Journal of Communication Disorders, Deaf Studies & Hearing Aids

Halder and Horne, Commun Disord Deaf Stud Hearing Aids 2014, 2:3
DOI: 10.4172/2375-4427.1000114

Case Report Open Access

Case Study: Empowering Deaf Patients to Chair CPA Meetings and Ward Rounds

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Received: July 22, 2014; **Accepted:** September 24, 2014; **Published:** September 30, 2014

Abstract

The Commission for Quality and Innovation introduced 'shared pathway' documentation to help service users have a better understanding of how they can have a more meaningful patient centred experience and better understand how they can move forward to achieve their goals. This article shares the experience of the Deaf services in a secure hospital using an example of the experiences of one service user, Tim. It discusses the nature of the Deaf Recovery and Outcomes meetings, and how the services enabled Tim to chair his own care programme approach meetings, and ward rounds. It supplies some practical guidance and time scales for achieving them, including potential barriers, to help other similar services.

Keywords: Deafness; Service users; Shared pathway; CQUIN

Background

Commission for Quality and Innovation (CQUIN) measures were introduced in services throughout the UK (both in the NHS and independent sectors) in 2009/10. One of the CQUIN measures involved using a 'shared pathway'. One of the main underlying concepts of what is being proposed is to ensure more service user involvement with their care in their pathway through secure services. It emphasises evidencing a 'collaborative recovery approach'. This was introduced in September 2012 throughout the UK. The Deaf service at Alpha Hospital, Bury, was chosen as a pilot site for implementing one of the CQUIN measures (Shared Pathway Recovery and Outcomes) in 2011.

In this article we use the example of one service user (Tim) to help explain how he and others in the service were supported in understanding and making his own decisions about his care plans, treatment and how he got to chair his own meeting at a formal Care Programme Approach (CPA) meeting.

Tim (not his real name) is a profoundly Deaf man with bilateral hearing loss who communicates using British Sign Language (BSL). He is currently in a Deaf secure psychiatric service in the UK with a severe and enduring mental illness. A Neuropsychological assessment identified significant cognitive deficits that included problems with planning and sequencing. He also had problems understanding various concepts and instructions. Tim was a service user representative in the Deaf services Recovery and Outcomes group and attended the regional Recovery and Outcomes meetings. Tim has been fully engaged and supported the implementation of Shared Pathway practice and principles as described below. His contribution to this process and his service user feedback has supported Recovery and Outcome focussed working within the Deaf service and Hospital.

To our knowledge, there is little evidence in the literature about how Deaf service users in forensic settings are helped and involved through their recovery. Our aim therefore is to share our knowledge gained in implementing the framework to hopefully aid our colleagues in other hospitals in overcoming potential service user communication and other practical barriers.

Implementation

Service-user led meetings – initial stages

A joint service user-professional meeting was set up once a month called the "Deaf Recovery and Outcomes Meeting" (DROM). The group commenced in January 2012, and is attended by five service users from the Deaf Male low secure service and by senior MDT representatives. Tim was one of the first patient representatives, and was chosen for this article as he gave his full consent, and the authors felt he gives a good demonstration of how someone with seemingly limited capabilities (as outlined in the neuropsychology report) could achieve a great deal given the right conditions. The patient representatives would go back to their respective wards and disseminate the information to the rest of the patients and receive feedback from patients to discuss in the next meeting.

This group is working towards embedding the shared pathway practice and principles and linking the process of Multi Disciplinary Meetings (MDTs), CPAs and Recovery and Outcome plans etc. The meetings completed a review of the 20 CPA standards developed by the i4i Network, in conjunction with the Yorkshire and Humber Specialised Commissioning Team (service user standards for CPA meetings is described in detail below) and agreed an action plan for the implementation of the standards.

1. You should be included in all parts of your CPA meeting. In exceptional circumstances, where there is third party information to be discussed, you may not be involved. Where possible you should be informed this is happening.

2. As far as possible your service will try to meet your needs when selecting the venue for your meeting. Prior to the meeting you will have the opportunity to discuss and agree the choice of venue. This will include:

- Choosing the room and its size
- Visit the room before to discuss the layout
- Choosing where people will sit

3. You will discuss, negotiate and agree with your care co-ordinator / named nurse who should be invited to your CPA meeting and ensure that plenty of notice is given to everyone. The named nurse has an important role in making this happen. Together you will make a joint decision on how to move forwards if people are unable to attend. You will also be given the opportunity to send out invites to the meeting in your name. This includes letters to your carers (with admin assistance).

4. Any cancellation of the CPA meeting should be done with yourself and your carers wherever possible. If it is not possible for the CPA meeting to take place another date will be made with you as soon as possible.

5. You and your care co-ordinator will talk through and agree a plan for the meeting – your named nurse will help with this. Extra items can be added by either party.

6. You should be made aware of the advocacy service and have the choice for advocacy support within the CPA process and meeting.

7. All reports will be written with your involvement, including future planning / discharge planning, at least one week before the meeting.

8. You will have the opportunity to attend ward round / MDT meeting nearest to your CPA meeting to discuss any issues which may arise at the CPA meeting.

9. You will have the chance to present your own views in your chosen format (written, verbal, etc). This will be done in time to go in to the CPA pack.

10. The chair of the CPA meeting is currently the care co-ordinator or your nominated individual, however this may change in the future to include your wishes – e.g. You may want to chair the meeting or continue to nominate a member of your clinical team.

11. You should have the chance to discuss how you would like to meet everybody before the meeting. You should have the opportunity to meet everyone invited informally over coffee immediately prior to the meeting.

12. You can choose how the meeting will be arranged. This might include:

- How and when people enter the room
- Where different people are invited to sit
- Decide on which way reports are presented and in which order

• A joint decision will be made when you want to respond to reports and issues arising from them

You and the service you are in will develop a checklist to help with this.

13. The people who write the reports should do everything in their power to be at the meeting.

14. At the end of the meeting there should be an agreement on what everyone feels is the action plan and there should be clearly identified people for each goal or action point, with clear timescales. The date for the next CPA meeting should be agreed at this point and important people who are necessary to attend should be identified (see point 2). A five minute break for you to gather your thoughts and ideas before devising your future plans / goals should be included in the meeting at your chosen point.

15. After the CPA meeting you should be shown a copy of the final draft report. You can change this if you feel it's not right. Somebody will help you with this. You will be told if the report is to be done by a certain date.

16. People who are reading or summarising the reports should talk to you directly, and not over you, making sure you feel included.

17. All reports should be written in straight forward language avoiding jargon.

18. Paper and pens will be available at the meeting for everybody.

19. All people present at your CPA meeting will be respectful of each other and their roles – and will behave in a respectful manner within the meeting.

20. You and your carers will be given a questionnaire after the CPA meeting to be sure that these standards are being met.

Note: CPA – Care Programme Approach; MDT – Multi Disciplinary Team; Third party information – Information which may include things about the victim or probation plans / issues for future safety planning.

Overcoming communication issues

The Deaf Service user group are of mixed abilities. The role of the Deaf service Communications Facilitator is important to support the Deaf service users' access to information within and outside the group. The Deaf Communications Facilitator meets with the service users outside of the group to communicate the minutes in BSL and adapts his BSL register to support their access.

A Nurse Consultant and Deaf Communication Facilitator have developed a Deaf service Recovery and Outcomes meeting poster for the Deaf wards that has been created to support accessibility and meaningfulness for Deaf service users. The Deaf service recovery and outcomes poster has been reviewed by the group representatives and is now on display in Deaf Ward communal areas and offices. Further work has been completed with the service users to support their understanding of the group and of their roles and responsibilities.

All professional meetings involving service users including Deaf Recovery and Outcomes meetings, Regional meetings, CPA meetings and ward rounds are supported by two qualified BSL interpreters, and when necessary a Deaf Communication Facilitator to ensure that Deaf staff and Deaf service users have access to communication.

Adaptation of materials

English based information remains inaccessible for the majority of the Deaf service users in the service as they are low functioning with significant cognitive limitation. Expertise within the Deaf service Communication and Multi-Disciplinary Team (MDT) supports the adaptation of materials and/or other communication approaches to ensure all interventions are Recovery focussed.

Adaptations have involved the creation of Recovery focussed visual materials and personal Recovery books supported with role play in

individual work to support the service users' understanding of their involvement in their care.

Ongoing progress

Tim was fully engaged and motivated to support positive changes to his and other service users' CPA meetings and suggested new standards in addition to those indicated in service user standards for CPA meetings. For example he wanted some name-tags for all attendees, and this was facilitated.

From August 2013 the service user representative agreed to commence and rotate chairing the Deaf Recovery and Outcomes Meeting.

Two of the service user representatives attend the Regional Recovery and Outcomes Group and feeds back details of the meeting (with staff support) into the Deaf Recovery and Outcomes Group.

The work around CPAs described above was completed by the end of 2013. Following this, in 2014, the group have been focussing on updating the patient information booklet, and producing a 'Buddy DVD' that helps new admissions team up with another service user to show them around, explain some of the activities, and help them settle into their new environment.

As far as possible, the service users lead the discussions and decide on the future areas of focus. They are currently involved in all stages from planning to implementation of schemes.

Results

The service users' contribution in the Deaf Recovery and Outcome Meeting (DROM) have in our opinion improved CPA/Shared Pathway practice in the Deaf low secure service in the ways as outlined below the improvements made since DROM started.

1. Adherence to CPA standards.

2. Additional good practice standards introduced by service users to enhance their CPA meeting experience e.g. name cards and option to bake cakes for the meeting.

3. Increase in service users chairing CPA meetings.

4. Planning meetings pre-CPA to support service users to chair their meetings.

5. Adaptation of the CPA agenda into visual more accessible formats for service users (with the support of the Deaf Communications Facilitator).

6. Increase in service user self-reports for CPAs.

7. Service users stating they feel more confident fully involved and empowered.

8. Enhanced therapeutic relationships between service users and the MDT.

There have been changes made to ward rounds too. Service users have been coming in and participating in their whole ward round and in some instances chairing their discussion whereas previously they would only attend after a professional MDT discussion. The service user does not attend the whole meeting in three circumstances. They are: 1) if the service user does not have capacity to follow the discussion; 2) if there are significant risks associated with their involvement for the whole ward round and 3) if they refuse. Otherwise they are present throughout the discussions and are active participants in their care. They may negotiate their leave conditions for example, or collaboratively agree to reduce their observation levels (example of best practice is described in detail below).

A Deaf service user on the Deaf low secure service has been a regular attendee at the monthly Deaf Recovery and Outcomes meeting. He met with his Therapist over several sessions pre CPA meeting to discuss a plan of support for him to co-chair his CPA meeting. His Therapist met him regularly to support him with his understanding of the new Shared Pathway agenda and allow him to practice his role as co-chair.

He was supported by his Named Nurse and two of his Therapists with the completion of his own self report .This included meeting with a BSL Interpreter to allow his BSL communication to be translated into English for his CPA report.

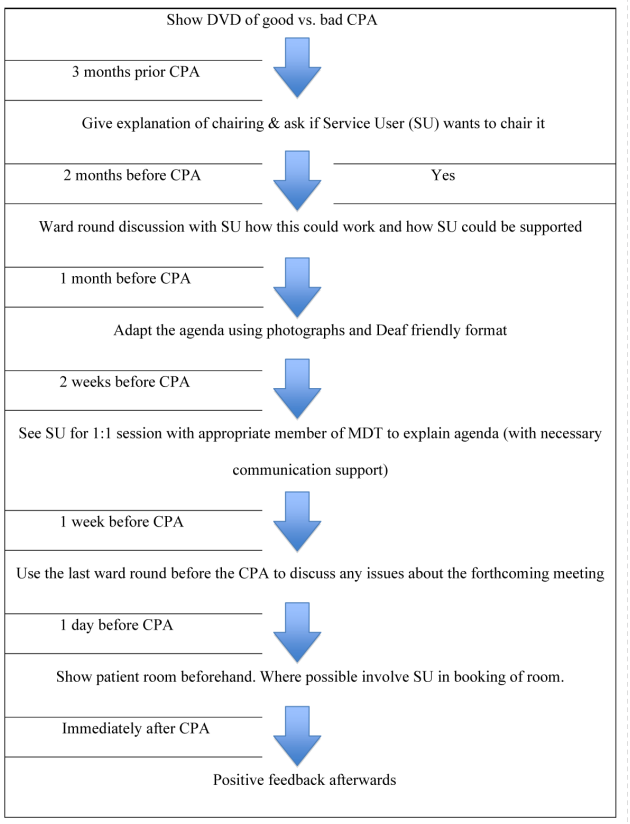
His meeting followed the CPA standards. The service user had been involved in reviewing the CPA standards within the DROM e.g. he was involved in setting up the room, placing name cards in the relevant places, deciding where people sat, deciding at what point to have a mid-meeting break and brought in his own baked cakes. His meeting/ agenda were structured using the Shared Pathway domains within the outcomes plan.

A service user from Deaf low secure service is involved in the DROM and the review of CPA standards as devised by the Yorkshire and Humber Specialised Commissioning Team. The service user asked for name cards to be introduced into CPA meetings. He met with his Responsible Clinician pre CPA meeting for a support planning meeting to enable him to co chair his CPA meeting. They went through an agenda that had been altered to be Deaf friendly and in a format and level that he understood. He practiced co-chairing and completed work to support his understanding of the agenda with his Responsible Clinician. The Deaf Communications Facilitator adapted the agenda into a visual and accessible format with involvement of service user. He successfully co-chaired his CPA meeting.

Discussion

We have devised a practical guide for how a service user may be supported to chair his or her CPA, with suggested timeframes that could help other professionals if they so wish (Box 1). We do not have similar cases to compare this to, but we think the suggested timescales given in Box 1 should be realistically achievable for most non-learning disabled Deaf patients with reasonable communication abilities.

There was some initial anxiety from some members of the MDT for implementing the changes described above as this represented a very different way of doing things. However both service users and professionals have seen the benefits. Ward rounds, for example, actually started to run more efficiently and are now underpinned by a Recovery and Outcome focussed philosophy. The service users also appreciated being involved from the beginning and there were no fears that anything was being kept from them. Some even chair their ward round as the headings used are now the same as those in the CPA documentation. This is made easier given the Shared Pathway paperwork meaning that the subheadings used in ward rounds are also the same ones for CPAs.



Box 1: Proposed practical implementation.

Increasing autonomy is a goal to strive towards for all patients no matter what degree of cognitive disability. Tim has been incredibly proud of his achievements and this has resulted in a noticeably improved confidence in his daily interactions. The therapeutic relationships are further enhanced between Tim and the other staff involved in his care.

There are certain obstacles to fully implementing the above (the potential obstacles to implementation of CPA standards is described below).

1. Professionals' reluctance and resistance to change.

2. Service users potentially reluctant to change (especially if institutionalised).

3. Extra time needed (for meetings and preparation of service users etc).

4. Practical difficulties (e.g. offering service user's choice of rooms for their CPAs).

5. Extra training required.

Conclusions

Increasing autonomy is a goal to strive towards for all service users no matter what degree of cognitive disability. Our take-home message is for professionals to continue to pursue service-user led initiatives and involvement even though this may mean a big change in practice.

Tim has been incredibly proud of his achievements. Some of them are listed below.

- Attended and chaired at the Deaf service and regional Recovery and Outcome meetings
- Motivated and contributed to review of CPA practice and implementation of CPA standards
- Fully participates and is supported to chair his ward round
- Involved in planning meetings pre CPA meetings to understand and adapt agenda into an accessible format
- Chairing CPA meetings
- Developed with the support of his Therapists a visual/BSL based personal Recovery book called" Help me stay well book"
- Supporting another service user to give him the confidence to chair his CPA meeting
- Nominated by the MDT for a national service user award- see below for outcome

This has resulted in a noticeable improvement in his confidence in his daily interactions and his therapeutic relationship with staff involved in his care has been enhanced.

The final word on this process comes from "Tim". His comments include: "I wish they'd had the Shared Pathway 20 years ago"; "before I didn't understand the Shared Pathway and I thought it was hard. I have learnt about the shared pathway in BSL ,using role play ,visual pictures and it has helped me to do the work in small steps"; "the different headings of the Shared Pathway on my CPA agenda have been adapted into pictures to help me understand so that I can chair my CPA meeting"; "I now have a much better understanding of what I need to do to finish hospital"; and "I want to help all Deaf people to know what they need to do to finish Hospital".

Tim was awarded a National Service User Achievement Award on Friday 15th February 2013. He won the category "Innovation in communication-My Shared Pathway".

Tim won a highly commended National service user achievement award with a group of service users in 2014 for developing a BSL DVD on the role of a "Buddy" that involves service users supporting and orientating new service users to the ward.

In 2014 Tim is involved in National work to support the development of a Deaf Recovery package.