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Alina J. Purcell
Western Washington University

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The Modular Table: A Potential Clue for the Future Dilemmas Concerning Bioethics in Human Genome Applications of CRISPR

By Alina J. Purcell

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Western Washington University

Advisor: Dr. Kathleen Brian
Imagine filling out a form for your unconceived child. Let us say it is the year 2030—although at this moment in history scientists are not sure when widespread use of genetic engineering will be available to the mass markets. There are a broad array of traits that you can opt into, though some may cost extra. Genetic trends have shifted to be more and more homogenous, but blue eyes are currently trending amongst newborns. You and your partner are both brown-eyed, yet, you do not want to socially disadvantage your child. You sign your initials next to the box on the next page, which asks for consent to remove and replace any genes in the embryo that may predispose your child to any kind of disease. This includes genes responsible for suppressing tumors, such as the BRCA gene. This seems like a good thing, right? A parent only wants the best possible future for their child.

In a world where those whose parents were able to access the latest genetic engineering technology are making their own elite group of engineered humans, however, there is little room for mobility. As this example highlights, conversations about gene editing are also, inherently, conversations about human diversity. Human variation is a natural phenomenon to be prized, not least of all because of the theoretical relationship between communal productivity and stability in an ecological setting. The creation of identity categories, however, as well as the corresponding and relative valuation of those categories, a multiplicity of groups, institutions, and processes have weaponized human difference. Within the political, legal, and sociocultural structures of the United States, whiteness and able-bodiedness have been particularly privileged categories of identity. Meanwhile, other bodies and minds have been systematically devalued and targeted for immobilization, incapacitation, and attempts at eradication (Cleland, 2011).

One of the more notorious iterations of this systematic devaluation in the United States was eugenics, a social movement that grounded its political ideology, as well as
the implementation of that ideology, in the biological science. Eugenics was first named and systematically developed by Francis Galton, a scientist in Britain who, in 1883, “coined the term ‘eugenics’ meaning ‘well born’ and theorized that humanity could be improved by encouraging the fittest members of society to have more children” (Norrgard, 2008). In large part a result of racist, sexist, and ableist norms pushed by elites in academic, political, and philanthropic circles that became institutionalized in local, state, and federal locations, eugenic policies impacted migrants, people of color, and people with disabilities in staggering ways. The civil rights movement that emerged in the United States across the middle third of the twentieth-century were, in part, a counterrevolution to the popularity of eugenics.

This period is generally remembered as seeking an end to the doctrine of “separate but equal,” as well as other laws and attitudes associated with the Jim Crow Era. Such a focus, however, tends to treat these processes as separate from the Disability Rights Movement that developed at roughly the same time. Historically, the emergence of public policy changes in the latter half of the twentieth century, which dismantled Jim Crow laws, attempted to guarantee the inclusion of marginalized groups in public spaces such as schools or other parts of civic life. Yet there was a gaping rift between the legal code, on the one hand, and, on the other, the manner in which it was implemented. Such failures and misalignments contributed to socioeconomic, political, and educational disparities that persisted into the twenty-first century. They also, importantly, allowed the core assumptions of eugenics to continue influencing institutions, policies, and sociocultural norms.

This project focuses on the problems created by the convergence of these two historical processes. It identifies, specifically, a lack of equity in accessible information that would allow the public to make informed decisions about their choices and values, and, subsequently, to
influence policy decisions. This will become increasingly relevant with the advent of emergent genome engineering tools like clustered regularly interspaced short palindromic repeats (CRISPR-Cas9). CRISPR, a viral defense mechanism utilized by bacteria, has been recognized as a biotechnological mechanism that humans can instrumentalize. It would, theoretically, allow for ‘designer babies,’ but would also allow for adult cells to be edited (Doudna 2017). It is not the first technology that has led to the theorization of genome editing, as older and more expensive technologies have existed before it. It does, however, hold promise as the first technology that could enable widespread practices of gene editing.

As we orient toward the possibilities opened by this novel scientific development, it is easy to be distracted by the sheer immensity of potential applications. I argue, however, that we must also consider that the science is accelerating at a rate that far exceeds awareness and consideration of ethical dilemmas raised in more humanistic fields. Critical Race Theory and Critical Disability Studies, in particular, represent paradigmatic shifts that cause turbulence amongst neoliberalists and other proponents of gene editing. To address these problems, I argue for the creation of a transdisciplinary, socioculturally diverse, and modular coalition within the National Institute of Health (NIH). Participants would participate in a radically democratic process in which self-reflexive and ongoing debate would allow for the identification and obtainment of common hopes and structuring values for the application of genome engineering to human beings. This coalition would make official policy recommendations to legislators, recommendations that would adequately address the ethical, legal, and social issues raised by scientific studies of CRISPR’s clinical and therapeutic applications. It would also be centered on the premise that human diversity is a critical asset.
Often considered a ‘necessary evil,’ academia is inherently an exclusionary model based on particular abilities. There are several barriers that block the matriculation of a wide variety of people, barriers that reward a select few who are often chosen through criteria that prospective individuals cannot control. As one moves through the ranks of academia, the criteria for having one’s voice heard and one’s ideas implemented in any official regard become narrower and narrower. As a result, the general consensuses amplified by the academic community are, at times, overly homogenous. Other barriers that hinder radically democratic engagement in academia include the rate at which conversations develop. Scholars seeking publication in academic journals must undergo rigorous peer-review processes before their ideas can be widely distributed to the academic community. Then, readers, who are most often themselves members of the academic circle with a certain specialized skill set, must replicate the findings in order for the original author to hold merit. Essentially, the current model of academia does not allow space for the support of dissenting opinions. In conjunction with the slow pace of publication, this reality inhibits the extent to which academic research can contribute to social change.

Despite these problems, those working in the fields of Critical Race Theory (CRT) and Critical Disability Studies (CDS) could contribute greatly to conversations about human genome editing. Both emerged from the civil rights movements of the twentieth century. Theorists working in CRT deviate from general discussion concerning the progression of equality in the United States. They question the effectiveness of landmark cases such as *Brown v. Board of Education* (1954), while also critiquing traditionally accepted values within the academic community. The most basic tenants are that “racism is ordinary”; that “white-over-color ascendancy serves important purposes, both psychic and material, for the dominant group”; and that “race and races are products of social thought and relations” (Delgado and Stefancic,
Although race is often discussed in essentialist terms, CRT scholars underscore that racial categories are neither inherent nor fixed. They do not correspond to a biologic or genetic reality. Rather, they are identifying markers that society invents, manipulates, and retires, when convenient, for maintaining and perpetuating unequal relations of power and uneven distributions of resources. As the voice-of-color thesis suggests, “…because of their different histories and experiences with oppression, black, American Indian, Asian, and Latino/a writers and thinkers may be able to communicate to their white counterparts matters that the whites are unlikely to know” (Delgado & Stefancic, 2012). CRT thus also prioritizes voices from people of color, which contributes to its diversity as a field of inquiry:

The critical race theory (CRT) movement is a collection of activists and scholars interested in studying and transforming the relationship among race, racism, and power. The movement considers many of the same issues that conventional civil rights and ethnic studies discourses take up, but places them in a broader perspective that incudes economics, history, context, group- and self-interest, and even feelings and the unconscious. Unlike traditional civil rights, which stresses incrementalism and step-by-step progress, critical race theory questions the very foundations of the liberal order, including equality theory, legal reasoning, Enlightenment rationalism, and neutral principles of constitutional law (Delgado and Stefancic, 2012, p. 3).

Scholars working in CRT do not simply offer critiques; they also seek to deconstruct them. The field of Critical Disability Studies (CDS) materializes within a similar framework, prioritizing different, but parallel, issues. CDS also demands a high degree of self-reflexivity
amongst academics by calling into question the historicity of both the medical and social model of disability. These models, CDS scholars argue, are predicated upon problematic assumptions about human value because the collective arrival at these models were designed by a very homogenous and dogmatic group of elite individuals. Instead, Alison Kafer’s hybrid socio-political model of disability is seen as a blueprint for the way forward (Kafer, 2013). CDS scholars also conclude that since disability is a social identification category that can be attached to any one person at any given time by the self or another, every member of society should be concerned with CDS topics and discussions. The experience of disability can happen to any one person at any time. Membership is especially fluid.

Both CDS and CRT argue for the fluidization of social categories that have functioned, historically, as rigid and debilitating. Scholars in both fields argue that the contexts in which “race” or “disability” emerge are always unique, and it is therefore critical to continuously question the implications and historicity of dominant narratives. Recognizing and accepting the imperfect nature of these discussions is also paramount to disassembling oppressive structures according to both schools of thought. Increasingly, scholars in both fields argue, as well, for the importance of understanding the ways that disability and race intersect and compound inequities.

Additionally, both CRT and CDS are relatively nascent fields of academic inquiry, a reality that gestures toward the ways in which, historically speaking, disabled and/or racialized people have been excluded from dominant locations of education. Brown v. Board of Education has long been viewed as a pivotal moment in the history of the United States on its journey from slavery to inclusion. It marked the reversal of the Plessy v. Ferguson decision just 58 years earlier, which gave rise to the acceptance of the constitutionality of ‘separate but equal.’ But other laws, too, have attempted to address earlier disparities in the protection of
historically marginalized groups, such as the Individuals with Disabilities Education Act (IDEA) of 1975 (most recently amended in 2004) Pub.L. 101-476. IDEA, originally called the Education of Handicapped Children Act (EHCA) called for the provision of free appropriate public education for all children, including children with disabilities. On the other hand, public policy has also been utilized to push the cultural values of eugenicists. For example, the history of IQ testing and forced sterilization both draw upon paradigms that favored certain bodies and minds over others. The way these bodies were viewed varied depending on varying definitions of ‘usefulness’ and ‘acceptability’ which can be changed by the group holding power. These definitions were membranous, and as many critical social theorists argue, individuals can move in and out at any given time depending on context.

This history, then, informs the problem at the heart of this project in two ways. On the one hand, it helps to explain fears that genome editing will disproportionately target disabled and/or racialized people because parallel events have unfolded in the past. On the other, it helps to explain why disabled and/or racialized people are less able to impact the discourses, decisions, and policies surrounding genome editing. Genome editing has been discussed in theory since the 1970s when scientists in Japan discovered chunks of DNA that seemingly were useless, at the time thought of as junk (Palazzo 2014). It turns out that these chunks of ‘junk’ DNA are actually not useless at all. In fact, they are your immune system’s defense mechanism. Basically, the base pairs are blueprints for the building blocks of proteins which control most of the body at a molecular level. As science has rapidly progressed over the last few decades, biotechnologists and biochemists have discovered methods to manipulate certain proteins to cut and insert different sequences of nucleotides into DNA strands. The goal of this manipulation is to construct organisms with different genotypes—and, therefore, different phenotypes. Changing
the DNA, in other words, changes the ways in which those genes are expressed, thereby
determining which bodyminds exist (or will exist), and which do not (or will not). When
examining the blueprints of a construction project, any adjustments to the materials or
instructions will result in a fundamentally different project than originally written. It may be
useful to conceptualize CRISPR as a pair of molecular scissors that allow for semi-precise
editing of the blueprints for an organism. Scientists would be able to modify DNA (blueprint) to
create an organism (buildings structure) with greater immunity to diseases (earthquakes) to align
with dominant values for aesthetics, productivity, and civic participation.

On the surface, it seems completely logical to have cities full of buildings that are
resistant to natural disasters, or does it? This only makes sense when holding values that center
around being resistant to natural disasters. What about editing blueprints to dictate that they must
all be exactly the same dimensions? The same color? The same layouts inside? What if all of the
buildings that we changed the blueprints for turn out to be earthquake-resistant but leaves them
more vulnerable to fires? The ability to artificially edit the blueprints of buildings raises a myriad
of ethical concerns including informed consent (if we switch the building to a human, how much
say should the future building hold in the primordial stages, if any at all?).

CRISPR is developing rapidly—the news of a rogue Chinese biophysicist, He Jiankui,
rattled the scientific community when news broke of the birth of twin baby girls who had been
edited as germ cells using CRISPR in 2018 (Greely, 2019). As germ cells, Jiankui engineered the
girls to be genetically resistant to HIV infection which the girls could also pass down to their
offspring and so on. However, the experiment was not authorized by the Chinese government
and ultimately led to Jiankui’s arrest. The controversy surrounding the experiment is
unmistakable upon closer inspection. Because the experiment was conducted in secret as well as
the court proceedings that followed, there is little known information about the extent of the knowledge the parents had which is a violation of informed consent. Second of all, such little research has been done in the relatively short amount of time that human applications of CRISPR technologies have been theorized. Little is known about side effects and other potential adverse implications.

A Call for a National Coalition to be Tasked with the Duty of Upholding Ethics in Emergent Gene Editing Research:

I call for a national commission to be tasked with the responsibility to create a set of governing principles to be postulated by researchers in the United States in the research and development of the use of CRISPR in relation to human clinical trials and practices. This governing body would carefully vet CRISPR projects to ensure they follow a set of principles that are to be determined, and reviewed at least annually, by a large body of paid individuals from a diverse range of perspectives and allow for a global precedent for other countries to follow. This body should be as close as possible to being representative of current globally marginalized groups. Also included in the responsibilities of the national coalition would be to formalize spaces where equitable opportunities for citizens to engage in forums to share their input. Those who serve on this body should be educated to the fullest extent possible of the potential ethical, legal, and social outcomes (short-term and long-term).

To give an example of what one of the functions of this governing body would be a reconsideration to the ethical issues raised by the Human Genome Project. This specific example proves to be helpful and worthwhile for considering implementing a similar program focused on
bioethics as it relates to editing the genome. In 1990, the Ethical, Legal, and Social Implications Program (ELSI) within the National Institute of Health (NIH) was established which, …legislatively instantiated in the National Institutes of Health Revitalization Act of 1993, when Congress, in establishing the National Center for Human Genome Research [the predecessor to the National Human Genome Research Institute (NHGRI)], mandated that “not less than” 5% of the NIH Human Genome Project budget be set aside for research on the ethical, legal, and social implications of genomic science (Pub. L. 103-43, 107 Stat. 181, Sec. 1521) (p. 482).

In a review of the program written by Jean McEwen of the National Human Genome Research Institute (NHGRI), McEwen details the current four main priorities of ELSI: psychosocial and ethical issues in genomic research, psychosocial and ethical issues in genomic medicine, legal and public policy issues, and broader societal issues (2014 p. 484). ELSI does not pursue policy as a part of their agenda. The coalition that the onset of human and CRISPR-related issues would be formulated around would differ from ELSI in that it would hold “…substantial responsibility for the development of policy solutions to the full range of complex ethical and societal issues raised by genomics research” (p. 482). This coalition would also have the goal of making the recommendations accessible for the general public—that is that the participants should be presumed to have little, if any, knowledge of biology, philosophy, or social sciences. There is a myriad of methods in which information can be made universally accessible. This is critical because people are individuals who have varying needs. One formatting style is not enough to adequately educate the general public.

Method

Such a coalition is warranted as the medical model’s and the social model’s views of disability have been at odds with one another. The medical model has had a longstanding history of being the traditional default approach to viewing disability. It views disability as something
that is an endeavor to be conquered or fixed. The social model, on the contrary, views disability as a “neutral” identity trait and places the environment and other structures as the bearer of responsibility for ensuring accessibility instead of the person with the disability (Goering, 2015). The social model also rejects deficit- and -cure-centered foci. Kafer aptly captures the notion of incorporating elements of both models of disability into a political/relational model that abandons some key elements of the medical and social model in *Feminist, Queer, Crip* (2013). Kafer also demonstrates the strong ties between the medical model of disability and perceptions of value in society when she recants a quote by James Watson, widely credited to be a co-discoverer of the structure of DNA and Human Genome Project director, “We already accept that most couples don’t want a Down child. You would have to be crazy to say you wanted one, because that child has no future’…he’s not alone in expressing this kind of sentiment” (2013, p. 3). There are countless of stories told and untold of leaders in science making claims that have led to eugenic thoughts and practices hence the need for oversight as the future of CRISPR is concerned.

In order to reach an intersectional, transdisciplinary approach that is inclusive and celebratory of all members of society, there needs to be dialogue between viewpoints. Therefore, the composition of the coalition should be composed of individuals of diverse origins and experiences. The most equitable way to feasibly ensure a random sample size would be diverse ‘enough’ to serve would be to mimic the jury selection process. Additional measures could be taken to level the playing field in the sample pool in terms of social identity like race, sex, gender, disability, sexual orientation, economic status, etc. There may not be a ‘perfect’ pool of individuals, however the more resources activated to close this gap, the more representative this body would become.
Additionally, the coalition should meet biannually to address developments within cultural attitudes and discourse and also within the biotechnological field. Certain issues may be difficult to legislate preemptively therefore regular meetings should occur. A committee should be tasked to ensure participants are provided with necessary accommodations in order to be able to fully participate in meetings. These accommodations could come in the form of assistive technology, interpreters, etc. The coalition should also determine the specifications for the ongoing meetings, research findings, and recommendations for policy makers.

Along with the previously listed responsibilities, this coalition should also be responsible for dispersing an amount of their budget to provide relevant and accessible information that is required to achieve a sufficient understanding of the background of gene editing, all the way from Darwin to current developing practices. Additionally, it is true that the matters at hand are ones of high degrees of complexity. In fact, there seems to be a paradox when it comes time for someone to make the ultimate decision about the way biotechnology is funded across the board. However, being reluctant to face complex issues is just as damaging as taking the side of the oppressor, for inaction is devastating to social movements past, present, and future.

Conclusion

At this moment in time, there is no legal responsibility on behalf of the government of the United States to ensure its citizens understand incoming ethical dilemmas. In order for broad consensus to be reached, uncomfortable and complex discussions must take place. Individuals will have to self-reflexively question their own values and the ‘why’ for them as well. This conversation will not happen overnight. In fact, in order to make this discussion as equitable as possible, there needs to be information that is accessible for the general public. This will require
incorporating many principles of universal design and a great deal of effort to discern which
details are paramount to understanding the greater picture. However, if there is any hope of
successfully tackling these issues, rigorous groundwork must be done to lead policymakers and
their constituents in the most ethical manner possible.

Equitable access to information concerns everyone because at any minute any person can
fall within a marginalized group because the requirements for membership are not set in stone. In
a country as massive and diverse as the United States, therein lies a challenge to prioritize
information and effectively communicate it so that citizens may decide the value this information
holds themselves. Combining equitable access to information and equitable access to a seat at the
metaphorical table in decisions where the line between cosmetic and therapeutic applications of
CRISPR-related technology is concerned is the most definitive method of being prepared for
these future conversations. Bloomberg news reported, “While the numbers were small, the
fastest-growing patent classifications were in the gene-splicing technology known as CRISPR,
hybrid plants, 3-D printing and cancer therapies…” (Jan 14 2020). While there is currently a
voluntary moratorium suggested. Indeed, there is a sense of urgency arising for an
interdependent conversation in which everyone may have an opportunity to have a seat at the
table.


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