a continuum of care ranging from secure facilities and highly structured rehabilitation, hospital based transitional living, community based transitional living and case management for individual clients. (Contact: 01604 29696).*

### **Neuropsychiatry Service**

- 6.53 A Neuropsychiatry service is required to offer expertise in the assessment, diagnosis, treatment and management of mental health problems in people with acquired neurological conditions, including epilepsy. This service should provide direct input to the care of people with complex mental health problems, together with a consultation/liaison role to a range of medical specialties, eg neurology, neurosurgery, rehabilitation medicine, psychiatry and to specialist community based services.

### **Recommendations**

191. Services should be developed to address the needs of carers and families including partnerships across statutory and non-statutory sectors.
192. Emphasis should be placed on the development of day care, respite, residential and supported living for people who present with emotional, cognitive, behavioural and mental health problems.
193. Priority should be given to the establishment and development of brain injury teams throughout Northern Ireland.
194. A consultant neuropsychiatry post should be established to provide input to the regional brain injury unit, to the neurobehavioural unit and a liaison role to acute hospital settings, local mental health services and community brain injury teams.
195. A neurobehavioural unit should be enabled to develop as a regional specialist service. This might provide services on an all Ireland basis.
196. A workforce strategy is required to ensure that there are sufficient numbers of appropriately qualified staff, across the range of disciplines, required to enable service developments in this area.
197. Attention to skill mix and opportunities to develop new job roles is required.
198. Attention to the training and ongoing development needs of specialist staff is required. A training strategy should be developed.
199. Formal links between brain injury services are essential for staff development and service networking.

200. Opportunities for collaborative working amongst professional groups across specialist brain injury services should be pursued by joint appointments, staff rotations, staff placements.
201. Specialist services should provide training and support to local community services and to care staff working in acute hospital, residential and day care settings.
202. Service planning must involve clinical leaders, users and carers and clinical managers.
203. Information including local data is required to plan and develop services sensitive to need. An information strategy is required.
204. The development of care pathways is required to develop links and networks between different services and service components.
205. Partnerships between statutory and voluntary sectors and within statutory sector organisations (health, housing, education, employment and training) should be pursued, to ensure a comprehensive range of service provision.

## **SERVICES FOR DEAF PEOPLE WITH MENTAL HEALTH PROBLEMS**

### **The Nature and Extent of the Issues**

- 6.54 It is estimated that 1 in 7 of the general population has some degree of hearing loss <sup>62</sup> Between 1 in 1000 and 1 in 1500 people are profoundly deaf from early life. Although more than 90% are born into hearing families, many grow up to use Sign (British Sign Language, BSL or Irish Sign Language, ISL) as their first or preferred language, and identify themselves as members of the Deaf Community. Deaf children, particularly those in hearing families, can face many obstacles during development. The diagnosis of deafness may be delayed, though the advent of neonatal screening should address this.
- 6.55 The UK Government has recognised British Sign Language as a language in its own right in Great Britain. Similar formal recognition of both BSL & ISL was announced by Paul Murphy, Secretary of State for Northern Ireland on 29<sup>th</sup> March 2004. This is an important development for the Deaf Community.

- 6.56 Digital hearing aids, cochlear implants and vitally, opportunities for early access to sign language should prevent the significant and potentially permanent language delays and deprivations characteristic of the recent past. Many deaf adults have had limited educational opportunities and may have poor literacy, which limits their access to written information, including television subtitles.
- 6.57 **Deaf People and Mental Health.** Deaf people encounter the same range of mental health problems as the general population. However, they are also at increased risk of having complex and organic disorders, as many of the non-genetic causes of deafness, such as maternal rubella, neonatal jaundice, prematurity, birth anoxia and meningitis, can be associated with a range of physical, sight and neurological problems.
- 6.58 A significant minority of deaf people are deaf/blind and their mental health needs are also complex.<sup>63</sup> Psychiatric illnesses such as schizophrenia<sup>64</sup> and affective disorders are the same in deaf as in hearing people, but are associated with difficulties in diagnosis.<sup>65</sup>
- 6.59 The developmental difficulties and social pressures affecting many deaf children give rise to an excess of emotional, behavioural and adjustment problems (40-50% compared with 25% for the general population) which can continue into adult life<sup>66 67</sup>
- 6.60 **Mental Health Services for Deaf People.** Deaf people, particularly sign language users, have considerable difficulty in gaining access to health promotion programmes and the whole range of medical services. There are however, some good examples of good practice in this area.

*Good Practice Example*

*Deaf Connections* recognised that traditional methods of health promotions were not reaching members of the Deaf Community effectively and what was required was to work directly with deaf people to identify their health needs and prepare programmes to tackle these. Training and support are provided

*to enable workers with the deaf deliver a range of health programmes to the Deaf Community. (Contact: 0141 4202820)*

- 6.61 Prelingually deaf people experience unacceptable rates of misdiagnosis and unjustified long-term admission in psychiatric hospitals often without their informed consent and are additionally afforded inappropriate treatment. Appropriate treatment is dependent upon diagnosis, which in turn is dependent upon accurate communication.<sup>68</sup>
- 6.62 **Communication.** Adequate communication is essential for effective mental health assessment and treatment. Sign language interpreters are essential if clinicians do not sign. Even so a service user's signing may be poorly developed, idiosyncratic or affected by mood or thought disorder. An interpreter can only say if effective communication is not taking place – he or she is not trained or empowered to assess or comment on a person's signing. Deaf professionals in mental health services therefore are the most appropriate people to facilitate or assess communication in these circumstances.

*Good Practice Examples*

***National Deaf Services**, South West London & St Georges, Mental Health NHS Trust, London, (Contact: 020 86826925)*

***National Centre for Mental Health & Deafness**, John Denmark Unit Manchester, (Contact: 0161 772 3400)*

***National Deaf Mental Health Services**, Denmark House, Queen Elizabeth Psychiatric Hospital, Birmingham. (Contact: 0121 678 2005)*

***RNID Community Support Worker**, Ulster Hospital & Community Trust RNID (NI) in partnership with Ulster Hospital & Community Trust employees or Deaf Community Support Worker to support Deaf people with mental health problems and learning disabilities in the community. (Contact: 02890 239619)*

## **A Vision for Services**

### **Specialist Mental Health Services for Deaf People**

- 6.63 With the introduction of the Disability Discrimination Act (1995) and the modernisation of Mental Health Services, particularly the development in community based provision, there is an opportunity to address issues of equality of access, and the needs of minority and excluded groups. The Department of Health Consultation document “Sign of the Times”<sup>69</sup> outlines proposals for future developments for deaf mental health services. There should be a tiered approach to the provision of mental health services for deaf people.<sup>70</sup>
- 6.64 Outreach Clinics in Northern Ireland from the Salford specialist service have provided assessment and treatment, and patients have been admitted to their beds. Teaching, liaison and joint working have established a basis for further local service development. The recent appointment of a part-time specialist consultant psychiatrist in Northern Ireland and the planned appointments of other team members, including a full time community psychiatric nurse, create an opportunity to offer locally based clinics and community services. The planning of future services will include consultation and involvement of service users and carers.
- 6.65 **Primary Care Services.** Patient access to primary care should be improved to comply with the implementation of the Disability Discrimination Act (1995). Deaf awareness training, technology such as loops and text phones, and access to interpreters should facilitate assessment and referral by GPs. At present Social Workers for deaf people initiate many psychiatric referrals. These need to be channelled through GPs, as for hearing people, but with joint working as required.

#### *Good Practice Example*

*Nottingham and Bristol are developing locally based Mental Health Services for deaf people, through specialist senior CPN’s and Approved Social Workers so that appropriate assessment and treatment can be facilitated at*

*primary, secondary and tertiary level. (Contact: Nottingham 0115 948 3268 and Bristol 0117955 6098)*

- 6.66 **Hospital Inpatient Facilities.** Hospital inpatient facilities are required for a small number of clients with more acute mental health problems<sup>71</sup>. Consideration should be given to developing such a facility on an All-Ireland basis.<sup>72</sup>
- 6.67 **Deafened and partially hearing people.** Specialist deaf services should have a low threshold for assessments, including for deafened or partially hearing people, in any circumstance where a mental health problem is suspected, and the persons deafness is significant to him or her. Mental health input to rehabilitation programmes for deafened people is essential to address the additional stresses due to anxiety and depression which frequently occur.

*Good Practice Examples*

***Link Centre, Eastbourne** – provides specialist rehabilitation to deafened adults through intensive rehabilitation programmes. (Contact: 01323 638230)*

***RNID (NI) Rehabilitation Project** – initially targeting people deafened as a result of NI Troubles. (Contact: 02866 329849)*

- 6.68 **Training.** There is clearly a need for training of mental health workers in the psychological, sociological and psychiatric aspects of deafness<sup>73</sup> and the training of staff as mental health professionals.

*Good Practice Examples*

***Manchester Metropolitan University** run a five-year distance learning **Masters of Arts in Social Work with deaf people**. This course is open to both hearing and deaf students. (Contact: 0161 247 2112)*

***The University of Salford's Deaf Peoples Access to Nurse Education Project** has created an educational environment that has enabled deaf people to become qualified mental health nurses. (Contact: 0161 295 2769)*

## Recommendations

206. There should be a tiered approach to the provision of Mental Health Services for Deaf People.
207. Service User and Carer involvement in planning and monitoring services should include deaf people and people who acquire deafness in adulthood.
208. Deaf Awareness training, appropriate technology and access to communication support, especially interpreters, are essential for those working with the Deaf Community.
209. The deaf service user must be given full information about his or her rights and referred as soon as possible to specialist services if they are required.
210. Primary Care Teams should be provided with appropriate information about Mental Health & Deafness services to enable them to refer service users for specialist assessment.
211. There should be effective interfaces and liaison between Primary Care, Social Services, Voluntary Organisations and the Deaf Community.
212. Protocols for effective joint working between local Community Mental Health Teams and services and the specialist mental health service for deaf people should be developed.
213. For deaf people being assessed for in-patient admission, protocols must be developed for the use of interpreters and other relevant professionals such as Social Workers with deaf people, in addition to the Approved Social Worker.
214. During the admission period, appropriate and accessible communication support must be provided within a maximum of 24 hours.
215. All service users should be enabled to give fully informed consent for their treatment, or to appeal against it.
216. Staff in Community Mental Health Teams and services must be provided with knowledge and skills to enable them to work, if necessary through interpreters, with deaf people, including staff in day services and out of hours services.

217. The Specialist Mental Health Service for Deaf People must:-
- develop a multi-disciplinary team which should include deaf professionals
  - provide assessment and treatment for service users at clinics in all the Health and Social Services Boards and in the community.
  - Work jointly with
    - primary care
    - local mental health teams
    - other specialist mental health services including Learning Disability, Old Age Psychiatry, Forensic and Psychological Therapy Services
218. The Specialist Mental Health Services for Deaf People should work with other agencies including Education, Social Services, the Independent Sector, Deaf Community Organisations, Employment and Housing to develop person centered care packages appropriate to deaf people.
219. The Specialist Mental Health Services for Deaf People should develop a teaching/liaison role and should carry out Audit and Clinical research
220. Long-term plans should be developed for the local establishment of in-patient facilities, possibly on an all-island basis.
221. Long-term plans should include programmes and supported housing for deaf people and people who acquire deafness in adulthood.
222. Provision should be made for deaf children and adolescents with mental health problems.

## **SERVICES FOR PEOPLE WITH PSYCHOLOGICAL TRAUMA**

### **The Nature and Extent of the Issues**

6.69 Over the last fifty years there has been significant progress in understanding the mental health implications of exposure to life threatening or other traumatic experiences. There have also been developments in our knowledge of the longer-term effects on well-being, economic and social functioning, and significant developments in assessment and treatment. Development and progress in policy, training, the purchasing and delivery of services in relation to psychological trauma, can and should make important contributions to the mental and wider health of the

community. In the context of the civil discord and violence of the period since the late 1960s in Northern Ireland a developing political context has permitted public discourse on the impact of the violence, and local studies suggest that there are significant needs arising from the civil violence to be addressed.

6.70 Exposure to traumatic experiences can lead to the development of a range of mental health problems including post traumatic stress disorder (PTSD), depression, specific phobias, personality disorders such as borderline personality disorder and panic disorder.<sup>72</sup> In relation to PTSD, it is often accompanied by other psychological or mental health conditions such as substance abuse and depression<sup>73</sup> (co-morbidity). PTSD defines a group of signs and symptoms that often occur together, forming an identifiable pattern that characterises a recognisable abnormality.\* Together these characteristics will usually induce levels of distress and disablement. This may in turn lead to dysfunction in social, occupational and relationship terms, and the exercising (or omission) of key life choices (based on the unhelpful appraisals arising from a traumatic experience) that have a long term bearing on the person and his or her family.

6.71 Key to understanding the levels of need arising from psychological trauma is knowledge about:

- the level of exposure to traumatic experiences;
- the incidence of psychological trauma following exposure; and
- the rate of recovery.

6.72 Whilst the Troubles in Northern Ireland have helped to draw attention to the needs arising from traumatic experiences, it is important to remind ourselves that citizens suffer from traumatic experiences which are found in technologically developed societies and which are not associated with political conflict. Accidents (including perhaps most strikingly road traffic accidents), assaults (including child abuse and sexual assault) and other traumatic experiences such as those associated with suicide or serious illnesses are well understood to give rise to risks of post trauma psychological implications for those who experience them. The needs of children (and of adults) who have suffered and continue to suffer psychological and other

health related needs arising from childhood traumatic experiences, including abuse, represent a particular professional challenge. In the terms of the Children (NI) Order 1995, children and young people considered to have suffered such experiences, and who as a result have post trauma related problems, could be deemed to be *children in need*.

- 6.73 Kessler and colleagues<sup>74</sup> reported upon a major study into the prevalence of PTSD in 1995 and concluded, "PTSD is a highly prevalent lifetime disorder that often persists for years. The qualifying events for PTSD are also common, with many respondents reporting the occurrence of quite a few such events during their lifetimes." Among adult Americans aged 15 to 54 years the estimated lifetime prevalence of PTSD is 7.8%, with women (10.4%) twice as likely as men (5%) to have PTSD at some point in their lives. A number of other epidemiological studies have reported on similar findings.<sup>75-78</sup>
- 6.74 Kessler and colleagues found that the most frequently experienced traumas were:
- witnessing someone being badly injured or killed;
  - being involved in a fire, flood, or natural disaster;
  - being involved in a life-threatening accident; and
  - combat exposure.
- 6.75 Other studies have reported on the incidence of development of PTSD after exposure to traumatic events. Green<sup>79</sup> reported an overall incidence of 25% of individuals exposed to traumatic events. In relation to rape, Figley<sup>80</sup> reported between 35% and a striking 92%. Norris<sup>81</sup> found an incidence of 69% in a sample of 1000 people exposed to traumatic events. Breslau and colleagues<sup>82</sup> found that the rate of PTSD in those who were exposed was 23.6%. The variation across studies might, in part at least, be due to the changing definitions of PTSD in the 1980s and 1990s and the severity of exposure in some of the studies. Nonetheless the findings point to significant consequences.
- 6.76 **Recovery from PTSD and the Implications for Treatment.** Kessler's work is also important as it endeavours to describe the recovery rate from PTSD. In short, 40% of sufferers recover (without treatment) by about 30 months after onset of symptoms.

At the other extreme, 35% suffer enduring (and what could be taken to be lifetime) PTSD.

- 6.77 **PTSD Risk Factors.** In a meta analysis by Brewin, Andrews and Valentine<sup>83</sup> three risk factors for PTSD were identified consistently across all studies namely, psychiatric history, history of childhood trauma and family history of psychiatric disorders. Specific studies point to other pre-existing personal and social circumstances, and post trauma appraisals and coping as also being related to the development or presence of PTSD.
- 6.78 **The Impact of the Troubles.** Of the work that has been carried out in this field, a number of relatively recent studies provide a view of what the impact might amount to. In a secondary analysis of a nationally representative population survey conducted in 1997, O'Reilly and Stevenson<sup>84</sup> concluded that "The Troubles are a separate and additional [public health] burden and therefore contributes significantly to the higher psychological morbidity in Northern Ireland", and "It is probable that mental health has been significantly affected by the Troubles."
- 6.79 In The Cost of the Troubles Study,<sup>85</sup> the researchers concluded that about 30% of those who participated in the study and who had been exposed to violence associated with the Troubles had needs approximating to PTSD. This finding seems high and might be associated with the methodology used in the study. Cairns and colleagues<sup>86</sup> found that the mean GHQ scores of a sample of 1000 adults from across Northern Ireland was 10.05, which was in line with the findings of an earlier study. That study had detected similar or higher rates of psychiatric disorder to that found in inner city London. Cairns and colleagues concluded, "the ceasefires have not led to any notable change in overall levels of psychological well-being in the Northern Irish population".
- 6.80 One Troubles related incident has been the subject of needs assessment and casts some light on the impact of a single incident. The Omagh bombing of August 1998 killed 29 people and two unborn children. Over 400 were injured, of whom 135 were seriously injured. In the course of the three and a half years following the bombing, over 670 people were seen by the Omagh Trauma and Recovery Team, which was

established in the wake of the bombing by the local health and social services provider, the Sperrin Lakeland Trust. In addition, an unknown, but probably very large, number of people were provided with support from a range of primary care, mental health, voluntary and occupational health related services.

6.81 A major community study (a needs assessment) commissioned by the Sperrin Lakeland Trust (unpublished) suggests that 7 out of 10 of those who were in the immediate vicinity of the Omagh explosion suffered PTSD. The Sperrin Lakeland Staff Study (a needs assessment) revealed that of those staff who were exposed to work associated with the response to the bombing, 38% of staff had developed PTSD in the period 4-17 months after the bombing.<sup>88</sup>

6.82 **The implications.** The following key points emerge from the above discussion:

- 25% (minimum) of those exposed directly to traumatic experiences will have developed PTSD;
- for some types of traumatic events the risks of developing PTSD are much higher;
- 8% of the young adult population will experience PTSD in their lifetime;
- whilst 40% of those who develop PTSD will recover to (at least) below threshold levels within about 30 months, a further 35% will have PTSD in the (very) long term;

6.83 This analysis suggests that psychological trauma has, most probably, not been sufficiently recognised as a specific health issue, and by extension that needs have not been addressed. Further, clinical experience shows that people with PTSD are thought to have other conditions and are treated on that basis. This results in long-term treatment programmes because the underlying trauma is not being identified and addressed. In the context of the Troubles and the development of post conflict initiatives to build and consolidate a non-violent society, the legacy of the psychological consequences must be faced and addressed as a special public health issue.

## **A Vision for Services**

- 6.84 **Policy and Philosophy.** Northern Ireland guidance on the management of PTSD in adults was issued in 2003.<sup>89</sup> This followed the guidance issued by the International Society for Traumatic Stress Studies<sup>90</sup> (2000) and the Department of Health,<sup>91</sup> which, on the basis of available research evidence, pointed to the treatments of choice for (*inter alia*) PTSD. The guidance is a key element in the development of an evidence-based approach to the understanding, recognition, treatment of PTSD and related conditions. It forms a key building block in the development of a response to this area of need and should form the basis for the development of policy, services and training.
- 6.85 Key to the recognition, assessment and treatment of people suffering from post traumatic stress disorder, and related conditions, is the level of awareness amongst professionals and organisations that represent first points of contact. Beyond detection of psychological trauma lies the important task of evidence based assessments, which examine in detail the specific impact on each individual who is referred, including associated needs, risks and complicating factors.
- 6.86 The development to date of services has been piecemeal and patchy, and lacks both a managerial and professional coherence. The development of the CREST guidance represents a significant building block in addressing these shortcomings.
- 6.87 Given the developing understanding of needs arising from exposure to traumatic experiences and the implications for functioning and health, the developing knowledge and skills base in recognition, assessment and treatment, and the emergence of clear guidance on treatment etc. we are well placed for strategic progress in this area.
- 6.88 **Identification, Referral and Treatment.** Whilst research demonstrates that those who have mental ill health are at higher risk of developing post trauma related conditions, other considerations are important in terms of identifying and providing treatment for trauma related needs. Clinical experience demonstrates, that many people who have had no significant mental health ill health prior to the trauma have

acquired a post trauma condition. Further, it is well established that avoidance of any reminders of the traumatic experience (including the prospect of seeking treatment) is a key component of trauma related conditions. These features (and the additional sensitivities required by the context of the Troubles) point to the need for specific response to needs and potential needs.

6.89 **Training.** Treatment services should employ appropriately trained staff preferably drawn from a range of professional backgrounds to provide added value and perspective to the assessment and treatment of people with trauma. Further, staffing levels, experience and skill mix must be geared to the provision of effective care at each level in the service tiers. Clarity about what a service can (and cannot) offer should inform recruitment and training strategies. Appropriate training in evidence-based practice (appropriate to each level) is required for staff involved in identifying, assessing, treating and supporting people with trauma related needs.

6.90 Viewed from a potential service user perspective the response of the health and social care services (statutory and non-statutory) should reflect the following characteristics:

- clear and non-bureaucratic points of access to information and services;
- proactive awareness of and sensitivity to potential trauma related needs by key first-point-of-contact professionals and organisations;
- effective first line responses offering reassurance, clear information, initial care, and onward referral;
- active response and follow up to reduce the potential for drop out associated with avoidance;
- individualised care to reflect the highly individualistic presentations of trauma related needs, and the personal associated circumstances (e.g. other illnesses, financial hardships, disability etc.) and any co-morbid mental ill health needs;
- access to a range of evidence-based therapeutic resources;
- services should place a clear emphasis on creating a safe and confidential treatment milieu;
- services should have in place key links and arrangements to respond to urgent and other needs that cannot be met within the specific service.

## Recommendations

223. The development and expansion of evidence-based services including CREST guidelines to address psychological trauma should be taken forward with urgency.
224. To facilitate progress, a coherent tiered strategy should be developed.
225. Service planning must involve clinical leaders, users and carers and clinical managers.
226. An audit of what is currently available (i.e. resources and skills), tested against the CREST guidance (2003), should be undertaken.
227. Primary care staff (and other front line services) should be provided with the necessary guidance, training and support in the detection, preliminary intervention and appropriate referral of people with trauma related needs.
228. A human resource plan, which addresses staff levels and qualifications, training and re-training, should be developed.
229. Future service configurations should build upon the experience and expertise that has been developed in both the statutory and non-statutory sectors.
230. The expertise developed in the non-statutory sector should inform the development of the overall trauma network.
231. Pre-professional training for health and social care professions should include appropriate content on the conceptualisation, recognition and treatment (including referral) of psychological trauma.
232. Advanced training for the treatment of PTSD (and related conditions) should follow current evidence-based guidance on the management and treatment of psychological trauma.
233. Further research should be commissioned into the prevalence of trauma related needs including the specific needs arising related from the civil conflict.
234. Health promotion programmes to address the specific needs of those affected by traumatic events should be developed in line with evidence-based practices and principles.
235. Organisations which employ people who, in the course of their work, may be exposed from time to time to traumatic experiences should put in place measures relevant to the nature of the work and risks.

## SERVICES FOR PEOPLE WITH PERSONALITY DISORDERS

### The Nature and Extent of the Issues

- 6.91 Personality Disorders exact a heavy burden on affected individuals and on wider society.<sup>92 93</sup> These are common and distressing conditions, prevalent in 1 in 10 of the adult community population and most commonly in those aged 25 to 44, equally among males and females in their child-rearing years. Estimates may be higher in those with Learning Disability.<sup>94</sup> These people experience a wide range of psychosocial problems including high rates of family disharmony, violence, crime, unemployment and homelessness, early unnatural deaths from suicides and accidents, high rates of associated rates of mental illness and worse outcomes for all illnesses, leading to high service utilization and the revolving door phenomenon.<sup>95</sup> They often present in crisis and in danger to themselves or others and are high users of primary care and Mental Health Services.<sup>96 97</sup> Their children can suffer significantly as a result.<sup>98</sup>
- 6.92 In mental health settings, people with Borderline Personality Disorder attract most clinical attention, and where 11-20% of psychiatric outpatients may have this disorder.<sup>99</sup> It is strongly associated with co-morbid substance misuse, anxiety and depressive disorders, unexplained medical conditions and eating disorders and has a 9 % suicide rate.<sup>100 101 102</sup> Psychological autopsy of suicides of individuals with personality disorder suggests that all may have had at least one mental disorder, and were chiefly a depressive syndrome disorder, substance misuse or both.<sup>103</sup>
- 6.93 Personality disorders are generally recognized as acquired conditions.<sup>104</sup> Models of causation for personality disorder derive from longitudinal child development studies and retrospective studies on the impact of personality function as adults. These studies show that early childhood adversity is a potent risk for the development of personality disorder in adulthood.<sup>98 105</sup> In adulthood exposure to frightening and traumatic events may cause change and damage to the personality.<sup>92</sup>
- 6.94 Mental health professionals have a long standing ambivalence towards the management and treatment of these disorders. Often these people may be regarded as difficult to treat because of lack of awareness of the condition and availability of

treatment options. Typically they present in chaos and often find traditional treatment options either not readily available or difficult to utilize. Inappropriate interventions can even make their situation worse.<sup>104</sup> Brief inpatient admissions can be beneficial.<sup>102</sup> The process of managing the disorder can be difficult and long term and emotionally difficult for all concerned.

- 6.95 The presence of severe mental illnesses such as schizophrenia and bipolar disorder with personality disorder is common and is one of the most frequent dual diagnoses found in clinical care. Between 36 and 67 % of those with psychotic disorders have a personality disorder<sup>106</sup> and the proportion tends to be higher in inpatient populations.<sup>107</sup>
- 6.96 The outcome for people with a personality disorder as well as mental illness is generally less good than for those with single mental state disorders, with less improvement in symptoms, poorer quality of life and greater dissatisfaction with treatment after 2 years.<sup>108 109</sup> The dual diagnosis is often not recognised in ordinary practice and thus may lead to poor reliability of assessment in psychotic disorders.<sup>110</sup>  
<sup>111</sup> Local survey suggests it may be under-recognized in the psychiatric population by as much as a factor of four.<sup>112</sup>
- 6.97 In line with guidance in other parts of the UK, the Review suggests the view that people with a personality disorder who experience significant distress or mental illness as part of their disorder and the mentally ill who suffer from co morbid personality disorders, are part of the business of mental health services.<sup>113</sup>
- 6.98 The needs of Personality Disordered Offenders within the criminal justice system are not considered in detail. They are considered separately by the Forensic Services Expert Working Committee.

### **Treatment of Personality Disorder**

- 6.99 There is no evidence that personality disorder is untreatable. However, there is no evidence that all personality disordered people would be treatable if only clinicians attitudes were right and there were enough resources.<sup>122</sup> Present evidence indicates that mild and moderate degrees of personality disorder are treatable with appropriate

interventions.<sup>104, 123, 124</sup> These are usually a combination of psychotherapy (psychoanalytic, psychodynamic, cognitive (CBT) and behavioural and dialectical behaviour therapy (CBT combined with Zen practice)) and pharmacological interventions delivered by clinical teams with experience and training.<sup>125, 126</sup>

- 6.100 Treatability may be a function of service availability.<sup>124</sup> People with personality disorders appear to achieve and maintain better outcomes in treatment in specialist services dedicated to care. The process of rejection and failure to identify the pathology itself affects the treatability of the condition, so that each negative encounter makes the condition worse. Some evidence exists that where specialist therapy is offered and completed the costs are offset by the subsequent reduction of service usage by people with personality disorder.
- 6.101 Most individuals who present with the diagnosis of personality disorder have more than one personality disorder with a predominant type. Different interventions may be indicated for different types of personality disorder.<sup>127</sup>
- 6.102 Psychotropic medications, particularly SSRIs and mood stabilisers, are useful adjuncts to treatment in the management of people with personality disorder.<sup>126 128</sup> There is a growing body of evidence for the use of the psychotherapies in the treatment of personality disorders, particularly those of borderline type.<sup>129</sup> In a randomised controlled trial of an 18 month psychoanalytically led day service for people with Borderline Personality Disorder significant improvements in symptoms and social functioning were found and maintained at 18-month review.<sup>130, 131</sup> There is some evidence that Cognitive-Behavioural therapy may also be relatively effective in the treatment of these disorders.<sup>132</sup> Dialectic Behavioural Therapy (DBT) has been shown to be effective in the treatment of Borderline Personality Disorder.<sup>133</sup> A randomised controlled trial of 18 weeks psychiatric and psychotherapeutic day treatment with 8 month follow for people with affective and personality disorders has shown improvement in social adjustment at the end of treatment.<sup>134</sup>
- 6.103 Lees et al concluded that “there is accumulating evidence of the effectiveness and particular suitability of a therapeutic community model to the treatment of personality disorder, and particularly severe personality disorder”.<sup>124</sup>

6.104 Those with personality disorders are heavy users of treatment services throughout the NHS. A number of studies have shown that appropriate psychotherapeutic intervention can change Health Service utilisation by people with Severe Personality Disorder before and after inpatient psychosocial treatment.<sup>135 136</sup> In one study carried out at the Cassel Hospital, using psychosocial and therapeutic community treatments for up to 18 months, use of inpatient and outpatient psychiatric and inpatient medical and surgical usage was significantly less in the post-treatment group and there was an average per annum saving of £7423 per patient (May 1992 costs). The Henderson Hospital, an inpatient therapeutic treatment with an average length of stay of 7 months showed that the cost of treatment for patients was recouped in under 2 years.<sup>137</sup>, through reduced Health Service utilisation. Therapeutic community provision at Regional District levels can offset the costs of acute psychiatric admissions in the 3 years post follow-up.<sup>138</sup>

### **Current Services**

6.105 In England there are currently 60 Therapeutic Communities provided for by statutory and voluntary sectors.<sup>113</sup> 17% of Trusts have a dedicated service for personality disorder, often day hospital or outpatient programmes, 40% have some level of services and 28% have no service at all.

#### *Good Practice Examples*

**Winterbourne House Reading:** *A therapeutic community as an intensive treatment programme. The district psychotherapy service draws from a catchment population of 800,000, takes 400-500 referrals per year from primary and secondary care and offers therapeutic community work of 18 months to 10%. Outpatient individual psychoanalytic or dynamic treatment for 2 years or group therapy for up to 3 years is offered to others for whom treatment is deemed suitable. The unit was cited in the 2003 NIMHE "Personality Disorder: No Longer a Diagnosis of Exclusion" policy guide, as a "Notable Practice Site". Service user involvement has always been a guiding principle in the therapeutic approach used, and several of the services users and ex-users participated in the user consultation exercise for*

*the NIMHE guide. It is at the forefront of providing modern, acceptable and pioneering PD services. (Contact: 0118 956 1250 or [www.winterbourne.demon.co.uk/news/ecellb.htm](http://www.winterbourne.demon.co.uk/news/ecellb.htm))*

*Other internationally renowned units in this category are the Henderson and Cassel Hospital units.*

**Halliwick Unit , Tottenham London :** *A Day unit and intensive outreach service. This Unit offers a treatment service tailored to the specific needs of people with severe personality disorder. A package of Group and Individual treatment is offered within a day-hospital over 5 working days or within an intensive outpatient programme involving three sessions per week. Patients are offered a self booking psychiatric clinic to discuss medication and a rapid response in emergencies. Engagement of the patient is important and assertive outreach is included in the programme. ( Contact: [www.halliwick.nhs.uk](http://www.halliwick.nhs.uk) or 020 8442 6528.)*

**Regional Psychotherapy Service Department, Newcastle upon Tyne:** *A specialist outpatient service for people with a personality disorder, offering psychoanalytically informed treatments leading to a reduction of self harming behaviour and the frequency and duration of hospital admissions. Patients become more skilled in managing emotions and relationships and improving the quality of their lives. (Contact: 0191 232 5131.)*

- 6.106 In Northern Ireland there are no services dedicated to the management and treatment of people with personality disorder. Bridge House, a residential unit run along therapeutic community lines by the voluntary sector has recently closed due to lack of funding. There are no plans to replace it.
- 6.107 Within General Adult psychiatric provision there are isolated attempts at good practice. For example, at South Belfast Day Hospital and Old See House Day Hospital, North Belfast, consultant psychiatrists involved in the care of day patients are analytically trained and provide psychoanalytic / psychodynamic understanding to other staff working with people with Borderline Personality Disorder or Co-morbid Personality Disorders.

- 6.108 For many years those involved in the more specialized provision of services for people with Eating Disorders, Addictions and Forensic Services have recognized the importance of associated Personality Disorders in the treatment and prognosis of those with mental illness. However, currently they are unable to offer specific treatments to those people who also have a Co-morbid Personality Disorder.
- 6.109 It is likely that the incidence of personality disorder in Northern Ireland is as high if not higher than throughout the rest of UK. Risk factors are increased by the impact of 35 years of trauma, low socio-economic status and increasing numbers of single parent families.
- 6.110 The lack of resources for the management and treatment of severe mental illnesses such as schizophrenia and bipolar affective disorder has meant that those with a personality disorder are viewed as low status patients and do not access readily the limited resources available to people attending psychiatry, psychology and psychotherapy services in Northern Ireland.
- 6.111 The limited development of psychological services in Northern Ireland (psychiatry, psychology and in particular psychotherapy services) has contributed to a limited understanding of the development of personality disorder, its management and treatment. There are no Therapeutic Communities and no-one is trained in Dialectical Behaviour Therapy in Northern Ireland.
- 6.112 Staff must train as Psychoanalytic or Psychodynamic therapists through one private training organization and Queen's University, Belfast, usually outside of the NHS and in their own time.

### **Recommendations**

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| <p>236. Specialist services for people with personality disorder must be established to augment secondary care services.</p> <p>237. Service planning must involve clinical leaders, users and carers and clinical managers.</p> |
|--|

238. Service requirements should be the subject of needs assessment.
239. In line with services in the rest of the UK, residential and day treatment services for people with personality disorders should be established in N. Ireland.
240. Specialist services must provide support and education for services at secondary level.
241. Specialist multi-disciplinary teams should be established to provide assessment, education and support to other services who may come into contact with people with personality disorders. Staff appropriately trained in psychological therapies must be appointed.
242. Specialist services for people with personality disorder should co-ordinate with other mental health services such as forensic services, substance misuse and learning disability services.
243. Education and support for staff in the diagnosis and management of people with personality disorders must be provided.
244. Awareness of the needs of those with personality disorders should be increased among such services as Primary Care, A&E, perinatal services, medical and surgical staff.
245. User and Carer initiatives to support sufferers and carers of those with personality disorders should be facilitated.

## **SERVICES FOR ABLE ADULTS WITH AUTISTIC SPECTRUM DISORDERS**

### **The Nature and Extent of the Issues**

6.113 Autism is a complex developmental disability, of life long duration, affecting the way in which an individual perceives their environment, behaves, communicates and interacts. Core features of the disorder are impairments in social interaction and social communication, with rigidity and repetition in thought processes, activities and behaviour.<sup>139</sup> The term ‘autistic spectrum disorders’ (ASD) has been introduced to include the range of presentations from those who are severely affected with a co-morbid learning disability, to the intellectually able ie those with Asperger’s Syndrome (AS) or High Functioning Autism (HFA). The latter are often used interchangeably, although increasingly Asperger Syndrome is used as a short-hand reference.

- 6.114 The National Autistic Society<sup>140</sup> (NAS) estimated the prevalence of all autistic spectrum disorders to be 1 in 110 of total population, whilst the Medical Research Council<sup>141</sup> cites 1 in 166. Similarly, there are varying estimates of AS/HFA. Several studies<sup>142,143,144</sup> suggest that approximately 1 in 300 people will have ‘able autism’. It has been found consistently that significantly more males than females are affected, with reported ratios averaging 4 to 1.<sup>145,146</sup>
- 6.115 Epidemiological studies continue to support opinion that the majority of people with ASD, between 75% and 90%, are within the ‘average’ or ‘above average’ range of intellectual ability.<sup>147</sup> Most are therefore well outside the remit of services that are commissioned to support those with a learning disability (generally accepted as IQ<70).
- 6.116 Presentation of symptoms may be more subtle than those displayed by individuals with significant intellectual impairment, but are often equally and indeed more disabling. As a result of less ‘obvious’ symptoms, many have been misdiagnosed during childhood, adolescence and even in adulthood. It is reported that 46% of people with AS/HFA in England and Wales are not diagnosed until over 16 years of age.<sup>148</sup> With improving recognition and increasing expertise, it is evident that substantial numbers of adults with High Functioning Autism/Asperger’s Syndrome are already in receipt of existing mainstream mental health services. Experienced mental health professionals generally feel ill-equipped to provide appropriate support and therapeutic intervention for patients/clients with the specific deficits that are characteristic of autism.
- 6.117 Priorities For Action.<sup>149</sup> recognised for the first time, that intellectually able adults with ASD are presenting to mental health services and require specialist provision to address their needs.
- 6.118 Studies of adults with confirmed diagnoses of Asperger’s Syndrome or High Functioning Autism indicate a high level of associated mental health problems, particularly affective disorders, often with onset during adolescence.<sup>150,151,152</sup> It is estimated that 15%-20% suffer from significant anxiety disorders<sup>153</sup> and 37% from

depression.<sup>154</sup> Recent evidence suggests that there is a 1 in 20 prevalence of co-morbid psychotic illness amongst able adults with ASD, frequently precipitated by extreme anxiety. In surveys conducted by Barnard et al,<sup>148</sup> 50% of parents whose son or daughter was not diagnosed until after the age of 30 reported that their child had experienced mental ill health. Of these, 56% had suffered from, and been treated for depression. A further 11% suffered a ‘nervous breakdown’ requiring hospital admission, and 8% expressed suicidal ideation or had attempted suicide. It is reported that able adults with ASD fit the high risk ‘suicide prone’ category.<sup>155,156</sup>

6.119 From the Down Lisburn Trust Pilot Project<sup>157</sup> (total population 180,000) over 16 months, a total of 36 adults with confirmed diagnoses has been identified, almost two thirds of whom were diagnosed after the age of 17. The majority (69%) were referred from, and already in receipt of, mainstream mental health services. Co-morbidity of autism and a mental illness is confirmed in 55% of those participating in the pilot project (N=29), although most experience an anxiety disorder to some degree. 84% reside in the family home, 13% live with their partner, and only 3% are living independently with support at present. Only 13% have full-time employment, 6% part-time work, 16% part-time voluntary work, 9% attend New Horizons, 34% attend College, Training Centre or University. 22% have no meaningful occupation. An additional 94 adolescents, aged 13 to 17, have a confirmed diagnosis of AS/HFA and will require access to adult services in the near future. Many have additional attentional and hyperactivity disorders.

6.120 Given the possible total prevalence of ASD, it is evident that many adults do not present for diagnosis and may not require specialist professional assistance, but the extent of need is inevitably difficult to ascertain in the absence of autism specific services and appropriate information systems. For those who do seek help, the following service components are recommended as representing a minimum standard of provision by the NAS.<sup>158</sup>

### **Current Provision**

6.121 **Assessment and Diagnosis.** Currently, there is a lack of expertise in the assessment and diagnosis of able adults with ASD throughout Northern Ireland. Clinics that specialise in this work are uncommon, not only in a regional context, but nationally

and internationally. One local community trust has established a diagnostic service, specifically for intellectually able individuals who are referred with a query of ASD. Many adults coming to attention of services have complex difficulties, often including co-morbid mental illness. It is essential that a comprehensive diagnostic evaluation is undertaken by professionals with expertise in autism and mental illness.

6.122 **Support.** Post-diagnostic support is extremely limited in Northern Ireland for all who have ASD, their families or carers. However, people with diagnoses of both autism and a significant degree of intellectual impairment are likely to fare somewhat better than those intellectually able individuals with autism as the former are ‘eligible’ for provision by learning disability programmes of care. At present, appropriate support is almost non-existent for able adults with ASD as they are usually excluded from learning disability (by virtue of their higher cognitive ability) and from mental health services unless a mental illness is confirmed.

6.123 A small number have been accepted by services for people with a learning disability as providers currently have nothing else to offer. Whilst this is clearly inappropriate, and draws on already scarce resources, in most areas of Northern Ireland it may be the only help available. These professionals with expertise in learning disability, like their colleagues in mental health, do not feel that they have sufficient knowledge of AS/HFA, the therapeutic skills required, nor an awareness of the types of services that may be needed.

6.124 To date, only one Health and Social Services Trust has developed a pilot project designed to assess the needs of individuals with AS/HFA and their carers, to support both, and to provide a therapeutic service specifically for this population. Some voluntary sector services have successfully provided sensitive individual support and accommodation.

### **A Vision for Services**

6.125 The following requirements have been identified consistently in research audits for adults with AS/HFA:

- a training and awareness programme to increase professional understanding across a wide range of community services including social, housing, school, continued education, health and employment services.
- a clear support pathway so families know who they can contact to request assessment regarding possible diagnosis.
- an improvement in employment opportunities, support and training.
- interventions to reduce social isolation and clinical mental health difficulties.
- interventions to develop independent living skills, relationships and personal development.
- better post-diagnostic emotional support, information and advice for people with AS/HFA.
- a range of appropriate supported and independent housing options.
- better social and academic support and learning opportunities within secondary schools during transition and continued education.
- carers' needs to be assessed and met, including education/information, advice, counselling (including genetic counselling if appropriate) and 'respite' type services, such as befriending for their sons and daughters.
- more appropriate service provision. Many adults are placed in services that are not suitable for AS/HFA, due to poor provision or misdiagnosis.
- access to advocacy services, for families and people with AS/HFA.
- sensitive crisis intervention (not necessarily mental health in-patient).
- forensic services (to support the minority of people who display behaviour likely to put themselves or others at risk of harm).

6.126 The Review recommends the establishment of a tiered service specific for the needs of adults with ASDS. The initial priority is the formation of a core regional team (Tier 3) with the necessary expertise and which can provide training and support for local providers. Based on current evidence such a team should include professional input from clinical psychology, occupational therapy, psychiatry, family support coordinators and intervention therapists to assess and support. Housing and employment services for people with ASD must be identified at local provider level (Tiers 1 and 2) in response to local assessment of need and with the support of Tier 3 services.

6.127 **Assessment and Diagnosis.** In considering the needs of intellectually able adults, the following points are highlighted:-

- complex cases require highly specialist diagnostic assessment. Professional background is largely irrelevant, whereas expertise in autism and knowledge of current diagnostic classification systems is of paramount importance.
- co-morbidity of ASD with mental illness, indicates strongly a need to have the combined knowledge of professionals experienced in each (few possess expertise in both mental illness and autism at the present time).
- co-working between programmes of care within H&SS will be necessary for the foreseeable future, until mental health professionals acquire the requisite additional skills in diagnostic evaluation.

#### **Therapeutic Interventions.**

6.128 A range of interventions are required:

- Management of psychological problems will require consideration of the social environment ie support needed to access employment opportunities and housing options, interventions to reduce social isolation, develop independent living skills and relationships, and to foster personal development.
- Drug treatment may be indicated if there is a clearly identified co-morbid mental disorder, but is never an effective long term solution for behavioural problems.<sup>159</sup>
- ASD is accepted as being neuro-developmental in origin. The resultant impairments of people with ASD mean that psychodynamic therapy and reflective counselling are not appropriate. Use of these approaches in the past has been reported to cause unnecessary confusion for the individuals and distress for their families.<sup>160,161,162</sup> Any therapy that attempts to ‘treat’ the core symptoms of AS/HFA as an emotional issue will be counter-productive, as will therapists and counsellors who do not understand the psychological theories of autism.<sup>158</sup>
- Cognitive Behavioural, Behavioural, and Personal Construct Therapy by a skilled practitioner who can adjust intervention to the deficits of ASD, are regarded now as the most beneficial.<sup>163,164</sup>

- Research on the inner experience of people with autism and AS/HFA also supports the use of visual strategies as appropriate and effective adaptations to such therapies for this population.<sup>165,166</sup>
- In addition, it is beneficial to help adults with AS/HFA understand the expectations and perceptions of others, to develop social skills, to understand personal needs and develop concrete strategies for meeting those needs, and to manage their anxiety.<sup>166</sup>

6.129 It is essential to provide support for the individual and their family in understanding the disability and adjusting to confirmation of a diagnosis – usually after many years of uncertainty and self-blame. Many cases have reached crisis point for both the referred person and those who are struggling in their efforts to live with, and help them. Local research indicates high levels of psychological distress and mental ill health amongst the parents of AS/HFA adolescents and adults. It revealed that 25% of carers have a diagnosed mental health problem, with an additional 28% reporting significant symptoms of stress and anxiety. These were attributed directly, by parents, to the difficulties associated in caring for their son or daughter.<sup>157</sup> Research carried out by the NAS<sup>160</sup> found that 70% of carers felt that finding appropriate care facilities as the major barrier to them accessing work. This research also highlighted the responsibility of social services to urgently prioritise support for carers. Bernard et al<sup>148</sup> noted that parents are often the sole carers for their son or daughter with ASD, providing regular and substantial amounts of care. It must be noted too that increasingly adults are being identified who are in long term relationships. Their spouse/partner, in such cases, requires equal support to parents of those with AS/HFSA. Carers of individuals with ASD can be supported in their caring roles. Yet, when this does not happen, costs to the individual and their family are considerable.

6.130 Some people with AS/HFA will not require any statutory services. However, most diagnosed adults need understanding and support from specialist services, but currently cannot access existing health and social care because they do not ‘fit’ the perceived remit of mental health or learning disability services.

- 6.131 Without appropriate provision many adults with AS/HFA will become socially isolated, drop out of school or college, will be unable to work, will suffer mental health problems and psychological breakdown. The suicide risk for people with this condition must be recognised also.
- 6.132 Lack of support services for people who are experiencing difficulties can lead to police involvement, prison sentences, admission to psychiatric units and trial-and-error drug treatments.<sup>167</sup> For many, these consequences could be avoided or reduced greatly by a relatively low level of ongoing support, saving severe distress and the costs of inappropriate agencies becoming involved.
- 6.133 The range of needs experienced by adults with AS/HFA demands a person centred approach from agencies to provide them with the required services and support. Many will need significant and ongoing assistance to achieve maximum independence. ‘There is need in some cases for specialist services, but there is a wide need for existing services to develop specialist approaches’.<sup>158</sup>
- 6.134 **Housing.** Only 54% of adults with ASD reported that they were satisfied with their living arrangements and only 3% with AS/HFA live fully independently.<sup>148</sup> More adults with a disability live in the family home than in any other setting. Many individuals with AS/HFA are vulnerable to abuse and exploitation and have a range of housing needs, from independent living to supported housing. Even independent living often requires an element of support to help people with ASD cope with day to day demands and unexpected situations.
- 6.135 Appropriate ‘respite’ care provision is required, from befriending to short-term breaks that would allow adults with AS/HFA, and their families, the necessary time apart to prevent the crises that can lead to ultimate breakdown.
- 6.136 **Employment.** NAS research reported that many more people with ASD could and would be able to work if better support were available. Despite having a strong desire for employment, only 12% of adults with AS/HFA are in a paid position.

## **Recommendations**

246. A community needs assessment of able adults within ASD should be carried out as a priority.
247. A regional multidisciplinary team specialising in services for able adults with ASD (Tier 3 services) must be established as a priority.
248. Service planning must involve clinical leaders, users and carers and clinical managers.
249. Local services including voluntary sector services must be developed to provide psycho-education, support and intentions following confirmation of diagnosis.
250. A senior manager in each Trust should have responsibility for adults with AS/HFA.
251. Specialist supported housing and respite provision should be commissioned, with specialist residential provision available within each Board area.
252. People who are in contact with a service already should not be precluded from accessing another following consultation regarding their needs.

## **SERVICES FOR PEOPLE WITH DISORDERS OF GENDER AND SEXUALITY**

### **The Nature and Extent of the Issues**

- 6.137 The Psychosexual Service as a component of mental health services is uniquely positioned to address the emotional and bodily based derivatives and expressions of disorders of gender and sexuality. The Service must offer an expertise that addresses both sides of the mind body equation within a psycho-physiological developmental framework. Although Northern Ireland has benefited from services located principally at the Belfast City Hospital since the mid 1960s, services throughout the United Kingdom are patchy. For example, in a recent survey<sup>168</sup> only 21% of commissioning authorities provide services at a local level for Transpeople (individuals regarded diagnostically as transsexuals).
- 6.138 Psychosexual Services provides for people with a diverse range of disorders of gender and non-organic disorders of sexuality. Rather than a spectrum of disorders, the diagnostic categories reflect quite different population groups with specific needs.

For example, Transpeople have a low prevalence (varying from 1/2900 for male to female and 1/8300 for female to male in Singapore<sup>169</sup> to 1/11900 for male to female and 1/30400 for female to male individuals in the Netherlands<sup>170</sup>) and constitute only 12-14 new referrals each year to the Northern Ireland Regional Service. However, due to the complexity and longevity of their needs they often require significantly more input from services (on average treatment and follow-up lasting for 5-10 years) compared to individuals with, for instance, sexual dysfunction. Evidence suggests that Transpeople demonstrate high levels of mental ill-health (requiring active psychiatric intervention) at the point of accessing services, often with high rates of parasuicidal behaviour and substance misuse<sup>171</sup> and it seems likely that this is a direct consequence of difficulties with their sexual identity. There is also convincing evidence to support treatment of Transpeople,<sup>172</sup> and that regret after sex reassignment is low, ranging from none to 3.8%.<sup>173</sup>

- 6.139 Although individuals with non-organically based sexual disorders constitute most referrals to psychosexual medicine (78% of referrals to the Belfast City Hospital Service) they tend to require shorter and less intensive interventions. This group of disorders appears to be very common throughout the general population, although precise data for Northern Ireland is as yet unavailable. However studies elsewhere suggest prevalence rates for women may be as high as 43%<sup>174</sup> (a substantial number of which would require the assistance of a psychosexual service), with disorders of female sexual arousal constitute 70%<sup>175</sup> of attendances at psychosexual services. For men erectile disorders have an incidence of between 7-25%,<sup>176,177</sup> and 59%<sup>178</sup> have a psychological basis.
- 6.140 Individuals with disorders of sexual preference (paraphilias) constitute the other main category of referral (14% of referrals to the Belfast City Hospital Service). There are few reliable sources of data in terms of incidence in the general population. Offenders tend to be dealt with through forensic and probation services. However, those who are referred to psychosexual services tend to have complex needs and may require specialist psychotherapeutic involvement over prolonged periods.

### **Current Services**

- 6.141 The Psychosexual Service based at the Department of Psychiatry in the Belfast City Hospital has offered services on a regional level from the mid 1960's. In the 1980's the Western Health and Social Services Board developed a local, consultant led service in Omagh. Some services for sexual dysfunction are also offered through family planning clinics and in the voluntary service similar treatment is available mainly through RELATE.
- 6.142 The largest and most comprehensive service remains that located at the Belfast City Hospital. The Psychosexual Team is led by a Consultant Psychiatrist and is constituted by multidisciplinary therapists including input from social work, nurse, general practice. Although there is access to inpatient places in Windsor House, this is only required on an exceptional basis and the vast majority of work is sessional and outpatient based. Most of the team members have accredited training in a range of psychotherapies. In addition, through the General Practitioner Therapist there is a skilled focus on the assessment and treatment of certain physical aspects related to psychosexual disorder. Referrals are accepted from General Practitioners and Consultants in other branches of psychiatry, surgery and medicine. There are currently established links with services in Great Britain for the purpose of sex reassignment surgery (as this is not available in Northern Ireland), organised through private medical facilities.

### **Service Development and Strategic Planning**

- 6.143 In the past year a strategy group has been established by the Department of Health with representatives from the four Board Areas to look at the provision of Psychosexual Services and in particular those for Transpeople. There is a general view that, as individuals with sexual dysfunctions often have comparatively less complex problems and usually require shorter periods of intervention often with simpler interventions, their needs usually should be addressed locally. This would mean that individuals with more complex cases (in particular Disorders of Gender and Sexual preference) would be referred to the more specialist services in Belfast (and where appropriate Omagh). This would also facilitate more of a focus in the

Belfast Service on the needs of Transpeople and individuals with disorders of sexual preference.

- 6.144 From a recent survey on services available for Transpeople in Great Britain<sup>179</sup> services were often so distant from patients' homes that there was real difficulty in supervising key areas of the patients' assessment and treatment due to unfamiliarity of service staff with the local circumstances of patients.

*Good Practice Example*

***Sandyford Initiative in Glasgow.*** *This project provides drop-in services for Trans people. It has received a very high level of approval by its clientele. Such initiatives may be directly transferable to appropriate locations in Northern Ireland, but due to the small numbers of Transpeople the maintenance of a co-ordinating central service would remain vital for preserving experience and expertise in relation to treatment. (Contact: 0141 211 8137).*

- 6.145 With the introduction into the Psychosexual Service in the Belfast City Hospital of psychoanalytically based treatments, there is now an opportunity in Northern Ireland for the management and treatment of patients with disorders of sexual preference who would previously have been referred to very specialist centres such as the Portman Clinic in London. This element of treatment could also provide a beneficial service to patients in the new Regional Secure Unit, as there is an acknowledged higher level of disorder of sexual preference in this group and an acknowledged link between violence and perverse behaviour. However, development of this element of service (as with gender services) will depend on whether more locally based services for sexual dysfunction can be progressed.

- 6.146 The planning and strategic process will need to address:
- the means of establishing a more locally available treatment for sexual dysfunction and the relationship of this to central specialist services;
  - the refocus of specialist services on the more complex conditions;

- a specific focus on Gender Identity Disorders, giving consideration to replicating in Northern Ireland the Scottish Needs Assessment (SNAP) Survey (2001), in order to identify fully the needs of Transpeople and also inform a more co-ordinated system of services.

### **Recommendations**

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|------|---|
| 253. | People with disorders of gender and sexuality in Northern Ireland should be offered the full range of services which have been shown to produce positive therapeutic outcomes.            |
| 254. | Service planning must involve clinical leaders, users and carers and clinical managers.   |
| 255. | As contact with services is often long term the majority of provision should be local and community based, with appropriate access to regional specialist services when this is required. |
| 256. | Services should be community based, people centred, taking into consideration a social model of health.   |
| 257. | Regional services should be targeted at individuals with the most complex needs.  |
| 258. | There is a need to evaluate the workforce requirements for service changes and for training.  |

