



**DEPARTMENT OF
ADMINISTRATION**

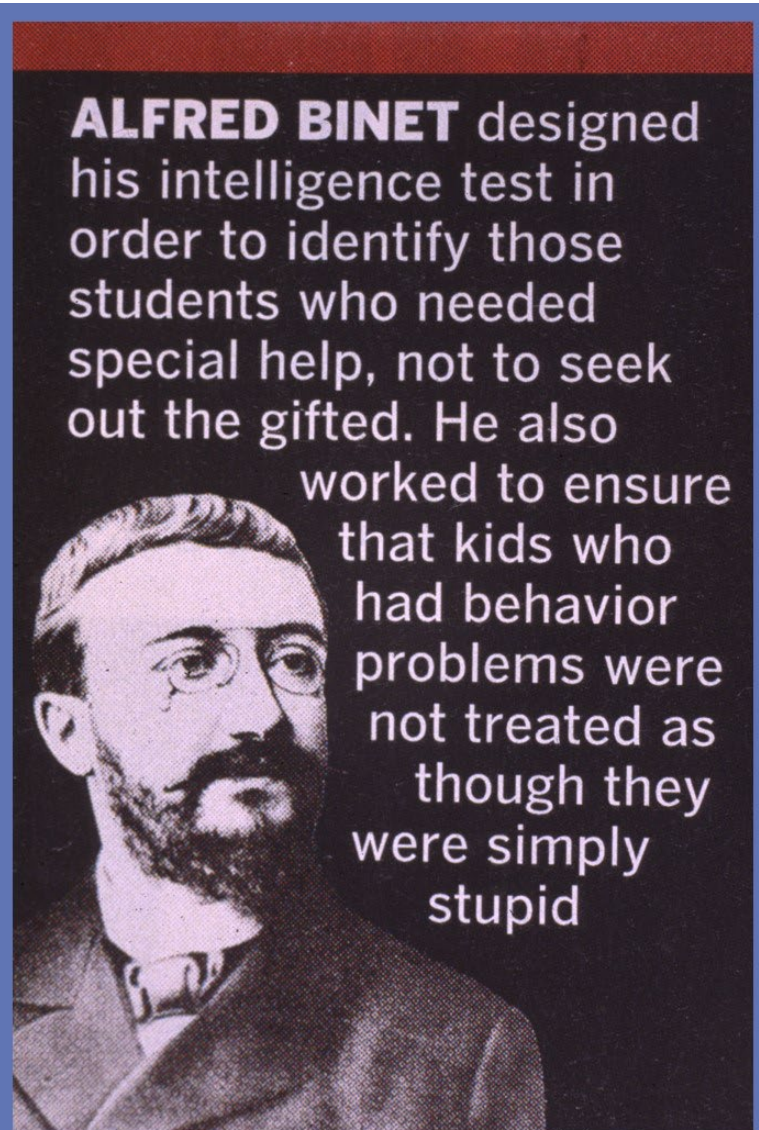
COUNCIL ON DEVELOPMENTAL DISABILITIES

Our History Part 2

Colleen Wieck, Ph.D., Executive Director

Minnesota Governor's Council on Developmental Disabilities

Alfred Binet – Early 1900s



Binet's Rules

At the beginning of the 1900s, Alfred Binet and Theodore Simon from France designed an intelligence test. Binet had three rules:

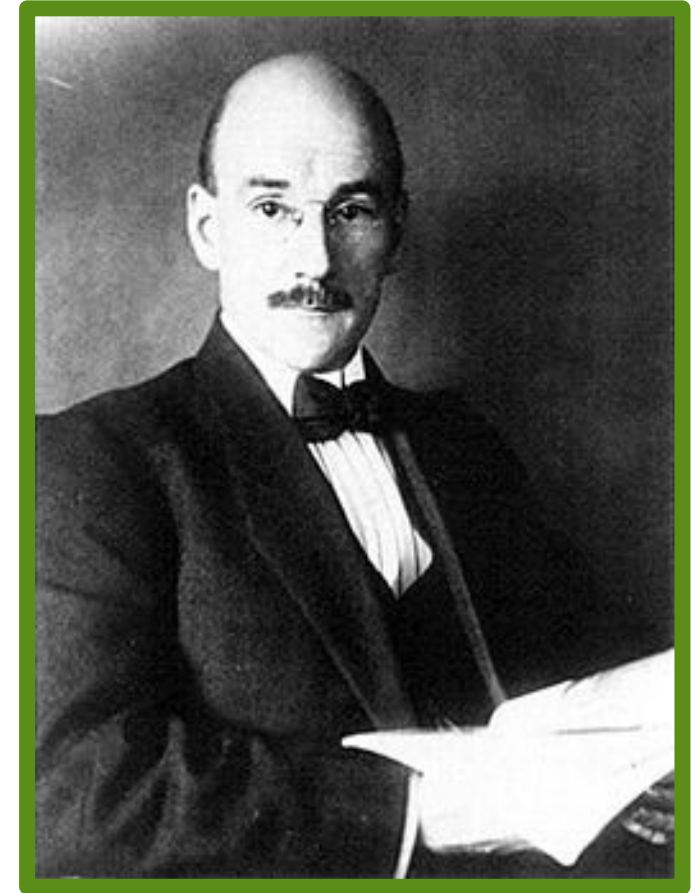
1. The scores do not define anything permanent.
2. The scale is a rough guide for identifying and helping children. It is not a way of measuring normal children.
3. Low scores do not mean a child is innately incapable.

We have violated every one of Binet's rules.

The test was imported to the U.S. Henry H. Goddard translated the scale in 1908. He standardized the test on 2,000 students in 1911 and then distributed 22,000 copies of the scale nationally.

Dr. Goddard believed that low IQs were caused by a single recessive gene, and therefore, we:

1. Must prevent breeding of feeble-minded people.
2. Need compulsory sterilizations.
3. Need institutions.



Immigration

There were several events coming together...the first was a large wave of immigration from eastern Europe which caused fear for jobs. Congress passed laws to regulate immigration, which prevented anyone who had a disability from entering the US.

Those restrictions changed in 1965.



Trendline

Tighter Immigration Laws

- 1882 No convicts, lunatics, idiots or someone unable to take care of himself/herself.
- 1891 No idiots, insane persons, paupers or persons likely to become a public charge, loathsome or contagious diseases, felons.
- 1917 No idiots, imbeciles, feeble minded, epilepsy, insane, alcoholics, paupers, felons, anarchists, or tuberculosis.

A child of 6 years can identify which face is prettier when given a pair of faces to compare.

A child of 7 years can identify the missing body parts.



Test Question

For Whom: 11-year mental age

Instructions: Put words into a sentence (Binet-Simon Test, revised)

Timing: You have 2 minutes

1. The for at an early hour we park started.
2. To asked lesson my I have teacher correct my.
3. A defends good dog his master bravely.

Paper and Pencil Test

F

With your pencil make a dot over any one of these letters **F G H I J**, and a comma after the longest of these three words: boy mother girl. Then, if Christmas comes in March, make a cross right here but if not, pass along to the next question, and tell where the sun rises If you believe that Edison discovered America, cross out what you just wrote, but if it was someone else, put in a number to complete this sentence: "A horse has feet." Write yes, no matter whether China is in Africa or not, and then give a wrong answer to this question: "How many days are there in the week?" Write any letter except G just after this comma,

In 1913 the U.S. Public Health Service administered the IQ test to a sample of immigrants. They concluded that 79% of Italians, 80% of Hungarians, 83% of Jews, and 87% of Russians were feebleminded.

Deportations increased 350% by applying Goddard's 2-step process of Visual Inspections:

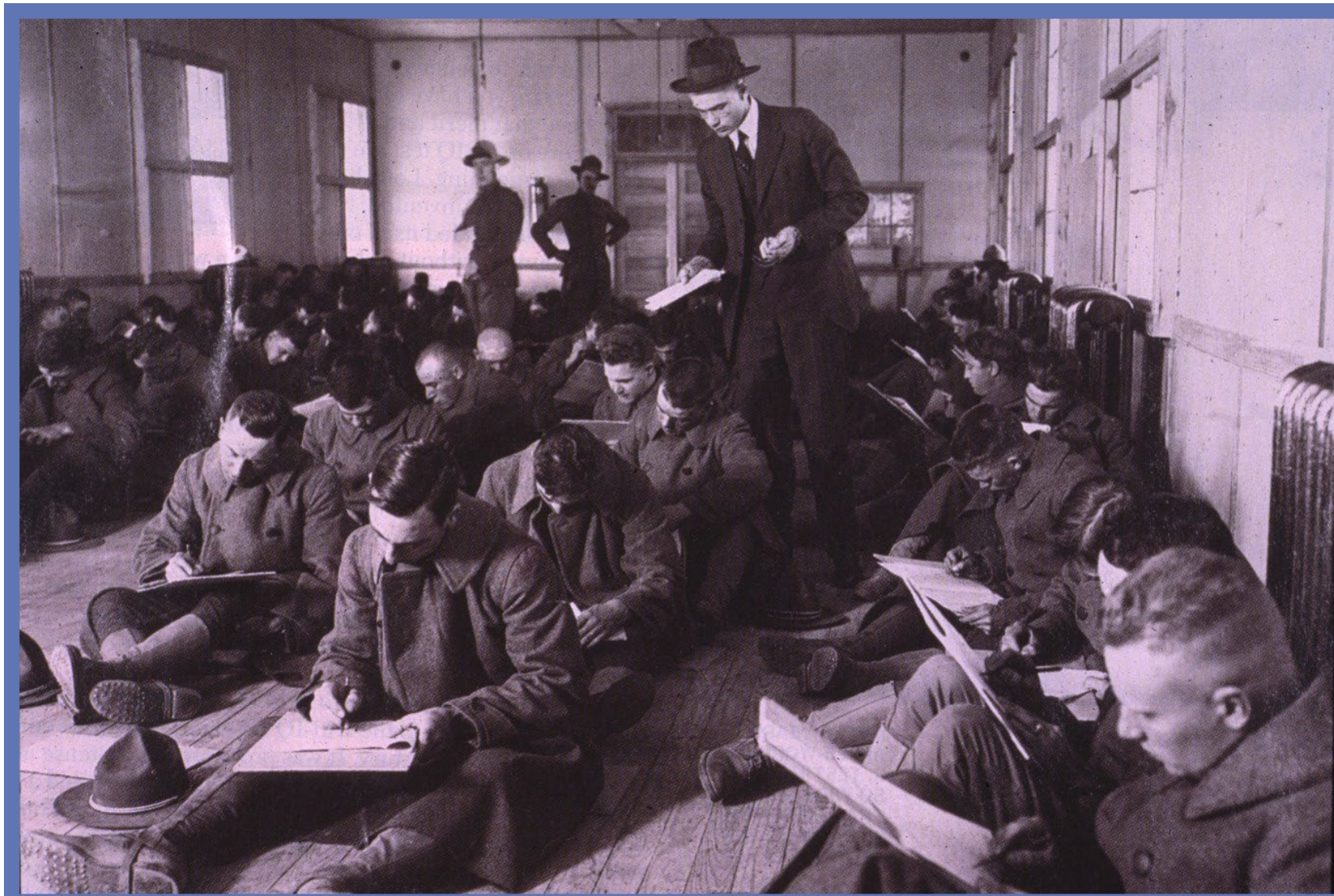
1. "You look defective;" with
2. A formal intelligence test.

Deportation



Over 5,000 people were entering Ellis Island daily.

Rather than challenging whether the tests were valid, people assumed the results were correct.



U.S. Army Testing

In 1917 Goddard worked with Psychologist Robert Yerkes to test 1.75 million Army recruits using the Army Alpha and Beta exam. It was a paper and pencil test administered by group. If you failed the Alpha test, then you took the Beta test.

❖ They concluded that 40% of white men are feeble-minded.

“IQ is derived by dividing Mental Age by Chronological Age.”

William Stern, German
Psychologist and Philosopher

Stern was influenced by the work of Binet's studies of intelligence in children. As a result, Stern developed the idea of expressing intelligence test results in **the form of a single number:**

- The Intelligence Quotient.



TYPES OF TESTS FORMERLY USED IN DIAGNOSING FEEBLE-MINDEDNESS

These tests failed to meet the demands of practicability, for they measured mental ability only indirectly and individual variations in performance proved excessive. For illustrations of the more recently developed tests consult case studies, pages 80-192.

LEFT. Ataxiograph, or Romberg test, designed to measure equilibrium. Experimental results indicate, in general, that normal subjects sway forward and back (eyes closed) and feeble-minded subjects sway sideways. The test is frequently used in cases of nervous disorder.

RIGHT. Stereognosis, recognition, or failure to recognize (astereognosis), by the sense of touch alone. Mental defectives are rather strikingly inferior in this ability. The test is of some service with the lower grades of mental defect but not with morons.

Romberg Test

The Romberg Test was created by the German neurologist, Moritz Romberg, and was used to measure equilibrium.

- If a person closes his/her eyes, a normal person sways backward and forward while a person thought to be feeble minded sways from side to side.

Another IQ test was based upon touch.

- Those with the lowest IQs had the hardest time identifying household objects by touch.



SOCIAL DIAGNOSIS BY HOUSES

Typical habitations of feeble-minded families. Would that we might present views of the interiors! One must not, however, confuse the living habits of different races and nationalities with those of mental defectives.

LEFT. Hut in the Pines of New Jersey inhabited by American whites. The woman in the doorway is a high-grade imbecile, and the little girl is one of her potentially feeble-minded children.

RIGHT. Mountain home of "Old John" and his family in the hills of the Delaware Water Gap. John is a high-grade imbecile and his wife is a middle-grade moron, both American whites. The known children of the family are all defective, and each daughter has a record of immorality. The little girl in the foreground is one of John's illegitimate grandchildren.

Drive by Tests

The “**Drive by Test**” determines whether you are feeble-minded based on where you live. The caption reads:

1. (On the left) Hut in the Pines of NJ. The woman is a high grade imbecile, the little girl is potentially feeble-minded.
2. (On the right) Mountain home of old John and his family. John is a high grade imbecile, his wife is a middle grade moron, and each daughter has a record of immorality.



Isolated Families

Genetic Feeble-mindedness

UNFIT HUMAN TRAITS
SUCH AS FEEBLEMINDEDNESS
EPILEPSY, CRIMINALITY,
INSANITY, ALCOHOLISM,
PAUPERISM AND MANY OTHERS,
RUN IN FAMILIES AND ARE
INHERITED IN EXACTLY THE
SAME WAY AS COLOR IN
GUINEA-PIGS. IF **ALL**
MARRIAGES WERE **EUGENIC**
WE COULD **BREED OUT**
MOST OF THIS UNFITNESS
IN **THREE GENERATIONS.**

THE TRIANGLE OF LIFE



YOU CAN IMPROVE YOUR **EDUCATION**,
AND EVEN CHANGE YOUR **ENVIRONMENT**;
BUT WHAT YOU REALLY **ARE** WAS ALL
SETTLED WHEN YOUR **PARENTS** WERE
BORN.
SELECTED PARENTS WILL HAVE
BETTER CHILDREN **THIS**
IS THE GREAT AIM OF **EUGENICS**

Poor People



SOCIAL TYPES OF FEEBLE-MINDEDNESS



SOCIAL TYPES OF FEEBLE-MINDEDNESS

Low IQs

Mixed marriages among races were outlawed because researchers at Stanford University had conducted IQ tests on children from mixed marriages, and concluded that children would have disabilities.

Goddard Table

INDUSTRIAL CLASSIFICATION OF MENTAL DEFECTIVES IN RELATION
TO MENTAL AGE AND TYPE (GODDARD)

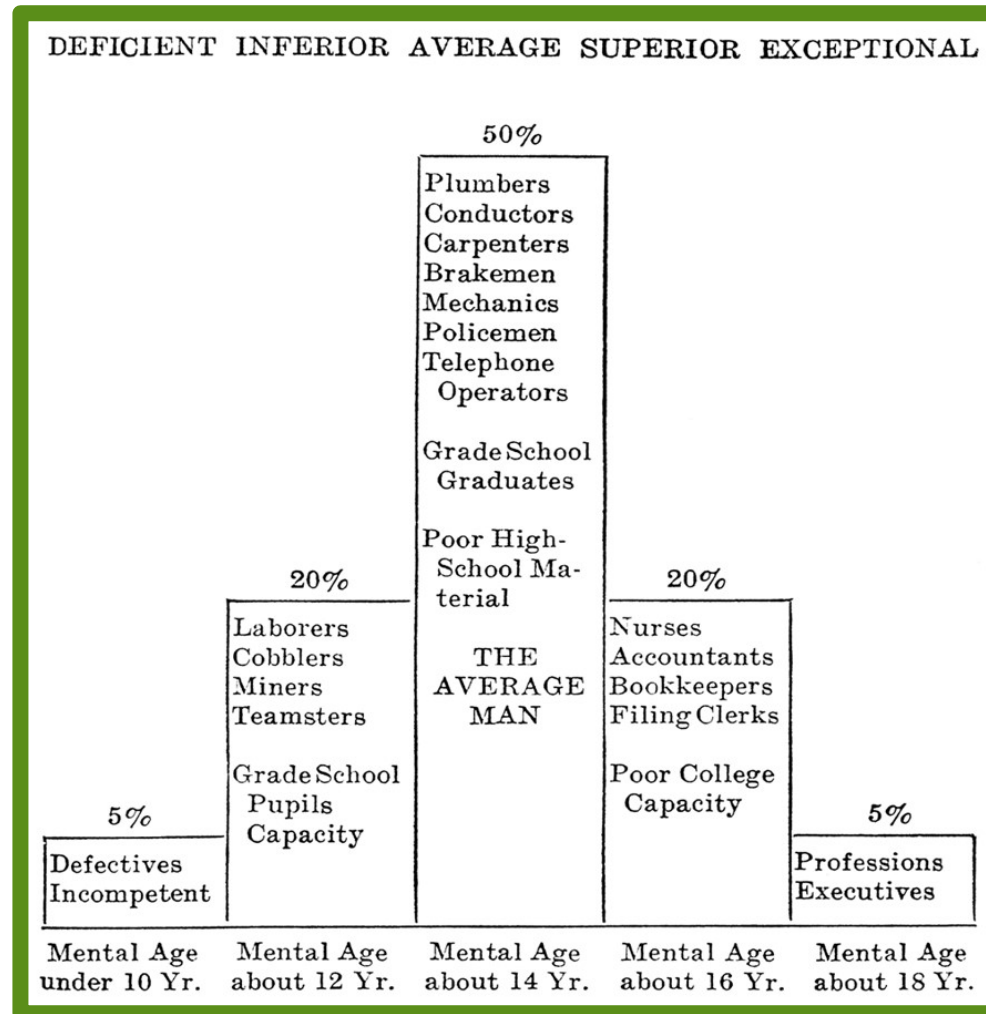
Mental Age	Industrial Abilities	Type	
Under 1 yr.	(a) Helpless (b) Can walk (c) With voluntary regard	Low	Idiot
1 yr.	Feeds self. Eats everything.	Middle	
2 yrs.	Eats discriminatingly.	High	
3 yrs.	No work. Plays a little.	Low	Imbecile
4 yrs.	Tries to help.		
5 yrs.	Only simplest tasks.	Middle	
6 yrs.	Tasks of short duration. Washes dishes.	High	
7 yrs.	Little errands in the house. Dusts.		
8 yrs.	Errands. Light work. Makes beds.	Low	Moron
9 yrs.	Heavier work. Scrubs. Mends. Lays bricks. Cares for bath-room.		
10 yrs.	Good institution helpers. Routine work.	Middle	
11 yrs.	Fairly complicated work with only occasional oversight.	High	
12 yrs.	Uses machinery. Can care for animals. No supervision. Cannot plan.		

The previous slide shows the combination of IQ with the belief that someone could predict the future of a person based upon their test score.

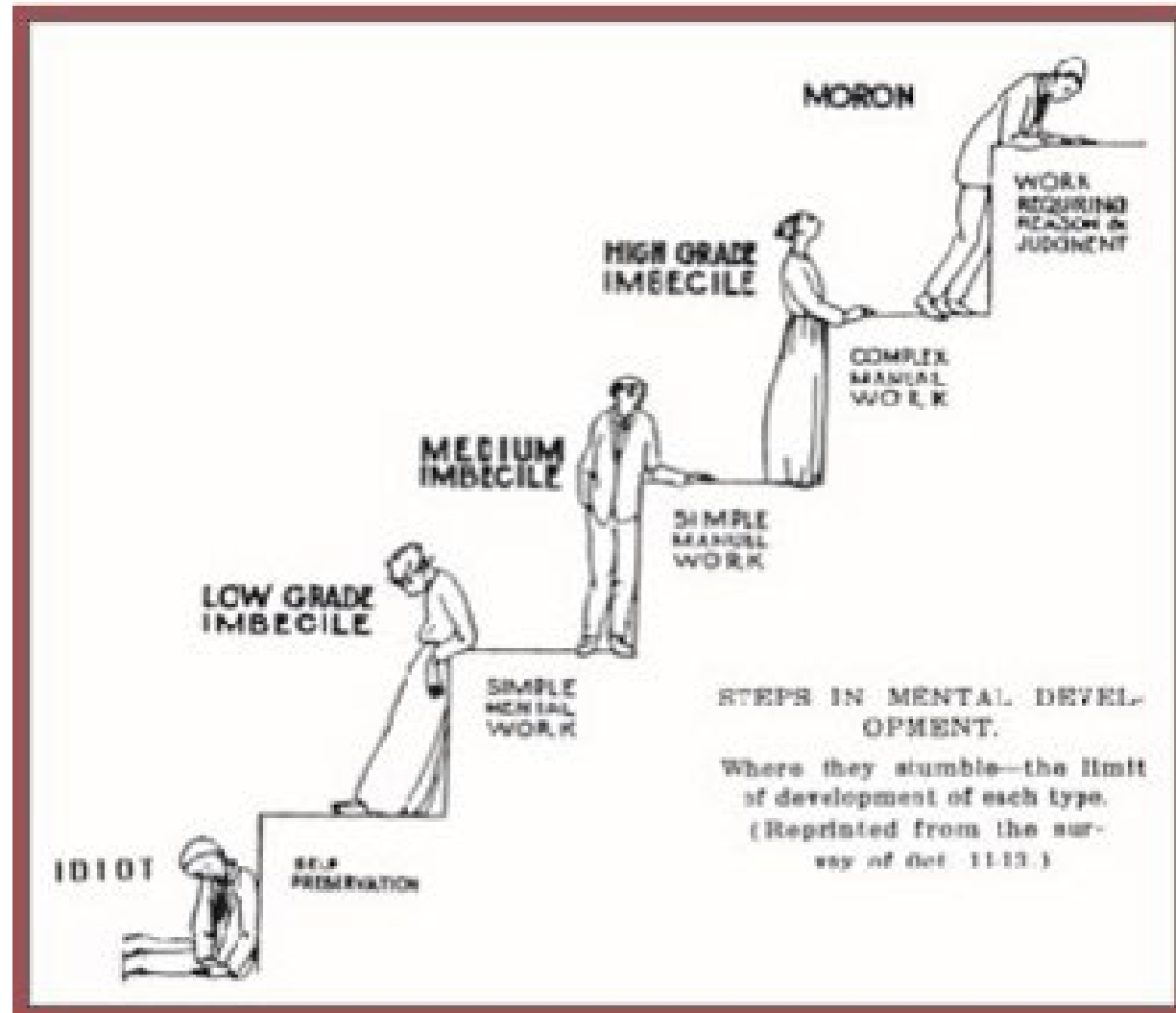
Every person in this room is still experiencing this chart in different forms.

Under 1 year, a person is helpless; a 5 year mental age is simple tasks; a 10 year mental age is a good institutional helper.

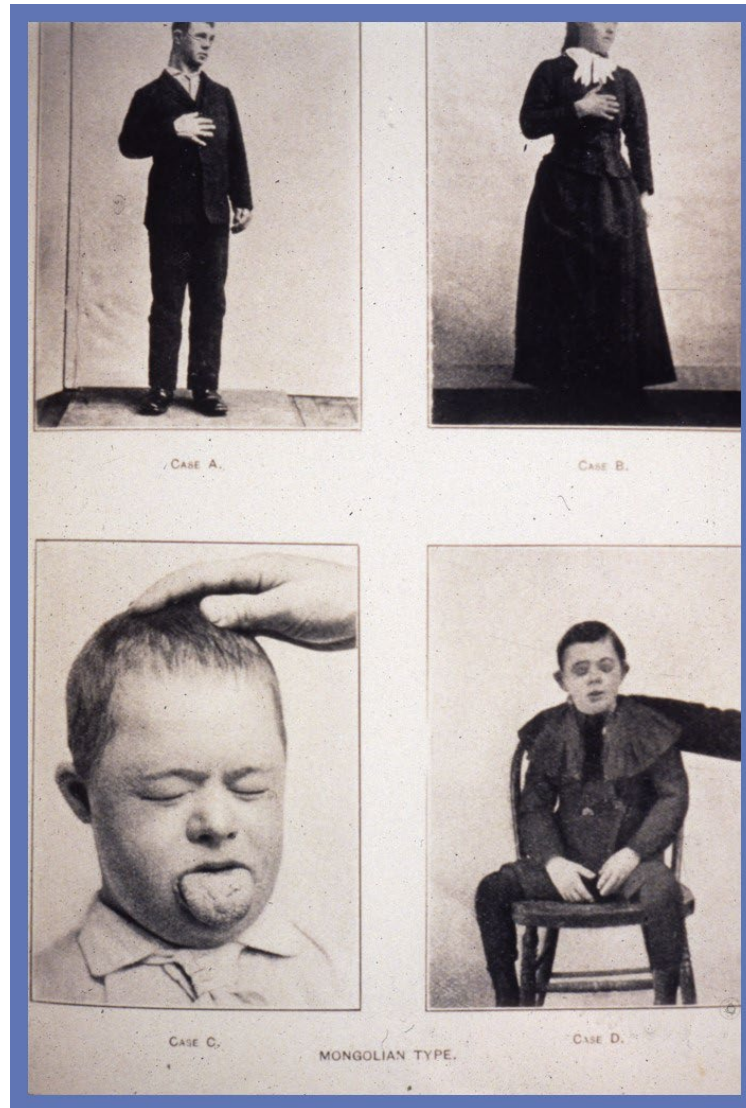
Normal Curve



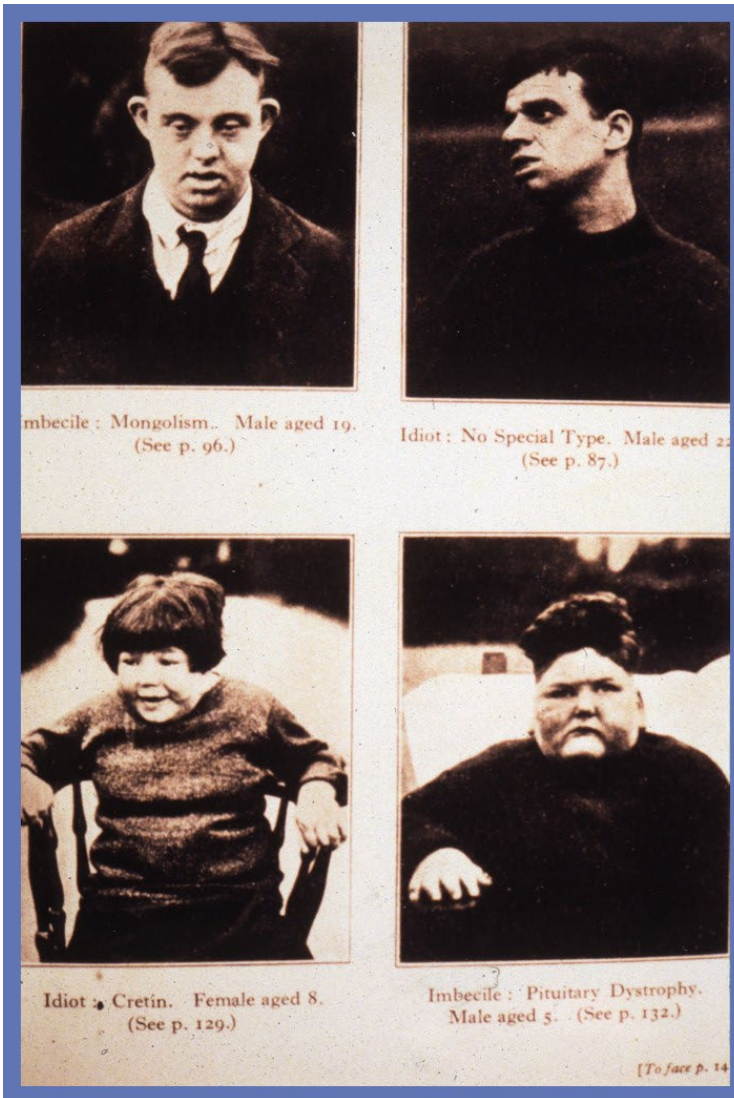
Continuum of Employment

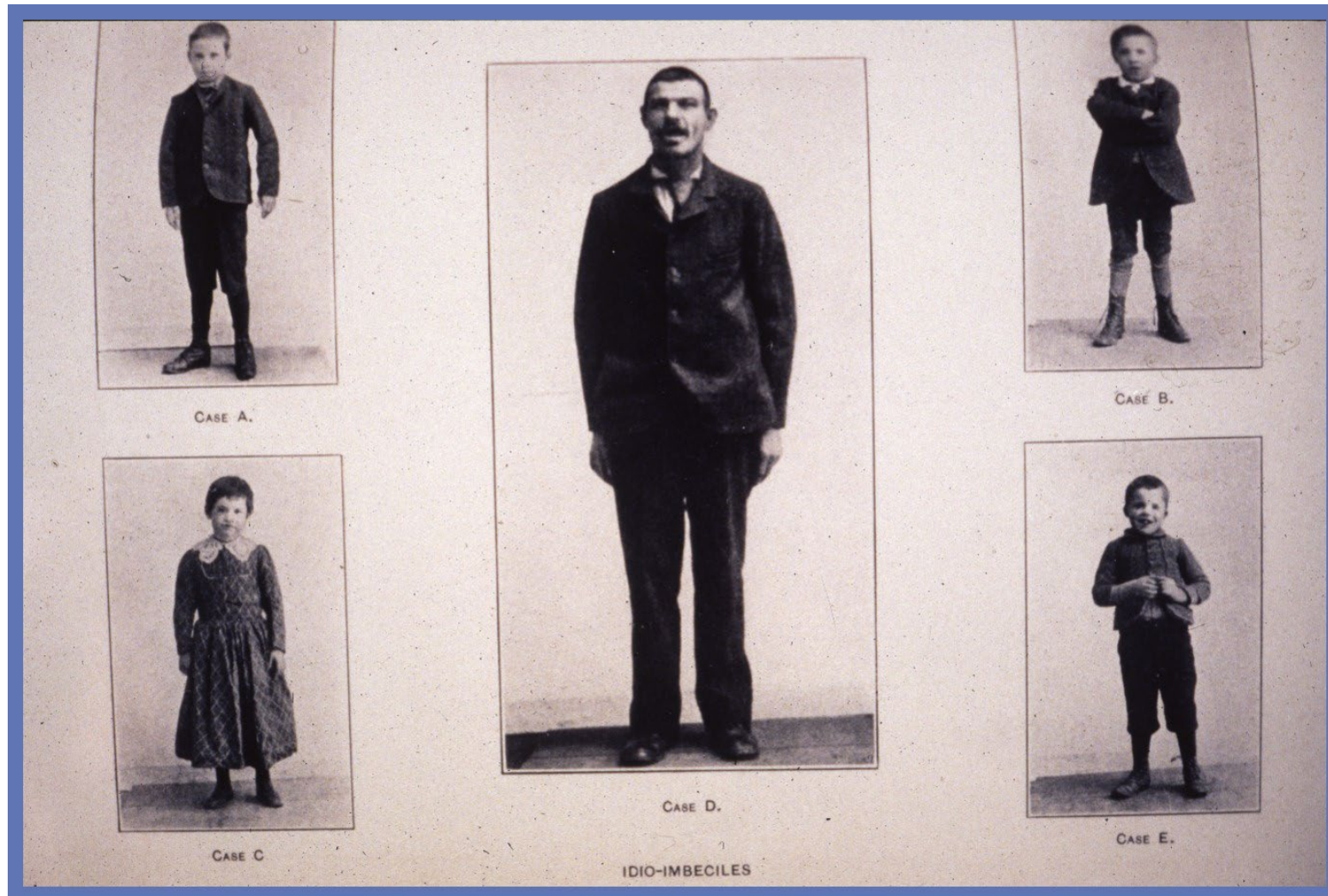


Visual Diagnosis



Photos of a Variety of Disabilities

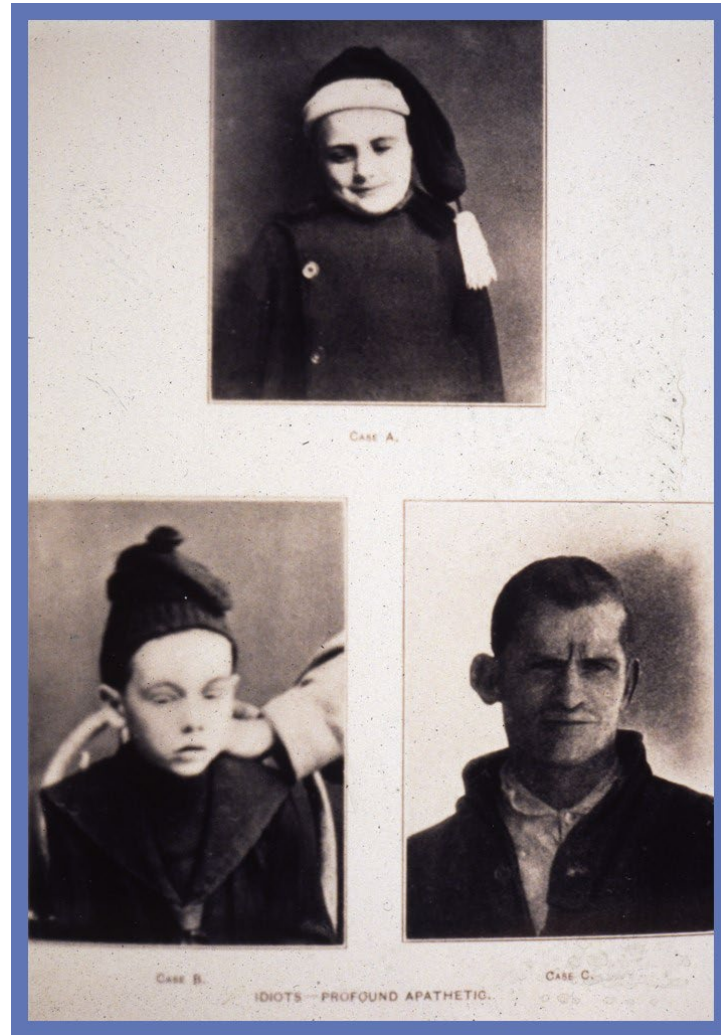




Moral Imbeciles with Lowest IQs



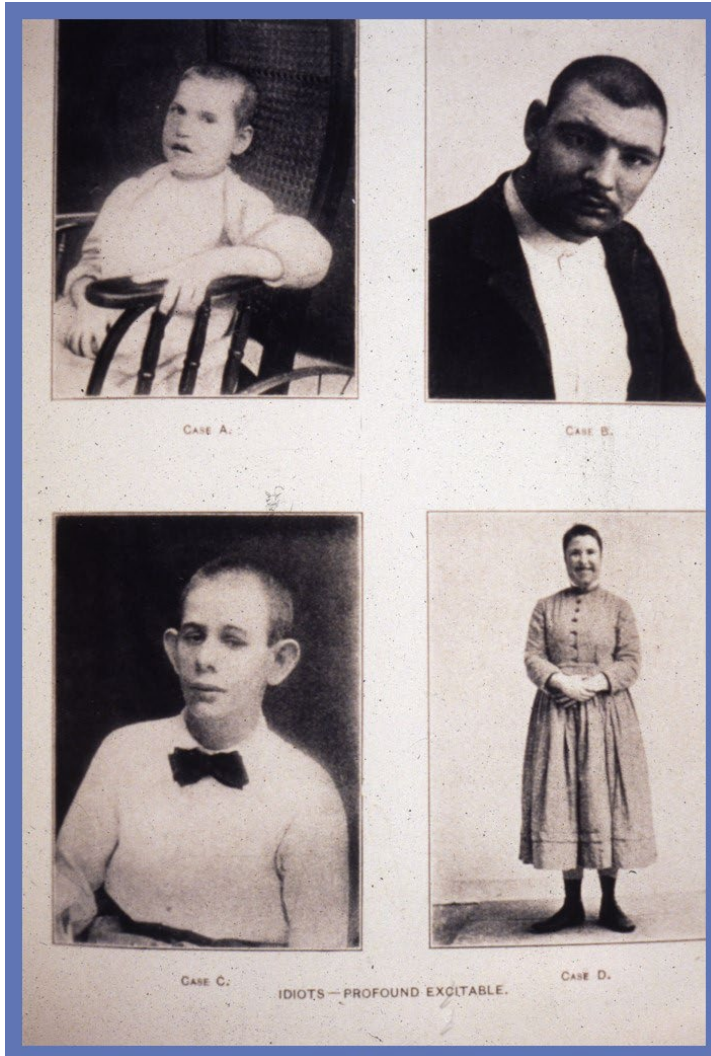
Lowest IQs and Apathy



Lowest IQs and Superficial Apathy



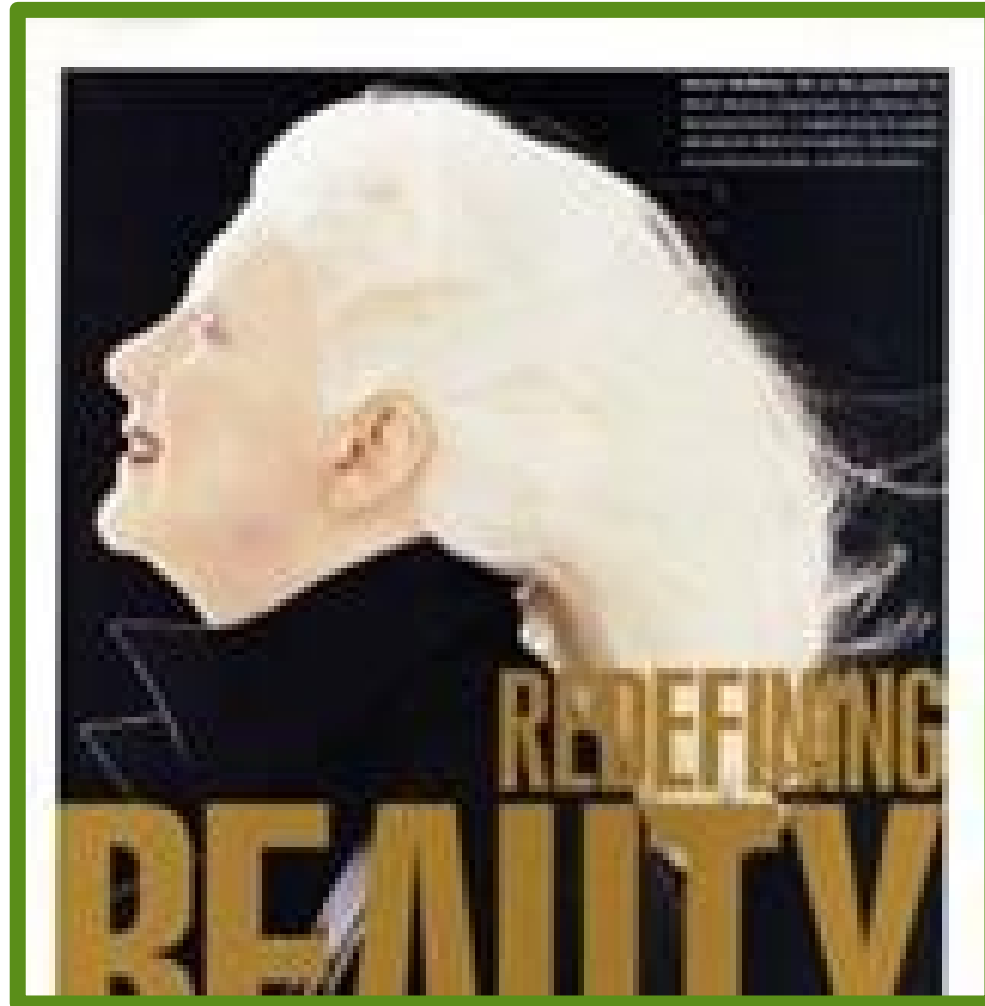
Lowest IQs and High Excitability



Higher IQs



Redefining Beauty



Melrose Child Murder Shows Menace of Mental Defective

Thirteen Thousand Such People at Large in This State
—Legislators Apparently Indifferent to
Protecting Public.

Criminals have disabilities

The spillover from the field of psychology and the professional literature went directly to the general media in the belief that criminals were people with disabilities.

The headline reads, “Melrose Child Murder Shows Menace of Mental Defectives, 13,000 such people at large in this state – Legislators apparently indifferent to protecting public.”

*(Think of what has happened. At first, we wanted to help people.
Now we want to lock them up).*

The themes are (a) PITY and (b) MENACE.



Jukes

Juke Family Study, 1874

- New York State “hill family” in jails—
 - Environment determines criminality, disease and poverty, so we must improve living conditions.
- The “family” of 42 different families related by blood cost the state millions of dollars.

Star Tribune (2013)

“‘Minneapolis Crime Families’ Claim True in General”

“Officials, community members concur with the
mayoral candidate’s theory to some degree.”

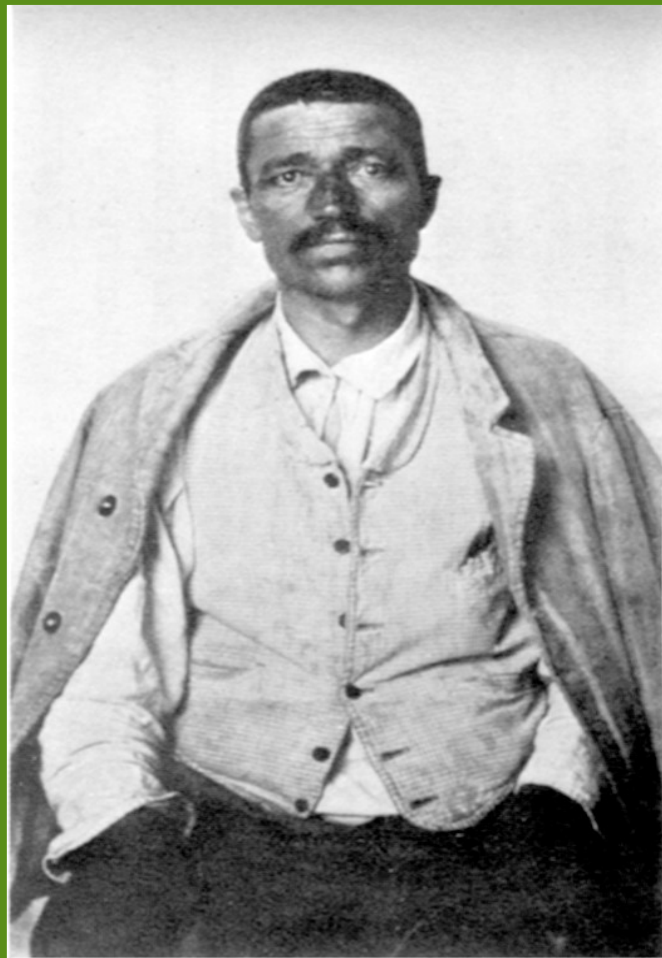
The claim that six families or groups are responsible for the bulk of the crime in Minneapolis has been a consistent theme of a mayoral campaign in Minneapolis, repeated at numerous forums and events throughout the summer.

- “Top law enforcement officials and community members said there is some truth to it, particularly with some families passing crime from one generation to the next.”

Delinquency and Feeble-mindedness

1. Feeble-mindedness leads to delinquency.
2. The great majority of criminals are feeble-minded.
3. A policy of sterilization and segregation is the only effective method of preventing crime.

Head and Ear of a Criminal

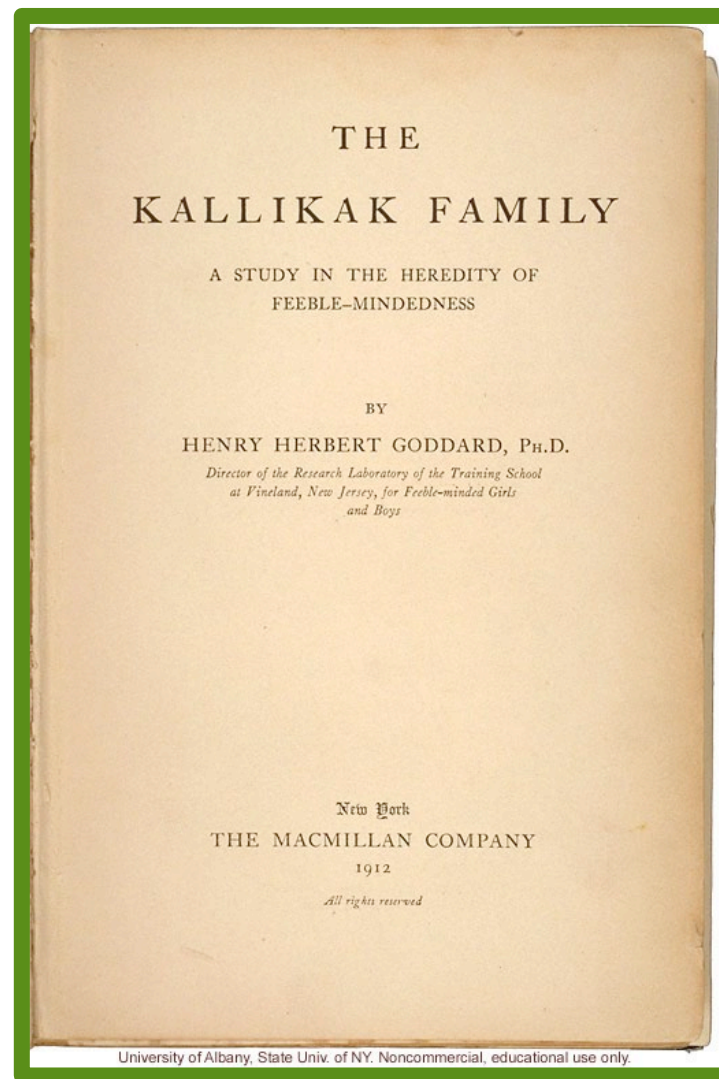


HEAD OF A CRIMINAL
Epileptic



Criminal's Ear

The Kallikak Family



The Heredity of Feeble-mindedness

The menace theme hit a peak in the early 1900s when Dr. Goddard declared that heredity is more important than the environment in determining disability.

The Kallikak Family was published in 1912.

- The name Kallikak is a pseudonym. Goddard came up with it by combining the Greek words for “good” and “bad.”

He used the case study and complicated family tree of Deborah Kallikak (real name Emma Wolverton).

Deborah's great great grandfather, Martin Sr., had been a soldier in the Revolutionary War. At age 15 Martin had relations with a feebleminded bar maid in 1774. From that side of the family tree came 480 descendants, mostly feebleminded, illegitimate, alcoholics, prostitutes, and criminals.

- Of the 480 descendants, only 46 were considered normal.

Good Families and Bad Families

After the war, Martin, Sr. married an upstanding Quaker woman from Philadelphia. With this woman, they had 496 descendants. None of the good side of the family tree were mentally deficient. Only one or two showed any problems.

This family is the natural experiment.

- **Feeble-mindedness is the cause of all social problems.**

Goddard said there are Kallikak families all around us.

- **They multiply at twice the rate of the general population.**

"A Remarkable Human Document — A Record of Astonishing Interest"

THE KALLIKAK FAMILY

A STUDY IN THE HEREDITY OF FEEBLE-MINDEDNESS

By HENRY H. GODDARD

Director of the Research Laboratory of the Training School at Vineland, N. J., for
Feeble-Minded Girls and Boys

Cloth, 8vo, \$1.50 net

A FEW OF MANY NOTABLE COMMENTS

"This history is the most important one that exists as an exposition of the transmission of feeble-mindedness through many generations."

— *Johns Hopkins Hospital Bulletin.*

"Dr. Goddard's book gives the thoughtful reader much food for reflection. It demonstrates most forcibly that the feeble-minded in our midst constitute a distinct menace to our social life." — *Medical Times.*

"No more striking example of the supreme force of heredity could be desired."

— *The Dial.*

"The most illuminating and complete of all the studies in heredity that have ever been made, with the view of showing the descent of mental deficiency."

— *Bulletin of The Medical and Surgical Faculty of Maryland.*

"This is the most convincing of the sociological studies brought out by the eugenics movement." — *The Independent.*

"The book is an exceedingly important monograph and will be of interest to all students of heredity and eugenics as well as to social workers and reformers."

— *Social Diseases.*

"Dr. Goddard has made a find; and he has also had the training which enables him to utilize his discovery to the utmost." — *American Journal of Psychology.*

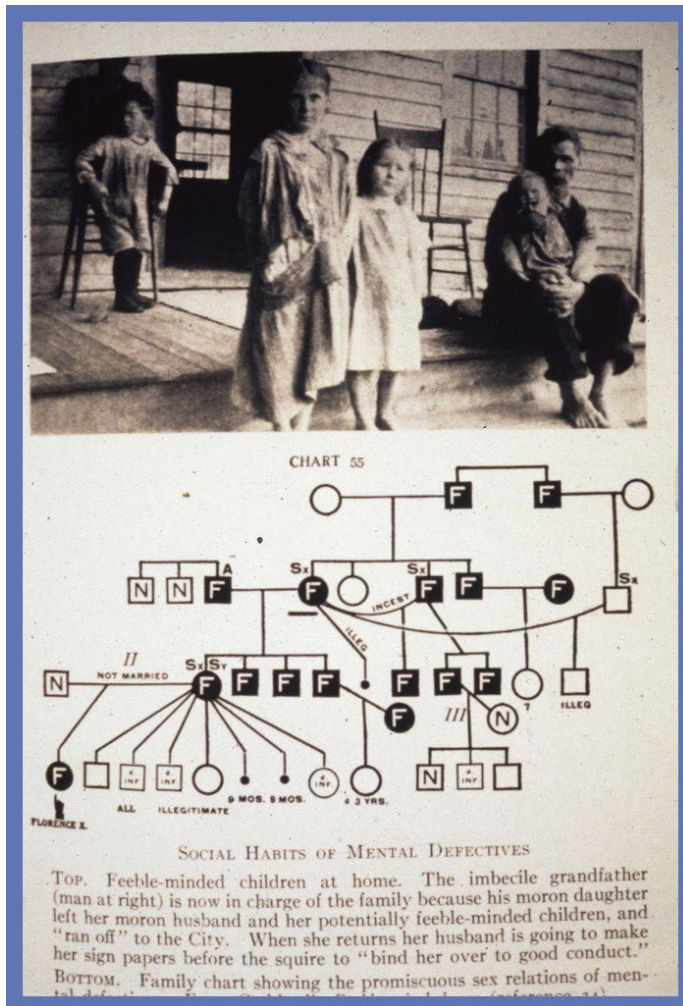
THE MACMILLAN COMPANY

Publishers 64-66 Fifth Avenue New York

Eugenics

We now enter the Eugenics Period, which leads to sterilization and deaths of people with disabilities.

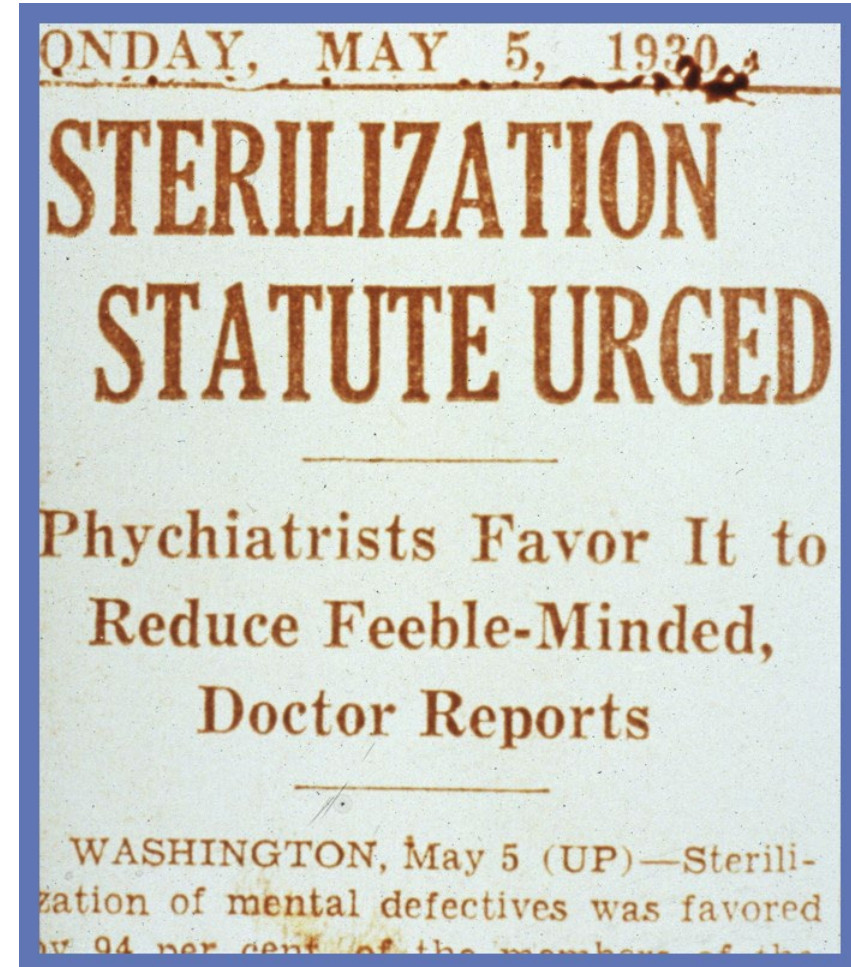
Eugenics means building a better human race by preventing unfit people from having children and encouraging those who are brightest to reproduce.



Sterilization Statutes

Goddard's work was used to pass legislation calling for mandatory sterilizations before release from any placement. Beginning with Indiana, 33 states passed similar laws until the 1980s.

In 1985, 19 states still had sterilization statutes.



Types of Sterilizations

In the beginning, men were castrated, and women were given hysterectomies or tubal ligations.

By the 1970s, people leaving institutions were given experimental birth control methods (probably without informed consent).

In 1922, Dr. Walter Fernald declared that 90% of feeble-mindedness was contributed by 5% of the families in the community.

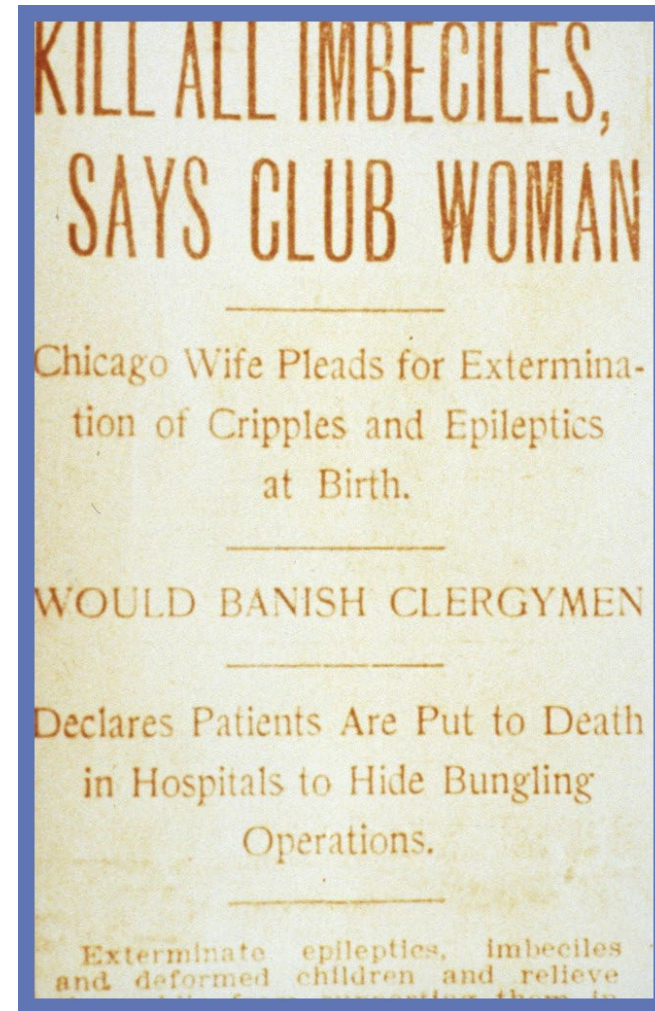
EUGENIC MARRIAGES

State Must Prohibit Wedlock f

The Feeble-Minded, Asserts

Dr. Walter E. Fernald

According to this headline, an infant born with disabilities or epilepsy should be “exterminated.”



Buck v. Bell

The U.S. Supreme Court was asked to rule on the constitutionality of forcible sterilizations in *Buck v. Bell*, 274 U.S. 200 (1927).

17-year old Carrie Buck was the first American woman to be involuntarily sterilized by law to stop the degeneration of the human race.

Dr. John Hendren Bell issued the order for Buck to be sterilized at the Virginia State Colony for Epileptics and Feeble-minded.



The Buck Background

Carrie was born out of wedlock to Emma, who had previously been committed to a Virginia asylum. Carrie was taken away as a baby, and placed in foster care. At age 17, she was sexually assaulted by a nephew of her foster parents, and became pregnant. Shortly after Carrie gave birth to Vivian, Carrie was committed to the Virginia Colony asylum herself. At 7 months, Vivian was also diagnosed as feeble-minded.

Officials at the asylum asserted that Carrie and Emma shared the hereditary traits of feeble-mindedness and sexual promiscuity. Doubtless, Vivian would eventually, too.

The psychologist described the family as a “shiftless, worthless class of Southern Whites.”

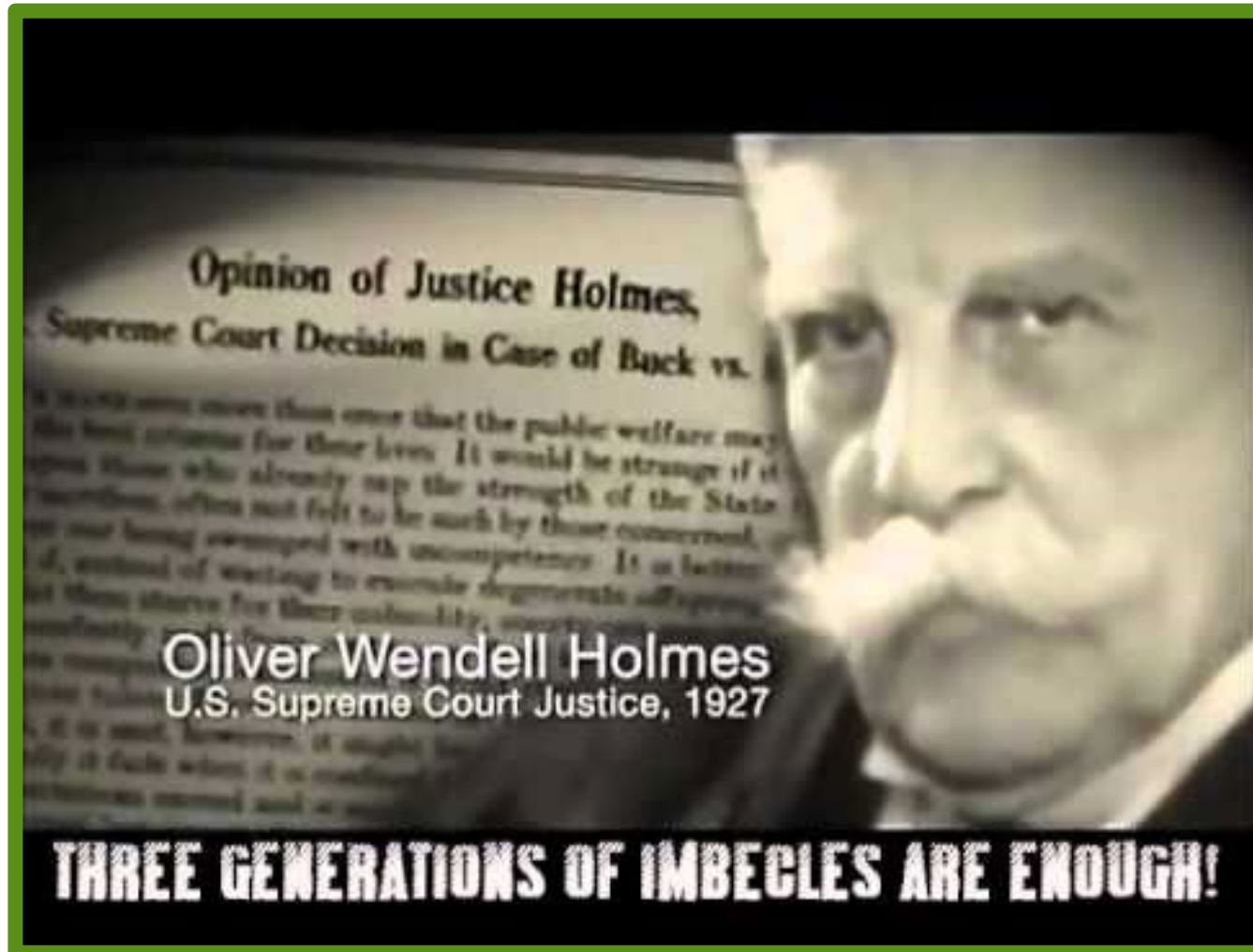
The Supreme Court Decision

On May 2, 1927, in an 8-1 decision, the U.S. Supreme Court upheld the constitutionality of the Virginia Eugenical Sterilization Act of 1924.

Justice Oliver Wendell Holmes, Jr. wrote the opinion. He stated that the interest of the public welfare outweighed the interest of individuals in their bodily integrity. He wrote about how the public welfare was sapped by the feeble-minded, and called upon them to make this “lesser sacrifice” in order that all of humanity not be “swamped by incompetence.”

“The principle that sustains compulsory vaccinations is broad enough to cover cutting the Fallopian tubes.”

Three Generations



In *Buck v. Bell*, the U.S. Supreme Court infamously stated that “society can prevent the unfit from continuing their own kind.”

This statement was read at the Nuremberg trials.

- The State of Virginia issued an apology to all those it had sterilized. North Carolina, Oregon, and other states soon followed.

What are some recent stories about sterilization?

Sterilization of Woman – 1994

The New York Times

SUNDAY, NOVEMBER 13, 1994

U.S. Ruling To Permit Sterilization Of a Woman

PHILADELPHIA, Nov. 12 (AP) — A Supreme Court Justice has refused to bar the sterilization of a severely retarded woman whose mother had sought for years to have her daughter sterilized.

But a legal guardian for the retarded woman, Cindy Wasiek, a 26-year-old with the mental capacity of a 5-year-old, has vowed to appeal the case to the full Supreme Court, even if it is too late to stop the sterilization.

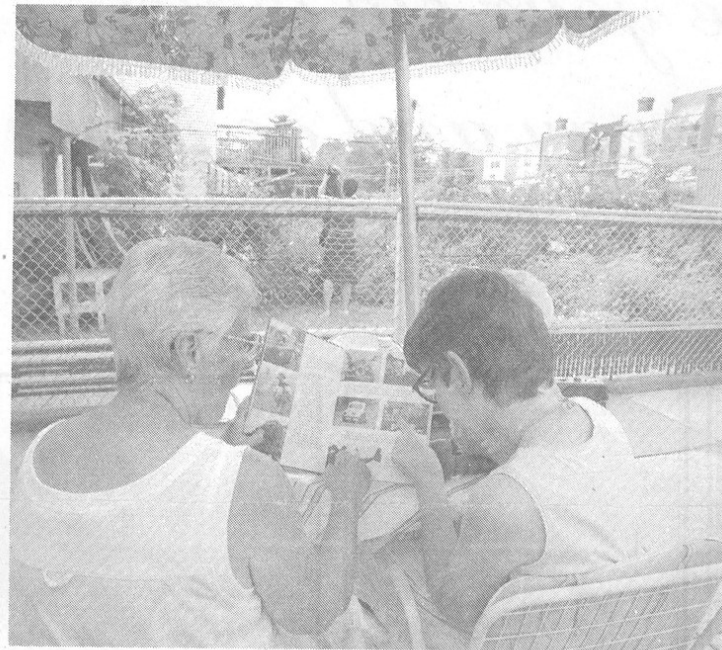
"There are such important issues at stake," the guardian, Lorrie McKinley, said after the decision by Justice David H. Souter on Friday. Ms. McKinley argues that the operation is unnecessary and would set back the rights of retarded people to maintain control of their own lives.

The mother of the retarded woman, Delores Wasiek, said she had been seeking the surgery since 1987 because she feared her daughter could become pregnant. Mrs. Wasiek says she is planning to go ahead with the surgery but is not sure how soon the operation can be performed.

"It's not like having a tooth pulled," she told The Philadelphia Inquirer. "It isn't something we would run right out and do. Cindy would need all of the workups and blood work. It would be at least weeks before we could have it done."

Even Lawyers Feel Bad

SAN FRANCISCO, Nov. 12 (AP) — Sixty-three percent of the lawyers in California say that there are too many of them, a survey conducted by the California State Bar and the Commission on the Future of the Legal Profession has shown. In addition, fewer than half of the lawyers questioned said that most lawyers have high ethical standards and nearly a third said they wished they had chosen another profession.



Delores Wasiek, left, has apparently won a fight to have her retarded daughter, Cindy, sterilized after Justice David Souter refused to bar the operation. Mrs. Wasiek and her daughter read a children's book in August.

Mrs. Wasiek says her daughter, who suffered brain damage as an infant from epileptic seizures that also left her mute, is vulnerable to assault because she does not understand the consequences of her affectionate behavior. Mrs. Wasiek went to court in 1987 seeking to have her daughter's Fallopian tubes tied after finding a male patient in her daughter's room at a group home while Cindy was dressing.

The daughter is now living in an all-female group home.

Ms. McKinley was appointed Mrs. Wasiek's legal guardian under a Pennsylvania law requiring one in such cases. Ms. McKinley made the

A retarded woman's guardian sees a question of rights.

emergency appeal to the Supreme Court on Friday after the Pennsylvania Supreme Court refused to ban the operation while the case was appealed. The appeal was denied by Justice Souter without comment.

Mrs. Wasiek's lawyer, Marta Engdahl, said: "It's enough already. She and her family made the decision on the basis of medical advice and with

all appropriate care seven years ago. She doesn't have to wait any more."

The Supreme Court has not ruled on sterilization for the mentally retarded since 1927 when, in *Buck v. Bell*, it upheld a Virginia law that allowed the sterilization of retarded people living in institutions.

Sterilization of retarded people is an issue with a long legal and social history. Tens of thousands of retarded Americans were sterilized in the early part of the century under state laws authorizing forced sterilization as a matter of eugenics. As recently as the 1970's, sterilization of retarded people was a widespread practice in Virginia.

In 1994, the U.S. Supreme Court refused to bar the sterilization of a woman by her mother. The woman was 26 years old.

In 1996-1997, Sweden became the first country to compensate 60,000 people sterilized between 1935 and 1976. Each person was given \$21,500.

In 1998, 2,000 scientists gathered in Beijing to discuss China's law that calls for compulsory sterilization for anyone with a genetic disability.

China Sterilization – 1997

SATURDAY-SUNDAY, AUGUST 30-31, 1997

EDITORIALS/OPINION

When Science Is Wrong and Theory Turns Deadly

By William Pfaff

PARIS — Until now it has been an unpleasant little secret that the countries which consider themselves the most advanced and civilized have been sterilizing “undesirable” people or taking their children away from them in order to improve the “race.” This was going on until the mid-1970s, in some places.

In Sweden, more than 60,000 people were sterilized against their will, or in their ignorance, between 1935 and 1976. These were mentally or physically handicapped people, or those congenitally ill, or socially “undesirable” women who had “too many” children and were considered living “bad lives.”

Among them were also Gypsies, vagabonds and people who were not “of pure Swedish race” (as that race was supposed to look, as set forth in a series of engraved plates produced at the Institute of Racial Biology in Uppsala in 1922).

But let’s not single out Sweden. The same thing was going on in other Nordic countries, and in Switzerland.

It was going on in the United States of America. As late as 1943, 30 of the then-48 states had laws on sterilization of the genetically “unfit.” In most states sterilization could be performed without the consent of the victim.

The rationalization for all this was a theory for improving mankind proposed by a cousin of Charles Darwin,

Francis Galton (1822-1911). It was based on Darwin’s arguments about natural selection in the plant and animal kingdoms. It said that humans should be “bred” in order to eliminate the allegedly unfit and to promote the propagation of the allegedly superior.

Eugenics, so-called, became a popular social cause in Britain after the Boer war, stimulated by the fear that Britain’s troubles were the result of “degeneration” of the British “race.” Later it was a response to manpower losses in World War I.

From that period until the 1950s, British children’s charities were sending children confided to them (some illegitimate orphans, some simply the children of people who could not afford to support them) to institutions in Australia, where some ended in more or less the condition of indentured servants, cut off from their origins.

All of this was based on clear assumptions about which “races” are superior and which inferior. Burned in today’s Australian consciousness is a comment made by Winston Churchill in 1942, when he diverted Australian troops to doomed Singapore, in place of British divisions. It was revealed only 50 years later. He said the Australians could be sacrificed because they were “bad blood.”

The United States at that same time was unconstitutionally interning its Japanese citizens in concentration camps, and drafting black citizens mainly to segregated army labor and transport battalions. Blacks weren’t allowed in the navy or Marines. The Navy Department believed they didn’t have what it takes for combat, and that white Americans would not share quarters with them on ships.

That is the way people thought, including some who might seem the least likely to have thought like that. In Israel, even in the late 1940s, when the Israeli state had barely been established, it now is revealed that hundreds of children of immigrant Yemeni Jews were literally stolen from their Arabic-speaking parents for adoption by families of European Jewish origin.

The blood of Ethiopian Jews was for a time segregated in Israel’s blood banks. The whole relationship between Israelis and Arabs, from the time of Mandate Palestine to the present day, has been tinged by racism.

One must judge all this in historical perspective. The Darwinian analogy with plant and animal kingdoms seemed convincing. Programs to “improve” the race seemed progressive, which is why Social Democratic leaders in Scandinavia were particularly attracted to them, as well as “progressive” thinkers elsewhere.

These ideas were also congenial to

an intellectual generation in the United States and Europe given to larger theories of social engineering and social planning. Eugenic programs resulted from the “best” scientific opinion of the time, the “best” medical opinion, and clearly were ordered and carried out with the best of intentions.

If some individuals suffered, that simply was the price of progress.

Nazism gave all of this a bad name. There is a nervous refusal now to admit that any differences at all exist between groups of people. It is all but impossible to talk about “race.” Probably this is a good thing. Possibly it is not, since there may eventually be a cost to be paid for the pretense that there are no problems here.

The lessons would seem to be that progressive theories can be deadly, and when theories require that people be made to suffer here and now in the cause of some grand future project, we should just say no. The second lesson is that scientists can be just as wrong as the rest of us, but when they are wrong the consequences can be worse than being wrong in other professions. The implications of this experience with eugenics suggests that we should be particularly cautious about the genetic engineering which some scientists now promote as offering us, once again, a vast improvement to mankind.

International Herald Tribune.
© Los Angeles Times Syndicate.

A former teacher's thesis delves into a topic both unexplored and painful: A survey led to a 1931 law that prompted several hundred forced sterilizations of "degenerates" deemed unfit to reproduce.

New book details Vermont sterilization effort

By Ellen Barry
Boston Globe

It changes the way you think of the paragons of New England society to learn that Vermont scientists had an active program to breed them.

But there it is, in the Burlington, Vt., archives: the long-abandoned paperwork of the Vermont Eugenics Survey, tracing the "degenerate" bloodlines that social scientists in the 1920s and '30s hoped to eliminate and the "old pioneer stock" that they hoped to replenish.

As she paged through the old records, Nancy Gallagher thought a dozen times about abandoning her project.

On the one hand, no historian had written a book about the 12-year study of "good" and "bad" families, which culminated in a law to sterilize several hundred poor Vermonters, Abenaki Indians and other people deemed unfit to reproduce.

The story of state-level eugenics, the science of human breeding that branched from social Darwinism, was largely untold. Somewhere, between Gregor Mendel's revolutionary work in genetics and the Nazis' distortion of it, there was a void in the teaching of history.

But on the other hand, she knew that there are people who would read about their family histories in her book.

IN DEPTH: Human breeding

sued reports with such titles as "The Results of the Matrimonial Adventures of Four Degenerate Offspring of the Fourth Generation of the Doolittle Family."

The reports drew on interviews with neighbors and local officials and sometimes were supplemented with estimates of the families' cost to taxpayers. One researcher reported that "the state of Vermont would have been better off had Richard, Simon, John and Joseph of Generation III not been allowed to produce children."

The work paid off for Perkins in 1931 when a sterilization bill finally passed. Between then and the early 1960s, the state funded and arranged sterilizations, often on young people living in institutions for the handicapped, frequently as a condition of release.

Although there is plenty of anecdotal evidence about the sterilization policy, particularly among the Abenaki, there is no docu-

mentation of how widespread it was, or how the option was presented to its subjects. The only published summary of state sterilization, from the 1940s, puts the number at 212, although many suspect that the actual number is higher, Dann said.

Pair of accidents

The eugenics movement radically changed direction in the 1930s, as people recoiled from the Nazis' "race hygiene." By 1940, Perkins realized that his earlier ideas were unacceptable, and omitted from his abstracts any mention of the years spent following Vermont's "degenerates."

And the project would have faded into obscurity except for a pair of accidents: Perkins' record-keeping and Dann's chance discovery of 40 crates of surveys in the laundry room of a state mental hospital in the mid-1980s. He quickly realized that the history was still painfully fresh.

Among the Abenaki — who, historians have established, made up a large contingent of the families that Perkins studied — the sterilization law is hardly a thing

of the past. Rushlow, the acting chief of the Abenaki, said that female relatives of her father's generation were sterilized without their consent. She said stories of the Perkins research weren't taught in school but were "passed down through the elders of the community."

To her, Rushlow said, Perkins always has seemed "just like Hitler."

She said that the scholarly interest has drawn mixed responses. On one hand, printing the history of Perkins' project could "finally let the public know what happened." But, on the other hand, the historians' interest also has churned up painful episodes that had been "kind of buried."

Gallagher is haunted by another possibility: That at some point, unknowingly, she may have popularized scientific inquiry with troublesome applications. Right now she's worried about the human-genome project. After reading through boxes of Perkins' pedigrees, she'll never be as trusting of science, or of herself. She said: "To their dying day, they probably thought they were doing the right thing."

Vermont Study — 1999

An obscure effort

Gallagher wasn't a revisionist historian. She's a former biology teacher who expected her doctoral thesis to "sit on a shelf." But then she stumbled into a subject that was unexplored, but painful.

"Every step of the way," she said, "I wondered if I should even be writing it."

When her book, "Breeding Better Vermonters: The Eugenics Project in the Green Mountain State," is published by the University Press of New England later this year, the wondering will be over. And what will be left will be the emotional fallout of a historical episode that no one, not even its victims, particularly wants to discuss.

The Eugenics Project, an obscure independent effort, shows a mindset so abhorrent that the historian who first discovered the records walked away from them.

"I don't have a real dark streak in me, and it's very dark material. You can try and not be affected by it, but there's a lot of hate in it," said Kevin Dann, a historian in Woodstock, Vt., who found the eugenics surveys in the mid-1980s and published the first article about it in 1986.

Vermont's social scientists were hardly alone in embracing eugenics. During the first two decades of this century, U.S. progressives were eager to prevent — not just manage — the misery of the poor. New science seemed to supply an answer: Domestic abuse and alcoholism, long blamed on social conditions, were thought to be caused by recessive genes and inbreeding. By reducing the numbers born to sick or unwed parents, and by attracting desirable settlers, social scientists thought they could build a healthier society.

In fact, Vermont was the 31st state to pass a law allowing for the sterilization of the handicapped or "feeble-minded." The number of sterilizations that took place in Vermont was a tiny fraction of the 60,000 that took place before the laws were rolled back in the 1960s and '70s, according to Diane Paul, a University of Massachusetts-Boston political scientist and author of the book "Controlling Human Heredity: 1865 to the Present."

But in some ways, Gallagher says, Vermont residents were uniquely ready to accept eugenic solutions. The state's population was dwindling, and the draft board was rejecting an increasing number of young men — trends that dealt a blow to the closely held Yankee Protestant ideal. In 1930, 71 percent of the state's 350,000 people were native Vermonters. This kind of population can be changed more readily, encouraging eugenicists to "improve the quality of its native stock," as one put it.

'Notorious' families

It was in this atmosphere that the University of Vermont zoology professor Henry Perkins threw himself into the project of tracing what Gallagher calls "pedigrees of degeneracy."

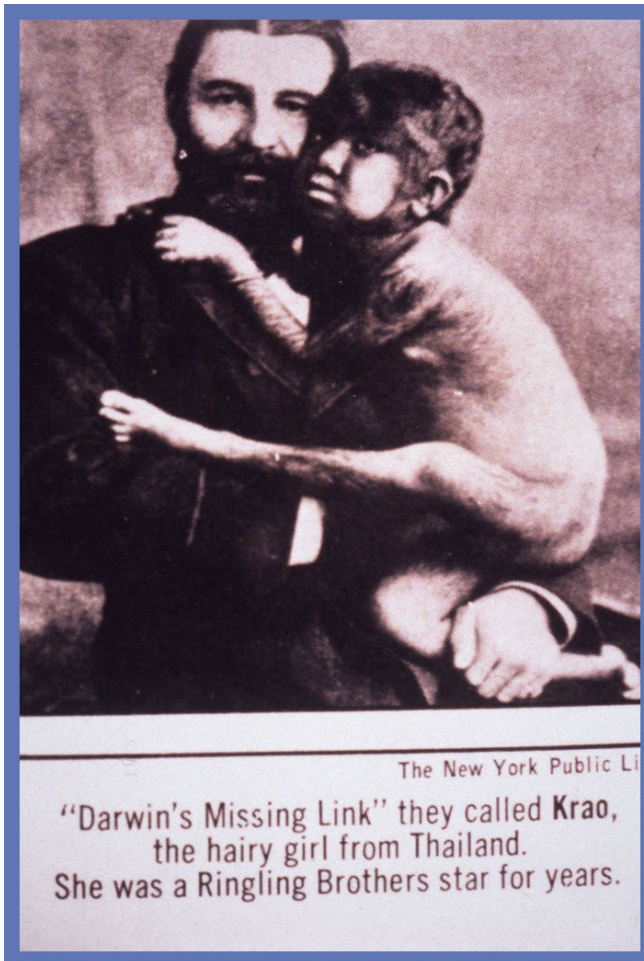
Field workers selected particular "notorious" families and is-

Dissertation Findings

Who was sterilized?

In 1999, a doctoral dissertation was published called “Breeding Better Vermonters.” It was a 12 year study of good and bad families that resulted in hundreds of poor people, American Indians, and people with disabilities being sterilized without consent.

Sideshow Continue

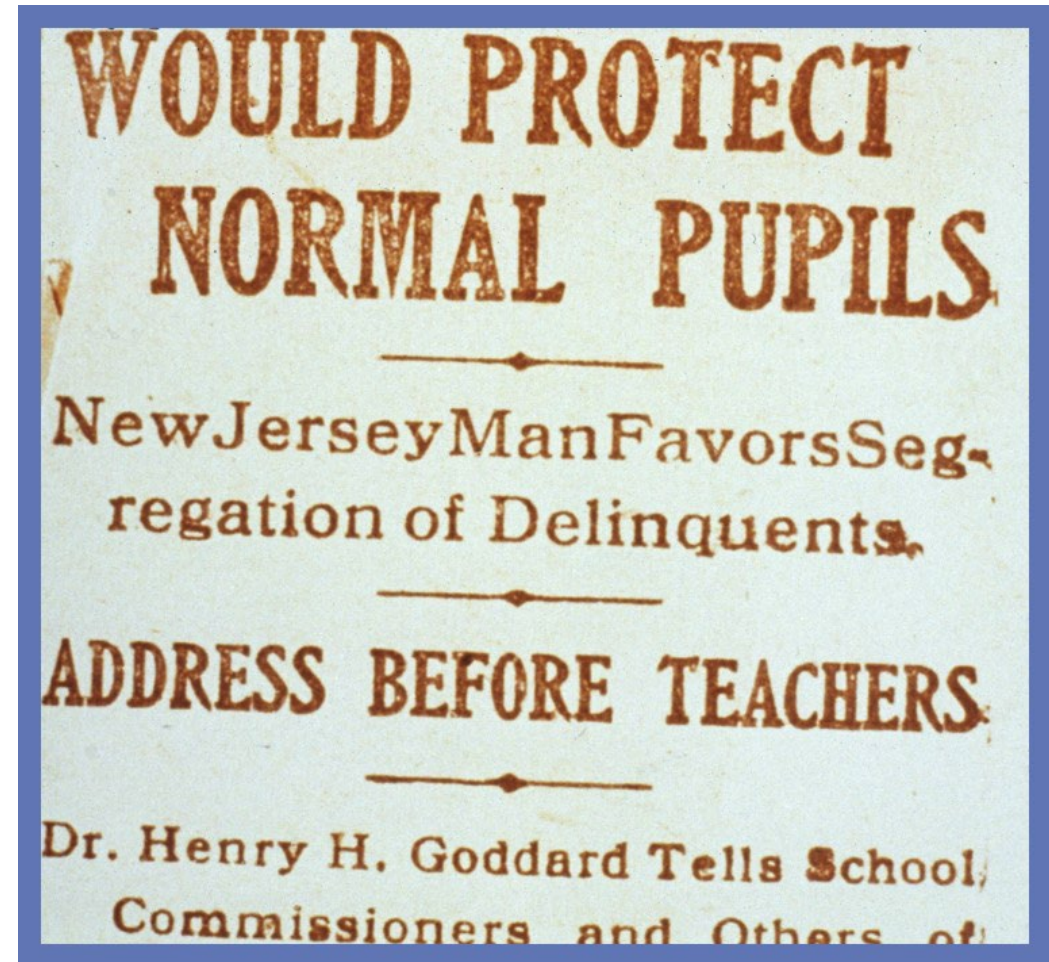


Throughout the 1900s as we already discussed people with disabilities were part of the sideshows at circuses and fairs.

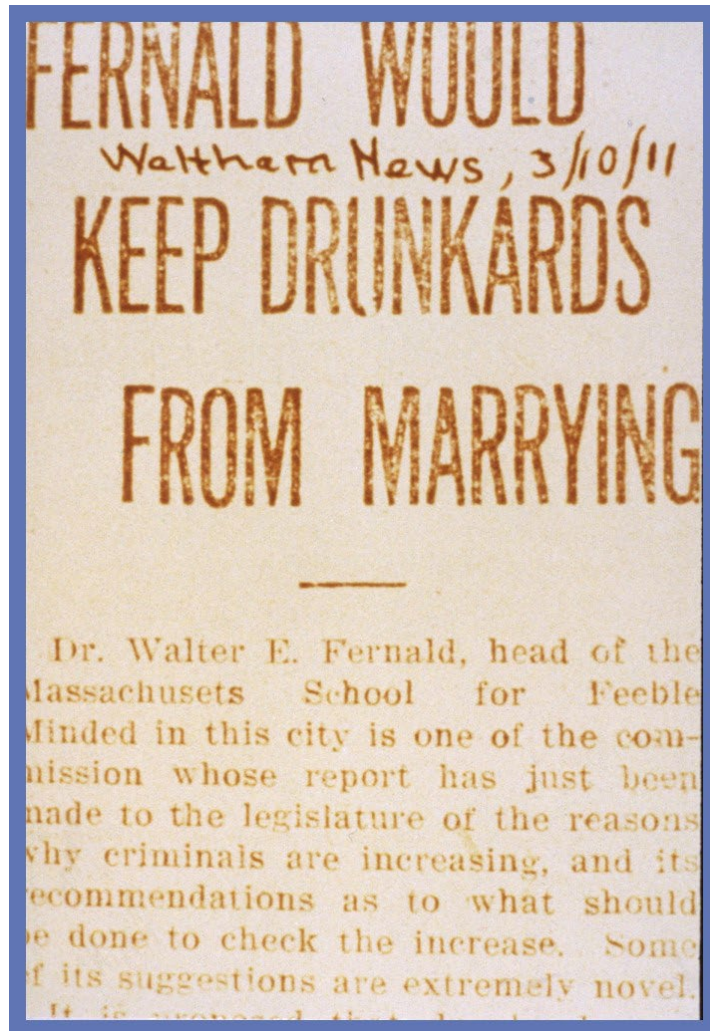
Here is Darwin's missing link between animals and humans.

Keep Kids Out of School

Now the campaign begins to keep children with disabilities out of classrooms in order to protect the typical students. “We have to protect kids from the delinquents,” says Dr. Henry Goddard.



Keep Drunks From Marriage



Another headline says,
“Keep drunkards
from marrying.”

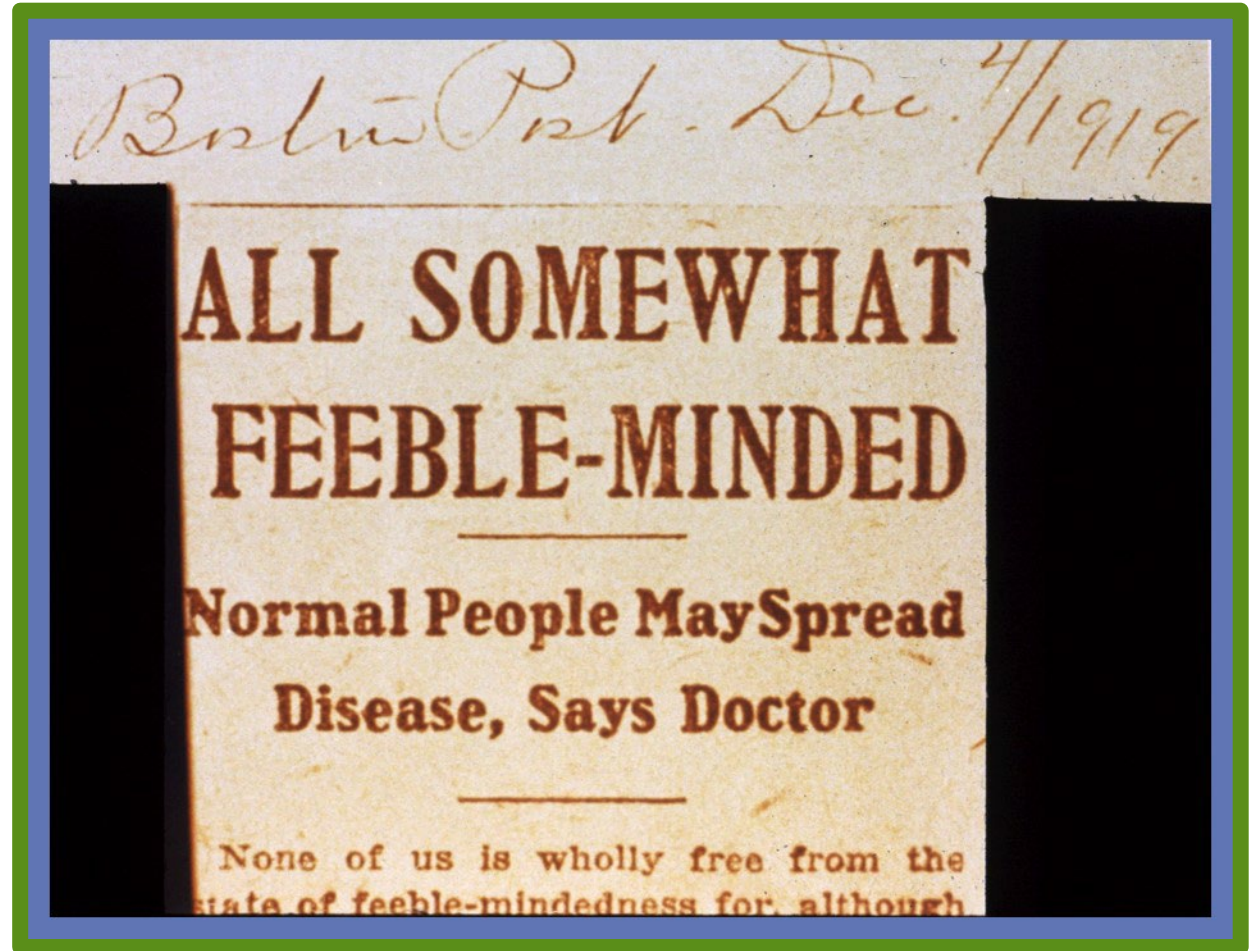


RESULTS OF CONCEPTION WHEN THE FATHER WAS INTOXICATED

Myth About Alcohol

All people are
feeble-minded.

“Normal”
people can
spread the
disease, too.





**"You are sharing
the Load!**

**"A genetically ill
individual costs
approximately 50,000
Reichsmarks by the age
of 60 years."**

Nazis travel to the U.S.

While the U.S. continued to put large numbers of people in institutions, the themes of sterilization, abuse, medical experiments, and death reached its extreme in Nazi Germany.

The Nazis studied eugenics and systematically killed people with disabilities.

At Tiergartenstrasse 4, Operation T4 was launched.

Operation T4 was the code name for this program. Physicians were critical to the successful of the operation. T4 began by targeting anyone with a disability in any institution.

Records were sent to the program directors of T4, who did not examine the patients. The doctors completed their assessments based solely on the medical records. The doctors marked each name with:

- A red cross, which meant death; or
- A blue quote mark which meant life.

Killing stations	Period of operation	Numbers killed
Grafeneck	Jan.—Dec. 1940	9,839
Brandenburg	Feb.—Sept. 1940	9,772
Bernburg	Jan.—Sept. 1941	8,601
Hadamar	Jan.—Aug. 1941	10,072
Hartheim	May 1940–1941	18,269
Sonnenstein	June 1940–Aug. 1941	13,720

Hospitals Became Killing Stations

Killing Approaches

People were bused to “hospitals.”

Initially, victims were given lethal injections, but on the advice of Dr. Werner Heyde, Hitler switched to using carbon monoxide gas, which was more efficient and less expensive.

Hitler built gas chambers disguised as showers, right down to the fake water nozzles, to deceive people.

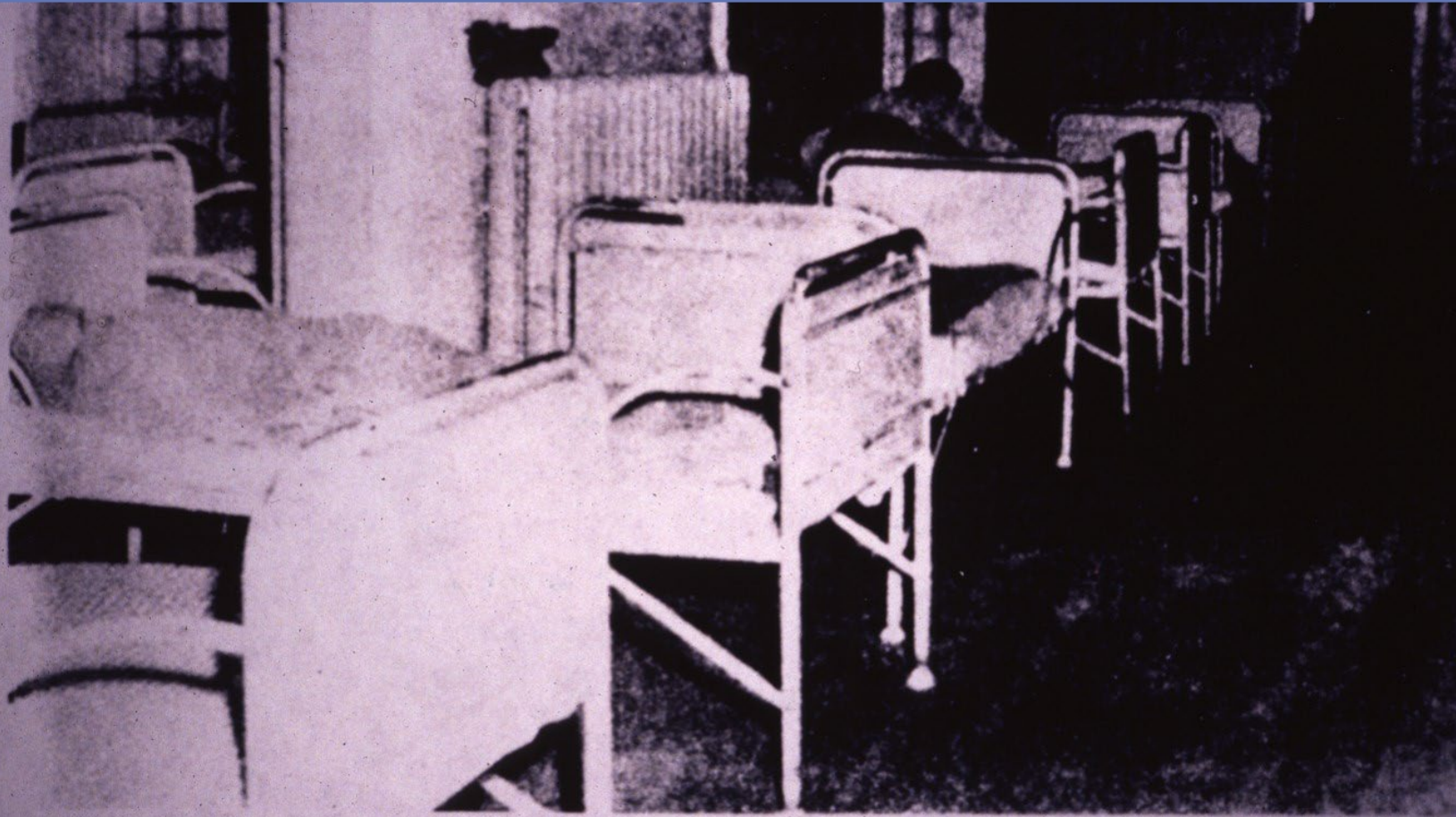


Death certificates were prepared and sent to the relatives.

Between 1940 and 1941, 70,273 individuals were gassed at euthanasia centers.

- In all 200,000 to 250,000 died in six years.

A detailed report to Hitler included a section on how much money Germany had saved by killing the “useless eaters.”



Ward I-B, Hadamar Institution, 1945. Patients unknown. "Most of the rooms were small and bleak. There was little furniture other than beds and these, without exception, were old and uncomfortable." *The Library of Congress*

Hospital Room

From Hadamar to Auschwitz

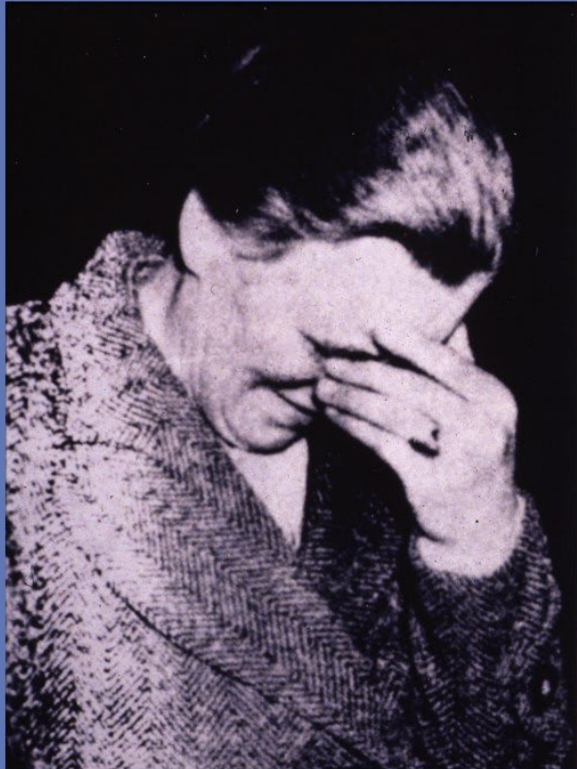
The previous slide shows a bleak hospital room in the Hadamar Institution.

The photo to the right shows the cremation ovens at Auschwitz.

A maximum of 6,000 bodies could be cremated in one day.



Less Punishment



Nurse Irmgard Huber on the stand: "The lives . . . are just as valuable as my life, but I could not change anything there. I didn't have any say. I couldn't report anything. I avoided the matter." *The Library of Congress*

This photo shows Nurse Irmgard Huber on the stand at trial, after the war ended.

"Their lives were as valuable as my life, but I could not change anything there. I couldn't report anything. I avoided the matter."

Even today, we are unable to grasp the reasons why seemingly typical men and women were able to commit such extraordinary crimes.



Bus Stop Memorial



Berlin's Blue Wall Remembers

Nazis Punished More Leniently for Crimes Against Handicapped

Libraries

Life News (Social and Behavioral Sciences)

Keywords

RELIGION POLITICS HANDICAPPED

Contact Information

Available for logged-in reporters only

Description

Nazi murderers of the mentally handicapped were treated much more leniently in postwar German courts than their counterparts who killed Jews during the Holocaust, a University of Florida study finds.

Newswise — Nazi murderers of the mentally handicapped were treated much more leniently in postwar German courts than their counterparts who killed Jews during the Holocaust, a University of Florida study finds.

Leniency

Black Holocaust

This Nazi propaganda photo depicts friendship between an “Aryan” and a black woman. The caption states:
“The result! A loss of racial pride.”

Photo: US Holocaust Memorial Museum

- Between 400 – 600 children were born of African and German unions. These Afro-German children were referred to as the “Rhineland Bastards.”



More of the Forgotten Victims

The black population of Germany at the time of the Third Reich was 20,000 – 25,000, out of a total population of over 65 million.

Some of the 400-600 “Rhineland Bastards” and their families fled Germany after the Nazis took power; others were killed in the round-ups that followed.

The Nazis passed a new law July 1933 that made it mandatory to sterilize:

- **People with disabilities;**
- **Gypsies; and**
- **Blacks.**

Most of the Rhineland Bastards disappeared, got arrested, or were at the least, forcibly sterilized. One concentration camp survivor said, “No, you cannot have my life; I will fight for it.”

Catalog of Camps

42,500 Nazi ghettos and camps were cataloged in 2013.

- Labor camps, POW camps, care centers, concentration camps, etc.
- The numbers are higher than expected. 15 to 20 million died or were imprisoned.
- This photo is of Holocaust survivors in Ebensee, Austria.



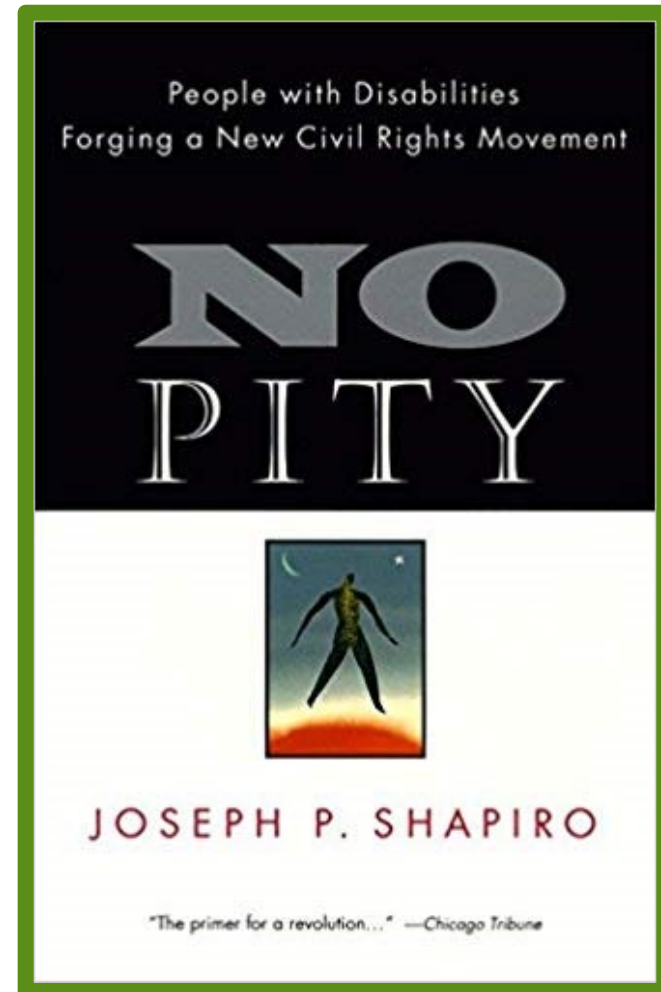


Stones

Faribault Cemetery

Joe Shapiro wrote the book, *No Pity*, a book about the battle for civil rights for people with disabilities in America today.

In the last chapter comes this description of the cemetery at the Faribault Regional Center in Minnesota.



Unmarked Graves



“With ease I spotted a six foot tall white cross that suggested a cemetery was nearby, but it took me several minutes of walking back and forth across the small field to realize that coffins were laid under my feet.

No headstones jutted from the ground. Each grave was marked by a plain stone just big enough for a number.

Each stone was set level with the ground. Once I found #1216 I could find #1217.”

Old Cemetery

“I know where to part the grass to find the others. Some 1,200 men, women and children had been buried there with no name, no date of birth or death and no epitaph to speak for their forgotten lives.

Another 487 people who died prior to 1934 had also been assigned anonymous digits and laid to rest at the bottom of an adjacent hill in an inaccessible plot overgrown with weeds and tall grass.” Joe Shapiro



Willowbrook State School

These next slides were taken at Willowbrook State School in Staten Island, New York.

The first shows children taken in the same year that Congress passed the federal special education law.



Locked Door



Go through this locked door at Willowbrook and you will discover how people with disabilities were treated.

The beds were always made because that's what licensing inspectors reviewed.



Bathrooms

The bathrooms had to be easy to clean and easy to supervise. There was no privacy, and no toilet paper.

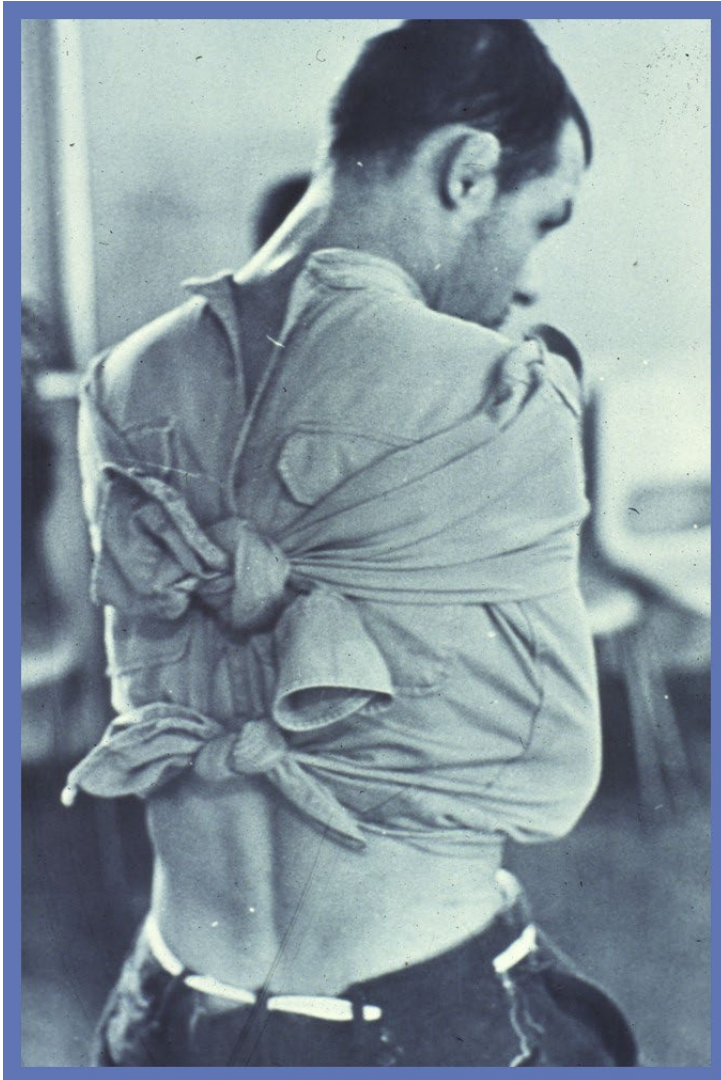


In Willowbrook there were only a few physicians for 6,000 residents.

Triage was important. Blood and broken bones had first priority.



Restraint



Restraints were common.

No professional association ever spoke up about conditions.

No parent group complained because of fear of retribution.

No licensing violations were ever reported.

Carts and Cribs



Medical Experiments



Children with developmental disabilities housed at the Willowbrook State School in Staten Island, NY, were intentionally infected with hepatitis in an attempt to track the development of the infection. Hepatitis is a deadly viral liver disease. The study began in 1956 and lasted for 14 years.

Physicians justified their actions by claiming that given the high rate of infection in the institution, it was practically inevitable that the children would become infected anyway.

Silence



No unions ever spoke up about the living conditions at Willowbrook.

No ethics complaints were ever filed about the medical experimentation being conducted.

No federal government agency was involved.

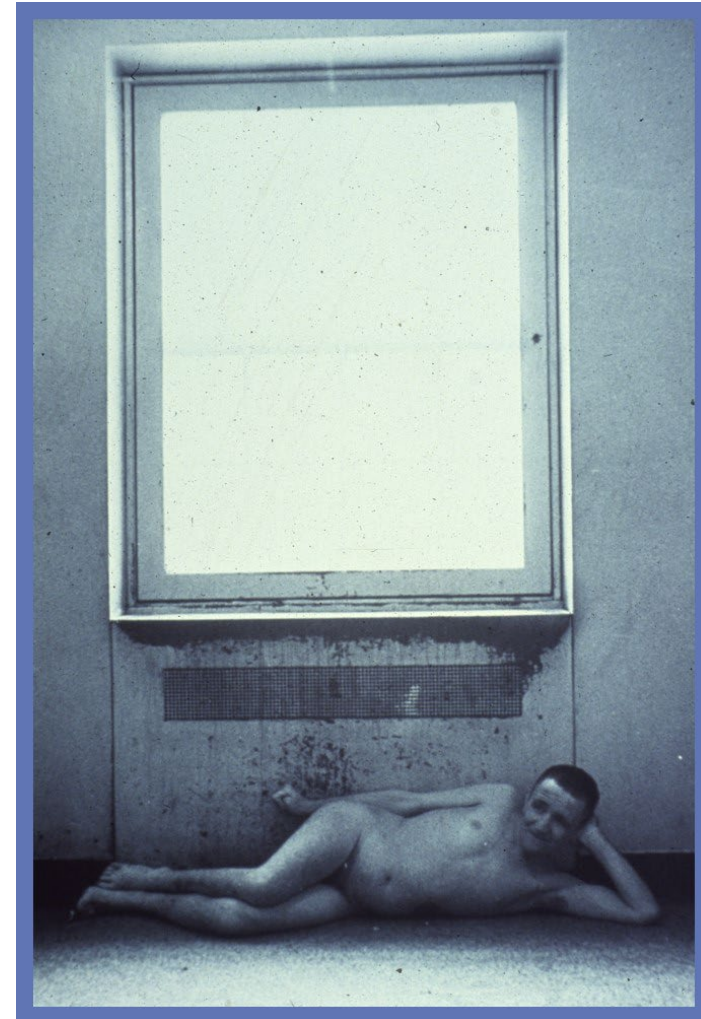
Children were abandoned.

If you meet individuals today who lived in these conditions then, you will find that their lives are totally different from a child who was raised in a family.

Radiator Man

Understaffed, overcrowded and underfunded, Willowbrook was little more than a “human warehouse,” according to William Bronston, a physician at Willowbrook.

This is Radiator Man, as photographed by Dr. Bronston. Bill wrote an essay about this fellow.



Essay: *Seeing*

by Dr. Bill Bronston, former physician at Willowbrook

***“Seeing** takes time.*

We live in a fast society, thirty miles per hour at least. What we see is so often like a billboard: colors, shape, a quick message, numbing.

It doesn't take long to withdraw from all that, there is only so much we can sort out, understand, respond to or use.

*For a health worker, seeing, **really seeing** is critical.”*

*“I guess it was the minute to minute struggle to **see** that made work at Willowbrook so exhausting.*

I don't think anyone can identify with people trapped in an institution without constant, conscious effort to redefine everything.”



Hard Surfaces

“On all the wards there is nothing soft. The stone floors, wood and fiberglass chairs, formica and chrome tables, steel and glass windows, iron beds are hard and cold.

There is no place soft, no place for warmth, solace, sanctuary, no place except the radiator. The radiator is four feet long and three feet high, an iron cover plate radiating something drastically different from the rest.”



Burned and Scarred



“It took me a long time to realize how important the radiator was to a community of people who had nothing.

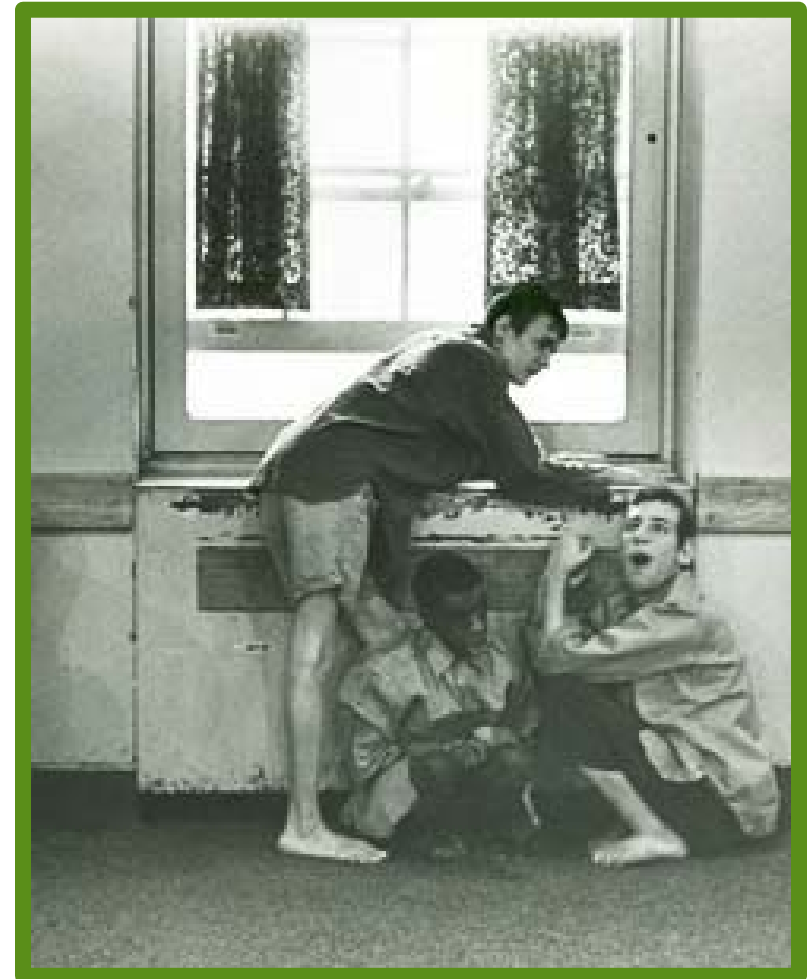
Once I saw the people huddling there, it still took time to really grasp, to feel the profound meaning of the radiator.

At first I was outraged at the burns I saw. People sought the radiator for a retreat, a sleeping companion, a mother fragment, then burned, they were unable to move.”

“Couldn’t the workers watch out for people next to the hot radiator plates.

How can we let the radiator be the sun for so many?

There is always some sort of radiator, some obvious substitute for the real thing, around which the lives of public hostages cling.”



What lessons can we learn from these slides?



Policies change because of previous practices.

Concepts like “least restrictive environment” come from court cases.

Outrage about aversives lead to the demand for positive approaches.

Individual planning as opposed to thinking about groups.

Active treatment meant doing something during the day.

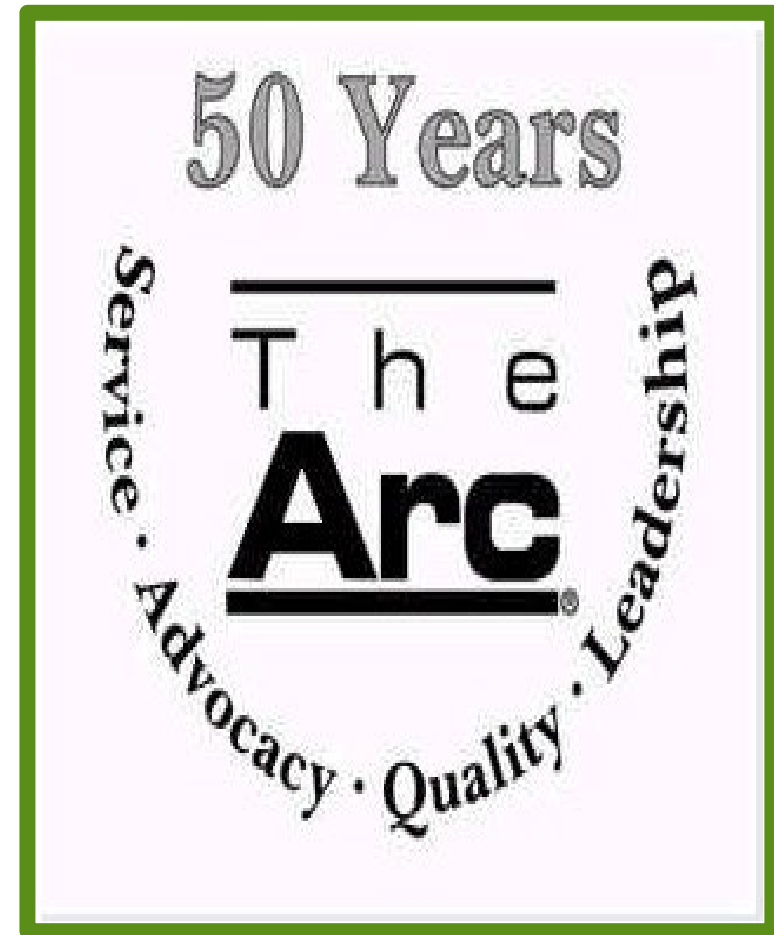
Change comes because of court cases, legislation, regulation, practices.

We stand on the shoulders of generations of reformers – Families who only had nightmares about the future and people who lived the nightmares.

Parent Movement (1950 – Present)

- Key Moments in History
- Litigation
- Legislation

The National Association
of Parents and Friends of
Children is founded in
Minneapolis.



The Parent Movement Begins

In the fall of 1950, ninety persons from across the country came together in Minneapolis to participate in the first national Arc conference. Minnesota Governor Luther Youngdahl was the featured speaker.

- CA, CT, IL
- MA, MI, MN
- MO, NJ, NY
- OH, TX, VT
- WA, WI

Parents with a Purpose

- No money
- No precedent
- No policies
- All are strangers with one goal—HELP all children and adults.

- We hope that 50% of our sons/daughters will not be tax burdens in the future.
- Grassroots
- “An idea whose time has come.”
- “Our great democracy can be measured best by what it does for the least of its little citizens.”

Minnesota Governor Luther Youngdahl

Governor Youngdahl speaks about the rights of children with disabilities being the same as the rights of all children everywhere.

“The right to play, the right to companionship, the right to develop to the fullest extent of their abilities.”



The Medical Model

“Place in an institution and go home and have another child.”



Brown v. Board of Education (1954)

Brown v. Board of Education

The United States Supreme Court finds that “[s]eparate...facilities are inherently unequal and state-supported segregation is illegal.”

Future disability legislation is influenced by Brown.

The photo to the right is of the plaintiffs of Brown, and their children.



Trudeau and Fogarty



In 1954, Mr. Arthur Trudeau invited his friend and former schoolmate, U.S. Representative John Fogarty, to the Christmas party of the Rhode Island Arc.

Parents talked with him about the absence and denial of services for their children, and the isolation and segregation they experienced.

This led to questions by Congress, and eventually, the Fogarty Hearings, which concluded that very little was being done in the field. Fogarty vowed to change that.



1956 – 1957

Special Education was based upon an IQ of 50 or higher.

- Must be able to walk, talk, and be toilet trained.
- Why? “We did not know any better.”

President Kennedy's Panel Report

1962

Expand special education:

- Only 25% of students with disabilities have access.

Most recommendations were about diagnosis, assessments, and research.



The NARC Poster Twins of 1963 — one retarded because of PKU, the other unaffected — visit President Kennedy in the White House. With the twins and their mother are Eunice Kennedy Shriver (l) Leonard Mayo (center), Chairman of the President's Panel, and Vincent Fitzpatrick, President, NARC.

1963 Kennedy

Ed Roberts was the first student with severe disabilities to attend the University of California at Berkeley.

- 1962 “Helpless Cripple”
Headline

He founded the Physically Disabled Students Program, which was the first of its kind.



1963 MR Facilities and MH Center Construction Act

Training, Research and Development Facilities, and provisions

Title V of the Social Security Act establishes a grant program to improve prenatal care for women from low income families because of the extremely high risk of children being born with disabilities.

Day Program Pilot



**Day
Activity
Pilot
Program
1961**

Day Programs created for individuals not covered by special education statute.

Expanded to include people with severe disabilities.

Vocational Rehab began as a program after World War I for veterans with disabilities who returned to the United States.



Social Security Act (1965)

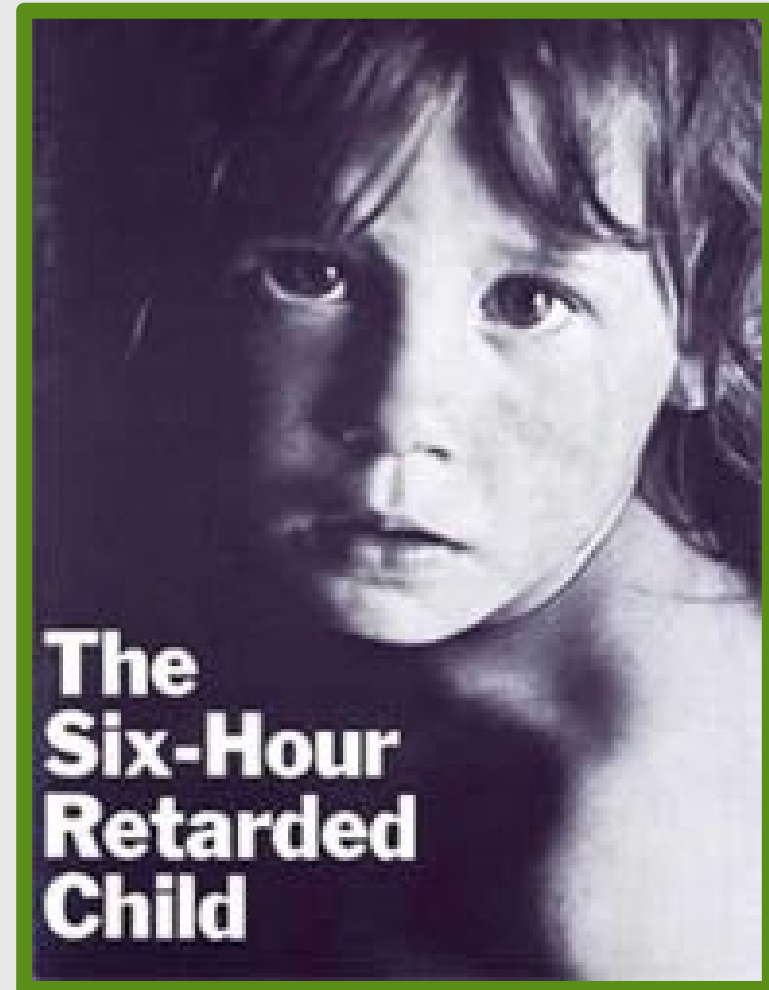
Initially, Medicaid included:

- Improvement of access to and quality of medical care for all low-income people;
- No provisions related solely to individuals with disabilities.

- 1965 Elementary and Secondary Education Act—
First federal support. Bureau of Education of
“H” established.
- 1968 Architectural Barriers Act—Most buildings
and facilities designed, constructed, or
altered with federal funds after 1969 must be
accessible to people with physical disabilities.

Children with Disabilities:

- 9:00 a.m. to 3:00 p.m.
based on IQ, not adaptive behavior.
- Part of the “War on Poverty”



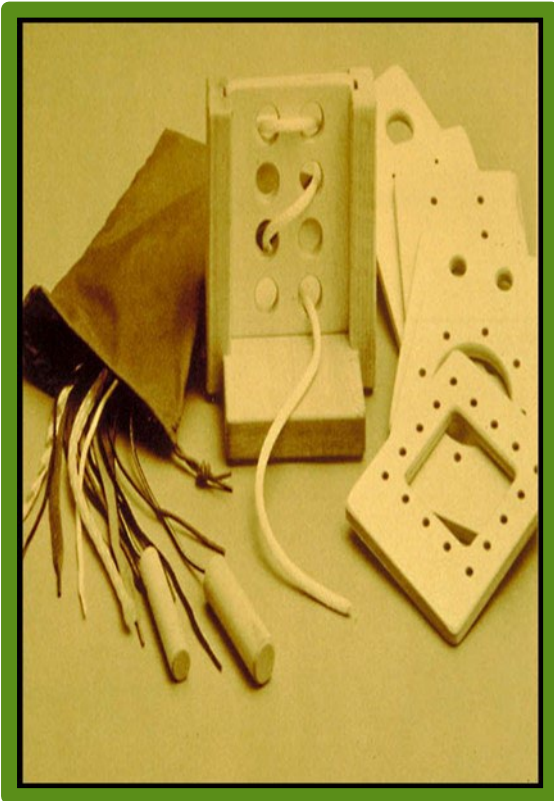
Education Court Cases

- Hobson v. Hansen* (1968). Washington DC educational placement decisions were illegal. Placement based on standardized tests.
- Fred G. Wolf v. Utah* (1969). Segregation has a tendency to “retard” development.
- Diane v. State Board of Educ.* (1970). California must test using the child’s primary language and appropriate tests.

Urban Mass Transportation Act (1970)

Local jurisdictions can plan and design mass transit facilities and services that are available to and usable by people with disabilities and people who are elderly.

The Developmental Model



Stairway to
Nowhere



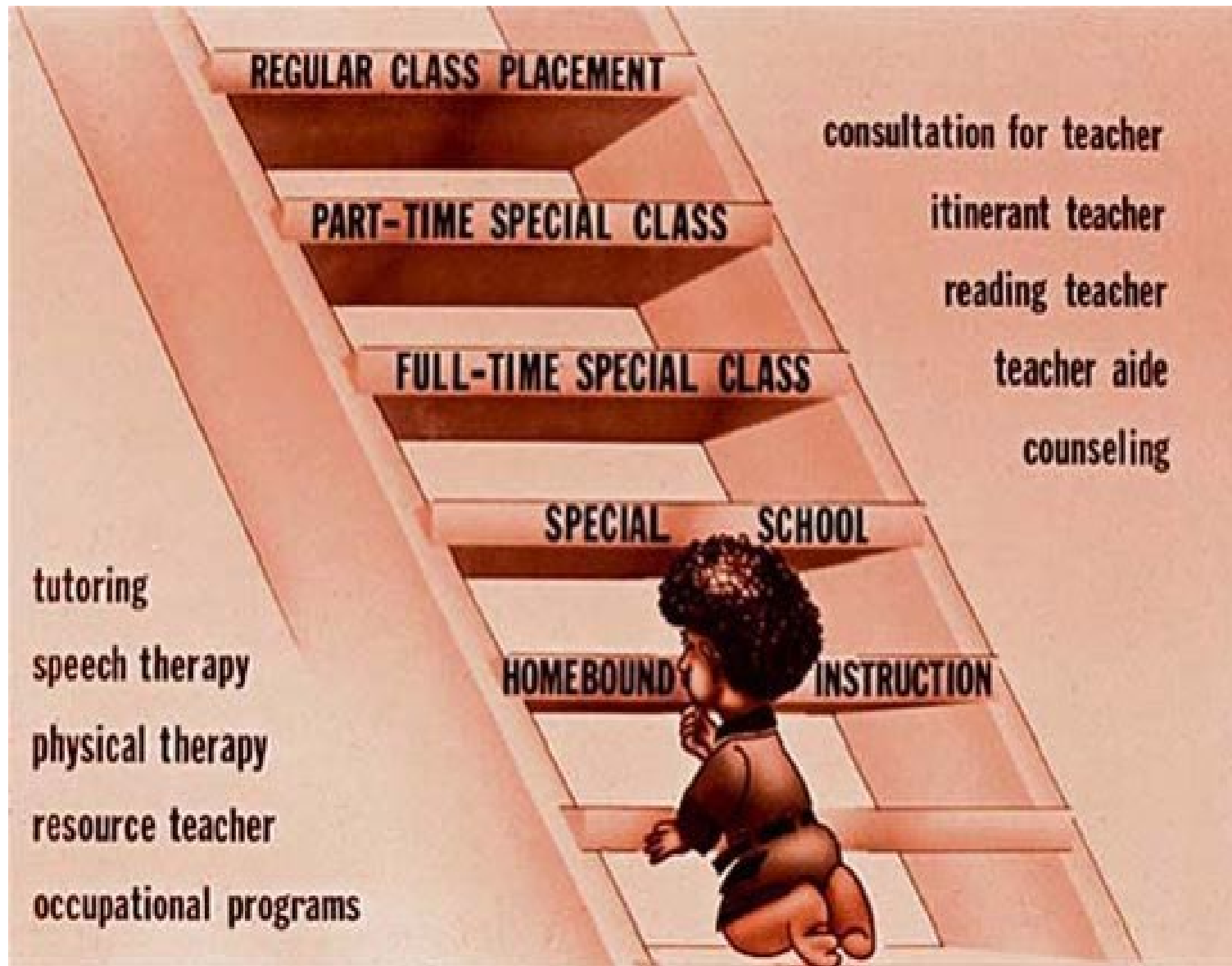
The Developmental Disabilities Act

The Developmental Disabilities Services and Facilities Construction Amendments are passed (1970).

Sixteen basic services are called for:

Evaluation	Diagnosis	Counseling	Treatment
Personal Care	Day Care	Special Living Arrangements	Training
Education	Sheltered Employment	Recreation	Protective Legal Services
Information	Referral	Follow-along	Transportation

Elizabeth Boggs, Ph.D., Elsie Helsel, Ph.D., and Senator Ted Kennedy



Continuum and Cascade



Is there life after sanding?

Children's Defense Fund Study

CDF in the 1970s:
Only one in five students
was being educated.
Estimate of one million
students were excluded.

The photo is of P. Mooney
the Puppet.



Medicaid Funding (1971)

- Nursing homes were funded by Medicaid.
- Elizabeth Boggs, Ph.D. lobbied Congress to fund a step down from Skilled Nursing Facilities (Nursing Homes). The step down was called Intermediate Care Facilities (ICF) for People with Developmental Disabilities.
- Minnesota applied for federal funding.

PARC v. Pennsylvania (1971)

Prior to 1971, children with disabilities were routinely denied a public education.

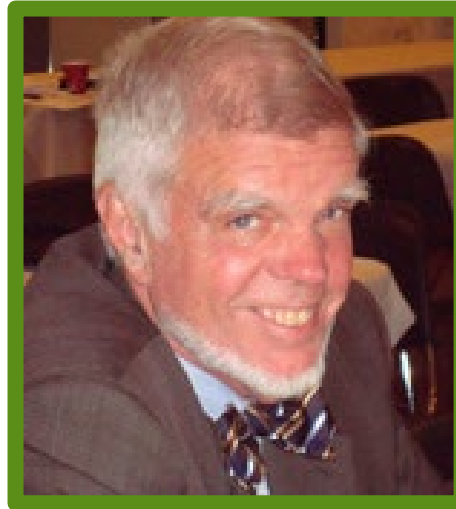
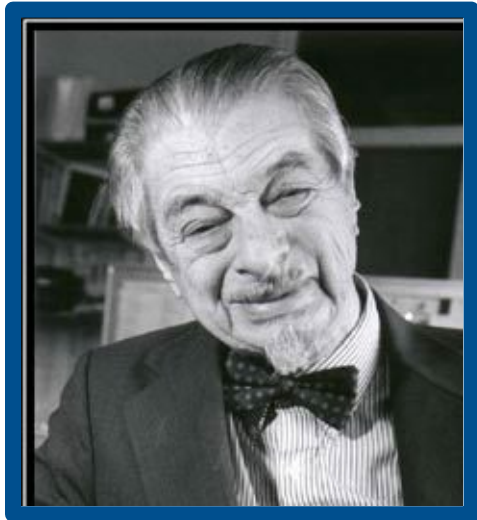
PARC v. Pennsylvania affirmed the rights of children with disabilities to a free appropriate public education and due process.

The Pennsylvania Association for “R” Children (PARC) sued the state. The Court found that:

“Placement in a regular school is preferable to placement in a special school class is preferable to placement in any other type of program of education and training.”

Autopsy Photos

Gunnar Dybwad and Tom Gilhool – the story behind the parent lawsuit.



Autopsy photos – of a little boy.

Wyatt v. Stickney (1972)

Ricky Wyatt v. Stonewall Stickney as Commissioner of Mental Health of Alabama

Ricky was a 15-year-old “juvenile delinquent” with no mental illness, who had been placed in the state hospital by the courts in an attempt to improve his behavior.

A federal court in Alabama held for the first time that people who are involuntarily committed to state institutions because of mental illness or developmental disabilities have a constitutional right to treatment that will afford them a realistic opportunity to return to society.

The Wyatt Standards

The Wyatt Standards became the national standards for the care and treatment of individuals with disabilities:

- Right to habilitation
- Implement normalization principles
- Right to least restrictive environments
- Prompt medical treatment
- Right to education
- Right to discharge plans
- Right to individual habilitation plans

AND more



Wyatt vs. Stickney



"No one judge can terminate Wyatt. I can enter an order terminating the litigation. But I can't enter an order terminating Wyatt. That is beyond my power."

*--U.S. District Judge
Myron Thompson*

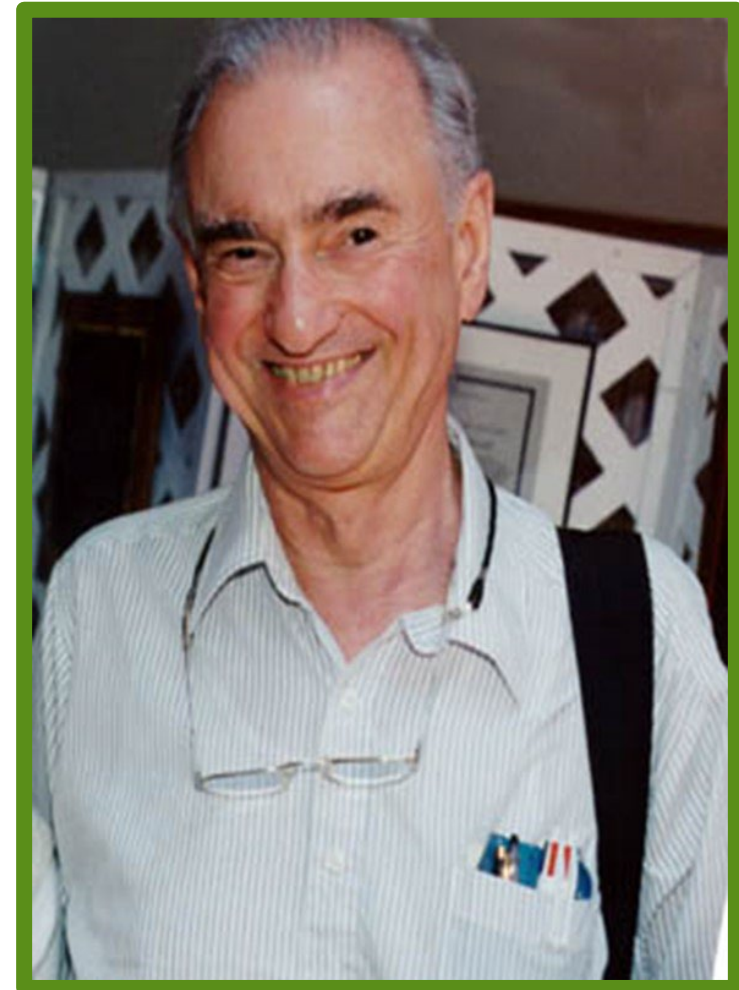
33 years

Dr. Wolf Wolfensberger

Father of Normalization principle in the U.S., which was based on Denmark and Sweden.

Created social role valorization concept.

Lecture is online and includes over 400 slides.



The Social Security Act (1972)

1. The Social Security Act of 1972 authorized a Supplemental Security Income (SSI) program of cash benefits for needy individuals and couples who are aged, blind, or disabled.
2. A basic federal income support level is established for eligible individuals. This replaced “Aid to the Permanently and Totally Disabled Program.”
3. Children with disabilities are eligible for SSI benefits if their disabilities are comparable in severity to adult recipients.

Equal Opportunity Act Amendments (1972)

- Required that not less than 10% of the total enrollment opportunities in Head Start programs nationwide must be for children with disabilities and services provided to meet their needs.

Mills v. Board of Education of D.C. (1972)

School districts are obligated to provide:

- “free public education and training appropriate to their learning capacities.”
- “whatever specialized instruction will benefit the child.”

This lawsuit applied to all children with disabilities.

(2 hours of education per week = 2 meals per week)

The Rehabilitation Act Amendments (1973)

The Rehab Act prohibited discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in the employment practices of federal contractors.

- \$1 Billion dollars in appropriations;
- Completely re-written law;
- Emphasis on those who are the most disabled; and
- New list of services that can be funded.

Section 504 (1973)



Section 504 of the Rehab Act protected people with disabilities against discrimination in all federally-assisted programs and activities:

“No otherwise qualified handicapped individual in the United States... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...”

The fight for regulations lasted 4 years.

Welsch v. Likins (1972 – 1989)



- Richard Welsch sues the State of Minnesota for treatment of his daughter, Patricia at Cambridge.
 - ***“It’s a hellhole.”***
- Judge Earl Larson writes his opinion.
 - ***“Everyone, no matter degree of disability, is capable of learning if given proper treatment.”***

Willowbrook Law Suit in New York

- Robert Kennedy visited.
- Geraldo Rivera did a one-hour special.
- Dr. Bill Bronston photographs.
- Families filed suit.
- Cruel and unusual punishment.



Key Impressions



Developmental Disabilities Act (1975)

The DD Act was amended to include:

State protection and advocacy systems are established to protect the rights of people with developmental disabilities.

- Geraldo Rivera testified because of Willowbrook.
- Also testifying was the first self advocate.

Education Of All Handicapped Children's Act

State and local education agencies must provide “a free appropriate public education” in the “least restrictive setting” for all eligible children with disabilities.

- An individualized education program (IEP) identifies annual goals and short-term objectives, and describes specific special education and related services.
- Regulations became effective in 1977.



FAPE — IEP — LRE



Early Special Education

Child Find Provision

When it was passed in 1975, P.L. 94-142 made it a legal requirement for schools to **find children** who had disabilities and needed services.

“Passage of P.L. 94-142 was the singularly most important piece of federal legislation in keeping families together.”

Impact of Federal Law

- The U.S. Supreme Court observed, “Prejudice once let loose is not easily cabined. Not until Congress passed this law were the doors of education opened wide to children with disabilities.”
- All Means All



Halderman v. Pennhurst State School (1977)

Patients claimed that their institutionalization at Pennhurst violated their constitutional right to be free from harm. The Pennsylvania court agreed.

"Conditions at Pennhurst are not only dangerous, with the residents often physically abused or drugged by staff members, but also inadequate for the 'habilitation' of the retarded."

Pennhurst went to the U.S. Supreme Court and was upheld in 1984. Judge Broderick was the first judge to close an institution.

Significant Disabilities



Hey! Don't forget about me!

Conference and book –
significant disabilities

The Arc U.S. argued for least
restrictive environments in
schools, but knew it would take
a long time for the guarantees of
the federal law to come true.

1978

Dr. Norris Haring spoke of a “functional curriculum.” Teaching must be aimed at increasing independence of the student—eating, toileting, dressing and walking for students with significant disabilities.

1979

Haring also told people to listen to parents; train new groups of teachers; provide the earliest intervention possible; and the need for more funding for research.

1978

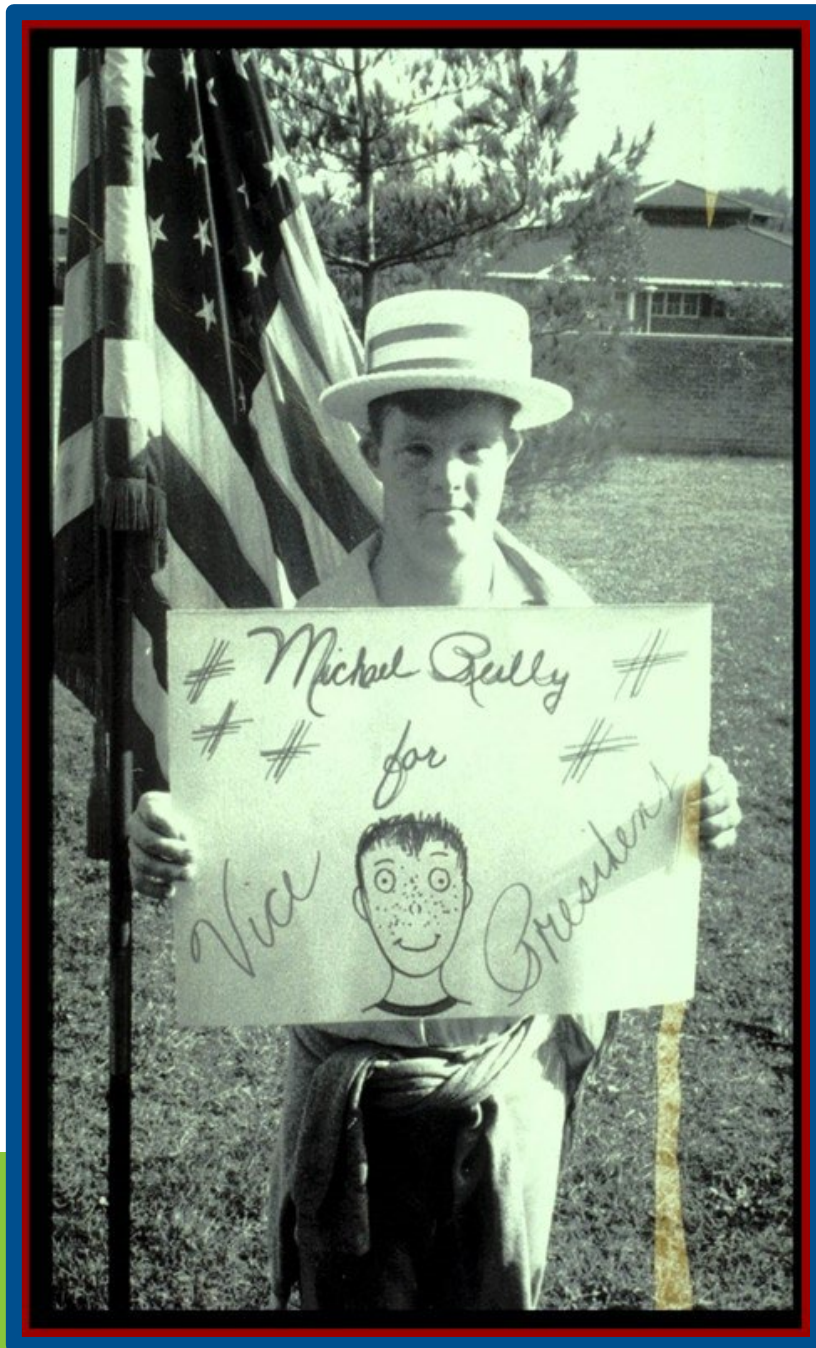
A National Institute of Handicapped Research was established.

It was later renamed the National Institute on Disability, Independent Living, and Rehabilitation Research – NIDRR.

1979

Criterion of Ultimate Functioning

Where will this student be as an adult? (from the parental viewpoint)



Place and Pray

- Individualized student objectives
- Task analysis
- Generalization of skills
- Natural proportion
- Age-appropriate
- Heterogeneous groups

Sections 1619(a) and 1619(b) were added to the Social Security Act. They outline work incentives.

- “Benefits For Individuals Who Perform Substantial Gainful Activity Despite Severe Medical Impairment”



1980 *Welsch Case*



Restraint Chair

§ 431.55 Waiver of other Medicaid requirements.

(a) *Basis and purpose.* This section implements section 1915(b) of the Act, as added by section 2175 of Pub. L. 97-35 and as amended by section 137 of Pub. L. 97-248, which authorizes the Secretary to waive the requirements of sections 1902 and 1903(m) (as permitted under paragraph (h) of this section) of the Act to the extent he or she finds proposed improvements in the provision of services under Medicaid to be cost-effective, efficient, and consistent with the objectives of the Medicaid program. This section also implements sections 1915(d), (e), and (f) of the Act, which govern how such waivers are to be approved, continued, monitored, and terminated. Additionally, paragraph (g) of this section implements section 1916(a)(3) and (b)(3) of the Act, which authorizes the Secretary to waive the requirement in those sections that cost-sharing amounts be nominal.

(b) *General requirements.*

(1) HCFA will consider only waiver requests submitted to HCFA by or through the Governor, State cabinet members responsible for State Medicaid agency activities, director of the State Medicaid agency, or by someone with the authority to submit waiver requests on behalf of the director.

(2) In applying for a waiver to implement an approvable project under paragraphs (c), (d), (e), or (f) of this section, a Medicaid agency must document in the waiver request and maintain data regarding:

- (i) The cost-effectiveness of the project;
- (ii) The effect on recipients regarding access to care and quality of services; and
- (iii) The projected impact of the program.

Waiver Text (1981)

Youngberg v. Romeo (1982)

Issue

Whether mentally “R” residents of state hospitals have the constitutional right to:

1. Be free from undue bodily restraint;
2. Personal security and protection; and
3. Adequate treatment.

Finding

Nicholas Romeo and all residents had the right to:

1. Reasonably safe confinement conditions;
2. No unreasonable body restraints; and
3. The habilitation they reasonably require.

Katie Beckett or TEFRA Waiver

A Katie Beckett waiver is a Medicaid waiver concerning the income eligibility for home-based Medicaid services for children under the age of 19.

- Mom's letter to President Reagan
- It is also called a TEFRA waiver because it passed as a provision of the Tax Equity and Fiscal Responsibility Act of 1982.



In 1983, the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), identified the **transition from school to work as one of the major federal priorities of special education programs.**

- “Transition” was officially established in federal law (by a mom, Madeleine Will).
- New Mexico was the last state to participate in federal funding (1994) under P.L. 94-142.

Roncker v. Walter (1983)

Issue

Neill Roncker was 9 years old with an IQ of under 50 when his mother sued the state of Ohio to have him included in a regular classroom, not just Special Education.



The Roncker Portability Test

Finding

- Placement decisions must be individually based.
- Cannot claim a segregated program is superior.
- Must ask whether the same superior service can be provided in a regular class?

Portability Test

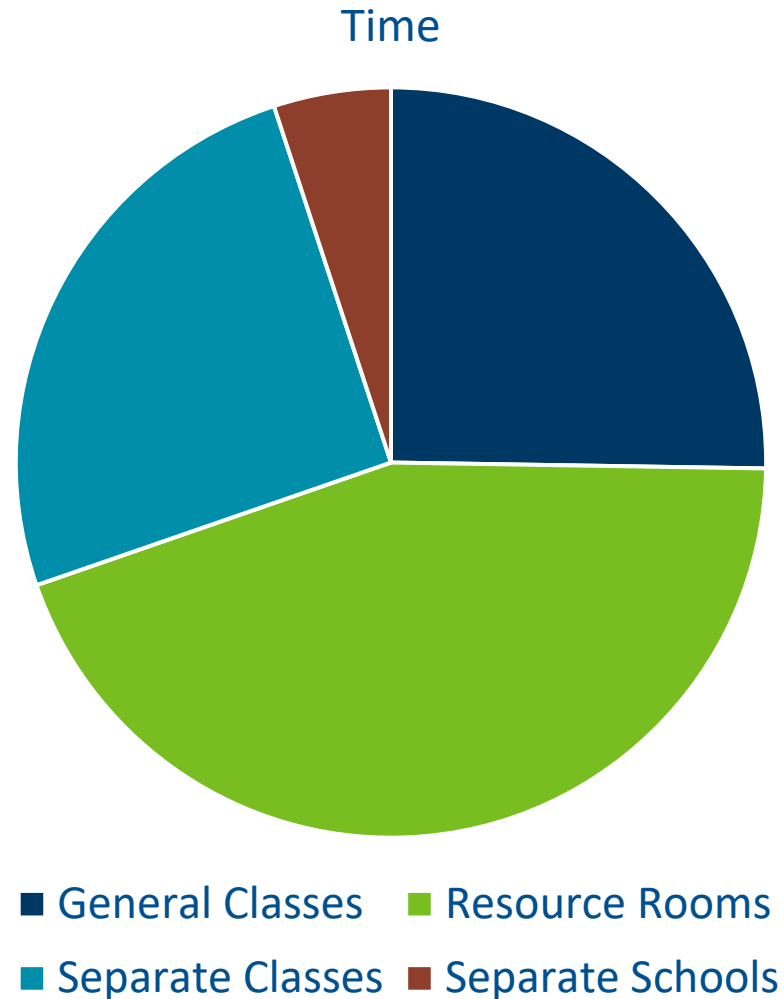
1. What is it in a segregated program that makes it better than an integrated program?
2. Can these things be provided in the regular classroom program?

If they can be, then they should be.

Where do students spend their time?

The answer did not change for 10 years:

- 25% General Classes
- 44% Resource Rooms
- 25% Separate Classes
- 5% Separate Schools



1984 Voting Accessibility for the Elderly and Handicapped Act

All polling places must be accessible to people with disabilities.

1985 Madeleine Will, OSERS, expressed concerns about “pull out programs.”

REI—Regular Education Initiative

What is integration?

- Everyone together
- Special services delivered in regular schools
- Support given to all teachers
- Involvement in all aspects of school
- Friendships
- Neighborhood schools
- Appropriate IEPs

1986 Education for All Handicapped Children's Act:

Part H assists states to develop a statewide network of early intervention services for infants and toddlers with disabilities.

Part C strengthens and coordinates education, training, and related services for youth with disabilities to assist in the transition process.

- Now changed; Part C is for infants and toddlers.



1980s Class

1986 Rehabilitation Act Amendments

States are required to have policies in place about the order in which individuals are selected to receive services (**“order of selection” process**) and to justify those policies.

State plans must:

1. Include a plan for youth transition to employment; and
2. Show how a supported employment program would be implemented.

1986 The Employment Opportunities for Disabled Americans Act

Social Security beneficiaries continue their Medicaid coverage when their eligibility for Supplemental Security Income (SSI) is lost due to receiving Social Security Disability Income (SSDI) benefits.

- “Severe handicap” includes functional and categorical criteria.
- A definition of “employability” is added.

1988 Fair Housing Act Amendments

Prohibit discrimination against individuals with disabilities in the sale or rental of housing.

Air Carrier Access Act

The Federal Aviation Act of 1958 is amended; discrimination is prohibited against “any otherwise qualified handicapped individual” in providing air transportation.

1988 Technology-Related Assistance for Individuals with Disabilities Act

Funds comprehensive statewide programs of technology-related assistance for individuals of all ages with disabilities.



Early AT

5,000 Stories of Discrimination

- Tour of all states to collect stories of discrimination.
- Stories told by people with disabilities and family members.
- Led to Congressional testimony and meetings.
- Task force was chaired by a parent (Elizabeth Boggs, Ph.D.), and a person with a disability (Justin Dart). One self-advocate served (Connie Martinez).

1990 Americans with Disabilities Act (ADA)

Landmark federal legislation provides a “clear and comprehensive national mandate for the **elimination of discrimination** against individuals with disabilities.”

Four Sections Under the ADA:

- ★ Title I prohibits discriminatory **employment** practices;
- ★ Title II prohibits discrimination in **public services**, including transportation;
- ★ Title III prohibits discrimination in public accommodations and services operated by **private entities**;
- ★ Title IV requires **telephone companies** serving the general public to provide interstate and intrastate telecommunication relay services for persons who are deaf, hearing and speech impaired. Closed captioning required for public service announcements produced or funded by a federal agency.



President Signing the ADA

1990 The Individuals with Disabilities Education Act (IDEA)

New name for the Education Of All Handicapped Children's Act.

1991 Civil Rights Act Amendments

The 1964 Act was amended to protect covered workers in employment discrimination cases. Money damages can be awarded for intentional discriminatory acts based on sex, religion, or disability.

Home of Your Own

1991 Federal “Home of Your Own” Initiative was launched.



Presumption of Employability

1992 Rehabilitation Act Amendments

Title I included a presumption that individuals with disabilities, including individuals with severe disabilities, are **“capable of engaging in gainful employment**, and the provision of individualized vocational rehabilitation services can improve their ability to be gainfully employed” (§100).

1992 Title VII of the ADA establishes standards and assurances for independent living centers and includes a statement of the independent living philosophy:

“Consumer control of the center regarding decision making, service delivery, management, and establishment of the policy and direction of the center; self-help and self-advocacy; development of peer relationships and peer role models; and equal access of individuals with severe disabilities to society and to all services, programs, activities, resources, and facilities, whether public or private and regardless of the funding source” (§ 725).

Oberti v. Clementon (1993)

- The Clementon School District had failed to provide training of staff;
- The burden was placed on the school and not the family;
- “**Inclusion is a right**, not a special privilege for a select few.”



Landmark Cases

1994 Developmental Disabilities Assistance and Bill of Rights Act

Amendments recognize that “**disability is a natural part of the human experience** that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and education mainstream of American society.” (§ 101)

1994 State Developmental Disabilities Councils

Required to conduct “systemic change, capacity building, and advocacy activities,” (§ 124).



1997 Amendments to IDEA

- 6 million students in special education
- Employment rates are better
- Zero reject
- Non-discriminatory evaluation
- Appropriate education
- Outcomes and standards



What is Inclusion?



- All children can learn.
- All children can attend age appropriate educational classes in local schools.
- All children can receive appropriate education.
- All children receive a curriculum/extra curricular activities that meet needs.
- All children benefit from collaboration.

Inclusion looks like ...



Congressional Actions

1998 Workforce Investment Act



Assistive Technology Act

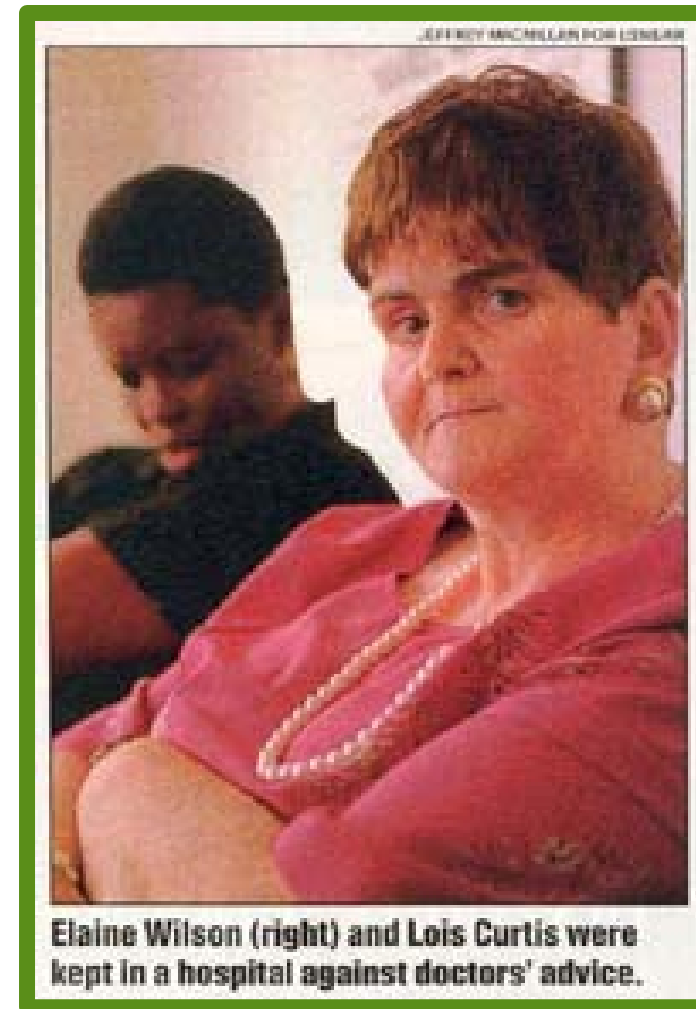


1999 Ticket to Work and Work Incentives Improvement Investment Act



Olmstead v. L.C. (1999)

The U.S. Supreme Court held that **unjustified segregation of persons with disabilities constitutes discrimination** in violation of Title II of the ADA.



National Council on Disability

- Every state is out of compliance with IDEA.
- Low expectations.
- Insufficient focus on research.



Congressional Acts in the 2000s

Legislation in the early 2000s

2001 No Child Left Behind Act

2002 Help America Vote Act (HAVA)

2004 Individuals with Disabilities Education Improvement Act (IDEA 2004)



Other legislation in the 2000s

2004 AT Act was reauthorized

2005 Air Carriers Rule – accessibility extended to foreign carriers

2008 Americans with Disabilities As Amended Act

2010 Affordable Care Act

- 2014 Work Innovations and Opportunities Act
- 2014 Achieving Better Life Experience Act (ABLE)
- 2014 Section 503 = 7% hiring goal for federal contractors
- 2014 Centers for Medicare and Medicaid Services (CMS) issues Final Rule for Waivers

Accessible Communications

- Lawsuits dealing with websites, testing, online banking and transactions (Amazon, Target);
- Lawsuits about theaters and closed captioning (CC);
- New standards for Information and Communication Technology.

In the last 10 years, there have been changes in the field:

- Person Centered Planning
- Positive Behavior Supports
- Department of Justice Actions

Thank You!

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