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# INNOVATION IN ACTION:

## Review of the Effectiveness of Centrally Commissioned Community Personality Disorder Services

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## **Declaration of Interests**

Dr Rex Haigh.....

Dr Lisa Wilson, DPsych independent researcher and chartered practitioner psychologist with special interest in complex emotional needs. Commissioned to conduct this research for the National Personality Disorder Unit.

## Executive Summary

This report presents a summary of the findings of the review of National Community Personality Disorder Pilots commissioned by the Department of Health in 2004. The aim of the commissioning of these pilots was to identify practice-based evidence regarding effective therapeutic interventions with individuals experiencing complex emotional needs. This was identified in Personality Disorder: No Longer a Diagnosis of Exclusion (2003) as an area of unmet need for a significant proportion of the national population. The report outlines the outcomes of the pilots with regards to Quality, Innovation, Productivity and Prevention. A number of key findings are identified that should inform the future development of policy and practice for this clinical population; furthermore a number of recommendations are made with regard to developing future services and the importance of maintaining those already in operation.

The report highlights the following points:

- ❖ Significant progress has been made towards the establishment of **practice-based evidence** for providing a therapeutic service for individuals with complex emotional needs. This evidence base can guide the development of future evidence based practice as well as service development.
- ❖ A range of service models and theoretical orientations were implemented by different services, and while no specific model amongst these emerged as superior, there were a number of **general therapeutic conditions** that were common to all the services.
- ❖ The pilot services all demonstrated the following **fundamental assumptions** to delivering the treatment.
- ❖ The importance of:
  - human relationships;
  - the psychosocial environment;
  - investment in the programme;
  - importance of leadership;
  - effective team work;
  - establishing good networks and partnerships.

- ❖ The national pilots have achieved significant results in relation to both **human and economic cost savings**.
- ❖ There is good evidence amongst the pilots of the **prevention** of continuing harm and the prevention of deterioration of conditions.
- ❖ The services have enabled individuals to access **employment and work-related activities**, as well as reducing the demands on a range of agencies.
- ❖ The services have succeeded in developing **recovery communities** and building **social capital** to ensure the maintenance of recovery.
- ❖ **Revolving door care** has been halted for the users of these services.
- ❖ **Organisational and recruitment characteristics** are identified as important to the success of this type of service, in particular a willingness to support innovative approaches to service delivery.
- ❖ The outcomes in relation to **quality of life** have been significantly improved for individuals accessing these services.
- ❖ The services have offered whole life treatments that are qualitatively different to those offered by traditional mental health and psychological therapy services, this relates particularly to the **quality of relationships**, the focus on **long-term outcomes** and the **therapeutic environment**.

## **Aim of this report**

This document provides an examination of the effectiveness of the eleven community projects which were commissioned in 2004 by the Department of Health (DH) for the treatment of personality disorder (PD), geographically covering 15% of the total English population<sup>1</sup>. This has been structured with reference to the DH Quality, Innovation, Productivity and Prevention (QIPP) Programme. The report identifies the outcomes achieved by each of the services, and the significant progress that has been made in relation to the development of the evidence base for improving services and outcomes for those with complex emotional needs

The clinical review was undertaken by a small team from the Department of Health to evaluate the initiative in line with the demands for economic efficiency in terms of QIPP evidence, and to demonstrate how the learning from these clinical innovations could support future development of PD services for the other 85% of the English population and contribute to the mental health QIPP work stream.

In Talking therapies: A four-year plan of action (2011a) the department of health identified that there are gaps in psychological therapies provision for individuals with personality disorder. Furthermore, the new Mental Health Strategy (DH, 2011b) The intention of policy-makers is to consider the ways in which individuals with such complex emotional needs may be better met. This report seeks to inform policy developments with regard to both the overall strategy and the IAPT for Severe Mental Illness considerations.

The report identifies the main conclusions of the Community PD programme and identifies recommendations in relation to the provision of services in the future for individuals diagnosable with personality disorders, or complex emotional needs.

## **Background to the Report – Setting the scene**

### **Purpose of the Community PD Programme**

The National Personality Disorder pilot was undertaken with the following aims:

- To develop new approaches to treatment and care of people diagnosable with Personality Disorder
- To strengthen the capabilities of the workforce through education and training

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<sup>1</sup> Total population of the eleven pilot areas = 7,572,000; of England = 51,446,000; data based on information taken from the Office of National Statistics.



- To reduce social exclusion
- To improve health and social care outcomes for individuals with problems that could be identified as Personality Disorder with respect to use of other services, gains in social capital, gains in well-being and other measures of recovery

The initiative was intended to have an impact upon the services received by a group of individuals who were newly recognised to be excluded from mainstream health and social care provision. As such this initiative was considered to have a potentially positive impact in terms of equality impact assessment.

This review has determined, through a process of individual service evaluations involving staff and service users, that the aims of the programme have been achieved overall for those who have been able to benefit from the services provided. However, this is not a finite process and requires continued effort and momentum to ensure the outcomes impact upon treatment and care nationally.

Box 1 identifies the experiences of an individual who was able to access one of the services in the pilot programme. Their experiences prior to entering the service are identified as typical of those for whom the pilots were set up to assist.

**Box 1: A Service User Experience**

*Gayle was 31 years old when was referred to the service in 2007 with a long history of problematic, persistent and pervasive problems that impacted on all her life domains. She had experienced a traumatic and troubled childhood punctuated by physical and sexual abuse from a significant care giver; this led to a significantly disrupted educational experience and ultimately resulted in exclusion. This led further to drug and alcohol use, abusive relationships and poor employment history. She took her first of many overdoses at 19 years old and the cycle of admission to psychiatric hospital began. She moved from city to city in an often desperate attempt to escape her troubled and disturbed mind. Her deliberate self-harm continued and mental health services avoided her, if at all possible. She unconsciously set up and constantly experienced rejection across services.*

*Eventually she found her way to this service, due to the persistence of her GP who continued to refer her to mental health services despite being told that there was nothing that they could do to help her. Her journey within this service was not easy with plenty of false starts and fragmented engagement particularly in the first year. Nonetheless with encouragement from other service users who could relate to her experience, Gayle gradually found the strength to engage in the treatment programmes on offer.*

*Gayle has been able to successfully move on from the service; she relocated to be with her partner; her life is more stable; she has a part time job and is in the process of coming off benefits. In her last update she acknowledged that she still has her struggles with life but she is much more optimistic about the future and expressed her desire to return to college to take up where she left off all those years ago.*

## Policy Context with regards to Personality Disorder

Two policy implementation guides were published by the National Institute for Mental Health in England (NIMHE) in 2003: *Personality Disorder: No Longer a Diagnosis of Exclusion* and *Breaking the Cycle of Rejection: the Personality Disorder Capabilities Framework*. They were produced in response to the policy proposals outlined in: *Managing Dangerous People with severe Personality Disorder (DSDP)* (1999).

Since the publication of *Personality Disorder: No Longer a Diagnosis of Exclusion* (NIMHE, 2003) there has been growing awareness of the impact upon individuals with complex emotional needs in the delivery of mental health services. Prior to this those with such problems were frequently excluded from services or received interventions inappropriate for their needs. The personality disorder diagnosis, more than any other, attracts pejorative attitudes including considerable stigma and blame (Lewis & Appleby, 1988; Haigh, 2002; see Wilson, 2011 for further discussion).

*No Longer a Diagnosis of Exclusion* outlined a need to involve specialist teams and specialist day services, particularly in areas with high morbidity; and indicated that funding would be available for such purposes. It also outlined the need for development of forensic services to fill the gap between the high security services, which were part of the programme for dangerous people with severe personality disorder 'DSPD', and forensic mental health services. Numerous further developments have followed, most recently the joint Department of Health and Ministry of Justice publication of the *Response to the Offender Personality Disorder Consultation*, on 21 October 2011.

*Breaking the Cycle of Rejection: the Personality Disorder Capabilities Framework* proposed the development of training and education programmes as essential for ensuring a competent workforce. As a consequence, the **Personality Disorder Knowledge and Understanding Framework (KUF)** was jointly commissioned by the Department of Health and Ministry of Justice in 2007, and widespread implementation commenced in 2009, further there is a planned programme of delivery to 2014-15.

The commissioned services described in this report were one of three parts of the National Personality Disorder Development Programme, the 'Community PD Programme'. The others were mental health of offenders diagnosable with PD in partnership with the Home Office, and the later Ministry of Justice; and interventions with children and families to prevent the development of PD in partnership with the Department for Children, Schools and Families, and later Education.

## The Community PD Programme

In 2002 a NIMHE survey of National Health Trusts in England identified that just 17% of respondents provided a dedicated personality disorder service, and 28% provided no service; 15% of trusts did not

respond. There was no parity of approach identified amongst those providing services, with a range of interventions, service leads and models being employed. There was no agreement identified in the need to provide specific services and many considered to do so fell outside the scope of health services. Amongst those Trusts providing specialist provision, this frequently occurred as a result of enthusiasm and commitment of a single individual, championing the cause within their locality and facilitating local funding and clinical interest.

While the evidence base for providing effective treatments for individuals with complex emotional needs is growing, it continues to be smaller and less well-resourced than for other mental health diagnoses, and this was one reason for commissioning a range of different pilot projects. Bateman and Tyrer (2002) reviewed the available evidence at the time and identified that therapeutic interventions could work; however, no single approach could be prescribed. They determined that a combination of psychological treatments alongside drug therapy at certain points was the general view of effectiveness. However, they were able to identify that therapeutic interventions needed to be: well-structured; focused; theoretically coherent to therapist and client; long-term; well-integrated; as well as placing importance upon achieving treatment alliance and treatment adherence. Bateman and Tyrer further identified Dynamic Psychotherapy; Cognitive Analytic Therapy; Cognitive Therapy; Dialectical Behaviour Therapy; and Therapeutic Communities, as potential options. They also identified variability in the use of antipsychotic, antidepressant and mood stabilising drugs. The lack of conclusive evidence with regards to the most effective treatments was later confirmed by the 2009 guidelines published by the National Institute for Health and Clinical Excellence (NICE: CG77 & CG78).

Based on the evidence-based knowledge at the time and research directly informing the development of *No Longer a Diagnosis of Exclusion* (e.g. Fahy, 2002), the following guidance for those wishing to develop specialist outpatient services was provided:

- Services should involve multi-disciplinary team input
- Treatment should be led by clinicians with appropriate knowledge and training alongside dedicated resources
- Referral and acceptance criteria should be based on the capacity of other services to provide appropriate interventions across a range of severity
- Service users should experience the service as a team-based approach
- Team relationships should be good to allow effective collaboration involving consideration of biological, psychological and social aspects of care provision
- Teams would ideally be based within existing psychotherapy, psychological therapy or psychology departments, although service delivery models would need to be more adaptive than conventional approaches in psychotherapy departments.
- Referral protocols and acceptance criteria should be clearly identified at the outset and set out to ensure that those most needing the service are not excluded from it

- The core service functions should include: principles of CPA; provide consultation, support, supervision and training; clear links with local and regional forensic services; development of a self-help network; out of hours/crisis arrangements
- The development of day units will be locality-dependant according to the needs of the population, those localities with highest morbidity should develop such facilities alongside specialist outpatient teams.

All the pilots under this initiative were commissioned in line with this guidance. Furthermore, the service evaluations conducted during 2011 by the clinical review team, determined all the services to have implemented this guidance. However, the knowledge gained through the on-going implementation of the services, enables this guidance to be developed further as a result of learning what works in different localities with different models of delivery.

The purpose of commissioning the pilots was to identify innovative approaches to working with a population who had previously been excluded from services or had received care that was of poor quality, ineffective with regards to outcomes, and consistently resulted in poor patient and carer experiences. This was driven by a change policy with regards to treatability, and a lack of evidence base with regard to best practice as well as the most effective specific treatments. **The focus was to improve outcomes, develop the knowledge base, improve patient and carer experience, and subsequently reduce impact upon other services, where many of those using the pilot services were frequent attenders.**

The pilot projects were initially funded with £6.9m directly allocated from the High Secure Commissioning Board, with a view to the later devolution of funds to Primary Care Trusts through mainstream mental health budgets. At the same time an additional £10 million was allocated to Primary Care Trusts for the provision of personality disorder services nationwide, however, this was not ring-fenced money. Latterly, the closure of several specialist residential services resulted in monies being reallocated across the pilots involved in provision in the relevant regions.

The eleven projects were originally researched by a two-year project commissioned through the Service Delivery and Organisation (SDO) Programme of the National Institute of Health Research. It was a four-part study (organisational, service-user, outcome and Delphi exercise) entitled 'Learning the Lessons'. It was led by Mike Crawford at Imperial College (See Crawford et al., 2007).

## **The Burden of Morbidity and Mortality**

Prevalence studies suggest that personality disorders are common conditions, although they vary in severity, level of disturbance and the degree of comorbidity (NIMHE, 2003). As many as 10-13% of the general adult population are thought to be effected, although more conservative estimates have been suggested more recently. The proportion of people with complex emotional needs is much higher than this within mental health populations, particularly inpatient units.

Those with complex emotional needs have been identified as being more likely to suffer from substance use problems, eating disorders, and numerous other mental health problems (e.g. Linehan, et. al, 1991; Zanarini, et. al, 1998). In addition they are more likely to experience adverse life events including relationship difficulties, housing problems, homelessness and unemployment. They are also found to have frequent and escalating contact across a range of services including mental health, social services, A&E, GPs and the criminal justice system. The presenting problems tend to be characterised by recurrent episodes of deliberate self-harm, substance abuse, interpersonal problems, anxiety, depression, brief episodes of psychosis, eating disturbances and sometimes violence, more commonly as victims than as perpetrators. Furthermore, where an individual experiences additional problems, such as schizophrenia, treatment is impacted and prognosis worsened (Moran, 2002).

In 2009, the National Institute for Health and Clinical Excellence (NICE) identified that the economic costs of personality disorders are high, **with regard to healthcare costs individuals with the most complex problems account for the greatest demands upon acute and mental health services which results in higher approximated costs than other diagnoses such as depression.**

Many individuals with complex emotional needs have treatment histories punctuated by revolving door care, including multiple admissions, inadequate care planning, infrequent follow-up, incomplete treatment, and unmet needs. In addition lack of understanding of their needs and effective treatment interventions have often resulted in negative experiences of services further impacting problems and increasing distress, as well as causing engagement difficulties in future contact with services (Haigh, 2002). Staff have been reluctant to work with individuals with complex emotional needs due to concerns about skills deficits and due to the complexity of the interactions that they may encounter. In addition this reluctance has been identified as resulting from previous universal opinion that 'personality disorder' is 'untreatable' (Crawford et al., 2007). **Training staff to increase understanding and establishing consensus regarding effective treatment and increasing the availability of that treatment would prevent multiple admissions, reduce revolving door care and consequently resulting in high cost avoidance.**

NICE (2009) suggests that 279,200 people across England over the age of 17 have a diagnosis of borderline personality disorder alone. Singleton et al (1998) suggest that within mental health populations more than 50% are thought to have borderline personality disorder. **The total number of people with complex emotional needs, or diagnosable with personality disorders is estimated to be 2.46 million**, with a projected increase to 2026 of 9.3% (McCrone, Dhanasiri, Patel, Knapp and Lawton-Smith, 2008).

NICE (2009) examined hospital episode statistics and identified that in England between 2006 and 2007 there were 1062 admissions for individuals due to personality disorder and 738 of these were emergency admissions resulting in 42,130 bed days at a cost of over £10 million. This is unlikely to represent the full costs as hospital episode statistics depend upon coding, accordingly it is likely that most individuals would not be coded as personality disorder admissions. Consequently, even assuming that this is only a minimal underestimate **preventing admissions could result in significant savings.**

The complexity of calculating the economic costs of mental ill health result in a wide variation of estimates. However, what is acknowledged is that mental ill health generally results in health and social care costs related to the direct provision of services, as well as the costs of informal care provided by those that support sufferers; the human costs related to quality of life; and output losses in the form of ability to work (Sainsbury Centre for Mental Health, 2003). The cost of NHS, social and informal care is estimated to be £22.5 billion per annum based on 2007 figures for all mental health problems, and these are predicted to rise to £32.6 billion by 2026 based on 2007 prices, although this rise is primarily due to the cost of dementia care for an aging population (McCrone, et.al, 2008). 13.8% of NHS costs are spent on mental health (Mental Health Strategies, 2008). The total costs of health and social care were further estimated by the Sainsbury Centre (2003) to be in the region of £77 billion a year in 2003. Comparatively, and only considering those in contact with primary care, service costs of £704 million were estimated in 2007 (McCrone, et. al, 2008). Taking into consideration the lost employment costs this figure increased to £7.9 billion. These costs are predicted to rise to £1.1 billion and £12.3 billion respectively by 2026. Thereby, a brief report by the Mental Health Development Unit (2010) identifies that there are **significant savings to be achieved across mental health with improved early intervention, reducing length of stays in hospital and as well as reductions in GP consultations and prescriptions**. Complex emotional need significantly predict increased total costs (Rendu, Moran, Patel, Knapp & Mann, 2002).

There is a **high risk of suicide** amongst those with complex emotional needs. In the consultation document published by the Department of Health (2011) with regards to a new suicide prevention strategy, many of the comorbid problems experienced by those diagnosable with personality disorders were further associated with increased risk of suicide. It is estimated that there are rates of up to 17% in those with borderline personality disorder diagnoses alone. This represents a high human cost as well as high economic costs (Sainsbury Centre for Mental Health, 2003).

## The Choice of Eleven Community PD Services

Proposals to provide specialist 'Community PD Services' were invited in late 2003; this was managed through the eight regional NIMHE centres. 25 applications reached the final stages of the bidding process and service user representatives were recruited as part of the final selection panel that determined the successful eleven bids (Haigh, 2007). The criteria for selection included:

- A diversity of approach
- A variety of stakeholders, internal and external to mental health
- Partnership working to create new types of services
- Meaningful service user involvement
- Use a pathways approach and not a single therapy provision
- Have good governance arrangements

- Emphasise evaluation and dissemination

All eight regions had at least one pilot, with London being allocated three smaller projects and two in the Eastern Region. The four largest projects selected were in Nottinghamshire, Leeds, Thames Valley and Coventry. The range of different approaches included one managed clinical network, four modified therapeutic communities, two service user led initiatives, one integrated skills service and one early intervention youth service for 16-25 year olds (Haigh, 2007). Table 1 identifies the services that were selected as part of the national pilot initiative.

**Table 1: The services selected to be part of the national pilot for community PD treatment**

Location	Service Name	Sector	Premises
SW London	Service User Network (SUN)	NHS and service user	MH hospital and other
Camden & Islington	The Skills Development Service (SDS)	NHS and employment	Community MH and other
Colchester	The Haven	Social enterprise	Detached suburban house
North Cumbria	Itinerant Therapeutic Community (ITC)	NHS	Local rugby club
NE London	Dual Diagnosis And Response Team (DDART)**	NHS	Community MH and public spaces
Cambridge & Peterborough	Complex Cases Service (CCS)	NHS	MH hospital and other
Coventry	The Olive Tree	NHS	Community MH
*Oxfordshire	Complex Needs Service (CNS)	NHS	Community MH and other
*Buckinghamshire	Complex Needs Service (CNS)	NHS	MH hospital and other
*Berkshire	Complex Needs Service (CNS)	NHS	Community MH and other
*Thames Valley Initiative	Support, Training and Recovery System (STARS)	NHS and service user	Quaker Meeting Houses and others
Leeds	Managed Clinical Network	NHS coordinated	Community MH and other
Nottinghamshire	Personality Disorder and Development Network (PDDN)	NHS and voluntary	Community MH

Plymouth	IceBreak	Youth services	Youth advice agency, 'The Zone'
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*\*Conceived as a single project but now separately managed within different Foundation Trusts*

*\*\* Now IMPART (Intensive Management of Personality Disorder Assessment Recovery and Treatment)*

**Early Discoveries from the National Pilots**

The initiative achieved good outcomes for service users within the first two years of operation (Crawford et al., 2007). A number of the individual services undertook economic costing activities to identify the potential cost efficiencies of these outcomes and the sustainment of these outcomes over time. It was anticipated by the national programme that this initiative was a long-term commitment to treatment provision that would deliver cost savings over a number of years. However, immediate cost savings were identified, mostly related to human costs early on. While different models were employed by the services, overall they all implemented an approach to treatment different to that employed by traditional mental health and social care systems; the characterisation and description of this was a major impetus for producing this review. One particular distinguishing feature was the apparent presence and support of organisational impact factors that were conducive to innovation and development. Differences in the extent of innovations amongst the services may be attributable to the degree of presence of these organisational factors. Furthermore, these pilot services all employed multi-disciplinary teams and attempted to work in partnership across agencies, thereby reducing the economic and human costs of duplication and communication delays.

**Negotiation of barriers**

There was a mixed reception to the initiative amongst stakeholders: this was a radical approach that many stakeholders were unable to fully comprehend. However, similar themes repeated throughout this review including the importance of recruiting the right people for the service. Furthermore, barriers relating to the treatment of risk by some organisations presented significant challenge. Local networking was used, and continues to be used, in order to develop strong relationships and improve accessibility through knowledge and recommendation of the service. Some services were also required to navigate the difficulties in providing a specialist service, when other services believed they should treat all individuals who presented with personality difficulties and not only those with the most severe and complex problems. In addition, some of the interventions provided initially required a 'bedding-in period' that meant effectiveness took time to develop, for example the need for intensive group therapy treatment programmes and therapeutic communities to mature for them to be most effective. Overall because of the tendency for services to exclude individuals with personality disorders many teams had to overcome negative attitudes of other stakeholders through networking and commitment to challenging stigma.



## Establishing the evidence for effectiveness

### Measuring Outcomes and Developing the Evidence Base

All the pilots were tightly monitored and all were expected to conduct local evaluation as well as participate in national evaluation. Due to the heterogeneity of approaches, limited funding, necessity of establishing a 'steady state' and complexity of treatment models, simple randomised controlled trials were not feasible at the outset. Therefore other methods were initially used to evaluate services and demonstrate effectiveness; however, an RCT is currently underway at one of the projects (Pearce & Autrique, 2010), and another service has plans for this (Denman, 2011).

Some services were not able to identify actual cost savings or verify self-reports of reduced health service utilisation necessary for evidence within the QIPP programme. However, they were able to identify other outcomes indicative of cost efficiencies and impacts upon patient safety and experience contributing to the establishment of evidence within the QIPP programme. The specific measures will be identified later in this report. **The data that has now been gathered by the local services would benefit from national collation to enable baselines to be established and to inform future costing templates and revision by NICE (e.g. 2009b).**

All the projects within this initiative were found to have contributed to the evidence-base through a range of peer-reviewed and non-peer reviewed journal articles; through evaluations by local universities; through use of audit; through presentations at conferences and workshops; through book publications; through newspaper articles; and one project was the subject of a PhD thesis; also the *People, Personality and Pathology* course run by the TVI STARS service requires each course participant to complete a project that will have an impact upon the way in which their local PD service works. The extant of literature produced by the services is extensive. In addition a number of projects have also been accredited the Royal College of Psychiatrists Centre for Quality Improvement's 'Community of Communities' programme.

### Outcomes determined by Qualitative Method

Examining the available literature, interviews with staff and service users at the projects, as well as the literature available advertising each service nine main themes were identified and connected the services irrespective of differences in the models employed. These could therefore be identified as the essential foundations for effective outcomes.

The nine main themes were divided into those that were important as inputs and those that were important outputs. A diagrammatic representation of these themes can be found in Appendix 3.

#### The inputs:

- Providing **the right environment** that is safe, accessible, welcoming, boundaried and valuing for staff and service users;

- Adopting a **service culture** that emphasises and places importance upon: effective team and multi-disciplinary working, investment in staff, organisational support, leadership, flexibility and adaptability, long-term vision, transparency, innovation and partnership working;
- Having an underlying **therapeutic philosophy**, irrespective of approach or model, that emphasised humanism, enablement, validation, acceptance, challenge and patience;
- **Reciprocal investment** by staff and service users, that was determined by real congruence, respect and valuing of the programme and each other, commitment and investment, compassion, collaboration and learning, transparency and ownership
- The importance of **shared experience** between service users, staff and the community as a whole that involved learning, enjoyment, collective responsibility, ownership, inclusion, belonging, identity and was emotionally restorative

### The outputs:

- Improving the **quality of relationships**, at several levels: with the service, with staff and each other, and with oneself. These were connected through the development of personal responsibility, challenge, trust, understanding, acceptance, patience, respect, each having been modelled by the services themselves;
- An effective sense of **personal agency** relating to identity, authenticity, resilience and humour, channelling creative expression, empowerment, sense of purpose, and increased knowledge about self and relating;
- Use of **social resources** and the ability to adapt and be flexible according to the needs of all, this encouraged reintegration, shared knowledge, inclusion, support, challenge, restoration and normalisation of experience;
- **Psychological safety and prevention of self-harm** through honesty, boundary setting, acceptance, nurturing, trust, collective responsibility, and patience.

While a theoretical understanding of these themes could be determined according to theoretical orientation, epistemology and ontology, in essence each places **emphasis upon providing humanistic principles to service delivery and placing service users as the foremost stakeholders in the development and continued delivery of the programme**. While one of the services places this as fundamental to the model, for example the Service User Network (SUN) in South West London, the majority of the services found various innovative ways of effectively incorporating this.

### Outcomes determined by Quantitative Method

With regard to quantitative outcomes measurement, a number of standard questionnaires were used in the first two to three years by all the projects in the programme as part of the research led by Imperial College. These included a PD screening measure (SAPAS), rates of health service use and serious incidents (SUQ), social functioning (SFQ), measure of self-harm (SHQ), and Clinical Outcomes in Routine Evaluation (CORE). Some services added others such as quality of life measures (EQ-5D), baseline diagnosis as identified by diagnostic tools (IPDE or SCID-II), and changes indicated through re-

administration of these. Furthermore, performance reviews with visiting teams from the Department of Health were conducted regularly during the first five years of the programme, and involved service user commissioners as members of the reviewing panels.

After the formal research data collection finished in 2007, there was no standard dataset required by the National Programme. However, the projects which operated as therapeutic communities and accredited as such by the Royal College of Psychiatrists, all continued to routinely collect a slightly modified version of the original dataset, under the coordination of the research committee of the Association of Therapeutic Communities (the 'Therapeutic Communities Research Network', TC-RN). All services collected local data and determined their own models of outcome measurement accordingly.

### **Replication of the New Service Models.**

This initiative involved eleven pilot projects across the eight regional development centres, and several of these projects have since been commissioned to develop replicated services, or consult on development of these, in other local authority and PCT areas. Examples include work undertaken by IMPART in North East London, North Cumbria's Itinerant TC expansion into the south of the county, the Thames Valley Initiative in producing further new service hubs in Milton Keynes and Slough, and the SUN project expanding to cover adjacent London boroughs. While it is too early to produce comprehensive evidence, initial outcomes suggest implementation of these replicated services in other areas has been successful producing similar outcomes to the original sites.

Furthermore, the National Personality Disorder Development Programme recognises that some of the approaches have been developed in other parts of the country independent of this, the pilot projects and their learning network. This has largely been through professional and service user networks and publications in relevant literature increasing awareness. Other local services have developed entirely independently. Although there is no definitive register of these, mechanisms exist to ask them to register their existence on the national programme's website and map of service coverage. The outcomes of these other projects have further supported the findings of this review, for example through the networks formed by *Emergence*, the national service user-led organisation for PD.

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## Examining Effectiveness through QIPP

The QIPP programme was identified by the DH as the method by which quality of care would be re-established at the centre of the NHS. This needed to occur through examination of outcomes from the service users perspective. The programme is designed to ensure that every pound that is spent on health brings maximum benefit and quality of care to service users (DH, 2011). This programme has focused upon physical health predominantly; this report has attempted to apply the same principles to mental health, and in addition through the consideration of complex emotional needs as requiring an approach similar to those of long term conditions with regards to economic costs. That is, while the human cost savings may be realised in the short to medium term along with wider service cost avoidance; more sustained cost savings and avoidances across services and in relation to employment losses will be realised over the longer term due to the complexity of the problems experienced across all life domains.

## QUALITY

### Quality Standards

The implementation of the pilot services programme preceded the publication of the NICE (2009, 2009a) guidance documents on the treatment of borderline personality disorder and the treatment of anti-social personality disorder. However, the recommendations of NICE have considered evidence gathered by the national programme and national policy documents that were the drivers of this initiative. As a consequence, the projects meet all the recommendations laid out in the borderline personality disorder guidance, as a minimum.

A recent development in various areas of mental health is the formation of quality networks and accreditation services, several of which have been developed by the Royal College of Psychiatrists' Centre for Quality Improvement. One of the first of these networks was 'Community of Communities', founded in 2002, to define, develop and support the work of therapeutic communities across all sectors (Haigh & Tucker, 2004). The process involved setting service standards in partnership with the NIMHE commissioning team which were then annually audited by self and peer review, and approved for accreditation by the Royal College in 2007. All the pilot services which include a therapeutic community (Nottinghamshire, Oxfordshire, North Cumbria, Berkshire and Buckinghamshire) have received accreditation through this process. A broader process, also managed by the Royal College and currently used in the prison service, for which a quality mark called 'Enabling Environments' is awarded is also being used by some parts of the pilot services.

### Improvements in care quality

For the purposes of this section care quality has been considered in relation to four strands: cost effectiveness, clinical effectiveness, patient and carer satisfaction, and patient safety. The evidence for this was gathered from a range of sources including peer and non-peer reviewed publications, service reports, and through information gathered during site visits for the purposes of this clinical review and

the earlier commissioning review. One of the difficulties with assessing care quality is in the difference between perspectives: service users, carers or supporters, service providers, commissioners, public policy-makers, or other performance managers. However, the projects have sought to address each of these.

Another difficulty with regard to establishing improvements in care quality is the recognised lack of benchmarking data that is available for this population (NICE, 2009b). As a result the services within this initiative had to determine their own particular measures locally, these included reductions in service utilisation pre and post involvement with the services, reduction in incidences of self-harm pre and post service involvement, improvements identified through use of outcome measuring tools such as CORE and EQ-5D, and the identification of activity rates. Furthermore, other self-reported measures of patient and carer satisfaction have been obtained and reported (see for example Miller & Crawford, 2010).

All of the services were asked to identify their commitment to service user partnership. The range of activities included service users collaborating on training, providing consultation, employed by the service. While there was a variety in the extent to which the service operated a flattened hierarchy, all services identified service users clearly within their service model. It was evident that the services where the service users experienced greatest ownership and investment were those where they had been part of the development of the service from conceptualisation to current date. Tokenism within this particular type of service does not produce effective outcomes (Haigh, Lovell, Lyon, & Duggan, 2007). The Personality Disorder National Service User Reference Group (PDNSURG) was formed upon announcement of the commissioning of the pilots and they were used to judge between the bids (Haigh et al, 2007). Service user commissioners were also employed as part of the performance review teams and as part of the clinical review team for this report. It was identified from the beginning that service user partnership must be fundamental to the proposals.

### *Biopsychosocial approach to recovery*

All of the projects within this initiative employ recovery based models. While different definitions of recovery exist (Pilgrim, 2008), within this review the services were identified as using this term to identify *a long-term view of service provision that encompasses systemic or whole life views of the individual and acknowledgement of the importance of supporting effective transitions*. They could be considered to take radical approaches to recovery – in particular giving back responsibility to people for their own well-being and safety. Furthermore, they empower and enable individuals to feel able to take responsibility for themselves and make their own decisions; within traditional mental health services the focus tends to be upon institutional responsibility and individual blame. Services include significant others, address other needs beyond symptom management, they do not ‘try to fix people’. Essentially, they embrace fully a biopsychosocial approach to mental health. In addition, the services were found to demonstrate their capacity for flexibility and adaptability - generally managing change, and continuing change, effectively. This further models an effective ‘way of being’ for service users.

The outcomes of this review match those identified in a review of the British evidence base for successful recovery in mental health, Stickley and Wright (2008) identified the following themes from the academic literature:

- hope and optimism
- bringing meaning to life
- activities promoting recovery
- clearly identified definitions of recovery

In addition, amongst the grey literature, they identified (2008b):

- philosophy of hope for the individual
- individual identity
- narrative

### *Driven by local needs networked by sharing fundamental assumptions*

Each pilot interpreted the needs of the local community while drawing on the same fundamental assumptions of:

- the importance of human relationships,
- the psychosocial environment,
- investment in the programme,
- importance of leadership, and
- effective team work, as well as
- establishing good networks and partnerships.

The culture of the services further encouraged and relied upon the generation of new ideas and continuing development approach to the model, resulting in renewed innovation based on local needs and feedback. Establishing an ethos of shared experience also provided an atmosphere which fostered and modelled the qualities which they seek to nurture and develop within their service users. Shared experience refers to an equality between staff and service users, where staff did not present themselves as 'all-knowing' but collaborators in the process of change. This brings the importance of transparency, honesty and congruence to the fore. In essence, the services provide a therapeutic space which is congruent with the philosophy and intended outcomes of the provision.

An analysis of the nuances, distinguishing features and ethos of each governing organisation was not possible within the scope of this review. However, as identified within organisational theory, the culture of the governing organisations will have an impact upon the programme that can be delivered. For example, some services who wished to take an alternative approach to risk management were required to defend this, and it took some time to convince the senior management of their organisations of its validity (Crawford et al, 2007). This was potentially due to the established ideology within mental health of institutional responsibility and corporate liability.

## Improved care pathways

Individuals with complex emotional needs struggle with interpersonal relationships and social relationships, so the task of navigating complex care pathways in order to receive care and understand the system is beyond their capabilities. This is difficult for professionals to do at times, let alone those who do not have the requisite skills to do so (Shields & Mullen, 2007). In terms of helping this navigation, all the services have contributed to improved care pathways for service users with complex emotional needs. For some services, this was fundamental to their model of delivery, for example Leeds, Cambridgeshire and Peterborough.

## Qualitative and Quantitative evidence of improved care quality outcomes

Rawlinson and Bennett (2010) completed a study of individuals completing treatment at the Reading therapeutic community (one of the Thames Valley clinical hubs). They found that improvements in CORE scores at the beginning and end of treatment were clinically significant. They also identified that 2 years after discharge the number of healthcare contacts was significantly lower than during the 2 years prior to contact. The number of contacts began to rise up to 8 years after discharge, although for those who had an unplanned exit from treatment it rose significantly more. However, those who completed treatment did not reach earlier levels of service use.

Miller & Crawford (2010) found through self-report that of a sample of 61 people who had accessed the service in South West London reported statistically significant reduction in unplanned use of almost all services, except telephone helplines. Shields and Mullen (2007) identified that in Leeds the Managed Clinical Network (MCNs) (see Holmes & Langmaack, 2002) enabled them to respond quickly and flexibly to change when needed, ensuring individual needs could be effectively met as required.

Table 2 provides a summary of the outcomes for Quality identified for each service and identifies that for each domain of care quality; as is clearly identified in this table collectively the services have had an impact and improved care quality. In particular the positive experience of service users is in contrast to the findings of Haigh (2002), with regard to what characterised their experiences with mainstream mental health services. The findings of this review lend further support to the view that **service user input to the services is essential to enhancing investment in treatment, ownership of, and input to service development, and overall service effectiveness.**

**The findings of this review with regards to Quality supports the earlier work of Crawford and colleagues (2007) that identified significant improvements overall in care quality for those diagnosable with personality disorders.**

### KEY to Table 2

*	reduced to nil	–	No information available/not applicable
**	identified as clinically significant improvements	+	positive
↑	reduction	✓	available
↓	improvement	±	positive and negative

**Table 2: Summary of outcomes for Quality**

Project		SW London	Camden & Islington	Colchester	North Cumbria	NE London	Cambridge & Peterborough	Coventry	Thames Valley	Oxfordshire	Buckinghamshire	Berkshire	Leeds	Nottinghamshire	Plymouth
Cost effectiveness	Inpatient bed use	↓	↓10%	↓85%	↓88%	↓12%*	-	↓	↓93%	↓100%*	↓91%	↓	-	↓33%	-
	Emergency service utilisation	↓	↓13%	↓45%	↓38.9%	↓	-	↓	↓	↓89%	↓88%	↓	-	↓	-
	GP use	-	-	↓25%	↓5%	-	-	↓	↓45%	↓60%	↓70%	-	-	-	-
	Medication use	-	-	-	-	-	-	↓	↓	↓65%	↓	↓	↓	-	-
	Out of Area costs	-	-	-	-	-	↓£1.75m	↓	-	-	-	-	-	-	-
	Total Number of health and social care appointments	-	-	-	↓73.3%	-	-	↓	↓	↓	↓	↓88%	↓	-	-
Clinical effectiveness	No longer meet criteria of PD Diagnosis	-	-	-	-	-	-	30%	38%	-	-	-	-	-	-
	Crises and emergencies	↓	-	↓	↓	↓	-	-	↓	↓	↓	↓	↓	↓	↓
	Coping skills	↑	↑	↑	↑	↑	↑	↑	-	↑	↑	↑	↑	↑	↑
	Partnership working	↑	-	↑	-	↑	-	↑	-	↑	↑	↑	↑	↑	↑
	Ease of access to service	↑	-	-	-	-	-	-	-	↑	↑	-	↑	-	-
	Quality of Life	-	-	↑	↑	↑	-	↑60%	↑	↑	↑	-	↑	-	-
	Social functioning	↑	↑54%	↑	↑	↑	-	-	↑	↑	↑	↑	↑	-	-
	Employment, training and education	-	↑33%	↑15%	-	↑57%	-	-	-	↑	↑	↑	↑	-	-
	Engagement	↑	↑46%	↑	-	↑	-	-	↑	↑	↑	↑	↑	-	↑82%
	Organisational skills	-	↑69%	↑	-	↑	-	-	↑	↑	↑	-	↑	-	-
	Meaningful activity increased	-	↑	-	-	-	↑	-	↑	↑	↑	-	↑	↑	↑
CORE outcomes	-	-	-	↓20%	-	-	-	-	↓**	-	↓**	↓**	-	-	
Patient and carer satisfaction	Service user satisfaction	✓	✓87%	✓	-	✓	-	-	-	✓	✓	✓	✓	↑	✓
	Service Users Views	+	+	+	+	+	±	+	+	+	+	+	+	+	+
	Carers support	✓	-	-	-	-	✓	-	-	✓	✓	✓	-	-	-
	Complaints	↓	-	-	-	-	-	↓	-	-	-	-	-	-	-
Patient safety	emergencies	↓	↓	↓	↓	↓	-	↓	↓	↓	↓	↓	-	-	-
	Inpatient bed use	↓	↓	↓	↓	↓	-	↓	↓	↓	↓	↓	-	-	-
	Self-harm incidents	↓	-	↓	↓46.9%	↓59%*	-	↓	-	↓88%	↓	-	-	-	-
	Suicide acts	↓	-	↓	↓30%	↓39%	-	↓	-	↓100%	↓100%	-	↓	-	-



## Cost of specialist services

There are a number of costs that maybe associated with this population: in-patient stays, emergency admissions, A&E attendances, increased visits to GPs, social worker involvement, criminal justice costs, substance use costs, loss of employment, benefits, cost of physical health problems or loss of life, as well as quality of life costs. NHS Confederation (2011) identify the need for all commissioners to examine their spending to determine where efficiency savings can be made within mental health to contribute to the £20 billion savings that must be made in order to reinvest money in the future to meet increasing demands. They identify that out of area placements are an area in which this may be done. These placements are expensive and occur due to a lack of available services in the local area. This is particularly the case for individuals with complex needs for whom specialist services most commonly do not exist except in expensive residential facilities. This has an additional human cost attached as individuals are removed from their local environment including their families and social networks. The service in Cambridge was able to report that they had saved the mental health trust in the region of £1.75 million by reducing use of out of area placements by providing a viable alternative locally. It is probable that other services made significant savings in this way, but did not have access to figures with which to report them.

Soetman, Roijen, Verheul and Busschbach (2008) determined that in the Netherlands individuals with personality disorder cost €11,126 per client per year prior to treatment, these costs may be considered an underestimate within the UK. They identified that the direct costs prior to treatment were higher than individuals with depression or anxiety. Similarly, Rendu et al., (2002) examining primary care costs in the UK, found individuals with personality disorder required twice the cost of individuals without, in relation to GP costs. Furthermore, Duggan (2007) highlights that while economic costs are still in need of further exploration the evidence suggests that they are high for individuals with complex emotional needs. **This suggests that the extent of this economic cost presents a convincing argument for prioritising effective treatment for this population.**

The funding allocated to each of the services from central funding is identified in Table 3. When examining the table it is clear that the allocation of awards was not directly related to the size of population alone; and future commissioning of other services would depend upon factors external to this also. In addition these services cover locations with varying geography and therefore some services subsequently had to set up additional sites to enable accessibility for some. This involved additional funds; others had to address geographical accessibility issues to begin with for example Cumbria, Oxfordshire, Buckinghamshire, Berkshire, and Nottinghamshire. In the future, restructuring of existing services would potentially reduce the costs for those wishing to set up these services, and co-location of services and improved partnership arrangements could further reduce initial costs as evidenced by the pilots. **Overall, the cost of services has demonstrated significant cost-avoidance for those who have accessed these specialist services.**

Part of the requirement of successful bids was to receive a portion of local funding, and some projects have also received additional funds since this. These extra funds were provided for a range of reasons:

- expanding the service into other local authority and primary care trust areas

- requirements for additional services
- provision of training
- award of research grants.

### Comparing the services in relation to quality

Comparing these services with nomothetic methods is not possible, and a number of other factors also make across service comparisons difficult. For example different sample groups, methods, service sizes and measurements. However, they should provide important considerations for those who may wish to set up similar services. For example, a major factor is determining which sample of the population you want to provide for. Jungjan and Brenner (2006) highlighted that 60-80% of acute psychiatric in-patient resources are used by approximately 20-30% of the mental health population, as such reducing the use of these resources requires focus upon those 20-30% of individuals. Given that the constellation of problems that are experienced by individuals with complex needs and evidence reported elsewhere in this document with regard to healthcare utilisation by this population, it would seem reasonable to assume that at least a significant proportion of these individuals may be appropriate for the interventions identified in this review.

### Example of savings delivered

While some services were more able to gather evidence of effectiveness and cost saving, not all had the expertise and access to data to be able to provide examples of economic cost savings. It was beyond the scope of this clinical review to calculate these where they were not available. The reasons for the lack of availability of data were related to resources and organisational capabilities as well as accessibility of the information.

There is no medication currently licensed for use in the UK for specific treatment of personality disorder, and most recent guidance from NICE supports this (2009). However, the use of anti-depressants, mood stabilisers and antipsychotics in combination is very common for individuals with diagnoses of personality disorders (Bender et al, 2001). Prescribed drugs are often continued after a crisis period when they have been initiated, this is used often as a preventative measure and other medications are added at the next crisis event (Tyrer, 2002; Paris, 2002). Zanarini et al, (2003) identified that 75% of individuals with a BPD diagnosis had at some point been prescribed combinations of drugs. These medications can result in dependence, side-effects, physical problems and additional psychological symptoms (Mackin et al, 2005). NICE recommends that sedative medications should only be used for secondary symptoms for short-term relief of approximately 1 week. Furthermore the costs of these combinations of drugs often used for many years continuously could therefore be said to be a high and unnecessary expenditure. The Thames Valley Initiative addressed this by having a requirement for individuals to come off all medication within 3 months of entering the programme. While for some service users this was contentious, others were satisfied with the removal of medication. The project in Leeds engaged a pharmacist who reviewed and advised on medications on a regular basis and was consequently better able to explain the facts about the medications, resulting in many individuals significantly reducing levels of psychiatric prescribing.

Bateman and Fonagy (2003) identified that intensive day services for individuals with borderline personality disorder resulted in considerable savings during and after treatment through reduced utilisation of other

**TABLE 3: OVERVIEW OF SERVICES, AREAS COVERED AND COMMISSIONING COSTS**

Region	Lead Organisation/Service	Name of service	Main Intervention(s) & target group	Main tiers	Additional Development	Areas covered and population	Central cost of service
London	Camden and Islington Mental Health and Social Care Trust	Camden and Islington Personality Disorder Initiative	Advice, support and training for adults with PD, and training for healthcare workers	1,2	Probation Service Training	Camden and Islington - 380,000	£331,000
	North East London Mental Health Trust	Dual Diagnosis assessment and response team (DDART)	Psychological Therapies for adults with PD and Substance misuse	1,2,3	IMPART including individuals without substance use problems in an additional 3 london boroughs	Waltham Forest - 307,000	£318,000
	South West London & St George's Mental Health NHS Trust	Service User Network (SUN)	Peer support for adults with PD	2	SUN STEP Programme of psychoeducational sessions for promoting people's interests and recovery; delivering service in additional london boroughs	5 boroughs across london - 1,000,000	£254,000
Eastern	Cambridgeshire and Peterborough Mental Health Partnership Trust	Cambridge and Peterborough Personality Disorder Network	Psychological Therapies and consultation service	1,2,3	Complex Case Service Carers group; Inpatient service for 12 women with severe personality disorders spring 2011	Cam 300,000; Peter. 220,000	£392,000
	The Haven Partnership	The Haven	Support, advice, psychological therapies and crisis beds for adults with PD	2,3	social inclusion project; KUF training	Essex - 25 mile radius of Colchester - 334,000	£412,000
South East	Oxfordshire Mental Healthcare NHS Trust	Thames Valley Initiative	Support, advice, and day TC's for adults with PD	1,2,3	Work with carers; young mothers; older adults; SCID group	Bucks - 480,000	£1,006,335
East Midlands	Nottinghamshire Healthcare NHS Trust	Nottingham Personality Disorder and Development Network	Support and advice, psychotherapy and day TC for adults with PD	1,2,3	Additional TC and non-TC group work in other parts of the country; Training	Nottinghamshire - 1,016,000	£937,000
West Midlands	Coventry Primary Care Trust	The Olive Tree	Out-patient individual and group psychotherapy for adults with PD	1,2,3	Additional groups; training; parents group	Coventry - 317,000	£841,000
North West	North Cumbria Mental Health and Learning Disabilities NHS Trust	North Cumbria Itinerant Therapeutic Community	Support and advice, internet-based peer support and a day TC for adults with PD	1,2,3	Extended into the whole of Cumbria	North Cumbria - 320,000	£359,000
North East	Leeds Mental Health Teaching NHS Trust	Leeds Personality Disorder Network	Care coordination, psychological therapies and advice for adults with PD	1,2,3	Training and KUF	Leeds - 750,000	£808,000
South West	Youth Enquiry Service/Plymouth Primary Care Trust	Icebreak	Information and counselling for adolescents and young adults with personality disturbance	1,2,3		Plymouth and surrounding areas - 340,000	£421,000
						N.B These columns contain the data regarding the original funding and population sizes in 2004	

services. Their findings suggest that initial costs could be recovered within 2 years. Soeteman, Verheul, Delimon, Meerman, den Eijnden, Rossum, Ziegler, Thunnissen, Busschbach and Kim (2010) conducted a study of cost effectiveness of psychotherapy for Cluster B personality disorders and identified that day hospital psychotherapy was the most cost effective compared to inpatient treatment when measured through annual costs per recovered patient year and per QALY. The projects who were able to provide this data demonstrated similar outcomes in relation to cost avoidance as these studies.

In the literature there is a convergence of consensus that implementation of intensive specialist services are likely to result in cost recovery within 2-3 years of treatment completion. This review identified a number of services whose local commissioners believed savings had occurred within the first years, for example in Colchester (Crawford et al., 2007). Further work by the Colchester service supports this finding since the original report.

Thus far, it is evident from this review that investing in long-term solutions with wider impacts enables real savings to be made for this client group. **All the projects were able to demonstrate reductions in costs to health services during the first two years of service that outweighed the costs of the services themselves – this suggests that, while wider savings maybe more long-term, such an approach can also have very positive economic outcomes in the short to mid-term.**

## INNOVATION

Briefly summarising the innovations of the pilots overall is not possible as it would not reflect the range and breadth of the innovations, and this shortcoming is testimony to the collective responsiveness of the services. In itself the national programme was innovative in enabling providers to develop bespoke services based on the needs of their local areas and the availability of their expertise, this has been identified by the national IAPT team (2011) as important for the development of future services for individuals with more complex problems. This opportunity for locally informed bespoke developments provided the services with the opportunity to be innovative, and through this to improve productivity and quality of care. A sample of the innovations offered by the services as a way of highlighting the breadth of these is detailed below:

- Service User Partnership integral to services
- Facilitation of leisure and social recovery activities
- Provision of specialist education, training and employment training tailored for those with complex emotional needs
- Psychotherapy outreach into community teams and Link psychotherapists for consultation to teams
- Practice-based evidence initiatives
- Parent and child programmes
- Outreach clinics
- Psychoeducation and training for family, friends and significant others
- Personality and pathology courses
- Large preparation groups
- Mini-therapeutic community models
- Focus on development of social capital
- Transition groups
- Managed clinical networks and co-location of services
- Pharmacist employed for medication management
- Multi-disciplinary staff teams
- Flattened hierarchy
- Case management models
- Engagement strategies including groups, tiered interventions similar to stepped care models. This involves matching an individual's level of engagement to the appropriate intervention rather than pure focus upon range of symptoms, severity or complexity
- Development of manualised treatments for low and medium intensity interventions
- Positive approach to risk management including use collaborative crisis management plans involving other service users
- Peer out of hours support
- Partnership working with police responding to attempted suicides
- Facilitating staff secondments from other services into specialist services

Reflecting on the early service descriptions from 2004-7 it was clear that services had expanded or redeveloped aspects of delivery to meet demands of their stakeholders and feedback from service users. Services had responded to the needs of their population, service user feedback, organisational pressures and their concern to ensure productivity such that they were reaching the individuals that most needed their services, whether directly or indirectly through training other providers. **This responsivity to local needs was identified through this review as essential to the on-going effectiveness of the services.**

### **Innovations in the resolution of common resource problems**

Innovations in **assessment methods** and reducing the possibility of **waiting lists** had also been addressed by several providers. Oxfordshire successfully implemented a SCID-II (formal diagnosis) assessment group; Berkshire provides an **open access** group that provides psychoeducational information and the opportunity for contact with the service and obtaining support from a **social network**. These groups were large but had no upper limit; SW London kept all groups open access and found that while the groups became what some would consider to be uncomfortably large, they still remained supportive and therapeutic with very few people disengaging. Nottinghamshire implemented extended **preparation** groups that provided skills training prior to therapeutic work commencing.

### **Services for friends, family and other supporters**

It is well documented that the extent and level of informal care provided by **friends, family and other** supporters of individuals with mental health problems generally provides a significant cost saving to the public sector budgets for health and social care. As such it is imperative that we provide appropriate support to those individuals. With this in mind, groups had been implemented for carers and supporters of service users that offered practical advice, support and psychoeducational materials about the problems that they were helping people with. This was evidence throughout the Thames Valley Initiative, particularly in Oxfordshire. Also in Cambridge a mutual aid group had been established amongst supporters with the facilitative input of the specialist team that gradually reduced their input over time as the group became established.

The main innovation appears to have been doing what is fundamentally human, that is reinstating **humanistic** philosophies and 'being with' a client rather than 'doing to' him or her. However, this is something which traditionally been lost from performance target and risk driven mental health management systems.

### **Service user partnership**

One particularly important innovation was the employment of **Service User consultants** in a number of services. However, through analysis of the information received during the reviews and the literature around service user involvement, care needs to be taken to ensure these individuals give sufficient priority to looking after themselves to maintain their own well-being. Also, by creating these possibilities we must ensure that an additional level of unhelpful hierarchy is not created. The positive impact of these employees within the services was to increase the levels of understanding in staff teams and to improve engagement of service users, as well as presenting hope for recovery and modelling a possible future for those new to services.

## The biopsychosocial approach to mental health

All the services placed an emphasis on a **biopsychosocial approach** to service delivery rather than a purely biomedical one, which is common within general mental health services. While this is an old idea (Engel, 1977) that has had much support voiced, it has not been uniformly implemented and so many services consequently continue to rely upon solely biomedical models of mental health. As such this can be considered to be an innovation that impacts upon the effectiveness of interventions. This involves the consideration of the individual as a whole, rather than separate parts; and seriously considers the impact of social and cultural factors, as well as those internal to the individual.

## Example of how innovations have improved and extended lives

Suicide rates amongst those with complex emotional needs have been identified as between 3-9.5% (Holm & Severinsson, 2011) with others quoting figures of up to 15%. There are a number of potential reasons why this is the case including the high levels of distress that individuals experience, comorbidity of other problems, high levels of self-harm and the lack of available crisis intervention services that can offer support that is appropriate. All of the services in this review identified reductions in suicide rates and self-harm, as evidenced in Table 2, with rates of suicide being reduced to as low as 1-2%; NE London identified that for a significant number of individuals self-harming rates had been reduced to nil.

The services all implemented crisis management procedures and developed ways of resourcing what needs to be a 24-hour service. Despite variation of approach, all service users were provided with a crisis management plan upon entry into the services; these were developed in collaboration with the service user themselves, and in the Thames Valley Initiative and SW London this was conducted with the assistance of other service users. Coventry and Cumbria worked with NHS crisis intervention services who were also provided with a copy of the crisis management plan. In addition, Coventry had a text messaging service in addition that enabled individuals to text whenever they needed, knowing they would be contacted first thing the next day. Leeds paid for a post within the service user-led crisis service. The therapeutic communities had in place a system of out of hours peer support. This involved service users sharing telephone numbers and providing support to one another through this, however, this was something that was always discussed within the therapy groups to ensure this was not simply a social exercise (which could adversely affect the group therapy itself). Furthermore, good social support has been shown to improve mental health outcomes and is sustainable beyond the end of treatment (Falzer, 2007). Cumbria received a BT award for their internet based peer support.

## Commitment to organisational improvement

Continuous organisational improvement and development is acknowledged as an essential aspect of today's society and in order to be able to adapt to the demands of the economic situation, organisations must constantly evaluate their cost-efficiency, quality and productivity as part of performance management (Kaye & Anderson, 1999). Furthermore, the development of the service user movement demands that we go further to ensure that organisations deliver quality care and adapt to changing needs. Kaye and Anderson in 1999 identified ten essential criteria for this to occur including factors that drive continuous development and those that enable it:

- Drivers: Senior management; leadership by all managers; stakeholder focus; measurement and feedback; learning from previous events
- Enablers: Culture of improvement and innovation; employee focus; focus on critical processes; quality management system; integration of improvement activities.

While not all services evidenced these to the same extent, the themes drawn out of the review clearly identify their presence. Active monitoring by the service of outcomes and feedback was most effective due to: improved monitoring, adaptability, reflection: also because evidence was more readily available for the demonstration of effectiveness. Moreover, the services that have developed with the greatest flexibility and adapted to the changing requirements and feedback received since beginning appear to have produced the most significant evidence of effectiveness. However, this could be related to the importance placed upon this by the governing organisation and the consequential allocation of resources for this purpose.

### **Staff recruitment and retention**

An additional cost saving and important innovation demonstrated by a number of the services was related to staff **recruitment and retention**. High performing teams are those that work well together, are invested in and supported by their organisations, but who also possess the characteristics required to perform a particular job well (Castka, Bamber, Sharp & Belohoubek, 2001). One approach that was taken to recruitment by Oxford TVI was to use an assessment centre type exercise that reflected the type of service they would be employed within. Service users were involved not just in interviews but also in informal time with potential employees and their perspectives sought with regard to suitability. While the staff themselves described this process as daunting and distressing, the services in question can report an exceptionally high retention rate in excess of 90%.

In response to difficulties in recruiting suitably qualified professionals, Coventry decided to focus upon securing individuals with the appropriate attributes, attitudes and potential for development, from across a range of disciplines. They were then provided with the training that they needed. The only identified staff turnover within this service has occurred as a result of their personal success as a result of this training programme, with staff leaving to progress through promotion.



## PRODUCTIVITY

Productivity is defined as the ratio of what is produced to what is required to produce it: it is a measure of efficiency. In clinical services the ultimate measure of this is the financial cost per 'quality adjusted life year', or QALY: NICE will not generally recommend treatments where that cost is above £30,000. To make accurate estimates, the calculations require complex methodology, and would currently be impossible for services such as the pilot projects in this review, although informal estimates have been made (Haigh, 2011). Definitive figures would require probabilistic calculations of lifelong 'quality of life' outcomes for a condition has hitherto been regarded as untreatable, and for which suitable numerical data has never been collected.

If each pilot project's product is considered to be 'provision of a specialist personality disorder service to those living in the geographical area', productivity can be easily calculated as population divided by cost. The population covered by for all eleven projects is 7.57m (14.7% of the total English population) and the overall central cost (in 2004) was £6.9m; this equates to £0.91 per head of population, these figures were obtained from the Office of National Statistics.

For the purposes of this review, 'what is produced' can be approximated to the throughput or activity level of a service, and 'what is required to produce it' as the cost of the service, or the number of staff. These will clearly omit any relevant factors which cannot easily be counted, including outcomes such as long-term quality of life, nature of interpersonal relationships and internal mental experience.

'Throughput' has several measures for these projects; the number of people coming into contact with the service can be counted in terms of

- referrals
- active caseloads
- numbers engaged and retained in treatment
- numbers discharged from the service following a successful treatment episode (as defined collaboratively between staff and service users)
- numbers who leave treatment in an unplanned way

Some of these measures are identified within Table 4.

### Service activity levels

This was not a comparative research study and as such making such deductions would be unhelpful, and would be inconsistent with the original intention of the national programme to explore innovations. There are a number of reasons for caution in relation to comparison including the differences in the size of the services, different funding levels, different recording methods, and different interventions provided. Also due to there being no baseline data available and the fact that most of the individuals who were provided with a service were ordinarily excluded from mainstream mental health services or provided with emergency reactive interventions only. Thereby, activity with complex emotional needs has not previously been reported through national systems. As such it could be suggested that any activity levels demonstrated an improvement on productivity, against a zero baseline. However, activity levels can meaningfully be compared

by identifying the predicted activity levels at commencement of the service and contrasting this with current levels.

Table 3 provides the activity levels identified by each individual service as an example and was provided to the clinical review team between January and March 2011; the original prediction as identified by Crawford et al., (2007) is also provided. It should also be noted that not all services provided data for the same 12 month period. Thereby, any national or regional trends could not be identified within the data, such as other initiatives impacting upon activity. Basic analysis of the ideographic comparisons suggests that all services have been more productive than anticipated and have improved activity for those who would previously not have received such a service.

A further area of development within these services has been with regards to engagement and retention, and consequently addressing attrition from the programmes. This is an area which previous mental health strategies have attempted to address through stringent performance targets. Crawford, Price, Gordon, Josson, Taylor, Bateman, Fonagy, Tyrer and Moran (2009) investigated the levels of engagement and retention within 10 of the pilots and identified that of 713 individuals taken into the services in the first 2 years of operation 164 (23%) dropped out without completing treatment. They concluded that while the services were good at engaging individuals who had been accepted for treatment, the populations who were most likely to drop out were younger and male. It should be identified that attrition or drop-out does not necessarily indicate a treatment failure – as the process of engagement itself may have produced transient or enduring benefits in an individual or those around them, and that might include a higher probability of retention and completion of a definitive treatment programme at any time in the future. However, this is important data to gather particularly when considering issues related to Quality. Since the collection of this attrition data by Crawford et al (2009), all the services have begun to address these issues, by introducing modifications and varying levels of interventions to their programmes. Where the data is available the services have demonstrated an increase in engagement as a result, indications of this are identified in Table 2.

A problem across mental health services generally has been with regard to the limited diversity of racial and cultural diversity across referrals and admissions. These tend to be unrepresentative of the general population, with reduced numbers from black and minority ethnic groups. Again, a number of the services have begun to actively address this, for example Thames Valley Initiative and NE London. The outcomes of these activities will be determined in due course.

**TABLE 1: PRODUCTIVITY AND ACTIVITY LEVELS BY SERVICE**

<b>Project</b>	<b>Original service activity level prediction - number of active service users</b>	<b>Retrospective and current level of service activity over most recent 12 month period recorded</b>	<b>Additional productivity information</b>
SW London	80	265	Impact of service improved performance of caseload management within CMHTs
Camden & Islington	Unavailable	Skills development service 73 - direct client work livework training programme 162 – IAPT staff 181 voluntary sector staff; 41 staff in supervision groups 43 foundation trust staff completed KUF training 19 primary care group consultations;	Livework aims to maximise productivity by using a small team to have maximum impact by providing training across Camden and Islington to increase the skills of the workforce to work with individuals with complex needs. Further with a small additional funding grant they were able to provide 18 KUF training sessions.
Colchester	100	150 active clients 28 referrals 24 accepted into treatment 14 completed treatment	2000 contacts a month
South Cumbria	80	44 - outreach 23 - TC	283 referrals were received; 41 people assessed for the TC programme
NE London	70	200 Approx 306 referrals for Waltham Forest	11,041 contacts in the previous year; 35 case per professional 52 new referrals a month overall since 2004 IMPART has dealt with 1801 new referrals
Cambridge	80	130 in case management) 80 referrals over 6 months;	currently enhancing service for young people (16-25) to cater for those with emerging personality disorder
Coventry	100	468 141 referrals 70 discharges;	
<i>Oxford</i>	<i>45 in each TC programme</i>	142 accepted into service 468 referrals 189 discharges	SCID assessment group increases efficiency

<i>Buckinghamshire</i>		259 in service 339 referrals in a year;	year on year increase in referrals , increasingly accessing users with complex needs while retaining a fixed size team; use of self diagnosis measurements during assessment phase
Berkshire		upto 15 members in each Link group; 18 group members in TC;	no waiting list except in reading - rolling groups enables people to join at any point - tiered approach prevents blocking
<i>STARS</i>	<i>Unavailable</i>	23	
Leeds	45	82 places available per week; 7000 contacts conducted per year	Resource pack on service user involvement; Mapping the Maze: ways to well-being
Nottinghamshire	20 – Therapeutic Community 60 - Stop and think programmes	100 500 referrals 1150 people have attended training courses 2006 - 2010	500 referrals a year; training programmes over 4 year period have provided training to 1150 people
Plymouth	Case manage up to 35 people and provide advice and support to others	60-90	30 people, at any one time awaiting assessment outcomes; consultation and training enables staff to assist service users who are not yet ready for a group programme; social connection of groups enables better reintegration; supportive service including 24 hours telephone support (peer) enables primary care service utilisation to be reduced

## Service inputs

The denominator of the productivity equation is 'what is required to produce it' and although this is easy to measure in terms of finance, the particular capabilities and attributes of the staff are more difficult to define. The need for a suitably skilled workforce that may come from a range of different disciplines and professions, as well as ex-service users, was highlighted by *Breaking the Cycle of Rejection: the Personality Disorder Capabilities Framework*. The *Knowledge and Understanding Framework* (KUF) is now operating in all the English regions to train people for this gap, and although it is not a required role for the pilot projects, several of them have taken on a role in delivering it. This is sometimes through providing the staff to deliver it, including both service users and clinicians, premises to hold it in, or using their professional and organisational networks to promote its uptake. Various projects have also developed other courses that either lead on from it, or lead into it – particularly tailored to local resources and demand, for example Nottinghamshire and TVI STARS.

The initial recruitment and selection process for the staff has already been highlighted as a cost-efficient innovation (p29); it was also a vital process to ensure that the services were fit for purpose. Several of the projects used novel staffing structures where all staff in a particular role, irrespective of their professional background, have the same job title. An example of this is the Oxfordshire and Buckinghamshire's hierarchy of Assistant Team Therapist (unqualified), Team Therapist (with MH qualification), Senior Team Therapist (with added experience, qualifications and responsibility), which have all been fitted within the NHS's 'Agenda for Change' framework. Also SW London similarly use this method, while identifying the roles differently.

As important as the individuals undertaking the work is the coherence of the way they work together as teams. Several projects also undertook extensive work in this area before starting clinical work, and maintain it through rigorous systems of continuing professional development, support and supervision. For example, the newly selected Thames Valley and Nottinghamshire teams both started with four day residential workshops with group relations, planning and team-building activities.

Several projects employ ex-service users within their clinical teams, and in the South West London Service User Network, they form the majority of the workforce. Some use the designation 'Service User Consultant', with substantive employment contracts as such (Cumbria). Others consider such a role as transitional, and recognise ex-service users with the title 'Expert by Experience' (often shortened to XBX in the Thames Valley Initiative) only as long as they want to be recognised as such; after this they either seek employment in the open job market or education as anybody else would. Such individuals often use their sophisticated psychological understanding and empathic capacity to seek work or training in mental health or similar caring professions. As such, they can provide a very high quality contribution to the type of team which is 'required to produce' specialist PD services. The Thames Valley Initiative STARS employs individuals who have completed treatment a minimum of 6 months previously to deliver training and consultation to other professionals and services.

## PREVENTION

This national initiative has addressed prevention from a range of different perspectives:

- prevention with regard to ever receiving a diagnosis of personality disorder (E.g. age specific early intervention – Icebreak)
- prevention of harm through crisis planning and contingency arrangements (all services)
- reduction of the chance of relapse through use of recovery approaches (all services)
- reduction of social exclusion and exclusion from services through delivery of training;
- prevention of need for entry into specialist services through training other services to deliver appropriate interventions and prevent individuals from deteriorating such that specialist services are required (Camden & Islington).

With regard to all of these the national initiative has demonstrated improvements across each of these qualitatively, and Camden & Islington service have been able to identify quantitative changes that may impact upon the overall target of preventing mental ill-health and length of time in secondary care and specialist mental health services. While ability to measure outcomes in relation to health prevention areas is, by definition, a complex and spurious task, the services have identified improvements. It would be helpful in the future to be able to measure outcomes in relation to prevention activities in a standardised way that would enable training programmes to be compared in relation to health impacts. However, a longitudinal long-term follow-up study would be necessary to effectively measure the impact of prevention programmes to a scientifically rigorous standard. Examples of how the services have addressed prevention in their localities are listed below:

- Training of other trusts in the model
- Open access visitors policy
- Development of Trust wide strategies for individuals with personality disorders/complex emotional needs
- Training focused on primary care and Tier 1 health and social care providers to address attitude change and early detection, including criminal justice workers, GPs and Health visitors
- Consultation and training to other teams
- Presentations and workshops
- Raising awareness activity days
- Proactive approach to risk management
- Interventions developed for working with less severe presentations for use in stepped care approaches, including manualised programmes
- Training and education posts within services to address prevention and awareness
- Tiered interventions enabling stepping up and stepping down processes
- Equipping mental health services to support those who disengage from specialist services or who do not meet the criteria for specialist services
- On-going supervision provided to training attendees

## Continuity and transition planning

We need to be aware that while it has become apparent that developments in PD service provision have achieved a great deal with these pilot sites, however, this has by definition only brought about change for a small proportion of those experiencing complex emotional needs. Furthermore, in relation to prevention we need to ensure that the projects are effective in terms of sustaining the system change in their areas, and also to support individuals who have planned exists into effective transitional arrangements. Berkshire service have been able to complete a longitudinal study over an 8 year period and identified there may be a need for a low intensity service further on in an individual's recovery. In addition, **the importance of step down approaches is acknowledged to avoid 'the cliff edge effect'** (p.119, Pearce & Haigh, 2008) at the end of therapy. Colchester and SW London services have developed a process whereby individuals can access the service on a long-term basis after they have completed treatment.

The pilots have learned lessons and employed critical reflection identifying the importance of reintegration, and offering people phased opportunities to return to education, training or employment for example. The Thames Valley Initiative included as part of its bid the Support, Training, And Recovery System (STARS) (Pearce & Haigh, 2008). This has successfully enabled a step down path for those who have completed treatment to begin to undertake employment and training opportunities on a sessional basis as a service user. This facilitates a transitional phase from treatment. In addition the STARS have undertaken significant amounts of training delivered a successful accredited training programme; they have also participated in the roll out of the national knowledge understanding framework training, they have also organised events, and been part of consultation and development of new services based on the TVI model in other areas. System outcomes for the Camden & Islington project have identified it has improved skills and knowledge among staff in primary care (Marriott et al.,2007).

## Forecasting future health needs

Brazier, Tumor, Holmes, Ferriter, Parry, Kent-Brown and Paisley (2006) indicate that, according to an Office of National Statistics Survey in 2000, for a primary care trust with a population of 500,000 those with Borderline Personality Disorder alone would represent 3,500. However, when considering the number of individuals with any diagnosable personality disorder this number will likely be significantly higher. McCrone et al., (2008) suggest that by 2026 projected service costs for personality disorders will be in the region of £1.1 billion, rising by 56% from 2007. Total costs are estimated to be between £8-£12 billion including loss of employment.

Given the extent of these figures, specialist services have a place in reducing costs over the long term and enabling service users to recover, particularly those with the most complex problems who would routinely be excluded from other services. However, there needs to be a range of services including training for staff of non-specialist services within the NHS and non-NHS providers, and within and beyond the wider health sector. Also, while it has been found that those who experience the most severe and complex problems do not benefit from short-term psychotherapies (NICE 2009). That is not to say that psychological therapies utilising a stepped care model such as described by proposers of IAPT for Severe Mental Illness (DH, 2011) would be unhelpful for those with less severe problems. However, unless specialist staff are trained in

recognition, appropriate interventions and allowed to be flexible within their model they are unlikely to be effective in engaging with this client group within primary care. The training that has been developed and piloted by the services has employed this rationale.



## Key findings from the review

- Addressing the needs of the whole person, not simply the presenting behaviours, or biological factors, are essential - including supporting significant others.
- Opportunities for innovation and to develop practice-based evidence should be encouraged, rather than relying upon limited state of knowledge in evidence-based practice. A biopsychosocial approach and not a purely biomedical one should be established.
- Establishment of General Therapeutic Conditions are indicated to be more important than the specific choice of model.
- The unique needs of the local community must be considered while drawing on the same fundamental assumptions of the importance of human relationships, the environment, investment in the programme, and the importance of leadership. NICE recommendations (2009) identify the importance of needs assessment, as local variations in population characteristics and care pathways will determine the type of services required.
- The therapeutic relationship is of fundamental importance in the establishment of safety (both physical and psychological) and stabilisation; this is required for the commencement of effective therapeutic work.
- Models from a range of theoretical orientations demonstrate efficacy, with no single approach emerging as superior at this time.
- Service user partnership as opposed to input is fundamental to investment, ownership and service effectiveness.
- A long-term approach to delivery and establishing an experience of continuity throughout 'recovery', is required for needs to be met effectively.
- Provision of active community integration extends recovery pathways through to education, training and career development opportunities.
- Flexibility and adaptability are required to manage change effectively, and to continue being able to do so.
- A range of services needs to be provided: using a variety of approaches, for all tiers of 'severity', as well as levels of engagement, that is coordinated across the systems of health and social care.
- Continuing research is required to:
  - identify baselines;
  - to understand what different models add;
  - to test out the phenomenon identified through the themes including general therapeutic conditions;
  - to identify the mechanisms of the fundamental therapeutic processes;
  - to identify how best to encourage, use, sustain and measure innovation.
- After-care (or 'next steps') arrangements need careful consideration; for some this will involve lifelong care.
  - Further NICE (2009) recommends: a continuing system of training for professionals, the establishment of multi-disciplinary teams, improved partnership working across organisations, and increase the use of *appropriate* services. This approach is likely to reduce

A&E use, admissions due to self-harm and the cost of medications, as has been evidenced through the work of the national initiative.

- Awareness is needed that the creation of specialist services in some areas can result in provision becoming a postcode lottery. This is already the case with the pilot projects providing services for only 15% of the English population. A strategy for insuring that all those who need such services for complex emotional problems can do so will reduce economic burden further.
- Prevention of deterioration of problems, by well-organised primary care and mainstream mental health services, can pre-empt much of the requirement for complex needs or specialist services.
- Training and information is required at all levels of the system to aid prevention attempts.

## Conclusions: QIPP

This clinical review has been able to identify that there is a rapidly increasing volume of evidence for the effectiveness of the projects, commissioned in 2004. Services have succeeded in delivering effective outcomes through innovation and are delivering good quality care in all four domains: patient safety, cost effectiveness, clinical effectiveness and patient satisfaction. This has occurred through a process of integration of developing practice-based evidence and evidence-based practice; an area which has also been established as important within physical health services (Horn & Gassaway, 2007).

Despite recognition of the basis of many problems being co-morbid with DSM-IV-TR classified Axis II disorders or ICD-10 classified 'Personality Disorders', there continue to be questions regarding the need for provision and reluctance to invest in services that have the capabilities to address these. However, recent recognition of this has been highlighted by the Health Minister (Burstow, 2010), Central Government (DH, 2011) and the National IAPT Programme (2011). Furthermore, expanding the criteria by referring to 'Complex Emotional Needs' would enhance service provision by recognising the impact of problems across all life domains and moving towards a biopsychosocial model of treatment provision. A research strategy, including a national reporting system for a minimum baseline and an outcome dataset for individuals diagnosable with personality disorder would enhance this further.

Complex Emotional Needs require multi-component complex interventions, and hence suitably complex research methods to understand and evaluate them. In the same way that individuals with complex emotional needs require coordinated efforts across numerous agencies, meaningful research utilising a range of research methodologies is required. This will likely involve coordinated efforts across a range of academic disciplines, potentially outside of the health and social care domains and using both practice driven and academia driven approaches. This should be in addition to the biomedical tradition generally used for research into mental health interventions.

The current IAPT strategy and system focuses upon relatively short-term treatments that are measurable by frequently applied brief psychometric scales and which lend themselves easily to RCT research; this particular model is unlikely to be helpful for this more complex range of problems as indicated in NICE guidance (2009). Although the process of thinking about provision through stepped care has been identified within this review as important for both engagement and prevention. Furthermore, with the introduction of European procurement rules and shortened contracts, the difficulty is in demonstrating sufficient cost-efficiency in a short space of time. The pressure of this is only set to increase with the introduction of GP-led commissioning consortia, when local systems are likely to be predominantly viewed only in terms of short-term outcomes. However, this national initiative has identified that there are short-term human cost savings to be made with a long-term approach to treatment for this population group.

It is therefore important to consider the impact of complex problems across the whole health care system: complex emotional needs are ubiquitous and lead to considerably adverse social consequences as well as individual suffering. Commissioning strategies will be required that enable investment in long-term solutions with wider impacts in order to secure real sustainable savings over the long-term. These pilot services have

been able to demonstrate reductions in costs to health services during the first two years of operation that outweighed the costs of the services themselves.

The services that were part of this initiative present a range of alternative models of approach that are suitable for transfer to other areas dependent. With efficient communication and knowledge transfer, those planning services in other areas of health and relevant public services will be able to draw on this learning once the desired service had been agreed, local needs assessment undertaken and the type of organisations suitable for managing delivery ascertained, particularly in relation to readiness for change. As this review illustrates, this may require considerable challenge to established working practices, and significant cultural shifts.

This review also highlights the importance of a variety of approaches, in essence a tiered system of care catering for individuals from primary care through to specialised services. To produce improvements in services that have an impact on the large numbers of individuals affected, this places emphasis upon the delivery of awareness training and raising the confidence of professionals to detect personality disorder and complex emotional difficulties. Furthermore, it places importance upon working with other teams to provide consultation and supervision.

In mainstream mental health services, it behoves planners to avoid recapitulating 'revolving door care' which for individuals with complex emotional needs is unhelpful and potentially more harmful. For example, if an individual has high levels of co-morbidity then serial Cognitive Behavioural Therapy treatment protocols are unlikely to be helpful. It is also likely to be expensive and fail to understand the full presentation of an individual's needs with the whole system biopsychosocial approach that this programme has successfully delivered.

Given wider scope, policy makers will need to consider prevention on a range of levels. This includes 'upstream' early intervention and pre-emption in vulnerable children (including considering the role and constraints of child protection services), through prevention of relapse in individuals' active and stressful middle years (including associated conditions such as alcoholism and drug dependency), to prevention of unhappily dependent and anguished later life (including coordinated biopsychosocial interventions in all relevant elderly care settings).

This programme has demonstrated that

- Numerous different approaches can improve the lives of people who were previously considered untreatable; however, we are able to identify general therapeutic conditions. These general therapeutic conditions emphasise the fundamental importance of quality relationships.
- They are also likely to deliver economic returns, in addition to the individual and social benefits.
- They require a coordinated facilitation of future work to build on the technical expertise gained in building the pilots' systems and services.
- These approaches, with the underlying value base used by the projects, may have wider applicability.

Continued investment in these services in their relative infancy is required, as well as wider spread development, to prevent the investment that has already occurred from being unproductive.

## **The final word to the service users**

**'I've used mental health services for fifteen years or more. At last I've found somewhere that's right for me and my diagnosis. I have stopped cutting and overdosing. It's saved my life really. I have stopped cutting and overdosing. Staff are always ready to listen and help twenty four hours a day, seven days a week. All the clients here are like my family and we are all in the same boat. The groups are really hard at times, but really good, and I can open up about my abuse. Since being here I have started doing voluntary work with children as a youth worker. For the first time in years I haven't ended up in the local psychiatric hospital during the summer holidays. It's changed my children's lives as well as mine. And...guess what...two weeks ago my psychiatrist discharged me from the mental health services all together and I never thought that would happen...'**

## Glossary

### ***Biomedical approach (or model)***

only recognises and considers physical processes, such as the pathology, the biochemistry and the physiology of a disease or disorder. It does not take into account the role of a person's mind or their interactions with others in the cause and treatment. Its strength is in offering clarity by limiting the number of variables operating on the system under study, and so has reasonable generalisability. Where the variables are predominantly biological (such as cell replication in cancer) it is extremely successful in identifying pathological diatheses and developing successful treatments. Its weakness is most evident in complex conditions with a large range of aetiological, developmental and maintaining factors: it cannot then measure, predict or control the process with any accuracy, or offer sufficient understanding to advance treatment. With a biomedical approach, the prevention of disease is also omitted. The approach is generally characterised as the alternative to a *biopsychosocial* one.

### ***Biopsychosocial approach (or model)***

is one that sees biological, psychological and social factors all as important determinants in the formation, development and maintenance of ill health and disorder. Biological includes genetic, neurological, hormonal, pharmacological and any other physical or physiological factors. Psychological involves feelings, fantasies, thoughts, behaviours and any contents of a person's mental 'inner world'. Social influences include any aspects of a person's life amongst others, and includes friendships, intimate relationships, past and present family relationships, poverty, education, living conditions and many other factors. Its advantages are that it can embrace complexity and uncertainty, and lead to helpful understanding of multifactorial systems – from prevention through to society-wide consequences. The weakness which accompanies this is the lack of precision and sureness it can offer, and generally more limited generalisability. This theoretical attitude is characterised as the main alternative to a *biomedical approach*.

### ***Complex emotional needs***

is a term which recognises the various non-health contexts in which 'personality disorder' presents, and indicates the pervasiveness of its social and interpersonal consequences. Various areas of life are liable to be disrupted in addition to any symptoms that individuals experience, including difficulty in sustaining employment or education, parenting, housing and finance, petty crime and antisocial behaviour, and physical health problems. These issues of complexity and severity are detailed with relevant vignettes in the 2009 Commissioning Guidance, '*Recognising Complexity*'. The term 'complex emotional needs' is preferred usage when 'personality disorder' may cause adverse consequences (for example, from stigma associated with the term), or the services, agencies, organisations or sectors concerned have no understanding of the 'PD' diagnosis.

### ***Evidence-based practice***

this involves the application of the best evidence, generally obtained from clinical efficacy research, within clinical settings. The National Institute for Health and Clinical Excellence produce guidance on the best

treatments for different conditions within physical and mental health. These guidelines are developed with specific consideration of the evidence obtained in controlled trials. While consideration is taken of evidence obtained through other methods, the gold standard is considered to be treatments that have been rigorously tested and efficacy established in highly controlled situations.

### ***Personality Disorder***

is a diagnosis recognised by the world's two main classifications of disease, the World Health Organisation's 'International Classification of Diseases' currently in its tenth edition (hence 'ICD 10'), and the American Psychiatric Association's 'Diagnostic and Statistical Manual' currently in a revision of the fourth edition (hence 'DSM IVR'). The diagnosis is subdivided into categories with different behavioural and emotional features (currently ten in DSM IVR, and eleven in ICD 10), but all include the requirement of existing throughout adult life. *Borderline PD (BPD)* and *Antisocial PD (ASPD)* were chosen to have clinical guidelines developed by the National Institute for Health and Clinical Excellence (NICE), and these were published in 2009 (CG78 and CG77 respectively). It is generally recognised that BPD is more common in community mental health services (which are the subject of this report) and ASPD is more common in forensic and criminal justice settings. Other informal diagnostic terms, such as '*complex trauma*', '*heartsink*', '*bipolar ii*', '*emotional instability*' are also commonly used in different settings and by different professional groups. '*Psychopath*' retains a legal definition, but is no longer in clinical usage.

### ***Practice-based evidence***

This involves the development of the evidence base for best practice through testing the effectiveness of interventions within clinical settings. This generally involves hypothesis testing in uncontrolled conditions and thereby there will be influencing factors and attributing the impact of a specific technique or intervention will be confounded by these other factors. However, this can be particularly effective in situations where limiting the complexity of a presenting problem reduces its usefulness in real clinical settings. This is particularly the case for conditions that may manifest in an infinite number of ways, for example complex emotional needs or personality disorders. Practice-based evidence will be based in theory.

### ***Therapeutic Community***

a residential or day programme in which the social environment or community is considered the main therapeutic tool. Day-to-day running of the community is shared between its members including staff. The therapeutic community operates according to a democratic style of interaction, reality confrontation and accountability for actions, with tolerance of mistakes. In principle not only the therapeutic groups but the interactions outside of them are considered to re-enact the social and cultural world in a safe environment. The idea is to alter interpersonal interaction by enabling it to be displayed in the community and challenged, consequently adapting psychosocial functioning. This is a longer term facility of 1-2 years, generally using psychodynamic principles. In this approach the therapists, or staff, are not positioned as 'all-knowing experts' but as senior members of the community acting as collaborators, facilitators or participant observers.

### ***Therapeutic Relationship***

This is a very specific type of relationship which exists between staff and service users in individual therapy settings, and also between fellow service users in group therapy and therapeutic environment settings. It is characterised by a level of trust and openness that is higher than experienced in most day-to-day relationships, and explicit and implicit *boundaries* which define what behaviour is and is not permissible. These boundaries vary between therapeutic approaches, but would, for example, always forbid violence or sexual relations.



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## Appendix 1: Methodology

This was an evaluation study using an explanatory multiple-case study strategy resulting in a conceptual framework for understanding the connection between the pilots, through the use of Framework analysis (Ritchie & Spencer, 2002). Overall this was a summative evaluation approaching the topic from a critical realist, ideographic and holistic ontological position. Due to the nature of the task this was primarily essentialist in nature involving the elicitation of people's own understanding, opinions or views. However, there was limited consideration of the social constructionist epistemological position in relation to the way that individuals construct the language and interact, in order to consider the context within which the evidence is gathered. The panel included a service user commissioner, a senior clinical advisor, and a research-practitioner. Due to time constraints and resource allocation the review was necessarily short duration and consequently includes recommendations for future development and investigation.

### Participants

Site visits were conducted by a representative from Emergence (Sue Ellis, Jenifer Dylan, Jo Thompson or Kayla Kavanagh), Dr Rex Haigh and Dr Lisa Wilson. One site visit was conducted by Dr Chris Newrith in place of Dr Rex Haigh due to previous involvement with the service.

14 site visits were conducted, while 11 pilot projects were originally commissioned, one of these projects being the Thames Valley Initiative, which was conceived and proposed as a single project but is now separately managed within different Foundation Trusts across three counties. It was therefore decided that each should be reviewed individually. These site visits took place over a three month period between January and March 2011.

Each site visit was conducted in three parts, except in two instances due to the different structure of these two services in relation to the other pilots. Generally, the three parts were:

- Focus group with senior clinicians
- Focus group with all staff who wished to participate and any service users and ex-service users who wished to participate
- Focus group with service users and ex-service users only

The total time available for each visit was 2 hours, approximately divided into the three 40 minute focus groups. The review panel met for approximately 30 minutes before the focus groups for briefing purposes and for a further 30 minutes following the focus groups for debriefing and reflection. Each service was also offered the opportunity to provide additional documentary evidence that they felt may be useful for evaluation purposes. Further information about the service that had been made available during the commissioning review in January 2011 was also provided by some of the services. The majority of the services also provided written information on referral criteria, catchments, assessment procedures, programme focus and vision, programme aims and type of interventions, involvement of other services,

additional feedback and outcomes of any other evaluation work that had been conducted, including media coverage, academic publications, and research studies.

All participants in the evaluation were advised with regard to informed consent and confidentiality. Where possible the focus groups were digitally audio recorded for the purposes of accurate note-taking and to facilitate framework analysis. This was carried out in thirteen site visits, with detailed notes being taken at the fourteenth site.

The participants in the review were determined locally, following written request and explanation of the format about a month (range 2-8 weeks) before each site visit. Therefore the selection of focus group participants was most usually dependant upon availability and self-selection; representation by a senior clinician with knowledge of the historic development of the service, other clinicians and service users being the only specific requirements identified by the panel. As a result overall the review included 52 senior clinicians, 76 staff, and 160 service users. Table 5 identifies the numbers of staff involved in each focus group. With regard to measures of central tendency, the mean number of senior clinicians in focus group 1 was identified as 4, in focus group 2 there was a mean average of 11 participants, and in the focus group 3 there was a mean average of 6 participants. Ideally, in a focus group there would approximately 6 participants. The most in one focus group was 18, this may have impacted upon the quality of information obtained and reduced the ability to discriminate between speakers in transcription. However, in keeping with the values of the services and the desire of individuals to want to participate it was determined that the larger focus groups would continue with increased numbers.

The roles of each member of the panel were identified prior to commencement and the questions used to guide each focus group were provided to both the panel and to the members of each focus group. All services were informed in advance and dates for site visits arranged as far as possible in consultation with the service leads. Further, all services were provided with information about the format and purpose of the reviews in advance. Where agencies provided additional documentary evidence prior to review this was not considered until after the site visit had been conducted to ensure that all services were visited without bias by the research-practitioner who was not familiar with any of the services.



**Table 5: Numbers of participants in each focus group by service**

Name of service	focus group 1	focus group 2			focus group 3
		Staff	SU	Total	
SW London	1	7	6	13	7
Camden & Islington	1	1	0	1	-
Colchester	4	8	9	17	9
North Cumbria	8	8	3	11	3
NE London	2	5	11	16	11
Cambridge & Peterborough	2	3	10	13	3
Coventry	3	10	4	14	4
Berkshire	6	6	3	9	9
Oxfordshire	3	5	9	14	9
Buckinghamshire	3	3	5	8	5
STARS	-	1	7	8	-
Plymouth	6	3	3	6	3
Leeds	7	10	8	18	8
Nottinghamshire	6	6	6	12	7
<b>Total</b>	<b>52</b>	<b>76</b>	<b>84</b>	<b>160</b>	<b>78</b>
<b>Mean</b>	<b>4</b>	<b>5.4</b>	<b>6</b>	<b>11.4</b>	<b>6.5</b>
<b>Median</b>	<b>3</b>	<b>6</b>	<b>6</b>	<b>12</b>	<b>7</b>
<b>Mode</b>	<b>4.5</b>	<b>-</b>	<b>3</b>	<b>11.4</b>	<b>6</b>

## Analytical Framework

The data considered within the analysis included audio-recording of focus groups and later short-form transcription<sup>2</sup>, written records of panel debriefing session, and panel members' written reflections. Service user representatives on the panel were asked to reflect on their experience using a set of questions identified by the clinical team. Once all of this data had been collated a thematic analysis was conducted. This involved the coding and recoding of data and the identification of themes resulting from this coding process. This was initially conducted using the focus group data and was then triangulated with the written records of the panel debriefing session and their written reflections. This was undertaken by the research-practitioner and further considered by the panel members for accuracy and concurrence with the identified themes.

The process of framework analysis described by (Ritchie & Spenccer, 2002) was utilised within the original research conducted by Crawford (2007) and colleagues. Further analysis of documentary evidence was conducted by way of literature review and collation of the types of documentary evidence provided. This provided information with regards to organisational and service drivers, extent of involvement in research and academia, extent of involvement with external and internal partners, areas of development since 2004, degree of service user involvement and the systemic factors of the services. Furthermore the thematic outcomes of this current review were compared with those identified by Crawford (2007) and those previously identified within important publications with national relevance.

In the time available it was not possible to conduct a full framework analysis, which would involve an emergent process of detailed transcription, coding and recoding, as well as more thorough triangulation. Further, given greater time, the thematic analysis overview would have involved more detailed feedback from key stakeholders and triangulation with the representatives from each of focus groups would have been conducted on a face-to-face basis. As a consequence, the outcome of this review must be considered in light of these limitations. This could be followed up in future research and evaluation.

With regard to transferability, impact and importance of this review, essential considerations for evaluations involving qualitative data, alongside the usual reliability and validity criteria of quantitative methodology, it was not the intention of the panel or the commissioners of the review to conduct a large scale research project that was compliant with the stringent requirements of the academic field, as resources were not available. However, it was the intention to provide useful information to policy makers, local commissioners including GPs, service providers, service users and other services with a document that would be useful in helping them to consider their own development needs, and to guide them in current best practice for achieving this by way of case example and efficiency. Thereby the researcher is aware of the limitations of this evaluation.

However, as a follow-up analysis to identify any developments since the previous in-depth research was conducted and the extent of concurrence with the views expressed in existing government publications from the previous 10 years, the transferability, impact and importance of this review is sufficiently identified to

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<sup>2</sup> Except in the case of one service where it was considered more appropriate and feasible to take detailed written notes of the focus groups.

provide basic concordance with qualitative analysis requirements. The reliability and validity criteria for the data, for example in relation to statistics and savings, have been assumed according to the integrity of the service providing them as they are self-reported outcomes that were not verified. Thereby, caution is advised in quoting absolutes from the data in this review without reference to the original collators of the data<sup>3</sup>. The findings are therefore provided as indicators and examples for the types of efficiencies that can be made and the associated effectiveness of the services.

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<sup>3</sup> This information can be made available by request to the Authors and in agreement with the appropriate service.

## Appendix 2: Additional detail related to findings of service evaluations

Over a period of three months the clinical review panel travelled the length and breadth of England to visit the eleven successful bidders, approximately eight years after being selected and approximately seven years after establishing the working services.

There are a number of themes that potentially tie up the successful aspects of the pilots and differences that indicate varying needs, models and drivers. In 2007(b), Haigh identified that the five key elements across the projects were emerging as critical success factors were: attachment, containment, inclusion (community), communication, agency. **This review lends further support for these factors although suggests some additional elements that are also critical for success in relation to organisational factors.** The reviewing panel also observed a phenomenon on the visits to each pilot that could only be described as a subjective experience of varying degrees of emotional intensity balanced with alacrity, this was recognised irrespective of theoretical orientation of the service or size of the focus groups, although tentatively there appeared to be a link between the extent of community atmosphere of the project and this subjective experience. This community feel may have further been related according to the reciprocal investment and ownership of staff and service users, along with the extent of collaboration and democratisation within the service. It did not appear to be the case that this experience was related to the intensity of the treatment provided.

With regard to effectiveness of the services, the examination of this in relation to the QIPP framework demonstrates improved outcomes in relation to cost and clinical effectiveness, as well as improvements in patient safety and satisfaction with the service provided. The models, service philosophy and method of intervention employed by each of the services with regard to theoretical orientation are summarised in Table 4. This demonstrates there is a range of provision across the projects. Despite this variation the distinguishing factors in relation to effectiveness did not appear to be determined according to theoretical orientation. However, a meta-analysis of effect sizes was not conducted and as such the measure of this is somewhat arbitrary and subjective, conducted only through analysis of the literature provided by each of the services and qualitative methodology. Furthermore the data provided with regard to effectiveness was not comparable without statistical manipulation, as the sample population and other characteristics along with the methodologies for measuring outcomes were all different. In order to test out this theory further statistical analysis would need to be conducted and this would be affected by the rigour of the methodologies of data collection.

All of the services presented their approach as being 'recovery-focused'. However, as Pilgrim (2008) highlighted there are different definitions of recovery, dependent upon the current mental health model being employed. In addition the analysis of overall themes, discussed later, suggests that the connection between each service and similarity of focus could also be identified summatively as a particular goal of enabling more adaptive relationships for service users, between staff and service users, between staff teams and across agencies through effective partnership working. Attached to this was an objective of increasing the coping resources of service users to enable them to manage relationships, emotions and crisis. Similarly, Brazier et al., (2006) identify that the similarities between effective psychological therapies for those with personality disorders include structure, consistency, theoretical coherence, focus on relationships, flexibility and are tailored to the individual needs. One of the evaluation criteria they used in their study was

effectiveness with regards to improved interpersonal and social functioning. They looked at both clinical effectiveness and cost-effectiveness overall. They identified that several approaches have the potential to be cost-effective including DBT and MBT but require further research.

Over the years the benefits of community treatment programmes and therapeutic communities have been documented (Bion, 1961; Foulkes, 1964; Jones, 1968; Rapoport, 1960). Winship (1999) provided an overview of the implementation of a therapeutic collectivism on a ward in Berkshire that drew on democratisation and the considerable therapeutic impact that this had and the improved outcomes for individuals. Barr, Kirkcaldy, Horne, Hodge, Hellin and Gpfert (2010) conducted a study of 4 one day therapeutic communities in the North of England and found significant improvements in mental health and social functioning as well as possible cost offsets after treatment completion within 16 months. They also found indications of improvements in self-harm patterns and service use. Their findings support the findings of this review that one day therapeutic communities demonstrate clinical and cost efficacy for individuals with personality disorder. Pearce and Haigh (2008) further identify the success of modified therapeutic community (TC) programmes through the use of a 'mini-TC'.

Overall, in a review of the British evidence base for successful recovery in mental health Stickley and Wright (2008) identified the following themes amongst the academic literature: hope and optimism, bringing meaning to life, activities promoting recovery, clearly identified definitions of recovery; in addition amongst the grey literature they identified philosophy of hope for the individual, individual identity and narrative (2008b). These themes are all evident within the findings of this review.

Each of the services could further be identified by difference according to levels of hierarchy and democratisation. While the scope of this review did not include an analysis of power relationships within the projects it is also important to note the differences in relation to how these matters were presented to the visiting team. Some of the services specifically stipulated that they operated according to a flattened hierarchy, which may otherwise be described as 'democratisation' as described by Rapoport (1960) and others in relation to therapeutic communities. Conversely, some of the services specifically stated that they operated within a hierarchical model. While the true extent of this democratisation versus hierarchical service culture was not measured, it is important to note that observation would suggest that in some services a level of hierarchy continued to be maintained even within those organisations who advocated a flattened hierarchy. The extent of this was tested through the approach to risk and crisis management. Some of the *services* employed a professional system of crisis management, while others predominantly set out for the risk to be managed collaboratively across the service and shared with peers, through collective responsibility and collaborative management of risk. All services employed positive risk management: that is they identified the coping resources within the individuals and encouraged them to take positive risk while also giving them back the responsibility to manage their own risk. This operates on the assumption that previous experience for most of the individuals within these programmes would have been the removal of individual responsibility for self-management and the use of hospitalisation and medication to manage suicidality and self-harm. This because it is the method employed most commonly within traditional mainstream mental health services. Furthermore, there is a connection between social capital and mental

health brought about by cognitive factors including trust, sense of community and reciprocity, however, the evidence base is currently insufficient to guide treatment of mental health problems (Falzer, 2007).

## Themes

Comparing the findings of the clinical review with those of the work by Crawford and colleagues in 2007, demonstrates concordance and replication with many of the earlier findings, particularly with regard to the organisational evaluation and user-led qualitative study. However, there were also a number of themes that were not present in this review with regard to understanding of group work processes and purpose, assessment procedures, and fears about endings. It was clear from the clinical review that these matters had undergone critical reflection and redevelopment or improvement and appeared to have matured with time. Crawford et al. identify that in the setting up of new therapeutic communities, in particular, time is required to establish the therapeutic environment and this can impact upon the outcomes and experience of the early participants. It would appear that the maturation of the services, commitment to, and human investment in, the population has resulted in some of the early problems being resolved. One service user provided feedback suggesting that communication about care pathways needed to be improved. In addition services have been able to develop services for carers and supporters of service users and the feedback suggested that this had been facilitated well by staff and the organisation and allowed to become self-facilitating.

The findings of the review also demonstrated concordance with the cohort study and Delphi study. However, the continued lack of consensus around some of the original Delphi items is interpreted here to identify the differences in systemic factors, care pathways and local population and geographical characteristics. The needs of people in an inner city service is likely to be very different to those of individuals in a rural setting.

**What this difference in consensus suggests is the importance of having different services for different assessed needs; that a traditional mental health team approach that is uniform across the country is unlikely to be successful. One size does not fit all, neither across individuals, all communities, all counties, or all regions.** Commissioners in the original study identified the importance of encouraging ring-fenced monies to secure futures and demonstrating outcomes including potential cost efficiencies (Crawford, et al., 2007).

The pilots have learned lessons and employed critical reflection identifying the importance of reintegration, and offering people phased opportunities to return to education, training or employment for example. The Thames Valley Initiative included as part of its bid the Support, Training, And Recovery System (STARS) (Pearce & Haigh, 2008). This has successfully enabled a step down path for those who have completed treatment to begin to undertake employment and training opportunities on a sessional basis as a service user. This facilitates a transitional phase from treatment. In addition the STARS members have undertaken training, delivered a successful accredited training programme, and led the regional implementation of the national knowledge understanding framework (KUF) training; they have also organised events, been part of consultation and development of new services based on the TVI model in other areas.

There are a number of ways in which the process of thematic analysis could have been conducted and further investigation of this would enable the theory-driven conclusions to be tested. For the purposes of this review the themes have been organised into two phases in Appendix 3 in a simple illustration. On the left of the

diagram the optimum general conditions upon which any treatment service offered to those with personality disorders/complex emotional needs should be provided. On examining the literature with regard to these themes there is clear theoretical basis for the those that were drawn out of the review (e.g. Gunderson, 2008; Linehan, 1993; Livesley, 2003; Paris, 2008).

The right side of Appendix 3 represents the outcomes of providing the general therapeutic conditions, these relate to how service users experience services and the foundations upon which any specific therapeutic conditions can then be provided. Overall the evidence base identifies the importance of providing safety and containment for individuals with personality difficulties and the development of the therapeutic relationship. Looking at the subthemes on the right side of the diagram it can be identified that these relate to quality of therapeutic relationships, investment in treatment, gaining a sense of self and others. The focus groups, interviews and literature examined for each service within the clinical review clearly drew out these themes, although not all themes were present to the same extent in all the services.

In summary the clinical review identified that the services placed fundamental importance and value on:

- Providing the right environment
- Service culture
- Philosophy of service
- Reciprocal investment
- Shared Experience

The establishment and combination of these themes then results in service users developing:

- relationships with self and others
- personal agency
- social resources and the ability to adapt and be flexible according to the needs of all stakeholders (innovation)
- safety and containment (beyond working hours)

These themes were identified irrespective of the specifics of the service model or theoretical orientation. While many theories could explain this dependant upon theoretical orientation, epistemology and ontology, Livesley (2003) also highlights that these general therapeutic conditions are necessary for effective treatment independently of problem formulation, service type, theoretical orientation or method of intervention. Further Paris (2008) examining the evidence base relating to the effectiveness of different therapeutic interventions, determined that there are common factors which have the most significant impact upon treatment outcomes. These common factors are related to creating the right environment, building therapeutic relationships, providing safety and containment, offering flexibility while also providing challenge. These common factors are in essence the same as those identified within this review. They appear to represent a point of convergence of all the therapeutic interventions that have demonstrated efficacy for working this population group.

Fundamental to the diagram of themes in Appendix 3 is the positioning of service user partnership. This appears to be a mediating factor of the interpretation of effectiveness. Qualitatively the services who demonstrated greatest congruence between staff and service user views of needs and provision, through genuine and authentic partnership, were also the services in which the majority of themes and sub themes

were present. This has not been tested for significance or correlative effects. However, this is something which would warrant further research to identify whether this is supported. This aspect of analysis has been identified through psychotherapy research into collaborative working as well as through service user participation research.

With regard to the interventions themselves, the evidence base indicates the effectiveness of the therapeutic models within the projects (Therapeutic community treatments, Dialectical Behavioural Therapy, Cognitive Analytical Therapy, Mentalisation-Based Therapy). This is supported by empirical research, although it is not possible to identify the intervention which is most effective. While this in part due to problems with comparing data which is heterogeneous, it may also result from the effect of general conditions. In all models the therapeutic relationship has been demonstrated to be fundamental to the success of any treatment, as such the effects may be the result of the identified therapeutic conditions, with the effect of the specific interventions being dependent upon personal preference, beliefs about the intervention being undertaken, and the opportunities for alternative interventions being available. While there is no manualised clinical approach or single theoretical psychological model or orientation, this review has discovered that focus group members across all eleven projects demonstrated a concordance with themes that can be attributed to the general therapeutic conditions. Thereafter, further research would be useful to determine the mediating effects of the different therapeutic orientations.

While research regarding the therapeutic alliance or relationship emanated originally from psychoanalytic paradigms, this has become increasingly applied to studies of other schools of psychological thought including behavioural models used most frequently in current health system (e.g. Hardy, Cahill & Barkham, 2009; Swales & Heard, 2009). Furthermore, Lejuez and Hopko (2006) identify that the success of behaviour therapies may be understood through therapeutic relationship variables; they considered a number of these therapies including those that have been provided as part of the pilots in this review. Hardy, Cahill and Barkham (2009) emphasise the several key factors within therapeutic relationship as summarised by hope, tolerance and resolution of ruptures, and understanding, all of which were identified by service users within this review.

An aspect that was not specifically demonstrated within the reviews was the issue of attrition. Due to the methodological approach of this review, services were asked to invite service users to the focus groups who were currently on the programme and those who had completed the programme. Thereby, the views of those who had disengaged from the service, or otherwise stopped using the service were not captured. It is well documented that individuals with personality difficulties struggle to engage with services and to handle ruptures in the therapeutic relationship (Livesley, 2003). Thereby, it can be assumed in the absence of statistics that there will be individuals who have disengaged from services. The conclusions do not therefore identify the reasons why individuals do not remain in the specialist treatment services. For example, the empirical research base has identified that certain therapeutic models are less well tolerated than others. Consequently, the conclusions that can be drawn from this review must be caveated by the fact that the voices of those who no longer engaged were excluded. This means that we can identify that these general therapeutic conditions and the specific therapeutic models that are then employed are effective for those who are currently in the services, or had previously successfully completed the treatment, and chose to participate in the focus groups. Further research would need to be conducted to specifically engage with



those who have not completed the programme or have disengaged from services. One of the services has worked with a local university to examine the reasons for attrition from their service (Booth, Farrand, Gilbert & Lankshear, 2009).

Furthermore, with regard to the identification of aspects of services that individuals within focus groups felt could be improved there were no consistent themes identified. A number of participants identified having difficulty with their time in the service coming to an end and what would happen if they needed help in the future. Further feedback was received from a few service users that, at times, it felt that communication could be improved with regard to changes in the service, or when awaiting the outcomes of assessment or transition to another part of the service. Overall, service users identified that problems came up - but in the services where partnership with members of the service was strongest, this was reflected as being resolved through interpersonal and group processes. This suggests that service user partnership which is genuine, authentic and effective provides an effective means for resolving problems. However, in relation to attrition, it may be that individuals do not yet have the required relationship to feel able to resolve these problems, and this would need to be explored further. Several service users also identified that peer support was particularly helpful when individuals had disengaged. Methods such as text messaging and asking people 'if they were okay and were welcome to return if they felt able' were identified as effective. Nonetheless, voices of dissent were absent from the focus groups generally, and it would be important to identify the reasons for this absence and to learn from those whose voices were not represented.

Crawford, Price, Gordon, Josson, Taylor, Bateman, Fonagy, Tyrer and Moran (2009) investigated the levels of engagement and retention within 10 of the pilots and identified that of 713 individuals taken into the services in the first 2 years of operation 164 (23%) dropped out without completing treatment. They concluded that while the services were initially good at engaging individuals who they accepted into treatment the populations who were most likely to drop out were younger and male. Since the collection of this data a number of the services have begun to try to address these issues, as well as the finding that people from Black and Ethnic Minority groups were also less likely to access treatment.

Costello (2010) conducted a 3 year study to uncover the meaning of recovery for a group of individuals with diagnoses of personality disorder. As result, a pathway for transitional recovery at one of the projects was identified. Within this Costello identified that there are certain foundational 'pillars' that need to be in place for individuals to commence therapeutic and meaningful paths to recovery. These are identified as safety and trust, feeling cared for, community and belonging, and boundaries. This demonstrates concordance with the findings of this review in relation to the general therapeutic conditions.

Many individuals who have diagnoses of personality disorder may have experienced complex trauma experiences in their past. There are similarities between the findings of this review and that identified through the empirical evidence for effective interventions in complex trauma. That is there is general agreement across the field that there are 3 phases of treatment, as originally proposed by Herman (1992): **safety and stabilisation**, processing and life integration and relapse prevention. All the therapeutic interventions that have been found to be effective have identified concordance with this tripartite model (e.g. Cloitre et al., 2002; Courtois, 2004; Ford & Courtois, 2009; Najavits, 2002; Shapiro, 2001; UKTG, 2009; van der Kolk, 1996, 2009; Wagner & Linehan, 2006). Further, the therapeutic relationship has been identified within trauma work as essential to issues related to attachment and relationship problems (Pearlman &

Courtois, 2005). The similarities with personality disorder treatment can be identified. It is therefore possible that across all therapeutic orientations that a number of phases exist where certain outcomes need to be affected in order for change to occur. This would require further examination.

In 2007, Haigh identified the crucial component of service user partnership within the pilots. He presents this as being more than democratisation, it actually requires involvement across the life-span of a service from conception to evaluation. Furthermore, he identifies the importance of ownership and empowerment, this review suggests that those projects whose service user partnership spanned the life of the project engendered greatest ownership and empowerment. This was identified through thematic analysis, and triangulation of methods with a brief analysis of cultural and social language use. However, additional linguistic and content analysis would enable this to be investigated further. It would suggest that investment in the project by service users was greater amongst those who were an integral part of its development and growth. Haigh and Benefield (2007b) highlighted the importance of new ways of working that do not follow a traditional mental health treatment model but lay in comprehensive multi-agency and multi-disciplinary working that place partnerships with service users at helm. Further this needs to be reciprocal, therefore while valuing the voices of service users and including them in decision-making, it also needs to be present for staff. It may be a reason for good retention of staff within the services. Overall, the services demonstrated that there was greatest investment in the project where there was reciprocal investment and shared ownership. Service users reported being included and empowered through being involved in the development of the service from the beginning (Miller & Crawford, 2010). When considering this in relation to the original evaluation by Crawford et al., (2007) it would appear that this was in place from early in the development programme: they noted that each project developed in accordance with service user feedback.

An observation by the review panel was made in visiting each project and this related to the characteristics of the parent organisation governing the project. While over half the projects were managed by NHS providers the other projects were managed by non-NHS providers. What was apparent at each visit was the importance of leadership, a balance between strong leadership, charisma and compassion balanced with an ability to be facilitative and not overpowering. This observation led to further observations through themes unfolding relating to some of the difficulties that projects had encountered with regard to change within their organisations. Upon analysis of documentation alongside the focus group and interview data there were a number of identified differences between organisations. The first was 'evidence-based provision' versus 'practice based evidence provision', or the extent to which organisations were willing to take risks and to pioneer new developments in the field where evidence did not yet exist; the second was commitment to outcomes monitoring and importance placed on research for contributing to and developing the evidence base through links with academic leaders. Within this review there was wide variation in the extent of research literature published by the services, although all services had contributed to the evidence base cumulatively.

Full analysis of the organisational similarities and differences was not possible in the time frame and was beyond the scope of this review. However, organisational theory identifies that the culture of the governing organisations will have an impact on the programme that can be delivered. For example, if the organisation is not supportive of the overall programme or does not recognise the specific needs of the client group they are

likely to be driven by targets and focused upon short-term solutions. This is unhelpful for clients with long-term complex problems in need of changing relationships and adapting their fundamental ways of relating. Furthermore, such an organisation is unlikely to value its staff who work in the area, and hence impact upon the morale of teams.

The Center for Applied Research (2000) has identified characteristics for success and failure of organisation change, or implementing new ways of working:

<p><b>Failure</b></p> <ul style="list-style-type: none"><li>Unrealistic expectations of the process of change and its outcomes</li><li>Inadequate support from top level management</li><li>Organisational unreadiness when the members of the organisation lack communication skills</li><li>Failure to follow through with change</li><li>Management resistance</li><li>Organisations that are too large</li><li>Unwillingness to model change</li><li>Inadequate skills for the tasks</li><li>Unwillingness to change due to firmly held beliefs about the current system</li><li>Trying to implement change from the bottom up</li><li>Assuming a change is needed and not exploring the reality of the situation</li><li>Trying to change too much too quickly</li></ul>
<p><b>Success</b></p> <ul style="list-style-type: none"><li>There is pressure to change</li><li>Drive from strategic leader</li><li>Willingness by strategic leaders to understand the needs</li><li>Leadership</li><li>Collaborative problem identification</li><li>Willingness to take risks</li><li>Realistic, long-term perspective</li><li>Willingness to face the reality of the situation</li><li>Rewards people for the effort of changing and improvement as well as short-term results</li><li>There are tangible intermediate results</li></ul>

These may be important questions to ask of any service trying to identify the potential hurdles that will need to be overcome in trying to implement a new service or project based on these services.

In addition, a commonality between all the projects was the importance of staff supervision. While there were varying extents and types of supervision offered the general view was that staff should receive regular support by way of clinical or line management supervision. Furthermore, one of the subthemes identified through the focus groups was the importance of the staff 'team'.

Castka, Bamber, Sharp and Belohoubek (2001) identify seven key factors for high performance teams : the support of the organisational culture, team focus, system focus, strong group culture, possess the

required knowledge and skills, the needs of the individual must match the needs of the team, performance management with rewards. Within the clinical review's focus groups, staff teams reflected their enjoyment of coming to work and the rewards it provided; furthermore, both service users and staff reflected upon the effectiveness of the 'team' and the congruence between them. This could be further reflected in projects that have retained the majority of the staff who were initially recruited, as in a number of projects this was the case. However, the reasons for higher turnover amongst other services appeared to be related to promotion opportunities, and the use of the services as training centres of excellence, rather than dissatisfaction with the service. This can only be identified anecdotally as the review panel did not set out to examine staff attrition and did not therefore contact any previous employees to verify this information. However, in this regard the barriers and obstacles to high performance teams include: lack of direction, lack of commitment to performance, skills gaps, external confusion or indifference (Katzenbach & Smith, 1993).

Continuous organisational improvement and development is acknowledged as an essential aspect of today's society and in order to be able to adapt to the demands of the economic situation, organisations must constantly evaluate their cost-efficiency, quality and productivity as part of performance management (Kaye & Anderson, 1999). In addition, the development of the service user movement demands that we go further to ensure that organisations deliver quality care and adapts to changing needs in ways that are 'user-friendly'. Kaye and Anderson (1999) identified ten essential criteria for this to occur, as 'drivers' and 'enablers':

Drivers: Senior management; leadership by all managers; stakeholder focus; measurement and feedback; learning from previous events

Enablers: Culture of improvement and innovation; employee focus; focus on critical processes; quality management system; integration of improvement activities.

While not all services evidenced these to the same extent, the themes drawn out of the review clearly identify their presence.

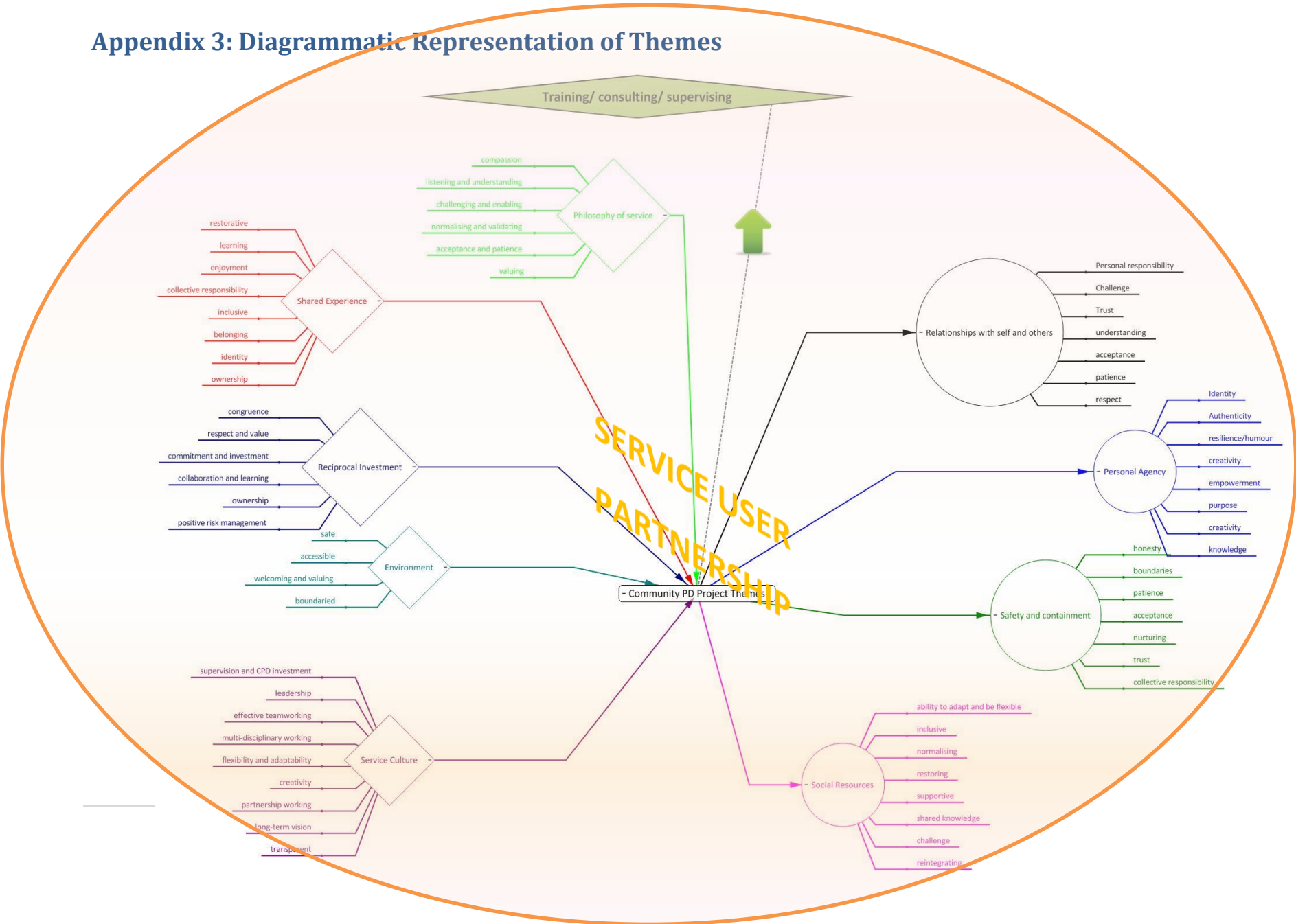
As reported in the main body of this report, the projects have identified strength in innovation. They have identified the importance of being responsive to a changing health economy and changing demands of service users. The pursuit of successful knowledge creation and innovation in a service or organisation depends upon collective creativity, collective learning, and collective knowledge. This requires knowledge sharing, critical reflection and communicating ideas effectively. The success of these projects is testimony to the extent to which the projects have been able to do this. Research in the business sector has found the factors that the reliability of successful innovation include the following and their associated variables determine the outcome of their influence (Merx-Chermin & Nijhof, 2005):

- Strategy: participation, information, formalisation and decision-making
- Structure: degree of individual autonomy, strictness, centralisation, layers of the organisation
- System and procedures : focus, connectivity
- Leadership: vision, stimulating role and motivation, coaching, modelling, expertise
- Organisational climate: focus, stability, communication and interaction, control and tolerance

- Personal characteristics : motivation, creativity, individual learning capability, expertise

These factors need to be considered by organisations wishing to provide effective personality disorder services and by those considering whether they should commission them. The demands of a significantly changing NHS, and the necessary savings that have been identified as needing to be made to secure the future demands of an aging population, will rely on successful innovation, and this is no less important for services providing for individuals with complex needs.

# Appendix 3: Diagrammatic Representation of Themes



Training/ consulting/ supervising

**SERVICE USER**  
**PARTNERSHIP**

- Community PD Project Themes

Philosophy of service

- compassion
- listening and understanding
- challenging and enabling
- normalising and validating
- acceptance and patience
- valuing

Shared Experience

- restorative
- learning
- enjoyment
- collective responsibility
- inclusive
- belonging
- identity
- ownership

Reciprocal Investment

- congruence
- respect and value
- commitment and investment
- collaboration and learning
- ownership
- positive risk management

Environment

- safe
- accessible
- welcoming and valuing
- boundaried

Service Culture

- supervision and CPD investment
- leadership
- effective teamworking
- multi-disciplinary working
- flexibility and adaptability
- creativity
- partnership working
- long-term vision
- transparent

Social Resources

- ability to adapt and be flexible
- inclusive
- normalising
- restoring
- supportive
- shared knowledge
- challenge
- reintegrating

- Relationships with self and others

- Personal responsibility
- Challenge
- Trust
- understanding
- acceptance
- patience
- respect

- Personal Agency

- Identity
- Authenticity
- resilience/humour
- creativity
- empowerment
- purpose
- creativity
- knowledge

- Safety and containment

- honesty
- boundaries
- patience
- acceptance
- nurturing
- trust
- collective responsibility

## Appendix 4: The service models

Service Example	Case Management		Intensive treatment models						Light treatment models				Step down services		Training/consultation/supervision
	Leeds	Plymouth	Coventry	The Haven	Nottingham	Oxford (TVI)	Berkshire (TVI)	Buckinghamshire (TVI)	Carlisle	SUN	IMPART	Cambridge	STARS (TVI)	Umbrella	CANDI
Care Coordination															
On-site RMO															
Professional crisis service access															
service user out of hours support															
Training															
Consultation															
Supervision															
Link w orkers															
3-5 day Therapeutic Community Programme															
Mini-therapeutic community 1-2 days															
Non-TC Group therapy															
Individual psychotherapy															
Skills development/psychoeducational work															
Access to social and recreational activities															
Service User Consultant roles															
Approach to risk management															
Occupational therapy programme															
Step-down n/Moving on programmes															
Assertive outreach															
Require diagnosis															
Accept/or require self-referral															
Any exclusions															
Work with families/carers/supporters															
Actively engaged in the development of practice-based evidence															
Open access policy once individuals have left treatment															
Lead Agency - NHS Provider															
Under 18's															

## Appendix 5: Practice examples from the pilot projects

Project	Service type	Philosophy	Treatment Model
SW London	Open access support groups for people with PD	Aims: to help people develop effective ways of coping, reducing emergencies and improve access to appropriate services. Fundamental principle of the project is the utilisation of service-users' own resources for support and a commitment to formally include these individuals as an integral part of service delivery. Inclusion - to achieve a lasting and stable positive difference it is necessary to include the people that suffer problems associated in having a personality disorder in seeking solutions.	Recovery approach integrates therapeutic community principles with coping process theory (Cognitive Theory) and utilises as appropriate an underpinning psychoanalytic epistemology
Camden & Islington	ETE programme - SDS; training resource - LiveWork	maximising productivity by using a small resource to have an impact across borough wide services and agencies;	Skills based client training; professionals training in DBT
Colchester	Individual and group therapy in day TC	Recovery model fostering hopes, desires and goals after building the foundations - pyramid model developed; use complementary therapies	A range of approaches are employed incorporating principles of therapeutic communities
North Cumbria	hub and spoke service integrated with psychotherapy service offering assessment, treatment and assistance in the management of those SUs with the greatest needs; providing skills to professionals in other teams and agencies treating higher numbers of clients; carers group	recovery model - developed from no longer a diagnosis of exclusion; designed locally to cope with rural geography and to reduce out of area demand; staff members provide safe settings and boundaries for Sus and space for Sus to reflect on and work through their difficulties by facilitating but not directing change	psychoanalytically informed with a range of individual and group psychotherapies but also applications of psychoanalytic, mentalisation-based and systemic thinking to outreach work, relationship groups and therapeutic community work
NE London	psychological therapies service with individual and group settings; assessments, treatment, consultation and	Recovery model	DBT, CBT and motivational interviewing



	training; services for carers		
Cambridge & Peterborough	Case management and day service		
Oxfordshire	Hub (Oxford) and Spoke (Wallingford, Witney and Banbury) service offering one 3-day TC with 'options groups' and mini-TCs in 'spoke' localities.	Working clinically to promote a recovery model by facilitating significant functional improvement. Its ethos is one of recovery and is underpinned by the premise that PD is not a lifelong debilitating mental illness, but that with appropriate intervention the associated morbidity can be reduced to such an extent, that people can resume a functional and rewarding life. Needs-responsive treatment programme conceptually understood to be a mini-therapeutic community	Integrative psychotherapeutic model; theoretical and practical integration of psychodynamic psychotherapy, psychodrama and action methods, sociometry, CBT, CAT, biological psychiatry, nidotherapy
Buckinghamshire	Hub (Aylesbury) and Spoke (High Wycombe and Amersham) service offering one 3-day TC and 'options groups' in 'spoke' localities.	Recovery rather than maintenance; to promote recovery in a disadvantaged group, and liaise closely with other agencies to improve the care pathways and minimise unnecessary care episodes, while reducing morbidity; to promote awareness and training in PD and related issues.	TC model of treatment - group based psychosocial treatment model incorporating a variety of therapy modalities including psychodynamic, CBT, CAT, MBT, creative and humanistic therapies, social therapy and occupational therapy - democratic
Berkshire	Hub (Reading) and Spoke (Newbury, Wokingham, Bracknell, Ascot and Slough) service offering 3-day TC with various other groups in 'spoke' localities as part of the trust's psychotherapy services.	Recovery, therapeutic community principles - change happens in group settings - transitional object - 4 tiers of treatment - pre, during and post services - improved coping skills, reduced suicidality and self-harm, symptom reduction, qualitative subjective change reported by service users, and improved relationships with other people (money was for addition of Tier 1 and Tier 2 service)	TC model of treatment - group based psychosocial treatment model incorporating a variety of therapy modalities including psychodynamic, CBT, CAT, MBT, TA, creative and humanistic therapies, social therapy and occupational therapy - democratic; link groups - psychoeducational groups x12; pathways group; leavers groups - incorporates psychotherapy service - single shared point of access
Plymouth	Early intervention Outreach service; group work; 1:1 personal action plan	Empowerment - self esteem and confidence development; coping resources; aim to include within the therapeutic relationship - acceptance; challenge; validation; humour and authenticity - empathic, collaborative and client-led and hold a belief in the human spirit	Early intervention and assertive outreach - solution-focused case management - team approach; providing enhanced CPA; sign-posting, advocacy, relationship building; engagement; normalisation; empowerment and assertive outreach - see model of service delivery diagram - all staff use attachment , protective behaviours, youth development and life span model - other models also available dependant on staff team at the time

