

Introduction

SUSAN BOUREGY, ELENA L. GRIGORENKO,
MEI TAN, AND STEPHEN R. LATHAM

It is widely accepted that two major scientific initiatives in the late twentieth/early twenty-first century, The Human Genome Project (HGP) and The Decade of the Brain, have resulted in tremendous progress in our understanding of how the genome and the brain work. Related fundamental discoveries have additionally reshaped classical biology and created new scientific fields, most notably the growth of neuroscience as a specific discipline. The former has burgeoned, expanding the horizons of genetics and introducing a family of “-omic” disciplines (e.g., genomics, proteomics, epigenomics, transcriptomics), of which genomics (i.e., a genetics subdiscipline utilizing recombinant DNA, DNA sequencing, and bioinformatics methods to sequence, assemble, and analyze the function and structure of genomes – the complete set of DNA within a single cell of an organism), in particular, is featured almost daily both in the scientific literature and mass media. The latter, neuroscience, though, has been challenged to generate translational applications for critical areas of practice, in particular, education and neuroeducation (Ansari, De Smedt, & Grabner, 2012; Carew & Magsamen, 2010; Devonshire & Dommett, 2010; Fischer, Goswami, Geake, & The Task Force on the Future of Educational Neuroscience, 2010; Grigorenko, 2015; Hardiman, Rinne, Gregory, & Yarmolinskaya, 2012), and educogenomics (Grigorenko, 2007a, 2007c, 2010). Specifically, we are describing the need to define the real-life impact of genetic/genomics and neuroscience phenomena *on* educational practice rather than educating students *about* these sciences.

Two actions are critically important for the successful translation of research into everyday human practice: (1) the bolstering of public knowledge and comprehension, and (2) the critical appraisal of fundamental discoveries and their connections to practice. Such a translation into the field of education (hereafter, K–12 education) – notably underappreciated and

understudied today – relies heavily on the views and beliefs of the general public, in particular, parents and educators, regarding the relevance and importance of translational applications of brain and genome research for education. Whereas there are limited informative “views-and-attitudes” studies (i.e., focus groups and surveys) on the role of the brain sciences in education (Howard-Jones & Fenton, 2012; Serpati & Loughan, 2012), there are no such studies on the role of the genomic sciences in education.

The literature on the integration of genetics/genomics and education is scarce compared to the literatures incorporating genetic/genomic knowledge with other sciences. It is represented primarily by writings on the heritable influences and molecular bases for individual differences in ability/achievement. Three ongoing developments substantiate the integration of education and genetics/genomics within the classroom: the ongoing mapping of high heritability estimates for ability/achievement onto testable genetic/genomic factors; the proliferation of direct-to-consumer genetic/genomic testing (DTCGT); and the spread of genetic/genomic literacy.

Academic ability/achievement is heritable, i.e., their development and manifestation are influenced by the genome, although these influences are exerted differently in different environments (Taylor, Roehrig, Soden Hensler, Connor, & Schatschneider, 2010). As the mapping of various facets of genetic/genomic and environmental control becomes more precise, there is growing interest in finding the most productive combinations of “predispositions” (i.e., characteristics of the genome) and “conditions” (i.e., characteristics of the environome) to maximize educational attainment, lifespan outcomes, and returns to schooling. Currently, this interest resides primarily within special interest groups dedicated to particular disorders impacting achievement (Collier, 2012; Greenbaum, 2012) and select families (Madsen, 2010; Maher, 2011), but scholars have long predicted that genetic test results will eventually become a driving force for the individualization of education (Nelkin & Tancredi, 1991). Educators and researchers need to understand this force and its pros and cons.

DTCGT, offered by companies such as 23andMe, deCODE, Navigenics, Pathway Genomics, and Athleticcode, among others, allows families to obtain information about ancestry, carrier status and traits ranging from disease risk and drug response to behavior and propensities for various common diseases and disorders (Gollust, Hull, & Wilfond, 2002; Gurwitz & Bregman-Eschet, 2009; Kaye, 2008; McGuire & Burke, 2008; Wright, Hall, & Zimmern, 2011). Technology continually increases the affordability/attainability of such testing. Just as psychological testing has become central to schooling and educational decision making in the twentieth

century, genetic/genomic testing will gain comparable significance in the twenty-first century.

The HGP and associated technology and information leap, as exemplified in such large-scale projects as The HapMap, ENCODE, the 1000 Genomes Project, 100,000 Genomes Project, and the Human Epigenome Project, triggered an outburst of data, resulting in unparalleled access to genetic/genomic information at multiple levels, from personal to systemic, giving it a prominent role in life decision making (Gymrek, McGuire, Golan, Halperin, & Erlich, 2013; Kung & Gelbart, 2012; Maher, 2011; Rodriguez, Brooks, Greenber, & Green, 2013). The concept of personal genetics/genomics, through professional utilization (e.g., in medicine and forensics) and public consumerism, has entered public life and, inevitably, will soon be as important as the concept of personal finances, contributing to present and future family and personal lifestyle decision making. As with personal finances or hygiene, a certain level of genetic/genomic literacy will be required to interpret and accept the notion that behavior, educational attainment, and other “features” of contemporary humans are influenced by the genome. How is that level defined? As the field’s understanding of the genome is still a “work in progress,” the initial key perhaps is in debunking common misconceptions (Bowling et al., 2008; Henderson & Maguire, 2000; Hook, DiMagno, & Tefferi, 2004; Lanie et al., 2004; Mills Shaw, Van Horne, Zhang, & Boughman, 2008) such as ideas of determinism, singularity of causation, and irreversibility of effects. Concepts that are crucial to becoming “genome-literate” include understanding family background, genetic risk and pleiotropic effects, and the co-action of the genome and environment in shaping traits and conditions. Yet, it is unclear how genetic/genomic literacy can be achieved. As a recent report indicates, these ideas are still inadequately covered both in school textbooks (Dougherty, Pleasants, Solow, Wong, & Zhang, 2011) and in professional courses (i.e., for professionals in healthcare [Feero & Green, 2011; Guttmacher, Porteous, & McInerney, 2007; Korf, 2011], social work [Kingsberry, Mickel, Wartel, & Holmes, 2011], and insurance [Korf, 2011]) and are loaded with unresolved ethical questions (Fisher & Harrington McCarthy, 2013).

In 2008 and 2011/2012, the National Cancer Institute Health Information National Trends Survey (2013) gauged public awareness of DTCGT in the US population, finding a significant increase of 7.6 percent. However, this awareness is not equally distributed throughout the population. Those in the age bracket of fifty to seventy-four years were significantly more aware of DTCGT than eighteen- to forty-nine-year-olds and individuals seventy-five years and older. This may be related to

the finding that those with a prior cancer diagnosis (quite prevalent in this age group) were also more aware than those without a previous history of cancer. In addition, awareness increased with level of education, and those in urban settings were more aware than those in rural locations (Health Information National Trends Survey, 2013). While specific numbers and demographic details on the actual consumers of DTCGT are not readily available, researchers have generally characterized them according to their motivations for seeking out such services. They belong to three comprehensive categories: first, identity-seeking individuals engaging in GT to explore ancestry and ethnicity or to determine paternity; second, patients undergoing testing that has been ordered by a physician to check on the potentiality of disease; and, third, novelty seekers searching for new ways to improve their lifestyles (Su, 2013). These motivations are likely to expand in scope and complexity as genetic/genomic research continues to reveal more links between phenotype and genotype, including educational phenotype, and as awareness of DTCGT grows. Individuals who have undergone DTCGT themselves or used these services to learn more about their children, and who believe that their or their children's genetic/genomic profiles merit a modified educational approach, will be thrust into the existing mechanisms that govern the ways that school districts grant accommodations.

Currently, all states' special educational practices for children are guided by the Individuals with Disabilities Education Act (IDEA), first established in 1986 and reauthorized in 2004 (now known as Individuals with Disabilities Education Improvement Act – IDEIA). IDEIA is based on the principle that all children, including those with disabilities, are entitled to a free, appropriate public education that can meet their unique needs. Under this legislation, a child whom a school professional believes may have a disability is entitled to all relevant evaluations; the creation of an Individualized Education Plan (IEP), which outlines specifically what is needed to reach the educational goals set by parents, educational providers, and the child him- or herself; and mandates placement in as unrestricted an environment as possible, i.e., a typical classroom, if viable. In addition, if a parent feels that an IEP is not appropriate or that the child is not receiving the warranted services, it is the parent's right under the IDEIA to challenge the educational system and engage in due process. Schools are thus charged to provide sound curriculum-based instruction to children with disabilities, and to work closely with family members to provide the most appropriate educational supports to the child to maximize the child's potential to participate productively in society. These evaluations, whether the literature

contains specific recommendations or not, may soon – and, in some cases, already do – include genome-related data.

Educators are ill-prepared to face parents who, armed with genetic/genomic data indicating a probability that their child is disabled or gifted, attempt to use those data to gain access for their children to enhanced education resources. There are anecdotal reports of such attempts already being made – and more will surely come. School systems need to decide what scientific benchmarks will justify their choice to regard any genetic/genomic data as a more reliable or useful indicator of a child's need for special intervention than currently utilized data from the educational process itself or related cognitive, academic, and behavioral assessments. Policies and procedures are needed for such determinations, lest ad hoc systems unfairly shower public resources upon squeaky-wheel parents. School systems, in turn, need to develop standards for the security and privacy of genetic/genomic data; standards governing the disclosure of such data to family members who may share traits controlled by the genome, rendering student data applicable not only to the student but also to close family members; and standards governing disclosure of “incidental findings” – health risks or genealogical information detected in genome-related data originally supplied for educational rather than diagnostic purposes.

If genetic/genomic data do end up playing a role in the allocation of school resources, this will raise difficult issues of justice and access. Poorer and less educated families may not be aware of the advantages to which GT may give them access. They may not know how to get such testing done, and, if they know, they may not be able to afford it. School systems will then have to decide whether fairness demands public support of genetic/genomic testing or whether, on the other hand, public schools should refuse to consider such test results because their constituents have unequal access to it. Whereas fair access to educational resources would appear to suggest a policy mandating the genome screening of all children, doing so would raise a number of concerns. Screening the genome is not the same as screening academic performance itself. In most cases, the presence or absence of a given allele (or other structural or functional variant) is unlikely to be perfectly correlated with student achievement, but will exhibit a complex and probabilistic pattern of additive and multiplicative effects, implicating other alleles/genes/variants, as well as environmental influences. Environmental influences that impact achievement (everything from family and peer contexts – from nutrition to study habits to parental role modeling) will moderate the impact in any given individual student. The subtleties of heritability and the amount of uncertainty generated by these subtleties can

be difficult to grasp for students, parents and teachers alike, necessitating a plan to educate teachers and administrators in the basics of genetic and genomic sciences, so that a child's genetic/genomic profile does not result in pigeonholing or in the unintentional creation of a self-fulfilling prophecy about that child's potential.

The accumulation of genetic/genomic data is impossible to stop. The dramatic changes triggered by the HGP have already reshaped the lay of the land (Hoppe, 2013), such that massive amounts of relevant data (and services) are not only available but are readily accessible to a sizable group of consumers, whether firms or individuals. Yet, while discussions of the ethical uses of genetic/genomic data in medicine, forensics, and economics are in full force, discussion pertaining to these issues in education has been tentative at best. Such discussion is clearly needed as the incorporation of genetic information into the education sphere seems inevitable, and we as a society should prepare ourselves to respond in a scientifically, ethically, and fiscally responsible manner.

The HGP's impact on biotechnology and medicine has been monumental. However, the HGP also introduced privacy and social issues that have led to federal and private monitoring of the use of genetic/genomic information by individuals and institutions. Ethical issues related to the HGP are expected to become even more complex as the knowledge is applied to human behavior and penetrates multiple societal systems, including education (Buchanan, 2011; Grigorenko, 2007a, 2007b). The future of the utilization of HGP knowledge across and within these multiple systems depends on society's readiness to incorporate the HGP's scientific advances and deliver them to these systems' customers in accordance with ethical principles and the highest standards of practice (Buchanan, Brock, Daniels, & Wikler, 2000; Hook et al., 2004). Where ethicists have discussed the impact of genetics/genomics on education, they have concentrated primarily on ethical principles governing the possible use of future genetic learning enhancements; these discussions are part of a much larger bioethics literature on biomedical enhancement of humans (Harris, 2007; Savulescu & Bostrom, 2009). But, apart from one prescient article in 1991 (Nelkin & Tancredi, 1991), ethicists have ignored the more pressing ethical problems that GT results could pose for our educational system in the very near future – long before genetic/genomic mind enhancement becomes possible. Very soon, as GT results become increasingly available to parents and pediatricians (Hensley Alford et al., 2011), school officials will have to learn how to differentiate traits from conditions, and to make corresponding decisions about institutional accommodations for those

with learning-related conditions. Schools will have to develop policies concerning issues of parental choice and student assent for interventions; right to know vs. obligation to share when it pertains to transmitting genetic risk to subsequent generations (Dickens, Pei, & Taylor, 1996); right to protect vs. right to breach confidentiality for the sake of the protection of relatives (Andrews, 1992); right to make a decision to test minors (Clayton, 1997; Hanson & Thomson, 2000; Howard, Avard, & Borry, 2011; Lucassen & Montgomery, 2010; McConkie-Rosell & Spiridigliozzi, 2004; Parker, 2010); the choices made in the aftermath of GT (Hook et al., 2004; Middleton, Hewison, & Mueller, 1998); potential for harm through stigmatization and discrimination (Kegley, 1996) or self-limitation; permissibility of certain types of genetic treatment (Hook et al., 2004); justice of unequal access to genetic/genomic information; and global and local issues of public protection.

Another special area of concern pertaining to genetic/genomic data addresses issues of informed consent, privacy, and confidentiality. Consenting individuals (whether DNA donors themselves or on behalf of their children) might not realize how much information they disclose by agreeing to subject their DNA to certain analytical techniques (Greenbaum, Sboner, Mu, & Gerstein, 2011; Gymrek et al., 2013; Rodriguez et al., 2013). This vulnerability arises from the very character of genetic/genomic data and their content (of which we still understand only a portion), size (which is massive, requiring specialized computing facilities and skills; in many cases, once generated and processed, the data cannot be “taken back”), and nature (possibly disclosing data across multiple generations of relatives – for an illustration, see Jim Watson’s case study; Davies, 2010). Thus, current and future usage of genetic/genomic data presents a nontrivial issue, where the boundary between access and protection remains elusive. The most stunning lack, however, concerns the omniabsence of any conversation about the utilization of genetic/genomic tests and the potential need for regulation analogous to The Genetic Information Nondiscrimination Act of 2008 (GINA, Pub.L. 110–233, 122 Stat. 881, enacted May 21, 2008) for educational purposes.

In summary, principles and standards for the utilization of genetic and genomic data, while rapidly developing in medicine, have not even begun to be discussed in education. It is the shortage of such discourse that moved us to put this volume together. The volume is broadly focused on two objectives: (1) to delineate the relevance of genetics/genomics to child development, in general, and education, in particular; and (2) to outline applied and ethical issues concerning the integration of education and

genetics/genomics and to consider the legal, regulatory, and public perception issues specific to that integration.

The volume opens with two introductory chapters to equip the reader with understanding of the relevant concepts and contexts. Mei Tan briefly reviews highlights of the field of quantitative genetics, focusing specifically on the concept of heritability. Sergey Kornilov presents basic concepts in the field of molecular genetics and genomics, preparing the reader to understand the specific technical details of the discussions that follow.

The relevance of genetics/genomics to education is discussed in the following seven chapters. Kathryn Asbury, Kaili Rimfeld, and Eva Krapohl briefly review research into the heritability of academic achievement, particularly stressing the findings from investigations on what they call the “dynamic” relationship between genes and experience. They straightforwardly pose the question of whether it is, or ever will be, possible to personalize education along genetic lines, contributing to the discourse by discussing the relevance, added value, and ethics of the utilization of information about a child’s genetic/genomic vs. environmental information in that child’s education. Katherine Beckmann and Kieran O’Donnell further develop the environmental line of reasoning briefly reviewing the main actors in the acute stress response system, before discussing a proposed framework to describe the maladaptive effects of chronic stress. They discuss how the emerging field of clinical epigenetics may contribute to the field’s understanding of how early-life experiences influence biology across the lifespan, and the ethical considerations for this new field of research and implications of recent findings for early care and education program and policy development. Elena Grigorenko and Samuel Mandelman return the volume’s discourse to the discussion of co-contribution of genes and environments to child development and education, focusing on what is known about the etiology of individual differences in general and specific cognitive abilities. To follow, Elliot Tucker-Drob and Paige Harden focus on non-cognitive skills and describe a transactional framework for understanding how individual differences in such skills relate to cognitive development and academic achievement. Then the volume’s discourse turns, from the discussion of abilities, to the discussion of disabilities. Callie Little, Connie Barroso, and Sara Hart focus on learning disabilities and, within this discussion, argue that the personalized medicine approach, applied through what they refer to as “precision education,” might provide the best educational care for individuals with such disabilities. Robert Hodapp and Marisa Fisher center their contribution on intellectual disabilities. In particular, among other relevant comments, they state and restate the advantages

of a genetically informed approach to teaching students with intellectual disabilities, although many special education researchers and teachers continue to disregard genetic information. The final chapter of this section serves as a bridge to the next section and is aimed at its second objective. Victoria Schenker and Stephen Petrill examine the ethical implications of the role of genetics and environment on education from the perspective of behavioral genetics. They provide examples of behavioral genetic studies to examine some of the promises and barriers to using genetic information in educational settings. Specifically, they focus on three issues: (1) difficulty in translating genetic studies into educational practice; (2) misconceptions concerning how genetic effects operate in individuals versus populations; and (3) the misapplication and misinterpretation of genetic information. In their discussion of these three issues, they set up the context for the discourse that follows in the next seven chapters.

The second section of the book starts with Kimberly Kaphingst's chapter focusing on the issue of genomic literacy in general, with a particular emphasis on health decision making. The chapter describes various definitions of genetic and genomic literacy and then presents prior research regarding knowledge about genetics and genomics and the effects of literacy and numeracy skills on responses to genetic and genomic information. Priority areas for research on genomic literacy and educational practice are described with the supposition that enhancing and creating genomic literacy in the context of educational attainment and schooling will be, perhaps, even harder than in medicine (where it is essential!). In their contribution, David Peloquin and Mark Barnes provide an introduction to some of the relevant laws and regulations at the intersection of genomics and education. Specifically, they focus on issues pertaining to (1) the heritability of achievement and (2) DTCGT, discussing primarily federal law. In addressing heritability for achievement, they explore how the use of GT in the education system (1) raises similar constitutional concerns to those raised by school drug screening and newborn screening laws, (2) implicates informed consent laws, and (3) interacts with federal laws governing special education. They then address how GT used in the education system might be regulated by the Food and Drug Administration and the Centers for Medicare and Medicaid Services. Despite their federal focus, the authors remind readers that it is important to keep in mind that the public education system in the United States is funded primarily at the state and local levels, and thus any attempt to use GT in the public school system on a wide scale would likely need to grapple with myriad, disparate state laws. Celia Fisher enriches the volume's

discourse further, illuminating ethical challenges arising at the junction of genomics and behavioral sciences, in general, and education, in particular, as well as steps that can be taken to ensure the responsible conduct of research involving GT. She addresses the need to incorporate principles of genetic literacy into informed consent practices and the unique ethical issues that arise for guardian permission and child assent procedures in cross-sectional and longitudinal studies and research involving data depositories and secondary analyses. She also talks about the tension between ensuring adequate privacy protections and the risks and benefits of disclosing research-derived personal genetic information to individual participants and their family members. Finally, she discusses ethical challenges of disseminating the results of susceptibility and intervention responsivity studies, with particular attention to the potential impact on marginalized populations. Next, Jorge Contreras and Vikrant Deshmukh bring into the discussion those segments of the commercial genomics industry that offer products and services to consumers, either directly or through intermediaries such as physicians, genetic counselors, or testing laboratories, a sector that we collectively refer to as “personal genomics” (Khoury et al., 2009). Specifically, their focus is on those products and services that provide genetic/genomic information to consumers, as opposed to drugs, vaccines or treatment regimens that may have been discovered using genomic information, or the administration of which may be influenced by a recipient’s genomic characteristics. But even limited thus, the field, as the reader will discover, is complex and multifaceted. This complexity is reflected further in the contribution from Susan and Krista Bouregy who provide insight into the difficulties of a foreseeable penetration of genetic/genomic information into the education system to influence educational decision making. This chapter highlights select legal and ethical issues discussed in this section of the volume and transitions the discourse to the last two contributions, reflecting public perception of the relevant issues – one from an educator (i.e., the chapter from Judi Randi) and one from a parent (i.e., the chapter from Carolyn Cowen). Both of these chapters revise and interpret, from a lay person’s viewpoint, a number of issues discussed throughout the volume.

Working on this volume has been extremely interesting and stimulating. We sincerely hope that getting familiar with these contributions will have the same effect on our readers. We are looking forward to a broad discussion of the related issues in both scientific and popular media outlets. We are confident that this discussion will unfold, and unfold intensely; it is only a matter of time.