

**Powerplay Minor
Research Document**

The Paradox of Biopolitical surveillance

Fleur van Stratum - 0953823

Lifestyle Transformation Design
Social Practices

December 2020

Abstract

Focused on biopolitical surveillance, this decolonial research explores biopower structures.

Biopower is the expression of knowledge/power used to rationalize bodies and perceive a part of the population as a problem to governmental practice. (Foucault) It translates in biopolitics that restrain human bodies to their biocapitalistic existence. (Helmreich) These practices lead to segregations and social control, limiting human rights on a basis of biological differences. This discriminatory behavior is justified by Galton's normal distribution curve and the concept of the "average man". In this project the argument is made that practices focused on social contexts rather than Galton's theories should be privileged.

The paradox of biopolitical surveillance is at the center of the problem. The friction is that the tools used to oppress physical and genetic minorities such as Galton's curve or institutional databases are also now the ones used to defend the rights of populations considered different. The question is then how human rights can be defended in a decolonial way that does not reinforce the biopolitical oppression led by governments and institutions?

In order to question the paradox, the research explores the implications of the surveillance tools and which power structures the system upholds. Using forecasting and speculative thinking, the

alternative of a non-existing surveillance is presented. What if bodies weren't rationalized by biopolitical surveillance? The challenge is if the paradox can be broken.

This research is linked to a practice of making the speculations visible through conversation pieces. The aim of these scenarios is to open perspectives on the paradox, allow new methods to emerge for activists to use and to collectively decolonize biocapital and human value.

Table of content

Introduction	P.4
The Paradox	P.5
Theoretical Framework	
Normalcy	P.6
Genetics	P.7
Biopower	P.11
Practice and Research Process	
Conversation Piece	P.12
Down Syndrome Prenatal Diagnosis	P.14
Gamification	P.15
Bibliography	P.16

Introduction

This research document is an element of the broader group study called Decolonial Listening led by students from the Willem de Kooning Academy minor Powerplay, part of the Social Practices. The general framework is that of Rolando Vazquez's work. The topic of this specific research is Biopolitics and the concept of Normalcy.

Focusing on the Paradox of Biopolitical Surveillance, the research questions how the tools used to oppress physical and genetic minorities are also the ones used to defend the rights of populations considered different. How can activists make a change without reinforcing the oppression at the same time?

This document presents desktop research and the different design methods used during the process of research and translation into practice. These methods are forecasting, speculation and gamification. The structure of the document follows the chronological process of the work.

The Paradox

The focus on the Paradox of Biopolitical Surveillance started with the study of Natasha Saltes' 2013 article "Abnormal' Bodies on the Borders of Inclusion: Biopolitics and the paradox of Disability Surveillance". This article was published by the Queen's University in Canada where Saltes obtained a PhD in Sociology, she also has a MPhil in Sociology from the University of Cambridge, and an MA in Critical Disability Studies from York University. She further completed a SSHRC post-doctoral fellowship in the Department of Communication at the University of Ottawa. Dr. Saltes' research examines disability in the context of access, inclusion and equality as well as the social impact of information and communication technology (Taylor&Francis). In this article she researches differences in disability definitions and argues that disability surveillance both contributes to the exclusion of people with impairments and to the promotion of their inclusion (Saltes, 55).

The definition of disability surveillance Saltes gives and the one this research follows is "the practice of collecting, documenting, monitoring and classifying personal data that pertains to the embodied characteristics and attributes of impairment"(Saltes, 56) She argues that the paradox lays in the oscillation between "biopolitical practices of social control that exclude people with impairments in order to prevent perceived economic 'risk' and practices of counting and classifying people with impairments in order to

promote rights" (Saltes, 56) One of the reasons for this paradox to exist is that both sides define the concept of disability in a different way. In the institutional and political realm disability has been in the disciplinary scope of medicine, that classification profoundly influences the perception of humans considered disabled, they are seen as sick, as invalid. It is defined as a corporeal problem (Saltes, 58) On the other hand, critical disability scholars and activists define disability as a relational experience emerging from the intersection of physical, sensory and/or cognitive difference with social interaction resulting in exclusion, discrimination and oppression (Saltes, 56)(Tremain, 104). The disconnection from social context is what leads to control and oppression whereas the perspective of social environment helps activists in the promotion of human rights.

Linking this article to personal experiences, the argument is that the paradox already appears at the existence of scientific definitions and diagnosis of human differences. Experiences and observations in the special education field, mostly at LSCA in Nice, France, reveal that a diagnosis can open accessibility to special care but at the same time closes opportunities of inclusion in mainstream systems. A practical example is the case of a young child diagnosed with severe ADHD that was welcomed in a special needs daycare but once the child got the right methods and knowledge enabling him to read and learn he was not accep-

ted in his local school on the sole argument of his diagnosis and without previous consultations of experts or his parents. The same data, his diagnosis, both oppresses and enables him. The paradox is that if you take away his diagnosis you end the oppression, but you also take away the argument for him to get care.

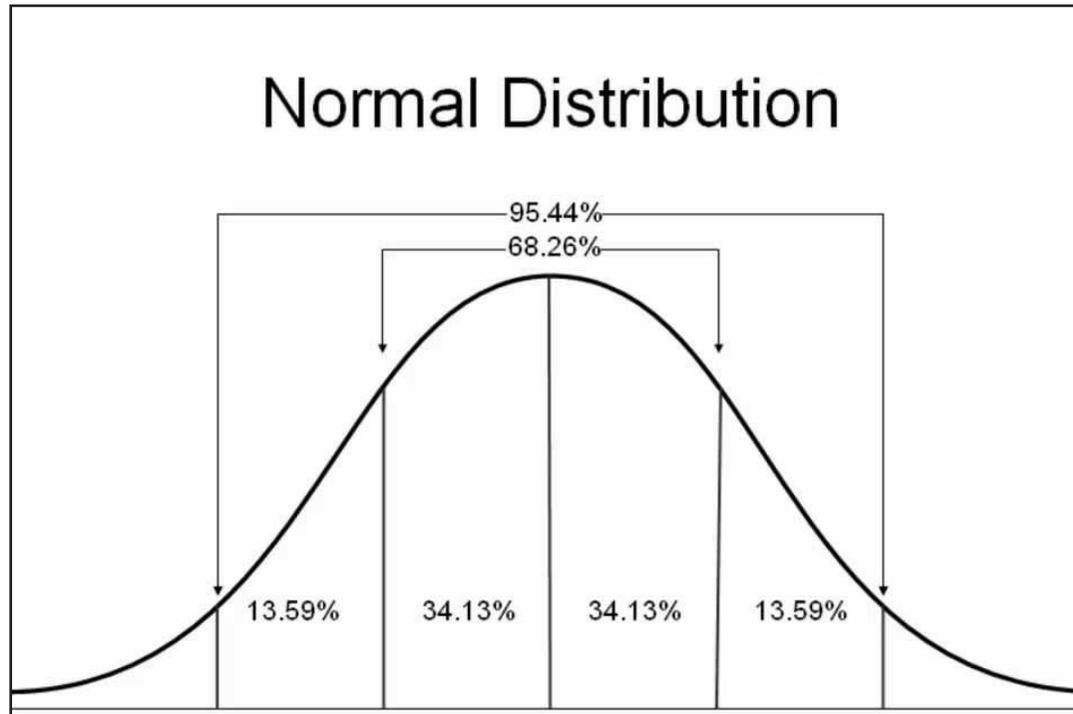
Theoretical Framework

Normalcy

The concept and definition of Disability exists because of a general understanding that there is a 'normal' way of being. We owe the emergence of this notion of normalcy to two statisticians, Adolphe Quetelet and Sir Francis Galton (Saltes, 57). Adolphe Quetelet, a mathematician, astronomer, statistician, poet and dramatist who lived from 1796 to 1874, is the creator of a new academic field he called Social Physics, it later became Sociology. He believed society could be analyzed without bias using statistics (Adolphe Quetelet - Biography, Facts and Pictures) He presented the concept of the 'average man' by extending the law of error principle used by astronomers to measure the true value of a measurement to the human body (Saltes, 57) This concept is visualized by the Bell Curve.

Sir Francis Galton, a 19th century polymath scientist, took the same principle also called Normal Distribution further by adding a layer of value in the normal/abnormal dichotomy. He argued that some human abnormalities had more value than others. If we consider an average muscular strength he argued that having more strength was valuable whereas having less was a problem. This is one of the concepts leading to eugenic ideologies he was a strong believer of.

Modern medical systems are closely linked to this 19th century principles. Kerry Taylor and Roxanne Mykitiuk research this connections and consequences in their 2011 article "Genetics, Normalcy and Disability". They establish that "The 'normal' is perceived to be an objective way to think about human beings, a means to represent or quantify



Galton's Normal Distribution curve

'what is' on the basis of statistical averages. However, the 'normal' also contains often opaque and unquestioned value judgments, and is used to represent what is right, and desirable. Often, when normalcy is invoked, there is a blurring of the distinction between fact and value, confusing what is, with what should be.' One of the examples is that medical attempts to eradicate differences are rationalized by the concept of normalcy and the fact that sameness is perceived to be the foundation of equality (Taylor and Mykitiuk, 1). There is a factual difference between patients but the judgment that medicine should thrive for sameness is based on moral values.

The measurement of equality focuses on corporeal sameness instead of treatment sameness. The argument is made that a switch in perspective would be more rightful. The goal would be to treat different bodies with the same quality instead of treating bodies in order to make them all have the same qualities.

Genetics

Genetic Sciences have an important influence on how we perceive normalcy as they establish common ground and differences. That explains why it is important to sketch a context of DNA study in order to get deeper into the research.

DNA stands for Deoxyribo Nucleic Acid, it is found in chromosomes. Most human beings pos-

sess 23 pairs of chromosomes forming the genome and present in the nucleus of every human cell the body is composed of. Each chromosome is composed of genes, a sequence of molecular base pairs, the genes tell the cells to create proteins and are therefore responsible for every function in the human body. The human genome is composed of approximately 3,2 billion base

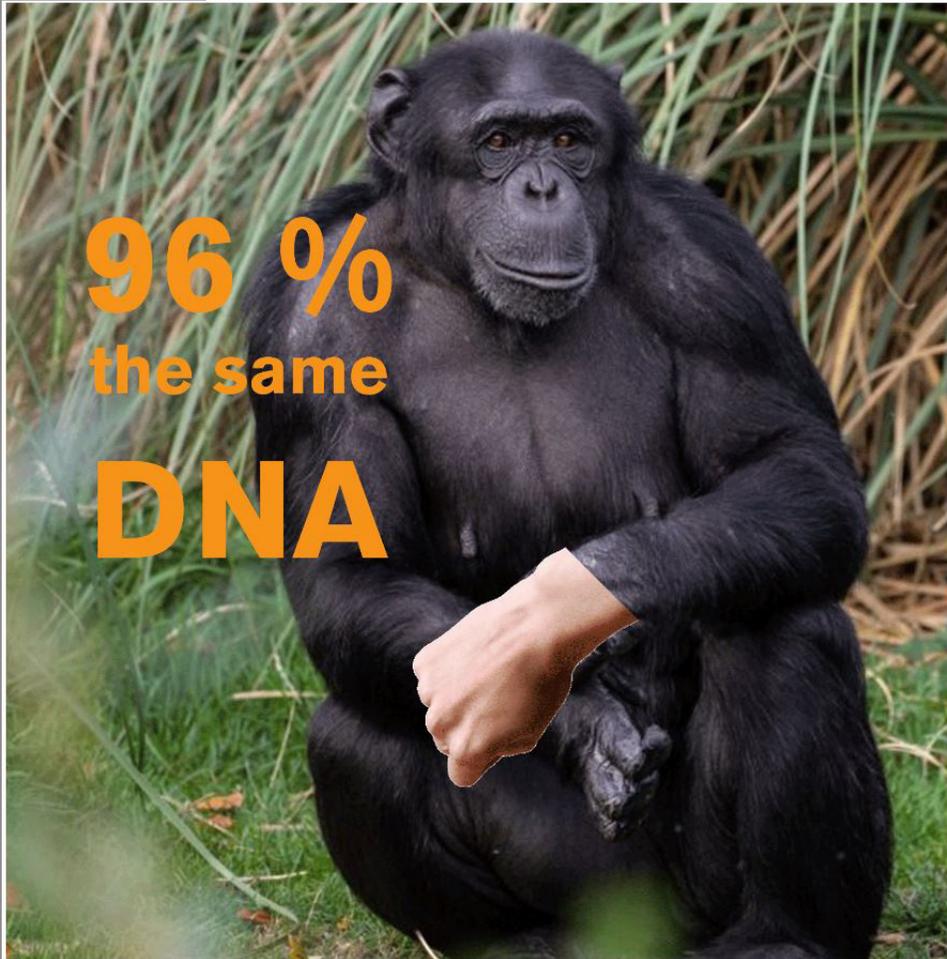
pairs, its first map was made in 2000. The effort to get to that map cost around 2,7 billion dollars (« Genetics »).

The fact that we first mapped the genome 20 years ago highlights a larger perspective important to keep in mind when discussing biopolitical and ethical subjects. It's in the last 65 years that we figured out how DNA works and that only represents 0,1% of human history (« Designer DNA »). Knowing that 99,9% of life on earth was before Homo Sapiens appeared, it is relevant to question how much power we should give to the knowledge of genetics and how much we should let it influence the future of our planet.

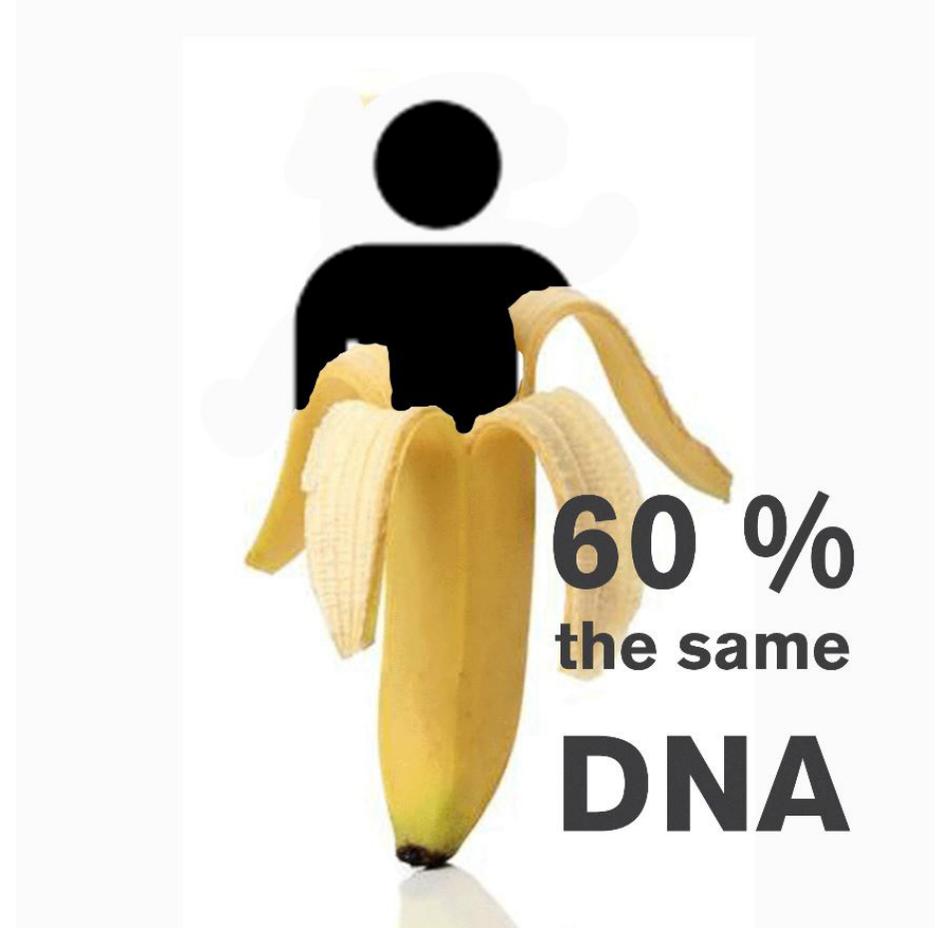
A different perspective is on how much DNA tells us, 1,2% of the human genome determines characteristics such as eye colors or how shy a person is but scientists still don't know what the other 98,8 % mean. This 1,2 % visible and measurable genetic characteristics make it common knowledge that humans are evolutionary closely related to chimpanzees. Indeed, we share 96 % of DNA with the apes but what is less known is that humans also share 60 % of DNA with bananas (« Genetics »). The question is if human behavior would change if that knowledge was more largely shared, would it question the Anthropocene era. Relating this information to the biopolitical paradox research, what does it mean to oppress someone with a slight difference in DNA if there is such a large part of common ground not yet

explored? Genetic testing offers the potential to demonstrate humans are all in some way 'impaired', that everyone has genetic 'abnormalities' by highlighting the magnitude of human genetic variation. In the article previously discussed, Taylor and Mykitiuk question if this could unite and allow to rethink the category of disability (Taylor and Mykitiuk, 5).

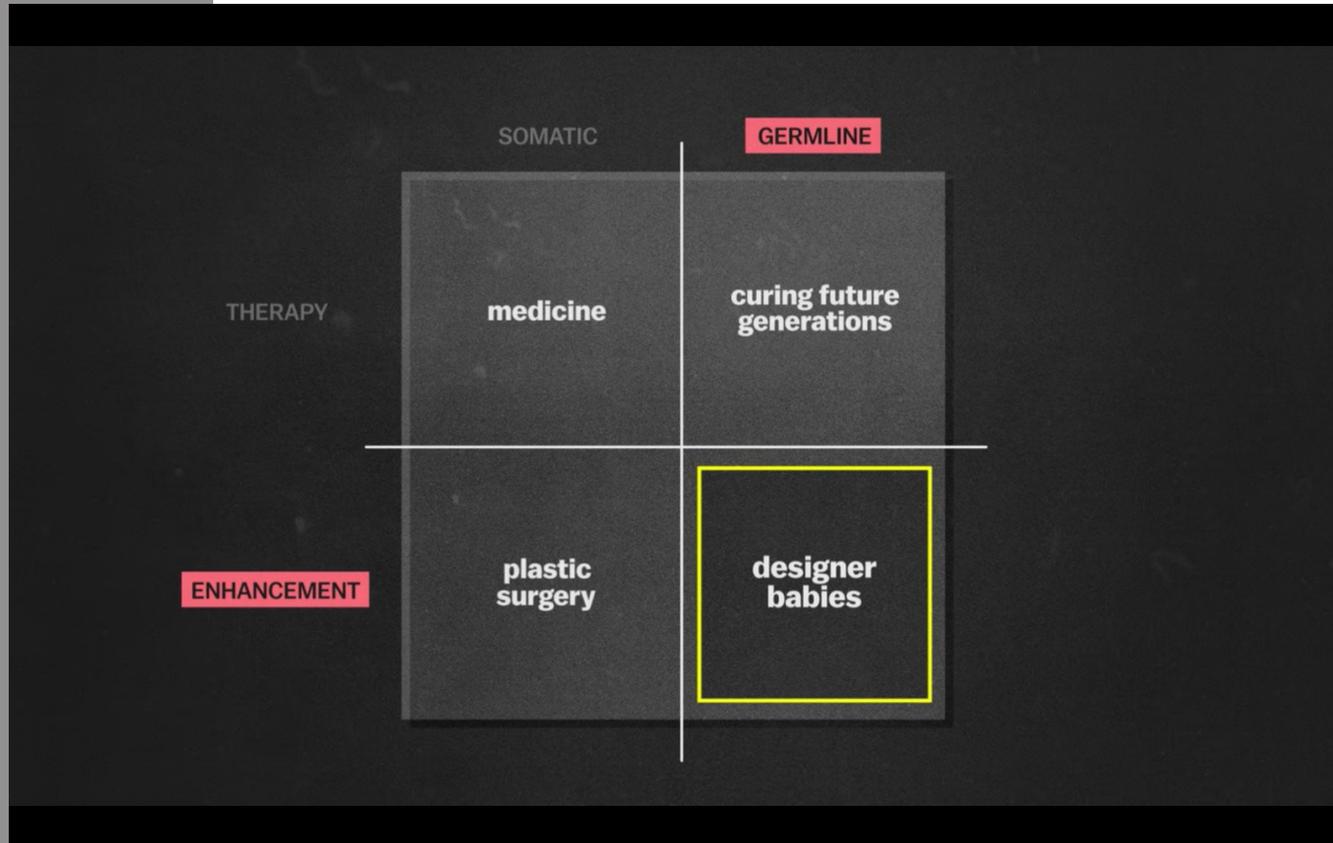
The first aspect of Genetic Sciences was to research the existing and enlarge knowledge but there is now a second aspect, the research on how to intervene and what can be done with the gained knowledge. Human intervention in the DNA field can take on different forms, gene editing is one of the most prolific research topics. Two types of gene editing need to be distinguished, Somatic gene editing and Germline gene editing. Somatic genes are most of the body's genes, the DNA does not get passed down to offspring. Meaning that editing these genes only impacts one individual and not the future generations. Germline genes on the other hand are found in sperm, eggs or embryos and the DNA is passed down to the next generation which means that editing it influences the future and human evolution (« Designer DNA »). Another distinction exists between Therapy and Enhancement even if that line is blurry and depends on different value settings. In order to make the distinction, there is a need to define what is considered a disease. Numerous cases like deafness or Dwarfism prove it difficult to establish this distinction.



Visuals from GIF - Fleur van Stratum - 10/12



Powerplay Minor - Research Document



Screenshot from «Designer DNA» - Netflix

These four definitions create different scenarios. The intersection of Somatic gene editing and therapy is in the realm of medicine, it's the only scenario already in use in 2020. Gene therapy is used as a treatment for HIV, cancers and different genetic diseases. The intersection of Somatic gene editing and enhancement would be in the

realm of plastic surgery, this is technically possible in 2020 but has not yet been done as it is still considered unethical by most societies. The intersection of Germline gene editing and therapy would be about curing future generations, the technology is not there yet but it is close so the ethical questions will have to be addressed in a near future. The last scenario, at the intersection between Germline gene editing and enhancement is the concept of Designer babies. For now this scenario is only existing in movies like Gattaca (Niccol) but could become real in the future (« Designer DNA »).

Technics of prenatal diagnosis are already widespread and with a smoother and more accessible access to IVF the easy and fast way to Designer babies would not be gene editing but gene selection. PGD, Preimplantation genetic diagnosis already exists for almost 30 years and is used to prevent genetic diseases or differences. The same process could soon be used to decide of the eye color of a fetus (« Designer DNA »).

Multiple problematics raise from this context. The first is the question of right to live, who gets the power to decide, who is allowed to exist? All these technologies being expensive and innovative a big issue to question is the access and wealth inequalities that already exist and will become stronger. But most importantly the field faces an important paradox, the question if positive progress should be stopped in scare of negative possible scenarios. The same editing technologies can cure deadly diseases but can also lead to unethical paths.

Biopower

Michel Foucault defined biopower as the endeavor (usually by 'authorities' of some kind) to rationalize the problems that the phenomena characteristic of a group of living human beings, when constituted as a population, pose to governmental practice (Tremain, 101). Michel Foucault, a French 20th century philosopher and historian of systems of thought, is at the origin of the concept of biopower. His work is centered around social control and the Power-Knowledge relation that upholds it. To Foucault power is everywhere as it represents all the ways of influencing others' behaviors and actions and it is always exercised through theory and practice of knowledge. His work therefor argues that Power and Knowledge are necessarily linked (Introduction to Michel Foucault: Power, Knowledge, and the Self - YouTube). Biopower is the strategic movement of knowledge-power that seeks to manage birth-rate, health, longevity and other similar concerns of a population (Tremain, 101).

With a focus on efficiency and rationality, biopower leaves out social complexities and normalizes people in order to make them governable. In this context, biopower creates oppression through a normalizing governmentality that sees

certain differences amongst populations as pathologies. The persons possessing these pathologies are rendered defective, are disabled and signified as less than human. These people become a 'problem' to be resolved or eliminated (Tremain, 102). This framework connects with the biomedical definitions of disability that Saltes presented in her article.

The concept of biopower is present in political decisions, especially in a neoliberal context. World politics and standards are influenced by the United Nations, the UN assumes that increased health assistance will result in increased economic development and less poverty. This assumption led to the World Bank's interest in the World Health Organization and the increase of its budget (Vesely, 51). From the perspective of this assumption, a person deemed able-bodied and healthy is seen as more valuable because of their ability to produce capital. It can be argued that humans are being treated as biocapital (Vesely, 52). Biocapital, a concept created by Stephan Helmreich, is described with an altered equation inspired by Marx: $B-C-B'$, where B is the biomaterial, C is the commodification of the biomaterial, and B' is the biotechnology that arises (Helmreich, 293-294).

Practice and Research Process

Conversation Piece

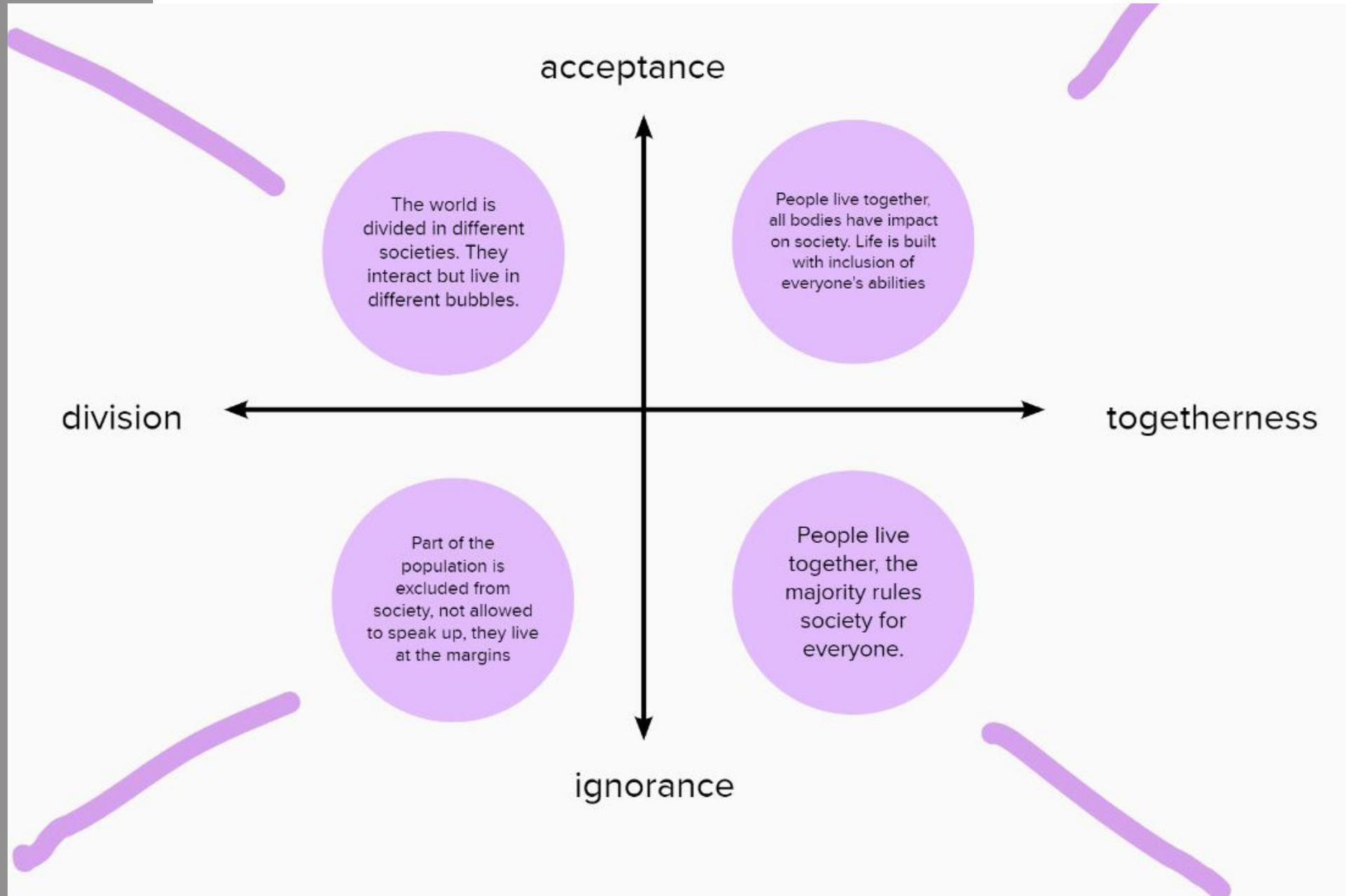
The aim of the design practice is to translate the knowledge extracted from the research. The goal was to express the paradox, question possible activism in the theoretical framework. The project was built around speculative scenarios that question the disappearance of some of the theoretical causes of oppression. What happens without the disability surveillance, without the biomedical definitions of disability? This scenario would be communicated towards the public thanks to a conversation piece.

While the scenarios were getting a basic structure and ideas for conversation pieces were born, it became clear that translating the concept of

paradox on a conceptual level was too broad. The conversation piece would either stay too abstract or express only one aspect of the research which felt frustrating.

A more specific starting point was needed to convey the message and the practice switched from discussion to experience. A conversation piece was not the best method for the abstraction level of the theory, the project started to focus on gamification instead. In order to decide on a more specific message, the research focused back on a practical case, prenatal diagnosis of trisomy 21 also called Down Syndrome.

Powerplay Minor - Research Document





Karl Emil Fält-Hansen, Denmark. (Julia Sellmann)

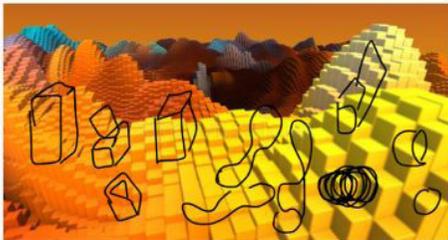
Down Syndrome Prenatal Diagnosis

The practice project needed more practical examples out of the theory so the research focused on prenatal diagnosis and selection in the specific case of trisomy 21. Down Syndrome is caused by a third chromosome 21 where most people only have two chromosomes. People with Down Syndrome are all unique but have some specific physical and cognitive characteristics. The karyotype demonstrating Down Syndrome was first discovered in 1959 by Jérôme Lejeune and Marthe Gautier but scientists found traces of population with Down Syndrome as far as 3000 before J-C (Wright).

The biopolitical surveillance paradox is present in this case study as since the genome screening in 1959, the framework of the syndrome took two opposite directions. On one hand it helped understand what was previously seen as a disease, activists were able to claim it was not and their hard work led to more inclusion. The different measures in care and education made the life expectancy more than double over the past 60 years (Zhang). But on the other hand, prenatal diagnosis was developed and high abortion rates followed, in Europe the termination rate tops 90 % with Down Syndrome eradicated in some countries like Iceland (Friedersdorf).

A PARALLEL WORLD

name?



multiple species
living together



A NEW SPECIE

the players
decide of its future

Will it live, change, disappear?

Gamification

The practical case of Trisomy 21 is the starting point of the practice project. The project makes the public experience the disability surveillance paradox in the form of a game. The game demonstrates that a same set of data or tools can be used to simultaneously oppress and defend. On the case of prenatal diagnosis for Down Syndrome, the players reflect on the fact that a multitude of individual decisions can lead to a general movement like the disappearance of people living with Down Syndrome (Zhang). There is also a reflection on the notion of choice, is it still a choice if you need to make a decision, if the system forces you to take a stand?

The storyline of the game takes place in a parallel world composed of different species. The players are an advice panel, a new specie is discovered, the players need to decide on its future through different rounds of questions and decisions. The players need to make personal decisions but also take in account what the other players think as their goal is to reach common ground.

Bibliography

Adolphe Quetelet - Biography, Facts and Pictures. 20 juillet 2018, <https://www.famousScientists.org/adolphe-quetelet/>.

Changing The Way We Talk About Disability | Amy Oulton | TEDxBrighton - YouTube. <https://www.youtube.com/watch?v=4WIP1VgPnco&t=2s>.

« Designer DNA ». Explained, Season 1 Episode 2, Netflix, May 23rd 2018

« Disability as Diversity: A New Biopolitics ». Somatosphere, may 2016, <http://somatosphere.net/2016/disability-as-diversity-a-new-biopolitics.html/>.

Do we really want a world without Down syndrome? | Chessie Henry | TEDxYouth@Christchurch - YouTube. <https://www.youtube.com/watch?v=uUpFzKE9Wk0>.

Foucault, Michel. Surveiller et Punir Naissance de la Prison. Gallimard, 1975.

Friedersdorf, Conor. « “I Am a Man With Down Syndrome and My Life Is Worth Living” ». The Atlantic, 30 october 2017, <https://www.theatlantic.com/politics/archive/2017/10/i-am-a-man-with-down-syndrome-and-my-life-is-worth-living/544325/>.

Galvin, Rose. « The Paradox of Disability Culture: The Need to Combine versus the Imperative to Let Go ». Disability & Society, vol. 18, n° august 5th 2003, p. 675-90. DOI.org (Crossref), doi:10.1080/0968759032000097889.

« Genetics ». History 101, Season 1 Episode 10, Netflix, may 2020.

Harari, Yuval Noa. Homo Deus: A Brief History of Tomorrow. Revised edition, Vintage, 2017.

Helmreich, Stefan. « Blue-Green Capital, Biotechnological Circulation and an Oceanic Imaginary: A Critique of Biopolitical Economy ». BioSocieties, vol. 2, nr 3, september 2007, p. 287-302. DOI.org (Crossref), doi:10.1017/S1745855207005753.

Het Nieuwe Instituut. Benno Premesela Lecture 2017 by Paul B. Preciado. 2017. Vimeo, <https://vimeo.com/245019294>.

I have one more chromosome than you. So what? | Karen Gaffney | TEDxPortland - YouTube. <https://www.youtube.com/watch?v=HwxjoBQdn0s>.

Introduction to Michel Foucault: Power, Knowledge, and the Self - YouTube. https://www.youtube.com/watch?v=sbBAghg7qRo&ab_channel=BrianGearity.

Niccol, Andrew. Gattaca. Columbia Pictures, 1997.

Saltes, Natasha. « 'Abnormal' Bodies on the Borders of Inclusion: Biopolitics and the Paradox of Disability Surveillance ». *Surveillance & Society*, vol. 11, nr 1/2, may 2013, p. 55-73. DOI.org (Crossref), doi:10.24908/ss.v11i1/2.4460.

---. « 'It's all about student accessibility. No one ever talks about teacher accessibility': Examining ableist expectations in academia ». *International Journal of Inclusive Education*, vol. 0, nr 0, january 2020, p. 1-27. Taylor and Francis+NEJM, doi:10.1080/13603116.2020.1712483.

Sir Francis Galton – The Galton Institute. <https://www.galtoninstitute.org.uk/sir-francis-galton/>.

Socially Constructing Down Syndrome: Confessions of a Rockin Mom | Cara Jacocks | TEDxACU - YouTube. <https://www.youtube.com/watch?v=Vk5RcCqnX9w>.

Taylor, Kerry, et Roxanne Mykitiuk. *Genetics, Normalcy and Disability*. march 2011.

The Eradication of Down Syndrome | Deborah Love Bradshaw | TEDxUniversityofTulsa - YouTube. <https://www.youtube.com/watch?v=eH9wdb1-6hVI>.

Things People With Down's Syndrome Are Tired of Hearing - YouTube. <https://www.youtube.com/watch?v=AAPmGW-GDHA>.

Tremain, Shelley. « The Biopolitics of Bioethics and Disability ». *Journal of Bioethical Inquiry*, vol. 5, nr 2-3, june 2008, p. 101-06. DOI.org (Crossref), doi:10.1007/s11673-008-9105-6.

Vesely, Leslie Marie. « The Biopolitics of Prenatal Diagnosis: How the Definition of "Health" Shapes the Use and Development of Prenatal Testing ». *Contingent Horizons*, vol. 4, nr 1, september 2018.

Wright, David. *Downs: the history of a disability*. Oxford University Press, 2011.

Xuan Thuy Nguyen. « Governing Difference: Reflecting on the Bio- Politics of Cure ». *Criticism*, vol. 61, nr 2, 2019.

Zhang, Story by Sarah. « The Last Children of Down Syndrome ». *The Atlantic*. The Atlantic, <https://www.theatlantic.com/magazine/archive/2020/12/the-last-children-of-down-syndrome/616928/>.