



# Participation of Children and Young People in Their Health Care: Understanding the Potential and Limitations

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The child-friendly health care approach, based on the United Nations Convention on the Rights of the Child (CRC) and endorsed by the Council of Europe,<sup>1</sup> establishes participation of children in their own health care, and in the development of health systems and policies as among the essential elements required to ensure children's access to health care and optimal health outcomes. Evidence from a growing body of European research indicates that children are generally excluded and not sufficiently involved in individual healthcare decisions. This exclusion includes their rights to information (CRC article 17) and the opportunity to express their views and concerns (CRC article 12)<sup>2</sup> in the context of clinical care, service improvement, and policy-making. In addition to the CRC, CRC Optional Protocol 3 speaks to the need for youth to participate in decision making, as do several of the CRC General Comments.

The evidence for poor participation of children in medical decision-making in many European countries is extensive and contradictory. Damm et al<sup>3</sup> reported that a lack of ongoing training of healthcare professionals in communicating with children is an important factor that negatively influences the participation of children. This is despite her associated finding that promoting children's competence in complex decision-making is an essential factor in improving their health.<sup>3</sup> A survey of the European Paediatric Association revealed that in 30 of 35 European countries, chronological age alone was identified as the main criterion for allowing children to participate in decision-making,<sup>4</sup> ignoring the principle of "evolving capacities" promoted in a number of CRC articles. Only five of 35 European countries regarded the developmental stage of competence as the key factor for involving children in decision-making.<sup>4</sup> In the same study, the age limit for seeking children's consent before invasive diagnostic or therapeutic measures ranged between 12 and 18 years. Health education was generally included in school curricula; however, it is unclear if the child's rights to health, participation, equity, and social justice were also included.<sup>5</sup>

The European Paediatric Association survey could not answer the question to what extent the concept of the "ladder of participation" has been implemented into everyday pediatric care. In two-thirds of countries the child's consent was regulated by national law and in one-third of countries by local professional practice. Training regarding access to

information, communication, and participation with children was reported to be rare in most European countries.<sup>4</sup> These and the previous divergent and sometimes contradictory findings indicate that national guidance with respect to youth participation in health venues is based less on science and more on culture and history.<sup>4</sup> They also highlight the spectrum of European countries' translation of the principles and standards of the CRC and children's rights into practice.

## Developing Trust from Mistrust

As all European countries have ratified the CRC, participation of children in society and in health systems is required. Ensuring participation of youth, especially young children, requires knowledge, self-confidence, imagination, and trust on the part of both providers and their pediatric patients. Pediatricians have expert knowledge about disease pathophysiology and treatment options that may be difficult to communicate to parents and children. Also, parents may have their own perspectives that they may superimpose consciously or unconsciously on their children. Children, to the contrary, are often open and receptive to new information and knowledge—regardless of their age. A core principle of child rights is that information must be provided in a language and/or form of communication that is congruent with the child's evolving capacity to understand and respond. Issues may occasionally arise in which parents' perspectives of what is in their child's best interest (CRC article 3) differs from that of the child and/or provider. It is important in these situations to ensure the child has access to information that s/he can understand and process in order for him/her to have an informed voice in decisions that are being made on his/her behalf.

Self-confidence of patients results from positive past experience and can be reinforced with positive feedback. Imagination is an important mental strength to anticipate what is going to happen in the future and, above all, what may be overcome by the child's mental attitude, as used in

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cognitive-behavioral therapy. Mistrust based on uncertainty is a healthy reaction towards social contacts; however, it may lead to an unhealthy behavior if it becomes an obstacle in medical care. Medical trustworthiness can be generated through ongoing performance, communication, and empathy of providers.

It is thus important to establish a rights-respecting environment in order to advance open communication and patients' self-confidence, imagination, and trust. The Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services has identified 12 specific rights of children, which, if fulfilled, will help ensure optimal participation of children and do much to advance their self-confidence, nurture their imagination, and maximize their feelings of trust.<sup>5</sup> In addition, the European Association of Children in Hospitals has a charter that should be made available to all children entering into hospitals that describe the rights due to children.<sup>6</sup> Both of these resources are relevant to health systems globally, including the US, despite its status as the only country that has not yet ratified the CRC.

### Rights Holders and Duty Bearers in Relation to Participation

Participation of children in pediatric care means that the child's voice must be heard and opinion respected. It is the responsibility of duty-bearers (eg, physicians, nurses, parents) to ensure the rights of rights-holders (children) are fulfilled. Participation is based on a positive mental attitude of all people involved, and should improve all aspects of health care delivery. If successful, it should generate a new culture of authentic partnership between all involved—including children and adolescents—whose views are required to improve hospital structure and function, as well as processes of medical care, systems development, the generation of health policy, medical education, and research. Participation of children and adolescents in pediatrics also includes developing new strategies for preventing illnesses by addressing risk-taking behaviors and positive health determinants, not only in vulnerable populations but by understanding and addressing the existential vulnerability of all young people. Developing these concepts together with young people to: (1) improve quality of health care; (2) design pathways for translating evidence into practice; and (3) monitor and evaluate patient safety will require focused participatory activities.

Pediatricians must understand and respect the child's right to health.<sup>7</sup> However, they and other caregivers are not the only duty-bearers. Another critical principle of child rights is that with rights come responsibilities. Thus, participation of children in medical decision-making places children in the roles of rights-holders as well as duty- and responsibility-bearers. Improving participation of children in medicine will thus require more than knowledge of their right to health. Empowering children in this sense requires them also to be authentic and collaborative duty-bearers. This process may be positively or negatively influenced by the child's family and physicians.

National pediatric associations and societies should be encouraged to discuss the principles of participation and actively implement, evaluate, and publish initiatives that involve children. Examples include the Austrian working group on "Politische Kindermedizin" ([www.polkm.org](http://www.polkm.org)) who published their articles in Supplement 1 of *Paediatric & Paedologie*,<sup>8</sup> the Royal College of Paediatrics and Child Health and its guidelines for limiting treatment,<sup>9</sup> and the practice of involving children in difficult decisions described by Bagcchi.<sup>10</sup> ■

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