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

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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:

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

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:

- describe the organisational form, activity and function of 11 pilot services
- compare aims and objectives of services with those they actually deliver
• measure health, social function and service utilisation among a sample of people referred to these services
• 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 was 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 546-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 outcome 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 two 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 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 1428 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 1017 (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 six 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 11 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

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Addendum

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