

Developing an Inclusive Approach to Care Programme Approach Review Meetings for People with a Learning Disability

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Summary of the project

This project used an experience based design approach (EBD) (National Institute for Innovation and Improvement, 2009a) to explore the experience of Care Programme Approach (CPA) review meetings for all stakeholders. Use of this approach enabled the identification of key points in the experience where care can be improved and led to the adoption of a flexible approach to ways of involving the service users and key stakeholders in the planning and delivery of CPA review meetings. Whilst a reorganisation of the Oxford Learning Disability Services is leading to the closure of the facility prior to completion of the project, the learning from this project can be applied in a variety of settings where the care programme approach is used to support those with learning disability.

Background

The Lanterns is part of The Ridgeway Trust (Oxfordshire Learning Disability NHS Trust) and is a residential unit which provides intensive support and therapy for individuals who have a learning disability which may vary from mild to profound. These service users may display challenging behaviour and have mental and physical health needs. At the time this project was carried out there were 6 service users receiving care at this facility.

The Care Programme Approach is a process that is used to facilitate the assessment of individual service user needs and the development and implementation of a care plan with their involvement (Department of Health, 2008). At The Lanterns, the care plan has been reviewed through fortnightly meetings to review progress, discuss treatment, management and therapy

Whilst there is recognition of the right for people with learning disability to be involved in decisions that affect them (Department of Health 2001a, 2001b, 2009)

consideration of the current way of conducting CPA meetings at The Lanterns indicated that practice has a long way to go to make involvement for people with a learning disability a meaningful reality with CPA review meetings being primarily driven and attended by senior nursing, psychiatric and psychology staff and service users and key carers rarely attending. All of the service users at The Lanterns have difficulty in using verbal methods of communication and their cognitive impairment may affect their ability to provide insight into their own experiences. They have also demonstrated a lack of capacity in being able to make complex decisions. Historical disempowerment of those with a learning disability may also contribute to their ability to question and challenge practice (Royal College of Psychiatrists et al., 2007).

The experience based design (EBD) approach has been developed by the NHS Institute for Innovation and Improvement (2009a) as a method of improving service users' experience of care. This is achieved by capturing, drawing out, understanding and using the experiences of service users and staff about how it feels to use or be part of the service. It allows the experience of service users and staff to be shared and can directly involve them as partners in service improvement and delivery through a co-design process.

Aim of the project

This project aimed to achieve an inclusive CPA process, to provide service users with a genuine opportunity to be involved and participate in their care planning and subsequent review meetings.

Objectives

- To use an EBD approach to allow the current experience of CPA review meetings for all stakeholders to be explored and understood
- To use EBD workshops to facilitate the development of action plans to improve the CPA review process
- To review the effect of the action plans on the experience of involvement and participation of service users and key stakeholders in CPA review meetings

Methods

Consent

As this project was a service development initiative it did not require review by a Research and Ethics Committee (NHS, 2009c). However, the tools developed for the EBD approach (National Institute for Innovation and Improvement, 2009a) provide resources for seeking informed consent from participants and recommend their application in ways which apply sound ethical principles. They also acknowledge the need to pay due attention to data protection. All data that was collected during the project was therefore kept in a locked cabinet which only the project leader had access to.

At the time of the project, all of the service users admitted to The Lanterns did not have capacity to consent to being involved and so personal or nominated consultees for each individual (Mental Capacity Act, 2005) were approached for consent. The documented decisions were noted on a 'Best Interests' form and filed in the service users records.

Initially, it was intended to video service users' participation at CPA review meetings. Whilst their learning disability prevented them from understanding and therefore consenting to participation in the project as a whole, their consent to this aspect of the project was seen as necessary and achievable. It is an act for which compliance and consent is needed and for which non compliance/lack of consent may be able to be identified. A consent form was developed for this purpose that specifically addressed the process and aspects of consent relating to individuals with learning disability and having mental capacity issues. Its development built on learning gained from a project in another facility which encountered challenges in being able to gain consent from service users with learning disabilities to having care plan review meetings recorded on video (National Institute for Innovation and Improvement, 2009b).

The EBD approach

The project team used the EBD approach to enable the achievement of the stated project aim. There are four key steps to the EBD approach which are identified as capturing, understanding, improving and measuring the experience (National Institute for Innovation and Improvement, 2009a)

Capturing the experience

Within the 'Capturing the experience' step of EBD, raising awareness about the project or initiative is an important element. Within this project, the key professional stakeholders were identified as being doctors, psychologists, speech and language therapists, community nurses and local advocacy services. When raising awareness with these stakeholders, the project team outlined the project, its key aims and objectives and provided opportunities for discussion at various formal and informal meetings. The project was also discussed at the Service User Forum.

The project team intended to use a number of approaches to capture the experience of stakeholders involved in CPA review meetings. These are outlined below.

A family event was planned to provide an opportunity for all families and carers to hear about the project and join in discussions. It was also hoped to establish interest amongst the families and carers for involvement in the project and to capture their experiences and stories around CPA review meetings. Invitations were given verbally to families and carers but unfortunately, no-one was able to attend. One parent did however subsequently provide information within a semi-structured interview.

The project was also publicised in the Ridgeway Partnership Trustwide magazine and posters were circulated at The Lanterns. Information was posted to families and carers of all service users to generate and explore interest in involvement from as many people as possible. Additionally, CPA training sessions were provided for all The Lanterns staff to enhance awareness and understanding of the principles and processes related to the CPA.

Whilst initially planning the project it was decided to capture the service user's experience of attending CPA review meetings on video. After consideration it was recognised that as service users rarely attended their meetings, to start encouraging

them to attend in order to capture data for the project could be perceived as being tokenistic and data captured would not be a true reflection of the current service user involvement. It was therefore decided to utilise other methods to capture how CPA review meetings were currently held.

An experience questionnaire adapted from the 'the ebd approach' (NHS Institute for Innovation and Improvement, 2009a) was developed to enable both service users and professionals to express their emotions/feelings about the CPA review meetings. These were adapted to include both pictures and words to gather the feelings/emotions experienced at identified points of the CPA review meeting process. The six key points that are identified in the questionnaire are planning, preparing, arriving, involvement in the meeting, action planning and leaving (see <http://www.fons.org/library/report-details.aspx?nstdid=6833>). However, over the period of data collection, no service users attended CPA review meetings and so in the end, these questionnaires were not used with this group of stakeholders. They were however used with the professionals who attended the CPA review meetings. Between November 2009 and January 2010, professionals who attended the meetings were invited to complete an experience questionnaire after the meetings; 50 questionnaires were completed in total. The responses were analysed by two of the project facilitators and emotions identified throughout the experience of CPA meetings were recorded and mapped out.

A variety of methods were used to recruit people to participate in semi-structured interviews which sought their stories of the CPA review meeting process. Those currently based at or visiting The Lanterns (family members, psychiatrists, community nurses and advocates) were approached opportunistically by the lead project facilitator; whilst letters were sent to previous service users now discharged from The Lanterns and their families and carers inviting them to take part in an interview. The interview guide provided prompts to help to capture experiences of the CPA review process and the interviewee's feelings around service user involvement in the CPA process. For example; 'What is your experience of the CPA meetings?' and 'How do you feel about service user involvement?' All interviews were carried out at The Lanterns. Some interviews were carried out on an opportunistic basis, when the project facilitators and interviewees were available at the same time; others made appointment times. The interviews were recorded in note form by the researchers as opposed to setting up the interview with recording equipment.

Fifteen people were interviewed. These comprised of nursing staff, two advocates, one parent, one care manager and one community nurse. Participants were able to read the notes from their interviews prior to consenting to the data being analysed and shared. The interview data was then analysed and themed by the project lead and an assistant psychologist working at the facility with discussion if needed to reach consensus. Themes emerging from data analysis were:

- Arriving at The Lanterns
- Preparing for meetings
- Venue of meetings
- Service user involvement
- Attending meetings

- The people present at meetings
- Content of meetings
- Contributing
- Action planning

Understanding and improving the experience

The data that had been gathered and analysed during the 'Capturing the experience' step was presented as emotional touchpoints and experiences of the CPA review meeting process at two workshops in February 2008. The workshops, 'Understanding the experience' and 'Improving the experience' related to steps two and three of 'the ebd approach' (National Institute for Innovation and Improvement, 2009a). Participants were invited to view this data on arrival and it was used as a basis for co-design at the workshops.

There was a range of stakeholders at each workshop consisting of nurses and care staff from The Lanterns, professionals and advocates who attended CPA review meetings and parents of service users. Over the two workshops all professionals and carers working at The Lanterns attended but not all relatives were able to attend. 15 participants were at the first workshop and 16 at the second workshop. This enabled all staff involved in providing support for service users to have the opportunity to be involved in the co-design process. They were facilitated by two external facilitators who had understanding and experience of using the EBD approach for involving service users with learning disability and their families. The external facilitators enabled fresh perspectives and new questions to be considered, allowed for potentially difficult questions to be asked and assumptions to be confronted. They were also able to move the group forward if blocks occurred when reviewing emotional touchpoints so that key areas to structure action plans could be identified (Schwartz, 2002).

The aim of the 'Understanding the experience' workshop was to get everyone involved with CPA review meetings together, to consider the information gathered during the 'Capturing the experience' step of the project and through discussion to explore emotions and experiences occurring at the touchpoints identified on the experience questionnaires and agree on areas for improvement.

At this workshop the following activities occurred:

- Participants were organised into groups, each representing a cross section of stakeholders and invited to share their views and perspectives about the purpose of CPA review meetings. Whilst a variety of perspectives were expressed, the participants reached a common understanding of the purpose and function of the meetings through discussion. All groups believed that the focus should be on the needs and progress of the service user and that a systematic approach is required for assessing and meeting the needs of service users
- The groups were invited to share their experiences of and concerns about the process of CPA review meetings. Again a variety of views were expressed which related to participant's roles, function and level of involvement at CPA review meetings. After facilitated discussion and negotiation, groups

expressed a common desire to improve the way CPA review meetings were planned and conducted

- All participants then individually reviewed the data provided from the 'Capturing the experience' step. This had been mapped out prior to the workshop by the lead project facilitator on a large scale diagram of the CPA review process using the six key touchpoints identified in the experience questionnaire. All participants then discussed and agreed upon areas where they believed the CPA review process could be improved. In particular, it was felt that improvements in the areas of planning and preparing for the CPA meetings could be pivotal in enhancing the experience for service users

At the second workshop, the focus was on 'Improving the experience' and turning understanding into action. Key areas were identified to work on and action plans were developed that aimed at improving the preparation of service users, families and staff for CPA review meetings. The following action points were agreed. To:

- Create a flow chart/map of the CPA review meeting process in terms of who was involved, what their role and responsibilities were, what decisions they would be involved in and what information, prepared by whom would support those decisions
- Prepare toolkits to support service user involvement. These would be created for each service user
- Develop an information booklet around the CPA review meeting process for service users and families/advocates

Enabling all stakeholders to develop a common understanding of the CPA review meeting process had the potential to improve the experience for all involved. The discussions that evolved allowed stakeholders to explore the ways in which service user involvement could be enhanced, providing scope for creative thinking around how the experience could have been made meaningful for them.

Unfortunately however, the project team were unable to move forward with the agreed action plans as shortly after the second workshop the Trust announced the decommissioning of The Lanterns. This unexpected news created many pressing issues regarding future care provision for the current service users, in addition to possible job losses for the staff. Consequently:

- The CPA review meetings from this point became primarily focussed around the future placement of service users
- The staff team were understandably concerned about their future employment; this affected their motivation to be engaged in the project. It was difficult for staff to be enthusiastic about moving the project forward knowing that The Lanterns was to going be closed within a few months. The focus for them became, of necessity, their future employment
- The loss of the lead project facilitators from the project team had a negative impact on the progress of the project as facilitated support and funded time was lost

It was therefore not possible to complete the 'Improving the experience' step or move on to step four, 'Measuring the experience' (National Institute for Innovation and Improvement, 2009a).

Discussion

Investing time and financial resources into a project that had the potential to make significant improvements to the service provided by The Lanterns appeared to help boost the morale of the staff. Many of the other stakeholders involved gave the impression that the EBD project was a positive move forward; this was reflected in their commitment to the project as it progressed through the earlier steps.

Reflective feedback collected on the day from participants who attended the workshops indicated that they found them to be particularly positive. The format of each of the workshops facilitated open and honest discussion between all stakeholders, where they felt their opinion was valued.

Further exploration through two interviews with staff who had attended the workshops conducted by a project facilitator and subsequently analysed and themed indicated a feeling that everyone attending was striving for a positive, successful outcome together and had the difficulties relating to the closure not been encountered this could have been achieved.

Other difficulties were also experienced at various points during the process. For example, although invitations to attend a family day at The Lanterns were sent to the families of the service users as part of raising awareness in the 'Capturing the experience' step, no one turned up on the day and it was not possible to gather specific evidence around the reasons for non-attendance. It was also difficult to arrange interviews with stakeholders as part of the 'Capturing the experience' step as many stakeholders were extremely busy and could not easily commit to being interviewed within the project timescale.

A further difficulty encountered was maintaining momentum in order for those involved to feel motivated to continue. Staff shortages and organisational changes at key points during the process exacerbated these problems. In addition the unavoidable absence of the two lead project facilitators impacted upon the ability to maintain the project momentum.

Whilst there were challenges in being able to directly involve service users (related to issues of capacity and consent) the process seemed to raise awareness and increase understanding of the experience of CPA review meetings from the service users perspective. This influenced the redesign action plan.

Key learning

Whilst it was not possible to implement and further develop the actions and ideas that emerged from this project within The Lanterns, several key points of learning have been identified that could be used to improve service user experience in other in-patient learning disability services. This learning includes:

- Identifying that at the outset of the project all stakeholders did not have a common understanding of the process, purpose and value of CPA review meetings. The experience of the EBD workshops allowed staff to share their own understandings of the CPA process. A flow chart to help stakeholders understand how they 'fit' within the CPA process, thus enhancing their own understanding and possible contribution to an individual's care, could be developed
- Recognising that the CPA review meetings had been conducted to meet clinical and audit requirements with limited involvement of key stakeholders such as service users, key workers, advocates and families. Consequently the information that was drawn on was not as complete or representative of the service user's abilities, needs and progress as it could have been. Participant feedback after attending the workshops had identified ways of gaining relevant information relating to service user progress and experience
- Review of emotions experienced at key touchpoints of CPA review meetings at the workshops helped stakeholders to understand the need to present information and evidence at CPA review meetings in ways and formats understandable to service users with learning disabilities so that they can participate in ways that are meaningful to them
- A booklet containing accessible information about the CPA process could be developed for service users and their families. This would include information about who the key stakeholders are in that person's life, and why they might be involved in the CPA (Department of Health, 2008). The booklet would also contain ideas about how to enhance service-users' own experiences, depending on that person's ability. Examples include a script (including pictures as visual cues) that could help explain the CPA review meeting process to an individual, and suggestions for items that could be used as objects of reference for individuals to use during their meetings
- It may not be appropriate to routinely involve the service user at all stages of the clinical review meeting or indeed have them present at all, due to aspects of individual ability and disability, behaviour and understanding. The emotional touchpoint mapping process and subsequent discussions identified that it was important that professionals considered each individual and used available evidence to help them to decide whether and at what stages the service user should be present, what tools could be used to facilitate involvement and contribution by the service user, and what form their involvement could take. This reflected a commitment to 'involvement' but identified a need for flexibility around the form that involvement could and should take
- Whilst the EBD resources, in particular the consent form and questionnaire, that were adapted for people with a learning disability were not used with service users in this project, they were helpful in identifying key points of the CPA review meeting experience and could be utilised if the experience of people with learning disability in other services is to be explored

Conclusion

The current approach to CPA review meetings at the Lanterns meant that service users were not involved in a meaningful way. This project therefore aimed to provide service users with a genuine opportunity to participate in their care planning.

An EBD approach involving key stakeholders was used to enable the current experience to be explored and understood. Action plans to improve the process, particularly around planning and preparing for the CPA meetings were developed.

Unfortunately due to the unforeseen decommissioning of The Lanterns, the action plans were not able to be realised. However, key learning from this work has been identified and this could be applied to other settings where the care programme approach is used.

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Further information

A copy of the experience questionnaire can be downloaded from:
<http://www.fons.org/library/report-details.aspx?nstd=6833>

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