Service users’ experiences of recovery under the 2008 Care Programme Approach

A research study – Dorothy Gould 2012

Executive summary
Acknowledgements

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Foreword

Introduced in 1991, the Care Programme Approach (CPA) was intended to create greater degrees of coordination between different practitioners and agencies involved with the support of an individual, but in its earliest incarnations it became associated with one of the landmark tragedies of community mental health care – the case of Christopher Clunis in 1992.

Christopher’s story will be familiar to many who read this piece of research, and while I was reading it I was thinking of him. Christopher, a young black man, had reached such degrees of mental distress that he fatally stabbed Jonathan Zito at Finsbury Park tube station in London. The subsequent inquiry into his mental health care concluded that Christopher had not got the support he needed and that there was a lack of consistency between different episodes of care, rather than support to live with and manage a continuing mental health problem. Issues of race and racism were also highlighted in discussions. Twenty years on, I wonder if things would be different for Christopher under the Care Programme Approach; how would he define and experience his recovery?

There have been ongoing questions over whether the Care Programme Approach is an administrative process or a therapeutic approach. Perhaps it is both, but given the imperative of focusing on the person, it is crucial for service users to keep asking questions about its effectiveness. Does the CPA genuinely provide ‘continuity of care’ for the individual? To what extent does it allow the individual to influence and direct their own life while managing their mental health? How can the CPA work with newer, person-centred recovery models to better support people to lead fulfilling lives?

This report gives a vital insight into how people are experiencing the Care Programme Approach and recovery, including those who, like Christopher Clunis, are from black and minority ethnic backgrounds. It asks and seeks answers to searching questions about two core approaches in the current mainstream mental health system. The research is grounded in lived experience – it is a rare piece of robust, user-led research which can be used to challenge and inform knowledge on the subject. (It is rare because user-led research is seldom funded.) The findings are authoritative and concerning. The challenges for the CPA today are the same as they were for the CPA twenty years ago – the approach needs to focus on and accommodate the whole person, particularly if it is to support them to define and lead their recovery.

This research clearly shows that a system which too often defines people by their diagnosis and medication finds it difficult to recognise the whole person and the unique individual. Participants said that they rarely had space to discuss non-psychiatric understandings of mental distress. Feedback from participants also indicated that they had limited opportunities to influence services: individually, or strategically. But in a context where choice and control for people who use services is a policy imperative, the room for such discussions on both individual and collective levels needs to be made. The voices of experience captured in this report should be sounding in this space and leading the discussion.

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Executive Summary

Part One: Introduction
1. Aim of the research study

This study was set up to explore how effective service users find the 2008 Care Programme Approach in promoting recovery as they understand it, to put forward their views and recommendations about the recovery role of the Approach and to produce a checklist of good practice for mental health professionals involved in this Approach.

2. Background to the study and reasons for it

2.1 The Care Programme Approach

At the time of the closure of long stay psychiatric hospitals and moves towards community services, the government thought it important to produce an updated framework for people receiving secondary mental health care. In 1990, therefore, the government introduced the Care Programme Approach. The Approach required that professionals from health authorities and local authorities worked closely with each other and with service users and carers to provide effective support. The Approach was implemented from April 1991 onwards. It was reviewed and refined in 1999 and then amended further in 2008. Since then, although everyone using secondary mental health services remains entitled to a high level of care, the Care Programme Approach has been designated for use only with people who have wide-ranging service needs, or are particularly at risk. In making this change, the Department of Health’s intention was to reduce bureaucracy for service users with less complex needs.

2.2 Recent recovery concepts

In the 1980s and 1990s, service users in the United States defined recovery as having a meaningful life for oneself, whether or not one could be cured, and spoke of the importance of factors such as hope, personal choice, self-determination, links with social networks and flexible resources rather than purely medical approaches. This concept of recovery was a challenge to the idea of mental illness as a life sentence and to the ‘maintenance’ system on which medical models had often been built.

Related ideas of recovery have gained momentum in a number of other countries, in particular in the UK, Australia and New Zealand. The North American recovery literature has, however, been criticised for taking an individualistic approach that does not allow for ethnic differences. In addition, UK and international recovery writings as a whole have tended to focus on the perceptions and outlooks of dominant groups in society and not to address social and structural injustice which may be experienced by, for instance, women, members of black and minority ethnic groups, people who are younger, older, or disabled and people who identify as gay, lesbian, bisexual or transgender.

2.3 Issues for service users

Service users in the UK have welcomed the fact that both professional bodies and the government in this country have endorsed recovery approaches. As recovery approaches have developed, however, quite a few service users have voiced the following concern: that mental health professionals and service users may both be talking of ‘recovery’ but may mean different things by it. A number of service users think, for example, that service user concepts of recovery have been re-interpreted in an essentially medical sense. In addition, service users from marginalised communities have raised the fact that descriptions of recovery may not fit their ideas of it.
An issue for various service users who access services under the 2008 Care Programme Approach is the link between this Approach and coercive elements of the Mental Health Act 2007; as people who are considered to be particularly at risk, or sometimes a risk to others, they are more likely to be subject to the coercive parts of this Act. They find this link contradictory to the rights-based ethos which is central to most service user concepts of recovery. In addition, quite a few service users think that the growing focus on risk-assessment and risk-management within the Care Programme Approach is at odds with the holistic approaches that they view as important for recovery. The above concerns have been particularly high for a number of service users from black and minority ethnic communities who are over-represented within compulsory services.

3. Methodology

The research study was a user-led project which took place between September 2011 and February 2012. The project lead, Dorothy Gould, put the research proposal together and then carried out all stages of the research, in partnership with the manager (now managing director) of the National Survivor User Network (NSUN) and with the support of the Mental Health Foundation.

Participants needed to be mental health service users who had personal experience of the 2008 Care Programme Approach, were aged 18 and above and lived in a London borough. To obtain as wide a range of opinions as possible, the researchers forwarded information about the study to an outer London NHS Trust and to a variety of voluntary and user-led organisations within the London area. Contact details for the research team were supplied, so that interested service users could then get in touch with one of the researchers to enquire further. Because of criticisms that recovery approaches are not taking sufficient account of service users who may face additional disadvantages (see sections 2.2 and 2.3 above), the researchers also put a particular emphasis on participation by service users who were as diverse as possible demographically.

Participants were invited to give their views through a combination of questionnaires, completed by 81 participants, and four focus groups, attended by a total of 22 participants. Quantitative data from the questionnaires was set out and analysed via Excel spreadsheets. Framework analysis was employed for analysing qualitative data from the questionnaire and from the focus groups.

The study was a small one and, whilst there was considerable demographic diversity amongst participants, there were some gaps; for example, there was little participation by people belonging to White Other and Chinese communities and none by Gypsy/Traveller communities. The study has, however, resulted in some significant findings that merit further scrutiny. (See Parts Two to Four below.)

Part Two: Findings and discussion

Approach taken

Data from the questionnaires and the focus groups were each analysed separately in relation to the research aims: how effective service users find the 2008 Care Programme Approach in promoting recovery as they understand it. Themes from each type of data were then collated and are set out in the ten sections that follow below. The themes relate to the sorts of concerns from services users that underlay the research, i.e. to those put forward in section 2.3 of Part One above, and to any further issues that participants raised about how well the 2008 Care Programme Approach supports their recovery. Each section starts with the findings and then moves on to a discussion of the findings in that section.

1. Descriptions of recovery

As has been indicated in Part One above,
concepts of recovery can vary. It seemed important, therefore, to start by finding out from participants what recovery meant to them.

Key findings

- In both the questionnaires and the focus groups, participants’ definitions of recovery were varied and might, or might not be bound up with a medical model.

- Focus group members mostly thought that there were marked differences between their ideas of recovery and professionals’ ideas. They found this unhelpful.

It appeared, therefore, that mental health professionals need to take more account of the diversity of service user views about recovery and to draw on service users’ own ideas about it if service users overall are to find the Care Programme Approach helpful for their recovery.

2. Experiences of participants from marginalised communities

For the reasons given in Part One above, the researchers put a particular focus on also hearing from service users who may face particular disadvantages.

Key findings relating to gender

- Female respondents to the questionnaire were markedly less satisfied than male participants about the extent to which professionals acknowledged non-medical explanations of mental distress and about their experiences of recovery services supplied under the 2008 Care Programme Approach.

- In the focus groups, female participants gave more negative than positive comments. Their concerns related to sexism and to a failure to address issues such as childbearing and physical change such as the menopause.

Key findings relating to ethnicity

- In their answers to the questionnaire, African and African Caribbean men and women were particularly dissatisfied with mental health professionals’ lack of openness to non-diagnostic explanations of mental distress. Their ratings for recovery services provided under the 2008 Care Programme Approach were also mostly lower than those given by participants as a whole.

- In the focus groups, participants from these communities all spoke at various points of being hindered by factors such as racial stereotypes, racist treatment and/or a failure to make use of alternative models and approaches in Africa and the Caribbean.

- Responses from Asian and Asian British participants were not markedly different from those of participants in general. Replies from participants belonging to other ethnic communities were not numerous enough, nor consistent enough for an analysis of their replies to result in clear findings.

Key findings related to physical disabilities and to age

- In the focus groups, participants indicated that the account taken of physical disabilities and of age issues was somewhat patchy.

Numbers of female participants and participants from African and Caribbean communities were comparatively small and so undue weight cannot be built on the above findings in isolation. If their responses are combined with other, similar literature, however, the picture that emerges is somewhat concerning. Similarly participants appeared to want more consistent account taken of physical disabilities and of age. Overall, therefore, the findings seem to support the concerns outlined in Part One above, that recovery approaches provided under the 2008 Care Programme Approach
should give more weight to demographic differences.

3. Qualities of mental health professionals

Many service users have underlined the importance to their recovery of the qualities which professionals bring to interactions with them. Research participants were, therefore, invited to say what part they find qualities from mental health professionals play in their recovery under the 2008 Care Programme Approach.

Key findings

- In both the questionnaires and the focus groups, participants stressed that professionals' qualities were at least as important to their recovery as any treatments. They mentioned hope, listening, respect, compassion, a supportive attitude, fairness, honesty and humility, for instance.
- Their feedback indicated that there is some good practice, but that there is also a considerable way to go before such practice becomes the norm.

These findings were, therefore, in line with the link made by other service users between professionals' qualities and effective recovery services and appeared to show a need for professionals involved in the 2008 Care Programme Approach to put a further focus on such qualities.

4. Explanations of mental distress

The research was partly undertaken because various service users have said that professionals put too much emphasis on medical models in their recovery work. Participants were, therefore, asked to give their views about psychiatric diagnoses and the impact of these on their recovery under the 2008 Care Programme Approach.

Key findings

- In the questionnaire, 89% of 79 respondents thought that it was important for professionals to acknowledge that there were more ways of explaining their difficulties than just psychiatric diagnoses.
- Only 36% of the 64 who gave ratings thought that this happened 'a lot', however, and 23% thought that it 'never' did. These ratings were the least favourable ones from participants.
- The use of psychiatric diagnoses alone satisfied some focus group members. Some had mixed experiences and the rest were left dissatisfied. The latter might prefer explanations linked to life experiences and to spiritual, or sociological phenomena.
- Whether they agreed with having a diagnosis, or not, most focus group members thought that their diagnosis had a negative effect on their recovery.

The findings seemed, therefore, to underline strongly the importance of professionals’ supporting recovery under the 2008 Care Programme Approach by working more fully with the explanations of mental distress which best suit any one service user.

5. What support was helpful

Participants were also invited to say what part they thought psychiatric medication should have in recovery services offered under the 2008 Care Programme Approach and what part other options should have. This was again because of service user criticisms that recovery services can be too medically based.

Key findings

- In the questionnaire, 96% of the 78 respondents wanted medication to support their recovery if it was prescribed. 59%

1Not all participants replied to each question
(n=40) of respondents who gave ratings described medication as supporting their recovery ‘a lot’.

- Most focus group members made negative comments about medication, however. One main reason was that they were concerned about unpleasant, or even dangerous side effects of medication.

- All respondents wanted a focus on whole-person (holistic) approaches, not on medication alone. They mentioned support with everyday life issues, access to a wide range of therapies and remedies, befriending schemes, support from other service users and self-management approaches, for example.

- Respondents cited some good examples of holistic practice, but many thought that there were considerable shortfalls, too.

Because quite a few service users have criticised medical models, it is interesting that as many as 59% of respondents regarded medication as helping ‘a lot’; this was one of the highest ratings in this category. Participants’ responses indicate a need to address service users’ concerns about negative aspects of medication, however. It also seems that that an increasingly strong focus on whole-person approaches is required if service users are to find the 2008 Care Programme Approach effective in promoting their recovery.

6. Recovery tools

Because formal recovery tools are very much part of the current recovery scene, focus group members were asked to say how useful they found such tools in supporting their recovery under the 2008 Care Programme Approach. They commented particularly on the Wellness Recovery Action Plan (WRAP) and the Recovery Star.

Key findings

- Some focus group members found one or both of these useful. Others were not in favour of them; they thought, for example, that the tools were too set to suit everyone.

Participants’ feedback may have implications for recovery tools such as these which, despite some flexibility within them, nonetheless draw on a particular framework and are intended to be applied consistently across organisations. This may be an issue, for instance, for recent initiatives such as the ImROC Project (Implementing Recovery through Organisational Change) and the REFOCUS study to consider further. There is seemingly a difficult balance to achieve between something that feels manageable organisationally and yet stays true to the fact that recovery means different things to different service users and that different service users have different ideas about the best ways to plan recovery.

7. Attitudes to risk

One reason for the research was that some service users have criticised the Care Programme Approach for putting too much focus on risk. Respondents to the questionnaire and focus group members had the opportunity, therefore, to say how helpful they found the focus on risk in promoting their recovery through the 2008 Approach.

Key findings

- 87% (n=69) of questionnaire respondents wanted the focus on risk in their care plan to be balanced and in proportion.

- 56% (n=34) of those who gave ratings said that this happened ‘a lot’, though 29% of those subject to compulsory treatment thought that it ‘never’ did.
Focus group participants were not always sure whether they had had a risk-assessment or not.

Quite a few focus group members emphasised the importance of being safeguarded against risk. Most did not think that the focus on risk in their care plans helped them to work towards recovery, however.

Given the rationale for the research, it is interesting that as many as 56% of participants were satisfied with professionals’ focus on risk a lot of the time; this rating was one of the highest ones. The figure still represents the view of only just over half the respondents, however. Because risk-assessments are part of the 2008 Care Programme Approach and should be carried out jointly with service users, it was concerning that focus group participants did not necessarily know whether they had had a risk-assessment. It seemed that there was also a considerable way to go before participants find that risk-assessment and risk-management processes support their recovery under the 2008 Care Programme Approach.

8. Attitudes to compulsory treatment

As has been indicated in section 2.3 of Part One above, quite a few service users see a conflict between their ideas of recovery and the compulsory powers of the Mental Health Act 2007. Participants were, therefore, invited to say what impact compulsory treatment since October 2008 had had on their recovery under the 2008 Care Programme Approach.

Key findings
- Questionnaire respondents who had been subject to compulsory treatment since October 2008 gave less favourable ratings in their answers to just over half the questions. Also, in 18 questions, they much more often described desired support as ‘never’ happening.

In the qualitative parts of the questionnaire and in the focus groups, most participants who had been subject to compulsory treatment thought that this treatment hindered their recovery, whether it had occurred before or after October 2008. Focus group members with no experience of compulsion had more mixed views about its value, however.

Quite a few focus group members were concerned about hospital staff’s telling voluntary patients that they would be sectioned if they tried to leave.

Because of the comparatively small size of the research study, an undue weight cannot be placed on the quantitative data in isolation. The lower ratings nonetheless appear worth noting, however, especially when combined with the qualitative data and with other research findings. Overall, it seemed, too, that participants wanted more progress made with resolving conflicts between their human rights and the compulsory powers of the Mental Health Act 2007, particularly if they had experienced compulsion themselves. Some, but only limited progress appears to have been made in this respect.

9. Involvement, influence and control

Involvement, influence, and self-determination for service users have tended to be central to service users’ definitions of recovery. In the questionnaire and the focus groups, therefore, participants had the opportunity to say how important these factors were to their recovery under the 2008 Care Programme Approach.

Key findings
- In the quantitative section of the questionnaire, almost all respondents said that their care plans should focus on their own recovery choices and wanted professional support with being the people
in control of their lives. The majority emphasised the value of support from other service users (peer support). Over 70% were also interested in service users’ influencing strategic planning about the Care Programme Approach.

- Fewer than half thought that the points above happened ‘a lot’, however.
- In the qualitative sections of the questionnaire and in the focus groups, there was also an emphasis on personal power, on peer support and on involvement.
- These respondents drew attention to some good practice, but again thought that this was patchy; discriminatory professional attitudes towards mental health service users might be a problem, for instance.

Given the existence of anti-discriminatory initiatives such as the Time to Change Programme and the commitment which the government has made to such programmes, it is concerning that quite a few participants spoke of prejudiced professional stances. Participants’ feedback would seem to imply, too, that some, but only partial progress has been made with recovery services which take into account government directives related to person-centred approaches, peer support schemes and a strategic role, too, for service users. Further attention to these elements seems needed, therefore.

10. Staffing and budgetary resources

In addition to the above themes, participants emphasised the importance of adequate resource allocation if they were to recover effectively under the 2008 Care Programme Approach.

Key findings

- In both the questionnaires and the focus groups, respondents stressed their need for professional time and for consistent, reliable and flexible services. They expressed mixed views about the extent to which they received such services, however.

- Focus group members were concerned that it was already difficult to obtain adequate support because of budget cuts, were worried about the impact of further cuts and, in some cases, thought that budgets were used wastefully.

By definition, both staffing and budgetary resources are finite. What seems to be key, therefore, is that professionals who are involved in the 2008 Care Programme Approach put their focus on ways of working which service users say support their recovery. It seems that considerable further progress needs to be made with this, however, despite the emphasis in recent government documentation that listening to service users can help to reduce costs.

Part Three: Conclusions

Overall, data from participants indicates that, whilst there is some evidence of good practice, services provided under the 2008 Care Programme Approach are patchy in the extent to which they promote recovery as service users understand it. There also appeared to be some particular issues for service users from marginalised communities. Participants’ feedback suggests, therefore, that considerable change is still needed in organisational cultures, approaches and practice if the 2008 Care Programme Approach is to be effective in promoting service user recovery. Participants’ responses would seem to imply, too, that further consideration should be given to the tensions which service users often experience between the coercive parts of the Mental Health Act 2007 and service users’ concepts of recovery. For service users, government recovery initiatives appear to have had only partial success therefore.

It remains to be seen, too, what effect the recently introduced implementation framework for the mental health strategy and the Health
and Social Care Act 2012 will have on recovery approaches. In its newly produced mandate for the NHS Commissioning Board, the government emphasises the need for the NHS to become ‘radically better’ at involving service users. Again, it is not yet clear, however, what impact this will have. How far the changes wanted by participants can and will be achieved is, in short, a huge challenge for politicians and mental health professionals alike.

Part Four: Checklist of good practice

As has been indicated in Part One above, participants were invited not only to share their experiences of recovery under the 2008 Care Programme Approach, but also to contribute points towards a checklist of good practice for professionals involved in this Approach. Feedback from participants resulted in the following list:
The Checklist

Are you:

1. Drawing on service users’ personal descriptions of recovery?
2. Taking special account, too, of recovery concepts that service users from particularly disadvantaged groups and communities find meaningful and valid?
3. Helping service users to find the ways of understanding mental distress that make most sense to them, rather than offering medical explanations alone?
4. Putting as much emphasis on the warm, human qualities that service users want from professionals as on skills and knowledge that service users find support their recovery?
5. Recognising in practice that medical treatment is useful only insofar as it assists service users with leading lives that they find meaningful and offering treatment accordingly?
6. Employing the full range of holistic approaches that are important to a particular service user?
7. Allowing for drawbacks that set recovery tools can have and varying tools to meet differing service user wishes?
8. Having adequate discussion with service users when medication is prescribed, acknowledging service users’ concerns about distressing side effects and working actively with service users to keep these to a level that service users find acceptable?
9. Tackling any staff discrimination towards people with mental health problems, including the additional discrimination which may be experienced by service users from marginalised groups and communities?
10. Helping service users to feel safe, whilst avoiding a focus on risk that service users say is counterproductive to recovery?
11. Making active use of positive risk-taking?
12. Addressing the tension highlighted by a number of service users: between the use of compulsion under the Mental Health Act 2007 and the exercise of choice, control and citizen rights that is fundamental to most service users’ concepts of recovery?
13. Making sure that service users have involvement, influence and control in relation to their individual care plans?
14. Acknowledging peer support in practice when service users find that this helps to promote their recovery?
15. Providing opportunities for service users to influence the Care Programme Approach at a strategic level?
16. Employing resources as effectively as possible by listening to service users’ expertise about useful recovery services, not to professionals alone, and by providing consistent and reliable support?