

Ashley, Two Born as One, and the Best Interests of a Child

GRANT GILLETT

Abstract: What is in the best interests of a child, and could that ever include interventions that we might regard as *prima facie* detrimental to a child's physical well-being? This question is raised a fortiori by growth attenuation treatments in children with severe neurological disorders causing extreme developmental delay. I argue that two principles that provide guidance in generating a conception of best interests for each individual child yield the right results in such cases. The principles are as follows: the *potentiality principle*, whereby every child should be able to develop its potential and is entitled to receive certain help in doing so, and the *principle of psychosomatic harmony*, whereby every human being is entitled to treatment that is appropriate to or enables a life in which mind and body are in tune with each other. These principles indicate a certain response to what we can call Ashley-type cases and admit certain caveats.

Keywords: neurological disorder; growth retardation; the Ashley treatment; potentiality; psychosomatic harmony

Introduction: Ethical Debates about Ashley

The case of Ashley, the pillow angel, has been extensively debated in the bioethics and medicolegal literature but continues to pose some important ethical issues relating to the best interests of children with severe developmental abnormalities.¹ It shares with the ethically challenging issues posed by some cases of conjoined twins an important key problem. In both cases the decisions turn on a plausible and principled clarification of the best interests of a child.² However, the clinical management of such cases and the ethical literature surrounding them has, on occasion, not only failed to focus on the crucial issues but also, to some extent, obscured the key features of the interests that ought to be heeded in such cases.³ Because Ashley's case, unlike the more stark trade-off between conjoined twins (one of whom may not be viable), can be viewed as raising many ethical issues (treatment of severely neurologically impaired infants, disability, growth attenuation, the sterilization of children with developmental anomalies, and parental decisionmaking for children), the debates are highly relevant to a wide range of cases that continue to come to the attention of pediatricians and ethicists, and it is worth revisiting the arguments that are commonly rehearsed. I argue that, when we do, two abstract principles emerge that clarify the welfare principle (the primacy of the best interest of a child) and the kernel of the *ratio decidendi* in cases concerning the care of children.

I propose that the best interests of the child turn on two neo-Aristotelian principles:

- 1) The *potentiality principle*, whereby the life due to each and every child is a life in which its potential is given full chance of being actualized.

- 2) The *principle of psychosomatic harmony*, whereby each person should be allowed to live a mode of life and enjoy a physical status maximally coherent with his or her psychological constitution (or, for Aristotle, her “soul”).

Between them, these ideas have an intuitive appeal in relation to current consensus in medical practice and bear up under philosophical scrutiny. I argue that they uniquely satisfy the requirements of reflective equilibrium in relation to the verdicts they yield.

Conjoined Twins Cases

The most famous case in this area is possibly that concerning Jodie and Mary,⁴ but an even more relevant case for neuroethics was *Queensland v. Nolan*, in which Judge Chesterman, faced with the difficulty of finding a legal justification for doing the right thing in a fraught human situation, remarked that “conventional legal terminology is pathetically inadequate.”⁵ He observed:

They are conjoined craniopagus twin girls. The condition is extremely rare. . . . Surgery to separate such twins is extremely complicated and the survival rate for even one of the twins is not high. . . . Alyssa has only one kidney. Bethany has no kidneys and no bladder. As well she has a condition commonly referred to as club foot which is sometimes an indication of underlying brain damage. Though joined at the head the girls have separate brains though they share the cranial draining veins. . . . They thus share blood flow. This has enabled Bethany to survive.⁶

The situation was precipitated into a medical emergency when it became clear that Bethany was imminently dying, which, if they were not separated, would also have resulted in the death of Alyssa. However, if an operation to separate them were carried out, “although necessary for the preservation of Alyssa’s life it would prove immediately fatal to Bethany,” therefore, *prima facie*, transgressing both law and ethics.⁷ It is hard to argue that such hastening of death is in conformity with normal interpretations of the *welfare principle*—the idea that we ought to be guided in medical decisions about children by the best interests of the child—given that in this case there were two children to be considered, one of whose death was to be hastened.

What ethical reasoning ought to guide such a decision? Utilitarian trade-offs among different human lives offer us a sensible response, but that conclusion does not sit well with our settled consensus about the sanctity of human life and a child’s right to life (although that should surprise nobody familiar with well-known utilitarian arguments in bioethics).⁸

Three possible situations arise in relation to conjoined twins cases:

- 1) A chance of life for twin A and certain death for twin B (as in *Nolan*)
- 2) Possible life for both, either conjoined or separated
- 3) Possible life for both if conjoined but a good chance of (quasi-“normal”) life for A and a high probability of death for B if separated.

In such cases, certain values commonly guide the decisions that are made, but they all attempt to capture “the best interests of the child” in some sense.⁹

This term summarizes a duty we owe every child as a human being in her or his own right¹⁰ and clearly becomes problematic when we think of neurologically impaired newborns and children with anencephaly, for whom letting die or withdrawing rescue treatment often seems the right thing to do. The *Nolan* case raises the issue a fortiori in that the court is bound to consider the best interests of both A and B and in that separating B (which, even though she is dying, hastens her death in a way usually considered to be against the best interests of a human being) seems necessary in order to save A's life.

The welfare principle, taken together with a strong legal bias toward the sanctity of human life (even when there is neurological impairment), implies that, as in other cases in which human beings have conflicting interests, the complex set of commitments and duties that come to bear on these cases produce a moral and legal impasse, given that something has to be done. That demands a clarification of the welfare principle or the best interests of a child and prompts the current suggestion.

In fact the possibility of a resolution in terms of the outcome realistically to be expected provoked Judge Walker to introduce a problematic concept—that of “wholeness”: “It is not a case of evaluating the relative worth of two human lives, but of undertaking surgery without which neither life will have the bodily integrity (or wholeness) which is its due.”¹¹ The following discussion articulates this problematic but appealing concept in terms of the principle of psychosomatic harmony already mooted, rather than accepting other possible justifications of the lethal but also life-saving operation.

Situation 1

The first possibility is that one child can be considered parasitic on the life of the other. Judge Chesterman debated several justifications for a “sacrificial operation” on this basis.¹² Does parental consent suffice to proceed with such an intervention in the best interests of both A and B? That does not seem to adequately address the question as to whether the operation constituted an unlawful killing of B. Judge Chesterman eschewed a judgment that B's life was “worthless or intrinsically worth less” than that of her sister (for reasons to do with the sanctity of every human life) and eventually some version of necessity prevailed (according to which a required act—the saving of A's life—was taken to be a justification for bringing about the death of B).¹³ Because the conflict cannot be resolved without some evil also being caused, we can say, in the light of the necessity of saving A, that an inevitable *bowing to nature* was the cause of B's death. The operation is therefore deemed lawful, taking due account of the strain placed on the relevant concepts, because it is “in the girls' best interests.”¹⁴ The ethics is a little more tractable than the law in such a case, because in ethics we can frame justification in terms of an analysis of the best interests of both children rather than just needing to relate the concept to a legal precedent about an individual human being, but the resolution does have a distinctly utilitarian flavor that would not commend it to some ethicists.

A reading of “substantial benefit”—here fleshed out in terms of realizable potential—avoids the utilitarian justification, offering instead the formulation that the operation to save A's life does not prejudice the best interests of B, despite hastening her death. If B has no further potential for meaningful life, she ought to be compared to those cases in which we no longer supply the necessities of life

because to do so would be of no benefit to the person concerned.¹⁵ We can lay out the argument as follows.

- 1.1. The operation can only save A and entails the death of B.
- 1.2. A must be saved.
- 1.3. B has already reached full potential and is dying, so further life would be of no benefit to her.
- 1.4. We have no medical duty to save or prolong life where there is no benefit to be gained.

Therefore, we should operate to save A, as there is no further medical duty to B. The argument then subtends the potentiality principle: The life due to each and every child is a life in which its potential is given full chance of being actualized.

Situation 2

A further and different case and a different *prima facie* ethical resolution arise when the conjoined twins both have a chance of life after operation.

- 2.1. The operation gives a chance to save A and B.
- 2.2. We have a duty to A to maximize her potential.
- 2.3. We have a duty to B to maximize her potential.
- 2.4. The separation would maximize the potential of both A and B.

Therefore, we have a duty to separate them.

There are, however, two possible variants of this type of case:

- 2.1a. The operation carries little risk of death or harm to one or both twins.
- 2.1b. The operation carries a significant risk of death or harm to one or both twins.

Therefore, if the facts are as in 2.1a (in the considered opinion of experts), we should operate (provided that 2.4 is defensible), but it is not so clear what should be done in 2.1b. On balance, it would seem that the situation in 2.1b can only be resolved by operation if a further premise is adduced:

- 2.5. The harm of continued conjoined life is unacceptable.

But 2.5 immediately raises two questions:

- 1) To whom is the harm of conjoined life unacceptable?
- 2) How great is the risk of harm or death?

If we were to determine that continued conjoined life was unacceptable to both A and B, then the course seems clear, but that is not always the case. In fact, the question is often not posed, and the answer is often presumed (by nonconjoined people involved in the situation). Thus we need to return to that issue and reconsider the ethical justification for operation in high-risk cases, for it may be that conjoined life should be seen as a variant of somatic life rather than an impairment or defect,

much as some would deny that being neurotypical is the only acceptable form of neurocognitive life and that, consequently, other forms should be considered impairments or deficits.¹⁶

Situation 3

A different case again arises when the separation operation has a chance of saving A but little chance of saving B. And here there might (as in situation 2) be two possibilities:

- 3.1a. A and B both have potential for significant ongoing life.
- 3.1b. A has but B does not have potential for significant ongoing life.

The difficult choice is again contingent on the unacceptability of ongoing conjoined life (as in situation 2), but, given that, 3.1b is still a difficult problem for the law because it is committed to regarding each child as a separate and inviolable individual whose best interests must be respected and preserved. If, however, we invoke the potentiality principle, then (in most cases) the life of B should be assimilated to that of an infant whose potential for life is very limited (who may or may not pose a risk of harm to her or his conjoined twin). In such a case, provided the ongoing conjoined life is genuinely unacceptable, it would seem that a *Nolan*-like resolution (framed in terms of the potentiality principle) allows the separation to go ahead. That is consistent with allowing the death of any newborn if the alternative were an unacceptable life for that child (even if her or his fate were immaterial to the fate of another child). But we should note that there is a conditional justification here based on the unacceptability of continued conjoined life, and thus there is a need for some further analysis of what is genuinely unacceptable.¹⁷

Where both have potential for significant future life (3.1a and 2.1b), we face much the same situation as in 2.1b, in which we noted the need for a strong ethical justification for the loss of B (through hastening her death). That ethical justification then needs to take account of the principle of psychosomatic harmony, whereby it may be possible that the conjoined surviving children (and future adults) would come to some acceptance (as in some historic cases) of their unusual somatic configuration (being joined together).¹⁸ If such acceptance were possible and both individuals valued their conjoined life as it is, then it seems unwarranted to expose them to severe risks to undo that situation, as no interest is being served and psychosomatic harmony prevails.

A Growth Attenuation Case: Ashley, the Pillow Angel

The two ethical principles—the potentiality principle and the principle of psychosomatic harmony—also help resolve another range of cases in which human life is severely affected by a neurological disorder. Ashley was born with a profound developmental arrest such that at six years she could not hold up her head, roll, change her sleeping position, sit, hold a toy, walk, or use language. Despite her extreme developmental impairment, she smiled from time to time, seemingly in response to care and affection. She received all her nutrition by gastrostomy tube and required others to meet her basic needs.¹⁹

Ashley's diagnosis was static encephalopathy, a prenatal or perinatal brain injury of such a type that "it was the combined opinion of the specialists involved in her care that significant improvement of her cognitive or neurological abilities would not occur."²⁰ Ashley's tendency to smile at people led her family to call her their "pillow angel," as she brightened up all their lives even though she never moved from the position in which she was placed and could only engage with others through the most minimal responses.

When she was nine years old, having begun to show signs of early puberty at six and a half years old, she had "the Ashley treatment": a high dose of estrogen to limit her growth, a hysterectomy to obviate the possibility of her becoming pregnant and to stop her menstrual periods, and a bilateral breast bud mastectomy to relieve possible discomfort and future breast disease.

An ethical storm broke when the case was publicized. Commentators expressed widely varying opinions, from those who argued that she had caring parents to those who seemed to think that the parents were playing God and doing Ashley a serious wrong, or even maiming her.²¹ Given reports of similar cases in recent literature, it is worth reassessing the ethical arguments to examine their cogency and generality and the principles that ethics committees, advisory and professional bodies, and courts throughout the developed world ought to follow in decisions being made about such children.

The ethical arguments in the literature can usefully be clustered under the following headings:

- 1) Issues to do with Ashley's well-being
- 2) Issues about making decisions for children and impaired adults
- 3) Issues concerning disability rights
- 4) The entanglements of different parties in pediatric ethics and the various dilemmas created by dependency

The principles formulate a way of ethically evaluating the arguments about the treatment of children with developmental delays and of asking whether severe disorders create a special subset of such cases. I argue that the two principles are helpful in evaluating claims about the best interests of the child in these cases.²²

Justifications for the Ashley Treatment

Well-being. Ashley would plausibly have a better life if she were to live with her family rather than being cared for in an institution, and although the family can manage her as a small person (with a body size commensurate with their abilities and her mental age), they cannot realistically see how they would cope with Ashley were she to have an adult body type with the increased physical and other burdens (such as menstrual care and toileting) that would inevitably arise and radically alter Ashley's place in the family and her relationship to them (for instance, through the intrusion of physical aids like hoists).

Therefore there is an argument based on well-being and on the fact that, neuro-cognitively, she is a dependent child with very limited capacities; this argument invokes both ease of care and the value of a family environment to support the idea that she should be enabled to continue in an environment where she is loved

and nurtured in a family-type way. Arguably, for cases like Ashley, the family has a highly significant role in “holding the child in being” in a distinctly moral and caring way that effectively coheres with her identity as a very limited psychological subject.²³ If she grew physically and could not be managed at home (or at least not without the intrusion of technologies such as hoists and other devices), the resulting changes would plausibly disrupt and even nullify significant “subjective goods” that arise from Ashley’s place in family life.

Prevention of harm. Health and risk avoidance furnish a further well-being-based argument. In the future, Ashley faces problems with menstruation, the risks of institutional care, and problems with physical management (which are significant for full-grown human individuals who lack the capacity for self-care). There are also other risks, such as pregnancy or sexual abuse if a situation should arise in which somebody takes advantage of Ashley’s passive but sexualized body. Given Ashley’s lack of the mental capacity to appreciate or enjoy the pleasures associated with these risks (the physical enjoyment of a range of bodily activities and settings and the emotional and sensual pleasures of sexual relationships), it is plausible that anyone with the mental age of a six-month-old infant—like Ashley—should not have to run them, nor should we create a situation that exacerbates them. The prevention of developments that are going to set the stage for those risks does not in any way preclude her from activities or experiences and engagements that plausibly contribute to her well-being—“the structures of intimacy where there is a responsibility to care for someone who is seriously ill or disabled.”²⁴ Pleasures of family proximity and caregiving make it possible for her to go on having experiences of the kind she seems to enjoy and that are constitutive of the fabric of life that emerges for her. These could be called relational goods of the type indicated by Nelson; they arguably create all the identity she could have, and they overlap with experiential goods of others.

Removal from her family poses other risks to Ashley, including the risk of nosocomial infection in institutions. Such infections are rife—as is indicated by the infamous Willowbrook experiments²⁵—but can be largely avoided by home management and caregiving contact limited to a small, dedicated circle of carers. Given that the prevention of potential harm is an ethical (and legal)²⁶ duty owed to any dependent person, it plausibly adds to the justification for Ashley’s treatment.

Realistic potential. Sterilization and the loss of her natural capacity for motherhood—as they are related to potential and individual dignity—are sometimes adduced as objective harms to Ashley,²⁷ but that claim depends on a biological view of motherhood that is not accepted in reproductive ethics and can be said to “devalue all other forms of parenthood . . . [and] the love and loyalty that can develop between rearing adults and the children who flourish under their care.”²⁸ Such arguments, despite giving a reason for not allowing the widespread sterilization of those deemed to have disabilities, are not relevant to Ashley (or those as severely affected as she seems to be), in that there is no capacity for any form of participation in parenting in such a child whose reduced state introduces a different set of ethical considerations.

If purely biological (as distinct from experiential) motherhood is all that is possible for a child like Ashley, and if any satisfying relationships in which sexuality can be explored and expressed are denied her, there is a real (and empirically justified)

concern about abuse in institutions.²⁹ Sexualized but cognitively immature and socially marginalized women seem to be particularly at risk in this way.³⁰ Thus, if the possibilities normally associated with sexuality and pregnancy are decoupled from any redeeming satisfactions and are also a source of health risks (pregnancy and/or sexually transmitted diseases) or clear objective harms, those considerations weigh only on the side of arguments for the treatment.

Objections to the Ashley Treatment

Lack of medical indications. Some regard Ashley's treatment as maiming her physically without any justifying benefit because there were no medical indications for it.³¹ However, that seems to ignore a sense of health benefit that takes account of the total effects of a medical intervention on the life of the person concerned—here, a severely impaired and dependent child. To focus the debate on medical conditions and their treatment, narrowly construed, ignores a realistic assessment of Ashley's potential and her ongoing identity.³² Such a focus would, for instance, speak against interventions prompted by life choice reasons, such as state-funded birth control, the legal termination of pregnancy for reasons other than an imminent threat to the health of the mother, and many cosmetic interventions (such as the removal of birthmarks), any and all of which, despite the fact that the indications for intervention are prominently social, are usually accepted as genuine medical needs.

Treatment for the sake of others. Some argue that Ashley's treatment in fact constituted treating her as a means according to a parental agenda and not as an end in herself,³³ but this is a very incomplete understanding of what was done for her. The decisions seemed to be determined by Ashley's best interests as a socially engaged human being who had an identity and presence especially valued within her family—a supportive and nurturing social context. Henaghan argues persuasively that in such cases “the best interests of the child” can be found by “weighing and balancing factors which are relevant in the particular circumstances of each case without any rigid preconceived notion as to what weight each factor should have.”³⁴

It is argued that Ashley, a developing human being, should not be infantilized and should be allowed to follow her natural developmental path³⁵ to safeguard her dignity. This is, however, rhetorical and underanalyzed (as I have indicated), in that a relational account of dignity and well-being in the light of a realistic assessment of her potential is best understood in the context of situated human lives and an adequate understanding of what makes our lives with one another meaningful and valuable.³⁶ Analyzed in that way, Ashley has already reached her potential and would be harmed by sexualization and further physical growth.

Were Ashley to be capable of the (perhaps “Gillick-competent”³⁷) life choices of a young woman, the arguments against her treatment would have some purchase, but, given that she has such severe arrested development, these arguments are so abstract that they lose touch with reality. She cannot be a lover, mother, or partner in a meaningful social and/or legal relationship, and so to argue that she should retain the mere biological substrate of those realities given that they may prove an

encumbrance (according to parental and medical assessments)³⁸ perpetuates a narrow and biologically reductionist view that both demeans our humanity and underscores Ashley's tragically limited potential.

Interference with nature. That we are interfering with nature and therefore playing God with Ashley adds little to the objections but also neglects the fact that clinical medicine and healthcare in general do interfere with nature, but for properly welfare-related reasons.³⁹ The concept of the natural is notoriously fraught and has been since Hume.⁴⁰ The interference itself is not an issue, provided only that it falls within an intent that is plausibly aligned with the best interests of the individual concerned. "Interference" in clinical practice (both adult and pediatric), supports at-risk neonates, combats life-threatening diseases, shunts Cerebro-Spinal Fluid CSF in children with hydrocephalus, modifies fertility, provides prophylactic radical surgical treatment for future breast cancer in BRCA1& 2-positive patients, addresses the potential effects of other genetic tendencies, and, specifically in pediatric medicine, prevents or mitigates the effects of PhenylKetonUria (PKU), cystic fibrosis, and gluten intolerance. In each setting we aim to counteract a natural anomaly so that that child can have as close to a fulfilling human life as she or he is capable of. The same consideration, in Ashley's case, gives considerable support to measures designed to allow her to be taken care of by her family and, as has been argued, gives no support to arguments based on the assumption that she could ever have a normal female life.

This objection is vulnerable not only to the arguments about realistic potential and what kinds of well-being a child like Ashley is actually capable of but also to reflections on what kinds of intervention in children—and for what ends—are within the ambit of justified healthcare. Such reflections can be legitimately used to critique some uses of drugs in children (for instance, treatments for ADHD that preempt their right to an open⁴¹ future and change them according to social norms),⁴² but, as has been argued, they are not cogent in Ashley's case, in which narrow or biological assessments of the aims of healthcare miss the richness of full human engagement and therefore can seriously distort our understanding.

Discrimination against disability—a deficit discourse. Detrimental evaluations of impaired human beings can lead to what Hacking calls "the looping effect of human kinds," whereby the potential of a human being is stunted by attitudes about that person and by a milieu constructed around him or her that constrains the kinds of future and role in society that the individual can attain.⁴³ This social construction of disability often works against children who are different, causing them to have their life choices restricted because they are credited with a lesser capacity than a careful and conducive assessment would reveal. That reality highlights the need for assessments to be revisited and informed by the best possible clinical evidence and for an open-minded, realistic view of potential social function.

There are, however, cases in which even the most optimistic and well-meaning efforts to enhance personal capacity hit a fairly hard limit. Severe and irreversible encephalopathy (like Ashley's) must inform any realistic projections about future developments, and, in Ashley's case, those seem to have been well grounded and properly taken into account in accordance with the potentiality principle and the principle of psychosomatic harmony.

Against these objections to the Ashley treatment (*viz.*, lack of medical indications and risk of medical harm, destruction of potential, treatment of the person as a means and not as an end, and discriminatory treatment against the disabled) certain positive considerations, in addition to the rebuttals already offered, seem to help clarify a good resolution for Ashley and her family.

First, as noted, inclusive assessments of health and well-being allow us to construe harm and benefit quite broadly to include the relationships, actual experiences, and realistic life activities open to a given human being; this approach allows us to avoid making decisions that may cause loss of, or harm to, any meaningful modes of interaction (given an individual's neurocognitive state). This avoids the danger of rhetorical abstraction applied to a given human on the basis of his or her merit according to considerations relevant to a wider group (such as children with developmental impairment in general). Such a realistic assessment must be addressed to elucidate questions often unhelpfully clumped together under the term "futility."⁴⁴

Children are an organic part of families, and thus decisions in their best interests should take due note of the relational facts that structure that context. Ashley cannot be anything more than a moral patient in many decisions about her; thus we should generally try to act in accordance with the family's values (provided they are not objectively contrary to widely shared conceptions of the best interests of a child). A parent's ideas might violate such an "objective" conception—for instance, in relation to objections to blood transfusion among certain religious groups or "faith healing" in conditions like type 1 diabetes. However, both of the examples cited violate the potentiality principle by posing significant risks to healthy development.

Assessments that pay careful regard to the potentiality principle⁴⁵ (which is closely related to the right to an open future and to a developmental interest⁴⁶) formulated with the aid of clinical and social assessments in a particular case would allow realistic projections that do not appeal to inappropriate considerations that might legitimately arise in the context of broader health policy relating to human development and the needs of certain groups.

Against the arguments about the right to a future that includes unimpeded or natural female development, we should repeat that there is no inherent dignity in sexualization, menstruation, or fertility, except insofar as they are part of a broader picture of female engagement with and growth in the human lifeworld (the broader aspects of motherhood mentioned previously). Ashley had very limited potential in that respect, and thus the future did not hold out for her the same prospects that it might have for (and that might be denied to) other female children who are sterilized.⁴⁷

Dignity, if we were to take that as a guiding thread in Ashley's treatment, must therefore be calibrated against her actual lived reality and must be commensurate with her own potential. The kind of dignity we afford a child should not involve inappropriate sexualization, and it may even be a type of abuse to enact or allow a child (or anybody who is genuinely unable to participate in healthy sexual exchanges and relationships) to become a sexualized individual (as is mentioned by George Dvorsky in relation to the case).⁴⁸ When that consideration is taken seriously, we see that sexual development is not plausibly a proper part of Ashley's life, as she is permanently and definitively unable to enter into a meaningful sexual or maternal relationship with another human being.

It therefore looks as if the various objections to the kind of treatment used in the Ashley case may or may not have traction depending on the details of the case. But is there any positive argument for treating her in the way that she was—with growth attenuation and desexualization?⁴⁹ At the very least, these disputes mandate that “plastic body issues and the ‘wrong body’ rhetoric that accompanies them be elaborated and explained,”⁵⁰ which brings us to at least one argument with considerable traction in another area of medicine—gender dysphoria—that may provide an ethical analogy applicable to the Ashley treatment viz. the idea of psychosomatic harmony.⁵¹

Reflections on Neo-Aristotelian Principles in Light of the Case

The Potentiality Principle

The potentiality principle reflects a child’s interest in development and requires that we give each child the best chance we can of fulfilling its inherent potential. Feinberg and others note the importance of inherent characteristics in young human beings and point out the legal recognition that it is in the interest of any child to develop as normally as possible,⁵² an intuition that is apparent in the following case:

Carl is in the 97th percentile for cognitive and sensorimotor development until 18 months old and then becomes unwell. The doctor diagnoses an intercurrent viral infection and advises clear fluids and observation. During the night, his parents become worried but, reassured by the doctor’s advice, only give the increasingly feverish and fractious child some energy drink. By the next morning Carl is seriously unwell and is taken to the emergency department of a local hospital. Meningitis is diagnosed, and Carl is treated but suffers severe brain damage. After it has settled down, he begins to fall through the percentile curves and ends up in the 15th percentile.

Such cases reinforce the ethical importance of potentiality—and its loss or compromise through events during a child’s life—in determining what is due to children. Aristotle distinguishes first potential from second potential. *First potential* represents the capacity to develop as a human organism typically does and to live a characteristically human life—a capacity not present in anencephaly. *Second potential* indicates the process by which a human being acquires a range of properties (such as speech, perception, or coordinated motor function) during development. For Aristotle, human beings have vegetative, animate, and intellectual capacities, which constitute characteristic human functioning. If properly developed, they interact to form a harmony or integrity of function unique to a human soul; thus a human being does not eat as an animal eats (and so haute cuisine, obesity, and anorexia are made possible) nor have sex in the same way (we fall in love, form stable and exclusive relationships, become jealous, sing silly love songs, send Valentine’s Day cards, move into mansions to impress former lovers, and create a myriad of other expressions of self related to our sexuality). We also move in ways that animals do not move (we dance, play sports, and affect cultural mannerisms), and our cognitive capacities are focused on truth and falsity (in an ultimate or even ultramoral sense) in a way that animal cognition is not.

The human soul (or psyche), as per Aristotle, is compatible with both secular and religious approaches to human life, unlike Plato's conception whereby the soul enters the human body at a given time and departs at death to return to heaven. In fact, one could argue that the Platonic thesis that the soul is wholly other than the body seems to imply that neither the physical vessel nor the span of earthly life has essential relevance to the life of the soul, apart from the need for a body capable of sustaining that life.

Aristotle's naturalistic approach focuses on a unity or harmony within the human form; thus to treat the facets of the soul reductively or in a piecemeal way (and run through the analytic mill of necessary and sufficient conditions) is to miss his point about what makes human life worthwhile. A plausible holism about the psychosomatic nature of a human being makes it clear that the potentiality of a human child is more relational than individual and affects both emotional and cognitive development, as is captured by Duff and Campbell's phrase "the capacity to love and be loved."⁵³

So a common remark of expectant human parents—"We will be happy as long as he or she has ten fingers and toes"—conveys the hope that a child lies within a broad conception of being a living human soul and that even a child who is not well formed may be considered to be "our instance"—entrusted to us in this place at this time—of something unique and quite irreplaceable. Of course we hope that she or he will not suffer and will have a "good enough" life, knowing that that is a somewhat vague idea and, as in the case of Carl, may be tragically cut off. The vagueness reflects the fact that a good enough human life does not have the stereotypy of most biological functions and that it may be tragic because of the possible mismatches between the vague and open-ended essence of humanity and an actual existing life. The many different ways of being human create an abiding problem in defining human identity and laying out in abstract but principled terms the moral demand instantiated⁵⁴ when a child is born; this problem necessitates that ethicists develop an appropriate sense of life to bring to mortal decisions.⁵⁵ With these holistic and psychosomatic thoughts in mind, we can consider the case of gender reassignment as an illustration of a principle imperfectly articulated but influential in our ethical decisions about children.

An Ethological Principle: Psychosomatic Harmony

The gender reassignment analogy. The rationale for gender reassignment is deceptively simple:

1. X is psychologically (or subjectively and unalterably) a woman/man.
2. X has unfortunately been burdened with a body that does not match his or her subjective/psychological identity.
3. X's subjective identity is inalienably X's and cannot be changed.
4. X's body should be redesigned so that X can enjoy psychosomatic harmony.

One possible rejoinder is the somewhat dismissive *Napoleon argument*: If somebody thinks he is Napoleon, you do not give him an army.

The Napoleon argument strikes one as insensitive and neglects a real need to decide what to do with those who experience gender dysphoria. Statistics about

psychological distress and the effects of surgery are not compelling, so decisions tend to be based on patients' and their doctors' assessments of how best to treat the problem and are constrained by a "reasonable medical practice" test based on evidence.⁵⁶ Despite the uncertainties here, a principle of psychosomatic integrity/harmony often underpins an implicit value whereby each person should be allowed to live a mode of life and enjoy a physical status maximally coherent with his or her own need for self-realization.⁵⁷ That could also be regarded as broadly in accordance with a form of the potentiality principle.

If we accept the broad idea of psychophysical harmony in human development, then an analogy appears in relation to a child who is developmentally limited. If an inherently female psyche (or subjective identity) creates a reasonable case for an intervention that enables the person concerned, as far as possible, to live a life that is fitting in terms of that identity, then certain medical interventions to that end may be justified.⁵⁸ We do, for instance, consider sexual orientation as an important element in identity and try to not impede the formation of relationships in accordance with that orientation. That may imply mere tolerance or may go as far as justifying medical intervention for gender reassignment. Reasonable physiological interventions, and even quite radical surgery, are assessed with that in mind. Thus an analogy arises: if a gendered psyche is a ground on which a person can be (re)assigned an appropriately gendered and perhaps modified body (*soma*), then perhaps a perpetually infantile psyche should be a ground on which we might consider assigning an infantile body. In both cases, certain critical facts as to the reality of the psychic (or subjective) identity and the harms involved in the proposed treatments need careful weighing, but, where the harms do not violate the realistic future potential of the individual and where the psychosomatic categorization is fairly secure,⁵⁹ there seems to be no further ethical impediment.

Points of disanalogy between the cases. In the case of gender reassignment, there is often quite a long history during which evidence has accrued that the patient's gender dysphoria and wishes for the future have been evaluated by a multidisciplinary team of experts. This allows patient consent to be evaluated against a narrative context that can be subject to various distortions (parental attitudes or biases, for instance).

Whereas, in the case of an adolescent who requests gender reassignment, doubts may be raised and perhaps allayed by an interview with the patient, no first-person perspective is available for Ashley and children like her, and the views of others (family members and professionals)—informed by realistic assessments of potential—form the only basis on which to decide what to do.

Patient distress is a powerful indication of therapeutic need for young people trapped in a gender-inappropriate body, but no such dysphoria, along with attendant sociocultural meanings and interpretations, can reasonably be discerned in Ashley-like cases. Given the lack of current distress and the alleged harm of the proposed interventions, one could argue that the burden of proof is too high to proceed in such cases. But that view puts disproportionate weight on a narrow medical view of welfare and fails to recognize that human well-being is highly relational and that Ashley's (severely limited) subjectivity can only adequately be expressed in the context of her family.⁶⁰

There is also a disanalogy that works in favor of the Ashley decision and is based on a firm and realistic prognosis about future neurological status. We can plausibly

discern a clear benefit (being able to live in an established context of care) that applies to an infant (such as Ashley and others like her),⁶¹ whereas in the gender reassignment case, the possibility of *meconnaissance*⁶² means that our interventions are based on an unclear prognostic benefit that depends on a subjective prediction of heightened future well-being, and there is a lack of first-grade clinical evidence along with lingering reservations about psychosurgery (physical interventions for psychological distress), both of which are relevant to such cases (perhaps the self-image, not the body, is broken).⁶³

On balance, something like a principle of psychosomatic harmony provides an attractive clinical rationale for Ashley's treatment in a way that is analogous to its implicit role in gender reassignment practice, where it allows us to make ongoing use of a classical ideal (that of harmony between mind and body as the key to health).

The Ashley Treatment: A Fine Balance of Reasons and Sensibilities

I have noted that the Ashley treatment can in some respects represent a compassionate and best-interest-based approach to a tragic human situation. It does not violate the potentiality principle that we recognize in most pediatric settings, and there is in such cases a parallel justification to that for gender reassignment based on the assessment of what is appropriate as a bodily expression of the holistic (psychosomatic) form of the individual concerned.

To accept such an argument for the Ashley treatment (or something like it) in relevant cases depends, however, on a firm prediction of future development and genuine concerns about what is fitting for the individual concerned, so as to maximally safeguard his or her best interests. That requires careful diagnosis and support for parents, to avoid a situation in which they are faced with the daunting prospect of being left to their own resources and are unsupported in coping with what has happened. That path led to a tragic set of events in the New Zealand context⁶⁴ as well as in Britain.⁶⁵

There are certain constraints to be met in cases like that of Ashley: decisionmakers must seek to justify interventions that allow her to continue in a loving environment; she must be protected from future harm or burdensome and inappropriate life events (such as pregnancy); the set of interventions chosen must have minimum adverse effects on her subjective well-being (such as it is); and medicalization and disruption of her context of care must be avoided. When these constraints are met, the decisions taken can be considered to be in her best interests in that they respect both her psychosomatic integrity (one way of reading the dignity of the individual) and her potential. In general we might conclude, in such cases, that for any child the most fitting thing to do is to preserve those relationships and connections that hold him or her in being.⁶⁶

Such a response to an Ashley-like situation in which there is a significant limitation of the normal developmental trajectory must, necessarily, be based within a framework of values that underpin that family and its culture as well as being in accordance with a quasi-objective (informed, considered, compassionate, and widely shared) assessment of the best interests of the child. I have argued that two broad constraints—the potentiality principle and the principle of psychosomatic harmony—can fill out our conception of best interests in a helpful way for cases in which it is hard to see a more simple and intuitive basis readily available. It is likely that cases of conjoined twins and infants with severe neurological impairments

will demand an attentive regard for what, in the human lives concerned, is genuinely of worth to the individuals concerned, but that may well run counter to the narrow biomedical assessments used by some to delineate the best interests of the child.

Notes

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5. *Queensland v. Nolan* [2002] 1 Qd R 454, at 460.
6. See note 5, *Queensland v. Nolan* 2002, at 455.
7. See note 5, *Queensland v. Nolan* 2002, at 455.
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9. See note 5, *Queensland v. Nolan* 2002, at 456.
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11. See note 5, *Queensland v. Nolan* 2002, at 458.
12. Dreger AD. *One of Us: Conjoined Twins and the Future of Normal*. Cambridge, MA: Harvard University Press; 2004.
13. See note 5, *Queensland v. Nolan* 2002, at 457.
14. See note 5, *Queensland v. Nolan* 2002, at 460.
15. Such as *Airedale NHS Trust v. Bland* [1993] AC 789; *Re G* [1997] 2 NZLR 201; *Re Quinlan* 429 US 922 (1976); *Re Guardianship of Schiavo* 851 SO 2d 182 (2003).
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18. See note 12, Dreger 2004.
19. See note 3, Diekema, Fost 2010, at 30.
20. See note 3, Diekema, Fost 2010, at 30.
21. Liao M, Savulescu J, Sheehan M. The Ashley treatment: Best interests, convenience, and parental decision-making. *Hastings Center Report* 2007;37(2):16–20. Caplan, A. Is Peter Pan treatment a moral choice? Debate over stunting a disabled child's growth pits comfort against ethics. MSNBC website, January 5, 2007. Available at: <http://www.msnbc.msn.com/id/16472931> (last accessed 29 Aug 2015).
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23. Lindemann Nelson H. What child is this? *Hastings Center Report* 2002;32(6):29–38.
24. See note 23, Gillett 2009, at 30.
25. Beecher HK. Ethics and clinical research. *New England Journal of Medicine* 1966;274(24):1354–60.
26. The New Zealand Crimes Act, section 151 <http://www.legislation.govt.nz/act/public/1961/0043/latest/DLM329292.html> (last accessed 10 May 2015) <http://www.legislation.govt.nz/act/public/1961/0043/latest/DLM329292.html> (last accessed 10 May 2015) states: "Every one who has actual care or charge of a person who is a vulnerable adult and who is unable to provide himself or herself with necessaries is under a legal duty—(a) to provide that person with necessaries; and (b) to take reasonable steps to protect that person from injury." Most legislatures have such a duty prescribed to caregivers and health professionals.
27. E.g., Diekema, Fost 2010 (see note 3); Liao et al. 2007 (see note 21).
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35. See note 3, Diekema, Fost 2010, at 34.
36. See note 28, Murray 1996; see note 23, Lindemann Nelson 2002; Gillett G. *Subjectivity and Being Somebody: Human Identity and Neuroethics*. Exeter: Imprint Academic; 2008.
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45. See note 22, Gillett 2009.
46. See note 37, Douglas 1992.
47. See note 3, Diekema, Fost 2010, at 38.
48. See note 21, Liao et al. 2007, at 19.
49. See note 21, Liao et al. 2007, at 17.
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