

# LOCAL INVOLVEMENT IN HEALTH CARE

March, 1997

## Executive Summary

- ◆ A cultural shift has been identified
- ◆ Some barriers have been identified to successful local consultation
- ◆ Many senior managers claim to be highly committed to local consultation, but this is not always manifested in their strategies
- ◆ Some front-line staff appreciate being given the insight into the user's perspective while others find it difficult to accept criticisms of their professional behaviour
- ◆ Most users appreciate the opportunity to have their voices heard; however, some are suspicious about the health authority's motives
- ◆ The list of methods of consultation recommended in *Local Voices* is used by many groups but criticised by several of the commentators
- ◆ It is possible in some cases that the participants' views are not always acted upon
- ◆ Some guidelines for conducting local consultations have been identified

### 1. Sources of information accessed:

- Journals used:
  - ◆ *BMJ*: 12 March 1994
  - ◆ *British Journal of Healthcare Management*: 1(11); 2(7)
  - ◆ *Care Plan*: March 1995
  - ◆ *Community Care*: 24 March 1994; 11-17 May 1995; 12 January 1995; 19 January 1995; 27 July 1995; 24 August 1995;
  - ◆ *Health and Social Care in the Community*: November 1994; March 1996
  - ◆ *Health Care Analysis*: August 1995
  - ◆ *Health Service Journal*: 12 May 1994; 10 November 1994; 2 March 1995; 16 March 1995; 27 April 1995; 11 May 1995; 21 September 1995; 12 October 1995; 1 February 1996; 2 May 1996; 18 July 1996; 5 September 1996;
  - ◆ *Health Services Management*: March 1994
  - ◆ *Healthcare Today*: September 1996;
  - ◆ *International Journal of Health Care Quality Assurance*: 9(1)
  - ◆ *Journal of Mental Health*: 5(3)
  - ◆ *Journal of Social Policy*: 23(4)
  - ◆ *KF News*: 17(4)
  - ◆ *Nursing Standard*: 7(10)
  - ◆ *The Health Business Summary*: July 1996
  - ◆ *The Health Summary*: June 1994
- Databases
  - ◆ King's Fund's Unicorn database

## **2. Information gleaned:**

### ***2.1 Introduction***

In 1992 *Local Voices* urged health authority purchasers to alter their practices and become the "champions of the people" and to ensure that their views have a "tangible influence on purchasing decisions". It recommended a variety of ways of involving the public and of altering the culture of the NHS so that users and the public at large would become central to the commissioning process<sup>1</sup>. By 1995 Liza Donaldson had concluded that public participation was still "patchy"<sup>2</sup>. A cultural shift seemed by then not to have occurred.

Nonetheless, the idea that a cultural shift is taking place has not disappeared. In 1994, Barnes and Wistow remarked that initiatives to involve users were no longer dependent on the enthusiasm and commitment of isolated groups of users and providers but that these initiatives were part of a wider shift in thinking<sup>3</sup>. This idea has continued into 1996. John Spiers comments that:

"We are on the threshold of a possible and huge cultural shift to a consumer-led health service...one in which the values of both professionals and patients can be effectively engaged with a new agenda."<sup>4</sup>

The cultural shift to a user-led service will be gradual and has not yet been completed; however, the notion that it is on its way refuses to go away. Some even point out that elements of it have been with us for some time, such as the ability of patients to select whichever GP they want. Shackley and Ryan go so far as to suggest that this particular choice is the greatest and possibly the *only* opportunity for consumer participation in the new culture of the NHS<sup>5</sup>. Indeed an article written in 1996 suggests that prejudices about the validity of the comments of the public and of professionals respectively still exist:

"Unfortunately the views of users and carers are frequently dismissed as "subjective", while the legitimacy of clinical decision making is unchallenged."<sup>6</sup>

Despite this, a change in ownership of health services is starting to appear. In 1994, Bob Sang used italics to emphasise this when he wrote of an advisory panel of local people who were "beginning to shape the future direction and quality of *their* services"<sup>7</sup>.

This cultural shift is gradually having an effect on health and social services. Although it is causing some problems during this transitional time, it is also spreading the belief that public involvement in health care is A Good Thing.

#### ***2.1.1 Why the involvement of the public is thought to be a good thing - and the implications of non involvement***

Alex Robertson quotes Robert Pinker who, in 1971 related an improvement in well-being to good communication between users and professionals:

"Welfare is promoted when service providers and consumers exchange as equals. Policies are acceptable when these exchanges do not stigmatise but empower the recipients of service."<sup>8</sup>

Robertson himself details a project which he managed, part of whose aim was to engage users and professionals in a manner that would address Pinker's challenge<sup>9</sup>. The idea that user involvement might be a good thing in itself, as it should empower users through the very process of being heard, appears elsewhere. Ruth Townsley for example explains that during

research at the Norah Fry Research Centre, some people with learning disabilities very obviously enjoyed being asked about their lives<sup>10</sup> and thus experienced a boost in morale from the exercise merely being undertaken.

Not only does the participation in such fora have positive effects on the communities and health services involved, but there are also potential negative implications of not involving the public. Spiers catalogues a series of states which, he says, impact on the immune system and which therefore need to be supported by health authorities' innovation (and, by implication, by local involvement initiatives) in order to prevent the possibility of ill health<sup>11</sup>. This list includes self-esteem, empowerment, future orientation, perceived personal status and effective personal coping strategies.

It also seems from what Hogg and Cowl write that the Patient's Charter could be raising patient expectations without improving the actual service provided<sup>12</sup>. By not involving users in a wider capacity than just as recipients of the Patient's Charter, the various parts of the NHS could be setting themselves up to be criticised. One important aspect of local involvement is to raise public awareness of the economic limitations associated with providing services. If the public are not informed about these financial aspects of healthcare however, they can be forgiven for expecting more than is possible.

Alison Spencer asserts that one of the reasons why it would be wrong not to obtain users' views is that it is morally correct to ensure that hospital is not a frightening or degrading place<sup>13</sup>. This implies that it could be morally wrong not to get users' views. The other two reasons she lists as important reasons for users' views to be sought are the need to find out if treatments are considered by the client to be effective and the reduction of the "them and us" barrier. This last theme is also taken up by Tranter and Sullivan who state that "[i]f users' and carers' views are not seen as integral to the process [of needs assessment] then an incomplete, even paternalistic assessment will be made"<sup>14</sup>.

Although user involvement is essentially a positive addition to the authority's role, it needs to be managed effectively. Sometimes, if the purpose of the involvement is not clear to either the users or the professionals then the ensuing confusion can be destructive to the user involvement project; it can lead to disillusionment and a reluctance to participate on both sides<sup>15</sup>.

## ***2.2 Some of the projects***

### ***2.2.1 Client and group involvement in actual projects***

Many articles have been written since 1994 detailing examples of user involvement in various projects in the UK. The projects written about range from focus groups and other panels established by health authorities and social services departments to the involvement of external organisations and groups which may or may not have been established prior to their participation in healthcare decision-making.

The following examples of user involvement in healthcare were reported as case studies in the professional press:

**Avon:** the Norah Fry Research Centre wanted to involve users of learning difficulties services in their research into services<sup>16</sup>. They achieved this via a questionnaire survey.

**Bedfordshire:** Bedfordshire Health Authority set up a user group to find out what the users of a continence service liked and did not like about the service itself<sup>17</sup>. The group communicates its views via meetings with the Health Authority.

**North Bedfordshire:** a standing panel of 300 members of the public taken from a cross-section of the community was established by Bedfordshire Health<sup>18</sup>. They debated a healthcare topic every year for three years. The three topics they were asked on were maternity services, dental services and out-of-hours services. Tangible outcomes are said to be in the pipeline.

**Birmingham:** from 1987-1990 the Birmingham Community Care Special Action Project (CCSAP) did several things:

- it undertook consumer research on the views of people with mental health problems concerning the services they had or were receiving;
- it ran a pilot citizen advocacy project for people in a psychiatric hospital which was due for closure;
- it supported the development of users councils for people with mental health problems in hospital and community based schemes;
- it established a series of public consultations with people caring for the elderly or for a disabled relative or friend;
- it sponsored a review of day services for people with disabilities which was completed via consultations with sensorially and physically disabled people;
- it undertook small scale separate consultations with people with learning difficulties and their carers as part of a review of day time opportunities for people with learning difficulties;
- it also ran a variety of activities to help people to find out more<sup>19</sup>.

**South Birmingham:** Shenley Fields Centre Study, a community mental health resource, attempted to find out what its users thought of the services it was providing through a consumer satisfaction survey in the form of a semi-structured interview<sup>20</sup>.

**Bristol:** Avon Health have paid Bristol and District Community Health Council £30,000 per year for a two-year project investigating how far it is possible to involve local people<sup>21</sup>.

**Bristol:** the Person to Person Project was undertaken here in order to review the current health services on offer<sup>22</sup>. It has many parallels with the Neighbor to Neighbor Project which was performed in Vermont using 100 meetings and 1,800 people over a period of six months. The Bristol project started in January 1994 when 350 local voluntary groups were invited to take part. In the end 25 meetings were held.

**Bromley:** the Bromley User Group (BUG) was established in 1991 by some users of mental health services in the area<sup>23</sup>. Both its staff and its membership are made up entirely of people with mental health problems. Since its inception it has been taken on by Bromley Health in a more formal role. It now has an annual £69,000 contract with the health authority to monitor services.

**West Dorset:** breast cancer services in West Dorset were evaluated in 1993 and 1995 by interviewing thirty and twenty-two women respectively who had been treated for breast cancer<sup>24</sup>. They were all interviewed in their own homes. The studies ran concurrently with a clinical audit of the service.

**Dumbidykes, Edinburgh:** rapid appraisal was used here to elicit the opinions of key members of the community<sup>25</sup>. This was done via group interviews, interviews in the homes or workplaces of the participants, data from written documents, interviews and observations, a feedback meeting and focus groups.

**Dyfed:** Dyfed Health Authority carried out a needs assessment exercise in the first stage of commissioning new services by asking the public in the area their thoughts on the services required<sup>26</sup>.

**Fife:** here, seven user panels each of six to eight members were set up By Age Concern Scotland in October 1992 to enable older people to articulate their thoughts on their care so that they could influence service planning and delivery<sup>27</sup>.

**South Glamorgan:** here, parents whose children have learning difficulties were involved in reviewing the services used<sup>28</sup>. They were paid a fee for their loss of earnings. They attended a one-day introductory course and then visited the service itself, spending time with users and staff over five days during a six-week period. They examined five aspects of the service: inputs (resources used), processes (the organisation of the services), outputs (the type and amount of services), outcomes (the impact of the services on the users) and responses (the comments of the users). This is an ongoing project.

**Haringey:** in 1993 the health authority and local social services department joint funded a consultants' course to help more survivors of psychiatric services participate in bodies like joint planning committees and to provide training for groups of local mental health services staff<sup>29</sup>. Please see also **Sutton and Haringey** for more information on projects undertaken here.

**Hertfordshire:** here, ten parish councils were approached and asked to discuss health issues in order to gauge public opinion on health services in the area<sup>30</sup>. The methods used were self-completion surveys, focus groups and a rapid appraisal project.

**Newcastle:** in 1995 it was reported that pilot audit projects had been set up throughout England in the course of developing and testing the Newcastle audit system for mental health services<sup>31</sup>. This resulted in the creation of a system which offered training and guidance on involving clients in audit. The Newcastle audit project involves clients as team members who plan and make decisions about audit in six workshops during which they undertake a variety of tasks. The Newcastle Mental Health Consumer Group has been in existence since August 1990 and is in touch with both purchasers and providers<sup>32</sup>. When working with trusts, the members visit each in turn and try to cover all 8 contract areas. Their views are recorded and related back to contracts managers and managers in the trusts.

**Oregon:** although not a UK project, the consultation of community representatives by Oregon Health Decisions, a civic group, on their values and how these relate to health care is an example of one of the first ways in which authorities tried to discover the public's views on services in order to inform a prioritisation agenda<sup>33</sup>. It was conducted via 47 community meetings and twelve public hearings and thus is very similar to many of the initiatives undertaken in the UK.

**Sheffield:** the Northern General Trust in Sheffield appointed one patient representative to take on a monitoring role for the trust's hospitals via ward visits. The representative is not a

true representative, however, as he or she is encouraged to act in a personal capacity and not as a representative of any particular group or interest.

**Solihull:** here, a project funded by the NHS Management Executive's *Developing Managers for Community Care* initiative brought disabled and professional people together to discuss the services provided<sup>34</sup>. The two parties were initially split into two groups to allow them to discuss the issues separately and were then brought back together to feedback their thoughts to the other group.

**Somerset:** in 1995 it was reported in the *Health Service Journal* that Somerset Health Authority had set up eight health panels each with twelve members located across the Somerset Health Authority area<sup>35</sup>. They were found using quota sampling to ensure representativeness. Each member is paid a fee and has a one-year term of office. This ensures that new voices are constantly brought into the system and a staggered turnover with four new members at each meeting means that continuity is also maintained. Each meeting is taped and transcribed allowing underlying values to emerge with clarity. Following the discussion, panel members vote on each issue, thus providing valuable quantitative information to balance the qualitative information taken from the discussions themselves.

**Sutton and Haringey:** People First, a self-advocacy group for people with learning disabilities, carried out an evaluation of people who had left hospital for a year or who had been discharged to live in the community. One of the aims of the project was to develop user-friendly and accessible ways of involving users in all aspects of the project. People First developed a questionnaire and used this to interview users in a semi-structured way.

**Wakefield:** the Richmond Fellowship Advocacy Project, located in the grounds of a local long-stay psychiatric hospital, was jointly established and funded by Wakefield and Pontefract Health Authorities, initially for three years in May 1990<sup>36</sup>. It had a two-fold aim in terms of encouraging user involvement: firstly it was intended to promote user views and support users in obtaining a greater voice and secondly it was to be used to assert the rights of users of mental health services. The project personnel used the project to explore the development of three types of advocacy: professional advocacy, in which the project manager would take up the user's case, self-advocacy, in which the advocacy would take place via a self-advocacy group, such as a patients' council and citizen advocacy, in which one citizen or volunteer acts on behalf of a user. Of these three types of advocacy, only the last is yet to be implemented.

### *2.2.2 Barriers to user involvement*

Despite a few other suggestions, such as the lack of economic incentive for health authorities in the involvement of the public in health care decision-making<sup>37</sup> or the difficulty in attracting users when no fee is offered<sup>38</sup>, the barriers to effective user involvement seem to fall into three categories. Certain language problems were defined as causing problems in discussions held between users and professionals; similarly, the attitudes of either side sometimes reinforced a "them and us" division between the two groups which occasionally prevented useful discussion from taking place; thirdly, some comments were made concerning the obstacles created by the users themselves, especially when the body they represented were users of mental health services.

### Language

Bowl, as has been cited, explains a simple but vital point: the purpose of the user consultation project must be clear to all involved<sup>39</sup>. Confusion, he suggests, can lead to disillusionment and a reluctance to participate. Naturally this requires excellent communicative and linguistic skills on the part of the organisers. The vocabulary they use will impact on the success of the consultation.

An example of this is found in the Bedfordshire continence group. Here, the users of continence services were encouraged to discuss these services<sup>40</sup>. They were then asked to revisit the issues they unearthed and reassess the services some time later. These additional user groups were entitled "reassessments". This resulted in some anxiety in the users who perceived that word as threatening. They thought that it implied that a reduction of services might take place with the reassessments. After these anxieties were expressed, the name of the additional user groups was changed to "follow-up". This has since been accepted as a forum in which clients can talk about treatment and issues of quality rather than an event which might result in a cut in services.

In some cases, it is language itself which becomes the topic of debate. Barnes and Cormie report that, in the Fife User Panels, some of the participants suggested using different terminology in order to make certain processes clearer<sup>41</sup>. The subject that the Panel was discussing was hospital discharge; it was suggested that this be renamed "transferring care" so that those involved, both professionals and users, would be able to view this as a process rather than merely the end of an intervention.

### "Them and Us" division

Two of the excuses cited by Donaldson for only a patchy spread of local involvement projects across the country relate to a "them and us" division: firstly, the public are sometimes cited as being either apathetic towards or ignorant of such projects; secondly, some old-school managers are cited as feeling that consultation delays necessary decision-making<sup>42</sup>.

Shackley and Ryan take a different perspective on the first of these excuses. They suggest that one of the barriers to effective user involvement is the unreasonable expectations held by health service managers regarding the public's behaviour as healthcare consumers<sup>43</sup>. They point out that the healthcare market is nowhere near to being perfect. This prevents both sides of the market equation from being fulfilled, which in turn implies that consumer involvement in this market can rarely be perfect. The users for example, do not have perfect information, as they do not often know what is available in the wider sense; the market itself is skewed as the government often intervenes in it; and it is not healthcare which is valued by consumers but rather health status, something which cannot be bought. All of this, say Shackley and Ryan, contributes to the disappointment on the part of healthcare managers when their clients do not behave like perfect consumers.

Harrison and Beresford describe five barriers to user involvement in the area of training the professionals<sup>44</sup>. All five of these can be put under the "them and us" banner. These barriers comprise the following: power inequalities between service users and educators; a lack of a strong history of trust between those eliciting the users' opinions and the users themselves; professional theories which emphasise dependence and incapacity on the part of users and which may form part of the professionals' own personal theories; inaccessibility of some of the educational institutions; and the basic fear of a negative attitude being displayed on the other side. Pleasingly Rowley reports elsewhere that the involvement of users in another

programme of local consultation actually helped to break down some of the barriers between users and professionals by giving the professionals an insight into the users' perspectives<sup>45</sup>.

Occasionally, the "Them and Us" syndrome alters its focus from users and professionals to front-line staff versus senior management<sup>46</sup>. Higgins explains that one of the problems in achieving successful user involvement in the Richmond Fellowship Advocacy Project lay in not taking account of the front-line staff's anxieties<sup>47</sup>. These members of staff often appeared to be unco-operative. The reason for this could have been that the project took place simultaneously with the closure of the long-stay psychiatric hospital where they worked. The Advocacy Project simply fuelled their job anxieties.

Communication between senior management and the front-line staff is just as important as clear communication about the purpose of user involvement. Without either, the user involvement will not be conducted effectively as only one - or perhaps neither - side will be aware of the aims which the project is designed to fulfil.

#### Problems with the users themselves

Many of the user involvement projects relate to mental health services. Barnes and Wistow explain that one of the problems in this area is that the users can confuse the empowerment which the fora are designed to give them with therapy sessions<sup>48</sup>. They describe the CCSAP in Birmingham and state that in its early meetings much anger was hurled at the psychiatrists by the users. They report that it may have been therapeutic for the users to let rip in this way but it certainly did not help the debate and also served to increase the frustration of other users who were hoping that their views might have some influence.

Spencer suggests that one of the reasons why consumer feedback in mental health services has not developed into more academic research into psychiatry is the concern that patients with mental illness are unable to give valid and reliable feedback<sup>49</sup>. This surely begs the question: why ask them at all in that case? It is possible that the main aim of some of the public involvement initiatives is merely to boost client morale rather than listen to, digest and then perhaps implement some of their suggestions (see section 3.4 for more information on this).

One project which can boast influence over healthcare decisions is BUG, the Bromley User Group. This group is made up entirely of mental service users and is therefore very much in tune with the needs of its members. The potential for confusion between discussion and therapy is not allowed to be a problem as one-to-one counselling and psychological support is made available for the participants when, as Standish puts it, "things get tough"<sup>50</sup>.

The final comment concerning obstacles created by mental health service users relates to their attendance rates. Bowl explains that a major logistical problem exists here as the participants mental distress is sometimes such that they do not know until the last minute whether they will be able to attend or not<sup>51</sup>. This is not only problematic organisationally but it also results in a loss of continuity in user representation and feedback.

#### *2.2.3 The professionals' views*

In several instances it has been reported that managers involved in the local consultations expressed surprise at both how forthcoming the users were in their comments and at how useful the exercise was in, for example, communicating information back to the users<sup>52,53,54</sup>;



however, some more negative views have also been identified. These include authority-wide perceptions as well as the views of individuals.

Sue Clarke of Outlook Associates, specialists in consumer issues in the health service, has been quoted by Donaldson as stating that health authorities often only pay lip service to the notion of local involvement:

"Health commission plans talk about their user involvement, but don't actually say how they are going to do it."<sup>55</sup>

She goes on to say that health service managers often have it tagged onto their performance reviews and that the token survey, although inadequate, is still used constantly and quite inappropriately.

The strategy adopted by the health authority will influence the success or otherwise of the consultation exercise. The key to successful implementation of public consultation initiatives seems to be the use of a planned strategy. This is one of Whiting's recommendations; "ad hocery", he states, must be avoided<sup>56</sup>. Bowl describes what he sees as the current situation though, in which "the most frequent form of "involvement" is post-hoc consultation - where, for example, draft plans are put out for comment and possible amendment"<sup>57</sup>.

Also vital is commitment at senior and chief officer level<sup>58</sup>. Barnes and Wistow advocate this and also suggest that inter-agency commitment across local authorities and health authorities is desirable<sup>59</sup>.

Lupton and Taylor examined the public consultation policies of the six health authorities in the old Wessex region and found that although all senior managers were keen to state their commitment to the process, the extent to which this commitment was translated into practice varied from authority to authority<sup>60</sup>. Three of the authorities had produced written public involvement strategies; they all claimed to discuss the issue at board level, but some said that it was "often displaced by more "fire-fighting" business"; and only one authority had it as a permanent executive agenda item.

The differences in the six authorities' approaches to public consultation may lie in the fact that they almost all seemed to be fulfilling different objectives in doing it. They all expressed uncertainty about the ultimate aim but those aims suggested were:

- in order to inform the public about health issues and concerns
- in order to establish accountability and credibility with local communities
- in order to seek feedback on current services and future needs
- in order to ensure that the widest possible range of consumer voices was heard
- in order to enable the public to participate more extensively at different levels of the commissioning process

Although it is vital to communicate the aim of the project to all involved, it is more important to establish what that aim is at the very start.

Barnes and Wistow submit another list of possible reasons for undertaking consumer consultation, thus increasing the confusion about the universal, underlying aim of the exercise:

- so that the participants can contribute to the development of services which are more sensitive to their needs

- in order to empower users in relation to the services and in relation to their lives generally
- to help solve individual problems relating to the receipt of services
- to enable people to "get things off their chests" and hence feel better

All of these aims are laudable; however, health authority staff have expressed confusion about which is the most important. This is an area of local consultation which requires clarification.

Another major factor affecting the health authority strategy will be the location of the project within the authority structure. Lupton and Taylor suggest that if it is situated in the Public Health Directorate then it will probably concentrate on identifying needs and priorities. If it is in Communications or PR, its emphasis will be on contact with the general public through the media and one-off consultations. If it is located in the Quality Directorate then its focus will be on direct service users and the development of monitoring mechanisms. Lupton and Taylor say that it is being increasingly acknowledged that local consultation is relevant to all organisational functions and that small teams of specialist staff should organise the exercise across all the directorates of the authority.

There is often a large gap between the professionals' and the users' points of view. Robertson split the two apart in his project hoping that they would independently come to similar consensuses on the subject of disability service models<sup>61</sup>. What happened in the event was that the professionals discussed structure and procedures while the disabled users' group looked more at need-related topics, such as assertiveness and confidence skills. When they came back together the two could not communicate as they were approaching the debate using different issues.

The inclusion of professional judgements is important though. Robertson also states that "[t]o suggest that disabled people are the only ones who know about themselves would be extraordinarily glib and detrimental to the training done by the professionals". Nonetheless, the theoretical knowledge of the professionals sometimes has to take a back seat - especially when they are confronted by the criticisms of the users.

The perspective of individual managers often reveals that they can feel very threatened by a local involvement initiative. Hughes and Bradburn note the need for "broad shoulders" on the part of the staff<sup>62</sup>. The inability to take on board criticism often manifests itself as defensive behaviour which in turn can come across as a lack of co-operation. Higgins records that not only did some of the Richmond Fellowship staff in Wakefield find it difficult to take the project seriously, but that some also felt that there was an implicit criticism contained within the involvement of users and that their professional judgement and competence were being questioned<sup>63</sup>. Barnes and Wistow also mention this sort of attitude among staff members<sup>64</sup>.

This attitude crops up also in the *Journal of Mental Health*<sup>65</sup>. Bowl records that some staff do not see increased user involvement as positive. The reasons for this given by the staff he contacted were as follows: some thought that the staff were in fact the best people available to judge the best interests of a large number of vulnerable users who may not be able to articulate their needs; others believed that it was better to protect users from the pressures of decision-making for which they were ill-equipped; a third view was that user involvement

was in essence useless as most users are interested only in service provision in as much as it affects them personally.

Other experiences described elsewhere by members of staff involved in consultation with the public include feeling initially isolated, lacking support and even experiencing downright hostility from colleagues<sup>66</sup>. The staff involved have also mentioned that the short-termism of their managers' attitudes is frustrating when the benefits of local involvement can only be measured cumulatively and in the long-term<sup>67</sup>.

Not all the comments from the professional side were negative, however; Rowley explains that for some professionals it was the first time that they had appreciated the impact that the services have on the users<sup>68</sup>. One stated that the most important part of the exercise was "seeing the field of mental health more from the user's perspective". Others found that they were emotionally affected by the users' descriptions of their service experience: one realised the "helplessness of a user in regard to treatment". The move from detachment to understanding seems to be highly valuable here.

#### *2.2.4 Professional skills needed*

Barnes and Wistow go on to state that the development of an initiative involving the public has profound implications on the skills needed of the professionals. Although not much has been recorded relating to the professionals' views of the need for these new skills, it is worth noting what they are in order to identify the extra training which might be necessary when undertaking a project like this. In several cases the additional work was taken on by an external consultant which naturally created extra costs for the organising authority<sup>69,70</sup>.

Shepherd lists those skills which he believes are needed to run a discussion<sup>71</sup>:

- the ability to generate discussions
- the ability to ensure the issues raised are explored in full
- the ability to ensure everyone has the opportunity to participate

Shepherd rates these skills much more highly than the need for inside knowledge of the NHS. Balogh and Bond also list some skills which they say would be important in running a discussion<sup>72</sup>. Theirs are less specific but more theoretical:

- careful recording
- detailed qualitative analysis
- facilitation
- ability to recognise consumers' expertise
- gratitude

One other skill is added by Beresford and Trevillion: the need to listen well because, as they say, people do not always say what they mean to have said<sup>73</sup>.

Balogh and Bond also state that at least two people are necessary for the management of a project of local involvement, one to facilitate the discussion and another to take notes. At the very least it seems, two current members of staff will either have to be seconded onto the project or will have to absorb responsibility for it into their current job descriptions.

#### *3.2.4 The clients' views and participation*

The general view held among clients was that they greatly valued the opportunity to have their voices heard<sup>74,75</sup>. Other positive reasons for attendance were that the fora gave the users

the opportunity for social contact with others in a similar position and that they also allowed them to find out things from the health or local authority which could be important<sup>76</sup>.

In Wales the parents of people with learning difficulties were particularly keen to monitor their children's services because, as one mother, Pauline Young, put it:

"We don't want our children to be fitted into the services offered. We want the services built around the actual needs of the individual."<sup>77</sup>

Sometimes involving oneself can be a daunting matter and this is recognised by the staff involved in this project. Judy Noble, Principal Social Services Officer in Cardiff is cited as acknowledging the anxiety sometimes experienced when having to voice one's opinions at meetings for the first time. She goes on to say, however, that the closer relationships developed between professionals and parents have helped to foster mutual understanding and "enables us to problem-solve before we get into conflict situations."

One of the easily-overcome problems in involving the public seems to be in convincing them that they have a valuable contribution to make. Rutt explains that although many people in the project she organised initially undervalued their knowledge of health needs, they invariably had a wealth of information about what was happening at a grass-roots level and ideas about what could or should be done<sup>78</sup>. Once they realised this they were very keen to discuss issues; in fact, the very exercise of asking their opinions may have convinced some that their involvement was desirable and useful.

One way in which public involvement can be less daunting is via a pre-established, independent forum, such as BUG<sup>79</sup>. Bowl explains how some people preferred this method of involvement<sup>80</sup>. It seems that self-advocacy organisations also appreciate local involvement, whether or not they are themselves included. One told Beresford and Trevillion that local consultation "[treats] people as individuals, [treats] them as humans."<sup>81</sup>

Not all of the reactions to local involvement from the client perspective were positive. Shepherd describes a cynical attitude on the part of the users in that they did not believe that their views would make any difference to the services provided and that many also believed that the health authority had hidden motives behind the consultation exercise and intended to use it as a screen to cut services<sup>82</sup>. This suspicion of the authority's motives is repeated in an article in the *Nursing Standard*. Janet Cox describes how one user of a social centre for the elderly perceived an attempt to empower users as an attempt instead to get the users to take on the responsibility for running the service and thereby save money<sup>83</sup>. Interestingly, Cox concludes that very few of the centre's users wanted to be empowered at all. Either they felt empowered already through the excellent relationships they maintained with the centre staff or they appreciated being able to come to a place where they did not have to make decisions. They liked the fact that other people were taking control.

Two frequent suggestions of public consultation are that, if asked, the public would demand every treatment to be made available for everyone and that interest groups would always rule for their own interests<sup>84</sup>. The evidence supplied in the literature accessed refutes both of these claims. The Oregon study reveals that, contrary to popular belief, the users did not ask for everything everywhere<sup>85</sup>. In a later article, Rutt also explains that, in Hertfordshire, most of the participants in the local involvement initiative were more concerned for the needs of other people whom they perceived to be worse off than themselves<sup>86</sup>.

Beresford and Trevillion suggest that public input in a rationing debate can be very useful as it ensures that the balance between needs and resources is kept in the limelight<sup>87</sup>. The ability of the public to contribute usefully here was confirmed by some work completed by Bromley Health which is also cited in the article on Oregon<sup>88</sup>. The work in Bromley revealed that the public do have an awareness of finite budgets and the need to prioritise and that they can provide responsible answers to rationing questions. This also refutes one of the other problems surrounding local involvement which has already been cited, that is, that "the views of users and carers are frequently dismissed as "subjective", while the legitimacy of clinical decision making is unchallenged."<sup>89</sup>

### *2.3 Various methods of involving the public: comparisons and notes*

Several of the commentators writing about local involvement initiatives have remarked upon the advantages and disadvantages of the methods used of eliciting the public's views. Others simply stated that they used a particular method and discussed instead the conclusions which the participants came to after debate on certain healthcare issues.

#### *Local Voices recommendations*

Donaldson reiterates the guidance contained in *Local Voices*<sup>90,91</sup>. She reminds the reader of the techniques for public consultation which this recommended. These are: public meetings; local voluntary groups; focus groups; health forums; rapid appraisal; community initiatives; telephone hotlines; surveys of public opinion; patient satisfaction surveys; one-to-one interviews; and complaints procedures.

She also reminds the user of the emphasis in *Local Voices* on the need for the use of a combination of techniques and the dangers of "over-reliance on any one method". The need to consider more than one technique is highlighted in one of the case studies she describes. In Leeds, she explains, initial attempts to draw the public to special meetings flopped and it was only when existing community groups were approached for their help that large crowds attended.

These suggestions seem to have been followed by many of those commentators who have organised initiatives for public involvement; however, Shackley and Ryan assert that the sorts of market research techniques recommended in *Local Voices* are not really useful when one wants to use the data afterwards<sup>92,93</sup>. They explain that although these methods are relatively quick and easy to implement, they provide no information on the intensity of preference of the participants, they disregard resource constraints and the existence of opportunity costs, they give little help in addressing policy questions and they do not address real-life situations facing purchasers. They suggest that instead organisers should combine the techniques of "willingness to pay" with conjoint analysis<sup>94</sup>.

Although the method of asking people to value services according to whether they would or would not pay for them could be corrupted into a function of *ability* to pay rather than *relative* willingness to pay, they still assert that it would be useful in order to find a strength of preference among the participants involved. Conjoint analysis they describe as a technique of presenting individuals with hypothetical scenarios comprising different levels of various attributes identified as being important and asking them to rank, rate or make pairwise choices with them.

Similarly to Shackley and Ryan, Whiting also dislikes such lists of methodologies from which the health service manager is seemingly invited to pick and choose:

"Many of these commentaries have presented a list of possible techniques for public consultation, like some *à la carte* menu. The reality is, however, that many of these techniques are not really appropriate for securing a representative picture of the public's views"<sup>95</sup>

He suggests instead that one should be more analytic about the whole process, planning the method to ensure that it will allow the relevant data to be extracted. He states that only two types of channel for consultation with the public are satisfactory. These are qualitative research in the forms of focus groups and in-depth interviews and quantitative research in the form of annual tracking studies. This latter example he states should be central to the information gathering strategy. He does concede that formalised market research may not always be affordable however and in these cases suggests the use of more pragmatic devices such as simple questionnaires handed to patients on discharge, suggestions forms in waiting rooms and an analysis of complaints received.

Despite some of these criticisms of the recommendations of *Local Voices*, many other commentators have employed its suggested techniques and have commented on the reasons why they did or did not find them useful. Included below are some of the more useful comments.

#### Rapid Appraisal

Murray et al employed this technique in Dumbidykes, a part of Edinburgh<sup>96</sup>. They describe it as a method which "uses selected people with knowledge of the area (key informants) both to identify problems and to contribute to solutions". One of the reasons why they found this method valuable was that it in fact did give them an idea of the community's strength of feeling, thus refuting Shackley and Ryan's criticism that none of *Local Voices'* market research techniques could do this:

"In contrast to the quantitative methods used by epidemiologists rapid appraisal offers very specific insights, helping to define what the problems are rather than how many people are affected by them. It helps identify the strength of feeling."

Although some intensity of preference could be gleaned here, without the hard statistics to back it up, one cannot be sure *how many* people felt strongly about the issues debated as well as how strongly the key informants felt.

#### Focus Groups

Rutt found focus groups to be useful mechanisms for public debate due to their open-ended quality<sup>97</sup>. If done well, they allow the lay participants to express their own opinions first without being influenced by the professionals. This point is also noted by Hogg and Cowl who alert the reader to the dangers of not planning meetings thoughtfully by explaining that "[i]f staff are present they may dominate and people will not feel free to talk."<sup>98</sup>

#### Questionnaires

A mixed response to the questionnaires used in Hertfordshire was recorded by Rutt<sup>99</sup>. One gentleman, she writes, refused to complete his questionnaire as it was too confusing. He wrote a long letter about this to the organisers, a task which must have taken him much longer than the completion of the questionnaire would have done. Other participants however

treated the questionnaire as another form of open-ended discussion as they added detailed comments to it as well as ticking the boxes. As Rutt states:

"It was almost as if they had something to say and did not intend to be constrained by the format of the questionnaire."

Once they had been given half a chance to speak the participants in this scheme were only too eager to articulate their views.

### Citizens' Juries

Ogden explains how citizens' juries encourage thought in their participants rather than gut reaction<sup>100</sup>. She explains how one vehemently anti-drugs juror was so influenced by his experience on the jury that he ended up questioning his own beliefs on the matter. Although he was finally confused as to the answer to the problem of drug addiction, he also ended up much better informed about the details of the problem itself.

Susan Elizabeth is quoted in the BMJ as explaining that this process of rational consideration of the issues is the point of citizen's juries:

"[They] allow people to work through a process of deliberation backed by a lot of information instead of speaking from a preconceived position arrived at with very little information."<sup>101</sup>

In the same article, Jo Lenaghan from the Institute of Public Policy Research is quoted as saying that this process of deliberation actually "encourages people to take a community perspective, to come together over issues as citizens rather than take the narrow view of individuals and neighbours."

McIver explains that instead of asking for a pat decision, juries ask for comments on proposals and recommendations<sup>102</sup> and so do not want to tap into pre-established assumptions. She also informs the reader however that bias is possible in the witness process and must be avoided in order to maintain credibility. Ogden also suggests that bias may be possible via the order in which the representatives or witnesses from either side of the argument appear<sup>103</sup>. She implies that this could influence the jurors' decisions.

McIver advocates the use of juries over other forms of consultation as she suggests that they, unlike other forms of market research and public meeting-type consultations are more flexible, less demanding of prior knowledge and yet more demanding of rational consideration while they are in process. They do not require summarised responses in a few words; they do not restrict participation to a small number of highly motivated but not necessarily well-informed individuals; and they do not presuppose individual knowledge about the issues concerned. This last non-requirement however caused a little confusion in one pilot jury in Cambridge and Huntingdon. The jurors here were not given much information on the topic they were to discuss and were quoted as preferring to have seen more beforehand<sup>104</sup>. This need for information however needs to be balanced with the problem identified by Rutt of leaving participants feeling "powerless in the face of expert knowledge" if they are bombarded with complicated data too early on in the discussion<sup>105</sup>.

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These forms of public consultation have been used by the commentators and, despite the warnings of Shackley and Ryan, Whiting and Lupton and Taylor (who criticise the "pick-and-mix" nature of the current forms of public consultation exercises<sup>106</sup>) a variety of methods are sometimes used without much thought.

### *2.3.1 Guidelines*

Some of the commentators have gone so far as to posit a series of guidelines which they suggest should be followed when undertaking a consultation exercise.

Barnes and Wistow urge the organisers of consultation exercises to find out who the users of the service under discussion are before anything else occurs<sup>107</sup>. They have drawn up a classification of users which, among other things, differentiates between voluntary and involuntary users, actual and potential ones and short- or long-term ones. They also insist that the sample used is truly representative so that the results gleaned have credibility.

Robertson records the following guidelines which his project eventually established:

- all participants to have a clear briefing
- collectively understood parameters to be set ensuring outcomes are based on the "real" world of health and welfare
- resources to be allocated to provide training, clerical support and transport
- the involvement of users with a representative base in their community
- time scales to be appropriate for users allowing them to acquire the necessary skills and knowledge
- meetings to be conducted outside the workplace to enable "the various masks to be discarded"
- users to be paid for their participation in order to obtain true quality (many of the case studies accessed did provide a fee for their participants)

Whiting includes a list of things which he asks organisers to remember<sup>108</sup>:

- the two types of research (qualitative and quantitative) are not interchangeable
- no survey should be commissioned without some kind of qualitative evaluation first
- all research undertaken should fulfil a clear objective and it must be clear beforehand how the results are to be used (he adds: "[t]his is not an academic exercise")
- research is only an aid to judgement; managers are still paid to make the decisions

Shackley and Ryan suggest that exercises in eliciting community values should have the following characteristics:

- they should give information which reflects intensity of preference
- they should address specific choices reflecting local health authority problems
- values should be in the correct marginal context, i.e., the scale of change should be realistic
- questions asked should include some notion of sacrifice

In relation to strategies, Bowl states that confusion and frustration can be avoided by ensuring that the strategies:

- make clear the degree to which their aim is power-sharing or consultation
- review decision-making structures and timetables to ensure that participation is possible for users



- apply consistently across all areas of departmental activity
- provide resources to support participation

## ***2.4 Implementation of the users' suggestions?***

Not all of the commentators describing case studies have indicated whether or not the results of the discussions with the public have been used to inform any sort of strategy or whether any concrete changes have been made in relation to the participants' suggestions<sup>109</sup>. For some this is definitely an essential part of the consultation process<sup>110,111,112</sup>, but for others it seems that the exercise of consultation may be an end in itself.

Barnes and Wistow quote one participant who wants the public's input to have an effect:

"We hope that this will not all be a waste of time - that something will change"<sup>113</sup>

This desire is not always fulfilled though. Barnes and Wisotw also state that any resulting outcomes from public debates seem to be much less certain than the intrinsic benefits gained by participants by participating in the first place. Examples of these benefits are increased confidence and self-worth. It is possible that for some health or local authorities the completion of the exercise is enough and that the results of the debates are not taken seriously.

Barnes and Wistow are sure that the user will be dissatisfied if nothing happens after their participation and that effective mechanisms are necessary for translating the users' messages into action<sup>114</sup>. They warn of a frequent pitfall: that service providers sometimes take on board only those recommendations to which they are most capable of responding or which fit in with professional thinking. They urge such providers to listen to the users' messages comprehensively, not selectively.

This is not to say that the mere completion of the exercise does not contain benefits. Robinson and Whitmore imply that in simply being asked about their views the participants' morale is boosted:

"The good news was that most users were satisfied with their assessment. They felt they had been given the opportunity to explain their problems..."<sup>115</sup>

The simple fact that the users are able to have their views and opinions heard gives them a boost in morale; however, the fact that they are only supplying views and opinions and that they are not involved in a more formal decision-making process might be one of the reasons why their suggestions are not always implemented. Rutt quotes J. Barker on the project undertaken in Bromley who states that "the approved level of involvement was seen to be giving views rather than formally (being) part of any decision making process"<sup>116</sup>. The less formal arenas in which the public can freely discuss their concerns certainly seem to allow them to relax and contribute; however, the fact that they are less formal might hinder the progress of the decisions they make in the health authority itself.

## **3. Conclusion**

Several case studies and academic analyses of local consultation have been written up in the professional press and from these the following points have been noted:

- ◆ A cultural shift has been identified in which local consultation is gradually being accepted as an essential part of healthcare planning
- ◆ Some barriers have been identified to successful local consultation:
  - the use of professional terminology which the users may not understand
  - a "them and us" division in attitudes
  - the potential problems involved with consulting users of mental health services
- ◆ Staff:
  - Many senior managers claim to be highly committed to local consultation, but the extent to which this manifests itself in support and in strategy documents is not always as strong
  - Some front-line staff truly appreciate being given the insight into the user's perspective while others find it difficult to take the exercise seriously or to accept criticisms of their professional behaviour
- ◆ Clients:
  - Most of the users appreciate the opportunity to have their voices heard; however, some registered suspicion about the health authority's motives in asking them what they thought
- ◆ *Local Voices* advocates the use of a certain list of methods of consultation. These are used by many groups but criticised by several of the commentators who would prefer to see more thought put into the planning of local consultations
- ◆ The question of whether the participants' views were acted upon or whether the consultation process is simply an end in itself has been asked
- ◆ Some guidelines for conducting a local consultations have been identified from the literature accessed

Much interest has been expressed in the possibilities of local consultation. This is apparent from the proliferation of articles which have been written on the subject and of which a selection have been evaluated for this report. A cultural shift towards a user-led service is taking place within the NHS, but as can be seen from some of the conflicts identified in this paper, it has yet to be accepted universally.

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