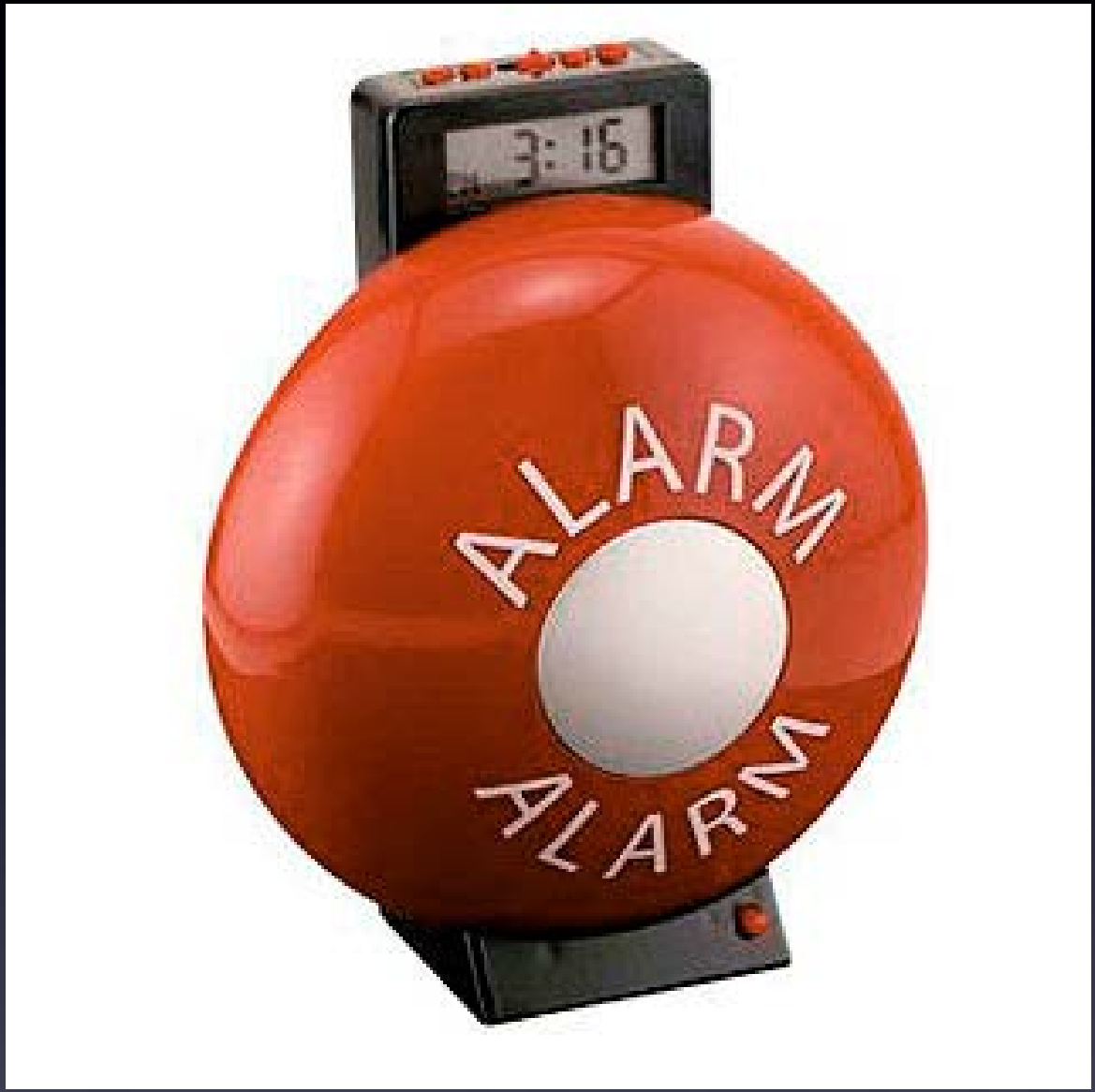
UNHS - [illegible] e started it

What are we achieving & *where* do we want to go?

Capi C Wever

7th Australasian Newborn Hearing Screening Conference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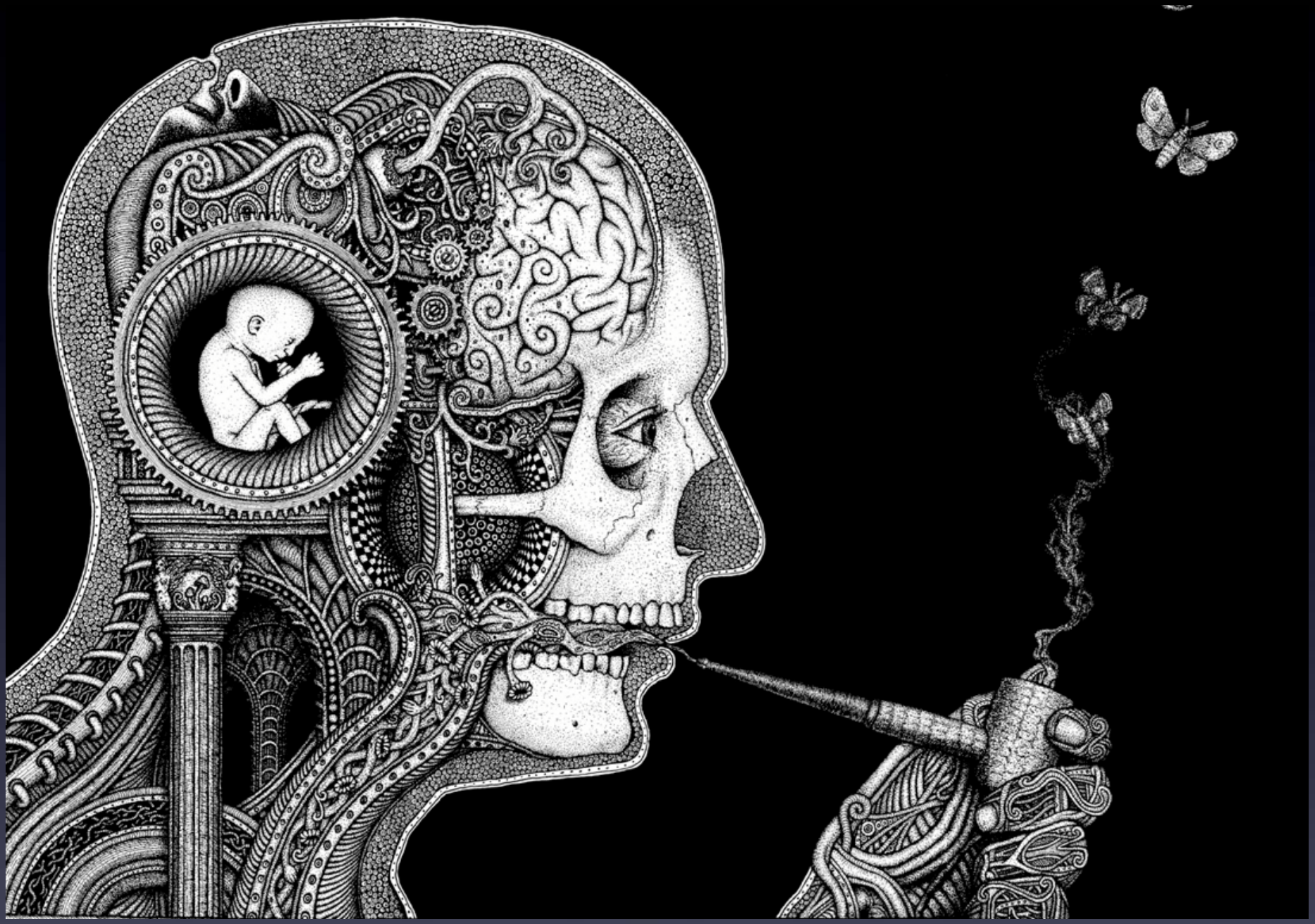
ALARM
ALARM



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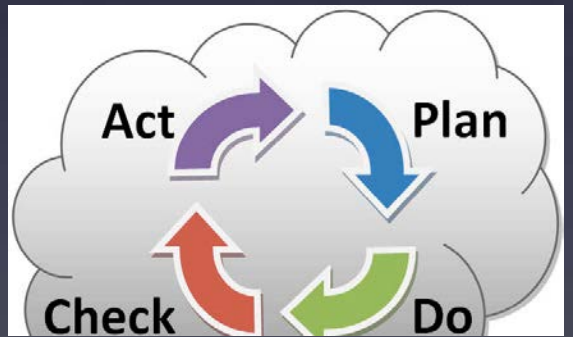
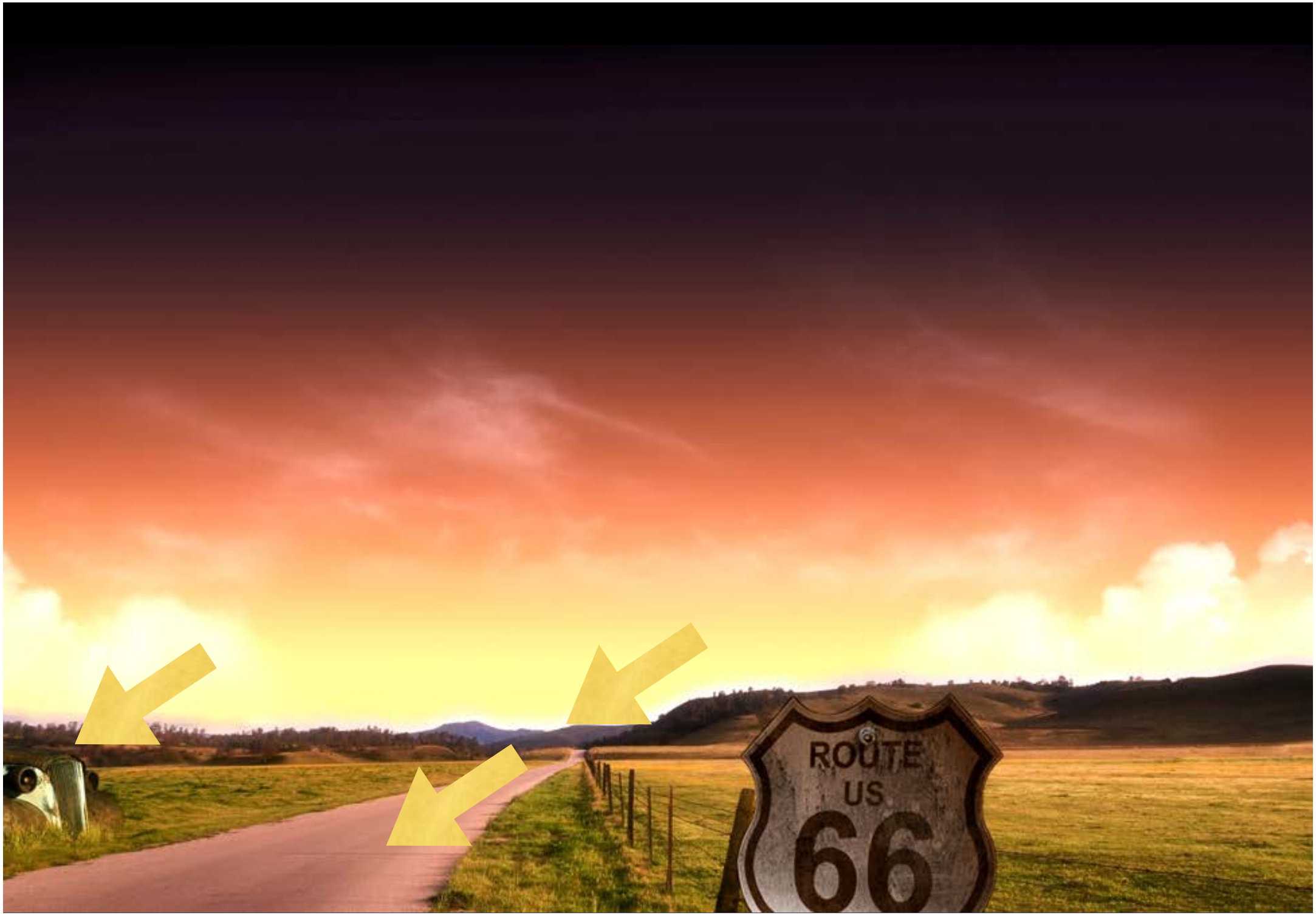
Overview

Today: Foundation - where do we stand, why do we do what we do and what does it mean?

Tomorrow: What does it mean to how we relate to parents?



STOP,
LOOK,
LISTEN
AND
REFLECT


ROUTE
US
66

Got to know

Point of departure: why we started it...

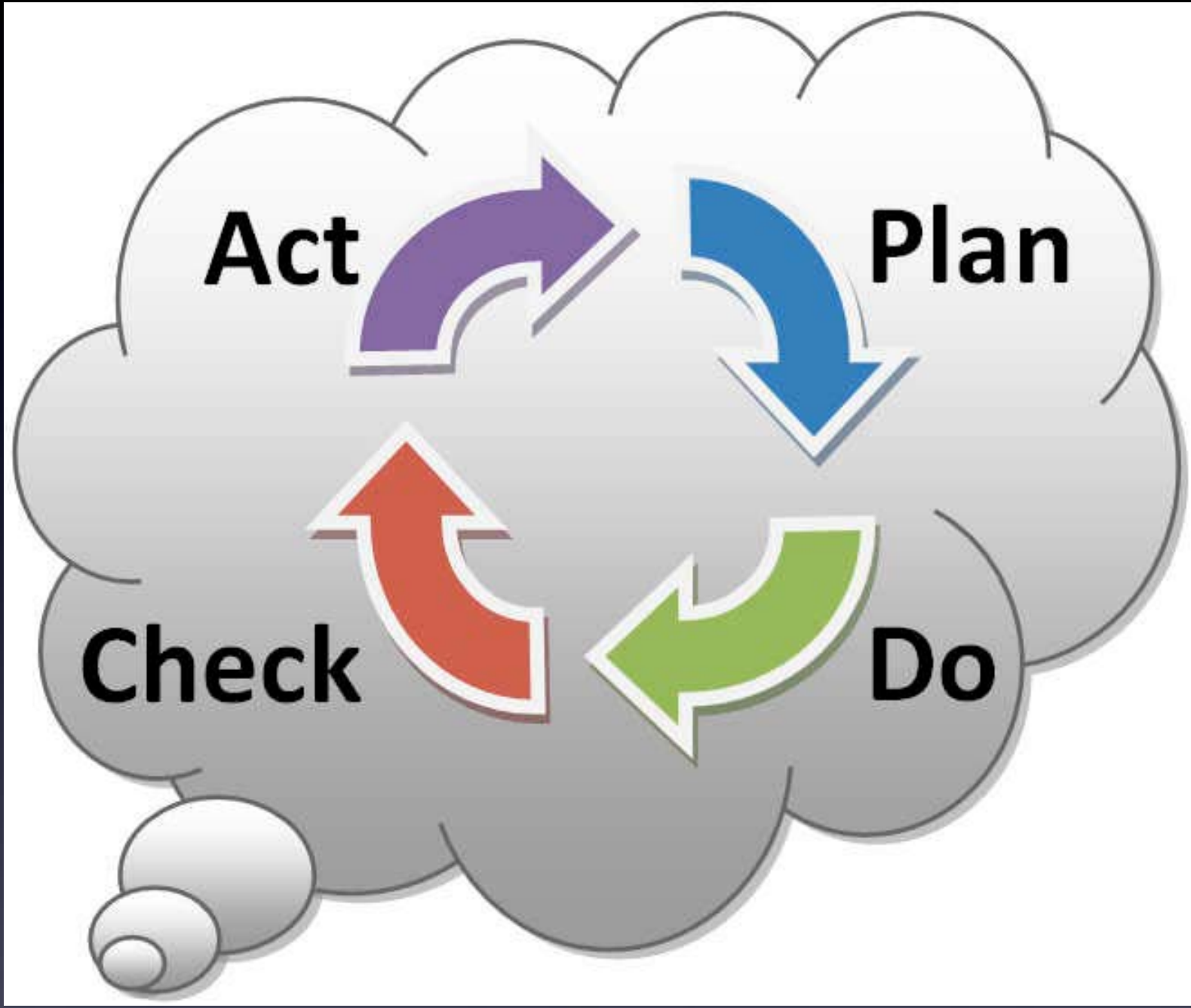
Heading

- What is/was our purpose...
- Where are/were we heading...
- What are/were we trying to achieve...

Check on our progress...

- Learn, reflect and improve wh do

R. Aber Vrach
Lanilis
R. Aber Benoit
Le Coq
Pte de Toulinguet
St. Matthews
Black Sea
Le Bouc
NW
NE
W
E
SW
SE
S


Act
Plan
Do
Check

Problem

Intervention?

- often mentioned that circumstance in Ewing/Capas age was “suboptimal”
- often NOT mentioned *what* intervention one is alludi to
- often hence NOT mentioned which gains are expect and based on which arguments
- ence *vexing* a critical test of gains vs liabilities -- no an “invitation” to scrutiny or self critique and improvement

Monitor

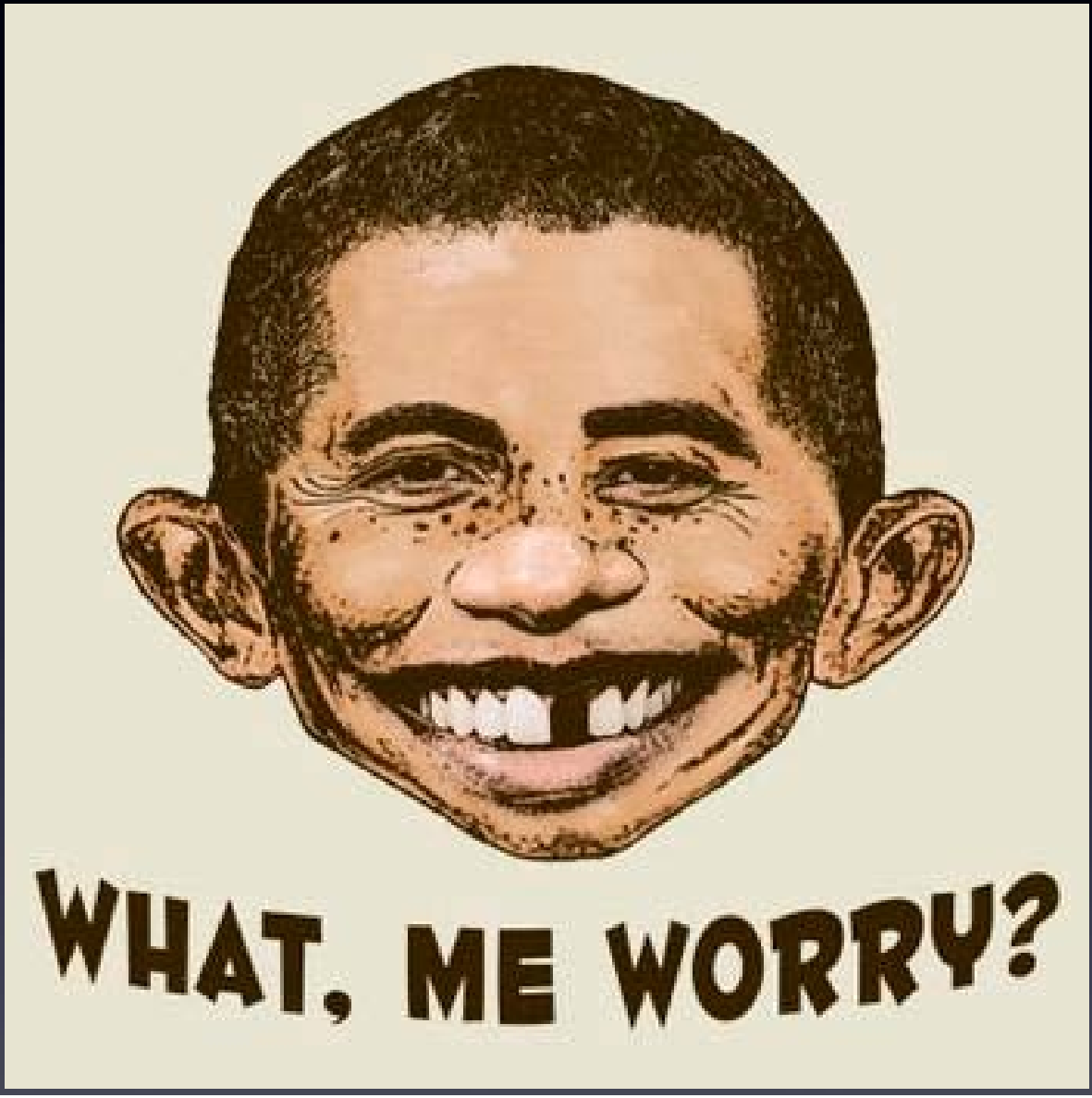
How to monitor such system?
What is the standard of care?
What are the outcome demands?
How do we improve ourselves?

UNHS Literature

NL --- no correlation speech
Australia --- no correlation speech
Belgium --- do not report on speech

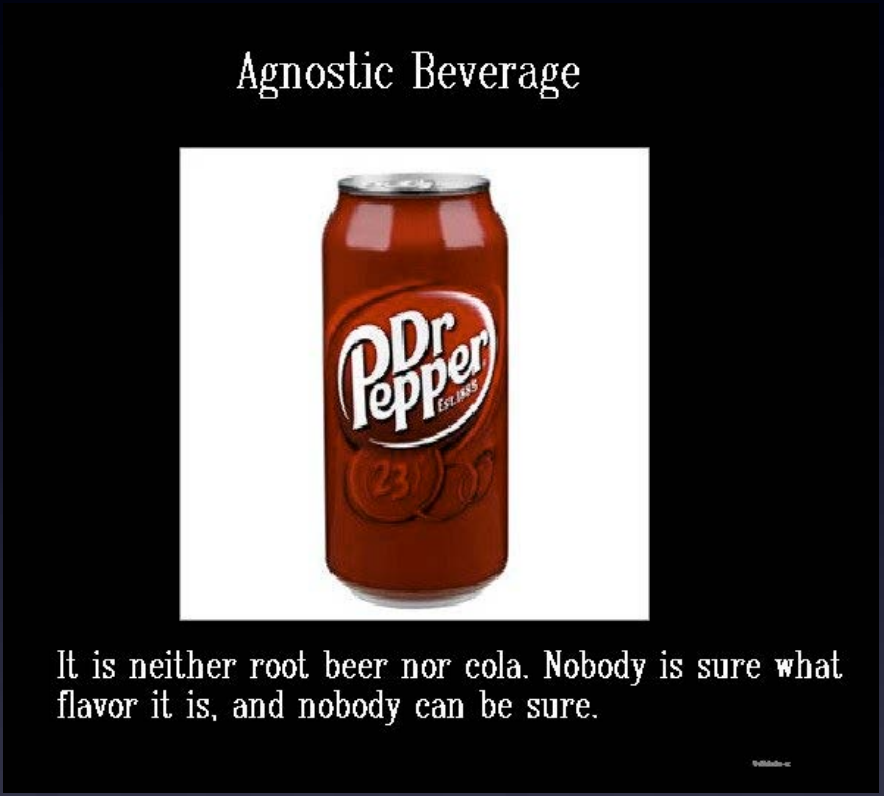
YET...

worried



right

agnosticism?



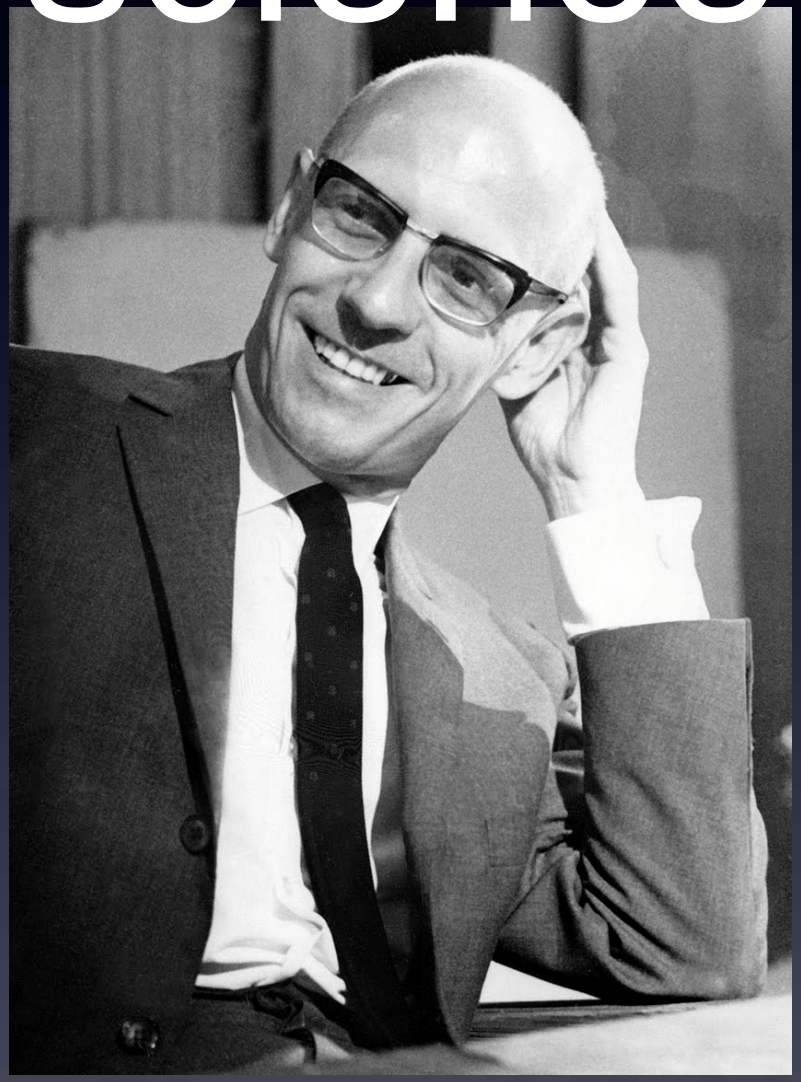
Lack of time-awareness & hence "stuck in the do" of every day

Symbolism:

(Hence its not about hearing at all!)

Some things don’t make sense without the symbolic context or “subtext”

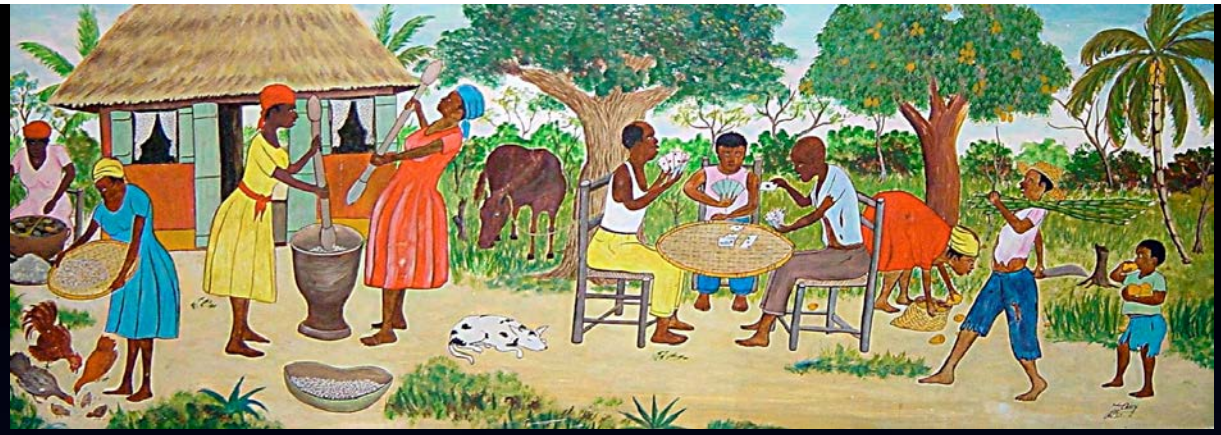
social, moral & science



Foucault

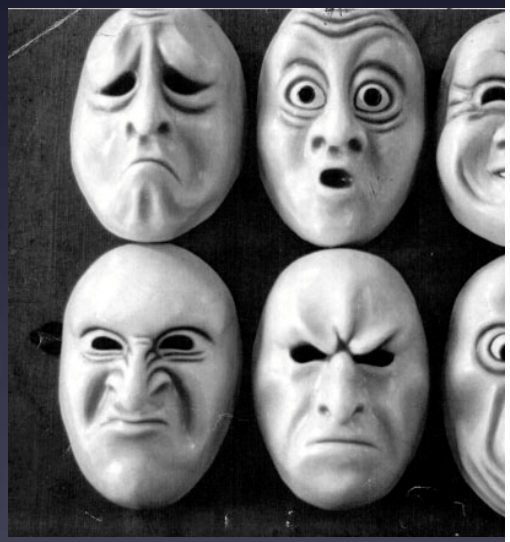
- Ethical and moral basis always main ingredient of debate - no short cuts!
- When we lose track of this, be alerted
- When people tell you these questions are now "irrelevant" or refer to statistics, be alerted
- When emotions, politics, society is involved, be alert
- Hegemony of debate & power intertwined

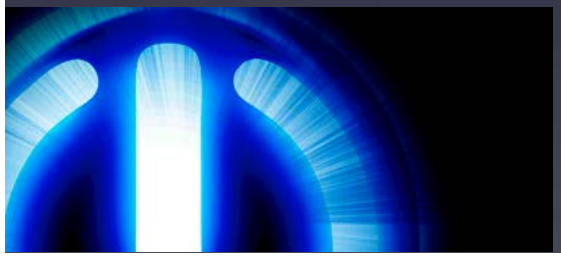
2+2
2+2
2+2
H2O

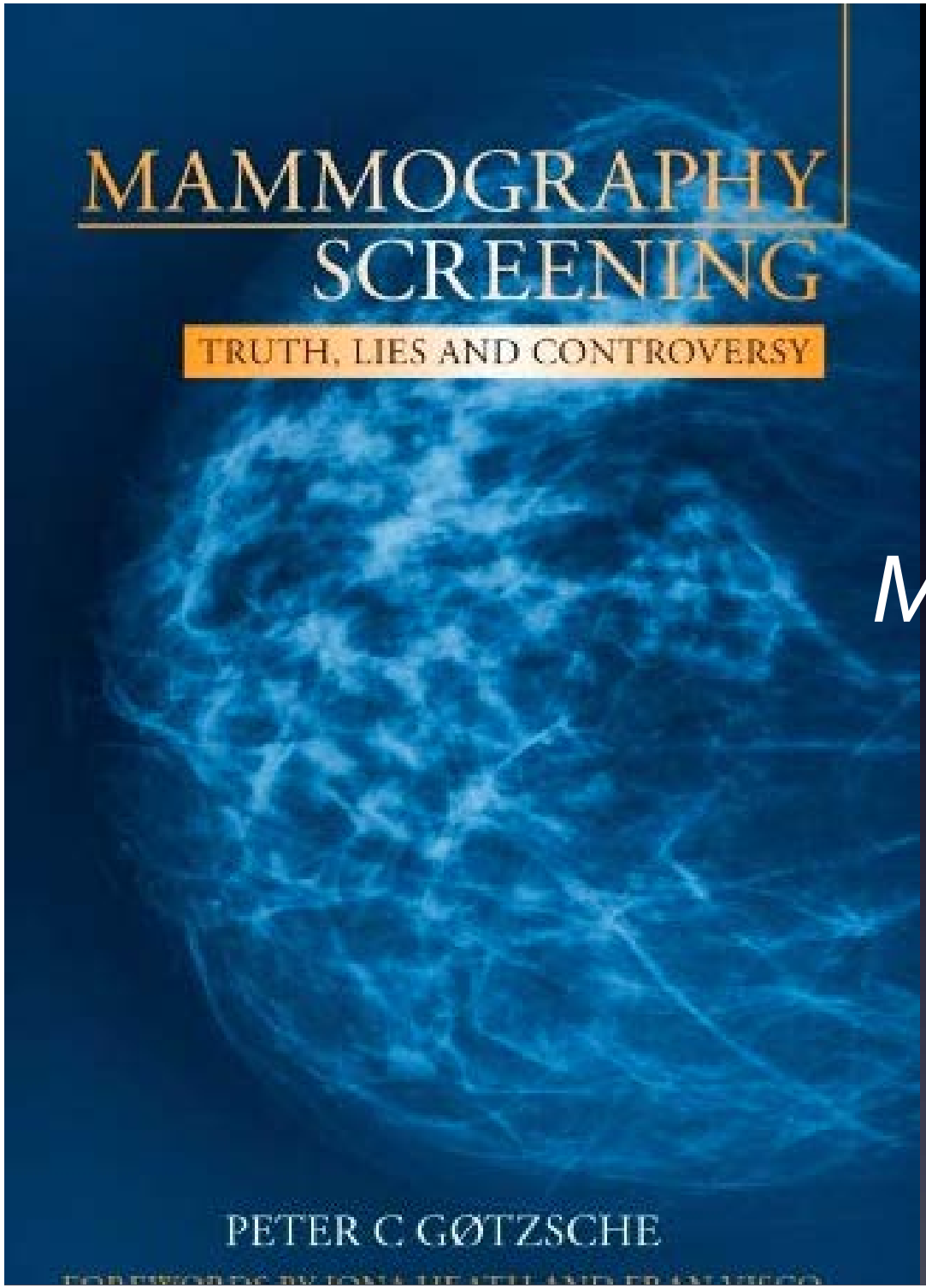


MCCCXXXIIII
BEAST 1333

2+2
√123
H₂O







McDaddy of all screeni
isn't it?

Gøtzsche's book tells of personal attacks on him and on other researchers by the pro-screening lobby, some of whom had financial interests in the continuation of screening programmes, he alleges.

He compares screening advocates to religious believers and argues that their hostile attitudes are harmful to scientific progress. A lot of false evidence has been put forward to claim that the screening effect was large, he writes. Those who tried to expose the errors came under personal attack, as if they were blasphemers. (The Guardian 2012)

JOURNAL of MEDICINE

RIGINAL ARTICLE

ostract for Effect of Three Decades of Screening Mammography on Breast-Cancer cidence

Bleyer and H. G. Welch

Engl J Med 367:1998, November 22, 2012

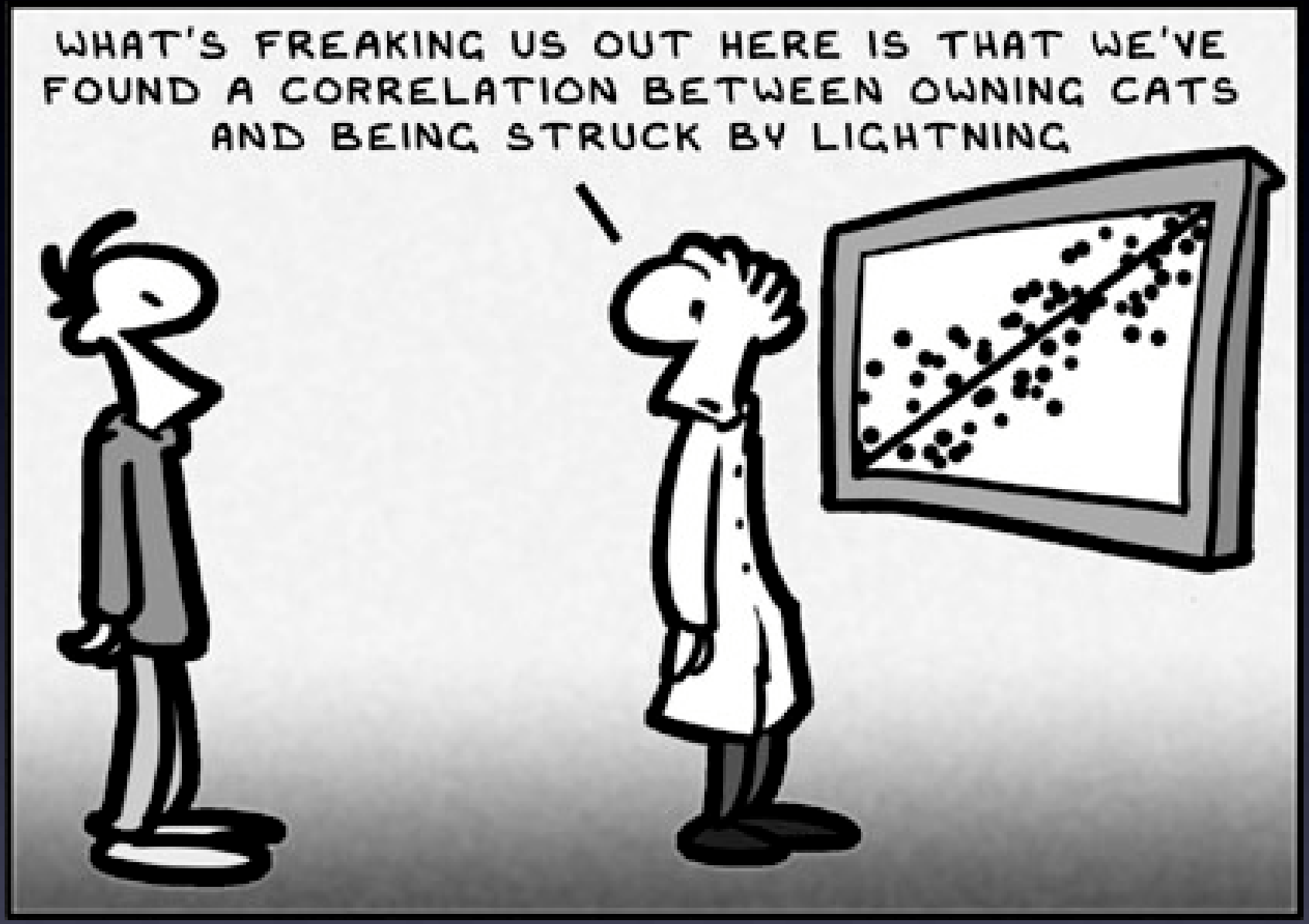
The New England Journal of Medicine • 860 Winter Street • Waltham, MA 02451 • USA

Critique

Normative undertone (“save women”)
Act of principle and heroism
Emotional subject & strong societal support
Neglect of collateral damage (false positives)
No self-critical evaluation of targets and costs

Grounded on the key of medical rhetoric

e save lives! Are you against


WHAT'S FREAKING US OUT HERE IS THAT WE'VE FOUND A CORRELATION BETWEEN OWNING CATS AND BEING STRUCK BY LIGHTNING

Confirmation bias

- Researchers tend to interpret data to fit a hypothesis
- This is *worse* when political, societal and emotional issues are involved
- P-value bias is another way of doing this

David Kirby's Final Moments

Photo © 1990 Therese Frare

HIV trial

51/8197

p = 0.04

74/8198

Vaccine

No Vaccine

"P-values speak for themselves"

Is the effect large enough for *practical* importance?

Significance tests [potentially] blur the distinction between *statistical significance* and *practical importance ()*

UCLA

P-value tells us nothing about the magnitude of the effect, let alone the meaning...which can be trivial

The larger the sample size, the greater this potential irrelevance

Ethical end-question

lways as essential as p-value

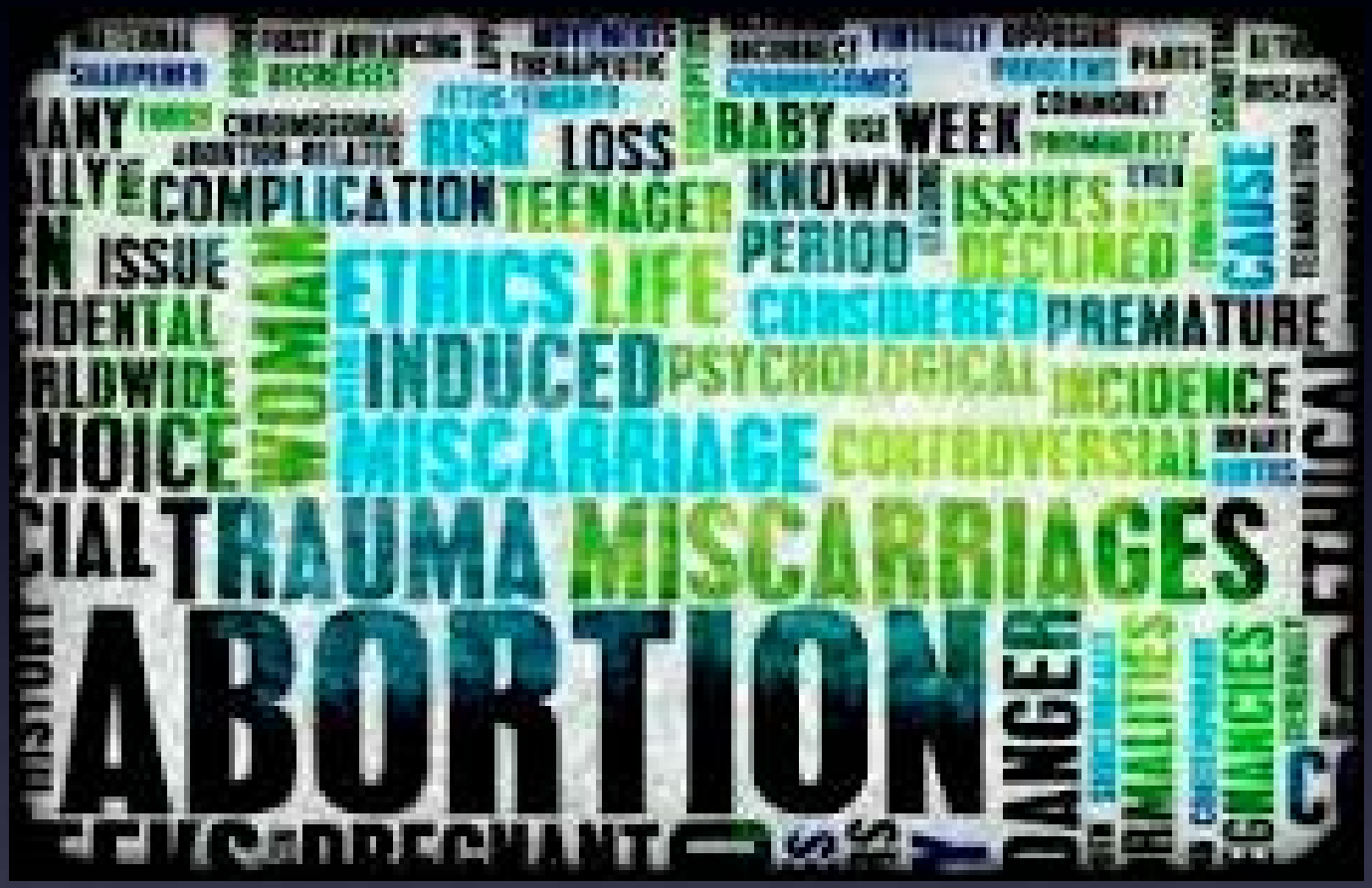
s the intervention worth a 0.3% lower chance of getting infected?

epends on *many* sub-questions

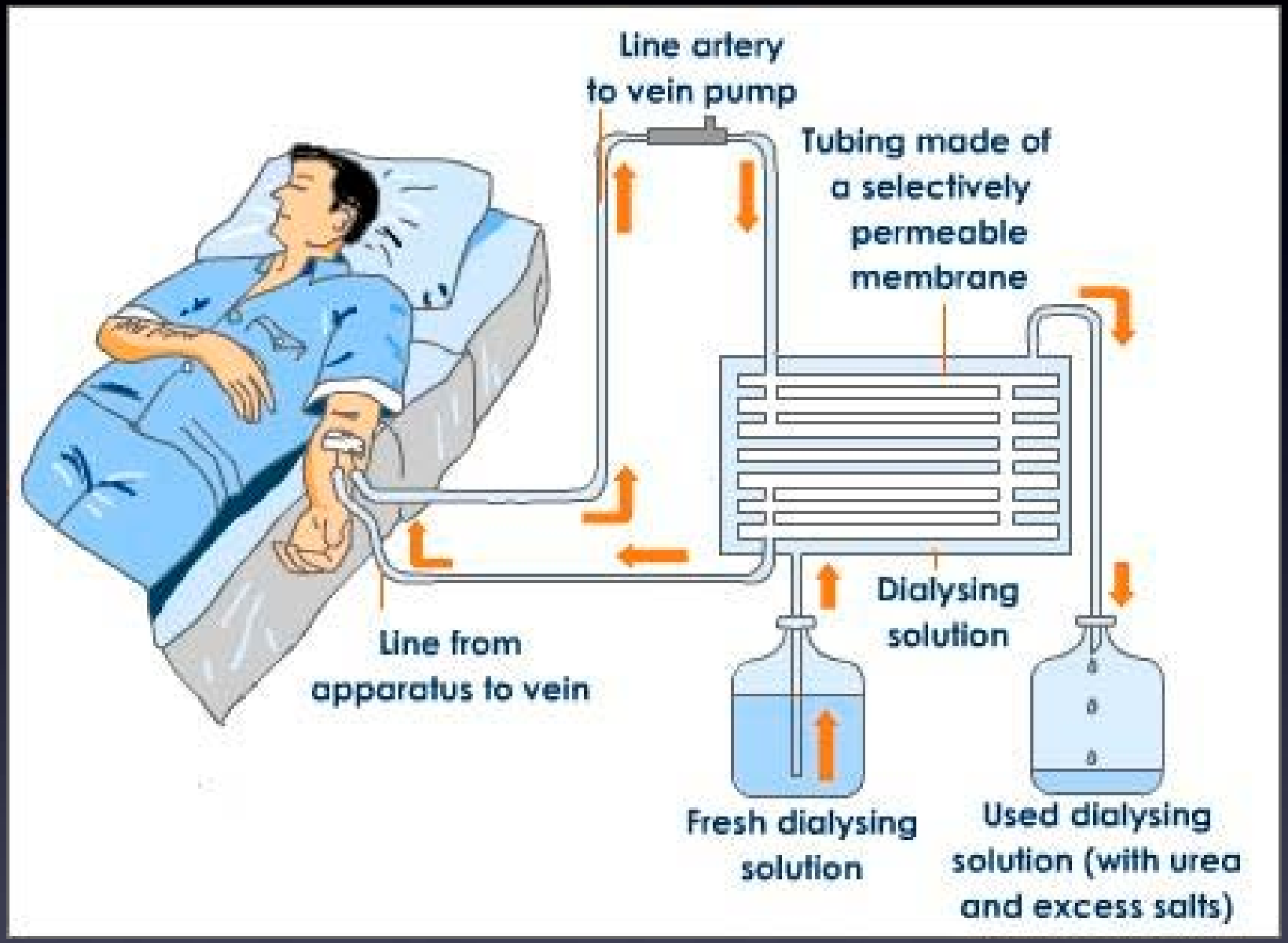
ide effects, invasiveness, morbidity, mortality, emotional burden, cost etc etc

roportionality

ethics


ABORTION
TRAUMA
MISCARRIAGES
MISCARRIAGE
ETHICS
LIFE
INDUCED
WOMAN
CONSIDERED
PREMATURE
PSYCHOLOGICAL
INCIDENCE
CONTROVERSIAL
CHOICE
ISSUE
COMPLICATION
TEENAGER
KNOWN
PERIOD
ISSUES
DECLINED
CAUSE
RISK
LOSS
BABY
WEEK
DANGER

No short cuts!


Line artery
to vein pump
Tubing made of
a selectively
permeable
membrane
Dialysing
solution
Line from
apparatus to vein
Fresh dialysing
solution
Used dialysing
solution (with urea
and excess salts)

Renal dialysis (*)

pensive technology developed early 1960's
72 added to Medicare (USA)
ial trial founded on "idealized population"
Young (37), healthy, end stage renal failure (ESRF)
adual shift to older (50) cases, with more morbidity
ial trials of little relevance today

he "new" dialysis population includes patient
th serious chronic illness such as cancer an
heart disease and senile patients who are
livered to dialysis centers three times a wee
from their nursing homes.

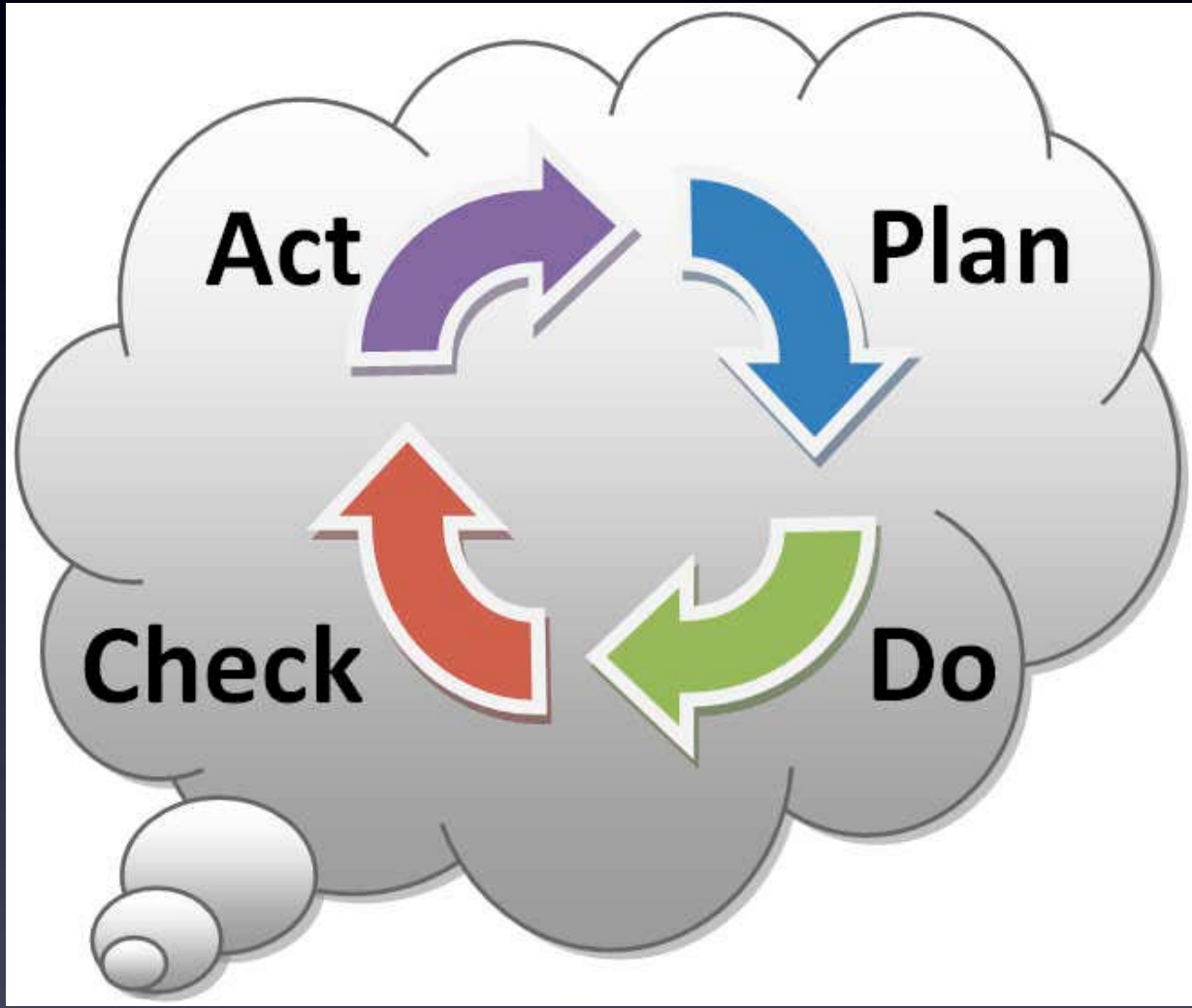
According to doctors who treat them, dialysis
patients are often deeply unhappy.

Kolata, Science 1980

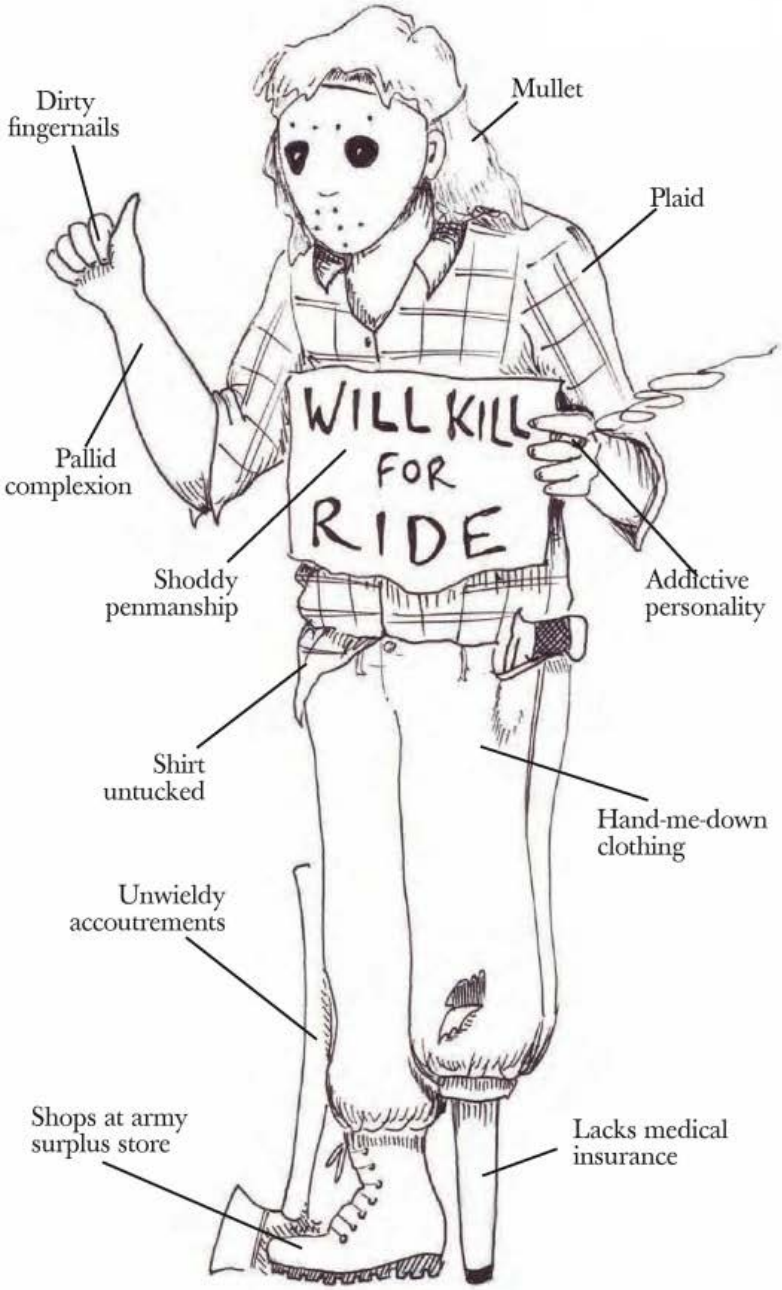
Dialysis today

MMPI score towards depression
Feel “captured” by medical profession
Suicide 7x higher (like other chronic disorders)

attitude



SIGNS OF A DANGEROUS HITCHHIKER

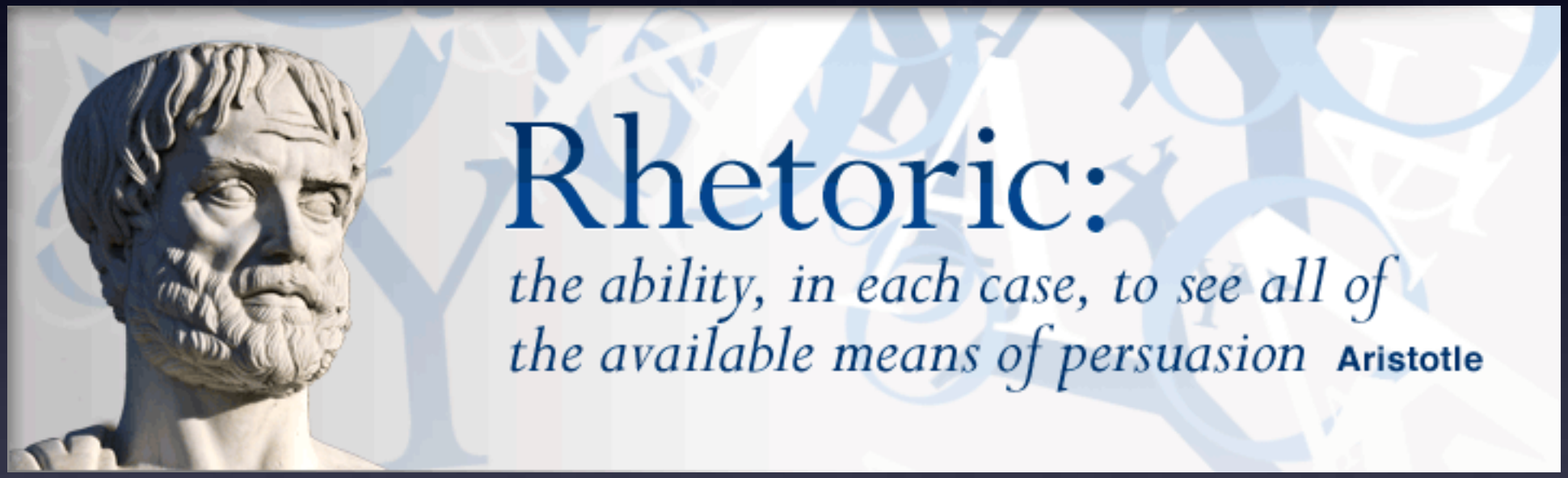


—Dounia Bredes, '11

of now....

Understanding rhetoric and unravelling it

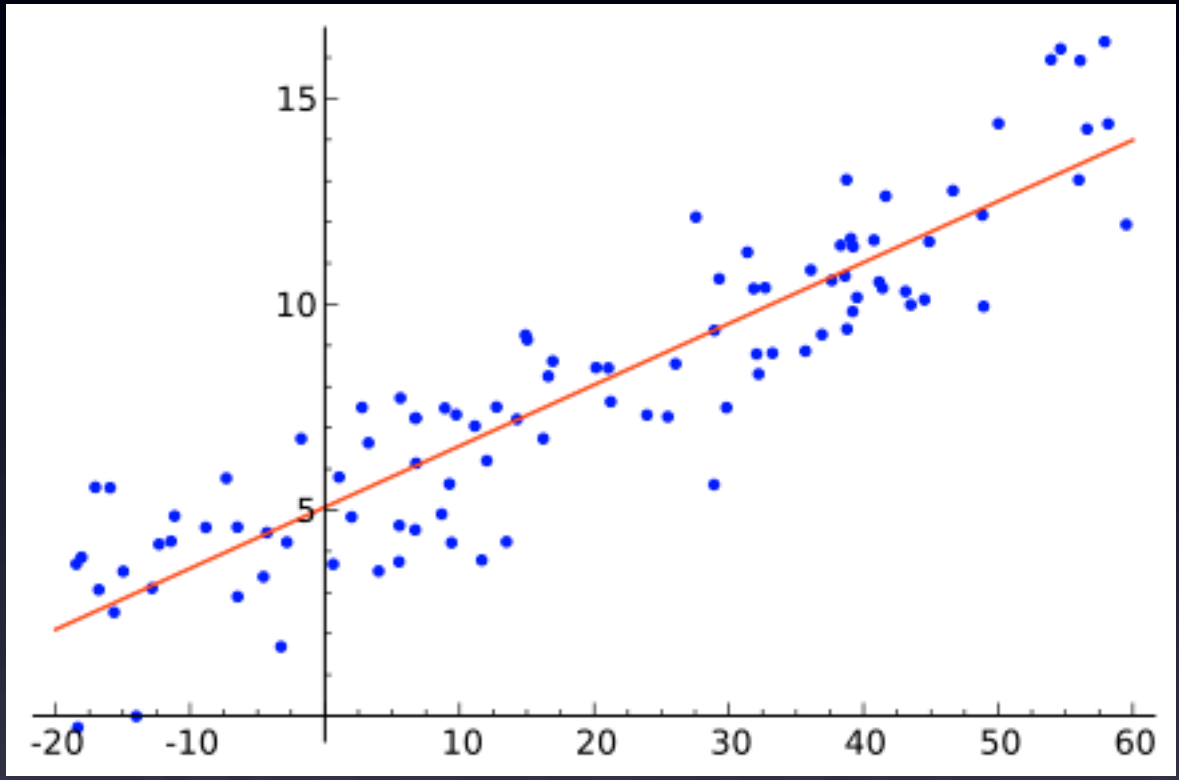
part of the deeper understanding that we ne



Symbolism & rhetoric

- “How can we deny someone the chance to live?”
- “How do we explain that the only thing that stands between life and death is dollars”
- *Back against the wall* erases all nuance and debate about liabilities
- Makes a three-dimensional debate two dimensiona

Linear absolute of life



Linear absolute of life

CHANGE

medicine

Circle of legitimacy of medical technology
Denial of heterogenous nature of values
Denial of ambivalence of values
Denial of value contradiction
Lack of irony and modesty
Rhetoric and truth

Paradigm ceiling

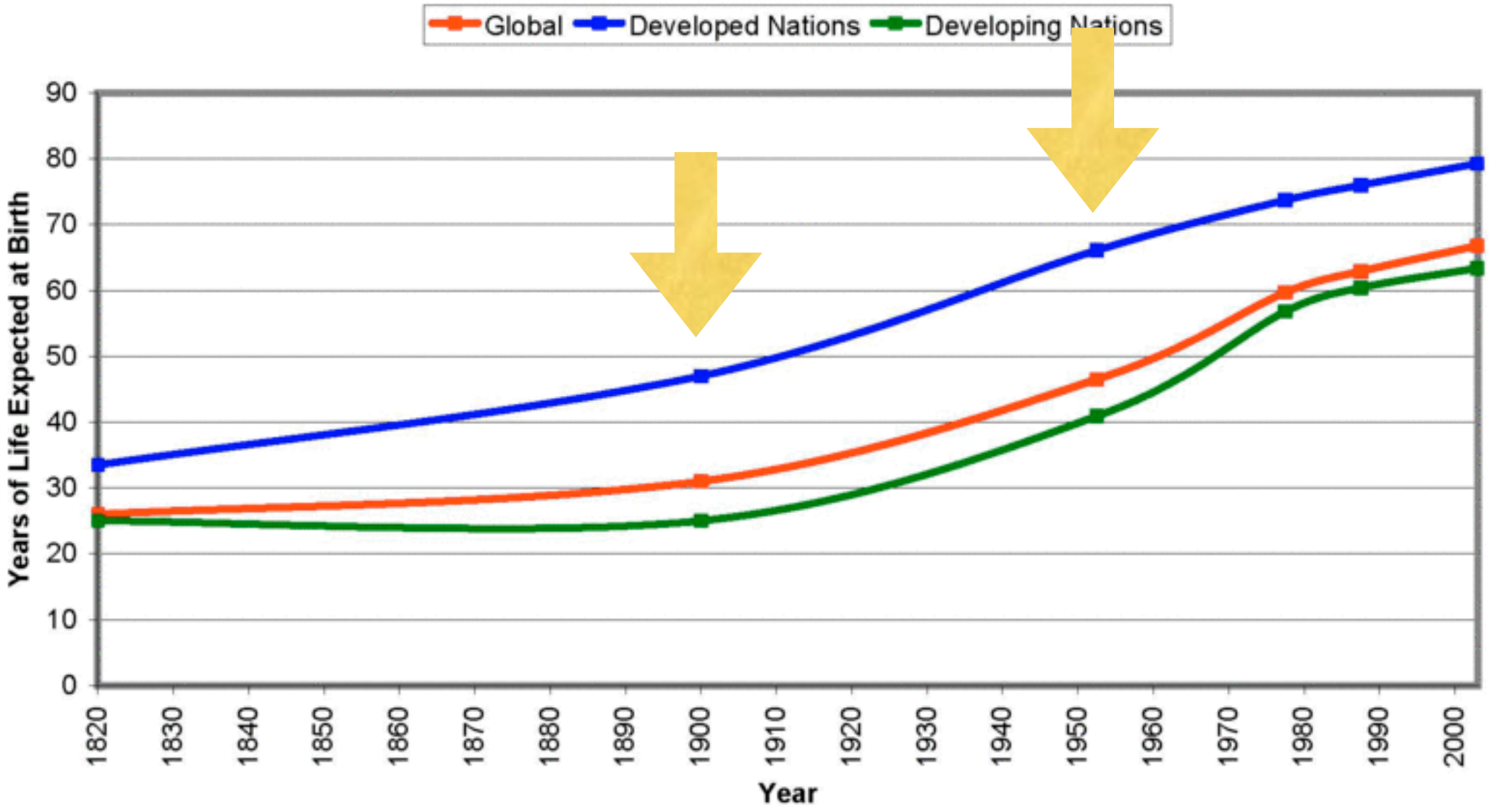
Pre 1950's medicine

fits evident in "life years"

Liabilities little

General hygiene
War trauma (1916)
Immunisation (1914)
Penicillin (1928)

Life Expectancy, 1820-2003



Source: Indur M. Goklany. "The Improving State of our World." Washington, DC: Cato Institute, 2007. 36. France used as a proxy for Developed Nations 1900 and earlier.

© 2008, Michael W. Kruse

Post 1950's medicine

its << evident in life years

Liabilities l

Childhood leucemia (1950)
Chemotherapy
Heart surgery (1950's)
Transplantation
Hemodialysis

Quality of l
Morbidity
Iatrogenic
(thalidomid

QoL

paradigm

ne outcome is life-death all statistic bend
at is why the p-value bias is often ignored - who is to
argue that a 0.3 lesser chance to die is not worth wh
s wrong in itself and even more so...
copy this outside of context of terminal disease is a
major err

science

“In *real world* situations, evidence

Wicked Problems
Difficult to define
Interdependencies and multi-causal
Solutions can lead to unforeseen consequences
No clear solution
Socially complex
Involve changing behavior
Sit astride organizational boundaries and responsibilities
Seemingly intractable with chronic policy failure

Wicked problems

at are multi-causal and idiosyncratic
mand eclectic approach
ay clear of “systemic” monolytic approach
ptimizing” to be avoided as a goal
agmatism and modesty in style

CAN YOU CHANGE THE STATION? THAT'S THE SAME MUSIC MY GRANDPA LISTENS TO ON HIS HEARING AID WHEN IT'S NOT WORKING RIGHT

R. Aber Vrach
Lanilis
R. Aber Benoit
Le Coq
Pte de Toulinguet
St. Matthews
Black Sea
Le Bouc
NW
NE
W
E
SW
SE
S

Why the opacity?

imperative

PARTIAL-BIRTH ABORTION?
NO, STEM-CELL RESEARCH
garyvanvel.com

technology

So why not use it?
There’s no use fighting it
It’s like Ewing-Capas, just better
There are no losers, just winners

mist?

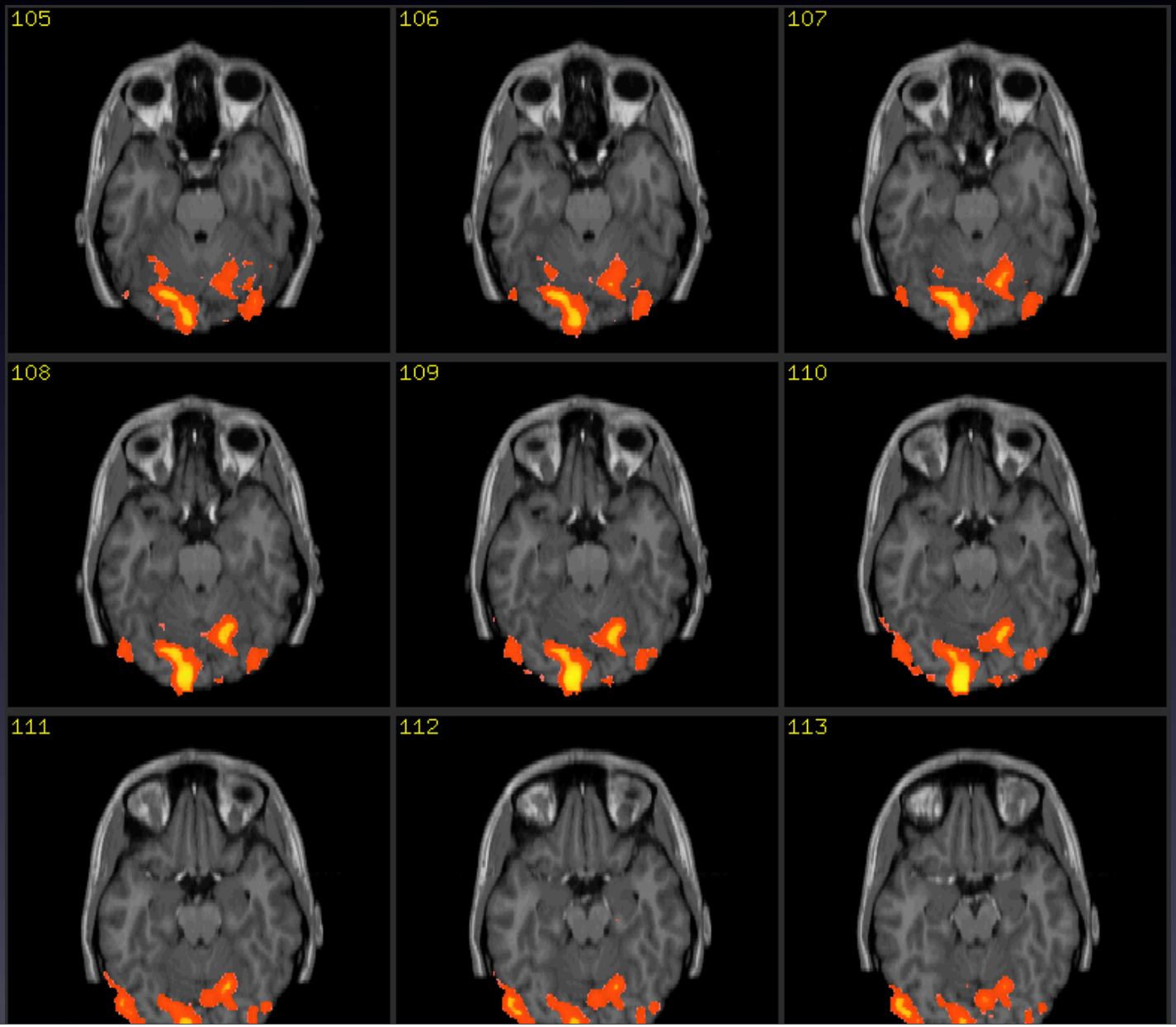
nclear “Purpose” definition can be convenient
olitical unspoken purpose premisses
rategic “boldness” to “launch” technology
xperimental stage: learn from experiments
eeper & implicit belief in the righteousness of action

Mistaken for “tame” problem....

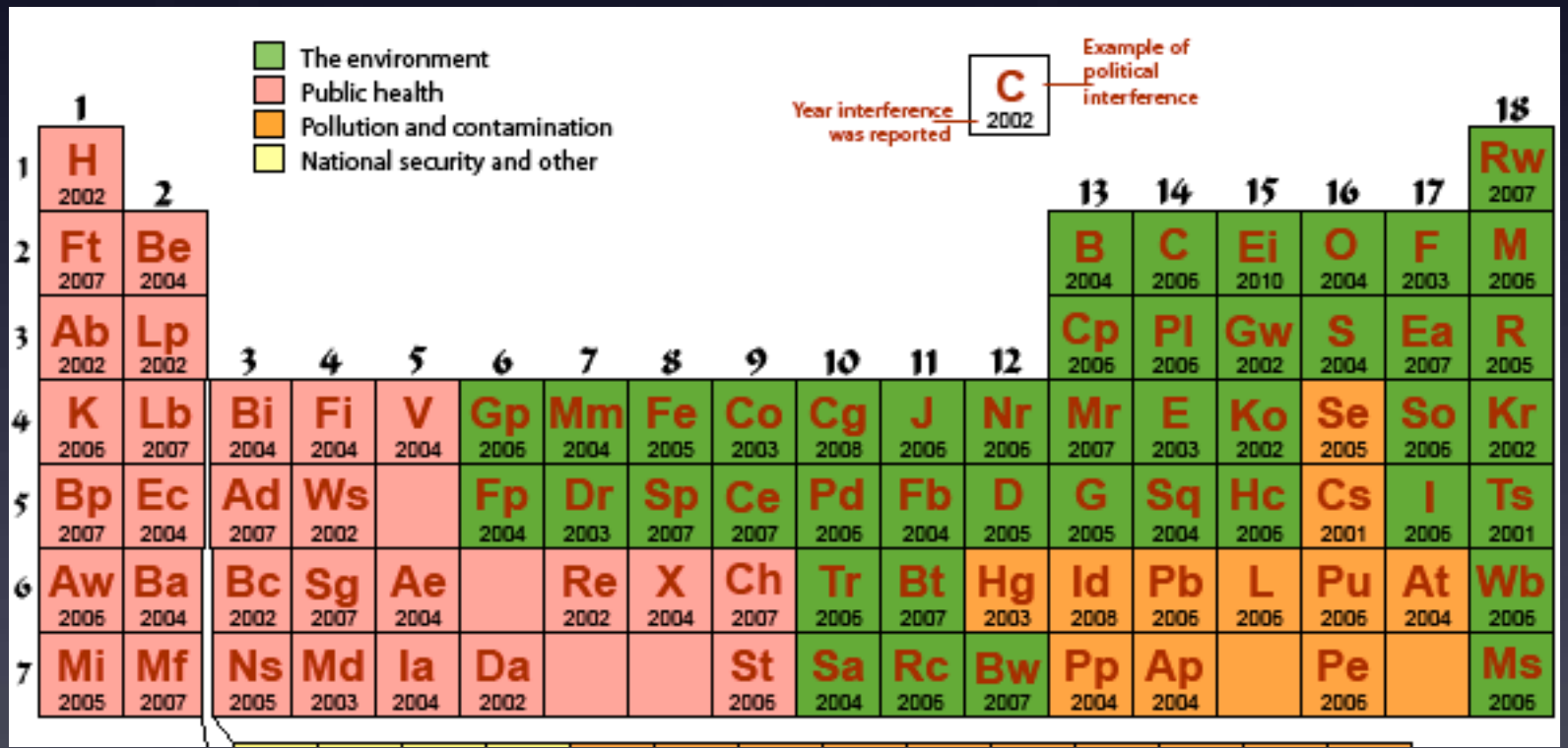
scrutiny either

Wicked problems *depower* and make things complex

Shortcuts?



wicked problem into a *value-free* scientific issue



How can one deny a child the right to hearing...even if its just a little?

Let Them Hear Foundation

Advocacy Program

Is *every word* gained <u>really</u> of practical significance?

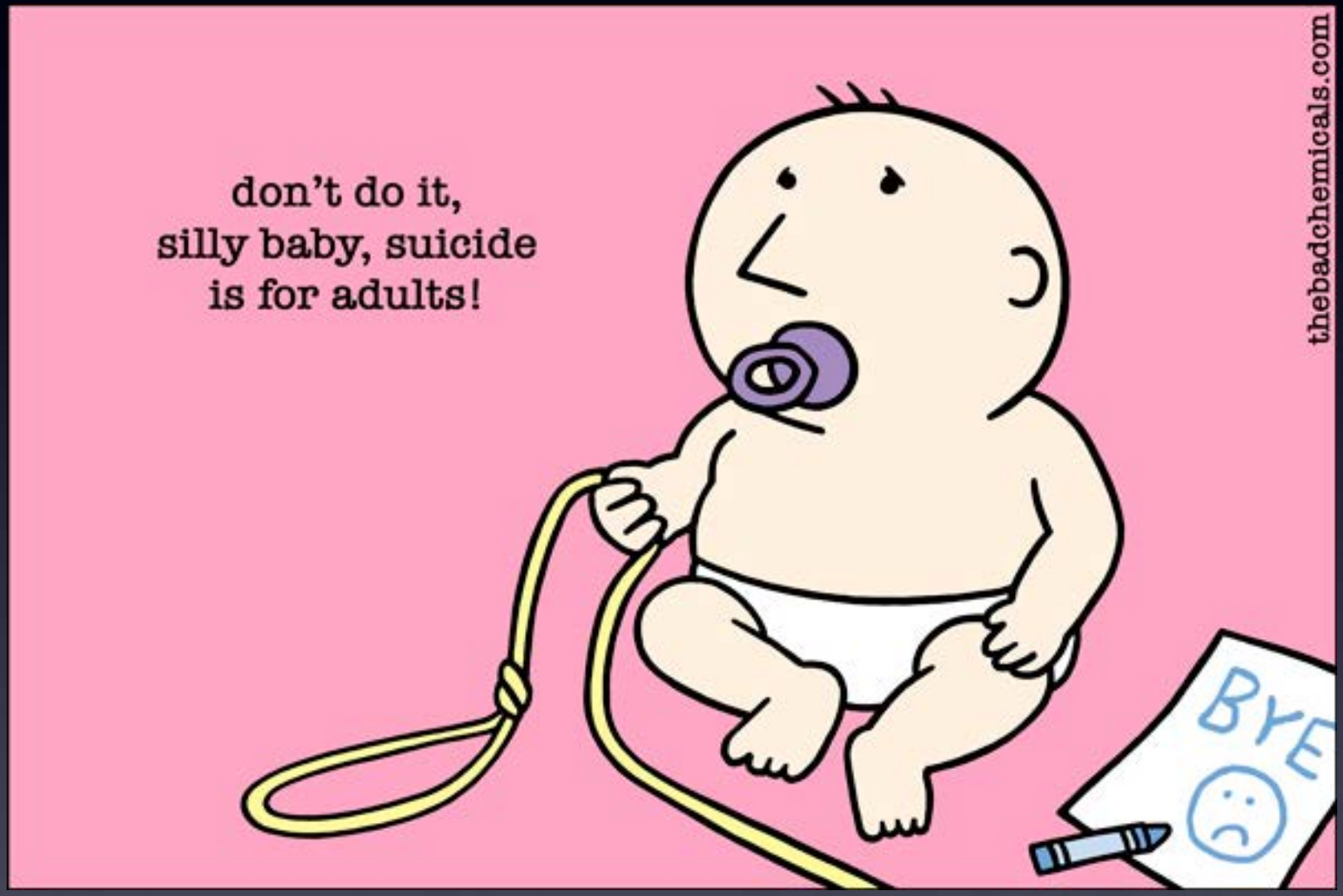
Blood brother?

Linear absolute

The linear absolute of hearing

"Audism is attitudes and practices base on the assumption that behaving in th ways of those who speak and hear desired and best. It produces a system privilege, thus resulting in stigma, bia discrimination, and prejudice—in overt c covert ways—against Deaf culture, th signed languages of Deaf people, an Deaf people of all walks of life."

Appropriate?



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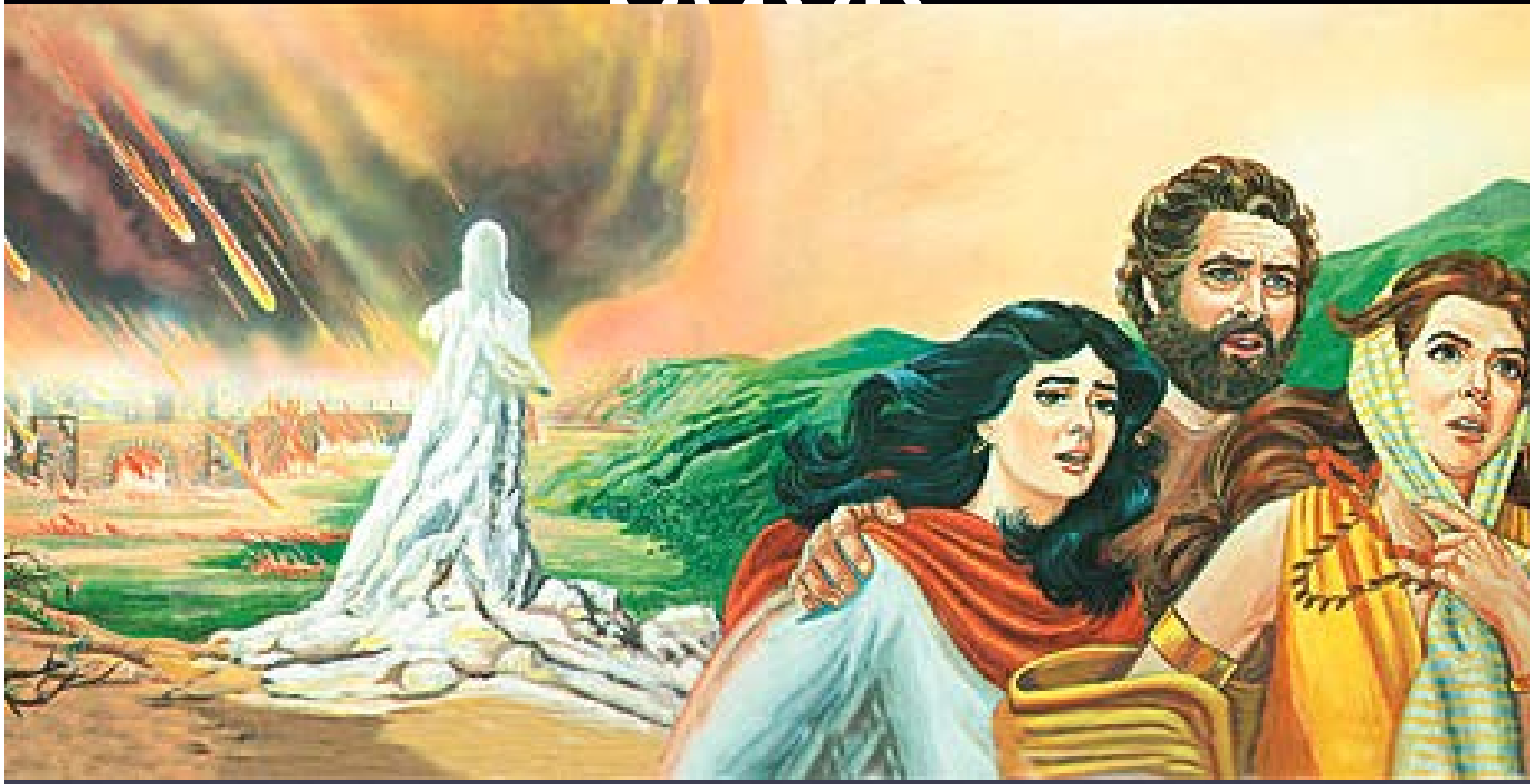
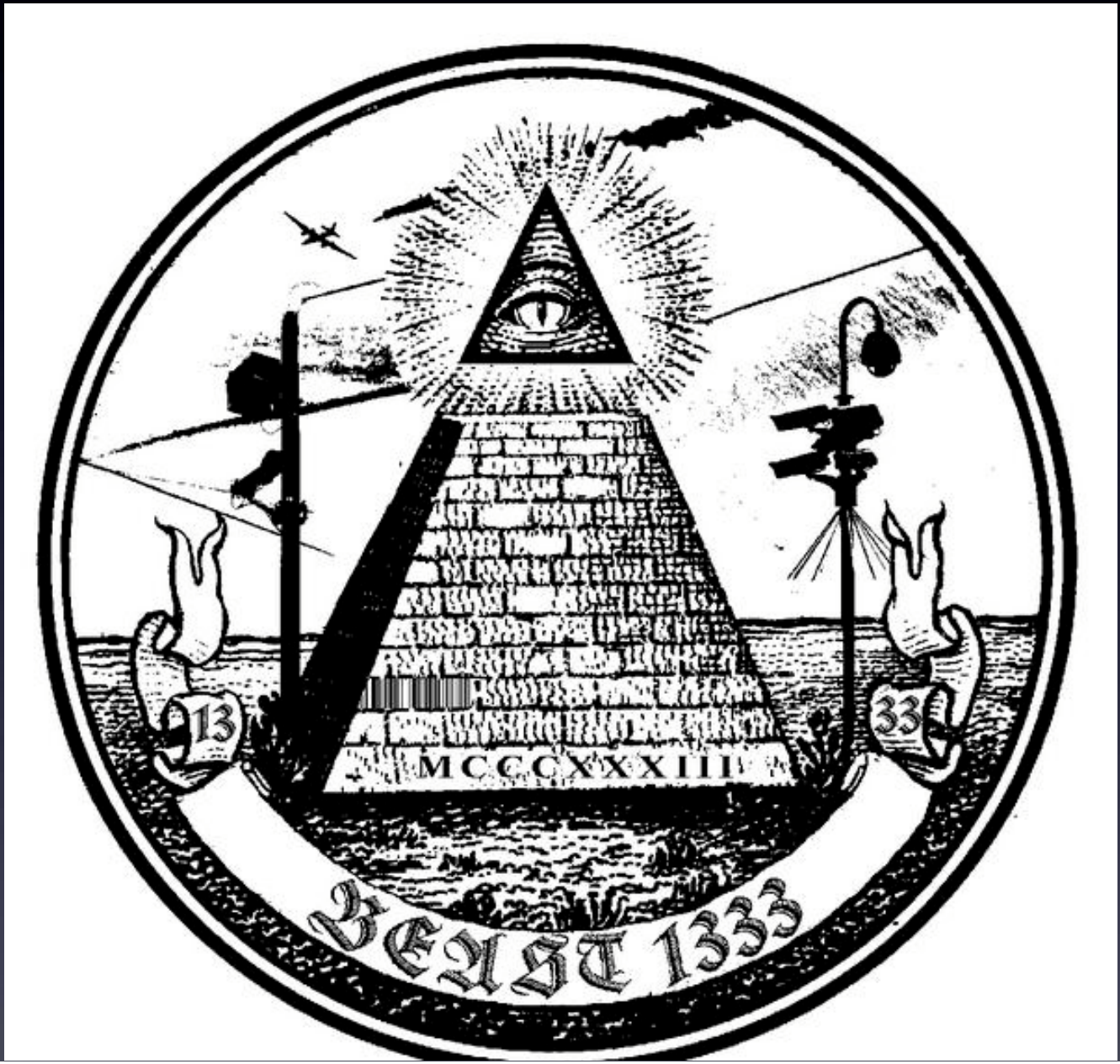
If not danger

Too repeat history
Children are *too* divers
Results too multifactorial and downstream
Values too diametrical positioned

back

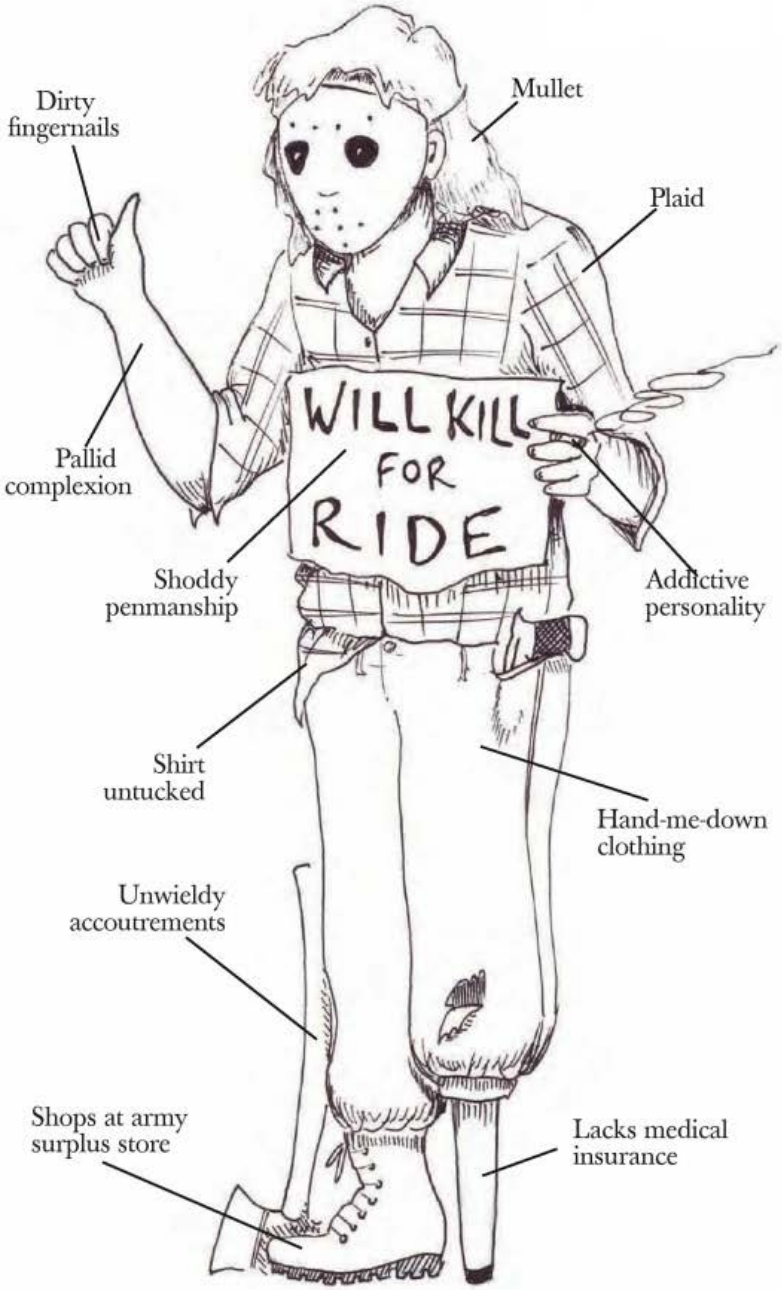


No symbolism, heroism or rhetoric



heroism

SIGNS OF A DANGEROUS HITCHHIKER



—Dounia Bredes, '11

The Parents