

# Panorama of Children's Bioethics in Ibero-America

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## Abstract

This work aims to offer an approach to children's bioethics in the Ibero-American world. We start from the differentiated status of the minor with respect to other stages of life as well as the historical development of bioethics in the Ibero-American space. First, a proposal is presented to classify the main topics that could be considered by Ibero-American children's bioethics. Next, the main problems and conflicts of child bioethics are discussed according to the bioethical, biomoral or biopolitical norms involved. This matter is exemplified by the debate on child labour and the debate between an autonomist or paternalistic bioethics. Likewise, two general criteria for action that commit public policies in favour of children are proposed. It is finalised emphasising that children's bioethics deserves a prominent and differentiated space within the bioethics in Ibero-America.

**Keywords:** Bioethics. Human rights-Child advocacy. Public policy. Adolescent-Child-Protection. Bioethical issues. Latin America-Spain-Portugal. Minors.

## Resumo

### Panorama da Bioética infantil na América Latina

Este trabalho tem como objectivo oferecer uma aproximação à bioética infantil no mundo iberoamericano. Começamos a partir do estado diferenciado do menor em comparação com outros estágios evolutivos assim como do desenvolvimento histórico da bioética na América Latina. Primeiro, apresenta-se uma proposta para classificar os principais assuntos que poderiam ser considerados pela Bioética da criança na América Latina. Logo, discutem-se os principais problemas e conflitos da bioética infantil de acordo com os padrões bioéticos, bio-morais ou biopolíticos envolvidos. Esta questão é exemplificada com o debate sobre o trabalho infantil e com o debate entre uma bioética autonomista ou paternalista. Assim mesmo, são propostos dois critérios gerais de ação que comprometem políticas públicas a favor das crianças. Finaliza-se enfatizando que a Bioética da criança merece um espaço excepcional e diferenciado dentro da bioética realizada da América Latina.

**Palavras-chave:** Bioética. Direitos humanos-Defesa da criança e do adolescente. Política pública. Adolescente-Criança-Proteção. Temas bioéticos. América Latina-Espanha-Portugal. Menores de idade.

## Resumen

### Panorama sobre la bioética infantil en Iberoamérica

Este trabajo tiene como objetivo ofrecer un acercamiento a la bioética infantil en el mundo iberoamericano. Partimos del estatus diferenciado del menor respecto de otros estadios evolutivos así como del desarrollo histórico de la bioética en el espacio iberoamericano. Primero, se presenta una propuesta para clasificar los principales asuntos susceptibles de ser considerados por la bioética infantil iberoamericana. A continuación, se discuten los principales problemas y conflictos de la bioética infantil en función de las normas bioéticas, biomorales o biopolíticas implicadas. Esta cuestión se ejemplifica con el debate sobre el trabajo infantil y con el debate entre una bioética autonomista o paternalista. Así mismo, se proponen dos criterios generales de actuación que comprometen a las políticas públicas en favor de la infancia. Se finaliza destacando que la bioética infantil merece un espacio destacado y diferenciado dentro de la bioética llevada a cabo desde Iberoamérica.

**Palabras clave:** Bioética. Derechos humanos-Defensa del niño. Política pública. Adolescente-Niño-Protección. Discusiones bioéticas. América Latina-España-Portugal. Menores.

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Declara não haver conflito de interesse.

In the present work we assume that bioethics is a consolidated academic discipline, where the diverse origin of its professionals (philosophers, physicians, psychologists, theologians, legists, among others) reveals its interdisciplinary character. Complementing this interdisciplinary nature, one should also affirm that among bioethicists there is no basic consensus around the principles or general theories of the discipline and there are strong doctrinal controversies in this regard. This being so, it can be said that the unity of the bioethical discipline is mainly of a pragmatic nature, that is, it is articulated around decisions, dilemmas and debates with respect to which a committed decision must be made.

However, despite this lack of consensus, bioethics is not an amorphous or chaotic field. In this regard, it should be noted that one of the ways to reveal its internal structure would be to record and classify the issues and practical problems raised by the bioethical controversies themselves according to clear and distinct criteria<sup>1</sup>. From the bioethical system that we take as reference and for the purpose of the present study<sup>2</sup>, it is opportune to begin by pointing out that the issues and problems with which bioethics deals (understood in a broad sense) include issues and problems of a (bio) ethical nature (in a restricted sense) but also, and in a disharmonious way as we shall see, of a (bio) moral and (bio) legal or (bio) political nature.

This being so, we will say that the practical behaviour of human beings is ordered according to three normative dimensions. At first, the subjects that appear as terms of the bioethical field appear given in a universal and distributive scale, constituting the specific scope of the "ethics". Ethics is thus "universal" because each and every one of the individuals of the human species make up its reference, and there can be no discrimination based on sex, age, religion, race, or any other reason. But it is an abstract universality because it has to be put in parentheses, that is, to make an abstraction of those constitutive and distinctive contents of every real human being (sex, language, culture ...).

Second, we must bear in mind that human subjects are also constituted on an attributive scale, that is, as subjects embedded in moral, social and cultural norms proper to different human groups (families, social classes, cultures, nations). This situation configures the proper space of morality. Moral norms support and protect the lives of individuals insofar as these individuals make up social groups. Moral norms (taking into account

the etymological meaning of the term, from Latin *moralis*, from *mos*, *mor*- 'custom, manners', (plural *mores*) can not be universal because human groups are different, given on a historical-cultural scale and often in mutual conflict. The third type of norms that inevitably affect the practical behaviour of mankind would be formed by the political-state norm. In effect, each individual either resides or is a citizen of a particular state and is subject to its political and legal framework<sup>3</sup>.

Having said that, we must state that all bioethical issues related to childhood are presented as a matter of maximum complexity since they reflect, in the first instance, the need for an interdisciplinary work that combines scientific, health, cultural, social and ethical elements. Children's bioethics can not be reduced to the application of bioethical knowledge to exercise of a paediatrics specialty and needs a global approach, related to all dimensions of childhood and all the contexts with which it is related<sup>4,5</sup>.

This document is based on a previous work<sup>6</sup> where we discussed what we consider constitutive principles of children's bioethics and where we developed a classification system that allows us to place all the issues that concern children's bioethics. We also explained how from the status of the child, as an entity irreducible to earlier ontogenetic stages (zygote, embryo, foetus) or later stages (the adult person), children's bioethics presents characteristics which can not be reduced to the reflection and practice of standard bioethics, which takes as a reference precisely the adult autonomous subject<sup>6</sup>.

The main purpose of the paper we present is to offer a panorama, that is, an overview, to the detriment of detail and specialisation, on bioethical reflection and practice in relation to the situation of Ibero-American childhood. In other words, it would be a matter of answering the question: why talk about a children's bioethics in Ibero-America? We begin by presenting a classification of the issues that could be considered by Ibero-American children's bioethics. To this end, we carried out an updated review of the most relevant general indicators on health issues and social issues for children and public policies for the protection of children.

Next, an explanation is proposed about what originates the main problems that occur in the reflection and practice of children's bioethics. This situation is illustrated by the controversial issue of child labour as well as the debate on a bioethics

that highlights the patient's autonomy, even when he or she is a minor, or that justifies certain forms of paternalism. Then, in spite of the difficulties in deciding between the priority of bioethical or biopolitical norms when they come into conflict, two general criteria of action are presented that compromise the powers and public policies in favor of children being considered as a priority. It ends by stressing that, taking into account the status of the child and the situation of children in Latin America, it would be justified to speak of an Ibero-American children's bioethics as a differentiated space within the reflection and practice of the bioethics developed in Ibero-America.

### Topics of children's bioethics in Ibero-America

The different bioethical systems are not independent of the historical, moral, political and cultural contexts in which they appear and develop<sup>7</sup>. In our work we will understand that the encounter and culture mixing between the Iberian culture and the cultures of the Amerindian peoples, without ruling out the influence of African cultures, so important for the syncretism characteristic of the Caribbean identity and of much of Central and South America, is what made possible the historical development of the Ibero-American bioethical field, as a space of culture and ethical values differentiated from the Anglo-Saxon culture, where bioethics emerged<sup>8</sup>. In another place we have pointed out *the contrast between a highly technical society and liberal ethics, and Ibero-American society, characterised by less technological development, a strong presence of the Catholic religion, both in the public and private spheres, and an ethics based on community values with aspects little emphasised by Anglo-Saxon thought, such as the importance of the role of the family in health matters*<sup>9</sup>. Thus, throughout our work we will sometimes refer to this general Ibero-American area but in others we will refer to more circumscribed and particular realities, mainly referring to Latin America, that is, excluding the Iberian countries, or mentioning a particular country.

We have tried to synthesise the characteristics that different authors have pointed out as idiosyncratic of Ibero-American Bioethics: 1) the importance of philosophical and anthropological reflection of a humanistic nature; 2) a global bioethics, since it aims to cover a wide range of problems (social, economic, environmental ...), without being reduced to the problems originated

in clinical practice; 3) an Intervention Bioethics that stands out for a strong political-social activism on diverse realities (ecology, indigenous peoples, inequality in access to health resources, poverty and marginalisation ...) since the Ibero-American countries are characterised by great social and economic inequalities which translates into great differences in access to health care; 4) the assimilation and recreation of bioethics according to intellectual, social and moral traditions typical of the Ibero-American cultural sphere. Although we can not extend more on this issue, it should be noted that one of the effects of the establishment of bioethics on Ibero-America led to the debate, still unresolved, about the existence of an Ibero-American bioethical thought with its foundations and distinctive characteristics<sup>10</sup>. It is necessary to place it within these coordinates and theoretical reflections for the understanding of our work.

In the following table, a criterion of classification of the subjects susceptible to be addressed by children's bioethics in the Ibero-American space is tested, taking into account, on the one hand, the anthropological space constituted by the personal agents involved in the bioethical issues, and on the other hand, the types of social norms involved. Although it would not fail to recognise the ambiguity that exists when classifying some of the topics in one type of social norm or another<sup>6</sup>.

Regarding social norms, we've already pointed out that we understand bioethics in a broad sense, that is, including bioethical, biomoral and biopolitical issues. With regard to the anthropological space and taking into account the pragmatic dimension of bioethics, it should be noted that it is necessary to take as a basic starting point the relationships between the different agents involved, that is, the complex nature of the relationship between minors and their families, the state of dependency but also the child's progressive autonomy and the work of health and social care professionals<sup>11,12</sup>.

Ordinary bioethics practice assumes as starting point the personal condition of the individual adult as a subject of rights and duties. But in the case of the child, the personalisation is still an open process and in its formation period. This is so since children, for their survival and personal development, inexorably depend on the ethical assistance of their social group, and this in turn is based on different moral rules (family, social, cultural), which in many occasions are confronted and legally regulated by the respective States<sup>13</sup>.

Relations between personal agents involved in bioethical matters can not, and should not, exclude the minor (except babies, disabled adults and other situations of total or partial weakness of the personal condition) in the decision-making process, treatments, clinical trials or any other health and social care intervention, to the detriment of the child's family, tutors or health and social care professionals. But neither would justify to exclude the family group completely as the child's abilities and autonomy progress. Thus, care and attention to minors has been adequately described as a triadic relationship, in which the minor, his family and health/social care professionals appear closely and necessarily involved<sup>14</sup>.

The present work can not develop or detail each and every one of the subjects that can be dealt with by Ibero-American children's bioethics. This would require more specific research that is beyond the scope and purpose of this study. We are satisfied with showing the pertinence of the themes in a table organised according to a classification system of our own. Whatever these investigations are or are proposed to be, it is expected that our classification system can be an instrument that serves to highlight the practical problems that arise depending on the type of social norms involved.

## Method

The most current and relevant indicators in relation to childhood and adolescence have been consulted for the preparation of the table. The indicators, as variables that try to measure and objectify a certain social reality quantitatively or qualitatively, provide us with information

regarding the general state of childhood in the Ibero-American sphere. The indicators that have been taken into account can be simple (for example, an absolute figure such as the mortality rate) or composite, that is, constructed on the basis of several single indicators. Those with a general descriptive value have been selected to the detriment of particularities. Subsequently, they have been grouped according to the distinction we established between bioethics, biomoral and biopolitics. This allows us to configure the issues and themes that together make up the specific difference of Ibero-American children and youth regarding the situation of children in general<sup>15</sup>.

The data and indicators come from the following organisations, institutions and sources: Unicef Latin America, Sistema de Información sobre la Primera Infancia en América Latina (SIPI - Information System on Early Childhood in Latin America), Secretaría General Iberoamericana (SEGIB - Ibero-American General Secretariat), Instituto Iberoamericano de la Primera Infancia (IIFI - Ibero-American Institute for Early Childhood), Comisión Económica para América Latina (CEPAL - Economic Commission for Latin America), Organización Panamericana de la Salud (OPS - Pan American Health Organisation), Instituto Interamericano del Niño, la Niña y Adolescentes (IIN - Inter-American Children's and Adolescents Institute), Centro Latinoamericano sobre Juventud (CELAJU - Latin American Center for Youth), Organismo Internacional de Juventud para Iberoamérica (OIJ - International Youth Organisation for Ibero-America), Observatorio de la Infancia del Ministerio de Sanidad, Consumo y Bienestar Social del Gobierno de España (Children's Watchdog of the Ministry of Health, Consumption and Social Welfare of the Government of Spain).

**Table 1.** Topics of Ibero-American Children's Bioethics

Social Norms	Anthropological space: health and social care professionals, family group, minors
Bioethics	<ul style="list-style-type: none"> <li>• Debates, issues and problems related to the very constitution and development of the organic individuality of the child: abortion, limits of the viability of premature newborns, resuscitation, euthanasia in the neonatal period, palliative care in paediatrics, treatment limits and biomedical therapies, disabilities and early attention, consent and confidentiality, experimentation and trials with children and adolescents etc.</li> <li>• High infant mortality rates.</li> <li>• Regional disparity in the existence and development of universal vaccination programs.</li> <li>• High levels of poverty, discrimination and exclusion that affect children, especially in indigenous and rural areas.</li> <li>• Persistence of situations of chronic malnutrition.</li> <li>• Attention to children in geographical areas of high or extreme risk (droughts, floods ...).</li> </ul>

continues...

**Table 1.** Continuation

Social Norms	Anthropological space: health and social care professionals, family group, minors
Biomoral	<ul style="list-style-type: none"> <li>• Family members or groups in conflict (religious, indigenous communities, social classes ...) in relation to matters involving the minor.</li> <li>• The “mature minor”; confidentiality and informed consent: is the consent from the family or individual? Autonomy of the minor patient.</li> <li>• The problem of child labour.</li> <li>• Issues related to child and adolescent sexuality (high rate of teenage pregnancies, abortion ...).</li> <li>• High levels of violence, abuse and neglect within the family, school, community and in the streets: minors in armed conflicts, deaths due to physical abuse, sexual violence ...</li> </ul>
Biopolitics	<ul style="list-style-type: none"> <li>• The integration of the United Nations Convention on the Rights of the Child ( UNCR ) in national legal systems.</li> <li>• Development of the integrated child protection system in each country.</li> <li>• Development of comprehensive children's health policies.</li> <li>• Administrative or judicial measures as a guarantee of the “best interest of the child” in situations of child abuse.</li> <li>• High rates of institutionalisation of minors in shelters as a measure to protect children.</li> <li>• Situation by countries of minimum legal ages and legal protection of the “mature minor”.</li> <li>• High non-compliance with article 7 of the Convention on the Rights of the Child, where it is specified that every child has the right to be registered immediately after birth.</li> <li>• Juvenile justice: proposals in some countries to reduce the age of criminal responsibility.</li> <li>• The situation of migrant children.</li> </ul>

### Problems of children's bioethics

There is no doubt that the main problems faced by children's bioethics in the Ibero-American space are of a practical nature and have to do with the state and future challenges of childhood<sup>16</sup>.

But together with these practical problems, that is, in a dissociated but never separate way, there are other problems of a gnoseological nature, related to the internal structure of the discipline, its basic principles and main values. And from the bioethical system that we take as reference, these problems of children's bioethics are common to the problems of bioethics in general, but always taking into account what has been said above about the status of children as an reality irreducible to the autonomous adult subject as well as the need to take into account the triad formed by the child, their social group of reference and health/social care professionals. Thus, these problems would have to do fundamentally with the conflicts between the (bio) ethical norms among themselves and between the (bio) ethical and (bio) moral norms, as well as the attempt of the legal and (bio) political norms to channel and resolve (as far as possible) the conflicts between ethical norms and moral norms as well as harmonise (also as far as possible) the conflicts between different moral systems existing in society. This in turn can generate new conflicts and dilemmas between the political

norms themselves on the one hand and ethical and moral standards on the other<sup>2,3,6</sup>.

Indeed, ethical norms are often compatible with each other, but this does not happen in some occasions and this situation leads to dilemmas and ethical conflicts, such as, for example, when the suspension of life support measures is proposed<sup>17,18</sup>. Or the conflicts when conjugating the same bioethical principles and the subject defined by the principle of autonomy is viewed as a term from the bioethical field. In these cases, authors like Baines<sup>19</sup> have revealed the problems that emerge when dealing with minors. The relationship of parents, guardians or different professionals with minors always implies, in a necessary way, the conjugation, not always harmonious but controversial, of promotion and restriction or channeling of rights and freedoms of the minor. This supposes then that of the four principles of liberal bioethics the only unquestionable one, in the case of minors, seems to be the principle of non-maleficence. Thus, the author concludes that bioethics of liberal orientation requires a critical approach before being considered as a reference in the case of minors.

Ethical and moral norms are also often compatible with each other, but not in other cases, such as when one of the parents, under pressure from the family, offers to donate his or her organs, even if it is very unlikely that their child will continue alive<sup>20</sup>; or in the conflicts that arise between the “mature minor” and his or her family members

or health and social care professionals<sup>21,22</sup>. Other problems may result from the confrontation between moral systems with incompatible practices and "world views", such as those as those that are pointed out on the traditional medicine exercise and Western scientific medicine, a reality that is very present in Latin America<sup>23,24</sup>.

The legal norms (ultimately political, because they are sanctioned and enforced only within a state) in numerous cases, aims to channel and resolve conflicts between ethical norms and between moral and ethical norms as well as coordinate the different morals of the different social groups constituting a political society. However, political norms have their own rhythms, guided by the management of differences and institutional stability, which are not always compatible with the urgency of ethical and moral problems and conflicts, adding new forms of conflict in the core of society<sup>1,2</sup>. For example, an issue of a (bio) political nature, with clear bioethical implications, is raised by the question posed by Bellver<sup>25</sup>: "what level of health care should be offered to children of international origin?"

Political norms are usually compatible with ethical norms and thus a substantial part of the legislation of a state can contribute and encourage the promotion of personal ethical virtues. However, sometimes both types of rules conflict because the abstract universality of ethical standards can not distinguish between people from different countries while state policies require taking into account borders, customs, deportations, limited budgetary resources etc. Thus, It is inevitable that the question arises about the health policy of the state and the care ethics towards these minors.

We would like to exemplify what we say with the problem of child labour, so present in many Latin American countries. There are currently two clearly polarised positions on the issue: the abolitionist approach and the critical appraisal approach<sup>26</sup>. These two perspectives characterise the action agenda of public and private organisations, governmental or non-governmental. The abolitionist approach is headed by organisations such as the International Labour Organisation (ILO) and the United Nations Organisation for Education, Science and Culture (Unesco), among others, while representatives of the critical appraisal approach would be the *Movimientos of Niños, Niñas y Adolescentes Trabajadores* (NATs - Children and Adolescent Workers) and some local and international non-governmental organisations, such as the *Instituto de Formación para Educadores de Jóvenes, Adolescentes y Niños Trabajadores de*

*América Latina y el Caribe* (IFEJANT - Training Institute for Teachers of Youth, Adolescents and Working Children of Latin America and the Caribbean), which together with the NGO "Save the Children", among other entities, sponsors the *Revista Internacional de Niños y Adolescentes Trabajadores* (International Journal of Children and Adolescents).

In any case, what we want to highlight is that child labour effectively mobilises (bio) ethical issues, regarding the impact it may have on the psycho-physical development of the child in all its extension (health, leisure, schooling, sex differences ...); but also (bio) moral, related to the help that child labour provides to support the family economy, the acquisition of status in their community, the promotion of participation and recognition of children in economic, labour and political spheres, work as one of the values appreciated in their ethnic group, etc<sup>28</sup>; and, of course, (bio) policies, since the state has to regulate and harmonise (as far as possible) these areas (ethical and moral): from the demands of the minors themselves in favour of child labour, through care to the commitments acquired with international organisations, which restrict or directly prohibit child labour, efforts to enforce their own labour legislation with respect to minors, etc., always within their own political norm, aimed at managing the different areas and interests faced. The decision adopted by Bolivia to allow certain forms of child labour, and the national and international reactions it has aroused, reflect the controversial nature of the matter.

In relation to these issues, it should be said that there is no general criterion for deciding a priori between (bio) ethical, (bio) moral or (bio) policies when they come into conflict, which often happens in bioethics dilemmas. For this reason, it is always good to take into account an overview that is neither partial or biased, but rather a global view of the different elements that are combined. Recognising that the three normative dimensions involved can shed some light on the problem of priorities between certain conflicting values that affect individuals, social groups and public policies as well as the adjustment or conflict between the same bioethical principles<sup>1,2</sup>.

Thus, we can say that this issue, the conflict between (bio) ethical, (bio) moral or (bio) political, underlies and emerges in numerous current bioethical discussions, such as the debates between a bioethics based on the autonomy of the person, even if the person is a minor or those approaches that justify paternalistic practices on the part of parents and professionals<sup>30</sup>.

Indeed, there are authors and professionals in favor of prioritising a (bio) ethical point of view (in the restricted sense that we are pointing out here) which manifests itself in an attitude of promotion and respect for the "autonomous" decisions of the "mature minor" considered in his or her abstract individuality<sup>6</sup>. From this approach it is considered that, just as it happens with the adult person, the informed consent of the minor would constitute the maximum expression and effectuation of his or her autonomy. It is then stated that children's maturity is measured by the formal capacity to judge and assess situations and problems that are posed, not for the content itself of the assumed values<sup>21,22,31</sup>.

Other authors and professionals, on the other hand, would be more inclined towards an approach in which family, group or community relationships would constitute the reference area where relevant decisions are made and in which minors gradually acquire spaces of autonomy and competence to make their own decisions, as long as these decisions do not cause irreversible harm to the minor<sup>32</sup>. As we have said elsewhere<sup>33</sup>, this assumes a biomoral orientation, according to what we have been saying, by which "the doctrine of mature minor "has to be applied with certain cautions and restrictions. Specifically, two: one related to age and another to the type of decision. In general, minors under fourteen are not recognised as "mature". Likewise, its application to decisions in which minors could put their life or health at serious risk has been controversial, since it underlies the idea that if minors adopt a decision detrimental to their health, they do so because they don't have enough capacity to make decisions. Then the protective and backer action of the social group and the institutions prevails.

From what we have been calling attention about the bioethical discipline (in a broad sense) as understood by (bio) ethics and (bio) moral, as well as (bio) law or (bio) politics, it follows that "bioethics" "Is the norm of action that limits the power of the group in the name of personal" self-determination ", as the norm that sanctions the authority of the group or community, by which relatives, tutors or health and social care professionals participate in the important decisions that affect the minor<sup>6</sup>. An action that qualifies as paternalistic may constitute an example of maleficence when, effectively, it harms the self-determination and the personal development of the minor, but it could also be considered as an example of beneficence when it favours the development and well-being of the minor, by guiding

and channeling the minor's behaviour, and protecting and guaranteeing the minor's rights<sup>34</sup>.

The complexity of the factors involved demonstrates the fragility of the exacerbated emphasis on the autonomy of the individual since it does not consider the specificity of each case<sup>35</sup>. Thus it has been pointed out that: *The defense of autonomy must be accompanied by a reasonable paternalism that has as its purpose the promotion of the real autonomy of the most vulnerable people. This type of paternalism not only does not contradict the principle of autonomy, but turns out to be one of its conditions*<sup>36</sup>.

Discussions on these issues bring into play different conceptions of childhood within heterogeneous cultural and historical traditions as well as arguments and doctrines on bioethical principles and children's rights without a consensus on the matter<sup>37,38</sup>. Despite the fact that the rights of the child are a characteristic of our times from a political, social and cultural viewpoint. However, this does not mean that its rationale ceases to be a controversial issue<sup>39</sup>.

### Priority of the best interest of the child and participation in children's bioethics

It is not the objective of this work to pronounce on each of the bioethical problems, some of them serious, that affect childhood. But bearing in mind that this question can not be avoided either, given the pragmatic nature of bioethics, we do want to mention two general criteria of action that, despite the difficulty in deciding between (bio) ethical, (bio) moral or (bio) policies when they come into conflict, can serve as a guide and general guidance for decision making.

These two general criteria give priority to states and their policies in favor of children (without prejudice to the necessary support from other social agents). Here the policy acquires a greater depth, a greater emphasis because it must commit to take charge of matters of a primarily ethical nature. For an author such as Denburg<sup>40</sup>, the development of epigenetics together with the existence of sensitive periods in childhood development would be more than sufficient reason to adapt the reflection and bioethical practice to these scientific evidences. The author thus proposes to combine synergies between bioethics and human rights for the analysis of early childhood development policies. As has been pointed out: *all the rights of children and adolescents are "social" rights in the sense that their guarantee is essentially political and therefore, it is up to society as a whole to implement them*<sup>41</sup>.

Thus, as a general criterion, when the moral norms of the family or the preponderance of social or cultural customs or habits may involve harm to the child and can lead to serious harm, priority must be given to the rule that determines the safeguard and ethical integrity of the person of the child, as a practical realisation of the doctrine on integral protection and of the principle of the best interest of the child that appear in the UN Convention on the Rights of the Child<sup>42</sup>. The reason we see to adopt this criterion<sup>13</sup> relies on the fact that although the social group is an indispensable requirement for the survival and constitution of the child as a personal subject, there would be, in principle, the possibility of incorporating the child into other social groups (extended family, foster family, adoption, judicial or administrative protection) when their reference group (the nuclear family, for example) is unable or can't meet their basic needs. These are situations in which episodes of abuse are taking place or decisions are made that may be severe for the life and integrity of the child, such as certain forms of child labour. Social intervention in these cases is sanctioned by a public mandate, since it is the legal-normative framework, ultimately political, which establishes the force of obligation of professional ethics that must ensure the rights of the person of the minor<sup>43,44</sup>.

Also, and in light of new studies on children and recognising in children their progressive agency<sup>45</sup>, it is necessary that public powers promote the capacity to recognise the meaning, interests, expectations and abilities that the minors have in relation to their own life and the integrity of their health. The goal is to ensure that in the management of the sectors responsible for health and social protection at the service of children and adolescents there is room for the legitimate exercise of children and adolescents' participation, which requires that this participation be constituted as a real and effective experience<sup>14,31</sup>.

But always in a protective environment and taking into account the evolutive development of the minors, their abilities and their family and cultural environment. As some authors have pointed out, there is no reason to suppose that a minor, even if valued as capable, always wishes to exercise responsibility in making decisions, assuming that is an ethical detriment to the minor to be impelled to adopt an "autonomous" decision instead of deciding and sharing with family or friends<sup>46</sup>.

The development of children's participation has already an extensive theoretical and programmatic trajectory and has been translated into numerous practices and initiatives<sup>47</sup>. Most of the published

experiences on children's participation activities have been carried out in the school environment, in social and political movements or participation spaces, more or less regulated, such as municipal legislative bodies, etc. However, the information on this type of activities in areas related to health or child protection systems is not so broad. In relation to the theme of children's bioethics, it would be necessary to highlight proposals and concrete experiences in hospitals, community and research areas in health care. It is no longer just a matter of attending to the principle of children's participation established in the UN Convention on the Rights of the Child, but also that various evidences show that participation becomes one of the conditions that directly affect the improvement of integral health (bio-psycho-social) while contributing to the empowerment of children and adolescents in their communities<sup>48-52</sup>.

### Final considerations

Taking into account the question that we formulated at the beginning of our work about the meaning of children's bioethics in Ibero-America, we are in a position to affirm that it is pertinent to speak of a children's bioethics as a differentiated field within Ibero-American bioethical activity. We justify this conclusion, firstly and with a general character, taking into account the status of the child, as a differentiated reality with respect to other previous and subsequent evolutionary stages of life and, secondly and with a specific character, taking into account the situation and future challenges of childhood in Ibero-America, as well as the development and implementation of the bioethical discipline in the Ibero-American space.

The reflection and standard bioethics practice with minors has focused on informed consent, the clinical practices that entail and lead to ethical dilemmas, the legal regulation of research with children. That is, it has focused on the clinical context. But in the Ibero-American space, a more global, social and committed reflection and practice is necessary, in consonance with the debates on the existence and peculiarities of an Ibero-American bioethics. A bioethics that considers the bioethical, biomoral and biopolitical aspects that affect and impact childhood and is aware of their internal conflicts in order to seek ways of resolving them. And all this in a context of openness to children's rights and their consideration as agents involved in all areas of health and personal and community well-being<sup>53,54</sup>. Children's bioethics in Ibero-America must combine the originality of its own reflection and practice with children's differentiated status and rights.

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