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Patients' advocacy: The development of a service at the State Hospital, Carstairs, Scotland

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Abstract

Advocacy is part of the process of empowering patients and involving them in the development of services. This paper describes the development of an advocacy service in the State Hospital at Carstairs and explores the issues involved in advocacy in a maximum secure environment. Using a model of citizen advocacy the service was started in September 1997. Patient involvement throughout the hospital was high with approximately 88% of patients having some contact with the service by January 2000. Most of the issues raised by patients are similar to those in any mental health advocacy project. Entrapment is a particular issue for some patients. Safety and security issues influence every aspect of the service. This ranges from advocates having to do more for patients rather than enable them to do things for themselves (e.g. make telephone calls) to the principle of the patients' wishes being paramount being tempered by security demands.

Introduction

Patients' involvement in the development of services, the development of patient's rights and a role in the decision making process are crucial to policy in mental health. Advocacy is a part of this process. Recent documents in both England and Wales and Scotland have reaffirmed these positions (Department of Health, 1991; NHS Executive, 1995; Scottish Office, 1997a).

Sam Galbraith, then Minister for Health at the Scottish Office, summarised the position: '...advocacy is recognised as an important way of enabling people to make informed choices about, and remain in control of, their

own health care. Advocacy helps people have access to information they need, to understand the options open to them and to make their wishes known' (Scottish Office 1997b).

The Scottish Office guide to good practice in advocacy (Scottish Office, 1997b) indicated that advocacy has two main themes: 'protecting vulnerable people; and giving them a stronger voice to make their wishes and need known.' It usually involves one person enabling another to achieve their goals through exercising their rights.

As Thomas & Bracken (1999) point out, there is little in the psychiatric literature on advocacy. This paper sets out to describe the

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development of a patient's advocacy service in the State Hospital, Carstairs, Scotland and to highlight some of the issues involved in advocacy in a setting of maximum security.

Advocacy is not well established in maximum-security hospitals. In England an advocacy service was established at Ashworth in 1992. A service based on this model was later set up in Rampton. Broadmoor is in the process of developing an advocacy service. The changes planned for secure accommodation throughout Britain, including the development of medium secure units, is likely to lead to the need for similar advocacy projects in such settings. To understand advocacy in a maximum-security hospital requires some background on the State Hospital and its patients.

The State Hospital, Carstairs

The State Hospital is the only special hospital in Scotland and provides psychiatric care for approximately 230 patients from Scotland and 16 from Northern Ireland in conditions of maximum security. It is these conditions, which both make the need for advocacy more acute and contribute to some of the unique issues in providing an advocacy service in this setting.

The regime at the State Hospital means that the relationship between the patients and the outside world is extremely limited. Individuals and their belongings are searched when they enter the State Hospital and on a regular basis subsequently (along with their rooms), and anything considered potentially harmful removed. Their mail, except for certain categories clearly defined in the Mental Health (Scotland) Act 1984, is screened. Outgoing telephone calls are restricted to approved numbers, can only be made at certain times of the day (with the exception of certain patients in the rehabilitation wards) and will be moni-

tored by a member of staff who is with them at the time. In general, incoming telephone calls cannot be received. Their visitors are searched on entry using a similar system to airports and are attended by a member of staff. Staff and official visitors are also screened on entry to the hospital and always carry personal attack alarms when with patients. There are good reasons for the security measures; staff, other patients and visitors need to be protected. Family, friends, victims and their families and members of the public need to be protected from possibly unwanted and abusive telephone calls or letters.

Patients' whereabouts in the hospital are known at all times. They are required to attend placements and therapies and to comply with treatment and where appropriate, to 'address their offending behaviour'. Psychiatrists, psychologists, nurses, occupational therapists, social workers, pharmacists and others provide a range of individual and group therapies. Patients are also encouraged to participate in 'recreational, social and spiritual activities' (State Hospitals Board for Scotland, 1999a).

The Patient's Charter emphasises that patients should be treated as individuals with respect and dignity, be given choices whenever possible and be given clear, understandable explanations (Department of Health, 1991). The reality, however, is not always perceived as such by patients. One patient describes the situation thus:

'Ye hae sartin reets
So sighs the Charter on the wall
Bit frae too blidy lang ye find
Ye have no blidy reet at aw!'

Patients are detained under the Mental Health (Scotland) Act 1984 or the Criminal Procedures (Scotland) Act 1975 or 1995 and equivalent Northern Irish legislation. Except for the first few weeks after transfer, patients have no right of appeal against being cared

for in the State Hospital. Their only appeal hereafter is against detention at all. The Medical Sub-Committee, a body of external professionals, approves transfer or discharge. For restricted patients, permission for discharge and transfer has to be granted by the First Minister of the Scottish Parliament (formerly by the Secretary of State for Scotland).

Patients in the State Hospital

A large proportion of State Hospital patients are from general psychiatric hospitals. This is unlike the English High Security Hospitals (Ashworth, Broadmoor and Rampton) and is a consequence of the lack of medium secure units either in Scotland or Northern Ireland. Figures for 1998–1999 indicate that 44% of patients came from other hospitals, 26% from the courts and 30% from prison (State Hospitals Board for Scotland, 1999b). The population was overwhelmingly male (92%), of whom 70% had a diagnosis of schizophrenia and almost 50% had a multiple diagnosis. With patients staying an average of four and a half years (range 3 months to 31 years) clinicians are usually able to stabilise a patient on appropriate medication with the consequence that although signs of chronic illness are seen it is relatively unusual to meet patients who are acutely ill. Patients were predominately young, 63% in their twenties and thirties (State Hospitals Board for Scotland, 1999b).

Patients have to meet the criteria of suffering from dangerous, violent or criminal propensities along with a mental illness to be at the State Hospital, but almost one-third of patients have not committed an offence. Some are detained because of the threat they pose to themselves rather than to others. This is particularly the case for the female population. Some patients who are transferred from prisons have developed mental health problems while being in prison.

At any one time approximately 45 patients (18%) have a learning disability. Most have a mild disability but also have severe challenging behaviour and serious difficulties with appropriate social interaction. Many have spent a long time in other institutions and many have a history of abuse, either by others, to others or both.

The patient population is heterogeneous with a number of small, sometimes overlapping groups who require special consideration. These include women, people with a learning disability, patients from Northern Ireland (because of being in another country), patients from ethnic minorities, patients who have been abused and patients who are abusers, patients who have committed crimes and patients who have not

Development of the Advocacy Service

It is against this background that management at the State Hospital took the very positive step of seeking to introduce an advocacy service. The model chosen was that of an independent volunteer advocacy service led by a paid, full-time co-ordinator with part-time administrative support. Both were to be employed and working within the hospital but managed externally from it. The model is essentially that of citizen advocacy (Scottish Office, 1997b). This was unlike the Ashworth model where all advocates were paid members of staff employed and managed by the Citizens Advice Bureau.

The establishment of external management took one year and was eventually undertaken by Scottish Association of Health Councils (SAHC) who, together with the hospital management established a Management Committee. The Chair of the management committee, the co-ordinator and a representative of SAHC meet bi-annually with the Quality and Standards Committee of the hospital.

Supervision and support of the co-ordinator was through the management committee. The first co-ordinator (KMcP) took up post on 1 September 1997.

The aim of the advocacy service was to provide an independent, highly skilled, responsive and professionally co-ordinated service with volunteer advocates within the State Hospital. It would observe the safety and security regulations of the hospital but working independently within it to promote patients as individuals, to support them and enable them to be fully informed and involved in their care and rehabilitation.

Use of the service

Advocacy services can be criticised for reaching only those patients who have the skills required to seek it out. There was a need to make the service accessible to as many patients as possible. A number of measures were taken. A leaflet advertising the service was produced and distributed to all wards.

In May 1999 a 'surgery' or drop-in system was started. This involved the advocacy service setting a fixed time when an advocate would be available on each ward so that patients could approach him or her at that time without any special measures needing to be taken. At one time all wards had a surgery once every 2 weeks and the admission ward a surgery once a week. Lack of advocates, however, meant that by November 1999 surgeries had to be cut to a more manageable once a month on all wards with the admission ward having surgeries once a fortnight.

Although hospital management had agreed that patients should have unimpeded access to the advocacy service in an environment where access to the telephone is restricted and supervised, access could be limited. An early agreement between the advocacy service and the hospital was intended to ensure

that all correspondence between the patients and the service was confidential. This confidentiality was compromised, however, because some people were unable to read or write and required help from staff in contacting the service. The surgeries were intended to enable patients to contact the advocate directly.

By the end of 1997 there were 24 patients in touch with the service, 48 by the end of January 1998, 71 by the end of June 1998 building up to 225 (approx. 88% of the population) in January 2000.

Patients can make use of the service for as many problems as they want. The range of the issues raised depends in part on how long a patient has been in touch with the service. There is no limit to the number of issues a patient can raise, the range being one to 21 separate issues. The majority, about 80% of patients, have raised eight or fewer issues.

Confidential records are kept in the advocacy service of all patient contact. Typically patients have had a long, but intermittent contact with advocacy. The initial issue may have been to do with something relatively straightforward such as ground access and then moved on to more complex issues such as problems with other patients, complaints about treatment by staff and hospital transfer. Some problems may not, strictly, be the remit of the advocacy service but the responsibility of other departments such as social work. Stretched resources elsewhere have meant that the advocacy service picked up some of these issues.

Outcomes from advocacy are difficult to define and measure. Some problems are quickly solved and others take many months and involve reference to external bodies. Others, such as supporting an entrapped patient in his/her desire to be transferred, can run for years.

The advocates

From the initial enquiries 20 potential advocates started training of whom 18 were subsequently formally interviewed. Of these, 14 were accepted as advocates with one dropping out during the probationary period leaving 13 advocates recruited over the two and a half years. Of these, six were men and seven were women. They range in age from late 20s to early 70s. In two and a half years only three advocates were lost.

Advocacy in a maximum secure hospital — the special issues

Although there are a number of special problems which arise working in a maximum-security environment, most of the issues raised by patients are variations of those raised in any advocacy project working with people with a mental illness; issues of treatment, medication, staff attitudes, detention, not being listened to and struggles with bureaucracy. There are a number of themes that will emerge in any consideration of advocacy and these will be considered in relation to the State Hospital, along with those specific to the setting.

Security

Security is obviously the biggest difference to other advocacy services and a challenge to the development of the service. There is no part of the service it does not touch and will be considered under each theme where appropriate.

Advocates have to be able to tolerate the secure environment and work comfortably in it without becoming complacent. The hospital is geographically fairly isolated and the obvious signs of security, such as the high fence, lights and the monthly testing of the siren, which indicates an escape, can be daunting. Less obvious is the emptiness of the hospital grounds since 'grounds access' (un-

til recently called parole) is strictly limited to certain patients at certain times of the day and is, for obvious security reasons, a highly regulated activity.

Safety

Security measures are there to maintain the safety of patients, staff and the public. Focusing on safety makes some of the otherwise difficult issues around security more understandable. There can be no negotiation over security.

This can be difficult where some patients are seen as being disadvantaged by the risks posed by others. For example, the move of one patient to a different ward may necessitate the move of another patient(s) with whom, for security reasons (which may involve their own safety), they are unable to associate. Moving around the hospital requires constant security arrangements, which can be both intimidating and irritating when they occasion delays.

Confidentiality

Any advocacy service is confidential but this has to be tempered with recognition of the special patient population and the need to maintain the safety of others. In the State Hospital however, where a patient's whereabouts has to be known for every minute of the day, it is not possible for a patient to visit the service without staff and probably other patients knowing of this. Advocacy is sometimes viewed by staff as threatening and in a situation where staff are accustomed to knowing every detail of a patient's day-to-day life then the advocacy session itself, which does remain confidential, can be experienced as even more threatening by staff. The fact that it is not possible to seek out advocacy anonymously and confidentially is a major problem. It has been solved in part by the introduction of the surgeries although access of these is still observed and by the success of the project itself. The numbers of patients

using the service gives some indication that their anxieties are overcome, or at least have been for some types of issues and that using the service can be deemed 'usual'.

Entrapment

'Entrapped' patients are those who no longer need to be in a maximum-secure environment and who should be discharged to other settings, but, for various reasons cannot or have not been discharged. The main reason is that until recently there was no medium secure provision in Scotland or Northern Ireland to discharge patients to. Health Boards and trusts have been unwilling to accept responsibility for patients who could be discharged to other appropriate accommodation within their area. This may reflect an unwillingness to pay for these patients' care. The State Hospital is centrally funded and thus costs are not borne locally. It may also reflect an unwillingness to accept such patients into the local community. These issues have been discussed by Thomson *et al.* (1998).

The Mental Welfare Commission for Scotland has raised this as a serious issue in their annual reports and on other occasions. The implementation of the European Convention of Human Rights might have an impact on these patients if it is possible for them to argue that they are being inappropriately detained. Although the problem may be seen as one of security it is also, fundamentally, a problem of finding appropriate accommodation, which is an issue for other patients awaiting discharge or in community settings in the mental health system.

At present there are more than 40 patients who have been approved for transfer out of the hospital but for whom no appropriate accommodation is available. It is the restrictions of the maximum security environment that make it seem so unjust for people who no longer require this degree of security.

Empowerment

Advocacy usually has the aim of empowering service users both in the content of their decisions (e.g. ensuring the person has the appropriate information to make an informed choice, valuing the person's own goals and choices) and in enabling them in the process of expressing that choice and achieving their goals. In a maximum-security environment both these aspects will be compromised by security and safety considerations.

Patient's goals can only be pursued within the limits of security. It would not, for example, be appropriate for an advocate to assist a patient to breach security or safety regulations nor to engage in (potentially) criminal behaviour. There is therefore the possibility of some element of judgement by advocates on which goals of the patient it is appropriate to pursue.

Likewise, enabling a patient to enact their wishes will be hampered by security considerations and advocates will have to act on behalf of the patient, rather than helping a patient act for themselves. Thus, telephone calls, even to a solicitor, may have to be made by the advocate because, if the solicitor is out, there is no opportunity for the patient to receive incoming calls. In other circumstances, a new and necessary telephone number will not be on the currently approved list for that patient.

Patients

As in other advocacy projects, the advocates have to be able to relate to patients, understand their needs and perceptions but avoid being manipulated by them. In any mental health service some people have concerns that some patients are manipulative and this is especially true in the State Hospital. Given the potentially major consequences of successfully manipulating an advocate, it might seem inevitable that attempts will be made. On the other hand, in an environment

where a patient is watched every moment of the day it is often difficult for them to express reasonable and natural frustration, anger, unhappiness, resentment, bitterness or even assertiveness without the possibility of it being labelled as 'ill or inappropriate behaviour'. The advocacy service can be particularly important in allowing patients to express appropriate frustrations and seek appropriate action and redress.

Any advocate must not prejudge the client group with whom they work. This is even more the case in the State Hospital where folklore surrounds some patients, even within the hospital and some patients seek to maintain their reputation. Everyone working in the State Hospital has to be able to cope with the crimes which some patients have committed and work with those patients in a wholly non-judgmental way. Life stories of many patients in mental health settings are tragic and upsetting to hear, but again, in the case of these patients it is often these experiences and their inability to cope with them, which have led, directly or indirectly, to their admission to the State Hospital.

Recruitment

In most projects, the possibility that an advocate might know a patient would not be an issue. Indeed, in projects, which deal with the whole range of the NHS including GPs, it may not be possible to avoid advocates knowing potential users. In the State Hospital context concerns were expressed over security implications. Would either the advocate or patient be more open to manipulation? Would the advocate give away security details? A policy was agreed with senior hospital management whereby an advocate who knows a patient would neither work with that patient nor on that ward. When visiting that patient as a friend they would do so at a separate time and under the same restrictions as any other visitor.

Employees of the hospital and their families cannot be advocates. Since the hospital is a major local employer in a rural area this further reduces the number of potential advocates. Recruiting advocates from across Scotland (the furthest lives 166 miles away) has an impact on the time advocates can give to the service (from 2 days per week to 5 hours per fortnight) and problems with cover (for holidays and illness) and response to urgent situations. The advocate who lives the furthest distance is the person who contributes 2 days per week, so distance need not be a barrier to commitment

As with other advocacy services selection is thorough. Following a selection process and a period of training (1 day a week for 6 weeks) there is a formal interview by a panel, which includes a senior member of the hospital. Unlike most other advocacy projects advocates have to undergo a police check.

Staff-advocate relationships

As Thomas & Bracken (1999) point out, it is inevitable that, in representing the patient's interests, advocates will come 'into conflict with psychiatrists'. This can be extended to all groups of staff. Many staff, nurses in particular, believe themselves to be advocates for their patients. They find it difficult to accept that when they are doing what they believe to be best for a patient this can, and should, be challenged. In such circumstances the patient's use of advocacy can be experienced as personal criticism. In a total institution such as the State Hospital advocacy can be seen as particularly threatening in challenging the power base of staff. Advocacy sessions are confidential (see above); they make it easier for patients to challenge decisions and practices and to make complaints.

In some cases hostility arises from complaints against staff. Although some patients may make malicious complaints some are justified and made against a background of

intimidation by staff. Hostility from this group will only cease when the behaviour that engendered the complaints stops.

Acceptance by the staff has been varied, ranging from support and enthusiasm to suspicion, covert and overt hostility as expressed to advocates and the co-ordinator. There is no reason to believe, however, that this is particularly different from any other advocacy service set up within an institution. The totality of the State Hospital as an institution may simply highlight some of the issues or make them more acute.

Thomas & Bracken (1999) suggest that for advocacy to succeed psychiatrists must change their approach to it and work more cooperatively with advocates and not view it as 'anti-psychiatry'. They suggest that psychiatrists need exposure to advocacy in their training. Involving all staff in training about the purpose and methods of advocacy as it is introduced into institutions might be useful.

Conclusions

Setting up an advocacy service within the State Hospital was not without its problems but, based on use by patients, has been judged a success. Advocacy in a maximum secure environment shares many of the same problems as advocacy anywhere, but the restrictions of security make for most of the differences. Although the service is accepted and welcomed by many staff this is not universal. The final words should be left with an advo-

cate: 'We have had a great deal of bother with a great many people at the State Hospital – but very rarely with the patients'.

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