

## A PILOT SURVEY OF SERVICE USER INVOLVEMENT IN CARE PROGRAMME APPROACH WITHIN A LEARNING DISABILITY CENTRE

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### Introduction

The care programme approach was introduced in 1991 (Department of Health 1989) and reviewed in 1999 (Department of Health 1999) to provide a formalised network of care in the community for people with mental illness. The Care Programme Approach (CPA) is also applicable to people with Learning disability (LD) who have added mental health problems and indeed has been operational for a considerable period of time in North Hertfordshire, UK. User involvement is an integral part of the CPA process. However, for people with learning disability this may be quite a confusing experience unless the process has been simplified and made user-friendly.

The Department of Health document 'nothing about us without us' (Department of Health, 2001) emphasises that the views of people with learning disability

should be taken into consideration when planning services. Similarly, the document 'Effective Care Coordination in Mental Health Services: Modernising the Care Programme Approach' (Department of Health, 1999) has recognised the need for this and expanded the person centred nature of CPA to provide service users with information about support, services and care plans.

Studies have been carried out previously to evaluate consumer satisfaction among informal carers (parents, siblings, friends or other relatives) regarding services provided by the learning disability teams (McGrother *et al.*, 1996). However, to the best of the author's knowledge no published study exists that looks at service user's views and knowledge about CPA. This survey was conducted in North Hertfordshire (UK) where the CPA process has been simplified, by the use of simple lan-

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guage and picture illustrations in the form of a booklet (Hertfordshire Partnership NHS Trust – Learning disability service 2001) specifically designed for people with learning disability. The survey is a pilot study and indeed the very first looking at learning disability service users' perspectives in this area.

## Aims and Objectives

- To understand service user's views on the process involved in CPA and its usefulness.
- If the service user felt involved and valued through the process.

## Methodology and Sample

The Hertfordshire Partnership NHS Trust had developed a semi structured questionnaire to obtain a feedback on CPA from the service users in general adult mental health services. The main themes of the questionnaire are to look at the information provided, service users' understanding of their care plan, and the provision of choice. Some questions were rephrased if participants had difficulty in understanding and prompts were used to facilitate the process. The interviewer, who was the first author, transcribed what the service users said. A carer or member of staff was present during the interview depending on the preference of the service user. Six service users from a total of twelve on enhanced tier of CPA (people who had more complex needs) were randomly selected from a geographic area different to where the interviewer worked and each one of them was seen individually either at their home or residential placement and the questionnaire administered. Five males

and one female within the age ranges of 18-45 years (mean age 33.33 years; SD 8.69) were interviewed. They all had mild learning disability.

## Results and Discussion

Achieving a response of 83.3% was considered to be a satisfactory target for the purpose of this survey. Although the sample size was small, this survey reveals significant facts about the CPA process and its implementation in relation to people with learning disability. This assumes importance since the participants of this survey were considered to be generally more able and articulate and had the ability to understand the CPA process better than others with more severe degrees of learning disability.

None of the six (100%) participants were aware of the tiers of CPA. (*Standard* for people whose needs are less complex and only one professional is involved in providing care. *Enhanced* for people with complex needs where several professionals are involved in provision of care). They were also not aware of the level at which they themselves were receiving care. Four (67%) of the service users said they have been given explanation/information about what the CPA process entails, but only one (17%) had received any preparation prior to the meeting with the aid of the booklet. Similarly, only one (17%) had felt supported during the meeting. Two (33.3%) of the service users knew whom to contact when their care coordinator was not available and one (17%) said that their CPA sets out a plan outlining how support will continue in case of an emergency. In a study of generic psychiatric patients and their attitudes and experiences of CPA, McDermott (1998) found evidence sug-

gesting that patients were unfamiliar with their treatment programmes and lacked knowledge regarding their care.

In our survey the majority of the participants acknowledged that their individual care plans did meet a wide range of their needs but appeared dissatisfied in relation to housing, finance and daytime activity. This is in keeping with the observations of McGrother *et al.* (1996) in their study of perception of unmet needs among residential carers of learning disability and their views on support received. It is interesting to note that in this study it was only one (17%) individual who understood the care plan fully, but they had all agreed to it and two (33.3%) remembered having signed the agreement (service users sign that they are in agreement with their individual care plan). In comparison 37% to 60% of generic users remembered having a written care plan (Carpenter *et al.*, 2004)

An equal number of participants (33.3%) either felt it did, did not or were not aware that their care plan reflected their ethnic and racial beliefs. However, on detailed analysis one (17%) female participant felt that her gender beliefs were not taken into account. Another participant (17%) felt that his cultural needs were not always discussed. Ethnic, racial, cultural and gender issues are as important for people with learning disability as for the general population and these issues should be sensitively addressed.

One (17%) individual stated that everything was decided beforehand by the professionals and the service user was not involved in the planning process. A similar study in generic psychiatry by Rose (2003) found that generic service users tend to be unaware of the way in which their care is coordinated and even less involved in it. This survey also highlighted the fact that individuals with learning disability did not have very much choice in domains relating

to either changing the care coordinator or meeting with him or her in terms of time or venue.

While participants said they were generally happy about these CPA meetings, a good number of them referred to feeling anxious about talking or facing a large group of people. One of them even stated she was not adequately listened to and felt fearful that people might tell her off. Some of them said these meetings were pretty boring and a waste of time. The fact that a majority of them felt that most of their needs were being met through CPA meetings testifies that they are largely successful. However, of concern is the general lack of preparation for CPA, the lack of understanding of contingency plans in place when the care coordinator is unavailable or in case of an emergency. One should be mindful, however, of the practical difficulties involved in explaining these issues to this subgroup of people and more important still, to secure their understanding. Similarly, Lawson *et al.* (1999) in their study in generic psychiatry found user involvement in needs assessment and decision-making poor, as was knowledge about care planning and information provision to users. The authors suggested possible improvements in the form of user led needs assessment, information pack provision and limiting attendance of professionals at CPA meetings.

As to the extent the aims and objectives of the survey were achieved we can say that the majority of the service users were happy with the major components and processes of their care plan. However, there were areas such as information provision, understanding of the care plan and contingency plan, preparation prior to the CPA meetings, support and choice offered during the meetings that clearly did not meet the standards required.

**TABLE I**  
**Participant's Responses to Questions Regarding CPA**

Please indicate what level of CPA applies to you

STANDARD -	ENHANCED -	NOT SURE 6 (100%)
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**INFORMATION**

1. I have been given information on, or had an explanation about the Care Programme

YES 4 (67%)	NO -	NA* -	DON'T KNOW 2 (33.3%)
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2. I know who my Care Co-Ordinator is (depending on your needs this may be a doctor, social worker, nurse, psychologist or other professional)

YES 5 (83.3%)	NO 1 (17%)	NA -	DON'T KNOW -
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3. I know whom to contact when my Care Co-ordinator is not available.

YES 2 (33.3%)	NO 4 (67%)	NA -	DON'T KNOW -
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**CARE PLAN**

4. I have a Care Plan which is a written statement of my needs, how they will be met and who will be helping me.

YES 5 (83.3%)	NO -	NA -	DON'T KNOW 1 (17%)
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5. My Care Plan meets my needs appropriately in the following areas.

(a) Accommodation

YES 4 (67%)	NO -	NA -	DON'T KNOW 2 (33.3%)
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(b) Financial (income, benefits, budgeting)

YES 3 (50%)	NO 2 (33.3%)	NA -	DON'T KNOW 1 (17%)
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(c) Leisure/Social

YES 5 (83.3%)	NO -	NA -	DON'T KNOW 1 (17%)
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(d) Daytime occupation (education and job)

YES 4 (67%)	NO -	NA 1 (17%)	DON'T KNOW 1 (17%)
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(e) Physical Disability (physical health)

YES 5 (83.3%)	NO -	NA -	DON'T KNOW 1 (17%)
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\*NA - not applicable

(f) Mental Health

YES 6 (100%)	NO -	NA -	DON'T KNOW -
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6. My Care Plan reflects my beliefs and values (such as gender, ethnicity, race or culture)

YES 2 (33.3%)	NO 2 (33.3%)	NA -	DON'T KNOW 2 (33.3%)
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7. I understand my Care Plan

FULLY 1 (17%)	PARTIALLY 5 (83.3%)	-	NOT AT ALL
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8. I have agreed to my Care Plan

YES 6 (100%)	NO -	NA -	DON'T KNOW -
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9. I have been given the opportunity to sign my Care Plan

YES 2 (33.3%)	NO 3 (50%)	NA -	DON'T KNOW 1 (16%)
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10. The Care Plan sets out how support will continue if something goes wrong (e.g. my carer is ill or I am very ill etc.)

YES 1 (17%)	NO 2 (33.3%)	NA -	DON'T KNOW 3 (50%)
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11. I know when my next review will be.

YES 2 (33.3%)	NO 2 (33.3%)	NA -	DON'T KNOW 2 (33.3%)
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12. At CPA meetings I felt that:

(a) I was listened to	YES 5 (83.3%)	NO 1 (17%)	NA -	DON'T KNOW -
(b) I had a chance to put my views forward	6 (100%)			

13. I was offered assistance

(a) To help me prepare for CPA meetings	YES 1 (17%)	NO 5 (83.3%)	NA -	DON'T KNOW -
(b) To support me at CPA meetings	1 (17%)	4 (67%)	-	1 (17%)

CHOICE

14. I am aware of what to do if I am unhappy with my Care Co-ordinator

YES 2 (33%)	NO 3 (50%)	NA -	DON'T KNOW 1 (17%)
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15. I am given a choice as to:

(a) Where I meet with my Care Co-ordinator	YES 3 (50%)	NO 2 (33.3%)	NA -	DON'T KNOW 1 (17%)
(b) When I meet with my Care Co-ordinator	4 (67%)	1 (17%)	-	1 (17%)

\*NA - not applicable

**TABLE II**  
**Additional comments of participants to questions regarding CPA**

Happy with these meetings. They are not too bad. They are alright. These meetings help me.	5 (83.3%)
Anxious about CPA. Anxious about facing a group of people and talking through. Just don't like facing group. Need to be a bit shorter. CPA is initially intimidating but gradually gets better.	5 (83.3%)
People do not listen to me in the meetings. Afraid that I am going to be told off.	2 (33.3%)
Muddled about who is meant to be doing what. Get confused between CPA and regular meetings.	2 (33.3%)
CPAs support me in some areas. Met some of my needs - not all of it. They could be better. Have to do bits myself. Information requested should be then and there and not people saying "I will find out and get back to you".	5 (83.3%)
Pretty boring and waste of time. There are better things to talk about.	3 (50%)
Speak of me beforehand, before I get there, and some decisions are already made.	1 (17%)
People talk in simple language.	1 (17%)
Need to be a bit more regular (3 monthly)	1 (17%)
Like my family and friends to come along.	1 (17%)
Cannot think of anything else.	2 (33.3%)

## Recommendations and Limitations

Recommendations for the shortcomings identified in this survey to be remedied are:

- a) The care coordinator needs to prepare the service user for the CPA meeting by using the care programme booklet and discussing the issues that the service user might wish to bring up at the meeting. Such preparation also gives a sense of predictability to the meetings and lessens the anxiety associated with the possible uncertainty that might otherwise be present.
- b) Accessible information in the form of user-friendly leaflets needs to be available for the service users.
- c) Gender and cultural issues need to be sensitively addressed.
- d) Choice needs to be offered to service users regarding venue and times of meetings with care coordinators.
- e) The CPA meetings are made more service user friendly by using a simpler language and by involving the service user more in the decision making process.
- f) Perhaps the CPA meetings should be in two parts. Initially the professionals should meet for a discussion and in the later part of the meeting the service user should be invited and the final decisions made.
- g) The findings of this survey should be cascaded to other professionals in multidisciplinary meetings.

The authors acknowledge that the major limitation of the survey is the small sample size. We wish to repeat the survey with a larger sample and include those with a more severe degree of disability. This pilot survey, however, demonstrates that if adequate time and care is taken

there could be a meaningful engagement of service users in the CPA process, hence, as stated by 'valuing people' (Department of Health, 2002) enabling them to live more fulfilling lives with choice and inclusion.

## Summary

The aim of this survey is to establish the views of service users with mild learning disability on the CPA process. Six people with mild learning disability were chosen randomly and administered a semi structured questionnaire and their responses noted. The questionnaire also had provision to record additional views expressed by the service user. Although the sample size was small, the survey revealed some significant findings. None of the service users were aware of the different tiers of the CPA and interestingly, only one had received preparation prior to the CPA meeting. Not surprisingly, 83.3% of the service users felt anxious over issues related to CPA and at the prospect of having to face a crowd of people. In addition to the above, several other interesting comments about getting muddled about meetings, dissatisfaction over gender and cultural needs being unmet were noted. We acknowledge that a small sample size is a major limitation in generalising these results and wish to repeat the survey with a larger sample, possibly including those with more severe degrees of disability.

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