NEURODEVELOPMENTAL EFFECTS ON MULTIMODAL ASSESSMENT & TREATMENT

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"Wiss – tah"

I Mention Hockey To Break The Ice

We Just Love Baseball…

OK, Hockey too…

GOALS!!!!

- Learn how a developmental perspective adds to our understanding the root causes of psychiatric and behavioral challenges in people with Intellectual and Developmental Disabilities (IDD)
- Integrate this in to a multi-modal approach/model

Developmental Psychology Neglected?

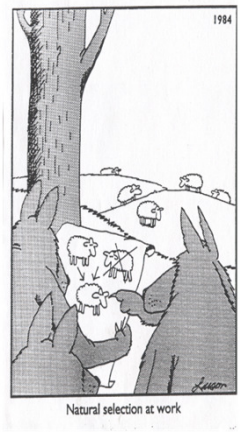
- Need to improve reliability and validity of psychiatric diagnostic assessment
- Trend to attend more to the impact of developmental features

Why Use Developmental Models ?

- Developmental models can help inform our work with people with MH/ID

Using a Developmental Model to Understand Dual Diagnosis

- **Developmental Psychopathology**
  - Developmental effects on the manifestation of psychopathologic states
  - The impact of developmental phenomena on behavioral outcomes
    - Nature –Nurture
    - Risk & Protective Factors



Aggression = Fever

- **Not diagnostically specific**
  - MANY OF OUR PATIENTS HAVE A "LIMITED BEHAVIORAL REPRTOIRE"
    - When tired,…
    - When upset about changes in routine….
    - When unhappy about an interaction with a peer…
    - When ill….

THE SAME SET OF symptoms of ALTERED MOOD AND BEHAVIOR MAY BE manifested for a different reason each time

Why medical problems get missed…Everyone is AGITATED!

- Most common reason for referral of a person with ID for acute mental health services:
  - Aggression, SIB or other "externalizing" behaviors
  - Psychiatrists get asked to save the day
    - What if the problem isn't psychiatric?

Charlot, 2010

What about treating aggression ?

- In many patients with ID aggression is a sign of distress
- Need to figure out what is the cause of the distress
- OR treatment will be ineffective

Charlot, 2010

Using a Developmental Framework

- Developmental effects
  - We may label some things as psychiatric disorder that are not
  - Accurately identify the cause of distress
- Understanding how developmental features can change the clinical picture of various psychiatric syndromes
  - Identify the correct disorder

Impact of Developmental Features on the Psychiatric Interview

Patients may not provide reliable self-report

Have you been feeling sad?	YES
Have you been feeling angry ?	YES
Have you been feeling happy?	YES
Are you feeling sick?	YES
Do you hear voices?	YES

OR……..

Have you been feeling sad?	I don't know
Have you been feeling angry ?	I don't know
Have you been feeling happy?	I don't know
Are you feeling sick?	I don't know
Does your head hurt?	

Words, words and more words…

- There is a point in development of language skills where we can make statements, but do not know what we are saying
  - No, I am not talking about American politicians
  - Yes, I am referencing 4-6 year olds
- Learning a new language – we acquire scripts and get lost rapidly when off script
  - Again, not referencing American pols
  - I can ask for directions in French

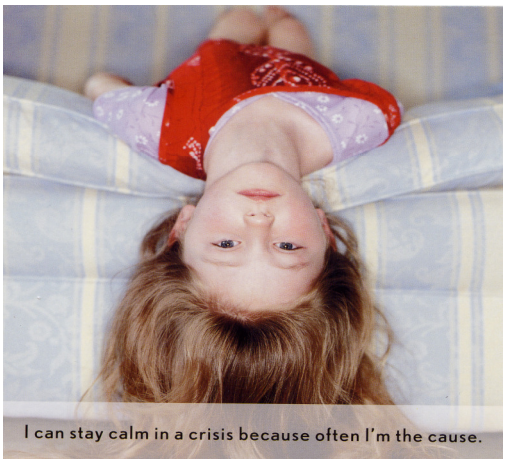
The "Chief Complaint"

The problem that brings the person in for mental health evaluation and help, in his or her own words…

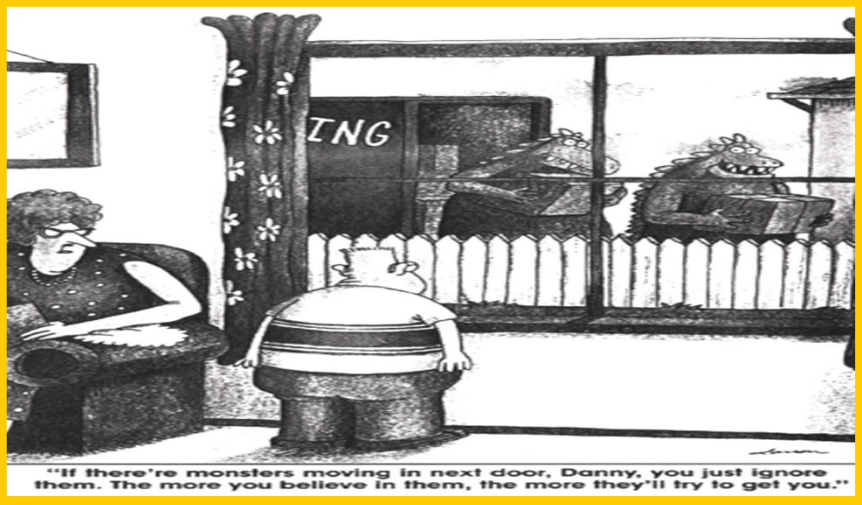
My personal favorite

"Cookie, cookie"

We may have to look at things differently…..



We often rely on informant reports: But, it can be difficult for informants to accurately describe the experiences of other people…….



It can be difficult for informants to know what others feel…..

- Ross & Oliver (2002) The assessment of mood in adults with severe or profound MR
  Clinical Psychology Rev.
- Some limited evidence to suggest facial expressions can be reliable and valid indicators of affective states
  - Unless you are from the US Mid-West

Using behavioral descriptions of symptoms….

INFORMANTS:

- Overemphasize externalizing symptoms
- Underreport internalizing symptoms

Behavioral Manifestations

- Methodology developed by Sovner and Hurley - Sovner and Lowry in the 1980s
- DSM symptoms operationally defined as they appear in people with ID
- How do developmental effects translate into observable behaviors - symptoms?
  - depressed mood = sad facial expression, crying, refusing activities he or she used to like

RELIABLE ID OF SYMPTOM

don't confuse phenomenology with etiology

- MANIA
  - irritable, restless, pacing, running back and forth, can't sit still, can't focus, can't get to sleep
- DEPRESSION
  - crying, won't get out of bed, can't work, won't hang out with people
- ANXIETY
  - frightened look on face, string at the ceiling, shaking, can't concentrate

- AKATHISIA
  - irritable, restless, pacing, running back and forth, can't sit still, can't focus, can't get to sleep
- CONSTIPATION
  - crying, won't get out of bed, can't work, won't hang out with people
- ACUTE DYSTONIC REACTION
  - frightened look on face, staring at the ceiling, shaking, can't concentrate

What Can We Do?

- Use multiple informants
- Use various data sources
- Insist informants tell you what they observe and not just what they feel might be wrong
- Resist pressure to prescribe when people who make referral have not done THEIR homework

Developmental Issues and Diagnostic Classification

USING DSM-IV TR

- Clinical diagnoses
- Multiple symptom criteria
- Must look at the whole picture "Gestalt"
- Describe syndromes

SYNDROMES

- PERSISTENT
- CAUSES FUNCTIONAL IMPAIRMENT
  - SYMPTOMS MUST BE SEVERE ENOUGH
    - "Clinically Significant"
- USUAL CLINICAL COURSE AND HISTORY
  - Age of onset
  - Nature of onset
  - Duration of Illness
  - OTHER CLINICAL CHARCETRISTICS BEYOND SYMPTOMS
- NOT BETTER EXPLAINED AS
  - Differential Diagnosis

Clinical Course & History: Ex. MDD

- Age of onset
  - MDD usual onset is in adolescence, early adulthood
  - More females > males after puberty
- Episodic with recovery between acute periods of illness
- Symptoms develop over days to weeks
- May be a prodrome for months
- Episodes (untreated) usually 4 mos
- Can become chronic (5-10%)

Clinical Course & History: EX. MANIA

- Episodes typically last a few weeks to months
- Abrupt onset unlikely
- Onset after age 40
  - more often -It's a medical problem
- 0.4-1.6% lifetime prevalence (recent estimates falling t the higher end of this range)
- 60-70% of manic episodes occur right before or right after depressive episode
- Most people 4 episodes in 10 years
- 4 or more in one year = rapid cycling
  - 4 OR MORE in 1 AFTERNOON =

A BAD DAY

Charlot, 2010

Beware of checklist psychiatry….

- Psychiatric disorders ≠ lists of symptoms or problems
- Human behavior is complex
- See Rutter, 2011 – Maybe we do not want to cut out the need to "THINK"

Rutter, M. (2011). Research Review: Child psychiatric diagnosis and classification: concepts, findings, challenges and potential. *Journal of Child Psychology and Psychiatry*, 52, 647-660.

Like most veterinary students, Doreen breezes through chapter 9.

DSM-V

- Much debate about classification
- In childhood psychiatric conditions, the plan is to reduce number of categories
- Identify broad areas of illness and then describe clinical variations within this
  - Combining a categorical with a dimensional approach
  - Autism Spectrum Disorder

Developmental Effects

- DSM describes age related features
  - DSM-V will have more focus on this
- Many of these are similar in people with ID
- Aggression, agitation impacted by developmental profile
  - limited behavioral repertoire
- Tendency to have global deterioration
  - appear "psychotic" when anxious, depressed etc.

DEVELOPMENTAL FEATURES ALTER THE CLINICAL PICTURE OF PSYCHIATRIC DISORDERS & SYMPTOMS

- ***Many people with ID :***
  - **Use cognitive strategies similar to mental age matched peers (similar structures**
    - ***Some exceptions i.e. ASD***
  - **Progress through similar stages but plateau at earlier stages (similar sequence)**

Genetics and Biomedical Markers of Psychiatric Disorder

- **Over time, the biological substrate for Psychiatric Syndromes will be characterized**
- **Genetic underpinnings will be better understood**
- **But – there are still not specific biomarkers for Psych Syndromes**

Structural changes in maturing brain correlate with developmental changes in cognitive functions

- Paus et. al. (1999) Structural maturation of neural pathways in children & adolescents. *Science.* 283(5409), 1908-1911.
- Sowell et. al. (2001). Mapping continued brain growth and gray matter density reduction in dorsal frontal cortex: Inverse relationships during post adolescent brain maturation. *J. of Neuroscience* 21 (22), 8819-8829.
- Tau GZ. Peterson BS. (2010) Normal development of brain circuits. *Neuropsychopharmacology. 35(1):147-68.*

Developmental Models

FINALLY, CONFIRMATION!

- Mother's of teenage girls redeemed!

How Do We Define Psychopathology? Developmental Frameworks

Some behaviors are normal at one age, but abnormal if they persist to later stages

i.e. fears, enuresis

Werry and Quay, 1971

- All k -2 children Midwestern university town
- Psychopathology tool applied to assess wide array of psychiatric symptoms and abnormal behaviors in the cohort

Conclusions: Children Are Strange

Case Example

- Individual was
  - Screaming, yelling and non-compliant with request to leave event
  - Could not be redirected, many attempts
  - Expressed belief that characters who were in costume were real
  - Could not be shaken from this false belief
  - Had to be physically escorted to leave
  - QUICK DIAGNOSTIC HYPOTHESES?

Nicole shows evidence of magical thinking

Cognitive Development

Magical Thinking:

- Fantasy reality distinctions are poor
- Not due to psychotic thinking, but to the nature of cognitive constructs.
- Individual may be talking to people not present, not because of hallucinations, but because he or she is fantasizing.
- Wishes may be expressed as beliefs, and can be misconstrued as delusions.

Developmental Effects

Pre-logical Thinking:

- Thinking that is typical of preschool-aged children - individuals with severe to moderate ID
- May seem "tangential," rambling.
- Not uncommon in conversations with preschool-aged children
- Not due to psychosis, but lack of appreciation of logical relations between subjects.

CONCRETE THINKING

When Chuck returned home, his door was a jar.

- Common for many people with ID at baseline
- Do you hear voices?
- Report thoughts and reviews of memories as voices or real
- Misinterpret things asked

Cognitive Developmental Effects

Concrete Thinking

- Thinking and reasoning are grounded in the here and now, what can be seen, counted, observed, etc.
- Example Mental Status Exam question:
  What does this saying mean: "People in glass houses should not throw stones"? Patient with ID answered: "Because the stones would break the glass."
- May be seen in brain injury, delirium, dementia etc.
- May be seen as a sign of a thought disturbance

Developmental Effects

Psychosocial development:

- Emotional expression becomes more complex
- Capacity for regulation of emotions develops
  - Global to more discrete
  - Fear, anger, happiness
- Greater difficulty with separations from parents caretakers
- Usual reported fears change over development
- Nature of aggression
  - Normative rates of anger responses change with development

Egocentrism

Developmental Effects

Egocentrism:

- Tendency for children to construe reality based only on what they experience.
- Related to cognitive capacities
- Sometimes confused with "narcissism,"

(a psychopathologic tendency to be overly self-centered)

- Pre-school-aged children fail to comprehend that others see or experience things differently.
- People w/ID may have difficulty understanding impact of their behavior on others
  - due to cognitive limitations, rather than being "oppositional."

Racing Thoughts - Flight of Ideas

- Lack of appreciation of logical relations among topics
- Common at <u>BASELINE</u> for many people with ID
- "Exaggerated" under stress

Case Example

- "Hi, its you. I like you. When is Dennis going to be here. I like the groups here. I had cereal for breakfast. My mother is coming later today. I don't want a needle."
- Patient greets me in the AM, just after her breakfast, and having seen her room mate have blood work done.

- **Differential Diagnosis of Psychosis : Developmental Considerations**

"LET'S TALK A LITTLE ABOUT THOSE HALLUCINATIONS."

CASE EXAMPLES

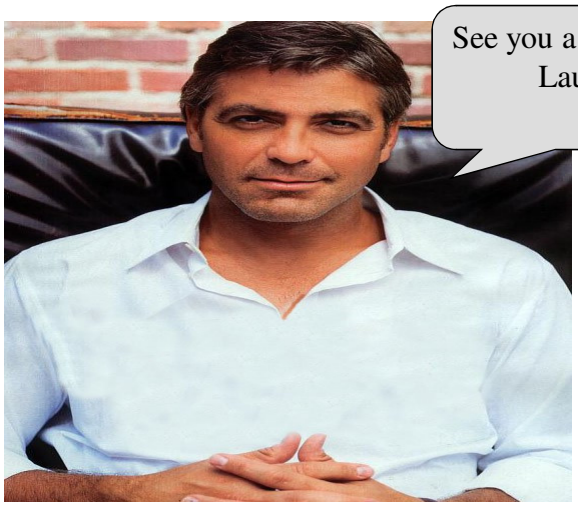
- His eyes bulged out
- He was VERY aggressive
- She talked about her children
- He kept referring to people not present
- She spoke to her stuffed animal
- He was constantly talking out loud and no one else was there
- He seemed to be responding to internal stimuli

CHARLOT 2010

Delusions

- **Great sadness and wishing to be "normal" can sometimes be mistaken for delusional thinking**

- **"Where would be without wishful thinking…."**



Charlot, 2010

COGNITIVE DISNITEGRATION

- Sovner & Hurley, 1982
- Patients with ID may regress under stress
  - Primitive behaviors related to baseline neurocognitive delays
- NOT a psychotic break or psychiatric decompensation
  - CRITICAL to learn this as the patient may be stabilized more rapidly with supports and less intrusive interventions
  - You can make the patient worse by adding treatments he or she does not really need that might actually cause further problems
    - Patient gets stuck in cycle of hospitalization

Have a "healthy degree of skepticism"

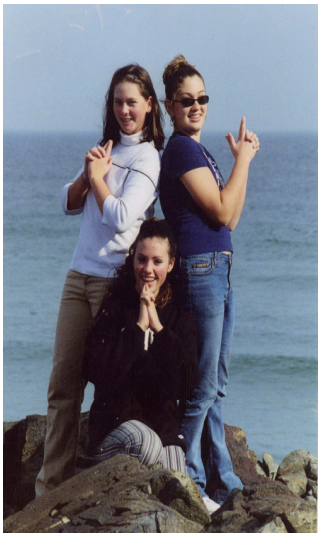
- Consider "psychosis" as lower on the list if it isn't clear
- Rule out all of the other common explanations for primitive behaviors
  - Developmentally typical response to stress, anxiety or illness
  - Wishing or fantasizing
  - Further compromise to a fragile neurological substrate
  - Cognitive "egocentrism"

Use Developmental Models

- **Because the clinical population is highly heterogeneous**
  - **Need to know what this individual person's baseline is like**
  - **Cannot use general population "reference group" to determine that something is a symptom**

Developmental features….

- **Clinicians may fail to use a developmental framework**
- **Some "symptoms" or behaviors may seem pathologic for a typically developing adult**
  - **YET - may be *typical* for a person with a particular set of skills and challenges (developmental profile), especially when under stress**



CONTEXT & DEFINING PSYCHOPATHOLOGY

The Importance of Context

- Context can be critical
  - Age or Developmental Context
  - What's going on around the person?
  - Impact of stressful environments
  - What does the person bring to the situation?
  - What are the effects of interactions with the context?

- The impact of stressful environments is often underestimated
- We each respond to stress in different ways
- We each find different things to be stressful

Developmental Theorists Emphasize the Importance of Context…

Not a Good Sign

Panic Disorder or Pretty Smart Move?

STRESS

- Not just provoking events, but ongoing stressful environments
- ENVIRONMENTAL EVENTS change our biology
- OUR BIOLOGY – effects how we respond to environmental events

Jovanovic H., Perski, A., Berglund, H. & Savic (2011) I Chronic stress is linked to 5-HT_{1A} receptor changes and functional disintegration of the limbic networks, *NeuroImage*, 15,1178-1788.

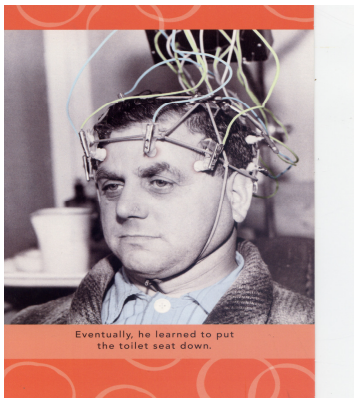
- "every day" psychosocial stress seems
  - r+ with a limbic reduction of 5-HT_{1A} receptor binding and functional disintegration of ACC/mPFC.
- Reflects impaired top-down regulation of stress stimuli

  >>>> Potential targets for early treatment.

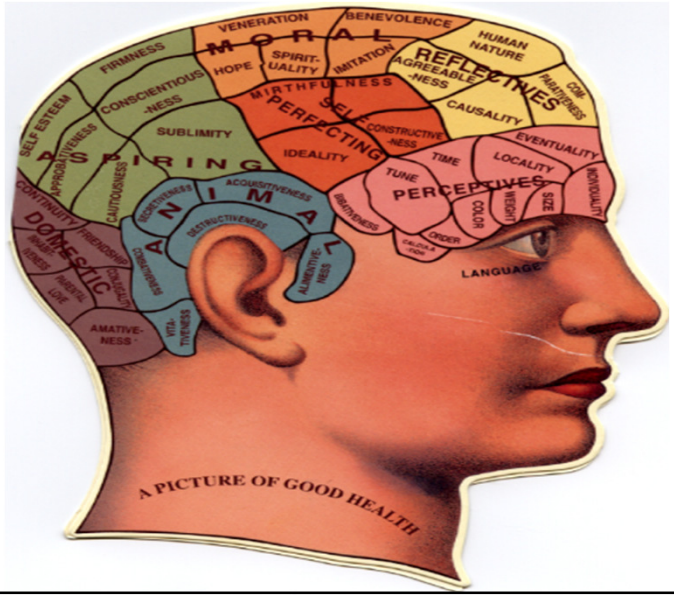
POSITIVE BEHAVIOR SUPPORTS

Carr, Edward. Helpfulness, Hopefulness. Journal of Positive Behavior Interventions. Vol 9(1) Win 2007, 3-14.

- **"Our chief concern is not with problem people , but rather with problem contexts."**



Brain – Behavior Relationships and Our Uniqueness



Other Developmental Pathways

- There is a dynamic interplay between experience and brain development
- Intellectual capacities are likely “modular” to some extent
- There may be greater disruptions to some circuits as compared with other
  - YET, many significant neuropsychiatric syndromes share features suggestive of a core problem with connectivity

Neurofunctional Pathways & Temperament

- Inherited behavioral tendencies or "character dimensions" (temperament) have neurofunctional substrates.
  - i.e. Zuckerman's "sensation seeking"
  - May predispose to bipolar disorder & antisocial personality disorder.

Why identify genetic and other syndromes associated with ID?

- Some syndromes associated with ID are associated with increased risk of psychiatric disorder
- These syndromes may also be associated with health problems
- There are some characteristic behaviors or "behavioral phenotypes"
- Temperamental tendencies have been described

Neurofunctional Model & People with ID?

- Are there subtypes of cerebral dysfunction linked w/ ID, also associated dysregulation of mood or behavior ?
- How often do such associations occur?
- Are there differences related to the pathways involved?
- Points to the importance of studying ID Syndromes and Genetic Syndromes – behavioral phenotypes

SYNDROME	Reported associations with psychiatric syndromes/symptoms	Suggested Reading
Down Syndrome	Depression, Obsessive-Compulsive Disorder (OCD), anxiety, obsessional slowness	Mantry, D., Cooper, S.A., Smiley E., Morrison,J., Allan, L., Williamson, A., Finlayso, J. & Jackson, A. (2008) The prevalence and incidence of mental ill-health in adults with Down syndrome. Journal of Intellectual Disabilities Research, 52:2, 141-155 Walker, J.C., Dosen, A, Buitelaar,J.K. & Janzing, J.G.E. (2011) Depression Down syndrome: A research review Research in Developmental Disabilities, 32:5, 1432-1440.
Fragile X	ADHD, anxiety	Cordeiro , L, Ballinger , E., Hagerman, R. & Hessl, D. (2011) Clinical assessment of DSM-IV anxiety disorders in fragile X syndrome: prevalence and characterization. Journal of Neurodevelopmental Disorders, 3, 57–67 Hayes, E.W. & and Reuben Matalon, R. (2009) Fragile X Syndrome. *Pediatrics*, 24,790-792.
Velo-cardio-facial syndrome (VCF)	Childhood: ADHD, anxiety and depression Adults: Schizophrenia/Psychosis, Bipolar Disorder	Jolin, E.M., Weller, R.A. & Weller, E.B. (2011) Occurrence of affective disorders compared to other psychiatric disorders in children and adolescents with 22q11.2 deletion syndrome. *Journal of Affective Disorders*, 136:3, 222-228.

SYNDROME	Reported associations with psychiatric syndromes/symptoms	Suggested Reading
Neurofibra-matosis (NF1)	Anxiety, depression	Maalouf, F.T., Hatoum, C., Atwi, M., Boustany, R.N.. (2010) Psychiatric comorbidities in common genetic disorders with physical disability. *Pediatric Health*, 4:6, 591–601.
Tuberous Sclerosis	Anxiety, depressed mood	Prather P, de Vries PJ: Behavioral and cognitive aspects of tuberous sclerosis complex. *J. Child Neurol*. 19, 666–674 (2004).
Fetal Alcohol Syndrome (FAS)	ADHD, Anxiety, depression	Hellemans, K.C.G., Sliwowska, J.H., Verma, P. & Weinberg J. (2010) Prenatal alcohol exposure: Fetal programming and later life vulnerability to stress, depression and anxiety disorders, *Neuroscience and Biobehavioral Reviews*, 34:6,791-807.

SYNDROME	Reported associations with psychiatric syndromes/symptoms	Suggested Reading
Phenylketo-nuria (PKU)	Depressed mood, generalized anxiety, phobias	Brumm, V.L., Bilder, D. & Waisbren, S.E. (2010) Psychiatric symptoms and disorders in phenylketonuria. *Molecular Genetics and Metabolism*, 99, 559-563.
Prader-Willi Syndrome (PWS)	OCD Depression	Cassidy, S.B. & Driscoll, D.J. (2009) Prader–Willi syndrome. *European Journal of Human Genetics*, 17:1, 3–13.
Williams-Beuren Syndrome (WBS)	Anxiety, specific phobias	Pober, B.R. (2010) Williams–Beuren Syndrome *New England Journal of Medicine*, 362:239-52.

SYNDROME	Reported associations with psychiatric syndromes/symptoms	Suggested Reading
Rubenstein Taybi syndrome (RTS)	Depression	Verhoevena, W.M.A., Tuiniera, B. S., Kuijpersa, H.J.H., Eggera, J.I.M., & Brunnerd, C. H. G. (2010) Psychiatric profile in Rubinstein-Taybi Syndrome: A review and case report. *Psychopathology,* 43,63–68
Myotonic dystrophy type 1	Depression, anxiety	Winblad S, Jensen C, Mansson J, Samuelsson L & Lindberg C (2010) Depression in myotonic dystrophy type 1: clinical and neuronal correlates. *Behavior and Brain Functions*, 6:25, 1–7.

Rates of AD in Various ID Syndromes and Disorders and Rates of these Disorders in AD

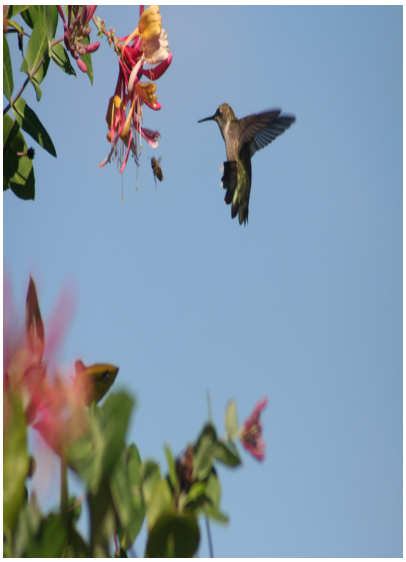
Childhood autism and associated comorbidities
Brain and Development, Volume 29, Issue 5, June 2007, Pages 257-272
Dimitrios I. Zafeiriou, Athena Ververi and Euthymia Vargiami

James Harris (*1998*)
Developmental Neuropsychiatry
Developmental Approaches to Psychiatric Assessment of the Individual

- **Critical considerations in a mental health assessment**
  - **Predisposing factors**
  - **Precipitating factors**
  - **Perpetuating factors**
  - **Protective factors**

Developmental Perspectives

- Complex models to explain behavioral outcomes, who develops what MH disorder?
- Emphasis of Gene x Environment interactions
- Transactions between the child –environment i.e. "evocative correlations"
  - Mediators and Moderators
  - Risk and Protective factors



Goals of a Developmental Psychopathology Model

- Predict/explain outcomes
- Characterize pathways in the development of MH disorders "pathogenesis"
  - Identify contributory factors
  - Determine how these factors transact to produce outcomes
- Develop Treatments
- Develop Prevention Strategies

Nature : Nurture Debate

What accounts for human behavioral outcomes?

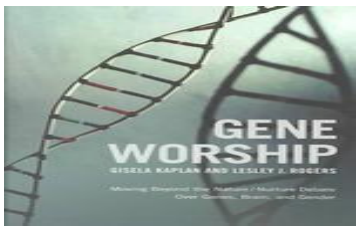
Michael Rutter (2002)

- **Three Major Domains of Study**
  - **Genetic**
  - **Environmental**
  - **Developmental**
- **"Numerous studies of twins, adoptees, and families …..have made it abundantly clear that genetic influences, as they apply to individual differences in the liability to show particular behaviors, are strong and pervasive but rarely determinative."** ***p.997***

The interplay of nature, nurture, and developmental influences: the challenge ahead for mental health Archives of General Psychiatry 59(11) 996-1000

Disorders with High Heritability (60-90%)	Disorders with Low-Moderate Heritability (20-50%)
• Autism • Schizophrenia • Bipolar disorder • ADHD	• Unipolar depression • Generalized anxiety disorder

If a disorder or trait or behavior is highly heritable, what are the implications?



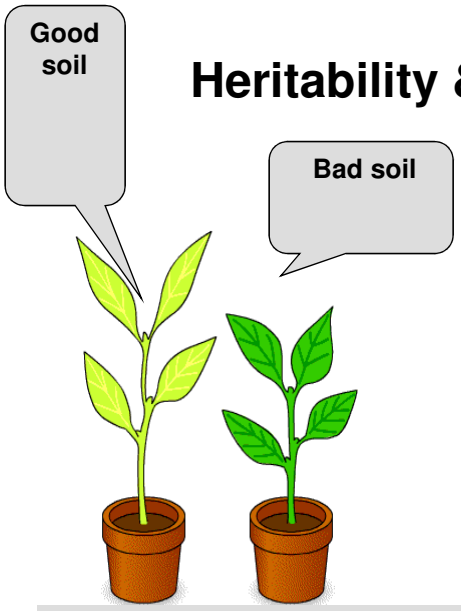
Example of Intelligence as Expressed by IQ

- IQ >>>> @ 50% heritability
- Genetic influences on cognition increase with age
  - Changes in the mix of skills that contribute to overall intellectual performance occur over the course of development
    - Spread between areas of strength and weakness may grow over the course of development and alter the measurement of IQ
  - People shape and select environments and adolescents and adults have more control over this selection
    - Not true of people with ID

Heritability and Outcomes in re to Intelligence

- "…..there is no necessary connection between within-group and between group heritabilities" *Rutter, p.49*
- High heritability has no bearing on whether or not interventions might alter individual outcomes

Heritability & Outcomes



Genetically identical seeds planted in 2 pots……

- Identical seeds grown in poor soil vs rich soil
  - grow to different average heights
- Numerous studies show improved outcomes when environments are improved
- Persisting benefits are dependent on continued positive environments

How does it all add up for Genes & MH disorders ?

- Genetic effects + Environmental effects
  ≠ 100%
- MH Disorders may result from synergistic interaction among *particular patterns* of genes (epistasis)
  - Not cumulative or additive effects of multiple susceptibility genes
- Small differences in genes > BIG differences in risk for MH disorders
  - monozygotic to dizygotic twins
  - first-degree to second-degree relatives
    - i.e. ASD MZ=60% DZ = 3%

How does a specific genetic disorder affect behavior?

Hodapp et al. 2003 Genetic syndromes of MR: Should they matter for early intervention? Infants & Young Children, 16(2), 152-160

- Probabilistic – increased likelihood of certain behaviors
- Unique versus shared behaviors:
  - "…not every person with a specific genetic disorder necessarily shows that disorders characteristic features.." (p.3)
- Be careful not to:
  - Expect every person with given syndrome has all the major features
  - Someone without all the features cannot have the syndrome

Genotype to Phenotype: Downstream Effects

- Genes affect proteins *not* behavior directly
- "Downstream" effects on behavior occur via effects of proteins on brain functioning
- "There is often astonishing variation in phenotypic expression…"
  - i.e fragile X, tuberous sclerosis
- Most psychiatric disorders are multifactorial
  - "other forms of indirectness need to be recognized."

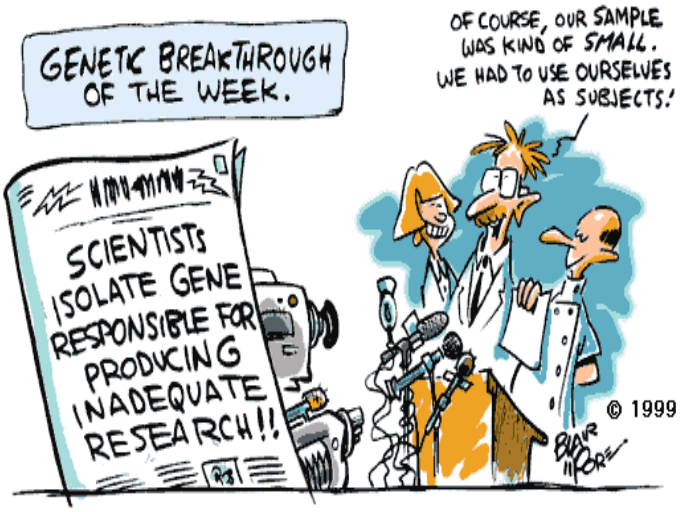
Treatments for FRA-X

Hagerman, R., Hoem, G. & Hagerman, P. (2010)

- Possible new treatment targets for fragile X syndrome (FXS)
  - animal models-fragile X knockout mouse
- lack of Fragile X Mental Retardation Protein (FMRP) >> dysregulation/overexpression its target genes
  - imbalances of neurotransmission
  - deficits in synaptic plasticity

Treatments for FRA-X

- **Reversal of cellular and behavioral phenotypes**
- **Metabotropic glutamate receptor (mGluR) blockers**
- **Gamma amino-butyric acid (GABA) agonists, and restoring proper brain connectivity in the mouse and fly models.**

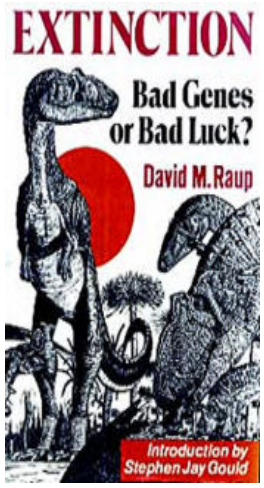


Good Gene … Bad Gene?

- Genetic influences may act indirectly via temperamental dimensions
  - Shyness as a risk factor for depressive d/o, anxiety d/o
  - Sensation-seeking as a risk factor for ADHD
- Dimensions may have risk & protective effects
  - Behavioral inhibition/emotional hyperreactivity - risk factor for anxiety d/os but protective factor for antisocial d/os
- "A simplistic subdivision of genes that are intrinsically bad and intrinsically good makes little sense." *Rutter*

Environmental Influences on Behavioral & Other Outcomes

- Environmental influences are strong and pervasive but rarely determinative



Sameroff & Chandler, 1975

Reproductive risk and the continuum of caretaking casualty. In FD Horowitz (Ed.)Review of Child Development Research. Chicago:Chicago Univ Press, vol 4 187-244

- **Looked at impact of anoxia at birth**
- **Effects diminished with repeated measures**
- **Children at extremes: high degree of perinatal insult or high degree of environmental stress, had poor outcomes that persisted**
- **Environmental influences were more powerful in predicting outcomes**
- **Proposed a transactional model**

Relationships Between Poverty and Psychopathology: A Natural Experiment

Costello, J Compton, S; Keeler, Gordon MS; Angold, A

Developmental Epidemiology Program, Duke University Medical School, Durham, NC. ***JAMA.***

290(15):2023-9, 2003 Oct 15.

- **Long observed strong positive correlation between poverty and childhood psychopathology**

Hypotheses About the Relationship Between Poverty and Mental Illness

- Social selection of mentally ill families into poverty accounts for high rates of mental disorders in children
- Factors associated with the state of poverty cause the higher rate of mental health disorders in children

The Natural Experiment….

- Prospective, longitudinal study
- DSM-IV disorders examined
- Native American families followed
- Casino planned and built resulting in 3 groups
  - Always poor
  - Never poor
  - Ex-poor

Outcomes

- Rates of disorder in children prior to and following the Casino
  - Highest in poor families
  - After the Casino, rates similar for Ex-poor and Never Poor families
  - Rates remained high for the Always Poor

Mediators: What factors explained lower risk in ex-poor families?

- Post – Casino or Ex-poor families more often able to provide more supervision to children

Mechanisms Involved in Psychiatric Risk:
We got more questions than answers

- People with ID at greater risk for MH problems and poor behavioral outcomes
- Are there genetic factors involved in the ID same as those associated with the increased risk?
  - Fragile X , Williams syndrome
- Is there risk due to cognitive disability itself ?
- Is risk due to other things associated with having ID? (mediators?)
- Is the risk for psychiatric disorder greater with > ID?
- Are there factors that can alter risk path (moderators)?

Depression in mothers and fathers of children with ID
Olsson & Hwang (2002) *JIDR*, 45 (6) 535-543

- Maternal depression is a risk factor for child psychopathology
- Mothers of children with ID (more so ASD) are at elevated risk for depression
  - Elevated risk for single parents

Environmental Risk Factors in Infancy.
Pediatrics **Sameroff (1998) 102:1287-1292**

- **Characteristics of environmental adversity**
- **10 factors showed cumulative effects**
  - **Maternal illness, anxiety, low level ed, single parent, larger family size, low skill job, rigid beliefs re development, few pos interactions, minority status, stressful life events**

Looking for protective factors in the child…

- **"The negative effects of disadvantaged environments seem to be more powerful contributors to the emotional health of the child at every age than the previous personality characteristics of the child. " (p1291)**
- **Studies show resilience in children removed from impoverished into enriched environments ---**
- **High stability of risk factors in the Rochester Longitudinal Study**

Implications from Developmental Research for People with ID : Risk Factors

- Impact of impoverished or adverse environments
  - Decreased structure and supervision may contribute to risk for vulnerable individuals
  - Tendency to graduate people to greater independence sometimes resulting in greater isolation

Implications from Developmental Research for People with ID : Risk Factors

- Quality of interactions – studies show attachment to caretakers may affect capacity to respond to adverse events, stress
  - Parents with MH Disorders
    - Risk for child disorder
  - Parents who are significantly stressed
    - Stressed caretakers or caretakers with lack skills

Classification in Child & Adolescent Psychiatry: ***Principles and Issues Child and Adolescent Psychiatry: A Comprehensive Textbook Volkmar, Schwab-Stone & First, 2002***

- **Temperamental dimensions**
  - ***Hyperreactive***
  - ***Difficult to console***
  - ***Inflexible***
- **"Clinical problems often relate more to issues of 'goodness –of-fit' between parents and infant than to disorder in the infant"**
    - **Chess & Thomas**
  - **Design interventions that promote a better fit**
  - **TRUE recognition of the importance of caretaker attitudes towards individuals in care**

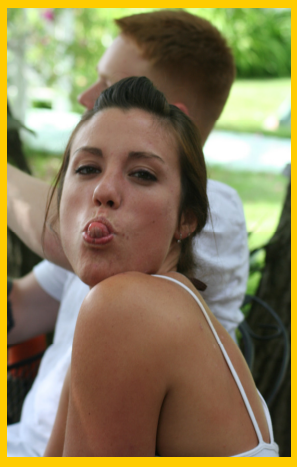
Continuities vs Discontinuities in Development & Temperament

While some things change, some things stay the same…..

Nicole Age 3

Nicole age 14

Nicole age 21



Case Example

- 30 y/o female with ASD, anxiety
- Over treated with medications that impaired capacity to engage
- Rx Team seeks more medications
  - d/t aggressive behavior
- House manager angry with individual for being demanding, having poor tolerance for change and chaos
  - Problem not in the individual nor the caretaker
  - In the transactions between 2 people existing within a system

Cognitive & Social Risk Factors

- People with ID present with > "disorganized" or "insecure" attachments
- Combo of vulnerability to stress and impaired coping may increase risk of negative behavioral outcomes
  - Janssen, Schuengel & Stolk (2002). Understanding challenging behavior in people with ID: A stress-attachment model. JIDR46(6),445-453.
  - Carlson et. al., (2003) Implications of attachment theory & research for developmental behavioral pediatrics Jn of Developmental Behavioral Pediatrics 24(5), 364-379

CAREGIVER EXPECTATIONS

- Expectations re a person's level of understanding is KEY to whether or not the person will feel supported, and will be understood
- Caregivers may over-estimate skills, set expectations that are too high, and actually provoke the problems they most want to control

Other Developmental Risk Issues

- Girls with ID report more symptoms of depression
- Children with ID who are in mainstreamed classes report feeling less competent
  - Heiman (2001). Depressed mood in students with mild ID: Students' reports and teachers' evaluations. JIDR 48(1),526-543.
- Adverse life events may create risk for mood and other MH disorders
  - Hastings et. al. (2004). Life events and psychiatric symptoms in adults with ID. 48(1), 42-46.

Risk Issues for People with ID

- Risk of medical problems
  - Improve education of caretakers and clinicians
- Susceptibility to drug side effects
  - Under recognition of drug effects
  - Educate and decrease reliance on drugs to solve complex problems

Individual Differences in Response to Adverse Events and Environments

- Large individual differences described
- Resilience: relative resistance to ill effects of psychosocial adversity
- Probably reflects wide range of mechanisms operating before, during, and after risk exposure
- Resistance to environmental hazards may be impacted by genetically influenced protective effects

Resilience

- **Why do some people with ID suffer extremely adverse events and environments and do NOT develop a MH Disorder?**
  - **Joe, mild ID h/o institutionalization - affable, sense of humor, flexible, has numerous advocates**
    - **Does not develop a MH problem**
  - **Kelly, mild ID raised with family, rigid and inflexible style, tends to put people off, anxious from young age, father "never accepted her"**

RAPPORT BUILDING

McLaughlin, D. M. & Carr, EG. (2005) Quality of Rapport as a Setting Event for Problem Behavior: Assessment and Intervention. *Journal of Positive Behavior Interventions*. 7(2): 68-91

Promoting Wellness: Protective Factors

- Can we promote factors associated with improved outcomes for people with ID?
- "Experiences that increase… exposure to success can bolster self-confidence and determination, leading to better performance. In these cases, the 'treatment' ….. involves education and training regimens that encourage full use of individual potential by removing psychological barriers."

Ziegler, E. (1993) Editorial: Can We "Cure" Mild Mental Retardation among Individuals in the Lower Socioeconomic Stratum? *American Journal of Public Health* 85(3), pp 302-304

TAKE HOME MESSAGE

- Much of the causes of challenging behaviors and emotional difficulties reside not within the person, but within the CONTEXT
- Effective intervention requires that we:
  - Change our behavior
  - Change the context
    - While understanding neurodevelopmental profile
- Specific ways we change these elements must be based on comprehensive, multidisciplinary assessment

Behavioral Psychology – Misunderstood?

- Older Models :
  - What triggers behavior?
    - Demands
  - What is reinforcing the behavior?
    - Attention, escape
  - How to change contingencies to alter future behavior
- Newer Models
  - Remote antecedents or "setting events" lower the threshold for problem behaviors
    - Pain
    - Stressful environments
    - Unrealistic demands

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Positive Behavior Support: PBS

- An approach to dealing with challenging behaviors that emphasizes:
  - Prevention
  - Environmental modification
  - The need for staff, caregivers, adults to change their behavior
  - Teaching appropriate alternative behavior
    - Requires understanding of neurodevelopmental profiles
- Like any ABA model, the basis is a comprehensive FBA

Charlot 5-10

William Gardner
A Unifying Model

- Introduced a model for assessment and treatment planning related to challenging behaviors and psychiatric illness in people with IDD
- The Model provides bridges a lot of existing assessment and treatment components
- The whole, however, is much greater than a mere sum of the parts

The Multimodal Habilitative Mental Health Model

- This model brings together the best of "all worlds"
- Helps us assess and understand challenging behavior and symptoms or problems experienced by people with IDD in terms of a number of different types of factors that influence outcomes
- Yields a "CASE FORMULATION"
  - OUR HYPOTHESES ABOUT WHY THE PERSON IS HERE FOR HELP, WHAT HAPPENED?
  - Causes of unsafe behavior in patients with IDD differ from those seen in "typical" patients

What Influences How We Behave?

- *"Multimodalities of Influence" Lots of different things will affect person's tendency to become aggressive*
  - Biomedical
    - Medical – Neurological – People with IDD have > neuro and medical problems and don't self-report well
    - Psychiatric – Depression, anxiety etc impact on how we behave when stressed and vice versa
    - Genetic - we are born with some areas of strength and weakness, temperament etc
  - Psychological-
    - Cognitive (How we process information and our beliefs)
    - Emotional (feelings and how we manage our emotional states)
    - Motivational, behavioral (what we learn and what matters most to us)
  - Environmental
    - Physical, social, interpersonal, program-related

Multimodal Contextual Case "MCC" Formulation Approach

- *Multimodal*–Recognizing its not just one thing but many things that influence how we behave
  - biomedical, psychological, and social-physical environmental influences.
- *Contextual*– Behavior happens in a context, and some of it comes from inside of us, some from without.
- These factors may transact and have varied degrees of influence on behavioral outcomes
  - Events may "instigate" or trigger,
  - How we think, learn and regulate our emotions
  - How others react to our behavior, what results when we engage in a behavior

Multimodal Contextual Case "MCC" Formulation Approach

- ***Case Formulation*** **- process of formulating a set of diagnostic hypotheses about the roles and relative influences of current *bio-psycho-social* influences and use of these to devise diagnostically-based interventions.**
  - **Because there are multiple influences from different factors, we can develop a plan that is directly related to our multimodal assessment**
- **Produces multiple diagnoses e.g., psychiatric diagnosis(es), other medical diagnoses, psychological diagnoses, social/physical environmental diagnoses.**

Behavior occurs in a context

- ***Influences on Behavior***
  - **Antecedent/instigating**
    - **Things that either "set the stage" for or "trigger" behavior**
      - **Setting Events are more remote antecedents like being tired, poor sleep, how hard a task demand is**
      - **Triggers are more immediate influences like asking person to do something he doesn't like (placing an unwanted task demand), telling a person no he cannot have something he wants etc.**
  - **Central Processing (How we are put together, what we bring to the situation)**
    - **The effects of medical issues, neurological issues, how we process information and reason, how we regulate emotions**
      - **Also known as "Vulnerabilities" behavioral tendencies and skill deficits**
  - **Maintaining/Reinforcing**
    - **Things that occur following behaviors we exhibit that either increase or decrease the likelihood that we will engage in that same behavior again**

USE the GARDNER MODEL to understand how people with IDD develop PBs or Problem Behaviors

- Vulnerabilities
- Antecedent /Instigating factors
- Maintaining factors
- Psychiatric symptoms may lower the threshold for or even trigger PBs

JOE

- Joe was able to speak in full sentences and could access a lot of sites on line
- He could repeat back strategies he was supposed to use in place of negative behaviors during his 1 x per week psychotherapy sessions
- Joe rarely used these strategies when he was upset and most needed to do so

JOE

- When staff and team saw Joe as not likely to be able to use these tactics "in vivo" and a structured approach was used with reminders and prompts, he showed significant improvement.
  - New formulation: Problem secondary to contextual factors and staff behavior
- Joe felt more successful
- Caregivers felt more successful

POSITIVE BEHAVIOR SUPPORTS

Carr, Edward. Helpfulness, Hopefulness. Journal of Positive Behavior Interventions. Vol 9(1) Win 2007, 3-14.

- "Our chief concern is not with problem people , but rather with problem contexts."
  - Attention maintained behaviors
    - Where, when, with whom does this occur more and les often?
  - Escape maintained behaviors
    - Where, when, with whom does this occur more and les often?

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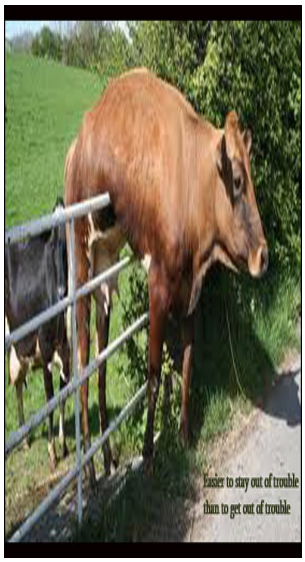
STUDY Profiles & Contexts

- More focus on profile and what types of support and teaching tactics person needs to be able to exhibit behaviors that will gain r+
- Often too much focus on the consequent events
- Increased study of profiles & context results in more effective interventions



UMass Multidisciplinary ID/ MH Consultation Team

- *Laurie Charlot, PhD*
  - *Developmental Psychologist*
- *Paula Ravin, MD*
  - *Neurologist*
  - *Movement Disorders Specialist*
- *Bob Baldor, MD*
  - *Primary Care*
  - *Family Medicine*
- *Van Silka, MD*
  - *Psychiatrist*
- *Kathy Collins, PhD – Clin Psych*
- *Mary Crane, BA - Behaviorist*
- *Kristen Schuler, OTR*

CHARLOT, 2011

HEALTH PROBLEMS
Individuals with IDD/ASD…….

- Have higher rates of medical problems
- Have a High Rate of Unmet Health Needs
  - Often lack access to appropriate and effective health care
    - Beange, McElduff, & Baker, 2005; Cooper et al., 2004.
  - Previously missed problems are found at high rates when screens and health checks are
    - Baxter et al., Cooper et al., 2006; Felce et al., 2008; Lennox et al., 2007.

Why do health problems get missed?

- Patients with ID often have a limited capacity to self-report medical problems, side effects and medical history
- At times, may evidence a high tolerance for pain
- Aggression makes it look like a "psych" or "behavior" event

Non-psychiatric health problems among psychiatric inpatients with Intellectual Disabilities.

Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. *Journal of Intellectual Disability Research* doi:10.1111/j.1365-2788.2010.01294.x

RESULTS

- **Inpatients with more medical diagnoses had longer lengths of stay**
  - **(r^+ .32, p < 0.0001).**
- **Inpatients taking more psychoactive medications had more medical problems**
  - **(Spearman r^+ .32, p < 0.0001)**

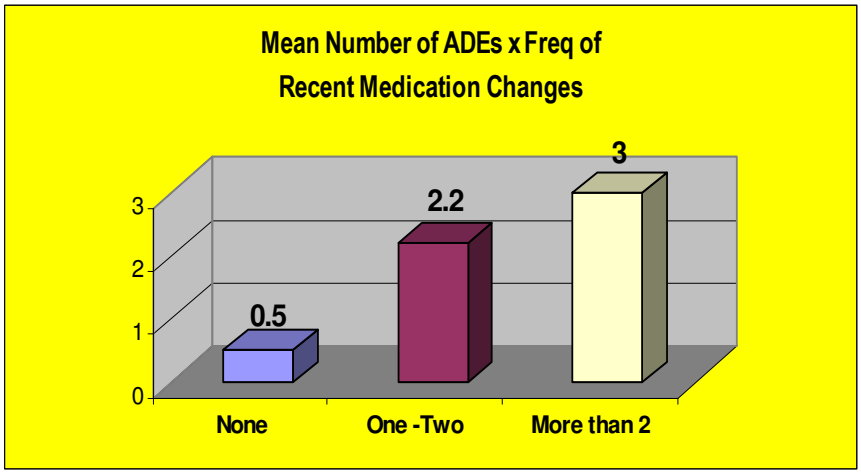
Mental Disorder due to a Medical Disorder

- For 41% the medical issue seem to be the cause of the problem behaviors leading to the admission?

FURTHER CHART REVIEWS

- N = 72
- Detailed review for evidence of medication side effects
- Average 2.5 ADEs per person

Patients with multiple recent medication changes had more ADEs



CONCLUSIONS

- We found a high rate of potentially treatable and preventable medical problems and medication side effects were likely causing changes in these patients' mood and behavior resulting in expensive and disruptive inpatient care or ineffective attempts reduce symptoms with psychiatric treatment

Multidrug Treatment

- Use of complex multidrug regimens may cause a cascade of troubles in patients with ID who have a fragile neurological and physical substrate

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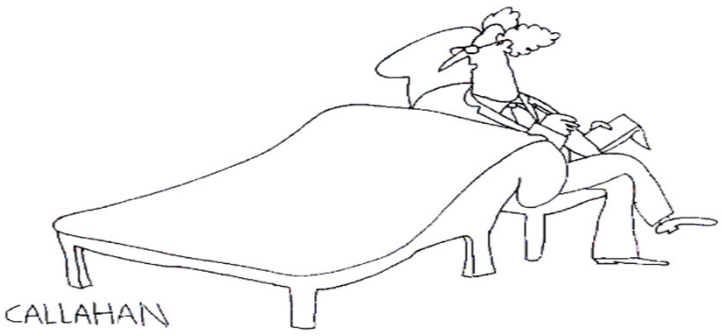
How can a toothache look like psychosis?



"LET'S TALK A LITTLE ABOUT THOSE HALLUCINATIONS."

In a NUTSHELL:

- Aggression is a final common pathway -eg IT ALL LOOKS THE SAME!
- People with ID/ASD don't report their own history or health issues well

In a NUTSHELL:

- Until proven otherwise, never assume someone does NOT have pain or physical distress

Evidence Based Care……
Its Important, yet....critically review

- **Thioridazine (Mellaril) a psycho-sedative virtually free of side-effects.**
  LJ Le Vann - *Alberta Medical Bulletin*, 1961

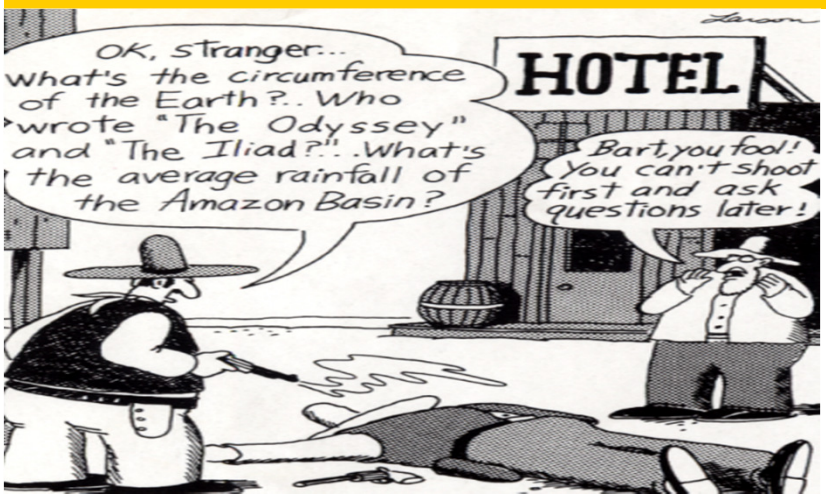
Always listen to what the doctors tell you.

But…don't give up…if you know patient has not had a thorough work-up

Overcome Barriers

- Recognize clues that behavior change may be d/t illness or physical distress

The Best Treatment Plans are Derived From a Comprehensive Multidisciplinary Assessment



Charlot 3-08

AND REMEMBER……

- **Risperidone is a lousy treatment for a toothache….**

AND

- **Psychiatric units may not be the best place to go if you need a colonoscopy…..**