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## DISABLED CHILDREN'S PARTICIPATION IN HEALTHCARE DECISION-MAKING

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## DISABLED CHILDREN'S PARTICIPATION IN HEALTHCARE DECISION-MAKING

*Radoš Keravica*

### **Introduction**

Almost all of us have had a lot of experience with doctors and in hospitals. As babies and small children we had many medical examinations. Some of us have even been in hospital for long periods. A few of us have already had major surgery. Some take medication, almost all of us take regular therapies. Doctors probably have a lot of work to do with us. We have had good, but also bad and sometimes very bad experiences with doctors. They are often friendly, but also sometimes rude and impatient. They don't always take us seriously and sometimes don't believe us. Even when we are in pain. It can happen that they say: 'We can't find anything, you imagine that you are in pain'. Then we feel very bad.

*(Youth Advisory Board for the Tyrolean  
Monitoring Committee 2020, p. 4)*

The UN Convention on the Rights of the Child (1989) (CRC) introduced Article 12, the right for every child to participate in all matters that affect them, colloquially known as the right to be heard (Lundy 2007). It guarantees the right to all children to freely express their views and those views to be taken into account when decisions are being made. Although the progress in the realisation of this right has been documented in different areas of life, healthcare decision-making has remained an area in which children's participation has been contested and heavily dominated by adults' concerns for a child's protection (Ehrich et al. 2015).

Disabled children experience a disproportionately higher number of medical encounters in their childhood in comparison to their non-disabled children. They are often subjected to different forms of remedial treatments which seek to ameliorate the effects of their impairment, reduce pain, increase their body functionality,

or eradicate an impairment altogether, including but not limited to surgical treatments, physiotherapy, speech and language therapy, or other forms of rehabilitation programs (Bricher and Darbyshire 2005; McLaughlin and Coleman–Fountain 2014). These treatments and related recoveries may lead to long absences from school, long hospital stays, and painful and potentially traumatising experiences. Due to their significant impact on children’s lives, it is important to ensure the ‘right to be heard’ is guaranteed to disabled children and to create space and opportunities for their participation in healthcare decision-making.

This chapter argues that the barriers to participation in healthcare decision-making disabled children face are related to attitudinal and institutional factors. The former is associated with a preoccupation of adults with the child’s capacities and competence to participate, their views of impairment and disability, and the relative importance they attach to the child’s participation. The latter refers to the embeddedness of the value of participation in institutional cultures in healthcare organisations, adequate skills and training of healthcare professionals to support disabled children’s participation, or available time for it. Further, it is argued that the UN Convention on the Rights of Persons with Disabilities (2006) (CRPD) provides higher human rights standards for children’s participation in decision-making and offers new light in which to interpret and understand Article 12 of the CRC.

### **What Counts as a Child’s Participation in Healthcare Decision-Making?**

Disabled children’s participation is approached in this paper from the standpoint of participation in *individual* healthcare decision-making. Individual healthcare decision-making refers to all decisions related to disabled child’s healthcare affecting their life, including the choices of medical treatments and related procedures as distinct to children’s participation at a more strategic level, such as the healthcare policy planning or healthcare service development (Brady 2020).

The meaning of participation of children in decision-making processes is contested, as there is no unequivocal agreement on how it should be defined (Percy-Smith and Thomas 2010). In general, definitions revolve around a hierarchical continuum of children’s involvement in decision-making processes reflecting various degrees of influence children have on the final decisions as the outcomes of decision-making processes. Among the most influential hierarchical typologies of child’s participation is Hart’s ‘ladder of participation’ (see Figure 12.1), which enunciates eight ‘ladder rungs’ of participation, among which the three lowest rungs denote ‘non-participation’ (manipulation, decoration, and tokenism) and the highest ‘rung’ corresponds with child-led initiatives in which decisions are shared with adults (Hart 1992, p. 8).

Similarly, Alderson and Montgomery (1996), in their study on children’s healthcare choices, apply the hierarchical conceptual framework of a child’s participation in the area of healthcare. They propose the following classification of levels of a child’s participation in healthcare decision-making: being informed, expressing a view, influencing the decision-making process, and being the main decider (Alderson

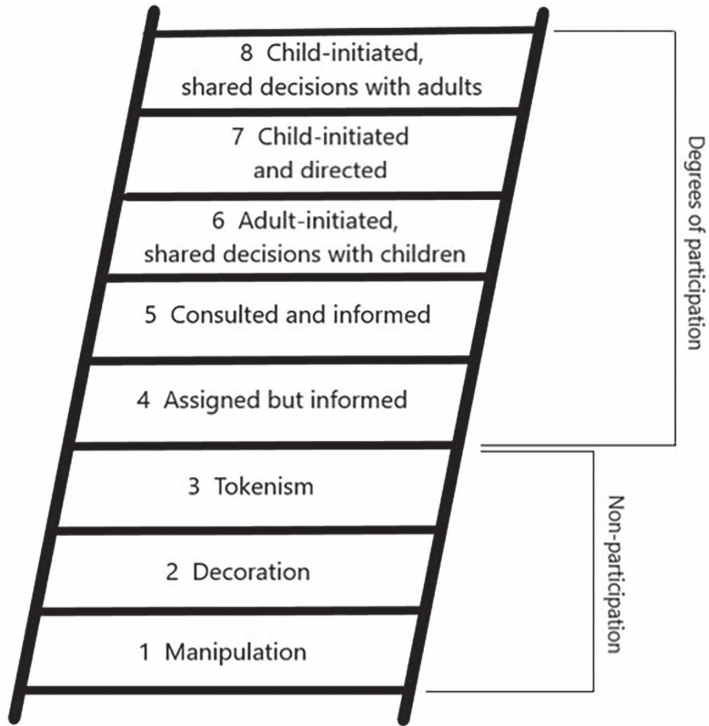


Figure 12.1 Image of ladder with eight rungs.

Source: Hart 1992. Children's participation: from tokenism to citizenship. Florence: UNICEF, International child development centre. p. 8.

and Montgomery 1996). It follows that participation is to be understood as a scale wherein the ultimate level of participation—'being the main decider'—implies the legal and practical possibility of children and young people to consent to medical treatments (see Figure 12.2).

While acknowledging the usefulness of these hierarchical outcome-oriented classifications of levels of participation, especially in terms of measuring the level of influence children exercise in decision-making processes, there is a need to explain what a participation continuum might mean for disabled children and how it can be realised in practice. This paper adopts a view of the participation of disabled children in individual healthcare decision-making as a *process* through which a child can influence decisions on their own healthcare, bringing about the change in themselves and the healthcare services they use (Brady 2020). Having said that participation is a process, I am interested to explore which actors are involved in this process and what role they might play to support or impede disabled children's participation.

Children's participation in healthcare decision-making is dependent on the support of adults involved in this process, typically healthcare professionals and parents

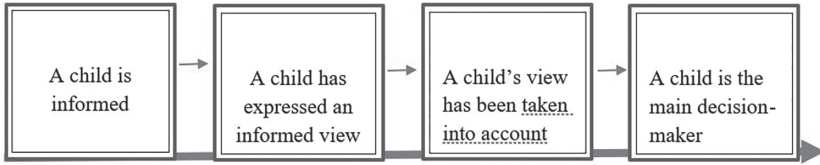


Figure 12.2 Graphic with four text boxes placed horizontally from left to right, with an arrow placed between them pointing to the right. Text written in the boxes in the order of appearance is the following: a child is informed; a child has expressed an informed view; a child's view has been taken into account; a child is the main decision-maker.

or other family members of disabled children. This is why it is important to reflect on the opportunities and constraints arising from the three-way relationships between disabled children, their family members, and healthcare professionals. However, participation of disabled children is also mediated and facilitated through non-human actors, such as international and domestic laws and policies, assistive technologies and communication devices, organisational cultures and practices or material artefacts (in/accessible physical space or information, availability of personnel or equipment). It is realised in an 'assemblage' of different human and non-human actors which are interconnected and influence each other in varying degrees and directions (Goodley and Runswick-Cole 2014; Feely 2016; Gibson et al. 2017). Thus, the participation is not an isolated or singular event but multiple events—'participation' as a process is something that is continually being produced and reproduced through a complex interplay of the aforementioned human and non-human actors in an 'assemblage' (DeLanda 2019; Feely 2020; Fox and Alldred 2015).

The following section explores the role of international human rights law and its standards of disabled children's participation in decision-making as an important discursive practice bearing influence on the national laws, policies, and practices. As such, the legal norms reflect the societal ideas about what children can and should do and shape the practice of child participation. In a Foucauldian sense, the law represents a power-knowledge network that produces and regulates both childhood and disability (Turek 1990; Tremain 2005). Foucault (1979, p. 144) claimed that:

[T]he law operates more and more as a norm, and the juridical institution is increasingly incorporated into a continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulatory. A normalizing society is the historical outcome of a technology of power centred on life.

The law is to be understood as a technology of power and a 'procedure of exclusion' which relegates children's voices to the peripheries of knowledge (Turek 1990). It reflects intergenerational power differences whereby children are scrutinised and expected to demonstrate adult-like capacity in order to have their say in matters that concern them. The issue of children's 'capacity' is paid special attention throughout

the analysis of standards of disabled children's participation enshrined in the CRC and the CRPD and potential divergences between the two human rights treaties.

### **International Human Rights Law and Disabled Children's Participation in Healthcare Decision-Making**

The CRC has challenged the view of childhood as a stage of vulnerability and natural dependency by introducing the participation principle (respecting the views of the child) alongside three other core principles, namely, non-discrimination and equality, primary considerations of the child's best interests, and the right to survival and development (Committee on the Rights of the Child 2009). The CRC embodies its principle of participation in Article 12, which entitles those children who have the capacity to form a view with the right to express their views in all matters that affect them and to have their views taken seriously by adults.

The first paragraph of CRC Article 12 makes it clear that the right of the child to express their views is contingent on their capacity/ability to form them. The CRC Committee's understanding is that this provision is not to be 'seen as a limitation, but rather as an obligation of States Parties to assess the capacity of the child to form an autonomous opinion to the greatest extent possible' (Committee on the Rights of the Child 2009, para. 20). It also stresses that the starting point should be the presumption of capacity rather than incapacity. This poses the question of what constitutes and demonstrates the capacity to form the view and in which situations can this capacity of the child become subject to adults' assessment. Needless to say, if disabled children are presumed by the healthcare professionals as lacking 'capacities to form their own views', that might mean that they are likely to not even seek children's views on proposed treatments.

Further, a requirement to 'give due weight' to a child's views implies that the imperative is not only to listen to the child's views but to take them seriously into consideration when reaching the final decision (Committee on the Rights of the Child 2009, para. 28). In the determination of how much weight will be given to a child's views, the child's capacities should be assessed, and age and maturity taken into account. The CRC Committee (2009, para. 30) defines *maturity* as the 'capacity of a child to express her or his views on issues in a reasonable and independent manner'. The usage of the qualifier 'independent manner' is indicative of how the CRC Committee conceives concepts of children's maturity as a marker of independence and self-sufficiency. This understanding establishes an express link between the cognitive abilities of a child and the weight attached to their views. It produces cognitive ableism, as all children who lack this 'essential' ability are placed in an inferior position and a 'diminished state of being' (Gregor 2008). This poses a particular risk for disabled children whose development may be considered as deviating from the 'norm' since their process of acquisition of experiences and abilities may be compromised due to different forms of barriers they face (Priestley 1998; Davis and Watson 2000). It would further abnegate the adults from the responsibility to invest in efforts to support the child to express their views. The Committee has stressed the

importance of providing aid in communication and disability-related accommodations to children to support them to express their views (Committee on the Rights of the Child 2009, paras. 21 and 78) but does not recognise the risk they face of being judged as immature and incompetent due to their impairments.

It is noticeable that the CRC Committee, when elaborating the principle of participation in relation to disabled children in its General Comment on children with disabilities, gave a stronger emphasis to the participation of disabled children as a collective through ‘bodies such as parliament, committees and other forums’ and in policymaking processes than it did *vis-à-vis* their participation in individual matters that affect their lives (Committee on the Rights of the Child 2007, para. 32).

The Committee stressed the importance of programmes and services aimed at the prevention of disability, early detection and information, and treatment and rehabilitation for disabled children (Committee on the Rights of the Child 2007, para. 21). Regrettably, there was little to no mention of the importance of participation of disabled children in healthcare, especially in terms of the right to express views in relation to the treatments and services mentioned earlier, which all have a profound and long-term impact on disabled children’s lives. Although the participation of adolescents in individual healthcare decision-making is supported by the recommendation of the CRC Committee in its General Comment 20, where it says that the ‘voluntary and informed consent of the adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure’ (Committee on the Rights of the Child 2016, para. 39), there is no such parallel in its General Comment on disabled children. The evident emphasis on welfarist concerns of the CRC Committee in relation to disabled children and its medicalised approaches to disability has also been recognised by Andrea Broderick, who asserts that the CRC regards disabled children as ‘subjects of protection, requiring “special care” and “rehabilitation”’ (Broderick 2017, p. 197).

In my view, this omission is not accidental, as the Committee’s emphasis on special protection of disabled children through access to and availability of programmes and services for prevention, detection, and treatment of impairments corresponds to its understanding of impairment as disruptive to a child’s development. Thus, if minimisation of the impairment or the absence of it is understood as necessary for a child’s proper development, then such an aspect would constitute a child’s best interests (Campoy Cervera 2017a). Consequently, in consideration of any health treatments which seek to enhance bodily functions or minimise the effects of the impairments, the treatment would likely be deemed in the child’s best interests, making it easier to override the child’s opinion if it goes against the healthcare professional’s recommendation.

The CRPD, adopted in 2006, includes a standalone article on disabled children (Article 7). The third paragraph of Article 7 refers to the rights of disabled children to be heard and draws from the text of Article 12 of the UNCRC while bringing added value to it in two important ways. First, it leaves out the condition of having the capacity to form the views (making sure in that way that no disabled child is precluded from participation based on presumed incapacity). Second, it adds the

requirement for the states parties to provide disabled children with 'disability and age-appropriate assistance to realize that right'. This requirement is particularly important as it counteracts the view that the signifier of sufficient capacity is an ability to express in an 'independent' manner. Instead, it recognises that disabled children may require various forms of additional support to fully enjoy and exercise their human rights due to environmental barriers. This is a significant qualitative difference and the value shift from 'independence' towards 'interdependence' as it acknowledges the responsibility of adults to provide support and maximise the capacities of children in that way in participation processes (Broderick 2017).

Another aspect of the CRPD that is relevant to disabled children's right to be heard is the right to equal recognition before the law enshrined in Article 12. The paradigm of Article 12 of the CRPD is that mental capacity and legal capacity are different concepts and should not be conflated, thus prohibiting any form of legal capacity deprivation based on presumed mental incapacity. Instead, supported decision-making regimes should replace guardianship systems (Flynn and Arstein-Kerslake 2014). Although the value of CRPD Article 12 for disabled adults is uncontested, it is less clear what—if any—relevance it has for children's rights. Still, its influence on the interpretation of the CRC is evident in the CRC Committee's General Comment 20 on the rights of the child in adolescence. There, the CRC Committee made explicit reference to supported decision-making, stating the following: 'Adolescents with disabilities should, in addition, be provided with opportunities for supported decision-making in order to facilitate their active participation in all matters concerning them' (Committee on the Rights of the Child 2016, para. 32). I have pointed out earlier to the Committee's expectation that the child expresses their views autonomously in a 'reasonable and independent manner' in relation to the child's maturity (Committee on the Rights of the Child 2009). In that light, the Committee's mention of supported decision-making is a positive development with possible consequences for the reframing of children's legal capacity and autonomy.

Various authors advocate for the universality of legal capacity for all people, including children, and an extension of supported decision-making systems for children in the same vein as for adults with intellectual and psychosocial impairments (Sandland 2017a; Clark 2018; Campoy Cervera 2017b). Campoy Cervera (2017a) claims that the limitations of children's legal capacity are inconsistent with the human rights model and universality of legal capacity enshrined in Article 12 of the CRPD and considers them as a feature of a 'renewed protectionism' paradigm underpinning the CRC. He claims:

The contrary would mean assuming that Article 12 of the CRPD establishes the support model instead of the will-substitution model for all people with disabilities, regardless of type or extent, but excludes (without justification), children from this concept of a person, permitting the will-substitution model to continue in force only for the child.

(Campoy Cervera 2017b p. 30)



Sandland (2017b) also points out that the CRPD has attempted to move away from decision-making capacity assessments of adults, which served to justify the restrictions of a person's legal capacity and questions the justification of retaining the best interests approach to children's decision-making if the supported decision-making model could be applied to them on the same basis as to disabled adults. Clark (2018) argues that the CRPD contains the potential to extend the legal capacity not only to disabled children but also to children as a class as its introduction of support (disability- and age-appropriate assistance) for the exercise of autonomy represents the move towards a relational understanding of autonomy.

Nevertheless, what is incontestable is that children can obtain legal capacity in certain areas of law before the age of majority if the law sets another age limit for exercising certain rights freely and independently. Most European countries prescribe the statutory age of consent to medical treatments between 12 and 18 (Day et al. 2015). It follows that a disabled minor who has reached the age of consent and thus acquired legal capacity in this particular area of law could potentially benefit from supported decision-making. But was the CRC Committee's intention to introduce supported decision-making only for those disabled adolescents who have reached the legal capacity in a particular area of law by virtue of their age? Let us look again at the Committee's reference to supported decision-making in their General Comment No. 20. According to the CRC Committee, supported decision-making for disabled adolescents should serve the purpose 'to facilitate their *active participation* in all matters concerning them' (Committee on the Rights of the Child 2016). This means that the CRC Committee put the supported decision-making concept in the context of participation rights for children, extending its reach and purpose beyond the legal capacity. Supported decision-making thus becomes relevant as the concept not only for disabled adults or for those children who have attained legal capacity before the age of majority but for participation rights of all disabled children.

In the context of healthcare decision-making, the human rights standards elaborated previously mean that healthcare professionals should not fail to inform a disabled child on proposed treatment and accompanying procedures in a manner accessible to the child and cannot deny the opportunity to a disabled child to express their views on proposed treatment and course of actions. Moreover, the 'expression of views' should not be limited to verbal modes of expression, and non-verbal communication, including non-verbal expressions of pain, discomfort, or similar should be taken as forms of a child's 'views'. The existence of impairment should never be the reason to assume that the child does not possess the capacity to express their views. If a disabled child uses communication devices or other assistive technologies, additional time required to communicate with a disabled child must never be an excuse not to engage in communication. If the views of a child contradict the proposed treatment, adults involved in the decision-making process should be able to demonstrate how they have taken their views into account, and if a decision has been made to pursue the treatment despite the child's views, it should be demonstrable how such decision is in the child's best interests.

This section has mapped out the key requirements of international human rights law that bear relevance for disabled children's participation in healthcare

decision-making and that should be translated into national policies and practices. Still, the realities of disabled children's participation in healthcare decision-making diverge from the guarantees made in the human rights treaties. Moving forward necessitates an understanding of the key barriers disabled children face in the area of participation in healthcare decision-making, and the next section provides a brief and certainly not exhaustive overview of these barriers.

### **The Barriers to Participation in Healthcare Decision-Making Disabled Children May Face**

Disabled children are facing a heightened risk of exclusion from participation due to their status as children and because of disability (Lansdown et al. 2013). This section highlights and systematises some of the barriers disabled children face, including attitudinal and institutional ones.

The issue of children's consent to medical interventions as a specific form of a child's participation in healthcare decision-making has been covered extensively in the literature (Alderson 1993; Alderson and Montgomery 1996; Fundudis 2003; Alderson 2007). Health laws that regulate consent are mainly concerned with identifying the main decision-maker and use age-based or competence criteria to restrict children's decision-making powers (Lansdown 2005; Ehrich et al. 2015). The focus on children's competence to consent calls for a more thorough discussion on the impact of competence assessments on the participation rights of disabled children. However, this is not the scope of this chapter, and this section offers a reflection on the barriers children face in other stages of healthcare decision-making proposed by Alderson and Montgomery (1996): being informed, expressing a view, and influencing a decision-making process.

The participation of children is heavily dependent upon the establishment of positive three-way relationships between disabled children, healthcare professionals, and parents. The attitudes and professional or parenting practices significantly influence the participation process, either positively or negatively (Franklin and Sloper 2005; Coyne 2006; McNeilly et al. 2017). Though parents or carers are instrumental to children's participation in healthcare decision-making, it cannot automatically be assumed that they will act as enablers of a child's participation. Research by McNeilly et al. (2017) has shown that parents, and in particular, parents of disabled children, can display overprotective attitudes towards their disabled children and may, for these reasons, withhold information on impairment and medical interventions, effectively limiting children's access to information significant for meaningful participation. Children who are adequately prepared and informed by parents before their encounters with healthcare professionals can participate more effectively in healthcare decision-making. The role of the parents is thus an ambiguous one. While some parents act as enablers of their child's participation and insist that healthcare professionals communicate to their children or help facilitate communication between their children and healthcare professionals, others assume the role of their child's advocate and, in that way, reduce the space for interaction of healthcare professional and a

child creating the barrier for their child's participation (Alderson 1990; Coyne 2006; McNeilly et al. 2017). The attitudes of parents towards impairment have also proved to be a potential barrier to participation. Parents who believe that there is no point in communicating to their child their complex medical information, as they assume the child would not understand it due to their impairment, may not challenge healthcare professionals' lack of communication with their child.

When it comes to impairment-related medical interventions which seek to 'fix' or even cure an impairment, the position of parents is even more delicate. Avery (1999) claims that parents are socialised into tragedy view of disability as soon as a disabled child is born. For this reason, they can feel the urge to look for the 'medical fix' and side with healthcare professionals even against the wishes of the child, leaving the latter disempowered, with little control of what is going to happen to them (Bricher and Darbyshire 2005; Franklin and Sloper 2005). A process of determination of the disabled child's best interests in the context of impairment-related medical interventions might be fraught with antithetical arguments that need to be taken into consideration. The wish of the parents/carers of the child themselves to pursue certain medical treatment may be driven by cosmetic reasons rather than an increase in body functionality (Parens 2006). Even if the goal of the proposed medical treatment is to increase bodily functions, the outcome can be uncertain, as most of the impairments cannot be eradicated completely and promises of heightened functionality may not become true, or at least not to the expected extent (Bricher and Darbyshire 2005). The adults involved in decision-making on the disabled child's health have to take into consideration, on the one hand, the disruptive potential of proposed medical intervention (e.g. long hospital stays and recovery periods, absences from school, experiences of pain) and, on the other hand, potential benefits of the intervention and level of un/certainty for achieving desired results. Moreover, the views of a disabled child should be sought and taken into account in the final decision. Some studies have shown that disabled children tend to develop a higher level of understanding of their medical conditions and related treatments due to acquired experience (Alderson 1993; McLaughlin and Coleman-Fountain 2014), which is the reason more for adults to actively consult them in these matters.

It should be borne in mind that a child's participation in any decision-making process should be based on voluntariness, subject to the child's desire and choice to participate. In fact, the studies which collected data on children's experiences in healthcare decision-making have consistently shown that children tend to prefer to share the decision on their healthcare with adults, usually their parents (Coyne 2006; Franklin and Sloper 2009; McLaughlin and Coleman-Fountain 2014). Thus, it is up to practitioners to check with the child what is their desired level of participation rather than assuming that participation is an end in itself (Alderson 2001).

The attitudes of healthcare professionals significantly impact communication and access to information for children and young disabled people as patients. Research has found that attitudes of paediatricians towards childhood and adolescence are sometimes patronising, seeing children as immature, incompetent to participate, and in need of protection and care (Beresford and Sloper 2003; Parsons et al. 2016).

Direct communication between healthcare professionals and adolescents has been proven to contribute to higher compliance with medical requirements and a better understanding of the condition, but the communication of healthcare professionals tends, however, to be directed to parents, at the expense of communication with children and young people (Beresford and Sloper 2003; Parsons et al. 2016). The focus of the conversations is often on the child's condition rather than their person, and the overuse of complex medical terminology by healthcare professionals can also preclude children's participation. Healthcare professionals also need to be ready to discuss wider social implications of children's conditions, including lifestyle and desired behaviours, or to share advice on how children can manage their condition and live with it. The statement of young disabled people given at the conference on children's rights and medicine in Austria highlights the lack of communication between disabled children and healthcare professionals:

Many of us often do not understand what doctors are saying. Most of the time there is no time for us to ask questions. That makes us angry. Our parents or carers then have to explain everything to us. People talk about us again and again, but not with us, even though we are there. Then we feel like a number, but not a person. Doctors sometimes see too little the whole girl or the whole boy. For example, they only see the part of the body that needs surgery, but they don't see the rest of the child who owns the part of the body.

(Youth Advisory Board for the Tyrolean Monitoring Committee 2020, p. 4)

A disabled teenage boy from Serbia who I interviewed as part of my ongoing research on disabled children's participation in healthcare decision-making shared his experience with the paternalistic attitudes of healthcare professionals:

I didn't have a chance to ask anything. In most of the cases, he [speaking of his doctor] ignored me and led the conversation with my father or mother, and he ignored me completely so . . . I was present there just like some sort of object to test his new ideas.

Particular difficulties for healthcare professionals who have clinical responsibilities for children arise in the case of conflict between a child's protection and participation rights—for example, when there might be a concern that respecting a child's wishes may lead to harm for the child (Ehrich et al. 2015; Brady 2020). Such situations may call for a balancing exercise in which the concerns for child's welfare and protection, along with the views of children as vulnerable and incompetent, may prevail at the cost of their participation. The type of decision which is at stake has been recognised as a significant factor in healthcare professionals' attitudes towards child participation, as they tend to support a child's participation in 'smaller' decisions and choices rather than seeking children's input in more important deliberations on medical treatments (Parsons et al. 2016).

The study by Franklin and Sloper (2009) on the participation of disabled children in decisions related to their care and service development has shown that, in order to be meaningful, children's participation needs to be supported institutionally and embedded in organisational culture. If that is not the case, there is a risk that participation becomes regarded as an isolated event, implemented on an ad hoc basis as a result of the dedication of a few committed staff members. Once those committed professionals leave the organisation, the know-how of participation and created resources tends to be under-utilised or even completely disregarded (Franklin and Sloper 2009). Unfortunately, there is evidence that children and young people are not systematically involved in healthcare decision-making and that their participation in practice depends very largely on individuals' commitment (Brady 2020).

Another form of institutional barrier to disabled children's participation is reflected in a lack of adequate training for skills development for healthcare professionals who work directly with children (Coyne 2006). Multiple studies have reported that the participation of disabled children is significantly diminished when professionals do not have communication skills or the knowledge of participation methods. The lack of knowledge and skills becomes even more pronounced when their clients are disabled children who do not communicate verbally and require alternative forms of communication, placing the children with cognitive impairments at heightened risk of exclusion from participation (Beresford and Sloper 2003; Franklin and Sloper 2009).

Time constraints can also play a significant role in limiting disabled children's participation in multiple ways. The issue of time comes to the surface in the context when children use alternative forms of communication and/or assistive technologies and require additional time to receive information in an adequate manner or to express their views. Healthcare professionals may interpret these needs as the lack of capacity to understand the information or to express their views and shift the focus of conversation towards parents as proxies for the child's voice (Franklin and Sloper 2009). Furthermore, time is described as a significant factor to develop the relationship of trust with the child, gain familiarity with their access needs or communication patterns, and plan enough time for meaningful participation. Research by Beresford and Sloper (2003), which included the experiences of young people with chronic conditions, confirmed that the brevity of clinical appointments and feelings of being rushed adversely affected the opportunity to develop the relationship of trust between doctors and young people. Allocating sufficient time for participation can be particularly challenging when healthcare professionals operate under time pressure and organisational demands for efficiency in under-resourced healthcare systems and can devote limited time to each patient (Runeson et al. 2001; Franklin and Sloper 2009).

Finally, the barrier to participation can be reflected in children's lack of confidence and hesitance to talk to healthcare professionals and ask questions, in particular, questions related to medical conditions perceived by young people as intimate or private. Again, the role of adults in boosting children's confidence is critical. The children of parents who invested time to prepare them and inform them before medical encounters were usually more confident, and healthcare professionals who communicated with children directly and encouraged their participation were perceived

by children as approachable, giving them a sense of equality (Beresford and Sloper 2003; McNeilly et al. 2017).

## **Conclusion**

The ideas about disabled childhoods have traditionally been underpinned by the tragic view of disability, resulting in the urge among adults, healthcare professionals, and parents alike to search for the 'cure' or medical fix (Bricher and Darbyshire 2005; Oliver and Barnes 2012). The common experience of disabled childhood is an exposure to a host of remedial surgeries or other treatments attempting to move disabled bodies as close as possible to the ideal of 'normal' (Cooper 2013; Mclaughlin and Coleman-Fountain 2014). If an impairment is seen only through a biological lens as disrupting 'normal' development leading to deficiency, the development of a child's positive identity may be impeded by the implicit messages sent to the child that their body should be fixed to be accepted (Runswick-Cole et al. 2018).

Perceptions of disability as a problem in need of fixing imply that any treatment undertaken with a goal to eradicate impairment or at least reduce its effects must be in the child's best interests. Long recoveries, absence from school, painful experiences, or inability to engage in favourite activities during recovery are not sufficiently valid considerations and can easily be trumped by the goal to remedy or eradicate impairment altogether. However, if we are to move away from disability perceived as personal tragedy, all these considerations need to be taken into account, making sure that disabled children have their say in decisions on remedial surgeries and treatments.

The value of including a disabled child in these decisions can be an insight into what constitutes a 'good quality of life' for that child and might help to view the child as a 'being' with aspirations and desires rather than viewing a child through disability as 'abnormality' which needs to be restored towards an ideal of 'normal' by any means. This does not mean that each impairment-related medical intervention is considered a 'pursuit of normality' or is unnecessary, but that such decisions need to avoid seeing impairment as inherently negative, taking into account the child's views and both the social and medical impact of the treatment on child's life. The principle of the best interests of the child is fraught with value judgements. Depending on who we ask about the best interests of the child, we may reach differing judgements based on different values people hold (Freeman 1997). Parents and healthcare professionals may think that 'normalisation' is always in the child's best interests. Listening to disabled children's views on what they perceive as constituting a good life allows for the child's voice to be included in the process of best interests determination.

A failure to ensure that disabled children are informed in the process of healthcare decision-making and have their say may lead to heightened distress throughout and after the treatment and the resistance of the child to comply with the requirements in the processes of recovery and rehabilitation (Alderson 1993; Bricher and Darbyshire 2005). Despite the difficulties associated with monitoring and measuring the outcomes of participation in healthcare decision-making for children's well-being, the studies have been reporting the positive outcomes, such as the children's feelings of

being valued when they were listened to by adults, gained confidence, and new skills acquired (Franklin and Sloper 2009).

International human rights law, in particular the CRC and CRPD, provides standards for children's participation in matters that affect them, which include individual healthcare decision-making. The CRPD provides added value to the norms enshrined in CRC, especially in Article 7, as it draws attention to the need to provide children with disability- and age-appropriate accommodations and supported decision-making mechanisms when needed. It remains questionable to what extent these obligations have trickled down into national policies and practice, given the barriers to participation disabled children still face. Still, the mention of supported decision-making systems for disabled children in the context of their participation rights is a very welcome development, especially in the context of the inhibitive potential of parents and healthcare professionals to children's participation in healthcare decision-making.

Thinking about supported decision-making for disabled children and young people in the context of healthcare and, in particular, impairment-related interventions leads us to think about the role of voluntary organisations, disabled people's organisations (DPOs), peer support or support by other disabled people with experiences of the same conditions and/or similar medical treatments.

Their role in 'participation assemblage' can be particularly significant to inform deliberation on healthcare choices, boost the confidence of children and young people, and help them learn about their conditions and potential risks and benefits of proposed remedial treatments. Further, the consideration of these actors expands the 'participation assemblage' beyond the three-way relationship between children, healthcare professionals, and parents/carers. Assemblage thinking is pertinent to Deleuzo-Guattarian 'flat ontology', wherein participation is produced through affects between the assemblage components (DeLanda 2019; Feely 2020). To answer the question of what makes child participation in healthcare decision-making more or less successful, one needs to think about the components of 'participation assemblage' and how they come into being. These components may include human and non-human actors and material and discursive components which all have the productive capacity to affect each other. Seeing participation as an 'assemblage' leads us to think about how welcoming and inviting hospital spaces or examination rooms are for children or how adults' perceptions of childhood and disability and adults' ideas of children's capacities impede or enable disabled children's participation. It leads us to think about the artefacts, such as assistive technologies and audio-visual materials, that can be deployed to enhance children's understandings of proposed medical treatments and procedures or even about the healthcare systems and available funding as structures which may support or constrain children's participation.

Participation in healthcare decision-making is not an isolated event. It is a product of components brought into life by an adult's actions. Instead of asking the question of whether children have enough capacity and competence to participate, one would do well by asking the question, 'What competences should the adults have to support disabled children to participate?'

## Open access resources

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## Disclaimer

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