

Obstacles to Adult ID Service Eligibility for People With FASD:



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I have been involved professionally in the field of Intellectual Disabilities (ID) for 35+ years (and as a family member for 65+ years)

A big reason for my interest in ID ➡



(AT ONE TIME
HE WAS
SERVED IN AN
ARC DAY
PROGRAM, IN
UPSTATE NY)

MY BROTHER ALAN GREENSPAN
A DIFFERENT KIND OF ECONOMIST

(HE COLLECTS QUARTERS—
BETTER THAN DERIVATIVES?)

MY INTEREST IN INEQUITIES
IN ID ELIGIBILITY PROCEDURES
REFLECTS IN PART THE FACT
THAT ALAN (WHO HAS AN
ASD) HAD AN IQ THAT WAS A
LITTLE TOO HIGH, AND AS A
RESULT IT WAS DIFFICULT TO
GET NEEDED SERVICES, IN
SPITE OF VERY SEVERE
SUPPORT NEEDS



SO EARLY ON, I BECAME CONCERNED ABOUT THE DISTORTING
EFFECTS OF IQ CEILINGS ON ID ELIGIBILITY FORMULAE—THIS IS A
HUGE PROBLEM FOR PEOPLE WITH FASD

PEOPLE WITH FASD (and other brain-based disorders, such as ASD, where IQ is often a little too high) RECEIVE



THIS UNEQUAL
TREATMENT STEMS FROM
THE FACT THAT THEY ARE
DENIED SUPPORTS AND
PROTECTIONS GIVEN TO
OTHERS WHOSE NEEDS
AND IMPAIRMENTS ARE
NO GREATER (AND
SOMETIMES LESSER) BUT
WHO HAVE FULL-SCORE
IQ SCORES THAT MEET
THE ARTIFICIAL
ELIGIBILITY CEILING



SERVICES,
SUPPORTS &
PROTECTIONS

When I lived in
Connecticut I
served on the
board of the
former Hartford
ARC



When AAMR was considering switching to AAIDD,
there were many HARC staff and board members
opposed to the new terminology

Within AAIDD I also was a board member and have served on their terminology and classification committee



When the switch to ID was being considered, I urged them to consider broadening the category to include people with brain-based disorders but where IQ scores often are a little too high

My suggestion was rejected for the same reason there was reluctance to adopt the switch from MR to ID

The reason for
this reluctance?



CONCERN THAT THE MONEY PIE IS NOT BIG ENOUGH TO
ACCOMMODATE MORE CLIENTS WITHOUT DILUTING
FUNDS AVAILABLE FOR PEOPLE ALREADY BEING SERVED

FASD IS A NEURO- DEVELOPMENTAL DISORDER



MEANING IT IS CONGNITAL AND REFLECTS A
PROBLEM IN BRAIN FORMATION THAT AFFECTS
COGNITIVE AND SOCIAL DEVELOPMENT

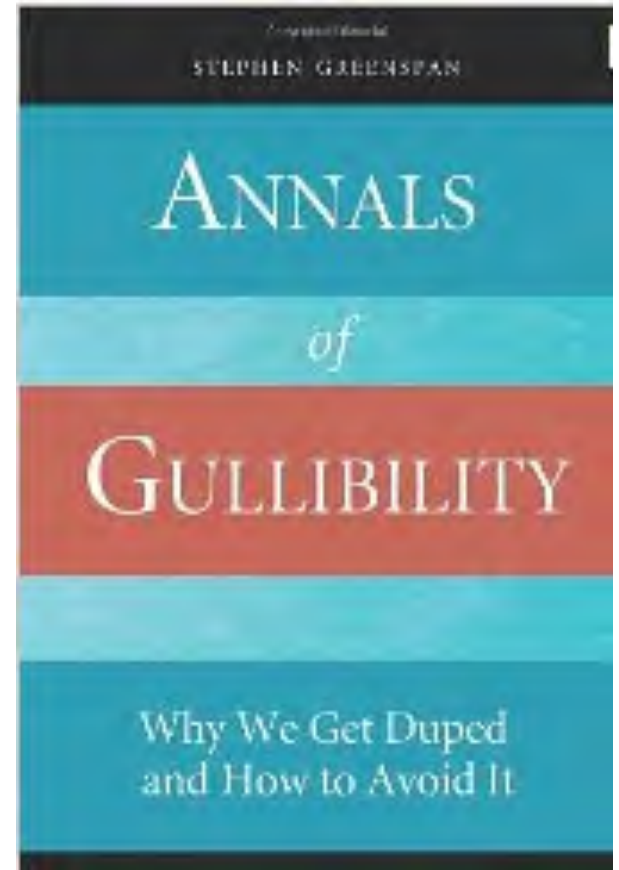
THERE ARE MANY OTHER SUCH DISORDERS,
MOSTLY LOWER IN FREQUENCY

ONE THING THAT FASD HAS IN COMMON WITH MANY OTHER NEURODEVELOPMENTAL DISORDERS IS THAT IQ SCORES MAY BE ABOVE OR BELOW 70 (SCORES HAVE GONE UP BECAUSE OF EARLY INTERVENTION) BUT THIS NUMBER IS NOT A RELIABLE BASIS FOR SAYING THAT SOMEONE DOES OR DOES NOT HAVE PROBLEMS IN JUDGMENT AND THINKING (OR NEED FOR SERVICES)



A CHILD WITH **PRADER-WILLI SYNDROME**, ONE OF MANY NEURO-DEVELOPMENTAL DISORDERS WHERE AVERAGE IQ FALLS BELOW AND ABOVE 70 IQ CEILING

I HAVE BEEN ARGUING FOR YEARS THAT SOCIAL INCOMPETENCE, SUCH AS EXTREME GULLIBILITY, IS MORE IMPORTANT AS AN INDICATOR OF ID THAN IQ SCORE



MY 2009 BOOK, DEDICATED TO RICHARD LAPOINTE, A MAN WITH DANDY-WALKER SYNDROME WHO WAS GIVEN A LIFE SENTENCE FOR A MURDER HE DID NOT COMMIT, AS A RESULT OF HIS GULLIBILITY IN AN INTERROGATION SESSION

WHEN I FIRST STARTED TO
WRITE IN THE 1990'S ABOUT
GULLIBILITY (JUST AS WHEN I
EARLIER WROTE ABOUT
SOCIAL INTELLIGENCE IN THE
1980'S) I WAS MET WITH
SKEPTICISM AND DOUBT BY
COLLEAGUES



Scoffers



BUT I HAVE YET TO MEET A FAMILY MEMBER OF SOMEONE WITH A NEURO-DEVELOPMENTAL DISORDER WHO DID NOT TELL ME THAT THE SOCIAL VULNERABILITY OF THEIR CHILD OR SIBLING TO MANIPULATION AND EXPLOITATION WAS AT OR NEAR THE TOP OF THEIR LIST OF CONCERNS

(JUST AS I EARLIER I MET FEW FAMILIES WHO ARE NOT CONCERNED ABOUT LACK OF FRIENDS, CAUSED BY IMPAIRMENTS IN SOCIAL INTELLIGENCE)

THE REASON FOR
SCOFFING STEMMED
FROM THE WIDESPREAD
BELIEF THAT SERVICE
SYSTEM ELIGIBILITY
(INCLUDING MITIGATION
IN CRIMINAL CASES) CAN
BE DETERMINED
ADEQUATELY MAINLY
THROUGH AN IQ
SCORE,BELOW AN
ARBITRARY NUMBER
(TYPICALLY 70)

KING IQ



STILL ON HIS THRONE

THIS OVER-EMPHASIS ON IQ IN CRIMINAL
CASES COMES UP ALL OF THE TIME



YOKOMAN HEARN HAD FASD, AND:

- BIG DISCREPANCY BETWEEN VERBAL
AND NONVERBAL IQ
- SUBSTANTIAL DEFICITS IN
“EXECUTIVE FUNCTIONING”

YOKOMAN HEARN
RECENTLY-
EXECUTED TEXAS
INMATE

**HE WAS DENIED “ATKINS”
RELIEF (EXEMPTION FROM
THE DEATH PENALTY
BECAUSE OF INTELLECTUAL
DISABILITY) SOLEY BECAUSE
HIS IQ SCORE WAS OVER 70
(SOMETHING THAT IS
TYPICALLY TRUE OF PEOPLE
WITH FASD)**



**IN AN AFFIDAVIT, I CONVINCED A FEDERAL JUDGE TO TAKE
A BROADER VIEW OF HEARN’S “INTELLIGENCE”
(BECAUSE IN FASD, OTHER INDICES SUCH AS EXECUTIVE
FUNCTIONING ARE MORE MEANINGFUL)**

I TESTIFY OFTEN AS A DEFENSE EXPERT IN CRIMINAL TRIALS (OR POST-CONVICTION HEARINGS) WHERE PEOPLE WITH ID ARE FACING THE DEATH PENALTY



ONE OF THE ISSUES THAT COMES UP IN SUCH SO-CALLED “ATKINS” CASES (NAMED AFTER THE 2002 US SUPREME COURT DECISION IN *ATKINS V. VIRGINIA*) IS WHETHER OR NOT THE JURISDICTION HAS A “BRIGHT LINE” PROVISION REGARDING THE IQ CEILING USED TO DETERMINE IF A DEFENDANT MEETS THE FIRST (“INTELLECTUAL FUNCTIONING”) DEFINITIONAL PRONG

A BRIGHT LINE

THE TERM REFERS TO THE
USE OF AN ABSOLUTE
CEILING SCORE, AS
OPPOSED TO AN
UNDERSTANDING THAT
NO TEST SCORE IS
COMPLETELY RELIABLE



THERE ARE SOME JURISDICTIONS (SUCH AS
ALABAMA AND ARKANSAS) WHERE THE
CRIMINAL STATUTE DEFINES PRONG ONE OF ID
FOR ATKINS PURPOSES AS AN “IQ BELOW 70”

(IN OTHER WORDS: 69 YOU LIVE, 71 YOU DIE)

THIS BRINGS ME TO A



(WHICH IS ACTUALLY NOT MUCH OF A SECRET), NAMELY THAT

DISABILITY CLASSIFICATION DEFINITIONS
EMERGE FROM A POLITICAL PROCESS IN WHICH
ECONOMIC CONSIDERATIONS PLAY A
PROMINENT (MAYBE THE MOST PROMINENT)
ROLE

(The Ontario Adult Developmental Services agency's website says: "One percent of Ontarians have a developmental disability". To which I say: **"YOU WISH"**)

AROUND JANUARY 2008, I WAS
ASKED TO WORK WITH A
COMMITTEE IN BC TO COME
UP WITH A PLAN TO REFORM
CLBC'S ELIGIBILITY CRITERIA TO
COMPLY WITH AN ORDER
FROM THE SUPREME COURT
OF BRITISH COLUMBIA
INSPIRED BY A LAWSUIT FILED
BY THE FAMILY OF NEIL
FAHLMAN



NEIL FAHLMAN

NEIL WAS AN ADOPTED CHILD WHO CAME TO BE DIAGNOSED WITH FASD AND AUTISM SPECTRUM DISORDER (ASD). HE WAS SERVED AS A CHILD BUT HIS APPLICATION FOR COMMUNITY LIVING SERVICES (NEEDED DUE TO HIS ACTING-OUT BEHAVIOR AND POOR JUDGMENT) WAS TURNED DOWN WHEN HE TURNED 19 (THE AGE WHEN ADULT SERVICES BEGIN IN BC).



THE REASON? HIS IQ SCORE HAD GONE UP AND AT 79 WAS NOW OVER THE CLBC CEILING OF 70 POINTS NEEDED TO RECEIVE ADULT SUPPORTS

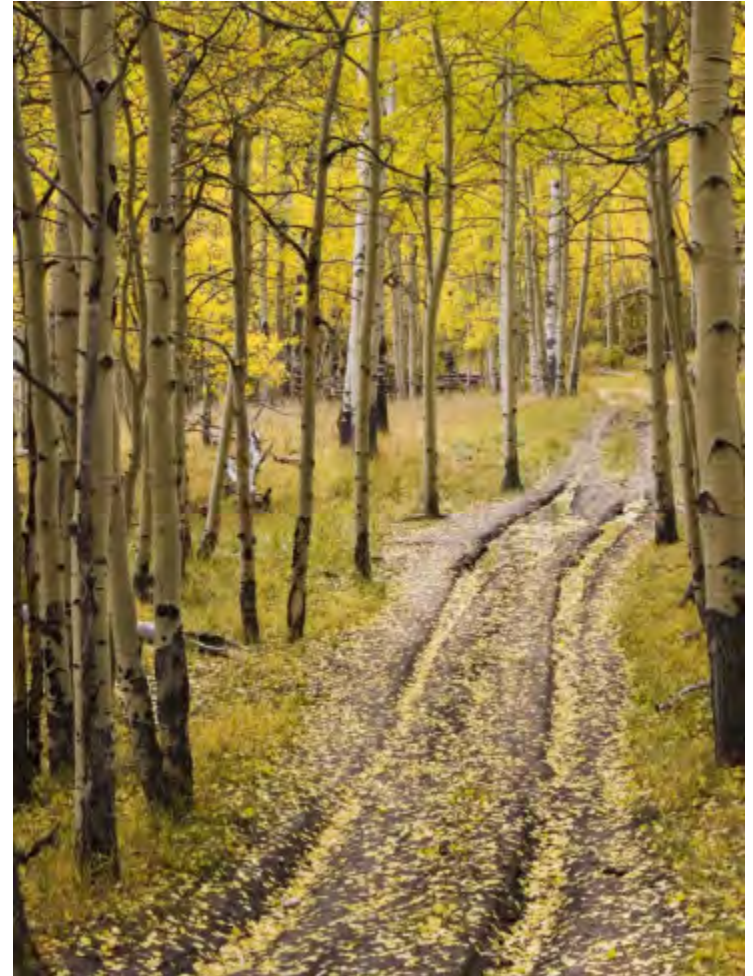
THE SUPREME COURT OF BC
RULED THAT IT WAS A
VIOLATION OF THE RIGHTS
OF PEOPLE WITH A NEURO-
DEVELOPMENTAL DISORDER
LIKE NEIL FAHLMAN'S TO
DENY SERVICES SOLELY ON
THE BASIS OF HIS IQ SCORE

The PROVINCIAL ID AGENCY
(CLBC) WAS CHARGED BY
THE COURT WITH COMING
UP WITH A FAIRER (I.E.,
MORE FLEXIBLE) ELIGIBILITY
FORMULA



THE BC GOVERNMENT'S SOLUTION WAS TO COME UP WITH A TWO-TRACK ELIGIBILITY PATHWAY:

- TRADITIONAL ID (IQ BELOW 70)
- FOR PEOPLE WITH FASD OR ASD, A LOOSENING OF IQ (IF OTHER STANDARDS ARE MET, SPECIFICALLY VERY LOW ADAPTIVE BEHAVIOR SCORES)



TWO TRACK

(forgive me if I oversimplify or get some of my facts wrong)

OBVIOUSLY, ID
SERVICES COST MONEY
AND SOME ELGIBILITY
PROCESS NEEDED TO
BE PUT IN PLACE IN
ORDER TO DETERMINE
WHO QUALIFIES AND
WHO DOES NOT
QUALIFY FOR
GOVERNMENT
FUNDED SUPPORTS



IN CONNECTICUT, AT ONE TIME THERE WAS A WOMAN GOING AROUND PICKING OUT CHILDREN (OFTEN ON GUT IMPRESSIONS), FOR PLACEMENT IN STATE SCHOOLS, USUALLY AGAINST THE WISHES OF THE PARENTS

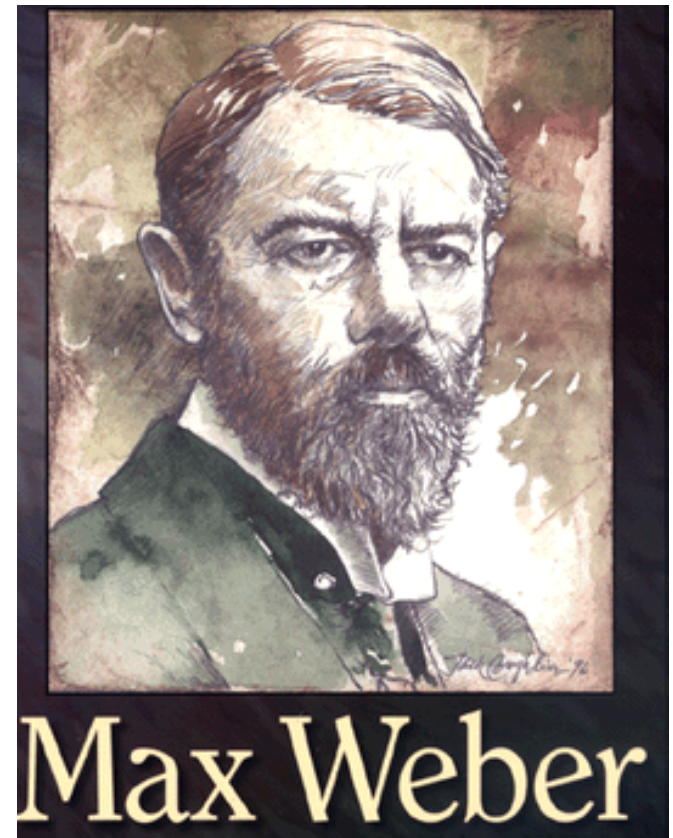


“EYEBALLING” HAS ITS PROBLEMS

AT ONE TIME, THERE WERE POORLY-TRAINED “MORON DETECTORS” LABELING IMMIGRANTS AS THEY CAME OFF THE BOAT AT ELLIS ISLAND, BASED ON HOW THESE (BEDRAGGLED AND SCARED) PEOPLE LOOKED AND ACTED

BUREAUCRACIES ARE ORGANIZATIONS OF UNELECTED OFFICIALS WHO ARE CHARGED WITH IMPARTIALLY IMPLEMENTING RULES FOR THE OPERATION OF GOVERNMENTAL OR QUASI-GOVERNMENTAL AGENCIES

SO THE ESTABLISHMENT OF NUMBERS-BASED ELIGIBILITY CRITERIA FOR DEVELOPMENTL SERVICES CAN, IN ONE SENSE, BE SEEN AS AN ADVANCE AND AS MORE FAIR THAN USING MORE SUBJECTIVE METHODS



A LATE 19TH CENTURY GERMAN SOCIOLOGIST, WHO COINED THE TERM “BUREAUCRACY” AND SAW IT AS PART OF THE INCREASING TREND TOWARDS A MORE RATIONAL SOCIETY

HOWEVER, TO HAVE A FAIRLY-OPERATING BUREAUCRACY FOR ADMINISTERING ELIGIBILITY FOR DEVELOPMENTAL SERVICES, THE NUMBERS HAVE TO MEAN SOMETHING



**THE MYSTIQUE
OF NUMBERS**

BOTH IN TERMS OF:

- WHAT THE UNDERLYING TESTS (THAT THE NUMBERS ARE DERIVED FROM) MEASURE
- WHETHER THE CUT-SCORE (e.g., IQ= 70) IS JUSTIFIED



IF IT DUCKS LIKE A
QUACK



IT'S A QUACK.

“SCIENTISM” IS THE ATTEMPT TO CREATE THE IMPRESSION THAT A METHOD OR ASSERTION IS “SCIENTIFIC” BY GIVING IT A NUMERICAL VALUE (EVEN WHEN THE NUMBER LACKS VALIDITY FOR THE PURPOSE USED)

THE HEAVY RELIANCE ON IQ AND OTHER TEST NUMBERS (AND STATISTICAL CUT-OFFS) IN THE ID FIELD IS AN EXAMPLE OF SCIENTISM, NOT SCIENCE

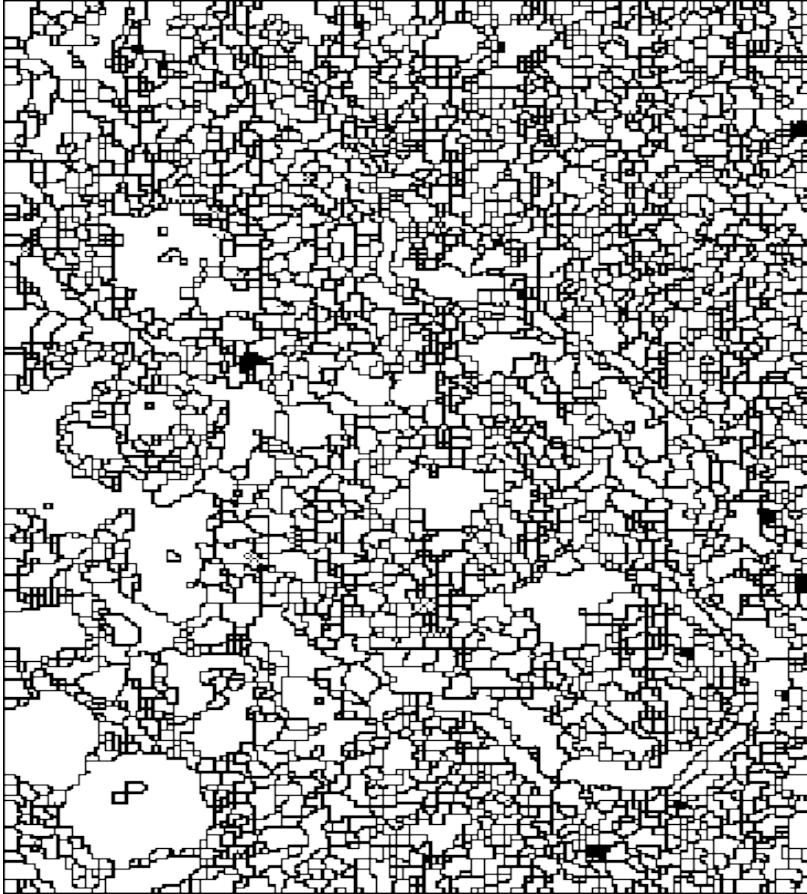
MYTH



THE USE OF THESE
NUMBERS IS BASED
ON THE NOTION
THAT THE
BOUNDARY
BETWEEN
“NORMAL” AND
“SUBNORMAL” IS
CLEAR-CUT

DISTINCT BOUNDARY
BETWEEN ID AND NON-ID

REALITY



FUZZY AND
OVERLAPPING
BOUNDARY,
ESPECIALLY FOR
PEOPLE WITH
MIXED
COMPETENCE
PROFILES (SKILLS
AND DEFICITS), LIKE
MOST FOLKS WITH
FASD

IN 1961 (THE FIRST MANUAL) THE CEILING SCORE WAS SET AT MINUS ONE STD. DEVIATION (AT 85) WHICH TAKES IN THE BOTTOM 17% OF THE POPULATION. IT WAS SET SO HIGH BECAUSE IT WAS ASSUMED THAT THE SECOND CRITERION—ADAPTIVE BEHAVIOR—WOULD BRING THE NUMBERS IDENTIFIED DOWN TO A MUCH SMALLER (3%) LEVEL.

THE PROBLEM IS THAT
IN 1960'S AND 1970'S
NOBODY BOTHERED TO
ASSESS ADAPTIVE
BEHAVIOR, SO TOO
MANY PEOPLE WERE
BEING LABELED AS ID



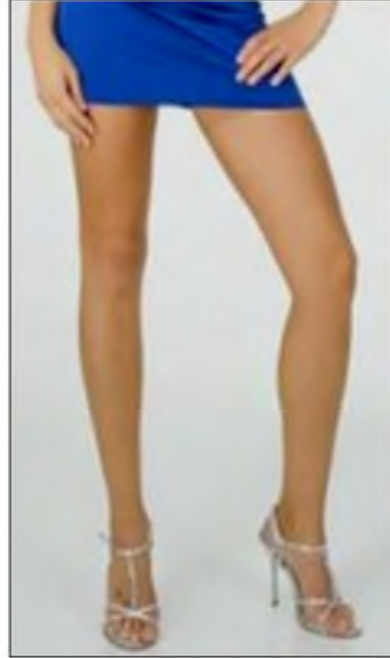
SO IN 1973, THE CEILING
SCORE WAS REDUCED FROM
85 TO 70 (FROM MINUS 1SD
TO MINUS 2 SD

IT WENT FROM THE
SEVENTEENTH PERCENTILE
TO THE SECOND

**THIS “CURED” 80% OF ID
(AND MADE THE CLASS TOO
SMALL, THUS CREATING THE
CURRENT NEED TO GET
AROUND THE 70 CEILING)**



(THIS WAS TOO DRASTIC, SO IN
1992 IT WAS RAISED TO 75—IN
2002 REFRAMED AS “70 TO 75”)



FLUCTUATING IQ
CEILING “HEM LINES”

(ATTEMPTS TO PERIODICALLY RECALIBRATE THE
PREVALENCE RATE FOR AN ARBITRARY
CATEGORY)



THERE IS SOMETHING WRONG WITH HAVING TO PLAY AROUND WITH AN ARBITRARY NUMBER, IN ORDER TO MAKE THE NUMBER FIT THE REALITY OF A PERSON'S DISABILITY (AS DEFINED BY THE JUDGMENT OF PEOPLE WHO KNOW HIM OR HER WELL)

(it should also be pointed out that full-scale IQ is itself a number that is no longer considered by intelligence experts to be a meaningful concept)

THIS BRINGS US BACK TO NEIL FAHLMAN
AND THE CLASS ACTION LAWSUIT BROUGHT
BY HIS FAMILY AFTER HE WAS TURNED
DOWN BY CLBC FOR ADULT SERVICES WHEN
HE TURNED 19



COMMUNITY LIVING
BRITISH COLUMBIA

YOU WILL RECALL THAT THE BC
COURT ORDERED THE AGENCY TO
DEVISE A NEW FORMULA THAT
WOULD BE FAIRER

THE HOPE AND EXPECTATION WAS THAT
THIS FORMULA WOULD KNOCK KING IQ
OFF HIS THRONE



The legislative solution was to create two eligibility portals into the CLBC adult system



ID



FASD
or ASD

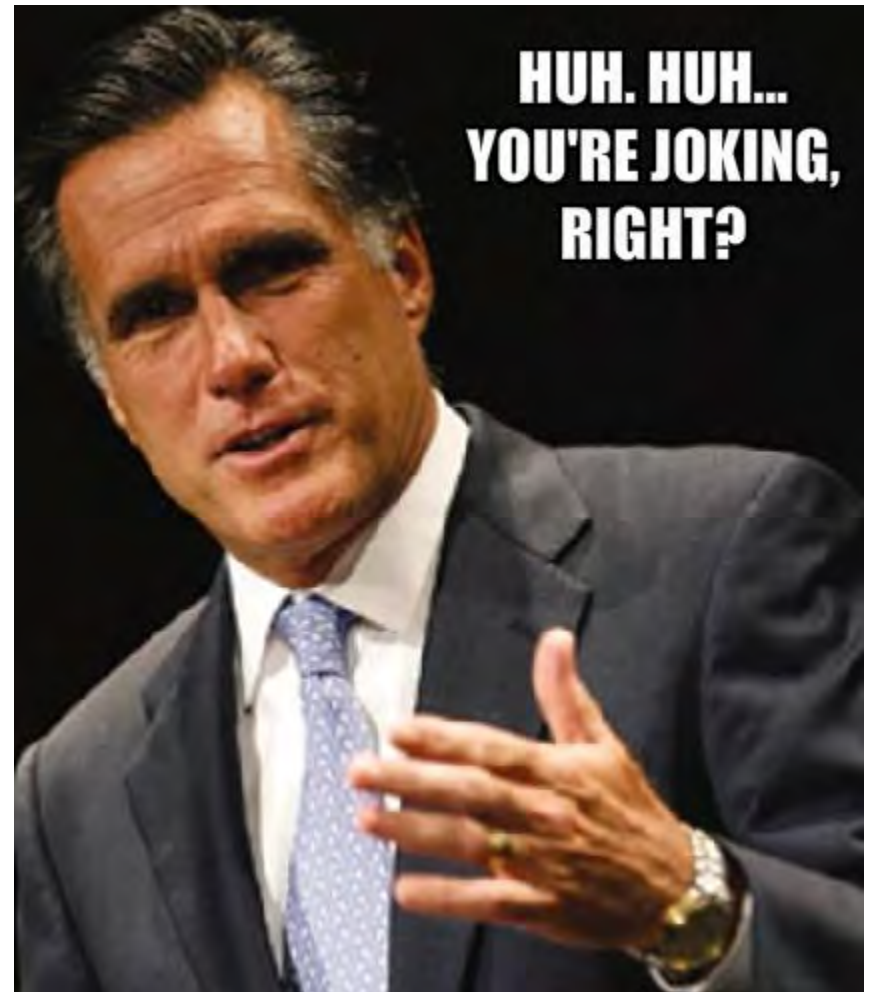
FOR THE FIRST
PORTAL
(TRADITIONAL
ID), THE 70 IQ
ELIGIBILITY
STAYED
EXACTLY AS IT
WAS



THE KING IS FEELING
PRETTY HAPPY ABOUT THAT
(not exactly a repudiation of
the reliance on IQ)

TO QUALIFY THROUGH THE
SECOND PORTAL, ONE
WOULD NEED A DIAGNOSIS
OF EITHER FASD OR ASD
(AUTISM SPECTRUM
DISORDER)

IF IQ IS ABOVE 70, THEN ONE
COULD STILL QUALIFY IF
ONE'S COMPOSITE
(OVERALL) **ADAPTIVE
BEHAVIOR SCORE IS MINUS
3 STANDARD DEVIATIONS
(STANDARD SCORE OF 55
OR LESS)**



A SERIOUSLY

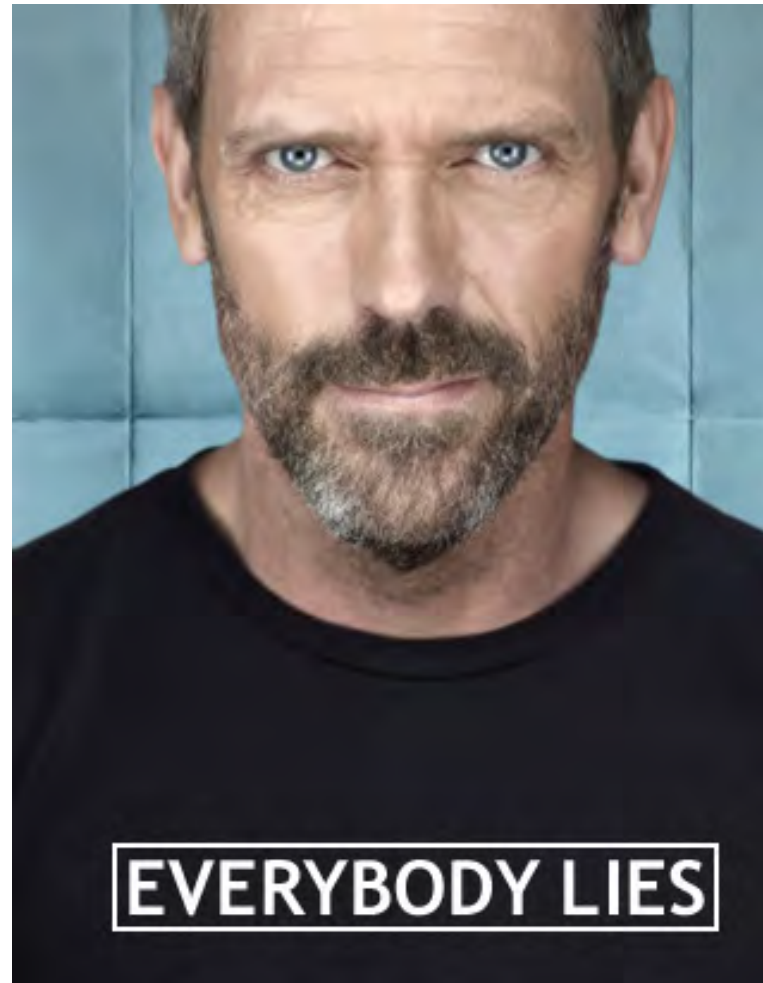
MINUS THREE STANDARD DEVIATIONS
(STANDARD SCORE OF 55) PLACES ONE AT
THE 0.13 PERCENTILE OF THE POPULATION.

IN OTHER WORDS, THE LEAST COMPETENT
OF 1,000 RANDOMLY SELECTED PEOPLE

A MUCH TOUGHER ADAPTIVE BEHAVIOR
STANDARD THAN FOR PEOPLE WHO
QUALIFY THE REGULAR WAY (WHERE ONE
ONLY HAS TO BE MINUS TWO STANDARD
DEVIATIONS IN ONLY ONE OF THE THREE
AREAS, NOT OVERALL)



IF A PERSON WITH
FASD WAS
ACTUALLY THAT
IMPAIRED
ADAPTIVELY, HE OR
SHE WOULD NOT
NEED TO BE
TESTED, AS HE OR
SHE WOULD BE
UNABLE TO FEED,
TOILET,
COMMUNICATE
OR DO ANYTHING
INDEPENDENTLY

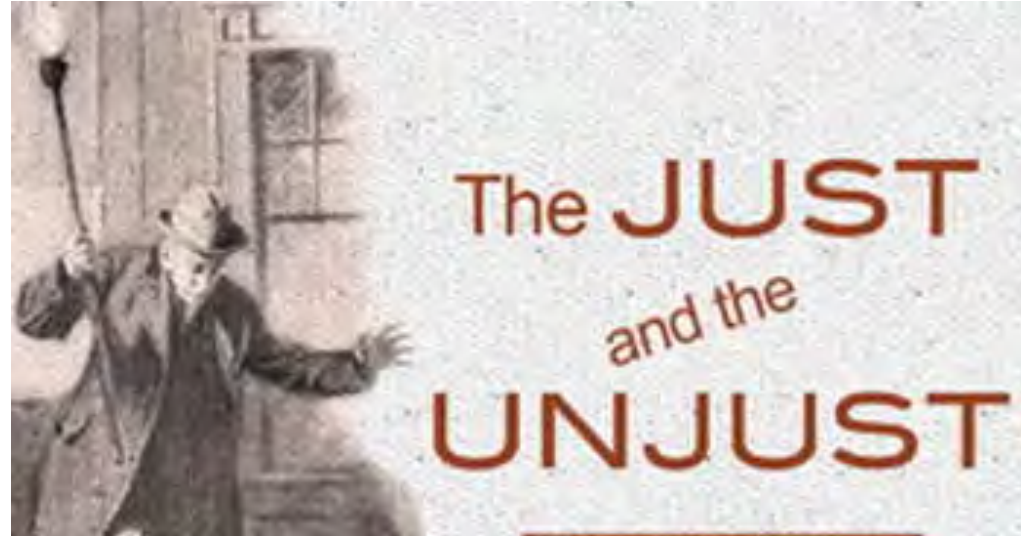


**(FAMILY MEMBERS AND MENTAL HEALTH CERTIFIERS)
ARE FORCED TO LIE IN ORDER TO MEET THAT
IMPOSSIBLE AND SCIENTIFICALLY INVALID STANDARD**

I'LL BET MY HOUSE ON IT

A FORMULA THAT FORCES
FAMILIES AND
PROFESSIONALS TO LIE IN
ORDER TO QUALIFY
DESERVING PEOPLE FOR
SERVICES IS HARDLY
RATIONAL OR FAIR

ESPECIALLY TO THE PEOPLE
WHO LACK THE
SOPHISTICATION OR
RESOURCES TO FIGURE
OUT (OR HIRE SOMEONE)
TO BEAT THE SYSTEM

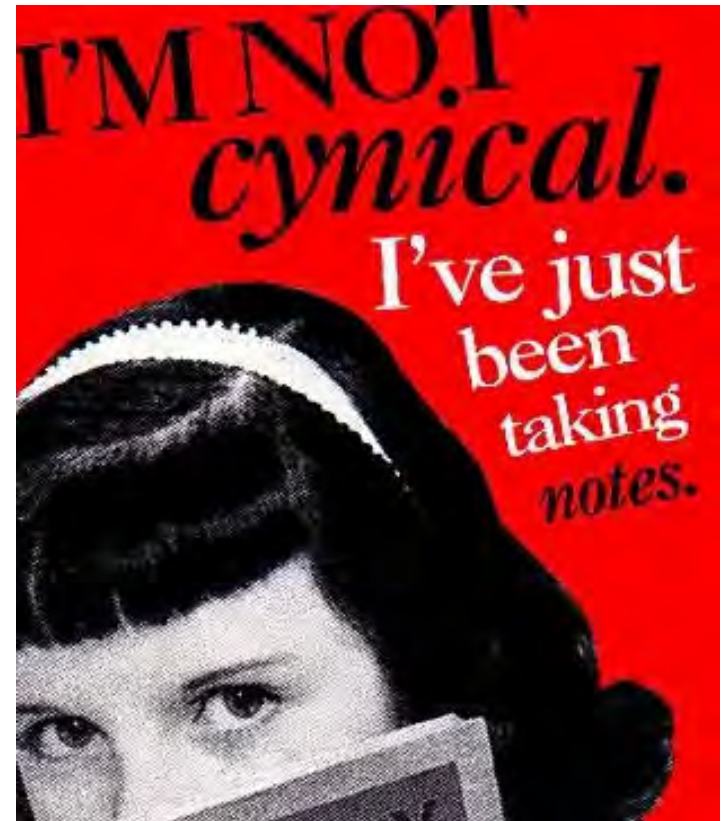


AGAIN THIS REFLECTS THE UNDERLYING PROBLEM, WHICH IS THE “SCIENTISTIC” RELIANCE ON NUMBERS, AND ESPECIALLY (EVEN NUMBERED) STANDARD DEVIATION UNITS TO CREATE AN IMPRESSION OF RATIONALITY, OBJECTIVITY AND FAIRNESS



The moral of this story is that the quest for a rational and fair, numbers-based (“scientistic”) eligibility formula can lead one into something anything but rational, or fair

FINALLY, WHY IS THIS
ALTERNATIVE PORTAL AVAILABLE
ONLY TO PEOPLE WITH FASD OR
ASD, AND NOT TO PEOPLE WITH
OTHER NEURO-DEVELOPMENTAL
DISORDERS (SUCH AS, SAY,
DANDY-WALKER SYNDROME--OR
OTHERS WITH FASD FOR THAT
MATTER)?



OBVIOUSLY, BECAUSE THE SOLUTION WAS TAILORED TO MR.
FAHLMAN (WHO HAS FASD AND ASD) AND HIS LAWSUIT

(WHICH IS HARDLY A BASIS FOR ADDRESSING A MORE GENERAL PROBLEM)

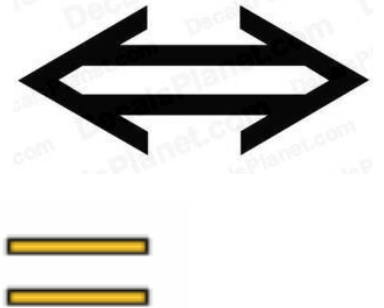
THE CURRENT SYSTEM IS
THUS BASICALLY AN
UNINTENTIONAL LOTTERY

A FEW (ESPECIALLY THOSE
WHO HIT THE JACKPOT
BEFORE THE MASHED
POTATOES RAN OUT) GET
MUCH, SOME GET A LITTLE,
AND MOST GET NOTHING



THE BASIC SOCIAL
JUSTICE/ FAIRNESS
NOTION UNDERLYING
MY REMARKS IS THAT
PEOPLE WITH THE
EQUIVALENT
DISORDER SHOULD
GET THE SAME
BENEFITS/
OPPORTUNITIES)

MATH SYMBOLS FOR
SAME, APPROXIMATE,
EQUIVALENT



THE QUEST FOR INCREASED ELIGIBILITY FOR PEOPLE WITH FASD IS BASED ON THE FACT THAT COMMUNITY LIVING FORMULAE GROUNDED IN A TRADITIONAL ID CONSTRUCT (WHERE IQ IS 70 OR LESS) SHOULD BE LOOSENED TO ACCOMMODATE PEOPLE WHO HAVE “ID EQUIVALENCE,” EXPRESSED SYMBOLICALLY AS:

FAS  ID

*

*FASD  FAS

FASD  ID

WHILE PEOPLE WITH FAS ARE MORE LIKELY TO HAVE IQ BELOW APPROX. 70, PEOPLE WITH PARTIAL FAS OR ARND ARE LIKELY TO HAVE IQ ABOVE 70. SO BY SAYING FASD EQUALS FAS, I AM SAYING THAT PEOPLE WITH ARND SHOULD BE VIEWED THE SAME AS IF THEY HAVE FAS

IN OTHER WORDS, HOW
CAN WE GET AROUND THE
DISTORTING/ PERVERTING
EFFECT OF RELYING ON IQ,
GIVEN THAT:

- IQ IS NOT AN ADEQUATE OR
COMPREHENSIVE MEASURE OF
“INTELLIGENCE”
- THE CUT-OFF SCORE IS ARBITRARY
AND UNSCIENTIFIC
- THE REAL SERVICE NEEDS ARE NOT
PREDICTED BY LEVEL OF IQ (EXCEPT FOR
THOSE WITH THE MOST PROFOUND AND
GLOBAL DISABILITY) OR ADAPTIVE
BEHAVIOR SCORE EITHER, FOR THAT
MATTER



ABOUT HALF THE STATES AND PROVINCES
HAVE BEEN GRAPPLING WITH THE "ID
EQUIVALENCE" PROBLEM, BY TRYING TO
COME UP WITH SOME LOOPHOLE THAT
WOULD ALLOW THEM TO PROVIDE
COMMUNITY LIVING SERVICES TO ADULTS
WHO ARE FELT TO BE DESERVING, BUT WHO
DO NOT MEET THE MORE TRADITIONAL (i.e.,
IQ-DRIVEN) STANDARD

FOLLOWING IS A PARTIAL



OF ACTUAL OR
POSSIBLE
APPROACHES

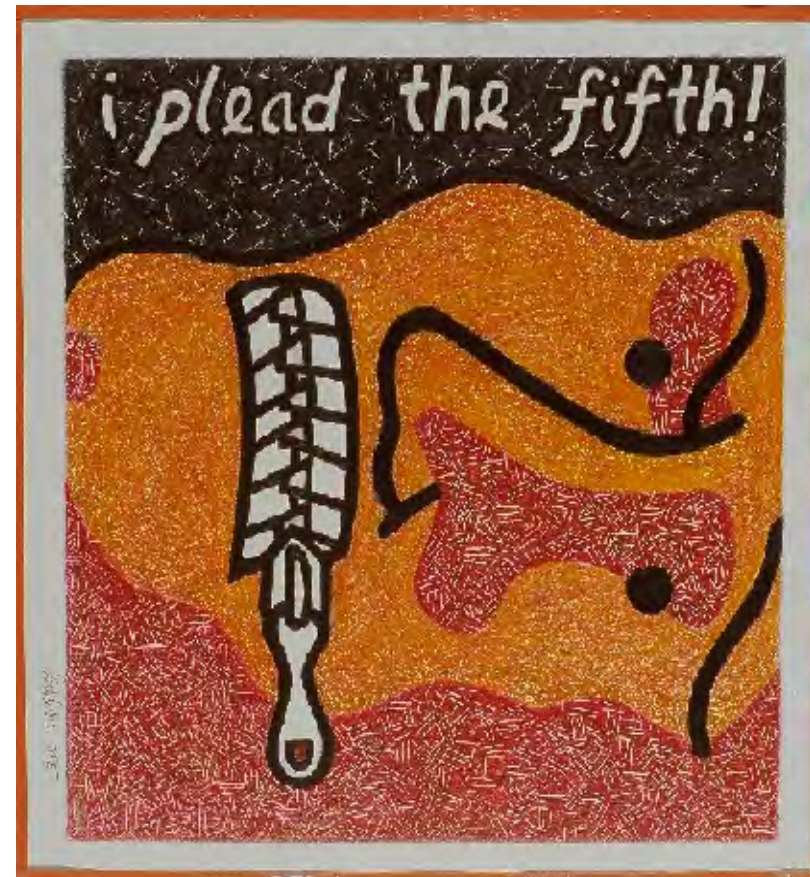
ONE OBVIOUS WAY OF ACHIEVING
GREATER FLEXIBILITY IS TO USE A
TERM, LIKE “DEVELOPMENTAL
DISABILITIES,” THAT IMPLIES A
BRODER CONSTRUCT



CALIFORNIA USES “DEVELOPMENTAL DISABILITIES”, AND
RELIES ON A CATEGORICAL APPROACH (ID, AUTISM,
CEREBRAL PALSY AND EPILEPSY) AND THEN HAS WHAT THEY
TERM A “**FIFTH CATEGORY**”

The fifth category is defined as follows:

“This term [DD] shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation...”



THIS EQUIVALENCE IS ESTABLISHED (BY THE CALIFORNIA “REGIONAL CENTERS”) THROUGH ADAPTIVE BEHAVIOR SCORES (BUT NOWHERE AS EXTREME AS THOSE REQUIRED BY CLBC FOR “PROTAL 2” ELIGIBILITY) AND BY CLINICAL HISTORY AND JUDGMENT REGARDING PROGRAM INTERVENTIONS THAT HAVE WORKED OR NOT WORKED.

ALL ID-EQUIVALENCE STATUTES,
EVEN WHEN THEY MENTION FASD
(AS IN MINNESOTA), HAVE A

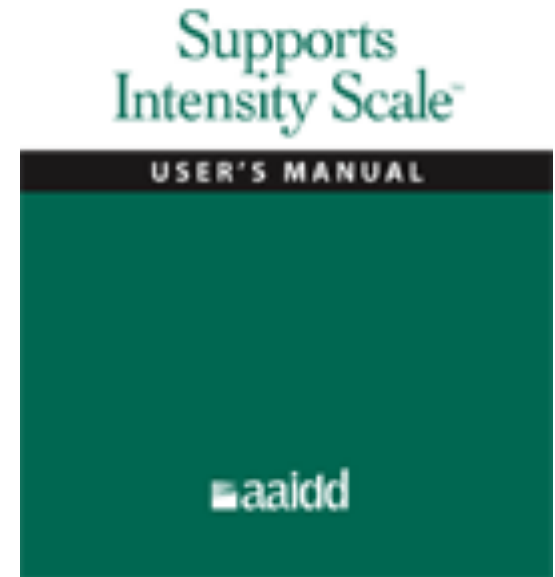
SEVERITY REQUIREMENT

THAT IS BECAUSE NEURODEVELOPMENTAL DISORDERS (LIKE ALL DISEASES) MANIFEST WITH VERY DIFFERENT DEPTH AND BREADTH OF IMPAIRMENT, AND SOCIETY HAS A LEGITIMATE INTEREST IN SPENDING ITS LIMITED HUMAN SERVICES SUPPORT DOLLARS WISELY AND IN RELATION TO PEOPLE'S ACTUAL NEEDS

THE PROBLEM IS THAT THE NUMBERS THAT ARE MAINLY USED TO MEASURE SEVERITY (IQ AND ADAPTIVE BEHAVIOR STANDARD SCORES) ARE POOR PREDICTORS OF ACTUAL NEED , AS REFLECTED IN THE FACT THAT THEY CORRELATE VERY POORLY WITH DOLLARS SPENT OF INDIVIDUALS RECEIVING SUPPORTS

(an indication both of poor measures and inadequate individualization of services)

IN ONTARIO, THEY USE THE SIS (AN ATTEMPT TO DEVELOP A BETTER WAY OF MEASURING SERVICE AND SUPPORT NEEDS) AS PART OF THE INTAKE PROCESS (IN DETERMINING WHAT SERVICES SHOULD BE PROVIDED)



OUR BC COMMITTEE (FORMED IN THE WAKE OF THE FAHLMAN RULING) PROPOSED GOING ONE STEP BEYOND THE SIS BY USING SUCH A MEASURE (WHICH WE RECOMMENDED BE DEVELOPED IN-HOUSE) FOR DEFINING DISABILITY BASED ON PERCEIVED NEED FOR SUPPORTS

(IN OTHER WORDS, IF SOMEONE IS BELIEVED TO NEED SUPPORTS, THAN WHY GO TO AN ARTIFICIAL AND POOR PREDICTOR LIKE IQ TO DETERMINE ELIGIBILITY?)

A COMMON
APPROACH TO ID-
EQUIVALENCE IS TO
DESIGNATE A SPECIFIC
DISABILITY CATEGORY



ELIGIBILITY CRITERIA FOR ADULT DD SERVICES IN CONNECTICUT:

“.... The individual’s IQ score must be 69 or less. At the same time, the person must also have deficits in adaptive functioning. **Individuals with a diagnosis of Prader-Willi syndrome are also eligible.**”

WHY IS IT THAT OF ALL THE MANY NEURODEVELOPMENTAL DISORDERS, PRADER-WILLI SYNDROME WAS SINGLED OUT FOR AUTOMATIC “ID-EQUIVALENCE” STATUS (WITH NO IQ CEILING REQUIREMENT AT ALL) IN CONNECTICUT?



THE ANSWER:

VERY EFFECTIVE LEGISLATIVE LOBBYING CAMPAIGN BY FAMILY MEMBERS AND ADVOCATES

IT ALSO DOESN'T HURT THAT IT IS A VERY RARE DISORDER (EST. PREVALENCE OF 1 PER 8,000)

WHEN AUTISM ADVOCATES ASKED THE CT LEGISLATURE FOR A SIMILAR EXEMPTION THEY WERE TOLD: “SORRY, THERE ARE TOO MANY OF YOU”

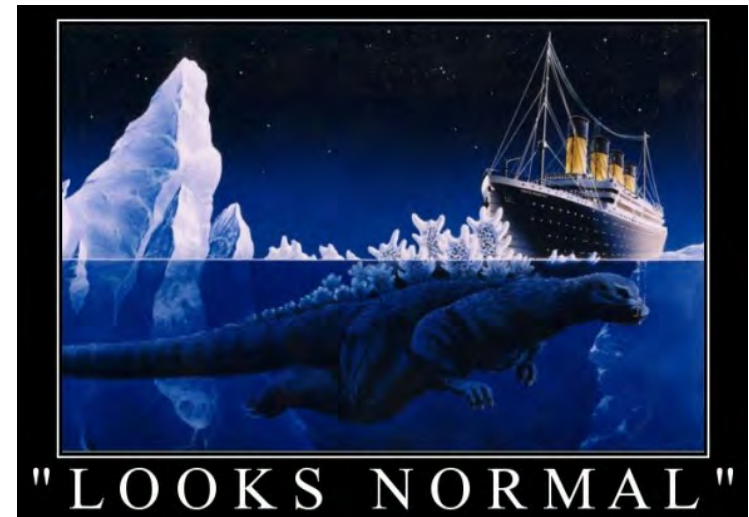
IT IS HARDLY FAIR THAT IQ EXEMPTION FOR DISABILITY SERVICE ELIGIBILITY SHOULD BE BASED ON SPECIAL INTEREST PRESSURE, GIVEN HOW MANY OTHER EQUALLY DESERVING NEURODEVELOPMENTAL SYNDROMES (ALSO CHARACTERIZED BY MANY WHO CROSS OVER THE 70 IQ DIVIDING LINE)



BUT PRADER-WILLI HAS TWO OTHER THINGS GOING FOR IT, THAT OTHER DISORDERS (SUCH AS AUTISM AND FASD) DON'T HAVE:

- LESS BUDGETARY IMACT (BECAUSE OF LOW PREVALENCE)
- A RELIABLE, CHEAP AND VERY DEFINITIVE MEDICAL DIAGNOSTIC (e.g., CHROMOSOMAL) INDICATOR

A MAJOR OBSTACLE TO GETTING SOCIAL JUSTICE (IN TERMS OF BEING RULED ELIGIBLE FOR ADULT COMMUNITY LIVING DISABILITY SERVICES) FOR PEOPLE WITH FASD IS THAT DIAGNOSIS IS NOT AS SIMPLE OR CLEAR-CUT AS IT IS FOR THOSE WHO HAVE A CHROMOSOMAL DISORDER SUCH AS PRADER-WILLI SYNDROME



- THERE ARE NOT THAT MANY PHYSICIANS WHO ARE KNOWLEDGEABLE ABOUT FASD OR TRAINED IN DETECTING OFTEN SUBTLE PHYSICAL (e.g., FACIAL) SIGNS
- GENERAL ABSENCE OF BRAIN SCAN ABNORMALITIES ABLE TO BE SEEN BY NAKED EYE
- A LARGELY BEHAVIORAL/ FUNCTIONAL DIAGNOSIS WHICH OVERLAPS WITH OTHER DISORDERS AS WELL AS “NORMALS WITH BAD CHARACTER”



"Here is a little-known, but important, fact"

ID, DD , ID-EQUIVALENCE AND ALL DISABILITY CATEGORIES FOR THAT MATTER, ARE INVENTED FUNCTIONAL CATEGORIES, THAT ARE DEFINED BY COMMITTEES, USING ARTIFICIAL AND ARBITRARY CRITERIA

THEY DO NOT CORRESPOND EXACTLY WITH UNDERLYING MEDICAL DISEASES (SUCH AS FASD) ALTHOUGH THERE IS GOOD REASON TO THINK THAT MOST PEOPLE WITH THOSE (ALSO SOMETIMES FUZZY) MEDICAL DISEASES HAVE A HIGH LIKELIHOOD OF NEEDING SERVICES

THE HISTORY OF ID IS THE QUEST AFTER THE CHIMERA OF FINDING A (IQ or AD. BEH.) NUMBER WHICH WILL GIVE US THE KIND OF CERTAINTY THAT COMES WITH, SAY, A BLOOD TEST FOR PRADER-WILLI (in other words, “nature carved at the joints”)



**A DOOMED SEARCH FOR
THE MAGIC NUMBER**

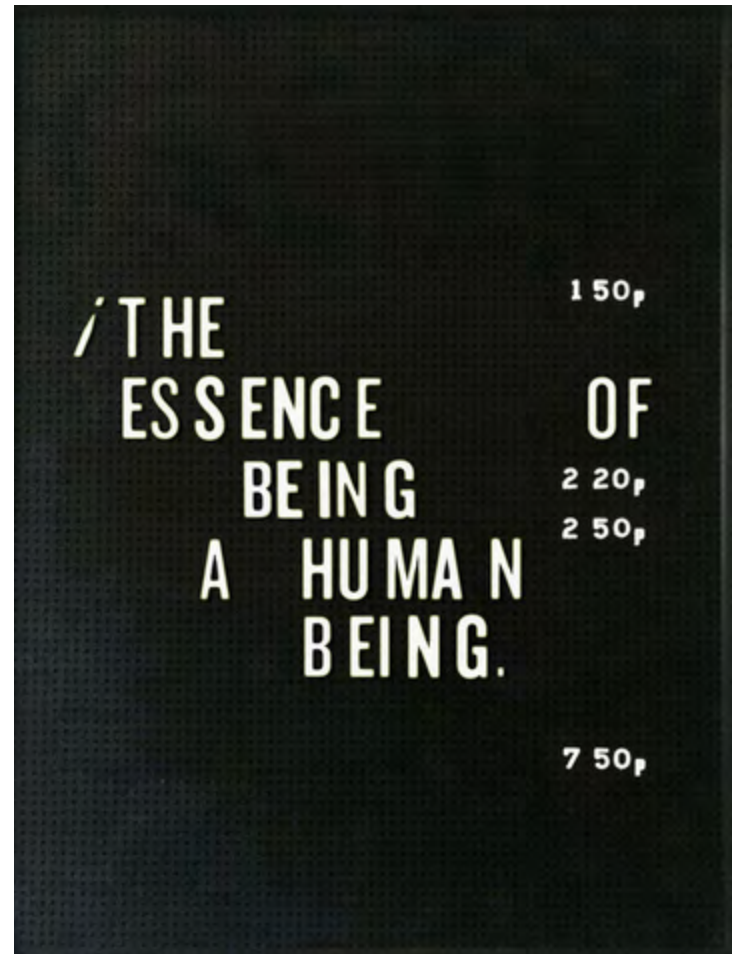
MY QUESTION: HOW MANY TIMES DOES THAT APPROACH HAVE TO FAIL BEFORE WE DECIDE TO TRY SOMETHING ELSE?

Emphasis on numbers interferes with the attempt to actually understand who people are and why they may deserve and need services

THE Human Equation



THE SOLUTION TO THE PROBLEM OF DEVISING A WORKABLE AND FAIR FRAMEWORK FOR DECIDING WHO SHOULD BE ELIGIBLE FOR DEVELOPMENTAL SERVICES IS LIKELY TO COME ONLY AFTER WE FIGURE OUT WHAT IT IS THAT ALL PEOPLE WITH BRAIN-BASED DISORDERS (WHETHER WITH IQ BELOW OR ABOVE 70) HAVE IN COMMON



MY COLLEAGUES AND I HAVE
ARGUED THAT THE ESSENCE OF
HAVING A DEVELOPMENTAL
DISORDER IS VULNERABILITY TO
SOCIAL AND PRACTICAL DANGER,
AS A RESULT OF (BRAIN-
MEDIATED) FAILURE TO
RECOGNIZE OR WEIGH RISK



Harvey
Switzky



George
Woods

Greenspan, S., Switzky, H.N. & Woods, G.W. (2011).
Intelligence involves risk-awareness and Intellectual
Disability involves risk-unawareness: Implications of a
theory of common sense. Journal on Intellectual and
Developmental Disability

**WE BELIEVE THAT FASD (AND ID) FALL IN THE
CLASS OF “COMMON SENSE DEFICIT DISORDERS”**

(COMMON SENSE IS AWARENESS OF OBVIOUS
PHYSICAL AND SOCIAL DANGER)

DOES ONE NEED A MEASURE TO KNOW WHICH
PEOPLE LACK THAT AWARENESS (AND HENCE ARE
IN DANGER OF CATASTROPHIC FAILURE?

(furthermore, IQ and Ad Behavior scores are very
poor indicators of common sense)

I DON'T THINK SO. IT IS WHY WE ADVOCATE FOR
PEOPLE WHO ARE FAILED BY OUR NUMBERS

(BECAUSE WE KNOW THEY ARE IN DIRE DANGER
WITHOUT SUPPORTS AND PROTECTIONS)

**How do you
measure up?**

HUMAN DECENCY

REQUIRES THAT:

- (a) We provide help to people with brain-based developmental disorders (such as FASD) who otherwise would be in dire straits
- (b) We stop thinking that human beings can be reduced to an arbitrary and meaningless number



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