Human Genome Editing and The Identity Politics of Genetic Disability

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As highlighted by Kleiderman and Kellner Stedman's (2019) recent article, the case for the use of genomic technologies, such as CRISPR/cas9 to undertake germline editing of human embryos has been gaining momentum in recent years. In the UK, for example, a license was granted to researchers in 2016 to allow CRISPR research using human embryos- although such embryos would not be permitted to develop past 14 days (HFEA, 2016).

Monogenetic rare conditions are amongst those most frequently targeted by those developing human genome editing technologies, with recent claims of curative editing techniques being achieved for Duchenne Muscular Dystrophy (Nelson et al, 2019), Fragile X Syndrome (Yrigollen and Davidson, 2019) and Cystic Fibrosis (Brothers et al, 2019), despite continued highly restrictive global governance of the practice, ongoing concerns about its future biological impacts and evolving debates regarding its social and ethical implications (Daley et al, 2019; Ormond et al, 2019).

Unlike other forms of reproductive genetic disease prevention, such as pre-conception or prenatal genetic screening, or the use of pre-implantation genetic diagnosis (techniques used to effectively filter out and eradicate embryos and foetuses affected by genetic conditions, or prevent their conception in the first place), germline genome editing techniques differ substantially in their approach to genetic disease prevention. As Cavaliere (2018) has argued, such technologies are targeted towards the correction or removal of disabling genetic traits, rather than the so-called 'seek and destroy' approach of currently used technologies (Rothstein, 2001). Through preservation of the life of the embryo (that would otherwise be disabled), and eradication only of the disabling trait, germline genome editing indeed appears to neatly sidestep one of the most critical social and ethical concerns levelled at current methods of genetic disease amelioration: that the disabling trait is considered more significant than the life of the embryo or foetus.

Parens and Asch (2000) have been amongst those who have most prominently developed this critique, initially in relation to prenatal testing and selective termination although more recently towards other technologies and practices. Parens and Asch argue that such technological intervention involves otherwise wanted embryos/foetuses being eradicated on the grounds of a single genetic difference; a genetic trait that is assigned such negative value as to render all other characteristics and traits of that (would-be) person irrelevant (Parens and Asch, 2000). Given the nature of this critique, it does not take a large intellectual leap to arrive at the second most commonly cited disability rights critique of selective reprogenetic practices, known as the 'expressivist objection' (Buchanan, 1996). This objection holds that selective reprogenetic practices not only prevent disabled people from coming into existence, but that their very availability- and the associated, and often clandestine, social pressures to use them (Clarke, 1991; Markens et al, 2010)- both convey and perpetuate negative views about the particular disabling conditions they are targeted towards, and, by extension, people who currently live with those conditions (Asch and Wasserman, 2015). Moreover, these negative appraisals of disability are seen as reverberating throughout wider society, affirming and reinforcing negative appraisals of the lives and worth not

only of people with screened/tested for conditions, but of disabled people as a whole (Peterson, 2012).

Recent empirical research by myself and other researchers clearly demonstrate the existence, ethical dilemmas and the ambivalence towards genetic technologies that emerge directly from these two concerns about reprogenetic technologies in the accounts of both genetically, and non-genetically disabled people (Boardman, 2014). My research has revealed, for example, that the majority of people with genetic disabilities feel that it would be a loss to society to have fewer people with their particular condition coming into the world (Boardman and Hale, 2018) and the majority (90%) of family members of people with genetic disabilities such as haemophilia, for example, feel uncomfortable with the idea of pregnancy termination for the condition in their family (Boardman et al, 2019).

Despite this burgeoning body of research (e.g. Roadhouse et al, 2018; Barter et al, 2017; Stern et al, 2002; Taneja et al, 2004; Maxwell et al, 2011; Potrata et al, 2013; Gollust et al, 2003), however, the voices of the disability community remain largely under-represented in dialogue around the future development of reproductive genomic medicine such as genome editing (Wolbring and Diep, 2016), and an ongoing and challenging relationship of mistrust and suspicion has been observed between the disability and genetics communities (Madeo et al, 2011).

The development of human germline genome editing is particularly significant, however, because unlike current practice, it directly challenges the first of the disability rights critiques of selective reproduction outlined above. By retaining- as an alternative to destroying- the (would-be) disabled embryo, and instead removing only the disabling trait, genome editing marks a significant departure in the way in which genetically selective reproduction operates. Whilst, as Kleiderman and Kellner Stedman (2019) outline, for many people with genetic conditions, this possibility suggests clear benefits for the embryo in question, their family and wider society, the assumption that this development is of universal benefit to the disability community may be challenged when expressivist objections and the identity politics of disability and personhood is taken into account.

As Shakespeare (2006) and others outline, research that explores the relationship between disabled people and the concept of cure, or other modes of disability removal (e.g. reprogenetics) is complex and multi-faceted, with disabled people experiencing particular forms of impairment (typically those involving pain, deterioration and shortened-life span) more likely to welcome the notion of disability removal than others (e.g. those with static impairments since birth). For example, recent research on adults with Spinal Muscular Atrophy has highlighted a degree of ambivalence towards the first, and only recently licensed, drug therapy for the condition, Nusinersen (Pacione et al, 2019). Some adults with SMA, particularly those with the static form of impairment (type II), regard their condition as an integral part of their personhood and identity and as a mediator of their interactions with the world. This deep cleft in the responses between genetically disabled people with contrasting experiences of their impairment, of disability and also the role of identity politics in their lives has also been mirrored in studies that explore attitudes towards genetic screening (Roadhouse et al, 2018; Boardman et al, 2017; Gollust et al, 2003). A recognition of the emerging literature that explores the role of impairment experiences and identity politics, therefore, is critical to understanding the broad spectrum of responses that are currently being observed amongst genetically disabled people to technologies that ameliorate genetic disability, of which genome editing is but one.

It is not yet possible to explore the new forms of personhood, identity and genetic relatedness that will inevitably emerge amongst individuals subject to embryonic germline genome editing in the future. The argument espoused by many prominent ethicists, that life without disability is

unequivocally preferable to one with disability, would render genome editing a technology of undeniable benefit to the embryo in question (Savulescu et al, 2015; Savulescu and Singer, 2019). However, such a focus on the benefit to individual embryos is to overlook the broader societal changes that genome editing will signal, as well as the potential negative impacts on existing persons with genetic conditions (Coller, 2019). Indeed, unlike currently used forms of reprogenetic selection, genome editing, by treating germ cells, not only eliminates genetic variation in the treated embryo, but also makes permanent and heritable changes to the germline, that will invariably be transferred to offspring, consequently reducing the incidence of the genetic condition in the human gene pool in ways that currently used technologies are not capable of.

People with lived experience of genetic conditions have much to offer our current understanding of the social, personal and ethical implications this technology will have. Expressivist concerns around genome editing, and the potential negative impacts on people with unedited genomes or spontaneous mutations are important considerations as we move towards genomic futures where genome editing is normalised (and non-use socially penalised) along with the inevitable changes to the demographic characteristics of society that will follow (Nuffield Council on Bioethics 2018: 78).

Whilst the technologies and methods of implementation of genomic medicine are likely to transform and shift overtime, the core ethical and social issues that genetic disability eradication and/or minimisation present, will invariably remain the same. It is critical, therefore, that the literature exploring the views of people with the most vivid and visceral insights into the lived realities of genetic disability are included and valued in the processes of development and evaluation of new technologies such as genome editing (Petersen, 2006). This is not only so that the potential impacts on them can be explored, but also so that informed decisions regarding which conditions are the appropriate targets of genome editing can be made. Indeed, given the inherent potential of germline genome editing, this inclusion is now of paramount importance, when it is considered that such voices and experiences could eventually become a resource of increasing inaccessibility in the future.

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