

**Opinion no. 44 of 23 June 2008 on
growth attenuation in severely
mentally disabled children**

**Request for an opinion made on 25 January 2007
by Mr R. Demotte, Minister for Social Affairs and Public Health
concerning growth attenuation in severely mentally disabled children**

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1. Delimitation of the object of the Opinion

The Minister for Social Affairs and Public Health asked for the Advisory Committee's opinion on surgical or pharmacological growth attenuation in severely mentally disabled children, with a view to facilitate contact with these children (girls or boys) when they reach adulthood. More especially he raises the question as to whether such practices are compatible with the protection of these particularly vulnerable children.

In the Minister's question the Committee recognises the problem posed by the "Ashley case". This case arose when the parents of a severely mentally disabled girl made a request to the doctors of a children's clinic in Seattle, in the United States. Her physicians described the case as follows, in a scientific publication they devoted to it in 2006¹:

Ashley is a girl aged six years and seven months who was originally referred to the paediatric endocrine ward on suspicion of a hormonal disorder because she was beginning to show premature signs of puberty (*pubertas praecox*). This disorder is characterised by the premature appearance of secondary sexual characteristics (breast development and growth of pubic hair) and a premature puberty growth spurt, although the final length is below normal, since the growth cartilage discs close earlier than normal². After her first month of life she began to present symptoms of hypotonia³, feeding problems, choreic⁴ movements and general development retardation. The diagnosis of static encephalopathy⁵ was made. The patient never developed mentally beyond the level of an infant. She cannot sit up straight, run or use language, is gastrostomy-dependent for feeding, but does react to others: she makes noises and smiles in response to care.

At the time of referral to the paediatric endocrinology ward, she had growth of pubic hair since one year and her mammary glands had been developing for three months. The parents were above all concerned about accelerated growth, because the patient had advanced from the fiftieth to the seventy-fifth percentile of height, in a period of six months⁶.

¹ D. F. Gunther, M. S. Diekema. Attenuating Growth in Children with Profound Developmental Disability. A New Approach to an Old Dilemma. Arch Pediatr Adolesc Med 2006; 160: 1013-1017.

² The various options in Ashley's case were: 1. To treat the *pubertas praecox* – as is done in most cases of *pubertas praecox* – to keep the premature puberty in check, but to increase the eventual physical height, 2. To opt for the chosen hormonal treatment, which in fact further accentuates the *pubertas praecox* due to the administration of extra female sex hormones, or 3. Not to intervene and "let nature take its course", which automatically leads to a smaller final stature.

³ A neurological disorder accompanied by reduced muscle tone (what is referred to as the "floppy child" or "floppy infant" syndrome).

⁴ Swift, powerful movements that seem coordinated but are made involuntarily.

⁵ Unchanging or permanent brain damage.

⁶ Statistics on the age/physical height ratio can be used to calculate growth curves, for a particular population, which reflect physical height in function of age. So the median line will be the curve that reflects that 50% of children are under a certain physical height for their age. By analogy with the median (or the fiftieth percentile line), the 5th, 10th, 15th, etc. percentile line indicate the height for the age under which 5%, 10%, 15%, etc. of the children are to be found. An individual's move between percentile lines can be used to reflect growth acceleration or retardation in respect of age. In the space of six

The parents were particularly concerned about the impact that accelerated growth would have on the possibility of continued home care, the risks of entrusting her nursing care to third parties, and the consequences of puberty, more especially the imminent commencement of menstruation.

After consultation with the parents, the doctors devised a treatment plan to attenuate growth using high doses of oestrogen. At the same time a preventive hysterectomy was suggested. The plan was approved by the hospital's medical ethics committee.

The website set up by Ashley's parents⁷ refers to the "Ashley treatment" as also including the surgical removal of the mammary glands before the beginning of the hormonal treatments, and a preventive appendectomy⁸.

In accordance with the Minister's question and the special characteristics of the Ashley case, the Advisory Committee limits the Opinion to the surgical and pharmacological (in particular hormonal) treatment aimed at growth attenuation of children with very serious, irreversible and combined neurological and cognitive development disorders.

The surgical interventions that form part of this so-called Ashley treatment only relate to girls. Analogously, in the case of boys, hormonal growth attenuation with male sex hormones can also be considered.

The Opinion is more particularly limited to children with a severe mental disability, of such gravity that the development of self-image or self-awareness is missing. This does not mean that there is no consciousness, but rather that the patient is unable (1) to form an image for himself/herself of the way in which he/she is viewed by others, (2) to gear self-perception to the expectations of third persons. This means that the patient is not able to recognise himself/herself in one or other role (the role of child versus adult, a sick or disabled person versus a "normal" person, a family member versus a stranger) and does not define himself/herself in one of these terms, either. The patient is therefore not aware of illness, disorder, specific relationship with others, the fact of remaining small, etc. It is assumed that this kind of self-awareness is missing under the mental development age of one year.

However, the specialists interviewed by the Committee stress that the lack of such self-awareness does not rule out the possibility of there being a neurological and mental development capacity present, which is related to the quality of life experienced by the patient. More particularly, various forms of capacities can be distinguished that appear out of step (e.g. a learning level of six months, a communication level of one and a half years, and an even better interaction level, which nonetheless never reaches the level of linguistic interaction). A certain evolution can also be seen in perception, which becomes rather

months Ashley thus moved up from a point where 50% of the children of her age were smaller than her, to one where 75% of the children were smaller than her. She therefore belonged to the top 25% in her age category in terms of size.

⁷ Ashley's Mom and Dad. The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels". http://ashleytreatment.spaces.live.com/blog/cns!E25811FD0AF7C45C!1837.entry?_c=BlogPart

⁸ There is a 5% risk of the development of appendicitis in the population at large. The parents feared that Ashley would not be able to communicate the pain of an appendicitis to her carers.

broader, in the sense that as they grow older the patients will react differently to music and visual stimuli than they used to.

2. Justifications for the “Ashley treatment”⁹

The standpoints of Ashley’s parents and doctors give an almost complete overview of the standpoints in favour of growth attenuation, which are listed below. Although these “pro” arguments are partly linked to the specific healthcare situation in the USA and to the individual patient, Ashley herself, they nevertheless have a general scope and can, *mutatis mutandis*, shed light on the Belgian situation. Some supporters make a distinction between the hormonal treatment with the aim of growth attenuation and the surgical interventions, and deem the first group to be admissible, and the second inadmissible (see below, in section 6, for a more in-depth discussion of that distinction). Others feel that both kinds of intervention are justified.

More specifically, the following arguments are cited in defence of growth attenuation by means of hormonal treatment:

- a certain convenience in home care and institutional care when it comes to the physical handling of severely mentally disabled persons, certainly those attaining a substantial body weight.
Weight reduction makes it possible for the parents and other voluntary care workers to assume the responsibility for home care in less awkward circumstances;
- the advantages of direct and personal contact with the carers instead of via equipment;
- a small stature is not a disadvantage for people who will never be able to act as adults;
- improved possibility of moving the patient, with a considerable impact on his/her health and welfare (participation in activities and social meetings, etc.);
- less risk of infections (pneumonia) and bedsores;
- delay in the development of scoliosis;
- the risk of thrombosis due to oestrogen treatment is acceptable, because it is comparable in size to the risks of hormonal menstruation and pregnancy control in the population at large;
- in minors who are able to give their consent and who risk becoming “too big” in puberty¹⁰, hormonal growth attenuation is an accepted treatment. The number of people qualifying for this treatment in Belgium is put at 50 to 100 cases per year¹¹. Growth attenuation in children with a very severe mental disability thus extends a widely accepted practice to other cases.

⁹ We use the term “treatment” here as a neutral descriptive term, without wishing to suggest that there is a legitimate therapeutic end underlying the “Ashley treatment”.

¹⁰ The generally accepted criterion in Belgium is 1.80 metres for girls and 2 metres for boys.

¹¹ Estimate made by Dr. J. De Schepper, Paediatrics, Endocrinology and Diabetology, University Hospital of Brussels.

The following points of view are advanced in favour of surgical interventions:

As regards hysterectomy:

- prevention of the discomfort, pain, cramps and bleeding associated with the menstruation cycle;
- if hormonal treatment is given, hysterectomy reduces the discomfort of the bleeding that this treatment entails;
- prevention of the risk of uterine cancer;
- pregnancy prevention in the event of rape.

As regards appendectomy:

- the preventive treatment of the risk of appendicitis, a risk affecting 5% of the population at large.

As regards removal of the mammary glands:

- freedom from the inconvenience of fully developed breasts;
- prevention of sexual abuse.

According to those who advocate them, these treatments are in the patient's interest. To support their position, they also invoke the following general arguments, which apply both to surgical and hormonal interventions:

- the adaptation of the patient's appearance to his/her mental age provides him/her with more dignity and integrity than the possession of the body of an adult man/woman;
- the treatment leads to a greater correspondence between the patient's physical appearance and his/her mental age, as a result of which social expectations of the adult are better adapted to his/her real capacities.

Ashley's parents opted for this non-conventional treatment out of a heartfelt concern to give their child the best possible prospects of being dealt with in a decent and dignified manner when she was older. In most cases, for that matter, it is the parents who are best placed to decide in the interest of their child. They have the legal and moral responsibility in this respect.

3. Arguments advanced by the opponents of the “Ashley treatment”

Ashley is de facto (and also legally) unable to give informed consent, which means that for the exercising of her rights she is dependent on her representatives, in this case her parents. On the basis of the literature consulted and interviews with experts, it has been possible to construct the following overview of the main arguments against the way in which Ashley’s parents have exercised their authority and against the way in which the doctors have used their medical skills¹²:

3.1. Violation of bodily integrity

Many commentators point out that the “Ashley treatment” is highly invasive. The hormonal treatment has a major impact on Ashley’s appearance and weight. The surgical operations have irreversible – and what some term “crippling” – consequences.

3.2. Failure to appreciate the child’s interest

Some argue that the parents and the doctors have not taken Ashley’s interests sufficiently into consideration, if at all. For example, not enough is known about the risks of thrombosis associated with a long-term hormonal treatment. In their article on Ashley, Gunther and Diekema do look into the issue of the scale of those risks, but in fact concede that too little is known about it to enable reliable conclusions to be drawn.

Others point to the disadvantage that a severely mentally disabled adult can experience when he or she is treated as a child. Even though the patient is not aware of the difference between a child and an adult, that consciousness is present among carers, who gear their actions to their own perception of the patient. Account should thereby be taken of the fact that talking of mental age is misleading. There is nothing enabling us to conclude that the states of awareness clinically characterised as a mental age of one year correspond to the states of awareness of a one-year-old infant. Moreover, there is the fact of a certain differentiation in the development of severely mentally disabled persons (see above), which means that the possibility of the “Ashley treatment” stopping certain real, albeit limited, development opportunities, and amounting to what one author termed “identity theft”¹³, cannot be ruled out.

Others still argue that it is impossible to assess the interest of a severely mentally disabled person, certainly when account is taken of the risks inherent in the treatment and the uncertainty as to the patient’s further development and his/her perception of that development. There is no knowing how someone like Ashley will experience her condition in twenty years’ time. Taking account of such a lack of knowledge and certainty, the decision to proceed with growth attenuation should not be allowed.

¹² Some arguments are also recognised in the article by Gunther and Diekema (see note 1).

¹³ N. Gibbs, *Pillow Angel Ethics. Part 2. Time*. Tuesday, January 09, 2007.

3.3. Irrelevance of the care providers' interest

Many media commentators feared, with reference to the Ashley case, that “convenience” was the real reason for Ashley’s treatment. The question is whether the convenience of the carers can form a basis for good care for persons with a severe mental disability. As is well known, there is nothing to prevent people using “Ashley treatments” in order to reduce the high price of home care for the parents, reduce the costs of institutional healthcare, or prevent violence by aggressive people with a severe mental disability.

3.4. Incompatibility with human dignity

Mutilating someone’s body by surgery or deliberately keeping them endocrinologically small (“infantilising”) robs the person of their human dignity. This argument can be formulated from both an objectivist and a subjectivist standpoint. In the first case it is assumed that “dignity” is an objective fact, which is imperative without any additional subjective conditions being linked to it for the person (such as self-awareness, linguistic skill, capacity to reflect and reason, etc.). This standpoint is well represented in legal literature, but it is also found in ethical literature. The idea here is that dignity is essential to the person concerned, who represents the category to which he/she belongs; it is consubstantial with human nature and social perception¹⁴.

In the second case, the subjectivist standpoint, the view is that growth attenuation generally speaking gives others an idea of what it means to suffer an attack on one’s human dignity. It is pointed out that severely mentally disabled children such as Ashley cannot suffer from an attack on their dignity, because that concept is beyond the reach of their intellectual faculties, but that others could experience the manipulation of the appearance of mentally disabled persons as degrading. The two approaches can thus lead to the idea that the “Ashley treatment” is incompatible with human dignity. Just because it is assumed that someone is not aware of an attack on his/her dignity, does not mean that that attack, *in se* or in the eyes of others, does not exist.

¹⁴ The best-known case in jurisprudence is the famous case concerning “dwarf throwing”, which has led to the French Council of State ruling – in the context of assessing whether prohibition of this attraction was legal – that using a person with a physical disability, who is presented as such, as a projectile, denigrates human dignity on account of the very object. For this reason it was not important that the dwarf involved in the case in question had not run any risk of serious injury and had given his consent, because for him this was a source of income and social recognition. Respect for his dignity (and by extension that of all dwarves) is obligatory for him and this fundamental requirement thwarts his consent (CE fr., ass., 27 October 1995, *D.*, 1996, jur. 177, note by Lebreton, , *J.C.P.*, 1996, II, 22630, note by Hamon, *RFD adm.*, 1995, 1024, concl. Frydman, *Petites Affiches*, 24 January 1996, note by Rouault). In the same sense we can cite the ruling of the Paris Court of Appeal of 28 May 1996 (*D.*, 1996, jur. 617, note by Edelman) concerning an action against an advertisement by Benetton, which showed parts of the human body, branded with the stamp “HIV”. In the absence of any specific normative text enabling it to ban these posters, the Court of Appeal judged that Benetton “had symbolically humiliated and stigmatised people, resulting in an attack on the dignity of these people, who were already stricken in body and soul, which could lead to their ostracism or an increase in their suffering”, whereby it is not important whether they had given their consent or not.

3.5. Interruption of a natural process

Some argue that the development to puberty and adulthood is a natural process, which, due to this natural characteristic, is best left uninterrupted. By way of a reminder: as far as Ashley's case in particular is concerned, she suffered from "pubertas praecox", a hormonal disorder in which premature signs of puberty manifest themselves. This disorder is characterised by the premature appearance of secondary sexual characteristics (breast development and the growth of pubic hair) and a premature puberty growth spurt (although in the end the final length is shorter than after a "normal" puberty, since the growth cartilage discs close earlier than normal). The various options in Ashley's case were 1. To treat the *pubertas praecox* – as is done in most cases of *pubertas praecox* –, to keep the premature puberty in check, but also to increase the eventual physical height; 2. To prescribe the chosen hormonal treatment which in fact further accentuates the *pubertas praecox* due to the administration of extra female sex hormones; 3. Not to intervene and to "let nature take its course", which automatically leads to a smaller final stature.

The view that "letting" something happen, even though the process can be reversed, is justified, whilst "doing" something which has the same result (or to further reinforce the result) is not admissible, has also been advanced by the experts who were interviewed. Although some were reluctant vis-à-vis deliberate growth attenuation in severely mentally disabled patients, in the case of *pubertas praecox* in severely mentally disabled children, which automatically leads to a smaller final stature, they would let this take its course.

3.6. Danger of the slippery slope or of improper use of the treatment

Allowing hormonal growth attenuation in severely mentally disabled children with *pubertas praecox*, or allowing preventive surgical interventions, would open the door for the practice to be extended to cases not falling under the original strict limitations. The argument is usually advanced in combination with the argument that reasons of convenience on the part of the carers may not constitute the underlying considerations for interventions such as those involved in the "Ashley treatment". For the sake of convenience, the frontier can quickly be pushed back to take in less seriously mentally disabled persons. The ultimate objective is to customise the patient in function of the possibilities and problems of the care provider. Hence the importance of a strict definition of the initial diagnosis.

4. Ethical considerations in the socio-political field concerning the "Ashley treatment"

4.1. Disadvantages of exclusive home care

Ashley's parents and physicians deny de facto that reducing Ashley's body weight by an estimated 40% actually serves their own convenience. As a matter of fact they argue that this

convenience is actually in Ashley's interest, because that is the only way of making high-quality home care possible. Some healthcare specialists interviewed by the Committee put forward an important counter-argument that has hitherto not been found in the literature on growth attenuation. The exclusivity of home care can sometimes be to the detriment of very seriously mentally disabled patients, to whom a variety of care situations proves more helpful. Part-time home care and part-time admittance, ambulatory care and institutional care, should be in a suitable proportion. Such a combination can not only lighten the duties of the voluntary care worker, but also meet the concern for the future of the child with a disability, once the voluntary care worker is no longer in a position to look after the patient himself/herself. If growth attenuation is part and parcel of an objective to have the child cared for exclusively at home, it may harm the long-term interest of the disabled child.

4.2. Unwanted social consequences

Various commentators draw arguments from the socially undesirable consequences of generalisation of the "Ashley treatment". In this view, the "Ashley treatment", an invasive and burdening method for the patient, is a problematic response to the demand for extension of social care. Medicine in this way helps shift responsibility for care from the society or community to the patient and his/her direct voluntary care providers. Surgery and hormonal treatment then replace the extension and improvement of the capacity for care in the broad social field.

Allowing the "Ashley treatment" could also lead to a paradoxical strengthening of the effects of financial inequalities between patients. Where the financial resources are available, and home care is therefore more probable, the bodily integrity of the children could be violated more quickly than in cases where, for financial reasons, children are more likely to be referred to institutional care.

Another unwanted social consequence sometimes cited is the fact that the "Ashley treatment" is totally at odds with a social and political trend towards emancipation of disabled persons. This trend consists in disabled and non-disabled persons being treated as equally as possible, except where this is not possible. The "Ashley treatment", on the other hand, permits practices to be carried out on mentally disabled persons which would be regarded as inadmissible were they performed on non-disabled persons. This could imply a form of improper discrimination.

5. Legal framework

5.1. Therapeutic purpose of the treatment and patient's consent

There are no legal provisions at all permitting or prohibiting the practices we are looking at, either expressly or implicitly. Given that this is a medical act, the legal analysis must be based on the provisions and principles of medical law. In this respect, two aspects deserve our attention.

Firstly, the requirement of a *therapeutic purpose*, which is of course one of the conditions for the admissibility of any medical act¹⁵. This objective must be observed and tested in respect of the child with a disability himself, on whom the treatment is carried out, and not – even implicitly – in respect of his parents. This appears to be the most important point.

It is recognised that the concept of therapeutic purpose should be viewed in a broad sense and may include all forms of welfare, both physical and mental. However, assessing this requirement proves to be an extremely delicate matter in the context of the practices we are looking at, given that the children involved cannot express themselves and considerable uncertainty exists as to the potential risks and effects of the treatment in the medium or long term. It cannot generally be stated that such treatments are necessarily salutary *for the child* that undergoes them. The doctor and the team that have to ascertain whether or not there is a therapeutic purpose should therefore be extremely prudent. From a legal point of view it is not the parents' interest that should take precedence, but the benefit that can genuinely be expected for the child himself/herself, which has to be assessed as accurately as possible, even though from a human standpoint the parents' wellbeing has a direct effect on the child.

Secondly, the vital importance of the *patient's consent* (Article 8, 1st para., of the law of 22 August 2002 on patients' rights, referred to hereinafter as "the law"). A typical characteristic of this case is that the patient is unable to express himself, and never will be. As a child, he falls under parental authority and his parents are the doctors' interlocutors and speak for him (Article 12, para. 1 of the law). Later, he will in all probability be placed under the status of extended minority (Article 487*b et seq.* of the Civil Code), i.e. he will continue to be equated with a minor as far as his person and his goods are concerned, on account of his serious mental retardation¹⁶, and consequently will remain under parental authority, in respect of medical matters (Article 13, para. 1 of the law). When the parents die, this patient's rights – except where there is a guardian – are exercised with reference to Article 14, para. 2 of the law. If there are no close family members, "the doctor himself acts in the patient's interests, as the case may be in multidisciplinary consultation". The importance of such multidisciplinary consultation, at all stages, cannot be emphasised strongly enough in the context of the proposed treatment. For that matter, this consultation is recommended in Article 4 of the law.

5.2. Human dignity and right to respect for physical integrity

In addition, the practices we are examining should be viewed from the dual viewpoint of the right of the child with a severe disability to respect for his human dignity, on the one hand, and respect for his physical integrity, on the other.

¹⁵ Leleu Y.-H. and Genicot G., *Le droit médical*, Brussels, Larcier/De Boeck, 2001, 18, no. 12; Dorsner-Dolivet A., *La responsabilité du médecin*, Paris, Economica, 2006, 28-139, *passim*; Swennen F., Legal principles for the criminal immunity of the physician, specifically the requirement of therapeutic purpose, *Rev. dr. santé*, 1997-1998, 3.

¹⁶ Described in Article 487*b*, para.2 of the Civil Code as "a state of mental deficiency, which is innate or commenced during early childhood, and is characterised by non-development of the joint capacities of power of reason, feeling and will". On this status, see Leleu Y.-H., *Droit des personnes et des familles*, Brussels, Larcier, 2005, 190-197.

The *dignity of the human person* is a “framework concept” that should be treated with circumspection given its vague and *a priori* non-legal content. Every patient has the right to respect for his human dignity (Article 5 of the law), which is also guaranteed by Article 23 of the Constitution: “Everyone has the right to lead a dignified life”, but then in the explicit and specific context of economic, social and cultural rights. The Constitution thus considers this as a right of a political nature and not a right of the person which can be renounced in specific terms with a view to interventions on the body¹⁷. Human dignity does not appear in the European Convention on Human Rights (ECHR), although it innervates all the guarantees provided for therein, but it does appear in the International Covenant on Civil and Political Rights¹⁸, in particular in Article 10. It is expressly mentioned in the Convention for the Protection of Human Rights and the Dignity of the Human Being in relation to the application of biology and medicine¹⁹. In the assessment of the practices under examination, the notion of human dignity can evidently be invoked both by the advocates of these practices and by their opponents, which reveals that we are dealing with an ambiguous concept. Given that the practical legal impact, barring a few special hypotheses, is limited, it is difficult to rely on this general notion to judge the legitimacy of the practices under examination, at least from a legal standpoint.

The higher right to respect for *physical integrity*, which is a strictly personal and wholly fundamental right of the person, in the sense that also people suffering from dementia, people with a severe disability, people in a coma and people in a chronic vegetative state enjoy this right, whereby their rights are exercised and the guaranteeing thereof is overseen by third parties, who inevitably have a delicate role and must show moderation and prudence. This is expressed in various ways in positive law, but its source must first and foremost be sought in various supranational instruments²⁰.

¹⁷ In France, on the other hand, Article 16 of the Civil Code (inserted by means of the first law on bio-ethics no. 94-653 of 29 July 1994) prescribes the following as a fundamental rule: the law guarantees the primacy of the person, prohibits any violation of his dignity, and guarantees the respect of his human being from the beginning of his life. Protection of the dignity of the human person against any form of subjection and humiliation is a principle with a constitutional value (Cons. Const. Fr., 27 July 1994, *D.*, 1995, jur., 237, note by Mahieu, *D.*, 1995, somm., 299, obs. Favoreu). The notion of human dignity is considered to be a fundamental source of medical law, whereby the doctor’s duty to inform his patient is based on the requirement of respect for the constitutional principle of protection of human dignity (Cass. Fr., 1^e civ., 9 October 2001, *D.*, 2001, 3470, report by Sargos, note by Thouvenin, *J.C.P.*, 2002, II, 10045, note by Cachard, *Petites Affiches*, 6 December 2001, note by Clément and 13 March 2002, note by Marmoz, *RTDciv.*, 2002, 176, obs. Libchaber).

¹⁸ Signed on 19 December 1966 in New York and approved by the law of 15 May 1981. This text does not have any direct effect and although sometimes it is worded more accurately, it is less intensive than the European Convention on Human Rights, which in general takes precedence and from which it takes most of the provisions. Article 10 concerns the rights of persons who are deprived of their freedom, and states that they should be treated “with humanity and with respect for the dignity inherent in the human person”.

¹⁹ Convention on Human Rights and Bio-medicine, signed on 4 April 1997 in Oviedo. This convention is not binding for Belgium, which has not ratified it. Article 1 determines that the signatory States should protect people’s dignity and identity and must guarantee anyone, without discrimination, that his integrity and his other fundamental rights and freedoms are respected as far as applications of biology and medicine are concerned.

²⁰ For an overview of these texts, see Delfosse M.-L. and Bert C., *Bioéthique, droits de l’homme et biodroit* [“Bio-ethics, human rights and bio-law”], Brussels, Larcier, 2005.

The most important general source of this law is Article 3 of the European Convention on Human Rights²¹, which states that nobody may be subjected to torture or inhuman or degrading treatment. Together with the right to life, which is guaranteed by Article 2, this provision contains a protective dimension, a prerogative of opposition²². According to the European Court of Human Rights this Article 3 upholds one of the basic values of democratic societies and contains an absolute prohibition²³.

The Court of Cassation recalled, in an important ruling dated 14 December 2001²⁴, that every person enjoys these rights and that they include the right to life and to *physical integrity*²⁵. The latter implies that the patient, and he alone, must give the consent needed for the admissibility of a medical treatment that violates his physical integrity. The court decided that the obligation on the part of the doctor to obtain this consent is alien to the agreement binding the parties, which immediately explains why the doctor has the obligation to provide the patient with sufficient information on the intervention he is planning to carry out.

5.3. UN Convention on the Rights of Persons with a Disability

A *Convention on the Rights of Persons with a Disability* was concluded at the United Nations headquarters in New York on 13 December 2006. The convention was signed by Belgium on 30 March 2007 and came into force internationally on 3 May 2008²⁶. In 50 articles, this text discusses various general principles, including “respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities” (Article 3, h). As such this text does not have any “automatic” legal impact, but requests the States party to the Convention “to undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the grounds of disability” and, in particular, to

²¹ Signed on 4 November 1950 in Rome and approved by law of 13 May 1955.

²² Article 7 of the International Covenant on Civil and Political Rights is the reflection of this provision, with the following addition: “In particular nobody may be subjected to medical or scientific experimentation without his freely given consent”. The right to respect for privacy, family life and domestic life, which is guaranteed by Article 8 of the ECHR and Article 22 of the Constitution, also contains a physical and psychological dimension.

²³ This in contrast to other provisions to which delimited and controlled exceptions are possible in certain circumstances. It follows from this that the (positive) obligation rests on States to take measures aimed at preventing persons falling under their jurisdiction from being subjected to treatments that could be described as inhuman or degrading, even if they are applied by private individuals (ECHR, Main Chamber, 10 May 2001, *Z. versus the United Kingdom*, indictment no. 29392/95 on the protection of severely abused children).

²⁴ Cass., 14 December 2001, *Pas.*, 2001, 2129, concl. Du Jardin, *J.L.M.B.*, 2002, 532, note by Leleu and Genicot, *J.T.*, 2002, 261, note by Trouet, *R.G.A.R.*, 2002, no. 13.494, *T.B.B.R.*, 2002, 328, concl. Du Jardin, note by Trouet, *Rev. dr. santé*, 2001-2002, 239, note by Fagnart.

²⁵ On the rights of the individual, and in particular the right to life and the right to respect for physical integrity, see, as part of an extensive bibliography, the summaries of Leleu Y.-H., *op.cit.*, 95-121; Terré F. and Fenouillet D., *Droit civil. Les personnes, la famille, les incapacités* [“Civil law, the family, and disabilities”], Paris, Dalloz, 7th ed., 2005, 54-95; R. Cabrillac, Le corps humain, in *Libertés et droits fondamentaux*, [“Fundamental freedoms and rights”], aforementioned, 157-169; Velu J. and Ergec R., *R.P.D.B.*, v, European Convention on Human Rights, compl. t. VII, Brussels, Bruylant, 1990, 207-233.

²⁶ This text and various additional information relating to it are available on the website <http://www.un.org/disabilities>. It establishes a Committee for the rights of persons with a disability (Articles 34 to 39), to which an optional additional Protocol is devoted, which was also signed by Belgium and came into force on the same date.

undertake to “adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention”, and “to take all appropriate measures (...) to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities” (Article 4).

This important Convention does not expressly prohibit the practices under examination, but forms the canvas on the basis of which the legal and social situation of persons with disabilities should henceforth be examined. In relation to children, Article 7 states that “the States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children”, that “in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration” and that the States Parties “shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right”. The Belgian law of 22 August 2002 on patients’ rights tallies with these requirements.

Article 15 of the Convention recalls that “no one shall be subject to torture or to cruel, inhuman or degrading treatment or punishment” and adds, wholly in line with Article 7 of the United Nations Covenant on Civil and Political Rights, that “in particular no one shall be subjected without his or her free consent to medical or scientific experimentation”. Article 17 protects the right of persons with disabilities to “respect for his or her physical and mental integrity, on an equal basis with others”.

Article 25, concerning health, recognises, in respect of persons with disabilities, “the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” and requests the States Parties to “take all appropriate measures to ensure access for persons with disabilities to health services ..., including health-related rehabilitation”. This involves in particular providing persons with disabilities with “the same range, quality and standard of free or affordable health care and programmes as provided to other persons”, and providing “those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons”. Healthcare experts must provide “care of the same quality to persons with disabilities as to others” and more especially “on the basis of free and informed consent”. The States Parties will meet these requirements by “by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities, through training and the promulgation of ethical standards for public and private health care”.

5.4. Other provisions

There appear to be *two other texts* of substantial importance for the legal concept of the problem under examination. Firstly, the Belgian constitution contains an article (Article 22*b*) which reads as follows: “Every child has the right to respect for his moral, physical, mental and sexual integrity”. This right should be guaranteed by law or by decree. It should be noted that the right to physical integrity *is generally speaking not explicitly* guaranteed by the Constitution, but *is for children*. The degree to which the practices under examination are compatible with this higher legal rule causes questions to be raised, although this rule, introduced by the review of the Constitution of 23 March 2000, does not as such have any direct effect or specific consequences. This provision appears hitherto not to have led to any specific commentaries and in jurisprudence seems only to be applied in disputes relating to the right of residence of an underage alien who has been living in the country illegally with his parents, or to the social or material assistance provided to these persons²⁷. This right could also be appealed to in the case of minors who have committed offences and in the framework of the criminal protection of children, in particular against sexual exploitation.

Secondly, the Convention on the Rights of the Child²⁸ contains a series of guarantees that are useful in understanding the situation of children in the medical field, in particular its Article 23 on children with mental or physical disabilities. These children “should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community” and have a “right [...] to special care”. The State must promote and ensure the provision of assistance to these children and those caring for them, seeing to it that this assistance is appropriate in light of the child’s condition and the circumstances of the parents or others looking after the child. This assistance “shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities, in a manner conducive to the child’s achieving the fullest possible

²⁷ It was deemed that for reasons of human dignity and in accordance with the provisions of the New York Convention of 20 November 1986 on the Rights of the Child, the under-age children of aliens residing illegally in our country are entitled to social assistance, which goes beyond urgent medical assistance and consists in them being clothed, fed and housed decently (Rb. Antwerp, 24 May 2004, *T. Vreemd.*, 2004, 365). This constitutional provision was also applied in the case of a Somali family which demonstrated that genital mutilation is still practised in Somalia today on a vast majority of young girls and that this risk, which is already very high pursuant to local customs, is further aggravated by the critical situation prevailing in the country, with a general climate of insecurity. On top of this there is the fact that applicants for refugee status who are repatriated are forced by those around them to prove their “reintegration” by respecting local customs. The court regards it as irrefutable that such practices constitute a serious inhuman and degrading treatment, against which the child should be protected pursuant to Article 22*b* of the Constitution and Article 3 of the ECHR, and that this justifies the Somali girl not being able to be sent back to the country on account of *force majeure*, seeing as the right to peaceful family life there is not guaranteed. The refusal of a residence permit or removal of her mother (who cannot return in the company of her daughter, given the risks the latter runs) would mean a violation of her right to respect for family life which is disproportionate to the legitimate objective pursued by the Belgian State, namely immigration control. The mother therefore does not have to comply with the order served upon her to leave the territory for reasons of *force majeure*, and is therefore entitled to social assistance (Arb.rb. Brussels, 17 February 2005, *J.D.J.*, 2006, 44).

²⁸ Signed on 20 November 1989 in New York and approved by law of 25 November 1991. Some provisions of this text which are sufficiently accurate are deemed to have a direct effect in domestic law, although there is some dispute over this point.

social integration and individual development, including his or her cultural and spiritual development”.

These two texts strengthen the protection of the rights of children with serious disabilities as regards their physical integrity and dignity, albeit in a general and not highly effective way. These higher requirements should form the criterion for the assessment of the admissibility of the practices under examination, in the ambitious framework of the United Nations Convention of 13 December 2006.

6. Discussion

Although the Advisory Committee makes a number of critical comments in the Opinion concerning the so-called Ashley treatment in general, it is in no way the intention to pass judgement specifically on the Ashley case itself. The Committee has every respect for the decision taken by the parents and for the opinion on the case that was issued by the competent medical ethics committee.

The Committee has reached an ample consensus on the problem at hand. It is pointed out that as regards the “Ashley treatment” a distinction needs to be made between the hormonal treatment and the surgical interventions. The latter, after all, are *preventive* invasive techniques. They protect the child against possible harm in the future, e.g. pregnancy, uterine cancer, appendicitis, inconvenience caused by breasts, sex attacks by third persons, and so on. The hormonal treatment, on the other hand, is the only method that can be used to achieve growth attenuation. This growth attenuation is aimed at maintaining or improving the individual child’s current wellbeing. There is no less invasive alternative to this.

6.1. Surgical interventions usually do not serve the child’s interest

The grounds for surgical interventions in the case of persons with a severe mental disability should be the same as for other patients. They should meet standard criteria, and should weigh up the benefits against the risks and disadvantages. If they are considered as preventive measures, a check should first be made to ascertain whether there are any less invasive alternatives, which for that reason would be preferable. For example, the American College of Obstetrics and Gynaecology (ACOG) has stated that a hysterectomy may only be considered for the treatment of menstrual symptoms and hygienic problems of menstruation in girls or women with mental disabilities if all other reasonable alternatives prove not to be effective enough²⁹.

The Advisory Committee certainly does not rule out invasive treatments in persons unable to give informed consent, with a mental age of less than one year. As a rule such interventions should aim at a justified goal proportional to the remedy, if they are not to constitute violations of physical integrity. Although the principle was not expressed in explicit terms, this

²⁹ http://www.acog.org/from_home/publications/ethics/co371.pdf

was the tenor of the standpoint adopted by the Advisory Committee on the sterilisation of persons unable to give informed consent or express their own view³⁰. That opinion deemed sterilisation in such cases sometimes to be justified to protect the family interests and educational opportunities of children born further to a person with a mental disability falling pregnant. *Mutatis mutandis* invasive interventions other than sterilisation could be admitted, provided they are sufficiently in the interest of the mentally disabled person himself/herself.

It should be pointed out that the interests of persons with a severe mental disability are in large measure specific. With the exception of the interests that everyone has in the protection of his life, food and shelter, a person's interests are also closely connected to the wishes, needs and abilities that that person has. For example, a person with a serious mental disability has no interest in ensuring his/her access to the job market, higher education, or free choice of partner, etc. In Ashley's case, her parents and doctors assert that since she cannot know that she is a girl, or what is "normal" for an adult woman, she is not harmed when some of her secondary sexual characteristics are removed or when she is deliberately kept small. In other words, because she does not have the intellectual and emotional capacity to see herself as a member of a group, or to make comparisons between her own appearance and that of others in the same group, she also has no interest in obtaining the size of an adult woman.

The question of whether or not surgical interventions serve the interests of a severely mentally disabled person can therefore only be answered satisfactorily if there is clarity as to the scope of the abilities, wishes and form of perception of persons with a severe mental disability. Generally speaking these people do not have the capacity for self-reflection and self-awareness that other people have. But what levels of experience determine the interests they have?³¹ It is clear that they can have perceptions (they are "sentient beings") and are at least able to experience feelings of desire and aversion. This capacity means that they can in fact be harmed by a treatment and that their interests must be respected by the prevention of unnecessary physical and psychological suffering. Their capacity to perceive desire and aversion is revealed, among other things, by the fact that the children in question for example know that they are being touched and that they can find this more pleasurable as they get older. By intonations in the sounds they make, they can indicate what they find agreeable and what they do not.

But there also appear to be more complex cognitive functions present than the mere capacity to experience desire and aversion. Children with a severe mental disability are for example clearly able to forge a bond with their carers. These children are, as one expert interviewed by

³⁰ Opinion no. 8 of 14 September 1998 on the problem of sterilisation of mentally disabled persons (see www.health.fgov.be/bioeth, click left on "Opinions").

³¹ There is a whole continuum of positions within ethics: at one extreme some make the capacity to enjoy interests and rights as a human being dependent on conditions of (self)awareness; at the other extreme there are those who base those interests and rights on the mere fact of belonging to the species *Homo sapiens*.

the Committee put it, “connected to the world through the body”. This form of perception can be stimulated and lead to stable forms of “proprioception”³² and perception of others.

It is also pointed out that the physical condition of these patients often also conceals the little development potential they possess. As a rule they suffer from several disabilities and the mental retardation is accompanied by epilepsy (in 50% of cases), motor disability (quadriplegia, hemiplegia), heart problems, lack of toilet training, lack of language development, etc. Yet there are adult persons with a mental disability and a development age of less than one, who ride a bicycle. Some bedridden children are able to follow a route in a wheelchair by pressing on a button. They react to bright sunshine by directing the wheelchair towards the shade. The resources we have today to adequately test the sight and hearing capacity of these children, for example, were not available in the past. It was recently shown that a simple correction in the strength of the glasses they wear can open up a whole world to them.

These children also have ascertainable benefits as regards their wellbeing and development in the functioning in a group (going to school, for example, or being admitted to an institution, which is the rule among these children at a slightly later age).

It can be deduced from these observations that the interests of persons with a very severe mental disability go further than the simple capacity to perceive sensations. They also go through a certain development, albeit it very modest, as a result of which they have an interest in the guaranteeing of what that development allows: social contacts, appliances that correct physical handicaps, institutional care, and so on. The fact that there is little reliable data on the precise nature of the development these children can undergo means that a certain prudence is called for before it is concluded that the proposed interventions are not detrimental to their interests.

In the light of these data, the surgical interventions associated with the “Ashley treatment” appear mostly to be insufficiently in the interests of children with a severe mental disability, except where specific medical reasons dictate. After all, the patient’s relationship with his/her body can also be checked or altered by invasive surgery, which is accompanied by the formation of scar tissue and pain.

The fact that seriously mentally disabled persons almost always suffer from more than one disability also means that they have to undergo numerous interventions (for example of a gastrointestinal nature, operations on the spinal column and the adductors) and mostly react with fear to the hospital environment. Exposing them to surgical treatment therefore causes a major additional stress, when it is known that persons with a severe mental disability are particularly vulnerable to stress. On top of this there is the physical burden associated with these interventions, and the fact that frequent periods of immobilisation are detrimental to their motor development.

³² The ability of an organism to perceive the position of its own body and parts of the body.

The Committee is of the view that for the patient all these negative experiences seldom counterbalance the benefit represented by the prevention of certain risks by the surgical interventions. The benefits of a preventive intervention (e.g. appendectomy) are small because there is a real chance that, by feeling pain, these children will express themselves and capture the adults' attention. The preventive removal of the appendix therefore does not really appear justified. However, there are conceivable cases in which the benefit is real. A hysterectomy could be considered when the psychological or hygiene problems associated with menstrual blood loss signify too great a burden.

6.2. Hormonal growth attenuation can be acceptable in some cases

Matters are more complicated as regards hormonal treatment. It has already been pointed out that growth attenuation is applied in the case of competent minors. An analogy with the existing practice of growth attenuation, with the limitations and reservations applicable to it, can therefore be appropriate in the case of severely mentally disabled children.

For example, it is plausible for hormonal growth attenuation to be considered in some cases, in the event of the expected excess growth being very considerable, not only in the general interest of the patient as regards maximum mobility, contact with others, and so on, but also for specific health reasons.

There is also the possibility of the patient's weight taking on such proportions as to exceed the usual standards for patient manipulability in institutional care. In such cases the use of growth attenuation for reasons of convenience is acceptable, in the view of some members of the Committee, who regard the "growth attenuation" remedy as justified in order to attain the goal of "weight reduction".

If growth attenuation is considered in children in respect of whom no excess growth is expected, careful consideration should be given to the question of whether the decision is in fact in the child's interest.

Some members feel that there should be no intervention in a natural process such as *pubertas praecox*, which eventually leads to a smaller size, and have objections to a hormonal treatment actively being set in train to attain this goal.

Other members regard it as contradictory for the effects of "natural" hormonal processes in keeping the person small to be allowed to have effect, even though these can be curbed, whereas achieving the same effect by deliberately setting in train the same hormonal processes should be prohibited.

The justification of hormonal growth attenuation should in any case be decided on a case-by-case basis³³. The treatment can be indicated if some health risks are substantially greater for the patient than for others in the same population.

In every treatment the patient's interest should take precedence. Convenience for the carers may not be the decisive reason for growth attenuation. Should this be the case, unacceptable conclusions would soon be drawn. After all, weight reduction can not only be achieved by (sometimes) letting nature take its course or by giving a hormonal treatment, but for example also by means of the amputation of limbs. The irreversibly immobile patient, it could be reasoned, does not use his/her legs, and so these can be amputated. The argument could be extended to persons who do not have a mental disability but only a physical disability. Such a practice of modification of the body for the convenience of the carers would obviously be subject to the informed consent of the person in question. A second condition is that at least a proportional contribution to the patient's welfare is required. This could consist in better institutional and/or home care.

Hormonal growth attenuation can also meet other purposes: financial savings and the prevention of violence committed by the person with a disability.

However, some members feel that modification of the body cannot in itself be a justified means of reducing financial costs or promoting the carers' safety. Allowing this would amount to a far-reaching instrumentalisation of the patient's body for ends that have nothing to do with the interests of the patient himself, and this would be incompatible with human dignity.

If consideration is given to hormonal growth attenuation, the Committee refers to the suggestions made in Opinion no. 8 of 14 September 1998, for an interdisciplinary team to be set up, in which the patient's parents/legal representatives would also be involved. According to the Opinion the interdisciplinary team should consist at least of one doctor (general practitioner or paediatrician), a social worker or nurse, and an educationalist or psychologist. In these cases it would be advisable for the team to be extended to include specialists from other fields, e.g. a psychiatrist and/or an endocrinologist. The competent medical ethics committee could play a major role in this consideration.

Finally, the Committee points out that the argument of identity theft (variant of point 3.2.) could possibly be unfounded. There is a consensus that the mental age of less than one year does not enable the person to develop self-awareness or a sense of personal identity. This means that these children cannot be "injured" by being treated as children, and for that reason they cannot be personally injured, either, by having some of their secondary sexual characteristics removed. On the other hand, some specialists point out that adults with a clinical mental age of one year do not necessarily have the state of awareness of a one-year-

³³ S. Matthew Liao, J. Savulescu, M. Sheehan, The Ashley treatment: Best Interests, Convenience and Parental Decision-Making. Hastings Center Report 2007, 2; 37: 16-20.

old infant, which means that a prudent approach needs to be adopted when interpreting the perception possibilities of these people.

6.3. No medical solution if quality of life can be guaranteed by increased social services

The Committee nonetheless points out that a connection exists between the relative acceptability of arguments of convenience and the social and political context in which the care is provided.

The decision taken by Ashley's parents was in part driven by the limited possibilities they had of providing their child with full-time home care once she got bigger, a situation that can often arise. In the context of US healthcare³⁴ the "Ashley treatment" appears to be an emergency solution in the absence of more - and more varied - care. In this kind of context the arguments of convenience seem less susceptible to criticism. The lack of healthcare resources means that two evils have to be weighed up, where "keeping the patient small" can be seen to be a lesser evil compared with the harm that larger size and weight would cause the child.

Broadly speaking the Committee acknowledges that care can be limited due to considerations of a just and fair distribution of social resources across the entire healthcare sector. However, it is of the opinion that in the specific case of children with a severe mental disability, the resources made available should offer the parents sufficient alternatives, so that they are not forced to opt for growth attenuation to make satisfactory care possible.

As a general guideline, the Committee therefore advances that invasive medical interventions and growth attenuation in a child who does not risk becoming excessively big should be absolutely forbidden if the patient's quality of life can be protected as well, or even better, by arranging for more care services. Account is taken here of the precondition that the social costs of increased care must remain affordable. After all, we are dealing here with quite a small group, so the additional costs of maintaining the care at a level at which physical interventions on the body are unnecessary, are rather small.

Allowing treatments of the Ashley kind to become current practice would moreover shift responsibility for the care of children with a severe mental disability from the political/social level to that of individual decisions taken by direct care providers. That would be a socially undesirable development. The specialists who were consulted pointed out, as far as home care in particular is concerned, that shifting care entirely to the home situation is usually untenable for the voluntary carers. Both the parents and any brothers and sisters of the severely mentally disabled child usually do not have the capacity to assume responsibility for

³⁴ The moving of children with a disability from institutional care to the home situation is a health objective that should be attained by 2010, according to the American Academy of Pediatrics (Johnson, C.P., Kastner, T.A., Committee/Section on Children With Disabilities, American Academy of Pediatrics, Clinical Report - Guidance for the Clinician in Rendering Pediatric Care, PEDIATRICS, 2005; 115: 507-511).

that care on their own in the long term. As was said earlier, a combination of care situations – home care and institutional care – is desirable.

7. Recommendations

7.1.

The Committee advises against Ashley-type treatments³⁵ as a general guideline for dealing with children with a very severe mental disability, more especially because the expected benefits for the patient are not proportional to the invasive nature of the treatment. This applies in particular to the surgical interventions forming part of this treatment. The Committee is of the view that surgical interventions are admissible when there are specific grounds for them, but feels that less invasive methods should be chosen in preference to more invasive ones. When it is difficult to accurately weigh up the benefits against the risks, and in particular when the risks are unknown, the utmost prudence should be used. The Committee opposes preventive surgery based on risks in the population at large.

7.2.

The Committee feels that hormonal growth attenuation can be justified in exceptional situations; these should be carefully assessed on a case-by-case basis. This assessment should be based first and foremost on the child's best interest.

7.3.

Decisions on this matter should be taken by a multidisciplinary team. The opinion of the hospital's medical ethics committee is very important in this decision-making process.

7.4.

The Committee is of the opinion that the care of persons with a disability is a collective social good and therefore a social responsibility. It is important to see to it that the parents - who are the people with ultimate responsibility for their child's welfare - and other voluntary carers receive enough social support so that they do not have to resort to a medical solution.

³⁵ By way of a reminder: this concerns the treatment of a very severely mentally disabled girl aged six years and seven months, who was showing the first signs of *pubertas praecox*. The treatment consisted of growth attenuation by means of the administration of high doses of oestrogen, on the one hand, and a hysterectomy and the surgical removal of the mammary glands prior to the hormonal treatment, on the other. A preventive appendectomy was simultaneously performed.

This opinion was prepared by the select commission 2007/1, consisting of :

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Experts consulted

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The **working documents of the select commission 2007/1** (request for opinion, personal contributions of the members, minutes of meetings, documents consulted) - are stored as Annexes 2007/1 at the Committee’s documentation centre, where they may be consulted and copied.

This Opinion is available on www.health.belgium.be/bioeth
