

## Right to an Open Future

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Dr. Jeremy Garrett shares why some parents would want to get their children's genetics screened and sequenced. However, is it beneficial for the children?



Featured Speaker:

**Jeremy Garrett, PhD**

Jeremy Garrett is a philosopher and bioethicist in Kansas City.

Transcription:

Welcome to the Peds Ethics podcast, where we talk to leaders in pediatric bioethics about a hot topic or current controversy. Here's your host, John Lantos from the Children's Mercy Bioethics Center in Kansas City.

John Lantos, MD (Host): I'm John Lantos, the Director of the Children's Mercy Hospital Bioethics Center in Kansas City, Missouri. And I'm here talking with my colleague Professor Jeremy Garrett. Jeremy is a research Professor of Bioethics at Children's Mercy and the University of Missouri in Kansas City and full disclosure; we wrote a paper together entitled Rethinking the Open Future Argument Against Predictive Genetic Testing in Children. Jeremy was the first author. We had a number of distinguished colleagues from the CAESAR Consortium Pediatrics Working Group and we are going to talk today about the open future argument and why we think it's flawed. Jeremy, could you start by just telling us what the open future argument is, what the concept is, how it developed and maybe a little about why you think it's problematic?

Jeremy Garrett, PhD (Guest): Sure. And let me just start by saying thank you for the invitation to participate in this podcast and discuss our argument a little bit. It was a great paper to work on and I was honored to have you and the other colleagues that worked with us on it. So, let me provide just a little bit of historical background as well as some conceptual background that I think is important for understanding the open future argument.

As many people will know the history of it goes back to the 1970s, the philosopher Joel Feinberg coined the expression the right to an open future in a paper that he wrote in the late 1970s where he was retrospectively analyzing the Supreme Court case of *Wisconsin V Yoder* from 1972. That case of course, was concerned the Amish practice of removing their children from formal education early and the question before the court was whether or not the Amish should be exempted from the school - compulsory school education requirements in Wisconsin. Of course, in that case, the Supreme Court ruled in favor of the Amish, but Joel Feinberg thought that this was problematic from a moral perspective and that it cut short the opportunities for Amish children to acquire certain skills and capacities that would allow them to freely choose a career other than being an Amish farmer.

So, fast forwarding ahead just a little bit; this really wasn't picked up on much by philosophers or bioethicists through the 1980s as far as I can tell. But it kind of exploded in the 1990s and in particular, it exploded with the issue that we take up in our paper on predictive genetic testing, it came to kind of

be a formative concept in the official guidelines of various genetics societies and pediatric societies with respect to whether or not it was permissible to test children or to disclose to them the results of genetic tests for adult onset conditions.

Host: Could you give an example of some sort of test where parents might want to test for an adult onset condition?

Dr. Garrett: Well really, any condition that is adult onset might be one that a parent might be curious about. They might be nervous about. They may want to know whether or not their child is going to have this in order to shape their childhood a certain way or protect them perhaps from negative consequences that they may experience.

Host: They want to know if their kid is going to get Alzheimer's or breast cancer.

Dr. Garrett: Alzheimer's or Huntington's, those were kind of the I think some of the classic tests that we could do with single gene testing. So, that concept of the right to an open future came to kind of dominate many of the ethical discussions of predictive genetic testing in the mid-1990s. And of course, many bioethicists will be familiar with Gina Davis's argument published in various law reviews and in the Hastings Center report where she tried to argue that it was wrong for deaf parents to deliberately conceive deaf children because it violated their right to an open future.

And then since the 1990s of course the concept of a right to an open future has been applied to many other bioethics issues, the sterilization of minors, questions about gender assignment or gender reassignment, fertility preservation is a recent one.

Host: Let's stick to genetics for this discussion. What's the problem in doing predictive genetic testing?

Dr. Garrett: Well there's two main arguments that have historically been given to support the restrictive stance that professional societies have taken on this question. One of them is a very simple one that appeals to the consequences, the purported negative consequences that is of predictive genetic testing and that is the psychosocial harm that might result to both the children and the families of children who receive that information. The idea being that it creates anxiety. It creates a host of negative emotive and cognitive states related to anticipating bad outcomes and it starts to close off the potential for parents to treat their children as if they will have an open future and start to treat them differently. Perhaps coddle them, protect them, be over involved in their lives because they perceive them in terms of their future illness.

Host: So, as a kid, I'm better off if neither I nor my parents know the I'm at higher risk for getting Alzheimer's Disease.

Dr. Garrett: On this particular argument, that is basically the point that I think people are making that I will be protected from a host of potential negative consequences of knowing this information while I'm a child. And it should be left to me –

Host: So that's the consequence based –

Dr. Garrett: Right, that's the consequence based. The right to an open future, the other main strand of argument that's often given in support of restricting predictive genetic testing on this argument, it doesn't really matter whether or not I have any negative consequences. In fact, I might have positive consequences. The idea here is that it's my information and I should be the one that decides whether or not I want to have it and the only way to do that is to wait to defer the decision until I'm an adult and capable of deciding for myself whether or not I want to know my status for Huntington's or Alzheimer's.

Host: So, if I want to know, once I turn 18, I can go out and get tested and my parents don't have the right to take that choice away from me. That belongs to me in trust and to take that choice away from me is simply wrong even if it leads to benefits.

Dr. Garrett: Yes, that's the idea of a more deontological framing of the right to an open future that it's my decision to make even those who are fiduciaries for me in childhood, my parents, my clinicians, they don't have the right to make a decision that's properly mine and so, ethically speaking, they should wait as long as possible so that I can be – participate in the decision making to the greatest degree possible and weigh in with my own values and preferences at that point.

Host: Well that makes a lot of sense. And as you say, professional societies have been endorsing that for decades. What's the problem?

Dr. Garrett: Well the problem that I see with it is that it takes what everyone would agree I think is an interest that people have, and it puts the strongest ethical constraints in our moral vocabulary with that interest and that's the concept of a right. What I object to is the idea that we elevate the interest in an open future so highly above all the other interests that children have and then protect it with the strongest constraints that we have at our avail and this leads to decision making that I think compromises the other interests that children have.

Host: So, in many cases, it might still be a good thing not to test kids for adult onset conditions but the argument you're making is that there are circumstances in which it might be appropriate to do so?

Dr. Garrett: Absolutely. I think that that's exactly the basic argument that in many cases, it is correct to think that the open future interest is one that deserves protection. What I oppose is the idea that from the very beginning, we basically are not open to the idea that it could be outweighed by the other interests that children or families have when they are making decisions around predictive genetic information.

Host: So, don't defenders of the right to an open future also admit that there might be exceptions?

Dr. Garrett: They do often and then that's sort of one of the replies that one hears all the time is that oh, we all know that rights have exceptions. I think that that argument doesn't hold muster though because if you really look at the exceptions, you realize they happen only rarely and really, it's hard to imagine many things arising in the normal context of pediatric genetics that would ever allow one to override the right. So, when you claim that the interests that children have in an open future is one that ought to be protected by a right; you're making a very, very strong claim about when it's permissible to violate that interest. And effectively it never is permissible in the context of genetics.

So, this puts into this world of pediatrics where we balance interests, we're regularly considering benefits against harms and trying to figure out what's best for children; this very rigid protection against ever violating their open future interests. And I think that that poorly fits with the other things that we do in pediatrics and I just don't think it's justified to give the open future that kind of protection as a matter of course all the time, regardless of what stage the children are at in their development, regardless of family context or all of the variety of factors that might come into a particular decision that a family makes with respect to whether or not to have testing or to have results disclosed to them.

Host: So in the paper, you site an Institute of Medicine report from about 25 years ago where they set some criteria for when you could breach the right to an open future. They said it's only when you have a really important goal such as the protection of someone from serious harm; there's a high probability of realizing that goal and there are no acceptable alternatives to reach the goal. Would those conditions be similar to what you would apply to the interest in an open future?

Dr. Garrett: I would not actually accept those conditions myself. I do think those are the conditions that would be in place if one does accept the interest in an open future as a right and as one can see, when you look carefully at those four conditions; it really is hard to imagine cases in pediatric genetics where all four of those conditions would be met and that would justify overriding the open future interest. Because I think there are lots of cases where it could be justified. I obviously don't accept the conditions as stated. I think that there are other things besides protection of others from serious harm for example that could justify some compromise of an open future interest. And we go into to some detailed cases at the end of the paper of course, where we look at some of those and we consider the interest that a child might have in planning ahead for their own future in terms of their education or their career. We look at interests that they may have in emotional development. We consider the not trivial fact that many times genetic testing reveals positive information, that is good news, and this allows the child to move on with their life and not have a cloud of uncertainty hanging over them.

So, there are many things that I think could weigh against the open future interest and not just something really strong like protection of others against serious harm.

Host: So, the positive findings are usually findings that you don't have the gene for a serious condition that runs in your family.

Dr. Garrett: Yes, it's not that you have a super gene exactly but that you have – that the thing you were worried about is actually not something you need to worry about anymore. And you are able to move on with your life with the knowledge that the thing you were worried about is not really a concern and so, this is of course a result that happens quite frequently especially in asymptomatic populations and I think that it's reasonable for someone to prefer to take that chance and I especially think that it's reasonable the further along we get in the stages of development. So, we consider a case in the paper where a - I can't remember what age we actually set him at but somewhere between 11 I think and we said he's kind of a precocious young child and he's been told that his grandfather has Huntington's, then his father had a test and realized that he had it as well and so, it's not unreasonable for this young man to suspect and actually believe he has it as well.

So, given his other interests in planning ahead for his future and his already probably justified belief that he likely has it himself; the idea that it would be impermissible for him to undergo testing for

another seven years until he becomes a legally recognized adult who can make his own decisions seems unjustified in this situation.

Host: Let me just unpack that case a little bit. That would be a situation to my mind where his – the 11 year old's future is already clouded that is if his father and his grandfather both had an autosomal dominant disease. He knows that he has a 50% chance of having it. And so, the gamble there is well defined. Would a similar argument apply in somebody who didn't have a family history?

Dr. Garrett: That's a good question. Real quickly though, I want to point out that the importance of what we just acknowledged though because if we want to think about the concept of a right to an open future, then the rationale that you just offered wouldn't matter. The right to an open future would prohibit us from telling this young man even if it was kind of a reasonable gamble that he was making. And it would say in fact, that we've done something wrong to this child by having him tested, allowing him to be tested. And so, just even conceding that point is important I think conceptually here in showing why we need to get past the concept of the right to an open future and shift to the language of interests.

Now as far as your particular question, I think again, this is why we need to avoid rigid ethical constraints in this territory because there just is so many variables at play when we talk about whether someone has a family history or doesn't, whether they receive screening in a context of information they have about their family history that leads them to be concerned about something versus general screening of a population that's asymptomatic. And so, I think the more flexibility we have with our ethical concepts, the better off we are able to be here in making decisions that make sense for individual families and individual persons.

Host: And it seems like the American Academy of Pediatrics agreed with it in their 2013 statement, they said it would be okay to test in "families for whom diagnostic uncertainty poses a significant psychosocial burden." Is that sort of the situation where talking about here?

Dr. Garrett: Yeah, and it's interesting. I'm glad that you brought this up because what one sees is that if you look back to the professional statements that were made in the 1990s, both by genetic specific societies and pediatric specific societies; many of them were strongly opposed to the idea that it would ever be permissible to test children for adult onset conditions or do carrier testing and these things. and then, when they've updated those statements, most of them occurring in the early 2010s one notices quite a shift, at least in tone, if not in explicit content and that shift is more in the direction of what we're defending in the paper. It's a recognition that the initial prohibition was probably not justified and that there are many cases where we would want to give parents and families, patients more flexibility to make decisions that recognized their unique situations and their unique values and needs.

And so, some of those statements actually explicitly noted that the prior guidance that they had given in the 1990s was overinterpreted, that is it was interpreted too strictly and my hypothesis is that part of what lead to that is the fact that the right to an open future was kind of inserted as the operative ethical constraint and just like clinicians don't tend to be in favor of violating the right to life or the right to bodily integrity or the other rights that people have; when they hear right to an open future; they're understandably reluctant to do anything that would seem to infringe on that right. And so I think that's part of the explanation for why when those original statements were made; people responded the way

they did and interpreting them basically as absolute constraints against this kind of testing.

Host: And do you think the updated statements go far enough that is does there have to be a significant psychosocial burden from not testing in order to justify testing? Or could parents decide they can test their children for anything that they are curious about?

Dr. Garrett: That's a great question. I think that the statements certainly do move in the right direction. I don't think they actually go far enough though and I don't think that our paper necessarily goes far enough either because I think what's really needed right now is even more guidance on how to both identify and weigh and balance against one another all of the different interests that children have that need to be considered in these kinds of decisions. And so, in the paper, we draw on the work of Janet Malik who looks at what does it mean to try to operate with a best interest standard and she identifies 13 different categories of interests that are at play when we make decisions with children and what we really need is more professional guidance on how to sort through all of these different interests including the interests that children have in their developing autonomy and in protecting their future autonomy through an open future interest.

And so, I would want to propose that people can be justified in making decisions about predictive genetic testing with far less than what the American Academy of Pediatrics has set out in their more recent statement. And I think it can make sense that simply on balance they think the interests of their child are better served through proceeding with testing.

Host: And are you working now on developing such a framework?

Dr. Garrett: I am somewhat. And it's a tough task of course and what one has to recognize again is the fact of value pluralism that we live in a world where there are lots of good things and they can't all be realized in any given decision and reasonable people can disagree about how to think about those and so that becomes the really challenging fact on the ground I think that makes it hard to come up with any kind of definitive ranking or priority mechanism for sorting through these. And so, what one really needs is some kind of general principles for how to make sure that all these interests are adequately considered, and that some kind of reasonable balancing is taking place in support of whatever decision is ultimately made by a particular patient, family or clinical team or all three together.

Host: And that's tough enough when you have only reasonable people in the room, sometimes there are unreasonable people. Thank you very much for going through this paper with us and participating in our pediatric ethics podcast series. Just a reminder the paper is by Professor Jeremy Garrett who is a research professor at Children's Mercy Hospital in Kansas City and the University of Missouri Kansas City. It was published in Genetics in Medicine in October of 2019. The paper is called Rethinking the Open Future Argument Against Predictive Genetic Testing of Children. Thanks so much for being here and we'll be back with another podcast next month.

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