Social Science & Medicine 278 (2021) 113924

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: http://www.elsevier.com/locate/socscimed

The double helix at school: Behavioral genetics, disability, and precision education

Maya Sabatello [a,b,*], Beverly J. Insel [c], Thomas Corbeil [d], Bruce G. Link [e], Paul S. Appelbaum [f]

[a] Center for Precision Medicine & Genomics, Department of Medicine, Columbia University, New York, USA
[b] Division of Ethics, Department of Medical Humanities and Ethics, Columbia University, New York, USA
[c] Research Foundation for Mental Hygiene (RFMH), New York, USA
[d] Division of Mental Health Data Science, New York State Psychiatric Institute, New York, USA
[e] School of Public Policy, University of California, Riverside, CA, USA
[f] Center for Research on Ethical, Legal & Social Implications of Psychiatric, Neurologic & Behavioral Genetics, Department of Psychiatry, Columbia University, New York, USA

ARTICLE INFO

Keywords:
Behavioral genetics
Precision education
ADHD
Genetic testing
Special education services

ABSTRACT

The prospect of using behavioral genetic data in schools is gaining momentum in the U.S., with some scholars advocating for the tailoring of educational interventions to students' genetic makeup ("precision education"). Public perspectives on testing for and using behavioral genetic data in schools can affect policies but are unknown. We explored public views in the U.S. (n = 419) on key issues in precision education. The introduction of a child's behavioral genetic information regarding Attention-Deficit/Hyperactivity-Disorder was associated with beliefs that such data should be considered in educational planning for the child and increased medicalization, but also a belief in treatment efficacy. Most participants expressed interest in learning about children's behavioral genetic predispositions but would disapprove of testing without parental consent. Differences by participants' race, ethnicity and educational attainment were observed. Our findings indicate the public's complex understanding of genetic information and the challenges for wide implementation of precision education in the U.S.

1. Introduction

The prospect of using behavioral genetic data in school settings is gaining momentum in the U.S. and elsewhere. Despite a troubled history of misuse of genetic information to justify racial, social and socioeconomic inequality (Nelkin and Tancredi 1991), studies are ongoing to identify genes that impact learning abilities and educational attainment and to generate polygenic risk scores (PRS) that could predict those outcomes (Belsky et al., 2016). Beyond molecular analysis, researchers increasingly call for a "personalized" or "precision education" model that would tailor educational interventions to children's behavioral and psychiatric genetic makeup (Grigorenko 2007; Reilly et al., 2015; Plomin et al., 2007; Haworth and Plomin 2012). To date, most of these efforts have focused on children with conditions that have a known genetic etiology (e.g., Down Syndrome, Fragile X syndrome, learning disabilities (Hart 2016; Erbeli, 2019)), though proponents of precision education suggest this approach could be used more broadly (Rothstein 2007). Studies have found that teachers and educational staff express interest in tailoring education to a child's behavioral genetic makeup (Walker and Plomin 2005; Martschenko 2019). Some proponents of precision education are promoting the involvement of educational psychologists in these discussions and seeking to incorporate genomic expertise in school-related decisions by including genetic experts in education committees that determine eligibility for special education services (Grigorenko 2007; Haworth and Plomin 2012). Despite the importance of public views regarding appropriate policies and practices for the use of genetic information in non-clinical settings, there is little research on public perspectives on testing for and using behavioral genetic data in schools.

In some ways, precision education may seem to be a natural

* Corresponding author. Center for Precision Medicine and Genomics, Columbia University Irving Medical Center , 1150 St. Nicholas Avenue, Rm 413, New York, NY, 10032, USA.
E-mail addresses: ms4075@cumc.columbia.edu (M. Sabatello), bji1@caa.columbia.edu (B.J. Insel), Thomas.Corbeil@nyspi.columbia.edu (T. Corbeil), brucel@ucr.edu (B.G. Link), psa21@cumc.columbia.edu (P.S. Appelbaum).

https://doi.org/10.1016/j.socscimed.2021.113924
Received in revised form 17 March 2021; Accepted 8 April 2021
Available online 20 April 2021

continuation of the increased geneticization of pediatric care. Over the past 2 decades, the use of genetic testing to identify the causes of syndromal behavioral and cognitive disabilities in children has become an integral part of clinical practice, and children showing developmental delays routinely undergo genetic testing for neuropsychiatric syndromes (Moeschler 2008). Parents express strong interest in genetic testing of their children for a variety of behavioral and psychiatric conditions, including predisposition for autism (Narcisa et al., 2013), mood disorders (Lawrence and Appelbaum 2011; Erickson et al., 2014), and Attention-Deficit/Hyperactivity Disorder (ADHD)(Borgelt et al., 2014); the primary justifications are parental desires to gain better insight into a child's behaviors and improve care, or to allow prevention and early intervention among asymptomatic children.

Public receptivity to the introduction of behavioral genetic information in schools may similarly be grounded in "clinical" rationales of prevention and treatment to achieve better mental health and educational outcomes. Proponents of precision education contend that ignoring genetics in education is unjustifiable at a time when genetics occupies an increasing role in research and clinical treatment, including its patient-centered approach (Asbury et al., 2017; Little et al., 2017). These justifications may find further support in the increasingly common perception of genomic data as information that individuals, including parents, have a responsibility to learn and act on (Leefmann et al., 2017). Studies show that children with behavioral and emotional problems are often not provided with necessary educational supports in mainstream classrooms, and that they are underserved in school settings when compared to children from other disability groups (Buchanan et al., 2016). This may be particularly pivotal for racial and ethnic minority children. Studies show that due to clinicians' and educators' biases, such children (especially African Americans) are less likely than non-Hispanic white children to be diagnosed with disruptive behavior disorder rather than ADHD and therefore to be deprived of supports such as access to medication, behavioral interventions and educational accommodation (Fadus et al., 2020). Insofar as behavioral genetic data can confirm a child's diagnosis and faciliate the determination of eligiblity for special education services (Borgelt et al., 2014), testing of children may be viewed as useful for promoting a child's interests and academic achievement.

However, there are differences between clinical and educational settings that may impact public views on behavioral genetic testing of children and use of these data in education. Although teachers are often the first to observe and suggest a diagnosis for a child's behaviors (Sax and Kautz 2003), they are non-medical experts, whose knowledge of the genetic basis or heritability and treatment of childhood behavioral conditions, including more prevalent ones such as ADHD, is limited (Mohr-Jensen et al., 2019). Schools are also not entities designed to provide clinical services and their privacy regulations are not as comprehensive as those in clinical settings (Sabatello 2018). Opponents of genetic testing in schools also reiterate the contentious history of misuse of behavioral genetics to devalue and segregate individuals from society (Nelkin and Tancredi 1991; Stein 2010; Callier 2012; Hodapp and Fidler 1999) and highlight the potentially coercive nature of genetic testing in schools, where students may constitute a "captive audience" (Rothstein 1997). These concerns may be further augmented by the stigma associated with child mental health conditions such as ADHD (Kellison et al., 2010). Testing children following a teacher's recommendation (rather than a pediatrician's) or allowing for children's behavioral genetic data to be used in educational settings may thus raise legitimate concerns.

The question of children's testing for behavioral conditions is further complicated. Even if we accept that a genomically informed education systen could be useful, there is need to consider who should be entrusted with the decision about testing children for behavioral traits in school settings. A libertarian view holds that genetic testing should be a matter of individual choice, and that, as in any other child-related decision, parents have the prerogative to make genomic decisions on behalf of their child (Wilfond and Ross 2009). However, it is also well-established that parental decision-making is not absolute, and it can be rejected if it contravenes the child's best interests. The 2004 Individuals with Disabilities Education Act (IDEA), for example, establishes "child-find" mandates that require states actively to seek out and find all children eligible for special education services (National Dissemination Center for Children with Disabilities 2004). Although parents' consent for their child's medical evaluation is needed, if they refuse such evaluation, the school may pursue its mandate with appropriate due process protections (e.g., due process hearing or use of mediation as stipulated in state law) (Weber 2008).

The conceptualization of precision education as a matter of significant public interest may further call for a utilitarian approach to testing in schools, allowing the state to act under the doctrine of *parens patriae* to protect children against future harm (Fulda and Lykens 2006). Studies show that children with behavioral problems have lower graduation rates, and later experience higher unemployment rates and more encounters with the criminal justice system (Wagner 1995; Snyder and Dillow 2013; Burrell and Warboys 2000). Insofar as precision education is viewed increasingly as consonant with both children's and broader societal interests, compulsory testing of children may become integral to schools' responsibilities to identify children at risk and to work towards improving the students' educational trajectories (Sabatello 2018).

Whether genetic knowledge will ever be ready for implementation through precision education has been contested. Notwithstanding some hype around efforts to generate and validate PRS that are associated with educational attainment (Belsky et al., 2016; Plomin and von Stumm 2018) and even calls to establish schools as sites for collaborative efforts among educators, clinicians, and researchers (Fisher 2009), the feasibility of this scientific endeavor is raising significant concerns (Sabatello, 2018). One issue relates to PRS transferability: existing datasets comprise mostly European-ancestry participants, making PRS biased and less accurate for other populations (Martin et al., 2017; Torkamani et al. 2018). Others highlight that the predictive accuracy of PRS depends not only on ancestry group, but also on the algorithm used and factors within ancestry groups, such as socioeconomic status, age, sex, and cultural variables (Mostafavi et al., 2020). Nonetheless, some scholars believe that these issues can be remedied through increased cohort diversity and analytic techniques that address the transferability challenge (Cavazos and Witte, 2020; Kullo and Dikilitas, 2020;), and proponents of precision education insist that such research is both important and unavoidable in the effort to improve societal outcomes (Plomin and von Stumm 2018; Torkamani et al. 2018). Better understanding of public views on precision education may indicate the extent of support for this scientific endeavor and help shape policies and allocation decisions related to students' educational success.

This paper reports findings from a large national survey of adults from the general public exploring the prospects and pitfalls of precision education. Our study focused on (hypothetical) genetic testing for a child who may have ADHD and assessed the impact of a child's behavioral genetic predispositions on education and other related decisions. It is part of a larger study that explored the impact of psychiatric genetic data on nonclinical settings. ADHD was selected because it is a behavioral condition highly associated with academic outcomes (Ronald et al. 2021). ADHD is also the most common psychiatric diagnosis among children aged 2–17 years (estimated at 9.4%) (Perou et al., 2013; CDC 2020), and it is included within the scope of the IDEA.

2. Materials and methods

2.1. Participants and procedures

We conducted an anonymous, 20-min online survey of adults from the general public (≥18 years old; n = 419) to explore interest in genetic testing and views about how behavioral genetic information should impact education-related decisions. Participants were identified and

recruited by YouGov, a research company that operates an Internet-based panel drawn from the general public. YouGov constructed a sample that was representative of the adult US population (based on variables of gender, age, race/ethnicity, education and geographical region), adjusted to oversample Blacks/African Americans (AA) (30%) to increase the power to detect differences between White and Black/AA racial groups. These racial groups were selected because of a high prevalence of ADHD diagnoses among White and Black/AA, non-Hispanic children (Perou et al., 2013; CDC 2020) and as Black/AA children 6–21 years old are twice as likely as White children to be served in special education programs (Moeschler 2008; National Center for Education Statistics 2012; Aud and Fox 2010). YouGov collected other demographic data (e.g., gender, income, education), administered the online survey, and offered participants "Polling Points" redeemable for small gifts (equivalent of $1) for their participation. Participants' demographic characteristics are in Table 1. The New York State Psychiatric Institute IRB approved the study.

2.2. Survey instrument

The survey comprised 2 vignettes, one of which is reported here. The experimental design was a 2 (family history: present; absent) x 2 (genetic test results: positive; negative) x 2 (child race: AA; White) x 2 (evaluator of child behavior: pediatrician; teacher) fully crossed, between-participants factorial design. Participants read a vignette about parents who registered their five-year-old son (described as either White or AA) for a public-school kindergarten, and were required, as part of the admission process, to submit information about the child's development and involvement in pre-K class activities. The child's initial evaluation, randomly assigned to be provided by either a pediatrician or a teacher, stated that he was "very active, has difficulty concentrating or sitting still, and has a hard time getting along with his peers." The child's parents were offered the possibility of testing the child for a gene that increases the risk of developing ADHD and were told that "early identification and intervention can significantly improve symptoms of inattention, hyperactivity and impulsivity and reduce a child's behavioral problems".

The different types of genetic evidence (family history, genetic test results) were introduced sequentially. Specifically, participants were randomly assigned to be told that the father was previously diagnosed with ADHD ("family history") or not told anything about the presence of familial ADHD. They were then asked whether as the child's parent, they would consent to have him tested for a gene that was causally related to the disorder, and whether, in the absence of parental consent, the school should require that the child be tested. Participants were subsequently told that the parents agreed to testing and were randomly assigned to receive information that the child had tested positive or negative for the "ADHD gene." The framing of "a gene for" aimed to provide participants with the necessary information in a simplified manner (a common characteristic, and limitation, of vignettes) and in language familiar to the general public. Although ADHD is a genetically complex condition and PRS may be a more valid means of assessing genetic risk than "a gene for," introducing new terminology into a survey for the general public might have diverted attention from the study's focus on genetics and biased the results. Moreover, there was no a priori reason to suspect that participants' responses to "a gene for" would be different than for a PRS score.

Randomization of participants to receive the different types of genetic evidence resulted in 4 categories of genetic evidence for analysis: 1) only family history; 2) only positive genetic test; 3) both family history and positive genetic test; and 4) no family history and negative genetic test ("none" or "neither")(see Fig. 1). Participants were then asked to rate their agreement with a series of statements that addressed issues relating to: 1) the use of genetic data in the child's education plan ("The school should consider this genetic result in developing an educational plan for [the child]"); 2) possible medical and other (imposed) interventions ("The child should go to one or more of the following options: 1) pediatrician, 2) psychiatrist and 3) other mental health professional for help"; "The school should require [the child] to receive interventions designed to improve behavior control and concentration"; "The school should require [the child's] parents to attend sessions to learn how to help [the child] with his behavior"; "[The child] should be given medications to reduce symptoms of ADHD"; and 3) likely treatment efficacy ("[The child's] situation will improve with the help of mental health professionals"; "[The child's] behaviors will improve with medication"). The wording of the various versions of the vignette was as similar as possible. We hypothesized that the introduction of positive genetic evidence (i.e., each of categories 1–3 above, with ascending impact) would be positively associated with interest in the data being used in educational plans and with endorsement of a need for treatment, including imposed interventions. Based on studies on adults' views on psychiatric genetics (Phelan et al., 2006), we also predicted that genetic evidence would be negatively associated with belief in treatment efficacy.

The survey, including the draft vignette, was reviewed by 3 educators and an expert in special education to ensure the portrayals were realistic. The final instrument was modified to address comments from these reviewers.

Table 1
Demographic characteristics[a] (n = 419).

Demographic Variables	n	%	Weighted %[d]
Age			
18–29 years	77	18.4%	20.8%
30–59 years	191	45.6%	41.4%
60 or older	151	36.0%	37.7%
Mean age = 48.6 years (SD = 17.5)			
Gender[a]			
Female	226	53.9%	51.0%
Male	193	46.1%	49.0%
Race[a]			
Black/African American	160	38.2%	14.3%
White	225	53.7%	74.7%
Asian	8	1.9%	3.3%
American Indian/Alaska Native	7	1.7%	2.3%
Native Hawaiian/Other Pacific Islander	2	0.5%	0.6%
Missing	17	4.1%	4.9%
Ethnicity/Hispanic[a]			
Hispanic	44	10.5%	14.7%
Non-Hispanic	375	89.5%	85.3%
Education Level[a]			
High School or less	161	38.4%	38.8%
Some-2years College	144	34.4%	32.1%
4 year of College/Postgraduate	114	27.2%	29.1%
Household Income			
Less than $20,000	83	19.8%	17.1%
$20,000 - $49,999	119	28.4%	32.1%
$50,000 - $99,999	113	27.0%	25.2%
$100,000 or more	56	13.4%	14.4%
Prefer not to say	48	11.5%	11.2%
State of Residence			
Northeast	70	16.7%	17.1%
Midwest	79	18.9%	32.1%
South	96	22.9%	25.2%
West	174	41.5%	14.4%
Marital Status			
Widowed/Divorced/Separated	88	21.0%	19.6%
Never Married	156	37.2%	32.1%
Married[b]	175	41.8%	48.2%
Parental Status[c]			
Yes	82	19.6%	17.4%
No	241	57.5%	61%
Missing	96	22.9%	21.6%

[a] Included in the logistic regression analysis.
[b] Includes Domestic/civil partnership.
[c] Parental status was defined as having a child under 21 years old, the age cut off for special education services.
[d] Weighted Percentage obtained from proc surveyfreq

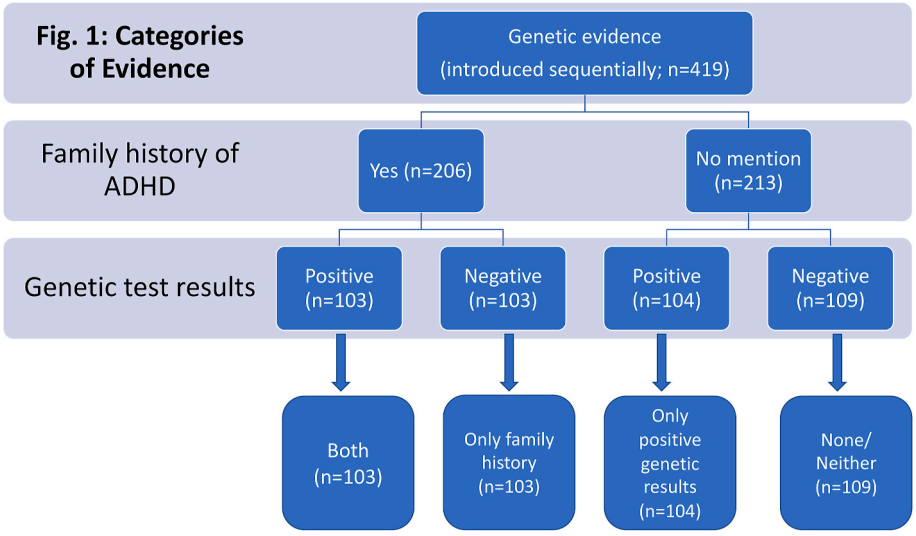

Fig. 1. Categories of evidence.

2.3. Analysis

Our power analysis was based on the primary predictor (psychiatric genetic data) and the primary outcome of interest (binary responses regarding education decisions). In the absence of prior research on this issue and data about likely effect sizes, we aimed to detect a difference of at least 0.18–0.2 in the proportions between the two closest groups under the assumption that the overall prevalence of predictors ranges from 0.3 to 0.7. This required n = 351 participants to have more than 80% power at 5% significance. Our final sample of 419 is thus sufficiently powered for this analysis. Using a nationally representative sample with the original sampling scheme of 351 would have yielded only 47 Black/AAs, allowing us to detect greater than 0.23 proportion difference between Black/AAs and White participants with 80% power at 5% significance. Our oversampling of Black/AAs to 160 participants allowed us to detect a smaller effect size of 0.15 proportion differences between two races.

Response options were measured using a 4-point Likert scale and collapsed into dichotomous categories (disagree/strongly disagree vs. agree/strongly agree). Multivariable logistic regression was conducted to examine the impact of genetic evidence (family history, positive genetic test, both, none) on the dependent variables. Variables in the model included the vignette child's race (AA/White), evaluator of the child's behavior (pediatrician/teacher), and participants' sociodemographic characteristics, i.e., race, ethnicity, gender and education (Table 1). The decision of which covariates to include in the final analysis was made by including all common covariates in the regression analysis (gender, race, ethnicity, education level, household income, marital and parental status) and retaining only those that showed a pattern of statistical significance. Household income, e.g., was significant in some models but only for those who "preferred not to say" their income, which precluded a substantive analysis. The race variable was collapsed (White, Black/AA, other racial minorities and missing); the education variable was dichotomized (≤high school and ≥some college).

Data were weighted to account for oversampling of Black/AAs. Analyses were performed using the SURVEY procedures in SAS 9.4 to incorporate these weights and appropriately construct standard errors around measures of association. Variables with p-values <0.05 were considered significant predictors. Analyses of evaluator and child's race found no effect on the variables considered here (Table 2), and they are not discussed further in this article.

3. Results

3.1. Genetic testing

Most participants stated they would have tested the child (82.2%) but only a minority (26.4%) agreed that the school should require the child's testing in the absence of parental consent. Family history did not impact either of these responses (respectively, p = 0.21; p = 0.70) (Table 2).

3.2. Educational plan

Most participants agreed that the genetic test results should be considered in developing an educational plan for the child (76.6%). Those provided with positive genetic test results alone (86.1%; OR = 3.42, CI: 1.25, 9.36, p = 0.02) or combined with family history (84.8%; OR = 3.09, CI: 1.14, 8.36, p = 0.03) were significantly more likely to concur with this statement compared to those who received neither. Family history alone was not associated with participants' responses (p = 0.73; Table 2).

3.3. Interventions

Most participants agreed that the child should go to a pediatrician (71.3%) and other therapist or counselor (75%) for help but only 45.3% endorsed the option of a psychiatrist. Those who received both family history and positive genetic test results (OR = 2.62, CI: 1.09, 6.26, p = 0.03) were more likely than those who received neither to agree about the child's need to see a pediatrician. Family history (OR = 2.93, CI: 1.37, 6.26, p = 0.01), positive genetic test (OR = 3.49, CI: 1.45, 8.42, p = 0.01), and both family history and positive genetic test (OR = 2.43, CI: 1.10, 5.37, p = 0.03) were all positively associated with selection of a psychiatrist.

A small majority of participants agreed that the school should require the child to receive interventions to improve behavior control and concentration (57.8%) and require the parents to attend training sessions (58%), but only a minority believed that the child should receive medication (37.2%). Neither type of genetic evidence (i.e., family history, positive genetic test, both) was associated with views on these items (all p ≥ 0.11; Table 2).

Table 2
Impact of genetic evidence, evaluator, and child race on genetic testing, educational and other interventions and treatment efficacy.

Dependent Variable (%)[a]	OR	95% CI[b]	P value
Consent to have child's gene tested (82.2%)			
Family history: Family history (no evidence, ref)	1.56	(0.78, 3.13)	0.21
Evaluator: Pediatrician (Teacher, ref)	1.68	(0.84, 3.39)	0.14
Case race: African American (White, ref)	0.74	(0.37, 1.49)	0.41
School should require genetic testing (26.4%)			
Family history: Family history (no evidence, ref)	0.87	(0.43, 1.77)	0.70
Evaluator: Pediatrician (Teacher, ref)	0.83	(0.41, 1.70)	0.61
Case race: African American (White, ref)	1.53	(0.74, 3.15)	0.25
School should consider genetic result in education plan (76.6%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.16	(0.49, 2.75)	0.73
Positive genetic test results (only)	3.42	(1.25, 9.36)	0.02
Both family history & positive genetic test results	3.09	(1.14, 8.36)	0.03
Evaluator: Pediatrician (Teacher, ref)	0.81	(0.39, 1.65)	0.55
Case race: African American (White, ref)	0.75	(0.38, 1.48)	0.40
School should require interventions to improve behavior (57.8%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.94	(0.86, 4.36)	0.11
Positive genetic test results (only)	1.35	(0.59, 3.11)	0.48
Both family history & positive genetic test results	1.11	(0.49,2.54)	0.80
Evaluator: Pediatrician (Teacher, ref)	0.92	(0.51, 1.66)	0.79
Case race: African American (White, ref)	0.99	(0.55, 1.78)	0.96
Child should go to pediatrician for help (71.3%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.22	(0.53, 2.78)	0.64
Positive genetic test results (only)	2.22	(0.92, 5.34)	0.07
Both family history & positive genetic test results	2.62	(1.09, 6.26)	0.03
Evaluator: Pediatrician (Teacher, ref)	1.61	(0.85, 3.02)	0.14
Case race: African American (White, ref)	0.89	(0.48, 1.67)	0.72
Child should go to psychiatrist for help (45.3%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	2.93	(1.37, 6.26)	0.01
Positive genetic test results (only)	3.49	(1.45, 8.42)	0.01
Both family history & positive genetic test results	2.43	(1.10, 5.37)	0.03
Evaluator: Pediatrician (Teacher, ref)	0.84	(0.46, 1.51)	0.55
Case race: African American (White, ref)	1.55	(0.86, 2.81)	0.14
Child should go to therapist/counselor (75.0%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	0.95	(0.40, 2.27)	0.91
Positive genetic test results (only)	1.45	(0.57,3.69)	0.43
Both family history & positive genetic test results	1.44	(0.56, 3.66)	0.45
Evaluator: Pediatrician (Teacher, ref)	1.28	(0.66, 2.47)	0.47
Case race: African American (White, ref)	1.09	(0.58, 2.05)	0.79
Child's situation will improve with help of mental health professionals (72.3%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.70	(0.71, 4.10)	0.24
Positive genetic test results (only)	3.79	(1.52, 9.41)	0.004
Both family history & positive genetic test results	3.86	(1.54, 9.68)	0.004
Evaluator: Pediatrician (Teacher, ref)	0.89	(0.46, 1.72)	0.74
Case race: African American (White, ref)	0.62	(0.32, 1.20)	0.15
School should require parents to attend learning sessions (58.0%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.22	(0.52, 2.85)	0.64
Positive genetic test results (only)	1.17	(0.52, 2.62)	0.71
Both family history & positive genetic test results	1.62	(0.73, 3.61)	0.23
Evaluator: Pediatrician (Teacher, ref)	0.65	(0.36, 1.17)	0.15
Case race: African American (White, ref)	1.66	(0.91, 3.02)	0.10
Child should be given medications (37.2%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.13	(0.45, 2.86)	0.79
Positive genetic test results (only)	1.26	(0.49, 3.27)	0.63
Both family history & positive genetic test results	1.74	(0.71. 4.2) 3	0.22
Evaluator: Pediatrician (Teacher, ref)	1.04	(0.55, 1.96)	0.92
Case race: African American (White, ref)	0.95	(0.50, 1.79)	0.87
Child's behaviors will improve with medication (44.2%)			
Genetic evidence (no family history & negative test results ("neither"), ref)	–	–	–
Family history (only)	1.09	(0.46, 2.58)	0.85
Positive genetic test results (only)	2.14	(0.86, 5.33)	0.10
Both family history & positive genetic test results	1.93	(0.83, 4.47)	0.12
Evaluator: Pediatrician (Teacher, ref)	0.95	(0.52, 1.75)	0.88
Case race: African American (White, ref)	1.03	(0.57, 1.88)	0.91

[a] All percentages displayed in table reflect agreement (agree/strongly agree) with statements and are weighted percentages.
[b] Variables in the model included independent variables (i.e., genetic evidence, evaluator, child race) and controlled for participants' race, ethnicity (Hispanic), gender, and education.

3.4. Treatment efficacy

A majority of participants believed that the child's situation would improve with the help of a mental health professional (72.3%). This response was positively associated with the presence of positive genetic test alone (OR = 3.79, CI: 1.52, 9.41; p = 0.004) or in combination with family history (OR = 3.86, CI: 1.54, 9.68; p = 0.004). Only a minority believed that medication would improve the child's behavior (44.2%),

but neither type of genetic evidence was associated with this response (all ps ≥ 0.10).

3.5. Impact of covariates

Participants' race/ethnicity and education impacted responses to these questions (Table 3; the model for analysis included the independent variables and demographic characteristics in Table 1). Hispanic participants were more likely than non-Hispanic participants to approve of compulsory testing (OR = 3.40, CI: 1.25, 9.26; p = 0.02); to endorse mental health treatment by a pediatrician (OR = 3.06, CI: 1.20, 7.79; p = 0.02) and a psychiatrist (OR = 3.12, CI: 1.17, 8.28; p = 0.02), with medication (OR = 4.03, CI: 1.58, 10.29; p = 0.004); and to believe in treatment efficacy of medication (OR = 3.18, CI: 1.22, 8.31; p = 0.02). Black/AA participants were more likely than White participants to concur that the school should require the child to receive interventions (OR = 2.55, CI: 1.28, 5.08; p = 0.01), including medication (OR = 1.99, CI: 1.07, 3.72; p = 0.03), and that parents attend training sessions (OR = 4.95, CI: 2.54, 9.63; p=<0.001). Participants from other racial minorities were more likely than White participants to endorse mental healthcare by a psychiatrist (OR = 4.45, CI: 1.66, 11.94; p = 0.003) and to agree that the child's parents should attend training (OR = 5.57, CI: 1.90, 16.38, p = 0.002). To further investigate differential response among racial and ethnic groups based on the different types of genetic evidence, interactions between race and evidence variables were added to all models. However, none of the race-by-genetic evidence interactions were statistically significant for these outcomes.

Participants with at least some college education were less likely than those with a high school education or less to agree to the child's testing (OR = 0.26, CI: 0.13, 0.54; p < 0.001)), endorse compulsory testing (OR = 0.43, CI: 0.20, 0.89; p = 0.02), or require interventions to improve the child's behavior (OR = 0.35, CI: 0.18, 0. 68; p < 0.002) and learning sessions for parents (OR = 0.29, CI: 0.15, 0.57; p < 0.001).

4. Discussion

Although scholars have long debated the ethical and practical issues surrounding genetic testing of children, the possibility of introducing behavioral genetic testing in schools—i.e., in a non-clinical setting—adds another layer of ethical complexity. Should such testing be conducted? Who decides? How should such information be used? How might it impact education-related decisions, such as development of educational plans and other interventions to improve the child's behavioral condition and educational attainment? Surveying a nationally representative sample of the general public, this study examined these questions.

The overwhelming majority of our participants stated that, as the child's parents, they would have tested him for a hypothetical ADHD gene, but they strongly rejected the suggestion of testing without parental consent. Participants thus clearly endorsed a libertarian perspective regarding genetic testing of children for ADHD in schools, preferring a decision made by the parents rather than the state. It is likely that the more utilitarian view was not endorsed due to Americans' respect for parental authority over decisions for their children and worries about outside interference in family affairs. The vignette's focus on testing that identifies increased risk for development of ADHD may have further contributed to this result. Predictive testing and "genetic fishing expeditions" involving children have been far more controversial than well-established diagnostic testing (Lethan 2017; Botkin et al., 2015). Although the testing in the vignette may have had some diagnostic indication (but see further discussion below), the ambiguity of the focus of the test (i.e., increased risk rather than a determinative diagnostic result) may have resulted in participants not thinking that the societal benefit/burden ratio in this case (as required by the utilitarian view (Fulda and Lykens 2006; Hodge 2004)) justified overriding the traditional deference to parental decisions (Wilfond and Ross 2009).

Table 3
The impact of participants' race, ethnicity, and education on genetic testing, educational and other intervention, and treatment efficacy.

Dependent Variable	OR	95% CI*	P value
Consent to have gene tested			
Race: Black/African Americans vs. White	1.25	(0.48, 3.22)	0.65
Race: Other/Missing vs. White	0.56	(0.19, 1.65)	0.29
Hispanic vs. Non-Hispanic	1.47	(0.46, 4.70)	0.52
Female vs. Male	0.54	(0.26, 1.11)	0.09
Education: ≥Some College vs. ≤High School	0.26	(0.13, 0.54)	<0.001
School should require to have genetic testing			
Race: Black/African Americans vs. White	1.91	(0.96, 3.81)	0.07
Race: Other/Missing vs. White	1.79	(0.54, 5.97)	0.34
Hispanic vs. Non-Hispanic	3.40	(1.25, 9.26)	0.02
Female vs. Male	0.74	(0.36, 1.53)	0.41
Education: ≥Some College vs. ≤High School	0.43	(0.20, 0.89)	0.02
School should consider genetic result in education plan			
Race: Black/African Americans vs. White	1.05	(0.41, 2.71)	0.92
Race: Other/Missing vs. White	1.25	(0.43, 3.66)	0.68
Hispanic vs. Non-Hispanic	1.11	(0.42, 2.92)	0.84
Female vs. Male	0.83	(0.42, 1.64)	0.59
Education: ≥Some College vs. ≤High School	1.28	(0.61, 2.65)	0.52
School should require interventions to improve behavior			
Race: Black/African Americans vs. White	2.55	(1.28, 5.08)	0.01
Race: Other/Missing vs. White	0.61	(0.23, 1.60)	0.31
Hispanic vs. Non-Hispanic	1.285	(0.54, 3.06)	0.57
Female vs. Male	0.89	(0.49, 1.61)	0.70
Education: ≥Some College vs. ≤High School	0.35	(0.18, 0.68)	0.002
Child should go to pediatrician for help			
Race: Black/African Americans vs. White	1.17	(0.60, 2.28)	0.64
Race: Other/Missing vs. White	1.70	(0.61, 4.80)	0.31
Hispanic vs. Non-Hispanic	3.056	(1.20, 7.79)	0.02
Female vs. Male	1.26	(0.67, 2.37)	0.47
Education: ≥Some College vs. ≤High School	1.24	(0.63, 2.43)	0.54
Child should go to psychiatrist for help			
Race: Black/African Americans vs. White	1.70	(0.88, 3.28)	0.12
Race: Other/Missing vs. White	4.45	(1.66, 11.94)	0.003
Hispanic vs. Non-Hispanic	3.12	(1.17, 8.28)	0.02
Female vs. Male	0.95	(0.52, 1.73)	0.85
Education: ≥Some College vs. ≤High School	0.90	(0.48, 1.68)	0.74
Child should go to therapist/counselor			
Race: Black/African Americans vs. White	1.00	(0.49, 2.08)	0.99
Race: Other/Missing vs. White	2.96	(0.88, 9.97)	0.08
Hispanic vs. Non-Hispanic	1.137	(0.38, 3.40)	0.82
Female vs. Male	1.51	(0.80, 2.85)	0.20
Education: ≥Some College vs. ≤High School	0.90	(0.46, 1.78)	0.76
Child's situation will improve with help of mental health professionals			
Race: Black/African Americans vs. White	1.63	(0.73, 3.66)	0.23
Race: Other/Missing vs. White	0.85	(0.29, 2.47)	0.76
Hispanic vs. Non-Hispanic	1.139	(0.38, 3.47)	0.82
Female vs. Male	0.91	(0.48, 1.72)	0.77
Education: ≥Some College vs. ≤High School	0.59	(0.28, 1.24)	0.16
School should require parents to attend learning sessions			
Race: Black/African Americans vs. White	4.95	(2.54, 9.63)	<0.001
Race: Other/Missing vs. White	5.57	(1.90, 16.38)	0.002
Hispanic vs. Non-Hispanic	1.461	(0.58, 3.66)	0.42
Female vs. Male	1.89	(1.03, 3.45)	0.04
Education: ≥Some College vs. ≤High School	0.289	(0.15, 0.57)	<0.001
Child should be given medications			
Race: Black/African Americans vs. White	1.99	(1.07, 3.72)	0.03
Race: Other/Missing vs. White	1.46	(0.51, 4.19)	0.48
Hispanic vs. Non-Hispanic	4.030	(1.58, 10.29)	0.004
Female vs. Male	0.62	(0.33, 1.17)	0.14
Education: ≥Some College vs. ≤High School	0.64	(0.33, 1.22)	0.17
Child's behaviors will improve with medication			
Race: Black/African Americans vs. White	1.62	(0.87, 3.04)	0.13
Race: Other/Missing vs. White	1.21	(0.43, 3.38)	0.72
Hispanic vs. Non-Hispanic	3.181	(1.22, 8.31)	0.02
Female vs. Male	0.76	(0.41, 1.39)	0.37
Education: ≥Some College vs. ≤High School	0.88	(0.46, 1.67)	0.69

Variables in the model included independent variables (i.e., genetic evidence, evaluator, child race) and controlled for participants' race, ethnicity (Hispanic), gender, and education.

Future research can explore participants' rationales underlying these findings.

With regard to medical and other interventions, most participants agreed that the child should seek help from a pediatrician or therapist and believed that such help would improve the child's situation. However, they were far less supportive of the child seeking help from a psychiatrist or receiving medication, as well as of the school requiring that the child and his parents undergo behavioral and educational interventions. The contested nature of ADHD as a medical condition (Stein 2010) may be a possible explanation for these findings. Although the child's behaviors as described in the vignette alluded to the symptoms of ADHD (i.e., being very active, having difficulty concentrating or sitting still, having challenges with peers), such behaviors are inconclusive in their diagnostic value and may have not been understood as sufficient to merit psychiatric treatment or imposed interventions, especially for a 5-year-old child (Sabatello 2016; Alvarado and Modesto-Lowe 2017; Parens and Johnston 2011).

The introduction of genetic evidence had limited but important impact on participants' views. Contrary to our hypothesis, family history had no significant effects on testing decisions (voluntary or compulsory) and neither family history nor positive genetic test had an effect on participants' support for medicating a child with possible ADHD or for the school requiring behavioral or parental interventions. However, participants who read a vignette with positive genetic test alone or in combination with family history were more likely than those who received family history alone or neither type of evidence to think that this information should be considered in educational planning for the child. Moreover, a positive genetic test as well as both a family history and a positive genetic test were associated with participants' agreement that the child should seek help from a pediatrician and especially a psychiatrist, as well as a belief that such help would improve the child's situation.

What can explain these seemingly inconsistent and even contradictory findings? It is possible that family history did not impact participants' interest in genetic testing for the "ADHD gene" because participants were already highly invested in testing, or because they were not sufficiently aware of the heritability of this condition (Moldavsky and Sayal 2013). Taken together, however, our findings reinforce other studies showing that the public's understanding of genetic information is complex and that such data generally are utilized to promote other values or goals (Condit 2019). Although similar to studies of adults (Phelan 2005), knowledge of the child's genetic predisposition increased the perceptions of need for pediatric and psychiatric care, it did not increase interest in medication for ADHD—a treatment option that has raised public concerns about the overmedication of children in the U.S. (Bussing et al., 2012). Positive genetic evidence was seen as valuable information that can, and should, inform the educational plan for the child—parents of children diagnosed with ADHD similarly express hope for genetic findings to support their quest for additional educational resources for their children (Borglet et al., 2014)—but it was not viewed as determining the child's behavioral outcomes. Consistent with other research on the use of children's genetic information in non-clinical settings (Sabatello et al., 2021a), and contrary to studies with adults (Phelan et al., 2006), our findings indicate optimism about the child's potential educational future, notwithstanding his genetic makeup.

Our findings also indicate that participants' racial/ethnic background may impact attitudes towards the use and impact of psychiatric genetic information in educational settings.

Hispanic participants in our study were more likely than non-Hispanic participants to agree to imposed testing of the child for the ADHD gene, to endorse mental health treatment by a pediatrician or a psychiatrist, to agree to the provision of medication for ADHD and to believe that the medication would be helpful. Similarly, Black/AA participants were more likely than White participants to support imposed educational interventions for the child, and all non-White participants were more likely to support imposed educational interventions for the parents. These findings are unexpected and counter-intuitive given the already excessive surveillance of parents and families from racial/ethnic minorities in the U.S. (Roberts 2014; Grimm 2007; Kreag 2015). Possible explanations include distrust of voluntary participation in such child- and parent-centered trainings, even as such educational interventions may be needed and potentially beneficial (e.g., a study of Latino parents found many parental/familial and social barriers to seeking care for a child with ADHD, regardless of perception of need (Gerdes et al., 2014)). Or conversely, they may reflect experiences of limited access to services within the educational system and interest in change. Specifically, studies show that non-White children are less likely than White children to be diagnosed with and receive services for ADHD and other behavioral conditions (Morgan et al., 2015), and it is possible that Hispanic and Black/AA parents in our study were aware of this disparity. Future research can explore these issues.

In addition, participants' level of education impacted most of the decisions. Specifically, lower educational attainment was associated with more interest in the child's being tested for the ADHD gene (both voluntary and compulsory) and in required interventions to improve the child's behavior or parental skills. The reasons for this disparity are unclear. Some studies have shown that higher educational attainment is associated with better knowledge of the disadvantages of and decreased interest in genetic testing (Jallinoja and Aro 2000), while other studies found that individuals with higher education assign higher value to genetic testing and information (Vermeulen et al., 2014; Wilkins et al., 2019). Although our finding of increased support for genetic testing among participants with lower education is consistent with the latter, further research can explore whether views on genetic testing for conditions that are associated with educational attainment are grounded in misunderstandings of risks and unrealistic expectations about the benefits of such testing or other explanations, such as less access to genetic-related services due to lack of health insurance, which is associated with lower educational attainment (Berchick 2018).

It is hard to predict whether the introduction of PRS for ADHD (rather than a "gene for") would have changed our findings. Studies on public views on a range of issues in genetics, from direct-to-consumer testing (Lee 2020) to return of secondary genetic findings (Botkin et al., 2018), and potential usefulness of psychiatric genetic data for improved health outcomes (Sabatello et al., 2021b) show high interest (or curiosity) in information about one's genomic makeup but also its strategic use, when such data fit with other individual values or goals (Condit 2019). Similar to our findings, it is likely that as PRS for traits related to educational attainment continue to emerge and be offered, there will be interest in learning about PRS for ADHD, especially among those who experience challenges in obtaining special educational services for their child. Yet, there is no reason to believe that the public will perceive PRS for ADHD as offering far superior accuracy to monogenic testing or will endorse a genetic deterministic view of PRS for educational attainment.

The likelihood of future scientific research untangling the multiple components of PRS in the near future is also questionable. Despite growing research on PRS of ADHD, including findings that it accounts for 5.5% of the variance in inheritance of the disorder, the usefulness of PRS information is limited by several factors. These include: the still only small percentage of variance accounted for, the uncertainty as to how much larger this variance can become, and the concurrent findings of genetic overlap with other psychiatric conditions such as depression which can further complicate even efforts to tailor pharmaceutical interventions, as well as by strong correlations with factors such as years of schooling and IQ (Demontis et al., 2019; Ronald et al., 2021). Significantly, for PRS of ADHD (and other behavioral traits) to revolutionize how the public views child educational success, such data will need to be far more informative about how to develop tailored educational interventions. Yet, such efforts are complicated by several factors, including the need to quantify the impact of numerous known and

unknown environmental factors that affect educational outcomes (Turkheimer 2006; Wray et al. 2007) and commitment to a heavy resource- and time-intensive investment in precision education—daunting tasks, especially given systemically unequal educational environments in the U.S. (Hart 2016; Sabatello, 2018; Martschenko et al. 2019). Regardless of how genetic information is studied by scientists or presented to the public, considerations of equity in education must be factored into discussions on precision education.

5. Limitations

The limitations of this study include the possibility, as suggested by some studies, that participants may have difficulty envisioning themselves in the role of a vignette's character, especially when the character is significantly different than themselves (Hughes and Hub 2004). However, responses of participants with children younger than 21 (the cut-off age for special education services; n = 241) were not statistically different than those without such children (analysis not shown). Moreover, vignettes do not require participants to have in-depth knowledge of the character, and significantly, their major strengths are that they elicit the automatic meanings that participants generate from the vignette and reduce the risk of socially desirable responses (Benedetti et al., 2018), as may arise in discussions on children's psychiatric conditions, including ADHD. Second, it is impossible to know whether participants who were confronted with similar scenarios in their lives would react in the same manner as in the survey. Studies with adults indicate that uptake of genetic testing is often lower than indicated in studies that ask hypothetically about their interest (Forrest et al., 2012; Sanderson et al., 2010; Ropka et al., 2006). Similarly, participants in our study who, in the future, may face recommendations to test their child for a genetic predisposition to ADHD, may not act on this recommendation even though they thought that the parents of the child in the vignette should do so. Nonetheless, the study provides important insights about the general public's views on genetic testing of children for conditions that may affect educational attainment and the use of behavioral genetics in school settings, and suggests directions for future research.

6. Conclusions

In his vision for the future of genomic research, NIH Director Francis Collins stated that the rise of genomics-based care will lead to increased efforts to utilize genetic risk factors to target prophylaxis and treatment—and to consider effective interventions in an array of settings, including educational institutions—from birth on (Collins 2014; Collins et al., 2003). With efforts underway to identify specific genes and PRS associated with academic attainment, this vision may become a reality faster than expected. But it may not have as smooth sailing as some may hope.

Even if the scientific conundrum of genetically-complex behavioral conditions that are associated with academic success is addressed successfully, it is unlikely that genetic testing, including PRS, for such conditions will be validated for children across racial/ethnic groups anytime soon. Beyond scientific availability, our findings clearly indicate that views about testing and use of children's behavioral genetic information to promote educational success are complex. Public participants show high interest in learning about children's behavioral genetic predispositions but equally high preference for maintaining parents as the gatekeepers of genetic decisions; high support for the use of behavioral genetic information to promote educational success but not to impose behavioral or parental interventions; and increased medicalization—but not interest in medication—in the presence of behavioral genetic evidence and beliefs in the efficacy of medication for a child with ADHD.

Moreover, we found important effects of participants' race/ethnicity and educational attainment on key issues at the intersection of behavioral genetics and precision education. Hispanic participants in particular seemingly were more willing to endorse both the genetic and environmental components of precision education compared to non-Hispanic participants, as were participants with lower level of education. Why this is the case is unclear, and as discussed above, it may be intertwined with issues of access and equity. Our findings thus highlight potential challenges for the wide implementation of precision education in the U.S.

Author contributions

MS led all aspects of the study design, development and implementation, including: project conceptualization, data analysis and interpretation, and preparation of the initial draft mansucript and its revisions for submission. BI and TC contributed to data analysis and interpretation and critical review of the manuscript. BL made significant contributions to the development of study material and critical review of the manuscript. PSA co-designed the study, made significant contributions to the study material and critical review of the manuscript. All authors gave final approval of the version to be published.

Declaration of competing interest

Maya Sabatello is a member of the NIH All of Us Research Program's Institutional Review Board. The authors declare no other conflict of interest.

Acknowledgements

This work was supported by NHGRI grants K01HG008653 and RM1HG007257. We thank Dr. Seonjoo Lee for her help with power analysis. We thank Nena Restrepo Gil, MA, Cochava Branigan, MA, Cassius Gil, MSEd, and Mark Weber, JD for their comments and insights as educators on the study material.

References

Alvarado, C., Modesto-Lowe, V., 2017. Improving treatment in minority children with attention deficit/hyperactivity disorder. Clin Pediatr (Phila) 56 (2), 171–176, 2017.

Asbury, K., Rimfeld, K., Krapohl, E., 2017. Can (and should) we personalize education along genetic lines? Lessons from behavioral genetics. In: Bouregy, S., Grigorenko, E., Latham, S., Tan, M. (Eds.), 63-85 in Genetics, Ethics and Education. Cambridge University Press, Cambridge.

Aud, S., Fox, M.A., KewIRamani, A., 2010. Status and Trends in the Education of Racial and Ethnic Groups. http://nces.ed.gov/pubs2010/2010015.pdf.

Belsky, D.W., Moffitt, T.E., Corcoran, D.L., Domingue, B., Harrington, H., Hogan, S., et al., 2016. The Genetics of success: how single-nucleotide polymorphisms associated with educational attainment relate to life-course development. Psychol. Sci. 27 (7), 957–972.

Benedetti, A., Jackson, J., Luo, L., 2018. Vignettes: implications for LIS research. Coll. Res. Libr. 79 (2), 222. Available at. https://crl.acrl.org/index.php/crl/article/view/16605/18603.

Berchick, E., 2018. Who Are the Uninsured? 2018, U.S. Census Bureau's Social, Economic, and Housing Statistics Division. https://www.census.gov/library/stories/2018/09/who-are-the-uninsured.html.

Borgelt, E.L., Buchman, D.Z., Weiss, M., Illes, J., 2014. In search of "anything that would help": parent perspectives on emerging neurotechnologies. J. Atten. Disord. 18 (5), 395–401.

Botkin, J.R., Belmont, J.W., Berg, J.S., Berkman, B.E., Bombard, Y., Holm, I.A., et al., 2015. Points to consider: ethical, legal, and psychosocial implications of genetic testing in children and adolescents, 2015 Jul 2 Am. J. Hum. Genet. 97 (1), 6–21. https://doi.org/10.1016/j.ajhg.2015.05.022. Erratum in: Am J Hum Genet. 2015 Sep 3;97(3):501.

Botkin, J.R., Mancher, M., Busta, E.R., Downey, A.S., 2018. Committee on the Return of Individual-Specific Research Results Generated in Research Laboratories, Board on Health Sciences Policy, et al. Returning individual research results to participants: Guidance for a new research paradigm [Internet]. National Academies Press (US), Washington (DC). Available from. http://www.ncbi.nlm.nih.gov/books/NBK513173/.

Buchanan, R., Nese, R.N.T., Clark, M., 2016. Stakeholders' voices: defining needs of students with emotional and behavioral disorders transitioning between school settings. Behav. Disord. 41 (3), 135–147.

Burrell, S., Warboys, L., 2000. Special Educaiton and the Juvenile Justice System 2000. Available from. http://youthjusticenc.org/download/juvenile-justice/juvenile-and

-criminal-representation/Special%20Education%20and%20the%20Juvenile%20Justice%20System.pdf.
Bussing, R., Zima, B.T., Mason, D.M., Meyer, J.M., White, K., Garvan, C.W., 2012. ADHD knowledge, perceptions, and information sources: perspectives from a community sample of adolescents and their parents. J. Adolesc. Health 51 (6), 593–600, 2012.
Callier, S.L., 2012. Swabbing students: should universities be allowed to facilitate educational DNA testing? Am. J. Bioeth. 12 (4), 32–40.
Cavazos, T.B., Witte, J.S., 2020. Inclusion of variants discovered from diverse populations improves polygenic risk score transferability, 2021 Jan 14 HGG Adv 2 (1), 100017. https://doi.org/10.1016/j.xhgg.2020.100017.Epub.2020.Dec.2.
Centers for Disease Control and Prevention, 2020. Data and Statistics about ADHD. https://www.cdc.gov/ncbddd/adhd/data.html.
Collins, F.S., 2014. Francis Collins says medicine in the future will be tailored to your genes; the director of the national institutes of health says cheaper DNA sequencing will make personalized care routine in Wall Street Journal. http://ezproxy.cul.columbia.edu/login?url=https://search-proquest-com.ezproxy.cul.columbia.edu/docview/1543350186?accountid=10226.
Collins, F.S., Green, E.D., Guttmacher, A.E., Guyer, M.S., US National Human Genome Research Institute, 2003. A vision for the future of genomics research. Nature 422 (6934), 835–847.
Condit, C.M., 2019. Laypeople are strategic essentialists, not genetic essentialists. Hastings Cent. Rep. 49 (Suppl. 1), S27–s37.
Demontis, D., Walters, R.K., Martin, J., Mattheisen, M., Als, T.D., Agerbo, E., etal, 2019. Discovery of the first genome-wide significant risk loci for attention deficit/hyperactivity disorder, 2019 Jan Nat. Genet. 51 (1), 63–75. https://doi.org/10.1038/s41588-018-0269-7. Epub 2018 Nov 26.
Erbeli, F., 2019. Translating research findings in genetics of learning disabilities to special education instruction. Mind, Brain, and Education 13 (2), 74–79.
Erickson, J.A., Kuzmich, L., Ormond, K.E., Gordon, E., Christman, M.F., Cho, M.K., et al., 2014. Genetic testing of children for predisposition to mood disorders: anticipating the clinical issues. J. Genet. Counsel. 23 (4), 566–577.
Fadus, M.C., Ginsburg, K.R., Sobowale, K., Halliday-Boykins, C.A., Bryant, B.E., Gray, K. M., et al., 2020. Unconscious bias and the diagnosis of disruptive behavior disorders and ADHD in African American and Hispanic Youth. Acad. Psychiatr. 44 (1), 95–102.
Fischer, K.W., 2009. Mind, brain, and education: building a scientific groundwork for learning and teaching, 1. Mind, Brain, and Education 3, 3–16.
Forrest, L., Delatycki, M., Curnow, L., Gen Couns, M., Skene, L., Aitken, M., 2012. An audit of clinical service examining the uptake of genetic testing by at-risk family members. Genet. Med. 14 (1), 122–128.
Fulda, K.G., Lykens, K., 2006. Ethical issues in predictive genetic testing: a public health perspective. J. Med. Ethics 32 (3), 143–147.
Gerdes, A.C., Lawton, K.E., Haack, L.M., Schneider, B.W., 2014. Latino parental help seeking for childhood ADHD. Adm Policy Ment Health 41 (4), 503–513.
Grigorenko, E.L., 2007. How can genomics inform education? Mind Brain Educ 1 (1), 20–27.
Grimm, D.J., 2007. The demographics of genetic surveillance: familial DNA testing and the Hispanic community. Columbia Law Rev. 107 (5), 1164–1169.
Hart, S., 2016. Precision education initiative: moving towards personalized education. Mind, Brain, and Education 10, 209–211.
Haworth, C.M.A., Plomin, R., 2012. Genetics and education: toward a genetically sensitive classroom. In: Harris, K.R., Graham, S., Urdan, T. (Eds.), APA Educational Psychology Handbook, Pg. 529-559. The American Psychological Association.
Hodapp, R.M., Fidler, D.J., 1999. Special education and genetics: connections for the 21st century. J. Spec. Educ. 33 (3), 130–137.
Hodge Jr., J.G., 2004. Ethical issues concerning genetic testing and screening in public health. Am J Med Genet C Semin Med Genet 125c (1), 66–70.
Hughes, R., Hub, M., 2004. The construction and interpretation of vignettes in social research. Soc. Work. Soc. Sci. Rev. 11 (1), 36–51.
Jallinoja, P., Aro, A.R., 2000. Does knowledge make a difference? The association between knowledge about genes and attitudes toward gene tests. J. Health Commun. 5 (1), 29–39.
Kellison, I., Bussing, R., Bell, L., Garvan, C., 2010. Assessment of stigma associated with attention-deficit hyperactivity disorder: psychometric evaluation of the ADHD stigma questionnaire. Psychiatr. Res. 178 (2), 363–369.
Kreag, J., 2015. Going Local: the Fragmentation of Genetic Surveillance, vol. 95. Boston University Law Rev, pp. 1491–1554, 5.
Kullo, I.J., Dikilitas, O., 2020 Aug 11. Polygenic risk scores for diverse ancestries: making genomic medicine equitable. J. Am. Coll. Cardiol. 76 (6), 715–718. https://doi.org/10.1016/j.jacc.2020.06.028.
Lawrence, R.E., Appelbaum, P.S., 2011. Genetic testing in psychiatry: a review of attitudes and beliefs. Psychiatry 74 (4), 315–331.
Lee, Sandra Soo-Jin, 2020. Excavating the personal genome: the good biocitizen in the age of precision health. Hastings Center Report. In: Reynolds, J.M., Parens, E. (Eds.), For "All of Us"? on the Weight of Genomic Knowledge, Special Report, vol. 50, pp. S54–S61 (3)(2020.
Leefmann, J., Schaper, M., Schicktanz, S., 2017. The concept of "genetic responsibility" and its meanings: a systematic review of qualitative medical sociology literature. Front. Sociol. 1, 18.
Lethan, S.R., 2017. Conclusion: how might school systems use genetic data? In: Bouregy, S., Grigorenko, E., Latham, S., Tan, M. (Eds.), Genetics, Ethics and Education. Cambridge University Press, UK & NY, pp. 383–394, 2017.
Little, C., Barroso, C., Hart, S.J., 2017. In: Bouregy, S., Grigorenko, E., Latham, S., Tan, M. (Eds.), Precision Education Initiative: the Possibility of Personalized Education, Pg 159-182 in Genetics, Ethics and Education. Cambridge University Press, Cambridge.
Martin, A.R., Gignoux, C.R., Walters, R.K., Wojcik, G.L., Neale, B.M., Gravel, S., et al., 2017. Human demographic history impacts genetic risk prediction across diverse populations. Am. J. Hum. Genet. 100, 635–649.
Martschenko, D., 2019. DNA Dreams': Teacher Perspectives on the Role and Relevance of Genetics for Education. Res Edu 0034523719869956.
Martschenko, D., Trejo, S., Domingue, B.W., 2019. Genetics and education: recent developments in the context of an ugly history and an uncertain future. AERA Open 5, 1–15. https://doi.org/10.1177/2332858418810516.
Moeschler, J.B., 2008. Medical genetics diagnostic evaluation of the child with global developmental delay or intellectual disability. Curr. Opin. Neurol. 21 (2), 117–122.
Mohr-Jensen, C., Steen-Jensen, T., Bang-Schnack, M., Thingvad, H., 2019. What do primary and secondary school teachers know about ADHD in children? Findings from a systematic review and a representative, nationwide sample of Danish Teachers. J. Atten. Disord. 23 (3), 206–219.
Moldavsky, M., Sayal, K., 2013. Knowledge and attitudes about attention-deficit/hyperactivity disorder (ADHD) and its treatment: the views of children, adolescents, parents, teachers and healthcare professionals. Curr. Psychiatr. Rep. 15 (8), 377.
Morgan, P.L., Farkas, G., Hillemeier, M.M., Mattison, R., Maczuga, S., Li, H., et al., 2015. Minorities are disproportionately underrepresented in special education: longitudinal evidence across five disability conditions. Educ. Res. 44 (5), 278–292.
Mostafavi, H., Harpak, A., Agarwal, I., Conley, D., Pritchard, J.K., Przeworski, M., 2020. Variable prediction accuracy of polygenic scores within an ancestry group. eLife 9, e48376. https://doi.org/10.7554/eLife.48376.
Narcisa, V., Discenza, M., Vaccari, E., Rosen-Sheidley, B., Hardan, A.Y., Couchon, E., 2013. Parental interest in a genetic risk assessment test for autism spectrum disorders. Clin Pediatr (Phila) 52 (2), 139–146.
National Center for Education Statistics, 2012. Number and Percentage of 9th-To-12th-Graders Who Dropped Out of Public Schools, by Race/Ethnicity, Grade, and State or Jurisdiction: 2009-10. Institute of Education Sciences. http://nces.ed.gov/programs/digest/d12/tables/dt12_126.asp.
National Dissemination Center for Children with Disabilities, 2004. The Basic Special Education Process under IDEA. Available from. http://www.parentcenterhub.org/wp-content/uploads/repo_items/10steps.pdf.
Nelkin, D., Tancredi, L., 1991. Classify and control: genetic information in the schools. Am. J. Law Med. 17, 51–73.
Parens, E., Johnston, J., 2011. Troubled children: diagnosing, treating, and attending to context. A Hastings Center special report. Hastings Cent. Rep. 41 (2), S1–S32.
Perou, R., Bitsko, R.H., Blumberg, S.J., Pastor, P., Ghandour, R.M., Gfroerer, J.C., Hedden, S.L., Crosby, A.E., Visser, S.N., Achieve, L.A., Parks, S.E., Hall, J.E., Brody, D., Simile, C.M., Thompson, W.W., Baio, J., Avenevoli, S., Kogan, M.D., Huang, L.N., 2013. Mental Health Surveillance Among Children – US, vol. 62. Morbidity and Mortality Weekly Report, Supplement, pp. 1–40, 2005-2011.
Phelan, J.C., 2005. Geneticization of deviant behavior and consequences for stigma: the case of mental illness. J. Health Soc. Behav. 46, 307–322.
Phelan, J.C., Yang, L.H., Cruz-Rojas, R., 2006. Effects of attributing serious mental illnesses to genetic causes on orientations to treatment. Psychiatr. Serv. 57 (3), 382–387.
Plomin, R., von Stumm, S., 2018. The new genetics of intelligence. Nat. Rev. Genet. 19 (3), 148–159. https://doi.org/10.1038/nrg.2017.104.
Plomin, R., Kovas, Y., Haworth, C.M.A., 2007. Generalist genes: genetic links between brain, mind, and education. Mind Brain Educ 1 (1), 11–19.
Reilly, C., Senior, J., Murtagh, L., 2015. A comparative study of educational provision for children with neurogenetic syndromes: parent and teacher survey. J. Intellect. Disabil. Res. 59 (12), 1094–1107.
Roberts, D.E., 2014. Child protection as surveillance of African American families. J. Soc. Welfare Fam. Law 36 (4), 426–437.
Ronald, A., de Bode, N., Polderman, T.J.C., 2021. Systematic review: how the Attention-Deficit/Hyperactivity Disorder polygenic risk score adds to our understanding of ADHD and associated traits. S0890-8567(21)00070-8. J. Am. Acad. Child Adolesc. Psychiatry 2021 (Feb 3) https://doi.org/10.1016/j.jaac.2021.01.019. Epub ahead of print. PMID: 33548493.
Ropka, M.E., Wenzel, J., Phillips, E.K., Siadaty, M., Philbrick, J.T., 2006. Uptake rates for breast cancer genetic testing: a systematic review. Cancer Epidemiol. Biomark. Prev. 15 (5), 840–855.
Rothstein, L.F., 1997. Genetic information in schools, pg. 317-331. In: Rothstein, M. (Ed.), Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era. Yale University Press, New Haven & London.
Rothstein, M., 2007. Legal conceptions of equality in the genomic age. Law Ineq 25, 429–471.
Sabatello, M., 2016. Children with psychiatric disabilities: bioethical and genomic dilemmas, pg. 328-346. In: Ruck, M., Peterson-Badali, M., Freeman, M. (Eds.), The Handbook of Children's Rights: Global and Multidisciplinary Perspectives. Taylor and Francis Publishers.
Sabatello, M., 2018. A genomically informed education system? Challenges for behavioral genetics. JLME 46 (1), 130–144.
Sabatello, M., Insel, B.J., Link, B.G., Phelan, J.C., Appelbaum, P.S., 2021a. The psychiatric genetic data of children in proceedings to terminate parental rights, 2021 Feb 12: JAAPL.200066-20 J Am Acad Psychiatry Law. https://doi.org/10.29158/JAAPL.200066-20. Epub ahead of print.
Sabatello, M., Chen, Y., Herrera, C.F., Brockhoff, E., Austin, J., Appelbaum, P.S., 2021b. Teenagers and precision psychiatry: a window of opportunity, 2021 Jan 27 Public Health Genomics 1–12. https://doi.org/10.1159/000512475. Epub ahead of print.
Sanderson, S.C., O'Neill, S.C., Bastian, L.A., Bepler, G., McBride, C.M., 2010. What can interest tell us about uptake of genetic testing? Intention and behavior amongst smokers related to patients with lung cancer. Public Health Genomics 13 (2), 116–124.

Sax, L., Kautz, K.J., 2003. Who first suggests the diagnosis of attention-deficit/hyperactivity disorder? Ann. Fam. Med. 1 (3), 171–174.

Snyder, T.D., Dillow, S.A., 2013. Digest of Education Statistics 2012 (NCES 2014-015). National Center for Education Statistics, Institute of Educatino Sciences, US Department of Education, Washington DC. http://nces.ed.gov/pubs2014/2014015.pdf.

Stein, Z., 2010. On the difference between designing children and raising them: ethics and the use of educationally oriented biotechnology. Mind Brain Educ 4 (2), 53–67.

Torkamani, Wineinger, N., Topol, E., 2018. The personal and clinical utility of polygenic risk scores. National Review Genetics 19, 581–590.

Turkheimer, E., 2006. Mobiles: a gloomy view of research into complex human traits,. In: Parens, E., Chapman, A.R., Press, N. (Eds.), Wrestling with Behavioral Genetics. John Hopkins University Press, Baltimore, pp. 100–108, 2006.

Vermeulen, E., Henneman, L., van El, C.G., Cornel, M.C., 2014. Public attitudes towards preventive genomics and personal interest in genetic testing to prevent disease: a survey study. Eur. J. Publ. Health 24 (5), 768–775.

Wagner, M.M., 1995. Outcomes for youths with serious emotional disturbance in secondary school and early adulthood. Future Child. 5 (2), 90–112.

Walker, S.O., Plomin, R., 2005. The nature–nurture question: teachers ' perceptions of how genes and the environment influence educationally relevant behavior. Educ. Psychol. 25, 509–516.

Weber, M.C., 2008. Special Educaiton Law and Litigation Treatise, third ed. LRP Publications, Horsham, Pennsylvania.

Wilfond, B., Ross, L.F., 2009. From genetics to genomics: ethics, policy, and parental decision-making. J. Pediatr. Psychol. 34 (6), 639–647.

Wilkins, C.H., Mapes, B.M., Jerome, R.N., Villalta-Gil, V., Pulley, J.M., Harris, P.A., 2019. Understanding what information is valued by research participants, and why. Health Aff. 38 (3), 399–407.

Wray, N., Goddard, M., Visscher, P., 2007. Prediction of individual genetic risk to disease from genome-wide association studies. Genome Res. 17, 1520–1528.