

# Ethics of Management of Gender Atypical Organisation in Children and Adolescents<sup>1</sup>

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**Abstract** Atypical gender identity organisation (AGIO) is a serious medical condition in which the phenotypical appearance is experienced as alien by the person affected. AGIO is source of great distress, and obtaining medical treatment is for many a life-or-death matter. Many of those who cannot receive treatment are at high risk of suicide. AGIO is not only a problem of personal health, but also a public problem, because sufferers are often exposed to discrimination, abuse and violence, and each act of discrimination, abuse and violence is a public issue. Thinking about AGIO represents a great challenge for us all. It involves rethinking about gender identity in a more comprehensive way, inclusive of phenomena that go beyond the classic gender divide 'male-female', and thinking of ways of ensuring all citizens, whatever their gender identity, a secure and peaceful place in society. I explain what AGIO is, how it manifests itself, and provide a brief history of AGIO. I offer an overview of risks and benefits of available treatments. I analyse the ethico-legal issues that surround AGIO. In particular, ethics of interfering with natural development, competence in minors, validity of informed consent, role of the family, moral and legal responsibility of professionals for omission of treatment and ageism. I conclude that medical treatment should be offered, even to minors just after the onset of puberty, if the child has a profound and persisting AGIO, if she/he is competent to make a judgement on the matter, and if treatment is likely to enhance his/her quality of life. Deferring treatment till adulthood is not a morally neutral option, and it is indeed unethical, if the child is likely to be harmed by pubertal development.

**Keywords** Gender identity disorder, suspension of puberty, acts/omission, ageism, competence in minors, informed consent, international guidelines for treatment of gender identity disorder

*Imagine how you would feel if, tomorrow morning, you were to wake up to find yourself in a male body, with a man's voice and a man's face looking back at you from the mirror, with early morning beard and moustache stubble, with no breasts,*

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<sup>1</sup> Part of this chapter relies on Giordano (2008a, b).

*an Adam's apple, large male feet and hands, a body covered in thick, black hair and a penis and testicles. [...] Do you think that you'd feel as if you were going crazy? [...] This terrible thing has happened to me and it is worse than you could ever imagine* (A patient, personal communication)

## Introduction

Atypical gender identity organisation (AGIO—term first used by Di Ceglie 1995, Chapter 2) is a 'rare condition in which individuals experience their "gender identity" as being incongruent with their *phenotype* [physical appearance]. The personal experience of this discomfort is termed *gender dysphoria*. In its profound and persistent form, it is known as *transsexualism*' (GIRES et al. 2006).

In many cases, the discomfort begins in childhood. Between 40 and 70 new children a year are referred to specialised clinics in the UK, whereas the University Hospital in Gent (Belgium) reports seeing one new child a week, and the numbers of applications seem to be growing exponentially (De Sutter 2006, personal communication).

AGIO is not just a problem of private health. It has important public repercussions. Growing in a body that is experienced as inappropriate is for many sufferers terrifying and intolerable, and taking whatever step is necessary to undergo transition to the other gender is for many a life-or-death choice. Many of those born in areas of the world where early treatment and sex-change surgery are unavailable emigrate clandestinely in countries where they will be able to transition to the other gender; they may become prostitutes in order to pay for reassignment surgery, thus exposing themselves to HIV, STDs, imprisonment, violence and abuse. Sometimes, in order to survive in the cold winter nights on the pavement, they resort to heroin, thus again adopting criminalised behaviours and exposing themselves to life-threatening conditions (Farias 1994). Even those who do not need to emigrate often do not receive timely medical treatment, and end up buying hormones off the illegal market and injecting them at unregulated dosages and without medical supervision and monitoring. Transgender people are also particularly at risk of abuse and violence. At school, bullying towards children with unusual gender/sex orientations is common practice (GLSEN 2005; see also 'Information for Schools', at [www.gires.org.uk/Web\\_Page\\_Assets/frontframeset.htm](http://www.gires.org.uk/Web_Page_Assets/frontframeset.htm)), and homophobic bullying has severe long-term effects (Adams et al. 2004; Grossman and D'Augelli 2006). There have even been cases of children killed by their peers by reason of their atypical gender identity (Di Ceglie 2000, p. 466). Transgender adults are also at high risk of violence; it is reported that 39 transgender people were killed in 2003 in brutal ways (December 4, 2003, issue of *Workers World* newspaper <http://www.workers.org/ww/2003/trans1204.php>). It cannot be claimed that these people choose risky lifestyles and willingly expose themselves to violence: Those who do not receive treatment are left without recourse, and 'people without recourse are not free' (Korsgaard 1993, p. 59).

Medicine now offers means to help children and adolescents with AGIO, and thus help to limit discrimination, ill health and criminalised behaviours. These are

puberty suppression, cross-sex hormones, surgery and, of course, psychological support. Cross-sex surgery is nearly invariably offered only to adults (one known exception is Natalia, from Argentina, who convinced the Courts to grant her permission to obtain cross-sex surgery at the age of 17; El Mundo, www.elmundo.es). However, if AGIO is tackled early enough, when the child has not yet completed pubertal development, he or she can be assisted in his/her gender development in a monitored and supervised way, with great advantages in terms of physical and psychological health as well as social functioning. With puberty suppression and administration of cross-sex hormones, children and adolescents would be spared the anguish of developing an unwanted body and could explore their real gender identity under medical supervision. This would protect them from taking hazardous steps to obtain medical help from non-medical sources and from spiralling down into depression, suicidality and even in the criminal system. Later they could undertake much less invasive surgery, as puberty suppression would prevent development of unwanted body characters of the biological gender, which only invasive surgery can remove.

Treatment of children and adolescents with AGIO is surrounded by important ethical and legal issues (see *Re Alex [2004] FamCA 297*. Reserved files—by Court Order the File Number and names of Counsel and Solicitors have been suppressed—narrate the long and heart-breaking story of Alex, who underwent a long and complex court case, at the age of 13, to receive early treatment). In order to understand whether it is ethical to offer treatment to minors with AGIO, it is necessary to clarify what AGIO is, what the condition of those affected is and the benefits and risks of available treatments.

I will argue that there are strong ethical reasons to suspend the development of children with profound and persistent AGIO at early stages of puberty, if deferring treatment exposes the child to great suffering and harm. It is important to bare in mind that many untreated children would rather take their life, and indeed try to take their life, rather than growing in the alien body. Considering the devastating effects of spontaneous development for these children, I suggest that, in order to assess the ethical legitimacy of puberty suspension, the overall welfare of the child needs to be considered, and not just the potential risks and benefits of the medications. If the child is competent to make a decision on the matter, if treatment is likely to prevent psychological suffering, to reduce painful, costly and more risky treatments in adulthood, to improve the patient's physical, psychological and social adaptation and to promote a overall better quality of life for the patient, treatment should be offered. Far from being an 'ethically neutral option', deferring treatment in these cases would be unethical.

### Brief History of AGIO

Gender identity disorder was first included in the DSM-III in 1980. The notion of transsexualism is also relatively recent. Harry Benjamin, an endocrinologist who worked in New York, introduced it in the 1950s. Although the nosology is recent, AGIO as always been part of human history (Mills 2006):

*God, said the Jewish chronicler, created man in his own androgynous image – 'male and female created he them', for in him both were united. Mohammed on his second coming, says the Islamic legend, will be born of a male. Among Christians, Paul assured the erring Galatians, there was no such thing as male or female – 'all one person in Christ Jesus'. The Hindu pantheon is frequented by male-female divinities, and Greek mythology too is full of sexual equivocations, expressed in those divine figures who, embracing in themselves strength and tenderness, pride and softness, violence and grace, magnificently combine all that we think of as masculine or feminine.*

*[...] The Phrygians of Anatolia [...] castrated men who felt themselves to be female, allowing them henceforth to live in the female role, and Juvenal, surveying some of his own fellow-citizens, thought the same plan might be adopted in Rome. [...] Hippocrates reported the existence of 'un-men' among the Scythians: they bore themselves as women, did women's work, and were generally believed to have been feminized by divine intervention. In ancient Alexandria we read of men 'not ashamed to employ every device to change artificially their male nature into female' – even to amputation of their male parts. (Morris 1974, pp. 35–38)*

*The Night*, sculpted by Michelangelo (Di Ceglie 1998b, p. 185), represents someone with both male and female attributes. In the representation of *The Night*, gender ambiguity is pictured as nearly a dreamy state.

Although gender ambiguity has always been part of human history, arts and mythology, western medicine has been caught unprepared to provide help to those who need to deal with the discordance between their gender identity and their sex characteristics. Jan Morris, who sought assistance for transition to the other gender in the 1950s, tells us of expensive and fruitless trips to Harley Street in London, visiting psychiatrists and sexologists:

None of them – she wrote – knew anything about the matter at all, though none of them admitted it. [...] Could it not be, they sometimes asked, that I was merely a transvestite, a person who gained a sexual pleasure from wearing the clothes of the opposite sex, and would not a little harmless indulgence in that practice satisfy my, er, somewhat indeterminate compulsion? Alternatively, was I sure that I was not just a suppressed homosexual, like so many others? (Morris 1974, p. 40)

Gender ambiguity struggles to find space among our mental categories (on this see Connolly 2003). The default assumption seems to be that a person is either a man or a woman, and that if a person transitions to the other gender he or she will then unequivocally belong to the other gender. This, however, is not the case for many people. Many of us live in a *chiaroscuro*; there are female and male parts to our selves, and gender identity for many of us includes both of these parts. The polarisation male/female fails to mirror the reality that many people experience—where they have male and female facets and they cannot force their identity to one or the other gender. Alice Dreger writes:

Some people really are born male by all conventional standards and really do end up with the gender identities of women. And vice versa. And some people's gender identities really do seem to change over time. Moreover, some people never settle into a simple male or female gender identity. But all these people are forced by the revisionist history required by the state and most of the medical profession and everyone else to tell only the 'man trapped in a woman's body' or 'woman trapped in a man's body' story. 'They got my sex

wrong at the start' is the only story that seems to be acceptable. Okay, you can be trans, but only if you cooperate in changing your whole history so that you fit into the two-sex model. (Dreger 2006)

This quote refers to the New York City's proposal to allow people who have not undertaken cross-sex surgery to change their birth certificates to match their innate gender identities. Although this theme is different from the topics of this chapter, Dreger's quote tells something of relevance here. AGIO is not necessarily an illness ('having the wrong body'), and is not necessarily a condition in which the person wants to belong to other gender. Gender organisation is individual and subjective, and can be monothematic or comprehensive. AGIO, thus, might not necessarily mean 'being born in the wrong body': it might also signify a more complex process of identification with different aspects of both genders. It is mistaken to assume that gender identity must be, for every person, either feminine or masculine.

### **Intra-psychic, Physical and Social Dimensions of AGIO**

AGIO has three interrelated dimensions: intra-psychic, physical and social.

#### ***Intra-psychic dimension***

Di Ceglie has described the intra-psychic experience of children as follows: 'Their interests, their play, their fantasies, their way of moving or talking, their way of relating to friends, or their way of seeing themselves do not fit the body that they have and the way that other people perceive them as a consequence of their bodily appearance. One might say that their psyche lives in a foreign body. [...] The child feels driven to live in this confusing and bewildering condition' (Di Ceglie 1998, p. 186).

#### ***Physical Dimension***

AGIO does not generally cause physical alterations. AGIO children generally develop 'normally', in accordance with their biological sex. It is this physical dimension that horrifies the sufferer, in that biological sex is experienced as alien. In some relatively rare cases, AGIO appears in concomitance with other conditions, which might alter normal development. These could be chromosomal, like the Turner Syndrome and the Klinefelter Syndrome. Other conditions are hermaphroditism, anomalous genitalia, congenital adrenal hyperplasia, androgen insensitivity

syndrome and alpha-reductase deficiency. In these cases, the sexuality of the individual might be ambiguous, for example, if the genitalia are ambiguous, or if enzymes prevent complete virilisation in biological male, or if chromosomal anomalies are present. Ghosh and Walker have provided a synthetic and clear account of these medical conditions and their relationship to AGIO (Ghosh and Walker 2006). As they explain, AGIO should not be confused with these other conditions, although sometimes it might be triggered by them, as some of these conditions might contribute to create profound uncertainty over the sense of the self and over gender identification. Typically, however, AGIO sufferers have a clear phenotypical appearance that reflects their biological sex and an incongruent gender identity. AGIO is thus classified as a psychiatric illness. Recent research suggests, however, that the causes of AGIO might be hormonal and neurological, and not just psychological (GIRES et al. 2006).

### *Social Dimension*

AGIO also has a social dimension, in two ways: first, AGIO is, to an important extent, shaped by social categories and stereotypes about gender identity. AGIO becomes particularly stressful within a certain sociocultural context. We struggle to contemplate gender ambiguity or differences as one of the many, normal paths open to individuals, and the psychological distress experienced by the sufferer and the family is partly due to the difficulty of accepting the reality of 'a third way' (Connolly 2003). Second, children and adolescents are exposed to bullying, abuse and denigration, as well as to open physical violence (Di Ceglie 2000, p. 458). When a person is discriminated against, or subject to abuse and violence, his/her story is no longer private, but assumes public connotations that deserve public attention.

The threefold distress to which children and adolescents with AGIO are exposed makes life unbearable to many of them: Young people with AGIO are at high risk of suicide (Di Ceglie 1998, p. 194; Di Ceglie et al. 2002).

### **Therapies: Three Stages**

Therapy for AGIO includes three stages (Royal College of Psychiatrists 1998, p. 5):

1. Wholly reversible interventions
2. Partially reversible interventions
3. Partially irreversible interventions<sup>2</sup>

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<sup>2</sup>I owe this original classification to Bernard Reed.

### *Wholly Reversible Interventions*

The first stage of treatment is temporary suspension of pubertal development. This treatment is offered in cases where the gender dysphoria is diagnosed as being profound and highly likely to persist. The endogenous production of oestrogen in girls and testosterone in boys is temporarily suppressed. *Gonadotropin-releasing hormone analogues* (GnRHa) are the best available drugs. These act on the pituitary gland and block the pituitary hormone secretion.<sup>3</sup> These drugs are sometimes called 'hypothalamic blockers', or simply 'blockers'. These could be given to children after the onset of puberty, but before the substantial development of secondary sex characteristics. This is around what is known as Tanner Stage two ([http://en.wikipedia.org/wiki/Tanner\\_stage](http://en.wikipedia.org/wiki/Tanner_stage)).<sup>4</sup> Puberty suppression releases the stress of the child and allows the child and the clinician to assess whether the dysphoria is likely to persist. If puberty is suppressed successfully, the child can have a 'real life experience'. This involves adopting the role of the other gender, in order to experience the congruence with presumed innate gender identity. In the centres that offer such endocrinological treatment, the child also receives psychological support. After a period on blockers, the child/adolescent might decide to go on with therapy, and, eventually, to begin cross-sex hormones (see next section). Alternatively, she/he might wish to revert to the phenotypical sex, and interrupt therapy. By resuming endogenous sex hormone production, the pubertal development would restart normally. For this reason, blockers are regarded as a reversible intervention (see Sections — 'Suspension of Puberty: Benefits' and 'Suspension of Puberty: Risks').

Both the British Society of Paediatric Endocrinology and Diabetes (BSPED), and the Royal College of Psychiatrists (Royal College of Psychiatrists 1998) regard 'blockers' as a therapeutic tool. Blockers, however, can also be regarded as a diagnostic tool, as one of their primary functions is to enhance understanding of the real nature of the patient's discomfort (Cohen-Kettenis T Peggy 1998).

The time at which suppression or inhibition of endogenous sex hormones should begin is controversial. The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders states that the adolescent (note: not the child) can receive the hormone-blocking medication, provided that he or she has commenced puberty and he/she has had a persistent desire to change sex throughout the childhood. Box 1 cites these guidelines.

The Royal College of Psychiatrists recommends that adolescents have experience of themselves in the post-pubertal state of their biological sex. However, it contemplates the possibility of earlier interventions (Royal College of Psychiatrists 1998, p. 5).

BSPED, instead, assumed that puberty should be complete before any treatment could start.

<sup>3</sup>I am grateful to Professor Mike Besser for this specification.

<sup>4</sup>The precise development can be measured by assessing testicular and breast development and levels of sex hormones (Delcmarre-van de Waal and Cohen-Kettenis, 2006).

**Box 1: The Harry Benjamin Standards of Care (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 10)**

Adolescents may be eligible for puberty-delaying hormones as soon as pubertal changes have begun. In order for the adolescent and his or her parents to make an informed decision about pubertal delay, it is recommended that the adolescent experience the onset of puberty in his or her biologic sex. [...] In order to provide puberty-delaying hormones to an adolescent, the following criteria must be met:

- (1) Through childhood the adolescent has demonstrated an intense pattern of cross-sex and cross-gender identity and aversion to expected gender role behaviors.
- (2) Sex and gender discomfort has significantly increased with the onset of puberty.
- (3) The family consents and participates in the therapy.

**Box 2: BSPED (BSPED, p. 2)**

An adolescent should be left to experience his/her natural hormone environment uninterrupted until:

- (A) Development of secondary sexual characteristics is complete.
- (B) Final height has been achieved.
- (C) Peak bone mass has been accrued (ideally).

BSPED withdrew its approval from its own guidelines in October 2006 after questions were raised about their clinical appropriateness (puberty cannot be 'suspended' if it has already completed its course) and credibility (no date of publication and authorship was claimed). However, it is important to understand the experience of children who have been treated according to the BSPED guidelines, in order to understand the ethics of treating minors with AGIO. The passage in Box 3 is written by an adolescent whose care has been organised under the BSPED guidelines.

This is not an isolated experience. Bran Fenner and Rickke Mananzala (FIERCE) in collaboration with Z. Arkles and Dean Spade (Sylvia Rivera Law Project) describe the state in which children are left, when they are refused blockers at the beginning of puberty:

*For these youth, being turned away for hormone treatment at clinics has a number of effects. First, it further alienates them from medical providers, about whom they may already feel distrust or fear. Because of this increased distrust, many may not return for*



**Box 3: Sixteen and a half-year-old (M→F) not been treated until pubertal development was complete.**

*I [...] began my puberty at the age of ten, so I have lived with this profound physical wrongness for over six and a half years. The last two and a half years have been horrendous for me, with my body becoming so disgustingly adult male that I cannot bear it. [...] My body will never, ever be as I would like it to be and now, unfortunately, it is really a case of damage limitation. [...] at the moment, I am living in a limbo land – my name is [...] and I dress in female clothes, but I have facial and body hair, which makes me feel horrible, I am the wrong shape for the clothes that I wear and I have genitalia which is completely alien and upsetting and which protrudes through my clothes. [...] If I could have started on blockers at Tanner Stage Two (this, for me, was at the age of about twelve) [...] I would have been able to avoid the worst physical effects of male puberty; as it is, I am going to have to spend years, and a lot of money, trying to get rid of the many physical male attributes that I could have avoided. [...] I still have many years of being covered, from head to toe, with thick, black hair to look forward to.*

*primary care, HIV testing, STD treatment and other essential care. [...] Besides creating a disincentive for other medical care and alienating youth from medical services, these age-based denials also create a necessity for youth who feel that hormone therapy is essential to their survival to seek this care out elsewhere. For many, this care is the only way to express their gender fully so that they can seek employment, attend school, and deal with every day interactions in their new gender. Without hormones, many have a difficult time being perceived by others correctly, opening them up to consistent harassment and violence. For many young people [...] taking hormones feels like a life or death need, and they will do whatever is necessary to get this treatment. Many, when rejected at a clinic based on age, buy their hormones from friends or on the street, injecting without medical supervision at dosages that may not be appropriate and without monitoring by medical professionals. This opens them up to high risk for HIV, hepatitis, and other serious health concerns. Additionally, many youth have difficulty raising money to buy these hormones illegally because they do not have parental support for their transition and face severe job discrimination as young transgender applicants. For many, criminalized behaviour such as prostitution is the only way to raise the money. Doing this work makes them vulnerable to violence, trauma, HIV, and STD infection, and entanglement in the juvenile justice system [...]. Once a young person enters the juvenile justice system, the stigma of delinquency usually follows them throughout life and they often cycle into the adult criminal justice system upon maturity. (Fenner and Mananzala, 2005)*

Delemarre-van de Waal and Cohen-Kettenis concur that: 'the experience of a full biological puberty may seriously interfere with healthy psychological functioning and well being' (Delemarre-van de Waal and Cohen-Kettenis 2006, online publication at p. 3). In February 2007, the UK newspaper *The Telegraph* reported the news of a 12-year-old boy, treated for AGIO in Germany. This appears to be one of the youngest children officially treated for AGIO. Experts claimed on that occasion that treatment

was administered in light of the *trauma* that can affect children with AGIO when their body begins to take the shape of the unwanted gender (*Telegraph*, 1-2-2007).

In order to understand whether there is any reason to defer treatment, thus leaving children and adolescents to grow in their biological phenotype, it is important to understand the clinical benefits and risks of various therapies.

### Suspension of Puberty: Benefits

1. Suspension of puberty immediately reduces the patient's suffering (Cohen-Kettenis and Pfafflin, 2003, p. 171).
2. 'Blockers' improve the precision of the diagnosis. Adolescents are given more time to explore their self and their gender, without the distress of the changing body.
3. 'Blockers' can also help identifying children who are false positives. Delemarre-van de Waal and Cohen-Kettenis argue that early administration of blockers might *increase* the incidence of false positives. However, later discussion in their paper suggests that appropriate diagnosis *decreases* the chance of treating false positives. 'Making a balanced decision on SR [sex reassignment] is far more difficult for adolescents, who are denied medical treatment (GnRHa included), because much of their energy will be absorbed by obtaining treatment rather than exploring in an open way whether SR actually is the treatment of choice for their gender problem. By starting with GnRHa their motivation for such exploration enhances and no irreversible changes have taken place if, as a result of the psychotherapeutic interventions, they would decide that SR is not what they need' (Delemarre-van de Waal and Cohen-Kettenis 2006, online at p. 12).
4. Suspension of puberty reduces the invasiveness of future surgery. In Female-to-Male (F→M), it would avoid breast removal; in Male-to-Female (M→F) it would avoid painful and expensive treatment for facial and body hair; moreover, the voice will not deepen, and nose jaw and crico-cartilage (Adam's apple) will be less developed. This will avoid later thyroid chondroplasty to improve appearance and cricothyroid approximation to raise the pitch of the voice<sup>5</sup> (Cohen-Kettenis and Pfafflin, 2003, p. 171).
5. Better psycho-social adaptation is associated with early physical treatment (Cohen-Kettenis and Pfafflin, 2003, p. 171).

However, there are risks to be considered in suspending puberty.

### Suspension of Puberty: Risks

A major concern is the impact of GnRHa on development. Administration of GnRHa slows the pubertal growth spurt. This can represent an advantage for M-to-F,

<sup>5</sup>I owe this clarification to Terry Reed.

as it makes it more likely for them to achieve an ultimate height within the normal female range. However, the obvious question is whether reduction of the rate of growth has any side effects on bone formation and metabolism. GnRH $\alpha$  inhibits the production of endogenous sex hormones and thereby impacts on the formation of bone mass. Later administration of cross-sex hormones can increase bone mass, but long-term effects on bone mass development and sitting height are unclear. Peak bone mass can only be measured when patients are about 25-years old, and such a long-term follow-up has not yet been performed.

Another concern is the effect of GnRH $\alpha$  on the brain. Males and females show different brain development, especially in amount of grey matter. The effects of suppression of puberty on the brain are not known (Delemarre-van de Waal and Cohen-Kettenis 2006, online at p. 13).

Currently, the only centre that monitors the consequences of blockers over an extended period of time is the Department of Medical Psychology and Pediatrics in Amsterdam. The Amsterdam team sees around 70 children every year. According to their estimates, two third of the *adolescents* (age 12–18) who apply for treatment are diagnosed as having profound and persistent gender identity disorder and will then be treated. Only 20–25% of *children* (under 12) who are seen at their centre suffer persisting dysphoria and, following the Department's procedures of assessment, will be treated (information kindly offered by Cohen-Kettenis, T. Peggy, personal communication 2007). According to the Royal College of Psychiatrists it is not clear how many children with gender dysphoria will become transsexual adults (Royal College of Psychiatrists 1998, p. 5; Di Ceglie 2000, p. 462). According to another study, nearly all those who experience dysphoria in adolescence will become transsexual adults (Wren 2000).

These estimates should only be taken as a rough indication. Given that patients who are refused therapy or who decide to suspend therapy are not followed up, it is impossible to establish whether they will eventually transition to the other gender as adults or elsewhere. This might be inevitable but to some extent impinges upon the reliability of statistics of incidence and prevalence of AGIO in the general population, and on the way AGIO develops when it is manifested early in life.

The selection process in Amsterdam includes rigid psychological and endocrinological assessments. Until they undergo surgery (after the age of 18) patients are seen by the endocrinologist and by the psychologist at least every 3 months, although the psychologist is available for more frequent sessions. The endocrinological and psychological follow-up is meant to observe and prevent any abnormal development and adverse consequences of treatment. All parties should be convinced that treatment is in the best interests of the child (Cohen-Kettenis, personal communication 2007; for more information see Delemarre-van de Waal and Cohen-Kettenis 2006)

Follow-up includes assessment of bone density and body composition—yearly; skeletal age—yearly, endocrine and metabolic parameters—every 6 months—and anthropometry (overall height, weight, sitting height, skin folds, waist and hips)—every 3 months. Laboratory measurements include levels of gonadotrophins and sex hormones, metabolic parameters such as fasting glucose, insulin, cholesterol, high-density lipoprotein and low-density lipoprotein levels. In addition, safety

parameters, such as renal and liver functions, are estimated' (Delemarre-van de Waal and Cohen-Kettenis 2006, online at pp. 8–9).

These studies show that later administration of cross-sex hormones makes it possible to manipulate overall height and achieve *quasi*-normal height. (Cohen-Kettenis and Delemarre-van de Waal 2005).

Additional concerns regarding blockers are their effects on the reproductive capability. Specialists in Belgium have explored these effects (De Sutter 2005). De Sutter explains that the use of blockers in early puberty might prevent the storage of sperm (for M→F children) and of ova (for F→M children) for future reproductive purposes. However, the suppression of spermatogenesis in males is temporary and can be restored by interrupting treatment. A boy, whose puberty has been suppressed before spermatogenesis has occurred, could decide to stop treatment long enough for spermatogenesis to start, once he is a bit older, if he wishes to collect and store sperm for reproductive purposes (this of course would mean that he would have to accept the masculinising effects of endogenous testosterone on his body). He can then continue with treatment for transition to female gender.

Collection of ova in females is less problematic. The treatment has little impact on the already formed ova. They may be collected and stored at the time of oophorectomy (De Sutter 2005).

An additional problem for trans-girls is that the genital tissue available for the later creation of a vagina will be less than would otherwise have been available, but this problem could be resolved with appropriate surgical intervention.

The results of current studies are encouraging. Suspension of puberty at an early stage seems to have no significant and non-controllable adverse side effects. Peter Lee and Christopher Houk (USA) write: 'We believe suppression of pubertal sexual characteristics is warranted when there is evidence of pubertal onset. Suppression of pubertal sex steroid production and thus secondary sexual characteristics can be effectively and safely accomplished using gonadotropin-releasing hormone analogues (GnRHa)—an intervention that is both temporary and reversible' (Lee and Houk 2006).

Preliminary evidence leads to the conclusion that there are sound clinical grounds for commencing treatment soon after the onset of puberty. Questions can be raised, however, as to the *ethical* legitimacy of suspension of puberty, and these will be discussed in the last seven sections. I shall now outline the partially reversible interventions, and their risks and benefits.

### *Partially Reversible Interventions*

Partially reversible interventions refer to masculinising and feminising hormones.

Cross-sex hormones have the following benefits:

1. They initiate the development of the secondary sex characteristics that accord with the innate gender identity.

2. They make it easier for the person to have a real-life experience by beginning to alter the physical appearance to accord with the new gender role.
3. They allow the person to explore what it feels like to be the other gender, thus making it possible to make a better-informed choice about irreversible interventions.

There is no agreed protocol as to the dosage, or as to the type of hormones that should be offered, as the case history below shows (Box 4):

The difference in national protocols has the inevitable and unfortunate consequence of promoting 'medical tourism'. US experts report<sup>6</sup> that patients, who are not treated adequately in some European countries, travel to the USA to receive privately paid treatment. Those who cannot afford this, as we have seen above, are forced to suffer or attempt other, often illegal, and, above all, unsafe routes.

#### Risks of Cross-Sex Hormones

Risks are mainly cardiovascular. Cross-sex hormones seem to increase the likelihood of occurrence of serious/fatal cardiovascular diseases in patients already at risk (smokers, obese patients, patients with heart diseases, hypertension, clotting abnormalities or some endocrine abnormalities). Most of these risks concern mainly adults and generally do not apply to children and adolescents.

In trans-women, oestrogens and progestins may also cause infertility, weight gain, emotional lability, liver disease, gallstone formation, somnolence and diabetes mellitus. In trans-men, testosterone may cause infertility, acne, emotional lability, increased sexual desire and hepatic dysfunction and even malignant liver tumours (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 15).

#### **BOX 4: Case history**

A sixteen and a half (M→F) at Tanner stage 5 (and therefore already fully grown in the biological male phenotype) is treated in the UK with analogue GnRHa, followed later by 5 mcg of ethinylestradiol per day. This would be increased every 6 months. In Gent, in Amsterdam and in the USA ethinylestradiol is not utilised in cases like hers. Beta oestradiol (in the USA this is called Estrace) is used, because it is a natural oestrogen and because it has shown lower association with thrombosis. The dosage of beta oestradiol that she would be recommended is comparable to 30–50 mcg of ethinylestradiol—much higher than the dosage that the patient would receive in the UK.

<sup>6</sup>Private communication.

One final important risk associated with cross-sex hormones is that the treatment is only partially reversible. If a patient decides to interrupt treatment, effects such as voice change and beard growth cannot be changed, although possibly ameliorated, and breast development in males through administration of oestrogens and progestins can be only removed with surgery.

International guidelines on treatment for AGIO recommend that masculinising and feminising hormones should not be administered before the age of 16 (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 10). These guidelines, moreover, insist on the support of the family. Later sections will examine the ethico-legal issues around setting age limits for access to treatment and around the involvement of the family.

### *Irreversible Interventions*

These refer particularly to surgery.

Surgery represents the final stage of treatment, although hormone intervention is an additional lifelong treatment. The benefits of surgery are self-evident. The patient has finally obtained a body in line with the innate gender identity. According to a study, body satisfaction significantly increases in the vast majority of cases (Cohen-Kettenis and Delemarre 2005).

Risks of surgery include normal risks associated with all surgery. Additional risks concern body dissatisfaction (Cohen-Kettenis et al. 2003): in some rare cases the person wishes to revert to the original gender. Reversing surgery involves expensive and invasive procedures, which in some cases can only be partially successful (GIRES 2005). Even for those who 'successfully' transition to the other gender, satisfaction might be incomplete. The reasons for partial satisfaction can be diverse. First, to be *one or the other* is not everyone's reality. For some, ambiguity is the reality, and such will be the case after transition. Incomplete satisfaction might also be a function of the life history of those who transition. It is possible that many of those who have had to struggle a great deal to have cross-sex surgery feel great uncertainty over the self due to their life experiences, often populated by unemployment, emigration, prostitution, abuse, criminalisation and violence or, at least, struggle with the medical system to receive adequate care.

International and national guidelines agree that surgery should not be carried out before the age of 18 (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 11; Royal College of Psychiatrists 1998, p. 6), although, as mentioned earlier, in September 2007 the Courts of Argentina granted permission for cross-sex surgery to a 17-year-old patient, Natalia. Section 'Ageism' will discuss the ethical issues around the determination of age limits for access to treatment.

### Ethical Issues: Playing God

The treatment for transsexualism in minors is surrounded by many ethical and possibly legal issues. One of the main issues that can be raised is about the ethics of playing God or playing with nature. There might be an intuitive distrust or revulsion over medical interventions that interfere with spontaneous development. Medicine itself is, however, a discipline aimed at changing the course of events and nature for the better. Other authors have rejected the objection against medical interference in the course of nature as unsustainable and I shall not repeat debates already widely covered in ethics and bioethics (Ryan 1995; Harris and Giordano 2003). If there is reason to believe that minors will benefit from suspension of puberty and cross-sex hormones, it is ethical to provide these treatments. Our emotions and intuitions should leave room for reasoned judgement upon the minors' welfare.

Other ethical issues concern children's competence to make informed decisions about their condition.

### Competence and AGIO

AGIO is currently classified as a mental illness. Mental illness can be believed to jeopardise the sufferer's decision-making capacity; in particular, his/her capacity to consent to treatment for the illness itself (MHA 1983, s. 63). There are grounds for challenging the classification of AGIO as a mental illness (Giordano 2008a). Arlene has also pointed out the potential damage of considering individual gender expressions as mental illnesses, and the ethical dilemmas of needing a psychiatric diagnosis in order to obtain medical treatment (Arlene 2006). However, even if AGIO was appropriately conceptualised as a mental illness, this would not *ipso facto* entail patient incompetence. Although there are difficulties inherent in the determination of competence (Mason and McCall Smith 2006, p. 334), the presence of a mental disorder does not necessarily affect capacity to consent to medical and psychiatric treatment, including treatment for the mental illness (Department of Health 2000, para 15.9–15.24; Mason and McCall Smith 2006, pp. 263–264; Giordano 1999, 2001). The fact that AGIO is currently classified as a psychiatric illness should not remove presumption of competence in patients and applicants.

### Minors and Competence

Another worry might be whether minors can give genuine and legally valid consent to treatment for AGIO. Health care professionals, in particular, might be concerned about legal liability for treating minors with AGIO. The first stage of therapy, in

order to be effective, should begin early in puberty, and it can be asked whether minors under the age of 16 can make competent decisions on treatment that has significant effects on their development.

In Anglo-Saxon jurisdictions a person is deemed competent if she/he understands in broad terms the nature of his/her condition, purposes of proposed treatment and alternatives, and can balance risks and benefits of proposed treatment and alternatives. It is not excluded that children can display competence. Competence 'does not depend on the age of the child, but on subjective features of the child in respect to the particular treatment proposed' (Jones 2006, p. 129).

Some jurisdictions protect the right of the child to consent to medical treatment. The UK Family Law Reform Act 1969, for example, at Section 8, states that a minor who has attained the age of 16 years *can give valid consent to any surgical, medical or dental treatment*. Where a minor has by virtue of Section 8 given effective consent to treatment, it shall not be necessary to obtain consent from his/her parent/s or guardian (Brazier 1992, pp. 361–371). 'Surgical, medical or dental treatment' includes any procedure undertaken for the purposes of diagnosis, and this section also applies to any procedure (including the administration of an anaesthetic) that is ancillary to that treatment. There is no apparent reason for excluding treatment for AGIO from under the umbrella of treatments covered by Section 8 of The Family Law Reform Act 1969.

In the Anglo-Saxon legal panorama, children *under 16* can also be competent to make medical decisions. *Gillick v West Norfolk and Wisbech Area Health Authority* ([1985] 3 All ER 402 HL) established that a child under 16 is competent and can give an effective consent to medical treatment providing that she/he had reached:

... sufficient understanding and intelligence to be capable of making up his own mind in the matter requiring decision. ([1985] 3 All ER 402 at 409 e-h per Lord Fraser and at 422 g-j per Lord Scarman; See also *R v D* (1984) 2 All ER 449)

Although the implications of *Gillick* in terms of children's right to autonomy are discussed (Freeman 2006), 'Gillick competence' is regarded as the landmark of adolescent autonomy in health care (Eekelaar 1986, p. 1).

In order to satisfy a request for treatment, not only the request has to be competently made, but also treatment has to be in the minor's best interests. Whether treatment is in the minor's best interests is a matter on which health care providers are called to deliberate, on the basis the evaluation of each individual child. However, should the health care provider find that treatment is in the child's best interests, there would be no reason to deny it on the ground that the applicant is incompetent by reason of age or by reason of AGIO. There is in fact no reason for assuming that children with AGIO cannot be competent, in the way described by law, to make a judgement upon medical treatment for their conditions (for more detailed discussion of competence and the courts in gender reassignment cases see Jones 2006; See also Whittle and Downs 2000).



There is, however, a more general issue. It can be asked whether informed consent for treatment of AGIO can be given at all.

### Can Informed Consent Be Given at All?

In order to be valid, consent needs to be informed. Information about the risks and benefits of treatment is material to the decision. However, Sections 'Suspension of Puberty: Risks', 'Risks of Cross-Sex Hormones' and 'Irreversible Interventions' have shown that the risks of treatment for AGIO (including risk of incomplete satisfaction) have not been fully established. It may be believed that this makes it impossible to give valid informed consent to gender transition. Children and adolescents might be believed to have greater difficulty in foreseeing how they will feel in the future, due to the scarcer capacity of their long-term judgement and scarcer knowledge of the self, and therefore more at risk of giving invalid consent.

The idea that partial unpredictability invalidates consent is mistaken. If it were not possible to consent to interventions whose outcome is uncertain, it would follow that medical research involving human beings is always unethical, and this is clearly not the case. In order to give valid consent, the applicant must receive as complete as possible information about treatment, and has to be informed about the unknown risks of each stage of therapy. The person will ponder the unknown risks of treatment with its potential benefits, and will set them against the all-known psychological and physical effects of non-treatment.

It could be objected that even if the person is competent to take unknown risks, and even if consent is genuine and legally valid, it is still unethical to expose people, especially minors, to unknown side effects that could affect their future life.

Although this concern is understandable, the belief that treatment is unethical if there is a degree of unpredictability is mistaken. Indeed the complete outcome of many medical treatments is unknown before they commence. If the potential risks were so high and of such a type that no reasonable person would take them, then indeed a question could be raised as to whether it is ethical to offer such a treatment, even if the applicants were fully competent. However, preliminary evidence suggests that no severe or uncontrollable side effects are involved in treatment for AGIO. Evidence shows that, instead, *not being treated* is devastating for most children and adolescents with profound and persistent AGIO, many of whom try to take their life if they do not obtain appropriate medical care, and therefore the certain and real side effects of *not receiving treatment* might, for many, outweigh any unknown potential risk of treatment. If it can reasonably be expected that therapy improves the applicant's quality of life or can save his or her life, it is not unethical to satisfy the request for treatment—it might indeed be unethical to deny it.

This has wider implications. This implies that, in judging whether or not to treat, health care professionals should evaluate what is likely to happen to the applicant if he or she does not receive treatment, and not only what is likely to happen if he

or she does receive treatment. In other words, health care professionals should take into consideration the consequences of their omissions, as well as those of their actions. This might seem to go beyond professional responsibilities: clinicians might feel that they should assess the clinical benefits and risks of therapies and that they are not responsible for what happens to people outside their clinics. Although the extent to which all of us, including health care professionals, are responsible for omissions is open to debate, it is a mistake to believe that omitting to treat is a morally neutral option. There are both ethical and legal grounds for considering carefully what would happen to the applicant if he or she was not treated, or treated with hormones and in doses that he or she finds unhelpful.

### Acts and Omissions

Doctors are not obliged to provide medical treatment upon request, if treatment goes against their clinical judgement or their moral values. However, the entitlement to omit treatment, like any other entitlement, is not absolute. For example, a doctor who refuses to perform an abortion on the basis of conscientious objection could be held negligent, if his omission exposes the woman to serious and imminent risks.

Gillick also implies that doctors should evaluate the consequences of their omissions ([1985] 3 All ER 402 at 409 e-h per Lord Fraser).

Doctors are required to look at what is likely to happen to applicants *if they fail to administer requested treatment*. I am not suggesting that a doctor should be held accountable for murder if he refuses to treat an applicant, and she commits suicide as a result: holding ourselves *equally* responsible for our omissions bears probably a too stringent moral responsibility (Husak 1980). However, certainly inaction is not necessarily a 'morally safe place' to be in. When we know that, if we fail to do something, the consequences for our omissions are serious and potentially fatal for others, we have some moral responsibility for those consequences. In fact, on Hall's account, the decision not to treat could be regarded as an action, not as an omission—and this would further explain in what sense doctors are responsible for not treating (Hall 1989). In AGIO, omitting to treat at the right age, or treating with doses of hormones that the patient finds unhelpful, may cause great harm to the child (see Section 'Wholly Reversible Interventions'). This harm can be prevented by blocking pubertal development and administering appropriate doses of cross-sex hormones at a later stage.

So far, we have seen that there is no reason to believe that treatment of children and adolescents with AGIO is undue interference with nature (or with God's will—an argument that should be left to the faith of each individual); there is no reason to assume that children with AGIO are incompetent to make decisions about their conditions, or that valid consent cannot be gathered; finally, I have argued that early treatment is not unethical—indeed, it might be unethical not to satisfy a request, when the child is competent and the risks of not treating appear to outweigh potential risks involved in therapy. There are further ethico-legal issues relating to the involvement of the family and determination of age of access to treatment, which will be examined in the next and final sections.

## The Involvement of the Family: Ethico-Legal Grounds

Anglo-Saxon jurisdictions accept that a competent 16-year-old person—and in some case, a competent child below that age—can commence treatment *without parental consent*. In Section 'Ethical Issues: Minors and Competence', we have seen that in the UK, the Family Reform Act 1969 establishes that where a minor has given effective consent to treatment, it shall not be necessary to obtain consent from his/her parent/s or guardian.

International guidelines on treatment for AGIO, however, state or imply that the family/guardian's consent is conditional to the initiation of therapy (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, pp. 10, 16), and experts agree that 'adolescents need the support of their parents in this complex phase of their lives' (Delemarre-van de Waal and Cohen-Kettenis 2006, online at p. 6).

The principle of consistency (Giordano 2008) requires that similar principles apply to similar circumstances. If different principles apply, there must be relevant differences that justify difference in treatment. For minors with AGIO, participation of the family is of crucial importance. Unlike other medical treatments (like, for example, the provision of contraceptive advice and treatment in Gillick), transition to the other gender involves the family in a profound way: gender reassignment determines a modification of the whole family dynamics, and it is essential that the family supports and participates into the various stages of the transition. This might explain why guidelines and experts insist upon obtaining consent of the family/guardian. Many applicants are indeed accompanied and supported by their parents. Due to the importance of family involvement in order to achieve good outcome, it might in reality be difficult for a child to persuade a health care provider that it is in his/her best interests to receive treatment for AGIO where the parents/guardian's consent is withheld.

However, a veto a priori against treatment without parental consent is difficult to justify. Unless it can be shown that parental consent is *always* essential to successful adaptation to gender reassignment, health care professionals should be open to the possibility—albeit remote—of treating children without parental consent. It cannot be assumed that parents always serve or even understand their children's best interests, and the decision to treat should ultimately be made in the best interests of the child. In the unfortunate and possibly rare cases in which parental support is not available, clinicians should assess whether *not receiving treatment* is ultimately better for the competent applicant than being treated without parental support.

### Ageism

International guidelines set out strict age-related criteria for access to treatment (see Sections 'Irreversible Interventions'). The determination of a particular age of access to gender reassignment is ageist. Ageism is unjust

discrimination by reason of age. Decisions regarding whether or not an applicant should receive treatment should not be based on age, but on the applicant's competence and capacity to benefit from treatment. Competence and capacity to benefit from treatment often are a function of age, but this is not always the case. Indeed, in AGIO capacity to benefit from treatment is inversely proportional to age, in that it decreases as puberty advances, and competence, which generally matures with age, sometimes is manifested very early in life.

The World Health Organisation (WHO) and the United Nations (UN) have formally established that 'ageism', including ageism in health care provision, is unethical (*Brasilia Declaration on Ageing*, WHO, 1-July 1996, Available at <http://www.oneworld.org/helpage/info/brasilia.html>; UN International Year of Older Persons 1999, Available at <http://www.un.org/esa/socdev/tyop/>).

Age-based discrimination is a violation of one of the most fundamental human rights, the right to equality meant as non-discrimination. According to the European Charter of Human Rights, age, together with sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability and sexual orientation (Article 21, Non-discrimination), is an arbitrary feature that does not justify difference in treatment (Besson 2005; Available at [http://www.europarl.eu.int/charter/default\\_en.htm](http://www.europarl.eu.int/charter/default_en.htm); See also the Convention for the Protection of Human Rights and Fundamental Freedoms as amended by Protocol n. 11, 4 November 1950, Article 14, Prohibition of discrimination, Available at [www.echr.coe.int/Convention/webConvenENG.pdf](http://www.echr.coe.int/Convention/webConvenENG.pdf); the Convention for the rights of the child (2 September 1990), Preamble, Available at <http://www.unhchr.ch/html/menu3/b/k2crc.htm>; the European Social Charter (Revised; 3 May 1996), Part IV, Article E., Available at <http://conventions.coe.int/Treaty/EN/Treaties/Html/163.htm>).

Ageism generally refers to the treatment of the older patient, and the declarations by the WHO and the UN are normally meant to protect the equal right of the older person to access medical treatment. However, there is no reason why one should think that only older patients can be discriminated against by reason of their age. Younger people can be discriminated against on similar grounds. Refusing to treat someone because he is too young is an unjust discrimination based on age. Setting up age limits for access to treatment, in one direction or the other, is a form of ageism. Health care professionals need to provide valid reasons to refuse medical treatment: they need to show that the treatment is not in the best interests of the applicant, or that the applicant is incompetent to make such a decision at this stage of his/her life and the risks of the treatment outweigh its expected benefits. Appeal to age alone is ethically unsound and incongruent with ethical principles stated in virtually all conventions and declarations of human rights and fundamental freedoms.

Health care professionals could argue that it is irresponsible to treat children, when the outcome of treatment is uncertain. However, if it is irresponsible and/or unethical to provide treatment whose risks and benefits are uncertain, then this is

so *regardless of the age of the applicant*. Treating an adult would be as unethical as treating a child.

This does not mean that treatment of AGIO must be offered, that doctors have a moral and legal obligation to treat children who request it. It means that the rationale for withholding treatment must be made out on other grounds, and not on the basis of the age of the applicant.

### Conclusions

AGIO is a serious medical condition: minors with atypical gender development sometimes begin to suffer as early as at the age of 4 or 5 and the distress increases as they grow older. Many of those who cannot receive treatment are at high risk of suicide. AGIO also represents a great challenge for society. The distress associated with AGIO is partly determined by rigid social categories and stereotypes relating to gender identity. It is expected that gender identity will conform to the phenotype and also that a person be either a male or a female. However, for many people it is not possible to identify themselves with one gender, and they experience both genders in their person. AGIO thus induces us to rethink gender identity in a more comprehensive way, inclusive of phenomena that go beyond the classic gender divide 'male-female'. AGIO is also a public problem because sufferers are often exposed to discrimination, abuse and violence, and each act of discrimination, abuse and violence is a public issue. Thinking about AGIO means thinking about ways of ensuring all citizens, whatever their gender identity, a secure and peaceful place in society.

Endocrinology now offers the possibility to suspend puberty and administer cross-sex hormones in adolescence. This raises ethico-legal issues that have not been addressed in depth in bioethics literature. This chapter has analysed these issues. In particular, the question of whether it is unethical (or even illegal) to offer treatment for AGIO to young adolescents has been examined. Some might believe that it cannot be ethical to interfere with nature, or that it is unethical to provide children with treatment whose long-term risks are not fully established. I have argued that there are no ethical or legal grounds for deferring treatment until puberty is complete and the applicant is a young adult, because, at that stage, the damage caused by natural development might be difficult to undo. Indeed, it might be unethical not to treat as requested, if treatment is likely to prevent great harm and to save people's lives.

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