

Meeting of the Interagency Autism Coordinating Committee

Day 2

April 14, 2022; 1:00 - 5:00 p.m. ET



Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health
(NIMH) and Chair, IACC

Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

Welcome



Oral Comment Session



Eileen Nicole Simon

Steve Mays

Lisa Morgan

Bob Williams

Edlyn Pena

Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

Research and Service Needs, Resources, and Policy Implications (1/3) - 153 comments

- Karen Barrett, B.B.A. M.S.
- Lena Reardon
- Arabella Sterwerf
- Autumn Scheske
- Hailey Teusink
- Mary Russell
- Ross Cameron
- Cornelius Hecker
- Brennen Balsamo
- Emily Swaim
- Kris Guin
- Theia Ware
- Brooke Nixon
- Amy Schmidt
- Amber Pepper
- Jasper Hardin
- Tori Madway
- Ari LaTourette
- Kristen Gorman
- Allison Mercer
- Criss Ittermann
- Lisa Jeanne Graf
- Heather Foxing
- Ira Eidle
- Adam Knapp
- Ira Kraemer
- Jo Adell
- Kimberly Miller
- Sarah Gillis
- Fiona Burgess
- Chloe Davis
- William Anderson
- Lydia Kolibar
- Alex Bassi
- Robin Bond
- Morgan Stallard
- Laura Comfort
- Roxanne Blask
- Jay Kristensen
- Heini Natri
- Lillie Ameling
- Nikki Satterlund
- Sarah Seigel
- Amanda Thomas
- Amaranthe Zinzani
- Courtney Johnson
- Lucy Greenwood
- Shereese H
- Darin Pyatt
- Alexandra Carter
- Alex Sprague
- Erin Jonaitis

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/april13-14/public_comments.pdf?ver=3

Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

Research and Service Needs, Resources, and Policy Implications (2/3)

- Tamara Griesel
- Clarissa Nielsen
- Judy Ferry Rohlfig, M.S. Ed.
- Barb Schneider
- Adam Brabender
- Sondra Hardgrave
- Benjamin Kerensa
- Brittany Daniels
- Robin Atlas
- Pandora Willcutts
- Jodie Rosenblum
- Corben Havener
- Marja Erwin
- Anonymous
- Julia Simko
- Yamen Staniford
- Richard Gallo
- Frank Carrillo
- Yuliya Thomas
- Audre Wirtanen
- Zachary Inkeles
- Katie Goidich
- Carmen Sweitzer
- Andrew Baxter
- Elizabeth O'Leary
- Shari Chase
- Tosha Brothers
- Jay Jackson
- Keith Halperin
- Em Johnson
- Bianca DelVecchio
- Rowan Briglevich
- Evander Smith
- Matthew LeFluer
- Rebecca McCabe
- Anna Haugen
- Rebecca Tienhaara
- David Shuck
- Sheri Waddill, M.A., LMHC
- Nik Castle
- Hana Gabrielle Bidon
- Emma Wilkinson
- Kenyon Chapman
- Katie Gatto
- Barbara Goldman-Sherman
- Matthew James
- Monique Taylor
- Lisa Kriegel
- Jared Stewart
- Michael Rathbun
- Jane Patrick
- Todd Woodward

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Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

Research and Service Needs, Resources, and Policy Implications (3/3)

- Irene R
- Leanne Claire Civiletti
- Aleksandra Ruminska
- Madeleine Calvi
- Kaitlyn Ballenger
- Anne Patton
- Caelan Thorne
- Rob Lagos
- Samantha Hua
- Logan Hau
- Duncan Park
- Jenny Tan
- Eugene Lam
- Ellen Yu
- Joyti Nath
- Elissa Leonard
- Keane Jones
- Adriana Oliveira
- Rachel Bussan
- Ryan Peng
- Ellen Alexander
- Kelly Israel, Autistic Self Advocacy Network
- Nicole Corrado
- Nicole Leblanc
- Kathryn Hedges
- Star Ford
- Cara Krebs
- Ange Marie
- Barbara Leaf
- Asher Gutman
- Kenny Dalton
- Max Shinske
- Maggie F
- Jennifer Dekany
- Jessica Weiler
- Christopher Merchant
- Jane Horn
- Alex Zheng
- Annalise Bussewitz
- Stephanie Huffaker
- Cassidy Whipple
- Ava Gurba, Elliot Gavin Keenan
- The Autistic Avenger
- Amanda Whitaker
- Ken Thomas
- Lee Rodman
- Jack White
- Oleksandr Kurtianyk
- Jhi-Young Joo

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Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

Concerns About Medical Practices – 43 comments

- Mara McLoughlin, M.S., C.C.C.-S.L.P.
- Courtney Munnings
- Morgan Gunn
- Rebecca Gladu
- Cinta Reyes
- Peter Kelly
- Lyric Holmans
- Kay Hardy
- Flora McNamara
- Jamie Atkinson
- Christina Gleason
- Taryn Rosner
- Stephanie Singer
- Roa Demille
- Sheila Majumdar
- Sarah Joyce
- Natalie Smith
- Skyler Sheldahl
- James Pope
- Priscilla Eyles
- Jake Morse
- Sage Rusboldt
- Sam Agnew
- Ryan Bingham
- Bethany Cattell
- Jamie Diamond
- Radiance Sheppard
- Kelly Vest
- Sarah Longstaff
- JP Mackey
- Nikki Satterlund
- Bernadette MacDonald
- Monique Marsten
- Anonymous
- Anonymous
- Imene Saidi
- Brandon Lorrekovich
- Oscar Hughes
- Caroline Rodgers
- Coral Treasures
- Cecilia Stonebraker
- Barry Prizant
- Carl Muhlbauer

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Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

The Role of the IACC and the Federal Government – 21 comments

- Inmara Fenumera
- Jo Choto
- Bonnie Johnson
- Michelle Skigen
- Georgia Wilson
- Florence Lin
- Tomas Vanhoof
- Isabel Yopp
- Adam Henderson
- Suzanne Leber
- Riley Cruickshank
- Kristina Hawley
- Siyu L
- Robert Rice
- Jenn Smith
- Julia Simko
- Theo Szpakowski
- Yesined Ajete
- Jennifer Brooks
- Sebastian Rubino
- Samantha Perry

Research, Services, and Supports for Adults with Autism – 22 comments

- Aleksandra Witkowska
- Julia Sevin
- Elle A
- Jessica Burde
- Rick Grossman
- Crystal Root
- Samantha Frie
- Gretchen Frankenstein
- Joshua Bernard
- Lisa Cooley
- Jay Wilson
- Pauli Gomez
- Cockerham
- Brian Galloway
- Catherine Cox
- Emmett Perkins
- Nimbid Ditavi
- Jack Schak
- Lydia Schiedermayer
- Roberta Walker
- Valerie Louis
- Joel Wilcox
- Jennifer Husek

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/april13-14/public_comments.pdf?ver=3

Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

Needs of the Direct Support Professional Workforce (3)

- Shahnnon Hawkins
- Anya Ashouri
- Naomi Hickey

Employment (4)

- Stephanie Tong
- Emily Nguyen
- Diana Allen
- Allen Smith

Potential Causes of Autism (8)

- Harold Frost, Ph.D.
- Edward Starr
- Richard Williams
- Daisy Tealer
- Charles Heiner
- Joseph Warren
- Eileen Nicole Simon, R.N., Ph.D.

Addressing the Needs of Autistic Individuals with High Support Needs (5)

- Theodore Seeber
- Kat Bjornstad
- Robin MacDonald
- Alison Boyce
- Jamie Cullen

Increase Autism Acceptance and Reduce Stigma (12)

- Julie Luepke
- Mindy Sebastiani
- Sarah Boon
- Laura Camacho
- Whitten Steele
- Samael Wolf
- Jacob Spanbauer
- Kevin Roach
- Lena Hearn
- Talia Flah
- Lindsay Mohler
- Rebecca Tienhaara

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/april13-14/public_comments.pdf?ver=3

Discussion





Break

Perspectives on Addressing Diverse Communication Needs in Autism



Judith Cooper, Ph.D.
Deputy Director
National Institute on Deafness and Other Communication
Disorders

Interagency Autism Coordinating Committee

April 14, 2022

Communication and Autism: NIH and NIDCD

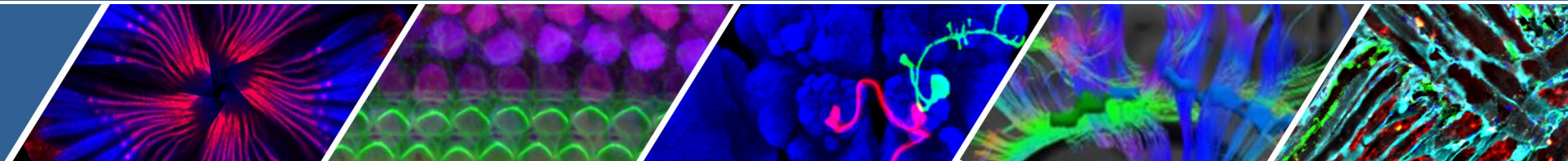
Judith Cooper, PhD

Deputy Director,

National Institute on Deafness and Other Communication Disorders, NIH



National Institute on
Deafness and Other
Communication Disorders



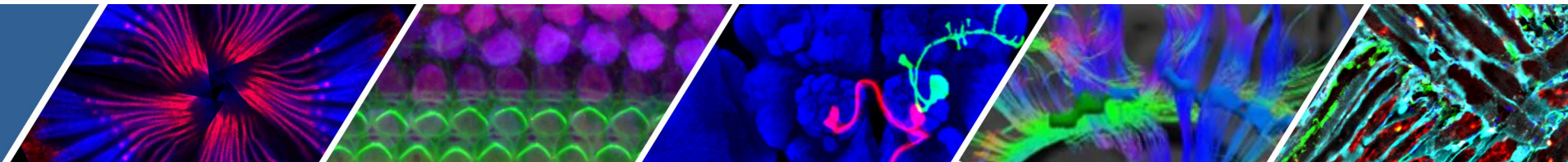
My Focus: Research Support for Communication and Autism

- Joint Action and attention by NIH
 - NIMH (National Institute of Mental Health)
 - NICHD (Eunice Kennedy Shriver National Institute of Child Health and Human Development)
 - NINDS (National Institute of Neurological Disorders and Stroke)
 - NIEHS (National Institute of Environmental Health Sciences)
 - NIDCD (National Institute on Deafness and Other Communication Disorders)
- **acknowledge: Dept of Ed, DOD, HRSA, non-Federal organizations

- NIDCD-specific Actions



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Communication and Autism

“impairments in communication”



“difficulty communicating nonverbally (gestures, eye contact..)”



“persistent deficits in social communication”



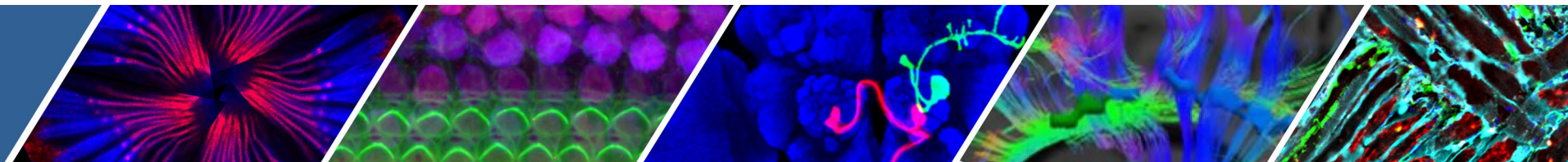
“difficulty developing language skills/ understanding what others say to them”

“delayed onset of communication”

“failure to develop sufficient natural speech to meet daily communication needs”



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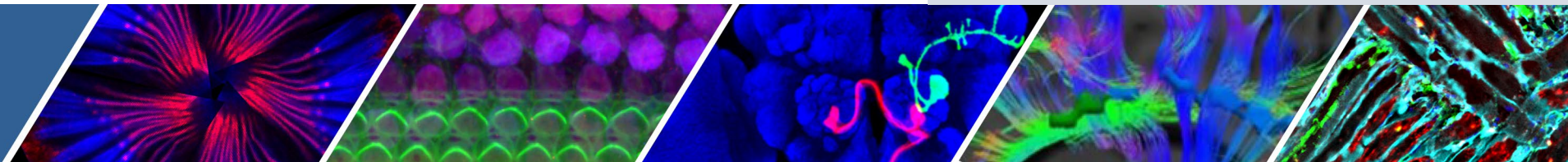


NIH Recognition and Attention

- Research support related to communication and autism
 - Decades of investigator-initiated projects
- Mechanisms for encouraging and supporting research:
 - Centers
 - Networks
 - Other solicitations



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NIH Autism Centers Solicitations

- 1997: **CPEA** (Collaborative Programs of Excellence in Autism)
- 2002: **STAART** (Studies to Advance Autism Research and Treatment)
- 2007-2021: **ACE** (Autism Centers of Excellence)

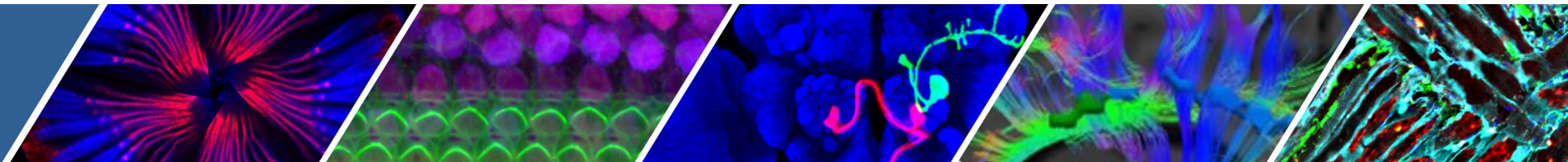
PURPOSE:

Support research that will lead to better understanding of the causes and mechanisms underlying ASD, improved efficiency of methods of early identification and diagnosis, and more innovative and cost-effective services for individuals with ASD across their lifespan.

- “Studies of language and disorders of communication”
- “Understudied subgroups within the ASD population (e.g.,minimally verbal individuals....”
- “Intervention projects: “... Assessment and interventions for nonverbal school-aged children with autism.”



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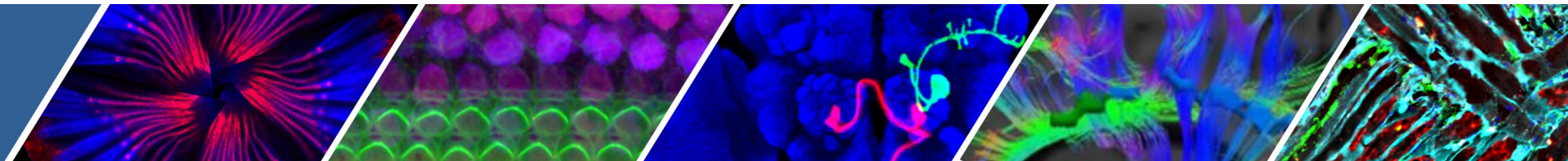
NIH Research Solicitations: Inclusion of Research Foci related to Communication

1998 to 2021: “Research on Autism and ASD” (Program Announcement)

- Communication skills: longitudinal, developmental studies of behaviors that are precursors to later communication, and emergence in children with ASD
- Sensory, motor, social-cognitive impairments that impact ...communication
- Predictors of atypical onset patterns in expressive language abilities
- Interventions designed to remediate communication... deficits across the life-span



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THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD)

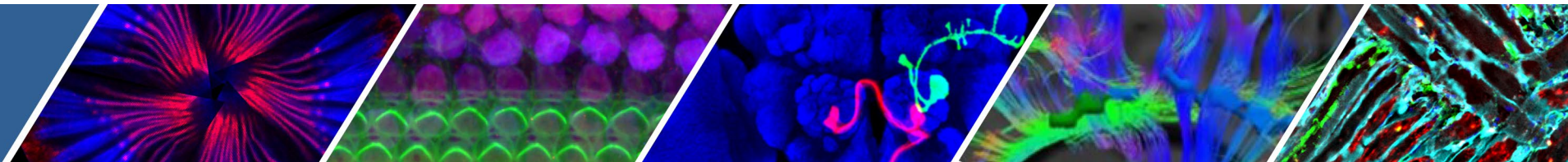
Mission: To conduct and support research and research training in the normal and disordered processes of **hearing, balance, taste, smell, voice, speech, and language.**

Research on autism within NIDCD:

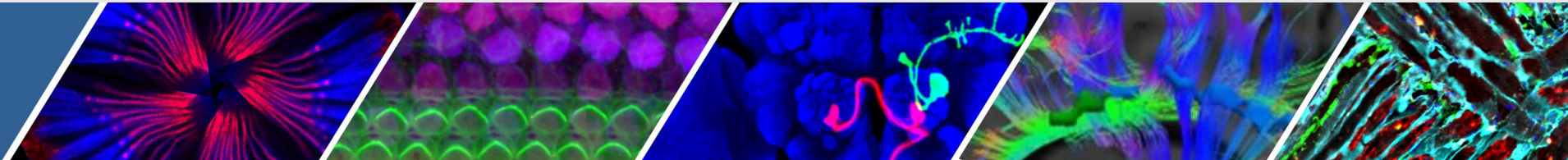
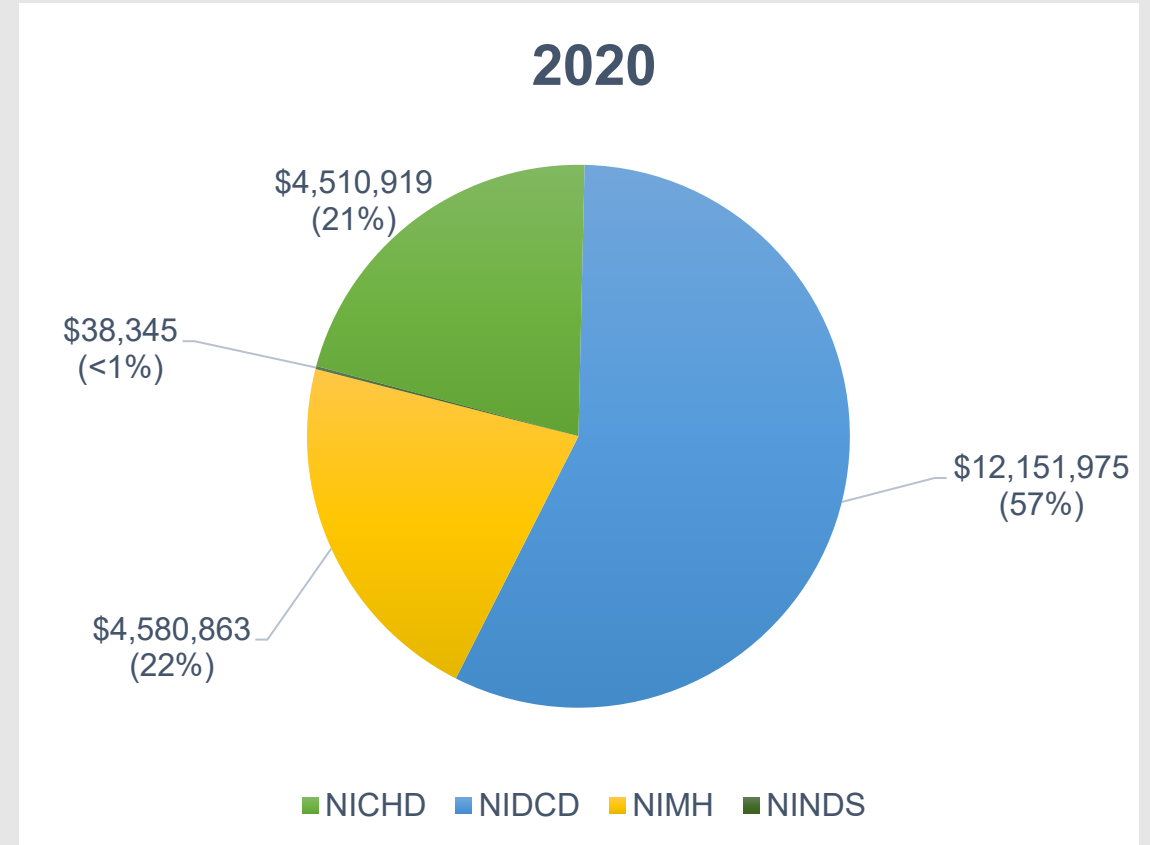
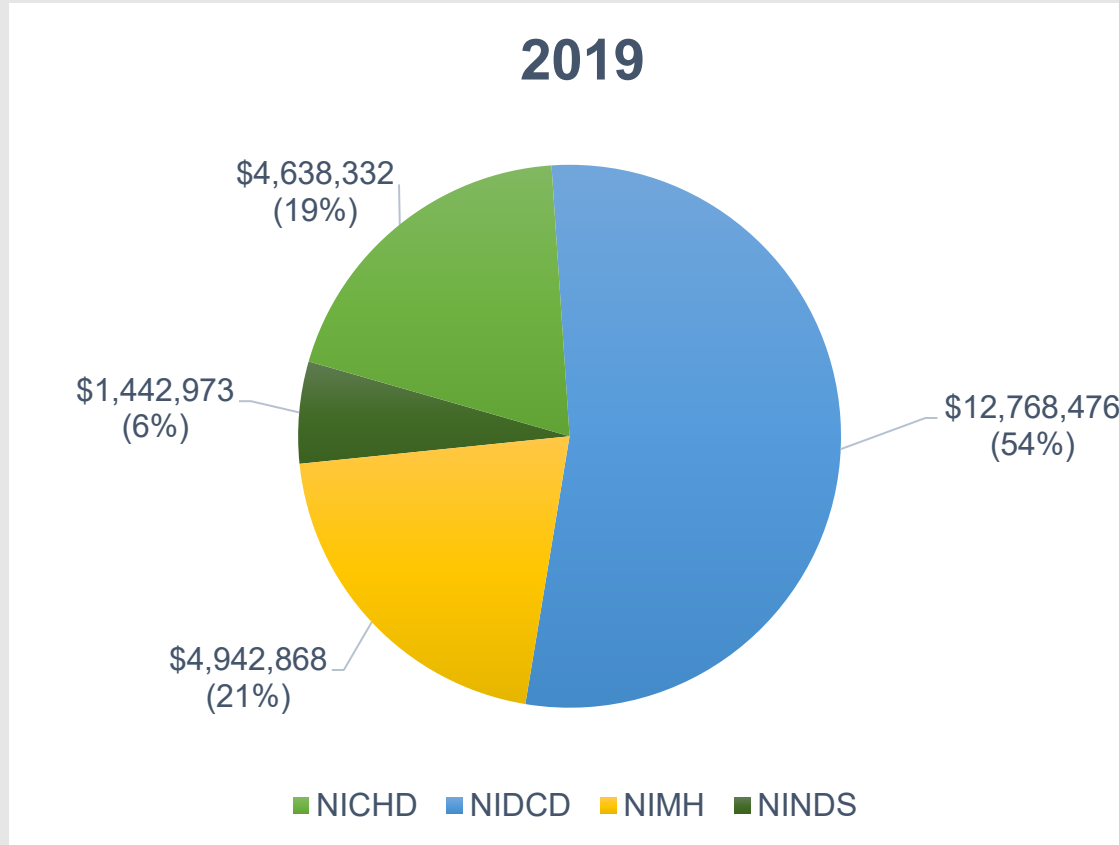
- Focus on speech and language, other areas (hearing, taste)
- Long commitment to autism research:
 - Participation in trans-NIH activities
 - Research on communication differences and challenges in individuals with ASD



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Within NIH,
NIDCD funded most communication projects,
followed by NIMH and NICHD

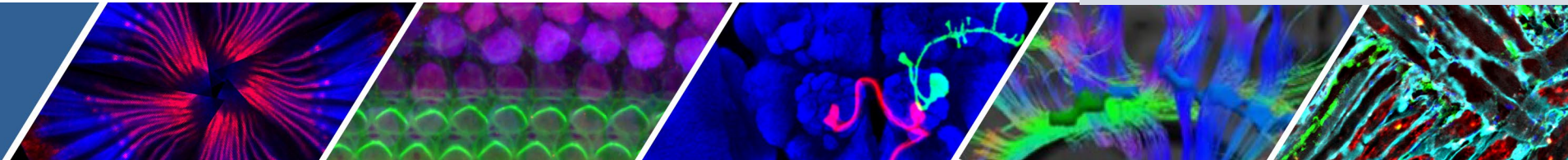


NIDCD Focus/Support in Autism

- Communication profiles: underlying mechanisms/strengths/weaknesses
- Minimally verbal individuals: basic mechanisms, appropriate assessment and intervention approaches
- Behavioral interventions to improve speech and language outcomes
- Alternative and augmentative communication approaches
- Communication differences and disorders in ASD siblings



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NIDCD Activities/Solicitations

Workshops

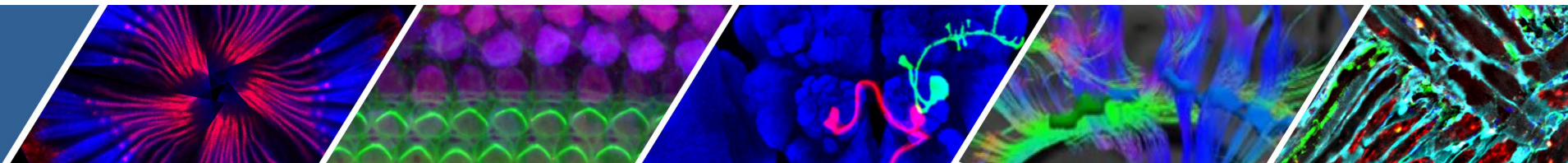
- Autism Language and Communication Research Workshop: 2004
- Augmentative and Alternative Communication Workshop: 1994; as well as in 2006 and 2015

NIDCD Funding Opportunities

- “Advancing Research in Augmentative and Alternative Communication (AAC): 2019
 - “to advance scientific knowledge in evaluation and treatment of individuals with complex communication needs”
- NIDCD Short-Term Enhancement Award for Research Careers in Language and Autism (K18): 2007
 - “offer established investigators in language disorders and those in autism research, a short-term mentored training experience to acquire new research capabilities in the sister discipline”



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Autism And Minimally Verbal: An NIDCD Story

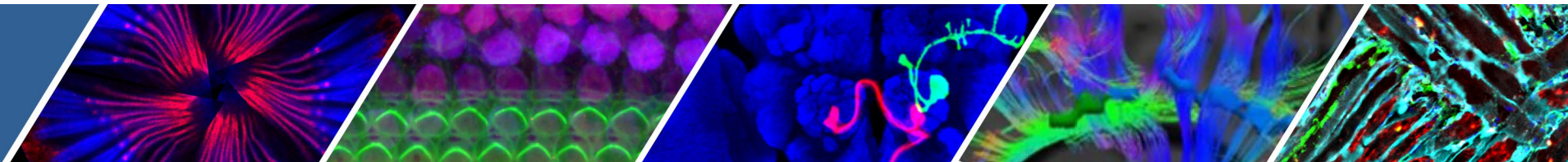


- A mother's request (2009)
- A neglected subgroup
- A need:
 - Research focus on non-verbal/low communicating children with autism
 - Start including in ongoing research

2009: **Planning committee, development of workshop on this population**



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The Workshop

April 2010: Multidisciplinary Workshop

FOCUS:

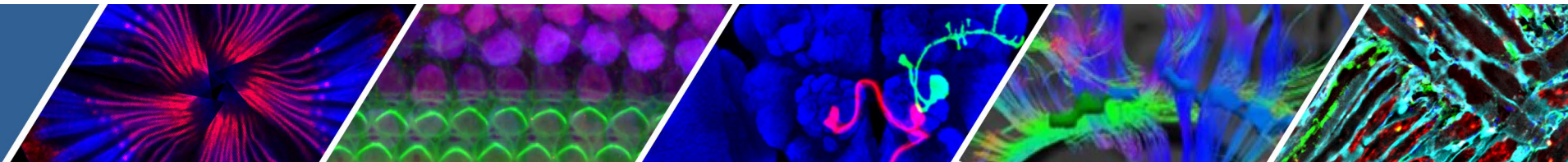
Subgroup of children with ASD who have not developed functional verbal language by age 5

- Who are these children? What do we know about the developmental trajectories?
- How can we assess their skills and knowledge across different domains relevant to language?
- What treatments/interventions are effective in improving spoken language and communication in these children?

<http://www.nidcd.nih.gov/funding/programs/10autism/detail>



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Post-Workshop: Focus shifts

- 2010 RFA: “**Targeted Research on Non-verbal School-aged Children with Autism**”

- For competitive supplements to R01 holders of clinical autism grants
 - ▶ Characterization of the population
 - ▶ Treatment pilot studies
 - ▶ Assessment pilot studies

- 2010-2012: **Working Group**

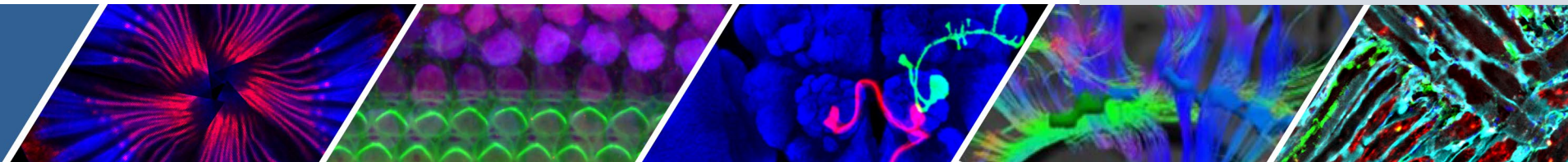
- How to best assess this population

- 2013: **Two important publications**

- Tager-Flusberg, H & Kasari, C (2013) Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum. Autism Research.
- Kasari, C., Brady, N, Lord, C., & Tager-Flusberg, H (2013). Assessing the Minimally Verbal School-Aged Child with Autism Spectrum Disorder. Autism Research.



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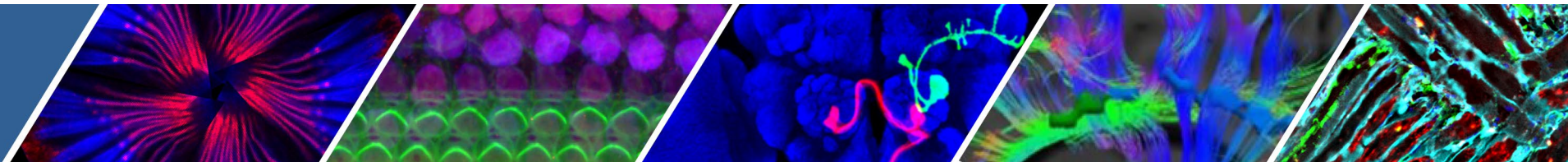
NIH Research Solicitations: Inclusion of Research Needs related to Communication (continued)

2011: Psychosocial/Behavioral interventions and Services Research in Autism Spectrum Disorders (Request for Applications)

- “Studies of adapted/novel treatments for nonverbal school-aged children with ASD”



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2012-2016 Strategic Plan

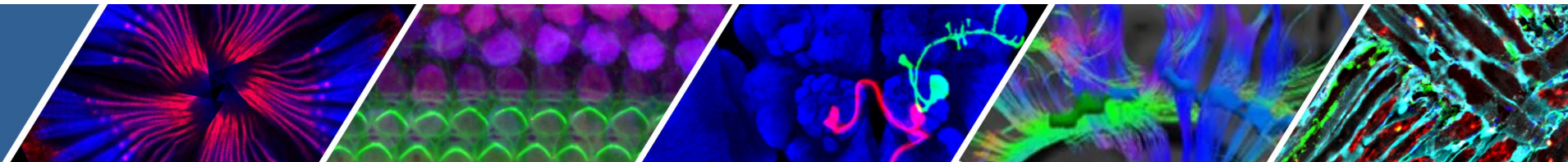
The Focus Continues...

NIDCD Strategic Plan 2012 – 2016

NIDCD is committed to supporting research efforts to improve the diagnosis of ASD and to develop new or improved existing treatments of language deficits in children with ASD...especially school-aged children with ASD who remain non-verbal



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NIDCD: Minimally Verbal Individuals

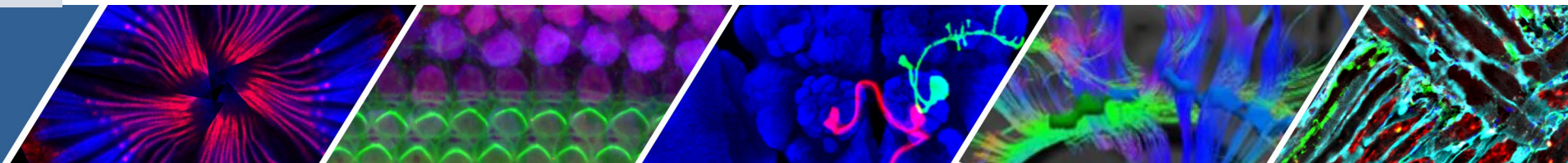


2012: NIH awarded an Autism Center of Excellence (ACE)

“Autism Minimally Verbal ASD: From Basic Mechanisms to Innovative Interventions”



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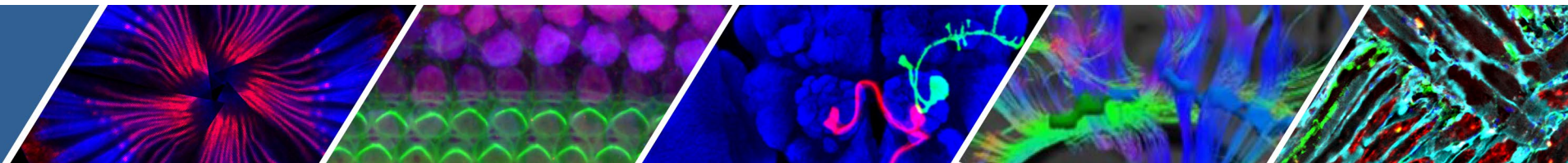
NIDCD: Minimally Verbal Individuals

2019: NIDCD-funded Clinical Center (P50)

“Predicting and Optimizing Language Outcomes in Minimally Verbal Children with Autism Spectrum Disorder”



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FINAL WORDS



NIH/NIDCD has had long-standing research encouragement and funding of communication challenges and needs of autistic individuals of all ages



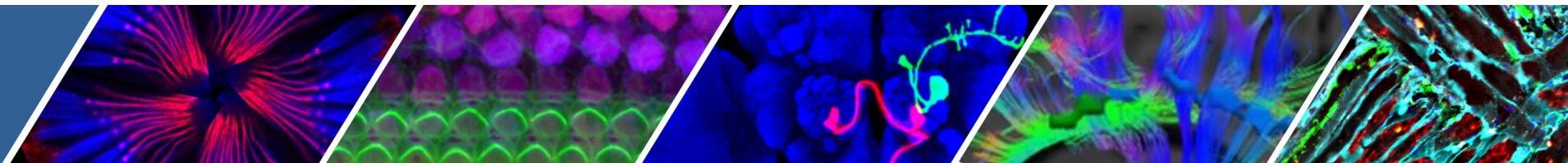
Many research questions and issues remain



Research opportunities and needs come from all venues



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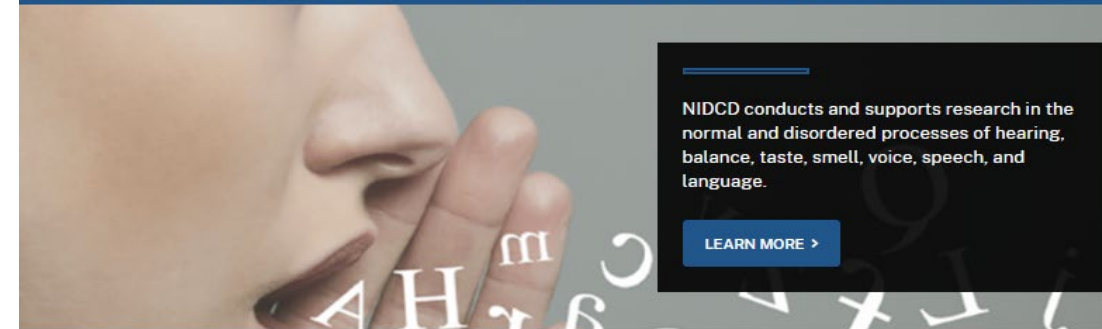
Thank you!



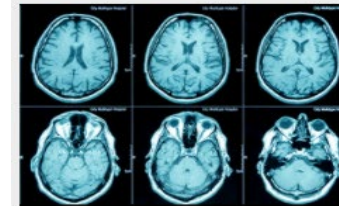
Visit our website:
<https://www.nidcd.nih.gov>



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Featured



Clinical studies at the NIDCD
(Intramural) >



Ring in the new year with
hearing protectors! Share this
image on social media >



New clinician-scientist
training programs and an
update on the NIDCD's
advisory council meeting >

NIDCD at a Glance



Who We Are

The NIDCD conducts and supports research in the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language.



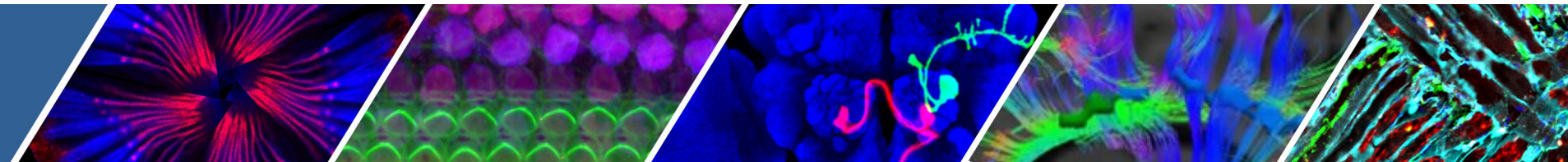
Messages from the Director

Debara L. Tucci, M.D., M.S., M.B.A., is the director of the NIDCD.



Research

The NIDCD supports approximately 1,300 research grants, training awards, and contracts at NIH and at labs across the country.



Advancing Research on Minimally Verbal ASD



Helen Tager-Flusberg, Ph.D.

Professor, Department of Psychological and Brain Sciences

Director, Center for Autism Research Excellence
Boston University

Connie Kasari, Ph.D.

Professor of Human Development and Psychology
Professor of Psychiatry
University of California, Los Angeles



Helen Tager-Flusberg, Ph.D.
Boston University
IACC Meeting April 14, 2022
**Perspectives on Addressing Diverse
Communication Needs in Autism**

Boston University

IACC Meeting April 14, 2022

Perspectives on Addressing Diverse Communication Needs in Autism



Overview

1. Novel approaches to assessing language in *MV* ASD
2. Exploring why spoken language is profoundly impaired in *MV* ASD



The forgotten end of the spectrum

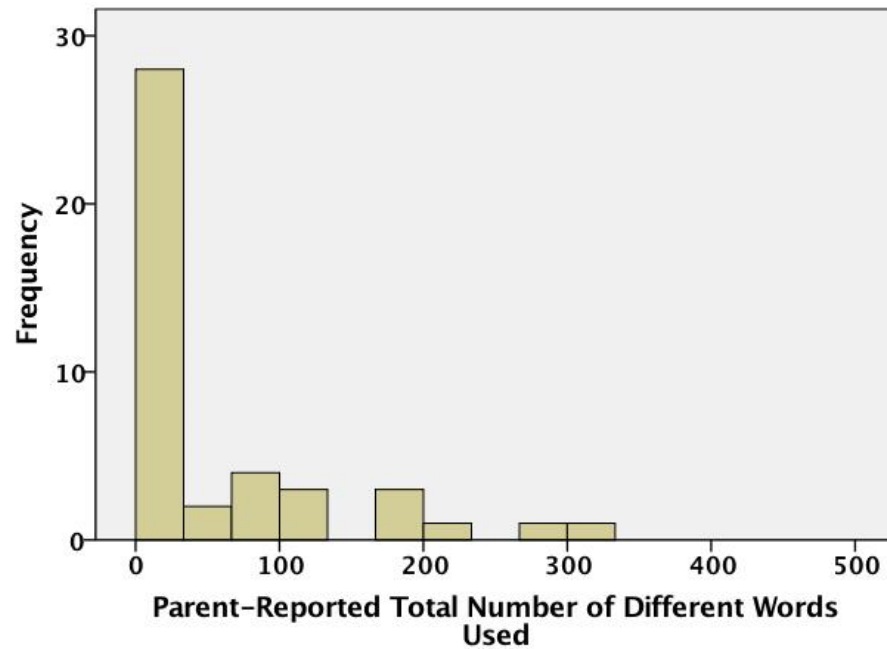


CARE center
for
Autism Research
Excellence

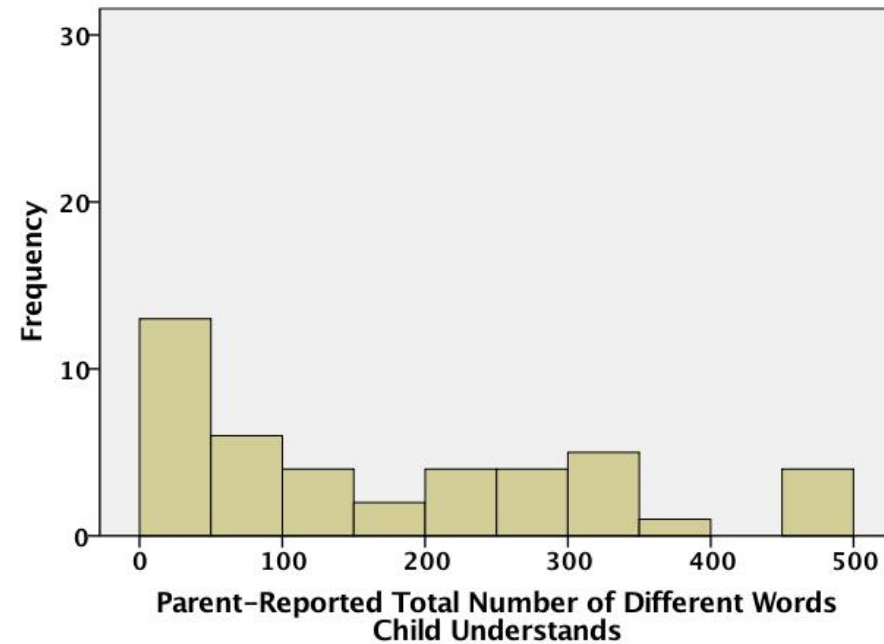
BOSTON
UNIVERSITY

Receptive vs expressive language in MV children and adolescents

Expressive Vocabulary



Receptive Vocabulary



Investigating language in MV children and adolescents

- Standardized tests may not capture the range of their receptive or expressive language abilities
- Need to explore novel approaches



Alternative ways to assess receptive vocabulary

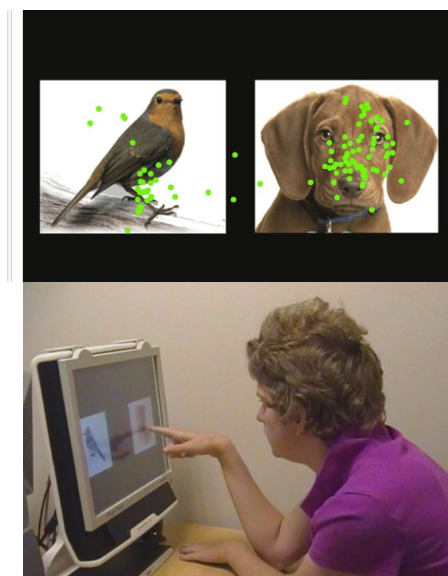
Standard Methods

1. Peabody Picture Vocabulary Test
2. Parent Report – *Word List*

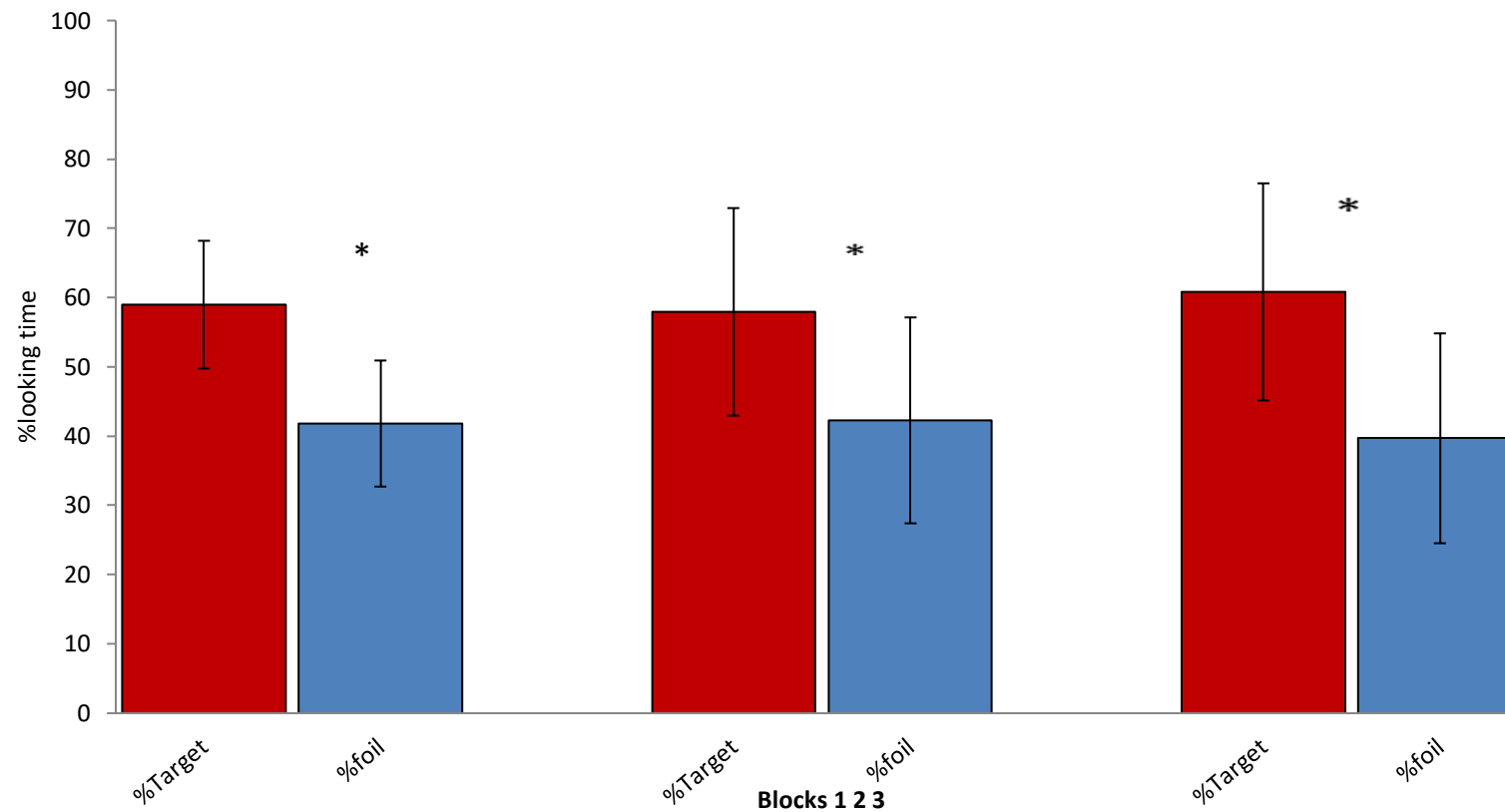


Novel Methods

1. Eye-tracking
2. Touch screen



Eye-tracking: MV adolescents look longer at target picture



Novel (and traditional) methods are valid

	PPVT	Parent Report	Eye Tracking	Touch Screen
PPVT		.68**	.71**	.80**
Parent Report			.50*	.60*
Eye Tracking				.64**

**Correlations between novel and standard measures
are strong and significant**

Individual differences in which method was optimal





Welcome to ELSA!

Eliciting Language Samples for Analysis



Eliciting Language Samples for Analysis (ELSA) is a language elicitation protocol developed by Dr. Helen Tager-Flusberg and colleagues at Boston University's Center for Autism Research Excellence.

Developed in 2016, ELSA is an innovative method for assessing improvements in language and communication skills. Access all ELSA materials and manuals, and our adapted toddler version, ELSA-T, on this site.

[About](#)

[ELSA-A](#)

[ELSA-T](#)

[ELAN Coding](#)

[Current Research](#)

[Publications](#)

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ELSA Team



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ELSA-A Activities

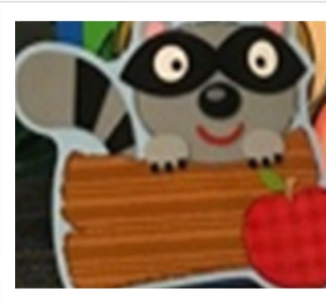
Leaf Falling



Planting an Acorn



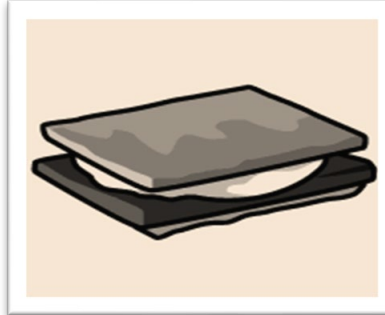
Hide & Seek Animals



Helping Animals



Making a S'more



Arts & Crafts



Bean Bag Toss



Movie Shorts



Who can administer ELSA-A?

Trained Examiners



Parents



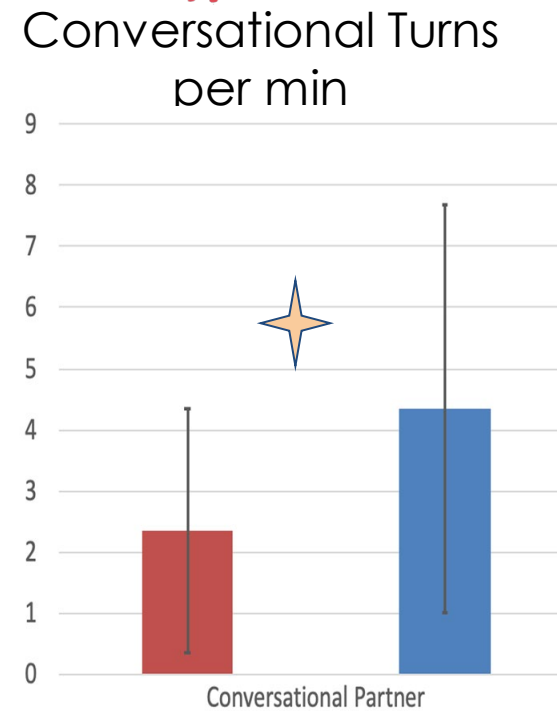
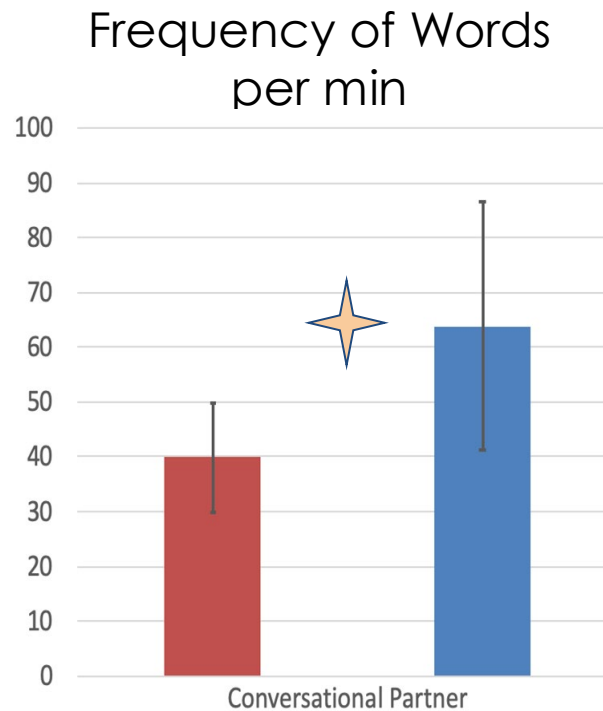
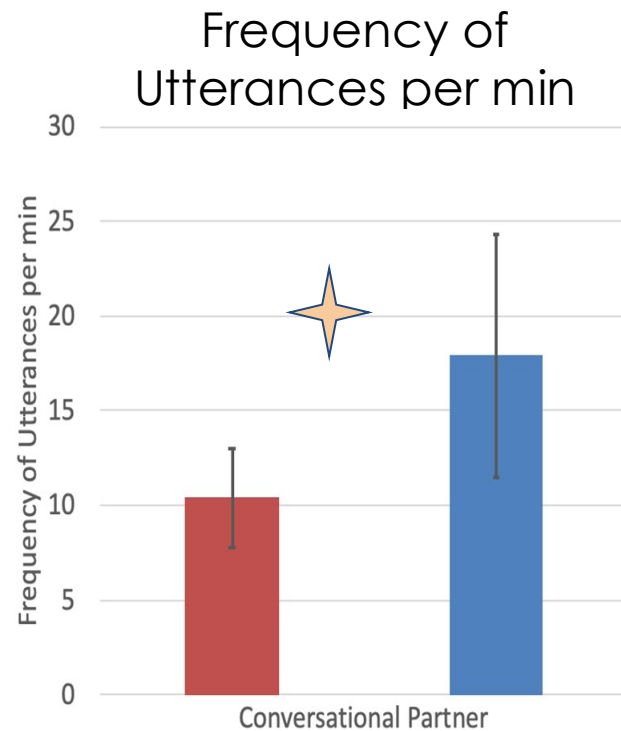
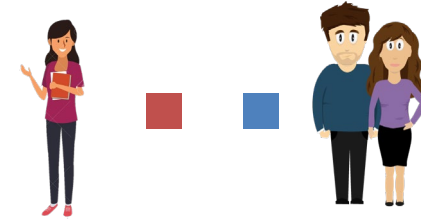
CARE center
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Autism Research
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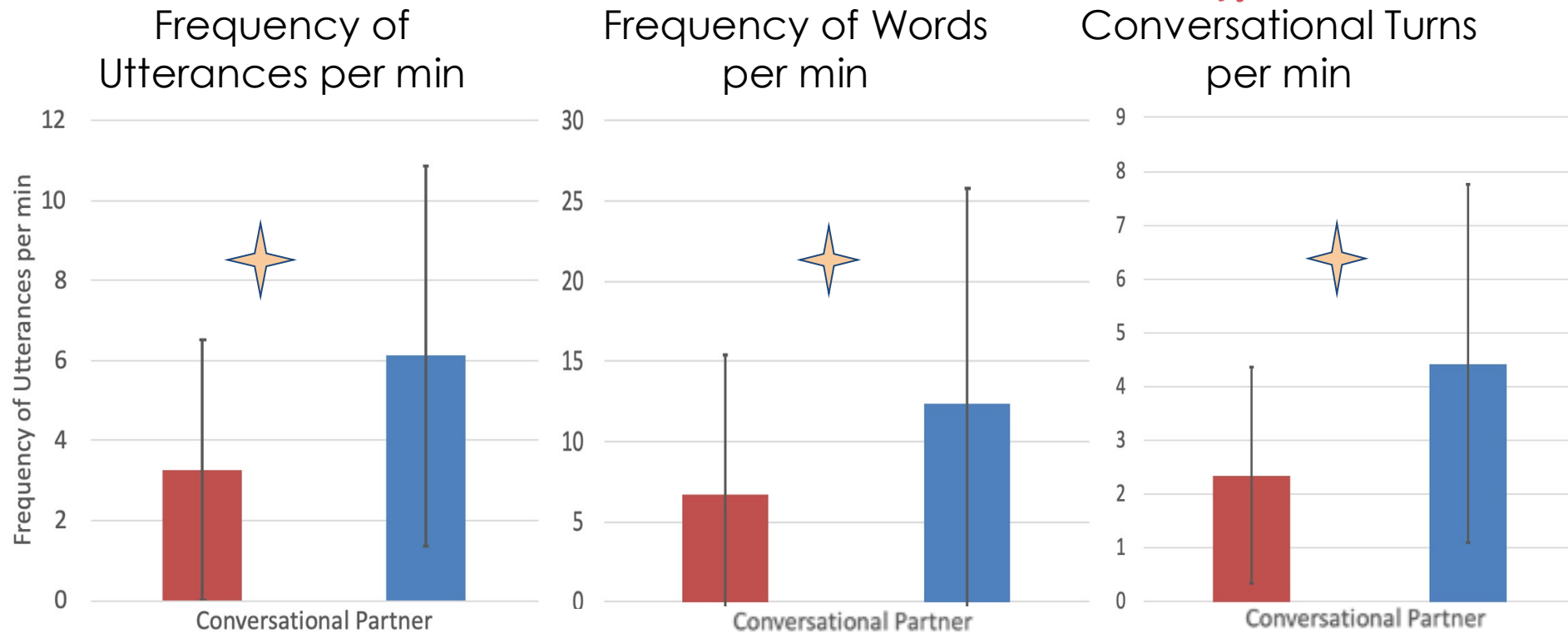
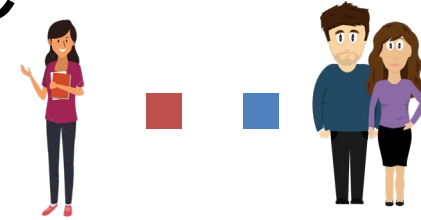
Barokova et al.,
JSLHR 2020

BOSTON
UNIVERSITY

Examiner v. Parent language



Child's language



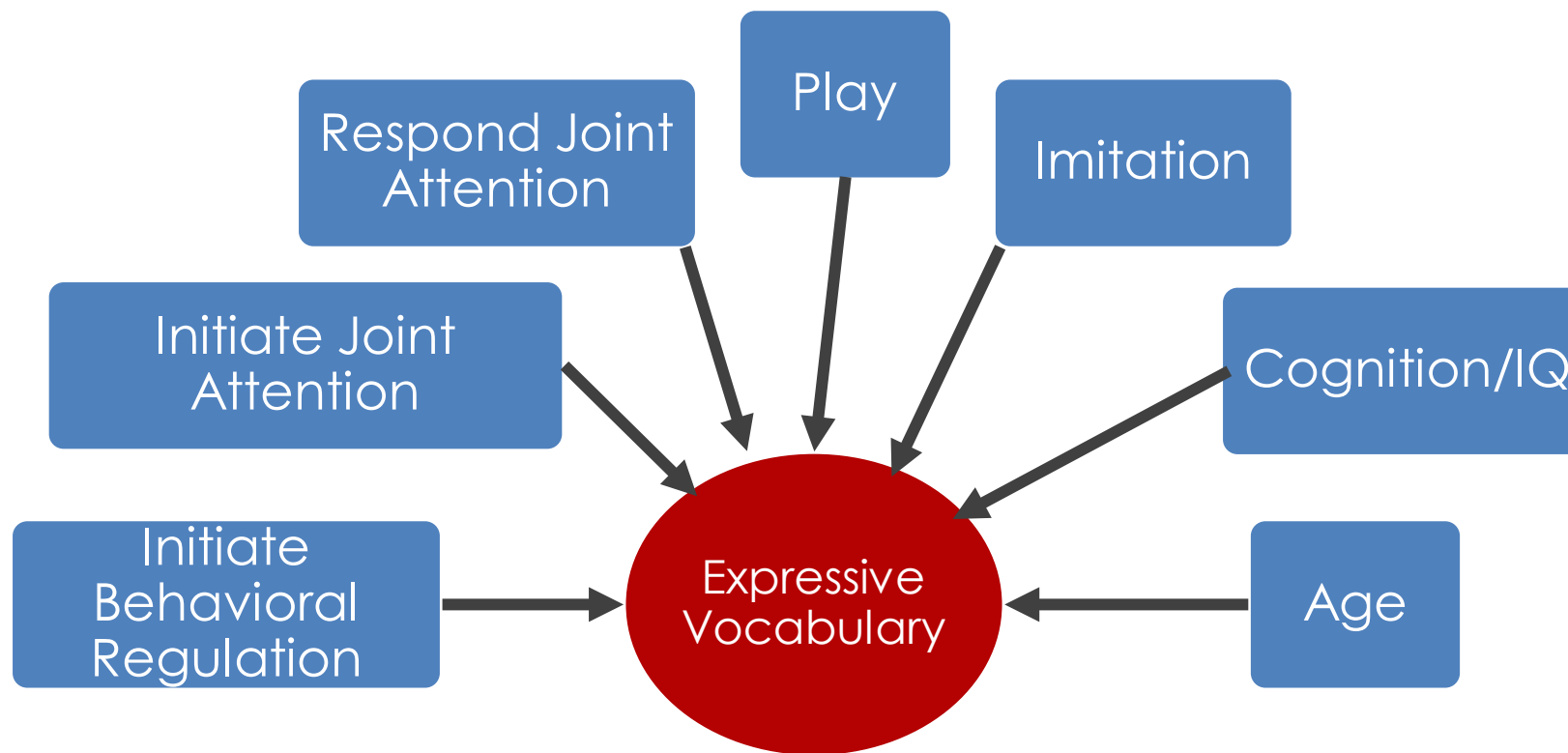
Why don't they speak?

Many *potential* explanations.... :

- Impaired understanding of intentional communication/joint attention
- Symbolic deficits – play/representation
- Impaired imitation
- Intellectual disability (NV cognition)
- Speech motor impairments
- Auditory processing



Behavioral correlates of expressive language in MV ASD



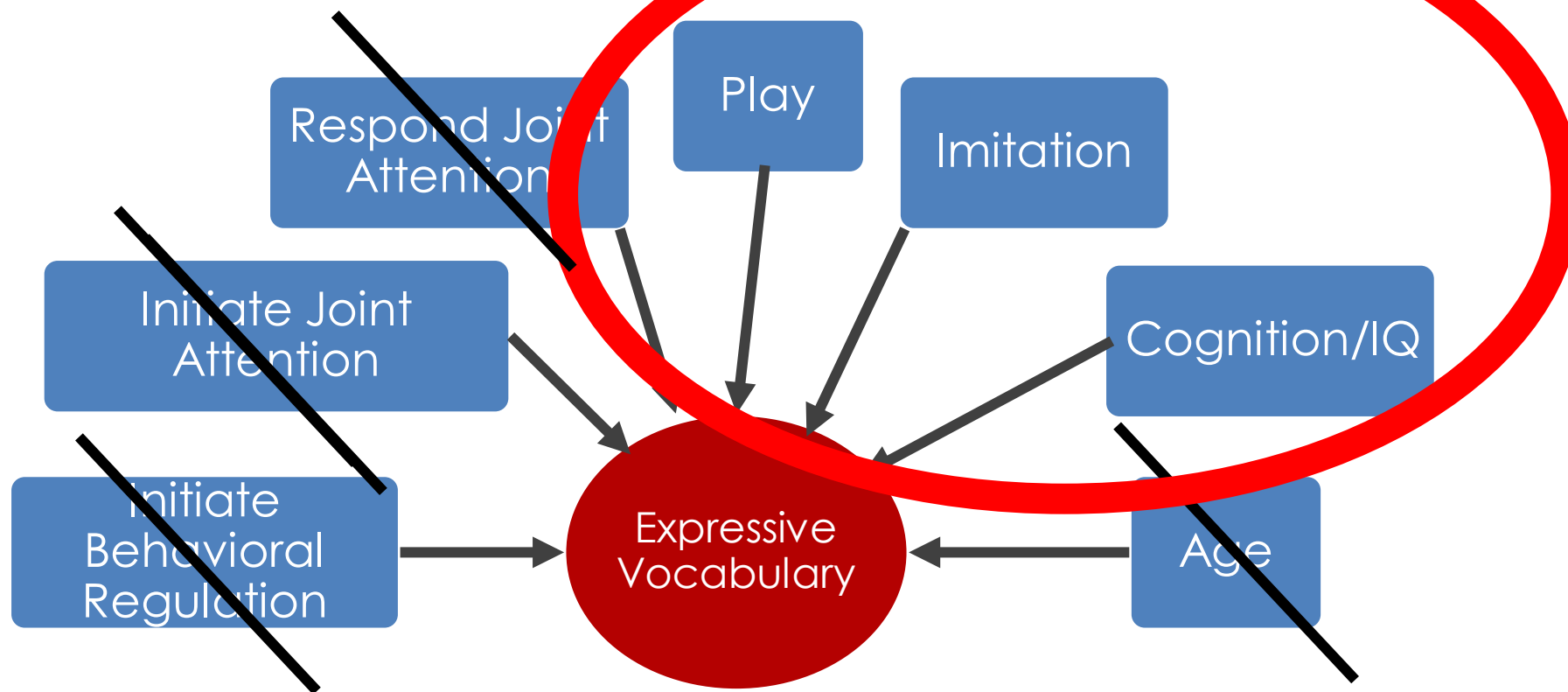
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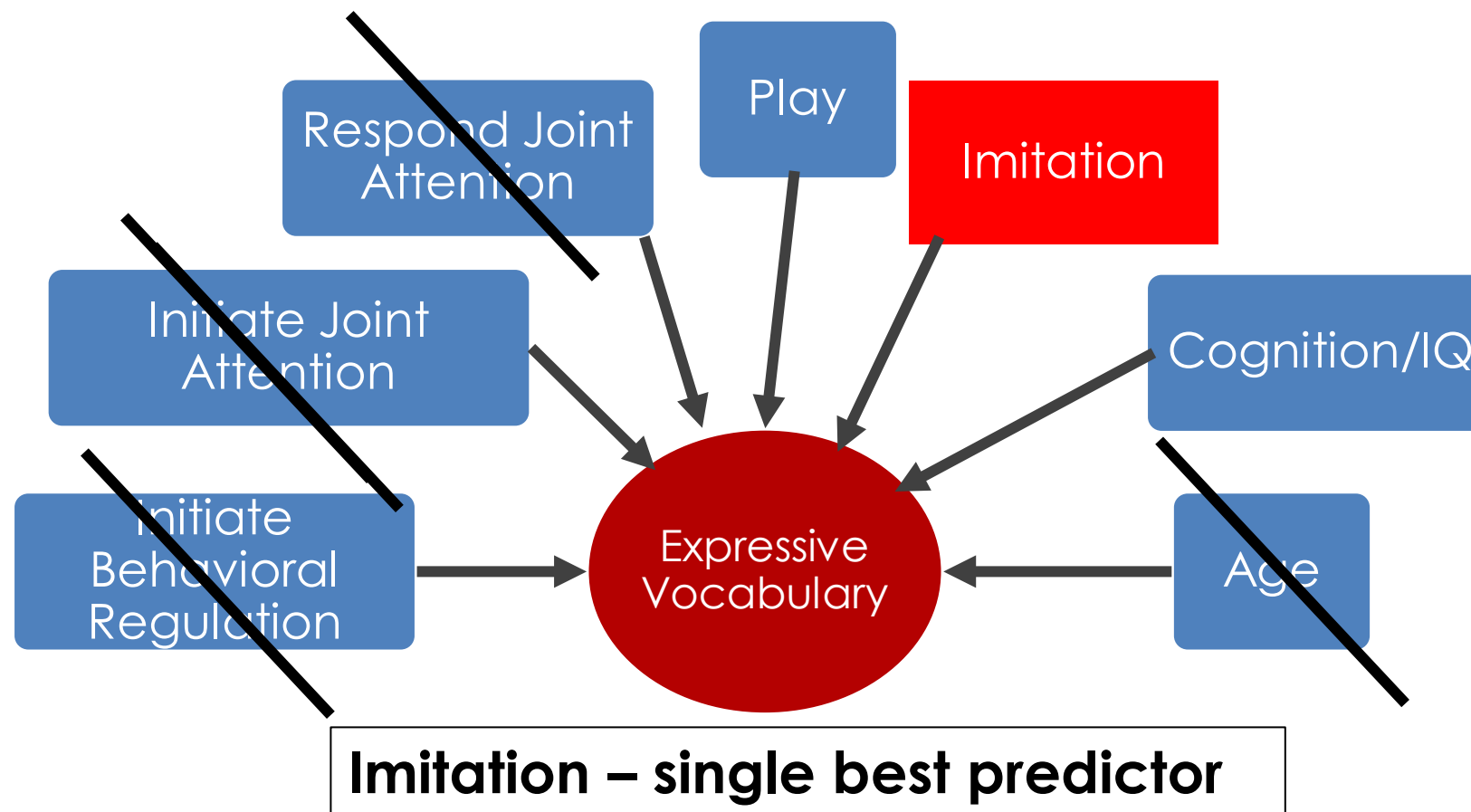
Pecukonis et al.
JADD 2019

BOSTON
UNIVERSITY

Behavioral correlates of expressive language in MV ASD



Behavioral correlates of expressive language in MV ASD





Speech motor impairments

Childhood apraxia of speech(CAS):

Rare *neurological* disorder – Impairments in speech movement precision and consistency



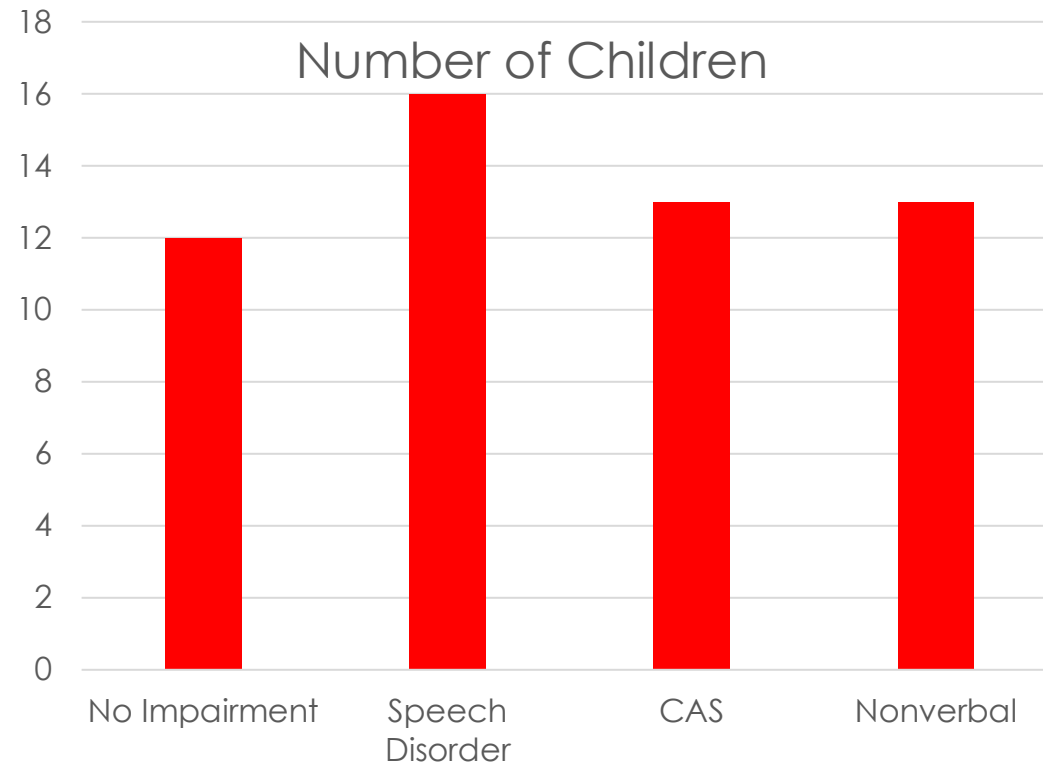
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Chenausky et al.
ADLI 2019

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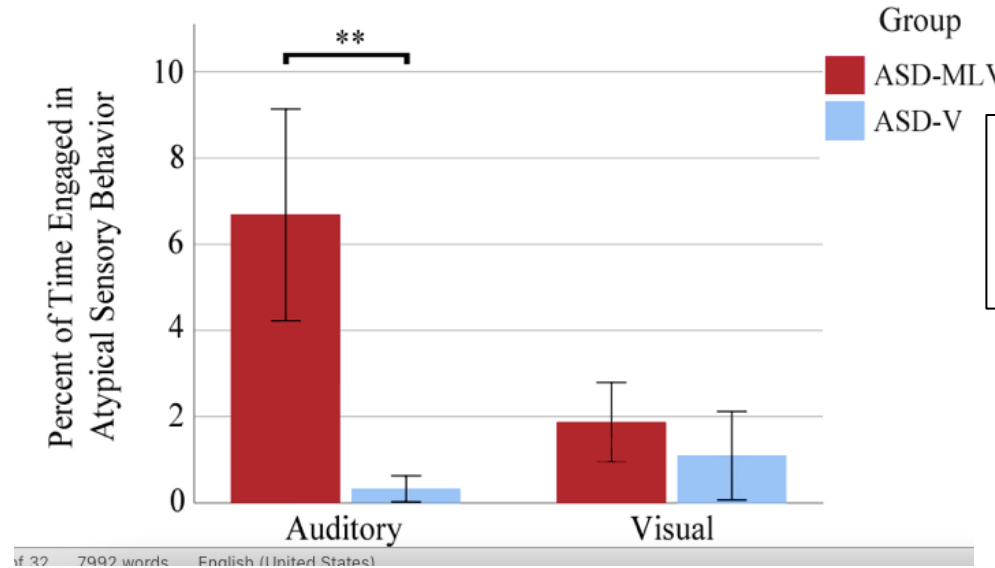
High rates of CAS among MV



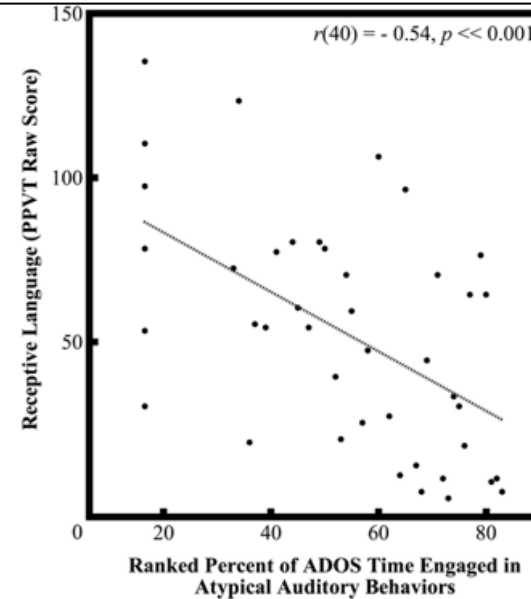
- CAS in ~25%
- Over 75% some speech/motor disorder



Auditory processing



Receptive language LOWER in children/adolescents with MORE auditory behaviors



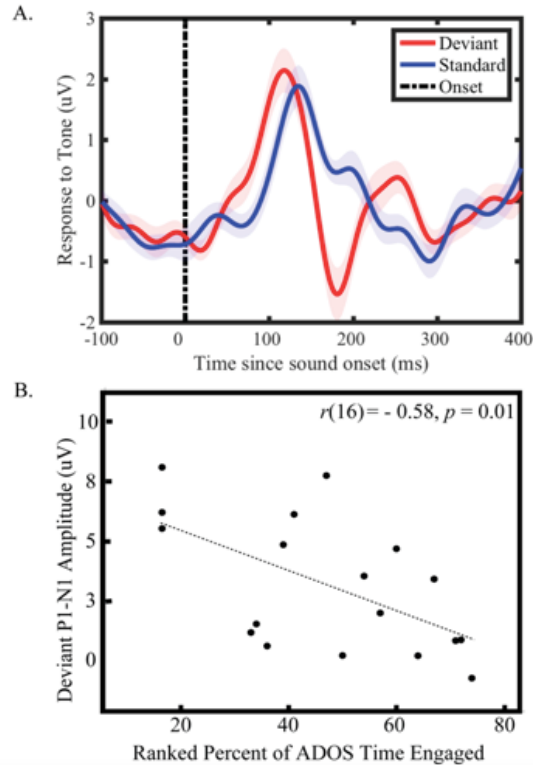
CARE center
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Schwartz et al.,
AR 2020

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Brain marker for auditory processing problems in MLV autism



Amplitude of ERP response to
deviant/rare tones SMALLER
in adolescents with MORE
auditory sensory behaviors



Summary

- Despite every effort, some children don't acquire spoken language
- We have methods for assessing receptive and expressive language – but need to tailor to each person
- Many explanations from behavior, to speech motor impairment, to how the brain processes sounds and speech
- Key takeaway: individual variation that can inform interventions



Collaborators

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Collin Lee

Steven Meyer

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Thank You!



*A very special thanks to all the families
children and teenagers
who have given their time and support!*



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INTERVENTION FOR YOUNG MINIMALLY VERBAL SCHOOL AGED CHILDREN

CONNIE KASARI, PHD

UCLA



INTERVENTIONS FOR MINIMALLY VERBAL

- Influential reviews,....
 - Minimally verbal often excluded from studies
 - Even at young ages (Flusberg & Kasari, 2013)
 - Assessments poorly designed to address needs
 - Standardized assessments; language samples in real world situations more likely to yield information (Kasari et al, 2013)
- Window of opportunity for learning spoken language (Pickett et al, 2009)
 - 5-7 years of age
 - Focus on requesting language, less often on joint attention language

MINIMALLY VERBAL OFTEN EXCLUDED

NIH Workshop

REVIEW ARTICLE

Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum

Helen Tager-Flusberg and Connie Kasari

It is currently estimated that about 30% of children with autism spectrum disorder remain minimally verbal, even after receiving years of interventions and a range of educational opportunities. Very little is known about the individuals at this end of the autism spectrum, in part because this is a highly variable population with no single set of defining characteristics or patterns of skills or deficits, and in part because it is extremely challenging to provide reliable or valid assessments of their developmental functioning. In this paper, we summarize current knowledge based on research including minimally verbal children. We review promising new novel methods for assessing the verbal and nonverbal abilities of minimally verbal school-aged children, including eye-tracking and brain-imaging methods that do not require overt responses. We then review what is known about interventions that may be effective in improving language and communication skills, including discussion of both nonaugmentative and augmentative methods. In the final section of the paper, we discuss the gaps in the literature and needs for future research. *Autism Res* 2013, **; **–**. © 2013 International Society for Autism Research, Wiley Periodicals, Inc.

Keywords: behavioral intervention < intervention; early intervention < intervention; school age < pediatrics; spoken language; minimally verbal ASD; alternative and augmentative communication; eye-tracking

Research in the field of autism spectrum disorder (ASD) has flourished over the past two decades. However, the vast majority of studies have focused on either young toddlers and preschoolers or older higher functioning, verbal children primarily because they are easier to evaluate using standard assessment tools, and they are more compliant during behavioral or neuroimaging experimental investigations. Recently, the Interagency Autism Coordinating Committee (IACC) highlighted the dearth of knowledge about nonverbal children with ASD (IACC 2011 Strategic Plan: <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>). As awareness about this issue grew in recent years, Autism Speaks held a series of meetings in 2009 on “Characterizing cognition in nonverbal individuals with autism,” and the National Institutes of Health (NIH) convened a workshop that was held in April 2010 to identify what is currently known, what are the gaps in our knowledge and what are the research opportunities that could address these gaps. In this paper, which grew out of the NIH workshop, we summarize current research on minimally verbal school-aged children with ASD, focusing on three main questions: (a) Who are these children? (b) What novel technologies

cognitive skills? (c) Which interventions may be effective in improving their language and communicative skills?

Minimally Verbal Children with ASD

It is not known how many children with ASD remain with little expressive spoken language abilities by the time they reach school age. Older statistics suggest that over half of all children with autism failed to acquire spoken language [National Research Council, 2001]; however, more recent studies suggest that this figure is now lower, at around 30%, in part because of the broadening of diagnostic criteria, in part because more verbal children are now identified as having autism and in part because of earlier diagnoses as well as greater access to more effective early interventions that significantly improve spoken language and communication skills in younger preschoolers with ASD, thus potentially preventing them from remaining nonverbal at later ages [Tager-Flusberg, Paul, & Lord, 2005].

We do not understand why, despite access to interventions, some children fail to make progress in acquiring

Who are the ‘minimally verbal’

- Clear most are not ‘nonverbal’
- Defined by number of functional words spoken
- Some can speak but rarely do or only in some contexts
- Intervention is often to do MORE of the same.....
- (or less, blaming child for lack of progress)

IMPORTANT CONSIDERATIONS

- What approach? Especially since current early interventions are having less success in language outcomes with at least one third of children.
- How long should we try an intervention until we change something?
 - What metric do we use to determine response to the intervention?
- What dose is necessary?
- What is a meaningful and realistic outcome?

ULTIMATE GOAL

- Personalization of interventions with meaningful outcomes
- Recognition that a single intervention will not be effective for all individuals



ADAPTIVE INTERVENTION DESIGNS SYSTEMATIZE CLINICAL PRACTICE

DEFINITION: A sequence of decision rules that specify whether, how, when (timing) and based on which measures, to alter the dosage (duration, frequency or amount), type or delivery of treatment(s) at decision stages in the course of care.

QUESTION ON INTERVENTION FOCUS

Controversy: Using augmentative device delays or prevents spoken language

INTERVENTION WITH MINIMALLY VERBAL

- 61 children aged 5 to 8 years
- Minimally verbal (fewer than 20 functional words)
- Had already received 2 years of intensive early intervention
- ALL received JASPER plus a spoken language intervention (EMT)
- HALF randomized to also receive Speech Generating Device (iPad) (Proloquo2go software)

Kasari, Kaiser, Landa, Neitfeld, Mathy, Murphy, Almirall,
JAACAP, 2014

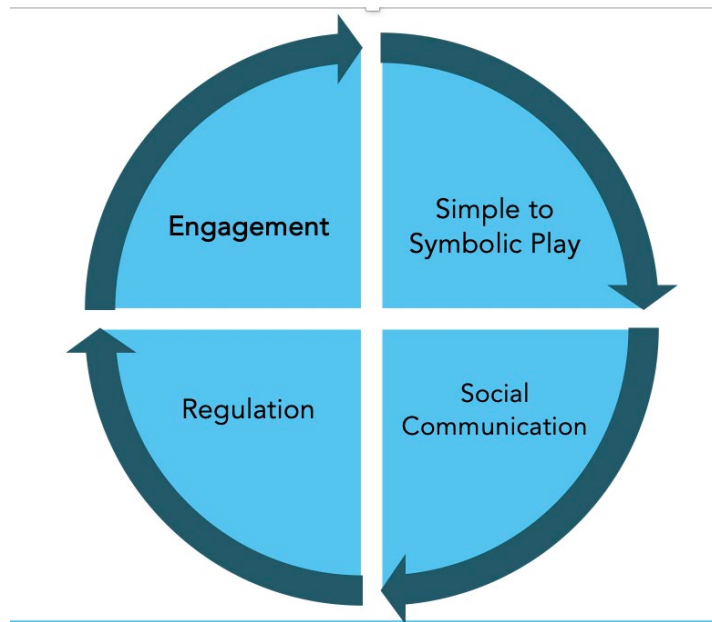


SAMPLE CHARACTERISTICS

- Primarily male, 83%
- 52% minority race/ethnicity; 48% White
- Ages between 5 and 8; mean age 6.31 years
- Average number of functional words on assessments: 17.23 words
- Nonverbal cognitive scores, average 4 years; avg NV IQ 68.18 (range from 38 to 140)

INTERVENTIONS BLENDED

JASPER prioritizes engagement and social communication to teach language

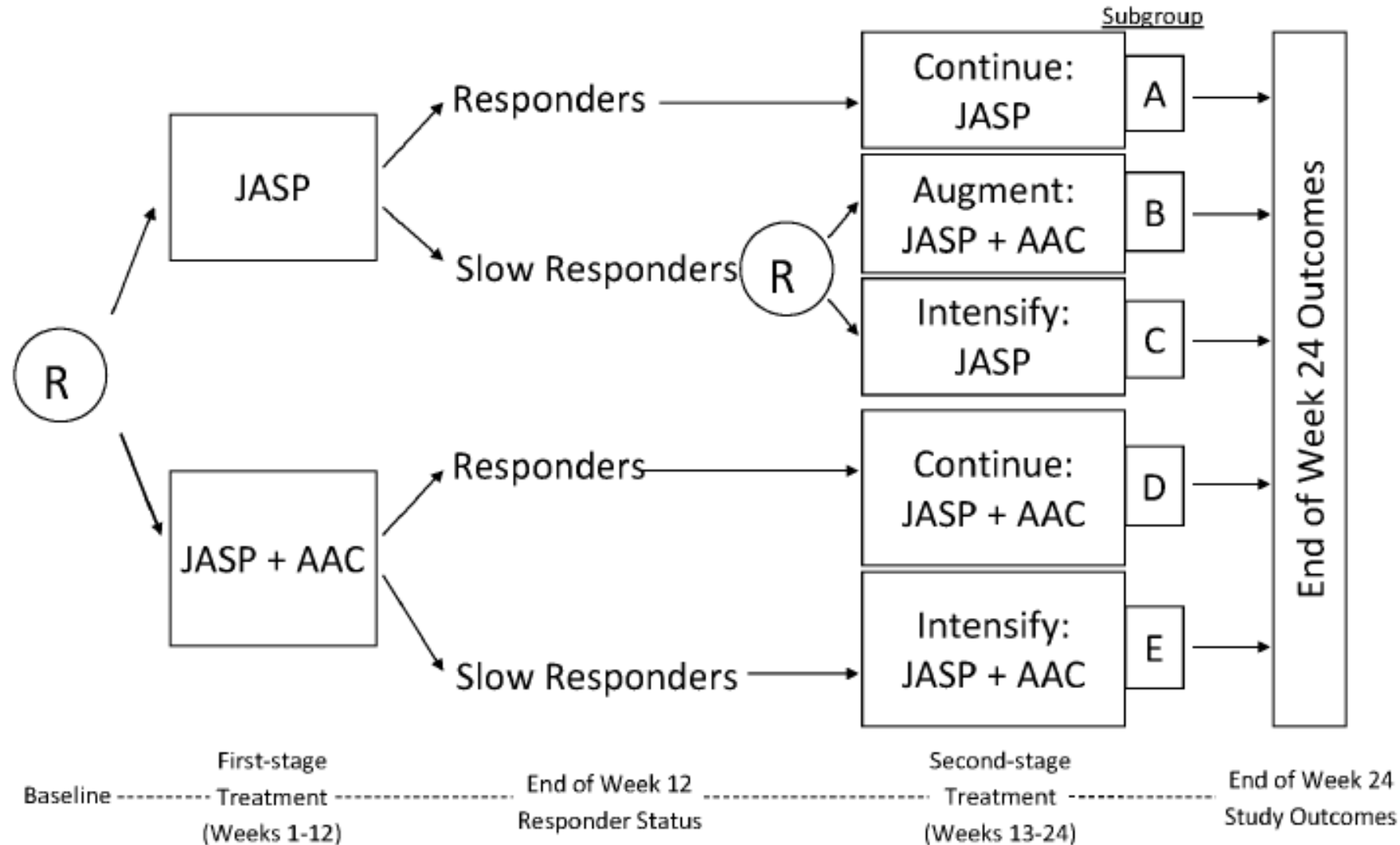


Enhanced Milieu Teaching structures language prompting procedures

- ☐ Time Delay Strategies: using strategies to elicit communication.
- ☐ Milieu Teaching Procedures: Following a prompting procedure at the child's communication level

Example of a SMART in Autism Research

PI: Kasari (UCLA).



PRIMARY OUTCOME MEASURE

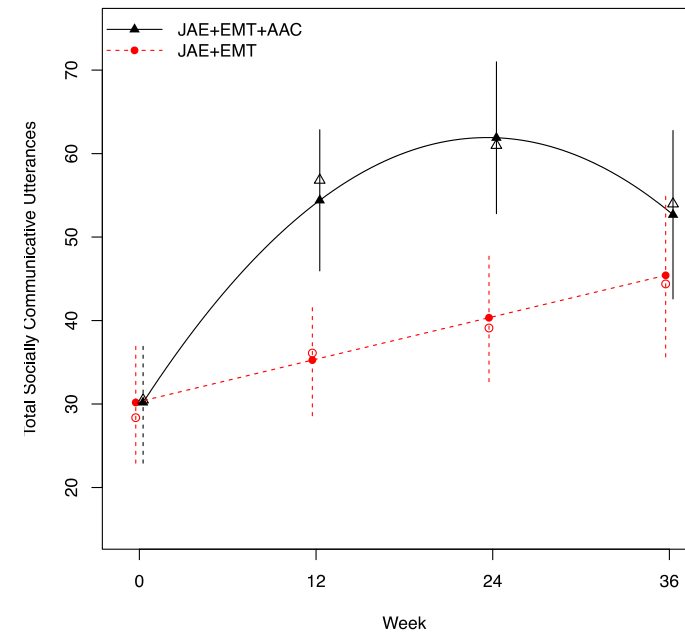


- Natural Language Sample: 20- minute interaction between adult and child
- Language samples transcribed using Systematic Analysis of Language Transcripts (SALT)
 - Independent coders noted each child utterance for generativity (not scripted), and communicative function (e.g., comment, request, other).
 - Both spoken and SGD-produced utterances were transcribed and coded.
- Total Spontaneous Communicative Utterances (TSCU) primary outcome

PRIMARY OUTCOME

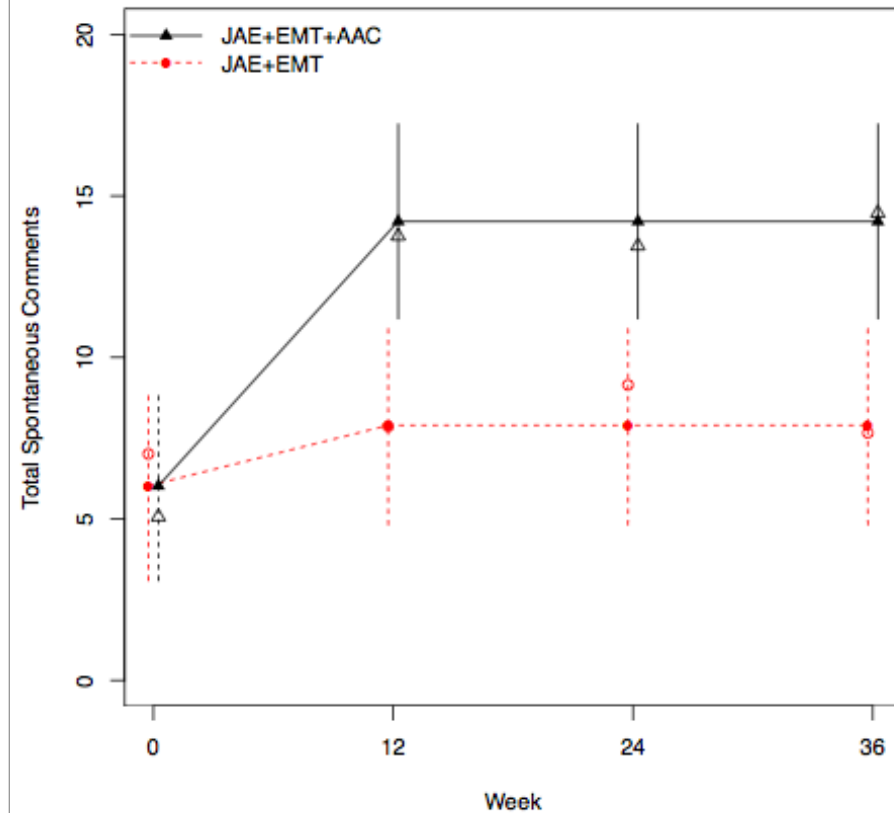
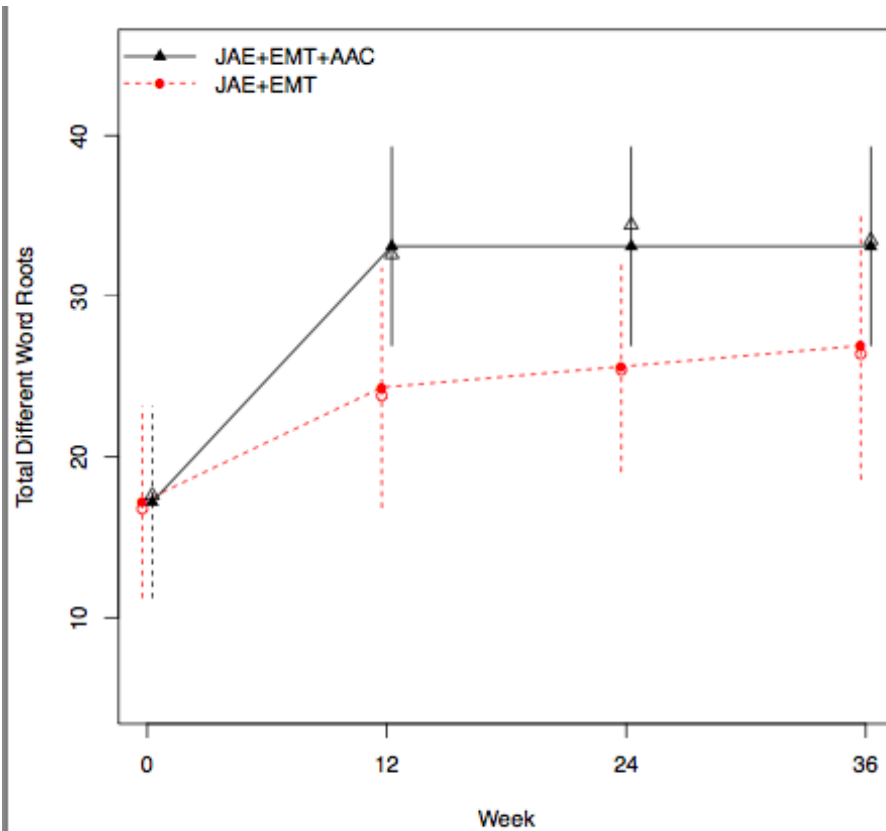


Socially communicative utterances



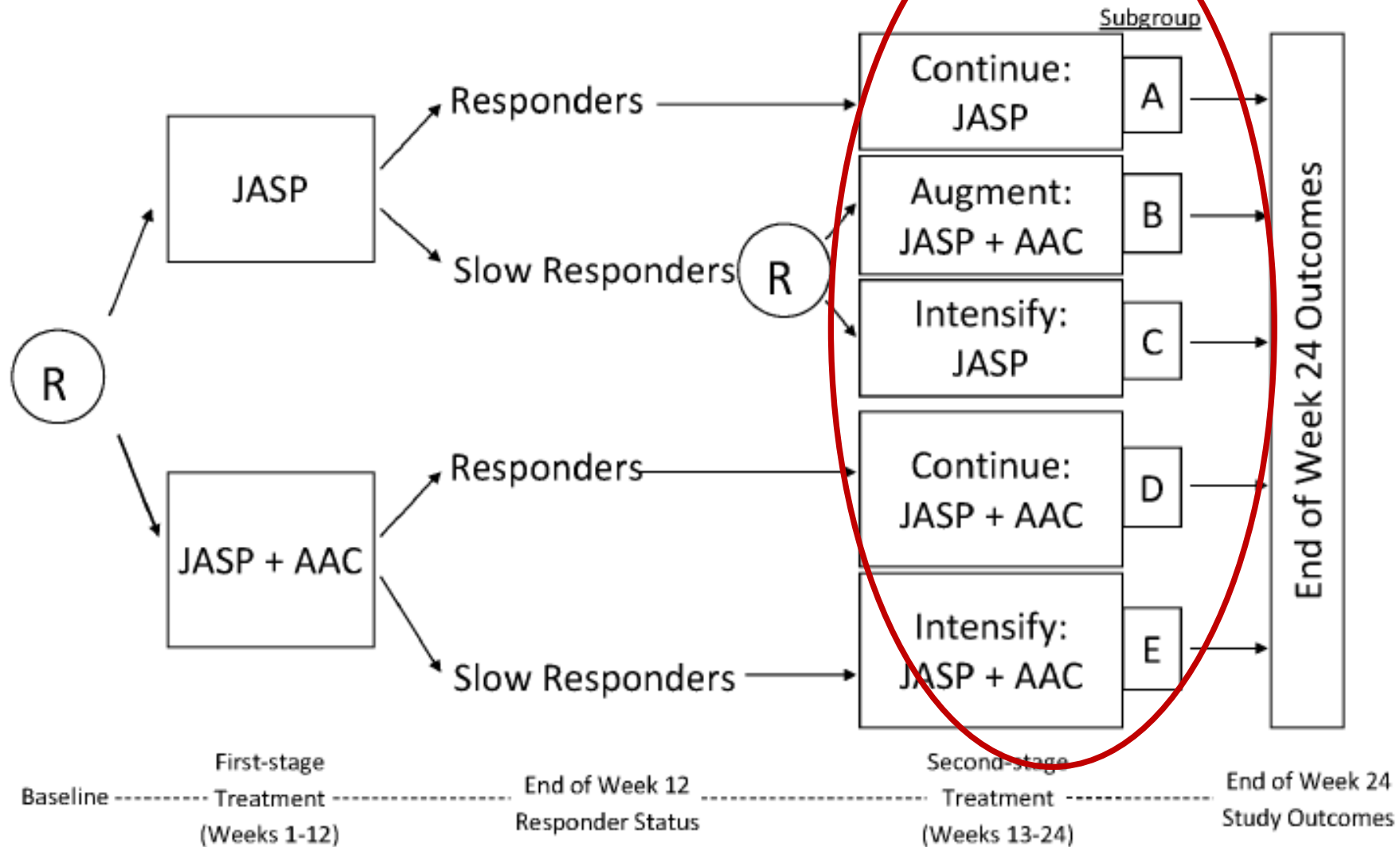
Kasari, Kaiser, Goods, Neitfeld, Mathy, Landa, Murphy, Almirall, JAACAP, 2014

NOVEL WORDS AND COMMENTS



Example of a SMART in Autism Research

PI: Kasari (UCLA).



EVALUATION OF EMBEDDED ADAPTIVE INTERVENTIONS

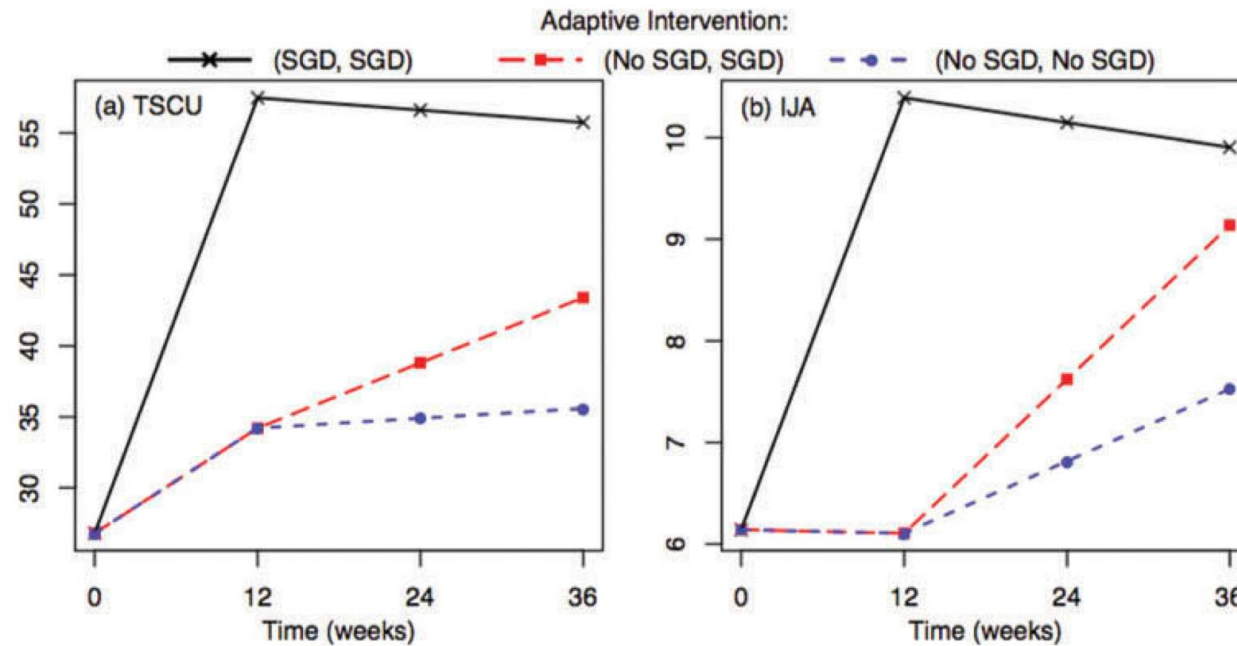


FIGURE 2 Estimated average trajectories under each of the embedded adaptive interventions. *Notes.* See Table 1 and Figure 1 to understand how the three adaptive interventions are defined. Trajectories are shown for the two significant outcomes: (a) total spontaneous communicative utterances (TSCU) and (b) initiating joint attention (IJA). Abbreviations: SGD—Speech generating device.

SGD IN CONTEXT OF INTERVENTION

- The importance of the SGD added into a behavioral intervention right from the beginning is clear in these data
- Approximately 10% of TSCUs (primary outcome) were generated on SGD
- Importance of the behavioral intervention should not be overlooked
 - Just giving a child an SGD will likely not be successful
 - Child needs support to learn, and a context for communication (in this intervention---adult modeling on the SGD in context of play interactions that prioritize communication)

RESEARCH ARTICLE

Communication Growth in Minimally Verbal Children with ASD: The Importance of Interaction

Charlotte DiStefano, Wendy Shih, Ann Kaiser, Rebecca Landa, and Connie Kasari

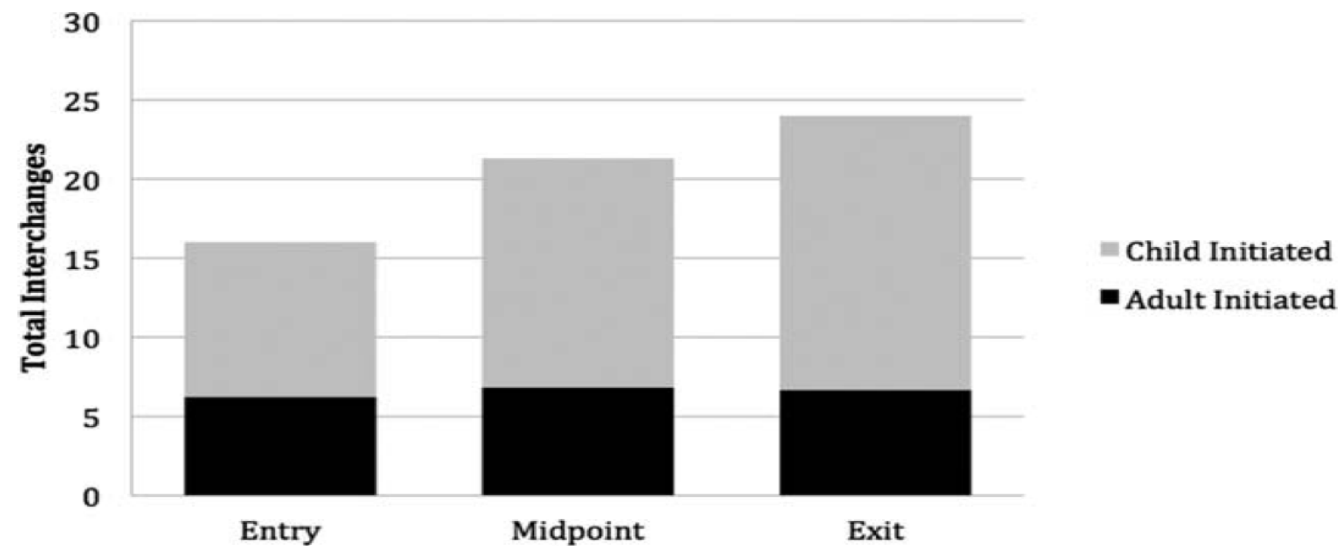


Figure 2. Child- and adult-initiated interchanges. The number of interchanges initiated by child and adult are presented for entry, (month 0), midpoint (month 3), and exit (month 6).

SUMMARY

- Minimally verbal children can benefit from interventions supported by technology
 - SGDs do not inhibit the development of speech, but rather support development
 - SGDs provide communication access
- More research is needed on active ingredients of these interventions that are likely to be multi-component
- Questions remain on how early we should add in technology to early intervention approaches, and the mechanism of how the SGD provides benefit
- More studies on adaptive intervention designs that can personalize interventions

Augmentative and Alternative Communication Supports for Individuals with Autism



Janice Light, Ph.D.

The Hintz Family Endowed Chair in Children's Communicative Competence

Professor of Communication Sciences and Disorders

Pennsylvania State University

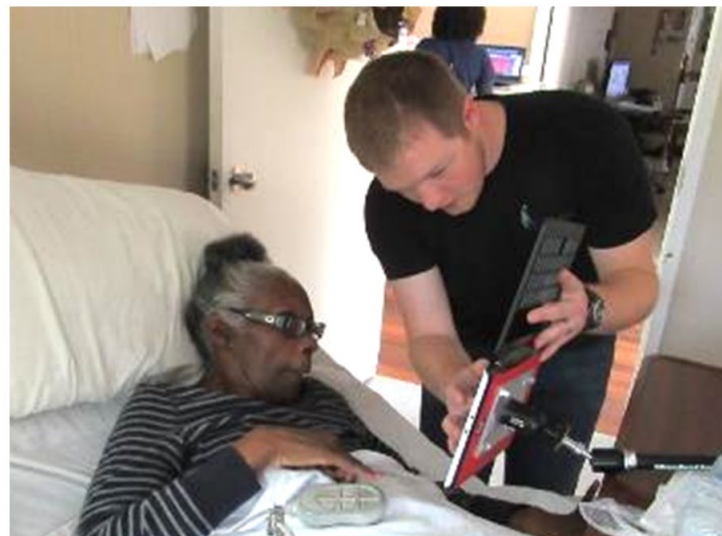
Augmentative and Alternative Communication Supports for Individuals with Autism

Janice Light, Ph.D.
The Hintz Family Endowed Chair
Penn State University
Director, RERC on AAC
JCL4@psu.edu



The need

- More than 5 million Americans have complex communication needs such that they cannot rely on speech⁴
- More than 97 million individuals worldwide
 - Across the life span
 - With a wide range of needs & skills
 - Including individuals with autism



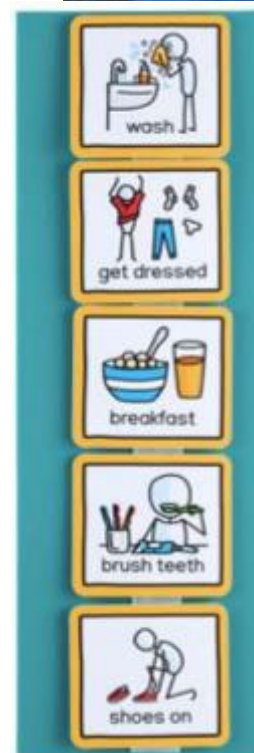
The challenge

- With limited access to speech, these individuals are severely restricted in their participation in society
 - Education
 - Employment
 - Health care
 - Family
 - Community living



Augmentative and Alternative Communication

- AAC offers the potential to
 - Enhance communication
 - Comprehension
 - Expression
 - Increase participation for individuals with complex needs
- AAC involves a wide array of tools, strategies, & techniques
 - Unaided AAC
 - Aided AAC
 - Low tech
 - High tech



Rehabilitation Engineering Research Center on AAC



- Our NIDILRR-funded RERC on AAC conducts
 - Research to advance knowledge & improve outcomes
 - Development to improve AAC technology solutions
 - Training to build capacity with service providers & technology developers
 - Dissemination to reach all stakeholder groups
 - To expand “what is possible”
 - To ensure “what is possible” becomes “what is probable”

Our vision

- Ensure that all individuals, including those with the most complex needs, have access to effective AAC technologies & interventions to realize
 - the basic human need,
 - the basic human right, and
 - the basic human power of communication



Effects of AAC for individuals with autism

- Research demonstrates that AAC intervention
 - Enhances communication
 - Increases participation
 - Enhances language development
 - Decreases challenging behavior
 - At no risk to speech development
 - AAC enhances speech production^{11, 12, 13, 16, 18, 26, 31, 34, 35, 39}



Ensure equal access to AAC

- Positive effects of AAC predicated on equal access to AAC
 - Sufficient intensity to attain meaningful gains
- Black children with complex communication needs receive less AAC intervention than their white peers³³
 - 35% of white children received <60 min of AAC intervention per week
 - 65% of Black children received <60 minutes
 - Insufficient to attain meaningful gains



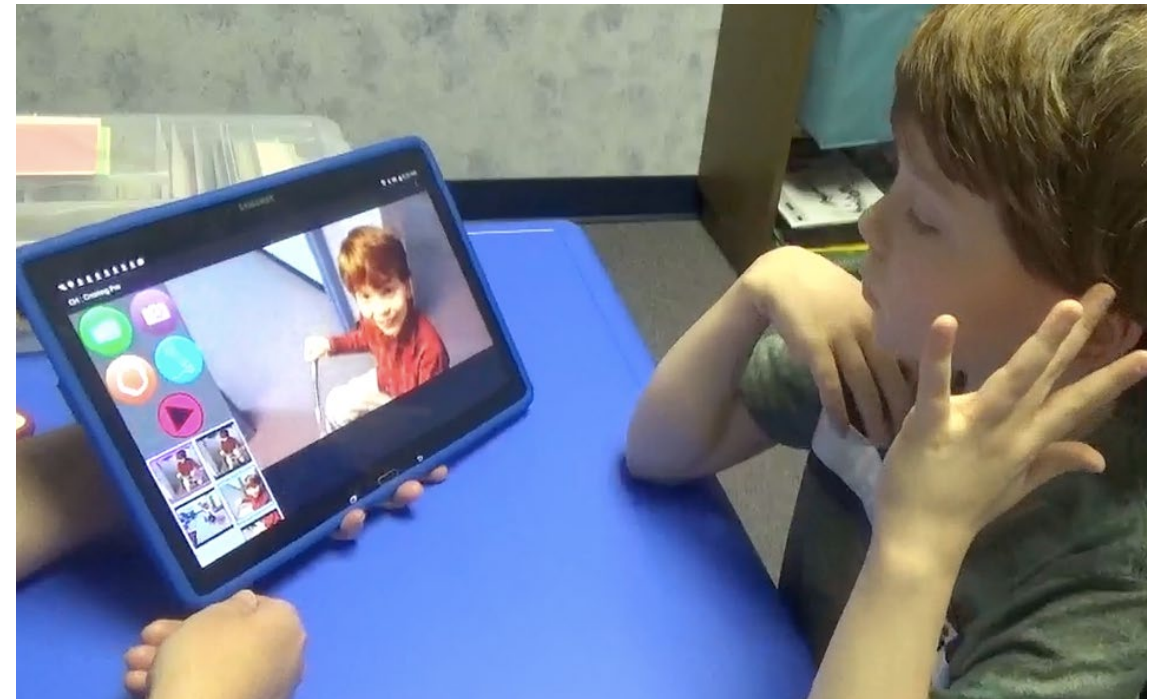
Provide AAC intervention as soon as possible

- Provide AAC intervention as early as possible
 - AAC should not be considered a “last resort”
 - Prevent children with autism from falling further and further behind their peers
- But it is never too late to provide AAC intervention
 - Many autistic adolescents and adults never had access to AAC



Leverage AAC to build communicative competence

- Too often AAC interventions focus solely on requesting ^{11, 16}
- Focus on building independent communication to
 - Express needs and wants
 - **Interact socially** ^{3, 9, 36}
 - **Share information and experiences** ^{6, 24}



Personalize AAC technologies

- Most AAC technologies developed by neurotypical adults
 - Do not reflect the ways children & adults with autism think about the world
- AAC technologies should
 - Be driven by the needs & skills of individuals with complex communication needs
 - Reflect what we know about motor, vision, hearing, cognition, & language development
 - Be appealing, easy to learn & use, powerful²³



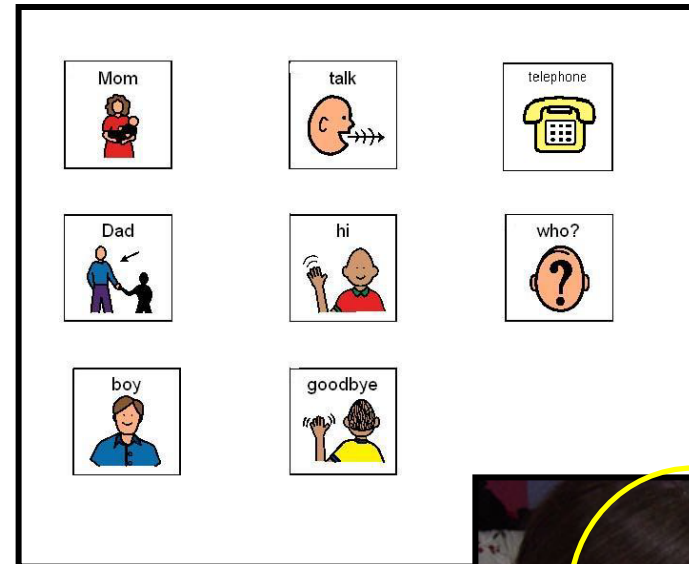
The Picture Communication Symbols for iPad and iPhone. © 2011 by Picture Communication Symbols, LLC. All Rights Reserved. Reproduction and distribution prohibited.

Personalize AAC technologies

- Too often individuals are forced to use AAC systems that are not a good fit²¹
 - One size does not fit all
- Should be personalized to meet the individual's needs, skills, & preferences⁴
 - Vocabulary
 - Representation
 - Organization and layout
- Even relatively small changes to AAC display variables impact accuracy, efficiency, & communicative use significantly²⁵
- **Which AAC technologies work best for whom under which conditions?**

Visual scene display AAC technologies

- Many AAC systems use grid displays
 - Represent language with symbols
 - Taken out of context in which language is learned³⁸
- Visual scene displays (VSDs) & video VSDs
 - Photos or videos of meaningful events within person's life
 - Embed language concepts as “hotspots” within the VSD & video VSD⁴



VSDs and video VSDs for beginning communicators

- Offer significant advantages
 - Processed visually very rapidly ^{32, 41}
 - Drive visual attention to key language concepts in the event ⁴⁰
 - People, actions, shared activity
 - Allow just-in-time programming of vocabulary as needed ^{15, 17}
 - Support increased communication & vocabulary acquisition and expression ^{10,14}



Use VSDs & video VSDs to support **social interaction**

- VSDs & video VSDs support increased communication & social interaction ²⁴
 - Shared book activities between young children with autism & peers ^{36, 37}
 - Shared preferred videos with young children with autism & adults in preschool ⁹
 - Play between school-aged children with autism & peers ^{20, 22}



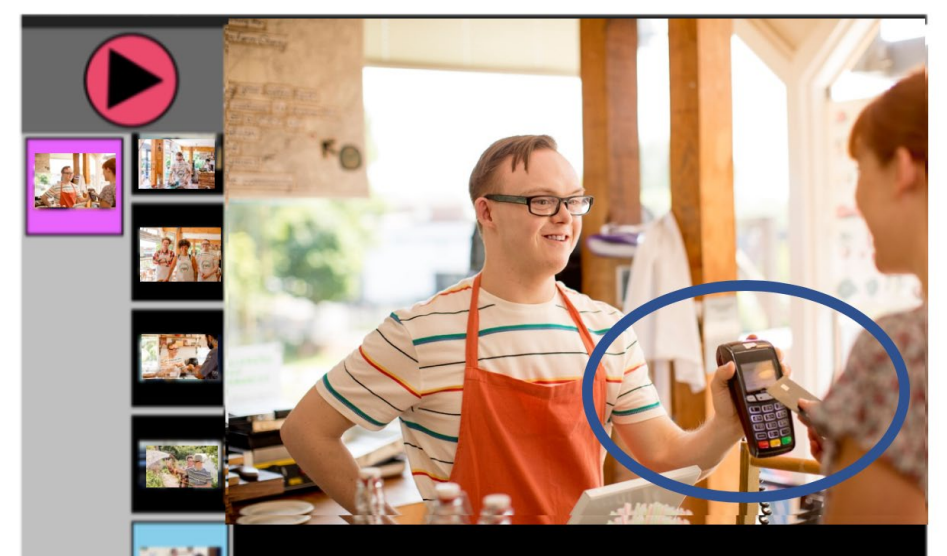
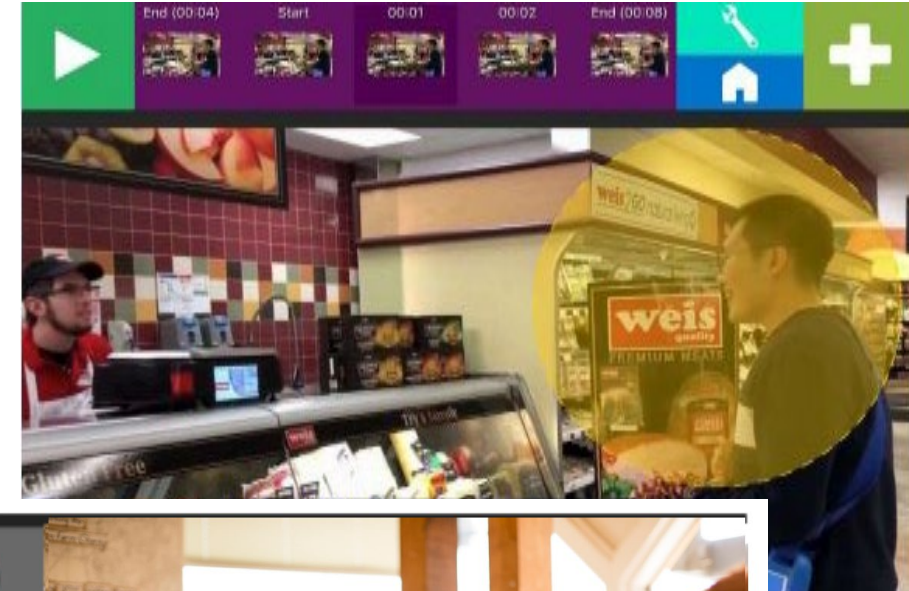
Use VSDs & video VSDs to support peer interactions

- Adolescents with autism & their peers in high school
 - Video VSDs with preferred videos
 - Brief mobile training for dyad
 - Pause video, add hotspots & record vocabulary
- Results
 - Significant increases in social interaction
 - High levels of consumer satisfaction³



Use video VSD technology to increase participation

- 90% of adults with limited speech do not have access to effective AAC to support participation
- AAC video VSD technology provides
 - Video models of steps in task
 - AAC supports for communication
 - Embedded into videos at key junctures
- Substantial increases in successful independent participation in community & vocational activities^{1,2, 30}



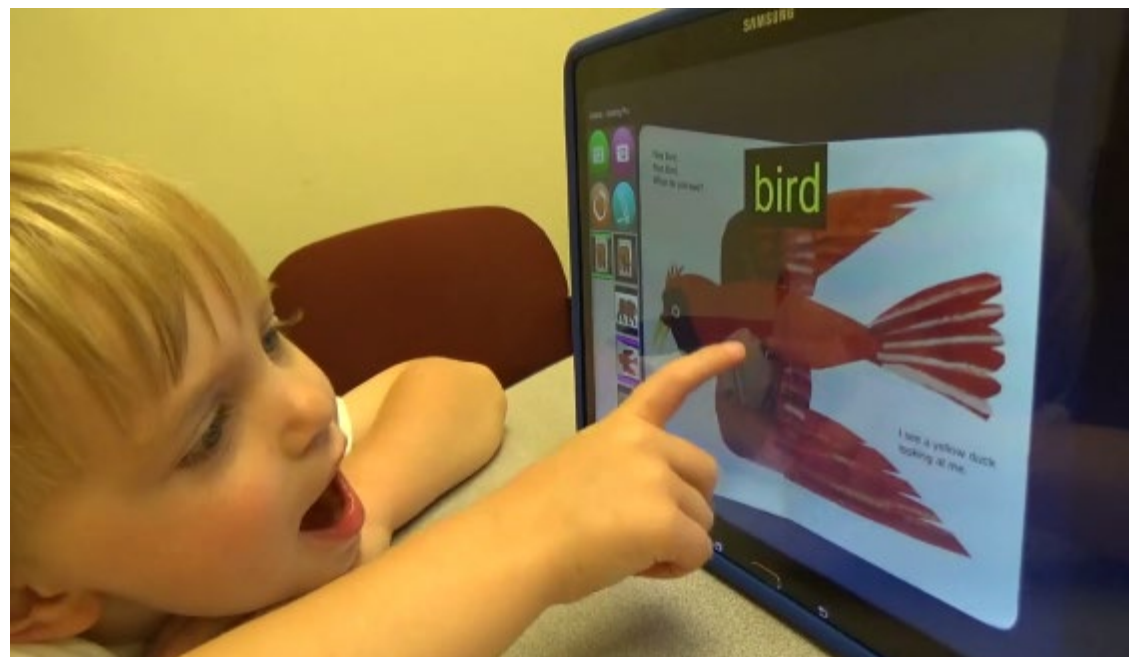
AAC technologies to support literacy learning

- Literacy skills are essential to participation in society
- More than 90% of individuals with complex communication needs enter adulthood without literacy skills
- Current AAC technologies do not support the transition from picture symbols to literacy



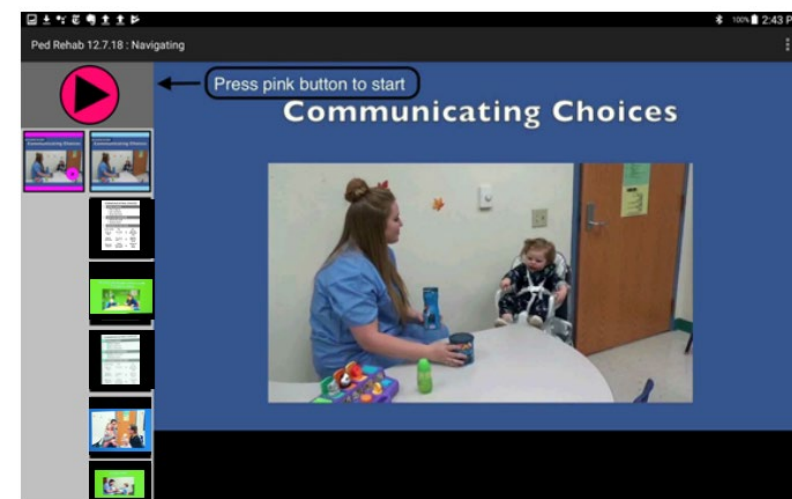
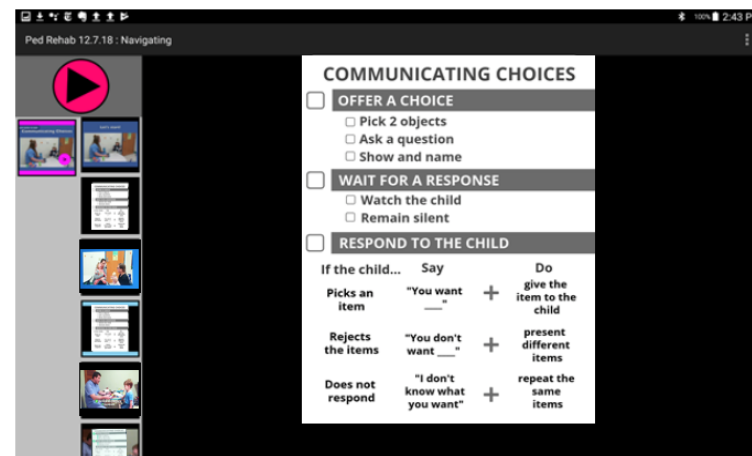
Use AAC technologies to support literacy learning

- **AAC transition to literacy (T2L) technologies**
 - Select a picture symbol from an AAC grid or VSD
 - Written word appears dynamically
 - Drives visual attention to text
 - Word is spoken out
 - Supports phonological processing
- 89% of participants increased literacy skills with AAC apps with T2L feature ^{5, 7, 8, 28}



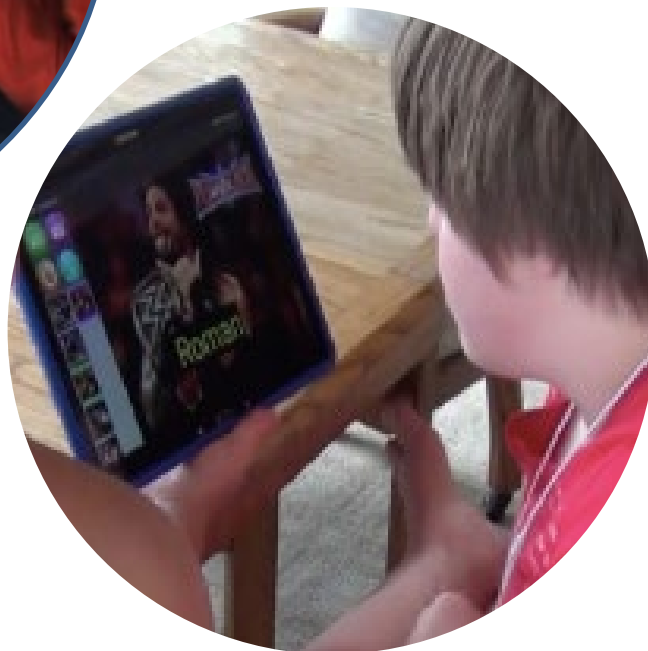
Provide training for communication partners to reduce societal barriers

- Communication partners may not be trained in AAC
 - Pre-empt opportunities for communication & participation
- Need to support family & communication partners^{19, 27}
 - User-friendly app to create mobile trainings that can be deployed “just in time” to train partners
 - Step by step instructions/ Checklist
 - Video demonstrations of each step

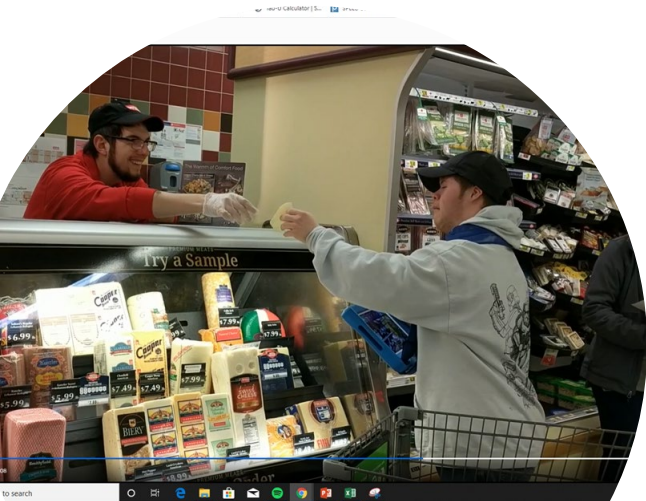




The success of AAC technologies and intervention is best evaluated



by the extent to which they **enhance communication and participation** in valued activities and experiences of everyday life.



For more information...

- For more information, please visit the AAC Learning Center at
 - <https://aac-learning-center.psu.edu/>
- Please also visit our websites at
 - <https://rerc-aac.org>
 - <https://aackids.psu.edu>
 - <https://aacliteracy.psu.edu>
 - <https://aac.psu.edu>



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 - The Hintz Family Endowment in Augmentative Communication

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Lived Experience Perspectives

Jordyn Zimmerman
Autistic Self-Advocate

Benita Shaw
Parent Advocate





Break

Round Robin Updates



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

Housing Resources Page on the IACC Website



U.S. Department of Health & Human Services | Get IACC Updates | Public Comments | Contact

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

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Resources

- About Autism
- Organizations
- Transition
- Employment
- Housing**
- Coronavirus

Websites and Programs

- Toolkits and Guides
- Reports
- Research Articles
- Videos

IACC Home > Resources > Housing

Housing



Housing plays an important role in ensuring the well being of people on the autism spectrum and helping them integrate into the community. Some people can live independently with minimal or no supports, while others require high levels of support. There is a variety of federal and private resources that can enable people to live in settings that best fit their needs. This page provides information about models of housing for people with disabilities and resources and programs related to disability housing.

Websites and Programs

Medicaid.Gov

- **Home & Community Based Services**

This page provides information on Home and Community-Based Services (HCBS) regulations. The page includes a training series for stakeholders, transition plans for individual states, technical assistance, and more. The **Final Regulation** page provides an overview of rules and regulations states must follow when providing HCBS under Medicaid.

The Arc

- **Housing Overview**

This page provides an overview of housing issues that people with intellectual and developmental disabilities (I/DD) encounter as well the Arc's advocacy efforts. The page also describes key federal housing initiatives that enable people with I/DD to live in the community and links to additional resources.

[More Websites and Programs ➡](#)

<https://iacc.hhs.gov/resources/housing/>

Closing Remarks

Joshua Gordon, M.D., Ph.D.

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(NIMH) and Chair, IACC

Susan A. Daniels, Ph.D.

Acting National Autism Coordinator
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC





Upcoming Action Items

- May 2022: Use emailed ballot to vote for top 20 advances for 2021 IACC Summary of Advances
- May 2022: Respond to IACC member survey on IACC Mission, Vision, and Values for new Strategic Plan
- Summer 2022: Provide global feedback on draft publication at IACC Strategic Plan Working Group Meeting on July 13-14, 2022 (all members welcome) and/or provide feedback via survey
- Next IACC Full Committee Meeting October 26, 2022 (virtual or hybrid TBA)

Join us for NIMH Special Event for Autism Awareness Month!



NIMH/OARC SPECIAL EVENT FOR AUTISM AWARENESS MONTH:

Animating the Future for Exceptional Minds



WEDNESDAY, APRIL 27, 2022 • 1:00 PM TO 2:30 PM
VIRTUAL EVENT • [HTTPS://IACC.HHS.GOV](https://iacc.hhs.gov)



National Institute
of Mental Health

OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

EXCEPTIONAL MINDS

<https://iacc.hhs.gov/meetings/autism-events/2022/april27/exceptional-minds.shtml>

INSAR 2022 Meeting: May 11-14



INSAR 2022

AUSTIN TEXAS ★ MAY 11-14

JW MARRIOTT AUSTIN TEXAS

INSAR 2022 will be a hybrid event, held both virtually and in-person
May 11- 14 from Austin, Texas, USA.

<https://www.autism-insar.org/page/2022AnnMtg>

Autism at Work Research Workshop: May 16-18



<https://www.microsoft.com/en-us/research/event/4th-annual-autism-at-work-research-workshop/>

RSVP: <https://docs.google.com/forms/d/e/1FAIpQLSesTUce22X0bwH2rrLZgTZbFLcQbD6dcTBk9O9fO-ppn0AxfQ/viewform>

Thank you to the OARC Staff!



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Adjournment - Day 2



Thank you for joining us for today's IACC meeting.

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