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A Genomically Informed Education System? Challenges for Behavioral Genetics

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Abstract

The exponential growth of genetic knowledge and precision medicine research raises hopes for improved prevention, diagnosis, and treatment options for children with behavioral and psychiatric conditions. Although well-intended, this prospect also raise the possibility—and concern—that behavioral, including psychiatric genetic data would be increasingly used—or misused—outside the clinical context, such as educational settings. Indeed, there are ongoing calls to endorse a “personalized education” model that would tailor educational interventions to children’s behavioral and psychiatric genetic makeup. This article explores the justifications for, and prospects and pitfalls of such endeavors. It considers the scientific challenges and highlights the ethical, legal, and social issues that will likely arise should behavioral genetic data become available (or be perceived as such) and are routinely incorporated in student education records. These include: when to disclose students’ behavioral and psychiatric genetic profile; whose genomic privacy is protected and by whom; and how students’ genetic data may affect education-related decisions. I argue that the introduction of behavioral genetics in schools may overshadow the need to address underlying structural and environmental factors that increase the risk for psychiatric conditions of all students, and that the unregulated use of student behavioral genetic profiles may lead to unintended consequences that are detrimental for individuals, families and communities. Relevant stakeholders—from parents and students to health professionals, educators, and policy-makers—ought to consider these issues before we forge ahead with a genomically informed education system.

Introduction

Knowledge of genetics is expanding at an exponential rate. Since the completion of the Human Genome Project in 2003, numerous genes that contribute to the development of disorders have been identified. Although isolating genes relevant to behavioral and psychiatric disorders has been more challenging, efforts are ongoing to identify and better understand the genetics of such complex conditions. These endeavors are further likely to accelerate with the rise of large biospecimen cohorts, including the All of Us Research Program (previously called, the Precision Medicine Initiative), and raise hopes for improved prevention, diagnosis, and treatment options for adult and pediatric patients with psychiatric

conditions. Significantly, behavioral genetic data—a term used in this article to connote inherited behavioral, including psychiatric and neurodevelopmental, conditions such as aggression, depression, and attention deficit hyperactivity disorder (ADHD)—are also increasingly being used, or considered for use, in non-clinical contexts.

One such example is school settings. Although in its infancy stages, there are increasing calls to utilize genomic knowledge to develop “personalized education,” whereby interventions in classrooms will be tailored to a child’s behavioral and other neuropsychiatric genetic makeup.¹ As proponents of a genomically informed education system postulate, understanding the genetic bases of behaviors that impact learning-related processes will enable identification of environmental and pharmacological interventions that may enhance students’ educational achievements.² Although some may view such a genomically sensitive education system as appealing, the prospect of behavioral genetic data becoming available and incorporated in students’ education records faces significant scientific challenges and also raise a host of ethical, legal, and social issues, including the possibility—and concern—that such data would be misused in school settings.

This concern of misuse of student medical information is not unique to behavioral genetic data. In the early 20th, as cities in the U.S. began paying attention to sanitary conditions in schools and begun requiring that certain health services are provided, they also instituted mandatory daily medical inspection of students—carried out by nurses and physicians—to identify and exclude those with contagious conditions from schools.³ Although this medical inspection enabled reducing the spread of major communicable conditions such as measles, in practice, even minor and preventable diseases such as head lice served as a reason to send children home. Without a simultaneous duty that such children receive care, this practice was particularly detrimental for poor children whose educational and employment prospects were negatively impacted as a result of this exclusion.⁴ More recently, stigma surrounding HIV/AIDS has led to school children being denied admission and educational opportunities because of their real—and suspected—HIV-positive status.⁵ However, the innate nature of behavioral genetic data, coupled with stigma and genomic illiteracy among educators, the general public and healthcare professionals, raise an even greater risk of misunderstanding and misuse of student medical information.

This article explores the justifications for, and prospects and pitfalls of disclosure of student behavioral genetic profiles in school settings. Although there is currently no genetic test that can provide a diagnosis of a behavioral and psychiatric disorder or an accurate estimate of a person’s proclivity for such conditions (some rare exceptions of genetic syndromes exist, e.g., Fragile X),⁶ studies that focus on candidate genes and, especially, genes that interact with environmental factors to produce psychopathological outcomes are ongoing and there is high hope that the use of next-generation sequencing technologies and large cohorts (e.g., the Psychiatric Genomic Consortium’s dbGaP datasets) will yield more systematic findings.⁷ The history of the scientific technologies further suggests that scientists’ and lay public’s endorsement of genomic-based practices, including more controversial ones, often occurs over time, and moreover, that genomic data are increasingly being used in non-clinical settings and daily lives, sometimes, also when the scientific validity of findings is weak. Thus, it is plausible to assume that the introduction and use of student behavioral and

psychiatric genetic data in school settings will become more common once genetic testing with sufficiently high positive predictive power for such conditions is developed. Conversely, and more concerning, is the possibility that without policies to regulate genomic uses in non-clinical settings, stakeholders will try to introduce behavioral genetic findings in schools, regardless of the evidence-base of the data.

Accordingly, the next section considers the rise of uses of genomic data in clinical and non-clinical contexts, followed by a discussion about the increasing use of and support for genetic screening programs in educational institutions, to project about the probability of behavioral genetic data entering into school settings. I then discuss the challenges for a genomically informed education system. First, I provide the scientific landscape of, and obstacles in current (and likely future) study of behavioral and psychiatric genetics, and the relevance thereof for a genomically sensitive education system. Second, I consider the ethical, legal, and social issues that will likely to arise should behavioral genetic data become available (or be perceived as such) and are routinely incorporated in student education records, specifically: *when* to disclose students' behavioral and psychiatric genetic profile; *whose* genomic privacy is protected and by whom; and *how* students' genetic data may affect education-related decisions. I argue that the introduction of behavioral genetics in schools may overshadow the need to address the underlying environmental and structural factors that increase the risk for psychiatric conditions of all students, and that the unregulated use of student behavioral genetic profiles may lead to unintended consequences that are detrimental for individuals, families and communities. Relevant stakeholders—from parents and students, to health professionals, educators, and policy-makers—ought to consider these issues before we forge ahead with a genomically informed education system.

The “Genomicization” of Medicine and Everyday Life

As the pace of genomic knowledge advances in giant steps and sophisticated technologies allow generating genomic data at plummeting costs, genomic applications are becoming more and more relevant for medical practice and everyday life. Since the completion of the Human Genome Project in 2003, and the subsequent development of next-generation sequencing such as Whole Genome and Exome Sequencing, the number of genetic tests that are performed in clinical and research settings has sparked. It is estimated that ~4 million infants in the U.S. undergo newborn screening each year, and while current programs focus on metabolic, hematologic, and endocrine conditions for which early prevention or intervention are available,⁸ there are ongoing initiatives to expand newborn screening programs to next-generation sequencing.⁹ The number of children who are tested for various neuropsychiatric syndromic conditions, including those associated with intellectual disabilities is on the rise,¹⁰ as is the number of children who participate in studies that utilize next generation sequencing technologies¹¹ and are offered at least some return of results.¹²

The ongoing expansion of genomic-based practices—including some of the most controversial ones—is further useful in projecting whether and how children's behavioral genetics may be obtained and used in the future. For instance, the use of pre-implantation genetic diagnosis technique began with significant public turmoil but has become more common,¹³ and its original aim of identifying monogenic and sex-linked disorders has

expanded to include over 100 conditions, including testing for genetic disorders with low penetrance and late-onset conditions.¹⁴ A long and extensive debate about the permissibility of mitochondrial replacement therapy has culminated in 2015 into its approval for use in the U.K.,¹⁵ and 2016 recommendation to approve testing for this procedure in the U.S.¹⁶ Germline gene editing—another practice that, for years, was viewed as “off limits” for researchers and NIH-approved protocols—was recommended in late 2016 for clinical trials by the National Academy of Sciences and National Academy of Medicine.¹⁷ And, the 2013 setback on the market of direct-to-consumers (DTC) genetic testing companies that offered (dubious) genetic-based health risk assessment for psychiatric disorders¹⁸ is already reversing its course. In 2015, the Food and Drug Administration allowed 23andMe to offer tests for carrier status of over 40 inherited conditions;¹⁹ 10 additional genetic tests, including for Alzheimer Disease were approved in April 2017.²⁰ Given findings that many parents are interested in utilizing the services of DTC genetic testing companies to test their children for common diseases,²¹ and that parents express high interest in genetic testing of their young children for psychiatric predispositions,²² it seems likely that aside from clinical testing of symptomatic children, a market for pediatric genetic testing for behavioral and psychiatric conditions (once available and permitted for DTC marketing) may develop as well.

The uses of behavioral genomic data have additionally begun to expand beyond their intuitive clinical and research locales to encompass non-clinical and non-research settings. Although behavioral genetic research with actionable findings is still in its infancy, stakeholders seem eager to utilize emerging findings—also when the replicability and scientific accuracy of these findings are questioned²³—to advance their cause. Indeed, behavioral genetic claims have already made their way into criminal procedures,²⁴ child custody proceedings,²⁵ and tort litigation;²⁶ other civil arenas such as real property rights are currently being considered²⁷ as is the incorporation of knowledge about epigenetic processes such as DNA methylation that may impact the development of psychiatric disorders²⁸ into life insurance’s policy and assessment of consumers’ mortality predictions.²⁹

Significantly, there are signs that the genomicization of daily life is making its way also into educational settings. As Francis Collins had envisioned, as we move to maximize a genomics-based health care, it will become more and more compelling to learn about genetic risk factors and to consider effective interventions for them at birth,³⁰ and an array of new users of such data, including educational institutions, are likely to emerge.³¹ As discussed in the next section, not only that this trend is likely to increase, but the rationales for using student genetic data in schools may be of particular relevance for behavioral genetics.

The Road to Student Behavioral Genetics in School Settings

The notion that schools and student genetics can intersect is not new. In 1972, Montreal launched the first pilot program to screen (primarily Ashkenazi Jewish) adolescents in high school for carrier status of Tay Sachs Disease, a neurodegenerative condition that usually results in death by age 5.³² While the goal of this and most of the subsequent screening programs in high schools has been to increase informed reproductive choices, the scope of testing and the justifications thereof have undergone notable changes over time. Thus, e.g.,

screening programs in high schools that developed since the mid-1990s in Australia, Israel, Hong Kong, and the US have expanded to include testing for carrier status of genetic conditions that are less severe than Tay Sachs, such as Cystic Fibrosis.³³ In addition, high school-based screening programs for personal health reasons—i.e., to identify increased risk to a condition or increased risk for *susceptibility* to a condition³⁴—are slowly emerging as well. In 2007, e.g., a pilot program in Australia began offering high school students genetic susceptibility testing for hereditary haemochromatosis, an adult onset treatable and preventable disorder that causes the body to absorb too much iron from the diet.³⁵ A total of 5,757 high school students were subsequently tested for this condition (consent was obtained from both parents and students), leading the researchers to conclude that genetic susceptibility screening in high schools was both feasible and acceptable to stakeholders in school communities.³⁶

College and university settings are also becoming hot spots for student genetic testing. To date, several leading medical institutions (e.g., Stanford and Icahn/Mount Sinai) have already developed and implemented courses that include students' analysis of their own genome.³⁷ Although these courses enrolled only health professionals (including medical students and MA genetic counseling students) and aimed to provide experiential training as a way to improve patients' care, in the future such initiatives may expand to other types of students. Another example is the 2010 decision of the National Collegiate Athletic Association (NCAA) to require student-athletes to be screened for a genetic sickle cell trait prior to participating in college sports (student-athletes can opt out of testing after attending an educational session).³⁸ Although sickle cell is not a behavioral/psychiatric condition, the rationale for the NCAA's position is important: the expectation that screening will enable school athlete trainers to tailor the practice protocol to students who test positive.³⁹

Other large-scale collegiate genetic programs focus specifically on behavioral genetics. In 2010, e.g., Berkeley University mailed saliva sample kits to all incoming students and offered them individualized DNA analysis as a way to promote healthier life choices among students.⁴⁰ While the program required students' consent, it planned to conduct the DNA analysis in-house, at a University's lab, and to focus on specific gene variants—most pertinent here: genes that regulate the ability to metabolize alcohol—with test results being preserved as data sets on the University's computers. And, in 2011, Virginia Commonwealth University launched its university-wide "Spit for Science" study.⁴¹ This longitudinal study—which has since enrolled nearly 70% of its incoming freshman class each year to participate in the project, with 97% also choosing to participate in the genetic component—aims to improve understanding of the impact of genes, environments and developmental factors on complex behavioral health outcomes (alcohol use, related substance use and mental health) and to develop tailored prevention and intervention strategies based on the findings.⁴²

Taken together, it seems plausible to assume that student behavioral genetic data will become increasingly appealing for use in elementary and high school settings. First, the rationales for students' genetic testing—specifically, the interests in identifying risks for and taking preventative measure to reduce the prevalence of certain health conditions—may be particularly strong for behavioral genetics. Aside from the impact of behavioral and psychiatric conditions on personal development, studies show that children with such

conditions are more likely to drop out of school,⁴³ to be unemployed as adults,⁴⁴ and to enter the criminal justice system.⁴⁵ There are thus both individual and societal interests in reducing the prevalence of psychiatric conditions among children. Second, emerging studies about gene and environment interactions and epigenetics processes that impact the development of psychiatric disorder (see e.g.,⁴⁶) could inform efforts to tailor personal and professional responses to students' genetic makeup (see further discussion below). As proponents of a genomically informed education system suggest, student behavioral genetic data can promote early identification of children at risk of developing behavioral and psychiatric conditions, advance new preventive educational and developmental tools, and enable more effective individualized pharmacological interventions and provision of tailored services to help such children in school settings.⁴⁷ Indeed, some scholars further emphasize that the notion of a personalized education, which has originated in the context of special education, should be more readily available and universally endorsed in mainstream classrooms to support higher educational attainment for all students.⁴⁸

Finally, the views of relevant stakeholders—researchers, parents, students, and educational staff and professionals—about genomic knowledge, especially behavioral genetics, further demonstrate the likely interest in a genomically sensitive education. A growing body of research aims to shed light on the impact of behavioral genetics and environmental factors on educational achievement,⁴⁹ and to provide recommendations for specific interventions in the classroom (presently primarily) for behavioral phenotypes that are associated with genetic syndromes. For instance, educators are advised to sit side-on rather than face-on when working with children with fragile X syndrome due to heightened anxiety and gaze aversion among such children.⁵⁰ Beyond special education settings, there are calls for genomic-based educational studies that will include multiple family members (beyond twins) to better understand child outcomes that are influenced by family/classroom or family/school interactions.⁵¹

Studies of parents and potential parents indicate high interest in genetic testing of their children for behavioral and psychiatric predispositions, preferably before adolescence,⁵² strong perceptions about the impact of both genetics and the environment on children's behavioral and psychiatric conditions,⁵³ and support for preventative behavioral, environmental and therapeutic interventions on the basis of children's genetic susceptibility for such disorders.⁵⁴ These parental views are particularly important for elementary school children whose parents are entrusted to make medical decisions on their behalf, including undergoing genetic testing. However, they are also relevant for adolescents who are legal minors but who are also increasingly involved, and opinionated about, whether to undergo genetic screening. As the Australian study mentioned above found, not only that parents of high school students indicated that they supported the idea of a school-based screening program for genetic susceptibility testing, but students expressed even more positive views about such screening than their parents, with 35% of students (n=748) further suggesting that they alone should give consent.⁵⁵ Although the Australian studies did not focus on behavioral genetics, their findings are useful in thinking about the role of students and parents as stakeholders in such genomic-based initiatives and the trajectory of using behavioral genetic data in schools.

Relevant studies with educators are few but significant. A 2005 survey of 667 primary school teachers in the UK found that many believe in the influence of both genetics and environmental factors on student behavioral traits.⁵⁶ However, while 57% of teachers believed that behavioral conditions such as hyperactivity are more influenced by environments than genetics, 91% of them believed that genetics accounts for at least half of the influence for psychiatric conditions. Importantly, 82% of teachers responded that knowing that a student had a genetically-influenced learning difficulty will influence their methods of instructing and tracking students, and overall, teachers expressed hope that “future genetically-sensitive research would provide solutions for the field of education” (p. 15), such as early identification of learning-related issues, and facilitation of effective preventative action. Similarly, a 2004 Australian study found that teachers held positive attitude towards genetic susceptibility testing in schools and reported that they would like their students to be offered such testing, the primary reasons being early detection and better management of the condition.⁵⁷ Finally, a study in Denmark that offered high school students ancestral testing through a DTC genetic testing company resulted in over 700 students who were genotyped and to which the researchers had access to their genetic data (the researchers limited the number of participants due to budgetary reasons).⁵⁸ Although this study did not involve medically relevant information or behavioral genetics, its’ importance lies in the response of educators who were the ones to be initially recruited to the study and assigned to introduce it to their schools. As the researchers described, teachers’ response was “overwhelming” and “warm,” with as many as 40 out of 168 high schools in the country expressing interest in joining the project.

Concurrently, efforts are underway to enhance educational psychologists’ embrace of research on the nature and nurture of behavioral traits and involvement in developing a genomically sensitive education system. These includes calls to expand current team-based approaches in education to encompass not only pediatricians, educators, and mental health providers, but also professionals with expertise in behavioral medicine, genetic counseling, and genomics (so-called “educogeneticists”) who will make “informed recommendations to both schools and families,”⁵⁹ and to require that educational psychologists actively consider how to translate genetically sensitive research into educationally relevant goals such as reducing classroom behavioral problems and improving academic performance.⁶⁰ With laws and court cases expecting educators and schools to conduct “full and individual” evaluation for children with behavioral issues before they develop individualized educational plans,⁶¹ it is thus plausible that should behavioral and psychiatric genetic testing achieve sufficiently high positive predictive power—or be perceived by stakeholders as having such power—it could be viewed as a first step in “footing the bill.”

Nonetheless, the calls for a genomically sensitive education system require scrutiny. In particular, the prospect of introducing student behavioral genetic data in schools raises scientific challenges as well as the risk of misuse and misinterpretation of student genetic information.

Is the Science There? Will It Ever Be?

A prime challenge for the trajectory of an educational system that is tailored to students' behavioral genetic makeup is the limitations of the scientific study itself, that is: the difficulty in finding robust and replicable associations between traits and genes.⁶² Although it is well established that common behavioral and psychiatric disorders run in families and that this is largely due to genetic inheritance, the etiology and genetic architecture of such conditions are complex.⁶³ They are highly polygenic, involving multiple genes with each contributing only subtle effect size to the overall risk of developing a disorder. Identifying a gene or even several genes that can be associated with the development of psychiatric conditions is thus unlikely (some rare exceptions of syndromic conditions exist, e.g., 22q11.2 deletion that significantly increases the risk for psychiatric disorders,⁶⁴ including anxiety and attention deficit hyperactivity disorder (ADHD) in children⁶⁵). Furthermore, studies demonstrate that environmental factors such as stress during pre and postnatal neurodevelopmental periods, and, especially, gene-environment interactions, including epigenetic processes, are prominent for increasing the risk of developing psychiatric conditions.⁶⁶ However, because neither the genetic nor environmental causes are linear or additive, it is very difficult to specify which environmental factors, and to what extent each one of them, influence behavioral and psychiatric outcomes.⁶⁷ As a result, current behavioral genomic research is far from fathoming the complexity of human behavioral and psychiatric traits, let alone translating behavioral genomic knowledge into behavioral, environmental, and pharmacological interventions that are tailored to individuals' genetic make up.

Whether this scientific state of affairs will change in the future is unresolved. For some, the prospect is "gloomy"⁶⁸ with doubts about the likelihood of continued behavioral genomic research to result in genomic-based personalized psychiatry as has been envisioned for other realms of medicine.⁶⁹ Others are more optimistic, holding that the tremendous expansion of knowledge base in psychiatric genetics in the past decade and the pace of transformation in knowledge, which is unprecedented in the history of the field, should serve as hindsight for future progress.⁷⁰ Thus, given the promise of genome-wide association studies (GWAS) to identify large numbers of risk loci,⁷¹ and the increased availability of large sample sizes for research—a major challenge for psychiatric genomics—there is hope that ongoing research will lead to more robust findings and tailored drug development.⁷²

Still, however, how such scientific advances, which are geared towards clinical care, will be translated into non-pharmaceutical, classroom interventions to produce improved educational achievement remains unknown. The complexity is further compounded by the phenotypic heterogeneity that exists within groups: educational interventions that are recommended on the basis of behavioral genetic findings at the group/population level may be off target for individual children, even when these children share a genetic syndrome or proclivity with the larger group.⁷³ It is difficult to see how teachers and others in the education system will be able to navigate these issues, especially in poverty stricken neighborhoods where the resources are significantly limited.

While the calls for using behavioral genetics in school are (at least) presently premature, consideration of the ethical, legal, and social issues that would arise from such uses is merited. Indeed, if the science progresses to provide sufficiently powerful findings, or more concerning, regardless of the scientific validity of findings, stakeholders may try to introduce and use student behavioral data in school. In turn, this prospect raises the risk of misuse and misinterpretation of student genetic information, and families, health professionals, educators, and policy makers should consider several issues before such data become available and are routinely incorporated in student education records. These include: when to disclose students' behavioral genetic profile; whose genomic privacy is protected and by whom; and how students' genetic data may affect education-related decisions.

The When Question

Given that the identification of students with behavioral and psychiatric disorders is important for advancing individual's and societal interests, the incorporation of genetic data in student education records—most likely through parents' or health professionals' provision of information—may appear as a straightforward measure to attaining these goals. Moreover, disclosure of a student's behavioral genetic profile may be unavoidable if educators are to implement, and students are to enjoy, the benefits of a genomically informed education system. Indeed, education law and guidelines already permit school officials to access student education records, including health information generated for such records, without parental consent, when certain conditions are met. Importantly, as stipulated in the Family Educational Rights and Privacy Act (FERPA), a Federal law that applies to all public schools and virtually to all private schools as recipients of federal funds, one such condition is that the access to student medical records serves a "legitimate educational interest."⁷⁴

However, questions arise as to which circumstances other than those directly aimed at benefiting a student's educational skills would justify disclosure of his/her behavioral and psychiatric genetic profile. In a recent court case, for example, a teacher disclosed to parents of two children with active cystic fibrosis (CF) that another student named CC was found to be a carrier of genetic markers associated with CF (*Chadam case*, 2014).⁷⁵ The parents subsequently requested, and the school district ultimately accepted, that CC be removed from the school. As explained in the court proceedings, the school's decision was based on the concern that CC may pose a cross-infection risk to two other students with CF. Although the concern in this case was erroneous—only active (not carrier status of) CF possess cross-infection risk—consideration of factors that present a risk to public health are generally regarded as a "legitimate educational interest," and may thus justify the disclosure of student medical information.

Comparable public health considerations may exist for children with genetic proclivities for behavioral and psychiatric disorders. The growing number of diagnoses of children and adolescents with mental health issues has long been seen as an epidemic, and as mentioned earlier, there is an increasing recognition of the personal and societal costs associated with psychiatric disorders. In addition, although the vast majority of persons with psychiatric disorders do not engage in violence against others, studies suggest that small subgroups of

persons with severe mental disorders are at increased risk of violent behavior, especially towards themselves (i.e., suicide).⁷⁶ Efforts to reduce the risk for, and subsequent prevalence of, psychiatric conditions by the utilization of, among other things, student genetic profile, could thus benefit public health interests. Specifically, it could be argued that if it were possible to identify factors that in the presence of certain genetic variants significantly increase or reduce the risk for developing such conditions or the likelihood of presenting antisocial outcomes (e.g., aggression), disclosure of student genetic profiles would be justified.

Support for such an argument can be found in research on genes-environment interaction. Since Caspi et al.'s seminal findings in 2002 about the interaction between child maltreatment, antisocial behavior, and the presence of an allele associated with reduced activity of the MAOA gene,⁷⁷ other researchers have found an impact of early childhood environmental stressors (e.g., abuse, maternal insensitivity, parenting style) on genetic vulnerability to psychiatric disorders, including depression,⁷⁸ and other children's externalizing behavior such as ADHD, impulsivity, and sensation seeking.⁷⁹ Emerging findings further indicate that broader societal settings, such as poor conditions in schools and neighborhoods, may also constitute adverse childhood environments and interact with individual's genetic sensitivity to affect the risk of psychopathological outcomes.⁸⁰ Furthermore, as a growing number of studies have illustrated, such gene-environment interactions are not unidirectional. That is, individuals with genetic sensitivity to the environment are as likely to benefit disproportionately from supportive environments as to be disadvantaged by adverse ones.⁸¹

Naturally, not all studies have supported these findings (see, e.g.,⁸²), and as discussed earlier, there is still much to be learned about the interplay between genes, environments and psychiatric disorders (e.g., which genes are relevant, what role epigenetic play, and what is the exact nature of gene-environments interaction). However, Caspi et al.'s findings have inspired ongoing research on these questions, and there is hope that such research will lead to even more conclusive findings (whether or not it is the MAOA variant or other gene candidates). Drawing on the essence of these studies to the education context, these findings suggest that disclosure of students behavioral and psychiatric genetic profiles could be justified in 3 circumstances: 1) if evidence exists about a student experiencing environmental stressors that amount to childhood adversity, a positive result of behavioral and psychiatric genetic sensitivity would allow for tailored interventions that reduce, and even reverse, the risk for developing a psychiatric condition; 2) if evidence exists about a student experiencing supportive environments, a positive result of behavioral and psychiatric genetic sensitivity would provide assurance that the interests of the individual and society in promoting mental health are properly addressed; and 3) if evidence exists about a student experiencing *either* environmental stressors or supportive environments, a negative result of behavioral and psychiatric genetic sensitivity would suggest that this student is not at an increased risk or is at the same risk as the general population for developing psychiatric conditions.

In practice, the circumstances that raise most urgency for reducing the prevalence and impact of psychiatric conditions, and which are thus most likely to be viewed as justifying disclosure of students behavioral and genetic profiles are those stipulated in (1), that is: the

presence of environmental stressor and positive results of behavioral and psychiatric genetic sensitivity. As some proponents of a genomically sensitive education system postulate, even if teachers' knowledge of students' behavioral genetic profile will not have much direct impact in the classroom, it will have significant implications in terms of early diagnosis and preventative interventions that impact students' behavioral issues.⁸³ Although the goal of prevention is clearly important, this prospect raises several sociocultural difficulties that should be considered.

Specifically, a major concern in the disclosure of student behavioral and genetic profiles is the risk of biases in determining childhood adversity and in addressing students' needs. As suggested, the most plausible circumstances to trigger the disclosure of student genetic profiles would require a determination of childhood adversity. However, distinguishing between adverse and advantageous childhood environments is not always easy. Although extreme parental behaviors such as sexual abuse or harsh physical punishment would qualify as child abuse or maltreatment, it is also the case that a universally accepted definition of child abuse and neglect does not exist,⁸⁴ and that racial and ethnic groups and communities differ in their childrearing practices and in their limits of acceptable behavior.⁸⁵ This may be critical in a genomically informed education system as teachers—who are overwhelmingly white—may misunderstand behaviors of non-Caucasian families⁸⁶ and disproportionality make determinations of childhood adversity with regard to students of diverse cultural backgrounds.

Concurrently, distinguishing among students on the basis of their genetic makeup when adverse environments are present may come at a high cost for students who experience childhood stressors but do not have high-risk genetic variance (e.g., students with alleles associated with increased activity of the MAOA gene (scenario 3 above)), and those who attend disadvantaged school environments—overwhelmingly racial and ethnic minorities⁸⁷—and have high-risk genetic variance (scenario 1 above). Whereas the former may be (erroneously) presumed to have less need for support⁸⁸ and less likely to pose burden on society, the latter would likely be missed, given the challenges involved in monitoring and improving poor educational settings.

This discussion highlights the caution required in calls to utilize student behavioral and psychiatric genetic make up as preventative measures in schools, and ties to a broader issue regarding the usefulness of genomic data in transforming social goals—such as educational attainment—at a population level. As has been discussed in the context of genomics and public health, socio-economic, structural and environmental factors rather than biological ones are the primary reason for health differences between and within groups, and the shift to a molecular-based medicine does not remedy these issues.⁸⁹ The calls for a genomically informed education system raise similar concerns. That is: children's predispositions to behavioral and psychiatric conditions, as are their educational outcomes, are largely impacted by structural and environmental impediments such as familial and neighborhood poverty, high stress, and poor nutrition.⁹⁰ And while perceptions of behavioral genomic data as “hard science” may contribute to their appeal as relevant information,⁹¹ a focus on such data may obscure the urgent need to address the underlying structural and environmental factors that increase the risk for behavioral and psychiatric conditions among all children

and that negatively impact students' achievements. Thus, before behavioral and psychiatric genetic data are incorporated in student education records and disclosed to promote educational and public health interests, measures are needed to ensure that a genomically informed education system is applied with cultural sensitivity and, importantly, that it offers the necessary supports to all students—regardless of their genes-environment interaction profiles.

The Who Question

A second issue to consider is whose genomic privacy is protected, and by whom, within the educational system—a question that taps into the broader discussion about whether or not there is a need for heightened privacy protection of genetic data. In clinical settings, the debate has centered on the need for balancing between the possible misuse of genetic data and the concern that “genetic exceptionalism” (e.g., not incorporating genetic data in patients' e-medical records) would compromise patients' care. The presumed lack of relevance of genomic data in non-clinical settings, in contrast, has given more weight to concerns of genetic-based discrimination and to greater support for increased privacy protections. The Genetic Information Non-discrimination Act of 2008 (GINA) was indeed adopted for this reason, prohibiting employers and health insurers from using genetic data in their respective decisions.

The education context, however, presents a unique challenge. Although a genomically informed education system is intuitively aimed to provide some form of medically-based interventions, schools are not considered to be entities that provide clinical services. And unlike medical records that are subjected to the privacy rule under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), student education records, including medical information that is incorporated in them, are regulated under the FERPA, which, as discussed above, allows for disclosure when a legitimate educational goal exists. The scope and limits of student genomic privacy are thus not as clearly delineated as they are for clinical settings.

A further complicating factor is that it is unclear whether the general legislative framework for protecting genomic privacy applies to student educational records. GINA is limited to employment and health insurance settings and it does not provide protection in other contexts, such as education, in which genetic data may be used or misused. The protection of students' genomic privacy under relevant disability laws is equally limited. The Americans with Disabilities Act, which aims to protect symptomatic individuals and those who are perceived as having a physical or mental impairment from discrimination, does not include a provision on genetic data or protection for asymptomatic individuals with genetic conditions.⁹² Although federal authorities have interpreted this Act to encompass employers' discrimination of employees on the basis of genetic test results, this interpretation is not legally binding.⁹³ It is also unclear whether this interpretation would—or should—apply to educational settings. After all, disability laws (including the Americans with Disabilities Act, the Rehabilitation Act and the Individuals with Disabilities Education Act) are designed to provide individually *tailored* educational services for children with disabilities. Insofar as students' behavioral and psychiatric genetic data could inform the

provision of such tailored services and interventions, they could be viewed as fulfilling the goals of disability laws. Indeed, some scholars have even argued that a genomically informed education system may promote an up-to-date concept of equality, by tailoring interventions to individual genetic differences.⁹⁴

Nonetheless, there are two reasons why consideration of students' genomic privacy is needed. First, the nature of genetic data as heritable conditions that are passed from parents to their offspring necessarily raises the risk that a student's genetic profile may reveal sensitive information not only about the child, but also about relatives, such as siblings and parents.⁹⁵ The potential loss of genetic privacy may thus extend beyond the student to other relatives, regardless of whether a "legitimate educational interest" exists. Second, and related, is that the absence of clear guidelines for disclosure of student genetic profiles raises the risk that families of students from poor neighborhoods or low socio-economic strata will be more excessively surveilled for their genomic makeup. Although such heightened surveillance may be based on the presumption that poorer families experience higher rates of environmental stressors (and are thus at higher risk for developing psychiatric conditions), it may also reinforce the marginalization of those who are already disenfranchised.

Consider, e.g., Caspi et al.'s findings of an interaction between stressful life events and the short allele of the serotonin transporter gene (5-HTT), to produce increased rates of depression.⁹⁶ (Note: it is not the specific presence of the 5-HTT gene that is of critical importance for this discussion, but the notion that there are genes, some of which are currently being investigated,⁹⁷ that interact with childhood adversity or "stressful life events" to produce depression.) Specifically, given that "stressful life events" could encompass a broad list of items, including employment, financial, housing, health, poor schooling, and relationship stressors (e.g., parents' divorce), a highly intrusive system for continuous reporting of such experiences to school officials will be necessary for implementing genomically informed interventions. Furthermore, almost any student—who may exhibit one of numerous possible combinations of stressors—could be viewed as being "at risk." Disclosure of students' genetic data on this basis would thus be too excessive, and, in practice, eschew notions of student (and families') genomic privacy.

Conversely, a high threshold for "stressful life events" would likely result in the singling out of students from poor neighborhoods and families where such stresses are prevalent.⁹⁸ Worse, the intergenerational transmission of poverty, and, as emerging studies in epigenetics suggest, of parental imprinted genes—i.e., the effects of environmental exposures such as poor diet, anxiety, and stress on gene expression, including increased risk of behavioral and psychiatric disorders⁹⁹—may call for increased surveillance of not only currently poor students but also of those with a family history of poverty. Genomic data of (current and past) socio-economically deprived students, who are predominantly from racial and ethnic minorities, will thus be more easily disclosed than those of wealthy and Caucasian students, and reinforce a wrong perception of low socio-economic and racial/ethnic minority groups as genetically inferior populations. Moreover, as the US culture is highly individualistic, it would likely also result in increased perceptions of poor parents as responsible for their children's experience of such stressors and, thus, poor behavioral outcomes, while, once again, structural impediments are ignored.¹⁰⁰

This concern is further exacerbated because it is unclear who within the educational system is, or should be, entrusted with student genetic data.¹⁰¹ Although existing education law and regulations permit school officials to access student education records, the term “school officials” is undefined. It may thus potentially encompass a significantly large number of people—from teachers to school administrators to other parties (as occurred in the *Chadam case*)—who normally wouldn’t have access to such data. Thus, even if a legitimate educational goal exists and can justify access to a student’s genetic profile, despite the loss of privacy, it is troubling that the scope, meaning, and implementation of such decisions may be left in the hands of individual teachers.

The How Question

The previous questions—when to disclose a student’s genetic profile, whose genomic privacy is protected, and by whom—have largely focused on the challenges arising from the lack of clear boundaries for the implementation of a genomically informed education system. The question of *how* would student genomic data affect related education decisions calls for consideration of broader issues surrounding behavioral and psychiatric genetics, specifically: the persistent association between psychiatric disorders and stigma, perception of dangerousness, and desire for social distancing, which is likely to be interwoven into education-related decisions.

Although these have been extensively discussed with regard to psychiatric disorders in general, and when the disorder is attributed to genetic causes, in particular,¹⁰² the education context is especially worrisome. Studies indicate that educators tend to endorse the promises of science and are eager to incorporate them into the classroom.¹⁰³ As the 2005 UK study of primary school teachers found, teachers expressed interest in adjusting their instructing and tracking methods to students’ behavioral genetic makeup and hope for genetically-sensitive solutions for the field of education.¹⁰⁴ However, studies also show that educators’ training in genetics and genomics is limited¹⁰⁵—interestingly, also when they are explicitly informed about neuropsychiatric genetic syndromes of their students¹⁰⁶; that school curriculums about gene-environment interactions for K-12 science education are particularly poor¹⁰⁷; and that genetic determinism with regard to health status is prevalent in the general public, which presumably includes educators.¹⁰⁸ Indeed, although many primary school teachers in the 2005 UK study believed that environmental factors had influence on children’s psychiatric conditions, it is of note that over 60% of respondents believed that such conditions are mostly caused by genes, and ~9% of respondents believed that such conditions are “all genes”.¹⁰⁹ Educators and administrators who become aware of a child’s genetic proclivity for a psychiatric disorder may thus assume that the child will necessarily develop the condition, irrespective of the presence of symptoms. In turn, this may lead to erroneous labeling of the child as “mentally disabled,” to lower educational expectations from the child,¹¹⁰ and to misguided educational placement decisions. In the context of behavioral and psychiatric genetics, such placement decisions may have long-term implications. They may result in a student being transferred to special education settings—a resolution that is difficult to reverse¹¹¹ and which often provide inferior curriculum and social opportunities compared to those in mainstream classrooms.

In theory, such consequences could be substantially mitigated were teachers' psychiatric classification of students and subsequent educational placement decisions required the confirmation of a physician. However, pediatricians and other healthcare providers may not be able to provide such assistance. Studies found that although primary care providers believe that they have a role in the diagnosis, treatment and management of psychiatric conditions in children, they often lack confidence in making a diagnosis and treatment decisions (also for some of the most prevalent conditions diagnosed such as ADHD) and have difficulty allocating the time necessary for in-depth evaluation of a child.¹¹² In addition, studies consistently show that many clinicians, including pediatricians and psychiatrists, lack requisite knowledge of genetics, especially psychiatric genetics,¹¹³ and, moreover, that they tend to demonstrate less empathy for potential patients whose psychiatric conditions are attributed to genetics (compared with patients for whom they have psychosocial information).¹¹⁴ Thus, notwithstanding the potential educational benefit of a genomically informed education system, caution is needed before behavioral genetic data are incorporated in student education records.

Conclusions

Although the rise of genomic data and knowledge may offer important benefits for adult and pediatric patients with behavioral and psychiatric conditions, their unregulated use in non-clinical settings—at present time and also in the future, as such data continues to emerge—may lead to unintended consequences that are detrimental for individuals, families and communities. A genomically informed education system is one such glaring example. As scholars and researchers call for increased “geneticization” of children’s behaviors in educational settings, there is an urgent need for inquiring how such initiatives are balanced against the necessity of investing in structural and environmental factors that increase the risk of all children for developing behavioral and psychiatric conditions and that negatively impact their educational outcomes. There is a further need for considering how such initiatives will impact those who are most marginalized, developing up-to-date programs to increase genomic literacy among educational stakeholders, including pediatricians and child psychiatrists, and drafting clear national regulations of when and how access to and use of student behavioral genetic profiles are permitted, as well as who is entrusted with this genomic responsibility. Without such initial steps, the risks for students (and families) with a genetic predisposition to behavioral and psychiatric conditions will outweigh the benefits.

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