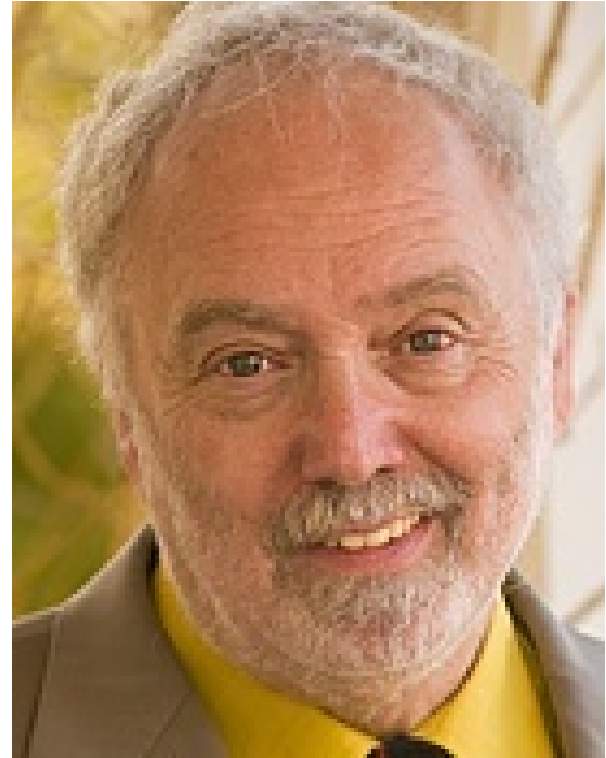


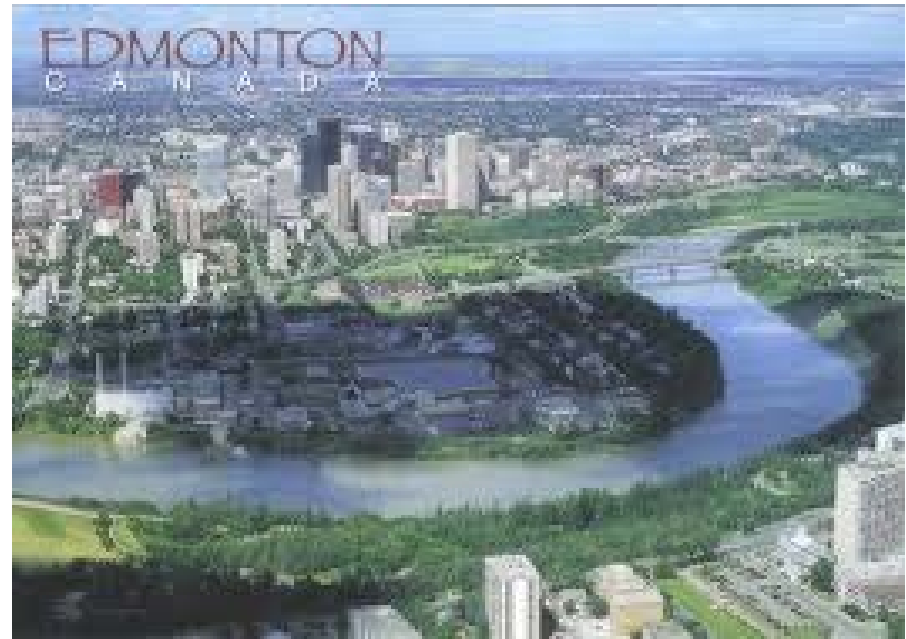
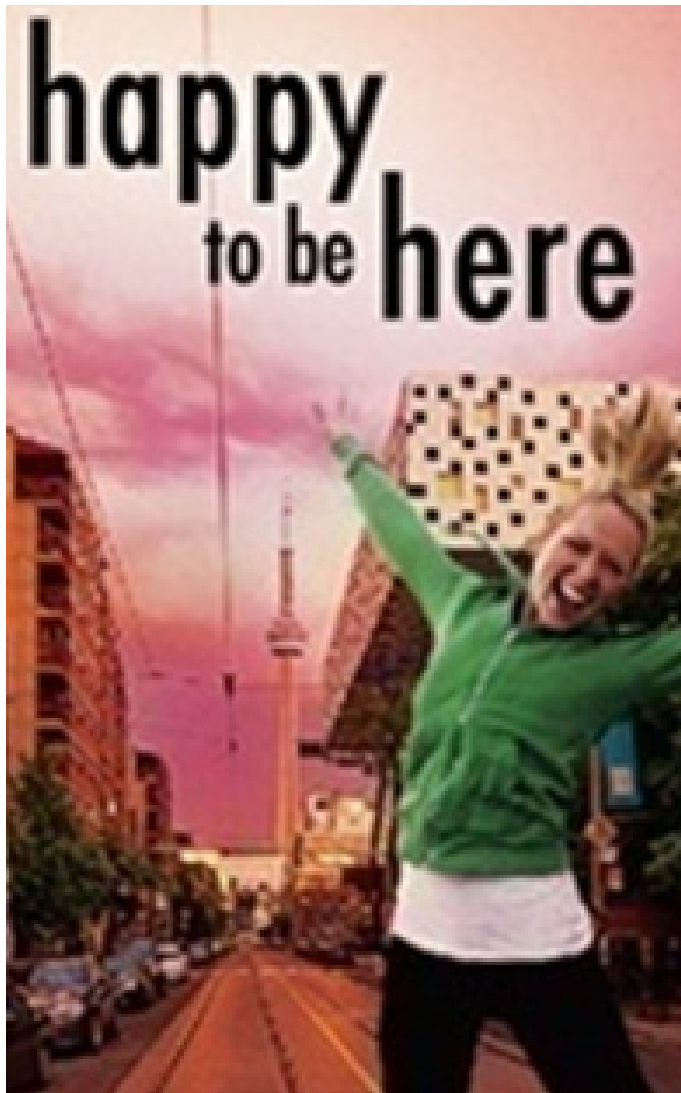
Risk-Unawareness as  
a Central (But  
Overlooked) Reason  
for Service Eligibility  
and Guardianship  
Protections for  
People with FASD



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SEPT. 2013

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LAW AND FASD  
CONSENSUS CONFERENCE

EDMONTON, ALBERTA

# 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 OTHER RELATED SUCH DISORDERS,  
MOSTLY LOWER IN FREQUENCY

ONE THING THAT FASD HAS IN COMMON WITH OTHER NEURODEVELOPMENTAL DISORDERS IS THAT IQ SCORES ARE OFTEN ABOVE 70-75 (THE USUAL CEILING FOR BEING ELIGIBLE FOR INTELLECTUAL DISABILITY SERVICES AND PROTECTIONS).



BUT PEOPLE WITH FASD  
TYPICALLY HAVE  
PROBLEMS IN  
JUDGMENT AND  
THINKING (AND HAVE A  
NEED FOR SERVICES)  
COMPARABLE TO OR  
MORE SEVERE THAN  
MANY WHO DO QUALIFY  
AS ID



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

YOKOMAN HEARN WAS DIAGNOSED WITH FASD, AND:

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

BUT HIS IQ SCORE WAS A FEW POINTS TOO HIGH TO QUALIFY FOR “ATKINS” EXEMPTION FROM THE DEATH PENALTY, SO IN JULY, 2012 THE STATE OF TEXAS PUT HIM TO DEATH



YOKOMAN HEARN

THIS OVERLY-RIGID EMPHASIS ON IQ COMES UP IN DEVELOPMENTAL SERVICES ELIGIBILITY AS WELL, AS ILLUSTRATED BY THE CASE OF NEIL FAHLMAN



NEIL FAHLMAN

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 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 solution  
(not one I  
proposed ) was  
to create two  
eligibility portals  
into the CLBC  
adult system



ID



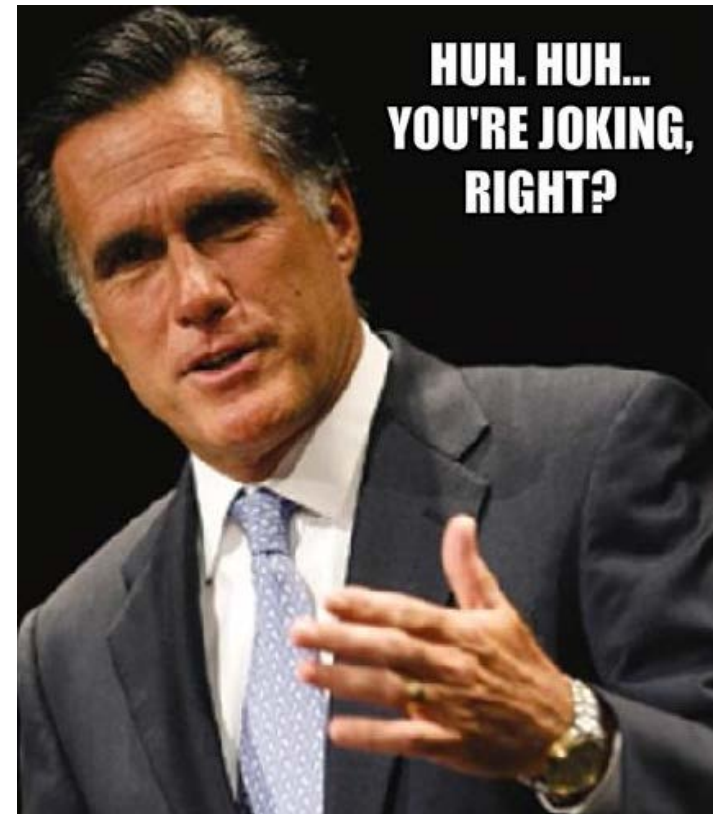
FASD or ASD

(Why these? Because they  
were Neil's diagnoses)

IT IS BETTER TO HAVE SOMETHING  
MORE UNIVERSALLY APPLICABLE

TO QUALIFY THROUGH THE  
SECOND PORTAL, ONE  
WOULD NEED A DIAGNOSIS  
OF EITHER FASD OR ASD

IF FASD BUT 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)**



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

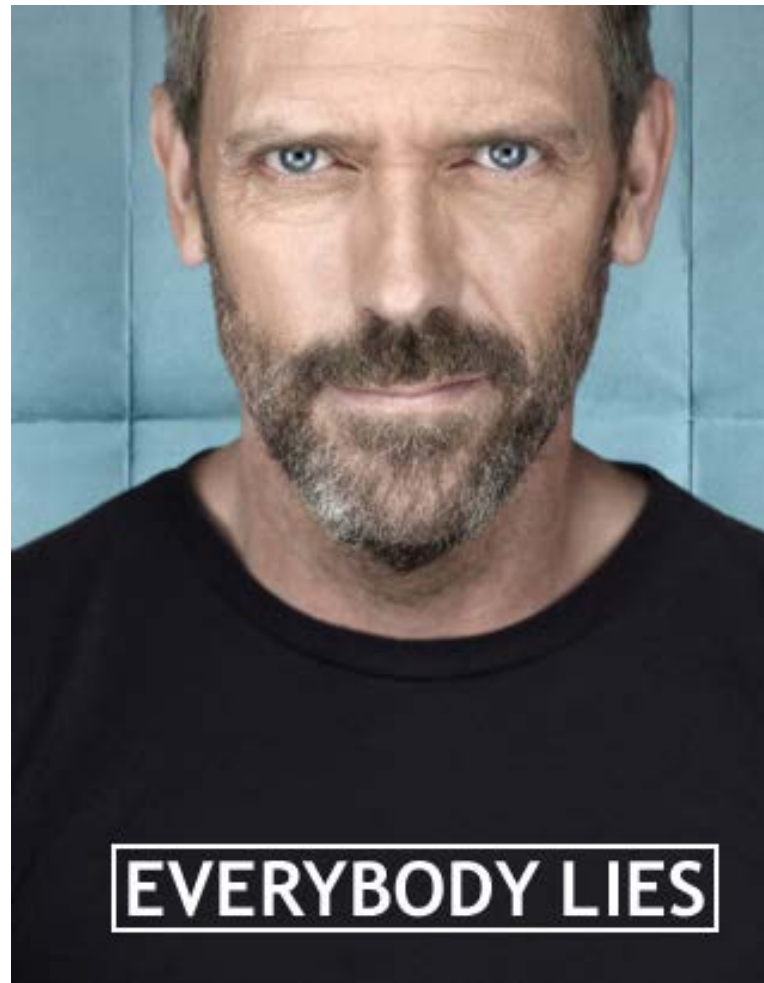
A SERIOUSLY

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, WHO ONLY  
REQUIRE 2 SD'S BELOW THE MEAN (2<sup>ND</sup>  
PERCENTILE) AND ONLY IN ONE OF THREE  
ADAPOTIVE FUNCTIONING DOMAINS  
(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 safe bet, as I have been told that is what occurs)

## THERE ARE TWO PROBLEMS OPERATING HERE:

- AN OVER-RELIANCE ON INTELLECTUAL DISABILITY (MENTAL RETARDATION) AS THE BASIS FOR RECEIVING DEVELOPMENTAL SERVICES (AND AN OLD-FASHIONED NOTION OF ID AT THAT, IN THAT THE FIELD IS RAPIDLY MOVING AWAY FROM FULL-SCALE IQ CUT-OFFS)
- A WORSHIP OF NUMBERS, ESPECIALLY EVEN-NUMBERED STANDARD DEVIATION SCORE CUT-OFFS





- SUCH CUT-OFFS ARE ARBITRARY AND ARTIFICIAL
- ALSO, ADAPTIVE BEHAVIOR SCALES DO NOT GET AT THE ESSENTIAL IMPAIRMENT IN FASD (OR MILD INTELLECTUAL DISABILITY FOR THAT MATTER)

These reflect



(TRYING TO MAKE SOMETHING LOOK MORE SCIENTIFIC THAN IT IS, BY ATTACHING A NUMBER TO IT)

A PROBLEM, OF COURSE,  
WITH MAKING PEOPLE  
WITH FASD ELIGIBLE FOR  
SERVICES AND LEGAL  
PROTECTIONS (INCLUDING  
GUARDIANSHIP) IS THAT IT  
IS A SOMEWHAT HIDDEN  
DISABILITY, AND THE LEVEL  
OF NEED MAY NOT BE  
OBVIOUS AND MAY NOT  
MEET THE (POORLY  
DEFINED AND INEXACT)  
ELIGIBILITY THRESHOLD



Minor



Moderate



Major



Critical

Severity Continuum



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



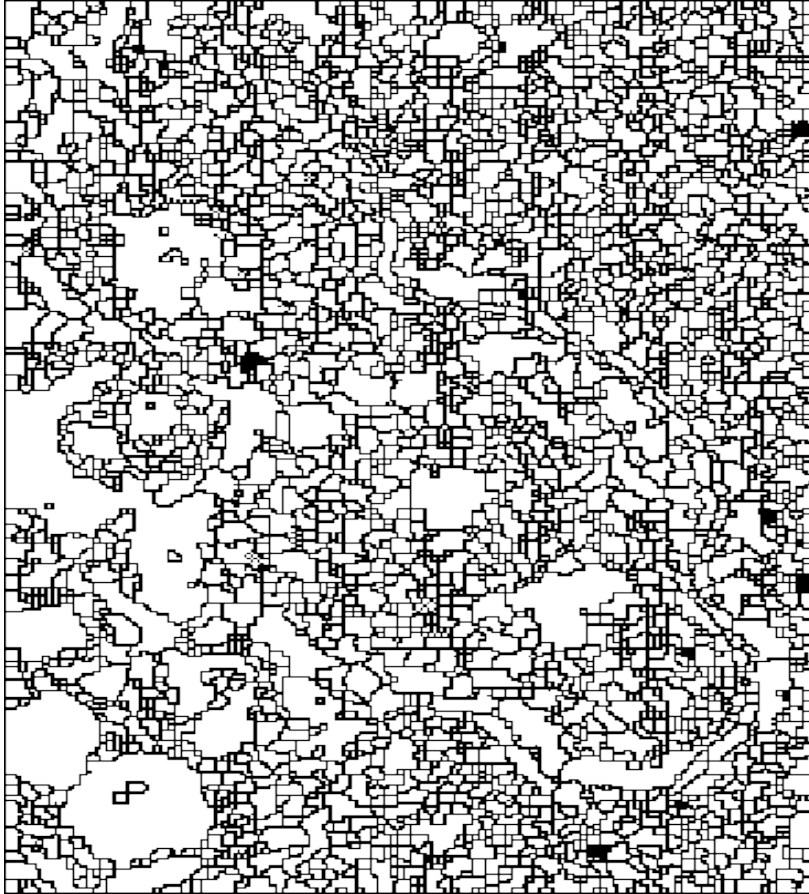
MYTH



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

DISTINCT BOUNDARY  
BETWEEN “NORMAL” AND  
“DEFICIENT”

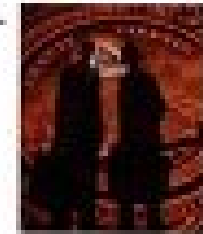
# REALITY



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

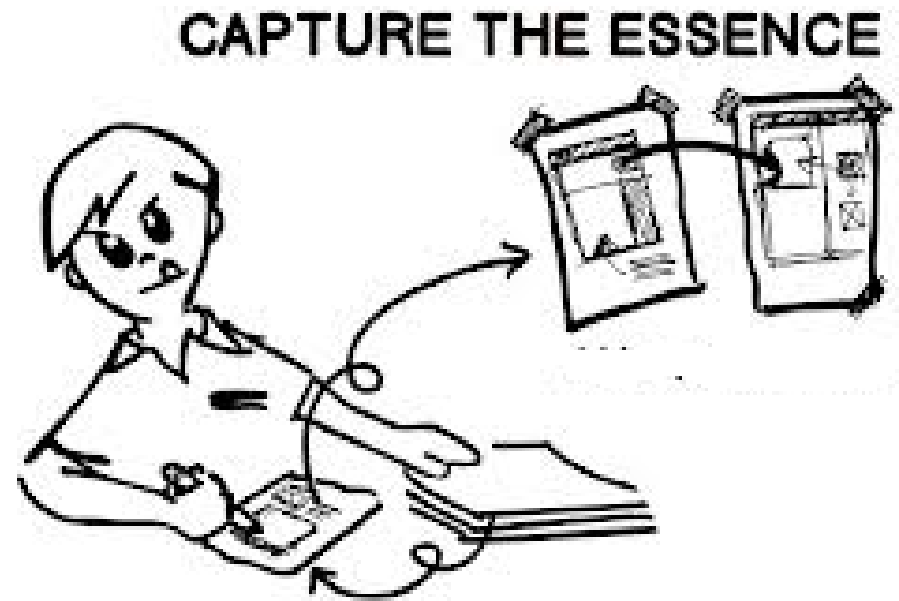
Emphasis on test numbers also interferes with the attempt to actually understand who people are and why they may deserve and need services

# THE Human Equation

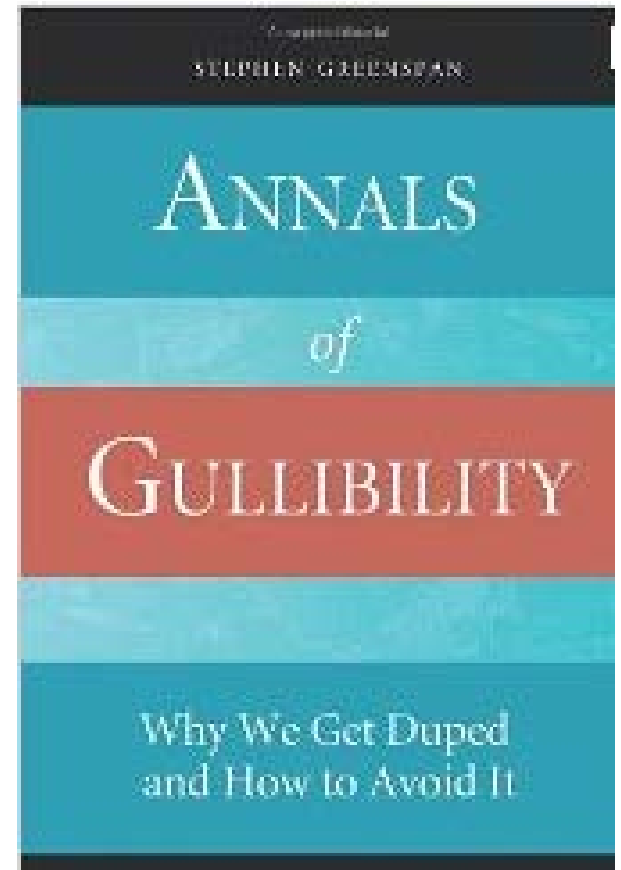


WHY THE DSM-5 SECTION ON “INTELLECTUAL FEVELOPMENTAL DISORDER” IS MOVING FROM A DISABILITY (NUMBERS) EMPHASIS TO A DISORDER (CLINICAL) EMPHASIS

THE KEY TO FINDING AN ADEQUATE BASIS FOR IDENTIFYING INDIVIDUALS WITH NEURODEVELOPMENTAL DISORDERS WHO NEED SERVICES AND PROTECTIONS IS TO FIND A NATURAL AND NOT AN ARTIFICIAL AND ARBITRARY CRITERION



I HAVE BEEN ARGUING FOR YEARS THAT SOCIAL INCOMPETENCE, SUCH AS EXTREME GULLIBILITY, IS MORE IMPORTANT AS AN INDICATOR OF NEED FOR DEVELOPMENTAL SERVICES AND PROTECTIONS THAN IQ SCORE



**MY 2009 BOOK, DEDICATED TO RICHARD LAPOINTE, A CONNECTICUT MAN WITH A NEURODEVELOPMENTAL DISORDER, WHO WAS GIVEN A LIFE SENTENCE FOR A MURDER HE DID NOT COMMIT, AS A RESULT OF HIS GULLIBILITY IN AN INTERROGATION SESSION**

I HAVE YET TO MEET A PERSON WITH FASD OR A RELATED NEURODEVELOPMENTAL DISORDER (SUCH AS AUTISM SPECTRUM DISORDER) WHO DOES NOT HAVE VERY POOR JUDGMENT IN SOCIAL SITUATIONS, AS REFLECTED IN A SUSCEPTIBILITY TO UNDUE INFLUENCE

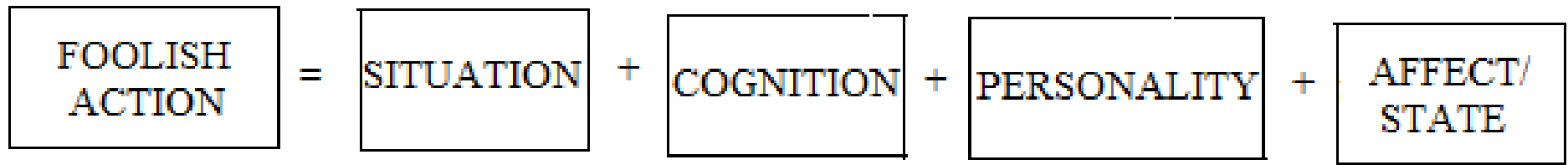


MY KEY RECENT INSIGHT IS THAT FASD AND RELATED DISORDERS MAY BE DEFINED AS COMMON SENSE DEFICIT DISORDERS”, WITH SUPPORTS AND SERVICES NEEDED TO PROTECT INDIVIDUALS FROM THE INCREASED THREAT OF DANGER STEMMING FROM BRAIN-BASED RISK-UNAWARENESS, ESPECIALLY RISKS EMANATING FROM MANIPULATION BY OTHER PEOPLE



LACK OF RISK-AWARENESS





### DYNAMIC MODEL OF FOOLISH ACTION

BEHAVIOR THAT REFLECTS AN ABSENCE OF RISK AWARENESS (OR COMMON SENSE) CAN BE CHARACTERIZED AS “FOOLISH”

MY MODEL OF “FOOLISH ACTION” HAS FOUR CAUSATIVE FACTORS. PEOPLE WITH FASD BEHAVE FOOLISHLY BECAUSE THEY LACK THE SOCIAL COGNITION TO RECOGNIZE DANGER AND THEY ARE SOCIALLY NEEDY (AFFECT AND PERSONALITY) DUE TO A LACK OF “NORMAL” FRIENDS

SITUATION (INDUCEMENT OR PROVOCATION) IS USUALLY PRESENT, BUT THERE IS A LOWER SITUATIONAL THRESHOLD REQUIRED

MEASURES OF  
INTELLIGENCE DO NOT GET  
AT RISK-UNAWARENESS  
DIRECTLY AND NEITHER DO  
MEASURES OF ADAPTIVE  
BEHAVIOR



**(THE VINELAND ADAPTIVE BEHAVIOR SCALE HAS  
ONE ITEM OUT OF WELL OVER 100 THAT MIGHT  
GET AT SUSCEPTIBILITY TO SOCIAL INFLUENCE AND  
THE ABAS HAS ZERO)**

GUARDIANSHIP IS NEEDED FOR MANY  
IF NOT MOST FOLKS WITH FASD  
BECAUSE OF VERY POOR SOCIAL  
JUDGMENT

AN EXAMPLE IS A YOUNG MAN I KNOW  
OF WHO WAS INDUCED TO GET ON A  
BUS TO VISIT AN UNDER-AGE GIRL IN  
ANOTHER CITY. HIS FATHER TRIED TO  
PULL HIM OFF THE BUS, BUT THE  
POLICE PREVENTED HIM FROM DOING  
SO, BECAUSE A LEGAL GUARDIANSHIP  
WAS NOT IN PLACE AND THE MAN WAS  
OVER 18



HE IS NOW SERVING  
A LENGTHY PRISON  
SENTENCE

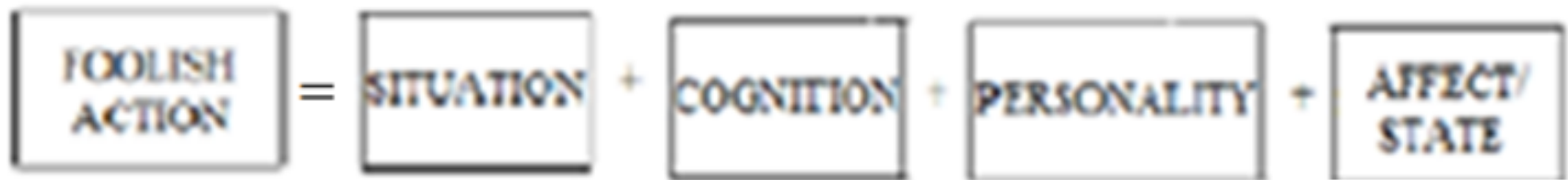
A YOUNG WOMAN I KNOW  
WITH FASD HAS A HISTORY OF  
GETTING INVOLVED WITH  
GUYS WHO EXPLOIT HER  
SEXUALLY AND FINANCIALLY  
AND SHE HAS BEEN UNABLE  
TO HOLD A JOB BECAUSE SHE  
GETS INTO ARGUMENTS WITH  
CO-WORKERS AND  
SUPERVISORS



SHE HAS BEEN UNABLE TO GET DISABILITY BENEFITS  
BECAUSE HER IQ IS IN THE 90s AND SHE HAS ADEQUATE  
SELF-HELP SKILLS ON ADAPTIVE BEHAVIOR MEASURES



USE OF THE FOOLISH ACTION MODEL TO EXPLAIN WHY A YOUNG MAN WITH FASD WOULD PUT HIMSELF AT RISK WITH AN UNDERAGED GIRL



SEXUAL INVITE



RISK UNAWARE

(MOST IMPORTANT)



EASILY LED



LONELY

SO HOW SHOULD WE  
APPROACH THE PROBLEM  
OF DETERMINING IF  
SOMONE WITH FASD OR A  
RELATED  
NEURODEVELOPMENTAL  
DISORDER IS  
SUFFICIENTLY “DISABLED”  
AS TO BE IN NEED OF  
GUARDIANSHIP AND/ OR  
DEVELOPMENTAL  
SERVICES?



**WHAT SHOULD  
WE DO?**

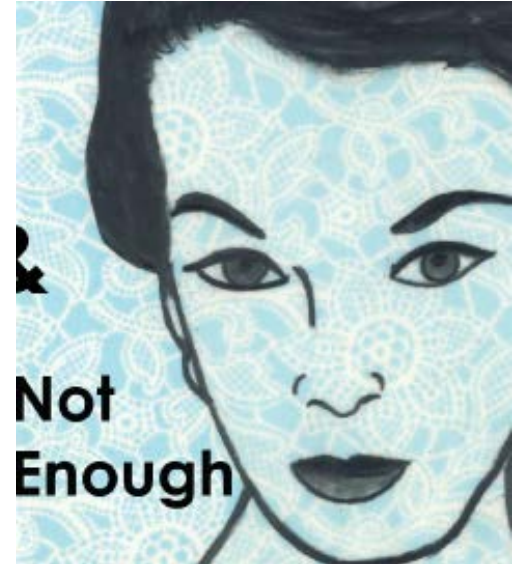
OBVIOUSLY, NEURO-  
PSYCHOLOGICAL  
MEASURES OF  
“EXECUTIVE  
FUNCTIONING” ARE  
IMPORTANT (MUCH  
MORE SO THAN IQ)

**Nobody Ever Did, Or Ever  
Will, Escape the  
Consequences  
Of His Choices.**

- Alfred A. Monapert

THAT IS BECAUSE ONE WAY OF THINKING ABOUT  
EXECUTIVE UNCTIONING IS THAT IT TAPS THE  
ABILITY TO THINK SEQUENTIALLY FROM A  
BEHAVIOR AND ITS CONSEQUENCES, AND LACK OF  
FORESIGHT OR FUTURE ANTICIPATION IS THE  
ESSENCE OF RISK-UNAWARENESS

BUT NEUROPSYCHOLOGICAL MEASURES ARE NOT DIRECT INDICES OF POOR SOCIAL JUDGMENT, AND RISK-UNAWARENESS, BUT RATHER ARE INDIRECT EXPLAINERS OF SUCH BEHAVIOR



IT IS UNDERSTANDABLE THAT BRAIN DAMAGE OF THE KIND FOUND IN PEOPLE WITH FASD, WOULD AFFECT JUDGMENT ABOUT PEOPLE AND SOCIAL RISK, BUT IT IS STILL IMPORTANT TO SHOW CONVINCINGLY THAT SUCH BEHAVIOR OCCURS AND IS LIKELY TO REOCCUR IN THE FUTURE



IT IS MY UNDERSTANDING THAT THE TREND IN GUARDIANSHIP LAW, IS THAT THE MEASURES USED SHOULD BEAR SOME LOGICAL CONNECTION TO THE RISK THAT IS THE REASON FOR THE LEGAL INTERVENTION



SO WHEN SEEKING PROTECTIONS (WHETHER GUARDIANSHIP OR SUPPORTS) FOR SOMEONE WITH FASD, IT IS ADVISABLE TO DEVISE A WAY OF COMPILING RISKY BEHAVIORS IN THE PERSON'S PAST WHICH, IN COMBINATION WITH EVIDENCE OF POOR EXECUTIVE SKILLS, SHOWS THAT THESE REFLECT BRAIN-BASED RISK-UNAWAWARENESS RATHER THAN POOR CHARACTER

WE SHOULD ALSO DEVELOP  
WAYS OF ACTUALLY TAPPING  
INTO SOMEONE'S ABILITY TO  
UNDERSTAND RISK  
(SOMETHING THAT I AM  
WORKING ON WITH  
COLLEAGUES)



SUCH MEASURES DO NOT EXIST. MEASURES OF “PROBLEM-SOLVING” ASK SUBJECTS TO GENERATE GOOD SOLUTIONS, BUT NOT TO EVALUATE TERRIBLE DECISIONS. YET THE ABILITY TO RECOGNIZE AND AVOID TERRIBLE DECISIONS GOES TO THE HEART OF WHAT IT MEANS TO BE A COMPETENT ADULT

MOST OF US MAKE NON-OPTIMAL DECISIONS FROM TIME TO TIME, BUT THE CONSEQUENCES ARE USUALLY MINOR. BUT ONLY THOSE WHO DESERVE TO BE CONSIDERED LEGALLY INCOMPETENT ARE CONSISTENTLY UNABLE TO RECOGNIZE AND AVOID TERRIBLE DECISIONS



**INDIVIDUALS WITH FASD ARE SUCH PEOPLE**



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CONTACT ME TO REQUEST COPIES OF PAPERS I  
HAVE PUBLISHED RELATED TO THIS TOPIC