# Developmental Disabilities Then and Now Where have we been? Where are we going?

James Coplan, MD, FAAP

Neurodevelopmental Pediatrics of the Main Line, PC Rosemont, PA 19010 www.drcoplan.com



Exceptional Family Member Program Annual Disability Awareness Day – 10/27/2011 Fort Campbell, KY Survival of the Fittest

**Eugenics** 

Discrimination

- Race
- Disability
- Other....

Universal human rights

### Eugenics

### **Darwin**, 1859

ON

#### THE ORIGIN OF SPECIES

BY MEANS OF NATURAL SELECTION,

OR THE

PRESERVATION OF FAVOURED RACES IN THE STRUGGLE FOR LIFE,

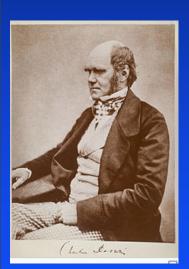
BY CHARLES DARWIN, M.A.,

FELLOW OF THE BOYAL, GEOLOGICAL, LINNEAN, ETC., SOCIETIES;
AUTHOR OF 'JOURNAL OF RESHABCHES DURING H. M. S. BEAGLE'S VOYAGE
BOUND THE WORLD.'

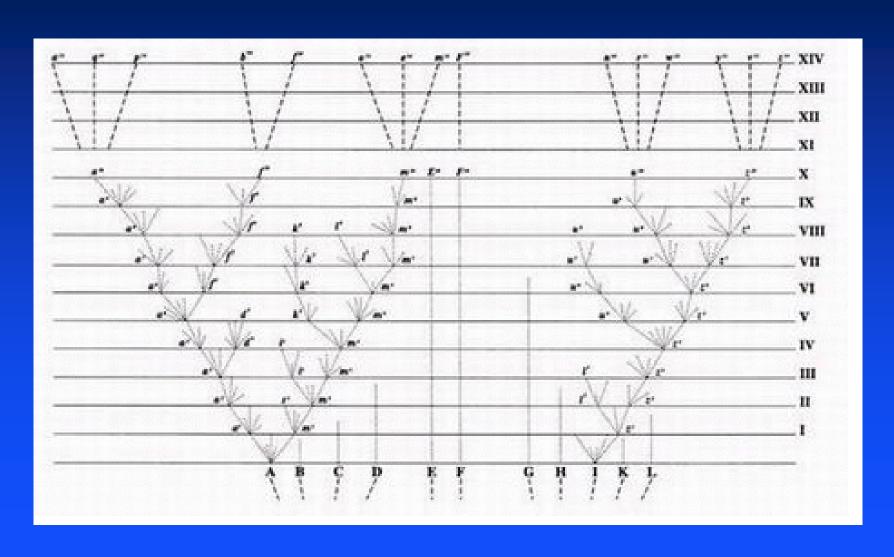
LONDON:

JOHN MURRAY, ALBEMARLE STREET.

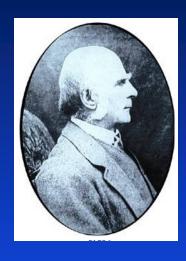
1859.



### Darwin, 1859



### Social Darwinism & Eugenics



#### **EUGENICS**

"IS THE STUDY OF THE AGENCIES UN-DER SOCIAL CONTROL, THAT IMPROVE OR IMPAIR THE RACIAL QUALITIES OF FUTURE GENERATIONS EITHER PHYSICALLY OR MEN-TALLY."

SIR FRANCIS GALTON. 1863

arean Date (intensity: Sensormental, educational case only

- Francis Galton (Darwin's cousin)
- Coined the term "Eugenics": Helping mother nature along by promoting breeding by "fitter" persons and discouraging or preventing breeding by less "fit" persons
- Social Darwinism: Inherent superiority of white race
  - Justification for Imperialism / Colonialism

### Alexander Graham Bell

"The influence of selection in modifying our breeds of animals is most marked, and it is reasonable to suppose that if we could apply selection to the human race we could also produce modifications or varieties of men."

A.G. Bell, 1883

### Alexander Graham Bell

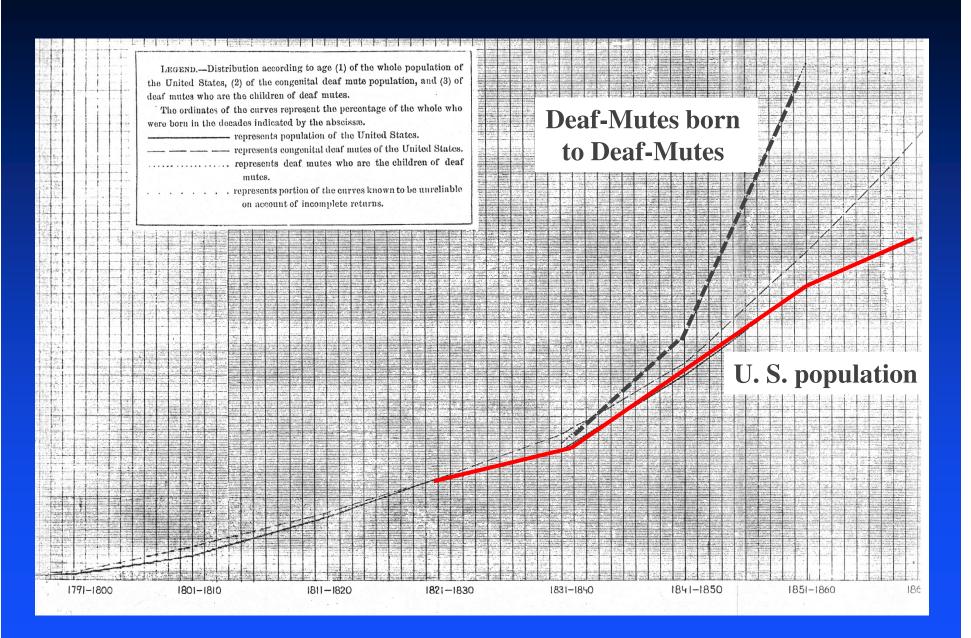
MEMOIR

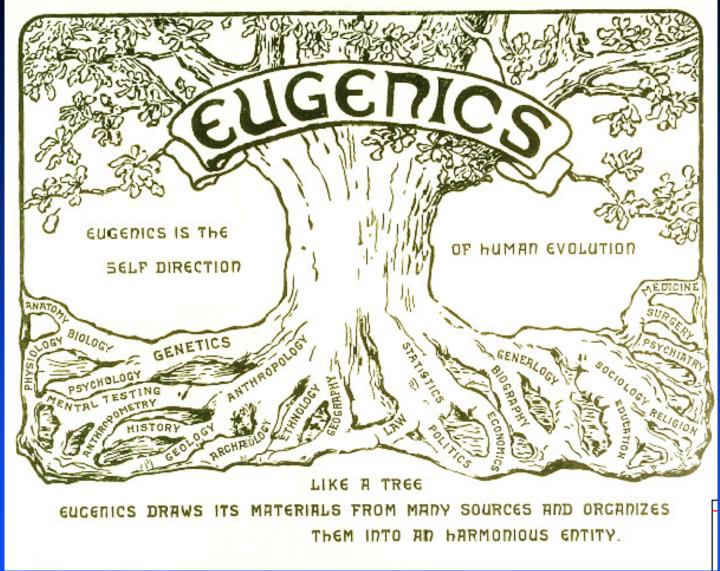
UPON THE FORMATION OF A DEAF VARIETY OF THE HUMAN RACE.

BY

ALEXANDER GRAHAM BELL

"The influence of selection in modifying our breeds of animals is most marked, and it is reasonable to suppose that if we could apply selection to the human race we could also produce modifications or varieties of men." A.G. Bell, 1883





http://en.wikipedia.org/wiki/International\_Eugenics\_Conference

Logo of the Second International Eugenics Congress, NY, NY (1921)

### "The White Man's Burden"

**Rudyard Kipling, 1899** 

Take up the White Man's burden-Send forth the best ye breed-Go bind your sons to exile
To serve your captives' need;
To wait in heavy harness,
On fluttered folk and wild-Your new-caught, sullen peoples,
Half-devil and half-child.....

Take up the White Man's burden-And reap his old reward:
The blame of those ye better,
The hate of those ye guard-The cry of hosts ye humour
(Ah, slowly!) toward the light:-"Why brought he us from bondage,
Our loved Egyptian night?"....

http://www.fordham.edu/halsall/mod/kipling.asp

"White people have an obligation to rule over, and encourage the cultural development of people from other ethnic and cultural backgrounds until they can take their place in the world economically and socially...The rich have a moral duty and obligation to help "the poor" "better" themselves"

http://en.wikipedia.org/wiki/The\_White\_Man's\_Burden

#### Brains and the Immigrant

(The Second Article of the Series on The Nordic Myth)

By MELVILLE J. HERSKOVITS

THE sea was rough, and there were few people in the dining-room. The chief officer, a tall, blond, blueeyed, stalwart American, was talking about it. "What do you expect from those Germans? They're so dumb they don't know enough to keep from eating dill pickles and salami when they're seasick. I tell you," and he grew reminiscent, "you'd be thankful, too, that they passed those restriction laws for immigrants if you could have run back and forth between Europe and America since the war like I have. Those Polacks! You see 'em looking around after 'em as if wondering where the mud of the barnyard is on the ship. And they're dumb, just dumb. They don't

accent, or contravenes some of the ways of action to which we are accustomed, excites in us an emotion out of all proportion to the action which has aroused the feeling in us. Even this, however, may be set aside if the pattern of the society calls for it: thus, in Europe, the mispronunciation of a word by a foreigner does not excite the ridicule which this act occasions in the United States; however, people do become irritated when inbred patterns of behavior are not adhered to.

The early rationalization of this irritation followed the studies on head-form which announced the existence of the Teutonic race. This race was supposed to be the

#### NEGROID SANE CRIMINALS AND NEGROID CIVIL INSANE

MOSAIC OF METRIC DIFFERENCES

More inner eyefolds

Higher eye-openings

Smaller brow ridges Higher, narrower nasal roots,

More downward inclined septa Thinner nasal tips

Thicker integumental and

malars and jaw angles

Fuller cheeks, more wrinkles

higher bridges

membranous lips More pronounced lip seams Broader jaws, less chin prominence More pointed chins, more prominant

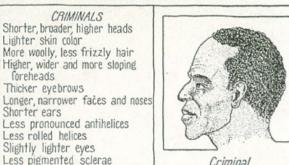
More prognathism



Criminal



Civil Insane



Criminal



Civil Insane

#### RACIAL DIFFERENCES IN MENTAL FATIGUE

PREJENTED BY THOS. R. GARTH. PH.D. DEPT. OF PSYCHOLOGY-UNIV. OF TEXAS WORK CURVES OF WHITES, INDIANS & NEGROES BEING RESULTS OF A CONTIN-UOUS MENTAL PERFORMANCE, WITH A COMPARISON OF WHAT WAS DONE IN THE FIRST & LAST SIX MINUTES-%3 WHITES INDIANS-NEGROES -

COMPARISON OF FIRST & LAST SIX MINUTES INDIANS GAINED 3.25% WHITES LOST 3.00% NEGROES LOST 12.10%

FIG-1- AVERAGE OF THE INDIVIDUAL CURVES ATTEMPTED PERFORMANCE-YOUNGER GROUPS 3D 4TH 5TH GRADBS

#### J. Langdon Down, MD

ON SOME OF THE

#### MENTAL AFFECTIONS

OF

#### CHILDHOOD AND YOUTH

BEING

#### THE LETTSOMIAN LECTURES

DELIVERED BEFORE THE MEDICAL SOCIETY OF LONDON IN 1887

#### TOGETHER WITH OTHER PAPERS

BY

#### J. LANGDON DOWN, M.D.LOND.

FELLOW OF THE ROYAL COLLEGE OF PHYSICIANS OF LONDON; SENIOR PHYSICIAN TO, ANI LECTURER ON CLINICAL MEDICINE AT, THE LONDON HOSPITAL; FORMERLY LECTURER ON MEDICINE, MATERIA MEDICA, AND COMPARATIVE ANATOMY AT THE LONDON HOSPITAL: AND PHYSICIAN TO THE EARLSWOOD ASYLUM

- First description of autism
- First description of what we now call "Down Syndrome" (Trisomy 21)
- First attempt to classify causes of mental disability

### "Observations on an Ethnic Classification of Idiots" J. Langdon Down, 1866

"Among the large number of idiots and imbeciles that have come under my observation....a considerable portion can be fairly referred to one of the great divisions of the human family other than the class from which they have sprung...A very large number of idiots are *congenital mongols*. So marked is this that, when placed side by side, it is difficult to believe that the specimens compared are not children of the same parents."

### "Mongolism" (Down Syndrome; Trisomy 21)





single palmer crease, short fifth finger that curves inward

widely separated first and second toes and increased skin creases

Copyright the Lucina Foundation, all rights reserved.

### **International Eugenics Movement**

#### First International Eugenics Congress (1912)

London, 1912. British Eugenics Education Society; American Breeders' Association; 400 delegates including many governmental dignitaries. Leonard Darwin, the son of Charles Darwin, presiding. One speaker proposes compulsory sterilization as the best method to cut off "defective germ-plasm."

#### **Second International Eugenics Congress (1921)**

American Museum of Natural History, NYC. Supported by U.S. State Department. Alexander Graham Bell honorary president. L. Darwin advocates eugenic measures aimed at "elimination of the unfit."

#### **Third International Eugenics Congress (1932)**

American Museum of Natural History. Predicts the doom of civilization unless eugenic measures are implemented. (Nazis cite conference recommendations as basis for their policies.)

## THE AMERICAN EUGENICS SOCIETY

Round Table Conferences
And Annual Meeting

General Topic:
A EUGENICS PROGRAM FOR AMERICA

Thursday, May 7, 1936

At DELMONICO HOTEL

502 PARK AVENUE, NEW YORK CITY

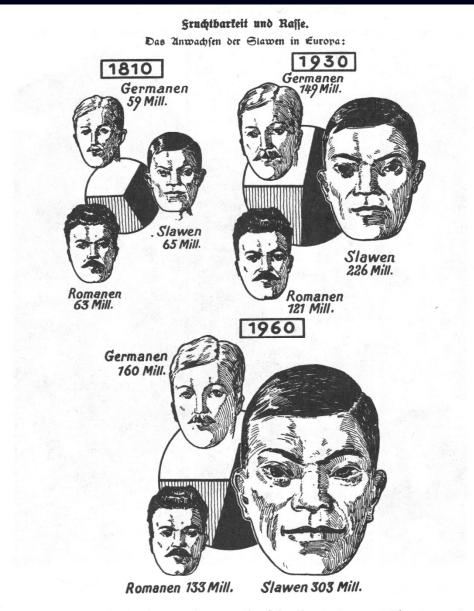


Figure 4. "Fertility and Race, the Growth of the Slav in Europe." The proportions of Germanic, Slavic, and Latin "races" in 1810 and 1930 are compared to those anticipated in 1960. From Helmut, Volk in Gefahr, p. 33.



"We are not alone." Nazi poster promoting forced sterilization of unfit persons. Flags: Other countries that supposedly had or were considering similar policies.



Figure 36. "The Prussian Government Provides Annually the Following Funds for: a Normal Schoolchild (125 RM); a Slow Learner (573 RM); the Educable Mentally Ill (950 RM); and Blind or Deaf-Born Schoolchildren (1,500 RM)." This illustration depicts the burden of maintaining the socially unfit. From Volk und Rasse, 8(1933): 156.



This poster (from around 1938) reads: "60,000 Reichsmarks is what this person suffering from a hereditary defect costs the People's community during his lifetime. Fellow citizen, that is your money too. Read 'A New People', the monthly magazine of the Bureau for Race Politics of the NSDAP."



### **American Eugenics Party**

P.O. BOX 38068
LOS ANGELES, CALIFORNIA 90038

#### AMERICAN EUGENICS PARTY PLATFORM

The following Platform of the AMERICAN EUGENICS PARTY is presented to unite individuals and organizations in the United States and throughout the world in opposition to the dysgenic forces. With an increasing number of supporters for all, if not most, of the Platform, the eventual attainment of a Eugenic Society is assured:

#### 1. RACE AND STOCK PURITY

National laws must be enacted to prohibit marriage between the races and to encourage stock (ethnic group) purity. The negroes are too different genetically and will always be a source of conflict. Negroes must be resettled in Africa. The remaining genetic types are similar enough to associate amiably with one another, but the tendency for the different genetic types to live, work, and play in separate ghettos is to be encouraged.

#### 2. NO PERSECUTION

No race or stock is to be harshly treated. All caucasian stocks (Germans, Jews, Italians, Poles, etc.) are to remain separate and free from persecution or abuse and must unite to ward off the non-caucasian genetic threat.

#### 3. QUANTITY CONTROL

The United States is already over-populated. We must stop all immigration and impose birth controls.

#### 4. QUALITY CONTROL

Those genetic types within each race and stock having better traits will be encouraged to produce more offspring and those having the lesser qualities will be restricted in the number of their offspring.



### Plessy v. Ferguson, 1896

Supreme Court of the Muited States,

No. 210, October Term, 1895.

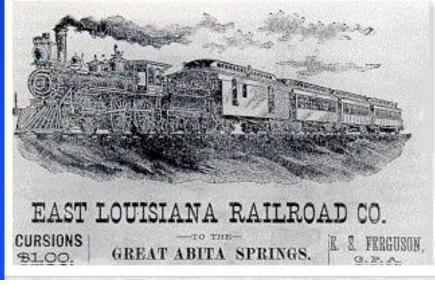
Aomer Adolph Plessy
Raintiffin Bror,

Vol.

J. A. Ferguson, Judge of Section "A"

Oriminal District Court for the Parish

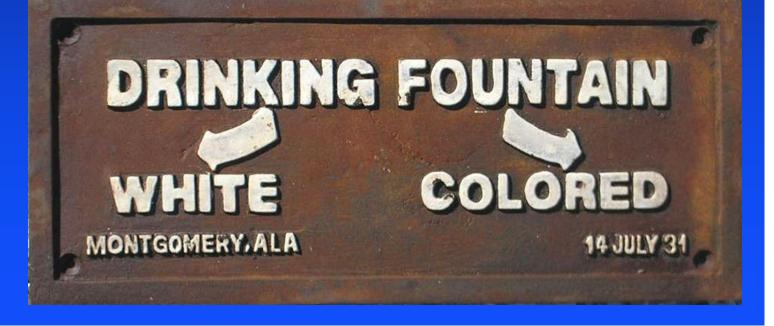
of Orleans.

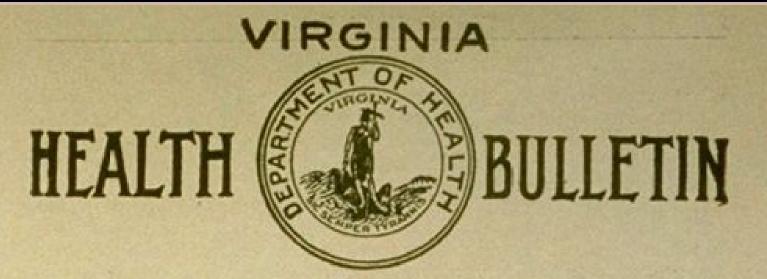


Supreme Court endorses "Separate but equal..."

8 to 1







Vol. XVI.

MARCH, 1924.

Extra No. 2.

#### The New Virginia Law

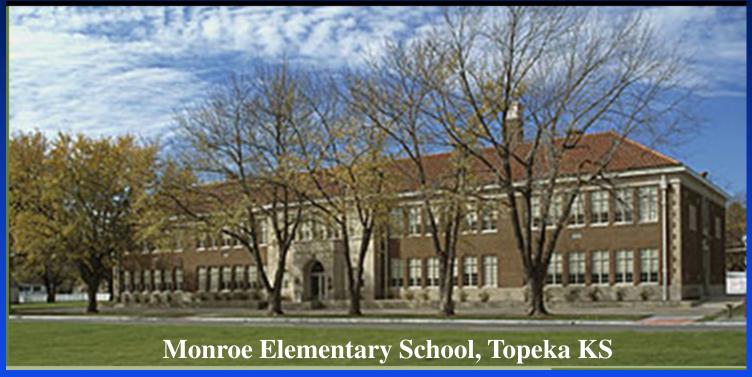
### To Preserve Racial Integrity

It is estimated that there are in the State from 10,000 to 20,000, possibly more, near white people, who are known to possess an intermixture of colored blood, in some cases to a slight extent it is true, but still enough to prevent them from being white.

In the past it has been possible for these people to declare themselves as white, or even to have the Court so declare them. Then they have demanded the admittance of their children into the white schools, and in not a few cases have intermarried with white people.

### Brown v. Board of Education, 1954

United States Supreme Court unanimously overturns Plessy



Linda Brown, a third grader, had to walk six blocks to her school bus stop to ride to Monroe Elementary, her segregated black school one mile away, while Sumner Elementary, a white school, was seven blocks from her house.

"In the field of public education, the doctrine of 'separate but equal' has no place. Separate educational facilities are *inherently* unequal."

### Little Rock, AK (1957)

• Gov. Orval Faubus orders AK Nat'l Guard to prevent black students from entering Little Rock Central H.S., defying Supreme Court ruling in *Brown* 



### Little Rock, AK (1957)

- President Eisenhower federalizes AK Nat'l guard, orders them to return to barracks
- Deploys units of the 101<sup>st</sup> Airborne from Ft. Campbell to escort black students, and to maintain order



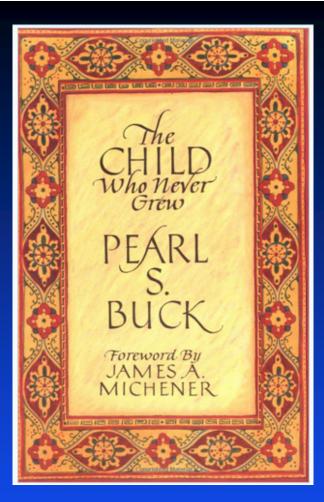


U.S. Army troops from the 101st Airborne Division disperse a crowd in front of Little Rock's Central High School.



"The Problem We All Live With" – Norman Rockwell, 1964

### Disability



"In a simple and moving little book, Pearl Buck has told her story; other parents in like case may find help and comfort from it."

> —TIME (July 1950)

#### The Child Who Never Grew

I have been a long time making up my mind to write this story. It is a true one, and that makes it hard to tell. Several reasons have helped me to reach the point this morning, after an hour or so of walking through the winter woods, when I have finally resolved that the time has come for the story to be told. Some of the reasons are in the many letters which I have received over the years from parents with a child like mine. They write to ask me what to do. When I answer I can only tell them what I have done. They ask two things of me: first, what they shall do for their children; and, second, how shall they bear the sorrow of having such a child?

The first question I can answer, but the second is difficult indeed, for endurance of inescapable sorrow is something which has to be learned alone. And only to endure is not enough. Endurance can be a harsh and bitter root in one's life, bearing poisonous and gloomy fruit, destroying other lives. Endurance is only the beginning. There must be acceptance and the knowledge that sorrow fully accepted brings its own gifts. For there is an alchemy in sorrow. It can be transmuted into wisdom, which, if it does not bring joy, can yet bring happiness.

The final reason for setting down this story is that I want my child's life to be of use in her generation. She is one who has never grown mentally beyond her early childhood, therefore she is forever a child, although in years she is old enough now to have been married and to have children of her own—my grandchildren who will never be.

### The ARC

- 1950: Founded as *National Association of Parents and Friends of Mentally Retarded Children* (shortened to "The Association for Retarded Children")
- 1952: Creates a Research Advisory Board
- 1963: Promotes passage of the Mental Retardation Facilities Construction Act (P.L. 88-164)
- 1964: Issues Manual of Information for Armed Forces Personnel with Mentally Retarded Dependents
- 1968 +: Advocates de-institutionalization
- 1973: Renamed Association for Retarded Citizens
- 1992: Renamed The ARC

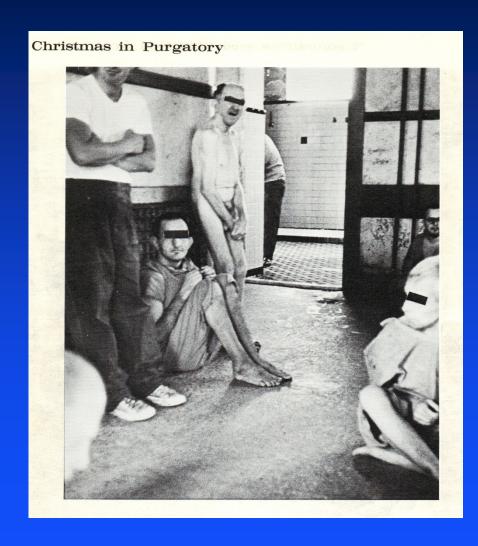
### JFK: 1960-1963

- 1961: Convenes panel of experts to develop "A National Plan to Combat Mental Retardation."
- 1963: Addresses Congress to urge passage of the Maternal and Child Health and Mental Retardation Planning Act, and the Community Mental Health Construction Act (passed, October 1963)

#### Today:

- Mental Retardation & Developmental Disabilities Research Centers (MRDDRS's)
- Leadership Education in Neurodevelopmental & Related Disabilities (LEND)
- Administration on Developmental Disabilities (ADD)
- University Centers on Excellence in Developmental Disabilities (UCEDDs)

### 1960s-70s: De-Institutionalization





#### CHRISTMAS IN PURGATORY

A Photographic Essay on Mental Retardation

To Jain & Judy leave with cipation who we were out it in hy to have and have been and the parties of the freedom to have been and the present of the present

BURTON BLATT
Syracuse University
Centennial Professor and
Director, Division of Special
Education and Rehabilitation

FRED KAPLAN
Black Star Corporation

HUMAN POLICY PRESS / SYRACUSE, NEW YORK / 1974

# Education for All Handicapped (EHA): Public Law 94-142 (1975)

- Federal Grant to the States, which requires recipient states to provide:
  - Universal access (Free and appropriate public education; FAPE)
  - Least restrictive environment (LRE)
  - Due Process
- Before PL 94-142, U.S. public schools educated only 1 out of 5 children with disabilities...More than 1 million children had no access to the public school system...Another 3.5 million children attended school but were "warehoused" in segregated facilities and received little or no effective instruction\*

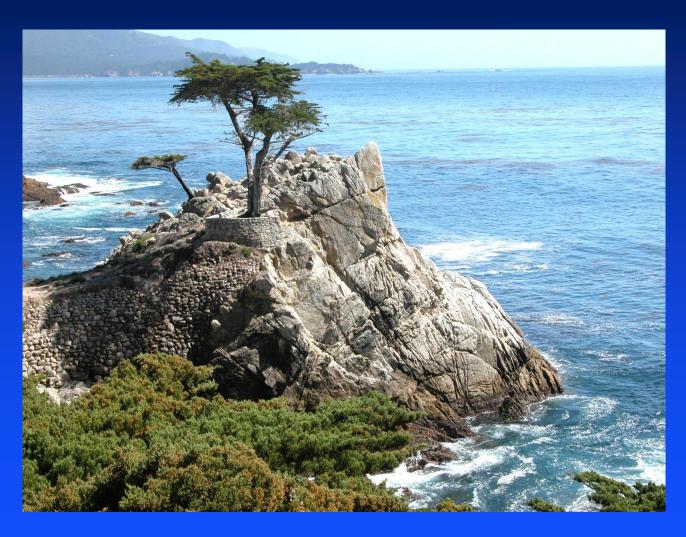
## 1990: Renewed & renamed Individuals with Disabilities Education Act (IDEA)

<sup>\*</sup> http://en.wikipedia.org/wiki/Individuals\_with\_Disabilities\_Education\_Act

#### Americans with Disabilities Act (1990)

- Non-discrimination in the workplace
- Physical access
  - Curb cuts
  - Wheelchair accessible bathrooms, etc.
    - Tennessee v. Lane 2004
      - George Lane: paraplegic
      - Polk County Courthouse: 2<sup>nd</sup> floor, no elevator
      - State claims "Sovereign Immunity"
      - SCOTUS: 5 to 4 in favor of Lane
- ADA updated & strengthened several times

### Summing Up



### "Then"

- White upper class monoculture
  - British
  - American
  - German
  - Many other "civilized" societies
- Pseudo-science
- Reinforced pre-existing behaviors in the dominant culture
  - Racial & ethnic stereotyping
  - Imperialism
  - Value set: Conformity, uniformity
- Those who were different received:
  - Exclusion / Punishment, or
  - Charity

### "Now"

- Greater tolerance of diversity, but the range of tolerance varies
- Help others not because it is "charity," but because it is the right thing to do
- Today's science is more open, but there is always the danger of "group think"
- Advances have occurred as a result of individual bravery plus cultural circumstances
  - Rosa Parks
  - Linda Brown; The Little Rock 9
  - George Lane

#### Resources

- www.wrightslaw.com
- http://www.wrightslaw.com/info/mil.children.barriers.htm
- <a href="http://www.wrightslaw.com/info/dod.index.htm">http://www.wrightslaw.com/info/dod.index.htm</a>
- http://www.stompproject.org/about.asp
- http://www.militarychild.org/education/special-educationleaders-institute/
- http://www.militaryk12partners.dodea.edu/index.cfm
- Married with special needs children (A couple's guide to keeping connected). Marshak LE & Prezant, FP. Woodbine House.
- Man's Search for Meaning. Victor Frankl. (Amazon)



Exceptional Family Member Program 5661 Screaming Eagle Blvd. Ph: 270-798-2727

Life Journey through Autism: A Guide for Military Families



### The Future....

NOT THIS.....

Survival of the Fittest

**Eugenics** 

Racial Discrimination

Rights of the Disabled

Universal human rights

### The Future

...BUT THIS

Survival of the Fittest

Universal human rights

### Challenges

- Special Education
  - Preserving legal gains in times of financial hardship
- Adult services
  - Mental Health
  - Housing
  - Employment
  - Life care ("Who will care for my child after I'm gone?")

#### Disability Rights Network of Pennsylvania

Home Publications Links Contact Espanol/Other Languages Donate About

#### ACT NOW TO PREVENT BURDENSOME CO-PAYS FOR PENNSYLVANIA'S FAMILIES!

ACT NOW TO PREVENT BURDENSOME CO-PAYS FOR PENNSYLVANIA'S FAMILIES!

October 21st, 2011

#### Friends -Does your child qualify for Medical Assistance because he/she has a disability?

If so, you should know about a new regulation that instructs the Department of Public Welfare (DPW) to require families to pay copays for services provided under Medical Assistance to children with disabilities.

Adjust text size: A

Search

Sea

#### **Publications**

- Accessibility ar
- Assistive Tech
- Assistive Tech Assistance (Me Eligibles
- Assistive Tech Facilities
- Assistive Tech
  Appeals
- Augmentative Devices (Spee
- Autism
- Children in Our
- Education
- Education: Fac

- Personal Value Set
  - Making meaning out of what life gives us
  - As the parent or caregiver for children with special needs, you are also the guardians of society's conscience.
  - Ignore your rights.....and they'll go away
  - Well-behaved people seldom make history
  - Be not afraid of greatness: some are born great, some achieve greatness, and some have greatness thrust upon them
  - "Be all that you can be."

## Thank you