

Meeting of the Interagency Autism Coordinating Committee

July 19, 2016

National Institutes of Health
31 Center Drive
Building 31, C Wing, 6th Floor, Conference Room 6
Bethesda, MD 20892

Conference Call Access:

Phone: (800) 369-3355

Access Code: 6950027

Meeting of the IACC

Morning Agenda

9:00 AM **Welcome, Introductions, Roll Call and
Approval of Minutes**

Bruce Cuthbert, Ph.D.

Acting Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive
Secretary, IACC

Meeting of the IACC

Morning Agenda

9:10 AM Autism Policy Update

Samantha Crane, J.D.

Legal Director and Director of Public Policy
Autistic Self Advocacy Network

9:25 Autism Society Lifespan-Based Strategy Update

Margaret Miller

Vice President of Strategic Advancement
Autism Society

Autism Policy Updates

Samantha Crane, JD., Legal and
Public Policy Director

Autistic Self Advocacy Network

2013 H St. 5th Floor • Washington, DC
20035

Voice: (202) 596-1056

www.autisticadvocacy.org



Who Are We?

- Nation's largest advocacy group by and for autistic people ourselves
- All-Autistic leadership, plus majority of Board is autistic – including people with significant communication and support needs
- 21 Chapters Nationwide, plus international affiliates and partners



How Does Self-Advocacy Inform Policy?

- Focus on needs of adults, not just children
- Focus on services and supports that meet pressing needs:
 - Health care
 - Communication
 - Long-term services and supports to enable independent living

What Demographics Do We Represent?

Our “base” is diverse, and includes:

- People with significant health care needs, such as epilepsy and chronic illness
- People with significant communication needs, including people who type to communicate
- People who require long-term supports to live independently
- Autistic parents of autistic children, including parents of children with very significant needs



Common Policy-Related Complaints

- Lack of access to quality health care
- Lack of access to transition, employment services
- Problem interactions with police, emergency services, mental health system
- Need for long-term services and supports, especially supports and services to live outside of group home or family home
- Exposure to abusive or counterproductive “therapies” – lack of access to interventions aimed at older children and adults
- Lack of access to communication supports and AAC

Policy Updates

- New guidance in HCBS Settings Rule
- State Supported Decision-Making Legislation
- Affordable Care Act: Habilitation Services
- Department of Labor Home Care Rule
- Updates on autism safety legislation

HCBS Settings Rule

- Implements quality controls for services receiving HCBS funding
- Unlike funding for facility-based long-term services, HCBS funding is capped – many wait for years on waiting lists
- Using HCBS funding for institutional services doesn't increase access to institutional services, but *necessarily* means some people can't access more community-based services.
- Many lack meaningful choice to live in non-disability-specific settings



Goals of Settings Rule

- Require *access* to non-disability-specific settings
- Maximum autonomy, respect, and choice
- Ensure day services focus on the actual interests, schedule, and needs of the person
 - No more “mall therapy” where autistic people must choose from limited options for group-based “recreation”
- Accountability: service providers cannot simply self-certify as “community-based.”

Current HCBS Developments

- Tennessee plan approved:
 - Conducted extensive site assessments
 - Communicating consistently with broad array of stakeholders (incl. individuals, families)
 - Partnering with DIDD, MCOs
 - Accountability guidelines
- Limits facility-based day services to:
 - Time-limited training OR
 - Based on person-centered plan and aimed at achieving community-living or employment goals

State Supported Decision-Making Legislation

- Adds a new option to avoid guardianship where possible
- Person with a disability selects a trusted support person to help make decisions, without losing legal capacity
- Passed in Texas; pending in DC (21-385), Delaware (SB 230, House version passed)

Affordable Care Act

- Essential Health Benefits: coverage of “habilitation services”
- Feb. 2016: Proposed definition of Habilitation Services:

“Health care services that help a person keep, learn or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.”

<https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/Uniform-Glossary.pdf>

Affordable Care Act

- Essential Health Benefits: coverage of “habilitation services”
- Feb. 2016: Proposed definition of Habilitation Services:

“Health care services that help a person keep, learn or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.”

<https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/Uniform-Glossary.pdf>

Transition to Independence Act

- Voluntary demonstration program
- States rewarded for increasing competitive integrated employment, integrated day services
 - S. 1604, Sponsors: Grassley, Casey, Wyden
 - H.R. 5903, sponsors: Van Hollen, McMorris Rogers, Sessions (R-TX), Langevin (D-RI), Crenshaw (R-FL), Foster (D-IL), Beyer (D-VA)

Home Care Rule

- Department of Labor now requires overtime + travel pay for almost all HCBS home workers
- Court challenge, based on integration concerns, rejected – SCOTUS denied review in June
- Future focus: ensure states budget for overtime/travel pay when necessary

Avonte's Law

- S. 2614, recently passed Senate
 - House version pending: H.R. 4919
 - Includes funding for safety training program in addition to tracking devices
 - Still no good evidence base for the most important outcome for tracking devices: preventing injury or death
 - Annual Report will track # of missing persons found but not reduction in missing-persons events
- = Opportunity for research!**

Questions?



National Strategic Plan, The New Outcomes Model and Lifespan Planning

Margaret Miller
Vice President, Strategic Advancement

National Outcomes Model

Mission: To improve the lives of all affected by autism.

Vision: Individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued.

Three Keys to Achieving Mission

The vision identifies three keys to improving the lives of those affected by autism:

1. Maximize Quality of Life
2. Treated With Dignity
3. Talents Are Valued

Strategic Plan

Strategic Planning Process:

- “How do we know when we have successfully helped an individual living with autism?”
- Goal: To define how best to assure opportunity and measurable outcome success in quality of life throughout an individual’s life
- Comprehensive, highly inclusive and transparent
 - Engaged over 200 key stakeholders including family members, professionals, Affiliate leaders, and individuals with an autism diagnosis
- Examined how best to assure that each person with an autism diagnosis would be able to maximize his or her quality of life each and every day

National Outcomes Model

- All efforts by the Autism Society focus on these three keys improving lives across the lifespan.
- Through our strategic planning efforts, the Autism Society identified 15 outcomes that best indicate improvement to the lives of those affected by autism.
- Each of the 15 outcomes supports one of the three keys: maximizing quality of life, being treated with dignity, and having talents valued.

Maximize Quality Of Life	Treated With Dignity	Talents Are Valued
Independent Living	Communication	Financial Stability
Health and Well-Being	Inclusion	Academic Success
Social Connections	Respect and Dignity	Pursuit of Dreams
Recreation and Leisure	Safety	Subjective Well-Being
Autonomy and Self-Sufficiency	Self-Identity and Acceptance	Meaningful Employment with Fair Wages

National Outcomes Model

Benefits of the National Outcomes Model:

- Consistent outcomes nationwide
- Maintains autonomy among the Affiliates to serve their local communities through local programs
- Clear language on what we do and why it matters

Core Services

- **Advocacy**
 - National, State, Local
- **Education**
 - Educating individuals with autism, their loved ones, professionals from multiple disciplines, and the public at large
- **Information & Referral**
 - Empowering those affected by autism through a one-on-one connection
- **Support**
 - Helping understand available services
 - Helping navigate often complex and confusing service systems
 - Training to local and statewide organizations on being autism friendly
- **Community**
 - Building autism friendly, inclusive communities where individuals with autism can live, work, play, socialize, learn and worship in the setting and manner of their own choosing

Core Services and Outcomes

Applying the Outcomes Model to our five Core Services:

- The strength of the Autism Society lies in the local knowledge and presence of our network of Affiliates.
- Programs and services are tailored to best serve the local communities
- All Autism Society activity across the country:
 - Provides one of our five Core Services
 - Advances at least one of the Quality of Life Outcomes

Lifespan Planning

About Lifespan Planning:

- Ongoing cradle to grave process where an individual's needs are anticipated and proactively planned for.
- Vital element in impacting positive outcomes for families and individuals living with autism.
- Includes assistance, guidance and programs which evolve over a person's lifetime, to improve their own quality of life in a manner that is meaningful to both the individuals and their families.

Lifespan Planning

Life Stages

- Like everyone else, people with autism move through significant life changes.
- Quality of life depends not only on the foundation provided in childhood, but also on ongoing supports that are specific to their educational, medical, social, recreational, family and employment needs.
- The Autism Society supports people with autism and their families through five critical stages of life:
 - Birth to 5
 - School Age
 - Transition to Adulthood
 - Adulthood
 - Older Adult

Lifespan Planning

Life Stages

- Birth to 5
 - Early identification of an ASD is crucial, as it means early intervention services can begin, making a huge impact on a child's behavior, functioning and future well-being.
 - Preparation for starting school.
- School Age
 - The school years bring innumerable challenges for a child with autism, but they also hold incredible opportunity for growth.
 - For parents, the challenge is to discover and leverage resources to maximize the child's avenues of academic learning, social experience and physical fitness.
 - Having a team of professionals is essential throughout this long life stage – getting help from those who know the system can reduce stress on the family and improve outcomes for the child with autism.

Lifespan Planning

Life Stages

- Transition to Adulthood
 - The transition from federally mandated services provided through the school system to adult services can be a challenge.
 - The first step in transition planning is to take a look at the individual's interests, abilities and needs.
- Adulthood
 - The Autism Society works to ensure that every adult with autism has access to services and supports that maximize independence and secure the highest quality of life.

Lifespan Planning

Life Stages

- Older Adult
 - Transition into older adulthood brings unique challenges in healthcare, housing, social supports, and financial management.
 - Autism research and support services have historically focused largely on children, but as more adults with an autism diagnosis transition into this life stage, communities are beginning to look more closely at how to best provide ongoing support for older adults on the spectrum.

Lifespan Planning

The Autism Society's Lifespan Planning Initiative:

- The Autism Society is the organization that is best positioned to provide assistance, guidance, advice, and direction to stakeholders across their lifespan.
- We are currently working to build a lifespan planning model that is sustainable, accessible and scalable, and that leverages community partnerships, so all individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued

Lifespan Planning

How you can help:

- Partnerships on milestones and program development
- Funding



QUESTIONS

Margaret Miller
Vice President, Strategic Advancement
mmiller@autism-society.org

Meeting of the IACC

Morning Agenda - continued

9:40 AM

**Simons Foundation Powering Autism
Research for Knowledge (SPARK)
Update**

Pam Feliciano, Ph.D.

Scientific Director, SPARK

Senior Scientist, Simons Foundation
Autism Research Initiative (SAFARI)

9:55

**National Autism Indicators Report:
Vocational Rehabilitation**

Anne Roux, M.P.H., M.A.

Research Scientist, Life Course Outcomes
Research program

A.J. Drexel Autism Institute, Drexel
University

Can research
really change
the future of
autism?

**You can SPARK
research with
one click.**



SPARK

**Powering Autism
Research
for Knowledge**

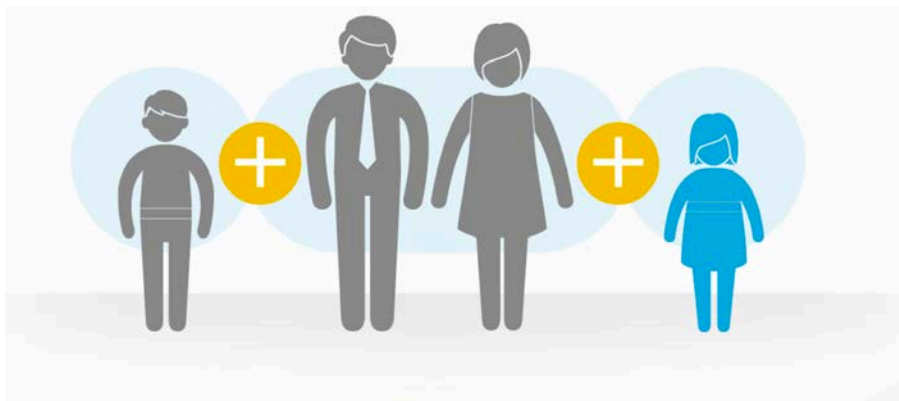
Pamela Feliciano, Ph.D.
Scientific Director, SPARK

July 19, 2016

SPARKforAutism.org

The goals of SPARK are to:

- Establish a research partnership with thousands of individuals affected with ASD and their family members
 - Participation in future studies is not required but participants agree to be re-contacted
- Accelerate research and improve understanding of ASD
 - SPARK will catalyze this by making access to the cohort and data available to ANY qualified scientist in the research community



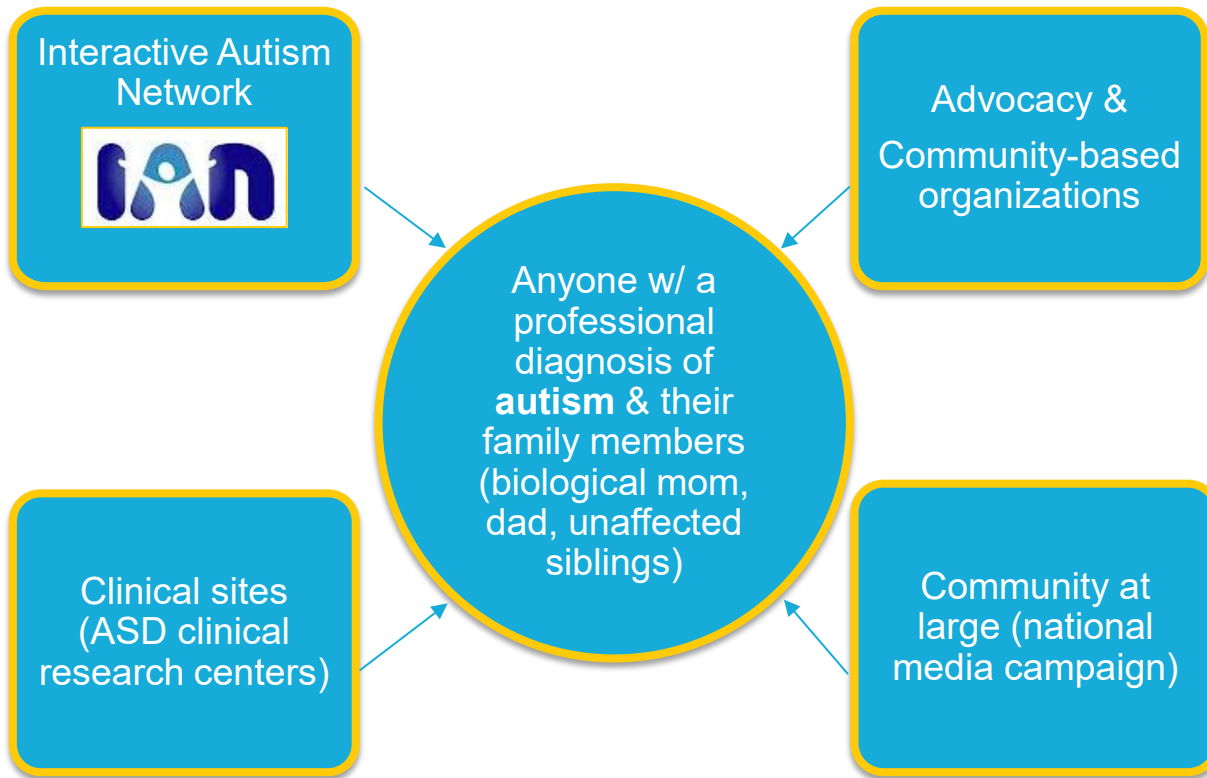
Participation in SPARK



Building a Research Partnership



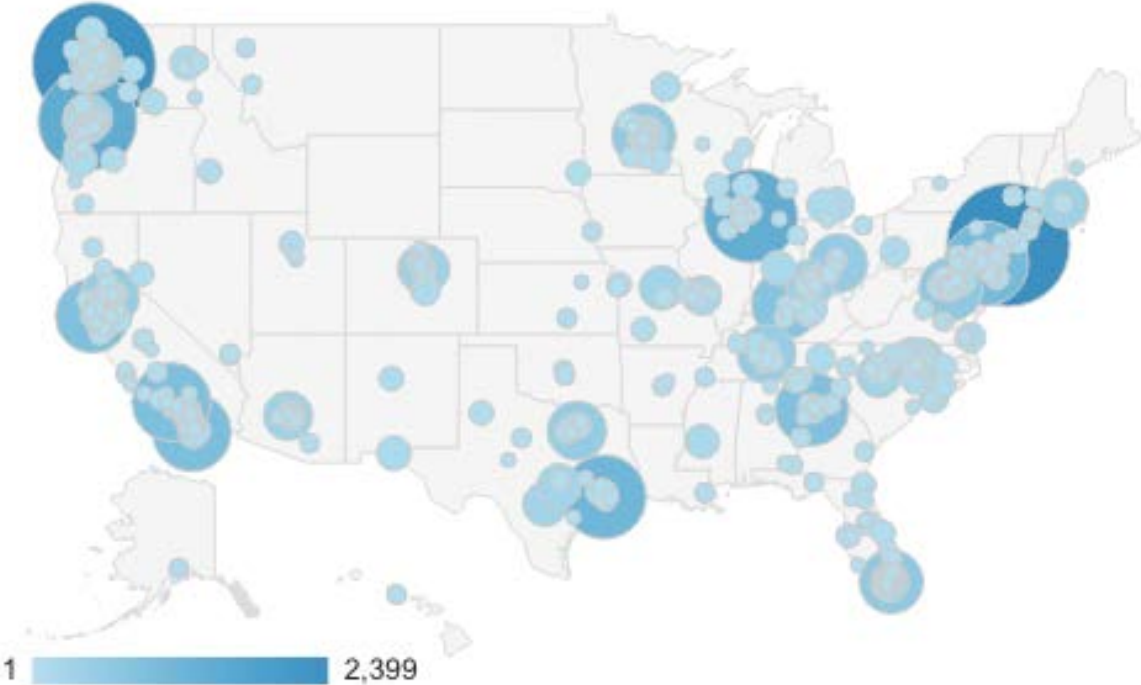
SPARK Recruitment



SPARK Clinical Site Network



Distribution of Unique Web Users on SPARKforAutism.org

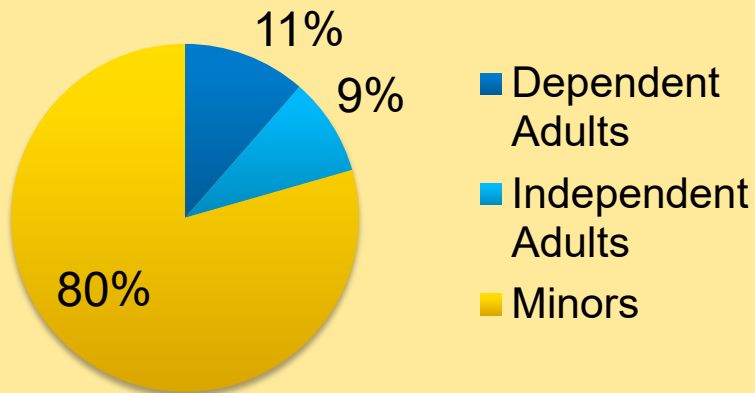


* Data as of 7.13.16

SPARK Participants

- Total number of participants: 17,659
- **67%** completion rate

Individuals with ASD (n=7,140)



	Children (n=5,672)	Adults (n=1,468)
Demographics		
Male, n (%)	4,560 (80%)	970 (66%)
Female, n (%)	1,112 (20%)	498 (34%)
Age in years, mean (SD)	8.7 (4.2)	32.2 (12.2)

* As of 7.7.16

SPARK Participants

Diagnostic characteristics	Children (n=5,672)
Ever intellectual disability diagnosis, n (%)	953 (17%)
Ever ASD services, n (%)	5,095 (90%)
Ever IEP, n (%)	4,749 (84%)
Age at ASD diagnosis in years, mean (SD)	4.1y (2.6y)
Language ability, n (%)*	
No words / does not speak	713 (12%)
Uses single words meaningfully	737 (13%)
Combines 3 words together into sentences	948 (16%)
Uses longer sentences	3,628 (63%)
SCQ total score, mean (SD)	23.0 (7.0)

* Data as of 7.7.16

Advancing Precision Research & Precision Medicine

- Autism is genetically & phenotypically heterogeneous
- New treatments are likely to be diverse
- SPARK will set up infrastructure required for targeted clinical research
 - Participants can be re-contacted according to genotype and phenotype
 - Investigators can recruit based on their study's criteria



Genetic Analysis in SPARK



Saliva Collection Kit



DNA extraction (CLIA lab) and exome production



Identify individuals with known genetic causes of ASD



Notification of research participant & provider, genetic report issued by a clinical lab contracted by SPARK

SFARI medical committee

Reanalysis every year



Return of genetic results to provider & participant



Next steps for SPARKforAutism.org

- Return of behavioral and genetic results
- Sequencing of thousands of ASD trios
- Data releases beginning end of 2016
- Open for recruitment by researchers
- Sign up for our newsletter at SPARKforAutism.org to stay abreast of our latest updates



Thank you to SFARI & the SPARK team



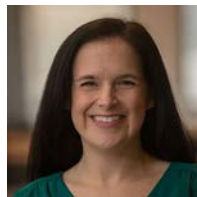
Wendy Chung
Dir. Clinical Research



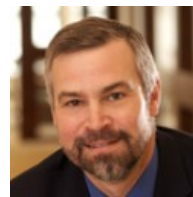
Pamela Feliciano
Scientific Director



LeeAnne Green Snyder
Clinical Research Sci.



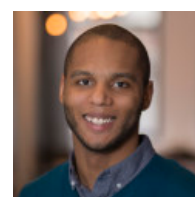
Amy Daniels
Project Manager



Alex Lash
Chief Inform. Officer



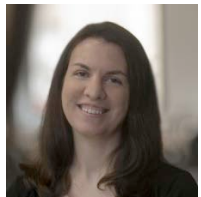
Jennifer Tjernagel
Proj. Manager, VIP



Noah Lawson
Res. Data Analyst



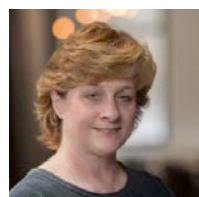
James Hohman
Software Engineer



Casey White-Lehman
Project Manager, SSC



Vincent Myers
Research Assistant



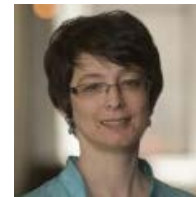
Karen Walton-Bowen
Clinical Operations



Julie Manoharan
Project Coordinator



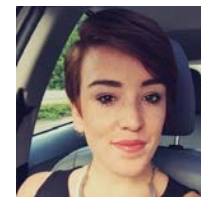
Elizabeth Brooks
Asst. Proj. Man., SSC



Natalia Volfovsky
Analytics Manager



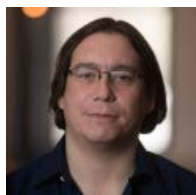
Chris Rigby
Sr. Software Engi.



Alex Stephens
Admin. Assistant



Alpha Amatya
Sr. Software Engineer



Richard Marini
Sr. Software Engineer



Martin Butler
Software Engineer



Andrei Salomatov
Bioinformatics Eng.



Hana Zaydens
Research Assistant



Luke Grosvenor
Administrative Assistant





National Autism Indicators Report:

Vocational Rehabilitation

2016



Life Course Outcomes
Research Program

 DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

National Autism Indicators Report series:

Anne M. Roux, MPH, MA
Jessica E. Rast, MPH
Paul T. Shattuck, PhD



Life Course Outcomes
Research Program



This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services under grant number, UA6MC27364, and title, **Health Care Transitions Research Network for Youth and Young Adults with Autism Spectrum Disorders** for the grant amount of \$900,000. The information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. government.



A.J. Drexel Autism Institute

A public health approach to autism

Primary

Reduce/eliminate
avoidable causes

**Modifiable
Risk Factors**

Craig Newschaffer, Ph.D.



Secondary

Identify
symptoms early
and intervene

**Early Detection
& Intervention**

Diana Robins, Ph.D.



Tertiary

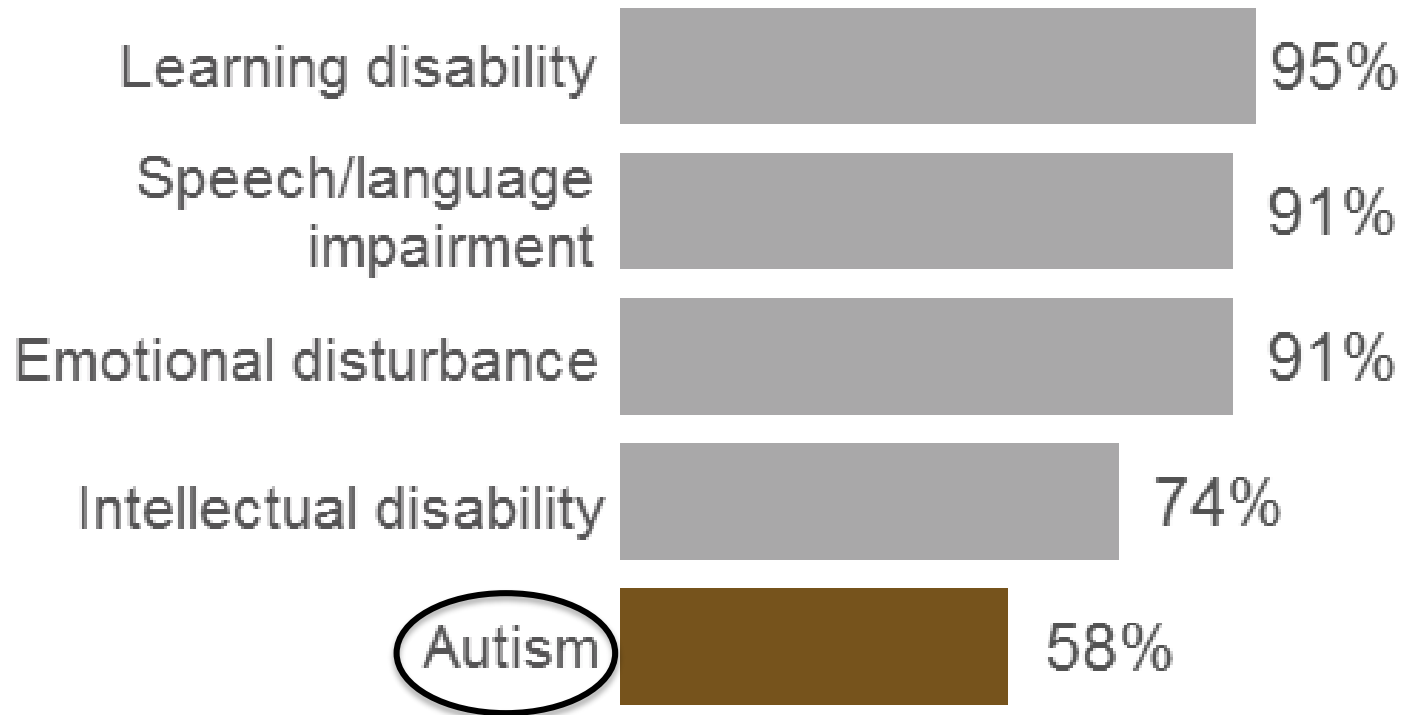
Minimize disability
and promote
quality of life

**Life Course
Outcomes**

Paul Shattuck, Ph.D.

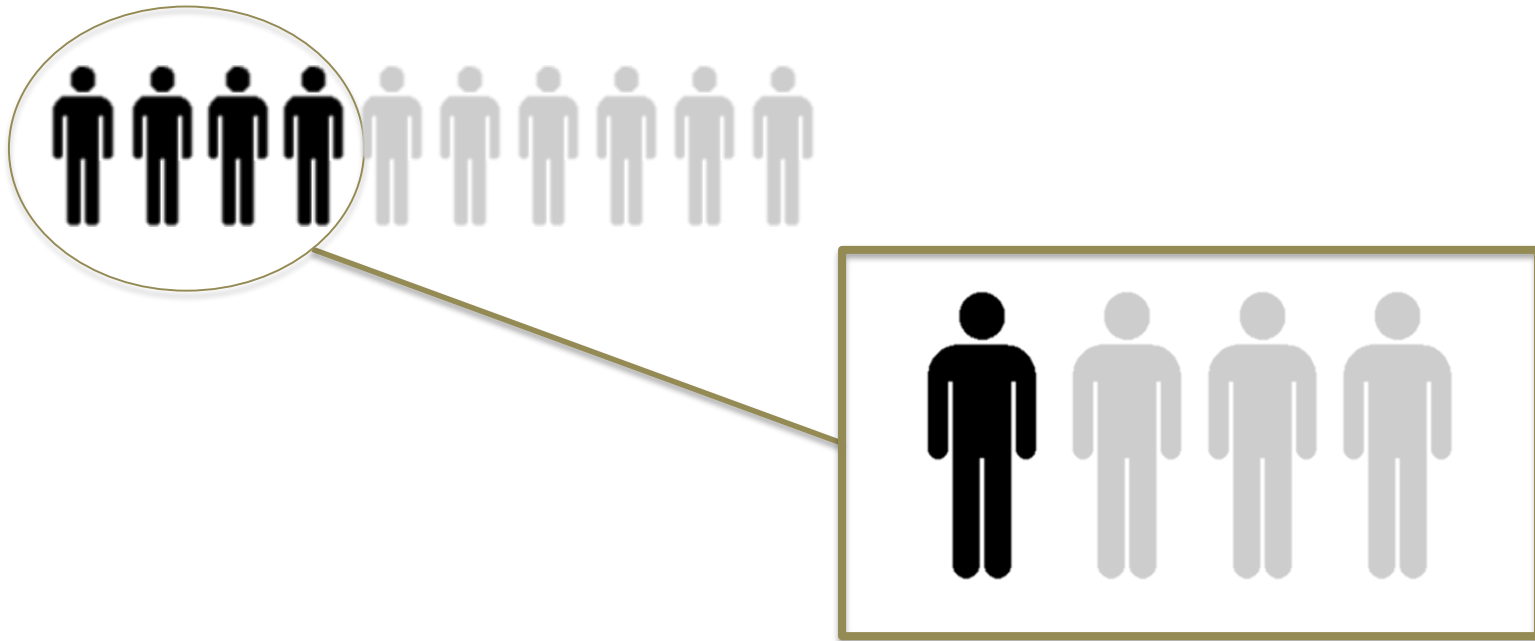


Rates of employment



Percent ever worked after high school





One in four who were **disconnected** from jobs and education after high school also had **no access to services**.

National Autism Indicators Report: Vocational Rehabilitation 2016

A comprehensive report from A.J. Drexel Autism Institute's Life Course Outcomes Research Program describing how people with autism use Vocational Rehabilitation services and their outcomes. Freely available for download.

drexel.lu/autismindicators16



Life Course Outcomes
Research Program

 DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

Vocational Rehabilitation Services

What is VR?

- Major funder of employment services in the U.S.
 - Paid for with federal + state funds
 - Grants funds to state VR agencies to implement services
- Serves transition-age youth and adults with disabilities

Vocational Rehabilitation Services

Who does VR serve?

- Individuals with significant physical or mental impairment
 - Who have substantial problems with employment
 - Who require services to get, keep, or regain employment

Vocational Rehabilitation Services

What does VR do?

- Funds a variety of services including:
 - Job search assistance
 - Counseling and guidance
 - Job placement
 - On-the-job supports

Why focus on VR?

- Guided by federal law
- Large, national public dataset
- Standard questions across states
- System for addressing user concerns
- Timely given recent legislative changes



Context

- Employment First
- Workforce Innovation and Opportunity Act (WIOA)
 - 15% of state VR funds directed to transition-age youth (Pre-Employment Transition Services)
 - Extended length of time youth may receive services
 - Addressed sub-minimum wage
 - 50% of state Supported Employment funds directed to those with most significant impairments

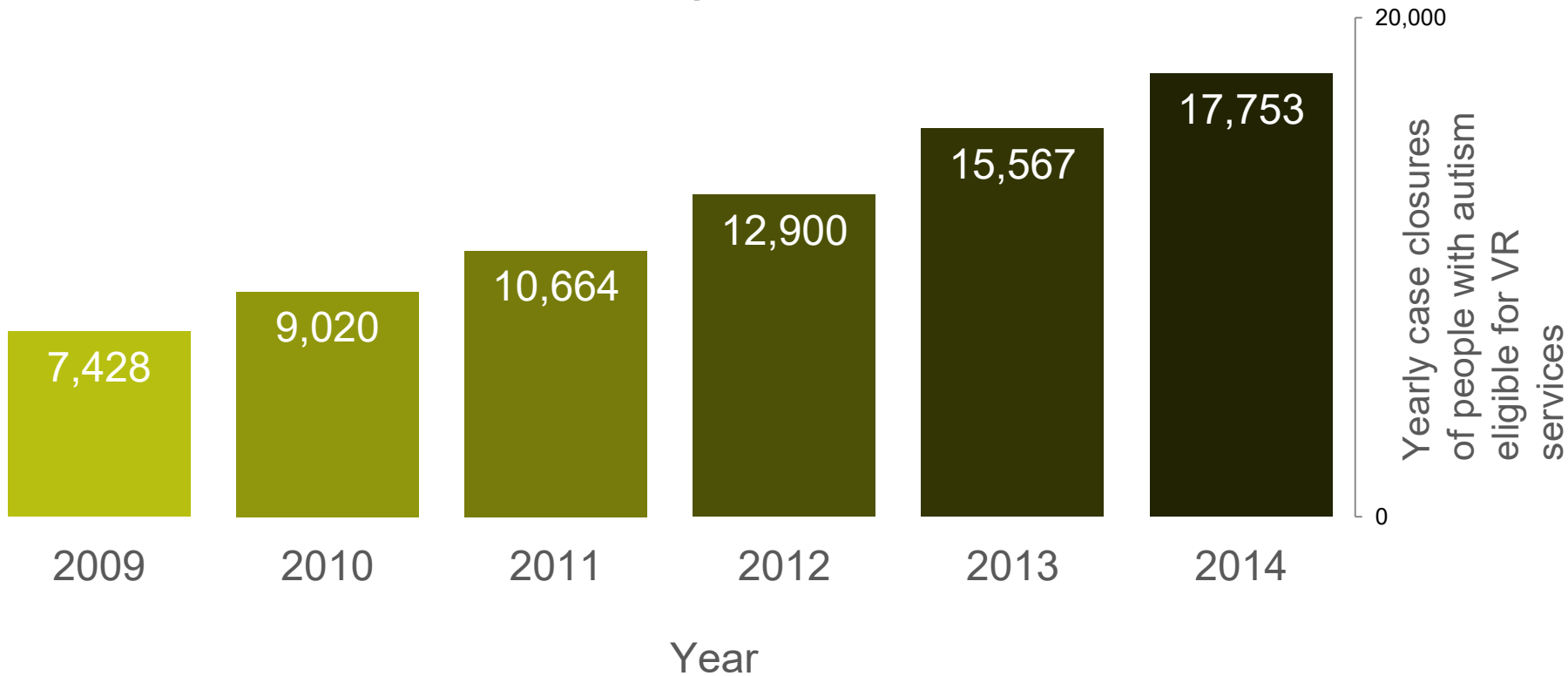


Data source

- Rehabilitation Services Administration
RSA-911 2014
- Administrative data
 - Complete
 - But no direct reporting by people with autism



Annual case closures for individuals with autism have increased steadily.



RSA-911, 2009-2014



Life Course Outcomes
Research Program

What do we know about VR service users with autism?



Characteristics

Most were unemployed, living at home, with both public and private financial supports.



Employment

Currently employed (11%)



Where they lived

**Private residence (96%),
Community homes (3%),
Other settings (1%)**



Insurance

**Private (38%), Public (33%),
Uninsured (25%), Both (5%)**

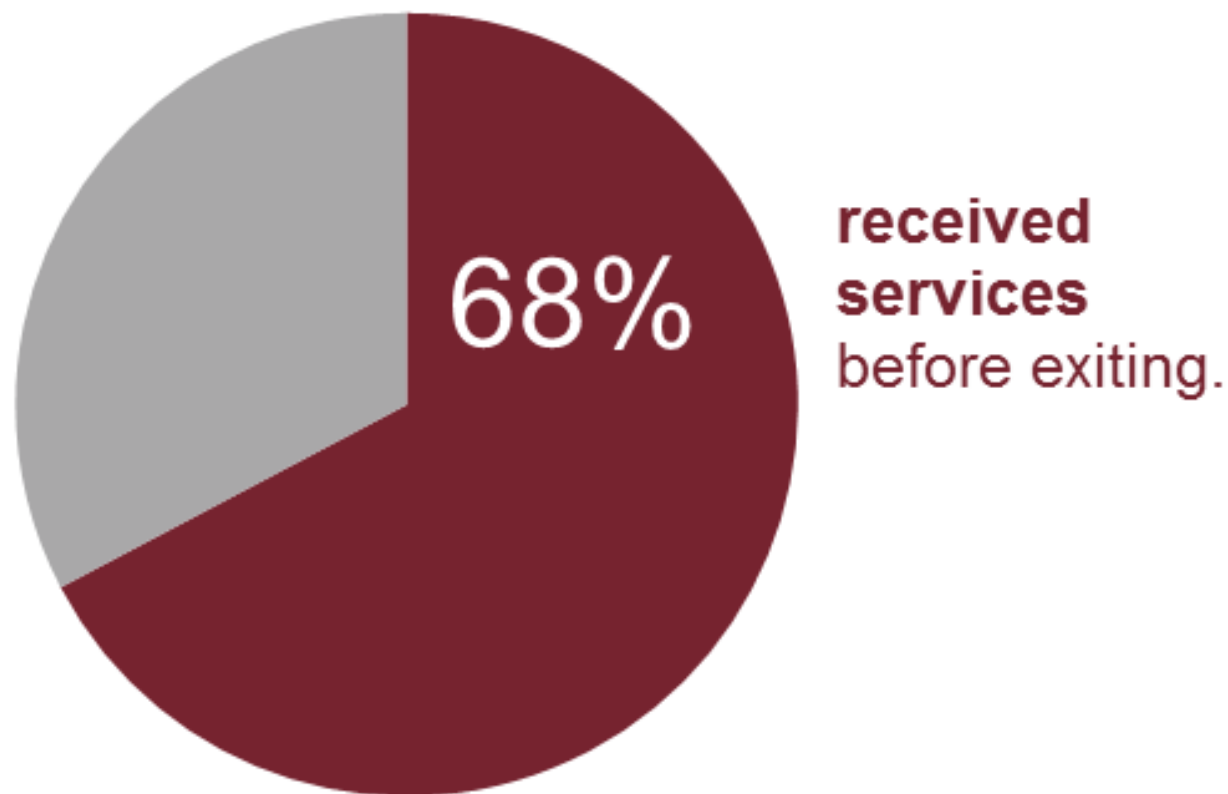


Benefits

**SSI (29%), SSDI (9%),
Other public support (5%)**



Two-thirds of eligible VR applicants with autism received services through VR.

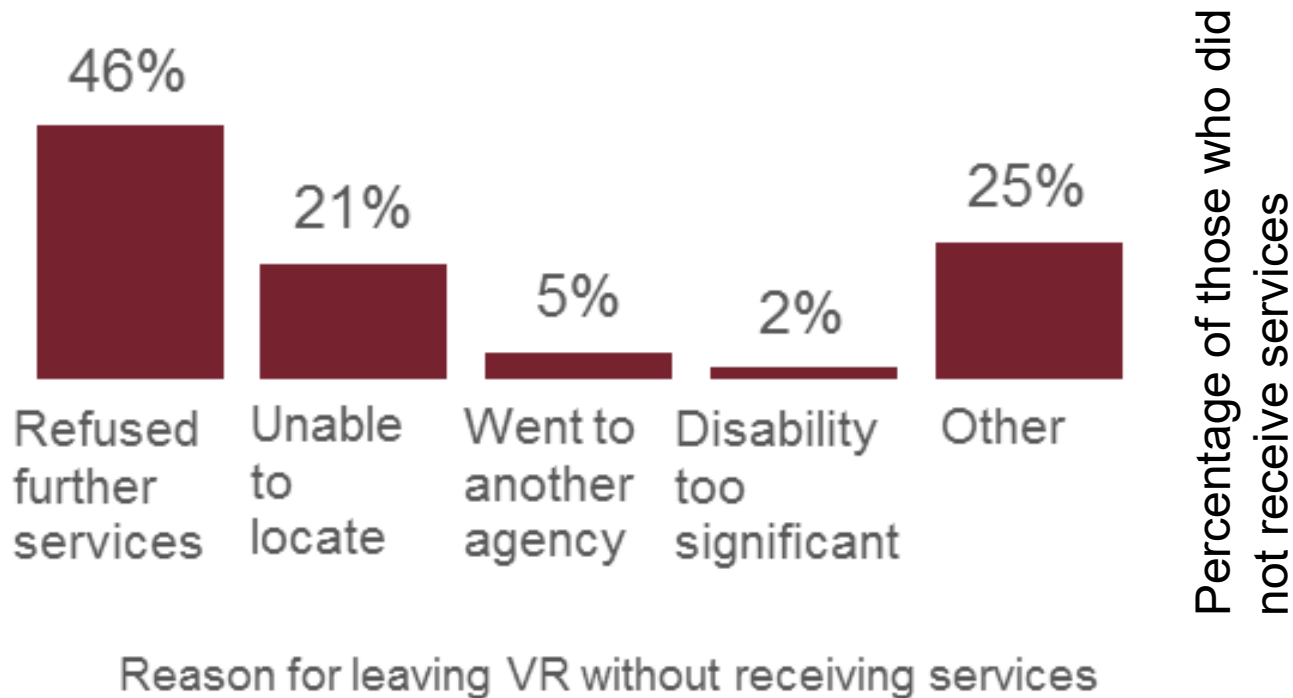


Source: Rehabilitation Services Administration (RSA-911), FFY 2014



Exit without service receipt

Refusing further services was the most common reason that eligible VR applicants with autism did not receive services.

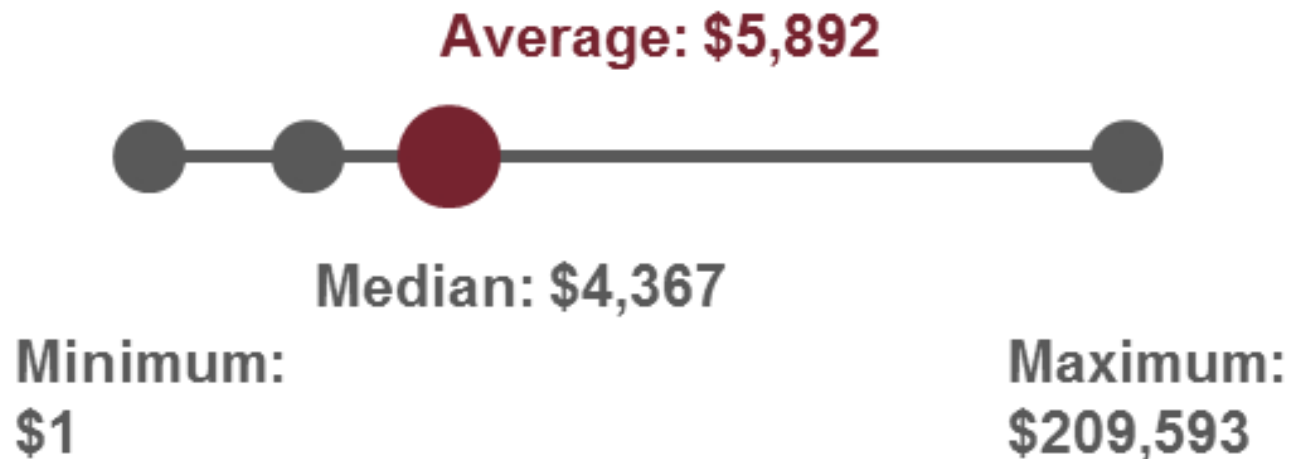


Source: Rehabilitation Services Administration (RSA-911), FFY 2014



Service expenditures

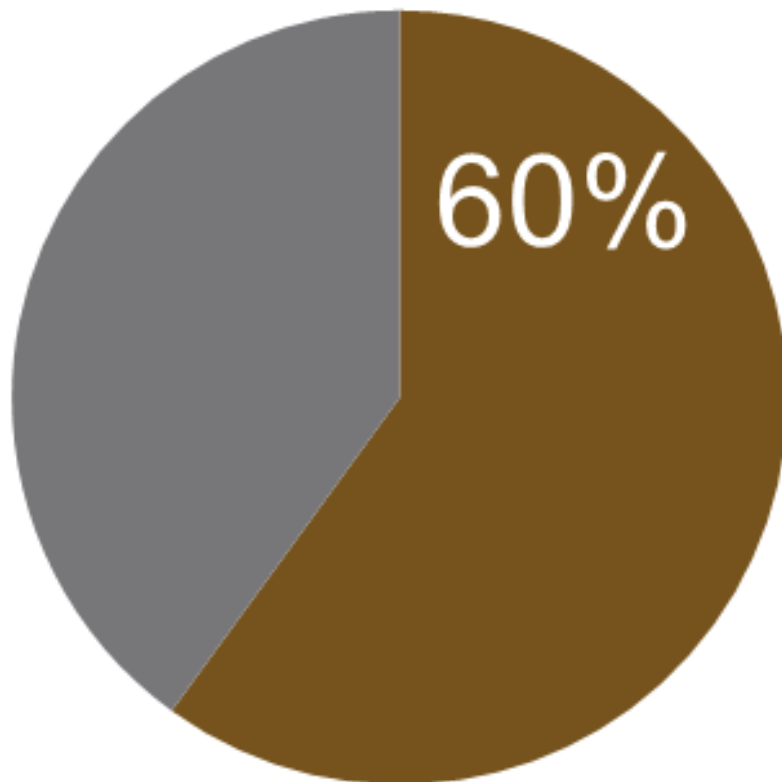
On average, VR service users with autism received almost \$5,900 per person in services through community rehabilitation programs across all services they utilized.



Source: Rehabilitation Services Administration (RSA-911), FFY 2014



Over half of VR service users with autism exited VR with a job.



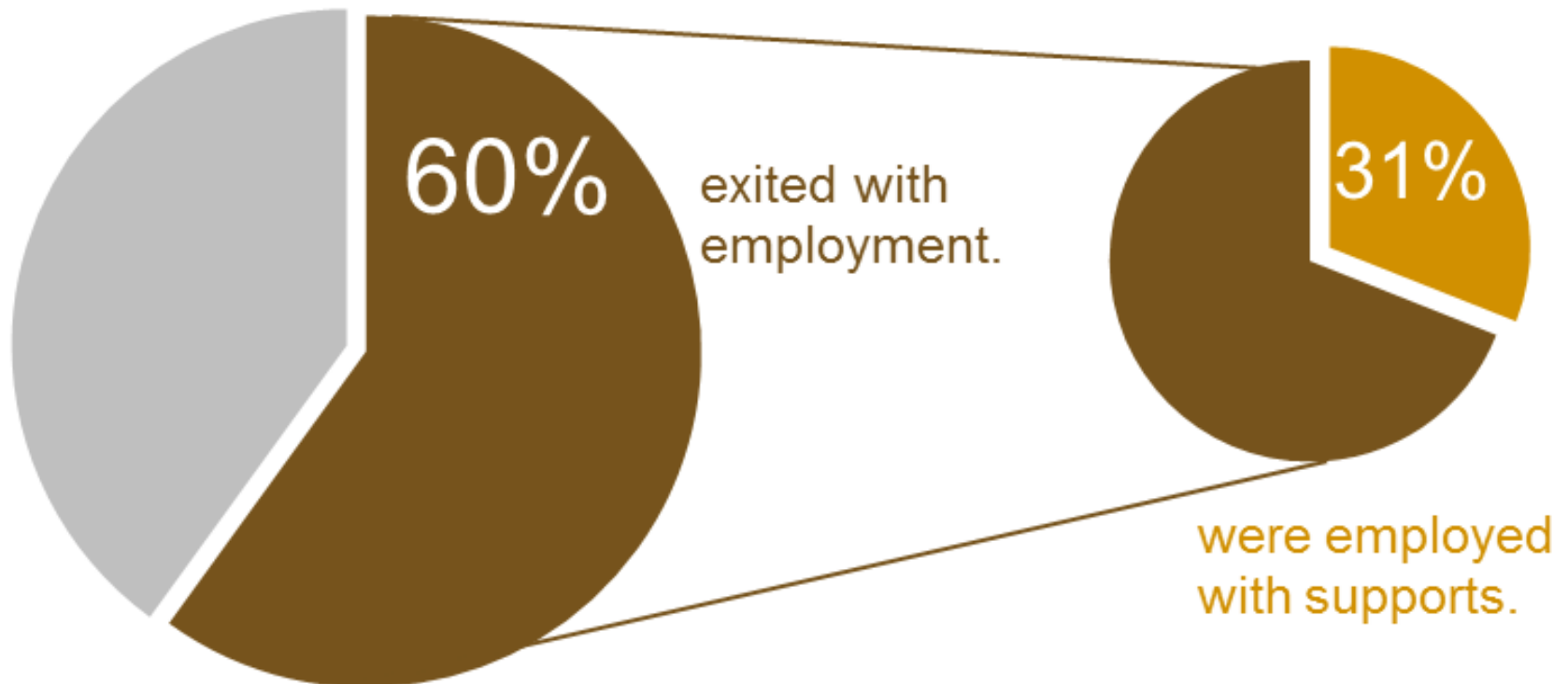
of VR service users with autism **exited with employment.**

Source: Rehabilitation Services Administration (RSA-911), FFY 2014



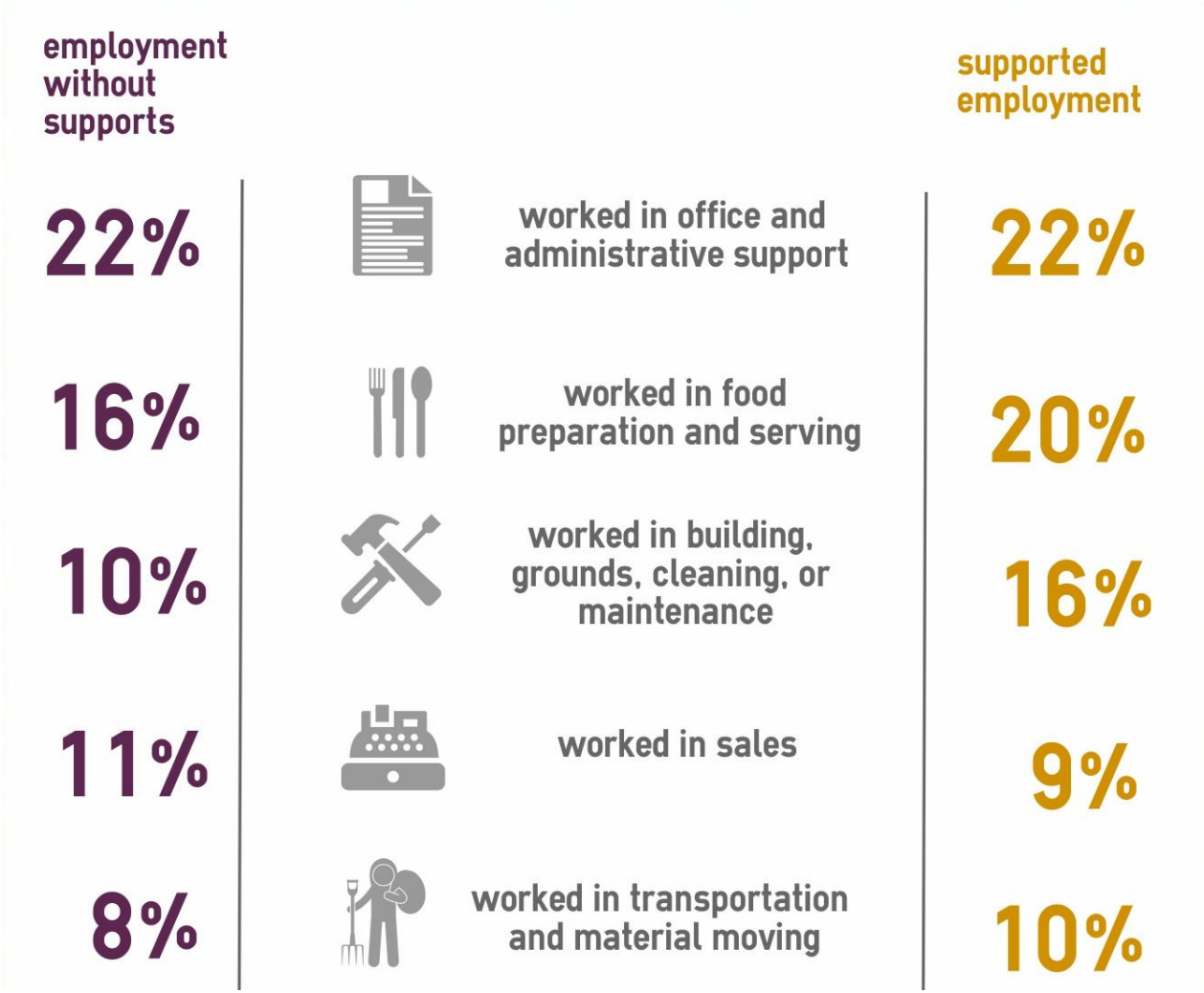
Supported employment

Almost one-third of workers with autism had on-the-job supports* when they exited VR.



Source: Rehabilitation Services Administration (RSA-911), FFY 2014

Top five job types for individual with autism.



Employment

Of those with autism who left VR with a job:

80% worked part-time.

\$160 was the median weekly income for part-time workers.

\$380 was the median weekly income for full-time workers.

69% were **employed without supports.**

31% were **employed with supports.**



Employment

Of those with autism who left VR with a job:

80% worked part-time.

\$160 was the median weekly income for part-time workers.

\$380 was the median weekly income for full-time workers.

69% were **employed without supports.**

31% were **employed with supports.**

76% part-time

\$170 week



Employment

Of those with autism who left VR with a job:

80% worked part-time.

\$160 was the median weekly income for part-time workers.

\$380 was the median weekly income for full-time workers.

69% were **employed without supports.**

31% were **employed with supports.**

90% part-time

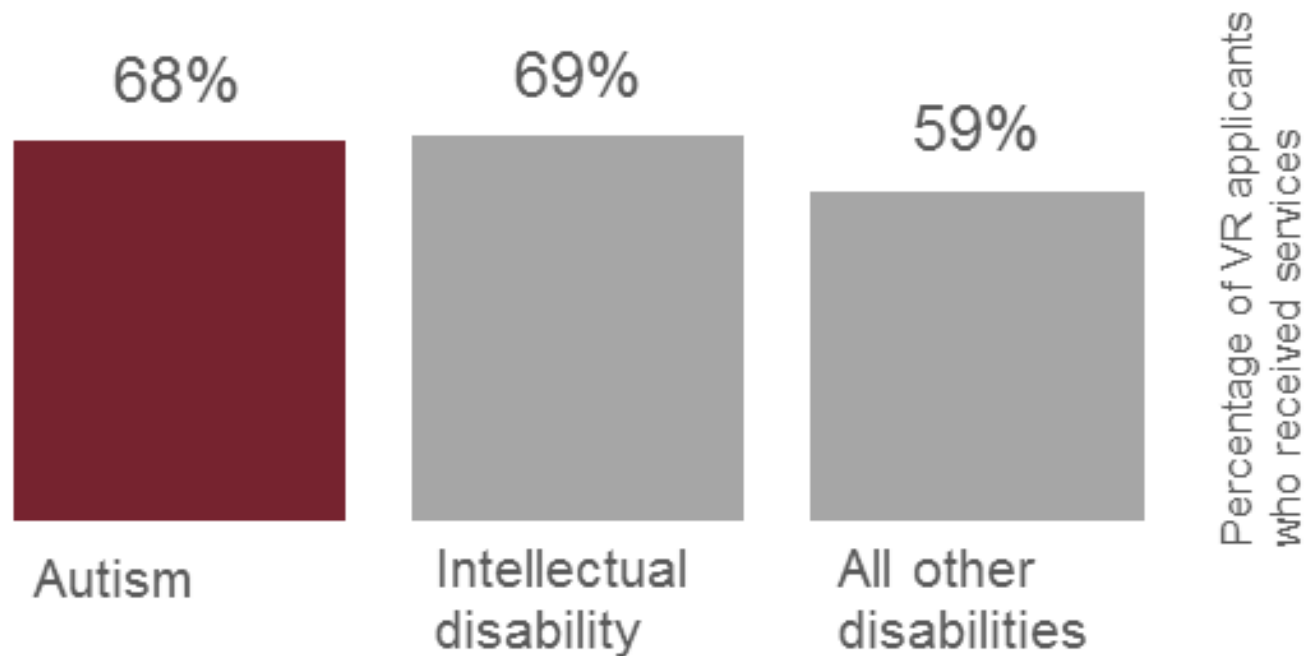
\$145 week



How do services and outcomes compare across groups and states?



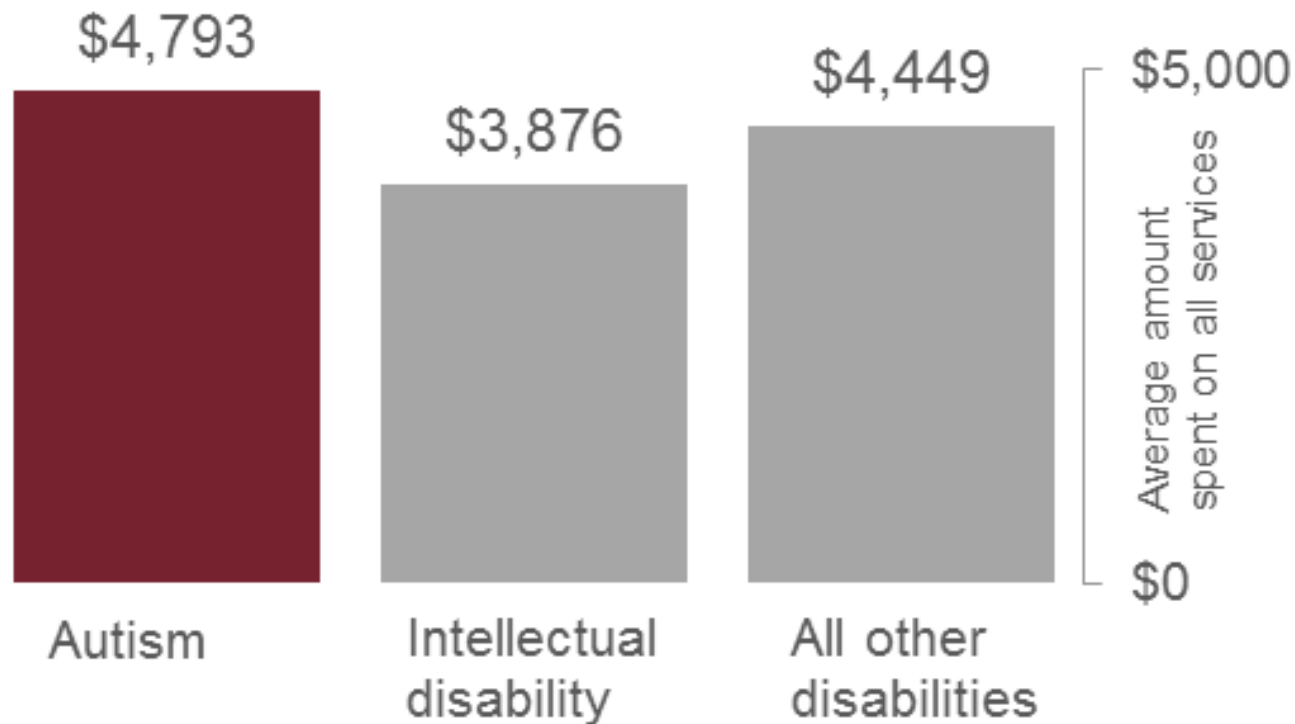
VR applicants with **autism received services at a similar rate as those with ID, and a slightly higher rate than those with other disabilities.**



Source: Rehabilitation Services Administration (RSA-911), FFY 2014



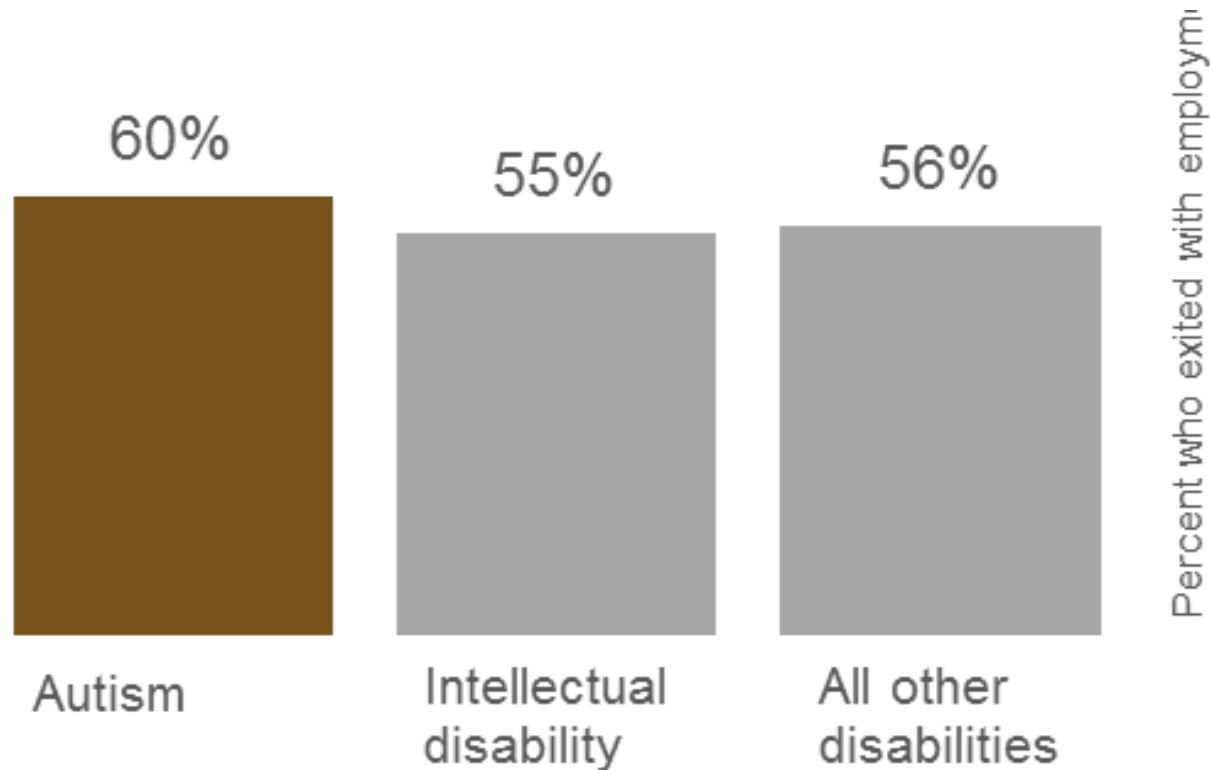
Average expenditures for total VR services were higher for service users with **autism than the other groups.**



Source: Rehabilitation Services Administration (RSA-911), FFY 2014



VR service users with autism exited with a rate of employment similar to those with ID and other disabilities.

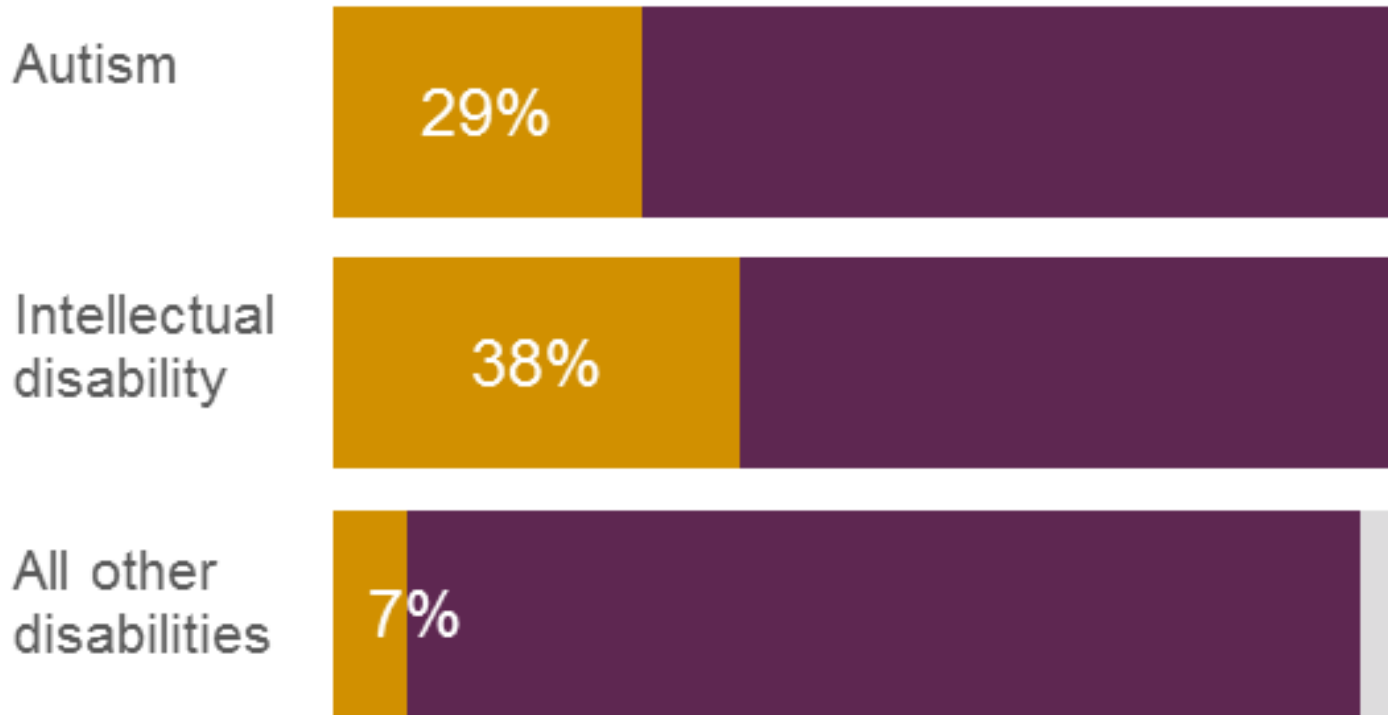


Source: Rehabilitation Services Administration (RSA-911), FFY 2014



Disability comparisons

VR service users with autism worked in **supported employment** less often than those with ID but more often than those with other disabilities.*

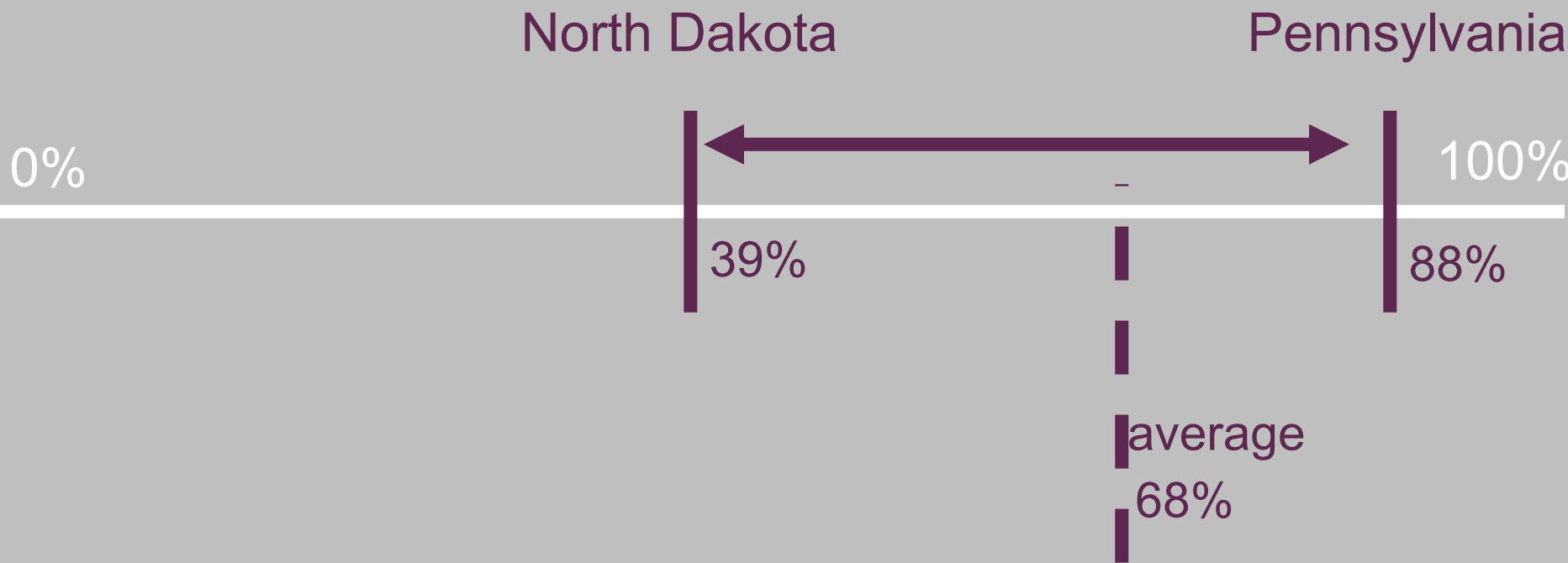


Where you live matters.

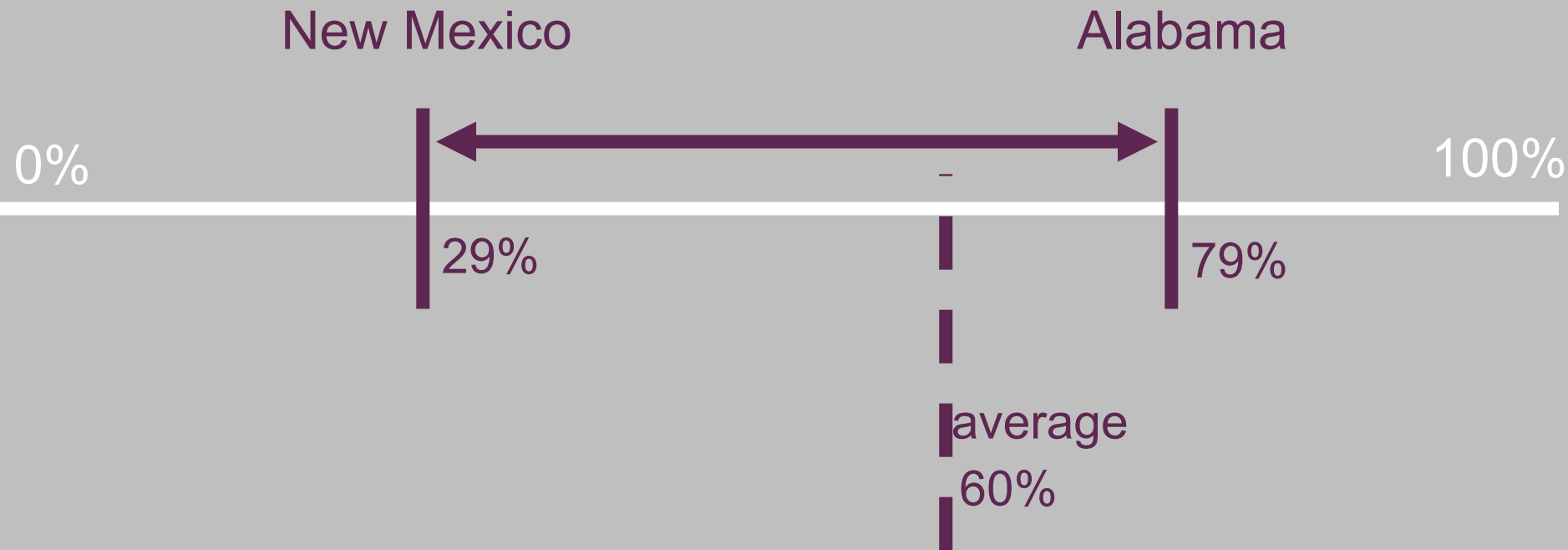


State comparisons

How many eligible applicants with autism received VR services?



How many with autism exited VR with employment?



State comparisons

What was the gap between hourly wages for workers with autism exiting VR and all workers in the state?



Limitations

- No reliable measure of impairment severity
- Likely inconsistencies in data collection and entry
- No direct reporting from service users with autism
- No info on those who do not receive VR or who exit before they have a job



Research priorities

- Service use patterns:
 - “Churn” in and out of VR services
 - Interaction of VR and SSI benefits
- State- and local-level variation
- Impact of WIOA state plans



Further Information

A.J. Drexel Autism Institute

www.drexel.edu/autisminstitute

Life Course Outcomes Research Program

www.drexel.edu/AutismOutcomes



Life Course Outcomes
Research Program

 DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

Meeting of the IACC

Break

Meeting of the IACC

Morning Agenda - continued

10:25

Break

10:40

**Parents' Perceptions about Supporting
Students with Autism to Transition to
College**

Edlyn Peña, Ph.D.

Associate Professor of Educational
Leadership

Director of Doctoral Studies

California Lutheran University

Parents' Perceptions about Supporting Students with Autism to Transition to College

Edlyn Vallejo Peña, Ph.D.

Jodie Kocur, Ph.D.

California
Lutheran
University

Background

- In 2008-2009, approximately 78% of four-year public institutions enrolled students with ASD (Raue & Lewis, 2011)
- 30% of students with ASD who complete high school attend college (Roux, Shattuck, Rast, Rava, & Anderson, 2015)
- Non-disclosure of disability leads to under-reporting of ASD numbers (Newman, Wagner, Cameto, & Knokey, 2009)

Statement of the Problem

- College students with ASD experience increased challenges with emotional regulation, stress management, socialization, intimacy, and managing academic demands (White et. al, 2016).
- Educators and parents need to better understand how to prepare students with ASD for the transition to post-secondary education, and how to best support them during their college experience.

Purpose

- Research Study: To understand the self-reported experiences and perceptions of parents who supported their students with ASD with college transition planning
- Today's Presentation: To highlight major findings of the study from various phases of data analyses that have been presented in journals and conference presentations.

Method- Participants

- Participants: Thirty-eight parents (34 mothers, 4 fathers) of students with ASD who were attending college or in the process of transition planning to attend college
- A recruitment e-mail was sent to various university support service offices, clinicians, autism support groups and social networking sites.

Method- Data Collection & Analysis

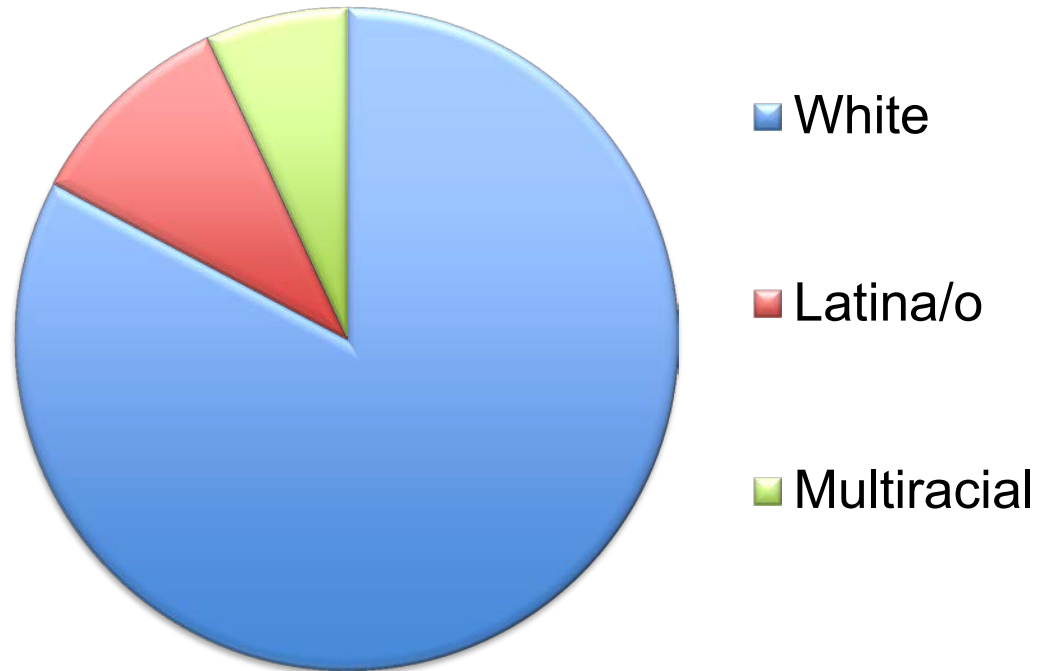
- Brief demographic questionnaire
- Semi-structured, one-hour interviews
- Interviews were audio-recorded and transcribed
- Open and analytic coding of significant statements by 5-person research team

Limitations

- No college students with ASD were interviewed. Adding their voices to the data would enrich our conceptions about transition experiences.
- Findings are not representative of all families whose students with ASD pursue college. The purpose of the qualitative study was to get rich information through in-depth interviews with a purposeful sample of parents.

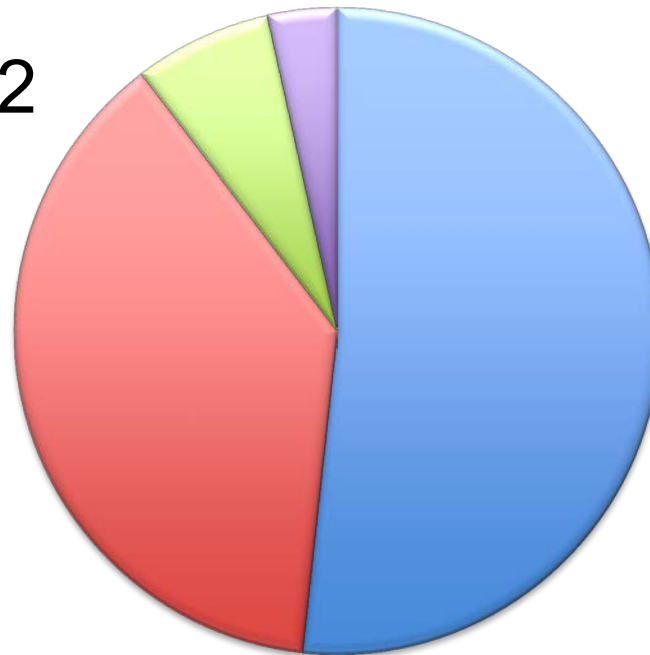
Race/ethnicity of Participants

- White = 24
- Latina/o = 3
- Multiracial = 2



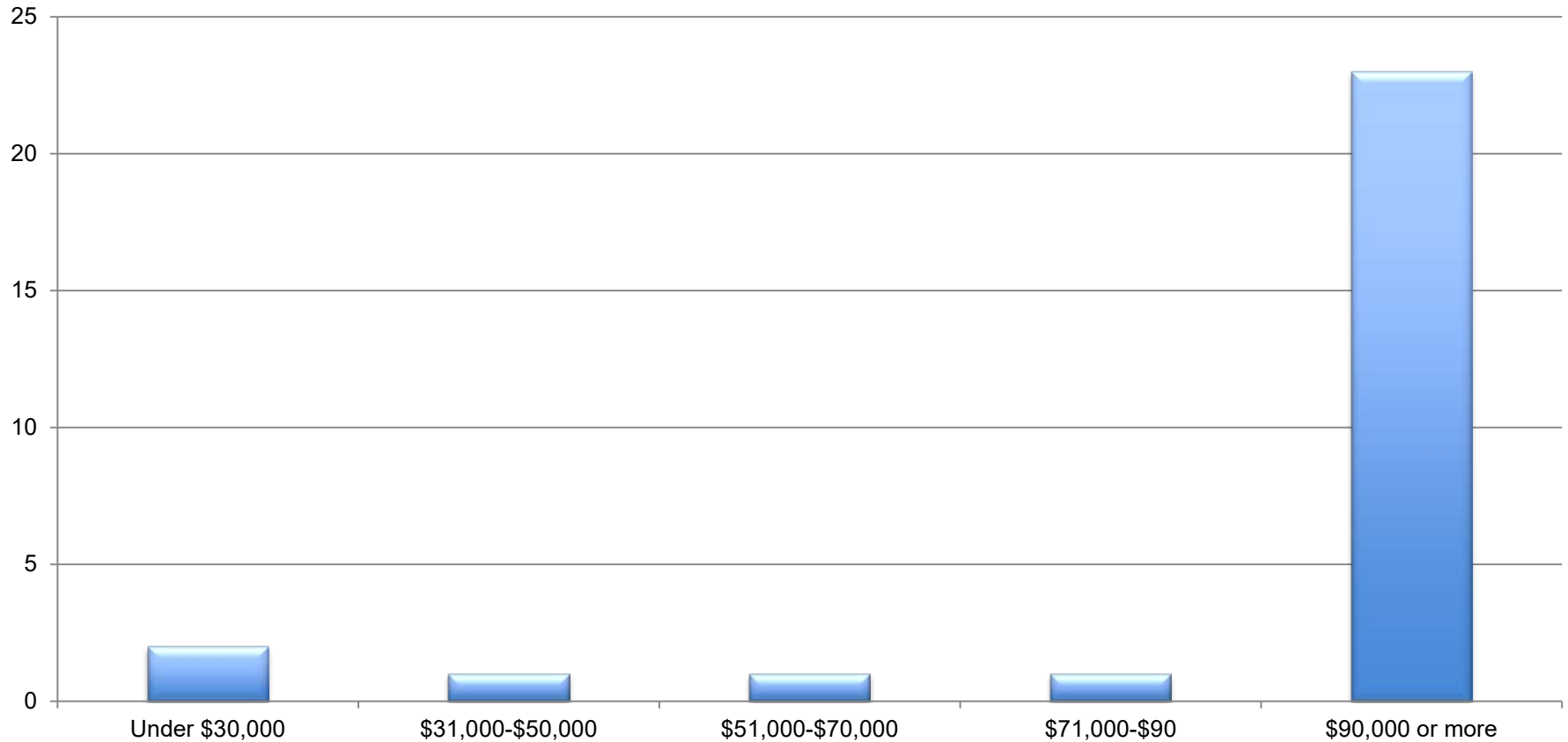
Educational Background

- Graduate degree = 15
- Bachelors = 11
- Some college = 2
- No college = 1



- Graduate Degree
- Bachelor's Degree
- Some College
- High School Graduate

Household Income of Participants



Cultural Capital

- Cultural capital is known as accumulated cultural knowledge that brings about social mobility, status, and power (Bourdieu, 1986).
- Parents exercised cultural capital by assisting students to
 - research postsecondary options
 - navigate policies for transition and admission
 - advocate for access to resources to support their college success and retention

Social Capital

- Social capital involves the development of networks and relationships to others in order to gain access to important resources for social mobility (Bourdieu, 1986).
- Parents generated social capital through relationships with educational advocates, disability coordinators and academic advisors to access opportunities, information, & resources

Coaching Students to Navigate College

Parents described themselves as
“orchestrating from behind the scenes.”

“The phone is very difficult for him; he is a very visual person. So I had to call to make an appointment to schedule an assessment or a counselor meeting... It is really hard for him... This [financial aid issue] is a really complicated thing.”

Encouraging Independence

“You want to build the independence and you want him to learn to take these things over... So sometimes I let him fall a little bit because that’s a learning process.”

“I’m not interested in jeopardizing graduation over having him learn a lesson. So we’ve tried to balance.”

Major Challenges

- Navigating the Federal Educational Rights and Privacy Act (FERPA): *“I received the message to ‘back off, mom!’”*
- Finding Supportive Faculty: *“Teachers at the college are not prepared to deal with his particular type of disability.”*

Discussion of Findings

- Findings suggest a pattern of inequitable educational access to college for students with ASD from low-income, first-generation, and underrepresented racial minority backgrounds
- According to Roux, Shattuck, Rast, Rava, & Anderson (2015), 41% of White students with ASD attend college compared to 23% of Black and 29% of Latino students with ASD.

Discussion of Findings

- While the challenges related to FERPA are unique to the post-secondary setting, parents' difficulties with school professionals, faculty, and feeling alienated are consistent with previous research regarding barriers faced by parents and students during transition planning (Defur, Todd-Allen, & Getzel, 2001; Roberts, 2010).

Implications for Practice

- High school and college professionals should involve parents and their students from marginalized backgrounds to develop cultural and social capital that will enable students to access and succeed in higher education
- Colleges can develop proactive partnerships with parents to define relationship boundaries (e.g. FERPA)
- Professional development for faculty

Future Research

- Include the perspectives of people with ASD. Without their voices, an incomplete body of knowledge about college opportunity, access, and choice is constructed.

For more information...

- Peña, E.V. & Kocur, J. (2013). Parenting experiences in supporting the transition of students with autism spectrum disorders into community college. *Journal of Applied Research in Community Colleges*, 20(2), 5-12.
- Kocur, J. & Peña, E.V. (2013). *Parents' Experiences in the Transition of Students with Autism Spectrum Disorders to College*. American Psychological Association (APA). Honolulu, HI.
- Peña, E.V. & Kocur, J. (under review). A Spectrum of (In)Opportunity: An Exploration of College Transition Experiences Among Students with Autism and their Families. *Journal of College Student Development*.

Thank You

Edlyn Vallejo Peña, Ph.D.

www.edlynpena.com

epena@callutheran.edu

California Lutheran

UNIVERSITY

Meeting of the IACC

Morning Agenda - continued

11:10 **Committee Business**

Susan Daniels, Ph.D.

Director

Office of Autism Research Coordination,
NIMH and Executive Secretary, IACC

IACC Strategic Plan Update

IACC Working Groups

IACC Summary of Advances

12:00 PM **Lunch**

IACC Committee Business

Susan Daniels, Ph.D.

Executive Secretary, IACC

Director, Office of Autism Research Coordination

National Institute of Mental Health

IACC Strategic Plan Update

- **IACC Strategic Plan Working Groups have been formed – see IACC website for roster**
- **Will be convening working groups by phone between now and October to work on Strategic Plan Update**
- **All calls will be announced in advance and open to the public for listening**

In the meantime, OARC has:

- **Prepared preliminary 2013 Portfolio Analysis data for use in the updating process**
- **Launched an open Request for Public Comments to collect public input on issues to consider for the 2016 SP update**

2013 ASD Research Portfolio Analysis Preliminary Data

Susan Daniels, Ph.D., Director

Julianna Rava, M.P.H., Science Policy Analyst

Office of Autism Research Coordination

National Institute of Mental Health

Preliminary Data: 2013 IACC Portfolio Analysis Report

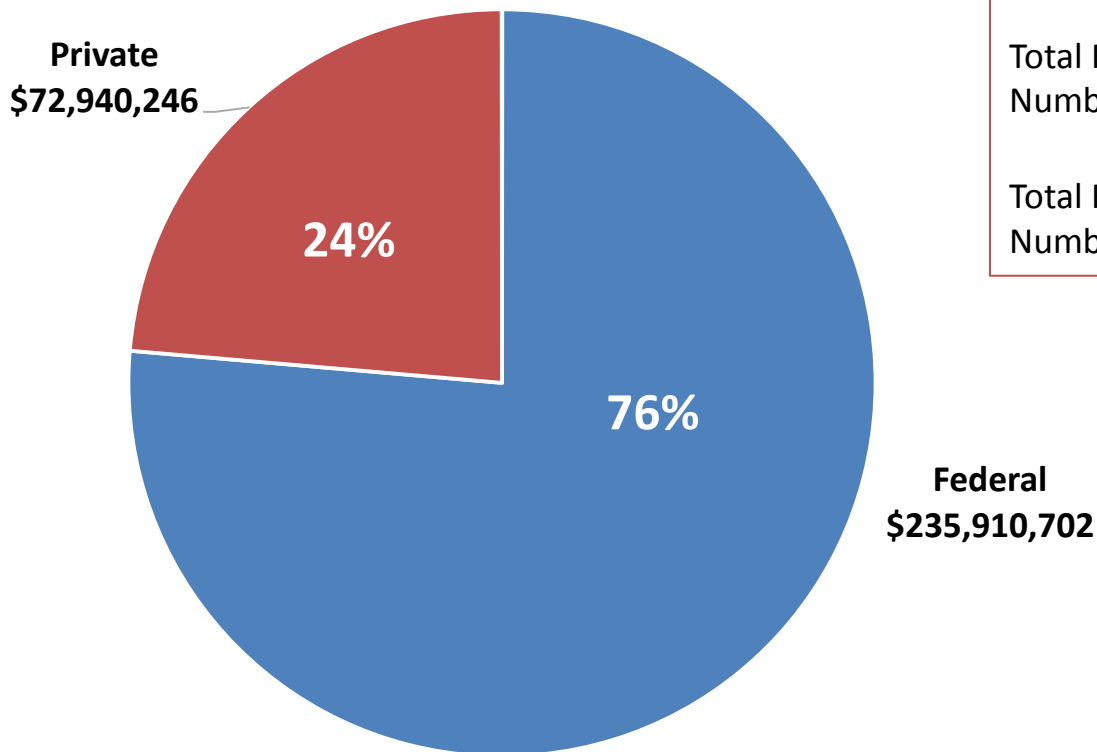


- 2013 ASD research portfolio data have been collected from 19 funders and preliminary analysis is available for use by the IACC for the IACC Strategic Plan Update
- The analysis provides detailed information about the ASD research portfolio across both Federal agencies and private organizations
- Informs the IACC and stakeholders about the research funding landscape and trends
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan

Proportion of Federal and Private Funds Supporting ASD Research - 2013

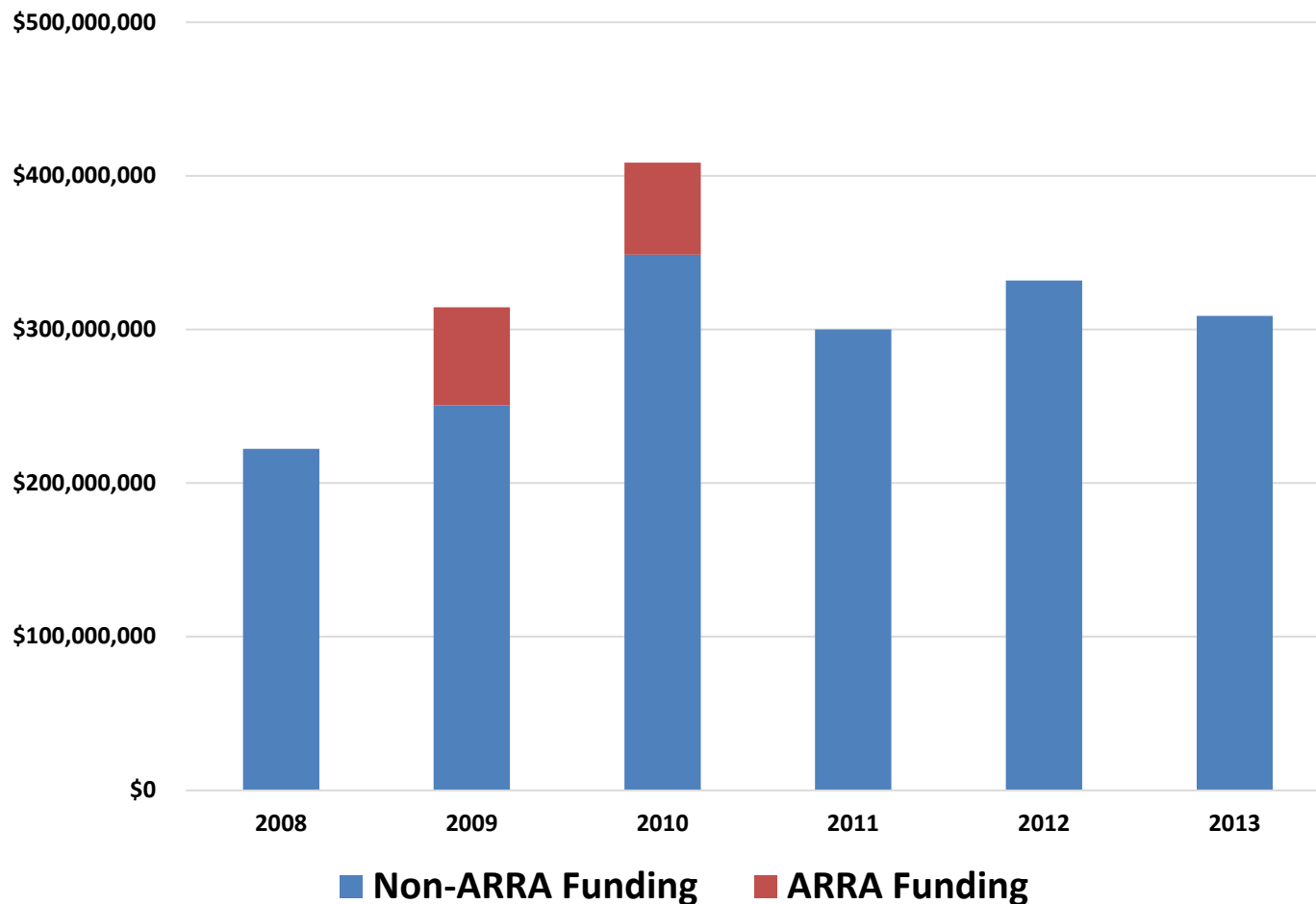
2013 Total Funding: \$308,850,948

Number of Projects: 1,291

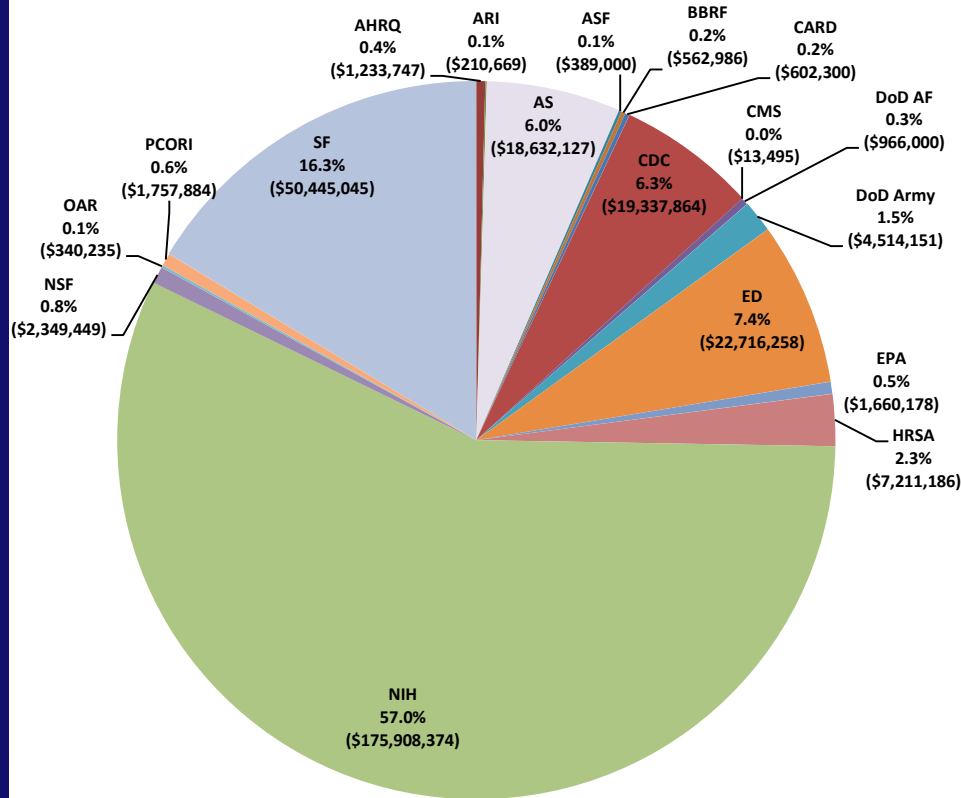


2008
Total Funding: \$222,215,342
Number of Projects: 744
2012
Total Funding: \$331,949,933
Number of Projects: 1,321

Combined Federal and Private Autism Research Funding 2008-2013



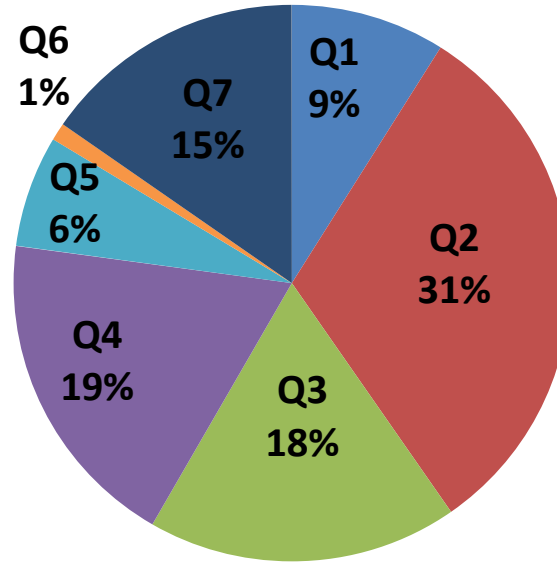
2013 ASD Research Funding by Agency/Organization



Federal or Private Funder	2013 Funding	Percentage of 2013 Funding
National Institutes of Health (NIH)	\$ 175,908,374	57.0%
Simons Foundation (SF)	\$ 50,445,045	16.3%
Department of Education (ED)	\$ 22,716,258	7.4%
Centers for Disease Control and Prevention (CDC)	\$ 19,337,864	6.3%
Autism Speaks (AS)	\$ 18,632,127	6.0%
Health Resources and Services Administration (HRSA)	\$ 7,211,186	2.3%
Department of Defense – Army (DoD Army)	\$ 4,514,151	1.5%
National Science Foundation (NSF)	\$ 2,349,449	0.8%
Patient-Centered Outcomes Research Institute (PCORI)	\$ 1,757,884	0.6%
Environmental Protection Agency (EPA)	\$ 1,660,178	0.5%
Agency for Healthcare Research and Quality (AHRQ)	\$ 1,233,747	0.4%
Department of Defense – Air Force (DoD AF)	\$ 966,000	0.3%
Center for Autism and Related Disorders (CARD)	\$ 602,300	0.2%
Brain and Behavior Research Foundation (BBRF)	\$ 562,986	0.2%
Autism Science Foundation (ASF)	\$ 389,000	0.1%
Organization for Autism Research (OAR)	\$ 340,235	0.1%
Autism Research Institute (ARI)	\$ 210,669	0.1%
Centers for Medicare and Medicaid Services (CMS)	\$ 13,495	0.01%
Administration for Children and Families (ACF)	\$ -	0%
TOTAL	\$ 308,850,948	100%

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

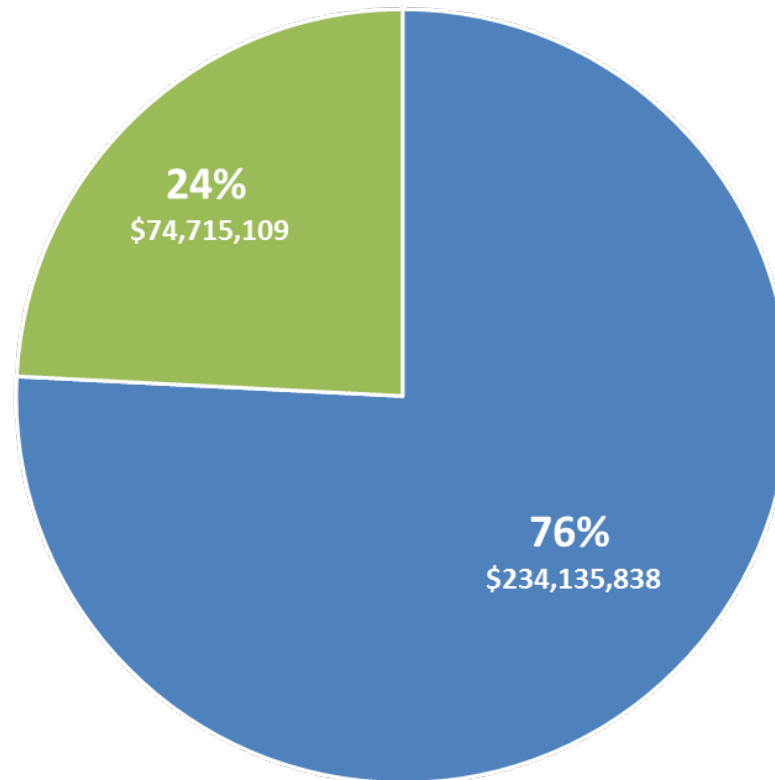
Percentage of 2013 Funding by *IACC Strategic Plan Question*



Strategic Plan Question	2013 Funding	Percentage of 2013 Funding
Question 1: Diagnosis	\$ 27,652,658	9%
Question 2: Biology	\$ 96,872,439	31%
Question 3: Risk Factors	\$ 55,666,351	18%
Question 4: Treatments	\$ 58,065,840	19%
Question 5: Services	\$ 20,026,744	6%
Question 6: Lifespan	\$ 3,152,885	1%
Question 7: Infrastructure	\$ 47,414,030	15%
TOTAL	\$ 308,850,948	100%

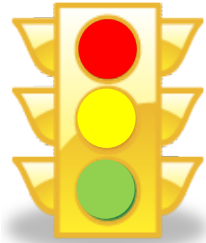
2013 ASD Funding: Alignment with IACC Strategic Plan Objectives

About $\frac{3}{4}$ of the funding was for projects related to the SP objectives.
About $\frac{1}{4}$ was directed toward core/other projects.



■ Specific to Question Objectives ■ Core/Other

Summary of Overall Progress in Strategic Plan Objectives through 2013

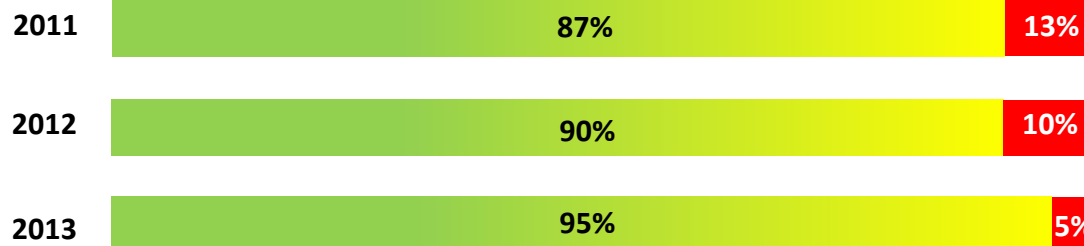


Inactive (Red) Objectives



Fulfilled (Green) or Partially Fulfilled (Yellow) Objectives

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Total	Percentage
Number of Fulfilled Objectives	4	5	9	4	3	0	9	34	44%
Number of Partially Fulfilled Objectives	4	4	6	8	6	8	4	40	51%
Number of Inactive Objectives	1	0	0	0	0	0	3	4	5%
Total	9	9	15	12	9	8	16	78	100%



Data on Progress Toward SP Objectives

Additionally, OARC will be providing the following items to the Strategic Plan working groups to assist them in their assessment of progress:

- **Table of objectives, funding, and status of each objective**
- **Full listing of projects for each objective that can be used to identify trends and gaps**
- **Breakdown of funding and projects according to research subcategories**

Question 1 Table of Objectives, Funding, & Status

	2013 Funding*	2013 Project Count	Percentage of 2013 Question Funding
Question_1_Diagnosis	\$ 27,652,658.19	128	100.00%
1SA. Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. IACC Recommended Budget: \$5,300,000 over 2 years.	\$ 3,200,651.80	10	11.57%
1SB. Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparative studies of general developmental screening versus autism-specific screening tools, in both high-risk and population-based samples, including those from resource-poor international settings and those that are diverse in terms of age, socio-economic status, race, ethnicity, gender, characteristics of ASD, and general level of functioning by 2012. IACC Recommended Budget: \$5,400,000 over 3 years.	\$ 3,634,193.24	20	13.14%
1SC. Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012. IACC Recommended Budget: \$2,000,000 over 2 years.	\$ 1,038,848.00	5	3.76%
1SD. Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. IACC Recommended Budget: \$6,000,000 over 5 years.	\$ -	0	0.00%
1SE. Conduct at least one study to determine the positive predictive value and clinical utility (e.g., prediction of co-occurring conditions, family planning) of chromosomal microarray genetic testing for detecting genetic diagnoses for ASD in a clinical setting by 2012. IACC Recommended Budget: \$9,600,000 over 5 years.	\$ 983,936.00	3	3.56%
1SF. Convene a workshop to examine the ethical, legal, and social implications of ASD research by 2011. The workshop should define possible approaches for conducting future studies of ethical, legal, and social implications of ASD research, taking into consideration how these types of issues have been approached in related medical conditions. IACC Recommended Budget: \$35,000 over 1 year. (This objective was fulfilled in 2011.)	\$ -	0	0.00%
1LA. Identify behavioral and biological markers that separately, or in combination, accurately identify, before age 2, one or more subtypes of children at risk for developing ASD, and evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening by 2014. IACC Recommended Budget: \$33,300,000 over 5 years.	\$ 9,357,850.65	37	33.84%
1LB. Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with ASD, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response and/or outcome by 2015. IACC Recommended Budget: \$71,100,000 over 5 years.	\$ 7,822,254.50	38	28.29%
1LC. Identify and develop measures to assess at least three "continuous dimensions" (e.g., social reciprocity, communication disorders, and repetitive/restrictive behaviors) of ASD symptoms and severity that can be used by practitioners and/or families to assess response to intervention for people with ASD across the lifespan by 2016. IACC Recommended Budget: \$18,500,000 over 5 years.	\$ 1,224,987.00	7	4.43%
10. Not specific to Question 1 objectives	\$ 389,937.00	8	1.41%

*Any objective colored **green** has funding which is greater than or equal to the recommended funding for the year (determined by annualizing the recommended budget associated with that objective); any objective colored **yellow** has active projects, but with funding that totals less than the annualized recommended amount, while any objective colored **red** has no active projects and received no funding in 2013. Objectives whose overarching aim (e.g., the ultimate goal of the research) was achieved in a previous year are colored **pale green**.

Question 1: Full Listing of Projects for Each Objective

QUESTION 1: WHEN SHOULD I BE CONCERNED?

2013 Projects: 128

2013 Funding: \$27,652,658

1.S.A

Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. *IACC Recommended Budget: \$5,300,000 over 2 years.*

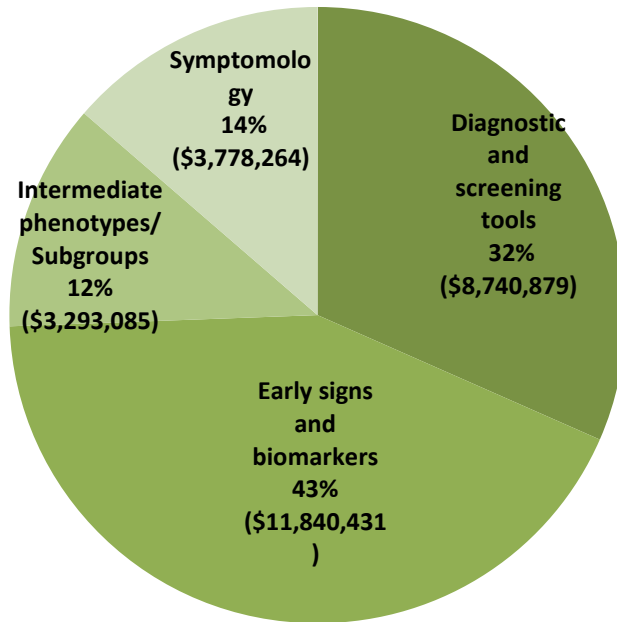
2013 Projects: 10

2013 Funding: \$3,200,652

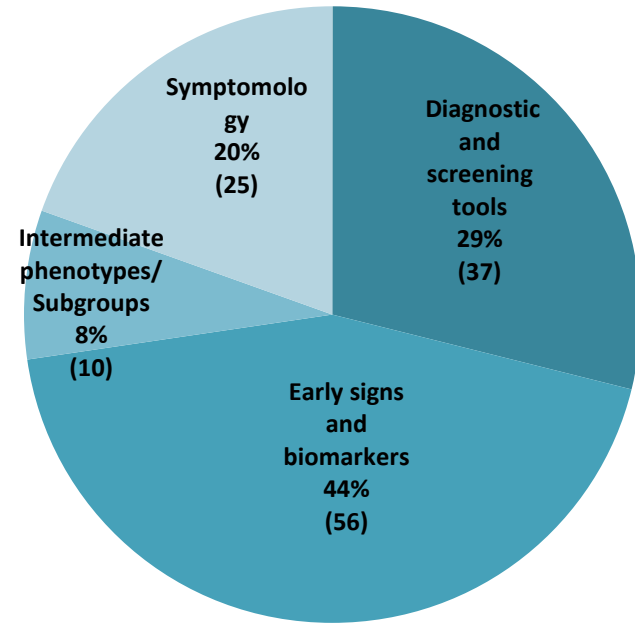
Project Title	Principal Investigator	Institution	Funding	Funder
Cross-Model Automated Assessment of Behavior during Social Interactions in Children with ASD	Naples, Adam	Yale University	\$5,000	Autism Science Foundation
Biomarkers and diagnostics for ASD	Bahn, Sabine	Institute of Biotechnology	\$0	Autism Speaks
Assessing the accuracy of rapid phenotyping of nonverbal autistic children	Law, Paul	Kennedy Krieger Institute	\$124,998	Autism Speaks
Early detection of pervasive developmental disorders	Fein, Deborah	University of Connecticut	\$924,542	National Institutes of Health
Solid-state patch clamp platform to diagnose autism and screen for effective drug	Garner, Craig	Stanford University	\$196,247	National Institutes of Health
Enabling use of blood spot cards for accurate high throughput Fragile X screening	Latham, Gary	Asuragen, Inc.	\$1,142,346	National Institutes of Health
The use of interactive television in identifying autism in young children	Reese, R. Matthew	University of Kansas Medical Center	\$217,440	National Institutes of Health

Subcategory Analysis: Question 1 – Screening & Diagnosis

Percentage of 2013 Funding by Subcategory



Percentage of 2013 Project Count by Subcategory



Question 1: Screening and Diagnosis	2013 Funding	Percentage of 2013 Funding	2013 Project Count	Percentage of 2013 Project Count
Diagnostic and screening tools	\$ 8,740,879	32%	37	29%
Early signs and biomarkers	\$ 11,840,431	43%	56	44%
Intermediate phenotypes/Subgroups	\$ 3,293,085	12%	10	8%
Symptomology	\$ 3,778,264	14%	25	20%
TOTAL	\$ 27,652,658	100%	128	100%

Questions or comments?

**Are there any other breakdowns
of data that would be helpful to
the working groups?**

Update on IACC 2016 Strategic Plan Request for Public Comment



2016 IACC Strategic Plan Request for Public Comment

- On behalf of the IACC, OARC issued a Federal Register Notice soliciting public comment on the research, service, and policy priorities for the topics addressed by the current strategic plan:
 - Diagnosis and Screening (Question 1)
 - Underlying Biology (Question 2)
 - Risk Factors (Question 3)
 - Treatments & Interventions (Question 4)
 - Services (Question 5)
 - Lifespan (Question 6)
 - Research Infrastructure and Surveillance (Question 7)
- Comments will be provided to Strategic Plan Working Groups by SP question, and will be made publicly available on the IACC website within 90 days of the closing date
- Within each question comments are grouped by themes addressed; some comments are coded for more than one theme
- **As of 7/18/2016, 827 comments have been received**

Current Responses and Preliminary Data

Response Demographics (based on Affiliations provided) (N=583 as of 6/29/16)	
Parent/Family Member	86
Service Provider	30
Researcher	19
Advocate/Professional Society	15
Educator/Educational Service Provider	12
Medical/Therapy Practitioner	10
Family Assistance/Navigator	7
Self Advocate	7
Community Educator	2
Research Trainee	2
Government Employee	1
International	1
No Affiliation Provided	391

Question 1: Diagnosis & Screening

(363 responses to Q1 rec'd as of 6/29)

- Need better recognition and diagnosis of subgroups
- Need better understanding of early signs and symptoms
- Families need emotional support following diagnosis and assistance in navigating access to services
- Improve accuracy and awareness of diagnosis in females/address sex and gender disparities in diagnosis
- Improvements in the accuracy and usability of screening and diagnosis tools
- Need more and increased access to genetic screening
- Need greater research and identification of biomarkers, and use of these biomarkers in screening and diagnosis
- Need improvements in access and accuracy of adult and adolescent diagnosis
- Need to address the multifaceted disparities in diagnosis across racial, cultural, socioeconomic, and regional lines
- Need to increase/decrease early screening and diagnosis of ASD in children
- Need to reduce the time to diagnosis by improving service access and diagnostic tools/process
- Need to strengthen link between initial diagnosis and access to services and interventions
- Parents and caregivers need greater education so that they can recognize signs and symptoms
- Practitioners need to listen to and consider parent concerns about early signs and symptoms
- Universal screening for ASD is needed
- Workforce development, including access to qualified practitioners and improvements in the training of the existing workforce
- Current priorities are appropriate (diagnosis and screening tools, early signs, symptoms and biomarkers, identification of subgroups, disparities in diagnosis)

Question 2: Underlying Biology

(351 responses to Q2 rec'd as of 6/29)

- Need further research on the genetics of autism, and genetic tests should be more accessible
- Need more developmental biology research
- Need more research and a better understanding of genetic syndromes related to ASD
- Need more research and better understanding of the biomarkers and symptoms of ASD, and the heterogeneity of symptoms
- Need more research into the contribution of immune and metabolic pathways to autism
- Need more research on cognitive and behavioral biology
- Need more research on the basic neuroscience of ASD
- Need more research on the biology and relationship of co-occurring conditions in ASD
- Need more research on the molecular biology of ASD
- Need more research on sex and gender differences, inclusive of both biological sex and self-identified gender
- Need research to better understand, differentiate, and treat subgroups of people with autism
- Need more research to better understand sensory processing and motor function in ASD
- Need more translational and interdisciplinary research to improve the lives of people with ASD
- Need to prioritize gut-brain interaction research
- Current priorities are appropriate (molecular biology and neuroscience, developmental biology, cognitive and behavioral biology, genetic syndromes related to ASD, sex differences, immune and metabolic aspects, and co-occurring conditions in ASD)
- Understanding the biology of ASD is not a priority, relative to other areas (i.e. treatment and services)

Question 3: Risk Factors

(363 responses to Q3 rec'd as of 6/29)

- Need better methods for testing contributions of risk factors from multiple domains to better understand risk of autism
- Need more research into better understanding of environmental risk factors, defined broadly to including both chemical and social environments
- Need more research on epigenetic risk factors
- Need more research on genetic risk factors
- Need more research on immune and metabolic risk factors
- Need more research on maternal and prenatal factors
- Need more research on the interaction of genetic and environmental factors
- Need more research on the risk factors for co-occurring conditions in autism
- Need more research on the role of the microbiome and gastrointestinal risk factors
- Need more research to better understand heritability and risk of autism in families
- Need more research to understand the role of vaccines in causing autism
- Need less/no additional research on the role of vaccines in autism
- Current priorities are appropriate (genetic and environmental risk factors, gene-environment interactions, and the potential role of epigenetics and the microbiome)
- The cause and prevention of autism are not a priority, either because resources can be better used in other areas or because preventing autism should not be a goal

Question 4: Treatments & Interventions

(385 responses to Q4 rec'd as of 6/29)

- Need a qualified workforce trained in providing treatments and interventions ; need both a greater number and improved training of current clinicians, therapists, and school employees
- Need to prioritize early intervention
- Need to educate parents about available treatments and interventions, and to help provide these interventions
- Endorsement of specialized or ASD specific treatments and interventions
- Improve availability and efficacy of treatments and interventions specifically for adult and adolescents with ASD
- Improve efficacy and availability of behavioral treatments and interventions
- Improve efficacy and availability of interventions in educational settings
- Improve the evidence base for treatments and interventions, and make that information more readily available and widely used
- Personalized combinations and types of treatments and interventions will be the most efficacious
- Positive and negative comments about searching for a “cure” rather than treatments or interventions
- Research and availability of technology based or assistive technology treatments and interventions
- Research and availability of treatments and interventions for co-occurring conditions
- Need research on biomedical and pharmacological treatments and interventions to improve efficacy and reduce side effects
- Need research on the efficacy and availability of complementary, alternative or integrative treatments and interventions
- Need research on long term outcomes of treatments and intervention, as well as the translation and implementation of research based treatments and interventions
- Improve coordination of treatments and interventions between services and practitioners
- Current priorities are appropriate (behavioral, medical/pharmacologic, educational, technology-based, and complementary/integrative interventions)

Question 5: Services

(467 responses to Q5 rec'd as of 6/29)

- Access to early intervention services is a priority
- Disparities in access to services should be addressed
- Families need access to services to reduce the mental and emotional burden of caring for those with ASD
- Improve the efficacy and cost effectiveness of services and service delivery
- Improve the quality and availability of services within the educational systems
- Improve the service systems and service models
- Increase the accessibility and utilization of services.
- Need better coordination between service providers, taking into account what is relevant for the individual and the choices of those with ASD and their families/caregivers
- Need for an adequately trained and compensated workforce to improve available services and service delivery
- Need for better services to foster community inclusion of those with ASD
- Need to be more and better access to specialized services for ASD
- Parents/caregivers need assistance navigating complicated service systems.
- Prioritize services to improve the health and safety, including addressing interactions with law enforcement and wandering
- The broader community needs to be better educated about ASD, to lead to better understanding and inclusion
- The cost of services is prohibitive, and research and policies are needed to reduce these barriers to access
- Current priorities are appropriate (service access and utilization, service systems, education, family well-being, efficacious and cost-effective service delivery, health and safety issues affecting children, and community inclusion)
- Focus on the treatment or cause of autism rather than the delivery of services

Question 6: Lifespan

(481 responses to Q6 rec'd as of 6/29)

- Improve access to and quality of adult services, including additional research to improve evidence based services for adults
- Improve access to diagnosis for adolescents and adults
- Improve community integration/inclusion, including social isolation and community education about ASD
- Improve the quality, accessibility of housing options
- Improve transition services, and provide better assistance for young adults and their families during transitions
- Long term and financial planning are a priority for research, services, and policy
- Need assistance for adults with autism and their families in navigating available adult services
- Need for a larger, better trained and compensated workforce for adults with ASD
- Research and services to improve health, medical care, safety and quality of life across the lifespan
- Research, services and policies are needed to improve vocational/employment and post-secondary education opportunities
- Services and research should take into account the perspective and choices of adults and their families/caregivers
- Current priorities are all important/relevant (health and quality of life across the lifespan, aging, transition, and adult services, including education, vocational training, employment, housing, financial planning and community integration.)
- Focus should be on early intervention or developing effective treatments; adults/lifespan are not a research priority

Question 7: Research Infrastructure and Surveillance (246 responses to Q7 rec'd as of 6/29)

- Improve services infrastructure
- Increase collaboration and coordination among services providers
- Increase collaboration and coordination of research including interdisciplinary research
- Increase the dissemination of research, and the translation of research into practice
- Need greater development of the research workforce
- Need more and improved surveillance of ASD prevalence, including by race/ethnicity, gender and age
- Need research infrastructure, i.e. databases, research and clinical trial policies
- Research should include the voices and participation of individuals with autism and their families
- Current priorities are appropriate/important (research infrastructure needs, ASD surveillance research, research workforce development, dissemination of research information, and strengthening collaboration)
- Prioritize services and interventions rather than research

Question 7: Research Infrastructure and Surveillance (246 responses rec'd as of 6/29)

- Improve services infrastructure
- Increase collaboration and coordination among services providers
- Increase collaboration and coordination of research including interdisciplinary research
- Increase the dissemination of research, and the translation of research into practice
- Need greater development of the research workforce
- Need more and improved surveillance of ASD prevalence, including by race/ethnicity, gender and age
- Need research infrastructure, i.e. databases, research and clinical trial policies
- Research should include the voices and participation of individuals with autism and their families
- Current priorities are appropriate/important (research infrastructure needs, ASD surveillance research, research workforce development, dissemination of research information, and strengthening collaboration)
- Prioritize services and interventions rather than research



Are there any specific topics that the IACC would like to hear about from the public about in addition to what has already been shared?

It's Not Too Late to Share your Thoughts with the IACC!

Comment Period is open until **JULY 29, 2016**
<https://iacc.hhs.gov/>



The screenshot shows the IACC website homepage. At the top, it features the U.S. Department of Health & Human Services logo and the IACC logo. Navigation links include "HOME", "ABOUT IACC", "ABOUT OARC", "NEWS", "MEETINGS", "PUBLICATIONS", "FUNDING", and "RESOURCES". A search bar is present with the text "Search IACC Website" and a "GO!" button. The main content area has a large banner with a red arrow pointing right and the text "Share your Thoughts" in a handwritten font. Below the banner, it says "2016 Strategic Plan - Open Request for Public Comment (June 15 - July 29)". To the right of the banner are three smaller sections: "Latest Publications" with a thumbnail and "View All Publications >" link, "Portfolio Analysis Web Tool" with a colorful chart thumbnail, and "Get Email Updates" with a thumbnail of hands typing on a laptop. Below the banner, there are tabs for "Latest Activity", "Latest Meetings", "Latest News", "Video & Multimedia", and "About IACC". Under "Latest Activity", there is a section for "IACC Full Committee Meeting" dated July 19, 2016, with a list of topics: "Strategic Plan Update", "Vocational Rehabilitation", "Interventions for Challenging Behaviors", and "Updates from Private Organizations". Below this is a "Publications" section with a red and grey bar and the text "NFWI Summary of Advances in Autism Spectrum". At the bottom right, there is a "Request for Comment" section with a red arrow and the text "Share your Thoughts".

Questions? iaccpublicinquiries@mail.nih.gov

2016 Summary of Advances Process



Summary of Advances Process

- **Monthly solicitation from OARC to collect nominated advances from IACC members**
- **Advances compiled quarterly and discussed at IACC meetings**
- **At end of year, after January meeting discussion, IACC will vote on top ~20**
- **Does the IACC want to select a certain number per Question area, or just select the top 20 overall?**
- **Selected advances will be prepared in summary format similar to current document?**

Comments?



OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

Susan Daniels, Ph.D., Director

Benjamin Feldman, Ph.D., Science Policy Analyst

Amanda Garton, M.S., M.P.P., Presidential Management Fellow

Angelice Mitrakas, B.A., Operations Coordinator

Karen Mowrer, Ph.D., Science Policy Analyst

Miguelina Perez, B.A., Management Analyst

Julianna Rava, M.P. H., Science Policy Analyst

Jeff Wiegand, B.S., Web Development Manager

Nam-Andrew Kim, B.S., UI/UX Designer

Meeting of the IACC

Lunch

Meeting of the IACC

Oral Comments Session

Meeting of the IACC

IACC Committee Member Discussion of Public Comments

Meeting of the IACC

2016 Summary of Advances Nominations

IACC Full Committee Meeting
July 19, 2016

Q1. When should I be concerned?



February, 2016

Screening for Autism Spectrum Disorder in Young Children: A Systematic Evidence Review for the U.S. Preventive Services Task Force.

McPheeters ML, Weitlauf A, Vehorn A, Taylor C, Sathe NA, Krishnaswami S, Fonnesebeck C, Warren ZE



June, 2016

School-age outcomes of infants at risk for autism spectrum disorder.

Miller M, Iosif AM, Young GS, Hill M, Phelps Hanzel E, Hutman T, Johnson S, Ozonoff S

Q2. How can I understand what is happening?

Brain Connectivity

June, 2016

Investigating the Microstructural Correlation of White Matter in Autism Spectrum Disorder.

Dean III DC, Travers BG, Adluru N, Tromp DP, Destiche DJ, Samsin D, Prigge MB, Zielinski BA, Fletcher PT, Anderson JS, Froehlich AL

Brain Connectivity

April 22, 2016

Underconnected, But Not Broken? Dynamic Functional Connectivity MRI Shows Underconnectivity in Autism Is Linked to Increased Intra-Individual Variability Across Time.

Falahpour M, Thompson WK, Abbott AE, Jahedi A, Mulvey ME, Datko M, Liu TT, Müller RA.



May 5, 2016

Methods for acquiring MRI data in children with autism spectrum disorder and intellectual impairment without the use of sedation.

Nordahl CW, Mello M, Shen AM, Shen MD, Vismara LA, Li D, Harrington K, Tanase C, Goodlin-Jones B, Rogers S, Abbeduto L, Amaral DG

Q2. How can I understand what is happening?

Cell

June 9, 2016

Peripheral Mechanosensory Neuron Dysfunction Underlies Tactile and Behavioral Deficits in Mouse Models of ASDs.

Orefice LL, Zimmerman AL, Chirila AM, Sleboda SJ, Head JP, Ginty DD

Journal of
**SPEECH, LANGUAGE,
AND HEARING RESEARCH**



JSLHR

February 1, 2016

Risk factors associated with language in autism spectrum disorder: Clues to underlying mechanisms.

Tager-Flusberg H

Science
AAAS

May 6, 2016

Autism-associated SHANK3 haploinsufficiency causes Ih channelopathy in human neurons.

Yi F, Danko T, Botelho SC, Patzke C, Pak C, Wernig M, Südhof TC.

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

International Journal of
Epidemiology

June 28, 2016

Acetaminophen use in pregnancy and neurodevelopment: attention function and autism spectrum symptoms.

Avella-Garcia CB, Julvez J, Fortuny J, Rebordosa C, García-Esteban R, Galán IR, Tardón A, Rodríguez-Bernal CL, Iñiguez C, Andiarena A, Santa-Marina L



Molecular Autism
Brain, Cognition and Behavior

January 19, 2016

Effect of co-twin gender on neurodevelopmental symptoms: a twin register study.

Eriksson JM, Lundström S, Lichtenstein P, Bejerot S, Eriksson E

JAMA Psychiatry
Formerly Archives of General Psychiatry

June 1, 2016

Risk of Psychiatric and Neurodevelopmental Disorders Among Siblings of Probands With Autism Spectrum Disorders.

Jokiranta-Olkonieni E, Cheslack-Postava K, Sucksdorff D, Suominen A, Gyllenberg D, Chudal R, Leivonen S, Gissler M, Brown AS, Sourander A

Q4. Which treatments and interventions will help?



June 1, 2016

Behaviorally Based Interventions for Teaching Social Interaction Skills to Children with ASD in Inclusive Settings: A Meta-analysis.

Camargo SP, Rispoli M, Ganz J, Hong ER, Davis H, Mason R



May 2016

Preschool Deployment of Evidence-Based Social Communication Intervention: JASPER in the Classroom.

Chang YC, Shire SY, Shih W, Gelfand C, Kasari C



February 1, 2016

Improvement in social competence using a randomized trial of a theatre intervention for children with autism spectrum disorder.

Corbett BA, Key AP, Qualls L, Fecteau S, Newsom C, Coke C, Yoder P

Q4. Which treatments and interventions will help?

JIDR

Journal of Intellectual Disability Research

Published on behalf of mencap and in association with IASSID

May 1, 2016

Intervention effects on spoken-language outcomes for children with autism: a systematic review and meta-analysis.

Hampton LH, Kaiser AP

THE JOURNAL OF CHILD
PSYCHOLOGY AND PSYCHIATRY

February 1, 2016

Children with autism spectrum disorder and social skills groups at school: a randomized trial comparing intervention approach and peer composition.

Kasari C, Dean M, Kretzmann M, Shih W, Orlich F, Whitney R, Landa R, Lord C, King B

International Journal of Language &
Communication
Disorders

May 1, 2016

Joint attention interventions for children with autism spectrum disorder: a systematic review and meta-analysis.

Murza KA, Schwartz JB, Hahs-Vaughn DL, Nye C

Q4. Which treatments and interventions will help?

Journal of the American Academy of

**CHILD & ADOLESCENT
PSYCHIATRY**

June, 2016

Antipsychotic Use Trends in Youth With Autism Spectrum Disorder and/or Intellectual Disability: A Meta-Analysis.

Park SY, Cervesi C, Galling B, Molteni S, Walyzada F, Ameis SH, Gerhard T, Olsson M, Correll CU

Q5. Where can I turn for services?

***No articles were nominated in
January-July 2016 for
Question 5***

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



March 1, 2016

Improving Empathic Communication Skills in Adults with Autism Spectrum Disorder.

Koegel LK, Ashbaugh K, Navab A, Koegel RL

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



May 5, 2016

Effects of an employer-based intervention on employment outcomes for youth with significant support needs due to autism.

Wehman P, Schall CM, McDonough J, Graham C, Brooke V, Riehle JE, Brooke A, Ham W, Lau S, Allen J, Avellone L

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

Morbidity and Mortality Weekly Report (*MMWR*)

April 2016

Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012.

Christensen DL, Baio J, Braun KV, Bilder D, Charles J, Constantino JN, Daniels J, Durkin MS, Fitzgerald RT, Kurzius-Spencer M, Lee LC, Pettygrove S, Robinson C, Schulz E, Wells C, Wingate MS, Zahorodny W, Yeargin-Allsopp M

Meeting of the IACC

Break

Meeting of the IACC

Afternoon Agenda

2:45 **Panel on Challenging Behaviors in Autism**

2:45 **Behavioral Interventions for Anxiety and Irritability in Children and Adolescents with Autism Spectrum Disorder**

Denis Sukodolsky, Ph.D.
Assistant Professor
Yale Child Study Center
Yale School of Medicine

Behavioral Interventions for Anxiety and Irritability in Children and Adolescents with Autism Spectrum Disorder

Denis G. Sukhodolsky, Ph.D.
Yale Child Study Center



Yale Child Study Center

FROM GENERATION
TO GENERATION

Disclosures

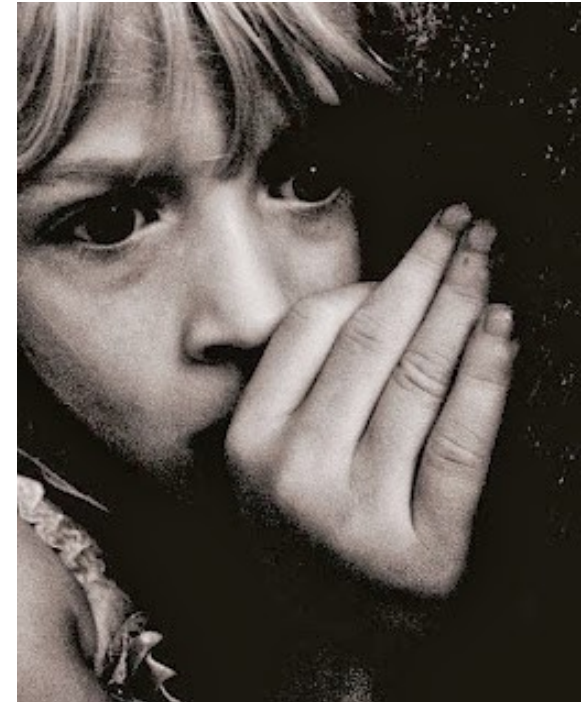
- Research support:
 - NIMH R01 MH101514
 - NIMH K01 MH079130
 - NICHD R01 HD083881
- Book royalty:
 - The Guilford Press

Autism Spectrum Disorder (ASD)

- Core symptoms
 - Impairment in social interaction and communication
 - Restricted interests and repetitive behavior
- Associated features
 - Cognitive impairment
 - Deficits in adaptive functioning
 - Anxiety
 - Disruptive behavior problems

Anxiety in ASD

- Excessive fearfulness
- Changes in routines and social situations
- Can be related to core ASD symptoms
- Co-occurring anxiety disorders may be present
- Social anxiety may be difficult to diagnose
- Contributes to impairment in functioning



Cognitive-Behavior Therapy for Anxiety

CBT is a well-established intervention for anxiety in children without autism.

Key components: education, emotion regulation, and exposure and response prevention.

Short-term duration, 8 to 16 weekly sessions.

Treatment is conducted with the child and includes parent involvement.



Is CBT helpful for anxiety in ASD?

REVIEW ARTICLE

Cognitive-Behavioral Therapy for Anxiety in Children With High-Functioning Autism: A Meta-analysis

AUTHORS: Denis G. Sukhodolsky, PhD, Michael H. Bloch, MD, MS, Kaitlyn E. Panza, BA, and Brian Reichow, PhD

Yale Child Study Center, Yale University, New Haven, Connecticut

KEY WORDS

autism spectrum disorder, cognitive-behavior therapy, anxiety, children, adolescents, randomized controlled trial, meta-analysis

ABBREVIATIONS

ADIS-C—Anxiety Disorders Interview Schedule—Child Version

ADIS-P—Anxiety Disorders Interview Schedule—Parent Version

ASD—autism spectrum disorder

CASI—Child and Adolescent Symptom Inventory—4 ASD Anxiety Scale

CBT—cognitive-behavior therapy

ES—effect size

OCD—obsessive-compulsive disorder

PARS—Pediatric Anxiety Rating Scale

RCMAS—Revised Children's Manifest Anxiety Scale

SCAS—Spence Children's Anxiety Scale

TAU—treatment as usual

Dr Sukhodolsky contributed to the development of the review protocol, made decisions about eligibility, drafted the full review, and revised the manuscript; Dr Bloch contributed to the development of the review protocol, extracted and analyzed the data, and reviewed the manuscript; Ms Panza made decisions about eligibility, extracted and analyzed the data, and reviewed the manuscript; Dr Reichow contributed to the development of the review protocol, made decisions about eligibility, extracted and analyzed the data, and drafted the full review, and all authors approved the final manuscript as submitted.

This trial has been registered with PROSPERO (<http://www.crd.york.ac.uk/prospero/>) (identifier CRD42012002722).

www.pediatrics.org/cgi/doi/10.1542/peds.2013-1193

doi:10.1542/peds.2013-1193

Accepted for publication Aug 27, 2013

Address correspondence to Denis G. Sukhodolsky, PhD, Yale Child

abstract



BACKGROUND: Anxiety is a common and impairing problem in children and adolescents with autism spectrum disorder (ASD). There is emerging evidence that cognitive-behavioral therapy (CBT) could reduce anxiety in children with high-functioning ASD.

OBJECTIVE: To systematically review the evidence of using CBT to treat anxiety in children and adolescents with ASD. Methods for this review were registered with PROSPERO (CRD42012002722).

METHODS: We included randomized controlled trials published in English in peer-reviewed journals comparing CBT with another treatment, no treatment control, or waitlist control. Two authors independently screened 396 records obtained from database searches and hand searched relevant journals. Two authors independently extracted and reconciled all data used in analyses from study reports.

RESULTS: Eight studies involving 469 participants (252 treatment, 217 comparison) met our inclusion criteria and were included in meta-analyses. Overall effect sizes for clinician- and parent-rated outcome measures of anxiety across all studies were $d = 1.19$ and $d = 1.21$, respectively. Five studies that included child self-report yielded an average $d = 0.68$ across self-reported anxiety.

CONCLUSIONS: Parent ratings and clinician ratings of anxiety are sensitive to detecting treatment change with CBT for anxiety relative to waitlist and treatment-as-usual control conditions in children with high-functioning ASD. Clinical studies are needed to evaluate CBT for anxiety against attention control conditions in samples of children with ASD that are well characterized with regard to ASD diagnosis and co-occurring anxiety symptoms. *Pediatrics* 2013;132:e1341–e1350

Main Findings:

- 8 randomized controlled studies of CBT for anxiety were located.
- CBT was superior to waitlist on parent and clinician-rated anxiety.
- Effect sizes were 1.19 for parent ratings, 1.21 for clinician ratings and 0.68 for child self-report.

Neural Mechanisms of CBT for anxiety in ASD

Subjects:

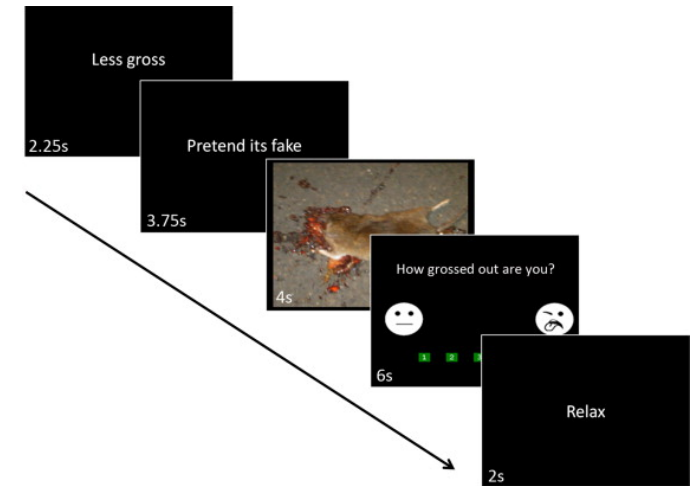
- 10 children with ASD and anxiety (3 girls, 7 boys),
- Age range from 10 to 13 years old
- Full Scale IQ ranged from 79 to 122
- Score ≥ 19 on the child symptom inventory anxiety scale
- 4 unmedicated and 6 on stable medication

Treatment:

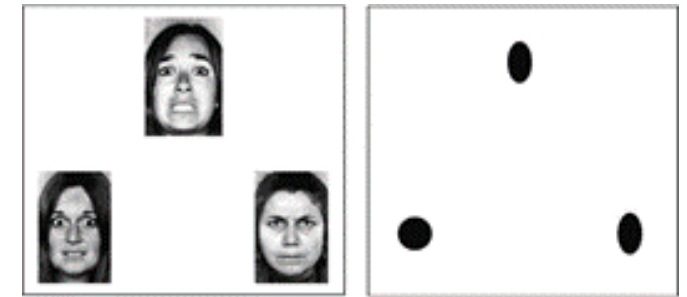
- 12-15 sessions of CBT for anxiety (Woods et al, 2009)

Outcomes:

- Clinician-rated Pediatric Anxiety Rating Scale (PARS)
- fMRI with emotion regulation and face perception tasks



Pitskel et al, Dev Cogn Neurosci, 2014



Hariri et al, Neuroreport, 2000

Exposure and response prevention

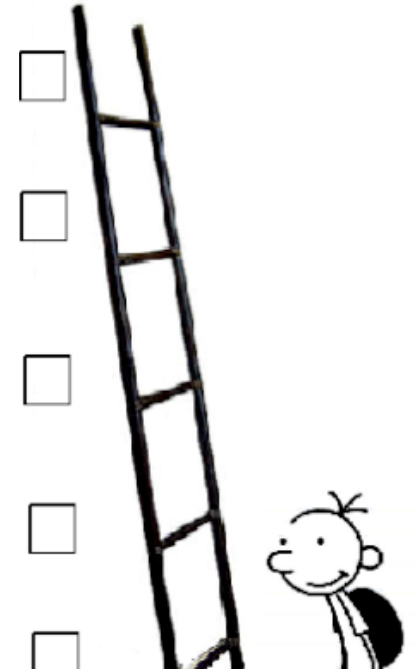
Social fears:

“Being rejected or offended in front of other children”

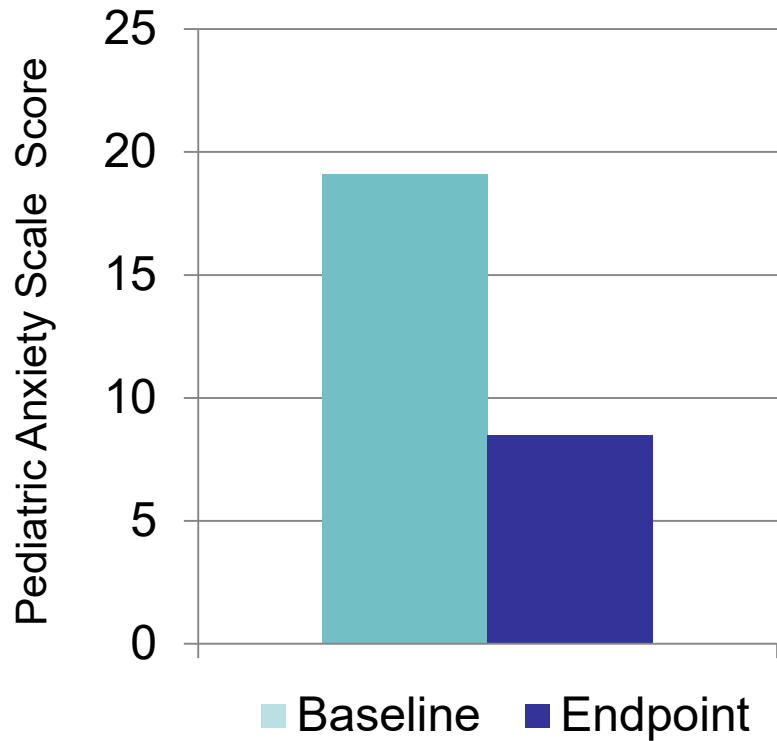
“I feel I will be embarrassed somehow...”

Exposure hierarchy:

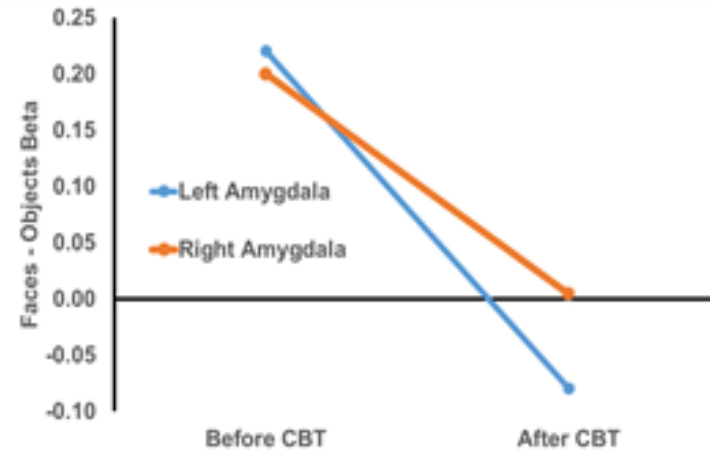
- Arrive to school 5 minutes before the first class.
- Say hi to one kid in the morning.
- Sit next to 7th grade children in the morning meeting.
- Participate in a group project at school.
- Spend at least 10 minutes in the lunch room.



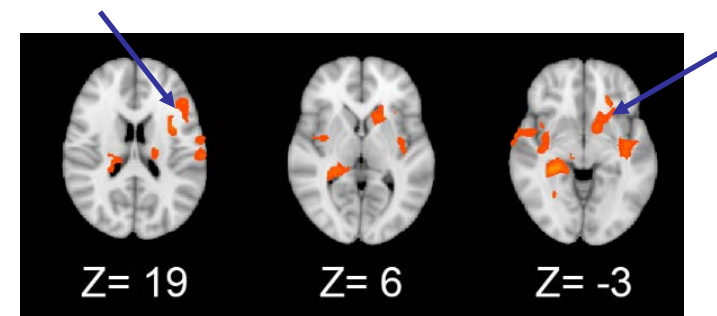
Biomarkers of CBT for anxiety in ASD



55% reduction in anxiety



a) Reduced amygdala activation to faces vs. objects

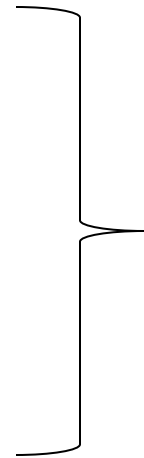


b) Increased activity in dorsolateral prefrontal cortex and anterior cingulate during emotion regulation

Disruptive behaviors in ASD

- Anger outbursts
- Tantrums
- Aggression
- Self-injury

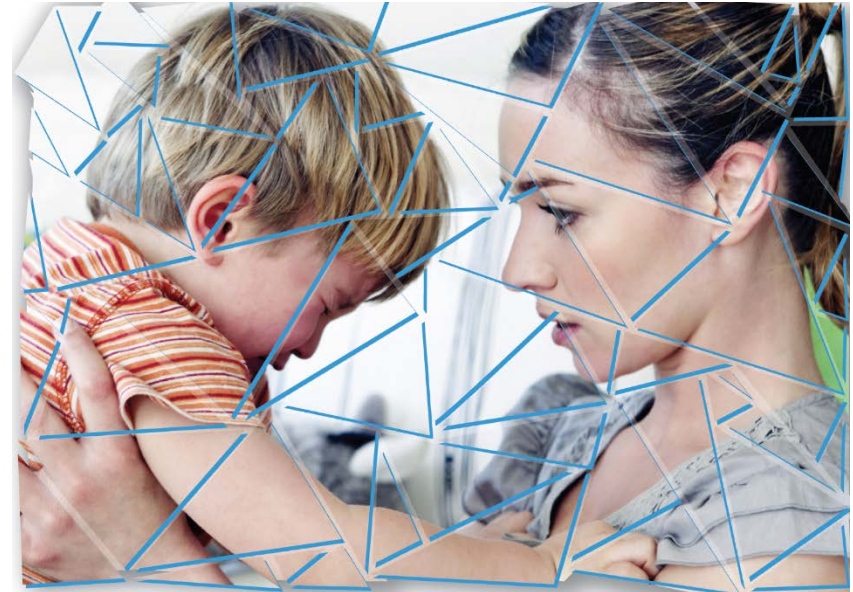
- Noncompliance



Irritability

Impact of disruptive behavior

- Impairing in their own right
- Burden on family
- Interference with education
- Risk of injury
- Risk of property damage
- Derail development



Role of core ASD symptoms

- Rigidity (*frustrated by minor changes in routines*)
- Failure to recognize social context (*cursing at school principal*)
- Unusual triggers of frustration (*rule violation*)
- Communication (*perseverating on topics of no interest to others*)
- Deficits in social domain (*frustration with social situations*)
- Exaggerated nonverbal expressions (*loud voice*)



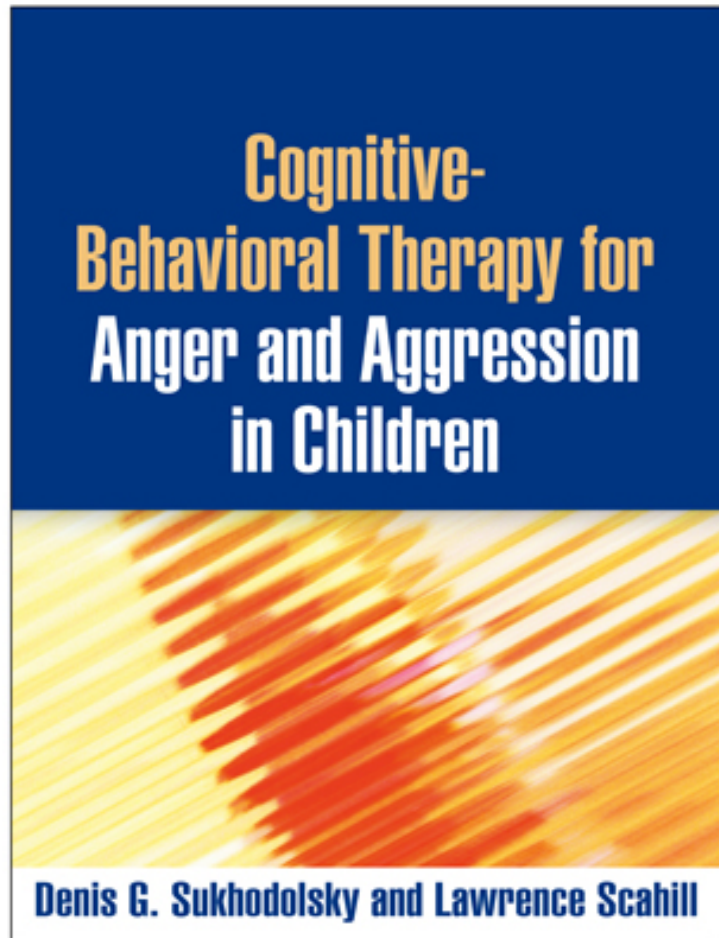
Primary treatment options for irritability

- Applied Behavior Analysis (ABA)
- Psychopharmacology
- Parent Management Training (PMT)

Irritability in adolescents with ASD

- Disruptive behavior is likely to persist in adolescence.
- Medication has side effects.
- Parent training and ABA programs don't make use of the cognitive and communication skills of adolescents with higher-functioning ASD.
- Why not try CBT for typically developing children with disruptive behavior disorders?

CBT for irritability in typical development



Treatment format:

- 12 weekly sessions
- Dedicated parent component
- Optional school consultation

Treatment goals:

- To reduce frequency and intensity of anger outbursts and aggression
- To increase skills for managing frustration
- To improve social problem-solving

Education about anger episode

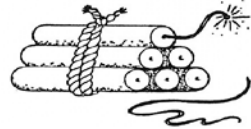
HANDOUT 1

Elements of an Anger Episode

Triggers



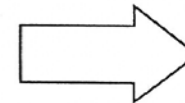
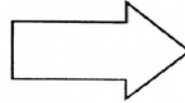
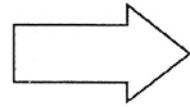
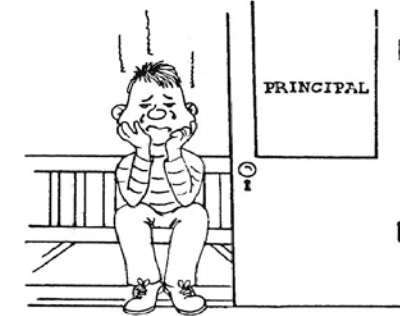
Feelings



Actions



Outcomes



Thoughts



Rules

Identify triggers of anger

HANDOUT 2

Anger Triggers

Common Anger Triggers

Your Anger Triggers



1. _____



2. _____



3. _____




4. _____



5. _____

Use calming thoughts

One child in our program reported that a kid in his music class was throwing paper clips at him when the teacher was not looking, and he made a list of thoughts that went through his mind:

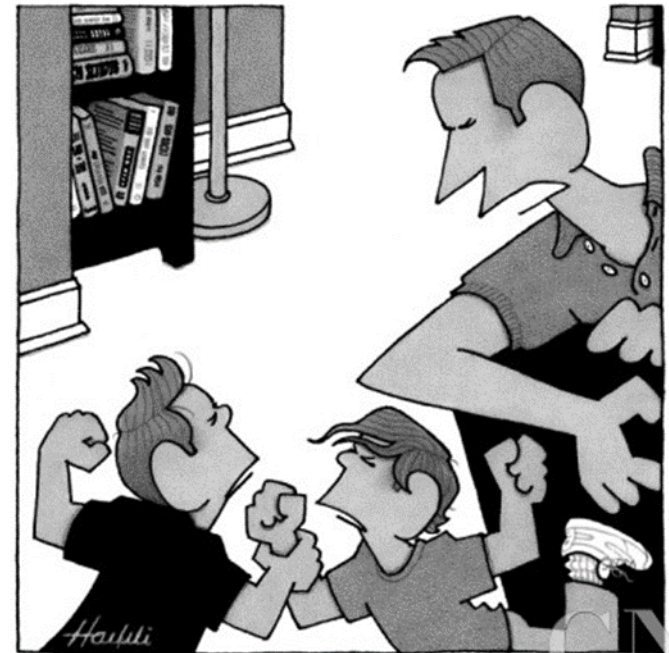
- *I'm gonna punch him in the face*
- *Human nature is driving me crazy*
- *It's not worth getting all worked up about* 
- *He is an idiot; I don't need to stoop to his level*



Parent training

Core principles:

- The ABC of behavior
- Differential attention
- Effective commands
- Praise and rewards
- Daily routines

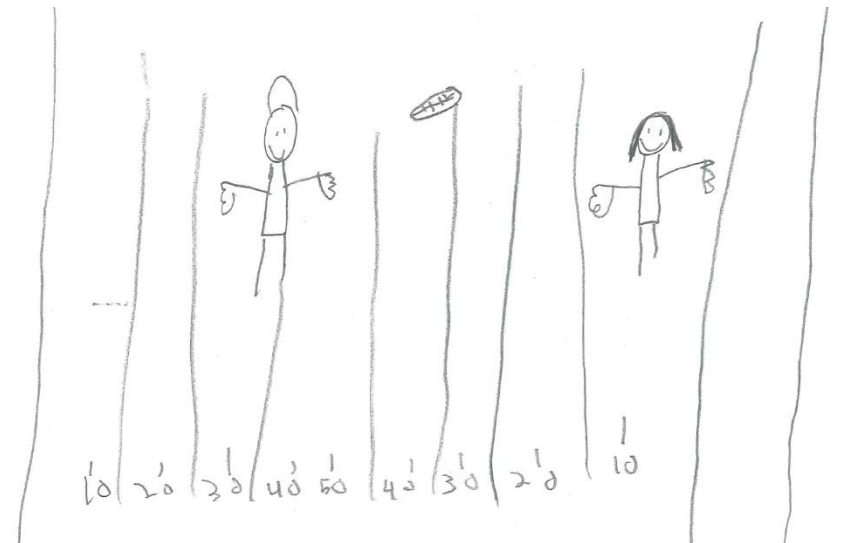


"Listen up and listen up good, 'cause I'm only going to say this a million times."

COIN
COLLECTION

Rewards

- Look for positive opposites
- “Catch them being good”
- Enjoyable interaction
- Child guided play
- Verbal praise
- Nonverbal praise
- Sticker charts
- Token economies



Behavior therapy for irritability in ASD

Subjects:

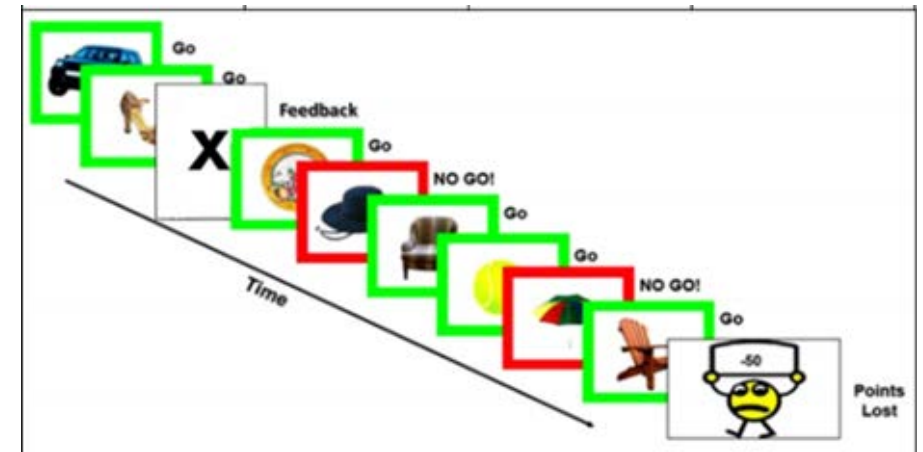
- 9 adolescents (1 girl, 8 boys),
- Age range 11 to 16 years old
- Full Scale IQ ranged from 80 to 112, mean 95
- Score ≥ 16 on irritability scale of Aberrant Behavior Checklist
- 2 unmedicated and 7 on stable medication

Treatment:

12-15 sessions of CBT for irritability

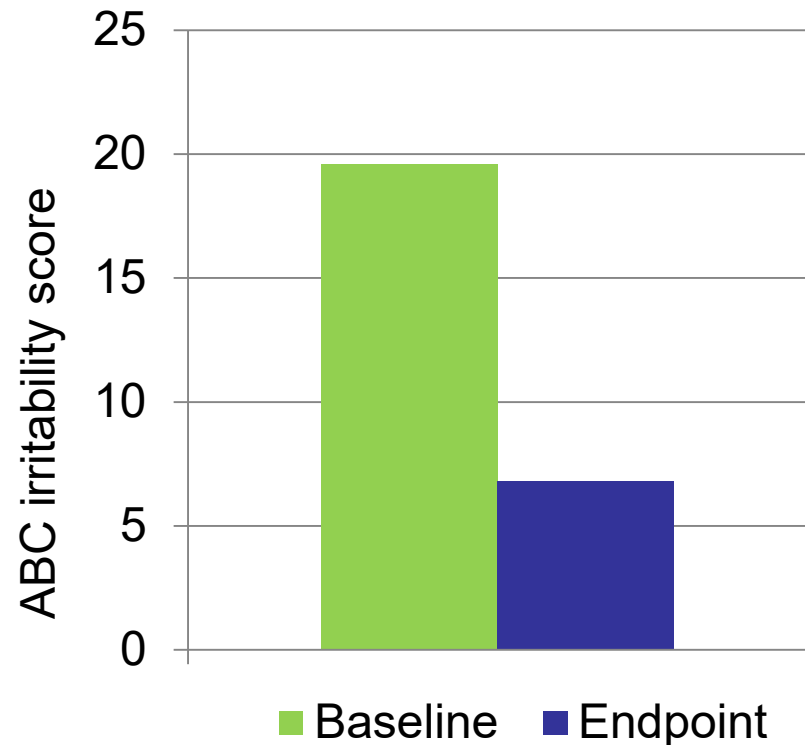
Outcomes:

- Parent-rated ABC irritability scale
- fMRI with frustration-induction GoNoGo task

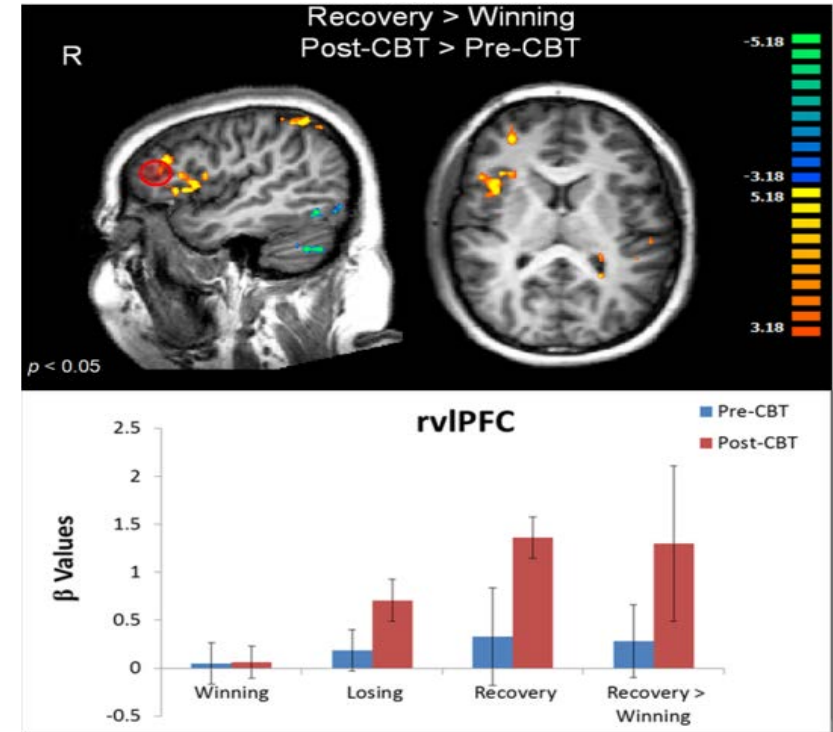


Perlman & Pelphrey, 2010

Behavior therapy for irritability in ASD



65% reduction in ABC irritability score



Increase in prefrontal activity after CBT

RDoC study of CBT for aggression/irritability

- Subjects are randomly assigned to 12 sessions of CBT or 12 sessions of Supportive Psychotherapy (SPT).
- Children perform neurocognitive tasks of emotion regulation and face perception during fMRI scanning and EEG recording at baseline and endpoint.
- Primary clinical outcomes are the Modified Overt Aggression Scale and the CGI-Improvement scale administered by an independent evaluator.

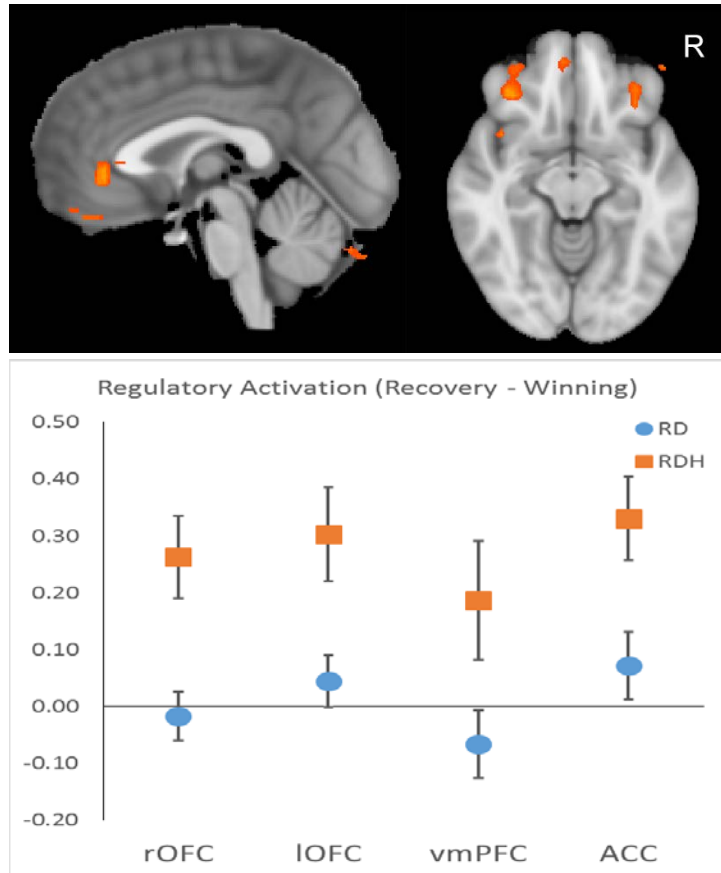


Frustration-induction GoNoGo

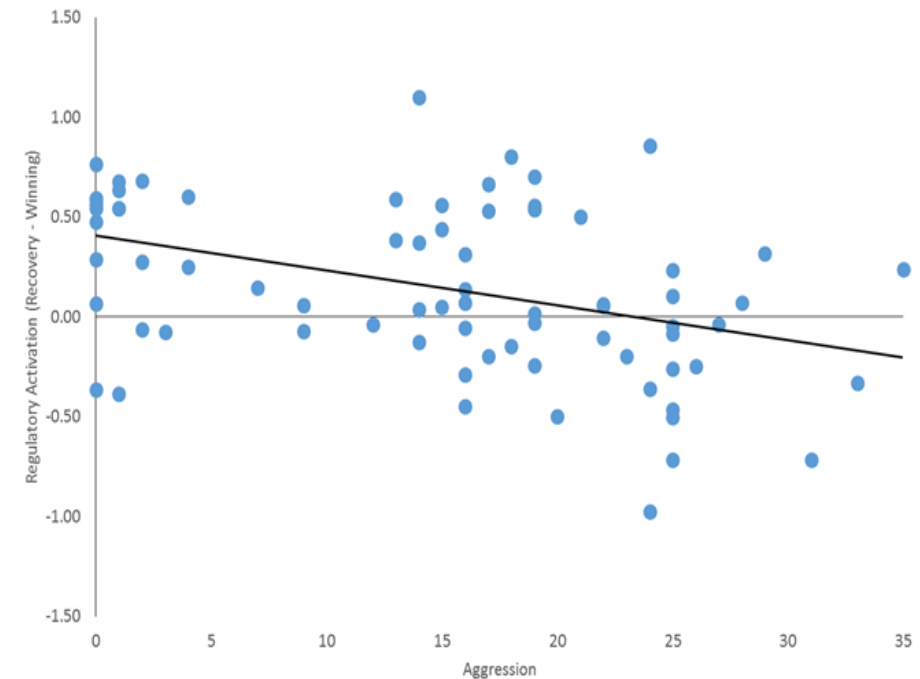
3 conditions: Winning – Losing – Recovery



Neural targets of behavior therapy for irritability



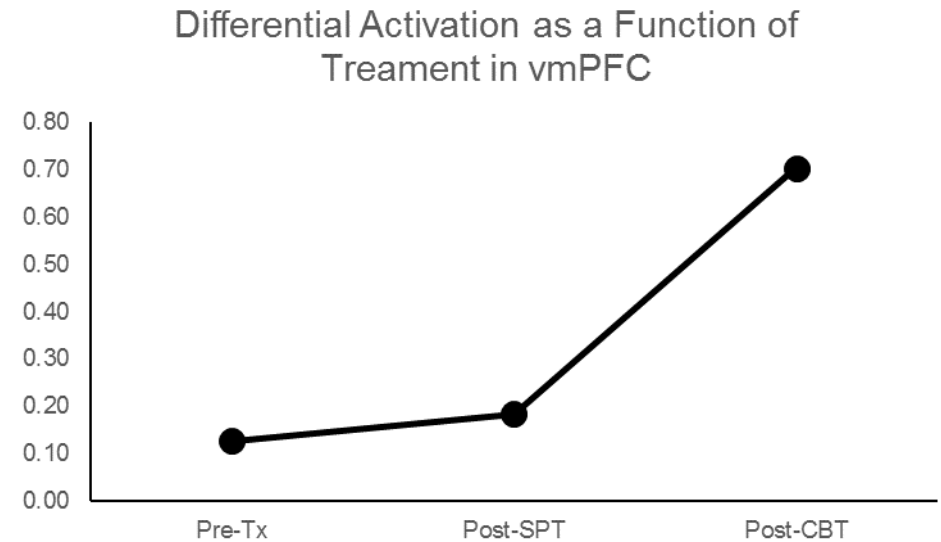
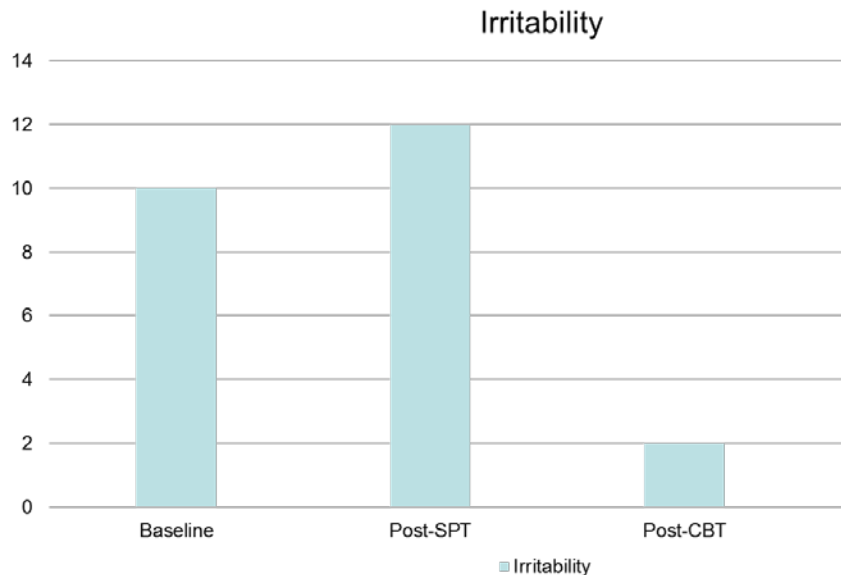
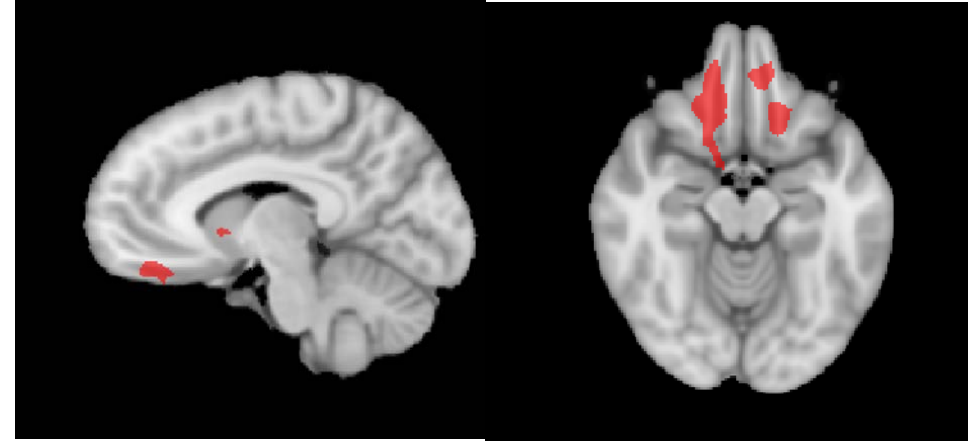
Reduced prefrontal activity in 50 children with aggressive behavior relative to 25 community controls without aggression



There is a negative correlation $r = -0.37$ of aggression with the ventromedial prefrontal cortex activation in the emotion-regulation contrast of the frustration-induction GoNoGo task.

Case illustration

Ruby, a 15 year-old girl with ASD, participated in a randomized trial of CBT for irritability. She presented with daily anger outbursts that lasted up to 10-15 minutes and with longer, multiple-hour outbursts 1-2 times per month. Anger was often triggered when routines were impeded or when another person disagreed with an idea that she found highly important. Specific behaviors included standing in one spot, tensing all her muscles, crying, screaming, and making verbal threats.



Modification of behavioral interventions for ASD

- Treatment is focused on target problems
- Flexible implementation
- Includes functional assessment
- Enhanced parent component
- Separate module to address unique social/communication deficits and restricted interests
- School visit or telephone consultation

Summary

- Cognitive-behavioral therapy can be useful for anxiety in children with ASD.
- More work is needed to develop and test effective behavioral interventions for irritability in adolescents with ASD.
- Research Domain Criteria (RDoC) approach offers a valuable framework for studying common and unique characteristics of children with ASD relative to children with other forms of developmental psychopathology.
- Understanding the neural targets of CBT will enable improvement of existing treatments and the development of novel interventions for children with ASD.

Acknowledgements

- Emilie Bertschinger
- Megan Tudor
- Karim Ibrahim
- Heidi Grantz
- Justyna Piasecka
- Kara Bagot
- Pamela Ventola
- Julie Wolf
- Lily Katsovich
- Aida Bikic
- Spencer McCauley
- Kevin Pelphrey
- Brent Vander Wyk
- Michael Crowley
- Jeff Eilbott
- Jia Wu
- Daniel Yang
- Danielle Bolling
- Erin MacDonnell
- Devon Oosting
- Megan Braconnier
- Sebiha Abdullahi

Thank you

Meeting of the IACC

Afternoon Agenda

2:45 **Panel on Challenging Behaviors in
Autism - Continued**

3:05 **Repetitive Inflexible Behaviors:
Measurement, Mechanism & Intervention**

James Bodfish, Ph.D.

Professor of Hearing & Speech Sciences

Professor, Psychiatry

Vanderbilt Brain Institute

Vanderbilt University School
of Medicine

Repetitive inflexible behaviors: *Measurement, mechanism, & intervention*



Jim Bodfish
Vanderbilt University



Interagency Autism Coordinating Committee

July 2016

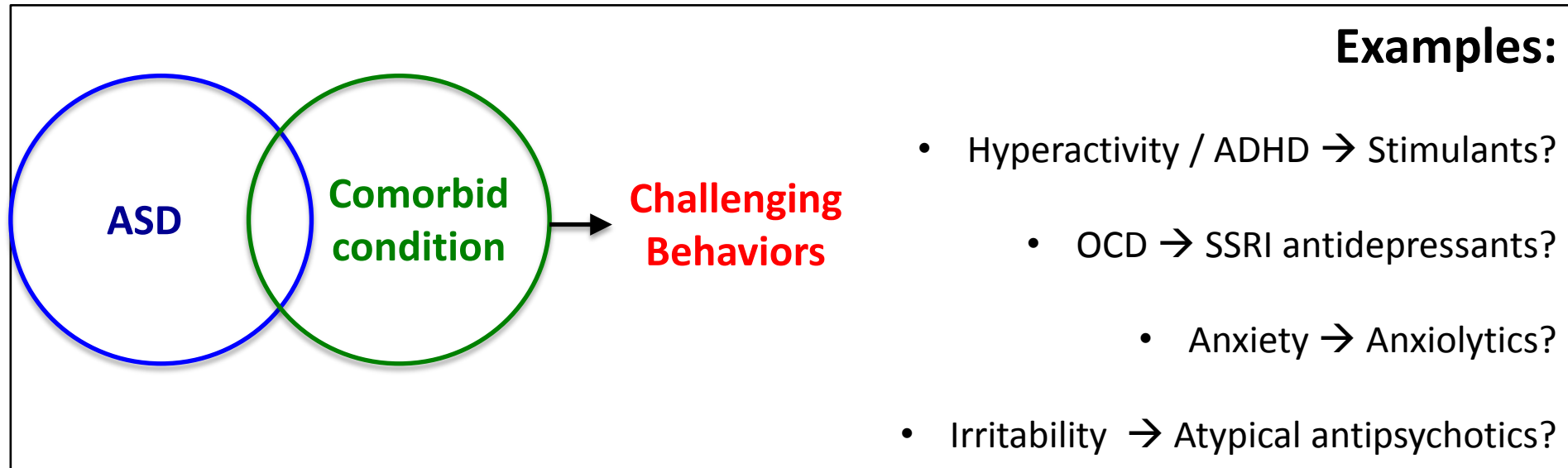
Autism & challenging behaviors

- Many forms:
 - “Meltdowns”
 - Wandering
 - Self-injury
 - Aggression
 - Food refusal
 - Mouthing / Pica
 - Overactivity
 - etc



- Common in ASD
- Can persist into adolescence, adulthood
- Stressful for families
- Limit quality of life
- Can diminish response to other forms of intervention
- Increase cost of care

Comorbidity Model

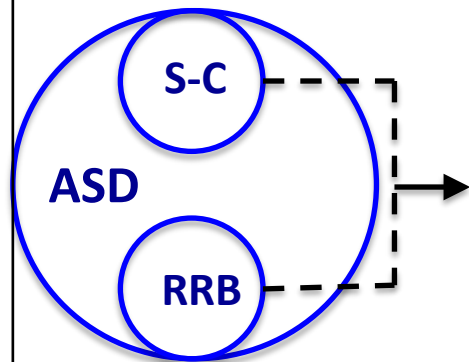


Limitations:

- Diagnostic challenges
- Limited efficacy of most existing medications
- Costly
- High prevalence of drug prescriptions & polypharmacy
- Limited applicability as early intervention

Core Features Model

Examples:



Challenging Behaviors

- Social isolation → anxiety / depression?
- Communication limitations → frustration / aggression?
- Lack of predictability → stress / self-injury?

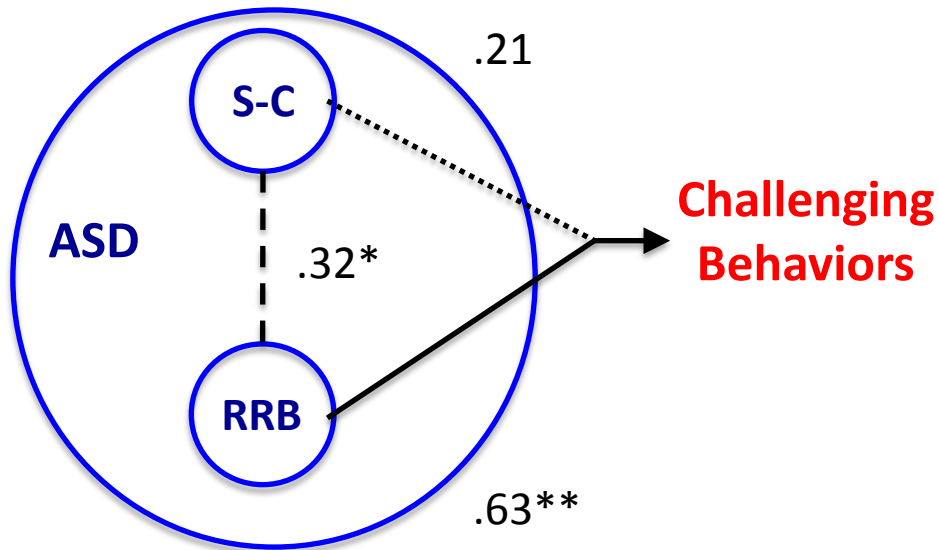
Limitations:

- Largely untested

Potential advantages:

- Parsimony & face validity
- Framework for novel intervention development
 - Developmental-behavioral
 - Pharmacologic
 - Early intervention

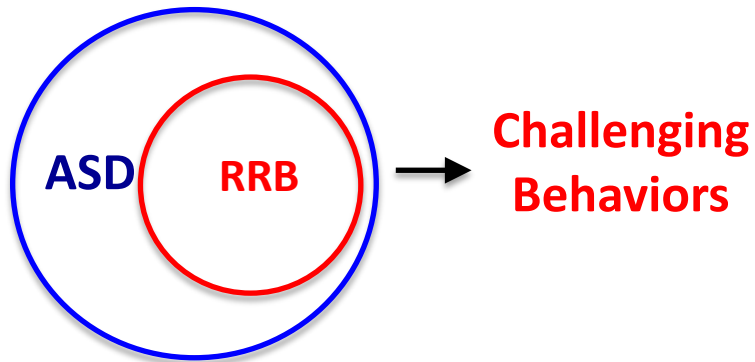
Testing the Core Features Model



Method:

- N = 221 ASD (ADOS, ADI)
 - 2 – 20 years
 - 61% verbal
 - 79% male
- Parent reported:
 - Social deficits (SRS)
 - Repetitive behaviors (RBSR)
 - Problem behaviors (ABC)

Repetitive behavior & challenging behaviors



Examples:

- When routine changes → meltdowns?
- To get access to special interest → wandering?
 - Sensory overload → self-injury?

Approach

Samples (children; adult)

- ASD: HFA, LFA
- Comparison: OCD, Depression, Social Anxiety
- Control: Typically developing

Methods

- Psychometric measures
- Biomarkers

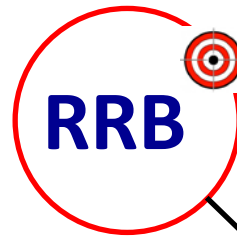
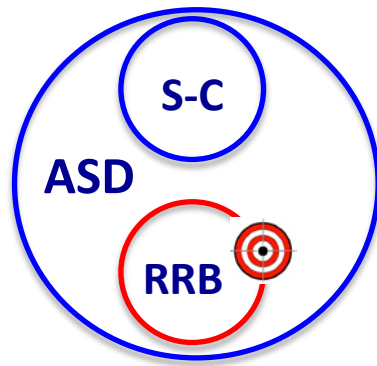
NIMH R01 Repetitive behaviors in ASD (Bodfish, Dichter)

NIMH K08 Autism & Depression (Gotham)

Autism Speaks Predoctoral Fellowship (Unruh)

NICHD R01 Behavioral Inflexibility – Outcome measurement (Boyd, Lecavalier, Bodfish)

From targeted phenotype to targeted treatment?



- How to measure phenotype?
- What is a plausible mechanism?
- How can this phenotype be modeled pre-clinically?
- How would this inform treatment development?

Research core services:

NICHD U54 UNC IDDRC (Piven)

NICHD U54 Vanderbilt IDDRC (Dykens)

Evidence for three subtypes of repetitive behavior in autism that differ in familiarity and association with other symptoms

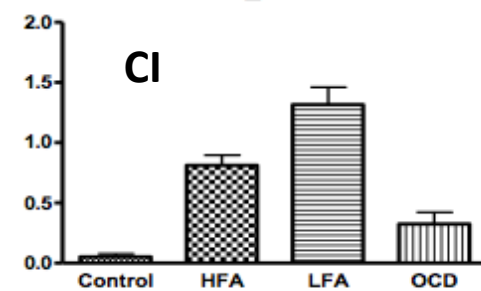
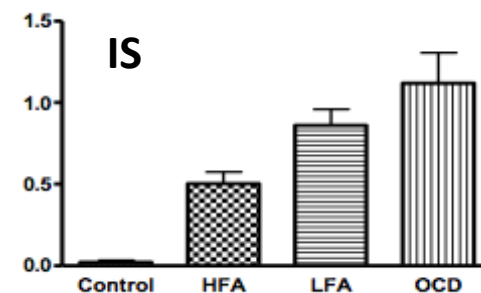
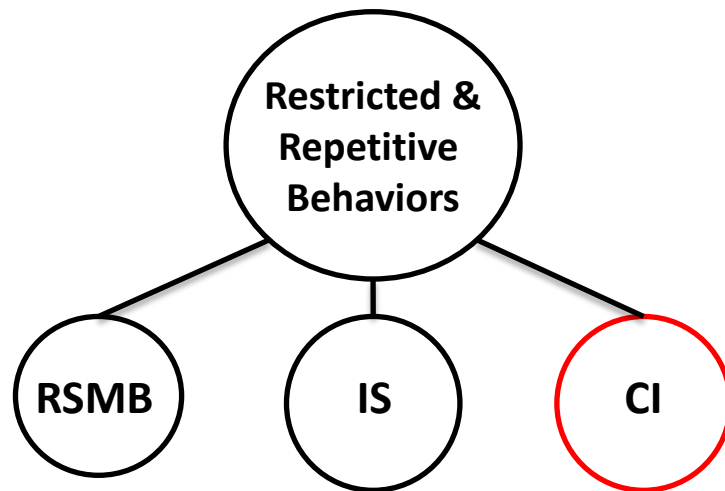
Kristen S.L. Lam,¹ James W. Bodfish,^{1,2} and Joseph Piven^{1,2}

¹Neurodevelopmental Disorders Research Center, University of North Carolina – Chapel Hill, NC, USA;

²Department of Psychiatry, University of North Carolina – Chapel Hill, NC, USA

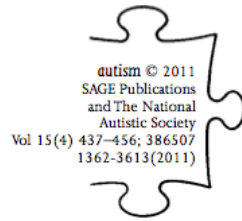
Table 2 Results of principal components analysis and exploratory factor analysis ($N = 316$)

ADI-R RRB items	PCA		
	RMB	IS	CI
70 Circumscribed interests	-.39	.23	.47
71 Unusual preoccupations	.09	.18	.67
72 Repetitive use of objects	.73	.01	.26
73 Difficulties with minor changes in personal routine & environment	.03	.75	.28
74 Resistance to trivial changes in environment	.03	.80	-.14
75 Compulsions/rituals	-.01	.67	.08
76 Unusual attachments to objects	.25	-.11	.60
81 Hand & finger mannerisms	.74	.05	-.15
84 Other complex mannerisms or stereotyped body movements	.77	.01	.09
85 Rocking	.37	.32	-.29



- Repetitive sensory motor behavior (RSMB)
- Insistence on sameness (IS)
- Circumscribed interests (CI)
 - Unique to ASD (ASD > OCD)
 - Not associated with social impairment or IQ
 - Heritable (sib-sib correlation)
 - Common (74% of ASD)

Phenomenology and measurement of circumscribed interests in autism spectrum disorders



LAUREN M. TURNER-BROWN Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, USA

KRISTEN S.L. LAM Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, USA

TIA N. HOLTZCLAW Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, USA

GABRIEL S. DICHTER Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, USA

JAMES W. BODFISH Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, USA

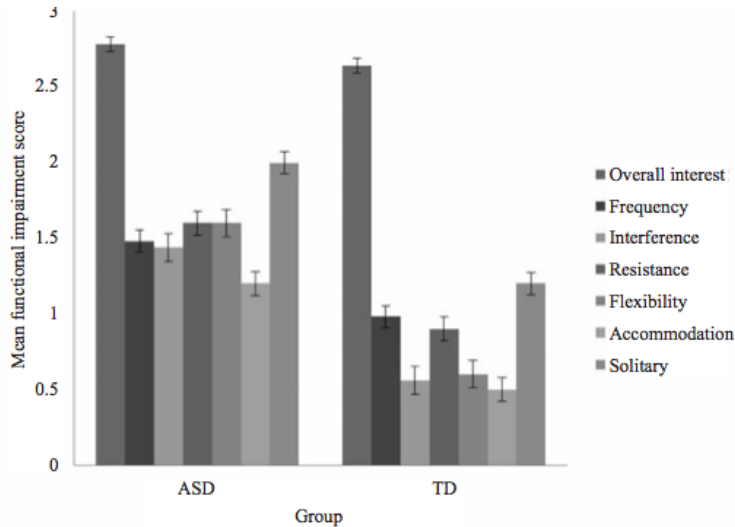
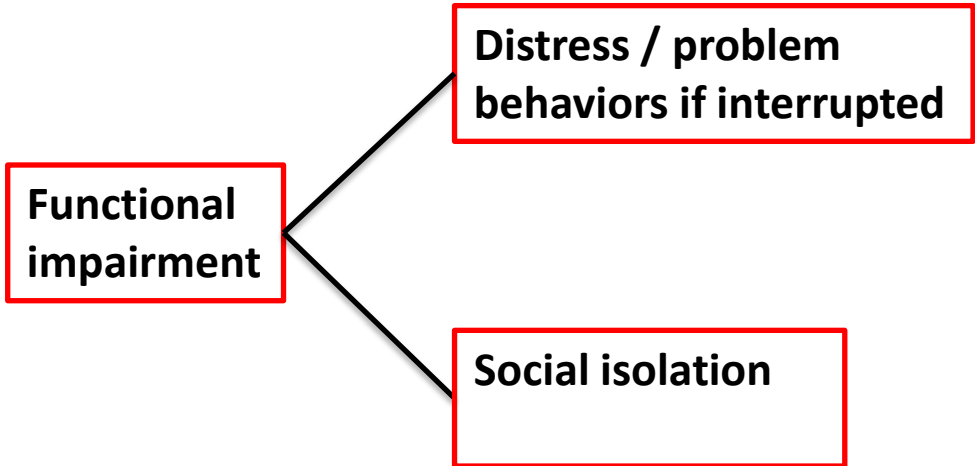


Table 3 The Interview for Repetitive Behavior: Circumscribed Interests in the ASD sample (n = 57)

Category	Percentage of children	Examples of circumscribed interests
Physics	56% (n = 30)	Cranes/mechanical function Preoccupied with trains Legos
Attachments	48% (n = 26)	Carries a piece of cloth with him everywhere Attached to stuffed dog Jewelry – upset when taken off
Taxonomy (primarily collecting)	33% (n = 18)	Pokemon card collecting Interest in dinosaurs – collects them Collects rocks
Television	30% (n = 16)	Cartoon network Star Wars movies Sponge Bob
Biology	17% (n = 9)	Birds of prey Evolution/dinosaurs Cougars
Facts	13% (n = 7)	Prints Wikipedia articles about videogame characters Details about actors/directors of movies Confederate wars
Mathematics	11% (n = 6)	N. 22 is his number; 22nd day of month is his day Interest in dates. Numbers – clocks, calendars, exit numbers Reads math theory books
Sensory	8% (n = 4)	Stares at anything in motion Fascination with running water for hours Watches washing machine spin



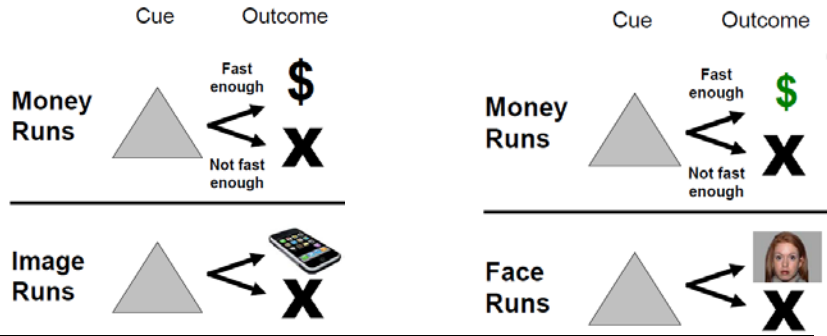
The family perspective:

- **“Parents report that preoccupations, and intense unusual interests are among the most difficult symptoms of autism to deal with on a day-to-day basis.”**

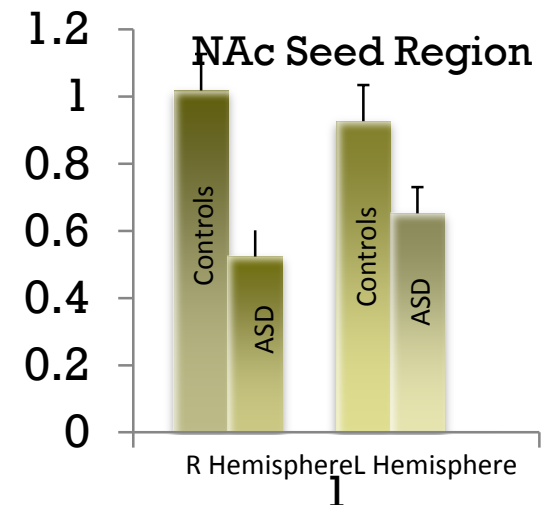
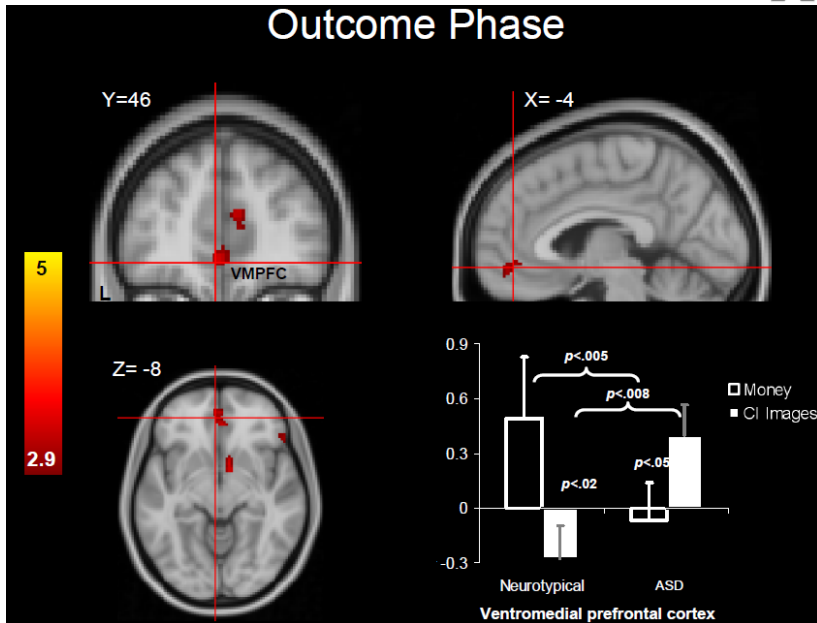
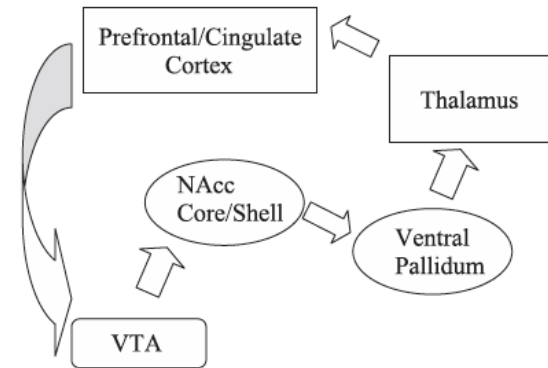
(South, Ozonoff, & McMahon, 2005)

Mechanism? Social & Nonsocial Reward in ASD

fMRI – Incentive Delay Paradigm



Functional connectivity of reward circuitry



Increased BOLD signal to nonsocial rewards + Decreased frontal → striatal connectivity

An addiction-like model of circumscribed interests & challenging behavior in ASD

- Addictions (substances, activities) evolve by “co-opting” adaptive reward processes; enhanced experience of reward (pleasure) leads to ever-growing anticipation of the experience and inability of consumption to meet anticipated outcome.
- Application to ASD?
 - Nonsocial interests develop early and increase in intensity with age
 - Intense interest narrows range of potential other experiences (including social experience)
 - “Motivational toxicity” – as idiosyncratic interest grows, interests in other areas may diminish
 - Mood and behavior problems may evolve as a reactions to interrupting intense interest (which can further restrict experiences).

Biomarker? Social & nonsocial visual exploration



- “Visual Exploration Task” (VET)
- Passive task
- 12 static arrays
 - Faces + Objects
- 10 seconds / array
- Feasible for infants / toddlers, minimally verbal

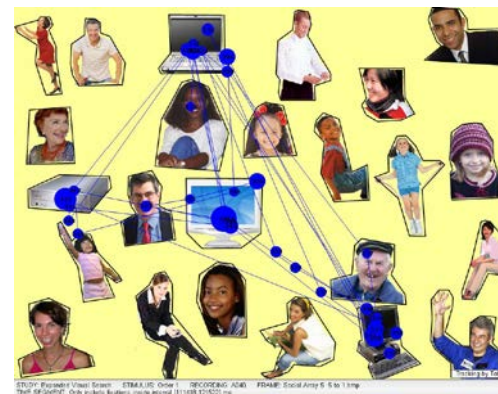
TYP example trial

ASD example trial

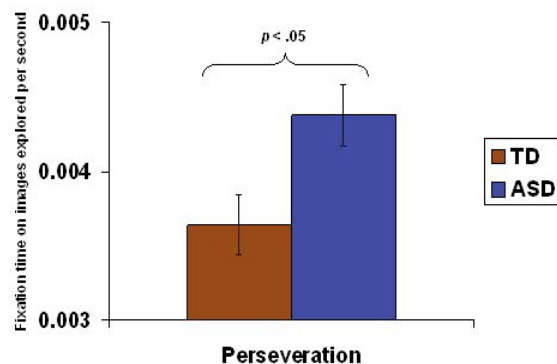
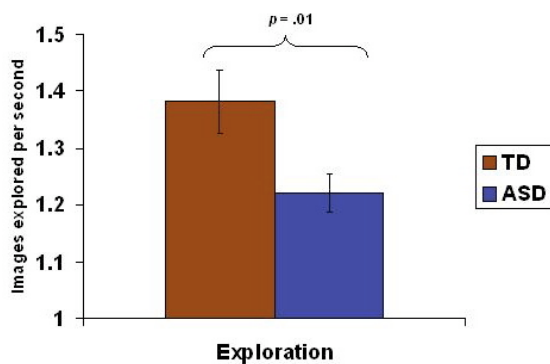
TYP



ASD



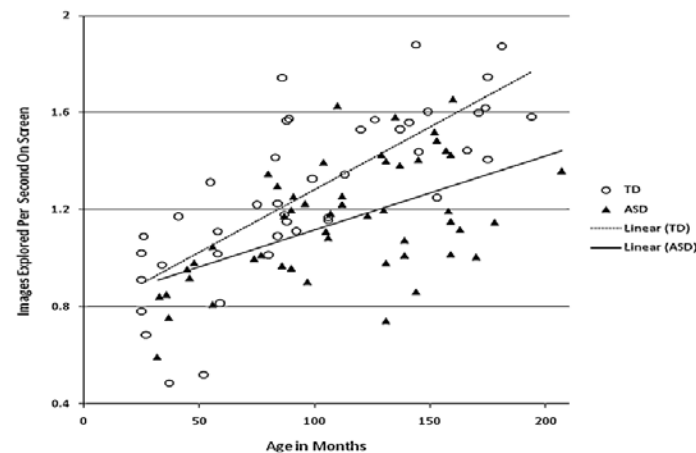
ASD explored fewer social images & perseverated more on nonsocial images:



Nonsocial bias increases with age in ASD:

Sasson et al., Autism Research 2008

Elison et al., JADD 2012

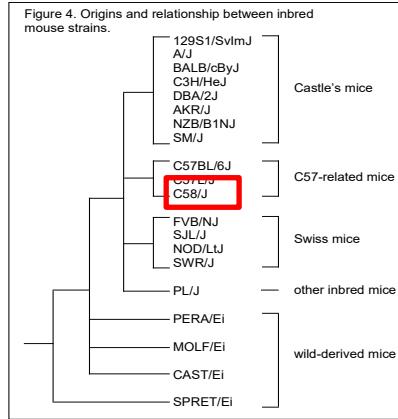


Preclinical model? Exploration / foraging is conserved across species

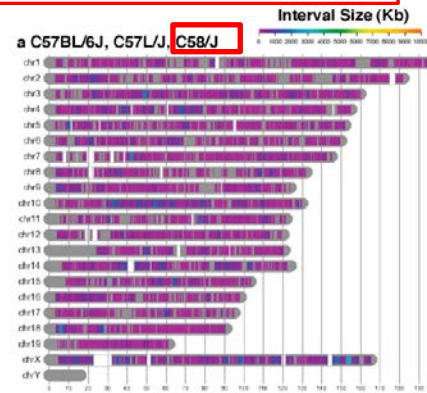
A. Behavioral assay



B. Screen ASD mouse models

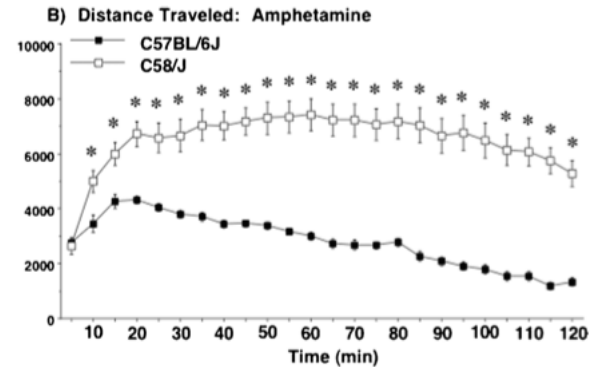
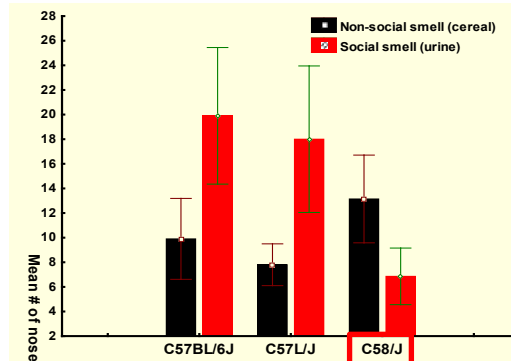


C. Genetic analysis



- CACNA1C
- CNTNAP2
- DISC1
- NRG2
- TPH2
- GABRA5
- GABRB1
- SLC6A4

D. Drug screening



Early intervention? Development of a family-implemented program



Treatment model:

- Begin: child's CI & family routines
- Goal: gradually broaden interests
 - tolerate delay, interruption of CI
 - try social contexts for CI
 - build new interests

Brian A. Boyd,¹ Cooper R. Woodard,² and James W. Bodfish^{3,4}



Feasibility of exposure response prevention to treat repetitive behaviors of children with autism and an intellectual disability: A brief report

Autism
0(0) 1-9
© The Author(s) 2011
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361311414066
aut.sagepub.com
SAGE

Brian A. Boyd
Division of Occupational Science and Occupational Therapy, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

Cooper R. Woodard
Grodan Center, Providence, Rhode Island, USA

James W. Bodfish
Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

J Autism Dev Disord
DOI 10.1007/s10803-010-1156-y

ORIGINAL PAPER

Effects of a Family-Implemented Treatment on the Repetitive Behaviors of Children with Autism

Brian A. Boyd · Stephen G. McDonough ·
Betty Rupp · Faraaz Khan · James W. Bodfish

Family Implemented Treatment for Behavioral Inflexibility (FIT-BI)

Developed by:
Brian Boyd
Stephen McDonough
Betty Rupp
James Bodfish



A Treatment Manual to Guide Therapist & Parent Implementation

Phenotype & measurement

Lauren-Turner Brown-UNC, Allison Whitten - Vanderbilt



Peripheral biomarker (eye-tracking)

Noah Sasson-UT Dallas, Jed Elison-U Minn, Kathryn Unruh- Vanderbilt



Reward circuitry (fMRI,fcMRI)

Gabriel Dichter-UNC, Tony Richey-Virginia Tech



Mouse model (behavioral genetics, pharmacology)

Sheryl Moy-UNC, Mark Lewis, U Fla, Robin Shafer-Vanderbilt



Early intervention

Brian Boyd-UNC, Cooper Woodard-Groden Ctr



NIMH

National Institute
of Mental Health

Adult ASD & Depression

Kaite Gotham - Vanderbilt



Meeting of the IACC

Afternoon Agenda

2:45

**Panel on Challenging Behaviors in
Autism - Continued**

3:25

Frank Symons, Ph.D.

Distinguished McKnight University
Professor, Department of Educational
Psychology

Associate Dean, Research & Policy, College
of Education & Human Development
University of Minnesota

3:45

Questions and Discussion

Severe self-injury in developmental disorders: *Sensory & immune findings from the periphery*

Frank Symons
University of Minnesota

Interagency Coordinating Committee for Autism
2016

Disclosures

None

Not an ASD expert

The Need

Good evening, my name is _____. I am typing on a phone, so excuse obvious typing issues. I am a mom to a 9 year old with autism. His repetitive head behaviors in toddler years grew into highly intense head punching a few years ago. The typography of his sibs has evolved and recently has gone back to chin and temple punching.

Your name came up a year ago and many things prevented me from reaching out to a complete stranger.

Fast forward to today and I find myself in a crisis. _____ was just released from _____ on Friday with an ng tube. He refuses to eat solids.....Unraveling this story is interesting, but insanity producing to us, parents. So now I have 2 major issues and depending on the day, he can be very physically aggressive too.

I could tell you so much more, but I reach out to you today in hopes you have ideas. The hospital was at a loss on how to support us as intense behavior issues are not their specialty and the pysch unit seemed really inappropriate for a young, autistic child with a new ng tube.

Parent Perspective

- Why?
- Help, please.

Scientific Puzzle & Clinical Paradox

- Why do some people with intellectual and developmental disabilities/disorders self-injure by almost any possible means without regard to the consequences? Actions that should normally be regulated by their outcome become 'out of control' among individuals with chronic self-injury.



Self-injury & ASD

- **Prevalence:** Estimates vary widely (8% - 72%)
 - Subgroups? (e.g. HFA vs. LFA)
- **Mechanisms:** unknown & understudied
 - We don't understand pathophysiology
- **Interventions:**
 - Established evidence base for behavioral interventions but ...
 - Evidence for more severe cases is limited particularly wrt maintenance
 - Biomedical intervention – no consistent evidence
 - Evidence-vacuum: sad/bad things happen (restraint, sedation, aversives...)
- **Cost / burden of care:** Significant
 - Society: NIH 1998 US estimate ... ~\$3 billion
 - Family: likely far exceeds impact of ASD alone
 - Person: significantly impacts quality of life

Self-injurious behavior (SIB): Some general conceptual models

- Developmental – Behavioral
 - Communication: SIB develops into a means of expressive communication in non/minimally verbal cases
- Psychological – Psychiatric
 - Linked to essentially all forms of comorbid psychiatric symptoms (irritability, anxiety, OCD, depression, hyperactivity)
- Neurological
 - **Sensory / Pain: common assumption is insensitivity to pain or increased pain threshold**

Self-injury & pain: Insights from animal models & pain-related neurologic conditions

- Self-injury is the standard behavioral marker of altered nociception and pain in animal models that involve damage to peripheral nerves.
- Consistent with human cases (e.g. sensory neuropathies) where damage to peripheral nerves can produce:
 - altered sensation at peripheral sites (focal → generalized)
 - “hyperalgesia” (increased sensitivity to pain) & “allodynia”(non-noxious stimuli perceived as painful)
 - self-injury targeted to site where sensation has been altered
- Inflammatory & immune-related mechanisms play a role in the development of altered nociception and neuropathic pain in both animal models and clinical conditions.
- By way of analogy think about scratch → itch or related sensory experiences you have had (e.g., sunburn)
- In all the clinical instances and preclinical models, it seems that SIB is driven by increased sensory sensitivity, NOT decreased sensitivity.

Our Overall Approach & Focus

- **Pain markers in persons with cognitive / communication deficits with and without SIB**
 - Sensory testing + pain biomarkers
 - **SIB associated with hyperalgesia: increased sensory sensitivity + altered autonomic & immune activity**

Collaborators

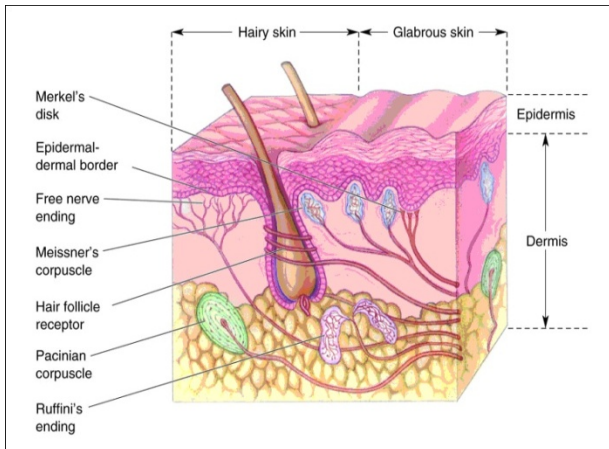
Supported, in part, by: NIH/NICHD (R,K) 35682;44763
McKnight Land-Grant Professorship, UMN Futures

- **James W. Bodfish**
 - Vanderbilt University
- **Lynn Breau**
 - Glenrose Hospital
- **G. Allen Finley**
- **Patrick J. McGrath**
 - Dalhousie University
 - IWK Health Center
- **Laura Stone**
 - McGill University
- **Tim Oberlander**
- **Ken Craig**
 - University of British Columbia
- **Raymond Tervo**
 - Mayo Clinic
- **Elizabeth Gilles**
 - Children’s Hospitals St. Paul
- **Jennifer McComas**
- **William Kennedy**
- **Gwen Wendelschafer-Crabb**
- **Angela Panoskaltsis-Mortari**
- **Adele Dimian**
- **Breanne Byiers**
- **John Hoch**
- **Tim Moore**
 - University of Minnesota

Self-Injury - saliva, skin, and sensory mechanisms

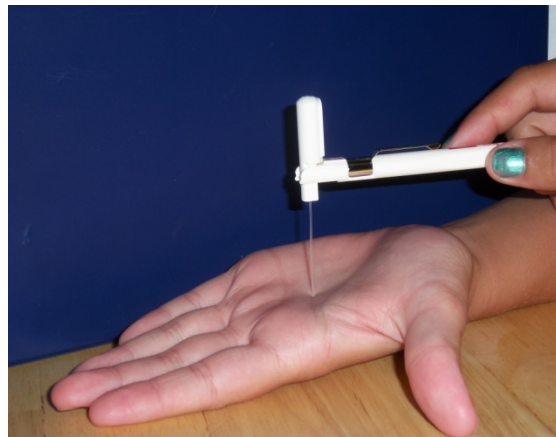
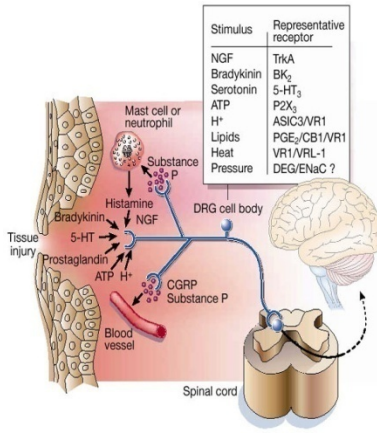


Saliva:
Non-invasive window;
vulnerable population



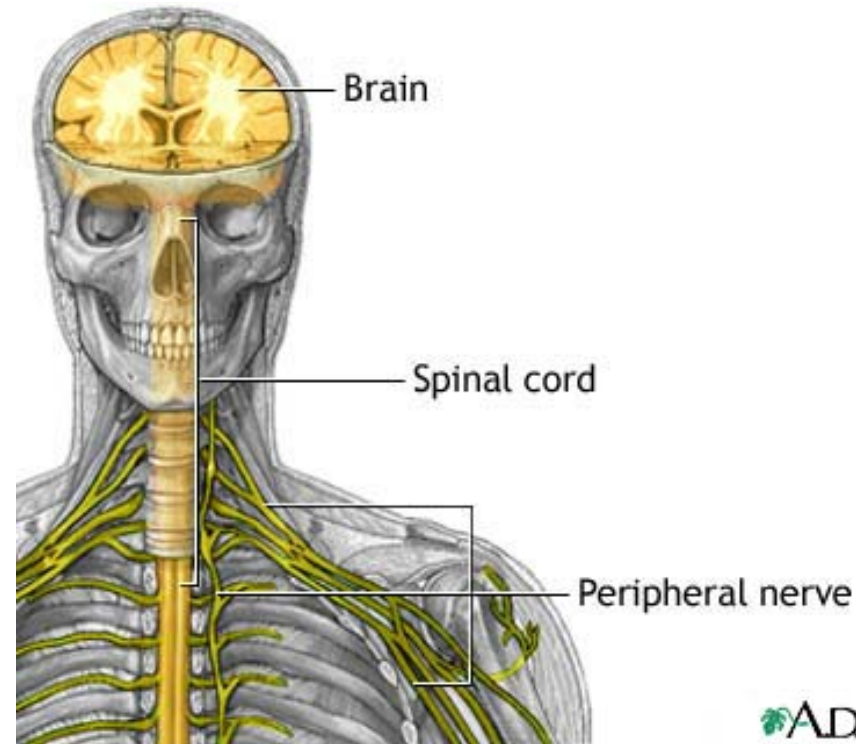
Skin:
Where behavior meets biology

Axons from skin	A α	A β	A δ	C
Axons from muscles	Group I	II	III	IV
Diameter (μ m)	15-20	6-12	1-5	0.2-1.5
Speed (m/sec)	80-120	35-75	5-30	0.5-2
Sensory receptors	Proprioceptors of skeletal muscle	Mechanoreceptors of skin	Pain, temperature	Temperature, pain, itch

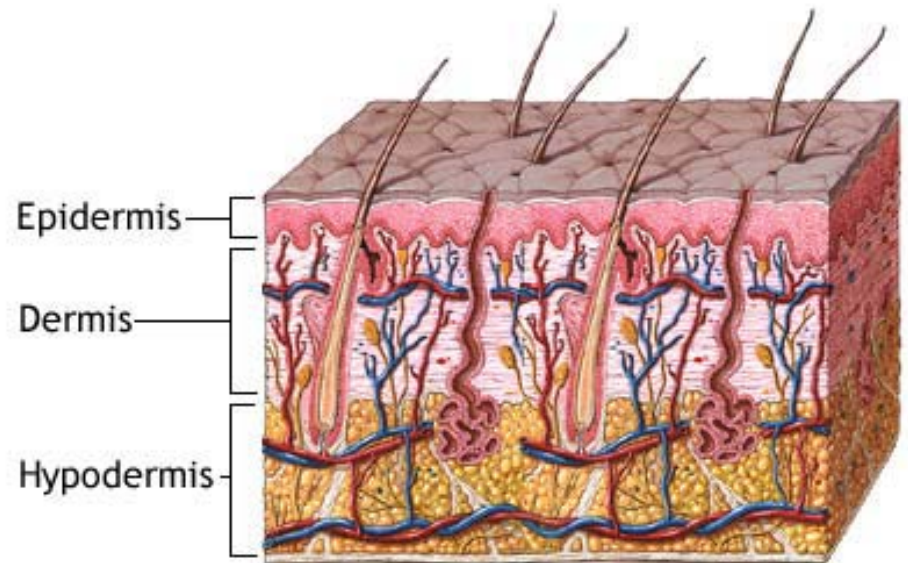


Sensory Mechanisms:
Thresholds – intact, altered?

Nervous System & Skin

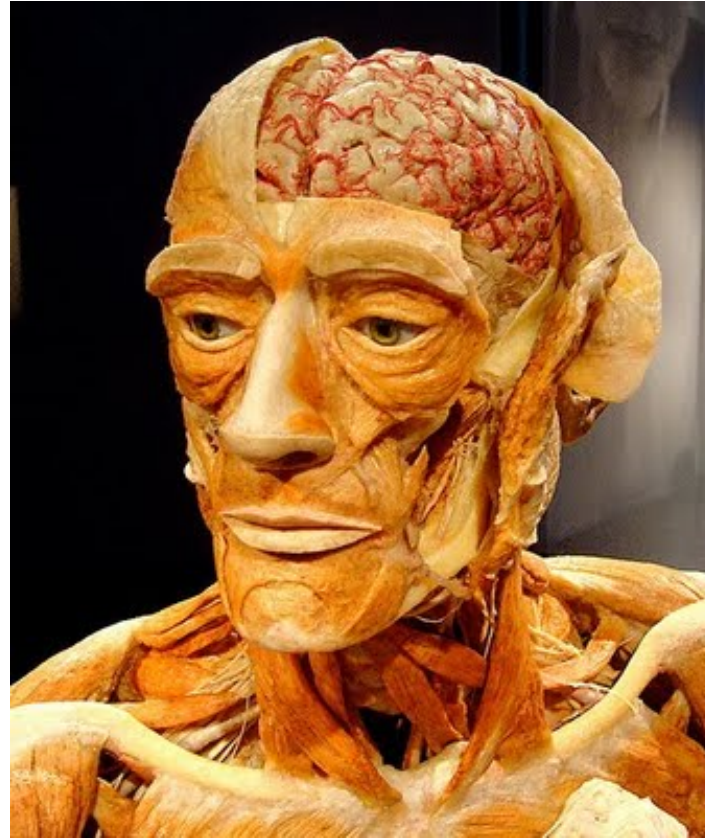


ADAM.



ADAM.

How Does Experience Get Under the Skin?



Direct Route

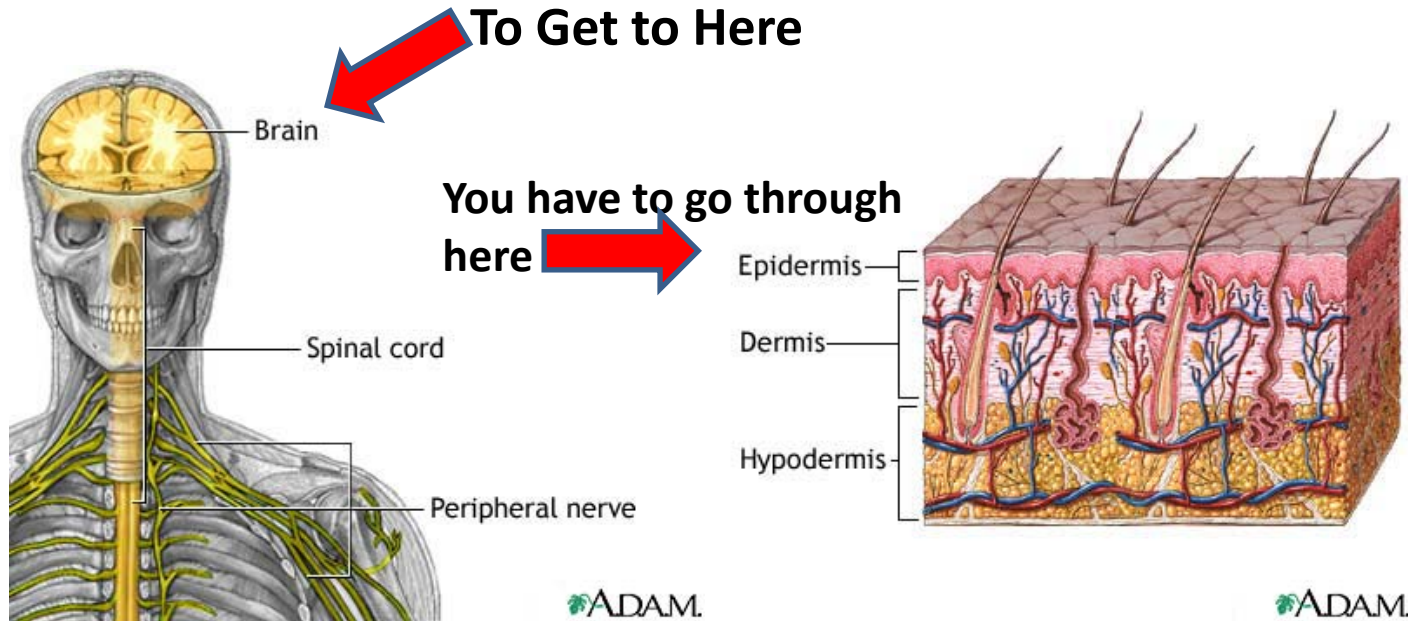


“Whoa! *That* was a good one! Try it, Hobbs — just poke his brain right where my finger is.”

Experience gets 'under the skin'through the skin

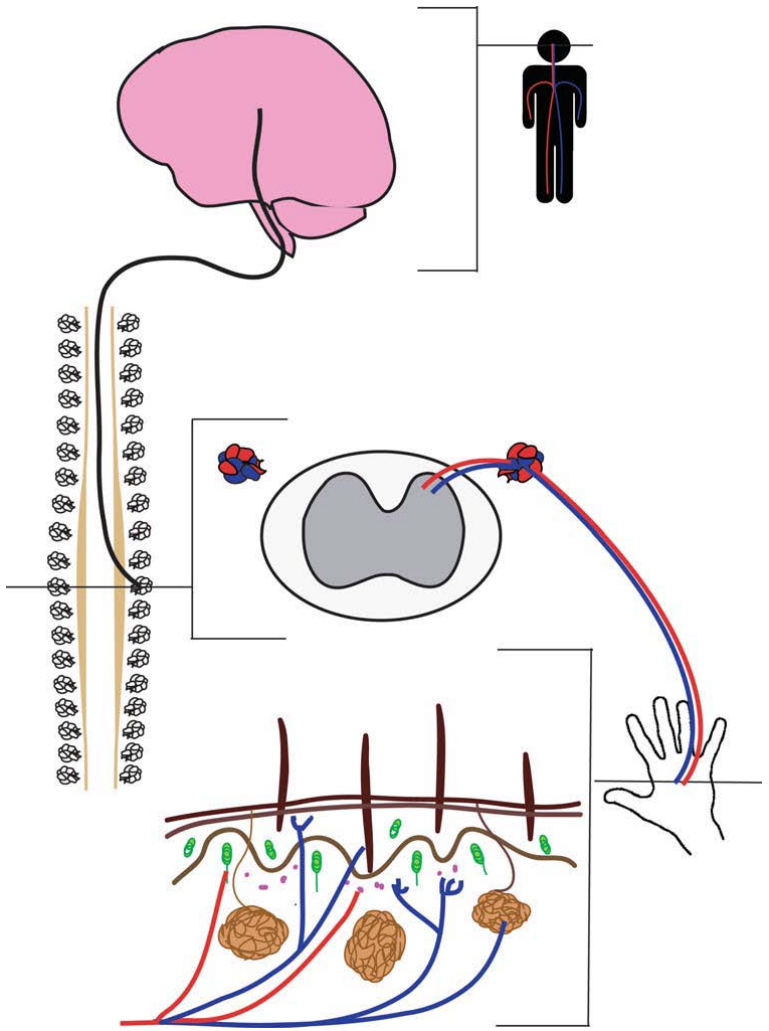


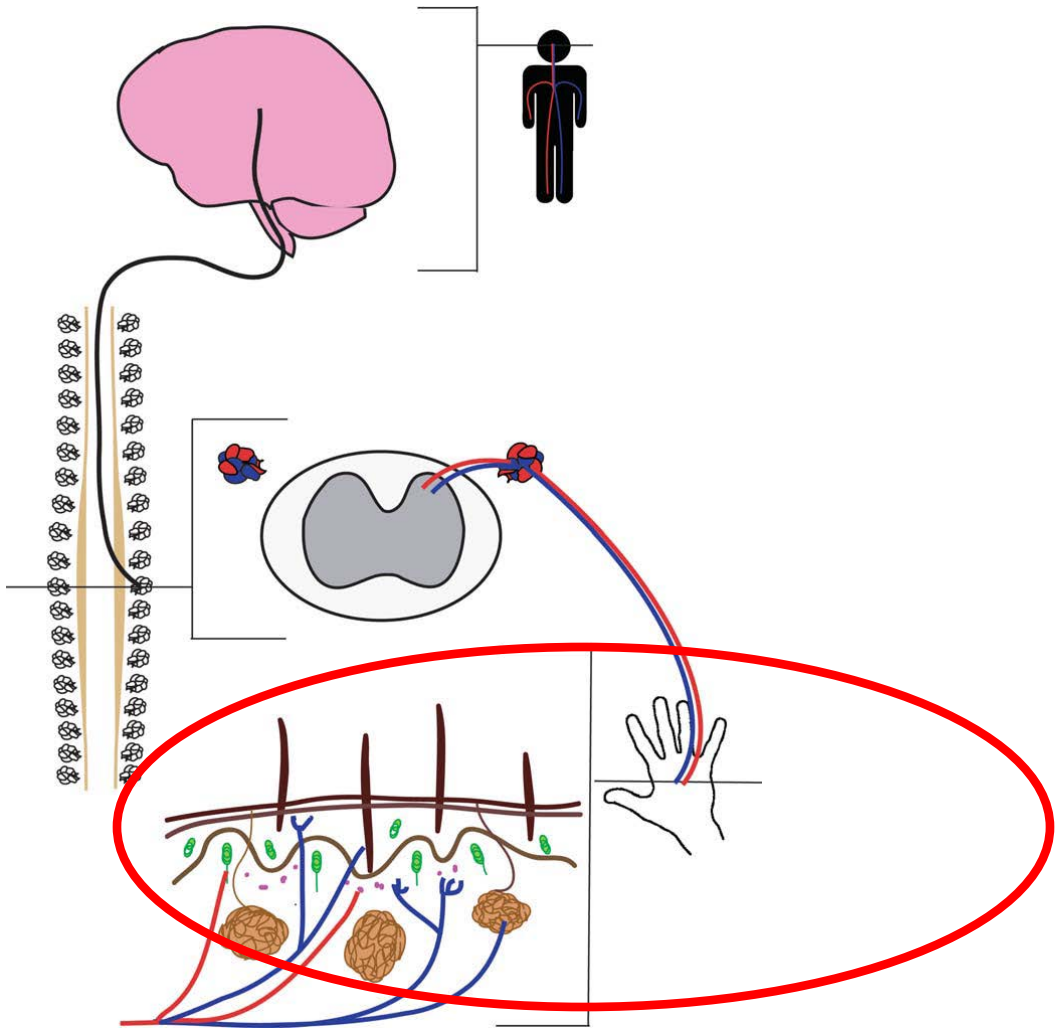
Peripheral Nervous System & Skin ...for touch/tactile and pain/nociception...



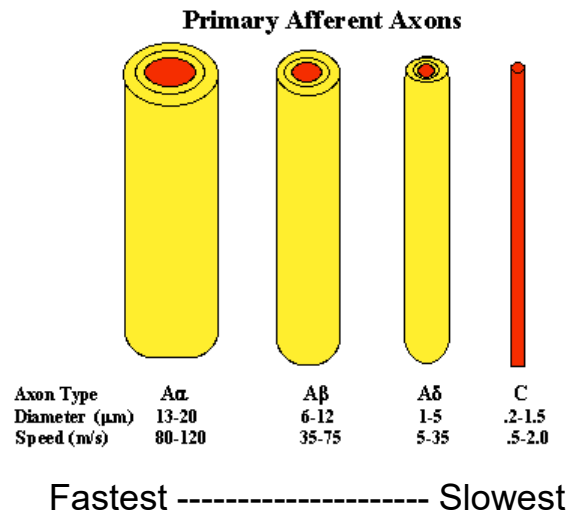
The skin is our body's largest sensory organ – comprised, in part, by an array of different specialized nerve endings.....







Background – Sensory Fibers



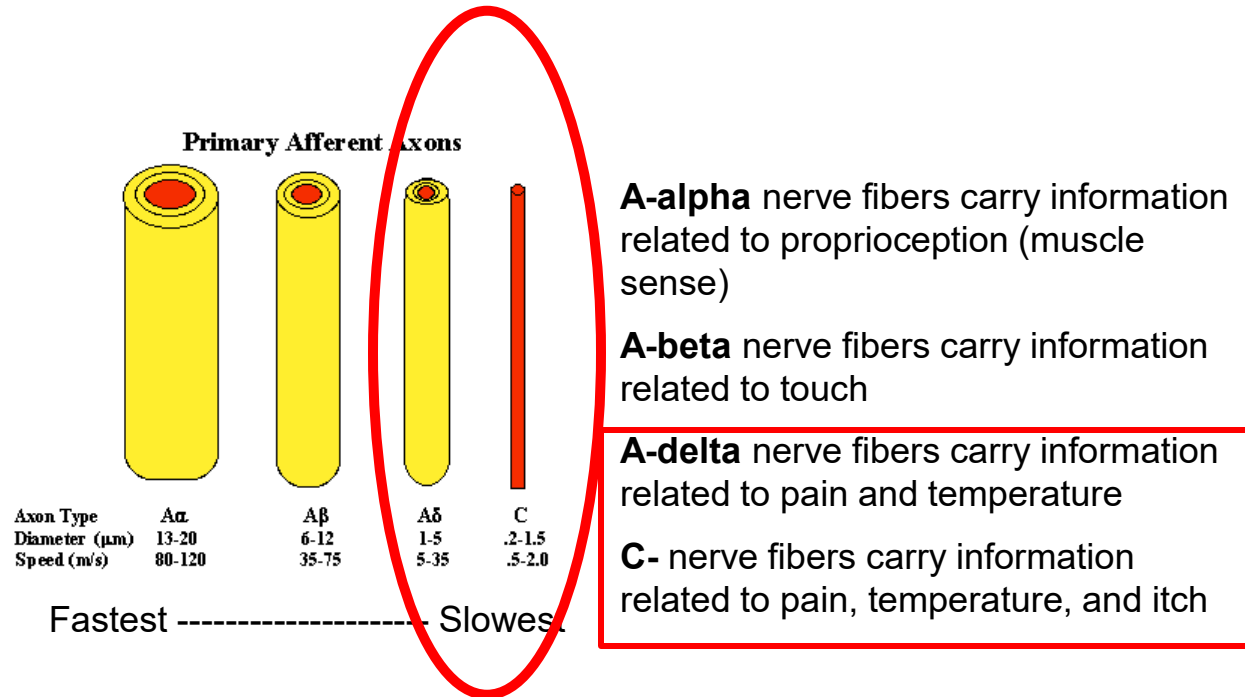
A-alpha nerve fibers carry information related to proprioception (muscle sense)

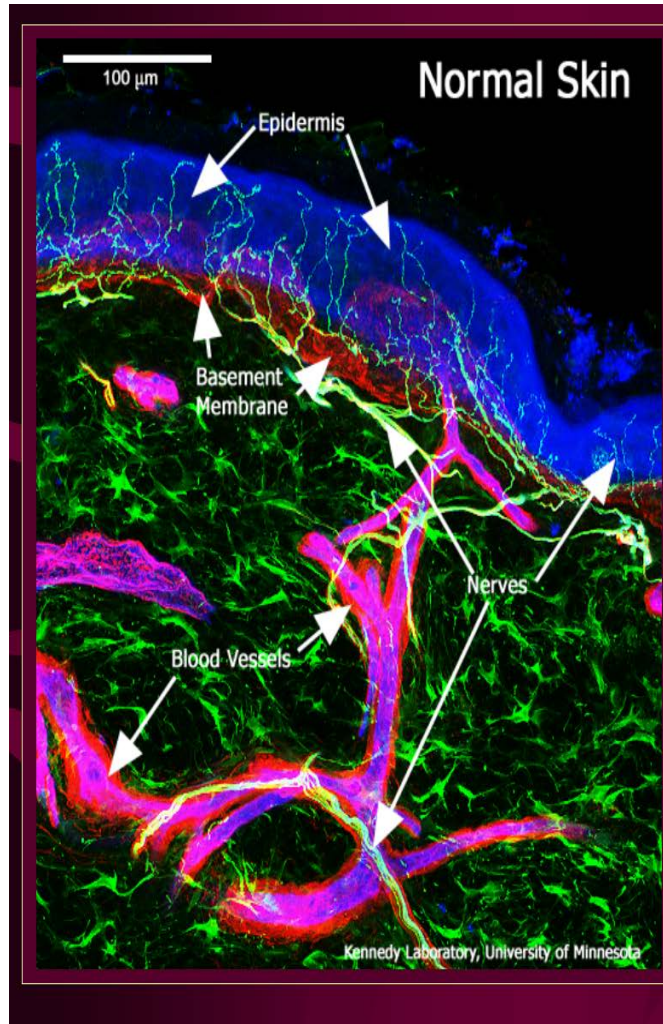
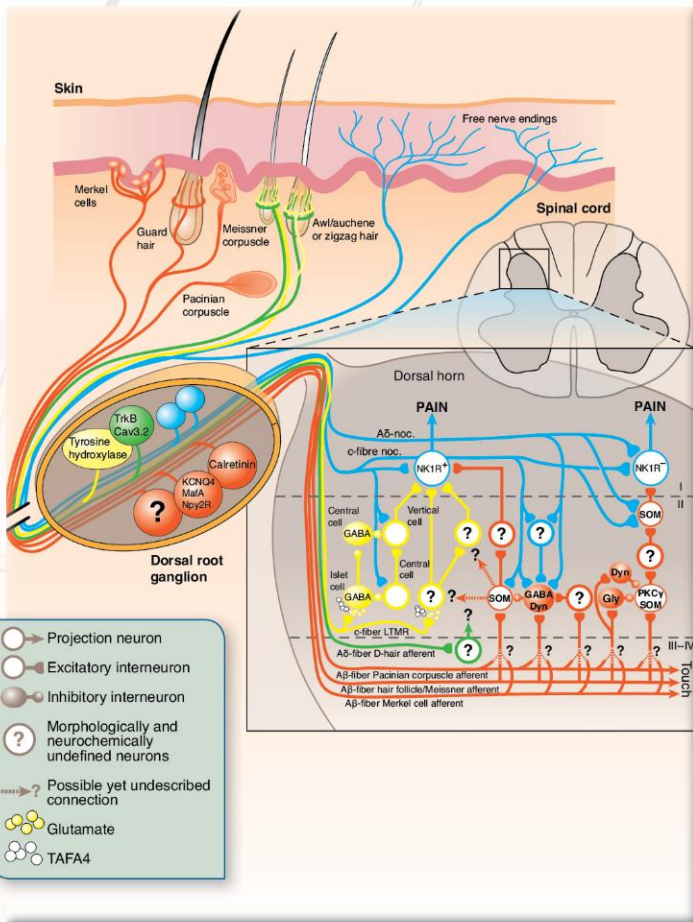
A-beta nerve fibers carry information related to touch

A-delta nerve fibers carry information related to pain and temperature

C- nerve fibers carry information related to pain, temperature, and itch

Background – Sensory Fibers





Normal Skin

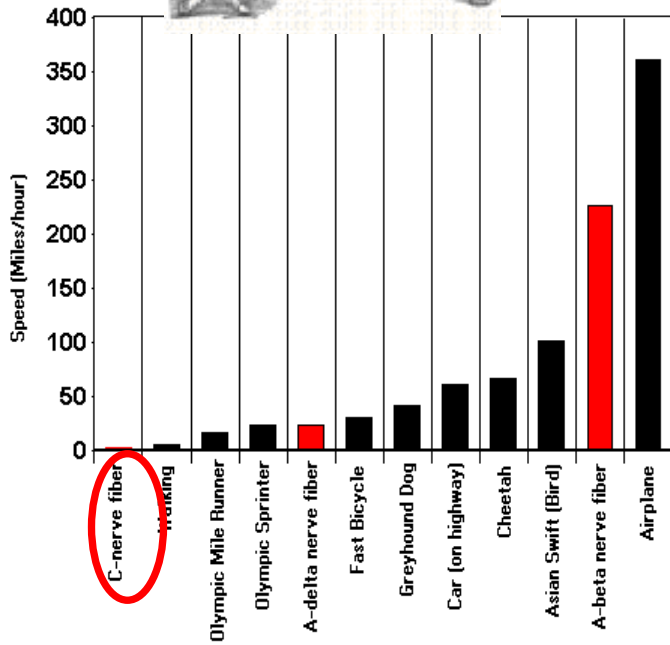
Sensory Nerves:
Nerve Bundles
Sub Epidermal Neural Plexus
Epidermal Nerve Fibers

Nerve Fiber Assessment
Epidermal Nerve Fibers
Basement membrane
Branch points and length

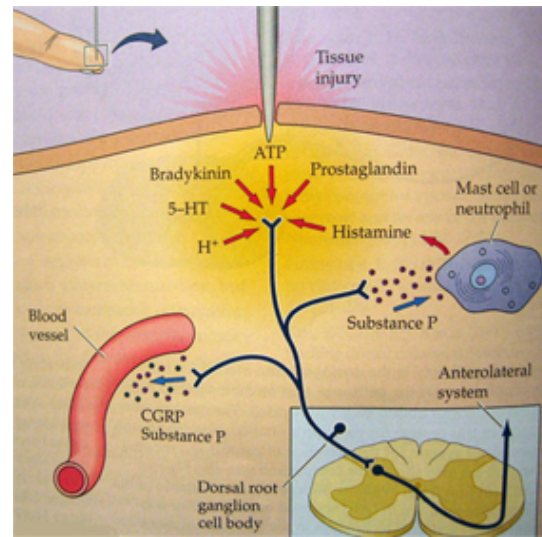
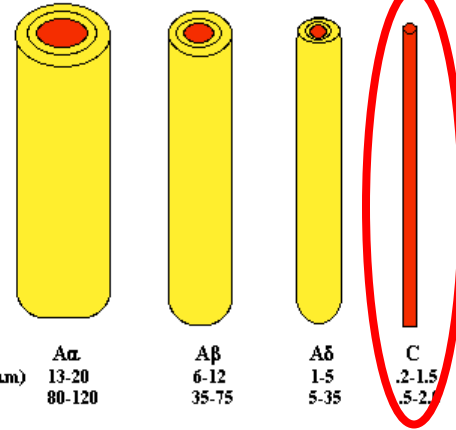
Epidermal Nerve Fiber Density
Accurate
Objective
Quantifiable

Bio-Behavioral Analysis of SIB, Sensory Mechanisms, and Pain

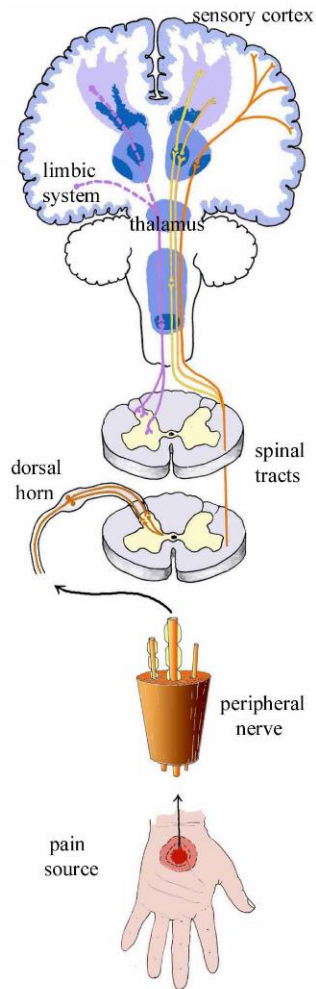




Primary Afferent Axons

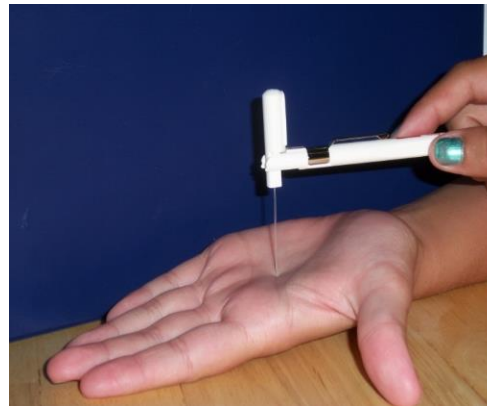


(m) Quantitative Sensory testing



Pain perception depends on the functioning of the peripheral nerves and their ability to transmit the pain **signal** to the central nervous system (Ji & Woolf, 1999).

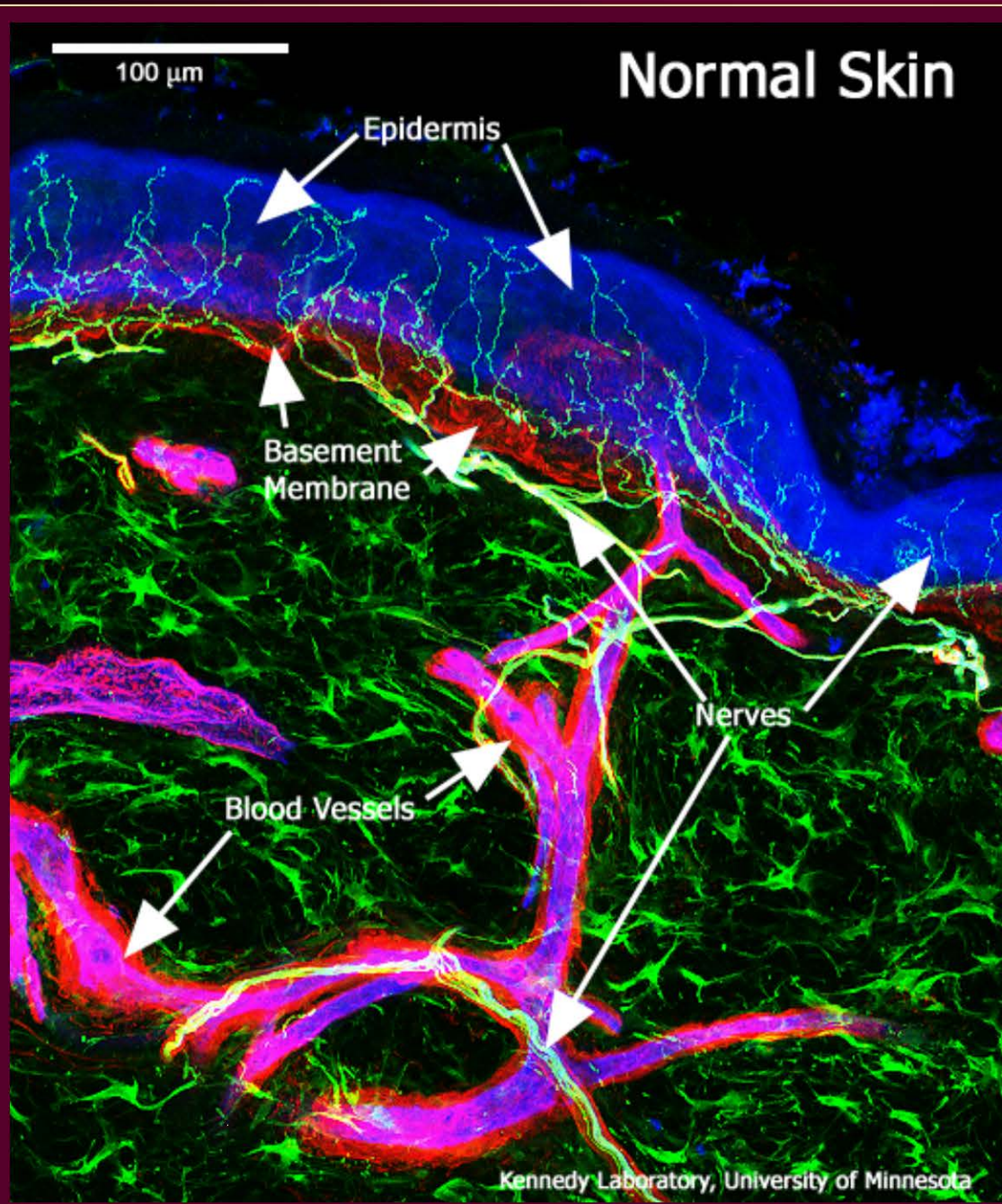
Quantitative sensory testing provides an opportunity to study **indirectly peripheral nerve functional integrity** (Greenspan, 2001).





Skin Biopsy Approach/Methods

- Sample to Date
 - SIB cases
 - 25 adult [80% profound cognitive impairment]/Residential
 - 5 pediatric [100% profound cognitive impairment]/Outpatient
 - 13 pediatric [global developmental delay]/Outpatient
 - No SIB with developmental disability/delay controls (N = 16/10)
 - No SIB with no developmental disability controls (N = 45 [but adult])
- 3 mm punch skin biopsy
 - SIB Group: non-self-injurious body site
 - Control: site-matched normal skin samples
 - No known primary chronic illness (e.g., diabetes) or genetic condition associated w/SIB (e.g., LNS).
- Dependent measures
 - Epidermal nerve fiber (ENF) structure: coefficient of variation (CV)
 - Peptide content: SP, CRGP, VIP
 - Immune activity: mast cell granulation



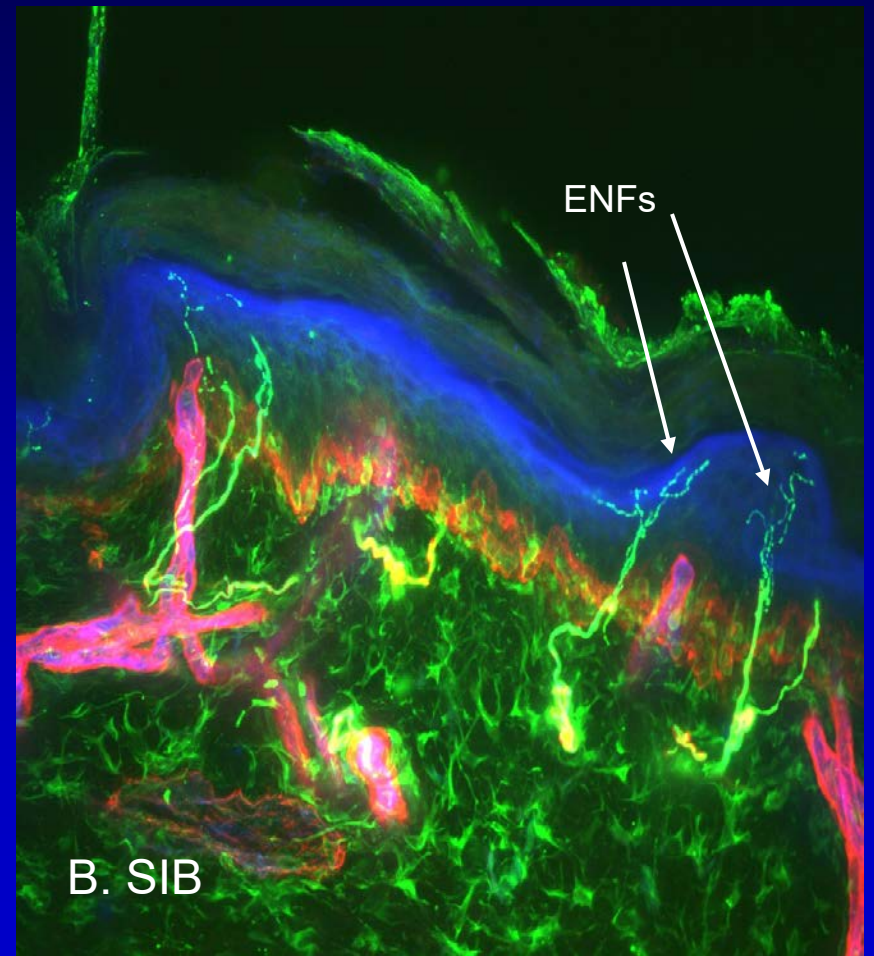
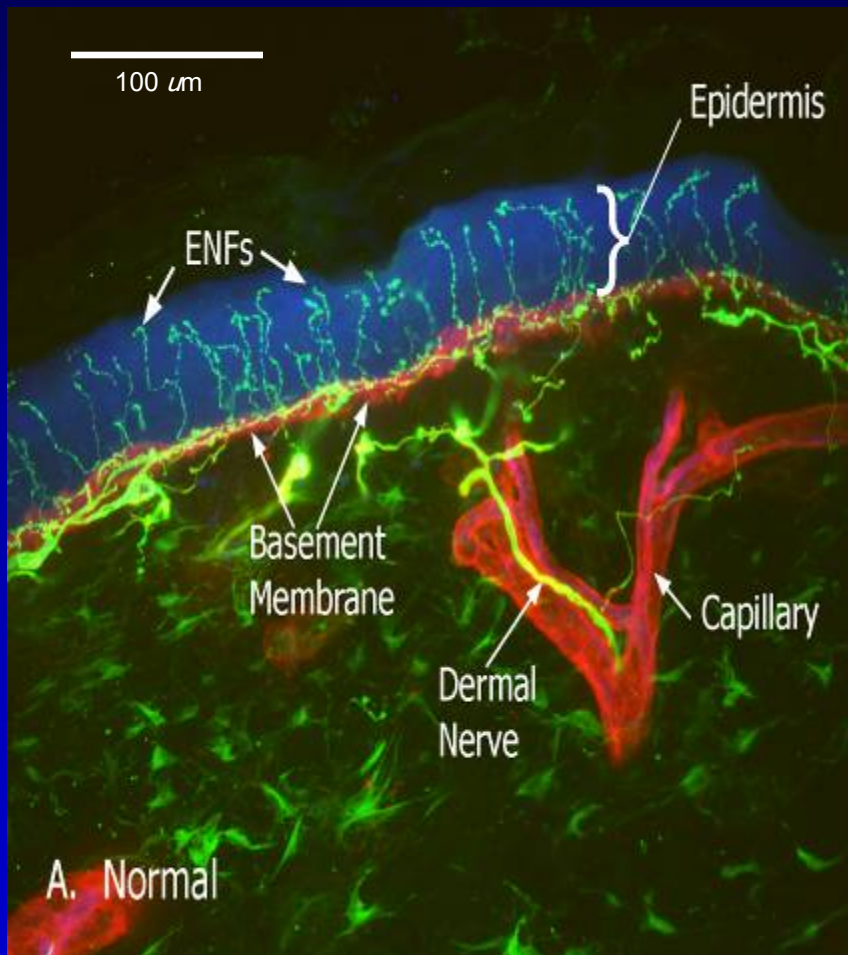
Normal Skin

Sensory Nerves:
Nerve Bundles
Sub Epidermal Neural Plexus
Epidermal Nerve Fibers

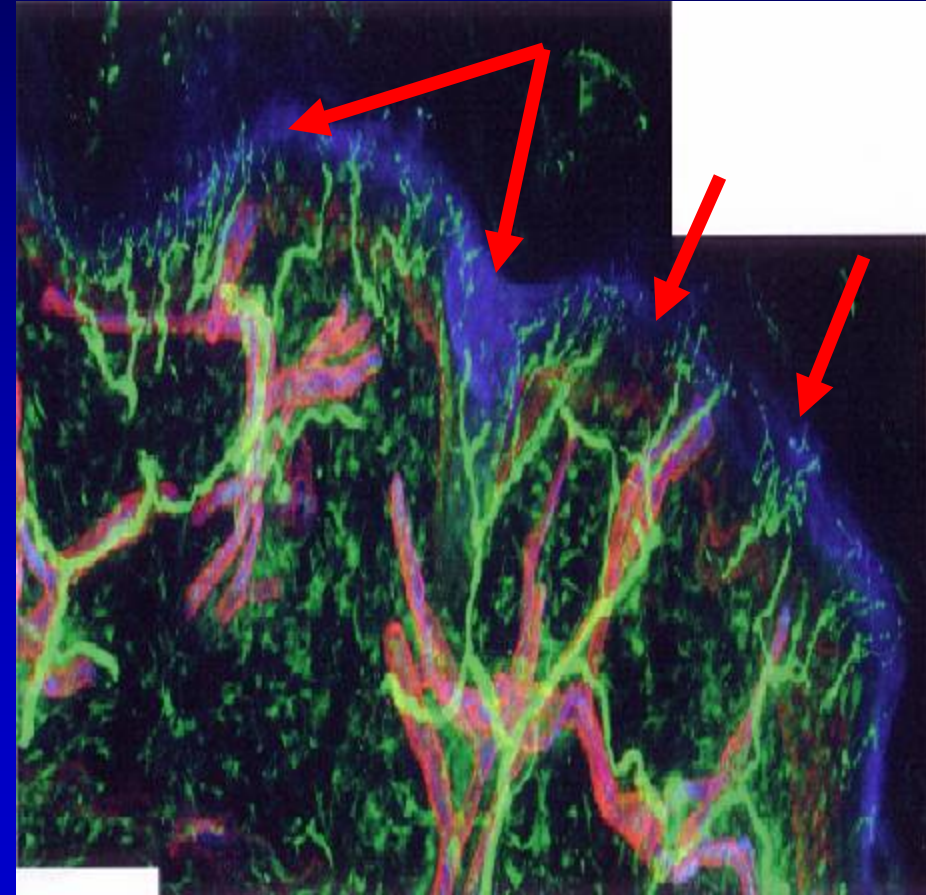
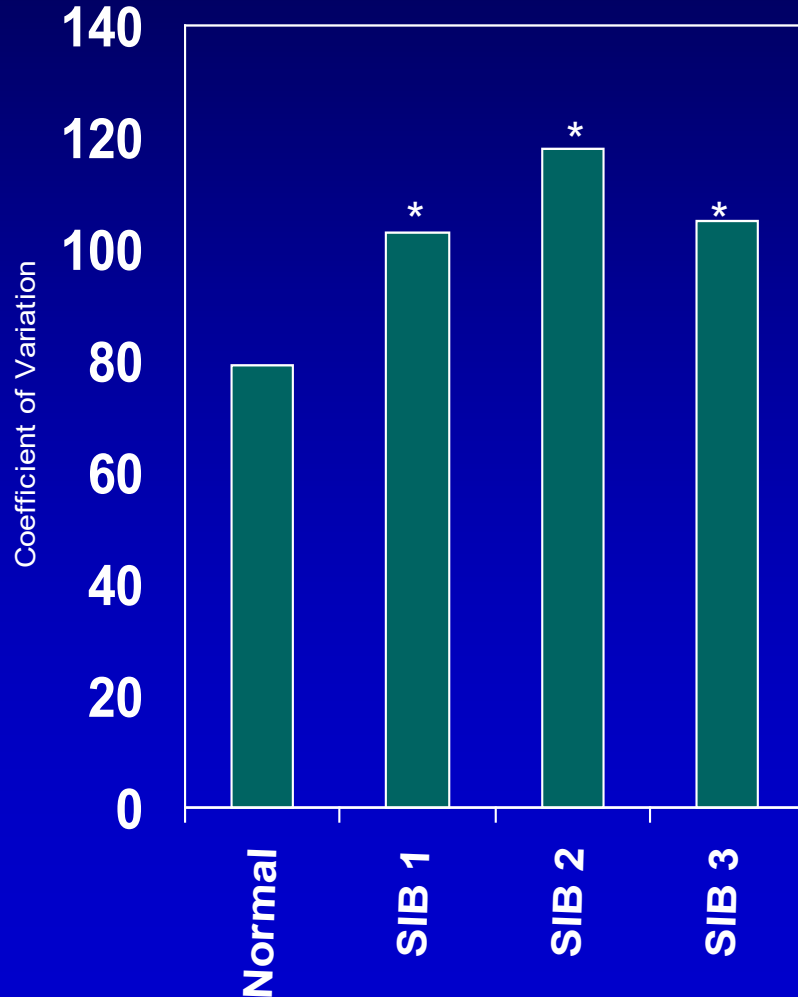
Nerve Fiber Assessment
Epidermal Nerve Fibers
Basement membrane
Branch points and length

Epidermal Nerve Fiber Density
Accurate
Objective
Quantifiable

Altered Peripheral Nerve Morphology



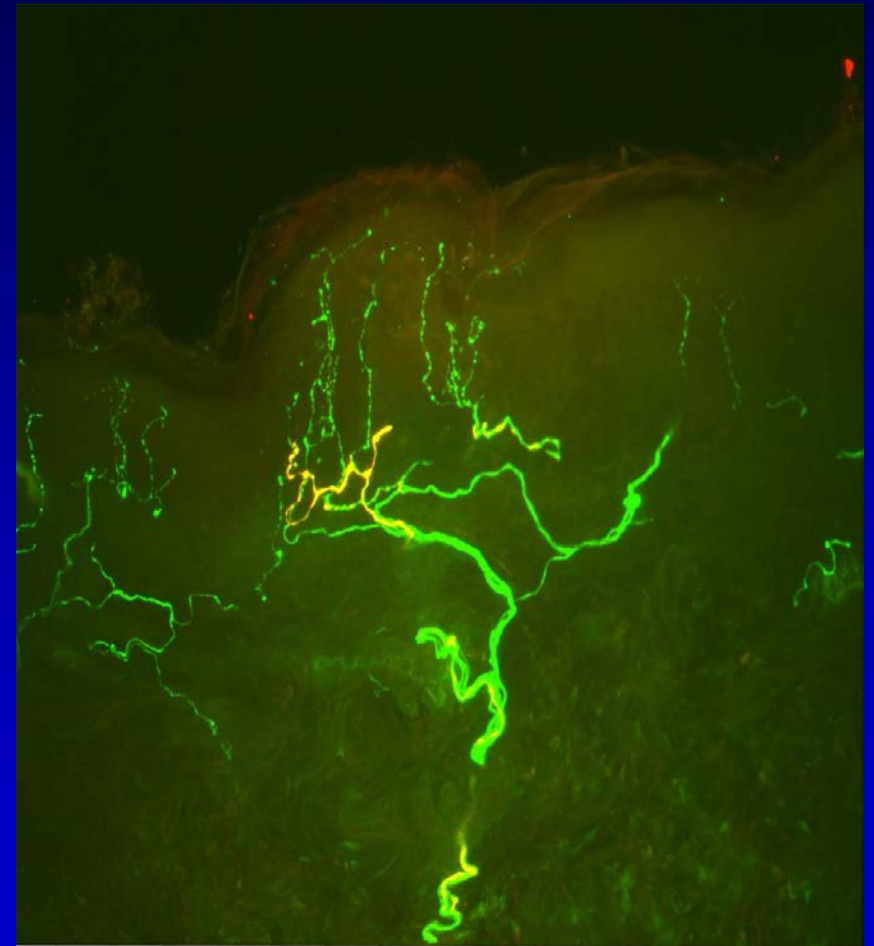
Epidermal nerve fiber (ENF) density: Coefficient of variation (CV)



Altered Neuropeptide Content

Density, Spacing, and Neuropeptide Content of SIB and Control Biopsies

Forearm Biopsy	ENF Density	Gap CV	SP	CGRP	VIP
SIB 1	27.6	105	5	12	0
SIB 2	31	118	9	10	0
SIB 3	37.2	103	7	12	0
Control	36.4 5% = 17.8 N=45	79 N=32	2.0 N=32	10.3 N=32	0



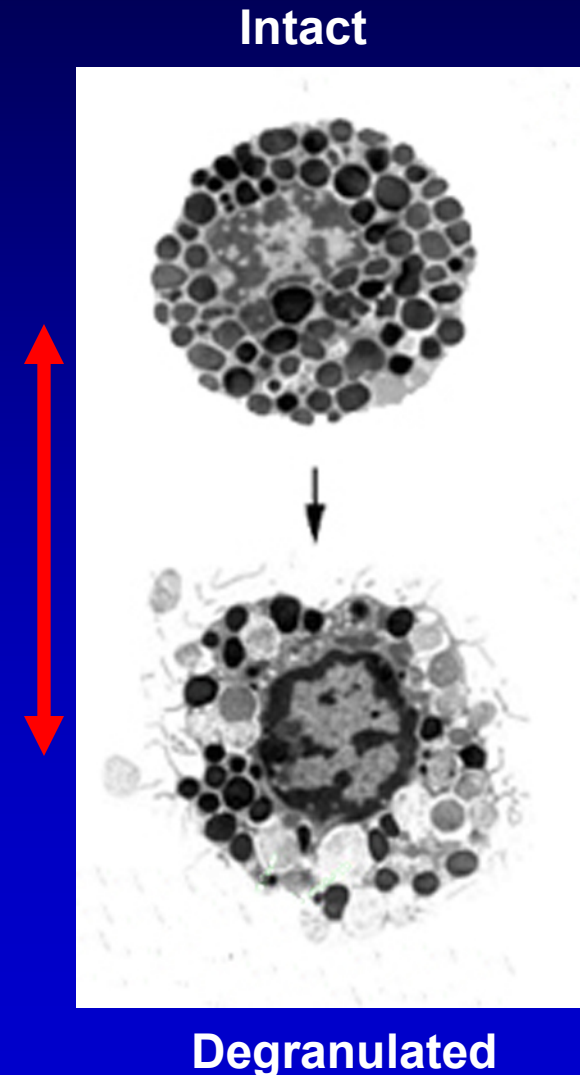
Immune Activity: Mast Cell Degranulation



Degree of granulation = Degree of Immune activity

SIB vs No SIB Controls

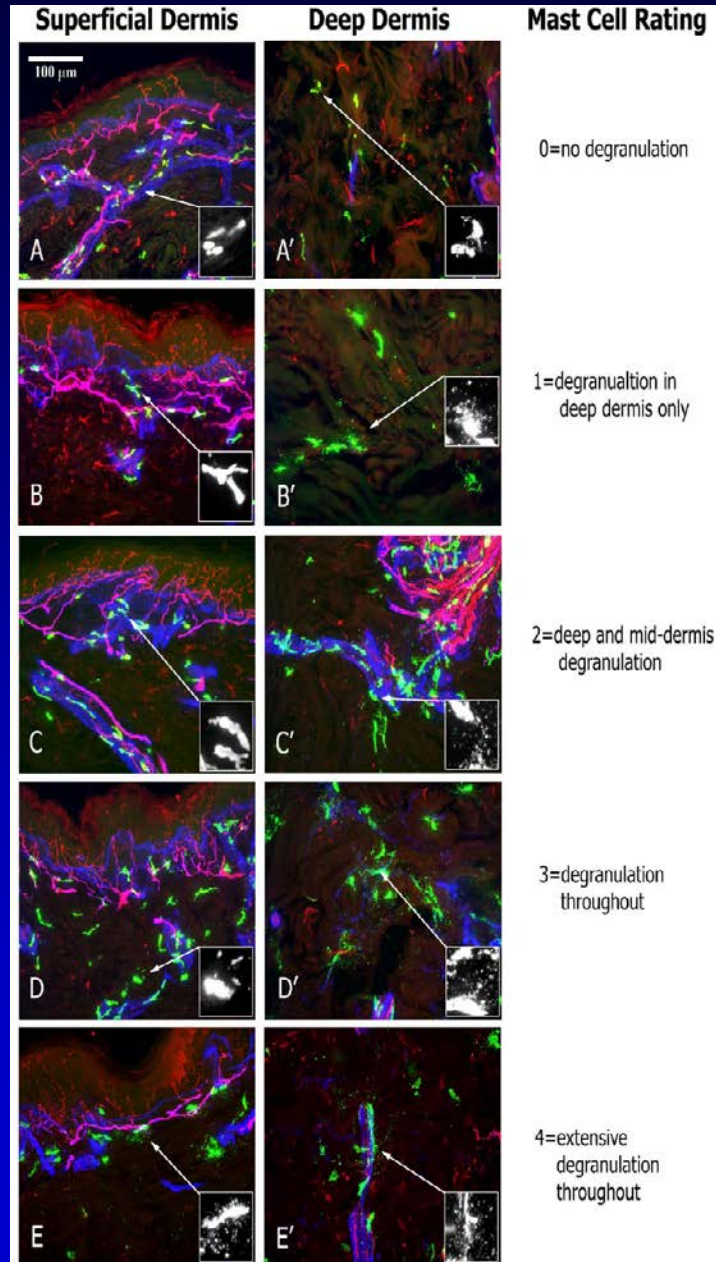
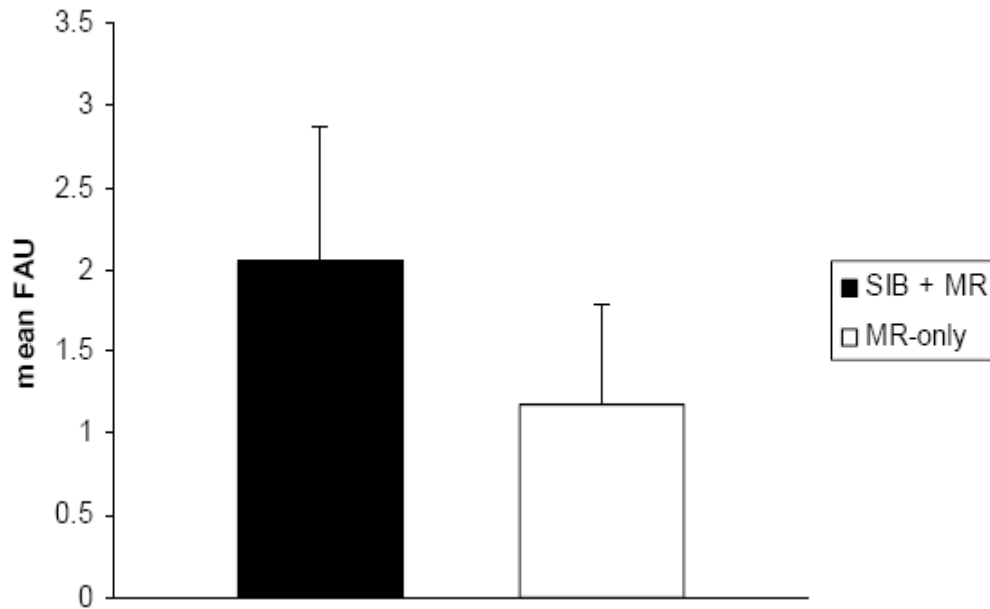
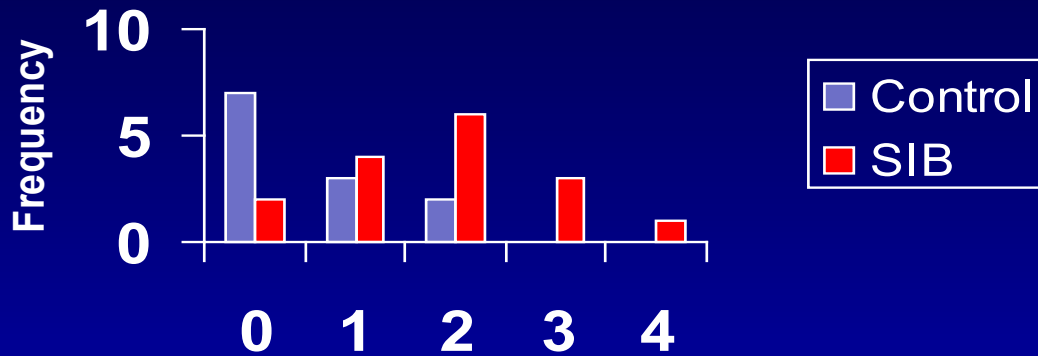
- p (SIB/dm) = 0.75
- p (CTL/dm) = 0.23
- $X^2 = 4.99 < 0.05$



Neuro-Immune Crosstalk:

Sensory Behavioral Effects?

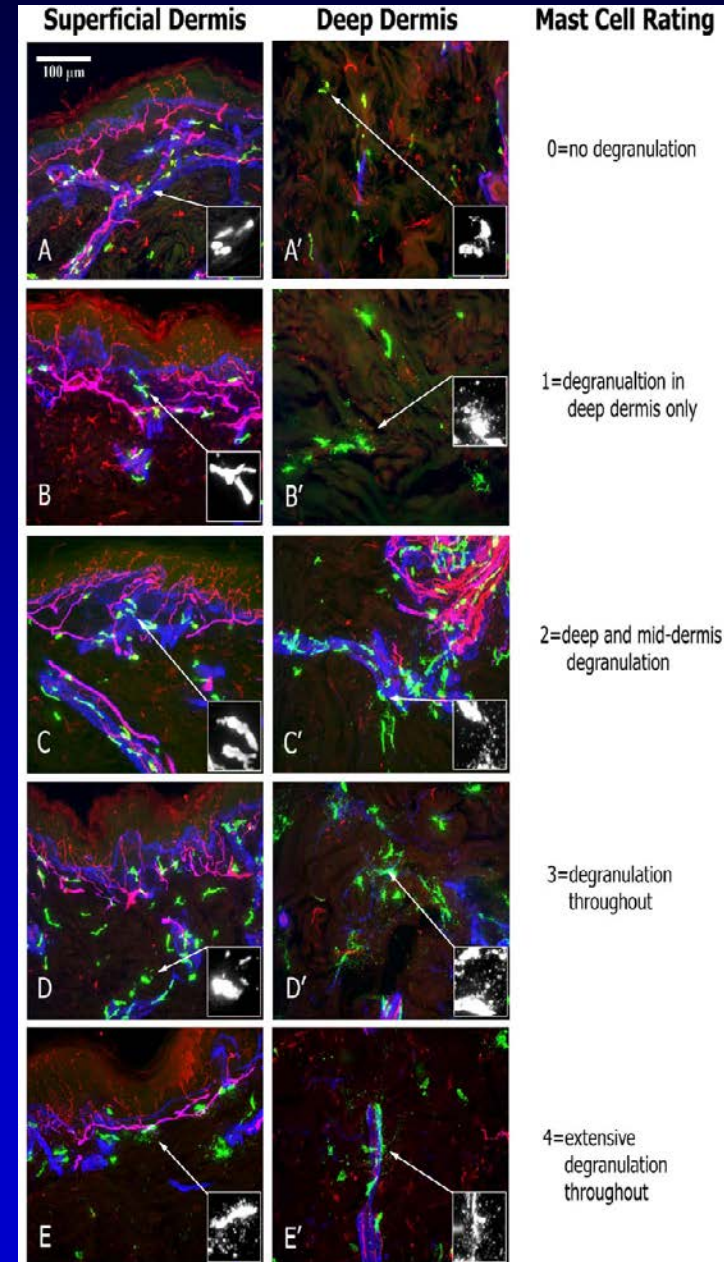
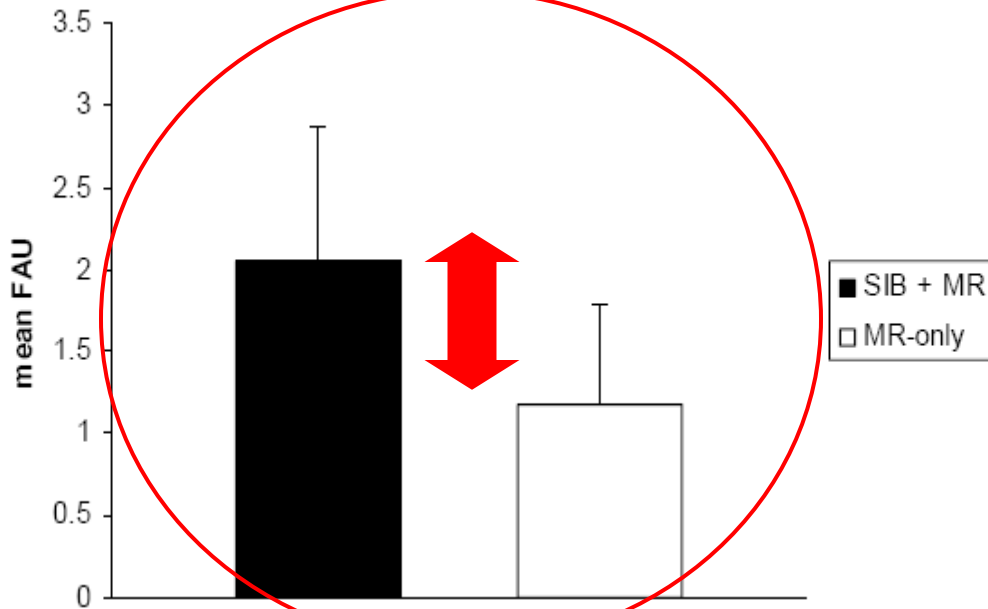
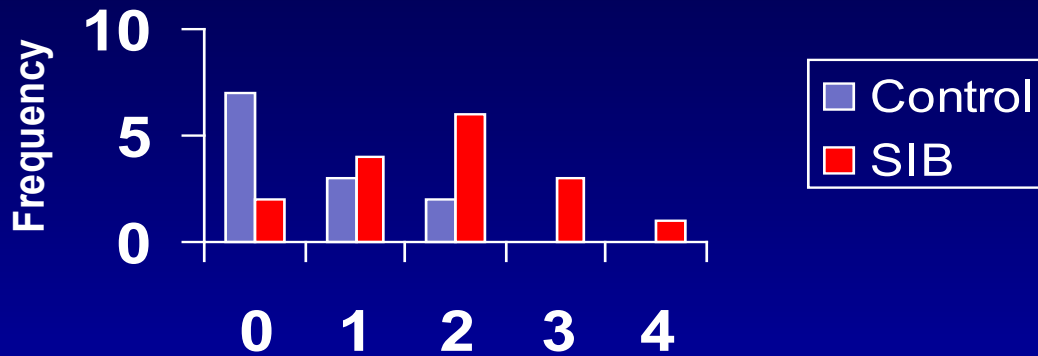
Symons et al (2009) *Brain, Behavior, & Immunity*, 23:365-370



Neuro-Immune Crosstalk:

Sensory Behavioral Effects?

Symons et al (2009) *Brain, Behavior, & Immunity*, 23:365-370



So What?

Peripheral ‘pain’ biomarkers = SIB risk markers?

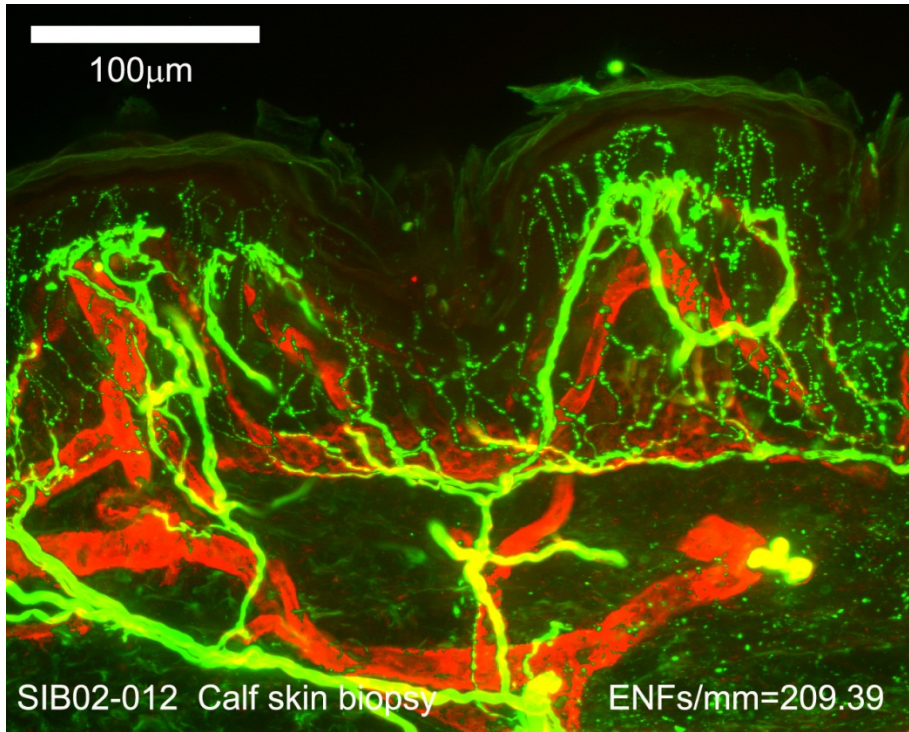
- initial observations of altered intra-epidermal nerve density differences in adult sample with chronic SIB (no controls)

Pain 134, 232-237.

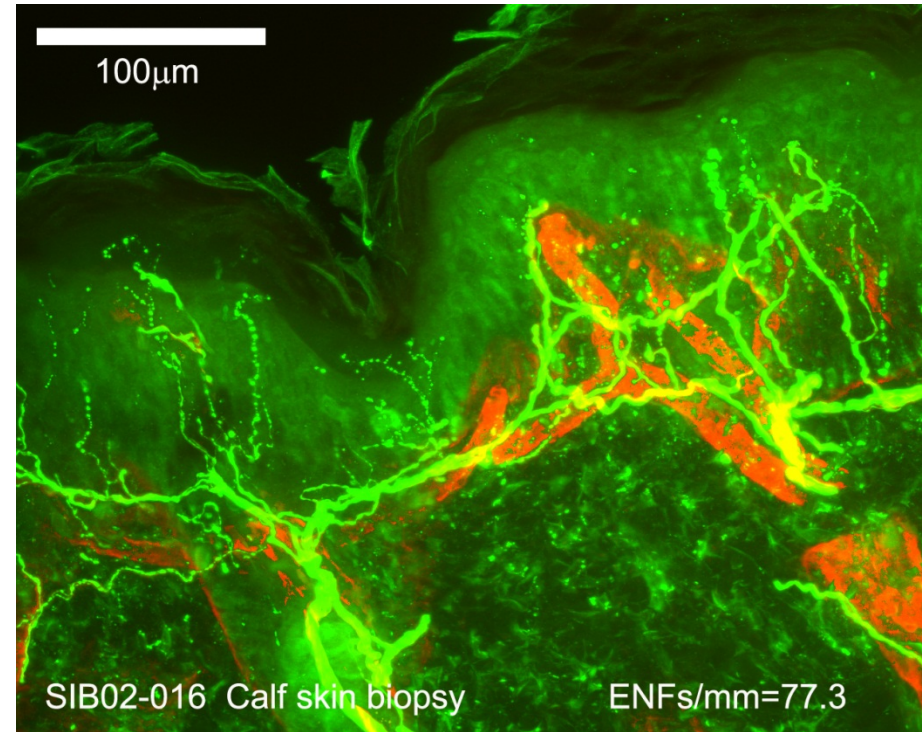
- replicated finding with a larger sample of adult SIB cases relative to matched controls *Brain, Behavior, & Immunity, 23, 365-370.*
 - observed increased SP-positive fiber counts in some but not all samples
 - observed extensive mast cell degranulation (consistent with immune mediated inflammatory response)
- also observed that adult individuals with SIB and altered peripheral markers (relative to matched controls) were more (not less) responsive during a modified quantitative sensory testing protocol *The Journal of Pain, 11, 773-781.*

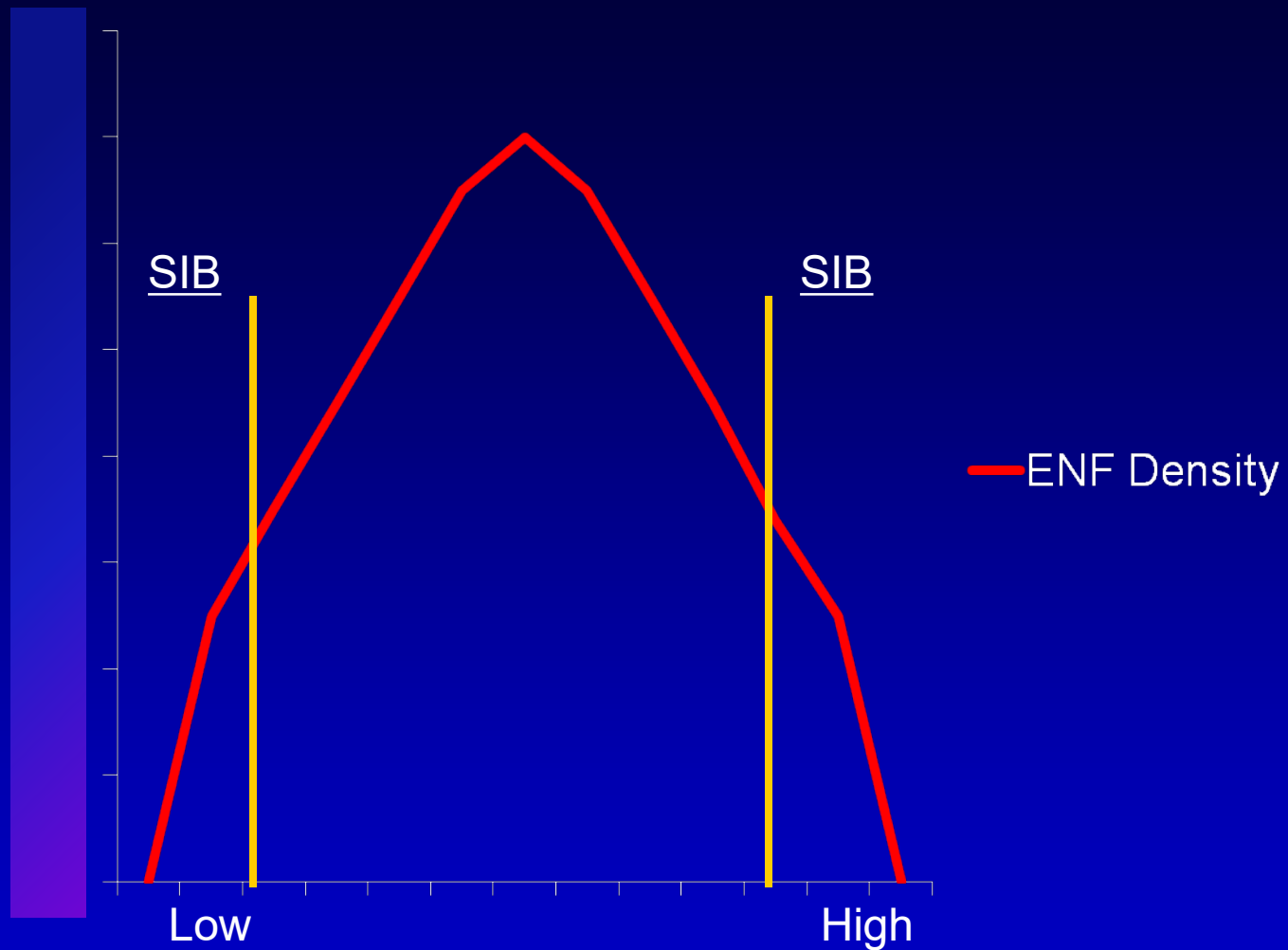
Early ENFd variation w/ 'At Risk' sample

At Risk: 'High' (?) ENFd



At Risk: 'Normal' (?) ENFd





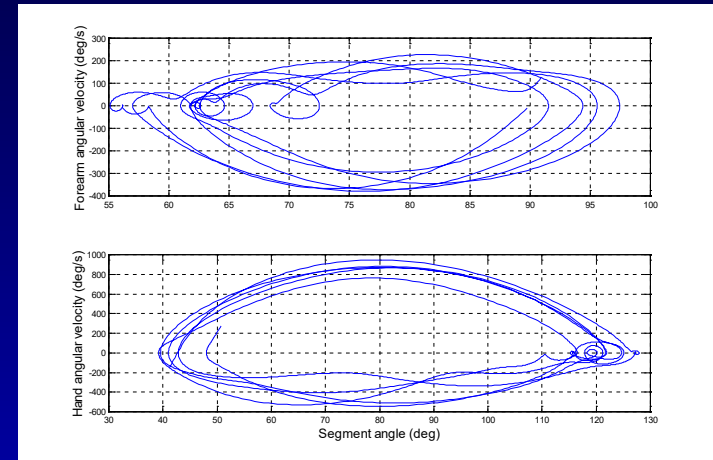
Hypothetical Plot of ENF Density Histogram

Evidence to date for extreme low and high density ENF innervation among SIB cases

(Symons et al., 2008 *Brain, Beh, & Immunity*, 23; Symons et al, 2008, *Pain*, 134.)

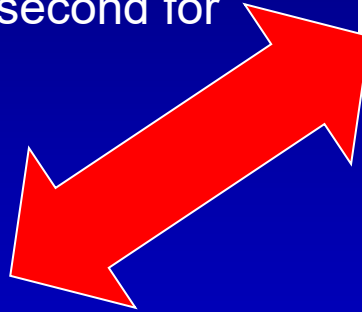
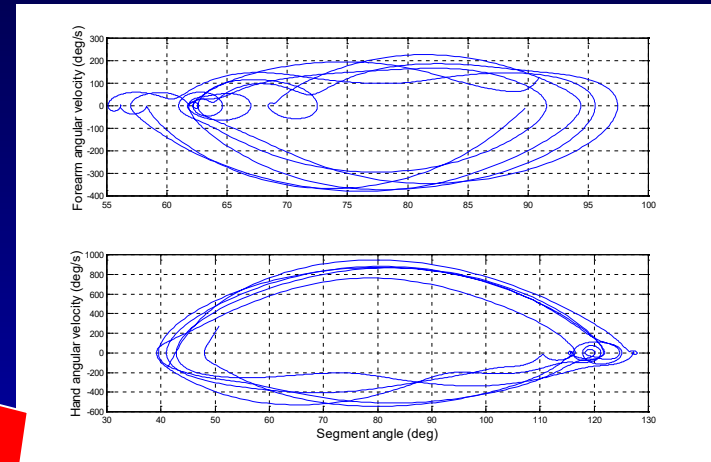
Closing Thoughts on Long-Term Effects of Chronic Tissue Damaging SIB

Coupling the impact forces with the frequency of blows during a single bout of self-injury would essentially be the equivalent of dropping a 48-oz (3-lb) hammer on your forehead every second for up to a half an hour.



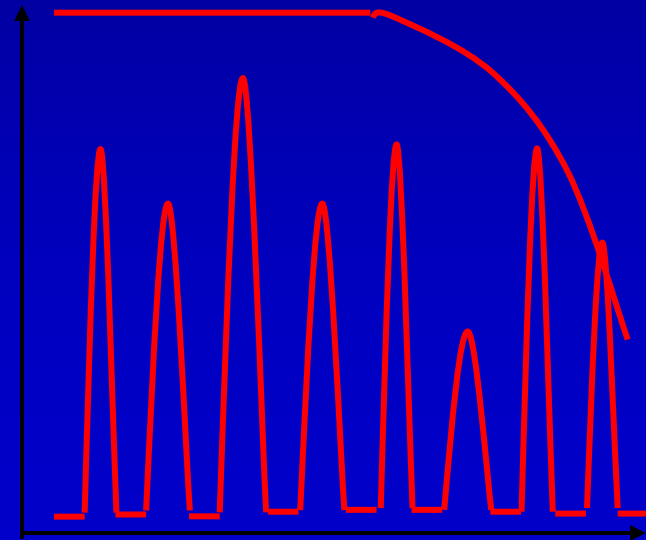
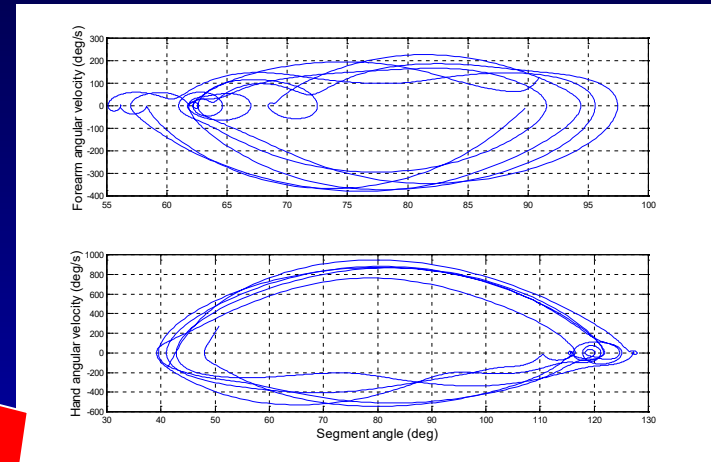
Closing Thoughts on Long-Term Effects of Chronic Tissue Damaging SIB

Coupling the impact forces with the frequency of blows during a single bout of self-injury would essentially be the equivalent of dropping a 48-oz (3-lb) hammer on your forehead every second for up to a half an hour.



Closing Thoughts on Long-Term Effects of Chronic Tissue Damaging SIB

Coupling the impact forces with the frequency of blows during a single bout of self-injury would essentially be the equivalent of dropping a 48-oz (3-lb) hammer on your forehead every second for up to a half an hour.

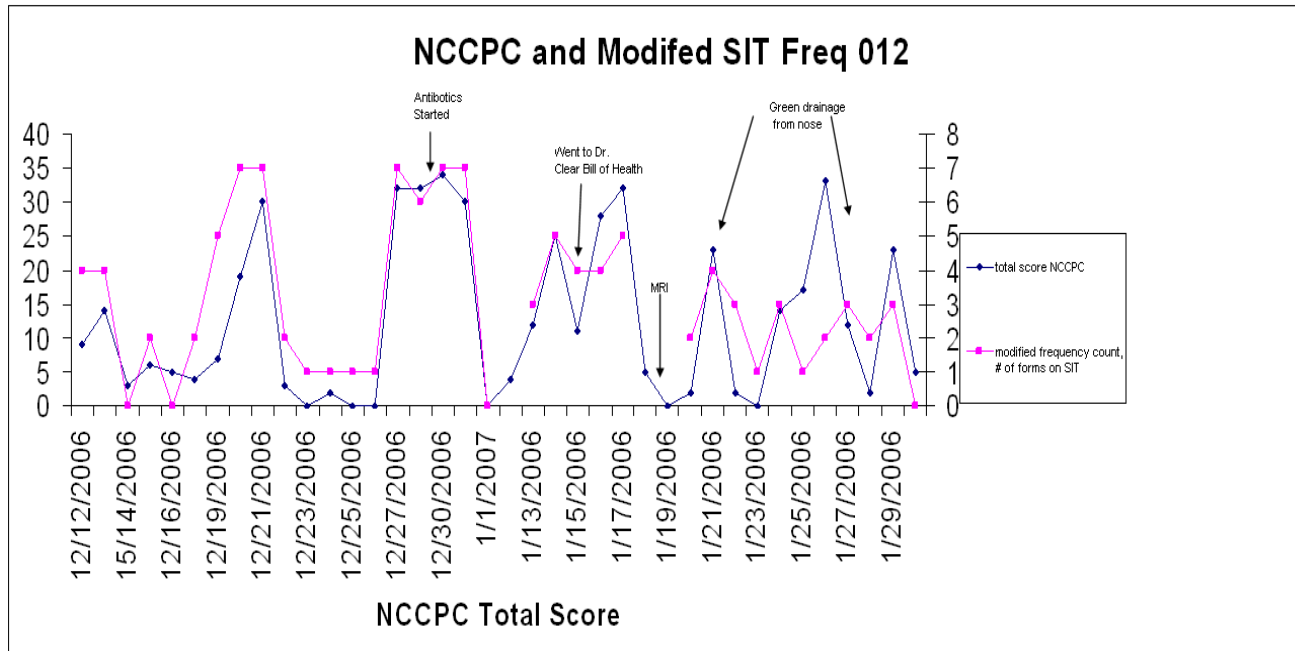


Summary of findings

- **ASD subtype** (ASD with or without IDD)
 - Clear differences in SIB phenotype
 - Severe & persistent SIB common in ASD+IDD
- **Objective methods** for measuring nociception in persons who are nonverbal
 - Quantitative Sensory Testing + FACS
 - Biomarkers
- **Altered nociceptive function** SIB in ASD+IDD findings consistent with allodynia / hyperalgesia
 - ↑ response to multiple sensory modalities suggesting that non-noxious stimuli might be perceived as painful (e.g. touch, temperature changes, etc).
 - Alterations in ENFs that could disrupt sensory/pain signaling
 - Alterations in immune-mediated inflammatory response

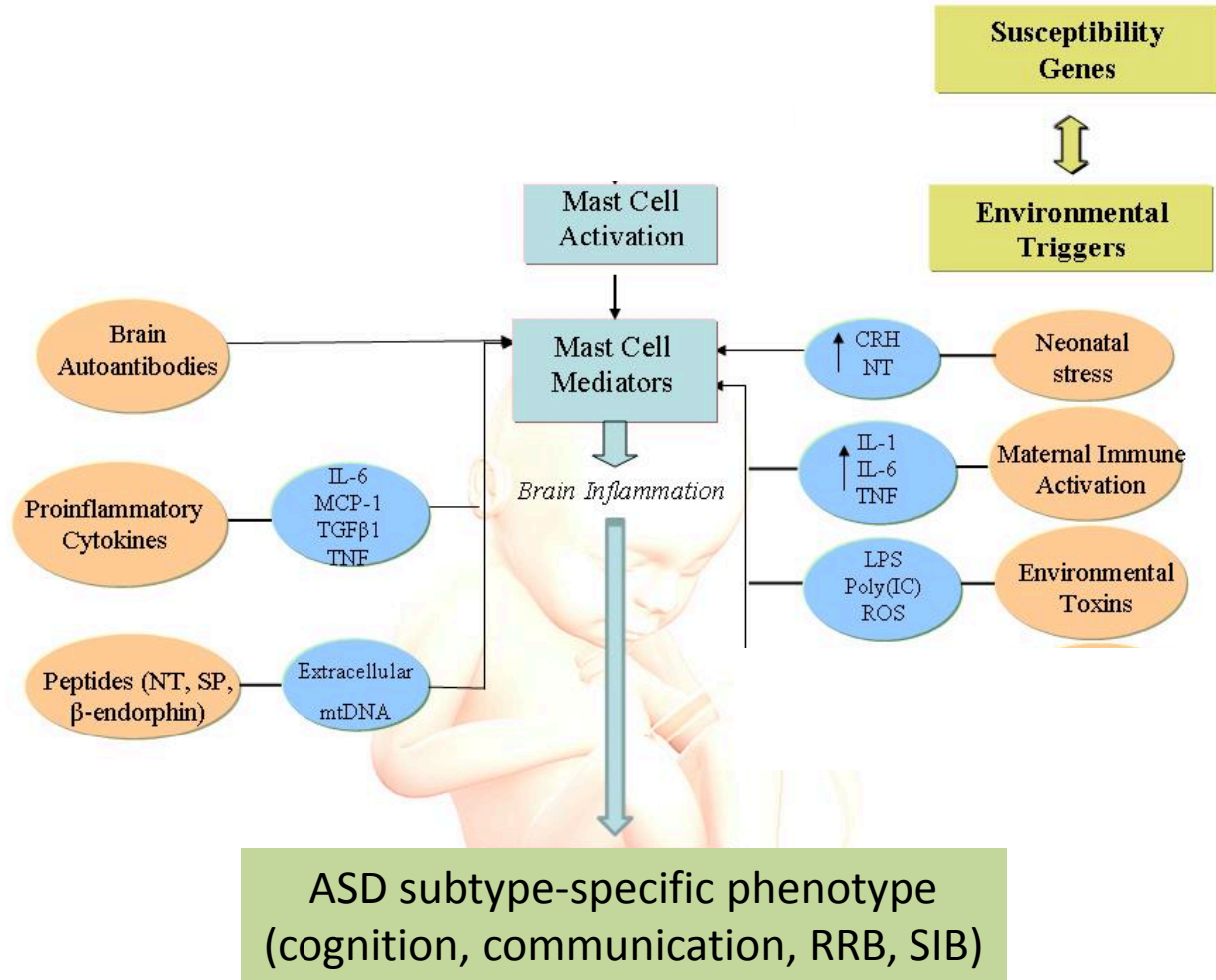
Clinical implications:

- **Assessment:** SIB & nonverbal pain signs
- **Intervention:** Tx pain, Tx SIB?



Research implications

from mechanism to treatment target



Meeting of the IACC

Afternoon Agenda - continued

4:15 Round Robin

4:45 Closing Remarks

5:00 Adjournment

Meeting of the IACC

Round Robin

NIMH ASD-PEDS Network

Comprised of 5 large-scale studies on early identification of ASD and linkage to treatment and services:

- **Addressing Systemic Health Disparities in Early ASD Identification and Treatment**, University of Massachusetts Boston, Alice Carter, PI (MH104400)
- **Early Identification and Service Linkage for Urban Children with Autism**, Boston University Medical Campus, Emily Feinburg, PI (MH104355)
- **Detection of ASD at the 1st Birthday as Standard of Care: the Get SET Early Model**, University of California San Diego, Karen Pierce, PI (MH104440)
- **A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention**, University of Washington, Wendy Stone, PI (MH104302)
- **Mobilizing Community Systems to Engage Families in Early ASD Detection and Services**, Florida State University, Amy Wetherby, PI (MH104423)

IMFAR 2016

IMFAR
INTERNATIONAL MEETING
FOR AUTISM RESEARCH
*Annual Meeting of the International
Society for Autism Research (INSAR)*

May 11-14 Baltimore, Maryland, USA

International Meeting for Autism Research 2016 Overview

Geraldine Dawson, PhD

President, International Society for Autism Research

Professor of Psychiatry and Behavioral Sciences, Duke University

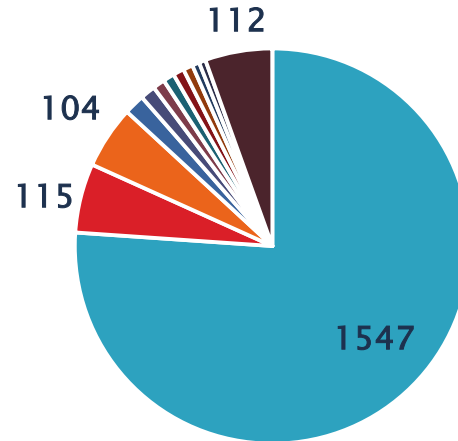
Director, Duke Center for Autism and Brain Development

INSAR

International Society
for Autism Research

IMFAR 2016

2031 Registrants – Representing 49 Countries



UNITED STATES

UNITED KINGDOM

ISRAEL

NETHERLANDS

BELGIUM

GERMANY

CANADA

JAPAN

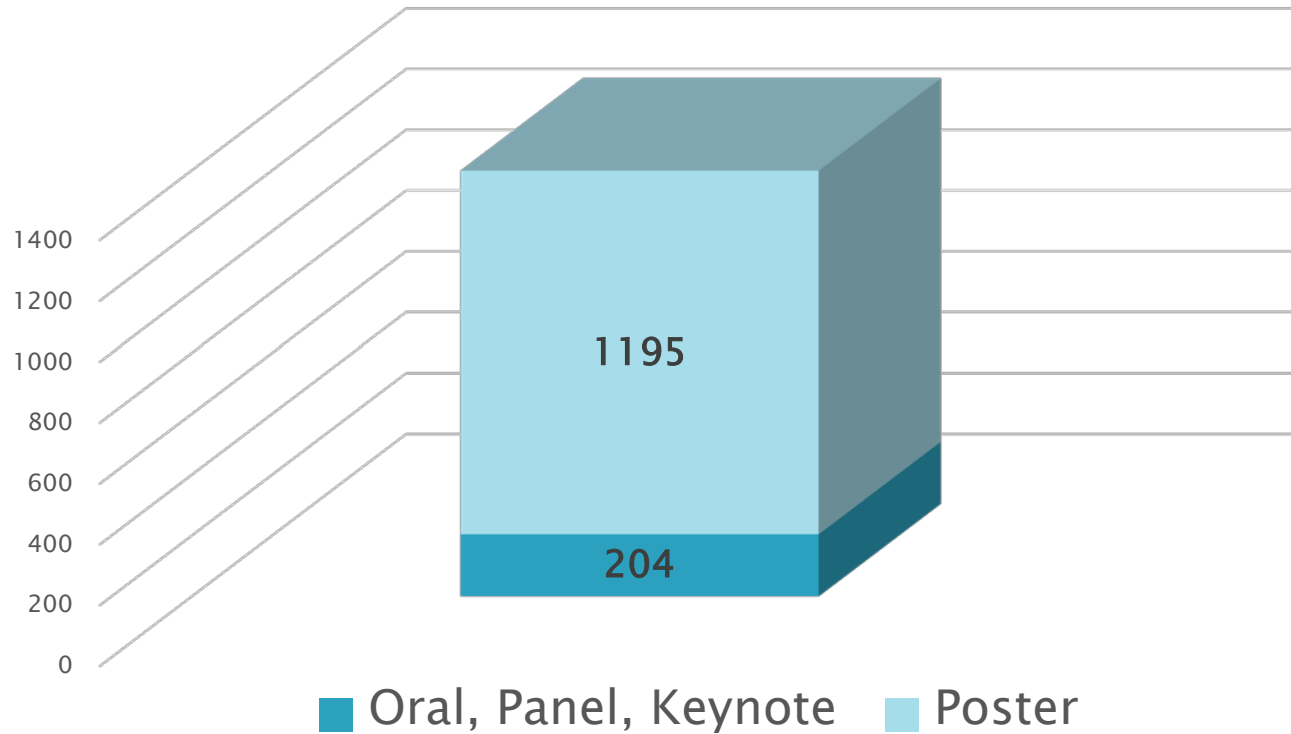
AUSTRALIA

SWEDEN

ITALY

Other (representing 38 countries)

IMFAR 2016 Presentations = 1,399



INSAR Annual Report 2015



- ▶ Published on INSAR website
- ▶ Highlights of past year
 - Updated strategic plan
 - Regional IMFAR in China
 - Summer Institute
 - 2015 INSAR Awards
 - Journal: *Autism Research*
 - Financial report
 - IMFAR 2015 highlights

INSAR Strategic Plan 2015–2018

Published on INSAR website

Strategic Initiatives

- ▶ Increase the quality of research at meeting and in journal
- ▶ Cultivate interdisciplinary and translational research
- ▶ Represent and serve a diverse and global community
- ▶ Foster next generation of ASD researchers
- ▶ Promote INSAR as the premier society for autism researchers
- ▶ Disseminate science-based knowledge to inform policy and practice
- ▶ Foster communication between autism researchers and individuals affected by ASD

IMFAR 2016 – Keynote Presentations



Irva Hertz-Picciotto, PhD

Environment and Autism: Understanding Causes



Guoping Feng, PhD

Dissecting Synaptic and Circuitry Mechanisms of Autism



Paul Shattuck, PhD

“Moving the Needle” with Life Course Research on Autism

IMFAR 2016 – Panel Presentations

Pushing the Boundaries for Understanding Environmental Influences on Neurodevelopment

Presenters: B. Lanphear, V. Rauh, S. M. Engel, M. D. Fallin

Transcranial Magnetic Stimulation (TMS) in Autism Spectrum Disorder

Presenters: L. Oberman, M. F. Casanova, S. H. Ameis, P. Enticott

Improving Early Access to Autism Screening and Specialized Services: Reaching Historically Underserved Communities

Presenters: R. S. Factor, I. Giserman Kiss, T. I. Mackie, E. A. Karp

Outcome Measures for Early Intervention Studies in Autism Spectrum Disorder

Presenters: H. McConachie, R. Grzadzinski, M. K. J. Pijl, A. Y. Hardan

Behavioral Interventions for Adults with ASD

Presenters: A. McVey, S. M. Eack, C. M. Schall, C. M. Conner

IMFAR 2016 – Panel Presentations

Recent Advances in Genetics and Neurobiology of Autism

Presenters: B. Neale, D. Arking, G. Choi, P. Arlotta

Growing Older with Autism: Cognition, Comorbidity and Quality of Life

Presenters: P. Howlin, A. G. Lever, E. Zivrali, A. Roestorf

What Is Different about Females with Autism: Where Are We and Where Do We Need to Go?

Presenters: K. Register-Brown, E. I. White, A. B. Ratto, C. E. Pugliese

Perspectives on Pain in ASD: Perception, Physiology, and Behavior

Presenters: D. J. Moore, E. G. Duerden, M. D. Failla, J. W. Bodfish

But It Worked So Well in the Lab! Measuring Implementation of Evidence-Based Practices for Children with Autism in Community Settings

Presenters: J. J. Locke, M. Pellecchia, C. Chlebowski, N. Stadnick

IMFAR 2016 – Panel Presentations

Life Course and Ecological Perspectives on Autism

Presenters: C. Anderson, S. K. Kapp, E. McGhee Hassrick, J. L. Taylor

Towards Big Data Approaches in Eye Tracking

Presenters: K. Pierce, L. Mason, J. Parish-Morris, F. Shic

Recent Advances in Statistical Methods for Autism Research

Presenters: A. Gross, D. Almirall, E. A. DeVilbiss, B. Lee

Understanding Cultural Differences in Diagnostic and Treatment Services for Children with ASD

Presenters: L. C. Lee, L. Franz, S. B. Vanegas, S. Magana

Efforts Towards a More Cohesive Understanding of Anxiety in ASD: Correlates and Underlying Mechanisms

Presenters: C. A. Mazefsky, C. E. Pugliese, N. L. Kreiser, J. Herrington

IMFAR 2016 – Special Interest Groups

- ▶ **Community-Based Early Intervention**
- ▶ **Novel Re-conceptualizations of the ASD Diagnosis**
- ▶ **Older Adults with ASD: The Consequences of Aging**
- ▶ **Suicidality in Autism Spectrum Conditions**
- ▶ **Anxiety in Autism**
- ▶ **Incorporating Autistic Intellect in Research Design and Evaluation**
- ▶ **Genetic and Environmental Risk Factors**

IMFAR 2016 – Awards



INSAR Lifetime Achievement Award Professor Christopher Gillberg

- ▶ The Lifetime Achievement Award is given annually by the Executive Board of the International Society for Autism Research. This award acknowledges an individual who has made significant fundamental contributions to research on autism spectrum disorders that have had a lasting impact on the field. The focus of the awardee's research can be in any discipline.



INSAR Advocate Award Thomas Insel

- ▶ This award honors community members/advocates who have influenced the ability to carry out autism research.

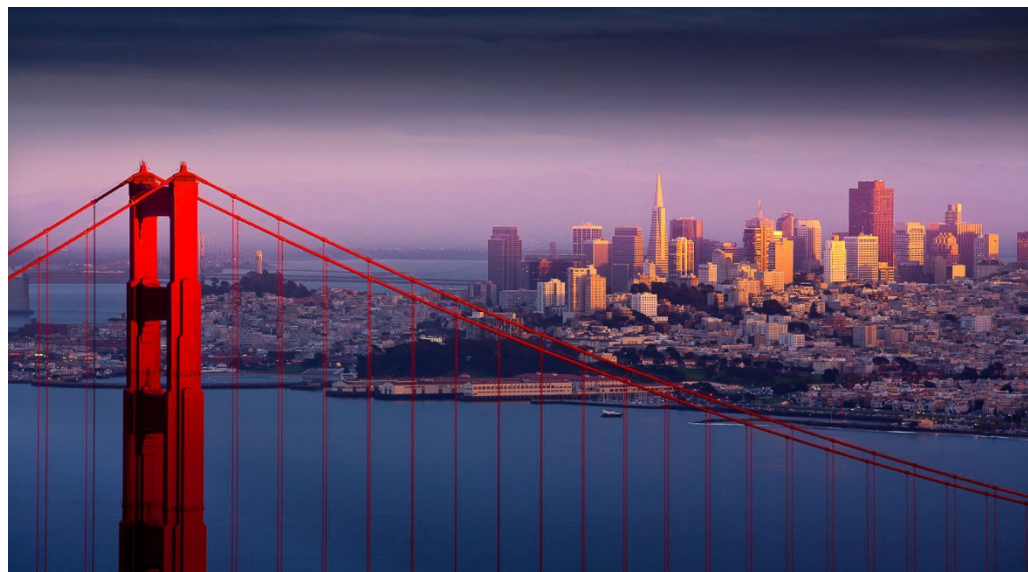


IMFAR 2017

May 10-13, 2017

Marriott Marquis

*San Francisco,
California, USA*



Meeting of the IACC

Closing Remarks

Meeting of the IACC

Adjournment