Meeting of the Interagency Autism Coordinating Committee

July 8, 2014

6001 Executive Boulevard
NSC, Conference Rooms C and D
Rockville, MD 20850

Conference Call Access:
Phone: (888) 946-7606
Access Code: 9653752

Meeting of the IACC

Morning Agenda

9:00 AM **Welcome and Introductions**

Thomas Insel, M.D.
Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive Secretary, IACC

9:15 **OARC/IACC Update**

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive Secretary, IACC

Thomas Insel, M.D.
Director, NIMH and Chair, IACC

Meeting of the IACC

OARC/IACC Update

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

Thomas Insel, M.D.
Director, NIMH and Chair, IACC

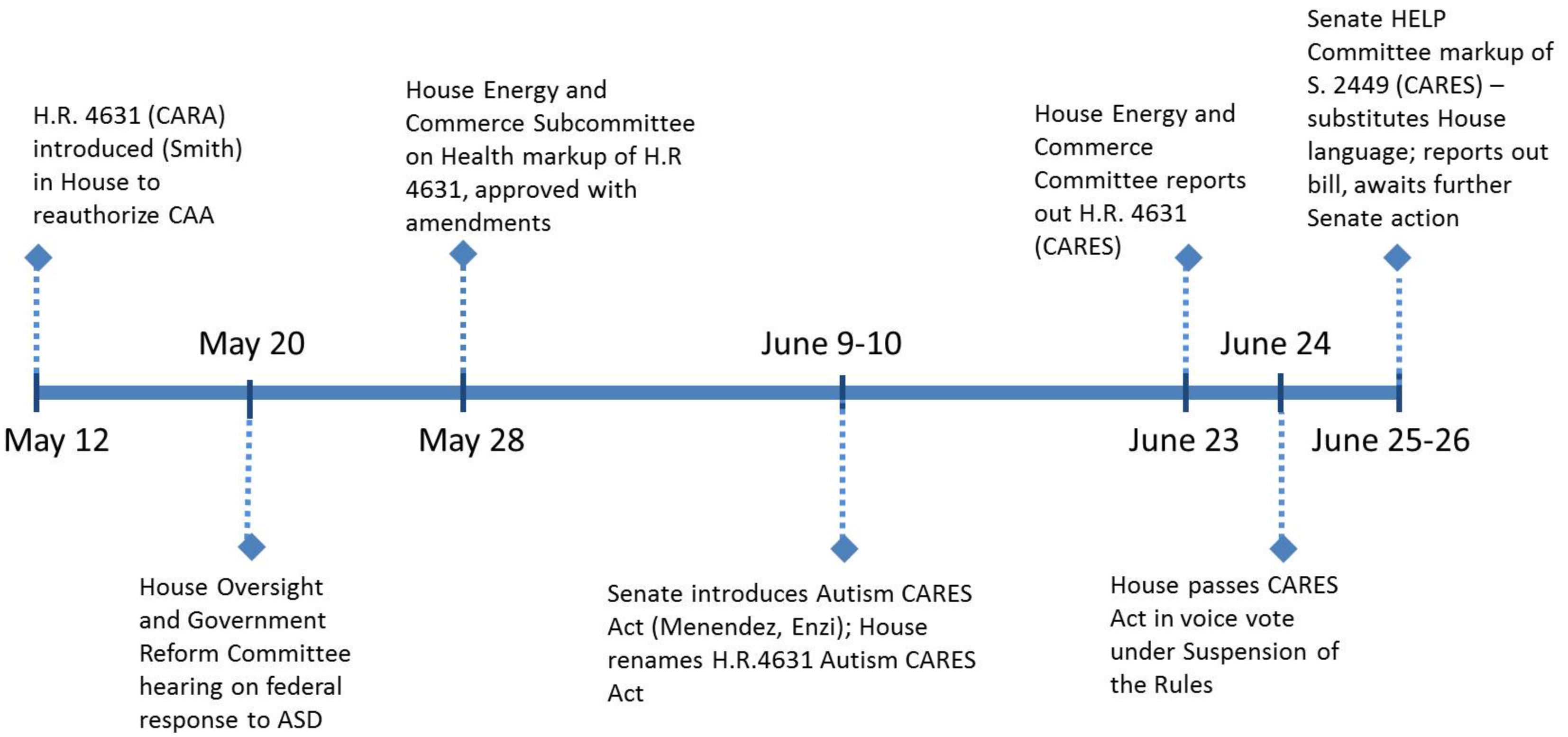
What is Next for the IACC?

The Combating Autism Reauthorization Act (CARA) of 2011 (P.L. 112-32) expires on September 3, 2014

- Without a new reauthorization, the IACC is scheduled to sunset on September 30, 2014
- Current IACC member terms expire on September 30, 2014
- If there is a reauthorization before September 30, 2014, the committee will not sunset (i.e., cease to exist), but current member terms will expire
- The next steps will depend on the provisions of the reauthorization
- If reauthorized, the IACC will be re-formed under the new law, with an open call for nominations from the public for new potential public members
- Members will be selected by the official authorized to make the appointments (the HHS Secretary, or any other person designated in the law)

INTERAGENCY AUTISM COORDINATING COMMITTEE

Autism CARES Legislation Timeline



May 12

H.R. 4631 (CARA) introduced (Smith) in House to reauthorize CAA

May 20

House Oversight and Government Reform Committee hearing on federal response to ASD

May 28

House Energy and Commerce Subcommittee on Health markup of H.R 4631, approved with amendments

June 9-10

Senate introduces Autism CARES Act (Menendez, Enzi); House renames H.R.4631 Autism CARES Act

June 23

House Energy and Commerce Committee reports out H.R. 4631 (CARES)

June 24

House passes CARES Act in voice vote under Suspension of the Rules

June 25-26

Senate HELP Committee markup of S. 2449 (CARES) – substitutes House language; reports out bill, awaits further Senate action

Autism CARES Legislation

H.R. 4631, S. 2449: The Autism Collaboration, Accountability, Research, Education and Support Act would:

- Reauthorize the IACC and other programs through 2019
- Establish a National Autism Spectrum Disorder Initiative within HHS, led by an official charged with implementation of autism activities and ensuring that HHS activities are not unnecessarily duplicative of other federal Department and agency activities
- Incorporate a greater emphasis on services into various activities of the IACC (e.g., Strategic Plan)
- Provide further specification for membership
- Incorporate a significant emphasis on adults and transitioning youth services into the Report to Congress

World Health Assembly Resolution

Comprehensive and coordinated efforts for the management of autism spectrum disorders

May 24, 2014

- Co-sponsored by over 50 countries and supported by all 194 member states of the WHO
- Briefly describes ASD and key issues for those on the autism spectrum, including healthcare and human rights
- Identifies key challenges and priorities for ASD policy in member states, including healthcare and service provision, and protection of human rights
- Requests the WHO Director-General to engage with and support member states in strengthening their recognition and support for people on the autism spectrum
- Establishes ASD as a global health priority

World Health Assembly Resolution

Executive Board

↔

World Health Assembly

- Work on a report and resolution on ASD began in 2013, led by Bangladesh, with significant contribution from nations including Qatar, India, Albania, and Panama
- The WHA Executive Board (the WHO advisory body composed of 34 elected experts) adopted the resolution In May 2013
- In May 2014, the full WHA, composed of health ministers from around the world, adopted a revised resolution
- The resolution represents a formal commitment from all 194 member states

World Health Assembly Resolution

Member State Priorities:

- Develop and update national ASD policies, strategies, programs, and laws, as a part of multisectoral and comprehensive plans to address mental health conditions and developmental disabilities
- Increase healthcare and social service capacity and infrastructure, focusing on community-based services
- Support research, data gathering/surveillance efforts, awareness campaigns and efforts to protect human rights and dignity
- Increase family support, integration of adults with ASD
- Reduce disparities and strengthen international collaboration

World Health Assembly Resolution

Requests to Director-General:

- Work with member states to support implementation efforts and collaboration
- Facilitate resource mobilization for challenged areas
- Implement changes to scale-up care for those with ASD
- Monitor and report on progress

Co-occurring Conditions Workshop

Tuesday, September 23, 2014

Porter Neuroscience Center, NIH

Focus on under-recognized co-occurring health conditions in children and adults with ASD and how the IACC can support research and community/provider awareness, and foster development of clinical practice guidelines in areas where they are needed.

Panel 1	Overview of co-occurring conditions in children and adults with ASD
Panel 2	Psychiatric disorders
Panel 3	Sleep and neurological disorders
Panel 4	Metabolic and immune disorders

Meeting of the IACC

Morning Agenda - continued

9:30 AM **Science Update**

Thomas Insel, M.D.
Director, NIMH and Chair, IACC

9:45 **Neuroimaging the Full Spectrum of Autism**
David G. Amaral, Ph.D.
Director of Research, UC Davis MIND Institute

Meeting of the IACC

Science Update

Thomas R. Insel, M.D.
Director, National Institute of Mental Health and Chair, IACC
IACC Full Committee Meeting – July 8, 2014

Q1. When should I be concerned?

CHILD DEVELOPMENT

June 30, 2014

Limited fine motor and grasping skills in 6-month-old infants at high risk for autism

Libertus K, Sheperd KA, Ross SW, Landa RJ

Autism Research and Treatment

June 22, 2014

Computer vision tools for low-cost and non-invasive measurement of autism-related behaviors in infants

Hasehmi J, Tepper M, Spina TV, Esler A, Morellas V, Papanikolopoulos N, Egger H, Dawson G, Sapiro G

Journal of Autism and Developmental Disorders

Jun 27, 2014

Brief Report: Assessment of Early Sensory Processing in Infants at High-Risk of Autism Spectrum Disorder

Germani T, Zwaigenbaum L, Bryson S, Brian J, Smith I, Roberts W, Szatmari P, Roncadin C, Sacrey LA, Garon N, Vaillancourt T

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

Q2. How can I understand what is happening?

Translational Psychiatry

May 6, 2014

Network inefficiencies in autism spectrum disorder at 24 months

Lewis JD, Evans AC, Pruett JR, Botteron K, Zwaigenbaum L, Estes A, Gerig G, Collins L, Kostopoulos P, McKinstry R, Dager S, Paterson S,Schultz RT, Styner M, Hazlett H, Piven J

Molecular Psychiatry

June 3, 2014

Elevated fetal steroidogenic activity in autism

Baron-Cohen S, Auyeung B, Nørgaard-Pedersen B, Hougaard DM, Abdallah MW, Melgaard L, Cohen AS, Chakrabarti B, Ruta L, Lombardo MV.

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

June 23, 2014

Autism spectrum disorders and race, ethnicity, and nativity: a population-based study

Becerra TA, von Ehrenstein OS, Heck JE, Olsen J, Arah OA, Jeste SS, Rodriguez M, Ritz B

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

Q3. What caused this to happen and can it be prevented?

ehp ENVIRONMENTAL HEALTH PERSPECTIVES

June 23, 2014

Neurodevelopmental disorders and prenatal residential proximity to agricultural pesticides: The CHARGE study

Shelton JF, Geraghty EM, Tancredi DJ, Delwiche LD, Schmidt RJ, Ritz B, Hansen RL, Hertz-Picciotto I

JAMA®
The Journal of the American Medical Association

May 7, 2014

The familial risk of autism

Sandin S, Lichtenstein P, Kuja-Halkola R, Larsson H, Hultman CM, Reichenberg A

nature genetics

May 25, 2014

Brain-expressed exons under purifying selection are enriched for de novo mutations in autism spectrum disorder

Uddin M, Tammimies K, Pellecchia G, Alipanahi B, Hu P, Wang Z, Pinto D, Lau L, Nalpathamkalam T, Marshall CR, Blencowe BJ, Frey BJ, Merico D, Yuen RK, Scherer SW

Q4. Which treatments and interventions will help?

BMC Neurology

May 15, 2014

Corticosteroid therapy in regressive autism: a retrospective study of effects on the Frequency Modulated Auditory Evoked Response (FMAER), language, and behavior

Duffy FH, Shankardass A, McAnulty GB, Eksioglu YZ, Coulter D, Rotenberg A, Als H

Journal of the American Academy of Child & Adolescent Psychiatry

June 2014

Communication interventions for minimally verbal children with autism: a sequential multiple assignment randomized trial

Kasari C, Kaiser A, Goods K, Nietfeld J, Mathy P, Landa R, Murphy S, Almirall D

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

June 23, 2014

Caregiver-Mediated Intervention for Low-Resourced Preschoolers With Autism: An RCT

Kasari C, Lawton K, Shih W, Barker TV, Landa R, Lord C, Orlich F, King B, Wetherby A, Senturk D

INTERAGENCY AUTISM COORDINATING COMMITTEE

Q5. Where can I turn for services?

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

May 26, 2014

Care Coordination and Unmet Specialty Care Among Children With Special Health Care Needs
Arauz Boudreau A, Goodman E, Kurowski D, Perrin JM, Cooley WC, Kuhlthau K

JAMA Pediatrics
Formerly Archives of Pediatrics & Adolescent Medicine

June 9, 2014

Costs of Autism Spectrum Disorders in the United Kingdom and the United States
Buescher AV, Cidav Z, Knapp M, Mandell DS

The International Journal of Research and Practice Volume 18 Number 1 January 2014
autism

June 9, 2014

Comparing service use and costs among adolescents with autism spectrum disorders, special needs and typical development
Barrett B, Mosweu I, Jones CR, Charman T, Baird G, Simonoff E, Pickles A, Happé F, Byford S

IACC
INTERAGENCY AUTISM COORDINATING COMMITTEE

Q6. What does the future hold, particularly for adults?

The International Journal of Research and Practice Volume 18 Number 1 January 2014
autism

April 29, 2014

The cost-effectiveness of supported employment for adults with autism in the United Kingdom
Mavranezouli I, Megnin-Viggars O, Cheema N, Howlin P, Baron-Cohen S, Pilling S

June 10, 2014

Depression and its measurement in verbal adolescents and adults with autism spectrum disorder
Gotham K, Unruh K, Lord C

Journal of Autism and Developmental Disorders

June 11, 2014

Adult Outcomes in Autism: Community Inclusion and Living Skills
Gray KM, Keating CM, Taffe JR, Brereton AV, Einfeld SL, Reardon TC, Tonge BJ

Q7. What other infrastructure and surveillance needs must be met?

JAMA Psychiatry
Formerly Archives of General Psychiatry

June 18, 2014

Evidence of Reproductive Stoppage in Families With Autism Spectrum Disorder: A Large, Population-Based Cohort Study
Hoffmann TJ, Windham GC, Anderson M, Croen LA, Grether JK, Risch N

Molecular Psychiatry

June 19, 2014

The autism brain imaging data exchange: towards a large-scale evaluation of the intrinsic brain architecture in autism

Di Martino A, Yan CG, Li Q, Denio E, Castellanos FX, Alaerts K, Anderson JS, Assaf M, Bookheimer SY, Dapretto M, Deen B, Delmonte S, Dinstein I, Ertl-Wagner B, Fair DA, Gallagher L, Kennedy DP, Keown CL, Keysers C, Lainhart JE, Lord C, Luna B, Menon V, Minshew NJ, Monk CS, Mueller S, Müller RA, Nebel MB, Nigg JT, O'Hearn K, Pelphrey KA, Peltier SJ, Rudie JD, Sunaert S, Thioux M, Tyszka JM, Uddin LQ, Verhoeven JS, Wenderoth N, Wiggins JL, Mostofsky SH, Milham MPHoffmann TJ, Windham GC, Anderson M, Croen LA, Grether JK, Risch N

Neuroimaging the Full Spectrum of Autism

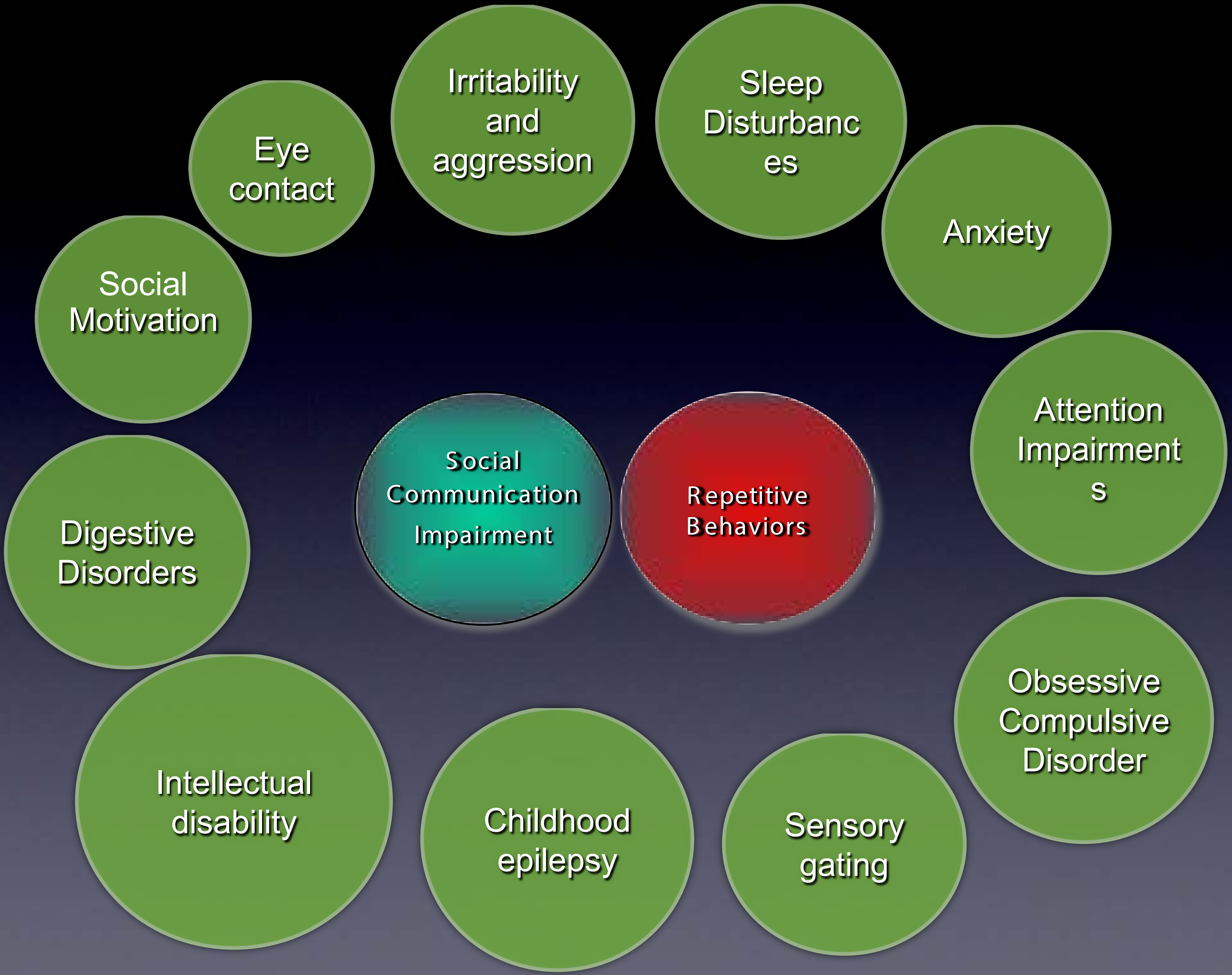
David G. Amaral
Director of Research
UC Davis MIND Institute

Neuroimaging the Full Spectrum of Autism

David G. Amaral, Ph.D.
dgamaral@ucdavis.edu

The M.I.N.D. Institute,
Dept. of Psychiatry and Behavioral Sciences,
California National Primate
Research Center (CNPRC)
UC Davis

M.I.N.D. INSTITUTE
UC DAVIS



Social Communication Impairment

Repetitive Behaviors

Social Motivation

Eye contact

Irritability and aggression

Sleep Disturbances

Anxiety

Attention Impairments

Obsessive Compulsive Disorder

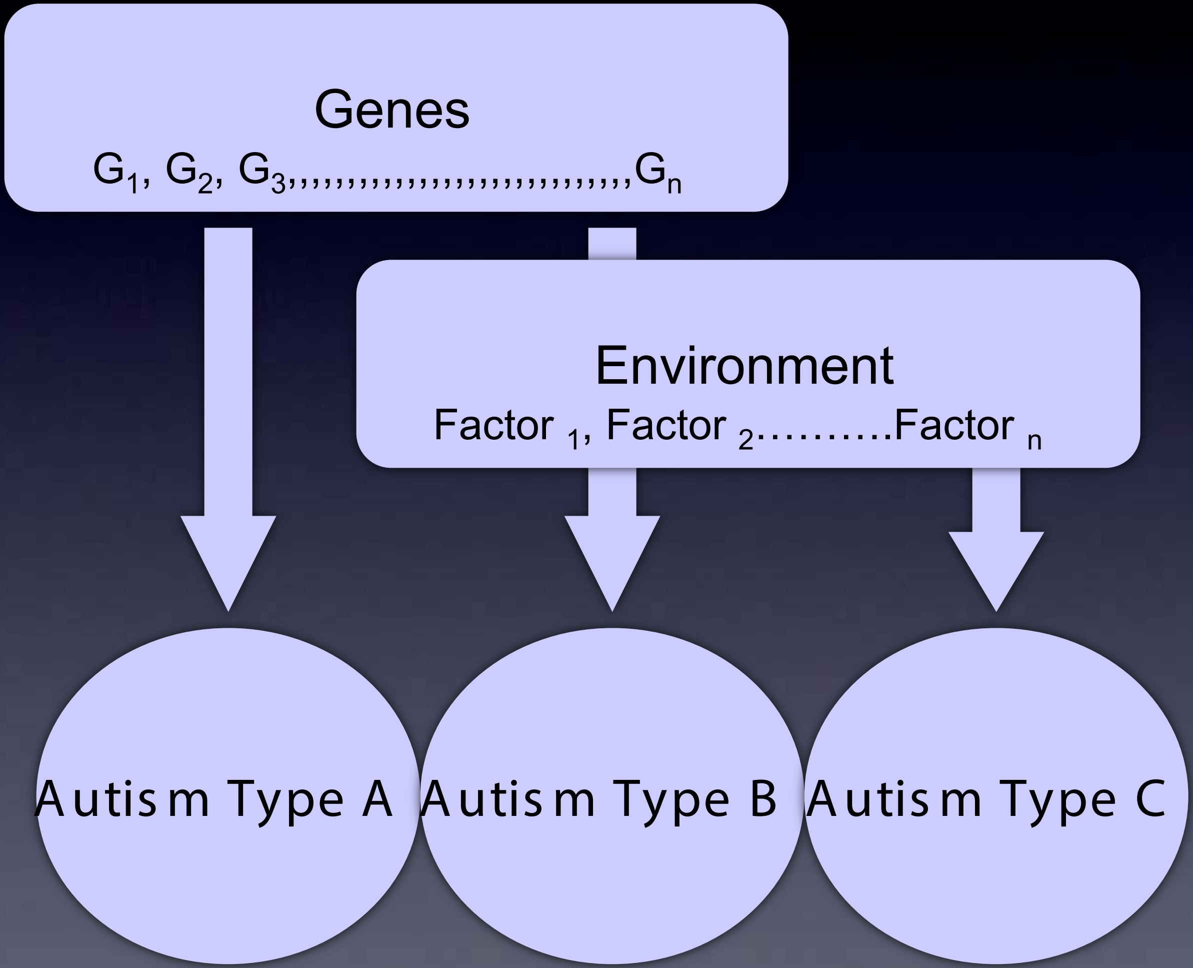
Sensory gating

Childhood epilepsy

Intellectual disability

Digestive Disorders

Heterogeneity of Causes?



Genes

G_1, G_2, G_3,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,G_n

Environment

Factor $_1$, Factor $_2$……….Factor $_n$

Autism Type A

Autism Type B

Autism Type C

Heterogeneity of Causes?

There are many causes of autism and many types of autism?

AutismS not Autism

M.I.N.D. INSTITUTE
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Heterogeneity of Causes?

Magnetic resonance imaging may provide evidence to help define different types of ASD

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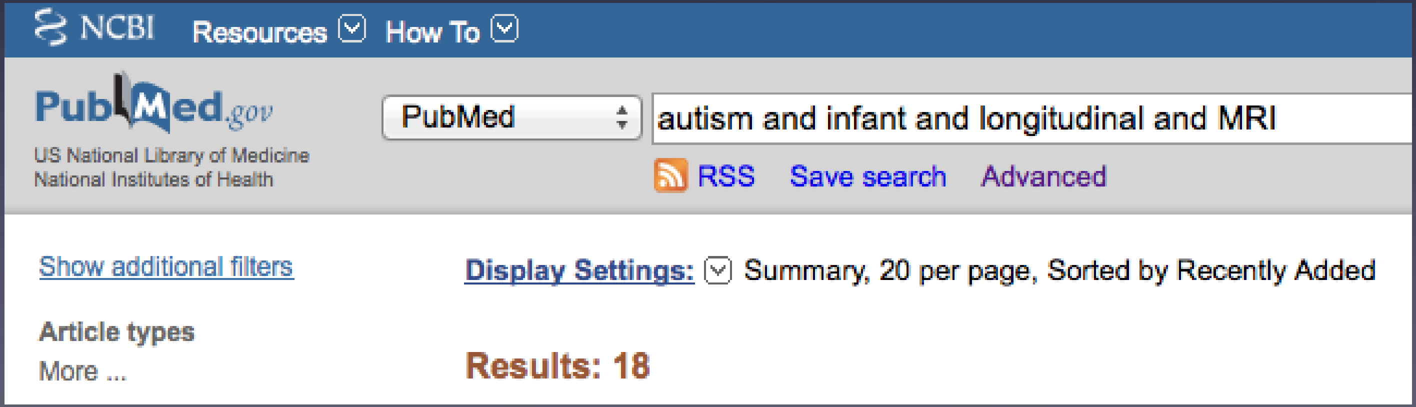
MRI of Autism Spectrum Disorder
Weaknesses of Earlier Studies

- Small sample sizes (dozens instead of hundreds)
- Heterogeneous samples
- Cross-sectional
- Focus on older and higher functioning individuals

There is a scarcity of large-scale, longitudinal neuroimaging studies of infants at all severity levels of autism spectrum disorder

Autism is a neurodevelopmental disorder



autism and infant and longitudinal and MRI

Display Settings: Summary, 20 per page, Sorted by Recently Added

Results: 18

Only a small number of papers have focused on children under age 5

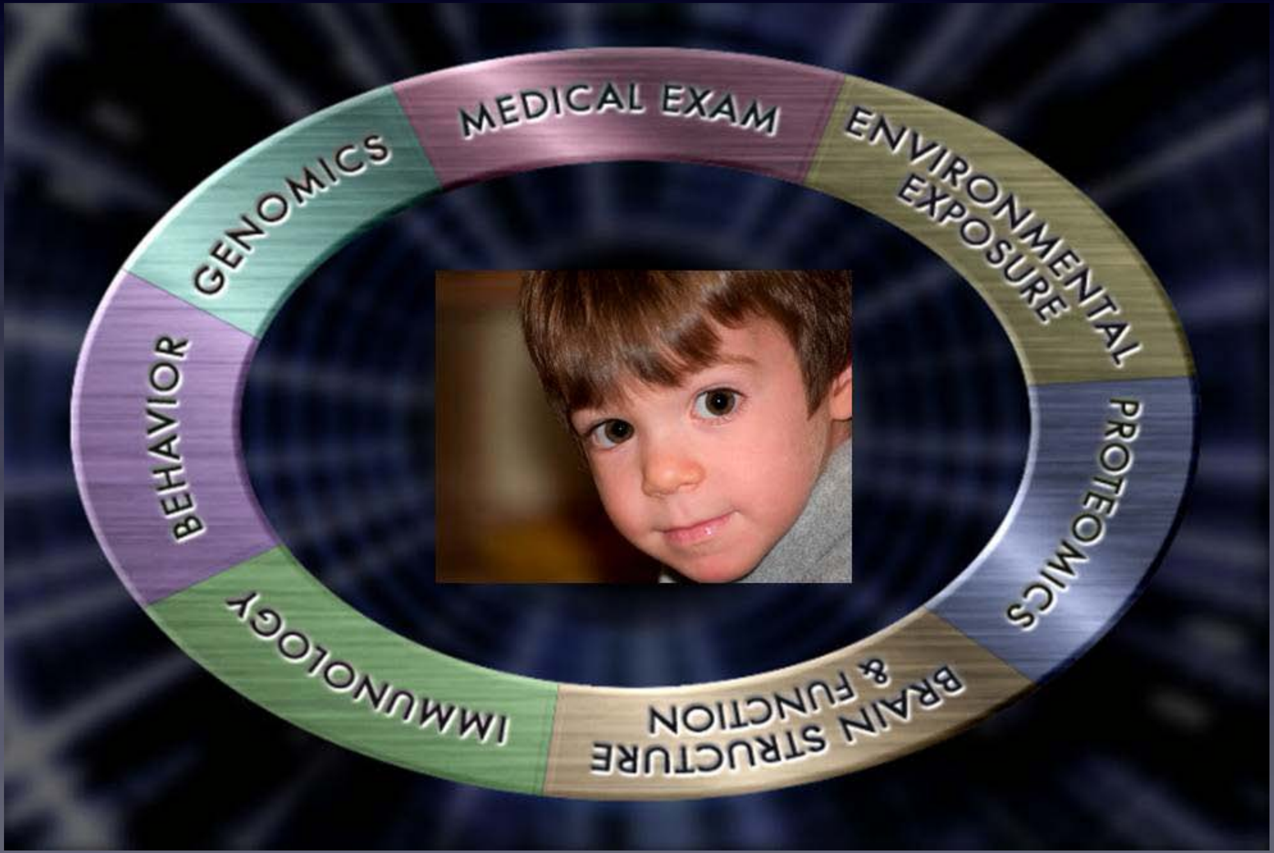
Overarching Hypothesis:

When you study the brains of young children with ASD using MRI, you will see different neurophenotypes.

Autism Phenome Project

Large-scale multidisciplinary project aimed at identifying subtypes of autism

2 to 3.5 year old children, longitudinal assessments



The MIND Institute
Autism Phenome Project (APP)

- Children are recruited between 2 and 3 1/2 years of age.

- Study includes all children with autism with very few exclusions.

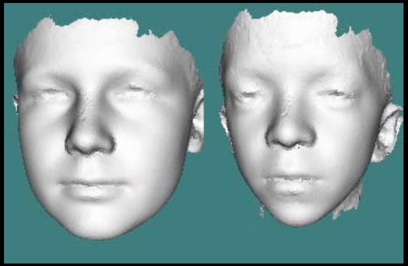
- Both boys and girls are included.

- Age-matched typically developing children serve as controls.

The MIND Institute
Autism Phenome Project (APP)

- The study is longitudinal - children return to the MIND Institute annually for further testing.

- Blood samples are obtained from subjects, siblings and from parents.



Visit 1: Diagnostic Confirmation, Cognitive Testing

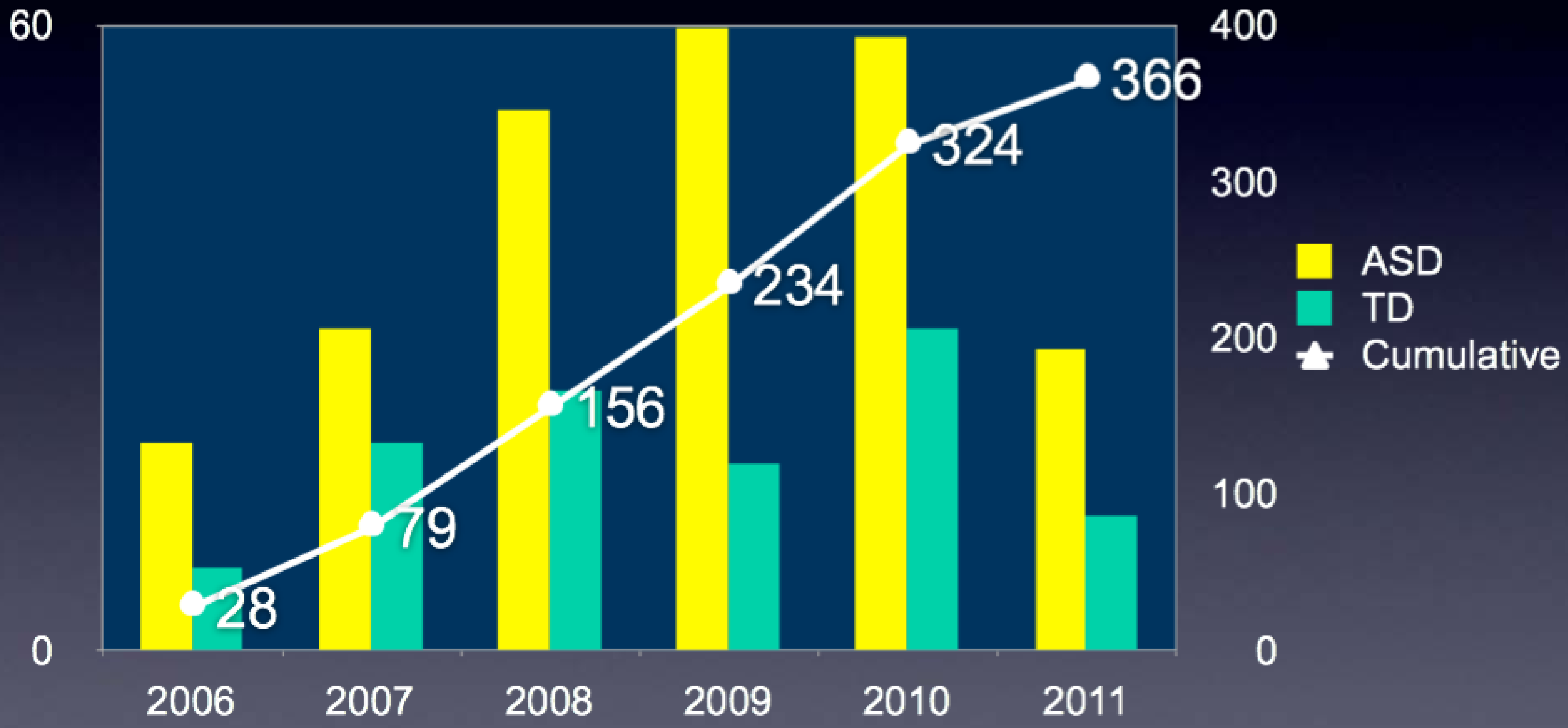
Visit 2: Language Assessment, Imitation, Handedness

Visit 3: Medical Exam, 3-D Photograph, Vitals Measurement and Blood Draw

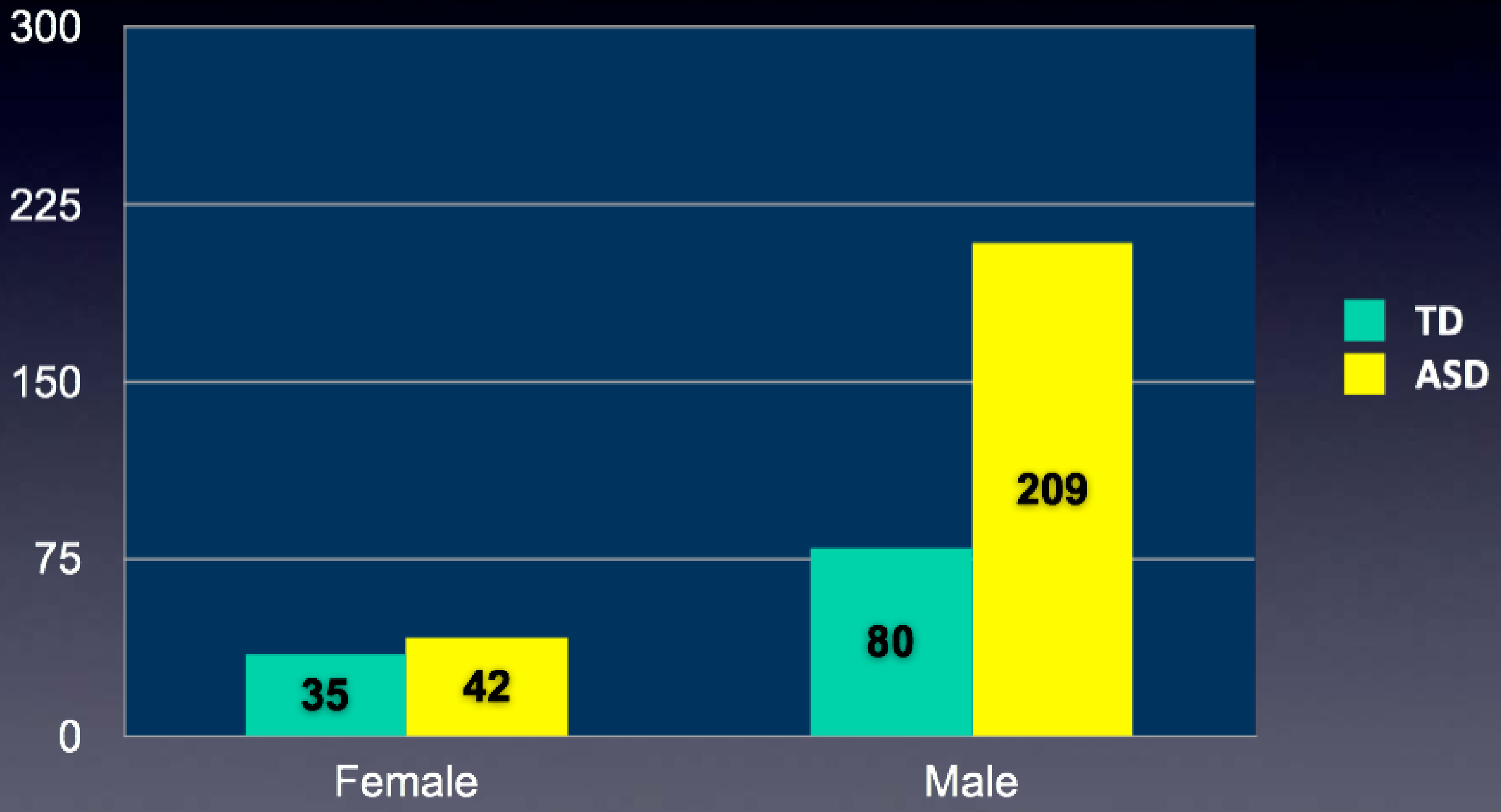
Visit 4: Nighttime MRI

Visit 5: EEG/ERP

Autism Phenome Project Background
Number of Families Participating



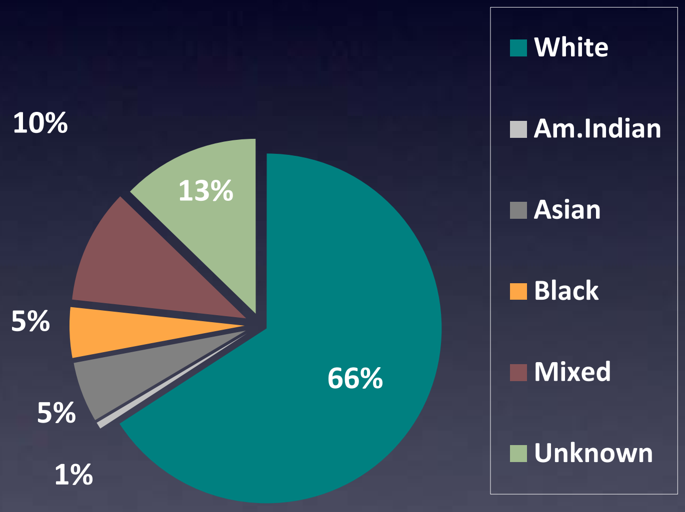
Autism Phenome Project Background Male and Female Participants



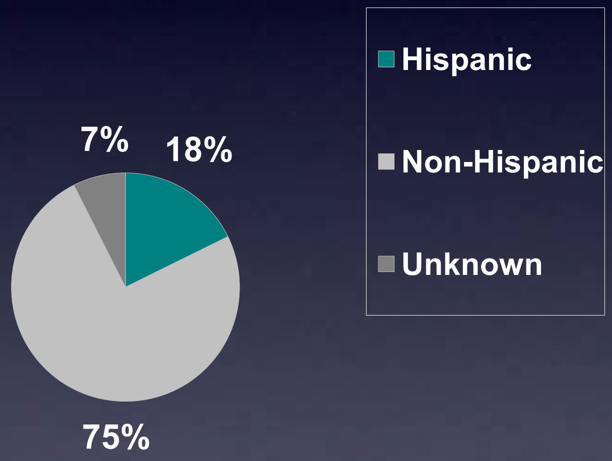
Autism Phenome Project Background
Age at Entry into Study

	Male		Female	
	ASD	**TD**	**ASD**	**TD**
N	209	80	42	35
Average Age (yrs)	2.97	2.86	3.05	2.89
Std Dev	0.50	0.55	0.43	0.56

Autism Phenome Project Background



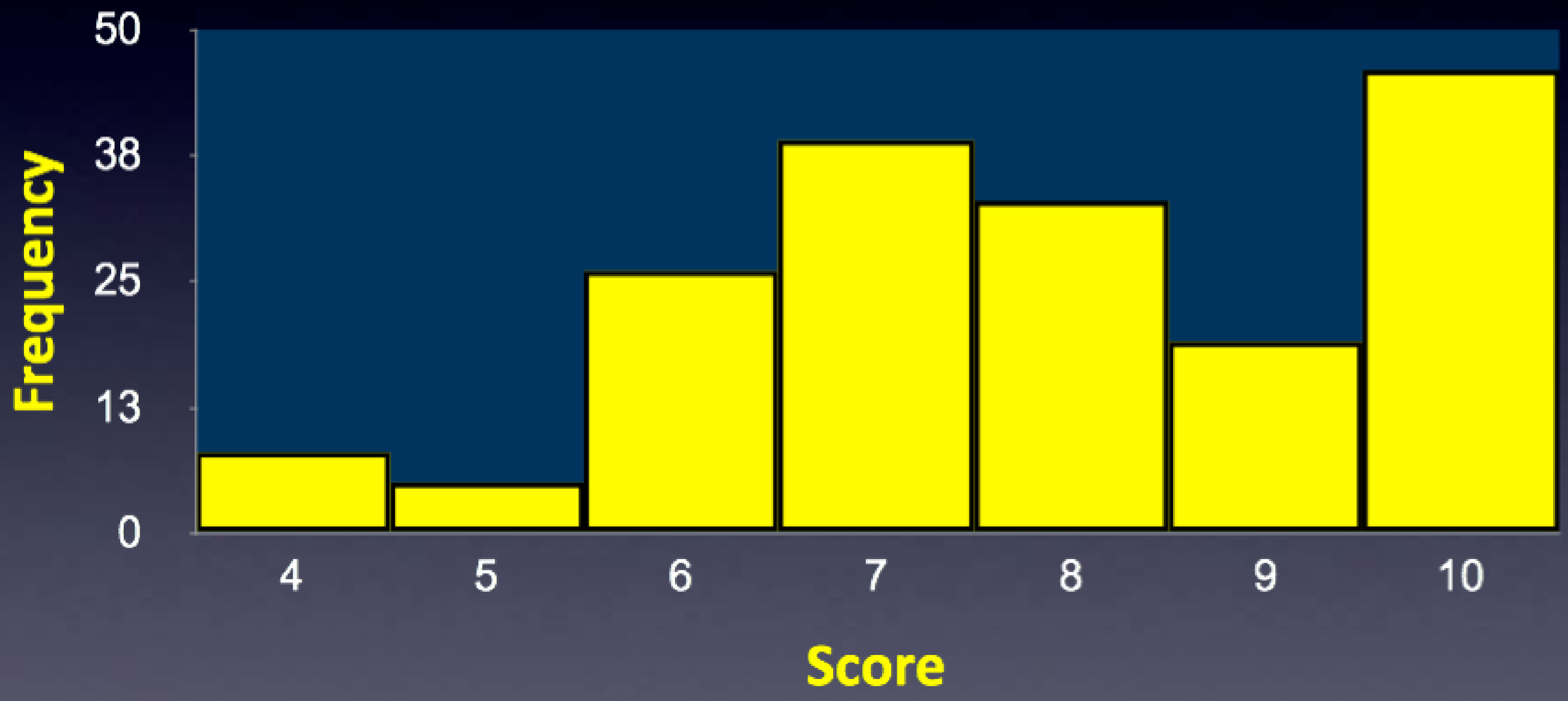
Race



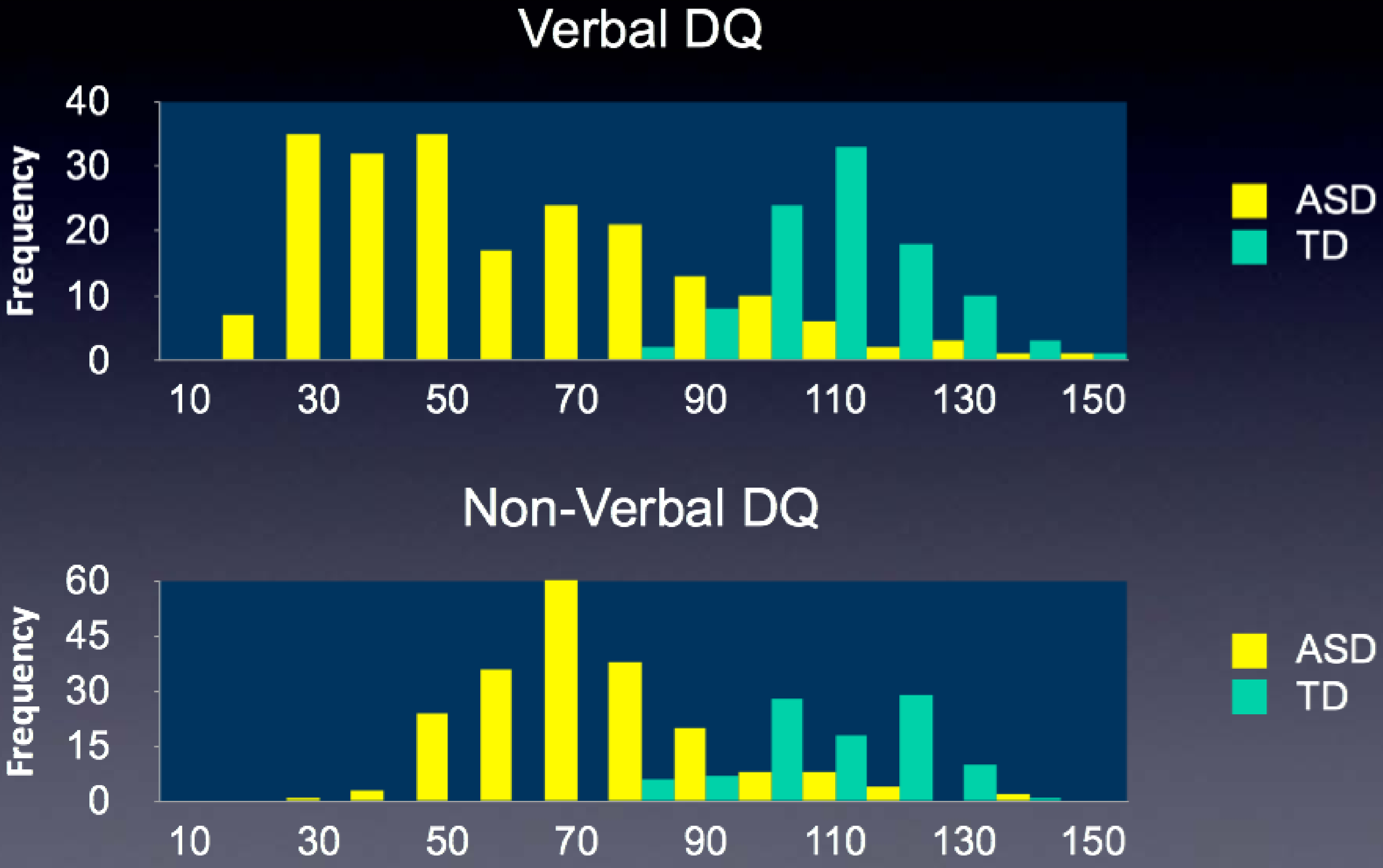
Ethnicity

Autism Severity Score

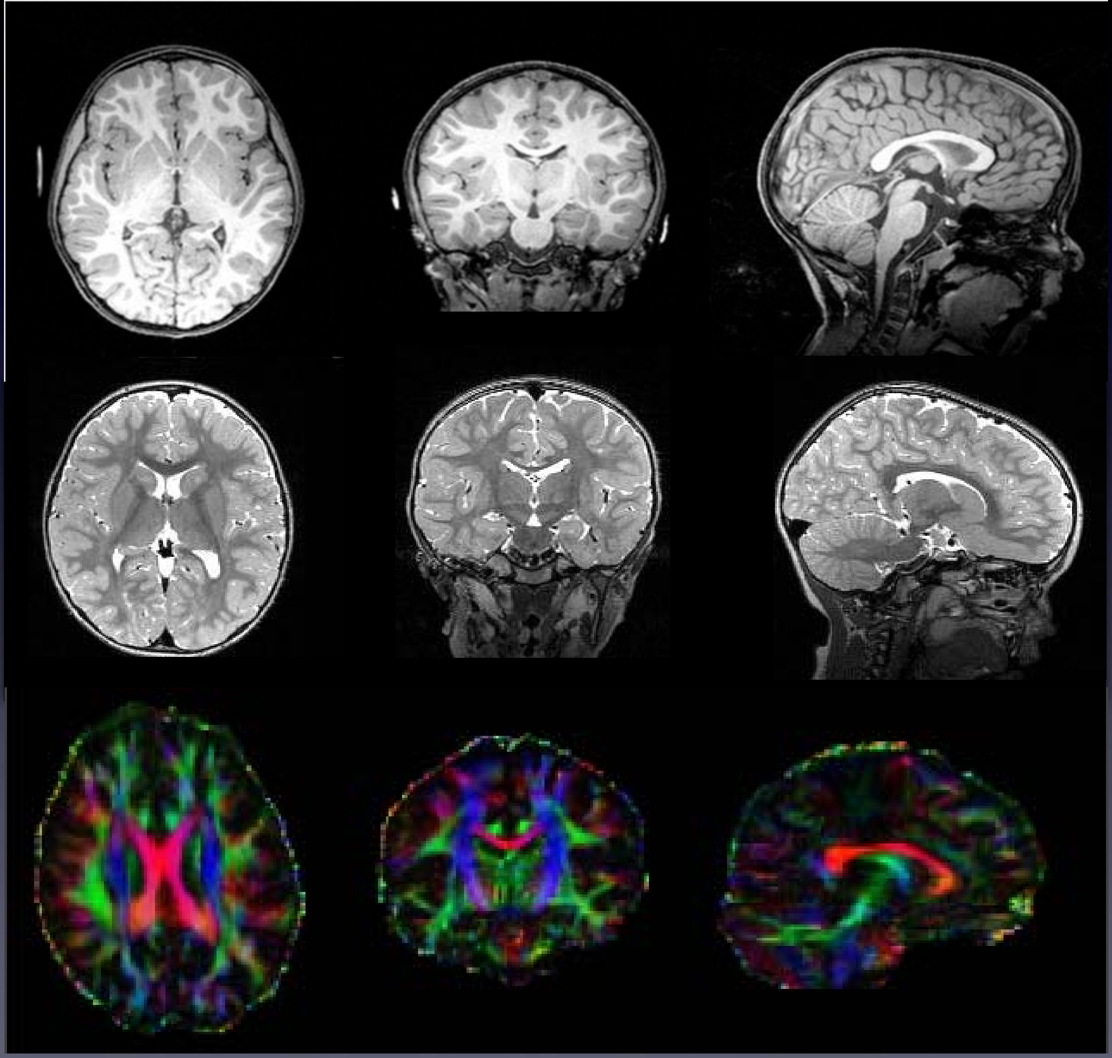
severity



Developmental Quotient



Brain Findings



MRI of Young Children

Thomas the Train Mock Session

MRI Practice Kit

MRI of Young Children

MRI Practice Kit

Child-friendly scanning environment

Before

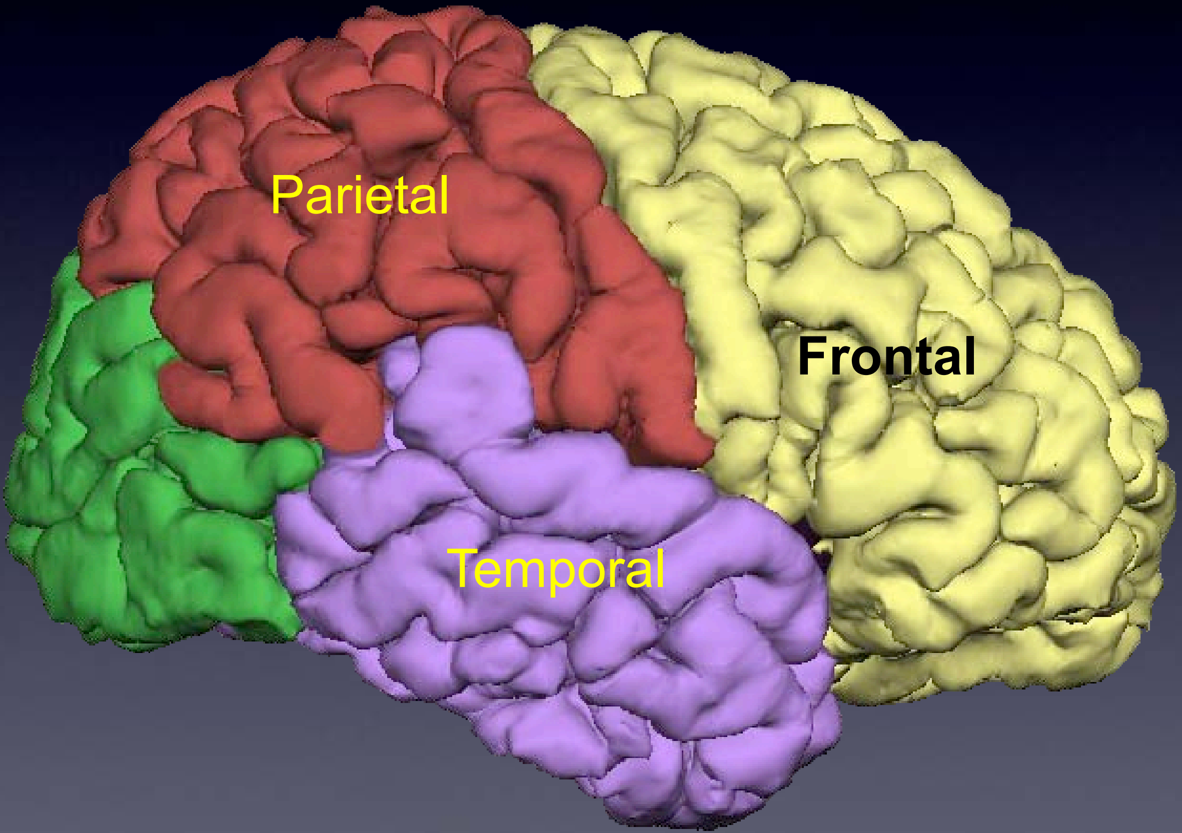
After

Christine Nordahl, Ph.D
and
MRI Team

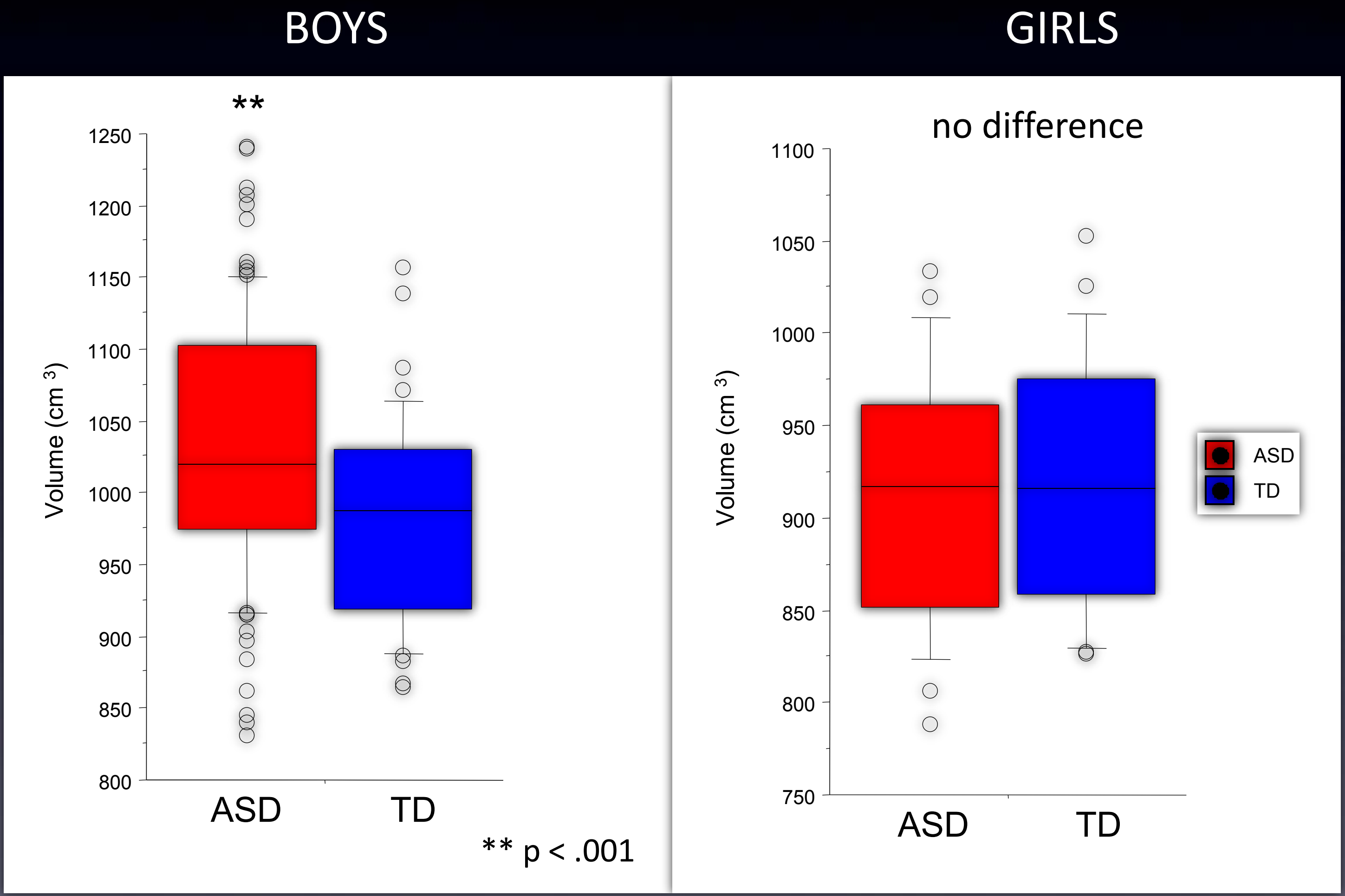
Subjects and Success

	Time 1 38 months		Time 2 51 months		Time 3 64 months	
	M	F	M	F	M	F
ASD	155	34	97	21	68	15
TD	59	31	48	25	39	20
Total	279		191		142	
Success Rate	88%		91%		88%	
Attrition			19%		21%	

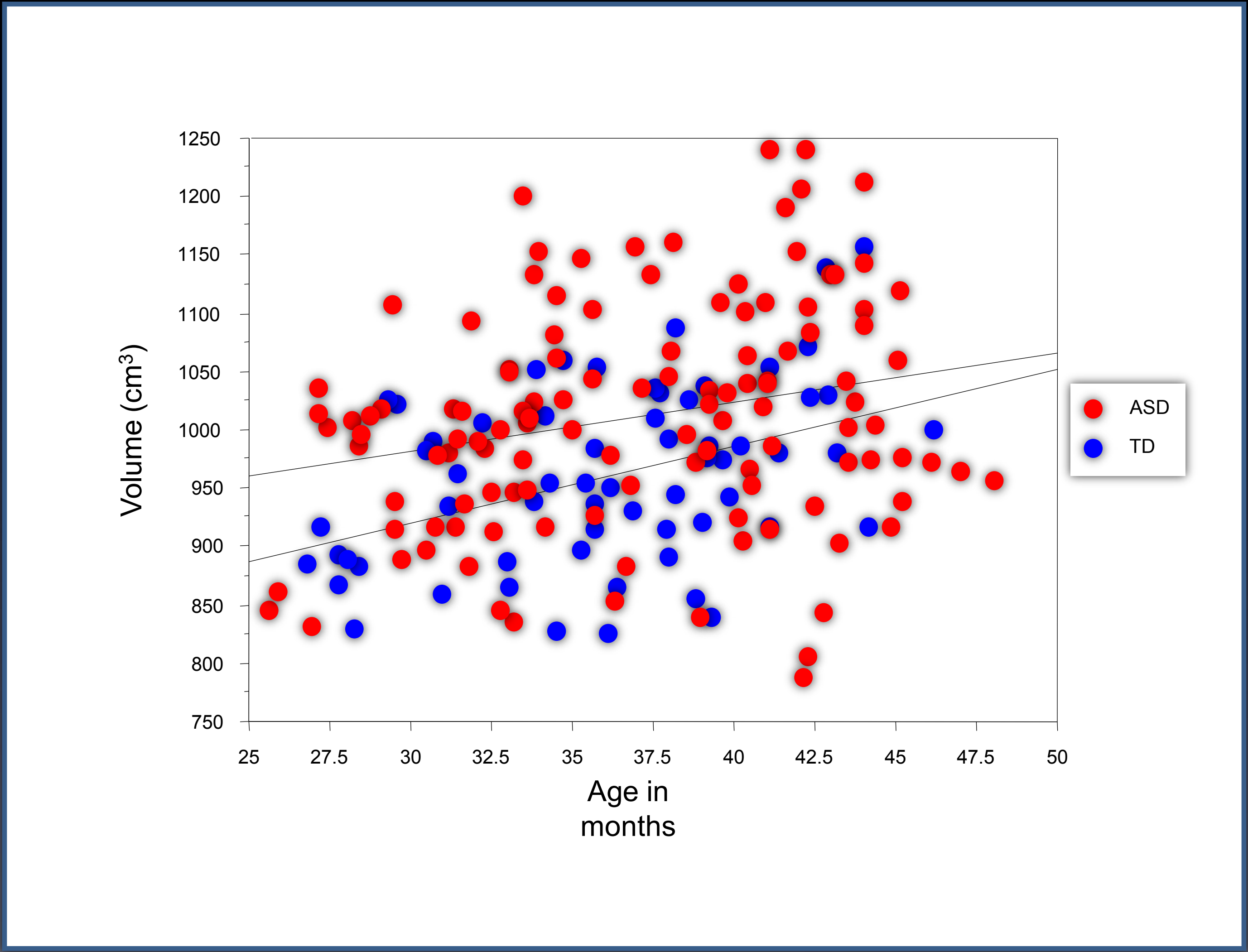
Total Brain Measurements



Total cerebral volume (TCV) is enlarged by 6% in boys with ASD



Total brain size is extremely variable in ASD



Autism Onset and Brain Size

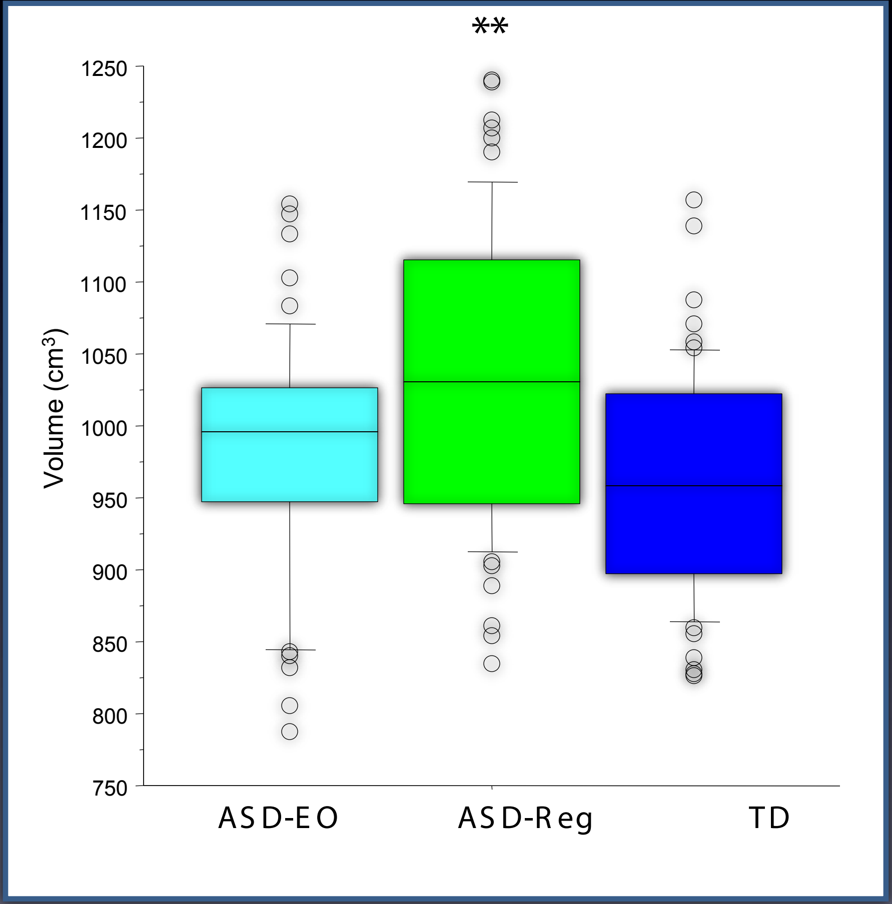
Onset status is based on parent report on ADI-R

Early Onset = 47%

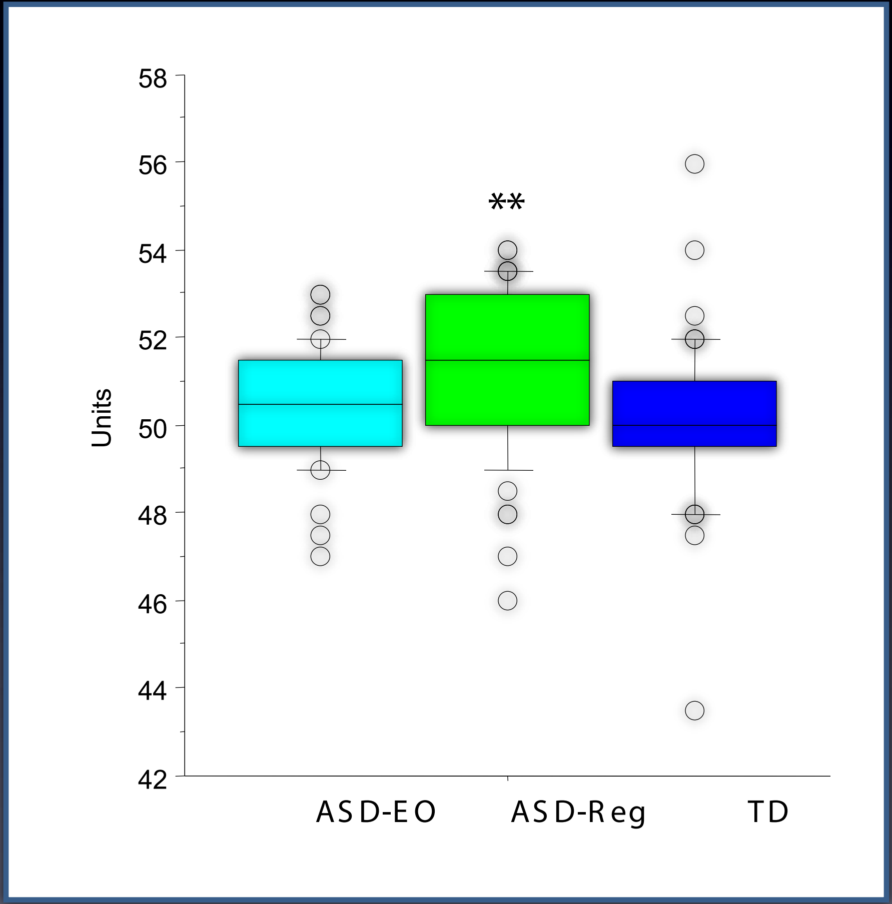
Regression = 53%

ASD children who regressed have enlarged brains

Total Cerebral Volume



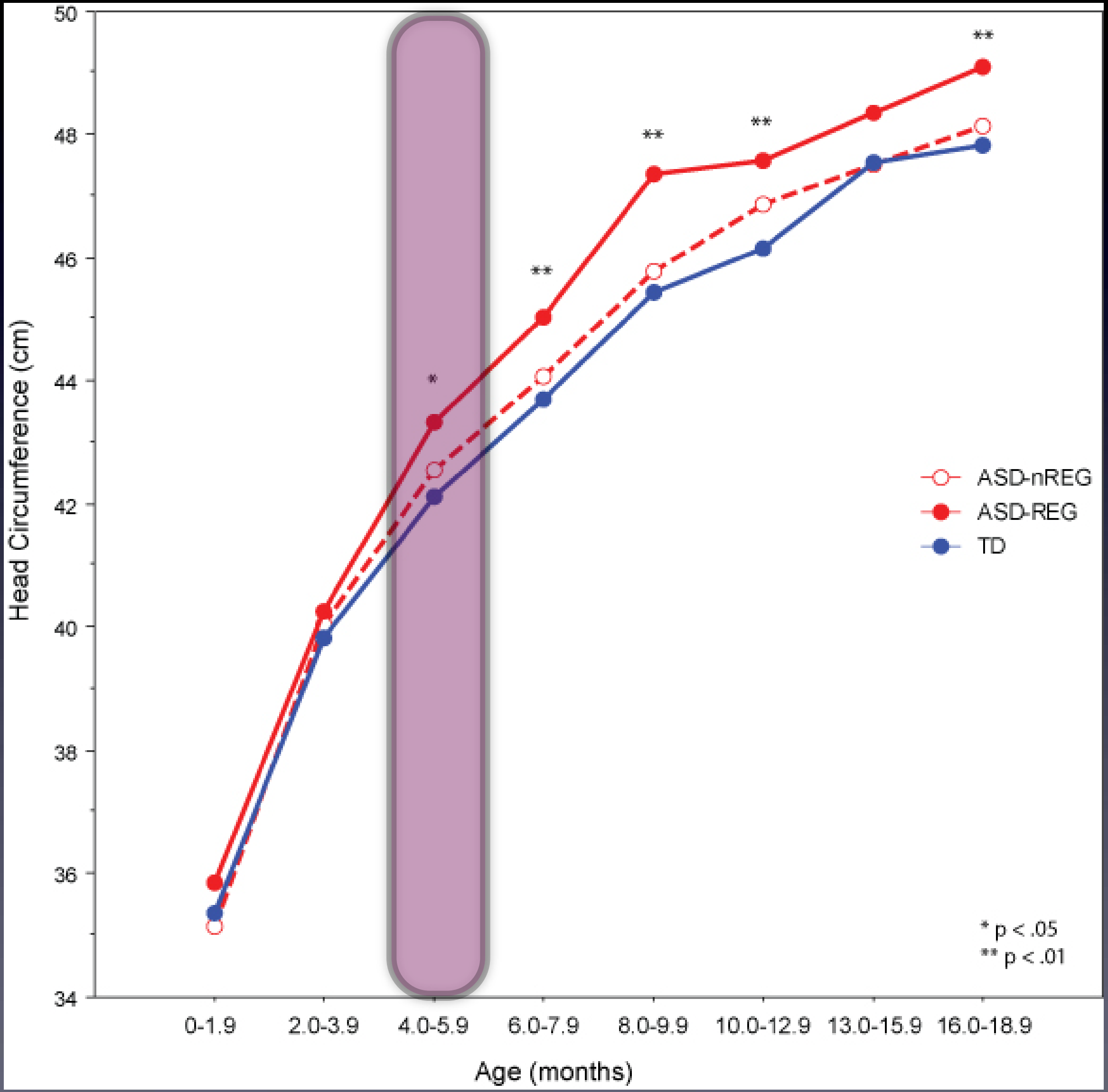
Head Circumference



ANCOVA – age, DQ, gender as covariates
** $p < .01$

ANCOVA – age as covariate
** $p < .01$ ASD-Reg > TD & ASD-EO

Retrospective head circumference shows divergence at 4-6 months



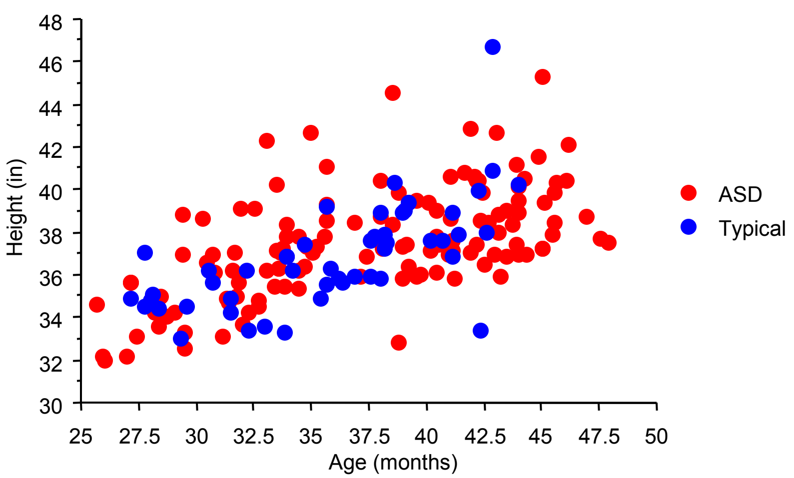
Surface rendering of children's brains

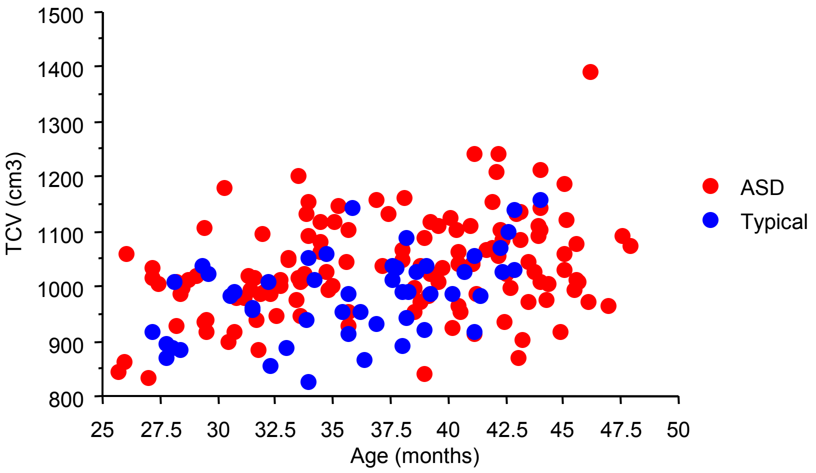
Typical Child
Age 31 months
TCV 981.96

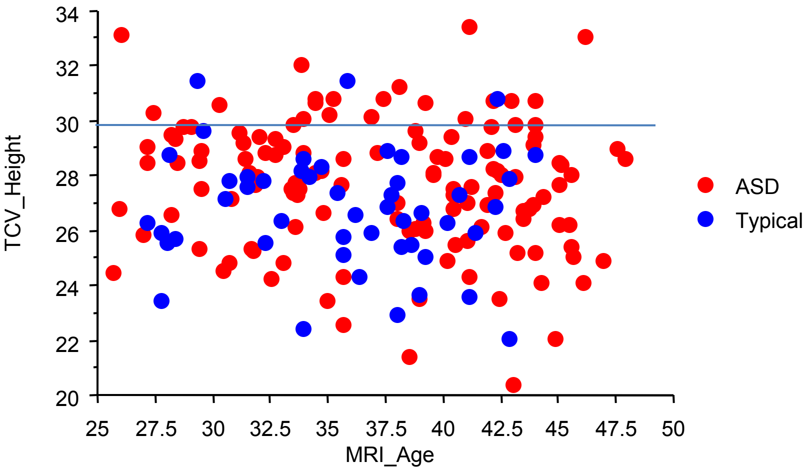
Autism
Early Onset
Age 32 months
TCV 984.57

Autism
Regression
Age 30 months
TCV 1180.98

Relationship of Total Cerebral Volume to Height





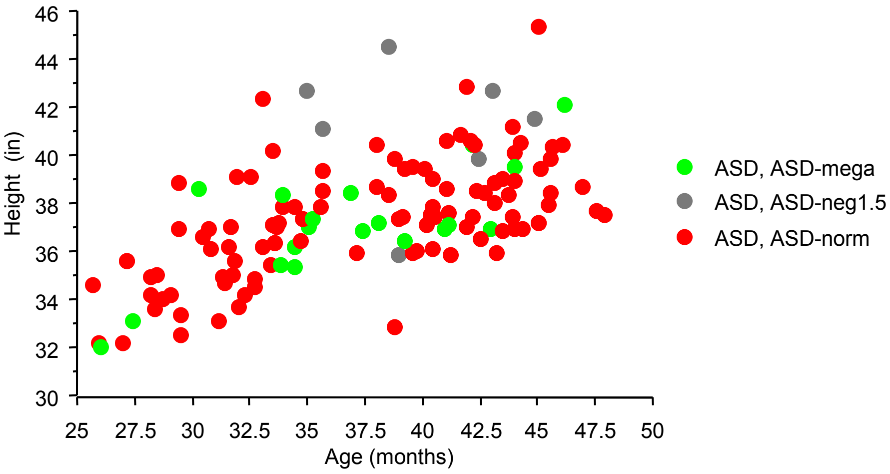


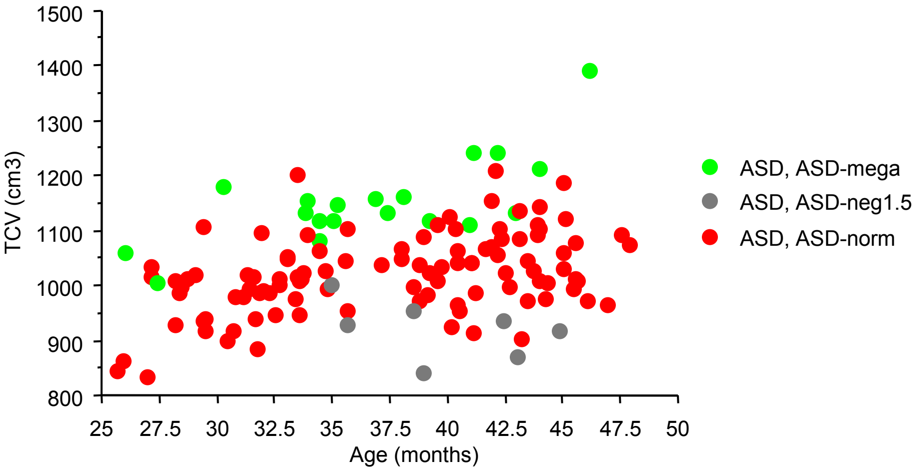
50 TD males
Mean TCV/height ratio 26.8, sd 2.11.
Cutoff for DM is 29.97

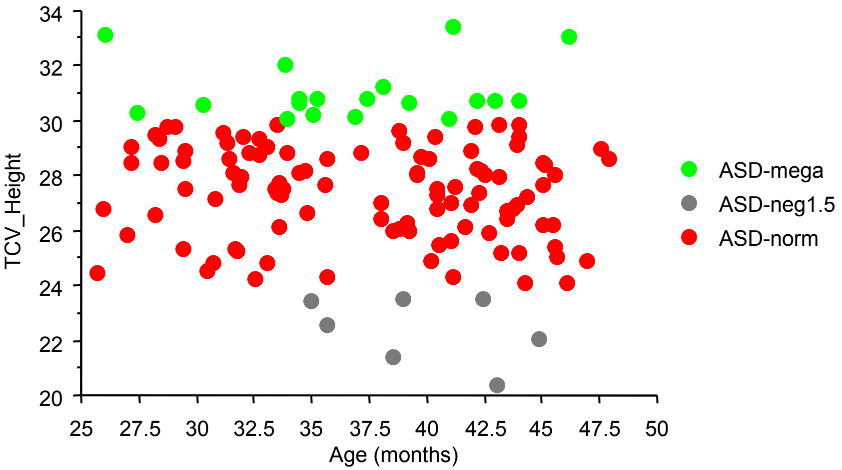
130 ASD males
Mean TCV/height ratio 27.6
19/130 ASD-DM (14.6%)
7/130 ASD-micro (5.4%)

On average, ASD kids are not taller than Typical kids

Relationship of Total Cerebral Volume to Height ASD only







– illustrates where the
Mega subgroups fall on height and TCV

One clear neurophenoptype is Disproportionate Megalencephaly (ASD-DM)

i.e. the ratio of brain volume to height is 1.5 standard deviations above control mean

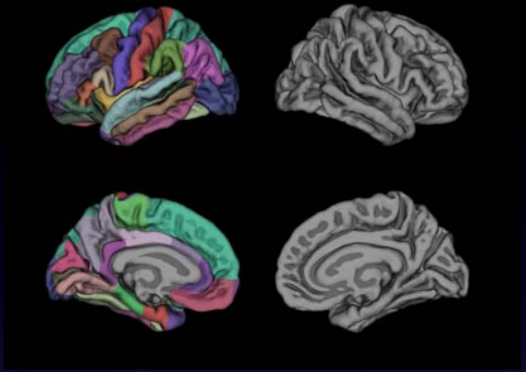
This accounts for 15% of our male, ASD cohort

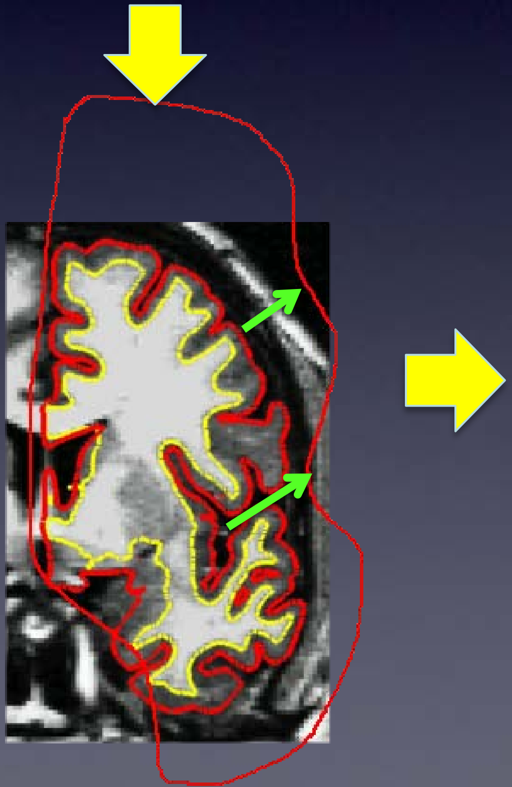
Is the cortex of the brain thicker?

or

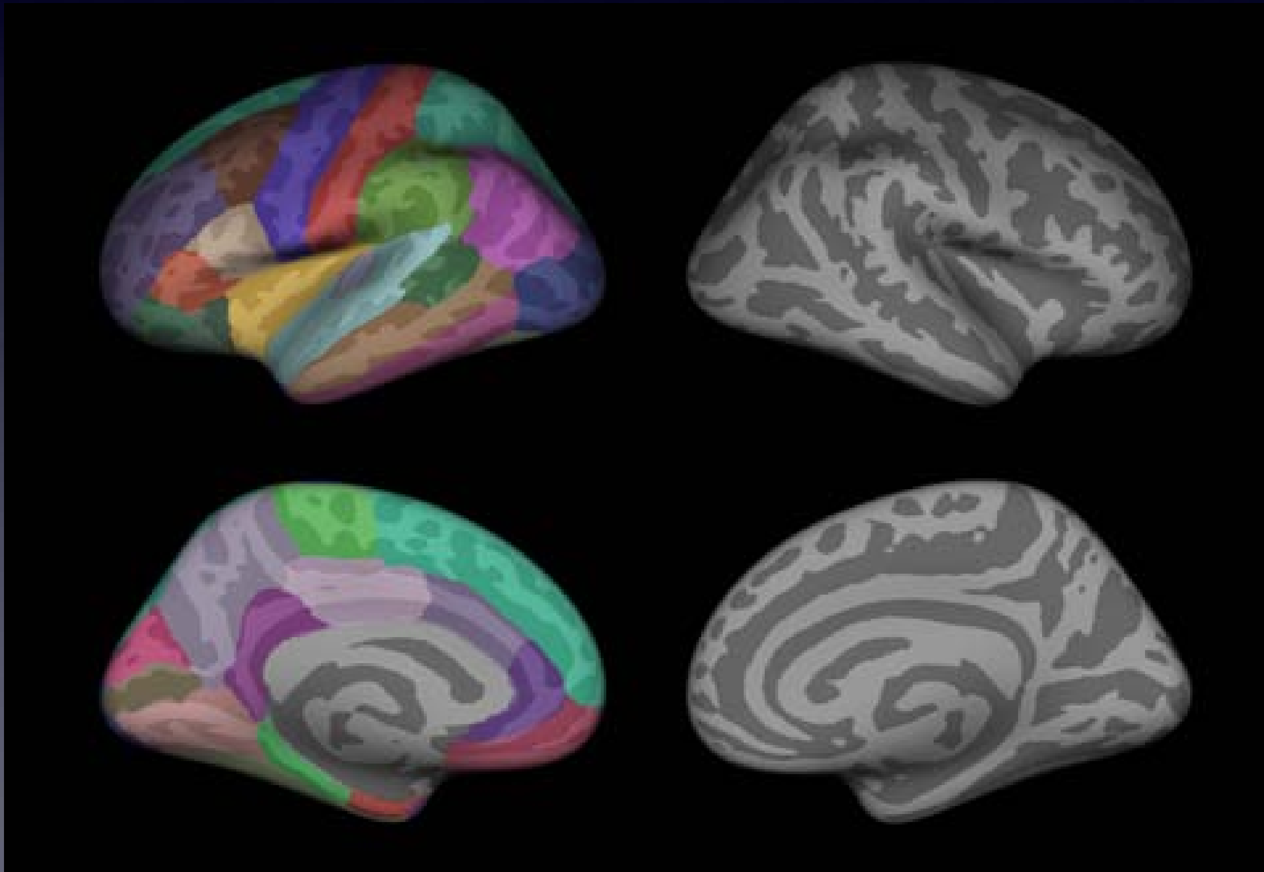
Is there more surface area?

Visualization in Freesurfer

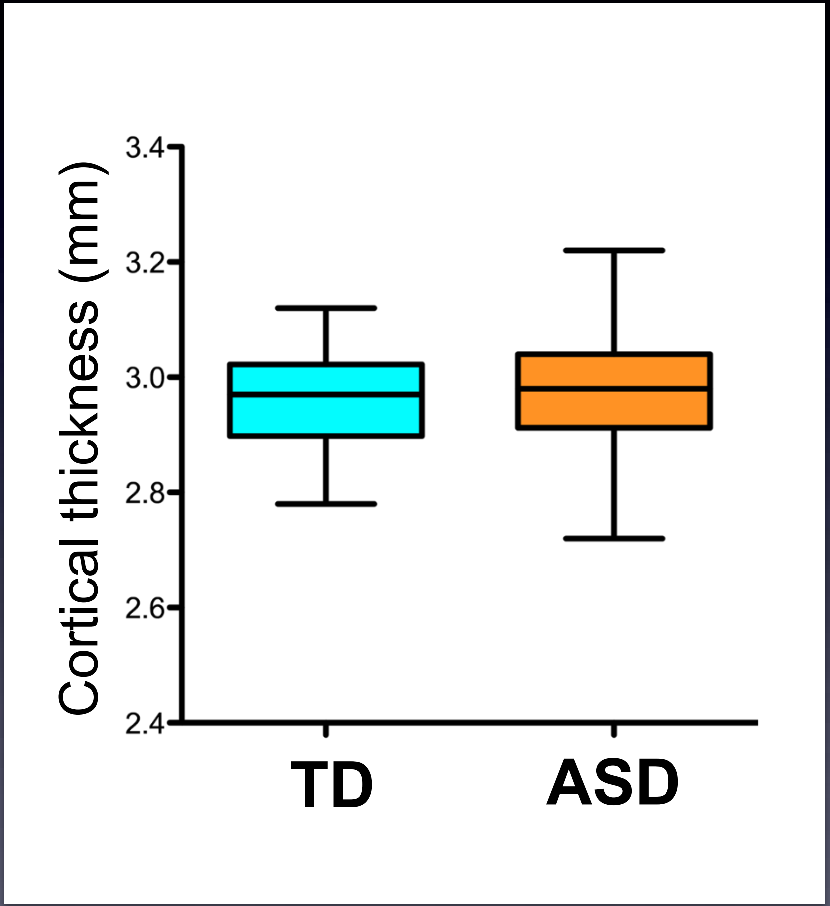




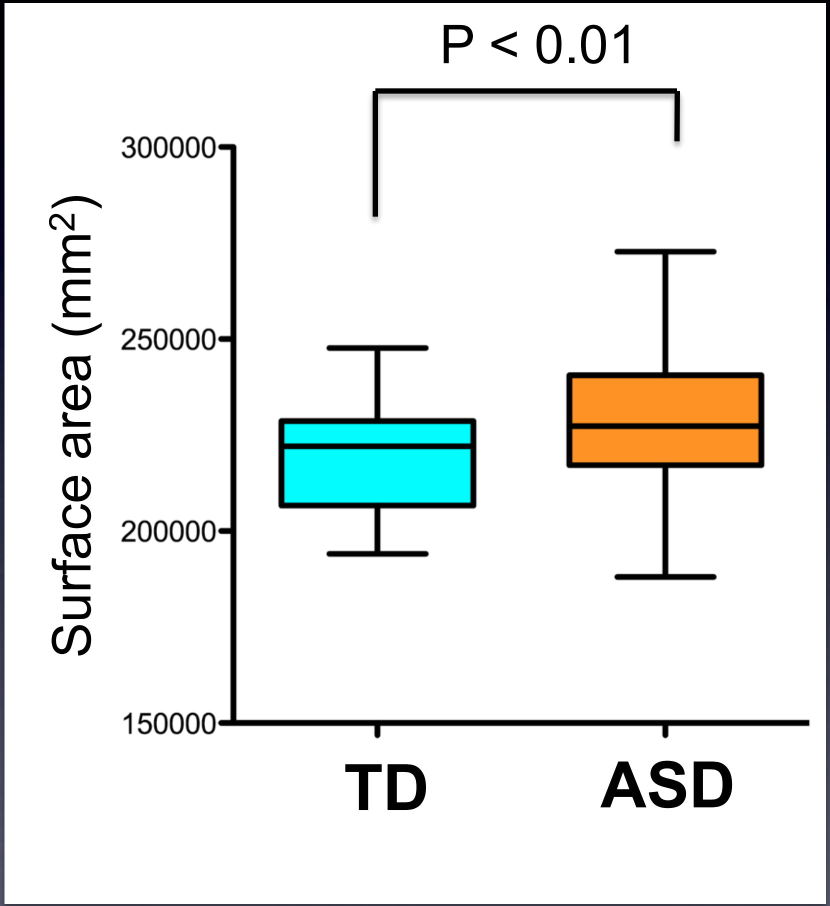
dark grey = sulci; light grey = gyri



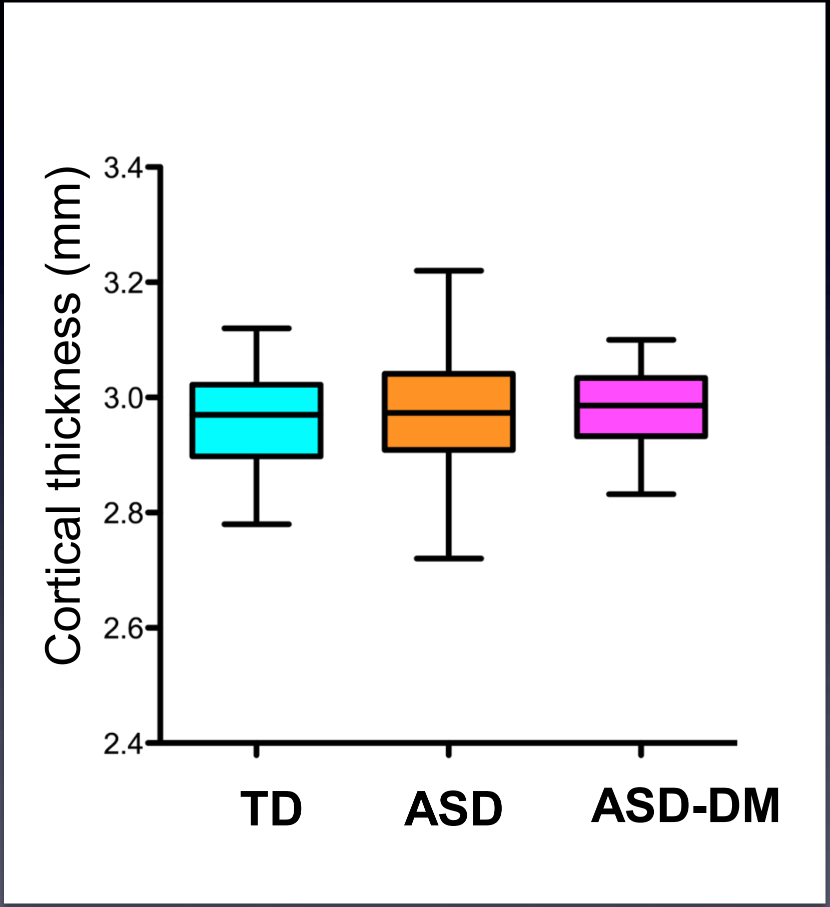
Average of cortical thickness of whole brain



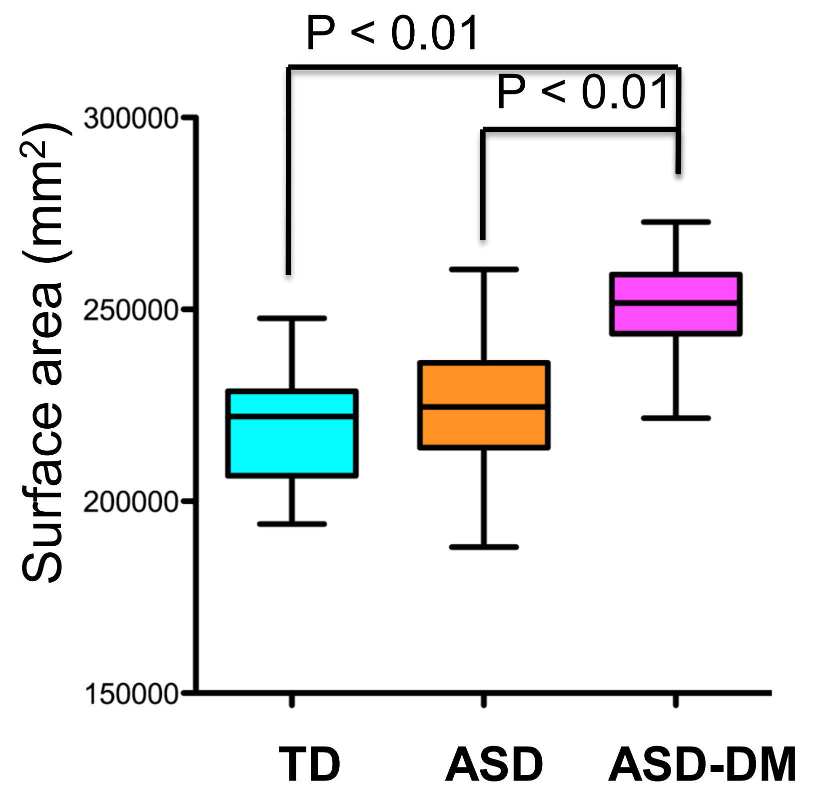
Cortical surface area of whole brain

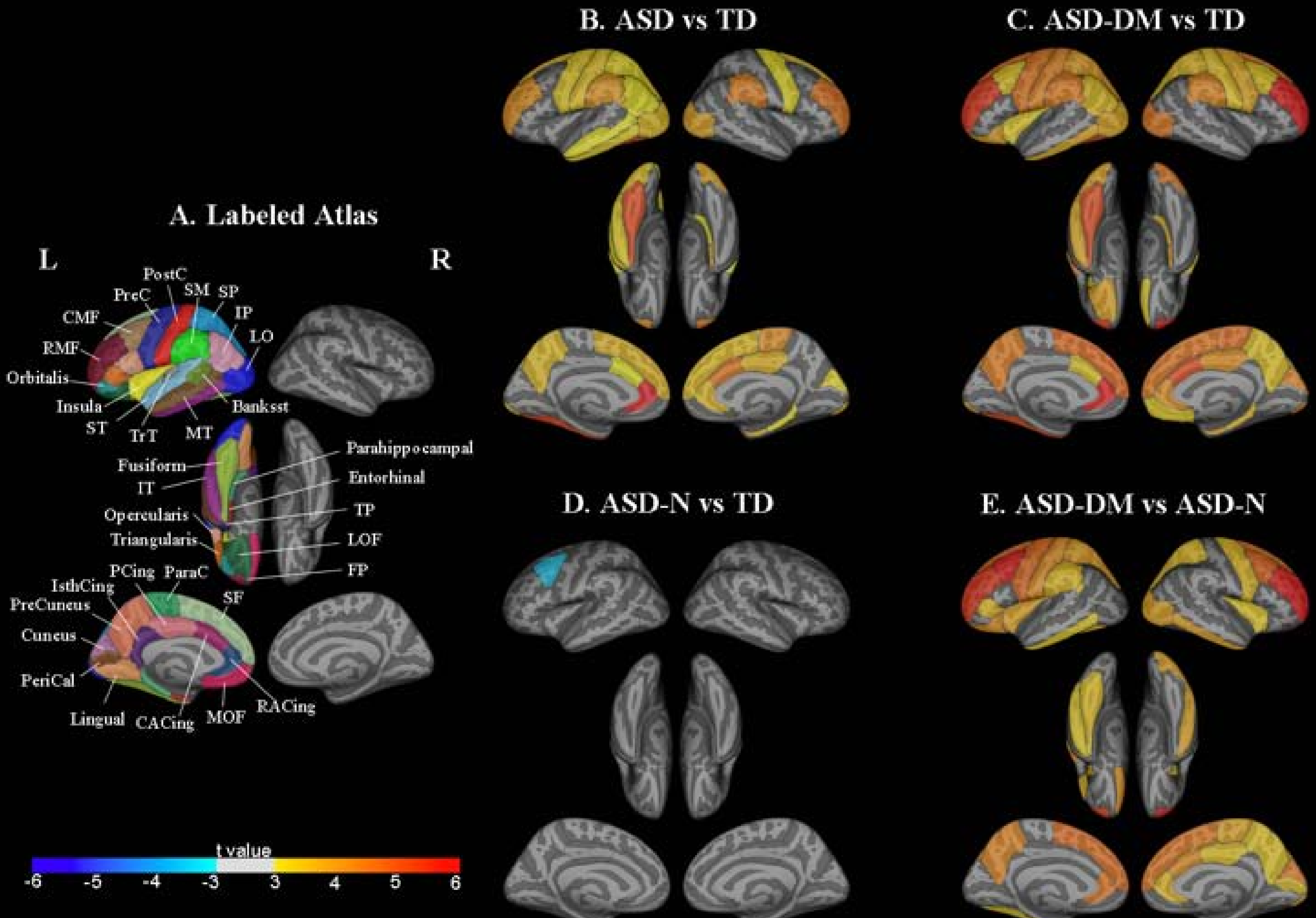


Average of cortical thickness of whole brain

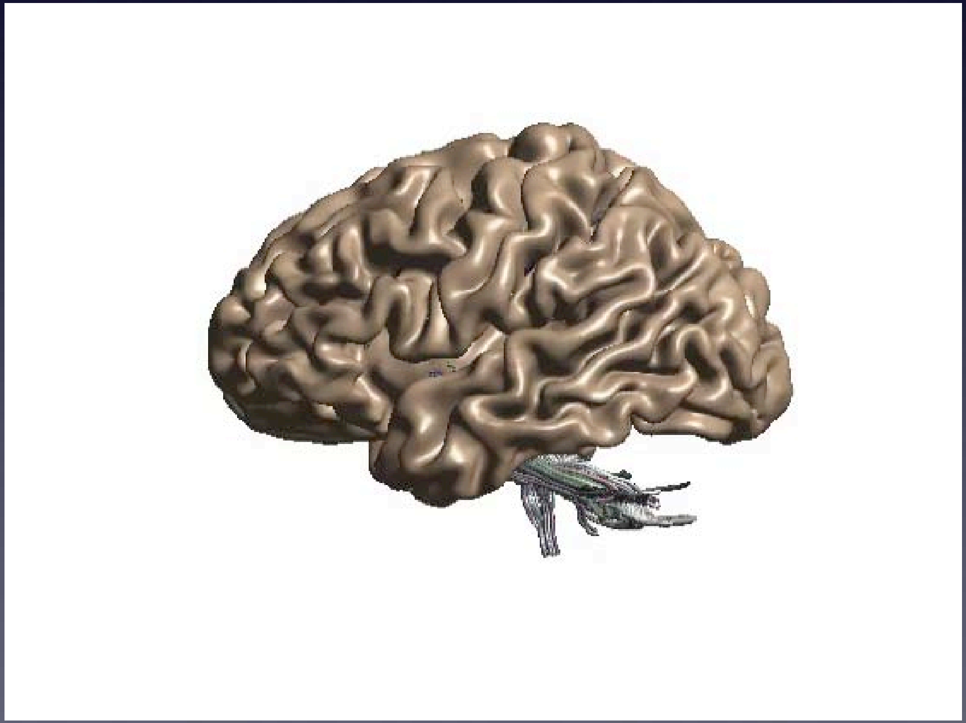


Cortical surface area of whole brain

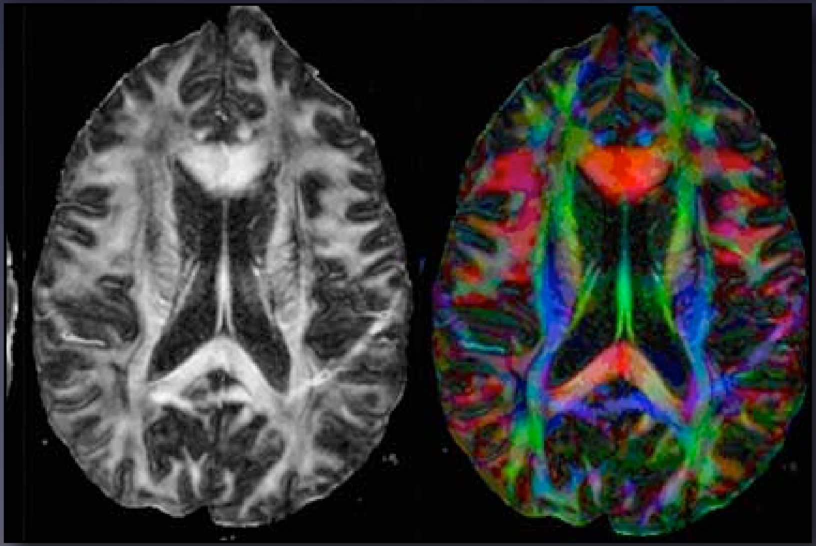



B. ASD vs TD
C. ASD-DM vs TD
A. Labeled Atlas
L
R
PostC
PreC
SM
SP
CMF
IP
LO
RMF
Orbitalis
Insula
Banksst
ST
TrT
MT
Fusiform
Parahippocampal
Entorhinal
IT
Opercularis
TP
Triangularis
LOF
FP
PCing
ParaC
IsthCing
PreCuneus
SF
Cuneus
PeriCal
Lingual
CACing
MOF
RACing
D. ASD-N vs TD
E. ASD-DM vs ASD-N
t value
-6
-5
-4
-3
3
4
5
6

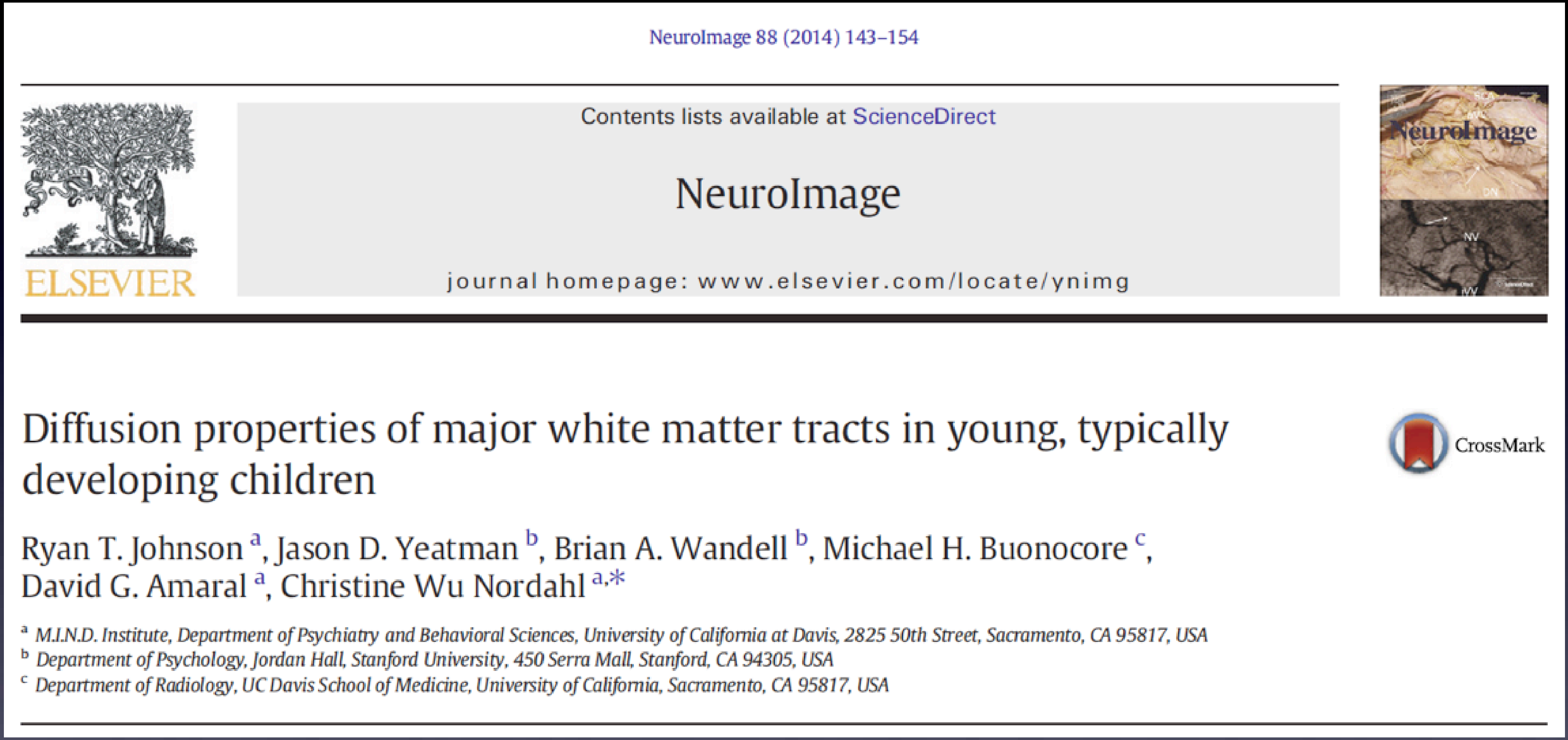
Is there evidence for different fiber connection alterations in the megalencephalic brains?



DTI Tractography



- Parallel bundles of fibers have high anisotropy
- White-matter can be isolated and investigated
- Fiber pathways can be reconstructed with good anatomic validity



NeuroImage 88 (2014) 143–154

Contents lists available at ScienceDirect

NeuroImage

journal homepage: www.elsevier.com/locate/ynimg

Diffusion properties of major white matter tracts in young, typically developing children

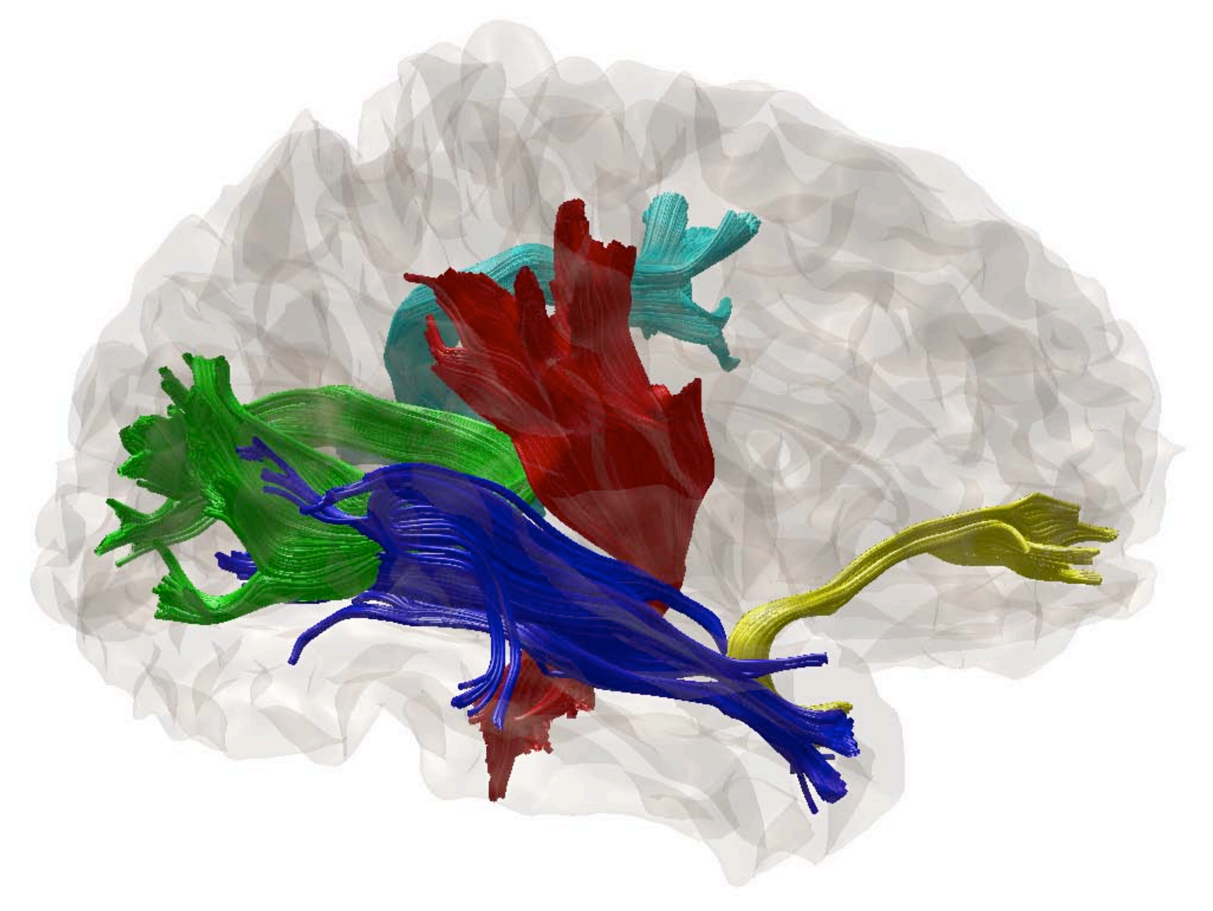
Ryan T. Johnson [a], Jason D. Yeatman [b], Brian A. Wandell [b], Michael H. Buonocore [c], David G. Amaral [a], Christine Wu Nordahl [a,*]

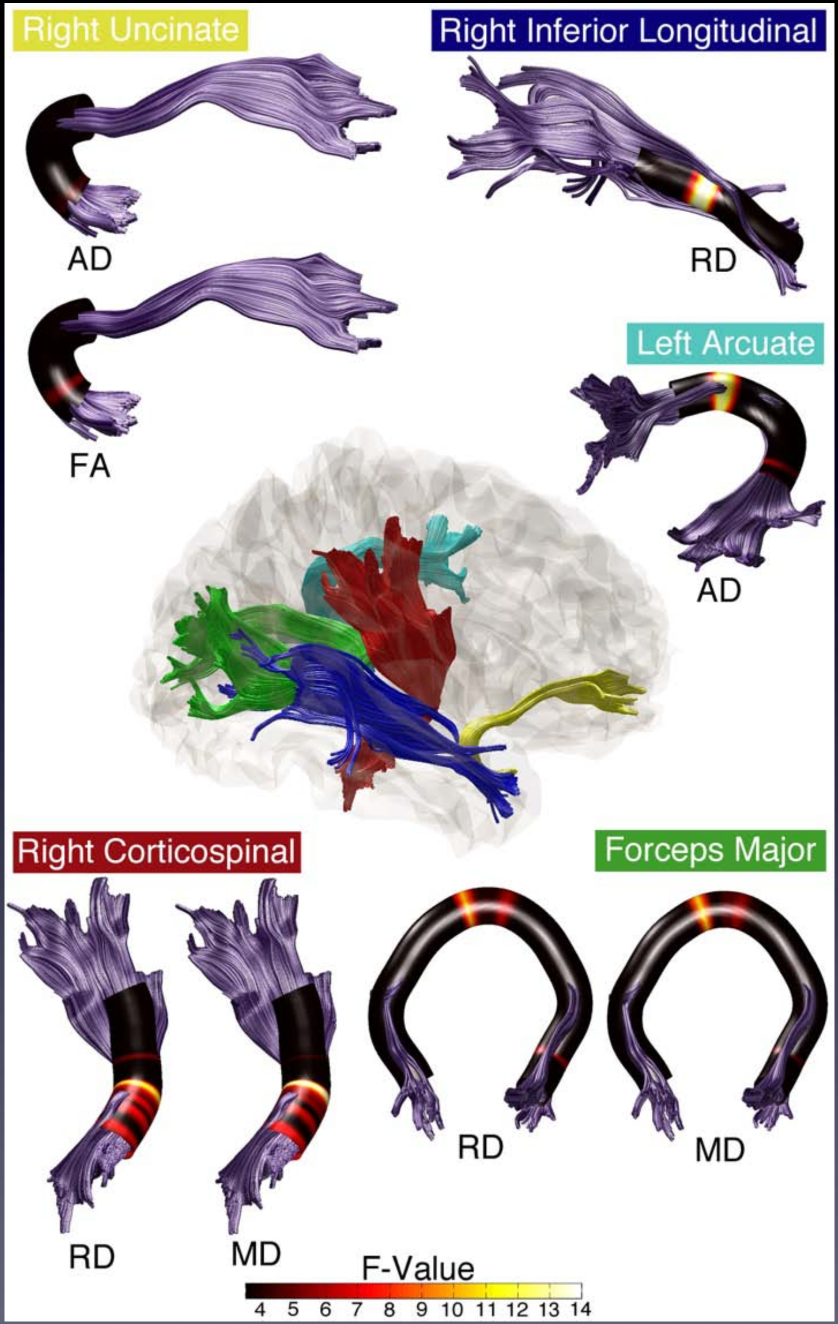
[a] *M.I.N.D. Institute, Department of Psychiatry and Behavioral Sciences, University of California at Davis, 2825 50th Street, Sacramento, CA 95817, USA*

[b] *Department of Psychology, Jordan Hall, Stanford University, 450 Serra Mall, Stanford, CA 94305, USA*

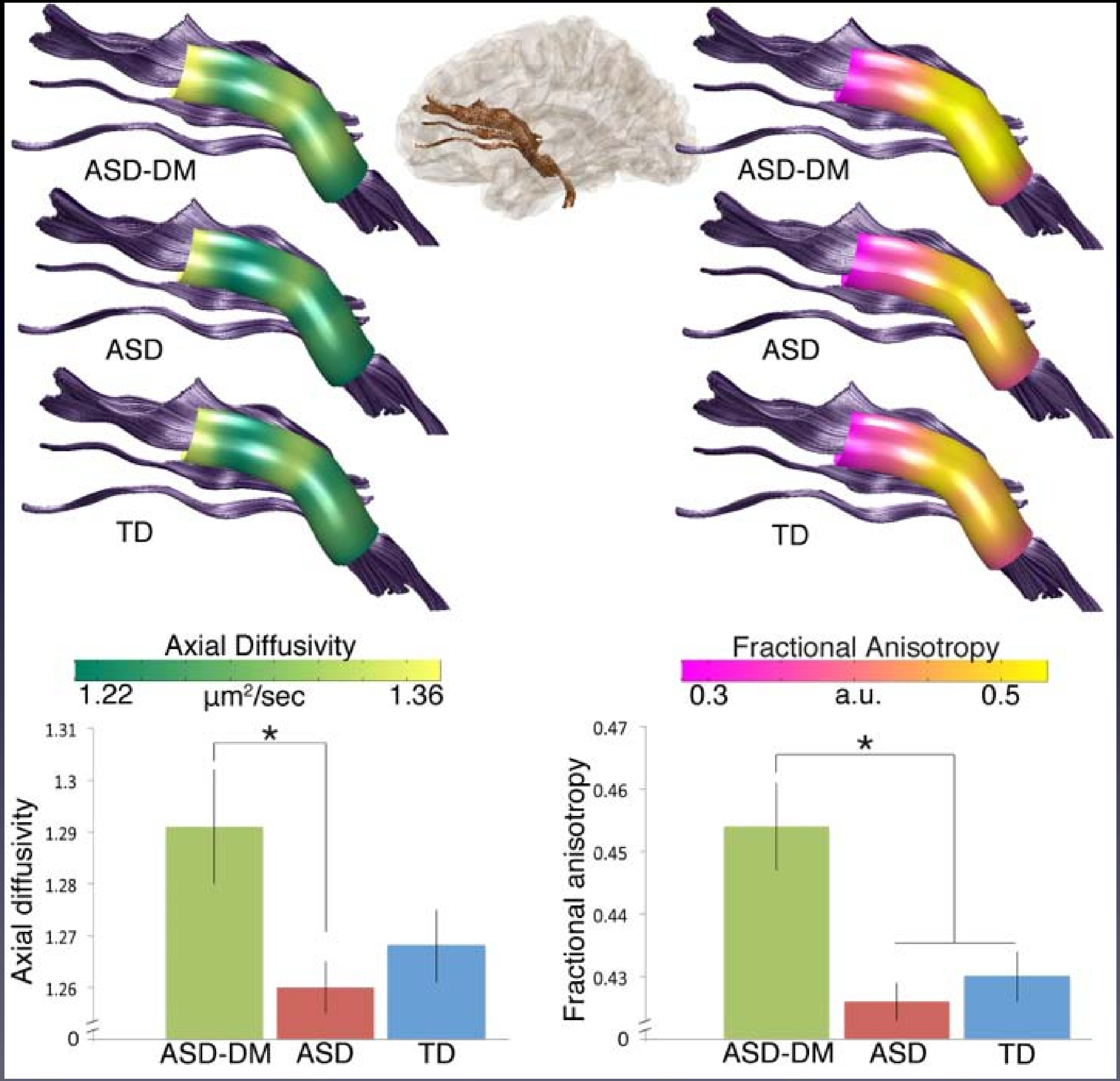
[c] *Department of Radiology, UC Davis School of Medicine, University of California, Sacramento, CA 95817, USA*

White Matter Abnormalities in Boys with ASD

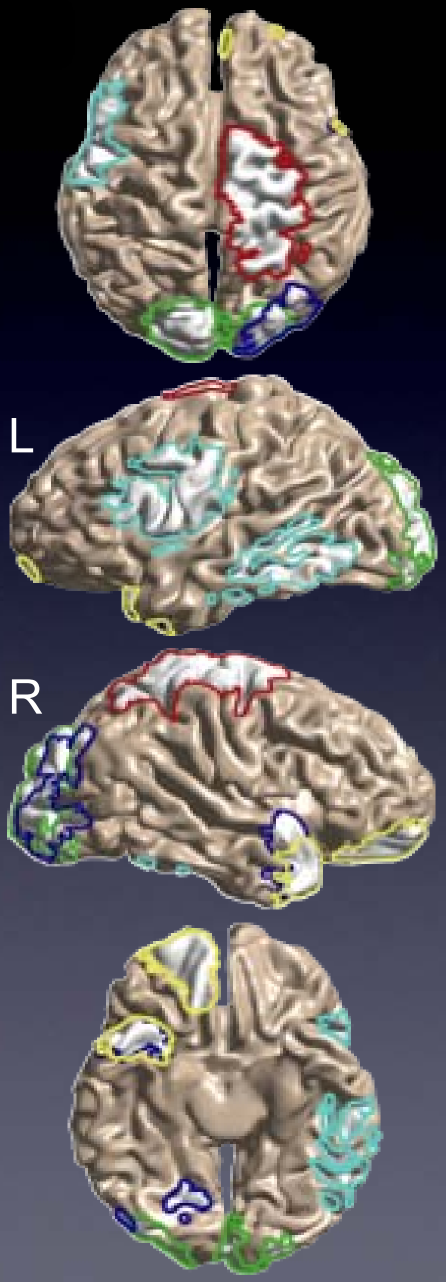



Right Uncinate
AD
FA
Right Inferior Longitudinal
RD
Left Arcuate
AD
Right Corticospinal
RD
MD
Forceps Major
RD
MD
F-Value
4 5 6 7 8 9 10 11 12 13 14

Anterior Thalamic Radiation

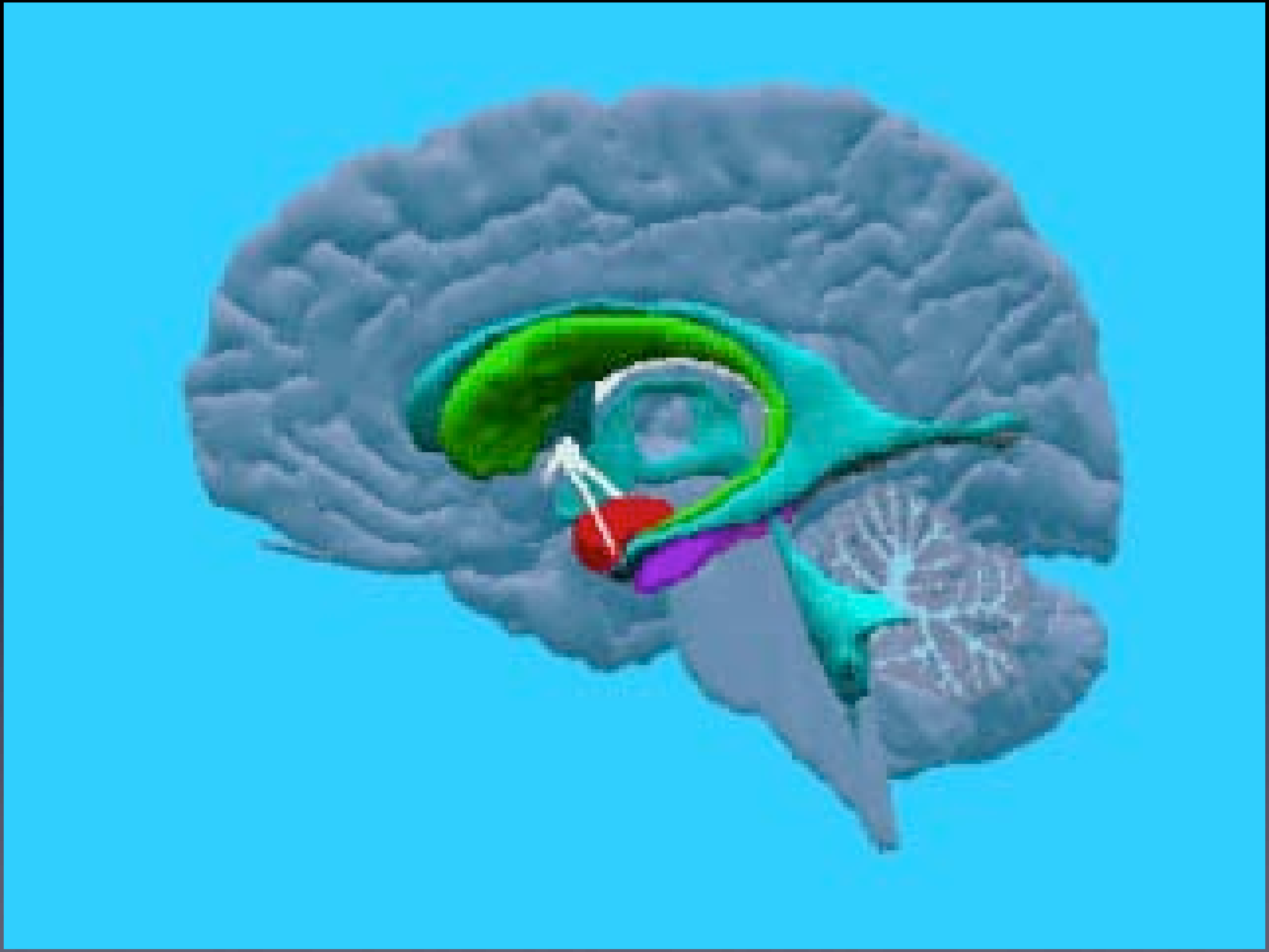


Fiber Tract Abnormalities in ASD males



Domain	Tracts Implicated
Social Communication	
Reception of Facial Communication	Uncinate fasciculus
Reception of Non-Facial Communication	Inferior longitudinal fasciculus
Production of Non-Facial Communication	Arcuate fasciculus, Inferior longitudinal fasciculus
Perception and Understanding of Self	
Agency	Inferior longitudinal fasciculi, Corticospinal tract
Self-Knowledge	Uncinate fasciculus
Perception and Understanding of Others	
Animacy Perception	Inferior longitudinal fasciculus
Action Perception	Corticospinal tract
Understanding Mental States	Uncinate fasciculus, Inferior longitudinal fasciculus
Positive Valence Systems	
Repetitive/Stereotypic/Compulsive Behaviors	Uncinate fasciculus
Cognitive Systems	
Language	Arcuate fasciculus

The Amygdala



Amygdala growth relative to TCV

- 40% of boys with ASD have an abnormally rapid growth of the amygdala
- 20% of boys with ASD have an abnormally slow growth of the amygdala
- 40% of boys with ASD have a normal growth rate of the amygdala

Questions Related to Outcome

- Do early neurophenotypes persist into middle childhood?
- Do early neurophenotypes predict different patterns of autism severity, cognitive function and co-morbid syndromes?
- Is there a pattern of early brain organization that is associated with optimal outcome?

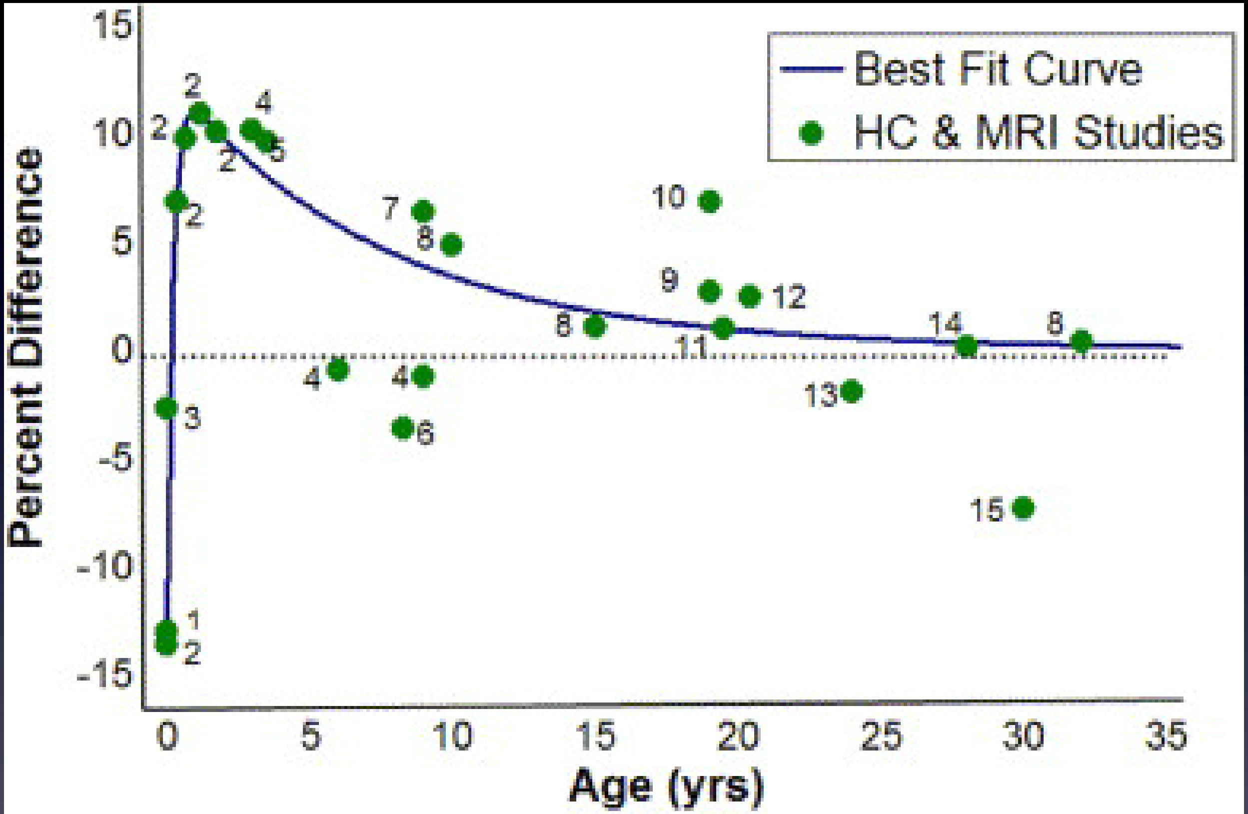


Figure 1 HC and MRI percent difference (%Diff) by age. %Diff values from all HC and MRI studies are plotted by the mean age of the study. The best fitted curve shows the most rapid rates of increased deviation from normal brain size in autism within first ...

Elizabeth Redcay , Eric Courchesne

When Is the Brain Enlarged in Autism? A Meta-Analysis of All Brain Size Reports

Biological Psychiatry, Volume 58, Issue 1, 2005, 1 - 9

Some low IQ

Few low IQ

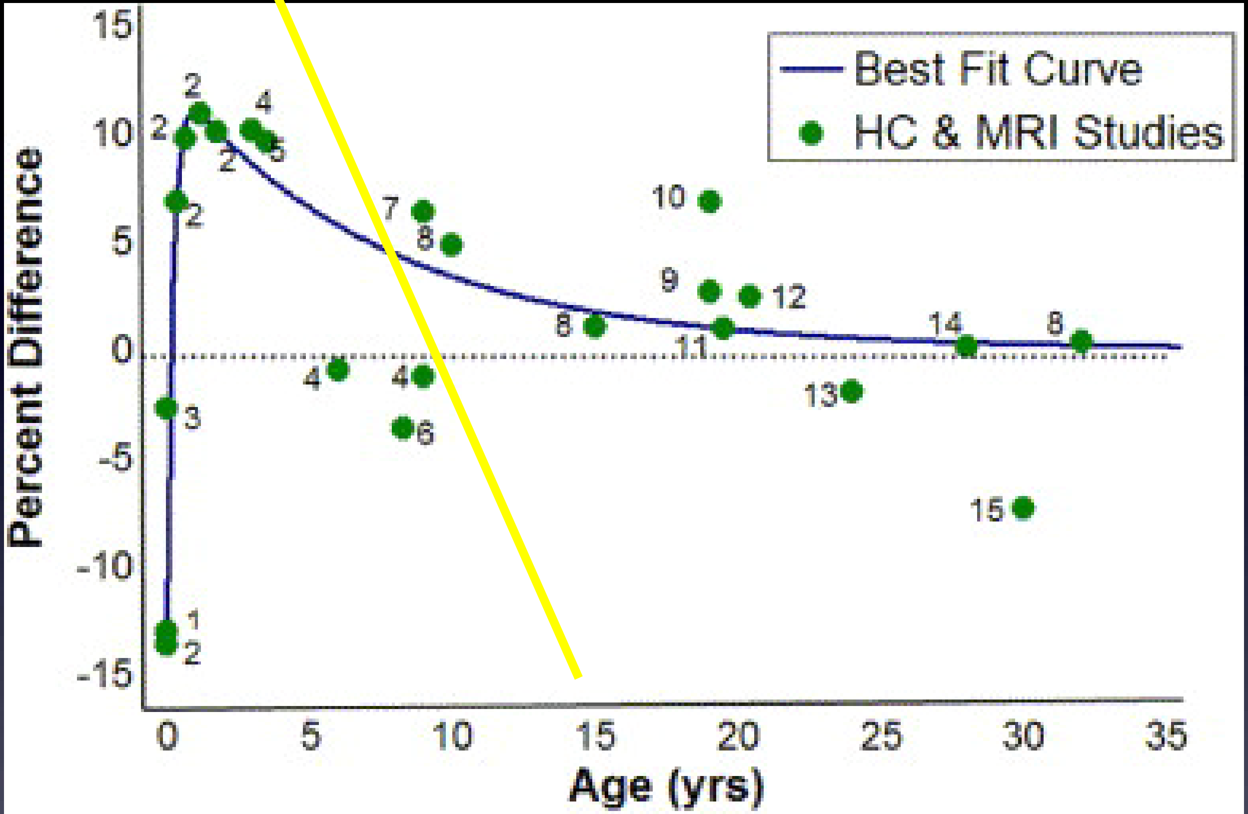


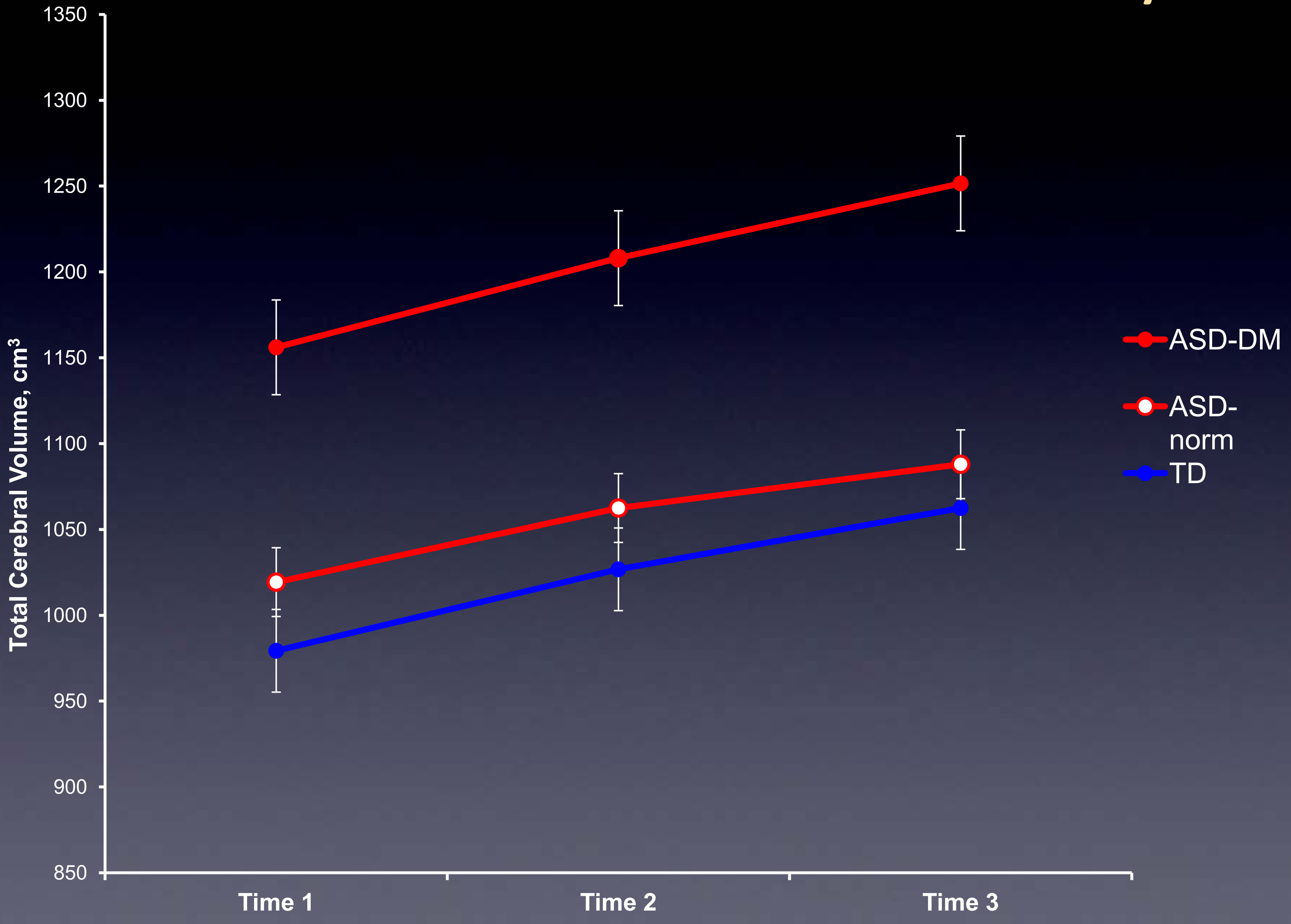
Figure 1 HC and MRI percent difference (%Diff) by age. %Diff values from all HC and MRI studies are plotted by the mean age of the study. The best fitted curve shows the most rapid rates of increased deviation from normal brain size in autism within first ...

Elizabeth Redcay , Eric Courchesne

When Is the Brain Enlarged in Autism? A Meta-Analysis of All Brain Size Reports

Biological Psychiatry, Volume 58, Issue 1, 2005, 1 - 9

Mean Total Cerebral Volume: 3-6 years



IACC 2009 Strategic Plan
Question 2: How Can I Understand What is Happening?

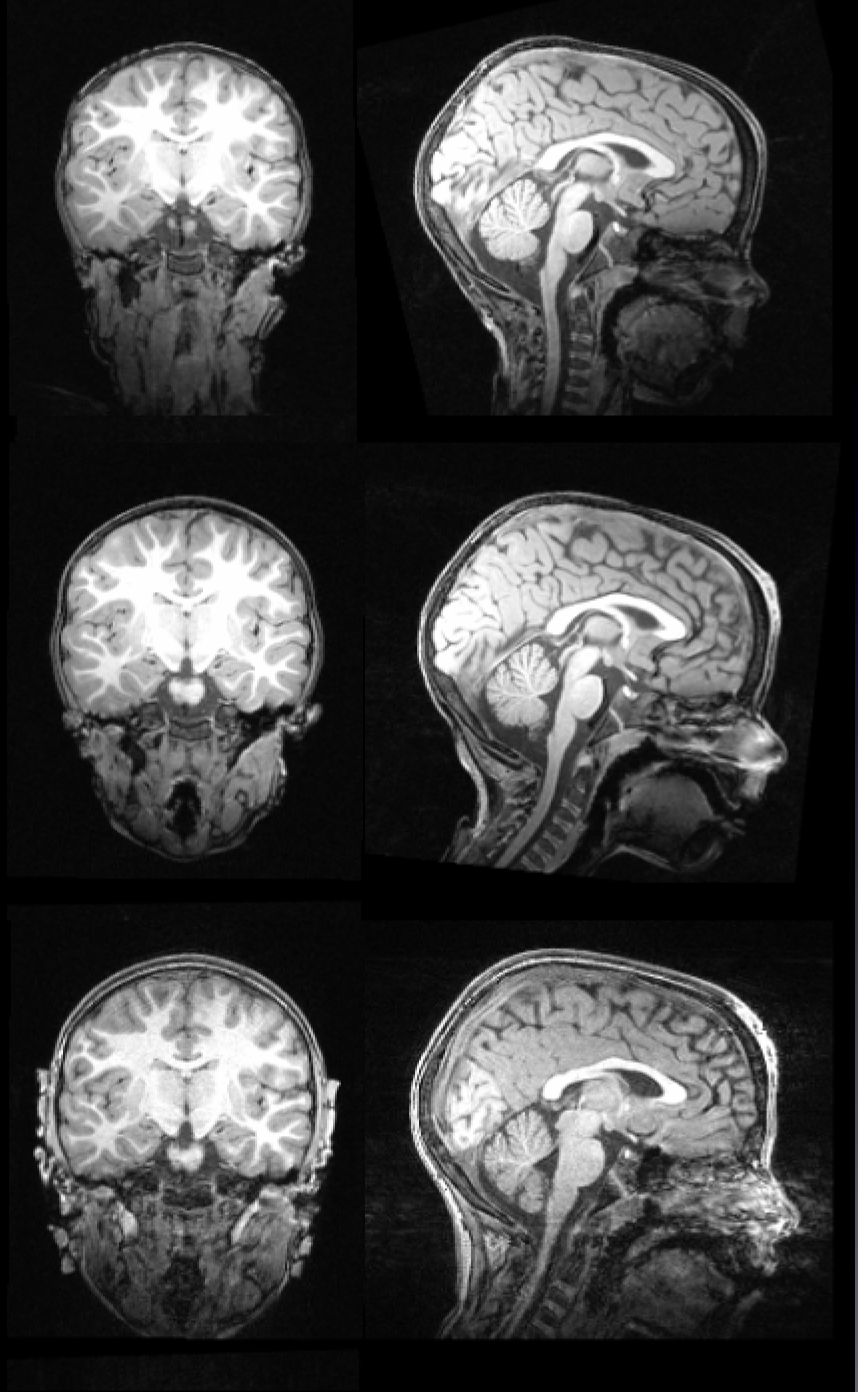
Research Opportunity

Multi-disciplinary, longitudinal, biobehavioral studies of children, youths, and adults beginning during infancy that characterize neurodevelopmental and medical developmental trajectories across the multiple axes of ASD phenotype and identify ASD risk factors, subgroups, co-occurring symptoms, and potential biological targets for intervention.

Subject NB

- 9 year old male
- I.Q. 41
- ADOS Total Score 19
- Non-verbal
- Self injurious behavior
- Aggression

NB scans

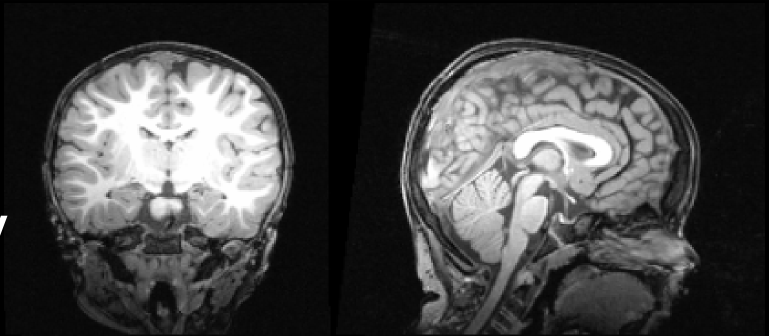


Time 1
Age 3.7 years

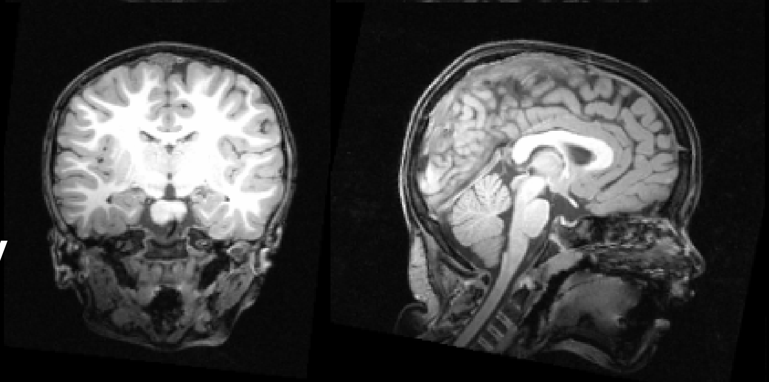
Time 2
Age 4.7 years

Time 4
Age 9.7 years

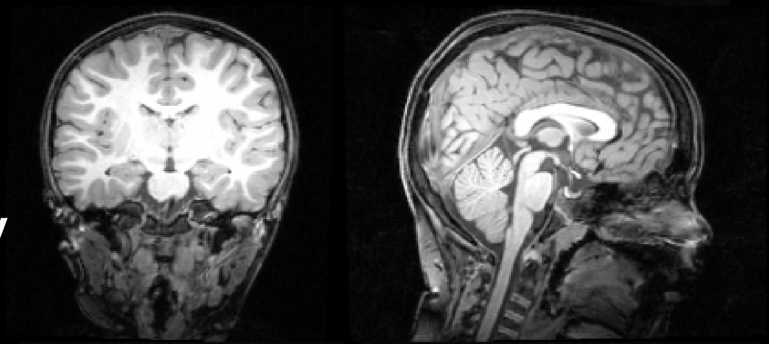
ACL



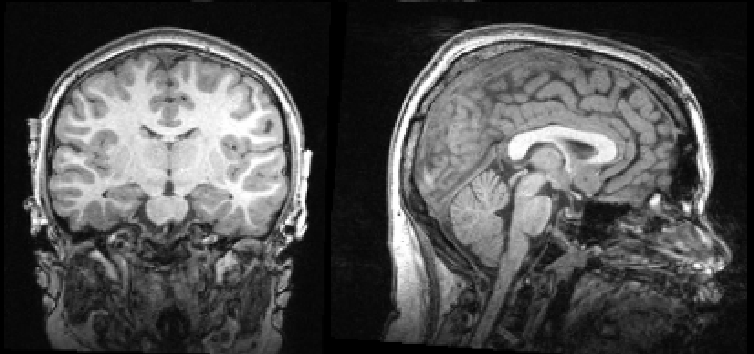
Time 1
Age 3.3y



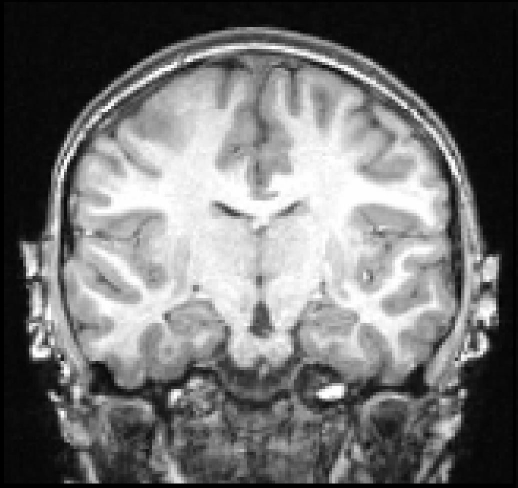
Time 2
Age 4.3y



Time 3
Age 5.6y

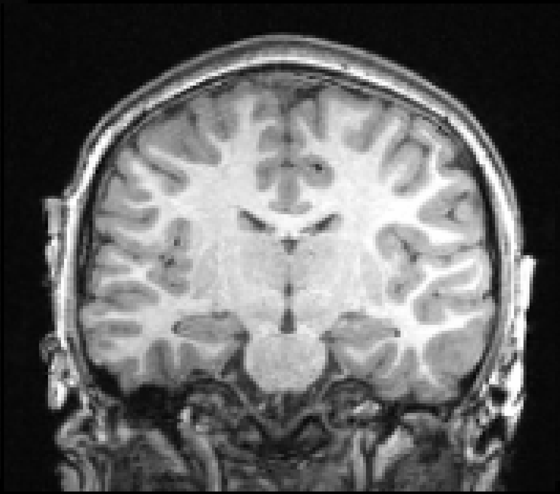


Time 4
Age 9.9y



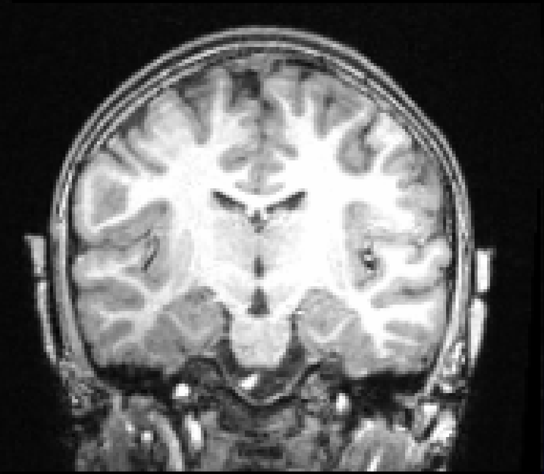
Age 12 y, male
IQ 58, ADOS total 16

LP



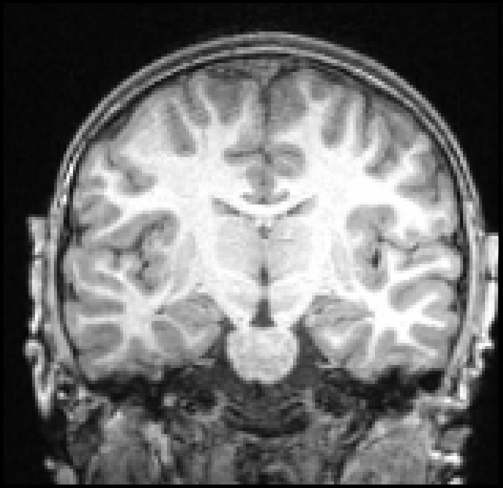
Age 9 y, male
IQ 49, ADOS total 17

ACL



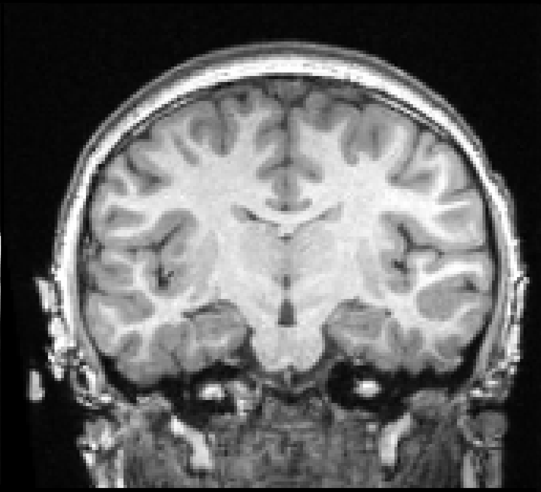
Age 9 y, female
IQ 42, ADOS total 17

OC



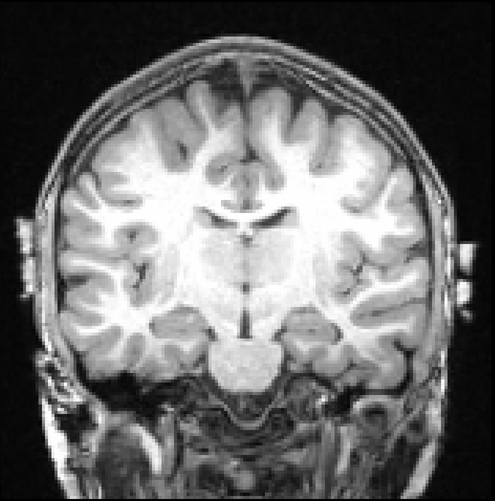
Age 10 y, male
IQ 41, ADOS total 19

NB



Age 10 y, male
IQ 52, ADOS total 17

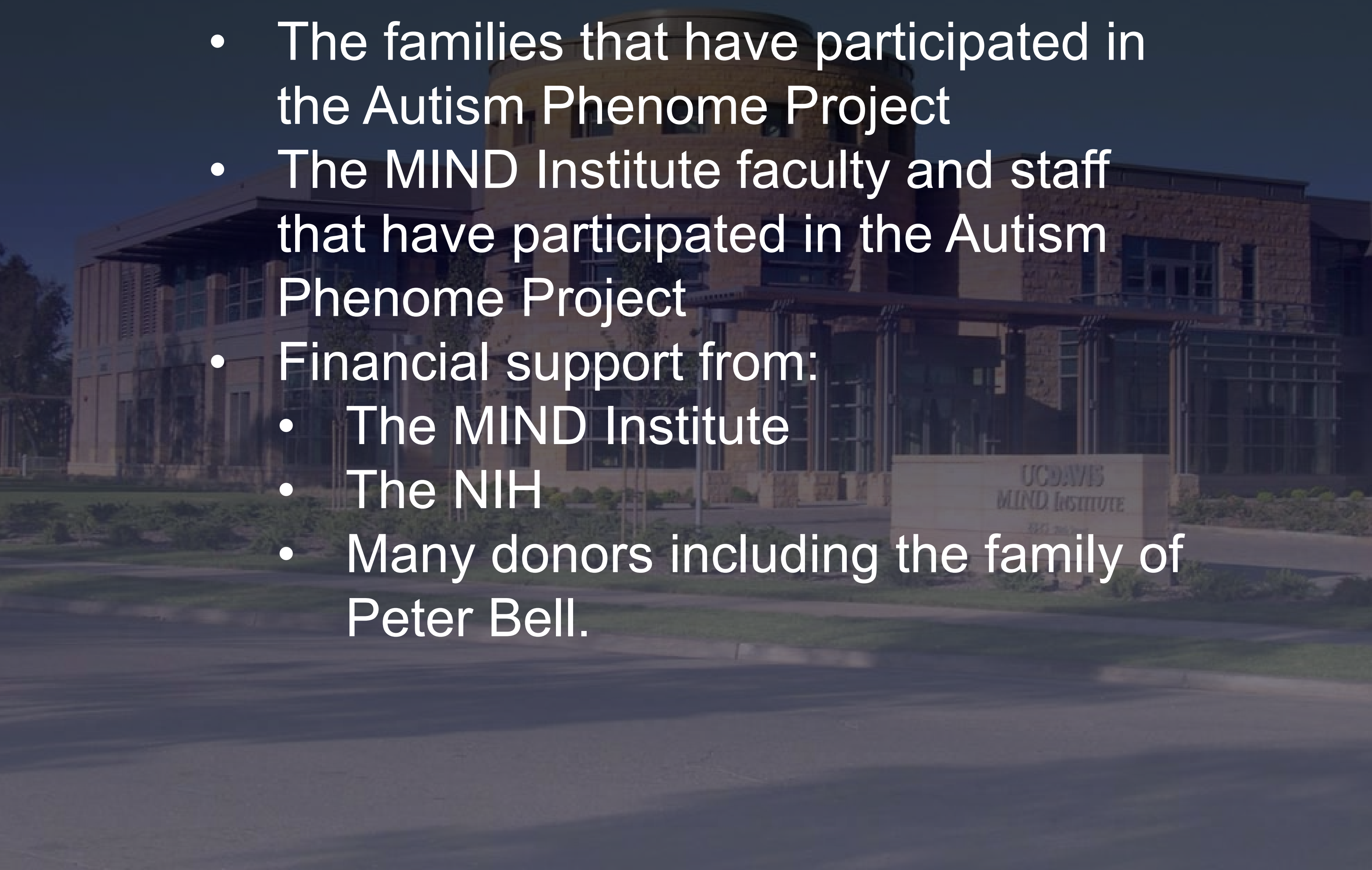
XC



Age 9 y, female
IQ 41, ADOS total 23

NS

Acknowledgments



- The families that have participated in the Autism Phenome Project
- The MIND Institute faculty and staff that have participated in the Autism Phenome Project
- Financial support from:
  - The MIND Institute
  - The NIH
  - Many donors including the family of Peter Bell.

Meeting of the IACC

Morning Agenda - continued

10:15	**Autism BrainNet**
	David G. Amaral, Ph.D. Distinguished Professor University of California, Davis
	Alison Singer President Autism Science Foundation (ASF)
10:45	**Break**

Meeting of the IACC

Autism BrainNet

David G. Amaral, Ph.D.
University of California, Davis

Alison Singer
Autism Science Foundation (ASF)

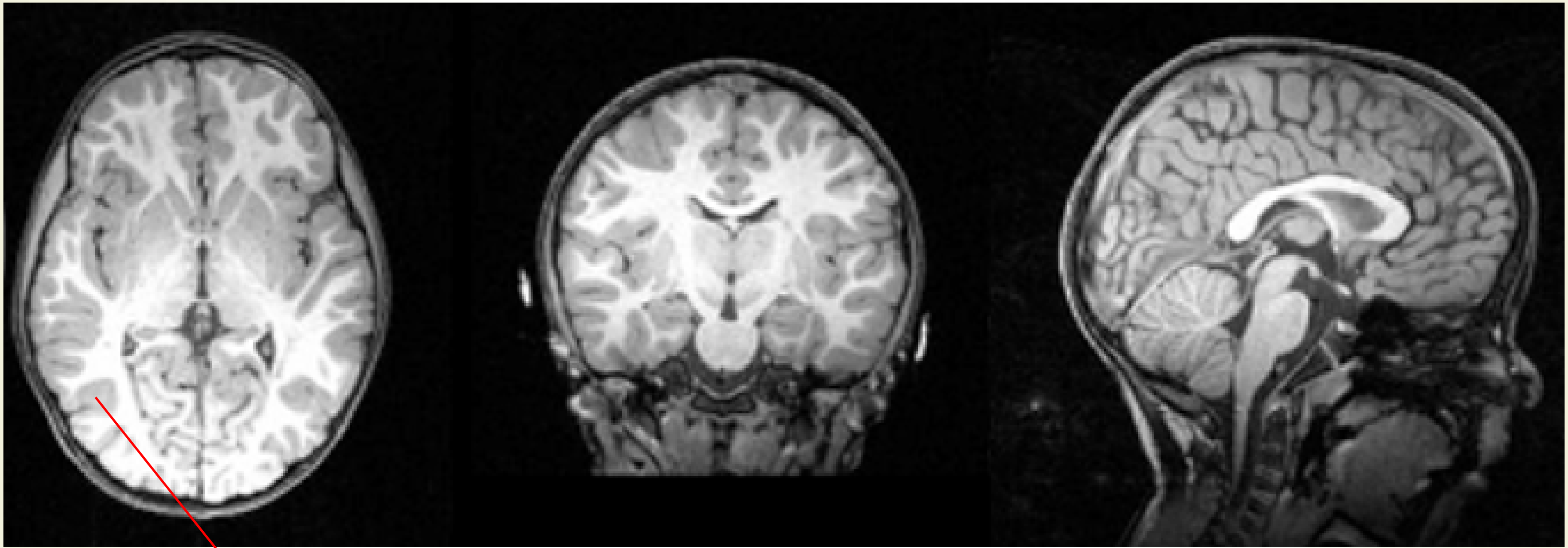
autism
BRAIN
NET

SFARI SIMONS FOUNDATION AUTISM RESEARCH INITIATIVE

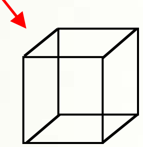
AUTISM SPEAKS®
It's time to listen.

AUTISM SCIENCE FOUNDATION

Resolution of MRI is too low to see neurons and networks



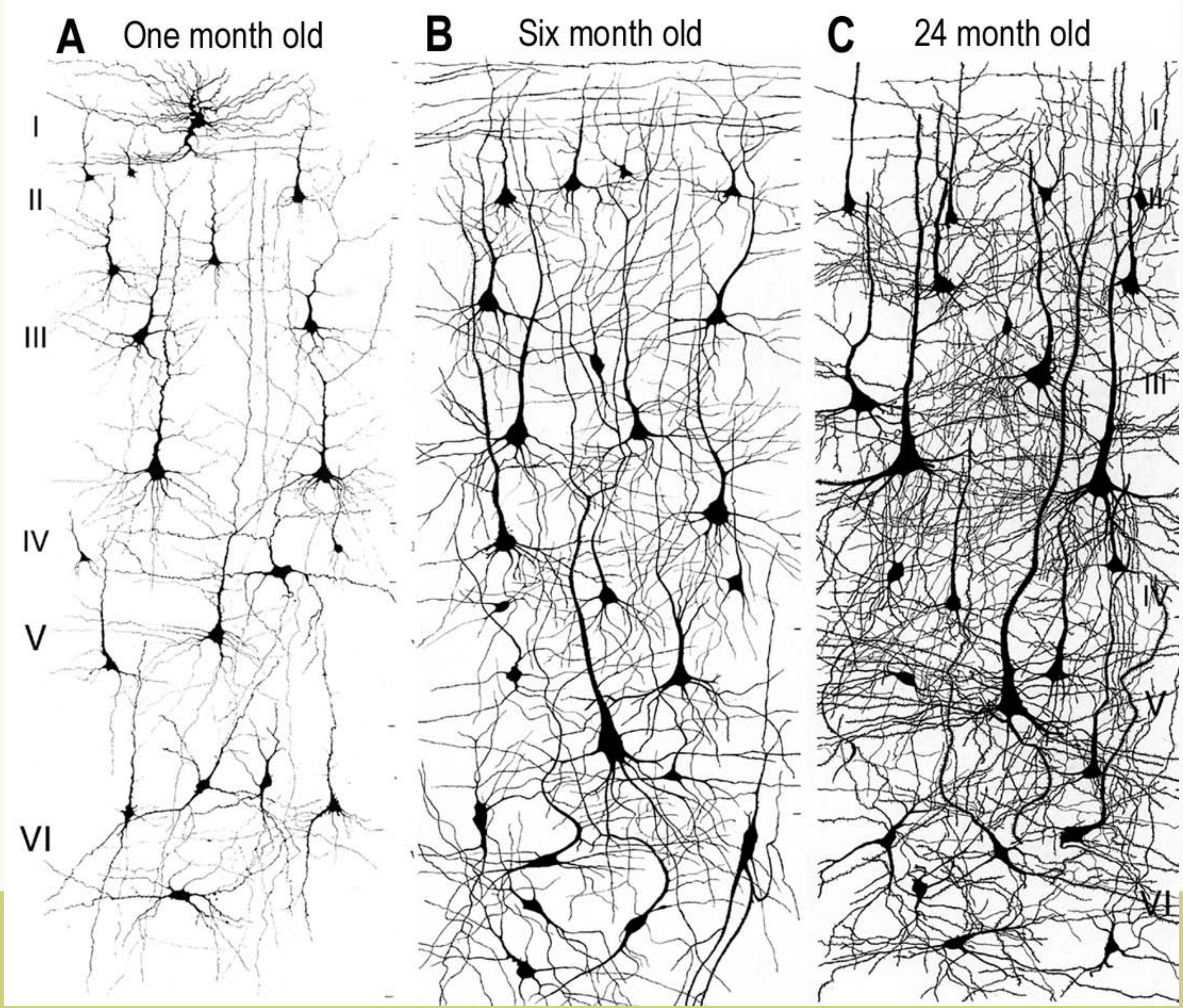
Voxel = 1 mm^3



Voxel = 50,000 neurons

Voxel = 100-300 million synapses

Resolution of MRI is too low to see neurons and networks




Neuropathology
Genetics
Neurochemistry

Based on findings from MRI, postmortem studies will require:

- A large number of clinically and genetically well-characterized brains for analysis
- Appropriate control brains for comparison
- Well organized cohorts to optimize research replication and complementarity.

Autism BrainNet

Autism BrainNet

Matt Anderson, M.D., Ph.D.

Cyndi Schumann, Ph.D.

Patrick Hof, M.D.

Carol Tamminga, M.D.

Autism BrainNet International

Oxford University

Olaf Ansorge, M.D

Autism BrainNet Web Site: AutismBrainNet.org

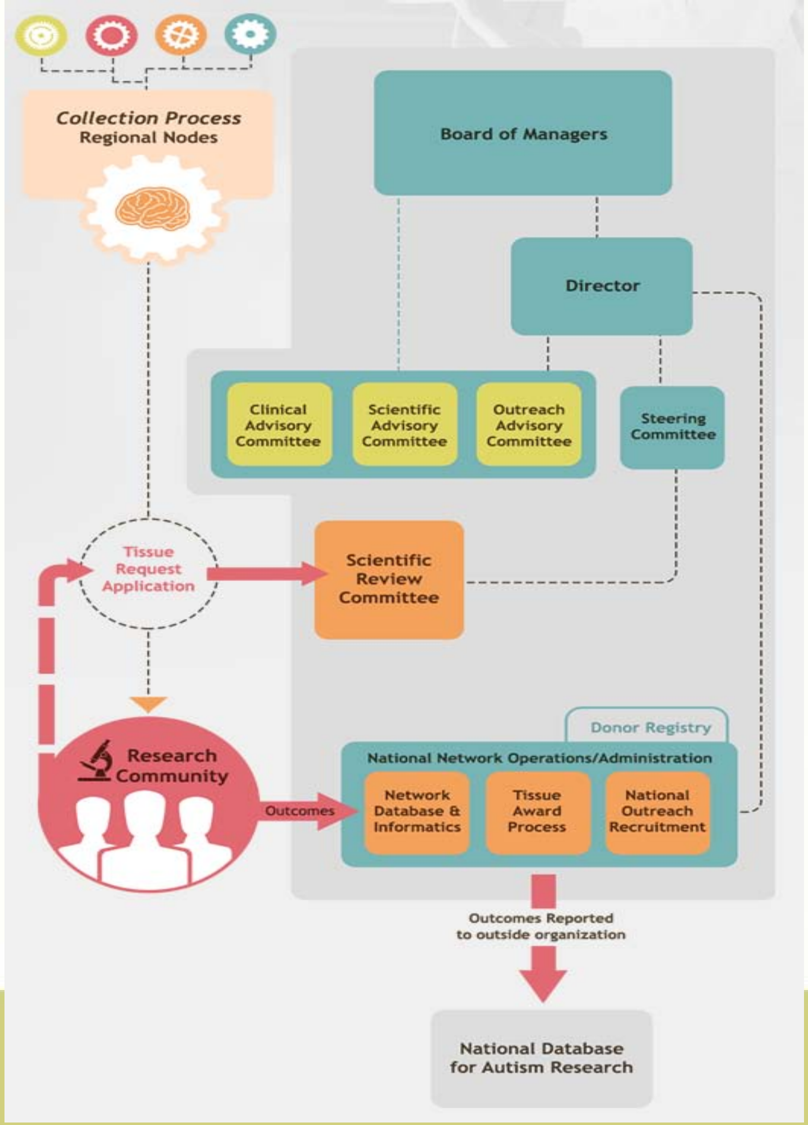
Promoting Research into the Causes of Autism Spectrum Disorder

Although there is substantial evidence from neuroimaging studies that the brain of a child with autism is undergoing abnormal development, little is known about the underlying cellular, molecular and genetic mechanisms that lead to the onset of autistic symptoms.

The Simons Foundation and Autism Speaks® forge a new alliance to foster postmortem brain research.

This initiative is supported by: AUTISM SPEAKS It's time to listen. SFARI SIMONS FOUNDATION AUTISM RESEARCH INITIATIVE

AutismBrainNet Organization



Collection Process
Regional Nodes

Board of Managers

Director

Clinical Advisory Committee

Scientific Advisory Committee

Outreach Advisory Committee

Steering Committee

Tissue Request Application

Scientific Review Committee

Donor Registry

Research Community

Outcomes

National Network Operations/Administration

Network Database & Informatics

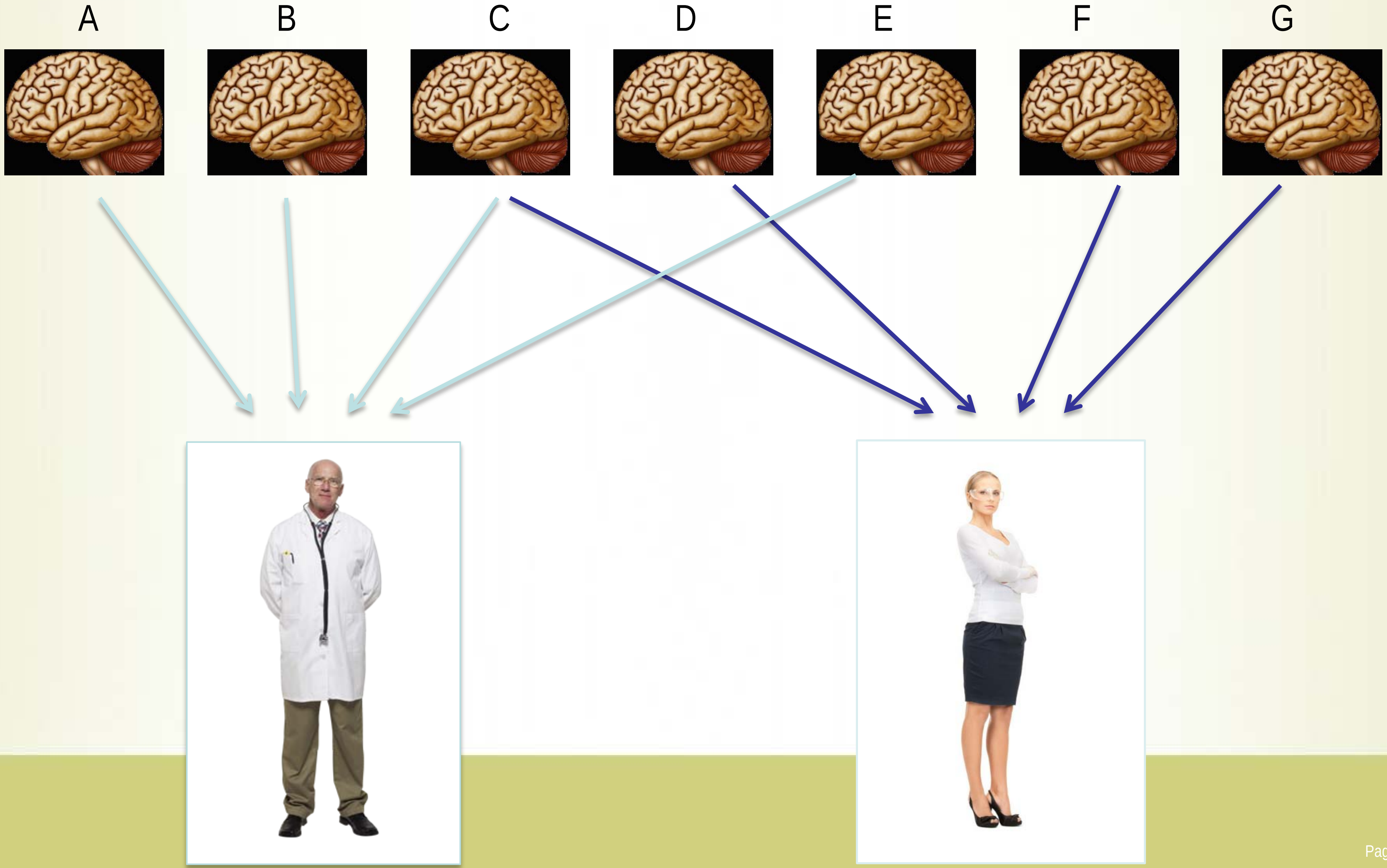
Tissue Award Process

National Outreach Recruitment

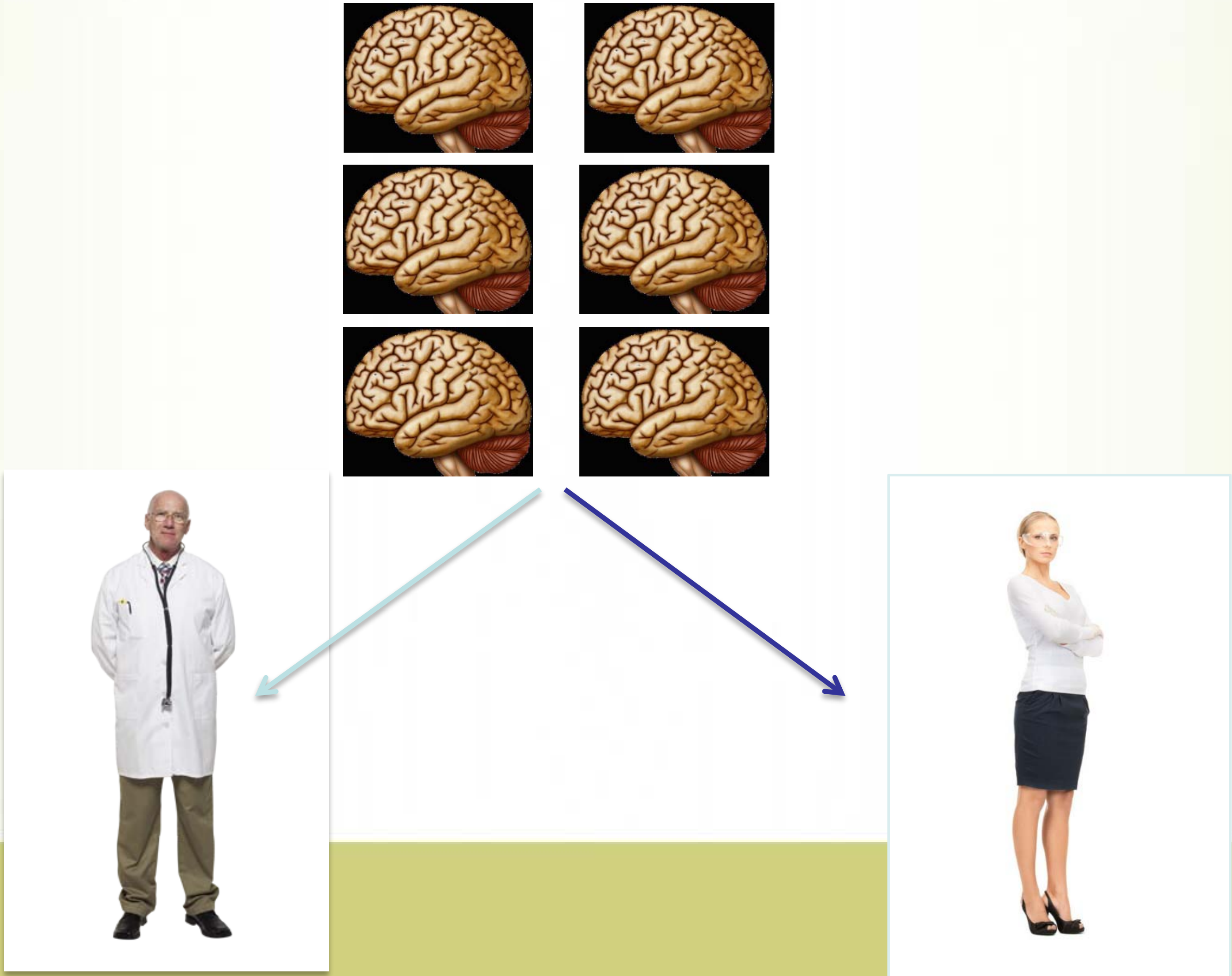
Outcomes Reported to outside organization

National Database for Autism Research

Development of cohorts of research brains



Development of cohorts of research brains



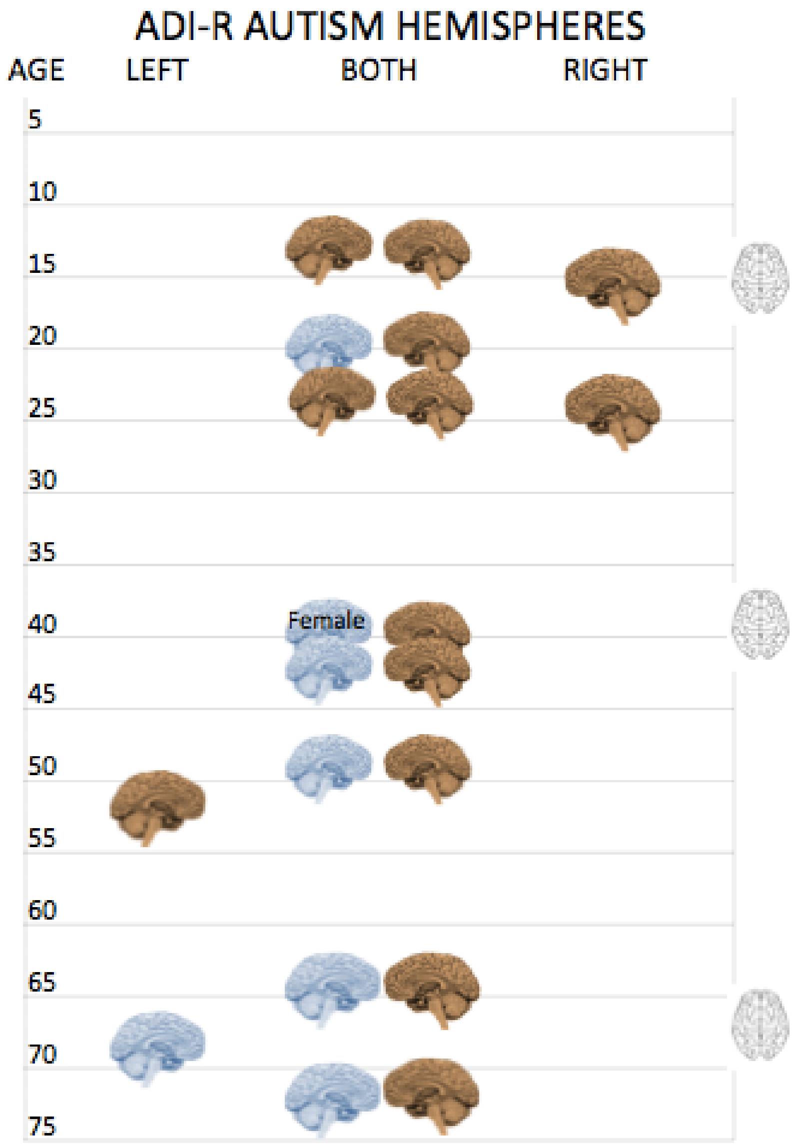
Cases

Controls

Development of cohorts of research brains

- ASD versus Age-matched Controls
- ASD versus Epilepsy versus Controls
- ASD with 16p11.2 deletion and Controls

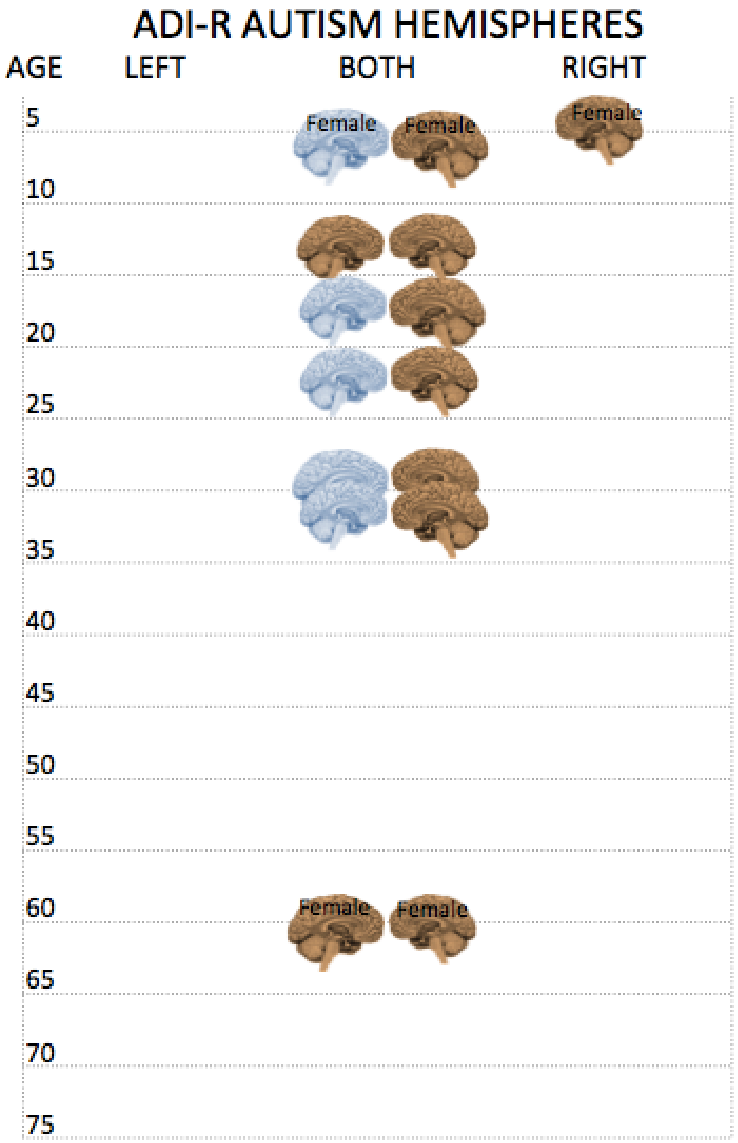
Autism BrainNet Cohort Candidates



Formalin Fixed

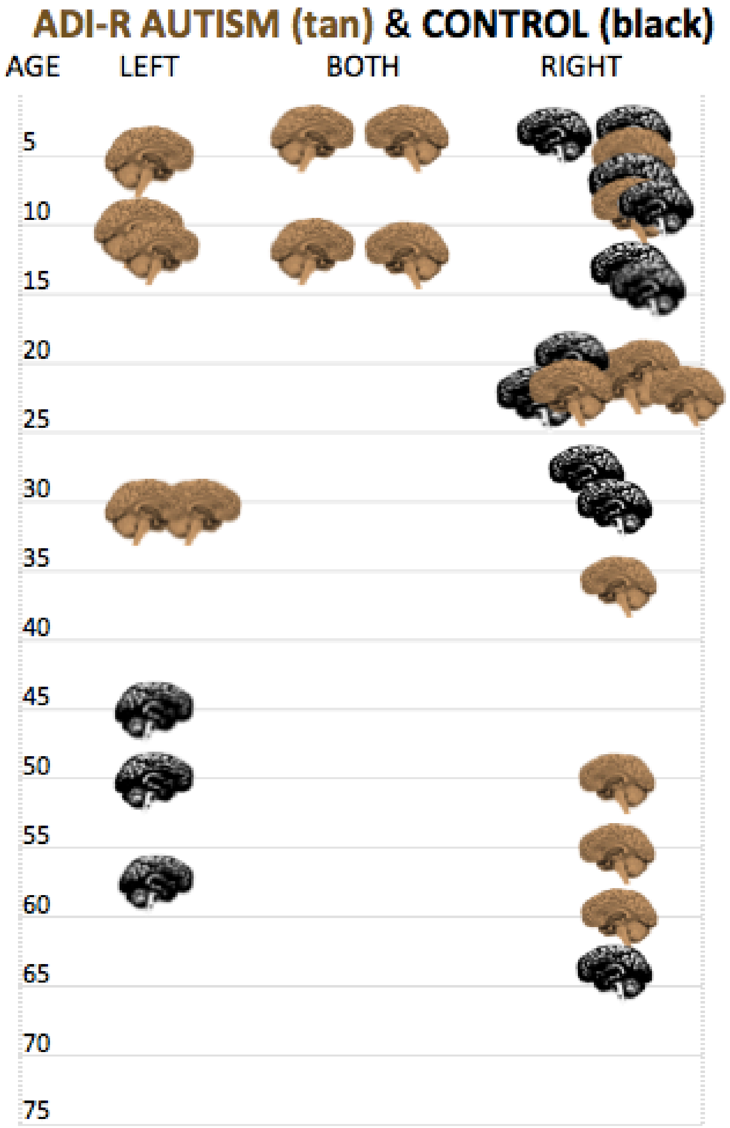
Liquid Nitrogen Frozen

BEARS
Cohort Candidates



Formalin Fixed

Frozen



Autism BrainNet Celloidin Cohort

#	Age	Diagnosis	Sex	Laterality
1	4	Autism - ADI-R	M	L
2	4	Autism - ADI-R	M	R
3	4	Control	F	R
4	4	Control	F	R
5	5	Autism - ADI-R	F	L
6	5	Autism - ADI-R	F	R
7	7	Control	M	R
8	8	Autism - ADI-R	M	R
9	8	Control	F	R
10	11	Autism - ADI-R	F	L
11	13	Autism - ADI-R	M	L
12	14	Control	M	R
13	15	Control	F	R
14	20	Control	F	R
15	21	Autism - ADI-R	F	R
16	22	Autism - ADI-R	M	R
17	23	Autism - ADI-R	M	R
18	23	Control	M	R
19	28	Control	M	R
20	32	Autism - ADI-R	M	L
21	32	Autism/Fragile X	M	L
22	32	Control	M	R
23	36	Autism - ADI-R	M	R
24	48	Control	M	L
25	51	Control	M	L
26	52	Autism - ADI-R	M	R
27	52	Control	M	R
28	56	Autism - ADI-R	M	R
29	59	Control	M	L
30	60	Autism - ADI-R	M	R
31	64	Control	M	R

Need for Community Involvement

This will only be successful if the community is fully engaged and supportive. This will require a nationwide outreach effort to communicate the message that

It Takes Brains to solve autism.

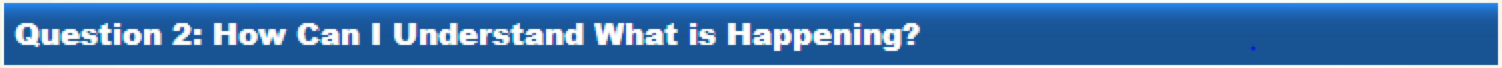
AUTISM
SCIENCE
FOUNDATION

It Take Brains to Solve Autism

Alison Singer
Autism Science Foundation

IACC Meeting
July 8, 2014

IACC Strategic Plan (2009-2013)



Question 2: How Can I Understand What is Happening?

Short-Term Objectives

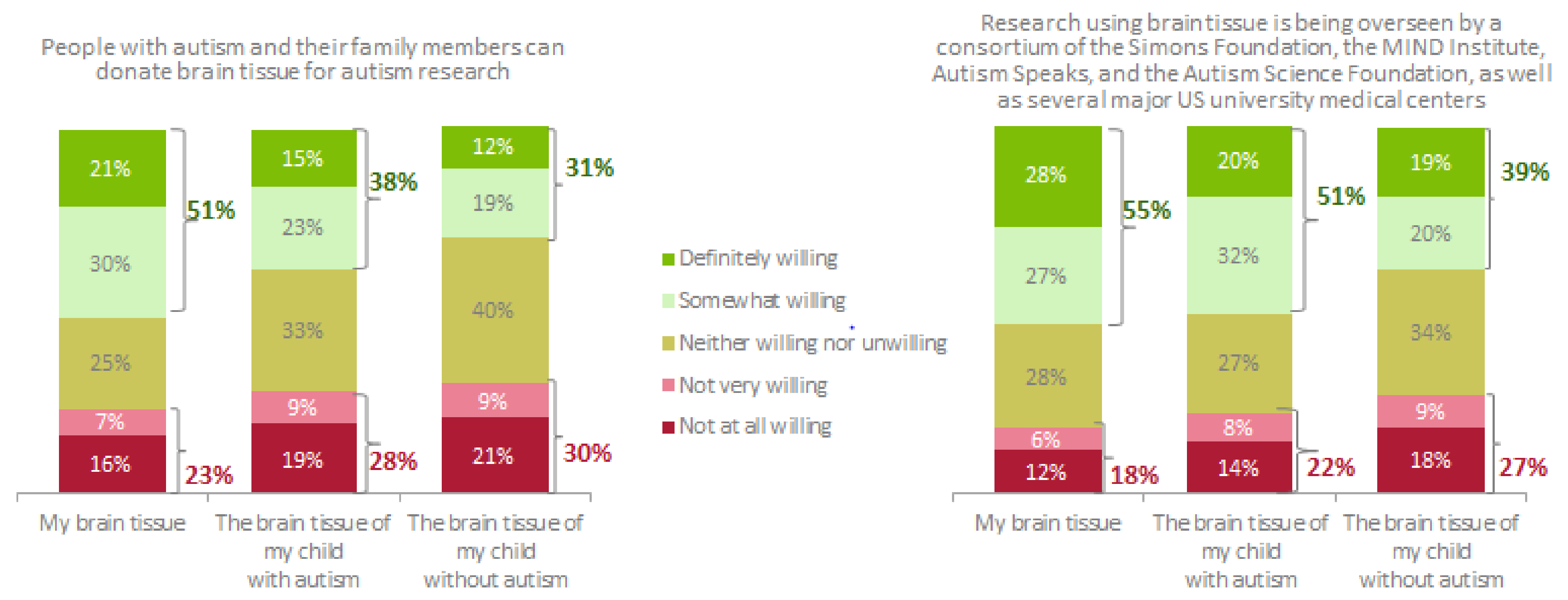
4. Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research..

Focus Group Behavior Change

After seeing this campaign, I would [CHECK AS MANY AS APPLY]:	**Group 1** Parents 3 – 10	**Group 2** Parents 11 - 17	**Group 3** Parents 18+	**Group 4** Adults with Autism*
Probably do nothing	1			1
Think about the issue	3	4	2	3
Seek more information about brain tissue donation	1	3	3	
Go to the website listed in the advertising		2	3	1
Google brain tissue donation		4	2	1
Speak to someone about brain tissue donation at an autism walk or meeting	1	2	1	
Speak to a friend/family member about brain tissue donation	1	3	3	
Register myself to become a brain tissue donor		1		
Register my child with autism to become a brain tissue donor		1		
Talk to my child's doctor about brain tissue donation		2		

Pre-Wave Online Survey; N= 412 Sept 1 – Oct 2, 2013

Willingness to Consider Registering

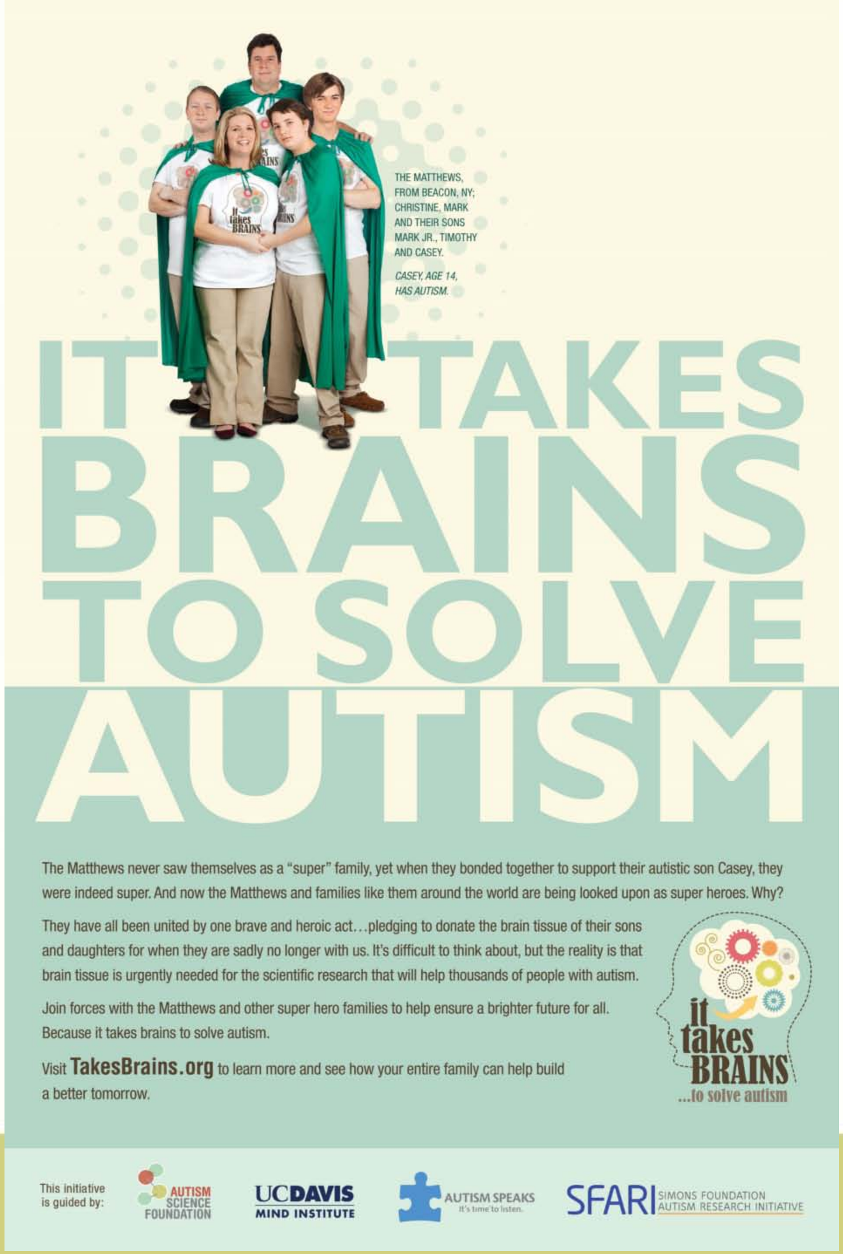


People with autism and their family members can donate brain tissue for autism research

Research using brain tissue is being overseen by a consortium of the Simons Foundation, the MIND Institute, Autism Speaks, and the Autism Science Foundation, as well as several major US university medical centers

Why Willing/Not Willing

- Would be Willing (55%)
  - Help other children (51%)
  - Support research (38%)
- Undecided (25-40%)
  - Wasn't aware (33%)
  - Haven't thought about it enough; need more info (27%)
- Are Unwillling (18-30%)
  - Unethical (28%)
  - Don't want to think about this topic while my child is alive (22%)



THE MATTHEWS,
FROM BEACON, NY;
CHRISTINE, MARK
AND THEIR SONS
MARK JR., TIMOTHY
AND CASEY.

CASEY, AGE 14,
HAS AUTISM.

IT TAKES BRAINS TO SOLVE AUTISM

The Matthews never saw themselves as a "super" family, yet when they bonded together to support their autistic son Casey, they were indeed super. And now the Matthews and families like them around the world are being looked upon as super heroes. Why?

They have all been united by one brave and heroic act…pledging to donate the brain tissue of their sons and daughters for when they are sadly no longer with us. It's difficult to think about, but the reality is that brain tissue is urgently needed for the scientific research that will help thousands of people with autism.

Join forces with the Matthews and other super hero families to help ensure a brighter future for all. Because it takes brains to solve autism.

Visit **TakesBrains.org** to learn more and see how your entire family can help build a better tomorrow.

This initiative is guided by:

THE MATTHEWS, CHRISTINE, MARK & THEIR SONS MARK JR., TIMOTHY & CASEY.

CASEY, AGE 14, HAS AUTISM.

IT TAKES BRAINS

...to solve autism

IT TAKES BRAINS is the outreach program of the Autism BrainNet, a new network of research institutions that will collaborate on groundbreaking brain research. Brain study is the key to solving autism, and our mission is to urge families to make the heroic decision to register for brain tissue donation.

Read More »

Q&A

Topics include:

- THE FACTS
- REGISTRATION
- DONATION

RESEARCH

Studies focusing on differences in brain structure, development, and genetic function will transform the understanding and treatment of autism.

SIGN UP

REGISTER TO DONATE brain tissue and ensure a brighter future for all.

This initiative is guided by:

TakesBrains.org

QUESTIONS & ANSWERS

Q: Why should my family consider donation?

Q: Why is there a shortage of brain tissue and how severe is the shortage?

Q: Why do scientists need to study brain tissue to solve autism?

Q: Why can't scientists use MRIs, EEGs, or other imaging methods to study brain tissue?

Q: Does registering as a donor mean that medical treatment will be altered?

Q: What are the various religious points of view on brain donation?

This initiative is guided by:

TakesBrains.org

QUESTIONS & ANSWERS

Q: Why should my family consider donation?

Q: Why is there a shortage of brain tissue and how severe is the shortage?

Q: Why do scientists need to study brain tissue to solve autism?

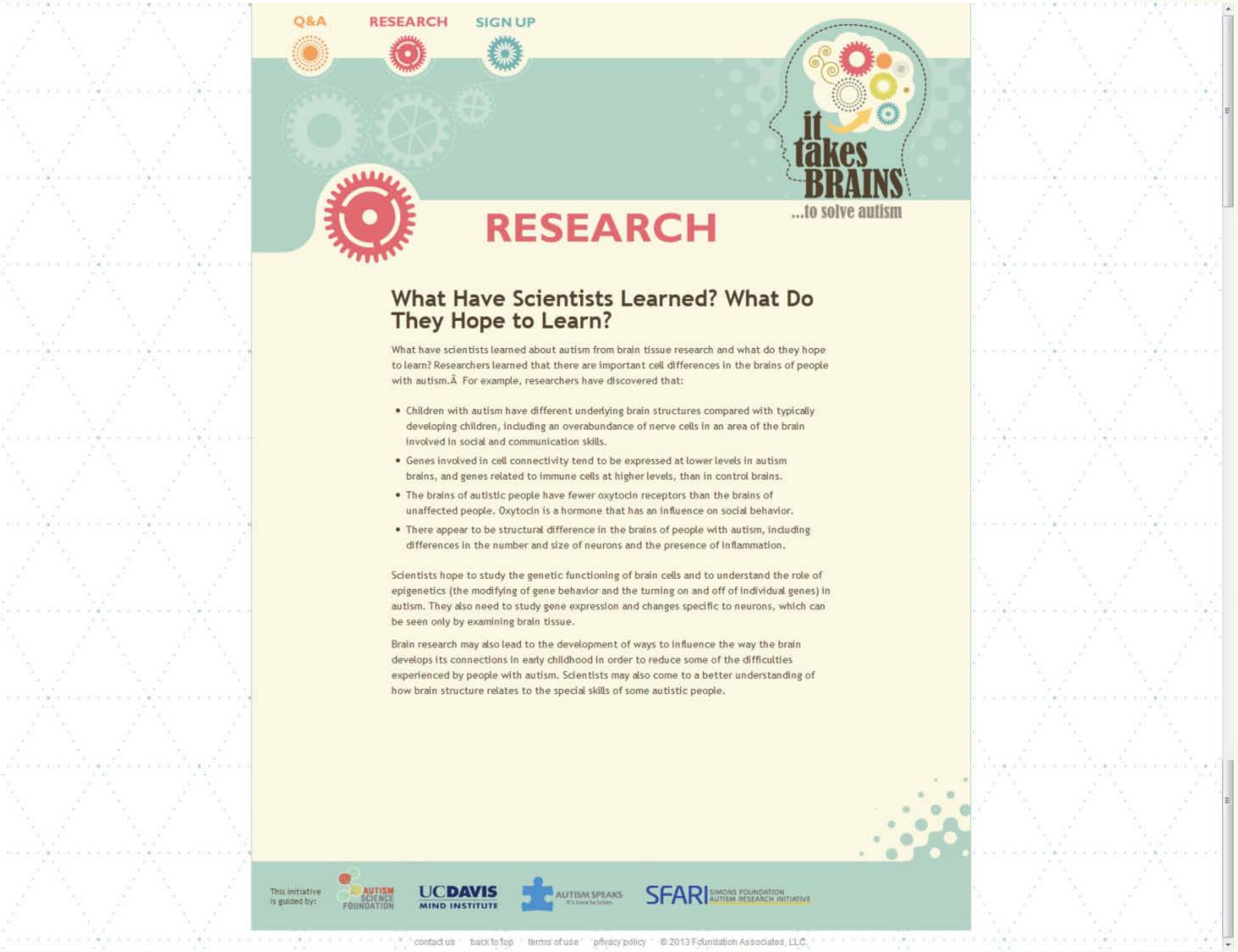
Q: Why can't scientists use MRIs, EEGs, or other imaging methods to study brain tissue?

A: *Currently, scientists can study the living brain by using imaging techniques and observing the electrical activity of the brain. Unfortunately, although research conducted using imaging techniques gives scientists some valuable information about brain structure and function, these methods only get us part of the way to the answers we seek. They do not allow scientists to see individual brain cells or study the very small molecular structures within the brain. Further, imaging techniques do not give scientists the information needed to understand the effects that genetic differences have on brain tissue. The only way to study brain structure and the structure of brain molecules is to examine the whole brain after death. These studies allow scientists to investigate particular pathways and look at the individual neurons of the brain to help understand both normal and abnormal brain development and activity. Similarly, the only way to see how gene expression occurs in different parts of the brain is to study the brain tissue itself.*

Q: Does registering as a donor mean that medical treatment will be altered?

Q: What are the various religious points of view on brain donation?

TakesBrains.org



RESEARCH

What Have Scientists Learned? What Do They Hope to Learn?

What have scientists learned about autism from brain tissue research and what do they hope to learn? Researchers learned that there are important cell differences in the brains of people with autism.Â For example, researchers have discovered that:

- Children with autism have different underlying brain structures compared with typically developing children, including an overabundance of nerve cells in an area of the brain involved in social and communication skills.
- Genes involved in cell connectivity tend to be expressed at lower levels in autism brains, and genes related to immune cells at higher levels, than in control brains.
- The brains of autistic people have fewer oxytocin receptors than the brains of unaffected people. Oxytocin is a hormone that has an influence on social behavior.
- There appear to be structural difference in the brains of people with autism, including differences in the number and size of neurons and the presence of inflammation.

Scientists hope to study the genetic functioning of brain cells and to understand the role of epigenetics (the modifying of gene behavior and the turning on and off of individual genes) in autism. They also need to study gene expression and changes specific to neurons, which can be seen only by examining brain tissue.

Brain research may also lead to the development of ways to influence the way the brain develops its connections in early childhood in order to reduce some of the difficulties experienced by people with autism. Scientists may also come to a better understanding of how brain structure relates to the special skills of some autistic people.

This initiative is guided by:

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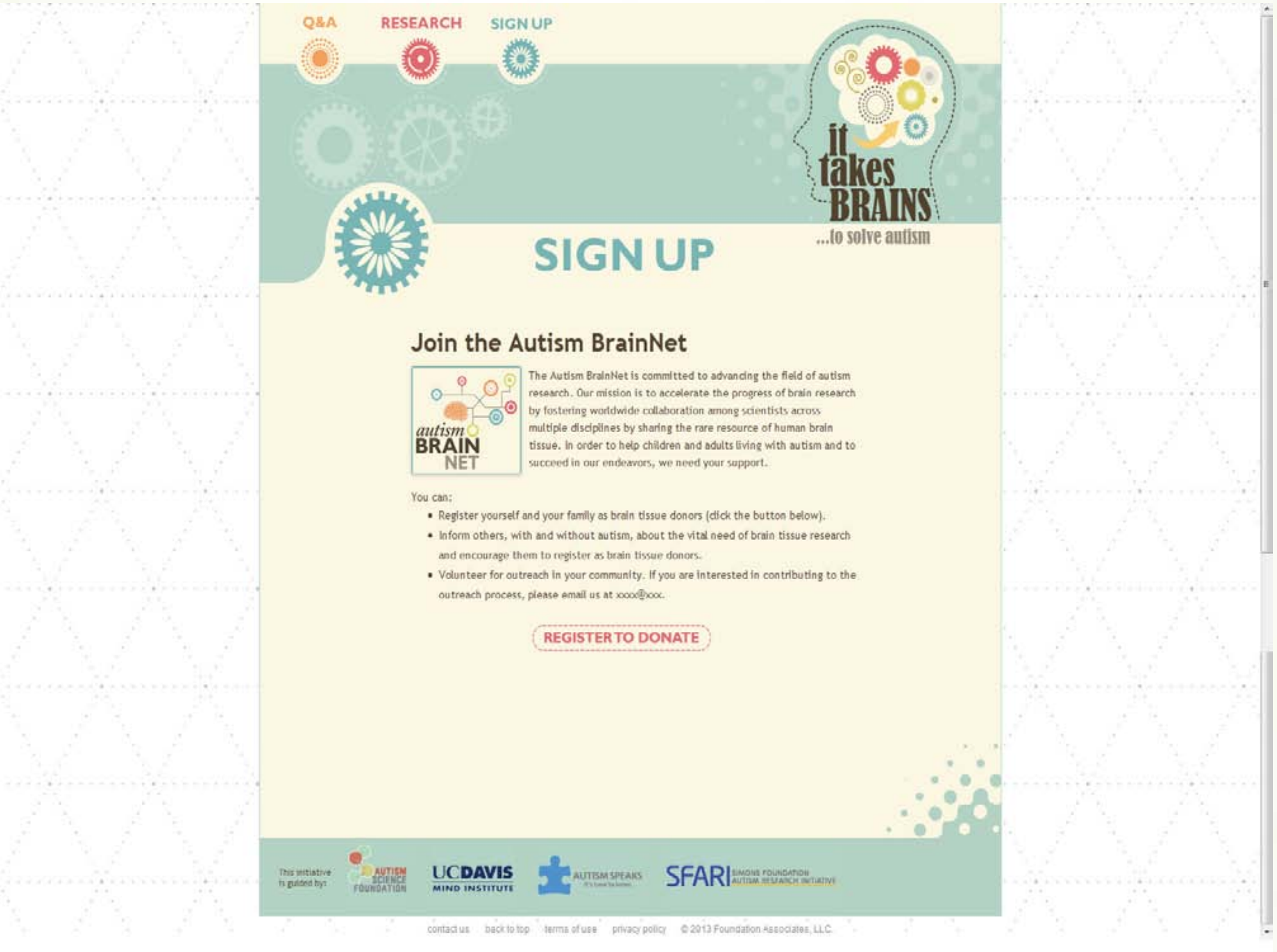
TakesBrains.org



SIGN UP

Join the Autism BrainNet

The Autism BrainNet is committed to advancing the field of autism research. Our mission is to accelerate the progress of brain research by fostering worldwide collaboration among scientists across multiple disciplines by sharing the rare resource of human brain tissue. In order to help children and adults living with autism and to succeed in our endeavors, we need your support.

You can:

- Register yourself and your family as brain tissue donors (click the button below).
- Inform others, with and without autism, about the vital need of brain tissue research and encourage them to register as brain tissue donors.
- Volunteer for outreach in your community. If you are interested in contributing to the outreach process, please email us at xxxx@xxx.

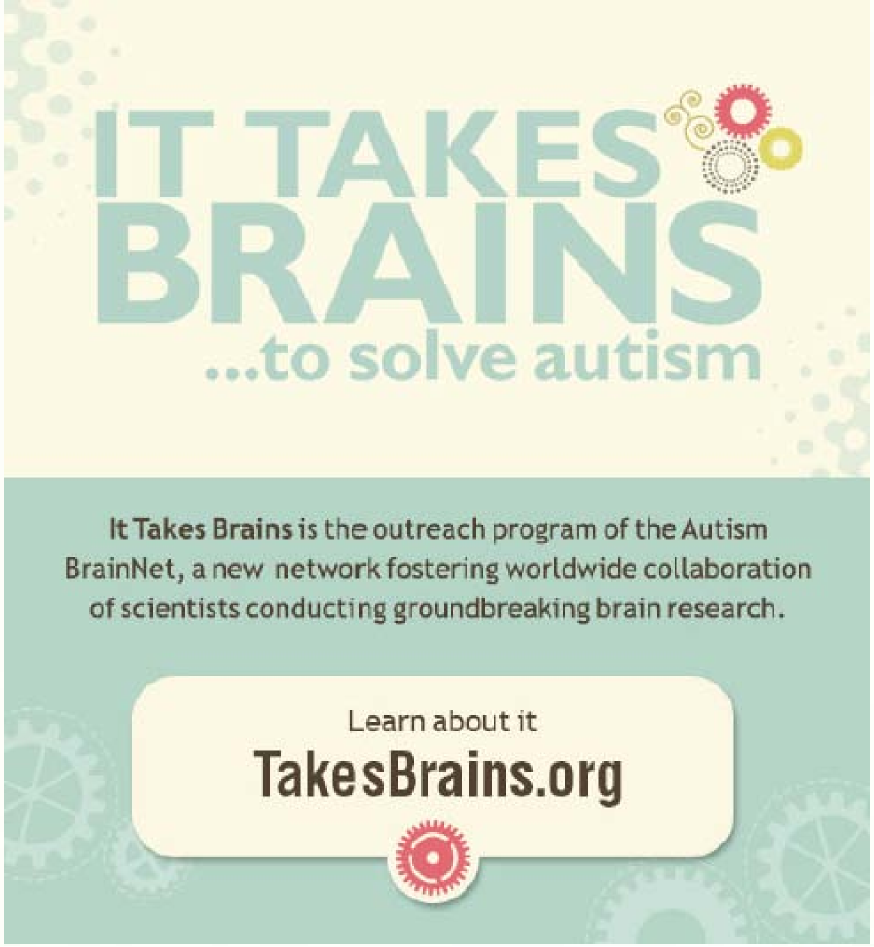
This initiative is guided by:


IT TAKES BRAINS
...to solve autism
RESEARCH
SIGN UP
it takes BRAINS
...to solve autism
BE A SUPER HERO
REGISTER TO DONATE
POST MORTEM BRAIN TISSUE
TODAY!
autism BRAIN NET


TAKES BRAINS
...to solve autism
RESEARCH
SIGN UP
it takes BRAINS
...to solve autism
BE A SUPER HE
REGIST


it takes BRAINS
...to solve autism
BE A SUPER HERO
REGISTER TO DONATE
POST MORTEM BRAIN TISSUE
TODAY!
autism BRAIN NET

You Can Register Right Now!



IT TAKES BRAINS

...to solve autism

It Takes Brains is the outreach program of the Autism BrainNet, a new network fostering worldwide collaboration of scientists conducting groundbreaking brain research.

Learn about it

TakesBrains.org

Meeting of the IACC

Break

Meeting of the IACC

Morning Agenda - continued

11:00	**NIH NeuroBioBank** **Michelle P. Freund, Ph.D.** Program Chief National Institute of Mental Health (NIMH)
11:20	**Briefing on State of the States** **Sonya Bowen, MSW** Health Insurance Specialist Centers for Medicare & Medicaid Services
11:50	**Lunch**
1:00 PM	**Public Comment**
1:30	**Discussion of Public Comment**

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Meeting of the IACC

NIH NeuroBioBank

Michelle P. Freund, Ph.D.
National Institute of Mental Health

NIH NeuroBioBank: A Platform for Postmortem Brain Research

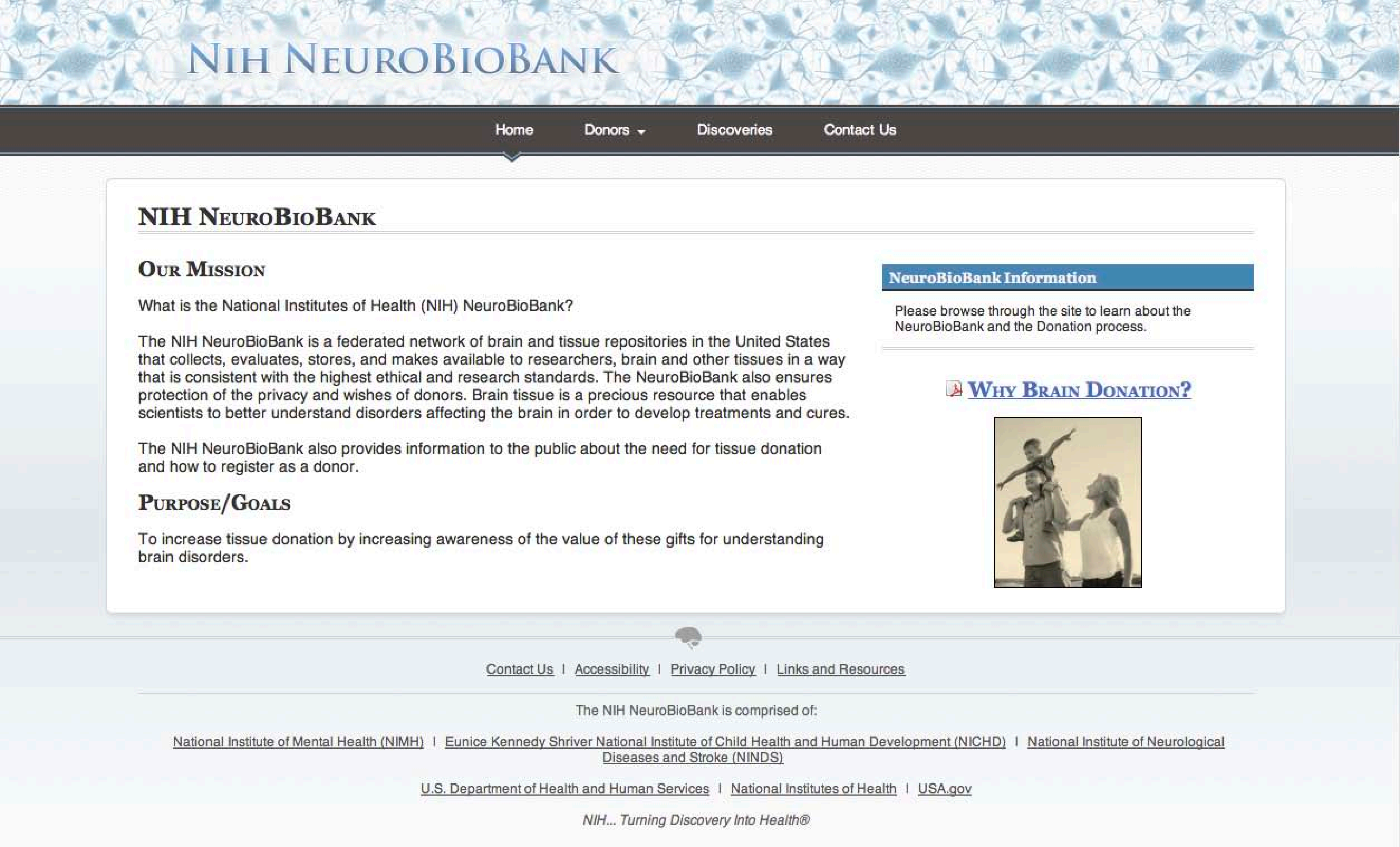
Interagency Autism Coordinating Committee

July 8, 2014

Michelle Freund, PhD

What is the NeuroBioBank?

- A federated brain and tissue repository network integrated by an IT system (https://neurobiobank.nih.gov)
- Brain and tissue repositories are now being supported with contracts (NIMH, NINDS and NICHD)
- Focus on quality management, sharing, outreach



NIH NEUROBIOBANK

OUR MISSION

What is the National Institutes of Health (NIH) NeuroBioBank?

The NIH NeuroBioBank is a federated network of brain and tissue repositories in the United States that collects, evaluates, stores, and makes available to researchers, brain and other tissues in a way that is consistent with the highest ethical and research standards. The NeuroBioBank also ensures protection of the privacy and wishes of donors. Brain tissue is a precious resource that enables scientists to better understand disorders affecting the brain in order to develop treatments and cures.

The NIH NeuroBioBank also provides information to the public about the need for tissue donation and how to register as a donor.

PURPOSE/GOALS

To increase tissue donation by increasing awareness of the value of these gifts for understanding brain disorders.

NeuroBioBank Information

Please browse through the site to learn about the NeuroBioBank and the Donation process.

WHY BRAIN DONATION?

Contact Us | Accessibility | Privacy Policy | Links and Resources

The NIH NeuroBioBank is comprised of:

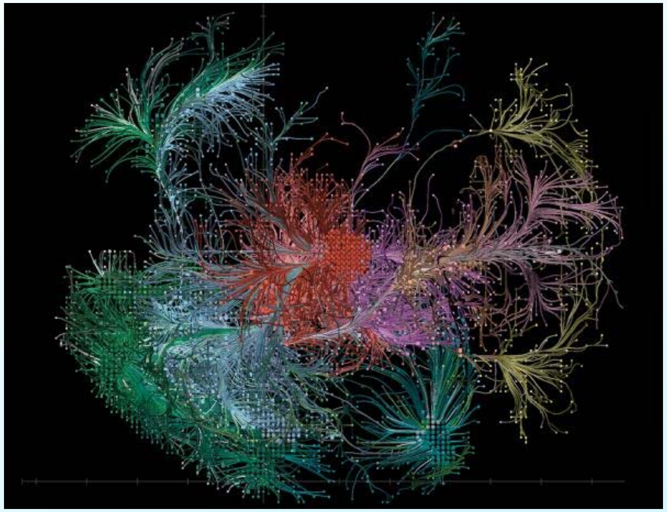
National Institute of Mental Health (NIMH) | Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) | National Institute of Neurological Diseases and Stroke (NINDS)

U.S. Department of Health and Human Services | National Institutes of Health | USA.gov

NIH... Turning Discovery Into Health®

https://neurobiobank.nih.gov

Why are we doing this?



- Increase the availability of tissue
- Standardize quality metrics
- Return data derived from banked tissues to public database
- Opportunities for discovery have never been greater (genetics, iPSCs, and –omics,)

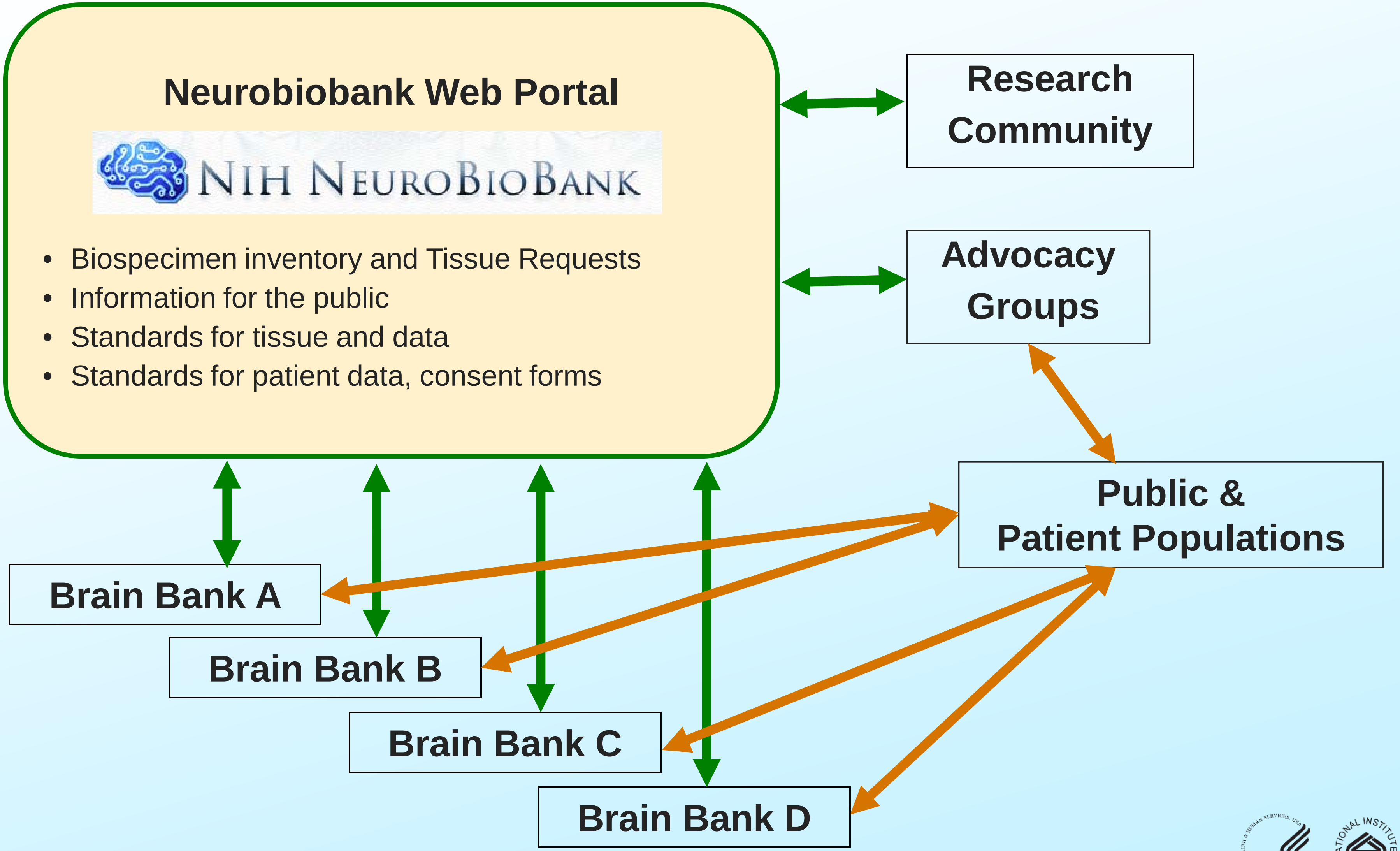
The NIH NeuroBioBank for tissue access

NIH NeuroBioBank

- Include specimen inventory and access information
- Set tissue quality and data standards
- Information/training for investigators
- Forum for collaboration among BTR Directors

The NIH NeuroBioBank for tissue access

NIMH
National Institute of Mental Health



Neurobiobank Web Portal

NIH NeuroBioBank

- Biospecimen inventory and Tissue Requests
- Information for the public
- Standards for tissue and data
- Standards for patient data, consent forms

Research Community

Advocacy Groups

Public & Patient Populations

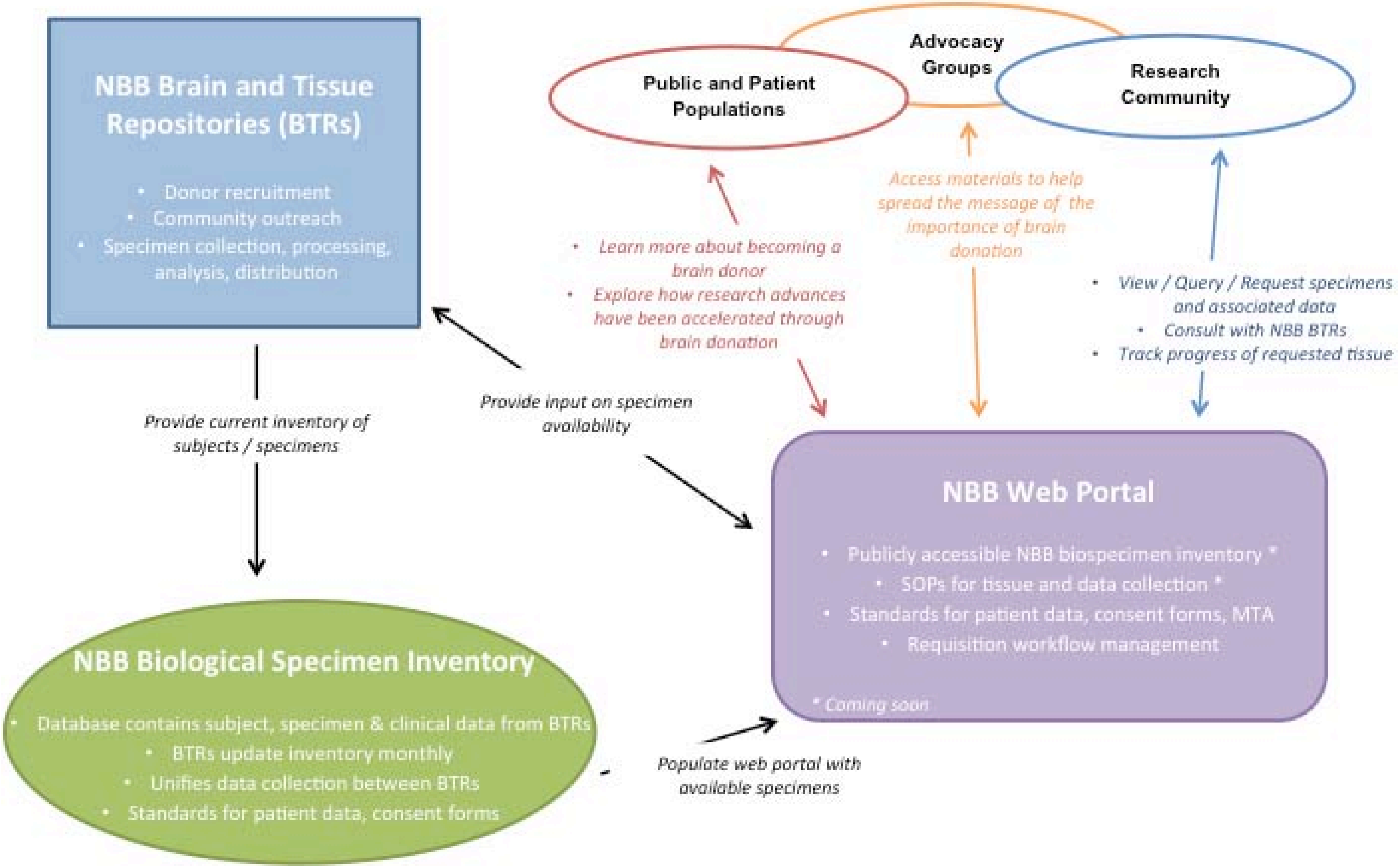
Brain Bank A

Brain Bank B

Brain Bank C

Brain Bank D

NIH NeuroBioBank



NBB Brain and Tissue Repositories (BTRs)

- Donor recruitment
- Community outreach
- Specimen collection, processing, analysis, distribution

Provide current inventory of subjects / specimens

NBB Biological Specimen Inventory

- Database contains subject, specimen & clinical data from BTRs
- BTRs update inventory monthly
- Unifies data collection between BTRs
- Standards for patient data, consent forms

Provide input on specimen availability

Populate web portal with available specimens

Public and Patient Populations

Advocacy Groups

Research Community

- *Learn more about becoming a brain donor*
- *Explore how research advances have been accelerated through brain donation*

Access materials to help spread the message of the importance of brain donation

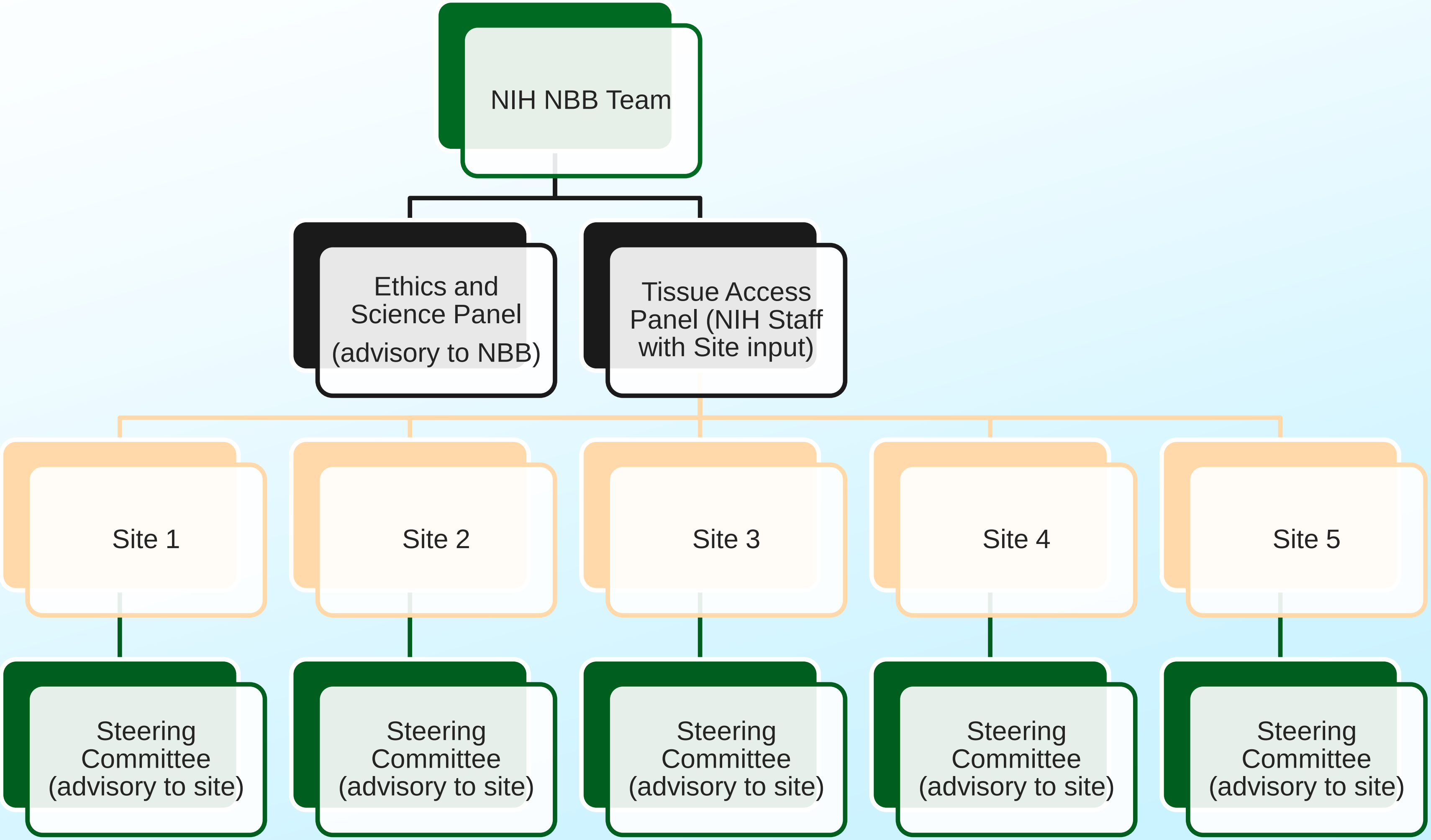
- *View / Query / Request specimens and associated data*
- *Consult with NBB BTRs*
- *Track progress of requested tissue*

NBB Web Portal

- Publicly accessible NBB biospecimen inventory *
- SOPs for tissue and data collection *
- Standards for patient data, consent forms, MTA
- Requisition workflow management

** Coming soon*

Governance



NIH NBB Team

Ethics and Science Panel (advisory to NBB)

Tissue Access Panel (NIH Staff with Site input)

Site 1

Site 2

Site 3

Site 4

Site 5

Steering Committee (advisory to site)

Steering Committee (advisory to site)

Steering Committee (advisory to site)

Steering Committee (advisory to site)

Steering Committee (advisory to site)

External Ethics and Scientific Panel

Name	Role
Daniel Perl, MD USUHS	Neuropathologist/End-user, CTE
Samantha Wetzler, MD National Association of Medical Examiners (NAME)	Chair, Organ and Tissue Procurement Committee
Jeffrey Brosco, MD, PhD University of Miami	Bioethics/Autism and Child Health and Development
Carol Tamminga, MD UT Southwestern	End-user, ATP Advisor
Elliot Mufson, PhD Rush University	End-user, Translational Neuroscience
*Mary Giliberti, Esq	Advocacy/Executive Director NAMI (*will nominate member)

Status of the NIH NeuroBioBank

- NeuroBioBank IT Portal is now live with information for the public, researcher site in development
- Contracts were awarded to five Brain and Tissue Repositories on September 1, 2013

University of Miami, PI: Deborah Mash
Harvard University, PI: Francine Benes
Mt. Sinai, PI: Harry Haroutunian
Sepulveda Research Corporation, PI: Rashed Nagra
University of Pittsburgh, PI: David Lewis

- Efforts to centralize/standardize toxicology testing are underway
- Proposals for FY14 sites will be reviewed at end of April.

Status of the NeuroBioBank

- **Neurobiobank implementation will focus on:**
  - Quality Management (pH, PMI, RIN)
  - Increasing tissue and data access
  - Setting Standards (phenotype and tissue quality, neuropathology)
  - Outreach

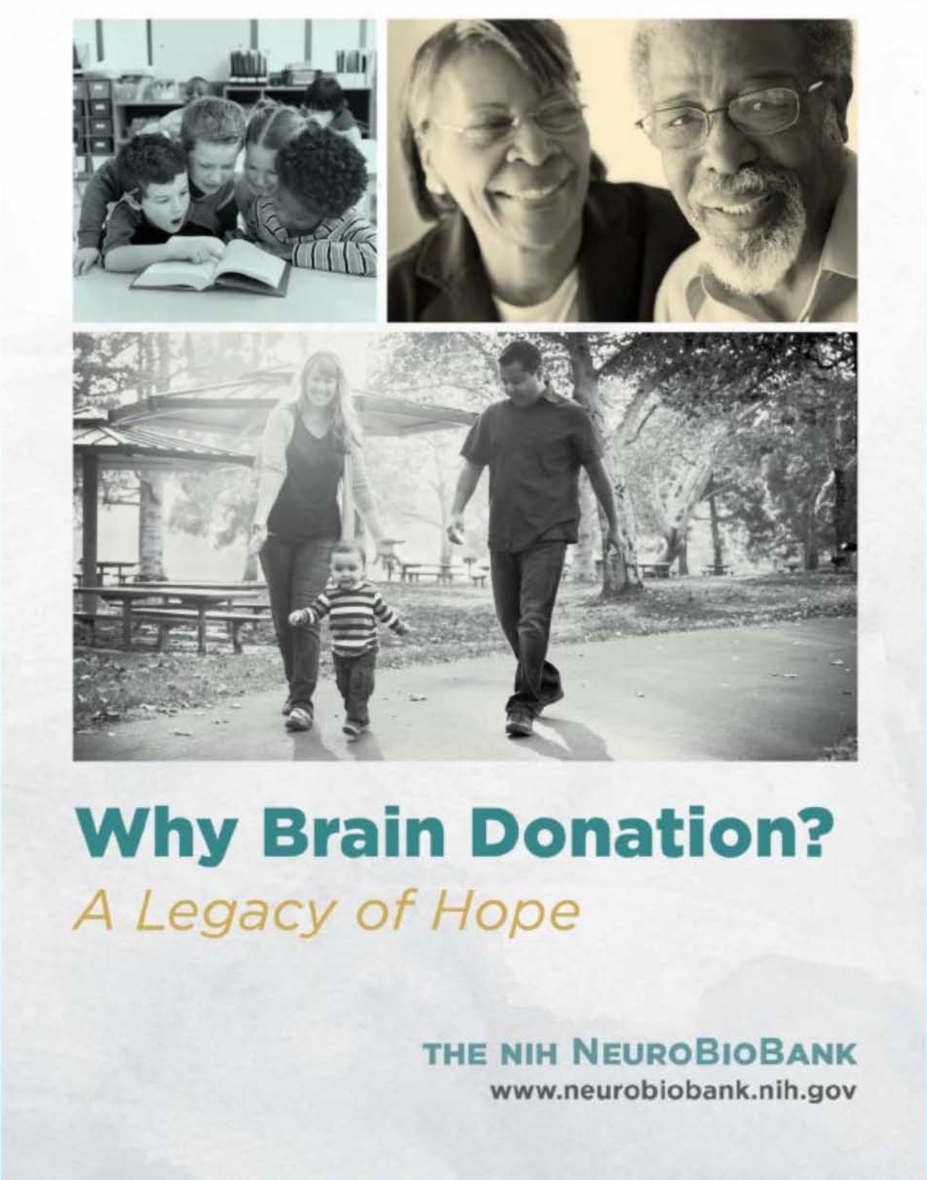
Increase access to human tissues

- Geographically distributed brain and tissue repositories
- Increase public awareness/prospective donation
- Partner with disease advocacy communities and local medical examiners (ME) to increase donation
- Incentivize current bankers to increase diversity of donor pool

Deliverables/Requirements for NBTRs:

- Participation in PI teleconferences
- Quarterly Progress Reports
- Transition Plans
- IT Security Documents
- Procedures Manuals made available through the Portal
- PI Meeting—April 25th

Thank You



Why Brain Donation?

A Legacy of Hope

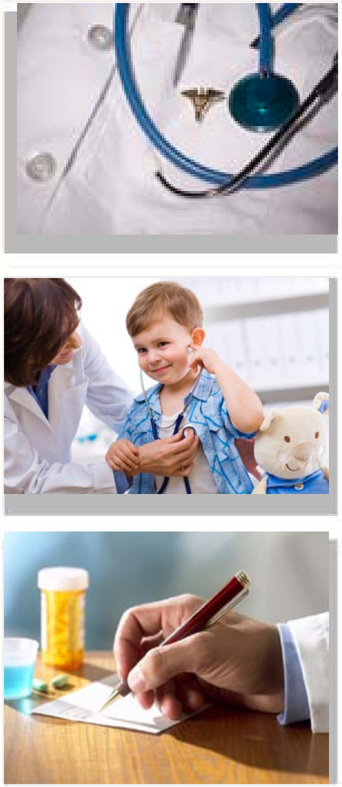
THE NIH NEUROBIOBANK
www.neurobiobank.nih.gov

Meeting of the IACC

Briefing on State of the States

Sonya Bowen, MSW
Centers for Medicare & Medicaid Services

State of the States of Services & Supports for People with Autism Spectrum Disorders



Disabled and Elderly Health Programs Group
Center for Medicaid and CHIP Services

July 8, 2014

Background

- CMS contracted with L&M Policy Research in 2009 to address the growing need among federal and state policymakers and stakeholders for comprehensive information regarding available resources for individuals with an autism spectrum disorder (ASD)
- The ASD state of the states study supported 2010 and 2011 Interagency Autism Coordinating Committee's strategic plan objectives

Study Goal

- Collect information on existing state and federal programs and supports for individuals and families living with ASD in 50 states and the District of Columbia

- Develop comprehensive, state-specific summaries of available programs and supports

Target Audience

The ASD state of the states report is intended to inform:

- Individuals with ASD and their families
- Advocates
- State policy makers
- Federal policy makers
- Research community

Data Collection

- 2012-2013 study period
- L&M interviewed state level staff crucial to the implementation of policy and programs supporting families living with ASD
- L&M reviewed publicly available resources from local advocacy organizations and state programs

Guiding Questions

- What are states and/or local government doing to provide services for people with ASD?
- What are the types of services and supports that a person with ASD can access?
- How are these supports and services funded?

State Profile Contents

- Interview approach
- State bills & legislation
- State insurance regulations
- Medicaid Home and Community-Based Service (HCBS) programs
- State services and supports
- Early Intervention
- School aged children
- Adults

State Profile Contents (con’t.)

- Systems Tracking
- Transitions and Coordination of Services
  - Early intervention to school
  - School aged to employment
- Training for direct service support workforce
- Corrections
- Long-term plans to expand supports and services

Service/Support Gaps

- ASD specific services for adults
- Options for individuals on program waiting lists
- Provider availability and access
- Supports for seamless transitions
- Best practices across the lifespan
- Insurance mandate barriers

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

Potential Report Uses

- Identify promising state policies and programs impacting individuals with ASD and their support systems
- Pinpoint service and/or support gaps
- Compare type and scope of services and supports available across states
- Identify opportunities to improve coordination across state systems of care

Access Report

The Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD is available on-line at:

http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf

Report Questions

Sonya Bowen

Sonya.Bowen@cms.hhs.gov

Meeting of the IACC

Lunch

Meeting of the IACC

Public Comments and Discussion

AUTISM & SAFETY

WENDY FOURNIER | NATIONAL AUTISM ASSOCIATION

NATIONAL
AUTISM
ASSOCIATION

WANDERING UPDATE

Autism-related wandering has resulted in another 27 fatalities since last year.

Based on our data, there have been at least 67 U.S. deaths since we first brought this issue to IACC in 2010.

NATIONAL
AUTISM
ASSOCIATION

NationalAutism.org

July 2014

TIMELINE

2008

- NAA's FOUND Established
- NAA Calls for AMBER/Silver Alert Modifications

2009

- NAA began collecting data
- NAA provided tracking funding for agencies

2010

- NAA IACC Statement
- NAA IACC Presentation
- IACC Safety Subcommittee Created
- AWAARE Collaboration Created

2011

- Wandering Diagnostic Code Goes Into Effect
- IACC Letter to Secretary Sebelius
- NAA Big Red Safety Boxes Launched
- Preliminary Data Released

2012

- Federal Search/Rescue Guidelines Created
- Data Published in *Pediatrics*
- NAA Lethal Outcomes White Paper
- NAA Big Red Safety Toolkits & Booth
- NAA YMCA List

2013

- NAA IACC Presentation
- Children's Health Group
- NAA Ongoing Training
- DoE Letter

2014

- PSA Campaign with NCMEC
- 12,300 Big Red Safety Boxes distributed to date
- iPads/AAC Devices
- Reviewing underlying conditions/root causes
- Research on Auditory Sensitivities as cause
- Swim lessons/ADA Title III
- Call for DoE Policy Guidelines and FDA Oversight on tracking technology

TRENDS

TRENDS

MORE REPORTS OF "BOLTING"

We are documenting more cases that we would classify as "bolting" – when an individual suddenly becomes frustrated or overwhelmed and quickly leaves his or her environment. We believe there are multiple triggers that can cause a fight or flight response including:

- Fears/Phobias
- Auditory Sensitivities
- Sensory Issues
- Frustration
- Confusion
- Communication Challenges

Research is needed!

TRENDS

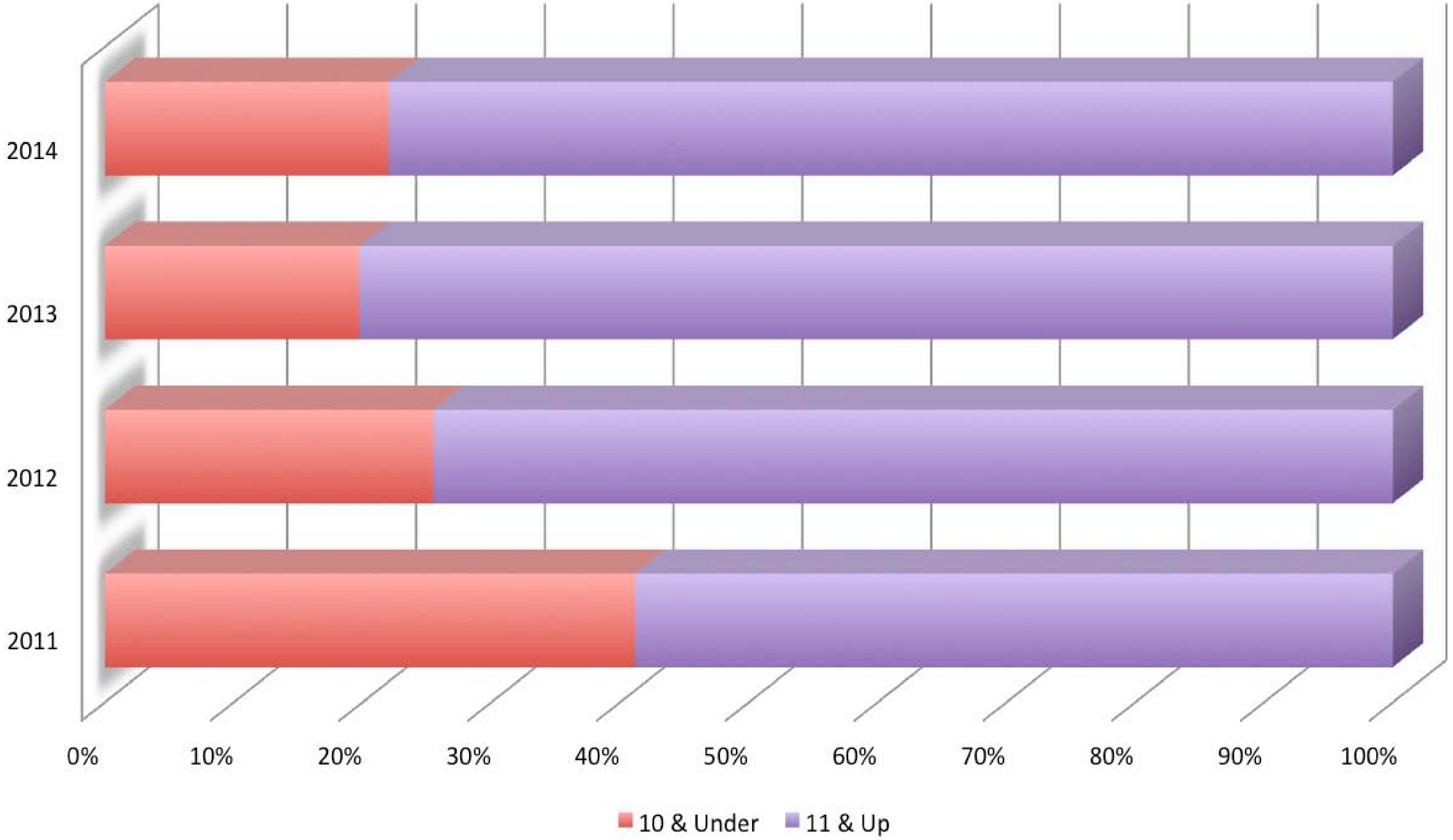
MORE TEENS AND ADULTS AT RISK

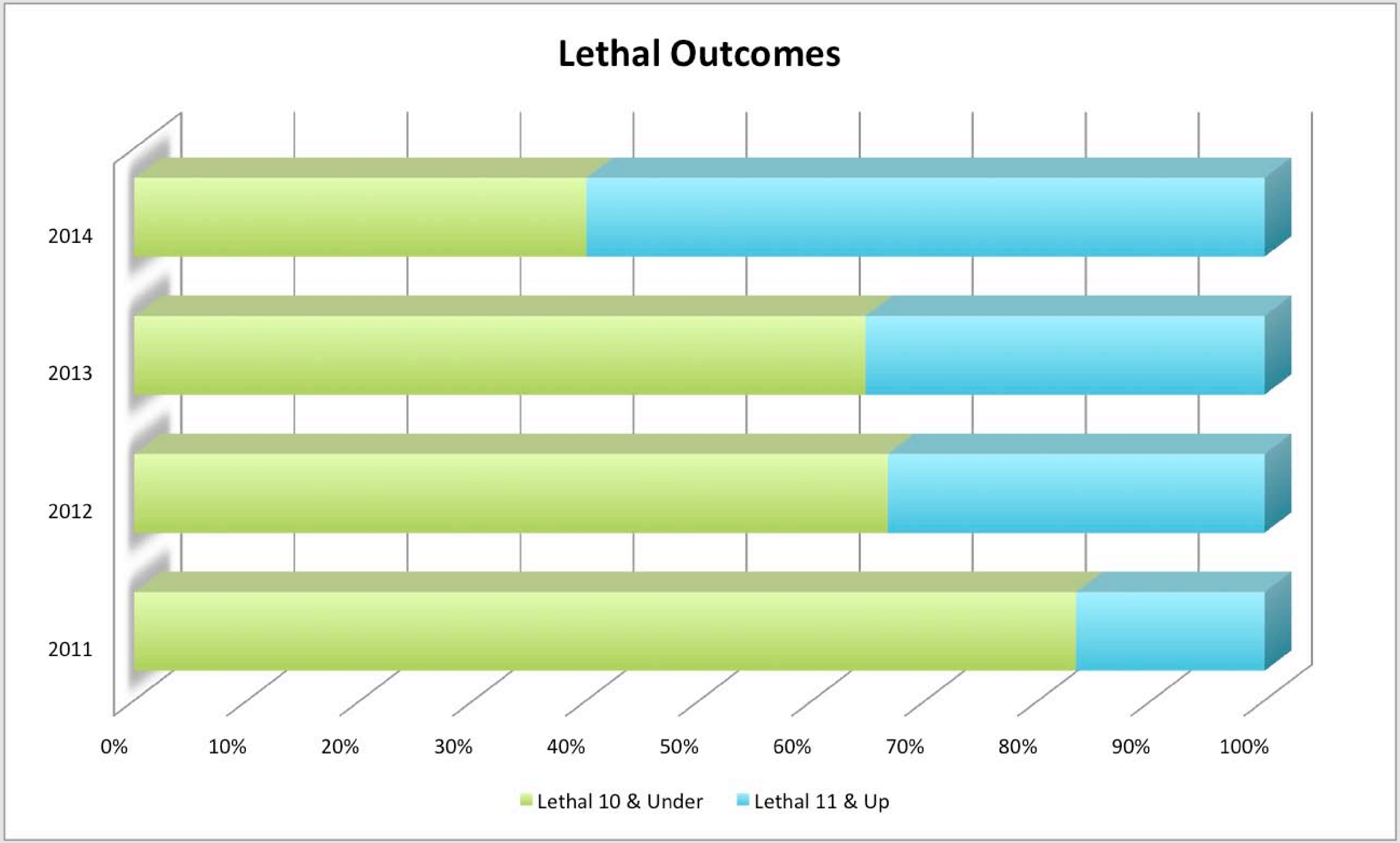
Romario Snow De la Torre
18 years old
Missing since June 27th
Minimally verbal
Functions at 10-year-old level

Christina Sankey
29 years old
Became separated from caregiver while shopping. Her half-naked body was found the next morning 5 miles away.

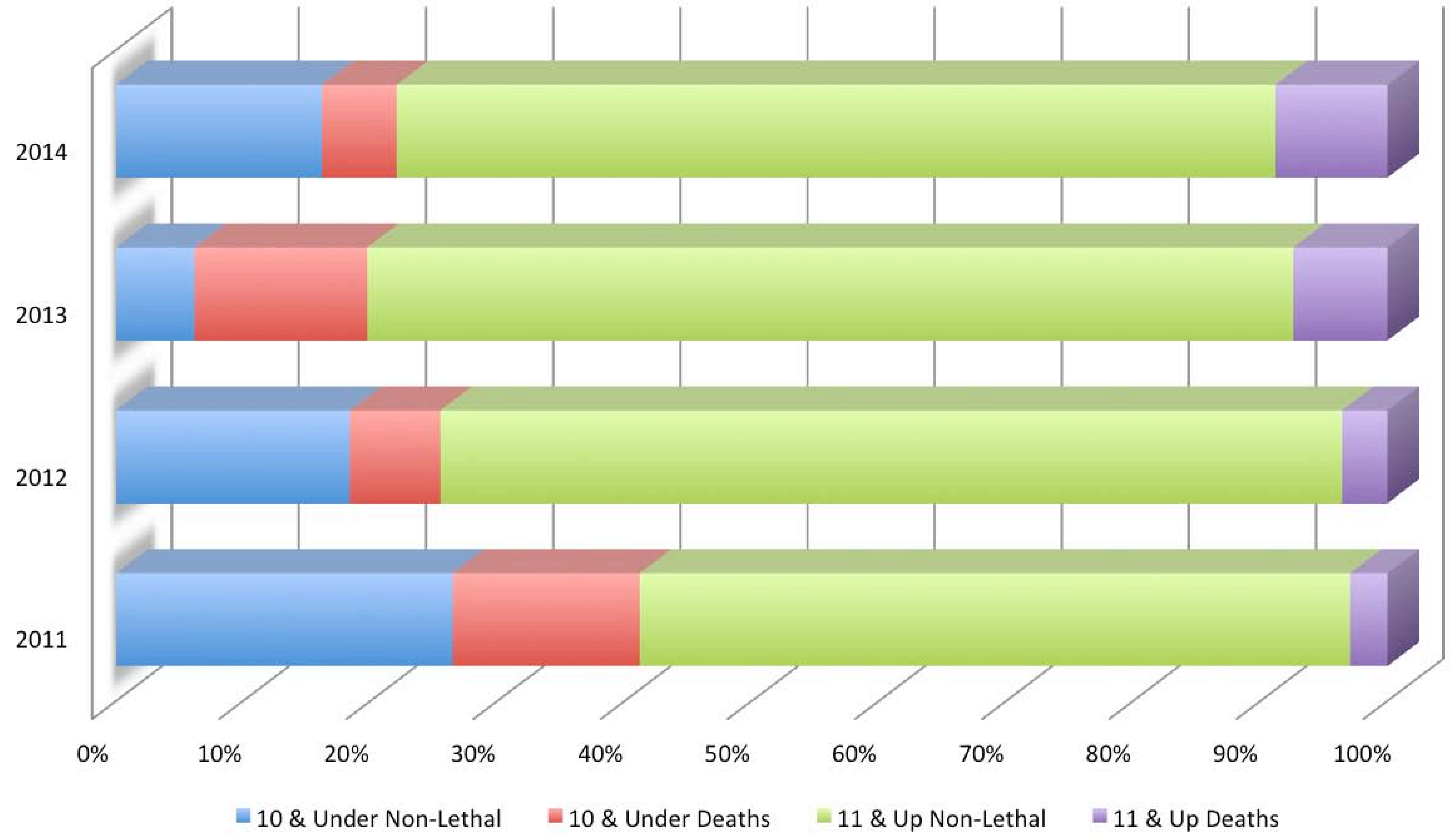
Jeffrey Perez
16 years old
Seen walking on a San Antonio freeway in the early morning hours.
Fatally struck by several cars.

All Cases




Lethal Outcomes
2014
2013
2012
2011
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Lethal 10 & Under
Lethal 11 & Up

All Cases



2014
2013
2012
2011
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
10 & Under Non-Lethal
10 & Under Deaths
11 & Up Non-Lethal
11 & Up Deaths

CAUSES

CAUSES

2012 IAN STUDY DATA

Parents reported their child:

“tries to reach a place he or she enjoys” (36%)

“tries to escape an anxious situation” (34%)

“tries to escape uncomfortable sensory stimuli” (30%)

“pursues his or her special topic” (30%)

Ref: Connie Anderson, J. Kiely Law, Amy Daniels, Catherine Rice, David S. Mandell, Louis Hagopian, and Paul A. Law. **Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders**. *Pediatrics*, October 8, 2012 DOI: 10.1542/peds.2012-0762

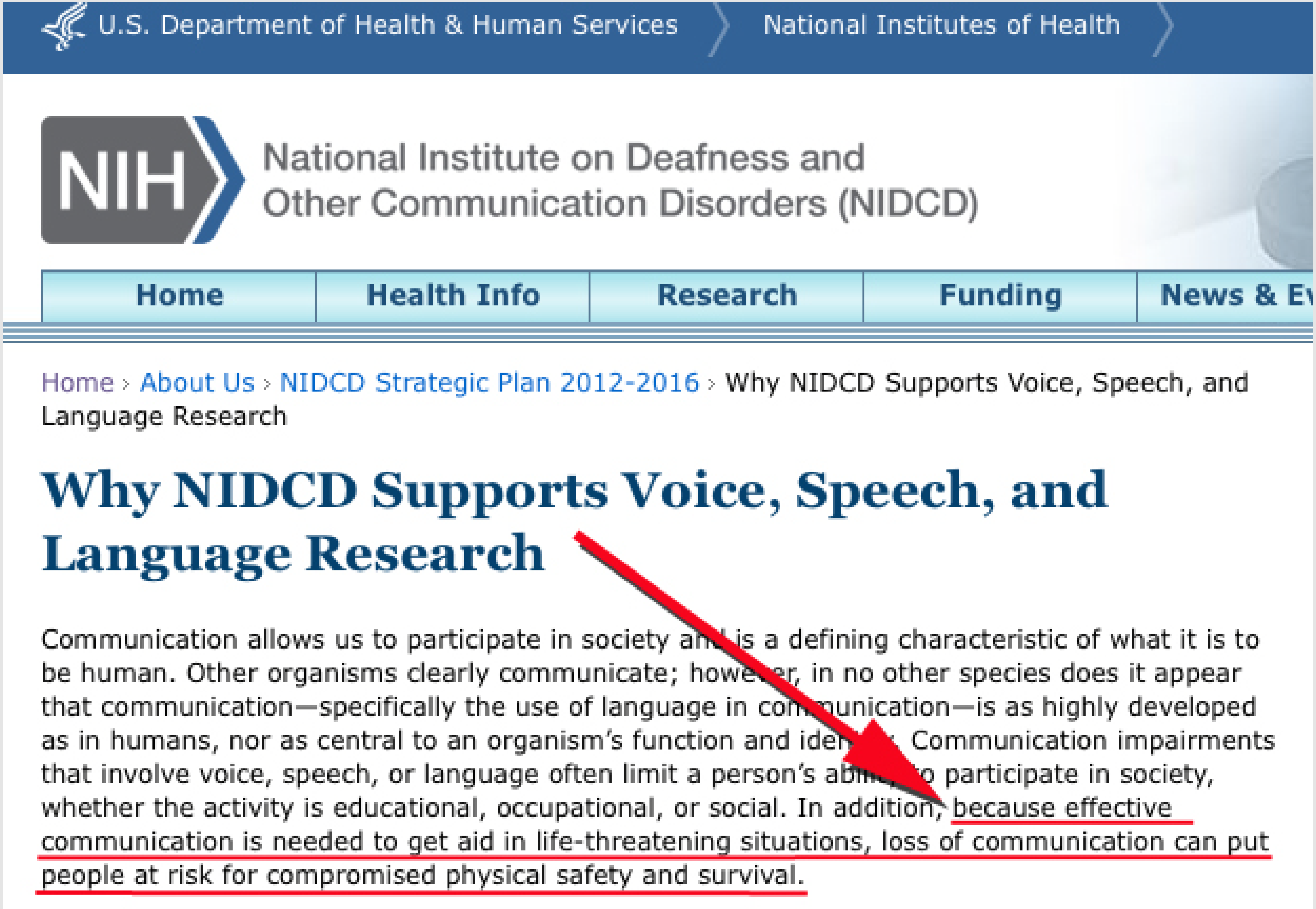
CAUSES

COMMUNICATION DISORDERS

According to CDC, approximately 40% of people with an ASD are non-verbal.

They are ***unable to communicate their wants and needs – which could be triggers for wandering/elopement.***

“It’s too loud, I need to leave.”
“I’m scared.”
“I want to go to the swings at the park.”
“I want to go home.”
“I want to go swimming.”



National Institute on Deafness and Other Communication Disorders (NIDCD)

Home › About Us › NIDCD Strategic Plan 2012-2016 › Why NIDCD Supports Voice, Speech, and Language Research

Why NIDCD Supports Voice, Speech, and Language Research

Communication allows us to participate in society and is a defining characteristic of what it is to be human. Other organisms clearly communicate; however, in no other species does it appear that communication—specifically the use of language in communication—is as highly developed as in humans, nor as central to an organism's function and identity. Communication impairments that involve voice, speech, or language often limit a person's ability to participate in society, whether the activity is educational, occupational, or social. In addition, because effective communication is needed to get aid in life-threatening situations, loss of communication can put people at risk for compromised physical safety and survival.

CAUSES

EVERYONE DESERVES TO HAVE A VOICE

With an iPad, Anthony has learned how to ask for help when needed without having tantrums.

CAUSES

When Max is outside, he prefers to wear airport headphones, otherwise he always covers his ears. He has always had sensory sensitivities, especially to loud sounds.

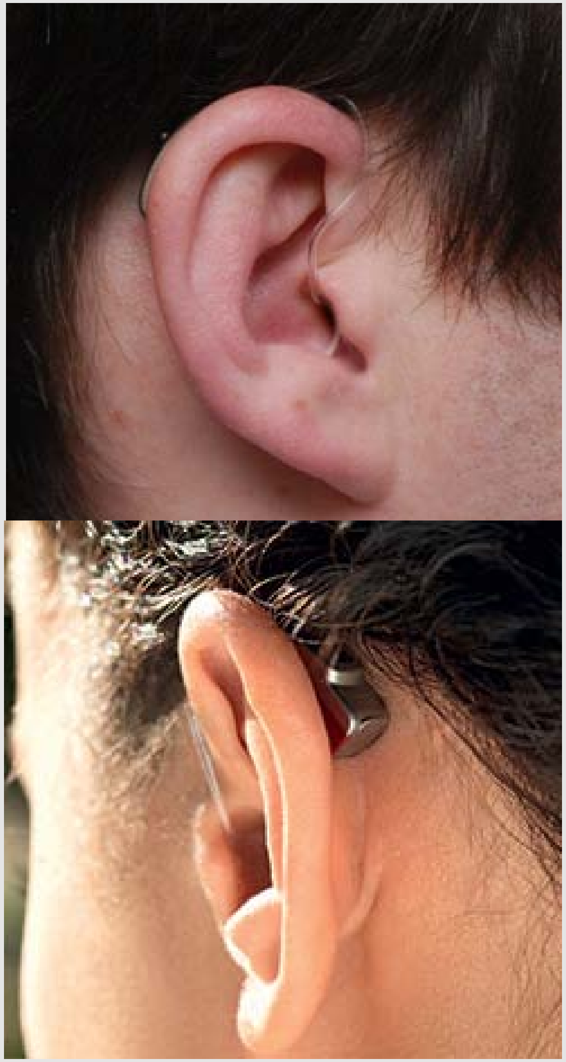
AUDITORY SENSITIVITIES

Anxiety. Stress. Pain.

Quality of Life?

“tries to escape uncomfortable sensory stimuli” (30%) – IAN study

IAN/NAA Follow-up study currently in development on auditory sensitivities as a safety risk.



It is well known that the use of directional acoustic sensing in hearing aids can be a very effective means of reducing the influence of unwanted background acoustic noise and as a result can significantly improve the understanding of speech in noisy environments.

(Amlani et al., 2006;Blamey et al., 2006; Hornsby and Ricketts, 2007; Ricketts et al., 2003; Walden et al., 2004)

In hearing aids, it is highly desirable that the distance between the points at which the pressure is sensed be kept to a bare minimum, on the order of a few millimeters in order for the size of the device to be ***cosmetically acceptable***.

Effective? Safe?

Cosmetically acceptable?

CAUSES

AUDITORY AND COMMUNICATION DISORDERS

Just part of autism? No!

How we categorize disorders influences how we treat them. These are significant medical issues that affect both quality of life and personal safety. They should never be overlooked or dismissed because of a co-occurring Autism diagnosis.

A medical model needs to be established through the NIDCD under the advisement of HHS through the direction of IACC. Our loved ones deserve access to effective technology and treatment for auditory and communication disorders.

WHAT WE NEED

WHAT WE NEED

RESEARCH

To discover underlying causes of elopement. To establish a medical model addressing auditory and communication disorders, focusing especially on how they relate to safety issues.

DATA

Coordination between agencies to collect data on wandering incidents, triggers and possible root causes that could be further researched leading to prevention of elopement incidents.

TECHNOLOGY

To assist in preventing wandering incidents, based on unique medical needs of individuals with autism including auditory sensitivities and communication disorders.
FDA oversight of GPS devices.

AAC DEVICES

Communication challenges create serious safety risks. AAC devices should be considered medically-necessary and covered by insurance providers.

RESOURCES

Families need support from physicians, schools, law enforcement and social workers. They need access to swimming lessons and an Emergency Alert System that applies to all who have a disability regardless of age.

EDUCATION

Training for caregivers, school administrators, clinicians, law enforcement officers, first responders, CPS workers and the public. Policy Guidance from Dept. of Education for wandering prevention in all schools.

THANK YOU.

Wendy Fournier
wendy@nationalautism.org
http://nationalautism.org

Meeting of the IACC

Afternoon Agenda

1:45 **Update on the South Carolina Children's Educational Surveillance Study (SUCCESS)**

Laura Carpenter, Ph.D., BCBA
Associate Professor of Pediatrics
Medical University of South Carolina

2:15 **Break**

2:30 **Panel on Autism Trajectories**

2:30–2:50 **Audrey Thurm, Ph.D.**
Staff Scientist , National Institute of Mental Health

2:50–3:10 **Rebecca Landa, Ph.D., CCC-SLP**
Director, Center for Autism and Related Disorders
Kennedy Krieger Institute

3:10–3:30 **Catherine Lord, Ph.D.**
Director, Center for Autism and the Developing Brain

Meeting of the IACC

South Carolina Children's Educational Surveillance Study (SUCCESS)

Laura Carpenter, Ph.d.
Associate Professor of Pediatrics
Medical University of South Carolina

The South Carolina Children's Educational Surveillance Study: SUCCESS

Laura Arnstein Carpenter, PhD, BCBA
Associate Professor of Pediatrics
Medical University of South Carolina

success

South Carolina Children's
Educational Surveillance Study

SUCCESS Research Team

MUSC
Children's Hospital®

Acknowledgements

- Autism Speaks
  - Michael Rosanoff
- CDC
  - Cathy Rice, Marshalyn Yeargin-Allsopp
- Young Shin Kim (consultant)
- Our *many* community partners

South Carolina Children's Educational Surveillance Study

Prevalence

- ASD Prevalence = number of people with ASD in a population/total population
  - How is ASD defined?
  - How is ASD measured?
  - Who is represented and who is missed?

- Understanding ASD prevalence is critical
  - Are we equipped to provide help to everyone who needs it?

MUSC Children's Hospital

SUCCESS
South Carolina Children's
Educational Surveillance Study

Methods for evaluating prevalence

- Surveys*
- Registries*
- Administrative counts of people receiving services for ASDs*
- CDC ADDM Network (active case finding approach)
- Population based screening and assessment

*Require prior diagnosis

MUSC
Children's Hospital

success

South Carolina Children's
Educational Surveillance Study

CDC

Autism Speaks

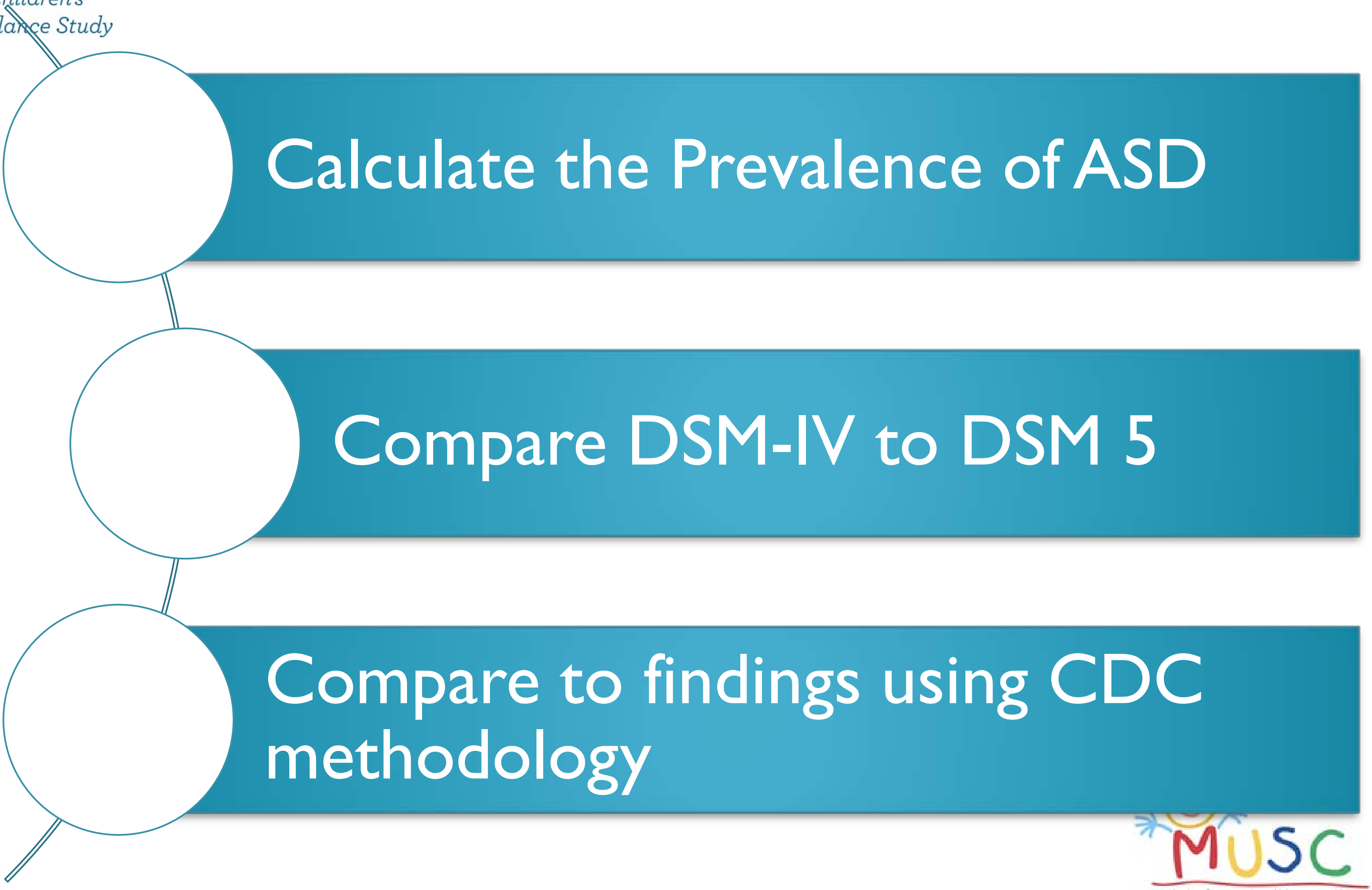
SUCCESS

Community

MUSC

SUCCESS
South Carolina Children's Educational Surveillance Study

IACC Question 7: What other infrastructure and surveillance needs must be met?



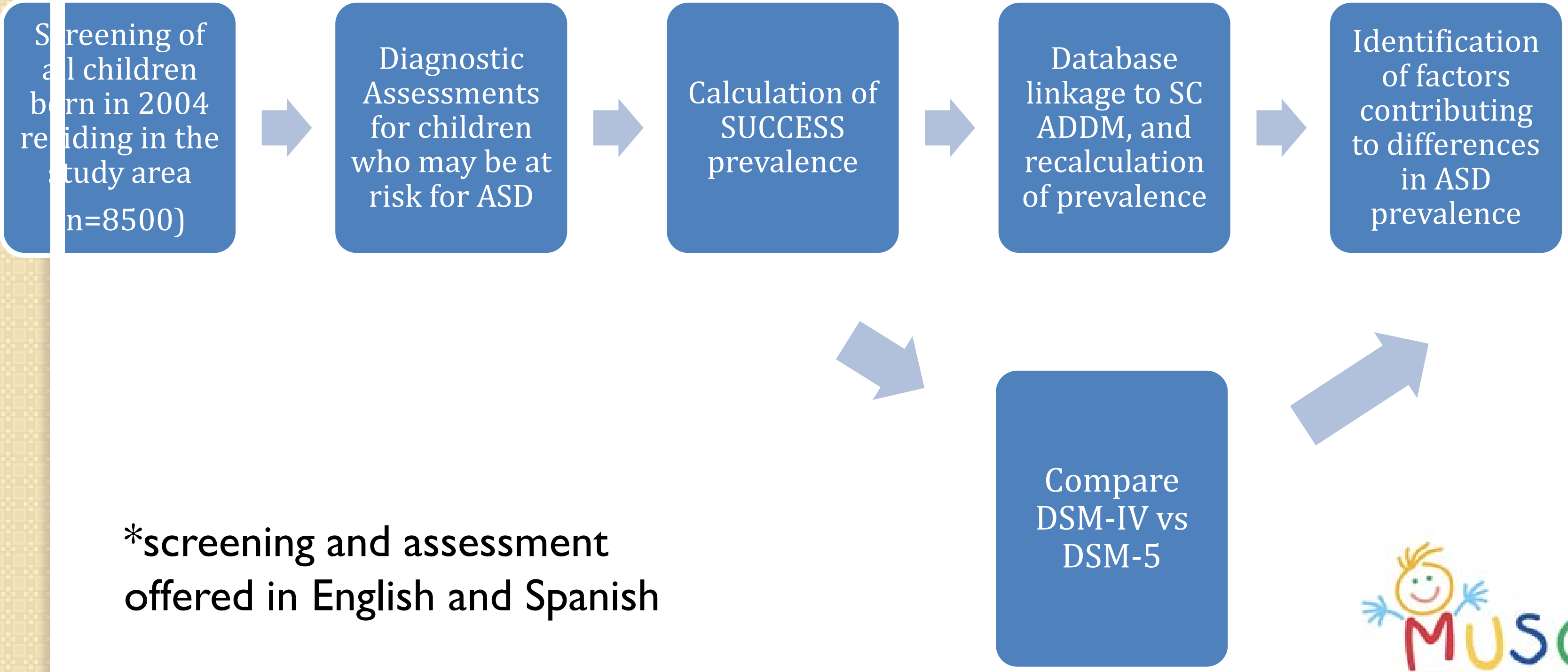
Calculate the Prevalence of ASD

Compare DSM-IV to DSM 5

Compare to findings using CDC methodology

MUSC Children's Hospital

SUCCESS:
A population-based screening and assessment study



S reening of a l children b rn in 2004 re iding in the tudy area

n=8500)

Diagnostic Assessments for children who may be at risk for ASD

Calculation of SUCCESS prevalence

Database linkage to SC ADDM, and recalculation of prevalence

Identification of factors contributing to differences in ASD prevalence

Compare DSM-IV vs DSM-5

*screening and assessment offered in English and Spanish

SUCCESS
South Carolina Children's Educational Surveillance Study

Timeline

Screening
- Fall 2014

Evaluations
- Winter 2015

Clinician Review
- Spring 2015

Reporting
- Summer 2015

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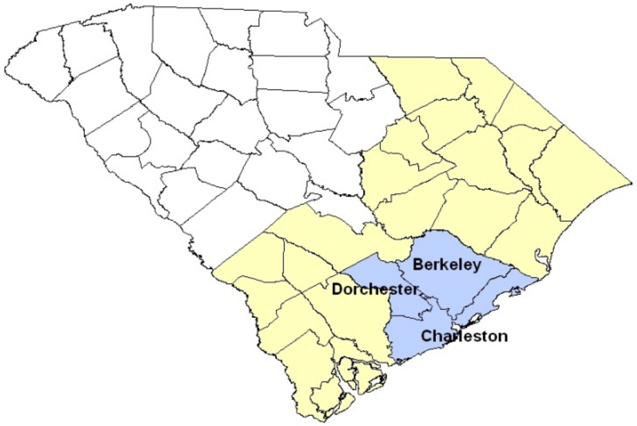
Characteristics of Study Area

- 3 counties in SC
- Racially diverse
  - 59% White
  - 32% Black
- Lower ethnic diversity (7% Hispanic)
- Economically diverse
  - 33% schools with Title I status
- Rural and urban population
- High rate of illiteracy



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Phase 1: Screening

- Goal: screen all children born in 2004 and living in target study area (n=8500)
- Social Communication Questionnaire (parent-completed)
- Distribution through partner schools, homeschool associations, and community events

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Screening Process

BEFORE

- *District level agreement*
- School level agreement
- Teacher meetings

DURING

- Introduction letter
- Screener (waiver of informed consent)
- Postcard reminder
- Last chance *(10% bump)*

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Partner Schools (106/134)

- Public Schools (73/85 completed)
  - 4 districts
- Private Schools (33/45 completed)
- Virtual Schools (0/3 completed)

- Home school associations (25)

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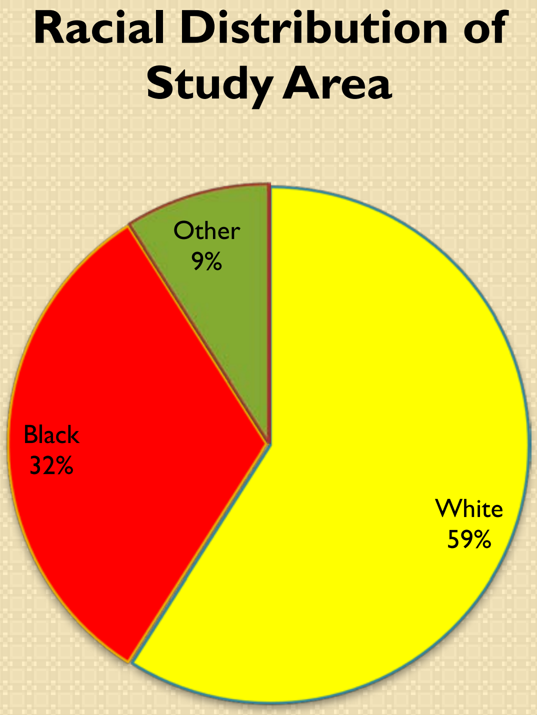
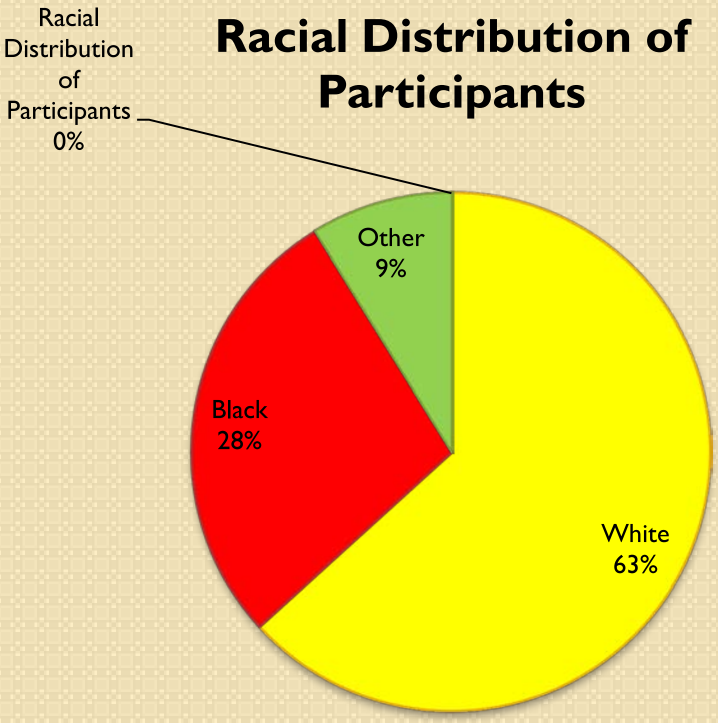
Interim Data on Response Rate

- **Survey response rate to date = 51%**
- Differential responding by race (p<0.0001)
  - White 46.3% (1167/2523)
  - Non-white 31.7% (749/2365)
  - *n=1515 with no racial information*
- Differential responding by ethnicity (p=0.5)
  - Hispanic/Latino 39.5% (166/420)
  - not Hispanic or Latino rate of 41.2% (1130/2741)
  - *n=3242 with no ethnic information*

RESPONSE RATE COMPARED TO STUDY AREA CHARACTERISTICS





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Community Events

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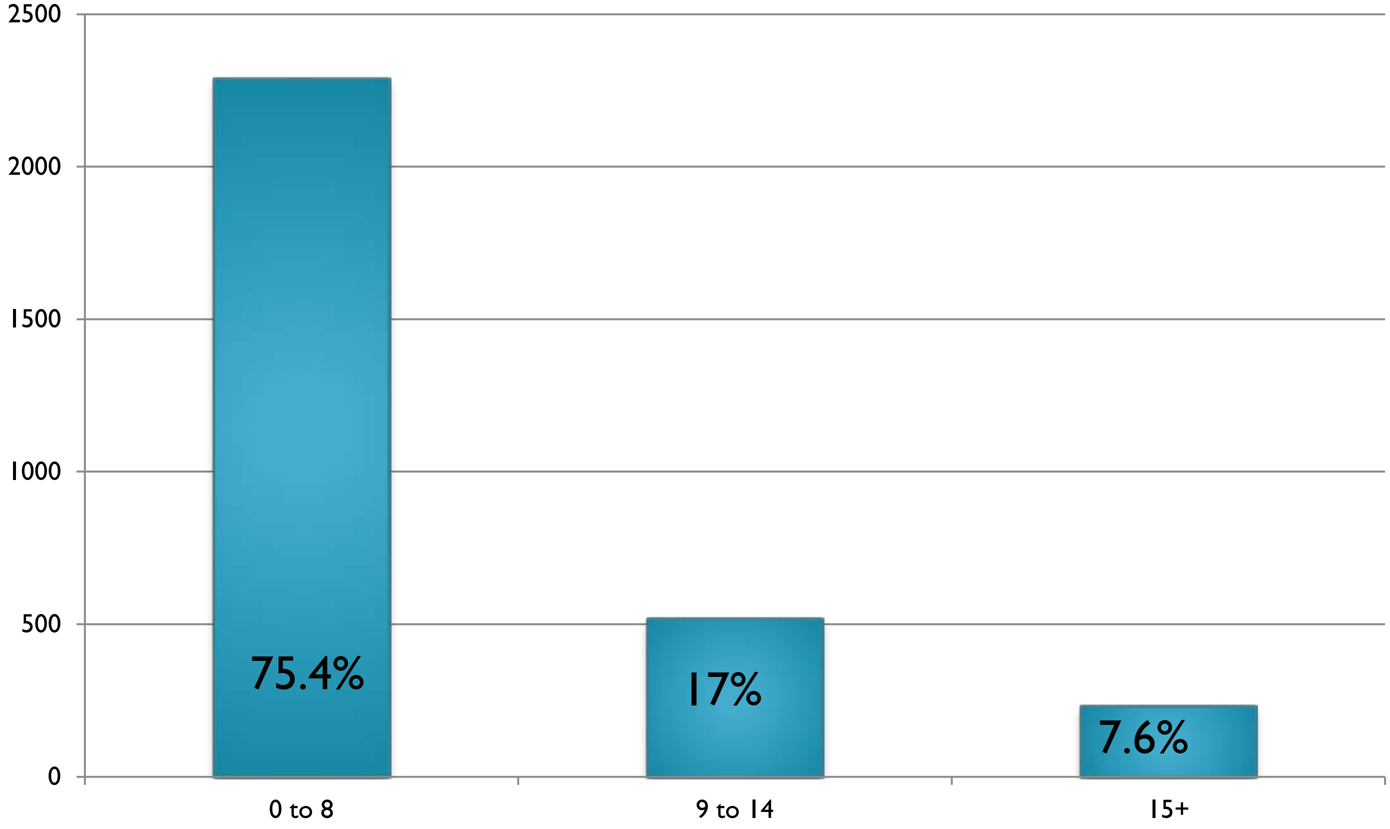
SCQ Scores in General Population of 8-9 year olds (n=3031)



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Suspected screening issues

Table 2. SCQ-identified risk for ASD (SCQ 15+), and overall SCQ score

	At Risk N(%)	Not at Risk N(%)	p-value	SCQ Score Mean (SD)	p-value
Gender					
Male (n=730)	69 (9.5%)	661 (90.5)	**0.009**	6.5 (5.8)	**<0.0001**
Female (n=768)	45 (5.9%)	723 (94.1)		5.1 (5.0)	
Race					
White (n=902)	51 (5.7%)	851 (94.3%)	**0.0002**	4.6 (4.0)	**<0.0001**
Non-white (n=504)	56 (11.1%)	448 (88.9%)		8.0 (5.5)	
Ethnicity					
Hispanic (n=130)	24 (18.5%)	106 (81.5%)	**<0.0001**	8.7 (6.0)	**<0.0001**
Non-hispanic (n=957)	66 (6.9%)	891 (93.1%)		5.7 (5.3)	
Title 1 status					
Title 1 (n=475)	70 (14.7%)	405 (85.3%)	**<0.0001**	8.7 (5.8)	**<0.0001**
Not Title 1 (n=1022)	44 (4.3%)	978 (95.7%)		4.5 (4.8)	

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Phase 2: Clinical Evaluation

- At risk for ASD (SCQ = 15+)
  - 100% (n≈325)
  - About 50% agree to participate
- Elevated SCQ (SCQ = 9-14)
  - 20% (n≈150)

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Clinical Evaluation

- Doctoral level clinical psychologists
- 3 hour assessment battery
    - Child
        - ADOS-2
        - Kaufman Brief Intelligence Test, Second Edition
    - Parent
        - DSM-neutral parent interview
        - Children's Communication Checklist
        - Vineland Adaptive Behavior Scales, Second Edition
        - Child Behavior Checklist (parent and teacher)
        - Social Responsiveness Scale – 2 (parent and teacher)

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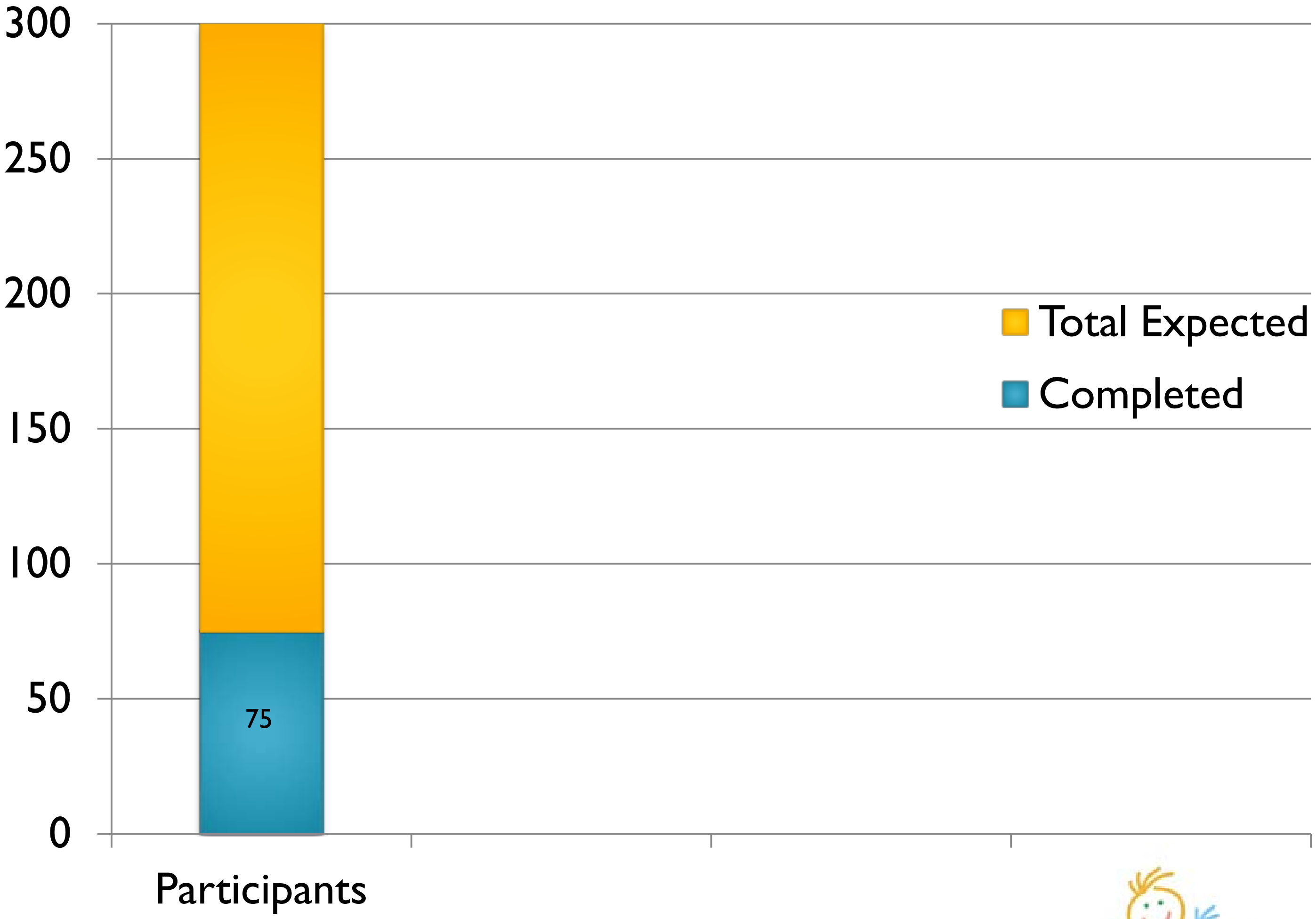
Progress



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Community-engaged research

1. Start at the top
2. Use foot in the door technique
3. Have professional materials and strong follow-through
4. Pilot materials and incentives
5. Anticipate significant IRB work
6. Use a community advisory board
7. Hire people with good social skills
8. Consider barriers specific to your community
9. Be visible in your community

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SUCCESS UPDATE

SUCCESS

South Carolina Children's Educational Surveillance Study

SUCCESS has been in progress since January of 2012. The study aims to better understand how many children are affected by Autism Spectrum Disorders (ASD), and to understand how prevalence might change based on how ASD is defined. SUCCESS uses a population-based screening and assessment methodology to determine the prevalence of ASD. This means that the team attempts to screen all children in a specific target area. In this case, children born in 2004 and living in Dorchester, Berkeley, and Charleston Counties are eligible. Following the screening process, about 10% of children are invited into the clinic for a free developmental assessment. The results of these assessments are used to calculate overall prevalence of ASD.

March, 2014

Where have we been?

- Berkeley County Public Schools
- Charleston County Public Schools
- Dorchester 4 Public Schools
- Many Private Schools

Where are we going next?

- Dorchester 2 Public Schools
- 13 Private Schools
- 24 Homeschool Associations
- 4 Virtual Schools

"Every Child Counts!"

SUCCESS Families and Teachers are Winners

Prizes and rewards help to keep our families and teachers excited about the study. Since the study began, we have given away over $2500 to teachers who have helped with our study by distributing surveys, encouraging participation, and completing questionnaires. We've also given 6 iPads, 10 iPodTouches, and many gift cards to families that have volunteered. "It's been fun to call families to let them know that they have won a prize. One round of iPads and iPod touches went out right before the holidays and families were so excited to have an unexpected gift under the tree," said Catherine Bradley, PhD, SUCCESS Psychologist.

Screening and Assessment Studies

- Diagnosis confirmed using gold-standard assessment tools and highly trained clinicians
- Prior diagnosis of ASD not required
- Rich information about cases

Limitations

- Participation affected by how you market the study
- Participation affected by attitudes towards ASD
  - Awareness of symptoms
  - Access to services and assistance
  - Beliefs about ASD
- School aged diagnosis is not the same as infant/toddler diagnosis
  - DSM IV vs 5

QUESTIONS/DISCUSSION

Meeting of the IACC

Break

Meeting of the IACC

Panel on Autism Trajectories

Audrey Thurm, Ph.D.
Staff Scientist
National Institute of Mental Health (NIMH)

Rebecca Landa, Ph.D., CCC-SLP
Director
Kennedy Krieger Institute

Catherine Lord, Ph.D.
Director
Center for Autism and the Developing Brain (CADB)

Classification and Measurement of Regression in ASD

Audrey Thurm, PhD
Pediatrics and Developmental Neuroscience Branch
National Institute of Mental Health

NIH National Institute of Mental Health

What is the phenomenon of regression in ASD?

- Regression: term used since Leo Kanner

  describes individuals with autism who lose skills during the onset of the disorder
- Regression also describes the significant decline in skills associated with (what was formerly known as) childhood disintegrative disorder, mitochondrial disorder, specific epilepsy syndromes and other neurologic problems (e.g. loss of motor skills in Rett Syndrome)

Behavioral "Outcome" of autism with regression vs. without regression

- Reports of worse ASD symptoms (e.g. Bernabei, et al., 2007; Kalb, et al., 2010; Richler, et al., 2006; Rogers & DiLalla, 1990)
- Slightly worse ASD sx, but no (or not clinically meaningful) differences in cognitive skills (Baird, et al., 2008; Meilleur & Fombonne, 2009; Hansen et al. 2008)
- No differences:

Fombonne & Chakrabarti, 2001; Werner et al. 2005 ; Shumway et al. 2011; Nordahl et al. 2011; Ozonoff et al. 2011

*** studies differing in type (language vs. other social-communicative regression) measurement, and outcomes studied`

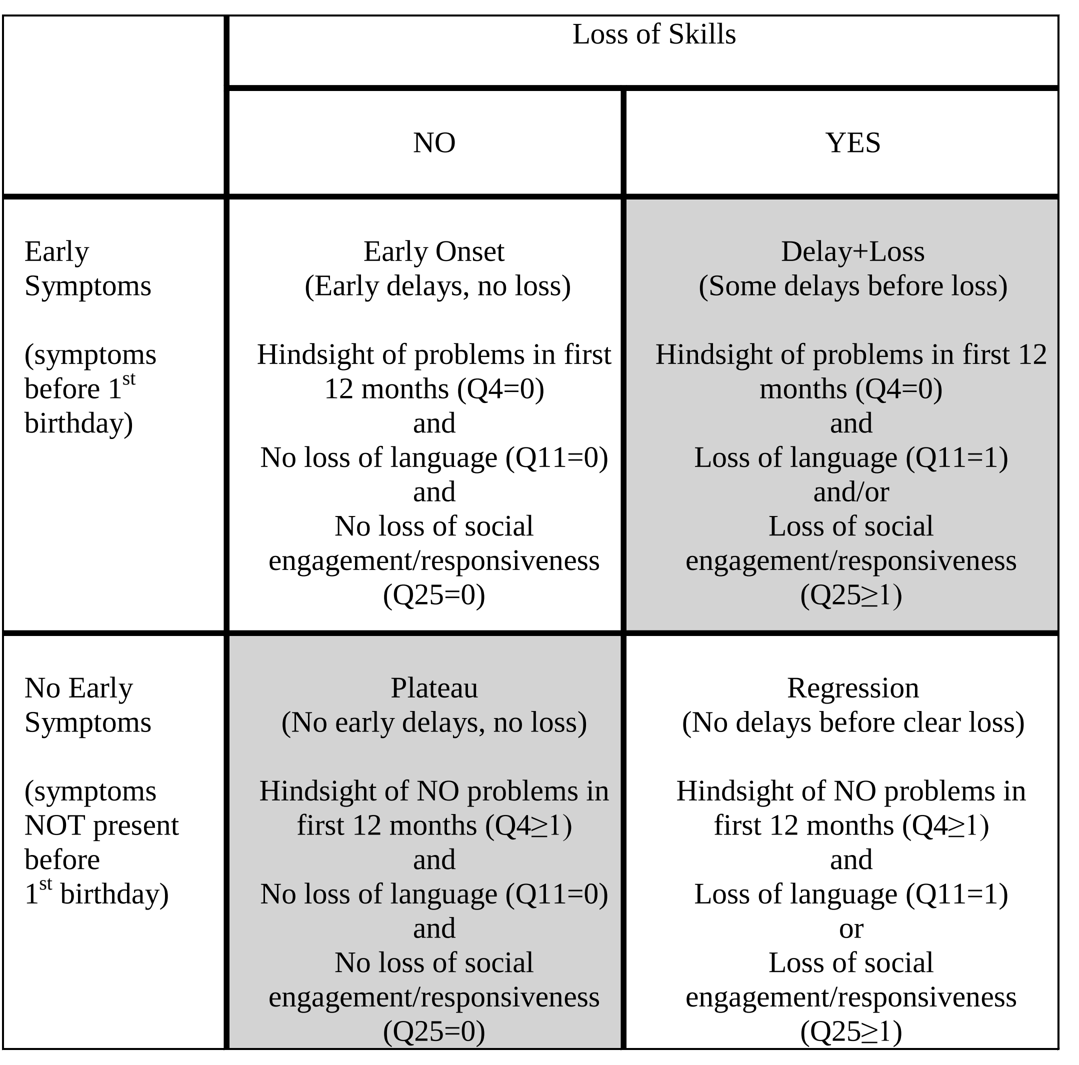
Regression in Onset of Autism

- Previous studies using categorical definitions often found regression occurs in ~25%
- Recent data indicate loss of skills OR decline in socialization behaviors, occurs frequently in the ontogony of autism symptoms
- Questions this raises:
  - what is pre-loss development like?
  - How frequent is pre-loss development "normal"?
  - Does all loss occur simultaneously?

Evidence for Early Delays in Children with Regression

- Werner and Dawson (2005) found developmental abnormalities of social, communication, repetitive behaviors, or regulatory behaviors in nearly **one-half** of children with autism and regression
- Ozonoff, et al. (2005) found 35% of the definite regression group also had delays in three or more different skills typically attained by 18 months of age
- Baird et al. (2008) examined language regression & found age of 1st phrases did not differ b/w those who regressed and not (but 1st words were earlier in language regression group)
- Luyster et al. (2005) first to consider pre-loss skills in defining social-communication regression (25% of the skills they had gained in an area, in at least three areas)

Taking Early Delays into Account: Four Categories of Onset Patterns in Autism



	Loss of Skills	
	NO	YES
Early Symptoms (symptoms before 1st birthday)	Early Onset (Early delays, no loss) Hindsight of problems in first 12 months (Q4=0) and No loss of language (Q11=0) and No loss of social engagement/responsiveness (Q25=0)	Delay+Loss (Some delays before loss) Hindsight of problems in first 12 months (Q4=0) and Loss of language (Q11=1) and/or Loss of social engagement/responsiveness (Q25≥1)
No Early Symptoms (symptoms NOT present before 1st birthday)	Plateau (No early delays, no loss) Hindsight of NO problems in first 12 months (Q4≥1) and No loss of language (Q11=0) and No loss of social engagement/responsiveness (Q25=0)	Regression (No delays before clear loss) Hindsight of NO problems in first 12 months (Q4≥1) and Loss of language (Q11=1) or Loss of social engagement/responsiveness (Q25≥1)

Hansen et al. 2008; Shumway et al. 2011

How can the amount and type (and timing) of early delays truly be measured?

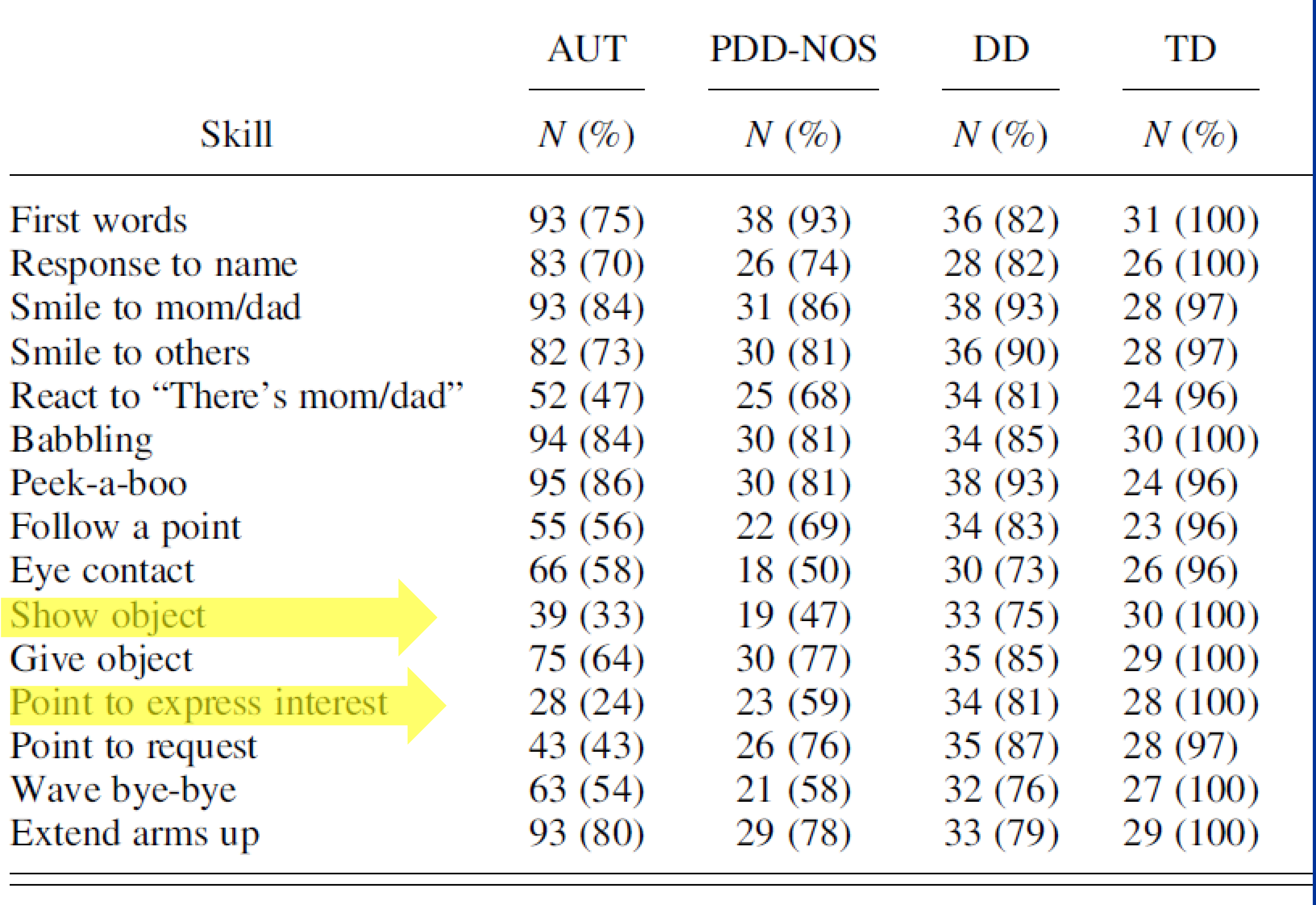
- Using Retrospective report, can consider whether *specific* skills were ever developed, when, and loss of these specific skills (and if so, when)

Study Showing Distributions of Delays & Loss

- Data collected on 244 children
  - 125 AUT, 42 PDD-NOS, 46 DD, 31TD
- Methodology:
  - Regression Validation Interview- Revised (RVI)
    - a detailed semi-structured interview that includes questions about attainment and loss of specific skills:
      - pre-speech behaviors, communicative gestures, and vocabulary.

Thurm et al. 2014

Percent of skills attained



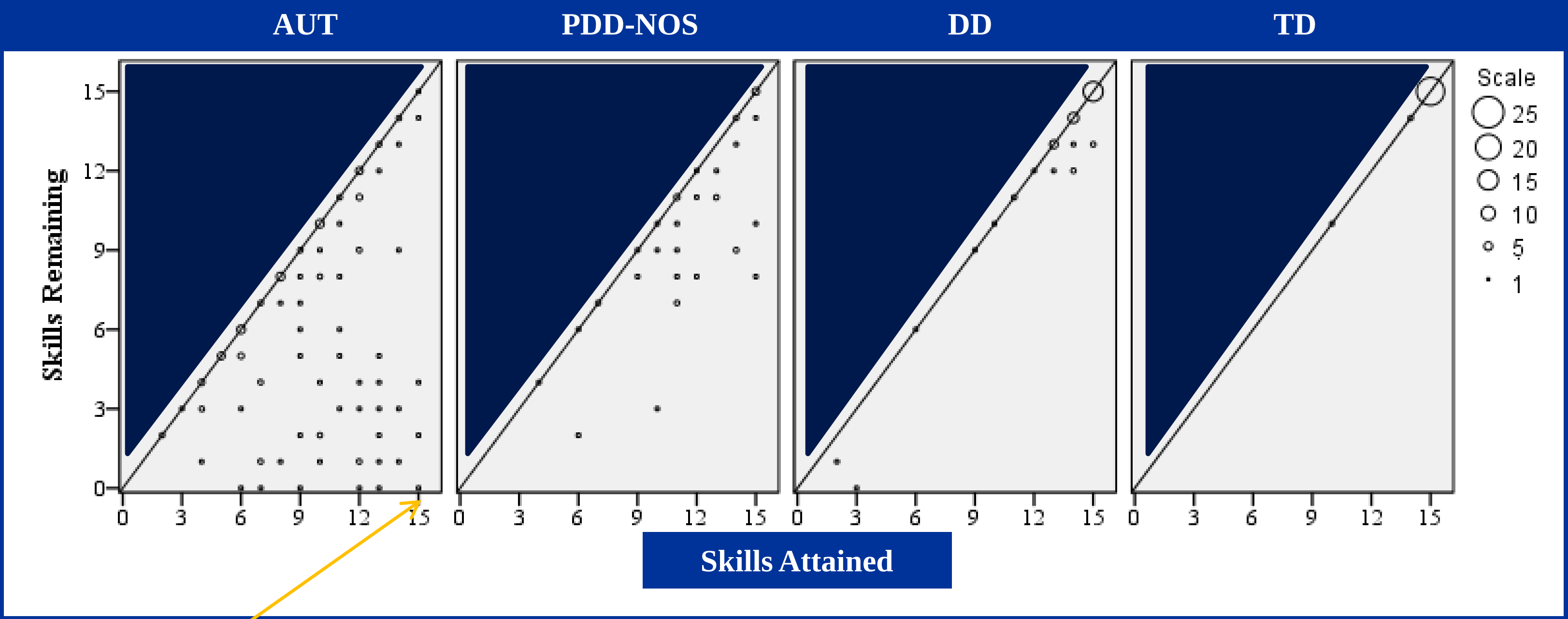
Skill	AUT *N* (%)	PDD-NOS *N* (%)	DD *N* (%)	TD *N* (%)
First words	93 (75)	38 (93)	36 (82)	31 (100)
Response to name	83 (70)	26 (74)	28 (82)	26 (100)
Smile to mom/dad	93 (84)	31 (86)	38 (93)	28 (97)
Smile to others	82 (73)	30 (81)	36 (90)	28 (97)
React to "There's mom/dad"	52 (47)	25 (68)	34 (81)	24 (96)
Babbling	94 (84)	30 (81)	34 (85)	30 (100)
Peek-a-boo	95 (86)	30 (81)	38 (93)	24 (96)
Follow a point	55 (56)	22 (69)	34 (83)	23 (96)
Eye contact	66 (58)	18 (50)	30 (73)	26 (96)
Show object	39 (33)	19 (47)	33 (75)	30 (100)
Give object	75 (64)	30 (77)	35 (85)	29 (100)
Point to express interest	28 (24)	23 (59)	34 (81)	28 (100)
Point to request	43 (43)	26 (76)	35 (87)	28 (97)
Wave bye-bye	63 (54)	21 (58)	32 (76)	27 (100)
Extend arms up	93 (80)	29 (78)	33 (79)	29 (100)

Continuous Distributions of Delays & Loss (cont'd)

- Results:
  - In the AUT group, loss of at least one skill was reported in 63% of children
  - Loss of point to express interest, wave bye-bye, and eye contact were all reported in more than 50% of children with AUT who had attained the skills.
  - Skill loss occurred at different age for different skills

Thurm et al. 2014

Skills Attained vs. Skills Remaining After Loss, According to Dx Group



Gained all skills and lost all

Note: those on the line did not lose any skills

Findings show distribution of skills lost, with lack of clear cutoff for "regression"

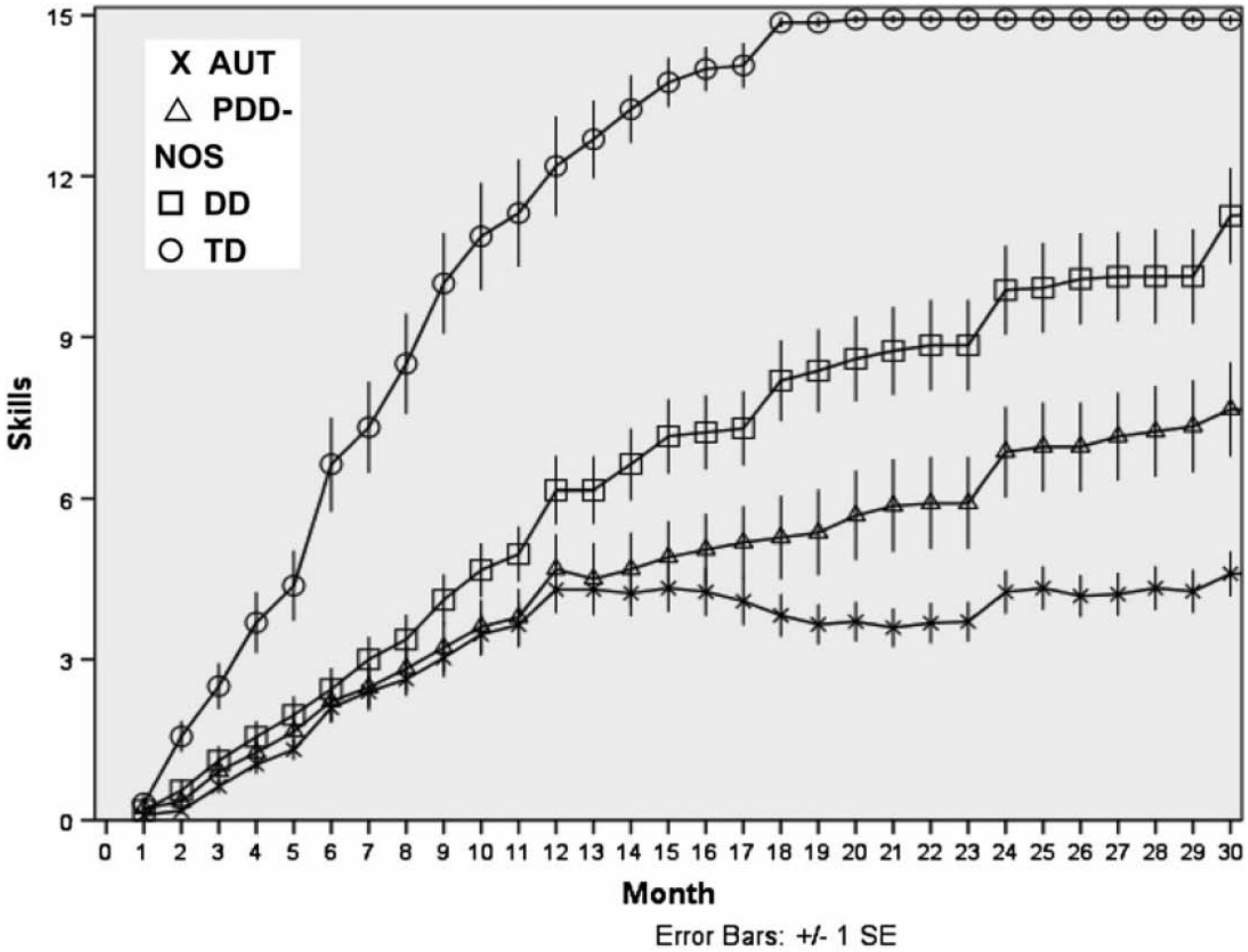
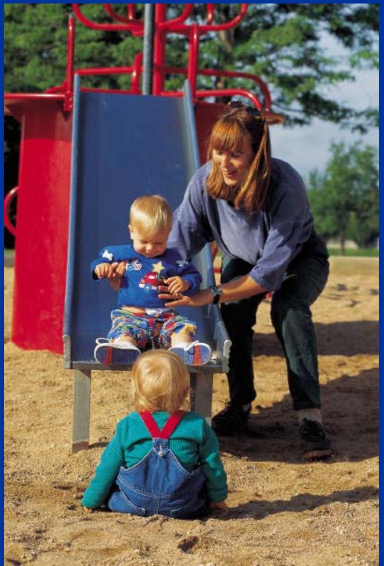
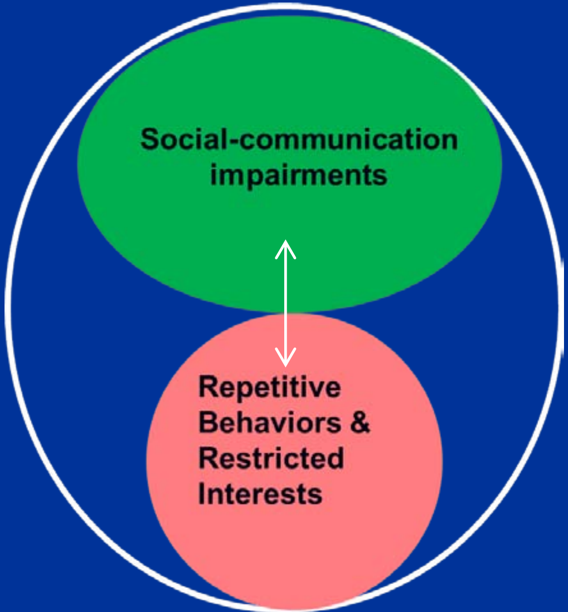


Figure 2. Patterns of skill attainment and loss over time in children. AUT, autism; PDD-NOS, pervasive developmental disorder not otherwise specified; DD, developmental delay; TD, typical development.

Beyond Onset Pattern of Social-Communication Skills

- Onset of ASD involves unfolding of deficits in social-communication skills AND development of repetitive behavior and restricted interests
- How does onset on each of these domains affect the other?





Social-communication impairments

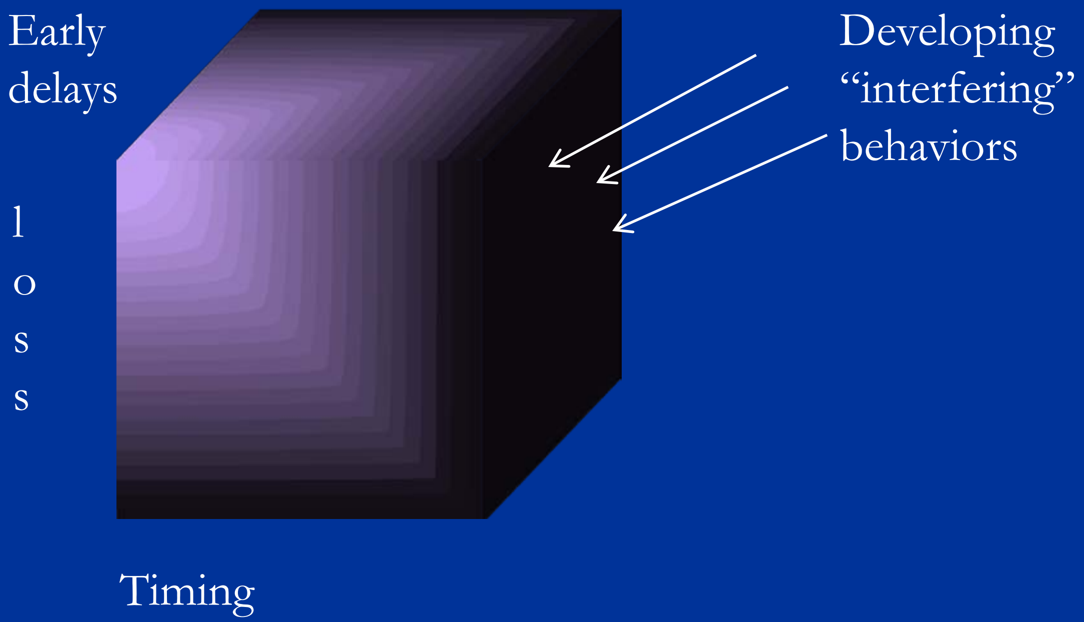
Repetitive Behaviors & Restricted Interests

Does the onset of repetitive behavior need to be considered in measuring regression?

Timing of Repetitive vs. Loss of Skills	**Percentage of Children**
Repetitive Behaviors Preceded Loss of Skills	25 (61%)
Concurrent Repetitive Behaviors and Loss of Skills	2 (5%)
Repetitive Behaviors Followed Loss of Skills	14 (34%)

Given the dimensions and factors, can regression be categorized alone?

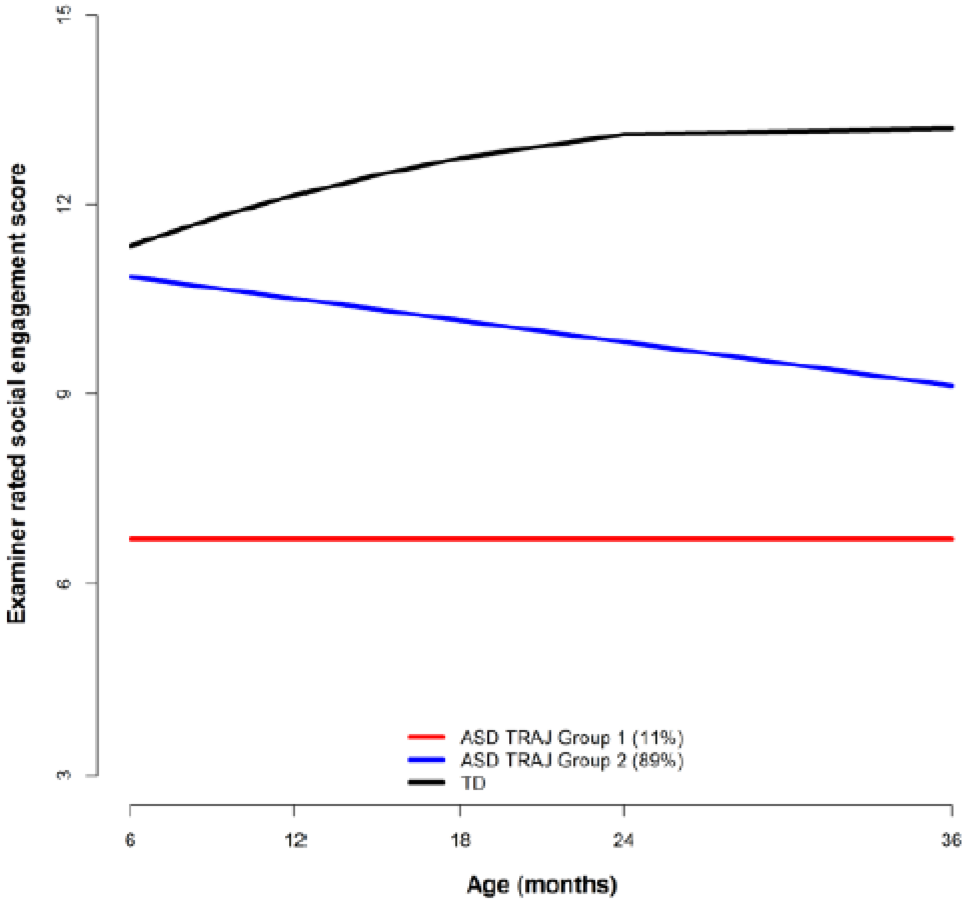
- How to "capture" on one variable, at least two dimension (early delays & loss) that vary at least somewhat independent of each other?



Reporting of Regression

- Parent report consistency over time
  - There are several reports of inconsistencies of up to 20% between parent reports of regression over 2 time points
- Parent retrospective report vs. Parent prospective reporting (vs. clinician observation)
  - Studies from infant siblings provide opportunity explore agreement among reports

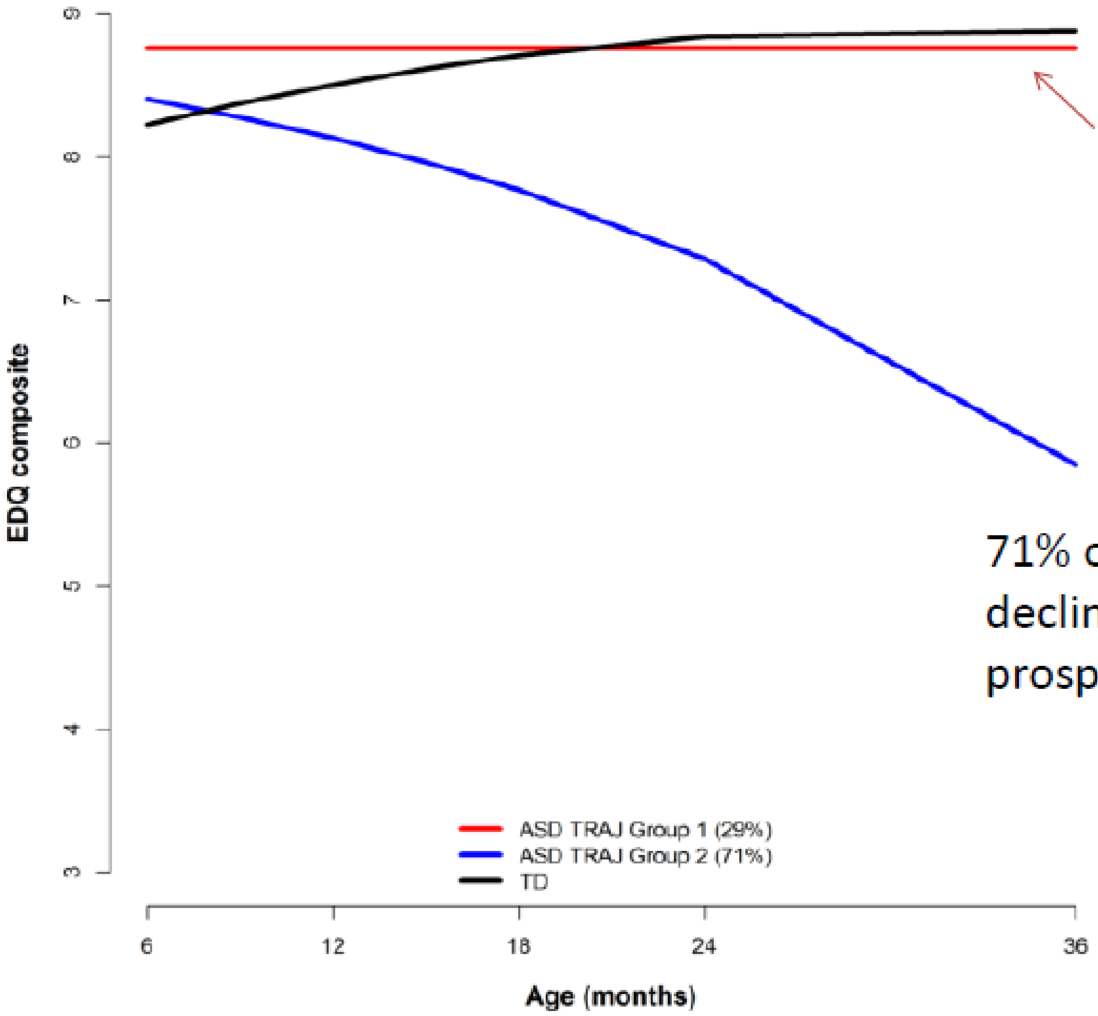
Phase II: Prospective Examiner Ratings



89% of ASD sample have a declining trajectory by prospective examiner report

Ozonoff et al. 2014; IMFAR

Phase II: Prospective Parent Ratings



valid reporting?

71% of ASD sample have a declining trajectory by prospective parent report

Ozonoff et al. 2014; IMFAR

Conclusions

- Need an algorithm to capture and measure onset patterns dimensionally to correlate with other neurobiologic continuous measures
- Need large N studies with in-depth phenotyping (starting as early as possible) to determine if and how onset pattern affects later course of symptoms and comorbid/biologic presentation

Acknowledgments

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- Paul Grant, M.D.
- Dave Luckenbaugh, M.A.
- Catherine Lord, Ph.D.
- The families that participate in this research

Developmental Trajectories Associated with Autism Spectrum Disorders

Rebecca Landa, Ph.D., Director,
Center for Autism and Related Disorders
IACC
July 8, 2014

Center for Autism and Related Disorders
at Kennedy Krieger Institute

Thank you

- NIH R01 MH 59630 (Landa, PI)
- Autism Speaks, Karma Foundation
- Families and children who participate
- My wonderful staff
- Dr. Margaret Bauman

Brief tutorial on early ASD signs

Autism.kennedykrieger.org

Bringing the Early Signs of Autism Spectrum Disorders into Focus

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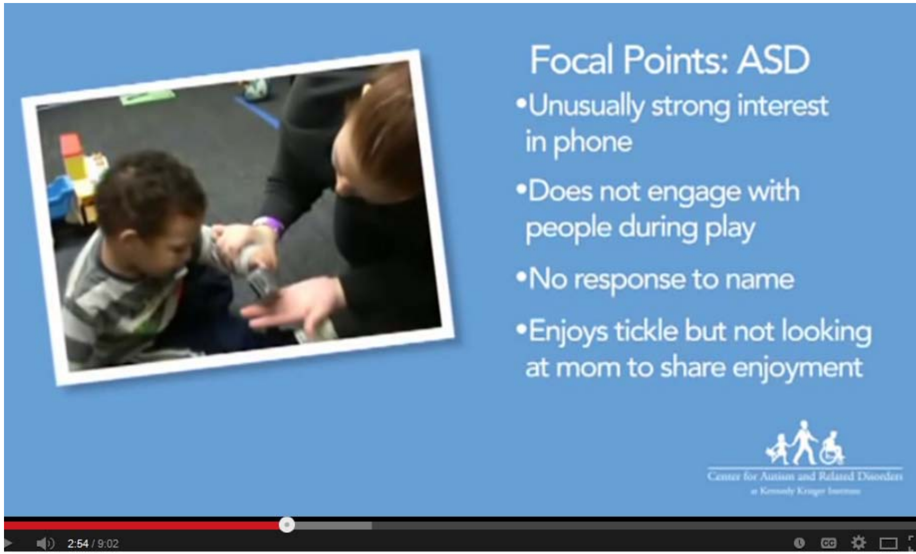
at Kennedy Krieger Institute

Seeing Social Opportunity Through Play

Focal Points: No ASD

- Engages others in his play
- Shows meaningful, purposeful, and pretend play
- Shares enjoyment by smiling at people
- Synchronizes with others through imitation



Focal Points: ASD

- Unusually strong interest in phone
- Does not engage with people during play
- No response to name
- Enjoys tickle but not looking at mom to share enjoyment

ASD as a disorder of development

- Things start off, in general, grossly within normal limits
- Disruption in developmental processes that converge, at different times and in different ways, and give rise to ASD behavioral phenotypes

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Trajectory: We used a prospective longitudinal design

- Prospective studies
  - – Highly efficient to study infants at increased genetic risk for ASD
  - – Can control the
    - Age at time of assessment
    - Context (cues, camera angle, difficulty, distractions)
    - Types of tasks to study specific abilities


[redacted]

To understand ASD in infants and toddlers

- Two groups studied:
  - High Risk (HR) for ASD: Infant siblings of children with ASD
  - Low Risk (LR) for ASD: No family history of ASD
- Recently added a group at increased risk for delay, but less risk for ASD than HR infants: Preterm

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High risk for ASD

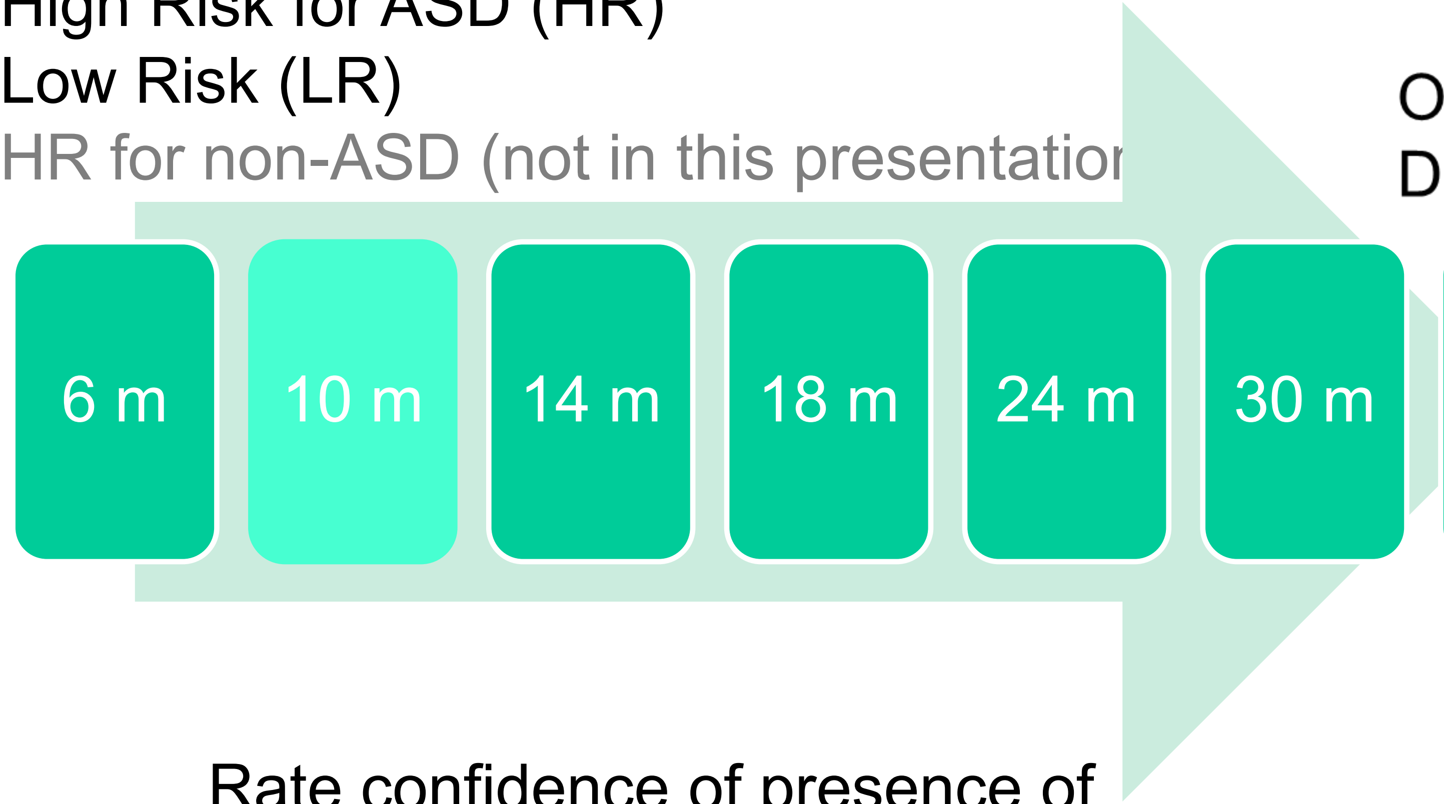
- High risk infants (younger sibs of children with ASD):
- 18.7% will have ASD

(Landa et al., 2006; Landa et al., 2007; Ozonoff et al., 2011)

- 30% will have non-ASD language and social delays by the third birthday (Messinger et al., 2013)

Assessment ages

High Risk for ASD (HR)
Low Risk (LR)
HR for non-ASD (not in this presentatior



Outcome Diagnosis

- 6 m
- 10 m
- 14 m
- 18 m
- 24 m
- 30 m
- 36 m

Rate confidence of presence of ASD at each age

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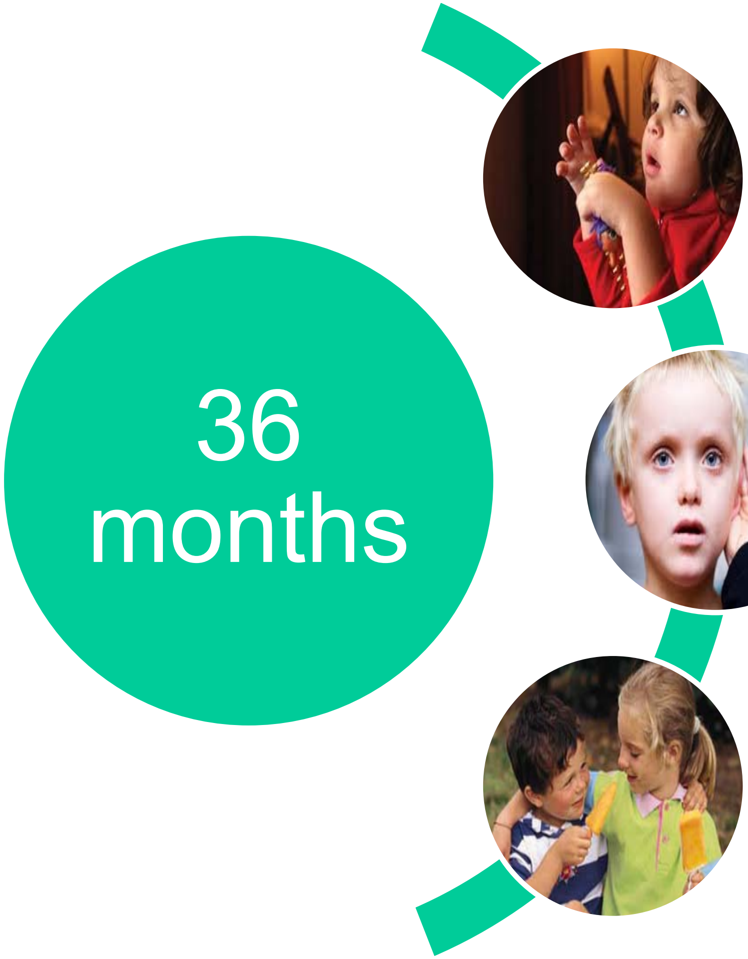
Outcome classifications

Autism Diagnostic Observation Schedule + Clinical judgment



36 months

ASD

Intermediate Phenotype

Unaffected

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Elucidating Early Signs

- Surprises
  - Expected overt social atypicalities by age 6 months but

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Elucidating Early Signs

- Surprises: Trajectories
  - Expected early (infancy) ASD with stability in presentation or
  - Typical development with regression in some cases

ASD: Altered Trajectory patterns

- Prodromal period through age 6 months
- ASD with early manifestation: Detectable by 14 months
- ASD with later manifestation: Detected after age 14 months
  - Delays present before ASD was diagnosable (Landa, Holman, & Garrett-Mayer. 2007. Archives of General Psychiatry)
- Language regression may occur within either (Landa et al. 2013. Child Development)

What is regression?

- Loss of words
- Decreased frequency of communicative use of words
- Decreased frequency of social initiation
- Deterioration in quality of social interaction
- Decrease in social responsivity (eye contact, social smile, etc.)
- Decreased diversity of behavior
- Reduction in quality or complexity of play
- What about appearance of atypical features?
- *This term has connotations that may or may not be helpful as we try to understand neurobiological mechanisms*

Trajectories

- Begins with motor – mid infancy
  - Quality of grasping, duration of grasp (Libertus et al., 2014)
  - Postural control (Flanagan et al., 2012)
  - Diversity of postures achieved (Bhat et al., 2012)

Relations Between Early Postural Control & Later Communication Functioning

ELSEVIER

Infant Behavior and Development

Relation between early motor delay and later communication delay in infants at risk for autism

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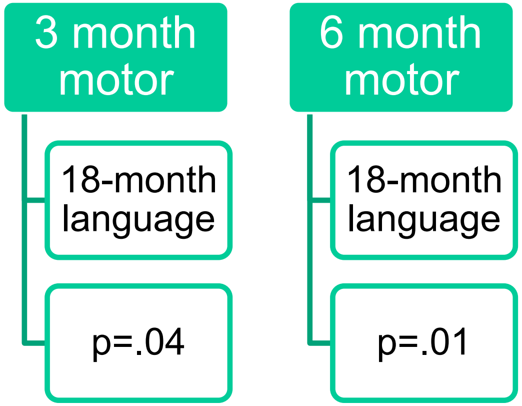
ABSTRACT

Background: Motor delays have been reported in retrospective studies of young infants who later develop Autism Spectrum Disorders (ASDs).
Objective: In this study, we prospectively compared the gross motor development of a cohort at risk for ASDs; infant siblings of children with ASDs (AU sibs) to low risk typically developing (LR) infants.
Methods: 24 AU sibs and 24 LR infants were observed at 3 and 6 months using a standardized motor measure, the Alberta Infant Motor Scale (AIMS). In addition, as part of a larger study, the AU sibs also received a follow-up assessment to determine motor and communication performance at 18 months using the Mullen Scales of Early Learning.
Results: Significantly more AU sibs showed motor delays at 3 and 6 months than LR infants. The majority of the AU sibs showed both early motor delays and later communication delays.
Limitations: Small sample size and limited follow-up.
Conclusions: Early motor delays are more common in AU sibs than LR infants. Communication delays later emerged in 67–73% of the AU sibs who had presented with early motor delays. Overall, early motor delays may be predictive of future communication delays in children at risk for autism.



3 month motor

18-month language

p=.04

6 month motor

18-month language

p=.01

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at Kennedy Krieger Institute

Gasping: 6-10 months

CHILD DEVELOPMENT

Child Development, xxxx 2014, Volume 00, Number 0, Pages 1–14

Limited Fine Motor and Grasping Skills in 6-Month-Old Infants at High Risk for Autism

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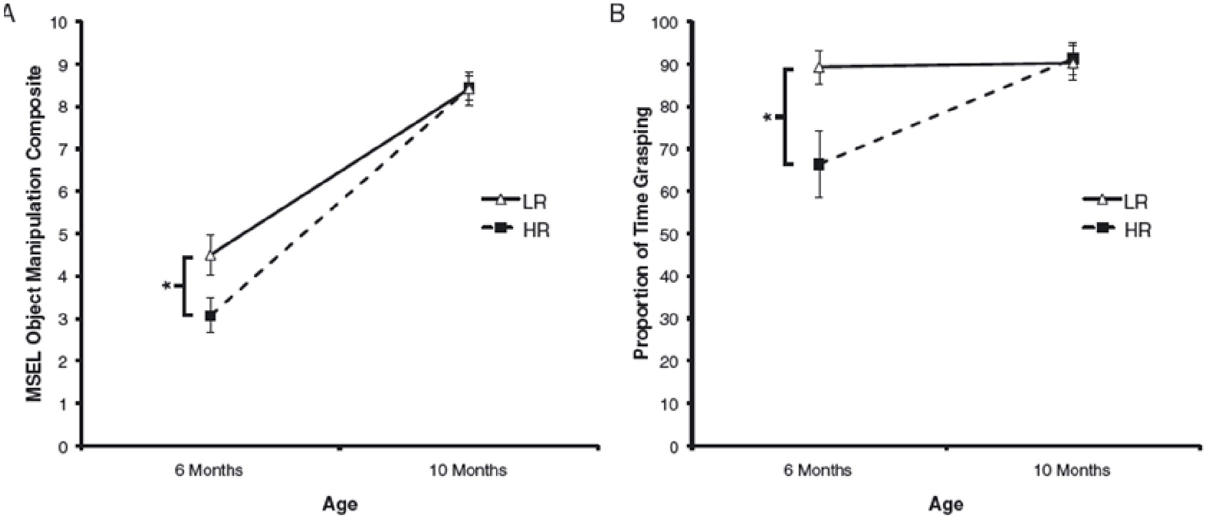

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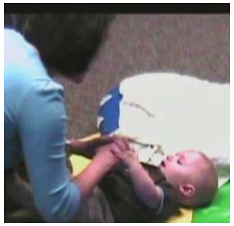
Examples of Early and Later Diagnosis

Early diagnosis

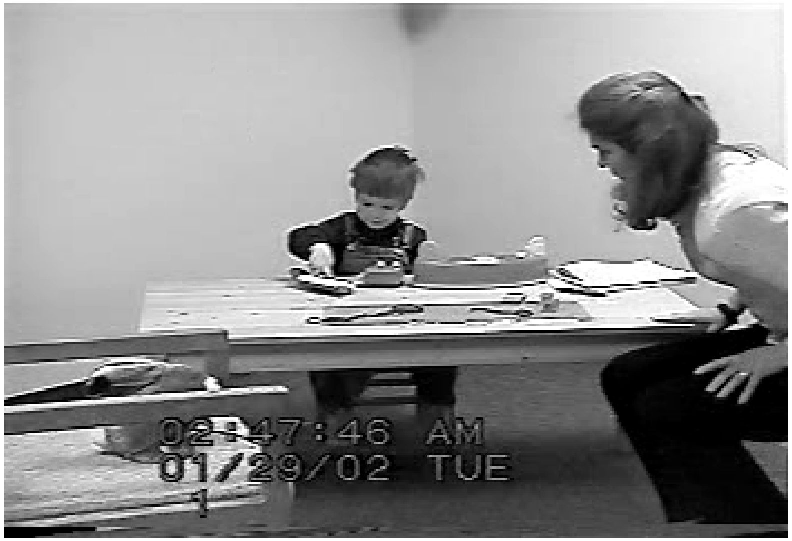


Later diagnosis

Trajectories

22 months Early Manifesting

24 months Later Manifesting



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Trajectories in Sibs-A with and without ASD

CHILD DEVELOPMENT

- HR n=204
- LR n=31
- Tested:
  - 6, 14, 18, 24, 30, 36 months
- Classified at outcome: Early ASD; Later ASD; Non-ASD
- Dependent Variables from:
  - Mullen Scales of Early Learning – raw scores
  - Communication and Symbolic Behavior Scales Developmental Profile

Landa, Gross, Stuart, & Faherty. (2013). Child Development.

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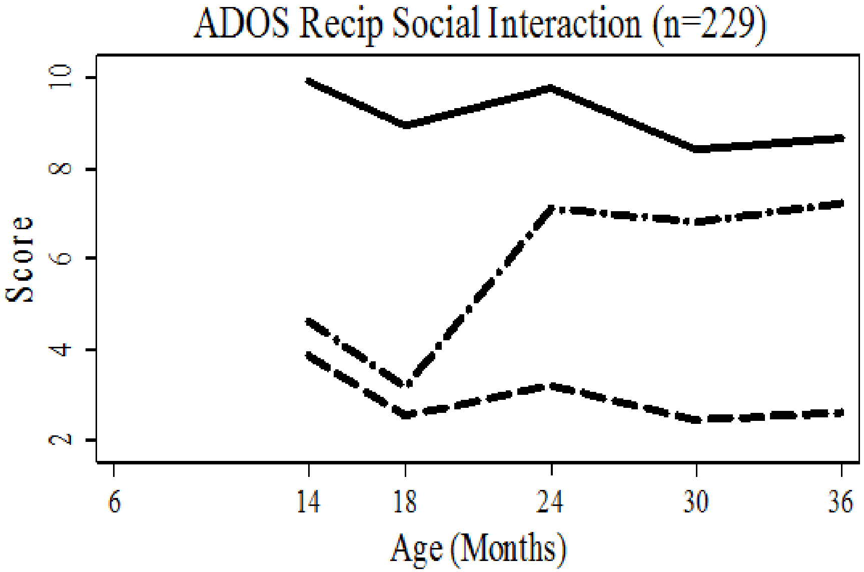
Early ASD vs Later ASD vs Non-ASD



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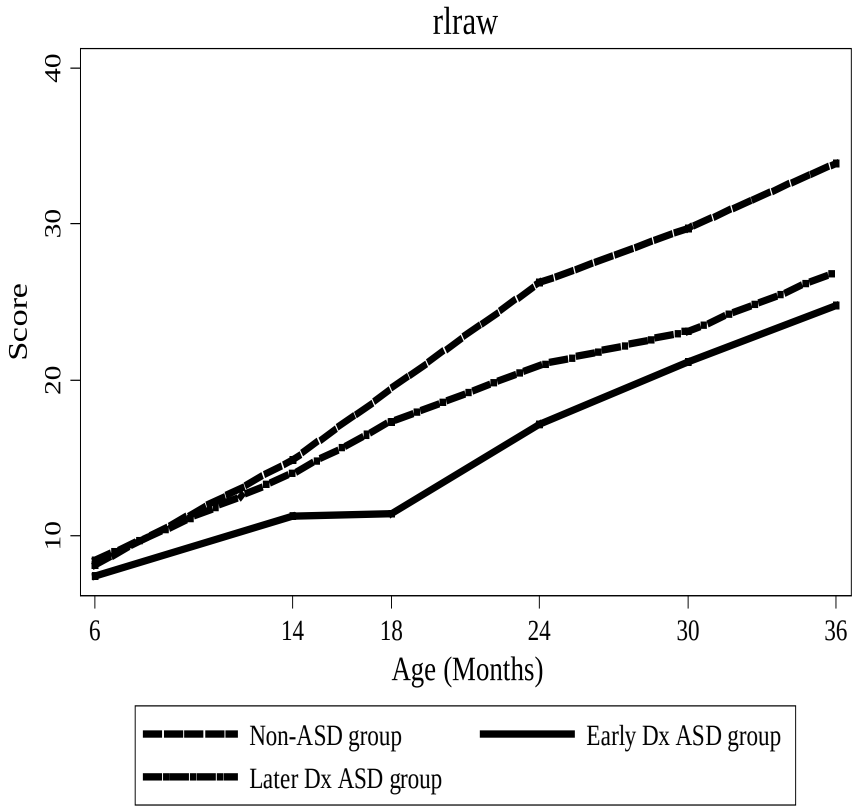
Receptive Language Raw Scores



- All groups WNL at 6 months
- Absence of typical language growth spurt in ASD
- Plateau in Early dx group

Landa, Gross, Stuart, Faherty. 2013. Child Development

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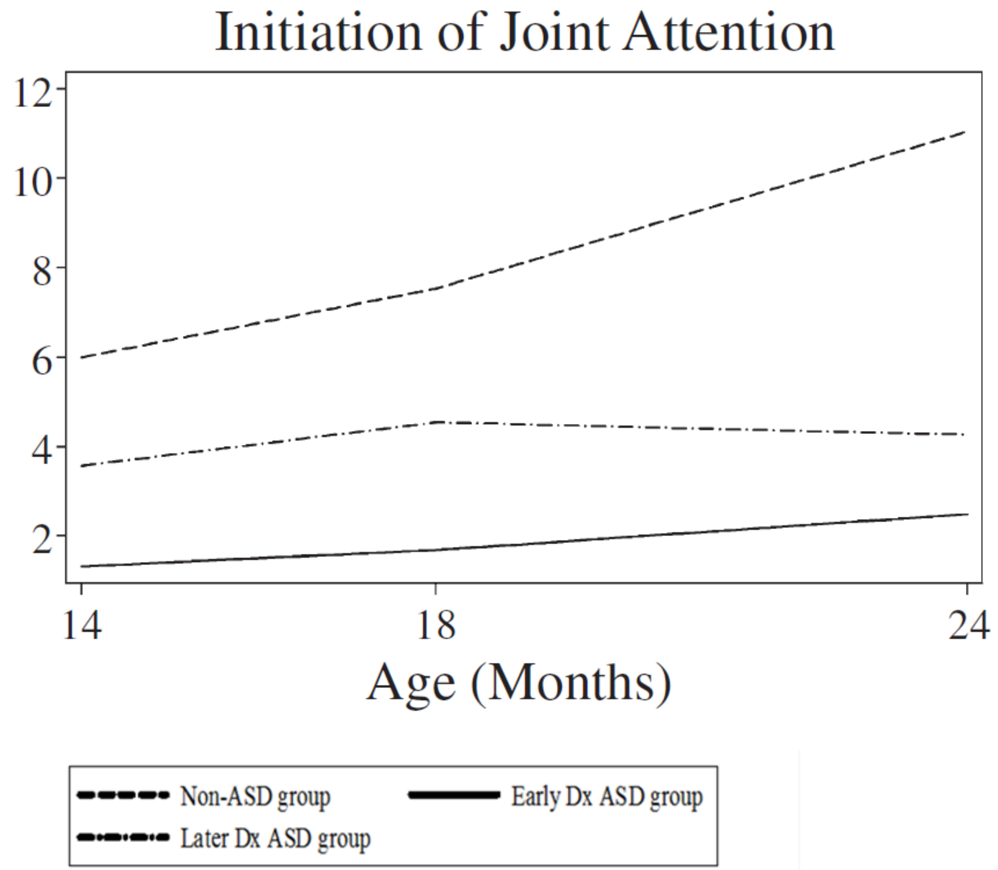
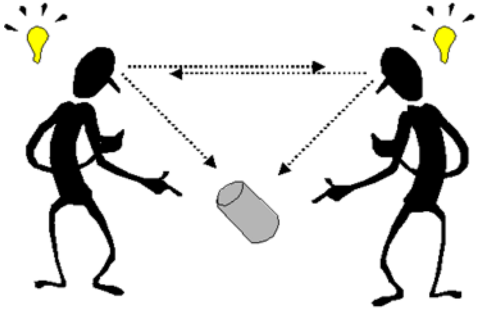
Social



Landa, Gross, Stuart, Faherty. 2013. Child Development



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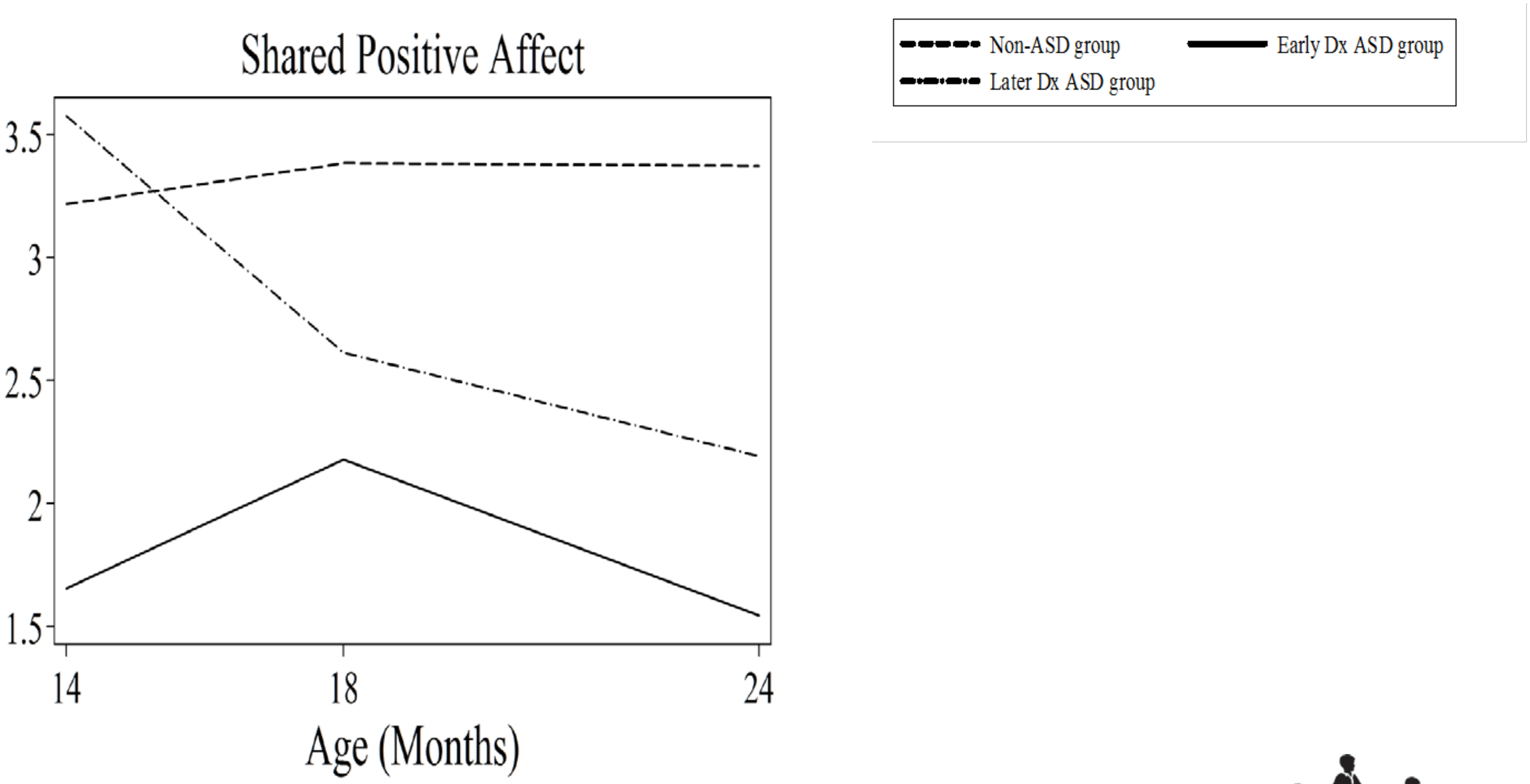
Frequency of Shared Positive Affect



Landa, Gross, Stuart, Faherty. 2013. Child Development

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Sharing positive affect (smiling)

Center for Autism and Related Disorders
at Kennedy Krieger Institute

No sharing positive affect (smiling)

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at Kennedy Krieger Institute

Question

- Is there developmental coherence within Early vs Later manifesting ASD vs non-ASD?
- Are there latent classes? Do our behavioral ‘outcome’ classifications really tell us anything about developmental trajectory across developmental domains?

Heterogeneity in Trajectories of Sibs-A

THE JOURNAL OF CHILD PSYCHOLOGY AND PSYCHIATRY

ACAMH

Journal of Child Psychology and Psychiatry 53:9 (2012), pp 986–996 doi: 10.1111/j.1469-7610.2012.02558.x

Latent class analysis of early developmental trajectory in baby siblings of children with autism

Rebecca J. Landa,[1] Alden L. Gross,[2] Elizabeth A. Stuart,[2,3] and Margaret Bauman[4]

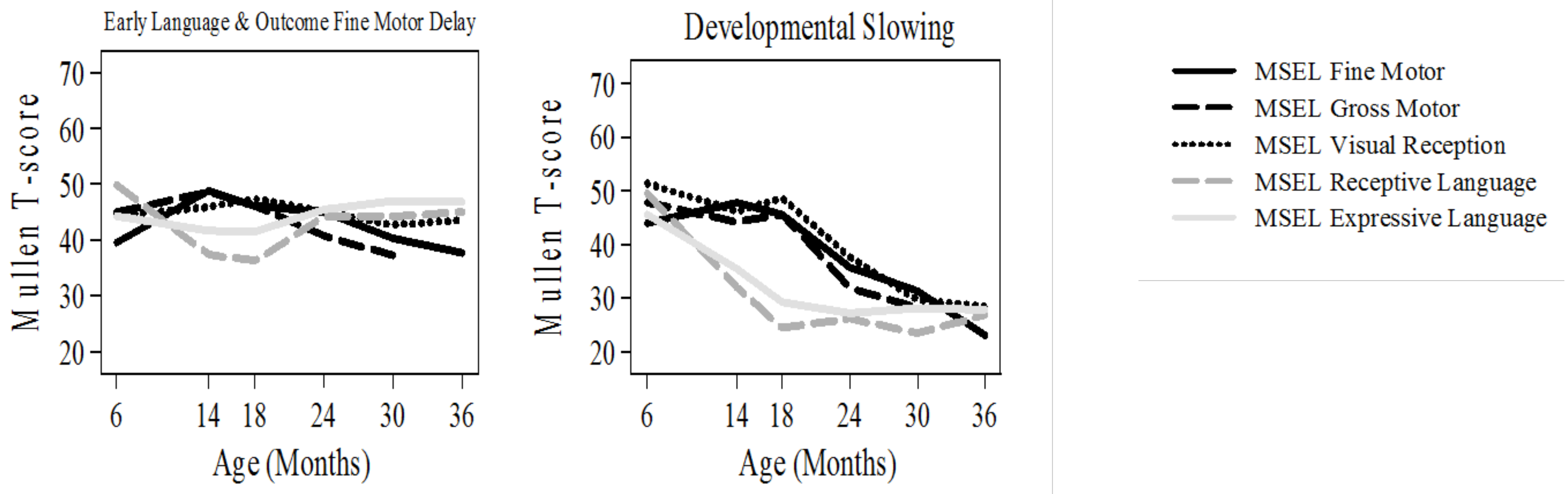
[1]Center for Autism and Related Disorders, Kennedy Krieger Institute, Psychiatry and Behavioral Sciences, The Johns Hopkins University School of Medicine, Baltimore, MD, USA; [2]Mental Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; [3]Biostatistics, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; [4]Lurie Center/LADDERS, Mass General Hospital for Children, Neurology, Harvard Medical School, Baltimore, MD, USA

Classes and distribution of the children with ASD

Group	N	Accelerated	Normative	Early language delay; later FM delay	Slowing
Early ASD	27	0.0%	14.8%	29.6%	55.6%
Later ASD	25	4.0%	36.0%	32.0%	28.0%

Trajectories in two of the classes

MSEL T scores



Landa, Gross, Stuart, Bauman, 2012, JCPP

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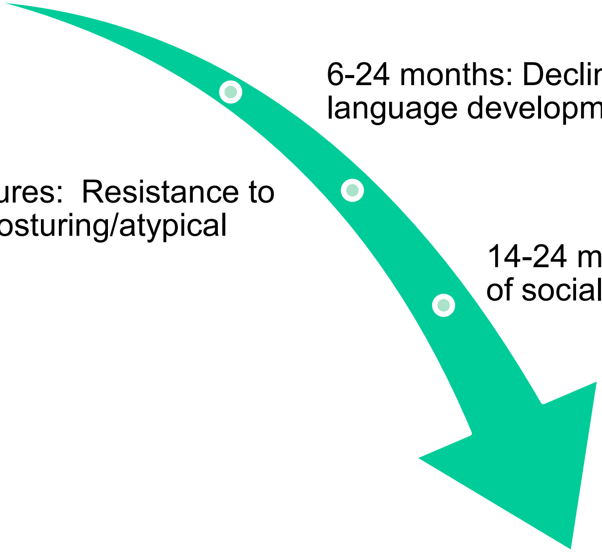
Emergence of ASD risk



6 months: Motor delay
(postural control,
grasping)

6-24 months: Decline in rate of language development

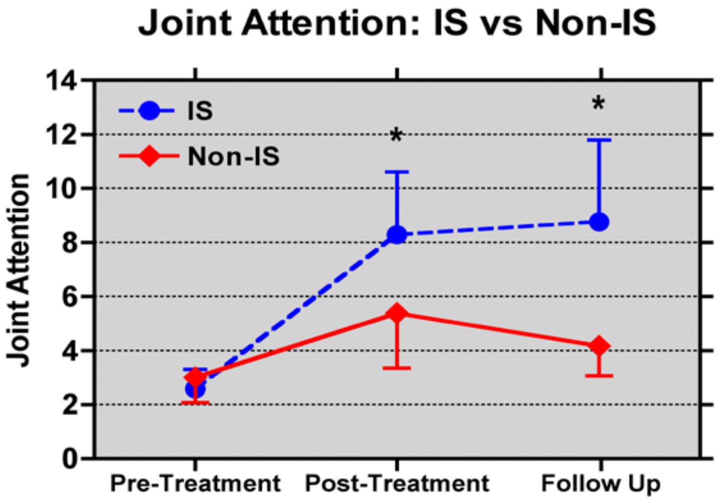
Appearance of atypical features: Resistance to change, intense interests, posturing/atypical movements

14-24 months: Frequency, diversity, quality of social approach & responsivity

ASD Risk

With early intervention, trajectory is alterable in most children with ASD

IS group made significant gains in frequency of IJA ($p<.01$) and shared positive affect (CSBS DP) ($p<.05$)



Landa et al. 2011 JCPP

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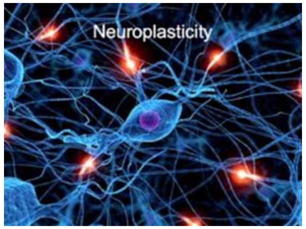
Development and neuroplasticity



- ASD is a disorder of development
- Behavioral abnormality emerges:
  - Atypical or delay in typical developmental processes
  - Early in development, expected phenomena appear but may not be adequately networked
  - Synaptic connections may be under developed – weak and vulnerable
- Connectivity becomes disrupted over time
- This disruption is time-sensitive and results in abnormal presentation of developmental phenomena

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Early Achievements: 1-year-olds

*Natural, meaningful activities

*Create predictable routines (actions, language) – high dosage

*Multi-modal (neurons that fire together wire together)

*Gradually build sequences of action

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Clinical implications

- Mid infancy (6 months):
  - Signs are subtle
  - Mostly motor delay
  - Nonspecific to ASD
  - Usually not detectable on standardized tests
- Declining rate of development and even reduction in frequency/diversity/quality between 6 and 36 months
- By 14 months, ASD signs clear in about half of children with ASD
  - Low social responsiveness and reciprocity
  - Infrequent initiation of joint attention and response to social cues
  - Language delay
  - Repetitive and stereotyped interests

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Treatment implications: Treatment should

- Begin early
- Be multi-modal (Hebbian principle: neurons that fire together wire together; particularly of different brain regions to build inter-regional connectivity)
- Be experience-dependent (i.e., embodied approach; child is cognitively and physically engaged)
- Be of adequate dosage (redundancy, repetition of experience to generate synaptic connections of adequate strength – reducing vulnerability to pruning of needed connections)

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REGRESSION AND AUTISM

Catherine Lord, Ph.D.
Center for Autism and the Developing Brain
New York Presbyterian Hospital
Weill Cornell Medical College

CONFLICT OF INTEREST

I receive royalties from the publisher of the diagnostic instruments, the ADI-R, ADOS and SCQ.

I have had research support from NIMH, NICHD, NINDS, NIDCD, HRSA, Department of Education, Autism Speaks and the Simons Foundation.

OUTLINE FOR TODAY

A few general issues related to regression in ASD

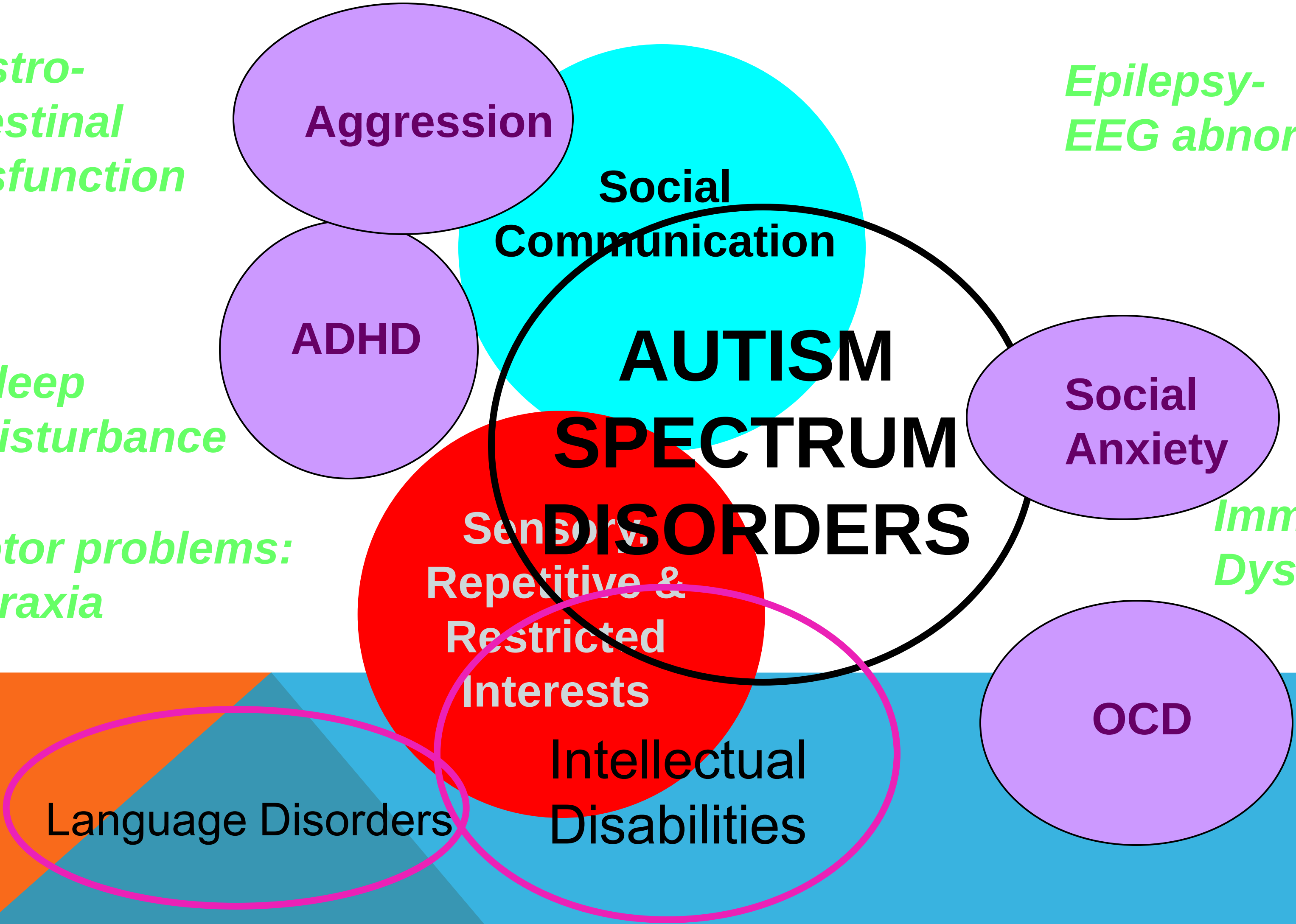
One study following 78 children under 15 months followed until age 3 and seen as close as possible to every month until 36 months (Lord et al., 2011)

Factors affecting how people report ages and events in the past

Reality check that there are marked regressions though they are rare

Summary

CORE SYMPTOM DOMAINS
PLUS ASSOCIATED MEDICAL FEATURES



Gastro-intestinal Dysfunction

Aggression

Epilepsy-EEG abnormalities

Social Communication

ADHD

AUTISM SPECTRUM DISORDERS

Sleep Disturbance

Social Anxiety

Sensory, Repetitive & Restricted Interests

Motor problems: Apraxia

Immune Dysfunction

OCD

Language Disorders

Intellectual Disabilities

- Both positive (abnormal) behaviors, and negative (the absence of normal) behaviors are required to make a diagnosis of ASD.
- This means that developmental level and contextual effects (in what kind of circumstances does the child or adult function?) can both have significant effects on diagnostic judgments.

ASD AS A NEUROBIOLOGICAL DISORDER OF LEARNING AND PROCESSING

A developmental disorder:

Having ASD affects basic aspects of behavior (e.g., eye contact, vocalization) and attention (to certain kinds of stimuli) and maybe motivation

Which in turn affect learning

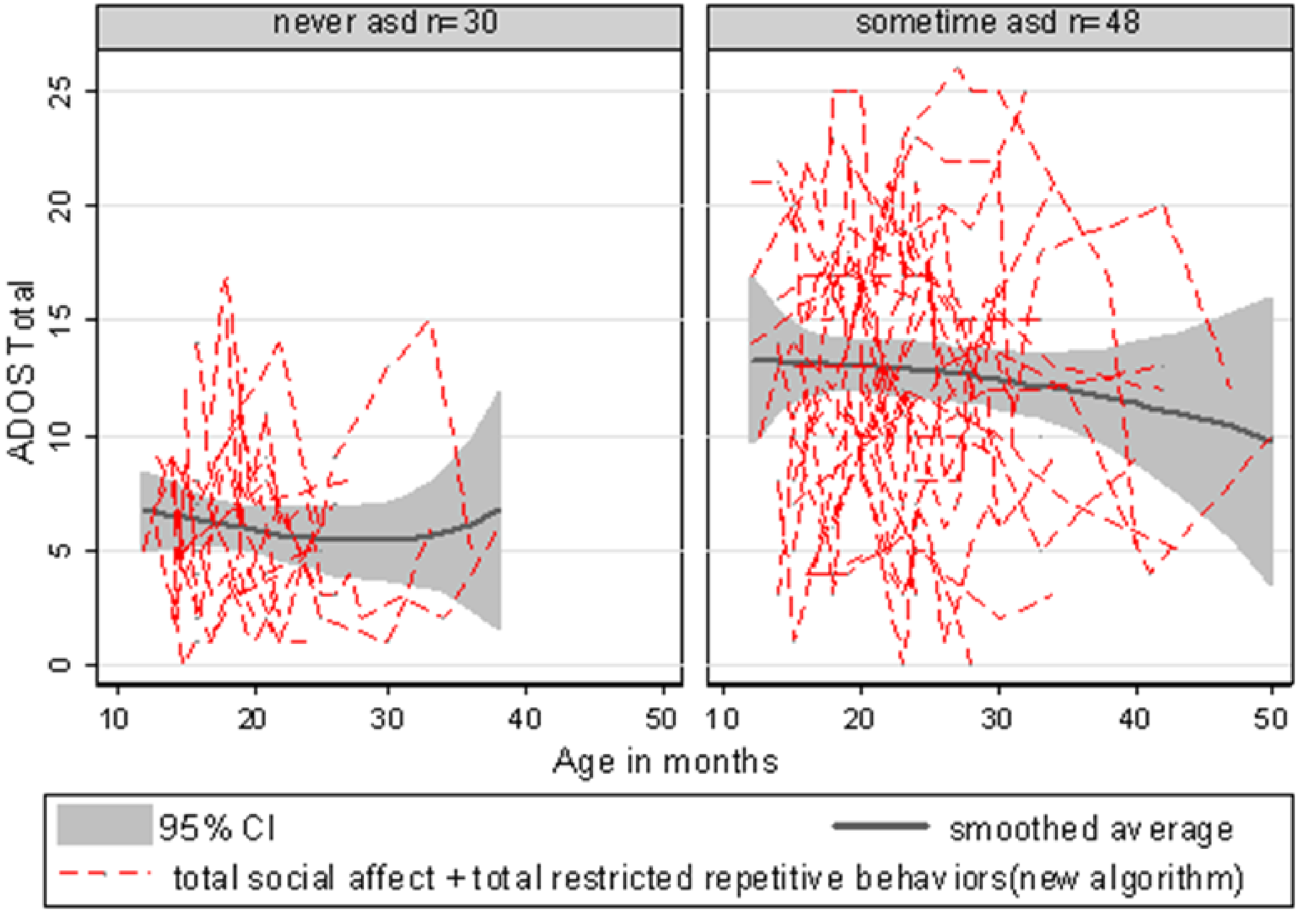
And opportunities for learning

And the families in which this learning occurs

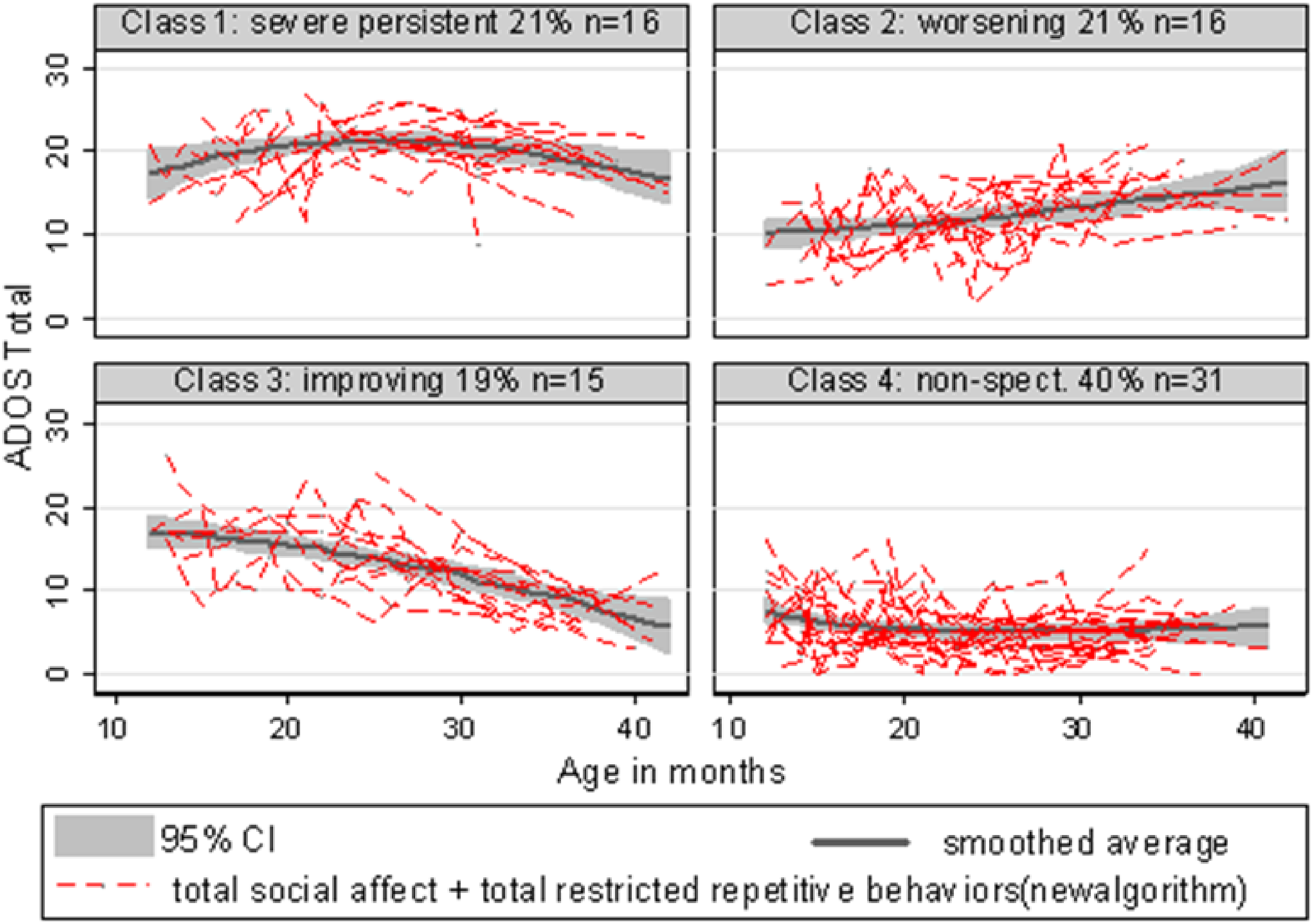
DEMOGRAPHICS (LORD ET AL, 2012)

	Autism (n=32)	**PDD-NOS (n=16)**
Gender		
Female	18.8%	14.3%
Ethnicity		
Caucasian	75.0%	90.5%
AfricanAmerican	9.5%	9.5%
Test scores		
New ADOS total	18.1 (5.5)	12.6 (4.0)
Nonverbal IQ	79.5 (21.4)	94.2 (26.2)

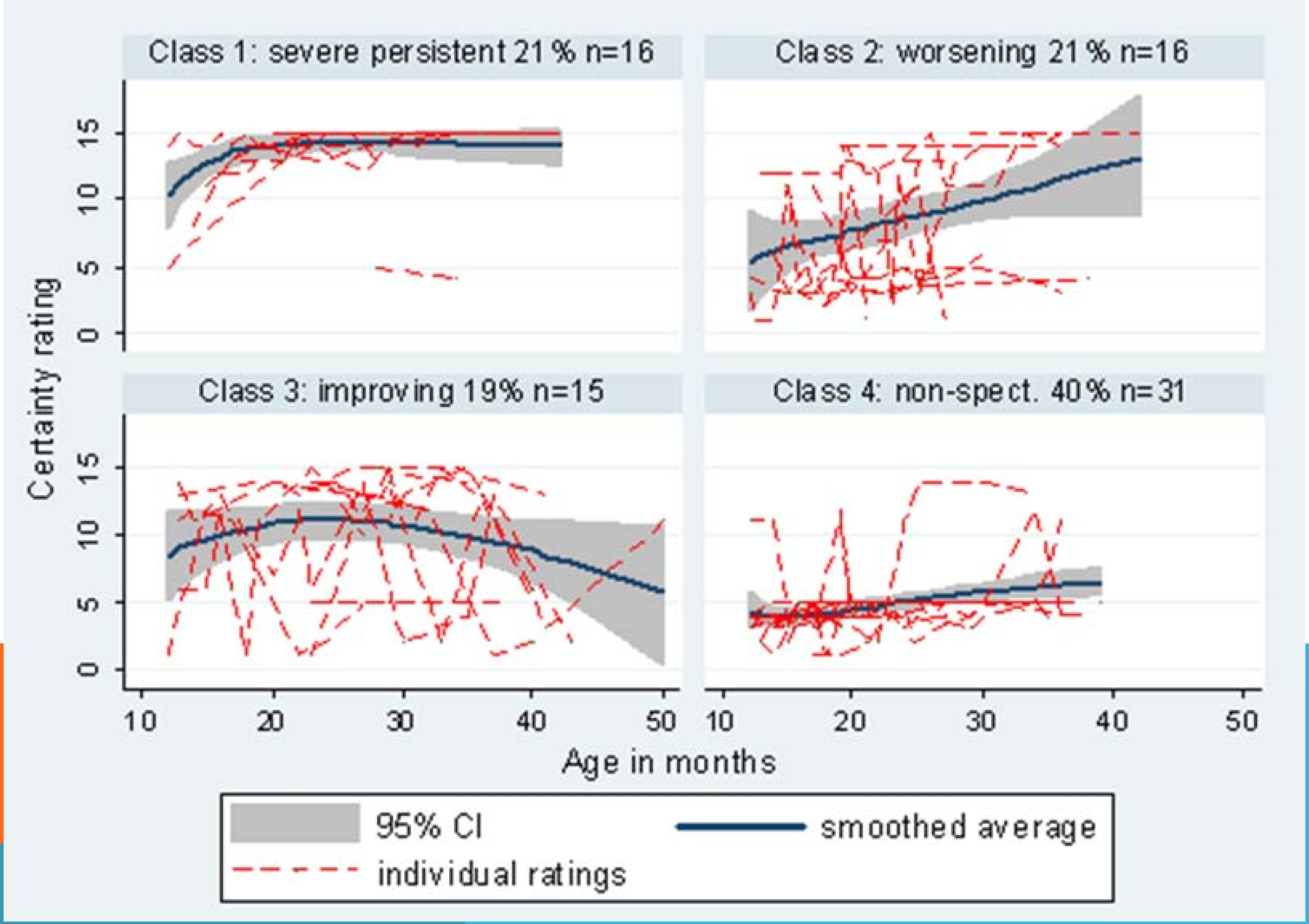
FIGURE 1. ADOS TOTAL ALGORITHM SCORE TRAJECTORIES FOR "EVER ASD" AND "NEVER ASD" CHILDREN



TRAJECTORIES FOR FOUR CLASSES



. Changes in Clinician Ratings of Probability of ASD Diagnosis for the Four Trajectory Classes



OTHER FINDINGS ABOUT THE 4 CLASSES

No differences in gender

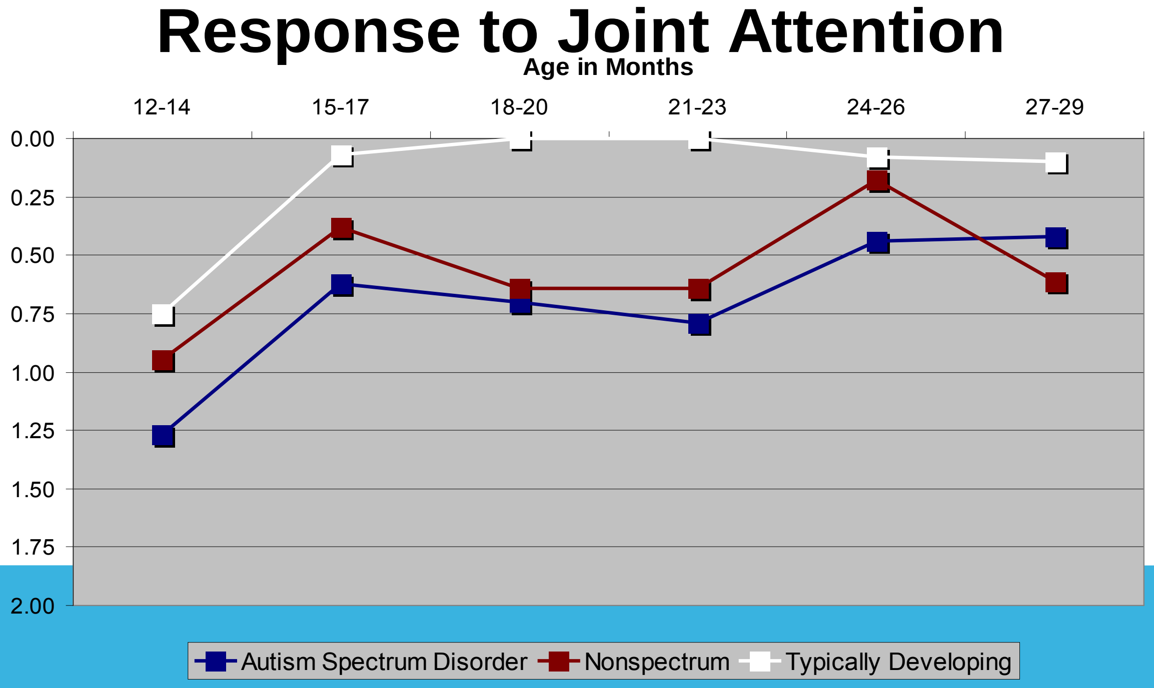
No differences in ethnicity

More siblings, proportionately in the “mild” group than other groups (recruitment)

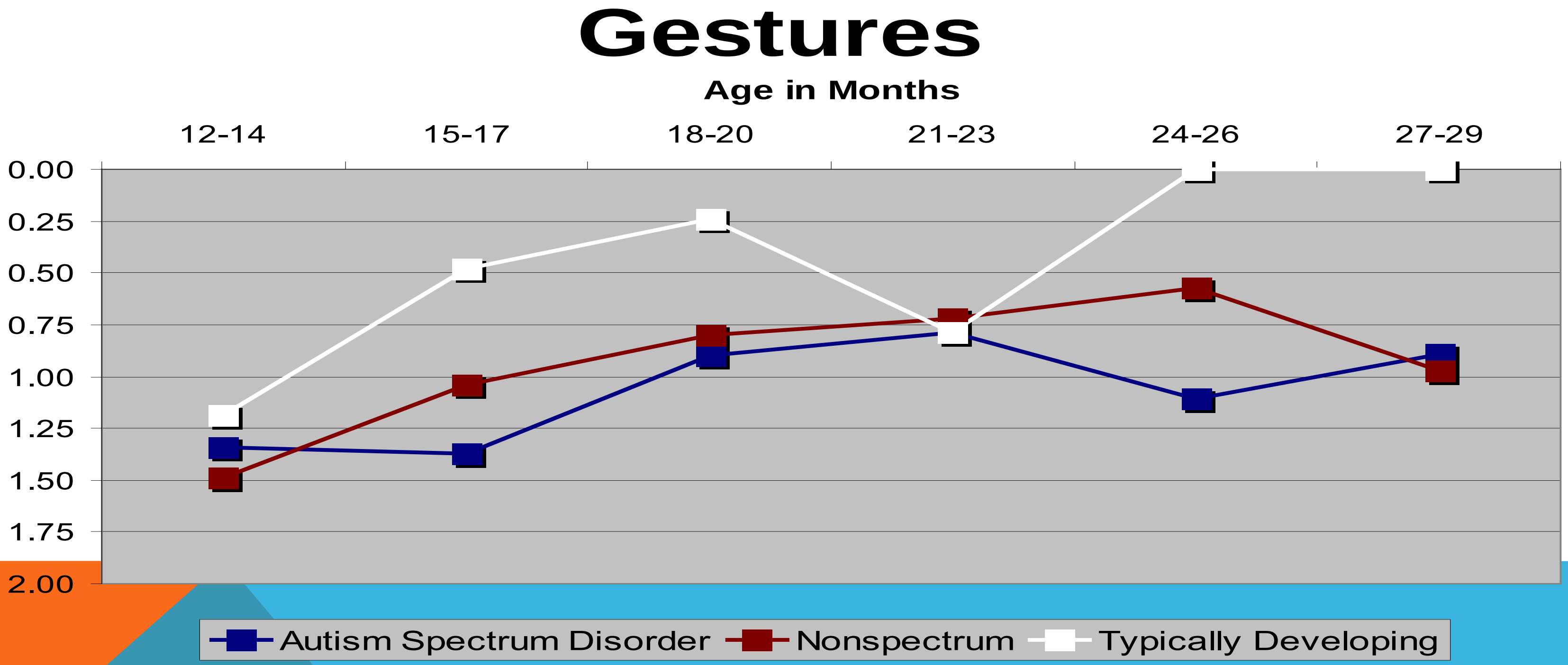
Still quite a lot of change at 30 months

INTERACTIONS OF AGE AND DIAGNOSIS: IMPROVING TRAJECTORIES

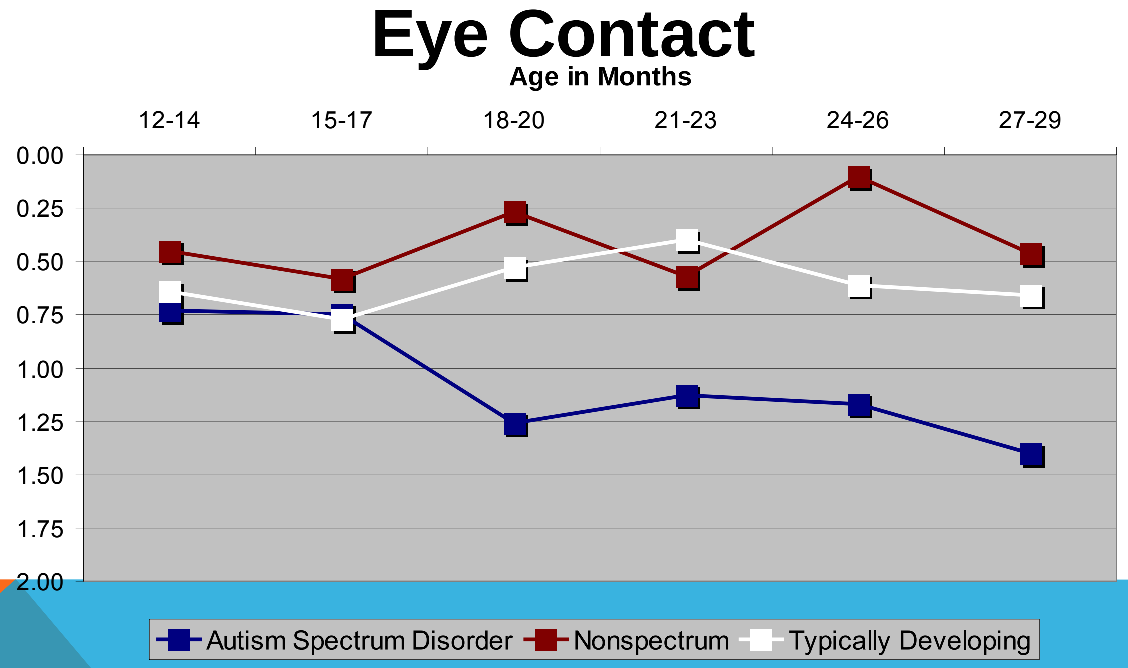
- All groups showed improvement over time in Joint Attention and Amount of Requesting.



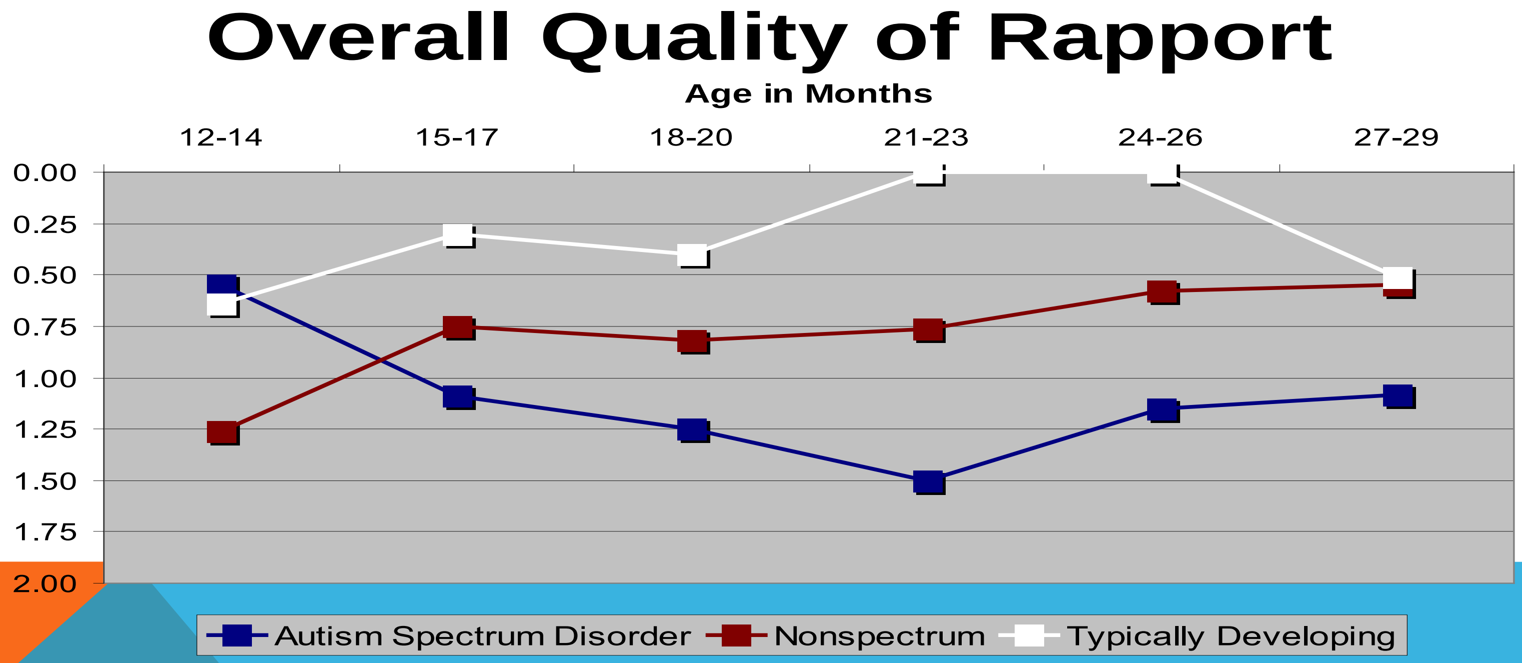
IMPROVING TRAJECTORIES



WORSENING TRAJECTORIES



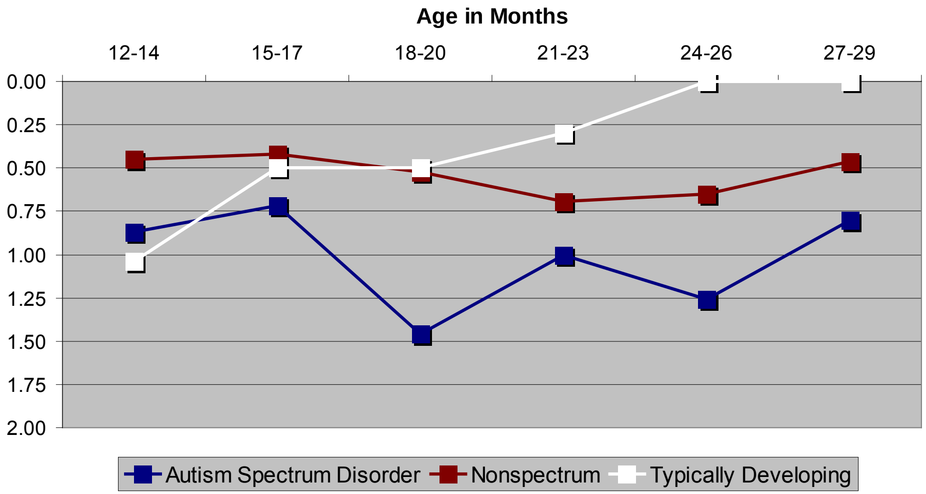
WORSENING TRAJECTORIES



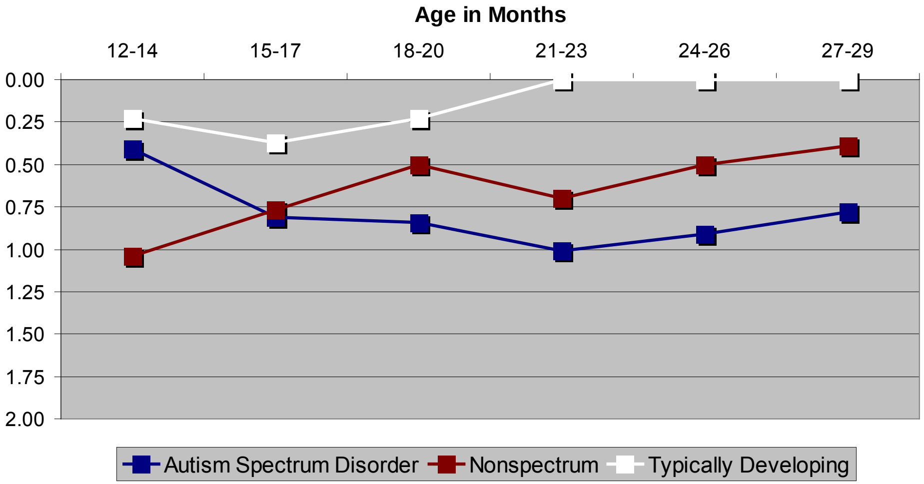
MAIN EFFECTS OF DIAGNOSIS:

ASD WITH LOSS VS. OTHER DX

Response to Name

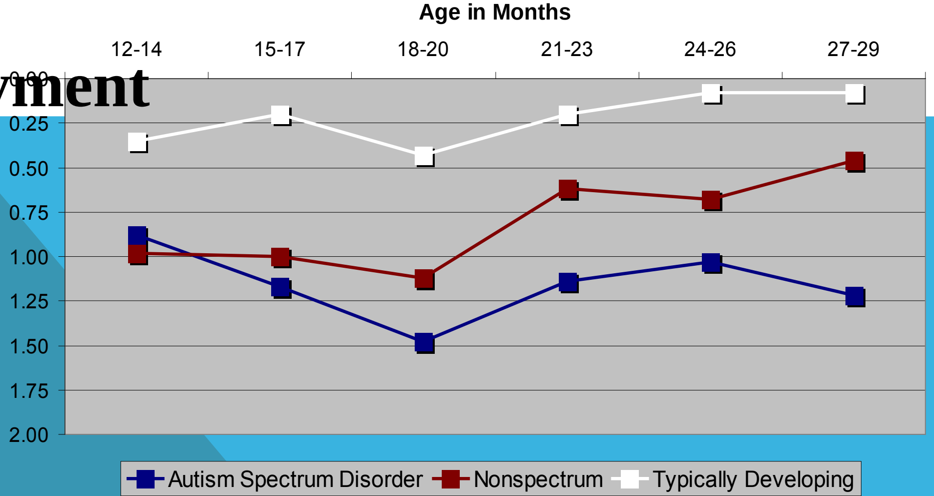


Level of Engagement



Amount of Overtures to Examiner and to Parent

Shared Enjoyment



REGRESSSIONS AS REMEMBERED BY PARENTS

Strongly linked to ASD diagnoses vs language disorders or intellectual disabiliy

Are more reliable across time and parent when they involve a child who was speaking and stops talking

Ages reported are affected by a number of factorrs that affect other behaviors that families are asked to remember

- Telescoping
- Rounding
- Tagging to significant events

Severity of behaviors reported are also affected by how parents are asked

TELESCOPING OF AGE OF FIRST WORDS

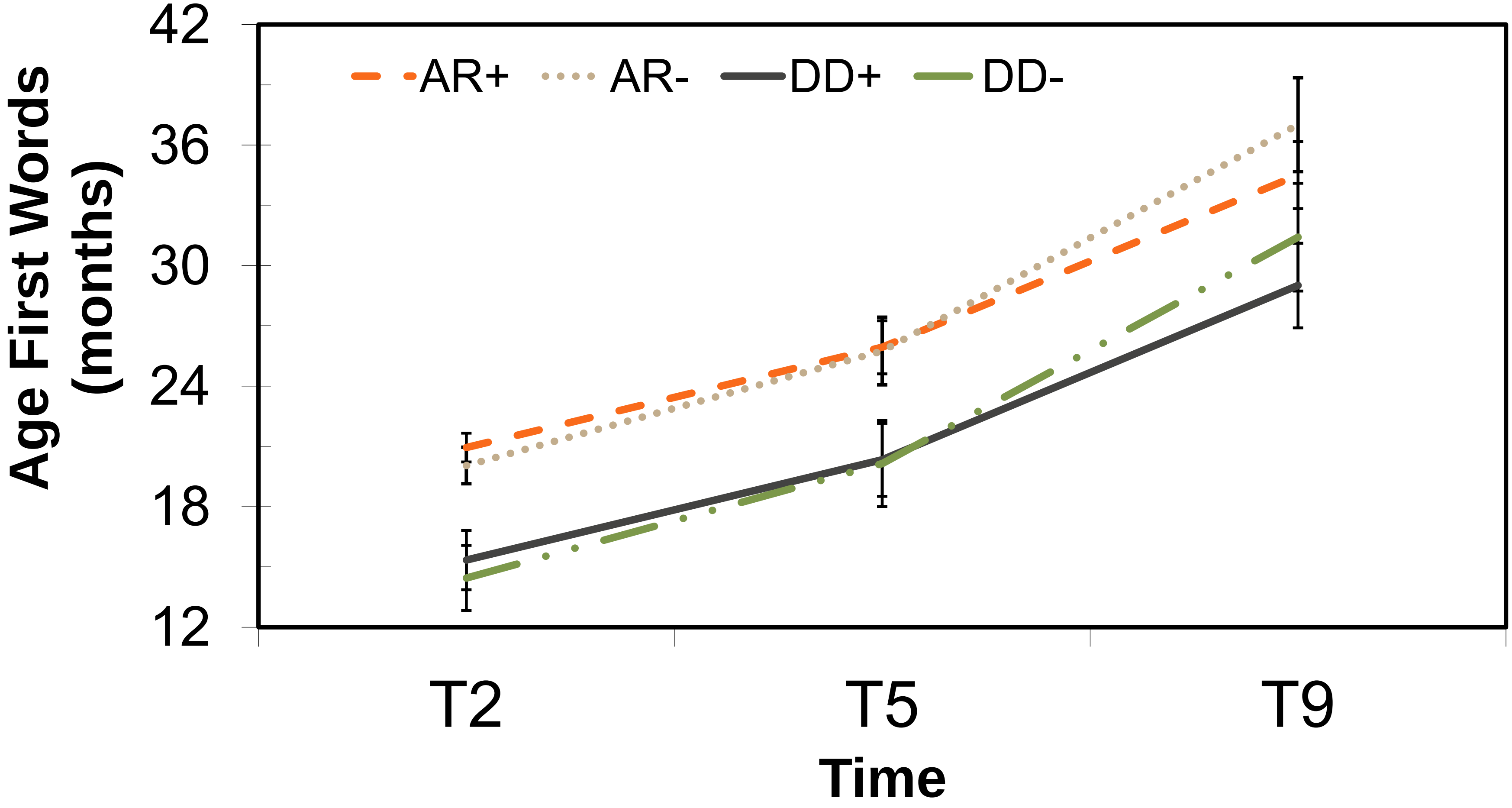


Figure 1. Caregiver-reported age of first words by referral group.
Error bars represent standard errors.
+ = centered Verbal IQ+15; - = centered Verbal IQ−15;

Hus, Taylor & Lord, *JCPP, 2011*

PROPORTION OF FAMILIES WHO REPORTED LANGUAGE DELAY WHEN ASKED AT DIFFERENT AGES

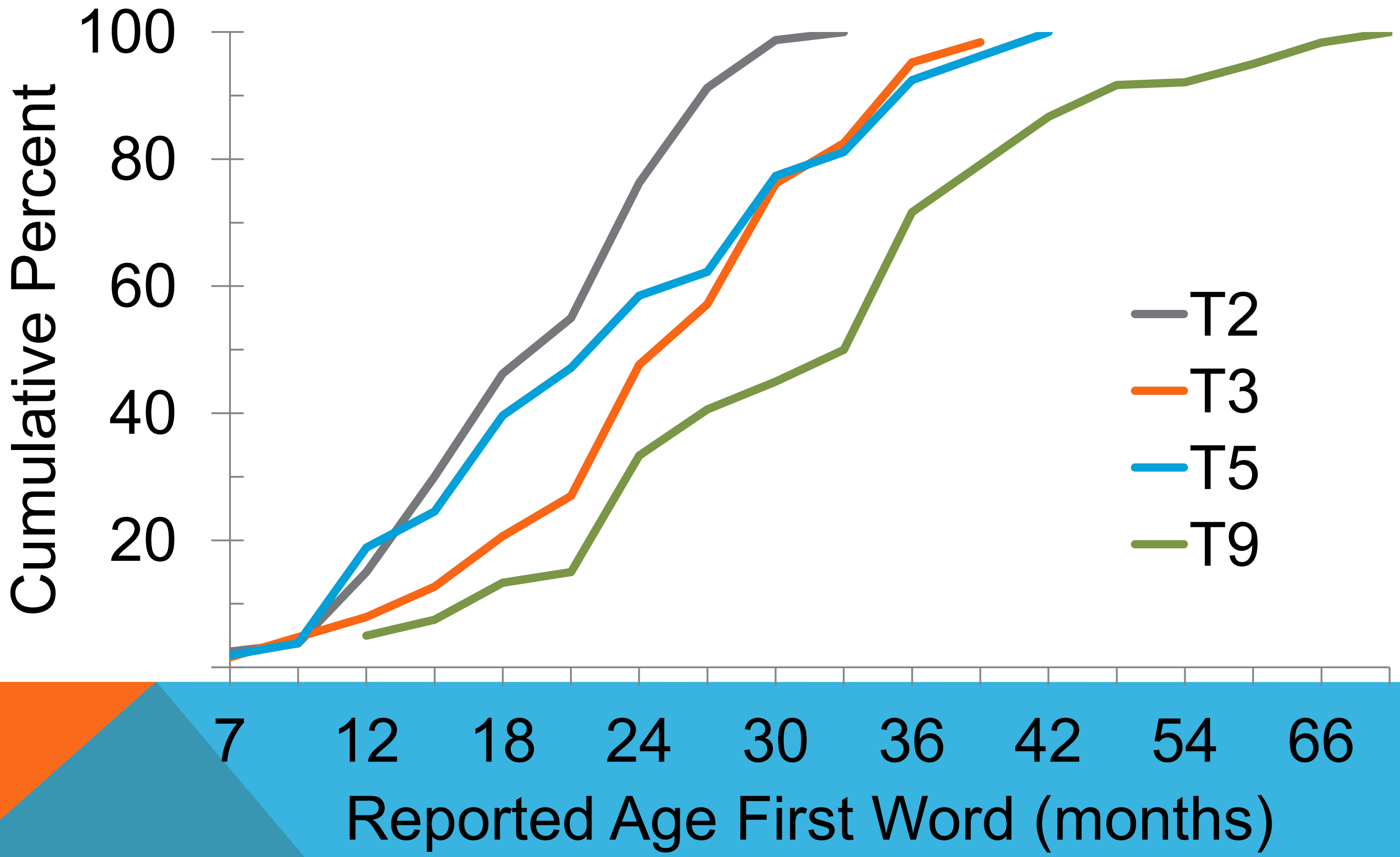
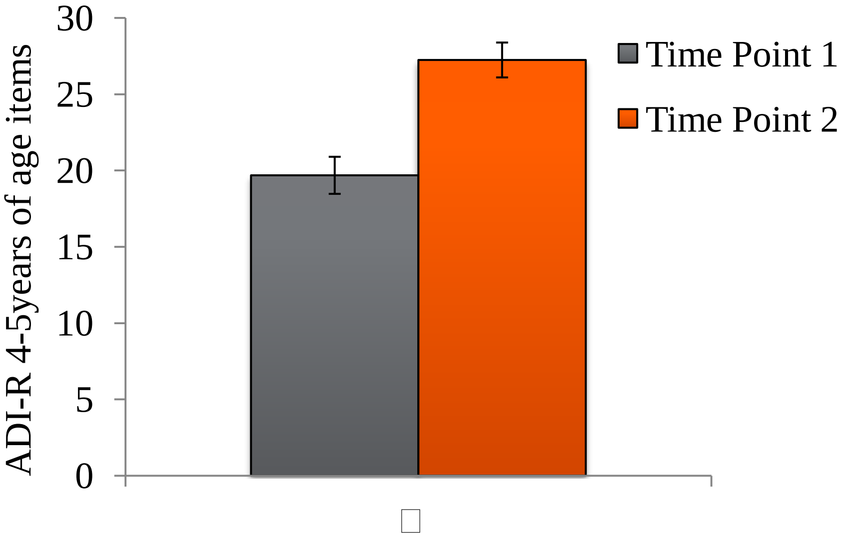


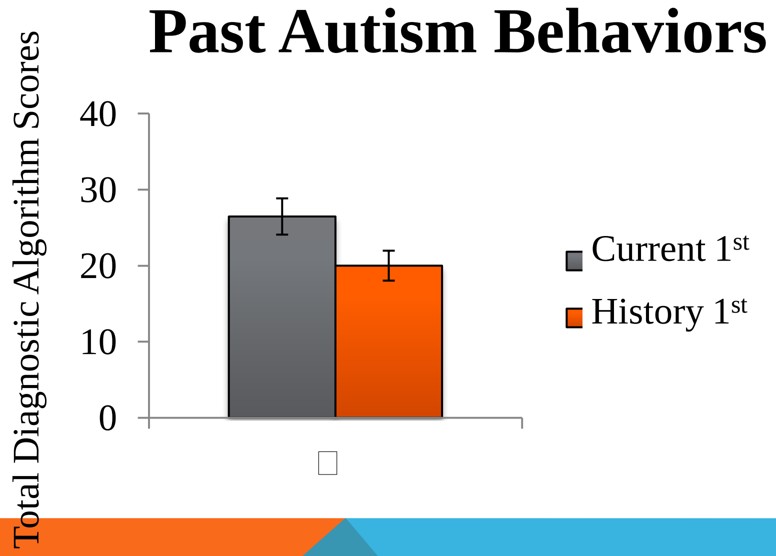
Figure S1. Cumulative percentage of reported age of first words by time point. At T2, 80

Does how caregivers remember symptoms in the past change over time?

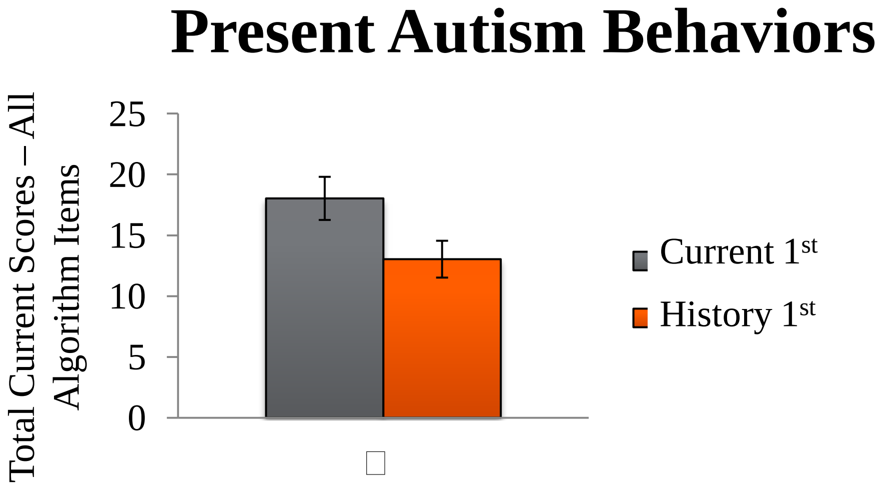


Jones, Wexler, Anderson, Risi, Corsello & Lord (*in prep*).

Does when in time caregivers are asked to remember their child’s behavior impact how they report symptoms on the ADI-R?



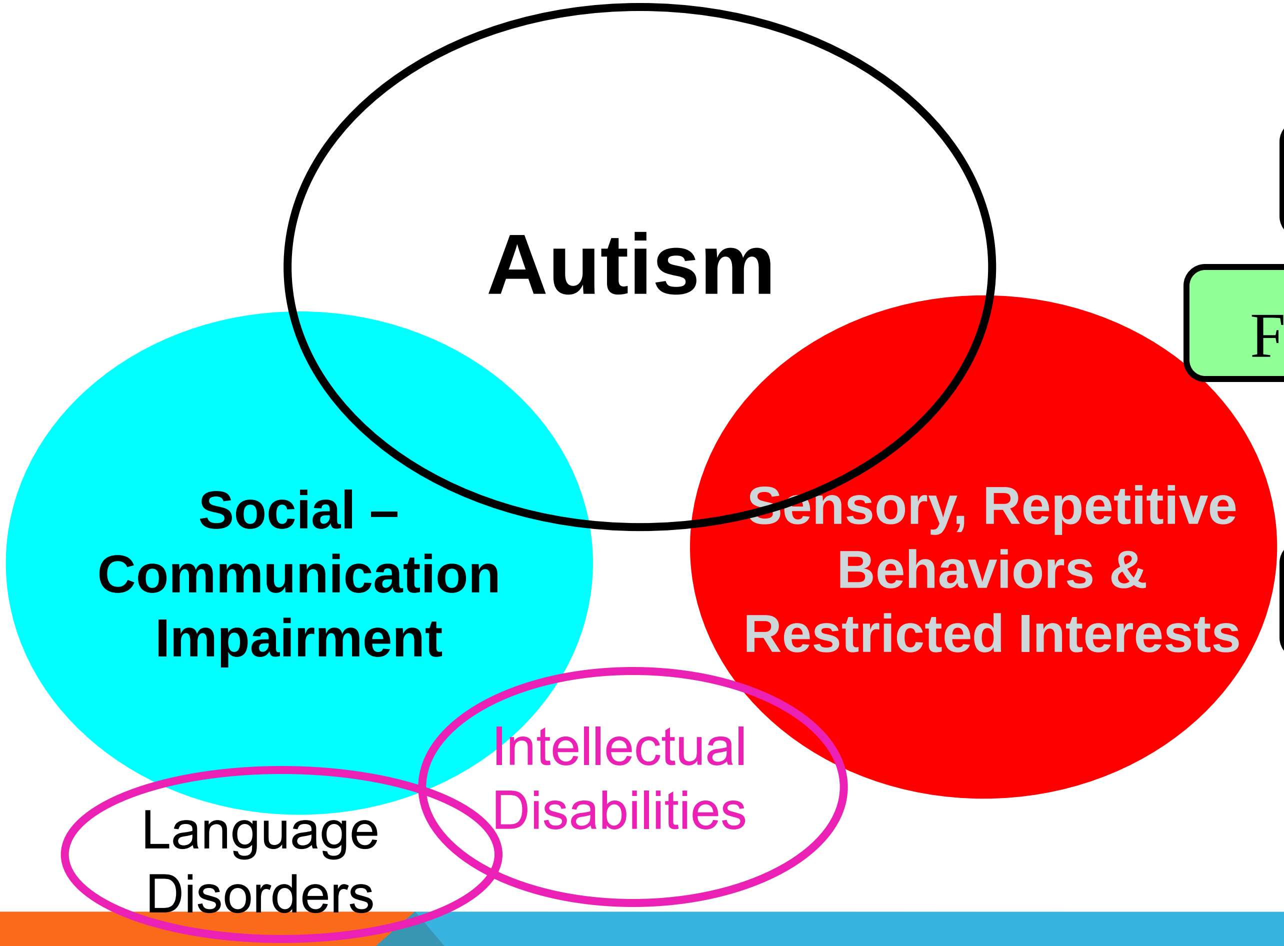
Past Autism Behaviors



Present Autism Behaviors

Jones, Wexler, Anderson, Risi, Corsello & Lord (*2014*).

PERVASIVE DEVELOPMENTAL DISORDERS



Autism

Social – Communication Impairment

Sensory, Repetitive Behaviors & Restricted Interests

Intellectual Disabilities

Language Disorders

Sense of humor

Fine motor skills

Predictability

Intelligence

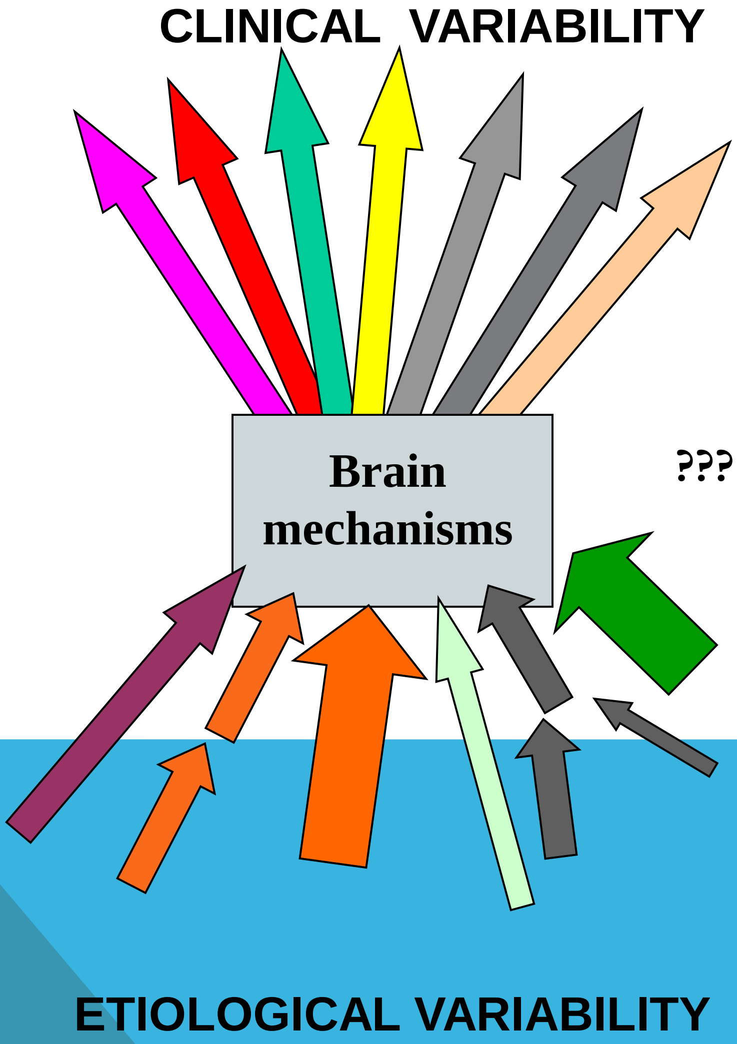
Visual-spatial skills

Curiosity

Attention to detail

Honesty

AUTISM SPECTRUM DISORDER (ASD) DIAGNOSTIC SYMPTOMS



CLINICAL VARIABILITY

Brain mechanisms

??? Final common pathways
leading to ASD

ETIOLOGICAL VARIABILITY

SUMMARY

There is a common phenomenon in autism where a child shows decreased social initiation and spontaneity going into the second year of life.

How many skills and how dramatic the loss is varies across children and depends in part on how many skills the child had before the loss.

Also in play is that most children with autism are gaining some at the same time as they may be “losing” others.

There are specific memory factors that affect parents’ and involved clinicians’ recollections of regression including telescoping and basing the past on exaggerations of the present.

We need more information, particularly prospective studies accompanied by biological measurements as well as remember the effects these trajectories have on families.

Collaborators

- Pamela C. DiLavore
- Susan Risi
- Cory Shulman
- Audrey Thurm
- Christina Corsello
- Families and children in the Early Diagnosis project
- TEACCH, University of Chicago and UMACC clinic staffs
- Deborah Anderson
- Marisela Huerta
- Michael Rutter
- Edwin Cook Jr.
- Andrew Pickles
- Glenna Fields
- Bennett Leventhal
- Rebecca Jones
- NICHD, NIMH, Autism Speaks

Meeting of the IACC

Round Robin

Meeting of the IACC

Afternoon Agenda – continued

4:00 Round Robin

4:00–4:15	**An Insider's Perspective on Autism** **Noah Britton, M.A.** Self-Advocate and Member, IACC
4:15–4:30	**Teen Transition** **Sally Burton-Hoyle, Ed.D.** Associate Professor Eastern Michigan University and Member, IACC
4:30-4:45	**Nevada's Autism Treatment Assistance Program (ATAP)** **Jan Crandy** Case Manager Nevada's Autism Treatment Assistance Program and Member, IACC

A Bunch of Stuff I Made up about Autism

By Noah Britton

A Bunch of Totally Real Facts about Autism

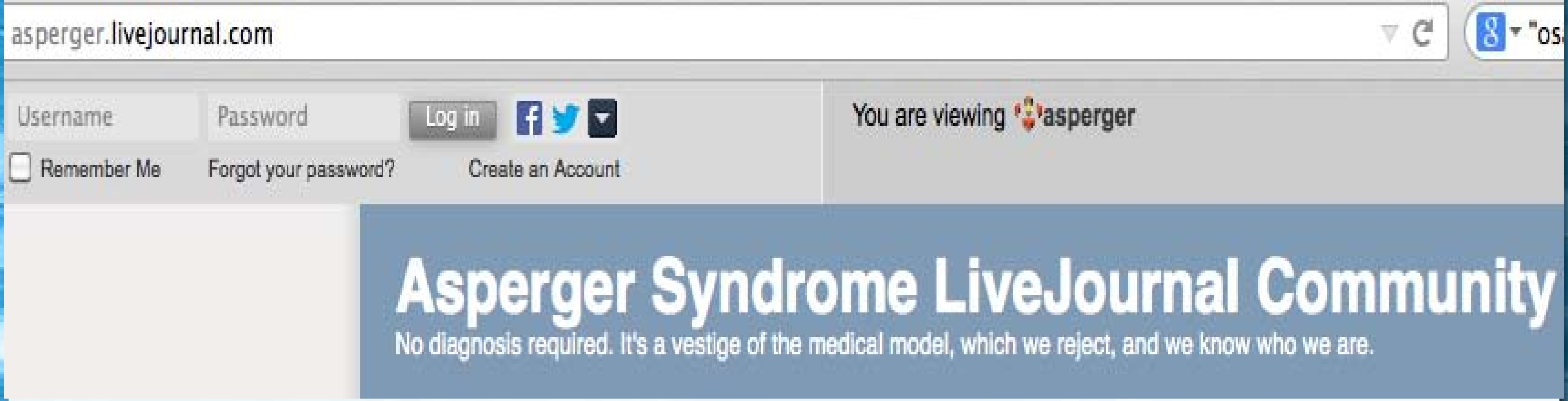
By Noah Britton

Photo by Ru Britton, used with permission

(NERDS)

(COOL PEOPLE)


OMING

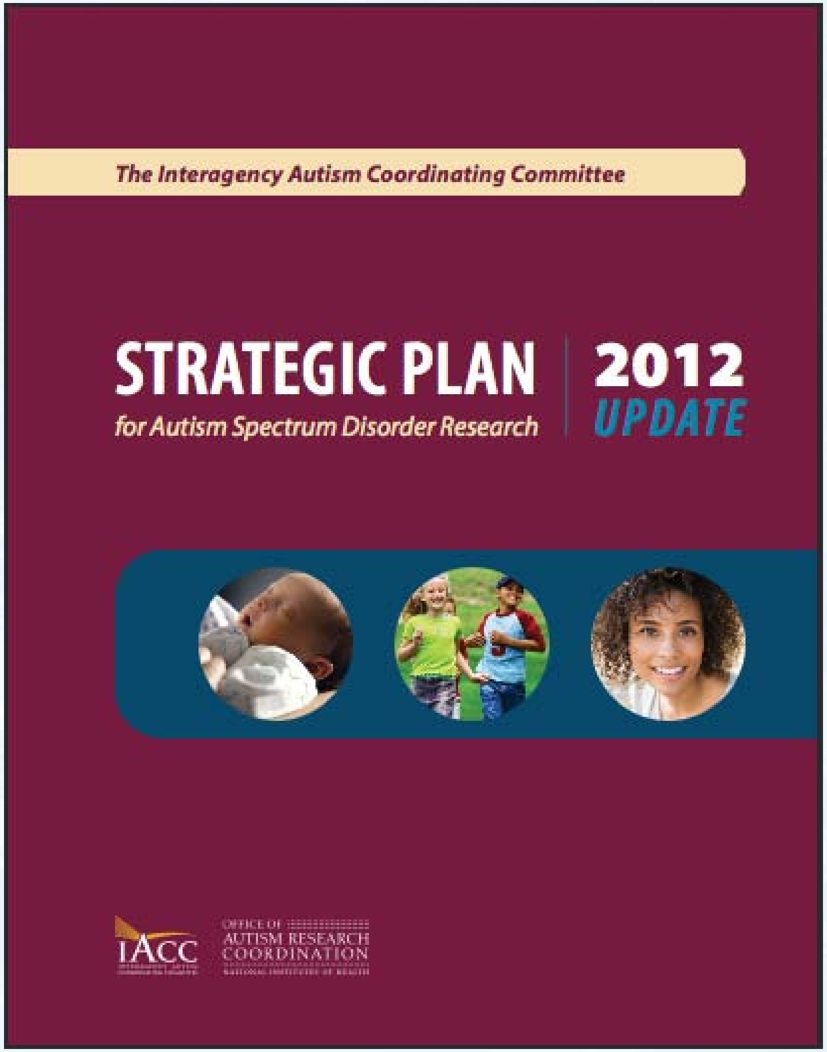


asperger.livejournal.com

You are viewing asperger

Asperger Syndrome LiveJournal Community

No diagnosis required. It's a vestige of the medical model, which we reject, and we know who we are.



The Interagency Autism Coordinating Committee

STRATEGIC PLAN
for Autism Spectrum Disorder Research

2012
UPDATE

IACC

OFFICE OF
AUTISM RESEARCH
COORDINATION

http://iacc.hhs.gov/strategic-plan/2012/index.shtml

Aspie Characteristics

Hypersensitivity

- To sensory input
- To mere presence of others/social interaction
- To change

McAlonan GM, Daly E, Kumari V, Critchley HD, van Amelsvoort T, Suckling J, Simmons A, Sigmundsson T, Greenwood K, Russell A, Schmitz N, Happe F, Howlin P, Murphy DG (2002) Brain anatomy and sensorimotor gating in Asperger's syndrome. *Brain, 125*, pp.1594–1606.

Madar, T. (1996). The Primary Characteristics of Asperger Syndrome, *Asperger United, 9*, 3-11.

Blakemore, S; Tavassoli, T.; Calò, S.; Thomas, R.M.; Catmur, C.; Frith, U.; & Haggard, P. (2006). Tactile sensitivity in Asperger syndrome. *Brain and Cognition 61,* pp. 5-13.

Baron-Cohen, S.; Ashwin, E.; Ashwin, C.; Tavassoli, T.; & Chakrabarti, B. (2009). Talent in autism: hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of The Royal Society B. 364*, pp. 1377–1383. doi:10.1098/rstb.2008.0337

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Evaluation Apprehension

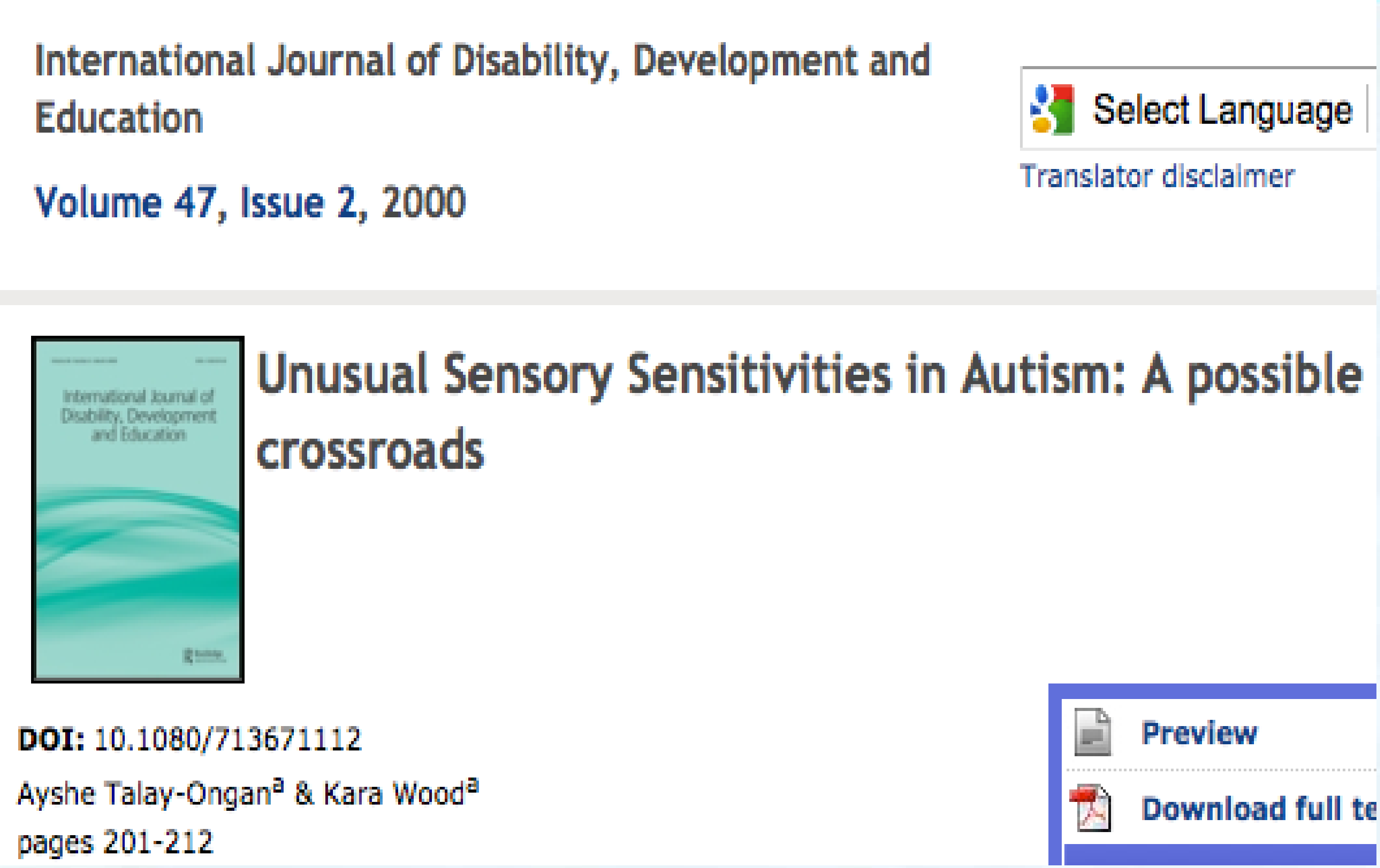
The presence of others distracts us, partially due to fear of being judged

Autistics are more sensitive to this than others, so many of us retreat inward to avoid being aware of the possibility of evaluation

We ignore or try not to notice when we're being judged – it's too painful to confront at the time, but we still can't concentrate until we're removed from the situation

Henchy, T.; Glass, D. C. (1968). Evaluation apprehension and the social facilitation of dominant and subordinate responses. *Journal of Personality and Social Psychology, 10*(4), pp. 446-454.

Sanders, G.S. (1981) Driven by distraction: An integrative review of social facilitation theory and research. *Journal of Experimental Social Psychology, 17* (3), Pp. 227-251. http://dx.doi.org/10.1016/0022-1031(81)90024-X (http://www.sciencedirect.com/science/article/pii/002210318190024X)



International Journal of Disability, Development and Education

Volume 47, Issue 2, 2000

Unusual Sensory Sensitivities in Autism: A possible crossroads

DOI: 10.1080/713671112

Ayshe Talay-Ongan[a] & Kara Wood[a]

pages 201-212

Talay-Ongan, A.; Wood, K. (2000). Unusual Sensory Sensitivities in Autism: A possible crossroads. *International Journal of Disability, Development and Education,* 47 (2) pp. 201-212.

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Baron-Cohen, S.; Ashwin, E.; Ashwin, C.; Tavassoli, T.; & Chakrabarti, B. (2009). Talent in autism: hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of The Royal Society B. 364*, pp. 1377–1383. doi:10.1098/rstb.2008.0337

Eur J Hum Genet. 2013 Mar;21(3):310-6. doi: 10.1038/ejhg.2012.175. Epub 2012 Aug 15.

Prevalence of SHANK3 variants in patients with different subtypes of autism spectrum disorders.

Boccuto L[1], Lauri M, Sarasua SM, Skinner CD, Buccella D, Dwivedi A, Orteschi D, Collins JS, Zollino M, Visconti P, Dupont B, Tiziano D, Schroer RJ, Neri G, Stevenson RE, Gurrieri F, Schwartz CE.

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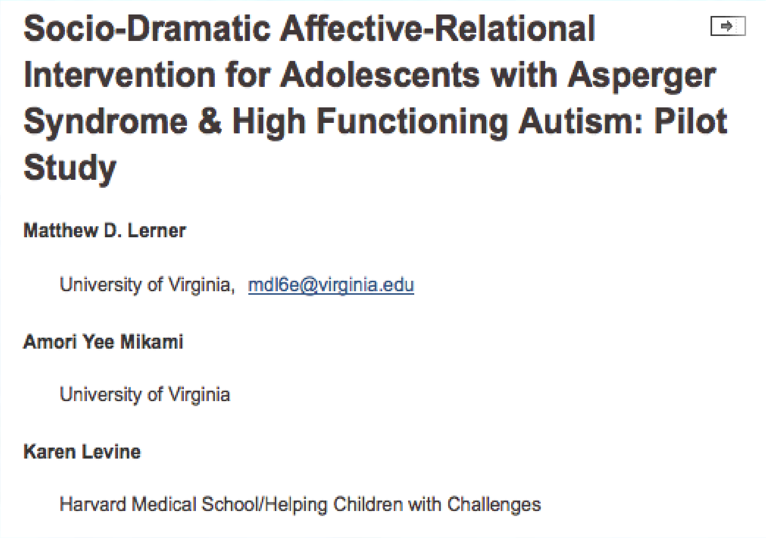

Socio-Dramatic Affective-Relational Intervention for Adolescents with Asperger Syndrome & High Functioning Autism: Pilot Study

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University of Virginia, mdl6e@virginia.edu

Amori Yee Mikami

University of Virginia

Karen Levine

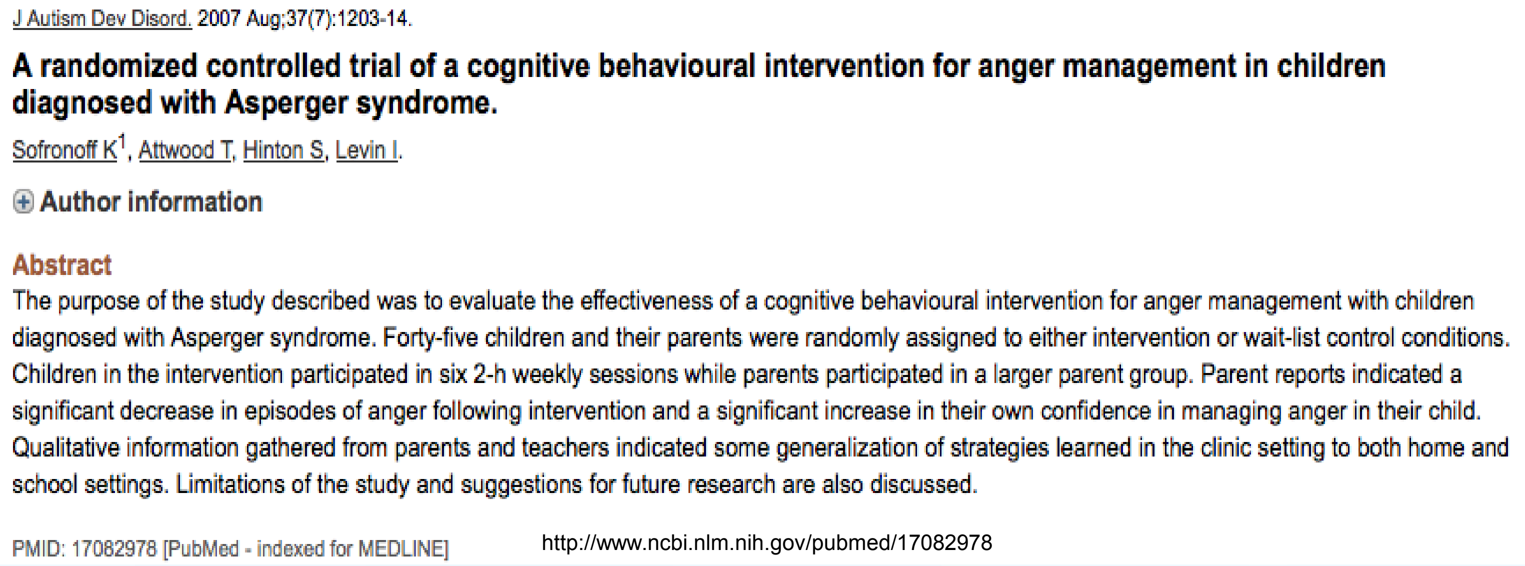
Harvard Medical School/Helping Children with Challenges

Long-term outcome of social skills intervention based on interactive LEGO© play

DANIEL B. LEGOFF Bancroft NeuroHealth, USA

MICHAEL SHERMAN Bancroft NeuroHealth, USA

https://wiki.inf.ed.ac.uk/twiki/pub/ECHOES/InteractionalFocusReciprocity/Loegoff2006.pdf



J Autism Dev Disord. 2007 Aug;37(7):1203-14.

A randomized controlled trial of a cognitive behavioural intervention for anger management in children diagnosed with Asperger syndrome.

Sofronoff K[1], Attwood T, Hinton S, Levin I.

⊕ Author information

Abstract

The purpose of the study described was to evaluate the effectiveness of a cognitive behavioural intervention for anger management with children diagnosed with Asperger syndrome. Forty-five children and their parents were randomly assigned to either intervention or wait-list control conditions. Children in the intervention participated in six 2-h weekly sessions while parents participated in a larger parent group. Parent reports indicated a significant decrease in episodes of anger following intervention and a significant increase in their own confidence in managing anger in their child. Qualitative information gathered from parents and teachers indicated some generalization of strategies learned in the clinic setting to both home and school settings. Limitations of the study and suggestions for future research are also discussed.

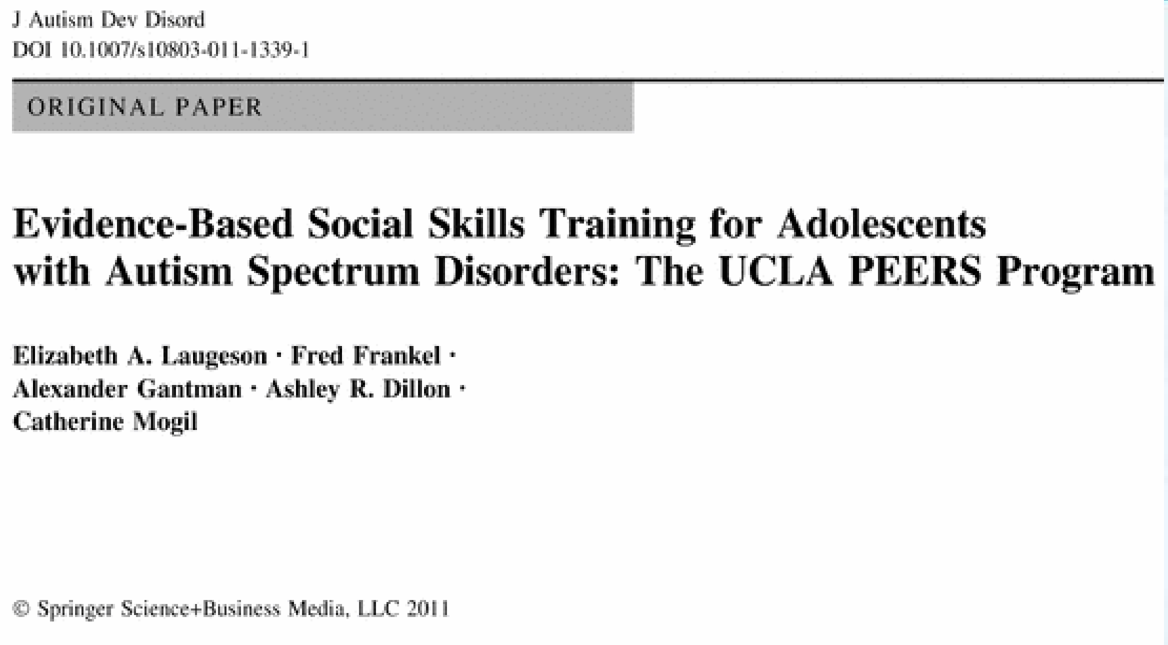
PMID: 17082978 [PubMed - indexed for MEDLINE]

http://www.ncbi.nlm.nih.gov/pubmed/17082978

Sofronoff, K; Attwood, T; Hinton, S; Levin, I. (2007). A randomized controlled trial of a cognitive behavioural intervention for anger management in children diagnosed with Asperger syndrome. *J Autism Dev Disord 37*(7), pp. 1203-14.

Lerner M.D.; Mikami, A.Y.; Levine, K. (2011). Socio-dramatic affective-relational intervention for adolescents with asperger syndrome & high functioning autism: pilot study. *Autism, 15*(1), pp. 21-42. doi: 10.1177/1362361309353613. Epub 2010

Legoff, D.B.; Sherman, M. (2006). Long-term outcome of social skills intervention based on interactive LEGO play. *Autism, 10*(4), pp. 317-29.

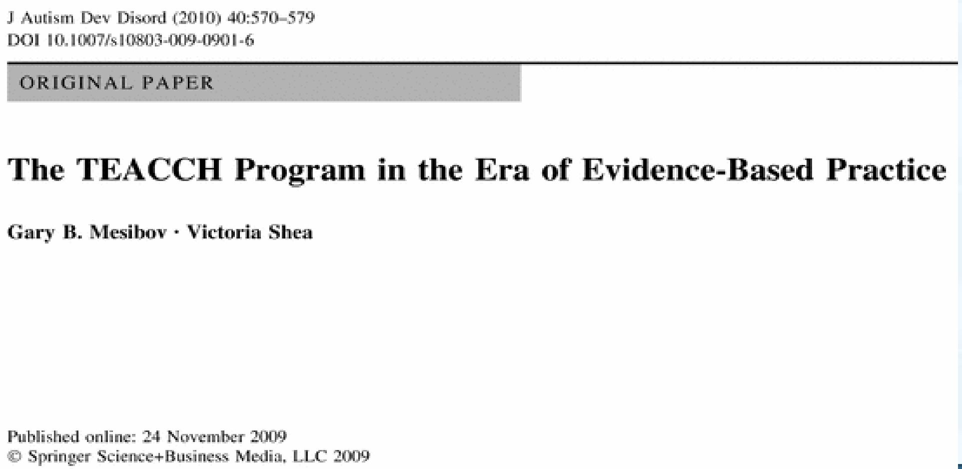


J Autism Dev Disord
DOI 10.1007/s10803-011-1339-1

ORIGINAL PAPER

Evidence-Based Social Skills Training for Adolescents with Autism Spectrum Disorders: The UCLA PEERS Program

**Elizabeth A. Laugeson · Fred Frankel ·
Alexander Gantman · Ashley R. Dillon ·
Catherine Mogil**



J Autism Dev Disord (2010) 40:570–579
DOI 10.1007/s10803-009-0901-6

ORIGINAL PAPER

The TEACCH Program in the Era of Evidence-Based Practice

Gary B. Mesibov · Victoria Shea

Laugeson, E.A.; Frankel, F.; Gantman, A.; Dillon, A.R.; Mogil, C. (2012). Evidence-Based Social Skills Training for Adolescents with Autism Spectrum Disorders: The UCLA PEERS Program. *Journal of Autism and Developmental Disorders, 42,* (6), pp 1025-1036. http://link.springer.com/article/10.1007/s10803-011-1339-1.

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Sources

Asperger Syndrome Livejournal Community. (2014) http://asperger.livejournal.com/ Accessed 7/3/14.

Baron-Cohen, S.; Ashwin, E.; Ashwin, C.; Tavassoli, T.; & Chakrabarti, B. (2009). Talent in autism: hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of The Royal Society B. 364*, pp. 1377–1383. doi:10.1098/rstb.2008.0337 6.

Belmonte, M.K.; Allen, G.; Beckel-Mitchener, A; Boulanger, L. M.; Carper, R.A.; Webb, S. J. (2004). Annual meeting mini-symposium. Autism and abnormal development of brain connectivity. *The Journal of Neuroscience, 24*(42), pp. 9228-9231. doi:10.1523/JNEUROSCI.3340-04.2004.

Blakemore, S; Tavassoli, T.; Calò, S.; Thomas, R.M.; Catmur, C.; Frith, U.; & Haggard, P. (2006). Tactile sensitivity in Asperger syndrome. *Brain and Cognition 61,* pp. 5-13.

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Henchy, T.; Glass, D. C. (1968). Evaluation apprehension and the social facilitation of dominant and subordinate responses. *Journal of Personality and Social Psychology, 10*(4), pp. 446-454.

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McAlonan G.M.; Daly, E.; Kumari, V.; Critchley, H.D.; van Amelsvoort, T.; Suckling, J.; Simmons, A.; Sigmundsson, T.; Greenwood, K.; Russell, A.; Schmitz, N.; Happe, F.; Howlin, P.; Murphy, D.G. (2002). Brain anatomy and sensorimotor gating in Asperger's syndrome. *Brain, 125*, pp.1594–1606.

Sanders, G.S. (1981) Driven by distraction: An integrative review of social facilitation theory and research. *Journal of Experimental Social Psychology, 17* (3), Pp. 227-251. http://dx.doi.org/10.1016/0022-1031(81)90024-X.

Sofronoff, K; Attwood, T; Hinton, S; Levin, I. (2007). A randomized controlled trial of a cognitive behavioural intervention for anger management in children diagnosed with Asperger syndrome. *J Autism Dev Disord 37*(7), pp. 1203-14.

Talay-Ongan, A.; Wood, K. (2000). Unusual Sensory Sensitivities in Autism: A possible crossroads. *International Journal of Disability, Development and Education,* 47 (2) pp. 201-212.

ACC Autism Collaborative Center
Service ■ Education ■ Research ■ Community
Eastern Michigan University

College Supports Program for Students with ASD

Sally Burton-Hoyle, Ed.D
Associate Professor
Department of Special Education:
Autism Spectrum Disorders Area
Director, College Supports Program

The Issue

- 1 in 68 children in multiple communities have been identified as having autism (2014)
- Levels of intellectual ability vary greatly among children with autism but many individuals have average intelligence.
- There is an increasing number of high school students with ASD who will be entering college.
- Students may struggle in college not because of their potential or academic prowess but because they are unable to navigate the university environment!

College Success is Possible With Supports!

Eastern Michigan University

- Eastern Michigan University is a comprehensive, co-educational public university located in Ypsilanti, Michigan. Ypsilanti is 35 miles west of Detroit and eight miles east of Ann Arbor.

- The University currently serves 23,000 students who are pursuing undergraduate, graduate, specialist, doctoral and certificate degrees in the arts, sciences and professions.

- In all, there are more than 200 majors, minors and concentrations are delivered through the University's Colleges of Arts and Sciences; Business; Education; Health and Human Services; Technology.

College Supports Program (CSP)

- CSP is an individualized and person-centered approach that is designed to support students with ASD as they transition to college and progress through graduation.

Key Components of the CSP

- Creating an ASD friendly university environment
- Honoring the culture of the disability
- Supporting deficits that may act as a barrier to successful completion of coursework
- Supporting relationship development
- The university community is defined by the student
- Career planning that focuses on the strengths of the student

Creating an ASD Friendly Campus: Administration

- Conversations, discussions, and ongoing training with the Board of Regents, University President, Provost, Student Health Center, Housing, Campus Life, Admissions and Enrollment Counselors and the Disability Resource Office.

OFFICE of the PRESIDENT

Creating an ASD Friendly Campus

- Community/Campus wide knowledge of ASD through ASD information sessions
- Frequent articles on ASD in university periodicals
- Mentors hired to support CSP students are graduate students from all departments and colleges.

Creating an ASD Friendly Campus: Training, Training, Training

- CSP staff have developed ongoing relationships through training and availability to provide 24/7 assistance to Housing Staff, Resident Advisors, Tutoring Supports, Food Service, University Police.

Creating an ASD Friendly Campus: Beyond 504 Accommodations

- Understanding that CSP offers services that are “Beyond Reasonable Accommodations of Sec. 504”

CSP Support Services

Fees are based on the individualized plan of service and are designed to lead toward increasing independence:

- Academic
- Organizational
- Visual Supports
- Daily Living Skills
- Social Living
- Campus employment
- Residential Life

CSP Support Services

- Relationships with faculty
- Support Groups
- Mentoring
- Recreation Groups
- Liaison with family
- Career planning
- Internship Opportunities
- Coordination with students' medical providers when appropriate.

Mentors are Critical For Success in College

Academic Supports

- A Personal introduction letter is written by the student; this letter will accompany the accommodations letter and will be sent to instructors prior to a meeting with each instructor.

- Before, or at the beginning of each semester, staff meet with each of the student’s instructors to review accommodations and to discuss the syllabus and course expectations in detail. Whenever possible the student participates in this meeting, and if not, the student schedules an appointment to meet the professor during office hours.

Academic Supports

- Students are encouraged to appropriately utilize instructors office hours.
- At mid-term (or more often) meetings are held with faculty and students to address any concerns about about progress in the course.
- Any assignments or tests that may be problematic are discussed in advance with problem solving by all parties. Accommodations are made, modification of content is NOT

Academic Supports

- A check-in/check-out plan for each day is established and monitored by staff and mentors assigned to specific students.
- Technology is utilized as much as possible to support students
- All students sign off on FERPA rights to allow staff to speak with professors and other university staff, as well as communicate with the family as needed.

Residential Supports

- Facilitate the establishment of routines for self care and getting up and to class on time.
- Orientation to laundry procedures and social rules related to this.
- Collaborate with the housing staff, especially the student’s RA, to create a physically and psychologically safe living experience.
- Morning and weekend “dorm checks” for a safety and a “healthy” environment.

Evidence Based Practices Used in CSP

- Visual Supports
- Social Mapping
- Google Calendar/Planner
- Video Modeling
- Scripts for social interactions
- Social Skill groups
- Recreation groups

Evidence Based Practices Used in CSP

- Speech/Language Therapy interventions
- Occupational Therapy interventions
- Sensory Informed Plans for emotional self management
- Daily organizational supports in the academic and residential settings on campus
- Fitness programs

Program Costs

- Prices range from $2,000 to $40,000 and upwards a year nationally
- EMU/CSP is $5,000-$8,000 a semester depending on the level of intensity of supports. Fees are determined individually rather than charging a flat fee.
- Students who live in the dorms generally pay the highest fees.

Funding/Scholarships

- Scholarships: http://www.autismspeaks.org/family-services/resource-library/post-secondary-education-resources
- Vocational Rehabilitation Services in some states and regions
- Planned College Saving Programs
- Medicaid -Specific community living supports in some states. This depends on how your Medicaid state plan is written

Resources

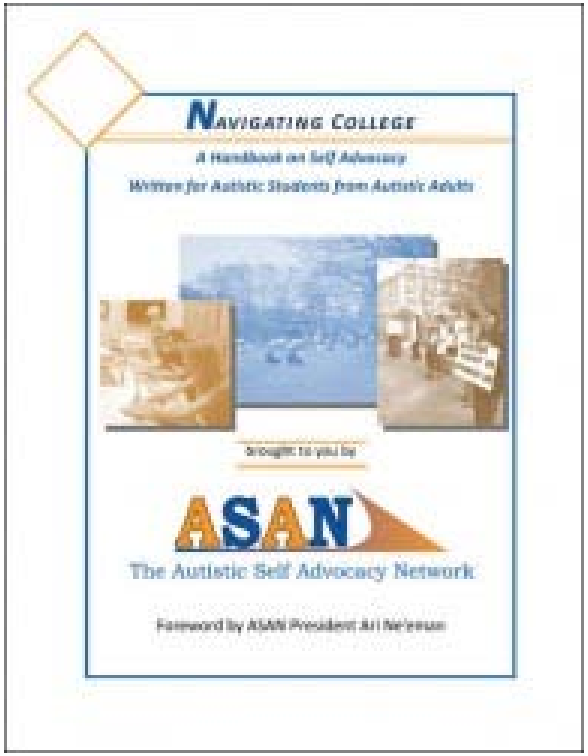
“Many autistic teens out there have the brains to make higher education a breeze, but are lacking in some of the social, time management and organizational skills they’ll need to make the grades they deserve.

Here are 10 of the growing number of colleges that can be a good choice for students with autism, as they can provide support groups, assistance with courses, special classes and all the information students need to get a degree.”

www.Collegeguide.com 2012, **10 Impressive Special College Programs for Students With Autism**

Resources

- “Navigating College” A Handbook on Self Advocacy. Written for Autistic Students from Autistic Adults



NAVIGATING COLLEGE

ASAN

The Autistic Self Advocacy Network

Know the Difference!

- Summer Programs are designed to identify interests for secondary students with ASD.
- Two Year Prep Programs are designed to acclimate students to what college may entail
- Four year degree programs within a university
- College Internship Programs that secure internships for students on the spectrum
- See the following for universities and programs nationally:http://www.collegeautismspectrum.com/collegeprograms.html

Nevada Aging and Disabilty Services Division

ATAP

Autism Treatment Assistance Program

A Community Based Self-Directed Program

ATAP, which began as a pilot in 2007, has had significant growth.

- Increases in the number of children served
- Development of plan types to ensure each individual child's needs are being met and cost-sharing is occurring
- Increases in treatment provider accountability and reporting
- Increases in parent training and involvement
- Progress measurement procedures

Even with these strides, cost-sharing needs to be expanded as well as funding for thorough and accurate analysis of program and child progress.

Authority

- In 2011, the Nevada Legislature established the Autism Treatment Assistance Program to provide and coordinate the provision of services to persons with Autism Spectrum Disorders (ASD). Pursuant to NRS 427A.872, the Aging and Disability Services Division created the ATAP program.

Funded

- In 2013, ATAP received $11.7M over the biennium through general fund and tobacco settlement dollars.

- FY 14 slots = 307 children
- FY 15 slots = 572 children

- Children are added to the caseload monthly to grow towards the maximum slots noted above.

Mission

- Our purpose is to eliminate or decrease the level of life-long supports.
- Our priority is to improve child outcomes and support changes that make a significant difference to the family

Program Outline

- Created to **assist** parents and caregivers with the expensive cost of providing treatment to their child with Autism Spectrum Disorder (ASD).
- ATAP provides a monthly allotment to pay for on-going treatment development, supervision, parent training and a limited amount of weekly intervention hours based upon a child's individual treatment plan, age, and income.
- ATAP only funds treatment that has been proven by research to be evidence-based.

Community Based and Self Directed by Parent/Caregiver

- The Parent/Caregiver…
  - Established as the Employer of Record
  - Selects plan type
  - Selects provider and treatment team
  - Selects home-based or provider facility
  - Manages budget, tracks treatment hours and approves payments online

- Treatment delivered across environments

Eligibility

- Be under age 19;
- Reside in the State of Nevada;
- Be diagnosed as a person with a Autism Spectrum Disorder by a physician, psychologist, child/adolescent psychiatrist, pediatric neurologist or other qualified professional. A Special Education eligibility of Autism from a multidisciplinary team is acceptable when in the company of an appropriate assessment report.

Caregiver/Parent Involvement

- ATAP requires participation at levels, which support positive outcomes for the child and family.
- ATAP recognizes parent training is essential for success.
- At least one parent is required to attend and participate in monthly training & program overview.
- Parents are required to do or fund hours to support their child’s treatment.
- Prior to exit, parents are required to demonstrate ability to promote desired behavior changes.

Provider Qualifications

- **Most plan types must be overseen by a Licensed Psychologist or a Board Certified Behavioral Analyst who has experience in the treatment of Autism**, although the actual supervision may be provided by other professionals, at their direction.
- Weekly treatment hours are delivered by behavior interventionists who receive ongoing, intense training based on the individual child’s needs.

ATAP Service Plans

ATAP supports evidence-based treatment through a variety of service plans.

- **Three types of plans**
    - *Comprehensive*
    - *Targeted Behavior Plans, with subtypes*
    - *Insurance Assistance/Collaboration*

    - Designed to support transition through plan types
    - **Maximum Consecutive Length in ATAP is 7 years**

Comprehensive Plans

- Addresses skills across all domains daily
- Must start by age 6
- A maximum of 4 years in plan type
- Must average 25 hours a week of treatment
- Direct supervision required at a MINIMUM of 4 hours monthly
  - ✓ Training for parents and interventionists
  - ✓ Direct observation with child and team
  - ✓ Bi-monthly progress reports
- Progress is evaluated to ensure treatment is effective
  - ✓ Progress must be demonstrated across at least four domains quarterly.
  - ✓ Percentage of Impact Targets mastered annually and mastery of Critical Impact Targets at the completion of year two to continue in plan type.

Targeted Behavior Plans

Narrow in scope and address a selected group of skills, which impact the child and the family

- **Addresses Parent/Caregiver Priorities**
  - *Crisis Intervention/Behavior Management*
  - *Selected Skills/Behaviors*
  - *Social Skills*
  - *Speech, Occupation or Physical Therapy*
  - *Transition*

Extensive Plans

- Addresses up to 10 plan targets a year
- A maximum of 2 years in plan type
- Must average 15 hours a week of treatment
- Direct supervision required at a MINIMUM of 3 hours monthly
  - ✓ Training for parents and interventionists
  - ✓ Direct observation with child and team
  - ✓ Quarterly progress reports
- Progress is evaluated to ensure treatment is effective
  - ✓ Progress must be demonstrated across at least 4 goals quarterly.
  - ✓ Percentage of ATAP Impact Targets mastered annually
  - ✓ Mastery of 2 hygiene routines, ability to transition without protest, Effective mode of communication at the completion of year one to continue in plan.

Basic Plans

- Addresses up to 3 plan targets (skills)
- Typically older children
- Maximum of 1 year and then exited from ATAP
- Provider & plan determine hours of treatment & supervision per month
- Clinic-based services or home-based options
- Direct supervision is required
  - ✓ Parent Training – only required last quarter
  - ✓ Direct observation with child & parent
  - ✓ Quarterly progress reports
- Progress is evaluated to ensure treatment is effective
  - ✓ Progress must be demonstrated quarterly

Therapeutic Plans

- Plans are written for 1 year at a time for a maximum of 2 years
- Supports up to 6 sessions per month
- Therapists are required to provide:
  - ✓ goals and objectives outlined for each month,
  - ✓ session notes with measurable data and
  - ✓ provide at least quarterly reports to demonstrate progress on the identified targets outlined in the Plan.
- Clinic-based services or home-based options
- ATAP recommends parent observe 25% of the sessions during the month and receive training to support generalization of skills to the home and community environment.

Social Skills Plans

- Maximum of one year
- For elementary, middle and high school age children.
- Monthly participation in social activities with typical peer(s) is required.
  - Child must be enrolled in a structured community/after school program by the 2nd quarter of plan.
- Requires the use of an approved curriculum with goals and outcome measures
- May include individual sessions and group sessions or group sessions only, but must include at least one group session a month
- ATAP recommends parent observe 25% of the sessions during the month and receive training to support generalization of skills to the home and community environment.

Transition Plans

- Written for a maximum of 1 year
- Outlines a systematic decrease in ABA treatment and supervision hours
  - Provider observations across settings to ensure acquired skills & behavior are maintained.
  - When exiting includes psychological evaluation to support exit & provide outcome assessment scores.
- **Last quarter is intended to only address increasing parent(s) capabilities**
- Address and define the transfer of information for receiving agency
  - Define levels of collaboration with receiving agency and proposed date of transfer

Insurance Assistance/Collaboration Plans

- **Designed to promote & utilize cost-sharing**
- Support families who need assistance in paying for co-pays or meeting their yearly deductible in order to access insurance coverage for ABA treatment.
- Plans may also address assistance when collaborating with another agency to allow the child access to research levels of treatment or to maintain child in the least restrictive environment by cost sharing.

Progress

- Safeguards have been put in place by ATAP to ensure **each child's treatment journey is guided by data-driven decisions to promote progress.**

  - Required Progress Reports
  - On-going Data Collection
  - Required specific amounts of treatment oversight
  - Mandated Reviews by Care Managers
  - Impact Data Targets assessed annually (64 targets/skills)
  - Online data system to track outcomes

Outcomes Measures

- At intake and at close scores are tracked on a select group of assessments:
  - Vineland Adaptive Behavior Scales (VABS-II)
  - I.Q.
  - Language assessment – Expressive/Receptive
  - PDD-Behavior Inventory
  - School Situation Questionnaire
  - Caregiver Strain Questionnaire
  - Home Situation Questionnaire
  - ATAP Impact Data Targets
  - Video

Annual Performance Indicators

Established to demonstrate the effects of treatment, outcomes and to support the continuation in current plan type.

Providers are required to access at intake and annually.

- **ATAP Impact Targets**
  - Progress measured on 64 Targets/Behaviors/Skills
    - Eight considered Critical Targets
    - **Required performance**
      - **10% year 1, 25% year 2, 50% year 3**

Critical Impact Targets

- Ability to demonstrate mastery at age appropriate levels on Critical Impact Targets is a priority.

  - Visually discriminate*
  - Generalized imitation skills*
  - Express wants and needs*
  - Follows two step instructions*
  - Ability to play appropriately with 5 toys*

  - Transition from preferred activity to non-preferred without protest
  - Uses an effective mode of communication
  - Independently completes two hygiene routines
    - Prioritize independent toileting

  *Parallel with Early Intervention Services skill set data requirement

Sample of Impact Targets

Tracked to forecast decreased level of care after exit.

- Aggression or self injurious behavior
- Ability to self-monitor own behavior
- Communicate personal Information
- 100% independent toileting
- Dresses independently
- Age-appropriate observational learning
- Spends time outside of school with friends
- Demonstrates on-task behavior for 30+ minutes

- % of time in regular education environment

Direct Service Cost Per Child Per Month

- Budgeted
  - $1329.00
    - Treatment hours
    - BCBA supervision
    - Case Management
    - Fiscal Management Agency
- Actual Spending for January 2014
  - $1495.49

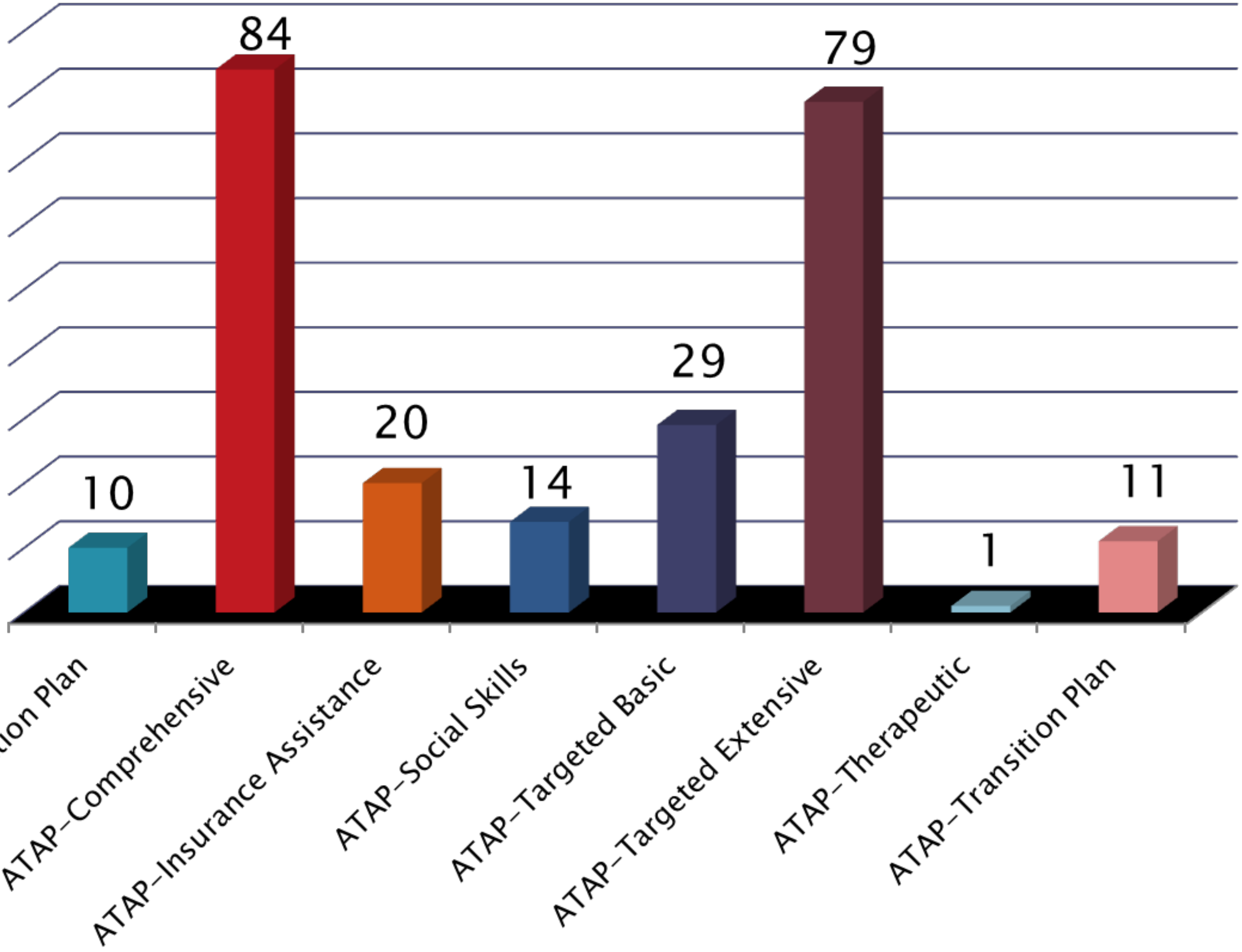
Active cost per plan type
January 2014

Plan Allotment	Plan Type	Current Active	Total Plan Allotment Monthly Max
$ 2,000.00	ATAP-Comprehensive	84	$ 168,000.00
$ 500.00	ATAP-Insurance Assistance	20	$ 10,000.00
$ 1,000.00	ATAP-Collaboration Plan	10	$ 10,000.00
$ 1,100.00	ATAP-Targeted Extensive	79	$ 86,900.00
$ 600.00	ATAP-Social Skills	14	$ 8,400.00
$ 700.00	ATAP-Targeted Basic	29	$ 20,300.00
$ 600.00	ATAP-Therapeutic	1	$ 600.00
$ 500.00	ATAP-Transition Plan	11	$ 5,500.00
	Current Total	248	$ 309,700.00

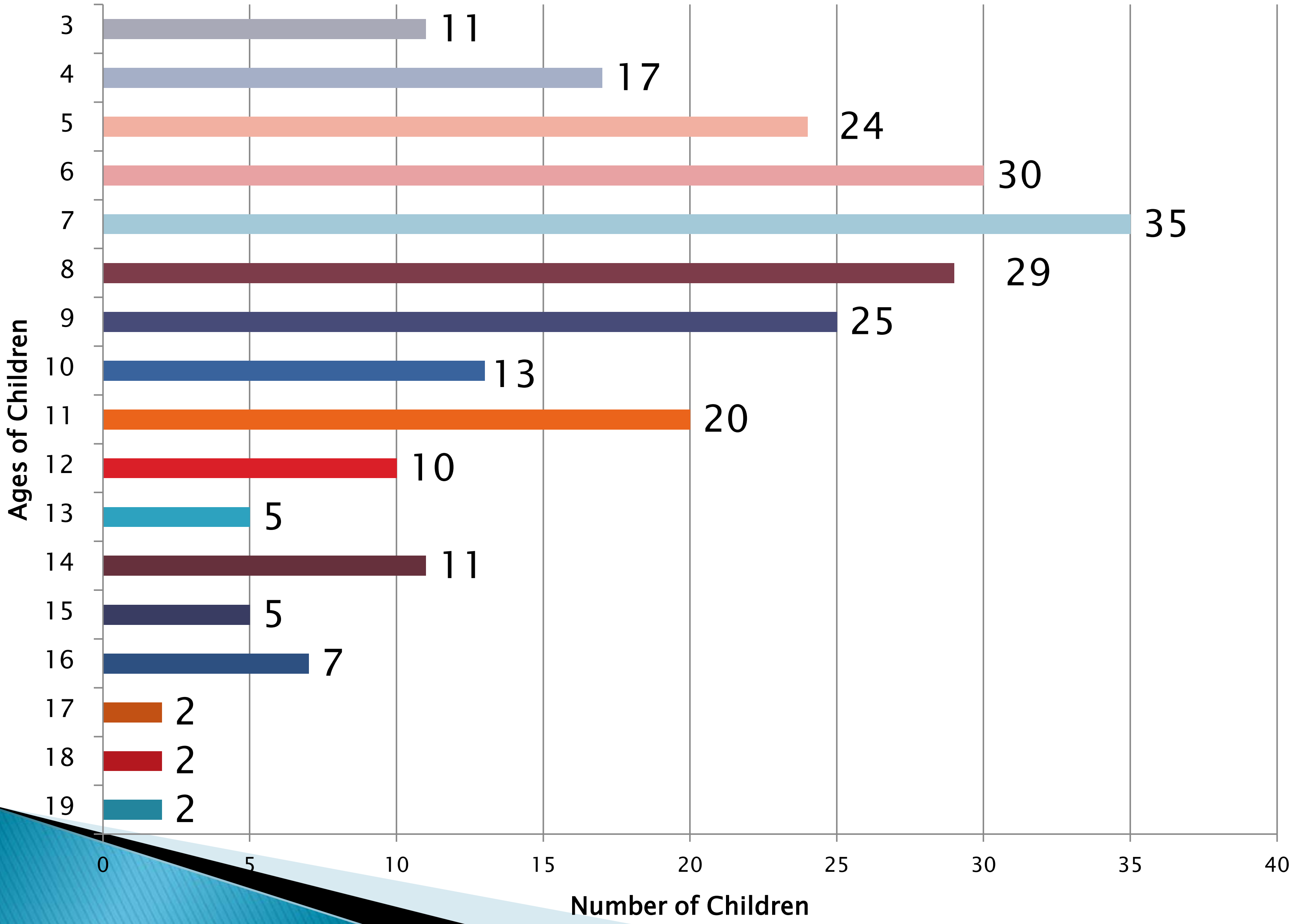
Caseload Statistics

The caseload statistics are a snapshot through April 28, 2014

Active Children by plan type



Current Status ~ Active (248)



Wait Times

- Longest number of days waiting
  - 1822

- Average days until placement
  - 560

Future Direction

- Utilizing more pay sources to enable all children access to research levels of treatment.
  - Medicaid coverage for ABA in state plan
  - Removal of statutory limitation of $36,000 cap per year on ABA Insurance Coverage to align with the Affordable Care Act.

- Now that child outcome measures are established and being collected, additional funds are needed to fully evaluate and analyze program outcomes and long-term child outcomes.

Aging and Disability Services Division

Autism Treatment Assistance Program (ATAP)

For more information contact:
Program Manager
Brook Adie, LSW
Social Services Program Specialist 3
3416 Goni Road. Bldg D #132
Carson Cit, Nevada 89706
775-687-0555
baadie@adsd.nv.gov

Meeting of the IACC

Afternoon Agenda – continued

4:00 Round Robin - continued

4:45-5:00 **Medicaid Coverage for ASD Services**
Melissa Harris
Director
Division of Benefits and Coverage
Center for Medicare and Medicaid Services

5:00-5:15 **Home and Community Based Services (HCBS) Waiver Programs**
John O'Brien, M.A.
Senior Policy Advisor
Center for Medicare and Medicaid Services and Member, IACC

5:15 Adjournment

Meeting of the IACC

Adjournment