

Literary review on evaluating dementia advocacy

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This section of research was based on evaluation report findings from dementia advocacy organisations and networks from around the United Kingdom (UK) which was collected over a three week period. The researcher was on University placement and was given six weeks to carry out two pieces of work for A4MHD advocacy organisation. The second section is a report based on feed back from an evaluative questionnaire which looks at the views of professionals who are in contact with the service and service users.

Introduction

In recent years there has been call for an evaluative system to monitor the effectiveness of dementia advocacy. There has, however, been very little literature on the subject. The need for measuring this service is necessary for individuals with dementia, funders and the advocates themselves in order to observe how effective this type of advocacy is and the implications for improvement. In the past, funding for advocacy has been justified on the grounds that it is a worthwhile cause. However, now the funding agenda has shifted towards the effectiveness of advocacy and the need to measure outcomes (Coyle, 2008). The problem with doing this is the difficulty of finding out the views of the individuals who it is intended to benefit most i.e. the person with dementia. As advocacy practice itself promotes the clients wellbeing it is important not to undermine the purpose of advocacy during the evaluation process.

Evaluating dementia advocacy services is by its very nature a niche problem which facilitates the need for a holistic, as well as a sensitive approach. Methods that appear to have worked use samples of professionals or family carers who have had contact with the services via referral or some other means. This is because the person with dementia is often unable to put forward a point of view about the services they have used due to their progressive illness. This in its self presents a problem because it is ultimately their views which are most valuable.

Methods of evaluation

Although it can be difficult for professionals to find the time to do long interviews, it has been a successful method when done in previous evaluations and appears to be a recurring approach in advocacy evaluation reports. Advocacy organisations have tended to achieve funding to employ an independent evaluator as, quite understandably, time is stretched for advocacy organisations to undertake such research by themselves.

Interviews have consisted of open ended questions and the resultant data was analysed thematically or by content analysis. This was to receive as wide a range of answers as possible. As mentioned the sample often consists of (in between 20-40) professionals that work with the person with dementia that have had contact with the advocacy. In some evaluations they have managed to include a small amount of service users, although important this amount cannot be reflective of the majority of service users.

instruction, representation and advocacy relationship. They found that there are clear guidelines in place for advocates to follow which are to be used in good practice. As service providers are well aware of these principles there are day to day gray areas that are apparent in regular advocacy practice which may call for substituted judgement. According to Cantley and Steven (2004) there are many dilemmas, ambiguities and uncertainties that advocates face regularly and in order to close the gap it is important to focus on the relationship between the principles of advocacy and the delivery of advocacy.

There has been only a small amount of questionnaire type research that has been used by advocacies. 'Mind' dementia advocacy in Brighton have separate evaluation forms for professionals and service users that they send out if people are willing to fill them in (this is aside from employing an evaluator). Questionnaires have been used mainly to get a flavour of what people's views are of the service or in situations where the person was not available for interview (see for example appendix 1). It would be unwise to rule out the use of questionnaires in this area of research because they have the potential to give an idea of how an advocacy organisation is perceived from the outside. This can then be used as a springboard to give some direction of what approach to take in the evaluation process.

A representative from Circles advocacy Network Project stated that after failing to receive enough feedback from evaluation forms had created a way which could potentially gain feedback from service users (see appendix 2). This was done by designing simple anonymous evaluation cards which were analysed and slightly altered by the patient's council and their local advisory group before distribution. These cards address some simple aspects of the advocacy role and can be completed in written or graphic forms which are then sent to the advocacy through the hospital mailing system. They will be piloting this on hospital wards over the summer of 2009. Their aim is to record their findings in a number of different ways to insure inclusion.

After looking at evaluation reports and reading replied emails it would seem that on average evaluation (in this area) has worked well for advocacy organisations by interviewing to acquire rich data. However many advocacy organisations have chosen a particular group of people for their sample group such as a particular level of health professional or local councils. This means that they are missing vital feedback from other people who are around the service user and are aware of the impact an advocate has had on them. Whilst taking the preferred methods of other advocacy organisations into account, the Beth Johnson Advocacy and Dementia Project fulfil the criteria for a sound holistic approach to evaluating dementia advocacy. They have involved family carers, professionals in the health service, local councils, advocates (paid or voluntary) and even the service users themselves when appropriate.

Evaluation Report for Dementia Advocacy

Abstract

The aim of this research is to gain feed back from people who have had contact with the service and service users about their experiences of 'A4MHD' dementia advocacy. Fifteen participants took part in answering questions from a questionnaire over the phone. The questionnaire was based on guidelines and principles taken from the advocacy charter. The received data shows that A4MHD scored on average good to excellently in almost all sections of the questionnaire.

Introduction

The purpose of this research is to get the views of professionals and family carers who are involved in the lives of people with dementia about their experiences of using a dementia advocacy. The advocacy organisation being evaluated is Advocacy 4 Mental Health and Dementia in Leeds (A4MHD).

The method of evaluation being used for this research has been done by designing generic questionnaires (see appendix 3) and then collecting data over the phone. There are four parts to the questionnaire that cover some of the guidelines taken from the Advocacy Charter. This is a code of practice that advocates follow in which contains the main principles for advocating. Some of the questions are scored on a Likert scale of one to five with five being excellent and one being very poor. Other questions require a simple yes or no answer except for the last part where participants can give their open views about the service.

The problem with this research is that it is difficult to gain feedback from service users directly due to their illness. The chosen method for collecting data for this research is necessary as firstly it would be unethical to have service users go into detail about their experiences as it may be distressing for them in time of mental deterioration; secondly they may not recall being visited or have known an advocate was involved at all.

There is very little literature in the area of evaluation of dementia advocacy, especially when using questionnaires. This is because there has only recently been a shift in the funding agenda towards the effectiveness of advocacy and the need to measure outcomes (Coyle, 2008). This makes comparing this type of study with other studies difficult.

Method

Rationale and Approach

The aim of the research is to evaluate an advocacy organisation to see how well it is viewed by professionals and family carers who have had contact with the service in the last year, and also what suggestions there may be for improvement in the future.

Study Design

A generic questionnaire was produced and data was collected over the phone. This was done so that data could be collected quickly.

Participants

There were 15 participants that took part in the research all of which were selected using cluster sampling. Two were family carers and the remaining 13 were professionals that have been in contact with the service users. These consisted of 5 nurses, 2 doctors, 2 social workers, 2 joint care managers and 2 Safeguarding Adults Enquiry Coordinators. The phone numbers of these people were given to the researcher by experienced dementia advocates who work for the organisation.

Procedure

All participants were contacted over the phone and were told about the nature of the study. They were then asked if they could answer a few questions. If participants agreed the researcher asked them questions from the questionnaire which were scored on a Likert scale of 1 to 5 (5 being excellent and 1 very poor) or answered by yes, no or don't know. The researcher then took notes on the final section as this gave the participants an opportunity to voice their views on the service. Finally participants were thanked for their time and the data was collected and analysed. Each interview lasted around three to four minutes and all took place at the A4MHD offices.

Reflexivity

The data was analysed using content analysis. After results were collected they were then divided into sections then tallied and written out. The findings reflected A4MHD in a very good light and all participants were very helpful in giving their views and comments.

Analysis/Discussion

Overall the results (see appendix 4) on average have been scored as either excellent or good. As the questionnaire was in sections it would be best to present the data in the same order.

The first section was on the accessibility of the service. When asked if participants had seen publicity material (1a), 11 out of 15 said yes. The next question (1b) asks, "Have you referred anyone with dementia to A4MHD for advocacy?" to which 9 out of 15 replied yes. This question sets the premise for this section as the rest of it consists of questions about referral. Participants mainly heard of how to refer by word of mouth and most said the referral was very quick and very easy to do. However when it came to understanding whether to refer to IMCA or IMHA participants were split down the middle in knowing the difference between the two. This could perhaps be improved by explaining in more detail what they are and what the difference is between them on promotional material.

The second section asked the participants questions on whether they thought it was a professional service. When asked to score approachability, knowledge, politeness, punctuality commitment, and reliability the service scored excellently in the overwhelming majority. The next set of questions was to do with how the service user understood what the advocate's role is and whether the advocate communicated well with the person. Most said that they didn't know because they were not around when the advocate spoke to the person. This meant that only a third of participants could answer the questions. When asked, "Did the advocate explain their role to the person?"(2b) and "How well do you feel the advocate communicated with the person with dementia to establish their views?"(2c) those who could answer said the advocate performed excellently. Participants scored mainly average when asked if the person understood the role of the advocate (2d), however this is not a reflection on the advocates performance as this is to do with the level of the service users illness.

Most scored excellently when asked if the advocate represented the persons wishes (2e) and had agreed that the person was more involved in the decision making process (2f), although some were not capable to do so. When asked, "did the person achieve their desired outcome?"(2G) there was a mixed response. This was because the situation had generally worked out for the best but it wasn't necessarily the person's desired outcome. Others had said that they were very happy about the outcome and two were still ongoing. The final question of the section asked, "Did the involvement of the advocate make a positive difference to you?"(2h) answers varied between good to excellent. When asked the same question but aimed at the person with dementia participants said that involvement made a very positive difference.

The third section is entitled "putting people first". When asked, "Was the person easy to contact?" (3a) almost all said yes. Almost all participants also agreed that the advocate had managed to spend enough time with the person (3b). Question 3c) asks if necessary, "Was there a translator available?" There was only one participant who said that the person needed a translator and there was one easily available.

The final section (section 4) asked the views of the participants. When asked, "What difference did the participant make?"(4a) Many complimented the service.

"Having an advocate made all the difference"
(Nurse)

"It gave the person support and helped to express their opinion"
(Joint Care Manager)

"It has improved her financial situation and helped with my own mental health"
(Family member)

There was a general consensus that an advocate had made a positive difference with things like CPA meetings and helping individuals voice their rights.

The next question asks, "Do you have any suggestions on how the service may be improved?"(4b). There was a call for more advocates by three participants.

"I think the advocate was a bit stretched for time so I think having more advocates would very beneficial"
(Nurse)

"More advocates because there are long waiting lists"
(Nurse)

"More advocates"
(Nurse)

Nurses are in contact with service users all the time so they have insight more than most from the patient's side as well as an understanding of the health service and the agencies surrounding it. This means that their views are invaluable because they come from a very central point of view and should be seriously taken into account when considering improvements.

There were a couple of suggestions made by a Joint Care Manager and a Social Worker about what they would of liked the advocate to be more involved with.

“I Think the advocate should have been less confrontational and more about facilitating the best interests of the person. It should be more about working together”.
(Social Worker)

“I wish they could have discussed issues with 3rd parties such as families”.
(Joint Care Manager)

Although few criticisms have been made about the service, these comments are worth taking into account because the objectives of advocates along with agencies surrounding a person with dementia are ultimately focused on an individual’s wellbeing and what would work best to support that individual. However it is the role of the advocate to see to the service users wishes without consulting any other family members or professional bodies as advocates are completely independent from them. Also the researcher has no knowledge of how much contact the advocate has had with these particular participants and to investigate this any further would mean interviews would have to take place with participants to gain richer data for a fuller understanding of the situation.

In conclusion the results were close to the researchers expectations as most answers were scored as good to excellent. The biggest limitation to this study was the sample size. There was initially intended to be at least 25 participants but this was difficult for two reasons, firstly the majority of participants had been difficult to get in contact with because they were generally busy. Secondly there was a time limit of three weeks to collect and analyse data. Ideally there would be more family carers in the sample because they are usually deeply involved in the service user’s life and would see the full impact of an advocate on the person’s life. Although this was not possible there was still a good spread of professionals involved which came from different positions in the mental health service.