

# LUND UNIVERSITY

# Involving children in non-therapeutic research: on the development argument.

Broström, Linus; Johansson, Mats

Published in: Medicine, Health Care and Philosophy

DOI: 10.1007/s11019-013-9486-0

2014

Document Version: Peer reviewed version (aka post-print)

Link to publication

Citation for published version (APA): Broström, L., & Johansson, M. (2014). Involving children in non-therapeutic research: on the development argument. Medicine, Health Care and Philosophy, 17(1), 53-60. https://doi.org/10.1007/s11019-013-9486-0

Total number of authors: 2

Creative Commons License: CC BY-NC-ND

#### General rights

Unless other specific re-use rights are stated the following general rights apply: Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

· Users may download and print one copy of any publication from the public portal for the purpose of private study

or research.
You may not further distribute the material or use it for any profit-making activity or commercial gain

· You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: https://creativecommons.org/licenses/

#### Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

#### LUND UNIVERSITY

**PO Box 117** 221 00 Lund +46 46-222 00 00

# Abstract

Non-therapeutic research on children raises ethical concerns. Such research is not only conducted on individuals who are incapable of providing informed consent. It also typically involves some degree of risk or discomfort, without prospects of medically benefiting the participating children. Therefore, these children seem to be instrumentalized. Some ethicists, however, have tried to sidestep this problem by arguing that the children may indirectly benefit from participating in such research, in ways not related to the medical intervention as such. It has been argued, for example, that non-therapeutic pediatric research does not instrumentalize the children enrolled since it has the prospects of furthering their moral development. We argue that this argument is far too undeveloped to be taken seriously.

# Keywords

Instrumentalization, Exploitation, Research ethics, Pediatric research, Indirect benefit, Non-therapeutic research, Children, Minors, Moral development.

# Involving children in non-therapeutic research: on the development argument

Linus Broström & Mats Johansson

## Introduction

Children benefit from good pediatric research, but not always the children who are involved as research subjects. The ethical challenge of non-therapeutic research on children was highlighted in a debate that started in the late sixties.<sup>1</sup> Ethicist Paul Ramsey did not hold back when commenting on the issue: "To experiment on children in ways that are not related to them as patients is already a sanitized form of barbarism" (Ramsey 1970, p. 12). Harsh words, no doubt, but they do make some sense. Non- therapeutic pediatric research seems to *instrumentalize* the research subjects—to use them for the sake of others—in a prima facie morally troublesome way, since such research typically exposes children to activities (a) that involve *some* degree of risk or burden, (b) that do not benefit them medically, and (c) to which they have not themselves agreed with sufficient, if any, understanding, rationality, and independence.<sup>2</sup>

Through the years a number of measures have been suggested to minimize the risk that children are instrumentalized when they are involved in non-therapeutic research. These include securing *indirect* benefits to participants (such as psychological benefits),<sup>3</sup> making sure that there is reason to believe that those individuals *would* have consented to research participation, had they been able to (rationally) address the issue, or securing the closest thing to consent that the child is sometimes able to offer: "assent".

It has also been suggested that the *moral* contribution of participating children could serve as a justification for enrolling them in valuable non-therapeutic research (McCormick 1976; Harris and Holm 2003; Williams 2012; Wendler 2010, 2012).<sup>4</sup> This proposal (or family of proposals) is problematic, for a number of reasons (see e.g. Lyons 2011). But often intertwined with it, and sometimes offered on its own, is the seemingly less contentious claim that children who are involved in non-therapeutic research need not be instrumentalized since research participation may contribute to their moral (or otherwise

<sup>&</sup>lt;sup>1</sup> For a summary, see e.g. Ross (2006), ch. 1.

 $<sup>^2</sup>$  Just how much understanding, rationality, and independence should be enough to address the relevant moral worry is obviously open to discussion, an issue closely connected to discussions about the appropriate criteria for valid informed consent. Children are interesting in this context precisely because, it is generally assumed, they are not able to offer such consent.

<sup>&</sup>lt;sup>3</sup> Nancy King terms these kinds of benefit "collateral benefits", and she characterizes them as follows: "benefit arising from being a subject, even if one does not receive the experimental intervention (for example, a free physical exam and testing, free medical care and other extras, or the personal gratification of altruism)" (King 2000, p. 333).

<sup>&</sup>lt;sup>4</sup> This suggestion could obviously be elaborated in a variety of ways. Two major ideas could perhaps be distinguished: one being that children ought to be taken seriously as bona fide moral agents, by being allowed to discharge the moral responsibilities they have towards society; the second being that the participating children will personally benefit, whether or not they appreciate it themselves, by helping others.

personal) *development*.<sup>5</sup> As long as this development is sought for the children's sake, they would not, according to this broadly educational idea, be instrumentalized in a morally objectionable sense.

An early hint at this *development argument*, as we shall call it, can be found in Beecher (1970, p. 63), and it was later elaborated and defended, with a few caveats, in Bartholome (1976). Since then, the argument has reappeared with some (albeit infrequent) regularity, in various guises. Sometimes it has been quite clearly endorsed (Gaylin 1982; Redmon 1986; Miller and Nelson 2006; Williams 2012). Williams, for example, being the most recent contributor, has argued that "[p]arents and educators have every reason to enlist children in those schemes of cooperation that they believe are worthwhile", including, on his view, certain non-therapeutic research. Thereby, he argues, children "gain the experience needed to manage their eventual status as *adults*." (Williams 2012, p. 430).<sup>6</sup> Miller and Nelson (2006) maintained in their conclusion about the appropriate role of assent that "[t]he principle of respect for children requires not that we treat children as autonomous beings, but that parents should protect their children and nurturing their moral growth and developing autonomy." (p. S29) Parents can nurture such growth, by allowing children to be part of an assent process that is appropriate to their ability.

The prospects of moral development have also played a role within a larger theoretical framework regarding the responsibilities of parents and the appropriate limits to state intervention (Ross 1998).<sup>7</sup> Other times the argument is laid out in a seemingly neutral fashion, with no thoughts voiced on whether or not it is sound (e.g. Brock 1994, p. 89). Even when presented in this noncommittal way, however, the argument is, in effect, offered as at least worthy of serious consideration.

The development argument has been criticized, but mainly in passing, and mostly regarding its limited scope (see section three below). Dave Wendler has fairly recently drawn attention to some further problems with it, and has made the important general point that the argument depends on empirical assumptions that may well turn out to be

<sup>&</sup>lt;sup>5</sup> Since the discussion is almost invariably phrased in terms of children's *moral* development, we shall do the same, but most of the points that we are about to make would be applicable to other kinds of personal development as well.

<sup>&</sup>lt;sup>6</sup> Williams, it should be said, cautions against reckless implementations of this general message. One of the things that he emphasizes is that children are treated as ends in themselves by being taught to cooperate under *reasonable* terms of cooperation, and that children are vulnerable by having limited ability to judge whether those terms are reasonable, and articulate any objections.

<sup>&</sup>lt;sup>7</sup> Ross (1998) argues, as did Ackerman (1980) before her, that there are moral reasons for giving parents considerable leeway in involving their children in activities that do not necessarily benefit the latter. But also on Ross' view it is critical that children are treated with due respect, and not solely as a means, and she contends that enrolling children in minimal risk non-therapeutic research need not imply that they are treated solely as a means. She maintains in this connection that even if parents coerce their children to participate in such research the children need not be disrespected. "Rather", she argues, "it is one way in which parents can attempt to steer their child's development into a socially responsible adult" (p. 93). Ross continues: "The model of constrained parental autonomy permits parents to override their child's dissent in minimal risk research if they believe that it will serve to guide his development according to their vision of the good life [...]" (p. 93). By implicature, then, she could be interpreted as claiming that when and because parents have the relevant educational reasons for allowing their children to participate, the children are shown sufficient respect. At a minimum, her views on the importance of parental leeway seem to lean on the presumption that parents will try to further their children's development.

false (Wendler 2010, p. 90–95). This article goes further. It summarizes what would need to be shown for the development argument to be convincing, and concludes that we are nowhere near a viable argument. The problem, we contend, has less to do with the fine points made by individual commentators (which we largely choose not to discuss), but with the many challenges that face anyone who relies on the mere possibility of moral development as a central part of the justification of non-therapeutic research on children.

Importantly, we do not take a stand on whether or not it can be morally justified to involve children in non-therapeutic research. Neither do we address whether it can sometimes be, all things considered, morally justified to instrumentalize individuals. Nor do we address whether children enrolled under the conditions (a) to (c) above are instrumentalized in some morally significant sense. What we do claim is that the *development* argument is seriously wanting that *it* fails to make likely that children enrolled in non-therapeutic research are not instrumentalized, in the moral sense worth caring about.

The exposition of the article is as follows. In the next section we call attention to the fact that in order for children's development to be the key to non-instrumentalization the prospect of such development must, in a strong enough sense, be a *reason* why children are involved in research. We argue that this takes more than is usually recognized. In section three we argue that in order for research involvement to have the desired educational effects a whole range of conditions need to be met, and that anyone considering enrolling children in non-therapeutic research must be attentive to these particulars in a way that this approach to justifying the enrollment of children has not yet encouraged. Section four focuses on the difficulty for ethical review boards or other "external" parties to protect children with respect to this particular aspect, and calls attention to the problem with delegating to parents so much responsibility for ensuring that their children are not instrumentalized when they are involved in research. A final section offers some concluding remarks, including the concern that the development argument is an ad hoc argument—an argument made solely to justify something we wish to do for other reasons, and which we have already accepted as legitimate.

### Involving children for the right reason

No doubt, the notion of instrumentalization, or of its opposite—of using people not only or primarily as a means to others' ends, but as ends in themselves—could be taken to mean a number of different things. Kant's second formulation of the categorical imperative is typically made the ethical starting point of the discussion. However, what Kant actually meant, and why, plays at most a marginal role in the debate, and there is much to suggest that the relevant idea is a fairly pretheoretical one.<sup>8</sup> Kant's principle may be useful in phrasing the idea in a familiar way, and some commentators may well take

<sup>&</sup>lt;sup>8</sup> From a Kantian point of view it might not even be possible to treat children (at least not the youngerones) as an end, since that would require something of them that they are not, which is *rational* (in a Kantian sense). Although some commentators accept this consequence (van der Graaf and van Delden 2012), and exclude individuals without decision making competence from their analysis, we see no reason to be faithful to Kant's own ideas in the present context. Instead we find it more reasonable (although not self-evident) to regard any sentient being (cf. Parfit 2011, p. 216) as at risk of being instrumentalized.

themselves to be, in one sense or another, Kantians, but neither does anyone in this discussion about research ethics seem to assume as axiomatic, much less argue for, Kant's moral system, nor is the debate likely to be vulnerable to exegetical disagreements. Rather, the concern seems to be that enrolling children when they have nothing to gain, and when they cannot make an autonomous enough choice of their own, indicates that one, as Derek Parfit might have put it, *regards* children merely as a means to others' ends, or that one comes close to doing so (cf. Parfit 2011, p. 214–216), in a way that is at odds with the requirement to treat everyone with due respect—*as this notion is understood in ordinary thinking*. We may usefully appeal to Kant's formulation because on the surface it expresses a well- entrenched moral intuition—not the other way around.

For present purposes, the most relevant condition under which we would not treat someone merely as a means, or be close to doing that, is if, in Parfit's words, "our treatment of this person is governed or guided in sufficiently important ways by some relevant moral belief or concern [for the well-being or moral claims of the person so treated]" (p. 214). In other words, whatever else is meant, it is safe to assume that treating children as ends requires involving them in research for the right *reasons*. For instance, were children to become research subjects on the sole basis that their participation would help others in need, those children would certainly be instrumentalized, even if it turns out their interests happen to be satisfied, or even if there is also evidence beforehand that they will be. Treating children as ends in themselves requires there to be a concern for those particular children, or an intention to approach them in a fashion that in some way engages their own will. In this case, children need to be involved in research *because* it has prospects of fostering their development.<sup>9</sup> This raises at least three issues.

First, *who* needs to be guided by the relevant concern, if children are not to be instrumentalized? Arguably anyone allowing them to participate in research, whether this be researchers themselves, parents, ethical review boards, or legislators. Researchers that try to recruit children, with eyes only on the value of the research, and little sensitivity to whether sufficient attention is paid to their well-being, instrumentalize those children. Parents who allow their children to participate in a study for the only reason that they have been asked to, instrumentalize those children. And so on. To what extent some of these agents could have an instrumentalizing approach and children still be treated as ends in themselves (as long as others allow for their participation for the right educational reasons) is something that certainly could be discussed. At a minimum, however, it would seem that the right reasons have to drive some of those in control of whether or not children are involved in research. Or if no single individual involves them for the right reason, at least the "system" needs to be designed to allow for the participation of children only when this is likely to further their moral development, and for that reason.

<sup>&</sup>lt;sup>9</sup> As has been pointed out, there are certainly ways to *use* others in a morally unproblematic sense. For example, typically we do not catch a cab in order to benefit the cab driver, but to get somewhere in a convenient and quick enough way. That in itself would not amount to using this individual as a means in an ethically problematic sense, in part, perhaps, because the cab driver would not be used solely as a means. The background assumption that the cab driver is doing this work freely, as part of a reasonably fair transaction with non-negligible chances of benefitting him or her, is part of our reason for allowing ourselves to take this cab—even if it may not be at the forefront of our minds when doing so. We *would* instrumentalize the cab driver if we had reason to believe that he or she was driving us under duress and was sure to suffer from it

Second, what concern do we have in mind? In order to be worth taken seriously, the intended personal development would need to have some specificity. While it seems possible to have very vague development related reasons for involving children in research, like *helping them mature in one way or another*, such indeterminate intentions would, if nothing else, offer little guidance as to how they could be fulfilled (see the next section). More specific reasons could include (but are certainly not exhausted by) helping children to become altruistic, to learn to take responsibility for their choices, to become attentive to others' interests, or to learn the conditions of successful cooperation.

Third, what role should the reason to enable moral development play, when it comes to deciding whether or not a child ought to be enrolled in a scientific study? No doubt, it needs to play a significant enough role (cf. Parfit's words above about being governed in sufficiently important ways by some relevant moral concern). But how significant is that? Here it seems that one needs to find a middle way between two extremes. On the one hand, it would certainly be too strong to require that prospects of moral growth should be the *only* reason for involving children in research. Children typically would not come into consideration as research participants unless the relevant research promised to result in knowledge that will be useful for independent reasons. In fact, the moral lessons that might be learned generally rely on there being prospects of valuable new scientific knowledge. On the other hand, were one to proceed with involving children in research anyway, regardless of whether or not one believed that research participation would help them learn or mature in the relevant sense, this development would seem to be more of a welcome byproduct than the purpose for which the children were involved. A serious intention to support children's development will also involve some sensitivity to what other, and possibly better, ways there might be to achieve this than to let them be enrolled in a research study. We return to this briefly in the next section.

Wherever exactly the line should be drawn, then, the importance assigned to children's development must be a significant part of the reason why they are involved in research, if they are to be treated as ends in themselves. But to what extent are operative enrollment mechanisms, and the actions of the parties involved, actually governed by such concern? To what extent is such concern encouraged or otherwise made likely? Anyone taking the development argument seriously would presumably wish to have these empirical issues explored. So far, however, not only is there little evidence of efforts in that direction, but there are few calls, even, for such scrutiny.

### How likely is research participation to contribute to moral development?

Proponents of the development argument also have to take seriously whether such development is *likely to occur* as a result of allowing the children to participate. Anyone who allows children to be enrolled partly for the reason that it will support their moral development should care about whether his or her expectations for that development are realistic. This, of course, is a critical question on almost anyone's account, and some of the participants in the discussion about non-therapeutic research on children may not have much invested in the issue of instrumentalization, or of how children are regarded, but focus instead precisely on the issue of whether or not the relevant children are likely to

benefit in some way or another from their research participation. It is easily seen, however, that whether the desired educational goal will be achieved depends on a variety of factors, all of which would have to be carefully assessed and/or controlled. Let us mention a few of them.

## The exact goal

For one thing, whether the endeavor will be successful depends on what exactly one hopes to achieve. Making children altruistic, for instance, is different from enhancing their cooperative skills, or making them adopt certain substantial values, strengthening their autonomy, or preparing them for future situations where they will have to adapt. The differences between these and other possible aims matter tremendously, since the conditions that need to hold in order for the relevant aims to be fulfilled typically vary too. For example, in not giving children a choice whether or not to participate, one is not likely to succeed in conveying the idea of altruism, whereas forced participation seems on the face of it to sit more well with helping children adapt to the fact that the interests of others can sometimes be deemed more important than their own.

As already indicated, unless one has some specific educational goal in mind, it simply isn't possible to tell whether research participation will contribute to it. And once a specific goal is articulated, some kinds of research participation may be conducive to it, while other kinds will have little or no prospects of furthering the relevant development. Anyone serious about the development argument must thus pay great attention to these details.

# Individual susceptibility

As has been noticed in the literature, whether any lessons will be learned at all, and what lessons that might be, depends also (and obviously) on the age and maturity of the relevant children (Bartholome 1976; Ackerman 1980; Redmon 1986; Miller and Nelson 2006; Wendler 2012). It goes without saying that involving newborns in research will contribute nothing to their moral or personal development, other than by farfetched and unpredictable routes. But complicating matters, some children are perhaps of roughly the right age to be able to appreciate the lessons involved in participating in research, but may still not, for reasons pertaining to their own particular situation, psychological history etc., be susceptible to the lesson taught. For example, the intended lesson might fail for those children who feel that their parents have previously exposed them to unreasonable demands, or who have a psychologically complicated relationship with the parents. In a worst case scenario it may even be, in the words of Sonja Grover, "that the unintended lesson taught is that the child too can make the decision to transgress the individual rights of others when he feels justified in doing so for some presumed greater good" (Grover 2003, p. 373). Ultimately this could mean that even if the development argument was fundamentally sound, its scope could be much narrower than first impressions might suggest.

# The enrollment procedure

Yet another factor to consider is the enrollment procedure. Should children be asked to take part in the relevant research, with a genuine possibility of refusing, or should their participation be compulsory? Who should approach them? What information should researchers and/or parents give them? Etc. Normally those are issues that are settled beforehand, based on various practical, legal and ethical considerations. But on the present account, this would not work. Depending, of course, on what moral message one is trying to convey, whether one will succeed in supporting children's moral development could often be expected to depend not only on the nature of the research that they will be subject to, but precisely on the way in which the children come to be enrolled. For example, some moral lessons might require that the children who are asked to participate are offered extensive information, in palpable terms, of the suffering that new scientific knowledge might help ameliorate. Those who have appealed to the prospects of children's moral development, as a safeguard against instrumentalization of children in research, should thus be expected to pay great attention to the issue of how enrollment mechanisms affect such development. There have been few indications of such concern, however.<sup>10</sup>

### The cost to the child

Furthermore, one would have to explore the relationship between the sought for development and the risks that participating children face or the inconveniences they have to endure. This relationship is not likely always to be straightforward, and may sometimes even suggest policies that go against common wisdom. Typically, for example, children are candidate subjects in non-therapeutic research only when the risks involved are minimal, and the costs of participating (in terms of discomfort, e.g.) are negligible. However, some educational efforts could perhaps succeed only if the children do have to make personal sacrifices of sufficient magnitude. It is an open question to what extent such correlations hold, of course, but one that a proponent of the development argument, if serious, would want to meticulously address.<sup>11</sup>

### Alternative educational efforts

Finally, as already mentioned, caring about the moral development of children implies caring about how to best achieve this goal, where participating in research is one of several options. Obviously there are other educational measures to consider as alternatives to allowing a child to participate in medical research, such as encouraging him or her to take care of a sick family member, or serve as a peer supporter at school—to mention just a few. If there is strong evidence that these other and sometimes competing options are clearly more conducive to the child's moral development, than participating in research, then the child would be instrumentalized if enrolled in non-therapeutic research.<sup>12</sup> Whether there *are* better alternatives obviously depends on the particulars of the case at hand. The important point, once again, is that parents who knowingly fail to address this issue when considering involving children in research also fail to treat those children as

<sup>&</sup>lt;sup>10</sup> Miller and Nelson (2006) is an exception, in the sense that the authors do connect development to one aspect of the enrollment procedure: assent. No evidence is offered, however, in support of the view that assent under some particular circumstances will make some particular kind of development probable enough not to have the children instrumentalized.

<sup>&</sup>lt;sup>11</sup> This point goes beyond Wendler's somewhat similar observation (Wendler 2010 p. 92) that moral lessons might be learned precisely because the participating children are not the ones expected to benefit

<sup>&</sup>lt;sup>12</sup> The idea is not, n.b., that children are instrumentalized as soon as the chosen treatment of them is suboptimal in relation to the available alternatives, but that evident large discrepancies between what is done for those children and what could instead have been done for them indicate the relevant kind of disrespect.

ends in themselves—and when knowingly allowing parents to fail in this regard, society, in effect, authorizes some degree of instrumentalization.<sup>13</sup>

To summarize this section, the mere fact that we can picture ourselves circumstances where participating in research will significantly help children develop one or another moral trait will not do. This effect must be likely enough, under the circumstances, to be taken seriously. Whether children will grow from the experience will depend on all of the factors above, and more. In many situations there may in fact be no prospects for the children of learning from their participation. In some situations lessons might be learned, but the wrong lessons. The outcome will be highly dependent on all sorts of things, and proponents of the development argument would in any given case have to be able to suggest a plausible mechanism by which the intended development could and probably would occur.

Ethical review boards, parental leeway, and the lack of checks and balances The greater the importance of involving children in research for the right educational reasons, and the greater the importance of actually contributing to children's development, the greater the importance of monitoring this. The body with special responsibility for protecting research participants is the ethical review board. The review board's ability to protect research subjects is limited, of course. The board typically does not have the resources to verify that research is conducted in accordance with what was intended (and neither is it supposed to); it often has limited insight into all vulnerabilities and possible reactions of potential research subjects; it can never guarantee that approved information to those recruited are actually understood by them; and so on. Nonetheless there are quite a few circumstances that would allow the review board to judge suggested studies to be unethical. Risks can be assessed and deemed too high; methods can be evaluated and found wanting; planned consent and assent procedures can be found to fall short of the requirements, and researchers will be asked to improve them. When it comes to the risk that there is not sufficient concern for the moral development of children, it is obviously different, however.

Suppose that researchers approach parents and ask them to allow their child to be part of a non-therapeutic study, and that parents are prepared to let the child be involved. On the present account, whether this would amount to instrumentalization depends in part on whether one could honestly assume that involving this child would further his or her moral development. As a rule, researchers will not have any particular thoughts on this, and if they do, they will generally not have any solid grounds for their conjectures. The same goes for the typical ethical review board. As everyone knows, this is not a kind of assessment that the board has any responsibility to make. And even if one imagines a future in which boards are instructed to address the issue of moral development in connection with non-therapeutic pediatric research, it would be a challenge, to say the

<sup>&</sup>lt;sup>13</sup> As we shall briefly elaborate in the next section, there might be good moral reasons for authorizing occasional instrumentalization, since there might be good moral reasons for giving parents the right to decide, within certain limits, what risks and burdens their own childen could be exposed to, and for allowing parents to fail to live up to some of their moral responsibilities. But those reasons for deferring to parents, as we shall emphasize, are not related to moral development in the way required by the moral development argument.

least, to make educated guesses as to whether a child might learn something important from the experience.

The standard situation, then, is one in which intimate knowledge of the person concerned is required, and thus one in which parents must be assumed to be best positioned to judge whether the child's development will be furthered (which is not to say that they are in a sufficiently good position to do so). Hence, barring special indications to the contrary, their word is virtually all there is to go by. Indeed, almost every commentator recognizes, explicitly or implicitly, the central role that parents would need to have, for the development argument to be taken seriously. But while many parents certainly may want the best for their children also in this situation, and may even have solid grounds for thinking that their children will learn in important ways from research participation, it would not be advisable to fully rely on parents' judgments, if indeed children's moral development is crucial to their not being instrumentalized in research. Some parents simply will not have their children's well-being and development in mind. Some of those who will, do not know their children well enough to make make reliable judgments about what in general contributes to it. Some of those who do, will not understand the relevant research study well enough to be able to make sufficiently educated guesses about its educational potential. And some parents, while in principle capable of all of this, simply will not tie it all together, for reasons pertaining to the particular situation at hand.

That it is crucial that children are not instrumentalized in research is, of course, the assumption on which the discussion depends. One might, for example, argue that there are moral reasons for giving parents considerable leeway in involving their children in activities that do not necessarily benefit the latter. Ross and Ackerman, as we mentioned, have made this case. But this, it must be stressed, is a different line of argument (although, as we have suggested, it sometimes seems to borrow from the development argument). It contends that parents have obligations not only towards the child considered for research participation, but to siblings and others, and that parents moreover have rights of their own. It might even contend that there are good moral arguments for a division of responsibilities, so that parents ought to be the ones to decide whether their child should participate in minimal risk non-therapeutic research even when there is significant likelihood that they will simply fail to show their child as much consideration as they ought to. For all that we argue in this article, this may well be true. But the argument under scrutiny here proceeds from the assumption not only that children ought to be treated as ends in themselves but that their (likely) moral development is the key to their not being instrumentalized. On that assumption, leaving all protective responsibilities to parents in this regard (i.e., to ensure that sufficiently significant moral development is sufficiently likely), with little or no instructions and little or no possibilities for checks and balances, seems hard to justify.

# **Concluding remarks**

The development argument is based on the idea that children may benefit from participating in non-therapeutic research since such participation could further their moral development. Indeed it could. But a major weakness of the argument is that all it typically does is establish this mere possibility. Those who have supported or seriously considered the development argument have shown remarkably little interest in pointing out that the mere possibility of moral development has virtually no implications for what our policies should be when it comes to enrolling children in non-therapeutic research. On the contrary, the conclusion we are implicitly invited to draw from the possibility of moral development is that involving children in research does not after all amount to an instrumentalization of children, and should be acceptable, as long as standard safeguards are in place.<sup>14</sup> However, only a significant likelihood of such development, given the specifics of the situation, could conceivably justify this conclusion.

One might also wonder if the development argument isn't more far-reaching than is typically acknowledged. If researchers basically are doing children a service by involving them in research, whenever there is the promise of moral or personal development, why should codes of ethics persist in requiring that research be done on children only when there are no other possible research subjects? This necessity condition does not seem that reasonable if it would preclude many children from taking part in something that would further their development. On the other hand, if such development could be achieved in other and much better ways, it is hard to see how involving children in research would not still conflict with treating them as ends in themselves. At a minimum there seems to be a tension here that needs to be resolved. Likewise, if it is probable that research participation would significantly contribute to something as important to the child as moral development, why should one persist in allowing minimal risk pediatric nontherapeutic research only when the inconvenience to the child is small? This too would have to be explained. Again, this is not to say that no such explanation could be forthcoming, but that there is a prima facie tension between giving children's moral development so much weight that it could make the difference between instrumentalization and non-instrumentalization while at the same time assuming that standard research ethics safeguards should always trump serious attempts to foster such development.

Some children certainly may grow from the experience of participating in research. But the apparent lack of interest in the actual likelihood that children in general will do so, and in the concrete factors that determine success, makes the development argument not unlike some other instances in research ethics, of just going through the motions of genuine moral concern. (Compare, for example, the often disproportionate emphasis on the importance of written informed consent in relation to efforts devoted to securing that the relevant information is actually understood.) In that sense, the development argument often appears to be a halfhearted attempt to justify practices that seem worthwhile for entirely different reasons. Research on children is important because it promises to result in knowledge that will be beneficial to other children, primarily. Making *ad hoc* appeals to mitigating concerns about education, when the agenda clearly is to publicly justify research one has already decided is justified, is highly problematic. In encouraging

<sup>&</sup>lt;sup>14</sup> At a minimum, these will include the requirement that there are no available alternatives to involving children, that the risks are sufficiently low, and that there is parental consent. Additional requirements often imposed are the ones that the children assent to their participation, and that those intended to benefit belong to the same group as the research subjects (i.e., in this case, are children).

practices that may have little prospects of treating children as ends in themselves, it reflects the same kind of disrespect that instrumentalization itself does.

Maybe there are other and more convincing arguments for why children can be enrolled in non-therapeutic research without being instrumentalized. There are certainly utilitarian and egalitarian arguments worthy of serious consideration for instrumentalizing children (and others) by involving them in such research. But absent some reason for thinking that children would also be treated as ends in themselves, involving them on the grounds that other children would benefit, could well be, in Ramsey's words, to ''sin bravely'' (Ramsey 1976, p. 21); to do what might be right all things considered, while acknowledging that the pediatric research subjects might still be wronged. In addition to being the more respectful thing to do, admitting that for research purposes we sometimes use people primarily to benefit others—*if* that is what we do—is also an important step towards protecting their interests. It is only when people's true situation is recognized and called by its proper name that it becomes possible to know what can and should be done for them.

### References

- Ackerman, T.F. 1980. Moral duties of parents and nontherapeutic clinical research procedures involving children. *Bioethics quarterly* 2(2): 94–111.
- Bartholome, W.G. 1976. Parents, children, and the moral benefits of research. *The Hastings Center Report* 6(6): 44–45.
- Beecher, H.K. 1970. Research and the individual. Little, Brown: Boston.
- Brock, D. W. (1994). Ethical issues in exposing children to risks in research. In *Children as research subjects: Science, ethics, and law*. M. A. Grodin, L. H. Glantz. New York: Oxford University Press.
- Gaylin, W. 1982. The competence of children: No longer all or none. *The Hastings Center Report* 12(2): 33–38.
- Grover, S. 2003. On the limits of parental proxy consent: Children's right to non-participation in non-therapeutic research. *Journal of Academic Ethics* 1: 349–383.
- Harris, J., and S. Holm. 2003. Should we presume moral turpitude in our children? Small children and consent to medical research. *Theoretical Medicine and Bioethics* 24(2): 121–129.
- King, N.M.P. 2000. Defining and describing benefit appropriately in clinical trials. *Journal of Law Medicine & Ethics* 28(4): 332–343.
- Lyons, B. 2011. Obliging children. Medical law review 19(1): 55–85. McCormick, R.A. 1976. Experimentation in children: Sharing in sociality. *The Hastings Center Report* 6(6): 41–46.
- Miller, V.A., and R.M. Nelson. 2006. A developmental approach to child assent for nontherapeutic research. *The Journal of Pediatrics* 149: S25–S30.
- Parfit, D. 2011. On what matters. Vol. 1. Oxford: Oxford University Press.
- Ramsey, P. 1970. *The patient as person; explorations in medical ethics*. New Haven: Yale University Press.
- Ramsey, P. 1976. The enforcement of morals: Nontherapeutic research on children. *Hastings Center Report* 6(4): 21–30.

- Redmon, R.B. 1986. How children can be respected as 'ends' yet still be used as subjects in non-therapeutic research. *Journal of Medical Ethics* 12: 77–82.
- Ross, L.F. 1998. *Children, families, and health care decision-making*. Oxford: Clarendon Press.
- Ross, L.F. 2006. *Children in medical research: Access versus protection*. Oxford: Clarendon Press.
- van der Graaf, R., and J.J. van Delden. 2012. On using people merely as a means in clinical research. *Bioethics* 26(2): 76–83.
- Wendler, D. 2010. The ethics of pediatric research. Oxford: Oxford University Press.
- Wendler, D. 2012. A new justification for pediatric research without the potential for clinical benefit. *The American Journal of Bioethics* 12(1): 23–31.
- Williams, G. 2012. Children as means and ends in large-scale medical research. *Bioethics* 26(8): 422–430.