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Rethinking the "open future" argument against predictive genetic testing of children

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Professional consensus has traditionally discouraged predictive genetic testing when no childhood interventions can reduce future morbidity or mortality. However, advances in genome sequencing and accumulating evidence that children and families cope adequately with predictive genetic information have weakened this consensus. The primary argument remaining against testing appeals to children's "right to an open future." It claims that the autonomy of the future adult is violated when others make an irreversible choice to obtain or disclose predictive genetic information during childhood. We evaluate this argument and conclude that children's interest in an open future should not be understood as a *right*. Rather an open future is one significant interest to weigh against other important interests when evaluating decisions. Thus, predictive genetic testing is ethically permissible in principle, as long as the interests promoted outweigh potential harms. We conclude by offering an expanded model of children's interests that might be considered in such circumstances, and present two case analyses to illustrate how this framework better guides decisions about predictive genetic testing in pediatrics.

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INTRODUCTION

For more than two decades, professional consensus has discouraged predictive genetic testing of children for adult-onset conditions (hereafter, predictive genetic testing) when no interventions in childhood might reduce morbidity or mortality.[1–8] More recently, this position has been extended to discourage disclosure of results produced by genome sequencing performed for other purposes. These professional recommendations are now being questioned. The ethical framework originally developed for single-gene testing requires re-evaluation given the ready availability of genome sequencing and the wealth of information it produces. Unlike single-gene testing, the use of genome sequencing to answer a clinical question can generate hundreds or even thousands of genetic findings. Many of these findings would not alter the care of the patient, and most fall well outside the indication for a test. Genome sequencing also has spurred studies of the psychosocial impacts of genetic information on pediatric patients and families that have deepened our understanding of those impacts. The time is ripe to re-examine the prevailing wisdom on this matter.

Historically, two primary ethical arguments have underpinned the consensus against predictive genetic testing in the position statements of leading professional societies.[1–8] One is empirically grounded and focused on the consequences of the decision. It warns of potential psychosocial harms resulting from children or parents learning about future risks for adult-onset conditions. However, accumulating evidence indicates such psychosocial harms are less common and less impactful than originally feared. Although important work is still ongoing, these preliminary data have begun to reduce concerns about the presumed psychological harms of this information.[9,10]

The second argument focuses on the special moral status of children as future adults. It invokes children's "right to an open

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future," which purportedly is violated when irreversible choices are made for them during childhood. Numerous literature reviews and qualitative surveys indicate that this argument is perhaps the most frequently cited objection to predictive genetic testing among clinicians and bioethicists.[11–14] Moreover, unlike the concern about immediate psychosocial harms, the violation of a moral right is a value claim that cannot be refuted by empirical evidence.[13] Hence, this argument against predictive genetic testing likely will become even more important as the evidence base develops and shifts.

Given this evolution in justification for restricting predictive genetic testing, it is imperative to evaluate critically the conceptual basis for the right to an open future. We undertake this task by analyzing the concept of an open future and the nature of moral rights, both in theory and in the context of two clinical case scenarios. We argue that children's interest in an open future can be protected adequately without imposing a strict ethical obligation to refrain from infringing that interest (i.e., a *right*). Rather, an open future should be regarded as one significant interest to weigh against other important interests when determining whether testing or disclosure would provide more benefits than harm.[15] Considered this way, predictive genetic testing is ethically permissible in principle, as long as multiple important interests are considered and balanced. We conclude that this shift in ethical frameworks better guides decision-making about both genome sequencing and standard single-gene testing for children.

HISTORICAL BACKGROUND

The philosopher Joel Feinberg is generally credited with coining the phrase, "the child's right to an open future." He did so in the context of a legal case, *Wisconsin v. Yoder*,[16] which considered whether Amish communities should be exempted from compulsory school attendance laws.[17] In his argument, Feinberg highlighted a category of rights held *primarily* by children—so-called "rights-in-trust," which "look like adult autonomy rights" but cannot yet be exercised in childhood.[17] Describing this class of rights further, Feinberg stated:

> When sophisticated autonomy rights are attributed to children who are clearly not yet capable of exercising them, their names refer to rights that are to be *saved* for the child until he is an adult, but which can be violated "in advance," so to speak, before the child is even in a position to exercise them… His right while he is still a child is to have these future options kept open until he is a fully formed, self-determining adult capable of deciding among them.[17]

For Feinberg, the Amish violated the rights-in-trust of the children whose formal education was cut short. He argued that this practice left children prepared for few careers or lifestyles outside of an Amish farm and, thus, curtailed many potentially desirable future options. Importantly, this argument did not carry the day in *Yoder*. The court decided in favor of the Amish. Nonetheless, the right to an open future took hold in numerous ethical contexts.[18–46]

The consensus against predictive genetic testing based on this right took shape in the early to mid-1990s.[47,48] Within the roughly 20-year period that followed, the right to an open future became prominently ensconced in the official position statements of many leading professional societies around the world[49] (Table 1). This restrictive consensus was endorsed and reinforced in the work of bioethicists as well. For example, Dena Davis, in both the 2001 and 2010 editions of her influential book, *Genetic Dilemmas*, argues that "[predictive genetic testing] is a decision each individual can make only for herself. Thus respect for the child's right to an open future supports the growing consensus in the United States against allowing parents to choose such testing for their children."[20] This interpretation of the right to an open future has, in turn, shaped many arguments against predictive genetic testing in the medical and bioethics literature and in clinical settings over the past two decades.[11,14,35,36,50–58] For example, in a 2017 article written for an audience of genetic counselors, Fenwick and colleagues summarize the status quo as follows: "The recommendations from these guidelines are well-established and have not changed significantly over time. Their primary message is that unless testing has current medical benefit, it should be deferred until a child is old enough to make her/his own decision protecting what Feinberg called the child's right to an open future."[14]

CONCEPTUAL AND ETHICAL ANALYSIS

While the right to an open future has influenced pediatric bioethics significantly, we believe it is a principle that is apt to sow confusion and ambiguity rather than clarity.

First, what it means for a child's future to be "open" or "closed" is not intuitively clear. Must future options be *permanently inaccessible* to be considered "closed"? Or is it sufficient that certain options are simply *more difficult to access*? Few decisions made during childhood permanently foreclose some future possibility. However, many decisions (including many standard parenting decisions) make certain futures more or less difficult to realize. It is, to take Feinberg's example, not literally impossible for Amish youth with abbreviated formal education to realize futures outside their community farm.[59] Indeed, a small proportion demonstrate this following their period of Rumspringa (the rite of passage for Amish teenagers preceding the choice between baptism within and separation from the Amish church), by deciding to leave the community and begin a new life. This first ambiguity, then, has real significance. If "closing" a child's future requires making some future state of affairs literally *impossible*, then the right to an open future will have few applications within pediatrics or parenting more broadly. But if closing a child's future refers to any decision that makes certain futures *significantly more difficult*, then this right will apply too widely, prohibiting many ordinary and even unavoidable parenting practices.[60]

Table 1 Selected official position statements by leading professional societies restricting predictive genetic testing by appealing to the child's future autonomy or right to an open future

Professional society	Years active	Relevant section
UK Clinical Genetics Society	1994–2010	The principle of "respect for autonomy" entails that "formal genetic testing should generally wait until the 'children' request such tests for themselves, as autonomous adults."[2]
American Society for Human Genetics & American College of Medical Genetics and Genomics	1995–2015	"If the medical or psychosocial benefits of a genetic test will not accrue until adulthood, as in the case of carrier status or adult-onset diseases, genetic testing generally should be deferred…[with exceptions limited to adolescents who meet standards of competence, voluntariness, and adequate understanding of information]…The unique potential of presymptomatic genetic testing to predict a child's future should be approached with great caution."[3]
American Academy of Pediatrics	2001–2013	Predictive genetic testing "inappropriately eliminates the possibility of future autonomous choice by the person"; thus, "pediatricians should decline requests from parents or guardians …until the child has the capacity to make the choice."[4]
Canadian Paediatric Society	2003–present	There is a "basic right for an individual to decide whether one wants genetic testing that will reveal genetic information…For genetic conditions that will not present until adulthood (susceptibility or predictive testing), testing should be deferred until the child is competent to decide whether they want the information."[5]
European Society for Human Genetics	2009–present	"Presymptomatic and predictive genetic testing of minors for conditions with adult-onset is acceptable only if preventive actions (eg preventive surgery or early detection aimed at therapeutic interventions) can be initiated before adulthood. Otherwise presymptomatic and predictive genetic testing in minors for adult-onset disorders should be deferred until the person has the maturity and competence to understand the nature of the decision and its implications."[6]
National Society of Genetic Counselors	2012–present	"[NSGC] encourages deferring predictive genetic testing of minors for adult-onset conditions when results will not impact childhood medical management or significantly benefit the child. Predictive testing should optimally be deferred until the individual has the capacity to weigh the associated risks, benefits, and limitations of this information, taking his/her circumstances, preferences, and beliefs into account to preserve his/her autonomy and right to an open future."[7]
Human Genetics Society of Australasia	2014-Present	"Pre-symptomatic and predictive testing in children and young people who cannot yet make a mature decision about testing removes the possibility for them to make an autonomous decision as an adult. It is for this reason that it is recommended that pre-symptomatic and predictive testing be limited to individuals assessed to have sufficient maturity to make an informed decision about testing."[8]

A second ambiguity arises regarding what the right to an open future is intended to protect precisely. We might view this right as requiring fiduciaries to ensure children have the fundamental resources to make decisions as adults. This could include *basic capacities* like the ability to reason from means to ends, as well as *basic preferences*, since adult decision-making requires mature desires and values.[61] Alternatively, we might determine specific *skills*, like learning a second language, to be vital to an open future.[61] Finally, we might instead focus on preserving specific *options* and *opportunities*, like becoming an Amish farmer or attending college.[61] Here again the choice of target matters. If the right to an open future merely requires preserving and developing children's *basic capacities*, then few medical decisions, including predictive genetic testing, will seriously threaten this right. However, if the right forbids foreclosing *specific options and opportunities*, then it will be far too strong, implying that parents routinely violate their children's open future by encouraging certain opportunities and discouraging others.

A third ambiguity relates to whether we should understand an open future *quantitatively* or *qualitatively*. Defenders of the right to an open future sometimes speak as if children have the right to "reach maturity with as many open options, opportunities, and advantages as possible"[17] and at other times as merely the right to reach maturity without a "radical narrowing"[18] of their options, opportunities, and advantages. However, defenders also sometimes focus less on the *quantity* of choices and more on their *quality*, entailing a right for children to reach maturity with certain *vital* options, opportunities, and advantages left open. Here again the choice of interpretation has important implications. A maximal ideal seems impossible to satisfy; parents make

future-effecting choices for their children every day and cannot avoid doing so. A minimal threshold, on the other hand, is more defensible on its face, but also less relevant to pediatrics: few single decisions made for children, including predictive genetic testing, "radically narrow" their future. Focusing on the moral quality of specific choices seems more promising, but leaves us with the task of determining, in a nonarbitrary manner, which choices are *vital* to the adults whom children will become. And even there it is unclear whether parents can, or should, *avoid* shaping such choices for their children, especially when doing so serves other important interests.[62–64]

Within the context of predictive genetic testing, these questions generate significant ambiguity. Obviously, *any* decision made for children in this context (to pursue testing or not) will affect their future. These decisions may even permanently close off certain options. Disclosing information about future risk does rule out the recipient *not knowing* that information. However, delaying testing/disclosure until adulthood is *also a decision made for the child in childhood*. Moreover, this decision to defer may close off important opportunities. We should emphasize that many test results alleviate anxiety and uncertainty, inform planning for a future health condition, enable children to begin—while in a stable and supportive environment—incorporating information into their developing identity and autonomy, or live out a limited lifespan in a way that prioritizes and maximizes what matters most to the child (i.e., meaningful time with family and friends, personal adventures, spiritual/religious pursuits, advocacy for political change or medical progress, and so on).[53,63,64] Either way, a decision must be made for the child *in childhood* and each opens some future options and closes others.[63,65,66]

In light of these concerns, it seems inappropriate for health professionals to appeal to a "right" to an open future to encourage some decisions about predictive genetic testing, while fervently discouraging others. The right to an open future is traditionally regarded as a "negative claim-right."[67] Within our common morality, negative claim-rights constitute the strongest ethical constraint on the actions of others.[68] This type of right protects an interest—in this case, the interest in having decisions deferred to make for and by one's future self—by placing all moral agents, including parents and clinicians, under a strict obligation to refrain from infringing that interest.[67] Violations of a negative moral right are permitted rarely and *only* under strict conditions. The 1994 Institute of Medicine report, *Assessing Genetic Risks*, proposes four conditions that would need to be met to justifiably override an individual's autonomy in the context of predictive genetic testing (Table 2) (ref. [1]). Crucially, all four of these conditions will be met only in very rare circumstances. *To assert that children have a negative moral "right" against such testing in childhood is to make a forceful moral claim, one that will override all other interests in nearly all realistic circumstances*.

Table 2 Proposed set of four conditions necessary to justify the breach of an autonomy-based right such as the child's right to an open future[1]

1.	The action must be aimed at an important goal—such as the protection of others from serious harm—that outweighs the value of autonomy…in the particular instance.
2.	[The action] must have a high probability of realizing that goal.
3.	There must be no acceptable alternatives that can also realize the goal without breaching those principles.
4.	The degree of infringement of the principle must be the minimum necessary to realize the goal.

Even setting aside these more theoretical concerns, the vast potential for misinterpretation and misuse by itself provides sufficient reason to refrain from rights language here. In our experience, many practicing clinicians and scientists have felt compelled to adopt the right to an open future but lack a nuanced understanding of the concept; for them, it is no more permissible to violate this "right" than to violate a child's right to life or bodily integrity. Indeed, in at least two significant cases, recent updates to professional guidelines noted that many clinicians have interpreted prior guidance as more prohibitive of predictive genetic testing than was intended or explicitly stated.[69,70] *A significant factor contributing to this widespread misinterpretation is precisely the way in which concerns about the open future became ensconced within the language of rights*.

Fortunately, the ethical construct of a "right" is unnecessary to identify and adequately protect the primary concern here—the child's *interest in* an open future. Children are more likely, in general, to flourish when certain future options are left open. Most parents understand this. The notion that children have interests in an open future fits well with standard ethical guidance in pediatric bioethics.[71] The child's interest in an open future is one important, but not automatically the *most* important, interest to consider and balance in the process of shared decision-making.[63] In other words, *an open future is best understood not as a separate principle of pediatric bioethics, but instead as one component of its traditional focus on interests and balancing benefits and harms to children and families*.[62,72,73] There is a robust literature on the interests of children in pediatric ethics. While a comprehensive examination of this literature is beyond the scope of this paper, examining one promising account of children's interests helps demonstrate how an open future interest can be weighed alongside other interests. This account, developed in 2009 by Malek,[74] utilizes extant statements about children's needs and interests to propose a list of 13 important interests that should be considered in pediatric decision-making (Table 3). Each interest is a capacity, activity, or state of affairs that contributes to the well-being of children, and most medical decisions will involve some tradeoffs among these interests. While an interest in an open future is not explicitly included in Malek's list, we propose that it should be added, perhaps as

Table 3 Proposed list of interests that should be evaluated when making decisions for children (adapted from Malek[74])

#	Proposed interest
1	**Life:** To live and to anticipate a life of normal human length.
2	**Health and health care:** To have good health and protection from pain, injury, and illness. To have access to medical care.
3	**Basic needs:** To have an adequate standard of living, especially to be adequately nourished and sheltered.
4	**Protection from neglect and abuse:** To be protected from physical or mental abuse, neglect, exploitation, and exposure to dangerous environments. To be secure that they will be safe and cared for.
5	**Emotional development:** To experience emotion and have appropriate emotional development.
6	**Play and pleasure:** To play, rest, and enjoy recreational activities. To have pleasurable experiences.
7	**Education and cognitive development:** To have an education that includes information from diverse sources. To have the ability to learn, think, imagine, and reason.
8	**Expression and communication:** To have the ability to express themselves and to communicate thoughts and feelings.
9	**Interaction:** To interact with and care for others and the world around them. To have secure, empathetic, intimate, and consistent relationships with others.
10	**Parental relationship:** To know and interact with their parents.
11	**Identity:** To have an identity and connection to their culture. To be protected from discrimination.
12	**Sense of self:** To have a sense of self, self-worth, and self-respect.
13	**Autonomy:** To have the ability to influence the course of their lives. To act intentionally and with self discipline. To reflect on the direction and meaning of their lives. *To have "future autonomy" protected by having future options and opportunities kept open.*

one component of the interest in autonomy, i.e., an interest in preserving future autonomy.

A nuanced interest-based framework like this better serves pediatric clinical ethics than a rights-based approach for two important reasons (Table 4). First, unlike a rights-based approach, an interest-based framework is not rigidly committed to a predetermined conclusion and can nimbly incorporate and respond to an ever-evolving evidence base. Second, it enables a comprehensive and systematic, but also flexible and balanced, assessment of children's many diverse interests. In particular, this framework facilitates better decisions about whether the full range of interests for any particular child are promoted more by opening or closing certain futures. The interest in preserving future autonomy is weighed alongside other interests identified by Malek, potentially supporting different conclusions in different circumstances. Foreclosing the opportunity to make certain choices later may promote a child's overall interests in some circumstances. For example, many parental and pediatric decisions—like disclosing to an 11-year-old child that he was adopted or removing an infant's supernumerary digit—*could be* delayed until the child reaches adulthood. However, while such delays might preserve one particular opportunity for autonomous choice, foreclosing those later decisions and proceeding with disclosure or surgery now will often open other opportunities that better serve the child's overall interests.[64] In other circumstances, though, producing or preserving openness may be most compelling. Decisions like career choice are frequently viewed this way: parents typically take measures to keep their child's future career options open, even though it might serve other interests to radically narrow this range earlier (e.g., strongly funneling them into a lucrative family business). Individual families working with their chosen care providers are best positioned to identify and balance competing interests in particular circumstances.[53,60,66,75,76] The presumed validity of a right to an open future has impeded that ideal approach for too long in too many pediatric contexts, including decisions about predictive genetic testing.

THE ADVANTAGES OF AN INTEREST-BASED FRAMEWORK

In what follows, we use case-based reasoning to contrast rights-based and interest-based approaches to children's open future. Admittedly, we cannot consider all factors that are ethically relevant to decisions about predictive genetic testing, such as the developmental status of the child, medical conditions, or clinical contexts. Nonetheless, the two vignettes we analyze represent commonly-encountered cases and, together, illustrate the value of an interests-based framework.

Case #1

Ariel and Lynch syndrome

Ariel is a ten-year-old girl with seizures but otherwise normal neurological development. Her neurologist specializes in the genetic basis of neurological conditions, and decided, after discussions with Ariel and her mother, to use genome sequencing to identify the cause of a seizure disorder, even though gene panels more narrowly focused on epilepsy are available. In analyzing the sequencing data, the neurologist determines that Ariel has a pathogenic variant in the MLH1 *gene, which causes Lynch syndrome. Ariel has no contact with her father, and her mother was not sequenced. It is therefore not known from whom this variant was inherited or if it is de novo. When she reaches 20–25 years of age, Ariel should begin biennial colonoscopies to screen for cancer. Ariel does not have a family history of colon cancer or other Lynch syndrome cancers, but her mother was adopted and has no information about her own parents. If Ariel's mother knew that Ariel had a pathogenic variant in* MLH1*, she could seek genetic testing for herself to determine whether she has that same variant, and thus pursue preventive measures that could provide substantial benefit. In fact, both Ariel and her mother might benefit if her mother's risk of dying from early-onset colon cancer is decreased, which would decrease the chances of Ariel losing the care, attention, and financial stability her mother provides for her.*

Table 4 A comparative analysis of rights-based and interest-based ethical frameworks when applied to decisions about predictive genetic testing of children for adult-onset conditions

	Rights-based framework	Interest-based framework
Focus	Future adulthood	Childhood/adolescence extending forward
Function	Singling out one future-oriented autonomy interest for exceedingly strong protection until adulthood	Weighing and balancing numerous competing interests comprising children's present and future health and well-being
Flexibility	Very low (applied to all not-yet-autonomous minors at all stages, in all contexts, and irrespective of shifting evidence base)	High (developmentally contoured, contextually tailored, and responsive to shifting evidence base)

In this case, a clinician must decide whether to disclose a secondary (or "additional"[77]) finding that identifies a child's predisposition for developing colon cancer. Although this information would not be *clinically* actionable for Ariel until adulthood, the clinician knows that Ariel's positive finding means her mother may have the same variant. Given that her mother is unaware of her family medical history and adults do not routinely undergo predispositional genetic testing, this "incidental" piece of information might provide her only warning.

If Ariel is understood to have a negative moral "right" to an open future, it would be irrelevant that her mother (and indirectly Ariel) might benefit from this information. After all, "rights" function as moral trump cards, overriding other competing interests.[63,78] An interest-based standard, however, provides a framework within which multiple competing interests can be weighed. In deciding whether to share this information, the clinician should consider potential benefits to Ariel's mother as a relevant interest, as well as potential benefits Ariel might receive from her mother avoiding morbidity and mortality.[79] Keeping Ariel's mother healthy could potentially support Ariel's interest in having her basic needs met (#3), having support for emotional development (#5), and having a relationship with her parent (#10) (Table 3). Ariel's interest in deferring the decision whether to receive this information until she can decide for herself as an adult is relevant, but it should be weighed alongside these other important interests.

Ariel's case also highlights an important asymmetry when the right to an open future is applied to secondary genomic findings. Typically, claims about this right assume that the decision to seek or disclose genetic information can be made *now*, while the child is a minor, or *later*, when the child has reached adulthood. The options are not always so clear, however. If Ariel is still receiving care from the same physician when she reaches adulthood, then she may have an opportunity to decide for herself whether to receive secondary genetic results, including variants in the *MLH1* gene. However, Ariel will not transition to adulthood for another eight years. In this time it is likely that Ariel's family will have moved, their contact information will have changed, or her neurologist will have relocated or retired. Even if Ariel's interests are, in principle, better served by deferring the decision until she reaches adulthood, nothing guarantees that she actually will be afforded this opportunity. An interest-based framework, however, can account for this possibility, weighing Ariel's interest in deciding later with her interest in not missing an opportunity to receive important genetic information that otherwise may be unavailable.

Case #2

Byron and Huntington disease

Byron is an 11-year-old male who has no chronic medical conditions. Byron's paternal grandfather recently was diagnosed with Huntington disease. After discussing the issue with a genetic counselor and his family, Byron's father decided to have a genetic test to determine whether he had inherited this condition. The test came back positive. Byron's parents explained his father's result to him, and all three decided to discuss genetic testing with his pediatrician and a genetic counselor. Although there were no pressing medical reasons for Byron to undergo testing, he and his parents agreed, after multiple conversations with his pediatrician and genetic counselor, that Byron should undergo genetic testing soon. The uncertainty was not causing psychosocial problems; indeed, all three were doing well in handling the uncertainty about Byron's risk. However, all three saw value in not waiting until Byron reached adulthood to learn this information. Byron had decided that resolving this uncertainty would help him think about his future career, mainly because that could affect his choice of high school magnet programs. His parents, for their part, were already planning for his father's long-term care, and wanted to understand how best to include Byron's future health in that planning.

In contrast to Ariel's case, neither Byron nor his parents have a time-sensitive medical interest in Byron undergoing genetic testing for Huntington disease as a minor. There is a strong argument for delaying testing until a person can decide for himself to undergo testing, especially since 85% of adults at risk for Huntington disease choose not to pursue testing.[80,81] On the other hand, Byron already has decided he wants to pursue testing and no evidence indicates that he is likely to regret that decision later. Both Byron and his parents want to plan for the future, and these choices could be informed by genetic test results that establish whether Byron is likely to develop Huntington disease as an adult. Given the many other contingencies in life, it is debatable whether a possible diagnosis far in the future should be a determining factor in decisions such as which high school to attend. But on the other hand, the desire to plan ahead in this way is well

within the bounds of reasonable (even laudable) behavior for parents and adolescents.

In theory, a rights-based approach is capable of accounting for the circumstance where a relatively mature minor and his parents agree about wanting testing. As the policy statements of the professional organizations referenced above demonstrate, the right to an open future has explicitly been construed as a right to have decisions delayed until the young person is capable of making autonomous decisions (an ethical concept), not necessarily until the young person gains the legal authority to make medical decisions when they reach the age of majority (a legal concept). Assent, for example, provides one strategy for legal minors to express their developing autonomy in medical decisions.[82,83] In this case, Byron's assent to Huntington testing would further justify the decision to obtain testing, while his parents' permission would render it legally effective.

In practice, however, this is not how the right to an open future has been applied in clinical and research genetics. While strategies like assent can encourage minors to contribute meaningfully to medical decisions, the rights framing fosters the assumption that it is unnecessary, or even inappropriate, for parents to influence these decisions. If children have a right for decisions to be delayed until they can contribute to such choices, then children must also have a right for these decisions to be delayed even longer until no legal obligation requires including parents in the decision.

In contrast to the rights framing, interest-based approaches benefit from development in a range of applications in pediatric ethics,[26,62] and thus provide a robust framework for balancing the developing autonomy of children with the authority of parents. In Byron's case, an interest-based framework incorporates and weighs multiple factors, even interests that are not "clinically actionable," such as Byron's emotional development (#5) and sense of self and identity (#11 and #12), his desire to plan for his education and career (#7 and #13), his relationship with his parents (#10), and his parents' desire to plan for long-term care (#2) (Table 3).

Within this framework, deliberation on multiple interests will not always generate identical guidance. In some cases, the child and his family may have compelling interests that override the child's interest in preserving his future autonomy. On the other hand, there will be cases when the interests served by testing a minor will not be particularly compelling, and the child's interest in an open future will remain the overriding interest. Consider what would happen if we changed the circumstances surrounding Byron's case. If Byron were seven years old and perceived no personal utility in learning about his risk for developing Huntington disease, and his parents were simply curious or nervous about what his results might reveal, then the balance of interests could look quite different. His pediatrician or geneticist might be well-justified in declining the parents' request for immediate genetic testing if the parents' reason for wanting testing are outweighed by Byron's interest in later making a decision for himself. This ability to discriminate among dissimilar cases is one notable advantage of the interests approach, and coheres with the intuition that compelling circumstances can override the child's interest in an open future.[60,63,64,69]

In 2013, the American Academy of Pediatrics (AAP) and American College of Medical Genetics and Genomics (ACMG) issued a joint policy statement on genetic testing in children. They recommended against predictive genetic testing unless interventions in childhood are likely to decrease morbidity and mortality. Departing from the former policy, however, they suggested that exceptions might be valid, and gave the example of "families for whom diagnostic uncertainty poses a significant psychosocial burden."[84] Our approach is consistent with the AAP/ACMG position, as well as a 2015 statement by the American Society of Human Genetics (ASHG) that makes a similar point.[70] We are providing a more substantive framework than the concise policy statements could offer for considering when exceptions might be made.

SUMMARY AND IMPLICATIONS FOR THE FUTURE

In this paper, we noted how new understandings of predictive genetic information raise questions about the ethical foundations of predictive genetic testing. We think those questions are best answered by a shift in the basic approach to children's open future from a rights-based to an interest-based framework. Childhood is inescapably subject to parental decisions that curtail and shape future choices in diverse and important ways. The idea of a right to an open future is thus impractical, ambiguous, and ripe for misinterpretation. Children need fiduciaries to make choices on their behalf, and nearly all such choices constrain a child's future in some way.

To be clear, while we have argued that our interest-based framework improves upon the status quo, we recognize that it requires further development. Future research and collaboration should aim to:

- Develop a compelling account of how to evaluate, balance, and prioritize the interests on an unranked list like Malek's (expanded to include a [future] autonomy interest)
- Translate this more detailed framework into specific professional guidelines that address the full spectrum of ethically challenging cases related to predictive genetic testing
- Apply this framework in other domains where the right to an open future has been evoked, including within the field of genetics (germline modification of the mitochondrial genome and reproductive cloning) and beyond (the sterilization of minors, growth attenuation in children with developmental delay, and many others)

Still, our proposed framework provides a more fruitful and nuanced approach to the complicated ethical issues surrounding predictive genetic testing. We hope it will help guide those who must make these difficult decisions.

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DISCLOSURE

The authors declare no conflicts of interest.

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