

PLEASE LISTEN TO MY HEART

PLEASE LISTEN TO MY HEART
PLEASE FORGIVE THESE CLUMSY WORDS
JUST HEAR ME FROM MY OPEN HEART TO YOURS
THE LANGUAGE OF MY HEART SPEAKS ELOQUENTLY
WHILE MY FINGERS GRAPPLE FOR THE LETTERS ONE AT A TIME.
MY MOUTH HAS NOTHING TO SAY.

HEART LANGUAGE REMEMBERS THE BEGINNING
AND FORSEES THE END
IT HOLDS MY WHOLE LIFE IN ONE SINGLE GLANCE
AND TRIES TO CONVEY EVERYTHING AT ONCE.

WORDS ON THE OTHER HAND
BREAK IT ALL UP INTO
A THOUSAND TINY PIECES
WHICH NEVER GO BACK TOGETHER AGAIN

*Roy Bedward, Age 29
Autism
Madison, WI*

North Dakota
Moving Forward Together

October 22, 2015

Nancy Minshew, MD
Professor of Psychiatry & Neurology
University of Pittsburgh

Autism Spectrum Disorder (ASD)

- Autism Spectrum Disorder is defined by underdevelopment (child-like or immature state) of skills for being social, communicating, recognizing and regulating emotions, understanding concepts, and functioning in a dynamic world.
- Most people do not have ASD but they do have problems constantly or situationally with one or more of these skills for varying reasons.
- What you learn about ASD students will be applicable to all students and people and to yourself.

The “ASD” in All People

- Immature state of skills for being social, communicating, recognizing and regulating emotions, and understanding concepts and functioning in a dynamic world.
- To recognize this immaturity as the cause of behavior: close your eyes so you are not confused by the age or appearance of the person and ask yourself how old is a child when they act or say things like this?

The “ASD” in All People

- Or, ask yourself if the undesirable thinking, speaking or feeling:
 - is socially inappropriate and why exactly
 - involves inappropriate, ineffective or inefficient ways of communicating
 - reflects difficulty regulating their emotions
 - reflects inadequate knowledge, inexperience, or poor models in life
 - disconnect between common sense and knowledge

Topic 1: The Latest on Prevalence

Prevalence: How Common is Autism Spectrum Disorder?

- Prevalence: 1/68, 1/50, 1/35
- Translates to: 1.5%, 2%, 2.9% of population
- Not an overestimate- probably an underestimate

Prevalence Estimates Do Not Include:

- Those with a fragment of ASD
- Those with functional social, communication and reasoning impairments due to abuse, violence, poor models, poverty, etc
- Those with social cognitive and non-social cognitive deficits but intact basic abilities- they are missed on usual autism measures and there is no real diagnostic category for them now.

The Real News:

50% have “normal” IQ scores and language

- **50% have IQ scores >85**
- **Another 23% have IQ scores of 71-85**
- In North Korea: 66% of these normal IQ ASD students are in regular classrooms and unidentified. The same is probably true here.

From DNA to Behavior: A Connected Sequence of Mechanisms

Abnormalities in Genetic Code for Brain Development



Abnormal Mechanisms of Brain Development



Structural and Functional Abnormalities of Brain



Cognitive & Neurological Abnormalities



Behavioral Syndrome

Topic 2: Adolescence and Adaptive Function

Adolescence As A Time of Increased Symptoms in ASD Students Who Have Relatively Intact Cognition and Language (RICLA)

- Most of the rise in prevalence is due to new diagnoses of ASD in adolescents with ASD who have relatively intact cognitive and language abilities

Changes in Prevalence of Autism Spectrum Disorders in 2001–2011: Findings from the Stockholm Youth Cohort

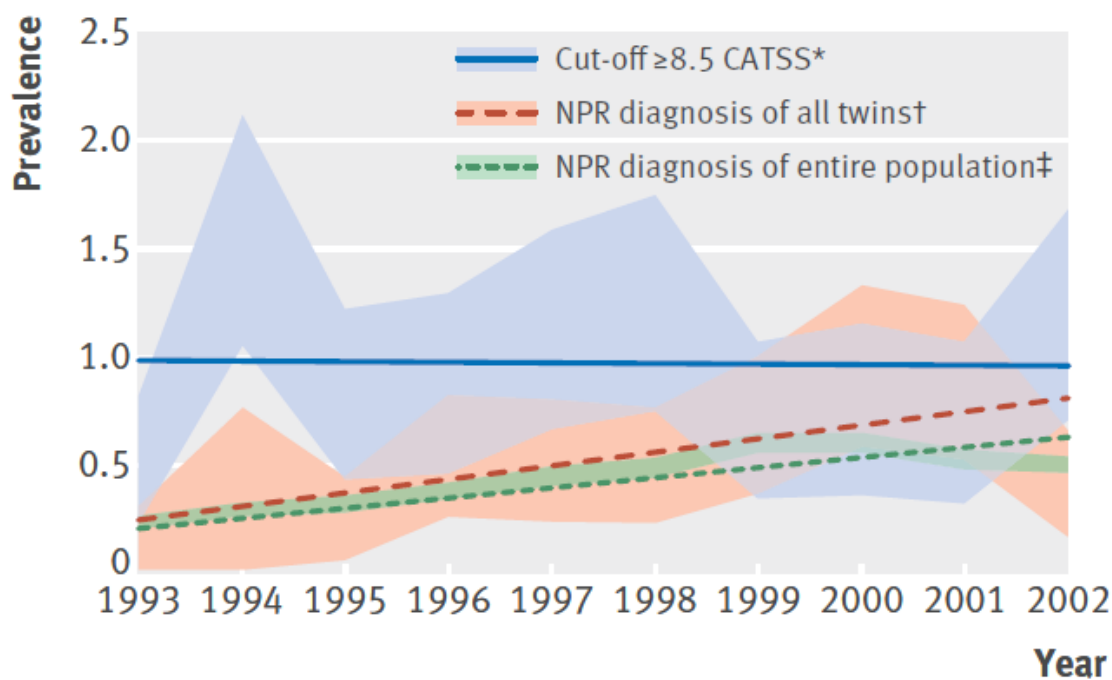
Selma Idring · Michael Lundberg · Harald Sturm ·
Christina Dalman · Clara Gumpert ·
Dheeraj Rai · Brian K. Lee · Cecilia Magnusson

J Autism Dev Disord (2015) 45:1766–1773
DOI 10.1007/s10803-014-2336-y

Abstract In a record-linkage study in Stockholm, Sweden, the year 2011 prevalence of diagnosed autism spectrum disorders (ASD) was found to be 0.40%, 1.74%, 2.46% and 1.76% among 0-5, 6-12, 13-17 and 18-27 year old.

Autism phenotype versus registered diagnosis in Swedish children: prevalence trends over 10 years in general population samples

Sebastian Lundström,^{1,2} Abraham Reichenberg,³ Henrik Anckarsäter,² Paul Lichtenstein,⁴ Christopher Gillberg¹



Adolescence

Why might adolescence be a time when these children come to attention for the first time?

What skills do they now need that they did not have before? What is different about the world they live in as adolescents?

A Two-Hit Model of Autism: Adolescence as the Second Hit

Giorgia Picci and K. Suzanne Scherf

Department of Psychology, Pennsylvania State University

Clinical Psychological Science

1–23

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DOI: 10.1177/2167702614540646

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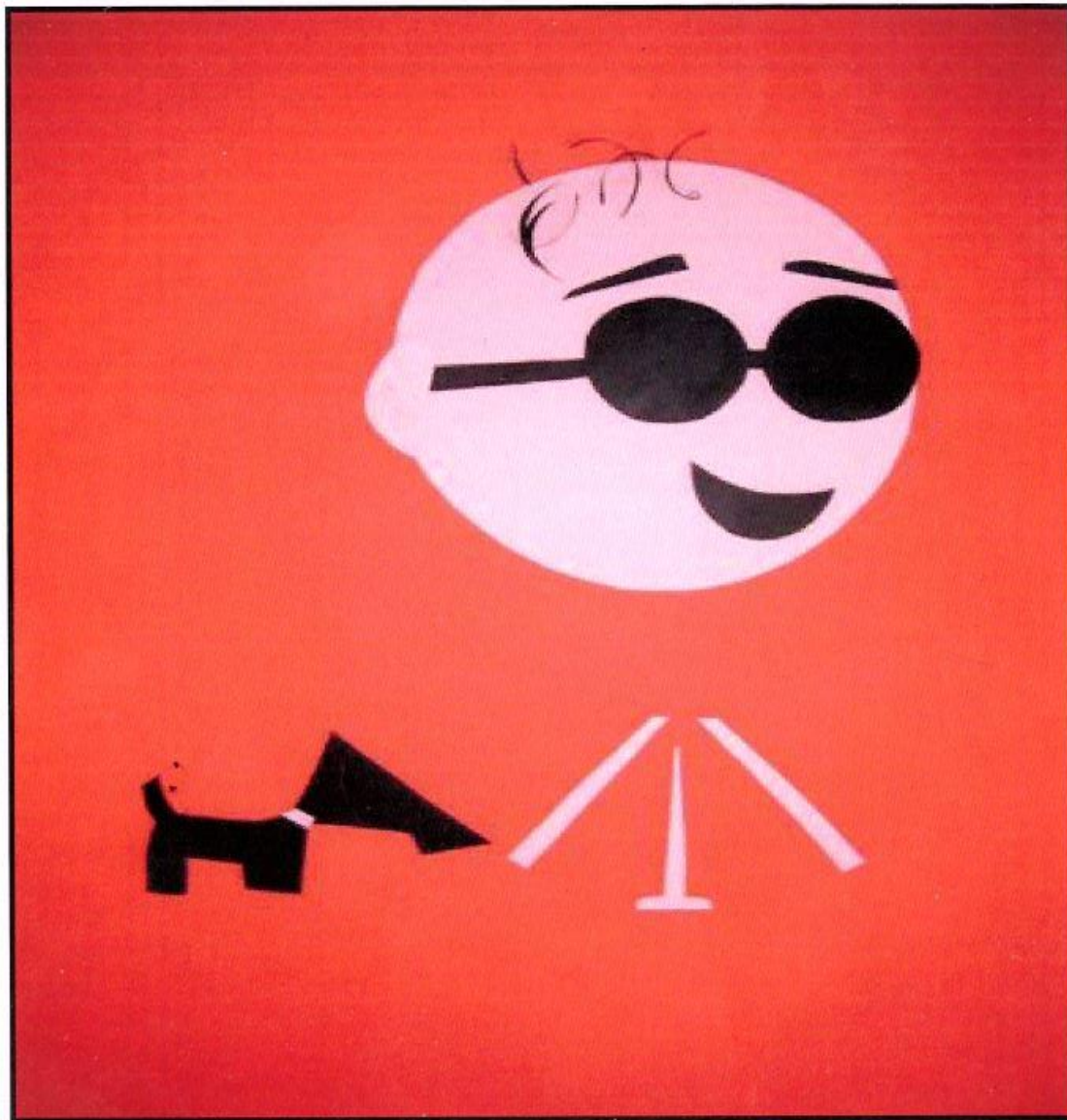
The “Second Hit” is Adaptive Behavior

Not exactly but almost.

The circuitry that supports connection of information into an integrated schema, to self and to function in a dynamic world likely starts very early in development but accelerates in adolescence. Externally imposed structure helps children to function without these skills but is inadequate in adolescence and adulthood.

Children are simpler than adolescents and life for them is simpler

- Clear rules and authority structure that they respect, value and conform to or try to
- Children value these rules and the opinion of their teachers
- They are child-like in their hearts and spirits
- They have yet to develop the cognitive capacity or desire for deception, manipulation, or retaliation, or choose not to
- **In the ideal world these things are true.**



Boy and Dog

Wil C. Kerner, Age 13, Autism, Renton, WA

Golden Hands

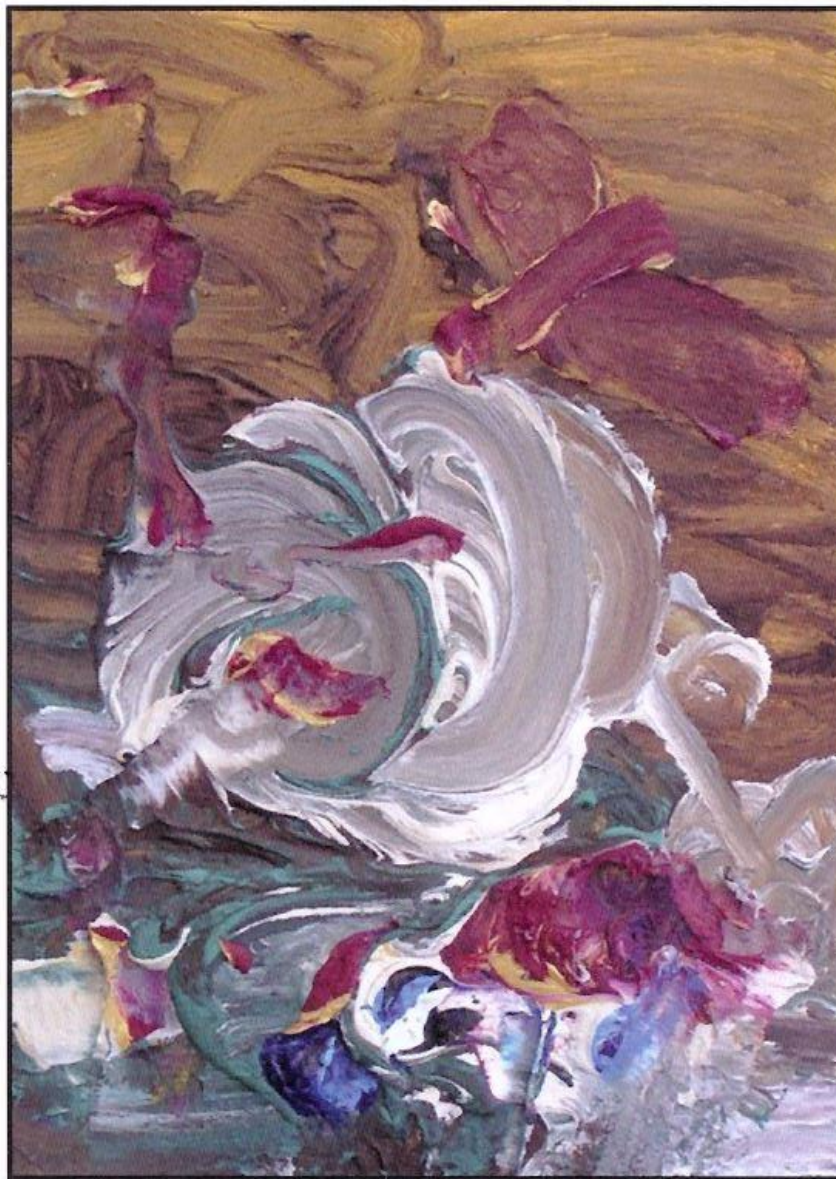
Matthew McCollough, Age 15, Developmentally Delayed



Life gets much more complicated and real world-like in adolescence

- Adolescence is a time of greatly increasing social, emotional and cognitive demands
- Students with ASD do not have the typical growth in advanced social, emotional and thinking skills that other students do
- But you will see impaired social, emotional, communication and problem solving skills for different reasons in many non-ASD students

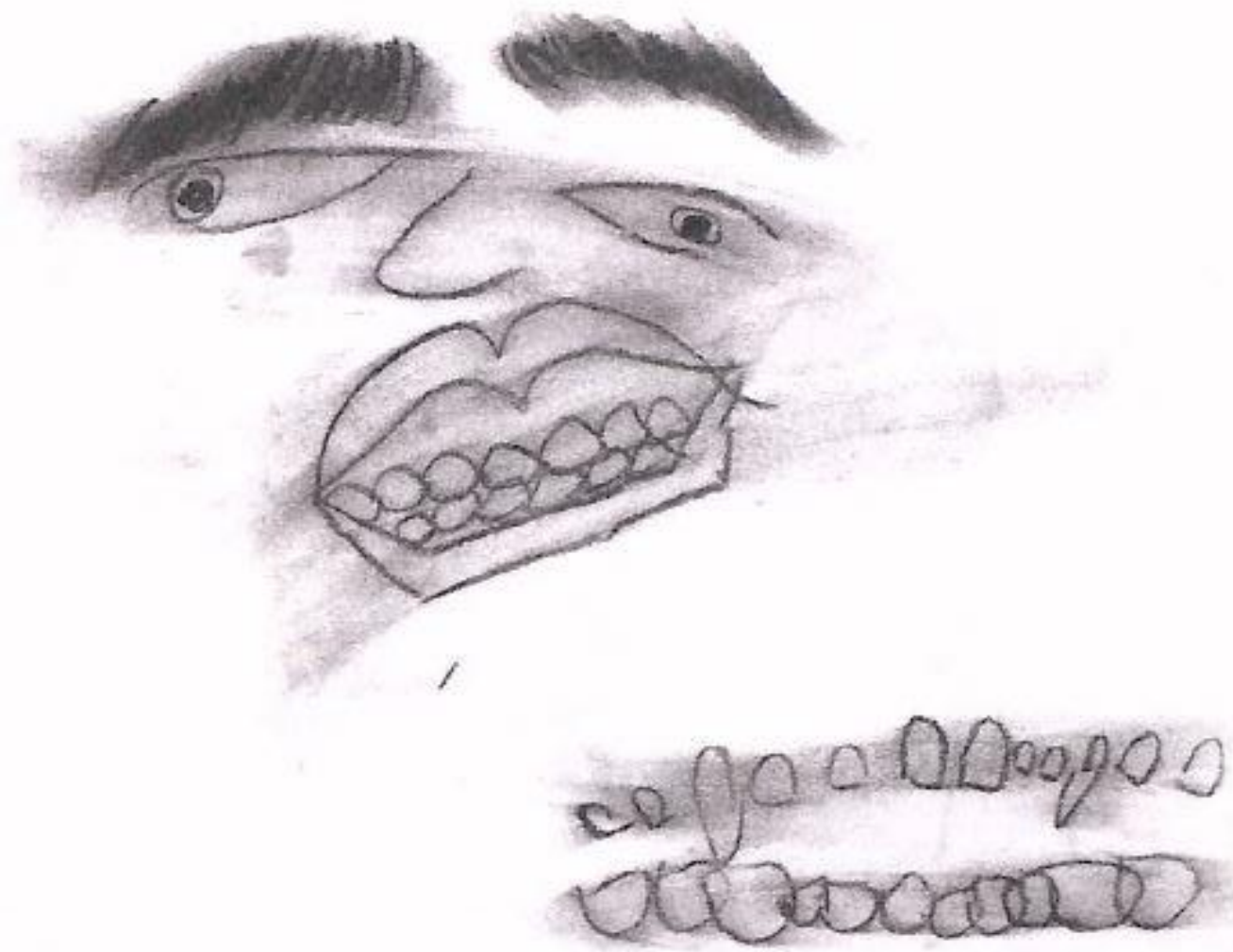




Flight of Chaos *Andrew Randall, Age 22,
Autism and Bipolar Disorder, Seekonk, MA*

Teaching Strategies That Reflect Developmental State

- Use fewer words and give the bottom line
- Say it slower and pause for it to sink in
- Write it down- Campbell Soup instructions
- Give them space- may mean not looking at them when you talk, no drama
- Give them a space to retreat to- a creative or thinking space- when they have had enough talking and group contact



2. 1997 9 x 12 in.

Teaching Strategies That Reflect Developmental State

- Provide structure: small, manageable pieces
- Be explicit- don't assume understanding of anything and be succinct-give the bottom line
- Model the desired activity/product
- Be sure no one is bullied or disrespected
- Assume that if they don't do what you want, they do not understand or they need more support to do it

Wise Old People: The Answer to Why

- It is what it is- see the reality

I heard one mom calmly say to her son “That is what you want to do, but this is what you will do. Wait until everyone in front of you gets off of the plane.” Pete the Cat says...

- Do what you have to do- do what needs to be done
- Help others whenever you can- it feeds your own soul and your self-esteem; we and our lives are defined by what we say and do; if you help others, they will help you when you need help.

Topic 3. Behavioral Hallmarks & Underlying Brain Impairments in ASD

Hallmarks of ASD: Recognizing the Student with ASD

- Perceived as odd or strange
- Often expressionless face or one expression
- Poor use of eye contact for communication
- Unusual memory for details but poor concepts
- Poor common sense, poor abstraction
- Obsessions/special interests with focus on details or facts
- To them, we are illogical, erratic and scary.



1. 1997 9 x 12 in.

- [Ethan.wmv](#)
- [Adam.wmv](#)
- [Ryan.wmv](#)

Two Basic Limitations of ASD Students

- They have lots of details and facts but their minds do not connect them into a meaningful schema. It is like having thousands of unmatched socks. They cannot integrate new information- don't learn from experience.
- They don't understand how the facts they know relate to how they would function in the external world or even what the facts mean about themselves (internal world). Poor adaptive function and poor sense of self.

Understanding what information means about and to themselves

- Brain imaging studies show that people with ASD lack a brain representation of “self”
- So social interactions like hugging others or being hugged are facts about the external world but not ones they experience in relation to themselves.

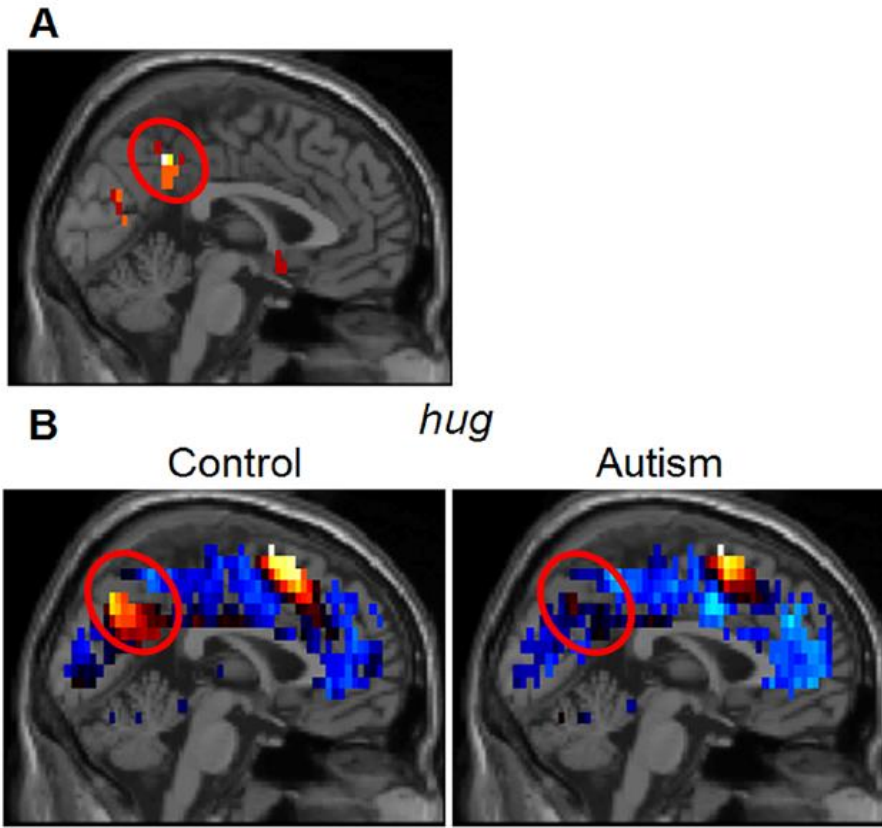


Figure 2. Posterior midline *self* factor location. A. Location of the voxels (circled) derived from the factor analysis of the Control Group that defined the posterior cingulate/precuneus sphere of this group's *self* factor. Voxels in this cluster (with MNI x-coordinates extending from 0 to -9) are shown projected on the mid-sagittal plane. (The coordinates and radii of all 6 spheres associated with this factor are shown in Table S1 in File S1). B. Mean activation in midline brain structures for the verb *hug* (averaged over agent and recipient roles) for the two groups, differing in posterior cingulate/precuneus. The verb *hug* was chosen for illustration here because of the salience of hugging as a social interaction in autism, where enveloping pressure is sometimes desired but without physical contact between oneself with another person, as in Temple Grandin's squeeze machine [40]. The depiction of the activation in this slice for all of the other verbs was very similar to *hug*, for both groups.

Potential Teaching Goals

- Learning to identify their own and others' emotions- feelings, naming them, strategies for dealing with them internally
- Learning to tolerate them and to express them in appropriate ways
- Feeling heard by others
- Learning the perspectives of other people
- Accepting that other people have different thoughts, ideas, and feelings that are valid
- Giving and receiving respect- personhood

The Artist Approach: Finding the Sacred Space of Self & Being

- Learning about faces and how they express emotion
- Individual variability in emotionality and ways of expressing emotion
- Learning to associate a name with a feeling leads to the “name it and you tame it”
- Talking about ways of expressing emotion and the consequences improves cognitive control over emotions- offers choices
- Journal entries provide an opportunity for learning what choices they make and what outcomes are linked to those choices- a form of self-reflection

The Toastmasters Approach

- Each person presents to the group
- Each listener writes down one thing they liked, one thing they think the person could do to improve and one thing the speaker did well
- Over time this builds perspective-taking skills
- Also builds “groupness” - trust needed to say things, to expose inner thoughts, to talk about experiences
- Over time students find out they and their lives are alike in many ways and different in some ways

Motivation For Change

- For a child, rules or authority may work; for adolescents, it is up to them to choose change.
- Life can go better for them.
- If the person continues to think and do things in the same way, the outcome will continue to be the same.
- If they would like life to have better outcomes for them, they will need to learn to think and act in new ways.
- They can do this. It is a process not an event.

Making This Choice Concrete

- Often do not recognize the connection between their choices of words and actions and outcomes
- Often do not appreciate that there are consistent patterns across situations that lead to undesirable/desirable outcomes
- Short journal entries as a way to insight
- Pictures (visual format) may help

Empowerment

- As long as students see themselves as victims, they see themselves as powerless.
- If they can come to see that they can do things to take care of themselves and determine their outcomes, they are empowered and powerful. This is a life changer.

Adult Outcomes in ASD

Howlin et al 2004; Mazefsky & White, 2014

- Limited data- that's a problem!
- Poor for majority with low IQ in terms of living independently, jobs, and significant social relationships
- 10 participants with IQ >70: did better than low IQ people with ASD but outcome highly variable and not predictable by IQ score

“Associations Between Conceptual Reasoning, Problem Solving, and Adaptive Function in High Functioning Autism”

Williams et al, In press JADD

- This and other studies highlight the impact of ASD on adaptive function, suggesting that use of acquired knowledge in life is a deficit in and of itself in ASD.
- Treatment studies of children and adults indicate importance of experiential learning.

Part 4. Criteria and Deficits

HETEROGENEITY

If you know one person with autism,
you know one person with autism.

Why is this true?

(Eventually you will recognize patterns.)

HUMAN BEINGS ARE COMPLEX

THEY CHANGE RADICALLY WITH AGE

We are just used to these changes.

THEY DIFFER GREATLY ACROSS THE IQ RANGE

We are less familiar with this at the ends.

Commonalities Also Exist

At 10,000 Feet

- Despite wide differences in behavioral manifestations, common characteristics are discernable and have resulted in diagnostic criteria that can be applied across the clinical spectrum (DSM-5)
- Genetic heterogeneity converges on a finite number of mechanisms
- Brain heterogeneity converges on altered cortical systems development and function

DSM-5 Criteria for ASD

- A. Persistent deficits in social communication and social interaction across multiple contexts
 1. Deficits in social-**emotional** reciprocity
 2. Deficits in nonverbal communicative behaviors used for social interaction
 3. Deficits in developing, maintaining, and understanding relationships

DSM-5 Criteria for ASD

B. Restricted, repetitive patterns of behavior, interests, or activities (at least two of the following)

1. Stereotyped or **repetitive** motor movements, use of objects, or speech
2. **Insistence on sameness**, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
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 the environment

Co-Morbidity

70% of those with ASD have one psychiatric disorder and 40% have two or more:

- ADHD
- Developmental coordination disorder
- Anxiety disorder
- Depressive disorder
- Specific learning disabilities (literacy, numeracy)
- Epilepsy, sleep problems, and GI problems

Long List of Deficits Categorized by Clinical Function/Domain

- I find it more useful to think in terms of altered information processing that is present across all domains- from motor and sensory to memory and learning to reasoning and social
- This construct of altered information processing makes it easier to think about an approach

Deficits Underlying Symptoms

- Social cognition
- **Emotion regulation**
- Executive function
- Abstraction (rule-learning, concept formation)
- **Processing speed**
- **Prototype learning/generalization**
- **Learning from experience**
- Formal language, semantic pragmatic language, nonverbal language
- **Automatic versus conscious processing**
- Motor learning, motor praxis, motor coordination, motor speed
- Postural control (multi-sensory integration)
- Sensory processing
- **Adaptive function** (deficit in its own right)

Overall: lack of integration of elementary features or input to form higher order schema that support comprehension, learning/wisdom and adaptive function

Part 5. Underlying Impairment in Automatic Thinking

Conscious vs Automatic Ways of Knowing Things

- Brain and mind have two broad ways of “thinking”: rapid automatic “thinking” and slow, conscious, verbally mediated thinking
- Vast majority of thinking is automatic and non-conscious- we are not aware of it
- We automatically know so much and assume therefore that everyone else knows and understands these things. Others are usually not thinking what you think they are.
- Check your students’ comprehension always and again and again. Watch their faces to see if it is clicking or not. Listen to what they say to hear if what they say reflects understanding.

How to Teach The Automatic

- How to know when you hit this wall: when saying it again in more detail does not work, when saying it more simply and slower as you would to a younger child does not work
- Identify the implied (Social Story method)
- Convert what you have to say to the equivalent of Campbell Soup directions (getting rid of the unnecessary, giving the bottom line)
- Ultimately it may be learning by doing- by experiencing it, keeping a diary of experiences and what was learned (what worked and what did not) and listening to others think outloud about these things in small trusted groups

Example of Rapid Prototype Formation

Note “rapid”. Slow speed of processing is common in ASD.

Pitt Infant and Toddler Development Center

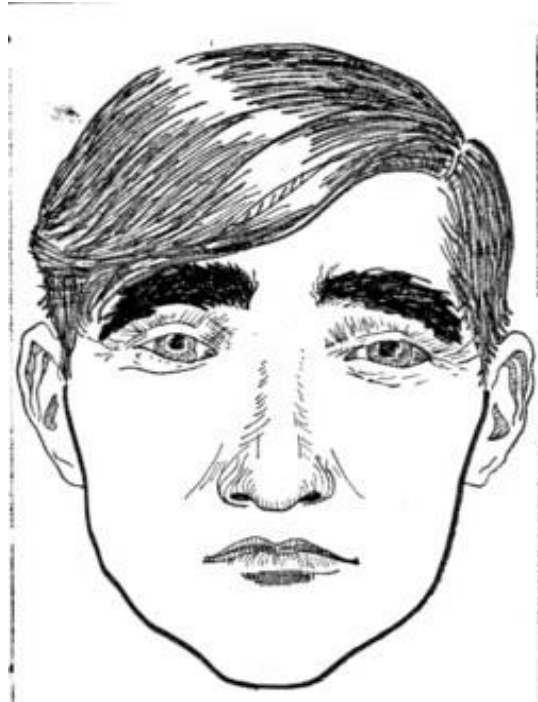


- Abilities that adults take for granted that normally develop in infancy and toddlerhood:
- For example:
 - Our abilities to recognize faces and emotional expressions
 - Our abilities to understand the difference between basic categories in the world– cats, dogs, lions ...

Infants are born with automatic mechanisms that allow them to form **Prototypical** Representations of Information

Or– Which of these is the best example
of a dog?



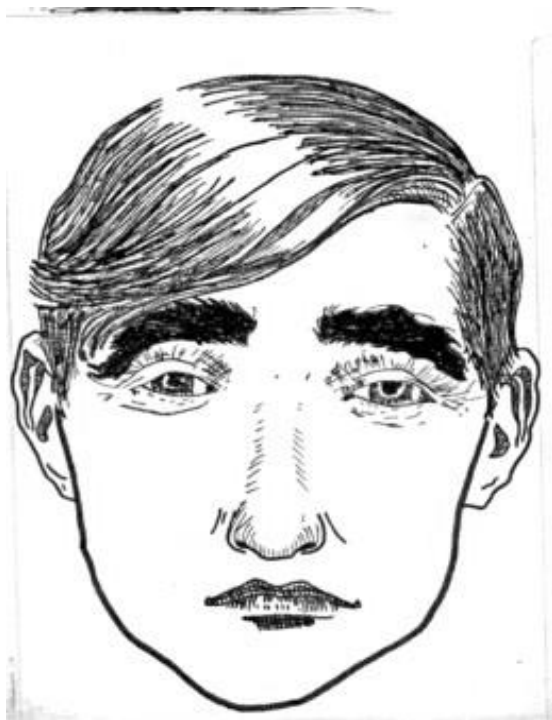




























Which of the following two faces
looks more familiar to you?



3



4

Prototype formation likely to be key to face recognition and all other facial features including affect. Also a key ability for all types of learning.

Can not take for granted that the individual recognizes faces as s/he may be using clothing, hair, environment cues. Or that they know other concepts as they may be reciting facts.

Implications For Treatment

- Learning from experience bridges the gap between knowledge and adaptive function (use of knowledge)
- Building cognitive over sight over behavior impulses

Successful Face Recognition is Associated with Increased Prefrontal Cortex Activation in Autism Spectrum Disorder

John D. Herrington, Meghan E. Riley, Daniel W. Grupe, Robert T. Schultz

This study examines whether deficits in visual information processing in autism-spectrum disorder (ASD) can be offset by the recruitment of brain structures involved in selective attention. During functional MRI, 12 children with ASD and 19 control participants completed a selective attention one-back task in which images of faces and houses were superimposed. When attending to faces, the ASD group showed increased activation relative to control participants within multiple prefrontal cortex areas, including dorsolateral prefrontal cortex (DLPFC). DLPFC activation in ASD was associated with increased response times for faces. These data suggest that prefrontal cortex activation may represent a compensatory mechanism for diminished visual information processing abilities in ASD.

Journal of Autism and Developmental Disorders
April 2015, Volume 45, Issue 4, pp 902-910

Peer Training Outperforms Traditional Autism Interventions

Training classmates produces greater gains in social inclusion than even one-on-one training between therapist and child



Kasari C, Rotheram-Fuller E, Locke J, Gulsrud A. Making the connection: randomized controlled trial of social skills at school for children with autism spectrum disorders. *J Child Psychol Psychiatry*. 2012; 53(4): 431-9.

Supported employment improves cognitive performance in adults with Autism

D. García-Villamizar¹ & C. Hughes²

Journal of Intellectual Disability Research
Volume 51 Part 2 pp 142-150 February 2007

Experience-Based Learning is Paramount

- Facts are not function
- Details-facts-knowledge-wisdom disconnect
- Need help in making these connections-called secondary learning, secondary socialization

Part 6. Brain Basis of ASD

From DNA to Behavior: A Connected Sequence of Mechanisms

Abnormalities in Genetic Code for Brain Development



Abnormal Mechanisms of Brain Development



Structural and Functional Abnormalities of Brain



Cognitive & Neurological Abnormalities



Behavioral Syndrome

Brain Basis of ASD

- Alterations in cortical connections locally and globally

Brain activation during sentence comprehension in autism

In Brain, 2004

Autism group has less activation in **Broca's area**

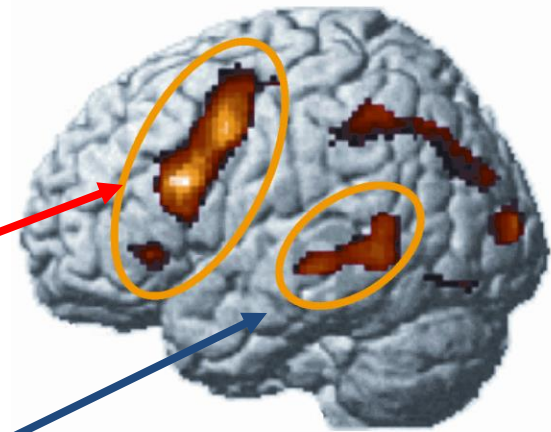
• (a sentence integration area)

than the control group and more in **Wernicke's area**

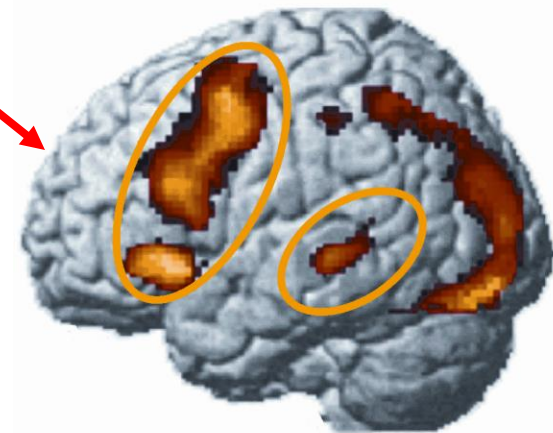
• (a word processing area)

Results are consistent with poorer comprehension of complex sentences, coupled with good word reading (spelling bee champs)

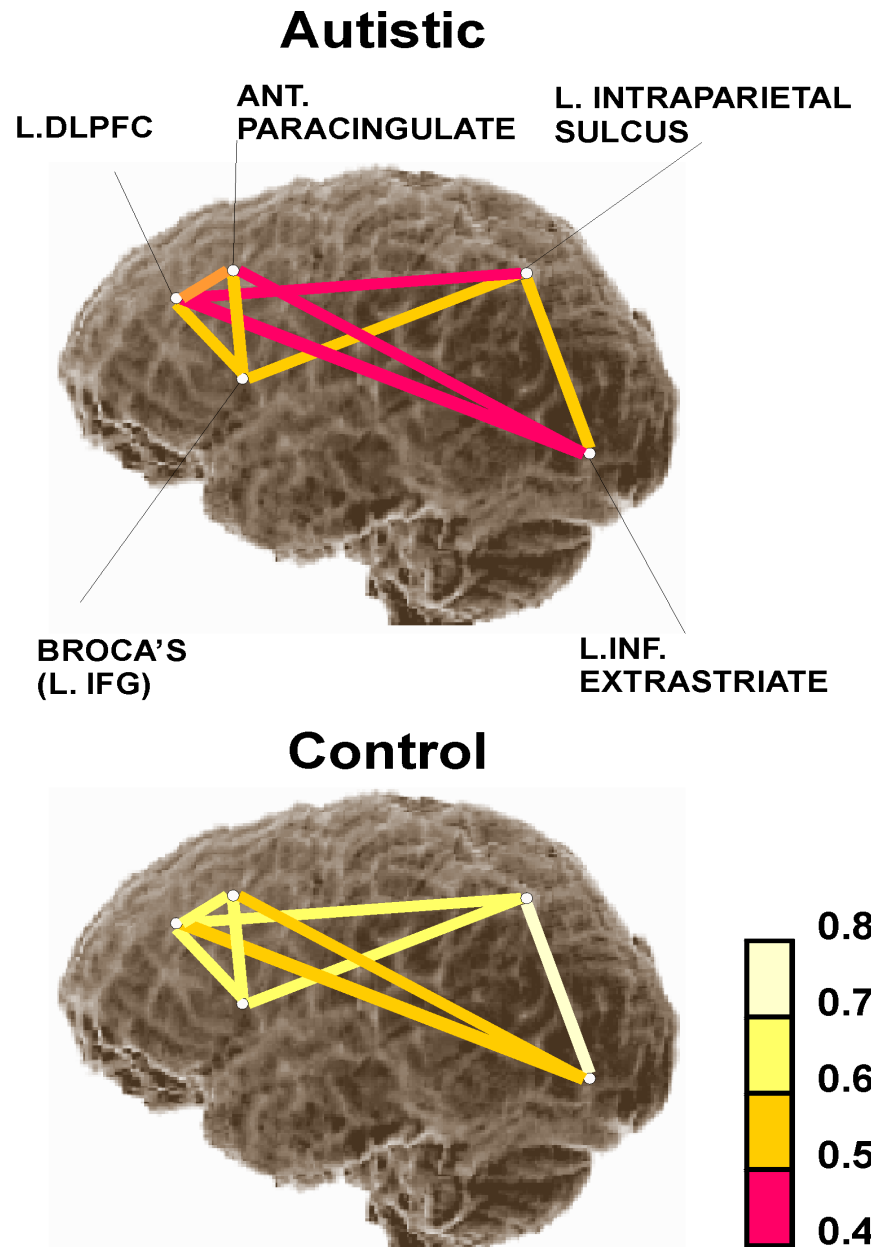
a. Autism Group



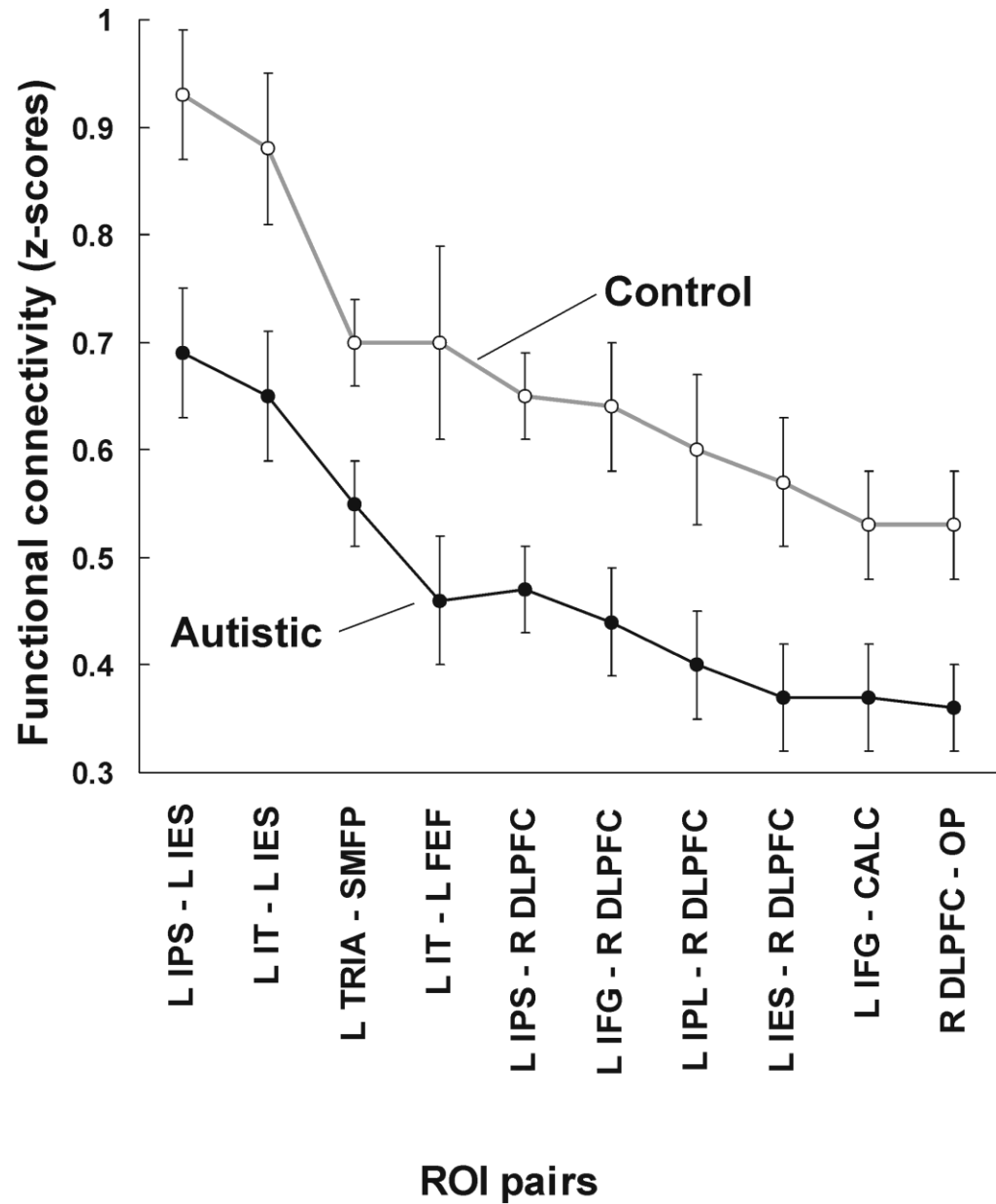
b. Control Group



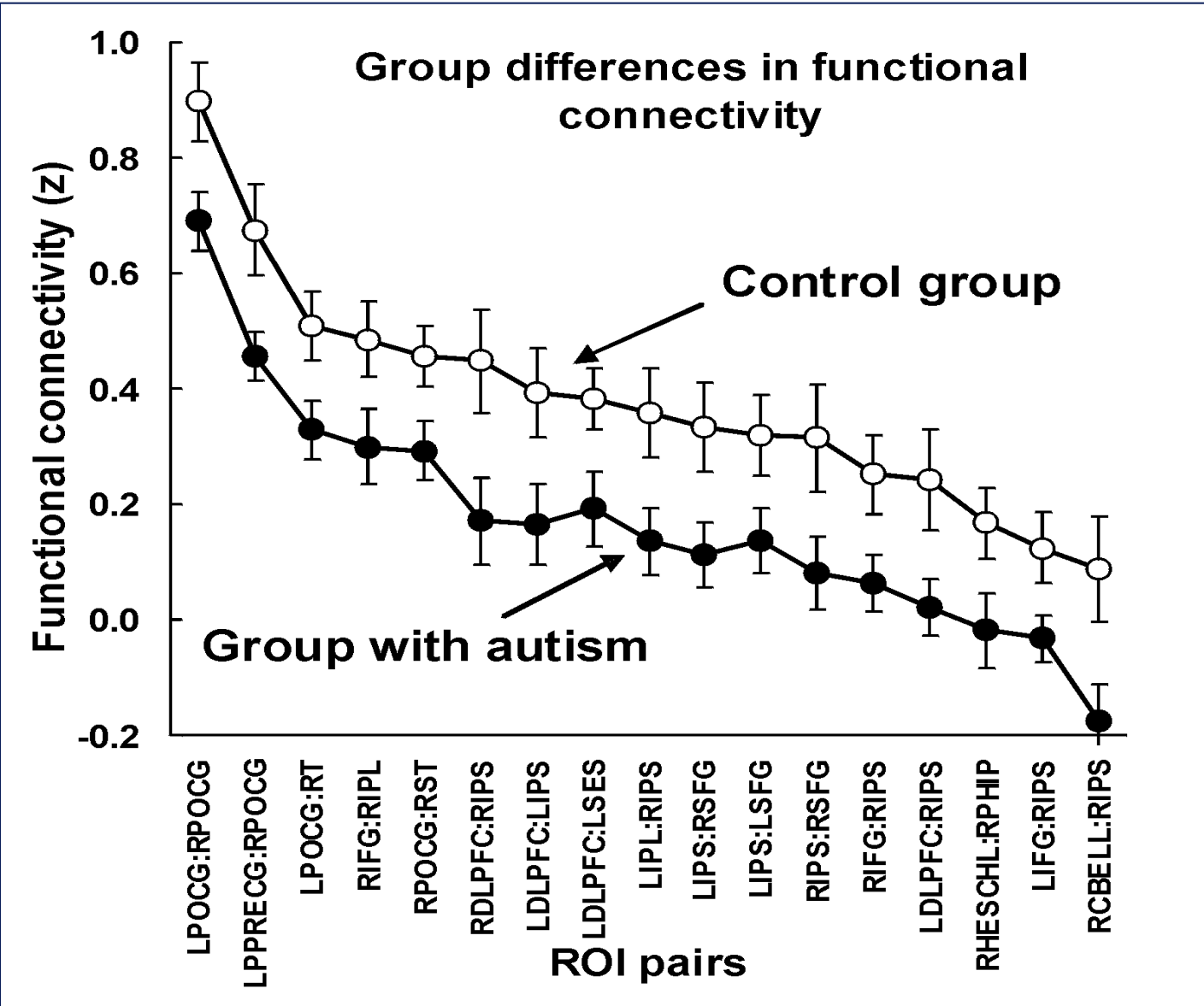
Reliably lower functional connectivity for autism participants between pairs of key areas during sentence comprehension (red end of scale denotes lower connectivity)

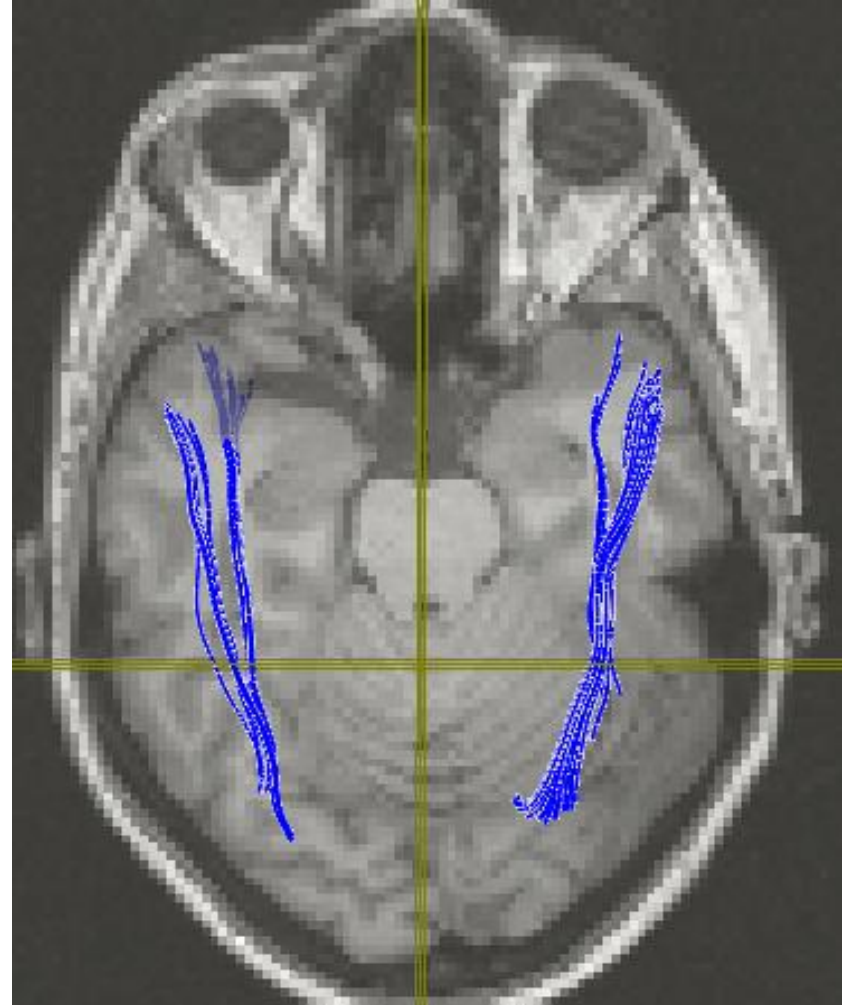
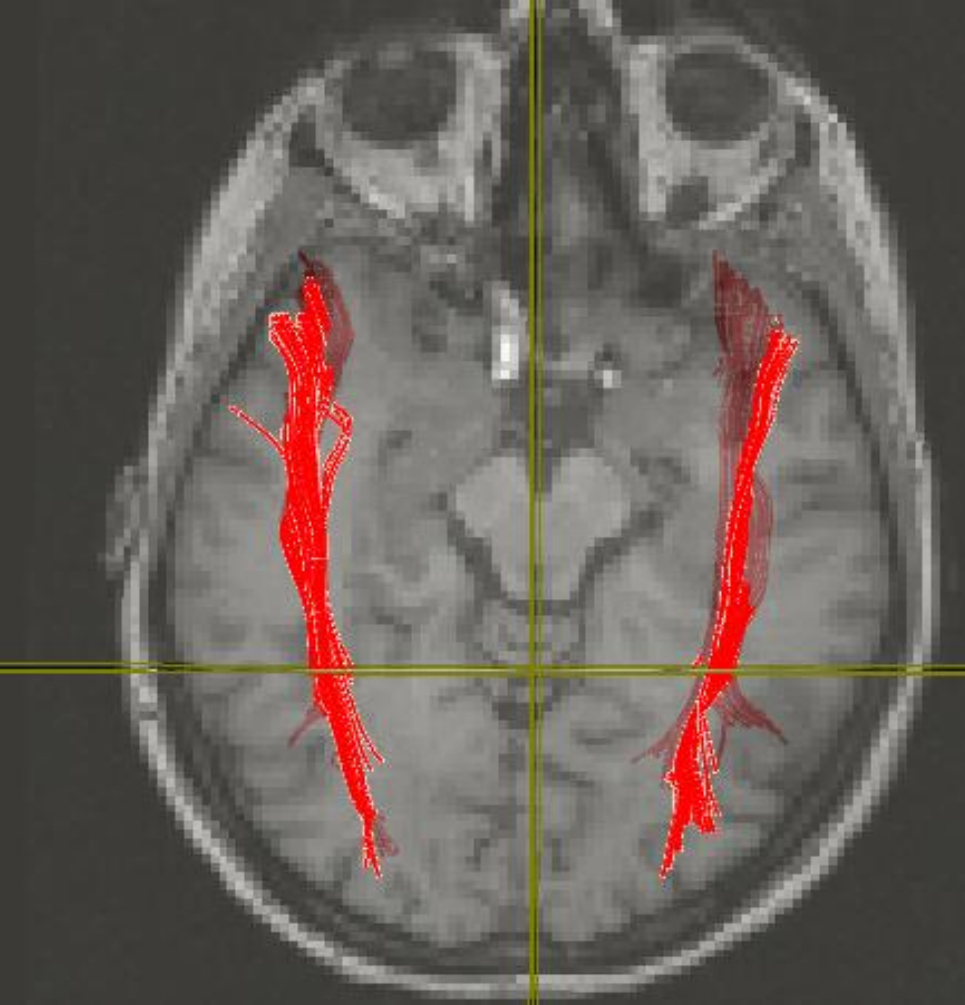


Reliable differences
in functional
connectivity: autism
group has lower
functional
connectivity but
same rank order



TOL Task: Bihemispheric Task





Neural Basis of Cognitive, Affective, Language, & Neurological Deficits

- Systems level abnormalities: within and between systems connectivity
- Cortical systems
- Broad but selective (see cortical systems)
- Gray matter and white matter reflections
- Plastic and responsive to treatment in many individuals, with measureable improvements at neural level

Part 7. Earliest Signs

- Based on studies of infants who have a sibling with autism; 20% will have ASD and another 20-30% will have language disorder, etc
- Postural instability apparent at 3-5 months, tripod sitting at 12 months- means cant use hands to manipulate objects (concept development) or to bring objects to mouth (stimulates language)

ASD in First Year of Life

- Eye gaze diminishes after 6 months of age
- Temperament changes
- Difficulty consoling themselves
- Emotionally labile, difficulty regulating their emotions and activity
- Sensory sensitivities emerge
- Unusual motor movements
- Unusual visual preoccupations

ASD Between 12 and 18 months

- At 12 months: language abnormalities on testing in some but not all (see “Asperger’s”)
- At 14 months, lack of response to name is one of most reliable indicators of ASD
- Impairments in use of eye gaze for social communication emerge- joint attention
- Delayed or no development of other aspects of nonverbal communication like pointing, face expression, voice tone, simple play acts

ASD Between 18-24 Months

- All manifestations become more obvious
- “Hyperactivity” is common
- Difficulty with change and stereotypic repetitive movements may become apparent now or later
- A substantial proportion have a large IQ drop
- Between 2 and 3: repetitive behaviors become more obvious resulting in identification

What does the early presentation mean about the autism syndrome?

- All of the signs emerge simultaneously
- One deficit does not cause the others
- All manifestations reflect common underlying mechanisms
- Common denominator relates to altered higher order information processing mechanisms in the mind and brain
- Common brain denominator is the connections of cortical systems

Brain Imaging Abnormalities By 7 months

- Diffusion Tensor MRI of infants at high genetic risk of developing autism demonstrates widespread abnormalities in the white matter tracts by 7 months of age
- These white matter tracts are the connecting pathways or cables between brain regions- the communication bundles- like phone lines.

Accelerated Early Head Growth Starts At 6-9 months: Further Evidence of Early Brain Basis

- Head growth reflects brain growth, which is why pediatricians measure it
- In ASD, there is an early overgrowth followed by a plateau- begins at 6-9 months
- This growth pattern means that the fundamental dynamics of brain development are altered.
- These processes are guided in minute detail by the plans encoded in DNA.

Autism Begins in the Womb

- Epidemiologic studies are consistent in showing that environmental contributors have their impact in pregnancy
- Much of brain development is established in utero
- Long ago Dr. Margaret Bauman said that the neuropathologic changes occurred no later than 30 weeks of pregnancy

The Biggest “E” Effect in ASD is Beneficial Impact of Interventions

- Lots of evidence that human environmental influences are strong and positive
- Studies are demonstrating brain changes as a result of these interventions
- Think about “E” effects in two ways

From DNA to Behavior: A Connected Sequence of Mechanisms

Abnormalities in Genetic Code for Brain Development



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Topic 8. Genetics of ASD

COMPLEX

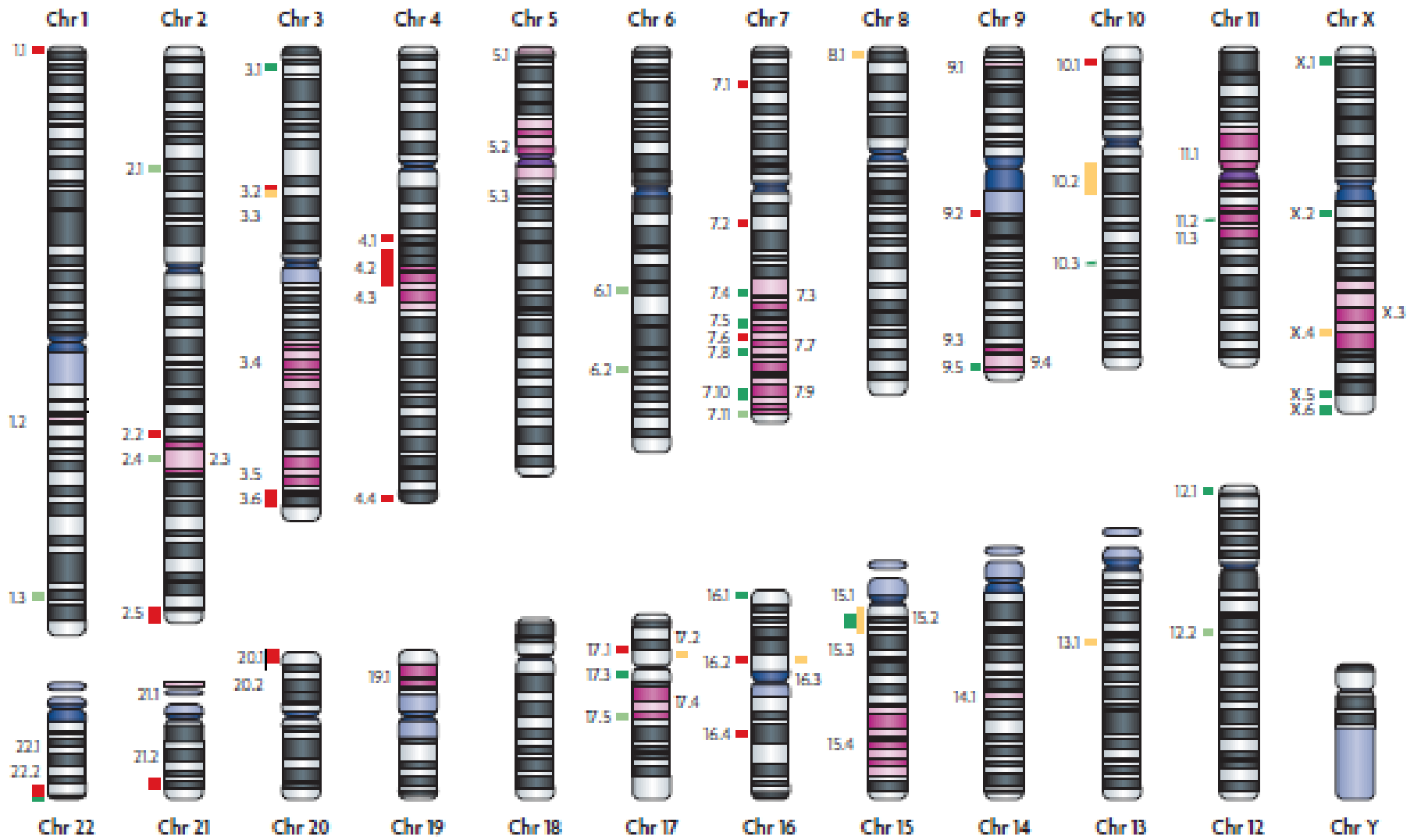
Copy Number Variations (CNVs)

The Awakening to Small DNA Alterations

Small (micro-) deletions or duplications of DNA distributed across chromosomes, inherited and spontaneous, occur constantly

Genetics of Autism: An Explosion

- Several hundred genes have been identified so far
- They converge on a finite number of cellular functions
- Goals are to link genes to cellular and molecular processes and to use them to identify environmental influences contributing to autism



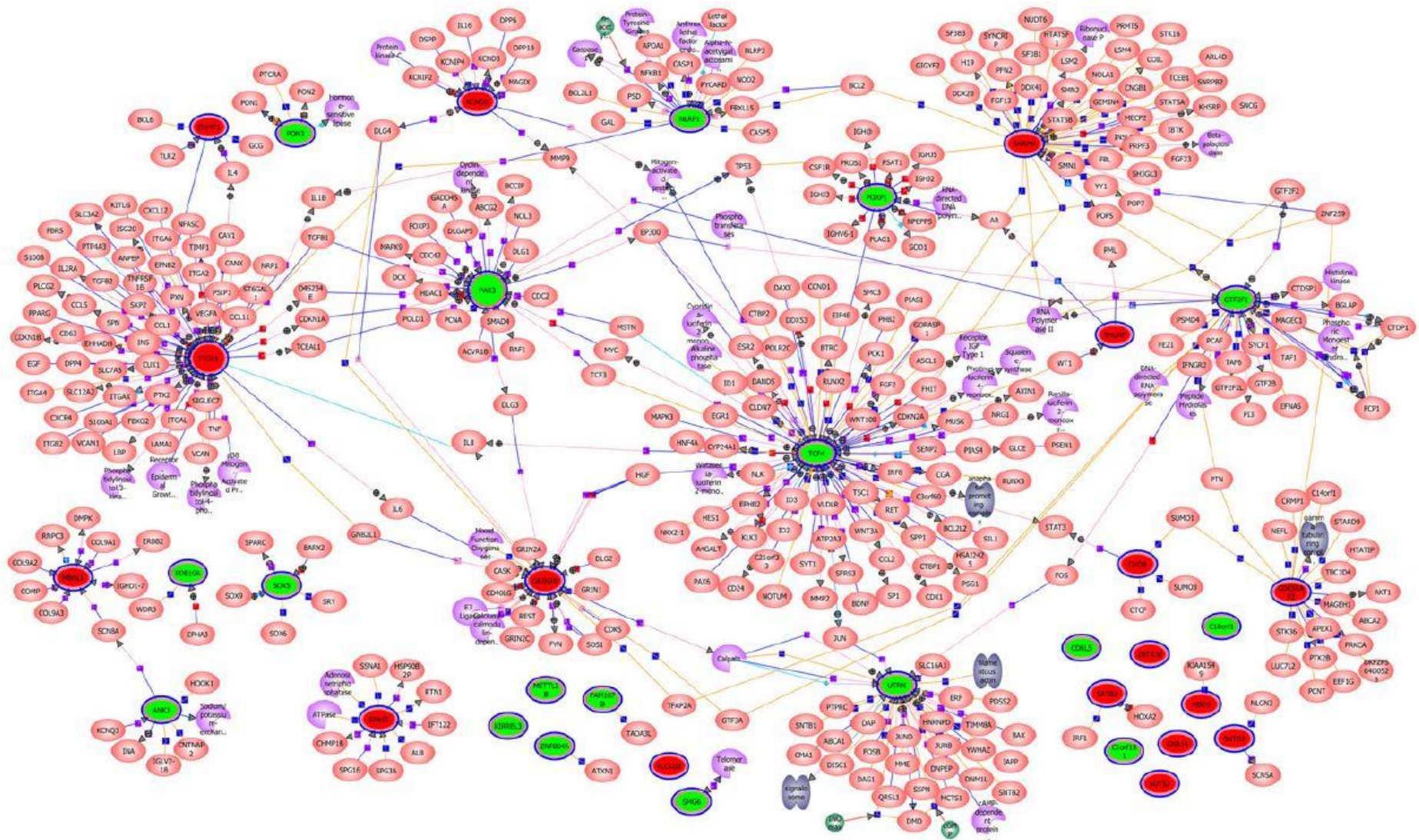
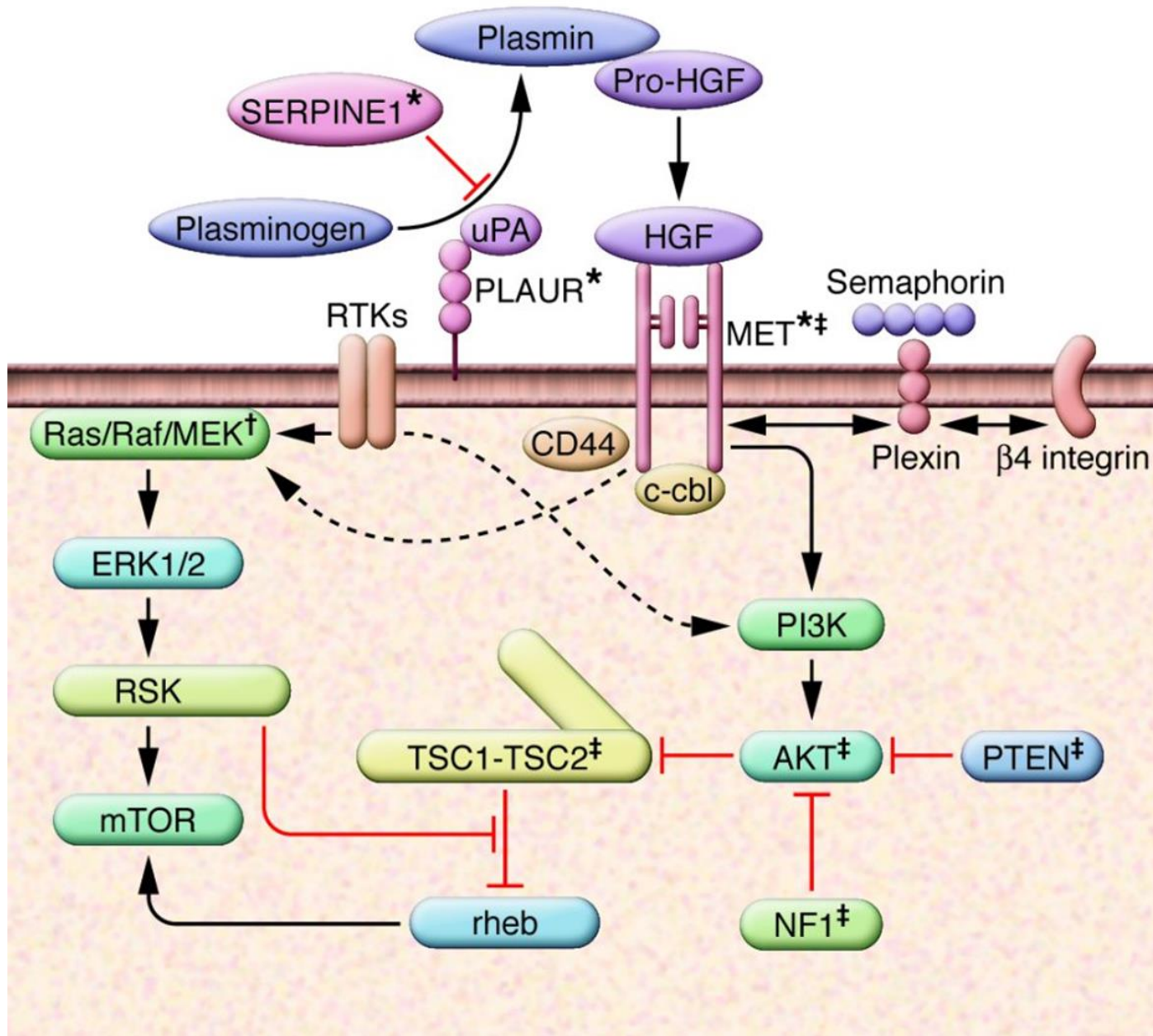


Figure 5. Network Analysis of Genes Implicated in Autism or Neurodevelopment in This Study

A large network of genes disrupted by BCAs in this study are connected by first-, second-, or higher-order interactions. No networks were significantly enriched for genes disrupted by BCAs after correction for multiple comparisons, though a number of loci have limited functional annotation available or remain of unknown function. See also Figure S4.



The genetic and neurobiologic compass points toward common signaling dysfunctions in autism spectrum disorders P. Levitt, D. B. Campbell. *Clin Invest.* 119, 2009.

Conclusions

- Understand much about the genetic architecture of autism; will understand much more very soon.
- More genes and more potential drug targets
- Momentum for discovery is huge and due to
 - Pooling data
 - Funding
- 5 years from now gene discovery in ASD will become passé: translation will be the key for ASD in the near future!

Topic 9. Treatment

Treatment Frontiers

- Earlier- infants and toddlers (Early Start Denver Model- ESDM)
- Evidence base for well-developed interventions like Pivotal Response Therapy
- Mindfulness combined with cognitive strategies
- Cognitive rehabilitation approaches
- Brain stimulation- rTMS, DCS- coming soon

Fundamental News

- The brain in ASD is “plastic” or changeable at all ages.
- That is the basis of the success of behavioral, cognitive and brain stimulation approaches.

Great Need For Interventions with Demonstrated Efficacy & For Dissemination of Those Developed

- Very few grant sources for treatment studies. Many treatment issues do not need to define brain mechanisms to define efficacy.
- There have been many advances and discoveries in treatment but they are rarely available outside of their sites of development. They may “die on the vine.”
- Confirming efficacy is a very slow process.