



An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality,
Disability, Integration and Youth



DCU
Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University

Scoping Document on the Inclusion of Disabled Children and Young People in Participation in Decision-Making

Prepared by researchers from the School of Inclusive and Special Education, Institute of Education, Dublin City University for the Department of Children, Equality, Disability, Integration and Youth.

October 2024
gov.ie

[Page 1]

Proposed citation: Kazmierczak-Murray, S., O'Mahony, K., & Carey, A. (2024). *Scoping Document on the Inclusion of Disabled Children and Young People in Participation in Decision-Making*. Department of Children, Equality, Disability, Integration and Youth (Ireland).

Acknowledgements

We thank the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) for commissioning us to author this project. Several organisations and individuals supported the creation of this scoping document. This included members of the project group, Hub na nÓg, the National Disability Authority (NDA), DCEDIY, and members of the Disability Working Group, whose contributions and recommendations were included throughout the creation of this scoping document. Thank you to the young people who took part in consultations on 'what works and doesn't work when involving children and young people in decision-making', and for their recommendations on what to include in the scoping document.

Members of the Disability Working Group included:

AsIAm

Chime

Disabled Women Ireland

Inclusion Ireland

Independent Living Movement Ireland (ILMI)

National Council for Special Education (NCSE)

National Participation Office

University College Cork (UCC)

Tusla – Child and Family Agency

Vision Ireland (formerly National Council of the Blind Ireland [NCBI])

[Page 2]

Contents

Abbreviations	4
List of Images	5
Statement on Language	6
1.0. Introduction and Background	8
1.1 Those involved	8
1.2 Why do we need this scoping document?	9
1.3 What is participation in decision-making?	10
1.4 How should this scoping document be used?	11
2.0 What to Think about to Ensure All Participation in Decision-Making is Inclusive and Accessible	12
2.1 Things to think about	13
2.2 Different ways of communicating	22
2.3 Communication partners	23
2.4 What is augmentative and alternative communication?	25
2.5 Accommodating all ways of communicating	26
2.6 Guidance on the use of augmentative and alternative communication	26
3.0 Steps in Planning Participation Initiatives	27
3.1 Recruitment of disabled children and young people	27
3.2 Working in partnership with disabled children and young people and those they already know and trust	28
3.3 Gaining consent and assent for participation	29

3.4 Gathering information	30
3.5 Preparation of resources	31
3.6 Supporting understanding	33
3.7 What to think about when designing questions?	37
4.0 Specific Methodologies for Participative Processes with Disabled Children and Young People	38
4.1 Introduction	39
4.2 Mosaic approach	39
4.3 Activity based participation methods including creative activities	39
4.4 Ranking activities	43
4.5 Talking mats	45
4.6 World café method	48
4.7 PhotoVoice and VideoVoice	50
4.8 Sensory story sharing	51
4.9 Observation	51
4.10 Online and digital participation	53
5.0 Evaluation of Participation and Giving Feedback	55
5.1 Evaluation of participation	55
5.2 Giving feedback to children and young people	58
Appendices	60
Appendix 1: Project group members	61
Appendix 2: Types of communication including augmentative and alternative communication	62

Appendix 3: 'Getting to know you' checklist 66

Appendix 4: Examples of visual schedule, social story script for participation and sensory story share 75

Appendix 5: Useful websites and resources 85

Abbreviations

Augmentative and Alternative Communication	AAC
Department of Children, Equality, Disability, Integration and Youth	DCEDIY
Disabled Persons Organisation	DPO
Dublin City University	DCU
National Disability Authority	NDA
United Nations Convention on the Rights of Persons with Disabilities	UNCRPD
United Nations Convention on the Rights of the Child	UNCRC

[Page 5]

List of images

Participation Framework: National Framework for Children and Young People's Participation in Decision-making



Rialtas na hÉireann
Government of Ireland

Participation Framework

National Framework for Children
and Young People's Participation
in Decision-making



Statement on language

There is no universally agreed consensus on which terminology to use in relation to disability. However, there are two main approaches which are commonly referenced, both in the literature and in the consultation findings. These are often referred to as the 'person-first' approach and the 'identity-first' or 'social model' approach. Person-first language places a reference to the person before the reference to the disability. Examples of person-first language include terms such as 'people with disabilities'. This approach seeks to emphasise that a person is first and foremost a human being entitled to human rights. Person-first language is favoured by the United Nations and is used in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). However, it is not a universally accepted approach.

The second common approach is often referred to as 'identity-first' or 'social model' language. Identity-first or social model language seeks to emphasise that people are disabled by barriers in the environment and in society, rather than by their impairment. Examples of this include terms such as 'disabled person'.

In Ireland, the National Disability Authority (NDA) consulted with disabled persons in Ireland and published an advice paper on disability language and terminology (2022). It reflected a mixture of views, with many disability rights activists preferring identity-first language but many others preferring person-first language. Stakeholders with an intellectual disability or mental health difficulty preferred person-first language. The paper noted that some disabled persons do not identify with either term (NDA, 2022). Key recommendations from the report advise taking a careful and flexible approach, asking people's preferences and avoiding stereotypes, euphemisms and medicalised and negative language.

Identity-first language is used in this scoping document, with person-first used in relation to the UNCRPD. However, in parts, terms may be used interchangeably. For those who do not use speech, 'non-speaking' and 'people who do not rely on speech to

communicate' are preferred (Inclusion Ireland, 2023). 'People who use augmentative and alternative communication (AAC)' or 'AAC users' are also terms used within the scoping document.

[Page 7]

The term 'special' is not widely accepted by disabled people. However, this term is still used in some education legislation and in various organisations, and as such we refer to it only in these contexts. There is no consensus on a fully satisfactory and acceptable phrase from an inclusive education perspective (NDA, 2022)

Our use of the terms 'inclusion' and 'inclusive' is based on the social model of disability which focuses on the removal of barriers to participation.

Irish Sign Language (ISL) is an official language and is referred to as such in the document. The term 'signs' is used when referring to aided communication methods, but these are tools for communication rather than a language.

The terms 'participation' and 'participation in decision-making' are used interchangeably. The terms 'participation initiative' and 'participation process' are used to reflect the inclusive ways of participation in decision-making.

Section 1: Introduction and background

1.1 Those involved

The Department of Children, Equality, Disability, Integration and Youth (DCEDIY), Hub na nÓg¹ and the National Disability Authority (NDA)² formed a partnership to produce resources for policy-makers and those who facilitate the participation of disabled children and young people in decision-making, with a particular focus on those who use augmentative and alternative communication (AAC). The aim of this scoping document is to provide advice on approaching participative processes and initiatives in the most accessible and inclusive way possible. It includes specific methodologies for this purpose, as well as practical considerations for ensuring that such processes and initiatives are accessible for all children and young people, including children and young people who are non-speaking.

A steering group with representatives from disabled persons organisations (DPOs) and other relevant organisations, including other civil society and advocacy organisations, supported the creation of this scoping document. DPOs are civil society organisations that are led, directed and governed by persons with disabilities. Persons with disabilities make up a clear majority of their membership. The DPOs are rooted in, committed to and fully respect the principles and rights recognised in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).³ Article 4(3) of the UNCRPD emphasises that, during the development and implementation of legislation and policies, as well as in

¹ Hub na nÓg is a national centre of excellence which supports Government Departments, state agencies and non-governmental organisations (NGOs) to give children and young people a voice in decision-making on issues that affect their lives, with a particular focus on seldom-heard children and young people.

² The NDA is an independent statutory body, providing research and evidence-based advice to the Government on disability policy and practice, and on promoting universal design.

³ National Disability Authority (2022). *Engaging and consulting with disabled people in the development and implementation of legislation and policy: A note for Government officials and staff of public bodies*. Retrieved from <https://nda.ie/publications/note-on-engagement-with-persons-with-disabilities-and-dpos>

other decision-making processes concerning issues related to persons with disabilities, it is required to closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations/DPOs.

The views of young people with disabilities were sought throughout the creation of the scoping document. The young people involved were supported through this process by their representative organisation or DPO. They were asked what works and what does not work with regard to decisions that impact their lives, as well as for recommendations on what should be included in the scoping document. Their perspectives and recommendations have informed and are included within the content of this scoping document. While their insights are shared in the document through quoted material, the consultations accommodated different ways of communicating. Similarly, although efforts were made to include a diverse range of young people, the consultations might not capture the full spectrum of experiences and perspectives of all disabled children and young people. However, the insights provided by those who participated in the consultations offer valuable guidance on how to improve the inclusivity of decision-making processes.

1.2 Why do we need this scoping document?

This scoping document is underpinned by both international agreements such as the UNCRPD⁴ and the United Nations Convention on the Rights of the Child (UNCRC).⁵ The national policy context for participation of children and young people is also important to consider, with the *National Strategy on Children and Young People's Participation in Decision-Making 2015–2020* and its successor, the *Children and Young People's Participation in Decision-Making Action Framework 2023-2028*, also underpinning the scoping document. *Young Ireland: the National Policy Framework for Children and Young*

⁴ United Nations (2006). Convention on the Rights of Persons with Disabilities. (UN doc. A/RES/61/106).

⁵ United Nations (1989). Convention on the Rights of the Child. Treaty Series, 1577, 3.

[Page 10]

People 2023-2028 also includes the participation of children and young people as a central theme. This scoping document aims to provide additional support and recommendations for policy-makers and those who facilitate the participation of disabled children and young people in decision-making. The scoping document will help support the dedication of DCEDIY and Hub na nÓg to nurturing an environment where the rights and voices of all children and young people are honoured and safeguarded.

The UNCRPD recognises the rights of persons with disabilities to live independently, participate fully in all aspects of life and have a voice in decision-making, while the UNCRC safeguards the rights of children and young people, emphasising their right to be heard and to participate in decisions affecting them. In addition to being a human right, the involvement of children and young people in decision-making ensures the development, monitoring and evaluation of more effective policies, services, programmes, facilities, learning approaches, clubs, cultural and sporting activities, and other initiatives.

1.3 What is participation in decision-making?

The UNCRC defines children's and young people's participation in decision-making as 'ongoing processes, which include information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes'.⁶

In practice, this means supporting children and young people in contributing meaningfully to decisions which are relevant to their lives by giving them due weight in decision-making processes. Children and young people should be involved in decision-making for everyday spaces and situations such as early learning and care settings, classrooms, hospitals and clubs, as well as for strategic developments, such as policies, programmes,

⁶ United Nations (1989). Convention on the Rights of the Child. Treaty Series, 1577, 3.

services, legislation and research. Further information about what participation is and what it is not can be found in the *Participation Framework: National Framework for Children and Young People's Participation in Decision-making* (2021).

1.4 How should this scoping document be used?

This scoping document should be read together with the *Participation Framework* and used in conjunction with the nine overarching principles recommended by the UN Committee on the Rights of the Child.⁷ The scoping document is written with the intention of supplementing the *Participation Framework* in order to further support adults in ensuring that all children and young people have an equal opportunity to make a meaningful contribution to decision-making. The scoping document should also be read with the document *Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making*⁸ (NDA, 2022).

This scoping document aims to ensure that best practice participation in decision-making can be fully inclusive and accessible to all disabled children and young people. Informed by approaches that respect the diversity within the disabled community, this scoping document will build on the guidelines, checklists and feedback forms provided in the *Participation Framework* and inform the development of resources to ensure inclusive and accessible participation in decision-making processes. This scoping document can be used to inform the development of bespoke approaches to including disabled children and young people in decision-making, and it can also be used to ensure that participation in decision-making initiatives is accessible for all children and young people.

⁷ UN Committee on the Rights of the Child, *General comment No. 12 (2009): The right of the child to be heard*, 20 July 2009, CRC/C/GC/12, at paras 132–4.

⁸ National Disability Authority (2022). *Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making*. Retrieved from <https://nda.ie/about/engaging-with-disabled-people/scoping-paper-on-consultations>.

[Page 12]

As previously mentioned, there are many ways that children and young people can contribute to decisions being made at service, organisation or national level. There is not one way to include children and young people in decision-making, and all children and young people are unique. This scoping document will not necessarily qualify someone to use all the tools mentioned; rather, the intention is to make policy-makers aware of the range of tools available and the general principles that should be applied when conducting consultations with children. This resource is intended to provide suggestions and ideas for practitioners and policy-makers to draw on within their own participation in decision-making contexts.

Section 2: What to consider in order to ensure that all participation in decision-making is inclusive and accessible for disabled children and young people

When planning and facilitating participation in decision-making, it is important to refer to the National Framework for Participation and the Participation in Decision Making Action Plan 2023-2028 for further guidance on the principles of effective participation with all children and young people (pp. 12–14), and to seek training, support or advice on good practice participation in decision-making if needed. The planning checklist (p. 18) provides a comprehensive guidance for policy-makers and facilitators on how to effectively plan, conduct and evaluate child and youth participation in decision-making in the development of policies, plans, services, governance, research and legislation at national, local and organisational level.

2.1 Things to think about

Empower children and young people

- Inform and educate disabled children and young people about their right to have a say in decisions that impact their lives.
- Inform and educate disabled children and young people on how policy decisions could affect their lives.
- Make sure that information is conveyed in ways that are easily understood and that take into consideration children's different styles and preferences of communication.

“Disabled people need to know from as early as possible...how these decisions are going to affect them. They need to know that they do have the right to talk.”
(quote from a young person)

Presume capacity

- Always presume that the child or young person has the ability to take part in the decision-making process.

“If people looked at the person and gave them a chance, it would be a better world...We would not have to advocate for our needs, which are human rights needs.”
(quote from a young person)

- Communicate with disabled children and young people with respect. It will be necessary to accommodate some children by speaking more slowly, while this may be inappropriate for others.

“No need to talk slowly...There’s nothing worse than being condescending and talking to us like we’re different, because we’re not.”

(quote from a young person)

- Always presume competence. This means that no matter what way a child communicates, we should assume they can understand and participate.

“People underestimate me because I’m a wheelchair user. I should have the same chance as an able-bodied person. They underestimate me for being an Irish Traveller. My disability isn’t my persona. Don’t look at the chair. Look at me. I’m very proud of my chair. They don’t see me, though, they see the chair.”

(quote from a young person)

Acknowledge individual identities and experiences

- Create a safe place where open discussion is possible – this may take time as trust is built with the young person.
- Ask questions about the young person’s disability, but know that it should only be one part of the dialogue.
- Have an open discussion: all aspects of a disabled child or young person are important.

“Be humble. Ask questions...It’s also about, when meeting them, they may have other aspects to their identity that are relevant to our conversations...It’s having a really good open discussion with the child, giving them a chance to tell someone about themselves, having an open discussion with the child, letting them express themselves how they want.” (quote from a young person)

- See the whole person. Value all aspects of their identity.

“For me and many people, being disabled isn’t just a thing of being, it’s a part of my identity, but on top of that I’m a woman, I’m a feminist, a proud Irish speaker. I’ve got loads of different parts to my identity. It’s a tapestry. None of them are less than each other, none of them are greater in value than the other.”

(quote from a young person)

Choice

Being able to choose and make choices is key for participation of children and young people.

- Find out their preferred space for engaging in participation in decision-making. This space may be a place that is familiar to them, like their school or their youth project, or it may be a virtual space.
- Respect children and young people’s choice to participate. Participation should always be voluntary.
- Promote a choice of participation methods and approaches before and during participation processes.
- Tailor communication aids and methods to the needs and preferences of individual children and young people. This may include the use of technology.

“Using different ways to ask people and different methods. Using technology to have different ways to engage. Asking people who don’t want to attend a place like this [DPO building] or a school, via online platforms, social media, or surveys.”

(quote from a young person)

- Enable the children and young people to make choices throughout the participation process.

“There’s no point making a decision about a child...they need to actually be in the room saying ‘this is what I think, this is how I feel’...They need to make an environment friendly, welcoming, and understanding.”
(quote from a young person)

Safe and inclusive spaces

Ensure the environment is safe and accessible.

- Consider whether the environment is accessible for those with mobility needs (e.g. wheelchair users). Are all spaces (including toilets) accessible?
- Consider whether the environment is comfortable for the participants and ensure that it does not act as a barrier to expression.
- Assess whether it is safe for the participants to move around. Remove potential distractions and unsafe items.
- Acknowledge and respect the individual identities and rights of children and young people.
- The young people consulted advocated for an atmosphere in which children and young people feel supported and able to share their thoughts and feelings without judgement. This is something that needs to be built over time, creating ‘psychological safety’ or a space where people feel they can trust the group and the facilitators.

*“Make sure the child feels supported, feels like they are not being judged...
It’s about creating that atmosphere.”*
(quote from a young person)

- Consider lighting and noise levels. Are there unfamiliar noises, smells or other distractions that may be uncomfortable or overpowering for the participants? Reduce ambient auditory and visual distractions.
- Ensure the layout of the room is clear, structured and predictable. Give participants choices of where to sit/stand and the option of whether or not to participate in larger groups. Offer a choice of a quiet space. Inform children and young people if they can take movement breaks and comfort breaks, engage in sensory regulation and use personal sensory aids as wished.
- Have fidget toys and noise defenders available.

“Help people be at ease. [The charity] provides noise-cancelling headphones and fidget toys. It puts me at ease and takes worry off me. To let people know stimming⁹ is ok and getting up. Put that out there at the start.”
(quote from a young person)

Inclusive language

Inclusive communication, including respectful and disability-specific language, is crucial for creating a comfortable environment that promotes open dialogue with all children and young people.

⁹ Self-stimulatory movement or ‘stimming’ involves repeated actions, movements or noises which are important for self-regulation.

[Page 18]

- Use plain language, avoiding highly technical language, acronyms or particular turns of phrases.
- The facilitators should look at terms and words they commonly use in advance and decide how they will explain these terms in plain English.

“If the language used makes the child feel under pressure, or it’s condescending...it’s deeply, deeply, draining, and very, very difficult...Language is so important.”
(quote from a young person)

- Ask or find out about a person’s individual experience and disability, e.g. what does their disability mean for them, what are the barriers they experience, what are their strengths?
- Ask about what language or communication method they prefer.

*“Identity is first. Anyone with autism will have a different view.
You can’t say it’s just one way.”*
(quote from a young person)

Predictability

All children feel more comfortable expressing their views when they are in places and spaces that are familiar to them.

- If you are inviting disabled children and young people to a new physical space, consider providing an information pack beforehand. This could include video with captions, audio or photographs of the space and of the people participants will meet beforehand.

[Page 19]

- Explain what will happen in a clear way. For example, break down the tasks, use a clear visual schedule and explain in a simple way what the child or young person is being asked to do. Indicate on the schedule when each task is completed and what is next.
- Clearly explain length of sessions, break times and length of breaks from the outset.
- Provide question areas in advance of the participation initiative.
- The young people consulted stressed the importance of providing sufficient time for disabled individuals to prepare their responses in advance of consultations and participation initiatives. They recommended sharing agendas (and also agreeing with the young person who will support them to understand the agenda and the materials in advance if necessary) ahead of meetings to enable thoughtful and meaningful participation.

“Having time in advance to prepare an answer...Having multiple days, even a week, to have answers ready and how we want them is important.”
(quote from a young person)

Trust and open-mindedness

Trust is critical in order to create a safe emotional space for all children and young people.

- Consider meeting the child or young person prior to the participation initiative in order to build rapport and learn about their preferences, interests and way of communicating.
- Consider your body language, the clarity of your speech and the tone of your voice. Non-verbal communication of adults is very important for all children and young people.

[Page 20]

→ Be open-minded and willing to learn and accept correction from those with lived experiences.

“...there is a part of our daily lives that a non-disabled adult wouldn't be able to understand or fully empathise with...The person meeting the child won't necessarily be able to fully understand what the person is feeling, but acknowledging that and saying because of that, they are not going to judge, or react, or be condescending.”
(quote from a young person)

→ Actively engage with feedback from those consulted. The opportunity to provide feedback may need to be in multiple formats to allow for communication styles and preferences.

“If something harmful or incorrect is said, if the young person can say ‘that isn't correct’...Receiving corrections, actively learning and engaging.”
(quote from a young person)

Time

Participation always takes time, but the participation of disabled children and young people may require more time and more forward and deliberate planning.

“Plan and think ‘what are this person's needs’?...You need to take time...Thought and planning are really important...It's about making stuff really flexible.”
(quote from a young person)

- The planning process may need to involve meeting the child or young person and/or people the child or young person knows and trusts, as well as getting to know the child or young person's preferred ways to communicate and how to accommodate them best.
- The planning stage may include observation of the child/young person in places where they are most comfortable. This can help ensure that the consultation questions and methods are meaningful, and it can support planning for any accommodations that are needed.
- Factor in time for preparation and/or adaptation of participation materials into appropriate and accessible formats (for example, into a visual format).
- You may need to have extra days and flexible times in cases where once-off participation initiatives are not suitable.

Supporting policy-makers and facilitators

- Policy-makers and those facilitating children and young people's participation in decision-making should refer to the *Participation Framework* in the first instance.
- Policy-makers may wish to consider seeking support or procuring services to design and deliver consultations and participation initiatives.
- Policy-makers and facilitators should consider seeking further support and training in order to increase awareness of, acceptance of and accommodation for those who are non-speaking.
- Some further suggestions are available in the appendices, however, spending time with disabled persons who are non-speaking and getting to know an individual's ways of communicating is a helpful and important first step.

2.2 Different ways of communicating

We all communicate in different ways, including speech, Irish Sign Language (ISL), body language (movement, gestures, facial expressions) and signs (e.g. Lámh,¹⁰ pictures, drawing), as well as using lots of different tools to aid communication. Spoken communication may not be the preferred way to communicate for some children and young people.

While some children and young people will choose to use speech to communicate their thoughts, views and opinions, some children and young people will communicate in different ways. It is important to be familiar with these ways of communicating and to ensure that participation initiatives are set up with these in mind. Disabled children and young people should have access to their preferred methods of communication at all times, and their individual ways of communicating should be accommodated fully in participation initiatives.

All ways of communicating should be valued equally. Some children and young people with disabilities will be able to understand topics or questions about decisions that are not in the “here and now” and others show their views or preferences “in the moment”, which are equally as important. Sometimes, a once-off meeting or survey may not provide enough time to accommodate the views of children and young people with disabilities, and more long-term methods will be needed (see examples of creative methods, such as PhotoVoice and sensory story sharing, below). Preparation is key to ensure topics are broken down in an accessible way, as is flexible thinking about how all disabled children and young people’s views can be gathered.

¹⁰ Lámh is a key word signing system that involves a combination of using signs with speech.

[Page 23]

Key pictures, symbols and objects that help to explain the topic of consultation or participation initiative may need to be shared in advance if they are not currently used by the child or young person participating. Be prepared to adapt and work with the pictures, symbols, objects and communication devices a child or young person uses frequently to either express themselves or understand others.

It is important to recognise and understand the diverse ways of communicating that children and young people can use during participation initiatives. Their communication preferences may include gestures, facial expressions and signs (for example, Lámh, eye-pointing, objects of reference, pictures and symbols, which includes the use of communication boards).

The young persons consulted for this document recommended tailoring communication aids and methods to the needs of individual children and young people.

“A range of different communication aids and approaches based on the young person’s individual communication needs.”
(quote from a young person)

2.3 Communication partners

Ensure accessibility for all children and young people, including children and young people who are non-speaking or who cannot rely on speech alone to communicate. For example, it may be valuable for some children to have the presence of a known person (i.e. a communication partner) and/or sign language interpreter to translate, to support their expression and understanding or to act as a scribe or a facilitator throughout the

[Page 24]

participation process. Some children and young people with disabilities may need a support person but not require a communication partner.

A communication partner may be a parent/guardian or a primary support or education professional who will support interpreting a child's responses during the participation process. A communication partner is an adult who knows the child or young person's ways of communicating very well. Communication partners are helpful for assisting in the use of AAC or for interpreting gestures, facial expressions and vocalisations. The young people consulted referred to communication partners as 'trained' support persons. Communication partners tend not to be siblings or peers; rather, they have a specific role in supporting the child or young person's communication, and as such they need to be able to understand the child or young person's communication methods.

How do we select communication partners?

Usually, these are people who the child or young person knows and trusts, and they have a very good understanding of how they communicate, what their communication means and the ways in which they prefer to communicate. It is important to allow for a child-led approach but also to ensure that the support is necessary, for example, by allowing the child or young person to choose their communication partner or, if they wish, to engage with a different person than usual. It is important to be mindful of the child or young person's comfort level and to ensure that they have opportunities to engage in participation and decision-making without a communication partner if this is appropriate and meaningful to gaining the child or young person's views.

When working with a communication partner, it is important to:

- Gain an understanding of how the child or young person already communicates (you can use the 'Getting to know you' checklist in Appendix 3)
- Communicate with the child or young person using methods that they understand and prefer

[Page 25]

- Fully accommodate a child or young person's existing communication methods
- Continue to engage directly with the child or young person. For example, ask or see if there are any responses to what their communication partner is saying, direct your attention to the child or young person, pause and wait for any responses (e.g. facial expressions, vocalisations or physical movements).

“Do they need easy-to-read materials? Do they use assistive and augmentative technologies?...Will a support person who is trained to help them communicate be in the room? If not, do I, or one of my colleagues, need to meet with them beforehand and be trained in helping them to communicate?”

(quote from a young person)

2.4 What is augmentative and alternative communication?

AAC is a range of tools and strategies used to either enhance a person's speech or provide an alternative to it. 'Augmentative' means to add to a person's speech, while 'alternative' means to use a method of communication instead of speech.

AAC can include any form of communication used with or instead of oral speech. This includes the use of eyes, facial expressions, gestures, Lámh signs, symbols, communication boards or books and technology-based systems such as voice output communication aids. Some children or young people may use more than one type of communication method. In some situations, a particular form of AAC may be used and speech may be used at other times. It is important to respect the child's preference on any particular day and at any particular time. All ways of communicating should be valued and supported equally.

2.5 Accommodating all ways of communicating

Inclusive participation involves valuing and accommodating all methods of communication equally, recognising that speech is just one method of many. Inclusive participation accepts that communication can take many forms, including gestures; use of the different senses; facial expressions and body movements; speech or vocalisations; use of different tones, pitch or volume of voice/vocalisations; computer-generated speech; signs; symbols; real objects; objects of reference; and pictures and photographs.

2.6 Guidance on the use of augmentative and alternative communication

- It is important to get to know disabled children and young people in order to familiarise yourself with the range of communication methods they use. Spend time reviewing any information on communication and sensory accommodations that has been provided (use the 'Getting to know you' checklist in Appendix 3 to support you in this).
- Find out how the disabled child or young person communicates – this may include, for example, a range of pictures, objects, symbols, etc., in which case you will have to anticipate any new pictures or photographs that may be needed.
- Have a range of signs, symbols, objects, pictures or photographs prepared that can be used for the participation initiative. Where possible or required, see what the child or young person already uses and include these communication aids within your initiative, as these will be more meaningful. Some disabled children and young people will already have signs, symbols, objects, pictures or photographs which they use. Some may require new signs, symbols, objects, pictures or photographs in order to understand the questions, and they will need time to understand these.

- Be prepared to print out and laminate photographs of items or places. Funding should be available for parents/caregivers/staff from educational settings should they wish to print and laminate new signs and pictures they think would be more meaningful to the child or young person. Some communication methods may require training, and in this case you should seek the support of a professional who is trained and experienced in these methods.
- You may also need to be aware of the wider range of assistive technology that accommodates disabled children and young people, e.g. screen readers, large print materials, use of captioning, voice-to-text software and voice amplifiers.

Section 3: Steps in planning participation initiatives

Start with the viewpoint that all children and young people, including children with disabilities, can take part in decision-making. For a comprehensive understanding, read this scoping document in conjunction with the *Participation Framework*. The planning checklist on page 18 of the *Participation Framework* can guide you on how to listen to children and young people and involve them in decision-making when you are developing policies, plans, services, programmes, governance, research and legislation at the national, local and organisational level.

In addition to the planning checklist, this section informs adequate consideration and planning to provide for accessibility and inclusion of disabled children and young people.

3.1 Recruitment of disabled children and young people

Work with local and community organisations that can provide a point of access to disabled children and young people and that have experience of working with diverse

groups of children and young people. These may include DPOs, advocacy organisations, local or national NGOs and/or services such as health centres, hospitals, residential homes or institutions, and educational settings, including schools and early years settings.

[Page 28]

Work in partnership with other people and organisations that the child or young person already knows and trusts. Reaching seldom-heard children and young people through schools may be worthwhile (see some suggestions in Appendix 5). When working with other organisations and service providers, be very clear about the selection criteria in order to ensure diversity in your selected group. At all times be clear about the scope of the participation initiative, including the level of influence children and young people will have on its process and outcome.

If the participants need to travel to the participation initiative, it is recommended that they (as well as communication partners, caring and personal assistants, and/or support persons) are reimbursed for travel and subsistence.

3.2 Working in partnership with disabled children and young people and those they already know and trust

- Children and young people with disabilities – along with parents, guardians and caregivers (if required) – should be given a clear explanation about what participation is and what it is trying to achieve.
- Highlight that every child and young person has a right to participate in making decisions that affect their lives.
- It may be helpful to meet with the child or young person's family, school or educational setting in order to understand how to accommodate their communication preferences and how to help them understand the question and process. You may need to spend time in these settings to build rapport and trust with the child or young person in advance of the participation initiative.

In some instances, the education professionals may be ideally placed to facilitate or support their participation, given their knowledge of communication methods and their understanding of the participating children and young people.

→ Rather than once-off meetings or surveys, it may be more meaningful to hold regular meetings over a period of time reviewing a portfolio developed with the child or young person (see more guidance below).

3.3 Gaining consent and assent for participation

Participation should always be relevant and voluntary, and children can withdraw their agreement to be involved at any time. Follow the data protection and safeguarding policies of your organisation.

Presume capacity and make every effort to gain informed consent from parents and assent from children and young people. However, if you are advised that the children or young people do not have the capacity to provide assent for participation, proceed with the participation initiative only if the following are met:

- Parents or guardians have given informed consent and made a decision on behalf of the child or young person, based on the disabled child or young person's presumed or previous willingness and preferences, to participate in the initiative.
- Risk and benefits have been weighed up sensitively. The child or young person's caregivers consider that exclusion from the participation initiative would be against the child or young person's best interests.
- The child or young person's method for communicating dissent is known, and arrangements have been made to observe the child or young person for signs of dissent and/or discomfort during the participation initiative.

In all circumstances, check for ongoing assent throughout the participation process. How would you know if the child was uncomfortable? Know how the child or young person communicates dissent (this can be done either verbally or non-verbally; the 'Getting to know you' checklist in Appendix 3 may help you in this).

- The child or young person can express dissent by showing previously agreed cards or cues indicating concepts such as 'stop', 'break' and 'pass', or through emotion cards, symbols or emoticons. You can also use a 'traffic light' system, whereby a child will show a yellow card if they do not want to answer a question, or a red card if they want to end the session.
- Body language, movements, expressions or non-verbal vocalisations may indicate they do not want to continue. Be responsive to the child or young person's expressive communication, with support where needed from the communication partner.
- Consider offering a choice of various activities simultaneously. The child's selection of a participation activity would be an indication of their assent.
- Be prepared to walk away from the participation initiative with little or no information if (despite preparations) the child or young person is not willing to participate on a particular day.

3.4 Gathering information

Find out more about the child or young person so that you can prepare appropriately. Find out what would be their preferred space for engaging in the participation initiative. This space may be their home or their school, or it may be a virtual space.

- What is their preferred type of physical and sensory environment?
- Do the participants need an interpreter, communication partner, personal assistant or advocate to meaningfully engage in the participation process?
- Would they benefit from having a scribe to support them in writing?

[Page 31]

- What is the child or young person's preferred way to communicate?
- What is their level of understanding in terms of abstract concepts?
- What are their interests and preferences?

Gather this information from the child or young person if possible, and if not, from their parents/guardians, from the professional support staff in their educational setting or from an organisation that supports the child or young person.

3.5 Preparation of resources

This section includes key principles and approaches for preparing resources for inclusive participation initiatives with disabled children and young people. Specific methods to be used are detailed in Section 4.

Co-creation of participation format and methods

'Co-creation' means developing something new together with other people. With regard to participation, this broad term often means working together with children and young people to create or improve the planned participation experience. Within co-creation, 'co-design' is a more specific term that refers to involving children and young people in designing something. It is important to include children and young people with disabilities in developing the format and methods of participation initiatives from early stages of planning. As with all participation in decision-making initiatives, you may establish advisory groups with children and young people to support your planning and pilot participation methods, or you may invite children and young people to submit their thoughts on the planned participation initiative. Inclusive participation methods may require more time for disabled children and young people to document their responses to ensure they are meaningful. This extended planning time for co-creation of methods should be considered from the outset.

Sometimes, participation methods need to be adapted and tailored to the preferences of each individual child/young person.

- A combination of participation methods may be needed to achieve meaningful participation. For example, you may provide a choice of participation activities to a group of participating children to accommodate their communication preferences in a once-off participation initiative, or you may plan for multiple participation activities to take place over a few days or weeks.
- Participation should be viewed as a continuum along which the type of participation activities engaged in, should be determined based on the unique strengths and needs of each child or young person. For example, for some children choosing between two options may be meaningful, while for others this may be only the starting point.¹¹

During participation initiatives, you will need to have a range of materials and resources in order to provide every participant with an opportunity to express their opinions. The children and young people's communication preferences will inform you in how best to present this information to them.

- This information needs to be accessible and may need to be differentiated for the participants, with methods including visuals, symbols, tactile objects, simplified or signed language, and/or audio and visual technology, for example, through digitally drawn illustrations of the participatory process, or in the form of a video/animation or a social story (see Appendix 4 for examples of these).
- Include photographs and short descriptions of the people who will conduct the participation initiative.
- Create a clear visual representation of the participation initiative process and refer to it throughout the participation initiative.

¹¹ Franklin, A. and Sloper, P. (2009). Supporting the participation of disabled children and young people in decision-making. *Children & Society*, 23(1), 3-15.

- Do you need other visual or auditory prompts and/or supports? These may include soundfield systems, captioning, speech-to-text and text-to-speech software and screen readers.

3.6 Supporting understanding

Overall, in order to support understanding, it is important to consider the following:

- Share the topic and the questions you will ask with the participants in advance of the participation initiative. Allow them plenty of time to prepare and plan. Meeting the children and young people before the participation initiative may also be helpful.
- At all stages (i.e. consent, consultation, evaluation, feedback) use a multi-sensory approach, including visual tools to support both comprehension and expression.
- Avoid last-minute changes.
- During the participation initiative, be aware of how your body language supports what you are trying to communicate.
- During the participation initiative, use the principles of the 'chunk, chill, check' approach.

Chunk

Use appropriately paced language and plain English and break down instructions into smaller steps ('chunk').

Chill

Use pauses, avoid unnecessary and ambiguous phrases, give the participants time to process the information and respond ('chill').

Check

'Check' whether participants understand what they have been asked to do. Allow time for clarifications or questions. Take time to acknowledge or respond to any changes in participants' body language or expressions, with support from communication partners. In addition, it may be necessary to check that the children and young people understand the communication options given (for example, visual depictions of a range of emotions) in advance of the participation initiative.

[Page 34]

- Plain language, minimal text and use of visuals and objects support understanding, enjoyment and meaning for participants.
- Topics can be represented by photographs, illustrations, symbols or tactile objects (including, for example, bricks and play objects).
- A range of creative methods such as visual storytelling and/or narratives, can be used as an alternative to or support for verbal communication.
- Some children may prefer photographs or illustrations, as they are less abstract than symbols.

Tools to support understanding

It is important to ensure that children fully understand the participation process, the topic and the questions asked. This can be done, for example, through:

Photographs

- Photographs help the children and young people to focus on the here and now, and they can be used in participation initiatives in many ways.
- Depending on the topic being discussed, photographs can depict activities, places, people or experiences (for example, the participating children can be photographed in different places and during different activities in advance of participation), and these photographs can then be used to support their expressions.
- Photographs represent activities and people concretely, which is easier to understand than symbols for many children.

Social narratives or social stories

- These are pictorial short stories or scripts that explain a situation or concept using pictures with minimal text.
- These stories are presented in advance of a new activity or to help communicate situations that may not be clear to some children or young people.
- These are typically used to support social communication, but they can also be adapted to help clarify more abstract topics as well as explain future events or activities. Social narratives or social stories should include the following aspects, but the process can be adapted based on participants' needs and levels of understanding.

The story should clarify for the child or young person what will happen during the participation initiative. You can consider the following:

- Where the event will take place with photographs?
- Who will be there?
- The order of what will happen, using terms like 'now', 'next' and 'later'
- How long a session will be?

- When breaks will be, clarifying that additional sensory or movement breaks are no problem, and
- How long participants will have to answer questions.

[Page 36]

In addition, specify that they can have extra time (and indicate options for following up)

- Specify types of tasks.
- Indicate clearly what the participants are invited to do.
- Provide a dedicated time for participants to answer questions, but also indicate that it is OK to ask questions at any time.
- Indicate how the participants can ask a question (e.g. raise their hand, use a symbol), and show them a photograph of the person they can ask.

See Appendix 4 for an example of a social story script that can be adapted.

Comic strip conversations

- This is another form of social narrative that may be helpful for communicating the purpose of the participation initiative and gaining insight into children and young people's thoughts, feelings and perspectives.
- It uses simple figures and other symbols in a comic strip format.
- Facilitators can design or co-create the comic strip conversations with a child or young person. For example, children and young people can draw line figures to represent themselves and others, and they can describe what is said and thought using speech and thought bubbles. Different colours can be used to indicate different emotions or states of mind.

Sensory stories and story sharing

- Sensory stories combine a few short lines of text with key sensory items and concrete objects – called 'objects of reference' – that represent the activities and ideas in the story. They can use all or some of the senses: touch, taste, sound,

smell and sight. Items can be an exact match (e.g. using real leaves for a story about autumn) or different (e.g. crushed biscuits representing sand for a story about the beach). Each line of the story will include an object or sensation the child or young person can take time to experience.

- Sensory stories can be used to support the child or young person in sharing items and representations of what is important to them. A range of items can be used, including objects and photographs. “Important to me” bags can be gathered over time and the sensory story used to share and experience these items. The child or young person’s reactions to this can be observed as part of the participation process.

[Page 37]

3.7 What to think about when designing questions?¹²

- Simplify the item wording and phrasing.
- Include pictorial communication symbols and visual prompts to represent the meaning of items.
- Change tense of questions from past to present (i.e. avoid asking the child or young person to recall past feelings and thoughts, and instead rephrase the questions to refer to ‘here and now’).
- Ask questions rather than statements to agree or disagree with.
- Reduce scales to dichotomous (yes/no) or maximum 3-point scales (yes/no/sometimes) and represent the options with coloured pictorial prompts (e.g. thumbs up and thumbs down or emoji faces).
- Provide question areas in advance of the participation initiative to help children and young people form a view.
- Present one question at a time during the participation initiative.

¹² Adapted from Davison, J., Maguire, S., McLaughlin, M., & Simms, V. (2022). Involving adolescents with intellectual disability in the adaptation of self-reported subjective well-being measures: participatory research and methodological considerations. *Journal of Intellectual Disability Research*, 66(7), 628-641.

- Offer alternate formats of expression to ensure inclusivity (for example, touchscreen devices).
- Think about whether more creative methods – for example, PhotoVoice or story share methods – might be more meaningful to participants.

[Page 38]

- The above methods still might not be enough to accommodate some children. It may be necessary to observe a child in their day-to-day environment to get a sense of their choices, preferences and decisions.

Section 4: Specific methodologies for participative processes with disabled children and young people

4.1 Introduction

There is no single method that will work with all children and young people. However, tangible and visual formats of participation practices and methods are often the most effective. This section outlines several methods which you may wish to consider when designing inclusive and accessible participation, based on the needs and requirements of the disabled child or young person. It is important to note that these supplement other methods used to enable children's participation in decision-making. All decision-making initiatives should aim to be as accessible and inclusive as possible, and in some cases this may mean using additional methods to remove barriers to participation.

Allow the children and young people to choose a participation method. Some of these methods include:

- Mosaic approach
- Activity-based approaches, including creative activities such as:

- Drawings, collages and other artistic media, including co-created and digital portfolios
- Play, drama, storytelling and other creative activities
- Ranking activities (e.g. diamond ranking or 'beans and pots')
- Talking Mats
- The World Café method
- PhotoVoice and VideoVoice
- Sensory story sharing
- Observation, and
- Online and digital participation.

[Page 39]

4.2 Mosaic approach

As the name suggests, the mosaic approach combines a range of approaches to gather children's views. For example, taking photographs (PhotoVoice), child-led concrete activities (e.g. outings), map making, combined with observations and interviews all form the basis of conversations with children in a mosaic approach. The mosaic approach can also involve some of the below methods and tools.

4.3 Activity-based participation methods, including creative activities

Activity-based participation methods involve concrete and engaging activities that children and young people can participate in, including outings or arts-and-crafts activities, such as making collages and/or co-creating various artefacts (including apps or games). Such informal approaches may be more appropriate for some disabled children and young people.

Within the activity-based methods, focus on co-creating with children and young people, using tailored methods to nurture their creativity and encourage engagement in decision-making. This could involve hosting a number of co-design sessions for children and young

people and incrementally introducing activities. Multi-method, multi-vocal creative activities, supported by visual artefacts, could be introduced to engage the participants.

[Page 40]

- Craft activities can use photographs of activities and people the children know, or can even use photographs that the children take themselves (see more information about PhotoVoice in Section 4.7).
- Drawing – for example, the Drawing the Ideal School Technique – may be used or adapted as a simple and easily accessible method for supporting conversations with children and young people.
- Use of play and storytelling, storyboards, puppets, drama and role-play, sketches and props can be very helpful in supporting children and young people’s thinking.
- Creative approaches can be used to present a topic and/or as a tool for participants to share their perspectives and experiences. For example, you can use tangible items (e.g. play wooden characters) and visual tools to support the participants in discussing their social network, and this can be augmented by storytelling and imagined scenarios (e.g. comic strips with blank speech bubbles to support the participants discussing online safety). Creative props and play items can encourage conversations and help to structure the activities with disabled children and young people.
- Flexible participation methods can allow children and young people with disabilities, or those they know and trust, to record important events over time on topics that are meaningful for them. For example, this could involve recording activities, moments and events over a period of time and then capturing the children’s responses when these are shown to them again.

The Drawing the Ideal School Technique

This method is used to encourage children and young people to express their thoughts, beliefs and preferences related to their ideal learning environment. It can be adapted for

a variety of settings (e.g. for an ideal sports club). It can provide valuable insights into how children perceive their experiences, which can inform decision-making and support.

[Page 41]

This method can be adapted to accommodate different participants: for example, simpler words can be used (e.g. 'best' or 'good' rather than 'ideal') alongside visuals. Children's 'blue sky thinking' can be captured through means other than written responses, such as photographs, recordings or use of a scribe or graphic harvester.

Part 1: Drawing the kind of school you would NOT like to go to

- The school:
 - Invite the child or young person to imagine a school they would not like to attend. Ask them to create a quick drawing of this imaginary school in the centre of the paper.
 - Encourage the child or young person to describe the characteristics of this undesirable school and explain what type of school it is.
- The classroom:
 - Have the child or young person imagine the least favourable classroom in this school.
 - Invite them to draw elements found in this classroom.
- The students:
 - Ask the child or young person to think about some of the students at this undesired school. Ask them to create a quick drawing of a few of these students and describe what these students are doing and what they are like.
- The adults:
 - Encourage the child or young person to think about some of the adults at this school. Invite them to sketch a few of these adults and describe what they are doing and what they are like.
- Me:

- Ask the child or young person to imagine themselves at this school they would not want to attend. Invite them to draw what they would be doing there and describe their feelings in this setting.

Part 2: Drawing the kind of school you WOULD like to go to

- The school:
 - Have the child or young person imagine their ideal school. Ask them to create a quick drawing of this imaginary school in the centre of the page.
 - Encourage the child or young person to describe the characteristics of this preferred school and explain what type of school it is.
- The classroom:
 - Prompt the child or young person to think about their ideal classroom.
 - Invite them to draw elements found in this classroom.
- The students:
 - Ask the child or young person to think about some of the students at this ideal school. Invite them to create a quick drawing of a few of these students and describe their activities and what these students are like.
- The adults:
 - Encourage the child or young person to think about the adults at this preferred school. Invite them to sketch a few of these adults and describe their roles and what they are like.
- Me:
 - Invite the child or young person to imagine themselves at this ideal school. Ask them to draw what they would be doing there and describe their feelings in this setting.

4.4 Ranking activities

Ranking activities involve sorting items into given categories, for example, according to which ones are most important or most liked.

One disadvantage of these activities is that the categories the children express their preferences about have been determined by adults. However, children can be invited to create the preferences in an advisory group. Children can also draw or ask for additional images if they think that something is missing. Examples of ranking activities include diamond ranking, 'beans and pots' or the use of like/dislike postboxes.

Diamond ranking

1. Give the participants strips of paper (e.g. Post-its) with statements written on them. Depending on the individual's level of literacy and understanding, the written statements can be supported with or replaced by photographs or illustrations.
2. Ask the participants to arrange the strips in a diamond shape according to their preference, with activities they like most at the top and those they dislike at the bottom.

'Beans and pots'¹³

1. Arrange pots (or other containers) that are clearly labelled to represent different options, such as 'true', 'not true' or 'unsure'. The options can also

¹³ Example from Goodall, C (2019). 'There is more flexibility to meet my needs': Educational experiences of autistic young people in mainstream and alternative education provision. *Support for Learning*, 34(1), 4–33.

be visually supported with, for example, a thumbs up, thumbs down or question mark, or another visual prompt.

2. Give the participants an object (for example, a personalised polystyrene ball) to place in one of the pots in response to a given statement.
3. Model the activity with simple statements first (for example, 'today is sunny' or 'today is rainy').
4. Ask the participants to place their object in a chosen category pot in response to a given consultation statement.

Like/Dislike postboxes

This adaptation of the ranking method uses postboxes labelled 'like' and 'dislike' and asks children to 'post' pictures and photographs of things they like or dislike (for example, cartoon characters, foods, animals) into the corresponding postboxes.

This is an adaptation of a ranking method similar to elicitation methods involving emotion reactions (see below).

Emotion-based reactions

Gauging emotion-based reactions is a method that allows participants to respond to a given topic by selecting an emotion that is presented to them in a picture, symbol or other appropriate visual. Such methods promote children and young people's voices in non-vocal communication. The limitation of this method is that it may not reveal underlying emotions that are not illustrated by one of the pictures or symbols. Examples of methods using emotion-based reactions include the Talking Mat.

4.5 Talking Mats

What is a Talking Mat?

A Talking Mat is a visual tool designed to support children and young people's communication and self-expression. These mats are visual and flexible, and they do not require a child or young person to use speech to communicate. They use multi-sensory stimuli to encourage children and young people to share their thoughts and feelings. Talking Mats are highly adaptable and can be tailored to suit children and young people's individual preferences.

Step-by-step guide to using Talking Mats for children and young people's participation in decision-making

Introduction:

Step 1: Preparation

- Gather equipment:
 - You will need a suitable mat, such as one made of felt, for the foundation for your Talking Mat.
 - Collect graphic symbols that represent emotions and preferences. These symbols could include thumbs up, neutral and thumbs down signs, for example. Arrange these symbols on the mat.
 - Prepare symbols, photographs, illustrations or other visual representations that correspond to the specific consultation topics or decisions to be discussed. These visuals will be given to the participants.

Step 2: Setting the stage

- Create a comfortable environment:
 - Ensure that the physical environment is welcoming and comfortable, promoting open communication.

Step 3: Explanation

- Introduce the Talking Mat:
 - Explain to the young people the purpose of the Talking Mat and how it will be used to facilitate their participation in decision-making.
 - Emphasise that the Talking Mat is a tool to help them express their thoughts and feelings, and there are no right or wrong answers.

Step 4: Symbol placement

- Using emotion symbols:
 - Start by arranging the symbols representing emotions (e.g. thumbs up, neutral, thumbs down) on the mat.
 - Ask the young people to place a symbol on the mat that represents how they currently feel about the topic being discussed. They can move the symbol as the conversation progresses.

Step 5: Discussing preferences

- Introducing topic symbols:
 - Transition to the symbols, photographs or illustrations related to the consultation topics.
 - Ask the young people to select and place the symbols on the mat that express their preferences or thoughts about each topic.

Step 6: Facilitating conversation

- Open-ended questions:
 - Use open-ended questions to encourage the young people to explain their choices: for example, "Can you tell me why you placed that symbol there?"

- Actively listen to their responses and seek clarification if needed.

Step 7: Recording and documenting

- Record responses:
 - Document the young people's responses as they engage with the Talking Mat.
 - Capture their thoughts, feelings and preferences accurately in a way that respects their input.

Step 8: Reflection and discussion*

- Reflect on the insights:
 - After using the Talking Mat, reflect on the insights gained and consider how they can inform the decision-making process.
 - Engage in a collaborative discussion with the young people, acknowledging their contributions.

*See Appendix 5 for useful link.

4.6 World Café method¹⁴

The World Café method is a collaborative and interactive group conversation technique designed to facilitate meaningful dialogue on a given topic. It encourages participants to share their insights, ideas and experiences in a relaxed and inclusive setting. One of the key elements of the World Café method is the use of placemats or large sheets of paper where participants can record their thoughts and ideas. Below is an overview of the World Café method and how to ensure that it is inclusive and accessible.

1. **Setting the stage:** Children and young people are seated at small tables (often in groups of six to eight) in a café-like atmosphere. Each table is covered with a large sheet of paper, which serves as the placemat. There is a central question or theme related to the topic of discussion.
2. **Rounds of conversation:** The session is divided into several rounds. In each round, participants discuss the central question at their table. They can draw, write or doodle their thoughts directly on the placemat. Alternatively, a scribe/communication partner can capture their thoughts. The conversations are open, exploratory and focused on collective learning.
3. **Rotating:** After each round, participants rotate to different tables, bringing their insights and ideas with them to the new group. The facilitator can update them or the participant can review the group's previous discussion on the placemat and build upon it. This process continues for multiple rounds.
4. **Harvesting:** Participants return to their original table and review key insights, themes and ideas that have emerged through the process. Facilitators may use additional large sheets of paper, a visual representation (e.g. a mural) or a graphic harvester (creative artistic note-taking) to capture and display insights for the children and young people.

¹⁴ Roy, A., McVilly, K. R., & Crisp, B. R. (2021). Working with Deafblind people to develop a good practice approach. *Journal of Social Work, 21*(1), 69–87. <https://doi.org/10.1177/1468017319860216>

Inclusivity and accessibility:

To ensure that the World Café method is inclusive and accessible to all participants, consider the following strategies:

1. **Diverse seating arrangements:** Arrange seating to accommodate various mobility needs and preferences. Ensure that tables are accessible to individuals using wheelchairs or with other mobility challenges.
2. **Clear communication:** Provide clear and concise instructions at the beginning of the session. Ensure that participants understand the purpose of the World Café and the process of rotating between tables.
3. **Visual and auditory accessibility:** Accommodate participants with visual or auditory impairments. Use large, easy-to-read fonts on placemats and provide written or verbal summaries of the discussions during the plenary session.
4. **Language accessibility:** If participants speak different languages, consider providing translation services or interpretation support to ensure that everyone can participate fully.
5. **Time management:** Allocate sufficient time for each round of conversation to allow participants to engage thoughtfully without feeling rushed. Ensure that breaks for rest and refreshment are scheduled.
6. **Facilitator sensitivity:** Facilitators should be trained in inclusivity and be sensitive to the needs of all participants. They should encourage equal participation and ensure that everyone's voice is heard.
7. **Feedback mechanism:** Provide a way for participants to offer feedback on the accessibility and inclusivity of the World Café process. Use this feedback to make improvements for future sessions.
8. **Alternative modes of participation:** Consider offering virtual or online options for participants who may not be able to attend discussions in person, allowing them to join remotely.

With these strategies in place, the World Café method can be a powerful tool for fostering inclusive and accessible dialogue, enabling diverse voices to contribute to meaningful conversations on question topics.

[Page 50]

4.7 PhotoVoice and VideoVoice

PhotoVoice supports children and young people's self-expression and empowerment by asking them to photograph what matters to them. As a participation tool, PhotoVoice is flexible and adaptable, and can be used to document participants' lived experiences in a range of ways.

1. Give participants a general topic or theme for taking pictures (e.g. 'my favourite places in the community').
2. Alternatively, allow participants, or those they know and trust, to take photographs that capture the moments or events that matter to them as they arise over a period of time.
3. Ensure that all participants, or those they know and trust, have access to cameras (e.g. on their phones or tablets).
4. Encourage participants to take photographs in response to the topic or theme.
5. Allow participants to choose to audio or video record subject matter if this would be more meaningful to them.

After taking the photographs, children and young people are encouraged to share their views and experiences around the theme, using the photographs as a prompt. They might express their views in a number of ways, such as facial expressions, vocalisations or movements, as well as through AAC. For some, an audio or video recording of the event may be more meaningful than a photograph. The advantage of PhotoVoice is that a child or young person's assent is built into its various stages and ongoing in PhotoVoice projects.

[Page 51]

PhotoVoice gives agency to children and young people with regard to how they would like to participate, and if and how they would like to represent themselves and their reality.

Disadvantages of this method are that it might not always provide usable information upon which practitioners and policy-makers can act.

4.8 Sensory story sharing

1. Allow participants, or those they know and trust, to take photographs capturing the moments or events that matter to them as they arise over a period of time.
2. Give participants dedicated time to share and experience the objects, photographs and recordings again.
3. Capture and record participants' reactions with support of a communication partner if needed.
4. Use a sensory story to help structure this so it can be repeated (see Appendix 4 for examples of sensory story scripts).

4.9 Observation

Observation can be used on its own, but where possible it should be used alongside other participation methods (e.g. a mosaic approach). However, where other methods are not suitable or meaningful, observation can be a helpful way to include children and young people in participation and decision-making. Observation of disabled children and young

people as a method of participation in decision-making can be used if other avenues of participation in decision-making have been explored and are not possible. If observation is used it is important that children and young people's views and opinions are translated and noted directly and not interpreted by adults.

1. Co-design the structure of the observation. Think about the time, location and activities included or not included. Think about how long the observation will take. Plan for enough time that meaningful conclusions can be drawn from the observation without too much interruption to the child or young person's usual daily routine.
2. Ask the child or young person (or someone they know and trust, where appropriate) when and where it would be suitable to observe them, e.g. lunchtime at school, playtime, when they are using public transport or taking part in particular activities, etc.
3. Be clear about what will or will not be included in the observation, e.g. the child or young person's choices, interactions with peers or preferred activities.
4. Have lots of breaks and plenty of ways for the child or young person to request a break or to stop. Communication partners may be helpful here (see Section 3.3 for more information on assent and consent).
5. Someone who the child or young person knows and trusts may be best placed to write down what they observe.
6. Think about ways of sharing observations with the child or young person, e.g. show the child or young person some of the photographs or digital recordings you collected of them (if agreed to from the start). Allow the child or young person the choice to retain or remove parts of what was recorded in the observation.

4.10 Online and digital participation

Below we include key considerations for how to make online and digital participation more inclusive for all children and young people.

Inclusive online consultations

Questions in online consultations and participation initiatives should be worded in easy-to-understand language with sign language interpretation and Braille format available where needed and wherever possible. Ensure that written information in electronic format is compatible with text-to-speech software. Check if the participants have access to supports such as voice-activated typing options and support persons such as communication partners, interpreters and/or scribes. The presence of communication partners and/or interpreters may also be needed for virtual meetings and online focus groups.

Innovative solutions to develop eParticipation should be explored going forward, such as establishing online platforms hosting virtual councils where users can take part in moderated discussion groups and use reaction buttons to agree/disagree. Such solutions may require partnerships with the ICT community.

Inclusive submission processes

Allow for a range of submission types in all consultations and participation initiatives. For those who prefer not to attend in person, or where it is more suitable (for example, deaf children signing answers using ISL through video), video and audio recordings can be sent. Give participants plenty of time to send recordings and to give them appropriate support. Give guidance on how long the video should be and how the recording will be stored, and allow adequate time for translation where required (this may include the hiring of ISL interpreters).

Interactive games and virtual reality

Games and play are often used and adapted as methods for participation in decision-making initiatives, and as ways for children to explore information on a given topic. Immersive virtual reality has the potential to safely simulate situations and contexts that are the focus of consultations and participation initiatives. Multimedia interactive games and virtual reality with a design of children-friendly environments and with a playful strategy have recently been used in shared decision-making initiatives in paediatric healthcare settings. Some examples of this include:

- Children sharing decision-making with a clinician regarding treating skin disease. A multimedia mixed reality (MR) interactive game was designed in which children were represented by apples. The apples rolled around before receiving treatment. After the treatment, they slept soundly. The children helped the apples in the game undergo treatments (feedback they provided included 'help the apple with the injection, please' and 'the untreated apple is still itchy, rolling around and can't sleep').¹⁵
- Playing cards have been used to engage adolescents in decision-making about hospital care, research and policy. The young people decided their own themes for the cards. A clinician led the game with a consultation question, and the players turned over the top card of the deck (with previously identified themes) and placed it face upwards on the gameboard.

Co-creating virtual environments with disabled children and young people requires significant investment, but it has the potential to transform inclusive participation in decision-making.

¹⁵ Example from Chang, L., Kuo, H., Suen, J., Yang, P., Hou, C., Sun, H., Lee, Z., & Huang, Y. (2023). Multimedia mixed reality interactive shared decision-making game in children with moderate to severe atopic dermatitis: A pilot study. *Children*, 10(3), 574.

Section 5: Evaluation of participation and giving feedback

5.1 Evaluation of participation

The *Participation Framework* includes guidance for the evaluation of children and young people's participation based on the Lundy Model of participation in decision-making.¹⁶

As with the consultation itself, the evaluation process of selecting which disabled children and young people will participate should use a multi-method approach, with visual supports and artefacts to support children and young people's reflection. For example, participants can use stars, 'smileys' or other emoticons to rate both the consultation outputs (e.g. posters, creative artefacts) and the tools used to support the consultation process (see Section 4.4 for more information on ranking activities).

Adapting consultation evaluation methods to be inclusive of disabled children and young people is crucial in order to ensure their voices are heard and their experiences are considered. Here are some examples of strategies for making evaluation methods more inclusive:

1. Use of alternative communication methods:

- **Symbol-based communication:** Consider using visual symbols or communication boards with symbols or images that represent the evaluation categories (space, voice, audience, influence). Participants can point to or select the symbols that best represent their feelings.

¹⁶ Department of Children, Equality, Disability, Integration and Youth (2021). *Participation Framework: National Framework for Children and Young People's Participation in Decision-making*. Dublin: Government Publications.

2. Emojis and symbols:

- **Emojis with descriptions:** Use emojis along with text descriptions to represent different aspects of the consultation. For example, a smiling emoji with the word 'happy' can represent a positive experience, while a frowning emoji with the word 'unhappy' can indicate a negative one.

3. Sensory feedback:

- **Tactile feedback:** Provide tactile materials like textured cards or objects that children and young people can use to express their feelings. For example, a soft plush star can represent a positive experience, while a rough-textured card can indicate a negative one.

4. Communication:

- **Assistance from communication partners:** If needed, a child or young person's communication partner can help them express their thoughts verbally or through alternative means. It must be clear that it is the child's will and preference and that every effort is made to ensure it's the voice of the child coming through.

5. Interactive technologies:

- **Accessible digital tools:** Utilise digital tools and apps that are designed to be accessible for disabled individuals. These tools may offer various methods of providing feedback, such as tapping, swiping or using assistive devices like switches.

6. Storytelling and artistic expression:

- **Narrative or art-based feedback:** Allow children and young people to express their feelings and experiences through storytelling, drawing or other artistic means. They can create visual representations of their thoughts and emotions related to space, voice, audience and influence.

7. Structured interviews:

- **Adaptive questioning:** Tailor your questions to the child or young person's communication abilities. Ask open-ended questions that allow them to express their thoughts in their preferred way, whether through speech, sign language or alternative communication methods.

[Page 57]

8. **Visual timelines:**

- **Timelines with symbols:** Create visual timelines or schedules using symbols to help children and young people understand and track the consultation process. This can aid in their comprehension and anticipation of evaluation moments.

9. **Group discussions:**

- **Small group discussions:** Consider conducting evaluations in smaller, more manageable groups, especially for children and young people who may feel overwhelmed in larger settings. This can create a more comfortable and inclusive environment.

10. **Feedback support tools:**

- **Communication aids:** Provide communication aids or devices that children and young people are familiar with and comfortable using, such as communication apps or assistive technology devices.

11. **Flexible evaluation formats:**

- **Written, verbal or visual:** Offer multiple formats for providing evaluation of the consultation, including written feedback, verbal sharing or visual representation, allowing children and young people to choose the format they are most comfortable with.
- Examples of feedback forms based on the Lundy Model of participation can be found in the *Participation Framework* (pp. 20–23).

12. **Collaborative evaluation:**

- **Support from trusted adults:** Allow children to involve trusted adults or advocates in the evaluation process, such as parents, caregivers or teachers, who can help interpret and communicate their feedback.

Remember that the key to inclusivity is flexibility and adaptability. Be open to adjusting your evaluation methods based on the specific needs and preferences of each disabled child or young person, ensuring that their voices are genuinely heard and valued in decision-making processes.

Most participation initiatives will be evaluated directly after they finish. The results of this evaluation can then be included in the feedback given to the participants.

5.2 Giving feedback to children and young people

The *Participation Framework* recommends Professor Laura Lundy's four 'Fs' feedback process for communicating feedback to children and young people following consultations or collective decision-making processes. More information on this can be found on page 11 of the *Participation Framework*. Providing feedback should be planned for and resources created at the outset of the initiative, and if necessary discussed with communication partners, parents and/or caregivers. Similar to the resources of the participation initiative, feedback should be in a format suitable to the child or young person, such as a multi-method feedback approach with visual and/or tactile support.

- Full: Provide comprehensive feedback to children and young people outlining which of their views were accepted, which were not accepted and the reasons for these decisions. This feedback should also note who is implementing their views and what is happening next.
- Friendly: Feedback or responses given by decision-makers to children or young people need to be in a format and language they understand. They need to be informed about the findings of a participation initiative and about how their views were given due weight.
- Fast: Children and young people quickly grow up and move on from things they are involved with, so decision-makers need to give them feedback acknowledging

their contribution, outlining initial progress and giving information on next steps as soon as possible. This applies to all key stages and developments.

- Followed-up: Decision-makers need to provide ongoing feedback and information to children and young people throughout the policy- or decision-making process.

[Page 59]

Feedback that is inclusive should be designed in partnership with children and young people to ensure it is meaningful to them. Disabled children and young people will need to see, experience and understand the extent of their influence in a way that makes sense to them. Some examples of this may include concrete items and outputs, posters with photographs, infographics, video recordings, webinars, social media, visits, talks or in-person experiences. Children and young people are experts in their own lives. Showing them they have been heard and their views given due weight, and explaining where their views have had an influence and where they have not, is crucial to ensure their rights are being met.

[Page 60]

Appendices

Appendix 1: Project group members

Appendix 2: Types of communication, including AAC

Appendix 3: 'Getting to know you' checklist

Appendix 4: Examples of visual schedule, social story script for participation and sensory story share

Appendix 5: Useful websites and resources

[Page 61]

Appendix 1: Project group members

Authors of the report from Dublin City University (DCU) School of Inclusive & Special Education

Hub na nÓg

National Disability Authority (NDA)

Department of Children, Equality, Disability, Integration and Youth (DCEDIY)

Members of the Disability Working Group included:

AsIAm

Chime

Disabled Women Ireland

Inclusion Ireland

Independent Living Movement Ireland (ILMI)

National Council for Special Education (NCSE)

National Participation Office

University College Cork (UCC)

Tusla – Child and Family Agency

Vision Ireland (formerly National Council of the Blind Ireland [NCBI])

Appendix 2 Types of communication, including AAC

Unaided communication

This involves the child or young person using their own body to communicate without devices. This can involve signing of key words, or gestures and expressions. Some disabled children and young people may communicate through vocalisations, movement of eyes and mouth or some physical movement. Communication partners will be able to interpret meaning in these instances, or this will be included in a communication profile for the child. For example, some children or young people may express joy by jumping, flapping hands and vocalising. Others may express interest, happiness and engagement by following and tracking an item with their eyes, or by pointing or leading someone to an item of interest.

Lámh

Lámh is a manual signing system that involves a combination of signs with speech. Key words are signed in a sentence and modelled with speech. The key word signs are based on Irish Sign Language (ISL), but Lámh is not a language. It does not have finger spelling, and users of Lámh speak the key word orally along with manually performing the sign. More information and video demonstrations can be found at <http://lamh.org>

Aided communication

This type of communication involves the child or young person using an external device or object that is separate to their body. These devices can be sophisticated (high-tech) or involve more simple systems (low-tech). Low-tech options usually do not need a battery.

Low-tech

- **Eye-pointing**

Children and young people may use eye movements to point at symbols/ photographs/pictures to indicate their choice or answers to questions. You may need to

display symbols, photographs or pictures that are larger than usual, or use a board that clearly separates the options, such as an E-Tran frame.¹⁷

[Page 63]

- **Objects of reference**

These are used to represent words and ideas in a concrete way, which the child or young person experiences by touching the item and feeling its shape (and sometimes by smelling it). Objects can be helpful for supporting understanding, and can also be used for the child or young person to express themselves. Objects can be used to represent activities and preferred items: for example, the child can feel the shape and texture, and the smell, of a ball to represent playing outside.

- **Core communication boards**

Typically, this is a rectangular piece of laminated board with signs and symbols that can be used for a range of topics with communication partners. The core communication board can also include text. Communication partners use core communication boards to model all language in the correct sentence structure without expectations of the child or young person. Symbols can also be integrated into a high-tech speech-generating device (see below).

- **Picture Exchange Communication System (PECS)**

This is a system that teaches children how to initiate communication through use of pictures. It begins with teaching functional and relevant communication skills by having the child or young person approach a communication partner with a picture of a desired item. PECS users can use a range of symbols to request what they would like or need, e.g. "I want break/I want drink." Some children may use a variety of pictures or symbols and not PECS.

¹⁷ An E-Tran frame is a plastic board that clearly displays words or pictures, supporting eye-pointing as a method of communication. See an example here: <https://www.communicationmatters.org.uk/what-is-aac/types-of-aac/e-tran-frames/>

- **Switches**

Switches can be used to enable access to a range of devices, including computers or toys. They can be positioned in locations where the child or young person has the mobility to use it, e.g. a head switch versus a leg switch. One type of switch called a BIGmack does not control a separate device but activates a pre-recorded message. The child or young person can be helped to press the switch to hear, for example, their name or a greeting.

[Page 64]

High-tech

- **Speech-generating devices (SGDs)**

Typically these are computer-based devices that produce an electronic voice. SGDs require the person to select an image or word, which the electronic voice then verbalises. A number of types of SGD are available, ranging from more durable types with fewer picture options (e.g. GoTalk) to mobile applications for a smartphone or tablet (e.g. Grace App, Proloquo2Go or Tobii Dynavox).

- **Eye gaze technology**

This is an eye-operated communication device where a person's line of vision is calibrated to select choices on a screen. It usually also includes a speech output system.

Communication using senses

This is a method of communication in which all senses (touch, taste, smell, sound and sight) are used to receive information. Everyday objects can be used for children to experience, or there may be more high-tech options available in settings where there is a sensory room or space.

- **Sound beams**

A sound beam is a musical device where any physical gesture can make a sound. While it is not used as a method of AAC in a formal sense, access to this type of equipment increases how responsive the environment is to any physical initiation a person can make.

- **Resonance boards**

A resonance board is a plywood board, slightly raised off of the floor and usually large enough to lie on, that provides sound and vibrational feedback. Items can be placed on the board, allowing for exploration as well as communication through games where one person taps on the board and the other person listens to the sound and repeats it. Then the second person initiates creating a sound on the board and the first person repeats it back in turn.

[Page 65]

Story massage

In some settings, communication partners, parents or caregivers may use story massage to share stories. There are ten key strokes they can perform, usually on a person's back or sometimes on their hand, foot or cheek, depending on their ability to receive touch. There are symbols to represent these movements. It is based on the understanding of the importance of nurturing touch in communication. Children are asked for their consent before starting, and only someone the child or young person knows and trusts engages in story massage with them.

The following appendices are suggested templates that policy-makers can use and adapt in partnership with children and young people.

Appendix 3: 'Getting to know you' checklist



Please tell us how you like to communicate.



- A communication partner, parent or professional may help you to answer this sheet.
- You may also share information in alternative ways that suit you better: for example, a communication passport, an 'all about me' book, a recording, or we can have a chat ourselves.

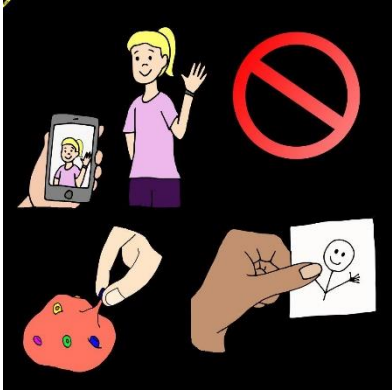
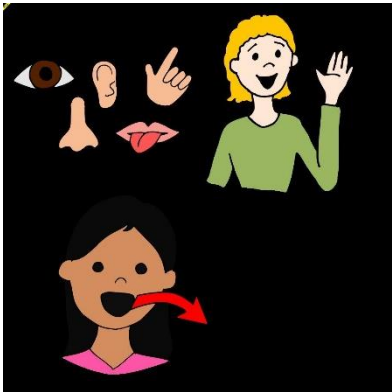
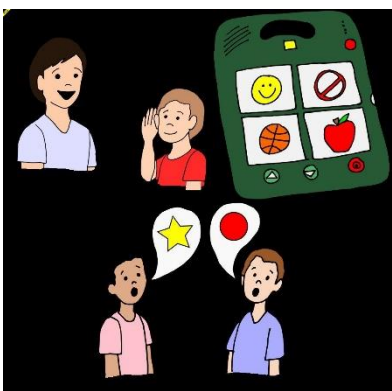
- You might like to share some audio or visual examples along with, or instead of, completing this sheet.


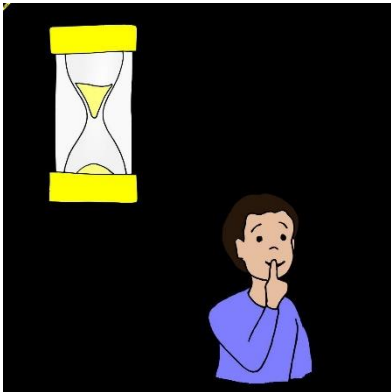


- Complete Sheet A (close-ended questions) or Sheet B (open-ended questions) or both.
- Provide as much or as little information as you want. It will help us to accommodate you.
- We will go through the information together. We won't keep any copies of any information without your permission.

Sheet A

<p>I use a device.</p> 	<p>Yes/No</p>	<p>Please provide more information here:</p>
<p>I use Lámh.</p> 	<p>Yes/No</p>	<p>Please provide more information here:</p>
<p>I use ISL.</p> 	<p>Yes/No</p>	<p>Please provide more information here:</p>

<p>I use pictures, symbols, photographs or objects.</p> 	<p>Yes/No</p>	<p>Please describe: e.g. size of pictures, type, number of pictures to present together</p>
<p>I use my senses, gestures and vocalisations.</p> 	<p>Yes/No</p>	<p>Please describe.</p>
<p>In a conversation, I understand some key words (e.g. favourite item) with either visuals or objects.</p> 	<p>Yes/No</p>	<p>Please describe.</p>

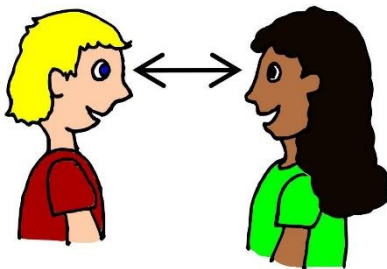
<p>In a conversation, I can understand questions with the words 'who', 'what', 'where' and 'when'.</p> 	<p>Yes/No</p>	<p>Please describe.</p>
<p>In a conversation I can understand a sentence with lots of words, but I need time to process it.</p> 	<p>Yes/No</p>	<p>Please describe.</p>

Sheet B

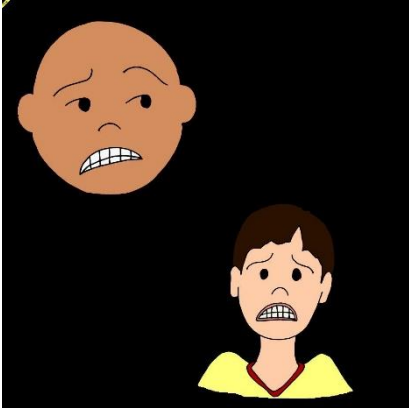
I like to communicate by:



I can understand others best when:



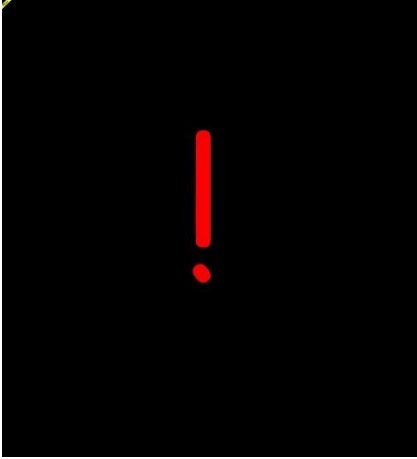
You will know I'm uncomfortable or unsure when:



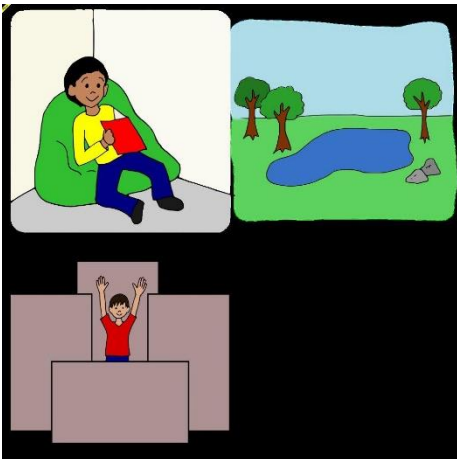
I'm best able to communicate and understand when:



Important things to know about me are:



I like my surroundings to be:



Appendix 4: Examples of visual schedule, social story script for participation and sensory story share

Steps for social story:

- Adapt as necessary depending on child or young person's level of understanding.
- Review alone or with communication partner.
- Review in advance of consultation as often as is required.
- Bring to consultation if desired.
- Have large cards labelled 'I have a question' and 'More time please' available.

Let's Participate and Make Decisions!

Participation is being included, where you can share what you think or feel about something important to you. What you think matters in making lots of decisions about important things in your life.

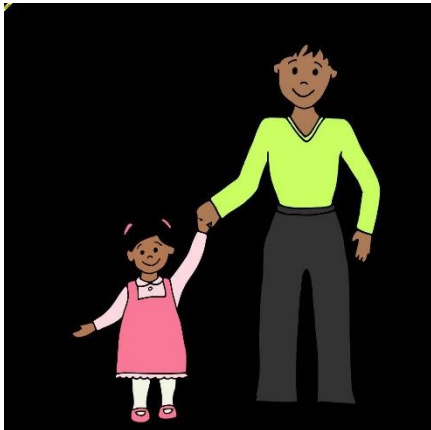


[Page 76]

Sometimes, this happens in a meeting. It might be online on a computer, or in a nice room in a building you travel to or sometimes in your school or centre. Sometimes, you and your parent will share with us what you think in a different way that suits you.

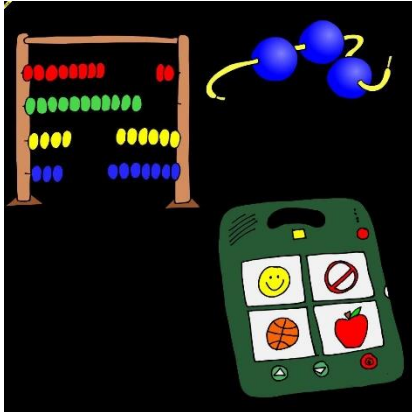


Your parent or someone else who knows you well can come too.

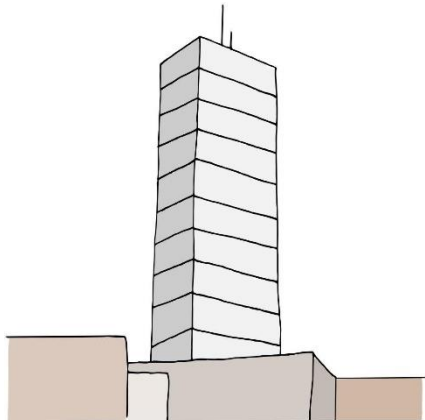


[Page 77]

You can bring your device and items that help you feel safe (e.g. photographs or sensory items and communication aids).



This meeting will take place here:

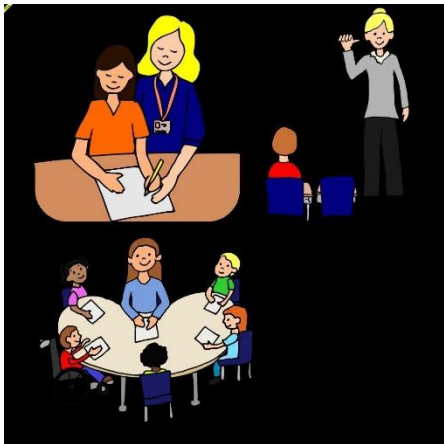


[Page 78]

You will meet other children and young people.

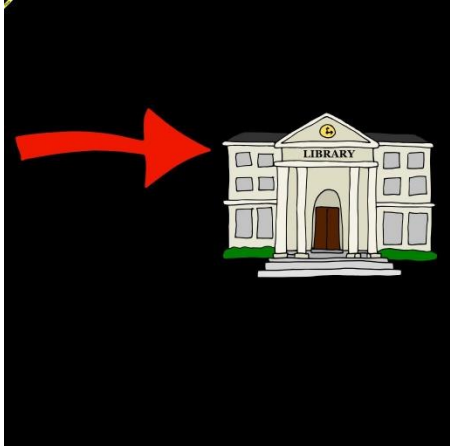


You will meet (insert names)

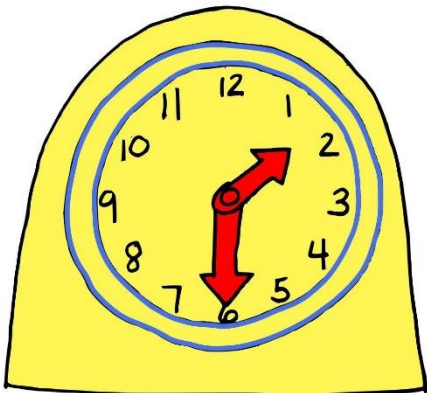


[Page 79]

This is the location:



It will take place from 00.00 to 00.00. (Insert actual time here)

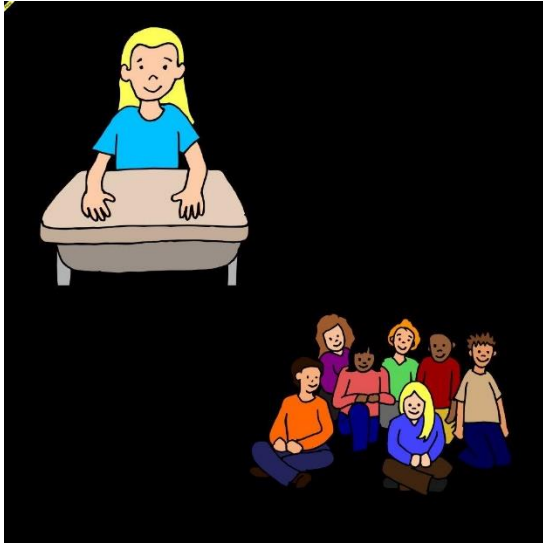


[Page 80]

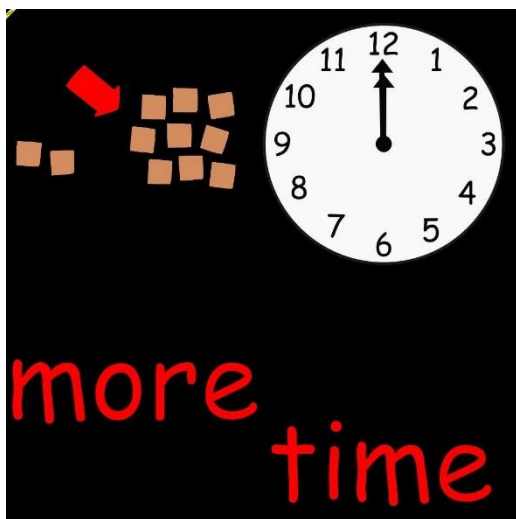
There will be three tasks:

Now	Next	Later
-----	------	-------

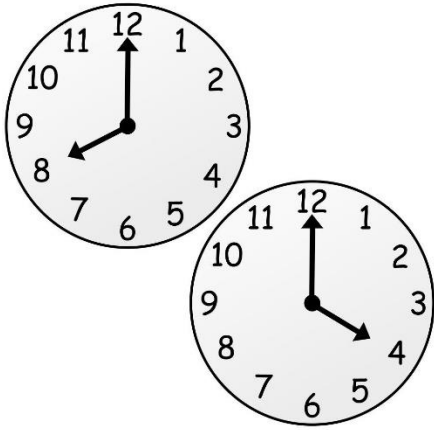
You will sit in groups or on your own - you can choose or go between.



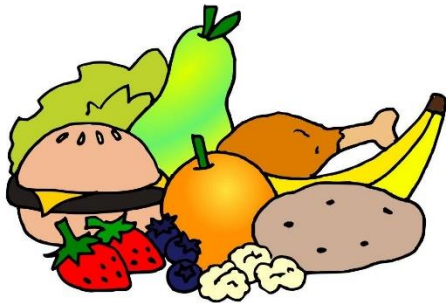
You will have lots of time to think about your answers. If you don't have enough time, that's OK - we can give you more time. If you need more time, you can ask or hold up the large time card.



There will be breaks at these times. (Update clocks to show break times)



You can eat and drink whenever you need.



You can take a comfort or movement break whenever you need - no need to ask!



[Page 82]

If you have a question, raise your hand or hold up the question card.



There are no wrong answers. You don't have to answer anything if you do not want to.

You will know it is finished when we _____

We will show you how your views mattered by _____

Thank you!



It's great to be able to participate!

Sensory story

Please see information on sensory stories and story share that may be helpful in Appendix 5.

This is a way to prepare for consultation, or it can be used as a structure to develop a portfolio of moments that matter to be used for consultation. This is suitable for disabled children and young people who communicate primarily using their senses and objects. Work in partnership with families, schools or services to be meaningful for children and young people. Review all relevant information on communication and sensory preferences.

Document what is important for people in an ongoing way over a period of time. This can be collated in a portfolio/folder or book. Use the sensory story time to share these moments and capture the person's views on what matters to them.

Take plenty of time.

Pick one meaningful activity for each sentence. Below are some suggestions.

Use objects that are meaningful and safe.

Can be read in different order. Adapt where needed.

Use music clips where useful.

I am seen, I am heard

Read or recall sentence out loud.	Suggested objects of reference/sensory items. Pick some that are most meaningful or choose your own. Less is more!
Let's make space for everyone.	Gather in a circle. Hold parachute and wave over and share or holding between. Make circle bigger, raise arms wide. Or

	<p>open up sensory umbrella with objects/pictures that are meaningful for each person</p>
<p>This is me, this is my voice.</p>	<p>BIGmack recording of vocalisations Mirror Ribbons on stick for voice Bubbles Large shell/stone Picture of person Item on sensory umbrella</p>
<p>Everyone, hear me.</p>	<p>Make sounds into toy microphone. Take turns making sounds on drum or other percussion instrument. Look in mirror to see reflection. Take photo on iPad. Twirl umbrella.</p>
<p>I am seen, I make a difference.</p>	<p>Look in mirror or take photo on iPad. Drop shell or stone into water and watch/feel the ripples. Pour dye into water and see how it changes. Share a new photo or object from the week. Ribbons blowing and moving. Add new item (photo, drawing, favourite texture) to umbrella.</p>

Appendix 5: Useful websites and resources

Further support for communication aids and methods

- Talking Mats

<https://www.talkingmats.com/talking-mats-and-the-voice-of-the-child-young-person/>

- Sensory stories

<https://www.thesensoryprojects.co.uk>

- Social narratives

<https://life-skills.middletonautism.com/background/teaching-life-skills/social-narratives/>

- Story sharing

<https://storysharing.org.uk/>

- Creative methods example, Involve Me project

<https://www.mencap.org.uk/learning-disability-explained/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me>

- Lámh Signs online

<https://www.lamh.org/communication/l%C3%A1mh-signs-online>

- Information on AAC

<https://www.communicationmatters.org.uk/what-is-aac/guidance/>

- Information on assistive technology

<https://nda.ie/assistive-technology/assistive-technology-research>

- CommunicationFIRST: The Words We Use

<https://communicationfirst.org/the-words-we-use>

[Page 86]

Suggested links to support wider recruitment

- NCSE list of special classes

<https://ncse.ie/special-classes>

- Department of Education list of schools (primary, post-primary and special schools)

<https://www.gov.ie/en/collection/63363b-data-on-individual-schools/>

- National Association of Boards of Management in Special Education (NAMBSE)

<https://nabmse.ie/>

Important frameworks, guidance and reports

- Council of Europe (2020). *Listen – Act – Change: Council of Europe Handbook on children’s participation.*

<https://rm.coe.int/publication-handbook-on-children-s-participation-eng/1680a14539>

- Department of Children, Equality, Disability, Integration and Youth (2021). *Participation Framework: National Framework for Children and Young People’s Participation in Decision-making.*

<https://hubnanog.ie/participation-framework/>.

- Department of Children, Equality, Disability, Integration and Youth (2023) *Young Ireland: the National Policy Framework for Children and Young People 2023-2028.*

<https://www.gov.ie/en/publication/80ac4-young-ireland-the-national-policy-framework-for-children-and-young-people-0-24-2023-2028/>

- Department of Children and Youth Affairs (2014). *A practical guide for including seldom-heard children & young people in decision-making*.

<https://www.ourvoicesourschools.ie/app/uploads/2019/11/A-practical-guide-to-including-seldom-heard-children-young-people-in-decision-making.pdf>

[Page 87]

- Department of Children and Youth Affairs (2017). *Children First: National Guidance for the Protection and Welfare of Children*.

https://www.tusla.ie/uploads/content/Children_First_National_Guidance_2017.pdf

- Department of Education (2022). *Autism Good Practice Guidance for Schools – Supporting Children and Young People*.

<https://ncse.ie/autism-good-practice-guidance-for-schools-supporting-children-and-young-people>

- European Commission (2012). *Creating child-friendly versions of written documents: A guide*.

<https://www.qub.ac.uk/research-centres/CentreforChildrensRights/CCRFfilestore/Filetoupload,1269252,en.pdf>

- Inclusion Ireland (2022). *Report on Alternative and Augmentative Communication Seminar*.

<https://web.archive.org/web/20230423230922/https://inclusionireland.ie/wp-content/uploads/2022/12/Report-on-Alternative-and-Augmentative-Communication-Seminar-October-19th-2022-3.pdf>

- Lundy, L. (2022). *How To Write a Child-Friendly Document*. Save the Children.

<https://resourcecentre.savethechildren.net/document/how-to-write-a-child-friendly-document/>

- National Disability Authority (2021). *NDA Advice paper on Disability Language and Terminology*.

<https://nda.ie/about/engaging-with-disabled-people/language-and-disability#:~:text=Language%20and%20Disability-.Language%20and%20Disability,speaking%20and%20writing%20about%20disability>

- National Disability Authority (2022). *Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making*.

https://nda.ie/uploads/publications/NDA-Participation-Matters_Web-PDF_092022.pdf

- National Participation Office of the Department of Children, Equality, Disability, Integration and Youth (2023). *Including young people on Committees: A brief guide for government department and agencies*.

<https://www.gov.ie/en/publication/e0099-including-young-people-on-committees-a-brief-guide-for-government-departments-and-agencies/>