

ROUTE MAP TO USER AND CARER PARTICIPATION

**PART 4
INFLUENCING THE PLANNING OF
MENTAL HEALTH SERVICES**

**Produced by
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CONTENTS

Individual resources of users and carers 3

Skills 4

Box 1 Person centred approaches to commissioning services 5

Time and timing 6

Structures and administration 6

Box 2 Making decisions 7

Box 3 Expense payments 8

Information and communication 9

Box 4 Collaborating on gathering information 9

Box 5 Using policy 9

Attitudes, culture and values 10

Box 6 Transparency 10

Box 7 Participation in planning services 11

Box 8 Negotiation 12

Box 9 Information to plan services 14

Different types of care and support 13

Reviewing and learning 15

INDIVIDUAL RESOURCES OF USERS AND CARERS

SUPPORT

Where do you as users and carers taking part in strategic planning groups get support? For example:

? From someone in your own organisation

From someone outside your organisation, for example, a local users' or carers' support group

Through getting the right information

What are local organisations and networks doing to help you continue to be involved?

TRAINING AND DEVELOPMENT

Are individual users and carers who take part in strategic planning groups offered training?

Has the organisation or network checked out what sort of preparation or training would be helpful to you?

If you have a specific role within a group, for example, as secretary or chairperson, are you confident that you know what your responsibilities are?

CHALLENGE

Do you feel that you are an equal member of the planning groups you attend?

Are you able to question or challenge other people's opinions?

CONTACTS

Are you in touch with other service users or carers who are involved in service planning? If you are not, would you find this useful?

INFLUENCE

In what ways do you think you can influence decisions about service planning and development?

SKILLS

LISTENING

Are those with responsibility for developing strategy and planning local services in touch with users' views on services?

If not, what could be done to improve the situation?

MEETINGS

In setting up working groups, what happens in your area or organisation to ensure that:

? The tasks involved are set out clearly so people know what is expected of them?

Members of working groups include people with the relevant skills and experience to complete the task?

WORKING TOGETHER

What attention is given in working groups to the process of how people work together to achieve what is expected?

PLANNING AND COMMISSIONING SERVICES

Do those responsible for commissioning services have experience of using person centred approaches?

BOX 1 PERSON CENTRED APPROACHES TO COMMISSIONING SERVICES

Person centred planning is a particular approach to helping people work out how they want to live, what they would like to achieve and what support they might want to do that. It 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.

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 that 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.

This is how commissioning services in community care should operate. First, the planning to see what sort of life we want to lead; then what support is needed to help us to live as we wish; then designing a service or services to provide those supports or treatments; and then commissioning that service. Someone might still need to receive specialised services, but that should not stop them leading an everyday life, if they wish.

TIME AND TIMING

ALLOWING ENOUGH TIME

Do user groups who take part in strategic planning consider that the time available for planning activities allows them to be adequately involved?

Is enough time allowed for debate and discussion?

Is enough time allowed for groups to comment on consultation documents?

LONG-TERM VIEW

Have local organisations or networks worked with users and carers to plan what the organisation or network needs to do to enable you to get more involved and have more influence?

Have local organisations or networks set themselves long-term goals to extend user and carer involvement and influence?

STRUCTURES AND ADMINISTRATION

JOINTLY AGREED APPROACHES

Have local organisations agreed an approach to involving users and carers?

? Who is signed up to this?

Who takes responsibility for reviewing how the approach is implemented?

How comprehensive is the local approach to involvement?

What areas of work does it cover and what is left out?

Are there 'no go' areas where involvement is not encouraged?

Are there identified points of contact for the different user and carer groups that want to feed into strategic level work?

Is it clear why user involvement is essential and what it aims to achieve?

DECISION MAKING

In making decisions and setting priorities, is it clear what criteria are used?

Are there written criteria which you can see?

How have these criteria been arrived at?

What part do service users play in setting criteria?

Is information from service users used to influence the setting of criteria?

BOX 2 MAKING DECISIONS

As users and carers, you should be involved in decisions from the beginning and not brought in at a later stage. It is important to maintain regular contact with senior managers through repeated involvement and follow through.

You will need to know how an organisation or network works. In particular, you will need to be able to track where proposals arise from, where they are developed, where ultimate decisions are made and at which points you can be involved. A diagram of the structure of the organisation together with its business plan will be useful in working out where and when you can exert influence in order to be most effective.

RANGE OF PERSPECTIVES

What steps are taken to include the perspectives of people with experience of different types of mental health problems?

FACILITATING USER INVOLVEMENT

Do you think meetings are run in ways that promote user participation?

What structures are used to give users a voice in the process of planning?

What has been done to adapt structures to facilitate user involvement?

From your perspective, how well do these work?

PAYMENTS

What arrangements have been made to pay you for the work you do at strategic level?

EXPENSES FOR MEETINGS

Are expenses paid to cover the costs of attending meetings?

For example, for:

? Travel

Other out-of-pocket expenses such as meals

Child care

Other care responsibilities?

If you are claiming expenses, most organisations will ask you to keep receipts such as train tickets or till receipts. If you do not have a bank account, you may want to be paid in cash rather than by cheque. You will need to let the organisation paying your expenses know this so that payment can be arranged to suit you.

INFORMATION AND COMMUNICATION

INFORMATION AND DISSEMINATION

Is there a coherent approach in your area to collecting information and to consultation with users?

BOX 4 INFORMATION

Local organisations can work together to streamline the information they gather and to avoid repeated consultation with users that covers similar ground. Some areas support a local group to co-ordinate local consultations and to provide collective advocacy. You could ask planning partners, for example, to fund a network of users to attend conferences and participate in planning groups.

HOW ORGANISATIONS MAKE DECISIONS

What information is there to ensure users and carers understand the way that organisations make decisions?

Is the information specific, without jargon?

Are users aware of the critical points in the organisation or in the work programme at which outcomes can be influenced?

Do important decisions go through, bypassing users?

BIGGER PICTURE

How do users and carers taking part in strategic level work get a sense of the 'bigger picture', so that they can make an informed contribution?

BOX 5 USING POLICY

Users and carers will be able to exert more influence by understanding broadly the way services are organised and funded. It also helps to have an understanding of the opportunities and limitations on future development faced by the organisation or network. People need to have a sense of how local plans relate to national policy. Users and carers can push for change by using official policy to support their case.

ATTITUDES, CULTURE AND VALUES

OPENNESS

Do you think that the strategic planning of the organisation or network is open and transparent?

BOX 6 TRANSPARENCY

Openness and transparency is largely dependent on information flow. It requires that:

- The general aims of local strategy are clear
- You know how and where decisions are made including the information considered and the criteria used to make choices
- The reasons for decisions are made explicit
- Feedback is provided on what is decided and on what will happen next
- The things that are fixed and that constrain local action are known
- It is clear to you how and when progress is reviewed.

FLEXIBILITY

How do planning arrangements create the conditions that encourage user participation?

How much do organisations and networks take account of individual circumstances in facilitating user involvement?

BOX 7 PARTICIPATION IN PLANNING SERVICES

Your participation in service planning 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 arranging your involvement in planning groups or networks.

STATUS OF USERS AND CARERS

Are users, carers and professionals clear about how influential they can expect to be in planning services?

Do users and carers take part as 'representatives'?

Who 'chooses' users and carers to take part in working groups?

Do you think users involved in strategic activities are viewed as 'tame'?
If so, why?

SHARED RESPONSIBILITIES

How do local organisations show that they recognise their individual and shared responsibilities to promote user involvement and influence?

What are they doing to strengthen involvement in the longer term?
For example, by:

? Funding user-run projects

Facilitating user participation in monitoring services?

Is user involvement promoted in key areas of strategic planning such as the Mental Health Framework, local Health Improvement Plans, or Community Care Plans?

How are those who make strategic decisions in the organisation or network answerable to local users and carers?

When conflicts arise between people participating in planning groups, how are these handled?

BOX 8 NEGOTIATION

Working effectively in partnership does not mean people have to pretend to be neutral. It helps if you can be open about your point of view. Healthy working relationships need ways of airing conflicts openly and of resolving difficulties through negotiation and compromise. It is important that you get feedback about the outcomes of your involvement, whether positive or negative.

DIFFERENT TYPES OF CARE AND SUPPORT

SUPPORT

Are local users groups and carer groups adequately supported by statutory organisations so that they are able to participate in strategic level work?

How far are statutory organisations prepared to go in supporting user involvement?

Are users involved in training, for example in feeding back on the delivery of care?

FUNDING

Are services that users find accessible and useful securely funded?

For how many years are they funded?

OPTIONS

How do those involved in planning, including users and carers, find out about the range of options that are possible?

EXPERIENCE INFORMING SERVICES

When new services are being developed, is full use made of information from users about:

? How you want to live your life

The support you require but are not currently getting (unmet need)

Features of existing services that you find helpful and less helpful, so that commissioning can take account of these

What your goals and preferences are?

COMMISSIONING SERVICES

How is a person centred approach applied to the commissioning of services for:

? Individuals

Small groups of people

Wider communities?

Person centred planning means that, in commissioning services, account is taken of:

- How people want to live their lives
- People's views of the types of support they find helpful.

This information is essential, rather than relying only on information about the prevalence rates of particular illnesses.

WORKING TOGETHER

How do professionals and users work together to identify acceptable service solutions?

CHANGING SERVICES

Are users involved in key areas of planning and commissioning that have the potential to lead to radical change in the shape and culture of services?

Do you know of any examples of user groups being commissioned to provide services?

DECISIONS ABOUT SPENDING AND RESOURCES

Are you involved in discussions about spending priorities and resource allocation?

Are you comfortable with these arrangements?

Have you been able to influence where and on what money is spent?

REVIEWING AND LEARNING

LEARNING

How does the organisation or network ensure that it continues to learn and develop?

Is there opportunity to take stock and consider progress in involving users?

How does the organisation keep up with what is happening elsewhere in policy and practice?

MAKING CHANGES IN SERVICES

What changes can you point to that have come about as the result of user and carer involvement in strategic level work?



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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for mental health

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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