"Newgenics": A Comparison Study of Parents of Children with Down Syndrome in Denmark

and The United States

By: Lauren Ganson

### **How | Got Here**

- Summer Job
- ✤ Influential People
  - Camper: "Coming here is like coming home. You guys love and treat me like family when so much of the world doesn't want me. I can be myself here.
  - Parents: Gave a talk on their experiences while raising a child with Down Syndrome
- Idea of Newgenics
  - "modern eugenic practices that have emerged in light of new technological developments, referring to ideas and practices that appeal to scientific advances and genetic knowledge with the aim of improving mankind and curing or eliminating genetically based illness" (eugenicsarchives 2013)
- The Last Children of Down Syndrome

## Where We Are Going





#### Theory

Ideas on how the movement was started and its success



**Methods** 

How the study was conducted and choices made



#### What Was Found

Here you could describe the topic of the section

# Background

- The History of Eugenics
  - Historical Eugenics
  - Modern Eugenics
- Current Research in the Field
  - US
  - Denmark

## Theory

- Foucault
  - Biopolotics
- ✤ Agamben
  - Thanopolotics
  - Bare Life

- ✤ Canguilhem
  - Normal to Pathological
- ✤ Charlotte Perkins Gilman
  - Feminist Eugenics
  - Historical Examplee of Eugenics

## Methods

- Denmark
  - Inspiration
  - Difficulties
- United States
  - Interviews
  - Participants
  - Collection
  - Difficulties
- Ethics

### What I Found

- Perceptions (Then and Now)
  - US- They have gotten more positive but have a way to go
- Pre-Natal Testing and Abortion
  - US- All but 1 has some form of testing done but most did not know about the diagnosis till birth
  - Denmark- All participants had full testing done
  - US- Only 1 participant said she would have chosen abortion had she known
  - Denmark- Almost all said they thought about having an abortion at some point or had one

## What I Found

- Reactions
  - US- Most commonly, support came from family. All most all parents had a negative experience with doctors' reactions
  - Denmark- Encountered the most negative reactions from family and outsiders. Did not mention doctor reactions
- Regrets
  - US- Most regretted not getting proper help or pushing their child to try new things. Only one expressed regret in having their child.

## What I Learned

- Parents in both the US and Denmark express the extreme stress placed on them during their decision-making process after testing is completed.
- Parents in both the US and Denmark face great societal pressures n how they raise their child as well as about their choice to have a child with Down Syndrome
- In Denmark, both of these are increased by their higher rates of testing. Which could account for the increased number of abortions and thus acceptance of Newgenics.

### What We Can Do

Conduct more research here in the United States as well as in countries that are appearing to breed out Down Syndrome
Work on our own opinions of Down Syndrome as a society
Listen and learn from not only individuals with Down Syndrome but also their parents and loved ones



- Newgenics. The Eugenics Archives. (n.d.). Retrieved April 7, 2023, from <u>https://eugenicsarchive.ca/discover/encyclopedia/5233c4395c2ec500000000</u> <u>8a</u>
- Zhang, S. (2020, February 15). The last children of Down Syndrome. The Atlantic. Retrieved September 2022, from <u>https://www.theatlantic.com/magazine/archive/2020/12/the-last-children-ofdown-syndrome/616928/</u>