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## Decisions about their Body: Children's Rights and Parental Responsibility in Chile

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### I. Introduction

The exercise of autonomy requires certain personal skills, including a minimum capacity for reflection and connection with one's own feelings, as well as several essential conditions such as having alternatives to choose from and a certain degree of freedom from interference from third parties. Notwithstanding any inadequacies in these capacities or conditions, we attribute normatively a basic autonomy to adults in recognition of their equal moral and political status.<sup>1</sup> But what happens in the case of children and adolescents? The United Nations Convention on the Rights of the Child views them as subjects of rights endowed with personality and progressive autonomy. This conception challenges classic regulations on the expression of the will of underage children in health and family contexts, as well as those referring to relations between parents and children. The models of substitution of will and parental authority have been only gradually replaced by more democratic ones in Latin America.

In Chile, the law, dogmatics and precedent on decision-making on health matters by underage children and possible collisions with the exercise of parental responsibility are inadequate. Moreover, existing regulations are unsystematic and, in many cases, contradictory.<sup>2</sup> Some limited analysis has emerged in the context of judicial proceedings when such issues arise, such as the regulation of emergency

<sup>1</sup>cf V Undurraga Valdés, 'Anticoncepción de Emergencia: Autonomía de las Adolescentes y Derechos de sus Padres' (2007) 3 *Anuario de Derechos Humanos*, Centro de Derechos Humanos de la Universidad de Chile 165.

<sup>2</sup>cf D Parra Sepúlveda, 'El Consentimiento Informado de Niños, Niñas y Adolescentes en el Ámbito Sanitario' in C Domínguez Hidalgo (comp), *Estudios de Derecho de Familia III* (Santiago de Chile, Thomson Reuters, 2018) 337–39.

contraception or applying laws with a strong value content, but, overall, the situation is particularly lacking when it comes to very young children. Furthermore, precedent does little to provide further analysis in resolving conflicts of this type. As a result, this chapter will address a number of cases and their interpretation by the most informed authorities.

## II. Patient Rights and Responsibilities in Chile

Article 17 of Law 20,584 on ‘Regulations on the rights and responsibilities of people in the context of actions related to their health care’, of 24 April 2012, addresses situations involving serious harm to health or risk of death, as well as the refusal to receive treatment or limit medical efforts. In both cases, the law assigns an important role to ethics committees.

Originally, this legislation included specific regulations for children and adolescents under the age of 18. The Presidential Message that accompanied the original text submitted to Congress for consideration noted that international law recognised children as rights-holders and alluded to respect for their psychological development, cognitive competencies and personal situation.<sup>3</sup> Although such regulations are absent from the final text, the general belief is that one of the principles underpinning this law is respect for underage children.<sup>4</sup>

Existing legislation fully reflects the status of underage minors when referring to questions about competency in decision-making. It is important to note that while minors are not necessarily, nor automatically, deemed incompetent, in our context, in which their autonomy is undervalued, a legal professional could easily claim incompetence. Something similar would probably occur in situations of babies with severe brain damage, such as the cases that inspired this book (*Great Ormond Street Hospital v Yates* [2017] and *Alder Hey Children’s NHS Foundation Trust v Evans and James* [2018] EWHC 308 (Fam)).

Furthermore, the legislation is based on the premise that children’s representatives are empowered to provide consent in their stead. If the decision of the person whose competency is called into question – or that of his/her representative – puts the patient at risk of serious harm to health or risk of death, which would be prudentially avoidable by following the recommended treatments, the opinion of the establishment’s ethics committee shall be sought. The same procedure is to be followed if treatment or medical effort are refused by the individual or his/her representatives. Article 17, subsection 2, second part establishes that if the opinion

<sup>3</sup> Chilean Library of Congress, ‘Historia de la Ley 20.584’, [www.bcn.cl/historiadela Ley/fileadmin/file\\_ley/4579/HLD\\_4579\\_37a6259cc0c1dae299a7866489dff0bd.pdf](http://www.bcn.cl/historiadela Ley/fileadmin/file_ley/4579/HLD_4579_37a6259cc0c1dae299a7866489dff0bd.pdf), 5. During discussions a note was made that the Bill failed to ‘sufficiently safeguard the rights of parents as regards their children ... and that debilitates the family’, 37.

<sup>4</sup> A Leiva López, ‘La Regulación de la Eutanasia, Según la Ley N° 20.584 Sobre Derechos del Paciente’ (2013) XLI *Revista de Derecho de la Pontificia Universidad Católica de Valparaíso* 528.

sought involves the care of minors, the committee must take into account the best interests of the child. This is the sole reference to this principle in the law. So, if the parents' decision puts the child at risk of serious harm, the doctors must refer to an ethics committee, which will determine what course of action is in the child's best interests.

The committee's decision can be appealed to the Court of Appeals for review and consideration. Furthermore, if the treating medical professional disagrees with the decision expressed by the person or his representative, he/she may declare his/her wish not to continue as the person responsible for the treatment, provided that said provider ensures that the responsibility will be taken on by another health professional.

This law solely limits the possibility of ordering involuntary treatments. Thus, if the representative does not agree to carry out the treatment recommended by the committee following the request for review posed by the physician, assuming that the committee has no power to compel such treatment, the only other option provided in the law is to allow the doctor or the committee (the law says 'either') to appeal to the Court of Appeals on behalf of the patient in an effort to secure a court order to proceed with the recommended treatment.<sup>5</sup> But, as in England and Wales, in Chile doctors cannot force them to; the courts can only authorise doctors to provide (or not provide) the treatment.<sup>6</sup>

Some observers have noted that in these cases the committee becomes a mediator for problems that have more to do with mistrust within the family than clinical ethics. While the committee can – and should – give its advice, turning to it should be the exception, not the rule.<sup>7</sup> These situations should primarily be resolved in the context of the doctor–patient relationship extended in these cases to include the patient's relatives.<sup>8</sup> While I agree with this approach for the most part, I disagree in that I believe that the decision is individual and, except when strictly necessary, the people closest to the child (who may not necessarily be family members) should not meddle in it.

<sup>5</sup> J Wilenmann Von Bernath, 'Lesión Punible e Intervención Terapéutica en un Incapaz de Consentir en el Derecho Chileno' (2017) 44 *Revista Chilena de Derecho* 229.

<sup>6</sup> In I Goold, C Auckland and J Herring, 'Medical Decision-Making on Behalf of Children in England and Welsh Law: A Child-Centred Best Interests Approach', in this book. Although there is no law expressly established by this prohibition, the Chilean Code of Medical Ethics establishes that the doctor from whom treatments are requested that go against his/her conscience or his/her clinical conviction may refuse to intervene. In these circumstances, he/she will ensure that another colleague continues to assist the patient, unless it causes serious and immediate damage to health of the patient (Art 20).

<sup>7</sup> In B Gray's chapter ('The Relevance of Cultural Competence to Resolving Disputes in Relation to Medical Decisions for Children') in this book, it is said that a clinician giving a second opinion could either see the role as reanalysing what is in the child's best interests, or they could instead function as a mediator, understanding what had undermined trust and relationships and facilitating the finding of a compromise. Similarly the role of clinical ethics support services vary as to how they approach their task.

<sup>8</sup> F Javier León, 'Información y Consentimiento Informado de Menores de Edad en Chile' (2012) 83 *Revista chilena de pediatría* 114.

Additionally, observers note that ethics committees appear to have powers of review even though it is not clear who the primary decision-making authority is. In addition, regarding the reference to the best interests of the child, although appropriate, it appears to be a particularly indeterminate principle. While establishing a decision by the representative or proxy that specifically allows for the treating physician to challenge such a decision, the regulation of medical challenge and third-party review is clearly contradictory: the challenge is filed with an advisory body lacking enforcement powers with its sole recourse against the recommendations emanating therefrom being the Court of Appeals. An ethics committee, rather than formulating a recommendation, has alternative decision-making powers, ie the power to review the patient's decision – or the parent's decision – and the one submitted by the physician.<sup>9</sup>

### III. Latin American Context

In Chile, the opinion and decision of parents are not in general contested by anyone – not society, not government agencies – since it is presumed that the parents know the life history and needs of their child best (except in cases of neglect or serious violation of the child's rights). In the medical field, however, discrepancies may occur more frequently, since it is the doctors who are, in principle, in the best position to determine the most appropriate treatment for the child, insofar as they are trained to make decisions about a patient's health on the basis of scientific criteria. The role of the parents would be to confirm or authorise, through their consent, the decision taken by medical professionals.

However, if the parents and doctors disagree, the law seems to give priority, in principle, to the decision of the parents, unless this puts the child at serious risk. Indeed, as noted above, according to the law, if the decision puts the child at risk of serious harm, the doctors must refer to an ethics committee which will determine what course of action is in the child's best interests. The committee will reason on the basis of the best interests of the child, and not on the basis of parental authority or medical judgement.

In the case of very young children, this situation becomes more complex as they do not have sufficient autonomy to express their own opinions or to give informed consent for the treatment in question. The information that parents can provide about their child, and especially their willingness to care for that child and to provide the best context for successful treatment, are essential to determine the child's chances of improvement. One could say that the physician is best

<sup>9</sup> Wilenmann Von Bernath (n 5) 218. The power of challenge to which this author alludes refers to the fact that it is not the physician who has the capacity/competence/power to decide which medical interventions are carried out on a patient. In the case of children, they have the power because they are the patient; the primary decision falls to the parents.

placed to decide based on the child's clinical needs, but what about the child's best interests overall?

Chilean jurisprudence does not yet reflect cases involving very young children. That said, on 14 May 2009, the Court of Appeals of Valdivia ruled on an unprecedented case having to do with an 11-year-old boy who refused chemotherapy that offered a 40 per cent survival rate.<sup>10</sup> The mother supported her son's decision. The Court noted that:

[T]he coercive action of the State can be well justified when the refusal of medical treatment of a minor meets the following test: the disease or condition is assuredly curable or holds a high statistical likelihood of cure; and, that does not cause physical or psychological deterioration of the patient in such a fashion that would compromise his essential dignity as a person, or that intolerably affects his quality of life. *If these circumstances occur with respect to a minor and his parents refuse treatment, that refusal shall not be deemed reasonable, in which case it shall fall to the State to intervene to safeguard the life of the child.* The aforesaid notwithstanding, in all other cases absent these conditions, the State must retreat and allow *the family*, with sufficient information provided in the context of the doctor–patient relationship, to make the decision that best suits its belief system, previous experiences, values, perception of what life is worth living, and understanding of what is best for them to exercise their right 'to live life'.<sup>11</sup>

In Argentina, the parents of young children always decide for them, in their capacity as legal representatives. But the limit of the parents' decision is the best interests of the child; the state can intervene if that interest is contradicted. Courts in Argentina have heard some cases involving very young children.<sup>12</sup> In 2006, faced with an action brought by the parents of a newborn with trisomy 18 seeking to avoid artificially prolonging his life, the court found that:

[T]he assessment by third parties in truly extreme situations entails an undue invasion of the sphere of privacy of the persons directly involved – in the case of co-patients – whose decision has been taken in the sphere of conscience and in accordance with reasoned convictions.<sup>13</sup>

<sup>10</sup> Rol 103-2009 FAM.

<sup>11</sup> *ibid*, Considerando 15 (emphasis added).

<sup>12</sup> Under Art 26 of the Argentine Civil Code, minors exercise their rights through their representatives. However, if they are of sufficient age and maturity, they are recognised as being able to exercise their rights themselves in acts permitted by law. In the case of adolescents between the ages of sixteen and eighteen, the person is considered an adult in matters pertaining to their healthcare. In addition, it is presumed that between the ages of thirteen and sixteen they are able to decide on non-invasive treatments; for invasive treatments that jeopardise their health or pose a serious risk to their life or physical integrity, consent must be given by the parents. (In cases where the parents disagree, medical experts must decide in the best interests of the child, taking into account the consequences for the child's life if the treatment is or is not performed.) It has been noted that, with regard to children under these ages, there is a degree of legal ambiguity due to provisions in the Argentine Constitution and international human rights treaties. (See G Gabriel Carranza and C Elizabeth Zalazar, 'La Autonomía de la Persona Menor de Edad en la Toma de Decisiones Sobre su Propio Cuerpo: Cuerpos Normativos en Argentina' (2019) 36 *Revista de Derecho Privado* 51.

<sup>13</sup> MdCM y NAA Juzgado en lo Correccional N° 4 de Mar del Plata, 27 December 2006.

Although in this case there is no dissent between doctors and parents, the ruling is interesting because it highlights the role of parents in these complex situations. On the other hand, in another case involving the vaccination of very young children, the court ruled that parental refusal should not stand because of the rights of third parties would be compromised, as would the best interests of society overall.<sup>14</sup> Similarly, in a case involving a child under eleven years of age who had suffered from an untreatable chronic neurometabolic condition since the age of three, the court found that the treating physicians should provide palliative care, provide for the child's physical and spiritual comfort, alleviate his suffering and facilitate the quality of his remaining life, but ordered that he not be admitted for invasive treatments. In this regard, the ruling upheld the parent's wishes.<sup>15</sup>

In Colombia, the Constitutional Court has stated that, as a general rule, the parents or legal representatives of children and adolescents must provide authorisation for any medical procedure or treatment. This is known as 'substitute consent'. However, this consent does not represent an absolute power because parents are not in fact able to make all medical decisions on behalf of their children. With regard to the capacity of children and adolescents to make decisions about medical procedures,<sup>16</sup> the Court has ruled that the application of the concept of parental 'substitute consent' varies depending on the age of the child and their intellectual wherewithal. Therefore, such consent will carry more weight when children are young than when they are closer to the age of majority, for example.<sup>17</sup> The Constitutional Court set important criteria in a 1999 ruling on an eight-year-old child's gender identity case and that test has been reiterated in subsequent decisions.<sup>18</sup> In that case, the Court concluded that since there was no obvious risk that the right to life of the child would be compromised if the sex-reassignment operation was not carried out, the mother could not authorise the surgery and hormonal treatments for her daughter.

The Court found that:

[T]he importance of family privacy in the development of pluralism has an impact on the ability of judges to exclude parents from making certain medical decisions on behalf of their children. ... [I]n the medical field there is also a certain pluralism, since there is no single way of dealing with ailments, so the displacement of parents by state authorities in healthcare decisions about their children should, in principle, be avoided.

Indeed, invoking the principle the Court calls *in dubio pro familia*, the ruling suggests that although the need and urgency of the treatment, its impact and risks,

<sup>14</sup> FS de BÑ y RNS de B Superior Tribunal de Justicia de la Provincia de Jujuy, 12 July 2016.

<sup>15</sup> Juzgado de Familia, Niños y Adolescencia N° 2, Neuquén, 20 March 2016.

<sup>16</sup> T-474-96. Art 14 of Act 23 (1981) provides that: 'A doctor shall not operate on minors, unconscious persons or mentally incompetent persons without the prior authorisation of their parents, guardians or close relatives, unless the urgency of the case requires immediate intervention.'

<sup>17</sup> T-1021-03.

<sup>18</sup> T-551-99, T-692-99, T-1021-03.

and the age and maturity of the child must be taken into account, there is also an element of closure involved that the Court describes as follows:

If the judge has lingering doubts about the proper decision, such questions must be resolved in favor of the respect for the privacy of the household and, therefore, displacements of parents by state authorities must be minimized.

It should be noted that Colombia is the only Latin American country that regulates child euthanasia. Resolution 825 of 2018, in compliance with a 2017 ruling of the Constitutional Court,<sup>19</sup> regulated the procedure to make the right to die with dignity effective for minors, including conditions for access to the euthanasia. The law recognises the right of children between the ages of six and twelve years with terminal illness or condition to opt for this procedure provided that: (i) they have achieved an exceptional level of neurocognitive and psychological development that allows them to make a free, voluntary, informed and unequivocal decision in the medical field; (ii) their understanding of death reaches the level expected for a child over the age of twelve.<sup>20</sup> In the case of children six years of age or older who have already given their consent in keeping with the law and are unable to repeat it, the substitute consent of the parents shall be admitted.<sup>21</sup>

This regulation is germane because when referring to pediatric palliative care, it states that if the child or adolescent lacks the capacity to make medical decisions, the individual who exercises parental authority or is otherwise responsible for care may refuse treatment and request that the principles of therapeutic proportionality and rationality be observed. They may also deny the application of treatments and clinical interventions that are futile or disproportionate given the patient's condition or that may result in dysthanasia or therapeutic obstinacy. The law also authorises such individuals to refuse paediatric palliative care.<sup>22</sup>

#### IV. Spotlight on the Children

The treatment afforded to the representative's consent is complex because it depends on politically and ideologically controversial decisions: parental responsibility and the limits that the state may establish for its exercise. In ascertaining the conditions under which adults may intervene on behalf of children, at least two conflicting values are in play: the extent of parental rights vis-a-vis state agency, and the decision-making autonomy granted to minors vis-a-vis their parents.<sup>23</sup>

<sup>19</sup> T-544-17.

<sup>20</sup> Art 3. This resolution suggests that, from the age of twelve, the concept of death 'is linked to the capacity for abstraction from which the understanding is achieved that everyone, including one's self, is going to die, sooner or later. In spite of this, death itself is perceived as very distant; there is a critical period of acceptance and fear of what may happen before [death]' (Art 2, [2],[3],[4]).

<sup>21</sup> Art 11.

<sup>22</sup> Art 6.

<sup>23</sup> Wilenmann Von Bernath (n 5) 224.

In the area of healthcare decisions, it has traditionally been understood that the legal representative is tasked with providing consent on behalf the minor. This tradition is now being replaced thanks to practices that redefine both the relationships between doctors and patients and between family members. In some Latin American countries, including Chile, the wishes of the patient are now included as a core tenet in the practice of medicine. In contrast with that, however, the Roman law model of *patria potestas* has not yet disappeared. The delayed enactment of an array of international instruments due to prolonged dictatorships, among other factors, has hampered the transition towards societies that are more democratic and respectful of the rights of the child across the region. As a result, with rare exceptions – such as we have seen in Argentina<sup>24</sup> – the statutes fail to address the issue of legal representation of the child when his or her most fundamental rights are affected.

To what extent and in what way does a child consent to an intervention or treatment? What role do their parents, legal representatives or caregivers play in this? What role do healthcare professionals play, especially when the patient him/herself refuses consent, is too young to consent, or in cases of a difference of opinion between parents and children? Finally, what role does the state play in these controversies and how does it ensure respect for the rights of the child without disproportionately limiting the rights and responsibilities of parents? All of these questions remain unanswered in Chilean law.

In bioethics,<sup>25</sup> the distinction between beneficence and non-maleficence has been shown to solve many adult issues, but in the case of children it poses a bigger challenge. Very young children do not have their own system of values, nor can they therefore define their own beneficence. On the other hand, the state cannot intervene directly in the determination of a child's value system, pushing him or her towards a type of life or determining the child's idea of good (beneficence). In fact, it can only address the child's non-maleficence. The question then arises as to how to determine the content of beneficence. The issue is one of the so-called 'decisions of substitution'. According to the classic model, substitution decisions were always made by projecting on the legally unfit person what the family, the doctor, the judge or society as a whole considered to be to the benefit of this individual. Today, this is not possible, since society cannot and should not determine the benefit to an individual but, rather, only protect him or her from harm. Some laws provide that such decisions are, in principle, the responsibility of the family. The reason for this is probably that the family is, at its root, a charitable institution. The role of the state is to ensure that parents do not overstep their limits and – under the pretext of promoting the best interests of their children – are not acting to their children's detriment, that is to say, maleficently. The doctor, moreover,

<sup>24</sup> See n 12.

<sup>25</sup> D Gracia, Y Jarabo, N Martín and J Ríos, 'Toma de Decisiones en el Paciente Menor de Edad' (2001) 117 *Medicina Clínica* 183.



should not be the one to define a child's beneficence. Despite deeply rooted traditions granting such power, that approach today must be deemed incorrect.

Therefore, those representatives who have the primary power must act and decide according to the best interests of the child or the adolescent, independent of their own beliefs. What happens if that fails to occur? A well-designed system should regulate the measures professionals can take, such as requesting the intervention of an ethics committee, or alternatively that of a judge. This is especially important for cases of subrogation of the will of very young children: the professional should be particularly attentive to the position of the representatives if it is contrary to the child's best interests.<sup>26</sup>

<sup>26</sup> Factors to consider include: whether the illness or health of the patient will improve with the medical treatment; whether the illness or health will improve without the treatment; whether the benefit the person can expect from the treatment is worth the risks of the treatment; and whether a less restrictive or less invasive treatment could provide the same benefit as the proposed treatment. See S Fernández 'Responsabilidad parental y autonomía progresiva de niñas, niños y adolescentes' in S Fernández (dir), *Tratado de Derechos de Niños, Niñas y adolescentes* Tomo I (Abeledo Perrot Buenos Aires, 2015) 685.

