Conceptualising the Development of the National Guidance on the Participation of Disabled Children and Young People in Decision-Making in Ireland through the Lens of Implementation Science

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Abstract: This paper describes the collaborative development of national guidance in the Republic of Ireland, specifically designed to support the upholding of the rights of disabled children and young people to meaningful participation in decision-making, as outlined in Article 12 of the UN Convention on the Rights of the Child (UNCRC), General Comments 5, 9, and 12, as well as the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We conceptualise this process within the Interactive Systems Framework for Dissemination and Implementation (Wandersman *et al*., 2008), which highlights the need for a shared planning process and multi-system support to ensure effective implementation. We propose that strategies from Implementation Science are essential to translate this guidance into practice, enabling the monitoring and evaluation of its effectiveness in safeguarding the participation rights of disabled children and young people. Our paper advocates for the application of Implementation Science as a critical tool to further the rights enshrined in both the UNCRC and UNCRPD, ensuring that disabled children and young people are actively involved in decision-making processes that affect their lives.

Keywords: Participation, Disabled Children and Young People, Implementation Science, Stakeholder Engagement

1 Introduction

This paper documents the process of developing national guidance in the Republic of Ireland (RoI) aimed at providing advice on how to meaningfully and effectively involve disabled children and young people[1] in the decision-making process and approach participative consultations and initiatives in the most accessible and inclusive way possible. We consider this process from an Implementation Science perspective to set a new direction for the future of children and young people's participation.

The guidance document described in this paper is aimed at assisting adults to realise disabled children's participation rights. Children's rights to participation should not be subject to conditions, however, in reality, meaningful implementation of all children's participation rights depends on adults' attitudes, knowledge and skills regarding how to listen to and communicate with children. From this perspective, the challenges of participation for disabled children and young people are especially exacerbated (Callus & Farrugia, 2016; Kazmierczak-Murray et al., 2024a). As all children's participation is 'dependent on the cooperation of adults' (Lundy, 2007, p. 929), and the guidance document is aimed to build the adults' capacity to involve disabled children in consultations we caution that meaningful participation however requires something more than mere involvement or consultation (Sandland, 2017), thus the guidance document described in

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[1] This paper uses identity-first language, except when referencing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), where person-first language is used. Identity-first language reflects the preference of many disabled individuals who see their disability as a core part of their identity. For those who do not use speech, we use the terms 'non-speaking' and 'people who do not rely on speech to communicate' (Inclusion Ireland, 2022). Our use of 'inclusion' and 'inclusive' is based on the social model of disability, which focuses on removing societal barriers to participation, rather than viewing disability as an issue within the individual (Shakespeare, 2006). This approach affirms the identity of disabled people and challenges exclusionary practices.

this paper must be seen as only a starting point for "an intense exchange between children and adults on the development of policies, programmes and measures in all relevant contexts of children's lives" (CRC Committee, 2009, para. 13).

In principle, children's right to participation should not be subject to caveats, though, the participation of *disabled* children and young people often is, as the wording of Article 12, within the United Nations Convention on the Rights of the Child (UNCRC), "in accordance with the child's age and maturity" implies the assessment of the child's capacity (Kaldal, 2023). These decisions run the risk of being subjective and they naturally depend on the adult's attitudes, knowledge and skills. In the guidance document, by providing support in methodologies that can be used to 'elicit' the 'voice' of disabled children, including children who do not rely on speech to communicate, we hope to increase the capacity of adults who ultimately make decisions about disabled children's participation through their assessment of the child's capacity for participation (Lundy, 2007; 2018; Sandland, 2017). Full and meaningful realisation of disabled children's participation rights, however, requires more than a commitment to hearing their views, and should include a real and tangible impact on decision-making (Lundy, 2007). Unfortunately, as the guidance does not include a mechanism for monitoring the implementation of full and meaningful participation, our work may have limited influence on the adults' decision-making about the weight that the child's view, elicited with the support of the guidance, will be given.

In February 2023, the CRC Committee published its Concluding Observations for Ireland with recommendations for what the State needs to do to progress the implementation of children's rights over the coming years (CRC/C/IRL/CO/5-6). Concluding Observations indicate the progress achieved by the reviewed State, the Committee's main areas of concern and recommendations to the State to improve the implementation of the Convention on the Rights of the Child and/or its Optional Protocols (O'Flaherty, 2006). The Committee urged Ireland to “strengthen measures to promote the meaningful and empowered participation of all children, including children in disadvantaged situations, within the family, the community, schools and in the realm of policymaking at the local, municipal and national levels" (p.5) and to “ensure the right of children with disabilities to be heard in all decisions that affect them” (p.9). In addition, the Committee urged that implementation of the UNCRC must be supported by “sufficient human, technical and financial resources” (p.2). The guidance document described in this paper and the development of associated resources are one action of such implementation support.

2 Barriers to Realisation of Disabled Children’s Participation Rights

Disabled children experience many barriers to their enjoyment of human rights and to their inclusion in society (UNICEF, 2007; 2013), and face intersecting forms of prejudice (de Beco, 2020). Both Irish and international literature indicates that attitudes towards disabled children and young people, including low expectations – due to age or disability or both – represents a key barrier to their participation (Bradbury-Jones *et al.,* 2018; Callus and Farrugia, 2016; Council of Europe 2012b; Kelleher *et al*., 2014; Sandland, 2017; Wickenden and Kembhavi-Tam, 2014). Low expectations are especially pronounced for certain groups of children and young people including those who have different ways of understanding or communicate differently including children and young people with intellectual disabilities.

Practitioners, and those who facilitate consultations for policy makers, may lack the experience, capabilities, skills, and resources to facilitate inclusive 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 (Bradbury-Jones *et al*., 2018; Callus and Farrugia, 2016; Gonzalez *et al*., 2021). These capacity gaps, combined with insufficient commitment and investment to meet individual child's requirements and preferences, further hinders participation.

The literature also highlights inaccessible physical environments, information and communication as major barriers to participation (Kelleher *et al*., 2014; McMellon and Tisdall, 2020; UNICEF, 2013b). Challenging both attitudinal and environmental barriers to participation aligns with the social model of disability (Shakespeare, 2006) which underpins both the UNCRC and the United Nations Convention on the Rights of Person with Disabilities (UNCRPD, 2006). As stated in General Comment 9 (GC9) 'the barrier is not the disability itself but rather a combination of social, cultural, attitudinal, and physical obstacles which disabled children encounter in their daily lives' (CRC Committee, 2006, para. 5).

In addition, 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 (Gonzalez *et al*., 2021). They thus require more opportunities to develop the skills and confidence necessary to exercise their rights effectively, and the guidance aims at increasing such opportunities.

3 Participation of Disabled Children and Young People

The need for a guidance document on participation in decision-making for disabled children and young people is underpinned by international agreements, namely the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and the United Nations Convention on the Rights of the Child (UNCRC, 1989). The provisions outlined in both are legally binding for the state parties that have ratified them. Both the UNCRC and the UNCRPD include specific provisions for children with disabilities (UNCRC Art 23; UNCRPD Art 7). The UNCRPD, ratified by Ireland in 2018, underscores the active engagement of individuals with disabilities, including disabled children, in decision-making processes. Article 7.3 of the UNCRPD particularly stresses the right of disabled children to express their views freely on all matters affecting them, ensuring these views are 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 realise that right* (emphasis added).

Before Article 7 in the UNCRPD which is considered the most fundamental human rights article for children with disabilities (Byrne, 2023; Campoy Cervera, 2017), the UNCRC, signed by Ireland in 1990 and ratified in 1992, emphasised the right of all children to be heard and participate in decisions that affect their lives. Frequently cited as the most important (Fortin, 2003), Article 12 of the UNCRC (1989) underscores the responsibility of state parties to take into account the views of children and adolescents in decision-making processes[2] and those views to be given due weight, with Article 23 ensuring that disabled children are afforded the same rights as their peers, and furthermore, Article 13 is pivotal in ensuring that children are not only passive recipients of information but active participants in the exchange and dissemination of ideas. This right is fundamental to the development of children’s personalities, talents, and mental and physical abilities to their fullest potential. The interaction between Article 12 and Article 13 is crucial: while Article 12 emphasises that children's views must be heard in decisions that directly affect them and their views being given due weight, Article 13 ensures that children have the broader

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[2] “State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.” (Article 12, para. 1)

right to express themselves freely on any matter, promoting their autonomy and development (Lundy, 2007; Lundy *et al.*, 2019; Lundy, 2023; UN, 2009, para. 80-81) .

State parties are mandated by the UNCRC to support children, including those with disabilities, who may encounter difficulties in expressing their views, by offering various communication modalities to facilitate their participation. General Comment 12 (GC12) of the Committee on the Rights of the Child emphasises “recognition of, and respect for, non-verbal forms of communication including play, body language, facial expressions, and drawing and painting” (CRC/C/GC12, 2009, para. 9). Article 13 further reinforces children's right to freedom of expression, encompassing the ability to seek, receive, and impart information through diverse media channels, underscoring the need for the development and utilisation of varied participation methods and resources, such as verbal, written, creative, and technological approaches, to enable all children, including those who are non-speaking or those who cannot rely on speech alone to be heard and understood and who communicate through means other than speech, to effectively express themselves.

Despite their rights protected by both the UNCRC and the UNCRPD, disabled children continue to experience exclusion and discrimination. Implementation challenges continue to be increasingly recognised–including weak implementation of policies and laws (Lenehan, 2017; Moloney *et al*., 2021) and barriers at institutional, environmental, attitudinal and individual levels (Cavet and Sloper, 2004; Feely *et al*., 2021; Price and Feely, 2021; Keenan *et a*l., 2021; Kelleher *et al*., 2014; McMellon and Tisdall, 2020). While rhetoric supporting participation is abundant, its translation into practice remains unclear (McMellon and Tisdall, 2020).

The Committee on the Rights of the Child provides General Comments (GC) to guide state parties in effectively implementing the UNCRC through analysis and interpretation of specific UNCRC articles and its Optional Protocols. Above all, GC9 on the Rights of Children with Disabilities (2006) places an obligation on state parties to ensure that "all children within their jurisdiction enjoy all the rights enshrined in the Convention (CRC/GC/9)" while GC12 (2009) on the Right of the Child to be Heard (CRC/GC/12) and GC5 (2003) on General Measures of Implementation are also relevant to the participation of disabled children (CRC/GC/5). GC12 is very clear that state parties cannot begin with the assumption that a child is incapable of expressing their own views. On the contrary, state parties should presume that a child has the capacity to form their views and recognise that she or he has the right to express them; it is not up to the child to first prove her or his capacity (CRC/GC/12). The concept of capacity (and competence) are inherent to the child, and are not contextual or relational (Tisdall, 2018) and capacity should be measured via a process which is rights-based (Daly, 2020). Lundy (2007) also emphasises the necessity of interpreting Article 12 in a manner that is "generous and child-empowering rather than negative and opportunity restricting" (p. 938).

In 2022, the CRC and the CRPD Committees issued a Joint Statement on the Rights of Children with Disabilities reaffirming the inherent dignity and rights of children with disabilities, and emphasising a human rights model over medical or charity-based approaches (CRC-CRPD, 2022). The statement calls for eliminating all forms of discrimination and ensuring the inclusion, participation, and protection of children with disabilities in society, focusing on their evolving capacities, rights to education, family life, and protection from violence. The Committees also called for state parties to adopt comprehensive strategies to ensure these rights are upheld and that children with disabilities are treated on an equal basis with others.

Despite these obligations, the participation of disabled children and young people and especially children and young people who do not rely on speech to communicate has not been meaningfully achieved, in Ireland or elsewhere (Doak, 2023; Lenehan, 2017; McNeilly *et al*., 2015). In 2003, the CRC Committee stressed the need for adopting comprehensive measures, such as national strategies, plans of action, including the allocation of necessary resources to ensure the effective implementation of their standards (CRC/GC5, para. 7-15). Recognising this, in March 2023, the Department of Children, Equality, Disability, Integration, and Youth (DCEDIY) in Ireland, in partnership with the National Disability Authority commissioned the authors of this paper to complete a set of guidelines on participation of disabled children and young people in decision-making, with a particular focus on those who are non-speaking or use augmentative or alternative communication. We consider the process of this guidance development from an Implementation Science perspective. The need to consider implementation in the context of participation of children and young people is especially important at this time because despite-plenty of rhetoric on children and young people's participation and inclusion, the efforts to develop inclusive consultations and participation initiatives have not always translated into practice.

4 Knowledge Dissemination and Implementation

Research has shown that translating knowledge and policy into practice is often inadequate (Brownson *et al*., 2018; Nielsen, 2015; O'Toole, 2000), with the implementation of practice guidelines frequently being poor (Sheldon *et al*., 2004; Wandersman *et al*., 2008) and inherently complex (Beauchemin *et al*., 2019). To address these challenges, researchers and policy makers often look for guiding concepts, approaches and strategies, many of which are broadly captured in a discipline termed

“Implementation Science” (Damschroder *et a*l., 2009; Nielsen, 2015). This discipline emerged to improve the translation of knowledge in real-world settings by advancing our understanding of the frameworks, methods and strategies that explain why implementation efforts succeed or fail (Bauer *et al*., 2015; Nielsen, 2015).

Within Implementation Science, ‘process models’ outline the stages of translation of evidence-to-practice. Numerous ‘models’ exist (e.g., Davis *et al*., 2007; Meyers *et al*., 2012; Wandersman *et al*., 2008) which generally identify a ‘staged’ process of implementation, including: a) *exploring and preparing*, b) *planning and resourcing* (also termed installation), c) *implementation* (or early implementation) and d) *sustainment* (or full implementation) stages (Metz and Barley, 2012). The first stage of exploring and preparing involves assessing, including needs and readiness as well as stakeholder engagement. The second stage focuses on resourcing such as staff capacity building and creating supportive structures such as implementation teams and other partnerships. Full implementation occurs in stage three and is supported by processes such as continued resourcing, staff coaching, evaluation and adaptations, all of which then support the fourth implementation stage of sustainment.

Our paper discusses the planning process for meaningful inclusion of disabled children and young people through a lens of the Interactive Systems Framework for Dissemination and Implementation (Wandersman *et al*., 2008). We believe that this framework is particularly useful for ensuring that the standards outlined within GCs 5, 9 and 12 of the CRC are met.

5 Interactive Systems Framework for Dissemination and Implementation

The Interactive Systems Framework for Dissemination and Implementation (ISF) (Wandersman *et al*., 2008) specifies and organises the systems and capacities needed for translation of knowledge into practice into three components: the *Synthesis and Translation System*, the *Support System* and the *Delivery System*. This framework emphasises the importance of capacity building at both individual and contextual levels within each system, and underscores the need for effective communication between stakeholders, including funders, implementers, and researchers. It is designed to accommodate multiple perspectives and provide a comprehensive understanding of bridging research and practice. Though developed in the context of mental health prevention research this framework is highly applicable to our work on the guidance development. It supports our understanding of the necessity of wide stakeholder engagement and the bidirectional flow of information between researchers, practitioners, and experts by experience, and positions this process within a wider system that supports the implementation of the guidance.

In the ISF (Wandersman *et al*., 2008), the *Synthesis and Translation System* focuses on converting existing research into accessible, practitioner-friendly formats (in our case, an accessible guidance document). This approach aligns with the recommendations in GC12, paragraph 7 (2009), which emphasises the importance of sharing guidance on involving children and young people in decision-making in multiple languages and child-friendly formats across government and civil society.

The *Support System* focuses on implementing this evidence into practice, providing both innovation-specific support (in our case, the use of specific, inclusive, and participatory methods) and general capacity-building. GC12, paragraph 7, explicitly recommends workshops and seminars to discuss Article 12's implications and its incorporation into the training of all professionals working with children and young people. General capacity-building focuses on enhancing the infrastructure, skills, and motivation necessary for conducting inclusive participation initiatives.

The *Delivery System* consists of the individuals and organisations responsible for executing these activities (in our case, truly inclusive consultations). GC12, paragraphs 13-17, highlight the need for child-friendly procedures at all decision-making levels, while GC9, paragraphs 21-23, underscore the importance of coordination and international cooperation in working with disabled children and young people. We refer to this framework (Wandersman *et al*., 2008) throughout this paper.

6 Planning for Implementation

Implementation planning typically begins upon a guidance document completion but could be more successful if integrated concurrently with guidance development (Gagliardi *et al*., 2015). Recognising this, some researchers have focused on techniques and strategies specifically used to enhance the adoption, implementation, and sustainability of the implementation of practice guidelines (Gagliardi *et al*., 2011; 2015; Powell *et al*., 2015). These approaches draw from Implementation Science highlighting the importance of stakeholder engagement and considerations of the needs and preferences of key implementation actors from the earliest design stage. This is also consistent with the principles of co-design, which denotes the collaborative development of novel initiatives alongside individuals or groups.

In the context of participation, co-design often entails partnering with children and young people to refine or innovate participation experiences to better suit their needs and contexts, the cultivation of trust and rapport, and ensuring that the youth co-creators have autonomy and ownership within the process (Maenhout *et al*., 2023). In our case, we co-created the national guidance document with Disability Persons Organisations (DPOs), advocacy groups, youth experts, as well as governmental bodies and departments. The process of co-creation included consultations with thirteen disabled young people whose recommendations were subsequently incorporated into the guidance.

7 Conceptualising the Guidance Document

The aim of the guidance document was to provide guidance to policy makers on approaching participative consultations and initiatives in the most accessible and inclusive way possible. This included exploring and outlining specific methodologies for this purpose with particular attention to ensure accessibility for all children and young people including children and young people who do not rely on speech to communicate. This process included a review and adaptation of participation methodologies from both academic and grey literature using predetermined inclusion and exclusion criteria (Kazmierczak-Murray et al., 2024a) and subsequent refinement of these following feedback from the project team and the Disability Working Group[3].

Within the *Synthesis and Translation System* of the Interactive Systems Framework (Wandersman *et al.,* 2008), we focused on exploring and outlining specific methodologies for inclusive consultations and synthesised the lived expertise of the young people consulted with the ever-increasing literature on participation of disabled children and young people into practical and digestible guidance. Our approach was collaborative and interactive, refining content through stakeholder feedback from youth experts, policy makers, participation experts, government agencies, disability advocates and guidance

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[3] The project team included the following organisations: Hub na nÓg, National Disability Authority (NDA), Department of Children, Equality, Disability, Integration and Youth (DCEDIY) and the Disability Working Group included the following organisations: AsIAm, Chime, Disabled Women Ireland, Inclusion Ireland, Independent Living Movement Ireland (ILMI), National Council for Special Education (NCSE), National Participation Office, University College Cork (UCC), Tusla – Child and Family Agency, and Vision Ireland (formerly National Council of the Blind Ireland.

users, to address challenges posed by jargon and the need for clarity to facilitate understanding and implementation by practitioners.

Thirteen disabled young people (aged 15-24), including a non-speaking young person, participated in three consultations, to provide their perspectives and insights on effective inclusion in decision making processes. These consultations were designed using the inclusive principles captured in the first draft of the literature review (Kazmierczak-Murray et al., 2024a) and the planning guidance included in the first draft of the guidance document (Kazmierczak-Murray et al., 2024b). Although we aligned with the universal design approach (Centre for Excellence in Universal Design, 2023), by avoiding targeted recruitment of young people from specific impairment groups, we acknowledge that this may have limited our understanding of disparities among different groups of disabled young people (Byrne, 2023).

The starting points were Hub na nÓg[4] drafting online and in-person interactive consultation methodologies following discussions with the working group which included the authors of this paper, representatives from the National Disability Authority (NDA), Disability Persons Organisations (DPOs), and advocacy groups. To ensure inclusivity and facilitate meaningful participation, the questions were provided in advance and structured to allow young people to prepare their responses. The consultations focused on three key areas related to the effectiveness of participation activities: what works?, what doesn’t work?, and what recommendations should be included in the guidelines? The voice of the young people who took part in the consultations was included in the final guidance document in the form of direct quotes. Both the literature review and drafts of

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[4] Hub na nÓg is an organisation that supports government departments, state agencies, public service and non-government organisations in providing opportunities for children and young people to participate in decision-making.

the guidance document, conducted alongside the consultations, were shared with representatives from DPOs and NGOs who were members of the Disability Working Group to ensure expert feedback on methodologies that were chosen for inclusion in the final guidance document.

8 Interactive Implementation: Co-Creation of the Guidance Document

The ISF emphasises the importance of interaction among all stakeholders, and the fact that implementation is an interactive system which begins with a shared planning process. Deverka *et al*. (2012) defines effective stakeholder engagement as “an iterative process of actively soliciting the knowledge, experience, judgement and values of individuals selected to represent a broad range of direct interests in a particular issue” (p.184). Below we report on the process for stakeholder engagement that underpinned the guidance development. We report on this process guided by Tricco *et al*’s (2018) framework for reporting stakeholder engagement. Table 1 below describes the different stakeholders involved in co-creating the guidance document.

Table 1. Description of stakeholders involved in guidance co-creation.

Stakeholders	
Young people (a)	13 disabled young people who took part in the consultations that informed the guidance.
Participation experts (b)	Independent researcher who is a member of a national panel of Participation Consultants and Hub na nÓg – an organisation that supports government departments, state agencies, public service and non-government organisations in providing opportunities for children and young people to participate in decision-making.
Policy makers (c)	Department of Children, Equality, Disability, Integration and Youth who commissioned the

	development of the guidelines and published all relevant legislative pieces, incl. the National Framework and National Participation Strategy.
Guidance users (d)	Represented through the Dept. and Hub na nÓg who will support the implementation of the guidance.
Non-governmental agencies (e)	National Disability Authority – independent statutory body, providing evidence-based advice and research to the Government on disability policy and practice promoting Universal Design.
Disability advocates (f)	Disabled Persons Organisations and NGOs, including AsIAm, Inclusion Ireland and Independent Living Movement Ireland.[5]
Industry experts/Content experts (g)	Authors from the School of Inclusive and Special Education with background in Inclusive and Special Education and Speech and Language Therapy.

Figure 1 below shows stakeholder engagement within each step of the Synthesis and Translation process of the guidance development.

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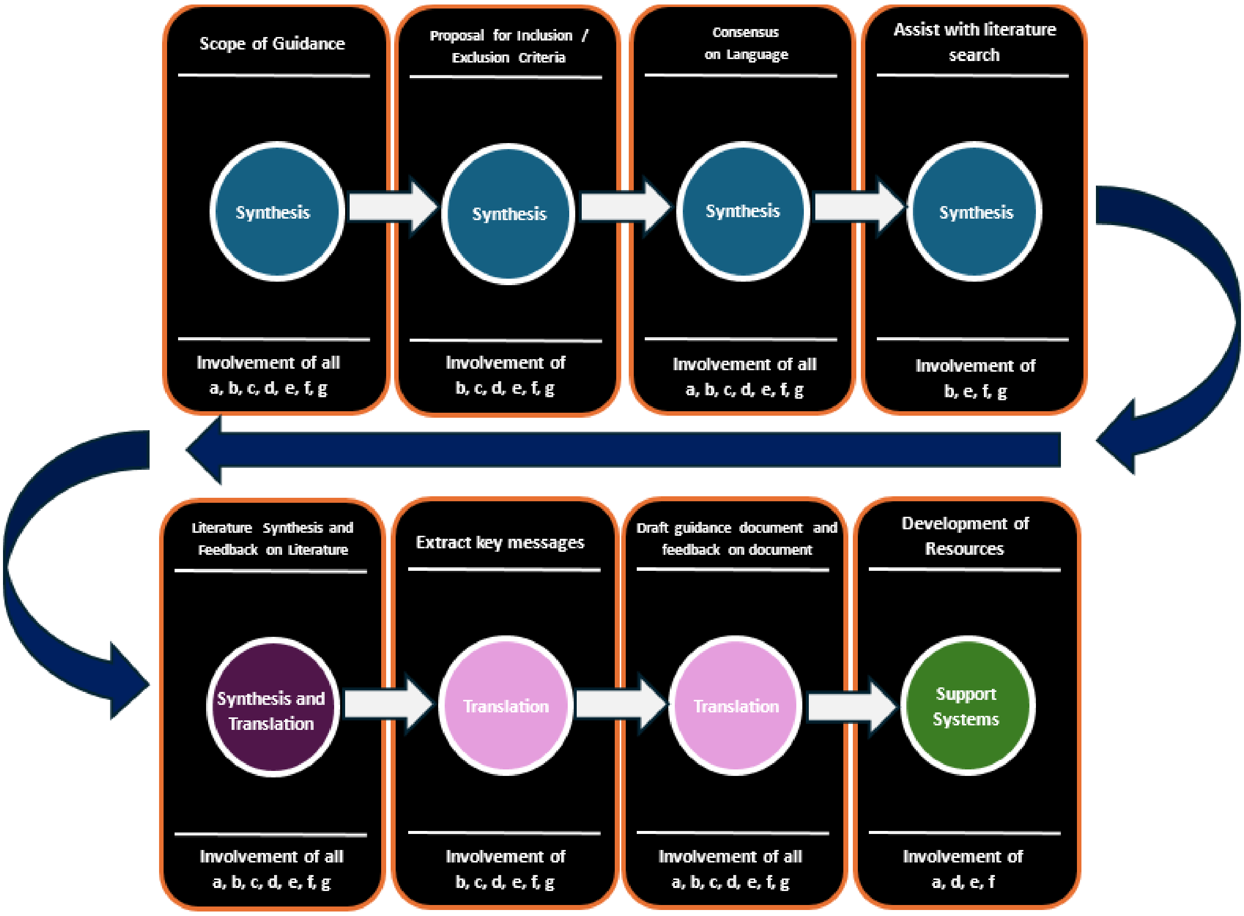
[5] AsIAm is an autism advocacy organisation. It works to promote an inclusive society for autistic people that is accessible, accepting and affirming. Inclusion Ireland: the national association for people with an intellectual disability is a campaigning organisation who works to change laws and policies for people with intellectual disabilities. They also provide accessible signposting and information services for people with intellectual disabilities and their families. Independent Living Movement Ireland (ILMI) is a national cross-disability organisation that promotes the rights and inclusion of disabled people. It works to ensure that policy decisions that impact on the lives of disabled people have to be directly influenced by those whose lives are directly affected.

Figure 1. Distribution of stakeholder engagement by steps in the development of guidance.



9 Stakeholder Engagement: Consensus on Approach and Language

Throughout the process of co-designing the guidance document, we encountered issues that needed consensus. Firstly, we needed a consensus on whether to use a dual or universal approach. Universal participation and consultation processes adhere to the principles of universal design (CEUD, 2023). This involves creating processes that are inclusive from the start, rather than attempting to retrofit accessibility later on or establishing a separate, accessible "disability process" alongside the main participation process (National Disability Authority: NDA, 2022b). While there may be occasions when targeted consultation (or a dual approach) with disabled participants is necessary, this should not replace efforts to ensure that all mainstream participation processes are accessible to everyone (NDA, 2022a). These considerations were important considering that the UNCRPD itself has a separate article on children with disabilities thus reflecting the ‘twin-track’ approach (Campoy Cervera, 2017; de Beco, 2020). Overall, our approach combined mainstreaming and ‘dual’ approaches to ensure that all consultations were fully accessible to all children with disabilities. Such a combined approach ensured that the rights of children with disabilities were considered holistically (Byrne, 2023, p.58).

Secondly, the length of the guidance document needed to be considered, to ensure that the guidance would be accessible and feasible to implement by policy makers who are not experts in this field. Truly inclusive consultations require an individualised approach to each participating child and it was necessary to ensure that the guidance would be attentive to this key principle. Thirdly, and most importantly, the language used in the guidance was considered with all stakeholders.

The language regarding disability is constantly evolving and there is currently no universally agreed consensus on which terminology to use in relation to disability. Person-first language, which emphasises that a person is first and foremost a human being entitled to human rights (Dunn and Andrews, 2015), is favoured by the United Nations and appears within the UNCRPD and within the United Nations guidelines on Disability Inclusive Language (2019). However, identity-first language, as in ‘disabled people’ is consistent with a social model of disability (Shakespeare, 2006) which emphasises that people are disabled by barriers in the environment and in society (Lawson and Beckett, 2021)[6] and is also preferred by most disabled persons in the Irish

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[6] Although using a person-first language, the UNCRC Committee strongly endorsed the social model of disability in their view that “the barrier is not the disability itself but rather a combination of social, cultural,

context (National Disability Authority, 2022a). In Ireland, the National Disability Authority (NDA) published its national guidance on the use of disability language and terminology based on consultations with disabled persons (2022a). 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, 2022a). Key recommendations from the report advised to take a contextualised and flexible approach, to ask people's preferences and to avoid stereotypes, euphemisms, medicalised and negative language, and we included this advice in the guidance document.

In the development of our guidance document there were sensitive discussions in relation to language and disability to reflect the nuanced preferences. Firstly, for example, the term 'impairment' may be used to describe an individual's condition but would not be appropriate for all contexts nor would it be adopted by all disabled persons or those in the Deaf community. We discussed how disability arises from the social experience of having an impairment and how the use of the term 'impairment' appropriately, with this understanding, would align with a social model approach.

Inclusive communication practices, including using respectful and disability specific language, were highlighted as crucial for creating a comfortable environment that promotes open dialogue by the disabled young people consulted. The disabled young people consulted noted the importance of asking children and young people how they describe themselves, as they observed that individuals may have their own preferences regarding identity first or person-first language. A clear statement on terminology was

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attitudinal and physical obstacles which disabled children encounter in their daily lives" (CCRC/GC 9, para. 5), provided therefore within the guidance that aligned with the NDA advice and reflected preferences that emerged from discussions.

10 Synthesis and Translation System: What Works in the Participation of Disabled Children and Young People

The goal of the synthesis and translation system is to consolidate information from multiple sources to create a comprehensive understanding of the effectiveness of a particular intervention or approach. Once the information is synthesised the next step is to translate it into practical formats that can be easily understood and used by those implementing the practices in real-world settings.

In accordance with international and Irish legislation (UNCRC, 1989; UNCRPD, 2006; DCEDIY, 2021; 2023), consistent with the Lundy's participation framework (2007), consultations with youth experts were undertaken to identify what works, what doesn't work (in relation to the participation of disabled children and young people), and what should be included in the guidance document.

This process involved integrating insights from the consultations with the disabled young people and the existing literature on inclusive, participative methods (Kazmierczak-Murray et al., 2024a), ensuring that the final guidance document was both grounded in lived experiences and supported by robust evidence. Key themes identified from the consultations with young people such as the importance of involving children and young people directly in decision-making, the necessity of creating safe and inclusive environments, use of inclusive language, supports for communication, presuming competence and recognising rights, understanding individual identities and understanding intersectionality, the need for adequate time and flexibility in planning, the need for training of professionals and for adults to being open to learning and corrections were cross-referenced with evidence from the literature which included predetermined inclusion and exclusion criteria and was refined with feedback from project team and Disability Working Group (Kazmierczak-Murray et al., 2024a). The literature review was not shared with the young people, however, their voices were included in the final guidance document which was based on this literature review. This final guidance document was shared by Hub na Nog with the young people who took part in the consultations.

For instance, the theme of creating safe and inclusive environments, as emphasised by the young people, aligns closely with the domain of ‘space’ in Lundy’s participation framework (2007) and literature advocating for a total communication approach. This approach, which values all forms of communication equally, is essential in ensuring that disabled children and young people can express their views effectively, whether through speech, sign language, 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, or other augmentative and alternative communication methods (National Council for Special Education, 2020). In addition, the recognition of Irish Sign Language (ISL) as a language recognised by the majority of Deaf people in Ireland needs to be valued equally. This is recognised in a CRC-CRPD Joint Statement on the Rights of Children with Disabilities (2022) and previously in CRC GC 12 (para 21) which state “state parties should ensure that children with disabilities are equipped with, and enabled to use, any mode of communication, including sign language, Braille, Easy Read, alternative and augmentative modes of communication necessary to facilitate the expression of their views, and that their opinion is given due consideration” (CRC-CRPD, 2022).

The theme of support for communication identified by the consulted young people was directly translated into recommendations for using a variety of communication aids and technologies, ensuring that all children, regardless of their communication preferences, can participate fully. These recommendations included activity-based consultations, arts based consultations, observation, gamification, and specific participation methods such as ranking activities and talking mats, and emphasise the importance of allowing the children and young people to choose a consultation method. The guidance document emphasises the importance of allowing children and young people to choose their preferred consultation method, recognising there is no single method that will 'work' with all children (Doak, 2023; Knight *et al*., 2006). Often a combination of participation methods, including tangible and visual methods, may be needed to achieve meaningful participation (McNeilly *et al*., 2021).

Our guidance document highlights that ideally participation methods, including communication supports, should be co-created with disabled children and young people. However, recognising the demands this may place on some disabled children and young people at certain times within their lives, at a minimum, participation methods need to be adapted and tailored to the preferences of each individual child. Participation should be viewed as a continuum with activities tailored to the unique cognitive, communication and sensory profile of each child (Kenny *et al*., 2023), aligning with Lundy's (2023) assertion that 'understanding and implementing children's rights is always child- , decision- and context-specific' (Lundy, 2023, p.5).

Thus, one of the key messages in the guidance document is the need to overcome the cultural tendency to over-value speech over other communication methods (Callus and Farrugia, 2016; de Haas *et al*., 2022). By advancing our understanding and use of diverse communication methods, we can achieve more meaningful participation for all children and young people.

The themes of adequate preparation time and the need for thoughtful planning and flexibility, as highlighted by the young people, were supported by literature that emphasises the importance of providing children with sufficient time to prepare their responses, thereby enabling meaningful participation (Lundy, 2007) and is reinforced by research advocating for adaptable methods that cater to the diverse needs of disabled children and young people (Bradbury-Jones *et al*., 2018; Kelleher *et al*., 2014). This aligns with the consensus in current research, which highlights that participation is a process underpinned by relationships rather than an one-off-event (de Haas *et al*., 2022; McNeilly *et al*., 2021; Teachman *et al*., 2018). This concept is also reflected in Article 12 and Article 13 of the UNCRC (1989), which guarantees children the right to express their views freely in all matters affecting them and protects their freedom of expression. Article 7 of the UNCRPD (2006) further reinforces this by requiring that children with disabilities be provided with the opportunity to express their views on an equal basis with others, all articles emphasising the need for *continuous* engagement and relationship-building to support their participation.

General Comments 5, 9, and 12 from the CRC Committee expand on these principles. GC12 (2009) explicitly describes participation as an ongoing process, underpinned by relationships, where children are engaged at every stage of decision-making. GC9 (2006) highlights the importance of inclusive participation for children with disabilities, underscoring that their involvement must be relational and continuous to truly reflect their experiences and perspectives. GC5 (2003) further supports this by advocating for the systemic implementation of children's rights, emphasising that such implementation must be sustained and relational rather than sporadic.

The importance of being open to learning from the expertise of those with lived experiences, accepting corrections, and actively engaging with feedback was emphasised by the consulted young people. Overall, an inclusive, flexible, multi-method 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 (CEUD, 2023) which should underpin all planning for inclusive participation initiatives.

The consultations also revealed the importance of using inclusive language, a theme that is echoed in the literature. The young people emphasised the need for communication practices that respect their individual preferences, including how they are addressed and the language used to describe their identities. This aligns with the literature that stresses the need for respectful and disability-specific language to create an environment conducive to open dialogue (NDA, 2022b).

To address the themes of presuming competence, recognising their rights, and understanding individual identities and understanding intersectionality advocated for by the consulted young people we reviewed the concept of ‘relational autonomy’ (De Haas *et al.* 2022) within the literature. This concept fosters inclusivity by truly understanding the lives and experiences of disabled people as the starting point. It supports an inclusive participation culture that values ‘being with’ as a core of its methodology. Sandland (2017) discusses the concept of ‘relational autonomy’ in the context of supported decision-making, arguing that while supported-decision making should be ideal for all children, it may be necessary for those who are disabled.

In addressing what doesn’t work, the theme of underestimation was crucial. The young people’s experiences of being underestimated due to their disabilities highlighted the need for professionals to presume competence and communicate respectfully. This was integrated into the guidance document as a key recommendation, supported by evidence that stresses the importance of recognising the expertise of those with lived experiences (McNeilly *et al*., 2021). Kelleher *et al*. (2014) caution against prescriptive approaches to participation, which can undermine its core principles by restricting young people's ability to engage in ways that are meaningful and appropriate to their unique circumstances. This caution aligns with human rights standards, particularly Articles 12 and 13 of the UNCRC (1989) and Article 7 of the UNCRPD (2006), which emphasise the importance of flexible, inclusive participation. This sentiment is echoed by Maenhout *et al*. (2023), who identify several critical factors that facilitate the co-creation process. These include the adoption of tailored methodologies sensitive to children’s and adolescents' needs, such as visual aids, concrete examples, and co-developed communication tools, the cultivation of trust and rapport, an understanding of group dynamics, and the involvement of relevant staff members.

The young people’s recommendation to empower disabled children and young people with knowledge and autonomy was incorporated into the guidance by emphasising the need for informed participation. The literature supports this by advocating for continuous engagement and relationship-building, recognising that participation is a process rather than a one-off event (UNCRC, 1989; UNCRPD, 2006). We highlighted within the guidance document that while parents or guardians may be included on behalf of their child or young person, consistent with Article 5 of the UNCRC which recognises the role of parents, legal guardians, or other individuals legally responsible for the child in providing direction and guidance in a manner consistent with the child's evolving capacities, the use of proxies must be viewed with caution and critically questioned (Gjermestad *et al*., 2023). Lundy and colleagues (2011) note that implementation of child and youth participation as set out under UNCRC Article 12 has proven to be problematic in practice as some adults may lack commitment to this principle or have a vested interest in non-compliance (Lundy, 2007), while others may not be accustomed to acknowledging children, particularly younger ones, as capable meaning-makers in their own lives (CRC/GC/5, 2003). Therefore consultations should plan to allow for meaningful involvement for the disabled child or young person themselves promoting their rights, empowerment and their evolving capacities.

11 Implementation Enablers in Support and Delivery Systems

Creating an inclusive decision-making environment for disabled children and young people may require meticulous and deliberate planning and support, which sits within the second and third domains of the Interactive Systems Framework for Dissemination and Implementation (Wandersman *et al*., 2008): the Support System and the Delivery System. The Support System provides support to those implementing innovations, while the Delivery System focuses on implementing innovations in the field.

Planning properly was emphasised by the young people consulted in addition to all the other stakeholder as something integral to include in the guidance document. Truly inclusive consultations require prior consultation with those who know the child and their preferred communication method, informal engagement and /or observation of the child, preparation and/or adaptation of consultation materials into appropriate and accessible communication methods, as well as physical and sensory considerations of the consultation space. For some children, repeat consultations may be necessary, and meaningful participation should not be viewed as a once off event (McNeilly *et a*l., 2021).

Meaningful participation often entails spending time with them and speaking to people who know them well (Knight *et al*., 2006). Participation should be seen as a tailored and context-specific activity, as opposed to a predetermined process.

The implementation of meaningful and inclusive participation demands urgent and ongoing capacity building across the entire system. This includes general capacity building—such as investment in time, resources, training, and evaluation mechanisms—as well as specific capacity building to support the implementation of particular participation methods. These processes are explicitly recommended as implementation measures in GC12 (para 7) (2009) and GC5 (paras 7-15) (2003).

At this point, it is crucial to transition from discussing the process we undertook to highlight the importance of delivery systems within the ISF framework. Delivery systems are essential for the practical implementation of these processes, and we now provide recommendations for the next steps. One immediate step to support implementation is the development of accessible resources for inclusive consultations, a commitment that the DCEDIY in Ireland has already made.

The literature highlights that participation must be embedded across organisations through a whole-systems approach, integrating it as an essential part of our relationship with children (Bradbury-Jones *et al*., 2018; Cavet and Sloper, 2004; De Haas *et al*., 2022). Meaningful participation cannot be achieved ‘on a whim’; it requires organisational buy-in, careful planning, appropriate resourcing, training, capacity building, and investment in participation methods. It also demands ongoing, long-term methodological and practice development (McMellon and Tisdall, 2020). Such investment is not simply a matter of charity or goodwill but is a fundamental component of realising universal human rights (UNICEF, 2013a).

For over a decade, researchers have highlighted that a lack of commitment and investment at the 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 (Kelleher et al., 2014). Lack of capacity—particularly in terms of time and resources—poses a significant barrier, especially when enabling participation for children and young people with communication differences. In Ireland, insufficient funding has, for example, been cited as a key obstacle to including those who use alternative augmentative communication (AAC) in consultations (Inclusion Ireland, 2022). Alongside capacity challenges, a culture of overvaluing speech as the main method of communication further exacerbates barriers for those who do not rely on speech to communicate. Increased investment is also necessary for participation tools that utilise arts, media, and digital engagement, where the most often cited challenge is that they are resource and time intensive (Dunn *et al*., 2018). Such investment is a matter of social justice (McNeilly *et al*., 2015; UNICEF, 2013a).

We identify the necessity of forming new partnerships to meaningfully include disabled children and young people in decision-making. Our guidance document outlines key principles for working with the child or young person's parents, guardians, and staff from educational settings. Staff from education 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, and who in some .instances, may be ideally placed to facilitate or to support participation, given their knowledge of preferred communication methods and their understanding of the participating children and young people (Bloom *et al*., 2020; Franklin and Sloper, 2009; Gonzalez *et al*., 2021; Kelleher *et a*l., 2014). The necessity of a 'supported decision -making culture' within the context of children's disability rights is further argued by

Sandland (2017). In some circumstances, disabled children's rights will be actualised through their parents or other adults acting as communication partners. The young people consulted stressed the need for the presence of skilled support staff who have undergone training to support them and who are open to corrections and the lived expertise of the young people themselves.

Effective implementation and sustainability of child and youth participation require robust monitoring, evaluation, and feedback mechanisms (Kennan *et al*., 2021; Kennan *et al*., 2017; Lundy, 2018). Participation rights should enable children to understand how their views and those of adults influence decision-making and outcomes (CRC Committee, 2009, para. 3). Rather than being a one-time consultation, these rights should foster ongoing, meaningful dialogue between children and adults, informing the development of policies and programmes across all key areas of children's lives (CRC Committee, 2009, para. 13). This is particularly important for children and young people whose views are less likely to influence decision-making, such as those with communication differences. Monitoring and evaluation have been cited as key enablers of the effective implementation of the National Participation Framework (DCEDIY, 2021) in Ireland, alongside organisational buy-in, training and capacity building, and resources (financial, human, and time resources), mirroring guidance provided in GC12 (2009), particularly paragraphs 48 and 49, which underscore the need for systematic evaluation of children's participation processes to ensure they are meaningful, inclusive, and effective. These principles are consistent with the framework outlined by Wandersman *et al*. (2008).

12 Conclusion and Future Directions

Our collaborative work on the guidance document has codified advice on how to meaningfully and effectively involve disabled children and young people in decision-making processes. This guidance also provides a blueprint for approaching participative consultations and initiatives in the most accessible and inclusive way possible. However, the success of this guidance document hinges on more than its creation—it requires a sustained commitment to its implementation, which will depend on a range of contextual factors that influence both individual and organisational capacity.

To ensure the guidance document is not merely aspirational, but a living tool that truly enacts the rights outlined in the UNCRC and UNCRPD, there must be a concerted effort to build awareness of the inclusive participatory methods it outlines. Capacity building is now the most critical next step. This involves not only developing accessible resources to support the initial implementation but also fostering the skills, knowledge, and infrastructure necessary to embed these practices deeply within organisations and communities.

In Ireland, the next crucial steps must include the rigorous evaluation of how the guidance document is implemented. This includes measuring both the extent of its usage and its effectiveness in achieving truly inclusive participation initiatives. It is essential to assess whether the guidance has succeeded in reaching "seldom heard" disabled children and young people, particularly those for whom speech is not the preferred method of communication. This evaluation will not only affirm the guidance document's impact but also identify areas for improvement and further refinement.

Implementation Science offers a valuable framework for this endeavour, guiding the careful assessment of implementation stages and identifying key enablers at each step. Collaborative engagement of all stakeholders, which lies at the heart of Implementation Science, has already been initiated in Ireland through the development of this guidance document. In this paper, we have discussed the application of the Interactive Systems

Framework (Wandersman *et al.,* 2018), highlighting its utility in bringing attention to context-specific implementation determinants such as stakeholder engagement, capacity building, and the dissemination of accessible information. Looking forward, the creation of tools that evaluate the holistic impact of disabled children and young people's participation on themselves, as well as on adults, policy, and practice, is imperative, transforming it from a well-intentioned plan into a fully realised practice.

As Sandland (2017) suggests, understanding how participation works in practice requires a careful study of outcomes. This direction is now critical for Ireland, and we believe that the processes and frameworks documented in this paper can support similar initiatives globally. Ultimately, the success of this guidance document will be measured not only by its adoption but by its tangible impact on the lives of disabled children and young people. It is through their genuine inclusion in decision-making processes that we will realise the full promise of the UNCRC and UNCRPD, advancing the rights of all children to have their voices heard and respected in matters that affect their lives.

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