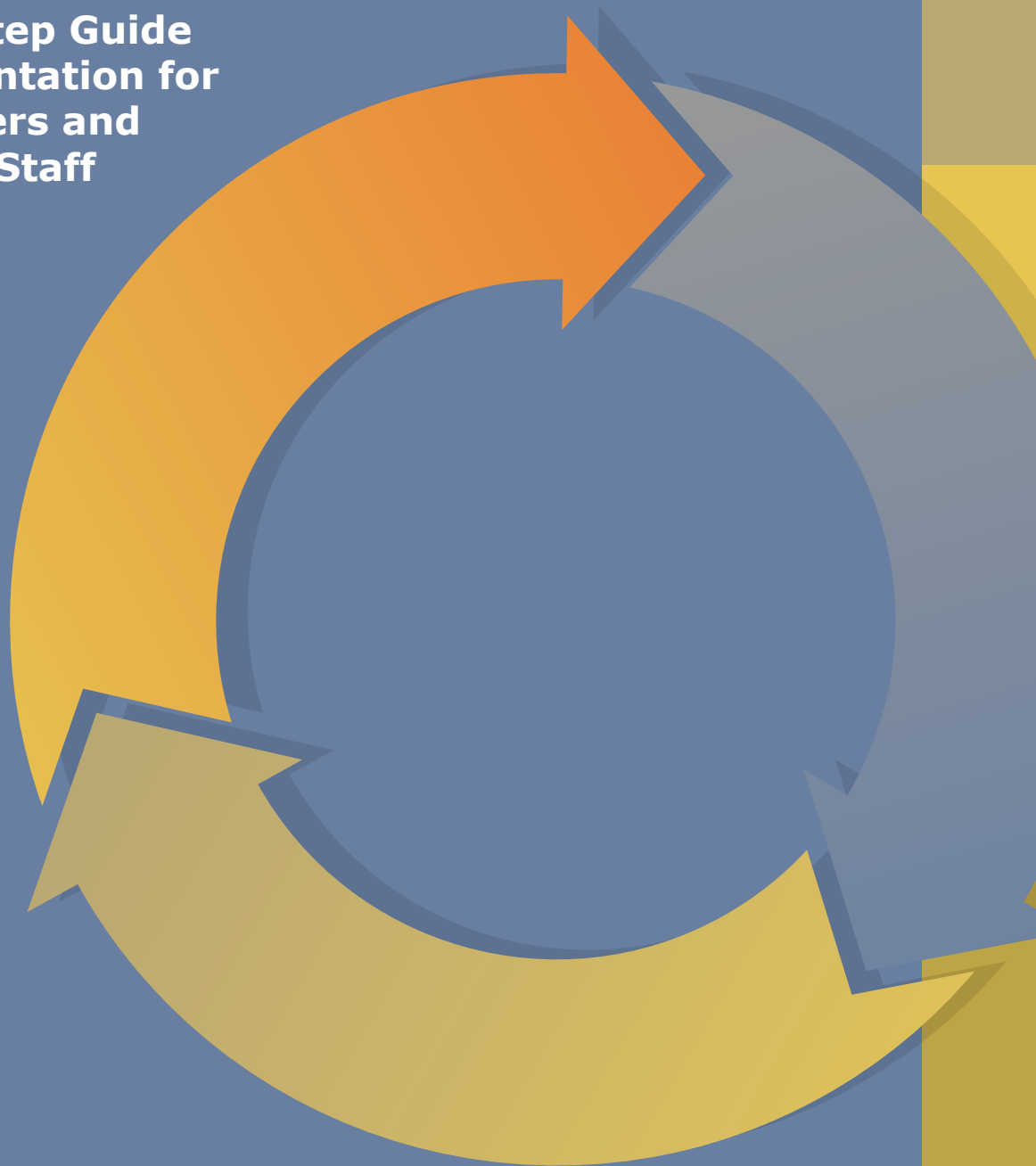




**Effective Participation in Decision-Making for
People with Disabilities and Families**

Planning for Ordinary Lives in Ordinary Places

**A Step by Step Guide
to Implementation for
HSE Managers and
Social Care Staff**





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About this Step by Step Guide to Implementation

This Step by Step Guide provides 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 decision-making processes that directly affect their lives. It is based on the Plan



Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places

and is designed for implementation at local and community regional and national decision-making fora. There are three sections to the Guide. These outline key themes, values and supports necessary for successful implementation.

Key Message



Effective participation recognises that people with disabilities have the right to participate 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, monitoring and evaluating of services that affect their lives. It is important to note that many adults with disabilities may choose to make their own decisions, while others may choose to include their families and/or independent advocates in the process.

The Purpose of this Guide

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

- Build the capacity of people with disabilities, their families/ advocates to successfully participate in effective decision-making processes through the provision of supports outlined.
- Ensure people with disabilities and their families are involved in the ongoing planning, development and review of services that affect their lives.
- Continuously monitor and evaluate the effective participation of people with disabilities in local, regional and national decision-making processes.

SECTION 1

Key Themes

Section 1 examines the key themes which inform an understanding of the process of effective participation in decision-making for people with a disability and where appropriate, their family or advocate.

Why is Effective Participation in Decision-Making important for Persons with a Disability?

Deep-rooted structural and cultural barriers continue to discriminate against people with a disability. Many people with disabilities are not supported to make decisions which affect their daily lives. Instead, individual decisions such as where to live, who to live with, what to do in one's spare time, what services they may or may not wish to use, and how and what to spend money on are made "in their best interests" - without consultation or participation and with no opportunity for people to express their will and preference. Effective participation recognises that people have the right to participate in decision-making processes that affect them.

A New Way to think about Disability

The **Social Model of Disability**, developed by people with a disability over the past 50 years, is a different way of understanding disability. The social model says that people with a disability are disadvantaged by the limitations imposed on them by social, cultural, economic and environmental barriers. **One of the main barriers to the inclusion of people with a disability is attitudes. Prejudices and stereotypes limit everyone's expectations of people with a disability.** The Social Model offers positive and constructive solutions to the removal of disabling barriers, with a strong emphasis on human rights, including civil, political, economic, social and cultural rights. It is the cornerstone to the effective participation of people with disabilities in the decision-making processes which impact on their daily lives.

Recognising disabling barriers: Questions for users of this Guide

Would you consider the following to be barriers to the effective participation of persons with disabilities in decision-making processes?

- Low expectations which focus on persons with disabilities as patients rather than active agents capable of affecting change in their own lives
- Inaccessible transport networks, inaccessible buildings and inaccessible facilities which pose real obstacles to inclusive participation in decision-making processes
- Inaccessible communication methods which restrict understanding of information and are disempowering
- The lack of supports, financial and human, that would ensure effective participation

Overcoming Disabling Barriers

To overcome the disabling barriers previously mentioned and many more which were identified in the Plan “**Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places**” requires a new working approach. This approach reflects the principles of the social model of disability which, once disabling barriers are removed, promotes the independence/supported independence of people with a disability and empowers people to realise their rights and have choice and control over their own lives.

This Guide and the Plan on which it is based are founded on the principle of recognising the vital input of '**Experts by Experience**' in the decision-making processes that affect their lives.

Experts by Experience are people who have personal experience of using, or caring for someone who uses health, mental health and/or social care services.

A new way of working together


For HSE Managers and Social Care staff a new way of working collaboratively will require:

- Their recognition of the range of disabling barriers that exist for persons with a disability
- Their understanding of the liberating and empowering principles of the Social Model of Disability
- Their ability to identify and challenge traditional working methods based on the medical model of disability
- Their capacity to be flexible and accommodating based on the social model of disability which means being able to think outside the box when one size does not fit all.
- Their recognition that effective participation requires their commitment to resourcing change in a meaningful way.

SECTION 2

Values

Section 2 looks at some recommended **values** in support of change.



It is important that these values are defined, understood and embedded in the thinking and working practices of social care staff and HSE disability managers.

The effective participation of people with disabilities in decision making will be enhanced once motivated and directed by these values.

Values Based Practice in support of Change

Values are a set of beliefs or views that people hold 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 and collective attitudes and behaviours.

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

Autonomy

The value of autonomy recognises the right, the freedom and the authority a person with a disability has to make their own choices.

Respect

Respectful decision-making processes will:

- Listen to what people with a disability have to say and trust people to know what they themselves need on a personal level
- Ensure a person's entitlement to privacy and confidentiality
- Ensure there is no discrimination or harassment

Creative Responses

Creative responses are a way of thinking outside the box and not presuming one size fits all. It is about working in a different way and finding a way forward when the way may not be clear. The value of creative responses is realised:

- When decisions recognise and consider the uniqueness of each individual with a disability
- When decisions acknowledge individual needs
- When a creative response frames the solution

Mutual Support

Effective decision-making ensures that the value of mutual support is central to the process. It recognises:

- People as well as being individuals are also relational and interdependent with valuable contributions to make to their own lives and those of their communities
- Life is better when people work together, form partnerships and find common ground to work together

SECTION 3

Implementation

This section identifies the processes required for the successful implementation of this Guide. It oversees the establishment and ongoing operations of

local disability community fora.

Local disability fora are shared spaces for people with disabilities and family members. Local fora will support the emergence of Disabled Person's organisations and provide a mechanism for people with disabilities and family members to share, discuss, engage, and address issues and experiences of living with a disability and living with/supporting a person with a disability, including their experience of services provided by the HSE. These fora, will be facilitated by persons with a disability, and will play a key role in shaping the future life experience of people with a disability as well as guiding the development of HSE services and supports.

Key Message



To maintain the integrity of the concept of effective participation of persons with a disability in decision-making processes, it is essential that the local disability community fora at all stages are independent of representative organisations and service providers.

STEP 1:

Deals with actions in the development of these local decision-making fora. Community mapping and promotion, will commence the work of activating meaningful participation and seed the formation of structures that will support continuous and ongoing participation.

STEP 2:

Outlines the supports and good practice needed to successfully convene the **local disability community fora**.

STEP 3:

Identifies and lays out the reviewing and monitoring process.

To ensure ownership of decision-making processes at all levels by people with disabilities, designated experts by experience will participate in all consultative fora at local, regional and national level.

STEP 1:

Community Mapping and Promotion

The Head of Social Care in a CHO will appoint and resource key staff to drive a mapping and promotions exercise.

Groups to target at this mapping stage might include:

- Existing self-advocacy groups of people with disabilities and contact details of individuals within this group
- Existing 'parents and friends' groups of people with disabilities and contact details of individuals within these groups
- Other existing self-representing Disabled Peoples Organisations (DPO's)
- Contact details of individual people with disabilities and supporters who have indicated an interest in getting information and/or being active in supporting the rights of people with disabilities
- Community development agencies who have a social inclusion role to support and build the capacity of people with disabilities.

Promoting local disability community fora

Advance publicity will promote and outline the purpose of local disability community fora as providing:

- The opportunity for persons with a disability and their families to talk about their experience of supports and services that are funded by the HSE
- The opportunity to identify the way in which these supports and services might better support people to exercise greater choice and control over their lives
- The opportunity to participate in decision-making processes that shape how these and other supports and services that impact on ordinary living are planned and delivered
- The opportunity to say what needs to change

STEP 2:

Convening local disability community fora

When convening Forum meetings key Staff must consider the barriers identified in Section 1 and in the Plan "***Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places***". Successful implementation is contingent on addressing these barriers through the provision of supports as follows:

Changing Attitudes

- Communication skills training and in particular, 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 building training for persons with disabilities

Accessibility Supports

Accessibility is of major concern to persons with a disability. Participation in a public forum can be highly sensitive and anxiety-creating for some individuals with disabilities. The following physical accessibility requirements should be in order:

- The venue in all regards is accessible including parking and route to venue
- Accessible bathroom facilities should be on same floor as meeting
- Transport networks to venue are accessible

Effective participation will be enabled and enhanced by ensuring an adequate budget to cover at a minimum people's transport and subsistence costs, appropriate supports and where possible a payment acknowledging significant time and expertise.

Universal Communication supports

- Develop communication strategies in partnership with persons with disabilities, organisations and advocacy groups to ensure barriers to communication are addressed
- All discussion fora will be appropriately facilitated by a person experienced in this area
- Provide inclusive and accessible information - sign interpretation, audio equipment and assistive technologies

Making Forum meetings work

Here are some things to consider in ensuring that local Disability Community Forum meetings are inclusive:

- Ascertain the information needs of all participants. Most impairments are not visible so do not assume that access requirements have been dealt with just because those with visible impairments have had their requirements addressed.
- Circulation of information in advance including clearly understood and agreed agendas. Ensure information is available in Plain English and alternate formats. Printed materials use a minimum 12 point font size such as Arial or Verdana. Materials provided 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. Avoid PDFs unless they are made accessible. If information is to be read before meetings, ensure it is sent out two weeks in advance.
- Consider the structure of meetings – length, breaks, small group discussion formats. Some people with disabilities may lose concentration or find sessions tiring. Try to keep sessions short. Ensure appropriate breaks for those who are using communication supports or support workers.
- Consider room set up and seating arrangements - have adequate 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 individuals with limited vision.

- Appoint an independent and experienced Facilitator
- Develop and agree costs of running Forum meetings with CHO Head of Social Care

Key Message



When inviting experts by experience to give of their time and expertise, consideration should be given to the provision of a budget that would allow for :

- a payment that acknowledges situations where significant time is being given, for example, membership of working groups rather than once off consultation events.
- a payment, when experts by experience are being asked to take very specific roles, for example, creating easy to read information, facilitating training or workshops.

Experts by Experience Oversight

Time needs to be given to developing guidelines and ways of working for local fora, including the role of leaders. Once the forum is established and underway nominated Experts by Experience will:

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

These features are representative of the new way of working together. To date the presence of people with disabilities on such fora has been weak. The participation of Experts by Experience at all forums will uphold the integrity of the commitment to participative decision-making processes.

They will require 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

A quarterly reporting on the progress and outcomes of local fora should operate through the local CHO Head of Social Care and Chief Officer. The Chief Officer will in turn report on implementation to the following:

- 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 appointed at local level to implement the Plan **"Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places"**.
- Confirm completion of mapping and promotion exercise of local and regional Disabled Persons Organisations (DPO's), self-advocacy groups and other groups.
- Outline the strategy for continuous communication with the above groups. This should include newsletters, social media, meetings, conferences, videos, etc.
- Confirm local fora led by Experts by Experience.
- Confirm established pathways for Experts by Experience to feed issues through local HSE to CHO level to National Consultative Forum.
- Confirm Disability Equality Training and capacity building training is in place for Experts by Experience
- Confirm the local forum is independently facilitated
- Confirm information is available in a number of accessible formats.
- Confirm budget agreed to remunerate all local forum participants for travel and subsistence, support including personal assistant hours and where possible a payment that acknowledges significant time and expertise.

Towards the goal of building a national infrastructure which will strengthen the representation of people with a disability in the development of disability policy and the practice and delivery of supports and services.

Through the process outlined below, in line with a commitment to the effective participation of people with a disability and families and a commitment to change, there is a bottom up and top down approach in acknowledging and responding to issues

1. Local community fora identify collective and/or individual issues in the planning and provision of supports and services,
2. Local fora members nominate/elect experts by experience to represent them on local, regional and national decision-making structures.
3. Local Fora representatives communicate collective and/or individual issues relating to the provision of supports and services directly to the HSE through Disability Committees and up to CHO level.
4. Simultaneously, these issues are fed into the NCF, on which there also sits experts by experience who are representatives of local fora. This in turn feeds into National Social Care Directorate.
5. National Social Care Directorate, communicates and monitors actions taken to address these issues at CHO level.



