

The Challenge of Parents with Developmental Challenge

Kerry Bowman PHD
University of Toronto



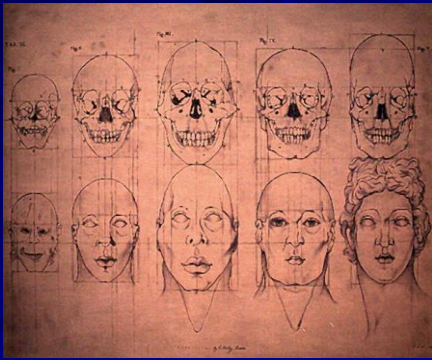
Definition of Eugenics

- Eugenics is Greek for “well born” or “good birth”.
- *“The study of agencies under social control that may impair or improve the racial qualities of future generations, whether physically or mentally.”*

Francis Galton 1887

Eugenics early history...

- Eugenics traces its roots to Britain in the early 1880s, when Sir Francis Galton coined the term to mean "well-born". Galton thought that biological inheritance of leadership qualities had determined the social status of Britain's ruling classes.
- In his view, nature was far more important than nurture in human development. Early in the 20th century, eugenics the American Breeders Association (ABA) focused on the presumed hereditary differences between human races, the ABA popularized the themes of selective breeding of superior stock, the biological threat of "inferior types," and the need for recording and controlling human heredity.



Early eugenics.....

- Financial support for the popularization of eugenics came both from individuals and foundations in America. ***The Race Betterment Foundation*** which sponsored a series of conferences in 1914, 1915, and 1928.

Early history.....

- By 1918, a group of socially prominent and influential men organized the Galton Society, the Society was concerned with presumed human racial differences and policies of differential breeding.
- This society brought together scientific and philanthropic leaders to popularize eugenics through a newsletter, the *Eugenical News*. Eugenics was also popularized through a series of International Congresses of Eugenics held in 1912, 1921, and 1932.
- After the second of these meetings, the American Eugenics Society (AES) was formed linking with Clergymen, Crime Prevention, Formal Education, and Selective Immigration.

The emergence of Eugenics ..

- Began early in the 20th century by the 1920s the United States became the world center of eugenic activity and social policy. Many other western countries including Canada followed suit.
- From 1907-1960 more than 100,000 Americans were sterilized in more than 30 states.
- Programs were established to purify the "race" of "lower grade" and "degenerate" people .
- This quickly gave impetus to profound racism and extreme discrimination of many by creating a new classification - the "genetically inferior."

Ideology....

- The eugenics movement, was rooted in assumptions of distinct and unique biological races; with *Anglo-Saxon Nordic* and *Teutonic* societies representing the superior and civilizing bedrock of society.
- Supporters of eugenics advocated policies of segregation, to protect the "well born" from contamination.
- Eugenics leaders believed that a variety of social successes (wealth, political leadership, intellectual discoveries) and social problems (poverty, illegitimacy, crime, mental illness, and unemployment) could be traced to inherited, biological attributes associated with "racial temperament."

Two types of Eugenics...

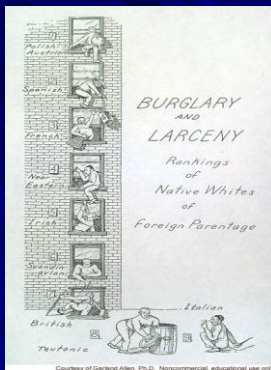
- **Positive Eugenics:** Creating incentives for those with desired traits to reproduce (example...cash bonuses, tax breaks)
- **Negative Eugenics:** Coercive laws to prevent those with undesirable traits from reproducing (example forced sterilization, execution, genocide)

In practice.....

- Grounds for sterilization included such classifications as "feeble-mindedness," "idiocy," "excessive masturbation," "immorality," and "hereditary degeneracy."
- For example "feeble-minded, unmarried women" were sterilized as a means of halting the "menace to the race at large."
- Sexual activity by single women was perceived as evidence of mental defect, irrespective of whether or not a patient met medical or psychological standards of "feeble-mindedness."

Eugenicists in North America strongly supported

- Strict limits on immigration from non-European countries.
- Sterilization of people perceived to be handicapped
- Restriction on welfare benefits to poor families.
- Bans on inter-racial marriage.



Eugenics in Canada

- Alberta's Sexual Sterilization Act of 1928
- Allowed forced sterilization of patients in psychiatric hospitals
- Nearly 3000 people sterilized, mostly of eastern European or Native and Metis descent
- Law repealed in 1972

Eugenics in Canada

- British Columbia also had similar law in effect from 1933-1979
- Sterilization approved of as means of controlling behaviour and ensuring "disability" not passed on to future generations

International links...

- In 1935, American eugenicist Charles M. Goethe praised the **Human Betterment Foundation** for "shaping the opinions of the group of intellectuals who are behind Hitler..."
- In 1936, Goethe acknowledged the United States and Germany as leaders in eugenics and described them as "*two stupendous forward movements*".

Eugenics internationally...

- By 1931, sterilization laws had been enacted in 27 states in the USA,
- By 1935 sterilization laws had been enacted in Norway, Sweden, Denmark, Switzerland and Germany.

Eugenics in Germany...

- In 1922, two men, a lawyer and a psychiatrist, (Karl Binding, J. D., and Alfred Hoche, M.D.) wrote a book entitled *Die Freigabe der Vernichtung lebensunwerten Lebens* (**Permission to Destroy Life Devoid of Value**).
- The book encouraged physicians who were, by now, beginning to practice euthanasia illegally.
- In the early stages eugenicists in other countries praised the Germans.









Third Reich

- Law for the Prevention of Genetically Diseased Offspring passed 1933
- Applied to people with Developmental delays mental illness, epilepsy, Huntington's disease, blindness, deafness, deformity and alcoholism
- Goal was health of the majority, eliminate burden of the weak

Third Reich

- Midwives and physicians registered all German children with birth defects with government
- Placed in special children's wards where they were killed with gradual overdose of Luminal
- Officials provided false causes of death to parents

Third Reich

- Healthy German mothers encouraged to have children
- Awarded gold, silver and bronze medals depending on number of healthy babies delivered and paid stipend (positive eugenics)

Contemporary Eugenics

- Genetic engineering, molecular biology
- Genetic termination
- Sex selection
- PGD (embryo screening) and genetic counseling

'Soft' Eugenics

- Can now detect carriers of genetic diseases
- Option to terminate pregnancy if embryo or fetus is predisposed to disease

Present day perspectives: The Case of Eve

- In the landmark case of *E. (Mrs.) vs. Eve* (1986), the Supreme Court of Canada set limits on the non-therapeutic and therapeutic sterilization of mentally incapable (incompetent) patients.
- While that case was decided more than 25 years ago, those limits still apply to medical practice today.

Background....

- The mother of Eve petitioned the courts to allow the sterilization of her daughter. The mother was almost 60 years old and a widow. Eve was 24 years old and mildly to moderately intellectually disabled. Eve did not understand the "consequential relationship between intercourse, pregnancy and birth," and was considered incapable of providing consent to sterilization.
- There was concern that she was developing a close relationship with a male student. Eve's mother feared Eve would at some point become sexually active and pregnant, with no one in the family able to assume responsibility and care for the resulting child.
- After a lower court decision refusing the request for sterilization and an appeal decision allowing it, the case was heard by the Supreme Court of Canada and decided in 1986.

Findings.....

- The Supreme Court considered issues such as: What was in Eve's best interest? Who can give consent for medical and surgical treatment of a mentally incapable person? What are the interests of society?
- The Court declared that sterilization should never be authorized for mentally incompetent persons for non-therapeutic purposes. Non-therapeutic here means the sterilization is for the purpose of contraception; therapeutic means the sterilization occurs as a consequence of the treatment of a disease.
- As well as applying to Canadian courts, this Supreme Court decision must be interpreted to also prohibit the ability of a parent or a substitute decision maker to authorize the sterilization of a mentally incapable person for non-therapeutic reasons.

Requests for non-therapeutic sterilization (not indicated for medical reasons)

Because of concerns about sexual activities, parents or substitute decision makers responsible for a person mentally incapable of providing consent may ask a physician to sterilize the person. They believe they are acting in the interests of the person.

Although the Eve decision was about the sterilization of females (e.g., tubal ligation), the same limitations would be expected to apply when dealing with requests for sterilization of males (e.g., vasectomy) who are mentally not capable.

Requests continued...

- **Requests for non-therapeutic sterilization should be refused.** Compliance to sterilization in these circumstances will expose a physician to serious medico-legal difficulty. ***Even when the parents or guardians of a patient have consented to the procedure,*** other parties can initiate legal actions or complaints to a regulatory authority (College) on behalf of the mentally incapable patient.

Capacity, what does it mean?

- A person who is able to understand the nature and anticipated effects of a proposed treatment and available alternatives, and appreciates the consequences of refusing treatment, is generally considered to have the necessary capacity (competence) to give valid consent.

THE NUREMBERG CODE

- The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision.

SPC Parent Enhancement Program

- Multiple referral sources.
- "Only show in town" at this point.
- Voluntary program.

Challenges

- Can be limited or fixed income...
- Challenges with planning, organization, problem solving
- Isolation
- Multiple children (single child the exception)

Challenges

- May be more likely to be victimized
- May include dual diagnosis

Case study

- 33 year old woman, ODSP subsidized housing
- 3 children one more on the way, all different fathers; none of which are present or involved
- Great problems with problem solving and organization

Case study continued

- Oldest boy 7 ADD
- Second child girl 6 managing fairly well in school quiet , needs of her siblings often trump for attention provided.
- 18 month old child, speech delay query Autism

Case continued...

- "Borderline coping" 4th child may be tipping point.
- Report pregnancy to child welfare?

The challenges of Advocacy

- Does client advocacy trump child welfare advocacy?
- Agents of child welfare staff?
- Aligned with Child welfare?
- Some professional distance from Child welfare required?

Client Advocacy may not always fit well with Child welfare

- The administration of assessments and testing when child welfare wish to use them.

Fertility assistance provided?

- No categorical rules about peoples cognitive disabilities applied; must be looked at case by case and be grounded in ability to care for a child rather than a diagnosis or label itself.

Reproductive rights/reproductive freedoms

- Inherent to all Canadians
- Must meet threshold for ability to understand and appreciate any choices related to fertility/reproduction
- Substitute decisions (SDM) not applicable in this case
