

# ROUTE MAP TO USER AND CARER PARTICIPATION

**PART 2  
INFLUENCING YOUR PERSONAL CARE AND SUPPORT**

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# INDIVIDUAL RESOURCES OF USERS AND CARERS

## CHOICE

Are you getting the sort of care and support that you want?  
If not, why not?

Do you think you know enough about other services that you might want to use?

## INFLUENCE

Do you feel you can influence decisions about your care or the services you use?

## QUESTIONS AND CHALLENGES

Do you feel able to question professionals or challenge their opinions?

In your experience, what happens if you do question or challenge them?

What would make it more likely for you to feel that you could challenge someone effectively?

## BOX 1 USER AND CARER OPINION

User and carer opinions and information are credible and valuable. In many organisations you will find workers who have an interest in or responsibility for listening and acting on user and carer views. Ask other users and carers to find out your best contacts.

## ADVICE

Can you get independent support or advice if you want to make your views known? For example, from advocacy services or legal services?

## CONTACTS

Are you in touch with other service users?

Do you have the chance to meet informally or to go to social events together?

Are you given help in any way to contact other users or self help groups and users' forums?

Are individual carers put in contact with each other? Or with carers' groups and forums?

## SKILLS

### LISTENING

Do you feel that people listen to you and respect your views?  
How do you know when this is happening?

### NEGOTIATING

Do you think that workers have the necessary negotiating skills to:

? Help you say what you want?

Set up the sort of care and support you want?

Support you in doing things you enjoy?

### BOX 2 PERSON CENTRED PLANNING

This 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. Person centred planning focuses on what we want and on our strengths rather than our weaknesses.

For it to work, there needs to be a willingness to come up with solutions that are not always traditional. This requires supports and services that are geared to helping us rather than us being fitted into existing services. 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. So compromises have to be made or we have to accept that it might take a long time to achieve a change.

Some key characteristics of person centred planning are:

- The focus is on you and your whole life. All your needs are important, not just health care or social care needs
- The control is with you and your advocates, and the people who care for you. Professionals are there to provide specialist advice, knowledge and support

- There is a commitment to address different views openly and honestly, and to reach a consensus for action

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.

#### **PERSON CENTRED PLANNING**

Do you know if your key workers have been trained in person centred planning?

Does this make a difference to you in the care and support you get?

Does this make a difference to carers?

#### **RECRUITMENT**

Are you involved in recruiting your key workers, for example by interviewing them?

# TIME AND TIMING

## SERVICES AT THE RIGHT TIMES

Are the services you use on a regular basis provided at the times when you want them?

Is emergency or unplanned care and support available when you want it?

If not, why not?

## ALLOWING ENOUGH TIME

How are you involved in deciding how much time a nurse, support worker, doctor or counsellor, for example, can spend with you?

How are you involved in deciding when you can be seen if you are feeling unwell or want a service urgently?

How much time is allowed for individual assessments and reviews?

Do you think that this is enough?

Can you say when you would like meetings to be held?

## BOX 3 MEETINGS

People tend to prefer meeting in informal groups rather than in ward rounds or review meetings.

You may find meetings with smaller groups of people more comfortable. Or you may prefer talking to other users about what you want than talking to workers.

## INITIATING A REVIEW

Can you suggest that a review meeting should be held?

If not, why not?

Can carers suggest that a review should be held?

If not, why not?

# STRUCTURES AND ADMINISTRATION

## DECISION MAKING

Do you feel that you are involved as much as you want to be in decisions about your care and support?

How are you involved in decisions about your medication or treatment?

How are you involved in decisions about your money?

How are you involved in deciding when a person providing you with a service, treatment or support should come to you and when you should go to them?

## ASSESSMENTS AND REVIEWS

Do you have a say in where assessments and review meetings are to be held?

If not, why not?

Who decides what will be discussed in review meetings?

Do you think you get the right information about:

? What will be discussed in assessment and review meetings?

Who will be at the meetings?

What has been decided?

What will happen next?

## CARERS AT ASSESSMENTS AND REVIEWS

Can you choose who else should be involved as carer, relative or friend?

Are you able to say:

? What level of involvement that person should have?

When or under what circumstances that person is to be involved?

What information they should get?

If you do not want your carers to be involved, is it clear what your carers can do and what information they can expect?

#### **BOX 4 INFORMATION FOR CARERS**

Guidelines can be developed by users and carers and local organisations to ensure that, within the agreed boundaries of confidentiality, carers are given information to support them in their role as carers.

#### **CONFIDENTIALITY**

Do you feel that the information you share is treated as confidential?  
Do you know when information is shared with other people and why?

#### **EXPENSES FOR MEETINGS**

If you have to travel to meetings to plan or review your care and support, are your expenses paid?

For example, for:

? Travel

Other out-of-pocket expenses such as meals

Child care

Other care responsibilities?

If you want to bring a friend, family member or other supporter along with you, are their expenses paid?

#### **BOX 5 CLAIMING EXPENSES**

If you claim 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

## ADVICE

Do you have enough information so that you know where and when you can get advice?

## YOUR CARE AND SUPPORT

Do you get the right information about your care and support? For example, do you know:

- ? Who your key worker is and how to contact them?
- What to do if you want to change key worker?
- Who does what as part of your care plan?
- Who can be contacted in a crisis?
- Where to get help out of hours if needed?
- How to raise concerns about the care you get or need?
- Where to get information about your rights and entitlements?

## GOING OUT

Do you get enough information about:

- ? Social activities?
  - Having fun?
  - Learning new skills?
- Do you get support to help you do the things you enjoy?
- Do you get support to help you with any changes you want to achieve in your life?

## ACCESS TO RECORDS

Do you have a copy of your own care plan?  
If not, why not?

Can you see the records kept about the services you get? For example:

- ? Your support agreement
- File notes kept by workers

? Risk assessment

Communications book - messages between workers

Incident book?

If not, why not?

### **ASSESSMENTS AND REVIEWS**

Do you get the information you need about assessments and reviews?

Do you think you get the right information about:

? What will be discussed?

Who will be at the meetings?

Who you can bring with you?

What has been decided?

What will happen next?

How you claim expenses for attending meetings?

### **IF YOU BECOME UNWELL**

Can you say what you want to happen if you become unwell?

Do you have a written copy of what has been agreed?

What can and cannot be covered by your agreement?

Do you think workers understand and respect the status of your agreement?

Are there situations where you think it might be necessary for your wishes to be overruled?

# ATTITUDES, CULTURE AND VALUES

## THE SERVICE YOU WANT

Are you getting the sort of care and support that you want?

Does it include any special interests or requirements that you might have?

For example, you may need assistance with signing, interpreting, or help with reading or writing.

If not, why not?

### BOX 6 YOUR OWN CIRCUMSTANCES

The service you want will be affected by your background and experience.

Issues which may be important in deciding what sort of services you want include your age, gender, sexual orientation, language, religion, ethnic group or social or cultural background. You may want to also 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.

Any or all of these may be important to you and should be taken into account when planning your care and support.

## **SUPPORT**

When things do not go as planned, what do workers do to support and encourage you?

Are your concerns listened to?

Do you feel that your problems are taken sincerely and understood?

Are you able to get help as soon as you want it?

## **VALUES**

What values are important to you?

How would you want these values reflected in the care and support you get?

## **USERS AND CARERS**

Do workers support you in meeting other service users and linking up with self help and support groups?

Do you think that your needs as a carer or family member are recognised separately from those of users?

If not, why not?

## **DAILY LIVING**

Do you think that you are supported in a way that focuses on what you want and how you want to live your life?

How are you involved in choosing where you live and with whom?

How are you involved in deciding what you eat and when?

Do the services you receive affect your income or benefits?

## BOX 7 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. They try to deliver their services and support in a person centred way, rather than having a set way of working. These organisations also try to help the person they support to recognise some of the constraints and work out how to deal with them.

See also Box 2, Person centred planning, on page 4.

### TAKING RISKS

Are you encouraged to take risks when you want to, to test things out?

Where might you get support to do this?

Might anyone try to prevent you?

## DIFFERENT TYPES OF CARE AND SUPPORT

### SERVICE PLANNING

Do you feel that the services you get are based on good individual planning and on what you want for yourself?

Do you think that what you want and need is used to decide:

? What help and support you get?

How support is provided?

When it is provided?

### SERVICE OPTIONS

Do you think you know enough about other services that you might want to use?

How could you find out about types of service available in other areas?

## **ADVOCACY**

Do you have access to independent support and advice when you want it?

Have you used advocacy services at any time to make your views known?

### **BOX 8 ADVOCACY**

Advocacy services are important in developing the voice of users and carers in mental health services. Advocacy provides a way of influencing both care planning and the services you use. Advocacy services can:

- Enable you to get what you need for yourself
- Enable you to get information about other options.

How did you find out about advocacy and what it can offer you?

How would you like advocacy to be developed locally?

## **NEGOTIATING**

Can you negotiate with the organisation providing services to match what services can offer with what you want?

Can you give examples of how your own goals match with what services can offer?

(You may be able to see this in your support agreement or care plan.)

## **SERVICES THAT EVERYONE USES**

Do you find that the services provided tend to keep you within the mental health system?

Do you have opportunities to use services that everyone uses?

## **BOX 9 TYPES OF SERVICE**

You may want to know about new ways of providing support and care. It would be useful to have a list of places where you could get information about service options.

It is important that choices about services include the opportunity for you to use separate user-run services or self-help groups as well as professional mental health services.

## **REVIEWING AND LEARNING**

### **INFLUENCING SERVICES**

Have you been able to influence the care and support you receive?

If so, how?

### **MAKING CHANGES IN SERVICES**

Do you know where to take concerns about services?

Do you find that when you express concerns, these are taken seriously and acted on?

Have you seen services change as a result?

### **CHANGING PRACTICE**

What opportunities are there for you to feed in comments about your own care and support?

Do you know how your comments and concerns are used to make changes in the way that people 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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