Empowering Mental Health Research: User Led Research into the Care Programme Approach

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Abstract

Within the context of a developing user led research movement, at a time when we are developing values and principles that are informing this work, a group of service users and survivors set out to undertake the task of discovering the effectiveness of the Care Programme Approach in Northamptonshire. We found that locally the Care Programme Approach was failing in all areas. At the very least, however, there is now have a baseline from which to evaluate the improvements that we are seeking. By undertaking this work we have also created a user led research team, open to service users and survivors who have an interest in research. We have an identity - we call ourselves ASSURT (Action by Survivors and Service Users Research Team.). We are currently undertaking the task of evaluating the effectiveness of CPA in Northamptonshire for a second time as compared to the baseline findings. We have also earned some credibility as researchers, are invited to provide independent evaluation of new services and are initiating research questions and proposals that are supported.

Keywords: user-led research, mental health, Care Programme Approach, mental health services, community mental health

Introduction

The definitions of user research range from those which ask service users the questions, through users being 'equal partners' with professional researchers to user led research (Ramon, 2003, Beresford and Wallcraft, 1997). Our aim in this project was to adhere to the definition which follows that described in' The DIY Guide to Survivor Research':

> *User-led research means that service users get the opportunity to ask the questions, as well as to design and carry out the research.* (Faulkner and Nicholls, 2002).

We would add the final report writing and consequent sharing of the results and recommendations to this definition.

Many of the values and principles that underpin the user movement: empowerment, collective action in order to effect strategic and political change, partnership and co-operation between service users, are applicable to user/survivor led research and they challenge the traditions of research within the National Health Service (NHS) in particular. Within the NHS, psychiatry continues to be heavily influenced by the central themes of psychiatric discourse (Rose, 2001). Health-related research continues to be dominated by randomised controls, biology, quantitative analysis and positivism. Although efforts are being made to consider the possibilities of user/survivor led research and the shift required to offer space to such a discourse in research, there are those in many corners who continue to resist them.

Whilst we argue for this shift and work towards the recognition and acknowledgement of user/survivor led research, it is still an activity that sits on the fringes of user involvement. Wallcraft (2003) describes the different activities that service user/survivor groups do and user led research is not identified. So we begin from a place that describes the history and current context of user involvement and yet omits an activity that has been identified as crucial to understanding and acting upon the user/survivor experience. It may be that the question was not included in Wallcraft's work or perhaps the evidence did not cite research as an activity. It remains an omission.

Lindow (2002) has already written of the need for a 'survivor research scene' and supports the efforts of Peter Beresford and others, including Jan Wallcraft and the Strategies for Living project at the Mental Health Foundation, in attempting to develop such a network. The User Focussed Monitoring Network currently facilitated by Nutan Kotecha at the Sainsbury Centre for Mental Health which has evolved from Rose's (2001) work '*User Voices*' also strives to support user/survivor led research and has recently formulated a values statement (Kotecha, 2002). In so doing, the efforts to carve out a place for user/survivor led research continue to be moulded. Yet we are still a long way from creating a dent in the ivory tower of academic and medical research. The principles set down in the National Service Framework for Mental Health attempt to open the door to the five identified levels of evidence, and perhaps we are trying too hard to 'toe the party line' by fighting to identify ourselves with type III and type II evidence (Department of Health, 1999).

We are anxious to ensure that expert opinion, including those of service users, is placed within credible research processes and we know that this is because expert opinion is not awarded the same value as formal research evidence. Yet, by doing so, we potentially collude with this hierarchical structure and so risk alienating ourselves as user/survivor researchers from other service users. At the Outcry conference held in September 2003, a conference which aimed to bring users/survivors together to strengthen their campaigning position as opposed to other national organisations speaking on behalf of/as representatives of users/survivors, there was indeed a sense of this alienation for some service users. Between a rock and a hard place is the expression that springs to mind.

As individuals and groups setting out to undertake research, the starting point does not necessarily mean the conscious consideration of the potential values and principles that underpin the practice, but we may arrive at these places, sometimes together and sometimes as individuals.

The above are but a small sample of the debates we have with and between ourselves when we try to identify the values and principles that underpin user/survivor led research.

What we are attempting to describe is the time and the place that our research has found itself in. We began because we believed that user/survivor led research could offer a different perspective on the Care Programme Approach, a core value which remains at the foundation of what we do. Users who have the opportunity to respond to other users as independent researchers are provided with an opportunity that is different:

> *User researchers carry more credibility in the eyes of other users - as participants rather that as professional researchers.* (Ramon, 2003: 20).

This article begins with how we planned the audit and the research methods we used. Some of the major findings are presented together with the implications for both mental health services and user-led research.

Planning the Audit

In November 2001 seventeen service users/ survivors came together in Northamptonshire to begin the process of the first ever piece of research into the Care Programme Approach in this county. Opportunities for involvement were publicised through service user forums, mental health organisations and service user contact points within the county. The service users who expressed an interest to be involved brought with them a range of skills, experience and commitment to this task.

This was also a first in terms of local users as an independent group carrying out an audit, or commissioned research of any sort, and many of us involved remain convinced that few people thought anything substantial was likely to come of it. Now, not only has the group's report become something of a landmark in local mental health circles, but has also been acclaimed nationally. The initiative is growing wings of its own - of which more later.

A worker from Daventry and South Northants mental health commissioning team and a social worker from the County Council were involved throughout in an advisory capacity due to their expertise in the field of research. However the goal was for ownership of the audit project to remain with those carrying it out - that is the service users. To this end the county's User Involvement Worker, from an independent user-led organisation (Users Support Service), played a vital role as a member of the team in ensuring that the service users were involved as a collective managed the project.

Before embarking on the audit itself, a user-trainer held three sessions with our group about the aims and objectives of the audit. We were able to discuss issues around the practicalities of the audit as user-researchers such as what we could or could not cover in the audit, confidentiality, timescales and payment - each user was paid to attend the training sessions, meetings, and travel expenses.

With hindsight, members of the group came from many different starting points, for example, some knew a lot about the Care Programme Approach, some knew very little, some had undertaken research before and others had never done so. It would have been helpful to acknowledge this at the

beginning so that we could look at what training we needed as user researchers rather than what training it was thought we needed to meet the demands of the audit.

Despite this, as a group we managed a small budget. It was positive that a budget had been found to support this audit but the exact amount was not communicated to us at the outset, which affected our ability to plan. Nevertheless, we decided on research methods that included both quantitative and qualitative data collection. We developed a questionnaire which addressed the eleven priority areas identified by the Department of Health: information; roles; assessment; the care plan; services; reviews; risk management; opportunities; choice; transition and carers. There was also a free text comments box. At the end of the questionnaire, service users were asked if they wished to have the opportunity to be interviewed by other users and if so to note a contact number. Otherwise the questionnaires were completely confidential.

It was our natural inclination to be as user-focussed in our research methods as we could. For example, the scope of the questionnaire was to send it to everyone on Care Programme Approach within the county rather than a sample. The interviews were semi-structured to allow people to introduce areas that were of concern to them. People were given a choice of venues for their interview and interviewees had control of what was recorded from their interview. Major topics raised within the interviews and the free comments section of the questionnaire were included in the report and recommended to be followed up in future audits.

During our discussions it was clear on several occasions that our approach and assumptions differed from that of what might be termed a standard research approach. For example, one of the advisors experienced in research questioned whether certain findings from the interviews and comments should be included in the report because they did not appear directly relevant to the specific area we had set out to research. The group took the view that we should do the minimum of editing (or censoring) of what people had voiced in response to our queries, that the answers had at least as much meaning as the questions. This seemed to us to be a different style of listening, representing a

fundamental and quite spontaneous difference in priorities and values that carries through to the research process, sometimes in quite subtle ways. In the same way that true user involvement aims at a move from 'doing to' towards a 'doing with'.

An obstacle specific to user led research was the Ethics Committee. We encountered some confusion locally but managed to address the issue by the mental health commissioning team worker getting agreement to go ahead from the Chair of the local NHS Ethics Committee at the last minute. Questions about Ethics Committee approval are the most frequently asked by suspicious and unconverted workers. It is an obstacle, not because we disagree with any principle related to ethical considerations for researchers but because for Ethics Committee members, user led research is new uncharted territory that can threaten the status of research. We challenged tradition and by doing so challenged stigma with a group of people who rarely have any background in user led research. An illustration of the paternalism that we face is evident in this quote from a service user researcher when answering questions of an Ethics Committee

We are told that user researchers volunteering to undertake this training and screened by us (the two 'professional' researchers) need to get the permission of their care manager and GP prior to commencing training. (Ramon, 2003: 20)

Carrying Out the Audit

Our insistence that the distribution of the questionnaire embody the widest possible consultation rather than the 'received wisdom' of selecting a representative sample paid an unexpected dividend in terms of uncovering a major problem. We did not want to rely on Community Mental Health Teams for distribution due to the possible selectiveness of that method. We were informed that the community health services management database could be used to reach everyone on Care Programme Approach, (though not of course for confidentiality reasons directly by us). We were told that there were about 4,000 people in the county receiving services under the Care Programme Approach so we stuffed and handed over 4,000 envelopes for the mailing. In the end the database could only identify 2,554

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people, and these people were duly sent out a questionnaire.

Shortly after the mailing, Users Support Services, to which questionnaires were to be returned, was inundated with calls from recipients. Calls included those from people who had seen a Community Psychiatric Nurse once some years ago, family members of addressees who were deceased, a firm of solicitors. People who had accessed general medical health care and could not understand why they would be on a Care Programme Approach database also contacted the User Support Service as well as people who wanted to know whether they were on Care Programme Approach and to establish who their care co-ordinator was. There was also a raft of anecdotal feedback from people all over the county who were on Care Programme Approach but had not received questionnaires.

Thus our first major finding was the inaccuracy of the database itself. We could not understand how the powers that be could manage the delivery of mental health services without reliable data as to how many people needed services in each area.

> *I was surprised to learn about the inaccuracy of the database and the amount of people who did not know about their care.* (ASSURT member).

Other feedback to the User Involvement worker was equally telling. Several recipients were so unused to being consulted that they were concerned it meant they would be losing services and one said that when they asked a worker for help with the questionnaire they were told to 'just bin it'.

Despite these difficulties 567 questionnaires were returned, overall response rate, 22 per cent, of which 206 questionnaires contained additional comments. Of these, 49 per cent did not know which level of Care Programme Approach they were on: 25 per cent were on standard, 9 per cent enhanced with 17 per cent not recorded. It is impossible to say how representative this is, given that the database at the time was so significantly and fundamentally inaccurate.

Forty-six respondents agreed to be interviewed and

the team felt it vital to see all of these even though the funding, which was still rather *ad-hoc* at this stage, no longer allowed for payment for this. Each interview was conducted by two service users - one to take the lead asking the questions on the schedule and the other to take notes.

> *It was a good opportunity to be involved in the audit and to hear other service users' views in the interviews. We are capable and the capacity for people to work together is very positive.* (ASSURT member)

At the end of the interview the interviewee was asked to read what was recorded to make sure they agreed that we had recorded accurately what they wanted to say. We were very glad we took this approach as the feedback from interviewees was often overwhelming and in many ways the most rewarding part of the process. People expressed being heartened by the fact that they were at last being listened to.

> *Users being interviewed are often more open and honestly critical when approached by other service users.* (ASSURT member).

The quantitative data was analysed by both a service user and the advisor from the commissioning team using EXCEL, whilst analysis of the qualitative data was undertaken by service users and the advisor from social services using the NUD*IST package.

Results

> *The collected data is a true reflection of current thinking and feelings from those people on the receiving end of services. Not a catalogue of statistics with no heart, no real meaning, to be filed away as a task done.* (ASSURT member).

We realise that many people are bored rigid by a raft of figures, but we feel that this article would be incomplete without at least a taster of the results. Table 1 gives a summary of users' views on how well they felt their needs had been met. (The number-phobes amongst you can skip the rest of this section without losing any of the gist.)

Table 1 - Views on how well identified need had been met					
Identified Need	**Fully met**	**Partially met**	**Not at all**	**Not relevant**	**Not recorded**
Medication/ Side effects	*53%*	*30%*	*10%*	*5%*	*2%*
Social Needs	*38%*	*25%*	*16%*	*15%*	*6%*
Physical Needs	*37%*	*26%*	*14%*	*18%*	*5%*
Emotional / Spiritual Needs	*33%*	*35%*	*20%*	*6%*	*6%*

Just over half (53%) of respondents felt their medication needs had been fully planned.

A third of respondents did not have or did not know they had a care co-ordinator, whilst almost half (47%) were unaware of the care co-ordinator's responsibilities.

> *No contact with Care coordinator. Care plan sent through the post. Asked for contact with CPN two months ago, hasn't responded even with a phone call.'*

The relationship service users developed with workers was seen as important as the mechanics of the Care Programme Approach itself with both positive and negative views being voiced.

> *The support from my community psychiatric nurse has been excellent - clear, regular, helpful and has given me lots of info on help lines, support groups and has always got in touch when requested.'*

> *One thing that really confuses and aggravates me is that I just get used to seeing a psychiatrist and then he leaves and I have to go through the whole thing again.'*

Only 46 per cent of respondents had a copy of their care plan that they had agreed to and signed, and only 37 per cent said they had a crisis plan.

> *It seems you either might get something when you're in a crisis or nothing. I have no care plan. .'*

Sixty-four per cent of service users had had a review within the previous twelve months although only half-understood decisions made about their care.

> *I don't find the CPA meetings helpful to me. New ideas are often put forward but rarely carried through. I found this frustrating and disappointing..*

> *Care-plan fine, no complaint. Recommendation — to give someone in care more leeway to be able to cope on their own.*

> *If I could change anything, I would like to get my medication reduced so that I could come off it eventually. I don't know about CPA or who my care coordinator is. I have been using services for 18 years.*

As Table 1 shows, social, physical, emotional and spiritual needs scored less highly.

> *Medication is the main focus. No one appears interested in the root causes of problems, preventative work or therapy.*

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Work on the actual report writing took quite a while. It was undertaken by a small sub-group, with the 'donkey work' being cheerfully provided by the commissioning team worker, and involved numerous drafts. We were very concerned with quality, clarity and credibility probably to the point of being more particular than some 'professional' researchers.

Outcomes

Watching the way in which different people approached a complex and difficult task has been inspiring. (ASSURT member)

We were determined that the end result of all our efforts would not be a report that sat on shelves gathering dust but would be a working document in as many ways as possible. The report of the audit contained 55 recommendations, which were incorporated into an action plan. The second part of the report described the process and the problems we encountered with recommendations for future audits.

The main problems we encountered were:

- Problems with the database. We learned that we needed to critically assess the accuracy of information given to us.
- Not knowing at the outset what budget was available. We have taken the initiative for the second audit and successfully bid for the funding we think we need.
- Some staff members were dismissive of the audit indicating a culture, which still exists within the Trust, of 'doing to patients' rather than 'working with people'.
- There was some initial apprehension by members of the group about carrying out the interviews but by 'doubling up' people felt supported. This part of the audit was extremely rewarding both for the audit group and the interviewees.

People said that it was very helpful to be interviewed by service users who knew what it was like to be on the 'receiving end' and to know they were not alone, either in their experiences of distress or their concerns about services' (Report of the Service User Audit of the Care Programme Approach in Northamptonshire, 2002).

The recommendations for future audits were that:

- Everyone needs to be clear about their roles, responsibilities and expectations both within the research team and with the commissioners of the audit.
- There needs to be honesty between workers and users in order to achieve effective user-led monitoring of services.
- The comments from the questionnaires and the interview data brought to light some areas we had not included in the questionnaire and this has been addressed in the second audit. For example, spiritual and emotional needs have been separated, advocacy has been included, relationships with staff have been incorporated as a separate question.

We hoped the report would prove a useful tool for other groups as well as ourselves. Our wish seems to have been granted as although we thought we initially had plenty printed we have had to have further print runs. The User Involvement worker is now getting very weary of photo-copying it as the requests continue to come in from both inside and outside the county.

The report was well received and much lauded by mental health professionals within the county as a fine example of what service users could accomplish. In fact the rather poor results which were generally recognised as 'what we all knew but no-one was saying' were in danger of being lost in the wash of complimentary comments. As many of the members of the research team are also on the county's Service User Reference Group, which provides user representation on various joint bodies including the CPA Monitoring Group, it was easier to co-ordinate efforts to ensure this wasn't the case.

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This was a unique opportunity for the service providers to embrace the views, feelings and needs of those in receipt of mental health services in our county. (ASSURT member).

An official action plan incorporating most of the recommendations of our report was issued by Northamptonshire Healthcare NHS Trust and our 'user reps' are playing their part in ensuring that this remains on the agenda and is monitored. It was also accepted, and incorporated in the action plan, that follow-up research should be undertaken in the same way.

There was a launch day for the action plan at which members of the research team gave a presentation and we were invited to do a presentation at a Mental Health Foundation event for excellence in user involvement.

The whole experience has been positive. Users of mental health services have proved that contrary to popular opinion, we are in possession of functioning intellects. We are capable of working together, reaching conclusions and making balanced decisions. (ASSURT member).

We have now formed as Action by Survivors/ Service Users Research Team (ASSURT). We are an independent group with its own bank account and the aspiration to have a research agenda as much influenced by grass-roots user concerns as by commissioners' areas of interest - as well as to explore how we can support other groups along the same path.

By carrying out this audit we have also equipped ourselves with evidence to take forward the user agenda. When we state that only 50 per cent of service users under the Care Programme Approach have a copy of their care plan this has more impact than saying 'I do not have a copy of mine and my friends don't either'. We can confidently challenge, armed with evidence and with constructive ideas on how to improve the services. This is why we began and this is why we continue. When we reflect on what we are doing, we know that we are contributing to a shifting paradigm. The values that support, encourage and promote user/survivor led research are the values that underpin our hopes for the future of mental health services and social justice in the wider society. The Care Programme Approach, when it offers the opportunity for a holistic approach, has the scope to go beyond the 'services' and into our lives and is therefore a useful test for how far and how quickly the paradigm is shifting.

If we were asked today what has changed since the report was completed our answers would probably vary. In relation to the effectiveness of CPA we would say that carrying out the second piece of research would give us those answers. What has changed is that ASSURT has earned the credibility to be trusted with an appropriate budget to pursue this work. It does appear that those responsible for providing services are more likely to be honest about what is really happening when the evidence is presented by independent user-led research. Perhaps they are not left with a choice. In relation to what it means for us as individuals we would describe greater confidence in our skills as researchers and in our capabilities as human beings. In relation to what it means for the group we have created a collective identity for user led research in Northamptonshire from which we will continue to encourage others with an interest to become more involved. Our collective credibility is also opening doors for us to research the questions identified from the grassroots local user movement such as ECT, as well as being invited to provide independent evaluation of developing statutory services for example Rapid Resolution Services.

As to what issues have been raised for the group, we would be naive to presume that the acknowledgement of user-led research and the opportunities for further work have been accepted wholeheartedly by those who commission, provide and develop knowledge in the academic sphere in relation to mental health services. We know we will be under heavier scrutiny. We have further to climb because we do not start on the same rung of the ladder. Under the dominant psychiatric paradigm 'our minds, our brains — the vehicles through which we process our experience and generate our ideas, views, judgements and knowledge - are damaged and defective.' (Beresford, 2002).

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In relation to the second investigation into the effectiveness of CPA, our enthusiasm is likely to wane if positive changes are not forthcoming. We expect challenges for us as a collective and we will need determination and commitment to continue.

However, we are very proud and rather surprised by what can be achieved by such a group, many of whom had little or no research experience at the beginning of this adventure. Although we are very much aware that we all still have much to learn and are thirsty for the training opportunities that are available to us now, most of all we are excited by the potential opportunities this venture is still leading us towards. It has been hard work but the group has also been great fun to be a part of and none of us would have missed this journey.

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