

Early Interventions and Autism: What we have learned and the promise of the future!



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Disclosures

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NIH (NICHD, NIDCD), HRSA

Knowing and
not knowing



What's next:
Personalizing interventions

Intervention &
examples

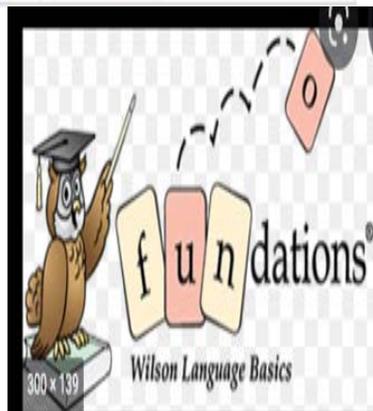
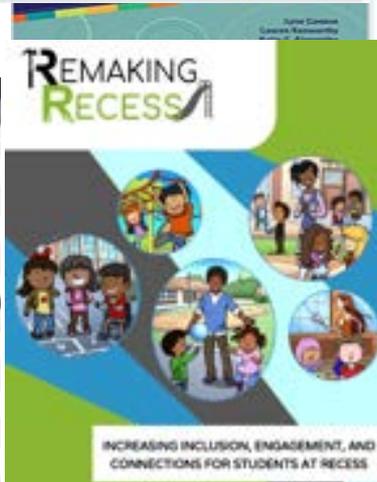
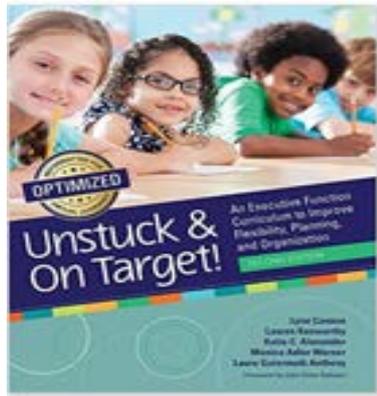
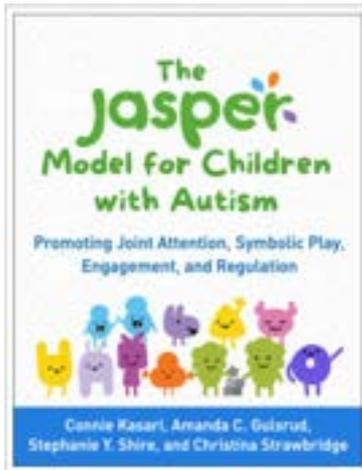
Knowing and
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What we know....We have made progress!



Early interventions likely responsible for improved language outcomes in autism....from 70% minimally verbal entering school in the 1980s to about 30% today (Tager-Flusberg & Kasari, 2013)

More rigorously tested interventions using **randomized controlled trials**

More individuals accessing inclusive education and community settings

More individuals experiencing 'optimal outcomes' (Georgaides & Kasari, 2018, JAMA Pediatrics)

What we know we know....

1. Increased knowledge of malleable intervention targets

Recognition of the developmental nature of autism

While specific targets change with development and context, nearly all autistic children require intervention on:



Engagement



Imitation



Joint attention



Play

Based on experimental studies

Targets identified through carefully conducted experimental studies in the 1980s

Autistic children compared to DD matched on MA, CA and typical children matched on MA (Mundy et al, 1986; Mundy, Sigman, Kasari, 1990)



Joint attention skills more delayed than requesting skills



Symbolic and social play more delayed than functional and independent play

Importance to Development

Language* by age 5-6 best social outcomes

(Lord, 2000; Rutter, 1978)

Joint attention predicts to language

(Kasari et al, 2008; Kasari et al, 2012; Mundy et al., 1986; Mundy, Sigman, & Kasari, 1990)

Play skills associated with cognitive abilities

(Kasari et al, 2012)

Engagement and regulation necessary for learning

(e.g. Shih et al, 2023; Smith, et al 2009)

*Speaking in phrases

Goal of Early Intervention

Reduce the number of children with autism who have significant language delays by the time they start school!

LANGUAGE IS THE SINGLE BEST PREDICTOR OF
LONG-TERM OUTCOMES

We also recognize.....

A single intervention is not effective for all individuals

Heterogeneity in how individuals present

Across a broad range of health, behavior, genetics, and background demographics

Heterogeneity in response to interventions

Including in the moment changes to health and behavior

What we know we don't know

For whom an intervention works?

We cannot predict with certainty the best intervention for an individual child.

Why does the intervention provide benefit?

What are the active ingredients (the important components) that make the intervention work?

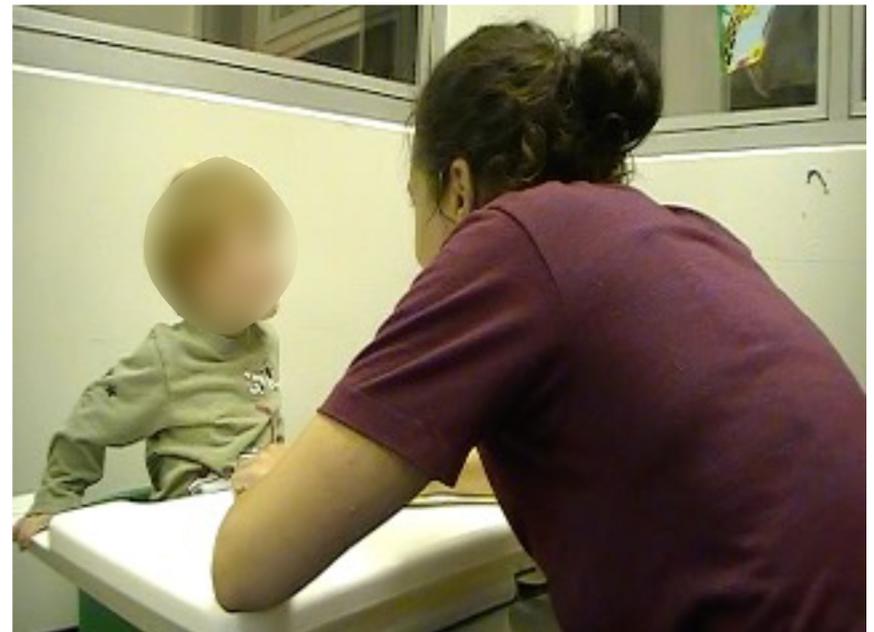
There are also challenges to the idea of
intervention

What are the core challenges that might trigger intervention?

Typical 18 mo.-old



18 mo.-old with autism



Early Core Challenges: Interactions can be difficult



Play can feel frustrating
or not enjoyable



Difficulty engaging the
child in an activity

Interventions important for most
children identified early

Questions are in how we intervene and
what we intervene on?

Shifting the conversation

Neurodiversity movement

Autistic adults have had a lot to say about what, when and how we study autism.

Community partnered participatory methods.....help to refine research questions, and meaningful outcomes

Listening to families

Families may have differing views

They have been particularly active in advocating for children who are intellectually disabled, and those at high likelihood for remaining minimally verbal at school age

Children less likely represented in research studies

We know the least about children who are most delayed....low DQ, limited language

These children often excluded from research studies---we know less about what interventions work best for them

As well as children who are low income. They may have transportation issues, or have less access to information about studies in their community

Knowing and
not knowing

What's next:
Personalizing interventions



Intervention &
examples

Modular interventions

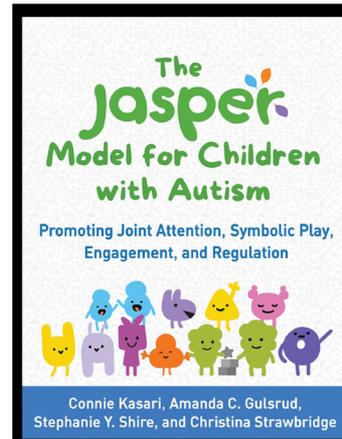
To address some of these early developmental and practical concerns:

modular interventions conducted in community (schools, home) may push the field further along

They can be added flexibly---not a one size fits all approach

Example intervention: JASPER

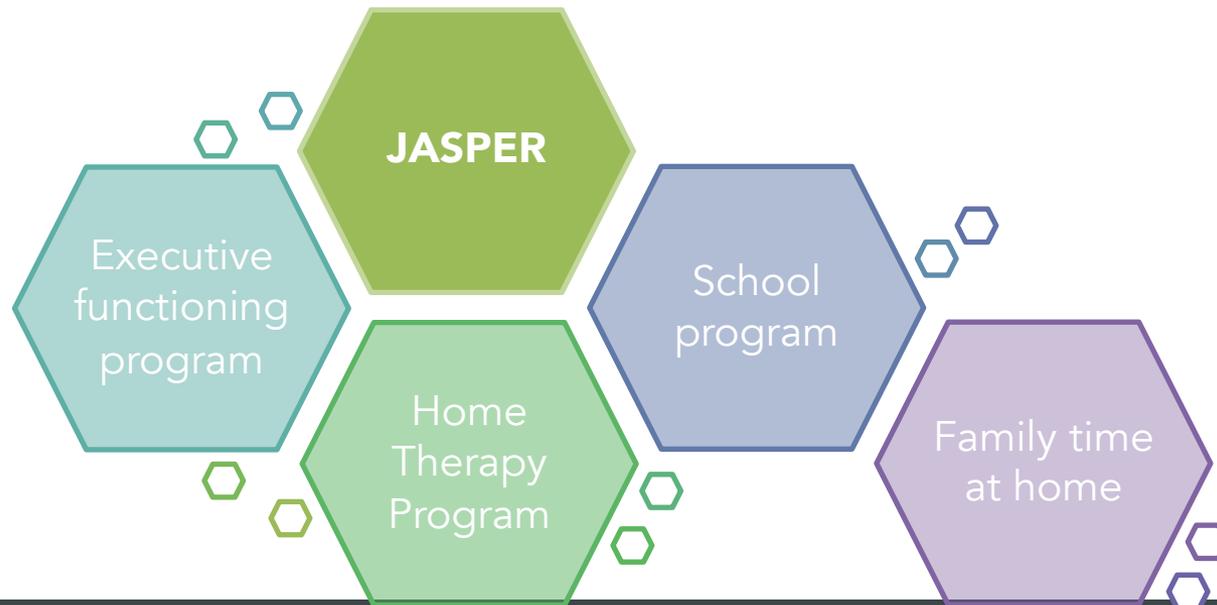
Improving language skills through gestures, play and engagement



Considered an NDBI---Naturalistic,
developmental, behavioral intervention

Modular interventions can begin to address questions of for whom and why

JASPER is a **module**---a comprehensive social communication/language intervention that can float inside other interventions, used on its own, or used sequentially.



Methods Matter.....

Issue: no standard of care for autism interventions

Solution: Important to use rigorous scientific methods to know what is effective and what is not---with whom and when!

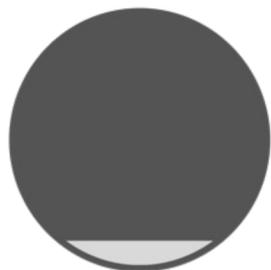
We also need to pay attention to meaningful outcomes

Joint Engagement is a primary outcome for JASPER studies:

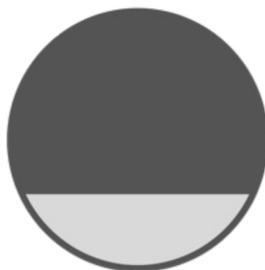
Different from Joint Attention

Foundation for language learning

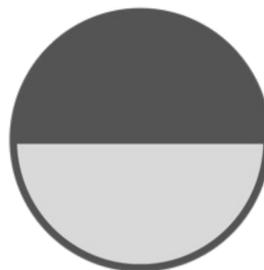
- Drawing on developmental language work of Lauren Adamson and Michael Tomasello



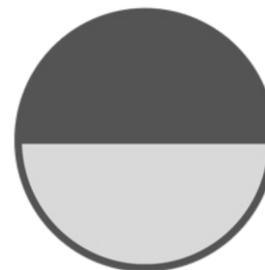
Unengaged



Onlooking

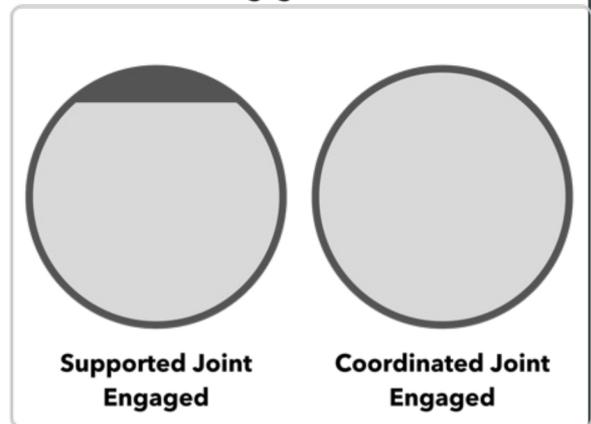


Person Engaged



Object Engaged

Goal Engagement States



Supported Joint Engaged

Coordinated Joint Engaged

Important outcome of early intervention improvement of Joint Engagement

Object engaged



Jointly engaged



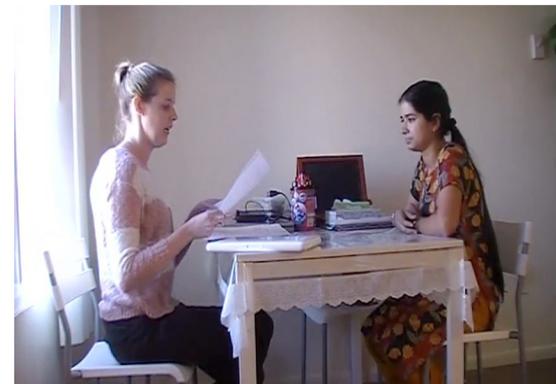
Early childhood interventions involve families

Family involvement can take many forms.....

- Involvement (coaching vs. education)
- Comparative efficacy
- Addressing heterogeneity
- CPPR methods
 - Mommy and me



Hands -on Coaching



Parent Education

Parent mediated interventions



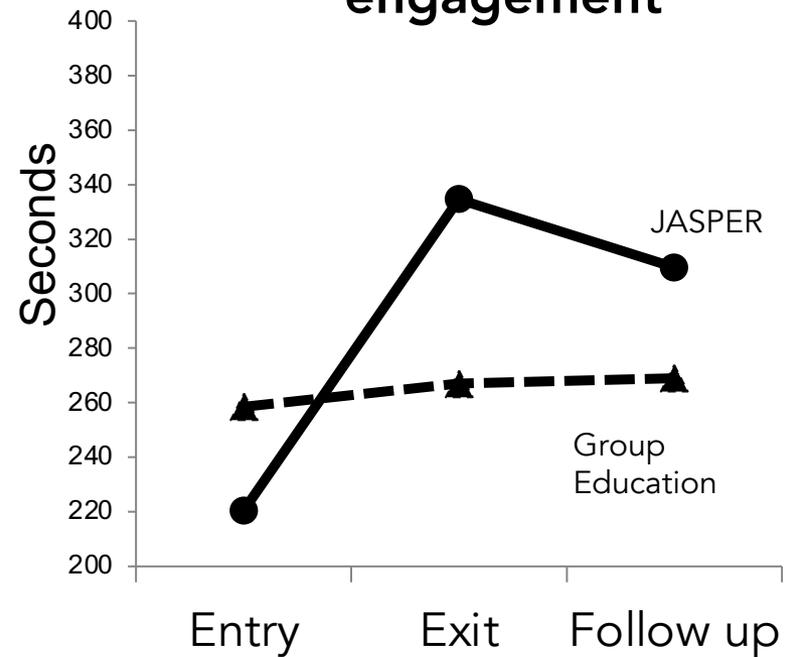
- Involvement (coaching vs. education)
 - **Comparative efficacy**
 - Addressing heterogeneity
 - CPPR methods
 - Mommy and me
- 112 children (2-5- year- olds)
 - >60% ethnic minority, low income families
 - Comparison 2 parent interventions
 - In home intervention or neighborhood group
 - 24 sessions over 12 weeks
 - 3 month follow up

JASPER group

- ↑ Joint engagement
- ↑ Symbolic play
- ↑ Initiating JA

RCT-Comparative Efficacy, Multi-site
N=112

Child initiated joint engagement



(Kasari, Lawton, Shih, Barker et al, Pediatrics, 2014)

Parent mediated interventions

Parent Involvement

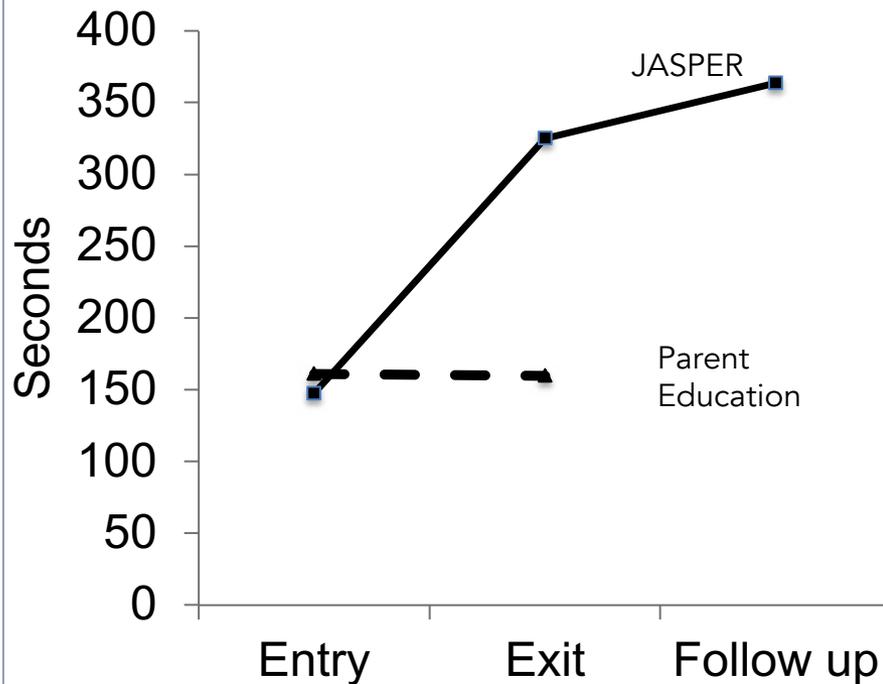


- Involvement (coaching vs. education)
 - **Comparative efficacy**
 - Addressing heterogeneity
 - CPPR methods
 - Mommy and me
- 86 children (2-3 –year- olds)
 - All enrolled in same early intervention program (30 hours ABA based)
 - Comparison 2 parent interventions
 - Blinded independent assessments
 - 20 sessions over 10 weeks
 - 6 month follow up

Randomized Comparative Efficacy Study of Parent-Mediated Interventions for Toddlers With Autism

Connie Kasari, Amanda Gulsrud, Tanya Paparella,
Gerhard Hellemann, and Kathleen Berry
University of California Los Angeles

Child Initiated Joint Engagement



JASPER group

- ↑ Joint engagement (primary)
- ↑ Play diversity
- ↑ Play level

Generalization to classroom

Information Group comparison

- ↓ Parenting stress

RCT—Comparative Efficacy
N=86

(Kasari, Gulsrud, Paparella, Hellemann, Berry, JCCP,
2015)

Parent mediated interventions

The Spectrum

- Involvement (coaching vs. education)
 - Comparative efficacy
 - Addressing heterogeneity
 - CPPR methods
 - Mommy and me
- There is great heterogeneity among children, **as well as their parents**
 - Models need to be flexible and attentive to where parents begin....

Where you begin matters....fit between parent and model

Parent strategies overall by group

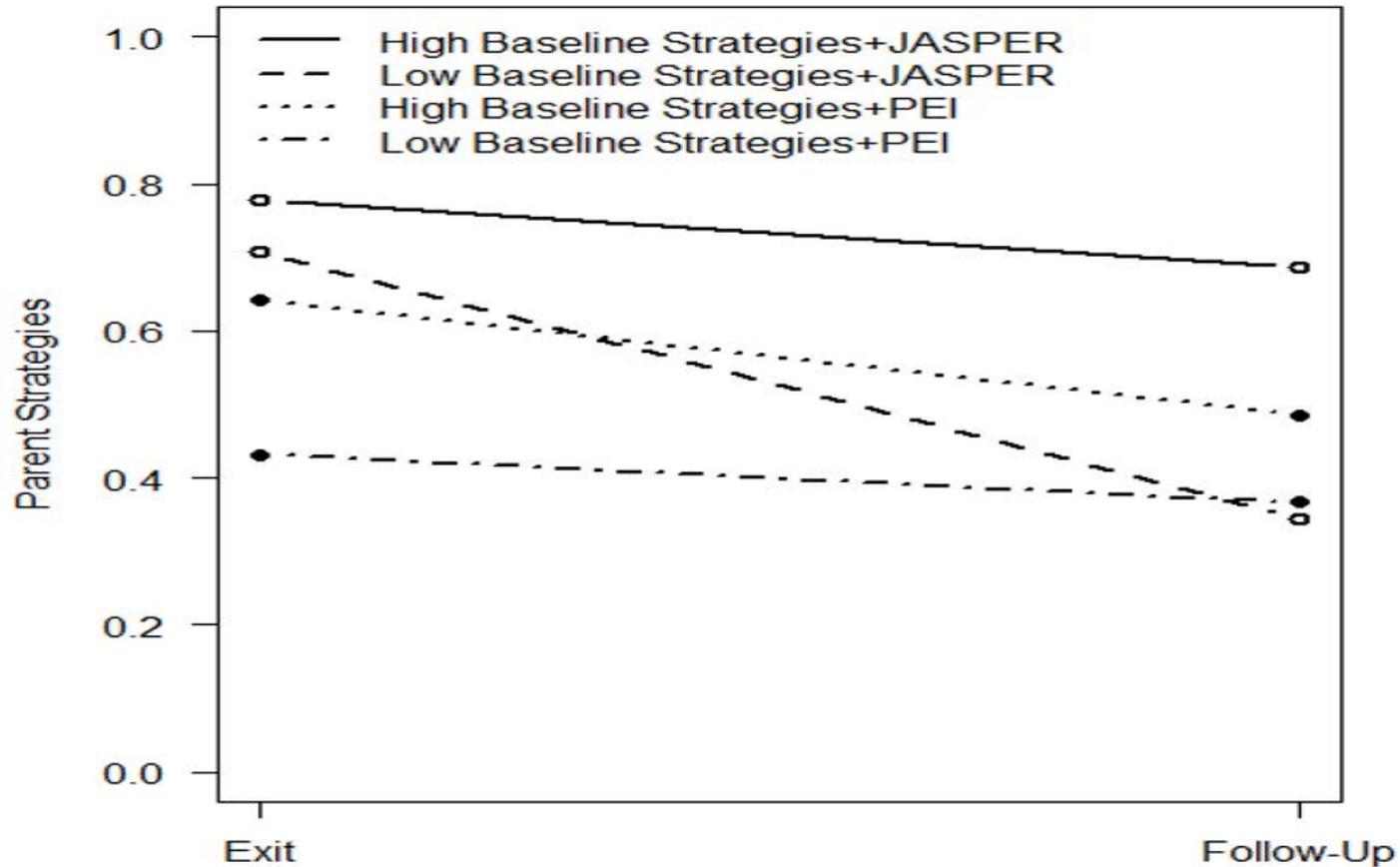
Table 2: Caregiver strategies by treatment group

	Parent Ed	JASPER
Overall Caregiver Strategies		
Baseline	48.6% (10.8%)	49.5% (11.1%)
Exit	53.1% (13.5%)	74.2% (16.4%)
Follow-up	42.2% (8.4%)	51.2% (15.7%)

Unpacking the data

High and low parent strategies before intervention predict sustainment

Where you begin matters....fit between parent and model



Parent mediated interventions

- Involvement (coaching \ education)
- Comparative efficacy
- Addressing heterogeneity
- CPPR methods
 - Mommy and me



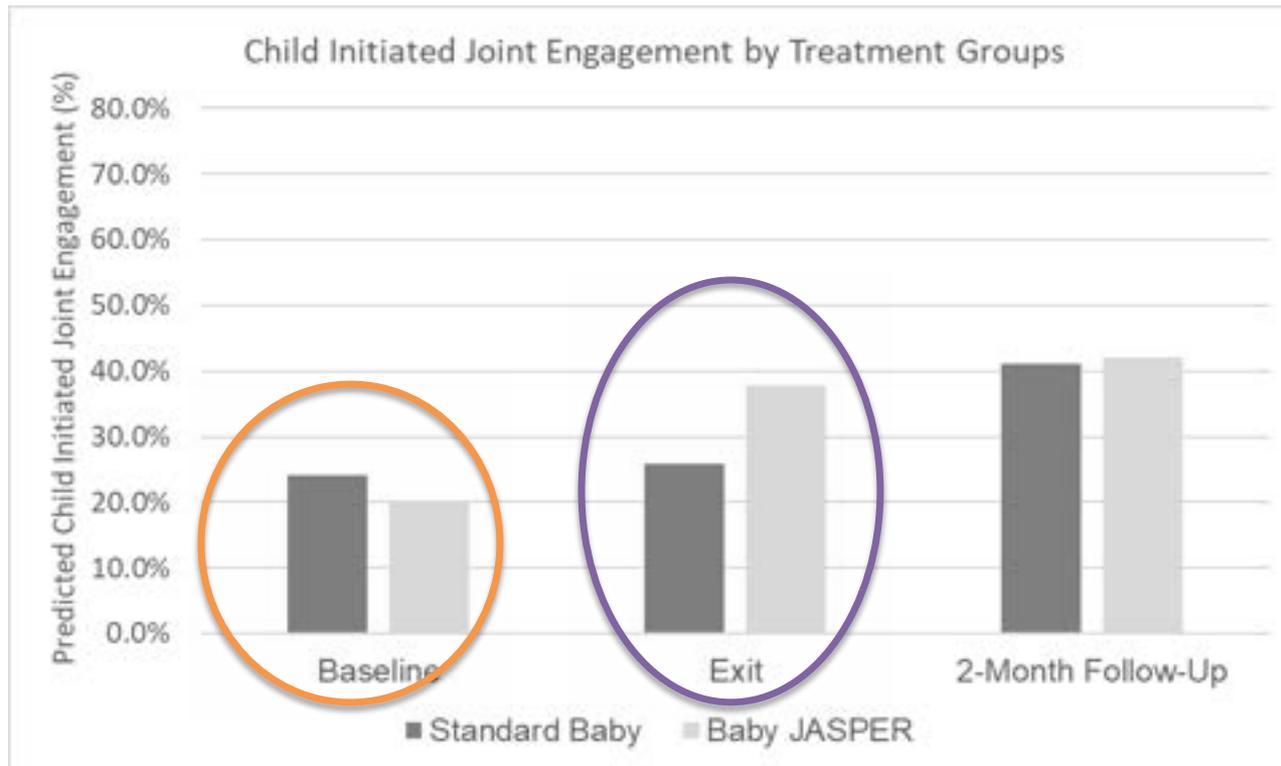
Comparative efficacy of an early intervention “parent and me” program for infants showing signs of autism: The Baby JASPER model

Amanda C. Gulsrud^{*}, Wendy Shih, Tanya Paparella, Connie Kasari

University of California, Los Angeles Seaver Institute for Neuroscience and Human Behavior, 760 Westwood Plaza, Los Angeles, CA 90024, USA

- Listening to families
- ‘Normalizing’ intervention
- 2 classrooms—same curriculum with JASPER enhancement in one
- Parent education for both

Baby JASPER vs. Standard Baby



Implementation in schools

Schools require specific adaptations

Schools important because all children go to school; more complex children, more diversity

Implementation in schools: Requires specific adaptations

- Schools important because ALL children go to school
- More complex children, more diversity



Teacher-mediated---Fitting into school routines

1:1 model

Social communication with adult



Small group peer model

Social communication with peers



Hybrid implementation model of community-partnered early intervention for toddlers with autism: a randomized trial

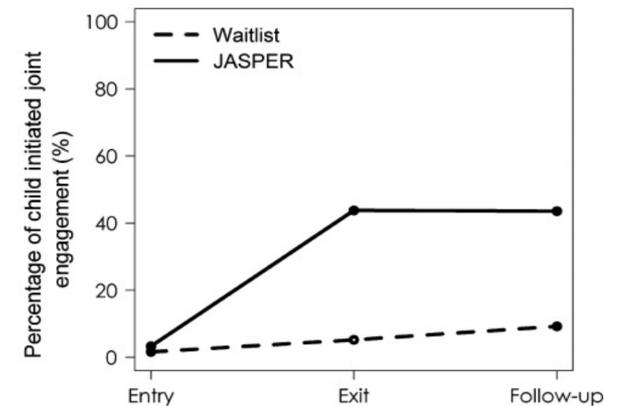
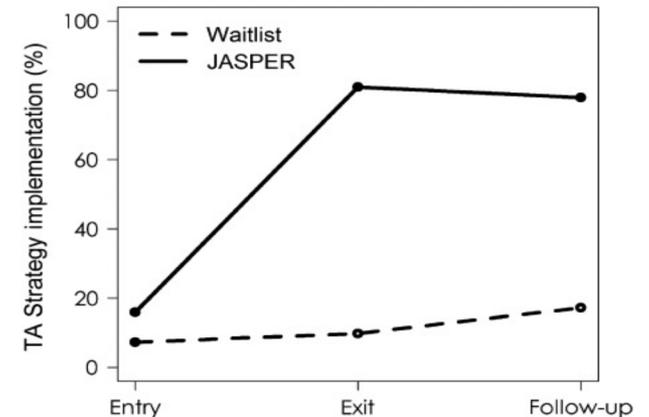
Stephanie Y. Shire,¹ Ya-Chih Chang,² Wendy Shih,¹ Suzanne Bracaglia,³ Maria Kodjoe,³ and Connie Kasari¹

¹University of California Los Angeles, Los Angeles, CA; ²California State University Los Angeles, Los Angeles, CA; ³New York Center for Child Development, New York City, NY, USA

N=113 toddlers,
45 teaching assistants,
14 group leaders



Shire, S. Y., Chang, Y. C., Shih, W., Bracaglia, S., Kodjoe, M., & Kasari, C. (2017). *Journal of Child Psychology and Psychiatry*, 58(5), 612-622.



Focus on non-speaking, minimally verbal autistic children

DOI: 10.1093/abbs/abaa012-3444-3

BRIEF REPORT

Preschool Based JASPER Intervention in Minimally Verbal Children with Autism: Pilot RCT

Kelly Strickles Goods · Eric Ishijima ·
Ya-Chih Chang · Connie Kasari

N=15

RESEARCH ARTICLE

Spoken language outcomes in limited language preschoolers with autism and global developmental delay: RCT of early intervention approaches

Connie Kasari¹ | Stephanie Shire² | Wendy Shih³ | Rebecca Landa^{3,4} |
Lynne Levato⁵ | Tristram Smith⁶

N=164

Communication Interventions for Minimally Verbal Children With Autism: A Sequential Multiple Assignment Randomized Trial

Connie Kasari, PhD, Ann Kaiser, PhD, Kelly Goods, PhD, Jennifer Nietfeld, MA, Pamela Mathy, PhD, Rebecca Landa, PhD, Susan Murphy, PhD, Daniel Almirall, PhD

N=61

NEW RESEARCH

Adaptive Intervention for School-Age, Minimally Verbal Children With Autism Spectrum Disorder in the Community: Primary Aim Results

Connie Kasari^{1*}, PhD, Stephanie Shire², PhD, Wendy Shih³, DrPH, Ann Kaiser⁴, PhD, Catherine Lord⁵, PhD, Lynne Levato⁶, PhD, Tristram Smith^{7,8}, PhD, Daniel Almirall⁹, PhD

*Tristram Smith, an original site PI, died prior to manuscript submission.

N=194

Focus on non-speaking, minimally verbal autistic children in school

10.1111/jcpp.14441

REVIEW REPORT

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Kelly Mickles Goods¹, Eric Tsigonis¹,
Yu-Chih Chang¹, Connie Kasari¹

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*Primary Author, **Principal Investigator, †Statistical Analysis

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Tris Smith



Becky Landa

Traditional ABA (DTT) versus JASPER

- 164 autistic 3-4- year- old children
- DQ average 45 (Mullen)
- Majority minority children (60%)
- Interventions delivered in school settings by research staff
- <30 single words at baseline
 - Average 17 words



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- Majority minority children (60%)
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- <30 single words at baseline
 - Average 17 words

Both groups make significant language gains

- Over 6 months of intervention, children made on average 6 months gain on standardized language tests
- 45% of sample moved to word combinations or phrase speech at exit
- A goal was to avoid label of MV at school aged or later Profound Autism

What we learn from these efforts

- We can implement interventions with rigor in community
- Increasingly samples are majority ethnic/racial minority children, mostly low income thus improving the overall evidence base of early interventions
- Outcomes vary using JASPER
 - With development
 - Sample characteristics (limited language, age)
- Implementation and sustainment vary
 - With context (home, school, community)

Knowing and
not knowing

What's next:
Personalizing interventions



Intervention &
examples

Personalizing interventions is improved when we have understanding for whom an intervention might work, and why

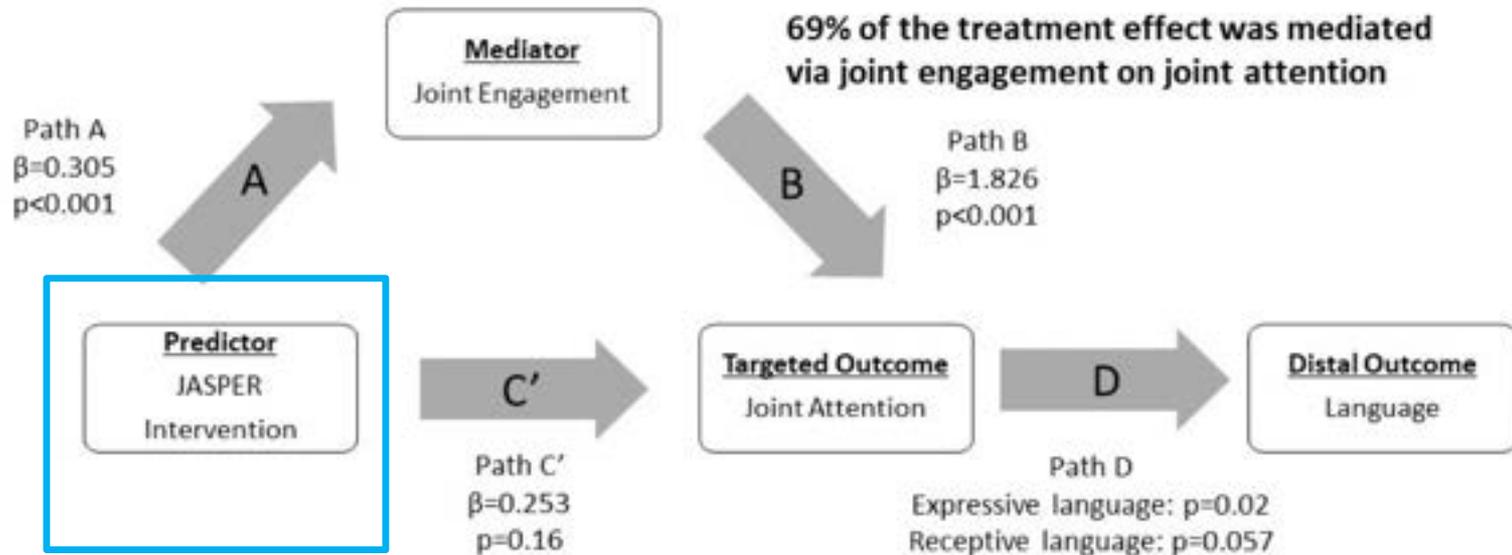
We have some understanding of mechanism for JASPER



Wendy Shih

179 autistic children
2-5 years old

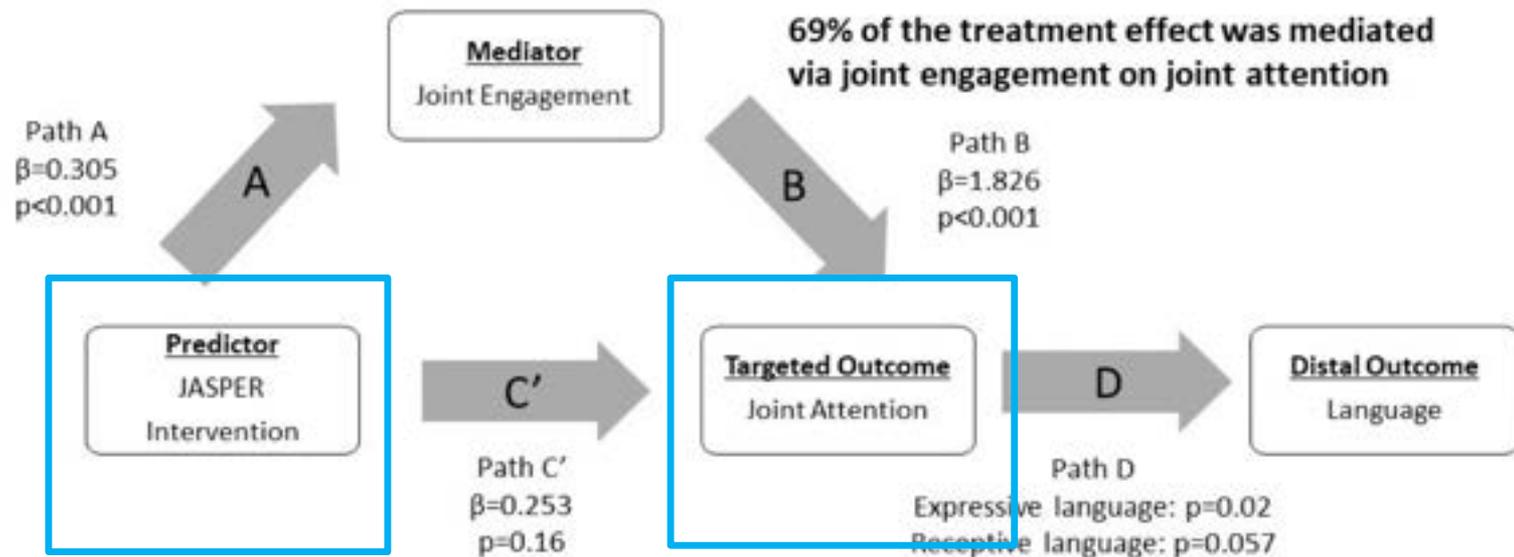
Figure 3: Joint engagement as a mechanism in social communication interventions



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Figure 3: Joint engagement as a mechanism in social communication interventions

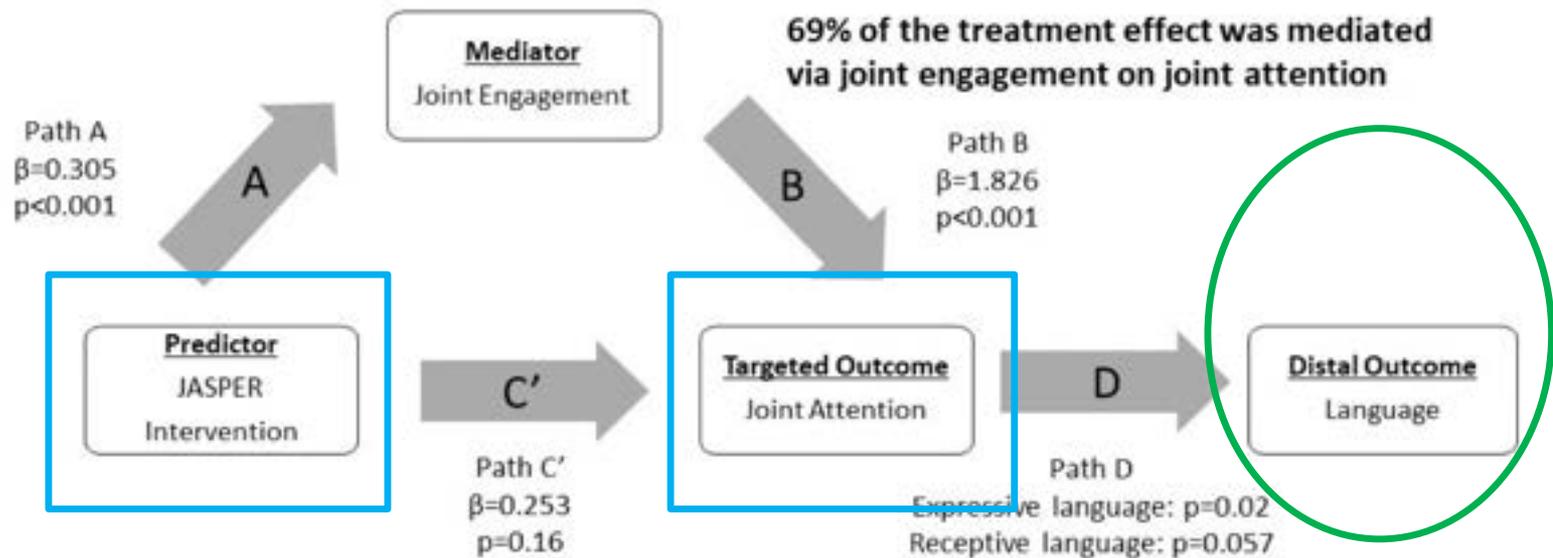


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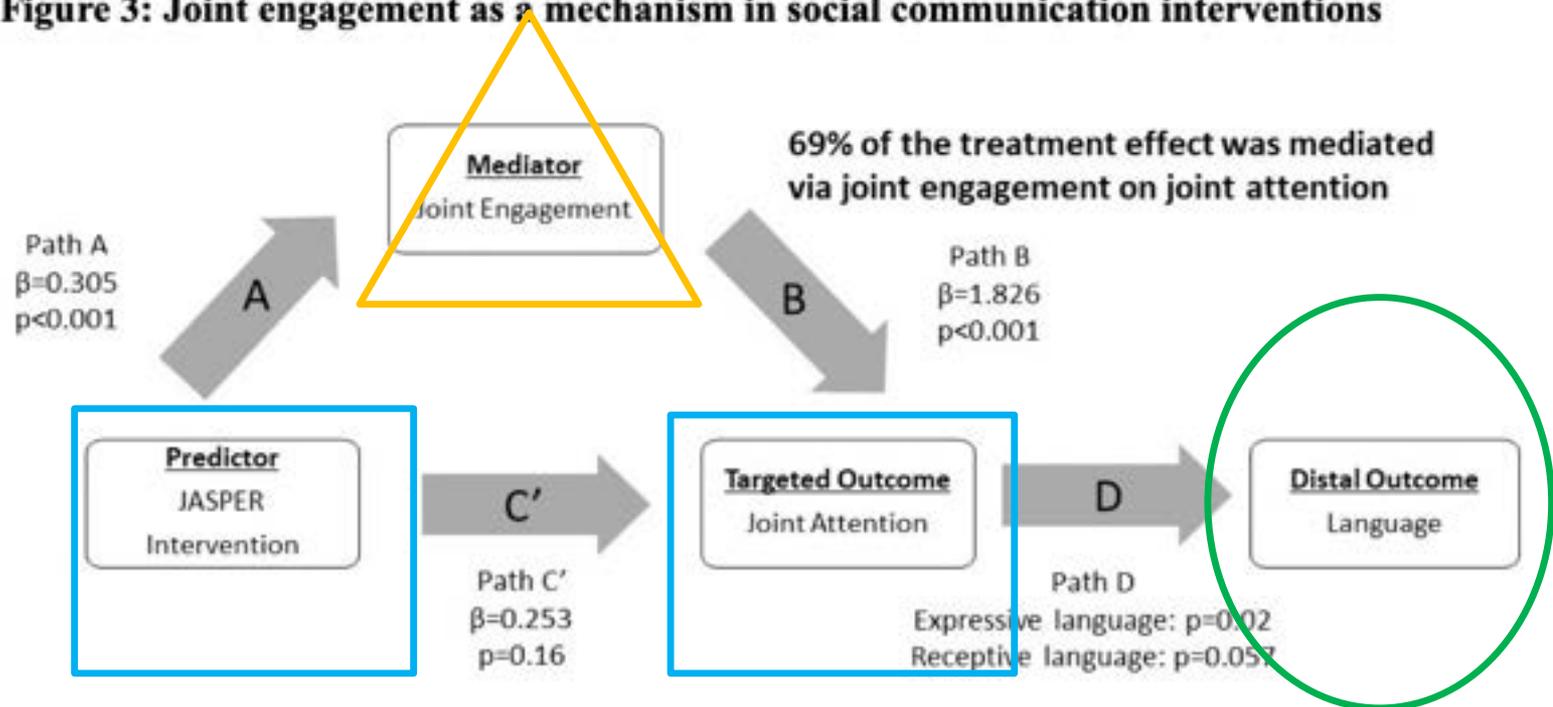
Figure 3: Joint engagement as a mechanism in social communication interventions



We have some understanding of mechanism for JASPER



Figure 3: Joint engagement as a mechanism in social communication interventions



For whom does an intervention work?

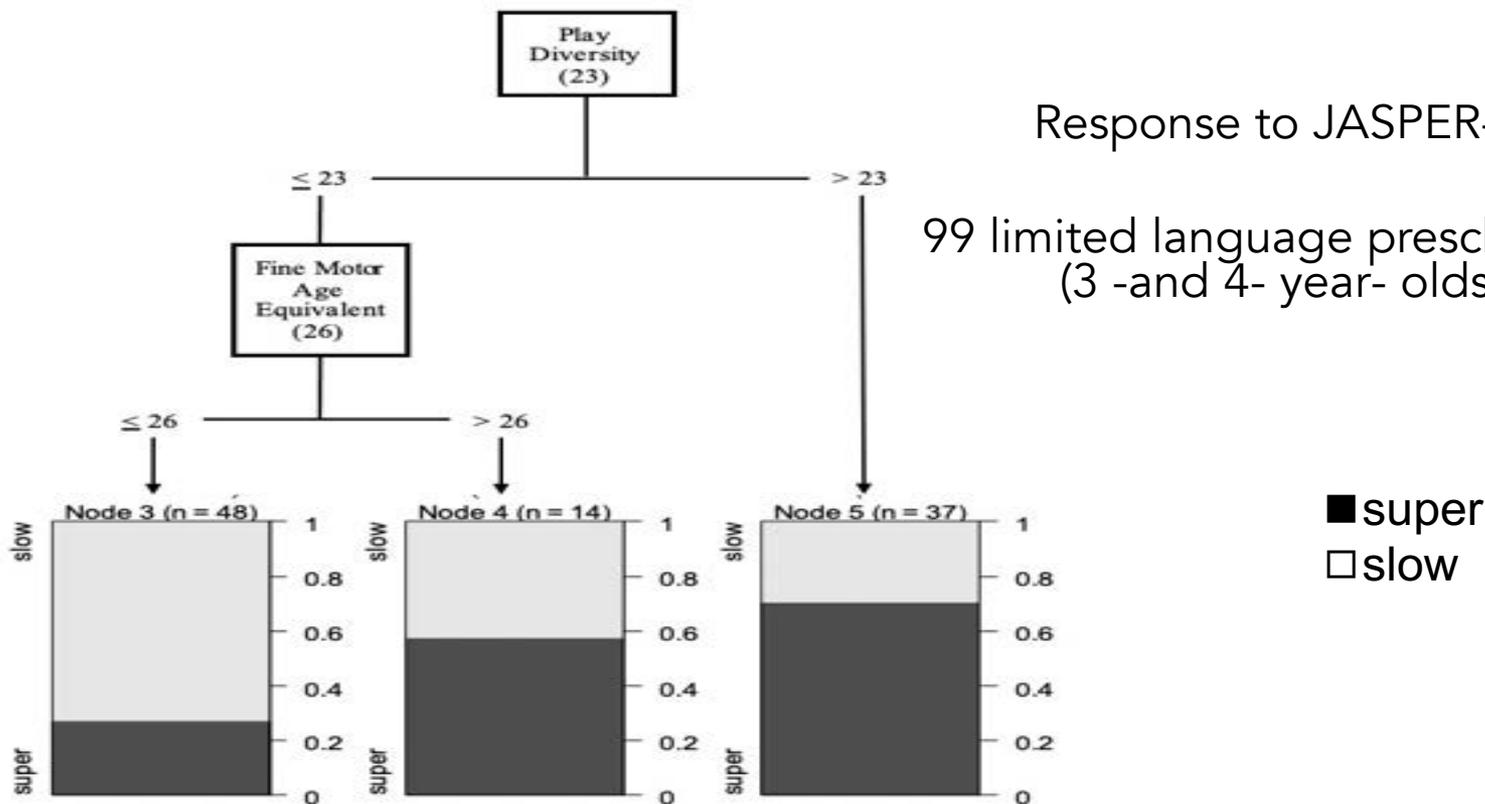


Figure 2. Conditional Inference Tree of Play Diversity and Fine Motor Predicting Super vs. Slow Responders, confidence level of .90. The final model identifies two predictive variables; play diversity and fine motor ability.

Heterogeneity in response to
interventions

Methodologies are needed to
personalize, tailor and target
interventions

Address for whom the intervention works,
and why.....

Personalization of interventions

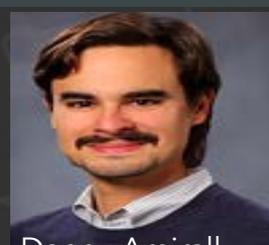
Sequence of interventions with adaptations based on individual response

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.



Susan Murphy



Danny Amirall

Sequential Multiple Assignment Randomized Trial

Focus on non-speaking, minimally verbal autistic children

10.1111/jcpp.12441

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*Presented at the 11th Annual Meeting of the International Society for Autism Research

N=194

Intervention for minimally verbal children

Primary Question: Would AAC support spoken language?

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)

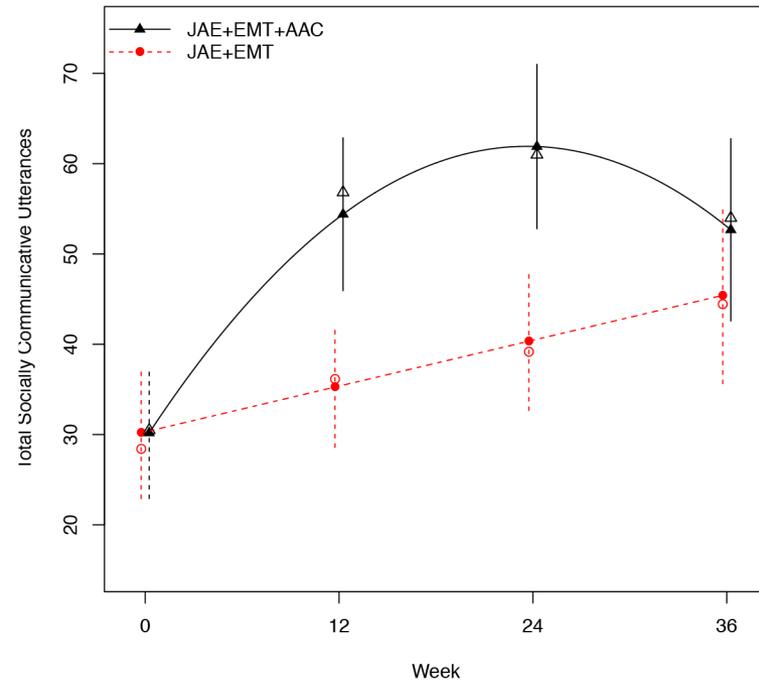
HALF randomized to also receive Speech Generating Device (iPad)



Minimally verbal and meaningful outcomes

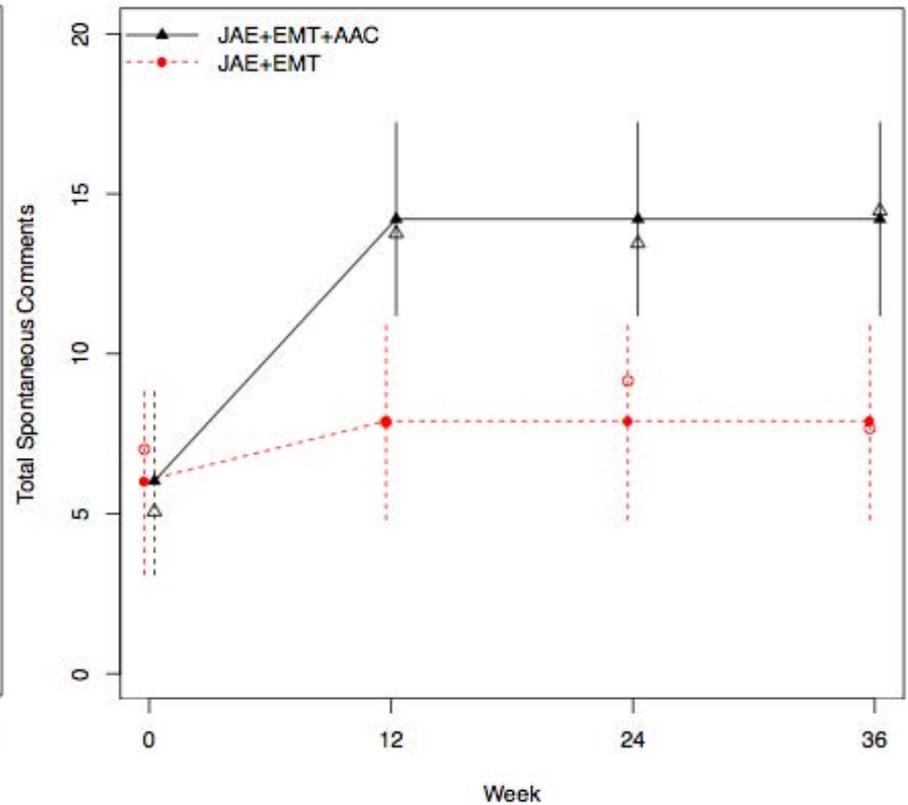
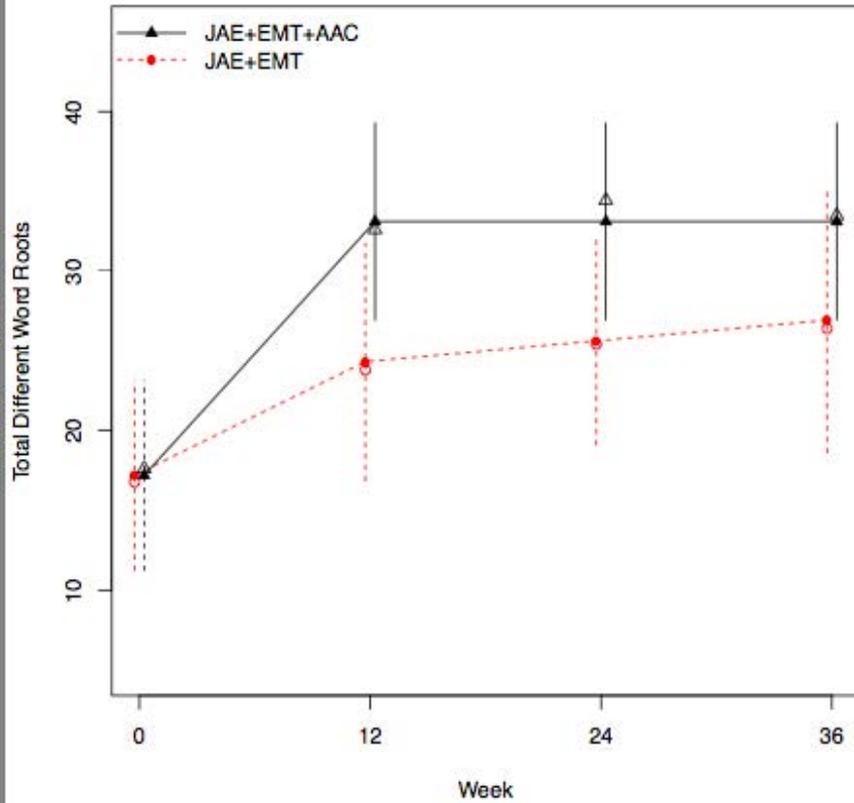


Socially communicative utterances



Novel words

Comments



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

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



Charlotte DiStefano

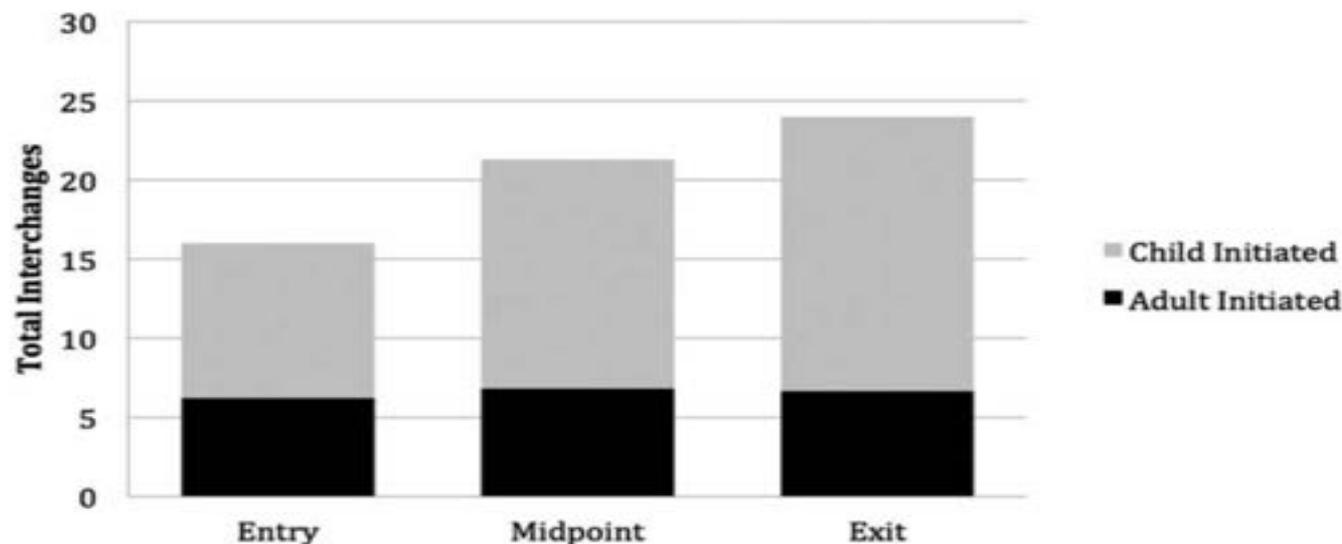


Figure 2. Child- and adult-initiated interchanges. The number of interchanges initiated by child and adult are presented for entry, (month 0), midpoint (month 3), and exit (month 6).

We now regularly add AAC into intervention with younger children

Age 3—NO WORDS, NO BABBLE



Day 1



Day 2



2 weeks later



Age 7

Variability among children *and* parents

Parent Involvement

- Parents have differing opinions about their own involvement
- Not all want hands on involvement right away
- May depend on age of child and level of disability

J Autism Dev Disord (2015) 45:1712–1724
DOI 10.1007/s10803-014-2329-4



ORIGINAL PAPER

Parents' Adoption of Social Communication Intervention Strategies: Families Including Children with Autism Spectrum Disorder Who are Minimally Verbal

Stephanie Y. Shire · Kelly Goods · Wendy Shih ·
Charlotte Distefano · Ann Kaiser · Courtney Wright ·
Pamela Matthy · Rebecca Landa · Connie Kasari

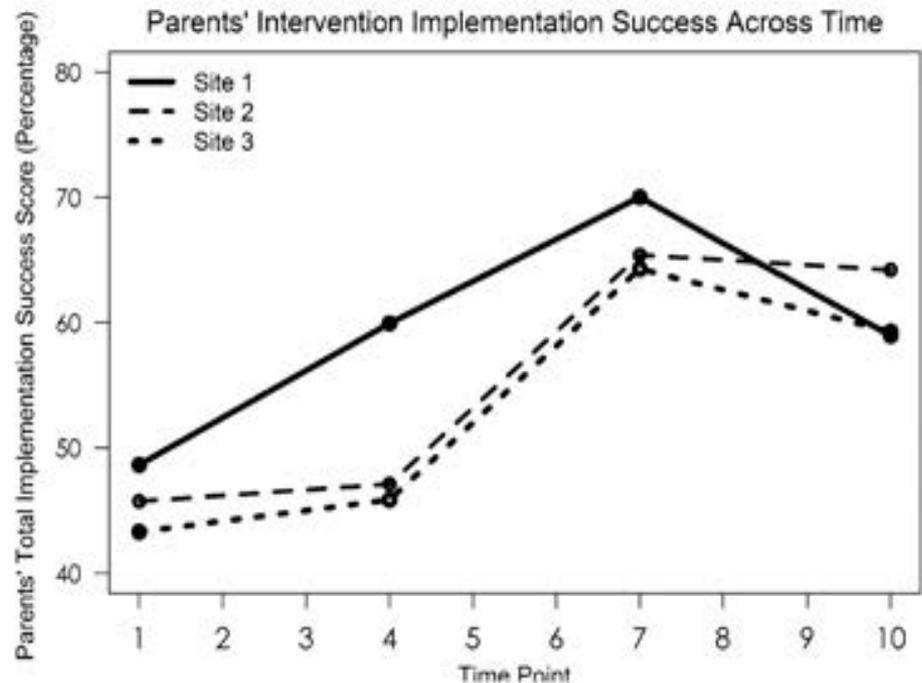
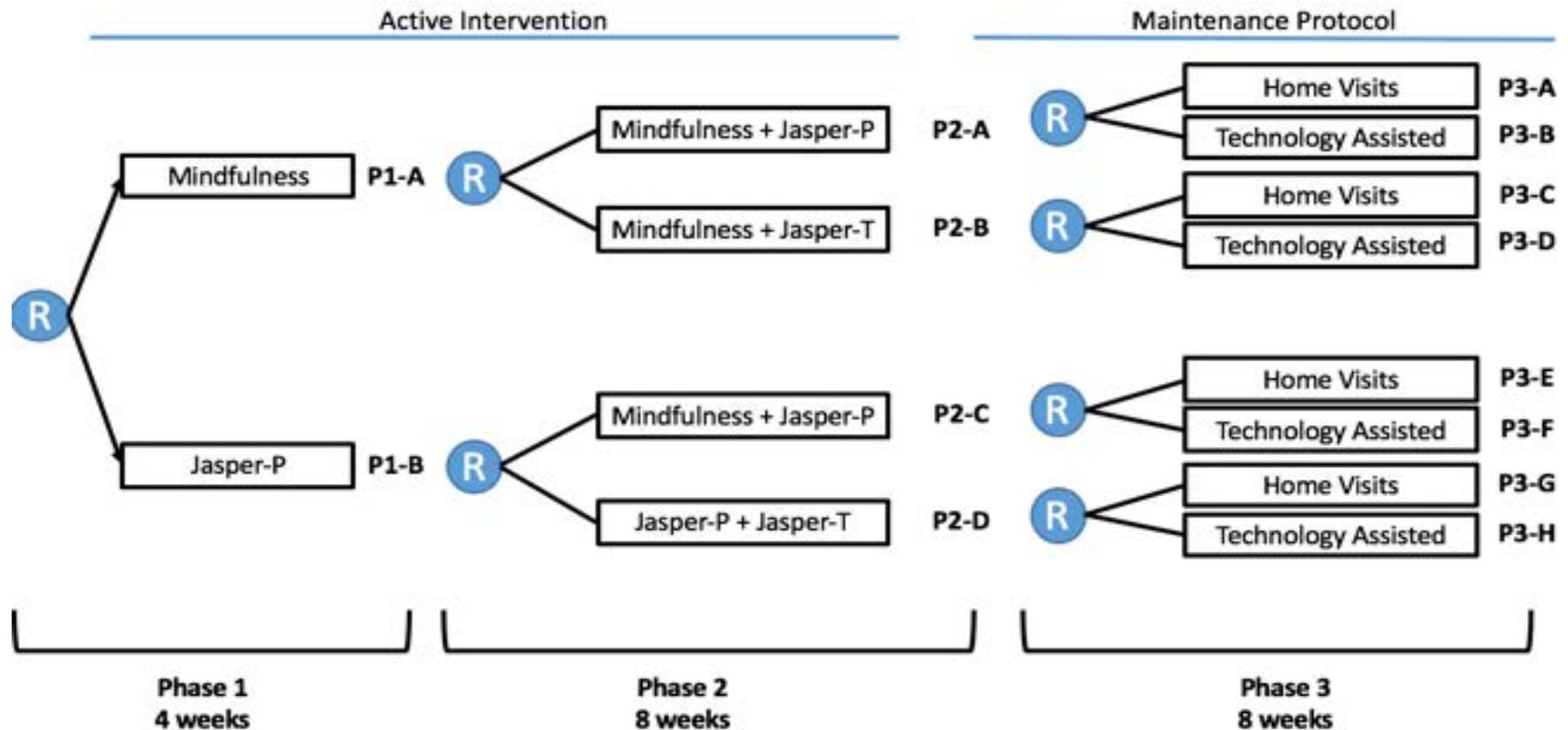


Fig. 2. Parents' successful strategy implementation across time by site

SMART designs applied to early
childhood

Example SMART design: Baby bears—12-36 month olds



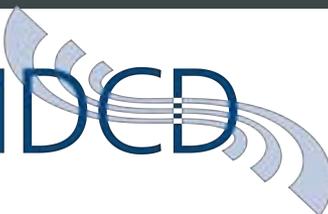
Summary—What we have Learned

- We can target important developmental areas and improve on social communication and language outcomes for autistic children
- What seems critical is what and how we target these skills for different developmental age groups
- Methods matter.... we need to pay close attention to how we are conducting research for rigor and replication
- Future: Personalizing intervention and learning from application of new designs

APPRECIATION...



NIDCD



Autism Intervention Research
Network On Behavioral Health

