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Beyond Bioethics:

a child rights-based approach to complex medical decision-making

Katherine Wade*, Irene Melamed†, Jeffrey Goldhagen‡

*Wellcome Trust Post-Doctoral Research Associate, Centre of Law and Medical Ethics, Dickson Poon School of Law, London.

†Bioethics and Health and Social Sciences Program, Latin American Faculty of Social Sciences (FLACSO), Buenos Aires.

‡Division of Community and Societal Pediatrics, University of Florida College of Medicine-Jacksonville.

Abstract

This analysis adopts a child rights approach—based on the principles, standards, and norms of child rights and the U.N. Convention on the Rights of the Child (CRC)—to explore how decisions could be made with regard to treatment of a severely impaired infant (Baby G). While a child rights approach does not provide neat answers to ethically complex issues, it does provide a framework for decision-making in which the infant is viewed as an independent rights-holder. The state has obligations to develop the capacity of those who make decisions for infants in such situations to meet their obligations to respect, protect, and fulfill their rights as delineated in the CRC. Furthermore, a child rights approach requires procedural clarity and transparency in decision-making processes. As all rights in the CRC are interdependent and indivisible, all must be considered in the process of ethical decision-making, and the reasons for decisions must be delineated by reference to how these rights were considered. It is also important that decisions that are made in this context be monitored and reviewed to ensure consistency. A rights-based framework ensures decision-making is child-centered and that there are transparent criteria and legitimate procedures for making decisions regarding the child's most basic human right: the right to life, survival, and development.

The case of Baby G raises some of the most difficult decisions confronting parents and health-care professionals. Given the context-specific nature of most medical decisions affecting children, the principles and standards of child rights and the U.N. Convention on the Rights of the Child (CRC) will not clearly articulate the best interests of the child in every situation (Cherry 2010; Hammarberg 2008). A child rights-based approach will, however, provide the factors (rights) that must be considered, methods for their analysis, and the procedural safeguards that must surround decision-making related to complex medical situations facing children, families, and providers. This approach can facilitate both decision-making for individual children at the bedside, as well as the development of rights-

respecting health systems and policies. It defines the obligations of parents, health professionals, organizations, institutions, and the state in the realization of children's rights and provides strategies and tools to do so.

Principles of a Child Rights-Based Approach to Medical Decision-Making

In order to understand the general relevance of the principles, standards, and norms of child rights and the CRC to bioethics, prior to their application to the case of Baby G, it is necessary to elucidate a number of critical points related to a child rights-based approach to complex medical decision-making.

The CRC articulates 40 substantive rights that apply to children of all ages (Article 1) without discrimination of any kind (Article 2). These articles provide a comprehensive inventory of factors that can be used in a rights-based approach to complex medical decision-making.

The concept of the best interests of the child (Article 3) is seen as a general principle of the CRC. As presented by Lansdown, Lundy, and Goldhagen (2015) in this volume, the best interests principle is a threefold concept that is defined as a substantive right that establishes the right of the child to have his or her best interests assessed and taken as a primary consideration; a fundamental, interpretative legal principle, and a rule of procedure. (UNCRC 2013, para. 6). With respect to the latter, whenever a decision is to be made that will affect a specific child, the decision-making process must include an evaluation of the possible impact (positive or negative) of the decision on the child. Justification of decisions must be transparent and demonstrate that Article 3 has been explicitly taken into account—in other words, what has been considered to be in the child's best interests, the criteria upon which the decisions are based, and how the child's interests have been weighted against other considerations.

It is important to note that the rights of the CRC are indivisible. As Hammarberg (2008) notes, the Committee on the Rights of the Child (Committee) seldom refers only to one article of the CRC, but rather interprets the Convention as a “comprehensive set of interdependent rules with the best interest of the child as an overarching principle” (3). Thus, in making decisions for and with children, determining the child's best interests requires an assessment and balancing of all substantive rights articulated in the CRC. As the Committee notes, a child rights-based approach to decision-making is about “respect for the dignity, life, survival, wellbeing, health, development, participation and non-discrimination of the child as a rights bearing person” (UNCRC 2013, para. 59).

The realization of children's rights requires the development of the capacity of duty-bearers to meet their obligations to respect, protect, and fulfill these rights and the development of the capacity of children to claim them (UNCRC 2011, para. 59). The CRC recognizes the state as a primary duty-bearer, whose obligation is to establish the laws, policies, infrastructure, and resources to support the realization of the rights of children (Article 4). Obligations to fulfill the rights of children as set out in the CRC are directed at all public and private sector entities (Article 3).

While the CRC recognizes that parents have a critical role to play in decision-making, this relationship is child-centered, in the sense that parents and guardians should ensure that their decisions have their child's best interests as their "basic concern" (Article 18) and that their decisions are based on the rights of their child (UNCRC 2013, para. 10). This differs somewhat from certain bioethical approaches, in which parents and guardians are identified as the primary rights-bearers. For example, Diekema (2004) argues that there should be a presumption that parents should make decisions for their children, providing such decisions do not place the child at "substantial risk of serious harm" (250). Ross also argues in her article in this volume and in an earlier article that parents are best placed to make decisions for children (Ross 2008, 2015). Using a Rawlsian framework, Ross claims that whereby parental decisions are justified insofar as these decisions do not deprive children of their basic needs.

Given these basic principles, the question that arises is the extent to which the articles of the CRC and the CRC supporting instruments can provide guidance in deciding the future care for Baby G.

Case Analysis: Realizing the Rights of Baby G

The following child rights-based analysis of the Baby G case uses the articles of the CRC as a framework for analysis and decision making.

Article 6. The Right to Life, Survival, and Development

Baby G has an "inherent right to life" under Article 6(1) of the CRC. The CRC also provides that "States Parties shall ensure to the maximum extent possible the survival and development of the child" (Article 6(2)). As mentioned above, the right to life, survival, and development must be considered in connection with all of the rights of the CRC. In this context, the centrally relevant rights are Article 24, which guarantees to children the right to "the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health"; Article 19, which mandates protection from maltreatment of any kind; and Article 37, which sets out the right to be free from "cruel, inhumane or degrading treatment." Article 6 must therefore be considered through the lens of these other rights of the CRC.

In this regard, Baby G's right to health must be protected. However, his health status and unique position must be borne in mind. His chances of long-term survival appear to be low, and his health is badly affected by his breathing and swallowing difficulties and scoliosis. It can be argued that, in such circumstances, enforcing invasive, burdensome, or futile treatment might not be in his best interests (Article 3). In this respect, Baby G is protected by the CRC from being "subjected to torture or other cruel, inhuman or degrading treatment or punishment" (Article 37). Additionally, states parties are required to take "all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation" (Article 19).

Dorscheidt (2008) provides a useful example of reasoning around the meaning of the right to life of impaired neonates under Article 6 of the CRC, which further articulates the above points. He states that the right to life of the child, as articulated in Article 6, has an inherent character, meaning that it is intrinsic to the person and “cannot be taken away, suspended or transferred to others” (183). He further notes that the essence of the right to life is that it contains the basic legal prohibition of deprivation of life. He then goes on to reason that it is arguable that a child could have a reasonable interest in waiving his or her right to life, “if the exercise of the right is accompanied by unbearable pain and suffering” (185). If the right to life of neonates is unconditionally protected in all circumstances, a situation of legal inequality might be created due to the neonate’s inability to waive his or her right, and multiple other rights defined in the CRC may be violated (185). However, he notes that if one argues that a neonate’s right to life can be waived, there is a risk that these decisions may be made on the basis of others’ interests as opposed to those of the child. Therefore, Dorscheidt argues that accepting the proposition that the right to life of neonates can be waived requires a process by which cases can be identified where it is not appropriate to protect the right to survival of the neonate, with particular attention to “cases of doubt” (186).

Such an approach is in line with a child rights approach. It maintains that the right to life must be assessed through the lens of other rights, as it recognizes that “multiple other rights defined in the CRC” may be violated if a neonate’s right to life is protected unconditionally. In addition, as is the case under a child rights approach, there is need for procedural clarity in relation to decision-making in this context. As set out above, the CRC is clear that decisions must be made for children through a rigorous and transparent rights-based approach in line with Article 3.

Article 3: Best Interest Assessments

In the circumstance of Baby G, a decision must be made as to how to balance the multiple rights due to Baby G through a rigorous and transparent rights-based approach to medical decision-making. As is the case in bioethics, a child rights-based approach uses the best interests principle as a framework to determine the actions that should be taken for children. Article 3(1) of the CRC states: “In all actions concerning children, whether undertaken by the public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”

General Comment No. 14 on the “Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration” establishes guidance for a child rights-based approach that should be taken when making decisions affecting a specific child or group of children. It states that decision-makers must conduct a “best interest assessment” and emphasizes that this assessment should first identify all specific circumstances that make the child unique (UNCRC 2013, para. 49). It identifies the elements that should be taken into account, including the child’s views, identity, preservation of the family environment, care, protection and safety, situation of vulnerability, right to health, and right to education (paras. 53–79). The list is not considered to be exhaustive, and other factors relevant in the specific circumstances of the individual child or group of children must be considered. In

considering the different rights involved in a best interests assessment, the content and weight assigned to each right will differ depending on the circumstances and decisions that must be made (para. 87).

General Comment No. 14 also stresses the procedural safeguards that must be involved in assessing and determining the best interests of a child or group of children. It asserts that: “States must develop transparent and objective processes for all decisions made by legislators, judges or administrative authorities, especially in areas that directly affect the child or children” (paras. 89–95). These procedures must respect the right of the child to express his or her views, ensure the procurement of relevant facts by well-trained professionals, avoid delays, and involve legal representation for the child when relevant. Decision-makers are also required to justify their decisions (paras. 89–96). As the Committee on the Rights of the Child has stated:

the justification of a decision must show that the best interests of the child has been explicitly taken into account. In this regard, States Parties shall explain how the right has been respected in the decision, that is, what has been considered to be in the child’s best interests; what criteria it is based on; and how the child’s interests have been weighed against other considerations, be they broad issues of policy or individual cases.

(para. 6(c))

States are also expected to establish mechanisms within their legal system to review or revise decisions (para. 98). In addition, as will be discussed, all policy, legislation, regulation, budget, or administrative decisions affecting children should be monitored and evaluated through a child rights impact assessment (UNCRC 2013, para. 99).

Applying this guidance to decision-making for severely impaired babies ensures that decisions are based on the rights of the child. Procedural safeguards involving transparent and objective processes ensure the child’s rights are considered, justification for decisions are based on the analysis of child rights as articulated in the CRC and its associated instruments, and mechanisms are in place for the review and monitoring of all decisions.

The Nuffield Council on Bioethics in the United Kingdom provides an excellent example of a rights-based approach to bioethical decision-making. Their charter states that “fair and transparent procedures are crucial for ethically acceptable decision-making processes” (Nuffield Council 2006, para. 2.45). The Council argues that there are situations where the imposition or continuation of life-sustaining treatment “imposes an intolerable burden upon the baby” (para. 2.11). It also stresses the need for a set of criteria that could be weighed in the balance in coming to a decision (para. 9.34).

The development of definitions and clear criteria for the assessment of severely impaired babies is consistent with requirements articulated in General Comment No. 14 (Best Interests). Having a set of criteria that are used for every baby in deciding whether or not to continue life-sustaining treatment brings consistency and transparency to decision-making. It ensures that, when decision-makers assess whether the burdens of continued living outweigh any benefits, they must consider the child’s chance of survival, future health condition, and

current levels of distress, as well as parental views. Following the guidance of General Comment No. 14, it can be argued that decision-making should also be monitored by a body independent of the hospital to ensure consistency in the utilization of such definitions and criteria. Justifications for decisions should also be developed by decision-makers, such as bioethicists, health-care teams, and clinical ethics committees, and be presented to such independent monitoring bodies.

Parental Guidance

Regarding parental and guardian authority in decision-making for cases like Baby G, it must be noted that parents and guardians are given strong recognition in the CRC. The Preamble to the CRC upholds the family as “the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children.” Additionally, Article 5 states that:

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

Article 18 of the CRC provides guidance as to how parents should fulfil their responsibilities, rights, and duties. It states that the best interests of their child will be their “basic concern.” General Comment No. 14 states that it expects that its requirements, as outlined above, will “guide decisions by all those concerned with children, including parents and caregivers” (UNCRC 2013, para. 10). Article 18(2) is also particularly relevant in this context. It states: “For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.”

Therefore, it is recognized that in order for parents to make decisions wherein the child’s best interests are their basic concern, parents must be given support and assistance. In this regard, useful guidance can also be drawn from the Nuffield Council on how to support parents in making such decisions. The Nuffield Council emphasizes that parents need timely provision of accessible information, available in different languages and formats in line with their needs (Nuffield Council 2006, para. 46). Additionally, guidance from the Royal College of Paediatrics and Child Health (2004) stresses that parents should be able to also seek advice outside the health-care team and suggests that advocates who are independent from the medical team could be utilized. Such individuals could be used to interpret medical information for parents and also assist the parents in conveying their views accurately to the health-care professionals. They could also be trained in children’s rights and the requirements of making best interest assessments for children in line with General Comment No. 14.

The failure of the United States to ratify the CRC is in part due to the misperceived perspective that granting children rights will diminish those of parents (Bennett Woodhouse

and Johnson 2009). This perspective is reflected in the near-paramount consideration granted by many pediatric bioethicists to parental rights to determine outcomes in cases like Baby G's. Such an approach is problematic from a child rights perspective, as it fails to fully recognize that children have rights independent from their parents, limits analyses derived from a focus on the child's rights, suggests that parents will inevitably make decisions that reflect the best interests of the child, assumes that parents are provided with and understand all of the information required to determine the child's best interests, assumes that the child's rights will be fulfilled without rigorous discussion and debate, and discounts the interests of the state and others in realizing the best interests of the child. In this context, "others" may represent medical professionals who are themselves duty-bearers with respect to ensuring the child's rights are fulfilled in pursuit of the determination of his or her best interests. That responsibility cannot be relegated by practice or policy solely to parents. The state, through its courts and welfare systems, is accountable to ensure the rights of children are fulfilled.

The Rights of the Disabled Child

From a disability rights perspective, the CRC does not discriminate on the right to life for all children (Articles 6 and 23) and their right to access facilities for the treatment of illness and rehabilitation (Articles 24 and 39). Other human rights conventions, such as the U.N. Convention on the Rights of Persons with Disabilities, include these basic rights as well.

The Groningen Protocol speaks directly to the guidelines and requirements that must be followed related to the active termination of life in infants with severe disabilities (Verhagen and Sauer 2005). These guidelines were translated into a rights-based protocol of the European Disability Forum in 2006. The protocol includes 10 domains that must be addressed in the process of decision-making related to the management of neonates with complex or chronic medical conditions. Most of the domains address prohibitions for discriminating against children with real or potential disabilities, but domains 6 and 7 address process metrics related to ensuring the rights of neonates with complex medical conditions are realized in medical decision-making. These domains address the adequate representation of independent advocates to ensure the rights of children are represented in proceedings, as well as the need for parents to be provided with sufficient information and support for informed decision-making.

Conclusion

The U.N. Convention on the Rights of the Child and its supporting documentation cannot provide neat answers to ethically contentious issues, such as those regarding treatment decisions for severely impaired neonates. However, it brings a perspective to the decision-making process in which the neonate is viewed as a rights-holder and states are obliged to develop the capacity of those who make decisions for them to meet their obligations to respect, protect, and fulfill those rights. It emphasizes the need for a rights-based process for deciding on behalf of children. As in bioethical theories, an exact formula for weighing harms and benefits is not provided. However, a child rights approach requires procedural clarity and transparency in decision-making processes. A set of substantive rights must be

weighed in the balance, and the reasons for outcomes must be given by reference to how these rights were considered. Decisions must be justifiable by reference to the child's rights and must be monitored and reviewed to ensure consistency.

The opinions of parents and guardians are also weighed in the decision-making process, and all efforts must be made to support them in making decisions that are in the best interests of their child. Clear information and the use of independent advocates are helpful in this regard. Such a rights-based framework ensures that decision-making is child-centered and that there are transparent criteria and legitimate procedures for making decisions regarding the child's most basic human right—namely, the right to life, survival, and development.

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