MONTCLAIR STATE UNIVERSITY

The New DSM V

Implications for Diagnosing Autism Spectrum in Diverse Populations

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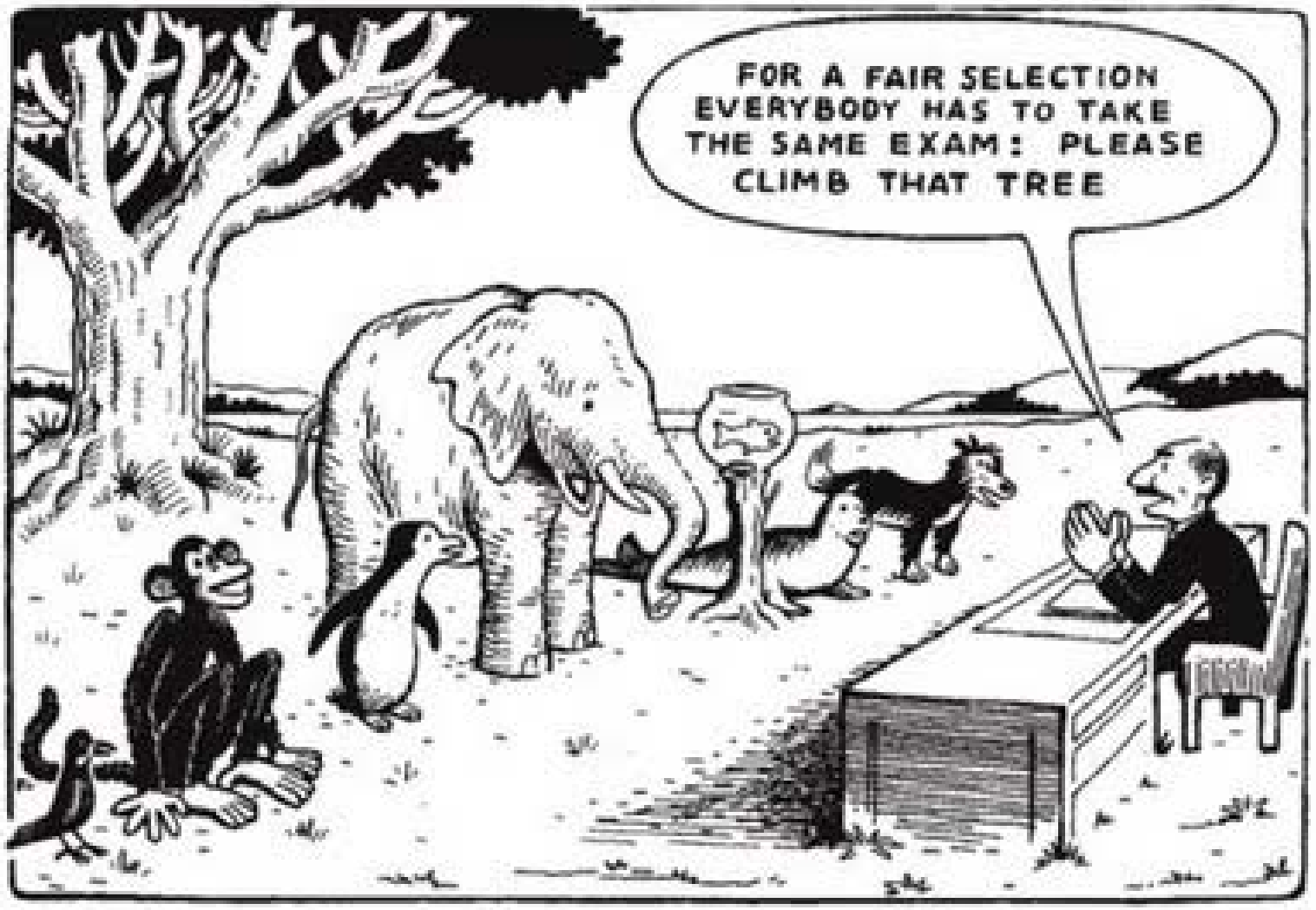
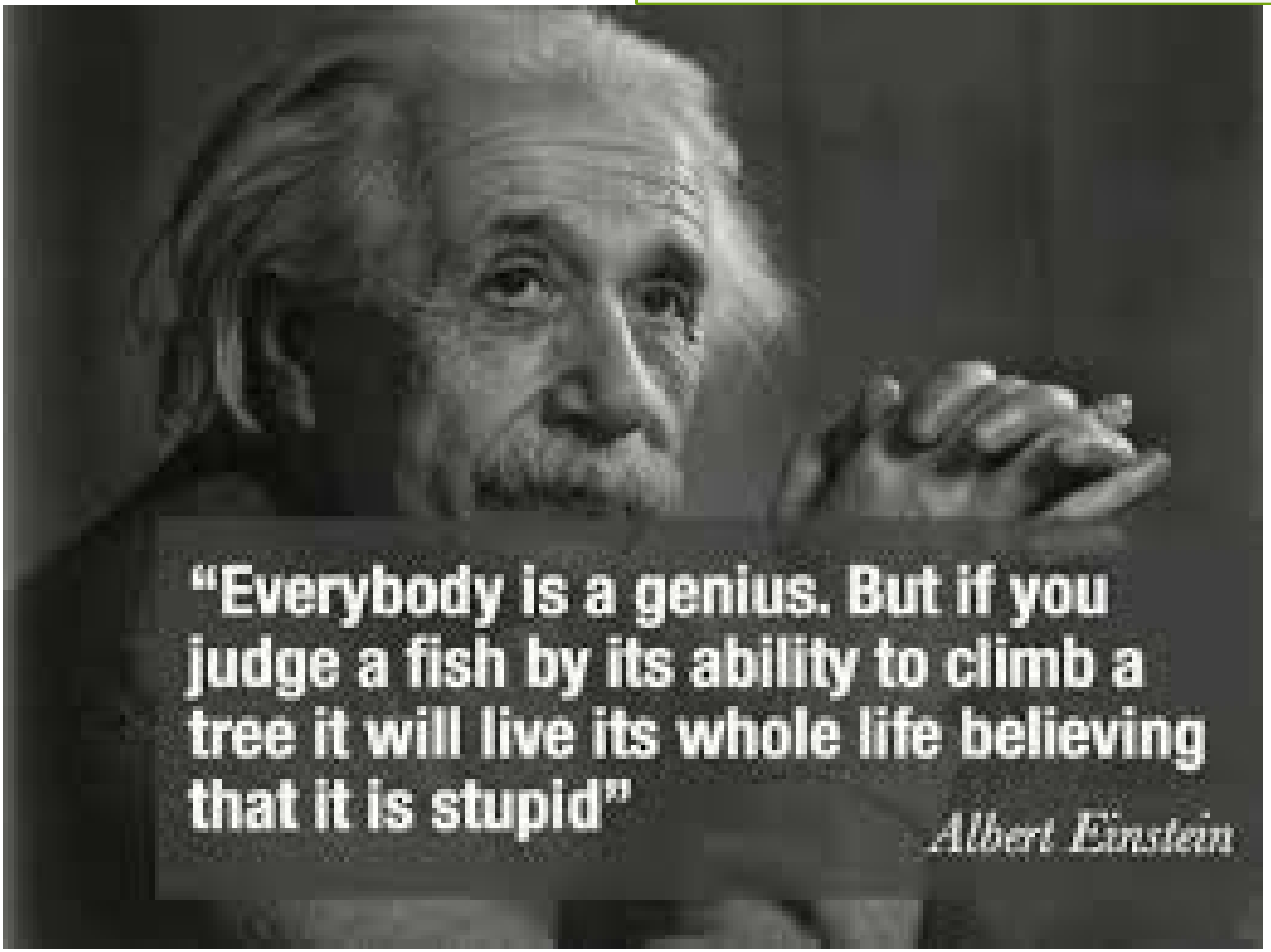

FOR A FAIR SELECTION EVERYBODY HAS TO TAKE THE SAME EXAM: PLEASE CLIMB THAT TREE


"Everybody is a genius. But if you judge a fish by its ability to climb a tree it will live its whole life believing that it is stupid"
Albert Einstein

First……..

- An informal survey about autism
- What do these signs evoke?

AUTISTIC
CHILD
AREA

CHILD
WITH
AUTISM
AREA
SPEED
LIMIT
40

Some questions to consider.

- So, what does is “autism” ?
- What does “autism” mean?
- What factors influence the meaning and assignment of the diagnosis?
- Does the term offer any “value added”?

Autism Spectrum Disorder

- Neurological disorder, with likely genetic origins, affecting the structure and function of the brain which controls reasoning, problem solving, memory, communication, sensory processing, regulation and motor planning.

Prevalance

- In 2007, the CDC estimated that autism occurs in 1 in 150 children. Among the states studied, New Jersey had the highest rate of 1 in 94.
- In 2009, NIMH studies reported that the rate is likely 1 in 100, reflecting both better assessment, and "buried" in the data, a real increase in incidence.
- Autism is likely a multiply determined disorder, leading to the term "Autism Spectrum Disorder".
- MARCH 2012: The CDC reports the diagnosis of autism has arisen 78% since 2000. Estimates now are that autism occurs in 1 of 88 children, and in boys the rate is 1 in 54

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CDC – March 2013

- Results of the 2007 and 2011-2012 National Survey of Children's Health (NSCH), using telephone calling.
- Based on 100,000 parents (less than 25% of those called agreed to answer questions.)
- **Prevalence rate of autism spectrum disorder among children aged 6-17 was 2% or 1 in 50, a significant increase from the 2012 report.**
- Unclear what this means – except that more research and more REFINED research are needed.

CDC - 2014

- 11 states in the ADDM study (2010 data)
- Diagnosis by age 8
- 1 in 68 in the US
- 1 in 42 in boys and 1 in 189 in girls
- l in 45 in New Jersey, 1 in 28 in boys
- 30% increase since 2012 study

- Consistent with previous reports from the ADDM Network, findings from the 2010 surveillance year were marked by significant variations in ASD prevalence by geographic area, sex, race/ethnicity, and level of intellectual ability.
- ***The extent to which this variation might be attributable to diagnostic practices*, *under-recognition of ASD symptoms in some racial/ethnic groups, socioeconomic disparities in access to services, and regional differences in clinical or school-based practices that might influence the findings in this report is unclear***

So – HOLD ON!

- What dose it mean?
- Is this a true "epidemic"?
- Is it an "epidemic" of the "diagnosis"?

Autism Awareness?

Autism Acceptance!

Autism APPRECIATION!

Self –advocacy movement!

Neurodiversity

Autism Spectrum Disorder DSM IV

- Three core indicators
  - Social Impairment
  - Communication impairment
  - Stereotypies (repetitive behaviors) and limited range of play

DSM 5
Autism Spectrum Disorder

Must meet criteria A, B, C, and D (Handout)

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,

2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated-verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects;
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change;
3. Highly restricted, fixated interests that are abnormal in intensity or focus;
4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;

Criteria C and D

- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
- D. Symptoms cause clinically significant impairment in social, occupational or other areas of functioning.

DSM 5 (2013)
Autism Spectrum Disorder (299.00)

- More dimensional (less categorical)
- No longer a diagnosis of Asperger's Syndrome
- Sensory difficulty now a feature – but not primary
- Social (Pragmatic) Communication now listed (315.39)

- While the DSM-V now acknowledges "sensory processing", the editors chose not to include a primary diagnosis of "sensory processing disorder" when in fact studies like the one below- and many others - reveal that "autism" is typically a reflection of underlying neurological differences which have been described in the literature for the past 10+years!

BUT

- *The neurological profile that is emerging suggests differences that go beyond these domains.*
- *These classifications do not account for emerging brain research.*
- *There is no clear focus on "core" and "derivative" concerns*

The Growing Field of Neurological Findings in ASD: Selective Differences

- Increased brain volume and enhanced early growth rate
- Differences in “mirror neuron” systems
- Differences in limbic system- notably the amygdala (social processing and affect?)

And

- Neurosensory processing differences

Steven Shore

Adult with Asperger Syndrome, author and advocate

"If you have met one person with autism, well, you have met one person with autism."

So, what is your conceptualization of ASD?

Is ASD

- **A "disorder of behavior"?**

Or

- **A difference in structure, functioning and processing of the brain and neurosensory system?**

Assertion

Your conceptualization of ASD and your diagnostic classification system, will determine to a very large extent, your assessment and intervention planning.

Dr. Thomas Insel, the Director of the National Institute of Mental Health (NIMH)

- .....courageously called into question the utility of the DSM-V with regard to the ASDs, as the clustering of symptoms without taking into account the emerging neurobiological scientific findings, renders symptom descriptions and treatment less meaningful and effective.

http://www.nimh.nih.gov/about/director/2013/ten-best-of-2013.shtml

- He wrote: "...(I)t is a promise from the NIMH to get beyond diagnostic categories based only on symptoms. Why is this important? For brain disorders, symptoms are generally a late manifestation of a years-long process. In medicine, early detection and early intervention have often been the best ways to improve outcomes."

Critical Dimensions to Consider

- "Core" versus "derivative" differences
- "Front-end" versus "back-end" conceptualizations
- Comprehensive *functional analysis of behavior (bio-psycho-social)*

Two Kinds of Functional Analysis of Behavior

Behavior = function of consequences

Behavior = function of biological, psychological and social factors (consequences)

Hypothesize about, assess and measure:

- Individual differences,
- Differences in brain structure, functioning and processing,
- Core vs. derivative
- Functional meaning of behavior
- Outcomes and change

Hoboken Proverb!

"If you drop a quarter in the middle of the block, you don't look for it at the corner where the light is better!"

For ASD – your concept and diagnostic system tells you where to shine your light!

BUT

Is that where "autism" is?

Two Critical Questions

- What are the child's behavior and affect attempting to communicate?

- What factors in the child's biology(sensory, regulatory, constitutions, state), psychology (history, experiences, developmental level), and social experiences (environment, family, culture) can we address to enhance the child's communication?

Six Organizing Principles

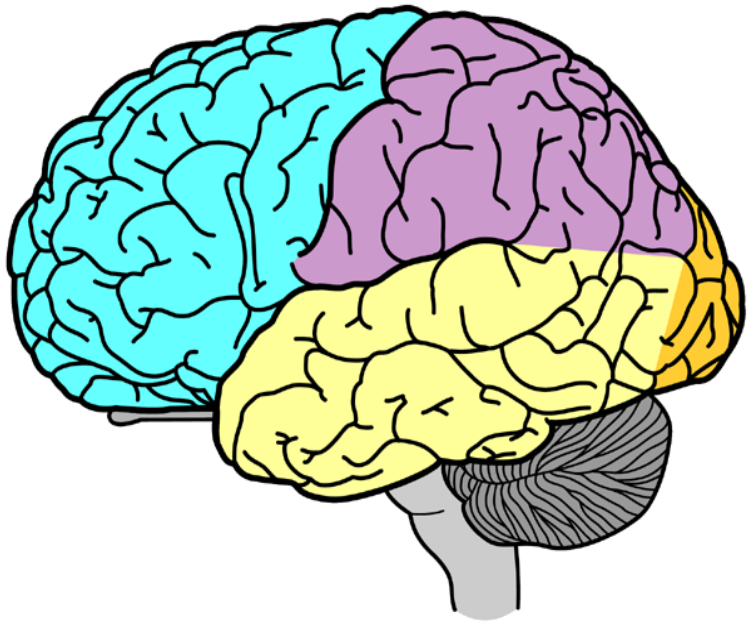
- Consider the distinction between competence and performance.
- Internal and external factors can moderate performance.
- All behavior is meaningful and occurs within a context. Not all meaning is inherently clear.

- Behavioral and affect regulation are enhanced through primary caring relationships.
- Misbehavior is not always misbehavior.
- Purposeful, organized and shared behavior requires the integration and cooperation of biological, psychological and social factors.

READ A "FIRST PERSON" ACCOUNT!

- Thinking in Pictures, (2006) by Temple Grandin
- Look Me in the Eye: My Life with Asperger's (2007) by John Elder Robison
- Carly's Voice: Breaking Through Autism (2012) by Arthur Fleischmann with Carly Fleischmann
- The Reason I Jump (2007) by Naoki Higashida
- Nobody Nowhere 1992 by Donna Williams

A Primer About Autism Spectrum Disorder and Emerging Brain Research

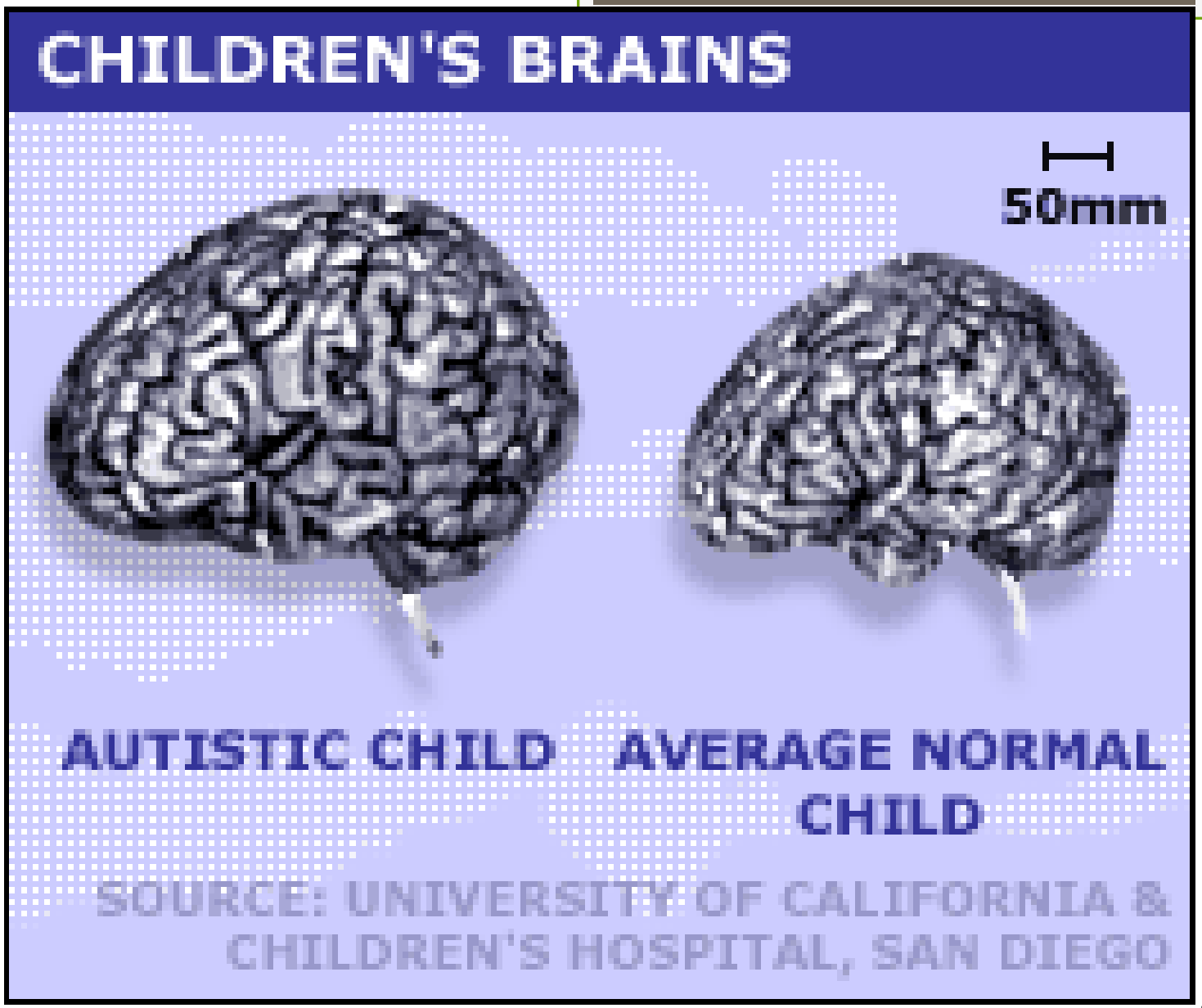


The Growing Field of Neurological Findings in ASD: Selective Differences

- Increased brain volume and enhanced early growth rate
- Differences in "mirror neuron" systems
- Visual Scanning patterns
- Differences in limbic system- notably the amygdala (social processing and affect?)
- Less density in corpus collosum
- "Whole brain" differences

University of California, 2003

- When the head size of infants who were later diagnosed with autism was measured, they were in the bottom 25% at birth. But by 12-14 months, their average head size was in the top 15%.
- From then on brain growth slowed


CHILDREN'S BRAINS
50mm
AUTISTIC CHILD
AVERAGE NORMAL CHILD
SOURCE: UNIVERSITY OF CALIFORNIA & CHILDREN'S HOSPITAL, SAN DIEGO

Provisional Hypotheses

- Excessive brain growth does not allow enough time for the child to properly process the experiences and emotions that guide and shape normal development and behavior.
- The normal process is believed to involve making and breaking internal connections in response to external stimuli, and the rapid growth interferes with this process.

Mirror Neurons

- Discovered in 1995 by Giacomo Rizzolati, Russian born Italian physiologist at the University of Parma in working with macaque monkeys.
- Since then, several indirect brain-imaging measures, including EEGs have confirmed the presence of a mirror neuron system in humans.

- He discovered that different neurons in the frontal lobes of monkeys fired when they performed different actions (e.g. pulling, pushing, grasping, etc.)
- HOWEVER, any given neuron fired when the monkey observed another monkey performing the same action! (Hence “Mirror” neurons)
- Rizzolati and his colleagues recently discovered that mirror neurons may actually convey cues to interact when a person is “near” versus “far away”. (e.g. a “pucker” to kiss when done closely)

Implications in….

- Imitation
- Reading “affects”
- Empathy
- Interpreting “intentions” of others
- Responding to social cues of others

Ami Klin, Ph.D:
Director,
Marcus Autism Center,
and
Director, Division of Autism and Related Developmental Disabilities,
Emory University
Early Diagnostic Indicators and Predictors of Outcome in Autism Spectrum Disorders

Yale University - 2009

- Looked at the ways 2 year old children with and without autism responded to distortions in motion and sound of a cartoon-like animated video clip.

Klin, Lin, Gorrindo, Ramsey and Jones, 2009. Nature, 2009.

NIH-funded study

Two side-by-side animated clips

- "Points of light" at body joints of a moving figure, synchronized with voice and sound. Animation was shown upright and forward
- Points of light" at body joints of a moving figure, shown upside and in reverse (not synchronized with voice and sound)

Tracked eye movements of subjects while they looked at these animations on a split screen display

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Findings

- 21toddlers with autism had no preference while 39 non-autistic children clearly preferred the upright figure.
- BUT – when the upright figure played "Pat-a-cake" children with autism shifted their attention to that figure. In this figure the "points of light" actually "cause " the clapping sounds- and this physical synchrony only existed in the upright version.
- Interpretation: Children with ASD prefer audiovisual synchronies – BUT typical children attend to many other socially relevant (affective, facial expressions, intonation,etc.) cues.

Ami Klin, Ph.D., Yale Child Study Center,

- "Typically developing children pay special attention to human movement from very early in life, within days of being born. But in children with autism, even as old as two years, we saw no evidence of this. Toddlers with autism are missing rich social information imparted by these cues, and this is likely to adversely affect the course of their development.... Attention to biological motion is a fundamental mechanism of social engagement, and in the future, we need to understand how this process is derailed in autism. Starting still earlier, in the first weeks and months of life"

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New Research – Klin and Team

Tracking eye movements on face (eyes, mouth, body) as young a 2 months of ages and following infants to see point of differences between infants who develop ASD and those who do not!

Limbic System

"Emotion"

(also Physiology and Memory)

Image: www.brainconnection.com

© 1999 Scientific Learning Corporation

About the Limbic System and the Amygdala

- "Serves as a source of social processing, stimulus appraisal and brain/body ("emotional") arousal." -Daniel J Siegel (1999)
- THIS MEANS – that the structures in the core of the brain that make up the "limbic system" "process" the meaning of social situations, and connects present perceptions of a situation with the memories of past situations.

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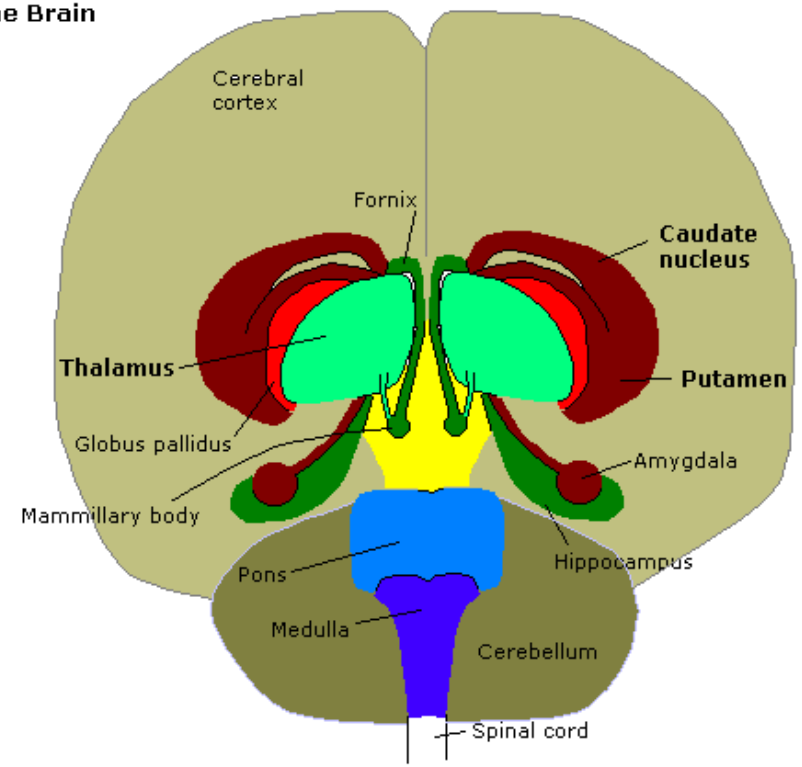
Amygdala

- This structure is part of the Limbic System- and in the development of brains in babies, this structure (based on real experiences with caregivers and the world) begins to get "wired" to "process" (interpret the meaning of) new experiences. Because the amydala is connected to other brain regions, what happens in the amydala affects the entire brain!

In other words, unlike Las Vegas….

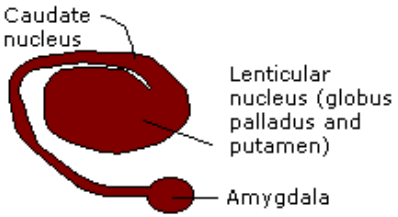
What happens in the amygdala ***DOES NOT STAY*** in the amygdala!!!

The Brain



The brain as viewed from the underside and front. The thalamus and Corpus Striatum (Putamen, caudate and amygdala) have been splayed out to show detail.

Corpus Striatum



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The Amygdala in children with autism

Researchers found that the amygdala was, on average, 13 percent larger in young children with autism, compared with control group of children without autism. In the study, published in a 2010 Archives of General Psychiatry, researchers scanned 50 toddlers with autism and 33 children without autism at age 2 and again at age 4. The study adjusted for age, sex and IQ.

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But

- Research on amygdala in older persons (typical)shows a positive correlation between volume and social relationships!
- The increased size in the amygdala is associated BOTH with impairments in children with autism AND with increased social complexity and connections in older neurotypical children and adults!

HOW IS THAT POSSIBLE?

The Amygdala and ASD

Speculation that it grows quickly in childhood, interfering with social processing by remaining too activated, then shrinks or slows in growth rate as a child ages.

- The new findings suggest that social fear in autism may initially trigger a hyperactive, abnormally enlarged amygdala, which eventually gives way to a toxic adaptation that kills amygdala cells and shrinks the structure, propose
- The brain's fear hub likely becomes abnormally small in the most severely socially impaired males with autism spectrum disorders, researchers funded by the National Institutes of Health's (NIH) National Institute of Mental Health (NIMH) and National Institute on Child Health and Human Development (NICHD) have discovered.

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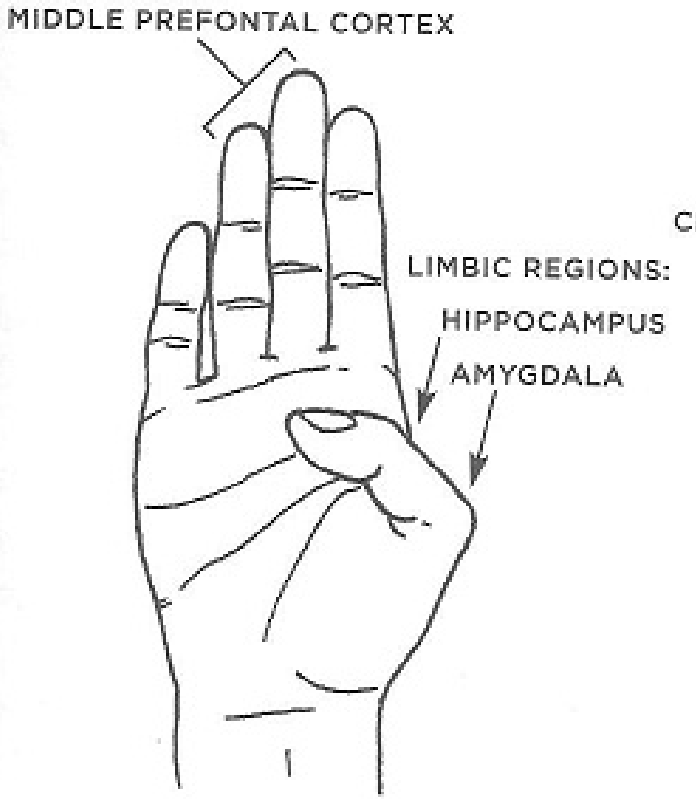
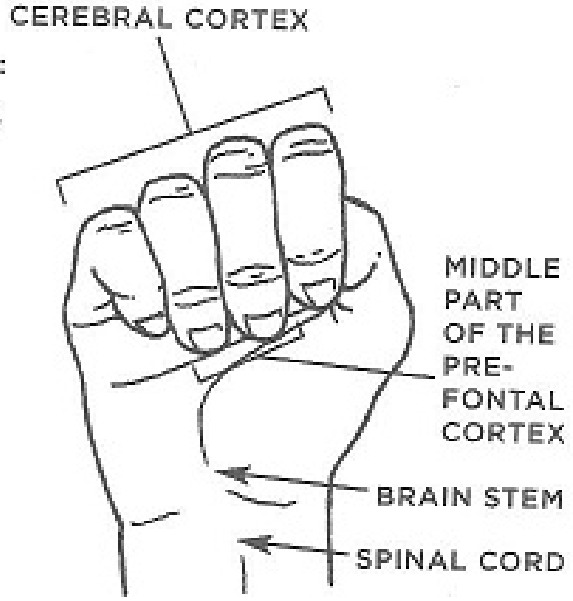
In both cases....

The sub-cortex hi-jacks the cortex!

Dan Siegel – "Hand Model of the Brain" (Mindsight, 2010)



Place your thumb in the middle of your palm as in this figure.



Now fold your fingers over your thumb as the cortex is folded over the limbic areas of the brain.

Daniel Siegel
The "Hand Model of the Brain"

"….Lift up your fingers and you'll have an image of how we 'flip our lids' and head down the 'low road' in our interaction with others."

Mindsight (2010), p. 22

For our purposes, this means...

- *Children with autism have brain differences that may lead them to respond to "normal" events as if they were traumatic.*
- *In these situations, the child likely has neurobiological vulnerabilities that transform typical experiences into ones which are experienced as powerful and dangerous stimuli and which overwhelm the child's capacity to regulate his or her emotions and behaviors.*

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The Growing Field of Neurological Findings in ASD

- Increased brain volume and enhanced early growth rate
- Poor synchronization/integration ("disorder of functional interconnectivity"); differences in corpus collosum
- Differences in limbic system- notably the amygdala (social processing and affect?)
- Differences in "mirror neuron" systems

Other Differences

- American Academy of Neurology 2008 study found that 65% of the children studied with autism, had deficits in the functioning of cellular mitochondria, resulting in muscular deficits and weaknesses
- Dr. Lucy Miller (Univ. of Colorado) found that 78% of children with autism in her study had significant symptoms of sensory processing disorder. although many children have SPDs who are not diagnosed with autism.

Diane Williams, Ph.D. (2008)

"What should the environment input be? Interventionists should start thinking about what a typically developing brain can do. Next, they should consider what a brain with autism cannot do." (2008, p.15)

Source: Williams, D. (2008). What neuroscience has taught us about autism. ZERO TO THREE, 28, 11-17.

Diane Williams, Ph.D.

- "… the brain with autism will process information in idiosyncratic ways."(p.15)
- Certain processing tasks (like reading) require, "large, highly integrated brain networks."(p.14). Persons with ASD appear to have less integrated brain systems.

Stanley Greenspan, "The Challenging Child"

"Imagine driving a car that isn't working well. When you step on the gas the car sometimes lurches forward and sometimes doesn't respond. When you blow the horn it sounds blaring. The brakes sometimes slow the car, but not always. The blinkers work occasionally, the steering is erratic, and the speedometer is inaccurate. You are engaged in a constant struggle to keep the car on the road, and it is difficult to concentrate on anything else."

DMIC

Diagnostic Classification of Mental Health & Developmental Disorders of Infancy & Early Childhood

Developed by ICDL (2005)

Based on research done by Greenspan & Wieder at the NIMH

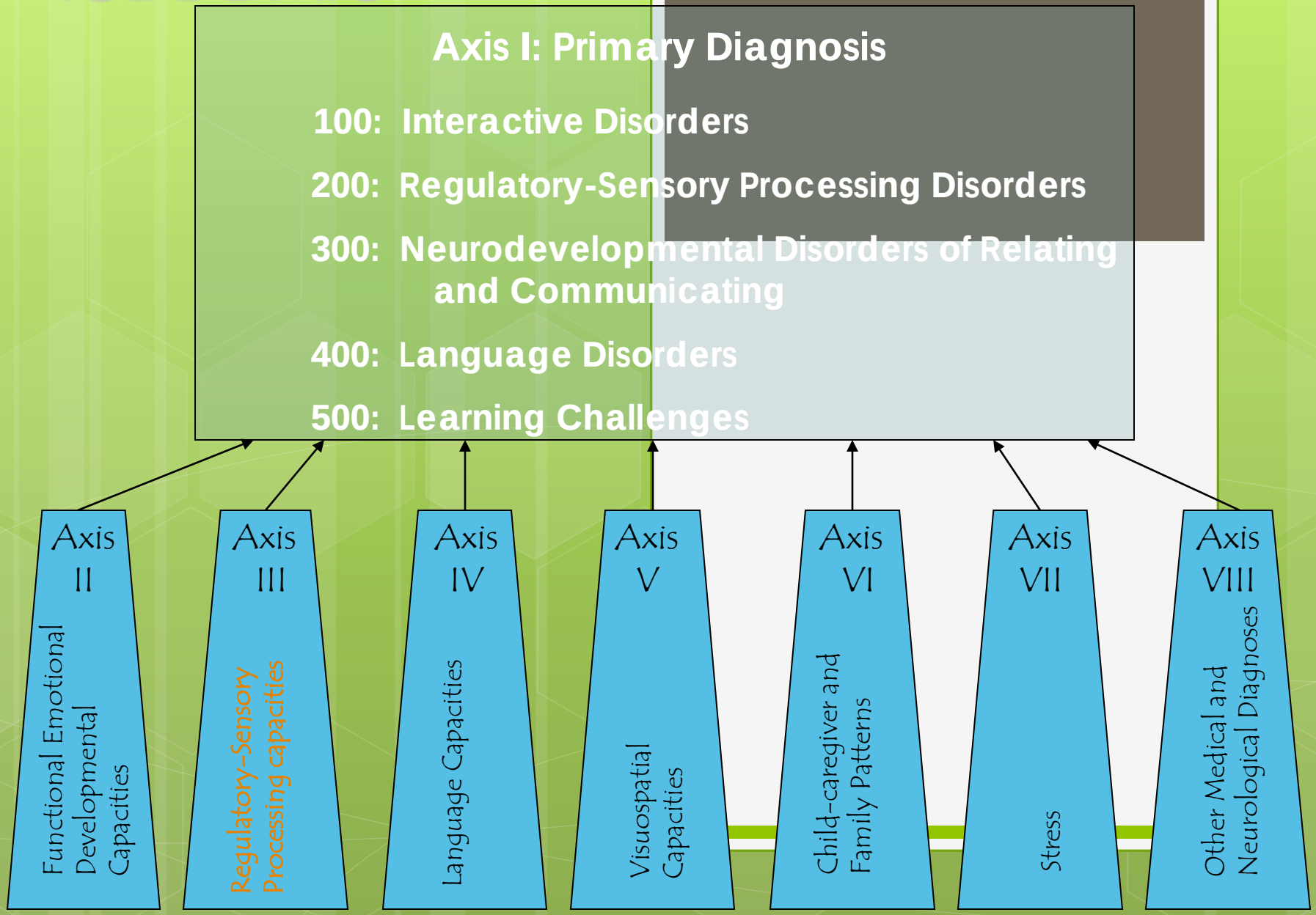
Classifications of healthy & disorder functioning

Models of intervention

Developmental pathways leading to disorders

interdisciplinary

ICDL-DMIC


Axis I: Primary Diagnosis
100: Interactive Disorders
200: Regulatory-Sensory Processing Disorders
300: Neurodevelopmental Disorders of Relating and Communicating
400: Language Disorders
500: Learning Challenges
Axis II
Functional Emotional Developmental Capacities
Axis III
Regulatory-Sensory Processing capacities
Axis IV
Language Capacities
Axis V
Visuospatial Capacities
Axis VI
Child-caregiver and Family Patterns
Axis VII
Stress
Axis VIII
Other Medical and Neurological Diagnoses

ICDL Multi-Axial Approach

- Axis I: Primary Diagnosis

*(predominant contributing factor) (** will be explored today)*

  - Interactive Disorders
  - Regulatory-Sensory Processing Disorders**
  - Neurodevelopmental Disorders of Relating and Communicating
  - Language Disorders**
  - Learning Challenges**

- Axis II: Functional Emotional Developmental Capacities
- Axis III: Regulatory/Sensory Processing Capacities

Multi-Axial Classification Approach

- Axis IV: Language Capacities
- Axis V: Visuospatial Capacities

- Axis VI: Child-Caregiver & Family Patterns
- Axis VII: Stress

- Axis VIII: Other Medical & Neurological Diagnoses

Source: Interdisciplinary Council on Developmental and Learning Disorders. (2005). Diagnostic Manual for Infancy and Early Childhood. Bethesda, Maryland: ICDL.

The Socio- Cultural Context of Disability

Culture

Culture is the vehicle through which we live our lives. Culture, as experienced, is **not** an *"aspect"* of life, it **IS** life as it is lived on a moment-to-moment basis.

Culture shapes the self and the human story.

- Monica McGoldrick

Culture shapes….

- Through a variety of means including routines, rituals and shared historical practices.

- Culture establishes a sense of ***tradition, history and belongingness.***

Consider.....

"The Spirit Catches You and You Fall Down"

By Anne Fadiman

Culture organizes:

- Expression of affect
- Dress and customs
- Language and gestures
- Interpersonal space and behavior - including eye contact, hand-shaking, behavior between men and women
- Art, music, movement and dance
- Origins and meaning of health and illness
- Diet and food choices

Culture organizes: (con't)

- Historical context and origins - "Legacy"; historical and personal "myths" or "narratives".
- Religious beliefs, values and world views - including belief in God, evil, afterlife, notions of equality, personal choice, freedom.
- Beliefs about role of government, and methods of social justice - including form of government, laws and punishment.

Culture organizes: (con't)

- Gender roles
- Family structure, marriage and community
- Views about, and treatment of authority
- Medical care and health practices; regard for seeking and acceptance assistance
- Parenting and childrearing beliefs and practices - including discipline practices, sleeping practices and belief in importance of achievement and autonomy

From:

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010

Surveillance Summaries

March 28, 2014 / 63(SS02);1-21

- Consistent with previous reports from the ADDM Network, findings from the 2010 surveillance year were marked by significant variations in ASD prevalence by geographic area, sex, race/ethnicity, and level of intellectual ability.
- ***The extent to which this variation might be attributable to diagnostic practices*, *under-recognition of ASD symptoms in some racial/ethnic groups, socioeconomic disparities in access to services, and regional differences in clinical or school-based practices that might influence the findings in this report is unclear***

- Approximately one in 42 boys and one in 189 girls living in the ADDM Network communities were identified as having ASD

- Non-Hispanic white children were approximately 30% more likely to be identified with ASD than non-Hispanic black children and were almost 50% more likely to be identified with ASD than Hispanic children.

- Among the seven sites with sufficient data on intellectual ability, **31% of children with ASD were classified as having IQ scores in the range of intellectual disability (IQ ≤70), 23% in the borderline range (IQ = 71–85), and 46% in the average or above average range of intellectual ability (IQ >85).**

- **The proportion of children classified in the range of intellectual disability differed by race/ethnicity.**

- **Approximately 48% of non-Hispanic black children with ASD were classified in the range of intellectual disability compared with 38% of Hispanic children and 25% of non-Hispanic white children**. The median age of earliest known ASD diagnosis was 53 months and did not differ significantly by sex or race/ethnicity.

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What do these data mean?

- Is it possible that the “symptoms” seen in one group are assigned diagnosis A, and the same symptoms in another group are assigned diagnosis B?
- Can such unintended practices result in differential intervention practices and engender patterns and trajectories that become self-perpetuating?
- Can an diagnosis of ASD which focuses on behavior and not underlying origins contribute to these patterns?

Key Messages

- The larger culture and belief systems have a profound influence on what is considered an illness or disorder.
- These also influence the assignment by the professional community of specific diagnoses to specific individuals.
- This can lead to both under and over diagnoses in certain groups.
- Confusion remains about the diagnosis of ASD and whether it adequately leads practitioners to proper assessment and intervention.

Recommendations

- We must attend to understanding the **provider's** (teachers, physicians, SWs, psychologists, behaviorists, OTs, PTs, SLPs, etc.) **"belief system" about ASD and cultural forces.**
  - This includes an examination of their underlying "models" of human development and "theories of change," and the explicit and **implicit assumptions** they bring to the table.
- This forces us to require the study of history and systems of beliefs and the varying views of **epistemology.**
- This requires education of providers to be done more comprehensively and holistically and necessitates the requirement for **reflective practices**.
- **This will alter, and make more transparent, diagnostic classification systems and how they are applied!**

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A word on ASD and Attachment

Secure Attachment in Children with Autistic Spectrum Disorder: The Role of Maternal Insightfulness

Oppenheim, David; Koren-Karie, Nina; Dolev, Smadar; Yirmiya, Nurit (2008), *Zero to Three*, 28, 25-30.

Discussion

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