

‘Asking The Experts’ – A Guide To Involving People In Shaping Health And Social Care Services

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‘Asking The Experts’ – A Guide To Involving People In Shaping Health And Social Care Services

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Why We Wrote This Guide

It was clear from talking with many people working in health, social care and the voluntary sector that:

- ◆ There is widespread enthusiasm for involving people in shaping the services that statutory and voluntary agencies provide.
- ◆ Practitioners do not always have the confidence to develop their practice in involving people.
- ◆ Although much has been written on 'user involvement', busy people do not always have the time to identify relevant information, or consider the wider context for 'user involvement'.
- ◆ Relevant and useful guidance labelled 'health' might not be easily available to social care staff, and vice versa.
- ◆ It is not easy for people to hear what others are doing, and share experiences.

We wrote this guide to:

- ◆ Bring together relevant research evidence and practical experience of involving people, focusing on community care settings.
- ◆ Indicate some of the conceptual issues that it is important to consider in order to involve people successfully.
- ◆ Help practitioners to consider the most appropriate ways of involving the people they serve.
- ◆ Provide some practical guidance on getting started.
- ◆ Provide examples of effective or innovative ways of involving people that could illustrate how an approach was used, and spark ideas.

What This Guide Is:

- ◆ A synthesis of currently available knowledge and practical experience. We have looked at the literature, some 'top down', from statutory agencies and government departments, some 'bottom up', from user groups themselves. There are many texts on general principles and methods of involving people.

(See: 'References' – p 37; 'Other Resources' – p 102)

There isn't as yet a great deal of research evidence on effectiveness in involving people, and even less formal evaluation of the involvement process, that is, how policy, planning and delivery of services have been affected by user involvement. (Although local work in the East Riding of Yorkshire is making a contribution. See: 'The Impact Project' – p 117).

Where we have found evidence we have quoted it, and we have also referred to work that is forthcoming.

- ◆ Designed to encourage you to think creatively, and use approaches flexibly and imaginatively.
- ◆ Written with community care services in mind, although the principles outlined apply in other service areas too. We have not covered children's services, where additional considerations apply.
- ◆ Written primarily for practitioners rather than people who use services, although we hope that service users will find some of it useful and interesting too.

In producing this guide we were being asked '**What works**'?

This is not a simple question, and there is no simple answer. What is clear is that there is no one 'right way' or 'best method' for involving people. The approaches you choose depend on what you want from the process. There are ways that are better or worse for particular ends, in particular circumstances, or for working with particular people. You will need to use a variety of approaches, not rely on a single one.

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Before you ask 'how?' you have other, and in many ways more important ground to cover:

- ◆ How committed are you?
 - ◆ Are you clear about your reasons for involving people?
 - ◆ Do you have an adequate budget?
 - ◆ Is there a strong lead within your organisation or workplace?
 - ◆ Are staff on board?
 - ◆ Have you considered the impact on the people you are asking to participate, and their information and support needs?
 - ◆ Are you prepared to act on what they tell you?
 - ◆ How will you deal with the change in the balance of power that meaningful involvement brings?

“Too often in the past the road to participation has been paved with good intentions only to lead up time consuming and wasteful dead ends which result in disillusionment and resentment for all concerned.”¹

This guide is intended to help you to avoid this experience. It provides information to help you through the thinking and planning you need to do to 'ask the experts' – the people who pay you to provide services on their behalf.

How This Guide Is Organised

The guide is divided into three sections.

The first section looks at the context for 'involving people', and the thinking you need to do to develop practice that routinely involves people who use the services you provide, as well as the wider public who pay for those services and may come to use them in the future.

The second section considers the 'fit for purpose' of some of the ways of involving people. Research or evaluation findings or experience from practice of using the particular approach are given where possible.

The third section looks at particular considerations when working with people who use health and social care services.

The contents pages list the topics covered, with their page number. Where it is useful to refer to another topic for further information, the page number for that topic is given in the text.

What We Are Talking About – Some Definitions

Who Should Be Involved In Shaping Health And Social Care Services?

People who have used a service in the past, are using a service now, or may do so in the future.

'Service users' include carers, who are service users in their own right, although they will experience services differently to those they support. Past and present service users are expert through experience. Others of us are potential service users, and contribute to shaping services as experts in our own needs.

(See: 'Public Consultation And User Involvement – What's The Difference?' – p 7; 'Consumers Or Citizens?' – p 21)

Involvement

'Involvement' was chosen because it has a wider meaning than other commonly used terms. According to the Oxford English Dictionary involvement means 'included, concerned in, emotionally engaged with'. This allows for concepts of active, ongoing joint working that are not encompassed in 'participation' (taking part in) or 'consultation' (looked to for information or advice).

What we are talking about is involving people in shaping health and social care services, by taking part in:

- ◆ Identifying priorities and formulating policy.
- ◆ The planning, management and delivery of services.
- ◆ Monitoring and evaluating services.

(See: 'Models That Describe Levels Of Involvement' – p 16)

Ways of working with individuals to increase their involvement in the choices and decisions they make about their own care or treatment are part of professional practice, and not within the scope of this guide, although the broad principles given here may apply in that context.

Public Consultation And User Involvement - What's The Difference?

“The processes by which services learn from those they serve.”²

User involvement might be defined as inclusion of people who have experience of service use in the planning and management of services, while public consultation is “a local attempt to seek the views of a broad constituency of persons”,³ who are not necessarily current or past service users.

Sometimes it is appropriate to involve only those who have experience of a service, but if you are planning to develop accessible, appropriate, effective services then you need to include the wider public.

This would include people who:

- Would be eligible for a service but don't receive one.
- Choose not to use services.
- May come to require services at a future date.

In this sense, we are all potential users. If services are to be needs-led you will want to engage with the wider community to allow:

- Identification of unmet need in people who do not use services, and in marginalised groups.
- Knowledge of what makes services unattractive or inaccessible to those who don't use them, but might benefit from them.
- Planning for the future. For example, what are the expectations of the recently retired? What sort of services would they want to see should they require support in the future?

(See: 'Who Should Be Involved In Shaping Health And Social Care Services?' – p 6; 'Consumers Or Citizens?' – p 21)

Why Involve People?

*"Community involvement... becomes a catalyst which helps organisations re-examine their purpose, cultures, systems and mechanisms thus improving their functioning at all levels and on all issues."*⁴

Because it is ethical, desirable, and required of you!

Advantages (Because You Want To)

*"Being in favour of better public consultation or more user involvement is rather like being against sin;... it is hard to find disagreement."*⁵

Involving service users has advantages, both to the organisation, and to the individuals who use the services they provide. They include:

- Rebuilding trust and confidence in a service as open, accountable and shaped by public views.⁶
- Developing local ownership of and commitment to health and social care services.
- Increasing local understanding of change, and confidence in the way it was planned.⁷
- A shared agenda promotes constructive working relationships.
- Decisions are more likely to be viewed positively by those who have had a stake in them.
- Improves legitimacy of the purchasing process. The purchaser may otherwise be reliant on provider knowledge, which may not equate with the best interest of the service user.
- *"Harnessing patients' and public views can help drive up standards and lead to a more responsive service."*⁸
- Ensures that the voices of users and carers as experts in defining their own wishes and needs are heard⁹ to increase sensitivity, effectiveness and appropriateness of services.
- Identifies areas where standards are not being met and provides positive feedback where staff are performing well.
- Better information leads to more appropriate use of services, maximising benefit to the greatest number.

(continued)

- Generates new ideas.
- Provides insight for staff into how service users and their families experience services.
- Provides a “*potential counterpoise for professional power.*”¹⁰
- Reducing dependency on staff and compliance reduces the risk that vulnerable service users will be abused.
- Protects individuals’ rights and increases their control over their lives.
- Mechanism for personal growth and development.
- An integral part of a service aiming to promote self-esteem and independence.
- **Demonstrates respect.**

Why Involve People?

The Policy Imperative (Because You Must)

All public services now have a duty to plan for and carry out ongoing consultation with the people who use those services, and the taxpaying wider public. They must demonstrate the impact that public involvement has on their plans, and how the outcome of that consultation is fed back to participants.

The tenor of government strategy and policy documents over the past ten years has been clear. Public involvement should be integral to service planning and delivery. There should be a systematic and continuous dialogue with service users and local communities rather than intermittent projects or activities. People should help set the agenda, not just respond to what has already been determined by provider agencies.

"The aim is to achieve an inclusive process with the accent on the widest possible local involvement from the outset, rather than consultation on a near-final product."¹¹

Hackney Social Services established groups consisting of 5-6 users, 3-4 carers and 2-3 staff, including staff from other agencies. The groups visited local services and produced reports as a starting point for the Community Care Plan.

Agencies are expected to involve people with regard to the services they receive, **at a personal level:**

"Patient and carer involvement is essential to help people make informed decisions about their own health care."¹²

(continued)

and in planning and service development:

"Health Improvement Programmes will provide the opportunity for user and public involvement in planning the strategic development of health services."¹³

"Users [of maternity services] should be actively involved in planning and reviewing services. The lay representation must reflect the ethnic, cultural and social mix of the local population."¹⁴ 'Changing Childbirth', an early attempt to involve service users, recommended that Maternity Services Liaison Committees had a lay chairperson as well as lay representation, recognising how this could change the balance of power within a committee.

Primary Care Groups are required to:

- Put in place plans for the early, systematic and continuous involvement of users and the public.
- Be able to demonstrate how in carrying out their role they have involved users and the public.
- Provide feedback to users and the public on the outcomes of their involvement.¹⁵

Local authorities are required to enter into partnerships with local people and community groups. They must consult with local taxpayers and service users on how services can be improved to achieve Best Value in terms of quality, efficiency and cost. People should be clear about the standard of service they can expect so that they can hold the authority to account.¹⁶

The 1994 Framework for Local Community Care Charters in England¹⁷ says that in developing **local charters** (for example, 'You and Your Services' for Housing, Health and Social Service) there should be:

"An entitlement to expect that users' and carers' views will be actively sought and listened to, including:

- *Involvement in local community care plans.*
- *Involvement in assessments.*
- *Involvement in inspection of care homes and other services.*
- *Opportunity and encouragement for users and carers to make comments and suggestions about plans and services."*

New Vehicles For User Involvement And Public Consultation:

Best Value

The best value process is intended to drive up quality and efficiency ("high standards at an acceptable cost") through responsiveness to the people who pay for and use local services. Local authorities are required to enter into partnerships with other local agencies, the business community, voluntary groups and *"local people, individually, and collectively through community groups, local women's organisations and residents' associations"*.

Communities must be involved in deciding on priorities and setting standards, so that they can be clear about what to expect of local services. Targets will be published in a local performance plan, and performance will be reviewed against these local targets as well as performance elsewhere, so that continuous improvement can be achieved. Only by understanding what people want and need can efficient, cost-effective services be achieved.

Performance Assessment Frameworks

The experience of service users, carers and patients is one of the dimensions of performance to be monitored within the Performance Assessment Frameworks for both health and social services.

'Modernising Social Services' requires councils to carry out annual satisfaction surveys *"to see how well people are being served."* (See: 'Satisfaction Surveys' – p 66)

The NHS will conduct an annual National Survey of Patient and User Experience *"to ensure that the NHS hears and acts on the voice of those which it serves"*.

Since health and social care services are so intermeshed the Association of Directors of Social Services has suggested that there might be a joint approach to obtaining user feedback.¹⁸

Health Improvement Programmes (Research Findings)

The King's Fund Centre used semi-structured interviews and document analysis in 4 health authorities, 17 Primary Care Groups and 8 local authorities in London to assess the early impact of joint Health Improvement Programmes.¹⁹

The study suggested that involving the public (as a community, rather than just as service users) was a key Health Improvement Programme principle that could improve responsiveness to local needs, build community capacity to meet health needs, and strengthen public sector accountability to local populations.

The study found that:

- Opportunities for involving the public as citizens, rather than solely as service users, were often inadequate.
- Presenting information in accessible ways, showing willingness to act on the public's views, and deciding who to involve and how, were identified in the study as weaknesses in agencies' performance.
- Primary Care Groups tended to rely on their lay members and Community Health Councils to represent the public.
- The Community Health Councils, voluntary organisations and lay members used as 'representatives' tended to represent service users and carers rather than the wider community.
- *"Health Authorities need to find ways of communicating their strategies in more appropriate ways to the wider public."* This would require community development approaches.
- Local councillors, suitably prepared, could play an enhanced role in health improvement by working closely with Primary Care Groups, and could help make the process more accountable.

There was a strong case for seeking to rationalise the process locally. It might be appropriate for one partner to take responsibility for co-ordinating public involvement on behalf of the Health Improvement Programme partners, on the basis of shared goals and agreed action plans.

The NHS Plan

The NHS Plan 2000 (www.nhs.uk/nhsplan/npch10.htm) states that "*patients must have more say in their own treatment and more influence over the way the NHS works*". Measures to bring this about include:

- A 'Patients Forum' in every health trust and primary care trust.
- Patient members of trust boards to be elected through the Patients Forum.
- Major increases in citizen and patient representation on regulatory and advisory bodies.
- A new patient advocacy service, the Patient Advocacy & Liaison Service, to be set up in every Trust.
- All Trusts, Primary Care Groups/Trusts and care homes to seek patients views and publish them, with action taken in response, as part of an annual Patient Prospectus.
- Health authorities to establish an independent local advisory board of residents to help determine priorities and policies, including the Health Improvement Programme.
- Better information to empower patients, for example, patients to hold a personal record of their health care, patient-friendly versions of National Institute of Clinical Excellence guidelines.

Primary Care Groups

Primary Care Groups and Primary Care Trusts are required to respond to *local* need when purchasing and commissioning services. "*There is already considerable scope [for local consultation] within primary care. Members of the wider primary healthcare team are already in touch with local networks. Community nurses have been producing community profiles which could be used to develop stronger links with the community.*"²⁰

The Human Rights Act

With effect from 2 October 2000 The Human Rights Act incorporates the rights people have under the European Convention on Human Rights into UK law.

The actions of all public authorities, as employers and as providers of services, will have to be compatible with the Act. If someone could argue that they have suffered, or might suffer, as a result of what you are doing or not doing, then they could appeal through the courts.

How might the Act relate to involving people? Consider a *possible* interpretation. The right to information could be implied from the right under Article 8 to consent to medical treatment. Article 14 provides for people to enjoy their rights without discrimination on any ground such as race, colour, language, or religion. It might follow that to exercise this right, people from ethnic minorities should have access to interpreters and information in appropriate languages.

Details of the Act can be obtained from the Home Office Human Rights Unit

<http://www.homeoffice.gov.uk/hract>.

Freedom of Information Act. This will give everyone a legal right to see information held by public bodies (with exceptions). For details see the Freedom of Information Unit website www.homeoffice.gov.uk/foi/.

Models That Describe Levels Of Involvement

The Range Of Ways People Might Be Involved

People might be involved:

- In an assessment process or treatment decision, as individuals.
- As someone contributing their own views and experiences.
- As someone reflecting the voice of a group or community with a particular interest in common, such as use of a particular service, living in a particular area, having a particular condition such as epilepsy in common.
- As citizens.

Private		Public		
Individual	In particular service settings	Service wide	In a locality	National

Contributing to:

- The strategic framework or vision for services.
- Identifying and prioritising needs and allocating resources.
- Planning and purchasing services.
- Developing assessments and providing services and packages of care and support.
- Monitoring, reviewing and evaluating services and taking part in inspections.
- Staff selection, training and development.

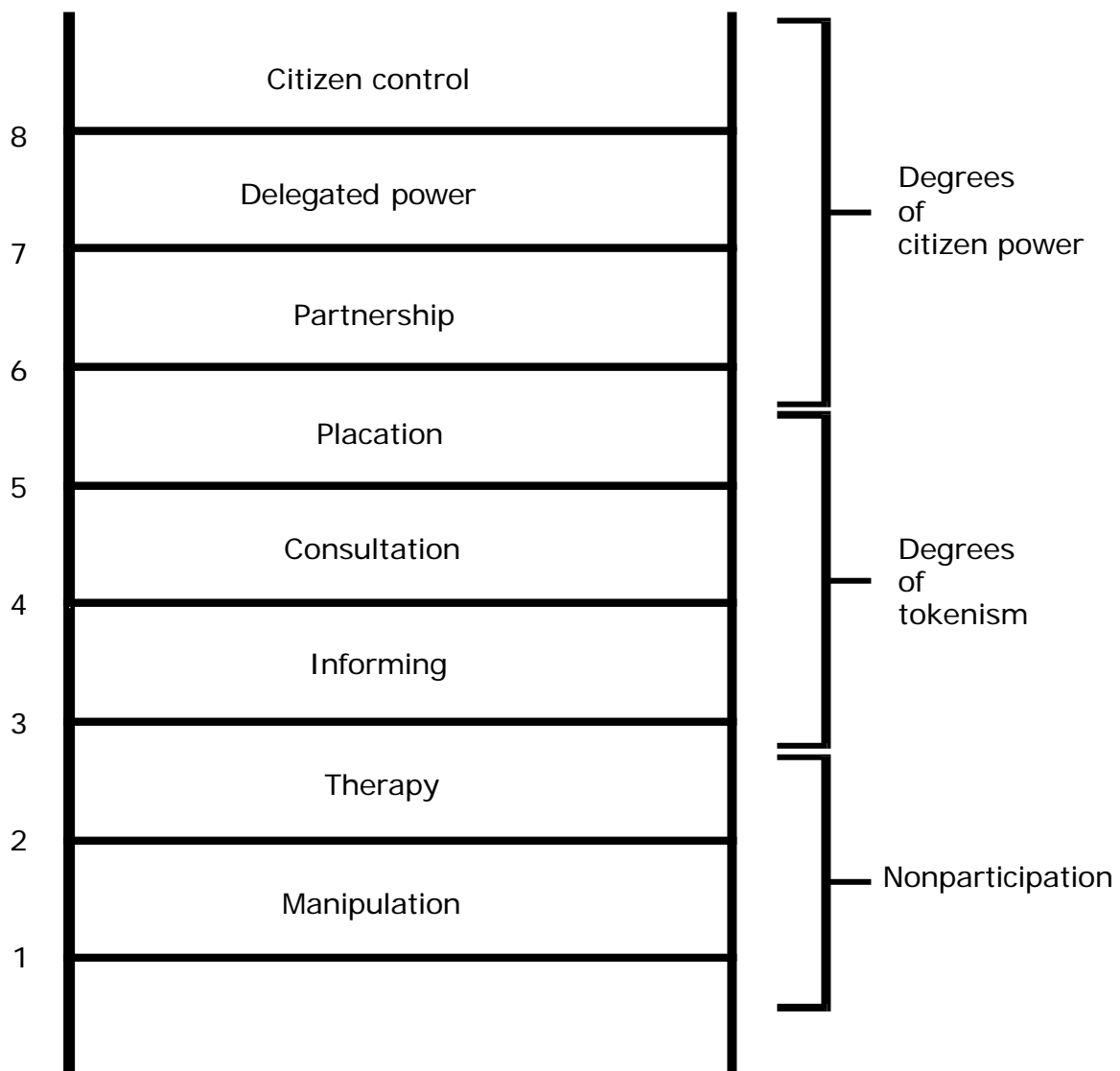
For the purpose of:

- Improving the quality of services by making them more sensitive or responsive to the needs of the individuals who use them.
- Participating in decisions about the way services are designed, managed and monitored.²¹

Arnstein's Ladder Of Participation²²

This model emerged from citizen involvement in planning in the USA. It is arranged as a ladder with each rung representing the degree of power the citizen holds.

"...the fundamental point [is] that participation without redistribution of power is an empty and frustrating process for the powerless. It allows the power holders to claim that all sides were considered, but makes it possible for only some of those sides to benefit. It maintains the status quo."



(continued)

Arnstein describes the type of “non-participation” represented by the lower two rungs on the ladder as attempts to ‘educate’ participants.

Levels 3 and 4 allow participants to hear and have a voice, but they have no power to ensure that their voice has influence.

At level 5 participants can advise, but the right to decide is retained by the agency.

True participation begins where ‘Partnerships’ enable negotiation and shared decision-making responsibility. Arnstein considers that partnership working is most effective when participants have an organised and resourced base from which to work, and to which they are accountable.

At levels 7 and 8 participants form the majority in decision-making arenas, or hold managerial power.

Applying this model to the traditional forms of user involvement within most agencies is revealing. Where are you on the ladder? Do you have clear, genuine reasons for being there?

Wilcox's Model

Arnstein's model has subsequently been adapted, for example by Wilcox²³

Your intent when involving people might be:

- Information giving.
- Consultation.
- Deciding together.
- Acting together.
- Supporting independent community interests.

Information Giving

Good quality, appropriate, accessible information underpins all involvement, but does not itself constitute involvement. Giving information alone is a one way process. It suggests that there are no alternative options and that no contribution is required from the public/service users.

Just giving information may be appropriate when:

- There is no possibility of negotiation - for example, you are following a legal requirement.
- You want to get a message across but don't require feedback or comment.
- You are initiating a process, and people need information to become involved at a later stage.

Consultation

Allows choice between limited, pre-determined options, but not an opportunity to propose alternatives or take part in putting plans into action.

Consultation (only) may be appropriate when:

- The range of options is genuinely limited.

Deciding Together

Views are shared, options are generated jointly, and a course of action decided upon.

Deciding together will be appropriate when:

- There is a possibility of negotiation.
- An agreed agenda needs to be reached amongst different interests.
- Implementation requires the co-operation of other people.

Acting Together

Working with others to make decisions and carry through the action agreed.

This may be appropriate when:

- There is a shared agenda.
- There is an ongoing process of development of trust and co-operation between the parties.
- The imbalance of power or resources has been addressed.

Supporting Independent Community Interests

Supporting independent groups to develop and implement their own solutions.

This may be appropriate when:

- There are adequate resources and support for the group.
- A longer time-scale is possible.

On one level, these models illustrate levels or degrees of participation that are appropriate for a particular purpose. On another level, they illustrate the progression that takes place as service users become more involved, and their power and responsibility develops and extends.

What We Are Talking About - Some Discussions To Have Before You Start

User And Carer Interests

Under the NHS and Community Care Act and Carers (Recognition and Services) Act 1995 service providers are expected to assess the needs of informal carers independently from those of the person being cared for. It can be difficult to ensure that both individuals can express their needs and preferences in privacy. The needs of carers and users may not coincide, and this can be a source of conflict.²⁴ Carers have become used to representing those they support, especially where communication is problematic, and care should be taken not to undermine working partnerships. However, it is clear from the literature and from discussions with service providers and voluntary/user groups, that a fundamental distinction should be made between users and carers that respects their respective roles and perspectives, and allows each to contribute independently.

Consumers Or Citizens?

“People have the right and duty to participate individually and collectively in the planning and implementation of their health care” Declaration of Alma Ata

World Health Organisation 1978

Service users have rights both as citizens and as consumers. In a democratic society citizens are entitled, by virtue of being a member of that society, to have a say in how the society is run. They have a reciprocal duty to contribute to the wider society.

Consumers have the right to information that allows them to consider how best to use their money and choose between goods and services. Regarding people as consumers was seen as a way of driving up quality.

If Sainsbury's offered a better service than Tesco, Tesco would have to improve its performance to compete. But health and social care service users can't generally take their money and shop elsewhere, so choice and preference cannot be exercised through purchasing decisions.

For public services, quality, responsiveness and flexibility are driven by citizens participating in decision making and holding service providers to account, not by the consumer in the market place. Current government thinking is that agencies should engage with service users as citizens.

Considered Opinion Or Instant Response?

“To give a considered reply people need information, an opportunity to hear others’ experiences and views and scope to develop opinions in a supportive social environment.”²⁵

When we ask people for their views we often expect them to give an ‘off the cuff’ response, without the opportunity to deliberate (weigh in their minds) or reflect. Or you may be asking someone about something of which they have no experience. Some approaches to involving people allow little opportunity for reflection, or for giving the information they would need to form a view.

For example, a survey that stops passers-by will give people no opportunity to think about their responses in any depth. Also, if they had not used the service you are asking about, they could not give an informed view.

Experience suggests that if people are given background information, an opportunity to hear others’ experiences and views and weigh them against their own, and time to reflect on and develop their opinions, they are able to deal with complex issues and weigh costs and benefits. They also then take a wider, or citizen perspective rather than acting purely in self-interest.

Service users themselves say that they want the opportunity to prepare, by having information in advance, or by knowing what they will be asked, for example. Approaches that involve people in groups can also be useful in helping people to formulate and test their ideas and opinions.

Choosing a way of involving people needs to take account of the relative values of considered and unconsidered, and perhaps uninformed, views.

Approaches that give people the opportunity to deliberate may be more time-consuming, but the value of the input you gain can compensate for this.

Representativeness & Accountability

Representativeness can mean either:

- **Statistical representativeness**

Referring to the sample (proportion) of people you would need to engage with (to respond to a survey, for example) to be confident that findings from your study group could be generalised to the whole population group you are interested in.

(See: 'How Many Is A 'Representative Sample'?' – p 63)

- **Democratic representativeness**

Referring to the ability of individuals (for example, on committees and in discussion groups) to reflect the views of a wider group or constituency.

Representative of...or being typical

Achieving statistically representative consultation is not always easy, and can be resource hungry. Where there is little tradition or experience of wider participation in public life it may be difficult to engage appropriate numbers and types of individuals and groups within the community. You will need to actively search for minority and marginalised groups to include their views.

In some circumstances the value of information from a small, targeted group may be greater than that from a representative section of the population as a whole. For example, the wider population cannot comment on how minority ethnic groups experience services.

Speaking of citizens' panels Vittles describes them as *“a pool of people who comprise, at best, a broad cross section of the population.”* But he feels their contribution is more representative than that of *“the collection of lobbyists and activists who have had disproportionate power...in the past.”*²⁶

A 'broad cross section' is likely to provide a perspective that others will relate to. Research has found that there is a high level of consistency in the views and values of service users, so that findings from smaller groups and from studies undertaken elsewhere can safely be used to guide action.²⁷

(continued)

Being a representative...

“There is no single community, but a number of over-lapping groups who identify with each other in the short term or over extended periods by virtue of the characteristics or interests they share, or the goals they wish to achieve.”²⁸

The more diverse a group, the more difficult it is for any one individual to represent them. Who, for example, could speak for all disabled people?

For agencies, including representatives from the voluntary sector is a traditional way of working. This favours the active and articulate, and is easier than working directly with service users. But how do such ‘representatives’ communicate with those on behalf of whom they are asked to speak?

Users themselves are often concerned about their accountability. Agencies can enable representatives to fulfil their responsibilities by providing funding and administrative support that promotes organised groups. Facilitating an election process can give the individual the confidence of having a constituency. Supporting the means by which the representative can engage in a dialogue with their wider group (through meetings, a newsletter or website, for example) is important. It is more difficult to represent those who do not form part of an organised group, or receive services on an individual rather than a collective basis, for example, home-care.

Good practice guidelines were drawn up after a survey of practice on user and carer participation in social services committees.²⁹

The guidelines suggest that it should be recognised that users and carers contribute views and perspectives based on their own experience. They should not necessarily be regarded as representing others, or made to feel responsible for representing their peer group.

People may be representative, or typical, users, but *not the representative of other users*. The legitimacy of their views rests in their personal experience, and it is likely that those in similar circumstances will share much of that experience. The roles in which people participate, and their responsibilities, need to be discussed and made clear for all concerned.³⁰

The 'Professional' User? – A Concept Challenged

It is suggested that agencies question 'representativeness' (in both senses) to:

(See: 'Representativeness & Accountability' – p 23)

- Challenge the validity of users' views.
- Allow rejection of suggestions and criticism.
- Provide an excuse for inaction.

People do need to be involved over a period of time in order to:

- Develop an understanding of the structures and processes they are engaged in.
- Contribute to evolving plans.
- See the fruits of their labour.

Yet users who have acquired skills, confidence and knowledge through their participation are no longer considered 'typical' of the 'ordinary' user, but to have become 'professionalised'. 'Professional' is a positive attribute when applied to paid workers, but used to invalidate the contribution of service users. Would it follow that the 'ordinary' user is someone who is uninformed, who has not had the opportunity to debate or reflect on issues, and so cannot challenge professionals? (See: 'Considered Opinion Or Instant Response?' – p 22)

If they are to participate on the same terms as the professionals, users need the same opportunities to develop their skills.

Training needs identified by service users³¹

- Assertiveness and 'speaking up' courses.
- Disability equality training.
- Equal opportunities training.
- Confidence building courses run by service user-trainers.
- Guidance on purchasers' and providers' decision-making structures.
- Training in committee procedures and negotiating skills.
- Information about what has and hasn't worked in other areas.
- Legal issues and rights under community care and other legislation.

Power

*"People make judgements about what they have heard, picking out what they consider to be quality contributions, weighing up what coincides with the values of the organisation, reconciling or arbitrating between views that conflict."*³²

We need to recognise that there is inevitably an imbalance of power between professionals and service users. Professionals have training, they command resources, and they represent agencies that have statutory powers and duties. Involving service users aims to tip the balance of power further towards the user. (See: 'Arnstein's Ladder Of Participation' – p 17)

Unless they recognise the influences upon them, professionals and organisations can exercise considerable control. They can be selective in whom they engage with (compliant users rather than the 'awkward squad' who might be more critical), and in hearing what service users say.

Before You Start – Preparatory Planning

Are You Ready?

A Checklist For Policy Makers, Planners, Commissioners...

- Are you prepared to commit yourself to user involvement as an integrated part of organisational activity rather than an occasional exercise?
- Are you prepared to take action as a result of what you learn?
- Do you have a clear, written strategy, developed with staff and service users, for involving people?
- Are staff and user groups fully aware of it, and has training been provided?
- Is there a named lead at a senior enough level with responsibility for user involvement, and the power to make things happen?
- Is there an adequate budget for the costs of involving people?
- Do you co-ordinate 'user involvement' activities with other departments and organisations?
- Do you know what information already exists?
- Do you have good knowledge of, and links with, voluntary, community and user groups in the area?
- Are you clear about why you are involving people?
- Have you made explicit the level of involvement possible and any genuine constraints on action?
- Have you made clear what is expected from participants? Have you developed an agreement with them setting out mutual responsibilities?
- Have you involved staff and participants in setting the agenda, and agreeing how they might be involved?
- Are you providing training and support for staff and participants?
- Are you taking practical steps to *enable* people to participate?
- Do you have mechanisms to keep participants informed about how their contributions influence planning and service delivery?
- Do you have a means of evaluating the processes of involving people?
- Do you have a means of assessing the impact of involving people?

(See: 'Promoting The Involvement Of Service Users - A Summary From Research Findings' – p 29; 'Supporting User Involvement - A Summary From Research Findings' – p 31)

Are You Ready?

A Checklist For Involving People In Service Settings³³

- In planning to involve service users, are you responding to what service users want, or are you initiating the process?
- If you are the ones planning an initiative, how will service users view what you are doing?
- What do you want to achieve?
- Who can help?
- What might restrict you?
- Are other staff committed?
- Have staff had opportunities to work through their fears?
- Do you have the skills and resources you need?
- Have you thought through the consequences of your actions in changing the balance of power between staff and service users?
- What might the service look like as a consequence of what you are doing?
- Who will have the final say over decisions? Can you deliver what service users want?

(Adapted from Wilcox D *Participation Guide* 1994)

This list looks daunting, and you will only be able to answer some of the questions as you develop your plan. There is plenty of evidence that considering these things, and getting everyone on board before you start, goes a long way toward ensuring that your initiative will be successful.

Promoting The Involvement Of Service Users - A Summary From Research Findings

“Any number of commentators currently provide guidelines for encouraging meaningful user involvement at both the individual level and for groups, with strategies designed for workers to use with their particular client groups but also for managers to encourage appropriate representation and involvement at decision-making levels. But it is only by acknowledging the changes in practice which are implied by encouraging greater user involvement that the rhetoric of participation can become an active reality.”³⁴

The Health Advisory Service Review ‘Voices in Partnership’³⁵ (which relates to involvement of mental health service users, but has wider applications) identifies the following as **ways of promoting user involvement**:

Direct methods:

- Appoint users’ support workers.
- Set up a user involvement interest group.
- Develop a networks of users.
- Construct a register of users.
- Involve users in writing community care plans.
- Train users to represent their own interests.
- Involve users in training staff.

Indirect methods:

- Improve publicity and information about services.
- Provide help-lines.
- Support development of resource centres for users.
- Aid users to form groups.

(continued)

Conditions for effective participation:

- Senior management involvement, with identified senior managers having clear responsibility for working at strategic level to ensure that participation is integrated effectively into commissioning.
- Access to staff with sufficient skills and confidence to undertake involvement activities and develop credibility with outside organisations.
- A positive organisational culture.
- Effective mechanisms for making good use of the knowledge of staff, and ensuring messages from service users and the public are fed into the organisation.

Clear expectations are an essential starting point. Principles should be agreed then a 'contract' drawn up setting out expectations on all sides.

Swindon People First (for people with learning difficulties) developed a contract for organisations wishing them to take part in committees. We couldn't have put it better.

Swindon People First Contract

If you want People First to be on your committee you must agree these things to make it OK for us:

- We should have a voice to say what we want.
- You need to listen to us and give us time to talk.
- We won't come to your committee just so it looks good.
- You need to let us know why you want us on the committee.
- You need to tell us what we will get out of being on your committee.
- You have got to make minutes and agendas on tape if we want them.
- The committee should pay for a supporter.
- Everyone on the committee needs to be trained to know how to involve us.
- The committee has to use words we understand.
- We must be able to stop meetings if we need you to say something again or explain it.
- Everyone should have their expenses paid.
- If the rest of the committee get paid then we should too.

Supporting User Involvement – A Summary From Research Findings

A Health Advisory Service review³⁶ based on reports, site visits, surveys and literature review suggests that adequate resources (time, money, support, and staff time) are one of the factors most likely to promote successful user involvement.

It recommends:

- Employment of salaried user/carer involvement workers to collect, collate and interpret information on opinions, wishes and needs.
- Development workers can also stimulate or co-ordinate actions by groups of users or carers.
- Creation of user and carer initiative grants.
- Training and time for users to develop knowledge and skills.
- Mainstream funding from health and local authorities incorporated within strategic plans. Funding is needed to cover facilities, (bases, office space, administrative and secretarial support) transport, personal expenses, setting up network registers and help-lines, and the costs to carers of replacements to substitute for them.
- Funding should be predictable and ongoing.

In another study³⁷ more than 200 service users in 19 day care centres across 3 local authority areas were interviewed, as well as 150 users and carers through independent user forums.

Service users felt that training was fundamental to their ability to participate meaningfully and actively in service planning and delivery.

Training requirements included:

- Assertiveness.
- Confidence building.
- Group-work and committee skills.

The research found that involvement depended on staff commitment to users taking part, and their willingness to accompany and support users.³⁷

Key Points - A Summary

“...the organisation, driven....by national requirements, requires instant action and clearly identifiable outcomes. This tends to skew their work towards the superficial and short-term, so missing opportunities for the development of more substantial and ongoing forms of public involvement.”¹

- Being involved in decisions about health or social care is a right, not a privilege.
- A ‘consultation culture’ starts within the organisation or work setting. Are staff consulted and involved?
- Top level commitment is needed to provide leadership, to express the importance the organisation places on ‘user involvement’, to maintain momentum and to make things happen. Identified ‘champions’ at every level within an organisation can act as a network to pass on information and ideas.
- Involving people in shaping health and social care services is a long-term, ongoing, developmental process, not a one-off project or exercise. It is a way of working that is integrated into practice.
- Be realistic about the time it will take for attitudes to change, for skills, knowledge and trust to develop and infrastructures to be built. The groundwork that you are doing now will bear fruit in the future.
- There is often disillusion about involving people. Agencies interpret low levels of participation as lack of interest rather than inappropriate choice of approach. Users feel that their views are not taken seriously, as they don’t see them acted upon. It takes time to overcome cynicism borne of previous poor experiences, establish trust and mutual respect, and for people unused to participating to develop confidence and skills.

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¹ Lupton & Taylor 1995 in Farrel & Gilbert 1996 Health Care Partnerships - debates and strategies for increasing patient involvement in health care and health services King's Fund

- Agencies, staff, service users and others with a key interest should work together to develop a clear and easily understood statement of values and a long-term plan. Be clear about why you want to involve users, and what you wish to achieve. Make this transparent to staff and service users.
- There is benefit in working across agencies to pool resources and avoid duplication. The public does not understand agency boundaries.
- To avoid duplication one partner agency might hold a database of initiatives. This would also help in identifying gaps and deciding on priorities. (The North Bank Forum hold a Directory of User Consultation Exercises in Hull and the East Riding of Yorkshire) *(See: 'Other Resources' – pg 102)*
- Resources are needed. Allocate a budget. Development and link-workers have been found to be of benefit. Recognise dedicated time for other staff.
- Build user involvement into contract specifications and job descriptions, and involve service users in monitoring to ensure that engagement is real and meaningful rather than token.
- Be clear about the consequences of involving users. Is the organisation or staff group prepared to make changes? Have people been able to work through their response to criticism? Provide training and opportunities for reflection.
- Agencies often consult too lightly, to meet their own needs without intention of change, or recognition of the cost to participants. If you are only interested in 'ticking the box', do as little as possible. Ill-conceived one-off initiatives can damage relationships for others.
- If resources are limited it is better to do something on a small scale well than to be over-ambitious.

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- Do you really need to undertake a particular exercise? Is the information already available? Has someone else, either nationally or locally, done a similar piece of work that will meet your needs? People all over the country make remarkably similar points. Resources are too scarce to duplicate work unnecessarily.
- Gather and make effective use of existing information.
- Do you need to do this yourself? Other people may be better at engaging with people than you. Provide resources and support to those who have the skills and contacts (user groups, community groups, voluntary organisations, staff, for example).
- Effectiveness in involving people comes from approach rather than technique. Successful user involvement derives from a genuine and positive approach that respects and values the expertise users contribute.
- There is no one method of involving service users that 'works'. You will need to use a variety of approaches. This allows a wider range of people to be involved and provides richer information and ideas.
- Be clear about purpose. The approaches chosen will follow from what you wish to achieve, and the characteristics of the group.
- Be open and honest about your intent and about any limitations on what is possible.
- Topics and methods are often defined by professionals. People are committed to what is important to them. They are more likely to become engaged when they own the ideas. Service users have their own agenda, and it may not match that of the agency or work setting. Negotiation will be needed to establish common ground.
- Involve users from the beginning of the process. The user perspective in defining priorities, setting and monitoring standards, devising surveys, staff training etc. will make the process more appropriate, accessible and effective.

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- Approach people individually to ask for their help. The most common motivation for getting involved is 'to make a difference for others'. *“Personal contact and preparation to take part in consultation exercises were much more effective than letters and leaflets.”²*
- In order to become involved people need information or awareness, a perception of benefit or relevance, and confidence about their own role. People need a clear explanation about what is involved, what is expected of them and the time commitment required. They need to know that any particular needs they have will be met, and what support will be available to them. Provide the opportunity to try something out before making a commitment.
- An ‘agreement’ with participants can ensure informed involvement, reflect the value placed on their contribution, and promote ongoing engagement.
- Users need to be sure that their input can have influence and be translated into practice. Feedback is extremely important to them. People need to see a result that has an immediate link to their participation, as well as to believe that things can be improved for others in the future. Small successes create confidence.
- Establish the level of involvement participants want initially, but be prepared for people to want to take on more as their skills and confidence develop.
- *“Service users need a range of support and training in order to be fully involved in decision-making.”³* Support or link-workers have been found to be of benefit. Similarly, community and user groups need resources and support to develop their skills in working with agencies.
- Don't expect service users to be representatives. Their own experience and perception is what is of value, and others are likely to relate to it.

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² Evaluation of National User Involvement Project 1999

³ Evaluation of National User Involvement Project 1999

- Users and carers will have a different experience of services. Carers should contribute in their own right, not as representatives of those they support.
- Good equal opportunities practice (expenses, childcare/ carer substitution, transport, accessible, comfortable venues, production of materials in other than written form, use of advocates, signers etc.) demonstrates to people the value placed on their contribution and allows a wider range of people to participate.
- Have a clear policy on payment. Pay people whose expertise you use.

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Ways Of Involving People In Shaping Health And Social Care Services

Ways Of Involving People - From Passive Recipients To Active Participants

“Talk is cheap when it comes to participatory services. Finding a way of making it a reality is a hard, unglamorous slog.”¹

Introduction

Involving people includes involving them in their own assessment processes and care and treatment decisions. Approaches to working with individuals are part of professional practice, and are not covered here. What follows are ways in which people can be involved in wider processes.

'How' to involve people is not the first question to ask. The first section of this guide deals with some of the considerations you need to address before you get to this point.

“Often, the success of your consultation will depend on your values – how committed you really are to listening to what your users tell you, not to what you want them to say.”²

Effectiveness in involving people comes from an approach rather than a method.

The words 'ways' or 'approaches' have deliberately been used instead of 'methods' or 'techniques'

Techniques can be	detached from context learned mechanically applied impersonally
Approaches are	grounded in the context value based broad and flexible ³

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There are many reference sources of information about *methods* of involving people; how to carry out a survey, for example. A number of these (national and local publications, web sites) are given in the resource section. It is not the intention to repeat readily available information here. What follows are brief outlines of **where it might be appropriate to use a particular way of involving people, and how effectiveness can be maximised**. These are drawn from reports of practice and 'live' experience, and from evaluations, where these have occurred.

*"...why are we trying to turn research tools and techniques into products - The Citizens' Panel, The Citizens' Jury- instead of seeing them as principles to be flexibly applied. We are in danger of closing down our options instead of opening up more possibilities for innovative approaches."*⁴

It can be hard to get people involved but the ways of involving them are not necessarily difficult. There are basic methods of engaging with people, and the challenge is to use them in flexible and innovative ways. Often, very similar ways of involving people are known by different names, which can make things seem more complex, and exclusive to 'experts', than they really are.

It can be useful on occasions to bring in an 'expert' with an independent perspective, or to learn from someone with experience, but this can perpetuate the idea that involving people is something that happens as a project or one-off exercise. User involvement is everybody's business, and should be integrated into normal working practice.

Agencies as corporate bodies may have difficulty in engaging with people, but staff already have many of the skills, and can acquire others, such as working with groups. Local multi-agency networks can share and develop skills, share costs and avoid duplication.

Key Principles To Follow:

- Be clear about what you want to achieve. The appropriate approaches will follow from your purpose.
- Involving people isn't a one-off project or exercise. It should be rooted in the culture of the organisation and part of everyday working practice.
- Use a variety of approaches. Only by using a combination of ways of involving people will a broad enough range of people be able to contribute in enough depth to shape appropriate, accessible, effective services.
- A variety of opportunities to contribute allow people to get involved at the level that suits them.

Who Are You Engaging With?

Some Characteristics Of The Population

You need to know the characteristics of the people you want to engage with to choose approaches that are fit for purpose. It is therefore important to know who the 'service user' might be.

In the general population:

- 104 per 1000 of the adult population living in the community are estimated to have a physical disability. 59.5 per thousand of these will have a concurrent sensory or mental impairment.⁵
- 1 in 7 people will have some degree of hearing impairment, rising to nearly half of all those aged between 61 and 80 years. 1 person in 1000 uses British Sign Language as their first language, and one in 16 has a hearing aid.
- 1 person in sixty is blind or partially sighted.
- 1 in 20 of the over 65s will have a dementia, rising to 1 in 5 of those over 80.
- 1 in 6 of the population will have a mental health problem, and for 1 in 100 the problem will be severe.
- 1 in 50 people of all ages will have some degree of learning disability, of which 4 in 1000 will be severe.
- At least 1 in 6 adults will be functionally illiterate.⁶
- There are 3.6 million people of minority ethnic origin in Great Britain, i.e. 6.4% of the total population. (1997 population estimate).
- 14 million people live in rural areas or outside identifiable towns and villages.
- There are estimated to be 50,000 travellers and 5,000 'new age' travellers in Britain.⁷
- The number of homeless people is difficult to estimate.
- One key group of people who felt excluded from their local community were people over 70, especially men, in a lower social class, on low incomes, who are council or housing association tenants and who live alone.⁸

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The cohort of people who use health and social care services will contain more people with characteristics such as those outlined above than the general population. Some will have multiple impairments; for example, people with a learning difficulty may also have a sensory impairment; the majority of people with physical impairments are over 65.

It can be seen that a variety of approaches will be needed to involve all the people you would wish to include.

It is also clear that one of the most commonly used methods of consultation, the survey, written in standard size print in the English language, and requiring a written response, will exclude a large number of people.

Literacy Levels

The ONS International Adult Literacy Survey 1998 found that 20% of the population of Britain, or eight million people, had reading and writing skills that fell below those needed in everyday life.

Basic Skills Agency studies⁹ found that 16% of people aged 16 to 60 whose first language was English, were functionally illiterate (defined as unable to read, write, and speak at a level necessary to function at work and in society in general). People with poor basic skills were less likely to participate in public activities. This suggests that those with literacy difficulties are less likely to be included in any form of consultation.

This suggests that exercises that are in written form, require a written response, or verbal articulacy, may exclude up to one in five of the population.

Why It Can Be Hard To Get People Involved

It is important to recognise that people not only have a right to be involved, but a right *not* to be, - or at least to choose for themselves when and how to be involved. You might feel that your time is not well spent taking part in consultation on the colour scheme for your doctor's surgery. But if s/he is going to change surgery times or the appointments system that may have more of an impact on you, and then you would value taking part in discussions.

There are many reasons why people don't get involved, including:

- People don't see any relevance to themselves in what you are doing or asking.
- There are costs to involvement – time, emotional cost, other activities foregone.
- Traditional ways of involving people have not always been the most appropriate.
- We are used to electing representatives rather than participating ourselves.
- Many people do not feel confident about their abilities to understand what is happening or express themselves.
- People may have had unsatisfactory experiences of 'authority', or with people they see as having power over them.
- There is a tendency to confuse criticism, which means judging the qualities of something, with complaint, which has entirely negative connotations.
- People are afraid that they may jeopardise the service they depend on, or their relationship with staff.
- People have their own interests and expectations which may be different to ours.

King's Fund research identifies barriers to involvement as:

- Structural systems that are not open and democratic.
- Adverse professional attitudes.
- Lack of resources.

How To Engage With People – Key Points

- Of overwhelming importance is genuinely wanting to. This comes from a sense of respect for people and a willingness to regard their perspectives as valid and of equal worth. The culture of the organisation needs to be one of openness and willingness to change. For staff to feel secure about involving people in planning and decision making, they need opportunities to work through their concerns.
- Everyone has an opinion - ask them! People may not volunteer, but they are usually pleased to be asked directly. There are plenty of opportunities for doing this - staff are in contact with large numbers of people, and individual invitations can be issued through community, voluntary and user groups.
- Include people from the beginning, in setting the agenda and agreeing priorities.
- Groups such as those detained under the Mental Health Act and people who abuse substances may not want to have contact with statutory agencies, but there will be others who are engaged with them. Once some trust is established, people will recruit others through their own networks. You seldom need a statistically representative sample, just a fairly typical one.
- The best motivation for people to participate is the feeling that they can improve things for others.
- Start small - success breeds enthusiasm and confidence.
- Go out onto people's own territory, (local venues, existing groups etc) - don't expect them to come to you.
- Be absolutely clear about what is expected of people, and what they can expect from you.
- It is a common misapprehension that if asked what they want people will ask for the impossible. They don't. Explain any genuine restrictions - people can understand.
- Don't put people off with formality and jargon. Informal doesn't mean amateur.
- Activities where there is opportunity for interaction are more enjoyable than formal ones. Make it fun!
- Communicate. Give feedback. People need to see the result of their efforts, and to see that they have made a difference.
- Don't expect anything to happen quickly. Gaining trust and developing good working relationships takes a long time. Community development approaches will be needed to allow people to develop the skills to represent themselves.
- User involvement needs resources - money, link people and staff time. Don't underestimate the resources require.

Involving Staff Within Organisations

What is often overlooked is that developing a 'culture of involvement' begins in the workplace. Staff empowerment, and job satisfaction, are increased by involving staff in decision making within organisations.¹⁰

The Report of the NHS Taskforce on Staff Involvement¹¹ found evidence that those services that involved staff in day-to-day decisions, planning and policy making:

- improved care through better service delivery.
- managed change more effectively.
- had a healthier, better motivated workforce and reduced staff turnover.

Involvement begins with the quality of the relationship between service users and staff. University of Birmingham research found that *"In those centres where staff did not feel valued by 'management' and were not routinely consulted about policy issues, there was less evidence of empowering user strategies."*¹²

There is much evidence that the support of staff promotes user involvement. However, an **evaluation in South Derbyshire** showed that staff working with disabled people wanted to involve them, but felt concern about raising expectations when they did not have the autonomy to make changes and could not guarantee that resources would be available. Although user involvement was expressed as a principle at policy level, structures and resources worked against it, and staff and users became cynical when they felt powerless to make any change.¹³

Cambridgeshire County Council has set up a Staff Panel in parallel to its Citizens' Panel to discuss issues of concern to staff.

Costs Of Involving People

Few agencies are able to cost precisely all the resources that go into their strategies to involve service users, staff and the public. Involving people isn't cheap, but some methods are more expensive than others, and the most expensive ways are not necessarily the best. Money can be wasted by not being clear about intent, or not choosing the most appropriate approaches for the purpose. Value for money can be increased by sharing skills, resources and costs across local agencies.

The Audit Commission¹⁴ point out that involving people can improve value for money, or save money, by:

- Not providing services that people don't want or need.
- Maximising take-up of services, especially those for which there is a charge.
- Providing services that minimise complaints and avoid expensive correction of mistakes.

There are costs to the agency in terms of criticism and loss of trust if their involvement practice is poor, or they are not seen to take action as a result of asking people what they think or want.

There are costs in that staff time devoted to involving service users cannot be used for other work. Staff may feel pressured if user involvement is seen as an additional task rather than recognised as part of their role.

Don't forget that there are costs to partner agencies too. Voluntary and service user groups may have little or no paid worker time. Increasingly, voluntary groups are refusing to devote precious resources to tokenistic involvement.

Individuals too are giving their time and perhaps limited energy, and sometimes there are emotional costs to participation.

Involving people is not something to be undertaken lightly.

Effectiveness

It takes time, money and other resources to involve people in shaping the services they use, so it would be a shame to get nothing out of it beyond the ability to tick the box that says you've met your obligation to involve service users.

There has been little research to date on how services are influenced by users' involvement. What would effectiveness in user involvement look like?

What you would be measuring is change:

1. Within participants themselves (service users becoming more confident, practitioners feeling less fearful).
2. Within the nature of the relationships between the participants (is there a more equal distribution of power? Are you 'climbing the ladder'?). *(See: 'Models That Describe Levels Of Involvement' – p 16)*
3. In attitudes and working practices.
4. In efficiency (the best result that can be obtained from the resources used) for example, by providing the services that make a difference to people's lives.
5. In effectiveness (services that do what they were intended to) measured in terms of service users' quality of life.

Feedback

- Says thank you - shows courtesy and reciprocity.
- Fosters trust necessary for an ongoing relationship.
- Summarises findings.
- Demonstrates that you have not only listened but heard.
- Outlines action to be taken.
- Explains the time-scale for action.
- Explains why any suggestions are not being implemented.

Giving feedback to those who have contributed their views, opinions and expertise is crucial if you want to be seen to take 'user involvement' seriously, and retain goodwill. It is a way of making 'payment' for the costs of participating. People feel exploited if their contribution is not acknowledged. It is often possible to incorporate feedback into existing media, such as newsletters or a regular local newspaper column or radio slot. Consider an immediate 'thank you' and periodic progress reports to retain interest.

Feedback should be given as soon after the event as possible. If there will be a delay, for example, because information will take some months to collect and analyse, this should be explained at the outset, with a date when it is anticipated that the information will become available.

If you don't deliver on this you won't get a second chance.

North Derbyshire Health produced short annual reports for the public on its Local Voices initiative. These reviewed the ways in which local people had been involved, how their views had influenced services, priorities for the next year, and ways in which local people could influence health services.

Choosing Methods - An Overview

A framework for choosing appropriate approaches that includes four major considerations:

1. What you want to involve people in doing.
2. What you want to achieve.
3. The approaches that are most appropriate for the people you want to involve.
4. How much time, money and support you have got.

Budget, resources and organisational capacity may influence scale and scope of activity, but limited budgets can promote carefully thought out and creative processes!

A Framework For Choice Of Method

1. Purpose	Most appropriate method options
Identifying need	Interviews and surveys, community development approaches, discussion groups.
Agreeing priorities	Surveys, discussion groups, ongoing relationships with partner groups and organisations.
Developing policy	Information giving, deliberative methods, task groups, ongoing relationships with partner groups and organisations.
Performance assessment	Surveys, information feedback systems including complaints, discussion groups.

(continued)

2. Goal	Most appropriate method options
Identifying values	All interactive methods.
Reaching consensus	Deliberative methods, decision-making discussions.
Ownership	Community development, polls and voting discussions, ongoing relationships with partner groups and organisations, methods that raise public profile.

3. Match with participants	Most appropriate method options
People who receive services	Planning meetings, discussions, surveys, ongoing relationships with partner user groups.
People without prior knowledge of services	Methods involving information giving and explanation, deliberative methods.
Level of involvement desired	Match method with intended contribution, short-term or ongoing.
People with clear personal or practical goals	Methods where process and outcomes are clearly defined, and clear result can be demonstrated.
People participating in the public interest	Participative, developmental or community based activities with long-term commitment.

Adapted from: Seargent J and Steele J **Consulting the Public Guidelines and Good Practice** Policy Studies Institute 1998

Practical Ways Of Involving People:

Information, Public Events And Other Ways Of *Giving* Information

Information

Start here! Good quality information is essential - the foundation for individuals to make informed choices and decisions, and for participation at any level.

There is evidence that people who have information feel more in control and report better states of health.¹⁵

But don't think that you have fulfilled your obligation to involve people just by giving them information. It is not sufficient in itself. When analysed, many 'consultations' are no more than attempts to inform service users or the public about decisions that have already been taken. (See: 'Models That Describe Levels Of Involvement' – p 16)

People continue to complain about poor communication and quality of information, despite the work that goes into producing it. The root cause would seem to be that information is provider-led, not user-centred, failing to consider the information needs or characteristics of service users.¹⁶ 'Changing Childbirth' recommended that service users were involved in the development of information materials,¹⁷ and this is now widely recommended and practised.

A study in an acute psychiatric ward in Northumberland showed that the existing information handbook was not read. Interviews with patients established the type of questions they would ask and the order in which they would ask them. This led to a new handbook with question and answer format and story-line headings, and included pictures and cartoons to get information across. The role for staff in reinforcing and supplementing information verbally was also established.

The aim of giving information might be:

- Increasing knowledge
- Education – information intended to change attitudes or behaviours
- Empowerment – increasing skills and confidence to enable participation in a dialogue.

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Good practice in giving information has been identified as:¹⁸

- Being clear about aim
- Setting information within a wider communications programme
- Considering the characteristics of the target audience
- Involving users in identifying their information needs
- Involving users in ongoing monitoring and evaluation of appropriateness and effectiveness of the information

Time and money could be saved by adapting communications materials already in use.¹⁹

It may be more cost-effective to adopt 'good practice' information that has been developed and evaluated elsewhere than to start from scratch. (*See: 'Other Resources' – p 102*)

The charter for long term care says that **local charters** should contain information on services available and how to access them, how people can say what they think about services and suggest ways of improving them, and how to complain. People should be helped to give their views through advocacy or representative organisations.²⁰

Information is generally service or theme specific, so people may need to look for information from a number of sources. They would benefit if agencies could co-operate to produce a joint information pack including information from health, social services, the Benefits Agency, education, leisure and voluntary groups.²¹ A user-led project group could produce such a pack, in appropriate formats.

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A local study found that information was not being provided in efficient ways, and did not adequately address the needs of people wanting information. People needed information that spanned a number of services, 'designed for the needs of service users rather than the structures of organisations'.

Information needs identified were:

- Services
 - what is available, how to access it, eligibility, costs, service standards, complaints procedures.
- Welfare benefits
 - rights and entitlements.
- Self help and healthy lifestyles information.
- Medical advice and information.

Partners in the East Riding of Yorkshire are therefore developing a comprehensive health and social care information system that can be accessed in a variety of ways according to individual preferences. Development of the system is being informed by consultation with people about their information needs, and how information might best be presented and accessed.

Johnson Leedham and Waddington Developing a Multi-Agency Public Information System in the East Riding Nuffield Institute for Health University of Leeds 1999

Email HEROS@northbankforum.karoo.co.uk

Options For Disseminating Information Include:

Written Information

*"You can expect key information to be available in a form which is accessible to you, for example in different languages, or, as necessary, on tape, and that an interpreting service will be provided if you need it."*²²

This is the most commonly used method of providing information about services, policy and planning, although as has been shown, it excludes considerable sections of the population. (See: 'Some Characteristics Of The Population' – p 42; 'Literacy Levels' – p 43)

It is known in education that visual cues help make sense of text for those with poor reading skills.

The one million people who are blind or partially sighted will need large print, Braille or Moon, or tape formats. **The RNIB²³ recommends** the following to increase readability for the additional 700,000 people who are unable to read newspaper print:

- Black type on white or yellow paper give best contrast. Avoid patterned backgrounds.
- Glossy paper that reflects light can make reading difficult.
- Documents for general readership should be in 12 point type. Large print needs to be a minimum of 14 point, but many people benefit from a larger size.
- Use medium or bold type weights.
- Use unjustified right hand margins and space between lines.
- Capital letters are harder to read than lower case.

Electronic Information

Studies in the 1980s²⁴ showed that information from a computer was preferred to printed material, and that increase in knowledge was greater than from oral or written sources. It may be that this effect has declined as computers have become less of a novelty. However, in 1991 when computer literacy was less wide-spread, a study²⁵ of computer use in 4 Merseyside GP waiting rooms showed that the majority of respondents did not find the system difficult to use. Touch screens have since increased ease of use.

Information via a computer can be used at an appropriate time, and the interactive element may increase effectiveness. For example, questions may be used to check understanding. Graphics make computer information accessible to those with reading difficulty, and voice simulation is becoming more widely available. However, the 'information divide' means that many people who use health and social care services may not have access to computers, or be able to use a computer in privacy.

The feasibility study for the East Riding information system (See: box – p 54) recommended an Internet based system.

A number of councils, for example Middlesbrough, put their surveys for Citizens' Panel members on their website. Of the first three surveys (1999) 1-2% were completed in this way. A recent community panel survey in North Lincolnshire found that a quarter or more of their panel members had access to the Internet. Others councils, for example, Liverpool use their website to recruit panel members, with application forms available in large print, tape and Braille.

On-line surveys might be a way of increasing the response from younger people, who are usually under-represented. For example, the Internet is being used to consult with primary and secondary school children in 70 schools (Kidscope).

There is potential for giving and requesting information using computer technology, as well as linking people and for on-line discussion groups. (See: 'HealthLINK' – p 138; 'Telephone Discussion Groups' – p 139)

Video

This is a familiar, attention-holding medium which is not literacy or necessarily hearing dependent, although not everyone, especially poorer and older people, own video equipment. A strength of the medium is its ability to simulate discussion and show role models. Videotapes are not expensive to reproduce, but the cost lies in producing a product of the quality people expect.

Audiotape

Does not rely on literacy or sight, and good sound quality tapes are not expensive to reproduce. Can be listened to and repeated at leisure. Retaining concentration to listen over longer periods can be difficult for those who are not used to the medium.

Exhibitions

- Site will determine reach to public - specific venues can be chosen to reach specific groups.
- Information can be presented in visual form.
- Public relations value, but can also be construed as a waste of resources.
- With adequate staffing, can be used in an interactive way with the public contributing views and ideas.

Seminars

Information giving to promote understanding of issues:

- Better for defined groups than the general public.
- Agency in a position to control what information is given.
- Limited opportunities for dialogue at this stage.
- Need to facilitate participation with childcare, travel costs etc.

Using The Media

Using the media can be a quick and effective way of reaching a wider audience. Local radio and the local newspaper can be used for publicising events, inviting participation, giving information or starting a local debate. Regularly contributing items of interest or having a regular radio slot or newspaper column not only builds a relationship with the media but raises the public profile of the organisation. The 'human' side of the organisation can also come across.

BBC Radio Nottingham followed a local woman through her pregnancy and post-natal care to show how the health system worked, and covered common issues that arise during pregnancy.

Advantages:

- Can reach a different cross-section of the public, for example, the housebound, older people.
- Local radio not literacy dependent.
- Radio and 'talking newspapers' reach visually impaired people.
- Helps build a perception of the organisation as part of the local community.
- Commonly asked questions can be answered.
- Media will often use items that are presented to them in 'media style' and with photos.

Consider:

- Only fairly simple messages can be communicated.
- You may not have control over how information is used (unless buying advertising space) or over the questions asked in interviews.
- You need to develop skills to present information in an appropriate form and to take part in interviews.

Public Meetings

An event that extends an open invitation to members of the public to attend. There is usually a speaker and there may be a panel of people to who will respond to questions from the audience. May be held to introduce a plan, strategy or report, or when there is a specific issue of public interest such as a change in service provision. Some agencies hold regular public meetings.

Some agencies hold meetings that are open to the public, but people are not usually invited to comment on the proceedings. Here the role for the public is of scrutiny, or holding the organisation to account.

Public meetings are often seen as democratic, offering an open invitation to the public to receive information, comment, raise issues, inform decisions and challenge service providers. They are high profile and regarded as good public relations and a way of meeting and listening to the public. However, the cost-benefit ratio is not favourable. This approach usually reaches only a small section of the community. Public meetings are not accessible for many of the people who would use health and social care services. The public relations element may be lost because of the unsatisfactory nature of the interaction and difficulty in providing feedback on the outcome.

Public meetings are most appropriately used to give specific information, and to air a single issue about which the public feels strongly. Using only public meetings as your strategy for involving people is never sufficient, and other forms of dialogue group may be more appropriate.

(See: 'Focused Group Discussions' – p 86)

(continued)

Consider:

- This is a formal process that excludes many. Poor attendance is wrongly interpreted as lack of interest rather than poor choice of method.
- People attending may have little information about the organisation holding the meeting, what it does, or how it works.
- Usually a 'one off' exercise rather than part of an ongoing process.
- The audience will contain many different interests, degrees of knowledge and sympathy with the organisation. It is difficult to know where to pitch a presentation.
- A glossy presentation suggests that the decision is made, and leaves little room for alternatives.
- Opportunities for people to contribute are limited.
- The agency agenda may not be that of the public – excluding contributions that seem off the point adds to the impression that the agency is paternalistic and does not listen.
- Issues raised may not be a reliable indicator of public perception or priorities. Interest groups may distort the wider view.
- A public meeting creates a setting for conflict between audience members as well as audience and presenters, which the organiser can have little control over.

Making the most of a public meeting:

- Think about your aim – is this the best way to achieve it?
- Keep purpose simple – trying to mix all elements, information giving, consultation, holding agency to account etc, will not work.
- Consider timing, location, access, childcare, travel arrangement and cost, to facilitate attendance by as wide a range of people as possible
- Personal invitations get a better response than a general open invitation, but don't rely solely on umbrella groups
- Avoid 'them and us' layouts and settings
- Meet with key groups first for common understanding of purpose and to agree agenda
- Allow time to break into small groups first to give more people chance to contribute, and to allow common themes to emerge

Consultation Exercises

Activities that are really opportunities for giving information are often labelled 'consultation'. True consultation has a dual purpose, both giving information and listening to and considering participants' responses.

(See: 'Models That Describe Levels Of Involvement' – p 16)

Hounslow Council held an interactive consultation day on Council services.

Half the participants were from community groups and half from people who had responded to residents surveys. Each had a computer-linked handset to record their responses and display them instantly. The aim was twofold, to inform – by improving knowledge about council services and the choices the council makes, and to hear – to gather opinion on priorities and budget choices. Participants logged their personal details and answered questions on what they knew about council services, their preferences, priorities and views. There were displays, interactive games and quizzes, a feedback wall and an opportunity to talk with the councillors who were present.

A day such as this takes considerable organisation, but has a number of advantages:

- It is a high profile event that makes the council appear open to public opinion.
- It informs and educates.
- A volume of information could be collected at one time, and in a format that could be easily analysed.
- The opinions given were informed to some extent.
- There was instant feedback to participants, and they could see how their views compared with others.
- It was fun to participate in.

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Meetings used as a consultation exercise by Parkside Health Authority were poorly attended.

Publicity information had been sent to 400 groups, and the meetings were structured around specific care groups and organisations. Community venues were used.

Researchers sought explanations, and discovered that:

- Agencies were not given sufficient notice.
- Publicity information was not clear.
- The agenda was considered too rigid.
- Agencies were not used to the health authority conducting such events.
- The issues were not a priority to the voluntary groups and agencies contacted, or they did not work in the specific area of focus.
- Insufficient groundwork had been done in the community to promote interest in a public consultation exercise.
- Publicity targeted groups and agencies, not users of services.
- Not all appropriate forms of publicity had been used e.g. local community radio and local press.
- Voluntary and user groups had too many meetings to attend.
- Community groups had insufficient staff to allow participation.
- The timing of the exercise was poor – within the holiday period.
- Some groups had negative past experiences of consultation attempts by statutory bodies.

Surveys, Interviews And Other Ways Of *Gaining* Information

Practitioners and agencies need information:

- To learn from the ways service users experience services.
- To develop services that meet the needs and expectations of the people who use them.
- To know how they are performing.

Surveys

Surveys are a way of gathering information using a questionnaire or an interview schedule.

“Questionnaires can be perceived as intrusive and interrogatory by users, and less in their interests than in that of the service provider”²⁶

Surveys may be distributed by post (or increasingly, via a computer) or within a service setting. They may be completed by the individual, or by someone who records the participant's response on their behalf.

To provide reliable information, a survey needs to reach a representative sample of all people in the study group (the public, users of specific services, residents of a particular area) and obtain a high response rate.

How Many Is A 'Representative Sample'?

There are statistical formulae for working out how many people you need to survey, and how many forms have to be returned, to give confidence that the responses you get from your sample population (say a random sample of one in ten of the people who use day centres) can be safely generalised to the population you are interested in (the total number of people who use day centres). If you need a statistically representative sample it is worth taking expert advice about sample size for a particular purpose. (See, for example, www.doh.gov.uk/pssuser/index.htm for guidance on sampling for the Personal Social Services user satisfaction survey).

If your sample is small (as may be the case with some groups of health and social care service users) you will get information that is *indicative*. You just need to be careful about what you claim from the data.

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The Office for National Statistics report that a written questionnaire survey will achieve a 30% - 40% response rate. This can be increased to between 60% - 75% by sending two reminders. The majority of forms are returned within the first 10 days.²⁷

Questionnaire surveys are good for:

- Counting – how many use a service, hold a particular view, and so on.
- Obtaining factual information.
- Obtaining an overview from which to identify priorities for more detailed study.

Advantages:

- Can reach large numbers of people.
- Provides baseline data.
- Responses confidential.

Consider:

- You need to be able to identify the target group from which to sample.
- Dependent on literacy and shared cultural concepts.
- Difficult to design to get the appropriate questions answered.
- Don't underestimate the difficulty of designing a questionnaire that provides good information. Consider using forms that have been tested elsewhere.
- Needs piloting with a sub-sample of the identified group.
- Can be unsatisfactory for respondents:
 - Questions may not seem relevant to respondent.
 - There is little opportunity for explanation or interaction.
 - Results are not owned by participants – people have commented that they feel like objects of research, not a person.
 - It may be unclear to them how the exercise will lead to action.
- Needs considerable administration time - can be costly.
- Open questions can be more difficult to analyse.
- With low response rates, there are concerns about how representative results are, even with a carefully chosen sample.
- You may learn how many think or do particular things, but not *why* - not the most appropriate method for investigation or exploration of issues. You may need to follow up with interviews or group discussions. (See: 'Interviews' – p 74; 'Focused Group Discussions' – p 86)

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Making the most of surveys:

- Improve by using discussion groups or semi-structured interviews with the target population to develop the survey instrument – to identify priorities, the preferred order of questions, check that appropriate language is used, establish shared understanding of meanings, for example.
- Use the language the target group would use, for example, use common rather than medical health terms or social work jargon.
- Providing information on what to expect from a service will give respondents a yardstick to judge the service by. (See: 'Monitoring & Standard Setting' – p 118)
- Increase inclusiveness by offering alternatives to a written self-completion survey form where possible (assistance with completion, telephone or face to face interview).
- Use large print, leave space to write comments, ask for personal information at the end²⁸.
- Make sure confidentiality is understood (numbered forms make people think you can identify them).
- People may need a polite reminder and a second form.

A survey of people over 70 was redesigned after comments from user panels of older people. It achieved a 70% response rate. The initiator attributed the good response rate to suggestions made by the older people which made the survey more acceptable and straightforward.

Satisfaction Surveys

"Factors peculiar to users will weight the outcome. Their demoralisation, gratitude for support, low expectations, unclear expectations, vulnerability, absence of other choices, over-dependence on professional expertise....."²⁹

Surveys are often used to measure 'satisfaction' - for which purpose they are *least* useful. Satisfaction surveys often report stunningly high levels of satisfaction - an average of 72% of respondents to Joint Review postal questionnaires report services as 'excellent' or 'good'. However, response rates are low, so validity is in question. '80% satisfied' may look good as a headline, but you have learned very little. Could you have spent that time and money to better purpose?

What is required of an instrument to collect user views is that it:

- Produces an accurate reflection of experiences, views and opinions.
- Produces information that is useful, in that it addresses issues that are important to users.
- Can result in action for change or to improve quality³⁰.

There are concerns about how satisfaction surveys meet this requirement:

- The term 'satisfaction' is not defined, and there is little clarity about what is meant.
- A service consists of many component parts. What is being evaluated? The process? Outcome? Degree to which needs are met?
- The concept of satisfaction relates to prior expectations, but service users may not have enough information to form expectations before they experience a service.
- Service users are being asked to evaluate or judge a service with no standards to measure against.
- Expectations will change over time, so measurement at different points is not measuring the same thing.
- Low expectation appears to produce high satisfaction ratings.
- The USA experience (where people are paying directly for services so can choose between providers) (See: 'Consumers Or Citizens?' – p 21) is that satisfaction is generally rated highly, but does not translate into behaviour. Very small differences in satisfaction rating, even at the top of a scale, related to large differences in the numbers of people changing their health care provider.

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Most people who require services want them to address quite specific needs. It is these that you need to identify and focus on, asking specific questions related to quality of life and achievable change, rather than attempting to address a general 'satisfaction with services'. Ongoing quality monitoring, using standards developed with service users, are more productive for gauging perceptions and experience of services than are periodic surveys.

(See: 'Monitoring & Standard Setting' – p 118)

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Hampshire Social Services Department set out to reconcile the limitations of user satisfaction surveys with government and management demands for systematic ways of collecting feedback from service users.

They worked with a local user group to establish the principles on which user surveys should be based. They should be:

- integrated into normal departmental processes.
- developed in partnership with user organisations - methods and materials.
- distributed by front line staff.
- safeguarded for confidentiality.
- returned to and analysed at a central point.
- findings fed back to managers, front-line staff and service users.

The routes chosen to obtain feedback from service users were through:

- Reception and Assessment Teams at initial contact with the department
(a quarterly survey of the first 30 contacts on a given date provided a *"small manageable exercise at local level, but resulting in over 1500 people being surveyed over a year."*)
- The care plan review system, for care management
(questionnaire handed out to everyone at review).
- Provider services, for service delivery.

Written surveys are used to ensure anonymity. Large print and tape versions are available.

The surveys have highlighted areas where change is needed to improve the service.

For example, although 79% respondents knew what action was being taken after assessment, less than 50% knew who would take action or when this would happen.

Staff hear about positive comments, and anyone reporting a negative experience is invited to provide contact details so their concerns can be followed up.

The department views this approach as 'one tool in their toolkit'. They can compensate for its limitations by supplementing it with in-depth interviews and other exploratory methods, but they are beginning to collect core information in a systematic way as part of existing processes.

Performance Management Unit, Hampshire Social Services

Panels

Panels range from large numbers of people contributing via postal surveys to smaller groups of people who meet to contribute their views. The key feature of a panel is that it continues to exist over a period of time. (Whereas focus groups meet on only one occasion).

Citizen panels are a random sample of the population large enough to be representative of the population they are drawn from (usually 1000 or over people).

Panels are recruited to provide a pool of people from whom to:

- Obtain information and feedback over a period of time.
- Draw smaller samples with particular characteristics, for example, people within a certain age range.
- Recruit for in-depth interviews, meetings or group discussions.

Most panels limit the length of time a panel member can serve, and replace them after that time. Others 'refresh' the panel by recruiting a certain percentage of new members each year, allowing new opinions to be introduced and new members to be absorbed. The aim is to avoid panel members becoming better informed than the average citizen by virtue of their participation.

The Somerset Health Panels

These were set up in 1993 to 'build a consensus on the values to be used to guide health resource allocation decisions'.

Eight panels of twelve people meet to discuss an issue posed by the Health Authority. This number was considered to be sufficient in number and coverage of the geographical area to give confidence that the wider public view would be represented. Members were chosen to mirror the social and demographic profile of the area. Panel members are given information on which to base their deliberation. Both participants and managers regard the process favourably.³¹

Panel members will be influenced by their own, direct experience, and by indirect experience such as that of family, friends and neighbours. They will also be influenced by seasonal factors (high winter demand for GP appointments) and media coverage of local and national issues and events.

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Panel Recruitment And Response Rates

Experience indicates that 10,000 postal recruitment questionnaires will result in 1,500-2,500 responses. In order to match the demographic profile additional efforts need to be made to recruit certain sectors of the population. For example, young people are otherwise under-represented. Media appeals are sometimes used to recruit panel members, and agencies are increasingly using their website to recruit and contact panel members.

(See: 'Electronic Information' – p 56)

Nugent suggests that a well-recruited and maintained panel should achieve a 65-85% response rate when surveyed.³¹

Vittles found response rates of 70%+ from face interviews, 60%+ from telephone interviews and 20%+ from postal surveys.³² North Wiltshire's 'The People's Voice' panel achieved a 92% return rate to its first three postal questionnaires. This was in the context of a high profile for community consultation activities generally, including a newsletter to feed back to panel members information gained from each questionnaire and its impact on Council actions.

Nugent suggests that **citizen panels have been used with two main objectives in mind:**

- Consultation about future policies and services.
- To measure performance and satisfaction with existing services.

He believes that the usual periodic sampling is poor for the latter. He suggests continuous sampling, of one twelfth of the panel each month, with results aggregated then averaged. This would give a better overview of cycles in satisfaction and the effects of media coverage of issues.

Smaller panels than those generally used by Councils and Health Authorities could provide useful, if not statistically representative feedback. Some might be derived from registers of people with a particular interest in common, for example, carers, people using a particular service on a long-term basis such as those with diabetes. The group could be provided with information and attend meetings or discussion groups so that informed views can be obtained. Smaller standing panels are cheaper to run and can provide more immediate feedback. Electronic panels are increasingly becoming a possibility.

(continued)

Panels are good for:

- Identifying particularly good or poor perceptions of a service for further research.
- Seeing how views change over time.
- Can be used to test the effect of external events e.g. media coverage.

Advantages:

- Can be recruited to represent the characteristics of the population or group so that findings (if response rates are adequate) can be generalised to the population as a whole.
- Means of collecting data from a fairly large sample of the population.
- Various means of collecting information can be employed, and initial data can be explored in greater depth.
- Performance monitoring requires that the same question be asked of the same people over an extended period.
- Organisation benefits from appearance of wanting to involve 'ordinary' people.
- Panel can be pre-informed to obtain more considered views.

Consider:

- May be difficult to achieve a reflection of the characteristics of the whole population or group.
- Needs considerable infrastructure to recruit and maintain a large panel and manage data.
- For ongoing performance monitoring, an increase in satisfaction may be an effect of being on the panel.
- Panel members need to be well motivated to continue involvement over time.
- Loss of panel members through natural wastage needs to be allowed for.

Timely acknowledgement and feedback, to include publicising how the information gained has been used to improve services, can help maintain interest. You might do this through the local press, or through a newsletter to panel members.

The Government has commissioned the 'People's Panel', a representative sample of 5,000 people who are being asked their views on public services and how they can be improved. Any publicly funded body can have access to the data collected, or use the panel themselves.

www.cabinet-office.gov.uk/servicefirst

The Fife User Panels³⁴ were established to ensure that older people could contribute directly rather than through voluntary organisations, to influence the planning of health and social care services. The project was supported by two half-time workers with secretarial and consultancy support.

Eight panels were established around the region " *to enable frail older people to discuss with each other their experiences of growing older and of using health and social care services, and to use the outcomes of such discussions to influence the provision of services to become more sensitive to older people's needs.*"

Seven of the panels consisted of frail older people while the eighth was matched in age, but consisted of people who were not dependent on services at that point.

Members were nominated through health and social care workers, churches and the local Age Concern group, but the 'snowball effect' (people recruiting others from their own networks) increased as the panels developed. Ongoing recruitment was needed to replace those who became ill or died, but the loss of members was not found to have a negative effect on the panels, and new members were successfully introduced.

The age range was 67 to 93 years with an average age of 82. Housebound older people and those with dementia were not included. The panels met monthly, with transport provided to accessible and comfortable venues. Reports were produced from their discussions.

Evaluation of the project was built in, to address three questions;

1. Is it possible to identify frail older people who are, or could be, users of health and social care services, and to involve them in regular panel meetings designed to encourage them to articulate their views about such services?
2. Do participants experience benefits from being involved in such panels?
3. Do the panels exert any influence over service plans and provision?

To address the second question *peer interviewers* helped design an interview schedule and conducted interviews with panel members.

To examine the impact of the panels on services three issues were selected as a focus for document analysis and key informant interviews. (These were domiciliary care, hospital discharge, and information and communication).

(continued)

The panels were described as an "effective but resource intensive" way of enabling older people to express their views and welcomed by service providers as an innovative way of engaging with older people.

There was some concern about how representative the panel's views were. Individuals were recruited not as representatives, but to contribute their own views and experiences. The report concludes that those who participated could be considered typical of older service users. (See: 'Representativeness & Accountability' – p 23) Credibility was increased when agencies were more aware of the process that generated panel reports - how topics were generated and explored, and had a quantitative idea of members' contributions.

There was also some tension between agencies' desire to use the panels for their own purposes and the aim of the panels; to enable older people themselves to identify and prioritise issues, and introduce new perspectives. As panels have progressed, the variety of issues discussed, and panel members' skills in responding when agencies needed quick feedback, increased.

The distance from statutory services enabled a free expression of views and maintained a user-led rather than bureaucratic feel. Participants felt valued as the ability to contribute, that many felt had been lost with age, was restored.

Analysis of how panels functioned to explore user views and to influence services revealed:

- Discussions were largely initiated by members recounting and reflecting on their own experiences and responding to service changes.
- Discussion was facilitated and supported by project workers in a variety of ways:
 - Direct questions.
 - Feeding in information members might not be aware of.
 - Using exercises or structures that facilitated discussion.
 - Making suggestions about potential ways forward.
- As panels started to develop their own agenda on an issue, they sought direct contact with service providers. This dialogue prompted specific proposals to be developed. Having established this contact and made proposals, members expected feedback.

Interviews

Structured Interviews

Data collection might be a more accurate description of a structured interview. The purpose is to gain specific and pre-determined information. The same questions are asked in a set order by someone who records the responses, usually in a tick-box type format. The interviewer does not have the same scope for exploration as in a less structured interview. A structured survey instrument does not have to be so 'user friendly' as a questionnaire, so can be set up in a way that makes it easier to analyse.

Good for:

Obtaining concrete information (numbers, yes/no, service use etc).

Advantages:

- Quicker and cheaper than less formal interviews.
- Requires less skill to administer.
- Quantitative data can be obtained in a form that is relatively easy to analyse.
- Allows for explanation of question if necessary, and checking of understanding.

Consider:

- Values, feelings and reasons for views can't be explored.
- Limited opportunity for dialogue might make experience unsatisfactory for participant.
- The answers you get depend on the questions you ask - easy to influence responses with a prescriptive framework.

Semi-Structured Interviews

General areas of enquiry are determined, but there is scope for the interviewer to explore the respondent's feelings and perceptions, and ask further questions in response to the information given.

(Unstructured interviews are described, but it could be argued that the interviewer always has at least a mental agenda).

Good for:

- Obtaining rich descriptive information.
- Exploring views, and why people hold them.

Advantages:

- Can be used for more sensitive topics and with people who don't function well in groups.
- Can enrich data from more structured methods.

Consider:

- Demands more skill and sensitivity of the interviewer.
- Interviewer/interviewee relationship can influence responses.
- Interviews time-consuming to conduct, record and analyse.
- Needs skills in analysing information gained.
- May need translation or signing if a peer interviewer is not possible.
- Some articulacy in speech or signing required of the interviewee.
- Number of interviews likely to be possible may limit how far you can generalise the information obtained.
- Needs quality control where more than one interviewer taking part to ensure consistency.
- Can raise uncomfortable issues for the respondent, and Interviewers may need emotional debrief.

Peer Interviewing

Using people to conduct interviews who share characteristics of those being interviewed.

For example, age, sex, experience of service use, class, language or ethnic origin.

Peer interviewing has been widely used in work with young people and in user-led service monitoring in mental health. There is potential for use in other service areas.

The Sainsbury Centre for Mental Health suggests a number of **advantages of user interviewers**, supported by their own and others' research.³⁵

User interviewers:

- Have a rapport with interviewee through their own experience.
- Understand difficulties with jargon.
- Are not discomfited by people hearing voices or having other difficulties during the interview.
- Are unbiased and independent.
- Are more likely to be told what users really think about their situation than 'professional' researchers or staff.
- Help users bring out views that may be different to those of professionals.
- Bring out issues that providers may not have been dealing with or seen as a priority.
- Help interviewees to think about and explain their problems, use of services and treatments in their own way.

Peer interviewing was used in an evaluation of mental health users' and carers' experiences of involvement in the planning of their care.³⁶

One third of the 78 people interviewed preferred a researcher to a service user, usually for reasons of confidentiality. The authors report that peer interviewers did not have difficulty in containing information gained during interviews. They were successful in developing a rapport with interviewees.

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Another study ³⁷ describes the development of a model of user-focused monitoring in mental health using peer interviewers.

12 volunteers from user groups and service settings trained as interviewers.

A semi-structured interview was developed through role play with user-interviewers as part of their training. This was used with a random sample of 58 mental health service users, contacted through their key worker. The authors note that the sample was small, but these were vulnerable users with severe and enduring mental health problems (in the top tier of the Care Pathways Approach) who would not have been contacted normally.

The interviews were used to find users' knowledge about services, views on, and satisfaction with, the service they received, and their perception of gaps in the service.

The study found that:

- User-interviewers were able to elicit clear responses from users with severe psychiatric and social disability.
- Users were more likely to participate if their key worker was enthusiastic.
- More work on engaging key workers was needed before the project so that user-focused monitoring would not be seen as a threat.
- Researchers felt that criticism of the interview as a method that does not encourage critical reflection, (Elbeck and Fecteau 1990 suggest focus groups are more effective), was not supported by the thoughtful and varied responses obtained.
- 'User interviewers elicit more open and honest responses than professionals do'. They created a relaxed atmosphere in which users felt able to be more open than they might have been with a professional who could influence the service they received.
- Seven of the final eight user-interviewers were felt to have conducted interviews in a consistent manner.

(See: 'An Example Of User-Led Monitoring' – p 119)

Other Ways Of Obtaining Information

Roadshows

The 'What Matters to You' roadshow toured the North Wiltshire Council area, providing daytime and evening opportunities for people to write what mattered to them on flipcharts. In a fortnight over 8,000 people visited the roadshow and more than 5,000 comments were obtained. Staff and elected members involved in the roadshow could see and hear what local people were saying. The issues identified were further explored in 'Visioning Days' in each of the five community areas in the authority to establish future agendas.

Observation

Watching and recording what happens.

Advantages:

- Provides feedback on actions or behaviours that may not be consciously recognised or articulated, for example, staff/service user relationships.
- Allows comparison between expressed knowledge or intent and actual practice.
- Where individuals do not communicate conventionally, allows preferences to be established through observation of behaviour and emotions.

(See: 'Engaging With People Who Have A Learning Difficulty' – p 163; 'Engaging With People With Dementia' – p 141)

Consider:

- Observer can influence behaviour.
- Observation not always ethically acceptable.
- Dependent on interpretation of observer where interpretation cannot be checked with people observed.

Story Telling, Life Histories, Diaries

Ways of obtaining descriptive information of richness and depth, that is not dependent on literacy (you can use audio diaries) and can be suitable for use with people with learning difficulties or memory loss. Although these approaches have the benefit of informality, the same rigorous standards of information giving to obtain informed consent apply. Skill is needed in using these approaches and in analysing the information obtained.

Stories provide a hypothetical situation that can be used to prompt discussion and draw out values and priorities. Being able to decide how someone else might act in a situation can be less threatening than direct approaches.

Life stories (or biographical interviews in research jargon!) allow people to share and reflect on their experiences in their own words and to identify what is or has been important or critical to them. It can be an affirming experience for people who feel devalued³⁸ and may not have the confidence to participate in other ways. Visual means can be used to prompt reflection (time lines, critical incident mapping, body maps, photos, music, poems and other reminiscence material).

Diaries provide a means of collecting information about activities, events, (giving some information on frequency), experiences and people's reflections on them. They can be more private than speaking directly to an interviewer. Diaries can reveal differences in what people think or say they do, and what they actually do.

Using Existing Information

“There are many ways of using informal mechanisms to collect information about the needs and views of...people. Too little use is made of complaints, helplines, the observations of front line staff and development workers, and opportunities to collect information as well as give it, such as health information sessions. Such information is often not valued because it is seen as unrepresentative – but if recorded, collated and analysed for patterns it can supplement and enrich information collected by more formal means.”³⁹

- Front-line staff hold large amounts of information, including local information and knowledge of unmet need, appropriateness of services and gaps in provision, but there is seldom any systematic means of capturing this.
- Councillors can be a conduit for information exchange. Taking part in consultations can help them to know what local people think and to represent them more effectively.³⁰ It is suggested councillors may have an enhanced role in working with Primary Care Groups.
- Community Health Councils are aware of issues causing concern to people using health services, and sometimes carry out specific surveys. For example, East Yorkshire Community Health Council surveyed 713 people using hospital outpatient departments to obtain views on healthcare provision in the area⁴¹.
- After a patient on the Stroke Unit kept a diary of their hospital experience the Occupational Therapy department of Ulster Community and Hospital Trust introduced a “Communications Book” for patients, relatives and staff to make comments and ask questions. It is “proving a very useful way of sharing opinions and experiences as part of the continuous improvement programme.”
- Information leaflets could include a tear-off slip for comments.

Using Information Collected By Other People

Information is collected by central government, by other agencies and by other departments. Gaining information is costly, so make sure you know what is already available before collecting your own. A joint approach to information gathering is cost-effective, avoids the same individuals being approached by different people, and gives an impression of ‘joined-up’ services.

Re-Orientating Complaints Procedures

Lose that word! It has only negative connotations, and people think that something has to go seriously wrong before they use a 'complaints procedure'. More informal comment or feedback mechanisms allow anonymous positive comments, descriptions of experiences, and constructive criticism requested to benefit others. Much more information on how a service is performing could be obtained, and could act as an early warning system to identify problems rather than waiting for things to go wrong.

A study⁴² with people with learning disabilities and their families identified barriers to the use of complaints procedures:

- 'Complaint' had negative connotations such as 'moaning'.
- People did not know the procedure to complain.
- Concerns about the consequences of complaining - fear of retribution, not being able to control the process or predict the outcome.
- Perceived messages that service providers discouraged responses, poor past experiences of other forms of participation, implicit threats of service withdrawal.
- Concern about complaining about one aspect of an otherwise valued service.
- Reluctance to be critical of front-line staff.
- Difficulty in questioning services in the independent sector.
- Worries about taking time when others seen to be in greater need.

People may be getting mixed messages from staff. The study found that few front-line staff had received any specific training about complaints procedures, but were aware of dissatisfaction or conflict that was not followed up.

Staff:

- Equated 'complaints' with 'disputes' and failed to distinguish between complaints and 'gripes'.
- Were reluctant to be seen to 'push' people into complaining.
- Believed it was only worth complaining about things that could (in their judgement) be changed.

Involving People In Group Activities Or As Communities

*“Communities are diverse and local interests may conflict with each other. If the community is seen as homogenous then only the most powerful voices will be heard”.*⁴³

Meetings

Can be for giving or gaining information, but usually a combination of the two. Although the following guidelines were to make meetings more accessible for people with learning difficulties they stand as a general rule and would help any service user (or director of services?) taking part in a meeting.

Guidelines for making meetings more accessible⁴⁴:

- Make meetings less formal.
- Build in breaks.
- Make sure the purpose of each meeting is clearly explained.
- Send out papers early enough for participants to study them.
- Prepare papers in accessible formats for example, large print, audiotape.
- Avoid all jargon and abbreviations, and explain all items clearly.
- Provide a supporter for individual participants, to facilitate their contribution as needed.
- Provide briefing and debriefing opportunities. People may need time to plan and prepare what they want to say and consider what has happened.

(See: 'Engaging With Older People' – p 135)

Committees And Similar Groups

Committees are a way of working within and between agencies. They are alien to many service users and members of the public. However, committee membership is widely used as a means of involving service users, often through representatives from user groups and voluntary organisations.

Good for:

Formal processes. Creative ones are better in small groups and workshops.

Advantages:

Ongoing contact with service user representatives.

Consider:

- Participants can be perceived as becoming aligned with the agency.
- Agencies often expect user participants to act in a representative role. This may not be comfortable for them. They may have no mechanisms for representing the views of their peers.
- Accountability for decisions is often unclear.

(See: 'Representativeness & Accountability' – p 23)

Making best use of committees:

- Is this the most appropriate process for purpose? Consider less formal arrangements to involve service users. Professional rituals and jargon exclude people and may intimidate them.
- Service users need training and support to participate effectively in such a process – professionals have it, why put users at a disadvantage?
- Make sure the group has a real purpose, with a jointly agreed remit, in writing, and regularly reviewed.
- Involve wider interests through informal contacts and preparatory workshops.
- Support consultative processes within voluntary organisations through funding and admin support.

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Research found that people with mental health problems or disabilities felt that their presence on committees compelled others to consider their experiences, and that their views were taken seriously. However, they were not sure what influence their views had on policy.⁴⁵

It may be more appropriate to assemble groups to work on particular issues rather than have a single standing group. User-group-specific forums, local working groups or reference groups can offer a more informal way of working. For example:

The continence service in one Trust has established a group of service users and their families, consultants, GPs and other health professionals. The group meets quarterly to discuss and revise procedures and set and review outcomes.

Quality Action Groups⁴⁶

This is a process that most people could take part in. Change can be broken down into small achievable steps and the visible result helps to sustain the process. Success breeds confidence. It is suited to residential and day care settings, but has been used in home care. Staff need to be open to change, and have the autonomy to put plans into action. They need to feel secure, so that they are not threatened by criticism, and understand power relationships so that they don't dominate and control the agenda. (See: 'Power' – p 26)

There are 6 steps:

- Bring people with an interest together (service users, carers and professionals).
- Agree what the service should be like.
- Compare with what is actually happening.
- Focus on something that can and should be improved.
- Agree on a plan and put it into action.
- Consider what has changed and what to do next.

Juries

Citizens' Juries developed in Germany, and were first used here by the Institute for Public Policy Research. People are paid to attend over a 3 or 4 day period, participating as citizens acting in the interests of the whole community rather than in a personal or interest group capacity.

Between 12 and 16 people are selected at random to reflect the socio-economic profile of an area. The jury is provided with detailed information and can examine expert witnesses.

There is time to consider and discuss the evidence before reaching a conclusion. The jury approach could be used with specific groups of service users where there are choices to be made about the future direction of a service, or priorities to be decided upon.

Good for:

Involving the public in decisions that affect them - strategic planning and service prioritisation, considering controversial issues.

Advantages:

- Seen as democratic – independent, lay views given weight, scrutiny of service provider.
- Deliberative process – develop a shared view.
- Complexity of decision making revealed.

Consider:

- Small numbers of people involved - the wider community may not be committed to decisions reached by the jury.
- Group dynamics (as with any group method) may influence decision.
- Jury may not reach a consensus.
- Expensive and time consuming to arrange.

Studies of Citizens' Juries working with Health authorities by the IPPR and King's Fund have shown that participants can deal with complex issues and reach constructive conclusions.

Examples include:

- Lewisham asked a Citizens' Jury to consider how to approach the issue of drugs and young people.
- Walsall Health Authority asked a jury to choose between four models of palliative care.

Deliberative Polls

These share features of panels/juries. People are given information before voting, but there is no attempt to reach a consensus view.

Focused Group Discussions

The 'true-type' focus group is a small group of ideally no more than 12 people given a particular topic or issue as the focus of discussion. Focused group discussions can allow participation of those who would only feel comfortable in a group of similar people. (For example, young people, women, rape victims).

Discussion groups can also be used to obtain views on a wider range of issues, although they will only work if there are a limited number of topics for the group to address in one session.

Group discussions can engage 'harder to reach' groups where other methods might fail to include them.

Good for:

- In-depth exploration.
- Identifying issues and framing questions for a larger sample.
- Identifying issues which require consideration or work.
- Interpretation of unexpected quantitative findings.

Advantages:

- Non-literate people can participate.
- Those with a hearing impairment or for whom English is not a first language can participate with appropriate facilitation.
- Allows clarification and expansion of views.
- Characteristics that might influence the outcome e.g. age, sex, socio-economic status can be matched.
- Small size, skilled facilitator and appropriate support allow difficult or sensitive issues to be explored.
- May draw out people who don't find a one-to-one interview easy.
- Individuals' views may be crystallised by hearing them articulated by others.

(continued)

Consider:

- Requires skilled facilitators.
- Usually recorded, transcribed and analysed - time consuming.
- Group norm may mean the dissenting voice is not heard.
- Participants may be influenced by social pressure, embarrassment and so on.
- Vulnerable people may be revealing information in a forum where confidentiality cannot be guaranteed.
- Post-group support might be needed for some participants.
- Cost/benefit ratio for information from a small and limited group may be high.

Research suggests that groups which mix lay people and professionals are not ideal and need clear ground rules. The user may be inhibited by the 'expert', and be inhibited from expressing their true feelings, while professionals may be defensive.⁴⁷

North Derbyshire Health Authority⁴⁸ used street interviews to recruit people for discussion groups about health issues and views about local services.

They excluded health service staff and their relatives and those who had no experience of using health services in the previous 5 years. This approach failed to recruit young people aged 16-24 and older people aged 70 and over, so these groups were recruited through the local college and from pensioner groups. Participants were paid a £10 fee (1993) and childcare costs.

From this exercise the HA found that:

- People were interested in and able to talk about health issues.
- Some were distressed by talking about personal experiences, and it was necessary to have more than one facilitator in order to deal with this.
- Participants wanted direct and honest answers about the purpose of the project and reassurance about confidentiality.
- People were interested in the outcome of the work and wanted feedback. Half of the participants of the groups discussing maternity services requested the final report.
- Some of the responses came as a surprise to the authority.
- Although running 11 groups was " a major undertaking" only around 100 people were involved.

Ways In Which All Key Interested Parties Come Together To Develop Shared Visions

Examples include Consensus Conferences, Future Search Conferences, Whole Systems Events.

Key features are:

- Event facilitated, but no one participates in expert role.
- Structured process moving from past experience to envisioned 'ideal' future.
- Action groups formed to realise solutions proposed.

These 'bring those with the power to make decisions together with those affected by decisions to try to agree on a plan of action.' The participants divide into smaller groups, moving from reviewing the past to developing a vision of an ideal future. Action plans are developed and groups commit themselves to action toward creating their vision. Sizeable numbers of participants from different backgrounds introduce a broad range of views.

Participatory Appraisal

"Participatory Appraisal is a family of approaches and methods used to enable people to present, share and analyse their knowledge of life and conditions, to allow them to plan and act".⁴⁹

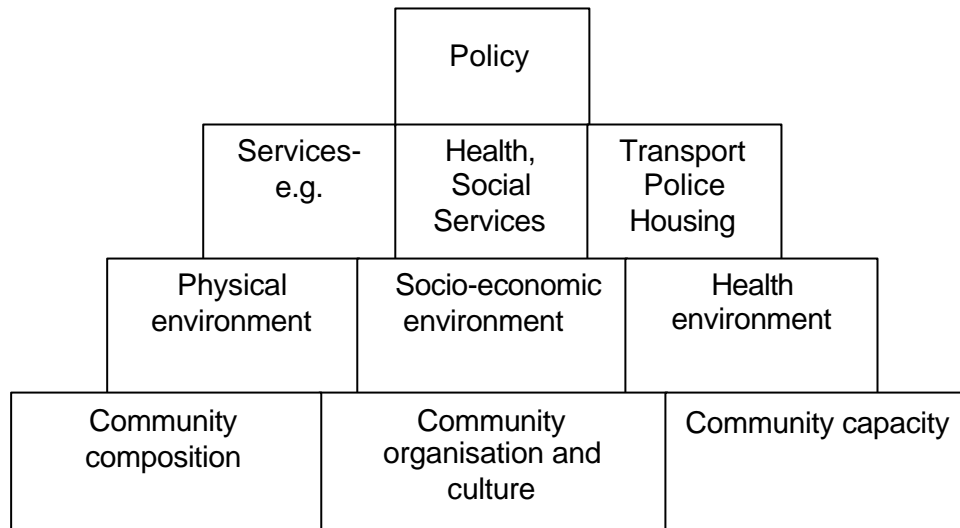
Participatory Appraisal is popular at the moment. It is a flexible 'family of approaches' so may look quite different in different circumstances.

PA is often used to seek the perspectives of a defined community or group. Community members may be trained to carry out the work. The community identifies its own strengths and weaknesses, priorities, issues of concern and solutions to problems or action that can be taken. Community members are participants in (rather than subjects of) research and 'own' the information collected.

A number of approaches are used in combination, including surveys, interviews and group discussions, using inclusive, visual means of communication such as mapping and network diagrams.

(continued)

PA is also used to develop a community information base, from existing data, observation, and interviews with 'key informants' (professionals working in the area, key community figures and community members). Information is considered valid when it comes from at least three sources or collection methods.



A community information pyramid⁵⁰ Information gathered using Participatory Appraisal approaches feeds into policy and decision making (such as where to target resources).

Participatory appraisal can be used as a rapid data collection exercise to provide baseline information, or as a means of understanding how a group or a community view themselves and what their priorities are. It can be the first step in engaging with the community for ongoing community development work.

Good for:

Engaging with defined geographic or interest communities.

Advantages:

- Can be done quickly.
- Can be used by community staff to produce locality profiles.
- Can excite local interest and ownership.
- Can reach a wide group who might not usually participate.
- In depth insight into how a community sees itself, and its priorities.

(continued)

Consider:

- As a one off data collection exercise, does not produce sustainable community development.
- May raise expectations, and a wide range of issues which the community/agency may not have the power to change.
- Needs the resources to support the exercise in a concentrated time period.
- Outcome can be skewed if only certain sections of the community participate.

A review of five studies using the technique in a primary care context⁵⁰ found that:

“Far from making huge and unreasonable demands, patients and community members made practical and achievable suggestions.”

As part of a review of health promotion activity and health inequalities a community appraisal was undertaken in each of the 21 most deprived electoral wards in Hull and the East Riding of Yorkshire.⁵¹ Co-ordinators who lived or worked in the communities involved set out to build on the skills existing in the community to gain a community perspective on health. Each ward produced a report reflecting community responses to four questions:

- What does being healthy mean to you?
- What affects your health (good and bad)?
- How has this community changed in the last five years, for better or worse?
- What do you think local people could do to improve health in this community? What could others do to improve health in this community?

It is intended that the work will “create and enhance baseline information to inform how specialist resources are used, identify key issues for local project planning and highlight the range of information currently available” on local populations.

The methods used for the community appraisal will be evaluated, and it is anticipated that this will indicate how far the participatory appraisal approaches used contributed to community capacity development.

Health Promotion Hull & East Riding Community Health NHS Trust

Community Development

Definition according to the United Nations, 1948:

“A movement to promote better living for the whole community with active participation and if possible on the initiative of the community, but if not forthcoming by techniques to stimulate it.”

This may be a geographic or interest community. The community identifies its own needs and is supported to develop its own projects and support systems. The lay view is predominant.

Community development builds 'social capital' - social trust, social cohesion, social networks, strengthening of voluntary organisations, neighbourliness, civic identity and community involvement.⁵²

Community development underpins involvement of the wider range of people agencies say they would wish to engage with. It allows otherwise marginalised individuals and groups to develop the skills and confidence to represent their own needs, priorities and solutions, and to work actively and constructively with service providers and agencies. Support for community development work should therefore be part of any strategy for user involvement.

Good for:

Developing support mechanisms and skills within a community. Allowing individuals and communities to develop through work on their own solutions to the problems they identify.

Advantages:

- Active ways of communicating views, concerns and priorities other than through verbal means, for example, through community arts schemes, can engage a wider range of people⁵³.
- Raises confidence and self esteem.
- New skills and knowledge developed.
- Participants enabled to take more control over their lives and environment.

Consider:

- Needs long term commitment.
- Specific outcomes can't be predicted.

(continued)

Crosby 21 is a local project designed to enable people in the Crosby district of Scunthorpe to take an active part in improving the social and economic life of their area. Residents, who include a minority ethnic population, are consulted through arts based activities, assisting them to identify and address issues that are important to them.

Working With And Through Others

Working With The Voluntary Sector

The voluntary sector has much useful experience to share from working with people both as users of their services and as volunteers. Voluntary groups often have the flexibility to work in innovative ways.

Advantages:

- May be expert in their particular field.
- May have a structure to support participants and canvass wider views.
- May have access to particular groups of people you would not otherwise easily reach.

Consider:

- The politics. There may be a number of organisations that relate to, for example, physical disability, with different perspectives. Are they all represented?
- Not everyone is represented in formalised umbrella groups. You will still need to engage with individuals who are not part of a group.
- Voluntary groups are not neutral – they have their own agendas.
- Group may be reliant on funding. It can be difficult to 'bite the hand that feeds you'.
- A large sector with groups of various sizes and in different stages of development. Many will not have the resources to participate without your support.

The voluntary sector is often perceived as being democratic, and controlled by its members, but this is not always the case. A study conducted in 1995 found that while voluntary organisations supported the involvement of users in control of the organisation, few had clear policies, progress was slow, and fear of the consequences of increasing user control was a substantial block to progress.⁴⁴

Working With User, Carer And Support Groups

These may be small and unique to your area, or part of a national organisation.

Advantages:

- Knowledgeable and engaged in their subject area.
- Relatively easy to make contact with.
- Way of making contact with users and carers to invite their participation.
- Ideas can be tested with the group before developing them further.

Consider:

- Groups may be limited in membership and range of views.
- May have a very specific agenda.

Working With Existing Community Groups

For example, pensioners' groups, groups around a particular religion or culture.

Good for:

Making contact with a range of people who might otherwise be hard for an agency to reach.

Advantages:

- Opportunity to get a range of views.
- People may appreciate agency coming to them, and be more prepared to enter into dialogue.
- Improves power in-balance – people feel more confident in their own territory/setting.

Consider:

- Group may not share agency's agenda and resent hijacking of personal time/space.
- May produce lots of anecdotal, non-specific information that is hard to use in positive way.
- Lack of an immediately visible outcome may affect your future credibility with the group.

Working Through Liaison Or Link Workers

“Dedicating resources to outreach work was an effective way of contacting service users from more marginalised groups.”⁶⁵

Appointing individuals who can act as a link between all parties is widely recommended. There is the potential for role conflict – is the individual neutral, or working to an agency agenda? This is often minimised by the voluntary sector or body such as the Community Health Council holding the funding and the worker's contract. Service users or past users might be employed to help develop and promote involvement.

Link workers can:

- Develop knowledge of a particular sector, group or area.
- Improve communication and co-ordination between statutory and voluntary organisations and user groups.
- Make links with individuals and groups that agencies find difficult to engage with.
- Provide training for service users and staff.
- Support individuals and groups in participation.

Development Workers

- Can seek out and reach people who don't participate through other channels.
- Can act as a resource to local individuals and groups as they develop, providing advice, support, practical help with funding, administration, printing.

Consider:

- Such workers have the power to set agendas. They need real awareness of power relationships and self-reflection.
- They can become viewed as the expert when what they are trying to develop are the skills of others.
- There can be the danger of creating dependency on an individual.

Bringing In External Facilitators Or Consultants

Good when:

- There is no time to develop the required expertise locally.
- An issue is particularly sensitive or contentious.

Advantages:

- It can be valuable to obtain an external, independent perspective.
- They may be perceived as more trustworthy than the organisation involved.
- Recommendations may carry more weight.
- Can provide a learning experience for the establishment or agency.

Consider:

- Often seen as putting off dealing with an issue.
- They need a very clear brief in order to be effective – by which time you may have done much of the work yourself.
- The organisation may lose opportunities to develop its own skills, and experience from 'first hand' contact with participants.
- Their work can be more easily compartmentalised, and viewed as a one off activity rather than a sustainable process of development.
- Can make it harder to avoid acting on conclusions - can you deal with their recommendations?

Advocacy

“Advocacy means making the case for someone or a group of people or helping them to express their own views, usually to defend their rights or promote their interests. The concept has special relevance for people who are disadvantaged in some way and as a consequence are less able to speak for themselves.”⁵⁶

The 1986 Disabled Person’s Act gave individuals the right to appoint an advocate, and local authorities a duty to develop advocacy schemes. Although the Act was never fully implemented, it is good practice that the right to an advocate, and access for advocates to service users, is written into service specifications.

Advocacy for patients is included in the NHS Plan (See: ‘The NHS Plan’ – p 14):

“...it is consistent with the aims of basing service provision on the needs and wishes of users that those who are unable to express their views.[should] be supported in securing independent representation.”⁵⁷

Forms of advocacy might include:

- Self-advocacy - service users acting individually or collectively in their own interest.
- Peer advocacy – the support of someone with a similar personal experience, for example, of disability or mental illness.
- Citizen advocacy - trained volunteers act as impartial witnesses and supporters, or represent other, usually vulnerable, people.
- Professional advocacy - representation by a paid, independent person such as a welfare rights advisor or legal representative.

Some would include practitioner advocacy, but there is debate about whether practitioners, who are influenced by professional or organisational agendas, can truly act as advocates for service users in a disinterested way.

Advocacy has the potential to allow those whose voices might not otherwise be heard to make their views and preferences known, and to influence policy and practice.

“If ..advocacy were to be recognised as a means of empowering....users (by advocates accompanying them to meetings), then many more of them would have a physical presence at formal events, rather than having their views represented by someone else while they stay at home..”⁵⁸

(continued)

The Health Advisory Service⁵⁹ suggests:

“Advocacy may be a means of ensuring that users’ views are brought into planning processes generally” as well as ensuring their voice in individual care.

The report proposed the development of a consultant advocate role, a paid professional who specialises in representing the interests of users and carers. (In this case for mental health services, although the principle could apply to other service sectors). The report suggests consultant advocates should have an understanding of mental disorder, service provision and management, planning and purchasing and relevant legislation. They should be independent of the service, linked through a national network, and have recognised training and accreditation. They could supervise other advocates and support service user involvement in the planning process.

The Royal Commission on long-term care for older people recommended that local advocacy schemes were developed that would provide an ‘independent intermediary’ for people in care⁵⁹. (See: ‘Engaging With Older People’ – p 135)

A review of advocacy⁶⁰ found that successful advocacy was promoted by awareness at all levels of what advocacy is, and what it can do. Another factor was well trained, supervised and supported advocates with time and skills to build good advocacy partnerships, but the insecurity of short-term funding of projects could limit the ability to recruit volunteers and provide ongoing training and support.

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Other Resources

General

Barker Jacqui et al *Reference Manual For Public Involvement* South Thames Regional Office 1997

⊗ Described as 'a practical tool kit to provide detailed advice' on how to consult the public effectively.

Barr, Drysdale & Henderson *Towards Caring Communities* Pavillion/JRF

⊗ Training resource pack "...to help staff initiate and implement community involvement in service planning".

Beresford P & Harding T (Eds) *A Challenge To Change – Practical Experiences Of Building User-Led Services* National Institute for Social Work 1993

⊗ Provides examples of a broad range of initiatives and participants' experience.

Bradburn J et al *Voices In Action: Training And Support For Lay Representatives In The Health Service* Royal College of Health 1999

Croft S & Beresford P *Getting Involved: A Practical Manual* Open Services Project 1993

Farrell C et al *A New Era For Community Care? What People Want From Health, Housing And Social Care Services* King's Fund 1999

Goss S & Miller C *From Margins To Mainstream: Developing User And Carer Centred Community Care* Joseph Rowntree Foundation 1995

Harding T & Oldman H *Involving Service Users And Carers In Local Services – Guidelines For Social Services Departments And Others* National Institute for Social Work and Surrey Social Services

Kelson M *User Involvement: A Guide To Developing Effective User Involvement Strategies In The NHS* College of Health London 1997

⊗ Contains sections on why user involvement is important, who to involve, methods for user involvement, checklist to help organisations evaluate their strategies. A good, basic overview.

⊗ The College of Health also provides training on user involvement. Tel. 020 8983 1225

Kemshall H & Littlechild R (Eds) *User Involvement And Participation In Social Care* Jessica Kingsley 2000 www.jkp.com

Lindow V & Morris J *Service User Involvement: Synthesis Of Findings And Experience In The Field Of Community Care* JRF 1995

Morris J *Community Care: Working In Partnership With Service Users* Venture Press Birmingham 1997

Seargent J & Steele J *Consulting The Public: Guidelines And Good Practice* Policy Studies Institute 1998

Stevenson J *Involving Older People In Health Developments* Briefing Paper 4 King's Fund Rehabilitation Programme 1999 www.kingsfund.org.uk

⊗ Clear and concise overview of 'user involvement', with general application beyond sectors title suggests. Good summary of 'Key Health Policy Developments'.

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Wilcox David *Participation Guide* Partnership Books Brighton 1994. Available online at www.partnerships.org.uk

⊗ Project supported by Joseph Rowntree Foundation. Contains description of levels of participation, framework for participation, glossary of terms, publication and organisation resource lists.

Public Involvement Techniques Report - A Summary Of Techniques North East Lincolnshire Community Health Council 2000

Developing A Strategy For Public Involvement In Health Within North Lincolnshire North West Lincolnshire Community Health Council 2000

In The Public Interest -Developing A Strategy For Public Participation In The NHS Department of Health 1998

⊗ Report of expert group from the NHS Executive NHS Confederation The Institute of Health Service Management

Public Engagement Tool Kit NHS Executive Northern and Yorkshire produced for Primary Care Groups in the Northern and Yorkshire region 1999 www.doh.gov.uk/nyro/

⊗ A comprehensive guide to why and how.

A Guide To Community Involvement Leeds Involvement Project, Leeds TUC Centre, 88 North Street, Leeds LS2 7PN

⊗ A good 18 page overview.

IDEA *Who Asked You? The Citizen's Perspective On Participation* Publications Catalogue 1999 <http://www.idea.gov.uk/>

⊗ "Explores citizen and community views about their involvement with local authorities on issues of local governance. Offering a critical assessment of the strengths and difficulties in engaging with citizens and communities, from the community perspective and based on this critique, guidance on good practice."

Patient And Public Involvement In The New NHS Department of Health 1999

Patient And Public Involvement In The New NHS -User Empowerment Conference held Feb 2000. Copies of presentations available from liz@hmc.co.uk price £50

Building Bridges Between People Who Use And People Who Provide Services The User-Centred Services Group National Institute for Social Work 1993 www.nisw.org.uk/pubs/building/bridtwo2.html

Directory Of User Consultation Exercises In Hull & The East Riding Of Yorkshire North Bank Forum 2000 email volorgs@nbforum.demon.co.uk

Approaches - General

Sykes W et al *Listening To Local Voices - A Guide To Research Methods* Nuffield Institute for Health Services Studies & Public Health Research & Resource Centre 1992

⊗ Directed at managers with little research knowledge who are involved in commissioning and managing research. Very brief summary of main issues, quantitative and qualitative method, research process.

Winn Liz Ed *Power To The People –The Key To Responsive Services In Health And Social Care* King's Fund Centre London 1990

⊗ Chapters on: Consumerism and information; Empowering older users; Consultation forums with carers; Involving people with learning difficulties in meetings; Community development: working with black and ethnic minority groups; Citizen advocacy for people with disabilities; Mental health self-advocacy; User group involvement.

www.pip.org.uk website of the *Public Involvement Programme*, run by the Institute for Public Policy Research. Aims to:

- Advise organisations wishing to involve the public in decision making.
 - Provide a clearing house for exchange of information, ideas and practical experience.
 - Develop criteria for assessing the effectiveness of different models.
 - Promote good practice and innovation.
 - Improve models of public involvement through practical experience, to ensure that they are fair and representative and to build their credibility.
- ⊗ Section on models that meet 5 criteria: innovative; informed; deliberative; independent; consult ordinary people.

Framework For Guidance On Public Consultation: Indicators Of Good Practice And Minimum Standards presented at IPPR/ local government association seminar on public consultation.

Information

Coulter A, Entwistle V & Gilbert D *Informing Patients: An Assessment Of The Quality Of Patient Information Materials* King's Fund 1998

⊗ Practical guidance on the development of information materials.

Duman & Farrel *The POPPi Guide - Practicalities Of Producing Patient Information* King's Fund 2000

⊗ From project that devised criteria for quality information. Includes 'how to develop an information policy'

Don't Panic: Making The Most Of Media Interviews Local Government Information Unit 1998
www.lgiu.gov.uk

The Centre For Health Information Quality was set up as part of the Patient Partnership Strategy. It aims to ensure that information is:

- Clearly communicated.
- Evidence based.
- Involves patients throughout production.

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PiPER (Patient information projects exchange register) is a database of information projects, with contact details.

PiPs (Producing Information for patients) is a database containing literature on developing good quality information and evaluating existing materials.

There is also an email discussion group for the exchange of information around quality information for health service users. www.hfht.org/chig

The Macmillan Directory Of Information Materials For People With Cancer was produced in collaboration with C.H.I.Q. www.chiq.org.uk/macmillan/

DISCERN online www.discern.org.uk

⊗ A tool for assessing the quality of written information. Can be used for evaluating existing information or producing new information.

www.information-society.org.uk National Inventory Project: 'aim is to provide a source of good quality information about current Information Technology (IT) and Information Society (IS) developments in central and local government and in the private sector'

⊗ Database of projects and initiatives listed by target audience, with health and local government sections.

The Plain English Campaign www.plainenglish.co.uk will edit or test information.

Surveys And Interviews

Stalker K et al *If You Don't Ask You Don't Get* Central Research Unit Scottish Executive 1999

⊗ Qualitative study of views of people with learning difficulties and their carers about health and social care services. Gives the 18 topic guides used for focus group work.

Code Of Practice - How To Effectively Involve The Public In Written Consultations Draft code (out for consultation until July 2000) from

www.cabinetoffice.gov.uk/servicefirst/2000/consult/code/content.htm

⊗ There are also plans to set up a web site register of consultation documents.

King's Fund Publications on user views and surveys

http://www.kingsfund.org.uk/ePublishing/html/publishing_main.html

Best Value and Audit Commission Performance Indicators for 2000/2001. Department of the Environment, Transport and the Regions: <http://www.local.detr.gov.uk/research/bvpi.htm>
Volume 1 *User Satisfaction Performance Indicators: Guidance On Methods Of Data Collection*

⊗ "The guidance concerns those indicators which involve user satisfaction surveys. It aims to provide an overview of the different methods that can be followed for the collection of data. As well as aiming to help authorities to meet the requirements set out in the order, the guidance offers useful tips on how the User Satisfaction surveys can be used by the authority to consult with the public on other issues which they perceive as relevant to their authority."

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The National Survey Of NHS Patients In England www.doh.gov.uk/public/nhssurvey.htm.

⊗ This is a rolling program of large scale surveys looking at patient experiences in the National Health Service. "The survey will enable local managers and health professionals to take direct account of users' views in improving services. The survey also provides data to inform the patient and user dimension of the Performance Assessment Framework."

The first survey on primary health care focused upon general practice, and was published in October 1999.

A second nationwide survey of patients treated for heart disease has been completed and will be published Summer 2000. Includes information at Trust level.

Priority Search Ltd. Sheffield Science Park, Arundel Street, Sheffield S1 2NS.

Tel 0114 2701006, email priority@syspace.co.uk

⊗ Priority Search is a process using computer software that allows analysis of responses to open questions. The questionnaire is designed using group work to identify issues of importance to the participants. Paired comparisons generated from the original consultation allow respondents to rate responses on a visual scale. Priorities from the whole population, or subgroups, can be derived from the way responses were ranked by individuals. North Derbyshire Health Authority used this method to identify women's priorities during their review of maternity services. They report that the exercise, in which 721 questionnaires were completed and analysed, produced quick results, taking less than 3 months to complete.

The Picker Institute www.picker.org

⊗ An American non-profit organisation with a European arm. Mission is to improve the quality of health care by incorporating the patient's perspective into all decisions concerning the design and delivery of health care services. Specialises in measuring patients' experiences of health care. Works with patients to develop surveys that ask people what happened to them rather than for satisfaction ratings. Eight 'dimensions of care' important to patients found through American and European work.

Monthly Bulletin.

For recent work with Lothian University Hospitals Trust see *Health Service Journal* 11 May 2000 p24-26

Panels

Barnes M & Bennett Emslie G '*If They Would Listen...*' - *An Evaluation Of The Fife User Panels* Age Concern Scotland 1997

Citizens' Panels; A New Approach To Community Consultation Local Government information Unit 1997 www.lgiu.gov.uk

Involving The Public/Communities

Burns D & Taylor M *Auditing Community Participation: An Assessment Handbook* The Policy Press for JRF 2000

Harris J et al *Developing A Whole Community Approach To Teenage Sexual Health: Participatory Appraisal In Hull* East Riding Health Authority & University of Hull 1997

Pratt J et al *Working Whole Systems* King's Fund 1999

Participation Works!- 21 Techniques Of Community Participation For The 21st Century New Economics Foundation (undated) www.neweconomics.org

⊗ Short items written by practitioners of the technique, including description, case study, resources needed and contacts/publications/training details. Includes 'Future Search', 'Guided Visualisation', 'Planning for Real', 'Participatory Theatre'.

Listen Up! - Effective Community Consultation, Audit Commission 2000, www.audit-commission.gov.uk

Involving The Public Local Government Management Board 1998. See Improvement and Development Agency publications <http://www.idea.gov.uk>

⊗ "A practical guide answering questions such as "What form of consultation should I choose?"; "How do I do it?"; "How much does it cost?"; "Who else has done it?". Describes community profiling, future visioning, surveys, area panels, user forums, citizens' panels, citizens' juries, consensus techniques and other approaches."

Involving Communities In Urban And Rural Regeneration- A Guide For Practitioners Department of the Environment 1995

⊗ A comprehensive 'why and how' manual including techniques and practice examples. Sections on defining communities, building partnerships, community involvement in design and management of projects, capacity building, techniques for community involvement.

Developing Effective Community Involvement Strategies - Guidance For Single Regeneration Budget Bids JRF March Findings 1999 no.169

⊗ Getting started; involving communities in partnerships; creating strong local organisations with their own assets; developing an infrastructure to build and sustain community organisations; monitoring progress. Contains 'good practice' examples and lists contacts.

Community Consultation: Spotlight on Best Value Series Local Government Information Unit www.lgiu.gov.uk

Hull & East Yorkshire Participatory Appraisal Network pranet@tinyonline.co.uk

The Centre for Social Action, Department of Social and Community Studies, De Montfort University, Scraptoft, Leicester LE7 9SU. Tel. 0116 2577777

⊗ 'A theory of community development based on the premise that change can happen, but will only work if the people concerned own it and are involved in the changes they want.' Facilitated groups following a 'what, why, how, action, reflection' process.

Citizens Involvement Support Centre, M.E.L Research Ltd www.m-e-l.co.uk

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Plain Talk www.aecf.org/publications/plaintalk/whatis.htm

⊗..An American community based 4 year long initiative aimed at reducing sexual health risks for young people. Strategies appropriate to individual communities developed through community mapping, creating a residents' network, peer-led education and skills development, community activities to disseminate key messages, developing sustained involvement and leadership.

www.cabinet.office.gov.uk/servicefirst/

⊗ This website contains a Best Practice section.

Community Self-help Policy Action Team Report 9: Social Exclusion Unit

www.homeoffice.gov.uk/vcu/selfhelp.htm

⊗ Remit to look at barriers to community activity in poor neighbourhoods and devise action plan to improve 7 principles for community empowerment. Recommendations include community resource fund for small and emerging groups.

Advocacy

Atkinson D *Advocacy – A Review* Research into Practice Series, Joseph Rowntree Foundation Pavillion Brighton 1999

⊗ Atkinson carried out a review of the literature, visited advocacy projects, and consulted key people and organisations to look at what advocacy is and what makes it work.

Bateman N *Advocacy Skills For Health And Social Care Professionals* Jessica Kingsley 2000 www.jkp.com

Booth W & Booth T *Advocacy For Parents With Learning Difficulties: Developing Advocacy Support* Joseph Rowntree Research into Practice series, Pavillion Brighton 1998

⊗ Report and evaluation of 18 month Parents Together project. Describes experience of advocacy support, strengths and limitations of advocacy as an approach, lessons for practice learned. Good section on the many and various roles advocates take on.

Advocacy For Older People: The Northern Ireland Experience Central Council for Education & Training in Social Work 2000

Forthcoming

Central Research Unit *Listening to Communities: Evaluation Of New Ways Of Testing Community Opinion* www.scotland.gov.uk/cru/

User Engagement Project Community Care Development Centre, King's College

⊗ DoH funding for 3 year project. The first stage aims to find and disseminate examples of good practice in engaging with service users with learning disabilities. A database and website are being developed. What it is that makes initiatives successful will be analysed. From 2001 materials will be produced for service managers to help them put research findings into practice.

Designing And Using Patient And Staff Questionnaires: A Review Of Best Practice NHS R&D Health Technology Assessment Programme

Projects also underway on:

- Action Research: standards for judging its appropriateness.
- The measurement of patient satisfaction.
- What is the value of public participation in priority setting?
- Involving consumers in agenda setting for R&D for the NHS.

See www.ncchta.org

User Involvement In Research, Monitoring And Evaluation

Research, monitoring and evaluation use similar skills and approaches, but there are distinctions between them.

Definitions

Research - an inquiry that seeks to reveal or extend knowledge through the systematic collection of information. While research in the natural sciences sets out to test a theory, social research aims to describe, interpret and better understand social processes, events or settings.

Monitoring - the root of the word is to remind or give warning. Monitoring compares what is actually happening to an agreed standard of best practice. Monitoring needs to be ongoing to ensure that services reach and continue to meet that standard. The element of scrutiny/accountability means that a service cannot monitor itself.

Evaluation - collecting information that allows an assessment of how well a programme, service or organisation does what it has set out to do, in terms of effectiveness, efficiency and social acceptability¹. For example, in meeting the needs of service users, as they themselves define them.

'Research' has been used in this section as the term to cover each form of inquiry.

Mental health and learning difficulty service users have led the way in actively participating in research and service monitoring and evaluation. Others can do so too, provided that they are:

- Adequately trained (being a service user doesn't make you a good interviewer; such skills are learned and practised).
- Supported (including access to advice on research method, debriefing after interviews, admin support).
- Paid for their work and expertise.

'User-led' does not mean amateur!

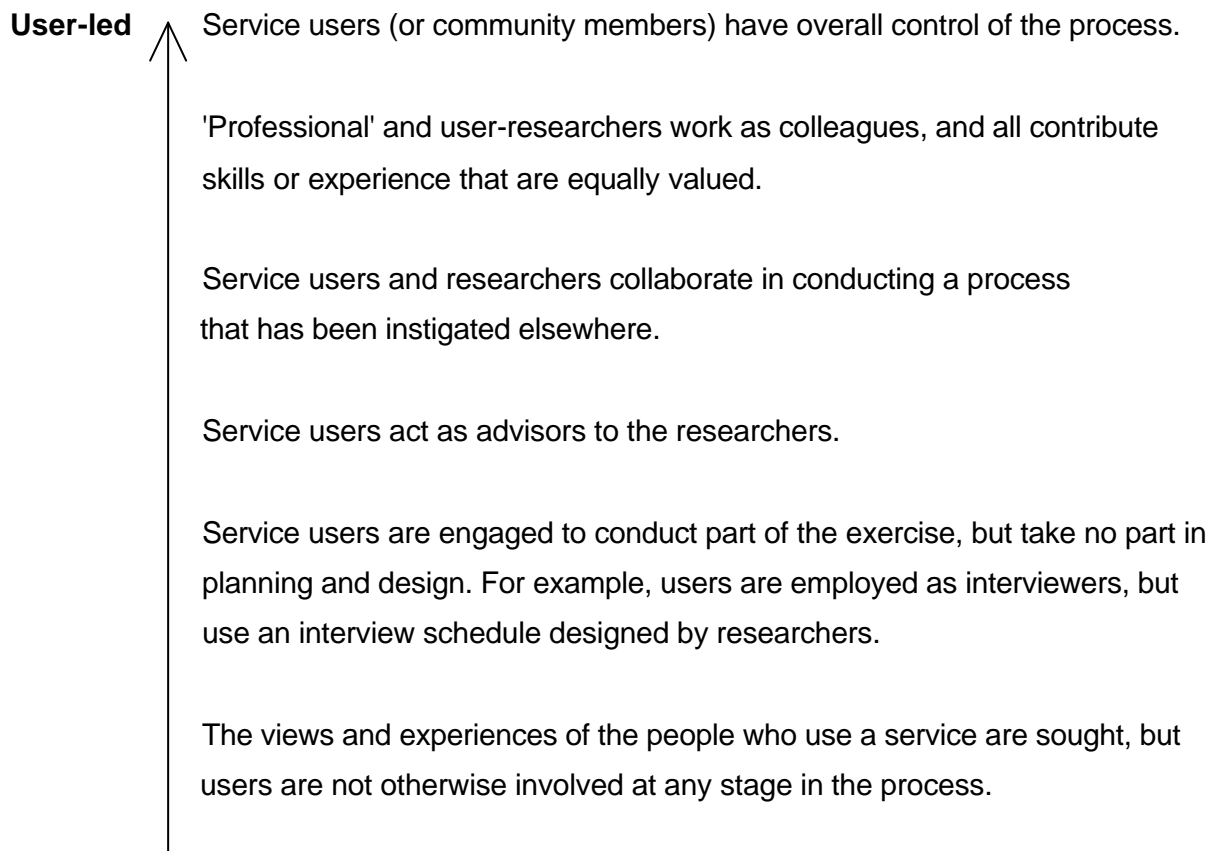
Why Should Such Exercises Be User-Led?

“The path along which research progresses depends partly upon who decides what matters are examined, and how”²

- To ensure that they are relevant in that they include the concerns and interests of service users.
- To help avoid professional/researcher bias by including many perspectives.
- To aid understanding and interpretation.
- To identify gaps in inquiry.
- To increase accountability to the people who use services.

A Ladder For Levels Of User Involvement In Research, Monitoring And Evaluation³

(See: ‘Arnstein's Ladder Of Participation’ – p 17)



Ways In Which Service Users Can Be Involved In Research⁴

- Identifying topics for inquiry.
- Prioritising topics for inquiry.
- Commissioning research.
- Designing research.
- Managing research.
- Undertaking research.
- Analysing and interpreting information obtained.
- Writing up reports.
- Disseminating results.
- Evaluating the process.

Recommendations To Increase User Involvement In Research⁵

- Resources should be made available to help user groups to initiate and carry out research.
- Funding for projects needs to take into account costs of involving service users in the process.
- Sufficient resources need to be allowed to include the views of under-represented groups (ethnic minority groups, or people who do not communicate conventionally, for example).
- All research which concerns service users should be disseminated in accessible ways.

Research Ethics (Standards Of Conduct)

Key issues are:

- Respect for, and guarding of, the rights and wellbeing of participants.
- Obtaining informed consent - not just giving information, but ensuring that it is understood.
- The appropriate use and protection of data.
(see www.dataprotection.gov.uk for details of the Data Protection Act 1998)
- Access to information about the research and its findings.
- The benefit from the work to service users.

Research that repeats work that has already been done, or does not contribute to existing knowledge in a way that is of benefit to service users, is never ethical.

It is good practice to seek advice on the ethics of your research. Other agencies can ask NHS Ethics Committees for advice.

In 2000 the Department of Health will be publishing 'A Research Governance Framework for Health and Social Care', setting out the standards to which all such research must be conducted. Standards relating to ethics, science, information, health and safety, and finance have been consulted on www.doh.gov.uk/research/index.htm.

Standards in the Draft Framework include:

- All research which involves patients, users or carers, their material or data is referred to independent ethical review to safeguard the dignity, rights, safety and wellbeing of the participants.
- Research is pursued with the active involvement of service users and carers, including, where appropriate, those from groups such as black and ethnic communities.

Participatory Research

*"Research is part of the process of people being involved, gaining their own information, developing their own agendas, taking part in decision making and changing the structures they work in."*⁶

Traditionally, research has been carried out by 'expert' researchers on passive research subjects. The researcher and their sponsors determine the research question, the methods by which information will be gathered, interpret the results, and make recommendations based upon that analysis. Since research cannot be value-free this gives them considerable power. Research subjects who cannot control the interpretation and uses of the information they provide can feel exploited and abused.⁷

Participatory research changes the power balance. 'Research subjects' become co-inquirers, taking part in defining priorities for research, formulating the research question, devising approaches to collecting information, gathering information and interpreting it. The professional researcher becomes a facilitator and consultant rather than director of the process. As with any research, the validity of the findings rests upon the assumptions made and approaches used being made explicit, so that the reader can decide whether the conclusions can be justified from the data.

This approach has a number of consequences:

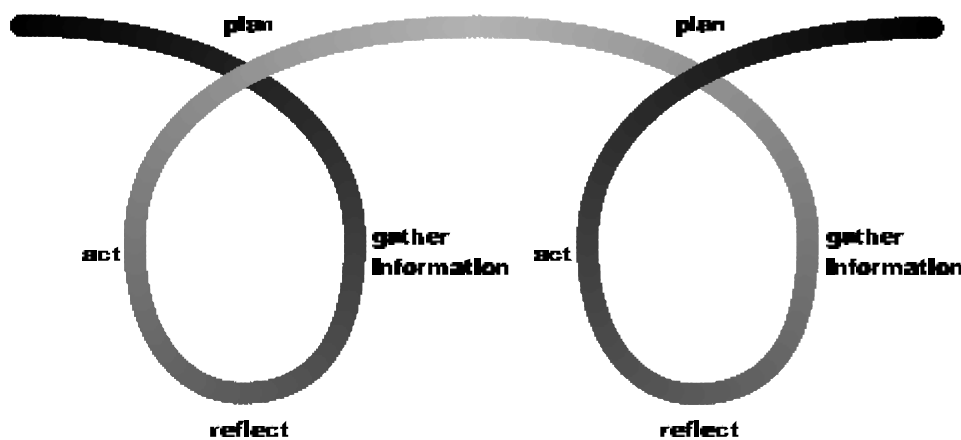
- The agenda for research and research question will be subject to negotiation, and may not follow the precise path envisaged.
- The pace at which the research proceeds will be dictated by participants.
- There may be a number of interpretations of findings. But if it is accepted that there is no single 'truth' then the resulting broad picture of meanings will be more consistent with the real life situation.
- Research partners may need supporters, people who will react, not initiate.
- User-researchers will need to be trained and paid for their work.
- There will be an expectation that findings will lead to action.

Action Research

Describes a dynamic approach where the understanding acquired is used to inform future action. Such an approach is appropriate when examining health and social care services because its aims are:

- Change to make improvements.
- Development of policy, of a service, of professional practice, of the individuals involved.
- Involvement of the subjects of the inquiry (service users and service providers) in the research process and in developing solutions to problems identified.

For example, the inquiry might identify areas where services are not performing optimally, gaps in services, or needs that are not being met. Participants in the process plan change and then evaluate its effect. The process continues over time, and is usually represented as a spiral:



These are the steps:

1. Group meets to decide focus for inquiry and how to gather information.
2. Information gathered.
3. Group analyse data and reconsider original focus in view of findings.
4. Group collect further information to test initial findings and to meet adjustments to focus.
5. Further analysis and reflection.
6. Plan for change.
7. Implement change.
8. Repeat process to evaluate change and establish new focus.

Advisory Groups

A group of actual or potential service users to advise a project can:

- Examine and challenge assumptions⁸.
- Keep the priorities and concerns of the group to the forefront.
- Take part in preparing information about the project so that those who participate do so with informed consent.
- Suggest questions for interview schedules and questionnaires.
- Advise on interpretation of findings.
- Present findings verbally.
- Prepare an accessible summary.
- Ensure dissemination of findings.

The research may be improved in this way, but control remains with the researchers. It is a good starting point for gaining experience, however.

In two research exercises conducted by mental health service users⁹ it was found that:

- User-researchers were able to undertake and complete research projects when adequately trained, and supported by a trusted person.
- Users were able to acquire necessary skills within a realistic time scale.
- Research was 'de-mystified' for the users involved.
- Time-scales need to allow for periods of personal difficulty (although user-researchers experienced periods of considerable mental distress during one project, research proceeded successfully).

Examples Of Research Involving People Who Use Services

The Impact Project

This is a local action research project to look at the impact of service user involvement on decision-making at clinical and policy level within mental health services. The topic was identified and prioritised by service users, who are working on the study in partnership with managers, clinicians and researchers. The team have received training in action research method.

The aims are to:

- Develop a transferable, flexible model for the evaluation of user involvement in decision-making.
- Measure current impact on decision making, as a baseline.
- Develop an action plan to obtain improvements in user influence on decision making.

Hull & East Riding Community Health Trust, The RED Unit, Bridlington Hospital, YO16 4QP.
Tel. 01262 607144.

Wiltshire Social Services funded the Wiltshire and Swindon Users Network to research users' views of the local Independent Living Fund (enabling people to purchase social care directly). A group of users obtained training, including ways of analysing qualitative information, to enable them to design, conduct and write up and disseminate the research.¹⁰

The Mental Health Foundation facilitated user involvement in research into people's strategies for living with mental distress.¹¹

The National Centre for Social Research were appointed as consultants to the study to ensure that standards of quality that would make the research widely acceptable were met, and to provide training and supervision for user-researchers:

- A user - researcher visited user groups to consult them and take advice on the relevance of the research.
- An advisory committee of representatives from mental health user groups was set up to oversee the research.
- Interviewers with experience of mental distress were appointed.

Monitoring & Standard Setting

Monitoring

The root of the word is to remind or give warning. Monitoring compares what is actually happening to an agreed standard of best practice. Monitoring needs to be ongoing to ensure that services reach and continue to meet that standard. The element of scrutiny/accountability means that a service cannot monitor itself.

A Prerequisite For Monitoring - Standard Setting

Monitoring and evaluating services and measuring performance depend on first defining criteria against which 'success' could be judged, or setting standards. Standards should be evidence-based where evidence of effectiveness is available, but they are also rooted in values.

In the past standards often reflected how well the agency performed, not how well services met the needs of service users. It is now widely recognised that standards should reflect the effect services have on the quality of life of the people who use them. You should involve service users and potential users in setting standards for services, or defining what a quality service looks like.

The most appropriate way of doing this is to use approaches that allow people to envisage their ideal situation, and what services to support such a situation would look like. Group work has advantages:

- Interaction allows ideas to be shared, clarified and refined.
- Themes, topics and principles that emerge can be 'tested' on other groups, and priorities identified.
- A consensus on what standards should include can be developed.
- Standards agreed are owned by service users themselves.
- Standards can be stated in a clear and user-friendly way that is free of organisational jargon.

Standards will change over time, so they need to be revisited regularly.

An Example Of User-Led Monitoring

Monitoring our services ourselves^{12,13}

Standards developed by mental health service users were produced and circulated as the East Yorkshire Charter. People who were involved in developing the charter formed a Monitoring Team to make sure that standards remained 'live'. They received training from the Health Trust, were paid for their work, and received support from the full-time project worker employed by the Trust to promote involvement of mental health service users. The monitoring exercise was incorporated into the purchasers' own schedule so that work was not duplicated, and the validity of the monitoring recognised. The team decided to implement a rolling programme, monitoring one of the four localities within the Trust each year. Team members developed the questions they wished to ask, offering a choice of approach – questionnaire, one-to-one interview or group discussion. Piloting the questions with a user group identified the need to define terms to ensure a common understanding. The team provided information to staff and service users prior to the monitoring exercise.

Answers to closed questions and free comments were included in a report to service managers and purchasers. The Team ensured that there were mechanisms to:

- Respond to the issues raised.
- Feedback to service users, particularly those who had contributed.
- Share positive comments with staff.

The first exercise led to an action plan for service improvement. The team produced a practical guide for others drawing on their experience (see references below).

“...the Team feel they have made a significant impact demonstrating that people using services can provide valuable and qualitative feedback which workers may find it impossible to discover themselves.”

Evaluation & Outcomes

An evaluation gives you a picture of how a policy, service or organisation is meeting its aims from a range of viewpoints. Views of staff, service managers, commissioners and other stakeholders are included, and weight is given to how people who use the service perceive it.

Evaluation is not an end in itself, but provides a baseline from which to implement and evaluate change. There are advantages to using people with experience of using the service to obtain the views of other service users, as well as taking part in planning and managing the process. (See: 'Peer Interviewing' – p 76)

Evaluation

Collecting information that allows an assessment of how well a programme, service or organisation does what it has set out to do, in terms of effectiveness, efficiency and social acceptability.¹ For example, in meeting the needs of service users, as they themselves define them.

A Prerequisite For Evaluation - Outcomes

Outcomes are "the impact, effect or consequence of a service or policy"¹⁴

*"Evaluations should focus on user definitions of needs and outcomes, and how effectively services enable users to achieve their aspirations. Outcome measures must reflect the users' perceptions of quality of life, rather than 'improvements' in objective criteria defined by service providers or funders."*¹⁵

Effectiveness of a service has often been evaluated in terms of things that could be objectively measured - the number of people receiving a service, for example, rather than how well service users' needs are met. But subjective or value-based assessment is also crucial when assessing the efficiency, effectiveness and appropriateness of services.

(continued)

When users judge the success of health or social care services, *how* a service is delivered (in a way that respects the person as an individual, for example), is as important as the *effect* of that service. Thus there are a number of considerations when evaluating a service, ranging from the aims of a service or intervention, to the impact of the service or intervention on the quality of life of the person receiving it, as illustrated below.

Overall Aim	Service Input -what is done	Service Output -(quantitative measurements)	Outcome From Process -the way services are delivered (qualitative measurement)	Outcome For Service User -end result for service user as they perceive it
For Mr Smith to continue to live at home (supporting everyday functioning)	<i>e.g.</i> -Information/advice -Aids/adaptations -Care management -Home care	<i>e.g.</i> -X Aids provided -Y hours Home care provided -Mr Smith able to prepare simple meals	Balance of independence and support achieved	'I feel confident and safe to remain at home'

Derived from ^{15,16}

Outcomes For Social Care, (OSCA)

In 1997 the Department of Health commissioned a major new research initiative on outcomes of social care for adults. The purpose of the initiative is to deliver research evidence which can inform the planning, commissioning and delivery of services which are:

- Valued by users and carers.
- Cost effective.
- Promote better outcomes for service users and carers.

The research programme consists of 13 studies, organised around different community care client groups, although the majority focus on services for older people. The key aims are to:

- Develop practical tools and systems for collecting information based on user defined outcomes.
- Evaluate the effectiveness of social care services from a user perspective.
- Develop an evidence base of systematic reviews of 'what works' similar to those developed in health services.
- Consider the costs and benefits of different social care interventions from a user perspective.

(continued)

Many of these studies are now approaching completion and the Department of Health plans to publish an overview of their methods and findings in December 2001. In the meantime, further information about the research programme including details on how some of the tools which have been developed can be obtained. (See: 'Other Resources' – p 126)

An Example Of A User-Led Evaluation

A user-run information and support organisation asked Anglia Polytechnic University to evaluate its activities.⁸ The university suggested that the organisation carried out the evaluation themselves, gaining skills for the future. Funding was obtained to appoint a research advisor and pay the user-researchers for 10 months work. Members of the group took part in appointing the research advisor. The group formed a research committee to work on the project. They:

- Identified what they wanted to evaluate.
- Decided on a method.
- Designed and piloted a questionnaire schedule.
- Used the schedule to obtain the views of half the members of the organisation, as well as past and potential members and professionals in contact with the organisation.
- Presented the findings to the organisation's management committee.
- Wrote up a summary report.

(See: 'Some Research Findings' for 'Engaging More Effectively With Disabled People' – p 173)

Involving Users In Staff Selection And Training

Service Users As Trainers And Consultants

Service users have experience of services and expertise on their own situation. All service users who, for example, sit on committees, take part in writing service specifications or in inspection and monitoring, are therefore consultants, and should be treated and paid as such. Serious involvement in any case means drawing up an agreement so that everyone is clear about their role and what is expected of them.

There is evidence that involving service users in staff training improves the way people experience services. Service users can offer disability awareness and deaf awareness training, for example, as well as taking part in developing programmes for staff induction, training and development.

A number of groups and individuals with direct experience of services are providing a professional service to participate in training, as well as offering training to other users. For example, the United Kingdom Advocacy Network in the mental health field.

Bringing in a token, unsupported service user to a training session is not ideal, although practitioners do value hearing first-hand experience. One health service manager described listening to an audiotape of patients' experiences as being "slapped around the face for half-an-hour with the truth".¹⁷

Involvement In Staff Selection

Again, most experience to date comes from the fields of mental health and learning difficulties. Few areas to date involve service users throughout the process, from drawing up the job description and post advertisement to equal weighting of interview scores. Many only involve service users in a preliminary informal interview or meeting and take their views into account in the formal process. While service users may take part in selecting basic grade care staff few are involved in managerial appointments!

Research into user involvement in staff recruitment in the field of learning disability found that:¹⁸

- Concern amongst service providers that people with learning difficulties would not understand confidentiality or equal opportunities practice were unfounded when adequate training, *practice* and support were given.
- Factors found to promote effective involvement in the recruitment process were commitment of staff, trade unions and personnel departments, and involving people from the beginning of the process.
- Those involved in the recruitment process believed that involving service users meant that more suitable candidates were appointed. For example, information about attitudes to working with people with learning difficulties could be gained.

The Community Health Trust in East Yorkshire involve mental health service users in appointing mental health nursing staff, and have produced guidelines for interviewers and notes for candidates to explain the role of the user - interviewer.

User- interviewers receive the same training as Trust staff. They sign a contract that commits them to confidentiality and working within Trust policies, and are paid expenses.

They are involved on an equal basis with Trust staff in planning the interview and scoring the candidates' responses to pre-determined questions.

Service Users can also be involved in selecting service providers given similar training and support.

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3. From Professor Gordon Grant, speaking January 2000
4. *Involving Consumers In Research And Development In The NHS: Briefing Notes For Researchers* Consumers in NHS Research Support Unit 2000
⊗ Includes checklist on budgeting for involvement and draft job description for people involved.
5. Lindow V & Morris J *Service User Involvement - Synthesis Of Findings And Experience In The Field Of Community Care* Joseph Rowntree Foundation 1995
6. Beresford P *Researching Citizen-Involvement: A Collaborative Or Colonising Enterprise?* 1992, in Barnes M and Wistow G (Eds) *Researching User Involvement* Nuffield Institute for Health, University of Leeds p23
7. Beresford P 1992 as above
8. Tozer R & Thornton P *A Meeting Of Minds: Older People As Research Advisors* Social Policy Research Unit, University of York 1995
⊗ Evaluation of a group set up to advise a research project.
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10. *Strategies For Living: A Report Of User-Led Research Into People's Strategies For Living With Mental Distress* Mental Health Foundation 2000
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13. Nocon A & Qureshi H *Outcomes Of Community Care For Users And Carers* Open University Press Buckingham 1996
14. Tozer R & Thornton P *A Meeting Of Minds Older People As Research Advisors* Social Policy Research Unit University of York 1995
15. Bamford C et al *Overview: Outcomes Of Social Care For Younger Disabled People And Their Carers* Social Policy Research Unit University of York
16. Qureshi H et al *Overview: Outcomes Of Social Care For Older People And Carers* Social Policy Research Unit University of York 1998
17. Moore 1995, quoted in Barnes & Warren (Eds) *Paths To Empowerment* The Policy Press Bristol 1999 p 135
18. Townsley R & Macadam M *Involving People With Learning Difficulties In Staff Recruitment* Social Care Research 91 Joseph Rowntree Findings Series 1996
www.jrf.org.uk

Other Resources

Research, Monitoring And Evaluation

Barnes M & Warren L (Eds) *Paths to Empowerment* The Policy Press Bristol 1999

Finch J & Orrell M 'Involving Users And Carers In Developing Standards For Mental Health Services For Older People' *Managing Community Care* December 1999 vol 7 no. 6

Kirby K *Involving Young Researchers: How To Enable Young People To Design And Conduct Research* Joseph Rowntree Foundation 1999

Raynes N 'Involving residents in quality specification' *Ageing and Society* January 1998 vol 18 part 1

Rose D et al *In Our Experience: User Focused Monitoring Of Mental Health Services* Sainsbury Centre for Mental Health 1998

Townsley R & Gyde K *Plain Facts: Information About Research For People With Learning Difficulties*

⊗ In 1996 the Plain Facts magazine for adults with learning difficulties was launched and distributed free to user-led groups across the UK. This report includes copies of the first 8 issues of Plain Facts and a concise guide to writing Plain Facts.

Turner M *Shaping Our Lives Project Report* NISW 1998

⊗ Research with service users and user groups on their views on outcomes and service quality and the ways in which they were seeking to define the outcomes they wanted for themselves.

Ward L *Seen And Heard: Involving Disabled Children And Young People In Research And Development Projects* York Publishing

Our Voice In Our Future: part of the Shaping Our Lives Project. Users produced three booklets:

- Services and support
- Benefits
- Mental health services

to give background information and encourage users to discuss and put forward their views. Free to service users

The Outcomes We Want. Statement on User Defined Outcomes - Shaping Our Lives National User Group www.nisw.org

A DIY Guide To Survivor-Led Research Mental Health Foundation 1999

⊗ Experience from 6 user-led research projects.

Rhetoric Into Reality Homeless Campaign, Help the Aged 1999

⊗ Through three pilot projects working with older homeless people, Help the Aged defined an action research process to be used in projects funded by the organisation.

Involving Older People In Planning And Evaluating Community Care: A Review Of Initiatives Social Policy Research Unit, University of York 1994

⊗ Describes voluntary sector, Community Health Council, and community group initiatives, some run jointly with the statutory sector.

(continued)

Research Policy And Planning Social Services Research Group_1994 vol 12 no 2
⊗ Special issue on researching service user views and working with particular client groups.

The Forum For Collaboration With Users In Research (Folk.Us) University of Exeter
www.exeter.ac.uk

Mental Health Foundation web site www.mentalhealth.org.uk/rsnurl1htm
⊗ Has an index of user-led research texts and user-led research update.

Consumers in NHS Research Support Unit, Help for Health Trust: quarterly Newsletter.
Publications downloadable from www.hfht.org/ConsumersinNHSResearch/pub.htm

- *Research: What's in it for Consumers?* (NHS Executive 1998)
- *Involving Consumers In Research & Development In The NHS: Briefing Notes For Researchers*
- *Involving consumers in commissioning health research*

Outcomes of Social Care for Adults (OSCA) programme

⊗ Department of Health funded research co-ordinated by Gerald Wistow at the Nuffield Institute for Health University of Leeds. "The purpose of this initiative is to deliver research evidence which can inform the planning, commissioning and delivery of services which are valued and cost effective, and which promote better outcomes for users and carers".

The Quest System

⊗ A system to enable the evaluation of services for people who need long-term support that can be used by service users themselves. Developed and tested by the Quest Team based at the University of Hull. There is a version to assist people who find it difficult to read and to speak. The East Yorkshire Learning Disability Institute, University of Hull, HU6 7RX

Participatory Inquiry And Action In Social Practice

www.cam.ac.uk/sphs/piasp/index.html

⊗ "Action research network for practitioners, service-users, carers, managers and researchers involved in improving services in social care and work, community work, health and education."

Consumer Involvement in the Health Technology Assessment Programme

www.hta.nhsweb.nhs.uk/consumer.htm

Social Policy Research Unit Outcomes Programme - research findings summarised in monthly Research Works www.york.ac.uk/inst/spru/pubs/research_works.htm

Social Services Research Group site <http://www.ssrq.demon.co.uk/>. Beginning to post public consultation surveys carried out by local authorities.

British Sociological Association www.britisoc.org.uk

⊗ Good Statement of Ethical Practice as well as 'How is Sociological Research Conducted?' and guidelines on non - disablist and anti - sexist language.

Social Research Association Ethical guidelines www.the-sra.org.uk/index2.htm

Department of Health Research & Development www.doh.gov.uk/research/index.htm

⊗ Includes Research Findings Register.

Staff Selection And Training

Lindow V *User Involvement: Community Service Users As Consultants And Trainers*
Department of Health NHS Executive Community Care Branch 1996

Townsley Howarth Le Grys & Macadam *Getting Involved In Choosing Staff* Pavillion in
association with The Norah Fry Research Centre & JRF

⊗ Pack designed to guide people with learning difficulties through the process for appointing
staff.

Community Service Users As Consultants And Trainers Department of Health 1996

Available in large print, Braille and on tape.

⊗ Produced by the National User Involvement Project as a resource for service users.

Includes information on acting as a consultant and running training events.

There is a National Institute of Adult Continuing Education training pack for learning disabled
people to become trainers, accredited by the Open College Network.

Payment Of People Involved In Shaping Health And Social Care Services

You will need to develop guidelines for payment of the people you involve in shaping health and social care services.

People should be paid for their time and expertise. However, many people who use health and social care services will be on benefits, and it is difficult to make payments to them without their falling foul of Benefit Agency and Employment Agency rules.

The consequences for them can be severe, so you should make sure that they are aware of their position.

There can also be consequences for an organisation deemed to have entered into a contract of employment by making payments. The voluntary sector is well aware of the position and could share its experience with statutory agencies.

Participation was often seen as a voluntary contribution that would be changed in character or 'professionalised' if a financial element was introduced. It is now accepted that people should not be put at financial disadvantage, and payment of travel expenses and carer costs are good practice. Many people can only become involved if you actually provide transport, childcare and respite care.

- Vouchers for small sums are sometimes given in recognition of the cost of completing surveys or interviews, and may help to engage some 'harder to reach' groups.
- A payment to club funds or a charity may be more appropriate than individual payments where groups are involved. It demonstrates worth while acknowledging altruism.
- Some forms of involvement do require a high degree of commitment, time and emotional cost, and need to be recompensed, for example, service users providing staff training. Community Health Sheffield's strategy recognises that users acting as consultants should be paid as such.
- Many lay members on committees sit alongside paid non-executive members. What message does this give about the value of their contribution? Good practice guidelines drawn from the Association of Directors of Social Services Survey suggest that co-opted members of panels and committees should receive the same payment or allowances as other members.¹

Definition Of Unpaid Work

Work done voluntarily for which there is no payment in cash or kind. Only expenses *actually incurred* can be paid.

Many people cannot afford to pay fares, babysitters etc up front and wait to reclaim the money, so they need to be paid in advance, or at least immediately and in cash, if they are to participate.

For use of a car the Inland Revenue set expenses per mile, depending on engine size and mileage, that are not liable to tax.

The law about what constitutes a contract between an organisation and people doing unpaid work, and what payments are allowable, is at present unclear.

The Position Of People Dependent On Benefits

Being paid, and giving their time, can present difficulties for people who are dependent on benefits. People who make a regular or time-consuming contribution (such as peer support, attending meetings, sitting on committees or taking part in staff training) are most likely to be affected.

An outline of the position is given here, but benefit rules are complex, and the Benefits Agency uses discretion in the way that they are applied. Service users should always be made aware of their position, and advised to inform the Benefits Agency. They should seek specialist advice from welfare rights services or the Citizens Advice Bureau if their benefit claim could be jeopardised.

Payments

Payments made to people on means-tested benefits to cover expenses are not regarded as income.

“Your Income Support will not be affected as long as you do not receive any pay other than to pay for expenses like fares or special clothing you need for the voluntary work.” DSS

However, you must take care if paying a flat or daily rate of expenses, as the Benefits Agency has the discretion to decide what is ‘reasonable’, and whether this could be classed as paid work.

The situation regarding payments in kind is contradictory. Guidance states that they are ignored for benefit purposes, but also that they *may* be regarded as income.

“You must also tell us if you are paid in any way. This includes things that are sometimes called payment in kind. This could be something like meal vouchers.” DSS

Regular sessional fees, a flat rate payment to cover expenses and subsistence, or honoraria, could be regarded as payment for work, and such payments would be taxable.

Participants receiving means tested benefits can do paid work for up to 16 hours a week. They are required to declare earnings, and after a small 'earnings disregard', benefit is reduced pound for pound. Currently (October 2000) those on Income Support or income based Job Seekers Allowance are allowed to keep £5 of any earnings. (Although couples are counted as a ‘claimant unit’, their disregard is £5 each). Lone parents, and those receiving a disability, severe disability, carers or higher pensioner premium as part of their Income Support can keep £15 of any earnings before they lose benefit.

People working for more than 16 hours a week have to 'sign off' while they are earning. If there is a break in claim of more than 12 weeks they will not be paid for the first three days of a new claim, and may have to restart the qualifying period for mortgage payments. Those working less than 16 hours can continue to 'sign on' for national insurance credits even if no benefit is payable.

People who have received sickness benefits for more than 6 months who find themselves unable to continue in a new job within a 52 week period, can return to their previous benefit without penalty.

Notional Payments

If a claimant is deemed to be providing a service, free or at less than the local going rate, then they could be regarded as having 'notional earnings' and their benefit reduced accordingly, even though they are not actually paid.

"If it is unreasonable [for an organisation] not to pay you, we will reduce your Income Support by an amount you could expect to be paid for the work you are doing, even though you are not being paid." DSS

This rule could be applied if an organisation normally employs someone to do the same kind of tasks the service user does. However, the Employment Service may accept that it is reasonable for someone to provide a service free of charge if they are gaining a non-monetary benefit, such as improving their confidence and self-esteem, or gaining skills that will improve their job prospects.

Giving Time

People signing on as unemployed must be available to work 40 hours a week, except in the following circumstances:

- Fewer hours are reasonable because of the individual's mental or physical health.
- People with caring responsibilities must be available for at least 16 hours.
- Restricting the number of hours available doesn't reduce prospects of employment.

People who have declared that they are doing unpaid work are considered to be available for work as long as they can be available at 48 hours notice. However, people with extensive unpaid commitments *could* be considered as not having sufficient time to be 'actively seeking employment'.

Incapacity Benefit And Severe Disablement Allowance

These benefits are paid to people who are deemed to be incapable of work because of sickness or disability. People on Incapacity Benefit must be extremely careful not to invalidate their claim when taking on any work. Voluntary work (defined by the Department of Social Security as “work other than for a close relative for which a person only receives reasonable expenses”) is exempt, as is some work, **if it is undertaken on the advice of a doctor to:**

- Improve, or to prevent or delay deterioration in, the disease or bodily or mental disablement (this is called ‘therapeutic work’).
- Form part of a treatment programme under medical supervision whilst the claimant is a hospital in-patient or out-patient.
- Or, is done while attending a centre that provides sheltered work.

There is an earnings limit, currently £58.80 a week, and work must not exceed 16 hours a week “on average” (DSS).

To avoid problems, claimants should always obtain a letter from their doctor stating that the doctor suggests or advises therapeutic work, and gain Benefits Agency approval **before** undertaking any activity that might be perceived as paid or unpaid work.

Many health and social care service users will be dependent on benefits. Distressing problems with benefits can be avoided by providing a clear statement for the Benefits Agency, as part of a ‘contract’ with the service user. This should state:

- That it is recognised that the individual is available for work, and could be available at short notice.
- That there is a contact number where the Employment Service can leave a message while the individual is engaged in ‘user involvement’ activities.
- The type of payment being made.
- The non-financial benefits of the activity, for example, gaining skills, getting a reference.

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Information from the DSS www.dss.gov.uk & Citizens Advice Bureau www.nacab.org.uk

Engaging With The People Who Use Health And Social Care Services – Experience And Best Practice

Introduction – Engaging With People

“It is often the most isolated and the least identifiable of users – the ones who are never heard - who have the sorts of experience which can be most valuable.”¹

This section looks at lessons from the literature, practical experience of working successfully with particular groups of people who use health and social care services, and the ways that best enable them to participate in shaping services.

“There is a tendency for professionals to divide the world up in ways that reflect the organisations in which they work”.²

'Client groups' are made up of people who may have nothing in common except the labels professionals use for them. People don't define themselves by the categories we put them into, they are individuals with their own needs and expectations. For example, in providing services for 'older people' you are trying to include at least two generations.

Some ways of involving people become associated with a particular client group. There is a danger that their wider application is overlooked. For example, ways of working with people who do not communicate through speech could be shared across learning disability, physical disability, sensory impairment, mental health and dementia service areas.

There are ways of engaging with people that are better or worse suited to particular individuals and their particular circumstances, but the same broad principles of good practice apply to all.

Successful involvement depends upon using a range of approaches so that individuals with different needs and preferences can be included.

¹ Averil Osborn Age Concern Scotland

² Simons K 1999 *A Place at the Table? Involving people with learning difficulties in purchasing and commissioning services* British Institute of Learning Disabilities Kidderminster

Engaging With Older People

“Older users wish to contribute a wide range of experiences and insights. The challenge is to put them to the fullest possible use, not to restrict older people’s contributions.”¹

“It is a mistake to lump together older people's views as the same. That's the clear message we received from our People's Panel research”²

Older people are the largest single group to use health and social care services. But 'older people' cover at least a 35 year age span, and include future users of services as well as those who will never need formal support.

Current and potential service users should be involved in developing services that are both acceptable to them and appropriate to their needs. This means involving people who have not yet reached retirement in planning the future shape of services. It also means supporting the activities of older people themselves to develop their own solutions to maintaining their independence and quality of life.

It is particularly important to include people from ethnic minority groups as the number of elders will increase considerably over the next twenty years.³ There is evidence, for example, that amongst Asian elders:

- Two-thirds did not know what services were available to them.
- Those who were aware of services perceived them to be inaccessible or inappropriate.
- Many of those who had used services "felt that their needs were not being met and that the people providing the services had not been respectful of such things as hygiene, privacy, religion and diet."⁴

Challenges In Engaging With Older People

Challenges arise because:

- Older people are a large and diverse group. The vast majority live independently or with informal support.
- Many of those receiving services do so on an individual basis in their own homes rather than collectively.
- One in five people over 75 are unable to leave the house without help.
- 6% of the over 65s will have some form of cognitive disability.⁵
- Ageism and the role ascribed to older people in society does not encourage them to feel that their views are valued.
- Older people can have low expectations, both of their own health and well-being, and of services, and so may be undemanding and uncritical.
- They may be afraid of appearing ungrateful and of upsetting those on whom they feel dependent.
- Services are often provided in a way that reinforces the idea that older people can no longer manage their own lives.
- The protective instincts of staff and carers toward vulnerable individuals can further restrict older people's right to make choices and decisions.⁶

Engaging More Effectively With Older People

- Self-completion surveys can fail to include older people with visual impairment, arthritis (20.8% of over 65s in a local survey⁷ reported difficulty in gripping and holding) or cognitive impairment. You will need to use other approaches to include them.
- The timing, location and conduct of meetings needs to be planned with care. Frailty and fear of crime mean that some older people are reluctant to go out. Transport and escorts should be provided. (See: 'Meetings' – p 82)
- Provide level space for wheelchairs and walking frames, a loop system and microphone amplification (one in three older people will have hearing difficulties), comfortable facilities with accessible toilets and adequate breaks, individual welcomes on arrival. Allow time for social contact as well as business.
- Help the Aged engaged housebound people to participate in its conferences through professionals, and through publicity in the local press and parish magazines.
- Interviews allow description of experience from which quality of life and of services can be gauged. Peer interviewing is particularly helpful in reducing the influence of wanting to 'protect' a younger interviewer, and the perception of a lack of common experience. (See: Peer Interviewing – p 76) Similarly, peer monitoring and evaluation of community and residential services can produce a more honest response. (See: 'Monitoring & Standard Setting' – p 118; 'Evaluation & Outcomes' – p 120)
- Focus groups have been shown to be effective with older people. Smaller group size, perhaps 6 participants for the older elderly or those with disabilities, and sessions shorter, an hour or less rather than the more usual 90 minutes, are suggested. Someone to record non-verbal communication can be useful with older or disabled participants who verbalise less frequently.⁸ (See: 'Focused Group Discussions' – p 86)
- Group events such as 'Whole Systems Events' allow a cross-section of older people who are not necessarily current service users to engage in a dialogue with providers about their own priorities and solutions to problems. (See: 'Ways In Which All Key Interested Parties Come Together To Develop Shared Visions' – p 88)
- A Development Worker provides continuity (*"a steady, continuing presence"*⁹) when frailness or illness mean someone may only be able to participate intermittently, and can provide administrative support to independent groups. (See: 'Development Workers' – p 95)

Some Examples Of Good Practice In Involving Older People

(See: 'The Fife User Panels' – p 72)

Wakefield health and social care agencies actively involved members of the Age Concern Service Users Action Forum in planning and consultative groups, but were aware that the voices of frail, housebound older people were unheard. The 'Talk-Back' Project teamed trained volunteer 'partners' with frail older people. Together they complete a diary of the user's views and needs, enabling systematic feed-back to service planners and providers.

An approach to engaging with people who receive services in their own homes was developed in Kirby.¹⁰

A project group of older people and professionals was set up. The team worked in pairs. They visited people in their own homes and in informal groups and clubs. The older person took the lead in conversations while the professional took notes. They asked people about their experiences of services and their quality of life. Review meetings were held to reflect on what had been learned and to assess the impact of policies and services (or the lack of them) on the lives of older people. The team considered what needed to change to improve their lives. The team prepared a report and made presentations to a wide range of agencies (including housing, leisure, transport, local traders, the local MP and British Gas!). An action plan was developed and the team continued, to oversee putting it into practice.

Two further innovative approaches to involving older people in their own homes have been reviewed.¹¹

HealthLINK is a postal network where members contribute their views and experience in written or audiotaped form via a freepost service, and get information and feedback through a newsletter. A survey about GP services suggested by members resulted in the production of a leaflet on making the most of GP consultations. Participants drew in others from their own networks.

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Other areas have retained the skills and interest of people who can no longer attend meetings by sending papers by post, which can be read (or listened to) and considered when the individual feels able, and their telephoned or written/taped responses included.

A telephone discussion group provided a way of giving a voice to isolated people. Members shared their experiences of service use, gained information and shared practical solutions to problems of daily living. Service managers joined the group once issues were identified, and advanced participants' views in service meetings. *"Meetings by telephone can offer the benefits of a group – society, stimulation and development of ideas – without the costs of disruption, pain, or exposure to the gaze of others."*¹¹

Both these methods may be particularly appropriate in rural areas where older people are isolated and travelling distances are an obstacle to participation. The research found that older people were motivated by a wish to improve the quality of life for others. People needed good explanation of the purpose of the groups, what was expected of participants, and what would happen to the information gathered.

Residents from homes in Manchester were recruited by external researchers and met together to identify what made a good home. Existing standards of good care were reviewed in the light of the concerns identified. A permanent panel to review quality standards emerged.¹²

Some Age Concern groups, such as Camden, support an advocacy scheme for older people in their own homes or in residential or nursing care.

A residential home is working in partnership with a local advocacy project to provide independent advocacy for residents with dementia. Two trained volunteers use activities, conversation and reminiscence to engage with residents, as individuals or in groups, during a half day a week. *"Feedback from the volunteers has led to developments in practice, procedure and policy."* The project did not have any additional funding.

Community Care 18-24 November.1999

Some Research Findings On Involving Older People

A study asked 88 older people who received community care services how they would like their views on services to be obtained.¹³

Findings included:

- Older people favoured face-to-face interviews over other methods.
- Their top priority was that they wanted to be interviewed by senior managers. They believed that senior managers needed to hear first-hand experiences, and would have the influence to act. (This finding was not repeated with younger service users)
- Many disliked telephone interviews, but these were an option for some, so could supplement face interviews.
- Written self-completion surveys were widely criticised and disliked (although the Older Person Needs Assessment survey conducted in South Humberside in 1998 got a 79% response rate).
- Carers liked group methods better than older people themselves. These could provide opportunities for a separate interview, which was not always possible at home.
- Focus groups mostly attracted people in the 65-79 age group, so would under-represent older service users if used as the sole method of obtaining views.
- Individual interviews proved better suited than focus groups for assessment of satisfaction.
- Women wanted to be offered the choice of a woman interviewer.
- Older people wanted to prepare, by knowing what they were going to be asked in advance.
- They wanted to be able to decline to discuss any topic without question.
- Feedback on how the information was used was considered important.
- Asian people preferred an own-language interview to translated written questions.
- Managers felt that the quality of information from a carefully selected small sample could match that from a questionnaire to larger numbers.

Engaging With People With Dementia

Linguistic ability deteriorates in people with dementia, but although challenging and time consuming, communication remains possible. A researcher worked with one individual over four and a half years. She found that even after the ability to use language was lost the individual recognised conversational turn-taking, indicated her recognition of personally relevant subjects and could request with sound that conversation be repeated.¹⁴ Those who live and work with people with dementia are well aware that preferences can be expressed and observed in mood or behaviour.

Some guidelines for enabling communication¹⁴:

- Use a calm environment without distractions.
- Allow sufficient time – to give full attention, to actively listen, to allow the person to understand what is being said and to respond. Allow long pauses. Processing information can take five times longer for someone with moderate dementia than for other elderly people.
- Establish eye contact and use touch where appropriate. Illustrate what you are saying with body language, and photographs and relevant items where possible.
- Use short, simple sentences.
- Listen for the meaning behind the words.

Some Research In Progress On Engaging With People With Dementia

The Dementia Services Development Centre is continuing to explore the ways health, social care and voluntary sector workers consult with people with dementia about their views of services.

Approaches being evaluated include:

- One to one interviews.
- Use of prompts such as pictures and objects.
- Discussion during activities such as music and singing, hand massage, personal care, walks and trips, food tasting.
- Storytelling and reminiscence.
- Group discussions.
- Observation and behaviour.
- Observing non-verbal interaction.

To discuss:

- Attitudes to services generally.
- Feelings on first coming into service.
- Food and mealtime routines.
- Activities and ways of spending time.
- Trips and outings.
- Personal care such as bathing and dressing.
- Other service users.
- Staff attitudes and behaviour.
- Being helped.
- Physical surroundings.
- Transport.
- Admission to hospital.

By building on the skills and knowledge of staff and providing them with opportunities for reflection the researcher has found that staff develop a growing sense of meaning and their self-esteem increases.¹⁶ Training materials will be developed by the end of 2000.

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Speaking Up For Our Age - Pack To Support Development Of Older People's Forums Help the Aged www.helptheaged.org.uk

Assessing Health And Social Needs Of Older People In South Humber South Humber Health Authority 1999

Primary Care Groups and Older People Project Community Care Programme
www.kingsfund.org.uk

Dementia Services Development Centre www.stir.ac.uk/dsdc/

JRF Findings series www.jrf.org.uk e.g. involving older people in community care planning.

Better Government for Older People www.bettergovernmentforolderpeople.gov.uk

Older People Have Their Say- Report On Research Using The People's Panel
www.cabinet-office.gov.uk/servicefirst

Family Involvement in Homes Project, The Relatives & Residents Association, 5 Tavistock Place, London WC1H 9SN

Julia Burton-Jones, Development Officer: Tel. 020 7692 4303

⊗ Offers training and publications on running friends and relatives groups in nursing and residential homes.

Engaging With Carers

*"Carers and service users should be regularly consulted about the quality and appropriateness of services available."*¹

The challenges in engaging with carers include:

- Working in partnership with people who are the major providers of care, and recognising their expertise.
- Agreeing the values on which services are based - priorities of carers and service providers may differ.
- Separation of interests. Carers have traditionally represented those they support, but need to be able to represent their own interests and needs.
- Making contact with isolated individuals. Many carers are not known to services and do not belong to carer groups. Hull and the East Riding of Yorkshire are setting up a register of carers which will allow communication with a wider range of carers.
- Participation takes time and emotional energy. There needs to be adequate support in place.
- Finding times and places to engage with carers that fit into their routines.
- 'Housebound' carers may have lost confidence and need support to speak up.
- Engaging with carer groups without diverting them from their own purposes – the group may be the only social opportunity a carer has, for example.

(See: 'Birmingham Community Care Special Action Project' – p 150)

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Engaging With Women

Many women, especially older women and some of those from minority ethnic groups, have not had the opportunity to participate in public life, and need the confidence to use their skills. They may feel inhibited when participating in forums dominated by men. Women only groups can allow free expression and provide a supportive environment in which to develop confidence. Assertiveness training is beneficial. The majority of carers are women, and many will be older too.

Engaging With Black And Other Minority Ethnic Groups

Challenges In Engaging With People Of Minority Ethnic Origin

Members of black and minority ethnic groups are often under-represented amongst service users. There is evidence that people are unaware of the availability of services, that services are not used because they are considered inappropriate, and that those who have used services felt that their needs were not being met.¹

To make services more culturally sensitive and needs-led, the ethnic perspective (which will include 'new' minority groups such as European asylum seekers) needs to be actively sought out. This is particularly important as the number of elders in the ethnic population will increase substantially over the next twenty years.

Institutional Racism – A Definition

This was defined in the Inquiry into the murder of Stephen Lawrence as:

“The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination, through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantages ethnic minority people.”²

The Social Services Inspectorate said:

“In order to overcome institutional racism, Social Services Departments should re-think the approach of providing a common service for everyone and treating both black and white older people the same.”³

Engaging More Effectively With People From Minority Ethnic Backgrounds

Investing time in building good relationships with communities will help to overcome suspicion and build confidence.

Successful agencies will⁴:

- Have an effective equal opportunities policy.
- Train staff in multi-cultural awareness.
- Gather information about the minority groups in the area.
- Have formal links with communities, such as a liaison group or working party.
- Have informal links through a development worker or community project.
- Have demonstrated that change results from the information obtained.

Other considerations:

- Not surprisingly, there is a low response to self-completion postal surveys, even when targeted at the areas where minorities live. Names and addresses are often poorly recorded, so information may not reach the intended recipient. One study got a better return by having liaison workers hand out surveys, and by taking them to community group meetings where explanations and assistance could be given.⁵
- Telephone surveys may exclude minorities. One study found that telephone use was less popular amongst Asians, possibly because the body language and gesture that normally supplements face-to-face communication is lost.
- Interviews are more successful, especially if the research is well publicised. One study found the refusal rate amongst Asians was higher when the interviewer was white, but Asian interviewers did not affect the agreement of white subjects.⁶
- Another study found that the Chinese community was most likely to decline an interview. The community suggested that they were not culturally comfortable with criticising authority.⁷
- Interviewers matched by gender, ethnicity and language are desirable.
- If interpreters are used to conduct interviews they need training in interview skills.
- Focused group discussions can work well, sometimes needing to be single sex, and in familiar and convenient locations. One study used a Chinese restaurant.

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- Consider escorted travel for some women, appropriate food, and appropriate venues for meetings. For example, premises serving alcohol may be unacceptable.
- Direct enquiries find high levels of dissatisfaction with services but this is not reflected in complaints, so agencies do not benefit from this feedback. Appropriate information about ways of making complaints may be lacking.
- Beware of one-off projects. These can increase feelings of marginalisation. Long-term community development approaches are needed, and links can be fostered by funding the development of community groups, who can then self-advocate and develop appropriate support. (See: 'Community Development' – p 91)

A Practice Example:

Birmingham Community Care Special Action Project

The aim was to develop a carer's programme. Consultation meetings, where interpreters were available, were advertised through community and religious groups, but did not attract people of Asian and Caribbean African origin. The King's Fund was therefore commissioned to obtain an understanding of minority ethnic carers' needs.

Letters to carers distributed through voluntary and statutory agencies, leaflets to community centres, advice centres, mosques and temples, and a jingle played on every program on local radio over 2 weeks, produced little response. What was most successful was a direct approach, identifying carers through service providers and health project link workers, once the community was well informed.

“What does seem to be important is the patient and careful building up of relationships with a variety of individuals in different networks who then act as intermediaries.”⁸

Some Research Findings

Johnson's Review Of Studies On Communication⁹

Johnson reviewed over 200 evidence based research studies relating to communication between individuals and practitioners, and communities and service providers. Communication is a two-way process that is not simply linguistic, but relies on body language and gesture, and ways of viewing the world and explaining meaning. Inability to communicate is a feature of interactions between, for example, lay people and professionals, different socio-economic groups, young people and adults. Yet it tends to be people of minority ethnic origin who are stereotyped as 'hard to reach'. It is more appropriate to consider that it is service providers and practitioners that have the communication needs, rather than to locate the problem with the service user.

Information does need to take account of language. A Health Education Authority Survey¹⁰ in 1995 found that of those giving their ethnic origin as:

- Indian - 85% spoke English.
- Pakistani - 72% spoke English.
- Bangladeshi - less than 60% spoke English.

Fewer older women were fluent in English, and significant numbers were unable to read any language. There is a diversity of languages, scripts, and formal and spoken language forms in an area like the Indian sub-continent, and there is no written form of some languages.

- Written material should be in bilingual format, in English and the appropriate language, written specifically for the purpose rather than translated. Use of culturally appropriate pictures provide non-verbal cues, and formats such as tape or video might be used.
- Community involvement is needed to prepare appropriate information or survey instruments, and to ensure that the agency can interpret responses correctly.
- Only trained interpreters should be used.

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Engaging With People With Mental Health Problems

The majority of people with mental distress will not be seen by specialist services. They will be supported by friends, relatives and carers, or be treated by their GP, so it can be difficult to involve them because of their invisibility, and their isolation from each other.

People with mental health problems are also more likely to be mobile or to be homeless than others. There are 15,000 people in England with a severe and enduring mental illness, and 14 - 200 per 100,000 of those are considered difficult to engage.¹

Mental health has been at the forefront of service user involvement with a well-developed self-advocacy movement. 'From above' (professional-led) and 'from below' (users' own activities) models are distinguished, and it is suggested that top down initiatives have had limited impact.

Professional-led activities have often been of the consumerist model. This emphasises the individual's rights - to information; to a clear procedure; to be consulted; and to complain if things go wrong. Mental health service users argue that if rights can't be exercised then this is an exercise in placation. The in-balance of professional power remains. (See: 'Arnstein's Ladder Of Participation' – p 17)

'Bottom up' initiatives from service users themselves are often critical of the medical model of mental illness, challenging the way in which service users are regarded, and the worker/user relationship.²

Service users are clear that they should play a role in shaping services, they are realistic about the stress this could create for them, and their own need of support for that role.²

Challenges In Engaging With People With Mental Health Problems:

- It can be difficult to contact past users and those who don't use services.
- Some people may be too ill or distressed to take part at certain times, and medication can affect concentration.
- The nature of their illness may cause suspicion about the purpose of the exercise.
- Some service users may be alienated by their experiences of care and treatment.
- Sectioned and secure service users who have lost rights may be particularly critical.
- There are often problems with jargon, and there are differences in definitions between users and service providers.³

Engaging More Effectively With People Who Use Mental Health Services

Consider:

- Mobility and alienation make postal surveys or recruitment ineffective. Individuals might be contacted through mental health user or support groups, but many will have no such associations. Voluntary organisations providing information and support or supported accommodation might be another avenue for contact. One study⁴ used key workers to engage service users with severe and enduring mental health problems. (For a description of this research, see: 'Peer Interviewing' – p 76)
- Involve users from the beginning. Start by establishing their agenda and definitions, using qualitative approaches such as one-to-one or group discussions. (See: 'Focused Group Discussions' – p 86)
- Use a variety of approaches to increase inclusiveness.
- The stigma attached to mental illness increases concerns about confidentiality. Employ extra reassurance about confidentiality, for example, by keeping activities as independent of the service as possible. This will also encourage uninhibited expression of views.
- Low self-esteem can mean low expectations. Since any judgement of the quality of a service relies on expectations, it may be more appropriate to ask for experience and judge that against an agreed standard of acceptability (such as standards developed by service users themselves). This is particularly important for long-stay users who have little to compare with. For example, levels of privacy could be established by asking specific questions with a yes/no answer, such as 'did all toilet doors have locks?'. (See: 'Monitoring & Standard Setting' – p 118)
- Use quality of life as a measure, not quality of service. Questions that tell you how the organisation is performing tell you nothing about the impact of the service on the individual.

It is suggested that the way forward is to promote activities that encourage service users to speak for themselves and understand their potential role in improving service quality. This might be achieved, for example, through assertion training, advocacy or supporting user groups and forums. Staff need support that helps them recognise the power differentials between themselves and service users so that they can avoid unconscious barriers to participation. (See: 'Power' – p 26)

An Example Of An Initiative To Involve People Using Mental Health Services

Northumberland User Voice is a project that aims 'to help service users to communicate their views and to influence the mental health services they receive.' When the Mental Health Trust consulted with service users to find what would help them to take part in decision making, the need for a paid worker was identified, and in 1993 a co-ordinator was appointed. The project now has two full time workers and full-time admin support, managed by the local Community Health Council. The project steering group of service users meets monthly with project workers. The group meets in various locality settings to allow service users from across the county to participate and hear about developments. The steering group is supported by an advisory panel of managers from the Health Authority, Trust, Social Services and regional user organisations.

The project supports existing user groups and promotes development of others, and facilitates networking of service users. It produces a quarterly newsletter and holds twice yearly user conferences. Service users are involved in the design and content of service information. They are involved in staff induction and training, and in appointments, including panels appointing senior managers. Users can also take up work placements with the User Voice team, and the project is taking part in the development of a café based User Centre. As well as offering in-house training in communication and meeting skills, User Voice has worked with partners to develop a training course accredited by the Open College for service users becoming involved in shaping services.

Northumberland User Voice Amble House, St George's Hospital, Morpeth NE61 2NU

Some Research Findings

At The Individual Level

There is evidence that *“When service users are involved in agreeing and reviewing [their care plan] the quality of care improves, and their satisfaction with services increases.”*⁵

The government initiative to develop programmes of self-management for those with chronic conditions is welcomed as a way of increasing user involvement.⁶ (The Living with Long-term Illness Project www.lmca.demon.co.uk). A randomised controlled trial in America found that although people in such programmes showed no difference in pain or psychological well-being to the control group, the study group did show improved management of symptoms, better communication with health professionals, and fewer hospital admissions.

A London health authority worked with the King's Fund⁷:

- To find effective ways of engaging users of mental health services.
- To establish views of current and future services.
- To inform strategy for improved involvement of, and collaboration with, users generally.

Three mental health workers were appointed to support user involvement. They recruited 30 service users into planning teams. These teams developed a work programme and were trained as facilitators for user events, chairing meetings and recording the views of other service users.

The resulting report identified some key themes:

- Users wished for a relationship with staff, but felt that they were treated with disrespect.
- Users felt powerless and were anxious that speaking out would jeopardise their care and treatment.
- Users lacked information about the system and treatments.

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The report was presented to purchasers at a conference. **Outcomes** included user involvement in staff selection and the setting up of a training co-operative for early input to staff training. User liaison posts were created.

The researchers found that:

- Participating service users had little understanding of the system so a longer period of induction was needed than had been anticipated.
- Payment of users encouraged involvement, and helped overcome initial scepticism.
- Payment encouraged a business-like approach (one user commented that it was 'like a job'), and users felt valued and valuable.
- Independent facilitation enabled the link to be formed and trust to develop between user and purchaser partners.
- Professional anxiety was reduced and there was a positive effect on the 'general culture'.
- Scepticism about genuineness and effectiveness was overcome.

The researchers suggest that a project such as this, by allowing sufficient education/training, development and time for trust to develop, overcame the experience of 'failure born of time limits'. They feel such failure is wrongly interpreted as a limitation of those involved and the incapacity of users to work in partnership.

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⊗ "Looks at how advocacy services can develop practical models of good practice."

Leader A *Direct Power* Pavillion 1995

⊗ "Tool for social and health care professionals who need to support and empower clients preparing for care assessments, discharge and aftercare arrangements, and in redeveloping care plans which are relevant to clients' needs."

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⊗ From 1997 workshop 'Citizens, Consumers Or Users?'

East Yorkshire Monitoring Team *Monitoring Our Services Ourselves* 1997

⊗ A practical manual and audiotape for mental health user groups and service providers.

Joseph Rowntree Foundation Findings Series

⊗ Evaluated initiatives, e.g. involving users and carers in the care programme approach in mental health www.jrf.org.uk

Mental Health Foundation website www.mentalhealth.org.uk/rsngui1.htmtransfer

(See: 'Other Resources' for 'User Involvement In Research, Monitoring And Evaluation' – p 126)

Engaging With Those Who Do Not Communicate Conventionally

Policy guidelines state that every effort must be made to establish a service user's preferences, however challenging that may be. It is suggested that everyone can communicate what makes them happy or sad, and what feels good or causes pain.

One author suggests:

- Establishing whether there is someone who is familiar with the person's way of communicating.
- Using this person to facilitate communication rather than as a substitute for communication.
- If the person uses a particular form of communication such as Makaton, enlist an interpreter.
- Consider whether observation might be a key way of establishing preferences.¹

Communication can be made more effective if those who know the individual well assemble information about them, that is then available to others. This could include, for example, significant people and events, experience of expressing choice and preference, ways of communicating, behaviours that have communication value, unusual behaviours and appropriate responses. **Biala**, a tool to systematically gather such information to enhance user participation, has been designed and evaluated in Australia.²

There are useful skills and experiences to be shared across disciplines.

(See: 'Engaging With People Who Have A Learning Difficulty' – p 163; 'Engaging With People With Dementia' – p 141; 'Johnson's Review Of Studies On Communication' – p 151)

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Other Resources

Fitton Pat *Listen To Me: Communicating The Needs Of People With Profound Intellectual And Multiple Disabilities* Jessica Kingsley, London 1994

⊗ Written by a parent for other parents. Describes the 'care book' illustrated with photos developed by the author to communicate to others her daughter Kathy's needs. This included a section describing the way in which Kathy communicated with sounds, facial expressions and body movements so that her pleasure, approval or disapproval could be recognised.

Engaging With People Who Have A Learning Difficulty

“The major disability faced by people with learning difficulties is not their difference from others. The major disability is...the systematic exclusion of people with learning difficulties from valued, contributing, participating roles in the community.”¹

“It takes a bit more time for me to work things out.”²

People with learning difficulties can speak up for themselves, and those without verbal communication can express their choices and preferences. They need to work at their own pace, and within their own timeframe. For example, sense of 'future' might be limited to what is going to happen today.

Engaging More Effectively With People With A Learning Difficulty

Some suggested ways of involving people with learning difficulties include:

- Using non-verbal means of communication. Pictures, photos and symbols can help to make information accessible, and act as a tool for supporters where information needs to be explained.³
- Observation can be used where people cannot communicate directly, to identify indicators of quality of life, such as taking part in meaningful activity.⁴
- Role-play to allow practice of situations, and drama to convey information and promote discussion.

Obtaining expressions of views can be difficult where people are anxious to please.

Learning to be assertive, defined as⁵:

- Knowing what you want.
- Having the confidence and being able to express needs and opinions honestly and openly.
- Having skills to negotiate with others.
- Respecting the rights of others.

is a recognised and important part of working with those with learning difficulties.

(continued)

It has a wider application, and could usefully form part of the preparation for all service users to promote effective and more inclusive participation.

The self-advocacy organisation People First gives **guidelines for involving people with a learning difficulty in meetings:**⁶

- Begin with informal gatherings to allow all participants to meet, get to know and become comfortable with each other.
- Keep numbers smaller.
- Use jargon free, clear language.
- Give clear explanations.
- Listen carefully to contributions.
- Accept that time and patience will be needed.
- A supporter may be needed, at least initially. This person should be independent, and guidelines should be developed so that their role is understood by all.

We all take time to develop 'meeting skills' and it would seem that these principles could benefit us all. It is suggested that limited participation may raise concerns about tokenism, but commitment to the right of someone with a learning difficulty to be involved means that their very presence will influence thinking.⁷

(See: 'Guidelines For Making Meetings More Accessible' – p 82; 'Swindon People First Contract' – p 30)

There are useful skills and experiences to be shared across disciplines.

(See: 'Engaging With Those Who Do Not Communicate Conventionally' – p 161; 'Engaging People With Dementia' – p 141; 'Johnson's Review Of Studies On Communication' – p 151)

Some Examples From Practice:

A local learning disability day-care service used art, music, drama and audio visual media to find creative ways for people with a moderate to severe learning disability to express their views. They explored issues under the headings of integration, accessibility, empowering users, life planning, and specialist support services. Sessions were videotaped so that interpretations could be checked and discussed. Workers' assessments of the original 4 workshop 'trial' established the value of the work. It identified the need to be able to undertake such work at a slower pace over an extended period.

Creative Ways of Working Towards Seeking Service Users' Views North Lincolnshire Council Social and Housing Services 1997

The National Development Team worked with Grampian Health Board to review services for people with learning disabilities. The researcher worked with a group of service users, their relatives and staff to develop their interview skills, producing an 'Interview Information Pack'. 300 people were then interviewed by their peers; relatives by relatives and so on.⁸

Some Research Findings

Research was carried out to obtain a user perspective of what service standards should be adopted.⁹

The researcher met 3 times with 5 groups of users. At the first meeting, the research was explained and the groups invited to take part. At the second service, standards were derived using 'The Five Accomplishments' (King's Fund 1980) as a framework, each written on a flipchart sheet with supporting symbols or pictures. (See: 'Monitoring & Standard Setting' – p 118) The third meeting shared the standards identified by all the groups, and individuals were invited to comment, using happy or sad face stickers to facilitate participation of those who found verbal comment difficult. Thus each individual had an opportunity to support or reject the group-derived standards to reach a final list of eight.

Factors promoting successful involvement of people with learning difficulty in staff recruitment were found to be:¹⁰

- Commitment of staff.
- Involving trade unions and personnel departments.
- A user involvement ethos within the organisation.
- Willingness to experiment and learn from experience.
- Involving people with learning difficulties at all stages, from drawing up the job description; not just in the 'informal' parts of the process.
- Training, preparation and practice, including issues of confidentiality and equal opportunities practice. Where this was provided, and opportunity was given to practice interviews, (including scoring candidates) discrimination and bias was rare.

These principles could be applied to staff recruitment in any service area.

(See: 'Involving Users In Staff Selection And Training' – p 123)

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5. Weston C 'Speaking Up For Yourself: Description And Evaluation Of An Assertiveness Training Group For People With Learning Disabilities' *British Journal of Learning Disabilities* 1999 vol 27 p110-115
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10. *Involving People With Learning Difficulties In Staff Recruitment* JRF Findings Series 1996

Other Resources

Booth W & Booth T *Advocacy For Parents With Learning Difficulties: Developing Advocacy Support* Joseph Rowntree Research Into Practice Series, Pavilion, Brighton 1998

⊗ Report and evaluation of 18 month Parents Together project. Describes experience of advocacy support, strengths and limitations of advocacy as an approach, lessons for practice learned. Good section on the many and various roles advocates take on.

Caldwell P *Getting In Touch – Ways Of Working With People With Severe Learning Disabilities And Extensive Support Needs* JRF Research Into Practice Series Pavilion Brighton 1996

⊗ Uses case studies to describe ways of engaging the attention of and communicating with, people with profound disabilities by finding the key to their own 'language' which might be through sound, vibration, or touch.

Stalker K et al *If You Don't Ask You Don't Get* Central Research Unit Scottish Executive 1999

⊗ Qualitative study of views of people with learning difficulties and their carers about health and social care services. Gives the 18 topic guides used for focus group work

CHANGE Picture Bank

⊗ Pack to increase accessibility of information, reviewed in *Community Care* October 2000 [vol 5-11](#) p 38

The Quest System

⊗ A system to enable the evaluation of services for people who need long-term support that can be used by service users themselves. Developed and tested by the Quest Team based at the University of Hull. There is a version to assist people who find it difficult to read and to speak.

The East Yorkshire Learning Disability Institute, University of Hull, HU6 7RX

People First

⊗ Groups run and controlled by people with learning difficulties to speak up for themselves. Website www.peoplefirst.org.uk.

Norah Fry Research Centre University of Bristol: www.bristol.ac.uk/Depts/NorahFry/.

British Institute of Learning Disabilities: www.bild.org.uk.

⊗ Research, resources, publications, newsletter, education and training

Engaging With Disabled People

There is a well organised and active disability movement advocating for disabled people, but because of the diverse nature of physical impairment, many individuals are not represented in existing groups.

The social structures that disempower disabled people make it harder to reach them, because of their possible isolation, and the absence of the practical support they may need to participate.

Although most people with physical or sensory impairments are over 65, they are classed for service delivery purposes as 'older people', so their perspective on disability may not be included.

Disabled people report having good days and bad days, and may not know in advance if they will be well enough to participate. For this reason it is better to engage with a larger pool of people. Where there is involvement in working groups or committees, absences make it easy to lose the link and stop attending. Those who are absent need to be kept informed; for example, with a personal telephone call, not just through minutes. People might also take part in 'partnerships', so that if either person cannot attend the other can keep their partner informed. (See: 'HealthLINK' – p 138; 'Telephone Discussion Groups' – p 139)

Challenges In Engaging With Disabled People

You will need:

- Information in accessible formats. (The Disability Discrimination Act 1995 prohibits discrimination in provision of information).
- To provide transport or transport costs and appropriate parking facilities.
- Accessible venues with comfortable facilities to minimise fatigue.
- Shorter working periods with adequate breaks.
- To pay for personal assistants where required.
- Communication facilitation where required.
- Outreach to those individuals who are not current service users.
- Outreach to those who are not represented by existing groups.

Engaging More Effectively With Disabled People

A conference of disabled people made recommendations to overcome barriers to user involvement, and involve a wider range of people.¹

These included:

- Developing a register of disabled people willing to participate, their interests, and preferred method of being consulted. *(See below)*
- Individual views gathered through home visits.
- Telephone conferencing. *(See: 'Telephone Discussion Groups' – p 139)*
- Building a user network.
- Developing a newsletter.

Developing a 'register' or database of potential contributors is a way of ensuring access to a pool of individuals, in addition to working with existing user groups. Such a register allows exchange of information, keeping service users and non-service users informed, enabling them to express views to influence service delivery, and giving feedback on how their views have been taken into account. While a co-ordinator may be needed to facilitate the project initially it has potential to become user-led. Registers of carers and of families with children with a disability are being set up locally.²

Some Practice Examples

When disabled people who used community care services in Shropshire were asked to share their experience of assessment, care management and service delivery, they made more than 80 recommendations for making services more effective. One result was that service users designed a new assessment model that they considered more relevant and easier to understand. They developed a leaflet for other users to explain the process of assessment and care management.³

Mystery Shoppers

Lancashire Social Services used volunteer disabled people as 'mystery shoppers' to check facilities and staff awareness in telephone and face-to-face contacts with the department. The five month project cost £5,000. It was intended as a one-off exercise, but the information provided proved so valuable that the project was extended.

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(continued)

The Local Authority and Health Authority in Leeds worked together to look at services for disabled people with physical disabilities, found out if they were meeting people's needs, and proposed changes. The development of a commissioning framework was overseen by a steering group including representatives from voluntary organisations. The emphasis was on consultation with disabled people (both using and not using services), carers, voluntary groups, and the staff providing services. The various groups were consulted separately, then brought together to exchange views. The consultation included:

- Meetings with a range of staff providing health and social care services.
- A survey advertised in the local press aimed at disabled people.
- Discussion with disabled people in care homes.
- Meetings with voluntary organisations.

A conference, planned by an advisory group including disabled people, brought together all these groups, and also included people from the independent sector and other local authority departments. The consultation exercise provided:

- Principles to guide service planning and delivery.
- Action points.

A short, easy to understand report of the process was produced, and a team set up to ensure implementation of the action points. A reference group of disabled people is being established to:

- Comment, and advise the team on proposed work and ways of working.
- Monitor work being done (or not being done) by the team.
- Bring ideas and suggestions for new areas of work to the team.

Members of the group are provided with transport, personal assistance and any other access requirements, and receive an allowance for attending meetings. Feedback and progress reports are provided in a newsletter available in large print and on tape and computer disc.

Implementation Manager Mick Ward, Thoresby House, 2a Great George Street,
Leeds LS2 8BB

Some Research Findings

The King's Fund studied service evaluations led by disabled people.⁴

Evaluation seeks to answer the question 'is the money being spent making a positive difference?' (See: 'Evaluation & Outcomes' – p 120) It examines:

- How users experienced services.
- Their appropriateness.
- Their effectiveness in meeting needs.
- Strengths and shortcomings.
- Value for money.
- Outcome in terms of quality of life.

Where service agencies conduct evaluations, both the process and outcomes will be influenced by their interests and perspectives. If evaluation is done from an independent base, the number of responses and their honesty can be increased.

For service developments to be needs-led, detailed information is needed from those who are expert in their own needs. In users being able to suggest solutions to problems the foundation for partnership working is established.

Users should conduct evaluations themselves, or at least be in a majority on the organising group. If they do not conduct the evaluation themselves they can act as consultants to the evaluators, actively participating in setting the terms, suggesting methods (which might include art, drama, use of case studies or life stories), analysing and presenting findings, and making recommendations.

(continued)

Evaluation of two projects led by disabled people ⁴ showed that:

- The planning phase took longer than expected, including identifying people to take part and providing support to facilitate their participation.
- Time was needed to avoid tiredness, allow for the communication and cognitive difficulties of both sides, and for both sides to 'unload' before a constructive working relationship could develop.
- A formal structure such as a steering group, with clear roles and responsibilities, was needed to manage the evaluation.
- Senior staff need to be involved, at least at the implementation stage, to authorise the process and influence change within organisations.
- Time spent gaining staff support was key to gaining access to disabled people, and staff attitude influenced whether they would respond.
- Clear statements and guarantees on confidentiality were important.
- There needed to be a code of practice for dealing with issues that arose, such as dealing with disclosed information, discriminatory views, and the procedure should a participant identify an issue they wanted addressed.
- Adequate supervision and support was needed for peer evaluators.
- Ways of harnessing the skills acquired during a project should be considered (both study groups wanted to continue involvement).

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2. For example: *Listening To Families* The East Riding of Yorkshire
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Other Resources

Achieving User Participation - Planning Services For People With Severe Physical And Sensory Disabilities Living Options in Practice 1992 Project Paper no. 3

⊗ A guide to the process of involving disabled people as partners in service planning and development, based on the experience of eight Practice Localities in England.

Engaging With People With Sensory Impairments

Challenges In Engaging With People With Sensory Impairments

When engaging with people with sensory impairments, it is worth bearing in mind that many older people and other members of the public will have some degree of hearing or visual loss.

Consider^{1,2}:

- Guiding needs of people with visual impairment, particularly in an unknown venue.
- Acoustics within the room, and background noise that will further diminish hearing.
- Good lighting (overhead fluorescent lighting is best) to facilitate the reading of information and seeing signers. It also enables those who lip read, or supplement their hearing, as many people do, with lip reading and facial gesture.
- Positioning of speakers, signers and interpreters with thought to light sources; for example, avoiding shadows on face or hands, and against plain backgrounds.
- Provide information in the preferred format, in advance, to allow prior familiarisation.
- Introduce everyone present at the beginning so that people with visual impairments can locate each individual, and repeat your name when you speak to identify yourself.
- Pace speech appropriately, speaking clearly and in short sentences, but remember that shouting distorts sound.
- Interpreters and others having to concentrate hard need frequent breaks - at least five minutes every half-hour is recommended.
- Allow additional time for the slower pace needed for communicating with deaf or deaf-blind people - an extra hour for every two hours needed by sighted and hearing people is recommended.

Engaging More Effectively With People With Sensory Impairments

A study exploring the barriers to effective involvement of deaf service users³ found that:

- Lack of accessible information inhibited deaf people's ability to participate effectively.
- Staff needed training about the deaf community and British Sign Language to enable them to adapt procedures to allow participation.
- Deaf people needed training, including confidence raising and assertiveness to participate effectively.
- A strategy for building partnerships with deaf people was needed, to include roles for deaf people and the action to be taken to facilitate their participation.
- Deaf people preferred meetings in British Sign Language.
- A deaf person as an independent link between deaf people and service providers was seen as valuing deaf people, and increased their confidence in the agency.
- "Relatively modest" resources to deaf groups increased their potential to support involvement, and to work democratically within the deaf community.

(See: Reference 1 – p 177)

References

1. *See It Right: New Approaches To Information For Blind And Partially Sighted People* RNIB 1993
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⊗ Detailed guidance on communicating directly; methods of communication; good practice in communication; contact through an interpreter; consulting with deaf-blind people; meetings and conferences; code of practice for meetings involving deaf-blind people; Braille and large print information.
3. *Deaf People's Participation In Local Services* Social Care Research 77, British Deaf Association & JRF 1996

Other Resources

- Stepping Away From The Edge* Department of Health 2000
⊗ Improving services for deaf and hard of hearing people
www.doh.gov.uk/scq/steppingaway.htm.

Engaging With People Who Misuse Substances

Challenges In Engaging With People Who Misuse Substances

It can be difficult for people who misuse substances to become involved. By coming forward, people identify themselves as having a problem, or as taking part in illegal activities.

Tackling Drugs Together (1995) says that **Drug Reference Groups** should include user and voluntary sector representatives. However, the Central Drugs Coordination Unit surveyed 78 of 279 Drug Reference Groups, and found that only 15% had service user, self-help or parent group representation.¹

It is difficult to 'represent' the wide group that misuses alcohol and illegal or prescribed drugs. The concern is that strong local voluntary groups can mean that one model or way of thinking predominates. The challenge is to ensure that there is a balance by engaging with people from other sources. Ensure the people you want to engage understand that their personal experience can make a valid contribution to the strategic development of services.

Engaging More Effectively With People Who Misuse Substances

- User groups and voluntary organisations are usually better placed than statutory agencies to work with people for whom uncritical acceptance and confidence in confidentiality is crucial.
- 'Snowballing', asking one contact to introduce others, can bring forward people who would otherwise not be included, and has also been used with homeless people, and other groups who are stigmatised.

Experience From Practice

A survey of user opinion was carried out to find out what a 'perfect service' would be like.²

The study was overseen by an independent researcher from University College, London. A semi-structured self-completion questionnaire was used with people recruited from voluntary and statutory agencies and projects, and a prison project. A £5 Boots voucher was given to encourage participation. 504 current service users took part, with a gender, age, ethnicity and unemployment profile similar to the regional Drug Misuse Database, so considered fairly representative of substance users. It was noted that only 28 had first sought help from a General Practitioner, so that practices were not an appropriate route for engaging participants.

Surrey Social Services³ considered that the process of involving people who misuse substances was more likely to succeed and to be sustainable if it was user-led. It was decided to hold a conference from which to establish an ongoing group. Finance was identified. A former service user now working for a local service was paid to organise and chair the conference. It was recognised that this was not ideal, and did prove to be a problem with conflict of interest, but *"it broke the log-jam and moved the process forward."*

The principles for the conference were:

- Attractive surroundings and good facilities.
- Reimbursement of travel costs.
- Limited presence/involvement of professionals.
- Advertised through service and in local press.

Service users worked in small groups to express their views. There was support for an ongoing group, and a steering group of volunteers was given a grant to cover administration costs.

A Users Forum was set up. Interest was sustained by a publicity programme, newsletter and local workshops.

(continued)

It was found to be easiest to attract interest from users/ex-users of residential facilities, but to avoid an imbalance, and to avoid a group aligned with any particular service provider, effort was made to include:

- People who 'failed' in treatment.
- People who had addressed their problem on their own.
- People whose treatment had taken place within primary care.
- People who were supported by voluntary agencies, housing associations etc.
- Carers.

The high drop out and relapse rate limited sustained involvement and made the maintenance of a bank of interested people crucial. Initial problems included a lack of clarity and vague expectations of the group on the part of agencies. These were overcome by establishing a detailed contract with Social Services which set down concrete tasks and objectives, and these were then monitored.

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2. Jones M et al 'Asking Around: The Theory And Practice Of User Consultation' *Drug Link* March/April 1998 p14-17
⊗ Report from apa 67-69 Cowcross Street, London EC1M 6BP
3. Surrey Alcohol and Drug Service Users' Forum *Who Knows Best? Developing User Involvement In Substance Misuse Services* Time is Right Publications Surrey 1995
⊗ "This booklet outlines the process undertaken in Surrey to generate service user involvement in the alcohol and drugs field. It outlines the problems encountered not only in setting up a user consultation facility - but in ensuring its ongoing effectiveness. It is not a guide on 'how to get it right', but rather an honest description of the struggles we went through and the innovative solutions we developed."

Other Resources

- Report Of An Independent Review Of Drug Treatment Services In England* Task Force to Review Services to Drug Misusers, Department of Health 1996
⊗ Chapter on 'Meeting Service Users' Needs'.

Engaging With People Who Use Primary And Community Health Services

The challenge is the number and diversity of people who have varying amounts of contact with services.

Research shows that patients prioritise different aspects of primary care services to service providers.¹

The issues of concern to service users are:

- The quality of relationships with staff - good communication; being treated as a person.
- Good information – to reduce anxiety; to inform of choices and decisions; promoting a feeling of personal control.
- The effectiveness of care and treatment.

Engaging More Effectively

Combining a number of ways of allowing patients to participate can be effective but relatively inexpensive.

These might include:

- Advertising in the practice population that feedback is welcomed, explaining how it will be used to influence service delivery, providing comment forms and boxes, and feeding back action taken.
- Having a clear, accessible 'complaints' procedure. (See: 'Re-orientating Complaints Procedures' – p 81)
- Setting up 'quality action groups' of individual patients and representatives of community groups. (See: 'Quality Action Groups' – p 84)
- Members of such groups can carry out observations, such as how patients are dealt with at reception, and feed this back into staff training. (See: 'Observation' - p 78; 'Mystery Shoppers' – p 171)
- Holding a regular 'patient's forum'.
- Regular 'end of contact' interviews, conducted by peer interviewers. (See: 'Interviews' – p 74; 'Peer Interviewing' – p 76)

(continued)

The Department of Health is funding *research “to increase understanding about ways of involving the general public in decisions about individual treatment, health services and health policy”*. It is anticipated that findings will be disseminated by the end of 2001.

Sarah Bruce, Research Associate, Graduate School of Social and Political Studies,
University of Edinburgh

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Working For Health: Primary Care Groups And The Community Primary Care Development Team, University of Hull 1999

⊗ Report from 1999 conference.