

Are Children's Rights Also Disabled Children's Rights?

Lecture Delivered on 10 January 2024

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The rights of disabled children are entrenched in the Universal Declaration of Human Rights (UDHR), the UN Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This lecture, therefore, discusses the rights of disabled children as human beings, as children, and as disabled persons. In the UNCRPD, disability is presented as 'an evolving concept' and the evolution of thoughts about the rights of disabled children is discussed in the first part of the lecture, with particular references to differences between the UNCRC and the UNCRPD. The lecture then moves on to review the issues highlighted by various studies and reports with regard to the contemporary experiences of disabled children and what these issues tell us about the extent to which disabled children's rights are implemented. Finally, the argument is presented that the single most important tool in ensuring that disabled children can fully enjoy their rights is their own voice and perspectives and making sure that they are given the importance they deserve.

Are children's rights also disabled children's rights? The short answer to that question is a self-evident 'yes'. A slightly longer answer is 'De jure, yes, but de facto it depends'. This second answer merits further discussion, which I am presenting in this lecture.

Human Rights

The reason for the short 'yes' answer is that disabled children have the same rights as other children, by virtue of being human and therefore also have the same rights as other human beings as they are enshrined in the Universal Declaration of Human Rights (UDHR), the International Bill of Rights which it forms part of, by virtue of being children in the UN Convention on the Rights of the Child (1989) (UNCRC) and by virtue of being disabled persons in the UN Convention on the Rights of Persons with Disabilities (2006) (UNCRPD). With so many international treaties safeguarding their rights, disabled children should have all bases covered.

However, as Hannah Arendt's (1973) concept of 'the right to have rights' in *The Origins of Totalitarianism* shows us, not all human beings automatically enjoy even the most fundamental human rights in practice. Arendt's focus is on the rights of stateless persons and on the fact that, even if human rights should automatically be enjoyed by all, regardless of which country they are citizens of, there are inherent inequalities in this enjoyment which are largely based on which country one happens to be a citizen of, if one is a citizen of any country at all.

In 'Two cheers for human rights', John Gray (2013) takes his cue from E.M. Forster's 'two cheers for democracy' to argue that for human rights too, 'we should give .. a rousing two cheers', but not three. This is because, however much important the concept of fundamental inalienable human rights is, on its own it is not enough. This insufficiency is also evinced by the fact that it is not only citizenship that determines one's ability to enjoy one's rights. We know full well how many other inequalities exist amongst citizens of the same country, inequalities which have different bases, including age, disability, gender, class, sexual orientation, belief, and ethnicity among others.

Regardless of how many cheers we think that the concept of human rights deserves, its fundamental role in rooting out injustice cannot be overemphasised. Likewise, the human rights model of disability is an important conceptual tool. The UNCRPD is based on a social relational understanding of disability, which it considers to arise 'from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (Preamble (e)).

Given that it is about rights, the Convention is also based on the human rights model, that is on an understanding of disability issues as human rights issues. Anna Lawson and Angharad Beckett (2021) compared the human rights model with the social model. They argued that the two models should not be seen as being mutually exclusive but as complementing each other. The two models are discussed by these authors as oppositional devices in the sense that, together, they oppose medical and individual models of disability which put the responsibility squarely on the disabled individual to fit within their environment. The aim of the two models is one and the same – that of working towards adapting the environment to address disabled people's needs. Lawson and Beckett pointed out the particular role played by the human rights model of disability in presenting disabled persons as rights-holders, focusing on social justice for disabled persons and on developing

policies shaped by their needs, engendering disabled persons' sense of self-worth and self-respect and solidarity between disabled and non-disabled persons as fellow human beings. It is therefore the human rights model that I am using to discuss the topic of this lecture, while being mindful of its complementarity with the social relational model of disability.

I should say at this stage that by using the term 'disabled children' I am making two moves. First of all, I am considering children who have a disability to be largely disabled by the material and cultural barriers they encounter in their lives, in line with the social relational model of disability. Secondly, I am mindful of the risk of eliding the myriad differences that exist amongst individual disabled children. I should therefore make it clear that, in this lecture, I discuss the broader issues that many disabled children encounter, the general nature of the many barriers that they experience, and the main principles and practices that can redress the gaps in their enjoyment of their rights.

Disabled Children's Rights

To go back to the question about whether children's rights are also disabled children's rights, it can be said that the latter's rights are doubly ensured through the UNCRC and the UNCRPD. That these conventions exist at all, together with many other human rights conventions, perhaps attest to the fact that the UDHR and the International Bill of Rights do not suffice to address all the rights-based issues faced by different sectors of the population. All these conventions refer to the UDHR and the International Bill in their preamble and they can be seen as ways in which these two fundamental human rights instruments are shaped to address specific needs.

The reverse also applies. With reference to the UNCRPD, O'Mahony and Quinn (2017) speak of 'migrating the issues of disability to the core of the human rights agenda' (p. xxiii). Thus, concepts related to human rights are also developed through these conventions. Incidentally, the authors speak of this migration as being 'a slow journey', a point which I will return to since it accords with one of the main themes of my lecture: that to date disabled children's rights have, at best, only partially been realised.

It is not only of migration that we can speak, but also of evolution. The UNCRPD itself describes disability as 'an evolving concept' in its preamble. The evolution of thought about disability and about rights can be seen when the wording of certain articles in the UNCRC (adopted in 1989) are compared with their counterparts in the UNCRPD (adopted 17 years

later in 2006). Here, I focus on the child's right to family life, to education, to play and leisure, and to have their views heard and taken into account.

UNCRPD Article 23 on 'Respect for the home and the family' partly repeats, and therefore also reinforces, what the UNCRC had already established in Article 9 regarding not separating children from their parents except when 'such separation is necessary for the best interests of the child'. The UNCRPD adds that '[i]n no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents'. This addition is necessary because, as we shall also see later, separation on the basis of disability is still a reality for many families. Another significant way in which the UNCRPD wording differs from the UNCRC is that there is no mention of institutionalisation. While the latter's Article 20 clearly privileges family- and community-based alternative care for children who can no longer live with their biological parents, it still allows for the possibility of 'placement in suitable institutions for the care of children'. In UNCRPD Article 23, on the other hand, no reference is made to institutional care. Instead, it establishes the need to 'undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting'.

Omitting the possibility of institutional care is in line with the overall basis of the UNCRPD in community inclusion and the right of disabled persons to lead independent and autonomous lives. Sadly, removing references to institutions from this convention has not translated into the closure of all institutions in real life, a situation which exemplifies the way in which developments in human rights concepts are not matched by practical developments on the ground. These conceptual developments are, nonetheless, important ones as they at least provide a firm basis on which developments in practice can occur.

The same pattern of conceptual development is notable when UNCRC Article 23, which focuses on the disabled child, is compared with relevant UNCRPD articles. Article 23 asserts

the need to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

This wording from the UNCRC speaks of ‘achieving the fullest possible social integration and individual development’ in, among other life domains, education. UNCRPD Article 24 Education, on the other hand, obliges ensuring

an inclusive education system at all levels and lifelong learning directed to:

- (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- (c) Enabling persons with disabilities to participate effectively in a free society.

The move from ‘the fullest possible social integration and personal development’ to full inclusion and ‘full development of human potential’ betokens the conceptual shift in recognising that the difficulties encountered by disabled persons cannot be simply explained with reference to what Carol Thomas (2004) called ‘impairment effects’ but need to take into account the massive impact that material and cultural barriers have on their lives. This shift, exemplified by what Mike Oliver (2018) termed the social model of disability, exposes the inadequacies of efforts to enable disabled persons to integrate into societal arrangements as they are. Thus, the UNCRC requirement, of integrating disabled children into existing educational institutions and practices as much as possible, is rightly replaced with the requirement for these institutions and practices and the general education system to be modified to ensure that they cater for the support needs of disabled children. Furthermore, Article 24 states that disabled children should access the same schools as other children ‘in the communities in which they live’ rather than, for example, being sent to special schools away from their local community. The importance of community inclusion is therefore also inscribed in this article.

Additionally, the UNCRC requirement to achieve the fullest integration possible for disabled children in ‘recreational opportunities’ has evolved into the following in UNCRPD Article 30 Participation in cultural life, recreation, leisure and sport:

- (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;

The extent to which the modifications for full inclusion in various childhood life domains are happening in reality is of course a different matter, one which I will return to in the second part of this lecture. However, before I do that, it is important to consider two other differences between the UNCRC and the UNCRPD.

One of these differences relates to children's participation rights, which are the subject of the final part of this lecture. UNCRC Article 12 states that

1. States 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.

Whereas, UNCRPD Article 7 Children with disabilities states that

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

There are two significant differences between these two articles. One comes at the end of UNCRPD Article 7, which establishes the need to provide appropriate support for disabled children to express their views and have them taken into account. This important requirement is based on the premise that the right to participation in decision-making processes affecting the child applies to *all* disabled children, regardless of the nature and severity of their impairment. Those who cannot express their views directly or with ease are to be provided with the support to do so. The application of participation rights to all disabled children is further reinforced in the other major difference between UNCRC Article 12 and UNCRPD Article 7. In the latter and more recent Convention, the words 'who is capable of forming his or her own views' were left out. The implication is that *all* disabled children are capable of forming views about their lives and have the right to do so, without needing to prove their capacity first. The question is how to enable them to articulate those views and to ensure that they are taken into account when decisions about their lives are being made.

It is almost as if disabled children have been accorded greater rights than other children, given that institutionalisation is not an option in the UNCRPD, as seen earlier, and

that no onus is placed on the child to prove that they can form their own views. Almost, but not quite. What can be seen as shortcomings in the UNCRC need to be considered in the particular historical and policy context of its time. As Ignacio Campoy Cervera notes, one of the differences in relation to disabled children between the UNCRC and the UNCRPD is that the former focuses on their care whereas the latter affirms their equality with other children. Consequently, the stronger expression of rights in the UNCRPD applies for all children. This is very much reflected in the explanation of UNCRC Article 12 by the Children's and Young People's Commissioner Scotland (2024).

The final difference between the UNCRC and the UNCRPD that I will consider relates to the last part of Article 23 that I quoted earlier, that is the right to 'cultural and spiritual development'. The right to cultural development is also found in the UNCRPD, both in Article 30, as mentioned earlier, and Article 3 General Principles:

(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

I come back to this specific right in the last part of my lecture. Here, I want to note that spiritual development, mentioned in the UNCRC, is nowhere to be found in the UNCRPD either in relation to disabled children or to disabled persons more generally. This is a lamentable omission as it ignores a very important aspect of human development. It is an omission which was discussed by Elena Jenkin et al. (2023) in their research with disabled children in Vanuatu and Papua New Guinea. They commented on how the importance given by the children involved in their research to their spiritual life does not have a place in the UNCRPD.

In this first part of the lecture, we have seen how ideas about how best to ensure that disabled children enjoy their human rights have evolved. The comparison between the UNCRC and the UNCRPD has shown how, for the most part, their rights have been strengthened through wording which clearly establishes the need to put in place societal changes to ensure that disabled children are fully included in families, mainstream schools, recreational activities for children, and in their communities. To return to the question which doubles up as the lecture title, we can safely say that, de jure, disabled children's rights are expressed more strongly than ever as being identical to the rights of all children. What can

be different are the means by which disabled children's rights can be made a reality. It is the need for these different means that creates the gap between what should be and what is.

Current Issues

Before delving into the second part of this lecture, where I present a review of various studies that shed light on the current situation of disabled children in different countries, it is important to point out that it is not necessarily only disabled children who encounter obstacles to enjoying their rights fully, if at all. Unfortunately, there are many children whose lives are not what they should be because of structural problems and societal barriers other than the ones related to disability. The focus on the difficulties experienced by disabled children should not be seen as implying that it is only they who encounter such problems. Some difficulties are also shared by non-disabled and disabled children, either because of wider societal problems or due to intersectional factors. There are, however, also obstacles which are particular to disabled children and it is on these obstacles that I am directing my attention, especially in relation to institutionalisation, education, and play.

Institutionalisation

The deleterious effect of being institutionalised have long been known. Goffman's (1961) *Asylums* was a ground breaking study and his insights are as valid today as they were 60 years ago. Being institutionalised as a young child can be even more detrimental, since the child is less likely to receive the attention and care needed for their cognitive, emotional, psychological, and even physical development (Open Society Foundation, 2016). For disabled children, institutionalisation can therefore be doubly harmful because, not only are they not growing up in a family environment that they have a right to, but the institutional environment can actually exacerbate the effects of their impairments. In a report on the 27 EU Member States published in 2020, Jan Šiška and Julie Beadle-Brown note that institutionalisation is still an option in most countries, including for disabled children. With the exception of Sweden, all EU countries have provision for placing disabled children in residential services where there are 30 or more persons. In the case of Austria and Ireland, such provision is available for disabled children only, not for other children. In the case of Luxembourg and Malta, large residential services for disabled children are only used occasionally.

Šiška and Beadle-Brown report a trend towards a decrease in the use of institutionalisation options for disabled and other children in most EU countries. However, in some European countries, including Denmark, Serbia, Slovakia, and the UK, disabled children are still more likely to be institutionalised than non-disabled children (Šveřepa, 2019). In other countries, like Bulgaria, these children are moved from large scale residences to group homes, which very often end up functioning as small-scale institutions rather than offering fully fledged community based care, as noted by Crowther (2019) and Šiška and Beadle-Brown (2020). Elsewhere, institutionalisation of disabled children is still the default option, as evinced in reports such as the one by Human Rights Watch (2020) in Kyrgyzstan and the UN Economic and Social Commission for Western Asia (2019) report about a number of Arab countries.

Even with a decrease in institutionalised care for disabled children, the fact is that, 16 years after the UNCPRD came into force in 2008, and with 187 out of 193 UN member states and the European Union having ratified it, we are still a long way away from the provision of 'care within the wider family, and failing that, within the community in a family setting' as required by UNCPRD Article 23. The Opening Doors for Europe's Children (2024) campaign notes that

The overwhelming majority of children enter institutions not because their parents have died or because they have experienced abuse or neglect at home, but rather because their parents live in material poverty and lack access to health, education, childcare, rehabilitation and other basic services that would enable them to adequately care for their children.

This observation highlights the key role that support services play in ensuring that disabled children can enjoy the rights inscribed in the UDHR, the UNCRC, and the UNCPRD. Crucially, the support needs to be extended to their parents and families to ensure that they have the wherewithal to provide disabled children with support themselves.

Education

Parental support is also crucial in education. Apart from the home being the first learning environment of the child, children who find support at home after school do better in their studies (Hattie, 2008). For many disabled children, that home-based support very often includes early intervention. Once they reach schooling age, being included in mainstream schools is essential, as attested by the wording of UNCPRD Article 24 which

upholds not just disabled children's right to education, but to *inclusive* education. Once again, the extent to which disabled children are fully included in their country's education system is a matter for debate.

In desk research carried out recently by myself and Georgette Bajada for a chapter on the current state of inclusive education, we found a mixed bag of results (Callus and Bajada, 2024). The tendency is for studies reporting the situation at a macro level to provide a discouraging picture and for studies that focus on specific schools and educational settings to find enough pockets of good practice to paint a more encouraging picture with. The macro reports include one by UNESCO (2022), which shows that, globally, 80% of disabled children live in low to middle income countries and are much more likely than non-disabled children not to be attending school at all. Another two UN documents, a report by the Special Rapporteur on Disability (2021) and the General Comment on the Right to Inclusive Education by the UN Committee on the Rights of Persons with Disabilities (2016), also note failings in the implementation of Article 24, with disabled children still being likely to be placed in segregated schools, in segregated units within mainstream schools, or to be placed in mainstream classes without all the support they need to enjoy meaningful inclusion.

Reports that focus on the situation in European countries are not any more positive. The Schola Europea (2018) *Report on Inclusive Education in European Schools* and the report by the European Agency for Special Needs and Inclusive Education (2020) note that disabled children are likely to experience education systems which do not provide effective inclusion and that they are more likely to be out of school than their non-disabled counterparts.

On the other hand, in terms of research at the micro and meso level, Van Mieghem et al's (2020) meta review of systematic reviews of research into inclusive education carried out since the year 2000 provides examples of good practice and an understanding of the factors that contribute to it. One of the most important factors is the beliefs about inclusion held by educators and by parents, what they understand inclusion to be and what support they receive to facilitate inclusion in the classroom and in schools. Sometimes, inclusion is misunderstood as only applying to some disabled children but not others. A systematic review carried out by Miyauchi and a report on inclusion in the Commonwealth by Reiser (2012) point to a tendency for children with physical, visual, or hearing impairments to be more likely to be included than children who have intellectual disability or show behaviours of concern.

These various reports and studies show that a full understanding of what inclusive education is still needs to be developed. Too much still depends on what particular educators think about their own role in adapting educational systems and practices to cater for the individual educational needs of different disabled children. Until all educational systems are transformed into ones that can adapt for these individual needs, until all educators and educational policy makers appreciate their own role in bringing about this transformation, the full realization of UNCRPD Article 24 will remain a pipe dream for most disabled children.

Play

If inclusion in formal settings, like classrooms, is proving to be difficult for disabled children, the enjoyment of inclusion in informal ones, such as in play and leisure activities, is likely to be a more daunting prospect. Disabled children's right to play is safeguarded in UNCRC Article 31 and UNCRPD Article 30. The obstacles to disabled children actually being able to have enjoyment of this right are clearly set out in the Position Statement of the International Play Association (2015) on 'The Play Rights of Disabled Children'. These obstacles include lack of physical accessibility, for example to playgrounds, lack of accessible transport, and lack of inclusion in facilities and activities designed for children. Furthermore, this Position Statement notes that disabled children need to have time to play and to engage in activities which are not imposed by adults. Similar issues are raised in the Position Statement issued by the Ludi Network (n.d.). Apart from stating the importance of play for its own sake, rather than as a means to educate or provide therapy, they note that:

Children with disabilities may encounter barriers to play due to their cognitive, sensory or physical impairments, and to unfriendly and inaccessible contexts (social and built environments); and they may not be afforded sufficient opportunities for play given that their time is often highly devoted to rehabilitation and educational activities. In this sense, they are all too often deprived of the fundamental engine for physical, cognitive and social development, and also of the possibility to exercise their right to play, with potentially negative consequences throughout their life.

Even if all environmental and structural barriers were to be removed, attitudinal ones would still need to be addressed. As noted by Barron et al (2017), there is a paucity of research about play for disabled children. The research that does exist, these authors noted, suggests disabled children tend not to be invited to the homes of other children or to

playdates and are often not supported to invite other children to their homes. Moreover, the research suggests that where disabled and non-disabled children have the opportunity to play together, the latter tend to take the lead and the former 'become onlookers, particularly in outdoor play, where the activities might be more physically demanding' (p. 24). Access to outdoor play, particular in nature, was discussed further by Angharad Beckett and Deborah Fenney (2023), who noted that, while the promotion of free play by children in natural settings is very justified, those who promote it rarely take disabled children's access needs into account. The importance that disabled children themselves attach to play for its own sake is clear from studies carried out by Marilyn Cini (2017), Vaska Stancheva-Popkostadinova and Besio (2018), and Mattea Tabone (2023).

The fact that there is not much research about disabled children's access to play is itself significant. This area tends not to be given the same importance as other life domains, especially education and healthcare. Furthermore, as Beckett and Fenney (2023) also noted, discussions on disabled children's play tend to consider it as a means to address functional limitations. But disabled children's lives should not be dominated by the need to learn and to do therapy, important as these activities are. They do need balance in their lives, just like any other child.

Like Other Children

The question remains whether disabled children are seen as being just like other children. From this discussion of various reports and studies, we can see that they tend to encounter significant obstacles in the realization of their rights. Disabled children have a higher tendency to be institutionalised than most other children, they are largely still expected to fit into existing educational systems in order not to be excluded from them, and play tends to be considered in terms of its therapeutic value for them rather than as being valuable for its own sake.

These tendencies run contrary to the strong affirmation of disabled children's rights, as noted in the first part of this lecture. On the one hand, their rights are not only safeguarded de jure, but their inscription in international legislation is stronger than ever. On the other hand, de facto there is still too much that is dependent on environmental and attitudinal factors for the realization of these rights.

Participation Rights

Johhny Mathis' song 'When A Child is Born' which is associated with Christmas (Wikipedia 2023), speaks of hope for a better future, a hope which is also part of Hannah Arendt's concept of natality in *The Human Condition*. For Arendt (1998), every baby's birth encapsulates new possibilities for the world, new beginnings, and new ways of doing things. Arendt argued that we carry this natality with us throughout our lives and actualize us when we act. By action, Arendt referred to our innate freedom to act on the world in new and diverse manners. In fact, 'freedom' and 'plurality' are central to her concept of what 'action' is. Freedom, or more accurately, fundamental freedoms, are also closely related to human rights. Like other human rights treaties, the UNCRPD opens its Preamble with a reference to the UN Charter and the UDHR.

- (a) Recalling the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,
- (b) Recognizing that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,
- (c) Reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination,

Thus, human rights are the foundation not only of justice and peace, but also of freedom. The three go together. The International Bill of Human Rights does not only proclaim rights but, with them, freedoms. And the human rights and fundamental freedoms of disabled people are universal, indivisible, interdependent, and interrelated. Simply put, there can be no enjoyment of human rights without fundamental freedoms. Having rights, therefore, also means having freedom, not only in the sense of having the freedom to make choices, take decisions, and act on the decisions taken, but also the freedom to act in the Arendtian sense and, as UNCRPD Article 24 puts it, 'to participate effectively in a free society'.

The question then is to what extent disabled children are able to act on their fundamental rights and freedoms. Children, whether they have a disability or not, are not

expected to be able to act in the same way that adults do. To foist such expectations on them would be detrimental. But children who do not have a disability are expected to develop their ability to act as adults while they are still children and to take an increasingly more active part in their own lives as they grow up. But these expectations are not necessarily associated with children who are born with a disability or who are diagnosed as having a disability after they are born.

Because of the functional limitations brought about by impairments, disabled children do not follow typical developmental trajectories, cognitively, physically, communicatively, and/or in other ways. Many of them are also likely to continue needing direct support in their daily lives into their adulthood. Expectations for them, then, become very different than for other children.

In *Nameless: Understanding Learning Disability*, Dietmut Niedecken (2004) took a psychoanalytic approach to analyse the factors that impinge on the development of babies who are diagnosed with an intellectual disability. Her insights can also be applied for babies and children with other types of disabilities. Niedecken's analysis shows how, from the moment of diagnosis, the relationship between the child and their parents or their main caregivers changes. The expectation of atypical development changes everything as all efforts, all interactions with the child are focused on maximising their functional ability. The intention is of course a good one and the aim an important one. After all, disabled children should be supported to fulfil their potential in attaining as much functional ability as possible. But when this is the only potential that they are supported to attain, they can very well end up being cheated of their fundamental rights and freedoms. When, as Niedecken observed, even playtime becomes an opportunity to watch out for signs of the disabled child's development, when even spontaneous behaviour – for instance eye contact – becomes something to examine, interactions with the disabled child can become artificial and potentially stressful. Such interactions could become like the situation described by Sally French and John Swain of a disabled person who remembers a childhood in which 'speech therapy as being a lot of hard work and I can remember getting extremely fed up'. The child was constantly supervised, even while eating.

'you get to a point when you think, "Wouldn't it be nice to just sit and enjoy your food?" [...] it becomes a technical exercise [...] getting to a point when I dreaded mealtimes' (French and Swain 2008, p. 25)

It is of course very important to stress that therapeutic interventions with disabled children are inherently good and can be extremely beneficial for them. The point is knowing when to stop such interventions, knowing how to achieve the right balance between doing therapy and allowing the disabled child to enjoy their childhood. The most effective way of reaching that balance is by understanding how interventions are being experienced by the disabled child.

This is where disabled children's participation rights come in. These rights, affirmed in UNCRPD Article 7(c) as discussed earlier, place an obligation on adults to provide disabled children with the opportunity and the means to articulate their views and to have those views taken into account when decisions about them are made. As Elvira Psaila (2023) argued, the mosaic approach developed by Alison Clark and Peter Moss (2011) is one of the most effective ways of enabling children to articulate their views and, perhaps more importantly, of adults to evolve their own capacity to learn how to listen to disabled children. As Psaila showed, although the mosaic approach was developed as a research methodology it can also be used in professional practice in clinical and educational settings as well as a means of supporting parents of disabled children. Psaila's (2017) own use of the mosaic approach in research with Alexander, a young boy who is a wheelchair user, revealed the chasm that can exist between how a disabled child sees their life and how it is perceived by some adults. By juxtaposing a series of quotations from Alexander and from his educators, Psaila showed just how wide this chasm is. To take just one example, one of the quotations from Alexander is 'At school I am happy when I am playing with the children'. This is in stark contrast to the assertion by one of his educators that 'He needs to walk daily. That's why we spend break time walking in the corridor, as walking in the playground is unsafe' (p. 176). If his educators took the time to listen to Alexander about what makes him happy, they should have been able to find a way of ensuring that he can get the physical exercise that he needs and also enjoy playing with the other children. More importantly, they would be able to move away from the deficit model of disability which permeates the way they talk about Alexander.

Unfortunately, this deficit model often underlies work carried out with disabled children. It is therefore important not only to consider what interventions are needed for each particular child but also how the need for and the provision of interventions are

framed. As Clare Reinhardt and Amy Robasse (2023) argued, an unconscious bias against disability can have very negative consequences, especially when this bias is held by health professionals themselves. Using a deficit model of disability, they argued, means that much needed treatment and interventions are often framed as tragic necessities rather than being seen as vital tools that the disabled child happens to need. They wrote that '[t]he normative, deficit-based way both the treatment and impairment are presented can unintentionally create stigma and other psychological suffering' (p. 377).

Disabled children can also be placed in a situation where, while most adults around them apply a deficit model of disability in their regard and see them mainly in terms of their impairments, they are denied the opportunity to see themselves as disabled persons. Niedecken argued that when disabled children are not given information about their own disability, they are 'not allowed to inquire into ... [their] own place in our world' (p. 93). As noted earlier, UNCRPD Article 3(h) asserts 'the right of children with disabilities to preserve their identities'. That preservation presumes a development of the child's identity in the first place, but that development cannot happen if the child cannot affirm their disability as an integral part of that identity. Developing an affirmative sense of who they are and of their place in the world entails that disabled children are, at one and the same time, not perceived only in terms of their impairment whilst being guided to understand the presence of an impairment as an integral part of who they are. After all, not being spoken to specifically about their impairment does not prevent a disabled child from knowing that they are perceived as different. This quotation from Alf, one of the students who participated in Georgette Bajada et al's (2022) research about inclusive education, is very revealing in this regard:

I accept everyone, but, in order to be accepted I have to be like them [peers]. Therefore, I do my best to look and act like them. But still, they see me as different, so they decide that I am not normal. I know from the looks they give me. I wish that they realise that I am like them. Because after all, I am like them. (p. 1262)

Developing an affirmative identity as a disabled child is an integral part of making participation rights a reality for disabled children. But they cannot do that if interactions with them are imbued with negative overtones, with a tragic view of disabled childhoods. Disabled children should not be at the mercy of the attitudes of the adults around them,

those who play a direct part in their lives and those who form part of the society they are members of. The exercise of participation rights by disabled children can itself challenge these negative overtones. The direct participation of disabled children in research, such as in the excerpts from Alexander and Alf quoted above and in that of many other researchers such as, for instance, Anita Franklin, attest to that. As Brady and Franklin (2019) argued, involving disabled children in research – including as co-researchers – challenges dominant notions of them as dependent and in need of protection.

We do well to take heed of the quotation from Ferguson and Ash (1989) that Eva Kittay (2019) used in her book *Love's Labor*:

The most important thing that happens when a child with disabilities is born is that a child is born. (Ferguson and Asch 1989, 108) (Kittay p. 157)

In her work, Kittay heavily criticised the view of human dependency as a mark of inferiority, weakness or inequality. Instead, she argued, we should value it as an integral part of being human. If we did that, we would be able to relate differently with disabled children. We would still attend to their impairment-related needs of course and we would still ensure that they are provided with the therapeutic and educational interventions that they do need to maximise their physical and cognitive potential. But we would not stop there, or even take these interventions as a starting point.

In a Ted Talk, Jacob King (2022) spoke about being born and growing up with a visual impairment. He started his talk by saying 'seeing less is not the same thing as seeing worse'. He spoke about not wanting to have his impairment fixed because 'I like being who I am and a big part of being who I am is being blind. So, I don't want to change that'. Furthermore, he said that 'having a disability means ... embracing all the things that you can't do and embracing all the things that you can do'.

Reaching that level of comfort with one's own disability takes time and involves a lot of work, which needs to start from childhood. Crucially, King said, it is something 'that you need help with'. King described how his mum deftly and creatively treaded the balance between treating him like his siblings while attending to his impairment-related needs, like teaching him how to vacuum the carpet barefoot. That meant that he was not going to be able to wiggle his way out of helping with the household chores and that he could do the

vacuuming in a way that was accessible to him – he could feel rather than see the mess he needed to clean.

King also described how his mum helped him with his education, not only in terms of supporting him with his homework and ensuring that he was provided with the reasonable accommodation he needed at school but also

by helping me to navigate the IEP process. ... When an IEP is written, especially when I was a kid, the child was never involved in the process ... and that really bothered my mum. She figured that, if these plans were supposed to affect me then, at the very least, I should be aware of them but really I should have some sort of say in them. So I'd been going to IEP meetings ever since second grade and by the time I was in high school, I was running my own IEP meetings. I was standing up to teachers and principals and I was saying 'yeah, you really do have to enlarge my homework every single time...'.

In the first part of his talk, King described the nature of his visual impairment and how he sees things differently. As he put it 'You don't see it in the way that I see it'. While, in the context of his talk, he is referring to seeing physical objects, what he said can be applied to how he sees his life in general and his own place in the world. It can also be applied to disabled children's perspectives more generally because how they see their lives can never be how we adults see it.

This is why making disabled children's participation rights an ordinary day-to-day reality is so crucial to ensuring that they can fully enjoy their rights as children and as disabled persons and ensuring that the 'slow journey' to having disabled children's rights fully realised, mentioned by O'Mahony and Quinn, which I quoted earlier, picks up much needed momentum, for institutionalization to be seen as unacceptable for disabled children as it is for other children; for the importance of being educated alongside children from their own community to be valued for disabled children as much as it is for other children; for play to be valued for disabled children as well as for other children; and for the views of disabled children and all other children to be given their full worth.

The '[r]espect for the evolving capacities of children with disabilities', affirmed in UNCRPD Article 3(h) alongside their right 'to preserve their identities', is not only about their right to develop as much functional ability as possible and not only about their right to learn as much as possible, which are also affirmed in the UNCRPD itself as seen in the first part of this lecture. Those rights are important but they are not enough and need to be

balanced with the right of disabled children to develop their capacities to articulate their perspectives and have them taken into account, to be agents in their lives on an equal basis with other children, and to become adults who can celebrate who they are and who are surrounded by people who join in that celebration.

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