Evaluating services for people diagnosed with personality disorder

Personality Disorder (PD) is a mental health problem that affects four per cent of the population. People with PD are at increased risk of mental distress and social problems and are more likely to have a history of violent crime, suicide and self-harm. There is no universal health care provision to treat PD and there has been a dearth of research to identify beneficial therapeutic programmes.

This research summary is based on two studies, one evaluating the development of pilot services in the community and the other services in prisons. Both studies were commissioned by the NIHR Service Delivery and Organisation (SDO), with additional funding from the Home Office towards the prison services study.

The first study (community pilot) combined qualitative and quantitative methods to examine a number of pilot services offering a range of innovative approaches to treating and supporting people with PD who are living in the community. The study was led by Mike Crawford and carried out by a partnership between Imperial College London, the Mental Health Foundation, University College London and Kings College London.

The second study is an evaluation of three pilot services for people with PD who have been convicted of criminal offences. This study aimed to compare the effectiveness and acceptability of the services provided by each service using multiple sources of data (forensic pilot). This study was led by Paul Moran and carried out by a partnership between Kings College London, Imperial College, London, Queen Mary University of London and Teeside University.

Key findings

- Treatment for PD requires long-term commitment but can be worthwhile. Service users and providers within the community pilot consistently described improvements in mental health and ways of coping that they were able to achieve with the support of high quality care. Within the forensic pilot there was recognition that it was too soon to say whether the services had brought about sustained change in behaviour.

- Clear communication between staff members and the opportunity to develop reflective practice are key elements of good practice in PD units. Providing effective support for people with PD requires meaningful cooperation between agencies including the NHS, social and voluntary services, local authorities and criminal justice.

- Men and people from ethnic communities were under-represented in referrals to all 11 community pilots.

- There is no agreement as yet on the role of outreach services for people with PD who are not motivated to change or to engage with a dedicated service. The use of prescription medication during treatment is also a contentious subject.

- The recruitment and retention of high quality staff is a particular challenge for specialist PD teams particularly in forensic sites where staff frequently feel exhausted and drained and occasionally frightened by their patients. When trying to identify staff who are suited to working in specialist PD services, personal qualities such as emotional resilience may be more important than the person’s professional background.
Background

Approximately four per cent of people in Britain have one or more of a number of diagnosable personality disorders. These are enduring patterns of inner experience and behaviour that deviate markedly from cultural expectations and are associated with considerable personal and social disruption. Four out of ten people in contact with substance abuse and mental health services have PD, as do six out of ten people in prison. People with PD are more likely to self-harm and seven times more likely to commit suicide.

Mental health and social care practitioners have been reluctant to work with people with PD largely because the disorder has been seen as untreatable. As a result, there is concern about the quality of services available for people with PD. Treatment frequently deteriorates following a diagnosis of PD with sufferers being labelled ‘attention-seeking’ and ‘bed-wasting’. Fewer than one in five Mental Health Trusts provide a dedicated PD service with 40 per cent providing some level of service and 28 per cent having no identified service.

Research has shown that people with PD have complex needs. But little evidence exists to which to base recommendations for the organisation and delivery of services for people with PD generally. With regard to offenders with PD, there is an additional complication: an absence of agreement on what constitutes a successful outcome of treatment. Possible outcomes include the impact of services on: mental health, recidivism, symptomatic change, social functioning, quality of life and re-hospitalisation.

In January 2003, the National Institute for Mental Health (England) published a policy implementation guidance, Personality Disorder, No longer a diagnosis of exclusion, (National Institute for Mental Health 2003b), building on two of the standards laid down by the National Service Framework for Mental Health (Department of Health 1999), outlining good practice for developing PD services in general adult-community mental health and forensic settings. A key stage in policy implementation was the commissioning in 2004 of the pilot services that are the subject of this report.

Practical findings

Community services pilot study

The aim of the study was to identify the organisational, therapeutic and other factors that service users and providers believe results in high quality, effective care for people with PD. It consisted of an evaluation of the impact of services, a user-led evaluation of quality of care and an examination of the demographic and clinical characteristics of people referred to the service. There was also a Delphi study examining the level of consensus among academics, service users and providers about lessons that can be learnt from the service.

Users were predominantly white and female. People (mainly men) with anti-social personality disorder (ASPD), alcohol or drug abuse problems or poor English were less likely to be referred to, and engage with services and there was a low rate of referrals of people from ethnic minorities.

The pilot services offer varied and flexible services with several options including peer support, one-to-one therapy, group therapy and support in getting involved in leisure and vocational activities. There was widespread agreement for this approach – and that services should deliver long-term interventions, tailored to the individual.

Service providers reported reductions in use of other services including emergency departments, inpatient beds and outpatient appointments. Feedback from service users was generally very positive with many describing improved self-awareness and the development of a better understanding of their feelings and an improved awareness of factors that triggered mental distress.

Forensic services pilot study

The three pilots consisted of in-patient medium secure units together with residential services. The researchers used multiple sources of data to build up a detailed picture of each service and its users with a view to comparing effectiveness as well as investigating the impact of the services on both users and staff.

The majority of service users had experienced childhood maltreatment and educational disadvantage and there was a high prevalence of substance abuse problems and self-harm. As expected, there was a high prevalence of sexual and violent offending, frequently characterised by extreme cruelty towards the victim. More surprising was the finding of comparatively low IQ in service users.

The primary focus of the clinical work at all three services was psychological treatment aimed at diminishing the risk of harm towards others. The in-patient units varied in their approach: one was run as a therapeutic community; another offered a largely CBT-based programme and the third was based on the Violence Reduction Programme, a psychological treatment programme that was originally developed in...
the Canadian prison system, targeted at violent offenders who lack the motivation to change. The residential services reflected this variety.

The multidisciplinary teams consisted of energetic, hard-working staff who found their work extremely demanding but were generally optimistic about the programmes they were running. There were reports of interdisciplinary disputes over leadership and clinical vision during the setting up of services at all three sites. By the end of the pilot, staff at one unit felt that its services were still at an embryonic stage of development.

Service users said there had been improvements in a number of areas including anger management, communication and self-harming behaviour. However, behavioural problems in the form of violence, self-harm, absconding and non-adherence with treatment continued and there were no statistically significant changes in the working alliance between staff and service users. Staff reported that any improvements were likely to be modest and that day-to-day support was probably the best that could be offered.

Senior clinicians within the forensic services said they were overburdened by administrative work that competed with heavy clinical commitments and the supervision of junior colleagues.

Residential service users complained of boredom because of a lack of practical activities and that they lacked a clear understanding of the nature and consequences of treatment before they were admitted.

Findings across the two studies

The assessment process

The length, depth and purpose of the assessment process for the community units varied considerably and caused distress to some users. Both staff and service users in the forensic pilots found the lengthy assessment process to be unwieldy.

Staff

The team leader should have a clinical background and senior staff needed a high level of administrative support. Good communication was seen as essential in order to foster close working relationships between service components. The opportunity and support to develop reflective practice was seen as crucial to better integration and communication. A professional background was less important than personal qualities such as self-awareness and the ability to observe boundaries and engage service users, according to the Delphi study.

Outcome

The issue of how to measure effectiveness in PD services was repeatedly raised by commissioners with the focus on whether these services resulted in a reduction in expenditure on other services. As yet, however, there is no evidence base for this exercise; self-harming behaviour among people with PD tends to reduce over time anyway and many people with PD make changes to their lives without input from services.

Other findings:

- The fact that many people with PD are unwilling to engage with dedicated services means that most people with PD will continue to be treated by general services. Support for those working in these services should be to be an essential component of the work of specialist PD services.
- There is a need for forensic treatment protocols for self-harm, drug and alcohol abuse.

Strength and limitations research

Strengths

Both studies involved the collection of both qualitative and quantitative data from staff and services users. The community study qualitative data was based on interviews with 89 service providers and over 100 service users. The perspectives of service users were fully incorporated into every stage of the research process and there was a consensus on the organisation and delivery of services among a broad range of stakeholders.

The forensic study involved the collection of detailed quantitative data from both case records and service users in multiple domains (health, criminal and economic) at two time points. Regarding the qualitative data, efforts were made to maximise the rigour of the data collection process and analysis. The research staff remained in touch with service leads in all three services throughout the evaluation and fed back findings as they emerged. Staff were also given the opportunity of commenting on a draft version of their service's case study.

Limitations

Both studies represent a snapshot of service activity levels at an early stage of developing services. The forensic study followed up service users at six months – a period of time too brief to evaluate the clinical impact of services. There may also have been bias in the smaller than ideal group of service users in this follow-up group. The finding of low IQ among forensic service users may also be unsafe. The focus groups set up to validate the qualitative data were also unrepresentative.
Conclusions

1. Commissioners, users and providers all welcomed the development of community services for people with PD. All the community pilots achieved a considerable amount over a limited period of time, delivering high quality care that helped some service users reduce the distress they experienced and to improve their quality of life.

2. The three forensic pilot services succeeded in engaging and retaining in treatment a challenging group of service users with extensive criminal histories as well as high rates of psychiatric morbidity, substance misuse and self-harm. Charting changes in patterns of re-offending will require much longer periods of follow-up.

3. All services need to find ways of meeting the challenges of recruiting and retaining high quality staff.

4. Services for PD should be based on open communication, explicit boundaries, consistency and support for those who provide the service. Services need to be delivered over relatively long periods with preparation and planning for leaving the service. There is a need to foster close working relationships between the different components of the services.

5. Assessment procedures need to be improved and adequate information be made available to potential service users.

6. The question of how much time and effort should be invested in treating people with high levels of need and low levels of motivation needs to be addressed.

Future research

There is a need for:

- Further assessment of the effectiveness of psychological interventions for helping people with PD.
- Further work to assess the potential for training people with limited previous professional experience to work in teams to deliver services for people with PD.
- Experimental studies to examine the effects and cost-effectiveness of innovative approaches to helping people with PD including day Therapeutic Communities (where the central feature of therapy is changing the environment), Dialectical Behaviour Therapy, case management services and user networks.
- An assessment of the effects and cost-effectiveness of residential treatment services for those who are unable to engage with or do not benefit from specialist community services.
- An investigation of further emerging research suggesting that the parenting programmes that developed within some of the pilot services, as well as educational interventions, can prevent the development of behavioural problems among younger people.
- The forensic pilot treatment packages are complex and if one package is shown to be effective, further research will be required to establish which components were effective.

Further information

The full report, this research summary and details of current SDO research in the field can be downloaded at: www.sdo.nihr.ac.uk

For further information about anything included in the report, please contact Mike Crawford, Department of Psychological Medicine, Claybrook Centre, 37 Claybrook Road, London, W6 8LN. Email: m.crawford@imperial.ac.uk

Feedback

The SDO Programme welcomes your feedback on this research summary. To tell us your views, please complete our online survey, available at: www.sdo.nihr.ac.uk/researchsummaries.html

About the SDO Programme

The Service Delivery and Organisation Programme (SDO) is part of the National Institute for Health Research (NIHR). The NIHR SDO Programme is funded by the Department of Health. The NIHR SDO Programme improves health outcomes for people by:

- commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care; and
- building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

This summary presents independent research commissioned by the National Institute for Health Research Service Delivery and Organisation 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.

For further information about the NCCSDO or the NIHR SDO Programme visit our website at www.sdo.nihr.ac.uk or contact:

NCCSDO, London School of Hygiene & Tropical Medicine
99 Gower Street
London WC1E 6AA
Tel: +44 (0)20 7612 7980
Fax: +44 (0)20 7612 7979
Email: sdo@slohtm.ac.uk

Members of the forensic study research team

Kings College, London
Paul Moran, Zoe Fortune, Barbara Barrett, Ruth Spence, Diana Rose, David Armstrong, Mike Slade
University of Teeside
David Mudd
Queen Mary University of London
Jeremy Coid
Imperial College London
Mike Crawford, Peter Tyrer

Members of the community study research team

Imperial College London
Mike Crawford, Deborah Rutter, Kathryn Price, Tim Weaver, Mill Jossin, Peter Tyrer
Mental Health Foundation
Sarah Gibson, Sarah Gillespie, Alison Faulkner, Iain Rynie, Kamladeep Dhillon
University College London
Anthony Bateman, Peter Fonagy, Bethany Taylor,
Kings College London
Paul Moran
Service User researchers
Judith Beckett, Helen Blackwell
Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk