"Personality Disorder: A Diagnosis for Inclusion"

The Northern Ireland Personality Disorder Strategy

NOVEMBER 2008
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EXECUTIVE SUMMARY

Personality Disorder (PD) is significant in terms of prevalence, morbidity and the challenge to a range of services presented by those with the most chaotic and disturbed behaviour.

People with Personality Disorders are already heavy users of health, social care and Criminal Justice services, however in the absence of dedicated provision may not receive optimal management. Unfortunately approximately 10% of people with a PD complete suicide and 12% of all people who complete suicide have a diagnosis of personality disorder.

PD Users and their carers are least likely to be satisfied with traditional provision of care and the Bamford Review of Mental Health Services recommended the development of dedicated PD services in both the reports on Forensic Services and Adult Mental Health Services.

There is now established evidence that Personality Disorders can be effectively managed, increasing the person's quality of life and decreasing use of health and criminal justice services, however to date there have been no dedicated services developed in Northern Ireland.

The purpose of this strategy is to provide an overarching framework for the development of services for people with a personality disorder.

This strategy recommends:

1. Service users and carers should be involved at all levels of service development, planning, implementation and evaluation. This is fundamental to the success of this strategy and to facilitate this, a Service Users and Carers network should be developed.

2. Dedicated Personality Disorder services should be developed using a tiered approach to care involving users, carers, voluntary agencies, Criminal Justice System (CJS), Housing Agencies, Education, Primary Care, A&E, local mental health services and dedicated specialist services.

3. Dedicated Personality Disorder services should be built on a Hub and Spoke model (P. 33) and work with CJS and Health and Social Care Services (HSCS).

4. A Regional Personality Disorder Network Group (P. 39) should be established to support the development of services through the implementation of the Personality Disorder Strategy. Dedicated regional coordinators and clinical leads (CJS and HSCS) to take forward this strategy should be appointed as a matter of urgency.
5. An underpinning Regional Training and Supervision strategy, providing General Awareness, Basic and Specialist training in keeping with recommendations of "Breaking the Cycle of Rejection: the Capabilities Framework for Personality Disorders (DH England 2003) and the Knowledge and Understanding Framework. (P. 31) should be developed.

6. Personality Disorder Services should be subject to service, therapeutic and economic evaluation, enshrined in the planning stages of their development.

7. A review of this Strategy should be carried out in 3 years, in partnership with key stakeholders and national experts, to report progress and set future direction.
1.0 INTRODUCTION

Generally a person is felt to have a personality disorder if their personal characteristics cause regular and long-term problems in the way they cope with life, interact with people and respond emotionally. Personality disorders are common disorders, present in approximately 1 person in 20, and can cause significant distress to both the sufferer and those around him or her. It is generally considered that personality disorders are caused by a combination and interaction of genetic vulnerability and adverse early experiences such as abuse and neglect.

Disorders have significant public health importance due to their association with smoking, drinking habits, higher rates of suicide and accidental death, sexual behaviour and also mental illness. Having a personality disorder during adolescence doubles the risk of having anxiety, mood disorders, self harming behaviour and substance misuse disorders during early adulthood. People with personality disorder also have higher rates than the general population of social problems, such as homelessness.

Currently people suffering from a personality disorder already make extensive use of existing health and social care service resources, both locally and also through placements outside Northern Ireland, however this does not always result in the most appropriate or effective response. To tackle this situation it is necessary to address several contributory factors through developing dedicated personality disorder services, improving training and appropriate skills among health and social care staff, increasing optimism about the treatability and decreasing the stigma associated with these disorders. Within the Criminal Justice System similar parallel improvements would benefit the individual, their family/carers and also the wider public.

The Bamford Review recommended the development of dedicated personality disorder services, in both its adult mental health services and forensic services reports, and this was accepted in the subsequent Government response. The timescale for achieving the Bamford vision is 10-15 years, however this strategy focuses on the first developments of such services over the next 3 years.

This strategy, drawn together by a multidisciplinary working group with user and carer representation (Appendix 2), outlines the current position in Northern Ireland, draws upon experience from elsewhere, taking account of the policy and legislative context, and provides proposals for future regionally coordinated service development. This strategy aims to outline a framework which will provide services that are safe, clinically effective and cost effective and is being issued for consultation now to inform how such dedicated services for people with a personality disorder can be best established and also integrated with our existing health services and other agencies.
2.0 BACKGROUND

2.1 Definitions

Detailed definitions of personality disorder are given in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 1994) as:

An enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early childhood, is stable over time and leads to distress or impairment.

and by the World Health Organisation (1992) in their Classification of Mental and Behavioural Disorders that describe personality disorders as:

These types of condition comprise deeply engrained and enduring behaviour patterns, manifesting themselves as inflexible responses to a broad range of personal and social situations. They represent either extreme or significant deviations from the way the average individual in the giving culture perceives, thinks, feels and particularly relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems in social functioning and performance.

A useful way to consider the different types of personality disorder is to place them into 3 groups or clusters which bear similar characteristics.

**Cluster A** - 'Odd or eccentric' types (paranoid, schizoid, schizotypal)

**Cluster B** - 'dramatic, emotional or erratic' types (borderline or emotionally unstable, histrionic, narcissistic, anti-social)

**Cluster C** - 'anxious and fearful' types (obsessive/compulsive, dependent, avoidant)

Cluster C are the commonest in the community and primary care setting, however it is Cluster B, in particular Anti-Social Personality Disorder (callous, irresponsible, low frustration tolerance, lack of remorse) and Borderline Personality Disorder (unstable and intense emotional relationships, impulsivity, identity crisis, suicidal thinking and self harm, transient psychotic symptoms) that provide the greatest challenge within Health and Social Care and Criminal Justice settings because of the stress these disorders cause to the person, their family and society.
2.2 Estimated Prevalence

<table>
<thead>
<tr>
<th>Population Studied</th>
<th>Prevalence of PD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>5%-11%</td>
</tr>
<tr>
<td>Primary Care Attenders</td>
<td>10%-30%</td>
</tr>
<tr>
<td>Psychiatric Outpatients</td>
<td>30%-40%</td>
</tr>
<tr>
<td>Psychiatric Inpatients</td>
<td>36%-67%</td>
</tr>
<tr>
<td>Prisoners</td>
<td>60%-80%</td>
</tr>
</tbody>
</table>

Due to differences in methodology, sample populations and potentially real differences across geographical locations, studies vary in relation to the reported prevalence of personality disorder. In the community figures between 4 and 13% are generally quoted. However the Psychiatric Morbidity Survey (Great Britain 2000) did measure the prevalence of personality disorders in GB and an analysis of the data collected reported in 2006 a community prevalence of 4.4%.

Most personality disorders occur in those aged 25-44 years and with equal prevalence across genders, although some disorders are much more common in specific genders, e.g. anti-social personality disorder is 5-6 times more common in men than women.

Within the community personality disordered individuals are more likely to experience adverse life events such as relationship difficulties, housing problems, long-term unemployment and also to suffer from alcohol and drug problems and offending behaviour. Importantly approximately 10% of PD patients complete suicide and 12% of all people who complete suicide have a diagnosis of personality disorder.

As shown in the table above personality disorders are not only common among the general public but prevalence increases markedly in specific populations. In the primary care setting studies report the prevalence of personality disorder as between 10 and 30%, with General Practitioners (GPs) most often encountering anxious, dependent and obsessive/compulsive disorders which can contribute significantly to their overall workload.

In mental health services personality disorders are extremely common additional conditions and affect the presentation and treatment of mental illness in about 30-40% of outpatients and approximately 50% of inpatients. Significantly the presence of personality disorders is linked to poor outcomes
for the treatment of the associated mental illness, increased risk of both deliberate self harm and completed suicide, and repeated unprofitable readmissions to hospital (revolving door syndrome).

In the prison population large surveys have found the prevalence of personality disorders to be between 60 and 80%. Unsurprisingly anti-social personality disorder has the highest prevalence with estimates of 63% among male remand prisoners, 49% of male sentenced prisoners and 31% of female prisoners. Although women make up a very small proportion of prisoners it has been reported that proportionately more women than men commit suicide in prison, unlike in the community, and five times more self harm.

2.3 Management

The concept of treatability has traditionally in relation to Personality Disorders been used to exclude patients not only from compulsory admission but also from other services. Adshead (2001) describes that in no other branch of medicine does treatable equate with curable.

However the principles of treatment of personality disorder are those of any other chronic condition - the condition may not always be eradicated but distress in impairment and functioning (disability) may be alleviated in some areas and associated conditions treated.

Also research suggests that treatment outcome, particularly for patients with borderline Personality Disorder, is much better than had previously been assumed with over half showing clinical recovery.

It is generally accepted the best management approach for most mental disorders is through a bio-psychosocial model that holistically meets a person's needs. In personality disorder the therapeutic relationship is particularly important.

(a) Biological Management

In clinical practice medication is used as an adjunct to psychological and social approaches and while there is no specific medication for personality disorder nevertheless medication has been shown to be effective in some personality disorders. Anti-psychotic medication for example can reduce paranoid symptoms in Cluster A disorders while anti-depressants can help with mood difficulties in Cluster B disorders and also reduce anxiety in Cluster C disorders. Medication is also effective in the management of co-morbid mental health disorders, such as depression or schizophrenia and the management of symptoms at specific times of crisis.
In considering medication it is worth noting that people with a personality disorder tend to have higher rates of placebo response, side effects, withdrawal symptoms and poor compliance than other groups. The key element in the use of medication for this group of patients is the therapeutic relationship with the prescriber.

(b) Psychological Management

There are a variety of psychological interventions that can be effective in helping people with a personality disorder and these include counselling, dynamic psychotherapy, mentalisation, cognitive therapy and dialectical behaviour therapy. These interventions can be provided in an individual or a group basis.

However what is essential is the context of treatment and the patient's engagement with it and this requires thorough assessment by appropriately trained, consistent staff who are able to work in a flexible and responsive way to provide a coherent treatment to the user. This approach requires a sound understanding of specific dynamic issues and the opportunity to recognise the impact of the patient/client on the clinician and team.

Given that personality disorder is a long-term complex problem it follows that treatment also needs to be consistent and of long duration.

(c) Social Management

Successful engagement in therapeutic work is more likely if basic social needs are catered for (Maslow's Hierarchy of Need). However people with a personality disorder often have a compromised ability to meet their own needs or access appropriate services. Practical issues to be addressed include housing, finance, availability of services locally and transport to and from appointments. Consideration must also be given to the needs of carers and dependents.

There is a need for emphasis on a readily accessible and socially inclusive seamless integration of social and other services to avoid the repetition of previous adverse experiences for the person. Repeated "setbacks" may actually worsen the user's prognosis.

For example the ethos of the Therapeutic Community (TC) model (Appendix 3) has been applied in the treatment of personality disorder for a number of decades and there is evidence of its effectiveness. TCs provide intensive psychosocial intervention which may include a range of
therapies but where the therapeutic environment itself is seen as the primary agent of change. In this approach members of the TC are given greater autonomy in planning and engaging in their treatment and have a significant role in the everyday running of the TC.

2.4 Specific Personality Disorders

There are 2 personality disorders that warrant specific attention, Borderline Personality Disorder (BPD) and Anti-Social Personality Disorder (ASPD), and for both of these disorders the National Institute for Health and Clinical Excellence (NICE) is currently developing guidance which they expect to finalise and publish in January 2009.

2.4.1 Borderline Personality Disorder (BPD)

People with BPD (emotionally unstable personality disorder) have unstable interpersonal relationships, fluctuations in self image and mood, fears of abandonment and rejection, a strong tendency towards suicidal thinking and self harm and may have brief psychotic episodes. BPD is often co-morbid with depression, anxiety, eating disorders, post traumatic stress disorder, alcohol and drug misuse and bipolar disorder.

Just under 1% of people in the community have BPD with women presenting to services more often than men. In 2006/07 of the people admitted with a diagnosis of personality disorder to local mental health hospitals over 40% were given the diagnosis of BPD.

The current draft of the NICE guidance has identified priorities for healthcare staff in the management of people with BPD. These include ensuring that sufferers are not excluded from any services, partnership working with sufferers to develop their autonomy, the development of optimistic and trusting relationships and the careful management of endings and transitions between services. NICE recommend community mental health services should be responsible for the routine assessment, treatment and management, using multidisciplinary care planning, of people with BPD. NICE also recommend specialist personality disorder services should be developed with roles including the assessment and treatment of people with particularly complex needs and/or high levels of risk, the provision of consultative support to primary and secondary care services and development of systems for communication and information sharing.

Brief psychotherapeutic interventions (of less than 3 months duration) are not recommended by NICE for borderline personality and also medication is not recommended for BPD, but can be used in the short-term at times of crisis or for co-morbid conditions.
2.4.2 Anti-Social Personality Disorder (ASPD)

People with ASPD (dissocial personality disorder) are characterised by callous unconcern for the feelings of others, disregard for social norms, rules or obligations, an inability to maintain relationships or experience guilt, and low thresholds for frustration and aggression. They often also blame others, or offer plausible rationalisations, for the behaviour that has brought them into conflict with society.

ASPD has major public health implications in terms of its association with drug abuse, suicide, early unnatural death, violent and sexual crime, unemployment, homelessness, and family violence.

In the community there is a lifetime prevalence of 2-3% for ASPD (similar to major mental illnesses such as schizophrenia and bipolar disorder). It is commoner in men, younger people, those of lower socioeconomic status, single individuals, the poorly educated and those living in urban areas. In prisons in England and Wales, a survey in 1998 reported the prevalence of ASPD was 63% for male remand prisoners, 49% for sentenced prisoners and 31% for female prisoners.(Singleton 1998)

The draft NICE guidance priorities for the management of people with ASPD include the development of optimistic and trusting relationships, the routine use of standardised assessment tools as part of structured clinical assessment, group based cognitive and behavioural interventions and the treatment of co-morbid disorders. Equally the preventative role of measures to tackle conduct problems in children are highlighted.

Crucial for the safe management of people with ASPD is multi-agency networking. NICE recommends establishing clear pathways, enabling effective communication among clinicians and organisations, so that the most effective multi-agency care is provided. Multi-agency networks should develop standards for the coordination of clinical pathways, monitor their effectiveness and provide training, specialist support and supervision for a range of staff.
3.0 UK STRATEGIC CONTEXT

3.1 England and Wales.

The National Service Framework for Mental Health issued by the Department of Health (DH) in 1999 aimed to improve service provision for all people with severe mental illness, including people with personality disorder. Recognising the particular need of this marginalised group the DH issued two specific documents regarding personality disorder, both published by the National Institute for Mental Health in England in 2003.

The first document, 'Personality Disorder: No Longer a Diagnosis of Exclusion', is policy implementation guidance for the development and provision by Trusts of services for people with personality disorder. The objectives of this guidance can be summarised as:

(a) To assist people with personality disorder, who experience significant distress or difficulty, to access appropriate clinical care and management from specialist mental health services.

(b) To ensure that offenders with a personality disorder receive appropriate care from forensic services and interventions designed both to provide treatment and to address their offending behaviour.

(c) To establish necessary education and training to equip mental health practitioners to provide effective assessment and management.

To achieve these objectives the guidance recommended:

(a) Development of specialist multi-disciplinary personality disorder teams.

(b) Development of specialist day patient services.

(c) Development of expertise within forensic services.

(d) Development of a small number of national personality disorder centres.

(a) Development of new training opportunities.

The second document, "The Personality Disorder Capabilities Framework - Breaking the Cycle of Rejection", outlines the skills and capabilities required by practitioners to deliver good quality services within new dedicated personality disorder services, mainstream mental health services, primary care and also in the wide range of other agencies involved in treating and supporting people with personality disorders. The fundamental aim is to help create a workforce that
has a better understanding of personality disorder, thus interrupting the cycle of rejection often experienced by people with personality disorders due to current negative attitudes and practices within many agencies. It was recognised that as implementation of this framework occurred the understanding of what is required, and in particular how these capabilities may be applied by different professional groups or within specific services, would evolve and grow.

Personality Disorder Capacity Plans (2005) driven by the DH and Home Office, provided a national overview of developments, commented on common themes and recommended a series of actions to improve services. There are some key themes which emerge from these plans, including:

- recognition of the need for a robust and coherent conceptual model to support PD capacity plans and strategy;
- the importance of partnership approaches across the many agencies involved in providing support to people with PDs;
- the need to develop appropriate and robust commissioning arrangements for PD services;
- the importance of engaging with primary care to support an improved response for people with PDs;
- the essential role of mainstream mental health services in providing for people with PDs;
- the importance of staff attitudes and skills within current mainstream services in ensuring appropriate provision for people with PDs. There are also a number of important issues that are relatively neglected in these initial plans, including:

- most plans do not adequately consider needs and service provision models for people with PDs and substance misuse problems;
- few plans mention the needs of people with learning disabilities and PDs;
- the importance of service user participation is only briefly considered;
- few plans have provided a clear view of the workforce impacts of their proposals;
- few plans have referred to the needs of children and young people with early indications of emerging PDs.
The emerging Knowledge and Understanding Framework (P 31) will provide appropriate awareness and training opportunities to underpin development of PD services. This is being developed by the Personality Disorder Institute at the University of Nottingham in partnership with the Tavistock and Portman NHS Foundation Trust, Open University and Borderline UK.

The Government also recognised, following several high profile cases, the public risk associated with those people suffering from a severe personality disorder and who present a significant danger to others. Subsequent to a joint Home Office/Department of Health consultation paper in 1999, there was a Government commitment to a Dangerous Severe Personality Disorder (DSPD) programme across England.

The overall purpose of this DSPD programme is to support the development and delivery of new services so that people who present a high risk of committing serious violent or sexual offences, as a result of severe personality disorder, can be managed and treated through the appropriate pathway of care. The services are being developed under a joint partnership between the Ministry of Justice and the Department of Health with the Department of Health taking the lead in developing the pilot services below high security.

The various initiatives above aim to develop more coherent, integrated services that promote inclusion and also develop a clear programme for training that enhances the capability and skills of staff to work with personality disorder clients. Together they have informed the subsequent development of such services across England and Wales.

3.2 Scotland

The Scottish Government's 2003 publication 'Mind the Gaps' recognised that their personality service provision was "rudimentary, despite a growing evidence base for effective practice, intervention/management" and recommended the provision of adequate and integrated care for those with personality disorder.

In the Scottish Government's 2005 "Delivering for Health", and later reinforced in their 2006 "Delivering for Mental Health" there was a commitment that NHS Quality Improvement Scotland (QIS) would develop standards for Integrated Care Pathways (ICPs). The QIS is a special Health Board which works with provider organisations to promote improvement in the quality of healthcare for the people of Scotland. These ICPs aim to be both generic for all patients accessing secondary care mental health services and also condition specific for schizophrenia, bi-polar disorder, depression, dementia and personality disorder. QIS in 2007 did produce these standards for ICPs in Mental Health Services, including the one for borderline personality disorder in relation to medication, and NHS Boards are charged with local implementation and are currently
developing their local pathways that QIS will first accredit and then subsequently monitor. It should be noted the generic standards will be as important in improving the care provided as the 1 specific standard for BPD.

The Scottish Executive Mental Health Division's document 'Personality Disorder in Scotland - Demanding Patients or Deserving People?' led to the establishment of the Scottish Personality Disorder Network in 2006. This Network brings together people from different professional backgrounds, users and carers to share relevant information and learning, to promote contact with other relevant networks, NHS bodies and the Scottish Government and to explore key issues including education, training, research, treatability, pathways of care and user and carer issues.

Scotland also has an established Forensic Network whose report in 2005 "Services for People with a Personality Disorder" recommended:

- personality disorder should not be a diagnosis of exclusion from forensic mental health services;
- improved assessment and evidence based management for people with personality;
- improved staff engagement and staff training programmes;
- development of community service pilots;
- development of inpatient initiatives; and
- development of prison based pilots.

3.3 Northern Ireland

The needs of people with a personality disorder and the paucity of local services have been highlighted in the Bamford Review, both in the Adult Mental Health and the Forensic Reports. In response the Government proposals issued in June 2008 recognised the need to develop a range of services for people with a personality disorder, thus promoting access to effective evidence based interventions, and recommended the development of a specific strategy.

The Northern Ireland Mental Health Service Framework, which aims to improve health and social care outcomes, reduce inequalities in health, social wellbeing and improve service access and delivery, is currently being developed. This Framework on publication in 2009 will include standards for personality disorder which have been developed in liaison with professionals working in both health and criminal justice settings.
Since 2006 the DHSSPS has also had a formal agreement with the National Institute for Health and Clinical Excellence (NICE) and the Institute’s Guidance is now to be applied, following local review regarding its applicability, to Northern Ireland. Two NICE Clinical Guidelines, on Borderline Personality Disorder and Anti-Social Personality Disorder, are expected in January 2009 and, following local determination and endorsement, should be issued as standards our local Health and Social Care Services are expected to achieve over time, with their progress being monitored by the Regulation and Quality Improvement Authority.

Within Northern Ireland to manage sexual and violent offenders, who pose a continuing risk to the public, are new sentencing and multi-agency public protection arrangements (PPANI) introduced under the NI Criminal Justice Order 2008. These new arrangements will result in more indeterminate public protection sentences and it is likely that a significant proportion of offenders subject to such indeterminate sentences, and who pose a risk of harm to the public, will have a personality disorder and will therefore require input from specialist services for their ongoing assessment and management. Also within Northern Ireland the lead responsibility for prison healthcare transferred to the Health and Social Care Services in April 2008, and the high prevalence of personality disorder within prisons will therefore lead to an increasing need for such specialist input both within custodial and community settings.
4.0  SERVICE USER AND CARER EXPERIENCE

Probably above any other group using mental health and other support services, people with personality disorder and their carers experience least satisfaction with what is provided traditionally.

Often already compromised (by definition) by suffering difficulties in their ability to successfully negotiate interpersonal relationships, maintain a stable mood and way of thinking, together with a tendency to act impulsively, interactions with health and social care, and other services, can then be problematic. Repeated poor experiences may actually worsen outcome.

In the "Learning the Lessons" review (2007), many service users attending community based personality disorder services in GB reported feeling rejected and dismissed by generic mental health services and expressed the importance in any service of flexibility and accessibility, including appropriate skills and qualities of staff, planned discharges from services after treatment, and the provision of good out of hours crisis support.

It is essential that the views of service users and carers, including adverse experiences, inform how future services, both specialist and general, develop. This principle is emphasised by the following extracts.

A Service User’s Experience

'B' is a 54 year old woman whose first experience of mental health services was in 1995 when she was detained due to risk of self harm.

For 10 years I floundered in the mental health institutions and services. I stumbled from crisis to crisis. I was hospitalised numerous times for varied reasons and various periods of time. During this time all my relationships broke down. I had a period of homelessness during which I lived in homeless hostels and rough on the streets. I had trouble accessing housing and benefits and often had no money or food.

Unsupervised I was abusing medication. Taking enough to knock me out for a few days at a time and not having enough to last for the month. I was cutting at regular intervals. I kept a rope in the house. Self harm became a habit, an addiction. Self harm had, in a grotesque way, become a comfort to me... I was carving graffiti into my body.
‘B’ was referred to a pilot service tackling self-harm where she was diagnosed with Borderline Personality Disorder and following assessment initially offered a 6 week group therapy programme.

There were 8-10 people who had been diagnosed with BPD, and like myself varied other mental health problems. In this group BPD was explained and discussed. We were given information about the disorder. I felt I had some say, that I could approach my treatment with some semblance of control. A course of treatment was negotiated.

There were other broader benefits to services that came from this group.

Most of us had presented in crisis to A&E and our experiences had been less than helpful. We discussed this at length. As a result I volunteered as a service user to a service improvement programme for people who presented to A&E in crisis. Over time we grew more confident about A&E since we knew they were making an effort in improving their approach.

Out of hours (5pm to 9am and weekends) no services were available. We put together and networked community and volunteer services and after hours medical services and distributed phone numbers. A number of us, including myself, suffered acute episodes of our illness. I experienced more supportive management of my episode and did not need to go in to hospital.

‘B’ then entered an 18 month group.

I was having less cutting episodes. Although suicide was still an option I was able to define this feeling and work my way through to life. They once even came out to my house and took a rope I had always kept at hand to end my life. It was such a big thing to hand over my means of suicide.
A Carer’s Experience

Living and caring for someone with Borderline Personality Disorder requires every ounce of maternal love that you have.

'R' was referred by her GP to child and adolescent mental health services where weekly therapy, together with anti-depressant medication, was commenced. However, because of concerns for her physical health she required admission to a children’s ward in a general hospital and then in order to access specialist eating disorder services ‘R’ had to go to St George’s Hospital, London.

For the next 5 months I lived alone in the flat, visiting ‘R’ briefly between meal times, therapy and school. It was a very lonely existence and often the only people I spoke to were staff and ‘R’. Every weekend her dad or one of her brothers travelled to help me manage when we had to bring her home to the flat. Often she did not want to see us, was distressed and despite her protestations was forced to leave the ward. She ran out into traffic in an attempt to get knocked down and jumped on to the underground train as the doors were closing, leaving us on the platform. We had to lock away all the sharp implements and drink from plastic glasses.

At this time we began to feel that there was something more wrong with ‘R’ than, dare I say it, only Anorexia. The family therapist vaguely suggested BPD, but insisted that this diagnosis could not be made in a patient who was under 18.

Following return to Northern Ireland ‘R’ initially intermittently returned to access therapy in London, however ‘R’ deteriorated, abandoned her school subjects, began self harming, vomiting and reducing her food intake.

After each overdose and very unpleasant stay with the unsympathetic staff in hospital, she was sent home. By this time we were living on our nerves trying to keep ‘R’ safe and my own mental health was suffering.

Following one overdose ‘R’ was sectioned under the Mental Health Order and admitted to a general hospital where there was no specialist nursing staff. She was subsequently admitted to an adult and then a newly opened adolescent
mental health unit, but only after we took legal action, as they claimed she was too difficult to manage.

We spent hours every day on the unit. When she self harmed we were contacted and often accompanied her, along with staff, to A&E. On these visits we encountered unsympathetic, seemingly uncaring and often rude staff. Local anaesthetic, before stapling, was refused, and she was told if she removed stitches again subsequent wounds would not be treated.

When ‘R’ became 18 to access specialist services she again went to England. The unit she went to operated on a therapeutic community model and she responded well to dialectical behavioural therapy. However after 8 months she was sent home, with only one week’s medication. She was then referred to the North Belfast Self Harm Team where some progress is being made. ‘R’ has now moved out of the family home however this is not without its ongoing stresses.

I worry when there has been no contact for a day or two and yet dread the phone ringing for fear of what news it may bring. The hardest thing to come to terms with is the permanency and long-term aspect of the illness. I also grieve for the life that my beautiful, clever, artistic daughter could and should have.
5.0 GOOD PRACTICE INITIATIVES

While there were already in GB various statutory healthcare, criminal justice and independent services that accepted people with a personality disorder for a variety of treatments in varying settings nevertheless a range of dedicated personality disorder service pilot projects were commissioned in 2004 to develop innovative approaches that would improve the quality of care of people with a personality disorder. These pilot services aim to provide up-to-date evidence of best practice and include:

- community based personality disorder services;
- Dangerous and Severe Personality Disorder (DSPD) programme;
  - medium secure and community forensic criminal justice services
  - high secure NHS and prison service pilots.

5.1 Community Service Pilots

There are 11 pilot community services which serve different populations from metropolitan boroughs up to county districts covering over 2 million people. Services provide a diverse range of approaches with 10 of the 11 services targeting adults and one for young people aged 16 to 25 years.

Guide to key services provided by the 11 pilots

<table>
<thead>
<tr>
<th>LEAD ORGANISATION/SERVICE</th>
<th>NAME OF SERVICE</th>
<th>MAIN INTERVENTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Camden and Islington Mental and Social Care Trust</td>
<td>Camden and Islington Personality Disorder Initiative</td>
<td>Advice, support and training for adults with PD, and healthcare workers</td>
</tr>
<tr>
<td>North East London Mental Health Trust</td>
<td>Dual diagnosis assessment and response team (DDART)</td>
<td>Psychological therapies for adults with PD &amp; substance misuse</td>
</tr>
<tr>
<td>South West London &amp; St George's Mental Health NHS Trust</td>
<td>Service user network (SUN)</td>
<td>Peer support for adults with PD</td>
</tr>
<tr>
<td>Cambridgeshire and Peterborough Mental Health Partnership Trust</td>
<td>Cambridge &amp; Peterborough Personality</td>
<td>Psychological therapies and consultation service</td>
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<tr>
<td>LEAD ORGANISATION/SERVICE</td>
<td>NAME OF SERVICE</td>
<td>MAIN INTERVENTION</td>
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<td>Disorder Network</td>
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<tr>
<td>The Haven Partnership</td>
<td>The Haven</td>
<td>Support, advice, psychological therapies and crisis beds for adults with PD</td>
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<tr>
<td>Oxfordshire Mental Healthcare NHS Trust</td>
<td>Thames Valley Initiative (TVI)</td>
<td>Support, advice, &amp; day-TCs for adults with PD</td>
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<tr>
<td>Nottinghamshire Healthcare NHS Trust</td>
<td>Nottingham Personality Disorder and Development Network</td>
<td>Support, advice, psychotherapy &amp; day-TC for adults with PD</td>
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<tr>
<td>Coventry Primary Care Trust</td>
<td>The Olive Tree</td>
<td>Out-patient individual and group psychotherapy for adults with PD</td>
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<tr>
<td>North Cumbria Mental Health and Learning Disabilities NHS Trust</td>
<td>North Cumbria Itinerant Therapeutic Community</td>
<td>Support and advice, internet-based peer support &amp; a day-TC for adults with PD</td>
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<tr>
<td>Leeds Mental Health Teaching NHS Trust</td>
<td>Leeds Personality Disorder Network</td>
<td>Care co-ordination, psychological therapies and advice for adults with PD</td>
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<tr>
<td>Youth Enquiry Service/ Plymouth Primary Care Trust</td>
<td>Icebreak</td>
<td>Information &amp; counselling for adolescents with personality disturbance</td>
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Following consideration of these pilots, members of the working group undertook a visit to the Thames Valley Initiative (TVI). This initiative is one of the largest and provides a service, using a hub and spoke model, for a population of 2 million across rural and urban areas. The service uses various therapeutic approaches and aims to provide support and treatment as close as possible to the person's home.

The service model is guided by the democratic principles of social inclusion, recovery, assertive outreach and therapeutic community. There is extensive service user and carer involvement at all levels of planning and delivery and the service uses a 4 tier model (Appendix 4).
All 11 pilot services, including the TVI initiative, were evaluated and a detailed report, "Learning the Lessons", published in 2007. This report outlined the views of service users and carers, service providers, referrers and commissioners on dedicated personality disorder services and concluded that specialist services can deliver high quality care to a group of people who have been poorly served in the past. Key lessons emerging included:

- The need to improve the initial assessment process to ensure that people receive more support.
- The need to ensure optimal group sizes.
- The need for greater flexibility and consistency in rules and boundaries in groups.
- The value of providing choice and the range of interventions on offer to service users (e.g. individual therapy at sites where only group therapy or peer support would be on offer, and telephone contact or crisis support at sites where these are currently not available).
- The need for services to improve their capacity to respond to diversity: efforts should be made to make contact with young people, with people from black and minority communities and with men.
- The importance of providing more support for carers, including carers' groups.
- The importance of developing service user involvement in the services.
- The need for better childcare support and access to benefits and housing advice.

5.2 DSPD Programme

While many people already receiving services within high secure hospitals and prisons have personality disorders nevertheless the DSPD Programme aims to support the development and delivery of specific new services in order that people who present a high risk of committing serious violent or sexual offences as a result of a severe personality disorder can be managed appropriately.

5.2.1 Medium Secure and Community Services

Various NHS Trusts host pilot services to deliver the Government commitment of 75 medium secure and specialist hostel places, with specialist community teams in support. These services have developed working relationships with a wide range of partners, including local forensic and general mental health
services, probation service, prison service, the high secure DSPD pilot units and voluntary sector service providers.

<table>
<thead>
<tr>
<th>Local Organisation</th>
<th>Service</th>
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</thead>
<tbody>
<tr>
<td>East London and City NHS Mental Health Trust</td>
<td>20 medium secure beds</td>
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<tr>
<td></td>
<td>8 residential places</td>
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<tr>
<td></td>
<td>Community team</td>
</tr>
<tr>
<td>Northumberland, Tyne and Wear NHS Trust</td>
<td>16 medium secure beds</td>
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<tr>
<td></td>
<td>Community team and access to hostel beds</td>
</tr>
<tr>
<td>South London and Maudsley Mental Health NHS Trust</td>
<td>16 medium secure beds</td>
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<tr>
<td></td>
<td>10 residential places and community team</td>
</tr>
<tr>
<td>Merseyside Probation Service and Mersey Care Mental Health NHS Trust</td>
<td>30 residential place Community Risk Assessment and Case Management Service (CRACMS)</td>
</tr>
<tr>
<td>Oxleas Mental Health NHS Trust</td>
<td>6 specialist hostel places and outreach team</td>
</tr>
</tbody>
</table>

Following consideration of these pilots members of the Working Group visited the Merseyside pilot - a partnership between Mersey Care Mental Health NHS Trust and Merseyside Probation Service. This service is a Community Risk Assessment and Case Management Service, CRACMS, (Appendix 5) aiming to provide management and treatment interventions for high risk men leaving either NHS or prison DSPD services or direct from normal prison pathways.

5.2.2 High Secure Services

Specialist DSPD high secure services for men have been developed in 2 prisons (HMP Whitemoor 70 places, HMP Frankland 86 places) and in 2 high secure hospitals (Broadmoor 70 places, Rampton 70 places). Pilot high secure services for women are being developed through a partnership between the prison service and Tees, Esk and Wear Valleys NHS Trust and are based at HMP Low Newton with 12 places.
6.0 NORTHERN IRELAND POSITION

In Northern Ireland there are currently no dedicated personality disorder services, however many people with a personality disorder present to local services where staff, within existing resources, respond to their various needs. Consequently local mental health services all have considerable experience in dealing with patients suffering from a personality disorder, although relatively few people are being treated explicitly for this.

In 2006/07 there were approximately 300 recorded admissions of people with a primary diagnosis of personality disorder to local mental health inpatient hospitals, accounting for nearly 5,000 bed days. If those with personality disorder and another mental health diagnosis co-existing were taken into account this rose to 400 admissions using over 7,500 bed days. The majority of such patients were between 25 and 45 years of age and there were 2 female patients to each male.

Secondary community mental health teams have reported that 5% of their caseload present with personality disorders but can take up to 30% of team time, partly because of the complexity of their needs but also because of the pattern of their interaction and attachment styles with team members. Research also indicates psychiatric outpatients and primary care attenders also frequently suffer from a personality disorder.

People with personality disorder represent a significant number of the more than 4500 people each year who need treatment at hospital due to self harming. Providing appropriate support can prevent an ongoing cycle of repeated self harm and the risk of suicide. The self harm service for North and West Belfast that provides follow-up to people attending A&E following an episode of self harm found over 80% of those with repeated self harm had a diagnosis of personality disorder. Through provision of ongoing treatment and support, particularly group interventions, for this group of patients there has been a marked reduction in self harming behaviour, reduced proportion of A&E attendances from 30 to 5%, fewer and shorter mental health inpatient admissions and greater engagement with education and employment.

In the community and voluntary sector many agencies provide a range of supports for people with personality disorders, from addressing practical issues such as accommodation through to therapeutic interventions. One local voluntary agency between 2002 and 2003 provided a specific initiative addressing personality disorder using a Therapeutic Community (TC) model. Even though this unit was only open for a short period of time there was indicative evidence of positive outcomes including that it had decreased self harm among the residents.
Within our local prison population, as across the UK, there is a high prevalence (60-80%) of personality disorder which can present issues for the prison, including challenging behaviour and self harm. One local initiative in HMP Maghaberry is the Reaching prisoners through Engagement, Assessment, Collaborative working, Holistic approach (REACH) Unit.

This Unit has 20 places for remand or sentenced prisoners and provides a therapeutic environment for those who present with poor coping skills, self harming or bizarre behaviours. The Unit is staffed by prison officers, who have received specific training, and aims to improve the prisoners social functioning and provide for improved prisoner/staff relationships through the concept of a meaningful day which is achieved through the use of structured participative activities.

Some local people with personality disorder require specialist inpatient treatment that is not available within Northern Ireland. Since the type of service they require varies, the 4 Health and Social Services Boards commission services for such patients in a range of specialist units in GB including specialist medium secure units for personality disordered offenders. For example in 2007/08 there were 17 people who received specialist treatment in GB in 10 different units at an overall cost of approximately £1.4M.
7.0 GENERAL PRINCIPLES FOR SERVICE PROVISION

The following are proposed as general principles for the development of services for people with a personality disorder:

- People with a personality disorder should have access to services that provide person centred appropriate therapeutic interventions taking account of the complexity of conditions, the holistic needs of the service user and available resources.

- Service users should be involved in a meaningful way in the planning and development of personality disorder services.

- Services should be safe for users, carers and staff.

- Services should be subject to ongoing evaluation of outcomes, with the involvement of service users, and benchmarked where possible against other comparable services.

- Services should be underpinned by effective communication and partnership working on a multidisciplinary, multiagency basis.

- Service users should be enabled to take control of, and responsibility for, their lives.

- Service users should be provided with choice in the interventions offered.

- Support should be available and planned for times of crises.

- Support should be provided for carers including carer groups.

- Staff should be appropriately trained, supervised and supported.
8.0 SERVICE MODEL AND KEY ELEMENTS

8.1 Tiered Model

Personality Disorder services are often described using a tiered approach which allows service users to be appropriately directed according to their needs and complexity of their personality disorder and their capacity to engage with services.

Structure for Tiered Personality Disorder Services Provision

Tier 0: General Education and Awareness

Tier 1: Recognition, Assessment, Engagement (Primary Care Services and Voluntary Sector).

Tier 2: Community Based PD Specific Treatments
   Therapeutic Community
   Community Case Management with PD Practitioners
   Generic Mental Health Services
   Access to mainstream CMHT/CADS

Mostly Male/mostly dangerous because of their behaviours towards others

Mostly female mostly risky because of their behaviour towards self
Tier 3: Intensive Day Treatment i.e. "Partial Hospitalization"
Access to Acute Inpatient Care

Tier 4: Specialist Inpatient Services (non criminal justice)

Tier 5: Secure Care and Criminal Justice Service

Tier 6: Dangerous and Severe Personality Disorder – access to medium and high secure facilities.

8.2 User Networks

Ex service users have been shown to provide key roles in many services. A good example where users (STARS-Support, Training and Recovery) and increasingly carers are involved at all levels in planning, designing and delivering services and in the teaching, training and recruitment of staff is the Thames Valley Initiative.

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Who are STARS?
STARS are a team of ex-service users and experts by experience (ex-service users formally employed by TVI to work in groups). Most have been through therapy with the Complex Needs Service.

When and where do STARS meet?
Monthly, on the first Thursday of the month from 1.00 - 3.00pm, at The Friends Meeting House, St Giles, Oxford OX1 3LW

What happens at meetings?
Meetings start with a review of the last months’ activities. Some months visitors come and talk about their work and find out what we do; some months there will be training opportunities; some months we discuss particular pertinent issues etc.

What sort of ‘work’ do STARS do?
All sorts!! Roleplays, vignettes, question and answer sessions, attendance of meetings, and there’s opportunities to help with clinical work too.

Who decides what work?
STARS members decide what they would like to, or feel able, to do from a list of requests for input. This happens at the monthly meetings. There is no pressure and new members are encouraged to ‘tag along’ with an ‘old hand’ to ‘learn the ropes’.

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What’s in it for me?
There is payment available and travel expenses are covered. There may also be training opportunities for those who wish to take up.

Will this affect my benefits?
We are not experts on the help systems but believe that a variable amount can be earned without affecting benefits, depending on the help being claimed. It is an individual's responsibility to check their own circumstances and earnings limits with the Benefits Agency.

What sorts of events have people been involved with?
Lead reviewer training with the Community of Communities; service user leadership course run by a local and national organisation; attendance at conferences in Cardif, Belfast, Southampton, Athens; training courses in London and Carlisle and lots of local events in Berks, Bucks and Oxon etc.
The Thames Valley Institute runs a year long course, Personality: People and Pathology in Oxford in which STARS members are an integral part. This course is for people from all a wide variety of areas both in the statutory and voluntary sectors.

What support is available?
Support is available by phone or from other members of the group – rather like the Complex Needs support system. Staff members from the Thames Valley Institute will also be involved at the meetings. Members also have a responsibility for their own health and wellbeing.
Service user networks are a key resource and the potential support available has also been shown elsewhere:

**The North Cumbria ITC (Itinerant Therapeutic Community).**

The Itinerant Therapeutic Community was launched in March 2005 as part of the National Development Programme for Services for People with Personality Disorder. It is an innovative service which develops and delivers treatment programmes for people with a diagnosis of Personality Disorder (PD) across North Cumbria.

The specialist multi-disciplinary team supports and treats people with moderate to severe personality disorders and through outreach has improved access to treatment across a huge catchment area. It has also allowed service users who had previously been unable to engage in treatment, or could not do so without unacceptable risks, to do so safely.

- **Innovation Corner: P2P : promote self-management and personal responsibility through user-led networks of out-of-hours care**

The ITC features P2P (peer to peer), a web-based initiative developed by service users and professionals in partnership with Xenzone Internet Technologies.

P2P is an exciting extension of an existing model, the user-led informal network of care pioneered at Winterbourne, a five day TC. One to one telephone support is replaced with a dedicated website with several levels of access ranging from a home page and magazine, through a message board, to on-line group conferencing in which service users can access peer support provided by three elected service users. The site is moderated by experts by experience (XBXs) and service user members of the ITC with a clear expectation that important events are reported at the next meeting of the community.

Equality of access is guaranteed by the provision of set top boxes which allow internet access for those service user members who do not have personal computers (a bonus is that free to view channels can also be accessed!).

While a key aim of the site is to provide out of hours interventions and support that aims to prevent service users entering into crisis, it also functions as a virtual rehearsal of the fundamental principles of TC work including personal responsibility and consideration for others.
8.3 Carer Networks

In the past 2 decades there has been an increase in awareness of the needs of Carers across the UK. However there have been few initiatives to support Carers of people with Personality Disorder despite evidence to suggest that enhanced family support can be beneficial to carers and can contribute to better outcomes for users. In Northern Ireland, Carers of People with Personality Disorder report feeling isolated and, while there has been no regional investigation of carers' experiences, they are likely to be similar to those carried out in other areas of the UK. Again the Thames Valley Initiative provides a good practice example:

8.4 Multidisciplinary Team Working

The preferred model for personality disorder services is a dedicated multidisciplinary team model where a group of specially trained practitioners work together, and whilst they may divide their roles, are all part of a specialist service. If good working relationships and close collaboration within the team are fostered, treatment is more likely to be consistent and implemented according to agreed protocols.

The multi-disciplinary approach of the dedicated team has advantages, particularly for patients with severe personality disorder who require frequent
risk assessment, have multiple needs, demand continual engagement if they are to remain in treatment and provoke powerful counter-transference reactions. Such reactions of staff to patients with personality disorder commonly subvert the task of treatment and can lead to inappropriate actions on the part of staff. Therefore careful attention to counter-transference can reduce likelihood of unprofessional conduct, aid risk assessment and inform treatment intervention. The team approach dilutes counter-transference and offers a protection against any one individual becoming over-involved. In addition a team model offers the potential to implement comprehensive treatment plans in a constructive and clinically sensitive manner.

8.5 Access to Acute Psychiatric In-patient Support

One long standing belief amongst those involved in in-patient mental health hospital care is that people with personality disorders should be kept out of hospital. This is made on the basis that those with personality disorder exploit the opportunities offered by admission and, despite the fact that they do not really need to be in hospital, they create the circumstances whereby it is difficult to discharge them. However people with personality disorders have fewer attachment and support figures in the community than others and few community teams can provide the level of support needed when their functioning begins to disintegrate. Unfortunately few services have any desire to treat this group of difficult patients however the common reason for refusal that they are “not suitable” should carry little weight.

Service Users are adamant that psychiatric inpatient care should only be for when there are no safe alternatives - they comment on the poor physical environment of inpatient facilities, lack of privacy, the use of medication and detention, the stigma associated with admission and the lack of staff training and knowledge of providing for people with personality disorder. However there are occasions when in-patient admission is appropriate and indications for such acute in-patient treatment include:

- Crisis intervention, particularly to reduce risk of suicide or violence to others.
- Co-morbid psychiatric disorder, such as depression or psychotic episode.
- Chaotic behaviour endangering the patient and the treatment alliance.
- To stabilise medication.
- To review the diagnosis and treatment plan.
- Full risk assessment.
Clinical experience suggests that in-patient admission to a general psychiatric ward should be:

- Informal with patient determined admission and discharge.
- Organised around specific goals agreed between patient, psychiatrist, nursing staff and others involved with the patient’s care.
- Arranged with the clear agreement of nursing staff.
- Brief, time limited and goal determined – user may be discharged if the goals of admission are not met.

8.6 Training Provision and Staff Skills

The behaviour of people with PD can often engender high levels of stress and helplessness amongst staff teams. Underpinning success in the development of any Personality Disorder Service is ongoing training and supervision.

The Department of Health (DH, 2003) England publication “Breaking the cycle of Rejection: The Personality Disorder Capabilities Framework” sets out key skills and competencies for staff. This capabilities framework should be linked to the National PD Knowledge and Understanding Frameworks (KUFs).

The Personality Disorders Institute (Pdi) based at Nottingham University is contracted by the Department of Health and Ministry of Justice to develop KUFs, in conjunction with partners Borderline UK, Open University and the Tavistock and Portman NHS Foundation Trust. The key purpose of the KUFs is to improve the quality of service user experience by developing practitioner attitudes, skills and behaviours. The KUFs will be constructed to meet the needs of groups in criminal justice, health, independent and voluntary sectors as well as service users and carers and will be available at different educational levels to meet the wide range of learning needs.

The materials should be available from Spring 2009 and all the modules will be designed to be delivered in both distance learning and classroom based formats through the Open University and franchised arrangements with local education providers.

**Good Practice Example**

The Thames Valley initiative (TVI) was developed between mental health trusts in Oxfordshire, Berkshire and Buckinghamshire, along with Grendon Prison and Broadmoor. The training team within this provides a locally accessible training for PD practitioners. This is designed to be accessible to workers from all agencies and at all levels of education and competence.
Three levels of training have been identified: awareness, basic and specialist. These correspond to the ‘training escalator’ training stages in the DH Capabilities Framework.

‘Horizontal reach’ is required for awareness: so all staff having contact with people diagnosable with personality disorder are aware of the existence of the condition and the services available. This needs to be across all agencies, and across the geographical area served.

Basic training is suitable for any professionals whose day-to-day work involves substantial contact with PD.

Specialist training is for those who work, or who aspire to work, in PD services: the ‘vertical reach’ describing pockets (or hubs) of specialist expertise and intensive treatment.
9.0 PROPOSALS FOR PERSONALITY DISORDER SERVICES

A well developed model for PD Services should be based on therapeutic services being available at all levels of care, delivered by well trained professionals and providing a pathway of care for individual service users. Such a tiered approach to service provision is in keeping with the future stepped care model being taken forward across our mental health services and should involve partnership working with user and carer groups and voluntary sector agencies.

As there are currently limited appropriately skilled human resources available, and in order to maximise access to services for people with a personality disorder, it is proposed to initially develop services at Tiers 0-3. Also due to the specialist nature of dedicated personality disorder services, and the complexity of service user needs, it is proposed to deliver services through a regional managed network with 1 hub and 4 spokes i.e. a hub in 1 Trust and a spoke in each of the other 4 Trusts.

It should be noted the immediate lack of appropriately trained staff may require expansion of the service to be incremental. Indicative staff requirements are outlined in Appendix 6.

9.1 TIERS 0-3

Tier 0:
General Education and Awareness
This will involve the regional network working across agencies to ensure that Basic awareness of Personality Disorder – as recommended by the Capabilities Framework – is rolled out throughout the region.

Tier 1/2 (Spokes):
This will involve dedicated teams working in partnership at a local level with the Voluntary Sector, Primary Care Mental Health Services, community mental health teams, community addictions teams.

Not all users with personality disorder require intensive specialized services. Early interventions may be effective in preventing progression to a more serious condition. This requires additional resources to support greater role/input from community mental health services, voluntary agencies and primary care in the diagnosis and management of personality disorders. These tiers should promote expert user and carer involvement. As outlined earlier in this paper, people with Personality Disorder sometimes require access to acute general adult mental health in-patient units. This can be a time of great distress for the users and dedicated personality disorder services would inreach to support the patient’s care.
The residential therapeutic community is also a recognised effective model and as already outlined there is currently no such provision within Northern Ireland and establishing such a unit would require significant resources and co-operation across several agencies. This option should be explored as this Personality Disorder Strategy is implemented.

**Tier 3 (Hub):**
This will involve dedicated Day Hospital Provision and access to Acute Inpatient Care

The functions of the Tier 3 service (hub) would include:

- Provide Tier 1-2 services to the Trust area in which it is sited
- Provision of an outpatient and intensive day patient service for complex and severe personality disorders and for those who have not responded to treatment within local services. Access to intensive day treatment should be supported by dedicated residential provision allowing people to live near to intensive treatment during the week, and return closer to home at weekends.

- Setting up of user and carer networks.
- Co-ordinate and lead the training and supervision of mental health care professionals and others working at primary and secondary care levels, with the involvement of expert users and carers.
- In consultation with other Trust areas lead and co-ordinate the development of out of hours services that are locally deliverable for people with personality disorder.
- Advise commissioners on the necessity for placements outside NI and contribute to monitoring the appropriateness of such placements and interventions. This gatekeeping role would be carried out in partnership with CJS and forensic mental health services for those people requiring forensic secure placements.

- Taking forward research agenda.
- Provision of specialist input to Criminal Justice Services.
- Provision of high quality reports to support the Public Protection Arrangements Northern Ireland (PPANI).
- In reach into prison establishments to support work with personality disordered offenders.
There are 2 options for the organisation of Tier 3 services:

• A regional centre with associated outreach service to all Trust areas.
• A regional centre with “outposts” in all Trust areas.

Both options are similar in envisioning a service network for Northern Ireland with a centrally located resource, emphasising the need for a critical mass of expertise, and services provided at a distance from this centre thus tackling the issue of ease of access for residents from all parts of Northern Ireland. The principal difference between the two models is that an outreach team would be based at the regional centre, using existing health (and other) service facilities for their outreach work. An “outpost” would be a dedicated facility located at a distance from the centre.

The advantages of an outreach service include:

• Greater geographical flexibility - allowing team members to travel nearer to patients.
• Greater consistency of approach.
• Lower capital costs.

The advantages of the outpost service include:

• A greater range of therapeutic activity may take place at the outpost.
• Locally based specialised staff may have better communications with local professionals and voluntary agencies and be better placed to assess their training and support needs.

9.2 Tier 4: Specialist in-patient services

There is a debate about whether a local personality disorder service should have local inpatient specialist services (Tier 4). The cost of a local specialist inpatient service would appear to be prohibitive both in absolute terms and in relation to its effect within current limited resources on other levels of the service (out/day patient, community-based and primary care). The experienced professionals required to staff such an in-patient unit are currently not available in Northern Ireland in sufficient numbers for a sustainable service.

Therefore consideration should be given to identifying assessment inpatient beds on acute wards staffed by generic mental health staff with support by
inreach from dedicated community personality disorder services staff. This would allow for Complex and Severe PD patients, who might normally be hospitalised in an acute setting or transferred to Tier 4 services in England, to become engaged in Tiers 1-3 treatment and help facilitate care beyond this assessment either in their own locality or in England. The Tier 3 Hub should be involved in the decision for transfer to Tier 4 services and offer support to local services in facilitating the return from Tier 4 services.

Where such specialist in-patient Tier 4 services are required, they should continue to be provided as at present from units located outside Northern Ireland. We would suggest that specific preferred providers should be identified to whom all such specialised referrals would be made. Extra contractual referrals to other provider units would not be possible other than in exceptional circumstances. Apart from the probable savings resulting from a contractual approach, this would have the benefit of allowing consistent and sustained communication between the in-patient unit and local professionals regarding treatment following discharge. Additionally, local professionals could be seconded to the designated unit for short periods of time to enhance their skills in the management of personality disorders.

9.3 Criminal Justice System

In determining the most appropriate model for services, particularly having regard to comprehensive assessment of client psychopathology, construction of individualized, efficacious, therapeutic interventions with the aim of contributing to the provision of the safe and effective management of personality disordered offenders, an exploration of established services in England and Wales was undertaken.

As a result the proposal is for a model similar to the Merseyside Probation Project referenced in this report (Appendix 5). This facility is a Criminal Justice sponsored project and would appear to operate within parameters not dissimilar to Northern Ireland, particularly in terms of demand for services and the Criminal Justice legislative framework.

Formal and informal links with DSPD Services have also now been established as a result of the work involved in developing this strategy and it is anticipated that through continued collaboration a local dedicated service would be strengthened through exchange of information, particularly regarding professional issues such as Clinical Governance, Audit, Training, Research and Practice Evaluation.

It is recommended that a dedicated Criminal Justice Residential Unit be established, as the ‘cornerstone’ of a comprehensive new Outreach Service
regarding offenders whose emotional and behavioural difficulties emanate primarily from personality based deficits and deficiencies, to support the work of the new arrangements, Public Protection Teams, the Criminal Justice Order (NI) 2008 and sentencing framework.

Overall Category 3 Clients amount to about 9% of those subject to PPANI Arrangements and this means that the Category 3 caseload should be approximately 37 cases. This figure will increase through natural growth by approximately 15% annually and will also increase by the addition of Domestic Violence Cases and Hate Crimes. Estimates would therefore suggest that by October 2011 the number of PBNI Clients subject to PPANI arrangements will increase from 359 to approximately 640 Clients with a possible 58 Category 3 Clients.

The aim of the above proposal is to produce a pathway for offenders linking prison, a dedicated residential unit and other placements in the community. It is recognized however progressing this dedicated residential unit is dependent upon further resources being identified from within the criminal justice system.

9.4 Tiers 5 and 6:
Secure care, forensic services, DSPD

Elsewhere the development of these highly specialised tiers is led by the CJS. It is therefore recommended that further work with the CJS explore the options within our current legal framework for development of such services.

9.5 Training

Across Northern Ireland dedicated treatment appears to be driven by the particular expertise of enthusiastic individual practitioners usually working in isolation and without supervision and support.

However a multidisciplinary, multiagency provision, with a coherent psychotherapeutic treatment structure and service delivery approach, offers the user the expertise of different professionals and reduces the inherent risks in professional's isolation, particularly any pathological counter-transference reactions, and the potential for acting out on these. The potential for abuse of users and burnout by staff is thus reduced.

To achieve this aim a robust training programme in Northern Ireland should be developed, with a University partner, and with the support of the Trusts and Criminal Justice Agencies. This programme should provide General Awareness, Basic and Specialist training in keeping with recommendations of "Breaking the Cycle of Rejection: the Capabilities Framework for Personality Disorders (DH England 2003) and the Knowledge and Understanding Frameworks."
Initially, external specialist courses will be recommended for those who are keen to undertake further formal training. Many suitable courses exist, such as training in specific therapies, and a few are now targeted specifically at working with PD, for example the evidence based Mentalization training provided by Batemen and Fonagy at the Anna Freud Centre in London.

It is anticipated that with time Northern Ireland, initially in partnership with expert external agencies, will become self-sufficient and develop its own regional training team to support training.

9.6 Evaluation

Research and evaluation have usually either been carried out on an established service or an enhanced service retrospectively. However, the development of new personality disorder services here offers the opportunity to undertake prospective study of the developing services, together with an economic evaluation of same. Such evaluation will also ensure services maintain their therapeutic model and quality of service.

It is therefore proposed Personality Disorder Services should be subject to a variety of appropriate service, therapeutic and economic evaluations, to be designed in the planning stages of service development.
10.0 IMPLEMENTATION PROPOSALS

The successful development of dedicated PD services, in keeping with the models proposed in this strategy, will be challenging. It is therefore recommended that a Regional Personality Disorder Network Group be established, and tasked, to take forward this strategy over the next 3 years.

This regional group would be representative at a senior level of the key stakeholder agencies, include users and carers, and would be initially established by the DHSSPS.

Terms of Reference for the group would be agreed between DHSSPS and other stakeholders and include an Action Plan for the first 3 year period with specific targets for achievement within set timescales. These actions would incrementally address the recommendations from the Personality Disorder Strategy with urgent appointment of regional network managers and clinical leads, development of detailed specification for future services including care pathways, establishment of links to National Centres of Excellence/Initiatives and progression of research proposals.

The Regional Network Group would produce regular reports on progress and potential for further service developments.
11.0 **RECOMMENDATIONS**

This strategy recommends:

1. Service users' and carers' should be involved at all levels of service development, planning, implementation and evaluation. This is fundamental to the success of this strategy and to facilitate this, a Service Users' and Carers' network should be developed.

2. Dedicated Personality Disorder services should be developed using a tiered approach to care involving users, carers, voluntary agencies, Criminal Justice System (CJS), Housing Agencies, Education, Primary Care, A&E, local mental health services and dedicated specialist services.

3. Dedicated Personality Disorder services should be built on a Hub and Spoke model (P. 33) and work with CJS and Health and Social Care Services (HSCS).

4. A Regional Personality Disorder Network Group should be established to support the development of services through the implementation of the Personality Disorder Strategy. Dedicated regional coordinators and clinical leads (CJS and HSCS) to take forward this strategy should be appointed as a matter of urgency.

5. An underpinning Regional Training and Supervision strategy, providing General Awareness, Basic and Specialist training in keeping with recommendations of "Breaking the Cycle of Rejection: the Capabilities Framework for Personality Disorders (DH England 2003) and the Knowledge and Understanding Framework. (P. 31) should be developed.

6. Personality Disorder Services should be subject to service, therapeutic and economic evaluation, enshrined in the planning stages of their development.

7. A review of this Strategy should be carried out in 3 years, in partnership with key stakeholders and national experts, to report progress and set future direction.
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APPENDIX 2

Personality Disorder Working Group

Membership

Ms Julie Alexander       NIHE
Dr Ian Bownes           WHSCT
Mr Eddie Finn            NIPS
Dr Raman Kapur           Threshold
Ms Julie Lamoureux       Service User Representative
Ms Gail Leeman          BHSCT
Ms Naomhin Love          DHSSPS
Dr Philip McClements    NIPS
Dr Niall McCullough      SHSCT
Dr Ian McMaster (Chair)  DHSSPS
Mr Colin McMinn          DHSSPS
Ms Geraldine O'Hare      PBNI
Dr Maria O'Kane          BHSCT
Ms Sharman Quinn         Carer Representative
Ms Anne Rafferty         NIPS
Ms Jackie Scott          BHSCT
Mr Alan Urquhart         DHSSPS

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Therapeutic Community

Therapeutic Community treatment offers a radically different group-based approach for serious neurotic, personality disordered and long-term mentally ill patients, in specialist units. Its principles can be applied to the therapeutic care of a wide range of patient groups in different settings, including the community. The therapeutic community embraces a set of methods which aim to treat people suffering from emotional disturbance in a communal atmosphere.

Therapeutic Community principles are based upon a collaborative, democratic and deinstitutionalised approach to staff-patient interaction. Highlighting this approach, patients are generally referred to as residents or members of the community. Traditional staff/staff and staff/member hierarchies are replaced by a more liberal, humane and participative culture.

The Therapeutic Community (TC) offers a safe environment with a clear structure of boundaries and expectations where members have the opportunity to come to terms with their past through re-enactment within a treatment setting involving other members and staff. Group psychotherapy and traditional psychoanalysis are integral to the treatment, but TCs also offer the individual experiences to awaken creative and social abilities. Members tend to learn much through the routine interactions of daily life and the experience of being therapeutic for each other. Through this psychosocial therapy the aim is to encourage members towards a better understanding of their previous behaviour and to enable them to improve their inter-personal functioning, first within the therapeutic community and ultimately in the wider community. Encouraging and reinforcing the notion of personal responsibility and sharing, members and staff meet together on a daily basis to discuss the management and activities of the community, to assess applications for admission and to support leavers.

Members of Therapeutic Communities are not normally detained under the Mental Health Act; attendance is generally voluntary, and to benefit from participation in a TC the member must be positively motivated to change his/her behaviour, to co-operate in group therapy and to accept the rules of communal living.
The Thames Valley Initiative TV1

Tier 1 - Assertive engagement and active assessment.

- Access by self referral to publicly advertised open groups held in easily accessible venues not traditionally associated with mental health provision.
- Organised with numerous agencies at locality level.
- Groups occur in 16 week cycles at the same time and place, take up to 15 people and are facilitated by 3 staff.
- On completion of 16 week programme users can choose to leave, repeat or be referred to another part of the service.

Tier 2 - Outreach, inreach and 'access to therapy'.

- Intensive outpatient treatment, e.g. 2 days per week for at least 16 months.
- Includes weekend programmes for those in full-time work or education.
- Requires larger geographical coverage for formation of appropriate groups.

Tier 3 - Day programme, definitive treatment.

- Locally accessible whole time daily programme 5 days each week and lasting up to 18 months.
- Either mixture of individual group therapies or only groups.
- Therapeutic day unit run as a non residential group orientated therapeutic community.

Tier 4 - Leaving process, graded disengagement.

- Primarily group and up to 18 months.
- Half day per week (or less).
- Liaison with other agencies, eg college, employment.
CRACMS

Resettle - Community Risk Assessment and Case Management Service

(A new service for personality disordered offenders in Merseyside to support the work of multi agency public protection panels.)

The Resettle (CRACMS) project is a 4 year researched pilot project, commencing in April 2008, funded by the Department of Health and Health and Offender Partnerships and led by Probation. It will establish an innovative, multi agency community based project in Merseyside for personality disordered offenders on release from prison.

It will be a researched pilot community risk assessment and case management service for released high risk prisoners.

It will:

- Be based in Merseyside.
- Take referrals from Merseyside Multi Agency Public Protection Panels.
- Provide a community based assessment and interventions service for level 2 and level 3 MAPP (Multi Agency Public Protection Panel) cases, with a personality disorder.
- The community based service will also provide in-reach services to prisons and hostels.
- The interventions service will provide long-term support based on a social therapy model, with a high staff: participant ratio.
- Participants will be tenants in the unit.
- The unit will also provide a base for staff, for programmes of work with offenders.
- Provide 24/7 out of hours telephone helpline service.
- A short term crisis and relapse bed will be provided within Probation Approved Premises.
- Interventions will include housing support, employment/education/training, social network, activities and psychiatric/psychological interventions to reduce risk, including substance misuse services.
The project will work to ensure the longer term support of the individuals at the end of the 3 year pilot, including the development of Circles of Support and Accountability, to maximize the possibility of people remaining in the community and leading productive, offence-free lives.

Research is integral to the project. This area of work is unresearched/poorly researched. The aim of this pilot is to establish whether a co-ordinated community psychosocial provision for Personality Disordered Offenders is effective in reducing re-offending and social exclusion, managing risk in the community and enhancing the quality of lives of individuals.
Indicative Staff Requirements

The Hub

To provide comprehensive psychotherapeutic care, supervision, training and support the following are indicative staff requirements for a regional centre:

1 Regional Manager Band 8 A/B
1 Consultant Psychiatrist in Psychotherapy
User Advocates
Carer Advocates
1 Team Leader Band 7
2 Clinical Psychologists/Psychotherapists Band 8C
2 Clinical Psychologists/Psychotherapists Band 8A
2 Psychotherapists Band 7
1 Staff Grade Psychiatrist
1 Specialist Registrar
1 SHO
6 Nurse Therapists Band 7
2 Occupational Therapists Band 7
2 Approved Social Workers Band 7
6 CSW Band 3-4 (to include housing support and education officers)
2 Band 6 /7 Addictions practitioner
2 Administrative Staff Band 3
2 Administrative Staff Band 4

It is also expected a team, with input from H&SC professionals, is developed to work in partnership with CJ Agencies. This team would comprise:

- Forensic Psychologist
- Forensic Psychiatrist
- Probation Officers
- Mental Health Nurses
- Programme Delivery Staff
- Housing Resource Officer
- Addiction Counsellor
- Employment/Education/Training
- Senior Management
- Activities Workers
A Spoke

An outreach team/outpatient service:

- 1 team leader Band 7
- 1 Clinical Psychologist/Psychotherapist Band 8A
- 1 psychotherapist Band 7
- 2 specialist nurses Band 7
- 1 social worker band 7
- 1 Occupational therapist Band 7
- User and Carer Advocacy
- 2 Community Support Workers
- 1 Administrative staff Band 3
- 1 Administrative staff Band 4