

ROUTE MAP TO USER AND CARER PARTICIPATION

**PART 3
INFLUENCING ORGANISATIONS THAT PROVIDE
CARE AND SUPPORT**

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BOX 1 PROVIDING SERVICES

It is important to make a distinction between the organisation or the project and the service:

- The organisation or project provides the service
- The service is how care and support are offered.

People may want to influence the way an organisation is run or the type of service that is provided or both.

INDIVIDUAL RESOURCES OF USERS AND CARERS

CONFIDENCE TO MAKE CHANGES

What has helped you to build up your confidence and the skills you need to participate?

In what ways does the organisation or project whose services you use enable:

? You as an individual to use your experience, skills and interests in the organisation or the service?

Users or carers as a group to apply their individual and collective experiences, skills and interests to participating in the organisation or the service?

Can you point to changes in services that you or other users have brought about or prompted others to make?

BOX 2 POSITIVE CHANGE

If you have been asked for your opinion, it is important that you can see how your contribution has made a change in areas of the service that are important to you. This experience of making an impact can boost your confidence and help to keep you involved.

WORKING TOGETHER

What practical arrangements and support does the organisation or project provide to enable users to meet together?

How does the organisation or project ensure that opportunities to participate are made available to a wide group of people using the service and not just to one or two key people?

What is done to include people with experiences of different mental health problems?

TRAINING AND DEVELOPMENT

Does the service make provision for the training and development of users and carers, as well as of staff, to support them in the roles they wish to play in the running of the organisation or service?

SKILLS

WORKING TO SUPPORT PARTICIPATION

Do workers have the necessary skills to support users coming together and to facilitate discussion?

TRAINING AND SUPPORT FOR WORKERS

Are staff trained and supported to work in participative ways?

Does this make a difference to the way the service is provided?

INVOLVEMENT IN RECRUITMENT AND STAFF TRAINING

When new staff are being recruited, do you have a say in what skills the new worker should have?

Are you actively involved in the appointment of staff?

If so, do you feel prepared for the task and supported by the organisation?

Are you involved in training staff? If so, how?

TRAINING FOR USERS

Do you know what training opportunities there are for those who want to play an active role in the organisation or the service?

Is anything being done to identify the particular skills and areas of interest that you would want to develop?

PERSON CENTRED PLANNING

How can frontline staff be encouraged to use person centred approaches in planning their care and support with someone?

BOX 3 PERSON CENTRED APPROACHES

Some organisations that support people have adopted a person centred approach. They base their work on the values of person centred planning that see us all as human beings with the right to lead our own lives in the everyday world.

Person centred planning takes account of particular requirements that we might have and the constraints that face us - such as shortage of money, health issues, safety, legal orders, the rights of people who help us. So compromises have to be made or we have to accept that it might take a long time to achieve a change. We need to be clear what is not negotiable and what can be compromised - but these decisions have to be made by us with help from people who are important to us and not behind our backs.

A person centred approach to working alongside people who use services keeps the needs of each person at the centre. The individual and the people who know him or her well are involved in all the decision-making processes. A person centred approach recognises that we all need support from families, friends and services in our lives, but they should not take over. Services help people work out how they want to live, what they want to achieve and what support they might want to do that.

TIME AND TIMING

LONG-TERM VIEW

Have local organisations or projects worked with users and carers to plan what the service or project needs to do to enable you to get more involved and have more influence?

Do you know if local organisations or projects have set themselves long-term goals to extend user and carer involvement and influence?

How are you involved in deciding what the organisation or project should aim for?

Do you have the opportunity to say what you think about how the organisation or project is progressing?

INVOLVEMENT AT AN EARLY STAGE

What is the organisation or project doing to ensure that you can get involved at an early stage in planning your care and support?

What does the organisation or project do to make sure that you can get involved at an early stage in any plans to change it?

ALLOWING ENOUGH TIME

Does the organisation or project work in a way that allows enough time in meetings for you to ask questions and raise issues?

STRUCTURES AND ADMINISTRATION

POLICY ON INVOLVEMENT

Does the organisation or project have a policy on the involvement and participation of users and of carers?

Do you know who is involved in developing the policy?

Do you know who is responsible for ensuring that the policy is implemented and monitored?

Are there opportunities to be involved in practice as well as on paper?

INFORMATION ABOUT THE ORGANISATION

Is there clear information on how:

? The organisation or project is run?

The service works?

Decisions are made?

You can be involved?

RUNNING THE ORGANISATION

Which aspects of running the organisation or project do you participate in?

For example:

? Staff recruitment, appraisal, training and development

Business planning and service development

Managing the service

Developing and reviewing policy and procedures that guide staff

Monitoring, reviewing and evaluation of its work

BOX 4 RANGE OF OPPORTUNITIES

You may want to be involved in a number of different ways and your capacity to take part may vary from time to time. The organisation or project must make sure that there are a range of ways in which you can be involved and that it does not expect you to fit in with staff expectations.

What do you think helps people get involved and stay involved?

What are the things that get in the way of user involvement?

DECISION MAKING

Is it clear to you how decisions are made in the organisation or project and who makes them?

Do you know if there are checks and balances in place to ensure that decisions have to have user input?

Do you know if there is a flowchart that shows how and where decisions are made, to indicate where users can best exert influence?

What are the things that are fixed and that cannot be changed?

How do people learn about what can be changed and what cannot?

Does the organisation or project make use of the direct experiences of users and carers in making decisions?

Can users and carers point to positive changes that have come about as a result of their involvement in making decisions?

RESOURCES

Do you know if there are resources earmarked to support involvement?

Is there someone with the authority, capacity and ability to act as a motivator to encourage involvement and sustain change?

INFORMATION AND COMMUNICATION

CONCERNS

How do people make their concerns about the organisation or project providing care and support known?

INFORMATION ON DECISIONS

Is feedback given on decisions to make it clear why a particular course of action was taken?

INFORMATION ABOUT THE ORGANISATION

How can you find out about what is happening within the organisation or project?

Do you think you have the information you need to be involved?

Do you feel free to express your views about the organisation or project?

Do you feel listened to and respected?

Do you think you are able to have influence over the things that matter to you?

INFORMATION AND ADVICE FOR CARERS

What is being done locally to provide advice and information for carers?

Is this the responsibility of specific workers?

How do carers rate what they get?

How are local agencies addressing the issue of confidentiality?

Could this mean that carers might feel excluded?

How does your organisation or project ensure that users and carers are getting information about:

? The range of options available

Specific mental health problems and treatments

Benefits

Sources of information and advice

Contacts for user groups

Contacts for carer groups

BOX 5 INFORMATION FOR CARERS

Local organisations can use a range of different ways to ensure users and carers are getting information they need. For example:

- Leaflets
- Information and advice points
- Advocacy services
- Recognising information provision as one of the core responsibilities of care workers.

ATTITUDES, CULTURE AND VALUES

FINDING OUT WHAT PEOPLE THINK

How does the organisation or project find out views from a range of people - both people who use the service now and those who might use it in the future?

What methods does the organisation or project use to gather views and ideas from users?

VALUES

Are the services provided by the organisation carried out in line with its values?

RELATIONSHIPS

Do you feel that the care and support provided is organised in a way that puts users' interests before other considerations?

Do managers act in a way that is responsive to what users want or ask for?

Do you think that people using the organisation's services can challenge the views of staff or other professionals effectively?

BOX 6 INFLUENCING ORGANISATIONS

Your participation in influencing the organisation or project may be affected by your background and experience. Important issues may include your age, gender, sexual orientation, language, religion, ethnic group or social or cultural background. You may also want to consider things like:

- Being a parent
- Being in or out of work
- Having a disability or disabling illness
- Looking after an older person or someone who is ill or disabled
- Having no permanent place to stay
- Being a refugee or asylum seeker.

Your particular circumstances should be taken into account when planning your involvement in the running of the organisation or project.

HOW DECISIONS ARE TAKEN

Can you think of an instance where hard decisions had to be made that affected the service and how it was provided?

? Do you feel there was openness about why the decisions were taken?

Were the parameters or constraints that shaped those decisions made plain to you?

Can key decisions be traced backed to what users require?

LIMITS TO USER INVOLVEMENT

Are certain aspects of the service deemed to be 'off limits' when it comes to user involvement? For example:

? Particular parts of the building

Certain types of information

Specific activities or meetings or decisions

Do you know who decided this and why?

DIFFERENT TYPES OF CARE AND SUPPORT

BRINGING IN CHANGE

What steps are taken to involve users in:

- ? Making changes to the organisation providing care and support?
- Making changes to or redesigning existing services?
- Planning and developing new services?

What do users say about their part in this work?

How are users' views about current services used to inform further developments?

OTHER OPTIONS

How do users and carers find out about other approaches to services and keep up with new ideas?

What does the organisation or project do to enable users:

- ? To meet and discuss ideas
- To formulate proposals?

Do you have examples of users being able to feed alternative proposals or ideas into planning?

What happened?

REVIEWING AND LEARNING

FEEDBACK AND CHANGE

Do you know how users' experiences and views inform how the organisation or service works?

How do users get something about the service changed?

What happens when something goes wrong?

Is there a tendency to 'blame' someone or something? Or is there a readiness to think what might be done differently next time?

Are issues raised by users treated as an opportunity to improve the service or as a troublesome distraction?

Are there specific examples of how the service has been improved as a result of issues brought forward by users?

MEASURING EFFECTIVENESS

In setting up a review or evaluation of the care and support provided by the organisation or project, who decides what to focus on?

Are users given support and training to take part in carrying out a review or evaluation as well as acting as sources of information?

How are users involved in deciding what should happen as a result of a review or evaluation?



Allies in Change is an alliance of people and organisations who want to see the participation and inclusion of people with mental health problems, their friends and families, promoted and developed.



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The Scottish Development Centre is an independent organisation that works with others to promote better mental health services and to improve mental health and wellbeing.

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