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## Deaf by Design: Disability and Impartiality

### Introduction

In 'Benefit, Disability and the Non-Identity Problem', Hallvard Lillehammer uses the case of a couple who chose to have deaf children to argue against the view that impartial perspectives can provide an exhaustive account of the rightness and wrongness of particular reproductive choices.<sup>1</sup> His conclusion is that the traditional approach to the non-identity problem leads to erroneous conclusions about the morality of creating disabled children. This paper will show that Lillehammer underestimates the power of impartial perspectives and exaggerates the ethical force of partial perspectives, which in turn commits him to providing weak justifications for the choice made by the couple in his example case.

The non-identity problem concerns how we should make ethical evaluations when the person or object in question will owe its identity to the particular evaluation that we make. Lillehammer's strategy is to provide six different cases of non-identity problems, three of which also involve pre-conception scenarios where the identity of a particular creature is involved. (His marriage example, although it doesn't involve reproduction, is also an unusual type of preconception scenario, although in this case the 'conception' results in a marriage.) His main device in the analysis of these cases is "a contrast between two distinctions, namely the distinction between person-involving and non-person-involving considerations on the one hand, and between partial and impartial considerations on the other."<sup>2</sup> Lillehammer sets out the background to the non-identity problem in some detail, but his assertion that "some non-person-involving ethical considerations are essentially partial" is not supported by the examples he provides.<sup>3</sup> Those of his examples that necessarily involve partial non-person-involving ethical considerations do not

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<sup>1</sup> H. Lillehammer. 2005. Benefit, Disability and the Non-Identity Problem. In N. Athanassoulis (ed.) *Philosophical Reflections on Medical Ethics*, Palgrave Macmillan. Online at: <http://www.palgrave.com/pdfs/1403945276.pdf>

<sup>2</sup> *Ibid.*, 25.

<sup>3</sup> *Ibid.*, 28.

involve the creation of agents with interests; those that do involve agents with interests can be resolved without recourse to partial considerations.

### The hammer, the painting, the puppy, the marriage and the superhuman

Lillehammer's first example is a hammer that he fashions out of steel and wood to repair the floor in his boatshed. Because he chose a piece of wood that is not suited to this task, it takes him a lot of time and effort to finish the job; if he had chosen the other piece of wood his job would have been easier. Was he wrong to make the tool that he did? Lillehammer thinks that "even with a hammer it is not obvious that I am subject to justified criticism for not maximising benefit impartially."<sup>4</sup> His point is that, although we can certainly say it would have been better from a prudential partial perspective to make a different hammer, making the bad hammer is not subject to criticism on impartial grounds. Thus we have a non-person-involving situation where partial perspectives are more helpful. We can already see Lillehammer's strategy: he wants to show that partial considerations can trump impartial considerations. The hammer example shows that this is indeed true for cases where the agent is creating something that has no interests and is created purely for the agent's benefit. However, it is a huge leap from this to arguing that partial considerations can trump impartial considerations when the agent is creating another agent with interests that is not created purely for the original agent's benefit, as in the case of creating deaf children. Lillehammer attempts to make a series of large jumps through his subsequent examples, rather than making this leap all at once, but the hammer case highlights the fundamental flaw in his argument.

The second example given is the gift case: Salvador, a surrealist painter, creates a painting in the style of Canaletto as a gift for his friend Pablo. The recipient of the painting is delighted, but the fact remains that the painting is not a prime example of Salvador's work, and an alternative in his own style

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<sup>4</sup> *Ibid.*, 30.

would be of greater worth. Yet if he had done this instead, “the Canaletto imitation would never have existed.”<sup>5</sup> Once again, we have a non-person-involving case where the agent is not open to criticism for creating a suboptimal object. The only real difference from the hammer case is that Pablo, another agent, is involved, and the same criticism applies: there is a fundamental distinction between creating objects without interests, and creating agents with interests, regardless of whether these agents are yet identifiable as persons.

In the third example, we are presented with the creation of an agent with interests: a puppy named Eric. Of all Lillehammer’s examples, this is the one which most closely resembles the case of the deaf children. Here we have a dog who is loved and happy, yet is “not well equipped to survive in an unprotected environment...prone to pick up diseases, a bad hunter and afraid of things large, noisy and threatening.”<sup>6</sup> Once again, Lillehammer argues that this is another bad candidate for purely impartial evaluation, as such a perspective would conclude that Eric is a suboptimal puppy, and a ‘better’ puppy could have been created instead. This is true. But an impartial perspective would not necessarily assert that another puppy *should* have been created instead. As Lillehammer says, “Eric is a perfectly normal pet”.<sup>7</sup> The hammer and gift cases are different from the deaf case because they do not involve the creation of agents with interests; the pet case is different because it involves a perfectly normal creation who is *prone* to disease, while the deaf case involves the intentional creation of children who *have* a disease. I will return to this point later in the paper. (Also, it might be argued that there is less of an obligation to create optimal pets than there is to create optimal persons, if we accept that pets exist primarily for our benefit.)

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<sup>5</sup> *Ibid.*

<sup>6</sup> *Ibid.*, 31.

<sup>7</sup> *Ibid.*, 32.

A marriage constitutes Lillehammer's fourth example: Javi and Pilar are happily married, but "the differences between their social backgrounds are a constant source of tension."<sup>8</sup> If they had married different people, the resulting partnerships could have been tensionless. Quite apart from the fact that this example reduces to saying 'two people who are happily married might have been ever so slightly more happily married with other people who they never met', Lillehammer has stacked the deck: this particular marriage is indeed a poor candidate for impartial evaluation, because the couple are happy and in love. We can't impartially say that they should have tried to meet other people, because, as Lillehammer puts it, "Love does not consist in maximising impartial benefit".<sup>9</sup> However, if Javi and Pilar were both unhappy and conducting affairs, we could quite easily say from an impartial perspective that they shouldn't have got married. (Also, an utterly blind impartial perspective, as uncharitably characterised by Lillehammer, might well say 'They should each have married someone else, because then we would have twice as many happy marriages as we currently have with them married to each other.')

It is a given that impartial perspectives won't have anything interesting to say in a situation where both or all agents are happy because of a situation that they entered into willingly (note that the deaf children, unlike Javi and Pilar, cannot consent to being deaf; although there was a chance they would have been able to hear with the chosen sperm donor, they would not exist had their parents chosen differently). Lillehammer's strategy, here as before, seems to consist in saying 'Here is a situation where X exists, and X is not quite 99% perfect. Does this mean that the creators of X should have created Y instead?' This is a straw man: what we need, and get in the case of the deaf children, is: 'Here is a situation where X exists, and is missing something very important.' In all his cases except that of the deaf children, the agent or object created is suboptimal only in a very minor sense, and in a way that is compatible with its fulfilling its purpose or being happy. As will emerge, however, the deaf case involves suboptimality of fundamentally unfair proportions.

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<sup>8</sup> *Ibid.*, 33.

<sup>9</sup> *Ibid.*

Lillehammer's penultimate example involves a couple, Jack and Jill, who are offered a pill that will endow any child that they conceive with superhuman intelligence. They refuse the pill, conceive naturally, and have a normal child. Lillehammer argues here that, from an impartial perspective, "it might seem obvious that normal healthy children should never be conceived if superhuman children could be caused to exist instead."<sup>10</sup> From the point of view of the beneficence principle – we should try to create more benefit rather than less - this is true. But we do not have an obligation to enhance our children beyond the norm, and an impartial perspective can easily accommodate an obligation to avoid harm (the nonmaleficence principle) without an accompanying obligation to provide benefit beyond the norm. An impartial principle could simply have as a condition the eradication of serious genetic disease. (I have argued elsewhere that there are independent reasons why enhancement is unethical, but removal of disease is not.[Genetic Morality].) Lillehammer goes on to argue that:

...the very existence of many of the aspects of their social world that Jack and Jill value most is premised on the fact that in their contingent historical circumstances most normal parents are happy to have normal children. To respect these aspects of the social world does not amount to fetishising normality for its own sake. As shown in the gift case and the pet case, it is possible to reasonably maintain an attitude of intrinsic valuation toward objects which fall short of perceived perfection in an indefinite number of ways.<sup>11</sup>

I will return to this passage in the next section, but several preliminary points can be made here. First, it could be argued that any parent who is not happy to have a normal child is by definition not a normal parent. Second, wanting your child to be deaf is different from wanting your child to be normal. And third, the last sentence here is equivalent to saying 'something that is not perfect can nonetheless be valuable', which is something of a truism.

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<sup>10</sup> *Ibid.*, 34.

<sup>11</sup> *Ibid.*

## The deaf case

Given the centrality of his last example, a real case, to Lillehammer's argument, it seems only fair to give it in full:

Consider Sharon and Candace, a deaf couple unable to conceive naturally. Both being successful health professionals, Sharon and Candace have access to expensive private IVF treatment. Using a sperm donor with five generations of deafness in his family, Sharon and Candace successfully conceive and bring to term two congenitally deaf children. If Sharon and Candace had chosen a normal sperm donor, they could have had a hearing child. But then their actual children would not have existed. While both children are congenitally deaf, they are otherwise healthy. Were Sharon and Candace [sic] wrong to have deaf children?<sup>12</sup>

Lillehammer's defense of the couple's decision has several aspects to it. First, he argues that "a contrary decision on the part of Sharon and Candace would entail that two worthwhile lives would never have been. While deafness is a serious disability, there is reason to believe that the children of Sharon and Candace would rather be deaf than not have existed at all".<sup>13</sup> First of all, there was a 50% chance that their children would have been born hearing anyway, even with a deaf sperm donor (see below). But even were this not the case, this phrasing is ambiguous: Lillehammer seems to imply that the only contrary decision would have been to have no children, rather than to try to conceive non-deaf children. It is obvious that a deaf child would rather be deaf than never have existed, but an impartial account might claim that it would be better for Sharon and Candace to have had non-deaf children. As Derek Parfit has pointed out, a woman who has an abortion might well have a child at a later date that she would never have conceived if she hadn't aborted the earlier fetus.<sup>14</sup> Choosing not to have a particular child doesn't mean that another one will not end up being born in its stead. There could have been two *other* worthwhile lives if Candace and Sharon had tried (via a non-deaf sperm donor) for normal children, or if their children had been lucky enough to

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<sup>12</sup> *Ibid.*, 34-5.

<sup>13</sup> *Ibid.*, 35.

<sup>14</sup> D. Parfit. 1987. *Reasons and Persons*. Oxford: O.U.P: 358.

not inherit deafness from the actual deaf donor. Furthermore, Lillehammer's first argument is insufficient to justify a reproductive choice: it could also be used to justify having babies in order to make slaves of them, as David Shaw has argued with regard to cloning:

Imagine an immortal society where children are only born to fulfil the society's need for slaves. Children are brought up normally, but on reaching adulthood are enslaved for five years before joining the equal members of society. During this time, they are occasionally whipped, but otherwise live quite comfortably working for their betters. Overall, their lives are worth living. Now, if we conquer and abolish this society, it will result in people with lives worth living not being born. But we will still have done the right thing.<sup>15</sup>

Second, Lillehammer returns to the idea that was introduced in the superhuman case: "Sharon and Candace make their choice in a particular personal and historical context. Like all prospective parents, they make that choice partly in light of partial ethical concerns. Thus, Sharon and Candace would like their children to grow up and flourish as members of their own community."<sup>16</sup> Thus, just as Jack and Jill should not be criticised for wanting a normal child, given their 'normal' context, Sharon and Candace should not be criticised for wanting a deaf child, given their 'deaf' context. Once again, we might ask why members of a slavery cult should be criticised for wanting a slave child, given their 'slave context'. But even taken on its own terms, Lillehammer's argument fails. He states that the couple, who are part of a thriving deaf community, want their children to be able to communicate with their deaf peers without feeling alienated. The most obvious response is that this argument has the hidden premise that being part of a flourishing deaf community precludes not being deaf. The couple's child could still learn sign language and be part of the community without being deaf, unless the community itself is guilty of discrimination against those who are not deaf. (A more frivolous response, given that Candace and Sharon are lesbians, might be to ask whether, if they are part of a thriving gay/lesbian community, it

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<sup>15</sup> D. Shaw. 2006. *Genetic Morality*. Berne: Peter Lang Publishers: 74.

<sup>16</sup> Lillehammer, *op. cit.*, 35.



would be acceptable to select an sperm donor who had a history of homosexuality in the family in order to make their child gay.)

In further support of the couple, Lillehammer argues that “there is an ethically relevant difference between risks due to natural accident and risks due to social prejudice, for example. It is at least arguable [again] that Sharon and Candace have adopted such a critical perspective. Consequently, it is not so wrong that they wanted to select for deaf children.”<sup>17</sup> Here he is talking about risks that the deaf children might run due to their disability if faced with natural disaster or discrimination, and it is true that there is a difference between risks due to discrimination and risks due to natural chance. But this ethically relevant distinction can also be used to differentiate between conceiving deaf children by accident (whether due to a recessive gene or physical abnormality) and conceiving them deliberately through sperm donation. As already mentioned, Candace and Sharon seem to be guilty of some type of discrimination against the non-deaf community, personified in the form of the non-deaf children they might have had; they assume that a non-deaf person could never participate in the deaf community. In fact, it seems likely that deaf children would be more alienated from the non-deaf community than non-deaf children fluent in sign language would be from the deaf community. (Candace argues that “black people have harder lives [because of discrimination]. Why shouldn’t parents be able to go ahead and pick a black donor if that’s what they want?”<sup>18</sup> But black people’s lives are harder because of the negative attitudes of other people: deaf people’s lives are harder, even without discrimination, because they are disabled and cannot hear.) Lillehammer writes that “the existence of special forms of communication like sign language and lip reading enables deaf people to participate in a valuable form of social life without removing their particular disability.”<sup>19</sup> Equally, however, sign language and lip reading enable *non-deaf* people to participate in deaf people’s valuable form of social life without *having* their particular

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<sup>17</sup> *Ibid.*, 36.

<sup>18</sup> L. Mundy. 2002. A World of Their Own. *Washington Post* 3 March.

<sup>19</sup> Lillehammer, *op. cit.*, 36.

disability. Why assume that deafness is a necessary condition for participation in the deaf community?

Another important point is that a deaf child would almost certainly be excluded from any musical community. To non-deaf people, this seems to be a great sacrifice to make in order to ensure integration into a particular disabled community. What makes this sacrifice worse is that Sharon and Candace have never fully experienced music, or anything else aural. (Lillehammer does not mention it, but Sharon was born with residual hearing which vanished by the age of 8, and Candace was born deaf.) The couple have decided to deprive their children of something of which they have next to no experience. In this particular case, the couple's disability precludes them from knowing what their children's lives would be like if they could hear: this alone ought to disqualify them from choosing such a life for their child. Candace herself acknowledged that "if they themselves – valuing sight – were to have a deaf child...they would probably try to have it fixed, if they could."<sup>20</sup> This indicates the lack of perspective that affected the couple's decision to have deaf children: they don't know what it's like to be blind, but they know that it's bad; the fact that they are deaf, though, blinds them to the fact that deafness is also a harm to be avoided if possible. (Somewhat ironically, Candace majored in medical ethics.) This is a microcosm of the problem: they are incapable of impartiality about hearing versus deafness, because they have only experienced the negative (deaf) perspective; not being blind, they have only experienced the positive perspective of sight. If they can easily judge blindness to be a harm, it can only be a lack of moral imagination that stops them from viewing deafness in the same way. Candace also stated that "I want to be the same as my child...I want the baby to enjoy what we enjoy."<sup>21</sup> This almost seems like an admission: the child could have been non-deaf, but Candace can't be, so she wants a deaf child. Why not try for a hearing child that can enjoy what the couple enjoys, and much more besides? In their seminal *Principles of Biomedical Ethics*, Tom Beauchamp and James

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<sup>20</sup> Mundy, *op. cit.*

<sup>21</sup> *Ibid.*

Childress mention the substituted judgement standard, where the surrogate must choose what the patient would choose for him or herself, if capable:

...if the surrogate can reliably answer the question, "What do *the patient* want in this circumstance?" substituted judgement is an appropriate standard. But if the surrogate can only answer the question, "What do *you* want for the patient?" then this standard is inappropriate, because all connection to the patient's former autonomy has vanished.<sup>22</sup>

Although this standard is intended for patients who have already lived, and not for pre-conception scenarios, we can still see that Candace and Sharon are choosing deafness for their own sake rather than their childrens'. The couple cannot possibly answer the question about what their children would want, because they have never heard anything themselves.

Lillehammer's 'context' argument has another problem. He justifies Candace's and Sharon's decision on the grounds that they are well-off and can provide their children with what they need in order to live happily with deafness. But this implies that a poor, working-class deaf couple would not be right to choose to have a deaf child. How can it be fair that only rich deaf couples can choose to have deaf children? The answer is that wealth enables people to make particular lifestyle choices for their children. It seems abhorrent that deafness should be the subject of such a choice. Furthermore, it seems very strange from any perspective that a child would be better-off being born to poor parents than rich parents because they would therefore be more likely to be able to hear, yet this is what Lillehammer's argument seems to suggest. Surely the ability to hear should not be dependent upon one's parents being poorer than someone else's?

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<sup>22</sup> T. Beauchamp and J. Childress. 2001. *Principles of Biomedical Ethics*, 5<sup>th</sup> edition. New York: OUP: 100.

## Fairness, impartiality and context

Shaw argues that allowing someone to run a race without having trained for it is nonetheless fair, while forcing him to run with a broken leg is not.<sup>23</sup> Equally, the type of sub-optimality in most of Lillehammer's examples is negligible, like not having trained for a race. In the case of the superhuman, the parallel would be taking performance-enhancing drugs before the race: this is unfair. Equally, deafness is like having a broken leg. These metaphors simply serve to illustrate the medical norm that deafness is bad: it is worth noting that, if Candace and Sharon died in a car crash and their offspring survived and were offered gene therapy to remove their deafness (were this possible, given the origin of the defect), they might well take it. Equally, if such therapy were available while they were still children and Candace and Sharon died, doctors would certainly presume consent to 'remove' deafness on the children's behalf. And furthermore, to adopt a Rawlsian perspective, those behind the Veil of Ignorance would not permit deaf-making choices such as that exercised by Candace and Sharon, as they would not want to find themselves deaf on the lifting of the Veil. Lillehammer is wrong: impartiality tells us everything we need to know here. The only possible exception to this logic is the alternative that Candace and Sharon wouldn't have had any children at all if they weren't allowed to try for deaf ones. But as already mentioned, this was not the case.

Lillehammer argues that, even if the couple were wrong to select for deaf children, "the explanation would not be exhausted by the consideration that they failed to maximise benefit impartially. Their failure would also consist in their inability to realise the essentially partial project of creating a flourishing family for themselves in their highly peculiar historical circumstances."<sup>24</sup> But this failure of a partial project is merely a subset of their larger impartial failure. They thought they had a partial justification that trumped impartial considerations, but they did not (and even had they succeeded, impartiality would still judge them as having acted wrongly). Thus their failure is

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<sup>23</sup> Shaw, *op. cit.*, 62.

<sup>24</sup> Lillehammer, *op. cit.*, 36.

exhausted by impartial justifications. Also, note Lillehammer's use of the phrase 'for themselves', which is redundant but perhaps indicative of the author's awareness of the selfishness of the couple's stance. Sharon actually said that "It would be nice to have a deaf child who is the same as us. I think that would be a wonderful experience. You know, if we can have that chance, why not take it?"<sup>25</sup> One might venture to ask whether hearing is not a better experience than deafness, but the second sentence makes it clear whose benefit is the primary concern.

In arguing against impartial principles, Lillehammer tends too much towards casuistry: he claims that "the relevant choice faced by a reasonable person in the deaf case is not whether to choose deafness in any arbitrary circumstances characteristic of our world, but whether to choose deafness in the particular context of a socio-economically privileged deaf community in early twenty-first-century California."<sup>26</sup> We can assume that he means *this* deaf case rather than deaf cases in general, although Sharon and Candace actually live in Maryland, not California.<sup>27</sup> But although he focuses very closely on this particular case, Lillehammer overlooks one absolutely vital detail: Candace's and Sharon's children, given that they each have two deaf parents, are likely to pass on their deafness to their children. Thus the couple's decision is not restricted to their children, but will also very probably affect their grandchildren, particularly if, as a result of being brought up in the deaf community, their children have children with other deaf people. (Given that the chances of the couple's children being deaf was 50%, with four generations of deafness on Candy's side and five on the sperm donor's side, their grandchildren will be more likely than not to be deaf if they are conceived with deaf partners.) All Lillehammer's arguments about context fail here, because we have no way of knowing whether the grandchildren will live in a similar society.

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<sup>25</sup> Mundy, *op. cit.*

<sup>26</sup> Lillehammer, *op. cit.*, 39.

<sup>27</sup> Mundy, *op. cit.*

Furthermore, there is a parallel between the couple's decision and germ-line gene modification. It is widely accepted that, while somatic cell gene therapy is acceptable, germ-line therapy, which would also affect future generations, is unethical. Although their decision does not affect an already-existing entity, and the hereditary deafness may not be genetic (Lillehammer says it is congenital, which covers a wide variety of possibilities) Candace and Sharon are choosing to deprive their child and probably their grandchildren of one of the five senses that make us part of the world. It is the most fundamental principle of medical ethics to avoid harm. Currently, even beneficent genetic interventions that will affect future generations are prohibited. Lillehammer is, in effect, arguing that maleficent tinkering with future generations might be permissible.

## Conclusion

Lillehammer mentions in a footnote that "The ethical problem of selecting for disabilities would remain had the deaf mother procreated with a deaf male in the conventional way", attempting to argue that the couple's status as lesbians does not affect the ethics here.<sup>28</sup> (Actually, their lesbian status does change things slightly; an equivalent heterosexual couple would not need a sperm donor, as neither Candace nor Sharon is actually infertile; the donation is necessitated by the fact that they are both women.) Generally, deaf people we can perhaps accept that people should be able to choose to reproduce with each other if they want, even if the child will certainly be deaf, although this point is also disputed. But Candace and Sharon, even more so than most other 'infertile' couples, cannot reproduce with one another, necessitating a *choice* of sperm donor. When a choice is available concerning our future children (another example would be IVF for a heterosexual deaf couple) although we do not have an obligation to 'perfect' them as in the superhuman example, we do have an obligation to avoid harm. And deafness *is* a harm. The simplest impartial perspective will tell anyone that being able to hear and

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<sup>28</sup> Lillehammer, *op. cit.*, 42, fn.20.

listen to music trumps any possible risk of alienation from a particular community. Lillehammer states that "...in the deaf case, for example, philosophers concerned with social justice have naturally adopted a different evaluative perspective than some deaf couples wanting to start a family. There is no immediate prospect of a resolution of these disputes."<sup>29</sup> In fact, there is immediate prospect of resolving these disputes, because the philosophers are using social justice to adopt the impartial perspective of what is best for the future child, while the parents are choosing what they want without any regard for fairness.

Lillehammer concludes by stating that "While it is not obviously incoherent, the idea that one form of life is better than another impartially considered is a dangerous one."<sup>30</sup> But the case for avoiding deafness is overwhelming. We have only five senses. If we had none, we could not function in the world. It is clearly best, both partially and impartially, for everyone to have all their senses. In choosing to preserve their disability across generations, Candace and Sharon become mired in the partiality of their own desires and prejudices, fetishising the disease of deafness for its own sake. There may be a good way to argue against impartial principles, but Lillehammer's example of choosing deafness fails to show that impartial perspectives cannot provide exhaustive accounts of pre-conception scenarios.

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<sup>29</sup> *Ibid.*, 40.

<sup>30</sup> *Ibid.*