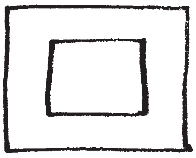
Inspired Working

participant notes

3~4 November 2005
Cairndale Hotel, Dumfries

Different ways of seeing the solution to the problem

Sometimes you can look at a problem and think that the solution would look like this.



"what we are doing right now is fine, we just need to do more of the same thing".

In this kind of scenario, you think the only problem is resources and you just need more of them. The type of resources you need to solve this kind of problem are more of the things you already know about - more money, more of the same people and more of the same models (buses, buildings, equipment, etc.).

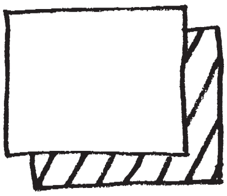
Sometimes this may be right. However, the danger with this kind of analysis might be a lack of clarity about the root cause of the problem.

Earlier in this course we explained the analogy of the Russian dolls. We used the imagery of the dolls fitting inside one another to try to explain the interlocking relationship between values and vision, service design, staff and resources.

Resources are represented by the resources doll, which is the outer shell of the whole Russian doll. The external shape was formed by the next doll in - the staff doll. Staff generally dictate the kind of resources required. The shape of the staff doll, in turn, was formed by the next doll in - the service design doll. The shape of the service design doll directly mirrored the innermost doll, the doll of values of vision.

Whilst you are busy campaigning for more of the same, you may not have stopped to fully evaluate how good "the same" is. Involving more people doing the wrong thing more prolifically doesn't make the wrong thing right. It just makes it more difficult to change.

Sometimes your analysis of the solution to the problem looks like this.



"what we are doing right now is ok, but we could do it slightly differently".

In this scenario, people often say things like "don't throw the baby out with the bath water" and suggest endless ways of tweaking what we do now to make it feel different and hopefully better. The problem with this kind of analysis is that it often avoids the hard work of looking critically a the current response and it's true effectiveness.

Sometimes this is the correct response. But again, we have to be careful that we are not correcting the delivery process without improving the contents of the package being delivered. Making assessment a more enjoyable or person centred process is useless if the services available are unchanged. There is no point in asking people what they want in a more creative way if you have no intention of adapting what you have to offer them.

Sometimes the analysis of the solution you need for your particular problem looks like this:

"what we are doing now is completely wrong, we need to do something totally different."

In some cases, this is completely correct. Simple exposure to a new way of doing something might help people be sufficiently creative to enable them to devise a new procedure or system. Suddenly seeing an alternative view of what's possible, clarifies what needs to happen.

However, imposing a new model on an existing system is always complicated. Resistance and sabotage are inevitable and it is easy to copy a model without identifying the secret ingredient that made it work in the first place.

It is easy to look at the outside of a model of good practice and think you have completely understood how it works. It is easier to see the outputs of the system than to see the workings inside, just as it’s easier to see the hardware of a computer and see what it produces, than to understand how the software really works.

It is difficult to accurately identify the key ingredient. Many people can try and copy a model of supporting people without realising that it was the personalities of the key staff which made the original model work, not the work schedules.

Copying is useful, but can be careless when you don’t fully understand the values and beliefs underpinning the original. For example, many people try to adapt person centred planning processes without any understanding of the core values that informed their design. The result is both disappointing and damaging.

Every situation in which people are trying to achieve change is unique. It’s in a particular place, at a particular time, in a particular social and organisational context, initiated by a particular person with a particular history. Those who would achieve the change are a particular group with their own particular agenda. This is not to say that imported solutions and techniques never work, but that they will be used in a particular way and have a particular impact in each place. Any recipe includes the ingredients, the quantities and the preparation process. Any one who has tried to create a great meal knows that even with all of this information, the outcome can go badly wrong!

Firstly you have to fully understand the core values of the model you are looking at. You then have to be clear about your own values. You can then adapt or create a model of support which is coherent and can thrive in your own environment. As once summed up by Pete Ritchie, Founding Director of SHS Trust:

“Copy good. Imagine better.”

Dealing with Adaptive, not technical, challenges

However, sometimes, we are not dealing with problems to which there are already devised, but not yet applied, technical solutions.

We are dealing with problems which pose "adaptive challenges", as described by Ronald A Heifetz and Marty Linsky in their book Leadership on the Line (published Harvard Business School Press, 2002).

Heifetz and Linsky explain that adaptive challenges require experiments, new discoveries, and changes in attitudes, values and behaviours. They require people to be creative, imaginative, thoughtful, reflective, courageous, honest and bold in the face of uncertainty.

We would suggest the job of effectively and meaningfully including people who are currently devalued and potentially marginalised in our society is our greatest adaptive challenge. Creating support systems and services that both meet basic human needs and increase the likelihood of individuals playing an active part in their communities is not something that we already know how to do well. It is something that we have to learn how to do well.

Heifetz and Linsky state that leading people through a process of adaptive process requires distinct leadership qualities.

"If leading were about giving people good news, it would be easy. Unfortunately many leaders avoid the hard work. How many leaders have you heard say something like this?

'We can't keep going on this way, but the new direction is yet undetermined, and how effective any plan will be in enabling us to thrive - or even survive - in the new environment is also unknown.
We're going to have to go through disagreements and conflicts as we sort through what's precious and what's expendable; loss as we abandon comfortable pieces of the past, old routines and even close relationships with people;

feelings of incompetence as we strive to innovate and learn new ways; and doubt and uncertainty as we make inevitable wrong turns on the way.' Clearly this is a very difficult message to deliver, however honest."

As Heifetz and Linsky stress, people generally resist change. When they are faced with an adaptive challenge, they can't see that the new solution will be any better than the current condition. All they see at the start of the process is potential for loss.

Part of the work of changing human services involves all of us in thinking carefully about what we are trying to do and why we understand it to be difficult. It requires us to gather our knowledge about what other people have tried and to think together creatively about what a good next step might be. It involves us each reassessing who we think we are in the process and the part we can each play. It also requires us to think about what we are willing to give up as well as what we hope to gain.

Heather main title?
Introduction

There are some people in the health service who think 'Involving people? Participation? It won't come to anything.'

There are some people in communities who think 'This isn't a partnership - they've got all the power, and it's us against them.'

But most of us, most of the time, genuinely want to work together, to listen and be listened to.

Involving people takes time and energy. Sometimes it works well, and everyone benefits. Sometimes we put in a great deal of effort but everyone is disappointed with the result.

There are 'set-piece' methods to involve people - where the communication is planned in advance around a specific issue, such as consultation about a new hospital.

But what makes most difference is the everyday, inconspicuous business of paying attention to people, providing information, giving feedback, treating them with respect and asking open questions.

If we are doing this work in the background, then the special efforts to involve and engage people will build on the existing culture. If we only listen to people when we are making a special effort, the gap between rhetoric and reality will soon show.

Why is it good to talk?

In the old days, doctor knew best; the hospital manager knew best; health board planners knew best; and the government knew best.

Times have changed. People expect to be involved and consulted in all aspects of their lives; are more likely to ask questions and are less trusting of experts. There are more organisations of all sorts wanting to have a say in decision-making; and public authorities are more open to scrutiny and challenge.

The founding principles of the Scottish Parliament are openness, accountability, sharing of power and equal opportunities. These principles apply to all areas of public service in Scotland. The day-to-day dialogue

between the people who use public services and the people who provide and manage them is part of the democratic process.

The health service has changed, too. The focus of the health service is no longer on acute disease but on helping people to maintain their own health and live well despite long-term illness.

> "When acute disease was the primary cause of illness, patients were generally inexperienced and passive recipients of medical care. Now that chronic disease has become the principal medical problem, the patient must become a co-partner in the process."
>
> Holman and Lorig, BMJ

So not involving people is not really an option. People expect to be involved, they have a right to be involved, and public services have a stated commitment to involving people. But involving people is not just a fashion accessory; it can also deliver practical, measurable benefits for health.

At an individual level

- People find better ways to integrate their health with their life.
- People recover better from illness.
- People have less pain.
- People get care and support from a wider range of people.
- People are less dependent on formal services and more self-reliant.
- People feel better - more in control, more confident.
- Staff learn more from service users, and are able to pass this on to other service users.

At a service level

- Services are designed and adapted to respond better to people's needs.
- Staff time and skills are used more effectively.
- Service users' experience and knowledge is used to benefit others.
- New ideas and approaches are introduced.
- Services tap into the enthusiasm and energy of their users to get things done.

- Staff get more encouragement and support from service users.
- Changes stick because they make sense to everyone affected by them.

At a system/community level

- Major decisions are more transparent and therefore more acceptable.
- Better decisions are made because more people's views, perspectives and suggestions are heard.
- Communities take a greater responsibility for promoting health and well-being.
- Other resources within the community are used more effectively.
- Trust is built between communities and the health service.

These benefits are never guaranteed: but they are more likely when we pay attention to:

- Clearing the ground
- Establishing principles
- Agreeing the question
- Defining success

As well as

- Processes, techniques and methods

Bill is head of planning for Midross Health Board, who are planning to open a new hospital and move services away from the cottage hospitals in various outlying towns. He organises a meeting in one of the cottage hospitals to explain to local people the benefits of the new hospital - better equipment, single rooms, higher standards of care. It's not a great success.

Talks about talks

Clearing the ground

When we start putting in new plants or building something, we first have to clear the ground. When we are starting to think about getting strong, healthy participation, we often have to do our equivalent of clearing the ground.

We often pay a lot of attention to systems and structures and policies, and forget that working together starts with people. The context in which the talks about participation take place includes the people who are round the table, and what they bring. We have different roles in this situation, and we bring different experiences and perspectives. If we take the time to discuss and clarify these roles and experiences, we are more likely to do some fresh thinking and come up with a good process.

> "If you always do what you've always done, then you'll always get what you've always got."

Past experience

We can bring some negative assumptions - which may or may not be based on previous experience of involvement in the health service - about what is likely to happen this time.

Is there any baggage we would like to check in before we start?

At the start of the discussions, it might be useful to tell each other about any bad experiences we have had around participation.

- What happened last time?
- Is there something we still feel angry about? Were we let down?
- What are we afraid will happen this time?
- What would help prevent this from happening again?
- If it goes well this time, what would happen? What would change?

Of course, we also bring positive experiences of things which have worked, so it might be helpful to share these now.

Briefly talk through the positive experiences of partnership working that people in this meeting have had:

- What has gone well before?
- What was particularly good about it?
- What would help make sure this happens again?

Authority and responsibility

It is important to recognise our own and each other's authority and responsibilities in this situation. Once we acknowledge these, the

conversation becomes less personal; we can see more clearly 'where the other person is coming from'.

As a patient, relative or community member, my authority might be:

- personal experience of living with this illness - it's my life
- being a friend or relative of someone who lives with the condition
- knowing many other people and families in similar situations
- extensive knowledge of research and practice relating to this condition
- knowing many people in the local community, and being widely trusted
- many years' experience as an activist
- being a formal representative of a consumer group or a community organisation.

The responsibilities that go with this might include:

- reflecting the experience of other people as well as my own situation
- checking back with the other people in my network.

As a member of staff, my authority might be:

- as a formal representative of the Board/local authority
- able to commit resources and to make decisions
- extensive knowledge of research and practice relating to this condition
- many years' experience of planning and managing change.

The responsibilities that go with this include:

- being accountable to the Board/Councillors/senior managers
- having to explain and justify my decisions and recommendations
- basing decisions on evidence, and taking as much evidence as possible into account
- balancing the interests of current service users with those of future service users
- making good use of public resources - resources I am directly responsible for and more generally
- keeping colleagues and other organisations informed
- taking account of the interests of staff and the wider public.

Why now?

How we approach the situation will also be influenced by the timing.

For example, is this a crisis? Has there been a complaint/investigation? Is this exercise being required by an external agency/head office/the Scottish Executive?

It helps when the people involved are open about the reasons for the discussions, and about any timescales associated with them. But it also helps when everyone is willing to be flexible when possible.
The other reason for pausing to think about 'why now?' is that the background can colour how we approach the situation. If it is a crisis, we all tend to find it hard to stand back and be reflective. If it is a complaint, people will generally feel defensive and take a 'them against us' position. If we are doing this because we've been told to talk to people, we might be more concerned with whether the meeting happens than in listening to what people say once they are there.

Points to think about might be

- What do we need to tell each other about the reasons for these talks?
- Even if the timing is not of our choosing, what are our reasons for talking to each other?
- What can help these talks be as useful as possible?
- Do we want this to be a one-off conversation or part of an on-going dialogue?

Summary

- Get the right people round the table.
- Let go of the past experience that gets in the way and use the experience that helps.
- Recognise your own authority and responsibilities, and respect other people's.
- Think about why you want to have the discussions, and why now.

Establishing principles

Effective talks are based on some principles, even when these aren't stated or obvious to the people involved.

When you are having talks about talks, it is a good idea to make the principles explicit.

Values

The talks will be more useful when the values are clear, and are shared by all the people involved (as far as possible).

You might decide that the principles you are working to are:

- Genuine respect
- Inclusiveness
- Willingness to learn
- Openness/disclosure
- Give explanations/feedback on decisions

Scope

The talks will also be more useful if people are as clear as possible about what the scope is.

What's negotiable? Is the discussion about how the new service will be organised really open, or has it already been decided that the staff will be based at the health centre and it will operate between 9 and 5?

Openness and disclosure might be one of our principles, but are there any limits to this?
Are we really asking the community for participation/joint decision-making? Or is this just consultation, where people are asked their views but the NHS will take the decisions and implementation alone.

Do we really want to be part of the solution, or is it easier to make comments and then leave the rest to other people?

How far can you go? Describing the problem? Coming up with solutions? Implementing the solutions?

What's in it for us?

One of the reasons why some people - staff in the health services and people from communities - feel disillusioned about partnership working is that it feels as if they have put in a lot of effort to help move on the problems that someone else has raised, but have got very little for themselves.

- Are all the people or groups who are helping make the participation happen going to get what they need from the process?
- Can we do something to help one of the groups move on an issue that matters to them at the same time as we work together on the first issue?
- Is it balancing out in the long-term?

Inclusiveness

Certain groups typically get left out of consultations and feel least involved in decisions about their own care.

- How much effort are we prepared to put in to tackle this in this process?
- If it will take longer to have a proper discussion with some people who are likely to get missed from the usual consultation methods, are the rest of us willing to wait?

Information and Knowledge

If people have only experienced what they have now, and don't know about any alternatives, how likely is it that they will come up with imaginative and practical options for change?

Move together to a new place

If the aim is to work together to find a new approach, or a new way to talk to each other, then we don't have to worry about defending the position we started out with.

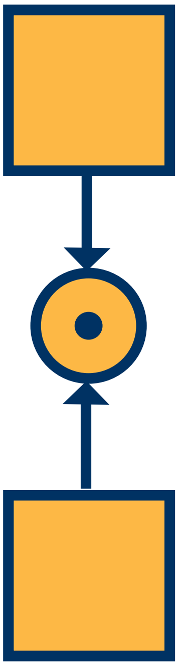
What we are trying to get away from is:

- seeing any change as a compromise or a sign of weakness,
- if someone has won then someone else must have lost
- defending a position - right or wrong.

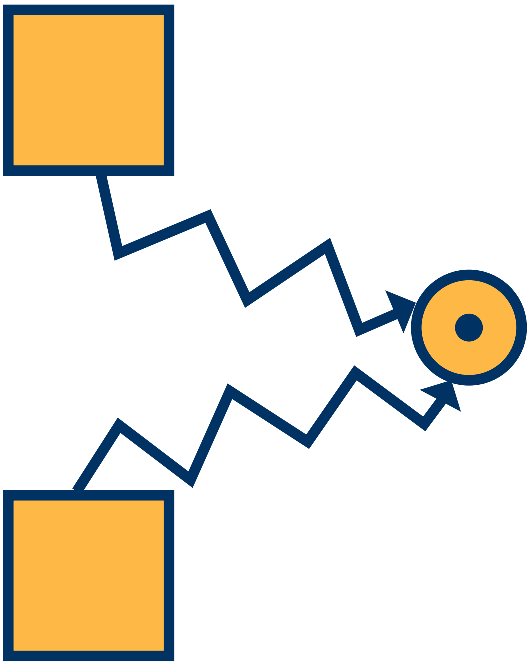
What we are looking for is:

- each person understanding the other person’s situation better
- each person contributing to the new ideas
- looking for a place where we are both getting what we need.

instead of people moving to a compromise,



people respond to each other and move together to a new position that they share



Summary

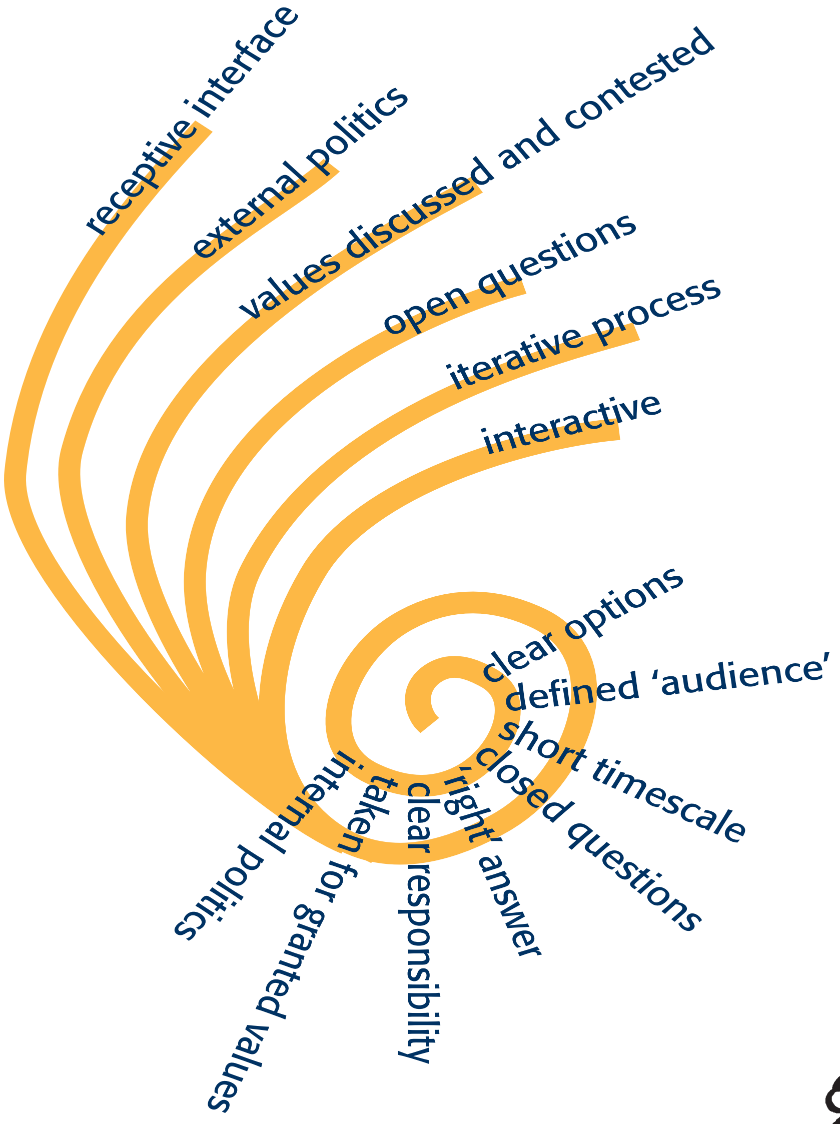
- Be open about the principles and values you want to work to.
- Recognise that working in new ways will involve some movement.
- Look for the advantages that come from working together.

Agreeing the question

If we are going to have talks that are productive, it will help if we are talking about the same things, and about the right things.

Some of the tensions that can happen are:

- One person looking for certainty while another wants to explore options.
- One person looking for the method that will produce the 'right' answer that will then stick for a long time, while another person is expecting that the whole context will have changed part-way through the dialogue.
- One person focusing on the internal concerns of their organisation, while other people are looking at how all the various organisations interact.



One way of thinking about it is a spiral, with one part a single strand and inward looking, and the other opening out to multiple strands. Points to remember are:

- Both parts of the spiral matter.
- Sometimes the questions we want to talk about are in the closed part and sometimes in the open part of the spiral.
- The people you need, and the types of methods you will use to have the dialogue, are very different in the 2 situations.
- It can be hard for individuals who are comfortable with one situation - perhaps because that is all they have known - to move to the other part.
- When the 2 people are in different parts of the spiral the dialogue is going to be difficult - so it will need longer and more checking out as you go.

The examples of people being in different parts of the spiral come up in all situations. And people from both the NHS and people from communities will be among those who are naturally comfortable in the closed and the open contexts.

- A GP who encourages her patients to make choices and take responsibility for their health might find that some patients like this responsibility while others still want her to make the decisions.
- Someone who wants to handle their illness in a particular way and get advice from several sources finds they are disagreeing with a clinical team who want to follow the 'best practice' guidelines.
- Two nurses are planning to start discussion groups with people who use their service: but one thinks the topic is 'should we hold the clinics on a Saturday?', while the other thinks the question is 'what is it like living with diabetes, and what can our service do to help you?'
- A manager thinks the consultation should be about a particular health service, because that is what is worrying a professional advisory committee within the NHS Board, while other people think the consultation is about exploring how people in a particular area use all sorts of resources.

The case examples in the rest of this section show some of the tensions that can arise when people are not clear about whether they are talking abut the right questions, and how the methods used to have the dialogue can make a difference.

Summary

- Take time to agree what the right question is.
- Think about whether it is a closed, certain issue or an open, fuzzy issue.
- Give yourself and other people space and confidence to ask different questions and think in different ways.

What is important to families?

This is a list of factors that some parents of children who have labels of special needs identified as important to them and other parents taking part in various consultation and partnership arrangements.

How to make involvement work

Commitment

There must be the belief not that involvement is only about political correctness. There is no point doing it because you have been told to do it or it is the latest 'thing'. The belief has to genuinely be that those who use services are the best placed to know what they need.

Timing

People must be involved in actual planning and policy formulation. There is no point producing a shiny document, on which the priorities and funding implications have already been decided - and asking what do you think of what we have done? There is usually no room for more than a comma or full stop - no wonder people do not respond.

Empowerment

Give people the training opportunities and they will be a huge asset for you. This is the role of Partners in Policymaking and similar opportunities. This way, all consultation and involvement is done with people and not to people - you may find that you ask completely different questions.

The Right Questions

Instead of asking 'what type of activities would you like us to provide in day centres?' - try asking ' how would you like to spend your day? Instead of asking 'what type of respite service would you like?' - try asking '’what sort of supports would you need to live a normal family life?'

Goal - Be absolutely clear what you are trying to achieve from a consultation or involvement exercise. Do not ask people for their views unless you intend to respond / act on what they tell you - this will also decide the method you use.

Method

It is important to believe that there are lots of ways to consult and all are legitimate and all need to be used appropriately. Inviting everyone to a public meeting to discuss a 40 page report is going to be impossible

- but having a few key people in at the planning stage of such a report is much more feasible. Not everyone wants to be consulted or involved - different methods for different people.

- Genuine partnerships - users/carers etc as part of the team - working on policy and plans - Joint Commissioning Team membership.
- Workshop model - invite larger groups but give presentations and use facilitators to work in small groups - usually works best if done with specific topics and not too wide ranging.
- Consultation days - open meetings to discuss a range of issues or a particular issue.
- Use local champions - people will generally respond better to someone they know and trust.

Working with families

Key points

- Commitment
  Based on a genuine belief that those who use services are best placed to determine what kinds of service they need.
- Timing
  Involving people in planning and policy formulation rather than consulting with them on documents that have already been written.
- Empowerment
  Giving parents training opportunities enabling them to become valuable and valued contributors to true partnership working.
- Clear Goals
  Being absolutely clear about the purpose of involving parents and children and being prepared to act on the contributions made by them.
- Method
  Using methods which are relevant and appropriate to the people you want to involve and being prepared to be creative.
- Right Questions
  Thinking carefully about the outcomes you wish to achieve...remember, asking the wrong questions will result in the wrong answers.

- Action
  Being prepared to implement suggestions to achieve tangible changes within a reasonable timescale.

Source: Josephine Cochrane and Dorothy MacDonald: workshop at Child Health conference, 27 February 2002

Summary

- Get a shared understanding of what you think is a success in this situation.
- What will be a success for the way the dialogue happens?
- What will be a success for people delivering and using real health services? What will be different for them?

Getting started: preparing for the participation

Even when we recognise that the dialogue could be better between the NHS and the people who use services, it can be hard to start making this happen.

It is easier when everyone is able to make the first move - and doesn't feel that this is someone else's role. It is also easier when the practical aspects are right.

Many of the approaches that are described in the other part of this toolkit have more detailed suggestions about the practical aspects, but there are some basic elements that help in any situation.

Making the first move

Sometimes people feel they want to talk to someone but aren't sure where to find the right 'other person'. Knowing who to talk to helps, but it is usually better to make contact with someone in the organisation, and ask them to bring in colleagues who should also be involved, than to take no action at all.

Possible starting points are:

- Many NHS Boards provide information of how the public can contact them.
- Staff such as public involvement workers will be able to help.
- The Health Council should be able to give advice.
- Community development workers and health promotion staff often have good networks among community groups and can put you in touch with colleagues in other departments.
- Volunteer co-ordinators in the NHS will know their way around NHS and community networks.
- Community Care Forums and Councils of Voluntary Service have contacts in many community groups.

What makes it hard to talk about health?

Communication is always difficult when one or more of the people are:

- rushed
- angry, or frightened
- uncomfortable - thirsty, sitting in a cramped seat, tired
- worrying or thinking about something else
- not talking about the same thing
- out of his depth
- assuming that he or she knows what the other person is going to say
- not taking what the other person says seriously
- unable to find the language for what she or he wants to say.

Talking about health can be difficult for all those reasons, and it is also by its nature difficult.

- The subject is upsetting or worrying.
- Often several issues are intertwined.
- We want to talk about the feelings aspect of ill health, but most of the conversation is about tangible aspects - symptoms, treatment etc.
- The conversations often involve talking about other people - so get caught up in issues around confidentiality.
- People put a lot of personal effort and commitment into the service, and any suggestion about changes can feel like a personal criticism.
- There are big differences of power and knowledge.
- Conversations about health care are often against the backdrop of money, or politics, or both.

Background to the meeting for Mary and Jean

When Mary went to the meeting about her aunt Jean, working out what the issue was that was being discussed wasn’t the only problem.

The meeting was arranged at very short notice. Mary had to drive over 60 miles to get there.

By the time Mary got to the hospital, she was angry and upset. She didn’t have a chance to talk to Jean about the suggestion that Jean go to a nursing home instead of getting back to her own house. It was hard to get away from work early, then the traffic was terrible and she got caught in the one-way system and was late.

The doctor had only seen Jean once and was working from Jean’s notes and a brief conversation with his colleague, who had been called away to an emergency. He was being bleeped by the ward while talking to Mary.

When Mary arranges the second meeting, she wants it to include Jean and discuss the issues that matter to Jean. She also wants it to happen in a calmer setting.

When and where?

Think about the discussion being in places where everyone will be comfortable and feel able to talk over the issues and ideas as equals.

Factors that get in way can be:

- Holding all the discussions in places that are clearly the territory of one person or organisation - such as someone’s office, the board room.
- Using venues that are difficult to get access to - not suitable for people who have problems walking or getting up stairs, or for people who have a hearing loss.
- Having meetings at times that make it difficult for people to get there, or to concentrate (when is the last bus? will I be back for the children getting in from school? will I be away in time for my next meeting?).
- Places where one or more people will be interrupted with phone messages or by people wanting to speak to them.
- Places where people tend to think in predetermined ways.

Factors that can help include:

- using different locations
- finding a venue where you won't be disturbed
- setting aside a day or half day for longer discussions
- talking to each other by phone or email to keep the communication going between meetings
- making sure people have any supports or practical help they need.

Other practical aspects

It is important to get the basic practical aspects right for the initial talks about talks as well as for the main dialogue.

- Enough time to have the discussions - on the day and allowing enough time between meetings for people to check out ideas with colleagues.
- Accessible information.
- Making sure that everyone is covered for travel costs and other costs like childcare or someone to stay with a relative.
- Access to interpreting and translation services - not just for people from minority ethnic communities but also for people who are deaf and people who do not use words to communicate.

The Partners in Change project has developed a set of Meetings Checklists, which have more suggestions on productive meetings which involve people from the community and staff.

Fair for All, which was launched by the Scottish Executive in early 2002, gives more policy advice and further contacts of making health services more accessible to people from minority ethnic communities.

Facilitation

There are also situations where it can be useful to have another person to facilitate the meeting.

Circumstances where this can be useful include:

- Where it is likely that someone will be upset or angry.
- Where there has been a history of difficult discussions in the past.
- Where you know you will find it difficult to keep to the point - for

example where there are a lot of interconnected issues.

- Where all of the people at the meeting want to contribute, so it is harder for any one person to take on the reflective or managing the meeting roles.

Points to think about around who can do it are:

- Is it better to have someone from outside any of the organisations or networks involved?
- Is it useful to have someone who knows the background and the context, but is not directly involved? - such as someone from another part of the NHS Board or a local authority, or one of the community networks; someone from another NHS Board or a community activist from another area.
- Have we any resources to pay for someone?: if not, look to colleagues from within your organisations or networks, or someone from another organisation who will do it on an exchange basis.
- Do we want to use or develop the skills of people that we know?
- Are we looking for a particular type of facilitation, such as graphic facilitation - because that will help the people at this meeting to contribute or reflect on what is emerging?

Even when you do use a facilitator, it may be useful to bring in this support at key stages, such as the first few meetings or if discussions get a bit fraught, rather than have them there all the time.

Summary

- Start talking to someone and ask for introductions, rather than delay until you find the 'right' person.
- Think about how to make the communication easier.
- Pay attention to the practical details

Pulling it together

By this point you will have worked though most of the issues and practical aspects that will let you have a healthy discussion about the type of participation you want to see happen, and how this can take place.

Main stages to having talks about talks

Define the problem.

Define how you will organise the discussions between the community and the health service (or with other people).

Consider who is the right person to lead the discussions from this point on. The person who first instigated the talks about talks can end up with all the work when it would be better to hand it on to someone else.

Accept that as soon as you do go out and the dialogue between the community and the service starts, other people will bring other ideas and issues.

Identify which tools you are going to use: the other parts of the toolkit are useful here.

Begin the dialogue

Try it, start your plan.

Reflect

- Is it a success in terms of the process? Are people having a say? Are you reaching the right people?
- Is it a success in terms of the likely outcomes? Are the changes to the way someone gets a service going to happen, or is there something else that needs to be tackled?

Revise your definition of the problem, or how you are tackling it, as need be.

Listen to what people are saying.

Reflect - what action is needed, and who is doing it?

Continue with the talks about talks

Do people still want or need to be involved in working with the NHS on this matter? What is the issue now, and how are we going to work together to get people be involved?

For each situation write down:

What the issue is

What the values are that you agree are important here, and that everyone will try to put into practice

Write down the plan of how you are going to take it forward

Making the participation happen

This section has 3 examples, to show how the talks about talks, choosing helpful methods and working to make changes happen can all come together. Like all the case examples in this guide, they are based on real situations.

Midross Health Board and the Cottage Hospital: trying again and opening the discussions

Bill was the manager at Midross Health Board, who found that the public were not as impressed as he was with the plans to replace the cottage hospital.

Bill had decided hold a few meetings in each of the cottage hospitals that were going to be closing. He invited representatives from the Health Council and a few other bodies, and mentioned that members of the

public could also come along. One reason was that this was how the Health Board usually handled consultations. Another was that the changes affected services that were used by various groups of people, and he felt that if he talked especially to one interest group he would have to talk to all the others.

The first public meeting was angry and difficult. Many more people turned up than Bill had been expecting - so the room wasn't big enough. People accused the Board of trying to hide the decisions - it was supposed to be a public meeting, but it hadn't been advertised in the local paper, etc. They said the Board did not really want to listen, and was making it hard for the people who were most affected to have a say.

Afterwards, Bill and some colleagues met with some local people. This meeting took place at the local library. Most of the first meeting was about what had gone wrong that time and on some other occasions, and also what had gone well with previous consultations and discussions.

The new consultation plan was arranged around:

- Going to places where older people (who were the main users of the services affected) would be, or could come along.
- Taking longer to explain to people what the changes would mean in practice.
- Getting people's ideas about other ways to make life easier for people who used these services - so also bringing in discussions about local authority services and community resources.
- People going to see the new facilities and fact-finding visits to similar hospitals that had replaced cottage hospitals in other places.

The approaches that were used included:

- A series of open meetings at libraries, community centres, community health projects, etc.
- Sessions at places such as lunch clubs, Women's Guild meetings.
- People having discussions with graphics and photographs of what they liked and what they wanted to change around the current services.
- Focus groups of people who were younger and who also used these services a lot.

- Meetings, focus groups and interviews with people from the minority ethnic communities, who tended to use the current services less often than other people: the new hospital was being planned in ways that were aimed at better reflecting the preferences of this group of people.
- Individual people sending in comments and suggestions.
- A series of discussions with the staff who worked in the cottage hospital.
- Having public meetings in the evenings and afternoons, but towards the end of the process to both check out and feed back on what was emerging so far.
- People from the local community leading many of the discussions - being the facilitators, going to meetings in a pair with Bill or another person from the Board.

Sam and Jill: more participation for one person leading to changes for other people

Sam has had a lot of health problems since he was a baby. He lived at home with his mum (Jill) and dad, with support from health services and from other services organised by the local authority. Eventually Sam's mum and dad were persuaded that Sam needed too much support, and that he should go to a residential school. Sam was not happy, and neither were his mum and dad.

Every time there was a review about Sam, Jill asked if could come home, and was told this wasn't possible. Jill began finding out about different ways in which children like Sam could be supported at home. This included ideas from other parts of Scotland and further afield. She also found other people who could help her work to get Sam home. The next time there was a review, she said the question ought to be not 'can Sam come home today?' but 'what will it take for Sam to be able to come home?'

It took nearly 2 years and a lot of hard work by people who worked in services as well as by Jill and people who were helping her. By then there was a voluntary organisation which was willing to try to provide Sam and his family with the kind of support the new assessment said that Sam would need to be at home. The local health services were also willing to try some things they had not done before in quite that way. And the senior managers were supporting the new arrangements.

Sam came home. It hasn't been easy all the time, but overall it has worked even better than anyone had expected. So the outcome has been good for Sam, Jill and the rest of his family and friends.

After the services were in place for Sam, the voluntary organisation, health services and other local services looked at the way the support was working, and began providing more flexible types of care and support as part of the range of things they did. So changes began to happen at the level of these services, and this meant more choices for other people who now have more opportunities to be involved in planning what happens to them.

The discussions that Sam's situation had started continued after Sam's arrangements had been agreed. Most of the agencies in that area are looking at what they do. The question now is 'how do we support people in the way they want to live?' These discussions will go on for some time and will include consultation with other people and families on the ideas that are emerging about types of support and how people can make choices.

Some of the approaches that have been used to make these discussions and changes possible have included:

- Individual planning with Sam and his family, especially the use of Essential Lifestyle Planning.
- Advocacy for Sam and sometimes for Jill.
- Circles of friends around Sam, to help him continue to be able to make choices and to be an on-going safeguard for him.
- Large-scale facilitation using PATH (one of the other person centred planning methods) when all the local agencies began reviewing how families can best be supported.
- Presentations on the support for Sam and what has happened in other places, to let people think about options that are not available in their local area.

The approaches that are going to be used in the next stage include:

- Consultation methods such as interviews, focus groups, for other families.
- Consultation with people who before have tended to be left out, because they communicate in different ways from most other people.

Quality Panel review of Cardiac Services: involving people in improving current services and planning for the future

The Cardiac Unit at a hospital wanted to look at the quality of their services from the point of view of the patients and their families, as part of a wider rethink of how services could be organised in future.

Some members of the Patients' Reference Group at the Trust volunteered to help, and worked with people who had been in the cardiac ward the previous year. They talked to patients at the outpatient and inpatient services, some families, and to staff. The report made suggestions about how the quality of the current services could be improved and ideas for longer-term changes.

Some suggestions were acted on almost immediately; some got fed into the review of Cardiac Services; and some were taken up by the Patients' Reference Group because they could apply to most people who came to that hospital.

The quality team had developed a list of points that people and families thought made a good quality cardiac service. Staff began using this list in discussions with individual patients to help make sure each person was getting the care and information they wanted, and people are now routinely more involved in planning their own care.

One of the points raised by the quality team was that many of the people who came to the cardiac unit were older people, but there did not seem to be any connection between making life easier for people who had heart problems and planning for all older people in that area. The next stage of the follow-up action will include making these links.
The Patients' Reference Group and the Trust had talked before about having a Quality Panel, but this was the first time people from the community had taken on this role. The Patients' Reference Group is now recruiting more people to join a Quality Panel for services across the Trust.

The approaches that were used for the initial quality team were:

- Building on the Patients' Reference Group.
- Advice and training from a Mental Health Users Group that had experience of user-led research on how to do surveys, and some advice from a researcher.

- The team gathered information through focus groups, face-to-face and telephone interviews and a small-scale survey, and through their own observations.

The approaches used to take forward the results and make the links with wider planning included:

- Some people joining the Cardiac Services Redesign Group as lay members.
- Taking some of the issues on through the Older People's Joint Strategy group.

Reading list

Holman, H. and Lorig, K. (2000) Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. BMJ (BMJ (Clinical research ed.), 320(7234), 526-7

Partners in Change (2001) Checklists for meetings (series of four booklets). Edinburgh, Partners in Change. Available from http://www.shstrust.org.uk/publications.html

Scottish Executive (2000) Our National Health: A plan for action, a plan for change. Edinburgh, Scottish Executive Health Department. Available from: http://www.scotland.gov.uk/library3/health/onh-00.asp

Scottish Executive (2001) Fair for All: Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland. Edinburgh, Scottish Executive Health Department. Available from http://www.scotland.gov.uk/library3/society/ffar-00.asp

Scottish Health Feedback (2002): User and Public Involvement in Health Services: a Literature Review; Partners in Change

Power

This presentation is heavily indebted to the work of the Craighead Institute and the Grubb Institute and is based on the papers these organisations prepared on the subject of power and authority. In particular these notes draw on a paper entitled "Reflections on Authority and Power in Groups and Systems", by Colin Quine of the Grubb Institute. This paper formed part of the course materials for a Diploma course in consulting and facilitating, organised by the Criaghead Institute in 2002.

The key extract from these papers refers to work undertaken by Bruce Reed of the Grubb Institute in the early 1970's which led him to define power and authority in the following ways:

> Power is an attribute or quality of persons or groups. Authority is an attribute or quality that is attached to roles within a system.

In this presentation we are going to focus on the term power. Reed distinguished between four different sources of power.

Px	Personal Power
Pi	Instrumental Power
Pp	Projected Power
Po	Official Power

Personal power (Px)

This is the power that each of us has, based on our skills, experience, know-how and personality, combined with our particular personal resources of appearance, intelligence, character, temperament etc. Your gifts are examples of your personal power.

This power can be inherited (how you look) or acquired (through developing knowledge and skills), but you have responsibility for how you use it.

Personal power is always available for our use because it belongs to us. However, we can be in circumstances where, for example we are experiencing high levels of uncertainty or anxiety, and we can lose touch with our personal power and feel "powerless" or "de-skilled"

Instrumental Power (Pi)

This is the power you have because you have control over resources. These resources can be money, information, contacts, equipment. All these resources are external to the person (unlike personal power) and their access to this power may be under the control of someone else (for example, their line manager).

Whilst control over and access to money is a very obvious example of this power, contacts, networks and information are also extremely important when you are trying to influence change. Exercising this power means developing these relationships and using those connections.

Projected Power (Pp)

Projected Power is power attributed to or given to you by other people. Leadership of groups and organisations depends on your capacity to attract projected power. When you are leading groups you are carrying this kind of power, projected onto you by the people who are following you or supporting you.

The person does not have any control over whether they are given projected power and projected power can be both

- positive. (for example, believing you are a good person because you are a priest) and
- negative (for example, believing you know everything about everyone in the office because you are the boss's wife).

Celebrities carry projected power. It can also be given to people because of their relationships to other people who are seen as powerful. As this power is given to you by others, you cannot control it.

People can be seen as charismatic leaders because others project a certain kind of power onto them. The power comes from the way others regard you, the qualities and attributes they assume you to have. If something disrupts this view of you (a scandal or previously hidden information) this power can evaporate in an instant.

This power is connected to reputation and public perception. It can operate negatively with people who have previously been socially devalued. People who are trying to change traditional attitudes have to be acutely aware of this kind of power.

Official power (Po)

This is the power that you have because of your title, office or position. This may be because you are called the Chief Executive, the Director, the Manager, the Head teacher, the Minister. The office of course also gives you access to instrumental power.

This type of power is based on people’s expectations of the title, not the person. Official power can operate, regardless of the person, their capabilities, their personality or whether they are even known or recognised. It can operate on the basis of their signature. This also means that the power will be passed onto the next post holder and not remain with the past post holder.

These different kinds of power help us understand why we might be powerful in some areas and powerless in others. By examining our own sense of the power we carry, we can increase the power we have and use it more consciously.

Individual Exercise
Mapping our power

Why do we do this

This is another attempt to help you reflect on and evaluate your current situation and think about how you might amend or improve it. Acknowledging and owning the power you have is an important part of the process of becoming a person who can make change happen. You have to also be aware of when projected power may be working against you.

How do we do this

Everyone will individually be given some time to think about their own personal power and take their own notes on the attached sheet. This information, together with the dream poster, the mission statement and the credibility map can be shared with members of your Locality Group when you meet before the next session.

Using the four definitions of power outlined in the presentation notes, please write down your own description of how these kinds of power are realised in your own life. If there is an obvious gap, you may want to think with members of your locality team what you can do about this.

Mapping my power

Please take this page to note down your own sense of the different kinds of power you think you have at this stage.

Personal power - Px

For example, your knowledge, skills, personality, appearance, ability, gifts.

Instrumental power - Pi

For example, your control over resources such as money, equipment, information and people. All the networks and connections you have access to.

Projected power - Pp

For example, the way others see you and what they invest in you. It can be influenced by public perceptions and attitudes. Remember that this power can be positive and negative.

Official Power - Po

For example, any posts you hold (chair, treasurer etc) or titles you have (for example, job titles or roles)

Where are you currently powerful?

Where are you vulnerable?

What can you do to change the current situation?

Change is dangerous - ways of losing credibility

It is important to recognise that people making change happen is disruptive. Any organisation facing disruption tries to restore balance. Heifetz and Linsky, in the book "Leadership on the Line" (Harvard Business School Press, 2002), talk about four basic methods organisations use to prevent change and restore equilibrium:

> "When exercising leadership, you risk getting marginalised, diverted, attacked or seduced...When people resist adaptive work, their goal is to shut down those who exercise leadership in order to preserve what they have."

Examples of marginalisation might include:

- demoting, sacking or relocating someone
- listening to the person only when they are talking about their designated area of relevance, i.e. women only being asked to comment on issues directly related to women, such as childcare or the shoppers crèche
- undermining someone's authority or credibility by the way you react to them, talk about them, behave towards them
- identifying someone entirely with the issue they represent - so you can ignore them when that issue is no longer a fashionable or pressing issue
- setting up a small scale, pilot project which has no impact on the mainstream.
- giving a small, generally insufficient amount of funding to a new group

Examples of diversion might include:

- encouraging or compelling someone to widen their agenda so broadly that they lose focus and impact
- promoting someone and giving them more responsibility
- overwhelming the person with other demands, ensuring that they are kept extremely busy

Examples of attack might include:

- turning the focus of attention away from the change issue and onto a personal issue, making the person the topic of conversation, not the issue
- being physically removed or controlled, e.g. demonstrators being restricted by police
- Being attacked for your character, your competence, your family or the company you keep
- Misinterpreting your views
- Being physically attacked, injured or even assassinated

Finally, Heifetz and Linsky talk about seduction, a politically charged word. They define seduction as taking someone out of action by attracting them with something that has special appeal to them.

Examples of seduction might include giving the person something they want:

- money
- power
- influence
- access
- status
- attention
- flattery
- position
- praise

in order to exercise control over them now, or later.

As previously said, leaders are given their position by people who support, admire and trust them. Maintaining the support of your supporters and key allies will sustain you in the struggle. However all change involves both sides agreeing to give up something. When leaders are in a negotiating position, they run the risk of disappointing their own core supporters, their key core allies, every time they negotiate a deal. They are at risk of being seen as compromising, or selling out, or betraying their supporters.

Leaders are similarly at risk of not being taken seriously by the people they are negotiating with if they can't be flexible when brokering the deal.

The leader always has to walk this tightrope, trying to remain credible with both sides.

Anyone exercising leadership has to be conscious of the above dangers and reflect on how they are safeguarding themselves from such dangers.

Remaining credible when working on behalf of others

The person working for change can often exercise influence, but not power. Their position may be in the gift of the people who manage the service system. Their invitation to the table can be withdrawn if their behaviour or suggestions are disapproved of.

They can be invited to make a contribution, but they cannot enforce any action. They can be critical of the current set up, but have no authority over it. Any power they feel they have may feel very transient and disapproval can come from any direction.

When someone is trying to keep them self grounded and safe in such an environment, you need to know whom you are working on behalf of and whose authority your carry within you. You need to know what makes you both credible and authentic.

If we think about this solitary person trying to make change happen, we can begin to imagine a triangular force field around the person. The three points of the triangle represent the following:

- Their personal credentials
- Their constituency credentials
- Their service system credentials

Each of these points carries their own positive and negative attributes.

Personal credentials

These include the person's natural authority. For example, being a parent of a child with a disability, being an older person etc. With the growth in 'user led' organisations, this credential has become increasingly important.

However, it is worth being aware that whilst a strong connection between a person's identity and the cause they are campaigning for is useful, it can also make the person vulnerable. Any time the external world devalues the issue they are wishing to be addressed, they can experience personal devaluation. Any expression of prejudice can be taken as a personal insult. Stigma is experienced not an abstract concept, but is acutely felt.
A person's beliefs and commitment to a cause or set of ideals can also give them personal credibility. People who are seen as genuinely being committed to a cause, without any obvious personal connection (such as having an impairment themselves or caring directly for someone else, etc), are of course essential to the growth of any movement. If the only members of your movement are people who have direct personal reasons to be there, you will not change the world.

Constituency credentials

These include the organisations, groups, clubs and families you consider yourself to be a member of and to represent.

Your influence can mirror the public reputation and power of the organisation. Some organisations are more powerful than others: they have larger bank accounts; they employ more staff, they have been around longer and they are members of the recognised disability establishment. Others are viewed as troublemakers or single issue groups, who have a very narrow focus. They may be seen as angry and destructive, rather than passionate and constructive. Trying to create a profile for a new issue or group is time consuming and organisations are often in competition with one another for restricted resources and influence.

Service system credentials

These include the groups, committees, steering groups and working parties you are a member of and the number of key people within that system you can count as allies.

The status you have in these groups will depend on the alliances you make, the personal relationships you develop and the knowledge you bring. If you are not involved within the service system, you have little chance of changing anything. You may have huge personal authority and strong support from your constituency groups, but you won't be making anything change.

Being centred

Imagine these three different kinds of credentials as points on a triangle around the person. Each point of the triangle is in tension with the other two and the task for the person is to remain an equal distance from each point in order to retain credibility with each party. If the person moves more towards one point than the other, then the whole structure becomes distorted.

For example, if the person is seen as being in the pocket of the service system, the people and cause they represent may begin to become uncomfortable and feel unrepresented or even betrayed. They will withdraw their support. Alternatively, if the person does not manage to maintain status within the service system, they may be strongly supported by their constituency but be of no use in negotiating change.

If the person is seen as being only interested in their own personal issue, they can be sidelined by the service system and marginalised by the constituency of interest they claim to be a member of. They can be accused of working only out of self interest.

If the person is seen as working on behalf of one group, they can again attract criticism in terms of self-interest, particularly when service provision contracts are being negotiated. However, if they have no connection with any group or organisation, it is difficult for them to act in a representative way as they may have no one to check anything out with or to mobilise.

The task for the person is to be aware of how healthy and balanced their own credibility map is and to take action to ensure that each point of the triangle is strong.

Little Group Exercise
Drawing our Credibility Maps

Why we do this

To help participants identify where their own credibility comes from and whether they are in a balanced and powerful position, or vulnerable.

How we do this

Participants will be asked to work in small groups, perhaps groups of 2 or 3. Each person will have a sheet of flip chart paper and with the help of the other members of their small group, they will begin to map out who they have in each corner of the triangle.

A template for the flipchart is shown at the end of these notes.

Personal credentials

List any personal authority you have. This may be being a parent of a child or adult with a label of disability; having an impairment yourself; experiencing a period or mental ill health; living with a long term medical condition which has significantly affected your life, or caring for anyone in such a situation.

You may want to quantify your experience in terms of years or members of your family. It is up to you.

Try and write down the beliefs you carry within you as a person - these may not have been clearly listed before, but they might include a commitment to the values of inclusion listed at the beginning of this pack, or a strong belief in the social model of disability, or a religious belief in the value of people. Whatever your personal values, please try and identify them here.

Constituency credentials

List any groups, organisations, clubs, associations, informal gatherings that you are part of where you work with others on the issue you want to change.

You may be a formal member of some of these groups; you may be a regular participant in some shared activity. You may just know a whole lot of people and be someone that lots of other people talk to. How are you using those connections?

Please try and identify any formal roles you have within these groups and whether you have any representative responsibilities. If you do, it may be worth thinking about how you ensure that you are being representative. What processes or structures do you use to consult with others and how widely do you consult?

Service system credentials

Try and identify who you know and who listens to you within the system. Who is your good fairy, your ally? Which committees, working groups, focus groups, networks are you a member of? Who invited you onto these and how much influence do you have over the work the group/ committee does? Who listens to you and who seeks your advice or support?

Once you have written down the names of the individuals and groups in each section, share with the other people in the group how healthy the map feels. Does it feel in balance and stable or out of balance and precarious? Do you have all your eggs in one basket? Are you completely tied up with one organisation, or do you have lots of different connections? What does it feel like?

Looking at the map, reflect on what you have learned from it. You may want to think about some of the following questions:

- What does the map tell you about how you live your life and where you are spending your energy?
- Where are you vulnerable?
- If you stay in the position you are in now, how will it impact on your ability to achieve your mission?
- Do you need to make some adjustments to the way things are now and what might they be?

My credibility map