A project conducted in partnership by the Mental Health Foundation, Imperial College London, University College London and Kings College London and commissioned by the National Institute for Health Research Service Delivery and Organisation Programme

Background
It is estimated that 5% of people in Britain have a diagnosis of personality disorder (PD). People with a diagnosis of PD have an enduring pattern of inner experience and behaviour that deviates markedly from cultural expectations. These problems manifest themselves in difficulties in coping and problems with relationships, ranging from a lack of interest in others to feelings of dependency and fears of rejection. Many people with a diagnosis of PD have distressing fluctuations in mood and long term feelings of emptiness and despair. They are more likely to experience mental illness, substance misuse, and social problems.

Concerns have been expressed about the quality of services for people with a diagnosis of PD. Many working in mental health and social care feel they are unable to help people with a diagnosis of PD and some believe that they should not be offered a service. Service users have reported being dissatisfied with services. In response to these concerns, the Department of Health funded a range of training initiatives and service developments aimed at improving the quality of care of people with a diagnosis of PD. These included funding for 11 dedicated community-based pilot services for people with a diagnosis of PD in England.

The research
This research evaluated the 11 pilot community services and captured the lessons learned during the initial phase of their development. These findings were used to make recommendations for future service development. The evaluation involved:

- An exploration of the characteristics of people who had been referred and taken on by the pilot sites
- In-depth interviews with service providers (managers and front-line staff at each of the services)

- In-depth interviews with referrers and commissioners for each of the services
- In-depth interviews and focus groups with service users who are currently using the pilot PD services, service users who had previously used the pilot PD services and carers of people who are using/had been using the pilot PD services
- A national survey aimed at finding out how service users, service providers and researchers believe services for people with a diagnosis of PD are best organised.

Service user involvement in this project
In this project, service users were active members of the Advisory Group and Steering Group. A team of 11 service user research interviewers were recruited and supervised by research staff at Mental Health Foundation. This team were involved at all levels of the project, including advising on the design of the interview schedule, carrying out interviews and focus groups with service users and carers, analysing data and contributing towards the final report.

A brief description of the 11 services
The 11 pilot services provide a diverse range of innovative approaches to helping people with a diagnosis of PD and serve areas ranging from metropolitan boroughs to county districts covering over 2 million people. Ten of the 11 services are for adults with a diagnosis of PD and personality-related problems and one 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 wide range of services and support. Most services take referrals from a range of different sources but one was only open to self-referrals and another took all their referrals from primary care.
Characteristics of the service users referred to and taken on by the pilot sites
We obtained basic information about 1,432 people who were referred to the 11 services over a 34 month period. The average age of those referred was 35 years and the majority of referrals were white females who 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. The 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 different services. The main reasons why people were not taken on was because they either did not attend or complete an assessment. Women were more likely to engage with services and complete treatment than men, white-British services users were more likely to engage with services and complete treatment than those from other ethnic groups, and young people (especially those aged below 20), were less likely to engage with services or complete treatment than older service users.

Service providers’ opinions on dedicated PD services
A total of 89 managers and front-line staff from the 11 pilot services were interviewed. There was broad agreement between providers about the basic structure of services for people with a diagnosis of PD:

- They should be delivered over a relatively long period of time
- They should be consistent, reliable and validating rather than dismissive of user’s experience
- They should promote independence and choice
- They should deliver more than one intervention to suit people with different levels of motivation and that interventions should be social as well as psychological
- Peer support and group-work are important interventions that can help people develop increased tolerance of others, improved insight and better ways of coping

They felt that staff in dedicated PD services should:

- Be responsive to service users
- Have the ability to work flexibly, but not at the expense of neglecting boundaries
- Work with service users to generate short and long term goals
- Help service users plan how they will deal with crises
- Help service users prepare for when they leave the service
- Work closely with the rest of the staff team
- Receive regular supervision and be managed in a way in which contains staff anxieties

Referrers and commissioners opinions on dedicated PD services
A total of 39 referrers and commissioners were interviewed. 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 a diagnosis of PD. Some felt that existing services were often unhelpful and that the development of dedicated services had challenged the notion that there was nothing that could be done to help people with a diagnosis of PD. Others were disappointed that dedicated services were unable to work with people who were very chaotic or not sufficiently psychologically minded.

Most of the commissioners interviewed had been involved in setting up pilot services and were positive about them. However, they expressed concerns about the small numbers which some had taken on and were keen that others expand the geographical area that they served. Some felt that PD services should become more integrated with other services. Others warned that services for people with a diagnosis of PD were not a high priority and that unless it could be demonstrated that they resulted in savings elsewhere, long term funding was uncertain.

Service users and carers experiences of services for people with a diagnosis of PD
Across the 11 pilot sites, 133 service users and carers were interviewed. These consisted of 108 current service users, 15 ex-service users and 10 carers of people using the services. In the interviews, a number of themes emerged:

1. The ‘coming in’ process
Many service users spoke of the ‘coming in’ process and discussed the dual themes of rejection and acceptance. Many talked of feeling rejected and dismissed by mental health services and so approached specialised PD services with a sense of hope combined with fears of rejection from what many had been told was their ‘last chance’. Some users reported that the assessment process was distressing and that they were not sufficiently supported during this time.

2. The Model of Service
There was a strong belief that no one service model or approach fits all. What was important to service users was flexibility and accessibility, the role and qualities of staff and the provision of good out-of-hours or crisis support. The extent to which rules were explained and negotiable was an important issue and 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, 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.

3. Relationships with Staff
The role and qualities of staff was a 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, genuine, flexible and knowledgeable. Criticisms of staff were relatively few.

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

5. Service User Involvement
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 spoke positively about feeling involved in decisions made about their own treatment or care and they valued the recognition, value and empowerment they gained through this. However, service user involvement was under-developed in some services at the time of the interviews and could be extended and developed to enable service users to have more say in their own care and in the day to day running of the service.

6. Outcomes
Nearly all of the services had been beneficial to people, many of whom spoke movingly about the changes they saw in themselves, in the way they felt about themselves and in the way they understood themselves. People saw changes in their behaviour and in the ways in which they related to or interacted with others. Very few service users discussed negative or insignificant outcomes.

7. Diversity – and lone voices
There were positive and 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, whilst in others, concerns were expressed about a gender imbalance and about the treatment of black and minority ethnic service users.

8. External factors
Some external factors were felt to have an impact on the service. Location was one key issue, particularly in those services based in rural areas where some service users were concerned about the travelling distance. Another important factor was the quality of the service facilities (e.g. whether the facilities felt warm and welcoming or whether they were seen as too noisy or too cramped).

9. Carers
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.

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 many service users, it was important that they were given clear information and preparation for endings.

National survey
Ninety-nine people responded to the survey, with approximately equal numbers of service users, service providers and researchers. There was agreement that there is a need for dedicated services for people with a diagnosis of PD and that interventions should be delivered over years rather than months. They also highlighted the importance of personal qualities of the 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. Participants rated out-patient 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 a diagnosis of PD. It was felt that services should be judged by their ability to improve quality of life and social functioning of people and decrease levels of mental distress.

**Conclusions**

The eleven pilot services 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. The lessons learned during the first phase of the development of these services and the feedback from service users can guide the development of new services for people with a diagnosis of PD. This feedback includes:

- The need to improve the initial assessment process to ensure that people receive more support
- The need to ensure optimal group sizes
- The need for greater flexibility and consistency in the rules and boundaries in groups
- The value of providing choice in the interventions on offer to service users (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 are not currently available)
- The need for services to improve their capacity to respond to diversity; efforts should be made to make contact with younger people, with people from black and minority communities and with men
- The importance of providing more support for carers, including carer groups
- The importance of developing service user involvement in the services
- The need for better childcare support and access to benefits and housing advice

The results of this study suggest that, while there are limits to what any service can deliver, people with a diagnosis of PD who are interested in making changes to their life can be helped by dedicated services. 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 dedicated 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.

Finally, dedicated community-based services for people with a diagnosis of PD are at 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. It is important for people taking on these roles to find out what support will continue to be available to them should they need it.

For more information on the project, visit:

[http://www.sdo.lshtm.ac.uk/sdo832004.html](http://www.sdo.lshtm.ac.uk/sdo832004.html)

Or call the Mental Health Foundation Research Team on 020 7803 1100 or email us at mhf@mhf.org.uk

This summary presents independent research commissioned by the National Institute for Health Research (NIHR) Service Delivery and Organisation (SDO) Programme. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. The NIHR SDO programme is funded by the Department of Health.