



# Participation

## and Mental Health

### Monitoring Your Engagement with Government

*“Effective provision of health service can only be assured if people’s participation is secured by states.” –United Nations CESCR, General Comment No. 14*

## What is this pamphlet for?

You have a right to be involved in decision-making about mental health services and policy in Northern Ireland. But your participation should be more than just a ‘tick box exercise’. Local and international policies require your participation to be meaningful and at every step of the way.

This pamphlet shows how one group is trying to hold the government accountable for keeping the promises they made to us in their policies. But more than that, it shows you how to get involved. Help us create standards that will make participation meaningful for mental health service users across Northern Ireland.



## More Inside

See our checklist for making sure we can participate fully in decisions!

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See the ways you can help our group!

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## In the Words of Service Users

The quotations below are from service users. They are describing their own experience with existing public consultation structures about mental health.

*Important decisions were made 'without us'.*

*'Meetings were draining;' we mainly spent time 'repeating our stories and other people's stories over and over'.*

*Government representatives 'spoke in double dutch;' we felt 'talked down to' because of the language they used.*

*Government 'always had the chair'; they 'controlled the agenda'.*

*Some service users have confidence during meetings, but it was often a 'matter of luck' that they did. Some had experience with the process.*

*We felt 'afraid of feeling stupid'.*

*Money and staff issues were used as 'excuses' for government inaction. But we almost never saw proof or explanations to justify this.*

*There was 'too much waffle and not enough focus on the purpose of the meeting' from government.*

## What should participation be about?

What I am saying is very simple: do not let user involvement become the next in-thing, like partnership working, empowerment, capacity building or, God forbid, the subject of a university degree. If that happens we will have lost what it is all about.

It is about my son, my daughter, and our lives. It is about how we treat others and how they treat us. It is about mutual respect, it is about hard work. There is room for everyone, particularly those whose life experiences have educated them far more than books ever could.

*—Anne Cullen, "Try, Try, Try Again"*

# What Will We Be Monitoring?

The PIPS-GSBF Rights Group will be monitoring how government engages with us during the implementation of a 'Card Before You Leave' appointment system across Northern Ireland. We will be using the checklist below to see whether our human right to participate is being met during this process.

## The way meetings work and whose voices are heard:

	Are service users involved in setting the terms of reference to ensure their participation meets human rights standards?
	Is there a clear and accessible way for service users to place items on the agenda for discussion?
	Are there arrangements to allow service users to chair meetings at times?
	Are meetings kept focused on purpose and agenda points?
	Are meetings well timed out, with service users receiving adequate time to participate meaningfully in discussion?
	Is there evidence that service users views have influenced the shape of decisions?

*"In order to be effective, participation must be active and informed."*

*Substantive issues arising in the implementation of the ICESCR: Poverty and the ICESCR, Statement adopted by the UN Committee on Economic, Social and Cultural Rights on 4 May 2001, E/C.12/2001/10, para 12*

## Making sure participants have the resources they need:

	Do service users receive enough advance notice of the meeting to be able to prepare and attend?
	Do service users receive relevant papers and documents far enough in advance of a meeting to prepare for their participation?
	Are papers and documents presented in an accessible format (e.g., without jargon or abbreviations)?
	Does government provide independent support to service users to assist them in preparing for the meetings (e.g., explaining unfamiliar language and processes, helping to research questions and concerns, administering expenses, etc.)?

*"The right to participate is inextricably linked to other rights, such as the right to freedom of expression, the right to freedom of information and freedom of association."*

*UN CESCR, General Comment No. 14, para 54*

## How participation of service users is encouraged:

	Are service users' expenses (e.g., transportation and childcare) covered during the participation process?
	Are the above arrangements to facilitate participation made public to service users considering being involved during and sufficiently prior to the process?
	Are service users given clear and accessible information on resources and staffing to allow them to participate meaningfully in these decisions?

*"Under international human rights law, the right of individuals and groups to participate in decision-making should be an integral part of all the policies, programmes and strategies intended to implement the obligation of States parties."*

*UN CESCR, General Comment No. 14, para 54*

## What You Can Do To Get Involved

We need your help. We want to make sure the work we do responds to your own experiences as a mental health service user. Have you ever worked to make services better and been frustrated? Have you ever wanted to get involved and not known how? Take a look at each of the steps below, and see how you can contribute. And if you have any questions, please contact us!

**1**

**Have you been involved in any government boards or committees working to improve mental health services?** We are collecting case studies of people's experience with these structures. All information can be anonymous, but it will help us make sure our works listens to your experience.

**2**

**Have you ever wanted to get involved to improve mental health services in Northern Ireland?** We would love to hear about your experience and the barriers that prevented your involvement. We are also always looking for new members of our group who have direct experience with mental health services.

**3**

**Are you (or is your organisation) interested in mainstreaming meaningful participation into decision-making about mental health services?** We want to make sure service users can participate in decisions about mental health policy and services in a meaningful and effective way. To do that, we will need to build a broad coalition. Let us know if you're interested!

## Contacts and More Information

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