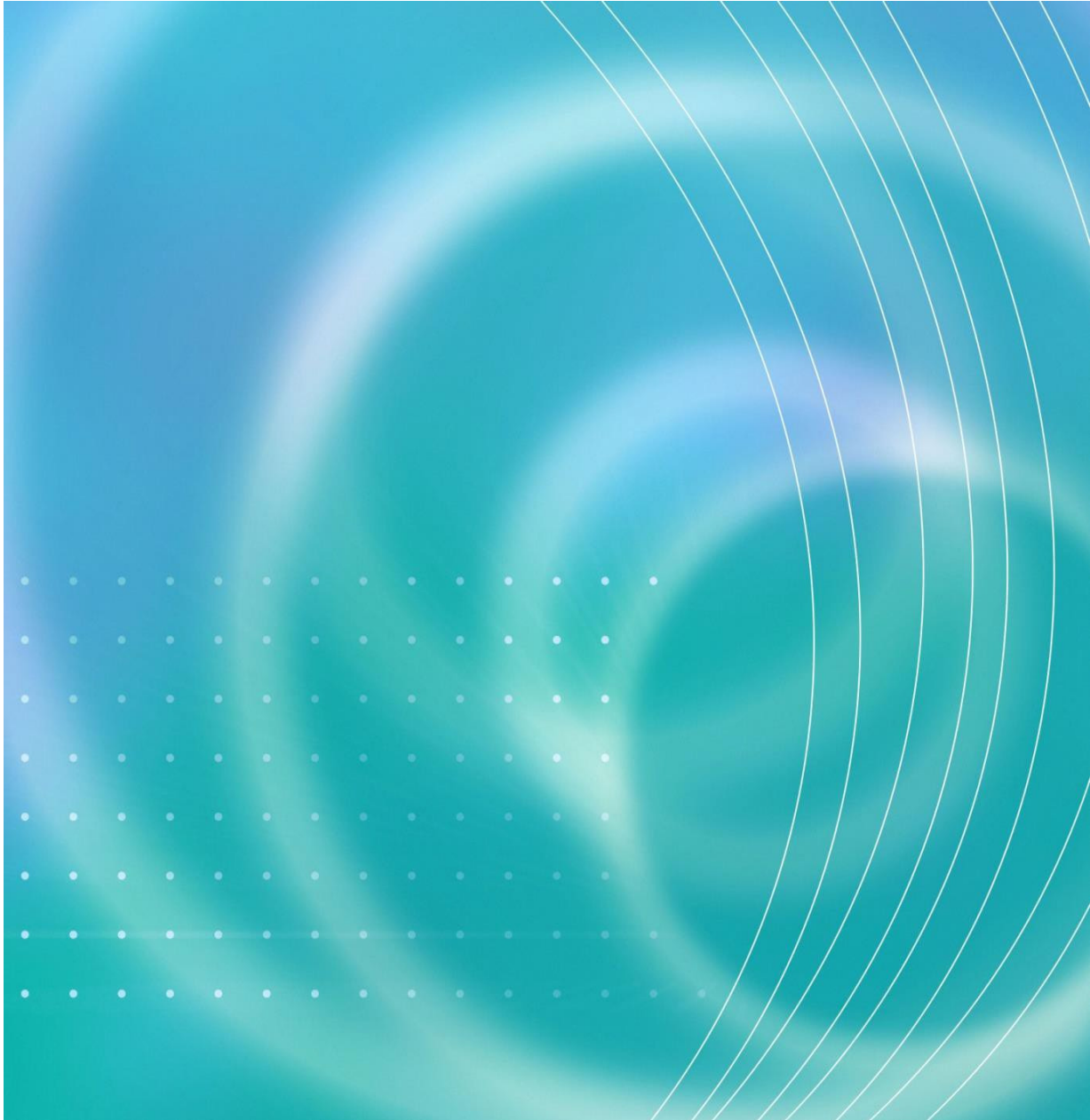




TRANSFORMING LIVES

*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**

**Working Group 3
September 2018**

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FORWARD

In my experience, what people with a disability and families, desire more than anything else, is to have a say and be able to access the supports they need to live fully included lives as valued members of the community.

This Plan offers a route-map to their effective participation in making decisions about the design and delivery of the supports they need to live ordinary lives in ordinary places.

More than anything this Plan urges Government, statutory bodies and exchequer funded agencies to think less about structures and committees and more about the process or way they go about including people with disabilities, and families, in decision-making.

It demands that we all think about the values which should underpin efforts to achieve effective participation. It identifies significant barriers and details the supports required at every level of decision-making, from the individual to the local level in communities, from the regional level to the national. All these supports require attention and dedicated resources to deliver effective participation in decision-making.

Finally, change will only be possible to achieve if there is a transformation in processes and structures to enable effective participation of people with disabilities and families in decision-making. Such transformation requires, action at many levels, including the statutory level as well as the development of Disabled Persons Organisations (DPOs), bodies led and controlled by persons with a disability.

The next step in this process is to design and develop an implementation guide for the effective participation of people with disabilities and families in decision-making processes and structures.

Working Group 3 is an inclusive group of people with disabilities, families, organisations working with people with a disability and the HSE. The experience and expertise of its members in designing this plan offers a valuable blueprint for its successful implementation.

Paddy Connolly, Chairperson

DEDICATION

This plan is dedicated to the memory of Martin Naughton, a member of Working Group 3, who died before this Plan was completed.

Members of Working Group 3 recognise and remember Martin as an inspirational leader, a strong communicator and networker who was greatly admired, both personally and professionally, by those who met him and who knew him.

Martin's work was very influenced by the 1960s Civil Rights Movement in the US. He was a tireless and visionary campaigner for the rights of people

with disabilities. He was involved in setting up the Council of People with Disabilities, in setting up the Centres for Independent Living and AT Network and for introducing Personal Assistant services into Ireland.

Martin's driving message was that other people shouldn't be making decisions for people with disabilities – people with disabilities should be making their own decisions. "Nothing About Us Without Us."

Martin will be sorely missed by his family and friends, by his personal assistants, by people with disabilities and by all who had the honour to know and work with him. May he rest in peace and may his powerful legacy and spirit continue to inspire everyone.

It is important that the work of this group continues and the group members agreed that the final Plan for Effective Participation in Decision-Making would be dedicated to Martin's memory.



EXECUTIVE SUMMARY

Transforming Lives is the name given to the process of reform of HSE-funded Disability Services in Ireland and it is under the umbrella of this programme that Working Group 3 – one of six working groups set up by the HSE - produced this Plan - Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places. While this Plan is primarily directed at the HSE and groups or organisations funded by the HSE, it has a wider relevance for Government Departments, public service bodies, community and voluntary organisations. It recognises:

- People with a disability and their families have a right to participate in decisions that affect them.
- Effective decision-making is not just about information provision and consultation processes, it is about making sure people with disabilities and their families are involved in the planning, development and review of services that affect their lives.
- To truly transform lives a sustained and consistent commitment to resourcing, monitoring and evaluating of decision-making processes is required.
- The UN Convention on the Rights of Persons with Disabilities (UNCPRD) provides an important framework for this plan. Barriers to inclusion in decision-making processes were identified and included some of the following:
 - 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

This Plan based on the Social Model of Disability offers positive and constructive solutions to the removal of disabling barriers:

Part 1 lays out the four core values of Autonomy, Respect, Creative Responses and Mutual Support which Working Group 3 agree are at the heart of effective participation in decision-making.

Part 2 identifies the range of supports that are needed to ensure the effective participation of people with a disability and their families in decision-making processes. These include:

- Changing and challenging attitudes through disability and equality awareness training for all
- Making communication accessible for everyone and addressing physical and structural accessibility deficits
- More efficient meetings through advanced planning, facilitated chairing and small group discussions
- Achieving change using proofing and feedback systems

Part 3 is about strategies. The strategies are presented against the backdrop of what Working Group 3 describe as the 'bigger picture' in terms of ensuring effective participation in decision making. An integrated strategy comprising four strategic goals will ensure people with a disability and families can effectively participate in decision-making within the HSE and HSE funded agencies.

1. The first strategic goal sets out the criteria for the legislative and policy context for effective participation in decision-making.
2. The second goal of building a national infrastructure, will strengthen the representation of people with a disability in the development of strategy, policy and practice.
3. The third strategic goal identifies processes and mechanisms to redress negative cultural attitudes and assumptions about disability which present barriers to effective participation in decision-making.
4. The fourth strategic goal consolidation - will ensure that effective participation in decision making is firmly embedded in strategy, planning, policy and practice into the future.

Final Recommendations include the drafting of a Step by Step Guide for the next phase – the Implementation stage in support of the development of the Community Health Organisations Disability Committees.

This will strengthen the progress of decision-making processes to ensure the effective participation of people with disabilities and their families/advocates.

INTRODUCTION

Persons with a disability are individuals, members of families, friends and neighbours and as people are owners of rights. National and international equality and human rights legislation, referenced in Part 2 of this Plan, protects and upholds these rights on an equal basis as all others. However, deep-rooted structural and cultural barriers continue to discriminate against people with a disability. In particular many people with intellectual disabilities are not supported to make personal 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, 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.

Ways to think about Disability

The traditional view of Disability called the Medical Model of Disability sees the person solely in terms of their 'disability'. This view is characterised by what 'they cannot do rather than what they can do' and what 'they need rather than what they can offer'. Individuals are seen as patients or service users, rather than active agents in their own lives. Such perspectives and approaches are core to the Medical Model of disability which has informed the segregation of many people with a disability and excluded them from the decision-making processes which directly affect their lives. Families of people with a disability are also frequently excluded from decision-making processes and their views and opinions disregarded.

The Social Model of Disability, developed by people with a disability over the past 50 years, is a different way of understanding disability. It is not the impairment of the person which is disabling. 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 and civil rights.

This is summed up in the preamble of the UN Convention on the Rights of Persons with Disabilities (UNCRPD):

Recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. (UN, 2006)

Hearing the Voice of All People with Disabilities

It is not up to us to know what each and every person who may have complex needs requires to live an ordinary life in ordinary places. But we do know that they need to have the same right to participate in making decisions that affect them. They need to be asked and listened to, like everyone else.

Working Group 3 Member

1. TRANSFORMING LIVES

In recent times, the Government has reiterated their commitment to creating the conditions that would empower people with a disability to live ordinary lives in ordinary places:

Central to the Programme for Government is the commitment to empower people with disabilities to live independent lives and to have greater choice and control over the services and supports they need to make that goal a reality. (Department of Health, 2016)

Part of this commitment has been Transforming Lives - the name given to the process of reform of HSE-funded Disability Services in Ireland. At its heart, Transforming Lives aims to ensure that:

- The **fundamental and constitutional rights** of people with a disability and families to non-discrimination and the right to effectively participate in making decisions that affect their lives is recognised
- The **voice of people with a disability and families** is included wherever decisions are being made about their lives - for example, in their own life and in the community, in relation to health and social services or at Government level
- The **effective participation** of people with a disability and families takes place at all levels and stages of the decision-making process

1.1 Overview of the Process of Developing the Plan for Effective Participation in Decision-Making

In 2014, as part of the Transforming Lives process, the Minister of Health asked the Health Service Executive (HSE) to set up six Working Groups to think about what needed to change, including the way the HSE fund and deliver supports and services for people with a disability.

Working Group 3, one of the groups set up under Transforming Lives, began its work in 2015. (See Appendix 2 for Terms of Reference.) This was a fully inclusive, facilitated group ensuring the effective participation of every member. 'Experts by Experience' members were remunerated for costs incurred, including personal supports and childcare and they received a stipend for their working time.

This group focused on the question:

How can people with a disability and families, be included in making decisions about how the HSE and other groups or organisations funded by the HSE, support people with a disability to live ordinary lives in ordinary places?

In response the group set about developing a plan, underpinned by a set of values and strategies that would support effective participation.

Key to the process was developing a shared understanding of the 'Terms of Reference' (ToR) for Working Group 3. (See Appendix 2 for ToR.) It is recognised by Working Group 3 that while this plan is destined for the HSE and groups or organisations funded by the HSE, having an 'ordinary life in an ordinary place' involves decisions-making within a much wider community context. For real change to happen in the lives of people with a disability, and where relevant their families, this plan needs to be taken on board by a wider range of Government Departments, Public Service Bodies, organisations and local community structures.

To further support the development of a Plan for Effective Participation in Decision-Making, Working Group 3 commissioned the National Disability Authority to research models of engagement and participation in other countries. The findings highlight while there is no model which could be translated directly into use in Ireland there are potential lessons and individual features in relation to practice which are valuable.

1.2 Key Terms in the Plan for Effective Participation in Decision-Making

Three key terms are used throughout this plan namely, people or persons with a disability, family or families and effective participation.

People/Person with a Disability

A sub-group of Working Group 3 explored how the term 'disability' would be defined or used within the plan. Language is not static and changes over time. Different countries use different language and ways of describing and defining this group of people. People with disabilities is used in the United States and in English documents of the United Nations. This plan has adopted the definition of disability from the UNCRPD. However, it acknowledges many people do not identify with this term to describe themselves:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (UNCRPD, 2006)

Family or Families of a Person with a Disability

People with a disability do not live in isolation but as part of close family, extended family and wider community networks. Parents/guardians have a very unique role to play in making decisions about the supports and services required by their children. Their perspective is often excluded from the decision-making processes of Government, the HSE, service providers and other relevant bodies. This results in family isolation and the potential for negative outcomes for their family members.

Family/Families

Whatever services and professionals do, they must not seek to separate or alienate people from their family and friends as it is they who constitute the enduring sources of love and support, however flawed at times, in people's lives.

Working Group 3 Member

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 in the process. It is also important to recognise the key role that independent advocates can play in decision-making processes.

Effective Participation

Effective participation recognises that people have the right to participate in decisions that affect them. Effective participation is not just about asking people for their opinions. It is about making sure they are involved in the planning, development, and review of services that affect their lives. The NDA research report identifies a number of different arguments for effective participation.

1.3 Barriers to Effective Participation in Decision-Making Attitudes

Many people with a disability and families experience negative attitudes towards disability. Low expectations in relation to a person's capacity to engage in debate and discussion present a significant obstacle in decision-making processes. This makes people feel disrespected, unequal and less important than others.

It's All About Attitudes ...

People don't think I'm capable....

People just don't think I can do it myself....

Just because I have a disability it doesn't make me any different – it's people's attitudes....

Feedback from Consultation

Accessibility

A lack of physical access is experienced as disempowering and limiting of people's life opportunities and choices. In relation to supporting individuals' effective participation, physical access issues were identified by the Working Group as a major priority. Inaccessible transport networks, inaccessible buildings and inaccessible facilities pose real obstacles to inclusive participation in decision-making processes. The many barriers caused by physical access deficits need to be redressed.

Communication

Communication is an equally important part of supporting people's access to information. People communicate in many different ways and languages. These include speaking, signing, reading, Braille, using images, multi-media devices and through body language including movement and facial expressions. The lack of accommodation in relation to the range of needs required results in frustration, misunderstandings and disadvantage when persons with a disability are excluded from decision-making fora.

Experience and Knowledge

The lived experience and knowledge gained by people with a disability is not always recognised. People are not always valued in their own right as 'Experts by Experience'. In addition, for persons themselves with a disability the lack of access to training or third level education creates barriers in terms of the language and concepts used in decision-making fora. This is experienced as unhelpful, disempowering and isolating.

How Meetings Work

How meetings are structured and organised present obstacles to effective participation. Issues include the communications needs and styles of participants, the length of meetings, the availability of supports and accessibility difficulties. These barriers contribute to exclusion, frustration and disrespect.

Good Chairing

The role of chairperson can be of significant importance when it comes to ensuring everyone's voice is heard. A good chair should ensure that everyone has an understanding of the business as its being conducted and that each person is facilitated to take an active part.

Working Group 3 Member

Lack of Change

People with a disability become disheartened and de-motivated when their participation in decision-making processes does not lead to change. It is important that participation is meaningful in securing positive change for people with a disability both individually and collectively.

Growing in Confidence and Expertise

When I first joined Working Group 3, I began to make friends with more people. This gave me more confidence as I was participating, learning about others stories and what they were going through.

However, as a result of my participation, I am now doing a project with another member. This would not have come about except that I learned about other organisations and had the chance to network.

Member of Working Group 3

1.4 Consultation Process and Feedback on Draft Plan

To strengthen the final Plan for Effective Participation in Decision-Making, a process of countrywide consultation was agreed by Working Group 3. A number of consultation groups were led by members of Working Group 3, and the facilitation team provided support as required. Accessible Drafts of the Plan for Effective Participation in Decision-Making were produced in the following of formats:

- A long and short Plain English version
- Five short videos explaining the background and different sections of the plan with voiceover, animation and subtitles to aid understanding
- The same five videos were then translated with subtitles and animation into Irish Sign Language

Various consultation methods were used:

- An online 'SurveyMonkey' captured individual feedback. All questions were optional with a range of multiple choice options for some questions and text space for others
- Resource materials were developed for organisation/community group consultations including checklists for setting up consultation groups; consent forms for participants; sample sets of questions; a PowerPoint presentation based on the plain English version of the draft plan and feedback forms

Feedback from Consultation

415 responses were received during the Consultation phase. (See Appendix for respondent breakdown.) While respondents identified a number of areas in which the plan and the consultation process could be strengthened, feedback was overwhelmingly positive. Individuals, groups and organisations identified the following:

- The absolute necessity for people with a disability and families with the support of advocacy services if required, to have their voices heard in personal, local, regional and national decision-making fora
- The importance of having an explicit plan to promote effective participation in decision-making
- The importance of the values of autonomy, respect, creative responses and mutual support as the cornerstones for building effective participation in decision-making.

- The range of barriers to effective participation as outlined in the draft plan as being accurate and valid
- The importance of appropriate supports at every level in the process, from information to consultation processes
- The importance of ensuring that any structures developed by the HSE, including primary care and health and well-being actively engage with people with a disability and families to ensure their effective participation when decisions are being made
- The need for adequate resources to implement this plan satisfactorily
- The need for a consistent and continuous review process to ensure that the plan continues to meet the needs of people with disabilities and families

2. A PLAN FOR EFFECTIVE PARTICIPATION IN DECISION-MAKING

2.1 Background: International Instruments, National Legislation and Policy

The development of a Plan for Effective Participation in Decision Making draws on commitments contained in international instruments and national legislation to safeguard the rights of people with disabilities to make their own decisions and direct their own lives.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and Human Rights

Human rights are set of basic rights and freedoms that everyone is entitled to, regardless of who they are. They are about how the State must treat you. They recognise that everyone is of equal value, has the right to make their own decisions and should be treated with fairness, dignity and respect.

The Convention is the first legally binding instrument in history to set out the obligations on States to promote, protect and ensure the rights of persons with a disability across the globe. It is an international human rights agreement written by and for people with a disability.

Specifically Articles 3, 4 and 19 reference the rights of people with a disability to be actively involved, equal to others, in decision-making processes which affect their lives. Article 7 of the Convention ensures that children with disabilities have the right to express their views freely on all matters affecting them.

The UNCRPD highlights the key role of civil society, in particular, people with a disability and their representative organisations, in the national implementation and monitoring process of the UNCRPD. In addition, the Optional Protocol of the UN Convention provides for an individual complaints mechanism.

When a country 'signs' the UNCRPD it means it agrees with what the Convention says about human rights of persons with a disability. When a country 'ratifies' the UNCRPD it agrees to do what the Convention says and make changes to ensure that the rights in the Convention are respected in practice.

Ireland's Equality Legislation

The Employment Equality Acts (1998-2011) and the Equal Status Acts (2000-2015)

These Equality Acts set out the legal requirement for employers in relation to employees and organisations in the provision of goods and services - including the HSE - in relation to discrimination, harassment, and reasonable accommodation of people with a disability, as well as positive action measures. Reasonable accommodation means providing specific treatment or facilities to make sure that people with a disability can avail of particular goods, services, housing, and so on.

However, if making these accommodations amount to more than a nominal cost, organisations and employers are not required to do so.

Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act 2015 strengthens the rights of persons with a disability and older people by ensuring there is a presumption of capacity for them to make decisions unless the contrary can be shown. The Act is critical in its provision for a range of decision-making support options to assist people to make their own decisions in relation to personal welfare, property and finances. This legislation repeals the Lunacy Regulation (Ireland) Act of 1871. It abolishes the system of Wards of Court and replaces it with a Decision Support Service and makes provision for Advance Healthcare Directives. Commencement Orders were signed by the Minister for Justice and the Minister for Health in October 2016, bringing some but not all of the provisions of the Act into effect.

HIQA National Standards for Residential Services for Children and Adults with Disabilities, 2013

Under Section 8 of the Health Act 2007 the Health Information and Quality Authority (HIQA) is responsible for national standards for health and social care services. These standards provide a framework for service providers, and for people who use services, to ensure that the person is at the centre of service development.

In relation to adults with disabilities in residential services, the standards state that:

- “Each person makes decisions and has access to an advocate and consent is obtained in accordance with legislation and current best practice guidelines.”

In relation to children the Standards require:

- “Each child participates in decision making, has access to an advocate, and consent is obtained in accordance with legislation and current best practice guidelines.”

National Strategy on Children and Young People’s Participation in Decision-Making 2015-20

The National Strategy on Children and Young People’s Participation in Decision-Making 2015-20 was developed to give voice to children and young people in their everyday lives. The HSE Disability Services are committed to developing a “framework document on how children’s voices will inform the design, implementation and evaluation of disability services”. The Department of Children and Youth Affairs is establishing a Children and Young People’s Participation Hub to assist in the strategy’s implementation. The Hub will support government departments and other organisations in implementing the strategy through training, documenting best practice and developing education on children’s rights for professionals.

Overall analysis

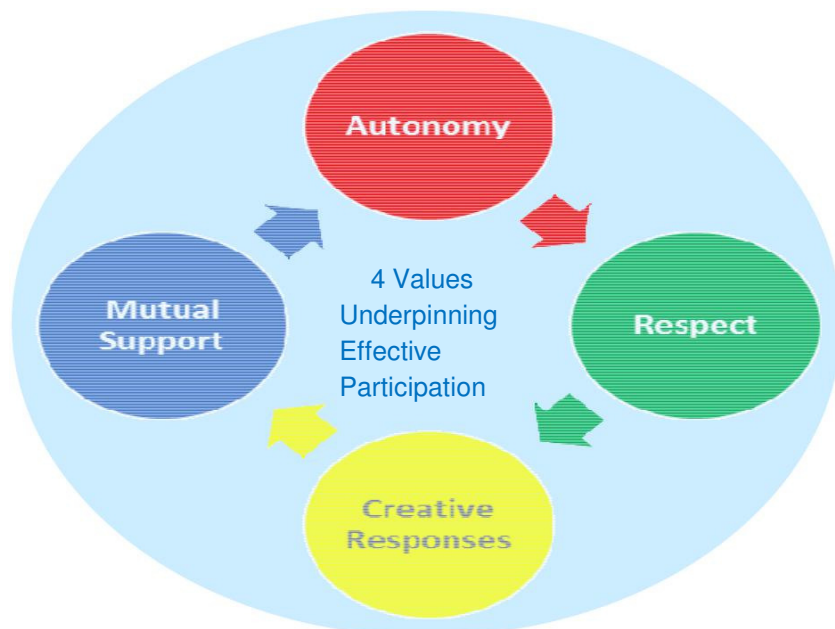
The international mechanisms together with national legislation outlined above, provide an important framework for this Plan for Effective Participation in Decision-Making. However, this will not be complete until Ireland has ratified the UNCRPD and a monitoring process commences.

The following section, outlining the plan itself, is divided into three inter-related parts:

- Part 1 lays out the four core values that Working Group 3 agree should uphold effective participation in decision-making.
- Part 2 identifies the range of supports that are needed to ensure the effective participation of people with a disability and their families in decision-making processes.
- Part 3 is about strategies. It identifies an integrated strategy to ensure people with a disability and families can effectively participate in decision-making within the HSE and HSE funded agencies, government groups and community structures.

2.2 Part 1: Values Underpinning Effective Participation in Decision-Making

Participation in decision making will be effective if it is motivated and directed by values. Guided by the principles of human rights, equality, including disability equality, Working Group 3 identifies four core values that will motivate, guide and direct the effective participation of people with disabilities, and families, in decision making. These four core values are indivisible, i.e. they cannot be seen in isolation from each other. They 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 has to make their own choices. This will include the provision of supports, if required for this to be realised.

I Want to Manage my Own Budget

My doctor has advised that I go swimming regularly. I have explained that I can't go without a Personal Assistant. However, at the moment the HSE will only fund primary care hours (9.00-5.00pm) so there is no financial support for what are called 'social hours'. I cannot employ a Personal Assistant. This has to change, I want to manage my own budget and choose my own service provider/support.

Member of Working Group 3

People have the right to direct and influence their own future, their own life's journey. Exercising one's autonomy fosters a growing sense of self-esteem and self-worth.

At a regional and national level, strategy, policy and planning decisions must be produced in partnership with people with the lived experience of disability, families and advocates.

Respect

Respect is an empowering value in relationships. Respect means that mutual trust exists between people, which recognises, values and reflects people's lived experience and fosters their growing confidence and expertise. Respectful dialogue listens to what people with a disability have to say and trusts people to know what they themselves need on a personal level.

- Respectful decision-making processes at all levels will:
 - Ensure a person's entitlement to privacy and confidentiality.
 - Ensure there is no discrimination or harassment.
 - Recognise and value the diverse/multiple identities of people with a disability to ensure their full and effective participation in decision-making.

Creative Responses

Creative responses are a way of thinking outside the box and not presuming that one size fits all. The value of creative responses is visible when decisions recognise the uniqueness of each individual, acknowledge their individual needs, and respond creatively to those needs. It is about working in a different way and finding a way forward when the way might not be clear. Responding creatively to facilitate the range and style of communication needs will ensure that each person's input is received clearly and fully.

Processing Information

It is not enough just to present autistic people with information... Time must be given to supporting people to process it. It is also really important to contextualise the information so that people understand its relevance to them. Visualisation is as important as vocalisation when communicating with autistic people. It is not that people do not want to participate - they might just not get the context or that it is relevant to them.

Working Group 3 Member

It means moving away from the more static approach of committees and consultation to using more responsive and innovative ways of engaging. This could involve thematic days, road shows, online forums and arts and cultural opportunities.

The Value of Creative Responses

Everyone has their own needs and they are different for every person. So the response has to be different for every person.

Consultation Feedback

If creative responses are valued at this level, they can give rise to more appropriate and meaningful policy development, implementation, monitoring and evaluation.

Mutual Support

In relation to persons with a disability the value of mutual support recognises that people are not just individuals requiring individual respect. People are also relational and interdependent with valuable contributions to make to their own lives and those of their communities.

The Value of Mutual Support

The HSE and others – we should all be working together to make sure that we have the power to make decisions. Sometimes we need the supports to fully make a decision and sometimes we make the wrong decisions in life but either way it was me that made the decision.

Feedback from Consultation

Life is better when people work together, form partnerships and find common ground to work together. Effective decision-making ensures that the value of mutual support is central to the process.

Whether at a personal or policy level, creating an inclusive decision-making environment for persons with a disability and their families achieves lasting outcomes which in turn will benefit a mutually supportive society.

2.3 Part 2: Supports Required For Effective Participation in Decision-Making

Working Group 3, through a series of round-table sessions, small-group sessions and brainstorming sessions, identified a number of processes in support of effective participation in decision making.



Changing and Challenging Attitudes

A significant change in attitudes is required to facilitate greater autonomy and respect, creative responses and mutual support for persons with a disability and their families and pave the path for more effective participation in decision making processes.

Achieving more effective participation in decision making can be enhanced by challenging attitudes including:

- Offering equality/disability equality and awareness training to people involved in decision-making to explore their conscious and unconscious attitudes towards people with a disability and equality
- Offer training to persons with a disability and their families in decision making processes and give people the tools to support their effective participation. It is important to empower people with a disability to be 'experts' and to recognise and trust their experience; 'we have been there, worn the t-shirt, walked the walk'.

Valuing Knowledge and Experience

To ensure effective participation in decision-making, everyone's experience and knowledge must be recognised and valued. It is also important to recognise that everyone's knowledge and experience increases and develops over time.

Practical steps that help remove barriers in the area of knowledge and experience and contribute to the rebalancing of power in decision-making processes include:

- Training for persons with a disability in confidence building strategies
- Including each person's own knowledge and experience meaningfully in discussions and in the decision making processes
- Disability awareness training for all the members of the group
- Ensuring that there is appropriate support available as required
- Ensuring all voices are heard equally and individual or group input is acknowledged, and where possible, acted upon.

Effective participation can be enhanced by the development of a culture and practice that place a value on the experience and expertise of those who experience disability in their own lives. There are differences in terms of levels of commitment between an invitation to a once off consultation and participating on a committee or working group. There are also differences between participating voluntarily, when others are similarly volunteering, and participating on or in groups where the majority are paid. In this regard Working Group 3 note that while not every activity requires remuneration or payment there are times when a commitment to remuneration or payment that is appropriate to the nature and level of participation is required.

Payment of expenses

Effective participation is developed when the costs of attending and participating in a range of fora including, committees or working groups is factored in from the outset. At a minimum this includes travel and subsistence costs, accommodation costs if required, and so forth.

Payment of supports

Effective participation is enabled when appropriate supports are made available and paid for. These include expenses that may only be relevant to experts by experience and not other contributors as described in the barriers to effective participation and may include personal assistance hours, special equipment or technology or sign language interpretation or accessible materials.

Payment for time and expertise

Effective participation is enhanced when people's experience and expertise is recognised and valued. 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.

Being Paid For What We Do

When we are doing things we like to get paid for it. We are working hard, and because of the time we give. There is no point in going to meetings in Dublin, going up on the train and not getting paid. I look forward to getting paid. Everyone is treated the same because everyone is then getting paid.

Working Group 3 Member

Improving Communication

When it comes to decision making good communications are key.

Improving Communication

I found it important that people talked slowly, so that I could pick up what people were saying. I also found the CD's of the report very helpful. I was under no pressure and was able to read and follow the words at my own pace. It was easier than at meetings, because when other people spoke I knew what they were talking about because I had heard it on the CD.

Working Group 3 Member

Poor communication styles including a lack of accessible information, can lead to confusion and misunderstandings between people.

This can be avoided by:

- Developing communication strategies in partnership with organisations or advocacy groups ensuring that barriers to communication are addressed
- Facilitated discussions and decision-making fora
- Including clear explanations of decisions/information when communicating with people
- Providing sign interpretation, audio equipment, assistive technologies
- Ensuring minutes of meetings and discussion topics are clear and communicated simply with a commitment from all groups to use Plain English and easy-to-read formats

Group Facilitation

I feel good group facilitation is really important to the success of any participation. I found the inclusiveness of our large group, when Working Group 3 and the Guidance Group merged, really encouraging and useful. We were able to share our viewpoints and differences of opinion and come up with strategies to cater for us all to participate well together.

Working Group 3 Member

Improving Accessibility

In supporting effective participation in decision-making, the barriers caused by access difficulties need to be redressed. This will require ensuring that the necessary resources and responses are in place

Measures to improve accessibility and enhance effective participation include:

- Provision of adequate resources that cover at a minimum participants travel, subsistence and support expenses and where appropriate payment for time or expertise.
- Using wheelchair accessible venues with permanent accessibility, not portable ramps, thereby ensuring that everybody uses the same entrance to a venue i.e. the main entrance
- Ensuring that meetings take place where accessible and 'easy-to-get-to' transport networks are available
- Ensuring that there is level access to all rooms, including eating areas, so everybody can participate together as respected and equal members of the group
- Taking account of the size of the meeting room

Making Meetings Work Better

Effective participative outcomes will only transpire if meetings are purposefully structured and organised. This can be helped by:

- Allowing people enough time to get to meetings
- Planning for consultative meetings is essential and needs to include the voices of all attendees
- Circulating information to all participants in a timely fashion
- Facilitated chairing of meetings is essential to ensure equal and effective participation
- Creating a positive working environment using introductions, putting people at ease, using 'ice breaker' methods
- Consideration given to the length of meetings including having breaks during meetings
- Using media other than PowerPoint
- Ensuring supports are available in meeting rooms as required
- Using small group discussion formats
- Ensuring agendas have been agreed in advance and are clearly understood

The Nature of Support

Actions speak louder than words...we need that extra support... Our support has to be people who are able to adjust and get down to our way of thinking. Only we will know if we have been heard from the actions that are taken by those who have the power and that will happen over time, hopefully.

Working Group 3 Member

Achieving Change

Participation in decision-making must contribute to changes in the lived experience of persons with a disability and their families. Achieving change can be supported by:

- Using proofing systems within the decision-making processes to assess potential impact, including unintended impact, on the lives of people with a disability and their families in advance of implementation
- Organisations need to be open to and proactively seek feedback making it very clear how and where people can give it
- Using meaningful feedback systems to assess outcomes for an individual or a group. This is really important as it will help track the contribution made to enable full equality in practice.

2.4 Part 3: Strategies to Ensure Effective Participation in Decision-Making

Working Group 3 recognise that developing effective participation of people with disabilities, and families in decision making, does not reside solely with any one group, agency or Government Department. In order to secure a sustained approach to supporting the effective participation of in decision making, for people with disabilities and families, it is important that this bigger picture is borne in mind.

The Bigger Picture

Working Group 3 believe that effective participation will benefit significantly from Ireland ratifying the UN Convention on the Rights of Persons with Disabilities. This is seen as an important step towards ensuring a proactive approach by the State in realising and ensuring the rights of people with disabilities are vindicated, including the right to be involved in making decisions that affect their lives. Further to this Working Group 3 believe in the importance of ratifying the Optional Protocol of the UNCRPD- the individual complaints mechanism for the Convention and adequate representation of people with the lived experience of disability, and families, on the National Implementation and Monitoring Group for the UNCRPD. The UNCRPD highlights the key role of civil society, in particular, people with a disability and their representative organisations, in this process.

Other mechanisms that could have a significant impact in supporting effective participation in decision making that lie outside the explicit remit of the Department of Health and the HSE, include the implementation of all the provisions of the Assisted Decision-Making (Capacity) Act 2015. This will ensure that all persons are presumed capable decision makers and have a right to the support of their choosing in making decisions or having their decisions recognised.

The group also recognise the importance of an independent review of the role of advocacy supports in decision-making, as this could provide valuable data for the Department of Health. This would also go some way towards ensuring that there are sufficient independent advocacy supports available for all people with disabilities and that they are funded and resourced appropriately.

Working Group 3 also identified the benefit that would accrue to effective participation in decision making if the full and effective implementation of the public sector duty under the Irish Human Rights and Equality Commission Act (2014) on all public bodies to have regard to the need to eliminate discrimination, promote equality of opportunity, and protect human rights in carrying out their functions.

At the local level Working Group 3 recognised that effective participation in local authority decision-making structures, including Public Participation Networks (PPN) which are now being established in local authority areas, give power to communities to drive change from local community level. These networks facilitate the identification of issues of common concern and elect representatives onto other decision-making bodies. Such networks also provide an opportunity to include people with a disability and families.

Strategic Directions for Department of Health and the HSE

Bearing this bigger picture in mind Working Group 3 sets out below a set of integrated strategies aimed at the Department of Health and the HSE as a means of developing effective participation in decision-making.

Key to the implementation of this integrated strategy for effective participation in decision making, is the development, by Government and HSE, in partnership with people with a disability, and families, of an overall implementation plan. This implementation plan would set out clear objectives, agreed outcomes and a mechanism for monitoring and evaluating its impact on the lives of people with disabilities, and families.

Integrated Strategy for Effective Participation in Decision-Making- 4 Strategic Goals

1. Creating the Legislative and Policy Context and interagency working
2. Constructing the Infrastructure
3. Creating the Culture and the Conditions
4. Consolidation

Strategic Goal No. 1:

Creating the Legislative and Policy Context and interagency working for Effective Participation in Decision Making

Given the importance of the bigger picture outlined above and to deliver on this strategic goal

1.1 The Department of Health would circulate this Plan for Effective Participation in Decision-Making amongst Government Departments through the National Disability Inclusion Strategy Steering Group (NDISSG).

1.2. The HSE would circulate this Plan for Effective Participation in Decision-Making to various state organisations and bodies with whom it works. This would promote greater awareness and understanding of effective participation in decision-making and in so doing support others to work, where possible, on the wider legislative and policy context.

Strategic Goal No. 2:

Building a National Infrastructure for Effective Participation in Decision Making

The second strategic goal, building a national infrastructure, will strengthen the representation of people with a disability in the development of strategy, policy and practice.

To deliver on this strategic goal:

2.1 Support and resources need to be made available where possible to address the lack of independent Disabled Person Organisations of Self-Representing Organisations as highlighted by the Irish Human Rights and Equality Commission (insert reference or name of report). Such organisations, which would be autonomous of service providers, would provide an appropriate mechanism for the HSE to identify concerns and issues relevant to the lives of people with a disability and families, access independent representation for their existing and emerging decision making structures, for example, at CHO level and/or National Level and allow for the development of communication and feedback processes.

2.2 Membership of the existing National Framework of HSE, CHO Regional Disability Committees and the HSE National Disability Committee needs to be expanded to include more people with disabilities and families. People with disabilities and families need to be adequately represented on any new and existing structures. Such committees, would be chaired by the HSE, and ideally supported by an independent facilitator. The independent facilitator would oversee the provision of appropriate supports required to ensure all committee members effectively participate in meetings at regional (CHO) and national level.

Strategic Goal No. 3

Developing the Culture and Conditions for Effective Participation in Decision Making

Key to creating the culture and the conditions for effective participation in decision making is a fundamental shift in culture, attitudes and assumptions about disability. To deliver on this strategic goal:

3.1. Awareness raising and appropriate training needs to be made available for all those involved in the delivery of supports and services on what constitutes effective participation in decision making. This training needs to be designed and delivered in partnership with people with a disability, families.

3.2. The engagement of people with disabilities and families as specialists and community connectors should be a key principle underpinning all activities carried out under the National Disability Inclusion Strategy. For example, when specific communication and/or consultation activities arise, whether these are short, medium or longer term, at local, regional (CHO) or national level, every effort should be made to facilitate and support more people with a disability and family members to act as specialists and/or community connectors including securing the necessary resources that would allow for those involved to be supported and remunerated.

3.3 Disability funding including personal budgets should be provided in a way that ensures people with a disability and families can direct and control their lives.

3.4. Capacity building will include training of 'Experts by Experience' in effective participation in decision-making. Mentoring, including peer mentoring should also be available for Experts by Experience throughout the decision-making process. Any mentoring and training provided by experts by experience should be budgeted for in advance.

3.5. Putting in place a variety of accessible points of contact between people with a disability and their families and the Government, the HSE, service providers and other relevant organisations. This will ensure a clearer connection between people's lived experience of disability, policy makers and those delivering supports and services. Organisations should proactively engage and initiate contact with people with a disability and families.

3.6. Service arrangements between the HSE and service providers should link provision of funding to a demonstrated commitment by provider organisations to the provision and implementation of service/support towards the effective participation of people with disabilities and families in decision-making processes

Strategic Goal No. 4:

Consolidating Effective Participation in Decision Making

Consolidation will ensure effective participation in decision making is firmly embedded in strategy, planning, policy and practice into the future. Consolidation requires a sustained and consistent commitment to resourcing, monitoring and evaluation. Achieving this strategic goal requires:

1. A transparent framework for data collection and monitoring of effective participation in decision making to be developed by the HSE, in partnership with people with disabilities and families, to review the progress of CHO Disability Committees and the National Disability Committee.
2. Ongoing investment, including funding, in advocacy and training for people with a disability, and families, so that they can continue to participate effectively in a range of decision making fora, at local, regional (CHO) and national level.

1. RECOMMENDATIONS FROM WORKING GROUP 3 TO TRANSFORMING LIVES NATIONAL STEERING COMMITTEE

In presenting this Plan for Effective Participation in Decision Making, Working Group 3 recommend that the Transforming Lives National Steering Group request that the HSE:

- Publish this Plan in a variety of formats to ensure that it is accessible to a wide range of people. Such versions should include: a short version, an easy to read chart/poster, a Braille version and a video version with sign language.
- Convene an inclusive Implementation Group to develop and oversee the rollout of a step by step guide to implementing the effective participation of people with disabilities and families in decision-making processes.
- To initiate this Plan, allocate sufficient resources to establish a Training Panel to deliver awareness-raising and training sessions on the Plan for Effective Participation in Decision-Making across each of the 9 CHO areas of the HSE.

4. CONCLUSIONS

If people with a disability are to secure their right to live ordinary lives in ordinary places, and experience full equality, the barriers as outlined in this Plan need to be recognised and addressed. At the highest level Ireland's ratification of the UNCRPD will explicitly challenge these obstacles and support the rights of persons with a disability and their families/advocates to participate in decision-making processes that impact on their lives. This will include their representation on the monitoring committee overseeing the implementation of the Convention.

Feedback from the Consultation stage of this process informs this Plan that the participation of persons with a disability in decision-making processes must be well supported and resourced. To consolidate effective participative decision-making processes a commitment to comprehensive data collection and monitoring will ensure that peoples' voices are not just listened to but acted upon and in so doing reflect their impact on the decision-making process.

As part of the next implementation stage, proposed Frameworks for the development of the Community Health Organisations Disability Committees will strengthen the development of decision-making processes to ensure the effective participation of people with disabilities and their families/advocates. These will reflect a significant increase in the direct representation of people with a disability to determine measures on an equal partnership basis and ensure a rebalancing of power in health and social care decision-making structures and fora at all levels and stages.

5. APPENDICES

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(b) Working Group 3 Original Terms of Reference

Develop the principles to underpin a framework that has as its starting point active participation and integration and in doing so articulate a narrative for the development of disability supports and services which place as their primary objective persons with a disability living ordinary lives in ordinary places and holding a socially valued role in the community.

Develop a shared understanding of the needs, experiences, capacities of the people with disabilities and their preferred method of engagement with the process and to advise and make recommendations on how the VFM process might achieve this.

Establish appropriate mechanism to enable people with disabilities to;

- Share their knowledge and experience

- Actively participate in the decision making process
- Influence service planning and policy development
- Identify barriers and highlight impediments to achieving bullet one

Build on the mechanisms employed in the National Consultative Forum structures to ensure enhanced people with disability involvement in the development of disability services.

Produce plans to identify a range of methodologies to ensure service user involvement.

People with Disabilities and their families' views will impact on decision making at all levels of service development and delivery.

Identify the appropriate process for the selection of a number of people with disabilities to participate in a meaningful way at both Area and National Fora.

(c) Participant Responses to Consultation

415 responses were received during the Consultation phase. A breakdown of respondents is presented below:

Fifteen [consultation groups](#) took place throughout the country. Of the 140 consultation group participants;

130 people with a disability (including people with physical / sensory / intellectual disabilities, autism, acquired brain injury, mental health challenges)

5 family members and 5 support staff

Individual Responses:

1 Person with a Disability

6 Family Members (including 1 sibling)

Organisational Responses:

1 National Organisation

Online Survey Responses (SurveyMonkey) 20

People with a Disability

110 Family Members 36

Support/Advocacy

101 Chose not to describe themselves

(d) Members of Working Group 3

Working Group 3 is an inclusive group of people with disabilities, family members, organisations working with people with disabilities and HSE representatives.

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