Gene editing: the burden of perfection

A curious aspect of the Anthropocene is the unprecedented level of detail in which we can now modify the world around us. Fuelled by the emergence of the programmable CRISPR-Cas9 technology, it is now possible to use a bacteria to modify specific bases on an organisms genome accurately and cheaply.[1] This development brings renewed attention to this field of gene editing and in particular its ethical implications have stirred the public conscience. An analysis of online news coverage showed 857 news articles mentioning CRISPR-Cas9 and ethics from 2012-2017, many in relation to the potential for CRISPR-Cas9 to edit the human germline.[2] Ethical interest rose when CRISPR-Cas9 was reported to edit genes on a human embryo and peaked when the International Summit on Human Gene Editing convened in 2015 to discuss the research.[3] Although this study confines itself to the google-sphere, public interest in germline editing ethics has not gone been ignored by our regulators. Royal Society Te Apārangi in their panel's report into gene-editing recognised that any regulation of these technologies needs to be informed with wide engagement with the public and their ethical views.[4] This creates a challenge of legitimacy for law makers, as they need to maintain an ethical position that aligns with their communities' views in a field of ethics that is deliciously broad and sinuous at best.[5] I will explore one stand of ethics in the debate, the expressivist argument concerned with gene-editing's potential to select against disability. Next, I look to how regulators can rise to the challenge to consider expressivist concerns around disabilities.

The challenge: an exploration of the expressivist position

A high proportion of inherited disorders are due to single base substitutions, so CRISPR- Cas 9's ability to erase these faulty bases has potential to prevent people to be born with inherited disabilities.[6] Despite this, sweeping claims that it will end all disabilities are simply puffery. Genotype alone does not equal phenotype and CRISPR-Cas9 at this stage cannot stop naturally occurring mutations and

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[1] Patrick D. Hsu, Eric S. Lander, and Feng Zhang "Development and Applications of CRISPR-Cas9 for Genome Engineering" (2014) 157 Cell 1262.

[2] The Annenberg Public Policy Centre "Annenburg Science Media Monitor-Report 2" (2018) The Annenberg Public Policy Centre <https://cdn.annenbergpublicpolicycenter.org/wp-content/uploads/2018/10/science-media-monitor-report-2.pdf>.

[3] Above n 1.

[4] Royal Society Te Aparangi "Gene Editing Legal and Regulatory implications" (2019) Royal Society Te Aparangi <https://royalsociety.org.nz/assets/Uploads/Gene-Editing-Legal-and-regulatory-implications-DIGITAL.pdf> at 5.

[5] R Brownsword and M Goodwin: *Law and the Tehnologies of the Twenty-Frist Century: Text and Materials* (1st ed, Cambridge University Press, New York, 2012) at 169.

[6] Nuffield Council on Bioethics "Genome Editing and Reproduction: social and ethical issues" (2018) Nuffield Council on Bioethics 33 at 2.11.

environmental factors that produce disability.[7] As a headline, a world with fewer disabilities sounds utopian but taking it at face value ignores ethical concerns. One of these concerns is the expressivist argument, first mooted by bioethicist Adrienne Asch as response to biotechnologies and their ability to select against foetuses with disabilities.[8]

The debate

Expressivists argue that selecting against disabling traits expresses a harmful and hurtful message to people with those same traits.[9] Behind this is a layering of different lenses.[10] The Synecdoche argument states that in selecting against a trait, you imply that a person's worth is based on them just having that single trait.[11] The fear stems from the disregard of the rest of a person's worth because the disabling trait trumps all other parts of their being.[12] This contrasts with the identity argument that regards a person's disability as a core component of their identity. To advocate the reduction of a condition to be morally desirable, it implies to those with that condition a harmful message that there is a moral wrong in their existence.[13] The factor that underlies the critique is the devaluation of disabled people within our society by others.

Empirically, even without new gene editing technology there is some force to this expressivist argument within western health care. In a review of the literature of the effects of prenatal screening and selection, it was found that within western systems of medicine there is a dichotomy between clinicians and patients attitudes towards disabled traits.[14] The former greater inclined towards foetal selection against abnormalities and termination of pregnancies in the presence of disabling conditions .[15] Pre-birth, the review examines literature where patients felt unsupported in making the choice to have a disabled child.[16] Post birth the review found that many health professional students held negative attitudes towards people living with disabilities.[17] In New Zealand the lack of literature in the area means that all we have is anecdotal evidence from those who felt pressured from the system

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[7] Above n 6 at 1.10.

[8] Asch A "Reproductive technology and disability" in Cohen S and Taub N (eds*) Reproductive Laws for the 1990s* Clifton, NJ: Humana Press 69.

[9] Bjorn Hoffman "You are inferior!' Revisiting the expressivist argument" (2017) 31 Bioethics 505.

[10] Hoffman, above n 9.

[11] Hoffman, above n 9.

[12] Kass LR "Implications of prenatal diagnosis for the human right to life" (1976) Biomedical Ethics and the Law 313.

[13] SD Edwards "Disability, identity and the "expressivist objection"" (2004) 30 Journal of Medical Ethics 418.

[14] David Alan Klein "Medical Disparagement of the Disability Experience: Empirical Evidence for the "Expressivist Objection"" (2011) 2 AJOB Primary Research 8.

[15] Klein, above n 14.

[16] Klein, above n 14.

[17] Klein, above n 14.

and approached the press.[18] They claim that they were pushed to terminate after finding the presence of a disability in their foetuses.[19] On the other hand our structures do not seem ablest. Within our medical code of ethics, Doctors must be aware of the health and disability codes which includes rights to dignity and freedom from discrimination.[20] Medical students get taught about bio-ethics in the clinical context during their time at medical school.[21] Our national screening programme prioritises individual choice to screen for disabling conditions.[22] It may be said that we have found a libertarian medium where we as a society are inclusive of disability as it's a parent's individual choice to choose.

Critics of the expressivist argument base their legitimacy in these liberal terms. As they see it, offence felt by disabled people by ones choice not to have a child who is disabled does not merit the suppression of their choice.[23] To some, the choice to not have a disabled child can be justified by the burdensome harms that it will bring to one's family.[24] They believe that expressivism is counterintuitive and implies that we should not as a society want to reduce disability or improve quality of life for the disabled.[25] They reject the identity constitution aspect of disability as triumphing over the choice of genetic screening and gene editing programmes.[26] Identity to them is developed after birth so in choosing against a foetus you do not favour one identity and discredit the other, as that gamete's identity never was present in the first place. The issues with these retorts are that they feel dismissive and do little to change the way disabled people experience the world. Many disabled people have a strong sense of identity and community related to their disabled trait.[27] Some such as the deaf community, do not see their condition as a disability at all in the normative connotations of disability being an impairment.[28]

Does CRISPR-Cas9 change anything?

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[18] Harriet Jackson "Christchurch mum Harriet Jackson on choosing not to have an abortion" (27 October 2017) nzherald.co.nz <https://www.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11933819>. Jane Matthews "Mother of Kiwi Man with Down syndrome calls for pre-natal testing to be banned" (4 August 2019) Stuff <https://www.stuff.co.nz/national/health/114604025/mother-of-kiwi-man-with-down-syndrome-calls-for-prenatal-testing-to-be-banned>.

[19] Above n 18.

[20] Code of Ethics for the New Zealand Medical Profession 2014 recommendation 25.

[21] John McMillan and others "Ethics Education in New Zealand Medical Schools" (2018) 27(3) Cambridge Quarterly of Healthcare Ethics 470.

[22] "Frequently asked questions" (4 Novemeber 2014) National Screening Unit. <nsu.govt.nz/pregnancy-newborn-screening/antenatal-screening-down-syndrome-and-other-conditions/frequently-asked>.

[23] Edwards, above n 13.

[24] Edwards, above n 13.

[25] Edwards, above n 13.

[26] Edwards, above n 13.

[27] Sheila Riddle and Nick Watson *Disability, culture and Identity* (Routledge, New York, 2014) at 11.

[28] Above n 27 at 13.

With CRISPR-Cas 9 technology you fix an embryo rather than choose against one, leading to the question of whether the expressivist argument can be upheld in this new situation. The degree of choice in this case swells and opens possibilities for disabling traits to be erased.[29] There are two ways to look at the development. One could say that it is just a surgery in utero and makes no difference to the end child, or instead say that it changes the character of who they will be when they are born.[30] Those who think it will change the character see any edit to be expressivist. Conversely, for the camp who see editing as surgery, expressivist concerns are defeated. This is because instead of selecting against a disability, the edit addresses the need to improve quality of life for the disabled which expressivists are not morally against. Practically, Robert Sparrow argues that most individuals who choose against disability just want their child to be ordinary, rather than thinking about expressive concerns.[31]

However, this choice given by the state to the individual is at the heart of the expressivist concern. Bhorn Hofmann states this concern arises as "the sum of individual legitimate claims may lead to a society that we do not want".[32] That behind that offer of the choice to parents is the states the goal of reducing disability. Put simply, if the state did not want to do this they would not offer the choice. Expressivists have trepidation that this goal of diminishing disability is mutually exclusive to valuing and supporting people with disabilities, that the latter would decrease with the elimination of disabling traits.[33] This sociological view of the expressivist position shows that it is the state rather than the individual who is the expressivist and reframes the argument to one of ideology; that is an idea which operates to vindicate dominion of one group over another.

It is argued by expressivists that this anti-expressivist ideology regarding gene editing can take a form of new eugenics.[34] Eugenics is an attempt to improve the gene pool to create healthier future populations.[35] It has emotive connotations due to the authoritarianism eugenic policies of the 20th century which involved overt discrimination, sterilisation and murder.[36] Lassiez faire eugenics on the other hand looks to individuals voluntarily choosing to improve their line.[37] In that sense, programmes

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[29] Above n 6 at 1.4.

[30] Robert Sparrow "Genes, identity and the 'expressivist critique" in Loane Skene and Janna Thompson *Sorting Society : The Ethics of Genetic Screening and Therapy* (Cambridge University Press, Cambridge, 2008) 111.

[31] Sparrow, above n 30.

[32] Hoffman, above n 9.

[33] Hoffman, above n 9.

[34] Sparrow, above n 30.

[35] Stephen Wilkinson *Choosing Tomorrow's Children: The Ethics of Selective Reproduction* (Oxford University Press, 2010).

[36] Above n 35.

[37] Wilkinson, above n 35.

such as CRISPR-Cas 9 gene-editing against disability are by definition eugenic. Whether this is moral is a second question and far more nuanced. Some proponents of lassiez faire eugenics think it is unproblematic to have the choice to eradicate disabling traits to alleviate suffering.[38] The expressivists state that this form of eugenics is negative due who decides which traits to alleviate.[39] In these scenarios one sort of people make decisions which primarily effect another.[40] To them, new eugenics is an issue of identity politics where people without disabilities make decisions to which form and existence of disabilities is acceptable.[41]

Expressivism as a critique of the disabled relationship with the state gives us a clearer view of the situation, rather than framing it as a pure individual choice. The difficulty lies in this ethical pluralism, that is, the need facilitate a discussion between these different constituencies and respond to them.[42] This is pertinent here as the debate is of open ethical pluralism, disagreement around baseline principles of should there be a choice and exactly what to choose.[43]

Regulation Strategies

The need for legitimacy in regulatory decision making is based on a key assumption that we value engagement with our constituents and how they feel ethically about an issue.[44] New Zealand legislator guidelines for law making insist on both a consideration of rights and public consultation when making good law, providing a space for legitimacy.[45] This is by no means the only way to regulate for gene editing and there is no legal onus to engage with expressivist concerns. We could always take a Chinese route, where there are claims of unregulated CRISPR-Cas germline editing without public consultation.[46]

Current approaches

Currently, New Zealand has a strict precautionary approach to the germline editing that CRISPR-Cas9 warrants. It is prohibited to implant into a human any genetically modified embryo or gamete under

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[38] Wilkinson, above n 35.
[39] Sparrow, above n 30.
[40] Sparrow, above n 30.
[41] Sparrow, above n 30.
[42] Brownsword and Goodwin, above n 5 at 59.
[43] Brownsword and Goodwin, above n 39.
[44] Brownsword and Goodwin, above n 5.
[45] Legislation Design and Advisory Committee "Legislation Guidelines" (2018) Legislation Design and Advisory Committee <http://www.ldac.org.nz/assets/documents/adaed3dc25/Legislation-Guidelines-2018-edition-2019-05-15.pdf>.
[46] Sharon Brettkelly "The Detail: the world's first gene edited babies" Stuff <https://www.stuff.co.nz/national/the-detail/115002359/the-detail-the-worlds-first-gene-edited-babies>.

s 8 of the Hazardous Substances and New Organisms Act (Hereafter HART Act).[47] Genetic modification is undefined under the HART Act, but the latest Royal Society Te Apārangi Report states that CRISPR-Cas9 editing would not comply with Act.[48] The aforementioned Royal Society Te Apārangi panel intends to raise public awareness of the issue, but that in itself does not mean that moral discourse around the expressivist objection will be heard.[49] When there are topics such as gene editing that do initiate ethical values, there is concern that debates around pure ethics will be undercut by other issues such as health and safety risks.[50] Moreover, public engagement in ethics can lead to moral confusion if there is just a soundbite analysis of an issue due to its philosophical tone.[51] Lastly, the apprehension in engagement is that one will automatically follow their personal beliefs rather than take an opportunity to reconsider their values in light of the breadth of moral concern.[52]

Historically, New Zealand has engaged with the ethical nuances of gene editing through a Royal Commission. Royal Commissions are the primary source of holding public investigations into policy matters.[53] They differ from traditional law reform processes such as select committees as they are independent from the government and their recommendations are usually held in high regard.[54] The Royal Commission on Genetic Modification was published in 2001 after a 14-month long enquiry hearing 400 experts and considering over 10,000 public submissions.[55] It considered varying ethical standpoints around Genetic Modification and acknowledged thoughts around disability, discrimination and eugenics in its conclusion.[56] They instructed the establishment of Toi Te Taiao: the Bioethics Council to develop guidelines to manage these concerns and engage with the public.[57] However, it did not lead to a lasting solution as it was destabilised in 2009 by the National Government.[58] It is argued that these Royal commissions have limitations, as the panels are government chosen and the government can choose to not respond to the recommendations

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[47] HSNO s 8 (1) and Schedule 1(8).

[48] Gene Editing Scenarios in Heathcare Summary (Royal Society Te Aparangi, August 2019) at 7.

[49] <https://royalsociety.org.nz/what-we-do/our-expert-advice/our-expert-advice-under-development/gene-editing-panel/>.

[50] Brownsword and Goodwin, above n 5.

[51] Andy Miah "Genetics, cyberspace and bioethics: why not a public engagement with ethics?" (2005) 14(4) Public Understanding of Science 409.

[52] Miah, above n 48.

[53] Andrew Geddis "Citizens' assemblies" (2007) 245 NZLJ 245.

[54] Alan Simpson "Commissions of inquiry - Functions, power and legal status" (10 June 2012) Teara.govt.nz <https://teara.govt.nz/en/commissions-of-inquiry/page-1>

[55] <https://www.mfe.govt.nz/more/hazards/new-organisms/genetic-modification-new-zealand/about-royal-commission-genetic-0>.

[56] *Royal Commission on Genetic Modification* (Royal Commission, At chapter 13 section 21).

[57] Above, n 56 at chapter 13 section 21.

[58] Bioethics council "Bioethics Council Rejects Government's Duplication Claim" (Press release, 16 March 2009).

delivered.[59] At a principled level, there is a criticism in placing a national issue in the hands of 'experts' whose views are meant to reflect those of the 'ordinary' citizens.[60] There is some evidence towards scepticism in outcomes produced by commissions in the general reception of the Genetic Modification Commission. Despite its recommendations being instructive, it failed to convince those who wanted NZ to remain GE free and instigate a full law reform.[61] Bringing an expressivist lens to the table, these institutions are state mandated and do not offer certainty that their concerns will be given the space that they desire.

A new way to regulate?

So, how do we regulate without othering the expressivist argument? A strategy that I find compelling as a legitimate means to regulate for such ethical needs is the use of citizens assemblies. An implementation of this form of deliberative democracy has been done in British Columbia, Ireland, the Netherlands and the United Kingdom.[62] Citizens in these constituencies have decided on a broad scope of issues from abortion, to electoral reform, to climate change.[63] These assemblies are unconstrained by uniformity, each novel in its choice of participants, period of assembly and how the topic is framed. The assembly acts as a teacher which aims to provide the 'ordinary' with the power to overcome apathy and consider complex issues with affect them.[64] Research shows that the public have higher levels of trust in the decisions made at these assemblies compared to the traditional decision making process.[65] It is difficult to gauge if New Zealand is experiencing a distrust of democracy despite our voter turnout declining;[66] nonetheless, an assembly could provide an extra layer of legitimacy and enable expressivists a chance to sway the tyranny of the majority.

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[59] Geddis, above n 50.

[60] Geddis, above n 50.

[61] Geddis, above n 50.

[62] Janine Hayward "Citizens' assemblies and policy reform in New Zealand" (2013) 9 Policy Quarterly 70.

[63] Janine Hayward "Citizens' assemblies and policy reform in New Zealand" (2013) 9 Policy Quarterly 70; Mark Rice-Oxley "Britain's first climate assembly: can it help fix democracy too?" (19 July 2019) The Guardian < theguardian.com/world/2019/jul/19/could-camdens-climate-assembly-help-fix-democracy-too>; David M Farrell, Jane Suiter and Clogah Harris "Systematizing' constitutional deliberation: the 2016–18 citizens' assembly in Ireland" (2018) 34 Irish Political Studies 113.

[64] Hayward, above n 59.

[65] Hayward, above n 59.

[66] Trust, distrust, and the end of politics-as-we-knew-it: the mood of the nation prior to election 2017

A structure

Ireland has dabbled in its fair share of citizens assemblies since the 2016 election promise to hold them to contemplate Ireland's most pressing issues.[67] I think that their abortion assembly is a good framework to base the potential for a gene editing assembly in New Zealand, as abortion similarly has inherent ethical contestation. Ireland's abortion assembly consisted of one hundred participants randomly chosen off the electoral role meeting over five weekends over five months.[68] Before the ethical aspects of the debate were heard by the assembly, citizens were given time to read briefing papers about the various standpoints that would be presented.[69] Next they listened to those presentations, then given time to personally reflect, before a discussion session with their peers in small groups.[70] There was also a period allotted to a question and answer session between those presenting and the citizens deliberating.[71] Over that period, the citizens voted on whether to change the constitution to allow abortion and whether they agreed with or had any recommendations for how the law should change.[72] The agenda, speeches, and documentation given to the citizens was available online alongside their final determinations.[73] Much of the assembly was broadcasted on You Tube.[74] A similar level of transparency could work with a gene editing assembly so that the ethical debates could have a larger reach outside of the assemblies doors.

Is this enough?

In Canada steps were taken within assemblies to create balance in gender, age and ethnicity.[75] The imperative to do that with an assembly in New Zealand could lead to disabled voices bought to the table as decision makers. Even without such a selection, the 2013 disability survey noted 24% of New Zealanders live with a form of disability, making it unlikely that the assembly would lack any representation.[76] Ensuring the voice of the disabled within the members may also run at a cost to other affected groups. Gene editing can be used for crops and if the assembly looked to this ethical aspect of the debate, farmers might insist that they have members on the board. With too much

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[67] David M Farrell, Jane Suiter and Clogah Harris "Systematizing' constitutional deliberation: the 2016–18 citizens' assembly in Ireland" (2018) 34 Irish Political Studies 113.
[68] Farrell, Suiter and Harris, above n 64.
[69] Farrell, Suiter and Harris, above n 64.
[70] Farrell, Suiter and Harris, above n 64.
[71] Farrell, Suiter and Harris, above n 64.
[72] "The Eighth Amendment of the Constitution" <https://www.citizensassembly.ie/en/The-Eighth-Amendment-of-the-Constitution/>.
[73] Above n 69.
[74] Above n 69.
[75] Geddis, above n 50.
[76] *The New Zealand Disability Survey 2013* (Statistics New Zealand Tatauranga Aotearoa, 2013).

tinkering, the 'ordinary' citizen becomes curated to the state pleasing different groups. However, if in the discussion of germline gene editing the selection of speakers and participants does not include those in the disability community, the expressivist argument of state sanctioned othering fulfils its own prophecy.

There will always be uncertainty around such schemes. As Andrew Geddis posits, the weight of an assembly's recommendations depends on the publics "preparedness to accept that thinking hard about an issue may cause one to change one's mind on it".[77] This cannot be answered before the fact but the reasoning is that the public will have trust in what is decided by their peers.[78] There is some proof this can be done as with the Irish abortion assembly, their votes to legalise abortion nearly mirrored the result in subsequent referendum.[79] At macro level within our scheme of democracy this is all that the expressivist can obtain, inclusion and a hope that they could sway the debate in their favour.

Conclusion

Moral arguments such as the expressivist position are tricky to grasp and are subject to robust pluralistic debate. Nevertheless, there is noise surrounding this burgeoning technology that has potential to change the outcomes of human lives. The current methods of grasping public ethical outlook may be in danger of stifling which provides an opportunity for regulators to try something new. Citizens assemblies provide such a medium to hear the expressivist position, although they cannot guarantee expressivists a moral win. As a citizen myself, I think this deliberative democracy is laudable. My conviction in this is primarily anecdotical. This is because during this research I spoke to friends and family about the expressivist argument. At first, they were confused and quick to negate the concerns, but after a time they were able to engage in its complexity. After much debate, we didn't all agree or come to the same conclusion as before, but it felt worthwhile. It enabled us to slow down the debate, to stop, reflect and listen.

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[77] Geddis, above n 50.

[78] Geddis, above n 50.

[79] David Wallace Lockhart "Citizens' Assembly: Can Scots learn from Ireland?" (28th August 2019) BBC News <https://www.bbc.com/news/uk-scotland-49477328>.