



TRANSFORMING LIVES

PROGRAMME TO IMPLEMENT THE RECOMMENDATIONS OF THE 'VALUE FOR MONEY AND POLICY REVIEW OF DISABILITY SERVICES IN IRELAND'



EFFECTIVE PARTICIPATION IN DECISION-MAKING: Planning for ordinary lives in ordinary places

Step by step guide to implementation

Plain English Version

**Working Group 3
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This guide was proof read by people with intellectual disabilities



About this Step by Step Guide to Implementation

This Step by Step Guide gives clear information for HSE Disability Managers and Social Care Staff on what they must do to support the effective participation of persons with disabilities, their families and/or advocates in many ways of decision-making that directly affect their lives.

Implementation means putting a plan into action and making it happen.

This guide came from the **Plan for Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places.**

This implementation guide will work at local, community and regional and national levels where lots of different kinds of decisions are made.



There are three sections to the Guide.

1. Key messages that support decision making
2. Values that support decision making and
3. Steps needed to make the plan happen for people.

Key message of Step by Step Guide to Effective Participation in Decision-Making

Effective participation is about people having the right to take part in decisions that affect them. Effective participation is not just about asking people for their opinions.

It gives people equality of voice, choice and control. It is about making sure they are involved in the planning, development, and review of services that affect their lives.

It is important to know that many adults with disabilities choose to make their own decisions without their family involved. Others choose to include their families in their decision making. It is important that both things can happen.

Independent Advocates also play an important part in supporting people to make decisions.

What is this guide for?

This Guide will support HSE disability managers and Social Care staff to:



- Support people with disabilities and their families and advocates to develop the skills they need to take part in effective ways of decision making with the supports they need.



- Make sure that people with disabilities and their families are involved in the planning and development of services they use in their lives and check to see how they are working.



- Monitor and evaluate the ways we do participation to make sure they are working well.

This should happen at a local, regional and national level now and into the future.



Questions for people who use this Guide about barriers for people with disabilities

A barrier is something that gets in your way of doing something. Think about the barriers below to the effective participation of persons with disabilities in how decisions are made?

- Low expectations where people don't think people with disabilities can do things.
- Low expectations focus on persons with disabilities as patients rather than active people who are able to make changes in their own lives.
- Transport networks, buildings and other services that are not accessible are real barriers to people taking part in decisions.
- Ways of communicating that make it hard to understand information takes the power away from people with disabilities.
- Not having enough support like money or other things stop people from taking part in making decisions.



Taking away the barriers

To take away the barriers we need to work in new ways together where people have support and have choice and control in their lives.

A new way of working together

HSE Managers and Social Care staff will need to:

- understand and see that there are lots of different barriers for people with disabilities.
- Understand how the Social Model of Disability gives people power (you can about this in the Plan)
- Challenge and change old ways of working like using the medical model of disability.
- Think outside the box, be flexible and understand that all people with disabilities are not the same, one size does not fit all.
- Understand that effective participation will need resources like money and other things to make it work well.

Section 2 looks at some recommended **values** to help change happen.

Values

Values are a set of beliefs or views that people have about what is right or wrong.

Acting as a set of guidelines or rules in different situations, they can have a strong influence on individual or group.

The four core values of **Autonomy, Respect, Creative Responses and Mutual Support** are at the heart of effective participation in decision-making.

You can read more about these in the Plan for Effective Participation in Decision Making.



Steps to implementation

Step 1: Community Mapping and Promotion

The Head of Social Care in a CHO or HSE area will give key staff the job of mapping and telling people about the Plan.

Mapping will be about finding out what people to involve in the Plan.

These people might include:

- Self-advocacy groups of people with disabilities and getting contact details of individuals within this group.
- Parents and friends' groups of people with disabilities and getting contact details of individuals within these groups.
- Other Disabled Peoples Organisations (DPO's) that represent themselves. This is a group made up of people with disabilities who make their own decisions in their group.
- Contact details of individual people with disabilities and supporters who have made contact to say they are interested in getting information and/or being active in supporting the rights of people with disabilities.

- Community development agencies who work in social inclusion to support and build the skills of people with disabilities.

Promoting local disability community forums meetings and committees

A forum can be a meeting or a group of people that work together.

Promote and explain local disability forums as a way to:

- Give persons with a disability and their families a chance to talk about their experience of supports and services that are funded by the HSE.
- Give people the chance to find ways in which these supports and services might better support people to have more choice and control over their lives.
- Give people the chance to take part in ways of decision-making that shape how we plan and give out other supports and services that impact on ordinary lives.
- Give people the chance to say what needs to change.



Step 2: Bringing together local disability community forums meetings and committees

When they are organising Forum meetings key staff must think about:

1. The barriers in Section 1 and in the Plan "***Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places***".
2. They must think about the supports that take these barriers away.

These supports include:



Changing Attitudes

- Communication skills training, including training in Plain English for those who may have no experience in communicating simply and clearly.

- Values based training for all persons with a disability, families and staff involved in decision making.
- Equality and disability equality awareness training to those involved in decision-making and persons with disabilities and their families.
- Capacity or skills building training for persons with disabilities.



Accessibility Supports

Accessibility is very important to persons with a disability.

Taking part in a public forum can be hard.

The following physical accessibility needs should be taken into account:

- The venue is accessible in every way including parking and getting to the room.
- Accessible bathrooms should be on same floor as the meeting.
- Transport to the venue is accessible and user friendly.

There must be budgets put in place so that people are paid for their expenses and costs and also paid for their time when they give a lot of time or skills to a project.



Universal Communication supports

- Develop ways of communicating in partnership with persons with disabilities, organisations and advocacy groups to make sure barriers to communication are taken away.
- Have a good, experienced and independent facilitator.
- Give inclusive and accessible information, easy to read information – sign interpretation, audio equipment and other technology.

Making Forum meetings work

Here are some things to think about to make sure that local Disability Community Forum meetings are inclusive:

- Find out the information needs of all participants. You cannot see all disabilities so do not assume that access is good because those with disabilities you can see are looked after.
- Send information before forums including clear and agreed agendas. Make sure information is in Plain English and other

formats. For printed information use at least 12-point font size such as Arial or Verdana.

Materials in a print or an electronic format must be accessible to persons with visual impairments.

Make electronic versions of materials available in plain text, rich text, or Microsoft Word.

Don't use PDFs unless you make them accessible first.

If people need to read information before a meeting send it out two weeks in advance.

- Think about the structure of meetings – how long it is, breaks, small group discussion formats.

Some people with disabilities may lose concentration or find sessions tiring. Organise breaks and your sessions well.

Try to keep sessions short.

Give time to people who are using communication supports or support workers to take part.

- Think about how you set the room up and seating arrangements – have enough open spaces for individuals using

wheelchairs, seats with a clear view of sign language interpreters for people who are Deaf, and seating close to the podium or stage for people with limited vision.

- Agree costs of running Forum meetings with CHO Head of Social Care.

Experts by Experience

Experts by experience are people with disabilities themselves who have lots of their own experience of important issues

Give time to developing guidelines and ways of working for local fora, including how the leaders will work. Once the forum is set up and running Experts by Experience will:

- Lead the local forums
- Be supported to feed into and back to local, regional and national consultative structures.

This will be an example of a new way of working together.

Up until now there were not enough experts by experience on forums.

Including Experts by Experience at all forums will make them more inclusive.

They will need the following supports:

- Independent disability awareness training
- Specific training on the Plan for Effective Participation of People with Disabilities in Decision-Making.



Step 3: Monitoring and Evaluation

Monitoring and evaluating is about checking that things are working well.

It will include making reports about the work.

Reporting will happen 4 times a year.

Key staff will report on the progress and what is happening in local forums through the local CHO Head of Social Care and Chief Officer. The Chief Officer will in turn report on how things are working to:

- The National Consultative Forum in the HSE
- The HSE National Disability Operations Office
- The National Disability Reform Office.

Each Chief Officer must report on the following:

- The name of the staff member whose job it is at local level to implement the Plan **“Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places”**.
- Report that the mapping was done of local and regional Disabled Persons Organisations (DPO’s), self-advocacy groups and other groups.
- Report on the strategy for ongoing communication with the above groups. This should include newsletters, social media, meetings, conferences, videos, etc.
- Report if local forums are led by Experts by Experience.
- Report on how Experts by Experience feed issues through local HSE to CHO level to National Consultative Forum.
- Report on Disability Equality Training and capacity skills building training that is in place for Experts by Experience
- Report on the local forum having an independent facilitator.
- Report on giving information in a number of accessible formats.

- Report the budget or money agreed to pay all local forum participants including accessibility costs such as sign interpretation.

About Local Forums

- 1.** Local community forums decide on group and/or individual issues in the planning and giving out of supports and services.
- 2.** Local forum members nominate/elect experts by experience to represent them on local, regional and national decision-making structures.
- 3.** Local forum representatives explain the group and/or individual issues they decided about at a local level directly to the HSE through Disability Committees and up to CHO level.
- 4.** At the same time, these issues are fed into the National Consultative Forum. Experts by experience who are representatives of local forums will also sit on the National Consultative forum. This in turn feeds into National Social Care Directorate.
- 5.** National Social Care Directorate communicates and monitors actions and steps taken to address these issues at CHO Level.

Conclusion

These steps make sure that people with disabilities are involved in decision making at all levels and the messages are all clear. Communication will happen from local regional to national level and back down again.

