



ORIGINAL ARTICLES

THE ASHLEY TREATMENT: IMPROVING QUALITY OF LIFE OR INFRINGING DIGNITY AND RIGHTS?

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ABSTRACT

The ‘Ashley treatment’ (growth attenuation, removal of the womb and breasts buds of a severely disabled child) has raised much ethical controversy. This article starts from the observation that this debate suffers from a lack of careful philosophical analysis which is essential for an ethical assessment. I focus on two central arguments in the debate, namely an argument defending the treatment based on quality of life and an argument against the treatment based on dignity and rights. My analysis raises doubts as to whether these arguments, as they stand in the debate, are philosophically robust. I reconstruct what form good arguments for and against the treatment should take and which assumptions are needed to defend the according positions. Concerning quality of life (Section 2), I argue that to make a discussion about quality of life possible, it needs to be clear which particular conception of the good life is employed. This has not been sufficiently clear in the debate. I fill this lacuna. Regarding rights and dignity (section 3), I show that there is a remarkable absence of references to general philosophical theories of rights and dignity in the debate about the Ashley treatment. Consequently, this argument against the treatment is not sufficiently developed. I clarify how such an argument should proceed. Such a detailed analysis of arguments is necessary to clear up some confusions and ambiguities in the debate and to shed light on the dilemma that caretakers of severely disabled children face.

1 INTRODUCTION

Ashley is a girl with severe cognitive and physical disabilities. She is expected to remain at roughly the developmental age of a three-months old child. When she was six years old, her parents started a controversial treatment, by now known as ‘the Ashley treatment’. The treatment included growth attenuation through high-dose estrogen therapy to keep her child-sized, hysterectomy (surgical removal of the womb) and breast bud removal.¹ The aim

of the treatment was, as her parents continuously maintain, to provide Ashley with the best possible quality of life.² The treatment was conducted as planned and was, according to Ashley’s parents and physicians, a great success.³ However, the first publication on the case in

¹ D.F. Gunther & D.S. Diekema. Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma. *Arch Pediatr Adolesc Med* 2006; 160(10): 1014.

² Ashley’s Mom and Dad, The Ashley Treatment, Towards a Better Quality of Life for ‘Pillow Angels,’ 2012, 3, <http://www.pillowangel.org/>.

³ E. Pilkington. The Ashley Treatment: Her Life Is as Good as We Can Possibly Make It. *The Guardian* 2012 March 15. <http://www.theguardian.com/society/2012/mar/15/ashley-treatment-email-exchange>.

2006 sparked a media firestorm. The case has raised a vigorous ethical controversy.⁴

This article starts from the observation that the debate on the Ashley treatment has not paid much attention to a careful philosophical analysis, which I will show to be essential for a detailed ethical assessment. Proponents and opponents of the Ashley treatment debate often fail to make their underlying assumptions explicit. In addition, it is also frequently unclear how the argument exactly proceeds and hence difficult to judge whether the arguments are sound. To give just one example, it is striking that a number of authors – either for or against the treatment – discuss the Ashley treatment as a package of the threefold treatment of the hormone treatment, the hysterectomy and the breast bud removal.⁵ However, the three different interventions subsumed under the heading ‘Ashley treatment’ demand a differential analysis and judgment. Hormone therapy with skin patches to keep someone at the current height and weight might involve other considerations than surgery that leads to infertility. It is possible to argue that one intervention is morally permitted whereas the other might not be. Not all authors separate these points. This is unfortunate because a more detailed analysis of the philosophical issues could be helpful for caretakers of children in a similar situation to Ashley who wonder about how to best take care for them.

I will argue that the contribution of philosophy to the discussion about the Ashley treatment is at least twofold: firstly, to shed light on the dilemma that those caretakers face, and secondly, to clear up some confusions and ambiguities in this debate. I will show what form good argu-

⁴ For readers not familiar with the case, it might be helpful to review the development of the discussion: the Ashley-treatment was first published in a medical journal at the end of 2006 by her attending physicians, see Note 1. A controversial discussion followed. Among the immediate reactions for and against the treatment, are A.L. Caplan. Is ‘Peter Pan’ Treatment a Moral Choice?. *Msnbc.com*, 2007 Jan 5 http://www.nbcnews.com/id/16472931/ns/health-health_care/t/peter-pan-treatment-moral-choice/; T. Shakespeare. Honey, We Shrunk the (Developmentally Disabled) Kid!, *BBC Opinion*. 2006 Nov 19 http://www.bbc.co.uk/1/health/2006/11/061119_ashley_kid.shtml; P. Singer. A Convenient Truth. *The New York Times*. 2007 Jan 26. sec. Opinion, <http://www.nytimes.com/2007/01/26/opinion/26singer.html>. At this point, Ashley’s parents set up a weblog to provide their perspective (<http://www.pillowangel.org/>). A few years later, two bioethicists involved in the case offered a defence of the treatment by discussing an impressive number of critical arguments: D.S. Diekema & N. Fost. Ashley Revisited: A Response to the Critics. *Am J Bioeth* 2010; 10(1): 30–44, doi:10.1080/15265160903469336.

⁵ A. Asch & A. Stubblefield. Growth Attenuation: Good Intentions, Bad Decision. *Am J Bioeth* 2010; 10(1): 46–48, doi:10.1080/15265160903441111; J.P. Jerosco & C. Feudtner. Growth Attenuation: A Diminutive Solution to a Daunting Problem. *Arch Pediatr Adolesc Med* 2006; 160(10): 1077–1078; S.D. Edwards. The Ashley Treatment: A Step Too Far, or Not Far Enough? *J Med Ethics* 2008; 34(5): 341–343, doi:10.1136/jme.2007.020743. Asch and Stubblefield, like Broscio and Feudtner, actually only analyse growth attenuation, but they equalize a judgment about it with a judgment about the Ashley treatment. Edwards bundles the different aspects of the treatment together.

ments for and against the treatment could take. By doing so, I want to develop a philosophical framework in which the empirical facts regarding the case can be interpreted. I will focus on two central arguments in the debate, namely an argument defending the treatment based on quality of life (Section 2) and an argument against the treatment based on dignity and rights (Section 3).

2 QUALITY OF LIFE

The treatment was mainly motivated by the wish to improve Ashley’s future quality of life. It is argued that the treatment is eventually beneficial for her if harms and benefits are balanced.⁶ Being smaller and lighter will make it easier for Ashley to be carried around and kept in motion. This is good for her blood circulation, digestion and to avoid bed sores, and her parents report that it is also enjoyable for her. Furthermore, according to them it will make it at least easier or even actually possible for her parents to continue caring for her at home and avoid institutionalization. The removal of the breast buds lets Ashley’s chest remain flat and according to her caretakers avoids uneasiness about lying down and being strapped in a wheelchair with the big breasts that she was likely to develop, given her family history. As her doctors report, removing the womb should mainly free Ashley from menstrual cramps, but it was also considered necessary because the hormone therapy she received would increase the risk of developing a tumor in the womb. In comparison to these benefits, it is argued that the operation itself to remove the womb and the breast buds induces only a small harm.

The contribution of the treatment to Ashley’s quality of life is still one of the main arguments discussed. Most of this discussion revolves around the question whether the treatment did indeed improve Ashley’s quality of life.⁷ Yet, there are many different conceptions of ‘quality of life’. To make a discussion about quality of life possible, it needs to be clear which particular conceptions are referred to. Only then it can be evaluated in a next step whether the treatment contributes to quality of life. Which of these notions of quality of life is used in the Ashley debate has so far not been sufficiently clear. I would like to fill this lacuna. Furthermore, I would like to reflect on the fundamental assumption of this argument that quality of life should be the guiding principle in deciding about the treatment. As quality of life is predominantly debated to argue in defence of the treatment, I will also focus on that side of the debate.

⁶ Ashley’s Mom and Dad, *op. cit.* note 2; Gunther and Diekema, *op. cit.* note 1.

⁷ Ashley’s Mom and Dad, *op. cit.* note 1; Diekema and Fost, *op. cit.* note 2; Gunther and Diekema, *op. cit.* note 1; Disability; Singer, *op. cit.* note 4.

Arguing for the Ashley treatment based on quality of life has to start with explaining why quality of life should be the guiding principle in the first place. How could such an argument proceed? Clearly, the decision to undergo or forego the treatment cannot be left to the patient, as is commonly required in medical ethics, because Ashley is unable to make her own decision.⁸ Therefore, her parents have to act as guardians. They cannot reflect on Ashley's values and way of life to make a decision that she would agree with because she has never been autonomous, not even in a minimal sense. However, Ashley has certain interests, at least an interest in avoiding pain, and she enjoys certain things, like for example being cuddled by her parents and siblings. The best her parents can do is to protect her interests and make a decision for her regarding what is in her best interests.⁹ This still leaves the question open what best interests, well-being or quality of life specifically mean for Ashley. In the philosophical literature, three prominent accounts of well-being are discussed:¹⁰ hedonistic theories, desire theories and objective list theories. I will examine all three theories in turn to see how they specify the well-being of someone like Ashley, and what each of those particular accounts of well-being imply for arguments defending this treatment.

First, hedonistic theories determine well-being in terms of mental states, that is, in terms of experiences of pleasure. Good quality of life is understood as a positive pleasure-pain-balance. In that sense, Ashley can have a good quality of life, as she can apparently experience pleasure in terms of enjoyable activities like being on the swing or having a bath. Ashley can also experience physical pain. What does it then mean to apply a hedonistic theory to this case? Even though the best interest standard is in the literature sometimes discussed as *maximizing* the fulfillment of someone's interests, it is commonly not understood as such.¹¹ For example, it does not seem reasonable to ask Ashley's parents to quit their jobs, leave their country and move somewhere else only because a different climate might be slightly better for Ashley. This introduces a difficulty for the best interest standard: there are often different interests at stake. First, the interests of

others will at some point provide a limitation for the interests of the child. Second, interests can be intertwined, which makes it unclear for whose pleasure-pain-balance they should count. Whereas the first problem is not important for the Ashley treatment, the second one plays a role. The treatment makes caring for Ashley less difficult for her caregivers. It is sometimes argued that this advances the interests of Ashley's parents, but actually not the interests of Ashley.¹² Letting someone who has no power of veto undergo an operation for the sake of someone else is difficult to defend. In defence of the Ashley treatment, it needs to be argued that the treatment serves Ashley's interests at least as well. That means that the degree to which her needs are met and her interests are protected and fostered is greater in the state with treatment than in the state without treatment. It is defensible to argue that being lifted up with a metal stander to be removed from bed and conveyed on pulley systems into the bath provides less pleasure or comfort than being carried and cuddled by a parent. Even if mechanical support systems are in general available, first, they cannot support every need, such as for example diaper changes and positional changes at night, or being carried into a friend's inaccessible home; and second, they simply feel different from human arms.¹³ It is sensible to assume that most of us prefer human touch to mechanical support.¹⁴ Besides, this argument assumes that if without the treatment Ashley has to live in an institution because her parents cannot handle the care anymore, this is worse for her pleasure-pain balance. Again, although difficult to prove, this seems reasonable.

Concerning the potential harms of the treatment, Ashley will be deprived of some bodily functionings that other women have. Specifically, she will be extraordinarily small, she will have no breasts, no menstruation and be infertile. Losing these functionings should not be considered a substantial enough harm to counter the treatment. A defender of the treatment within a hedonistic account could say that Ashley will in any case not be able to make use of those functionings. Normally, a full-grown and developed body is at least advantageous if not necessary for doing certain things such as having children, a sexual life or even applying for a job. Regardless of her bodily size and degree of sexual maturity, many opportunities as these remain in all likelihood

⁸ See for a discussion of informed consent to let a patient make a treatment decision according to her or his own values N. Eyal. Informed Consent. In: E.N. Zalta, editor. *The Stanford Encyclopedia of Philosophy*. Fall 2012, <http://plato.stanford.edu/archives/fall2012/entries/informed-consent/>.

⁹ For a discussion of the best interests standard, see D.W. Archard. Children's Rights. In: E.N. Zalta, editor. *The Stanford Encyclopedia of Philosophy*. Summer 2011. <http://plato.stanford.edu/archives/sum2011/entries/rights-children/>; A.E. Buchanan & D.W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making* Cambridge University Press; 1989; 122–134.

¹⁰ D. Parfit. *Reasons and Persons*. Oxford: Clarendon Press; 1984. 493–502.

¹¹ Archard, *op. cit.* note 9; L.M. Kopelman. Children and Bioethics: Uses and Abuses of the Best-Interests Standard. *J Med Philos* 1997; 22(3): 213–217.

¹² G.D. Coleman. The Irreversible Disabling of a Child: The Ashley Treatment. *Natl Cathol Bioeth Q* 2007; 7(4): 711–728; E.B. Ellis. Disabling Children with Disabilities. *Arch Pediatr Adolesc Med* 2007; 161(4): 419–420; D. Sobsey. Ethics or Advocacy? *Am J Bioeth* 2010; 10(1): 59–60, doi:10.1080/15265160903460962.

¹³ Compare the narrative of Sandy Walker in B.S. Wilfond et al. Navigating Growth Attenuation in Children with Profound Disabilities. *Hastings Cent Rep* 2010; 40(6): 36, doi:10.1002/j.1552-146X.2010.tb00075.x.

¹⁴ A. Solomon. *Far From the Tree: Parents, Children and the Search for Identity*. Simon and Schuster; 2012. 389f.

unavailable for her. Of course, we cannot completely exclude the possibility that one day, Ashley's capacities could develop and these could then be real opportunities for her. Yet, despite the stimulating environment that is provided for Ashley since her birth, her capacities remain as little as they are and for all we can know, they will not develop further. It means that as Ashley has no use for growth and sexual maturity, one could argue that they have no value for her¹⁵. It means that bodily functionings have a merely instrumental value. Those functionings only have a value for something else, but not in themselves. Alternatively, one could claim that these functionings do have an intrinsic value¹⁶. Independently of the question what use Ashley can make of these functionings, being as tall as other women, having breasts and a womb would then be considered good. Clearly, a reason needs to be given why this should generally be the case and why this should be the case for a severely disabled child. It raises questions about the relationship between the person and the body. It is questionable what exactly the intrinsic value of functionings mean and whether it can be justified. Leaving those questions aside: in order to argue for the treatment, losing these functionings should be outweighed by the benefits of the treatment. Hence, if those functionings are valuable in themselves, this has to be a relative value that can be balanced against other values and also only a comparatively low one as it is outweighed by other values.

Yet, further argumentation will be needed. Suppose that within a hedonistic conceptualization of well-being the post-treatment state is better for Ashley than the no-treatment state. Then it would still need to be the case that the difference in quality of life between these two states is great enough to warrant surgical intervention which clearly involves temporary pain and discomfort. Only if the pleasure-pain balance is positive, is the treatment warranted. After all, if the philosophical analysis is accepted so far, more empirical information is needed to draw a definite conclusion. For example, we need to understand better how high is the risk of developing a tumor in the womb as a result of hormone treatment, or whether it is a real problem to have menstrual cramps so severe that birth control pills are not sufficient to alleviate the problem. Ashley's parents and doctors maintain that

these are sufficient risks to justify a hysterectomy, but others question these empirical facts.¹⁷ It is, however, not unreasonable to believe that the empirical evidence can be given, which makes the pro-intervention claim based on the quality of life, if properly spelled out and backed up with evidence, a plausible argument.

The second set of wellbeing theories holds that what is best for someone is that her desires should be satisfied.¹⁸ However, it is not straightforwardly clear how to determine Ashley's desires. There are certain activities which Ashley enjoys, but desires are not simply what provides one with pleasure. Desires and pleasures are conceptually distinct. Fulfilling a desire does not necessarily provide one with pleasure. For example, satisfying a desire to climb Mount Everest will most likely go together with stress and anguish, with a fear of failure and an experience of austerity. Desires are not valued, or at least not all desires, for the sort of experiences that result from them. There are different conceptualizations of desire discussed in the literature, but they all associate desiring with acting, feeling and thinking in certain ways.¹⁹ As far as we know, Ashley does not act or think in the relevant sense of these terms and if she does it, we have no means to have access to it. If a desire is only connected to feeling in a certain way, Ashley's desires would have to be interpreted as what she apparently enjoys. The desire account would then boil down to a mere hedonistic account. That means that desire theories of well-being are not applicable to Ashley and have to be omitted.

Third, objective list theories argue that some things are good for a person independent of that person's attitude towards them. Typical items on such a list are friendship, love and knowledge. It is possible that these things are in accordance with what one desires or what brings one pleasure, but the important difference to hedonistic and desire theories is that the 'good-maker' of items on an objective list has to be an objective reason as, for example, an account of human nature.²⁰

Using an objective list avoids the problem of assigning certain subjective states to a severely cognitively disabled person like Ashley. Whether an objective list theory of

¹⁵ Diekema and Fost, *op. cit.* note 4; Solomon, *op. cit.* note 14; M. Spriggs. Ashley's Interests Were Not Violated Because She Does Not Have the Necessary Interests. *Am J Bioeth* 2010; 10(1): 52–54, doi:10.1080/15265160903460863.

¹⁶ E.F. Kittay & J. Kittay. Bioethics Forum Blog – Whose Convenience? Whose Truth? A Comment on Peter Singer's 'A Convenient Truth'. *Bioethics Forum*. 2007; February 28, <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=350>; E.F. Kittay, Forever Small: The Strange Case of Ashley X, *Hypatia* 2011; 26(3): 610–631, doi:10.1111/j.1527-2001.2011.01205.x. In the next section, I provide a more substantial analysis of the argument given by the Kittays.

¹⁷ S.M. Liao, J. Savulescu & M. Sheehan. The Ashley Treatment: Best Interests, Convenience, and Parental Decision Making. *Hastings Cent Rep* 2007; 37(2): 18.

¹⁸ C. Heathwood. Welfare. In: *The Routledge Companion to Ethics*. Routledge; 2010. 650–652, who also discusses various problems of desire theories, most of which do not play a role in Ashley's case (for example the difference between current and future desires or hypothetical circumstances like full information that might change an evaluation of the situation).

¹⁹ T. Schroeder. Desire. In: E.N. Zalta, editor. *The Stanford Encyclopedia of Philosophy*. Winter 2009. <http://plato.stanford.edu/archives/win2009/entries/desire/>.

²⁰ See for examples of such an account R. Kraut. *What Is Good and Why: The Ethics of Well-Being*. Harvard University Press; 2009; M. Nussbaum & A. Sen, editors. *The Quality of Life* Oxford; New York: Clarendon Press; Oxford University Press; 1993.

well-being provides a reason for the treatment or not depends ultimately on the more specific conceptualization of the list. To employ such a theory to argue for the treatment, a few assumptions should be made. First, even though not all items on such a list are probably reasonably attainable for Ashley, one has to assume that at least some items are attainable for her, like for example giving and receiving love, having a bond with the family and laughing. Second, if not all items on the list are attainable for Ashley, it needs to be assumed that the merely partial applicability does not make the whole list irrelevant. It must be valuable to attain only some of the items on the list; it is not an all-or-nothing question. Third, one has to select and weight the items on the list in a way that suits the Ashley treatment. The capacities that were mentioned just now would probably all be improved by the treatment. Yet items like 'having a mature body' or 'growing', would counter the treatment. If those items are represented on the list at all, they have to be weighted in a way that the treatment provides Ashley with a higher wellbeing than the choice to not treat her. Thus, they cannot be understood as absolute entitlements, but should have a relative weight and also a comparatively low one. In the aggregate evaluation, they should be discounted. Again, it means that these bodily functionings cannot be considered as having a high intrinsic value. Alternatively, these items could be not represented on the list at all. This is the case when they are considered to be only valuable *for* something, for example, for sexual relationships, but not in itself. In this case, they have only an instrumental value. If all this is given, the Ashley treatment could be justified by reference to an objective list.

In my analysis of the application of all three theories of well-being, and I think in any reasonable analysis of well-being, Ashley's disability stands central. Because she is different from other children, quality of life means something else for her. Her disability is thus morally significant. Importantly, the moral significance of her disability does not have to imply that Ashley has a lower moral status. She might have morally to be taken into account to the same degree, but because her quality of life is determined by different factors due to her disability, accounting for quality of life simply means something else.²¹ I have argued that desire theories are not applicable to the case, but both hedonistic and objective list theories could be argued in support of the Ashley treatment if a few qualifications are made. Most importantly, these arguments have to assume that bodily functionings either have an instrumental value or a relative and comparatively low intrinsic value and that the aggregate gain in quality of life from the treatment is bigger than the temporary decrease in quality of life because of the surgery.

²¹ Compare section 3 for a more extensive discussion of dignity as a high moral status.

3 DIGNITY AND RIGHTS

One of the most prominent arguments against the Ashley treatment holds that the treatment is not compatible with Ashley's rights or dignity. Even though general theories of rights and dignity are discussed to a great extent in the philosophical literature, there is a remarkable absence of references to this literature in the debate about the Ashley treatment. Consequently, this argument against the treatment is not sufficiently developed. In the following, I will firstly show that the arguments as they currently stand are not philosophically robust, and secondly clarify how such an argument should proceed.²²

3.1 The argument in the literature

How do authors argue who think that the treatment interferes with Ashley's dignity or rights? Two rights are primarily taken to be relevant: a right to bodily integrity and a right to grow and develop. It is certainly correct that the treatment interferes with bodily integrity – as does Ashley's feeding tube, which is virtually never disputed for comparable severely disabled people. It is also correct that Ashley no longer grows anymore and her body will not reach puberty as other children's bodies do – as it is true that her body does not work in many ways like other children's bodies. Hence, it is questionable what the nature of these rights in general is and what they should protect in Ashley's case.

Eric Schmidt argues that a developmentally disabled child has only a minimal right against interference with her growth.²³ He thinks that there is a right to grow and develop, but this right only exists in a weak form for cognitively disabled children. He claims that if the child does not have a personal interest in developing a body of adult size, growth may be stunted to facilitate care (provided that this is the least intrusive means to facilitate that care). This still leaves open how such a minimal right can be justified. Apparently, having a personal interest in growth and bodily development plays a part in a

²² It means that I proceed differently to others who argue that the appeal to dignity in bioethical discussions is in general insufficiently developed. Ruth Macklin argues that these appeals are either vague or mere slogans and concludes that hence, dignity is a useless concept (R. Macklin. Dignity Is a Useless Concept. *BMJ* 2003; 327(429): 1419–1420, doi:10.1136/bmj.327.7429.1419). However, this conclusion seems only warranted to me if Macklin can show that there is no possibility of employing the notion of dignity without avoiding the apparently confusing and arbitrary use of it which is, according to her analysis, prominent in the discussion.

²³ E.B. Schmidt. Making Someone Child-Sized Forever? Ethical Considerations in Inhibiting the Growth of a Developmentally Disabled Child. *Clinical Risk* 2007;13(3): 103–108, doi:10.1258/135626207780560039. Schmidt argues for the Ashley treatment out of considerations of rights and thereby represents an exception to other authors who mainly refer to rights to argue against the treatment.

justification, but neither as a necessary nor as a sufficient condition. If this condition is no longer fulfilled, the right may be invaded under certain provisions. That means that in this situation, the right still exists in a weaker form. Yet, how is this weaker right then justified? Schmidt does not provide such an account.

Rights to bodily integrity and development are established in legal human rights documents like the *UN Convention on the Rights of the Child (CRC)* and the *UN Convention on the Rights of Persons with Disabilities (CRPD)*. Here, rights are established as an especially important rights category, namely, as human rights. Some authors refer to these conventions that are signed and ratified by the vast majority of world countries.²⁴ In the relevant article, the CRC claims that we must 'ensure to the maximum extent possible the survival and development of the child' (CRC, article 6.2) which includes according to Dick Sobsey physical growth and sexual development.²⁵ The CRPD states that 'every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others' (CRPD, article 17). Edwards and Sobsey then go on to simply claim that henceforward, the Ashley treatment is not allowed. However, referring to a legal right embodied in a treaty is an authority argument: it is not a philosophically robust argument, since for all we know some rights protected by such treaties may not be morally defensible in the way stated in those Conventions and declarations. In order to provide a robust argument, it is essential to provide an ethical justification and interpretation of these articles and explain why exactly the Ashley treatment is incompatible with them. Why, for example, should 'survival and development' be interpreted as regarding developing a full-grown body instead of as regarding enabling participation in social activities? And how can we understand the requirement 'on an equal basis with others' mentioned in the CRPD, given that things are in a relevant sense necessarily different for profoundly disabled people? An ethical discussion of these legal articles could indeed prove interesting for the Ashley case, but simply stating the relevant articles does not provide much insight and does not amount to an argument showing that the Ashley treatment is not morally allowed.

A discussion about human rights is often linked to a discussion about dignity. This can also be observed in the debate about the Ashley treatment.²⁶ These authors do not clarify the relation between rights and dignity, but

they explain that certain normative requirements follow from dignity and rights. It is argued that having dignity and human rights means being treated 'as human beings with their own agency'²⁷ and being provided with the means to reach one's full human potential.²⁸ How can these claims be understood?

First, it is questionable how someone like Ashley can be treated as having agency. Normally, treatment according to agency is understood as being allowed to make autonomous decisions about one's life without manipulation or interference, to live one's life according to motives and reasons that are one's own. This presupposes that someone is an agent. There is philosophical disagreement on the question what exactly autonomy or agency is and what conditions need to be fulfilled for having it. Yet, whatever criteria are used – for example, autonomy, rationality or self-determination – it seems reasonably clear that for all we know about Ashley, she does not qualify as having agency.²⁹ However, it is sometimes argued that there is no need to actually possess the capacity in question, but that it is enough to stand in a suitable relation to that criterion. That means that the potential for that capacity, ever having had the capacity in question or having it to a certain degree, would suffice. Thereby, newborn infants who will in any likelihood become autonomous or self-conscious or rational, as well as children who are so to a degree and people with dementia who have once been autonomous and self-conscious would qualify for having human dignity. Ashley has never been autonomous and, given the description of her range of capacities, we cannot even consider her being autonomous to a certain degree. Albeit we can never be certain that a future development of her capacities is impossible, for all we know her capacities will remain unchanged. Hence, Ashley does not stand in a relation to any of the proposed cognitive or psychological criteria. It is quite astonishing to consider that Ashley should be treated according to her own agency if she lacks agency.

Second, it is similarly dubious why providing Ashley with the means to reach her full human potential³⁰ would speak against the Ashley treatment. Coleman explains at no point what he means by this statement. If 'full human potential' consists in a grown and sexually mature body, then she has been deprived of that opportunity. However, due to her condition, her body and mind do not function according to these dubious criteria of 'full human potential' understood in that sense in many other ways. It is another question what this potential should be 'potential

²⁴ Discussed by Edwards, *op. cit.* note 5, p. 342; Sobsey, *op. cit.* note 12, p. 59.

²⁵ Sobsey, *ibid.*

²⁶ Coleman, *op. cit.* note 12; S.E. Smith. Is the Ashley Treatment Right? Ask Yourself If Disabled People Are Human. *Guardian*, 2012 March 16. <http://www.theguardian.com/commentisfree/2012/mar/16/ashley-treatment-disabled-people>; Kittay, 'Forever Small'; Kittay and Kittay, 'Bioethics Forum Blog – Whose Convenience?'

²⁷ Smith, *op. cit.* note 26.

²⁸ Coleman, *op. cit.* note 12.

²⁹ See also N. Tan & L. Brassington. Agency, Duties and the 'Ashley Treatment,' *J Med Ethics* 2009; 35(11): 659f, doi:10.1136/jme.2009.029934.

³⁰ Coleman, *op. cit.* note 12.

for' in her case. As I argued earlier (see Section 2), many opportunities like having a sexual life or deciding to have children are in all likelihood not available for Ashley regardless of the treatment decision. It is difficult to say that Ashley can make use of having a tall and mature body. In another interpretation of full human potential, one could argue that full potential is exactly what her parents are trying to develop by providing her with the treatment. They aim at exposing her to physical contact, activities and social gathering and relieving her from discomfort. These are all very human needs and the treatment is providing her with the potential to have those needs and interests met. Coleman's account thus hinges on the interpretation of full human potential. Without giving an explanation for and justification of why this potential is good and what it is good for, his argument cannot convince.

Eva Feder Kittay and Jeffrey Kittay employ a conception of dignity to argue against the Ashley treatment. They claim that 'all individuals have intrinsic worth, the source of their dignity'.³¹ Intrinsic worth seems to be different from dignity if intrinsic worth is the source of dignity. But what is it then that makes for intrinsic worth and accordingly dignity? This is left open. Furthermore, they argue that there are different strokes of dignity for different species. Even an elephant can have dignity, which is however a different kind of dignity from human dignity. This makes it even more difficult to specify any criteria for having dignity. They make clear that at least intellectual capacities are not the right place to search for it, but this leaves many questions open.

Concerning the normative requirements that follow from dignity, the Kittays connect dignity with letting the body be as it is or at least not engaging in extensive body modification. Eva Kittay argues that bodily integrity is an intrinsic good.³² It is not decisive whether someone can make use of her bodily functions such as an ability to procreate. Kittay writes: 'We take pleasure and pride in our bodies as they grow and mature because . . . we do. Full stop. It needs no further justification'.³³ Our bodies are a constitutive part of ourselves. If we treat the body as an instrument, we would treat the person as an instrument. On the other hand, valuing bodily integrity is not equivalent to never invading the body. A broken leg should be operated on and a tumor removed. If imminent danger to life, health or function – however these concepts are precisely understood – is present, an intervention is justified.³⁴

This account is employed as an argument against the Ashley treatment. Ashley could survive without the treatment and Kittay also seems to assume that her health and function were not (sufficiently?) affected to justify the

Ashley treatment. According to Kittay, attention to Ashley's thriving, flourishing and well-being would have been possible, even though maybe more difficult, without the treatment.³⁵ Yet, it remains unclear at what point a body modification is then allowed or even obligatory and why this is not the case for Ashley. Claiming this requires a more specific conception of human flourishing and the role of the body in human flourishing than Kittay provides.

To conclude, so far none of the arguments against the Ashley treatment based on rights and dignity convince. The arguments that I have analysed leave many questions open and are not sufficiently developed to make a case against the treatment. One would expect an account of human dignity and rights to be provided, why Ashley qualifies for them and to what extent dignity and rights are violated by the treatment. To be fair, such an elaborate argument cannot be expected from parents who are blogging about their disabled children and newspaper reporters who write a short note on the case or on the controversy. But it is reasonable to expect such robust analysis from ethicists who get involved.

3.2 What should a dignity- and rights-based argument look like?

To test the plausibility of an argument against the Ashley treatment based on dignity and rights, the argument should be presented in its strongest possible form. I will in the following first develop such an argument and then critically analyse it. This will allow us to judge the validity and plausibility of this argument.

An argument against the Ashley treatment in terms of dignity and human rights would have to discuss and justify

- why Ashley has dignity,
- the relation between dignity and human rights,
- which specific rights are concerned in this case,
- why these are human rights,
- how and to what extent the treatment does not respect those rights.

Initially, two general points concerning my approach: First, even though not all authors talk in terms of human rights instead of rights alone, I assume that the vocabulary of human rights, as especially important rights human beings have as human beings, is actually adequate (and maybe also what most authors mean). Second, I am referring to a will-theory of rights instead of an interest-theory. Will-theorists maintain that rights protect the will. Rights are seen as giving the right's holder control over another's duty. Interest theorists hold that rights

³¹ Kittay and Kittay, 'Bioethics Forum Blog – Whose Convenience?'

³² E.F. Kittay, *op. cit.* note 16, p. 620.

³³ *Ibid.*: 621.

³⁴ *Ibid.*: 618.

³⁵ *Ibid.*: 619.

promote the holder's interests.³⁶ I make the choice for a will-theory because the reference to human dignity is commonly used within such a theory of rights.

There are several possible ways of according dignity to Ashley. First, one could argue that Ashley has the relevant capacities (call this dignity-capacities, in short *dignity-c*).³⁷ Here, a common argumentation strategy is to refer to various different cognitive or psychological attributes that give one dignity: autonomy, rationality, self-determination, the capacity to act for reasons, self-consciousness etc. Given Ashley's severely limited capacities, it seems reasonably sensitive to argue that whatever that capacity exactly is, Ashley does not possess it despite all efforts of her caretakers to develop her capacities. Even more, she does not even stand in a suitable relationship to agency because unlike babies and small children, for all we know she is not expected to acquire it and unlike comatose or demented people, she has never had it in the past.³⁸ Ashley has no *dignity-c*.

Secondly, Ashley could be granted dignity because she is a human being (dignity-species or *dignity-s*). This is a biological criterion of species-membership. It is not meant to say that species-membership alone provides the ground for normative claims. Such an argument would fall prey to the famous counter-argument provided by Peter Singer

who explained in what sense the special treatment of a certain biological species is not any better than racism or sexism.³⁹ Rather, a further reason needs to be provided why species-membership is normatively relevant. Sigrid Graumann argues in the following direction:⁴⁰ certain cognitive capacities could be qualifications for having human dignity in combination with a principle of precaution that demands to also include those human beings who actually do not have the capacity in question. Defining a threshold for who is and who is not included is notoriously difficult and maybe also unavoidably arbitrary. Therefore, it might be safest to include the whole species. Yet even then, it is clear that Ashley does not fall into such a grey area, but that she is a clear case of not having the criteria in question. The need for including the whole species does not automatically follow from precautionary considerations. Yet, *dignity-s* might be accorded to Ashley on different grounds: allowing to establish a threshold for who falls within the scope of dignity on the basis of certain capacities would imply that someone or some institution has the authority to make that judgment. This could be considered too dangerous and therefore be a reason to include the whole species. Based on this line of argumentation, one would conclude that Ashley has *dignity-s*.

There is still a third way in which Ashley could be seen as endowed with dignity. Ashley could be seen as having dignity because others recognize and value her.⁴¹ Dignity is then an attribute that Ashley has because of a social practice of recognition (call this dignity-practice, *dignity-p*). Here, dignity is not based within the individual, but comes into existence because others treat and value her as such. Ashley is a full member of her family. Her parents lovingly describe how she fulfills a binding role within their family and takes part in their activities. A certain attitude is practiced towards her. Clearly, Ashley has *dignity-p*.

I will bracket a discussion about the relation between human dignity and human rights and assume that dignity is understood as the foundation of human rights. Human rights protect dignity. If a being has dignity, it needs to be treated according to human rights.⁴²

³⁶ For an overview of different right-theories see L. Wenar. Rights. In: E.N. Zalta. *The Stanford Encyclopedia of Philosophy*. Fall 2011. <http://plato.stanford.edu/archives/fall2011/entries/rights/>; M. Kramer. *A Debate over Rights: Philosophical Enquiries*. Oxford: Clarendon Press; 1998.

³⁷ Compare also the discussion in the last section about attributing agency to Ashley where comparable criteria are suggested. Of course, there are accounts discussed in the literature that attribute a lower moral status to infants and/or the cognitively impaired in general. Compare for example the discussion of the cognitively impaired in comparison to animals in J. McMahan, Cognitive Disability, Misfortune, and Justice. *Philos Public Aff* 1996; 25(1): 3–35. and the analysis of 'time-relative interests' in J. McMahan, *The Ethics of Killing: Problems at the Margins of Life*. Oxford University Press; 2002, especially chapter 2.6, 3.2 and 4.8. On this and comparable accounts, Ashley would clearly not qualify for a higher moral status.

³⁸ Additionally, more sophisticated accounts that refer to capacities are proposed in the literature. Agnieszka Jaworska and Julie Tannenbaum for example also argue that Ashley has a higher moral status – yet not necessarily full moral status – than an animal who is cognitively similar to her. This is due to the value of her capacity to engage in certain activities within a person-rearing relationship. These are activities that model what a self-standing person does and are transformed by the person-rearing relationship into incomplete realization of what a self-standing person does (A. Jaworska & J. Tannenbaum. Person-Rearing Relationships as a Key to Higher Moral Status. *Ethics* 2014; 124(2): 242–271, doi:10.1086/673431.). To my mind, their account seems promising concerning the moral status of small children and babies, but it is unclear to me why, as they argue, 'Ashley's flourishing involves her becoming an SSP [self-standing person]' Ibid: 263. David DeGrazia also argues that their account is unconvincing (D. DeGrazia. On the Moral Status of Infants and the Cognitively Disabled: A Reply to Jaworska and Tannenbaum. *Ethics* 2014; 124(3): 550–553, doi:10.1086/675077. Due to space constraints, a more detailed analysis of the account by Jaworska and Tannenbaum falls outside the scope of this article.

³⁹ P. Singer. *Animal Liberation. A New Ethics for Our Treatment of Animals*. New York, New York: New York Review; 1975.

⁴⁰ S. Graumann. Human Dignity and People with Disabilities. In: M. Düwell et al., editors. *The Cambridge Handbook of Human Dignity. Interdisciplinary Perspectives*. Cambridge: Cambridge University Press; 2014. 487f, <http://www.cambridge.org/co/academic/subjects/law/human-rights/cambridge-handbook-human-dignity-interdisciplinary-perspectives>.

⁴¹ B. Williams. *Philosophy as a Humanistic Discipline*. Princeton University Press; 2006; R. Forst. *Das Recht auf Rechtfertigung: Elemente einer konstruktivistischen Theorie der Gerechtigkeit*. Suhrkamp; 2007.

⁴² For arguments establishing this relationship between dignity and human rights by building on Kantian theory see A. Gewirth. The Epistemology of Human Rights. *Soc Philos Policy* 1984; 1(2): 1–24, doi:10.1017/S0265052500003836; J. Habermas. The Concept of Human Dignity and the Realistic Utopia of Human Rights. *Metaphilosophy*

Next, it needs to be clear which specific rights are concerned in Ashley's case. It is the intended direct aim of the treatment that Ashley does not grow and mature bodily. To argue against the Ashley treatment, one would therefore have to establish the right to grow and the right to develop to sexual maturity. On what grounds could these rights be human rights? I assumed that human rights protect dignity. The justification of specific human rights thus refers to a specific conceptualization of dignity. I argued above that there are two possibilities for granting Ashley dignity. Ashley can be seen as having *dignity-p* and as having *dignity-s*. I will consider the implications of these two options in turn.

First, Ashley has dignity in the sense of *dignity-p* because others value her as such and stand towards her in a certain practical attitude. Human rights should protect this social practice. This means that the social practice is considered valuable. Something must make this practice normatively good. There are two possibilities. First, Rainer Forst argues that the practice of recognition is self-evident.⁴³ It is inherent in the concept of a human being that it needs to be treated in a certain way, but this is not something we can provide arguments for. As such, the practice is ultimately groundless. Consequently, Forst does not provide further reasons for it, nor does he believe that one *should* provide reasons for it. Admittedly, this approach cannot convince those who do not believe in the social practice, and can hardly be seen as an argument for it. Secondly, one can argue that the social practice has a normatively important aim and is therefore itself valuable. Axel Honneth holds that a praxis of recognition is important for the development and maintenance of a person's identity.⁴⁴ This praxis is a precondition for self-realization: 'the conditions for autonomously leading one's own life turn out to be dependent on the establishment of relationships of mutual recognition'.⁴⁵ Leaving out the question whether this is an empirical or a normative claim or a combination of both, the argument still does not seem to hold. Even if it is accepted that the development and maintenance of identity is important, we do not accept everything that contributes to this aim. If the social practice is in itself repugnant, its aim does not make it acceptable. If a violent drugs dealing gang has a social practice of only considering someone a recognized and valued member of the gang after having raped a few young girls and if

belonging to that gang helps to develop and maintain an identity, this does not mean that we approve of the social practice of the gang. It is still unclear why a social practice is valuable. We cannot make a valid argument against the Ashley treatment based on granting Ashley *dignity-p*.

Second, I argued that Ashley can be considered as having *dignity-s*. Every member of the human species would be accorded dignity in this sense because no one should be authorized to judge whether an individual falls above the threshold of a certain capacity. Even though *dignity-s* is not directly explained by reference to capacities, capacities are indirectly important. Ultimately, which normative implications follow from *dignity-s* depend on which capacity is protected. To argue against the Ashley treatment, an argument should be provided showing that a grown and fully developed body is required to protect a life appropriate to the relevant capacity. It does not make a difference that Ashley might never be able to live a life according to that capacity due to her condition. She cannot be treated differently from other human beings because no one should make the decision which human beings fall under the scope of human rights. There are different ways to flesh out such an argument.

The first possibility is to argue that autonomy or self-determination is the relevant capacity and that a mature body gives one the opportunity to live an autonomous life. It is clearly convenient to have a mature body if one wants to be recognized and treated as an autonomous person. This might be sufficient reason to establish a right to such a body. Clearly, the Ashley treatment would be an immoral bodily deformation if it was administered to a non-disabled child. If no distinction should be made between Ashley and healthy children, a mature body is good for Ashley as for every other child and as such, the treatment should never be morally allowed.

Such an argument runs into two problems: first, it has to explain how Ashley can then be treated differently from other children at all. We think that Ashley should be treated differently in many ways. For example, her parents cannot ask her to help set the table for dinner, as her siblings probably do, to tidy up her room or to get dressed on her own. They could still provide her with a pacifier if she likes this, and so on. Ashley is treated differently all the time as, due to her disability, she is different from other children. Hence, the treatment might therefore also be indicated for her, but not for other non-disabled children. Second, even if a right to a mature body is recognized because of its value for an autonomous life, Ashley's parents could say that in Ashley's case, other considerations are more important and that therefore, the right needs to be waived. A right is not a duty; it does not need to be exercised. In Ashley's case, there might be good reasons to make no use of it. To

2010; 41(4): 464–480. One could argue for human rights out of different considerations and one could argue that having dignity has normative implications that cannot be grasped in the language of human rights. But this will not be the subject of my concern.

⁴³ Forst, *op. cit.* note 41, p. 70.

⁴⁴ A. Honneth. *The Struggle for Recognition: The Moral Grammar of Social Conflicts*. Cambridge MA: MIT Press; 1996.

⁴⁵ J. Anderson & A. Honneth. *Autonomy, Vulnerability, Recognition, and Justice. Autonomy and the Challenges to Liberalism: New Essay*. Cambridge University Press; 2005. 131.

argue that the right cannot be waived, it needs to be shown that a mature body is not only convenient for a life according to a specific capacity, but that it is a *necessary* condition for such a life.

This is a second option to develop an argument against the Ashley treatment based on *dignity-s*: a full-grown and developed body should be a necessary precondition for a life according to a specific capacity. Not just any body can fulfill this requirement, but only a mature and developed one. The only capacity that I can think of here is procreation. It seems that everything else is possible, although maybe more difficult, with just any body and not a specific one. Clearly, we need a body to navigate in this world and to act, but we do not need any particular body to do so. It is only procreation that demands a particular body, namely a sexually mature and fertile female body. This argument could at least be used against the hysterectomy, but not against the breast bud removal and growth attenuation. More importantly, it is difficult to accept this argument given that it is probable that Ashley will never have a chance to choose to procreate. I therefore doubt that it is a truly convincing argument.

A third way to flesh out the argument would specify an earlier argument made by the Kittays (see above). This relies on the idea that the body is in general of special value for the person. Such an argument would have to claim that the person cannot be distinguished from the body because the person is essentially the body. To intervene in the development of the body, especially imminent dangers to life or a conceptualization of flourishing should be present. It needs to be shown that for Ashley, this is not the case. The cut-off point above which intervention is allowed needs to be set in the way that the Ashley treatment is excluded. This could in principle be a cut-off point that only allows interventions to save life. But that cut-off point could then no longer be justified to operate for example on a broken leg and is thus not convincing. It might be possible to define a cut-off point in the spirit of a Boorsian account of species-typical functioning. According to Boorse's theory, health is a statistical normality of biological functions.⁴⁶ If this is the standard according to which Ashley should be treated, one could argue that she and her body should as closely resemble the statistical normal person as possible because this is in itself valuable. This could be used to argue against the treatment as Ashley will look different and develop differently compared to the average person as an intended result of the treatment. Yet, this account has to

find answers to the numerous general criticisms Boorse's and other naturalistic accounts encounter.⁴⁷

To conclude, I think that this last option is the strongest possible way to argue against the Ashley treatment based on dignity and rights. As I made clear, this argument encounters various problems and might not be convincing. For one thing, one would have to assume that statistically normal functioning is normatively valuable. Most importantly, I hope that it has become clear that providing such an argument requires various argumentative steps that need to be fleshed out. The current literature does not accomplish this in a satisfactory way.

4 CONCLUSION

I have analysed two central arguments in the debate on the Ashley treatment to raise doubts whether the debate as it stands is philosophically robust. I showed that both arguments in their strongest form have to make substantial and controversial assumptions concerning the value of bodily functionings. The arguments I have analysed and then interpreted in a charitable way would benefit significantly from a thorough philosophical discussion to debate their force. Equally, a philosophical debate about the assumptions of the arguments is needed to provide sound recommendations for how children with severe disabilities should be treated.

I conclude that philosophy and philosophers can and should contribute more to the debate than is currently the case. Robust philosophical arguments could clear up certain confusions in the debate and support caretakers as well as policy makers in making responsible treatment decisions for severely disabled children.

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⁴⁷ Most objections argue that Boorse's account fails in various regards concerning its general commitment to be objective and value-free. R. Amundson. Against Normal Function. *Stud Hist Philos Biol Biomed Sci* 2000; 31(1): 33–53; R. Cooper. Disease. *Stud Hist Philos Sci Part C: Stud Hist Philos Biol Biomed Sci* 2002; 33(2): 263–282; E. Kingma. 'What Is It to Be Healthy?' *Analysis* 2007; 67(94): 128–133; E. Kingma. Paracetamol, Poison, and Polio: Why Boorse's Account of Function Fails to Distinguish Health and Disease. *Br J Philos Sci* 2010; 61(2): 241–264, doi:10.1093/bjps/axp034. For a helpful summary of various criticisms see E. Krag. Health as Normal Function: A Weak Link in Daniels's Theory of Just Health Distribution. *Bioethics* 2013; 3: 427–435, doi:10.1111/bioe.12007.

⁴⁶ C. Boorse. Health as a Theoretical Concept. *Philos Sci* 1977; 44(4): 542–573; C. Boorse. A Rebuttal on Health. In: J.M. Humber, F. Robert & R.F. Almeder. *What Is Disease?* (Humana Press, 1997), 1–134.