

# The Right of Disabled Children to Be Heard: Individual and Collective Entitlements

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*Every child has the “right to be heard.” This fundamental right is typically brought up in judicial proceedings and before administrative authorities. In fact, the UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes that disabled children face unique barriers to accessing this fundamental right, and policies must be put in place to ensure all children can fully exercise their right to be heard. Although a disabled child’s right to be heard seems self-evident, in practice most states render it unattainable because disabled children are often denied full legal capacity and recognition of their legal personality. As a result, the right to be heard is ultimately only exercised by those enjoying substitute decision-making powers, such as guardians and conservators. An important dimension of this right—as enshrined in the CRPD—is its collective entitlement to all persons including those with disabilities, which is troublingly absent in the Convention on the Rights of Children (CRC). Applying this collective entitlement to disabled children to allow them to be fully heard has the potential to become a formidable tool to formulate strategies that ultimately contribute to the welfare of disabled children.*

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## INTRODUCTION

There has always been a dilemma concerning whether disabled children should be treated and protected in the same manner as non-disabled children.<sup>1</sup> However, international law makes clear that they should be treated the same. Since the rationale underlying the CRPD was an adaptation of the existing human rights armory to the disability context rather than the recognition of “new” rights, the extension of these rights to disabled children is necessary.<sup>2</sup> Before the CRPD, Article 23 of the CRC<sup>3</sup> was novel, since it highlighted the minimum protections and rights that should be afforded to each child, including those with disabilities. Soon after the CRC was passed, the disability movement began to see it as outdated, since it did not explicitly acknowledge disabled persons as right holders or provide serious emphasis on the need for equality triggering the need for the CRPD.<sup>4</sup> More significantly, the CRPD effectively shunned the medical model of disability, which focused on ‘impairment’, in favor of the social model of disability.<sup>5</sup> The latter emphasizes that it is the adaptability of the built and natural environment that creates disability, and therefore, the way to increase access is by altering the environment.<sup>6</sup>

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1. Article 1 of the U.N. Convention on the Rights of Persons with Disabilities defines disability generally, so does not define a disabled child. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/RES/61/106 (Jan. 24, 2007) [hereinafter CRPD], <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html> [<https://perma.cc/UVU7-LR4S>]. The U.S. Individuals with Disabilities Education Act (IDEA) defines a “child with a disability” to mean a child with “mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, . . . orthopedic impairments, autism, brain injury, other health impairments, or specific learning disabilities.” 20 U.S.C. § 1401 (3)(A)(i).

2. See generally Theresia Degener, *Disability in a Human Rights Context*, 5 L. 35 (2016) (discussing the shift in the “catalogue of human rights” to the disability context); Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and Its Implications for the Rights of Elderly People Under International Law*, 25 GA. ST. U. L. REV. 257, 571 (2009) (describing the importance of the CRPD in applying human rights instruments to people with disabilities, and the possibility for the CRPD to be used as a blueprint for extending additional protections to other groups); see also Dimitris Anastasiou & James M. Kauffman, *A Social Constructionist Approach to Disability: Implications for Special Education*, 77 EXCEPTIONAL CHILD. 367, 377 (2011) (discussing the impact of the theoretical model used to analyze rights of disabled children and problems that can present themselves when services are presented uniformly across populations).

3. Convention on the Rights of the Child, G.A. Res. 44/25, U.N. GAOR, 44th Sess., Supp. No. 49, at 166, U.N. Doc. A/44/736 (1989) [hereinafter CRC].

4. Michael A. Stein, *Disability Human Rights*, 95 CAL. L. REV. 75, 75–121 (2007).

5. Rhoda Olkin, *Conceptualizing Disability: Three Models of Disability*, AM. PSYCH. ASS’N, (Mar 28, 2022) <https://www.apa.org/ed/precollege/psychology-teacher-network/introductory-psychology/disability-models> [<https://perma.cc/R5D6-83DG>].

6. *Id.*

In essence, the CRPD reframed the human rights held and afforded to people with disabilities, particularly those held by disabled children.

Each provision empowered the world's largest minority to access their legal rights in the international arena. For example, the CRPD in Article 23 recognized disabled children's right to live a "full and decent life" and to participate in the community contained. Additionally, the CRC recognized four key principles which should be considered in the provision of all pertinent rights, all of which apply irrespective of context or disability.<sup>7</sup> These principles are: (a) The best interests of the child;<sup>8</sup> (b) A respect for the views of the child;<sup>9</sup> (c) The right to life, survival, and development of the child;<sup>10</sup> and (d) A non-discrimination principle.<sup>11</sup> Some of these have long been recognized as general principles, but others are new for many states. The CRPD's principles are meant to be applied based on the particular circumstances of each case and as peremptory norms. This means they can—and should—be applied to substantive laws (for example, to interpret the child's right to leisure) as well as procedural laws in order to provide equal access in all areas of law.<sup>12</sup> While these principles may seem clear, for children with disabilities, our understanding of equality and the unique barriers faced by those with disabilities has had to evolve.

By the late 1990s, it became evident that Article 23 of the CRC failed to consider the particular context of child disability,<sup>13</sup> especially since the language used does not appear to be predicated on the social model of disability.<sup>14</sup> For one thing, children with intellectual disabilities are not afforded legal capacity, and states generally strive to ascribe substitute decision-making powers to third persons (and away from the

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7. See Elizabeth Bartholet, *Ratification by the United States of the Convention on the Rights of the Child: Pros and Cons from a Child's Rights Perspective*, 633 ANNALS AM. ACAD. POL. & SOC. SCI. 80, 88–93 (2011) (referring to these as the "four P's," namely participation, protection, prevention (of harm), and provision (of assistance)).

8. CRC, *supra* note 3, Art. 3.

9. *Id.* Art. 12.

10. *Id.* Art. 6.

11. *Id.* Art. 2.

12. See Committee on the Rights of the Child [hereinafter CRC Committee], General Comment No. 14: The Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration, U.N. Doc. CRC/C/GC/14 (May 29, 2013), <https://www.refworld.org/legal/general/crc/2013/en/95780> [<https://perma.cc/8B6K-VR2B>].

13. See Maya Sabatello, *The Politics of the Child's Right to Identity in a Disability-Free Society*, 17 INT'L J. CHILDREN'S RIGHTS 171, 174–81 (2009) (who argues that prior to the CRPD, the identity of disabled children was subsumed within that of other children and hence no differentiation was made in law and policy).

14. Bronagh Byrne, *Minding the Gap? Children with Disabilities and the United Nations Convention on the Rights of Persons with Disabilities*, in LAW AND CHILDHOOD STUDIES: CURRENT LEGAL ISSUES 419, 422–27 (Michael Freeman ed., 2012).

disabled child), as opposed to assistive decision-making authority that allows people with disabilities to retain their decision-making authority.<sup>15</sup> This has a detrimental effect on disabled children's capacity to enter into binding agreements, which in turn limits their access to property and other socio-economic rights.<sup>16</sup>

An illustration is apt to show the inequality afforded to people with disabilities that does not align with the ideals in the CRPD. In certain countries, parents or guardians are given authority under the civil law to determine whether a child not only has intellectual disabilities, but also whether the child is prodigal, inattentive and an 'imbecil'.<sup>17</sup> Such characterization effectively allows the parent or the guardian to strip a child from its capacity under the CRPD to enter into contracts (with assistance if needed), to seek employment, and to dispose of its property.<sup>18</sup> In order to rebut this problematic characterization, the child must be present in court to challenge their parents or guardian's argument and to demand that their full capacity is recognized by the courts.<sup>19</sup> If the child is unable to disprove erroneous characterizations, then the child's rights are obliterated.<sup>20</sup> If legal capacity and personality are removed or impaired, the right to be heard—which also encompasses access to socio-economic rights—is meaningless before the courts and administrative authorities.<sup>21</sup>

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15. Bernadette McSherry, *Legal Capacity Under the Convention on the Rights of Persons with Disabilities*, 20 J.L. & MED. 22 (2012); see Lucy Series, *Legal Capacity and Participation in Litigation: Recent Developments in the European Court of Human Rights*, 4 EUR. Y.B. DISABILITY L. 132, 132–38 (2015) (discussing the debates around substituted decision-making, and describing what measures could be provided in a support-focused paradigm to allow for disabled children to make their own decisions).

16. STEVE BROACH & LUKE CLEMENTS, *DISABLED CHILDREN: A LEGAL HANDBOOK* (3d ed. 2015); ANNE-MARIE CALLUS & RUTH FARRUGIA, *THE DISABLED CHILD'S PARTICIPATION RIGHTS* (1st ed. 2016); see generally Sabatello, *supra* note 13, at 174–78.

17. Qatar is one such country. Even though Law No. 22—promulgating the Qatari Civil Code—suggests that capacity comes with discretion (*i.e.*, maturity) under Article 49, Article 50(1) clarified that capacity exists when a person is deemed to have “imbecility (al-ma'tūh) or insanity.” Qatar Legal Portal: [https://www.icnl.org/wpcontent/uploads/Qatar\\_29\\_Qatar\\_CivilCode\\_2004.pdf](https://www.icnl.org/wpcontent/uploads/Qatar_29_Qatar_CivilCode_2004.pdf) [<https://perma.cc/A7YN-KTZK>]. Neither a minor nor those deemed to have “imbecility or insanity” can contract or undertake other transactions. *Id.* Art. 50(1).

18. See *id.* (discussing when the courts can remove access to “civil rights”).

19. *Id.*

20. See *id.* Art. 51 (describing when people retain no legal capacity).

21. In the United Kingdom, for example, litigation capacity was governed by the rule set out in *Masterman-Lister v. Brutton & Co.*, which described it as “whether the party legal proceedings is capable of understanding with the assistance of such proper explanation from legal advisers and experts in other disciplines as the case may require the issues on which his consent or decision was likely to be necessary in the course of those proceedings.” [2002] EWCA Civ 1889. See also Piers Gooding, *Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns*, 15 HUM. RTS. L. REV. 45 (2015) (analyzing concerns related to achieving equality in exercising legal capacity by people with disabilities around the world).

Moreover, the measures of “special care” afforded to disabled children under Article 23 are resource-dependent, while no similar resource constraint is placed on other articles—focused on the rights of non-disabled children—in the CRC. This means under the CRC, disabled children’s access to rights is limited by current societal resources and direct government intervention, and when those are unavailable, this may result in restriction of their rights. The CRPD removes these limitations and retains a consistent standard afforded to disabled children not only in Article 7 (the general provision) but also in all other provisions that affect disabled children’s rights, such as the right to education.<sup>22</sup> Therefore, for the first time these rights were treated as absolute for disabled children not conditional.

The breadth of the CRPD should not be understated. Article 7 of the CRPD is clearly situated within two distinct, yet wholly interrelated fields of law: general international human rights law and international child law.<sup>23</sup> While the latter is effectively a branch of the former, the distinction serves to underline its *lex specialis* character, particularly through the enunciation of discrete rights that are not found in general human rights law.<sup>24</sup> More specifically, these two discrete rights are (1) The child’s best interests and (2) The right of the child to be heard.<sup>25</sup> These two rights, which are specifically provided for in the CRPD, aim to provide an additional layer of protection to children, who are considered a vulnerable group; there are no equivalent rights to these for adults.<sup>26</sup> Besides these two distinct rights, Article 7(1) of the CRPD makes *all* existing human rights and fundamental freedoms available to children through its language: “State Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.”<sup>27</sup> This

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22. Gauthier de Beco, *The Right to Inclusive Education According to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background, Requirements and (Remaining) Questions*, 32 NETH. Q. HUM. RTS. 263, 265–87 (2014) (discussing the right to education); see also Elaine Unterhalter, *The Many Meanings of Quality Education: Politics of Targets and Indicators in SDG4*, 10 GLOB. POL’Y 39, 39–51 (2019) (analyzing barriers to inclusive and equitable education).

23. Stein, *supra* note 4, at 93–100 (discussing the human rights paradigm of disability and the move towards subsuming disability rights into the existing human rights ecosystem).

24. *Id.*

25. Although little scholarship is available on the right of disabled children to be heard, there has been research on the rights of disabled children to access the education of their choice. Special education scholars, among others, argue that disabled children should not be forced to attend special education schools and should instead be able to make a choice about whether they want to be educated. Anastasiou & Kauffman, *supra* note 2, at 368.

26. See generally AISLING PARKES, CHILDREN AND INTERNATIONAL HUMAN RIGHTS LAW: THE RIGHT OF THE CHILD TO BE HEARD 40–44 (2013).

27. CRPD, *supra* note 1, Art. 7.

language should not be taken for granted and has a twofold dimensions. The first dimension encompasses all the rights in the CRPD, some of which are available to all disabled persons, while some are available solely to children, such as Article 24 of the CRPD, which deals with the right to education.<sup>28</sup> The second dimension, however, is even more important. Reference to *all* rights includes every right, whether exclusive to children or not, that is found in human rights treaties (and customary international law) and which lie outside the text of the CRPD.<sup>29</sup> This observation is significant because even if a state party to the CRPD has not ratified any other universal human rights treaties or refutes the existence of a particular customary right, it is still bound to recognize such rights to disabled children in its territory or under its control by virtue of Article 7(1) of the CRPD.<sup>30</sup> For children generally, the most significant source of obligations will naturally stem from the CRC, but all other treaties like the CRPD are equally applicable *mutatis mutandis*.

Even before the CRPD, the foundational principle underlying any decision, judgment, or action (legislative, administrative, or otherwise) concerning children is that it must be in the best interests of the child.<sup>31</sup> In the context of disability, the determination of what is in the best interest of

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28. *Id.* Art. 24.

29. PARKES, *supra* note 26, at 40–44 (describing how in one of the few studies on the application of the right to be heard to disabled children, even if only in a chapter, the author argues that this entitlement was only largely glossed over by the courts and children services); Michael A. Stein & Janet E. Lord, *Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities and Future Potential*, 32 HUM. RTS. Q. 689, 692–95 (2010).

30. Although the application of the CRPD is territorial, general international law, largely stemming from the European Court of Human Rights [hereinafter, Eur. Ct. H.R.], has long sustained the notion that states owe human rights obligations not only within the strict confines of their boundaries, but also in territories under their full control. *See e.g.*, *Al-Skeini v. United Kingdom*, App. No. 55721/07, 18 Eur. Ct. H.R. 53, ¶ 74 (2011), <https://hudoc.echr.coe.int/fre?i=001-105606> [<https://perma.cc/74XM-3AP6>]; *Chiragov v. Armenia*, App. No. 13216/05, Eur. Ct. H.R., ¶ 186 (2015), <https://hudoc.echr.coe.int/fre?i=001-155353> [<https://perma.cc/8ZNX-RB8Q>].

31. CRC, *supra* note 3, Art. 3; *Maumousseau & Washington v. France*, App. No. 39388/05, Eur. Ct. H.R., ¶ 62 (2007), <https://hudoc.echr.coe.int/eng?i=001-83823> [<https://perma.cc/V2M-H-MBNK>]; *Gnahoré v. France*, Judgment, App. No. 40031/98, Eur. Ct. H.R., ¶ 59 (2000), <https://hudoc.echr.coe.int/eng?i=001-58802> [<https://perma.cc/UJ2N-ET7U>]. Eur. Ct. H.R. has claimed in unequivocal terms that the award of custody to one parent following divorce or separation constitutes an interference, albeit a legitimate one, to the right to family life of the other under Eur. Ct. H.R.’s Article 8. This interference is justified by the “best interests” principle enshrined in CRC’s Article 3. *See Hoffman v. Austria*, App. No. 12875/87, Eur. Ct. H.R., ¶ 29 (1993), <https://hudoc.echr.coe.int/eng?i=001-57825> [<https://perma.cc/5WMK-XPYE>]. The “best interests” principle exists also, among others, in Art. 24(2) of the Charter on Fundamental Rights of the European Union. *See Charter of Fundamental Rights of the European Union*, 2010 O.J. C 83/397, <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:083:0389:0403:en:PDF> [<https://perma.cc/M9K8-4JT6>].

the child needs to be individualized. Under Article 3(2) of the CRC, the application of the “best interests” principle must take into account “the rights and duties [of the child’s] parents, guardians or other individuals legally responsible.”<sup>32</sup> Therefore, a child’s best interests must be assessed on an individual basis by the courts and administrative authorities, and hence pertinent decisions must be reasoned as to their effects and outcomes on the particular child in question.<sup>33</sup> The application of this principle in the drafting of disability-appropriate laws, especially since these will impact children, requires that drafters use language that reflects the needs of children in a disaggregated fashion.<sup>34</sup> For example, there should be different types of protections for children who are refugees, members of indigenous communities, marginalized groups (such as Roma), socially excluded, disabled, or abandoned, among others.<sup>35</sup> Such disaggregation allows the state, including welfare authorities, to adapt and enforce specific policies and procedures into their work, as opposed to applying the same model to *all* disabled children. Disaggregation of this nature clearly serves the child’s best interests because it allows the state to focus on ‘that’ child rather than treating all disabled children under the same blanket policies and by applying a single voice to all despite their vastly different disabilities and contexts.

A child’s best interest must even supersede any related violation of a preemptory domestic law.<sup>36</sup> In *Paradiso and Campanelli v. Italy*, a couple relied on surrogacy (illegal in Italy but legal in Russia) to bring a child to Italy, however, neither spouse had a genetic relationship with the child.<sup>37</sup> Since the nine-month-old child was not biologically related and was not the product of a lawful surrogacy, the child was placed in foster care for more than two years and treated as abandoned by Italian

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32. CRPD, *supra* note 1.

33. CRC Committee, General Comment No. 14, *supra* note 12, ¶ 22.

34. Committee on the Rights of Persons with Disabilities [hereinafter CRPD Committee]: Concluding Observations on the Initial Report of Canada, U.N. Doc. CRPD/C/CAN/CO/1, ¶ 18(a), (May 8, 2017), <https://digitallibrary.un.org/record/1310638?ln=en> [<https://perma.cc/W67D-A5Y5>]; CRPD Committee: Concluding Observations on the Initial Report of Tunisia, U.N. Doc. CRPD/C/TUN/CO/1, ¶¶ 16 and 17(a) (May 13, 2011), <https://nwm.unescwa.org/resources/508> [<https://perma.cc/2JM7-APBT>]; CRPD Committee: Concluding Observations on the Initial Report of Kenya, U.N. Doc. CRPD/C/KEN/CO/1, ¶¶ 13, 14(a) (Sept. 30, 2015), <https://digitallibrary.un.org/record/811095> [<https://perma.cc/N8TZ-LG6W>].

35. *See* CRC Committee, General Comment No. 11: Indigenous Children and their Rights under the Convention, U.N. Doc. CRC/C/GC/11, ¶ 5 (Feb. 12, 2009) (noting that indigenous children face discrimination in several fields, particularly access to healthcare and education), <https://www.refworld.org/legal/general/crc/2009/en/102812> [<https://perma.cc/Q4BE-W58K>].

36. *Paradiso and Campanelli v. Italy*, App. No. 25358/12, Eur. Ct. H.R. ¶ 193 (2017), <https://hudoc.echr.coe.int/fre?i=001-170359> [<https://perma.cc/D26Z-Y236>].

37. *Id.* ¶ 47.

authorities.<sup>38</sup> The European Court of Human Rights (Eur. Ct. H.R.) held that even though the couple had breached Italian and international law regarding inter-country adoption, the removal of the child was in error.<sup>39</sup> According to the Eur. Ct. H.R., the best interests of the child comprise two prongs: maintaining family ties and ensuring the child's development within a sound environment, which would not harm its health and development.<sup>40</sup> Neither of which were properly weighed in this case.<sup>41</sup> Despite the CRC's directions to primarily consider the best interests of the child, the authorities failed to do and relied instead on an extreme measure that should only be used when there is immediate danger.<sup>42</sup> Indeed, a disaggregated application of the best interests principle to children with disabilities will culminate into a series of individualized solutions in accordance with context and needs. The courts and authorities should not fear such an outcome (as discriminatory) but promote it.

Transnational disability law—including its domestic implementation—straddles between the CRC, as expounding rules of general applicability (chiefly the “best interests” principle) and the CRPD (with its more focused application of disability-specific rules). Both, however, should be construed within the general framework of international human rights law to provide the most individualized coverage and the full breadth of rights—namely, the right to be heard.

Within this context, this article aims to examine a very narrow area of disabled children's rights, focused mainly on their right to be heard under the CRPD. As the article will go on to demonstrate, the CRPD recognizes both an individual and a collective right to be heard. The latter is a rarity in international law and little attention has been paid to it in the literature. As far as this author is concerned, no court has ever entertained a suit in order to clarify its scope and applicability and whether it is even compatible with general international law, but this article argues that it should be utilized to ensure the law is acting into the child's best interest.

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38. *Id.* ¶ 193.

39. *Id.* ¶¶ 208–15.

40. See *Neulinger and Shuruk v. Switzerland*, Judgment, App. No. 41615/07, Eur. Ct. H.R., ¶ 136 (2010), <https://hudoc.echr.coe.int/eng?i=001-90480> [<https://perma.cc/DER7-5Q5N>]; see generally 3 MICHAEL FREEMAN, COMMENTARY ON THE UN CONVENTION ON THE RIGHTS OF THE CHILD, ARTICLE 3: THE BEST INTERESTS OF THE CHILD (2007).

41. *Paradiso and Campanelli*, *supra* note 36, ¶¶ 208–15.

42. *Id.* ¶ 215.



I. THE CRPD’S “RIGHT TO BE HEARD” FOR *ALL* DISABLED CHILDREN

Paragraph 3 of Article 7 of the CRPD iterates in the disability context the general principle (if not a customary rule) of the child’s right to be heard, as follows:

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.<sup>43</sup>

The right of children to express their views and be heard is predicated on scientific findings about how children are able to form views even before developing their ability to express themselves.<sup>44</sup> As a result, it is natural, but certainly radical (as a legal entitlement) for children to have legal standing in matters that affect them and to substantially affect pertinent legal relationships and decisions.<sup>45</sup> Under Article 12 of the CRC children are entitled but not obligated to express their views in legal or administrative proceedings—such as in cases of custody disputes or adoption—and by implication, states are obliged to give due weight to these views.<sup>46</sup> Paragraph 3 of Article 7 of the CRPD emphasizes that disabled children have the right “to express their views” and that such views shall be taken into consideration in accordance with the age and maturity of the disabled child.<sup>47</sup> This wording differs greatly from Article 12(1) of the CRC, whereby only children that are “capable of forming [their] views” have a right to express these freely, again subject to their age and maturity.<sup>48</sup> It is, therefore, quite an achievement that Article 7(3) of the CRPD has removed one of these limitations in the context of disabled children. Specifically, paragraph 3 of Article 7 of the CRPD considers that *all* disabled children are capable of forming some degree of view on matters that affect them, whether directly or through supported decision-making, and that such views are to be considered by judicial and

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43. CRPD, *supra* note 1.

44. CRC Committee, General Comment No. 12: The Right of the Child to be Heard, U.N. Doc. CRC/C/GC/12, ¶ 21 (2009), <https://www.refworld.org/legal/general/crc/2009/en/70207> [<https://perma.cc/J3KA-DH8W>].

45. *Id.* ¶¶ 32–33.

46. *Id.* ¶¶ 44–45.

47. CRPD, *supra* note 1.

48. See generally Roberta Botisio, *Children’s Right to be Heard: What Children Think*, 20 INT’L J. CHILD’S RTS. 141 (2012) (focusing chiefly on the views of children in custody proceedings in Italy, demonstrating that the courts rarely take these into full consideration).

administrative authorities. Unlike the CRC, therefore, the CRPD obligates states to *always* allow a disabled child to be heard. This is important because adults, even disabled adults, are incapable of fully sharing and understanding the emotions and desires of disabled children. The available literature on the specific wants and needs of disabled children should become core reading for those involved with decisions concerning this population.<sup>49</sup>

As will be demonstrated in a subsequent subsection, the right of a disabled child to always be heard as a substantive and procedural right is distinct from the authority of the entity, judicial or otherwise, before which the child is making a claim, to make a judicial or other determination.<sup>50</sup> The court or other entity deciding a matter affecting a disabled child is not bound by the expressed views of the child; however, decisionmakers must consider them in cases where failing to take the child's views into consideration would go against the best interests of the child. This is true, for example, in custody or adoption proceedings.

Most states pay lip service for the right of children to be heard.<sup>51</sup> They may allow a child—disabled or otherwise—to be heard, they provide no guarantees that the courts or administrative authorities will consider the child's views.<sup>52</sup> By way of illustration, those involved in the proceedings may fail to engage in a true dialogue with the child over several days or court sessions, there may be an absence of *in camera* proceedings to ensure the sensitivity of the process, the disabled child may not be given the technological or communicative means to converse with the judge, or the maturity of the child may be difficult for the judge to assess because of the child's disability and the judge may avoid trying.<sup>53</sup> There are of course

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49. See, e.g., JESSICA KINGSLEY, *GROWING UP WITH DISABILITY* 1–21 (1998) (discussing the social implications of being a disabled child).

50. Daniel O'Donnell, *The Right of Children to be Heard: Children's Right to Have their Views Taken into Account and to Participate in Legal and Administrative Proceedings*, UNICEF Innocenti Res. Centre, Working Paper No. 2009-04 (2009), <https://ideas.repec.org/p/ucf/inwopa/inwopa09-56.html> [<https://perma.cc/H26S-PYQ3>].

51. See generally Ilias Bantekas, *Paternal Discrimination in Greek Child Custody Proceedings: Failing the Child's Best Interests*, 24 INT'L J. CHILD RTS. 330 (2016) (arguing that courts in Greece by default confer custody upon mothers, regardless of whether in the particular circumstances a father was by far more suitable to serve a child's best interests. In all these cases, children were either not allowed to express their opinion, or their opinion was effectively sidelined or dismissed).

52. *Id.*

53. See e.g. Ann-Christin Cederborg & Clara H. Gumpert, *The Challenge of Assessing Credibility when Children with Intellectual Disabilities are Alleged Victims of Abuse*, 12 SCAND. J. DISABILITY RESEARCH 125, 125 (2010) (where it is argued that "if knowledge about intellectual competence and functional level of an individual child witness was perceived as necessary when putting an adapted legal norm into praxis, this may increase the chance that

many more impediments. It is, therefore, imperative to establish a secure link between the right to have a disabled child's views heard and the proper mechanisms to ensure the enforcement of this right. This link could be achieved, for example, by requiring reasoned decisions with specific mention as to how the child's views were considered and "respected" and why, if at all, their perspective was rejected.<sup>54</sup> Equally, the decision should explain how the maturity of the child was assessed and the methodology used in this decision-making. This evaluation requires a sound and coherent methodological framework that is predicated on scientific criteria and not a random assessment by untrained civil servants or judges. Domestic laws should render decisions not reasoned in the manner explained above as appealable. It comes as no surprise that the CRPD Committee has chastised most states parties for failing to consult or adopt appropriate policies and procedures by which disabled children can be consulted in matters that affect them.<sup>55</sup> This is a systemic issue that requires concrete legislative action, so stakeholders are aware how and when they are expected to participate in the relevant processes.

## II. THE DISABLED CHILD'S RIGHT TO BE HEARD AS A COLLECTIVE RIGHT

While the individual right to be heard is important, the CRPD also creates a collective right for disabled children to be heard. This is a largely ignored innovation of the CRPD, which was the first to establish a collective right for disabled children to have their opinions and desires heard by courts and other authorities prior to any determination about their collective status. Before attempting to explain how such a collective entitlement might exist and be exercised by disabled children acting as a whole, it is essential to explain the nature of collective rights.<sup>56</sup> Readers

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assessments of credibility are based on knowledge rather than on a simplified general legal classification").

54. CRPD Committee, Concluding Observations on the Initial Report of Cyprus, U.N. Doc. CRPD/C/CYP/CO/1, ¶ 22 (May 8, 2017), <https://documents.un.org/doc/undoc/gen/g17/112/67/pdf/g1711267.pdf?token=115eA8v124WXtPz4qP&fe=true> [<https://perma.cc/8SVG-T2ZR>].

55. CRPD Committee, Concluding Observations on the Initial Report of Luxembourg, U.N. Doc. CRPD/C/LUX/CO/1, ¶ 17(b) (Oct. 10, 2017), <https://digitallibrary.un.org/record/3850065> [<https://perma.cc/8UMF-PGF9>]; CRPD Committee, Concluding Observations on the Initial Report of Montenegro, U.N. Doc. CRPD/C/MNE/CO/1, ¶ 15(a) (Sep. 22, 2017), <https://digitallibrary.un.org/record/794909?ln=en> [<https://perma.cc/JR36-AF6A>]; CRPD Committee, Concluding Observations on the Initial Report of the United Arab Emirates, U.N. Doc. CRPD/C/ARE/CO/1, ¶ 16(b) (Oct. 3, 2016), <https://digitallibrary.un.org/record/1310669?ln=en> [<https://perma.cc/Q7QU-HLNB>]; CRPD Committee, Concluding Observations on the Initial Report of Sweden, U.N. Doc. CRPD/C/SWE/CO/1, ¶¶ 19–20 (May 12, 2014), <https://digital.library.un.org/record/779625?ln=en> [<https://perma.cc/A3B6-XVXK>].

56. B.G. Ramcharan, *Individual, Collective and Group Rights: History, Theory, Practice and Contemporary Evolution*, 1 INT. J. ON GRP. RTS. 27, 30–33 (1993) (discussing the difference

will come to appreciate that while the collective nature of a right favors the group and entitles, any member of the group can make a pertinent claim on behalf of the group even if no harm has been incurred by the claimant. Additionally, the exercise of collective right enforcement in the context of the harmed party (disabled children) is fraught with barriers, especially in countries where the will of disabled children is subject to substitute decision-making.<sup>57</sup>

#### A. The Nature of Collective Rights

Rights pertaining to groups, as opposed to individual members, are also known as collective rights or solidarity rights.<sup>58</sup> However, not every conceivable group possesses such rights by the mere fact that it is organized as a collective.<sup>59</sup> Rather, collective rights are limited to particular groupings and are typically conferred by treaty, soft law,<sup>60</sup> or customary international law.<sup>61</sup> They are premised on the rationale that

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between minority and other group-related rights from collective rights and how the latter evolved through the processes of international law).

57. See Amita Dhanda, *Conversations Between the Proponents of the New Paradigm of Legal Capacity*, 13 INT. J. OF LAW IN CONTEXT 87, 91–97 (2017) (discussing how substitute decision-making was an integral part of the pre-CRPD disability paradigms and how such decision-making has crept back in the law in many states).

58. See DOUGLAS SANDERS, *CULTURAL RIGHTS AS COLLECTIVE RIGHTS: AN INTERNATIONAL LAW PERSPECTIVE* (Andrzej Jakubowski ed., 2016) (suggesting that cultural rights constitute collective entitlements of peoples, although this idea is not wholly shared in other literature).

59. For example, political parties, activists, persons with disabilities, and others are not endowed with collective rights. See generally CORSIN BISAZ, *THE CONCEPT OF GROUP RIGHTS IN INTERNATIONAL LAW: GROUPS AS CONTESTED RIGHTS HOLDERS, SUBJECTS, AND LEGAL PERSONS* (2012). Both Article 27 and Article 1 of the International Covenant on Civil and Political Rights demonstrates the limited conferral of collective rights. International Covenant on Civil and Political Rights *adopted* Dec. 19, 1966, 999 U.N.T.S. 171 (entered into force Mar. 23, 1976).; See also Office of United Nations of High Comm’r for Human Rights, *International Covenant on Civil and Political Rights* (Dec. 16, 1966), <https://www.ohchr.org/en/instrumentsmechanisms/instruments/international-covenant-civil-and-political-rights> [http://perma.cc/43RF-2HER].

60. That is why collective rights are not always viewed seriously by governments and alternatives result in a fuzzy and practically unenforceable legal regime. Douglas Sanders, *Collective Rights*, 13 HUM. RTS. Q. 368, 369–40 (1991).

61. It has always been the case that many collective rights are contested. For example, scholarship suggests that N.Y. General Assembly Res. 47/135, entitled Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, conferred a collective entitlement upon indigenous persons, however, many states reject the application of collective rights to indigenous populations. See Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, *adopted* Dec. 18, 1992, G.A. Res. 47/135, U.N. GAOR, 47th Sess., Annex, U.N. Doc. A/Res/47/135/Annex (1992), <https://www.oas.org/dil/1992%20Declaration%20on%20the%20Rights%20of%20Persons%20Belonging%20to%20National%20or%20Ethnic,%20Religious%20and%20Linguistic.pdf> [https://perma.cc/8V9V-HE95]. See generally ALEXANDRA XANTHAKI, *INDIGENOUS RIGHTS AND UNITED*

certain entitlements are meaningless outside the group and that their justiciable character is dependent on the group's continued existence and coherence.<sup>62</sup> The limited nature of collective rights is meant to decrease the gamut of collective claims that might be used to dissolve or create new status, thus bringing disruption to the international legal order. Thus, the notion of statehood is redundant without a stable population that enjoys the collective right to self-determination and in which in turn wishes to form a new nation state; it is exactly in this populace, through its duly appointed representatives, that the state finds expression and not any random self-conceived collective claim.<sup>63</sup> As a result, the powers of the state are vested in its people, and it is natural that they be endowed with entitlements that cannot be conferred on discrete individuals.<sup>64</sup>

By way of illustration, although the right to elect and be elected is meaningful in its personal dimension, the choice to form, secede, or unite with another state cannot be exercised individually. Instead, such decisions are best taken by the affected collective acting as a single entity in accordance with predefined rules.<sup>65</sup> General international law informs a large part of the discussion on group rights and human rights considerations have increasingly been viewed as central to the rights of peoples.

The existence of collective rights is not self-evident but is greatly beneficial. International law is rather hesitant to grant particular rights to groups; this is not because it refuses to acknowledge their distinct identity,

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NATIONS STANDARDS: SELF-DETERMINATION, CULTURE AND LAND (2007) (arguing that indigenous cultural rights are collective rights); see also Toby Morantz, *Individual Rights versus Collective Rights: The Debate on the Aboriginal Peoples of Canada*, 46 SOCIO. BULLETIN 173, 185 (Sep. 1997) (discussing how some states believe the focus should be on individual rights and not collective rights, but indigenous populations argue individual rights only protect the majority, not the minorities).

62. For the leading case on this issue, see *Lovelace v. Canada*, 36 U.N. GAOR Supp., No. 40, Annex XVIII, U.N. Doc. A/36/40 (1981). Although the U.N. Human Rights Committee emphasized in this case that membership in a group is a matter of self-identification, it is implicit that in order to claim a right belonging to a group, one must necessarily be a member of that group on the basis of objective criteria. *Id.* at 171–73.

63. See *Legal Consequences of the Separation of the Chagos Archipelago from Mauritius in 1965*, Advisory Opinion, 2019 I.C.J. Rep. 95, ¶¶ 178–79 (Feb. 25). In this advisory opinion, the International Court of Justice (hereinafter, I.C.J.) confirmed that while self-determination is a fundamental human right, there is little support for its application to situations of secession, therefore a safety valve is necessary when people are grossly oppressed. See Diane Marie Amann, *Legal Consequences of the Separation of the Chagos Archipelago from Mauritius in 1965*, 113 AM. J. INT'L L. 784, 784 (2019) (discussing how the majority opinion by the I.C.J. cemented the idea that all people have a right to self-determination).

64. Advisory Opinion, *supra* note 63, ¶¶ 144–57.

65. *Id.* ¶ 158. However, the I.C.J. pointed out there is no specific mechanism for bringing this about.

but because states are wary of the effects of collective entitlements.<sup>66</sup> There is also an argument in favor of the individualization of rights in order to offer protection and remedies to the immediate victim.<sup>67</sup> For example, if police officers kill a protestor, then this may be perceived as a violation of the victim's right to life as well as an attack on the protestors as an identifiable group with distinct claims. Whereas human rights law would view the attack against the protestors as a violation of their freedom of expression or the right of peaceful assembly, it could not possibly render all protestors victims of the unlawful killing as this would, at the very least, hamper the family of the deceased in seeking its rightful redress. Moreover, although not impossible, it is difficult to collectivize freedom of expression and assembly in those cases where the participants do not fully share the same ideas, beliefs, motivations, and characteristics. Even if the right to protest was somehow elevated to a collective right, there is no guarantee that all participants would wish to subsume their individual entitlements into a more impersonal group claim. This was certainly the underlying rationale in the construction of the International Bill of Human Rights, which was criticized by developing states for its perceived Western bias in favor of the individual to the detriment of the person's community.<sup>68</sup> The critique is that although the idea of individually justiciable rights is attractive because it is not dependent on the actions or omissions of other actors, in fact the separation of the individual from the group reduces the power and protection offered by the group.<sup>69</sup> This Western bias, it is further argued, is evident from the fact that the International Bill of Human Rights wholly disregarded the centrality of interdependence inherent in community life in the developing world.<sup>70</sup> It

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66. See, e.g., European Parliament, *The Situation of Indigenous Children with Disabilities*, Directorate-General for External Policies (Dec. 2017) (aligning with the collective indigenous entitlement recognized in U.N. Resolution 47/135), [http://www.europarl.europa.eu/RegData/etudes/STUD/2017/603837/EXPO\\_STU\(2017\)603837\\_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/STUD/2017/603837/EXPO_STU(2017)603837_EN.pdf) [<https://perma.cc/L8JY-AHBN>].

67. ARVIND SHARMA, ARE HUMAN RIGHTS WESTERN? A CONTRIBUTION TO THE DIALOGUE OF CIVILIZATIONS 78 (2006) (arguing that while the Universal Declaration of Human Rights was predicated on individual rights, human dignity should be seen as entailing responsibilities, roles, and relationships to the state).

68. Jane Mende, *Are Human Rights Western – And Why does it Matter? A Perspective from International Political Theory*, 17 J. INT'L POL. THEORY 38, 43–44 (2021).

69. Dominic McGoldrick, *The Boundaries of Justiciability*, 59 INT'L & COMP. L. Q. 981, 993–97 (2010); see generally Edward W. Wierdag, *The Legal Nature of the Rights Granted by the International Covenant on Economic, Social and Cultural Rights*, 9 NETH. Y.B. INT'L L. 69, 73–78 (1978) (demonstrating how justiciability works in respect of individual rights, all of which are justiciable as individual entitlements, even if the demand is by a collective of rights holders). One example of the power dynamic mentioned above is clan leaders.

70. See generally Rachel Murray & Steven Wheatley, *Groups and the African Charter on Human and Peoples' Rights*, 25 HUM. RTS Q. 213 (2003) (the article discusses the multifaceted tribal/minority landscape of Africa and highlights the importance of community).

is no wonder that the African Charter on Human and Peoples' Rights (ACHPR) has, in addition to self-determination, included a significant list of solidarity or collective rights.<sup>71</sup> The collective rights embraced by the ACHPR include the right to continued existence,<sup>72</sup> the right to development,<sup>73</sup> the right to peace and security,<sup>74</sup> and the right to a generally satisfactory environment.<sup>75</sup> The recognition and enforcement of collective rights can help safeguard rights on a larger scale than on an individual basis.

The debate on collective rights is far from over in international human rights discourse. Activists, scholars, groups, and other stakeholders are not satisfied with the narrow scope of collective rights as they currently stand, and which are predicated on the right to self-determination and the dangers of majoritarian rule that often follow. Indeed, just like Article 7 of the CRPD, there is a push towards extending the ambit of collective rights through the collectivization of certain individual rights.<sup>76</sup> Collective rights based on self-determination presuppose the existence of a group with common characteristics centered around actual or potential forms of statehood, underpinned by the concept of *peoples* (i.e. majority groups).<sup>77</sup> The protection of *peoples* is best achieved through rights, as well as through international criminal justice mechanisms. The crime of genocide, for example, constitutes an indirect way of protecting the right to life of the target group's members.<sup>78</sup> An additional benefit from the conferral of

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71. African Charter on Human and Peoples' Rights [hereinafter ACHPR], OAU/CAB/LEG/67/3/Rev.5 (Org. of African Unity) (1996), *reprinted in* 5 HUMAN RIGHTS LAW IN AFRICA (Christof Heyns ed., 1996).

72. *Id.* Art. 20.

73. *Id.* Art. 22.

74. *Id.* Art. 23.

75. *Id.* Art. 24. In fact, United Nations General Assembly, U.N. Doc. Res A/76/L.75 (July 26, 2022), operative in ¶ 1, recognized the "right to a clean, healthy and sustainable environment as a human right," presumably of a collective nature, although this is not entirely clear.

76. See Douglas Sanders, *Collective Rights*, 13 HUM. RTS Q. 368, 373–78 (1991) (one of the early scholarly attempts at defining not only the narrow, but self-determination also based, contours of collective rights and identifying calls for broadening their ambit in order to encompass other groups in need of collective protection).

77. Siegfried Wiessner, *Indigenous Sovereignty: A Reassessment in Light of the UN Declaration on the Rights of Indigenous Peoples*, 41 VAND. J. TRANSN'T'L L. 1173, 1156 (2008) (taking the view that the U.N. Declaration on indigenous peoples effectively preserves their culture, at the very least, by recognizing the necessity of self-determination, self-help, and empowerment of indigenous groups).

78. Article II of the Convention on the Prevention and Punishment of the Crime of Genocide defines the crime of genocide as consisting of any enumerated act contained in Article II with intent to destroy, in whole or in part, a national, ethnical, religious, or racial group. Convention on the Prevention and Punishment of the Crime of Genocide, *opened for signature* Dec. 9, 1948, art. II(a), 102 Stat. 3045, 3035, 78 U.N.T.S. 277, 280 (entered into force Jan. 12, 1951) [hereinafter Genocide Convention]. In *Republic of South Africa v. Israel*, South Africa

group/peoples' rights is that resource or power-related rights are predicated on the institutions inherent in democratic governance and self-determination. These collective institutions cannot give rise to conflicts between individual members of the group. For example, the right to development and the right of peoples to have control over their natural resources concern values that produce benefits for all, and which are not susceptible to individual ownership and the exclusion of property from others. These rights are better served through a single collective entitlement as opposed to a myriad of individual ones.<sup>79</sup>

On the other hand, groups that do not qualify as *peoples* (i.e. non-majority groups) cannot rely on entitlements stemming from the right to self-determination. Although the welfare interests of such groups, including minorities and indigenous peoples, cannot possibly conflict or harm the welfare of the majority, until recently there was strong opposition to the granting of collective entitlements.<sup>80</sup> It was feared that such entitlements would ultimately lead to claims of self-determination by the non-majority group.<sup>81</sup> In reality, the collective entitlements of such groups

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claimed that the state of Israel was breaching the U.N. Convention on the Prevention and Punishment of the Crime of Genocide in the Gaza Strip. In response to the application, on January 26, 2024, the I.C.J. issued an order on interim relief, which compelled Israel to undertake six action points after finding that the existence of an ongoing genocide was "real and imminent." The I.C.J. relied on the definition of 'genocidal acts' as identified in Article II of the Genocide Convention in its call for Israel to halt certain activities. See Application of the Convention on the Prevention and Punishment of the Crime of Genocide in the Gaza Strip (South Africa v. Israel) Provisional Measures, Order, ¶ 5 (Mar. 28, 2024), <https://www.icj-cij.org/sites/default/files/case-related/192/192-20240126-ord-01-00-en.pdf> [<https://perma.cc/ZK4K-JPQV>]. By publishing steps for Israel to take only a month after the first public hearing, the Court is affirming to the public that South Africa's claims have a legal basis. Paula Testa, *South Africa v. Israel: The ICJ Ruling Explained*, ISTITUTO ANALISI RELAZIONI INTERNAZIONALI (Feb. 21, 2024), <https://iari.site/2024/02/20/south-africa-v-israel-the-icj-ruling-explained/> [<https://perma.cc/6DW6-9722>].

79. Their collective nature makes it easier for the international donor community to finance development-related projects, such as the Sustainable Development Goals (SDGs) even in the absence of treaty arrangements. See generally Ilias Bantekas & Katerina Akestoridi, *Sustainable Development Goals, between Politics and Soft Law: The Emergence of Political Normativity in International Law*, 27 EMORY INT'L L. REV. 499 (2023).

80. See Benedict Kingsbury, *Reconciling Five Competing Conceptual Structures of Indigenous Peoples' Claims in International and Comparative Law*, 34 NYU J. INT'L L. & POL. 189, 194 (2001) (discussing how indigenous peoples often call for basic human rights like self-determination claims that are already held by the majority).

81. Robert T. Coulter, *The U.N. Declaration on the Rights of Indigenous Peoples: A Historic Change in International Law*, 45 IDAHO L. REV. 539, 543 (2009) (noting that the U.N. Declaration on the Rights of Indigenous Peoples was a watershed not only for indigenous peoples but also for international law, because now one minority group was explicitly no longer subject to the problematic individual rights regime under the International Covenant on Civil and Political Rights and was effectively granted a new collective entitlement); Dwight G. Newman, *Theorizing Collective Indigenous Rights*, 31 AM. INDIAN L. REV. 273, 273–74 (2007) (focusing on indigenous Native American groups arguing that we should take into account the



are guaranteed either by the granting of individual rights—as is the case with Article 27 of the International Covenant on Civil and Political Rights (ICCPR)—or through policy initiatives that do not possess ‘collective normativity’ (i.e. collective rights status). LGBTI persons, for example, can rely on non-discrimination where their rights have been affected due to their sexual orientation. LGBTI persons do not, however, possess distinct justiciable group rights.<sup>82</sup> The non-majority groups discussed in this paragraph enjoy different levels of protection under human rights law, with indigenous peoples generally deemed to possess a group entitlement,<sup>83</sup> despite the absence of hard law. The benefits and difficulties associated with collective rights is further explained below.

In the context of disabled children, collectivization of individual rights would mean that states must view such children as a single entity and not only address their needs collectively but recognize that each disabled child can exercise a claim on behalf of all other disabled children. There are benefits and pitfalls associated with such an approach. One of the key benefits is that a single claimant can force a fundamental policy change for the entire group and in the process achieve a positive transformation of the relevant law. The question, however, remains whether it is beneficial for disabled children to be perceived as a unified collective entity. Past practice clearly demonstrates that where disabled persons are viewed in this light, states are justified in not disaggregating impairments and competencies and thereafter adopting appropriate policies and discreet adaptations. The collectivization of disabled children’s rights may present some issues, such as it may allow states to assume the same patronizing stance of the past and speak on behalf of all disabled persons and in the process silence disabled voices. Further, a policy or law predicated on an alleged collective claim is far more difficult to amend, as opposed to an individual claim that was struck down by the courts; or even a successful individual disability claims which have

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concerns of dissenting nations and build adequate responses to such concerns that involve the concerned groups).

82. See Eleni Polymenopoulou, *LGBTI Rights in Indonesia: A Human Rights Perspective*, 19 ASIA PACIFIC J. ON HUM. RTS. AND THE LAW 27, 28–33 (2018) (suggesting that LGBTI persons do not possess a collective entitlement and in many cases are deprived of other rights, but equally emphasizing that LGBT activists do not necessarily desire to be seen as a minority with collective rights).

83. The recognition of collective rights of indigenous peoples to lands, territories and resources is found, among other instruments, in the United Nations Declaration on the Rights of Indigenous Peoples (Articles 3 and 26) as well as in the International Labour Organization’s Indigenous and Tribal Peoples Convention No. 169 and its predecessor Convention No. 107. See also Ronald R. Garet, *Communitarity and Existence: The Rights of Groups*, 56 S. CAL. L. REV. 1001, 1002–10 (1993); XANTHAKI, *supra* note 61. This author’s entire thesis underpins the argument that indigenous land and identity rights are collective in nature.

become outdated and requires other individual petitioners to annul it or build upon. It is important, therefore, that the individual dimension of disabled children's rights are not lost in any discussion concerning collective entitlements. The starting point of this article is that both individual and collective entitlements are necessary to protect disabled children and their right to be heard.

#### B. The Importance of the Disabled Children's Collective Right to Be Heard

Throughout this article, attention has been paid to the fact that there are benefits and pitfalls to both individual and collective entitlements. While the rights of disabled children require significant disaggregation to preserve their individual character, there is equally a need to acknowledge that certain aspects of child disability require a collective voice. This section explores where and how this collective voice exists in law and examines its underlying rationale and overall utility. The CRC Committee has made a significant distinction between the individual right to be heard, as analyzed above, and the collective right of particular groups of children to be heard. The latter is not a collective right, in the sense of self-determination, but a *sui generis* entitlement that pertains to groups of children sharing common interests. For example, common interests can consist of children in similar situations such as those being marginalized or who are indigenous or disabled. However, a common interest can also take the form of a shared activity like going to school. This collective right, sometimes referred to as a participation right, arises in situations where a policy or action directly affects a group of children.<sup>84</sup> For example, the removal of a teacher by the school's headmaster, the demolition of a playground, or the introduction of an educational program for indigenous children are all issues in which the affected children should be allowed to express their views. This is not mere rhetoric but an obligation on all states party to the CRC.<sup>85</sup> The CRC Committee has made it clear that:

When the interests of a large number of children are at stake, Government institutions must find ways to hear the views of a representative sample of children and give due consideration to their opinions when planning measures or making

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84. See ANN A. CALLUS & RUTH FARRUGIA, *THE DISABLED CHILD'S PARTICIPATION RIGHTS* 1–23 (2016) (analyzing four particular participation rights, namely health, education, home life, and relationships); Patricia McNeilly et al., *The Participation of Disabled and Young People: A Social Justice Perspective*, CHILD CARE IN PRACTICE (2015) (arguing in favor of a two-pronged, social justice approach is recommended as a mechanism to advance the participation agenda).

85. CRC Committee, General Comment No. 12, *supra* note 44, ¶¶ 72–73.

legislative decisions which directly or indirectly concern the group, in order to ensure that all categories of children are covered. There are many examples of how to do this, including children’s hearings, children’s parliaments, children-led organizations, children’s unions or other representative bodies, discussions at school, social networking websites, etc.<sup>86</sup>

In the disability context, disabled children are not effectively represented at national and sub-national decision-making processes, thus their views on matters that affect them are not fully heard or considered.<sup>87</sup> The concept of “nothing about us without us”<sup>88</sup> should apply post-CRPD to disabled children in all areas of political and legal life, but this rarely occurs as of now. The CRPD Committee expressed concern in the national parliament and congresses about the lack of effective representation of children with disabilities and the lack of opportunity to express their views on matters that concern them.<sup>89</sup> As a potential solution, in the case of Morocco, the CRPD Committee recommended the adoption of:

A mechanism for conducting effective consultation with children with disabilities through their representative organizations, . . . ensur[ing] the full inclusion of children with disabilities in the national forum of children, the

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86. CRC Committee, General Comment No. 14, *supra* note 12, ¶ 9.

87. CRPD Committee, General Comment No 7: The Participation of Persons with Disabilities, including Children with Disabilities, through their Representative Organizations, in the Implementation and Monitoring of the Convention, U.N. Doc. CRPD/C/GC/7 (2018), <https://digitallibrary.un.org/record/3899396?ln=en> [<https://perma.cc/A34Q-28G7>]. The drafters recognized the importance of including those effected within the conversation. Paragraph 24 adds to this idea by stating “Article 4(3) also acknowledges the importance of systematically ‘including children with disabilities’ in the development and implementation of legislation and policies to give effect to the Convention, and in other decision-making processes, through organizations of children with disabilities or supporting children with disabilities. These organizations are key in facilitating, promoting and securing the individual autonomy and active participation of children with disabilities. States parties should create an enabling environment for the establishment and functioning of representative organizations of children with disabilities as part of their obligation to uphold the right to freedom of association, including appropriate resources for support.”

88. ‘Nothing About Us, Without Us’ was the key political slogan for the disability movement in the run up and the deliberations of the CRPD. Politicians discussed disability without the voices of disabled persons ever being meaningfully heard, which resulted in laws that didn’t fully address disabled people’s needs. See United Nations Enable, “*Nothing about Us, Without Us*”: *International Day of Disabled Persons* (2004) <https://www.un.org/esa/socdev/enable/iddp2004.htm#:~:text=The%20motto%20%20Nothing%20About%20Us,and%20with%20persons%20with%20disabilities> [<https://perma.cc/Z7D2-HSBJ>].

89. CRPD Committee, Concluding Observations on the Initial Report of Morocco, U.N. Doc. CRPD/C/MAR/CO/1, ¶ 19 (Sept. 25, 2019), <https://digitallibrary.un.org/record/1310663?ln=en> [<https://perma.cc/XMU9-7QQF>].

children's parliament and children's governorate and municipal councils, on an equal basis with other children.<sup>90</sup>

In order to concretize the collective right to be heard, the adoption of regulations and programs at national and sub-national level is necessary to ensure effective participation and consultation of children in decision-making.<sup>91</sup> Such regulations must explicitly confer legal standing on representative bodies and ensure that relevant decisions can only be achieved by a quorum that includes sufficient participation by organizations that advocate for the rights of children with disabilities.<sup>92</sup>

A collective right would also safeguard the individual right. Although a child's perspective is enhanced by their age and maturity, a child's maturity level is a matter of assessment and can never be presumed,<sup>93</sup> otherwise, national authorities would render it defunct in practice. In fact, children's levels of understanding are not uniformly linked to their biological age.<sup>94</sup> The CRPD Committee has chastised states with mandatory legislation stating a specific age at which a child is considered capable of expressing their views.<sup>95</sup> The CRPD Committee emphasizes this misconception, and explains that since age and maturity differ from one child to another, the existence of maturity must be assessed on a case-by-case basis irrespective of age.<sup>96</sup>

Additionally, the CRPD Committee has emphasized the importance of disability and age-appropriate support to ensure the right for disabled children to have their views heard and respected.<sup>97</sup> Furthermore, such

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90. *Id.*

91. CRPD, Concluding Observations on the Initial Report of Cyprus, U.N. Doc. CRPD/C/CYP/CO/1, ¶ 19 (May 8, 2017), <https://documents.un.org/doc/undoc/gen/g17/112/67/pdf/g1711267.pdf?token=115eA8v124WXtPz4qP&fe=true> [<https://perma.cc/8SVG-T2ZR>]; CRPD Committee, Concluding Observations on the Initial Report of Gabon, U.N. Doc. CRPD/C/GAB/CO/1, ¶ 19 (Oct. 2, 2015) (calling on states to involve disabled children in the drafting of laws that affect them), <https://digitallibrary.un.org/record/811090> [<https://perma.cc/UZ4E-6WX9>].

92. See Anita Franklin & Patricia Sloper, *Participation of Disabled Children and Young People in Decision Making Within Social Services Departments: A Survey of Current and Recent Activities in England*, 36 BRITISH J. SOCIAL WORK 723, 735–38 (2006) (discussing the level and effect of participation of disabled children in comparison to non-disabled children).

93. CRC Committee, General Comment No. 12, *supra* note 44, ¶ 21.

94. *Id.* ¶ 29.

95. *Id.*

96. *Id.* ¶ 52.

97. CRPD Committee, Concluding Observations on the Initial Report of Moldova, U.N. Doc. CRPD/C/MDA/CO/1, ¶ 17 (May 18, 2017), <https://digitallibrary.un.org/record/1310661> [<https://perma.cc/RZ8M-WQSU>]; CRPD Committee, Concluding Observations on the Initial Report of Qatar, U.N. Doc. CRPD/C/QAT/CO/1, ¶ 16 (Oct. 2, 2015), <https://digitallibrary.un.org/record/1326785> [<https://perma.cc/P5XN-NPKV>]; CRPD Committee, Concluding Observations on the Initial Report of the Czech Republic, U.N. Doc. CRPD/C/CZE/CO/1, ¶ 16 (May 15, 2015), <https://digitallibrary.un.org/record/811110> [<https://perma.cc/P5XN-NPKV>].

assistance must be accessible.<sup>98</sup> This requirement stems from the reference to equality in paragraph 3, but it is also consistent with the disabled child's best interests. While non-disabled children simply require age-appropriate assistance to have their views heard, disabled children sometimes require additional, disability-appropriate assistance. In many cases, such additional assistance may be no different than that provided to a non-disabled child. For example, in judicial and administrative proceedings a disabled child may not receive a fair trial if not assisted by appropriate legal counsel. Such counsel must be provided by the state in the same manner as for non-disabled children.<sup>99</sup> Regarding children with cognitive and intellectual impairments as opposed to children with physical impairments, disability-appropriate assistance is particularly crucial in the context of the right to be heard.<sup>100</sup> Children with cognitive or intellectual disabilities may be unable to vocally express their views and can easily be ignored in processes affecting them, which only further hurts their ability to be heard.

An effective policy should ensure that intellectually disabled children are provided the means—technological or otherwise—to have their views heard by the courts or decision-makers.<sup>101</sup> This will require additional resources, but thankfully access to the right is not conditional on resource availability. The CRPD Committee correctly identifies the supportive function organizations of parents of children with disabilities can have at the local level, whether to reinforce the views of the child or for other purposes related to the child's best interests.<sup>102</sup> In many cases,

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98. CRPD Committee, Concluding Observations on the Initial Report of Guatemala, U.N. Doc. CRPD/C/GTM/CO/1, ¶ 24(e) (Sept. 30, 2016) <https://digitallibrary.un.org/record/1310647?ln=en> [<https://perma.cc/66FB-7B2C>].

99. CRPD Committee, Concluding Observations on the Initial Report of Luxembourg, U.N. Doc. CRPD/C/LUX/CO/1, ¶ 17(b) (2017), <https://digitallibrary.un.org/record/3850065> [<https://perma.cc/8UMF-PGF9>].

100. The CRPD has identified children suffering from specific physical impairments in particular countries—namely blind and deaf-blind children in Uganda—as requiring explicit assurances for effective consultation. CRPD Committee, Concluding Observations on the Initial Report of Uganda, U.N. Doc. CRPD/C/UGA/CO/1, ¶ 13(b) (2016), <https://digitallibrary.un.org/record/830776?ln=en> [<https://perma.cc/YQK5-HRP8>].

101. CRPD Committee, Concluding Observations on the Initial Report of Lithuania, U.N. Doc. CRPD/C/LTU/CO/1, ¶¶ 17(b), 18(b), (2016), <https://digitallibrary.un.org/record/830769?ln=ar> [<https://perma.cc/3CJV-BWMH>].

102. CRPD Committee, Concluding Observations on the Initial Report of Bosnia and Herzegovina, U.N. Doc. CRPD/C/BIH/CO/1, ¶ 15(b), (2017), <https://digitallibrary.un.org/record/1310653?ln=en> [<https://perma.cc/FWW6-AJ6U>]; CRPD Committee, Concluding Observations on the Initial Report of the European Union, U.N. Doc. CRPD/C/EU/CO/, ¶ 25 (2015), <https://digitallibrary.un.org/record/1323503?ln=en> [<https://perma.cc/4XK8-KK3Y>]; CRPD Committee, Concluding Observations on the Initial Report of Kenya, U.N. Doc. CRPD/C/KEN/CO/1, ¶ 13(c), (2015), <https://digitallibrary.un.org/record/811095> [<https://perma.cc/E9XN-EE26>].

children with disabilities, especially psycho-social and intellectual disabilities, cannot express themselves fully absent their support network. Therefore, the exclusion of that support network from pertinent processes is a clear violation of the obligation to provide disability-appropriate assistance. A collective right can ensure needed supports and policies remain in place to best serve the disabled child.

#### CONCLUSION

Disabled children enjoy both an individual and a collective entitlement to be heard in matters concerning their person and wellbeing. While the collective right has not been tested in practice, there is little doubt that CRPD member states are under an obligation to engage with disabled children in all matters that concern them and for which the state is planning to undertake legislative action. It is unclear how this collective entitlement might take shape. It is expected that organizations advocating for children with disabilities will have a significant role to play in giving a voice to their stakeholders. However, to successfully take advantage of the collective right, it is important that advocates frame their statements around it. It is also crucial that the advocates publicize any claims or statements within the disability context and under the banner of Article 7 of the CRPD and simultaneously educate the courts and the state about their collective right to be heard. Equally, in matters concerning disabled children, NGOs and other interested parties may submit amicus briefs relying on Article 7. But what should the courts and the authorities do with these statements and submissions? While there is no requirement that the courts to accept them, it is undoubted that state authorities will at the very least take them into consideration when acting in the best interests of disabled children (as the “best interest of the child” principle is fully engrained within our society). It should be remembered that until the adoption of the CRPD—and in many countries up to now—disabled children had no meaningful voice, and even in the few instances that they were portrayed as being heard, ultimately their voice was treated as having no value whatsoever. A collective right to express their opinions and aspirations is a tremendous weapon for future generations as a tool for strategic litigation, advocacy, and activism.<sup>103</sup>

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103. This is true, for example, in respect of the campaign to introduce inclusive education in schools. See also Yael Cannon et al., *A Solution Hiding in Plain Sight: Special Education and Better Outcomes for Students with Social, Emotional, and Behavioral Challenges*, 41 *FORDHAM URB. L. J.* 403, 429, 497 (2013) (emphasizing that disabled children are effectively hidden in the United States’ educational system because there are significant pressures exerted against their inclusion in regular classrooms).

The individual right to be heard is meaningless without full recognition of the legal personality and capacity of disabled children, in exactly the same way as their non-disabled counterparts. Disabled children's status of full legal capacity and recognition of personal autonomy is yet to be achieved in most countries, particularly where decision-making has been conferred to third parties on the assumption that it is in the best interests of intellectually disabled children to have others decide on their behalf. It is crucial for disabled children to have their voices heard and respected and for states to realize that disabled lives are worth living.<sup>104</sup> Caution should, however, be applied. The unique tool that is composed of the collective right of disabled children to be heard must not be allowed to be used as a means of implementing individual rights or as a justification for failing to disaggregate existing rights.

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104. See generally Meng Deng & Genevieve Manset, *Analysis of the 'Learning in Regular Classrooms' Movement in China*, 38 MENT. RETARD. 124 (2000) (describing the development of China's efforts to educate its disabled population in childhood).