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A Literature Review on the Inclusion of Disabled Children and Young People in Participation in Decision-Making

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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 in the literature. 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 appears within 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. Examples of this include terms such as ‘disabled person’. Identity-first or social model language instead seeks to emphasise that people are disabled by barriers in the environment and in society, rather than their ‘impairment’.
In Ireland, the National Disability Authority (NDA) consulted with disabled persons and published guidance on the use of disability language and terminology (2022). While identity-first was the term preferred by most, stakeholders with an intellectual disability preferred person-first language. It was noted that some disabled persons with disabilities do not identify with either term (NDA, 2022). Key recommendations from the report advise to take a contextualised and flexible approach, to ask people’s preferences and to avoid stereotypes, euphemisms, medicalised and negative language.

Identity-first language is used in this literature review, with person-first used in relation to the UNCRPD. However, in parts, terms may be used interchangeably. For those who do not use speech, nonspeaking 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 this review.

The term ‘special’ is not widely accepted by disabled people, however, it is recognised that this term is still used in some education legislation and in various organisations, and 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/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 referenced as such in the document. The term ‘signs’ are used when explaining aided communication methods, but these are not the same as ISL.

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.

Executive Summary

Introduction

In Ireland's steadfast dedication to human rights, social equity and justice, the imperative to amplify the voices of all individuals, regardless of their unique experiences or age, stands as a paramount principle. Guided by both international agreements such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCRC), and national agreements such as the National Strategy on Children and Young People’s Participation in Decision-Making (2015), the National Framework for Children and Young People’s Participation in Decision-Making (2021), the Children and Young People’s Participation in Decision-Making Action Framework (2023-2028), and Young Ireland: The National Policy Framework for Children and Young

People (2023-2028), this literature review - commissioned by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) - examines the available evidence concerning the participation of disabled children and young people in decision-making. This evidence is needed in order to inform the development of a toolkit on how to meaningfully and effectively involve disabled children and young people in the decision-making process and approach participative consultations and initiatives in the most accessible and inclusive way possible.

We adopted a narrative approach to the synthesis of the literature on this broad topic, based on searches on EBSCO databases Academic Search Complete, PsycARTICLES, PsycINFO, and Scopus (with interdisciplinary coverage), online searches for policy and practice guidelines, and grey literature. Our search included the following restrictions: (a) published since 2002, (b) containing selected keywords in the abstract, (c) with full text available, and (d) in the English language. Sources were identified using all possible combinations of the following groups of search terms: a) "participation" "rights" "decision-making" "shared decision-making" b) "consultation" "research" "policy" "policymaking" c) "disabled" "impairment" "communication difficulties" "PMLD" "intellectual disability" “autism” “nonspeaking” “AAC” d) "children" "adolescents" "young people".

The legislative context

The common theme in the legislative and policy context is the Irish Government obligation and commitment with regard to the participation of disabled children and young people. These are underpinned by relevant articles of the United Nations Convention on the Rights of the Child (UNCRC), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and other relevant obligations, laws and policies which set out the basis for child and youth consultation and participation, including, for example, EU 2030 Sustainable Development Goals, European Youth Strategy, provisions included in the European Child Guarantees and Council of Europe Recommendations, the National Participation Strategy and the Participation Framework. The Children and Young People’s Participation in Decision-Making Action Framework 2023-2028 and Young Ireland: The National

Policy Framework for Children and Young People 2023-2028 also have the participation of children and young people as a central theme.

Key definitions and concepts

Key concepts and definitions relevant to the participation of disabled children and young people emphasise the importance of viewing participation as a tailored and situated activity, as opposed to a predetermined process. Our review acknowledges that disability is an evolving concept, and we outline the evolution of different models of disability, followed by a discussion on disability related language and terminology. There is no universally agreed or international consensus on terminology, and this review advises to take a contextualised and flexible approach, and to ask people's preferences and avoid stereotypes, euphemisms, medicalised and negative language. Identity-first language is used in this review with person-first used in relation to the UNCRPD. However, in parts, terms may be used interchangeably. In addition, terms like high or low functioning are avoided. For those who do not use or choose not to use speech, AAC user or nonspeaking tends to be preferred.

The literature points to taking an intersectional approach to consultation which recognises how different forms of social, cultural, political and economic discrimination impact people with different identities. The intersectionality approach is complemented by the concept of Universal Design, in which consultation mechanisms and processes are designed to be inclusive to the greatest extent possible to all people, regardless of their age, size, ability or disability.

Child and youth participation

Child and youth participation is defined in the literature as an ongoing process by which children and young people have active involvement and real influence in decision-making on matters affecting their lives. Nine basic requirements for meaningful participation as identified by the UNCRC are outlined and discussed in relation to what they mean in practice for inclusive consultations. These requirements include that the process must be transparent and informative, voluntary, respectful, relevant, child-friendly, inclusive, accountable, safe and sensitive to risk, and supported by training.

An acknowledgment of different models of child and youth participation is made, and a rights-based Lundy participation model is described. The Lundy model contains four interrelated elements following a chronological order. These four elements are Space, Voice, Audience and Influence. In addition, contexts for child and youth participation are reviewed - these include individual or personal participation/decisions and collective or public participation/decisions, formal and informal participation, consultative and collaborative approaches to participation, as well as mainstream and disability specific participation. We also define the concept of decision-making capacity as one's ability to understand when a decision is being made and the nature and consequences of the decision in the context of the available choices.

Overall literature suggests that participation methods need to be adapted and tailored to the preferences of each individual child and/or young person. There is no single method that will 'work' with all children, however, for disabled children and young people often tangible and visual formats of the consultation are the most effective. Often a combination of participation methods may be needed to achieve meaningful participation.

Benefits and barriers to participation

The literature highlights that participation is particularly important for disabled children and young people as they may be uniquely experienced in relation to health, education, employment and social areas. Participation for disabled children and young people has a number of individual and collective benefits. For example, shared decision-making, especially when using arts-based participatory methods, can draw out children and young people's strengths, resilience and optimism. It empowers children and young people, develops their creative skills, builds their sense of self, identity and self-esteem. At a collective level, their participation benefits organisations and public policy development, contributes to more appropriate services, and society as a whole. Participation can be a means by which children and young people realise their other rights.

Much of the relevant literature focuses on barriers to participation and the list of challenges of participation is lengthy. Disabled children and young people face barriers at many levels including institutional, legislative and policy level, environmental, attitudinal and individual levels. Implementation challenges continue to be increasingly recognised by researchers, and this includes weak implementation of policies and laws. There appears to be a lot of rhetoric supporting participation, but it is unclear how this has translated into policy. Multiple and intersecting discrimination can further intensify these barriers.

The literature indicates that attitudes towards disabled children and young people, including low expectations – because of their age or disability or both – represents a key barrier to their participation. Low expectations are especially pronounced for certain groups of children and young people including:

- those who have different ways of understanding or communicate differently
- children and young people with intellectual disabilities
- very young children.

Often, practitioners may lack the experience, capabilities and skills to facilitate participation and this may be especially the case when consulting with children and young people who may not use speech as their main or preferred method of communication. Lack of capacity of practitioners in terms of skills, time and resources is a key barrier for enabling participation of these children. Similarly, when it comes to utilising arts-based participatory methods, the most often cited challenge is that they are resource- and time-intensive. Thus, a lack of commitment and investment to meet an individual child's requirements and preferences is a key barrier to participation.

The literature also highlights inaccessible physical environment, information and communication as major barriers to participation. The literature demonstrates that disabled children and young people often have less experience making decisions in their own lives, both at the personal/individual level and in public decision-making. They thus require more opportunities to develop the skills and confidence in participation, and, like the practitioners, need increased skills and training.

Child and youth participation in practice

The review provides an overview of different variations of child and youth participation in practice, policy and research. From local and EU level children's councils and youth parliaments to children's research advisory groups and advocacy services as a means to support children and young people's participation, we give various examples that promote individual or collective decision-making, formal and informal process, disability-focused or mainstream issues, and constitute varying degrees of influence or shared power with adults.

We include available evidence on how to make participation work for disabled children and young people. The literature highlights the importance of identifying and removing barriers to participation at all levels. At an organisational level, the literature highlights that participation must be embedded across an organisation in a whole systems approach and embedded as an integral part of our relationship with children. It is acknowledged that meaningful participation cannot be done 'on a whim' and that an organisational buy-in, careful planning, preparation and execution are all needed. This includes appropriate resourcing of participation, training and capacity building, investment in appropriate participation methods and investment in ongoing long term methodological and practice developments in this area. Partnerships developed over longer time frames may be needed to ensure inclusion of underrepresented groups. Finally, monitoring and evaluation mechanisms must be in place to enable effective implementation and sustainability of child and youth participation in practice.

At the project level, key considerations for planning a participation initiative are outlined. These include:

- planning the scope of the participation initiative
- recruitment of children and young people including underrepresented groups
- familiarisation with key communication and sensory information of participants
- safeguarding and gaining consent
- and planning flexible and appropriately differentiated consultation methods.

Key messages in the literature are that the methods used must be responsive to the needs and preferences of disabled children and young people in order to facilitate meaningful participation. Overall, an inclusive, flexible, multi-method and multi-media approach that may be tailored to individual needs of children and young people is recommended. Such an approach is consistent with the concepts of universal design and universal accessibility which should underpin all planning.

The principles for working with the child or young person’s parents/ guardians and staff from the educational settings are outlined. Staff from the educational settings are mentioned in the literature as stakeholders that may be especially important in relation to gaining access and promoting the participation of “seldom-heard” disabled children and young people, who in some instances may be ideally placed to facilitate or to support participation, given their knowledge of communication methods and their understanding of the participating children and young people.

We outline general strategies and methods for overcoming barriers to creating inclusive consultation environments and emphasise the importance of a total communication approach. The total communication approach involves using and valuing all types of communication equally, recognising that speech is just one method of many. This approach accepts communication in many forms, including:

- natural gestures
- 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, pictures and photos.

We outline practical tips for supporting understanding and simplifying written communication, and discuss the use of arts and technology to support inclusive participation. We describe a range of alternative and augmentative communication tools and outline the role of communication partners.

Participation methods: Practical activities and tools

Our review highlights that ideally, participation methods should be co-created or co-constructed with disabled children and young people. Due to the demands this may place on disabled children and young people, at a minimum, participation methods need to be adapted and tailored to the preferences of each individual child or young person There is no single method that will ‘work’ with all children. Often tangible and visual formats of the consultation or participative process are the most effective. Often a combination of participation methods may be needed to achieve meaningful participation. We emphasise the importance of allowing the children and young people to choose a participation method and present a range of methodologies and approaches, including:

- the mosaic approach
- activity-based consultations
- arts based consultations
- gamification
- and specific methods such as ranking activities and talking mats.

The language used or the method of communication the children use every day will determine the methods for consulting. This may include speech or Irish Sign Language (ISL) and/or other means that augment communication. This means that some children may express their views through pictures and/or symbols on a computer programme, or through gestures and emotions.

Methods supporting gaining assent and engagement for children who may not use speech as their preferred communication method, may need to be further differentiated and may require more specialist support, as well as increased investment of time and resources. While parents or guardians may be included on behalf of their child or young person, consultations and participative processes should plan to allow for meaningful involvement for the disabled child or young person themselves. Simple explanations of the consultation and participative process can be provided, for example, through broadly defined storytelling, including social narratives and social stories, comic strip conversations or sensory stories. Digital storytelling is also discussed as an effective approach promoting participation.

Practical considerations for planning advisory groups and conducting child-friendly focus groups, questionnaires and/or written consultations with disabled children and young people are outlined. We emphasise the importance of children and young people's meaningful participation at all stages of the consultation process.

Evaluating the effectiveness of participation

The literature highlights the importance of evaluating the effectiveness of participation with disabled children and young people. This includes evaluating both the outcomes for children and young people themselves and evaluating the effectiveness of the process, as well as the scope, quality and outcome of the consultation. This is especially important for children and young people whose views are less likely to influence decision-making, such as very young children, care experienced children, and children with communication differences.

Conclusion

This literature review informed the development of a scoping document aimed at providing advice on how to meaningfully and effectively involve disabled children and young people in decision-making and approach participative consultations and initiatives in the most accessible and inclusive way possible. Both the process of the scoping document development and the document itself are informed by the evidence and best practice principles reported in this literature review.

Background and Introduction

The Department of Children, Equality, Disability, Integration and Youth (DCEDIY), Hub na nÓg, and the National Disability Authority (NDA) were seeking a guidance document for policy makers and those that facilitate the participation of disabled children and young people in decision-making with a particular focus on those who use augmentative or alternative communication (AAC). The aim of this literature review is to provide current evidence on approaches to participation of disabled children and young people including those who use AAC or are nonspeaking in consultation, policy development, monitoring and accountability processes. The review includes specific methodologies and considerations for this purpose needed to ensure accessibility for all children and young people including children and young people who are nonspeaking. A steering group with representatives from Disabled

Persons Organisations (DPOs) as well as Hub na nÓg and the National Disability Authority (NDA) provided observations and recommendations that supported the final draft of this document.

The literature review examines the available evidence concerning the participation of disabled children and young people in decision-making, including policy development and monitoring processes.

This includes:

- An overview of the obligations and commitments of Government with regard to the participation of disabled children and young people underpinned by international and national level legislation and policy
- Key concepts in disability and the participation of disabled children and young people
- Benefits of participation of disabled children and young people
- Principles of meaningful participation of children and young people
- Models of child and youth participation
- Various configurations of participation including examples in practice
- Barriers to the participation of disabled children and young people
- How to make participation work for disabled children and young people at all levels
- The critical/important role of parents and caregivers and staff from educational settings
- Creating an inclusive environment for disabled children and young people
- Examples of inclusive consultation tools for disabled children and young people who do not rely on speech to communicate/use AAC/are nonspeaking
- Evaluation of participation and consultation processes with disabled children and young people who do not rely on speech to communicate/ use AAC/ are nonspeaking.

This literature review will inform the development of the scoping document that will provide advice on approaching participative consultations and initiatives in the most accessible and inclusive way possible. This scoping document will provide additional support and recommendations for policy makers and those that facilitate the participation of disabled children and young people in decision-making and will inform the development of resources that will support this participation.

Literature selection

To identify literature for the review, a search of the EBSCO databases Academic Search Complete, PsycARTICLES, PsycINFO, and Scopus (with interdisciplinary coverage) was carried out, as well as online searches for resources and policy and practice guidelines from relevant organisations. Our search included the following restrictions: (a) published since 2002, (b) containing selected keywords in the abstract, (c) with full text available, and (d) in the English language. Sources were identified using all possible combinations of the following groups of search terms: a) "participation" "rights" "decision-making" "shared decision-making" b) "consultation" "research" "policy" "policymaking" c) "disabled" "impairment" "communication difficulties" "PMLD" "intellectual disability" “autism” “nonspeaking” “AAC” d) "children" "adolescents" "young people". Ancestral searching was conducted from key relevant articles (King et al., 2020).

Expert opinion was also sought through the NDA and Disabled Persons’ Organisations for key literature to include. This was carried out alongside an initial gathering of the literature by Maeve O’Reilly (NDA) in 2021 and 2022 including an analysis of the literature in relation to the legislative and policy context and participation structures in practice, policy and research. Building on this, following our own review of literature, we adopted an overall narrative approach to the synthesis of all available evidence. We considered this a suitable approach to deepen current understanding of this broad topic and associated themes at research, policy and practice levels.

Chapter One: Legislative and policy framework

Introduction

This chapter outlines the legislative and policy context underpinning the Irish Government’s obligation and commitment with regard to the participation of disabled children and young people. Relevant articles of the United Nations Convention on the Rights of the Child (UNCRC), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and other relevant obligations, laws and policies which set out the basis for child and youth consultation and participation are outlined. The Children and Young People’s Participation in Decision-Making Action Framework 2023-2028 and Young Ireland: The National Policy Framework for Children and Young People 2023-2028 also have the participation of children and young people as a central theme.

UN Convention on the Rights of Persons with Disabilities

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in March 2018. The CRPD sets out in clear terms the obligation of State Parties to include persons with disabilities, including disabled children, through their representative organisations as active participants in the implementation and monitoring of the Convention and other decision-making processes. The Articles contained in the CRPD are binding on those State Parties that have ratified the Convention.

The UNCRPD includes economic, social, cultural, and civil and political rights. States which ratify the Convention commit themselves to immediate delivery of civil and political rights to persons with disabilities, and to progressive realisation of social and economic rights. According to the UNCRPD Committee, “The right to participate is a civil and political right and an obligation of immediate application, not subject to any form of budgetary restriction, to be applied to decision-making, implementation and monitoring processes related to the Convention.” (UNCRPD, 2018, p.28).

In practice, the Committee on the Rights of Persons with Disabilities observed a gap between the spirit of the Convention and the actual involvement of persons with disabilities, including disabled children, by State Parties. In order to clarify the obligations of State Parties in this regard the Committee developed **General Comment No. 7** in 2018. General Comments are utilised by the UN committee to clarify accepted norms or themes relevant to the Convention on the rights of the child. They offer guidance about practical measures of implementation and outline what is expected of State Parties in implementing these obligations. Although the General Comment, unlike the Convention itself, is not binding on States Parties, Ireland, through its former focal point - the Department of Justice and Equality - committed to following the guidance provided by the General Comment. The implications for the participation of disabled children in both the UNCRPD and General Comment 7 are outlined below.

Article 4(3) of UNCRPD (2018) states that “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including disabled children, through their representative organizations” (para. 3). General Comment 7, however, clarifies that Article 4 (3) obliges State Parties to include children “through organizations of disabled children or supporting disabled children” (para. 24). It also sets out the obligation of States Parties to “create an enabling environment for the establishment and functioning of representative organizations of disabled children as part of their obligation to uphold the right to freedom of association, including appropriate resources for support” (para. 24).

The Committee, through its General Comment 7, establishes a definition of a Disabled Persons’ Organisation (DPO) as distinct from a civil society organisation or an organisation ‘for’ persons with disabilities such as service providers. DPOs are organisations which are “led, directed and governed by persons with disabilities” and which are “rooted, committed to and fully respect the principles and rights recognized in the Convention” (para.11). The Committee further outlines that DPOs can be national, regional or international in scope; they may be based on one type of disability or open to all persons with disability; they are independent of any political party or NGO; and they may operate as an individual organisation, coalition or umbrella organisation. Organisations of disabled children are considered DPOs under the Convention.

Article 7 emphasises the rights of disabled children with regard to participation stating that "States Parties shall ensure that disabled children have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right"(para. 61). The language within this Article reflects the language of the UN Convention on the Rights of the Child which is outlined in the next section.

Article 33 addresses the participation of persons with disabilities in national implementation and monitoring processes stating that 'civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process' (para.3). General Comment 7 states that State Parties must "provide disability and age-appropriate assistance for the participation of persons with disabilities, through their representative organizations, in public decision-making, consultation and monitoring processes" (para. 94n). Analysis by Moloney et al. (2021) also states that under UNCRPD, State Parties are obligated to support disabled children to participate in both personal and public decision-making and in the monitoring of the UNCRPD.

General Comment 7 also addresses the role of adults in supporting the participation of disabled children and young people. The Committee states that "adults have a key and supportive role to play in promoting an environment that enables children and young persons with disabilities to establish and act, formally or informally, within their own organizations and initiatives" (para. 12f). The Committee recognises the important role of organisations of family members of persons with disabilities but emphasises that their role should be "to assist and empower persons with disabilities to have a voice and take full control of their own lives" (para.12d). It further states that "disabled children are themselves best placed to express their own requirements and experiences" (para.25).

UN Convention on the Rights of the Child

The UN Convention on the Rights of the Child was ratified by Ireland in 1992. **Article 12** of UNCRC sets out the obligation of State Parties with regard to the right of children to form their own views and express them freely and for the views of the child to be "given due weight in accordance with the age and maturity of the child."

(para.1). **Article 23** of UNCRC states that disabled children have the same rights as any other child or young person. This includes the right to information.

The UNCRC Committee has outlined more specific guidance in relation to the participation of children and young people in its **General Comment 12 "The Right of the Child to be Heard"** published in 2009. The UNCRC Committee identified the right to be heard (Article 12) as one of the four General Principles of the Convention, and therefore as both a right in itself and a means to the implementation of all other rights. The General Comment guidance states that:

'All children are capable of forming a view'

The UNCRC Committee states that this right applies to all children without exception. In the General Comment, it is clarified that there is no age limit on this right, meaning it applies to all children from birth. The Committee states that the obligation is on the State Party to assess the capacity of the child to form its own view to the greatest extent possible. It also affirms that State Parties have an obligation to ensure that children who have difficulty forming a view are supported to do so. The Committee declares "disabled children should be equipped with, and enabled to use, any mode of communication necessary to facilitate the expression of their views" (para 21). It also states that efforts must also be made to recognise the right to expression of views for children who do not understand the majority language. In Ireland, this would include children who use Irish Sign Language.

'Children have the right to express views freely'

UNICEF (2018) in its analysis highlights that this means that children must be provided with information about their right to express their views, be free from coercion or pressure, and be able to express their views within safe environments.

'Children have the right to express their views on all matters affecting them'

UNICEF (2018) explains that the interpretation of the term 'matters', according to the General Comment, is meant to be broad. This means that it includes "not only concerns most obviously associated with children, such as education, play, health, family life, and child care, but also, for example, the environment, public expenditure, transport, planning and the economy" (p.10).

‘The views of children are to be weighed according to age, maturity and experience’

According to UNICEF (2018), "It is not sufficient just to enable children to express their views: these views also must be given serious consideration" (p.10). The weight accounted to those views must take into consideration the age and maturity of the child, and their level of understanding. Lundy et al.(2011) further elaborates that due weight only applies if the child's perspective will improve the quality of the outcomes. Therefore it is not an unqualified right, but they are also entitled to receive guidance in forming a view. Appropriate recognition must be given to skilled professionals to ensure the best interests of the child. Views must be taken into consideration but not at the risk of undermining their other rights. UNCRC asserts there is no hierarchy of rights but Article 3 notes that ‘the best interests of the child must be a primary consideration’ in all actions concerning the child. Best interests normally refers to decisions made about children's welfare and safety. Lundy et al. (2011) warn that simply substituting a child's views for an adult's view whenever it deviates from the adult norm amounts to tokenism. Therefore if children's suggestions cannot be taken on board then this must be explained to them in a way they can understand.

The UNCRC Committee in its General Comment also welcomed Article 7 of UNCRPD which obliges State Parties "to ensure that disabled children are provided with the necessary assistance and equipment to enable them to freely express their views and for those views to be given due weight" (p.7).

The literature highlights that in addition to Article 12, other Articles contained within the UNCRC are connected to the participation of children. The Council of Europe (2012) note that Article 12 "is connected to all other articles of the convention and in particular to Article 2 (the right to non-discrimination), Article 3 (primary consideration of the best interests of the child), Article 5 (guidance by parents and evolving capacities of the child), Article 6 (the right to life, survival and development), Article 13 (the right to freedom of expression), Article 15 (the right to freedom of association) and Article 17 (the right to information)" (p. 4). UNICEF (2018) similarly states that participation needs to be understood to include “the wider civil rights embodied in the CRC – the rights to freedom of expression; to association; to thought, conscience and religion; to privacy; and to information (articles 13, 14, 15, and 17). These rights are preconditions for participation: the right to express views, have them taken seriously, and influence matters of concern to them” (p. 7).

In particular, **Article 13** on the freedom of expression states that “the child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice” (p.4). This article places an obligation on us all to develop and use a range of participation methods which enable the expression of disabled children and young people, including nonspeaking children and young people and those children and young people whose preferred means of communication are other than speech. The participation of disabled children and young people in consultations is a means of fulfilling their right to self-expression.

The UNCRC Committee also outlined principles of meaningful child and youth participation which are discussed under the same heading further down in this review.

Other obligations with regard to participation

While the UNCRPD and UNCRC are prominent instruments with regard to consultation with and participation of disabled children and young people, there are other relevant obligations, laws and policies which set out the basis for child and youth consultation and participation. The most relevant are set out below.

- **2030 Agenda for Sustainable Development**

The 2030 Agenda for Sustainable Development is a commitment adopted in 2015 by all UN Member States to end poverty in all its forms, reduce inequalities within and between countries and address climate change by 2030. UNCRPD General Comment 7 references Agenda 2030, stating “States parties should also consider the general principles of the Convention in all measures taken for its implementation and monitoring, and in advancing the 2030 Agenda for Sustainable Development and its goals" (UN, 2018, para. 9).

Agenda 2030 includes 17 **Sustainable Development Goals** (SDGs) (UN, 2015) with 169 targets and 232 indicators. All of the Goals within Agenda 2030 apply to persons with disabilities based upon the universality of each Goal and the guiding principle of Agenda 2030: Leave no one behind. However, thirteen SDGs make particular reference to persons with disabilities or 'vulnerable groups' including in relation to inclusion within 'follow-up and review' processes. Notably, SDG 16 'Peace, Justice and Accountable Institutions' includes two indicators in relation to inclusive representation and decision-making to be disaggregated by sex, age, and disability. The Preamble also recognises children and young people as "critical agents of change" (p.12). which emphasises the need for their inclusion within participation processes.

Unlike UNCRPD, the SDGs are not a legally binding instrument. Member States report on progress periodically through the Voluntary National Review (VNR) process at the UN High Level Political Forum (HLPF). The most recent review was in 2023 where Ireland reported on its progress based on the National Implementation Plan for Sustainable Development Goals (22-24).

- **European Youth Strategy 2018 – 2027**

The European Youth Strategy 2018 – 2027, under its guiding principle of 'Participation', states that all policies and activities concerning young people should uphold young people's right to participate in the development, implementation and follow-up of policies affecting them through the meaningful participation of young people and youth organisations. The Strategy states that special attention should be given to young people at risk of marginalisation based on discrimination, including young people with disabilities.

- **EU Strategy on the Rights of the Child and the European Child Guarantee**

Published by the European Commission in 2021, this strategy includes 'Child participation in political and democratic life' (p. 4) as its first thematic area. It protects the child's right to be heard, in line with Article 12 of UNCRC. Under this strategy, the

European Commission commits to establishing an EU Children's Participation Platform; to connect existing child participation mechanisms at local, national and EU level; to involve children in the decision-making processes at EU level; to develop and promote accessible, digitally inclusive and child friendly versions and formats of the Charter of Fundamental Rights and other key EU instruments; to develop and promote guidelines on the use of child friendly language in documents and in stakeholders' events and meetings with child participants; to include children within the Fundamental Rights Forum of the EU Agency for Fundamental Rights (FRA) and the Conference on the future of Europe; to conduct child-specific consultations for relevant future initiatives; and to strengthen expertise and practice on child participation among Commission staff and the staff of EU agencies, including on child protection policies and safeguarding policies.

- **Council of Europe Recommendation CM/Rec (2012)2 of the Committee of Ministers to Member States on the Participation of Children and Young People under the age of 18**

This recommendation was adopted by the Committee of Ministers of the Council of Europe on 28 March 2012. It sets out recommendations for Member States with regard to child and youth participation and recommends to the Council of Europe itself to include children and young people in standard-setting, co-operation and evaluation activities. The recommendation states that "listening to children and young people and giving due weight to their views in accordance with their age and maturity is necessary for the effective implementation of their right to have their best interests be a primary consideration in all matters affecting them and to be protected from violence, abuse, neglect and maltreatment" (p.5).

- **General Data Protection Regulation (GDPR)**

The General Data Protection Regulation 2016/679 (GDPR) is a regulation in EU law on data protection and privacy in the European Union and the European Economic Area. Although it is an EU regulation, it imposes obligations on organisations anywhere in the world if they target or collect data related to people in the EU. GDPR gives children the same data protection rights as adults, as well as including additional child-specific provisions. According to the Data Protection Commission (2019), under GDPR Article 12.1, information about data processing which is addressed to a child must be in clear, plain language which the child can understand. Article 8, also known as the ‘age of digital consent’, sets the age at which online service providers can take the child’s own consent to gather their personal data. In Ireland, this is age 16. If the child is under 16, consent must be given by a parent or person with parental responsibility for the child. As well as data protection, further considerations in relation to consent, assent and the inclusion of disabled children and young persons are discussed later in this review.

- **Better Outcomes Brighter Futures and Young Ireland Policy Frameworks**

At the national level, ‘Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020’ set out the priorities of the Government in relation to children and young people under the age of 25 and provided the overarching framework for developing and implementing policy and services. The Framework set out six goals for achieving five national outcomes. Fundamental to all five outcome areas is that children and young people have a voice in decisions that affect their lives. Its recently published successor ‘Young Ireland: The National Policy Framework for Children and Young People 2023-2028’ also has the participation of children and young people as a central theme.

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

Ireland was the first country in Europe to develop a National Strategy on Children and Young People’s Participation in Decision-Making. The strategy builds on the infrastructure for children’s participation established since the publication of the National Children’s Strategy in 2000. The goal of this strategy is to ensure that children and young people have a voice in their individual and collective everyday lives across the five national outcome areas set out in Better Outcomes, Brighter Futures (and its current successor Young Ireland). The strategy is primarily aimed at children and young people under the age of 18, but also embraces the voice of young people in the transition to adulthood. It is guided and influenced by the United Nations Convention on the Rights of the Child and the EU Charter of Fundamental Rights.

- **National Framework for Children and Young People's Participation in Decision-Making and Action Plan**

The National Framework for Children and Young People's Participation (2021) and the Children and Young People's Participation in Decision-Making Action Plan 2023-2028 aim to support Departments, agencies and organisations to improve their practice in terms of child and youth participation in line with the UNCRC and UNCRPD.

- **The Education for Persons with Special Needs Act 2004**

The Education for Persons with Special Needs Act (ESPEN, 2004) includes provision for children's participation in planning their education and transitions. However key parts of this Act containing this provision have not yet been commenced and therefore have no legal force. The EPSEN Act is currently under review (Department of Education, 2022).

- **Progressing Disability Services for Children and Young People**

Progressing Disability Services for Children and Young People Programme (PDS) is a change programme for the provision of therapeutic services for disabled children in Ireland. It is being rolled out nationally by the Health Service Executive. It includes the HSE (2013) 'Outcomes-Focused Performance Management and Accountability Framework'. This Framework includes an outcome around hearing the voice of children and young people in all matters affecting them.

- **Tusla Child and Youth Participation Strategy 2019-2023**

The Tusla Child and Youth Participation Strategy aims to ensure that the views of children and young people are taken into consideration in the decision-making process. The Strategy states that the participation of children and young people is fundamental to a child-centred, rights-based approach to working with children and young people. Tusla's 'Child and Youth Participation Toolkit' sets out how this can be implemented in practice.

- **HIQA National Standards for Residential Services for Children and Adults with Disabilities**

The Health Information and Quality Authority (HIQA) National Standards for Residential Services for Children and Adults with Disabilities sets out standards for good quality, safe residential services for adults and disabled children. Standard 1.6 requires that children participate in decision-making. Standard 2.1 outlines a requirement that a child's personal plan be developed with the maximum participation of the child.

- **The Assisted Decision-Making (Capacity) Act 2015** (and the Decision Support Service established with its commencement in 2023) is about maximising a person's capacity to make decisions. The act establishes a legal framework for supported decision-making. It allows people to make legal agreements on how they can be supported in decision-making, including co-decision-making, decision-making assistance, and decision-making representation. At the moment, the act only applies to people over 18. Parents or guardians remain the decision makers for children and young people under the age of 18 unless they are a ward of court.

Conclusion

This chapter outlined the legislative and policy context relevant to the participation of disabled children and young people in an Irish context. Relevant articles of the United Nations Convention on the Rights of the Child (UNCRC), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and other relevant obligations, laws and policies were reviewed. These included EU 2030 Sustainable Development Goals, European Youth Strategy, and provisions included in the European Child Guarantees and Council of Europe Recommendations as well as relevant provisions in the national policy. Participation of children and young people is central in the National Participation Strategy and Participation Framework as well as in the Children and Young People's Participation in Decision-Making Action Framework 2023-2028 and Young Ireland: The National Policy Framework for Children and Young People 2023-2028.

Chapter Two: Key Concepts and Definitions relevant to the participation of disabled children and young people

Introduction

This chapter outlines key concepts and definitions relevant to the participation of disabled children and young people. The importance of viewing participation as a tailored and situated activity, as opposed to a predetermined process, is emphasised throughout. There is an acknowledgment that disability is an evolving concept, and we outline the evolution of different models of disability, followed by a discussion on disability related language and terminology in literature. The chapter includes a discussion on adopting an intersectional approach to consultation which recognises how different forms of social, cultural, political and economic discrimination impact people with different identities. The intersectionality approach is complemented by an overview of the concept of universal design in which consultation mechanisms and processes are designed to be inclusive to the greatest extent possible to all people, regardless of their age, size, ability or disability.

Definition of children and young people

The UNCRC defines a child as anyone under the age of 18. In Ireland, under the Child Care Act (1991, currently under review) and the Children Act (2001), the definition of a child is the same.

Definitions of ‘youth’ vary more between national contexts and amongst global institutions. The United Nations (UN), for example, defines ‘youth’ as those aged 15 to 24 for statistical purposes, but also recognises the variance in definitions between national and regional contexts, and recognises that ‘youth’ should be understood not as an age bracket but as a stage of transition from dependence to independence (UN,1981). The European Commission (EC) in its Working Document on EU Indicators in the Field of Youth, similarly recognises that the definition varies from one Member State to another (EC, 2011). However, with regard to implementing the EU Youth Strategy, it states that its dashboard of indicators operates with three 5-year categories, covering the age-range 15-30. According to Ireland’s ‘Better Outcomes, Brighter Futures’, the definition of ‘youth’ includes those aged 10 to 24

(DCYA, 2015a). Thus, there is some overlap between the definitions of children and youth in Ireland, as is the case in many contexts.

Models of disability

In the context of participation, it is also necessary to understand the evolution of different models of disability.

The literature discusses two main models of disability - the medical model and the social model. According to the ISO/IEC (2014) guide 71, the earliest model was the medical model, which “described disabilities with reference to the medical conditions they were seen to arise from” (p. 39). Similarly, the NDA (2022) states that the medical model considers disability as a medical ‘problem’ and defines disability in terms of a person’s impairment that can be ‘cured’ by the intervention of medical science and techniques (p.3)

The social model arose in response to the medical model. According to Lang (2007) this model identified disability as a “socio-political construct”. According to the NDA (2022) this perspective gives rise to an emphasis on the ‘disabling barriers’ caused by economic and environmental factors and social attitudes that take no account of and make no provision for people with intellectual and physical disabilities. Similarly, ISO/IEC argues that this revolutionised the understanding of disability by arguing that it was not mainly caused by impairments but by the way society was organised and responded to people with disabilities. In the social model, disability is the product of the physical, organisational and attitudinal barriers present within society. UNICEF (2013) similarly outlines that the social model of disability focuses on the barriers created by the environment (rather than by impairment), including in physical, information and communication contexts, the attitudes and prejudices of society, policies and practices of governments, and the often exclusionary structures of health, welfare, education and other systems. Through this lens, disability is seen as a social construct, rather than an attribute of an individual. Lang (2007) adds that “in focusing upon the manner in which disability is socially produced, the social model gives precedence to the importance of politics, empowerment, citizenship and choice” (p.3).

The social model is widely acknowledged to have played a significant role in shaping the UNCRPD. This is reflected in the preamble of the CRPD which states:

“Recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (p.3).

According to ISO/IEC, the social model informed the development of the human rights model of disability, which “typically expresses a moral and political commitment that countries, states and organizations should take in regard to persons with disabilities” (p.39). According to research commissioned by the Office of the Ombudsman for Children (Moloney et al., 2021), the human rights model of disability builds on the social model, going beyond anti-discrimination law and embracing a vast array of ‘indivisible and interdependent’ civil, political and economic, social and cultural rights (p.2). UNICEF (2013) similarly states that a human rights-based approach recognises people with disabilities as key actors, instead of passive recipients of benefits. It acknowledges the systematic exclusion of people with disabilities and seeks to address these gaps.

Language and Terminology

The language used regarding disability is constantly evolving and may differ according to variables such as national context or personal preferences. The literature suggests that there is no universally agreed or international consensus on terminology.

A paper by Lawson and Beckett (2021) suggests that the evolution from a medical model to a social model approach has taken place alongside a shift from person-centred to identity-first language with regard to disability. They outline that “use of the terminology of ‘people with disabilities’ as opposed to ‘disabled people’ is advanced by proponents of ‘people first’ language, according to which reference to the person should be situated before reference to their (perceived) functional limitations” (p.353). By contrast, on the basis of the social model of disability, “the term ‘disabled people’ refers to people experiencing a particular type of oppression or disadvantage” (p.353). Lawson and Beckett (2021) further state that while the content of the UNCRPD is widely accepted as reflecting a social model, its use of the term ‘persons with disabilities’ is not.

In Ireland, Government Departments and public bodies tend to use person-centred language (see for example the National Disability Inclusion Strategy 2017-2021[1]). By contrast, identity-first language tends to be preferred by Irish DPOs. Irish autism DPO, AsIAm, in its 2019 ‘Understanding Autism Handbook for Public Servants’ states that “Many within the autism community prefer to use identity-first terms when talking about themselves [...] That is to say, they might refer to themselves as ‘I am autistic’ instead of ‘I have,’ or ‘I'm living with autism’” (AsIAm, 2019). Other DPOs in Ireland similarly use identity-first language. For example, in the press release for its 2021 campaign, ‘Disability Isn’t a Dirty Word’, Disabled Women Ireland (DWI) states “Language can often be a difficult thing to grapple with. The best way of learning is to listen to us, join us and use the word we use to describe ourselves, that word is disabled. The discomfort that persists around the word stems from some very outdated ideas about disability” (DWI, 2021, n.d.). Similarly, Voice of Vision Impairment (VVI) states on its website, “The recognition of the Social Model means that DPOs are likely to prefer the term ‘disabled people’ in recognition that we are disabled by society rather than our impairments” (VVI, n.d.).

Mostafa (2021) in the guidelines for autism-friendly universities developed for Dublin City University (DCU) states that the guidelines use identity-first language (e.g. the term autistic individual/person/people) to describe individuals from the autism community. The guideline states that “this is based on current literature and preferences of autism self-advocacy and autistic individuals I work with around the world as communicated to me through our work together” (p.8). On the other hand, in a UK survey, Kenny et al. (2016) found that the terms ‘autism’ and ‘on the spectrum’ were most favourable, however the term ‘autistic’ was mostly favoured by autistic adults while person ‘with autism’ was adopted more so with professionals. The authors concluded there is no universally accepted way to describe autism.

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[1] At the time of writing this literature review, the NDIS has expired and work is underway to develop the next National Disability Strategy. Engagement with relevant DPOs will inform the language used in the new strategy.

Identity-first language is used widely in the UK by DPOs, civil society, Government and public bodies. Disability Rights UK, for example, states that the term ‘people with disabilities’ implies that disability is something caused by the individual, rather than society. It states that the term ‘disabled people’ is used instead to describe “people with impairments who are disabled by barriers constructed by society” (Disability Rights UK, 2022). The Disability Unit within the UK Cabinet Office with responsibility for coordinating UK disability policy also employs identity-first language, for example in its National Strategy for Disabled People.

There is however also an acknowledgement in the literature that some individuals may have different preferences in terms of language. Mostafa (2021) remarks that “there are alternative and equally valid terminologies that may also be preferred by some individuals and groups – such as ‘individuals with autism’ and ‘individuals on the autism spectrum” (p 8). Similarly, Disability Rights UK acknowledges that some individuals do not relate to the term ‘disabled person’ and therefore it is “essential that organisations also engage in regular conversations with disabled people to find out an individual’s preference around disability and the use of language” (Disability Rights UK, 2022).

In Ireland, the National Disability Authority (NDA) consulted with disabled persons and has published guidance on the use of disability language and terminology (2022). While identity first was the term preferred by most, stakeholders with an intellectual disability preferred person- first language. It was noted that some disabled persons with disabilities do not identify with either term (NDA, 2022). Key recommendations from the report advise to take a contextualised and flexible approach, to ask people’s preferences and to avoid stereotypes, euphemisms, medicalised and negative language. Identity first language is used in this review with person first used in relation to the UNCRPD.

In addition, terms like high or low functioning are avoided (As I Am, 2019) as are references to levels of severity or service user (NDA, 2022). For those who do not use speech, people who do not rely on speech to communicate or nonspeaking tend to be preferred (Inclusion Ireland 2023) and the term non-verbal is avoided (Donaldson et al., 2023). Phrases such as ways of understanding and communicating are used for this review instead of terms like impairment or difficulties.

Intersectionality

Intersectionality is a concept used to describe how different social identities (e.g. gender, race, class) can overlap or ‘intersect’, compounding an individual’s experience of discrimination. The importance of taking an intersectional approach with regard to participation is set out under UNCRPD General Comment 7 which instructs State Parties to:

“Guarantee and support the participation of persons with disabilities through organizations of persons with disabilities, reflecting a wide diversity of backgrounds, including birth and health status, age, race, sex, language, national, ethnic, indigenous or social origin, sexual orientation and gender identity, intersex variation, religious and political affiliation, migrant status, impairment groups or other status.” (UNCRPD, 2018, para.94g).

Issues concerning the rights of women with disabilities and disabled children specifically are also identified under Article 6 and 7 of the Convention. The Committee on the Rights of Persons with Disabilities in its General Comment No. 3 offers a framework within which to address the rights of women and girls with disabilities.

According to Adams (2020), taking an intersectional approach to consultation means recognising how different forms of social, cultural, political and economic discrimination impact people with different identities (such as class, race, gender, disability, ethnicity, religion, age and sexual preference). She states that it requires looking at the needs and issues of the most disadvantaged groups in order to tackle discrimination and equality.

Similarly, Irish Human Rights and Equality Commission (IHREC) guidance (IHREC, 2019) on taking a consultative approach to assessing the Public Sector Duty sets out the importance of engaging with groups across the nine equality grounds (gender, marital status, family status, age, disability, sexual orientation, race, religion, and membership of the Traveller community). This provides another useful framework within which to apply the concept of intersectionality.

Universal Design

The definition of Universal Design is set out under the **2005 Disability Act** as

> the design and composition of an environment so that it may be accessed, understood and used to the greatest practicable extent, in the most independent and natural manner possible, in the widest possible range of situations, and without the need for adaptation, modification, assistive devices or specialised solutions, by persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability, and means, in relation to electronic systems, any electronics-based process of creating products, services or systems so that they may be used by any person (Government of Ireland, 2005, para. 52).

According to the ISO/IEC (2014) Design Guide 71, the concept of universal design goes “beyond concepts such as barrier-free design, by removing differentiations between persons with and without disabilities and including all persons as potential users within a diverse population. It is the intent of these concepts that ‘mainstream’ systems be usable by as many persons as possible (although this does not mean that all users can be expected to use a system in the same manner)” (p.40).

Mainstream consultation processes should be accessible for all while persons with disabilities may also engage in disability-specific consultations (NDA, 2022). The concept of universal design is important in terms of understanding how consultation mechanisms and processes must be designed to be inclusive to the greatest extent possible to all people which complements an intersectional approach.

Augmentative and Alternative Communication (AAC)

Inclusive methods will involve further understanding of a range of methods used to communicate. Communication barriers limit the participation of people with disabilities. Culturally there is a tendency to overvalue speech above other methods (De Haas et al., 2022). Augmentative and alternative communication (AAC) are a range of tools and strategies to either enhance a person's speech or to provide an alternative to it. Augmentative means to add to a person’s speech while alternative means to be used instead of speech. It can include any form of communication used with or instead of oral speech. This includes the use of eyes, facial expression, gesture, Lámh signs, symbols, communication boards or books and technology-based systems such as voice output communication aids.

Some users of AAC may use more than one type of communication and all ways of communicating should be valued, accepted and supported equally (Mansell & Beadle Brown, 2012). It is important that people respect the child's preference on a particular day at that particular time. All ways of communicating should be valued and supported equally. AAC has been shown to increase participation for people with disabilities (McNaughton et al., 2019), however, further awareness, acceptance and support in wider society is needed (Inclusion Ireland, 2022).

Further information on this is available in Appendix 1 at the end of this review.

Conclusion

This chapter outlined key concepts and definitions relevant to the participation of disabled children and young people. We emphasised the importance of viewing participation as a tailored and situated activity, as opposed to a predetermined process. The evolution of different models of disability was outlined, followed by a discussion on disability related language and terminology associated with the evolving concept of disability. This chapter included also a discussion on adopting an intersectional approach to consultation which recognises how different forms of social, cultural, political and economic discrimination impact people with different identities. The chapter concludes with an overview of the concept of universal design in which consultation mechanisms and processes are designed to be inclusive to the greatest extent possible to all people, regardless of their age, size, ability or disability, and a brief outline of AAC and its key role in enabling this inclusivity. The following chapter will discuss the definitions and key principles of effective child and youth participation.

Chapter Three: What is child and youth participation?

Introduction

This chapter conceptualises child and youth participation as an ongoing process by which children and young people have active involvement and real influence in decision-making on matters affecting their lives. Nine basic requirements for meaningful participation as identified by the UNCRC are outlined and discussed in relation to what they mean in practice for inclusive consultations. The chapter includes a description of the Lundy Model of Participation (2007) and its four elements of Space, Voice, Audience and Influence. It concludes with a review of the contexts for child and youth participation, and a discussion on the concept of decision-making capacity.

Definition of child and youth participation

According to Kennan et al. (2021), the UNCRC Committee describes participation 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 (UN Committee on the Rights of the Child 2009: 5)".

According to Kelleher et al. (2014) understanding child and youth participation requires a shift in perception from young people as 'mere recipients of adult protection' to 'protagonists in the exercise of rights – as active agents in their own lives' (United Nations, 2004, p.272). They note that the concept of young people's participation recognises the unique perspectives and expertise of young people and acknowledges that they have an essential contribution to make. Across the literature reviewed by Kelleher et al. (Checkoway 2011; Couch & Francis, 2006; Council of Europe, 2008; Save the Children, 2005; United Nations, 2004), participation is defined from this perspective as the process by which young people have active involvement and real influence in decision-making on matters affecting their lives, both directly and indirectly. Kelleher et al. (2014) also highlight that young people can be involved in making decisions at national, local, organisational and global levels and may participate in shaping policy, in the development and provision of services, in research, in communities, and in decisions affecting them personally (National Children's Office et al., 2005; McNeish & Newman, 2002).

According to UNICEF (2018), child and youth participation must be recognised as different from adult participation. Depending on their age, children and young people may lack full legal independence. Participation is not synonymous with autonomy and often benefits from the support and facilitation of adults. Adults will have differing levels of involvement with respect to the concept of 'evolving capacities' of children and young people, depending on the age, competencies and the context in which participation takes place. Adults, in supporting and facilitating child and youth participation, must promote the best interests of the children and young people involved. UNICEF (2013) also highlights that participation can be an end in itself or a means by which other objectives are achieved.

In the Irish context, the National Strategy on Children and Young People's Participation in Decision-Making defines participation as 'the process by which children and young people have active involvement and real influence in decision-making on matters affecting their lives, both directly and indirectly' (DCYA, 2015, p.20). This definition is compliant with Article 12(1) of the UNCRC and Article 7(3) of the UNCRPD.

Principles of meaningful participation of children and young people

Nine basic requirements for meaningful participation have been identified by the UN Committee on the Rights of the Child. Many organisations, entities and governments reference these principles in their approaches. See for example, World Vision (2007), Council of Europe (2012), and Government of Ireland (2021).

UNICEF (2013; 2018) analyses what each of these requirements set out by the UNCRC Committee means in practice.

1. **The process must be transparent and informative.**

In practice this means that children must receive accessible, age-appropriate information about their rights to express their view. They need to be informed about how the participation will take place, the scope, purpose and potential impact. The participation must have a clear purpose, roles and responsibilities are well understood, and children should agree with the goals and targets regarding their participation. All information at all stages of participation needs to be accessible and differentiated for the participants’ unique cognitive, communication, sensory and physical requirements. This may include visuals, symbols, tactile objects, simplified or signed language, and/or audio and technology (examples of these include digitally drawn illustrations of the consultation process or information in the form of a video/animation, or a social story). Visualisation and contextualisation of all information are especially important to enable meaningful participation of disabled children and young people, and time for preparation and/or adaptation of consultation materials into appropriate and accessible communication methods must be factored into planning.

2. The process must be voluntary

In practice this means that children are given time to consider their involvement. They must be able to provide informed consent, and it should be clear that they can withdraw at any time. Specific consent and assent considerations in relation to participation of disabled children and young people are outlined in Appendix 2. Their other commitments (such as work and school) should be respected and accommodated. Children must never be coerced into sharing their views and their choice in relation to participation and participation methods should be respected. Choice is key in participation of disabled children and young people (Franklin & Sloper, 2009). It is also important to find out what space is the preferred space for the child to engage in consultation. This space may be their home (for example, McNeilly et al. (2015) interviewed children in their homes) or their school, or it may be a virtual space. Children and young people should also be enabled to make choices throughout the consultation process (for example, through being given a choice of consultation/expression methods). McNeilly et al. (2021) remind us to be prepared to walk away from the consultation with little or no data (despite preparations) if a child or young person is not willing to participate on a particular day.

3. The process must be respectful

In practice this means that children are able to freely express their views and be treated with respect; if there is a selection process, it should be based on principles of democracy and involve children themselves in the selection processes. Disabled children should be afforded the same respect as all children. Facilitators should speak directly to the child and not to an interpreter or caregiver. Children must be able to choose how they want to express themselves. The approaches used should build self-esteem and confidence and enable children to feel that they have views to contribute. Some children and young people may have a known adult and/or interpreter as a communication partner present with them during the consultation. This may be a parent/guardian or a primary support or education professional who will support interpreting a child's responses during the consultation process. If a child is consulted in the presence of their parents/support professional, it is important to continue to engage directly with the child. Goodwin and Edward (2017) list the responsibilities of a communication partner as a) to gain an understanding of how the person already communicates, b) to communicate with people using methods that they understand, and c) to effectively enable a person’s existing communication methods. All of these are crucial in enabling respectful communication.

4. The process must be relevant

In practice this means that the issues under discussion that children are involved in are relevant to children’s lives and allow them to draw on their experiences, knowledge and abilities. Relevant participation for disabled children and young people also means that the benefits of the consultation for the participants (for example, in terms of self-esteem, confidence, social skills, and enjoyment) outweigh the demands the consultation may place on them (Raman & French, 2021). The UNCRC states that best interest must be 'a primary consideration' in all actions concerning the child and that the best interests of the child should always supersede their right to participate and any other right within the UNCRC. General comment 14-UNCRC expands the concept of best interests and states that the child's best interest is a threefold concept as follows:

- A substantive right: The right of the child to have their best interests assessed and taken as a primary consideration when different interests are being considered in order to reach a decision on the issue.
- A fundamental, interpretative legal principle: If a legal provision is open to more than one interpretation, the interpretation which most effectively serves the child’s best interests should be chosen.

•A rule of procedure: Whenever a decision is to be made that will affect a specific child, an identified group of children or children in general, the decision-making process must include an evaluation of the possible impact (positive or negative) of the decision on the child or children concerned.

5. The process must be child-friendly

In practice this means that the environment and methods of working must be child-friendly and approaches must be adapted to children's capacities. Meeting places must be child-friendly and accessible to disabled children and other minority groups. Children must be given accessible information in child-friendly formats. Children will need time and resources in order to prepare and feel confident to express their views, therefore adequate time and resources must be available to support children effectively. Methods should be developed in partnership with children. Trust is critical for creation of safe emotional space for children. The adults' manner of engagement including their body language, the clarity of their speech, and the manner and tone of their voice all matter in the consultation process. The nonverbal communication of adults is very important for many disabled children and young people (McNeilly et al., 2021).

6. The process must be inclusive

In practice this means that children are not discriminated against on any grounds, and efforts are made to include children from all backgrounds, recognising that disabled children are not a homogenous group. Some children experience multiple layers of discrimination – for example, girls with disabilities. Some groups of disabled children are more excluded than others – for example children with intellectual disabilities. Participation should be flexible enough to respond to the needs of different groups of children and the age range, gender and abilities of children are taken into account. Some disabled children and young people may use a range of methods to communicate. All ways to communicate whether intentional or not should be valued equally (Goodwin & Edwards, 2017). Some disabled children and young people may use some methods sometimes. It is important to be flexible and allow disabled children and young people to use a range of methods when communicating as this is the most meaningful for them. The involve me project (MENCAP, 2011) provides eight key messages to involve persons with profound and multiple learning disabilities (PMLD). These include: knowing the person really well, taking lots of time including spending time with people with PMLD, avoiding making assumptions, being responsive to the person, exploring creative and new ideas of involvement, learning from what the person “tells” you, acting on the learning, and helping the person to recall and share things about their lives.

7. The process must be supported by training

In practice this means that adults working with children are provided with appropriate training and tools, and are effectively supported. Training may be especially important in relation to understanding multiple means of communication, in particular the use of alternative and augmentative communication (AAC). Inclusion Ireland’s (2022) report on AAC noted that training for families, professionals as well as the wider community in this area is lacking in Ireland. Taking time to get to know the child or young person using AAC, engaging with the child or young person while they use AAC, and becoming familiar with how communication is shared are very important (Communication Matters, 2015).

8. The process must be safe and sensitive to risk

In practice this means that safeguards are put in place to minimise risks and prevent abuse, and keep children safe from harm as a result of expressing their views. Children should be made aware of their right to be safe from abuse and know where to go for help if needed. A formal complaints procedure should be set up for children and children should know how to access it. Consent must be obtained for the use of all information provided by children, and information identified as confidential must be safeguarded. Consent and assent considerations for consultations with disabled children and young people, including those children and young people who do not use speech as their communication method are included in Appendix 2. Safety considerations must also include considerations of physical safety, including mobility and physical accessibility barriers. Potential ambient and visual distractions should be minimised and unsafe items should be removed from the consultation venue. The consultation environment must be comfortable for the child and must not act as a barrier to engagement and expression. Lighting and noise levels should be considered with consideration of each individual child and young person’s unique sensory preferences.

9. The process must be accountable

In practice this means that there must be a commitment to follow-up and evaluation. Children, including disabled children, should be supported to participate in follow-up and evaluation processes. Staff and partners are accountable to children for their commitments. Children must be informed about how their views have been interpreted and used and to be able to challenge the analysis. They should be given feedback on the impact, outcomes and next steps as a result of their participation. Lessons learned through the evaluation should be used to improve participatory processes in the future. Similarly to the consultation itself, the evaluation of participation should also use a multi-method, multi-vocal approach, with visual supports and artefacts to support reflection and individual and collective feedback (Raman & French, 2021). Children and young people should then be ideally provided with an accessible, permanent record of the consultation that they can refer to and view as an achievement (Franklin & Sloper, 2009). The empowerment of disabled children and young people and the benefits of the consultation for them (in terms of self-esteem, confidence, social skills, and enjoyment) should be considered in the evaluation.

Models of child and youth participation

There are many different models of child and youth participation. Perhaps the earliest model is Hart's Ladder of Participation (1992), which builds on a general model of participation developed by Sherry Arnstein in 1969. The Ladder of Participation includes eight steps along a spectrum of participation, with the steps higher on the ladder representing more meaningful engagement. The first three steps, manipulation, decoration and tokenism, are considered not to represent a meaningful engagement. The highest step is one in which the young people initiate the idea and invite adults to join in, sharing decision-making. Other models include Treseder's Degrees of Participation (1997); Shier's Pathways to Participation (2001); Kirby et al.'s Model of Participation (2003); and Lundy Model of Participation (2007).

The **Lundy Model of Participation (2007)** was developed to support practitioners to implement Article 12 of the UNCRC and is the model used to underpin Ireland's National Strategy on Children and Young People's Participation in Decision-Making

(2015), and the National Framework for Children and Young People's Participation in Decision-Making (2021) and its associated Action Plan (2023), and is the approach recommended by UNICEF (2018). It is a rights-based model which contains four interrelated elements following a chronological order. These four elements are **Space, Voice, Audience and Influence**. Kennan et al. (2019) describes the meaning behind these four elements. **'Space'** refers to the idea that children must be provided with the opportunity to express a view in a space that is safe and inclusive. Creating space "involves actively creating the opportunity for children and young people to communicate their views in a space that is safe from 'fear of rebuke and reprisal'" (p. 210). **'Voice'** means that children must be facilitated to express their view. The concept of **'Audience'** requires going beyond 'Voice', meaning children "must be guaranteed an opportunity to communicate their views to an individual or body with the responsibility to make decisions" (p. 213). Put simply, this means that their views must be listened to. Finally, **'Influence'** means going beyond just listening to children's views and allowing those views to have influence, as appropriate. The use of the term influence in the Lundy Model encapsulates the concept of 'due weight' as expressed in Article 12 of the UNCRC.

Context of child and youth participation

Individual and Collective Decisions

The literature distinguishes between individual or personal participation/decisions and collective or public participation/decisions.

Ireland's National Framework for Children and Young People's Participation (DCEDIY, 2021) describes individual decisions made by children and young people as those pertaining to the health, education or social care they receive. Collective decisions, on the other hand, refer to those decisions which affect children and young people as a group, for example in settings such as schools, youth clubs, or the development of national legislation and policies.

Similarly, Kelleher et al. (2014) describe personal participation as those decisions which are about young people as individuals, such as in judicial proceedings and medical interventions. Public participation, on the other hand, is described as decisions about the collective interests of young people as a group, or decisions affecting the wider population. The authors note that personal and public participation do not occur in isolation from each other and that in fact, research has shown that through increased decision-making in the personal context, young people can develop the skills, understanding and motivation to participate in wider decision-making processes. In addition, they note that personal participation may be a greater priority than public participation for some children and young people at a particular point in time.

Decision-making capacity

Capacity is one’s ability to understand when a decision is being made and the nature and consequences of the decision in the context of the available choices. Under the Assisted Decision-Making Capacity Act (2015) one is always presumed to have capacity. However, the legislation sets out a functional test for the assessment of capacity. This means that a person's ability to make a decision is assessed based on the decision that has to be made at that time. One, however, does not lose the capacity to make decisions in general. The test for capacity recognises that the capacity can change over time, meaning one might need more or less support in the future. It should be noted that at present this act is specific for those over the age of 18. Inclusion Ireland (2016) state that a person can be said to lack capacity to make a decision if they are not able to understand the information relevant to the decision, retain that information long enough to make a voluntary choice, use or weigh that information as part of the process of making the decision, communicate his or her decision in whatever way they communicate. Further considerations, especially in relation to obtaining assent and consent from children and young people who may be seen to lack capacity for this are included in Appendix 2.

Formal and informal participation

The literature highlights the difference between formal and informal structures and methods of participation. Formal structures (e.g. Youth Advisory Group, Youth Council, consultation processes) tend to be emphasised or favoured (Kelleher et al. 2014; UNICEF 2013; DCYA 2014). DCYA (2014) highlights that ‘participation’ tends to be interpreted as the involvement of children and young people through a structured and formalised mechanism, such as an Advisory Group, but that these structures can deter ‘seldom-heard’ children, which includes disabled children.

Children can be deterred for a number of reasons including unfamiliarity with these processes, lack of confidence, and the tendency for these groups to become dominated by confident and articulate children and young people.

The role of informal participatory activities is increasingly recognised as a platform for participation for seldom-heard young people. Kelleher et al. (2014) outlines that informal participation mechanisms are usually unstructured, short-term, and not executed through a formal policy. DCYA (2014) similarly advise that informal participation can be less intimidating and may attract seldom-heard children to participate. These might include casual chats between service providers and children, social activities, specific project involvement with a clear goal, e.g. painting the local library, online tools such as discussion forums, social networking sites and polling, or a one-off consultation on a particular issue of relevance to them. It has long been recognised that more informal approaches to consultation may be more appropriate for disabled children and young people (Franklin & Sloper, 2009). Informal, activity-based consultations involve concrete and engaging activities that the children can participate in, including outings or arts and crafts activities, for example, making collages and/or co-creating various artefacts (incl., apps or games). Most children and young people would often discuss the most relevant issues while doing something else (McNeilly et al., 2021). However, UNICEF (2013) also highlighted that even informal, individual and everyday opportunities are routinely denied to disabled children.

The literature also highlights that it is possible to combine the structure of formal approach with the use of informal methods. For example, Kelleher et al. (2014) advise that while formal participation structures such as a Youth Council may be daunting for some young people, the use of informal and creative methods within it can create a more inviting environment for young people to participate. Creative approaches can be used to both present a consultation topic and/or as a tool for the participants to share their perspectives and experiences. For example, Raman and French (2021) used tangible artefacts (i.e., play wooden characters) and visual tools to support the participants to discuss their social network and storytelling and scenarios (incl. comic strips with blank speech bubbles) to support the participants to discuss online safety. Creative props and play items can enable conversions and help to structure the activities with disabled children and young people in both formal and informal consultations.

Kelleher et al. (2014) highlight that informal initiatives may offer participation opportunities to ‘non-organised’ young people and those who are not ‘reached’ even when targeted measures are used. DCYA (2014) further highlight that informal processes can be used as ‘a stepping stone’ towards inclusion within a more formal process. Their guidance shows that informal methods can be effectively used within a structured, formal process, or indeed alongside such a process. For example, originally designed to facilitate expression of children younger than five years of age, the Mosaic approach (Clark & Moss, 2001), as the name suggests, combines a range of formal and informal approaches to elicit children’s views and so is in essence a multi-method of elicitation. For example, taking photographs (photovoice), child-led concrete activities (e.g., outings), map making, combined with observations and interviews may all form the basis of conversations with children in a mosaic approach. The Mosaic approach can involve some of the methods and tools that will be described later on this review.

Levels of participation in terms of shared power

Researchers increasingly recognise the need to empower researched and ‘consulted’ communities through meaningful co-creation and co-design (Fraser-Barbour, 2023; Maenhout et al., 2023; Ward & Gormley, under review). Co-creation means developing something new together with other people. In participation, this broad term often means working together with children and young people in creating or improving the planned participation experience by making it more acceptable and contextually appropriate.

Maenhout and colleagues (2023) exemplified this approach by co-creating a physical activity intervention with adolescents with intellectual disabilities. They emphasised that several key factors bolstered the co-creation process: the presence of relevant staff members, establishment of trust and rapport, understanding and responding to group dynamics, and utilisation of methods tailored to the target group of adolescents (such as visual aids, using concrete examples, development of communication tools in collaboration with the co-creators, and keeping language simple and concise). Giving the co-creators autonomy and ownership to steer the process ensured the interventions aligned with the needs and preferences of these adolescents. Additionally, they underscored the significance of certain traits in the co-creator researcher: openness, enthusiasm, patience and flexibility.

Within co-creation, co-design is a more specific term that refers to involving children and young people in designing something. It is important that disabled children and young people are involved in developing the format and methods of participation initiatives from early stages of planning. Co-creation and co-design in disability research and participation processes are essential components of ethical and respectful work that is grounded in human rights (Fraser-Barbour, 2023).

The literature commonly highlights three levels of child and youth participation in terms of shared decision-making power: consultative, collaborative or child-led (UNICEF 2013, 2018; Kelleher et al. 2014; DCEDIY 2021). Consultative approaches are characterised by being adult-led, in which the views of the child or young person are sought and children do not have control over the outcomes. Although adult-led, this approach does recognise that children have expertise and experience to contribute to decision-making. Collaborative processes are also adult-initiated, but empower children and young people to influence the process and outcome and take a partnership approach with children. Child and youth-led initiatives are characterised by children and young people identifying the issue of concern and controlling the process, with adults acting as facilitators and providers of information and advice rather than leaders.

DCEDIY (2021) highlights that these ways of participating should not be perceived as a hierarchy. Different modes may be appropriate in different contexts, and in practice, many child/youth participation projects or programmes use all three modes of participation. For example, “it may begin with adults consulting young people, after which adults and young people work on some aspects together and young people lead on other aspects on their own” (p.16). Kelleher et al. (2014) similarly state that different approaches may be suitable depending on the group or the decision being made and that no one approach is superior to another. At all stages, it is important to focus on co-creating with children and young people, using tailored methods to nurture their creativity and engagement in decision-making (Raman & French, 2021).

Franklin and Sloper (2009) suggest that a more helpful model for understanding participation of disabled children is to view participation as a continuum depending on the type of activity and the children participating. For example, the levels may include being informed, expressing a view, influencing the decision-making process and being the main decider. The view of participation as a process also underpins the National Participation Framework (DCYA, 2021) and its successor the Children and Young People's Participation in Decision-Making Action Framework 2023-2028. Franklin and Sloper (2009) state that for children with intellectual disabilities for example, the level of participation they can engage in may be choosing between two options. They argue that this should still be considered valid participation and that for some children this might be a starting point on which to build on.

Similarly, Kelleher et al. (2014) state that attuning approaches to the needs and circumstances of the young people is of utmost importance and note that the UNCRC states that as children and young people gain confidence, skills and abilities, they may be able to exert more control in the decision-making process. Overall, participation methods need to be adapted and tailored to the preferences of each individual child. There is no single method that will 'work' with all children (Knight et al., 2006), however, for disabled children and young people often tangible and visual formats of the consultation are the most effective. Often a combination of participation methods may be needed to achieve meaningful participation (McNeilly et al., 2021).

Conclusion

This chapter defined child and youth participation as an ongoing process by which children and young people have active involvement and real influence in decision-making on matters affecting their lives. The UNCRC basic requirements for meaningful participation were outlined and discussed in relation to what they mean in practice for inclusive consultations. These requirements state that the process must be transparent and informative, voluntary, respectful, relevant, child-friendly, inclusive, accountable, safe and sensitive to risk, and supported by training. We acknowledged different models of child and youth participation, and described one of these models, namely the Lundy Model of Participation with its four interrelated elements of Space, Voice, Audience and Influence. This chapter also provided a review of diverse contexts for child and youth participation, including individual or personal participation/decision-making and collective or public participation/decision-making, formal and informal participation, and collaborative approaches to participation. We defined the concept of decision-making capacity as one's ability to understand when a decision is being made and the nature and consequences of the decision in the context of the available choices. Concluding this chapter, we restated key principles of effective child and youth participation.

Chapter Four: Benefits of participation of disabled children and young people

Introduction

This chapter focuses on the benefits of participation. We outline both individual and collective benefits of participation. At an individual level, we discuss why it is important to include disabled children and young people in decision-making, and how different participation methods can empower children and young people. At a collective level, we outline the benefits of participation for organisations and public policy development, and discuss how participation contributes to more appropriate services, and society as a whole.

Why it is important to include disabled children and young people

The literature highlights that participation is particularly important for disabled children and young people compared to those without disabilities for a number of reasons.

UNICEF (2013) highlights that disabled children are subject to much greater adult intervention, which limits their scope for making day-to-day choices themselves. They may also face a high number of medical interventions compared to other children in which they are denied involvement in decision-making. Furthermore, they are more likely to be reliant on multiple caregivers who may not be trained to understand their communication needs. Their dependency can result in greater vulnerability than children without disabilities. Similarly, Mitchell et. al (2009) found in their review of the literature that disabled children are subject to more assessments and medical interventions than other children and experience more surveillance over their lives, meaning it is even more important that they be consulted. More recently there has been increased recognition of the importance of not just consultation but co-creation in healthcare (Maenhout et al., 2023).

Individual benefits

The literature outlines both individual and collective benefits for children and young people who participate in decision-making. At the individual level, UNICEF (2013) outlines that involvement can contribute to a child or young person's personal development, allowing them to develop skills, expand their aspirations and gain confidence. UNICEF (2018) in its guidance to include children in the work of National Human Rights Institutions similarly states that participation offers children an opportunity to develop their capacities and may also contribute to enhanced protection for children in that creating a culture of listening will empower children to seek help if they are being abused.

Franklin and Sloper (2009) interviewed a small number of disabled children involved in participation activities related to service development and found that the reported benefits from their perspective included that they enjoyed talking and being listened to, taking part in fun and creative activities, and socialising with others.

The Department of Children and Youth Affairs (2014) in its guidance for including seldom-heard children and young people in decision-making also identifies the individual benefits to children and young people including the chance to have their voice heard, opportunities to build confidence, experiencing a feeling of belonging, developing their skills and knowledge, and being able to contribute to more relevant decisions being made.

Overall, shared decision-making, especially when using arts-based participatory methods, can draw out young people's strengths, resilience and optimism. It empowers young people, develops their creative skills, and builds their sense of self, identity and self-esteem (Nathan et al., 2023). Nathan et al. (2023) note that arts-based participatory methods can also have direct therapeutic benefits which may be especially important for children and young people with complex psychosocial profiles.

Collective benefits

The literature also highlights the collective benefits of the participation of disabled children and young people. This includes, for example, the benefits to organisations, to public policy development, and to society as a whole.

Participation can be a means by which children realise their other rights. For example, Moloney et al. (2021) states that the participation of children as rights holders through an accessible society, and equality and non-discrimination are pre-conditions to children exercising all their other rights. Hart (2008) similarly argued that participation by children is not only a right in itself but also a vital means to the realisation of children’s other rights. UNICEF (2013) states that the participation of disabled children can contribute to social transformation. “Disabled children have unique insights, knowledge, and perspectives into their own lives and engaging them in participation initiatives can harness their experiences of barriers they face in society, e.g. those which impede inclusive learning in schools or accessibility within the community, in order to make improvements” (pp. 9-10). Furthermore, UNICEF (2013) outlines that creating opportunities for disabled children to be heard is vital to improving practices regarding adoption, placement in care, juvenile justice, health care or monitoring standards of care in institutions. UNICEF (2013) also states that “participation promotes active citizenship and that disabled children, alongside other children, can contribute to the creation of peaceful and democratic societies which are respectful of human rights. Including disabled children can also strengthen accountability” (p.10). Cavet and Sloper (2004) found some evidence, although from very small scale studies, that consultation with disabled children can result in more appropriate services.

The Involve Me Project (2011) supported by MENCAP in the UK developed practical ways to support the involvement of persons with profound and multiple learning disabilities (PMLD). This included everyday life and regular daily choices, their own support and services, community involvement and national policy and planning. The impact of the project led to persons with PMLD directly and indirectly having greater influence on services and policy. There was greater job satisfaction for staff and greater enthusiasm toward decision-making activities with persons with PMLD.

Families valued working with staff and the opportunity for staff to see their family members as they did. As a result of being involved in the project the services invested in more resources for communication and placed a greater emphasis on including persons with PMLD in decision-making (MENCAP, 2011).

DCYA (2014) states that the participation of seldom-heard children, including disabled children, benefits organisations by bringing in new ideas and perspectives, ensuring the organisation is responsive to the needs of children and young people. In addition, the inclusion of children and young people in decision-making increases their commitment to new programmes, policies or services, reduces costs and time, and increases credibility. Furthermore, it benefits society by promoting inclusive societies, developing social responsibility among young people, and creating opportunities for improved relationships between adults and children.

Conclusion

This chapter outlined the benefits of participation. The literature highlights that participation is particularly important for disabled children and young people as they may be uniquely experienced in relation to health, education, employment and social areas. Participation for disabled children and young people has a number of individual and collective benefits. For example, shared decision-making, especially when using arts-based participatory methods, can draw out children and young people's strengths, resilience and optimism. It empowers children and young people, develops their creative skills, and builds their sense of self, identity and self-esteem. At a collective level, their participation benefits organisations and public policy development, contributes to more appropriate services, and society as a whole. Participation can also be a means by which children and young people realise their other rights.

Chapter Five: Barriers to the participation of disabled children and young people

Introduction

This chapter outlines the barriers to the participation of disabled children and young people. Similarly to Kelleher et al. (2014), we discuss barriers at many levels, including institutional, legislative and policy level, environmental, attitudinal and individual levels, as well as implementation challenges of both policy and research. We highlight that a lack of commitment and investment at policy level which translates to a lack of capacity in practice to meet an individual child's requirements and preferences is a key barrier to participation. We also discuss inaccessible physical environments, information and communication as major barriers to participation. The chapter concludes with recommendations for increased resourcing of participation.

Legislative and policy level

Kelleher et al. (2014) state that although Ireland ratified the UNCRC, it has not become adopted into Irish law. However, Ireland does have a strong policy framework setting out its approach to child and youth participation, including the participation of 'seldom-heard' groups such as disabled children and a National Framework for Children and Young People's Participation in decision-making which is grounded in the UNCRC and UNCRPD.

However, weak implementation of laws and policies was identified as a key barrier to the participation of children in a 2021 report published by the Ombudsman for Children's Office, 'Mind the Gap' (Moloney et al., 2021). For example, relevant sections of the EPSEN Act regarding the participation of children in Individual Education Plans have not been commenced (note that this act is currently under review). The Indicators Set for the Better Outcomes Brighter Futures (2014-2020) National Framework published in 2022 included no specific data on children and young people's participation in decision-making. However, Young Ireland: National Policy Framework for Children and Young People 2023-2028 includes a commitment to using a detailed Cross Government Action Plan for Participation to progress its high-level actions which include participation of children and young people.

In terms of the HSE Outcomes-Focused Performance Management and Accountability Framework, there is no published data on the indicator relevant to child participation. The report also cites research that found that Tusla practitioners were experiencing difficulties consulting with harder-to-reach children and young people, including disabled children.

More generally, Lundy (2007) emphasises the necessity of interpreting Article 12 in a manner that is “generous and child-empowering rather than negative and opportunity restricting” (p. 938). She underscores that Article 12, which is among the most frequently referenced but commonly misconstrued provisions of the UNCRC, often gets abbreviated as 'the voice of the child,' 'the right to be heard,' 'the right to participate,' and 'the right to be consulted.' These abbreviations are used for convenience to simplify the intricate language of Article 12. However, Lundy contends that relying on such shorthand can potentially dilute the article's impact and provide an imperfect summary of its actual requirements.

Lundy further argues that these abbreviations tend to overlook crucial aspects of the article, notably its applicability to "all matters affecting the child" without limitations (Lundy, 2007, p. 930). She firmly believes that a well-informed interpretation of this phrase holds critical importance and that a conservative understanding has the potential to severely curtail and constrain the application of Article 12.

Lundy and colleagues (2011) also state that implementation of child and youth participation as set out under UNCRC Article 12 has proven to be problematic in practice as it is dependent on the cooperation of adults in many cases.

Similarly weak implementation was reported as a barrier in the UK. According to research by the National Children’s Bureau Research Centre (2013), despite policy and commitment to children’s participation in the UK, achieving this in a sustainable and meaningful way is challenging. The report notes that there is a lot of rhetoric supporting participation, but it is unclear how this has translated into policy. Having examined the underpinning ideologies behind some of the major policy decisions concerning children, the report found that there is often an unwillingness to adopt a rights based approach to participation and unwillingness to share power.

Implementation challenges continue to be recognised by more recent researchers and in an Irish context (Feeley et al., 2021; Price & Feeley, 2021).

Attitudinal barriers

The literature indicates that attitudes towards disabled children and young people – because of their age or disability or both – represents a key barrier to their participation.

Much of the literature highlights that persistent negative attitudes and low expectations regarding the participation of disabled children in decision-making represents a key barrier (UNICEF, 2013; The National Youth Council of Ireland, 2012; UK National Children's Bureau Research Centre, 2013; Health Service Executive, 2016; Wickenden & Kembhavi-Tam, 2014, Kelleher et al., 2014; Council of Europe 2012b).

According to UNICEF (2013), the continued dominance of the medical model of disability means that barriers to children's participation are often overlooked. A review of the literature by the National Children's Bureau Research Centre (2013) in the UK also suggested that the continued dominance of the medical model of disability creates barriers for disabled children and young people's participation (Morris 1998b; Beresford, 2002). This results in attitudes which locate the problem in the child with a disability rather than considering the barriers created by social, physical and organisational structures that contribute to their exclusion and working to reduce those barriers.

According to the National Children's Bureau Research Centre (2013), children's participation often depends on the cooperation of adults and therefore negative perceptions about their ability to participate can act as a barrier. For example, Saaltink et al. (2012) found that young family members with an intellectual disability follow an age-typical yet restricted pattern of participation in decision-making. Parents feel their children could be at risk of harm due to a lack of understanding or limited accommodations provided in the participation process. Similarly, Kelleher et al. (2014) in their review of the literature on participation of seldom-heard young people found that there is often a lack of agency attributed to these young people and that their participation depends on adults recognising their skills and abilities. In addition, Wickenden and Kembhavi-Tam (2014) highlight that adult gatekeepers may assume disabled children have nothing to say and may therefore prevent disabled children from taking part in participation or research initiatives. Where there are opportunities for influencing decision-making that involve gaining views on topics that lie outside of the family's usual practices and values, there is hesitancy in order to protect their disabled children or family members (Saatlink et al., 2014).

The literature also highlights that low expectations are often more pronounced for certain groups of children including children who do not rely on speech to communicate, who have different understanding or cognitive abilities and very young children. For example, research by the National Children's Bureau Research Centre (2013) in the UK demonstrated evidence of negative attitudes towards children and young people who do not rely on speech to communicate, including an assumption that they cannot express their views. In addition they found that those with intellectual disabilities in particular may face additional barriers in that people may assume that they lack the necessary cognitive abilities to make decisions. Similarly, Franklin and Sloper (2009) found that a number of respondents in their research had concerns about the capabilities of children with intellectual disabilities to engage in decision-making. There were also concerns expressed about accurate interpretation of a child's views in cases where the child communicates differently.

According to research by the National Children's Bureau Research Centre (2013) attitudinal barriers to participation may to some extent exist because this is a relatively new way of working. Practitioners may lack the experience, capabilities and skills to facilitate participation and this may be especially the case when consulting with children and young people with disabilities especially those who may not use speech as their main or preferred method of communication. They also highlight that some professionals might be concerned about involving children and young people and raising their expectations about possible outcomes.

Lundy et al. (2011) states that the direct engagement of children is often skewed towards older children and that it is rare for children younger than age eight to be involved directly in research design, interpretation, and dissemination. This report states that sometimes young children's contributions may indeed lack relevance and they may find it hard to focus. The younger the child and the more complex the issue, the more likely it is that they do not have sufficient understanding to have their views taken into account. However, the key point is that the onus is on adults to listen respectfully. The UNCRC Committee advises that assumptions about the capacities of young children must be challenged. However, the ethical issues, especially in relation to gaining assent and consent for participation of disabled children and young people continue to act as a barrier to their participation. We discuss assent and consent considerations in Appendix 2.

Environmental barriers

The literature highlights inaccessible physical environments, information and communication as major barriers to participation. Inaccessible physical environments can include inaccessible buildings, inaccessibility for children with mobility or physical disabilities, sensory barriers like lighting and temperature and inaccessible transport (UNICEF, 2013; HSE, 2016; WHO, 2011).

The literature also highlights a lack of accessible and appropriate information as another key barrier (UNICEF, 2013; National Children's Bureau Research Centre, 2013; Council of Europe, 2012b; WHO, 2011). Children cannot participate in decisions if they are not fully informed of the options available to them and the implications of those options. Inaccessible documents, websites, forms, surveys and questionnaires can prevent disabled children and young people from participating. Inaccessible communication is another major barrier highlighted by the literature. According to UNICEF (2013) children with communication differences face barriers because of a lack of access to, for example, sign language or hearing aids, or as discussed earlier, it may be incorrectly assumed that they are unable to communicate.

Research by the National Children's Bureau Research Centre (2013) in the UK found that many disabled children face a lack of access to communication systems and methods. Furthermore, there may often be a lack of understanding of their communication method among those carrying out the consultation or a lack of willingness to learn or not giving children enough time and support to communicate. Similarly, the National Youth Council of Ireland (2012) reported that many young people with a learning disability have described situations where people have not taken the time to communicate with them or who treat them like a child.

Creating an inclusive decision-making environment for disabled children and young people may require intense and deliberate planning, and a lack of commitment for such planning does not solve many environmental barriers. The planning may need to involve consultation with those who know the child and their preferred communication method, observation of the child and/or prior informal engagement, and preparation and/or adaptation of consultation materials into appropriate and accessible communication methods, as well as physical and sensory considerations of the consultation space. McNeilly et al. (2021) remind us also that repeat consultations may be required for some children and that participation must be viewed as a process and not a single occurrence.

Institutional barriers

Organisational culture

Cavet and Sloper (2004) found in their literature review that organisational culture is known to have an effect on the participation of children in decision-making. Both attitudinal changes and staff training are needed for cultural changes. According to Kennan et al. (2021) meaningful participation has been difficult to implement by many organisations because of ambiguity around the concept of participation and how to implement it in practice.

Franklin and Sloper (2009) found in their study that participation of disabled children was fragmented and relied on a few dedicated professionals with an interest in doing it. Staff turnover negatively affected participation opportunities. Participation tended to happen in isolated activities rather than being embedded in the culture of the organisation. Participation must be seen as a process rather than a one-off event. This means changing relationships between adults and children, changing attitudes, and developing new ways of working. Participation in decision-making is a multidimensional construct, and it can occur at many levels of an organisation. Meaningful participation with disabled children and young people often entails spending time with them and speaking to people who know them well (Knight et al., 2006). Thus, it is important to think of participation as a tailored and situated activity, as opposed to a predetermined process.

According to research by the UK’s National Children’s Bureau Research Centre (2013), some key challenges to involving young people in decision-making processes include that it: takes time, involves developing new skills for adults and young people, requires an investment of resources, can entail a major shift of attitude on the part of organisations, and like any process of negotiation, it can make decision-making slower.

Expectations of fitting in to bureaucratic processes

The literature highlights that children and young people are often expected to fit into adult led structures or organisations.

For example, Prout (2003, p.32) as quoted in the National Children's Bureau Research Centre in the UK (2013) suggests that "...too often children are expected to fit into adult ways of participating when what is needed is institutional and organisational change that encourages and facilitates children's voices" (p.47). These structures are frequently child-unfriendly in their procedures and culture. For example, according to this research, children and young people repeatedly state that venues, timing, procedures and jargon often act as a barrier to their participation. Furthermore, the evidence indicates that when children and young people are consulted they are generally asked about issues of importance to adults. Related to this, the review found that often a bureaucratic approach to participation is adopted which centres upon fulfilling organisational and procedural requirements in relation to decision-making which may leave little space for effective child and youth participation.

Similarly, Kellet (2010) highlighted barriers to participation in youth forums identified by a group of disabled young researchers. These barriers included people speaking too fast and using complex language and jargon, minutes of meetings not being sent out in advance, minutes and agenda papers with small print and no pictures, being hard to read, timings of meetings being often fixed for straight after school when young people are hungry and tired, and places of meetings being inaccessible. It is important to emphasise that simplified language, minimal text, visuals and objects support comprehension, enjoyment and meaning of participation for all children but they may be necessary for disabled children and young people. Specific guidelines for simplifying language used in consultation activities have been proposed for example by Davison et al. (2022).

In Ireland specifically, the report published by the Ombudsman for Children's Office, 'Mind the Gap' (OCO, 2021) stated that the existing child and youth participation structures are not adequately supporting disabled children to be heard in public decision-making. The report cites findings from two studies which suggest this may be down to lack of skills and confidence and also inaccessibility. Previously, the HSE's 'Transforming Lives' (2016) also identified the structure and organisation of meetings as a barrier.

According to UNICEF (2013) there is often too much emphasis on formal methods of participation, rather than opportunities for informal participation which would be welcomed by children. Kelleher et al. (2014) suggests that ensuring participation structures are suitable and meaningful to the needs of seldom-heard young people. Children and young people and/or the organisations they engage with see limited or no relevance in formal participation structures. While formal structures are unlikely to be an appropriate forum to facilitate participation for all young people, it does not detract from the need to critically examine the relevance of these structures for seldom-heard young people and the extent to which the processes and practices contained within them facilitate or thwart participation.

Inaccessible process

The report of the consultative meeting by Council of Europe (2012b) raised that the accessibility of administrative procedures was a barrier. Many disabled young people missed the opportunity to participate as invitations were distributed through professional networks. Often disabled young people are not connected with youth organisations at local or national level, let alone with international youth organisations and youth work which can hinder participation. In addition to this, the limited time between the launch and the deadline for applications is often problematic.

Perceptions/skewed participants

According to Kelleher et al. (2014) youth organisations in Ireland have reported that "middle-class, well educated, articulate" young people are most likely to be involved in participation activities. In their review, they found that the work of Carnegie UK Trust (2008) indicates that a perception of participation structures as elitist acts as a deterrent to involvement for some young people. Kelleher and colleagues conclude with a recommendation to avoid the monopolisation of decision-making by elite groups of young people and increase the inclusion of seldom-heard groups.

Similar findings have been highlighted by Price and Feely (2021) and Feely et al. (2021) who studied the practice of participation of children and young people in Irish organisations. For example, Price and Feely (2021) raised concerns about the lack of diversity on a Youth Advisory Panel of a large mental health organisation in Ireland. They acknowledged that efforts had been made to include people from different backgrounds, but these efforts did not reach everybody that needed to be represented. Thus, beyond willingness, new and ambitious approaches are needed to progress advances in participation of children and young people (Simmons et al., 2021).

Exclusion from disability consultation mechanisms

Kelleher et al. (2014) state that real influence in decision-making requires proximity to decision-makers, yet they note that participation mechanisms available to children and young people are not always fully integrated into adult decision-making structures such as local and central government structures. Findings from the Mind the Gap report (OCO, 2021), for example, indicate that disabled children were not meaningfully included in consultation and monitoring mechanisms such as the Disability Participation and Consultation Network and the Disability Stakeholders Group and IHREC's Disability Advisory Committee.

The DCYA (2014) reported that it can be challenging for organisations when children have a different view on how things should be done. Expectations should be realistically set on what outcome can be achieved from the participation process and may need to be flexible. It is necessary to think about who is not being heard and develop strategies to engage them. Most importantly, it is necessary to break the stereotype that disabled children and young people lack capacity or knowledge (UNICEF, 2018).

Tokenism

Franklin and Sloper (2009) argue that it must be examined whether a sample of disabled children can represent the views of other disabled children and if they are being adequately supported in their role as representatives. This is particularly important as disabled children and young people are very diverse with a wide range of strengths and needs. For example in terms of terminology we know there are different preferences (NDA, 2022) as well as differences in understanding impacts of different models of disability and views on educational and communicative approaches (Inclusion Ireland, 2022).

In their systematic review involving disabled children and young people as partners in research, Bailey et al. (2015) found that tokenism is a challenge. Similar conclusions have been reached by Montreuil et al. (2021) who called for active prevention of tokenistic participation and genuine inclusion of children in research which includes co-identifying with them how and if they want to be involved in knowledge production from the beginning of a project. Gallacher and Gallagher (2008) caution against suggestions that participatory research with children is necessarily ‘empowering’ and they cite other researchers who are wary of the essentialising of children’s voices. Raman and French (2021) emphasise the importance of ensuring that the benefits of the consultation for the participants (for example, in terms of self-esteem, confidence, social skills, and enjoyment) outweigh the demands placed on them by adults.

Kelleher et al. (2014) also cite research which note that attempting to pursue a child or youth-led approach when it is not appropriate (such as when a young person does not feel sufficiently comfortable or motivated to participate) may be considered tokenistic. The importance of this has also been highlighted by Feely et al. (2021) in an Irish context. However, Lundy (2018) argues that tokenism may be used as an excuse for non-participation and that it may sometimes be a necessary first step toward more meaningful participation and that from a human rights perspective, it is ‘difficult to think of another situation where it would be presented as honourable to deny an individual the enjoyment of their rights on the basis that full compliance is impossible’ (p.343). Lundy (2018) exemplifies this through the unacceptability of suggesting that without sufficient resources to provide ‘a good quality education that meets all the requirements of Article 29 of the UNCRC, 344 Childhood 25(3) then no education will be given at all’ (p. 343).

Lack of training and support

Council of Europe (2012b) cites examples of challenges encountered by trainers and participants in participatory group settings including lack of experience working with young people with disabilities and lack of awareness of disability issues. Challenges pertaining to group interactions, participant attention and retention that may be associated with the use of creative and unstructured approaches with insufficient training and support were reported also by Nathan et al. (2023) who conducted a systematic literature review on the use of arts-based methodologies with young people with complex psychosocial profiles.

Similar barriers have been noted in UNICEF reports (2013; 2018). For example, UNICEF (2018) have called for investment in building the skills of professionals working with children and suggested that some adults who work with children lack confidence for this. In its earlier report, UNICEF (2013) noted there are few training resources available to facilitate the participation of disabled children. Adults may require training in how to support children with communication.

Lack of training and support for adult facilitators and young people participating has been reported by several other authors and researchers, for example, Cavet and Sloper (2004). Franklin and Sloper (2009) highlight the barriers evident from their literature review. These include the time it takes to involve children in decision-making and the need to develop new skills among both adults and children. They emphasise that shared decision-making requires investment of resources, shifts in attitudes within organisations, and can make decision-making slower. Lack of training and support for adult facilitators and for children is again highlighted.

In particular, Franklin and Sloper (2009) found that training is needed among staff particularly in methods of engaging children who do not use speech. Training and confidence in using the different tools and adapting them to different situations is also suggested. In an Irish context, this has been highlighted in a recent report on the use of AAC by Inclusion Ireland (2022) which stated that up to date training for families, professionals and wider community is sorely lacking.

Kelleher et al. (2014) highlight that securing and sustaining young people’s participation requires the involvement and commitment of trained staff as well significant investment to cover the costs associated with providing access to youth-appropriate locations, training, transport, and other supports to ensure that young people have opportunities for meaningful participation. From the review of literature, they conclude that insufficient resourcing is one of the most significant barriers to engaging young people from diverse backgrounds in decision-making. This is also emphasised below in relation to funding the cost of AAC.

Lack of capacity in terms of time and resources are a key barrier for enabling participation of children and young people with communication differences. This has, for example, been cited as a key barrier for including AAC users/people who use AAC. Along with this a culture of overvaluing speech as the main method of communication also increases barriers for AAC users/people who use AAC (Inclusion Ireland, 2022).

Similarly, when it comes to utilising arts-based participatory methods, the most often cited challenge is that they are resource and time intensive (Dunn et al., 2018).

Perceived cost

UNICEF (2013) highlights lack of funding to meet an individual child's requirements as a barrier to participation but suggests there are often low cost solutions. However a lack of funding is a considerable barrier to ensure meaningful access to AAC for those who require it to communicate their views (Inclusion Ireland, 2022).

Kelleher et al. (2014) found that the resource-intensive nature of including seldom-heard young people and a perception of a lack of return on investment may prevent their participation. Also Wickenden & Kembhavi-Tam (2014) suggest that researchers may consider it methodologically difficult and expensive to include disabled children and young people. De Haas et al. (2022) in a paper describing including persons with PMLD in research suggest that while there are positive developments, inclusive research is in danger of excluding people with PMLD. Researchers may feel it is considered too difficult or consider use of proxies as the only option. However, authors advocate for an inclusive research culture that finds a way of researching with and alongside persons with PMLD. In this study use of "small stories" with photographs were used to reflect the core idea of "being with" persons with PMLD to enable their voices.

Individual barriers

Experiences of decision-making in own life

The literature demonstrates that disabled children and young people often have less experience making decisions in their own lives, both at the personal/individual level and in public decision-making.

DCYA (2014), for example, states that seldom-heard children are not generally asked for their views and may have difficulty engaging in participation processes without first developing the skills. Similarly, UNICEF (2013) notes that disabled children have fewer opportunities to develop the skills and confidence to participate and may not have the confidence to communicate their view. Kelleher et al. (2014) also indicated that disabled children are less likely to be involved in decision-making than their peers who do not have disabilities, even when the decision directly concerns their personal health (Davey, 2010). Kelleher et al. (2014) also found that there are fewer opportunities for young people from these groups to participate. For example, their paper references The World Health Organisation (2010) which outlines that young people with disabilities have fewer opportunities to participate in public decision-making.

Wickenden and Kembhavi-Tam (2014) make reference to the concept of ‘learned helplessness’ which occurs when disabled children are underestimated or parents used as proxies for their views. According to a review of the literature in the UK by the National Children’s Bureau Research Centre (2013) it is not unusual for children and young people to internalise beliefs that they cannot take part in certain activities because of a lack of skill or competency rather than because they have not had the opportunity. They argue that from such a disempowered position, it would be a challenge to suddenly be expected to take part in strategic decision-making without support. Similarly, Kelleher et al. (2014) highlight that in situations in which a young person has to self-nominate to get involved in a participation initiative, this may act as a barrier to those without the confidence or skills to put themselves forward.

Franklin and Sloper (2009) also found that children need support and training to participate. For many in their case studies, it was their first time being asked their view. Bailey et al. (2014) similarly listed feeling intimidated by professionals, not being used to giving their opinion, losing confidence or interest as barriers to participation.

According to Wickenden and Kembhavi-Tam (2014), cultural factors in particular contexts may inform what disabled children expect or conversely are allowed to do or discuss. Being invited to choose, criticise or to offer opinions may be unfamiliar to many. The power differential between adults and children, which may be particularly marked in some cultural contexts, may be exaggerated for disabled children whose agency is not recognised.

According to research by the National Children's Bureau Research Centre (2013) in the UK all of the available evidence indicates the importance of nurturing and facilitating self-expression in children and enabling decision-making to be part of everyday relationships and activities between adults and children. This will enable children to develop their capacity to make choices and express their feelings, thoughts and preferences and feel that their views are valued.

Consultation fatigue

According to the HSE 'Transforming Lives' (2016) a feeling among participants based on previous experiences that participation does not lead to change, is identified as another barrier. Similarly, Kelleher et al. (2014) highlight that participation experiences that do not lead to demonstrable outcomes may lead to cynicism, disillusionment and consultation fatigue among participants.

One way of mitigating this potential consultation fatigue is through a provision of meaningful feedback to children which clearly explains how their views were used and why certain views were not. Lundy (2018) argues that such feedback is meaningful only if it is sufficiently full, appropriately child-friendly, fast and followed-up in order to create the optimal conditions for adults to engage seriously and sufficiently with the views that they have sought or been given.

From their analysis of children and young people's participation literature, McMellon and Tisdal (2020) concluded that children and young people can be overly pressured to participate, especially in the contexts of education and residential care, and may experience negative consequences should they not wish to participate.

Overall, McMellion and Tisdal (2020) note that the list of challenges of participation is lengthy, and that the literature lacks specific solutions.

Conclusion

This chapter outlined the barriers to the participation of disabled children and young people. Much of the relevant literature focuses on barriers to participation and we outlined these barriers at multiple levels, including institutional, legislative and policy level, environmental, attitudinal and individual levels. Especially, implementation challenges continue to be increasingly recognised, and this includes weak implementation of policies and laws. Our review of literature indicates that attitudes towards disabled children and young people as well as lack of training and support for inclusive approaches to facilitate participation represent key barriers to participation. At both policy and practice levels, a lack of commitment and investment to meet each individual child's requirements and preferences is a key barrier to participation, and this is particularly true in relation to children and young people for whom speech is not the preferred way of communication. The literature also highlights inaccessible physical environment, information and communication as major barriers to participation. In the concluding section of this chapter, we outline again that disabled children and young people often have less experience making decisions in their own lives, both at the personal/individual level and in public decision-making, thus we propose that they require more opportunities to develop the skills and confidence in participation, and, like the practitioners, need increased skills, training and support.

Chapter Six: Where can disabled children and young people participate?

Introduction

This chapter provides an overview of different variations of child and youth participation in practice, policy and research. From local and EU level children's councils and youth parliaments to children's research advisory groups and advocacy services as a means to support children and young people's participation, we give various examples that promote individual or collective decision-making and formal and informal participation processes. These examples constitute a non-exhaustive overview of varying degrees of influence or shared power with adults.

Child-led initiatives and organisations

According to paragraph 25 of the General Comment No. 7 of the Committee on the Rights of Persons with Disabilities (2018), “Children with disabilities are themselves best placed to express their own requirements and experiences, which are necessary in developing appropriate legislation and programmes in accordance with the Convention” (p. 6). However, according to UNICEF (2013), more opportunities are needed for disabled children to be involved in any child-led organisations. They highlight that this requires capacity building, financial resources, review of potential barriers as well as awareness raising with all stakeholders, including all children.

Save the Children (2011) gives an example of child-led initiatives in Zimbabwe which it established in which children run their own groups with some support from adults. The groups include children with and without disabilities. Save the Children provided training to the children on child rights and the UNCRC and facilitated dialogue between the children’s groups and community leaders, policy makers and government officials.

UNICEF (2013; 2018) lists a range of structures and mechanisms for promoting children and young people’s participation, and we outline them below.

Representation on local bodies

Local committees should include representatives from child-governed organisations and include the perspectives of children. For example, Children and Young People’s Services Committees (CYPSC) are county-led committees that bring together statutory, community and voluntary providers of children and young people services to ensure effective inter-agency coordination and collaboration to achieve the best outcomes for all children and young people in its area. This is achieved through effective planning, coordination and oversight of policy implementation and service provision locally. CYPSC acts as the structure whereby services can work together in a systematic manner to achieve shared goals and bridge national policy with local provision. An action included within the CYPSC Shared Vision, Next Steps 2019-2024 document is to increase the involvement of children and young people, including seldom-heard children and young people, children and young people with disabilities and children and young people from LGBTI+ and diverse backgrounds, with their local CYPSC. This will ensure that the voice of children and young people is embedded into the planning and delivery of local services.

Local authorities can build a commitment to children's participation into their planning and budgeting processes and support local forums for children. For example, Comhairle na nÓg is a grouping of child and youth councils operating in each of the 31 Local Authority areas across Ireland. Comhairle na nÓg gives children and young people the opportunity to be involved in and have a voice in the development of local and national services and policies and any issues that affect them in their local area. It is the recognised national structure for participation by children and young people (aged 12-17 years) in decision-making.

Local youth parliaments, children's councils and schools' councils

Local youth parliaments and children's councils can create opportunities for all children to be involved in local decision-making. Goal One with Comhairle na nÓg's Five Year Development Plan is to extend their reach and engage more broadly with young people and decision-makers to strengthen the voice and influence of all young people in local and national decision-making.

Formal educational programmes should be based on the principles of equality and full participation. Children and young people with disabilities and their representative organisations should be involved in these programmes at all stages of planning and implementation (Skhiladze, 2023). School councils should include disabled children as representatives who can support the development of inclusive school environments. The importance of this representation was highlighted more than a decade ago in the Inclusive Education Framework (NCSE, 2011), yet this recommendation is still not consistently implemented.

Targeted consultations on local issues

UNICEF (2013) highlights that disabled children can help with community accessibility audits or identification of local child protection issues. For example, they have varied experience of the design of parks, school playgrounds, health facilities and local transport systems, and this experience is invaluable in the design of these structures. They propose that disabled children can contribute to local newspapers, run their own local initiatives, or lead any local media and arts initiatives. Creative arts in particular have been recognised as effective advocacy and awareness tools on issues affecting all children.

Advisory groups

Children and young people's advisory groups can inform not just policy dialogue, but also service planning, service reviews and even adult-led research. From their experience of implementing a Youth as Researchers (YAR) Programme in Ireland, Kennan et al. (2021) suggest that there are clear opportunities for the advisory group members to engage in small-scale social research projects with their peers to bring advice to the decision-making table.

Many authors have called for children's involvement in the broader aspects of the research process, including its design, implementation, the interpretation of the data and the later dissemination of results (Horgan & Martin, 2021; McMellon & Tisdal, 2020; UNICEF, 2013). Disabled children can identify the gaps in knowledge about a particular dimension of their lives, develop research questions and methodology, carry out surveys or interviews, analyse data and write recommendations (UNICEF, 2013). Horgan and Martin (2021) propose Children's Research Advisory Groups (CRAGs) as mechanisms for promoting children's deeper and more meaningful participation in research concerning them. Such advisory groups empower young people, allow the researchers to tap into young people's qualities such as empathy, innovation and creativity, provide valuable 'insider' perspective, and may improve engagement with research (Horgan & Shirley, 2021). They identity the following considerations for working with CRAGs - these are consistent with guidelines offered by UNICEF (2018) and DCYA (2014):

- Group formation;
- Capacity building;
- CRAGs' role in designing and validating methods;
- CRAGs' role in data analysis;
- CRAGs' role in research sharing; and

- Recognition of children's contribution in CRAGs (i.e., the issue of payment/reward, see this discussed in chapter seven).

McMellon and Tisdal (2020) also argue for more intense forms of children and young people's participation in knowledge production and authorship in academic as well as other outputs. They note that some academic journals have started experimenting with specific spaces for children and young people to contribute and highlight opportunities for co-authoring publications with children and young people.

At policy level, there are existing examples of co-authoring with children. For example, the EU Strategy on the Rights of the Child has been developed for children and with children. Children should have access to information provided in a child friendly way so they can clearly know what their rights are and, in this case, what the EU plans to do for them. The child friendly versions of the strategy were co-designed by children and present the information in a digestible way for their readers. Children advised on the language, images and examples used in the leaflets. Moreover, the child friendly version of the strategy is accessible for visually impaired readers and can be accessed using assistive devices and technology.

Monitors of local services

UNCRC General Comment 12 which refers to the voice of the child highlights that State Parties should introduce measures enabling children to contribute their views and experiences to planning and programming of services. Children and young people should be involved in decision-making about service provision, supports, treatments, effects and outcomes consistent with evolving capacities. UNICEF (2013) suggests that disabled children can "help monitor discrimination or exclusion or help remove barriers keeping disabled children from accessing services" (p. 13). They argue that disabled children are best placed to evaluate whether the indicators related to removing discrimination or exclusion have been met, and to share and discuss these findings and possible solutions with service providers.

Participation across government

Disabled children can offer unique insights for legislative reform, policy making, planning, data collection and resource allocation, for example through highlighting attitudinal, communication, and physical barriers faced (UNICEF, 2013).

Council of Europe (2012) advised that States Parties should enhance the highest achievable legal safeguards for the participation rights of children and young people, encompassing constitutional, statutory, and regulatory provisions. Conduct regular evaluations to appraise the degree to which the voices of children and young people are acknowledged and respected within current legal frameworks, policies, and procedures, and ensure that these assessments give due weight to the evaluations provided by children and young individuals themselves. They emphasised the need for a more coordinated approach to strengthening children and young people's participation and mainstreaming participation in decision and policy-making structures across governmental and non-governmental organisations. More than a decade after, despite an increased awareness of the need to incorporate children's voice in matters that concern them, children still have little impact on public decision-making (Cummins, Horgan & Martin, 2021).

Save the Children (2011) facilitated the engagement of 34 child-led groups in Zimbabwe in a 'Child Friendly National Budget Initiative' led by NGOs and engaging with the Ministry of Finance. The purpose was to raise awareness among policy makers of the importance of dedicating more resources to children. Advocacy from these groups led to increases in budget allocations to child rights issues including education, healthcare, and birth registration. It also led to increased understanding of budgets among children. The children now produce annual shadow budgets for schools and local authorities.

UNCRPD General Comment 7 suggests "States parties can organize seminars/meetings in which disabled children are invited to express their opinions. They could also make open invitations to disabled children to submit essays on specific topics, encouraging them to elaborate on their firsthand experiences or life expectations. The essays could be summarized as inputs from the children themselves and directly included in decision-making processes" (para.26).

Monitoring children's rights

According to UNICEF (2013) disabled children can be involved in selecting indicators to track progression of implementation of rights and can be directly involved in research as participants or researchers. Council of Europe (2012) emphasises the need to assist children and young people, and their affiliated organisations in engaging actively in the assessment of the execution of Article 12 and other applicable provisions of the UNCRC, alongside the implementation of relevant Council of Europe accords and other global benchmarks concerning children's rights.

Children can contribute to reporting processes to the Committee on the Rights of the Child as well as other international or regional mechanisms such as the Universal Periodic Review or the Council of Europe. UNICEF (2018) includes some of the issues to consider:

- Support can be given to enable children to produce their own independent reports as well as contributing to those produced by the National Human Rights Institutions (NHRI): this has been done, for example, in the United Kingdom and Republic of Ireland
- Children can be invited to attend and participate in the pre-sessional meetings of the Committee on the Rights of the Child or Universal Periodic Review sessions
- The NHRI can support children to audit local services (such as local police, hospitals, or schools) to assess compliance with human rights standards.

Reporting to UN Committees

The UNCRC Committee (2014) stated in its statement ‘Working methods for the participation of children in the reporting process of the Committee on the Rights of the Child’ that child-led organisations or groups fall within the definition of “competent bodies” that may be invited under Article 45 (a) to provide expert advice on the actual implementation of the Convention to the Committee.

According to paragraph 131 of UNCRC General Comment 12, the Committee “welcomes written reports and additional oral information submitted by child organizations and children’s representatives in the monitoring process of child rights implementation by States parties, and encourages States parties and non-governmental organizations (NGOs) to support children to present their views to the Committee” (p. 27).

According to UNICEF (2013), disabled children can be involved in the reporting processes to the Committee on the Rights of Persons with Disabilities and the Committee on the Rights of the Child. In many countries, non-governmental organisations have involved children in shadow reporting processes, including pre-session country briefings with the UN Committee. The Committee also encourages governments to include children in reporting, including shadow reporting efforts. World Vision (2007) also suggests that children can be invited to participate in the pre-sessional meetings with the Committee, as well as the session to observe the State Parties report.

World Vision (2011) carried out an analysis of alternative reports to the UNCRC Committee which included children. A UNCRC Committee General Comment published in 2006 encouraged State Parties and NGOs to directly involve children in the monitoring process. The report notes that children's participation in the reporting process is not yet common practice among State Parties, but it highlights that there are some examples of child participation in the periodic reporting process of the Netherlands, Sweden, Norway, India, UK, Peru, Thailand, and Cambodia. In addition, the report found examples of adult-led child rights NGOs which have consulted with children in the preparation of shadow reports. There are also some examples of child-led initiatives independently engaging in the process, although these are relatively fewer. In its analysis of 16 alternative reports, World Vision found a range of methods and approaches were adopted. The number of children who participated in the reports varied from a few dozen in Uganda to about 9,000 in Latvia. The ages ranged from as young as 12 months in the UK to young adults aged 20 in Belgium, with the most common age range being 9 to 17 years old. The most common techniques used to gather information were surveys/questionnaires, interviews, conferences and workshops. Some reports focused on directly responding to the State Party report while others took a more general approach asking questions about what it is like to be a child or young person in that country. Many of the reports include information relevant to all parts of the UNCRC. Others focused on specific themes relevant to children and young people in that country.

A report by Save the Children (2011) also highlights that children took part in the development of Zimbabwe's report to the UNCRC Committee for the period 1995 to 2010.

Ireland runs a UN Youth Delegate Programme in which two young people are chosen as delegates representing the views of Irish young people at various UN

Forums such as the UN General Assembly and the High-level Political Forum on Sustainable Development. This process is coordinated by the National Youth Council of Ireland in collaboration with the Department of Foreign Affairs and has been running since 2015.

Digital tools and engagement

Kelleher et al. (2014) highlight that the potential for ICT to facilitate participation by young people is significant. They cite evidence from the EU Kids Online study of 1,000 children in Ireland which demonstrated that over half of children in Ireland use the Internet daily or almost daily (53%) and a further 36% use it once or twice a week. It is likely that these figures are even higher today. One example of the use of ICT to promote participation given by Kelleher and colleagues is the Being Young and Irish Initiative (2012) where young people were invited to express their views by emailing their contributions in a number of formats such as typed text, audio material, or video material, and in a number of forms, including, narratives, poetry, song, and Irish sign-language.

World Vision (2007) noted that the most common methods used to include children are having the children give their opinions by responding to questionnaires, surveys and interviews. Nearly two decades later this is often still the case (McMellon & Tisdall, 2020).

Murray (2012) highlights that IT and assistive technology allows opportunities to enhance the participation of all children and young people, especially those who communicate differently. It has been highlighted that the use of social media and technology in consultations with children and young people must be more advanced (Nathan et al., 2023). In Ireland, a recent report on AAC has highlighted the need for an increased investment to support the development and implementation of assistive technology and to improve capacity of all stakeholders in this field (Inclusion Ireland, 2022).

For at least a decade the researchers have called for the use of other technologies beyond the traditional photovoice and photo elicitation used in past research with young people (Drew et al. 2010; Nathan et al., 2023). For example, a systematic review of literature on digital storytelling (which involves using images and/or video to explore experiences) conducted by Jager et al. (2017) has concluded that digital storytelling has a particular potential to reach policymakers and create positive social change (Jager et al., 2017). Digital storytelling has, for example, been successfully used to elicit the voices of young autistic children (Parsons et al., 2021). The development of such visual tools can improve the participation of all children and young people but may be especially important to promote the participation of disabled children and young people.

The Youth at Heart strategy (2020) developed by the Government of Netherlands surveyed 1,000 young people from the Middle East and North Africa, the Sahel, and the East and Horn of Africa. It was found that just 14.3% of respondents felt that young people's voices are represented in their societies. In addition 45.3% felt that Covid-19 has increased the opportunities available for young people to be heard and engage in decision-making. Results from focus groups indicated that social media and online participation presented opportunities to increase the diversity of participation compared to physical spaces. However it was also highlighted that many online advocacy spaces are dominated by educated young people from urban areas, and often by young men (Government of Netherlands, 2020).

Advocacy services

Advocacy services can be a means to support child participation. In their 'Mind the Gap' report for the Ombudsman for Children's Office in Ireland, Moloney et al. (2021) have noted that children have consistently reported the value of having an advocate. At the time of the publication of this literature review, the National Advocacy Service in Ireland only supports adults, though Inclusion Ireland is currently investigating the need to establish an advocacy service for disabled children and young people.

Kelleher et al. (2014) found evidence to suggest that an advocacy service can sometimes be most appropriate (e.g. in care proceedings or in cases of separated minors seeking refugee status). They caution, however, that there is potential for a child or young person's issues to be lost in translation by adults or end up as representations of adults' interests instead. Despite this, they note that adults are potentially powerful representatives of young people's interests and may be in a stronger position to move children’s interests onto the political agenda than children themselves.

We discuss related concepts of child self-advocacy, child activism, and children as human rights defenders in the following chapter.

Conclusion

This chapter provided an overview of different variations of child and youth participation in practice, policy and research. These included local and EU level children’s councils and youth parliaments, children’s research advisory groups and advocacy services. We discussed how these various structures promote individual and collective decision-making and promote varying degrees of influence or shared power with adults.

Chapter Seven: How to make participation work for disabled children and young people

Introduction

This chapter includes available evidence on how to make participation work for disabled children and young people. We outline what the literature says regarding considerations for planning and execution of participation at a project level, and what factors enable participation at an organisational level. The principles for working with the child or young person, their parents/ guardians and/or support persons are also outlined. The chapter includes general strategies and methods for overcoming barriers to creating inclusive consultation environments. We include discussion on the importance of a total communication approach which involves using and valuing all types of communication equally, recognising that speech is just one method of many. Furthermore, we outline practical tips for supporting understanding and simplifying written communication, discuss the use of arts and technology to support inclusive participation, and describe a range of alternative and augmentative communication tools.

Organisational level: Whole systems approach

The National Participation Framework (2021) cites four enabling factors underpinning its effective implementation, namely organisational buy-in, training and capacity building, resources (financial, human and time resources), and monitoring and evaluation. Departments, agencies and organisations that strive to involve children and young people in decision-making need to ensure that all of these factors are in place. Below we cite literature that supports the importance of these enabling factors, and discuss key associated concepts needed for the effective implementation of participation.

Embedding a culture of participation

The literature highlights that participation is an ongoing process, rather than a one-off event and that in order to achieve this, a culture of participation must be embedded across an organisation in a ‘whole systems approach’.

According to Kelleher et al. (2014), effective participation requires an approach that combines four key elements within an organisation: structure, culture, practice, and review. This is described as a ‘whole systems approach’. The culture refers to an ethos shared by all staff which values participation. The structure refers to the planning and resourcing of participation. Practice refers to the ways of working, skills and knowledge and methods which enable participation to take place. Review refers to the monitoring and evaluation of participation to demonstrate evidence that participation leads to change.

Kelleher and colleagues (2014) also note that organisational culture will influence the approach to participation and consequently the quality and outcome of the participation process. They conclude that participation needs to progress beyond one-off, discrete activities, to become an ongoing embedded process whereby young people are listened to and are enabled to effect change within services and organisations.

The Department of Children and Youth Affairs' (2014) toolkit for including seldom-heard children notes that inclusion must be "embedded in the culture and structure of an organisation if it is to result in their increased and meaningful participation […] It is best to adopt a whole systems approach and framework to ensure the effective participation of seldom-heard children and young people" (p. 15). The report notes that this takes time, resources and a concerted effort from management, without which it simply will not happen. Helpful cited tips include developing a participation charter or strategy, putting participation in an organisation's mission statement or strategy with a particular focus on seldom-heard participants, nominating participation champions, ensuring all staff understand participation and how to include the seldom-heard, putting child and youth participation on the agenda of meetings, and adapting processes and decision-making structures to include children and young people (e.g. in Advisory Groups). In a practical sense, supporting staff to 'give over the reins' to children and young people can be done by providing sufficient resources and promoting tips such as for example scheduling meetings for a suitable time (for example, 5pm can be good because it is after school but during working hours).

Moloney et al. (2021) provides an example of how a whole systems approach can work in practice. Tusla aimed to embed a culture of participation across the agency taking a whole systems approach. Tusla developed a Child and Youth Participation Strategy (2019) and a National Children and Young People's Charter. It also developed a Participation Toolkit (2016) for practitioners and an associated Quality Assurance Framework to assess compliance with UNCRC. It delivered training to all staff in child and youth participation practices and provided seed funding to support innovative participatory practices. It provided awareness-raising to children and set up participation structures in foster care and a child-friendly complaints mechanism.

Similarly, research carried out by the UK National Children's Bureau Research Centre (2013) suggests that factors which appear to support the participation of disabled children and young people in decision-making include embedding a culture of participation and staff members having a positive attitude to participation.

Sinclair (2004) argues that if children and young peoples' participation in decision-making is to be more meaningful to children and effective in influencing change, it is necessary to move beyond one-off or isolated participation and consider how participation becomes embedded as an integral part of our relationship with children.

Kirby et al. (2003b) draw on research from 29 case studies which indicate how organisations can develop the role of participation within their organisation and move from being consultation-focused to participation-focused to child-focused. Their study highlights ways in which organisations can start to build cultures of participation through making changes in attitudes, procedures and styles of working across all levels, creating champions of participation to support change across the whole organisation, and developing a shared vision and understanding of participation. The authors identify that the key to this is senior management support and a mainstreaming of practice.

Similarly, World Vision (2007) advised that meaningful participation cannot be done 'on a whim' and that careful planning, preparation and execution are all needed.

Staff training and development

The literature highlights that staff training is necessary in order for a whole systems approach to child and youth participation to work. The literature highlights that staff at all levels may need training in order to understand their obligations with regard to participation, training targeting attitudinal changes regarding the value of including disabled children and young people, training in consultation methods and communication methods, and training in facilitation skills. Training and capacity building are identified as one of the enabling factors in the implementation of the National Participation Framework (2021).

Moloney et al. (2021) state that training and capacity building of staff on the meaning and practical achievement of participation is needed. Kelleher et al. (2014) similarly highlight that staff training is necessary in order to address attitudinal barriers to become consistent with a 'whole systems' approach. The Council of Europe (2012) advises to enhance professional capacity concerning children and young people's participation.

Evidence from the review of the UK literature by the National Children's Bureau Research Centre (2013) highlights that training and development programmes need to address attitudinal changes in professionals about childhood and adolescence, particularly concerning consent and competence, and training in methods of communication with children who do not use speech. Similarly, Franklin and Sloper (2009) highlight the need for training in the use of creative methods and IT, and training in theory and methods of participation with particular reference to children with communication needs and learning disabilities. Again, in Ireland, the recent AAC report highlighted the same need (Inclusion Ireland, 2022).

The literature also notes that extensive knowledge and skills are not necessary in order for staff to carry out participation initiatives. The Council of Europe (2012b) states that trainers conducting activities with young people with disabilities do not need exceptional competences. However, relevant knowledge, good organisation and facilitation skills, some creativity and an open-minded attitude are necessary. Similarly, Wickenden and Kembhavi-Tam (2014) state that as researchers with pre-existing skills and experience in working with disabled children, they would actively encourage ‘non-specialists’ to include disabled children in their studies. They state that highly technical skills are not needed, but just an awareness of the necessary adaptations to make, flexibility, optimism and an inclusive, respectful approach which recognises disabled children as having things to contribute.

Investment

At the senior management level, resourcing participation is another important consideration. Provision of resources (financial, human and time) is identified as one of the enabling factors in the implementation of the National Participation Framework (2021).

Franklin and Sloper (2009) found that effective participation can be extremely labour and time intensive. Resources are required to provide training, support and skills development as well as to provide specific practical costs such as transport, resources and equipment for groups and also to ensure that young people are compensated for their time and contribution. Increased investment is especially needed for participation tools that utilise arts, media and digital engagement. They also highlight the need for flexible approaches to funding and timetables when it comes to research that involves disabled children and young people.

UNICEF (2018) suggests it is also a good idea to invest in recruitment, training and support for new groups of children on an on-going basis. This will help organisations avoid the risk of working with only a few 'professionalised' children who often take part in these initiatives, and also replace groups of children as they grow older and are no longer eligible to take part in initiatives for children. McMellon and Tisdal (2021) name the challenges related to which children and young people participate as one of the major challenges of participation that need urgent methodological and practice developments. They state that one concern is that some young people (often older children and those from higher socio-economic backgrounds) are easier to involve than others and that, particularly when resources are limited, access to participation opportunities is not equal. They also highlight that participation of specific groups of children whose views are less likely to influence decision-making: such as very young children, care experienced children and children with communication difficulties is limited.

Payment or reward

The literature is scarce regarding whether or not children should be paid or somehow rewarded for their time. Bailey et al. (2014) in their systematic review, however, did find that many research initiatives thanked children for their time by providing vouchers, payments, outings or social occasions. These alternative ways of recognising and compensating children's contribution are recognised also by Horgan and Martin (2021). Horgan and Martin (2021) note also that most researchers would agree that it is ethical practice to compensate children and young people for their participation. They emphasise however that token payments are often not the only motivation for participation.

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 (NDA, 2022).

Project level: planning

At the project level, there are a number of considerations to make when planning a participation initiative including:

- Planning the scope of the participation initiative
- Recruitment and selection of children and young people
- Capacity building and support for children and young people
- Child and youth protection
- Consent and assent
- Working with parents or family members
- Working with staff from the educational settings
- Planning flexible and appropriate methods.

Planning the scope of the participation initiative

According to the principles of meaningful child and youth participation set out by the UNCRC Committee (outlined above), the scope must be clear from the outset including the level of influence children and young people will have on the process and outcome in order for the process to be meaningful.

Recruitment and selection

UNICEF (2013) highlights that disabled children can be more isolated from their peers and communities and suggests that local DPOs can be a source of information about where to reach disabled children and their families. It also recommends working with children's organisations such as NGOs who can provide a point of access to disabled children and also have experience working with them effectively. Other points of access may include community organisations and services such as churches, health centres, hospitals, child protection committees, schools, residential homes or institutions and early years' settings. Finally, it also suggests that social media is another avenue through which to reach disabled children and young people.

Bailey et al. (2015) in their systematic review found that disabled children were commonly reached through schools, hospitals, in the community and online. Common ways of advertising included internet forums, websites, newsletters and direct mail. It is advised in the literature they reviewed that it should be made clear what the opportunity involves and use appropriate language with a variety of formats.

Franklin and Sloper (2009) found that unless particular efforts are made to reach disabled children considered 'hard-to-reach' (for example children with learning disabilities or those who do not rely on speech to communicate) then the disabled children who participate “will continue to be the easiest to reach, most able to communicate and the most articulate and confident” (p.12). Gonzalez et al. (2021) and Kelleher et al. (2014) conclude that directly targeting the involvement of seldom-heard young people in mainstream participation structures may be needed as an approach to increase the likelihood of their participation.

World Vision (2011) in its analysis of 16 alternative reports to the UNCRC Committee found that the most common way that organisations reached out to children and young people was through other organisations that had direct contact with them. Other methods included the use of different media outlets such as newspapers and the internet. In one case (Netherlands) participants were reached through a magazine that was specifically sent to youth facilitation institutions. In Denmark, they contacted student councils.

World Vision (2007) recommends using a variety of methods of communication to disseminate information about the opportunity to participate, for example, contacting other organisations known for having direct contact with different groups of children, publishing a request for participants in a newspaper, on the radio or online. Mencap (2011) also indicates that spending time with persons with PMLD is important in the participation of persons with PMLD. Longer term planning to involve hard-to-reach groups is required to build relationships and increase confidence for all involved.

DCYA (2014) sets out ways to engage seldom-heard children in a participation initiative. It suggests that informal approaches such as one-to-one chats, social experiences, or online forums dedicated to a particular issue may be more suitable. It recommends working in partnership with other organisations that the young person already knows and trusts. Other considerations include choosing suitable meeting times, using accessible language and visuals, choosing an accessible venue and having several means of contact.

There are some examples from Comhairle na nÓg in Ireland in recruiting seldom-heard young people, which includes young people with disabilities. For example, Cavan Comhairle na nÓg asked organisations engaged with seldom-heard young people to directly nominate members to join the Comhairle committee. Fingal

Comhairle na nÓg sought nominees from partner organisations engaged with seldom-heard young people and introduced a ‘buddy system’ for support between new nominees and existing members (McEvoy, 2009b). Fingal Comhairle na nÓg also undertook outreach type consultations with young people who tend not to be represented at Comhairle events. Westmeath Comhairle na nÓg reserved eight places for seldom-heard young people linked in with its partner organisations.

Council of Europe (2012b) in its paper on participation of young people with disabilities, suggests reaching them by sending out the call for participants through disability partner organisations who can forward the information in their networks. In practical terms, it advises that the call should not be too long and should allow plenty of time for participants to respond. It should make it clear that young people with disabilities should apply and that the venue, materials and activities are accessible. It further suggests having an easy-to-read version of the call for potential applicants, including a version with images to illustrate the questions. The report also advises that application forms should ask participants to note any accommodations required in order to participate which will help with planning. It also outlines the importance of creating an accessible application form. The NDA’s Customer Communication and Accessibility Toolkits may be helpful in this regard (NDA, 2012).

Capacity building and support for children and young people

Lundy at al. (2011) highlight that taking a UNCRC-informed approach means that it is not for the child to prove his or her capacity to engage with the issues under discussion but for the researcher to ‘‘presume that the child has the capacity to form his or her own views’’ (UN, 2009, para. 20).” UNCRC Article 12 also states that children should be supported to form their views which “can be influenced by information provided, as well as experiences, environment, social and cultural expectations, and levels of support (UN, 2009, para. 29). The literature shows that activities may be used to introduce consultation and research topics to children and to support them to form their views.

Young people may need support and training to increase their confidence and self-esteem, or may need skills development, for example, in group work or giving presentations (Kirby & Bryson, 2002; Kirby et al., 2003b). Franklin and Sloper (2009) note that preparing disabled children to express their views can take time and may need an individual approach. For example, in Bloom et al.'s (2020) study which engaged children with communication differences, the researchers spent several hours in the children's educational settings, observing and collecting information, so they could develop and contextualise the questions that are meaningful for each individual child. Similarly McNeilly et al. (2021) suggest at least two visits when consulting with disabled children and young people: an introductory visit to build rapport with the child or young person, learn about the child or young person's way of communicating and their preferences, and the second visit for an actual consultation.

Similarly, Kelleher et al. (2014) state that the development of capacity building measures focusing on confidence building, communication skills and exploring participation can play an important role in supporting seldom-heard young people to become involved in participation. Their paper highlights that capacity building initiatives developed to support the participation of seldom-heard young people in Comhairle na nÓg resulted in increasing the numbers of seldom-heard young people at Comhairle meetings. For example, the Carlow Comhairle na nÓg had 15 seldom-heard young people in attendance at its AGM, four of whom were elected to the main committee following a capacity-building programme initiated by partner organisations in advance of the event.

Inclusion Europe (2014) in its guidance for participation with children with intellectual disabilities highlights the importance of training in self-advocacy so that children and young people can take the lead and express their opinions on subjects considered relevant to them. It is based on the principle that young people themselves must be supported to identify the issues that are meaningful to them and what actions and strategies they want to use to achieve their goals. Taking this approach, the power to make decisions remains with the children and young people, while adults participating in this process are facilitators or supporters.

Murray (2012) states that children and young people are experts in their own needs but that it is also necessary for them to learn about others in order to represent the diverse needs of disabled children and young people. In addition, they need to learn about how policy making works. World Vision (2007) states that children first need to understand their rights under the Convention on the Rights of the Child (UN, 1989), how the monitoring process works, be supported to get to know previous Children's Rights Committee comments, and what laws and policies are in place to support children. This information should include what the goals of the report are, what the goals for children's participation in the reporting process are, why it is important for the children to participate, and how their ideas and opinions will be used.

In their discussion on concepts related to children's agency, competency, and autonomy, McMellon and Tisdall (2020) recommend the need to expand this field further to ideas like child protagonism, child activism, and children as human rights defenders. These concepts signify a shift towards recognising children as active and influential participants in societal processes. Child protagonism acknowledges children's capacity to instigate change and play a proactive role in their communities, reflecting ideas of active citizenship and participatory democracy, particularly prevalent in Latin American contexts (Larkins et al., 2015). The term "children as human rights defenders" integrates children into the wider human rights discourse, challenging traditional assumptions about childhood vulnerability and dependency, while fostering collaboration between children and adults. Additionally, the concept of child activism emphasises children's ability to advocate for social change, challenging conventional norms and power dynamics. These concepts collectively broaden the horizons of children's and young people's participation, offering innovative perspectives to address the intricate challenges in this field.

De Haas et al. (2022) also discuss the term 'relational autonomy' to be considered as a means to foster inclusivity, particularly for individuals with PMLD. Rather than approaching inclusive research from the traditional standpoint, which may inadvertently marginalise this group and exclude them from research and decision-making processes, the authors emphasise the importance of truly understanding the lives and experiences of people with PMLD as the starting point. This approach can help establish an inclusive research culture that values 'being with' as a core element of its methodology. This enables the voices of individuals with PMLD to actively contribute to the creation of shared knowledge, supporting children and young people to navigate the world, interpret their perspectives and communicate them, recognising this as an integral aspect of their authentic autonomy rather than a potential impediment. This approach promotes a more inclusive, respectful, and empowering way to involve people with PMLD in the research process.

Child and youth protection

At a practical level, Jenkin et al. (2015) suggest that the researchers working with children must undergo police background checks. They also advise that a third party should always be present, there should be supervision of the researcher, and the researcher should engage in reflective practice. The ethical considerations relating to assent, consent, minimising risk and safeguarding in research with children and young people have received considerable attention in recent years, but the available literature still lacks detail on the specifics, such as for example supervision of researchers and consent procedures for children who are deemed not to have the capacity to give assent (see section below on consent and in Appendix 2). Even comprehensive reviews offering specific approaches, methods and examples for supporting participation and inclusion of children with complex communication profiles within qualitative research studies (for example, Kenny, Doyle & Horgan, 2023), while considering consent, do not include discussion on safeguarding.

Jenkin et al. (2015) also highlight that children may disclose information that puts them at risk (e.g. disclosure of abuse). Safety, protection and safeguards are necessary in all activities involving children and young people. They also suggest continuously advising children that they can withdraw or not share things they do not want. It is also necessary to advise children and young people of our child protection obligations that may include taking necessary actions should a child or a young person disclose something that puts them at risk.

According to Wickenden and Kembhavi-Tam (2014), child protection issues are particularly important with disabled children. Given positive relationships with ‘outsider’ researchers with time to listen and use of appropriate communication support, a disabled child may disclose sensitive information about their situation which they have not revealed before.

Bailey et al. (2015) in their systematic review found that researchers have to balance children’s right to participate with an obligation to keep them safe. The need for such a balance is recognised within the UNCRC. Bailey and colleagues identify the potential risks of participation for young people may include: imposing responsibilities for which they have not been prepared, exposing them to peer pressure, involving them in tasks for which they do not have the confidence or skills, involving them in public presentations or media activities where they have not fully understood the possible implications, or involving them in project activities to the exclusion of other interests in their lives. It could be argued that these risks are not inherent in participation itself, but can result from poorly planned processes (Lundy et al., 2011).

Consent and assent

Consent involves a process of communication about the proposed intervention, investigation, receipt or use of a service or participation in research, consultation, or teaching (intervention) in which the person has received sufficient information to enable them to understand the nature, potential risks and benefits of the proposed intervention (HSE, 2022). Assent is the expressed agreement of someone not able to give legal consent (HSE, 2022). It is an expression of willingness or affirmative agreement given by a child or young person/adult who cannot provide legally valid consent. The assent procedure should reflect all practicable efforts to support the child or young person/adult to understand and communicate what their agreement would involve (HSE, 2023).

Cameron and Murphy (2007) and Jenkin et al. (2015) outline some strategies for ascertaining consent and assent. Firstly, Jenkin et al. (2015) note it is important to check the specific legal context regarding consent in the country in which the research is taking place. They highlight that the process of ascertaining consent and assent must be made accessible and should not be passive or tokenistic. Both Cameron and Murphy (2007) and Jenkin et al. (2015) highlight that consent and assent is a continual process and must be re-gained as the process continues. In a study by Calvely (2012) the methods of gaining consent and assent were described that included adults who lacked capacity. These included consent by proxy where consent is given on someone else's behalf and implied assent where assent is not a once off event but an ongoing process observing the participants' nonspeaking reactions to the research or the researcher. In Ireland, key ethical considerations and principles for disability research, including legislative basis for including people who cannot consent in research are included in NDA's Ethical Guidance for Research with Disabled People (2024).

In order to make sure children are informed about what they are assenting to, it is necessary to provide them with information about the research or consultation, in a format that is accessible to them. For example, it is suggested that information about the research or consultation may be provided in different formats and may include photos of the researchers, simple language, pictures and symbols, information provided in sign language, use of a doll that children can communicate with, stickers indicating thumbs up and down, pictures of facial expressions, cameras, tape recorders and drawing (for examples see O’Keeffe and McNally, 2024). Similarly, Wickenden and Kembhavi-Tam (2014) highlight that the approach to gaining children’s assent depends on the child. For example, assent forms may be used but may be adapted to a symbol and picture version, an ‘easy read’ written format, alongside verbal or sign language explanations. More recently, audio and technology have been used to further differentiate methods used in communicating research and consultation topics to children and young people. This can be done for example through digitally drawn illustrations of the consultation process or in the form of a video/animation (McNeilly et al., 2021). Dee-Price (2020) inverted the onus on the participants with an intellectual disability to demonstrate their capacity to communicate to the researchers’ ability to understand the communicative interaction of participants.

The Involve Me project (MENCAP, 2011) used a range of creative approaches including story sharing, creative communication, multimedia advocacy and peer advocacy to include persons with PMLD in decision-making. They advocate for persons to be involved with the process of decision-making as much as possible even if the person lacks capacity to make that decision themselves. During the Involve Me project, if people could not give consent, they were involved as far as possible and those close to them were consulted to ensure that taking part in research would not be harmful. Decisions about taking part in activities such as sharing stories had to be made in their ‘best interests’. Debates over gaining informed consent can impede processes and risk non-involvement of disabled persons and the opportunity to influence policy or practice. In reality, consent processes are asking disabled people to agree to something very abstract which needs to be acknowledged, planned for and accommodated. MENCAP (2011) advises that if there is certainty that someone is not able to give clear consent, the researchers should involve a parent/guardian or person who knows the disabled person well in making the decision.

Jenkin et al. (2015) further highlight the need to respect the dissent of the child expressed through expressions or body language that might be indicative of lack of assent. Knight et al. (2006) suggest using a previously agreed, appropriately differentiated method for communicating discomfort such as for example a ‘traffic light’ system, whereby a child will give a yellow card if they do not want to answer a question or a red one if they want to end the consultation session.

Wickenden and Kembhavi-Tam (2014) also highlight the importance of respecting children’s dissent. They note that children may refuse to participate in one particular activity or choose to leave the whole project. McNeilly et al. (2021) remind us to be prepared to walk away from the consultation with little or no data (despite preparations) if a child or young person is not willing to participate on a particular day.

While it is the right of every person to be included in decision-making, where a person cannot give informed consent (over 18 years) or provide assent, they tend not to be included to remove the potential for any harm. However, this has led to an underrepresentation of disabled children and young people. In some cases parental consent for those under 18 can be accepted, however, the consultation/participation process must be of direct benefit to the child. It may be outside the scope of practitioners and policy makers’ expertise engaging in consultations or participative processes to make this decision. In the absence of clear guidance in relation to consultations and decision-making (a legal right) as opposed to participation in research, practitioners should proceed with caution but to also put in place longer-term developments to work with underrepresented groups. The legislative basis for including people who cannot consent in research is also outlined in the NDA’s Ethical

Guidance for Disability Research (NDA, 2024). Further considerations on consent and assent are available in Appendix 2.

Working with parents

The literature recognises both the benefits of working with parents (Tesfaye et al., 2019) and the potential barriers that parents can create to their child's participation (Mitchell et al., 2009). UNICEF (2013) notes that parents will have expertise on their child's needs or communication methods. It is suggested to involve parents in initial meetings so the child feels comfortable. The report notes that parents can also be powerful advocates for their children and can support participation through activities in the home. Tesfaye et al. (2019) also found that parents may provide valuable insights on how best to conduct participation initiatives with their children and can thus enable more meaningful participation.

However, UNICEF (2013) also notes that some parents may be protective and not wish to allow their child to participate. Some parents "may not yet perceive the potential of their child to learn, communicate and contribute to decisions in their own lives" and can therefore be a barrier to a child's participation. It is suggested that parents should be supported with information about the process and safeguarding that will be in place. An example of this approach working in practice is described by Mitchell et al. (2009) with a case study from the UK, 'Choice and Change', in which researchers wished to work with children who did not communicate using speech. Many parents were initially reluctant for their child to be involved and felt that they could not participate. However, a number of parents reconsidered after the researchers explained the project in detail and described the alternative communication methods they would be using. Mitchell et al. (2009) also noted that allowing parents or carers to be present during the research was valuable in terms of providing interpretation support and reassuring the children. Another example is provided by Franklin and Sloper (2009) in its participatory work with children with learning disabilities. The practitioners spoke with parents and children about the benefits and disadvantages of participation, methods to be used and any outcomes of participation. They found that parents wanted to be part of the process, wanted information and examples of successful participation initiatives and they wanted an opportunity to talk through any concerns. They found that some parents were pleasantly surprised when they saw their child participate and give feedback on the service.

However it is also recognised that the presence of others can influence the research process. For example, Mitchell et al. (2009) found in their case study of the 'Deaf Services' project in the UK that the preferred communication method indicated by the parent on behalf of the child sometimes differed from the communication method preferred by the child. This was influenced by whether or not the parent regarded the child as part of the 'hearing' community (using English and spoken language) or 'Deaf' community (favouring the use of sign language).

Bailey et al. (2015) in their systematic review on involving disabled children and young people in research found that parents, carers, hospital and school staff can act as facilitators or barriers. Ways in which they may act as a barrier include discouraging or preventing the child's involvement, speaking on the child's behalf, or interrupting the flow of communication. When acting as 'proxies' parents or carers' may unintentionally overshadow the authentic representation of their child's views, preferences or experiences. This can have implications on the reliability of the information gathered and also can minimise the voice of the child (Maenhout et al., 2023). However, it is also recognised that parents can provide invaluable information. The review suggests that these 'gatekeepers' should be informed of their role and responsibilities.

Cavet and Sloper (2004) cite research involving young people with disabilities who indicated that their parents are a valuable source of information for them. This indicates that parents' information needs should also be addressed in participation initiatives.

Jenkin et al. (2015) highlight the difficulty in balancing privacy and support, defining privacy as whether or not a child participates without a parent/guardian present when working with a researcher. They state that the parent may want to protect the child from exploitation/power imbalance, but that the child also has a right to privacy. The researchers suggest that dialogue with parents and children should include an explanation as to why privacy is something to be considered. They note that this issue is particularly pertinent for adolescents where they may wish to disclose information that is unknown to their parents. However, this report also notes that it could also be argued that young children, without the company of their parents, may feel uncomfortable participating in research. ‘Limited confidentiality’ is an approach which could be pursued in which it is explained to parents and children that confidentiality will only be breached for child’s safety.

Similarly to others, Jenkin et al. (2015) also highlight the importance of giving primacy to the views of the child rather than adult. They note that parents and caregivers may provide additional information to add context to children’s stories or they may assist with communication, acting as an interpreter of the child’s mode of communication. However, this role differs from the role of ‘proxy’ where an adult is asked to give their view on behalf of the child.

More recently, McNeilly et al. (2021) added to the discussion on managing the presence of others who can play an interpretive role and provide much support during a consultation, but whose presence can have unhelpful consequences (for example, adults can dominate the interview and speak for the child, and they may have a vested interest in offering certain types of information). The authors give specific advice including that if a child is consulted in the presence of their parents/support professional, the researchers should continue to engage directly with the child, for example, by asking the child to comment on what the adult is saying.

Parental involvement is an important area to explore in the context of recently increased focus on shared-decision-making in healthcare. In Ireland, Coyne and Martins (2021) demonstrated that parents and health care professionals’ protective beliefs, doubts about children’s competence and assumptions about children’s age and maturity were the reasons for not supporting children’s participation in healthcare decision-making. For health care professionals, the movement between supportive and non-supportive roles was also influenced by contextual factors, such as time constraints, workload pressures, communication skills, treatment protocols and type of procedure. The authors concluded that these obstacles are consistent with those reported by other researchers of pediatric shared decision-making.

Working with staff from the educational settings

Education staff are mentioned in the literature as stakeholders that may be especially important in relation to gaining access to promote the participation of disabled children and young people (Bailey et al., 2014; Franklin & Sloper, 2009; Gonzalez et al., 2021; Kelleher et al., 2014). Evidence suggests that directly targeting the involvement of seldom-heard children and young people in mainstream participation structures can increase the likelihood that they will become involved in them (Gonzalez et al., 2021; Kelleher et al., 2014).

Other researchers mention direct involvement of the education staff in the research process and/or the involvement of the researchers in the educational settings. For example, in Bloom et al.'s (2020) study, the researchers spent several hours in the children's educational settings, observing and collecting information, so they could develop and contextualise the questions that are meaningful for each individual child.

Similarly, McNeilly et al. (2021) suggest spending time with disabled children and young people in advance of a consultation, to build rapport and trust and to reduce anxiety. They suggest at least two visits to an educational setting: an introductory visit to build rapport with the child or young person, learn about the child or young person's way of communicating and their preferences, and to obtain initial consent, and the second visit for an actual consultation. The 'getting to know' stage can take place during an informal outing or can be an engagement in a creative activity (for example, art and craft activity). Best practice aligned with the Lundy Model of Participation (2007; 2011) would suggest two additional stages. A third visit to check the information gathered in the consultation is representative of the children and young people's inputs. Followed by a final visit to provide feedback of how their inputs were used.

McNeilly et al. (2021) also note that in some instances the education professionals may be ideally placed to facilitate or to support participation, given their knowledge of communication methods and their understanding of the participating children and young people. De Haas et al. (2022) explain how for some individuals due to the culture of prioritising self-advocacy, autonomy and the verbal voice, those with communication and cognitive differences can be excluded. The role of communication partner to help interpret or translate for some should be welcomed as part of someone's authentic autonomy rather than seen as undermining it (Davy, 2019).

In their research on Children Research Advisory Groups (CRAG), Horgan and Martins (2021) relied on schools to recruit children. They state that although they emphasised the need for diversity in the group, they were "sceptical" that this was sought by the schools and conclude that how CRAGs are formed is an important consideration. They suggest that if the schools are involved in such collaboration, "it is important that the criteria being used, whatever they are, are made clear, so that all involved know what they are" (p.173).

Planning for inclusive consultation environments

From the outset the principles of Universal Design should be utilised in the planning and implementation of participation processes (NDA, 2022). As Jenkin et al. (2015) point out it is important to facilitate the comfort, engagement and understanding for the participating children and young people. Similarly, Inclusion Europe (2014) emphasises that "it is important not only to vary activities, but also to include regular breaks to allow [the participants] to relax, as often as needed" (p.12). As I Am (2019) also emphasises the importance of being open to making changes to enable participation.

Jenkin et al. (2015) and UNICEF (2013) list strategies to overcome barriers to inclusion that are specific to different disabilities. Contrary to these previous guidelines, for the purpose of this literature review, we do not list these tips 'per disability type', but rather, and consistent with the social model of disability (NDA, 2022), we outline general strategies and methods for overcoming barriers to creating inclusive consultation environments.

A key principle for creating inclusive consultation environments is a total communication approach (Goodwin & Edward, 2017). Total communication approach is the ability to communicate using all means available. This may comprise a mixture of different methods that a person will use depending on the context, who they are with or intention for communicating. Some of these methods may include: natural gestures including pointing, facial expressions and body movements, speech, or vocalisations, use of different tones, pitch or volume of voice/vocalisations, computer generated speech, signs (e.g Lámh), symbols, real objects, objects of reference, pictures and photos. This approach helps the two way process of communication which assists the person to understand what is being asked while also helping them to communicate what they would like to express (Goodwin & Edward, 2017). Valuing all types of communication is of central importance.

It is important if possible to always ask the child what mode or modes of communication would work best for them – for example, Irish Sign Language interpretation, captioning, or text messaging (UNICEF, 2013; Jenkin et al., 2015). If a child does not use speech as their main or preferred method of communication, familiarise yourself with how they communicate and ensure this is accommodated fully.

Planning flexible and appropriate methods

Literature highlights that a continuum of participative methods must be used and all must remain flexible and adaptable during implementation. Flexibility in methods should allow all children to access, engage and enjoy the participation processes. Facilitators need to allow for a range of communication methods to be used as suited to the children and must be sensitive to the diversity of communication styles preferred as these may change during the participative process (Mitchell et al., 2009). Key considerations include:

- Differentiating methods to the needs and preferences of individual children and young people;
- Involving children and young people in the design and selection of methods;
- Being flexible to adapt methods;
- Co-designing and selecting engaging, creative, child and youth-friendly methods; and
- Identifying the needs of participants with them.

Kelleher et al. (2014) state that the key message to emerge from their review of the literature is that the methods used must be targeted to the specific needs and preferences of children and young people in order to facilitate meaningful participation. As well as using methods which encourage participation, practitioners must also question if their chosen methods exclude any child or young person. They state that organisations should adhere to principles rather than blueprints and that "such an approach emphasises the need for flexible practices tailored to the unique circumstances of the young people in question" (p.65). Kelleher and colleagues remind us that prescriptive approaches to participation are contradictory to the ethos of participation, as they do not enable children and young people to participate in ways appropriate to their unique circumstances. Similarly, the UK's National Children's Bureau (2013) states that flexibility and the use of a wide range of methods and approaches is important. Inclusion Europe (2014) also states that "It is important that all the tools selected be available and adapted to the needs and abilities of each child with disabilities involved" (p. 13).

Ireland's National Framework for Children and Young People's Participation in decision-making states that children and young people should be involved in developing methods that are age-appropriate, engaging and accessible to disabled children and young people.

Cavet and Sloper (2004) summarised the evidence surrounding inclusive approaches to involving disabled children and young people. From the available evidence, they highlighted the following as of particular importance:

- use of a multi-media approach or variety of methods;
- availability of resources such as communication aids or interpreters;
- use of advocates or mentors and multiple contacts in order to get to know the young person;
- flexibility about how children participate and recognising that children communicate in mediums other than speaking;
- independent facilitators so that children can give their views about services they use in confidence; and
- the need to make participation fun and rewarding.

In Kelleher et al.'s (2014) research, young people reported that they wanted participation activities to be fun, use youth friendly language and youth friendly space, leading the authors to conclude that standardised approaches are not recommended given the heterogeneity of the views of young people and their likely differing perceptions of these concepts.

In their guidance on Training Design, the Council of Europe (2012b) lists practical considerations for group workshops such as smaller sessions and more breaks, developing a “group agreement” in order to provide participants with the opportunity to fully understand the importance of following some of the “rules”, and they emphasise for participants with disabilities to be included in all activities. Other considerations include being flexible in time management and planning additional time. The guidance states some people with disabilities may need more time to express themselves. The importance of devoting sufficient time in order to effectively include disabled children and young people in consultations is emphasised by several researchers (Bloom et al., 2020b; McNeilly et al., 2021; Raman & French, 2002).

The guidance from the Council of Europe (2012b) suggests focusing on the desired outcome, rather than on the method; stating that if one knows the outcome one can adapt the appropriate methodology; and working without generalising the needs of people with certain types of disability (e.g. if you have worked with blind young people, it does not mean you know how to work with all blind people). Support should be identified *with* the person, not *for* a person with a disability. Needs of people with disabilities should not be generalised: each person, even with the same type of a disability, may have different needs and coping strategies. An individual-based approach is therefore crucial. Every person is different and the key point is to be prepared to adapt the methodology to each child’s individual needs. Similarly, UNICEF (2013) states that the child should be considered the ‘best expert’ about their disability and should always be asked how best to meet their needs.

Kelleher et al. (2014) conclude that for disabled children and young people to have the same opportunities to access participation, consideration needs to be given to identifying practical barriers to their participation and the implementation of measures to remove or at least minimise any obstacles to participation. Cavet and Sloper (2004) also found that flexible, tailored and child-centred approaches are necessary for meaningful participation. Similarly, Franklin and Sloper (2009) emphasise the importance of flexible and tailored approaches. They note however that in practice often a ‘one-size-fits-all’ model is used.

Several guidance documents list practical advice for supporting inclusion of disabled children and young people in consultations. For example, in their ‘Diversity Toolkit for Youth Work Sector’ the National Youth Council of Ireland (2012) advises to be welcoming and supportive and to ‘ask before you assist’ and to focus on the person, not their carer or parent. UNICEF (2013) suggests creating time for children participating in groups to get to know each other. If the group includes children with and without disabilities it is suggested to use games and activities to help them learn about each other and address any preconceptions. They also highlight that disabled children should be given the same opportunities and responsibilities as children without disabilities in a group and to focus on their strengths.

Use of arts and technology

Arts-based methodologies are known to promote more meaningful dialogue than more traditional qualitative methods, support discussions around complex or sensitive issues, and generally promote thinking differently, deeply and empathetically (Nathan et al., 2023). Nathan et al. (2023) note that arts-based methodologies that include the use of art forms such as poetry, drawing, mapping, collage, photographs/photovoice, participatory video, digital storytelling, drama and image theatre or theatre have been recognised as especially effective in engaging disabled children and young people and young people with complex psychosocial profiles.

The use of arts-based methodologies in consultations with children and young people should be further developed. Similarly, the use of social media and technology in consultations with children and young people must be more advanced. For at least a decade the researchers have called for the use of other technologies beyond the traditional photovoice and photo elicitation used in past research with young people (Drew et al. 2010; Nathan et al., 2023). For example, a systematic review of literature on digital storytelling (which involves using images and/or video to explore experiences) conducted by Jager et al. (2017) has concluded that digital storytelling has a particular potential to reach policymakers and create positive social change (Jager et al., 2017). Digital storytelling has, for example, been successfully used to elicit the voices of young autistic children (Parsons et al., 2021).

Kelly et al. (2021) note that the improved accessibility of mobile devices and digital technologies has the potential to increase involvement and engagement with children and adolescents. They argue that many global organisations, including the WHO and the Lancet Commission, are using online technologies, including social media and surveys, to gather information about health priorities directly from young people to inform strategy and policy. Since the COVID-19 pandemic these approaches have gained traction and urgency.

Visual aids, audio or video

According to Inclusion Europe (2014) “For children who do not use written communication, visual aids, audio or video are of great utility in complementing or substituting for written information. These tools can be created and used individually or collectively. They can be prepared for children by others or developed by the children themselves. Children can use drawings as a way to describe and comment on their lives and their environments, as well as to voice their opinions.” […] “Videos or animated movies can open up and facilitate discussion, especially on some sensitive issues or difficult topics. Children can comment on videos, but they can also shoot them themselves as a way of formulating their points of view” (p.13).

Franklin and Sloper (2009) used photographs with children to stimulate memory and discussion after attending consultation events. Overall, photographs have been used by many researchers to support children’s expression (for example, Bloom et al., 2020b; Courcy & Koniou, 2022; Mannion, Fitzgerald, & Tynan, 2021). Photographs help to focus the children on the here and now, and can be used in a consultation process in many ways. Depending on a topic, photographs can depict activities, places and people and/or the experiences of the children. For example, in Bloom et al. 's (2020) research, which studied the children’s experiences of school, the participating children were photographed in different places around their school in advance of interviews, and these photographs were then used to support their expressions. Photographs represent activities and people concretely, which is easier to understand than symbols for many children.

Wickenden and Kembhavi-Tam (2014) note that cognitive psychological research shows that information is understood much more easily visually than through hearing. Therefore, activities that are supported by visual information are more easily accessible for everyone. In their work, for the younger groups and for children with cognitive and communication differences, pictures (e.g. to support vignettes), mind maps, visual timetables and ‘talking mats’ were essential to enable them to contribute (Cameron & Murphy, 2002). In parallel, for visually impaired children, objects and tactile versions of charts were important.

Further guidance and examples of specific participation methods will be outlined in chapter eight.

Planning for accessibility

Moloney et al. (2021) state that accessibility is a key requirement under UNCRPD and it extends to the built environment but also to accessible information and ICT. They note further that the UNCRPD Committee has clarified that States Parties’ obligations regarding accessibility are ‘an *ex ante* duty’ which require infrastructure, information, goods, services etc. to be accessible without relying on an individual to first request access. This is in contrast to reasonable accommodation requirements which is enforceable only when requested and only if it does not place an undue burden on the entity providing it. The UNCRPD Committee report notes that this distinction means that failure to provide reasonable accommodation amounts to disability-based discrimination but a failure to provide accessibility does not. Universal design of ‘goods, services, equipment and facilities’ is also an obligation under UNCRPD.

Bailey et al. (2015) in their systematic review found that having an accessible venue is a key practical consideration. There has been much progress in relation to accessibility both in the literature and in the legislation. In Ireland, there are existing requirements for public bodies in terms of buildings, information and services under the Disability Act 2005. In 2012, the National Disability Authority published ‘Accessibility Toolkit’ offering specific advice on planning for accessibility. The concepts of universal design and universal accessibility have now been recognised by several organisations, for example, in Ireland in a guidance document for autism friendly universities authored by Mostafa (2021). The European Accessibility Act

(EAA) will introduce further accessibility requirements for products and services across the European Union. The provisions of the EAA will apply in Ireland and across all EU Member States from June 2025.

UNICEF (2013) and NYCI (2012) offer practical tips and strategies that enhance accessibility and safety of the consultation environments, including:

- Make sure the facility that you are using is accessible, in particular that the toilets can accommodate a wheelchair, that ramps are in place where there are steps, and that doorways are wide enough to fit wheelchairs.
- Remove any unnecessary obstacles – for example, chairs, plants, footstools, piles of papers, and alert the children (especially those who are blind) to these obstacles. Do not move objects around without telling the children about the change.
- Make sure the child knows where doors, windows and furniture are, how to find the toilet, etc.
- If the child uses a hearing aid, hearing loop or other assistive hearing device, avoid holding activities in places with lots of background noise. The devices usually pick up this noise making it difficult for the child to focus on what is being said.
- Use accessible digital content that can be read by screen readers.

The autistic SPACE framework developed by Doherty, McCowand and Shaw (2023) provides the key considerations of how to create a supportive environment for autistic individuals. This includes, knowledge of and accommodation of sensory sensitivities, providing predictability, acceptance and accommodation of difference as well as the diversity of how autistic individuals communicate and ensuring that the perspective of the autistic individual is considered.

Mostafa (2021) identified a range of barriers in higher education environments including sensory overloads including noise, overly bright or flickering lights, crowds and smells; large open-plan spaces and double height spaces; and other barriers in the form of unclear signage and entrance/exit distinction and lack of transition spaces. The range of solutions identified encompassed various strategies, including operational measures to improve predictability, such as the ability to reserve desk space, as well as the utilisation of sound field systems to enhance lecture acoustics. Additionally, flexible furniture arrangements were proposed to tailor spaces to specific needs, along with the provision of compartmentalised areas for different student groupings, ranging from individuals to small groups. Implementing one-way circulation systems, especially in crowded areas, was also suggested, alongside maximising natural lighting, ensuring effective signage, and providing access to technology supports such as charging stations and other devices. In addition, alternative parallel pathways were proposed to offer more sensory-friendly and appropriately transitioned pedestrian circulation throughout the campus.

NYCI (2012) also highlighted that some 'environmental' factors can 'frustrate' someone with sensory issues, e.g. overpowering smells (disinfectant, perfume, etc), noise (e.g. alarm going off unexpectedly), touch (difficulty handling certain textures).

At all times, all children should be treated with dignity and respect and their opinions and thoughts should be included in discussions. Children may feel anxious, worried or stressed when placed in situations where they lack control or where they may feel their needs may not be accommodated (Jenkin et al., 2015). Adults should always allow for choice and autonomy and be familiar with and responsive to individual accommodations.

DCYA (2014) note the importance of creating a safe environment for participation, through for example:

- Having information and lists of services to refer people to e.g. information on disability services or welfare services. Liaise with relevant agencies to get stocks of their materials.
- Forging links with organisations that can provide expert information on a particular cohort of children and young people e.g. organisations that support children and young people's mental health needs or that support children and young people in care.

They also note that "seldom-heard children and young people can often have a number of needs that facilitators should be aware of, be sensitive to and have a plan of action for dealing with" (p. 44). This may include issues related to being stigmatised/mocked and other social worries, or language and literacy needs.

According to Inclusion Europe (2014) “Age-appropriate and accessible language and information available for disabled children is a fundamental basis for equal participation, and a key to its success is the use of visual support to communicate” (p.7). For example Sign Language interpretation must be provided for members of the Deaf community who use Irish Sign Language (ISL). Occasionally, parents or siblings may offer to interpret for a Deaf child or young person. However, sometimes to be able to express their views openly and safely, a Deaf or deaf/hard of hearing child or young person will need privacy and confidentiality. In these situations, it is necessary to provide a sign language interpreter (UNICEF, 2013). For some disabled children and young people a communication partner will support interpretation and translation of nonspeaking ways of communication. A person that disabled child or young person knows and trusts well should be accommodated to act as a communication partner to support the disabled child or young person to express their views. It is important to note that this person is there to facilitate the child’s views to be understood, and not to speak on behalf of the child (Jenkin et. al., 2015). For some disabled persons, a family member acting as communication partner may not be a best fit if decisions are outside of the family’s normal practice and values (Saatlink et al., 2012). It is important to be aware of this and aim to avoid competing agendas that do not reflect the views of the disabled child or young person. Lawson et al. (2015) discuss the protection - participation dilemma, where the family’s high or low expectations influence a disabled child or young person’s potential and opportunity to participate fully.

Conclusion

This chapter included available evidence and practical recommendations on how to make participation work for disabled children and young people. We highlighted the importance of identifying and removing barriers to participation at all levels of an organisation, acknowledged that meaningful participation cannot be done ‘on a whim’ and outlined the steps for its careful planning, preparation and execution. We outlined key considerations for planning a participation initiative, including planning its scope and recruitment of children and young people. We outlined the principles for working with the child or young person’s parents/ guardians and staff from the educational settings and stressed the importance of safeguarding and gaining consent, as well as planning flexible and appropriately differentiated consultation methods. We emphasised the importance of a total communication approach. Overall, inclusive, flexible, multi-method and multi-media approach that may be tailored to individual needs of children and young people is recommended. Such an approach is consistent with the concepts of universal design and universal accessibility which should underpin all planning.

Chapter Eight: Participation methods: Practical activities and tools

Introduction

This chapter includes a review of participation methods that can be used in inclusive consultations. Consistent with a total communication approach, we outline a range of participation methods and consultation tools, including methods that support gaining assent and engagement for children who may not use speech as their preferred communication method. This chapter also includes practical considerations for planning advisory groups and creating inclusive focus groups, questionnaires and/or written consultations with disabled children and young people. We emphasise the importance of children and young people's meaningful participation at all stages of the consultation process.

Participation methods

It is important to first consider the purpose of the consultation tools being used. In addition to gathering the views of children and young people, the tools discussed in this chapter may be used for the purposes of consent and assent, capacity-building and relationship building with children and young people, and evaluation of the participation initiatives with children and young people. For all of these purposes, participation methods need to be adapted and tailored to the preferences of each individual child. There is no single method that will 'work' with all children (Dockett et al., 2012; Knight et al., 2006), however, often tangible and visual formats of the consultation are the most effective. Often a combination of participation methods may be needed to achieve meaningful participation. Participation should be viewed as a continuum along which the type of participation activities should be determined based on the unique cognitive, communication and sensory profile of each child. Thus, for some children choosing between two options may be meaningful, while for others this may be only the starting point (Franklin & Sloper, 2009). It is best practice to allow the children and young people to choose a consultation method. Some of these methods include:

- Mosaic approach;
- Activity-based participation methods including creative activities;
    - Drawings, collages, and other art pieces, including co-created portfolios and artefacts,
    - Play, drama, and other creative activities including creative communication.
- Ranking activities (e.g., diamond ranking or 'beans and pots' activity);
- Talking Mats;
- Digital Portfolios, Photovoice and Video Voice;
- Gamification (incl. virtual reality);
- Storytelling; and
- Observation.

The mode of communication the children use in everyday communication will determine the methods for consulting. This may include speech or Irish Sign Language (ISL) and/or other means that augment communication. This means that some children may express their views through pictures and/or symbols on a computer programme, or through gestures and emotions.

McNeilly et al. (2021) suggest incorporating an element of surprise, for example, keeping resources in a brightly coloured box or bag and asking the child or young person to unpack them.

The Mosaic approach

Originally designed to facilitate expression of children younger than five years of age, the Mosaic approach (Clark & Moss, 2011) as the name suggests combines a range of approaches to elicit children's views and so is in essence a multi-method of elicitation. For example, taking photographs (photovoice), child-led concrete activities (e.g., outings), map making, combined with observations and interviews may all form the basis of conversations with children in a mosaic approach.

This approach has been subsequently adapted by many researchers, for example, for use with autistic children and young people to establish their views about the outcomes they wished to gain from social care and support services (Beresford et al., 2004). The Mosaic approach brings together a range of visual and verbal methods to enable children to take an active role in expressing their views, forging traditional tools such as observation and interviewing and triangulating them with methods harnessing children's creativity and physical engagement with their world using tools such as cameras, tours and map making of the child's environment (Clark & Moss, 2011). The Mosaic approach can involve some of the below methods and tools.

Activity-based consultations

Activity-based consultations involve concrete and engaging activities that the children can participate in, including outings or arts and crafts activities, for example, making collages and/or co-creating various artefacts (incl., apps or games). Most children and young people would often discuss the most relevant issues while doing something else (McNeilly et al., 2021). It has long been recognised that more informal approaches to consultation may be more appropriate for disabled children and young people (Franklin & Sloper, 2009).

Craft activities can use photographs of activities and people that children know or even those that the children take themselves (see about photovoice below). Drawing, for example the Ideal School Drawing Technique (Bloom et al., 2020b), is often used as a simple and easily accessible tool to support conversations with 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 engagement in decision-making (Raman & French, 2021). This could involve hosting a number of co-design sessions for children and young people during which activities are introduced incrementally. Multi-method, multimedia creative activities, supported by visual artefacts, could be introduced to engage the participants. The use of play and storytelling, storyboards, puppets, drama and role-play, sketches and props (e.g., craft materials) are especially effective in co-creation and can be used to support children's conceptual thinking (McNeilly et al., 2021).

Creative approaches can be used to both present a consultation topic and/or as a tool for the participants to share their perspectives and experiences. For example, Raman and French (2021) used tangible artefacts (i.e., play wooden characters) and visual tools to support the participants to discuss their social network and storytelling and scenarios (incl. comic strips with blank speech bubbles) to support the participants to discuss online safety. Creative props and play items can enable conversations and help to structure the activities with disabled children and young people. The Involve me project described using creative communication utilising ways a person communicates already, encouraging to express likes and dislikes and using sensory objects that are important to the person. Story Sharing (Grove, 2017) is also a way to support involvement by helping a person to recall an experience or event and share it. Use of AAC, for example a speech generating device or messages recorded on a "Big Mack" device, can support this. Rather than answering questions, documenting sharing of important events can be an effective way to be consulted in an inclusive and flexible way.

Other inclusive tools especially helpful for gaining consent/safeguarding/talking about feelings may include the use of puppets. For example, Jenkin et al. (2015) suggest that using a doll can be a way to approach gaining consent, while UNICEF (2013) suggests using puppets as a means of helping children share their ideas, feelings and experiences. Puppets can be made out of socks or any common materials. Children can give puppets a name and introduce themselves. This approach is recommended for younger children or children with learning disabilities. Children can feel more comfortable talking about uncomfortable issues through the puppet. Inclusion Europe (2014) highlights that role-play, games and drama including puppets are very effective to support participation of children and young people with disabilities where interviews are less suitable. These methods are more meaningful to help better understand concrete situations, try out different situations, and comment upon them rather than engaging with more abstract ideas or conversational topics. All these activities allow children to present their doubts and problems and clearly state their opinions and feelings on the matter.

Overall, arts-based methodologies are known to promote more meaningful dialogue than more traditional qualitative methods, support discussions around complex or sensitive issues, and generally promote thinking differently, deeply and empathetically (Nathan et al., 2023). Arts can be also very effective as activities for identifying issues for discussion with children and young people. For example, in their guide for engagement of seldom-heard children and young people, DCYA (2014) lists a diverse range of creative and arts-based methods of engagement including vox pop, post-its, graffiti wall, wish box, and body map (which includes drawing/writing how children and young people want something to look and feel).

Ranking activities

The ranking activities ask children to sort given items into given categories, for example, to sort them according to which ones are most important or most liked. This method provides assistance and structure to children with communication and learning needs, thus enabling the children to have a voice, however, it still requires a degree of reasoning ability (Bloom et al., 2020b). One disadvantage of these activities is that the categories the children make preferences about are pre-constructed by adults. Examples of ranking activities include the diamond sorting activity, the ‘beans and pots’ activity, or the use of like/dislike post boxes.

Diamond sorting activity

In the original diamond ranking activity (Thomas & O’Kane, 2000), children were given post-it notes with statements written on them, and were asked to arrange them according to which activities they liked most at the top, and disliked at the bottom, thus forming them into a diamond shape. Depending on the cognitive profile of the child, the written statements can be replaced by photographs or illustrations.

‘Beans and pots’ activity

An example of a ranking activity that involves concrete objects is a ‘beans and pots’ activity (Goodall, 2019). In this activity, the participants choose given options, for example Goodall (2019) used ‘true’, ‘not true’ or ‘unsure’ in response to given statements by placing an object (e.g., personalised polystyrene ball) in one of the pots (with the options). The options can be also visually supported with for example thumbs up, thumbs down and a question mark or another visual prompt.

Like/dislike post boxes

To build rapport with the children during an introductory visit, McNeilly et al. (2021) used an activity of posting pictures and photos of things the children liked/disliked (based on prior information, for example, cartoon characters, foods, animals) into like/dislike post boxes. This is an adaptation of a ranking method, which is also similar to elicitation methods involving emotion reactions (see below).

Emotion-based reactions

Emotion-based reactions are methods that allow the children to respond non-verbally to a given topic by selecting an emotion that is presented to them in a pictorial, symbolic or other appropriate way. Such methods promote children's voice in non-vocal communication and may also reduce anxiety associated with the participation event (Bloom et al., 2020b). The limitation of this method is that it does not necessarily give an understanding of what is underlying the expressed emotions.
Wickenden and Kembhavi-Tam (2014) gave an example of using a visual scale depicted by emoticons showing different responses. For example, the research question focused on 'Things I like and things I don't like.' The emoticons depicted answers on a scale (like, don't mind, don't like, don't know). The researchers suggested topics they may like or dislike and the children were invited to put their response on the grid using stickers or fingerprints or their initials. UNICEF (2013) similarly outlines a methodology of a questionnaire which uses happy, sad or neutral faces as the possible answers to questions. Participation methods based on emotion-based reactions can be adapted to a child's or a young person's individual communication strengths and ways of understanding.

Examples of methods using emotion-based reactions include the Talking Mat. Below we give an example of an adaptation of a talking mat called Your Voice, Your Choice (YVYC) proposed by Bloom et al. (2020a).

Talking Mats

A Talking Mat is a well validated visual tool that supports children's expression. The mat contains graphic symbols to facilitate 'conversation'. For example, the mat can contain symbols depicting feelings and/or preferences (for example, thumbs up, neutral, thumbs down) and the child is given a selection of items or topics to place under these symbols as a record of their response. Talking mats are highly adaptable. They are also low tech and inexpensive to create (UNICEF, 2013). Typically, three sets of symbols representing topics, options and visual scale are displayed on a mat. The topic includes what is being talked about (for example, school, health); the options include symbols relating to each topic (such as types of activities); the visual scale includes symbols which enable the children to indicate their feelings about each option – for example, whether they are happy, unhappy, or unsure. Franklin and Sloper (2009) used talking mats to supplement verbal interviews with children with learning disabilities and communication difficulties. Questions were written on cards (e.g. "Were you listened to?") and children could choose from symbols for their response.

The Your Voice, Your Choice (YVYC) method below shows an example of how the talking mat can be adapted for different children.

Your Voice, Your Choice (YVYC) (Bloom et al., 2020a)
The YVYC is an example of a non-verbal, visually-based, flexible method that uses a combination of multi-sensory stimuli that can be adapted to suit the individual. This method facilitates children's communication through emotions. The YVYC evaluated by Bloom et al. (2020) comprised a felt mat with Velcro bases on areas that the children could manipulate. Emotions were provided at the bottom of the mat, represented pictorially by symbols familiar to the child (for example, smileys, thumbs-up, and so on). The range of emotions could be differentiated for each individual child, simplified or extended as needed. For example, some children may choose from 'happy/sad' while others may have a wider range of emotions, some children may have a 'not at all', 'a little', 'quite a bit', 'very' and 'extremely' added to achieve a more nuanced expression of emotional intensity (Bloom et al., 2020).

A consultation topic can be presented to children using photographs, symbols or tactile objects, and the children could place them on the scale on the mat according to how a particular experience made them feel (see also section below on Supporting Understanding)

Photovoice / video voice

Developed by Wang and Burris (1994), photovoice supports children's expression by asking them to photograph what matters to them. In this process the child is given a camera over a period of time and takes photos (or videos) to help answer the research questions. According to Jenkin et al. (2015) this method has been found to be accessible for a range of children with diverse disabilities. Photovoice has been an established method of participatory research for a while now (see for example Courcy & Koniou, 2022 for a review) and has been found to be especially valuable as a participation method for children who may not use speech as their main or preferred method of communication or for those who have intellectual disabilities (Wickenden & Kembhavi-Tam, 2014; UNICEF, 2013).

This visual participation method promotes children's empowerment but it has been noted that it might not provide usable information upon which practitioners and policy makers can act (Bloom et al., 2020b). As a participation tool, photovoice is flexible and adaptable, and can be used to document the lived experiences of participants in a range of ways. When the photographs are taken, children are encouraged to share their view and experiences with the prompt of these photographs.

According to Wickenden and Kembhavi-Tam (2014), an important and novel aspect of photovoice may be the element of choice and control the camera imparts, as well as the objectivity and distance from what the children are describing. For those with cognitive or physical differences, the demands of using a camera are much less than drawing, although some participants may need physical assistance.

The advantage of photovoice is that an informed assent is built into its various stages and ongoing in photovoice projects (Mannion, Fitzgerald, & Tynan, 2021). Photovoice gives ownership to children on if and how they would like to participate and if and how they would like to represent themselves and their reality.

Photographs may be used in participation in other valuable ways. For example, Jenkin et al. (2015) collected a series of photos which represented human rights areas related to the UNCRPD which children could select from in order to answer the research questions. This was then used as a prompt to facilitate a discussion about the topic. This method was termed a Photo Library, and is similar to a Sound Library (also quoted by Jenkin et al. 2015) which uses short audio recordings of sounds relevant to the research questions which the child then selects to help them answer. An extension of this is digital portfolios as a form of multimedia advocacy (MENCAP, 2011). This includes film, photos and sound recordings of people and things the person knows well. It supports the person to start to show preferences through their responses or body language as they look and review this information.

Gamification (incl. virtual reality)

The use of multimedia interactive games and virtual reality with a design of children-friendly environments and a playful strategy have recently been used in shared decision-making in paediatric healthcare. For example, Chang et al. (2023) designed a multimedia mixed reality (MR) interactive game to engage children in clinical decision-making about their treatment of skin disease. In the game, the children were represented as apples which were rolling around before the treatments and sleeping soundly after the treatments, and they helped the apples in the metaverse to undergo treatments ('help the apple with the injection, please' 'the untreated apple is still itchy, rolling around and can't sleep'). Similar type of game format was also used as an engagement tool by Teele et al. (2022) who used a more traditional format of playing cards to include the voice of adolescents in decision- making about hospital care, research and policy. The young people involved in the project came up with their own themes for the cards. The clinician led the game with a consultation question and the players turned over the top card of their decks (with previously identified themes) and placed it face upwards anywhere on the game board.

Storytelling

Methods supporting gaining assent and engagement as well as explaining the consultation process may need to be further differentiated and may require more specialist support, as well as increased investment of time and resources. It is important that children fully understand the consultation process and the questions asked. This can be done through for example broadly defined storytelling as in the below approaches.

Social narratives or social stories

These are pictorial based short stories or scripts that explain a situation or concept using minimal or little text with pictures. Developed to support social communication, they can be presented in advance of a new activity or to help understand situations that may not be clear to some children or young people. Gray (2010) developed social stories that can be written by anyone according to a set of key criteria. While these are a teaching tool for social communication they can help to make more abstract topics clear as well as make future events or activities more predictable. The story should clarify for the child or young person what is expected or allowed, for example, movement breaks and/or use of sensory toys etc. in consultations.

Comic strip conversations

These are another form of social narrative that may be helpful to communicate the purpose of the consultation and to gain pupils' thoughts, feelings and perspectives. This method uses simple figures and other symbols in a comic strip format to help create a more concrete representation of abstract topics. Children and young people can draw line figures to represent themselves and others, describe what is said and what is thought in speech and thought bubbles. Different colours can be used to indicate different emotions or states of mind. Facilitators can design or co-create the comic strips conversations with a child or young person. Originally developed to support children and young people to understand the sub-text of social situations, they can be used to support more concrete understanding of abstract topics (Massetti et al., 2018). These can be flexible and adapted to ensure no social norms are imposed on the child or young person.

Sensory stories (Grace, 2022)

These stories are a very short narrative with the emphasis on using key sensory stimuli and concrete objects to represent the activities and ideas in the story. Grace and Bell (2022) argued that the views of profoundly intellectually disabled people are usually gained by proxy through parents or professionals and more creative methods are required. They report on one such creative method, namely how a listening sheet was completed by people close to the participants that outlined how each participant expressed themselves and their reactions to experiencing sensory story.

Story massage (Atkinson, 2021)

In some settings communication partners, parents or caregivers may use story massage to share stories. There are ten key strokes and symbols that are used based on the understanding of the importance of nurturing touch in communication (Barnes & Hewett, 2015). Only those known to children and young people who regularly use and have consented to story massage would carry this out. Illustrations and photographs depicting the activities and people involved in a consultation could be included.

Story sharing (Grove, 2017)

In this method, the emphasis is placed on social participation and emotional engagement rather than a well formed narrative structure where significant events are captured and retold. Suggestions for implementation include to ensure people are actively involved in the activities happening around them and to include stories about smaller events as well the bigger ones that were funny, surprising, tricky or unexpected. Props and AAC can be included to support. The story is told together so as to ensure there is space for the person to join in when they can and avoid too many questions (MENCAP, 2011).

In general, storytelling can be used in diverse ways to engage disabled children and young people. In the example by Wickenden and Kembhavi-Tam (2014), a story was told about a disabled child being excluded from sports. The story was supported by singing and pictures. Afterwards the children had a discussion about it. Haas et al. (2022) used “small stories” to include people with profound and multiple learning difficulties (PMLD) in their research on belonging using “sensory ethnography”. Life Story methodology has also been used to capture important events in the lives of people with disabilities (McCormack, 2020). This involves using various methods for people to share their lives in a meaningful way. Instead of interviews, Kennedy and Brewer (2014) analysed photographs, scrapbooks and songs. Objects and memory boxes have also been used (Hewitt, 2006).

Jenkin et al. (2015) describe a method called a ‘story in a bag’ which involves filling a bag with objects familiar to the child which are relevant to the research question. It is suggested that some topics to consider could include health, education, housing, play, friends, family, food and drink, or transport. The kinds of objects suggested for this activity are everyday objects such as a book, cup or a toy. The child then selects an object in order to help them answer the research questions. Similar method called "Bag Books" as cited by Preece & Zhao (2014) provided a range of multi-sensory stories using concrete items covering a wide variety of topics that are highly valued by families, professionals and children themselves.

A systematic review of literature on digital storytelling (which involves using images and/or video to explore experiences) conducted by Jager et al. (2017) has concluded that digital storytelling has a particular potential to reach policymakers and create positive social change (Jager et al., 2017). Digital storytelling has, for example, been successfully used to elicit the voices of young autistic children (Parsons et al., 2021).

Observation

Observation methods are often included as part of multimethod approaches, for example, as part of mosaic approaches and photovoice as earlier outlined. Often observation is cited as used as part of participatory research with children (Gonzalez et al. 2021). Observation can help to influence decision-making in more indirect ways, in particular for children who do not rely on speech to communicate (Commissioner for Children, Tasmania, 2015). Watson (2016) used observation alongside interviews and questionnaires for people with profound and intellectual and multiple disabilities (PIMD) and their supporters to ascertain key themes for their participation and decision-making processes. Similarly, Bloom et al. (2020) spent several hours in the children's educational settings, observing and collecting information, so they could develop and contextualise the research questions that are meaningful for each individual child. While observation may be viewed as adult directed, co-designing and co-creating what observation entails with children and young people is important. When considering consent and assent for observation of a person with PIMD it is important to consider that "autonomy for a person with PIMD is viewed as a relational construct, best realised in collaboration with those in the person's life who know him or her well" (Watson et al., 2017, p. 1023).

Making traditional consultation methods more inclusive

Inclusion Europe (2014) highlights that focus groups and interviews are a common methodology used for gathering information from children. Their guidance states “both interviews and focus groups have to be conducted in a manner in which the child feels comfortable to share his/her point of view and feels that he/she has control over the process and the situation. Again, accessible and age-appropriate language must be used – visual aids can also help children during interviews or focus groups. Children can also interview one another, or interview other interlocutors of their community. The preparation of the interviews and material should take the child interviewers’ abilities and needs into consideration. The material should be accessible, easy to use (with enough space to take notes), and pictograms may facilitate the interview process; children may learn to interview in pairs, for example, in order to support each other: One can ask the questions while the other writes down the answers” (p.14).

The World Café methodology serves as an interactive participative group conversation technique aimed at fostering meaningful dialogue and consensus building. It encourages participants to openly share their insights, ideas, and experiences in an inclusive and relaxed environment. A pivotal aspect of this method involves the use of placemats or large sheets of paper for participants to record their thoughts and contributions. Roy and colleagues (2019) found this is a good practice approach for consulting with Deafblind participants. Participants were informed that familiar support staff would assist in coordinating the rounds of questions to ensure effective communication and safe navigation within the venue. Notably, the duration of the World Café event was extended to five hours, surpassing the typical three-hour timeframe. This adjustment was made in recognition of the complexities involved in sign language and tactile interpreting, allowing participants, and supporting professionals, ample time for engagement throughout the research process. Each World Café session comprised three rounds of questioning, with each round lasting approximately 50 minutes. Following each round, a designated participant from each table assumed the role of a 'host' and provided a summary of the key findings. Importantly, all rounds incorporated a diverse range of communication modalities, including Auslan, tactile sign language, and spoken English, to accommodate the varied needs of participants. To facilitate data collection, participants were asked to indicate their preferred communication style on a badge, enabling professional note-takers to record data accurately according to

Auslan, tactile sign language, spoken English, or a combination thereof (Roy et al., 2019).

Inclusion Europe (2014) highlights that “materials involving written languages need adjustments to be accessible by children with intellectual disabilities”(p.14). They note that European standards on how to make information accessible must be taken into consideration when drafting written consultations. Images, drawings or symbols may be used to facilitate the understanding of a text, but care must be put into the selection of such visual aids in order that they not become obstacles. They also state the importance of cultural sensitivity in designing and using pictograms and drawings.

In addition to visual support, several researchers propose specific guidance for phrasing of written language. For example, Davison et al. (2022) proposed specific adaptations of surveys, co-created with adolescents with intellectual disabilities, to ensure full understanding and full participation, as below:

- 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 participants to reflect upon and recall past feelings and thoughts, 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 (for example, thumbs up and thumbs down).
- Present one item at a time during administration; and
- Develop alternate formats of the survey to ensure inclusivity (for example, using touch screen devices).

Some specific tips for supporting communication will be helpful for all children and young people, including disabled children and young people. For example Jenkin et al. (2015) and UNICEF (2013) give the following tips:

- Use plain language, avoiding jargon. Supplement this with audio/visual supports.
- Take time to make sure that the person understands the topic or activity to be completed.
- Keep the format of questions simple and short (ask one thing at a time).
- Allow plenty of time to answer. Give children adequate time for expression.
- Use simple answer choices such as a 2 point scale.
- Use **visual** prompts (pictures, objects, symbols, text) to support communication and key imagery to break down concepts which may be difficult to translate. Visual images such as photos, drawings, or videos can help to promote communication, especially when discussing abstract ideas or to help children explain their feelings.
- Consider the use of audio, audio description, easy access, subtitles, simplified (or plain language) and other adaptations.
- Use alternative forms of communication, for example, symbol boards or computer-assisted systems. For guidance on AAC see Appendix 1.

Several researchers, including Jenkin et al. (2015) and the authors of the NYCI (2012) add further the following strategies, which again will be beneficial for all children and young people:

- Use plain language in any written communication.
- Use large font high contrast text.
- Have an option to hear the question.
- Use tactile prompts such as objects associated with the question or objects to feel and select as an answer.
- Offer Braille translation if the person uses Braille.
- Offer to record the participants' answer and allow them to listen back to confirm it.

Including children in the analysis of and reporting on consultation

It has been recognised for some time now that directly involving children in the process of data interpretation as co-researchers is crucial to ensuring that findings are grounded in the perspectives and experiences of children themselves as opposed to reflecting adult interpretations of children's perspectives (Lundy et al., 2011; Horgan & Shirley, 2021; Kelly et al., 2021; Montreuil et al., 2021).

World Vision (2007) guidance states that the methods that are used to collect the data will also help to determine the methods that will be used to analyse the information. The final consultation report should include a summary of all of the children's ideas and opinions presented during the information-gathering phase. A summary of the procedures used to analyse the data should also be provided. The guidance cites an example of how a consultation report was put together with the involvement of the participating children. The consultation team collected all of the responses and recorded the main themes in a spreadsheet; they then tabulated how many times each theme was mentioned. The results were brought back to a steering committee of approximately forty children, who reviewed them and gave their own opinions and helped to prioritize the topics.

World Vision (2007) highlights that having children participate in the writing of the report, and/or including direct quotes from the children, helps to give the report weight. For example, depending on children's capabilities they may be able to write some of the report or assist with editing, have a say which sections need more focus, or assist with formatting. However, as Lundy et al. (2011) noted, our assumptions about the capacity of children (especially disabled children and very young children) to interpret data means there are very few examples of including children in the interpretation stage of the consultation findings in the literature.

Conclusion

This chapter included the review of inclusive participation methods and approaches, including the mosaic approach, activity-based consultations, arts-based consultations, gamification, storytelling, and specific methods such as ranking activities and talking mats. We highlighted that ideally participation methods should be co-created or co-constructed with disabled children and young people. Due to demands this may place on disabled children and young people, at a minimum, participation methods need to be adapted and tailored to the preferences of each individual child. There is no single method that will 'work' with all children. Often tangible and visual formats of the consultation are the most effective. Often a combination of participation methods may be needed to achieve meaningful participation. Methods supporting gaining assent and engagement for children who may not use speech as their preferred communication method may need to be further differentiated and may require more specialist support, as well as increased investment of time and resources. Practical considerations for creating inclusive focus groups, questionnaires and/or written consultations with disabled children and young people were also outlined. We emphasise the importance of children and young people's meaningful participation at all stages of the consultation process.

Chapter Nine: Evaluation of the effectiveness of participation and the feedback process

Introduction

This chapter is focused on evaluating the effectiveness of participation and the feedback process. We highlight the importance of evaluating both the outcomes for children and young people themselves and evaluating the effectiveness of the process, as well as the scope, quality and outcome of the consultation. This is especially important for children and young people whose views are seldom-heard or influence decision-making, including very young children and children who do not use speech as their preferred method of communication. In addition, we discuss the importance of feedback within the decision-making process. Feedback ensures that those consulted receive a formal response about how their views have been considered and the extent of their influence. Similarly to the consultation itself, the evaluation of participation with disabled children and young people and feedback provided must use inclusive methods, and we outline approaches to achieve this inclusivity in this chapter.

Measuring the impact of participation

UNICEF (2013) suggests measuring the impact of children's participation by measuring the Scope, Quality and Outcome of participation. To assess the scope of participation it is necessary to examine the point of engagement and the level of engagement. The point of engagement refers to how early in the process children were involved. The earlier they are involved, the greater their level of influence. The level of engagement refers to whether the process was consultative, collaborative or child-led. To assess the quality of participation it is necessary to obtain feedback from children to establish to what extent standards for quality participation have been met. The outcomes should be assessed in terms of the objectives for involving disabled children. For example, the objective may be to build the skills of the child, to change a law or policy, or to allow children to develop ways to make complaints when their rights are not upheld. Objectives should be set at the beginning and this will guide the indicators to be used to measure outcomes. Types of outcomes could include outcomes for disabled children (for example, increased knowledge, skills, and awareness of rights) or outcomes in relation to the attitudes or behaviour of parents, staff, services, or organisations with regard to disabled children. Outcomes can also include structural outcomes which have a wider impact (for example, community development, legal reform, media access).

The DCYA (2014) guideline on including seldom-heard children also states the importance of evaluation. It is recommended to establish realistic aims at the outset, capture competencies and learning throughout the process, invite feedback from the children and young people from the outset, and to be willing to change course when things are not working effectively.

Similarly, World Vision (2007) suggests evaluating the process on both a macro and a micro level. At the macro level this could be assessing whether there is greater transparency between government and children as a result of the process. At the micro level this could mean assessing gains in the child’s capabilities, knowledge, and confidence as a result of engaging in the process.

The UK National Children’s Bureau Research Centre (2013) in its literature review found that there is a lack of evaluation of the participation of disabled children and young people both in terms of process and outcomes. As a result, there is a severe lack of systematic evidence that the participation of disabled children and young people is having a major effect on decisions related to policy, practice and resources. Also Kelleher et al. (2014) note that “identifying the actual impact of young people’s participation in public decision-making processes is hindered by a dearth of documented evaluations of participation initiatives. Young people’s voices are largely under-represented in the existing national and international literature on outcomes from participation" (p. 50). We know from this literature review that this is even more so the case for seldom-heard children and young people.

In terms of practical advice for evaluating consultation, Kelleher et al. (2014) cite research proposing that indicators of effectiveness of participation should be jointly identified by young people and the adults who work with them.

Several previous papers mention specific groups of children whose views are less likely to influence decision-making, such as very young children (Hester & Moore, 2018) and children with communication differences (Franklin & Sloper, 2005). There should thus be an increased effort to engage these groups of children in decision-making and we need to evaluate their engagement, the consultation process itself, and the outcomes of these consultations to inform further developments in this area. The use of inclusive evaluation methods are critical in this evaluation.

Inclusive evaluation methods

Similarly to the consultation itself, the evaluation of participation with disabled children and young people should use a multi-method approach, with visual support and artefacts to support children and young people's reflection. For example, both the consultation outputs (e.g., posters, creative artefacts) and the tools used to support the consultation process can be rated using stars, smileys or other emoticons (see Chapter eight for specific methodologies).

Adapting consultation evaluation methods to be inclusive of disabled children and young people is crucial to ensure their voices are heard and their experiences are considered. Below are some strategies and examples of evaluation methods that can be made 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.

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, children and young people'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 ways to provide feedback, such as tapping, swiping, or using assistive devices like switches.
6. Storytelling and artistic expression:
    - Narrative or arts-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/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.
8. Visual timelines:

    - Timelines with symbols: Create visual timelines or schedules with 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 options for evaluation, 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 National Participation Framework on pages 20-23 (DCEDIY, 2021).
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 participation. The results of this evaluation can then be included in the feedback given to the participants.

Giving feedback to children and young people

In the context of children and young people's participation initiatives, feedback is a critical component of the decision-making process. It ensures that those consulted receive a formal response about how their views have been considered and the extent of their influence. Lundy (2007), in creating the Lundy Model of Participation, emphasised the importance of a feedback process to create conditions where it becomes uncomfortable for adults to solicit children's views and then disregard them.

Children and young people highly value feedback for several reasons, including gaining insights into different perspectives, understanding planned changes and their timelines, and comprehending the reasons behind decisions that do not align with their ideas (Lightfoot & Sloper, 2002). Unfortunately, there is evidence that feedback is not consistently provided, leading to negative outcomes, such as disillusionment with participation and perceptions of tokenism (Franklin & Madge, 2000).

For instance, Franklin and Sloper (2004) conducted research to assess the extent of participation, including feedback provision, within initiatives involving disabled children and young people across social service departments in England. Out of 129 departments, 102 were involved in such initiatives and agreed to participate in the survey. The provision of feedback varied among departments. In the context of individual care packages, 11 out of 64 areas/teams did not provide feedback to the young people involved. Among the remaining 52, seven did not offer specific details about the feedback process. Of the 45 that did provide feedback, verbal communication through social workers, key workers, or advocates was the primary method, often integrated into the review process. Few had established alternative feedback mechanisms, and when written information was provided, it was consistently directed to parents.

Some respondents expressed concerns that feedback was either inconsistent or not tailored to the needs of young people. Only one respondent mentioned trying to use communication methods suited to the young person. In one instance, an authority had developed a written booklet for social workers to use after a review, providing information about "What was said and what people are going to do!". Some believed that young people could perceive the results of their involvement through the implementation of decisions or changes in services. However, it is important to recognise that young people may not always associate their involvement with such changes, especially if decisions are not made immediately or if changes take time to initiate.

In the area of service development, feedback to disabled young people was inconsistent, with some indicating that feedback was directed to their parents. Among the 70 initiatives, 23 stated that they did not provide feedback to the young people involved, often citing it as too early in the process. Good practice guidelines in participation (e.g., The National Participation Framework, 2021) stress the importance of providing feedback, even in longer-term participatory activities. Out of the 70 initiatives, 43 provided some form of feedback to disabled young people. Verbal feedback remained the most common method, with many using forum meetings as a means of disseminating information. Several forums produced accessible meeting minutes, some of which were created by forum members.

Some initiatives reported sharing reports with young people, though the accessibility of these reports remained unclear. Additionally, a few initiatives extended invitations to participants for events like the launch of local play strategies or board meetings. Furthermore, some forums arranged meetings with service managers. Once again, respondents believed that concrete changes or outcomes resulting from young people's involvement served as evidence of its effectiveness.

While it is likely that the feedback process has improved since the research mentioned, other specific examples were not found in the literature. To ensure this essential element of participation is upheld, guidance is available in the National Participation Framework (DCEDIY, 2021).

The National Participation Framework recommends Professor Laura Lundy’s four ‘Fs’ feedback process for consultations or collective decision-making processes with children and young people (Lundy, 2007; Lundy et al., 2011). More information on this can be found on page 11 of the Participation Framework (DCEDIY, 2021). Feedback should be planned from the outset and, if necessary, discussed with communication partners, parents, or caregivers. It should be tailored to the preferences of the child or young person, incorporating a variety of communication methods, both verbal and non-verbal. This includes the use of communication frameworks like Talking Mats or the Mosaic approach and the incorporation of communication supports such as objects of reference, photos, symbols, videos, Voice Output Communication Aids (VOCA), and other Augmentative & Alternative Communication (AAC) supports.

The 'Four Fs' feedback process entails:

- 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.

This approach helps ensure that feedback is not only provided but is meaningful, accessible, and responsive to the needs and preferences of children and young people involved in participation initiatives.

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 may include concrete items and outputs, posters with photos, infographics, video recordings, webinars and social media, visits, talks or in-person experiences. Children and young people are experts of their own lives. Ensuring we show them they have been heard, their views have been given due weight, and explaining where their views have had (or have not) an influence in a way that is understood by them is crucial to ensure their rights are being met.

Conclusion

In this chapter we highlighted the importance of evaluating all outcomes and processes of the consultations and participation initiatives, including their scope and quality. This is especially important for children and young people whose views are less likely to influence decision-making, such as very young children and nonspeaking children, as for them especially ongoing methodological developments in this area are urgently needed. In addition, the importance of providing feedback to those consulted is underscored, as it is not only valuable for the children and young people, it creates conditions where it becomes uncomfortable for adults to solicit children's and young people's views and then disregard them. This literature review informed the development of a scoping document aimed at providing advice on how to meaningfully and effectively involve disabled children and young people in the decision-making process and approach participative consultations and initiatives in the most accessible and inclusive way possible. Both the process of the scoping document development and the document itself are informed by the evidence and best practice principles reported in this literature review, including the consultation with disabled children and young people. They were asked what works and what does not work when asking them to have a say in decisions that impact their lives and their recommendations on what should be included in the scoping document.

In relation to evaluating the effectiveness of consultations, our literature review showed that the knowledge on how the concepts of audience and influence can be operationalised in practice, especially for disabled children and young people, remains limited.

Conclusion

This literature review shows extensive both international and national legislative and policy context which underpins our obligations to disabled children and young people’s participation. Despite these obligations, most of the literature focuses on the barriers and challenges of participation, and remains short on solutions. However, there is an acknowledgment that with genuine commitment and sufficient investment meaningful participation can be achieved, and some practice examples can be found in the literature. Meaningful participation cannot be done ‘on a whim’ - careful planning, preparation and execution are all needed. This includes appropriate resourcing of participation, including staff training and development, investment in appropriate participation methods, and ongoing investment in methodological and practice developments in this area. Key message from the literature is that the participation methods used must be responsive to the needs and preferences of disabled children and young people in order to facilitate meaningful participation. Inclusive, flexible, multi-method and multi-media approach that may be tailored to individual needs of children and young people is recommended. Such an approach is consistent with the concepts of universal design and universal accessibility which should underpin all planning for inclusive consultations. Above all, participation must be embedded across all structures and organisations, in a whole systems approach and embedded as an integral part of our relationship with all children and young people, regardless of their age, size, ability or disability.

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Appendices

Appendix 1 - Types of 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 (e.g., Lámh), gestures, expressions and body movements. For some disabled children and young people communication may be through vocalisations, movement of eyes, mouth or some physical movement. Communication partners will be able to interpret meaning here or this will be included in a communication profile. For example, for some children or young people expressing joy could look like jumping, flapping hands and vocalising. For others' interest, happiness and engagement could be through following and tracking an item with eyes, pointing or leading someone to an item of interest.

Lámh is a key word signing system that involves a combination of using 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 a communication aid rather than a language. It does not have finger spelling and users of Lámh speak the key word along with the sign. The Lamh website (lamh.org) provides lots of useful information

Aided Communication

This type of communication involves the child or young person using an external type of device that is separate to their body. This includes sophisticated types of devices (high tech) and more simple systems (low tech). Usually low tech options do not need a battery.

Low Tech

- **Eye Pointing**

Children and young people may use eye pointing at symbols/photos/pictures to indicate their choice or answers to questions. The child's eye gaze will let you know. You may need larger symbols, photos, pictures or use a board that clearly separates the options.

- **Objects of reference**

These are used to represent words and ideas in a concrete way through touching the item and feeling its shape (and sometimes its smell). They are helpful for understanding and objects can be used for expression also. Objects can be used to represent activities and preferred items. A small piece of a larger item known as a remnant may be used also.

- **Core Words Boards**

Typically a rectangular piece of laminated board with 36 universal signs that can be used for a range of topics with a range of communication partners. Symbols include text. 3D options can be developed also. Communication partners use core boards to model all language in the correct sentence structure without expectations placed on the child or young person. Symbols can also be integrated into a more high tech Speech Generating Device (see below).

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

This is a programme to teach children how to initiate communication through use of pictures. There are key phases through which communication is taught. It begins with teaching very functional communication skills e.g. single picture requesting and learning how to approach communication partners to request. People who use PECS can use a range of symbols to request what they would like or need and can be expanded for wider expression also. Some children may use a variety of pictures or symbols and supports.

High Tech

- **Eye gaze technology**

This is an eye operated communication and access where the person's eye gaze is calibrated to select choices on a screen. It usually also includes a speech output system.

- **Speech Generating Devices (SGDs)**

Typically these are computer based devices that produce an electronic voice. It requires the person to select an image or word to produce the sound. A number of SGDs types are available from more durable types with less picture options. Battery operated devices are available for example large buttons known as “Big Mack” where a message can be pre-recorded and the child or young person can be supported to press the Big Mack button to hear their name or a greeting for example.

- **Switches**

Switches can be used to enable access to a range devices including computers or toys. They can be positioned where the child or young person has the mobility to use it e.g head switch versus leg switch. It can allow for starting or stopping of toys, or computer programmes for example.

Communication using senses

This reflects children and young people who use all senses to receive information through touch, smell, sound and sight. Everyday objects can be used or more high tech options that are available in sensory rooms.

- **Resonance Boards**

A plywood board usually large enough to lie on but slightly raised from the floor provides sound and vibrational feedback. Items can be placed on the board allowing for exploration as well as communication through tapping turn taking games (hearing sound and repeating it, initiating creating a sound on the board and it being repeated back to you).

- **Sound Beams**

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

Appendix 2: Consent and Assent Considerations

Key consent and assent considerations

- Engage in early planning of the consent and assent procedures.
- Identify the stakeholders in the consenting process (e.g., parents/guardians, education staff).
- There is no one-size-fits-all approach to obtaining consent and assent for participation of disabled children and young people. For a group of disabled children and young people, it is likely that two or three versions of consent and assent will be necessary, appropriate to each child's developmental level.
- Ensure that the benefits of the consultation for the participants (for example, in terms of self-esteem, confidence, social skills, and enjoyment) outweigh the demands the consultation may place on them.
- Communicate the purpose of the consultation and what the participants will be asked to do using methods accessible to and differentiated for the participants,

including visuals, symbols, tactile objects, simplified language, and/or audio and technology (for example, through a digitally drawn illustrations of the consultation process or in the form of a video/animation, or a social story). You may include photographs of the people who will conduct the consultation/participative process, or use play items like dolls. Observe children's facial expressions and body language to ascertain assent.

- When the children have received accessible information about the consultation and participation process, allow the children to make an informed decision about whether or not they want to participate in a consultation event or participation process and about their preferred participation method. At all times if a child indicates that they do not wish to participate or that they wish to cease participation, best practice is to see the child's wishes as trumping any counter wish on the part of the parent(s) or other responsible person(s) for the child's participation to commence or continue (BPS Research Ethics Code, 2021).
- In research with children, informed consent must be obtained from the parents or guardians of the child. Once this is received, it is generally acknowledged that a child's expressed willingness to participate (i.e., 'assent') is sufficient for children and young people once they understand the activity in general and what is expected of them (Cotrim et al., 2021). Detrick and Peterson (2021) suggest that choice and a so-called 'concurrent chains procedure' (i.e., when the child has two activities available simultaneously and selects one of them) could be a useful procedure for gauging assent for participation of children who are deemed to not have the "capability" to assent using typical assent procedures. The child's selection of a participation activity would be an indication of assent. In accordance with the HSE national consent policy on involving children, once informed consent from parents and guardians is given then assent from the child should be obtained also. Where it is not possible for children to give assent formally, their wishes and opinions should be taken into account. The child's assent or decision to dissent should be documented (HSE, 2023).
- Check for ongoing assent throughout the consultation and participation process. How would you know if the child is uncomfortable? This can be done through cards or cues indicating concepts such as 'stop' 'break' 'pass' or through emotion cards, symbols or emoticons. You can also use a 'traffic light'

system, whereby a child will give a yellow card if they do not want to answer a question or a red one if they want to end the consultation session. Monitor the child’s behaviour and body language and be sensitive to signs of discomfort such as lack of cooperation, fidgeting, withdrawing from an activity etc. Be prepared to walk away from the consultation with little or no data if (despite preparations) a child or young person is not willing to participate on a particular day.

- Recording consent: Consent can be recorded by any means (e.g., in field notes of the teacher or the researcher). A written consent form (e.g., a signature, circled smiley face etc.) is just a record of a consent, and is not in itself consent (BPS Research Ethics Code, 2021).

The HSE National Consent Policy (2022) defines decision-making as ‘the person’s ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by them in the context of the available choices at that time’ (p. 25). The policy recognises that the appropriate way to address consent varies in accordance with the age and maturity of the child and young person.

Ideally, all disabled children and young people give assent/consent for their participation. However, if a child or a young person is assessed as not having the capacity to consent, the following safeguarding steps may be taken which are in line with the BPS Guidelines for conducting research with people not having the capacity to consent to their participation (2020).

In accordance with the Code of Practice for Supporting Decision-Making and Assisting Capacity “When interacting with a person whose capacity is in question or may shortly be in question in relation to a certain decision, your starting presumption must be that they have capacity to make that decision. This presumption must be made irrespective of any pre-existing disability or medical condition, reflecting Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. This guiding principle states that capacity must be presumed unless the contrary is shown, in accordance with the provisions of the Act (Decision Support Service, 2023, p.9).

“Even where children are unable to give a valid consent for themselves, they should nonetheless be as involved as possible in decision-making as even young children may have opinions about their healthcare and have the right to have their views taken into consideration by giving their assent to the proposed treatment or service. This principle is in keeping with legal and international human rights standards and ethical guidance which provide that the child's wishes should be taken into account and, as the child grows towards maturity, given more weight accordingly" (HSE, 2023, p.73).

The BPS Code of Ethics (2021) emphasises the necessity of consultation with others not involved in the project who can state the participant's 'presumed will' (i.e., what their wishes would be if they had capacity). This process will include an appraisal of the participant's involvement in a participation activity, with assurance that the interests of the participant are considered as having greater importance than any potential benefit to others from the consultation.

The exclusion of participants who cannot decide for themselves from a consultation activity would deprive them of access to an opportunity to be consulted and potentially influencing the consultation outcome, and would further reduce their voice and empowerment. Article 3 of the UNCRC states that in any matter relating to children and young people, the child/young person's *best interests* are of paramount importance. Further, Article 13 of the UNCRC declares, in part, that 'The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds...'. The participation of children in research provides a means of fulfilling this human right to self-expression (Jenkin et al., 2015).

The same requirements to provide adequate information and to ensure informed consent identified in Part One apply to parent(s)/legal guardian(s) whose consent is sought on behalf of a child.

In line with best practice when working with adults (as stated for example in HSE National Policy on Consent, 2022), the default position should be to assume the adult's capability to give an informed consent, provided they are given adequate information in *a form that they can understand.*

The NDA's Ethical Guidance for Research with Disabled People (NDA, 2024) provides guidance for practising ethical research, including legislative basis for including people who cannot consent in research and the implications for consent arising from the Assisted Decision-Making Capacity Act (2015).

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