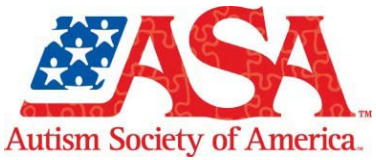
Services Subcommittee Update

May 4, 2009

Ellen Blackwell & Lee Grossman
Co-Chairs



Services Subcommittee

- **Vision**
- All people with ASD have the services and supports they need and desire throughout the lifespan to lead productive lives in the community and to reach their fullest potential
- **Mission**
- To assess and improve services and supports for people with ASD

Members of the Services Subcommittee

- Gail Houle (Department of Education)
- Larke Huang (SAMHSA)
- Denise Juliano-Bult (NIMH)
- Christine McKee
- Jennifer Johnson (ACF)
- Cathy Rice (CDC)
- Stephen Shore
- Alison Singer (Autism Science Foundation)
- Bonnie Strickland (HRSA)
- HHS Office on Disability

Services Subcommittee Request for Information (RFI) Responses

- RFI open Fall, 2008
- 137 responses
- 497 comments
- 21 respondents self-identified as people with ASD
- Stakeholder priorities and emergent categories identified

Stakeholder Priorities

1. Adults with ASD
2. Community
3. Family Support
4. School Services
5. Providers
6. Infrastructure

Emergent Priorities

7. Employment
8. Evidence-based Services and Supports
9. Health & Safety
10. Early Diagnosis & Treatment
11. Transition to Adulthood
12. Therapies

Other Services Categories of Interest

13. Legal/Guardianship
14. Dental
15. Medical Treatment
16. Assistive Technology/Augmentative Communication
17. Diet

ASD Services & Supports Recommendations

- February 24, 2009 meeting - new focus from the ASD Roadmap to "ASD Services and Supports Recommendations"
- Several Recommendations would be sent to the Secretary
- The document would align with the IACC Strategic Plan for ASD
- The Subcommittee will develop a plan and timeline, including evaluation of the need to convene Expert Working Groups
- Public input would be used to develop the Recommendations
- The Recommendations could be updated annually

Other Activities of the Services Committee

- The Subcommittee will hold regular presentations at each meeting from Subcommittee members, Federal government and state staff, ASD experts, advocates, people with ASD and other stakeholders to increase understanding of ASD services issues
- The first presentation will be at the next meeting
- CDC and HRSA staff will discuss the “Learn the Signs Act Early” campaign

Other Activities of the Services Committee (continued)

- The Subcommittee will list Federal agencies who are, or may be, providing services and supports to people with ASD
- A letter will be sent to each agency
- Lead staff on ASD will be identified
- Information will be gathered on ASD services-related programs and activities presently underway
- Agencies will include the Social Security Administration, the Department of Housing and Urban Development, Department of Labor, others
- This activity is congruent with the Combating Autism Act directive to "monitor Federal activities with respect to autism spectrum disorder" [Section 399CC(2)]

Town Hall Meeting

- Proposed for Friday, July 22, 2009
- In partnership with the Autism Society of America's Annual Conference
- St. Charles, Illinois (outside Chicago)
- 10:30AM-1:15PM time slot available

Discussion Regarding Town Hall Meeting

- Would a Town Hall Meeting a full Town Hall Meeting, or a Services Subcommittee Town Hall Meeting?
- Identify facilitator-moderator, format, broadcast options
- What is the objective?
- Who would the IACC participants be?
- What would the topic(s) be?

Potential Topics

- Suggestions related to the development of the next version of the Strategic Plan for Autism Research (Blackwell, Grossman)
- Discussion regarding IACC monitoring of Federal activities
- Potential recommendations to the Secretary, future presentations to the Services Subcommittee (Blackwell)
- Open on all IACC issues (Grossman)
- Receive feedback from the community on how the IACC has conducted itself and what is recommended for the future (Grossman)
- Additional suggestions?

Future Services Subcommittee Presentations to the IACC

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Report from the IACC Subcommittee for Planning the Annual Strategic Plan Updating Process March 17, 2009 Meeting

Thomas R. Insel, M.D.
IACC Chair and Director, NIMH
May 4, 2009

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IACC Responsibilities

- Combating Autism Act of 2006

  (Public Law 109-416 SEC. 399CC.(b)(5))

  "…develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research, including proposed budgetary requirements…"

Subcommittee Charge

- On February 4, 2009, the IACC established a subcommittee to develop a process for monitoring and updating the IACC Strategic Plan for ASD Research

Subcommittee Roster

Federal Members

- Ellen Blackwell, M.S.W., CMS
- Thomas Insel, M.D., NIH/NIMH
- Story Landis, Ph.D., NIH/NINDS
- Ed Trevathan, M.D., M.P.H., CDC

Subcommittee Roster

Public Members

- Lee Grossman, Autism Society of America
- Lyn Redwood, R.N., M.S.N., SafeMinds
- Stephen Shore, Ed.D., Autism Spectrum Consulting
- Alison Tepper-Singer, M.B.A, Autism Science Foundation

Topics Discussed March 17, 2009

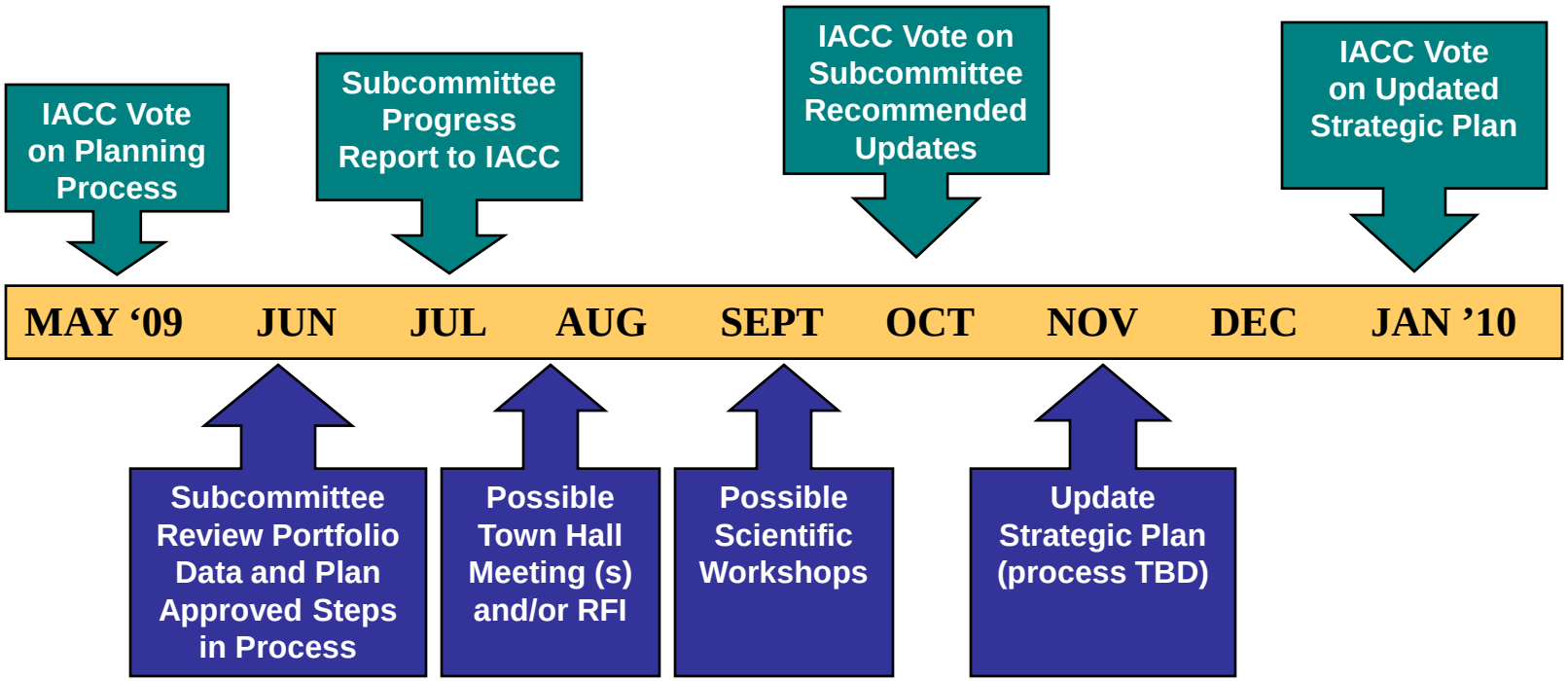
Updating the Strategic Plan

- Possible Approaches
- Possible Timeline
- Recommendations

Possible Approaches

- Analyze ASD research portfolio
- Measure impact of funded research
- Identify scientific gaps in strategic plan
  - Convene workshops, conferences, or satellite meetings
- Solicit public input
  - Town hall meeting(s)
  - Request for Information (RFI)

Possible Timeline



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Subcommittee Recommendations

1. Initiate portfolio analysis of ASD research funded in 2008 (IACC authorized via e-vote)
2. Reconvene subcommittee to:
   - Review portfolio analysis of 2008 ASD research
   - Plan town hall meeting(s) and/or RFI to inform scientific workshops
   - Plan scientific workshops
   - Revise timeline for updating process
3. Authorize subcommittee to review data gathered and recommend updates to the strategic plan

Portfolio Analysis Update

- Request sent to 19 Federal and private funders of ASD research
  - Total dollars spent on 2008 ASD research
  - Dollars and grants categorized by SP Question and Objective
- Subcommittee review and discussion planned for June 2009

ASD Research Funders Solicited

Federal Funders of ASD Research

Administration for Children and Families (ACF)

Agency for Healthcare and Research Quality (AHRQ)

Centers for Disease Control and Prevention (CDC)

Centers for Medicare and Medicaid Services (CMS)

Department of Defense (DoD)

Department of Education (ED)

Department of Housing and Urban Development (HUD)

ASD Research Funders Solicited

Federal Funders of ASD Research

Health Resources and Services Administration (HRSA)

National Institutes of Health (NIH)

Social Security Administration (SSA)

Substance Abuse & Mental Health Services Administration (SAMHSA)

ASD Research Funders Solicited

Private Funders of ASD Research

Autism Consortium

Autism Speaks

Autism Research Institute (ARI)

Center for Autism and Related Disabilities

Organization for Autism Research (OAR)

Southwest Autism Research and Resource Center (SARRC)

The Doug Flutie Jr. Foundation for Autism

The Simons Foundation (Simons)

IACC Decisions Today

Vote on including the following approaches in the process to update the Strategic Plan:

1) Town hall meeting(s)
   - Purpose
   - Timing
2) RFI
   - Purpose
   - Timing

IACC Decisions, Cont'd.

3) Scientific Workshops

- Possible Workshop in Fall 2009

- Possible Satellite Conference May 2010 (IMFAR) for the January 2011 update of the Strategic Plan

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•Vote on authorizing the Planning Subcommittee to:

- Review and analyze data gathered and make recommendations to the full IACC regarding updates to the Strategic Plan

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Update on IACC Summary of Advances CY 2008

Della Hann, Ph.D.
IACC Executive Secretary
May 4, 2009

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Initial ASD 2008 Comprehensive Publications List: Process and Criteria

- Comprehensive Library Search
  - Original science and reviews
  - Published in peer-reviewed journals
  - Calendar year (CY) 2008
  - Broad search terms: “autism” and “autistic”
  - Articles divided into 6 categories

Diagnosis	Biology
Risk Factors	Treatment
Outcomes	Services and Supports

Initial ASD 2008 Comprehensive Publications List: Process and Criteria

- Multiple sources to identify which articles are significant:
  - Biomedical literature databases (e.g., PubMed, Scopus)
  - News sections of major journals *(*e.g., Science, Nature*)*
  - Publications that highlight findings from scientific journals (e.g., Science News)
  - Databases of ratings/reviews of scientific publications (e.g., Faculty of 1000 Biology, Cochrane Reviews)
  - Newspapers (e.g., NY Times, Washington Post)

Article Selection Process

- On February 4, 2009, the IACC agreed to a structure for CY2008 Summary of Advances, similar to the previous year's document
  - Selection Process for IACC Members
    - Phase I: Add and delete articles from Comprehensive list (Completed)
    - Phase II: Finalize selections
- 6 IACC Members submitted articles for the final list (3 Federal, 3 Public)

Options to Consider

- Articles for Summary of Advances based on selection of <u>at least:</u>
  - 1 IACC Member

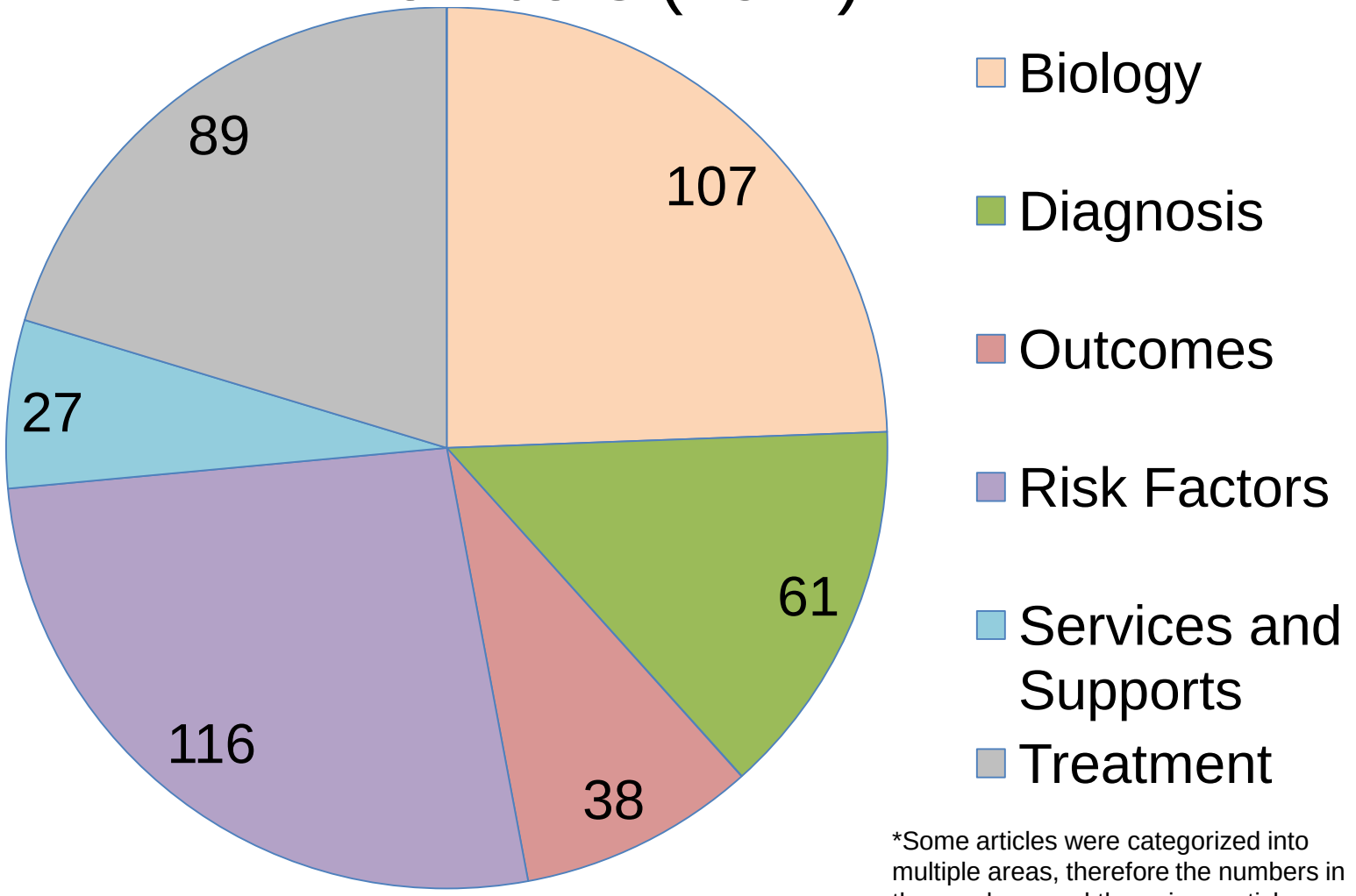
    (257 Unique Articles: 153 Research, 104 Review)
  - 2 IACC Members

    (120 Unique Articles: 97 Research, 13 Review)
  - 3 IACC Members

    (41 Unique Articles: 41 Research, 0 Review)

Option 1

Articles Selected by 1 or More IACC Members (257*)



*Some articles were categorized into multiple areas, therefore the numbers in the graph exceed the unique article count

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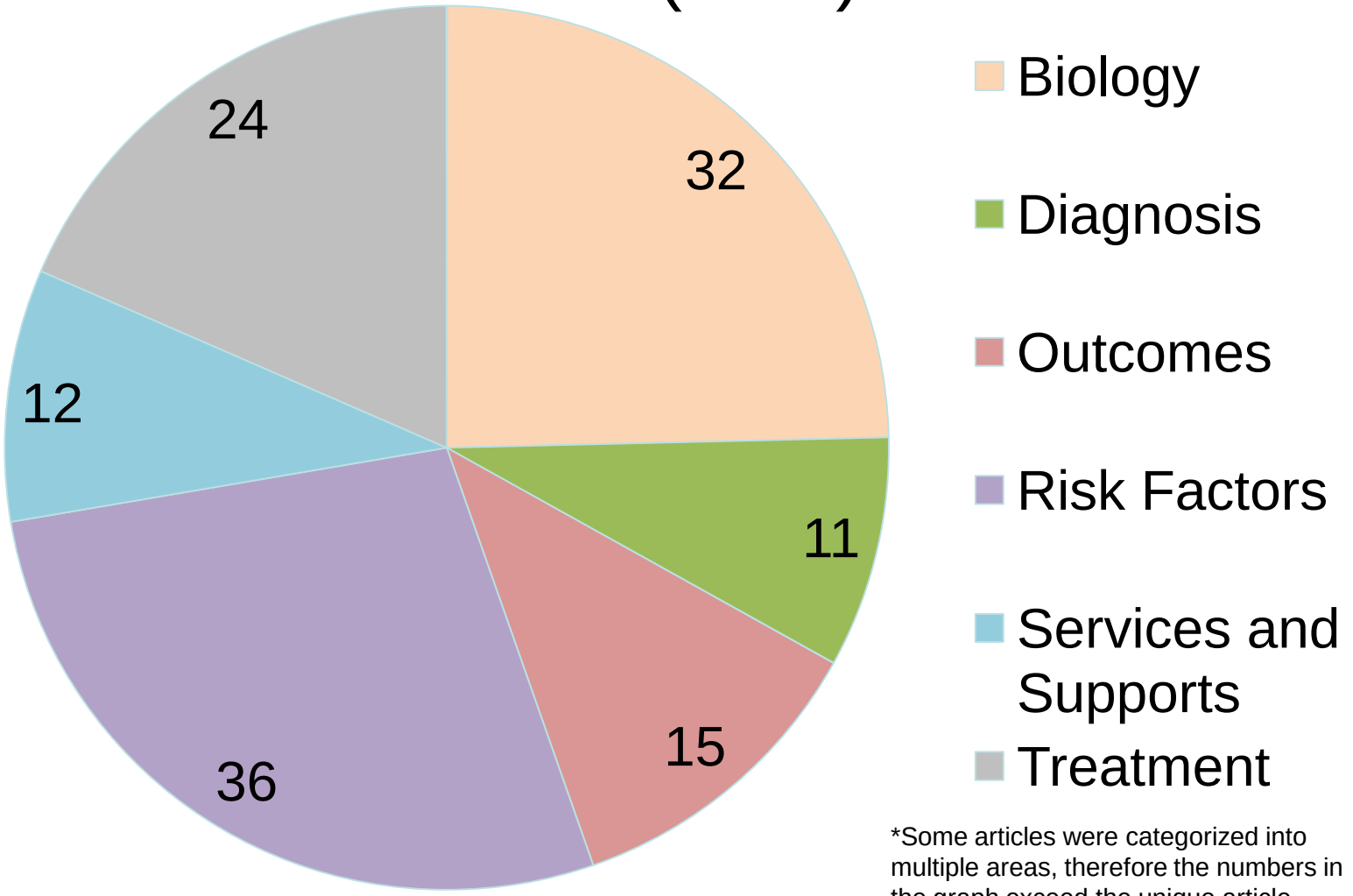
Option 2

Articles Selected by 2 or More IACC Members (120*)



*Some articles were categorized into multiple areas, therefore the numbers in the graph exceed the unique article count

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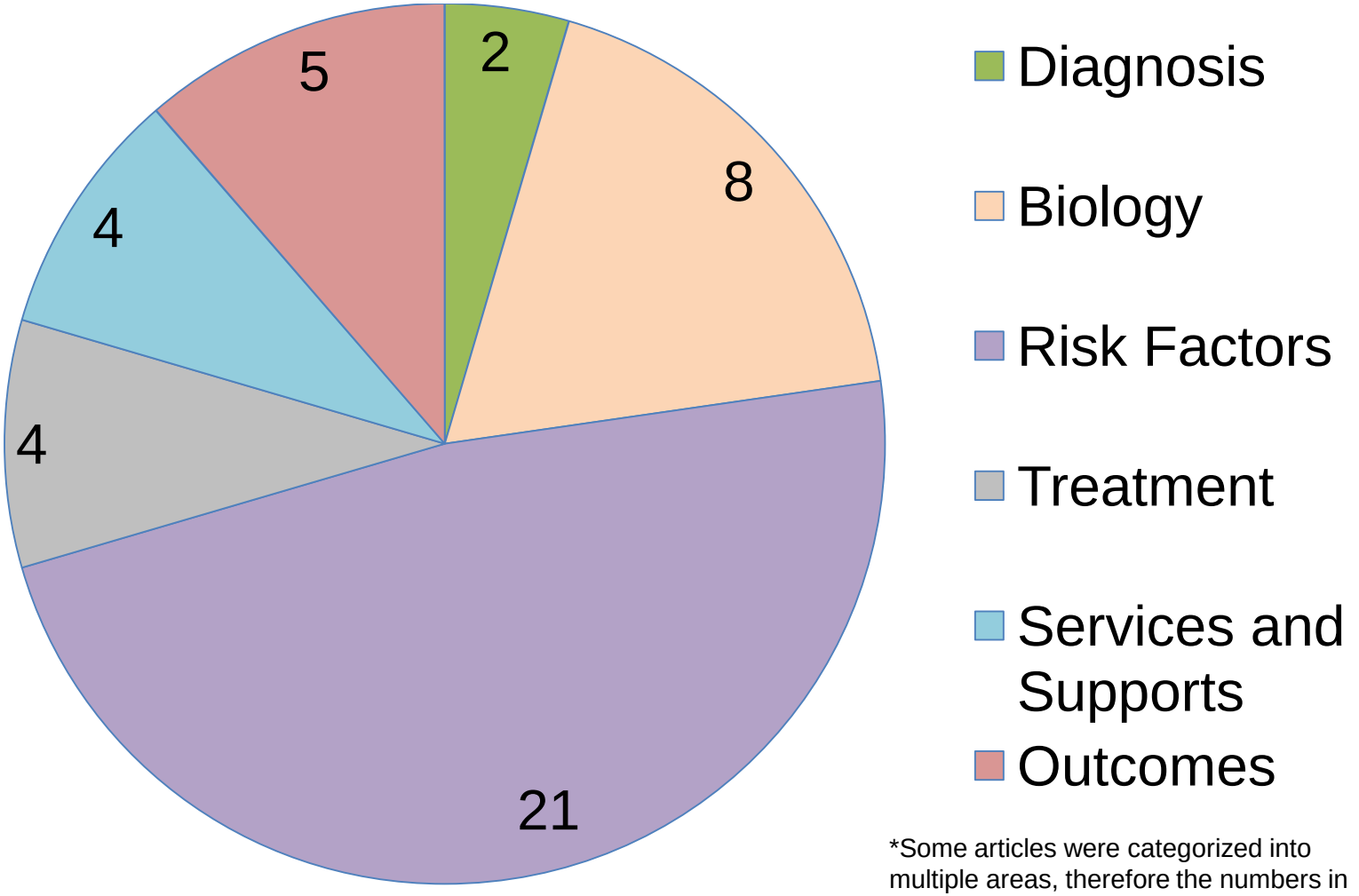
Option 3

Articles Selected by 3 or More IACC Members (41*)



*Some articles were categorized into multiple areas, therefore the numbers in the graph exceed the unique article count

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Duplicate Articles from 2007 Summary of Advances

Alarcón M et. al. (2008). Linkage, association, and gene-expression analyses identify CNTNAP2 as an autism-susceptibility gene. Am J Hum Genet. Jan;82(1):150-9.

Arking DE, et. al. (2008). A common genetic variant in the neurexin superfamily member CNTNAP2 increases familial risk of autism. Am J Hum Genet. Jan;82(1):160-4.

Bakkaloglu B, et. Al. (2008). Molecular cytogenetic analysis and resequencing of contactin associated protein-like 2 in autism spectrum disorders. Am J Hum Genet. Jan;82(1):165-73.

Duplicate Articles from 2007 Summary of Advances

Braunschweig D, et. al. (2008) Autism: Maternally derived antibodies specific for fetal brain proteins. Neurotoxicology. Mar;29(2):226-231. Epub 12/15/07.

Martin LA, et. al. (2008). Stereotypies and hyperactivity in rhesus monkeys exposed to IgG from mothers of children with autism. Brain Behav. Immun. Feb 7 [Epub].

Weiss LA, et. al. (2008). Autism Consortium. Association between microdeletion and microduplication at 16p11.2 and autism. N Engl J Med. 2008 Feb 14;358(7):667-75.

IACC Decisions

- Vote on which option to be used
- Vote on inclusion or non-inclusion of duplicate articles
- Timeline
  - First Draft
  - Final Report

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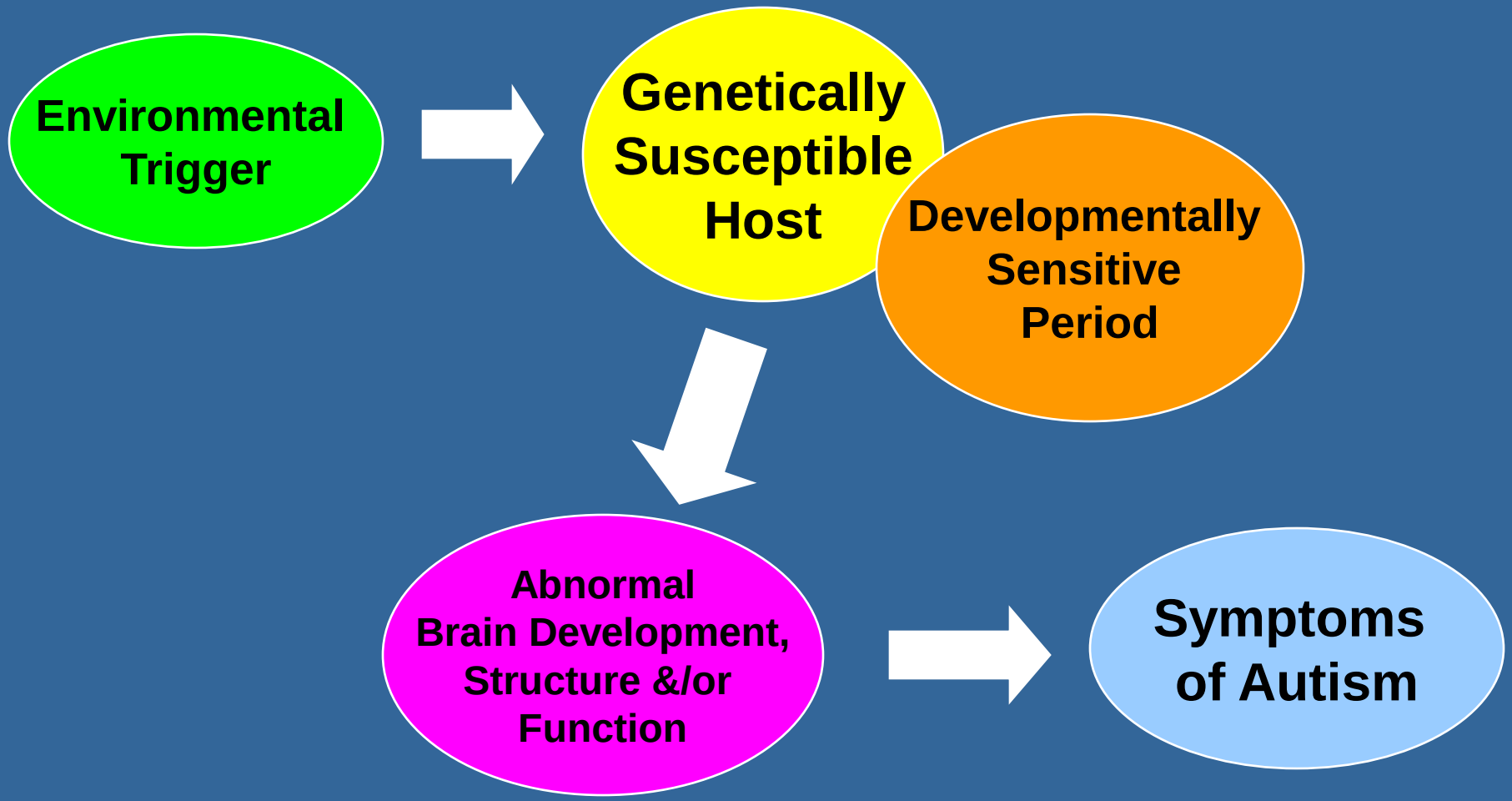
NIMH Autism Research Program

Discovering the Causes & Cures of Autism and Conducting Meaningful "Until Then" Research

Susan E. Swedo, M.D.
Pediatrics & Developmental Neuroscience Branch
National Institute of Mental Health
NIH Intramural Research Program

Finding the Causes & Cures for Autism



NIMH Autism Research Program

- **Multi-disciplinary Clinical Research Team**
  - **M.D.’s – Pediatrics, child psychiatry, neurology**
  - **Ph.D.’s – Developmental & clinical psychologists**
  - **Other professionals – Social work, biostatistics**
- **Support staff and Trainees**
  - **Administrative and support staff**
  - **Clinical and research fellows – Physicians, psychologists, speech and language pathologist**
  - **Post-baccalaureate IRTAs who plan to attend medical school or graduate school in 1 – 2 years**


You are here →
Our Office
To Cedar Lane

Collaborative Relationships

- **Within NIMH**
  - **CBDB: Emotional processing**
  - **CHP: DTI and Structural MRI scans**
  - **LBC: Social cognition; executive functions; fMRI (resting state)**
  - **LBN: Animal models**
  - **LNT: Proteomics/metabolomics**
  - **MAP: Co-morbid disorders; treatment trials; biostatistics**
  - **MIB: Magnetic resonance spectroscopy**
- **Within NIH**
  - **NCI: Neuroinflammatory markers**
  - **NHGRI: Specific genetic syndromes (e.g. SMS)**
  - **NIAID: Lymphocyte phenotyping and viral titers**
  - **NICHD: Clinical genetics (WAGR, SLO); CTDB; stem cell models (from skin fibroblasts)**
  - **NIDCR: Dysmorphology**
  - **NINDS: Electroencephalography & polysomnography**
  - **CIT: Database development**
  - **Clinical Center: Sedation safety; pharmaceutical development**

- **With Extramural Investigators**
  - FL State Univ: OCD in autism; speech/language abnormalities; early identification screening tool
  - Johns Hopkins: CSF/blood immune markers; cytokines response to minocycline; cholesterol study (also NICHD & OSU)
  - Mass General: MRI Clinical Findings; polysomnography studies
  - M.I.N.D: Phenome project; behavioral phenotyping
  - N.Y.U. Child Study Center: Sleep disorders in autism
  - UCLA: Genetics (expression profiling; SNPs)
  - UC Davis: Immunology; environmental factors
  - Univ Michigan: Diagnosis in toddlers
  - Vanderbilt: MET gene (Levitt); sleep and EEG abnormalities
- **Others**
  - Autism Treatment Network (Autism Speaks)
  - Clinical Trials Network (Autism Speaks)
  - Children's National Hospital: CSF collection
  - DSM-V Neurodevelopmental Disorders workgroup
  - Emory & Baylor: Genetic microarrays and MECP-2 testing
  - Medical Neurogenetics: Neurotransmitter metabolites
  - NIMH Autism Genetics Repository
  - IVIG Treatment Trial (Industry/Yale/Okla.)

Screening Study is Entry Point

- Comprehensive Diagnostic and Behavioral Evaluation
  - ADOS & ADI-R
  - IQ and Adaptive Functioning
  - Additional testing as needed

Cedar Lane clinic opened in Fall 2006
Since then, the Behavioral Evaluation Team have conducted more than 400 in-person screenings with more than 200 subjects eligible for PDN studies

Types of Investigations

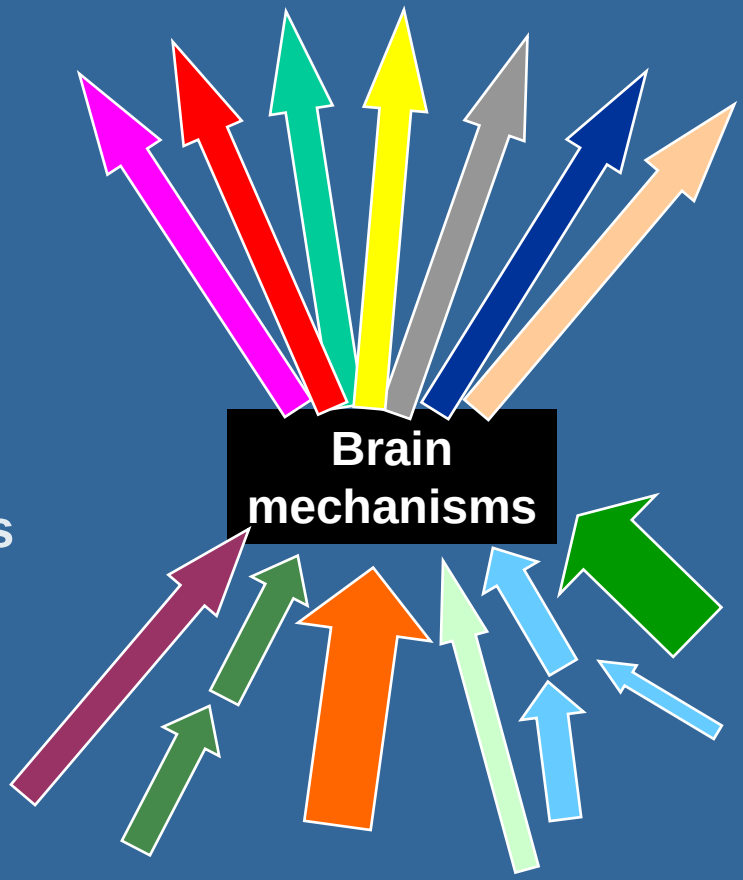
- **Phenomenologic (Phenotyping) Investigations**
  - **“Subtypes” study of 1 – 4 yr old children**
  - **Individuals with Remitted Autism**
  - **Specific neurodevelopmental disorders (e.g. SMS)**
- **Therapeutic Trials**
  - **Hypothesis-driven/generating studies**
    - **Minocycline for anti-inflammatory effects**
  - **Symptom-specific therapies**
    - **Riluzole for repetitive behaviors**
    - **Donepezil for REM sleep deficits**
- **Hypothesis-testing Experiments**
  - **fMRI study of oxytocin vs. vasopressin vs. placebo**
  - **MRS evaluation of treatment effects and response**


MRI Suite
Outpatient Clinic
EEG Suite
Pediatrics Unit
To Cedar Lane Clinic

The Autism Phenotyping Study

CLINICAL OR PHENOTYPIC VARIABILITY

There are many ways to trigger disruption of development AND there are many different outcomes of that disruption, but all are products of the brain … the proverbial "black box"



Common pathways leading to autistic outcomes – number and type is unknown

ETIOLOGIC VARIABILITY

The Autism Phenotyping Study

- Also called the Subtypes Study
- Comprehensive baseline evaluation with extensive behavioral and medical work-up
- Longitudinal follow-up for 3+ years
- Young children (ages 12-60 months)
  - 50 with AUTISM (no regression)
  - 50 with REGRESSIVE AUTISM
  - 50 Typically Developing CONTROLS
  - 25 with non-ASD DEVELOPMENTAL DELAY

The Regression Subtype

	No regression	Regression
No early signs	**Typical child**	**Regressive Autism**
Early signs	**Autism**	**Autism with Regression**

The Regression Subtype

- **However, it's not actually that simple**
- **Continuum, not dichotomy**
- **Does pattern of onset provide clues to etiology and pathophysiology?**

	No regression	*Some Regression*	Significant Regression
No early signs	Typical child		Regressive Autism
Some early Signs		Seen frequently	Seen occasionally
Many early signs	Autism	Seen frequently	Autism with regression

Subtypes Study: Preliminary Findings Electroencephalography (EEG)

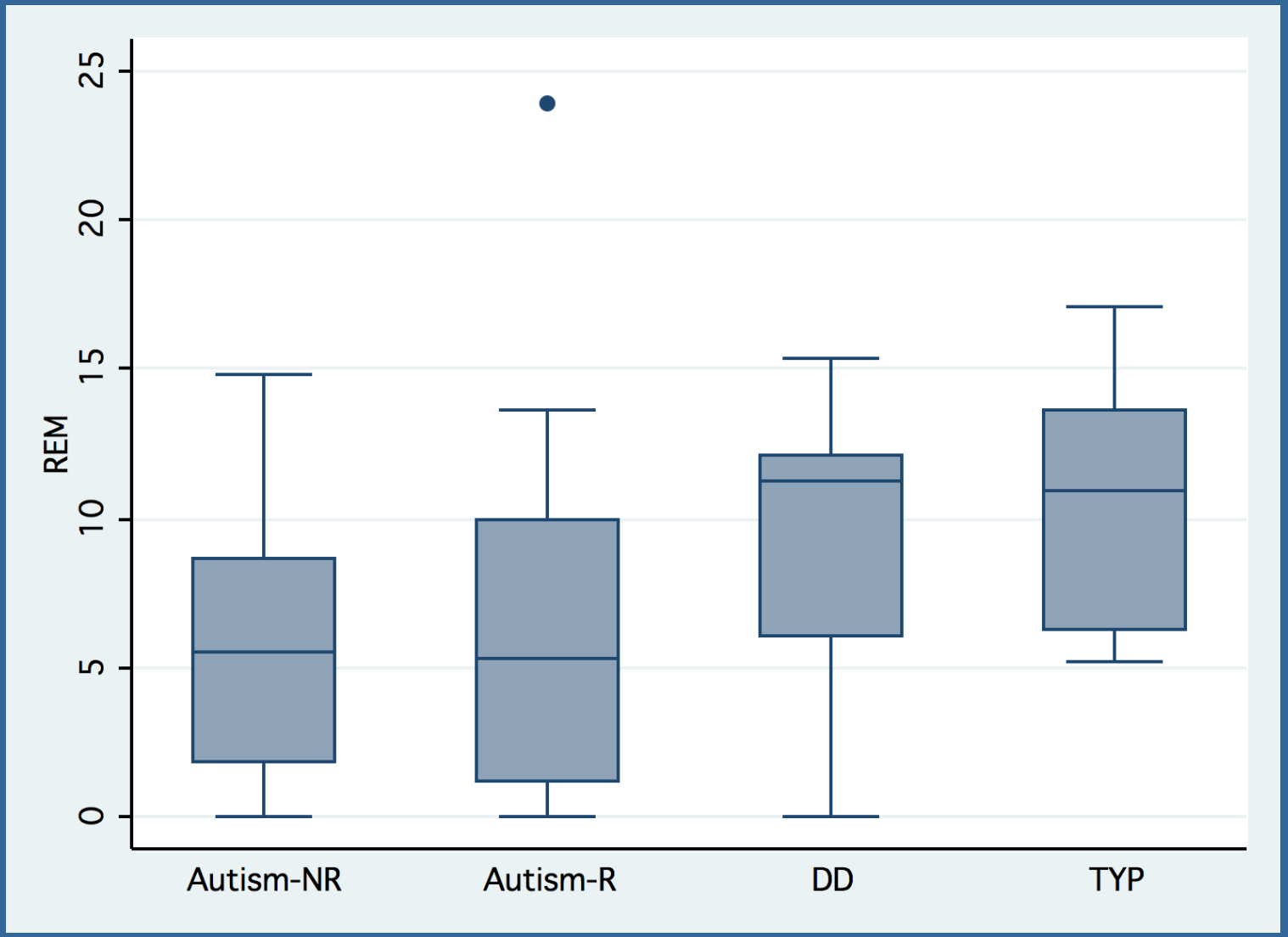
- **EEGs in first 50 autistic pts without epilepsy**
  - **Routine EEGs abnormal in 10 studies (20%)**
    - **Nonepileptiform 3**
    - **Epileptiform 9**
  - **Overnight EEGs abnormal in 30 studies (60%)**
    - **Nonepileptiform 5**
    - **Epileptiform 25**
      - **15 frequent and 9 infrequent**
      - **11 diffuse, 4 multifocal, and 11 focal (mostly left temporal)**
- **Epileptiform discharges may provide new therapeutic target**

Subtypes Study: Preliminary Findings Sleep Abnormalities

- **Modified Polysomnography (PSG) can measure sleep parameters in real-time**
- **Preliminary Findings (n = 50):**
  - **Decreased sleep efficiency**
  - **Prolonged latency to REM sleep**
  - **Decreased total time spent in REM sleep**

NOTE: Most of these children did NOT have reported sleep difficulties

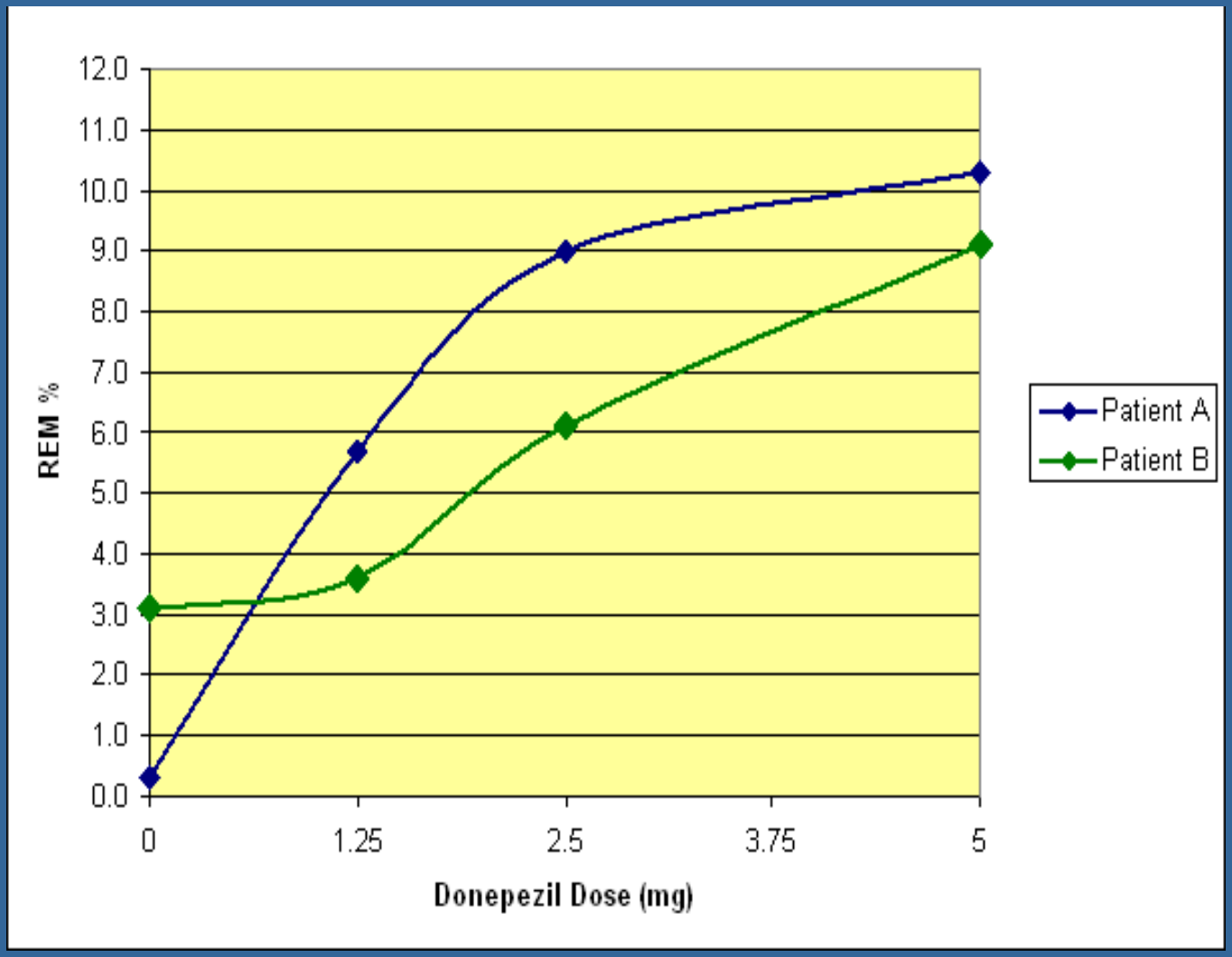
Comparison of Mean REM Percentages for Regressive and Non-Regressive Autism, Dev. Delay and Typically Developing Groups



Trial of Donepezil to Treat Sleep Abnormalities in Autism

- Clinical trial to determine whether donepezil (Aricept) has an effect on REM sleep.
- Among elderly adults, donepezil increases REM.
- Open label trial with 3 doses of donepezil and repeated overnight sleep studies (polysomnography)
- Titrate dose to maximize response and ensure sustained effects

Donepezil Dose-Response Curves

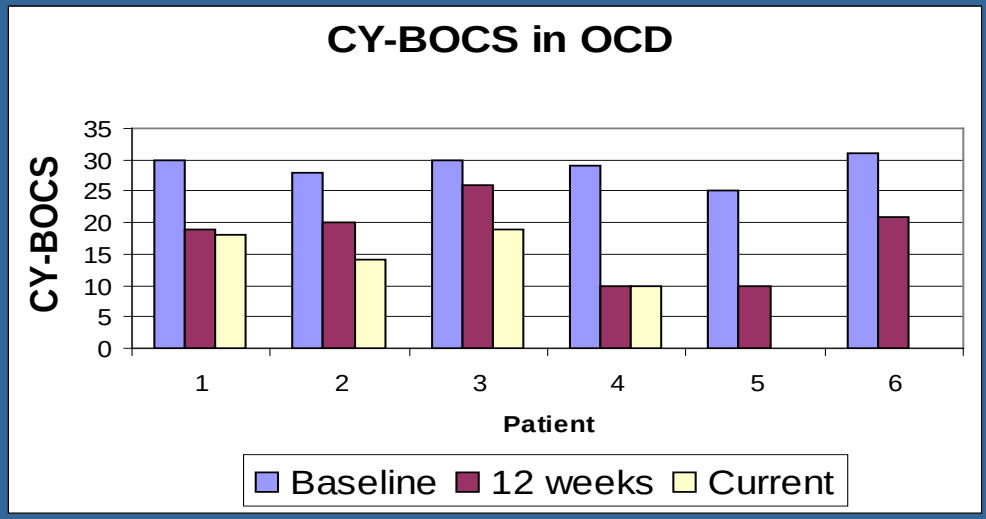


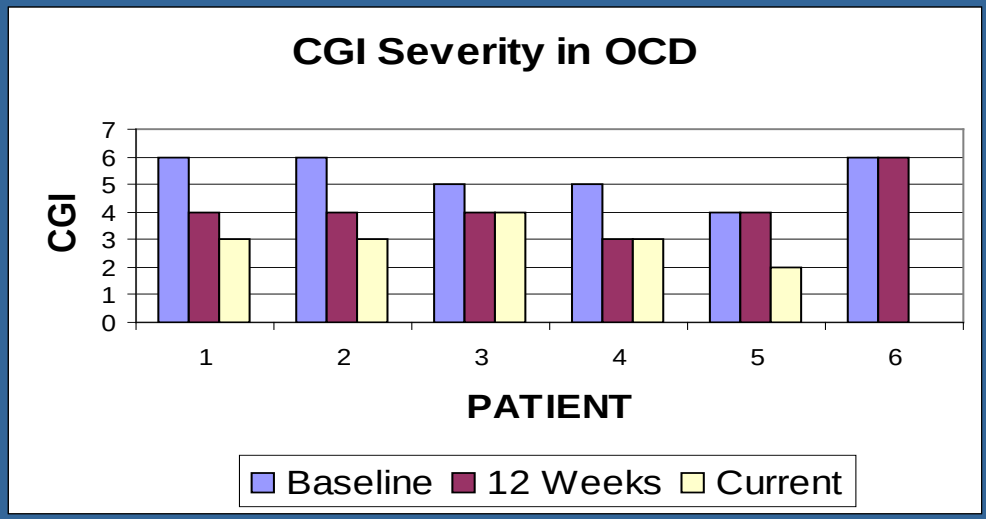
Minocycline Treatment Trial

- Has shown benefits in neurodegenerative conditions (Huntington's, ALS, MS)
- Mechanism may be its anti-inflammatory properties (blockade of NF-kappa B)
- OPEN LABEL trial in 15(10) children with regressive autism
- Measures include:
  - Changes in CSF & serum cytokine and chemokine analyses before and after therapy (Analyses by Dr. Carlos Pardo at Johns Hopkins Univ)
  - Effect on behavioral change
- Placebo-controlled trial will enroll children with "responders" pre-treatment CSF profile

Riluzole Treatment Trial

- Riluzole is a glutamate "antagonist" -- glutamate is the primary excitatory neurotransmitter in the fronto-cortical-striatal circuit (involved in OCD and tic disorders).
- Placebo-controlled trial
  - 30 subjects w/ OCD
  - 30 subjects w/ OCD + ASD
- 12 weeks double-blind
- 9 months open-label
- Recruitment is ongoing





Open Label Trial in 6 pts w/ OCD

REMITTED AUTISM STUDY

- **Purpose is to identify effective treatment regimens and predictors of remission as first step in developing new, more effective therapies.**

- **Comprehensive evaluation of:**
  - **40 children whose symptoms have remitted**
  - **40 children (similar at baseline) who retain symptoms of autism.**

REMITTED AUTISM STUDY

- NIH review of medical and developmental records
- Comprehensive medical and behavioral evaluation
- MRI, EEG, and Neuropsychological testing during 2 days inpatient stay

NIMH Contact Information

- **Remitted Autism Study**
  - **Phone: 301-435-6205**
  - **AutismOutcomeStudy@mail.nih.gov**

- **Other Studies**
  - **Phone: 301-435-7962**
  - **NIMH-ASD@mail.nih.gov**
  - **http://patientinfo.nimh.nih.gov**

NIMH
National Institute of Mental Health

Autism and Augmentative and Alternative Communication: Research-based and Promising Practices

Interagency Autism Coordinating Committee
National Institute of Mental Health
May 4, 2009

Joanne M Cafiero, Ph.D.

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Topics to Consider Today:

- Definition and features of ASD and AAC
- Evidence-Based Practices in AAC
  - Functional Communication Training, PECS, Visual Supports, Activity Schedules
  - Augmented Input Strategies
  - Speech-Generating Devices (SGDs)
  - Keyboard Communication Systems

Myths about AAC and Autism

- **AAC will inhibit or preempt the development of speech.**
- **AAC is not needed if an individual with ASD has speech.**
- **If AAC is provided to an individual with ASD, he/she will use it.**
- **If an individual is provided with AAC and does not use it within a certain time frame he/she will never use it.**
- **No and low-tech are better options for people with ASD.**

Learning Characteristics in ASD

- Cognition
- Visual processing
- Multiple cue responding
- Stimulus over-selectivity
- Affective & Social Learning
- Sensory Issues
- Motor Planning: motor movements including speech

Autism and Mental Retardation

(Edelson, 2006)

- **Autism and Intelligence Timeline**
- **Reviewed 215 articles (1937-2003)**
- **74% of claims non-empirical sources**
- **53% of 74% not traced to any data**
- **Empirical data was from developmental or adaptive scores rather than cognitive scores**
  - **Language based**
  - **Unanswered questions considered wrong**

Autism and Motor Impairments

- Kanner (1943) & Asperger (1944)
- 100% of Sample children with ASD had below average gross or fine motor skills
  - (Provost, Lopez, & Heimer 2007)
- 41% of children 2-6 with ASD had oral motor or hand/muscle apraxia
  - (Ming, Brimacombe & Wagner, 2007)

Autism and Motor Planning

- Atypical “Reach to Grasp” Movements
  - (Rhinehart et.al. 2005)
- Atypical Movement Preparation
  - (Mari et.al, 2003)
- Impaired Motoric Preparation & Initiation
  - (Rhinehard, Bellgrove, et.al., 2006)
- Impaired Movement Toward Goal
  - (Vernazza-Martin, et. Al., 2006)

Autism and Co morbidity with Affective Disorders

- **Oppositional-Defiant Disorder**
- **Obsessive-Compulsive Disorder**
- **Anxiety Disorder**
- **Psychosis**
- **Selective Mutism**

Communication and ASD

- **50% with no functional language**
- **Limited to requesting and refusing**
- **Inconsistent patterns of language expression**
- **Unique developmental sequence of language skills**
- **Symbolic language (speech or sign) sometimes emerging in adolescence**
- **Functional spontaneous communication is key in facilitating quality of life outcomes (NAS, 2001).**

What is Augmentative and Alternative Communication? (AAC)

- **NO pre-requisites required**
- **Compensates for or replaces speech**
- **Multi-modal**
- **Provides supports for *development* of language**
- **Includes no-tech, low-tech, high tech**
- **Unaided and Aided AAC**

Interface of AAC (aided) and ASD

ASD	AAC
Visual processing	Uses visual medium
Motor planning	Requires less motor skill
Multiple Cue Responding	Scaffolding for complexity
Social difficulties	Buffer and bridge
Interest in inanimate objects	Uses tools & technology

Aided vs. Unaided AAC

(Millar, Light & Schlosser, 2006, Mirenda, 2003)

- Unaided - Manual Signs
  - Requires good fine motor abilities
  - Unlimited vocabulary
  - Portable
  - Not readily comprehensible
- Aided - SGDs, communication boards, keyboards, email
  - requires lower fine motor skills
  - more readily comprehensible
  - Not readily portable

  - ***Neither Aided nor Unaided have been found to be superior to the other!***

Effects of AAC on Speech Production in Children with ASD

Schlosser & Wendt, 2008

- Systematic review 1975-2007
- Stringent criteria for inclusion
  - Calculation of % non-overlapping data (SSD)
    - 20/22 data sets- PND between 80-100%
  - Calculation of effect size (group studies)
- Peer-reviewed journal or approved dissertation
- Included SSD and Group Studies
  - 5 PECS, 1 Manual Sign, 3 SGDs

AAC does not inhibit speech production; most studies showed AAC effected modest *increases* in speech

(Schlosser & Wendt, 2008)

Autism and Aided AAC: What are the Evidence-based Practices?

- Functional Communication Training
- Picture Exchange Communication System
- Augmented Input Strategies
- Speech Generating Devices

Evidence-based Practice: FCT with Aided AAC

- Functional Communication Training
  - PCS, objects, SGDs, Ideographs
  - Views all behavior as communicative
  - Replaces aberrant behavior with communication
  - Must be efficient, acceptable and recognizable
  - ***FCT produced "immediate, substantial and sustained" decreases in aberrant behavior (Mirenda, 1998)***

I need a break.

I need help

I want some chips.

I want the Quiet Room

Evidence-based Practice: PECS

- Systematic sequential protocols
- Exchange a symbol for a desired item
- Expressive communication only
- Acknowledges communication partner
- Approximately 1/2 children developed speech
- (Bondy & Frost, 1994; Lancioni et.al, 2007)

Evidence-based practice: Speech Generating Devices (SGDs)

- **Low-tech (1 - 32 cells, single & multi-level)**
- **High-tech**
- **Summons attention of communication partners**
- **Model for speech**
- **Used alone or with other aided AAC**
- **Schepis, Reid & Behrman, 1996; Schepis, Reid, Berhman & Sutton, 1998)**
- **Augmented input model (SAL, Romski & Sevcik, 1996, 2006, 2008).**

Speech Generating Devices

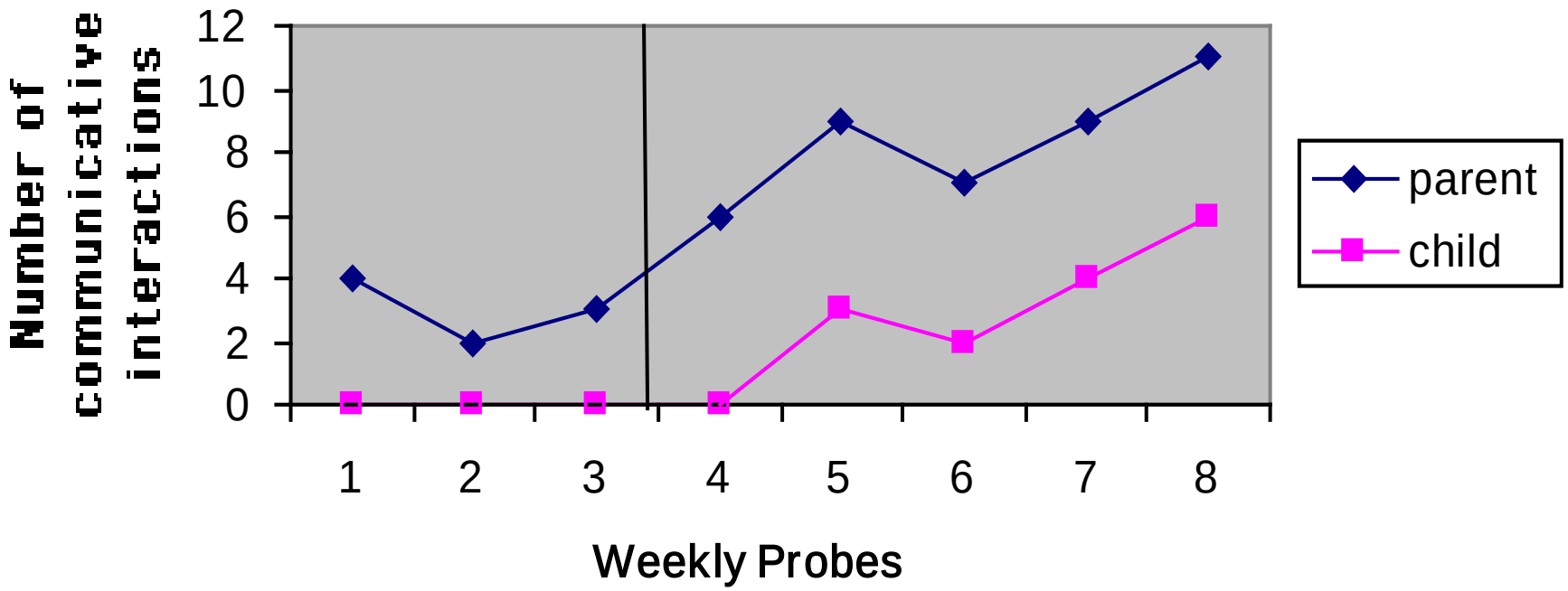
- **Use of SGD was not immediately preceded by prompt** (Datillo & Cammerata, 1991, McGregor et.al, 1992; Schepis et.al, 1996; Schepis et.al, 1998).
- **Use of SGDs increased communicative behaviors such as vocalizations, words, gestures** (Sigafoos, Didden & O'Reilly, 2003; Schepis, Reid, Behrmann & Sutton, 1998).

Evidence-based practice: Augmented Input Strategies

- Communication partner essential
- Receptive language training (INPUT)
- AAC viewed as legitimate language
- Natural Aided Language, System for Augmenting Language, Visual Routines, Aided Language Modeling
- **Effective in increasing spontaneous communication** (Cafiero, 1995, 1998, 2001, 2005; Dexter, 1998; Acheson, 2006; Light & Drager, 2005; Drager et.al. 2006, Romski & Sevcik, 2006; Romski et.al., 2008).

I want 	more 	please 	open 	thank you 	yummy 
sit down 					yucky 
share 					trash 
wipe face 					upset 
wait 	drink 		cookies 		finished 

Number of Communicative Initiations and Responses: Parent and Child with and without NALS



apple

pretzel

free time

fan

raisins

rub

drink

cookies

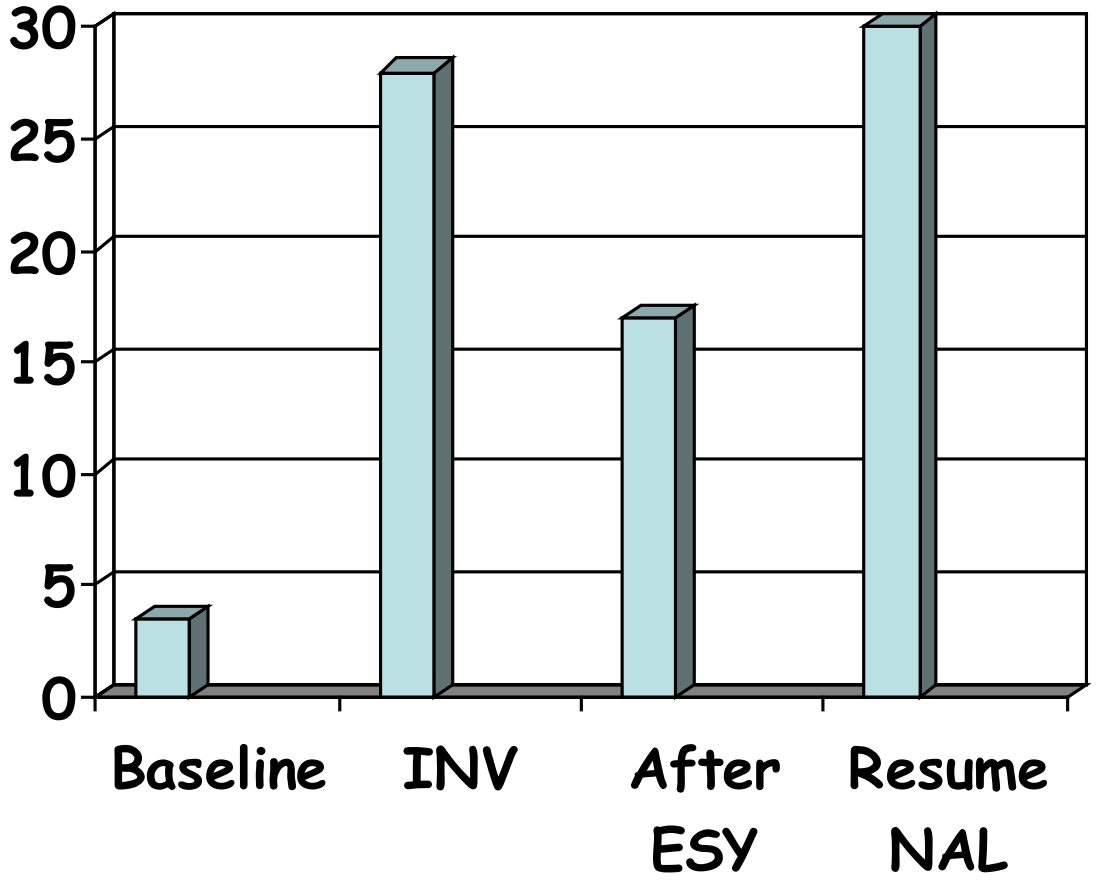
bathroom

no	good job	I need help	please	more	thank you	yummy	yucky	yes
								
I want	eat	sit	pour	cooking spoon	plate	pancakes	upset	free time
								
my turn	drink	wait a minute	spread	frying pan	fork	cereal	waffles	hungry
								
	set table	taste	sit	toaster oven	spoon	bowl	butter	thirsty
								
	serve	wash dishes	hot	honey	napkin	syrup	wash	finished
								

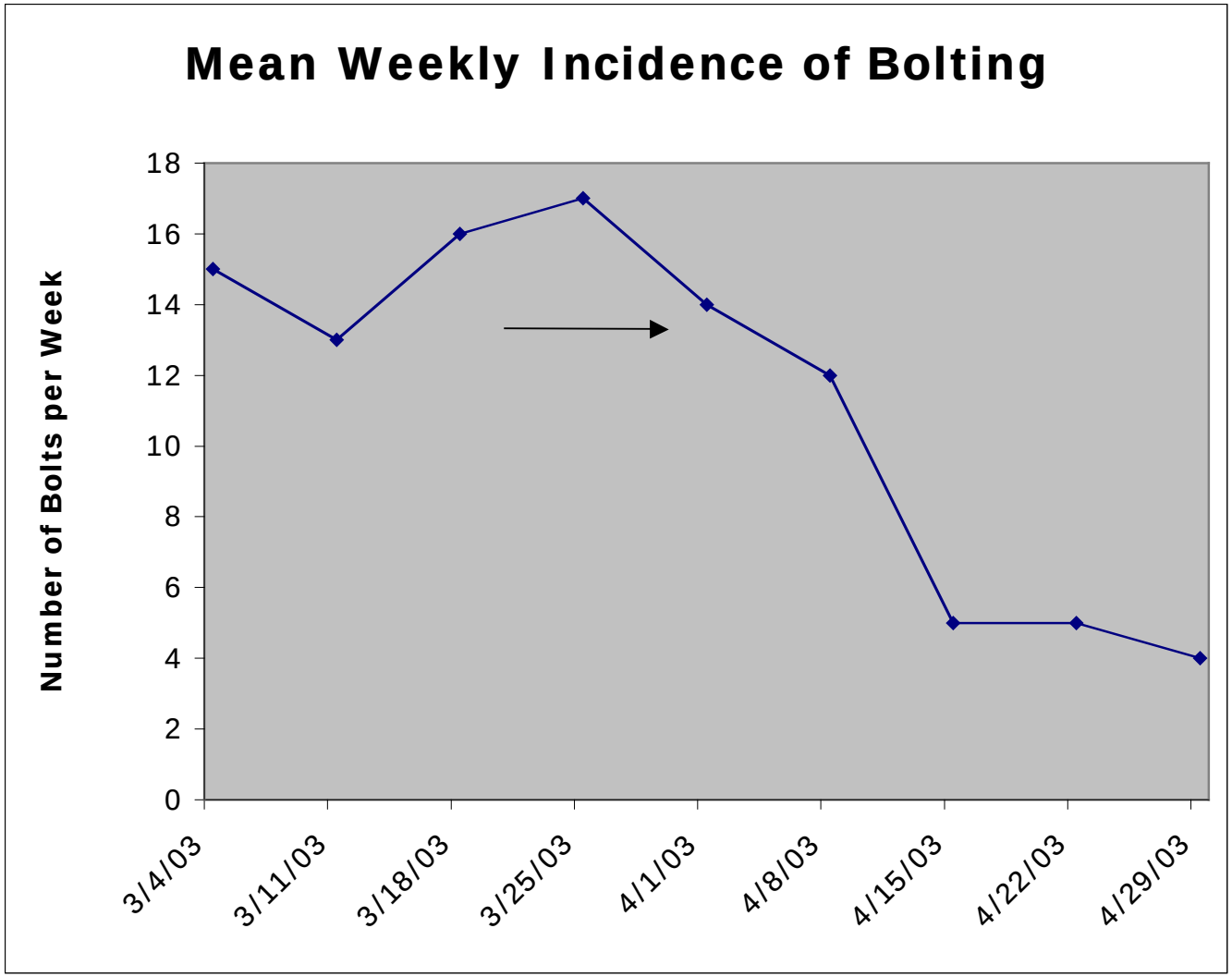
Timothy- Natural Aided Language Intervention

- Increased augmented communicative input (visual symbols) from 9 to over 60
- Engineered all environments and activities for communication
- All staff trained in Natural Aided Language

Number of PCS Initiations with Natural Aided Language Intervention



Charting “Bolting” (standing up, leaving instructional group without directions to do so)



SGDs & Autism: Toddler Study

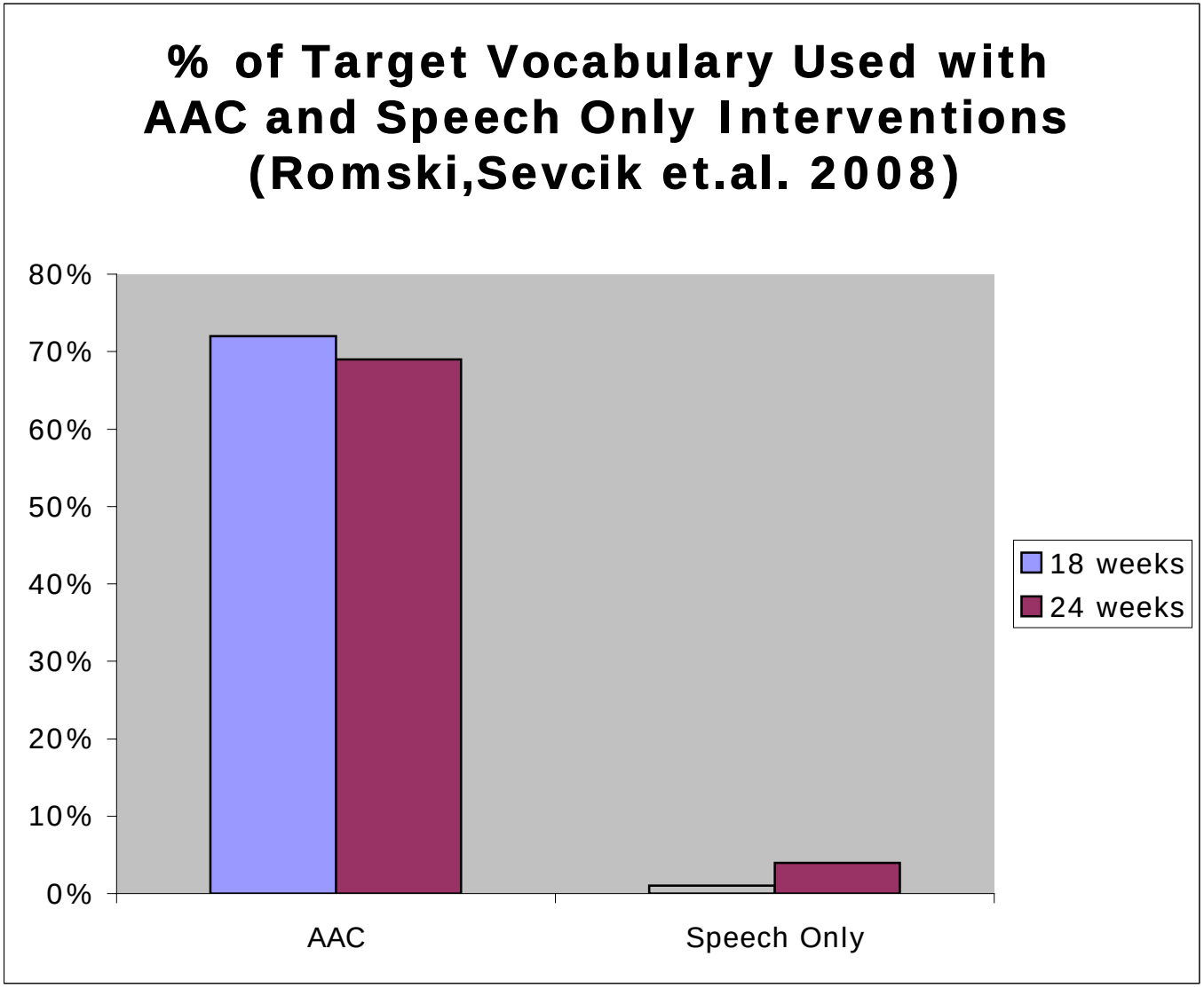
Romski, Sevcik, Smith, Barker, Folan & Barton-Hulsey, 2008

- Retrospective analysis
- 3 groups of 20 toddlers: 14ASDs
- Parent training in stimulating speech
- Group 1- no AAC, speech supports only
- Group 2 - aided AAC, focus on comprehension (augmented input)
- Group 3 - aided AAC (augmented input) focus on input and child's output

System for Augmenting Language

(Romski & Sevcik, 1996)

- Speech-Generating Device
- Relevant Lexicon/vocabulary & visual/graphic symbols
- Teaching through natural communicative exchanges
- Communication partners integrated SGDs into their own spoken language


% of Target Vocabulary Used with AAC and Speech Only Interventions (Romski,Sevcik et.al. 2008)
80%
70%
60%
50%
40%
30%
20%
10%
0%
AAC
Speech Only
18 weeks
24 weeks

System for Augmenting Language Results:

- Children who received ACI or ACO Interventions were able to communicate using symbols after 18 sessions and generalized & maintained this language at home.
- Children in SCI group could produce only few words by 18 sessions and had no conventional way to communicate while learning to speak.

- “…results of related studies in Natural Aided Language, Aided Language Modeling and System for Augmenting Language provide preliminary support for the suggestions that language modeling with symbols in natural contexts may be a viable language intervention for young children with ASD” (Mirenda, 2008).

Non-activity specific Communication Displays and Devices

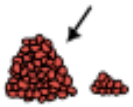
- Motor planning?
- Core vocabulary?
- Device with capability for increases in vocabulary and communicative function
- Motor memory or visual discrimination?
- Preliminary data

Core & Fringe Vocabulary: both are required for communication

- Core
  - More open ended
  - Applicable to many situations

- Fringe
  - Specific to a particular activity
  - Vocabulary size across activities can be enormous

Core

I want 	more 	stop 
my turn 	need help 	yummy 
you 		I don't wan 
uh-oh 	I don't know 	finished 

Fringe

on 	waffle 	hot 
spread 	cream 	toaster 
butter 	syrup 	sprinkle 
plate 	honey 	sugar 

8 Location Phrase-based Core Vocabulary

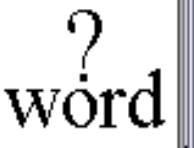
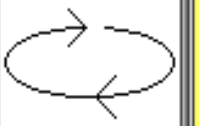
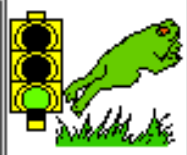
hi 	I don't understand 	I need help 	something different 
yes 	more 	Write it 	Good bye! 

AAC Systems: Visual Discrimination or Motor Memory?

- Visual Discrimination
  - Strong visual processing
  - Supports literacy
  - Requires huge number of icons/symbols
- Motor Memory
  - Speech is motoric; AAC should be too
  - Promotes more “automaticity”
  - Training essential

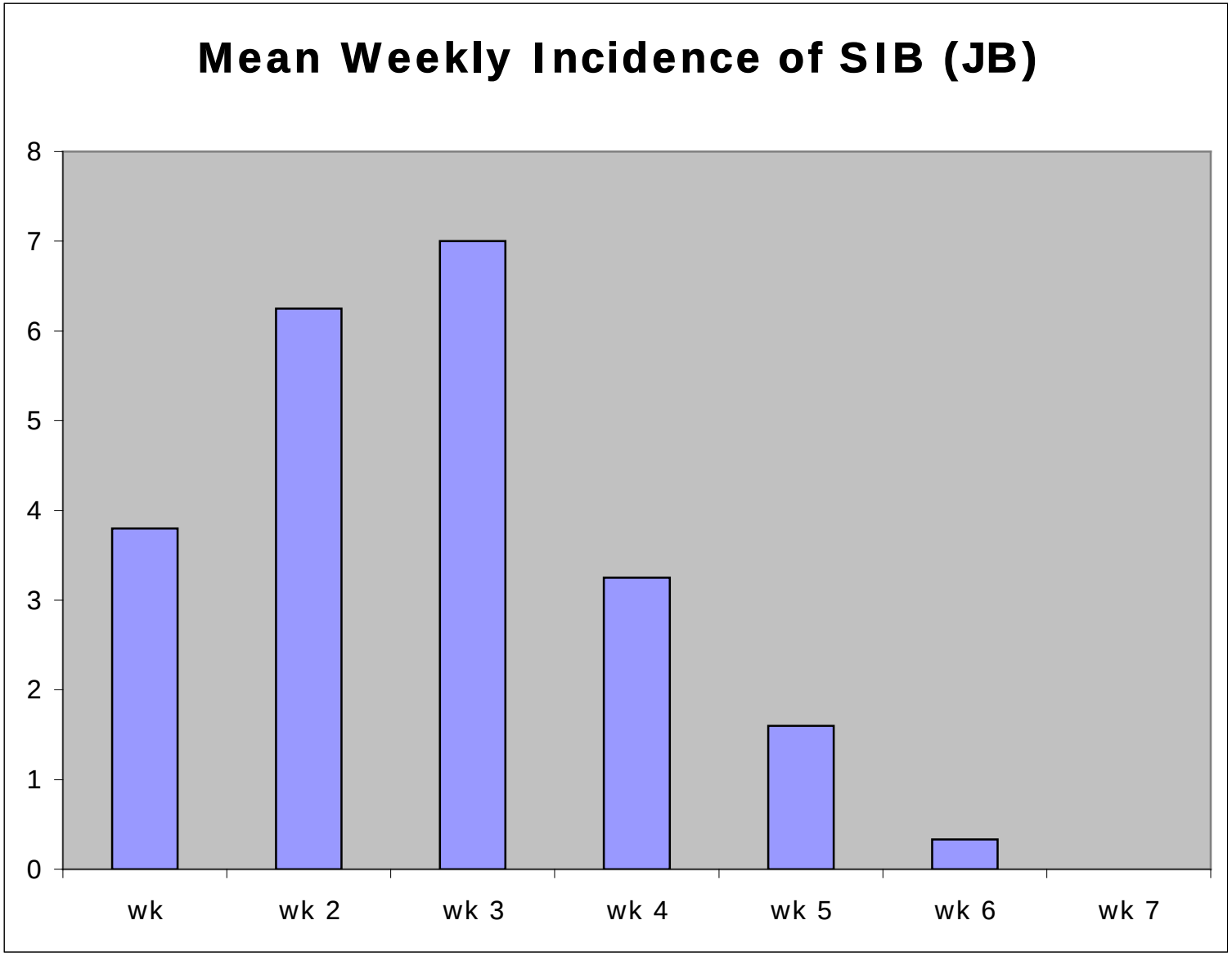
Case Study: Jacob

- 6 years old
- 3 years of no-tech communication boards, books, wallets
- “barking” as primary requesting behavior
- emergence of SIB
- introduction of High-Tech AAC
  - Springboard
  - Training of communication partners

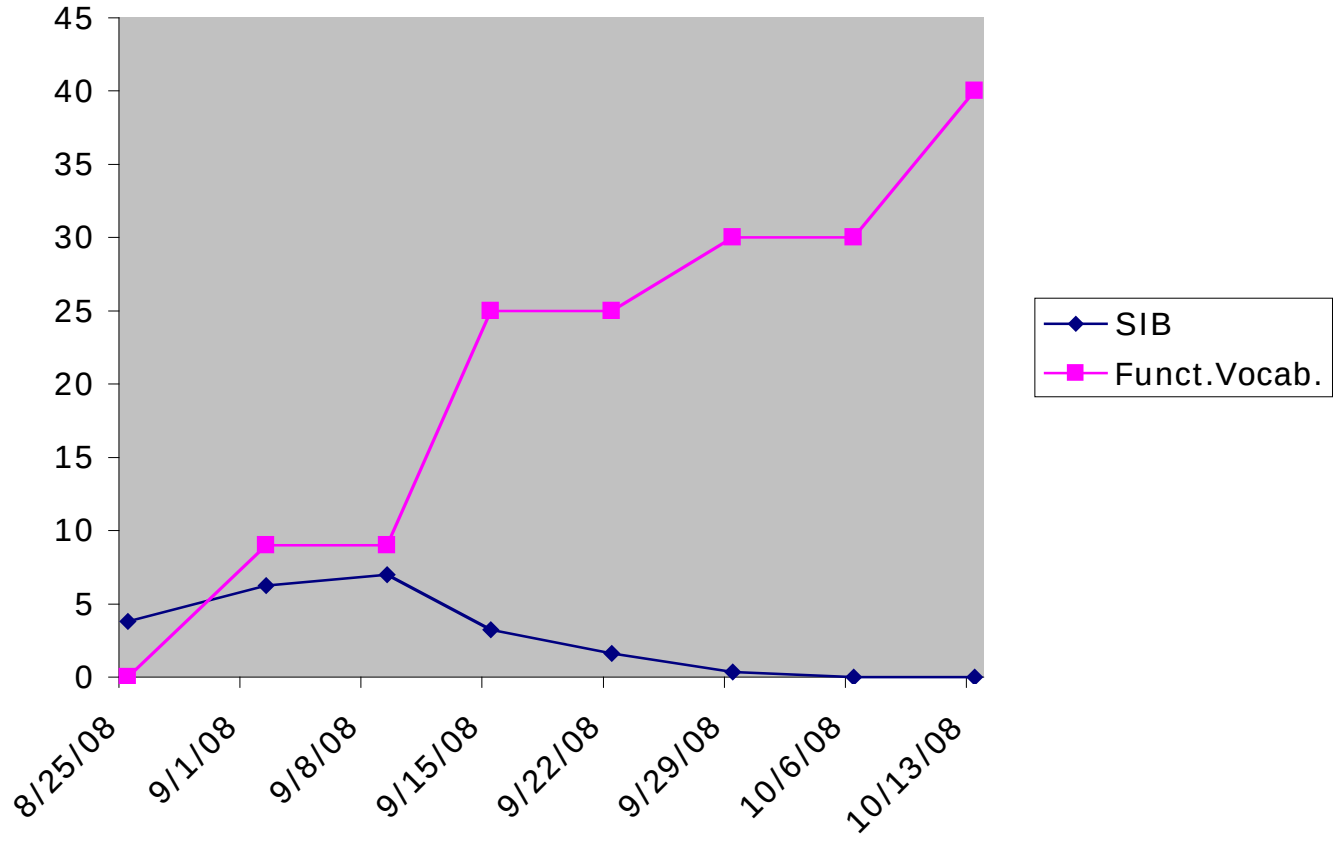
 NAME	 my	 is	 please	 that	to	 more	 what
 PAGES	 I	 play	 like	 get	 read	 put	 help
 ACTIVITY	 you	 want	 come	 FAMILY	 do	 go	 look
CLEAR	 it	 don't	 eat	 make	 drink	 feel	 stop

Jacob's Springboard™ Intervention

- Introduced Springboard during structured academic settings
- Communication partner viewed Springboard as Jacob's voice and ears & provided augmented input
- Navigation strategies were modeled naturally
- Jacob's requests were immediately acknowledged
- Incidences of SIB charted


Mean Weekly Incidence of SIB (JB)
8
7
6
5
4
3
2
1
0
wk
wk 2
wk 3
wk 4
wk 5
wk 6
wk 7

Functional Vocabulary on High Tech AAC and Incidence of SIB



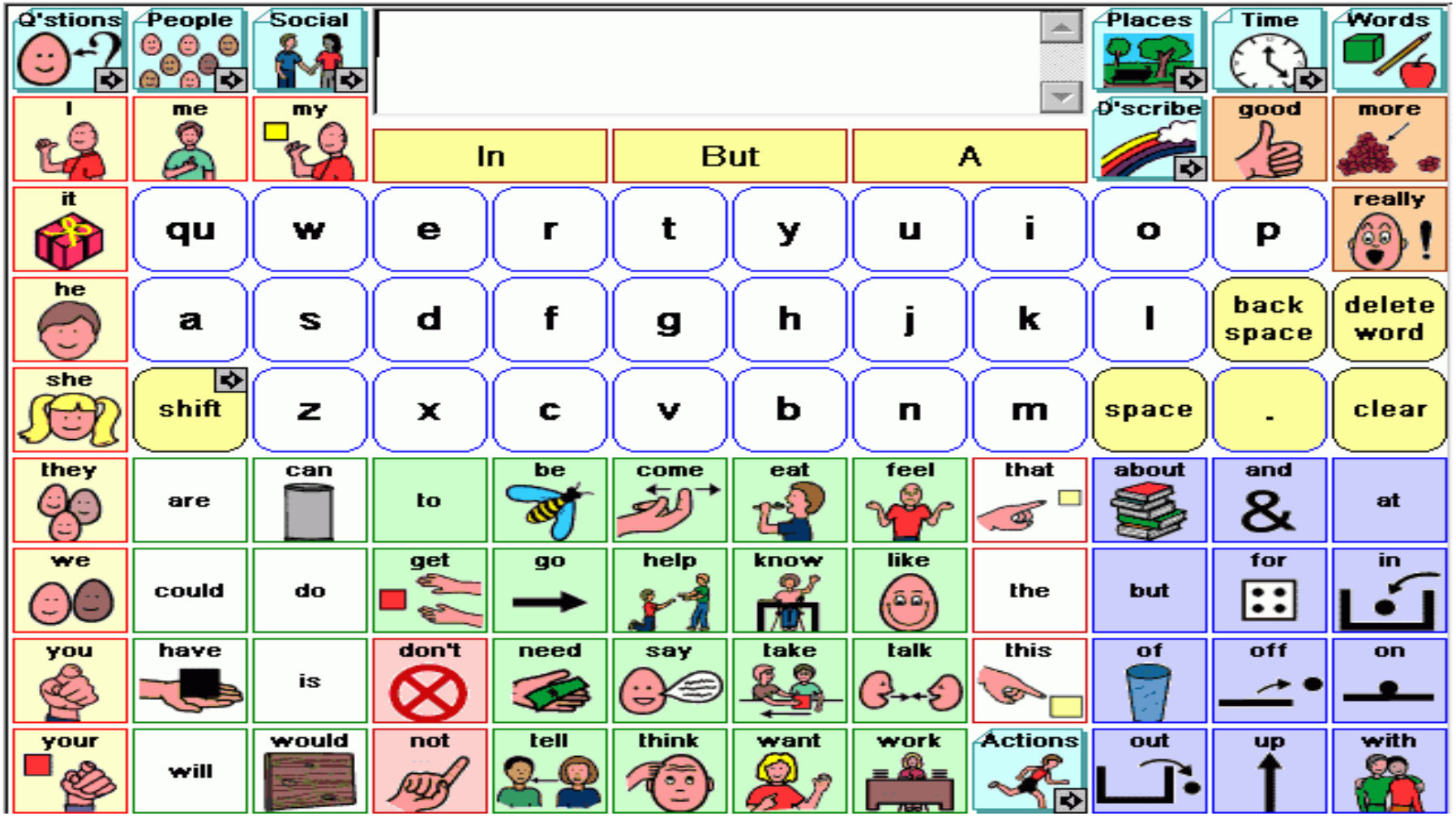
Observational Results: Jacob

- Used device during academics, meals, and preferred activities
- Navigated and found new vocabulary not previously modeled by communication partners
- Vocalized while activating SGD
- Continued to use and accept low tech for some receptive and expressive language
- Vocalized to make requests and engaged in SIB when Springboard was not available

Sample of SGDs Currently Used by Individuals with ASD

- Static display, multi-level devices (GoTalk, Tech Talk, Lingo, Talk Trac)
- Dynamic display devices (DynaMite ™ Chat PC, Proloquo2Go)
- Communication Programs
  - Unity
  - Picture Word Power & Word Power
  - Speaking Dynamically

Picture Word Power



Literacy *In* AAC

- Limited literacy opportunities for students with ASD
- Visual processing, hyperlexia
- Essential to acknowledge, honor, expand emerging literacy skills
- Target comprehension & communication

Keyboard Communication

- Adult Autism Advocacy Movement
- Keyboard Communication vs. “real time” communication
  - Wait time, coordinating listening & communicating
  - Mechanics of the device, positioning
- Note qualitative difference between our own spoken vs. written language
- Former speaking communicators as adults transitioned to AAC
- Model is the same; communication partner gives consistent augmented input.

Assessment Tools for AAC

- SETT (Zabala)
  - Student, Environment, Task, Tools
- **Social Networks** (Blackstone & Berg)
  - Circles of Communication Partners
- **Participation Plans** (Beukelman & Mirenda)
  - What does the student need to participate? What are the barriers? What AAC tools facilitate participation and eliminate barriers?

Critical Research Questions

- **How does a clinician match an AAC tool/strategy to the individual?**
  - **Entry level AAC: no, low or high tech?**
  - **Motor memory or visual discrimination?**
  - **Structured, direct instruction or aided language approaches?**
  - **Maintenance AAC: No-tech, low-tech or high tech?**

About Communication Partnerships:

- Communication opportunities are created by the communication partner.
- Speaking ***communication partner*** must view AAC as the voice and ears of the student
- Speaking ***communication partner*** must use the AAC device, pairing speech with AAC to acknowledge, repair, expand and model the language.
- Speaking ***communication partner's*** investment is essential for a successful AAC intervention.

What is the ultimate goal of AAC? *SNUG*

- ***Spontaneous***
- ***Novel***
- ***Utterance***
- ***Generation***
  - The ability to access individual words, expressions, and commonly used phrases.
  - Allows an individual to say anything, ***about*** anything at anytime.

Key Points

- **Augmented communicative input is key.**
- **Assumption of communicative potential regardless of and perhaps because of of behavioral issues**
- **AAC helps *develop* language.**
- **No Arbitrary timelines on AAC intervention**
- ***Functional spontaneous communication***

- “…in the immortal words of Mick Jagger, we ‘can’t get no satisfaction’ until we have figured out how to provide every individual with ASD with a viable, robust, flexible, and generative communication system that will support long-term language development.”
  - (Mirenda, 2008)

Augmentative and Alternative Communication

Dora Raymaker
Co-Director, Academic Autistic Spectrum Partnership in Research Education
Board of Directors, Autistic Self Advocacy Network

IACC 2009/05/04

ASAN
The Autistic Self Advocacy Network

Why We Care About Communication

“One of the biggest keys to an autistic person getting the life they want is for that autistic person to be able to express, in a way that allows the largest number of people to understand, their own desires and thoughts.”
-Joel Smith

“Communication freed me from the pain of compressing the human dimension into empty silence.”
-Alberto Frugone

“One of the most important pieces of ammunition people have for their own self protection is the ability to ask and the ability to explain.”
-Donna Williams

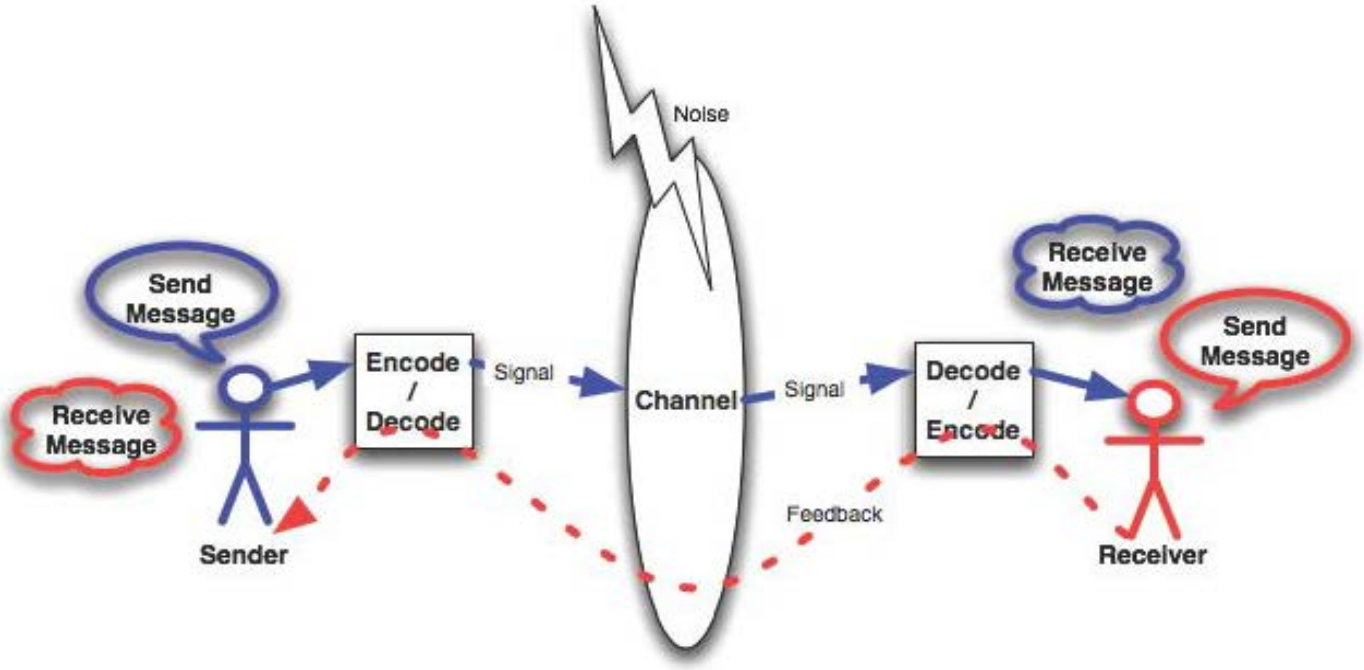
Overview

Communication and Speech

Devices and Technology

Access and Attitudes

What Is Communication



Communication is a (reciprocal) dynamic process

Elements of Communication

Communication is not speech

- Message
- Mode (medium of channel / transmission)
- Timing (pattern of send/receive feedback)

Communication and Autistic Experience

- Sensory differences (noisy channel)
- Movement differences (apraxia/dyspraxia)
- Processing differences (message exchange too fast to process)
- Language differences (cognitive processing of certain kinds of language)

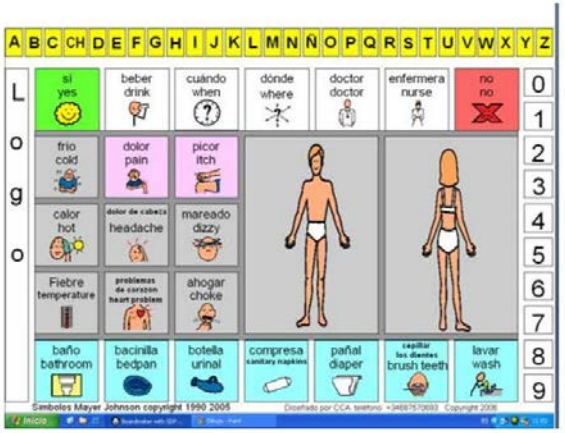
AAC and Building Bridges

Augmentative and Alternative Communication

- Change the message encoding (from e.g., English to ASL or pictures).
- Change the mode (from e.g., speech and/or hearing to writing and/or reading).
- Change the timing (from e.g., "real time" to asynchronous).

AAC can bridge between one type of communication and another (from e.g., writing to speaking, pictures to text).

AAC Devices



Message type: literacy-based, picture-based, symbolic-based

Technology type: "low tech" paper, "high tech" speech synthesis, "mid tech" recorded messages

Many options!

Other AAC & Communication Systems

Non-device forms of AAC

- Gesture
- Body language
- Sign languages
- Consistent idiosyncratic behavior

A device is not a communication system.

Communication systems can involve any combo of devices, other forms of AAC, and typical spoken or written messages.

Variable Roles for AAC

- Most of the time
- Part of the time
- Situationally (e.g., when under stress, when communicating with strangers)

Most AAC users do not use a single method of communication 100% of the time.

Everyone, not just people with disabilities, use some form of AAC at some time.

Understanding Autism-Specific Needs

Technical needs: designing devices (e.g., portability--wheelchairs are rare)

Strategies for use: considering autism-specific abilities and disabilities in AAC training (e.g., avoiding assumptions about sociocultural norms)

Cognitive needs: avoiding incorrect assumptions about autism (e.g., that we all "think in pictures.")

Examination of Disability Bias

- Viable AAC strategies are discounted due to incorrect assumptions about autism.
- The role of speech is over-emphasized for autism.
- AAC traditionally used with a different disability may benefit autistic users.

Improving Technology

Speech Synthesis Improvements

Application of New Technology

- Incorporate current advances into AAC products
- Develop new technology for AAC devices
- Develop more affordable devices

Evaluation and Inclusion

Evaluate AAC Devices and Therapies

- Existing
- New

Include Autistic People in Development Process

- We know what works and doesn't work--ask us!
- Success of technology depends on end-user involvement in development.

Access to Communications is a Civil Right

It is the position of the American Speech-Language-Hearing Association (ASHA) that communication is the essence of human life and that all people have the right to communicate to the fullest extent possible. No individuals should be denied this right, irrespective of the type and/or severity of communication, linguistic, social, cognitive, motor, sensory, perceptual, and/or other disability(ies) they may present.
-American Speech-Language-Hearing Association

- Access to communication is a civil right.
- Communication accommodations (e.g., use of an AAC device or ASL) is covered under the Americans with Disabilities Act and similar laws.
- Focus on speech may deprive autistic people of their right to communicate.

Cost Barriers to Access

- Device costs
- Picture or language library costs
- Evaluation and training costs
- Ability to demo a device before committing to purchase may be limited
- Insurance not typically helpful

Attitudinal Barriers to Access

- Inappropriate emphasis on speech rather than communication
- Social stigma associated with disability

Other Barriers to Access

- Limited access to devices
- Lack of understanding of disability accommodations

Evaluating Service Delivery and Therapy

- Service delivery systems
- Therapy that focuses on AAC
- Therapy that focuses on communication
- Therapy that actively involves communication partners

Summary

Devices and Technology

- Understanding technology needs
- Improving technology to meet those needs
- Increasing communication between developers and end users

Access and Attitudes

- Understanding access barriers
- Removing access barriers
- Involving communication partners and the community

There Are Many Ways to Communicate

In some cases, an autistic person may want to speak. If that's so, then they should be given every opportunity to learn. However, a lot of us have other ways of communicating. With a keyboard to type on, I feel a lot more free than I do talking or being expected to talk when I can't communicate adequately that way. There are other times when I can't use language at all, and I am having a really hard time finding assistive technology to deal with that. But the fact that I am having a hard time finding that technology doesn't mean I shouldn't.

I have a right to communicate in whatever means is possible for me to communicate...And not only do I have that right, but I have the right to choose what means of communication is appropriate for me...

-A.M. Baggs

Why We Care About Communication

"One of the biggest keys to an autistic person getting the life they want is for that autistic person to be able to express, in a way that allows the largest number of people to understand, their own desires and thoughts."

-Joel Smith

I would not have been able to give you this presentation today without AAC.

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National Center for Complementary and Alternative Medicine

U.S. Department of Health and Human Services
Interagency Autism Coordinating Committee

May 4, 2009

NCCAM 10 years of rigorous research

Topics

- NCCAM's history and mission
- Data on CAM use in America
- Achievements of ten years of NCCAM research – and lessons learned
  - in mind body research
  - in natural product research
- Challenges of CAM research
- N of one trials

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NCCAM 10 years of rigorous research

Legislative language

"The general purposes of the National Center for Complementary and Alternative Medicine (NCCAM) are the conduct and support of basic and applied research…research training, and other programs with respect to identifying, investigating, and validating complementary and alternative treatment, diagnostic, and prevention modalities, disciplines and systems."

P.L. 105-277

October 1998

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NCCAM 10 years of rigorous research

NCCAM: Mission

- Explore complementary and alternative healing practices *using rigorous scientific methods* and develop the evi for safety and efficacy of CAM approaches
- Support the development of t researchers
- Disseminate authoritative info the public and professionals

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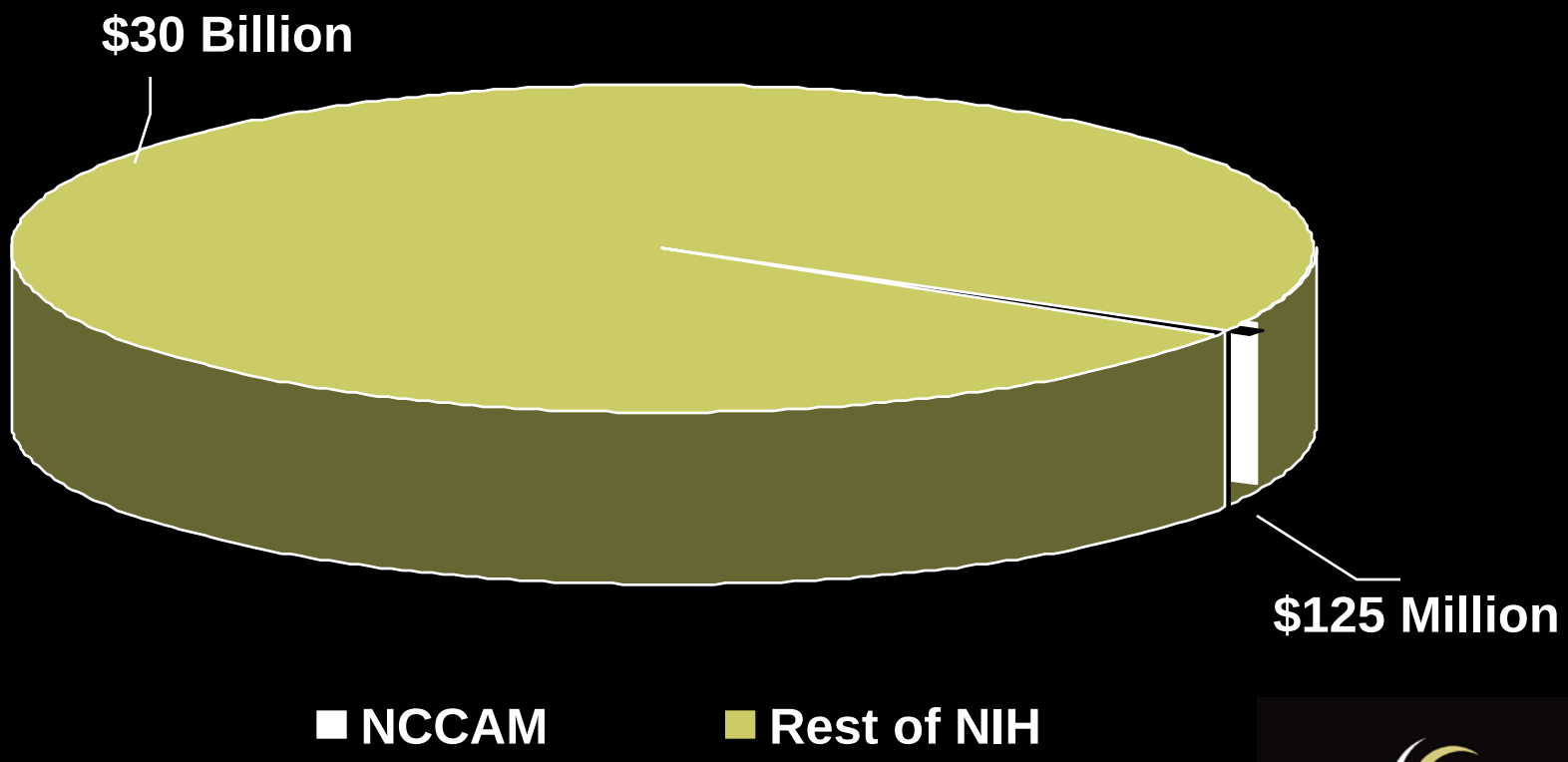
NCCAM's Budget: 0.4% of the NIH Total



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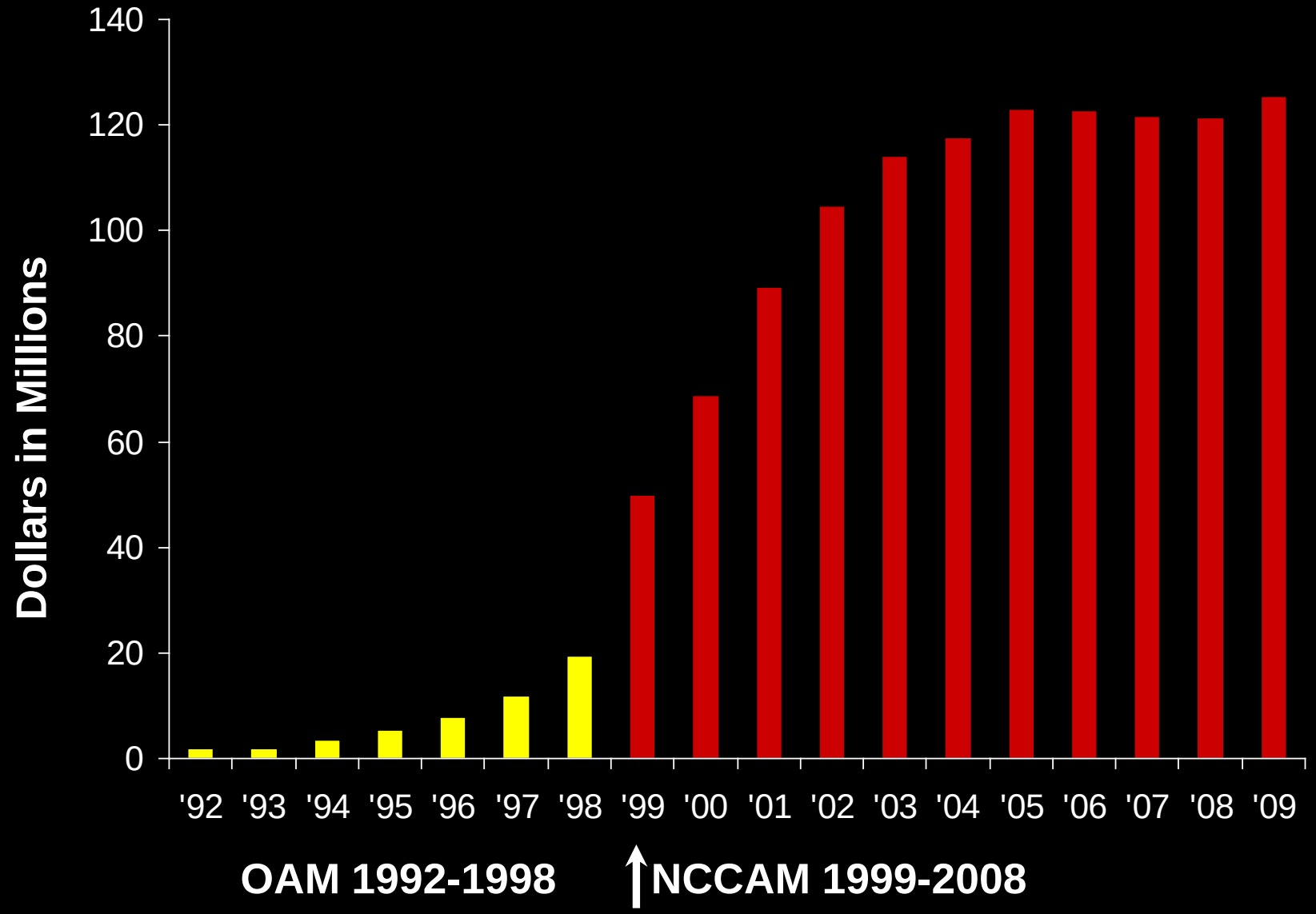
NCCAM's Appropriations History



NCCAM is a TEAM PLAYER

Examples

- Ginkgo Evaluation of Memory Study (GEMS) – NCCAM, NIA, NINDS, NHLBI, NIH ODS
- Glucosamine/chondroitin Arthritis Intervention Trial (GAIT) – NCCAM, NIAMS
- St. John's Wort for Major Depression of Moderate Severity – NCCAM, NIMH, NIH ODS
- National Health Interview Survey – NCCAM and CDC
- Systematic evidence-based reviews – NCCAM and AHRQ

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NHIS CAM Modules: 2002 and 2007

- 2007 Survey: 36 different CAM therapies for 81 different diseases/conditions
- Sample of 23,000 adults

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NHIS CAM Module

The 2007 NHIS collected CAM information on a subset of 23,393 adults and 9,417 children

This sample is representative of the civilian, non-institutionalized U.S. population

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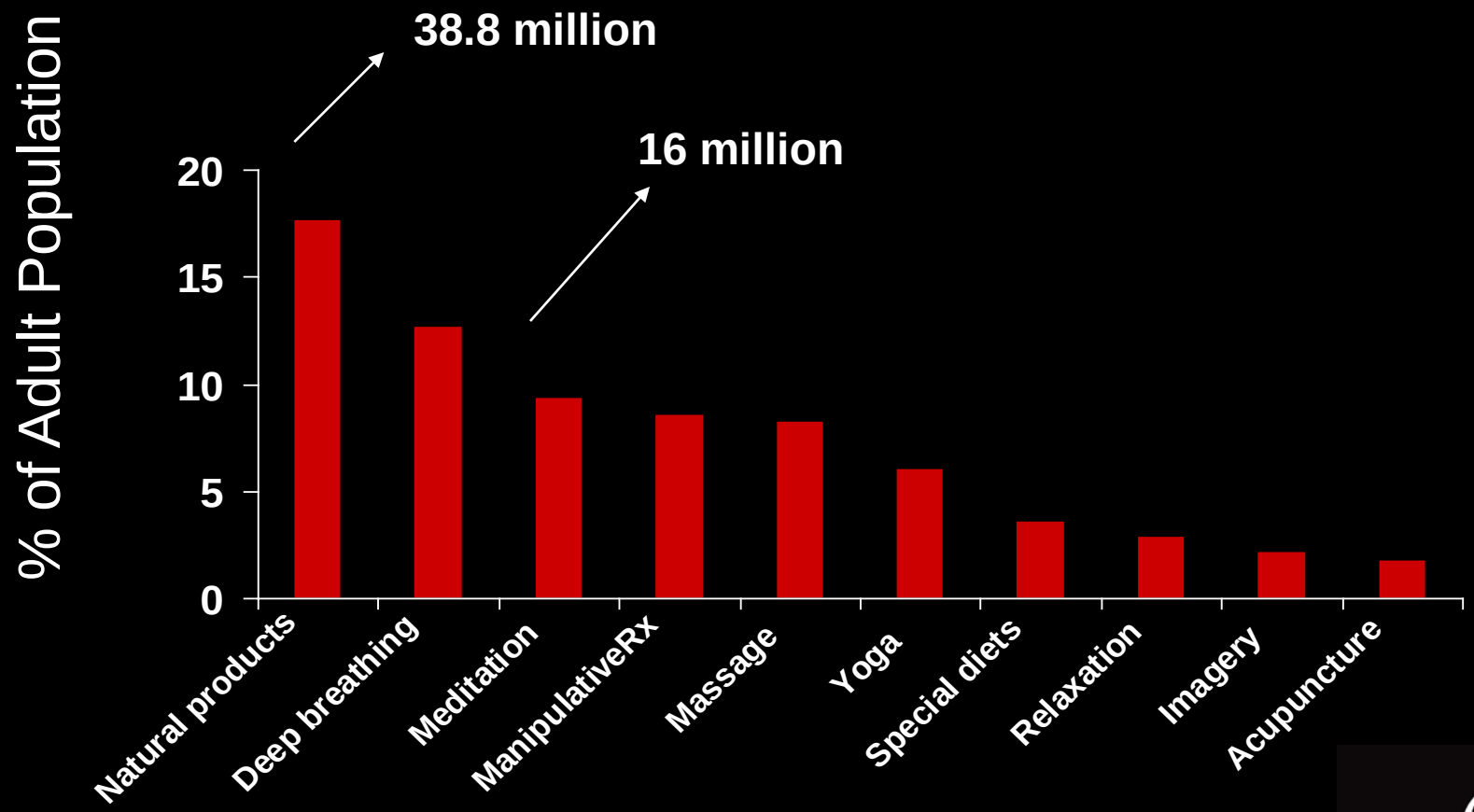
NCCAM 10 years of rigorous research

NHIS CAM Module Survey: Demographics of CAM Use, 2007

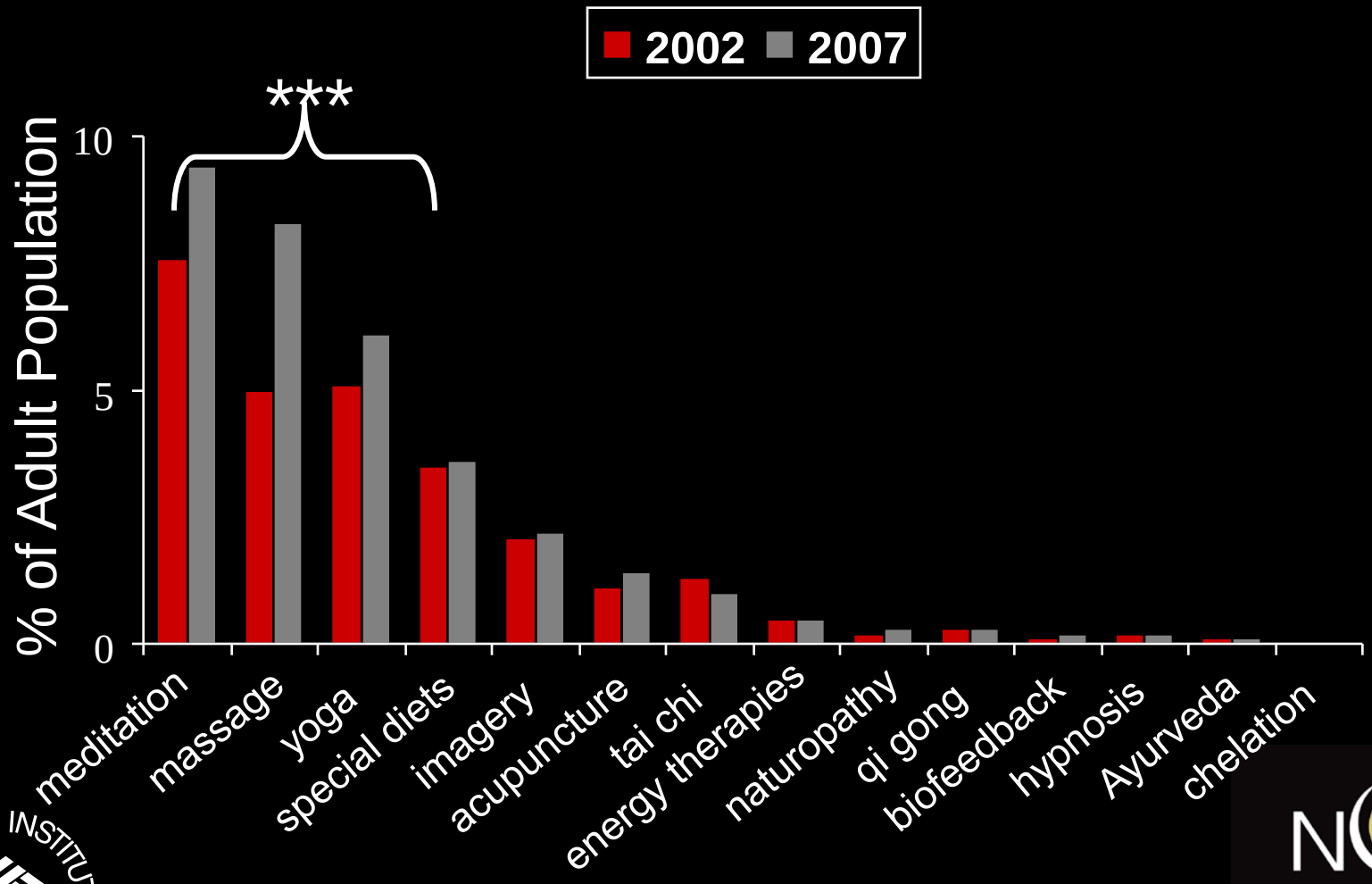
- Approx 40% of American public use CAM, consistent with earlier surveys
- 1 in 9 U.S. children use CAM
- Widespread in all demographic groups
- Women > men
- West >Midwest >Northeast >South
- Greater use in people with higher education levels

Adult Use of Selected CAM Therapies: United States, 2007



Barnes et al., 2008

Adult Use of Selected CAM Therapies: 2002 vs. 2007



Barnes et al. 2004, 2008

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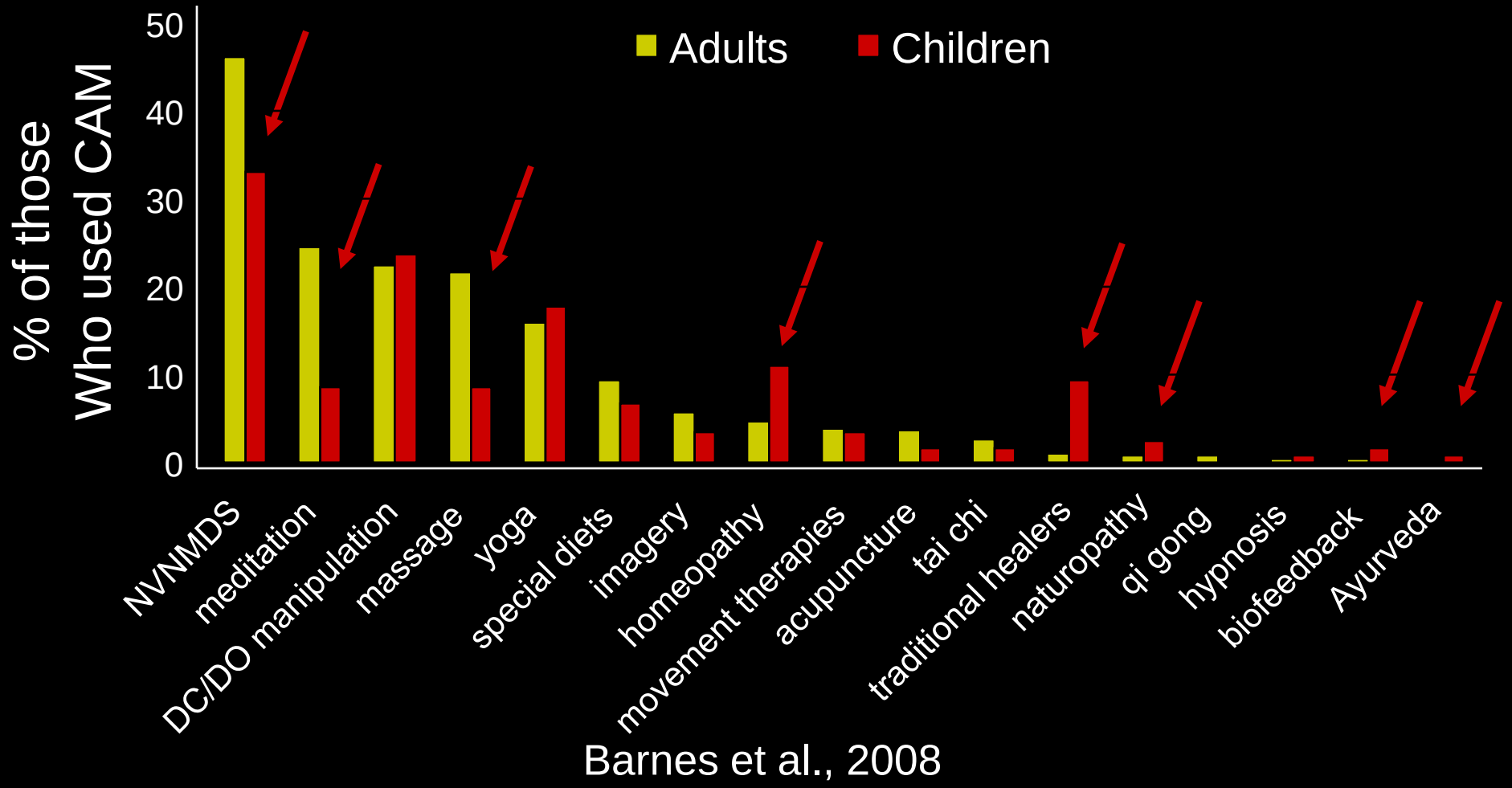
Use of Selected CAM Therapies: Adults vs. Children



Barnes et al., 2008

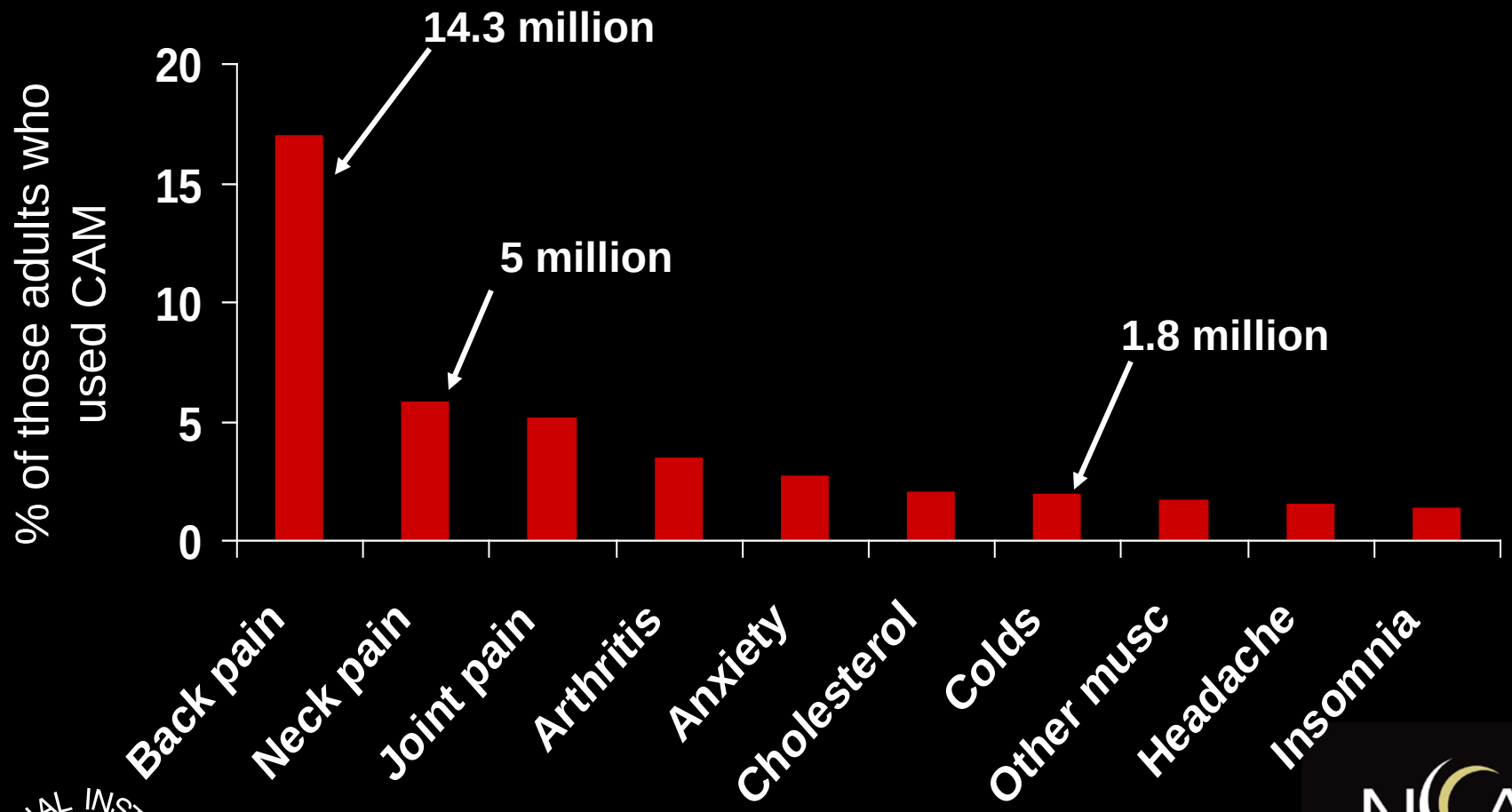
Why do people turn to complementary or alternative medicine?

To promote health and wellness

To treat specific health conditions and symptoms

(Mostly as an adjunct to conventional care)

Adult Use of CAM for Selected Health Conditions



Barnes et al., 2008

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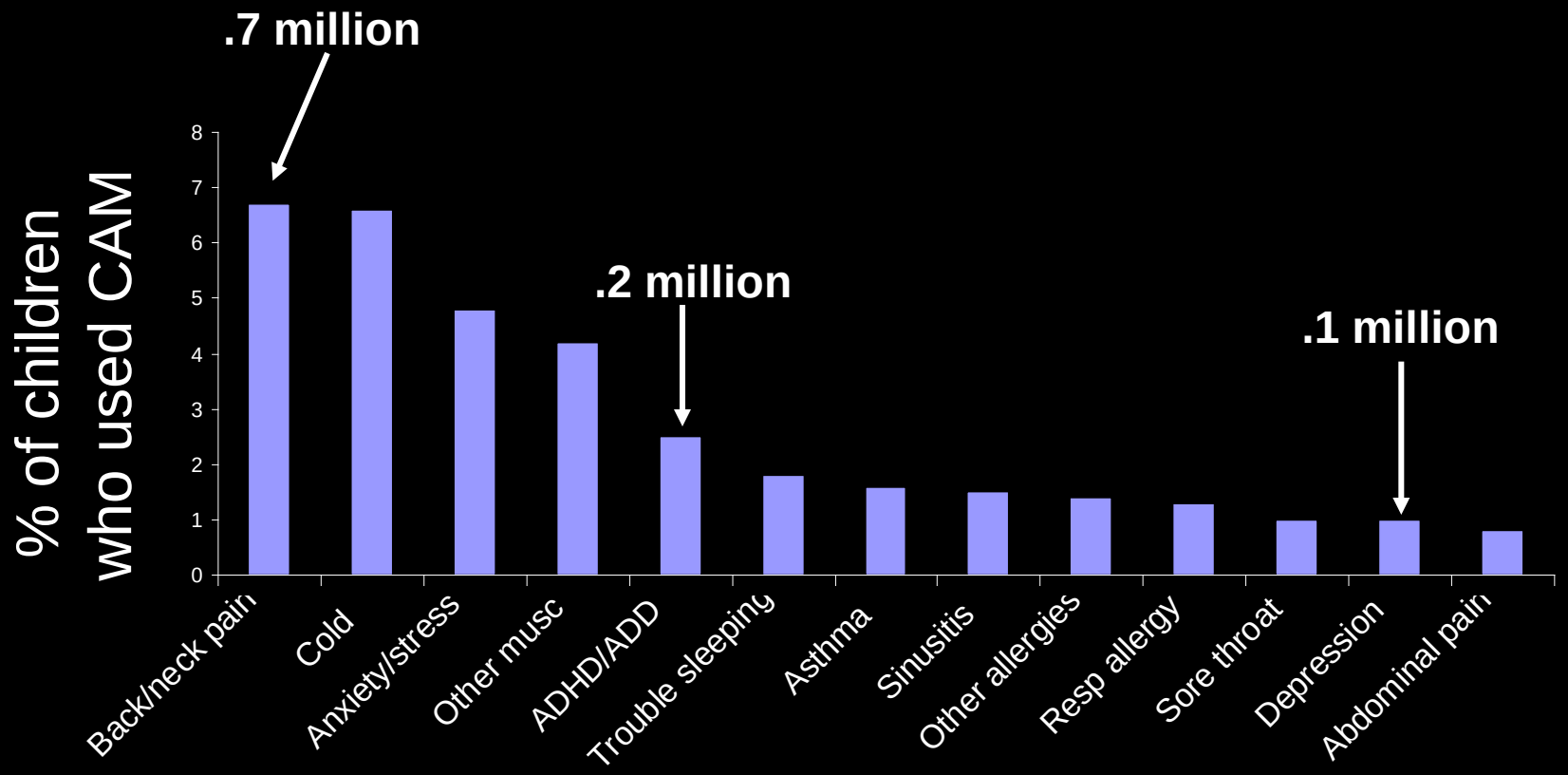
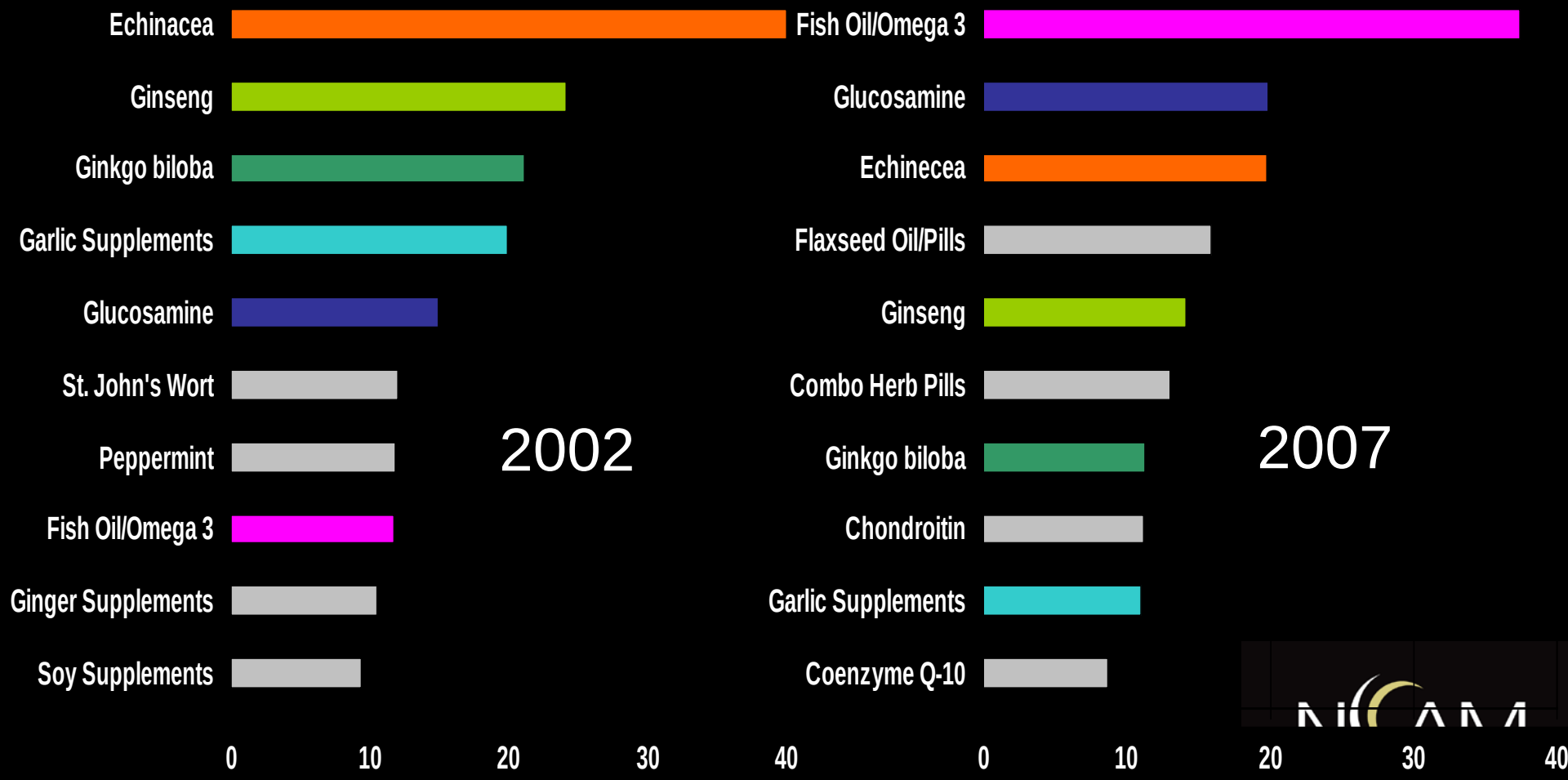
Children's Use of CAM for Selected Diseases



Barnes et al., 2008

Top Herbal Medicines and Other NVNMDS:

NVNMDS = non-vitamin/non-mineral dietary supplements



% of adults using NVNMDS

What do the numbers tell us?

- Complementary and alternative health practices, especially natural products, meditation, massage, manipulative therapies, and yoga are widely used by the American public, including children
- Chronic pain, especially back pain, is the most common reason
- Media coverage and public interest is strong
- NIH Research influences the public

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NCCAM: Our Research Expertise

Studying Real World Health Practices

CHALLENGES

- Need to partner with disease experts
- Need careful product characterization
- Need strong preliminary data

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Preliminary data needed for major RCT's of CAM interventions:

- Strong biological hypothesis
- Well described intervention
- 'Proof of concept' preliminary clinical data
- Good chemistry of any natural products (ADME) and marker(s) to verify biological effect *in vivo*
- Maximally sensitive outcome measures and trial design

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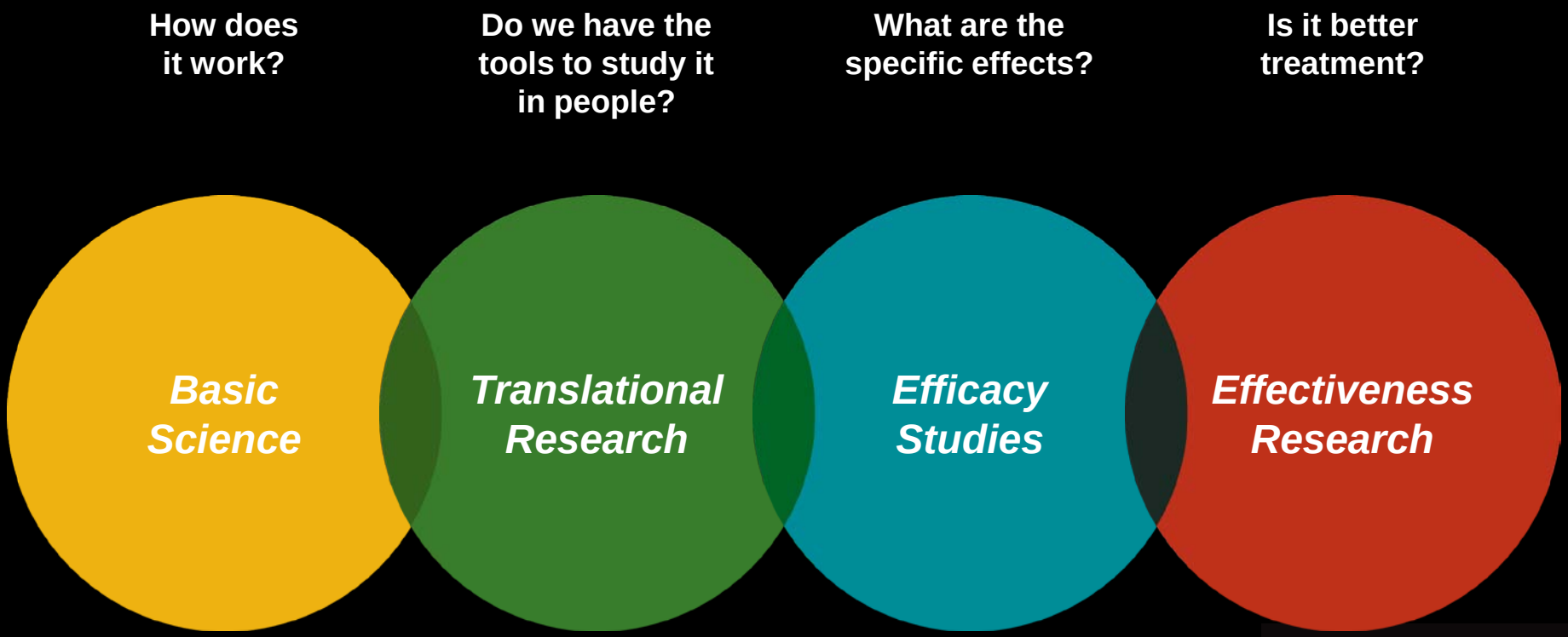
NCCAM: The CAM Research Paradigm



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NCCAM Research: Areas of promise in mind and body CAM approaches

- Benefits of mindfulness mediation for stress reduction and quality of life - for examples for Alzheimer care givers
- Benefits of yoga and Tai chi for balance and avoiding falls in elderly people
- Insight into of central mechanisms of reassurance and expectancy
- Contribution of acupuncture and other mind and body practices to pain management

NCCAM: Achievements in natural product research

- Implementation, in partnership with other IC's, of 6 major high-quality RCTs of widely used natural products

- Rigorous processes to assess quality and consistency of herbal and other natural products used in NCCAM research

  (PIWG: Product Integrity Working Group)

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Autism Spectrum Disorders: CAM for Symptom Management

- Numerous provider and parent reports suggest that certain CAM practices show promise to contribute to symptom management
- Limited scientific evidence
- Children's safety paramount

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NCCAM: Expertise in studying untested therapies already in use by the public

- CAM research, as a scientific discipline, has advanced dramatically in the last ten years
- NCCAM has established a CAM research enterprise at the Nation's premier biomedical research institutions
- Partnerships with CAM practitioners are critical to our efforts
- NCCAM has special expertise in applying rigorous scientific inquiry to health and wellness promotion practices already in use
- Experience has taught us that the evidence base for a particular therapy's use must be developed incrementally

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First Steps: The road from anecdote to proven efficacy

"The plural of anecdote is not evidence." S. Straus

- Therapies are in current use without scientific proof of safety, efficacy, or effectiveness
- How do we find out if they work?
  - Investigator-initiated research
  - Collaborations with NIH Institutes and Centers and other Federal agencies with specific expertise

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Study of Omega-3 Fatty Acids for Children with Autism Spectrum Disorders

- Double-blind, placebo-controlled, RCT
- Comparing omega-3 fatty acids with placebo to assess effects on
  - Aggression and irritability
  - Functional ability

Credit: NLM MedlinePlus

PI: Sherie Novotny, M.D.
Robert Wood Johnson Medical School

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n-of-1 Trials

- Randomized, double-blind, placebo-controlled crossover comparison trials in a single patient
- Patient-centered approach to testing therapeutic efficacy for symptom management
- Useful in patients with chronic diseases or conditions to test short term effects

n-of-1 Controlled Trials

- What are they?
- How are they designed?
- Could they be useful in determining the role of CAM in the management of symptoms associated with Autism Spectrum Disorders?

n-of-1 Trials: Role in testing CAM therapies for Autism Spectrum Disorders?

- Develops “proof of concept” data required before larger-scale studies are conducted
- Helps determine if, when (e.g., response variations), and how a therapy might be used effectively for symptom management
- Encourages provider, parent, patient partnerships

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CAM and Autism

- Complementary and alternative health approaches have substantial promise to contribute to practical management of symptoms and burden of ASD on patients and their families

- NCCAM welcomes opportunity to partner in trans-NIH Autism Coordinating Committee

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National Center for Complementary and Alternative Medicine

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