Learning the lessons:
a multi-method evaluation of dedicated community-based services for people with personality disorder

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A project conducted in partnership by Imperial College London, the Mental Health Foundation, University College London and Kings College London
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GLOSSARY

‘Dedicated’ services
We use the phrase ‘dedicated personality disorder service’ to describe services such as the 11 pilots which focus exclusively on the needs of people with personality disorder (PD). We used this in preference to ‘specialist service’, because many other services, especially departments of psychology and psychotherapy, work extensively with people with PD and often have considerable specialist expertise in this area.

Direct and indirect service provision
In addition to delivering ‘direct’ services to service users, each pilot service undertook to work with other local agencies to provide support and training on PD. Throughout this report we refer to this aspect of their work as ‘indirect service provision’.

Interventions
The 11 pilot services provided a broad range of different services to users including general support and advice, psycho-education, and specific social, occupational, psychological and medical interventions. We have used the word ‘intervention’ to refer to any form of service they provide, and the word ‘therapy’ to refer to formal structured psychological and psychotherapeutic interventions.

Personality disorder (PD)
People with a PD have ‘enduring patterns of inner experience and behavior that deviate markedly from cultural expectations’ (American Psychiatric Association, 1994). Methods for classifying personality disorders include those based on groups or ‘clusters’ of personality traits and those based on the severity. Both are referred to in this report. There are three ‘clusters’ of PD: cluster A (characterised by social distance and eccentricity); cluster B (flamboyance and emotional instability); and cluster C (in which anxiety, perfectionism and a tendency to worry predominate). Classification based on severity distinguishes ‘simple personality disorder’ in which there are significant problems associated with disturbance in only one cluster, and ‘severe PD’ in which there is disturbance in more than one cluster with severe disruption both to the individual and to others.

‘Pilot’ service
When the 11 services we evaluated were commissioned they were referred to as ‘pilot’ services to signify that they were being funded for a limited period to test whether they could form the basis for a viable service. Since then several have moved on to become an integral component of local services and are therefore no longer ‘pilots’. However, in this report we have retained the phrase pilot to refer to the 11 services that were originally funded and we were asked to evaluate.

Service users
Service providers used a range of different terms to refer to the people they work with including: ‘client’, ‘service user’, ‘member’ and ‘patient’. The word they most commonly used was ‘client’. Members of our Project Advisory Group stated that they preferred the term ‘service user’. The terms ‘client’ and ‘service user’ are used interchangeably in the remainder of this report.

Tiered services
National recommendations on services for people with PD have been categorised as a series of tiers, ranging Tier 1 support for general services, Tier 2 outpatient services, Tier 3 intensive services (such as day services and case management), Tier 4 specialist inpatient services, Tier 5 secure and forensic services and Tier 6 residential units for people with Dangerous and Severe Personality Disorder.
**ACRONYMS**

We have endeavoured to use acronyms sparingly in this report, and to define each before using it in the text. However we sometimes employed commonly used acronyms including;

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ASPD</td>
<td>Antisocial Personality Disorder</td>
</tr>
<tr>
<td>BME</td>
<td>Black &amp; Minority Ethnic</td>
</tr>
<tr>
<td>BPD</td>
<td>Borderline Personality Disorder</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behaviour Therapy</td>
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<tr>
<td>CJS</td>
<td>Criminal Justice System</td>
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<tr>
<td>CMHT</td>
<td>Community Mental Health Team</td>
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<tr>
<td>CPA</td>
<td>Care Programme Approach</td>
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<tr>
<td>CPN</td>
<td>Community Psychiatric Nurse</td>
</tr>
<tr>
<td>DBT</td>
<td>Dialectical Behaviour Therapy</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department – sometimes referred to as A&amp;E</td>
</tr>
<tr>
<td>FTE</td>
<td>Full time equivalent</td>
</tr>
<tr>
<td>NIMH(E)</td>
<td>National Institute for Mental Health (England)</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>PD</td>
<td>Personality Disorder</td>
</tr>
<tr>
<td>SAP-AS</td>
<td>Standardised Assessment of Personality – Abbreviated Scale</td>
</tr>
<tr>
<td>SFQ</td>
<td>Social Function Questionnaire</td>
</tr>
<tr>
<td>SU</td>
<td>Service User</td>
</tr>
<tr>
<td>TC</td>
<td>Therapeutic community</td>
</tr>
<tr>
<td>XBX</td>
<td>‘expert by experience’, a service user employed to help develop or deliver services</td>
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IDENTITY OF PILOT SERVICES AND STUDY PARTICIPANTS

In Appendix A we provide a detailed description of each of the 11 pilot services. Service leads consented to their service being named in these case studies and were given an opportunity to comment on a draft version. In the other sections of the report we have generally not referred to the pilots by name, but have described the kind of service they provided. We decided not to include views of referrers and commissioners of local services in the case studies because of the small numbers involved. We were concerned that their views might not be representative. Instead we have placed these data in the Section 4.2 of the report in an attempt to reflect the diversity of their views.

In Section 5 we have not named the pilots but referred to each by a number and given a brief description of the service it provides. We did this at the request of some of the pilots who were concerned that these data provide an incomplete account of the work they have done and may not reflect current levels of service activity. While acknowledging that the limited number of services means that it may be possible to identify them, we agreed not to name them in this section of the report. Again we gave services an opportunity to examine these data in order to identify errors or omissions.

In order to protect the identity of individual participants we simply referred to ‘staff’, ‘service users’ and ‘managers’ in the case studies. In Section 4 we have provided a code for each of the participants based on their being a commissioner (C), referrer (R), service user (SU), carer (Carer), manager (M), or other member of staff (S). We have used the acronym ‘FGSU’ to refer to quotes from service users from focus groups.
EXECUTIVE SUMMARY

Background
Personality disorders (PD) are important conditions that have significance for the individual, their family, and society at large. It is estimated that 4% of people in Britain have a PD. People with a PD have an enduring pattern of inner experience and behaviour that deviates markedly from cultural expectations. They are more likely to experience mental illness, substance misuse and social problems and the rate of suicide is seven times higher among people with PD. Some forms of personality disorder are characterised by quick-temperedness and impulsivity and levels of PD are far higher among those in contact with criminal justice services.

Concerns have been expressed about the quality of services for people with personality disorder. Many working in mental health and social care feel they are unable to help people with PD and some believe that they should not be offered a service. Service users report being dissatisfied with existing services and many believe that the treatment they received deteriorated as a result of being given this diagnosis.

As part of their response to these concerns, the Department of Health funded 11 dedicated community-based pilot services for people with PD in England. While evidence has begun to emerge showing that psychological interventions can benefit people with PD, little is known about the most effective way to deliver these. The role that dedicated services can play in supporting the work of others in health and social care is also unclear.

Aims
To evaluate the 11 pilot community services and capture lessons learned during the initial phase of their development. In order to achieve these aims we set out to:
1. Describe the organisational form, activity and function of 11 pilot services;
2. Compare aims and objectives of services with those they actually deliver;
3. Measure health, social function and service utilisation among a sample of people referred to these services;
4. Identify organisational, therapeutic and other factors that service users and providers believe result in high-quality care for people with personality disorder.

Methods
A multi-method study comprising: (a) an organisational evaluation examining the context, form, and function, of the 11 pilot services; (b) a user-led qualitative evaluation of service users’ and carers’ views and experiences; (c) a cohort study examining demographic and clinical characteristics of a sample of those referred to the services; and (d) a Delphi study examining the level of consensus among expert authors, service users and providers about key aspects of the organisation and delivery of dedicated services for people with PD.
a. Organisational evaluation
Documentary evidence from each of the 11 pilot services was examined and in-depth interviews conducted with managers and front-line workers. We interviewed a range of staff delivering different aspects of each service using a topic guide specifically developed for the study. Interviews were conducted on at least two occasions. Data were audio recorded and verbatim transcripts made. Data were analysed using a grounded approach in order to generate a thematic framework which addressed study aims.

b. User-led qualitative study
Service user researchers were trained and provided with ongoing support to interview a sample of users and carers at each of the pilot sites. The sample were selected purposively in order to include both current and former service users and ensure that age, gender, component of service used, and length of contact with the service were broadly similar to the mix of users at each service. Interview schedules were developed in consultation with the project Advisory Group and on the basis of previous literature on the subject. Data were audio recorded and verbatim transcripts were analysed by researchers trained and supervised in a qualitative framework-based approach.

c. Cohort study
In collaboration with service leads at each of the 11 pilot services a ‘care pathway record form’ was developed and used to record basic demographic data on a sample of those referred to each service. The form included information on the assessment process, the services which users were offered and those they received. We also asked pilots to incorporate three short questionnaires into their existing assessment procedures: a screening questionnaire to assess the likelihood of personality disorder, an assessment of social functioning, and a measure of service utilisation during the previous six months.

d. Delphi study
We designed a 54-item Delphi questionnaire based on data collected during the first phase of the study and feedback from users, providers and commissioners of services. Delphi propositions focused on the organisation and delivery of dedicated PD services, staffing issues, user involvement and peer support, priorities for service development and outcomes measures. The Delphi panel comprised 99 people with approximately equal numbers of users, providers, and expert authors who had published at least one paper on community services for people with PD in Britain during the previous 10 years. Three waves of questionnaire were sent out together with feedback on individual and group responses from previous rounds.

Findings

a. Organisational evaluation
The 11 pilot services provide a diverse range of innovative approaches to helping people with PD and serve areas ranging from metropolitan boroughs to county districts covering over 2 million people. Services received between £280,000 and £1 million per annum. Despite these differences there was broad agreement about the basic parameters for providing services to people with PD. They should:
• Be delivered over a relatively long period of time
• Validate rather than dismiss users’ experiences
• Work flexibly with service users while ensuring the service they provide is consistent and reliable
• Promote autonomy and choice
• Deliver more than one intervention of varying intensity to suit those with different levels of motivation
• Facilitate access to peer support and group work
• Help service users generate short and long-term goals
• Help service users plan how they will deal with crises
• Ensure that service users are given time to prepare for leaving the service
• Deliver social as well as psychological interventions
• Combine direct service provision with support for colleagues working in other settings aimed at increasing their capacity to work with people with PD and decrease social exclusion
• Ensure that staff work closely together and receive regular supervision

Staff working in general health and social care told us that pilot services were valuable because general services lacked the time and skills needed to help people with PD. Some felt that existing services were often unhelpful and that the development of dedicated services challenged the notion that there was nothing that could be done to help people with PD. Others were disappointed that dedicated services were unwilling to work with people who were very chaotic or not sufficiently psychologically minded. Staff who had received training and support on the management of people with PD generally welcomed this. Most of the commissioners we interviewed had been involved in setting up pilot services and were positive about them. However, they expressed concerns about the small number of service users that some had taken on and were keen that others expand the geographical area that they served. Commissioners felt that PD services should become more integrated with other services. Others warned that services for people with PD were not a high priority and that unless it could be demonstrated that they resulted in savings elsewhere, long-term funding was uncertain.

b. User-led qualitative study
• Service users often came into dedicated PD services with painful experiences, both in their own lives and in relation to previous contact with services. Many talked of feeling rejected and dismissed by mental health services.
• Service users approached PD services with a sense of hope combined with fears of rejection from what many had been told was their ‘last chance’.
• Some service users reported that the assessment process was distressing and that they were not sufficiently supported during this time.
Service users appreciated flexibility and choice and the easy accessibility of both services and staff.

Services that offered a range of options for therapy, peer support and extra help at times of crisis were highly appreciated.

Members of staff at pilot services were valued for their sincerity, non-judgemental approach, for being caring, supportive and knowledgeable, and for treating service users with respect.

Many service users spoke of the value of peer support, of sharing problems and coping strategies with other people, and of the power of learning from and helping others. There were difficulties, too, in peer relationships. In some services, people encountered cliques or felt burdened by other people’s problems.

The extent to which rules were explained and negotiable was an important issue: in some, service users were able to appreciate and feel some ownership of the rules as a result of contributing to their formulation. Equally, it was important that rules be interpreted and applied consistently.

Group process and group therapy gave rise to both critical and appreciative comments. In some instances, service users felt that the way in which group therapy operated was not properly explained and felt mysterious. Others were appreciative of what they learned in groups, and of the peer support they gained there. Nevertheless, there was an appeal for individual therapy in services where this was not an option.

Most service users spoke of positive changes resulting from their contact with the pilots, including: the way they felt about themselves, their behaviour, and in the ways they related to others. Negative or insignificant outcomes were mentioned by only a few. Service users expressed concerns about what would happen to them when their time in contact with the service came to an end.

Few services had begun to provide systematic support for carers and family members at the time of this study. In the few services where they had, carers greatly appreciated both the information and advice they were given and the chance to meet and talk with other carers.

c. Cohort study
We obtained basic demographic data on 1,428 people referred to the 11 services over a 34 month period. Mean age of those referred was 35.2 years (SD = 9.3), 500 (35.1%) were male, 90 (7.8%) non-white, and 1,017 (94.4%) had had previous contact with mental health services. Most referrals were made by secondary care services, with the exception of those where self-referral was either encouraged or required. Main reasons for referral were mental distress, social problems, self-harm and suicidal behaviour. Between 31% and 100% of those referred were taken on by the service. The main reason why people were not taken on was because they either did not attend or complete an assessment. Men were less likely to engage with services than women.
Detailed clinical data were obtained on 457 people at 10 of the 11 services. Levels of personality disturbance were high across all 10, with between 92% and 100% meeting criteria for probable personality disorder. Levels of social dysfunction were also high, and greater than those reported in a previous study examining people presenting to emergency medical settings with acute mental health problems. There were also high levels of utilisation of other services with 47% reporting having attended an Emergency Department, 37% being admitted to hospital and 7% having been charged with an offence during the previous 6 months. 335 (44.4%) of 755 users who started to use a service were no longer in contact with it. Approximately a third had completed an intervention, with the remainder dropping out of contact with the service or leaving prematurely for other reasons. BME service users and men were less likely to remain in contact or complete an intervention. Those with higher levels of inter-personal problems were more likely to drop out of contact with services and there was a trend towards people who referred themselves to services being more likely to remain in contact or complete an intervention.

d. Delphi study
Consensus was reached on only 21 (39%) of Delphi items. These included the need for dedicated services and the belief that interventions should be delivered over years rather than months. Delphi respondents highlighted the importance of personal qualities of staff working in PD services, the value of teams which included people with different professional and non-professional backgrounds, and the need to provide staff with a regular forum to reflect on their practice. There was a marked lack of consensus around issues such as the role of home-based assessment, assertive outreach, medication, in-house crisis support, and whether all people with PD should have access to user-led services. Delphi participants rated outpatient psychological services, day treatment programmes and consultation services as priorities for service development and stated that all services needed to work to reduce stigma and discrimination experienced by people with PD. Services should be judged by their ability to improve quality of life and social functioning of people and decrease levels of mental distress.

Conclusions
This study coincided with the first two years of the operation of most of the pilot services. While this allowed us to track some of the challenges they faced, services were in transition and it is possible that some of the problems that we identified were resolved in the period after data collection stopped.

The 11 pilot services delivered a broad range of interventions for people with PD over a short period of time. Pilots succeeded in engaging and retaining many people in services, although half of those referred were not taken on for direct service provision. Despite major differences in the organisation and content of interventions delivered by the pilots, there was widespread agreement about key aspects of how such services should be
delivered. Services need to deliver psychological and social interventions, provide opportunities for peer support and help people access leisure activities, training and employment. They should provide long-term interventions, take on responsibility for coordinating care, and consider accepting self-referrals. Teams providing dedicated PD services need to have regular supervision, preferably with an external supervisor.

Given the high prevalence of PD, services face the challenge of how best to use their limited resources. Dedicated services may be able to increase their capacity by developing structures that facilitate peer support. The unwillingness of many to engage with dedicated services as they are currently configured mean that most people with PD will continue to be treated by generic services. Support for those working in these services will therefore continue to be an essential component of the work of dedicated PD teams.

Referrers, commissioners and service users stated that general mental health services had often not served people with PD well in the past. Service users told us that contact with the pilots had helped them change the way they felt about themselves and related to others and challenged the notion that there was nothing that could be done for people with PD. Service commissioners told us that services for people with PD were not a national priority and highlighted the need for research and audit to examine whether dedicated services resulted in direct cost savings.

Expert authors, service users and providers believe that outpatient services delivering psychological treatments, dedicated day services and consultation services are the priorities for service development, but consensus is lacking about important aspects of service delivery such as the role of outreach services and the use of medication.

The eleven pilot services achieved a considerable amount over a limited period of time and they appear to be delivering high-quality care to a group of people who have been poorly served in the past. We believe that the lessons they learned during the first phase of their development and feedback from service users can guide the development of new services for people with PD. Dedicated PD services need to continue to monitor the impact of their work on the extent to which other services are used. Further attention also needs to be given to the impact of assessment procedures and the needs of men with PD and BME service users.

**DISCLAIMER**
*Please note: The views expressed in this report are those of the research team and are not necessarily shared by those of the Department of Health or the funder (National Coordinating Centre for NHS Service Delivery and Organisation).*
1 BACKGROUND
Personality disorders (PD) are a heterogeneous group of conditions in which there are pervasive and inflexible patterns of inner experience and behaviour that deviate markedly from cultural expectations (American Psychiatric Association 1994). High levels of mental distress and impaired social functioning mean that these disorders have a significant impact on the lives of the person affected, their families and carers, and society as a whole. It is estimated that between 3% and 7% of people in Britain have a personality disorder (Coid et al. 2006). Most forms of PD are more prevalent among men than among women, and in inner-city areas compared to suburban and rural ones. Emotional and inter-personal problems associated with PD mean that the prevalence of personality disorder is generally higher in healthcare settings than in the general population. Approximately 40% of people in contact with substance misuse and mental health services have a PD (de Girolamo & Dotto 2000); (Bowden-Jones et al. 2004). Levels of PD are also higher among people in contact with criminal justice services, with as many as 80% of people in prison having PD (Singleton et al. 1998).

1.1 Current service provision
The evidence base for the effectiveness of interventions for people with PD is limited. Most research that has been conducted has focused on Borderline PD. However, small numbers of randomised trials with small sample sizes mean that even in relation to this disorder there is considerable uncertainty about the value of specific interventions (Binks et al. 2006); (Brazier et al. 2006). It seems likely that psychological treatments can help to reduce mental distress and self-harming behaviour, and that selective use of psychotropic medication can also help to alleviate symptoms experienced by people with Borderline PD (Leichsenring & Leibing 2003); (Binks et al. 2007), but the generalisability of these findings to other forms of PD is unclear.

There is even less evidence on which to base recommendations about the organisation and delivery of services for people with PD. Observational studies suggest that therapeutic communities help people with PD who have complex needs (Chiesa et al. 2002) and experimental research has demonstrated that psychodynamically informed psychotherapy delivered in the context of a specialist day hospital reduces the level of inpatient treatment that people subsequently use (Bateman & Fonagy 1999).

A survey of Mental Health Trusts in England in 2002 (National Institute for Mental Health 2003b) reported that 17% provide a dedicated personality disorder service, 40% provide some level of service, and 28% provide no identified service. The remainder did not respond. General principles, based on expert opinion, have outlined the approach that should be taken to managing people with PD (Holmes 1999); (Sampson et al. 2006). It has been argued that, in England, people with PD should have access to specialist Outpatient Services with specialist PD Day Unit in areas of high morbidity and Regional Residential Units to meet the needs of those with very severe problems (Fahy 2002).
In January 2003, the National Institute for Mental Health (England) published its policy implementation guidance on services for people with personality disorder: *Personality Disorder: No Longer a Diagnosis of Exclusion* (National Institute for Mental Health 2003b). This built on the National Service Framework for Mental Health’s (Department of Health 1999) standards four and five on effective services for people with severe mental illness. It outlines good practice for developing services in general adult-community mental health settings and forensic settings. This was followed by the publication of recommendations on the design and commissioning of education and training on PD (National Institute for Mental Health 2003a). While services for people with PD were not included in the original National Service Framework for Mental Health, Special Health Authorities have been required to report on services for people with PD during the last two annual reviews.

### 1.2 Service user views

Previous studies have examined the views of people with PD and shown many feel stigmatised by this diagnosis and dissatisfied with existing services. People with PD have described being told they would not be treated, being called ‘attention-seeking’ and labelled ‘bed-wasters’ (Haigh 2002). In a survey of 50 service users in Essex, less than half said they had been helped by mental health services and 80% believed their care had deteriorated as a result of their being given a diagnosis of PD (Ramon et al. 2001). Haigh (Haigh 2002) found that service users would like to experience services that are reliable, help them to develop personal skills, and foster openness and trust. Service users also reported they wanted more choice, the ability to refer themselves to services and direct access to 24-hour crisis care.

### 1.3 National service developments

In 2004, the Department of Health and the Home Office commissioned NIMHE to deliver a National Workforce and Training Programme. This aimed to improve access to treatment by investing in workforce capabilities and continuing professional development. In 2005 local commissioners and stakeholders developed Capacity Plans for personality disorder services. These aimed to facilitate and support development of appropriate services locally and regionally by: mapping current services; highlighting need and demand in services; defining pathways through services; identifying capacity of current services and outlining development targets for meeting this capacity.

To supplement these initiatives the Department of Health commissioned a range of new services for people with PD: five largely residential specialist forensic services and 11 community-based ‘pilot’ services. The community-based services were asked to develop innovative interventions that promote personal recovery and social inclusion for people with PD. The aim was to commission a variety of pilot services that reflect a wide range of approaches to helping people with personality related problems. It is the 11 pilot services that are the subject of this study; the specialist forensic services are the subject of a separate research project.
1.4 Lessons learned
Although evidence about the effectiveness of specific treatments for people with PD is increasing, relatively little is known about how services to deliver these are best organised. The establishment of these 11 pilot services provided an excellent opportunity to learn lessons about organisational, therapeutic and other factors that result in high-quality care. Through comparing different services and their outcomes we set out to generate knowledge that can help inform the development of future services for people with PD.

1.5 Study aims
To evaluate pilot community services for people with personality disorders, and to use findings to make recommendations for future service development.
In order to achieve these aims we set out to:
1. Describe the organisational form, activity and function of pilot services and compare these with national guidelines for the management of people with PD;
2. Compare aims and objectives of services with those they actually deliver;
3. Measure changes in service health and social outcomes, service utilisation and direct costs of a cohort of patients using these services;
4. Identify organisational, therapeutic and other factors that service users and providers believe result in high quality care for people with personality disorders.

In our original study proposal we also set out plans to measure changes in service utilisation, clinical and social outcomes, and the direct costs of care among a cohort of people using the pilot services. However we were unable to devise a system for obtaining informed consent to collect follow up data (see section 2.6.2) and were unable to fulfil this study aim.
2 STUDY METHODS

2.1 Overview

In deciding the optimum design of this study we needed to take account of several important methodological and logistical considerations. From a methodological perspective, we needed to combine qualitative and quantitative approaches in order to capture the complexity of the services and the outcomes they sought to achieve. Logistical issues included the diversity of the pilot services and their geographical spread over the length and breadth of England, from Cumbria in the north-west, to Essex in the east and Plymouth in the south-west. Because all the pilot services had been required to develop methods for locally evaluating their services, we needed to ensure that the methods we used minimised inconvenience to providers and users and did not disrupt service provision. Having been asked to use the data we collected to make recommendations for service provision, and in anticipation that views about the development of PD services would be mixed, we decided to include a formal consensus-building exercise in order to capture the expertise of a wide variety of different stakeholders and see if it would be possible to build a consensus around key aspects of the organisation and delivery of services.

In consultation with the Department for Health and service leads of the 11 pilots, we therefore agreed to focus on collecting qualitative data from users, providers and commissioners of the services. We set up a method for quantifying levels of service activity and exploring the demographic and clinical characteristics of a sample of all those referred to the services in a way which would facilitate cross-comparison between the different services. In addition to holding regular project management meetings we set up a Project Advisory Group to which representatives of each of the 11 pilot services were invited, together with service users who were involved in commissioning the pilots’ and other ‘experts through experience’.

The final study design comprised four interlinking components:

- an organisational evaluation of the context, form, function and impact of all eleven PD pilot services;
- a user-led qualitative evaluation of service quality from the perspective of service users;
- a cohort study examining the demographic and clinical characteristics of a sample of people who are referred to and use these services; and
- a Delphi study examining the level of consensus there is among academics, service users and providers about lessons that can be learned from the study and recommendations for future service developments.

2.2 Study setting

The 11 pilot projects provide the setting for this study. Details of the location and a summary of services provided by each of these pilots are provided in Table 3.2.
2.3 Project Advisory Group

Members of the Project Advisory Group (PAG) are listed on page 176. The PAG met on four occasions during the course of the study and played an important role in helping us finalise topic guides for use in the organisational evaluation and user-led qualitative study. The group also played a role in deciding the content of the ‘minimum data set’ for use in the cohort study and suggested items for inclusion in the Delphi questionnaire. At a meeting of the group in March 2007, draft findings from the study were presented and feedback from members was used in drafting the final project report.

2.4 Organisational evaluation

The aim of the organisational evaluation was to examine the formal and informal structure and care pathways of each of the 11 pilot services. Through collecting longitudinal data on services we set out to examine changes in structure and staffing and compare aims and objectives of services at baseline with those they actually delivered. We aimed to investigate the sustainability of services and the effect they have on other local services, including any change in attitudes towards PD. This component of the study involved an examination of service-level agreements and other written information and collection and analysis of qualitative data from in-depth interviews with service commissioners, referrers and staff at each of the 11 pilot services.

2.4.1 Data collection

A senior researcher with previous experience of conducting organisational studies (DR) began by examining available policy documents, and arranged early visits to interview the clinical leads of each service. Subsequent interviews were arranged by asking service administrators or managers to put out a call for volunteers, with the suggestion that DR would visit on at least two days to permit a range of staff with different backgrounds and commitments to take part. We selected potential referrers for interview from suggestions made by service leads. We asked service leads to nominate a number of potential referrers, including those who had many and few referrals. We used these contacts to generate further suggestions for potential interviewees. For those pilots that provided more than one intervention we tried to speak to a least two for each component of the service. Commissioners for each of the pilot services were also interviewed – one for each of the commissioning bodies responsible for purchasing services in the area(s) served by each of the pilots.

Semi-structured topic guides were drawn up on the basis of the literature on PD, in consultation with the research team, to stimulate reflection and prompt exploration of some of the themes that were likely to be important to all stakeholders. The organisational aims of the study led us to consider the model of therapy, patient pathways, developmental and staffing issues, crisis management, risk management and governance, relations with other providers, and user involvement as important. Topic guides were reviewed and revised frequently throughout the study, as interviewees raised issues that were important to them. Midway
through the project, topic guides for use with providers, commissioners and referrers were shared with members of the Project Advisory Group (PAG), which allowed us to consult both providers and users of services, and to promote any areas of discourse that we had inadvertently neglected.

The key challenge in this aspect of the study was to manage the enormous wealth of data collected in the interviews, and to limit the interview length to what seemed reasonable. This was achieved by carrying out constant and incremental review of the data collected from each pilot, in order to identify gaps in understanding of the model that could be addressed in subsequent interviews with staff from the same site. Those issues and practices (e.g. reflection on leadership and supervision, functions of staff within user-led groups) which generated a range of contemplative responses were worked into most interviews with staff (time permitting); those which appeared less controversial and more factual (e.g. how referrals were handled) were eliminated once two or more matching responses from the same service were recorded. All interview files were stored in pilot-specific computer folders.

In all cases bar one (the Icebreak service in Plymouth) the data were collected on at least two visits in order to track the development of services, with three visits being the median. All interviews with service providers were digitally recorded with signed consent of respondent and transcribed for the purpose of detailed analysis. Interviews with referrers and commissioners were conducted by telephone. In each instance verbal informed consent was obtained to make a digital recording of the interview.

2.4.2 Data analysis

Transcripts and interview summaries were subject to thematic hand analysis. The researcher (DR, who also carried out the provider interviews) achieved immersion in the data by reading transcripts of all interviews as they were generated. Analytic induction was employed to build an initial framework from the first round of interviews: emerging themes were identified and incorporated into subsequent interviews. The initial coding framework was based on the aims of the organisational study, and therefore linked into the topic guides. A reflective approach was taken, continuously reviewing and refining both the topic guide and the coding framework to ensure that (a) gaps in the data were taken into subsequent interviews; (b) all areas that respondents had spoken about had been covered by the framework.

The transcript data then was largely analysed as it was generated, in order to amend topic guides to fill gaps in the data. The initial framework for the case studies was drawn up from early interviews at the first two sites, extended to take in the further information which came from reviewing the interviews, and then reduced, in consultation with the Project Management Group, to a common structure to fulfil the need for brevity of reporting. A thematic framework grounded in the data therefore emerged and grew during the course of the study. Every single interview was extensively reviewed on-line, in batches focusing upon the individual pilot service. Each interviewee was given a unique coding. Extracts of the interviews – sourced to the speaker – were cut and pasted into (a) the coding framework for the case study and (b) the coding framework for Section 4. The framework headings were added to and, less often,
amalgamated. Triangulation of data sources from different staff members was important to justifying inclusion and, toward the end of the study, the qualitative researchers were able to interrogate and make comparisons with quantitative data on each service to check some of the more factual statements made in interviews.

Early on in the project, it became clear that two types of data were emerging from the organisational study: data specific and important to the individual model, and common themes in the data that could inform an underpinning service philosophy and model for a variety of services for people with PD. It was therefore decided that the same interviews should be analysed to reflect these two parts. This also permitted us to report on material, especially about difficulties, which providers kindly shared for the greater good, but which they might have been reluctant to see identified directly with their services. None of the difficulties reported was peculiar to individual pilots, which is highly suggestive that they are predictable and the account can therefore help others to plan for them. Confidentiality was important to the reporting of this project. The final case studies were shared with the service leads in order to reduce inaccuracies and introduce recent changes.

Given the amount of data collected and the limits of staffing, it was not possible to conduct independent analysis by a second researcher, although a second researcher (KP) exclusively and independently carried out and analysed the interviews with referrers and commissioners.

2.5 User-led qualitative evaluation

This service-user-led module of the study employed qualitative research methods to evaluate the pilot services from the perspective of their current and past service users and carers. The aims of this component of study were to explore individuals’ experiences of the services with a view to identifying factors which are believed to influence perceptions of service quality and outcomes for service users, and those which affect eligible service users’ decisions to engage with or end contact with services.

2.5.1 Recruitment, training and supervision of service-user researchers

A team of 11 Service User Research interviewers was recruited via service user research groups and networks across England during the autumn of 2005. In January 2006, they undertook four days of intensive training delivered by a Mental Health Foundation-based research team. The training provided information about the background to the project, as well as detailed information on qualitative research methods, including managing bias, recruitment and sampling strategies, interviewing skills, use of the interview schedule, ethical issues and plans for supporting and supervising user researchers, in order to ensure consistency of approach across the different pilot sites. Telephone and face-to-face peer support and research supervision were provided throughout the period of data collection by senior members of the Mental Health Foundation research team. Services also ensured that a familiar member of staff was available to provide support and debriefing for service user/carer participants at the time of or directly after the interview in case they felt the need for support.
2.5.2 Sampling and recruitment strategies
A purposive sampling strategy was employed in order to achieve the aims set out above. The primary sampling frame sought seven to ten current service users and up to three carers and past service users at each site for individual interviews, plus a further six current service users for at least one focus group interview where this was appropriate to the model of service provision at that site. Within these categories a secondary list of sampling criteria was employed to seek a mix of gender, ages, component of service used and length of contact with the service which was broadly conversant with the mix of service users in contact with each service. Service users who were currently in the process of engaging with the site or ceasing contact with the site and for whom taking part in the research might disrupt their formation or maintenance therapeutic relationships, and service users for whom interview participation might be considered potentially distressing at that point by the staff responsible for their care and support were not asked to participate in the study.

In order to assist with determining the application of this sampling and recruitment strategy to each site a researcher visited each site and met with a named staff member. Within the overall strategy, sampling and recruitment was tailored to the service model, level of service-user involvement and client group at each site. In most cases information about the research was disseminated via staff, site-based service-user groups using accessible information sheets and flyers that gave service users the opportunity to put themselves forward as possible interviewees. Where possible, past service users were identified and contacted by staff at the sites and asked for their consent to be contacted by the research team. Carers were identified where possible by service-user participants and only interviewed with service users’ consent.

2.5.3 Interview schedules and topic guides
Interview schedules for interviews and focus groups with service users and carers were developed on the basis of a review of service users’ and carers’ views and experiences of personality disorders services as represented in published research and feedback from members of the Project Advisory Group. They consisted of a series of open-ended questions covering the following themes: information received, deciding to try the service, the process of coming in, assessments and diagnosis, support received, contact and relationship with staff, relationships with other service users, service-user involvement, outcomes and ideas for improvements.

2.5.4 Data collection methods
Each site responded differently in the ways that they were able to assist the research team on appropriate access to participants, sampling and recruitment. For this reason the numbers of current service users, carers and past service users accessed at each site varied quite widely. Specific examples included a site that was working with a local research team which had asked participants in the local evaluation to sign an assurance that they wouldn’t participate in any further research, sites that freely contacted past service users – even those
with very negative perceptions of the service – in order to give them a voice in the research, and sites in which access to past service users was impossible.

From March to June 2006 pairs of service-user researchers (and in one instance a member of the MHF-based research team) visited each service site in order to recruit and interview research participants via one-to-one interviews and focus groups, as appropriate to the sites and participants. The great majority of qualitative data were tape-recorded and transcribed verbatim. Where participants did not consent to their interviews being tape-recorded, researchers took comprehensive field notes by hand, using verbatim language where possible, which were checked back with participants for accuracy at interview.

2.5.6 Data analysis and validation

All taped interview and focus group data were transcribed. Seven of the service-user researchers were trained alongside Mental Health Foundation-based research team members in Richie and Spencer’s Framework approach to qualitative analysis (Ritchie & Spencer 1993). An initial analytical framework was developed based on items in the interview schedule. This was then applied consistently to the data from each site, allowing researchers to identify emergent themes for inclusion in the framework and feedback to the central validation team at the Mental Health Foundation via regular validation supervision meetings during the analytical process. Qualitative data were analysed and findings validated by one of the researchers who had been present at the interviews.

From this in-depth analysis of verbatim transcripts site summaries were produced detailing issues arising from service users’ journeys from first contact with sites through to outcomes. Learning points were extracted from these summaries and these are presented in Section 3, Full summaries, for all but one site, are presented in Appendix A. At this site, the Leeds Personality Network, the number of interviews conducted was too small to assure anonymity of the respondents. The findings from this site are included along with others in Section 4. This analytical process was supervised and validated via group and individual meetings with members of the validation team comprising Mental Health Foundation lead researchers (SLG, AF & IR). Validation focused on credibility and auditability as the analytical processes of each researcher were trailed from raw data, through coding, charting and summarisation stages. Through this process the initial thematic framework was augmented with emergent themes from analyses across sites, which were then formed into an over-arching framework to describe the study findings across the whole national data set as presented in Section 4.3.

2.6 Cohort study

At the start of the study the principal investigator (MC) contacted service leads at each of the pilot services and obtained information about methods they were using to collect data from their service users. It quickly became apparent that services were at different stages of development; some had already started providing services and others were still in the planning stages of their development. Some services had implemented plans for local evaluation and others had not. It was also clear that those services that had either agreed
plans for collecting data, or were already collecting it, were collecting a wide range of different variables with very little data in common across the services. At the first meeting of the Project Advisory Group, we reached agreement with representatives of the pilot services that they would endeavour to use two data sheets designed specifically for the study which would provide a consistent method for recording data and facilitate comparison across the study sites. We asked pilot services to complete a ‘Care Pathway Record form’ for all those referred to their service and a ‘Minimum Data Set’ on all those taken on by the service. We also made suggestions for questionnaires that could be used to measure other key variables across the 11 services and agreed arrangements for obtaining written informed consent from service users that would enable researchers from the National evaluation team to obtain follow-up data one year after the collection of baseline data.

2.6.1 Study questionnaires

A. Care pathway record
A two-page datasheet that we asked service providers to complete for a consecutive sample of all people referred to their service. The sheet was designed to provide a means of comparing demographic characteristics and details of the assessment process and services provided across each of the 11 pilots.

B. Minimum dataset
This single sheet of paper comprised four items:
1. The Standardised Assessment of Personality – Abbreviated Scale (Moran et al. 2003). An eight-item screening questionnaire which provides a valid measure of the likely presence of Personality Disorder;
2. A single item question exploring motivation to change (Tyrer et al. 2003a);
3. The Social Functioning Questionnaire (Tyrer et al. 2005a). A 12-item measure of social functioning that has been used in previous evaluations of interventions for people with personality disorder;
4. Seven questions on service utilisation, which were specifically developed for the study.

C. Additional baseline data
1. Mental Health Inventory. A five-item measure of general mental health (Berwick et al. 1991);
2. Current use of alcohol or illicit drugs;
3. The Helping Alliances Questionnaire. A four-item patient-rated measure of quality of care (Priebe & Gruyters, 1993);
4. The four-item Patient Satisfaction Questionnaire (Shipley et al. 2000).

2.6.2 Data collection methods and follow-up
The original plan was that staff in pilot services would obtain written informed consent from service users and collect baseline quantitative data. Contact details would then be passed on to researchers from the study team who would collect follow-up data 12 months later. However, it did not prove possible to implement this plan because services were unhappy
about asking service users to provide written informed consent to participate in the study. Service providers told us that asking users to provide informed consent may interfere with the process of engaging users who may already be ambivalent about seeking help. In a minority of instances, procedures for obtaining informed consent to participate in a local evaluation project precluded involvement in the national evaluation. Three of the 11 pilot services agreed to approach new service users and ask them to provide written informed consent to be followed up as part of the study. However, only a small minority of service users at each site agreed to participate.

We therefore devised an alternative strategy which involved pilot services agreeing to incorporate items from the minimum dataset into their routine assessment and our obtaining ethical committee approval to obtain copies of clinical and demographic data on people referred to each of the services.

We attempted to collect data on all those referred to services for at least six months after their inception. In examining services pilots provided users we used a cut-off point of 30 April 2006 in order to ensure that follow-up data were available over a period of at least six months (i.e. until November 2006).

2.6.3 Sample size
We based the sample size on previous studies that have demonstrated large reductions in service utilisation among people with borderline personality disorder who receive structured psychosocial interventions. For instance a sample of 24 patients would be needed to have 80% power and 5% level of statistical significance to demonstrate a reduction in the mean number of inpatient days from 17 days to 8 days (SD = 11) that were found between day patients and control patients in the first 12 months of the evaluation of a day hospital-based treatment by Bateman & Fonagy (Bateman & Fonagy 2001). Anticipating that many people referred to pilot services would not engage with them and that many who were offered services would not accept them, we set out to collect data on 100 consecutive referrals at each of the 11 pilot services.

2.6.4 Data analysis
All data were entered onto SPSS (Version 14.0) for data analysis. Distribution and central tendency (such as Standard Deviations (SD) for normally distributed continuous data) were examined and simple descriptive statistics used to examine differences in characteristics of those referred to and taken on by services. In exploring the proportion of people who were referred to services and who engaged with them we have excluded all referrals made after April 2006 (because some of these had not been fully processed by the end of the period of data collection). We also excluded those referred to two services; one where the population were young and people had personality disturbance rather than disorder, and the other which provided a case consultation service rather than delivered direct services to users. Univariate and multivariate tests were used to compare the characteristics of those referred to services by health and social care professionals and those who self-referred. Finally we examined characteristics associated with early drop-out from services, using binary logistic regression.
2.7 Delphi study

This component of the study was designed to examine the degree of consensus among service providers, service users and researchers regarding the form and content of specialist services for people with PD. Delphi studies involve obtaining views of experts and using controlled feedback on individual and group responses in order to stimulate reflection and consensus (Murphy et al. 1998).

2.7.1 Development of the Delphi questionnaire

Items for inclusion in the Delphi questionnaire were derived from the first round of data collection from the organisational evaluation and the user-led qualitative component of the study. A series of propositions based on views of service users and providers about the focus, form and organisation of specialist services for people with PD were drawn up, to which we added further items suggested by members of the project management group and Project Advisory group. The items were then reviewed by the research team including service-user researchers. The first round of the Delphi survey consisted of 49 statements categorised into: organisation of services (13 items); service delivery (19 items); staffing issues (9 items); service user involvement and peer support (8 items), and two ranking items on service development (11 items) and service outcomes (7 items).

Each proposition was accompanied by a 9-point rating scale ranging from 1 (disagree strongly), through to 5 (neither agree nor disagree) to 9 (agree strongly). For the ranking questions on priorities for service development the scale was marked from ‘should not be provided’ to ‘highest priority’. For the ranking questions on outcomes that should be used by services for people with PD the scale was marked as ‘unimportant’ to ‘most important’. All participants were asked to state their background and main therapeutic approach at the start of the exercise. A copy of the full first-round Delphi questionnaire can be found in Appendix C. Space was provided in the first-round questionnaire asking participants to suggest additional items in round two. Eight additional suggestions were made which were collated into five additional items which were included in the round-two questionnaire, i.e. responses were obtained on 54 items (plus two ranking items) during the course of the Delphi exercise.

2.7.2 Selecting members of the Delphi panel

We attempted to identify equal numbers of service providers, service users and expert authors for the Delphi panel. We approached service leads at each of the 11 pilots and asked them to nominate three people who had had a central role in developing and delivering the service. We used contacts with the Department of Health, researchers from the Mental Health Foundation and the voluntary organisation ‘Borderline UK’ to identify an equal number of service users who had either used or advised on the development of services for people with PD. Finally, we used contacts of the project management group and an electronic search of bibliographic databases to identify expert authors who had published at least one peer-reviewed paper on the organisation and delivery of community services for people with PD in Britain during the previous 10 years. Invitation letters were sent to academic experts as defined above, and from this 31 were recruited. With 33 service providers and 34 expert
service users, there were 99 members of the Delphi panel in total. Service-user participants were offered a £40 postal order as an honorarium after completion of the third-round questionnaire.

2.7.3 Data collection and analysis
Surveys were mailed out to all participants by e-mail unless the participant requested a hard copy. Two reminders were sent to those who had not responded. Surveys were coded, and participants were not asked to identify themselves on the questionnaire. Results were entered into SPSS and Excel and the median and interquartile range calculated. For analysis of consensus, the 9-point scales were divided into 1–3 ‘disagree’, 4–6 ‘neutral’ and 7–9 ‘agree’. The percentage of participants from all groups falling into each of the bands was calculated. Where 75% or more of participants were in the same band for each item, this was said to have reached consensus. Calculations of median, interquartile range and consensus were also made by participant group (i.e. service users, service providers and academic experts). Items on priorities for service development and outcomes were ranked by median, then mean.

For the second round, those items with consensus above 75% were excluded. The ranking items were also removed. Next to each item a box was included indicating the individual participant’s response to the first round, the median response (described as the ‘group response’) and the interquartile range (described as the ‘consensus level’). Where there were notable differences in responses between participant groups (variance greater than or equal to 2), a statement was added indicating this. This feedback was designed to give participants as much information as possible about the responses of the group.

For round 3, consensus levels were calculated as in round 2. Again, individual and group responses as well as interquartile range were indicated, together with new statements about group difference. Feedback was given to participants on those items on which consensus had been reached over rounds 1 and 2, together with results on priorities for service development. In addition, several of the items were reworded slightly as some participants had indicated that the statements were ambiguous or unclear. It was hoped that this would better enable consensus to be developed.

2.8 Ethics
Ethical committee approval was obtained via the Central Office for Research Ethics Committee prior to the start of data collection. Early on in the study it became apparent that most of the pilot services were happy to use the minimum dataset and Care Pathway record form to collect demographic and clinical data, but were not prepared to obtain written informed consent from their service users (see section 2.6.2). We therefore wrote to the reviewing Ethics Committee and asked for amendment to the original application. This provided approval for researchers from the national evaluation team to receive de-identified copies of data sheets from the pilot services without written informed consent from users, provided that – as was planned – the researchers had no means of identifying the subjects.
Potential participants in the user-led qualitative study were identified by service providers and asked to provide verbal consent to be approached by a member of the National Evaluation Team. Each participant was provided with an information sheet, which stated the purpose of the study, the need for their involvement, what their participation would entail, issues surrounding ethics and confidentiality and a contact number for the study team. Participants were also given opportunity to discuss any queries about the research with the service user researchers. Written informed consent was gained from all participants and all were debriefed and thanked for their participation at the end of the interview/focus group. Data were handled and analysed according to good ethical practice, using anonymised participant codes at all times.

All data from the study were stored in accordance with the requirements of the Data Protection Act, with electronic files password protected and held on a secure server and hard copy files stored in locked filing cabinets.
3 CASE STUDIES

Findings from the organisational evaluation and the user-led qualitative study of service quality from the perspective of service users are presented in the following two sections of the report. In this section we provide a brief summary of the aims, organisational form and function of each of the 11 pilot services in tabular form. This section is accompanied by detailed case studies of each of the pilot services which can be found in Appendix A. Rather than reduce their length and remove information that may be of interest to those wanting to obtain a detailed account of service models, we decided to place them in a separate appendix. The following section is therefore limited to a short summary of the case studies in tabular form. Those wanting to obtain a proper picture of the services provided by each of the pilots are referred to Appendix A.

In Section 4 we present overarching themes based on interviews with service users, providers, referrers and commissioners. Learning points from service providers are based on comments received by the research team at the start of 2007, except those from the Leeds Personality Disorder Network, which are based on discussions at a Learning Forum organised by the Department of Health and held in November 2006, which was attended by members of the research team.

3.1 Data collection

Details of the number of interviews and focus groups we conducted at each service are presented in Table 3.1. We interviewed a total of 89 service providers, 26 referrers, and 13 commissioners. Data were collected from 108 current service users via individual interviews and/or focus groups. Individual interviews were also conducted with 10 carers and 15 ex-users who had either completed their treatment or dropped out of contact with the service. Seventy per cent of service users who were interviewed were female. Ages ranged from 18 to 69 (median = 37.2 years). Ninety interviewees provided data on ethnicity, of whom 64 (71%) were British white, 16 (18%) were white other, and 10 (11%) were from BME communities.

3.2 Summary of service provision

Details of the lead organisation responsible for overseeing each of the pilot services, together with a brief description of the main services they provide, are presented in Table 3.2. Ten of the 11 services are for adults with PD and personality-related problems. One, the Icebreak service in Plymouth, is for young people aged 16 to 25 who have interpersonal problems and are judged to be ‘at risk of social exclusion’. Most of the pilot services deliver a range of tier 2 and tier 3 services combined with tier 1 interventions aimed at supporting the work of colleagues working across a range of other settings. Most services take referrals from a range of different sources but the Service User Network, was only open to self-referrals and the Community Links component of the Camden and Islington Personality Disorder Initiative, took
all their referrals from primary care. Further details of the aims organisational form and function of the 11 pilot services is provided in table 3.3 below. While most of the pilot services consisted of several interlinking components, two of the services (Camden and Islington, and Cambridge and Peterborough) provided distinct interventions for different groups of people delivered by separate teams – each of the service components provided by these two pilots is therefore described separately.

**Table 3.1 Details of interviews and focus groups**

<table>
<thead>
<tr>
<th>Name of service</th>
<th>Service providers</th>
<th>Referrers</th>
<th>Commissioners</th>
<th>Users &amp; carers (interviews)</th>
<th>Users (focus groups)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Camden and Islington Personality Disorder Initiative</td>
<td>1 (May 05) 7 (Aug-Oct 05) 3 (June-Aug 06)</td>
<td>5</td>
<td>1</td>
<td>9 (1)</td>
<td>-</td>
</tr>
<tr>
<td>Dual diagnosis assessment and response team (DDART)</td>
<td>3 (May 05) 6 (Jan 06)</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>1 (with 5 service users)</td>
</tr>
<tr>
<td>Service user network (SUN)</td>
<td>3 (Mar-May 05) 4 (Jun-Aug 06)</td>
<td>0</td>
<td>2</td>
<td>10</td>
<td>1 (with 2 service users)</td>
</tr>
<tr>
<td>Cambridge &amp; Peterborough Personality Disorder Network</td>
<td>3 (July 05) 8 (June-Aug 06)</td>
<td>2</td>
<td>2</td>
<td>9 (2)</td>
<td>-</td>
</tr>
<tr>
<td>The Haven</td>
<td>5 (May 05) 4 (Nov 05)</td>
<td>2</td>
<td>0</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>Thames Valley Initiative (TVI)</td>
<td>6 (May-Jul 05) 9 (Jun-Jul 06)</td>
<td>5</td>
<td>3</td>
<td>10</td>
<td>5 (28 service users)</td>
</tr>
<tr>
<td>Nottingham Personality Disorder and Development Network</td>
<td>4 (Aug 05) 8 (July-Aug 06)</td>
<td>2</td>
<td>0</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>The Olive Tree</td>
<td>3 (June 05) 8 (May 06)</td>
<td>2</td>
<td>1</td>
<td>8</td>
<td>1 (with 8 service users) (3)</td>
</tr>
<tr>
<td>North Cumbria Itinerant Therapeutic Community</td>
<td>4 (June 05) 5 (Mar 06)</td>
<td>2</td>
<td>1</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>Leeds Personality Disorder Network</td>
<td>9 (June-Sep 05)</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Icebreak</td>
<td>7 (Aug 05)</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>-</td>
</tr>
</tbody>
</table>

(1) All from the Umbrella service
(2) All 9 from the Cambridge Complex Cases Service
(3) Focus group comprised 8 people who also participated in individual interviews
<table>
<thead>
<tr>
<th>REGION</th>
<th>Lead Organisation/Service</th>
<th>Name of service</th>
<th>Main intervention(s) &amp; target group</th>
<th>Main tiers</th>
</tr>
</thead>
<tbody>
<tr>
<td>London</td>
<td>Camden and Islington Mental Health and Social Care Trust</td>
<td>Camden and Islington Personality Disorder Initiative</td>
<td>Advice, support and training for adults with PD, and healthcare workers</td>
<td>1, 2</td>
</tr>
<tr>
<td></td>
<td>North East London Mental Health Trust</td>
<td>Dual diagnosis assessment and response team (DDART)</td>
<td>Psychological therapies for adults with PD &amp; substance misuse</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td></td>
<td>South West London &amp; St George’s Mental Health NHS Trust</td>
<td>Service user network (SUN)</td>
<td>Peer support for adults with PD</td>
<td>2</td>
</tr>
<tr>
<td>Eastern</td>
<td>Cambridgeshire and Peterborough Mental Health Partnership Trust</td>
<td>Cambridge &amp; Peterborough Personality Disorder Network</td>
<td>Psychological therapies and consultation service</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td></td>
<td>The Haven Partnership</td>
<td>The Haven</td>
<td>Support, advice, psychological therapies &amp; crisis beds for adults with PD</td>
<td>2, 3</td>
</tr>
<tr>
<td>South East</td>
<td>Oxfordshire Mental Healthcare NHS Trust</td>
<td>Thames Valley Initiative (TVI)</td>
<td>Support, advice, and day-TCs for adults with PD</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td>East Midlands</td>
<td>Nottinghamshire Healthcare NHS Trust</td>
<td>Nottingham Personality Disorder and Development Network</td>
<td>Support and advice, psychotherapy &amp; day-TC for adults with PD</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td>West Midlands</td>
<td>Coventry Primary Care Trust</td>
<td>The Olive Tree</td>
<td>Out-patient individual and group psychotherapy for adults with PD</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td>North West</td>
<td>North Cumbria Mental Health and Learning Disabilities NHS Trust</td>
<td>North Cumbria Itinerant Therapeutic Community</td>
<td>Support and advice, internet-based peer support &amp; a day-TC for adults with PD</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td>North East</td>
<td>Leeds Mental Health Teaching NHS Trust</td>
<td>Leeds Personality Disorder Network</td>
<td>Care coordination, psychological therapies and advice for adults with PD</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td>South West</td>
<td>Youth Enquiry Service/ Plymouth Primary Care Trust</td>
<td>Icebreak</td>
<td>Information &amp; counselling for adolescents with personality disturbance</td>
<td>1, 2, 3</td>
</tr>
<tr>
<td>SERVICE</td>
<td>Summary of service aims</td>
<td>Premises &amp; location</td>
<td>Client group, exclusion criteria</td>
<td>Anticipated source of referrals</td>
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<tr>
<td><strong>Camden and Islington: Skills development service</strong>&lt;br&gt;Note: this pilot also included a consultation service which is detailed in appendix A</td>
<td>To improve access to employment adult education and related activities for people with PD</td>
<td>Services delivered through a community-based voluntary sector agency (Umbrella).</td>
<td>• Over 18 years&lt;br&gt;• Registered with a local GP&lt;br&gt;• Diagnosis of PD (or persistent difficulties in relationships)&lt;br&gt;Exclusion: significant comorbid mental health problems if not supported by secondary care</td>
<td>Secondary care, primary care with option of self referral</td>
</tr>
<tr>
<td><strong>Camden and Islington: Community links service</strong></td>
<td>To support the management of people with PD within primary care and tackle social exclusion</td>
<td>Service delivered via 44 local GP practices</td>
<td>• Persistent interpersonal difficulties&lt;br&gt;Exclusion: presence of major mental illness or significant involvement of secondary care mental health services</td>
<td>GPs and other primary care workers</td>
</tr>
<tr>
<td><strong>Dual diagnosis assessment and response team (DDART)</strong></td>
<td>To provide a specialist psychological therapies service to people with PD and co-morbid substance misuse&lt;br&gt;To support staff in other health and social care agencies who work with this client group</td>
<td>Premises shared with an existing community team for people with PD within grounds of a community hospital. Access to rooms in community-based clinics</td>
<td>• Aged 18 or above&lt;br&gt;• Cluster B or C personality disorder&lt;br&gt;• Significant substance misuse&lt;br&gt;• Some evidence of motivation to change&lt;br&gt;Exclusion: Cluster A PD or antisocial PD (unless accompanied by other personality problems).</td>
<td>Primarily secondary care (including mental health and substance misuse services). The service is also willing to take referrals from primary care, social services and criminal justice system</td>
</tr>
<tr>
<td>SERVICE</td>
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<td>Anticipated source of referrals</td>
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<tr>
<td>Service user network (SUN)</td>
<td>To develop a Service User Network that provides an inclusive service for people with PD. To support, train and empower key service users themselves to be an integral part of the service.</td>
<td>The service is run from offices located within a mental health unit. Groups are provided in a range of community-based health and social care facilities.</td>
<td>• People who believe they have a PD or inter-personal problems that may be helped by contact with the network In order to attend groups prospective users must be willing to complete a crisis plan.</td>
<td>Self referral only. The service was publicised through mental health and social care services.</td>
</tr>
<tr>
<td>Cambridge &amp; Peterborough: Cambridge complex cases service</td>
<td>To provide access to specialist services for people with personality disorder and a network of services and expertise across agencies.</td>
<td>Attached to psychotherapy service at a general hospital</td>
<td>• Adults aged 18 or over who have a personality disorder There are no absolute exclusion criteria but severe substance misuse, history of violence and lack of motivation to change may mean direct services can not be provided</td>
<td>Primary and secondary care, social services and the criminal justice system.</td>
</tr>
<tr>
<td>Cambridge &amp; Peterborough: Peterborough personality disorder service</td>
<td>To provide consultation, support, supervision to those working with PD in health and social care settings</td>
<td>Based at a psychotherapy department in a community hospital</td>
<td>• Adults aged 18 or over who have a personality disorder</td>
<td>Mainly primary care and secondary mental health services</td>
</tr>
<tr>
<td>SERVICE</td>
<td>Summary of service aims</td>
<td>Premises &amp; location</td>
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<td>Anticipated source of referrals</td>
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</table>
| The Haven | To provide an accepting and safe community that instils a sense of ownership for service users and is accessible 24 hours, 7 days a week. | A large house with garden in a residential area of Colchester. | • A current or previous diagnosis of PD  
• An address within a 25-mile radius of the centre  
No formal exclusion criteria but those who present ‘unacceptable risks to others’ are excluded. | Predominantly secondary care services and self-referral. Though referral is also open to primary care, social services and criminal justice system. | A full-time Chief Executive, a full-time service manager, and a group of full and part-time staff that ensure that there are at least two members of staff present at all times. Most staff do not have professional qualifications but all have relevant experience in health/ social care. | Service users have access to a day service offering practical help, support, friendship and a range of informal and formal therapies, an out-of-hours refuge providing up to 5 hours of contact in evenings and weekends, and access to a respite bed for a period of up to 3 weeks at a time. | Up to 100 service users. |
| Thames Valley Initiative (TVI) | To develop a ‘functionally and geographically tiered service’, comprising: day treatment, outpatient groups and support for other services across Oxfordshire, Berkshire, and Buckinghamshire. All three services are sited in community-based facilities. The Berkshire service is at the site of an exiting TC. | All three components of the service are made up of a multidisciplinary team of managers, therapists and administrative staff. The Oxfordshire team consists of 12.7 FTE team members, the Berkshire team consists of 5.3 FTE staff and the Buckinghamshire team of 5.8 FTE. | • Aged 18 or over  
• Persistent interpersonal difficulties/ PD  
• Some motivation to change  
No formal exclusion criteria but those with psychosis or severe substance misuse may be unsuitable. | Predominantly secondary care services and self-referral. Though referral is also open to primary care, social services and criminal justice system. | All three components of the service base their interventions on the therapeutic community model. Within this model each service runs outpatient groups, a day-TC programme and a consultation and training services for others working locally with people with PD. | Up to 45 people can use the three day-TC programmes at any7 one time. People tend to stay for between 12 and 24 months, though people can access outpatient groups over longer periods of time. |
| Nottingham Personality Disorder and Development Network | To support a wide range of agencies in contact with people with PD, to facilitate the development of service-user networks and advocacy, and provide a range of therapeutic interventions. The service is based at the Mandala Centre – which is situated near the centre of Nottingham. Community-based groups are often sited elsewhere. | The Network has three staff teams: The Advice & Information service employs four part-time workers, a FTE team leader and a part-time coordinator. The ‘Stop & Think’ programme has 4.4 FTE staff, headed by a clinical psychologist and the day-TC employs 2 full-time and 3 part-time nurses, a part-time consultant psychiatrist and a consultant psychotherapist. | • Aged 18 or over  
• Meet diagnostic criteria for PD  
• Some motivation to change  
No formal exclusion criteria but all those who use the service have to give an undertaking to abide by service rules | Predominantly secondary care services, though self-referral and referral from primary care, social services and criminal justice system are also possible. | There are three main components; the Advice & Information service aims to support the work of other services and develop user involvement, the ‘Stop & Think’ programme provides a weekly outpatient group over a 16- week period and CBT-based group psychotherapy and the day-TC provides a group-based treatment programme. | The 5-day service is made available to up to 20 service users for 12-18 months. The service has the capacity to run up to five Stop and Think groups each with up to 8 participants. |
### Table 3.3 continued

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>Summary of service aims</th>
<th>Premises &amp; location</th>
<th>Client group, exclusion criteria</th>
<th>Anticipated source of referrals</th>
<th>Staffing level and staff training</th>
<th>Interventions delivered</th>
<th>Number of clients &amp; length of interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Olive Tree</td>
<td>To provide evidence-based interventions that improve the health and social care of people with PD, and to increase the capacity of staff working with people with PD in other organisations.</td>
<td>The service is provided from community-based mental health premises on the outskirts of Coventry.</td>
<td>A clinical diagnosis of personality disorder. No formal exclusion criteria.</td>
<td>Predominately mental health services, though GPs can also refer directly to the service.</td>
<td>Two full-time team leaders and 10.8 FTE therapists, two skills facilitators and three part-time administrators.</td>
<td>All those taken on by the service are provided with care coordination. A care plan is agreed with the service user which may include individual psychotherapy, structured and unstructured psychotherapy groups and support for referral to occupational activities.</td>
<td>Up to 100 service users. Length of interventions is tailored to individual circumstances but is generally around 18 months duration.</td>
</tr>
<tr>
<td>North Cumbria Itinerant Therapeutic Community</td>
<td>To deliver outpatient psychotherapy and day TC programmes for people with PD and to support other agencies working with people with PD.</td>
<td>The service is run from a psychotherapy unit in North Carlisle and runs groups in community-based units.</td>
<td>• A clinical diagnosis of PD • Recognition of a problem and some desire to explore this No formal exclusion criteria but as people are asked to make an active choice to use the service those involved in legal proceedings are treated under the Mental Health Act would not be included.</td>
<td>Predominantly secondary care services, though self referral and referral from primary care, social services and criminal justice system are also possible.</td>
<td>Two part-time psychoanalytic psychotherapists, two half-time psychotherapists, two full-time outreach workers, one clinical psychologist, one part-time secretary, and a part-time Expert by Experience (0.6 FTE).</td>
<td>The day TC offers accesses to a group-based treatment programme and peer support within the framework of therapeutic community. People who want to receive a service but are unable to use the day-TC receive follow-up from outreach workers. All those taken on by the service have access to internet-based peer support.</td>
<td>Up to 80 service users with up to 15 attending to day treatment programme. Length of interventions is tailored to individual circumstances but is generally around 18 months duration.</td>
</tr>
<tr>
<td>SERVICE</td>
<td>Summary of service aims</td>
<td>Premises &amp; location</td>
<td>Client group, exclusion criteria and source of referral</td>
<td>Anticipated source of referrals</td>
<td>Staffing level and staff training</td>
<td>Interventions delivered</td>
<td>Number of clients &amp; length of interventions</td>
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<tr>
<td><strong>Leeds Personality Disorder Network</strong></td>
<td>To reduce stigma and improve the management of people with PD by taking on clients for assessment, treatment and care coordination and enhancing the capabilities of staff in other services through support, supervision and training.</td>
<td>The network has a central base but staff working for the network spend most of their week working within other health and social care teams.</td>
<td>The service aimed to work with people with PD for whom existing services had tried to help with limited success. Local services were asked to prioritise referral of people who were on enhanced CPA, had a history of poor engagement with services, experience high levels of mental distress and presented some form of risk to self or others.</td>
<td>Predominantly secondary care services. The service was also open to referral from social services and criminal justice system.</td>
<td>The Network had 27 staff members (22 FTE) including: a clinical team manager, psychologist, assistant psychologist, three half-time psychotherapists, two voluntary sector workers, an occupational therapist, two half-time probation officers, two accommodation support workers, an advocate, a user/self-help worker and administrative staff.</td>
<td>Assessment, care planning, care coordination. Outreach - individual sessions offered in service users homes or at other resources in the community.</td>
<td>Care coordination for up to 45 services users. Length of intervention is not specified but intended to be long-term.</td>
</tr>
<tr>
<td><strong>Icebreak</strong></td>
<td>To target people aged 16–25 who are at risk of social exclusion but not necessarily diagnosed with PD. To improve social cohesion and social capital; provide new services driven by client need; support carers and dependants and; promote a 'more positive experience of life'.</td>
<td>The service runs from a youth counselling and advice service (the Zone) which is a highly visible shop front premises within walking distance from Plymouth city centre.</td>
<td>• Aged between 15 and 25 • Registered with a GP in the local area • Significant interpersonal problems/ at risk of social exclusion The service will not work with those who are already receiving input from adult mental health services.</td>
<td>Predominantly social care and the local youth advisory service. The service is also open to referrals from child and Adolescent Mental Health Services, Youth Offending Teams and other elements of the criminal justice system.</td>
<td>One team leader, 6 FTE care coordinators, 0.2 of a GP with special interest in mental health and input from a consultant psychiatrist from Plymouth psychotherapy services. Care coordinators generally have a background in mental health nursing, youth work, counselling services and creative therapies.</td>
<td>Individual counselling, advice and support. Assertive outreach, when indicted. Referral on to other services including counselling, education and training and social services.</td>
<td>To case manage up to 35 people and provide advice and support to up to 55 others. Length of intervention is not specified but long term support is available.</td>
</tr>
</tbody>
</table>
4 OVERARCHING THEMES

4.1 Service providers

In this section we explore some of the dominant themes that emerged during interviews with managers and staff working in the 11 pilot services.

4.1.1 ORGANISATION OF SERVICES

4.1.1.1 Service development

The principal factor that appeared to determine the structure and philosophy of pilot services was the expertise and capacities of the lead clinician(s) and their partners who put together the application for funding. This is as one might expect, given the absence of evidence about the optimal organisational structure of a dedicated service for people with PD. Plans for the pilots were strongly influenced by the Department of Health brief, which asked services both to provide direct services for people with PD and to include methods for supporting others in their work with people with these problems. As a result, nine of the 11 pilot services were loosely based on a ‘hub and spoke’ model: an intensive therapeutic hub addressing the needs of individual clients, together with some commitment to enhancing the capacity of voluntary and statutory health, social care and other agencies around them to work effectively with this user group.

Where pilot services were based on an expansion of an existing service, such as The Haven, feedback from existing service users influenced the development of the proposal. However, there was little evidence of service user involvement in development of most of the innovative services, where structures for involving prospective service users rarely existed (see Section 4.1.7.1 below).

The bids did not entail detailed estimates of the numbers of people in each area who had PD. While some services had attempted to gauge levels of PD among those in contact with mental health services, very little was known about the extent of PD among people not engaged with mainstream mental health services – the very people whom several services wanted to try to engage. The capacity of the pilots was, then, not clearly linked to need, but to available resources.

In recognition of the heterogeneous needs and capacities of people with PD, most of the pilots set out to provide a range of services. Provision of more than one service or treatment option also enabled most pilots to present a choice to potential service users, a capacity that many believed important in promoting engagement. These options included case management; support in engaging with vocational and social activities; outreach (in which individual staff go to the users); groups to consider choices of therapy; individual assessment and treatment formulation by a therapist; one-to-one therapy (psychodynamic or psychoanalytic or psycho-educational, DBT or CBT); peer support; group therapy (skills-based or psychodynamic) and community participation (whether structured, as in TCs, or more casual, as in drop-in).

Most of the pilots offer more than one type or ‘intensity’ of approach. Several of the pilots recognise the value of combining individual therapy sessions with group work. There is a
general recognition that ‘one size does not fit all’. Those services that offer peer-led social support encourage service users to bring in a range of practical and social difficulties: advice sessions are available, the groups have access to phones to support service users to deal with issues during the group, and service users are encouraged to run their own Care Programme Approach (CPA) reviews and to plan appropriate action. Integration with the Care Programme Approach is managed by the pilots in different ways: there has not been a straightforward adoption of CPA procedure – common within community services and recommended by NIMH(E) (National Institute for Mental Health 2003b).

In the last funded year of the pilot process, staff were increasingly reflecting on the needs of different types of service user, and devising interventions which might improve life for those who appeared unsuited to the current model. Some of this mismatch related to overly intense interventions where resources could be better expended in a more diffuse way over a larger group of service users. At least three of the pilot services are offering or planning to offer interventions around parenting, aimed at women. We were told that responsibility for parenting is overwhelmingly that of women: ‘the men are either dead or gone’ (S4). Staff told us that, as parents, service users do not have good experience of parenting to draw on, so may do poorly in general parenting classes.

‘It helps parents to talk about their anger, shame and disempowerment, to say some pretty ghastly things and to reframe these. The sense of empathy can be very profound.’ (S4)

4.1.1.2 Target population

Within their remit of providing services for people with PD, most of the pilots aimed to be inclusive. Despite this, several had formal exclusion criteria concerning capacity and the need for some indication of motivation to engage in therapy. Presence of a psychotic illness, use of medication or uncontrolled substance misuse, the presence of significant learning difficulties, and past history of significant violence or aggressive behaviour were the most common exclusions. The extent to which pilot services require people to have a diagnosis of personality disorder varied: one service which aimed to work with young people before they came to the attention of mental health services did not use this terminology; a pilot taking referrals from primary care relied on the judgement of GPs; some of the pilots that were open to self-referral effectively worked with self-diagnosis; while some of the services that deliver structured psychological therapies instituted formal procedures for diagnosing PD. Staff at most of the pilots told us that they worked predominately with people with Cluster B and C, with Borderline PD, the most common diagnosis.

In contrast, most services reported that they did not work with people whose foremost diagnosis was antisocial personality disorder (ASPD). Reasons for this included doubt about whether interventions they were providing could help people with such problems and concerns about the risk to others posed by people with this disorder. Although several pilot
services take referrals from probation services and two of the networks have probation officers on their staff teams work with people with ASPD has been limited to advice and consultation delivered to probation staff.

Services also varied in their capacity for working with people with co-morbid Axis 1 disorders. Nearly all work with people with eating disorders and substance misuse problems, but none would take on service users who were dependent on alcohol or other drugs. One pilot service was set up to try to meet the needs of people with PD and substance misuse, but the threshold for accepting a referral was lower than would qualify a person for substance misuse services.

‘We decided that it had to be problematic to their mental health, and that wasn’t problematic in relation to alcohol and drug (service) standards. So our criteria was that when they misused it, it was problematic and that within the last six months. So there are some people who managed to not drink for three months and four months but it’s still there, still a problem.’ (M32)

Other pilot services also provide help with substance misuse problems, which were reported to be common among referrals. Several services sought to work with people with ‘severe’ PD but did not define what was meant by this. One service planned to offer intensive case management to 50 people, and instructed the local community teams to refer:

‘The people who are most difficult, the people who you worry about, the people who present the greatest level of risk and greatest challenges to yourself … The clients who are beyond the reach of the CMHT, or have exhausted the CMHT resources.’ (M53)

There were no structured measures of severity of PD in any of the service criteria: here and in other services, this approach was designed to prioritise those people with whom mainstream staff were most ‘stuck’. In this service, a comprehensive assessment process required that referrers demonstrate that they were unlikely to be able to move the person forward. Other services, including the TCs, sought to engage not the staff, but the users, directly, minimising entry criteria so that a diagnosis of PD was not required. The potential service user’s ability to make use of the therapy, their commitment to engage, and in some cases the views of existing service users, have been driving eligibility for the service. Both approaches appear to have attracted people with a range of different functional abilities and support needs.

Staff at most services believed that they were working with people with different levels of severity. Services characterised by peer-led group interaction told us that this was useful, as the more able might support the less able, and people could model their progress either prospectively or retrospectively. Services concentrating on more complex cases appear to be more likely to specialise in one-to-one work, at least in the early stages of therapy.
Staff at pilot services told us that mainstream services found it difficult to assess personality status or consider the psychological needs of people who are unable to communicate effectively in English, because of the difficulties associated with trying to conduct in-depth assessment.

4.1.1.3 Source of referrals

Most pilot services saw community mental health services as their primary source of referrals. Almost half were also set up to accept self-referrals. Some service leads felt that self-referral was an important means of being able to respond positively to people with PD who had made a decision to make some sort of change in their lives, and others felt that self-referral was important as it could enable people who had been excluded from mainstream mental health services to access the service. Specialist secondary services, primary care services, Emergency Departments, and social care services such as housing teams were also seen as likely sources of referral. In the early phases of the funding, most pilots visited such teams and put together written information to describe the services and who could apply, with much of the material being aimed at service users to supplement discussions with staff. Service users – from other services where the pilots had not yet recruited – were often involved in developing written materials. These were seen as key tools in engaging service users, and in presenting the philosophy and approach of the service. The use of terms such as ‘personality disorder’ was widely debated in these contexts.

One service relied almost exclusively on referrals from primary care. As a general rule, staff suggested that GPs were not able to reliably discriminate between PD and other long term mental health problems. GPs were also inclined to see the emotional distress experienced by people with borderline PD as evidence of clinical depression.

**KEY MESSAGES – service organisation**

Plans for pilot services were developed on the basis of the expertise and capacities of lead clinicians in consultation with other service providers. There was little formal assessment of local needs or (with a few notable exceptions) involvement of service users.

Pilot services offer varied and flexible services: many have several options with which clients can engage. Choice and flexibility tailored to client needs are key values.

Most pilots work with a variety of clients, with different types of PD, and different levels of difficulty. Rather than confusing treatment approaches, this variety is reported to be useful, especially in models relying on peer interaction.

While few services have formal exclusion criteria, people with antisocial personality disorder, dependence on alcohol or other drugs, and those unable to communicate in English are generally excluded.
4.1.2 DELIVERY OF SERVICES

4.1.2.1 Generic factors when delivering dedicated services to people with PD

Staff highlighted a number of common themes around working with this group. These themes were reported on numerous occasions across pilots where different types of services were delivered. Staff believed they were generic issues and should be considered by all those delivering dedicated services to people with PD. They included:

1. The service should be realistic in its aims, and not claim to undo prior abuse, neglect or experience. ‘We cannot change the future or repair the past.’ (M32)
2. Attachment and the development of trust are important to all models, although the object of attachment may be the service or group, or one or more individual therapists (see 4.1.2.2 below).
3. Goals of therapy should be negotiated with service users. This requires a flexible and client-centred approach to outcomes.
4. It is useful to distinguish between long- and short-term goals, so that service users can identify and acknowledge their achievements, but also be aware that they are moving toward ‘larger’ aims, such as preparation for leaving the service.
5. The person should be treated in such a way as to confirm that they are valued and valuable. The response to service users and their disclosures should be non-judgemental.
6. The person should be treated in such a way as to encourage self-acceptance – among people with a high degree of self-loathing this was considered a key goal of therapy.
7. The approach should be validating, rather than dismissive, of the person’s experience. Service users should be encouraged to see their feelings as real and reasonable according to their circumstances and the difficulties they have had to manage.
8. Staff may lead or facilitate, but the general approach to leadership is by example and suggestion rather than control, with a view to empowering the individual service user or group to identify and manage their difficulties.
9. Efforts need to be made to help a person develop emotional regulation: ‘to help clients express feelings and find ways to speak that aren’t emotionally devastating’ (S61); to enable service users ‘to stay with the mental state for seconds rather than reacting in a traumatic way’. (M45)
10. The service user should be encouraged to live in the moment, the here-and-now. Agonising over the past or future is likely to be counterproductive. ‘Not about changing circumstances, so much as changing the meaning of life events.’ (M45)
11. Thinking can be more important than doing. ‘There is something about psychoanalytic training that helps you to persist with something and to keep thinking about something rather than having to do something.’ (M38)
12. The service, led by its staff, has to be able to sit with negative, uncomfortable, demoralising feelings: ‘For a while, you have a patient who is compliant and apparently then able to think. But … I don’t think it lasts, I think you have to be able to deal with the
very negative aspects of the relationship as well, where you don’t actually move these people on.’ (M38)

13. The service should offer the user ‘containment’: that is, a secure base within which they can acknowledge feelings without falling prey to their destructive power.

14. Staff working with this group are also prone to potentially destructive emotions, such as anxiety and antipathy, and they also need mechanisms to identify and express them within a ‘contained’ environment.

15. Whether formally or informally, the service should offer skills that can be used to promote better lives and which the person can utilise independently of the service.

16. Many of the pilot staff talked about encouraging self-awareness of psychological processes, states and emotions. Whether the interpretation was given in terms of mindfulness, emotional regulation or psychological thinking, there was general agreement that therapy for this group needs to act upon a person’s ability to identify and manage the responses of themselves and of those around them.

17. Consistency – across time and between personnel – is a key value, not just because it reduces the potential for chaos but because it gives service users and staff security.

18. Comprehensive communication within staff teams is seen as vital. Services should have a clear information-sharing policy, communicated to the service user at induction. Most teams insist on the right to share information within the team, or within the community, and remind service users of this if personal information is disclosed.

19. Group or community settings are valued by all services because of the power of peer support and the opportunity they offer for practising relationships (see 4.1.2.4 below).

20. Discharge or disengagement from the service is likely to be difficult and threatening for some service users: it may be viewed as abandonment and may precipitate an increase in behaviour designed to demonstrate need or risk. Some services address this by working toward discharge or self-sufficiency as a specific goal at a specific time from the point of engagement, while others have provisos for re-entry into the service. Some services are developing models for less intensive, ongoing support so that discharge need not be absolute.

4.1.2.2 Attachment, trust and sharing

The extent to which attachment to an individual worker is woven into therapy varied between pilot services. In the context of one-to-one work, the therapeutic relationship is very much seen as a tool of both engagement and therapy. In TCs, on the other hand, the member is encouraged to attach to the group or community, through which as much as possible of the person’s difficulties are submitted for processing. One of the proponents of this model said: ‘It's a much better way for the onus of support not to fall on one person: it's safer, more containing, if it falls on the whole TC.’ (S65) A mid-point is where service users are encouraged to feel contained by the staff team, not the individual, giving both staff and service users different options ‘If key relationships become a bit ragged’ (S15), or if staff members leave or take holidays.
The theme of attachment, and who the service user is held by, is closely linked to policies governing confidentiality. For the safe containment of anxiety, and to facilitate support, almost all the services shared information between staff.

'We tell them from day one, and whenever it arises that we cannot have confidences with them: that if they tell one of us, the whole staff team has been informed.' (S64)

Services based on community or group provision also encourage members to communicate with the group as a whole, not with individual members. Whoever was included in the sharing of information, there was agreement that ‘secrets are bad’ (M11) and have the power to isolate the individual and prevent recovery.

### 4.1.2.3 Peer support and group work

Peer support is an integral element of pilot services based on the TC approach but is also an important part of service provided by several other pilots. Staff told us that other people can provide an important means of self-validation, act as role models, and help a person to develop tolerance of others. With the exception of a single manager, who stated that group work increased the likelihood of service users damaging each other, most providers subscribed to the value of group work, albeit in some cases alongside one-to-one sessions.

'It’s ideal to learn the skills in groups because you get to share other people’s experience and recognise that you’re not the only one struggling with these things ... Most people can see faults in other people before they can see them in themselves. And they get that “yeah, so you can see that in them but oh my God, do you think I do that too?” So it does speed up the process. And it’s cost-effective too.’ (M33)

However, not all services had been able to engage service users in group work: in the first few months of their development some discontinued groups through lack of attendance. The use of groups is perceived differently by different services. For example, in one pilot, individual sessions were seen as providing a means of helping people use groups to best effect. However, in the TCs and the Service User Network, users are asked to bring everything that impacts on them into the group, subject to that person’s own ability and desire to share it. Groups need to be managed by experts, although the input of staff may be difficult to identify. Suggested roles include the moderation of interaction, so that vulnerable people are not incapacitated – one worker described her role as to ‘soften the edges’ (S19). TC workers have expressed their function as ‘containment’, and ‘keeping the group safe’.

### 4.1.2.4 Combining different interventions

Across the different pilot services social activities were seen as important in helping people develop skills and increase self-confidence. Involvement in structured activities was also seen as an important means to combat social exclusion and stigma. Even in pilots that specifically
aimed to provide psychological therapy for people with PD, social and other occupational activities were seen as central to the success of these interventions. One provider pointed out that structured activity is an inherent part of the DBT model that is often neglected. Several services aimed to intersperse psychotherapy sessions or groups with social activities, as a means of developing capacity to deal with conflicting emotions:

‘It was really difficult for people initially… to say, play a game or, you know, to even be happy. It was like they daren’t laugh because if they laugh it’s saying, “I’m alright, and I’m not,” so the (mixed) agenda plays an important role’. (S65).

Many of the services promote the use of mainstream social and leisure facilities and build them into care plans: ‘We are now sending people to the gym: there is value in these low-level interventions.’ (M1) One pilot was primarily concerned with the provision of vocational support to patients referred through (predominantly but not exclusively) primary care, with a focus on combating social exclusion and the stigma of mental health services. The mixture of the pragmatic and the psychotherapeutic in these services is innovative, and requires staff to take on work that previously they could leave to some other service. For example, psychotherapists and advice workers have been brought together in the same teams and with the same service users, and in some circumstances, either could be delivering interventions that relate to both areas. Finding a common language and common values has been difficult.

‘The education and skills facilitators are both social workers – and what they would call therapeutic is different from what psychotherapists would call therapeutic … sometimes that’s created rumours, battles in the team or lack of understanding of each other and we need to do a lot of work on that to be able to keep talking to each other, to value the fact that people have very different perspectives and all the perspectives are really important’. (S47)

The development of advice services for service users among the pilots was not a prominent part of the bids, and it is instructive that so many of the pilots have become not just educators, trainers and consultative partners with service providers, but are also working directly to improve the practical skills of users.

4.1.2.5 Specific therapeutic models

Most of the pilot services set out to deliver innovative interventions for people with PD that have not been attempted before. Exceptions to this were services providing TC-based intervention and one that delivered DBT. While several pilots stated that they provided groups which were ‘DBT-informed’, only one pilot ran (from a menu of options) a rigorous DBT programme. This placed particular demands both on staff and service users.
‘DBT, it takes commitment and it takes intelligence and a intellectual capacity, so people need to want to change to commit to DBT. They need to agree to the targets that we put forward because the hierarchy is that suicidal thoughts and self-harm are the first priority, you don’t go anywhere else until that's sorted. Now there are a lot of people who don’t want to stop self-harming, so DBT is not for them.’ (M33)

Pilots included several day therapeutic communities: none was residential but they achieved a high degree of consistency through the guidance of shared consultants (staff and service users) and the Association of Therapeutic Communities. A TC is:

‘A safe and secure environment, a place of safety, where people can come and learn how to make relationships.’ (S65)

‘It creates an environment where people engage in normal interactions that trigger behaviours and feelings they have difficulty with: it’s got to be an emotionally safe environment, where they can reflect on and interpret those feelings, so they don’t have adverse consequences.’ (S41)

In TCs staff aim to ‘contain’ the anxiety in the group, maintain boundaries that keep the community safe, and soften the impact that service users may have on each other. In order to allow the community to take responsibility, staff intervention is minimised. Community members learn to recognise the need for, and to arrange, support for each other, but this is one of many capacities that develop as the community matures. The model of democracy and accountability in TCs is difficult for people to grasp.

‘It still feels very much like it’s a staff role to reinforce the boundaries of behaviour that are therapeutically helpful or that we can work with … the community not being quite robust yet. I mean people are starting to question things and each other and boundaries … So we’re now going through a bit of a stage of being the enemy at the moment, bad parents and that’s only a natural part of the process …’ (S62)

Eventually, members should take over enforcement of rules. All the pilot TCs are part time, operating between 1 and 4 days per week. Staff stated that there may be advantages to the part-time model: ‘people get the chance to practise skills’ (M38), and there may be less tendency to drop out of TC services because they are largely confined to school and work hours. However, all of the new pilot TCs have acknowledged the difficulty of importing the TC culture within the time limits of the pilot funding. One of the key sticking points is the assessment and voting in (or rejection) of potential recruits by the members.
4.1.3 THE SERVICE USER’S JOURNEY
In this sub-section we highlight some of the factors that staff view as important when service users are referred to, start attending, and leave services.

4.1.3.1 Finding the right place
Most of the pilots expressed commitment to considering the individual’s needs in a broad sense: the interest of providers went beyond recruitment to their own service, and assessment, advice facilities, pre-groups were built into most of the pilot models, often at the point of first contact. Some services shared a single access point with the psychological therapies, or psychotherapy, service; another was attached to a walk-in advice service, and another, offering distinct interventions, has chosen to establish its own advice service to give applicants a better introduction to the available options. Some services, such as the early intervention service, attach value to keeping service users out of mental health services altogether if possible. Only one of the pilot services was set up to take referrals from primary care. Unfortunately, because of the model of stepped care in the Trust, there were barriers to primary care staff wishing to refer patients directly into a tertiary service, such as a specialist psychology service for people with PD.

‘Have a real problem in getting through the cycle of exclusion: GPs who identify suitable patients cannot refer to (tertiary psychology service): they have to refer to the CMHT and get them to take person on … So we cannot keep clients out of mental health services: and CMHTs can say they won’t take them, as don’t meet their criteria.’ (S29)

A universal requirement of those pilots that worked directly with service users was that they were informed about the nature of the service and, by implication, about the nature of their problems. This did not necessarily mean that pilots adhered to the term ‘personality disorder’, as several rephrased their literature in less medical terms.

4.1.3.2 Engagement
Staff working in pilot services told us that little things can make a difference when trying to engage people. One therapist told us how they put smiley faces on appointment letter...
envelopes to distinguish them from the post a service user states she cannot face opening. Another service provider told us how one person would only respond to text messages during the early phase of engagement with one of the pilot services. Having access to a waiting room and a kitchen – or a room shared with staff – can make service users feel more at home when they come in for appointments. Knowing different members of a team can help, because it allows substitution when therapists are away, but it is also friendly and respectful.

‘It’s not appropriate if I inundate them with appointments … but I want to know them. I tell my staff, “if I’m in the corridor when you’re going in and they have appointments, introduce me” … Nobody solo works, that clients do get to know … and if they’re linking into other groups, they are getting to know other facilitators because all our groups are run by two facilitators.’ (M33).

Staff spoke of working hard to overcome the potential ‘us and them’ division which they feel is common in patient–professional relations within health services. One way of doing this has been to share results of any screening or assessment tools that services have used. For instance, one pilot service that routinely used a standardised assessment tool shared findings from this in order to provide feedback to service users about the difficulties they reported experiencing; the template was then used to help with the development of a care plan. Similarly, one service routinely discussed psychological treatment options, so that treatment was a partnership.

‘We normalise diagnosis and I believe that we work through the stigma component. And in doing that diagnostic stuff … this starts to make sense of why I’m experiencing those things and that it’s not abnormal, it can be defined … Then there’s something you can do about it. So it’s very containing I think for people because they’ve all been sold the story, “there’s nothing you can do for PD” … if we work on these theories and support you in this way, you can start to work through these and they’ll be less problematic for you.’ (M33)

Services highlight a number of ways in which engagement was facilitated:

- allowing self-referral;
- having a facility permitting immediate ‘drop-in’ casual attendance;
- not requiring lots of forms, and assisting service users to fill in the necessary paperwork;
- having two staff involved in early assessment, with one from the service whom the user was guaranteed to work with in early days of therapy;
- offering alternatives, including referral to other services;
- making information exchange two-way, so that people knew what to expect and were responsible for deciding to engage or not;
- self-help groups;
offering contact with existing or ex-service users;
integrating client-identified goals and desires into therapy goals.

‘What is important to engagement of this group, who are often mistrustful, let down? One: honesty. I’m always shocked that people come back because I (tell them) I can’t give you anything really, I can’t offer any definite guarantees. Two: I also think the not wanting to make it better – which is the natural impulse, if somebody’s talking about suicide or self-harm, not trying to make things okay because that’s more about us than them.’ (S50)

Several of the services use assertive outreach techniques, particularly when trying to engage people with Cluster A PD. Several also prioritise service users with high needs and make considerable efforts over time to engage them, but staff admit that there must come a point when such efforts must be seen as unproductive and a waste of scarce resources.

4.1.3.3 Assessment
Some pilot services stressed the thoroughness of their assessment practice. Several staff discussed assessment as simultaneous to engagement: it might then take months, as trust and communication developed. ‘We often get to know the person better than the referrer does’ (S58). Assessment may then be an intervention in its own right (M54). The services that placed greatest weight on assessment employed strategies to reduce attachment (so as to reduce trauma associated with detachment and disappointment). However, the most common reason cited by services for not taking clients following assessment was the person’s lack of interest in changing: ‘Sometimes they have their way of doing it and they’re not really interested in a new point of view …’ (S48). Having no desire to change, and perhaps too much invested in current ways of thinking and behaving, were the commonest reasons for a person not being offered a service. In contrast, two of the pilot services providing case management for people with severe PD agreed to take on service users whether or not they were motivated to try to make changes. The aim of these services was to provide high-quality support and try to promote interest in other interventions, following a period of stable engagement.

In contrast, those services offering structured therapy need to assess the individual’s ability to benefit, their capacity and vulnerability. Would the person manage (during and after) group work? Were their basic needs sufficiently met to benefit from therapy? Were they too frustrated by external issues (e.g. conflict with family or neighbours) to concentrate? Could they benefit from skills training to manage problems such as self-harm, in order to reach the point where they might manage psychotherapy? Many services highlighted the difficulties faced by service users when confronted with the prospect of group work. Some of the services offer individual sessions to prepare new service users for this work. In contrast, some of the day TCs did not assess service users as fully, seeing preparation groups as a better means for the individual and the group to assess their ability to make use of the TC.
If people referred to pilot services were not subsequently taken on, teams still tried to provide something of value – alternative options, or an invitation to re-apply in the event of particular changed circumstances – to them or to their professional carers.

4.1.3.4 Transfer of care and CPA

Pilot services varied in whether or not they took on CPA responsibilities for people using their services. Some services were specifically set up to take on case management of people with PD and saw taking on CPA responsibilities as a central part of their work. Others preferred to keep the service user under their previous care coordinator and psychiatrist. One service manager stated that taking on CPA responsibilities could lead to dependency, and that by not taking on care coordination the service was able to distance itself from medication and the ‘abuses’ of mental health services. Other pilots took on service users who were not currently on CPA and believed that registering them for this could be stigmatising and counter to the aim of helping them move away from contact with mental health services. Not all services offered long-term interventions: transferring CPA responsibility during a 16-week skills course, for example, was not appropriate. Service managers also highlighted the additional administrative burden that taking on the role of care coordination implied, and felt that time would be better spent delivering psychological therapies and other interventions. Others argued that it was a mistake for dedicated services for people with PD to distance themselves from CPA.

‘It was assumed that, to be this psychotherapist, they have to be “hands off” from all of that nitty-gritty. As though CPA had to be the “coercive” part of medical model. And I actually think they’re wrong. I think to be the psychotherapist, to be involved in the nitty-gritty, you can have a much better outcome.’ (M46)

Staff at this service told us that it was important to combine what were traditionally seen as CPA responsibilities and the traditional psychotherapeutic role. They argued that this enabled staff to take a holistic approach to people and to develop a better understanding of how their lived experience combines the practical, the emotional and the psychodynamic, and that care services should also do this. Another reason for taking on CPA responsibilities was that in most areas referrers expected pilot services to take on this role. Some staff working in pilot services felt that it was important for the service to take on CPA responsibilities in order to maintain credibility and support from hard-pressed CMHT staff. Service users were sometimes referred when it was felt that care provided by local mental health services had been unproductive, and referrers were keen that responsibility for care coordination was passed over to someone else.

A common model among the pilots was to request continued CPA coordination from the existing provider, with responsibility to be transferred when the client had ‘settled’ in the service, provided that the therapy model was of sufficient duration. Some services, including
the TCs, wanted the individual to take on their own CPA coordination, with a view to withdrawing from the register as they became more self-reliant.

4.1.3.5 Retaining service users in the service

Staff working in pilot services told us that retaining people in services was difficult because of the ambivalent feelings towards others that many people with PD have. People may also leave a service prematurely in order to avoid or control what they fear will be the trauma associated with discharge. Abandonment is a common experience of people with PD. In order to mitigate the possible impact of staff absence, most services that offer a key working relationship with a staff member introduce at least two key staff. In some services, those in early contact with the service user at the assessment and engagement stage will plan to be involved in the therapy stage.

‘(We) make a commitment that (one of the two people) who do the assessment will be coordinating the group, so that people do know someone when they start.’ (S63)

Most services have some rules or boundaries around attendance, and challenge non-attendance. In community or group services, members were encouraged to phone in to explain absences, and group members might phone out to check on absent members. The process may include occasional communications, quite commonly from the group or community, to show that the person is ‘kept in mind’. Staff reported that this seems important to people who may feel particularly excluded and not valued.

Staff told us that when users have disengaged from a service people are given written notification that they can no longer use the service, together with information about how they could go about re-entering or re-applying to join.

There is a difficult balance in all the services in setting treatment goals and personal challenges that are meaningful achievements, but that do not set service users up to fail. All services have some rules about behaviour that will instigate discharge or suspension from the service. In user-led services, rules are designed by the group or community, and typically relate to attendance, use of substances or dealing drugs on the premises, and aggression. Expulsion or suspension for infringement of rules sanctioned by members was usually felt to be a positive part of therapy for the individual concerned and for the collective. More difficult to codify and enforce are rules governing communication: casual talk about self-harm may be detrimental to other clients; the development of relationships between service users outside service premises may be common, but rules may be in place discouraging the expression of such ties in the service. Conversely, in TCs, there may be a rule that any contact is brought into the community and openly aired. Several of the pilot services also have guidelines governing staff–client interaction, such as limits on the amount of time clients can spend in one-to-ones during crises. Ideally, user-led services should take over the administration of discipline in relation to breaches of rules and attendance, so that the staff do not always take on enforcement roles. Consistency is highly valued. User-led services, it is hoped, take on
increasing responsibility for enforcing boundaries, such as attendance without staff support, as they mature. However, there may be times when staff are in the difficult position of knowing of good reasons why a service user is breaching boundaries, but being unable to advocate for exceptions because the client’s circumstances are confidential. Where staff alone have responsibility for rules, there is the possibility of more flexibility in individual cases. Paying travel costs or facilitating transport is important in encouraging attendance, and vital in some rural areas. A staff member at a rural TC told us of a service user who left the service because she felt she was too upset to drive home safely after groups.

4.1.3.6 Discharge process
Because most of the pilots work with people for long periods of time and this evaluation was conducted within the first two years of their operation, many providers had limited experience of discharging users when these data were collected. Staff told us they were sensitive to how difficult endings were for many people with PD, and that the process of disengagement therefore needed to be planned carefully. Several services told us of plans to develop a phased discharge aimed at minimising feelings of abandonment. Some staff said that it may be more productive to keep people on caseloads with minimal contact rather than to discharge completely.

‘(We) need to be prepared to work with a person for a long time … Discharge can totally destabilise a person with attachment problems: to avoid what they see as abandonment, they will escalate unstable presentation. So don’t discharge them, you can maybe see them less often.’ (S10)

Some of the pilots did not fully consider limits on capacity as a driver of discharge until they reached capacity. A service that does not have the ability to discharge people may inadvertently deny others access: those that can should be moved on, and it may be helpful, as is common in many services including therapeutic communities and some psycho-educational groups, for a timescale to be set from the point of engagement. Some staff of open-ended services felt that there should be a cut-off point, and that allowing ongoing use of a service encourages dependence and reduces motivation and the development of coping strategies for existing clients, while denying others the opportunity of using the service.

‘Within 3 months we should work towards leaving … the project will have failed if we can’t move them on.’ (S14)

Some services are also exploring the role that service users might play in running ongoing peer-support groups for people who are no longer in contact with service providers. ‘I think we try to get people to a point where they can get by without very much at all from services: but there is an enormous gulf between minimal input and discharge.’ (M8)
4.1.4 MANAGING CRISES AND SELF-HARM

4.1.4.1 General approach

Pilot services have attracted a large number of people who regularly self-harm. A key theme in addressing these behaviours is to discourage dramatic responses and to have contingency plans in place, ideally equipping the individual to implement them before undertaking self-harm. ‘Because crises are predictable, we can plan for them’ (Minutes of Learning Network, Sept 2005).

It is a precept of DBT that the service user should be helped to develop strategies to avert self-harm before any more exploratory work can be undertaken. While tending not to draw on DBT discourse, most pilots prioritised this issue, helping service users to identify the pathways into self-harm and the warning signs, and develop alternative practices, such as seeking support and/or distraction of some kind. Pilot services avoid punitive or disapproving responses to self-harm and place emphasis on alternative strategies, or upon the value of the person.

‘If you did that to someone else, or someone else did it to you, I would have to take measures to stop it, it would be against the law: so I can’t condone it just because you did it to yourself.’ (S4)

There is general recognition that no external agent can stop a person self-harming: responsibility lies with the only person who can change course of events, the service user him- or herself.
‘Putting self-harmers into hospital on suicide watch backfires: it takes responsibility away from them. It is better to talk to them about how it comes about and find something to divert them from it.’ (S5)

Staff from several pilot services have commented that self-harm becomes less scary once you know you can talk about it openly with clients. Opening an unemotive dialogue with the person about their behaviour was reported by staff – not all of whom had clinical backgrounds – as useful. ‘If you have a sense of – an ability – to communicate, risk can often be minimized.’ (S50) Mainstream providers, it was said, might avoid a topic that is manifestly uncomfortable and unpleasant, but staff reported increased confidence in managing their own anxieties, and reducing the risk of repetition, if they talked to the person about it:

‘What happens often is the responsibility is handed over to the care staff. Getting into dialogue with the patient about the conflict within themselves about their self-destructive behaviour and enabling them to take charge of themselves again can be phenomenally useful … You can then get into a negotiation rather than an action–reaction dynamic. So both feel they have more control in the situation.’ (M8)

Working with people with PD appears to involve acceptance of some level of risk. Among the pilots, risk to self was relatively commonplace; while people felt to represent an active risk to others were often rejected at the referral stage. None of the services took people who had perpetrated violent crimes, although information around criminal behaviour, if not known to the referrer, would usually have to come from the client. Asked about risk assessment, providers did want to know the worst, and to plan with the client to manage that if it recurred.

‘Gatekeeping relies on an old-fashioned view of risk … the most useful thing to know is the worse thing they’ve ever done, as bad as they’ve ever been … There are no settings in which the risk falls to zero. By turning them away, we’re not helping the patient: the most ethical thing is to recognise need and to take the most seriously unwell that we can.’ (M1)

4.1.4.2 Twenty-four-hour support

In recognition that crises can occur at any time of day or night, pilot services had developed a range of different approaches to helping support people outside of normal working hours. These included: telephone contact with staff; access to a crisis centre and crisis beds; peer-support structures, including telephone contact and contact via an internet chat-line; and crisis plans devised by service users and reviewed by groups. Where pilot services did not provide out-of-hours support directly they provided information to service users about existing sources of 24-hour support such as local crisis teams and home-treatment teams.
Pilot services such as some day TCs and the Service User Network have developed comprehensive protocols outlining how service users can obtain peer support at times of crisis. These plans initially met with resistance/anxiety among some senior Trust personnel, despite the likelihood that such protocols arguably result in less risky and more supportive contact than the unsupervised contact between service users which might otherwise occur. Specialist legal opinion was sought in one Trust before the protocol was accepted. It is ironic that services that do not acknowledge the ‘unofficial’ contact known to arise between service users in crisis may consider themselves less culpable in managing risk than user-led services that seek to govern that contact.

Many crises occur outside ‘office’ hours. Staff report that service users may initiate crises outside normal working hours in order to provoke a response that breaches the accepted boundaries of everyday care. ‘Preventive’ day services, versus ‘reactive’ overnight crisis services may require different approaches and it can be difficult for the strategies and boundaries enforced by day staff – including the crisis plans devised by the user – to be implemented in the context of a seeming emergency. Most services, whether or not they had a crisis support component, had an interest in devising shared protocols with local crisis and home-treatment teams, and some would make specific arrangements, with the user’s knowledge, over evenings and weekends. One pilot was offering training to Samaritans to support consistent approaches to people with PD.

Approximately half of the pilots did not have an in-house facility for out-of-hours crisis support. In contrast, all of the service user-led pilots had or were developing some out-of-hours support system, though rarely did it run beyond 2–3 hours per night. The pilot delivering 24-hour services has developed a comprehensive range of methods to support people in crises, but has found the staffing of posts with anti-social hours challenging and expensive. Staff who can work anti-social hours may require longer breaks between periods of work than those in day services, and in a small service, continuity is difficult to sustain.

### 4.1.4.3 Some innovative approaches to crisis management

Two services among the pilots offer phone contact with staff outside normal working hours because it is an essential part of the therapy model; the TCs offer, or are developing, peer-support contact out of hours. In all cases, users are taught to use it only for specified purposes: ‘It’s not a crisis phone call, it’s a support phone call … you really are trying to make a difference here, not just patch up the mess afterwards.’ (M33). There is a sense that the availability of support reduces need for it.

TCs have user-led support as part of their remit. However, all the TCs in the pilot suggested that they needed to reach a certain level of maturity before members could coordinate and offer this service because it works best when both needs and responsibilities are shared over a larger number of members. One pilot (the North Cumbrian Itinerant TC) has pioneered the use of a website and message-board, P2P (or peer to peer). Staff members have access to P2P, but not to the message-board, and clients can be suspended from the website, so there are incentives not to abuse the facility. The facility was researched and developed to extend
the TC, as members are dispersed over a rural area with limited transport. The set-top box
doesn’t need a modem. Guidelines include a ban on imminent threats or accounts of
deliberate self-harm. The system allows the community’s ‘Top 3’ service users to monitor,
access and delete entries, and a log is kept so that messages can be brought back into the
community meetings. Staff suggest that the act of recording messages has advantages over
phone calls because it introduces a slight delay which inhibits impulsiveness and allows a
natural pause for consideration. Other services have suggested that e-mail messages to the
service have a similar function, even though they will not be read until the next working day.

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<tr>
<th>KEY MESSAGES – managing crises and self harm</th>
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<tr>
<td>Crises can be anticipated and planned for and need not be viewed as emergencies. Pilot services manage crises and self-harm by engaging in dialogue with the person concerned, helping them to develop improved coping strategies, and avoiding drama and containing staff anxieties.</td>
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<tr>
<td>Methods for supporting people in crisis developed by pilot services seek to actively involve service users and tend not to provide an instant response. Service providers report that if people have been helped to prepare for crises, a delayed response can help ensure the service user plays an active role in crisis management.</td>
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<tr>
<td>Despite concerns about safety and feasibility, user-led out-of-hours support may represent the most viable type of support that can be offered by dedicated services for people with PD. Clear protocols are required governing who can provide and receive such support, how the contact should proceed and end, and how various eventualities should be met.</td>
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4.1.5 STAFFING THE PILOTS

4.1.5.1 General issues

Most pilots found it challenging to recruit staff during their setup phase; several service leads reported that some of those initially employed proved to be unsuited to working with people with PD. However once services had become more established pilots generally managed to retain staff and levels of staff turnover were lower than some service leads had expected.

One manager recommended that probationary periods for staff working in PD services be made standard practice. When asked, ‘What kind of staff work well with this client group?’ most respondents said their answers were qualified both by the need to deliver their particular vision of the service, and by what they had learned from making mistakes. Professional background was said to be less important than personal qualities and the ability to engage service users. A minority thought it better to recruit staff from non-mental-health backgrounds as they were less likely to have preconceptions about the service and its users. This was less of an option where the service focused on delivering psychotherapy, requiring training, experience and aptitude: but even here, personal qualities were highly influential, and there were a fair number of workers – CPNs, social workers – from mainstream service backgrounds who wanted to change direction and develop psychotherapeutic skills. The downside of preferring personal qualities to qualifications is the amount of training needed at induction. Some of the qualities singled out include:
1. The ability to engage service users, but not at the expense of neglecting appropriate boundaries

2. The ability to engage service users, but not at the expense of neglecting appropriate boundaries. Ability to empower users by letting them make some mistakes. Staff who are controlling were considered unsuitable for PD services. ‘People with boundaries … with the boundary that allows them to not want to look after people, not want to get in and fix things…’ (M33)

3. Staff need to have a high degree of personal resilience. Staff who are vulnerable to resonance between their own and the clients’ problems may be unable to work in this setting.

4. Staff need to have emotional maturity: ‘People who have an emotional maturity, a flexibility, a sense of humour, an ability to not take themselves too seriously.’ (M33)

5. Staff need to be able to accept the limitations of what can be done. ‘People do understand that we’re very busy and they will get their turn … (but) there’s more people needing something than you can give. You need to rationalise and accept that: there is a limit to what you can do. And there’ll be clients that don’t respond, and those that will die. You have to protect yourself and be realistic about what you can achieve. Our clients sabotage your best efforts at times, or go backwards. You can’t take any of that personally. They’re responsible for their choices. You need to respect that.’ (S14)

6. Staff need to have a capacity and a willingness to reflect on themselves and their work. ‘Somebody that has the ability to reflect on themselves … You know you can’t ask the service users to be able to reflect on something if you can’t do it.’ (M39) ‘To work in a therapeutic community you’ve got to have a lot of self-awareness, you’ve got to be prepared to keep looking at yourself and I think a lot of other professionals don’t want to do that. I think it’s a bit scary for some colleagues in the other team, especially when we say “how does that make you feel?” you can feel them backing off.’ (S64)

7. Staff need to be able to discuss their own mistakes or uncertainty, as this is considered crucial to maintaining boundaries, security and containment of both staff and service users.

8. Staff need to be able to balance their work life with other aspects of their life. ‘The capacity to be take a clear-eyed view of things and not be driven too often by hatred … someone who can maintain ego-strength, personal security. And all members of our team have substantial lives, go home to something as substantial as their work.’ (M1)

9. Staff need to be willing to work as members of a team, to reach compromises and accept the process of shared decision making, and/or the decision of the clinical lead, when agreement is not possible.

10. Empathy and non-judgemental approach, possibly borne of experience. ‘I suspect that people who have had no emotional issues have had a genuinely wonderfully happy, fine upbringing with no complex issues, no emotional problems: why would they want to work in a service like this?’ (S61)
4.1.5.2 Recruitment issues

Staff recruitment was a challenge in the first few months of the development of several pilot services, especially those that were developing new and innovative services. Service managers reported that new staff sometimes wanted to carve out their own vision of the post, but did not, in their view, have the experience to know what was needed. Some then found the post did not fit their preconception of it; or that the post, since being advertised, had changed not only in title but also in content (examples: from community recovery to skills facilitator; from social inclusion worker to care coordinator). The training and setting-up phase, when therapists saw no clients but were used to publicise and present to CMHTs to recruit clients, was particularly difficult: ‘It is hard for therapists not to see patients: they feel lost’ (M45). There was uncertainty about new models of working: some of the TCs took staff who had no experience in this area, and the early days of working with clients were very challenging. Most services tried to recruit a mix of people.

‘When we recruited people we’d rather have talent than experience so we had quite a few talented people but not many experienced people, so what you want in supervision is a talented, experienced person there who can recognise dangers and lead discussions about solutions.’ (S48)

In some of the pilots, the staff came from existing services within a local Trust: not all of these posts were replaced. This effectively meant that funding for pilots resulted in reductions to expenditure on existing services. It may be that Trusts see investment in a PD service as more politically imperative than, for example, the maintenance of an existing psychotherapy service. In one large pilot area, the pilot monies and services have initiated a full-scale revision of services: this is potentially positive, but in some cases, the gains made for PD services have represented losses for others. The Networks have also found that some anticipated secondments did not happen because staffing pressures on local services did not allow the person to be released. Training opportunities for local staff to spend time in the pilots have also been inhibited in this way. Service managers believed that these staff would have added something to the capacity and skill mix of the pilots, and to the dissemination of the model. One pilot set out to attract young psychology graduates who were seeking placements that would contribute toward the experience needed for entry into clinical training. This strategy resulted in high-calibre, motivated employees who were not concerned about the limited length of employment. High-quality supervision from a senior practitioner was made available, and the only drawback of the strategy was the inevitably high turnover.

4.1.5.3 Use of professional skills

Because the pilots forged new generic roles, some staff felt they had to let go of, or refashion, the clinical, professional and therapeutic roles they had invested in. Service managers told us that some could not do that, and left, while others initially felt very deskillled. ‘Why do we need a new model? I’m a psychotherapist; I know about talking to people. Why are you telling me
how to do an introduction?” (M18) Clinical leads found that those without a clinical background – uncertain expectations, and no model in mind or status to defend – tended to settle down quicker, and ‘got it’ (grasped the model) more quickly. It can be difficult to predict whether professionals want to maintain their particular skills and be called on to exercise them: or conversely joined the team to do something completely different (S60). Several services had to redefine roles: therapists have had to take on social- or advice-worker roles; unqualified people have taken on therapy. Some staff found that expectations for the work they would be doing were not met, causing resentment.

It is difficult then to consider the pilots as ‘multi-disciplinary’ in the established sense of the term. Despite the range of professions involved, most staff were recruited to deliver the service model, which may have had no precedent. A TC facilitator does not need to be of a particular professional background, although experience in TCs will be useful. Most services, including the TCs and group-based models, aimed to deliver a mix of psychotherapeutic and practical support. One team, advertising for staff wishing to acquire competence in psychotherapy, was inundated with applications: but few applicants wanted to also engage with the users’ housing problems or need for dentures. Most of the services have demanded this degree of flexibility in attending to the hierarchy of service users’ needs.

‘This is a bigger role … it’s in your job description, this is not sitting in the same room week after week you know, talking to the same person. This is being out there, doing the things that the individual needs, to be able to move forward in a therapeutic way …’ (M45)

Several members of front-line staff told us that working in pilot services had left them feelingly deskilled or demoted.

‘There are six of us nurses working here. We (nurses) represent the highest in the one discipline in the service … I think we carry quite a lot and I have felt quite deskilled at times that I’m not at that sort of level of expertise where my opinion matters that much.’ (S62)

The demands of running multiple service components have meant that, at least in the early stages of service development, staff often had to take part in publicising the service. Some staff who had previously worked in psychotherapy services found tasks such as handing out leaflets and telling teams about the new PD service frustrating.

4.1.5.4 Team working

Team working – the sense of joint responsibility for service users and mutual support between staff – was very important to pilot services, even though there were rifts between some individuals and teams. Sharing the difficulties of working with particular service users and getting advice is hugely important and several teams have ‘back-up’ workers, who may or
may not be known to service users. Handovers and post-group meetings are considered important means for sharing responsibility and containing staff anxieties. Team working and clear communication is also necessary to minimise ‘splitting’ (the tendency among some people with PD to separate significant others by identifying them as either wholly good or wholly bad).

Where there are different functions within a single pilot, and different teams, there is a predictable potential for splitting, poor communication, divergence of aims, accusations that the other team take soft options and ‘Chinese whispers’ (M11). Several pilot services have considered how communication between staff teams could be improved. Ways of doing so include ensuring that at least some staff work across the different components of the service or swapping some staff between different components of the service.

4.1.5.5 Staff ‘dysfunction’ and supervision

There was widespread agreement that staff who have unresolved psychological issues were unlikely to be able to work productively with people with PD. Concerns were expressed that staff with such issues may even further damage people with PD. Service managers described problems associated with employing people who became increasingly demanding of support, and increasingly like service users. One manager speculated that health and social care services attract vulnerable people, and empathy with users may degenerate into need.

‘Because our clients are so fragile, they don’t deserve a therapist that’s fragile. You (the therapist) can talk about anything that you have resolved or is not current. You can keep people at bay.’ (M33)

Clinical leads varied in how much weight they placed on the calibre of the staff member, and how much on the support that should be given to supporting staff to reinforce their resilience. One said: ‘It is not our role to contain the problems of the therapists: we are here to work as professionals, not to be patients.’ (M45). Another felt that – provided staff had the right qualities – it was reasonable to offer open-ended support because it would not be abused. A therapist from this team clarified:

‘We believe that the needs of PD service users are likely to be compromised when anxiety in the professional system is high, in whatever setting they find themselves … We maintain that the work of actively engaging PD service users in their care and making change cannot proceed without a well-supported and experienced core group of professionals operating from a safe base.’ (S38)

Most of those teams who work psychodynamically hold the clients as a team, and inform them that information divulged will be shared throughout the team. This is vital to the containment of risk and anxiety, reduces the capacity for splitting, manipulation and inappropriate attachment, and also permits more creative thinking.
‘New clients are informed of this policy: why it is so important that nobody is sitting in a corner with just their client and not sharing. And the client knows that as well – the therapists tell them that the information is shared with the unit, so there is a feeling of belonging.’  (S52)

Staff said that their own humanity was important to their interaction with service users and, from time to time, they should recognise their own vulnerability. ‘Everybody is vulnerable to something at some point in their lives’ (S61). Examples might be a staff member with bereavement issues deciding not to take a group on this issue on a significant anniversary. One TC nurse suggested that those who have had therapy as part of psychotherapy training may be fortunate: it teaches them to ‘recognise their own buttons’ (S61). As one manager commented, the problem with recruiting people who did not have this background has been the amount of time it has taken to get them to recognise and accept their own vulnerabilities: ‘It is especially difficult to provide containment for people who don’t realise they need containment.’ (M45) In some services there are clear distinctions between those who have had therapy and those who have not: often they are running different aspects of the service. Splitting within the teams – often along predictable fault lines between sub-teams with different functions – has been a tangible problem within most of the pilots. Service users may characteristically split staff into good and bad: or staff may do this themselves.

‘It sometimes comes out in a weird direction, but it is always the same split: those who would overindulge the patient versus the unfeeling bastards.’ (M1)

Some of these splits reflect different ways of working: e.g. psychotherapeutically trained staff and those from more pragmatic, perhaps social-work backgrounds, may have different ideas about the type of discourse that the team should use in talking about the work. The latter may resent what appears to be prying into their own personal motivation. There may be splitting between the hub and spoke aspects of the team: those training staff in the wider arena may feel marginalised compared to those working directly with service users. Psychotherapy is also founded on a model of supervision that other professions may not subscribe to:

‘Psychotherapy can’t work without supervision … you need to have the third eye, the learning and the observing you get or whatever you want to call it. You have to have that otherwise you just get caught up in something mad and you can’t stand outside of it. So it’s vital and I don’t think you can do without it.’ (S61)

It was universally acknowledged that the client group was, and would continue to be, challenging. Some staff recognised the tendency for staff groups to ‘mirror’ the very splits and antagonisms shown by the client group. There were also acknowledged tendencies for
service users to try to cross boundaries, e.g. between staff and users: and some examples were made known to us of cases where staff had entered into relationships with service users, gave their personal phone numbers to users, or otherwise acted in an unprofessional manner. In some respects, these incidents may arise from the desire to reduce discriminatory practice, to engage with service users as equals: but the balance between this and consistency of boundaries needs to be carefully monitored. Staff talked about the balance between being a real and honest person with service users, and giving them appropriate feedback on the effect of their behaviour on others, and the real need to maintain some level of humane detachment. Service leads told us that while these problems are not confined to services for people with PD, the tendency for splitting and pushing the boundaries in professional behaviour are particularly clear in this context. It is not clear how any manager could rule out such misconduct before it happens, except through active measures to anticipate and reduce these occurrences.

‘I suppose the most challenging thing is the emotions that they bring out in you and how you manage those emotions and where you take them ... Or people kind of wanting to make everything better and kind of rescue somebody when probably that's not helpful either ... And for myself as well, sometimes not knowing what to do for the best really, what's going to be most helpful, feeling a bit stuck at times.’ (S63)

Most clinical leads thought supervision was extremely important, but there were a range of ‘controversies’ and difficulties which they highlighted. Staff of several pilots felt that external supervision by a person who is otherwise independent from the team is also important. Benefits of external supervision were seen as: enabling the team to examine their feelings without the restraints which might apply if a manager were present in a supervisory role; enabling the manager to participate and benefit equally; obtaining input from a person who was less likely to be drawn into the personalities of individual service users and staff members. It was also argued that team working and external supervision were important methods for avoiding staff burnout.

Several stated that both individual and group supervision were important, but limited time meant that both were seldom possible. Scheduling group supervision was made more difficult by part-time working; night shifts; the pressures of running a group programme; and in some instances working across very dispersed geographical areas. Some staff reported wanting supervision from a senior practitioner of their own professional background, which was not always possible. Some staff were also reported to be reluctant to share feelings in groups or expose their practice, particularly psychotherapeutic sessions, to the supervisor e.g. through the use of taped therapy sessions.

There were no service models in which staff did not have some criticisms of the way they were supervised. Administrative staff felt that they needed more training and supervision to work with this client group: they were likely to spend time with them (organising expense
payments, etc) and could be subjected to difficult behaviour, including self-harm, theft of personal belongings and threats. Several pilot managers expressed interest in organisational audit (see Appendix A1) as a useful tool for their teams.

‘It actually helps workers to survive in their work, if they have a place to think … One of the main theories about, you know, personality disordered people is that they don’t have the capacity to reflect on themselves and so if (they are involved with) an organisation that equally can’t reflect, you’re going to have this sort of mirroring that goes all the way up from the client themselves all the way up through the organisation that’s trying to help the client.’ (M21)

Pressures to increase caseloads reduced the amount of time available for reflection in several services, though service leads were keen to make sure that these pressures were resisted: ‘There’s always the pull to do more: in this kind of work, it’s better to think more’ (M19).

4.1.5.6 The rewards of working with people with PD

There were many comments about the satisfactions of working with this client group. Despite the boundary issues, staff felt that their difficulties were part of a continuum of the human condition: we can all relate to them, and we may also share the use of strategies for managing them. Most of the models used by pilot services utilised groups and peer support.

‘What gets missed out of the account of people with PD is how sensitive, aware and supportive they can be: our role is to harness that.’ (M19)

Other positive aspects of working with people with PD were stated to be that work was never boring, and that people with PD were often caring of others, honest, supportive and creative. Work with users appeared to generate strong attachments and shared insights and vision.

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### KEY MESSAGES – staffing issues

There is a high degree of consensus about personal qualities needed by people working in services for people with PD. Among these emotional maturity, acceptance of limitations, ability to work as a member of a team and a high degree of personal resilience were regularly mentioned.

Service managers highlighted the importance of personal attributes over professional backgrounds. Front-line staff in most pilot services are asked to combine psychological ways of working together with a willingness to help people solve practical/social problems they often encounter.

There are ‘predictable’ and insidious pitfalls for staff working in these contexts, and proactive – not just reactive – measures need to be in place. Although not all staff were comfortable with the prescription, it appeared that these measures are most likely to fulfil
4.1.6 LEADERSHIP AND MANAGEMENT

4.1.6.1 Management functions

Service managers and front-line staff highlighted a number of roles which they believed leaders of PD services needed to fulfil. These included:

- Clinical supervision, including taking responsibility to permit new ways of working;
- Operational management;
- Carrying the vision (and enforcing it to prevent dilution);
- Being accountable, including bearing the brunt if things go wrong;
- Gate-keeping the service: all referrals are considered by some managers to ensure they meet criteria and can be safely contained;
- Containing workers, especially through personal consistency (and a safe pair of hands);
- Disciplining workers who overstep boundaries;
- Promoting the interests of the pilot service to commissioners;
- Bringing back (repackaged where necessary) criticisms from outside from which service needs to learn;
- Championing, protecting and promoting the service in relation to external organisations.

‘Because quite often the staff just don’t have the full knowledge … I sit on all the upper management committees across the Trust, and I know the bigger picture. I know the national picture. I know the Trust picture. I know what’s tolerated and not tolerated and I know what will stand up in an untoward-incident report or a coroner’s report.’ (M32)

Service leads stated that strong, confident and visionary leadership was needed to gain funding for and deliver the pilots. Containment of staff anxiety also requires strong leadership. Many of the pilot staff felt it was essential that a person in this role should have a clinical background: although there was clearly a real need for administrative and managerial skills, it was felt that clinical management and supervision was the more vital role.

4.1.6.2 Recruitment of managers

In some services, clinical and operational leadership has been provided by the clinician who led the initial proposal, generating consistency and vision, but perhaps some inflexibility. Elsewhere, recruitment into management posts has been more difficult. In some pilots existing managers of other services were asked to take on this role, and had to combine it with other major responsibilities. Staff in such services generally felt that their anxieties had not been well contained. We note that pilots with insufficient management time resulting from either late recruitment or managers having to combine these tasks with other management responsibilities have been slower to evolve into fully functional services. Front-line staff in several pilot services stated that PD services should be operationally managed by someone with a clinical background, implying that operational management must take into account the clinical needs of service users and staff.
'I don't think I'm being supervised in a management capacity by somebody who has more experience than I have ... In most of the roles I've had I think my manager's had more experience in management, managing people and I've often missed that.' (S62)

'I think it is extremely important for people in that position to have a clinical background, and to have worked with this type of person: managers in the NHS often haven’t. Clinicians understand each other.' (S35)

While some pilots had to share a manager with another service, others were effectively led by a partnership of two people loosely aligned to general and clinical management functions, and this was felt by both staff and the managers themselves to be hugely successful if they had good communication and trust. A prerequisite of a good partnership was the need to debate differences openly but privately, so that staff witnessed consensus: otherwise differences between managers could exacerbate ‘splitting’ within the service. ‘If you have a clinical lead and team manager working together and having good communication, that’s an ideal team …’ (M19).

4.1.6.3 Management style

The same managers were both criticised and applauded by different staff for their style of leadership. Most prominently, these were charismatic and autocratic: but some staff found them containing and reassuring. In general, it seemed that more confidence was placed in this type of leader (than in less influential leaders): and these leaders have stayed with the service. There are clear parallels here between the client group and the staff group: both may respond well to consistent containment: authoritative but supportive, omniscient and all-knowing. Several managers described themselves as ‘parenting’. Several service leads have a charismatic approach to managing their teams, which may be necessary if their ‘parenting’ functions are to be accepted by the team.

‘I am the strong parent, I pull the team into line, I pull my clients into line ... I consider their needs, I have a huge amount of compassion for my staff and my belief is that I look after my staff and then they look after the clients. But with the clients being so chaotic and that I’m expecting them to work is so demanding, something’s got to be solid, and that’s me.’ (M33)

There is a tendency for leaders to attempt to quell dissent by taking a firm, unequivocal stand. Service leads told us that this could help prevent splitting. For example, in one service, a single middle manager was given total authority to decide who could use a resource highly valued by service users: this avoided the possibility of people trying to manipulate other staff members to concede use of it. Several managers said that, having consulted their staff, they insisted on having the final say in decisions: where consensus was unlikely, there was a need for a decision and further discussion appeared wasteful.
‘We don’t have time to try out every idea … because most people are used to working in psychiatry or psychotherapy very independently: there is a hierarchy, but a distant hierarchy. Here we need much tighter control and sharing of information. We need clear boundaries, clear aims and clear messages. I find the same with therapists as with patients: they need clear control, clear containment, clear messages. We don’t have time to debate.’ (M45)

The lack of an authoritative and containing leader can keep the tension for supremacy alive, particularly where there are dissenting models and teams.

‘I think our hierarchical and management lack of structure is really clear sometimes when they get us all together in a meeting that actually we’re not sure who’s in charge or who should be doing what.’ (S62)

Managers tended not to resent challenge: what they did object to was dissent being conveyed between staff in clandestine ways, rather than overtly. However, most of those leaders who were happy to be challenged retained the determination to preserve and implement their own vision. Charismatic and visionary leadership can become burdensome and disempowering. This approach also raises issues about sustainability of the service if the service lead leaves. However, questioned about this, pilot staff and managers said they could now carry the service forward.

4.1.6.4 Hierarchy and democracy

Many of the pilots perceive themselves as ‘flat hierarchies’, by which they mean that there are few hierarchical distinctions, implying that power and accountability and personal weight are relatively evenly spread. However, these are relative concepts. Within the pilots, there are examples of levels of middle management creating rifts, with different functional ‘teams’ headed by different figureheads for staff to take grievances to. This would appear to be one reason why a service with a relatively ‘autocratic’ leadership with a single figurehead or arbiter is less commonly split. Even in TCs, which place a particular importance on democracy, staff may feel that responsibilities are more readily shared than rights.

‘(The consultant) said to me, “we’re all in this together, we’re all in a flattened hierarchy, it is down to you, you can do that” but then I think “hang on here, really I’m an E grade nurse, why should I have to do all this when other people are being paid thousands more than me, maybe it’s more their role” … but I suppose that’s just something that I have to sort out myself. Because although we’re all equal, not so far as salaries.’ (S64)

Security is understated: where transgressions are uncovered, they are brought out into the open. In one service, tranquillisers were being sold among clients. An amnesty was offered to
uncover the extent of the dealing so that people could discuss the ramifications and how to deal with them.

The TC projects and the service-user network show varying levels of reliance on users to make decisions about the service, as this can hardly be imposed but should develop as the culture does. One puts every decision to a user vote; another will ensure that staff never outnumber users on any given day. Getting the informed majority view from users definitely slows up decision making, and can provoke major anxiety among service users. There were issues among staff and users about how much democracy should be offered, and how differences would be accommodated. The principle in some user-led services seemed to be: ‘where there’s been no discussion, nothing will happen’ (S17). Similarly, if no agreement or compromise could be reached, nothing could change. The desire to involve service users in all decisions requires active measures to resist ‘natural’ tendencies to exclude them from some decisions or knowledge. Paternalistic decisions about what they should/shouldn’t be involved in are not then appropriate, although they may be practised by managers in relation to staff as a means of containing anxiety.

Some staff felt that service users have all the rights and staff have no say. One service manager felt that it was disingenuous to offer openness to clients unless you had similar relations with staff.

‘(The managers) don’t necessarily contain all the issues and anxieties, you come out with them and say, “I made a mistake, can you help me find a way round that?” People don’t normally do that in management, they don’t really own up to that.’ (M19)

In many of our pilots, driving forward the service, and complying with the vision already laid down in the original bid, placed great limits on democracy within staff teams: at some point, discussion had to be shut down and a plan implemented. What are the desirable limits of democracy in staff teams; among service users?

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<tr>
<th>KEY MESSAGES – management and leadership</th>
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<tr>
<td>Like service users, front-line staff working with people with PD also need containment and consistency. Service leads and clinical managers play a key part in providing this.</td>
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<tr>
<td>Front-line staff value managers who have a strong clinical background and can combine operational management with clinical supervision. Where this is not possible clinical and management functions can be split between two senior team members, provided they have clear communication and present a united front.</td>
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<tr>
<td>Charismatic and autocratic leadership style were evident among many service leads. While this approach provides the strong leadership that such services may require, it places a burden on service leads and may affect the sustainability of the service when they leave.</td>
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4.1.7 INVOLVEMENT OF SERVICE USERS AND CARERS
There are a large number of ways in which service users can add value to PD services, not all of which can be fully described here. Examples from the pilot services include:

- in designing the service specification, and reviewing and auditing the work;
- in running therapeutic communities and user networks;
- in crisis management and out-of-hours support;
- in understanding and managing their own therapy, goals and outcomes;
- in critiquing and reviewing services;
- in recruiting staff;
- as employees of the service, whether paid or voluntary.

4.1.7.1 Involving service users in service development
Among the pilots, services that intrinsically rely on peer groups such as TCs have felt confident of their ability to work closely with service users; those with some group structures have found a clear basis for association and feedback; while those who work primarily with individuals have had the greatest difficulty in capturing user feedback. The latter services report that clearer methods for involving users have emerged as group-based interventions have developed as part of the services they deliver.

User involvement (UI) was a particular challenge for new services. In the initial stages of developing a service, there was no clear means of involving ‘prospective’ clients. Several services therefore ‘borrowed’ experts by experience (XBX) from other services to act in a training and advisory capacity. This was particularly important to services planning to ‘import’ a TC model. One pilot organised a local stakeholder event and used the cohort of service users from the first group to advise and support the next cohort in the network. Pilots invited service users from national organisations, from other specialist services and from their own contacts to help design the service and/or carry in the culture. Some pilots have invited the voluntary sector (e.g. Mind) to work alongside them to develop UI, but this may have the disadvantage of making involvement an add-on.

However, some providers have concluded that there is a particular difficulty in canvassing the views of service users new to a PD service about what they think or that service users may then feel that providers are unprofessional, and do not know what is best for them. Service users may also be less interested in expending time on issues of service design than on their own personal and treatment agendas. An ex-user commented:

‘It’s an absolute nightmare, it is, absolutely … Because people are apathetic. Service users are that much more apathetic and people diagnosed with PD are doubly apathetic, and I can say that, because I am. I set one up in our inpatient hospital and that was easy because they are there, they’re bored stupid and need something else to do.’ (S28)
A further cost of high levels of service-user involvement is the amount of time that is required. One pilot was committed to sharing all policy decision making with service users, including the details of negotiations with Trusts. However, staff reported that users were often not interested in this detail. One manager stated that sharing information about negotiations with the local Trust had left service users and staff feeling less contained.

4.1.7.2 Delivery of services by service users

The ultimate commitment to service-user involvement is to train users to replace staff, e.g. to take over group facilitation. While a minority of pilot services aspired to this model, none had implemented the approach during the period of this study. One service had started to train volunteer service users, but faced a series of obstacles including the impact on benefits and the need to have flexible work patterns in case service users fell ill. This meant that users were being temporarily assigned unpaid ‘bank’ work while more formal arrangements were being developed.

Therapeutic communities also rely heavily on service-user input. It is possible for meetings to involve little or no verbal interjection by staff. User-led models need clarity about purposes, relationships and accountability, and governance, risk management and confidentiality. In some pilots, user-led groups were seen as a step-down intervention, where graduate users could develop skills and confidence and support each other after detachment from the service proper. Experienced service users are used in some of the TC pilots to guide people into more intensive services, and could also play a role in supporting people on waiting lists. Service users can then expand a service’s capacity. It is also important to such models that members sign up to and enforce the disciplinary aspects of the service. It is a source of satisfaction to staff that members own and implement much of the activity of the group.

‘Now the members know that if anybody comes along to the group saying, “I’ve overdosed,” or, “I’m going to do this,” then it’s … “Okay we need to stop the group here and we need to get the risk protocol and we need to go through this”’. (S20)

Staff reported that service users have sometimes been able to iron out ambiguities in procedures that staff had failed to spot.

4.1.7.3 Employment of service users

At least four of the pilot services employed people who were explicitly service users. There are boundary issues, and it is generally accepted that one cannot be both a user and provider of a service. This precept is close to the assertion made by managers that they are not there to offer therapy to staff (see Section 4.1.5). A time lapse between use of, and working within, the service may be sufficient to implement the boundary: one service makes the proviso that employment in the service disqualifies the person from being a service user ever again. These provisions must provoke some reflection about the reality of a person’s recovery and their future resilience.
If service-user employment is to become a reality the provision of training appears crucial. Staff report that it has been time-consuming to draw up contracts according to Trust policies. There are some differences in the terms of employment for these service users: for example, they may not be covered for sick leave. In one service, there is commitment that all interested service users can undergo the training offered for these posts so as to ensure equal opportunities, although they will be interviewed in the normal way before recruitment. One service lead suggested that employing a service user may be more difficult for the staff than it is for the service user themselves. One employed service user suggests there are advantages:

‘I class myself as a service user who now has a job, and I don’t actually identify as a client because it’s not appropriate, but I think it gives me a slight advantage in that I know the system and I know how it works and also doesn’t work … I know what it’s like to have a diagnosis, I know the system, and I know what a lot of tosh it is to assume it’s so-called untreatable, and I know professionals’ attitudes …’ (S28)

There is some acknowledged tension between service user-initiated groups and professional-led groups. One group with no staff input has been given permission to use the Trust and PD service logo, but in recommending it to vulnerable service users, the Trust cannot take responsibility for outcomes: ‘Because it’s got the PD network logo on and it’s run by service users I feel uncomfortable’ (S67). Accountability then remains an issue where service users work autonomously.

4.1.7.4 Services for carers
Few of the pilots have so far succeeded in delivering services to carers. While one pilot has managed to set up regular groups which combine psycho-educational and peer support, another had been unsuccessful in its attempt to set up a similarly organised forum. One service lead reported that working with carers was challenging because service users and their carers may have conflicting interests, particularly around the use of existing services. Too often, it was felt, the main demand of carers was that people with PD should use a service that the potential service user did not want.

At the pilot site where a psycho-educational and support group has been set up, staff felt that the term ‘carer’ may not be appropriate in this context. People with PD may provide support and care for others and value the support and care provided to them, but unmet dependency needs in the lives of some people with PD mean that long-term relationships based on receipt of care may be counter-productive. While the term ‘carer’ has been extensively used in the context of physical illnesses and those with psychosis, it was felt that in relation to people with PD, the term ‘friends and relatives’ may be more appropriate.

Staff at several pilots stated that they wanted to develop something for carers, but that this had not been a service priority. However, they felt there was a need for ‘some carer training
on boundaries, how to manage and how to live with someone who’s presenting difficult borderline type stuff or whatever, how to handle self-harm, how to manage …’ (S67).

4.1.8 WORKING WITH OTHER LOCAL SERVICES

4.1.8.1 Means of engagement with local services

Pilot services have engaged with local health, social care and other frontline services in a number of ways. This account deals with some of the common themes arising from these encounters from the perspective of the pilot staff. Pilot services worked with other local services to:

- Promote and publicise their service: through attending team meetings and supplying literature;
- Establish good working relationships: through development of shared protocols (e.g. with crisis services), memoranda of understanding, and harmonising areas of practice such as risk management;
- Provide opportunities for learning about PD: through offering basic awareness, participatory training, more advanced/ accredited training, individual and team supervision, work and training placements and staff secondments;
- Assess people with complex problems in order to determine the nature their problems, develop formulations and treatment plans;
- Co-work cases with existing key workers or take people on for direct service provision.
- Contract out aspects of their work (e.g. to the voluntary sector).

The range of services with which pilots engaged was broad. As well as community mental health teams, some pilots worked with primary care teams, housing and benefit agencies, and organisations as diverse as the police and the Samaritans. Some of these contacts were at the suggestion of service users who had found the service that they received wanting. All of the bids for pilot monies involved consortia or networks of local services. Although all have relationships with local mental health services, at the very least by referral, a minority of the services have utilised resources from other statutory and voluntary-sector agencies, in

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**KEY MESSAGES – user and carer involvement**

High levels of service-user involvement are integral to some service models. Service models using associative methods, such as groups, may find it easier to develop involvement than those delivering one-to-one interventions.

Involving service users in service development is seen as beneficial for the service and potentially therapeutic for service users – as a means of supporting efforts to reduce low self-esteem and increase their sense of agency.

Service users with PD can be responsive, creative and supportive, and may go on to become full employees of care services. However, all levels of involvement require boundaries and safeguards.

Competing demands during the first phase of the development of these services mean that few have implemented systems for working with and supporting friends and family of people with PD.
some cases taking on part-seconded staff. This has exposed some of the limits of joint working. For example, where probation staff have been seconded, the reciprocal sharing of information has been useful in individual cases, and educational in general, but has not overcome the exclusion of mentally disordered offenders from the PD service. It has clearly been difficult for frontline services to share/second staff members, and requests for increased hours have been refused. In other areas where there is a shortage of qualified staff, the new services have recruited voluntary-sector staff, which ultimately reduces choice for service users. Some of the Networks have contracted out aspects of their brief to voluntary-sector partners, but may be planning to renegotiate or revoke such arrangements because the agendas of such agencies do not necessarily support their own strategic development. Several pilot services offer case consultation with staff, away from the patient.

‘There needs to be a space to think about that without the patient being there … It also gives the care coordinators the freedom to talk about how the patient is impacting on them. One of the problems I have identified in supervising staff is they say, “I’ve been really professional, I never show my feelings” … it’s as though they mustn’t have feelings. But we’re saying, you are allowed them, they’re your tools. If you don’t allow yourself to have them, you will act on them in a different way or space.’ (M8)

The management and support of people who self-harm was one area where pilot services thought they did have much to offer other mental health services. Some services were particularly keen to work with inpatient staff, as service users who self-harmed often ended up on wards, to the discomfort of both staff and patients. A challenge here was the inconsistency in ward staffing across shifts and locations.

4.1.8.2 The scope for indirect service provision

The balance of direct and indirect service provision across the pilots was driven by different factors. Many providers referred to their commitment to hard-pressed local statutory services: but the more clients they took into their care, to the relief of local services, the faster they reached the point of full capacity. Some of the pilots were actively engaged in seeking ways they could continue to deliver something of value to statutory providers once this point was reached. Others felt that the delivery of training and consultation to statutory providers was more likely to deliver sustainable benefits to service users than the taking over of direct care. Some pilots were hard-pressed to deliver direct services across a wide catchment: there was little time left to deliver indirect ones. Another service relied heavily on the commitment of its lead clinicians to deliver training initiatives effectively out of hours. Several services engaged designated staff members to promote awareness and deliver training. This latter approach was not entirely successful, as these staff reported difficulty in maintaining credibility with their audiences unless they could demonstrate experience in direct working. Credibility may not be enough without other incentives, such as taking on the management of difficult people.
‘One of the learning points is here: if you see patients (for the staff), the staff will be open to training and liaison, so it’s an opportunity. I tried to train people before, but they weren’t interested: having the patient resource has opened them up.’ (M45)

Pilot services almost all stress the importance of team support and containment in explaining how they work with clients: whether directly stated or not, the comparisons are likely to become clear. One of the pilots was particularly concerned with supporting provider teams to explore their own issues and needs.

‘The culture of CMHTs pushes staff to see a lot of people and move them on quickly: really important to have space for reflection, to “stop and think”. You need to be prepared to work with a person for a long time, and to relax with that.’ (S10)

There was a sense from the majority of pilots that they want to ensure that they offer as many service users and staff as possible some benefit which will at least keep them in contact with the PD service.

‘There are simple things you can do, very low level interventions. You can explain to the staff why they behave as they do, you can tell them about PD. There’s nothing else around here: that’s the horrid bit.’ (M1)

Other strategies may include the offer of additional support if and when a place arises, or if and when the client has overcome a particular hurdle. There is a ‘danger’ that such accommodating services will overstretch themselves.

‘The ambition within the team to deliver different things along with the demands of complex needs and new service and the bureaucracy required by Trust may have led to unsustainable workloads.’ (S6)

Support to individuals and teams by pilot services may have large benefits for individuals, the system and financial savings. In some cases, direct or indirect supervision, or the offer of a place to a client, has enabled people with long experience of confinement on hospital wards to be discharged to community settings, rather than referred on to secure settings. The cost savings in individual cases can be very large. Pilot staff suggested that their ‘indirect’ supervision of service providers had some advantages over direct service provision. It could:

• Contain anxiety of frontline workers in relation to risky service users;
• Raise awareness and confidence in these workers;
• Transfer skills in how to manage people with PD;
• Support people with PD – many of whom had attachment problems – to remain in valued relationships;
• Support the premise that PD sufferers should not be artificially excluded from MH services;
• Provide a more cost-effective and accessible service (than direct provision) in areas of low population density;
• Reduce costs where people with PD are high service-users.

4.1.8.3 Engagement with local Mental Health Trusts
Developing and maintaining support from and collaboration with local mainstream services has been important to the security of pilots and particularly to the managers who have acted as liaison. It was part of the early experience of several pilots to feel disparaged by seniors (from whom general attitudes flowed), and they have worked to find diverse ways to be useful and supportive. Some workers, for example, have wanted to keep their PD clients, so services offer consultation and joint working options as an alternative to taking over client care. Because of the ‘fire-fighting’ ethos of CMHTs, where there is little space for reflection, there have been resentments about the apparent ability of pilots to ‘select’ clients; to refuse to take on CPA roles or other statutory responsibilities, and to spend time deliberating and reflecting.

‘A new service being developed for people with personality disorder is enormously provocative to mainstream services, you know. You can say, “This group of people have been marginalised and they’ve not been provided with the services that they should have had,” all you like but you mustn’t forget the impact that they (clients) have on those mainstream services.’ (M19)

‘In the beginning, the neighbouring Trusts viewed us with hostility and envy: I was fighting for boundaries, money, services; some people saw their own images as compromised. It was a very vulnerable time for me, for the unit …That was a big, big problem at the beginning. After a year, I have come back into the circle, and all this has changed. But all this has made me a stronger, wiser politician: people respond better to you when you are stronger.’ (M45)

The reduction in workloads when Trust patients engage with a PD service may be delayed. One member of staff was told by a referrer,

‘you know I hated you for distressing my client who has been hard work for the last eight years … but then all of a sudden I’ve been able to reduce (contact) to six weeks.’ (S50)

One service referred to particular difficulties in the reorganisation of its host Trust: having ‘convinced’ one set of managers about the viability, usefulness and risk management of the service, they were all replaced and the task began again.
In most cases service leads told us that relationships with host Trusts have improved over the life of the pilots as mutual understanding has developed.

‘We need to fit in with the Trust clinical governance and the risk management processes, and that is what we will do, but … it’s a two-way process, we need to help educate the trust and the clinical governance processes about why the service is different, and why it needs to be different, and why we’re being creative, and perhaps a different way of approaching things.’ (M59)

Key areas identified as contrasting with traditional Trust practice have been the different models of risk management (particularly in relation to self-harming), and the emphasis placed on valuing and trusting users to design and deliver therapeutic services.

4.1.8.4 Other issues
Promoting the new service with the right balance of expertise and uncertainty or humility has been challenging. It was difficult to promote the setting up of a specialist service without implying that existing services had somehow failed this client group.

‘It is important to not locate ‘blame’ in either the patient or the worker’ (who may naturally feel her/himself to be the brunt of criticism). (S30)
‘And it’s a double-edged sword: they want to refer to you, but success is resented: you have to work with that.’ (M19)

Managing the expectations of staff in local mainstream services has also been difficult. Some mental health services had hoped that the pilot service would take on their existing clients. Several pilots targeted those not engaged in services, including one that only took self-referrals: local CMHTs didn’t necessarily understand or sympathise with this emphasis, as they have not experienced a reduction in their workload resulting from the advent of the new PD services.

There is some disquiet among local services, reported by pilot staff, about the failure of services to take the most risky clients, particularly if risk is felt to be to other people. This is an issue closely related to the paucity of services for people with violent and/or offending services in the community, and so disappointment expressed by local stakeholders cannot fairly be seen as the responsibility of pilots, and may reflect the disproportionate emphasis in mainstream services on people with antisocial PD. Another criticism from mainstream services was that some pilot services were not taking clients with other mental health problems.
4.1.9 ISSUES IN SETTING UP AND RUNNING NEW SERVICES

Many of the factors that service providers discussed when describing their experiences of organising and delivering these services were not about personality disorder per se, but about the challenges of setting up a new service and the impact that 'pilot' status and funding arrangements had on the way that the service was managed. Some have been referred to in previous sections, others are described below.

4.1.9.1 Pace of development and expectations of the service

Several pilots were unable to get up and running as quickly as had been hoped. The slow start affected recruitment of suitable staff and staff morale, and created slippage in the budget. The way that the pilots were funded meant that they had to recoup money from the host organisation. In some instances this created uncertainty about the time and resources that were available. This in turn impinged on the ability to plan recruitment of staff and the management of other resources.

Some staff reported that time schedules for setting up services were optimistic and in some instances may have been unrealistic. This was especially true in those pilots where the amount of management time available in the first year was limited. Some staff told us that setting up, steering and supervision of innovative services with challenging clientele needed more management time than was available. Some pilots had a part-time service lead who had responsibilities for other services. Setting up the pilot service very often put a huge burden on lead people. This was especially true of those pilots that had set out to provide a range of different services and made commitments to support and train staff at other services.

“We were lucky, we were a tiny little team and we had a very clear plan of action and we just implemented it … We didn’t say we’d do more than what I thought we could do with
£300,000. I think if you have £1 million, then you have to agree to do everything under the sun.' (M32)

These challenges were compounded in pilots that had to develop services over a wide geographical area. Replicating services at a number of different sites was inevitably time consuming and needed more complicated systems for managing services and supervising staff. In one instance staff reported that this led to problems around ownership, with unequal participation in further development of the service.

Service leads told us that uncertainties about long term funding made it more difficult to manage the service. Pilots were told that they would be funded centrally for their first two years after which recurrent funding would need to be negotiated with local Primary Care Trusts. This meant that managers did not know how long the service would be funded for. Almost all pilot services found this difficult, not least because most were committed to a service model that anticipated long-term contact with patients. Most services were also committed to being open with clients about what they could expect, not least because many had experiences of being let down by services in the past. However, talking to service users about uncertainty over future funding and the possibility that services might be closed, created anxieties and was not necessarily therapeutic.

4.1.9.2 Finding suitable premises

Some service managers were concerned that if pilot services were based on an established hospital or CMHT sites users would associate them with unsatisfactory or traumatic experiences of previous contact with services. For instance the premises offered to one of the pilot services were located between a children’s dentistry service and the ECT suite. Independent settings were generally preferred as it was felt they would facilitate engagement and would be less stigmatising. However, such premises were often not available, and some had to spend a large amount of time identifying suitable premises. The potentially temporary status of the pilots also led some to difficulty in competing for appropriate sites. The use of voluntary sector or community venues raised issues for staff travel and security. One pilot, determined to establish a base away from mental health services, had a long battle to get planning permission in a residential area. Those that were situated in existing mental health units sometimes faced the challenge of how to mark out separate territories.

4.1.9.3 Staffing and staff training

Almost all of the pilots reported difficulties in sustaining staff morale and confidence during the set-up period, and this period was in many cases much longer than had been anticipated. Team building was necessary to raise morale and promote mutual support. Staff training was a huge task in the first year of most pilot services, and especially in those whose founders were developing an innovative way of working. Many services employed diverse people for their personal qualities, so there was no shared value system.
‘I thought I could delegate at the beginning, but I couldn’t … you couldn’t ask them to take too much responsibility: even to learn new things really … And the constraints we have on time – the huge constraints from DoH – we don’t have time to debate, or to have our own problems, except for some discussion in the team.’ (M45)

4.1.9.4 Establishing new ways of working within a limited timeframe.

Pilot services that focused on providing group-based interventions and were not based on the expansion of an existing service struggled in the first few months to build up a large enough cohort of service users to support the development of a group culture that could sustain this way of working. This was especially true of therapeutic communities. Service leads told us that TCs take time to ‘mature’, especially when there is no ‘neighbour’ from whom to import the culture. Policies can be imported, but must be tested and agreed to. Such services do not function well as a TC until there are sufficient numbers of people to generate interaction and peer support.

‘They had that very powerful experience of authority being misused and their first experience of the therapeutic community is of the staff being warders, or screws, who were out to get them, when in fact the staff are bending over to help them. That has to be worked through.’ (M38)

With previous negative experience of services, and difficulty in forming trusting relationships, pilot staff felt they had to win clients over, and offer a level of consistency which was at times wearing. On the other hand, it was reported that having the capacity to innovate, to experiment, to try things, rather than be tied to ways of doing, or strategic ‘must haves’, has been a real benefit for pilot services, although at times they have had to fight their way through established clinical governance arrangements. Flexibility has been a key value of pilot services. Working in new ways was challenging, and staff felt uncertain. Several staff admitted there were times when they did not know what to do, but many felt that their own practice, and the model for the service, stood to develop most when ‘something comes up and you don’t know what to do’ (M38).

‘The greatest revelation for me is that I don’t have to have all the answers myself, or go and find them: but yet they can be found. Not necessarily that day or hour: but something will come up. We learn through the difficult times … And it’s been terribly important to change our minds about things … There’s always the pull to do more: but in this kind of work, it’s better to think more.’ (M19)

4.1.9.5 Evaluation and inspection

From the outset, each pilot was required to evaluate the service they provided. Some services involved external groups and devised formal methods for collecting qualitative and
quantitative data. In addition to this the Department of Health conducted regular reviews which involved meetings with service personnel and organised site visits by service-user commissioners. These reviews, together with visits by researchers from the team involved in the project reported here, meant that pilot services were involved in multiple evaluations and inspections. Service leads at pilot sites reported that these placed additional burdens on them and some told us that they felt they were being over-evaluated.

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<tr>
<th>KEY MESSAGES – setting up new services</th>
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<tr>
<td>Many of the challenges faced by staff in these services were generic and reflected the demands of setting up a new service. Others reflected the ‘pilot’ status of services which involved a complex funding process and involvement in a variety of research and evaluation processes.</td>
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<td>Other challenges were particularly pertinent to personality disorder services. Because there are no established ways of working, clients needed certainty and consistency and perhaps a long period of attachment, and interventions that involved groups and peer-support needed time to develop.</td>
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4.2 Referrers and commissioners

4.2.1 Referrers
At least two referrers from each pilot service were interviewed (see Table 3.2), except for the service user network, which only accepted self-referrals. Where there were different arms to the pilot, attempts were made to interview at least one referrer for each arm. The survey sample achieved range and diversity in terms of the referrers’ professions (CPNs, social workers, psychiatrists, psychologists, GPs) and team affiliations (CMHTs, crisis resolution and home-treatment teams, a day hospital, a drug and alcohol team, primary care liaison team, a probation service and a non-statutory sector community services team for people with complex needs).

4.2.1.1 Referring service users into the PD services
Respondents had referred between 2 and 30 service users to the services (mean = 7). Two people interviewed were service managers who had not referred people directly, but had managed a number of people who had. One respondent working in probation had not made any referrals. Reasons cited for low referral rates were lack of awareness, uncertainty about the new service and differences in service culture.
Referrers linked with six services mentioned that they would have referred more people, but that service users were either not ready for that level of service, or did not want to be referred. Referrers told us that some people with PD were too chaotic to decide whether or not they could use the service and others felt anxious about what this would entail. One referrer mentioned that they screened people before referring, as they had had previous experience of people ‘not being (of) sufficient priority’ (R22). Another talked about the same service, saying she had experienced a number of rejections of referrals before assessment. On the
other hand another, referrer mentioned being pleasantly surprised at the range of people that were taken on (e.g. people with alcohol and drug problems).

A primary objective for referring service users into the pilot services was that referrers perceived that existing mental health services were often not equipped to help people with PD. They felt that the PD services could provide the containment, specialist skills, time, intensity of service and approach that mainstream mental health services were unable to deliver. Those referring into the young persons’ service valued the fact that these service users would avoid entering mainstream secondary mental health services. For the vocational support service, referrers talked of wanting to help people feel more socially included through accessing work and education. Referrers to two services talked about trying to reduce unhelpful use of services for the service user, such as admission to mental health units or A&E visits.

Most referrers had a good understanding of what the services were trying to achieve, whether that was in terms of outcomes, such as reduced distress, or unhelpful service use, or in terms of the service model. Several mentioned the value of having written material about the service, or having had presentations from the service, in increasing their understanding.

The majority of referrers were fairly happy with the inclusion and exclusion criteria the services used. Where frustrations were voiced they related to the exclusion of service users who were too chaotic, not able to work psychologically or who presented with drug and alcohol problems or ASPD and offending behaviour. Referrers told us that, rather than being excluded on the basis of formal criteria, many of those who were too chaotic to make use of services were effectively excluded because they were unable to make the commitment required to engage in treatment. Although this was a frustration for referrers, they appreciated that if such people were taken on this could have a negative impact on the service received by existing service users. Several referrers expressed concerns that if a person with problems related to PD was not taken on by the pilot service there were no other options for them. One referrer described a negative experience in which a person they referred (to a day TC) was subsequently excluded from the service for behavioural problems and not allowed to rejoin:

‘So we had this community meeting and there was kind of my client and myself, it felt a little bit like we were in a courtroom, um, well the inevitable happened obviously the community who know … some of them didn’t even know her, but obviously some who knew her kind of said well we don’t want her back her because her behaviours are more challenging than we can cope with.’ (R21)

### 4.2.1.2 Referrer’s views of assessment and treatment

One of the strongest themes that arose when discussing the experience of assessment and treatment was the importance of good communication from the PD pilot services. Referrers relating to seven services talked positively about the extent, frequency and quality of
feedback and general communication about assessment and treatment. Referrers to two services talked about a problem of poor communication, and one in particular highlighted the problems in terms of risk and containment that can arise when communication fails.

‘Then when they’ve taken them on we don’t always hear about really important things that are going on for that person … that can be a worry because it can be about self-harm, or really important life events coming up, and so on, and of course these patients take great delight in exposing your ignorance. So it can be really undermining to find that one half of the service knows something that the other half don’t.’ (R11)

The majority of referrers made reference to the assessment as an important part of the process, and some stated that having an assessment was one of the reasons for referring someone to the service. Referrers linked to two services made specific comment of how much they valued the provision of a comprehensive assessment, even if the service user was not taken on. Benefits included helping the referrer to develop their own management plan or to better understand the service user’s problems and building confidence and trust for the service user. The nature of assessment varied widely between services, and this was reflected by the referrers, one stating that the assessment from the non-statutory service was a holistic, non-psychiatric assessment. Referrers for three services mentioned that the time taken to conduct an assessment was too long. In the case of a crisis-resolution team this was a particular issue as their timeframes for referring service users on was very tight.

‘We have a problem getting referrals assessed by them. It's the speed, because… our timing is crucial to make sure that we've got a throughput because it's very quick turnover.’ (R15)

Some made particular mention of the skills of the service and their way of working. This ranged from valuing the effectiveness of engaging with service users and validating their experiences, trusting the service to be able to cope with challenging problems, through to commenting on the importance of combining group and individual therapy. More negative experiences of the process included one example where the referrer felt the service had promised their service user a number of aspects of a service which were then taken away. Another felt that the service was perhaps pushing service users too quickly to give up certain coping mechanisms and supports, such as medication and contact with their existing team.

4.2.1.3 Perspective on working with the PD Services

Referrers for ten of the services had carried out some degree of joint working with their local service, ranging from formal CPA meetings to staying in close contact less formally. Of those that had not undertaken joint working, the reasons cited included concerns about ‘splitting’ when more than one team was involved, limited time to continue to work with service users once referred, and the timescale of work (in the case of crisis-team members). Where there
was joint working this was mostly seen as successful, though complex and challenging to get right. Good communication, having a clear and respectful idea of what each party’s responsibility was, having clear boundaries, transparency of working, having a joint care plan, sharing a therapeutic framework and geographical proximity were mentioned as important in managing risk and avoiding splitting of teams. Several referrers had had more difficult experiences with joint working. One, from a home treatment team, found they were working jointly due to crises rather than in a planned way. She felt this was due to the service working in office hours only and not being obliged to hold as much risk. Issues also arose around decisions about which team would retain care coordination where PD services took this on. Another referrer mentioned the problem of the PD service wanting the referring team to retain care coordination when the service user was no longer engaged with the CMHT. In another area the PD service ‘insisted’ (R24) on taking on care coordination and the referrer reported that the service user reacted very badly. The situation was reviewed and she was allowed to keep her care coordinator in the CMHT. Referrers relating to six services felt there was a significant reduction in workload both for them and for other services such as A&E and inpatient services. This was especially felt to be true when care coordination was taken over and the actual caseload was reduced. Even when the numbers of service users was small, the impact could still be significant if the individuals referred required intensive input and had complex case-management needs. Referrers to two services felt that their workloads had increased, though this was thought to be in a productive way. One was providing more psychological therapies to service users, which he felt was a result of the PD service raising awareness of what to expect. Another was of a voluntary-sector service who were receiving more referrals since the opening of the service of people who were not yet ready for the PD service. They felt, however, that as they now had somewhere to refer for longer-term support, throughput was greater and so it was worthwhile. One, however, felt that their crisis team had to manage the difficult cases that the PD service couldn’t contain. All the referrers who commented on the potential impact of the closure of their local PD services felt strongly that it would be a great loss to them and local service users. Some felt that closure would be a waste of the effort taken in setting services up, would exacerbate loss and rejection issues for service users and reinforce their historical exclusion from services.

4.2.1.4 Indirect service provision

Referrers linked to six services had directly received training or supervision from the local PD service. All spoke very positively about their experiences and described gains such as greater understanding of PD, developing skills in validation, being more aware of emotions that could be provoked by working with these service users, and providing better focus for their work with people with PD.
‘It gave me that sort of added permission to back off a bit. I felt I was getting in knee deep with this client and I realised that it was doing her more harm than good by doing that.’ (R6)

With the exception of the consultant psychiatrists we interviewed, all those who had not received training expressed an interest in doing so. One referrer felt that training worked well, but that ongoing consultation was too demanding of her time, and was not effective on an ad hoc basis. One referrer who had been very positive about supervision did think that while she benefited from increasing her learning, the service users may be better served by seeing the specialist directly rather than her under supervision. Others talked about the benefits of more generic awareness raising such as leaflets and presenting to teams. One felt that these activities were vital in getting support from local teams. One referrer felt that PD services should have a stronger role in raising awareness and reducing stigma more systematically.

4.2.1.5 Outcomes
Referrers for eight of the services spoke about the importance of outcomes. The main outcomes which people spoke of were reductions in use of other services such as Emergency Departments, inpatient beds and outpatient appointments. Two mentioned the cost-effectiveness of achieving these outcomes. Others spoke of the importance of social inclusion either as developed by social networks encouraged by the service (e.g. in a community) or through direct vocational support provided. Some mentioned specific psychological changes which were important outcomes such as ‘learning the capacity for feeling’ (R14), ‘sense of understanding themselves and being able to be who they are’ (R9). Outcomes that were perhaps less easily measurable, but felt to be highly important, were service-user satisfaction, quality of life and long-term hope.
Several spoke of the importance of thinking in the long-term about outcomes: the chronic nature of the problems of this group of service users suggested that two or more years in therapy might be needed to achieve significant change. They were aware therefore that changes may not yet be evident in people that they had referred. Referrers also spoke of the need to look at how people were functioning after leaving the service as this may be the test of success.

4.2.1.6 Capacity, coverage and staffing
Of the 12 referrers who mentioned waiting times, five were very pleased with the speed of response, particularly in comparison to waiting times for psychological services. Six felt disappointed by waiting times and limited capacity, and some expressed the specific difficulty of raised expectations when a service became available, only to have it closed off to them as it reached capacity. However, one referrer felt that, had there been a longer waiting list, some of the people he referred may have had time to be more ready for the therapeutic community that they were entering, with better engagement and outcomes as a consequence. Several referrers described gaps in the services delivered by the pilots. Most of these were specific to the local service but more general issues included;
• Where there was no preparatory groups the transition from mainstream mental health to an intensive service was often thought to be too challenging.
• Gaps remained for particular sub-groups which services would not work with and who were left to ‘bounce around the system’. (Notable among these were the chaotic, those not ‘psychologically minded’ and those with antisocial PD or offending histories.)
• Referrers for two services felt that service coverage was inequitable and patchy: one in terms of meeting the needs of the town only and not the surrounding areas; the other because coverage was not uniform across the catchment.
• One referrer felt that the siting of the service within a general acute hospital was not appropriate and was off-putting for service users.
• Several referrers suggested desirable developments for the services, such as expanding into antisocial PD and anger management in one case, and practical workshops for another. One felt that the proposal for one service to expand into working with offenders should be viewed with caution and carefully assessed in a research context.

4.2.1.7 Staff at pilot services
Referrers for four of the services mentioned the importance of the individual qualities of the pilot staff members: attitudes of respect, service users liking them, flexibility and willingness to try new things as well as skill, knowledge and calibre were commented upon. Referrers for two services mentioned the importance of support for these staff to avoid burn-out and the need to value and nurture those who were enthusiastic about working in this challenging area. Problems were mentioned with sickness and staff absences, or the effects of staff leaving, in respect of three services. One referrer in particular talked of the negative impact this had in terms of consistency for the service user.

‘Continuity of care gets lost particularly if there’s no recognition that if patients … get ill somebody needs to deal with that patient, not just cancel the appointment, and I feel very uncomfortable when that happens’ (R11)

Several pilot services employ a mix of professionally trained and non-professionally trained staff. The skill mix was something that was picked up by referrers, most of whom felt this was appropriate. Referrers for a small number of services, however, reported concerns with the employment of non-professionally trained staff. One told us that they felt that such staff might be challenged beyond their capacity.

‘Non-professionally trained people trying to carry caseloads that they aren’t experienced or qualified to do and don’t have the support networks to manage these really challenging people. I mean there’s not a huge number of the really challenging people, but when they do (need help) they’re very difficult’ (R15).
This referrer also mentioned problems of the (non-statutory) service being too anti medical-model. Another felt that the low numbers of experienced and trained staff was a problem early in the pilot, referring to a particular service user that they were not experienced enough to work with who nearly ‘sank’ (R9) the service. Several mentioned that there had been significant changes, and lessons learned over the time that the pilot had been up and running. While referrers felt that most jobs in mental health and social care were demanding they told us that demands on staff working with this group of service users were particularly high.

**4.2.1.8 Funding and intensity of the service due to pilot funding**

Six referrers made mention of the nature of funding for the services. Three of these referred to the intensity of service that pilot funding meant they could deliver. They questioned whether this could be sustained once pilot funding ended and one told us that they felt that these special funding arrangements could provoke envy amongst other services.

> ‘People might be anxious that if they support (the service) their own jobs may be under threat in some way. Sense that perhaps a service is too luxurious or attitudes haven’t particularly changed towards people with PD - that services are not necessary.’ (R8)

Others admired resilience in the face of uncertain funding and would like to see more funding provided.

**4.2.1.9 Dedicated versus mainstream services**

A strong theme that came through from most of the referrers interviewed was that CMHTs were not generally well equipped to help these service users. Some told us that their CMHTs excluded people with PD and that the dedicated services had a far more helpful approach. Some referrers felt that the psychiatric approach was unhelpful as it reinforced the idea for service users that they could only receive more help when they were in crisis; that it did not deal well with management of behaviours and emotions for this group and that medication was not helpful. Several stated more strongly that they thought CMHT care was actively damaging for and discriminating towards this group.

> ‘In my experience, mental health services can be quite prejudiced towards people with a diagnosis of personality disorder. Quite damaging often. Because CMHTs are so stretched, people seem to get quite inconsistent services, frequent changes of workers etc. Also get treated quite badly really …. Some workers in my experience really dislike and talk malevolently about people with PD’ (R4)

Those who suggested reasons felt that the less positive experiences in CMHTs may be due to a lack of awareness about and skills in managing PD. Others talked of a risk-averse culture which led to fear of some of the behaviours associated with PD such as self-harm or aggressive behaviour. A third point was that CMHTs prioritised, and were designed for,
working with people with Severe Mental Illness such as schizophrenia and bipolar disorder, rather than for working with people with PD.

Dedicated services were seen to be able to offer a respectful and validating environment that was skilled in working with these particular problems and tailored to service users’ needs. PD services were perceived to provide better containment for these service users, a greater degree of consistency, a team approach and the ability to work in a group.

One referrer from the voluntary sector felt that having a dedicated service gave the message that CMHTs and outpatient services did not need to work with this service user group and allowed them to let go of their responsibility. Primary care referrers talked about the value of maintaining care (with skilled support) in primary care and the voluntary sector where possible.

**KEY MESSAGES – from interviews with referrers**

- Regular, comprehensive feedback at each stage of the referral process and clear communication from PD services are important
- Flexible entry criteria and a flexible approach to assessment and helping people engage in the service are considered valuable
- Referrers value PD services, would feel the impact of closure were this to happen and were concerned about the potential impact on service users
- When working jointly, communication, coordination and transparency are required to keep service users safe
- Training and supervision are important in developing the practice of local staff and helping them to feel more confident in working with service users at risk (but finding time to participate can be challenged in hard-pressed CMHTs)
- Dedicated services need to pay particular attention to the personal qualities of staff that the recruit, in order to ensure that they are able to work effectively with people with PD

**4.2.2 COMMISSIONERS**

Commissioners for each pilot service were approached for interview but those linked to two pilot services were not available. Two commissioners were interviewed in the case of two of the pilots because these services covered more than one PCT area (see table 3.2). The commissioners had a range of roles but the majority were responsible for commissioning mental health services.

**4.2.2.1 Initiation of the service**

Eight of the 13 commissioners had had direct involvement in the bid to establish the pilot services. For those that had not, it was common for their predecessor to have been involved. Being involved in the process from the beginning seemed to help give commissioners a sense of enthusiasm, pride and investment in the pilot.

Commissioners outlined a variety of drivers for initiating the service. Demand mostly came from existing services in the area, or from a recognition of unmet need for people with PD.

Commissioners from two services mentioned a formal needs analysis done by commissioners
and local clinicians, one looking at the high use of inpatient beds by PD service users. Another mentioned the gap in services at a multi-agency level. One commissioner spoke of developing the PD service as part of a wider review of services for people with PD including a non-pilot funded day hospital. Several mentioned that service users had been important in the development of plans for the service, by voicing concerns about existing services which they felt did not meet their needs. One was open about the fact that it was quite an opportunistic development in light of the available funding. He also stated that guidance from the National Institute for Mental Health had acted as a driver.

4.2.2.2 Interaction, impact and outcomes:

From a commissioning perspective, having a demonstrable, measurable impact on other services was an important priority. Several mentioned this as a key factor in decision-making around the ongoing funding of a service. The sort of impact that commissioners were primarily interested in was reduction in high use of services such as A&E and inpatient bed days. Several mentioned saving money on out-of-area placements to residential facilities for PD service users. These put figures on each out-of-area placement at £150,000 to £200,000 per service user per year, and mentioned having saved around three per year. They emphasised that this meant that only a small number avoided could have a big cost impact.

Commissioners linked to four services felt the service had paid for itself, in one case, at least 4 or 5 times over (C1, C3, C8, C10). Others felt less able to demonstrate this at the moment, and several were asking the services for more data on cost-savings. Several talked about the importance of less easily measurable outcomes, such as user satisfaction, reduced self-harm, increased engagement with services, reduced chaoticness, fewer people losing jobs and greater social inclusion for service users.

One mentioned the difficulty of not necessarily being able to recoup cost savings. For example a reduction in visits to Emergency Departments was not necessarily money that could be recovered. She mentioned more tangible cost savings such as reduction in medication use or reduction in bed days as possibly being an area where costs could be actively avoided. Another went on to say that the service needed to show not just cost-effectiveness, but cost-effectiveness in relation to an alternative. For example would extra support for CMHTs have the same impact but for less investment? For some service models, including a preventative service, and a service giving indirect consultation and support to other providers, commissioners felt that cost savings could not yet be proven. One talked about an increased load on the crisis team as a result of the service being in place. This was felt to be because service users had greater awareness of what was available and did not feel excluded from services.

Commissioners also talked about the reduction in use of non-health agencies, such as police, probation, housing or benefits as an important impact of the services. Whilst they saw this as important, it was often hard for them to measure (as it was out of their remit) and any cost savings would not be seen by health budgets. This led several to talk about the importance of considering these services and their impact at a multi-agency level. They felt that someone
with PD would have problems that impacted on all areas of their life; therefore the solution should also involve all agencies. Some went on to say that, as the impact would be felt by other agencies (some felt more so than in health), that they should be encouraged to jointly fund and commission the PD services in the future.

4.2.2.3 Training and consultation

Around half of the commissioners talked about the importance of the indirect service provision that the services carried out. This ranged from raising awareness of the service with other teams, to raising the profile of PD within other services. Others talked about direct training, which helped to change the way others worked:

‘(Helping) others to see that the needs of people with PD can be met and not just, if you like, ‘oh well they have got PD and therefore that’s the excuse for not doing anything’ or, ‘they are challenging the way in which we have always provided it, why should we change just to meet their needs’, so a lot of the negative stereotyping that has grown up in some places, almost part of a culture’ (C7)

Another talked about the limitations of the consultation model. He felt that some of the clinicians were reluctant to take this approach:

‘They react to that like ‘someone’s looking over our shoulder but we still have to do the work’, so some clinicians are not overly enthralled by that approach’ (C2)

He did feel though that attitudes would be more positive in time when the impact of consultation became apparent. Some commissioners felt that indirect service provision aimed at raising awareness and skills in other services working with people with PD was an important part of the work of dedicated services. They told us that this was highly valued by other agencies involved with service users (e.g. police, probation, housing, ED, voluntary sector). Two commissioners told us that indirect work was not yet in place. One said that the service themselves thought they were engaging with local services, but the commissioners felt they were not. Another said that the service had struggled to establish its core work, and so had not yet managed to do work with other services, but that this may develop in time.

4.2.2.4 Local context

Several of the commissioners talked of the importance of integration of the PD service with other local services, but that this was currently compromised by their pilot status.

‘Ensuring that they’re well integrated into the services, because that’s the problem we have, when you set up new services, they always see themselves as unique, and yes, they may have some unique expertise but they have to be integrated into whatever we’ve already within the system, because they can’t sit on their own, they can’t sit away from the rest of it’ (C4)
Others talked about this more specifically in terms of having a coherent care pathway for service users and planning PD services in a coordinated way across the local area. One of the pilot commissioners was in the process of reviewing all the PD provision in the area to ensure smooth transition and reduced duplication. Others reinforced the concept of awareness raising and ‘marketing’ (C8) the service adequately with local services to ensure good links. One said that this had been a shortcoming of their particular service as they had not had capacity to do this whilst setting up the service. Some discussed the challenges of this, with the different way of working of the PD service compared to traditional psychiatric models being a barrier for some local teams.

4.2.2.5 Dedicated services versus mainstream services
Most of the commissioners talked about how much better the PD services were at being able to support service users compared with mainstream mental health and social care services. Examples of how these needs were better met were having a network of support, using innovative approaches and group work, and reducing the feeling of abandonment at the end of a service in the case of a user network. One commissioner described the change for service users of moving into a dedicated service:

‘They don’t necessarily always get much of a solution for them, whether that’s housing or CMHTs or school system. They generally fail them because they try and approach it from a mono discipline way. What actually they don’t understand is that dealing with people in a different way, perhaps less confrontational, perhaps more group based work, challenging but in a more structured way, does have a better effect.’ (C3)

4.2.2.6 Organisation and delivery of services
Most commissioners talked very positively about the specific model that was in place locally. In particular their comments were often around how well suited the model was to the local situation (e.g. hub and spoke supporting wider areas, peer support to supplement clinical contact, consultation work for where the critical mass was too small to warrant direct specialist work). Many thought that their local service model was one that could be applied to other areas, both geographically and across other areas of mental health (e.g. peer support network). One area had had specific enquiries from other trusts as to how they could develop a similar model.

Five of the commissioners felt that service user involvement was one of the weaker areas of the service. Reasons suggested were in some cases that there was not an existing body of service users as they had often not had the services before. Others however felt that this was a key part of the work, for example service users developing their roles within the service, increasing their levels of responsibility. One talked about teething problems, such as conflicts of interest for service users, and issues around payment of those in responsible roles. As
mentioned above, the degree of service user involvement supported did not always match apparent interest from the service user population.

Those commissioners that talked about staff members talked very positively. Several talked about the service leads as being enormously instrumental figures in setting up and maintaining the services. Several talked about the importance of having a significant amount of time to develop a strong foundation in terms of recruiting and training staff and developing links with the local services. Others mentioned challenges in recruiting the right staff.

‘I suppose a certain sort of naivety in terms of thinking that we could go out and recruit the right people with the right skills sets…needed to be a robust in-house training and support package available for staff, and we have now got that, but as I say, it took a while for the penny to drop but you know, the people with this sort of skills, knowledge and experience aren’t two a penny.’ (C7)

Several commissioners mentioned that the intensity of service provision had had an impact on the capacity of the service: a less comprehensive service could have been delivered to more people. Conversely one felt that their service was still building up to reach their capacity (they were not currently meeting targets of numbers of service users seen) and that low numbers of staff to begin with had been a contributory issue.

4.2.2.7 Funding

The majority of the commissioners felt that securing funding for the services would be a significant challenge. Most said that when funding was no longer ring-fenced it would be enormously difficult to keep the money away from other priorities such as acute services. Many felt that even if the service was successful, it would be hard to argue for it against other pressures on baseline funding for PCTs. Several referred to the specific financial crisis that PCTs were currently in as a reason for this, and said that the situation had significantly changed since the initiation of the service. Other issues in prioritising funding were PD ‘not being a target’ (C9) and not being part of the National Service Framework. (Note: While services for people with PD were not included in the original NSF for Mental Health, Special Health Authorities have been required to report on services for people with PD during the last two NSF reviews.) Several mentioned future restructuring with regard to potentially decreasing funding to tier 4 services and increasing lower tiers due to the change in funding mechanisms from cost price funding to cost per case. Several commissioners had already had confirmation of the money being devolved on a regular basis, but still stressed the importance of securing the money for the PD service within the PCT. Again they emphasised the importance of demonstrable cost savings in supporting the ongoing funding of the services. Almost all of the commissioners told us that they thought it would be a great setback if the PD service did not continue. One commissioner felt that the impact would be less great:
‘There would be what 12 clients 3 times a year, what 36, a year that wouldn’t be seen. Which compared to the number of acute medical MH admissions we have that is quite a small number’ (C9)

4.2.2.8 Sustainability and development

Many of the commissioners talked about developments in the service being a key part of their sustainability. They felt there was a need to continue moving forward in order to demonstrate that they were increasingly meeting needs of the local area. For some this was expanding geographically to cover new areas that had been taken on by the trust. For others this was in terms of creating stronger links with other agencies. Some specifically mentioned greater links with primary care as a priority as it was felt that GPs often had difficulty working with people with PD. One mentioned the planned recruitment of a liaison worker for A&E. Others talked about working more in prisons (in-reach work) or with police and the CJS. Other potential developments were extending the type of service users that they worked with to cover forensic or antisocial PD populations. Others were keen to expand to work in different tiers (for example where there was a tier 3/4 service, to develop more at the tier 2 level). One commissioner discussed the risk to sustainability of the service seeming to depend on the clinical leadership of a specific individual. Several had discussed the drive of individual leaders as being key to the service’s success, but also saw this as a risk for the future if they left. A solution was thought to be to develop a critical mass of leaders (e.g. more than one lead) to keep moving forward.

4.2.2.9 Critical success factors of the service

Several of the commissioners felt that there were key factors for successful services. These included:

- A clearly thought out design for the local service model
- Clear service aims and objectives aimed at addressing local requirements
- Senior clinical engagement in the other local services
- Focus on appointing the right staff and training them effectively
- Demonstration of impact on other mental health services

**KEY MESSAGES from interviews with commissioners**

Demonstrating a measurable impact on other services is key to sustainability of PD services

Services need to secure ring-fenced funding to guarantee their future

Integration with the local health system and close working with other agencies necessary if dedicated PD services are to be sustained.

The service model should be designed to fit the local situation both geographically and in availability of resources

Time should be taken to build a foundation in a PD service for staff recruitment, training and integration with local services
4.3 Service users and carers
This section covers the main themes that arose from the qualitative interviews and focus groups with service users and carers in the general order of the interview process, from the ‘coming in’ process through to outcomes and suggestions for improvement. It is not our intention here to identify the individual sites, but rather to identify the significant themes that emerged from service users and carers at all of the sites.

4.3.1 The ‘coming in’ process
The ‘coming in’ process involved a number of possible stages: finding out about a service, expectations, assessment and early impressions before starting to attend the service. Obviously, the significance and experience of each of these stages varied across the different sites, with some presenting more challenging assessment procedures than others, for example.

4.3.1.1 Desperation and hope
One of the complications for many of the service users approaching any one of these new services was that they were influenced by their previous experiences; many described being rejected, dismissed or treated badly within mainstream mental health services. One of the main reasons they gave for this was the personality disorder diagnosis and/or the complex needs or difficult behaviours associated with the diagnosis.

As a result of these experiences, many service users talked of their desperation for help and a willingness to try anything. They did not feel as if they had any choice about using the service; a significant minority referred to the pilot PD service as a last chance or ‘last resort’, or told us it was ‘this or nothing’.

'It was a case of (this service) or jack shit. There is nothing else available. I don’t come under the system for mental illness. I don’t have a mental illness'. (SU44)

'I was just kind of used to being passed from pillar to post.' (SU33)

This desperation and lack of hope was expressed by many service users whom we interviewed across nearly all of the sites. It clearly influenced their expectations of the pilot sites. Some people were relieved and grateful to be offered anything:

'I’m still at the stage where if anyone offers me a service I’m just really grateful, so I’m not really going to criticise what it is.' (SU55)

A related issue here is the identification of the service as being a specialist service for people with a diagnosis of personality disorder. Obviously this does not apply to those services that avoided the use of the diagnosis, but for some people this identification of the service meant a great deal, as it implied that the service was designed and intended for them. In contrast to the above-mentioned lack of hope, it raised positive expectations and hope for many people, partly because they had experienced rejection from other services but also because it implied
specialist skills and knowledge on the part of the staff. In addition, it meant meeting other people with similar problems and potentially shared experiences, which links to the powerful theme of peer support (explored in Section 4.3.4).

‘I also kind of felt that at last there is someone, somewhere that may possibly be able to help with something, whereas before there was no one and nowhere helping with nothing …’ (SU22)

Equally, some service users felt very anxious and fearful about further rejection, and the possibility that they would have nothing to fall back on. Indeed, some said that other services had been withdrawn from them on entering the pilot service, which was a further source of anxiety should they find subsequently that the service was not right for them. Ex-service users in a couple of sites said that this had indeed happened: they had no support to fall back on when they left the service.

4.3.1.2 Information

At the time of the interviews, some of the services may not have finalised the information and publicity they were circulating to local professionals and/or to potential service users. There were mixed views and experiences of the information people were given. In one or two sites, people were simply told by a local professional that it was a new service for people with a personality disorder or with complex needs. This was sometimes enough, but many people would have liked written information to take away and read.

‘I would have quite liked a leaflet on the service and what they offered, I think that was kind of missing … now we’ve got a website but we didn’t have that when I started but I think if I could have seen the website when I started, that would have been great because it’s got a lot of information on it.’ (SU19)

Others had received written information, in the form of leaflets seen at local resource centres or given to them at the time of referral. This was of variable quality; in some cases it was referred to as confusing or unclear, whereas in other cases it was found to be sufficient. Some people reported needing time to absorb the information. In a couple of sites, people felt that mental health professionals and GPs needed to have more information to pass on about the new service. Others felt that they could trust the information they were given because they could trust the people who had given it.

‘I had been referred a couple of years previously by a psychiatrist I had a very good relationship with and he assured me that he believed it was the best possible approach for what I was going through …’ (FGSU15)
The quality of information seemed to be most significant where the service was significantly different from mainstream services, because people did not know what to expect. In a couple of the therapeutic-community-style services this was particularly noticeable: service users did not feel sufficiently informed about the nature of the service they were entering or did not know to expect a predominance of group therapy (for example). In contrast, leaflets circulated about the peer-support network, designed and written with the service users, were found to be self-explanatory for the most part.

4.3.1.3 Assessment

Service users in six of the services described the assessment process as difficult and daunting, and in some cases traumatic or upsetting. It was experienced as over-long and thorough in some sites, involving tests or questionnaires as well as interviews and taking place over several weeks. Although some people appreciated the need for a comprehensive assessment process and felt that it engendered confidence in the staff and the service, many talked of the distress caused by focusing on painful past experiences and the difficult feelings that this raised. It made a considerable difference to service users if they felt that the staff were there to answer questions and offer support. However, there was a general feeling that this was an unduly traumatic process in some sites.

‘It was all negative, there was no sort of shining light at the end, it was all you know, “what are your three worst problems?”, you know, “have you ever been abused and who abused you and when?” and it was just horrific … I mean they wanted dates and everything and I had to ask my mum and it brought up problems for her and, very traumatic all round.’ (SU46)

‘I found the assessment really difficult; a lot of stuff came up and there was no support outside.’ (SU11)

In some cases, it was the tools used during assessment that provoked strong reactions; in one site, service users talked of tearing up the questionnaire they were required to complete:

‘I’ve ripped it up and burnt it a few times. It got me very, very stressed. It should have a health warning on it.’ (SU52)

The services that did not present service users with such a difficult assessment process included those that offered self-referral or focused particularly on ensuring easy access. These services did not present quite the same concerns to people around assessment, possible rejection or entering the service. Assessment was an issue identified by many service users as an area requiring improvement; they strongly advocated the provision of additional support for people during the process, whether arranged externally or by the service itself.
4.3.1.4 Diagnosis
There were very mixed views, experiences and feelings about receiving a diagnosis of personality disorder. Many of these were influenced by the implications the diagnosis had for accessing services, both in the past and in the present. Many people talked of past experiences of being rejected by services as a result of the diagnosis. The more recent experience – of being offered a service as a result of the diagnosis – gave rise to some ambivalent feelings in people. Whilst some people had been diagnosed with personality disorder some years ago, others had received the diagnosis only very recently, and found out about it in connection with being referred to the new pilot service.

‘I said (to the facilitator) “Look, now I’ve never actually been told I’ve got personality disorder. I’ve done this questionnaire thing and, you know”, I said, “have I got PD?” And she says “Well, you wouldn’t be sitting here if you hadn’t”. ’ (SU54)

Perversely, it had become the key to a service where once it had been a barrier. The irony of this was not lost on some people.
Many of the service users we spoke to had been given a number of different diagnoses and variations of diagnoses over the years, resulting in a somewhat resigned, if not sceptical, view of the current one.

‘Um, before I came here there was lots of different reports about personality disorder, first it was borderline, then it went to severe, and then it went to psychopathic disorder and now, I’m back to borderline, since I’ve been coming here.’ (SU7)

Many service users found the diagnosis to be negative, even derogatory and insulting. The terminology itself gave rise to these views: simply being labelled as having a ‘disordered personality’ was sufficient to give rise to feelings of resentment, anger and frustration. Some people talked about the stigma attached to the label and the possibility of being turned away from mainstream services once again when no longer using the pilot PD service. They felt that they had been stereotyped and judged by doctors. They also felt that it was unfair to be labelled with a derogatory term when the disorder you have developed is due to abuse at the hands of others, causing them to feel like victims all over again. Some people felt that the diagnosis just did not ‘fit’ them.

‘…so when I discovered that I had BPD, I was like “well, how the fuck have I got BPD?” because I don’t do any of the things that one ordinarily associates with it.’ (FGSU24)

There were also many people who had come to accept or to welcome the diagnosis, perhaps because they had struggled with mental health services and treatments for many years and
found nothing helpful, or because they had come to feel that the symptoms and behaviours associated with the diagnosis fitted them quite well. Some people expressed resignation at this, whilst others revealed more positive attitudes towards a label they felt they could (at last) identify with.

'I'm beginning to see actually that's not a disorder that's just who I am.' (SU6)

'For the first time I had an answer as to why everybody used to call me a weirdo or an odd-body …' (SU54)

'It's hard to accept but it does fit in. It's hard to accept because of the stigma associated with PD … It fits with my behaviours, interaction with other people, being in the mental health system for quite a few years.' (SU10)

A few of the services had actively helped with this, giving a positive ‘spin’ to the diagnosis through providing information and explanation, but also through the sense of belonging engendered by a shared identity with other service users:

‘… (other services) don’t tell you anything, they just tell you and expect you to know what (personality disorder) is, whereas here you actually get leaflets and get told what it means …’ (SU7)

‘It’s not about what your actual label is. It’s about “we’re all people” and … you need time and space and you need to know that you are worth it.’ (SU62)

4.3.1.5 Early impressions

First or early impressions were important to people; a couple of services made an immediate positive impression when service users entered the service for the first time. People described an air of warmth, friendliness, and a welcoming environment.

'My first impression was “Oh my God what have I let myself in for?” but since I walked through the air of warmth just landed you and … and the staff acknowledged you wherever you went and were very kind and very, very loving and supportive.' (FGSU1-7)

In another service, where a service user’s first introduction to the service was to enter a group, the existing members had been told in advance that a new member would be joining them and consequently they created a welcoming atmosphere. The service for young people provided an easy entry point through a youth service, which resulted in an easy access and assessment process.

Some people were initially reluctant to join groups, or to join a service that focused entirely on groups or group therapy. While some people managed to overcome this initial reluctance through experience, others chose not to attend groups if they had a choice, preferring to
access only individual therapy. One service began with a case conference consisting of 18 community members to whom the new arrival had to present their case for joining: many experienced this as daunting and off-putting.

The skills development service attracted most of its service users due to its focus on vocational development, education, training and employment. Those who came here did so because this was something they felt that they needed and wanted in their lives.

4.3.2 The service model
In this section we begin to see the significance of the service model for the service users, both in terms of general satisfaction and in relation to specific elements singled out for praise or criticism. Some of the pilot services were clearly experienced as being more complex than others in terms of the different service options or stages available to people. This inevitably resulted in more complex responses by service users.

Different aspects of service provision were picked out for praise in different sites and by different people, with the strong implication that no one service model or approach fits all. There were some strong overarching themes, however. Features highlighted as positives by service users were flexibility and accessibility, the role and qualities of staff, peer support and the provision of good out-of-hours or crisis support. Some services were praised for providing long-term support, as opposed to the inadequacy of short-term support received in the past from mainstream services. Several services were praised for helping people to work through their problems in a safe and supportive atmosphere, often through the medium of psychotherapy.

4.3.2.1 Flexibility and accessibility
The themes of flexibility and accessibility or responsiveness were highlighted in several different services. In some ways, these words are easy to articulate and rather more difficult to pin down in relation to service provision. For many people, flexibility and accessibility were embodied in the attitudes and roles of staff, which we explore in more depth in Section 3. The facts that staff were present and available, and responsive to the needs of service users, were all features highlighted by service users.

KEY MESSAGES FROM SERVICE USERS – referral and assessment

Adequate support needs to be provided for people as they pass through lengthy and sometimes traumatic assessment procedures for entry to a service.

Consideration needs to be given to the experiences with which people come to the pilot services and the desperation and hope with which they may be approaching this new service.

Clear and accessible information needs to be provided about a service, both to local professionals and to potential service users and carers, particularly where the nature of the service is very different from mainstream services.
'I've also been told that at any time that I need to I can phone up and I'll be able to speak to someone, either C if she’s around, or if not, one of the group therapists, or if not somebody else will be able to speak to me. So it’s like, it’s gone from me having no support at all to three times a week plus whatever else I need.' (SU81)

In one service, the service users were able to contact their care coordinators by text or phone and reported receiving quick and supportive responses; the care coordinators themselves were described as accessible and flexible in the ways they responded to clients. In another service, service users could access their therapists by email, and again highlighted this as a key positive feature.

‘you can sit on the computer and just pour out everything and I've found that really helpful because I’m not good on the phone.’ (SU16)

Another feature of flexibility and accessibility lies in the overall service model providing a range of service options to choose from, or to access at different times. Services where this was the case received very positive comments. In one service, for example, service users could book ‘one-to-one’ sessions with staff, and phone-support calls, alongside accessing groups, but could also ask for unplanned support if needed. In addition, crisis beds were available to them. In one service, there was an Open Clinic every day from 9am to 10am which, again, was highlighted as a positive element of the service. The flexibility of telephone support and other means of accessing or communicating with staff, such as texting and emailing, were appreciated by service users in the services where these were in operation.

‘They've been really helpful. I mean, like, if you’re having a bad day like, and you just call up and you come in, you can speak to one of the staff and I don't know, make it not seem as bad as what you've been thinking it has been sitting at home on your own … and you come and just relax for a bit, a couple of hours and then go back again.’ (SU7)

Service users valued the flexibility and consistency of the support available at another highly praised service; many spoke about the relaxed atmosphere, and several people said they felt reassured that therapy was not dictated by time limits but by recovery. Service users described this service as a service that listens, understands and cares, with no time limits or pressures, and one with a community spirit that works with you rather than against you.

4.3.2.2 A sense of belonging

Many service users talked of finding a strong sense of belonging within the service. For most people, this was associated with the specialist PD focus of the service, or the ability to identify with other service users, coupled with the relationships established with staff. For some, the service became a family or community.
‘I did feel quite low on Monday and then left quite cheerful because the one thing that I am feeling is a belonging with some of the others.’ (SU49)

‘It’s just the fact that the (service) really is a community. That I find incredibly helpful because I think for years you know I’ve been looking for a sense of belonging and it’s just evaded me so many times and … here you really get that strong sense that you belong you know …’ (FGSU1-7)

This issue is strongly associated with peer support, and hence arises in that section also. However, it also links back to the desperation and hope with which people approached these services, having often found rejection and dismissal elsewhere.

4.3.2.3 A positive focus

A theme highlighted by a number of the service users was the positive focus of a service: the fact that it seemed to be helping them to move forwards, and that staff believed in their individual capacity for change and improvement. This was significant for the many people who had negative experiences of life as well as of mainstream services.

‘This is the only service that is concentrating on getting me better, everything else seems to be just keeping me in the same place, everything else is about keeping me stable and keeping me, um, so I don’t tip back over the edge. Here they’re willing to push me over the edge if it involves me making steps forward’ (SU46)

In at least one site, this positive focus had begun to emerge into discussions about recovery, both on an individual level and in relation to the focus of the service as a whole.

4.3.2.4 Psychotherapy and group process

Psychotherapy, whether individual or group, stimulated a range of views and feelings. Many people acknowledged that it was complex or challenging but also helpful or positive in terms of helping them to engage with their difficulties. The support of therapists was also valued and appreciated. Therapy was highlighted for helping people to understand themselves and their behaviour better, and for the opportunity it provided to practise behaviours or communications in a safe environment. Therapy was identified as one of the elements in a service that led to significant changes and positive outcomes for people (see Section 4.3.6). Some people gave very positive feedback about DBT in particular, including a Skills Group which taught people new ways of thinking or coping with things.

‘DBT … actually teaches another way of thinking which … I didn’t know was possible.’ (SU6)

‘(The Skills Group) is almost like going to college and learning how to … and learning about yourself and relationships and the way your mind works and the way to
However, there were also some negative comments about therapy, particularly, it seems, where people felt they had little say or control over the way it operated. A small minority of service users described therapy as humiliating or patronising; one said it caused her to behave like a child. There was a general plea for individual therapy where group therapy was the only option.

Group therapy aroused some mixed feelings. Many service users expressed reservations about group therapy on joining a service, although some went on to find it helpful or surprisingly positive. In particular, people valued the opportunity it gave for peer support and for sharing problems and experiences with others. Some service users had come to appreciate the benefits of group therapy even if, given the choice, they would have preferred individual therapy at the start. They felt that the professionals had known what was best for them and that they had made more progress in a group and community setting. However, in one service, where individual therapy was not an option, the groups became highly charged and a few people reported leaving the service because they found the groups unhelpful or ‘a waste of time’. In a couple of other services, the main concern was that service users did not know or understand the ‘rules’ or the way in which the group was supposed to operate. Some wanted to ask direct questions of therapists and found they received no responses, leaving the other service users to let them know that they could not expect to receive direct responses from the therapists:

‘you know, we need some kind of response and, if it was made clear initially that those responses don’t exist, it would be easier to deal with. But it is not and it is so frustrating.’ (FGSU29)

In all of the TC services, service users expressed concerns about the groups designed to prepare people for entry into the full therapeutic community (referred to variously as the MAC group, Options Group, TAC). Their concerns were focused on the degree and quality of support on offer in the therapeutic community at this stage leading to a reluctance to open up and talk about difficult issues. In some cases it was felt that the group was too large for people to have much time to talk or gain support, and that they could be left with difficult feelings at the end of the session. Others were concerned that there was no one-to-one support or peer-support phone line at this stage. In one site, service users felt unclear about the rules and boundaries and did not know how to support each other. Either way, service users said they were reluctant to raise difficult issues that might not be dealt with within the time available. A few people expressed concerns about the ending of therapy, explored further in Section 4.3.10.
4.3.2.5 Boundaries and rules

The existence of boundaries and rules was a contentious issue for many service users in certain services. The degree to which rules were made explicit and transparent was an important mediator for people, as was the extent to which they were open to negotiation. In addition there were some specific rules that gave rise to strong feelings.

In some of the TC services, rules or boundaries seemed to be implicit; some service users felt that they had to find out about the rules as they went along, often from other service users, and they felt frustrated about this. This applied to the way in which group therapy was conducted, but also sometimes to the boundaries maintained between staff and service users. In one site, service users talked about the rules being written in a handbook but interpreted differently at different times depending on the current membership. In another site, service users talked of the different conditions surrounding the provision of therapy, for example, not missing more than three or four sessions in a row and being required to attend group sessions in order to receive individual therapy. People were not entirely comfortable with these conditions and felt they were non-negotiable.

Perhaps the strongest feelings were aroused in relation to the rules operating in some of the services concerning peer relationships and friendships. These were felt by many to be too rigid, and also impractical in some instances. For example, one service user reported being told that people were not permitted to travel together to and from the service on public transport despite the large geographical distances involved and the poor public transport service.

Another rule or policy that received a lot of criticism was the one concerning medication. In the therapeutic community-style services it was required that service users come off psychotropic medication before joining (or shortly after joining) the full therapeutic community. This was a source of some anxiety and distress for some people, who felt that they needed the medication or that there was insufficient support available to take its place.

‘I am just not happy about the medication thing … I mean, I am living alone. I can’t not have meds … You know, to go home, three days to me is part time anyway, you know, nine ’til three, and then to have to go home and face all my demons and all … you know, what if I start seeing things again? What if I start getting aggressive, drinking, all sorts of things that some of the medication might just dampen down and I have got to go home on my own.’ (SU49)

Conversely, some service users appeared to agree with the medication policy, suggesting that therapy might not have the same effect if medication was altering their perception of, or ability to feel, the full range of their emotions. In addition, some service users saw the policy as giving them positive encouragement towards permanent freedom from medication.

Some services operated strict rules surrounding self-harm; for example, people were not permitted to ring the peer-support line if they had already self-harmed; or reported that they
had to stop self-harming before they could move on to talk about other issues of importance to them. One woman, who had experienced a bereavement the year before, was not permitted to discuss this until she had stopped self-harming. In one service, service users were not permitted to self-harm on the premises nor to talk about certain potential 'triggers' to self-harm, such as the use of drugs and alcohol.

There were mixed views about these rules; some service users could appreciate the need for them or the benefit of them, whereas others were far more critical of their inflexibility. Some people felt that boundaries helped them to feel safe so long as they were applied consistently. A key mediating factor in all of this was whether or not the rules were open to negotiation. In one service, where service users felt that they had more input into creating and influencing the rules, they were less critical of them and appeared to feel a greater sense of 'ownership' of the rules.

'We … as clients of the (service) we make our own policies … sometimes I disagree with the policies … sometimes I agree with them but then you go by the majority which is a good thing … Our rules and regulations are a hell of a lot stricter than what the mental health institutions are. Because we want the place to run properly … we want it to be a safe place for everyone.' (SU1)

4.3.2.6 Crisis/out-of-hours support

The absence or inadequate provision of crisis or out-of-hours support was raised as an issue in some of the services. In one service, for example, it was expected that people contact their own GP or CPN or go to A&E if they experienced a crisis when the service was closed; otherwise, during service hours, they could call a special crisis-group meeting. There was some dissatisfaction about this, as people pointed out they did not tend to have crises during the hours of 9 to 5 when the service was open. At another, service users were critical of the crisis support made available to them by a local crisis team, saying that they would choose to use other services such as the Samaritans or friends and family. One of the issues raised by these service users and those at another service was that staff would respond inappropriately to someone in a crisis. Similarly, in another service, service users said they would choose to use alternative services rather than contact the PD service in a crisis.

'People like us, it's at night when you get lonely and you've done everything you wanna do for the day and then you're on your own at night and things start going through your head and you can't phone any of them 'cos there's nobody here 'cos they're shut.' (SU47)

Services that received praise in this respect were those with a responsive and person-centred out-of-hours service that people could access when they needed it.
‘... if I was in crisis I would just pick up the phone and I might just need to talk to them ... they're on the end of the telephone.’ (SU1)
‘they have a text, so you don't actually have to phone them, you can just text them anything and say “Help” – and then they'll ring back.’ (SU7)

A couple of the sites were rather different in this respect. The skills development service did not aim to provide comprehensive support to people and therefore (perhaps) did not raise any expectations in relation to crisis support. An out-of-hours peer-support line was planned at the other with the intention that it be run entirely by the service users. However, legal and health and safety concerns within the Trust had led to severe delays to this, and at the time of interviewing it had not been established. People were critical about this, although many were also concerned about the responsibility and the need for the service users running the line to be well supported themselves. It was a feature of most of the services that they sought to enable people to prevent or pre-empt a crisis, and many of the service users commented on this. In one service, contacting the crisis service to talk to someone had helped to prevent self-harm:

‘that was the only thing that sort of stopped me from (taking an overdose) again ... they calm you down and make you think straight.’ (SU33)

<table>
<thead>
<tr>
<th>KEY MESSAGES FROM SERVICE USERS – the service model</th>
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<tr>
<td>No one service model or approach fits all: some degree of choice or a range of options needs to be made available to service users.</td>
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<tr>
<td>Some degree of transparency about therapy would enable people to understand and perhaps therefore appreciate the approach taken by therapists in both group and individual therapy.</td>
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<tr>
<td>Good, accessible crisis or out-of-hours service was a valued part of some services.</td>
</tr>
<tr>
<td>Boundaries and rules need to be carefully dealt with, transparent and consistently applied; a degree of flexibility or open negotiation can increase service users' understanding and appreciation of their role and value.</td>
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4.3.3 Relationships with staff

‘Other services where I've been in, the staff are always in the office, the doors always shut and like, none of them could be bothered to get off their chairs and come whereas here they're in the lounge, one of them is in the lounge, one in the smoking room, having a one to one, maybe one or two of them are in the office dealing with, like answering phone calls, for crises.’ (SU7)
The role and qualities of staff constituted a remarkably consistent and positive theme across all of the services. Many positive comments were made about members of staff and stark comparisons were drawn with staff encountered in mainstream mental health services. Staff were described as:

- non-judgemental
- helpful, supportive
- caring, understanding
- genuine, ‘real’
- positive
- flexible, accessible, responsive
- skilled, knowledgeable

In addition, it was important for service users that staff treated them as ‘whole people’ rather than focusing solely on their negative characteristics, symptoms or diagnosis. Below, we have grouped some of the positive characteristics into themes in order to understand some of the ways in which staff created a positive environment for service users.

A key quality identified by service users was that staff were accepting of them and non-judgemental. This was a vital component of the staff of a service that was accepting them as service users and as whole people.

‘… the only person I contacted and could trust … who wouldn’t judge me or what I was doing.’ (SU33)

‘I’m acceptable, first time I’ve ever felt accepted …’ (FGSU1-7)

Many people highlighted the responsiveness and accessibility of staff: the fact that they could be telephoned, texted and/or emailed (and would respond) was highly valued. At the young people’s service the support provided was almost entirely reliant on the relationships formed between service users and their care coordinators. These members of staff were enormously valued by the young people using the service. They were valued for their accessibility and responsiveness, and were described as reliable, friendly, supportive and understanding. In addition, it was important to the young people that their care coordinators were ‘unshockable’ and ‘not afraid’. Several of these service users described the service or their care coordinator as ‘a lifeline’.

‘He’s more like a friend, but he’s not as it’s not personal.’ (SU36)

‘When I am with him I feel good about myself.’ (SU35)

In a couple of services, service users appreciated the fact that staff came over as genuine and ‘real’, that they were honest about themselves to some degree whilst maintaining realistic boundaries.
'I trust them all. I think they’re all wonderful and um, I’m actually quite protective of them … They’re honest with us and if they’re having a bad day, they’ll tell us … And they’re more sort of friends than staff.’ (SU46)

Again, in a couple of services, the positive approach of staff was highlighted: the fact that staff believed in the service users and their capacity for change, encouraged and supported them towards achieving their goals. This was notable in the skills development service where service users were encouraged and supported towards educational and employment goals, but also in another complex service where service users were facing some difficult personal challenges.

In a number of services, interviewees highlighted the equality that they felt existed between staff and service users, an absence of barriers or of the traditional ‘them and us’ ethos. Ways in which they observed this varied; some staff would cook or share meals with service users or spend break times in their company, they might dress similarly to service users or share some aspects of their lives that would enable service users to see them as fellow human beings.

‘We all pull together, it’s not just like the staff and then the clients, it’s like everybody pulls together, that’s how it works here and that’s how it keeps going really.’ (SU5)

For some people, it was important that the staff were skilled and knowledgeable about personality disorder, in a way that staff in mainstream services might not be:

‘they’re clued up, you know, to the hilt about PD as much as they can … and they do they give sound advice and very good advice …’ (FGSU1-7)

Criticisms of staff were relatively few. Most comments arose in relation to the difficulties encountered by service users in one or two of the therapeutic community services where group therapy had proved a challenge. A lack of flexibility in the relationships between staff and service users was identified, as was the tendency for staff to be unresponsive or make few interventions in group sessions. The latter relates to the lack of clarity about the model of psychotherapy or the way in which such transactions are expected to work (as mentioned earlier). In one service, there was concern about disagreements between staff and a sense that staff relationships were strained.

In a couple of the TC services, it was suggested that staff were spreading themselves too thin in the process of setting up new services, or were less available due to cuts; some service users were concerned that staff were not as consistently present as they had been at first. In a couple of other services, service users also expressed concerns about staff absences due to sickness or maternity leave causing inconsistency.
A violent incident in one site, shortly before the interviews took place, had resulted in some service users losing confidence and trust in the staff of the service. They felt that the incident had not been dealt with appropriately – that staff had left it to service users to intervene – and, as a result, they felt less safe in the service than they had before the incident.

4.3.4 Relationships with other service users
A powerful theme to emerge from these interviews was the role and value of peer support. In some services, this was seen as the most important or most highly valued feature of the service and was described with considerable passion. However, peer support did not emerge as a theme in all of the pilot sites. In some services, due to the model of service provided, peer support could not feasibly develop as service users rarely met each other during the natural course of attending the service. People were seen largely on an individual basis, and user involvement was in its infancy.

In the remaining sites, there were differences in the extent to which peer support was promoted or encouraged to develop. Some services operated limited elements of peer support, such as a peer-support phone line, or peer-support board on the internet. In some sites, formal structures were in place to develop and make use of peer support as a feature of the service. This was true of the peer-support network, in which one-to-one contact with staff was discouraged, but people were actively encouraged to meet and support each other away from the service.

Conversely, in the TC services, the fact that social contact outside the service was forbidden discouraged the growth of these relationships into friendships. As we have seen earlier, some people were critical of the service creating this boundary. Nevertheless, people valued the support of the people they encountered in groups with whom they could identify and share experiences. For a couple of people, this was the most important aspect of the service.

‘Everything that I say, you know, or do stuff, like locking doors and checking and, you know, getting flustered and it’s, it’s just everything that I’m like, they’re exactly the same so we, we get on like a house on fire and have a right good laugh.’ (SU54)
4.3.4.1 Benefits of peer support

Service users discussed many benefits gained from peer support; for some it was the most valuable aspect of the service, a turning point, and a key element in their journey to recovery. Many service users appreciated being able to share experiences with people with similar problems and gain support and ideas for coping. For others it was important to discover that they were not alone with their problems.

‘I think it helps your mind knowing that other people are suffering as well … it means, um, like, recognising myself, knowing that I’m not alone.’ (SU47)

People often talked of peer support specifically in relation to the sense of shared identity or shared understanding that came with sharing the same diagnosis or symptoms and behaviour associated with the diagnosis. This was clearly enormously important to some people, regardless of the service model in operation.

‘… you realised that you weren’t the only one feeling like that, there were other people in the world that felt the way that you did and being able to talk to them and hear their experiences of how they were dealing with it was helpful.’ (SU23)

In a few services, the service users described an all-embracing sense of community or family that included both service users and staff and engendered a sense of commitment and belonging.

‘I know it sounds strange, but we are like one big family, like when we’re all together – everybody helps everybody else.’ (SU5)

In some services, people talked of extending relationships with each other beyond service hours, developing friendships and supporting each other through a crisis. In the peer-support network, people talked of meeting and supporting each other both within and outside the group meetings, and texting and sending cards to group members when they were unwell.

‘A network of people who know you’re alive is just wonderful.’ (SU66)

A couple of people had been very isolated prior to attending a service; attending the PD service was the first time they had felt part of a social network.

‘I didn’t have any friends once I came out of hospital but I came here and I made friends and the groups weren’t anything like I thought they were going to be, they were just relaxed and cool …’ (SU7)
Finally, there were some service users for whom helping others through the process of peer support was highly valued. In one or two cases, people almost seemed to be surprised that they could come out with a piece of advice or a suggestion that might help others. In doing so, they seemed to help their own progress and self-esteem.

‘We all seem to be supportive of other people, whereas again that is what you don’t get when you go and sit in front of a shrink. You don’t get that support and you don’t get that opportunity to support somebody else.’ (FGSU30)

‘Giving support is one of the most therapeutic things I did.’ (FGSU14)

4.3.4.2 The challenges of peer relationships

Spending long periods of time together in an intense atmosphere with some challenging difficulties to deal with sometimes led to tensions: ‘sometimes it feels like trench warfare’. For a few people in services where peer support was the primary focus, it was sometimes difficult to get the balance right between giving and receiving support; they sometimes found that their own needs were not being met and needed to seek support elsewhere. Similarly, in a few services, some people talked about continuing to feel concerned or anxious about their fellow service users outside of groups or service hours, or ‘taking on’ other people’s problems.

‘It’s just too many people’s issues to deal with because I take it all on board and I go home and that’s it for the week I’ve got everyone’s problems as well as my own’. (SU52)

In a couple of the sites, service users talked about the development of ‘cliques’ within the community and tensions forming around these with the potential for some people to feel excluded. There were a couple of occasions where this had become a problem, and service users were concerned that staff were either not aware of it, or did nothing about it.

‘I’d like (staff) to be more aware of what happens when people are outside having a smoke, a cigarette and things … There is this, like, group of people, little cliques, that don’t have those values and focusing a lot of energy on putting people down … So I’d kind of like a bit more support on how to handle that, but it’s really awkward because what I’ve got to do is actually take it into the group meetings, but then it’s fear of you being on the receiving end of whatever is happening if you actually speak up.’ (SU51)

### KEY MESSAGES FROM SERVICE USERS – relationships with other service users

Peer support is a highly valued element of services, and can be usefully supported to enable people to get the most out of the support and friendship of their peers.

Care needs to be given in services where peer support is the core of the service, to ensure that adequate support is in place to sustain it.

There needs to be some provision in place for people to talk to staff about difficulties that arise between groups or cliques in a community.
4.3.5 Service-user involvement

Service-user involvement was explored at different levels within the service: involvement in individual care and treatment, in different elements of the service and in the overall service planning or delivery. There was a general feeling throughout the pilot sites that service users were genuinely listened to, that their voices were heard, and this was highly appreciated by people. Many service users across different services spoke positively about feeling involved in decisions made about their own treatment or care. One example given was the way in which care reviews were handled at one service: service users felt that they were consulted and involved in their care reviews and that their opinions were listened to. In a couple of services, service users spoke of having their own support plans and feeling very much in control of the support they received.

’I think there’s nothing that is done without my consent … the very process of therapy is in between the hands of my individual therapist – obviously she’s the one who’s qualified to do that, but every change or every step … is discussed anyway. I can, I’ve got the choice to stop at any time if I want to.’ (SU15)

’Nothing actually gets done without my say so.’ (SU37)

In a few of the services, there were service users who expressed more ambivalence about their sense of involvement. In one, there were some service users who did not feel that they were involved in their own care or in the running of groups. In another, some felt that, although they were consulted about their care and treatment, ultimately it was the therapists who held the power and made the decisions. Nevertheless, in some of these services all members of the community, including the service users, have the power to vote to accept or reject new members, and to apply the rules or boundaries.

In many of the services, service-user involvement in a broader sense was still in development at the time of the interviews. A few had begun to establish forums or community meetings, many of which had been poorly attended, difficult to participate in or resulted in little change to date. In one or two of these, it was felt that these meetings could potentially develop into something useful and user-led. In one of the TC services, service users had been involved in contributing to and updating the handbook given to new members. In another service, service users had been involved in designing and writing the publicity leaflets. However, in general, whilst many service users talked of feeling involved in or consulted about their own care and treatment, few talked of their involvement in the wider running or management of the service.

Two services stood out in this respect, both of which had set out to be user-led or to actively involve service users from the start.

One of these held regular community advisory meetings, through which service users could influence decisions made about the day-to-day running of the service and the rules about acceptable behaviour. There was also a suggestions box in operation, and service users took part in interviewing new staff as well as participating in a research group that was evaluating
the service. The service users displayed a sense of ownership of the service which was unusual amongst the pilot sites:

‘... you know it would be totally different if it was just the staff taking the decision. It’s not, it’s the client community that takes that decision and we’re a bit tougher than the staff. We make the rules as the community, and for good reasons.’ (SU2)

The other service to engage more actively with service users was established as a peer support network. Here, the aim was to enable service users to take on more of the responsibility for the groups and the support through first establishing groups with staff facilitators. Here too, many of the service users expressed a sense of ownership of the service and a commitment to sustaining it:

‘it’s our decision whether to go or stay … We make decisions about the groups we want.’ (SU67)

One member of this network said that if she had a complaint or a problem with the service, she would take it to the group ‘so the whole group can discuss it and work through it.’ However, there were criticisms of the length of the initial consultation period for this service and of the delays to establishing some of its more user-led aspects, such as the Lead Service User role and the peer-support phone line.

In both of these services and in some of the other services too, we interviewed people who had become involved in regional or national events about personality disorder, attending seminars and conferences and speaking about their own experiences. Those who had done this were enthusiastic about the opportunities it had given them to appreciate the wider context and to feel valued by the service. In only one service was it felt that this kind of activity had been dismissed or discouraged, and they were highly critical of the service for doing so.

### KEY MESSAGES FROM SERVICE USERS – service user involvement

Many people valued the recognition, value and empowerment they gained through service-user involvement.

Service-user involvement was underdeveloped in some services at the time of the interviews; there are ways in which some services could extend and develop methods of involvement, to enable service users to have more say in their own care and in the day-to-day running of the service.

### 4.3.6 Outcomes

Questions about the outcomes that service users felt they had gained through attending the PD pilot sites gave rise to a wealth of information and feelings about personal change. Nearly all of the services had been beneficial to people, many of whom spoke movingly about the
changes they saw in themselves. Most service users across most services spoke of changes in the way they felt about themselves, changes in behaviour; of understanding themselves and their behaviour better; and of changes in the ways in which they related to or interacted with others. There were only a couple of services where service users discussed negative or insignificant outcomes.

Two services stood out as having exceeded people’s expectations. The service for young people was described in particularly powerful terms when it came to outcomes; some of the young people had seen ‘massive change’: ‘I’ve got my life back’. Two of these young people said that they would not be alive today if it were not for this service. It seemed that the service had given them a lifeline in the form of the care coordinator: someone to stand by them and almost bear witness to their lives and experiences.

‘I feel less in fear … it feels like an army has been created for me.’ (SU38)
‘Before, I didn’t have a future. Now I know I am strong as a person and have a future.’ (SU35)

The other service to have exceeded expectations was described as going beyond the individual therapies and service elements and becoming a community or family. Service users’ degree of involvement in the service led to a sense of belonging and responsibility. In many ways it was an all-embracing service which, for some people, meant that they needed little outside the service.

‘… well the therapies are good but it’s not just the therapies … it’s everything all together.’ (SU1)

This was potentially a problem for family carers, however; one carer talked of feeling somewhat excluded from what was going on for his wife.

Across different services, many people talked about experiencing changes in the feelings they had about themselves. People talked of increased confidence and self-esteem, and of becoming more assertive and independent. Probably the most common word to occur within the whole section on outcomes is ‘confidence’. These changes in feelings were attributed to a variety of causes: peer support and the sense of community in the service, the experience of psychotherapy and therapists, members of staff and fellow service users.

‘… they’ve really raised my confidence and through raising my confidence they’ve shown me that I’ve had purpose and that I have abilities that were quite frankly written off by … psychiatrists years ago …’ (FGSU1-7)

Many service users talked of improved self-awareness: understanding their feelings better, coming to understand their behaviours and to recognise early warning signs or triggers for
themselves. Very often, these changes were attributed to group or individual therapy but peer support and the sharing of experiences with others also figured highly.

‘The (service) is trying to get me to notice warning signs before impulsivity kicks in.’
(SU3)

Changes in behaviour were also mentioned by many service users. Some people talked of reducing or stopping self-harm or alcohol consumption; others talked of making less use of A&E services, of having fewer crises or managing them better, of getting out of the house more or of managing to leave hospital. These changes were sometimes put down to the service itself and its boundaries or rules, to the support of peers, the attitudes of staff and/or to therapy or therapists.

‘Since coming to (service), I’m actually getting out of hospital now – which is a major step and my self harming has improved so much.’ (SU5)
‘I’ve stopped taking drugs, I’ve got my life back on track, I do things now, I don’t hide away. I don’t shy away anymore, I don’t use drink and drugs to get away from things. I am able to stand up to people.’ (SU33)

Many people talked about improvements in their relationships with others, improved communication skills and interactions with people and making new friends. These changes were largely attributed to the network of people they encountered in the services: the support of people who are able to share experiences and understanding. Some of these changes were put down to the skills and experiences learned in therapy, which was often seen as a medium through which things could be worked out or practised.

‘I think it’s the opportunity to work out things and practise relationships with, come to a safe, safer place to practise ways of being… to practise getting angry, knowing that everyone is not going to leave you when you’re angry. Seeing that you can make mistakes and that you, if you sit with it and work it through, that the world does not stop revolving.’ (FGSU37)

Another theme to emerge encompassed learning new coping skills, new ways of thinking about things or new ways of coping with or managing feelings. In addition to learning to manage anger better, some people talked of coping with the desire to self-harm by doing something else, such as picking up the phone to talk to someone instead of self-harming, or using a less harmful means of releasing the feeling.

For some people, an important outcome was learning to care about and for themselves, and to allow others to care for them. Through this it had become possible to reduce self-harming behaviour:
‘… taking better care of myself, perhaps. They encourage us to look after ourselves and take better care of ourselves. So I’ve perhaps been spending a bit more time looking after me.’ (SU81)

‘… (they’ve) taught me to care about myself for a start which means that I’m less likely to self-harm…’ (FGSU1-7)

Although vocational outcomes, such as employment interviews or training, were predominantly mentioned at the skills development service, people in other services also talked of managing to remain in work or to think about work or study again as a result of attending a service. This was attributed to the rise in confidence and self-esteem, but also to a positive attitude or a sense of hope engendered by a service.

4.3.6.1 Facilitators of change

As we have seen, the primary elements of services that were identified as facilitating change were often the people: staff, therapists and fellow service users. Therapy itself was seen as an important change agent, as was peer support. Hope was a powerful theme that emerged in several services. Some people found hope in seeing others improve and recover around them; other people found it in the positive and encouraging attitude of staff and therapists. For some people, an important element of the service was that they felt listened to; this had enabled them to feel more in control of their lives – as against feeling themselves to be the passive recipients of services and professionals. This theme emerged in quite different services: a peer support network and a therapeutic community.

‘… (In other services) other people have the control; they could section me, they could force me to take medication, they could choose what treatment I could and couldn’t receive … and yet, here, I feel coming here, it is like I have control over what happens in my life’. (FGSU28)

Another vital element in the change process – in the view of the service users – was the sense that they had of feeling genuinely cared for in a service. The sense that staff and other service users cared about and for them, and created an atmosphere of care, could engender positive feelings within them that could move towards change.

‘As time’s gone on I’ve found that people around me, staff included, are just so genuine and caring it just becomes easy to start talking to people, you know clients well as staff and … I believe I’ve a bit more confidence through it … that’s true for clients as well as the staff.’ (FGSU1-7)
4.3.6.2 Negative outcomes

In a couple of the services, there were a few people who felt that therapy had been damaging to them: that the emotional demands of psychotherapy had proved too great or that therapists themselves had caused distress. In addition, a small minority of people found therapy to be humiliating or distressing.

'I think just, as I say, I've been more apologetic for everything and more conscious of what I'm doing and I think more insecure; I think it's going to have a detrimental effect on my life rather than a positive one.' (FGSU9)

'I'd like it to be a bit more clearer why I'm there and what it's for, rather than just coming away every time and just feeling even more angry … I'm feeling worse, I want to sort of cry.' (FGSU11)

In one service, it was younger service users who felt most dissatisfied with the therapy and support on offer to them; one felt compelled to undertake DBT or she would be obliged to go back to work, which she did not feel able to do. Finally, some service users attending the service in which the violent incident had taken place identified negative outcomes from this incident, including reduced trust and confidence in the staff and feeling less safe in the service as a whole.

<table>
<thead>
<tr>
<th>KEY MESSAGES FROM SERVICE USERS – outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many very positive outcomes were reported by the service users in this study, often attributed to the other people present in the service: service users, staff and therapists.</td>
</tr>
<tr>
<td>Outcomes for some people were as much about process and experience as they were about hard or measurable outcomes; it is important to take these ‘softer’ outcomes into account.</td>
</tr>
<tr>
<td>Several service users found psychotherapy demanding and a minority reported feeling damaged by this.</td>
</tr>
</tbody>
</table>

This is an important section, as it gives space to those people who were in the minority in the services for a variety of reasons. Within individual site summaries, it has been difficult for us to represent these voices fully, because of the possibility of identifying individuals. The majority of service users across the sites were white (British) women. This meant that men were a minority in most services as were people from BME communities. Sexuality was also an issue in a couple of the services, due to the presence of a large minority of lesbian women. An important point to note is that a community may develop its own culture which may then be difficult for some people to participate in for a variety of cultural and access-related reasons.

There were some positive and some negative comments made about the capacity of different services to address issues relevant to minority groups. A couple of services were described
as open and genuinely welcoming to all; a transgender person in one service was pleasantly surprised by her reception and acceptance into the group. Some people did point out that they were themselves a predominantly white and female group, and suggested that the service should make an effort to reach people who were not well represented.
Concerns were expressed in a couple of services about the gender imbalance being potentially difficult for men coming into the service. An observation made by one male service user was that personality disorder in men tends to be criminalised; he suggested that the service consider how it might develop to take account of this. In another service, where there were some BME service users, concerns were expressed about the way in which staff had responded to racist and other discriminatory remarks made in a group session. The service users who expressed these concerns felt that staff would benefit from group-work training and clearer anti-discrimination policies.

‘I do not expect to be in a therapeutic group where someone comes out with all sorts of stuff like ‘niggers, pakis, I hit my gay friend’ … I do not want to sit in a group and have those remarks go unchallenged.’ (SU40)

Equally, concerns were expressed in a couple of services about the potential for the significant presence of lesbian women attending the service to present difficulties for some heterosexual women coming in to the service. Many of those currently attending these services did not express these concerns about either gender or sexuality for themselves; rather, they appeared to be concerned for new people coming in to the service.
There was some suggestion from a few people at a couple of services that it might be more difficult for someone who does not fall into the majority group of service users (i.e. white and female), to find the service helpful. In one of the therapeutic community services, the service users who were most critical about the service were those from minority groups. They did not feel that the service was adequately meeting their needs. In another service, people expressed concerns about literacy and language where English was not a first language.

<table>
<thead>
<tr>
<th>KEY MESSAGES FROM SERVICE USERS – diversity</th>
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</thead>
<tbody>
<tr>
<td>The tendency for these pilot services to be dominated by white British women means that it is vital for them to take into account the needs and voices of the minority groups also served by them.</td>
</tr>
<tr>
<td>Training, supervision and group work should take the needs and priorities of minority groups into account.</td>
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</tbody>
</table>

4.3.8 External factors
External factors include a range of features and issues impacting on the service from outside the immediate remit of the service itself. Location was one key issue to affect a number of services and service users, particularly those based in rural areas. In a couple of sites, service users were concerned about the travelling distance, or about not being able to attend
as much as they would wish to. In one service, which covered a large rural catchment area, some people would have to make a 70-mile round trip to attend. However, even in a London-based service, there were concerns about access for people in one borough because the service was based in the other of the two boroughs it served. With the frequent mergers of NHS Trusts, catchment areas are constantly becoming larger and making access more of an issue.

Some people commented positively on the venue and facilities available at the service. Several services were praised for their pleasant, welcoming and safe environments; the fact that a service was not based in a hospital setting (or did not look like one) was important to people. One service was based in a house with its own garden, was on good travel routes, and close to the town centre in a nice, quiet location. Due to resource problems in the local mental health services this building was due to be sold and there were significant concerns amongst the service users about possible new locations. These included fears about experiencing stigma from members of the wider community into which the service might potentially be relocated.

Equally, some comments were made about facilities being too cramped and noisy and lacking in printing and internet facilities. In a couple of sites, service users expressed concerns about funding and behind-the-scenes politics. In one TC service, it was thought that funding cuts had affected the number and availability of staff at the service; it was thought that they were increasingly being spread amongst competing services.

4.3.9 Carers
Overall, few of the pilot sites had begun to offer support specifically to carers at the time of the interviews. There were signs that this was changing, but as a result it was difficult to make contact with carers at some of the sites. In total we interviewed only 10 carers across seven of the 11 sites. In only one site were carers apparently receiving support for their role as carers; a carers’ support group had been established in one of the TC services. Carers at this site appreciated the educational and information-giving aspects of the group as well as the mutual support they had found there. They had been offered the option of continuing with the group as a support group once the educational sessions had finished, and were optimistic about doing so.

Carers, friends and family members were sometimes mentioned by service users in connection with helping to make the decision to start attending a service, and with noticing changes in themselves some time later.

‘We were taken into the quiet room and it was very informal, extremely friendly… and my husband was quite impressed because he was made very welcome …’ (SU6)

Most, although not all, of the carers expressed the wish for more support in the form of a support group or informal opportunity to meet with other carers, as well as more information about the diagnosis of personality disorder. A key theme to emerge was the desire for ideas
and suggestions about how to help their partner or family member, as part of the information about the diagnosis and how to manage it:

‘... To make (carers) part of the healing process, to involve them at times in the actual therapy itself, because it gives you a greater understanding on how to help your wife or whoever you’re caring for.’ (CARER1)

A couple of people expressed reservations about asking for more support as it made them feel selfish, but there was little doubt that they would have appreciated it. A few carers felt that they could be more involved in the service itself, attending meetings with the service user, if the latter wished it. A couple of carers felt quite strongly that they should receive more information about the care and treatment received by their family member. Service users in several services also felt that carers needed to be offered more support.

‘... If there was to be a monthly carers’ group they could see what the (service) actually offers and (staff) could explain a bit more about the diagnosis and what to expect...’ (FGSU1-7)

‘... Sometimes you haven’t got the opportunity to talk to people who know anything about it ... just being able to talk is a very powerful thing.’ (CARER3)

Some carers were highly appreciative of the changes they had observed in their partners/family members and of the support they were receiving. One husband of a woman attending a TC service was pleased to see that she was engaging with the children more, and he had been able to relax more himself as a result. One of the positive outcomes mentioned by service users was improved relationships and interactions with other people in their lives, including family members, and this was borne out by the comments of some of the carers interviewed.

One carer, however, talked of feeling let down by the service at a time when his wife was going through a crisis. He felt that support was withdrawn at a critical time and their daughter also became unwell. He was now finding it stressful having to deal with all of the agencies involved with both his wife and his daughter. He was critical that the pilot service did not involve him at an earlier stage, and felt that carers should be more involved in the care and treatment of their family members.

In another site, a carer said that he was able to contact the service directly when concerned about his family member, and talk to a member of staff without the knowledge of the service user. In the same service, some ambivalence was expressed by a carer about the all-encompassing nature of the service; he felt somewhat excluded from what was going on for her.
4.3.10 Endings

There was not a great deal of discussion about endings or leaving the services in these interviews, as most services were relatively new and most of the service users were actively attending the service at the time. Nevertheless, some service users expressed anxieties about leaving, or being required to leave before they felt ready to do so. For example, the service for young people had an age limit and one or two of the service users were anxious about hitting this age limit and having to leave before they felt ready.

Some of the past service users talked about how and why they had left the service. In one service, where we interviewed several past service users, the reasons given for leaving concerned aspects of the service itself. The past service users were critical of the rules regarding contact with other service users, and of the group work, and expressed the wish for access to individual therapy.

Some of the TC services had given serious consideration to endings, through setting up groups to prepare for leaving or groups for people who had left the community, which they could attend for a limited period. However, past service users in one service were critical of how this had happened. They felt they had had no involvement in the decisions made to end two different groups and described how members were ‘devastated’ and ‘literally begging to keep it’. One or two said they were beginning to return to old patterns of behaviour, including self-harm, and were struggling to cope without the support of the group members and the facilitator.

‘They decided (when the group would finish). They did say that we have a say in it but we didn’t. When we first started, they did say ‘Oh, we’ll see how it goes and you can tell us whether you want, you might want a few more, you might want a few less’, that sort of thing, but when it actually came to it it just suddenly became like it was fixed on 20 weeks and someone had decided that and that’s how it was, you know.’ (SU55)

For these reasons, it was felt that the service should have a more structured approach to ending groups and that service users who have completed their treatment programmes should be able to retain some link with the service and/or the service users. There were plans to develop a self-help group for leavers and for those who were waiting to get on to the course or waiting to be referred to the service.

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**KEY MESSAGES FROM SERVICE USERS – carers**

Few of the services had established support for carers; those that had were very much appreciated by the carers we interviewed

Support for carers needs to make peer/mutual support available to carers, as well as providing information and education about the symptoms and problems associated with a personality disorder diagnosis.
In one service, some people expressed concerns about the ending of therapy, although these had largely been allayed by the service in question offering a couple of people the opportunity to restart therapy if they found themselves to be in a crisis. However, one person did feel his therapy had ended quite abruptly with little opportunity to prepare for the ending. Another service user talked of trying to end therapy in collaboration with her therapist, but finding it too difficult to follow through. Another talked of reacting very badly to talking about ending therapy, and needing extra support. She had been reassured that she could remain in contact with other aspects of the service when therapy had ended. Despite preparing for ending therapy, it had somehow crept up on her:

‘It just didn’t seem real; I think that’s one of my problems is until it happens, I can’t grasp how it’s going to feel and, I think, I don’t know whether it was because therapy was coming to an end that things had got so much worse, but I hate to admit that because then they’re probably right!’ (SU17)

Similarly, a past service user had concerns about the way in which the ending of therapy had been managed.

‘I would have liked that to have gone on a bit longer, but it can’t go on for five years, ten years, the rest of your life, can it? … (I: so how did that come to an end?) It just stopped. We agreed, say, in a month’s time that that would come to an end and it did. I think at the time I was a bit upset. You know … it was loads and then all of a sudden nothing.’ (SU16)

A couple of the pilot services with different service models had preferred not to place time limits on people’s contact with the service. The peer support network, for example, did not feel the need to do so. Another service wished to remain as a long-term safety net for people; one service user described wanting to leave and being persuaded to stay or, at least, to remain registered with the service.

<table>
<thead>
<tr>
<th>KEY MESSAGES FROM SERVICE USERS – endings</th>
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<tbody>
<tr>
<td>People need clear information about, and careful preparation for, endings.</td>
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<tr>
<td>Careful consideration needs to be given about how people can access services in the future following the end of their contact with dedicated teams.</td>
</tr>
</tbody>
</table>

4.3.11 Suggestions for service improvements

The following points are based on the suggestions for improvements made by the service users themselves:
• One clear theme to emerge concerned a need to improve the initial assessment process, primarily to ensure that people in future receive more support to assist them through the process. This suggestion was made in a number of services where the assessment and induction procedures were lengthy and involved a series of interviews as well as questionnaires to complete.

• Another key suggestion for improvement emerged from most of the TC-style services. Many comments were made about the size of the different groups and the need to ensure an optimal group size for each group to be effective, but the strongest criticisms were made of the TC preparatory groups (Options Group, MAC group, TAC). Suggestions included that these early groups be smaller to ensure that people receive sufficient support, or that other support (such as telephone contact) be made available to people at this stage. At present, there was a strong feeling across several services that service users felt they were not getting enough support at this stage, and were anxious about talking about difficult issues for fear of being left with painful feelings at the end of the session.

• Another issue that emerged from a number of the sites, again primarily the TC-style services, was a need for greater flexibility in the rules and boundaries in place; examples given were the medication policy, and the boundaries enforced around peer relationships. In some services, the concern was for the consistent application and interpretation of rules and boundaries.

• Flexibility as a theme continues into the next issue, which concerns the different therapeutic and other service options on offer at a service. Service users asked for more flexibility and choice, e.g. individual therapy at sites where only group therapy or peer support was on offer, and telephone contact or crisis support at sites where these were not currently available.

• In several sites, improvements to the information made available to service users and professionals to publicise the service were suggested. In some cases, this was more specifically targeted at the accessibility of the service.

• A number of concerns were raised in rural sites about the difficulties for some people in accessing the service, and suggestions were made about how to improve this through the hours of service, provision of transport or use of different venues.

• A related issue was the capacity of the services to respond to diversity; service users across different sites commented on this, and suggested that efforts be made to make contact with younger people, with people from black and minority communities and with more men. The issue of diversity in the service user group, however, also extended to the service’s capacity to address the issues raised. In a couple of services it was suggested that staff needed more training (e.g. in group work) or that some practical factors (e.g. childcare) needed greater consideration by the service.

• Another suggestion to emerge from several sites was improved support for carers.
• Other suggestions for improvement included access to complementary therapies to be made available, a buddy scheme for service users new to the service, more user involvement in the service. Pleas were also made for better childcare support, and access to benefits and housing advice.
5 COHORT STUDY

Information about the size and funding of services, together with the demographic characteristics of the populations they serve are presented in Table 5.1. While several pilots provided services on more than one site, two included components that were managed separately and delivered very different interventions. At site 1, funding was provided for brief primary care based intervention and a separate, voluntary sector-based skills development service. At site 4 an outpatient service delivering a range of psychosocial interventions was funded alongside a case-consultation service that served a separate catchment area. Data from these components of the two pilots are presented separately.

Data on referrals and assessments were collected from all 11 pilots over variable periods of time between January 2004 and October 2006, ranging from 6 months to 27 months. Reasons for this variation include the stage of development of the service at the start of the study (some had not started providing direct services by January 2004), the way in which data were collected, and the rate at which pilots received referrals.

We aimed to collect data from a consecutive sample of all referrals until we had information on 100 people.

5.1 Demographic and clinical characteristics

We obtained basic data on 1,428 referrals to the 11 services. While data on a consecutive sample of referrals were obtained from seven of the 11 pilots, we estimate that at the remaining three data were collected on between 30% and 67% of all those referred (see Table 5.2 below). For the service with the smallest sample (30%), we compared the age and gender of the sample with the service’s referrals as a whole to check if it was representative on these measures. The mean age of the sample was 36.2 (SD = 11.0) and of the referral population 36.0 (SD = 10.2). The proportion of males in the sample was smaller than the referral population at 25.0% compared to 31.0%. In all but one service (the information and counselling service for adolescents) the proportion of women referred was greater than the proportion of men. Women formed 65% of the sample as a whole (ranging from 49% to 79%). Mean age of those referred to the adolescent service was 20.2 years; at the 10 services for adults with PD mean age was fairly consistent, ranging from 34.8 to 39.0 years. Data on ethnicity were collected by 10 services. Black and Minority Ethnic residents make up between 1% and 36% of the local populations that pilots serve. The proportion of BME service users referred to each of the pilots varied widely between 0% and 27%. At 7 of the 11 pilots the proportion of BME service users referred was lower than local population estimates. For three services the proportion of BME users referred was far lower than general population estimates. Data on previous contact with mental health services was collected on 1,077 service users at 10 sites. The majority of service users had had previous contact with mental health services across all the pilots (ranging between 77.9% and 100%). Source of referrals to the different pilots are presented in Table 5.3. Mental health services formed the main source of referral, with 16% of service users being referred by self or friend/family member. Reasons for referral are presented in Table 5.4. Mental distress was by far
the most frequently stated reason for referral, and concerns about self-harm and substance misuse also frequently mentioned. Concerns about aggression, violence or risk to others were mentioned in fewer than 5% of referrals.

5.2 Assessment and service provision
Data are presented on assessment and service provision for only those service users whose assessment started before April 2006 (see Table 5.5). This is because we wanted to allow sufficient time to elapse between referral and the end of data collection (autumn 2006) to ensure that we were describing a group for whom assessment would have been completed and decisions made about what services they were to receive.

The proportion of those referred to services that was taken on varied considerably between the services: ranging from 100% at one service (where once someone made contact in person with the pilot they were offered a service) to 31.3% at a service delivering structured psychological therapies. In comparing the characteristics of those referred to pilot services with those who actually engaged with them we excluded data from three services: the service user network (in which all those who contacted the service in person were offered it), a case consultation service (in which direct services to service users were not provided at the time data were collected), and the service for adolescents (which we excluded because not all those referred had PD). Results of this comparison are presented in Table 5.6. Those referred to services were similar to those who received them, except that the latter were less likely to be male. Men made up 429 (33.5%) of referrals and 189 (27.2%) of those taken on by the services (difference in proportions = 6.3%, $\chi^2 = 8.8$, p = 0.003). Reasons why people were not provided a service were often not stated, but among those that were, failure to take up repeated offers of assessment appointments, absence of PD, presence of ASPD and substance misuse problems were regularly mentioned. In Table 5.7 the length of time between referral, assessment and being taken on for services is presented. This varied substantially across the services. Data in this table need to be interpreted with caution as they refer to people taken on to different components of the services. Qualitative data from services suggested that the main reason for delayed assessment was that some service users failed to attend initial appointments but continued to be offered further assessments over a longer period of time.

5.3 Minimum dataset
Minimum dataset (MDS) data were not collected by the pilot that provided information and advice to adolescents, but some data were collected at all 10 pilots working with adults with PD. Data were collected on 457 (32.0%) of those referred to services. At those pilots where a range of services were provided MDS data tended to be collected from those who were offered formal interventions such as psychological treatment, case management or a place in a day hospital or day-TC. Characteristics of those who were offered a service for whom we have and do not have data are compared in Table 5.9. It can be seen that ethnicity and the
proportion who had been in contact with mental health services are similar, but those with MDS data were a little older and less likely to be male.

Interpretation of quantitative data was made more complicated by changes to original versions of questionnaires made by two of the services. At one, one item of the Social Function Questionnaire (SFQ) concerning the service user’s sex life was dropped. At another the scale used to rate items on the SAP-AS and SFQ was altered slightly and total scores had to be recalculated (see Table 5.10).

Mean SAP-AS scores across the services ranged from 5.2 to 6.2, with between 92% and 100% of the sample receiving a score of 3 or more which indicates the likely presence of PD (Moran et al. 2003). The majority of the sample (90.9%) stated that they wanted to change something about their personality. The proportion who endorsed this statement was lower at the case management service than at other pilot services (difference in proportions = 18.8%, $\chi^2 = 6.73$, $p = 0.009$).

High levels of social dysfunction were found across all 10 services. Almost half the total sample had attended an emergency department (ED) in the 6 months prior to data collection, with over 60% of those taken on by the team delivering psychological therapies to people with PD and comorbid substance misuse having attended an ED during this period. Levels of contact with other types of health and social care were high, with 37% of the sample having spent time on an inpatient mental health unit during the previous 6 months. Levels of service utilisation tended to be lower among users of the voluntary sector-based skills development service than at other pilots: for instance 8 (17.8%) of 45 of their service users reported having been admitted to hospital in the last 6 months compared to 133 (41.2%) of 323 taken on by other services (difference in proportions = 23.3%, $\chi^2 = 9.13$, $p= 0.003$).

Levels of contact with criminal justice services were generally lower, with 6.5% of the total sample having been charged with an offence in the 6 months prior to data collection.

### 5.4 Additional data

Six services collected further clinical information, which is presented in Table 5.11. Levels of suicidal ideation and behaviour were high, with 70% having thought about ending their life during the previous 12 months, and 47.0% reporting trying to end their life during this period. Levels of substance misuse were also high, with the proportion misusing drugs more than twice as high in the dual diagnosis service than at other sites where this information was collected. Mean score on the Mental Health Inventory was 29.8 (SD = 18.5), with over 90% of the sample experiencing a level of mental distress suggestive of a mental disorder. Levels of satisfaction with services were generally lower than those reported among users of general mental health and psychology services (Shipley et al. 2000).

### 5.5 Self-referral

Information on source of referral was obtained from 1,324 people referred to the 10 adult services for people with PD. Of those 197 (14.9%) were self-referrals and 8 (0.6%) were from
family or friends. In Table 5.12 the characteristics of those who were referred by self/family or friends are compared with those who were referred by a professional. People who self-referred were on average three years older. But apart from this there were very few differences between the groups, e.g. levels of personality disturbance and social functioning and service utilisation were similar.

5.6 Ending contact with services
By the end of the period of data collection 335 (44.4%) of 755 service users who started to use a service were no longer in contact with it (see Table 5.8). Approximately a third had completed an intervention, with the remainder having dropped out of contact from the service or left early for other reasons.
Characteristics of those who left the service early are compared with those who completed a package of care or remain in contact with services, in Table 5.13. This comparison was restricted to seven services. Data from the service user network (which remained open to most service users) and case-management service (which planned to work with people long term), the case consultation service (as data do not relate to direct service provision) and the young people (as not all had PD) are excluded. BME service users were less likely to remain in contact or complete an intervention and the trend was for people who referred themselves to services to be more likely to remain in contact or complete an intervention. Marked variations were also seen between services, so ‘site’ was also an important predictor of whether the participant dropped out of contact with services ($\chi^2 = 58.3$, $p < 0.001$).

By the end of follow-up 328 (76.1%) of 431 white participants had either completed or were still in contact with services compared to 18 (50%) of BME participants. Binary logistic regression revealed that the association between ethnicity and likelihood of dropping out of contact with the service was independent of the potential confounding effect of age, gender, site and self-referral. A trend towards self-referral being associated with remaining in contact or completing an intervention also remained.
<table>
<thead>
<tr>
<th>Number</th>
<th>Main interventions</th>
<th>Funding in 2006/07 (£)</th>
<th>Catchment area</th>
<th>Population</th>
<th>Proportion non-white (%)</th>
<th>Deprivation index*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1a – voluntary sector-based skills development service</td>
<td>373,000</td>
<td>Inner-city area of large city</td>
<td>374,000</td>
<td>26</td>
<td>6 to 19</td>
</tr>
<tr>
<td></td>
<td>1b – primary care workers (plus organisational consultancy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2</td>
<td>Outpatient psychological treatments for people PD and substance misuse</td>
<td>353,000</td>
<td>Urban and suburban areas of large city</td>
<td>457,000</td>
<td>36</td>
<td>47 to 163</td>
</tr>
<tr>
<td>3</td>
<td>Peer support for adults with PD</td>
<td>283,000</td>
<td>Inner-city and suburban area of large city</td>
<td>580,000</td>
<td>9 to 16</td>
<td>128 to 301</td>
</tr>
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<td>4</td>
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<td>(14.2)</td>
<td>(4.7)</td>
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<td>(9.5)</td>
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<td>–</td>
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<td>(9.1)</td>
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<td>History of abuse/PTSD/trauma – N (%)</td>
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<td>–</td>
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<td>(1.5)</td>
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</tr>
<tr>
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<td>–</td>
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<tr>
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<td>1</td>
<td>48</td>
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<tr>
<td>– N (% valid cases)</td>
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<td>(0.5)</td>
<td>(4.9)</td>
<td>–</td>
<td>–</td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>–</td>
<td>(1.6)</td>
<td>(2.5)</td>
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<td>(2.1)</td>
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<td>–</td>
<td>–</td>
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<td>–</td>
<td>0</td>
<td>–</td>
<td>0</td>
<td>9</td>
<td>0</td>
<td>12</td>
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<tr>
<td>– N (% valid cases)</td>
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<td>(0.5)</td>
<td>(0.0)</td>
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<td>–</td>
<td>(1.3)</td>
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<td>–</td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>(3.3)</td>
<td>(0.0)</td>
<td>(0.5)</td>
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<td>13</td>
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<tr>
<td>– N (% valid cases)</td>
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<td>(2.4)</td>
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<td>(10.1)</td>
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<td>–</td>
<td>(3.2)</td>
<td>(1.3)</td>
<td>(0.4)</td>
<td>(1.0)</td>
<td>(2.1)</td>
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<td>Physical problems – N (%)</td>
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<td>6</td>
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<td>–</td>
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<td>–</td>
<td>0</td>
<td>–</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>– N (% valid cases)</td>
<td>(0.9)</td>
<td>(3.2)</td>
<td>(0.2)</td>
<td>–</td>
<td>–</td>
<td>(0.0)</td>
<td>(0.9)</td>
<td>–</td>
<td>(0.0)</td>
<td>(1.3)</td>
<td>(0.4)</td>
<td>(0.0)</td>
<td>(0.7)</td>
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</tr>
<tr>
<td>Other – N (%)</td>
<td>8</td>
<td>1</td>
<td>6</td>
<td>–</td>
<td>–</td>
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<td>3</td>
<td>–</td>
<td>5</td>
<td>–</td>
<td>6</td>
<td>9</td>
<td>1</td>
<td>41</td>
</tr>
<tr>
<td>– N (% valid cases)</td>
<td>(3.5)</td>
<td>(0.5)</td>
<td>(1.1)</td>
<td>–</td>
<td>–</td>
<td>(2.5)</td>
<td>(1.4)</td>
<td>–</td>
<td>(8.1)</td>
<td>(1.5)</td>
<td>(3.3)</td>
<td>(0.3)</td>
<td>(1.8)</td>
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* Multiple responses allowed if more than one stated on CPR form
Table 5.5: Assessment and offer of services (NB tables from here on include those referred into the services in or before April 2006)

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<tr>
<th>Service</th>
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<th>3</th>
<th>4a</th>
<th>4b</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>TOTAL</th>
</tr>
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<tbody>
<tr>
<td>Sample size: CPR data</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1317</td>
</tr>
<tr>
<td>Number offered assessment – N (% of valid cases)</td>
<td>94</td>
<td>73</td>
<td>120</td>
<td>100</td>
<td>94</td>
<td>36</td>
<td>121</td>
<td>128</td>
<td>108</td>
<td>107</td>
<td>112</td>
<td>86</td>
<td>99</td>
<td>1194</td>
</tr>
<tr>
<td>Attended assessment – N (% of those offered one)</td>
<td>69</td>
<td>61</td>
<td>105</td>
<td>100</td>
<td>93</td>
<td>29</td>
<td>120</td>
<td>117</td>
<td>88</td>
<td>95</td>
<td>69</td>
<td>40</td>
<td>79</td>
<td>1065</td>
</tr>
<tr>
<td>Met criteria – N (%)</td>
<td>67</td>
<td>60</td>
<td>82</td>
<td>100</td>
<td>47</td>
<td>29</td>
<td>120</td>
<td>117</td>
<td>84</td>
<td>69</td>
<td>64</td>
<td>34</td>
<td>69</td>
<td>942</td>
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<td>Offered service – N (%)</td>
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<td>57</td>
<td>59</td>
<td>100</td>
<td>47</td>
<td>27</td>
<td>120</td>
<td>106</td>
<td>84</td>
<td>63</td>
<td>47</td>
<td>31</td>
<td>69</td>
<td>867</td>
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<tr>
<td>Received a service – N (% of those offered a service)</td>
<td>53</td>
<td>45</td>
<td>51</td>
<td>100</td>
<td>39</td>
<td>–</td>
<td>119</td>
<td>100</td>
<td>75</td>
<td>61</td>
<td>38</td>
<td>29</td>
<td>58</td>
<td>768</td>
</tr>
<tr>
<td>Received a service (% of those referred)</td>
<td>54.1</td>
<td>59.2</td>
<td>31.3</td>
<td>100</td>
<td>41.5</td>
<td>–</td>
<td>91.5</td>
<td>78.1</td>
<td>69.4</td>
<td>57.0</td>
<td>33.9</td>
<td>33.7</td>
<td>58.6</td>
<td>58.3</td>
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Table 5.6: Demographic and clinical characteristics of those referred to and using pilot services. (Excludes referrals to 3, 4b and 11)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Referrals (n = 1087)</th>
<th>Offered an assessment (n = 985)</th>
<th>Attended assessment (n = 866)</th>
<th>Offered a service (n = 681)</th>
<th>Started the service (n = 621)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age – median (SD)</td>
<td>35.7 (9.9)</td>
<td>35.7 (9.9)</td>
<td>35.7 (9.9)</td>
<td>36.2 (10.0)</td>
<td>36.1 (9.9)</td>
</tr>
<tr>
<td>Gender – male N (%)</td>
<td>371 (34.2)</td>
<td>324 (32.9)</td>
<td>274 (31.7)</td>
<td>194 (28.5)</td>
<td>170 (27.4)</td>
</tr>
<tr>
<td>Ethnicity – non-white N (%)</td>
<td>71 (6.5)</td>
<td>67 (6.8)</td>
<td>63 (7.3)</td>
<td>46 (6.8)</td>
<td>41 (6.6)</td>
</tr>
<tr>
<td>Previous contact with mental health services – N (%)</td>
<td>865 (94.1)</td>
<td>772 (93.9)</td>
<td>674 (93.9)</td>
<td>555 (93.8)</td>
<td>516 (94.5)</td>
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Table 5.7: Time interval (in days) between date of referral, assessment, start and end of treatment

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<th>3</th>
<th>4a</th>
<th>4b</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median time from referral to assessment (range)</td>
<td>26</td>
<td>17.5</td>
<td>35.5</td>
<td>-</td>
<td>57</td>
<td>50</td>
<td>0</td>
<td>48</td>
<td>60</td>
<td>29</td>
<td>55</td>
<td>44</td>
<td>16.5</td>
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<tr>
<td>Median length of time from assessment to treatment (range)</td>
<td>18</td>
<td>1.5</td>
<td>63.5</td>
<td>-</td>
<td>175.5</td>
<td>41</td>
<td>0</td>
<td>49</td>
<td>26</td>
<td>40</td>
<td>63</td>
<td>153</td>
<td>5</td>
</tr>
<tr>
<td>Median length of time in treatment (range)</td>
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<td>35</td>
<td>233</td>
<td>179</td>
<td>251</td>
<td>-</td>
<td>288</td>
<td>140</td>
<td>171.5</td>
<td>195</td>
<td>84</td>
<td>291.5</td>
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Table 5.8: Ending contact with services

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<th>1b</th>
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<th>2b</th>
<th>3a</th>
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<th>9</th>
<th>10</th>
<th>11</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number who received a service</strong></td>
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<td>45</td>
<td>51</td>
<td>87</td>
<td>39</td>
<td>–</td>
<td>119</td>
<td>100</td>
<td>75</td>
<td>61</td>
<td>38</td>
<td>29</td>
<td>58</td>
<td>755</td>
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<td></td>
</tr>
<tr>
<td><strong>Ended contact with service – N</strong></td>
<td>35</td>
<td>38</td>
<td>21</td>
<td>26</td>
<td>15</td>
<td>–</td>
<td>17</td>
<td>55</td>
<td>49</td>
<td>15</td>
<td>20</td>
<td>2</td>
<td>42</td>
<td>335</td>
<td></td>
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</tr>
<tr>
<td>(% who received a service)</td>
<td>67.3</td>
<td>84.4</td>
<td>41.2</td>
<td>29.9</td>
<td>(38.5)</td>
<td>–</td>
<td>(14.3)</td>
<td>(55.0)</td>
<td>(65.3)</td>
<td>(24.6)</td>
<td>(52.6)</td>
<td>(6.9)</td>
<td>(72.4)</td>
<td>(44.4)</td>
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<tr>
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<td>–</td>
<td>15</td>
<td>–</td>
<td>17</td>
<td>55</td>
<td>49</td>
<td>12</td>
<td>19</td>
<td>2</td>
<td>41</td>
<td>300</td>
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</tr>
<tr>
<td>(valid cases – N)</td>
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<td>23</td>
<td>7</td>
<td>–</td>
<td>1</td>
<td>–</td>
<td>4</td>
<td>27</td>
<td>27</td>
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<tr>
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<td>(22.2)</td>
<td>(49.1)</td>
<td>(55.1)</td>
<td>(38.5)</td>
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<td>(0.0)</td>
<td>(31.0)</td>
<td>(38.3)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>(% of total who have ended contact)</td>
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<td>6</td>
<td>8</td>
<td>–</td>
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<td>20</td>
<td>5</td>
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<tr>
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<td>(16.7)</td>
<td>(21.8)</td>
<td>(40.8)</td>
<td>(38.5)</td>
<td>(57.9)</td>
<td>(50.0)</td>
<td>(38.1)</td>
<td>(32.3)</td>
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<tr>
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<td>–</td>
<td>2</td>
<td>–</td>
<td>0</td>
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<td>–</td>
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<td>–</td>
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<td>(6.7)</td>
<td>(22.2)</td>
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<td>(0.0)</td>
<td>(0.0)</td>
<td>(1.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other – N (%)</td>
<td>10</td>
<td>5</td>
<td>1</td>
<td>–</td>
<td>9</td>
<td>–</td>
<td>3</td>
<td>11</td>
<td>2</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td>5</td>
<td>55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(29.4)</td>
<td>(13.2)</td>
<td>(4.8)</td>
<td>(60.0)</td>
<td>(16.7)</td>
<td>(20.0)</td>
<td>(4.1)</td>
<td>(7.7)</td>
<td>(42.1)</td>
<td>(50.0)</td>
<td>(11.9)</td>
<td>(18.7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Many of those who completed packages of care or left for other reasons were also provided with information about other services
Table 5.9: Comparison of characteristics of those with minimum dataset data and those without

<table>
<thead>
<tr>
<th></th>
<th>Minimum data set</th>
<th>No minimum data set</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (n = 1341) (SD)</strong></td>
<td>36.2 (10.0)</td>
<td>34.5 (10.7)</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(p = 0.01)</td>
</tr>
<tr>
<td><strong>Gender (n = 1341) – male N (%)</strong></td>
<td>114 (28.6)</td>
<td>388 (37.6)</td>
<td>- 9.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(p = 0.01)</td>
</tr>
<tr>
<td><strong>Ethnicity (n = 1111) – non-white N (%)</strong></td>
<td>23 (6.3%)</td>
<td>53 (7.1%)</td>
<td>0.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(p = 0.595)</td>
</tr>
<tr>
<td><strong>Previous contact with mental health services (n = 1088) – N (%)</strong></td>
<td>330 (93.2)</td>
<td>697 (95.0)</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(p = 0.261)</td>
</tr>
</tbody>
</table>
Table 5.10: Baseline clinical data from the minimum dataset (MDS)

<table>
<thead>
<tr>
<th>Service</th>
<th>1a</th>
<th>1b</th>
<th>2</th>
<th>3</th>
<th>4a</th>
<th>4b</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size: MDS data – N (%)</td>
<td>45</td>
<td>11</td>
<td>57</td>
<td>42</td>
<td>39</td>
<td>29</td>
<td>53</td>
<td>88</td>
<td>25</td>
<td>23</td>
<td>23</td>
<td>22</td>
<td>0</td>
<td>457</td>
</tr>
</tbody>
</table>

**SAPAS – valid cases**

| Proportion scoring ≥ 3.00 | 34 | 9 | 50 | 32 | 27 | 18 | 46 | 70 | 19 | 23** | 20 | 21 | - | 369 |

**Mean SAP-AS score (SD)**

| | 5.3 | 6.2 | 5.4 | 5.3 | 5.8 | 5.5 | 5.2 | 5.3 | 6.0 | 6.0** | 5.7 | 5.3 | - | 5.6 |

**Proportion scoring ≥ 3.00**

| | 34 | 9 | 50 | 32 | 27 | 18 | 46 | 70 | 19 | 23** | 20 | 21 | - | 369 |

**Type R/S – valid cases**

| Treatment seeking – N (% of valid cases) | 38 | 10 | 50 | 38 | 31 | 20 | 44 | 77 | 22 | 22** | 23 | 16 | - | 391 |

**Six month service utilisation – valid cases**

| Emergency contact with GP – N (%) | 14 | - | 6 | - | 23 | 12 | 28 | 49 | 12 | 11 | 14 | - | - | 169 |

| Admission to hospital – N (%) | 12 | - | 32 | - | 18 | 14 | 29 | 36 | 14 | 12 | 12 | - | - | 179 |

| Contact social services – N (%) | 8 | - | 17 | - | 17 | 14 | 22 | 35 | 11 | 11 | 6 | - | - | 141 |

| Contact with police – N (%) | 17 | - | 21 | - | 15 | 17 | 22 | 34 | 12 | 7 | 11 | - | - | 156 |

| Charged with an offence – N (%) | 37.8 | (38.9) | (40.5) | (58.6) | (42.3) | (40.5) | (50.0) | (33.3) | (52.4) | (40.9) |

| Social functioning – valid cases Mean social function (SD) | 11.4* | - | 15.0 | 14.1 | 14.5 | 17.3 | 13.7 | 14.1 | 16.1 | 11.7** | 14.1 | 12.6 | - | 14.1 |

| | (3.2) | - | (4.1) | (3.5) | (5.2) | (4.2) | (4.9) | (3.9) | (3.6) | (3.8) | (4.6) | (4.1) | - | (4.1) |

*11 items only **Transformed data
<table>
<thead>
<tr>
<th>Service</th>
<th>2</th>
<th>3</th>
<th>4a</th>
<th>4b</th>
<th>6</th>
<th>7</th>
<th>9</th>
<th>11</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size: MDS data – N (%)</td>
<td>57</td>
<td>42</td>
<td>39</td>
<td>29</td>
<td>88</td>
<td>25</td>
<td>23</td>
<td>22</td>
<td>325</td>
</tr>
<tr>
<td>Proportion thinking life is not worth living in the previous week – N (%)</td>
<td>17</td>
<td>–</td>
<td>16</td>
<td>17</td>
<td>40</td>
<td>16</td>
<td>11</td>
<td>–</td>
<td>117 (45.5)</td>
</tr>
<tr>
<td>Proportion thinking life is not worth living in the previous year – N (%)</td>
<td>43</td>
<td>–</td>
<td>34</td>
<td>24</td>
<td>66</td>
<td>23</td>
<td>18</td>
<td>–</td>
<td>208</td>
</tr>
<tr>
<td>Proportion who thought of ending life in last week – N (%)</td>
<td>13</td>
<td>–</td>
<td>15</td>
<td>15</td>
<td>36</td>
<td>13</td>
<td>10</td>
<td>–</td>
<td>102</td>
</tr>
<tr>
<td>Proportion who thought of ending life in last year – N (%)</td>
<td>27</td>
<td>–</td>
<td>32</td>
<td>23</td>
<td>60</td>
<td>21</td>
<td>16</td>
<td>–</td>
<td>179</td>
</tr>
<tr>
<td>Proportion who attempted to take life in last week – N (%)</td>
<td>0</td>
<td>–</td>
<td>2</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>–</td>
<td>11</td>
</tr>
<tr>
<td>Proportion who attempted to take life in last year – N (%)</td>
<td>27</td>
<td>–</td>
<td>18</td>
<td>15</td>
<td>37</td>
<td>13</td>
<td>9</td>
<td>–</td>
<td>119</td>
</tr>
<tr>
<td>Excessive alcohol use in the last month – N (%)</td>
<td>33</td>
<td>–</td>
<td>9</td>
<td>10</td>
<td>23</td>
<td>7</td>
<td>8</td>
<td>–</td>
<td>90</td>
</tr>
<tr>
<td>Excessive alcohol daily/almost daily – N (%)</td>
<td>10</td>
<td>–</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>–</td>
<td>25</td>
</tr>
<tr>
<td>Used cannabis in the last 3 months – N (%)</td>
<td>12</td>
<td>–</td>
<td>7</td>
<td>5</td>
<td>19</td>
<td>4</td>
<td>4</td>
<td>–</td>
<td>51</td>
</tr>
<tr>
<td>Used stimulant substances in the last 3 months – N (%)</td>
<td>9</td>
<td>–</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>–</td>
<td>22</td>
</tr>
<tr>
<td>Used opiates in the last 3 months – N (%)</td>
<td>3</td>
<td>–</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>–</td>
<td>7</td>
</tr>
<tr>
<td>Therapeutic alliance – valid cases</td>
<td>44</td>
<td>29</td>
<td>20</td>
<td>24</td>
<td>65</td>
<td>21</td>
<td>20</td>
<td>20</td>
<td>243</td>
</tr>
<tr>
<td>Therapeutic alliance – Mean (SD)</td>
<td>19.0</td>
<td>19.7</td>
<td>19.9</td>
<td>19.2</td>
<td>20.7</td>
<td>20.4</td>
<td>22.2</td>
<td>22.5</td>
<td>20.5</td>
</tr>
<tr>
<td>Mental Health Inventory – valid cases</td>
<td>55</td>
<td>–</td>
<td>33</td>
<td>27</td>
<td>76</td>
<td>24</td>
<td>22</td>
<td>–</td>
<td>237</td>
</tr>
<tr>
<td>Mental Health Inventory – Mean (SD)</td>
<td>28.5</td>
<td>–</td>
<td>29.7</td>
<td>24.6</td>
<td>36.4</td>
<td>25.8</td>
<td>33.8</td>
<td>–</td>
<td>29.8</td>
</tr>
<tr>
<td>Mental Health Inventory – Proportion scoring &lt;60.4 – N (%)</td>
<td>53</td>
<td>–</td>
<td>31</td>
<td>25</td>
<td>66</td>
<td>24</td>
<td>19</td>
<td>–</td>
<td>218</td>
</tr>
<tr>
<td>Satisfaction – valid cases</td>
<td>50</td>
<td>–</td>
<td>20</td>
<td>20</td>
<td>55</td>
<td>21</td>
<td>22</td>
<td>–</td>
<td>188</td>
</tr>
<tr>
<td>Satisfaction – Mean (SD)</td>
<td>11.2</td>
<td>–</td>
<td>7.3</td>
<td>7.8</td>
<td>8.6</td>
<td>5.7</td>
<td>8.2</td>
<td>–</td>
<td>8.1</td>
</tr>
<tr>
<td></td>
<td>(1.7)</td>
<td>(2.9)</td>
<td>(4.1)</td>
<td>(2.2)</td>
<td>(3.6)</td>
<td>(2.9)</td>
<td>(2.9)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5.12: Characteristics of self-referrals* and those referred by professionals

<table>
<thead>
<tr>
<th>Variable</th>
<th>Self-referral*</th>
<th>Referred by professionals</th>
<th>Difference in proportions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (N = 1236) S.D</td>
<td>38.9 (10.0)</td>
<td>35.9 (10.0)</td>
<td>3.0 (p &lt;0.001)</td>
</tr>
<tr>
<td>Gender (N = 1320) Male n (%)</td>
<td>60 (41.6%)</td>
<td>387 (53.0%)</td>
<td>- 11.4 (p = 0.17)</td>
</tr>
<tr>
<td>Ethnicity (N = 1010) Non-white n (%)</td>
<td>14 (9.8%)</td>
<td>61 (7.0%)</td>
<td>2.8 (p = 0.32)</td>
</tr>
<tr>
<td>Previous contact with mental health services (N = 1076) n (%)</td>
<td>6 (5.0%)</td>
<td>54 (5.6%)</td>
<td>-0.6 (p=0.95)</td>
</tr>
<tr>
<td>SAP-AS score (N = 345) Mean (SD)</td>
<td>5.3 (1.5)</td>
<td>5.5 (1.6)</td>
<td>0.2 (p = 0.33)</td>
</tr>
<tr>
<td>Proportion who want to change something in their personality (N=376) n (%)</td>
<td>58 (90.6%)</td>
<td>282 (90.4%)</td>
<td>0.2 (p=1.00)</td>
</tr>
<tr>
<td>Social Function Questionnaire (N = 305) Mean (SD)</td>
<td>14.0 (4.0)</td>
<td>14.1 (4.3)</td>
<td>-0.1 (p = 0.93)</td>
</tr>
<tr>
<td>Proportion attended AED in last 6 months (N = 319) n (%)</td>
<td>17 (50.0)</td>
<td>143 (50.2)</td>
<td>-0.2 (p = 1.00)</td>
</tr>
<tr>
<td>Proportion admitted to hospital in last 6 months (N = 312) n (%)</td>
<td>12 (36.4%)</td>
<td>108 (38.7%)</td>
<td>-2.3 (p=0.942)</td>
</tr>
<tr>
<td>Proportion charged with an offence (N = 325) n (%)</td>
<td>1 (2.9%)</td>
<td>21 (7.2%)</td>
<td>-4.3 (p=0.563)</td>
</tr>
</tbody>
</table>

*Includes 8 people who were initially referred by family and friends
Table 5.13 Comparison of characteristics of those who remain in contact with services or completed an intervention to those who left prior to completion

<table>
<thead>
<tr>
<th>Variable</th>
<th>Completed or still in service</th>
<th>Left prior to completion</th>
<th>Difference in proportions or means</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (N = 516) Mean (SD)</td>
<td>36.6 (9.9)</td>
<td>35.2 (10.2)</td>
<td>1.4 (p = 0.17)</td>
</tr>
<tr>
<td>Gender (N = 538) Male – n (%)</td>
<td>99 (25.2)</td>
<td>47 (32.4)</td>
<td>-7.2 (p = 0.118)</td>
</tr>
<tr>
<td>Ethnicity (N = 467) non white – n (%)</td>
<td>30 (6.4)</td>
<td>17 (12.0)</td>
<td>-4.0 (p = 0.046)</td>
</tr>
<tr>
<td>Previous contact with mental health services (N = 467) n (%)</td>
<td>333 (95.1)</td>
<td>107 (91.5)</td>
<td>3.6 (p = 0.211)</td>
</tr>
<tr>
<td>Self referral (N =529) n (%)</td>
<td>69 (17.7)</td>
<td>15 (10.7)</td>
<td>7.0 (p = 0.07)</td>
</tr>
<tr>
<td>SAP-AS score (N =224 ) Mean (SD)</td>
<td>5.4 (1.5)</td>
<td>5.7 (1.6)</td>
<td>-0.3 (p = 0.19)</td>
</tr>
<tr>
<td>Proportion who want to change something in their personality (N=235) – n (%)</td>
<td>158 (89.8)</td>
<td>54 (91.5)</td>
<td>-1.7 (p = 0.889)</td>
</tr>
<tr>
<td>Social Function Questionnaire (N =194 ) Mean (SD)</td>
<td>14.0 (4.4)</td>
<td>14.2 (3.9)</td>
<td>-0.2 (p = 0.73)</td>
</tr>
<tr>
<td>Proportion attended AED in last 6 months (N = 229) n (%)</td>
<td>84 (48.8)</td>
<td>26 (45.6)</td>
<td>3.2 (p = 0.788)</td>
</tr>
<tr>
<td>Proportion admitted to hospital in last 6 months (N = 223) n (%)</td>
<td>58 (34.5)</td>
<td>23 (41.8)</td>
<td>-7.3 (p = 0.415)</td>
</tr>
<tr>
<td>Proportion charged with an offence (N =232 ) n (%)</td>
<td>8 (4.6%)</td>
<td>6 (10.5%)</td>
<td>-5.9 (p = 0.187)</td>
</tr>
</tbody>
</table>
6 DELPHI STUDY

6.1 Response rate

Eighty-eight people (88.9%) responded to the first-round questionnaire. The response rate was greater among service providers than among the other two groups (87.1% expert authors, 97.1% providers, and 82.4% of service users responded). The response rate in round 2 was 84.8% (83.9% of expert authors, 91.2% of service providers, and 79.4% of service users), and 81.8% in round 3 (74.2% of expert authors, 79.4% of providers, and 88.2% of service users).

Delphi respondents who were service providers or expert authors came from a range of backgrounds and used a variety of approaches to working with people with PD. Respondents were able to indicate more than one background or therapeutic approach e.g. psychiatrist and psychotherapist/ Therapeutic Community and psychodynamic psychotherapy etc. Twenty-one (33.9%) respondents stated that their professional background was in psychiatry, 13 (21%) in psychology, 12 (19.4%) in psychotherapy, 8 (12.9%) in nursing and 2 (3.2%) in social work.

Fifty-seven (91.9%) respondents provided information on their main therapeutic approach. The most frequently reported of these were psychodynamic psychotherapy (N = 17, 29.8%), therapeutic community (N = 13, 22.8%), DBT (N=8, 14.0%) and CBT (N = 8, 14.0%).

6.2 Consensus items

Consensus was reached on ten items in round one, five items in round two and six items in round three. Items on which consensus was reached are listed in Table 6.1 below. A detailed breakdown of items that reached consensus among each of the three stakeholder groups is presented in Appendix D. Each group reached consensus on 19 items, with 10 items reaching consensus level among all three stakeholder groups.

The item that attracted the lowest degree of consensus was: It does not matter if PD services do not have a clear treatment model, as long as there are demonstrable positive outcomes for service users and others, which was supported by 25% of respondents and opposed by 36%, with the remaining 39% neither supporting nor opposing the item. For seven other items fewer than 50% of participants fell into any of these three groups. These were:

- Dedicated services should use assertive outreach in order to work with people with severe PD who do not attend their appointments (41% supported this statement).
- Dedicated PD services should provide service users some form of access to their own staff 24 hours a day (39% opposed this statement, 40% were neutral).
- Dedicated services for people with PD should help service users reduce, with a view to stopping, using psychiatric medication (40% supported the statement, 49% were neutral).
- When people with PD have significant housing or social problems these need to be addressed before the start of psychological treatment (39% supported this statement, 47% were neutral).
• People with personality disorder usually need to be seen at home for at least one occasion to enable a full assessment of their problem and its likely treatment to be made (34% opposed this statement, 41% were neutral).
• Service users should be encouraged and supported to run out-of-hours crisis support (38% supported this statement, 49% were neutral).
• All people with PD should have access to user-led services (43% supported this statement).

Differences also emerged between expert authors and service providers from different professional and therapeutic backgrounds. These included:
• People from a psychodynamic psychotherapy background are more likely to disagree with the statement that people with PD should be treated in the community under powers of the Mental Health Act (77.8% of people from this background disagreed with this statement compared to 55.6% overall)
• Psychiatrists were more likely to endorse the statement that dedicated teams should have regular input from a psychiatrist (88.9% of psychiatrists endorsed this statement compared to 50.0% of psychologists and 58.6% of service users)
• Psychologists were more likely than psychiatrists to disagree that it does not matter if there is a clear treatment model in place as long as the outcomes are positive (80% of psychologists compared with 38.9% of psychiatrists)
• People from a CBT background are more likely than others to disagree with the statement that services should NOT be expected to work with people with a history of violent offending. (75% of people from a CBT background, compared with 60.5% overall)
• All people from a DBT background agreed that there should be input in a dedicated team from a service user worker (100% of people from a DBT background, compared with 81.3% overall)
• People from a therapeutic community background were more likely to agree with statements about peer support (91.7% compared with 66.7% overall), peer enforced sanctions (100% compared with 61.7% overall) and peer run out of hours support (75% compared with 37.0% overall) than other participants.

6.3 Ranking items
Priorities for service development were rated by all 88 people who responded to the first-round questionnaire. Top rating items in each of the three groups and for the group as a whole are presented in Table 6.2. Responses of all three stakeholder groups were similar, with four services scoring consistently highly:
• A service which aims to reduce stigma and discrimination
• A community-based service providing psychological treatments
• Dedicated day service
• A consultation service providing expert guidance
Two types of service – therapeutic communities and inpatient units for people with severe PD – were rated as not being high priorities by all three stakeholder groups.

Preferences for outcome measures for services are presented in Table 6.3. All measures scored highly and differences between the six items were not great. Quality of life was ranked highest across all three groups. Expert authors and service providers placed social function as the next most important outcome, with service users opting for symptoms of mental distress. User satisfaction with quality of care was rated the least important outcome measure by all three stakeholder groups, but even this measure received a median rating of 7.0.

Table 6.1 Items reaching consensus

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Statement</th>
<th>Round when consensus was reached</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Most people with PD require dedicated services to help them cope with their problems.</td>
<td>R3</td>
</tr>
<tr>
<td>1.10</td>
<td>Dedicated PD teams should provide services for people who have PD and sometimes hear voices or experience other psychotic symptoms.</td>
<td>R1</td>
</tr>
<tr>
<td>1.12</td>
<td>Dedicated PD services should be open to self-referral.</td>
<td>R3</td>
</tr>
<tr>
<td>1.13</td>
<td>When mental health services refer someone to a dedicated PD service it is important for a member of the referring team to remain in regular contact with them.</td>
<td>R3</td>
</tr>
<tr>
<td>1.14</td>
<td>It is unacceptable for community mental health teams to have a policy of NOT working with people with a primary diagnosis of PD.</td>
<td>R2</td>
</tr>
<tr>
<td>2.3</td>
<td>Interventions aimed at helping people with PD develop better coping strategies need be delivered over years not months.</td>
<td>R1</td>
</tr>
<tr>
<td>2.4</td>
<td>Services for people with PD should provide care coordination under the ‘care programme approach’ (CPA).</td>
<td>R3</td>
</tr>
<tr>
<td>2.5</td>
<td>Care plans with short- and long-term treatment goals agreed by the client are important if progress in treatment is to be both achieved and recognised.</td>
<td>R1</td>
</tr>
<tr>
<td>2.7</td>
<td>Dedicated services for people with PD should be able to arrange more intensive support at times of crisis such as home treatment or residential care.</td>
<td>R1</td>
</tr>
<tr>
<td>2.8</td>
<td>Limits on the availability of staff and other boundaries need to be made clear to service users at the start of treatment and stuck to throughout treatment</td>
<td>R1</td>
</tr>
<tr>
<td>2.9</td>
<td>Responsibility for client welfare should be shared by a team and/or the community, rather than by individual staff members.</td>
<td>R1</td>
</tr>
<tr>
<td>2.11</td>
<td>Some PD clients cannot cope with groups or environments where people have to interact.</td>
<td>R1</td>
</tr>
<tr>
<td>2.13</td>
<td>Risk management for people with PD involves placing a high degree of choice and responsibility with the person who is harming her/himself.</td>
<td>R1</td>
</tr>
<tr>
<td>2.15</td>
<td>Services for people with PD should try to obtain users’ consent to contact, support and inform carers.</td>
<td>R2</td>
</tr>
<tr>
<td>2.18</td>
<td>Users and their carers should be involved in making decisions about service development.</td>
<td>R1</td>
</tr>
<tr>
<td>3.1</td>
<td>The personal qualities of staff – such as self-awareness and ability to observe boundaries – are more relevant to working well with PD clients than professional qualifications.</td>
<td>R2</td>
</tr>
<tr>
<td>3.2</td>
<td>Teams delivering services to people with PD need to consist of people with a range of professional and non-professional backgrounds.</td>
<td>R2</td>
</tr>
<tr>
<td>3.5</td>
<td>Teams delivering services for people with PD should have regular input from an ‘expert by experience’ (a service-user worker).</td>
<td>R3</td>
</tr>
<tr>
<td>3.6</td>
<td>It is essential for staff of PD services to have a forum to come together to reflect on their practice, their relationships with clients and the impact their work has on team members.</td>
<td>R1</td>
</tr>
<tr>
<td>3.8</td>
<td>Training in this field should ideally be given to teams, rather than individuals.</td>
<td>R2</td>
</tr>
<tr>
<td>4.5</td>
<td>Service users are able to successfully run groups for people with PD as long as they are provided with training and support.</td>
<td>R3</td>
</tr>
</tbody>
</table>
Table 6.2 Priorities for service development

<table>
<thead>
<tr>
<th>Rank order</th>
<th>Service development priorities</th>
<th>Expert author Median (mean)</th>
<th>Service Provider Median (mean)</th>
<th>Service user Median (mean)</th>
<th>TOTAL Median (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A service which aims to reduce stigma and discrimination</td>
<td>7.0 (6.3)</td>
<td>8.0 (7.7)</td>
<td>9.0 (8.0)</td>
<td>8.0 (7.4)</td>
</tr>
<tr>
<td>1</td>
<td>A community-based service providing psychological treatments</td>
<td>7.0 (6.8)</td>
<td>7.0 (7.2)</td>
<td>8.0 (8.1)</td>
<td>8.0 (7.4)</td>
</tr>
<tr>
<td>3</td>
<td>Dedicated day service</td>
<td>7.0 (6.9)</td>
<td>7.0 (7.0)</td>
<td>8.0 (7.4)</td>
<td>7.0 (7.1)</td>
</tr>
<tr>
<td>3</td>
<td>A consultation service providing expert guidance</td>
<td>7.0 (6.5)</td>
<td>7.0 (7.4)</td>
<td>7.5 (7.4)</td>
<td>7.0 (7.1)</td>
</tr>
<tr>
<td>5</td>
<td>Training and support to enable people to get back into employment</td>
<td>7.0 (6.8)</td>
<td>7.0 (7.3)</td>
<td>6.0 (6.3)</td>
<td>7.0 (7.1)</td>
</tr>
<tr>
<td>5</td>
<td>Organisational change and service developments to non-specialist services</td>
<td>6.0 (6.4)</td>
<td>7.0 (7.1)</td>
<td>7.0 (6.8)</td>
<td>7.0 (6.8)</td>
</tr>
<tr>
<td>7</td>
<td>A dedicated case-management team</td>
<td>7.0 (6.5)</td>
<td>6.0 (6.2)</td>
<td>7.0 (7.1)</td>
<td>7.0 (6.6)</td>
</tr>
<tr>
<td>8</td>
<td>Deployment of dedicated PD workers working within existing CMHTs</td>
<td>5.0 (5.6)</td>
<td>7.0 (6.1)</td>
<td>7.0 (7.1)</td>
<td>7.0 (6.2)</td>
</tr>
<tr>
<td>9</td>
<td>A service user network</td>
<td>5.0 (5.4)</td>
<td>7.0 (6.8)</td>
<td>7.0 (6.5)</td>
<td>6.0 (6.3)</td>
</tr>
<tr>
<td>10</td>
<td>A therapeutic community</td>
<td>4.0 (4.6)</td>
<td>5.0 (5.6)</td>
<td>6.5 (5.7)</td>
<td>5.0 (5.3)</td>
</tr>
<tr>
<td>11</td>
<td>An inpatient unit for people with severe PD</td>
<td>4.0 (4.3)</td>
<td>5.0 (4.8)</td>
<td>5.5 (5.8)</td>
<td>5.0 (5.0)</td>
</tr>
<tr>
<td>Rank order</td>
<td>Outcome measure</td>
<td>Expert authors</td>
<td>Service Providers</td>
<td>Service users</td>
<td>Total</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>----------------</td>
<td>-------------------</td>
<td>--------------</td>
<td>----------</td>
</tr>
<tr>
<td>1</td>
<td>Improved quality of life (a person's level of comfort, enjoyment, and ability to pursue daily activities) to normal levels</td>
<td>8.0 (7.5)</td>
<td>8.0 (8.0)</td>
<td>8.0 (7.8)</td>
<td>8.0 (7.8)</td>
</tr>
<tr>
<td>1</td>
<td>Improved social functioning (e.g. so people can sustain long-term relationships in their work and personal life)</td>
<td>7.0 (7.6)</td>
<td>8.0 (8.2)</td>
<td>7.5 (7.5)</td>
<td>8.0 (7.8)</td>
</tr>
<tr>
<td>3</td>
<td>Reductions in impulsive behaviour so that self-harming, aggression and/ or violence stops</td>
<td>7.0 (7.3)</td>
<td>7.0 (7.4)</td>
<td>8.0 (7.0)</td>
<td>7.0 (7.3)</td>
</tr>
<tr>
<td>4</td>
<td>Reductions in symptoms of anxiety, depression and mental distress to normal levels</td>
<td>7.0 (6.7)</td>
<td>7.0 (6.9)</td>
<td>8.0 (7.6)</td>
<td>7.0 (7.0)</td>
</tr>
<tr>
<td>5</td>
<td>Reduced levels of use of inpatient care and contacts with emergency medical services</td>
<td>7.0 (6.7)</td>
<td>7.0 (6.9)</td>
<td>7.0 (6.8)</td>
<td>7.0 (6.8)</td>
</tr>
<tr>
<td>6</td>
<td>User-rated satisfaction with service quality</td>
<td>6.0 (6.1)</td>
<td>7.0 (6.6)</td>
<td>7.5 (6.8)</td>
<td>7.0 (6.5)</td>
</tr>
</tbody>
</table>
7 DISCUSSION

In this section we summarise our findings and examine study limitations before considering implications of the study for commissioners, providers and users of services for people with PD.

7.1 Overview of study findings

7.1.1 Case studies and overarching themes

The case studies provide a detailed picture of the first phase of the development of the 11 pilot services. By spring 2007 all of the pilot services were operational, working with people with PD and liaising with colleagues in other services. The speed with which pilots developed varied considerably and reflected differences in the extent of services already working with client group prior to start of funding to the start of funding as well as problems faced by some pilots in recruiting staff and identifying suitable premises. Many of the challenges faced in setting up pilot services were generic to setting up any new service. Other challenges were more specifically related to setting up dedicated community-based services for people with PD. For instance, service leads did not have a workforce with the skills needed to undertake this work and often had to train new team members to deliver psychological interventions and provide practical help and support; services that delivered interventions that relied on group work and peer support needed additional time to develop.

While the range of approaches to providing services detailed in the original plans for the pilots varied greatly, there was a degree of convergence in the content of interventions that were subsequently delivered. Services which originally planned to place a greater emphasis on direct service provision found that limited capacity to deliver this meant that training and support for other service providers became a larger part of their work. Pilots that initially placed greater emphasis on indirect service provision found that direct work with people with PD helped build relationships with local referrers and increased the credibility and valued attached to their efforts to support and train mainstream staff. Several services expanded the range of different interventions they originally planned to offer. This provided a way of increasing the numbers of people that pilots could work with, but was also done in an effort to promote autonomy and choice, and in response to the broad range of needs and abilities that people referred to services presented with. Staff at pilot sites repeatedly told us that ‘one size does not fit all’.

Many of the service users we interviewed had previous experiences of feeling rejected by health and social care services, and spoke of the relief and hope they experienced on finding out there was a service that had been specifically designed to try to help them. These feelings were accompanied by concerns about would happen if their contact with the pilot service did not work out or came to an end. Service users felt that referral to a dedicated PD service was a ‘last chance’ to get help and support.

Service users appreciated the flexible and welcoming approach of staff and the relative ease with which they were able to access services. The outcomes discussed by service users were largely positive and constructive. Most service users spoke of positive changes in the way
they felt about themselves and related to others. Negative or insignificant outcomes were mentioned by only a few. Service users appreciated staff at the pilots for being sincere, for their acceptance of people and non-judgemental approach, for offering their support and knowledge, and for treating service users with respect.

Staff working in general health and social care told us that pilot services were valuable because general services lacked the time and skills needed to help people with PD. Some told us that existing services were sometimes unhelpful and that the development of dedicated services for people with PD had helped to challenge the notion that there was nothing that could be done to help people with these problems. Some referrers were disappointed to find that dedicated services were unable to work with people who were very chaotic or not sufficiently psychologically minded. Staff who had received tier 1 interventions welcomed this aspect of the work of dedicated services. Opinions were divided about the optimal content of such interventions, with some preferring general training on PD treatment approaches, while others found specific case consultations on specific cases more useful.

The commissioners we interviewed had generally been involved in setting up pilot services and were also positive about them. They told us that gaps in the service concerning PD had been signalled by service users and carers. However they expressed concerns about the small numbers which some services had taken on, and were keen for others to expand the geographical area that they currently cover. Commissioners felt that PD services should become more integrated with other services such as primary care and criminal justice services. Some warned that services for people with PD were not a national service priority and told us that, without ring fenced funding, pilot services would need to be able to demonstrate that they reduced use of other services, particularly out-of-area placements and in-patient mental health services.

7.1.2 Cohort study

Pilot services received a large number of referrals of people with PD. As with reports from other treatment services, people referred to pilots were more likely to be female and have a younger mean age than people with PD in the community (see Table 7.1). At four of the pilot services the proportion of people referred who were from BME communities was similar to the proportion in the general population. In the remainder it was lower, for instance in two services where BME residents make up one in six of the population, less than 3% of those referred to the service were from BME communities. While most pilot services set out to encourage referrals from a range of different sources, over 90% came from community mental health services, and most of those who came from other sources had had previous contact with them.

There was marked variation in the proportion of people referred to each of the pilots who were eventually taken on for direct services. Two pilots provided access to services following an initial meeting where service users completed a basic assessment (and in one a simple crisis plan). As a result they took on between 90% and 100% of all those referred. In contrast, the remaining pilots took on, on average, half of those referred. However it should be noted that,
for most pilots, people were sometimes referred for assessment with the aim of helping
existing service work more effectively rather than with the expectation that they would be
taken on by them. Nonetheless variations in the proportion of people taken on are interesting
as are differences in the characteristics of those who were and not taken on for direct service
provision. Men were less likely to be taken on by services than women, an association that
was largely the result of people with a past history of violence towards others being less likely
to be taken on by services.

Table 7.1 Comparison of characteristics of people referred to and taken on by pilots, with those from
previous studies of people with personality disorder (and *borderline PD only).

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Sample Population</th>
<th>Sample size</th>
<th>Mean age (SD)</th>
<th>Gender (male %)</th>
<th>Ethnicity Non white (%)</th>
<th>Previous mental health contact (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning the lessons 2007</td>
<td>Cross-sectional study</td>
<td>Treatment Population All PD</td>
<td>1087</td>
<td>35.7 (9.9)</td>
<td>34.2</td>
<td>6.5</td>
<td>94.1</td>
</tr>
<tr>
<td>Learning the lessons 2007</td>
<td>Cross-sectional study</td>
<td>Treatment population All PD</td>
<td>621</td>
<td>36.1 (9.9)</td>
<td>27.4</td>
<td>6.6</td>
<td>94.5</td>
</tr>
<tr>
<td>Moran et al. 2000</td>
<td>Cross-sectional study</td>
<td>Primary care attenders</td>
<td>303</td>
<td>41.9 (14.6)</td>
<td>32.7</td>
<td>20.5</td>
<td>–</td>
</tr>
<tr>
<td>Davies &amp; Campling 2003</td>
<td>Cohort study</td>
<td>Inpatient treatment</td>
<td>52</td>
<td>27.2</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Chiesa &amp; Fonagy 2000</td>
<td>Cohort study</td>
<td>Inpatient treatment</td>
<td>46</td>
<td>31.6 (7.9)</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Hubbard et al. 2007</td>
<td>RCT</td>
<td>Treatment population</td>
<td>87</td>
<td>36.2 (9.6)</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>*Bateman et al. 1999</td>
<td>RCT</td>
<td>Borderline personality disorder</td>
<td>42</td>
<td>30.3</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>*Davidson et al. 2006</td>
<td>RCT</td>
<td>Borderline personality disorder</td>
<td>106</td>
<td>31.9 (9.1)</td>
<td>–</td>
<td>–</td>
<td>0</td>
</tr>
</tbody>
</table>

Detailed clinical data were obtained from only a minority of service users, so these need to be
interpreted with caution. These data show that across all 11 pilot services levels of personality
disturbance and impairment in social functioning were high. 95% of people had a SAP-AS
score indicating the likelihood that they had a personality disorder. A mean score of 14.1 on
the SFQ is similar to that reported in studies of people with PD who engage with services (Huband et al. 2007) and is equivalent to levels of disturbance seen in acute mental health settings (Tyrer et al. 2005b). Data on suicidal behaviour collected by five of the pilots showed that almost half had attempted to end their life during the previous 12 months, in contrast to population-based studies which suggest a life-time rate of 3% (Crawford et al. 2005).

Approximately half those taken on by services had left by the end of the follow-up period, with 14.0% having completed an episode of care and 25.1% having dropped out of contact with services or having left the service early for other reasons. Previous observational studies have reported similar levels of drop-out among people with PD, with baseline levels of hostility and impulsivity predicting those most likely to leave early (Gunderson et al. 1989); (Huband et al. 2007). The associations between retention in the service and self-referral, and between leaving early and ethnicity that we found require further investigation.

7.1.3 Delphi study
After 3 rounds of the Delphi exercise consensus was reached on 21 (39%) items. The level of consensus we found was lower than that reported in most other Delphi studies (Murphy et al. 1998); (Fiander M. & Burns T. 1998). This was despite the fact that the benchmark we set for consensus lower than that used in most other Delphi studies (Cheadle et al. 2000); (Weigl et al. 2004). The lower level of consensus we found may be because of the broader range of participants that we included (e.g. service users), or it may reflect the early phase in our understanding of the development of dedicated services for people with PD and the relative absence of evidence in this field. Higher levels of agreement among expert authors than among the other two stakeholder groups provides tentative support for the former hypothesis.

Participants reached consensus in favour of 20 items and against one: the proposition that ‘Most people with PD do NOT require dedicated services’. This proposition is particularly significant because of the implications it has for current service provision. At present most areas of the country have no dedicated service for people with PD and this situation could not be changed without considerable new investment in services, or reconfiguration of existing services. Most of the other findings from the Delphi study support the views of service users and providers obtained in the qualitative components of the study and are discussed further in sections 7.3 to 7.6 of this report.

Views on outcomes which should be used to judge the performance of dedicated services showed small but important differences between stakeholder groups. Differences in views of service providers and service users have been seen in other settings (Perkins 2001); (Wensing & Elwyn 2003). The greater emphasis that service users placed on symptoms of mental distress is noteworthy because previous treatment studies have suggested that improvements in mental health are less likely to occur than other outcomes, such as reductions in self-harming behaviour (Binks et al. 2006).

Preferences for service development showed a higher degree of consistency, with a preference for outpatient psychological services, and little support for inpatient treatments for those with severe PD. The low ranking of therapeutic communities is perhaps surprising,
given the emphasis on day-TC models among the pilots: it is possible that this item was interpreted as referring to inpatient TCs rather than the outpatient models being evaluated in this study. The item to receive the highest ranking was one which was suggested by service users: ‘A service which aims to reduce stigma and discrimination experienced by people with PD’. While this would appear to be the aim of much of the support that dedicated services offer to those working across a range of health, social care, voluntary sector and forensic services the optimal organisational structure through which services may achieve this aim remains unclear.

7.2 Study strengths and limitations

The wide variety of different treatment approaches adopted by the different pilots meant that we were able to examine a range of different ways of working with people with PD. A large amount of qualitative data was collected and analysed. The study involved interviews with 89 service providers and over 100 service users. We believe that the approach we took to obtaining data from service users is the first time that a user-led research project has incorporated national recommendations for this type of study (SURGE 2007). The service user research team were involved at every stage of the study: from sampling and data collection through to analysis and writing of the case studies. This high degree of involvement meant that the perspectives of service user researchers were fully incorporated into every stage of the research process.

Having collected data from a range of different perspectives we have been able to capture key learning from the development of these services. Analysis of data from the organisational evaluation and user-led qualitative study was conducted by two separate teams. While the two teams worked closely during the planning stages of the project and in preparing this report there was no consultation during the process of data analysis. Comparison of findings from these two aspects of the study allowed a degree of triangulation to occur and the emergence of several key themes across these two aspects of the project increases the internal validity of the study findings.

In an effort to facilitate synthesis of data we planned a consensus-building exercise to examine the level of consensus there was on important aspects of the organisation and delivery of services and the broad range of stakeholders we included together with the high response rate we obtained means that we can have confidence in the findings of this exercise.

However, the study had a number of limitations that we would like to discuss before considering implications of the study findings.

7.2.1 Timing of the study

The timing of this study coincided with the first two years of the operation of most of the pilot services. While this meant that we were able to track some of the challenges services faced and report on the steps they subsequently took to manage these, it is important to note that services were in transition and that some of the problems that we identified may have been
resolved in the period after data collection stopped. Most of the pilots were based on innovative models for working with people with PD and were reviewing and adapting the services they provide during the course of the study. Correspondence with staff and service users in the pilots suggests that this process has continued since data collection ceased and it is important to note that these data therefore may not describe services as they are currently being delivered. This is equally true of the qualitative data collected from the first wave of service users and quantitative data on service provision, which also represent a snapshot of service activity levels at an early stage of the development of these services. Conversely, issues related to how services manage new referrals once tier 3 interventions have reached capacity were only just beginning to emerge.

7.2.2 Response bias
During the period when study data were being collected, plans for future funding of the pilot services had not been agreed. Those working in the pilot services may have viewed this study as part of a process of evaluation that would influence future funding decisions. In this context it is likely that service providers, and, to a lesser extent, service users, may have felt they needed to present their service in the best possible light. This limitation needs to be taken into account when interpreting study findings.

7.2.3 Study samples
Initially we relied on managers and clinical leads at pilot services to identify service users and referrers who might be willing to participate in the study. Some of service users who took part were identified opportunistically when conducting interviews with other users. Referrers were asked to suggest the names of colleagues who might be willing to be interviewed; however most of those who took part were nominated by service leads. We do not know how representative service users and referrers were of all those who had used services provided by pilots or tried to refer people to them. Some of the service users and referrers that we interviewed were critical of aspects of the pilots but it is possible that teams directed us to users and referrers who had a good experience of the pilot service. In consultation with service providers we decided that service users who were still in the process of being assessed or had had difficult leavings should not be asked to participate in the study. We would have liked to have obtained a complete list of users and referrers to these services and attempted to interview a purposive sample of each. However we did not have sufficient resources (nor ethical clearance) to do this and our reliance on pilots to direct us towards those willing to be interviewed may have affected the data we subsequently collected.

7.2.4 Cohort data
Our failure to develop a method for obtaining informed consent from service users that was acceptable to staff in the 11 pilot services means that we were unable to collect longitudinal data on clinical and other outcomes. The absence of follow up data on service utilisation is particularly disappointing given feedback from commissioners about how important this information is to decisions about long-term funding for these services. In retrospect, our original plans to collect detailed longitudinal data on mental health, social functioning, service
utilisation and other outcomes were overly ambitious. The geographical spread of the services meant that it was impractical for the small research team employed on the project to collect baseline data from the study sample. Front-line staff in the 11 pilots usually had no previous experience of obtaining informed consent from their service users and were concerned about the impact that asking people to take part in a study would have on their efforts to engage people in their service. The situation was further complicated by detailed plans that some of the pilots had for conducting local evaluations, some of which were already in place at the point at which this project was commissioned. However, we were able to reach agreement with most of the pilot services about measuring key clinical variables as part of their assessment process. We were then able to obtain Ethics Committee approval to access anonymised copies of these data.

Differences in the stage of development of pilot services and differences in the approach that pilots took to data collection meant that the quality and quantity of data we collected varied. We were not in a position to insist that pilots collect these data and some pilots chose to modify the instruments that we hoped they would use: this further limited data quality. Nonetheless we were able to obtain basic demographic data and information on service provision from all 11 pilot services and collect additional baseline data on personality traits, social functioning and service utilisation from most of the services. These data have allowed us to compare the 11 pilot services and explore differences in characteristics of people who made contact and used these services.

Minimum dataset data were collected from a minority of all those referred to services and while we collected data from over half those taken on by services, missing data mean that differences in SAP-AS scores, social functioning and service utilisation need to be interpreted with caution.

7.2.5 Delphi study

The primary aim of the Delphi study was to examine the level of consensus around key aspects of the organisation and delivery of dedicated services for people with PD. Our response rate was generally higher than that obtained in such studies. We included a broader range of stakeholders and provided more feedback to participants on the responses that others had given in previous rounds (Murphy et al. 1998).

While we included a sample of 30 service users, we were unable to identify a sample of carers who could participate in the exercise. We considered whether to include a sample of commissioners of mental health services in the exercise but interviews with commissioners suggested that while they had clear views about the place of dedicated services for people with PD within other health and social care services, most had insufficient knowledge of services to feel able to comment on specific aspects of service delivery. While the three stakeholder groups we used were well placed to comment on the organisation and delivery of services, they all shared a commitment to services for people with PD, and may not be best placed to judge whether dedicated services should be more widely delivered.
7.3 Areas of convergence
In several key areas, views of service users were congruent with those of providers and these, in turn, which supported by findings of the Delphi study. These were principally around the organisation and delivery of direct services, the personal attributes of staff working in dedicated services, the way that front-line staff should be supported and managed, and the most effective methods for delivering indirect service provision.

7.3.1 Organisation and delivery of direct services
Interviews with service providers identified key features of the organisation and delivery of dedicated services for people with PD that were widely supported across most of the pilot services. Several of these features were echoed by responses of service users and carers whom we interviewed and others were endorsed in the Delphi exercise. These key features are listed in Text Box 7.2.

<table>
<thead>
<tr>
<th>Text Box 7.2: Important features of dedicated services for people with PD</th>
</tr>
</thead>
<tbody>
<tr>
<td>• They should be delivered over a relatively long period of time, e.g. years not months.</td>
</tr>
<tr>
<td>• The service must be consistent and reliable.</td>
</tr>
<tr>
<td>• Comprehensive communication within staff teams is vital; services should have a clear information-sharing policy, communicated to the client during induction.</td>
</tr>
<tr>
<td>• Teams should be made up of people with a range of professional and non-professional backgrounds.</td>
</tr>
<tr>
<td>• Users and their carers should be involved in making decisions about service development.</td>
</tr>
<tr>
<td>• Responsibility for client welfare should be shared by members of a team and/or the community, rather than by individual members of staff.</td>
</tr>
<tr>
<td>• Limits on the availability of staff and other boundaries need to be made clear to service users at the start of treatment and stuck to throughout treatment.</td>
</tr>
<tr>
<td>• Services need to demonstrate that the user is valued and valuable. The approach should be validating, rather than dismissive, of the person’s experience and aim to increase self-acceptance.</td>
</tr>
<tr>
<td>• Short and long term goals should be set negotiated with clients at an early stage.</td>
</tr>
<tr>
<td>• Services should provide and promote choice, self-efficacy and personal responsibility and avoid trying to control or coerce service users.</td>
</tr>
<tr>
<td>• Services need to be able to deliver social as well as psychological interventions</td>
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<tr>
<td>• Services should be able to arrange more intensive services at times of crisis, including home treatment and/or residential care.</td>
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<tr>
<td>• Services should try to obtain users’ consent to contact, support and inform carers.</td>
</tr>
<tr>
<td>• Systems should be in place for ensuring that users are prepared for leaving and that the process through which they will leave is made clear and discussed well in advance.</td>
</tr>
<tr>
<td>• Services need to offer cultural sensitivity, mindful of the experiences of discrimination on the basis of race and ethnicity.</td>
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7.3.2. Personal attributes of staff working in dedicated PD services

One of the items in the Delphi study that attracted the highest level of consensus was that ‘the personal qualities of staff – such as self-awareness and ability to observe boundaries – are more relevant to working well with PD clients than professional qualifications’. Interviews with service users and providers generated a more detailed description of personal qualities that staff working in dedicated PD services should have. These are listed in Text Box 7.3. While these qualities include many features that would be desirable in anyone working in any health or social care context, they place particular emphasis on a person’s capacity to reflect on their work with service users and an ability to hold back from trying to make decisions for people or to control their behaviour.

Text Box 7.3: Desirable characteristics of staff working with people with PD

- The ability to be responsive and work flexibly with service users, but not at the expense of neglecting appropriate boundaries.
- The ability to empower service users, even if this means letting them make some mistakes. Staff who are controlling may be unsuited to working with people with PD.
- Staff need to be emotionally mature and have a high degree of personal resilience.
- While retaining a positive attitude, staff need to be able to accept the limitations of what can be done.
- Staff need to have a capacity and a willingness to reflect on themselves and their work.
- Staff need to be able to discuss their own mistakes or uncertainty.
- Staff need to be able to balance their work life with other aspects of their life.
- They need to be willing to work as members of a team, to reach compromises and accept the process of shared decision making and/or the decision of the clinical lead when agreement is not possible.
- Staff need to be informed and knowledgeable about personality disorder: its aetiology, its impact and the psychological processes through which problems occur.
- Staff need to be empathic, non-judgemental, open, genuine, ‘real’, and accessible.

7.3.3 Managing and supporting front-line workers

A consistent theme of interviews with service providers was that staff working in dedicated services needed to be supported by clear management structures and have ring-fenced time to meet together and reflect on their practice. Service leads described how staff working in PD services needed support from strong leaders who were able to contain the anxieties that were often induced by working with this client group. Commissioners of services recognise the importance of dedicated, strong leaders but warned that the leadership skills of others need to be developed in order to ensure that services could become self-sustaining.
The view that staff working in dedicated PD services need to have an opportunity to come together to reflect on their practice, their relationships with clients and the impact their work has on team members, was one of the items that reached the highest levels of consensus in the first round of the Delphi study. Staff in several pilots stated that these fora should ideally be facilitated by a person who is independent from the team because this enabled people to examine their feelings without the restraint which might apply if a manager were present in a supervisory role. Pilots services that comprised more than one team, those employing large numbers of part-time staff and those that have to provide services over dispersed sites reported difficulties in organising team supervision. Where team supervision is not possible, regular individual supervision takes on additional significance.

7.3.4 Delivering indirect services

Service providers gave a detailed description of their work in training and supporting people working with people with PD in other settings. Service providers delivered this training and support to people across a wide range of different settings, though much of the focus was on working with staff in mental health and social care. Key themes to emerge from these interviews were that training worked best when it was delivered to teams rather than to individual members of staff, and when it focused on specific examples of working with people with PD as well as general principles. Service leads told us that support and advice from those working in dedicated PD services was valued more highly when it was delivered by people who were involved in direct service provision. Student placements and secondments from other services were also seen as important methods for increasing understanding of PD and its management. Several services offer case consultation, which is seen as providing staff with time to reflect on their work – a resource which is often limited, especially among staff working on inpatient units and in CMHTs. People working in these services welcomed the support and training they received from pilot services. Some told us that it was difficult to find time to schedule meetings around case consultations and that their preference was for general training sessions. Service providers told us that case consultations had helped to improve the quality of care of people with PD, and resulted in better use of available resources and cost savings. This view was supported by several of the commissioners whom we interviewed.

7.3.5 Involving service users

Staff at pilot services told us that user involvement is an important part of their plans for improving the quality of the services they provide. However, the extent of service user involvement and the methods used varied considerably between the pilots. Service commissioners identified user involvement as a weakness in some of the pilot services. While all involve users in making treatment choices and decisions about the services they receive, several have been unable to set up and sustain ongoing methods for involving users in planning the development of services. In some pilots, such as The Haven, users have been central to the development of services. In others, particularly those that had little or no PD service prior to the pilot, there was no culture of involving people with PD in local service
developments. As pilot services mature and numbers of people with PD who have used dedicated services increase, user involvement should become easier. Given the early stage of development of dedicated PD services, active user involvement is important in shaping future changes to services.

7.4 Areas of divergence

7.4.1 The assessment process

Accounts of service users and providers were notable for the high levels of agreement on many of the key elements of service delivery. A significant exception to this was around the issue of assessment. The length, depth, and purpose of the assessment process varied greatly between different pilot sites, ranging from a basic requirement to describe current problems and agree a crisis plan, to more detailed assessments conducted by the case-management service and those delivering day-treatment programmes. Staff at pilots where detailed assessments were used emphasised the importance of getting a complete picture of a service user's problems, their personality and their personal history. While a minority of service users told us that they appreciated the detailed assessment they received because it gave them confidence in the service, most were concerned about the level of support they had been offered while being assessed. Some service providers told us that it was important to limit the amount of support that a person received prior to a decision to take them on, in order to try to limit the disappointment service users would experience if it was decided that they could not use the service. Several service users spoke of the distress they experienced during the assessment period as a result of conversations exploring painful past experiences and uncertainty about whether they would be taken on by the service. We believe that these data support the view of Delphi panellists that it is important that those referring people to dedicated PD services continue to provide regular support during the assessment period.

Findings from interviews with service users suggest that the length of assessments that dedicated services provide should be reviewed and, where possible, reduced.

7.4.2 Use of the label 'personality disorder'

Given the commitment that pilot services make to being open and honest with service users it is interesting that not all are explicit about the use of the term ‘personality disorder’. While some are clear that they provide services to people with PD, others use terms such as ‘interpersonal problems’ and ‘complex cases’ to describe the focus of their work. Views of Delphi panellists also varied, with 61% rating their response to the statement: "Information about services for people with PD should always use the term personality disorder" as neutral. The use of the term ‘personality disorder’ also gave rise to a wide range of different reactions among the service users we interviewed. Whilst some people felt angry and resentful about being labelled with a personality disorder, others identified with the label and felt it helped them understand the nature of their difficulties and gave them a better idea about how they could try to overcome them. Previous research has reported that service users feel that the treatment they are offered becomes worse when they are given this label (Ramon et al.)
and service users in this study were concerned about the impact the term might have when they no longer had contact with this dedicated service. Clearly it is important that where this label is used, services take time to explain its meaning and explore the response that service users have to its use.

7.4.3 Care Programme Approach responsibilities

Consensus was reached in round 3 of the Delphi study that ‘Services for people with PD should provide care coordination under the care programme approach’. Most, but not all the pilot services took on CPA responsibilities and services that did this felt that it provided a helpful means of coordinating the care that people received. Service providers told us that people with PD were sometimes in contact with multiple agencies prior to their referral, and that the Care Programme Approach provided a structure to review this and ensure clear communication between all those involved. Some pilots were concerned that CPA procedures were primarily designed for people with mental illness and were not suited to the approach they were using which emphasised the importance of service users becoming more self reliant. A novel approach to this problem was being pursued in some of the day-TCs, where service users become coordinators of their own care. Other services which took on CPA responsibility did so with the explicit aim of working with service users to discharge them from care under CPA at a later date. There was widespread agreement that it is impractical and inappropriate to take on CPA responsibilities when delivering short-term or Tier 1 services to service users. Disruption to continuity of care that would result from care being transferred when people are being taken on for a limited number of sessions of skills training or psychological therapy may also make this impractical. However the data we collected suggests that the benefits of transferring care under CPA when people are taken on by Tier 3 services outweigh the potential harms.

7.4.4 Provision of 24-hour crisis support

While there was general consensus that people using dedicated PD services need to have access to 24-hour support at times of crisis, service providers did not agree about whether this needed to be provided by the PD service itself. Among Delphi study participants 40% were neutral when asked whether out-of-hours crisis support should be provided ‘in house’, a clear majority (67%) of service providers stated that they should not. In contrast, 71% of service users who took part in the Delphi exercise stated that dedicated services should provide their own crisis support service. This echoed finds from the user-led qualitative study where users of pilot services that provided an in house crisis services told us that they were greatly valued and service users at pilots where this was not provided told us they wished it were.

Several services provided some kind of support outside of normal working hours: for instance the service that works with people with PD and substance-misuse problems gives service users access to staff by telephone up to 8.00pm every evening, in keeping with the DBT model. Other services have organised formal systems through which service users can access peer support outside normal working hours. One of the pilot services provides access...
to face-to-face support 24 hours a day. Users of this service told us how much they valued this. Other service providers told us that organising special access to care at times of crisis ran counter to their efforts to help people become more self-reliant. They argued that people with PD needed to be helped to develop ways of coping with crises that did not rely on eliciting an immediate response from service providers. An intermediate model was the offer of a guaranteed emergency appointment at set hours every weekday morning, and the use of e-mail communication, with response on the next working day. It seemed that people in crisis can sometimes wait for support if they have certainty that it will be delivered at the expected hour – and this was true also of the use of crisis beds in one service, where use is predominantly booked in advance on a respite model.

Service users told us about their dissatisfaction with sources of urgent help such as EDs. Many of the pilot services provide training and support to colleagues working in EDs aimed at helping them understand the nature of crises that people with PD experience and how to intervene at such times. Previous research demonstrating that staff who work in emergency medical services may respond to people who self-harm with frustration and even hostility (Jeffery 1979) provides support for these initiatives. However, time pressures and the need to prioritise those who require urgent medical treatment mean that EDs are not an ideal environment in which to try to manage the emotional crises of people with PD. Provision of in-house crisis arrangements was recommended as part of the development of dedicated PD services (National Institute for Mental Health 2003b) but comes at a cost, and the cost–benefits of providing separate services have not been evaluated. Dedicated services for people with PD must attend to people’s need for more intensive support at times of crisis; peer support networks may provide a cost-effective way of providing this.

7.4.5 Self-referral

All but two of the pilot services received most of their referrals from providers of health and social care. The exceptions to this were the service user network, which would only accept self-referrals, and the youth advisory service. Several other pilot services were prepared to accept self-referrals, but only four of these (including the voluntary sector-based skills development service and the information and counselling for adolescents with personality disturbance) took appreciable numbers of people who self-referred. Other services explicitly stated that they could not take people who self-referred. Reasons for this included a concern that the service user was not in receipt of support during the assessment process, and that allowing access to self referral might mean that the services would end up taking people whose level of need was not high enough to be prioritised by a specialist team. Those services that were open to self-referral told us that they were keen to be able to work with people who might have been excluded from services, and that allowing self-referral would promote personal agency and self-reliance. While the Delphi study generated consensus that people with PD should be able to self-refer to dedicated PD services, it is noteworthy that only 54% of service providers supported this view.
The quantitative data we collected revealed that people who self-referred were just as likely to have had previous contact with mental health services. Mean SAP-AS and Social Functioning Questionnaire scores did not differ between the two groups. A non-statistically significant reduction in rate of drop-out from services among those who self-referred provides tentative support for the notion that encouraging self-referral may be one method for increasing retention in services.

Previous research conducted in mental health and substance misuse settings has generated conflicting findings on the relationship between self-referral and engagement with services, with studies reporting both higher and lower levels among those who self-refer (Raynes & Warren 1971); (Allan 1987); (Bell et al. 1997). Previous work using focus groups to obtain the views of service users reports that the people would like the option of referring themselves to services (Haigh 2002). Given the emphasis that pilot services place on promoting choice and autonomy, these data provide limited evidence to support the view that dedicated services for people with PD should be open to self-referral.

7.4.6 The role of medication

Service providers varied in whether or not they believed that medication was of value in the treatment of people with PD. Service providers generally told us that people referred to them were taking too much medication and that they had an important part to play in helping to reduce this. Some commissioners saw reductions in use of medication as a way of generating cost savings to support future funding of dedicated PD services. Some of the pilots that provided day-TCs stated that coming off medication was a requirement for entering tier 3 services: for instance, it was stated that high use of benzodiazepines could blunt psychological awareness and insight. Interviews with service users at these sites revealed that many had found this difficult and some had decided against using them because of this requirement.

While most services took an interest in medication that people were being prescribed, opportunities for changing this were limited in some by the absence of medical input. Two-thirds of Delphi participants supported the statement that ‘Teams delivering services for people with PD should have regular input from a psychiatrist’. Some service leads told us that their budgets were insufficient to pay for what is a relatively expensive resource, but others felt that the presence of a psychiatrist could promote a medical model of PD that they were keen to counter.

When asked whether ‘Dedicated services for people with PD should help service users reduce, with a view to stopping, psychiatric medication’ most stated that they were neutral. Service users were less likely to state that they were neutral than providers and expert authors, with 16% disagreeing with this statement and 48% supporting it. While research evidence suggests that long-term use of psychotropic medication is unlikely to benefit people with PD (Roy & Tyrer 2001), people with PD are at higher risk of developing depression and other mental disorders for which psychotropic medication can be of value. While most services report that helping people to stop taking psychotropic medication can facilitate the
development of better ways of coping with emotional distress insistence that medication be stopped may deter some potential users from engaging with services.

7.5 Innovation

While health and social care services in general and psychotherapy services in particular have always assessed and treated people with PD, few services in Britain have focused specifically on the needs of people with PD. Those that have, have generally provided residential services - very few have delivered community-based services. As a result all 11 pilot services have had to innovate. The case studies in Appendix A provide a detailed description of these services. In this section we highlight notable examples of innovation that link some of the pilot services.

7.5.1 Day therapeutic communities

Therapeutic communities are one of the best-established models for working with people with PD. With their emphasis on group learning and peer support, they aim to promote insight and self-efficacy. While therapeutic communities have always assessed people in the community, historically their emphasis has been on residential treatment. Observational studies comparing the outcome of people with PD who are treated in residential therapeutic communities suggest they are less likely to self-harm and have lower levels of subsequent service utilisation than those who are not so treated (Davies & Campling 2003); (Chiesa & Fonagy 2003). Five of the 11 pilot services stated that the development of their service was based on or influenced by therapeutic community principles: four involved setting up day treatment programmes and the fifth, a series of outpatient groups for people with PD. Like residential TCs, the day-TCs use a variety of techniques to empower service users and promote insight. Service users, or ‘members’, are involved in decisions about content of groups and whether someone new can join the programme. They also share the responsibility for ensuring that agreed boundaries are adhered to. Established members are elected to more senior positions and given additional responsibilities for overseeing the service. Opportunities for involving members in practical decisions about living arrangements are inevitably more limited than those in residential TCs, and members can not be included in discussions following crises as quickly as when members live together 24 hours a day. Concerns have previously been raised about the high level of commitment required of service users if they are to leave their home and live in a residential TC. This may be one of the reasons why residential TCs work with a minority of the people that are referred to their service. Day-TCs ask less of their members and our data suggest that the proportion of people referred to these day-TCs who engage with services is higher than for those providing residential treatment (Rutter & Tyrer 2003).

Previous research has indicated that TC services that combine residential and outpatient treatment are at least as effective as those based solely on the former (Chiesa et al. 2004). However, given that the intervention is one which is based on peer interaction and support, there presumably comes a point where it effectively ceases to be a ‘community’. Therapeutic
communities are cultures which take time to develop and mature, and this was especially
difficult within the life of the pilot funding. Service commissioners questioned the intensity of
the service provided by some of the day-TCs and other pilot services. Treatment programmes
at pilots using a day-TC model varied from five days to one day per week. The intensity of the
service has important implications for the capacity of the service and its cost-effectiveness.
The impact of different models has not been examined. It is also unclear whether the
advantages of a day-TC in terms of reduced cost and increased level of engagement are
offset by a reduction in impact on treatment outcomes as compared with their residential
counterparts.

7.5.2 Encouraging peer support
Service providers across the pilot sites described the value of peer support and most provided
some form of intervention that brought service users together in groups. Several services had
developed ways of harnessing peer support as a method of helping people cope with crises
outside normal working hours. The internet-based ‘P2P’ (peer to peer) service developed in
North Cumbria provides a notable example of this which may have particular application in
areas that are sparsely populated (see Appendix A9). Such services offer the potential for
service users to develop ways of coping with crises that do not rely on contact with health-
and social-care professionals. The role that service users play in supporting each other may
also help to improve self-efficacy and self-esteem.

However, some service users reported that they had encountered problems with systems
designed to facilitate peer support, stating that they felt they ended up taking on other
people’s problems. Others talked of cliques developing which led to new sources of tension
and distress. Systems for facilitating peer support are still at an early stage of development
and methods for guarding against abuses of such services may need to be further refined.

7.5.3 Other examples of innovation
Many people with PD describe a childhood characterised by inconsistent or absent care
(Widom 1989); (Luntz & Widom 1994). People with PD often present with concerns that they
have been denied help and support later in their lives, which are often based on actual
experiences of being excluded from mainstream services. Several pilot services have
responded to this sense of unmet need by providing access to help and support that people
may have been denied in the past. For instance, at The Haven in Essex service users have
access to short-term residential support. In other services, such as the Complex Cases
service in Cambridge, service users are given the right to book themselves in to an open-
access clinic with a senior member of the team. Users of these services told us that they
valued them, and service providers told us that, contrary to expectations, they are rarely
overused.

Innovative approaches used by other pilots involved extending access to a service that was
already available to people with other mental health-related problems. The ways that services
such as support for primary care workers, case management and early intervention for
adolescents were modified to suit the needs of people with PD are described in detail in Appendix A.

7.6 Challenges

Most of the data we collected suggest that pilots were delivering services that were valued by users, referrers and commissioners. However, several concerns were raised, some of which have been discussed in Section 7.4. Others include the effectiveness of services, the management of people with ASPD, working with people who show little motivation to change, working with carers, and procedures for discharging people from dedicated services and providing aftercare.

7.6.1 Service effectiveness

Some of the referrers we interviewed raised the issue of how effective dedicated services were in helping people with PD to change. The issue was also repeatedly raised by commissioners, who tended to focus on whether dedicated services resulted in reductions in expenditure on other services. Several service providers have collected local data that charts reductions in use of emergency medical and other services among people taken on by their service. However, some referrers commented that there were many other people with PD in the local area who were not motivated to make use of the service and for whom the development of the local service had therefore made no difference. These comments raise the issue of whether, and if so, how, dedicated services should try to engage people who have PD and who have little motivation to change (see below). They also highlight how weak the evidence base is for the effectiveness and cost-effectiveness of community services for people with PD. With the exception of the DBT model being used by one of the pilots, and the Social Problem Solving groups run by another, none of the interventions being delivered by pilot is based on evidence from high-quality research studies. It is therefore unsurprising that Delphi respondents did not oppose the statement ‘Evidence from research studies about “what works” for people with PD is too limited to guide service delivery’ (60% responded that they were neutral, 22.5% supported the statement and only 17.5% opposed it).

Data we collected from users of pilot services suggests that many people value the service provided by the pilots, and their accounts provide personal testimonies in support of the value of these services. However, it is equally clear that self-harming behaviour among people with PD tends to reduce over time and that many people with PD make changes to their lives without input from dedicated services (Zanarini et al. 2003).

In the short term the support of colleagues in other services and the personal accounts of users should be sufficient to ensure that such services continue to be funded. All pilot services have collected some audit data tracking changes in service utilisation among people prior to and following referral to their service. We believe that they should need to continue to audit the impact of their work on levels of use of other services and that further research is required in order to compare different approaches to helping people with PD if such services are to be sustained and extended in the future.
7.6.2 Motivation to change

Many, perhaps most, of the users taken on by these pilot services were ambivalent about whether they wanted to receive a service. Many users told us that previous experiences of health and social care had left them suspicious of services and doubtful about whether or not they could be helped. Staff working in all pilots told us that they expected that many people referred to them would be unsure whether they wanted a service and agreed that a central part of their work involved efforts to build trust and promote engagement.

Pilot services provided a range of interventions to individuals and groups aimed at providing information about PD. Some groups were explicitly set up to explore and promote motivation to change. Service providers told us that a degree of motivation to change was essential if people were to use individual or group psychotherapy. Data from the cohort study shows that 91% of people on whom we obtained clinical data believed there was ‘something they wanted to change about their personality’. While the degree of motivation to change among people with PD in community settings is unknown, one study reported that only 25% of those with dual diagnosis of mental disorder and PD who were receiving services from an assertive outreach team wanted to do so (Tyrer et al. 2003a). The high degree of willingness to change among people in contact with these services suggests that many of those with PD who were not willing to change were not referred to or taken on by these services: this view was supported by referrers who told us that they worked with people with PD who had declined referral to these services.

One exception to this was the Leeds Personality Disorder Network, which specifically targeted people on the basis that existing services had not found it possible to work successfully with people, rather than on the basis of their interest in using a dedicated PD service. A quarter of those on whom we received quantitative data from this team stated that they did not want to change aspects of their personality. Local referrers whom we spoke to valued the willingness of this team to work with what were seen as being those difficult users. Perhaps not surprisingly, this team reported difficulties in trying to engage service users in psychological treatments and this illustrates a dilemma in planning services for people with PD – how should services respond to those with high levels of need and low levels of motivation to change? Most members of our Delphi panel did not support the use of home visits or assertive outreach for people in contact with PD services. While pilot services encouraged people to attend, few undertook outreach and they tended instead to emphasise the importance of peer support and helping people with social and other practical problems as a way of promoting engagement with services.

Methods for working with people with PD who do not want to change their personality are being developed. One such approach, nidotherapy, focuses on efforts to change the person’s environment rather than their personality (Tyrer 2002); (Tyrer et al. 2003b). Such methods could play a role in helping dedicated PD services in their efforts to engage and work with people who have severe PD but show no interest in understanding and modifying their emotions and behaviour.
7.6.3 The needs of ethnic minority service users
The proportion of people from BME communities who were referred to pilot services was generally lower than estimates of the proportion of BME residents in the local people. Reasons for this are unclear. It has been suggested that PD is less prevalent among BME communities in Britain (Strakowski, et al. 1995), but there is little evidence to support this notion. The prevalence of PD among people from BME communities was slightly lower in the Household Survey of Psychiatric Morbidity, but the difference was not statistically significant and was based only 18 people from BME communities who were thought to have PD (Coid et al. 2006). An alternative explanation for the low rate of referral is that people with PD from BME communities were less likely to be referred to dedicated PD services. Previous studies have reported lower levels of referral and uptake of psychological services among people BME service users (Littlewood & Lipsedge, 1989), and reports from service leads highlighted the problem of assessing the minority of BME users who find it difficult to communicate in English.

We also found evidence that BME service users who engaged with PD services were less likely to leave them prior to completing a package of care. Again reasons for this are unclear. This finding was not based on an apriori hypothesis and while it was statistically significant it is possible that it was merely a chance finding. There was also missing data, one service did not have data on ethnicity on a quarter of referrals. Interviews with service users raised issues about how minority groups are treated especially in group settings.

Delivering race equality in mental health care is a national service priority (Department of Health, 2003) and we believe our data highlighted the importance of dedicated PD services accurately record ethnicity and ensuring that the interventions they deliver are culturally sensitive.

7.6.4 Working with people with ASPD
Most of the pilot services excluded people with ASPD and several explicitly excluded people with this diagnosis. While a substantial minority of people taken on by pilot services had a forensic history (between 3% and 9% of those who provided quantitative data had been charged with an offence during the previous 6 months), few if any appear to have had ASPD. Several pilot services provided tier 1 support to probation officers and other criminal justice workers and the case-management service employs part-time probation officers as part of its network.

Providers of dedicated services spoke of their concerns that people with ASPD may be unresponsive to psychological treatment and could disrupt the care of other service users. Some referrers we interviewed spoke of their frustration that people with ASPD could not be referred to their local service, though others shared the concern about the impact people with ASPD could have on the care of other people with PD. Commissioners pointed out that as most of the costs associated with ASPD are borne by criminal justice services rather than mental health and social care, the criminal justice system may need to finance the development of such services.
While an evidence base for community-based interventions for people with ASPD does not exist, this is equally true of other forms of PD that pilot services are prepared to work with. Randomised trials of Cognitive Therapy and Mentalisation Based Therapy for people with ASPD are in progress. Should such interventions be demonstrated to be beneficial, further consideration will need to be given by dedicated services as to how they can engage and treat such people: if not, ASPD will remain a diagnosis of exclusion. These issues will also be explored in greater detail in a report on a parallel study on the organisation and delivery of forensic services for people with PD which is due to be published in autumn 2007 (see: http://www.sdo.lshtm.ac.uk/files/project/84-sci-summary.pdf).

7.6.5 Carers

While several pilot services planned to work with carers as part of their original application for funding, we identified few where this had occurred. All services recognised the important role that family and friends may play in supporting people with PD and service users were generally asked if they wanted carers to be included in review meetings. However, specific services for carers were rarely provided and several pilots told us that providing direct services to people with PD and indirect services to colleagues had been a greater priority. A group set up by the Thames Valley Initiative was a notable exception to this. The group combined psychoeducation with efforts to promote peer support. Interestingly, members decided that they should call themselves a ‘family and friends group’ rather than a carers’ group. Much of the discussion in the group was about the way that members tried to support someone important to them who had PD and it was felt that the term ‘carer’ provided too narrow a definition of this role. Members talked about having to balance the service user wanting to be cared for with their hope of helping the person to become more self-reliant. Service users told us of the central role that family and friends sometimes played in helping them make progress. Pilot services have been slow to work with significant others, but the work that has been conducted suggests that this can be an important intervention that helps to support some people with PD.

7.6.6 Compulsory treatment

The issue of compulsory treatment of people with PD was notable by its absence from interviews with service providers and commissioners. Proposals for the reform of the 1983 Mental Health Act make it clear that the definition of mental disorder that will be used will be simplified in order to ensure that it can be applied to people with psychopathy and other forms of personality disorder (Department of Health 2006). While consensus was not reached on whether ‘There are circumstances when it is appropriate to use the Mental Health Act to compel a person to attend community-based services for treatment of personality disorder’, more people opposed (56.3%) than supported this statement (11.3%); service providers were more likely to oppose it (74.1%) than were expert authors or service users. This finding is in keeping with results of surveys of mental healthcare professionals who have previously voiced their opposition to plans extend use of
the Mental Health Act in England and Wales to include people with ‘psychopathy’ (Crawford et al. 2001).

While forthcoming reform of Mental Health Act legislation may lead to a change in the way that services assess and treat people who are considered to pose a danger to others, providers of community-based services for people with PD clearly see little role for its use in the services they provide.

7.6.7 Discharge
Service users told us of their anxiety about being asked to leave pilot services. Services providers told us that they were concerned that people with PD may have had previous experiences of being rejected or abandoned by others and that the discharge process had to be handled with great sensitivity. Most services took people on for set time periods that were made clear from the start. For instance, users of the primary-care-based community links service know in advance that they will be offered up to six sessions with a worker. For most other services a more flexible approach was taken to the date at which people might leave. The Haven and the Service User Network aimed to keep open a place for all those who made contact with the service. Similarly the Leeds PD Network undertook to deliver long-term support to people with PD. However, service providers were also mindful of their limited capacity and accepted that without throughput they would no longer be able to take on new referrals. Despite this, several services were still at an early stage of developing plans for when someone left the service. In some instances the plan being discussed with service users was that they would be discharged without specialist interventions but with continuing support from primary care. In this respect the approach used by the GP liaison service in north London may be important in helping dedicated services work out how best to support GPs in their longer-term work with people with PD. Other services were exploring the possibility of formal mechanisms through which service users might continue to access peer support.

7.7 Implications for providers of dedicated services
7.7.1 More than one intervention
The diverse range of problems that people with PD experience means that dedicated services have to be able to deliver a range of interventions. Delivering more than one intervention means that people can be offered choice, which may of itself be therapeutic for a group of people who have often been denied choices in their pasts. Limits on capacity to deliver direct services mean that dedicated PD teams need to be able to provide tier 1 support to colleagues working in other services. Dedicated services need to be able to provide access to peer support, group and individual therapies and practical assistance to help people manage their social problems. Dedicated services need to consider how to develop interventions for people with PD who have significant needs but are unwilling to engage with psychological interventions, including those who present risks to others (see Section 7.6.2).
7.7.2 Assessment and engagement
Many people with PD are told that general services are unable to help them, and may therefore see dedicated services as ‘the end of the line’. The stakes involved at the time of the assessment are therefore very high, and the process of assessment is often a stressful one. It is important that assessment processes are no longer than required and that service users are given clear information about what support is available to them during this process. The way that feedback from assessment is delivered also needs to be carefully considered: reasons why someone is considered unsuitable for a service need to be carefully explained and options for alternative sources of help provided. Those services that use the term PD need to explain its meaning, to be aware of the negative connotation that this term has in the minds of many, and to consider the impact that using this term may have on the ability of the user to access other services in the future.

7.7.3 Delivering direct services
We have listed important considerations for those delivering dedicated services to people with PD in Text Box 7.2. Chief among these are the qualities of front-line staff (see Text Box 7.3), and arrangements for providing staff support. Service users want to know about the therapeutic approach that the PD services use. Maintaining a mystique about therapeutic process can leave users feeling disempowered most services therefore made concerted efforts to talk to users about the treatment approach they used. The rationale and extent of boundaries that service users will be expected to adhere to need to be carefully explained, as do arrangements for out-of-hours support and any boundaries relating to contact with peers. Service users highlighted the contact they have with administrative staff; training and support for administrative staff are also important.

7.7.4 Endings
Providers of dedicated PD services need to prepare users for moving on from the service at an early stage. The service users we interviewed told us how hard they thought moving on would be and many were worried that ending contact with the dedicated service would mean they would be denied all access to mental health services. Some services have responded to these concerns by allowing long term use of their service. However this approach is likely to limit the number of new referrals some services accept in the coming years. Most services had therefore begun to develop ‘step-down’ programmes through which people who have received a period of regular treatment can continue to access a less intensive component of the service, such as an open peer support group or occasional review meetings. Such approaches may enable service users to retain and further develop coping strategies and other skills they developed in their initial period of using the service. Consideration should be given to providing some form of further contact with the service, opportunities to access peer support, or means by which users might access the service again in the future.

7.7.5 Tier 1 interventions
Limited capacity of dedicated services to deliver interventions to people with PD mean that indirect service provision will remain an important part of the work of such teams. Staff
mobility in the public sector means that this needs to be part of a rolling programme and not seen as a one-off event. Service users can help to direct provision of tier 1 interventions to those services they have experienced the greatest problems with. Indirect service provision may be more effective when it is delivered by those who also provide direct services. It is thought to be more helpful when delivered to teams rather than individual members of staff. General teaching on the aetiology and management of PD as well as detailed discussions of individual service users are both valued by recipients of tier 1 interventions.

7.7.6 Audit and research
Providers of dedicated services will need to continue to provide evidence of the impact of their interventions. While efforts continue to explore the impact of interventions on mental health, social functioning and quality of life, commissioners of services may be more interested in changes in service utilisation among those in contact with the service. Commissioners highlighted reductions in use of out-of-area placements and in time spent on mental health units. Service providers will need to ensure that they are working with people who are high users of other services and that ongoing systems are in place for monitoring changes in service utilisation among the people they work with.

7.8 Implications for general services
Dedicated PD services need to provide information and support to potential referrers about their service, how to prepare users for referral, and how to manage people with PD who are not referred. For those who are referred the assessment process can be a stressful one and users need support during this period. Not all those referred to a dedicated team will be provided with a service, so a message that referral represents a final or last chance of their gaining support can make the assessment process more stressful and potentially harm the service user.

Those working in dedicated services have identified a range of process factors that they feel should guide the delivery of services to people with PD (see Text Box 7.2). These stress the importance of open communication, explicit boundaries, reliability and consistency and support for those who provide services. We believe that these factors are also relevant to those working with people with PD in other contexts, including mental health and social services.

7.9 Implications for service users
7.9.1 What dedicated services can provide
Dedicated services vary in what they provide. This is because of the area they serve, differences in the availability of other types of mental health and social services, and the local expertise and training of those working with people with PD. Those providing dedicated services recognise that people with PD have a range of problems including emotional and social problems: the interventions they deliver aim to combine practical help with psychological approaches to help people understand themselves, their relationships with
others and try to help people develop better ways of coping. There are limits to what any service can deliver and services should be made clear at an early stage.

7.9.2 The assessment process
The assessment process can be difficult and may stir up distressing feelings. Services should make sure users are clear about what sources of help are available during this time. Not everyone who is referred to a dedicated PD service will want to use it. Some people may not be suitable for the service. For instance people who use alcohol or drugs every day may need to take steps to reduce their use of these substances. While dedicated services are used to helping people who have angry feelings and may find it difficult to control their temper, they need to be able to provide a service which is safe for staff and other service users and are usually unable to work with someone who threatens or tries to harm others. The team needs to explain the results of their assessment to service users and discuss alternative sources of help and support that are available should these be required.

Most, but not all, dedicated services use the term ‘personality disorder’ because they believe it summarises a group of problems that some people experience and indicates an approach to providing services that is most likely to help. However people who have been given this label sometimes feel that the treatment they receive is harmed as a result. Dedicated need to explain the terms they use, provide you with alternative sources of information about PD, and discuss the impact that the use of this term may have on the services that people subsequently receive.

7.9.3 Using the service
Those delivering dedicated services understand that many people with PD have had previous experiences of contact with services that have been unhelpful and in some instances harmful. They understand that these experiences often leave people unsure about whether they want to have contact with health and social care professionals. Most of the service users who took part in this study told us of the benefits they experienced as a result of using dedicated PD services (see Section 4.3.6). They hoped that these might encourage people who are unsure about using these services to try them out.

One of the aspects that people told us had helped most was also one of which they had initially been most wary – contact with other service users. People told us how hard it was to trust others. Those who went on to use groups successfully told us that they had originally thought they could not talk to others in groups. For many, group work and peer support were the things they had found most helpful about a service.

Most services set rules and boundaries that govern what service users can expect and what is expected of them. These boundaries aim to make the service reliable and safe and are considered important by people who deliver services and those who use them. Staff at dedicated services need to take time to explain their boundaries and to help service users understand their importance.
7.9.4 Getting involved
Dedicated community-based services for people with PD are in an early stage of development. Staff are keen to get feedback from people about their experience of services. Service users who get involved can make a difference to the way that services develop in the future. Some dedicated services also provide opportunities for users to play a more active role in delivering services and supporting others. Information about what people are expected to provide if they take on these roles, and what they may gain must be made available. It is also important for people taking on these roles to find out what support will continue to be available to them should they need it.

7.9.5 Ending contact with the service
For many people, ending contact with a dedicated service is a positive step in response to progress that has been made. However, endings can be difficult, especially for those who have had previous distressing experiences of other endings. Staff at dedicated services need to take time to encourage service users to talk and think about endings and make plans for endings well in advance of a leaving date. Services need to ask users to prepare for leaving and consider other sources of help that will be available when this time comes. Some services will continue to provide access to a part of the service and others allow people to re-contact the service at a later date in order to review the situation and think about the pros and cons of further contact with the service.

7.10 Implications for commissioners
7.10.1 Priorities for service development
While general mental health and social care services need to be able to assess and support people with PD they currently lack that capacity to deliver interventions aimed at treating people with these problems. Existing psychology and psychotherapy services are able to deliver treatments for people with PD but may struggle to provide sufficient support and containment to enable people with severe PD to successfully engage with treatment services. Dedicated PD services deliver psychological and social interventions for people with severe PD and have the ability to combine these with structures to foster peer support and group-work and provide tier 1 interventions aimed at supporting colleagues working in general health and social care settings. Those involved in delivering community-based services for people told us that 'one size does not fit all', users of services told us that they valued services that offered choice. While the data that we collected do not allow us reach conclusions about the cost-effectiveness of different approaches to working with people with PD, our findings suggest that a dedicated service for people with PD should offer a range of individual and group-based interventions that combine psychological and social approaches to helping people with their problems and optimise opportunities for people to obtain peer support. This recommendation is in keeping with findings of our Delphi study that also highlighted the value of case management and day-treatment programmes and highlighted the importance of efforts to support people back into training and employment. Limited
capacity of dedicated services means that direct work with people with PD needs to be combined with efforts to support and train people in non-specialist services.

7.10.2 Evidence-based services
The evidence base to support the delivery of community-based services to people with PD is poor. While personal testimony of service users who participated in this study suggests that many people with PD can and do benefit from their contact with dedicated services, further effort needs to be made to establish optimal ways of working and those interventions that are most effective.

Randomised trial of Dialectical Behaviour Therapy (Linehan et al. 2006), Cognitive Behaviour Therapy (Davidson et al. 2006), Transference-Focused Therapy (Giesen-Bloo et al. 2006) and psychoanalytically informed psychotherapy (Bateman & Fonagy 2001) for people with borderline personality disorder have demonstrated a positive impact on health and social outcomes. Clinical trials of Social Problem Solving (Huband et al. 2007) and CBT (Emmelkamp et al. 2006) suggest they may be helpful for people with other forms of PD. Data from evaluations of residential therapeutic communities suggest that this is also an effective approach to helping people with PD (Lees et al. 2004). Dedicated services for people with PD should be encouraged to continue to evaluate the impact of the work they do and to deliver interventions that are evidence based. Quality of life, social functioning and level of mental distress are the outcome measures that service users and providers believe should be included in such evaluations. Consideration should be given as to how services that aim to deliver evidence-based interventions monitor the quality of the interventions they provide.

7.10.3 Timescale for service development
There is widespread agreement that it takes time (years rather than months) to help people with PD develop better ways of coping. Data from this study suggest that it also takes time to develop successful dedicated services. Services that aim to foster peer support and deliver group-based interventions need time to allow service users to understand their approach to treatment and develop a culture that helps new users understand the model and provide mutual support.

7.10.4 The role of inpatient services
Many of the most important and valued services for people with PD in Britain have delivered residential treatment. Much of the learning that has enabled community-based services for people with PD to develop is based on their expertise. However, the development of community-based services has threatened these established units, not least because commissioners, keen to support continued funding of community services at a time of budgetary constraints, have argued that community services save money that would otherwise need to be spent on more costly inpatient treatment.

This study has not explored important questions about whether there is a group of people with severe PD who are unable to use community-based services and may benefit from residential treatment. However, we did explore the views of expert authors, and users and provider of services about priorities for development of services for people with PD. All three groups...
stated that the development of community services was a high priority and placed the inpatient services as the lowest priority. Given the consistent reports of improved health and social functioning reported by providers and users of these pilot services we believe that, in those areas where dedicated services exist, community-based treatment should be tried prior to considering the need for referral for inpatient treatment.

7.10.5 Role of voluntary sector and criminal justice system

Nine of the 11 pilot services that we studied were nested within existing statutory services. However, several of the pilots had developed links with the voluntary sector and one included funding to a voluntary sector organisation aimed at helping people access work and training. All the pilot services emphasised the importance of avoiding coercion and paternalism and supporting choice. We believe that services in the voluntary sector are well placed to deliver these approaches to helping people with PD and that future commissioning of services should explore opportunities for funding partnerships between statutory and voluntary-sector service providers. The voluntary sector may be particularly well placed to coordinate and support service user led initiatives such as peer support groups.

Considerable uncertainty surrounds the issue of whether and how dedicated PD services can work with people with ASPD. If evidence begins to emerge that people with ASPD can be helped by community-based services, dedicated PD teams would be well placed to deliver these. Given that most of the costs associated with ASPD are borne by the criminal justice service, commissioning such services would need to involve partnerships between healthcare and the CJS.

7.10.6 Cost savings and cost-effectiveness

Previous research has demonstrated that people with PD incur health and societal costs that are much greater than those with other mental health related problems (Perry et al, 1987; Knerer et al, 2005). Previous studies have also shown that interventions for people with PD can lead to substantial reductions in the use of emergency medical and inpatient mental health services (Bateman & Fonagy, 2004; Davidson et al, 2006). These findings are supported by audits conducted by several of the pilots showing reductions in the use of these resources. At a time of budgetary constraints expansion of dedicated PD services may depend on their ability to demonstrate cost savings. However, as with other components of the healthcare system, consideration should also be given to improvements in mental health and quality of life and the cost-effectiveness of interventions delivered by such services.

7.11 Areas for future research

7.11.1 Indirect service provision

All 11 of the pilot services provided some tier 1 interventions and staff made a variety of suggestions about how these could best be delivered. However, we are unaware of any previous research that has tried to examine the impact of such interventions or compare the different approaches that are used. Anecdotally, service providers gave examples of instances where people who were being treated on inpatient units were subsequently
discharged following case consultation. Those in receipt of indirect services told us that they felt more confident working with people with PD. However, at a time when an evidence base for the effectiveness of psychological interventions for helping people with PD is beginning to emerge, the impact of indirect service provision has not been quantified. A recently published randomised trial of Social Problem Solving (Huband et al. 2007) suggested that it is possible for people with limited previous experience of working psychologically with people with PD to be trained to develop an effective intervention. The relative impact of training people in general teams to deliver such interventions, compared to advice and support delivered by dedicated services, should be examined.

7.11.2 Direct service provision

Experimental studies should be conducted to examine the effects and cost effectiveness of the approaches being used by pilots to help people with PD - notably day-TCs, DBT, case management services and service user networks. Further work also needs to be conducted to examine the effects and cost effectiveness of residential treatment services for those who are unable to engage with or benefit from dedicated community-based services.

7.11.3 ASPD

We believe that pilot studies combining qualitative and quantitative methods should be undertaken that would examine methods through which people with ASPD can be treated in community settings. Approaches such as day-TCs, nidotherapy and social problem solving have the potential to help people whose personality disorder is characterised by impulsivity and disregard for the rights of others. While there are likely to be major challenges associated with offering interventions to people with ASPD in community settings and services may need to separate from those delivering interventions for people with other forms of PD, people with ASPD experience high levels of mental distress and social dysfunction and efforts should be made to see if it is possible to extend services in order to provide interventions for people with this disorder.

7.11.4 Prevention

Research is beginning to emerge that suggests that parenting programmes and educational interventions can prevent the development of behavioural problems among younger people (Raine et al. 2003); (Hutchings et al. 2007). Such interventions also offer the potential to reduce the incidence of personality disorder. Several of the pilot services are developing interventions aimed at parents: these offer the prospect of reducing the likelihood of the social transmission of personality-related problems. The Icebreak service in Plymouth also aims to intervene at an early stage in order to halt the development of inter-personal problems. Research into interventions that aim to reduce the development of personality disorder also need further evaluation. Such studies should adopt the staged approach to evaluating complex interventions and incorporate both qualitative and quantitative research methods (Campbell et al. 2000).
**8 CONCLUSIONS**

The development of the 11 dedicated services for people with PD appears to have been welcomed by commissioners, users and providers of local services. Dedicated services are seen as having the capacity to combine delivery of help with social problems, access to peer support and psychological interventions aimed at reducing emotional distress and improving quality of life.

There was widespread agreement about principles that should underpin service delivery, including the need for open communication, explicit boundaries, consistency, and support for those who provide the service. Services need to be delivered over relatively long periods and to take time to help people plan their leaving. However, there is a lack of consensus about important issues such as the role of outreach and medication.

Service users praised the personal qualities of staff at the services and spoke of the value of peer support. Most told us that contact with dedicated services had helped them understand their problems better and change aspects of the way they feel about themselves and relate to others. However, concerns were expressed about assessment procedures and what would happen when their period of contact with the dedicated service came to an end.

Pilot services have succeeded in working with a substantial number of people with PD who have high levels of social dysfunction and suicidal behaviour. However, there are many people who are thought to be unable or unwilling to use services as they are currently configured. These include those who are very chaotic and people with antisocial personality disorder. Men were under-represented among referrals and those taken on by services.

Given the high prevalence of PD, services face the challenge of how best to use their limited resources; in particular the balance between direct and indirect service provision, and how much time they should invest in those with low levels of motivation at the expense of those who decide to try to use such services. Dedicated services may be able to increase their capacity by developing structures that provide peer support.

The long-term survival and expansion of dedicated services for people with PD will require the commitment of policy makers, and further evidence that intervention leads to improved outcomes and reduced use of other services. People with personality disorder are known to incur health and societal costs that are much greater than those with other mental health problems and if the cost of providing services could be at least partly offset by savings this could provide justification for further service development.

The 11 pilot services we evaluated achieved a considerable amount over a limited period of time. They appear to be delivering high-quality care to a group of people who have been poorly served in the past. We believe that the lessons they learned and feedback from service users can guide the development of new services for people with PD.
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**DISCLAIMER**

Please note: The views expressed in this report are those of the research team and are not necessarily shared by those of the Department of Health or the funder (National Coordinating Centre for NHS Service Delivery and Organisation)
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