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special articles

# Service innovation: a virtual informal network of care to support a 'lean' therapeutic community in a new rural personality disorder service

This article presents a brief overview of service user-led informal networks of care in therapeutic community practice before discussing the design and evolution of a new kind of network in one of the pilot services of the Department of Health National Programme for the Development of Services for People with Personality Disorder (National Institute for Mental Health in England, 2003a). This network employs well-established internet messaging and chat room facilities uniquely structured and moderated to encompass therapeutic community principles and provide equality of access across a huge mixed urban and rural catchment area. Both hardware and software are inexpensive, easily transferable to similar services and could be modified to suit other applications. The success of this system in allowing challenging work to proceed in a much reduced therapeutic community programme may offer the prospect of many more community-based therapeutic communities at the heart of new personality disorder services.

Service user-led informal networks of care have been developed to provide out-of-hours support and to extend the work of a number of day therapeutic communities for service users with moderate to severe personality disorders. They share a number of purposes:

- to provide greater containment of anxiety and to avoid total hospitalisation
- to extend therapeutic community principles outside the working day allowing more opportunities for new learning and real-life opportunities to take responsibility for self and others
- to promote attachment to, and exchange within a group, both to avoid the repetition of unhelpful dynamics between individuals and to practice appropriate help-seeking behaviours
- to reduce the burden of care on the professional network beyond the therapeutic community.

Until now, these systems have relied on a series of one-to-one contacts by telephone or text in order to coordinate a group response to a service user in distress. Typically, support and advice are offered and a joint decision is made as to whether the problem can wait until the next meeting of the community or whether more immediate action is needed. The latter might involve a decision to monitor the situation, offering further remote support as needed, or might involve contact with the professional network. In some cases, for example at Winterbourne Therapeutic Community (Higgins, 1997), 'physical support' may be offered as a further possible response. Here, a designated group of service users may arrange a meeting at an agreed venue or, if necessary, a

home visit. Higgins describes in detail how the telephone support network reflects the developmental process for service users in the therapeutic community:

> '. . . from the early stages of attachment and belonging – characterised by the struggle to share in and use the network – through to maturation and a more consistent ability to find healthy ways of meeting their needs . . . by using the support network effectively and after leaving, by appropriately seeking out help . . .'.

All such systems operate agreed rules and boundaries, including the requirement for verbal feedback at the next available community meeting when the process can then be reviewed by the whole community, that is, staff and service users.

These systems are probably best suited to urban situations where service users are likely to live within reasonable distance of each other and the therapeutic community, and where the community meets formally on most days of the working week. Although in practice working well, they might suffer from not being able to guarantee the safety of a group-based response and carry a risk of loss of privacy.

## Itinerant therapeutic community

The North Cumbria Personality Disorder Pilot Service itinerant therapeutic community service has been established following a successful bid to the Department of Health National Development Programme for the Development of Community Personality Disorder Services in 2004. It has developed a number of new structures to extend an existing multi-modality out-patient psychotherapy service. These structures are intended to allow psychotherapeutic work to take place with service users with moderate to severe personality disorder who would otherwise be difficult to engage or for whom out-patient work would involve unacceptable risks, and also to overcome significant problems of access in a large, mainly rural trust. The area currently served covers over 2000 miles$^2$ with a population of 320 000, and has areas of both urban and rural deprivation. The service has been designed with necessary economies of scale in relation to staffing and time available for direct clinical work.

The itinerant therapeutic community service has five main strands:

- dedicated outreach work available to service users and their carers to assess needs, facilitate engagement, liaise with the professional network and provide after-care

- 'relationship groups' as preparation for the intensive treatment programme at the therapeutic community or as a complete treatment; these groups are more directive than the formal analytic groups provided for service users with lower morbidity
- a 2-day per week democratic analytic therapeutic community housed in a rugby club in a small central market town, Aspatria. This 'lean' or 'mini' format is typical of a new breed of therapeutic communities offering a treatment programme ⩽ 3 days each week, in contrast to traditional in-patient or 5-day programmes
- a service user-led informal network of care – a peer-to-peer (P2P) internet website comprising message boards and a chat room
- a comprehensive package of multi-agency and experiential trainings in line with the Capabilities Framework (National Institute for Mental Health in England, 2003*b*; Rigby & Longford, 2004).

The itinerant therapeutic community shares an administrative base with the psychotherapy service in Carlisle and has common systems for referral, allocation for assessment and clinical governance. It shares some senior members of staff and can call upon a range of expertise and out-patient therapies, allowing considerable flexibility in tailoring treatment pathways suitable to the needs of each service user at a particular time.

The therapeutic community is entirely group-based, following in large part the Henderson model (Norton, 1992) in which sociotherapy, psychotherapy and action therapies are blended. All service users take jobs necessary for the day-to-day running of the community, which increase in seniority as engagement proceeds. Elections are held monthly. The 'Top 3' service users – chairman, deputy chairman and secretary – have considerable responsibilities for the conduct of meetings including setting agendas with staff and bringing important matters to the attention of the community. These Top 3 roles have been extended to include responsibilities for moderating the P2P website, operating the chat room and reporting significant matters to staff. Service user members may remain in the community for up to 18 months.

Aspatria is at the centre of the catchment area, but at some distance from the main urban centres which are widely dispersed at opposite ends of the trust. Although enjoying relatively good public transport links this site could be said to provide equality of poor access. Making robust arrangements for each service user to travel to the therapeutic community, therefore, has become one part of the therapeutic work. Travel by service users across the catchment area to provide out-of-hours support has, however, never been considered a realistic proposition, hence the need for a new kind of service user-led informal network of care.

## The P2P system

The P2P system has been developed jointly between our service, Xenzone Internet Technologies and the National Institute for Mental Health in England North West. The aim was to develop message boards, a chat room facility and protocols to form a virtual therapeutic community complementary to a relatively lean day programme, while ensuring a safe group response in order to avoid potentially untherapeutic individual contacts.

It is a synthesis of three lines of experience:

- clinical work in therapeutic community and out-patient settings in which service users have been engaged as far as possible in developing treatment plans and strategies to self-manage, and in agreeing boundaries and lines of communication outside treatment time
- development, moderation and usage guidelines of Borderline UK's internet message boards that facilitate information-sharing and peer support for people with personality disorder and their carers (http://www.borderlineuk.co.uk)
- experience in online professional counselling with Kooth, a service developed by Xenzone Internet Technologies for young people in Cheshire (https://www.kooth.com).

The final ingredient was extensive consultation between members of each of these groups and also regional and national service user representatives, as well as members of the Department of Health's Personality Disorder National Service User Reference Group.

The agreed format includes a public area of the site and password-protected boards. The public area provides information about the pilot, the national development programme and personality disorders, and is intended as both a resource and to showcase the work of the community. The password-protected boards include:

- a support board providing a forum for service user members to offer and receive support
- a real-time chat room which allows individual service user members to converse with at least two members of the Top 3. These sessions can be pre-booked or arranged online
- a significant matters log allowing the Top 3 to provide short reports of chat room conversations to staff and, at their discretion, other matters of concern arising on the site.

Unless requested by the community, staff members do not moderate the support board or chat room – this function is largely provided by the Top 3 using an agreed written protocol, but any service user member may raise concerns. The protocol outlines appropriate conduct and guidelines with respect to safe practice, and may be amended in the light of new experiences by discussion followed by a vote involving the whole community.

A number of other boards are active:

- a rules and guidelines board providing an online reference to these but also a forum to discuss and review the terms of use of the P2P
- a technical problems board to allow service users and staff to raise any difficulties they may be having with operation of the site or hardware

- a service users' and staff board providing a general forum for announcements, news, events and other business of the therapeutic community.

Other boards can be supported at the request of the community. Currently these include: poetry and quotes; minutes of the community meetings; and temporary project-specific boards; for example, a board to revise the welcome pack for new service user members and a digital camera board intended to generate guidelines for use of the therapeutic community's camera to record events and post artworks made by members of the community.

Each message board includes a choice of 'emoticons' which can be added to messages to aid understanding but also to practise linking feeling states to verbalised thoughts, a particular difficulty for most of our service users.

## Access

At the outset we appreciated that not everyone has easy access to the internet. To overcome this difficulty we bought a number of Netgem i-Player set-top boxes which allow internet access on an ordinary television monitor providing that a phone line is also available (as an added bonus they allow access to free-to-view digital television and radio). I-Players remain the property of the trust – service users are required to sign an agreement outlining appropriate use and arrangements for return of the equipment on discharge.

## In use

The P2P website has proved popular and has become one part of the sophisticated folkways by which a therapeutic community operates, raising both practical and emotional issues which the community address together. Confidence in its use has paralleled the gradual development of a therapeutic culture in what is still a relatively new therapeutic community. The system went live on 27 July 2005 following training sessions for service users and staff provided by Xenzone Internet Technologies.

At times in the early months, use of the chat room was suspended by joint agreement between staff and service users when it was felt that the Top 3 were either insufficiently experienced or if they did not feel confident to operate the system. Service users were initially reluctant to discuss problems on the message boards and to rely on, or risk burdening the Top 3.

Use of the whole system really took off through gradual discovery of its utility for making practical arrangements, for example arranging cooking rotas and responsibilities for bringing ingredients for community meals – out-of-hours emotional support quickly followed. Use of the system is now an expected part of membership together, of course, with regular attendance at the therapeutic community. To maintain the security of the system, a member's P2P 'account' is temporarily suspended if they fail to communicate adequately about non-attendance at the therapeutic community until such

time as face-to-face contact is re-established. This is to prevent possible exploitation of other members by a service user acting beyond the ordinary checks and balances of the day therapeutic community.

The P2P system has become a standard agenda item at community meetings and time limits have been set by the community for new members to 'get on line'. The community now takes responsibility for helping new service users to address whatever practical issues may be involved, including advice on paying bills and negotiating with their telephone service provider if reconnection of a line is required. Community members now hold regular P2P training sessions, both for new members and members taking on a Top 3 role for the first time, using two computer terminals at Aspatria Library and our 'dummy' website. Service user members have also joined with staff in snagging the system and suggesting a number of innovations requiring negotiation with Xenzone, the web hosting and software provider.

As in face-to-face therapeutic community practice, service users have shown themselves to be capable of raising concerns with the whole community when worried or angered about the behaviour of another service user – a number of behaviours are proscribed, in particular threats of imminent or recently completed violence to self or others, which could only generate anxiety rather than be worked with towards more practical resolution.

When alone and distressed, service users have found that the decision to use P2P creates a thinking space that would otherwise not be available to them: they need to access the internet, verbalise their distress and perhaps label it with an appropriate emoticon, all of which precedes the possibility of any actual help. In analytic terms we see asking for and offering help online as another way to begin the process of internalising the community as a good internal object, taking back projected aspects of the self and, in parallel, developing a capacity both to be alone and to have concern for one's objects.

In practice, there have been few occasions when members of staff have been asked to view the service user message boards and chat room contents: indeed, requests for chat room conversations are also relatively few, most business being conducted on the support and other boards which can involve a substantial wait for a response. Here, the group is powerful in conveying the sense that help is potentially available from other service users and staff, if required, but that it may prove unnecessary.

## Does it work?

The pilot has been subject to stringent local and national evaluation. The results of the former have shown highly significant symptomatic relief and falls in rates of self-harm, bed usage, use of other services and considerable cost offset; the latter is yet to report. However, in common with other studies of therapeutic communities it is hard to determine whether it is the whole treatment package which is helpful or whether some components

may be more helpful than others. As practitioners, our impression is that P2P has contributed significantly to containment of a high level of disturbance in a reduced therapeutic community programme, allowing highly challenging work, more usually associated with 5-day or in-patient therapeutic communities, to proceed without compromise. We believe that adoption of this system makes the development of many more local therapeutic communities a cost-effective and realistic proposition, and that such communities should be central to the development of new community-based personality disorder services.

## Acknowledgements

## Declaration of interest

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# End of the paper trail: moving towards a paperless ward round

The use of electronic notes is fast becoming the ideal towards which the modern National Health Service (NHS) strives. Electronic note-keeping and records have many advantages. Legibility ceases to be problematic, information can more readily be shared among professionals (who may be considerably separated geographically), information is far less likely to be misplaced and bulky notes do not have to be stored and transported.

Baggaley *et al* (2005) described the introduction of a liquid crystal display (LCD) projector to the ward round. They documented many advantages, including the fuller involvement of the multidisciplinary team in the ward process, since all were able to clearly see the information and feed into what was being recorded. The trust in which the new system was being implemented already had an electronic note system that was being used throughout the trust. We describe the introduction of a similar system of electronic records in a trust which was still relying on paper notes.

## Use of generic text-based software

The system we describe was set up in Bourne Lea, a specialist in-patient unit for assessment and treatment of people with mental health needs and learning disabilities.

Previously, the ward had been run on very traditional lines (i.e. the junior doctor would furiously transcribe the discussions of the team, without the team checking the accuracy of the notes). Reviewing past notes would mean transferring a heavy file round to each individual member of the team. The unit itself was remote from the community mental health learning disability service, social services and generic mental health services. This meant that the transfer of information was cumbersome at best.

Lacking a dedicated local clinical information system, we developed our own note-keeping system utilising Microsoft Word. A template was made for use at the weekly ward round. This contained important information about attendance at ward round, status under the Mental Health Act 1983 (including need for second opinions and tribunals), care programme approach (CPA) and risk assessment dates, current medication and capacity.

Prior to the ward round, a senior nurse would summarise the nursing notes for the week, which would be entered onto the template for each individual patient. At the ward round, each patient would thus have a ready template with the summary projected via LCD projector for all to view. We found this system highly effective in streamlining the ward round.