

ORIGINAL RESEARCH

# Adolescents' Right to Participate: Opportunities and Challenges for Health Care Professionals



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## Abstract

**BACKGROUND** Health care professionals and patients are partners in health care delivery, and this partnership is critical in the treatment of adolescents. International children's rights law establishes that all children have a right to participate in decisions that affect their lives. Fulfillment of that right is as critical in health care settings as any other area of children's lives.

**OBJECTIVES** In this article we examine the right to participate under international children's rights law, its relevance to health care settings, and how health care professionals can foster adolescents' participation to fulfill children's rights and improve health care outcomes.

**FINDINGS** The Convention on the Rights of the Child establishes a legal mandate—where ratified—that adolescents have the right to express their views in health care settings and that such views must be given due consideration. In many health care settings, adolescents are not adequately consulted or have limited opportunities to express their views. A review of research finds that both processes and outcomes can improve when youth participation is cultivated.

**CONCLUSIONS** Health care providers and organizations have numerous opportunities to cultivate adolescent's participation rights and in doing so improve health care delivery and outcomes. Health care providers and organizations should further develop structures and processes to ensure opportunities for children and adolescents to be heard on matters relevant to their health care and health status. Creating opportunities for adolescents to realize their right to participate means engaging youth at every stage in the process, beginning with the design of such opportunities. It also means addressing all aspects of health care, from the built environment to patient-provider communication to follow-up services, so that the entire process fosters an environment conducive to meaningful participation by adolescents.

**KEY WORDS** adolescent, children's rights, health care, health care professionals, human rights, participation, rights.

## INTRODUCTION

Article 1 of the Universal Declaration of Human Rights proclaims that “All human beings are born free and equal in dignity and rights.” Today the idea that every individual has rights is uncontroversial. Application of that concept to children, however, has been met with greater skepticism. Childhood is seen as dif-

ferent. Legal and cultural views of children have evolved from early constructs that deemed children to be property of their father, to late 19th century ideas that children are a special population in need of protection, to more recent recognition that children are rights holders.<sup>1</sup>

This “age of rights” for children commenced with the adoption of the United Nations (UN)

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Convention on the Rights of the Child (CRC) in 1989.<sup>2</sup> This comprehensive treaty on children's rights is the most widely accepted human rights treaty in history. Every country in the world except the United States has ratified the CRC.<sup>3</sup> Among its core principles, the CRC establishes that every child has a right to be heard and to participate in decisions that affect her or his life.<sup>4</sup>

Implementation of children's right to participate confronts not only philosophical resistance but also practical considerations. The developmental nature of childhood fits awkwardly with a liberal notion of rights built on the autonomous individual, especially in the case of young children. Yet there is also evidence that listening to children improves outcomes across a range of issues.<sup>5</sup>

Although many professionals who work with children, including health care providers, broadly support the idea that we should listen to children, in reality meaningful participation by children and adolescents happens infrequently. Researchers have found that children are consulted infrequently in health care decisions, "[e]ven in situations regarding their own health."<sup>6</sup>

This article seeks to detail the relevance of children's rights law, specifically children's right to participate, to health care services for adolescents. We begin by delineating the child's right to be heard under international law. The article then discusses the value of advocating for, and ultimately securing, children's rights in the health care context. Finally the article then explores ways in which health care providers can promote children's right to be heard in health care settings.

We believe that the rights of children and adolescents should be reflected in the entire health care process, from the moment they call to make an appointment, to the built environment where they access care, to the interactions with all staff, including clinicians, to the treatment plan, and finally to any follow-up care. By empowering youth at every stage in this process and by giving youth a voice in the design and implementation of these processes, health care professionals can create a collaborative process that improves outcomes.<sup>7</sup>

## THE RIGHT TO PARTICIPATE IN CHILDREN'S RIGHTS LAW

The CRC establishes that children and adolescents have the right to participate in decisions that affect their lives. Specifically Article 12 provides the following<sup>4</sup>:

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.

To appreciate the potential of this requirement, this provision deserves some explanation. To begin, it is important to recognize that the child's right to be heard applies in "all matters affecting the child." Therefore, even though subsection 2 of Article 12 provides that a child "shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child," Article 12's first requirement is not restricted to judicial proceedings. In other words, children and adolescents have the right to be heard in health care settings too.

Next, Article 12 applies to any child who is "capable of forming his or her own views."<sup>4</sup> That includes everyone from very young children to older adolescents and children with developmental limitations. As Laura Lundy explains, "Children's right to express their views is not dependent upon their capacity to express a mature view; it is dependent only on their ability to form a view, mature or not."<sup>8(p935)</sup> Similarly, the Committee on the Rights of the Child, the UN body that oversees implementation of the CRC, has stated that there is no minimum age for the right to express one's views and a child should not have the burden to prove that he or she is capable of expressing a view.<sup>9</sup> A child's stage of maturity does not determine whether the individual has rights, but rather what weight is given to the child's view.

Under the CRC, children have the right to be heard, and their views must be "given due weight in accordance with the age and maturity of the child."<sup>4</sup> Article 12 thus establishes that children have the right to be heard, but it does not necessitate that children be allowed to decide an issue. With this balancing, the CRC takes into account the evolving and developmental nature of childhood. As parents and health care providers know well, sometimes adults must make informed decisions on behalf of a child to ensure the optimal outcome. Lothar Krappmann, a former member of the UN Committee on the Rights of the Child, explains that Article 12's due weight requirement "means that the [child's] views are seriously considered. . . . The final responsibility, however, remains with the adult."<sup>10(p507-8)</sup> This approach comports with what many children prefer; children often express that they want the opportunity to provide input and want to feel heard but do not want the burden of having to make the final decision.<sup>11,12</sup>

Finally, participation must be meaningful. As the Committee on the Rights of the Child has explained,<sup>13</sup>

[A]ppearing to “listen” to children is relatively unchallenging; giving due weight to their views requires real change. Listening to children should not be seen as an end in itself, but rather as a means by which States make their interactions with children and their actions on behalf of children ever more sensitive to the implementation of children’s rights.

The Committee’s mandate is applicable not only to governments but also to individuals who work with children and adolescents. Ensuring children meaningful opportunities to be heard and to participate in health care decisions is consistent with children’s rights law, in particular the CRC.

## WHY YOUTH VOICES MATTER

Supporting children’s right to be heard matters. Participation can contribute to positive child and adolescent development. Studies show that allowing children to play a meaningful role in, and have some sense of control over, their lives has potentially significant intrinsic value.<sup>14(p294)</sup> Children’s participation can enhance self-esteem, reduce fear about situations they confront, and foster a greater sense of connection with outcomes of decisions.<sup>15</sup> On the other hand, denying children the opportunity to participate can lead to feeling excluded, devalued, and anxious about their future.<sup>16</sup>

In health care settings, providing opportunities for children to be involved in decision-making has a measurable impact on outcomes. Coyne and Gallagher found that enabling child participation in health care settings can yield a range of benefits, including “better provision of information; opportunity to express feelings; developing confidence and competence; feeling valued, increased locus of control, [and] increased adherence [to treatment protocols].”<sup>17</sup> Other research has found that involving children in the process of developing a treatment plan improves the effectiveness of subsequent treatment.<sup>18</sup> It results in better treatment compliance among adolescents, which in turn improves their health outcomes and reduces the amount of school they miss.<sup>18</sup> Conversely, research indicates that “[l]ack of involvement in the communication and decision making process had a negative effect as children reported feeling: disappointed, sad, confused, angry, worried, shocked, betrayed, lonely, ignored and rejected.”<sup>17</sup>

Health care providers often interact with adolescents (or any patients) when they are ill, injured, or otherwise at a heightened state of vulnerability. For many youth, the clinical experience triggers feelings of fear and a lack of any sense of control over their bodies and their lives. And for at-risk and exploited youth, who have suffered trauma, the stakes are even higher. It is critical that the health care system “get it right” when dealing with vulnerable youth. Part of ensuring the best possible outcome requires attention to children’s right to be heard.

## ENGAGING AND HEARING YOUTH IN HEALTH CARE SETTINGS

Adolescents, like any patients, have a critical role to play in their own care and well-being.<sup>19</sup> That said, adolescents, even those who have reached the age of majority, are not adults. Nor are they young children. Developmentally, they are different, and it is critical for both clinicians and staff in health care settings to understand these differences and interact with teenagers in a developmentally appropriate way.<sup>6,20</sup> Engaging adolescents in a developmentally appropriate way can help avoid frustration on the part of both the clinician and patient, improve communication, and ultimately improve care.<sup>21</sup> Interacting with youth in a developmentally appropriate way does not mean treating them as if they cannot understand critical concepts. To the contrary, engaging in a developmentally appropriate way means ensuring successful communication and creating opportunities for meaningful participation by adolescents.

As part of this process, health care professionals and institutions need to ensure that their practices are structured so that adolescent patients feel engaged and can realize their right to participate.<sup>22</sup> Creating an environment conducive to adolescent participation requires thinking about all aspects of practice, from initial interactions to follow-up care.<sup>20</sup> It also requires youth input at all stages in the process, including the design, implementation, monitoring, and evaluation of hospital or clinic processes aimed at serving children and adolescents.<sup>23</sup> Those providers and institutions with no processes in place should collaborate with youth in design and implementation of new processes and ensure adolescent input throughout. For those institutions with existing procedures, engaging youth in an evaluation of existing processes can identify opportunities to further improve current practices. Whether one is creating a new structure or building on an existing one, every step in the health care process should be considered. Next we

offer illustrative examples of opportunities to foster youth participation in health care settings.

**Setting the Tone.** Adults and children alike feel frustration when administrative barriers hinder access to care. Although many adults will persevere, appreciating the importance of connecting with care, adolescents may conclude it is not worth the trouble, meaning access barriers might lead them to abandon efforts to connect with health care.<sup>24</sup> Health care providers and institutions need to be sensitive to these initial impressions.<sup>25,26</sup> Among other things, this means scheduling an appointment should be easy and hassle free. When youth seek care by calling to make an appointment, they should not have to confront lengthy telephone decision trees and extended waiting times before reaching a live person. A live person who interacts in a warm manner can help adolescents feel that they are treated with respect and heard.

Other youth might prefer a more anonymous means of making an appointment, such as through an online portal. The goal should be to offer means of scheduling that are responsive to what youth want. That is, if an adolescent feels more comfortable speaking with a live person, that should be readily accessible. Youth should not have to resort to other scheduling means because their preferred method took too long to access or had other barriers. Ultimately, because initial interactions can set the tone for whether an adolescent feels his or her input will be considered in a meaningful way, it should be considered part of the continuum of care and not just a triage tool for the health care provider or institution.

Once adolescents are on site, the priority during patient registration should be ensuring adolescents feel welcome, comfortable expressing their views, and not judged.<sup>27</sup> For clinics that serve at-risk youth, allowing walk-in appointments is critical. During initial interactions, checking insurance or other billing matters should not be the most important issues. Those issues matter, but making them the first priority can alienate youth and discourage them from seeking care. Staff should also consult with adolescents on health insurance billing preferences, so that confidentiality is not compromised inadvertently when health insurance statements are mailed to the adolescent's home afterward.<sup>28</sup> Such missteps can expose some adolescents to risk of harm and further discourage them from following up with care. If a young person is without insurance, mechanisms should be in place to ensure that he or she can receive care. In short, adolescents like to go to places where they feel welcome, respected, connected, and safe.<sup>29</sup> All staff should be educated or trained on how to interact with

adolescents so that youth feel welcome and supported and are inclined to return for future visits.<sup>30</sup>

This training should situate best practices for interacting with youth in the context of children's rights. Staff should operate from a standpoint of recognition that children and adolescents have a *right* to participate in decisions about their care. Questions from youth should be welcomed as part of the process of helping them realizing their right to be heard and to have their opinions and concerns be taken seriously, as recognized in the CRC. Furthermore, as discussed earlier, listening itself is not the end goal.

**The Built Environment.** Health care professionals and institutions also need to be attune to whether their physical space is one that both encourages youth to feel welcome and empowered to exercise their right to be heard and enables clinicians and staff to respond to youth in a way that makes youth participation meaningful. The office environment must be welcoming, with messages that support diversity including race/ethnicity, gender, sexual orientation, developmental stage, class, culture, geographic region, language, and religion. Furniture should be appropriate for this age group, and the place should be colorful, well lit, and clean. In short, the environment needs to reflect the culture of adolescence.<sup>31-33</sup>

By being attuned to the culture of adolescence and acknowledging what matters to youth—for example, opportunities for expression, identity formation, fitting in, etc.—health care settings can foster trust, promote youth participation, and alleviate fears and anxiety. Clinicians and staff should also be consulted and encouraged to consider how the built environment could better position them to foster youth participation.

**Clinician-Adolescent Care Relationship.** Health care providers need to create safe settings in which adolescents feel comfortable and empowered to open up about their health status and concerns. Adolescents want and need to talk about important health issues. However, many adolescents will not discuss their health concerns unless asked directly by their providers.<sup>34</sup> In other instances, providers do not do enough to make adolescent patients feel safe talking about what is going on in their lives or ask relevant questions that would spur an adolescent to share a concern.<sup>35,36</sup> By investing time to build relationships, clinicians can encourage young patients to open up.

Privacy is important to adolescents, even though adults might think adolescents treat privacy very differently.<sup>27</sup> Thus it is critical to discuss confidentiality with adolescents at the outset and allow them time to ask questions about the parameters of privacy

policies. For adolescents under the age of majority, it is important to engage parents when possible and to discuss with the young person the parameters of confidentiality with respect to his or her parents.<sup>37</sup> Even when a parent or legal guardian accompanies a young person, it is important for the clinician to have time alone with the child to provide space for the young person to discuss whatever matters to them.<sup>38</sup>

In all interactions with adolescents, avoiding judgment is critical. Thus it is important to explain to the adolescent patient before taking a history that you ask all young people similar questions to give them the opportunity to share in case something is going on in their lives. When taking a history, it is valuable to start by asking youths about their strengths and interests, to develop a relationship, before moving on to sensitive, more difficult questions.<sup>39</sup> Identifying strengths and interests early can be helpful in navigating the more challenging issues later because the provider can refer back to and incorporate the adolescent's assets into treatment plans in a way that empowers the young person. Both active questioning and active listening are essential at every stage of an appointment with an adolescent.

Once a very detailed history and comprehensive physical examination are completed, the health care provider needs to develop an individualized treatment plan based on what he or she learned from the young person and found in the physical examination. Health care providers should see the development of a treatment plan as a shared endeavor with the patient.<sup>40</sup> At each step, the provider should explain the what, why, and the how of the plan and ensure that the adolescent feels like he or she is an active participant in this process.<sup>41</sup> The provider should also be sure to address the issue that brought the young person in, even if the provider does much more than that or feels that other issues are more significant.

It is important not just to serve young people, but to empower them—that is, to help young people exercise their rights and develop and voice their opinions.<sup>42</sup> Health education is an important component of the treatment plan for most adolescents, including learning about their rights and how to get their needs met.<sup>43</sup> As part of this collaborative process, using a shared decision-making model is important, so that youth feel simultaneously empowered and supported and so the provider and adolescent patient agree on a treatment plan and any follow-up.<sup>40</sup> The purpose of the first visit is to get a second visit, and the purpose of the second visit is to get a third, and so on.

In developing a treatment plan and delivering care, the goal should be to ensure high quality, comprehensive, integrated care. When serving adolescents, particularly at-risk youth, the more services are in one place, especially if integrated, the more likely that young persons will receive all the services they need and want.<sup>44</sup> If possible, a teenager should not have to travel to one place for primary care, another for family planning, and yet another for counseling. Having all relevant services in one place with easy access will help young people receive the different services they need and encourage them to return for follow-up services. In smaller clinics and practices, remote areas, or under-resourced communities, where it is not possible to have all services under one roof, it is important to develop alternative ways to ensure services are as integrated as possible.<sup>45</sup> This might require the development of creative partnerships with other providers, more active use of technology and telemedicine alternatives, or additional transportation support for adolescents so they can readily travel to each location for needed services.

Finally, clinicians need to be cognizant of the ever-evolving needs of young people and remain alert to their changing health care needs. Health care professionals need to follow youth closely, constantly assessing, reflecting, learning, and innovating, always with the young person at the center.

The discussion given here offers suggestions for ways in which health care providers and entities can address and foster adolescents' participation rights in health care settings. Ranging from the built environment and initial interactions through clinician-patient interactions to follow-up care, there are numerous opportunities to improve youth engagement in their own health care. The examples discussed in this article are illustrative. A particular provider or entity's approach must account for available resources, geography, and other local variables. Most important, the specific approach taken by any health care provider must be informed by the young people he or she serves. Youth perspectives must inform all aspects of health care delivery if it is to be responsive to the needs and rights of children and adolescents.

## CONCLUSION

The right to participate is arguably the most progressive right in the CRC.<sup>11</sup> It has potentially powerful implications for children's day-to-day lives now and for their potential to develop into engaged adults who

possess the fundamentals of good citizenship. It also makes a difference in health care delivery and outcomes.

Despite widespread acceptance of the CRC, as noted earlier, the United States is the only country in the world yet to ratify the treaty; thus it is not legally binding in the United States. However, this article is not aimed at detailing the legal obligations of health care providers—whether they are derived from international, national, or state law. We do not believe clinicians are motivated only by legal mandates. In fact, physicians and other health care professionals are guided by many ethical guidelines and principles that are not technically law. Instead,

we argue that the CRC, even in the United States where it is not legally binding, offers a valuable guiding framework for health care professionals. Fulfilling children's rights is supportive of child well-being. And supporting child and adolescent well-being has broad implications for communities and societies. "Adolescents are the barometer by which we can measure the health of our society....Healthy teens mean healthy communities in the future. When adolescents do well, society does well."<sup>46</sup> Health care professionals are well positioned to support adolescent development and empower youth to exercise and enjoy their rights, while meeting the health care needs of young people.

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