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Reducing Disability Associated with Autism through Very Early Home-Based Support

Update on a 15+ year Partnership of La Trobe University Researchers and Victorian Maternal and Child Health Nurses

A/Prof. Kristelle Hudry

27th May 2022

Acknowledgement of Country

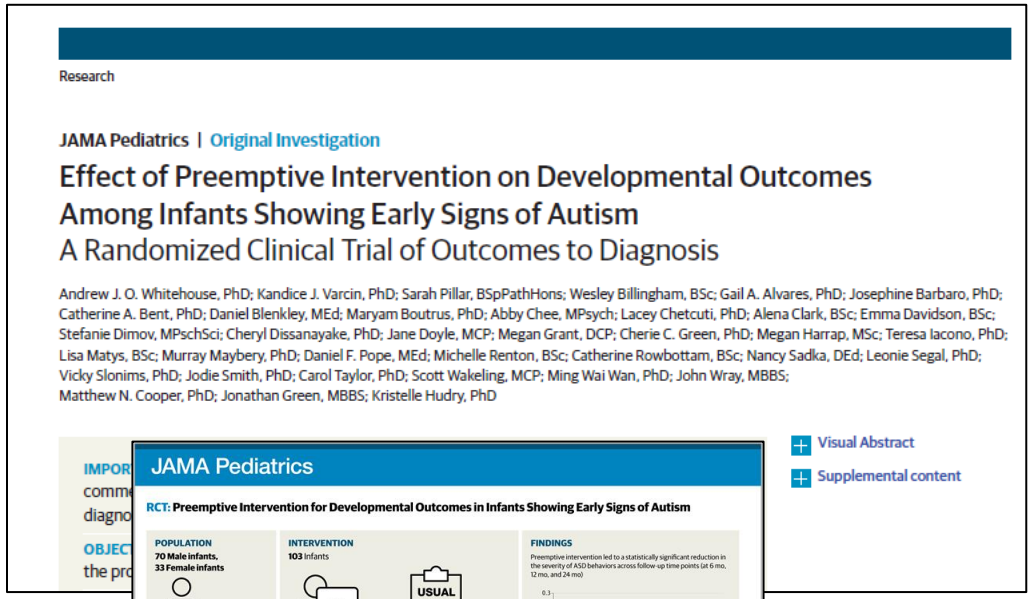
La Trobe University acknowledges that this event and our participants are located on the lands of many traditional custodians in Australia.

We recognise that Indigenous Australians have a continuing connection to land, water and community, their living culture and their unique role in the life of these regions, and value their unique contribution to the University and wider Australian society.

We are committed to providing opportunities for Indigenous Australians, both as individuals and communities through teaching and learning, research and community partnerships across all our campuses and online.

We pay our respects to Indigenous Elders, past, present and emerging and extend this respect to any Indigenous participants joining us online today.

The Australian Infant Communication and Engagement Study (AICES)



Research

JAMA Pediatrics | Original Investigation

Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism

A Randomized Clinical Trial of Outcomes to Diagnosis

Andrew J. O. Whitehouse, PhD; Kandice J. Varcin, PhD; Sarah Pillar, BSpPathHons; Wesley Billingham, BSc; Gail A. Alvares, PhD; Josephine Barbaro, PhD; Catherine A. Bent, PhD; Daniel Blenkley, MEd; Maryam Boutrus, PhD; Abby Chee, MPsych; Lacey Chetcuti, PhD; Alena Clark, BSc; Emma Davidson, BSc; Stefanie Dimov, MPschSci; Cheryl Dissanayake, PhD; Jane Doyle, MCP; Megan Grant, DCP; Cherie C. Green, PhD; Megan Harrap, MSc; Teresa Iacono, PhD; Lisa Matys, BSc; Murray Maybery, PhD; Daniel F. Pope, MEd; Michelle Renton, BSc; Catherine Rowbottam, BSc; Nancy Sadka, DEd; Leonie Segal, PhD; Vicky Slonims, PhD; Jodie Smith, PhD; Carol Taylor, PhD; Scott Wakeling, MCP; Ming Wai Wan, PhD; John Wray, MBBS; Matthew N. Cooper, PhD; Jonathan Green, MBBS; Kristelle Hudry, PhD

Visual Abstract

Supplemental content

JAMA Pediatrics

RCT: Preemptive Intervention for Developmental Outcomes in Infants Showing Early Signs of Autism

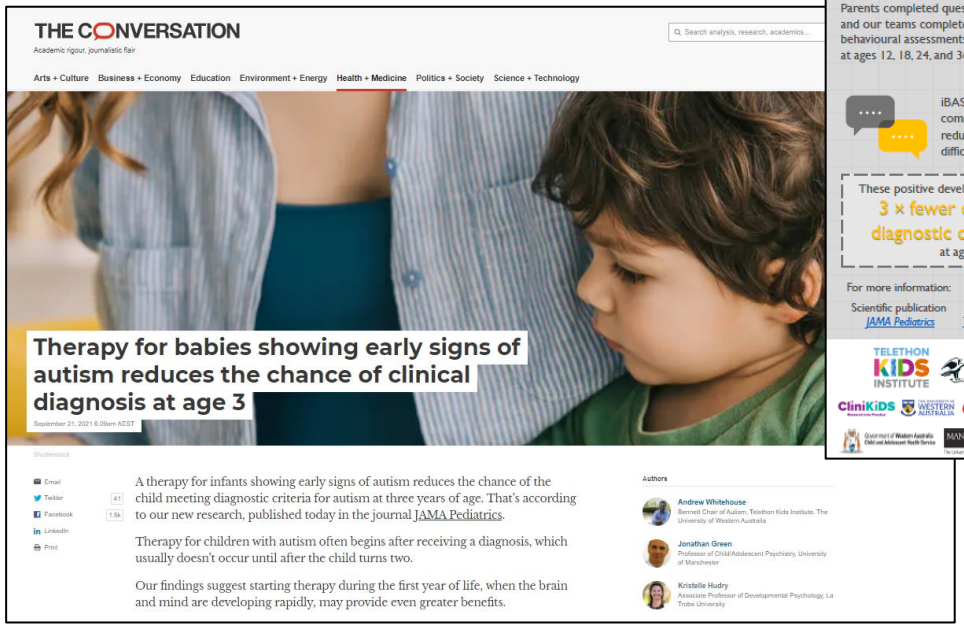
POPULATION
70 Male infants, 33 Female infants
Infants (9-14 mo) showing behavioral signs associated with later autism spectrum disorder (ASD)
Mean age: 12 mo

INTERVENTION
103 Infants
50 Preemptive intervention
A 10-session video feedback intervention to help parents adapt to their infant's communication style
53 Usual care
Services recommended by health professionals within the local community

FINDINGS
Preemptive intervention led to a statistically significant reduction in the severity of ASD behaviors across follow-up time points (at 6 mo, 12 mo, and 24 mo)
Area between the curves -5.53 (95% CI, −∞ to −0.278; P = .04)

SETTINGS / LOCATIONS
2 Research centers in Australia

PRIMARY OUTCOME
Combined measures of severity of ASD symptoms (Autism Observation Scale for Infants and Autism Diagnostic Observation Schedule-Second Edition) at baseline and 3 follow-up time points: about 18 mo, age 2 y, and age 3 y



THE CONVERSATION

Academic rigour, journalistic flair

Arts + Culture | Business + Economy | Education | Environment + Energy | Health + Medicine | Politics + Society | Science + Technology

Therapy for babies showing early signs of autism reduces the chance of clinical diagnosis at age 3

September 21, 2021 6.09am AEST

A therapy for infants showing early signs of autism reduces the chance of the child meeting diagnostic criteria for autism at three years of age. That's according to our new research, published today in the journal JAMA Pediatrics.

Therapy for children with autism often begins after receiving a diagnosis, which usually doesn't occur until after the child turns two.

Our findings suggest starting therapy during the first year of life, when the brain and mind are developing rapidly, may provide even greater benefits.

Authors

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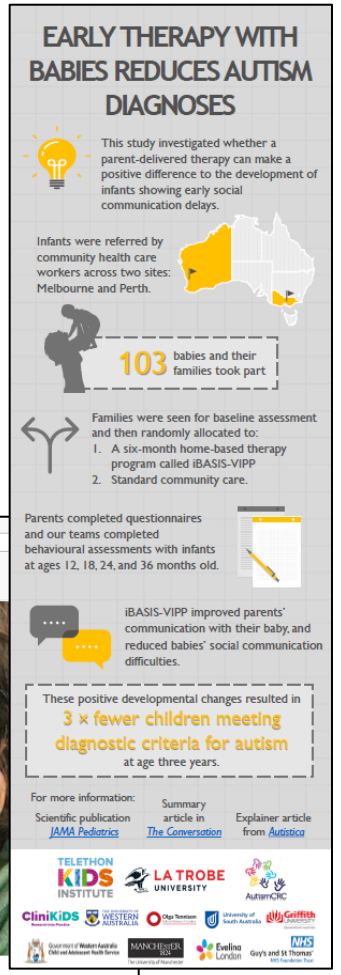
Jonathan Green
Professor of Child/Adolescent Psychiatry, University of Manchester

Kristelle Hudry
Associate Professor of Developmental Psychology, La Trobe University



EARLY THERAPY WITH BABIES REDUCES AUTISM DIAGNOSES

This study investigated whether a parent-delivered therapy can make a positive difference to the development of infants showing early social communication delays.

Infants were referred by community health care workers across two sites: Melbourne and Perth.

103 babies and their families took part

Families were seen for baseline assessment and then randomly allocated to:
1. A six-month home-based therapy program called iBASIS-VIPP
2. Standard community care.

Parents completed questionnaires and our teams completed behavioural assessments with infants at ages 12, 18, 24, and 36 months old.

iBASIS-VIPP improved parents' communication with their baby, and reduced babies' social communication difficulties.

These positive developmental changes resulted in 3 × fewer children meeting diagnostic criteria for autism at age three years.

For more information:
Scientific publication JAMA Pediatrics
Summary article in The Conversation
Explainer article from Autistica

TELETHON KIDS INSTITUTE | LA TROBE UNIVERSITY | AutismCRC | CliniKids | Olga Tennison | University of South Australia | Griffith University | Manchester | Evelina London | Guy's and St Thomas' NHS

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AICES Project Work to Date

AICES
The Australian Infant Communication and Engagement Study

This Topic = Testing a new way to support children with autism and their families

(Whitehouse et al., 2019, *Lancet Ch Adol Health; 2021, JAMA Ped*)

Other focus on:

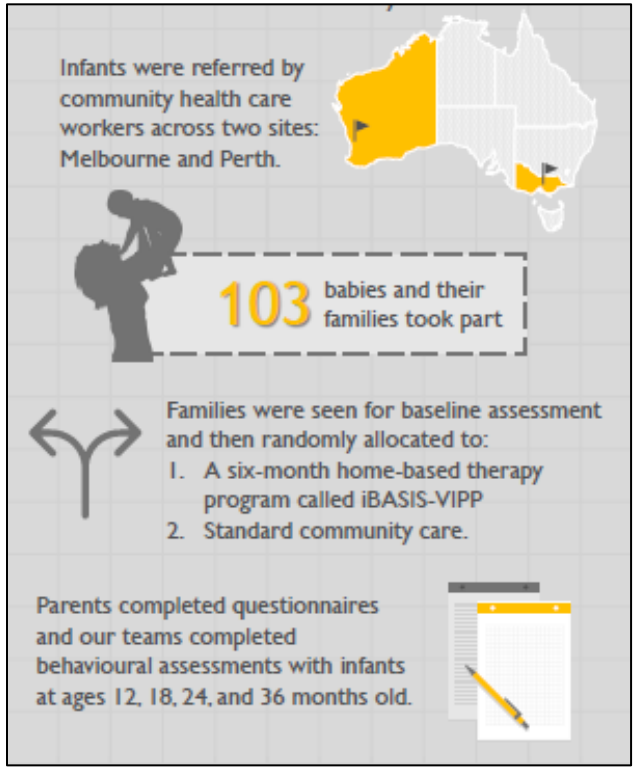
- How assessments work with local (and clinically-indicated) samples (Hudry et al., 2021, *Autism*)
- How children learn language (in preparation)

- How child temperament shapes development (including toward internalising/externalising problems)
- Impact of early child skills/differences on parental wellbeing

(Chetcuti et al., 2021a,b, *Autism Res*; 2021, *Res Child Adol Psychopathol*)

AICES Project Work to Date

AICES
The Australian Infant Communication and Engagement Study



Babies first seen when:

- Aged between 9 and 15 months
- Referred by Vic MCH nurses (WA Child Development service) due to showing early social-communication difficulties/differences:
  - ❑ Spontaneous eye contact
  - ❑ Pointing to show interest
  - ❑ Social gestures (e.g., waving)
  - ❑ Imitation
  - ❑ Response to name

Social Attention and Communication Surveillance – Revised (SACS-R)
(Mozolic-Staunton et al., 2020, *Res Autism Spect Disord*)

Autism in Australia

Life-long neurodevelopmental condition

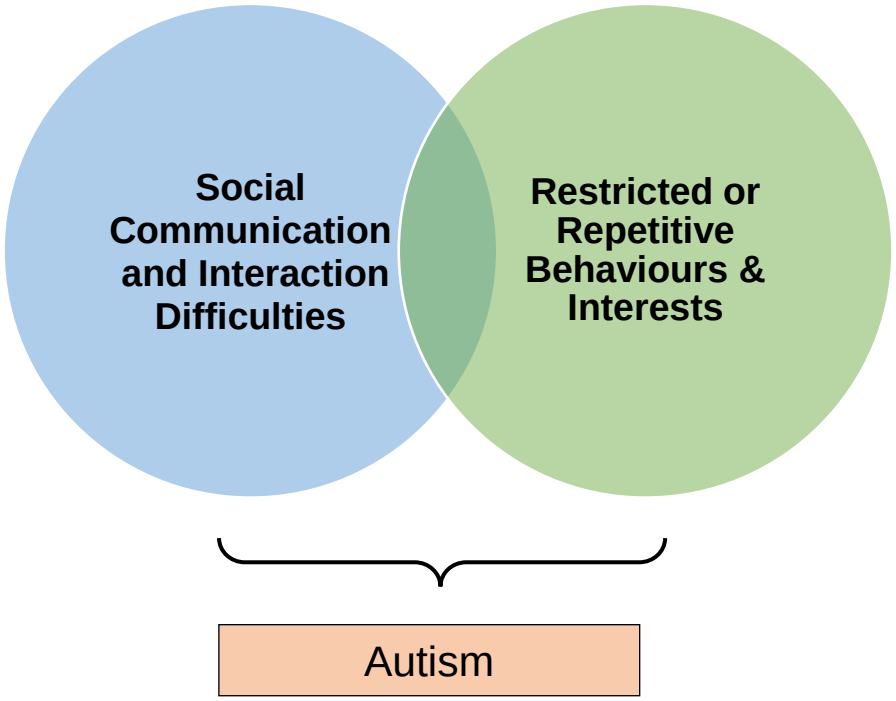
Affects 1-2% of people

Median local early diagnosis = 4 years (Bent et al., 2015)

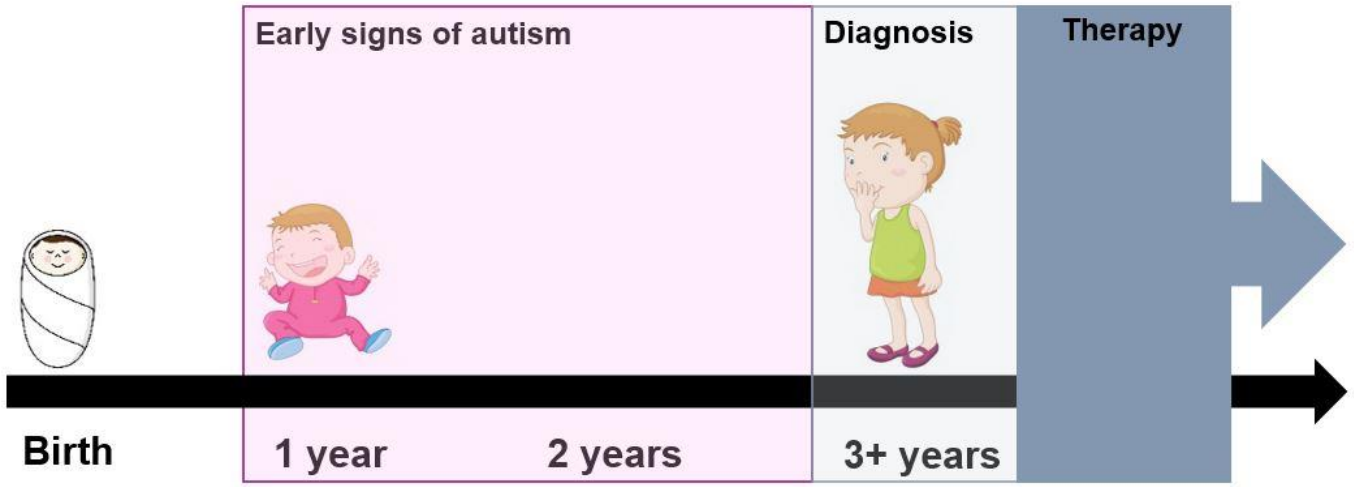
~50% also with intellectual disability (AIHW, 2017)

National Disability Insurance Scheme (NDIS)

- 53% of all child-aged (0-14 years) participants
- 32% of all participants



Current Support Pathway



But…

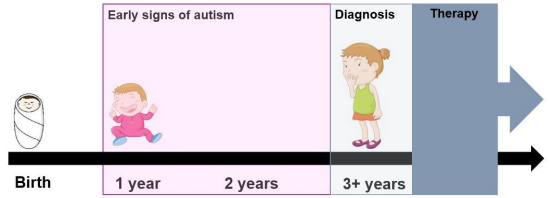
- Critical brain development and learning in first two years of life
- Autism therapies currently miss an opportunity in these critical early years
  - Pre-emptive therapy could help by targeting precursor skills, prior to autism diagnosis

A New Idea: Pre-emptive therapy for autism

Handful of prior studies of therapies, most promising:

Video-feedback Intervention to promote Positive Parenting (**VIPP**)

- Well-evidenced for neurotypical children



iBASIS-VIPP adaptation (Green et al., 2015, *Lancet Psychiatry*; 2017, *J Child Psychol Psychiatry*)

- Studied with ~50 'infant siblings' of children with autism (first aged 6-9 months)
  - Found a reduction in autism behaviours to age 3 years
  - But small relatively sample size and questions about target group

AICES
The Australian Infant Communication and Engagement Study

AICES scale-up and adaptation (Whitehouse et al., 2019, *Lancet Ch Adol Health; 2021, JAMA Ped*)

- Studied with ~100 community-referred children (first aged 9-15 months)

Conceptual Model

Underscoring Parent-Mediated, Communication-Focused Intervention for Autism

Consequences of subtle, very early difference/regression ⇨ Altered early learning environment:

Limited child social attention/skills

... so ...

Parent has little to 'work with'

... and therefore...

Parent attempts to compensate (more directive)

... so ...

Child gets practice with certain skills (but not others)

... and therefore...

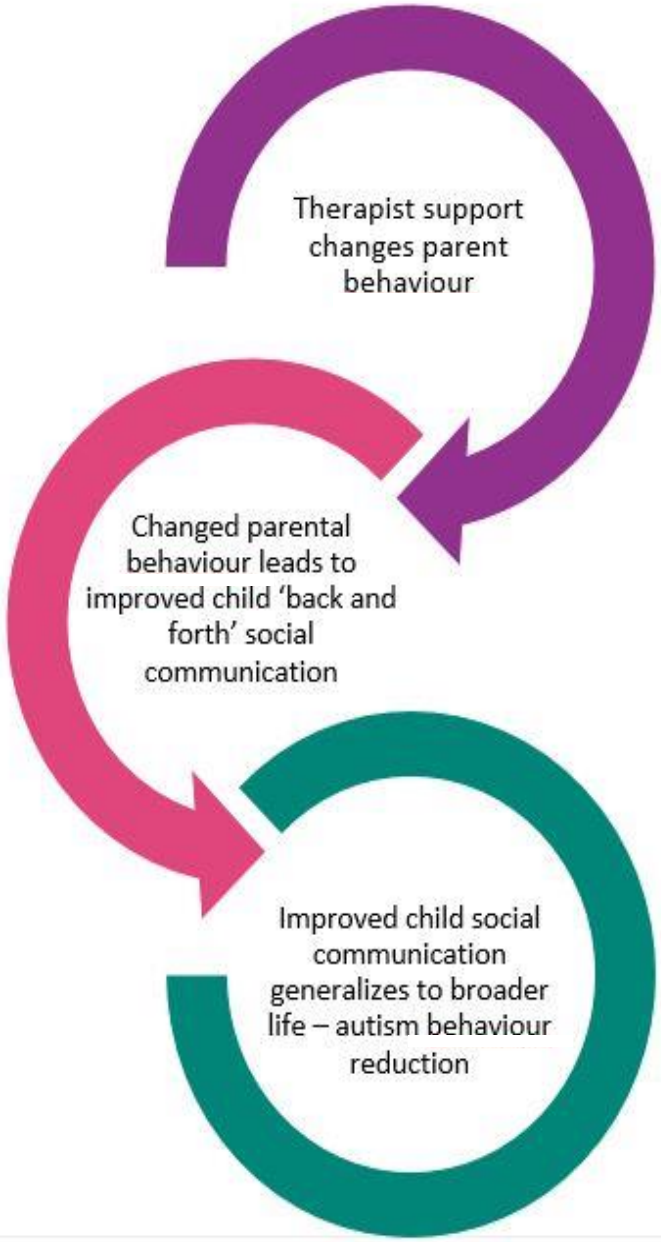
iBASIS-VIPP: Parent-Mediated & Video-Guided

- Focus on social-communication and natural family environment and routines

- Parent-mediated
  - Efficient – limited professional time
  - Builds parental empowerment & confidence
- Viewing videotaped interaction for positive examples
  - Powerful adult learning tool for observation and reflection
  - Infant behaviors (unique to that child)
  - Caregiver responsive interaction

Does not imply poor parenting

iBASIS-VIPP within the AICES Project



AICES
The Australian Infant Communication and Engagement Study

103 infants with some social-communication delays/differences (9-15m)

Baseline Assessment (9-15mo)

12 months of age

iBASIS-VIPP 10 sessions over 5-months	**Local Best Practice** Services offered in the community
18 months of age — **Follow-up Assessment 1**	**Follow-up Assessment 1**
24 months of age — **Follow-up Assessment 2**	**Follow-up Assessment 2**
36 months of age — **Follow-up Assessment 3**	**Follow-up Assessment 3**

Hypotheses & Outcome Measures

Improve parent-child interaction quality

- Ratings of parent, infant, and dyad (MACI; Wan et al., 2015)

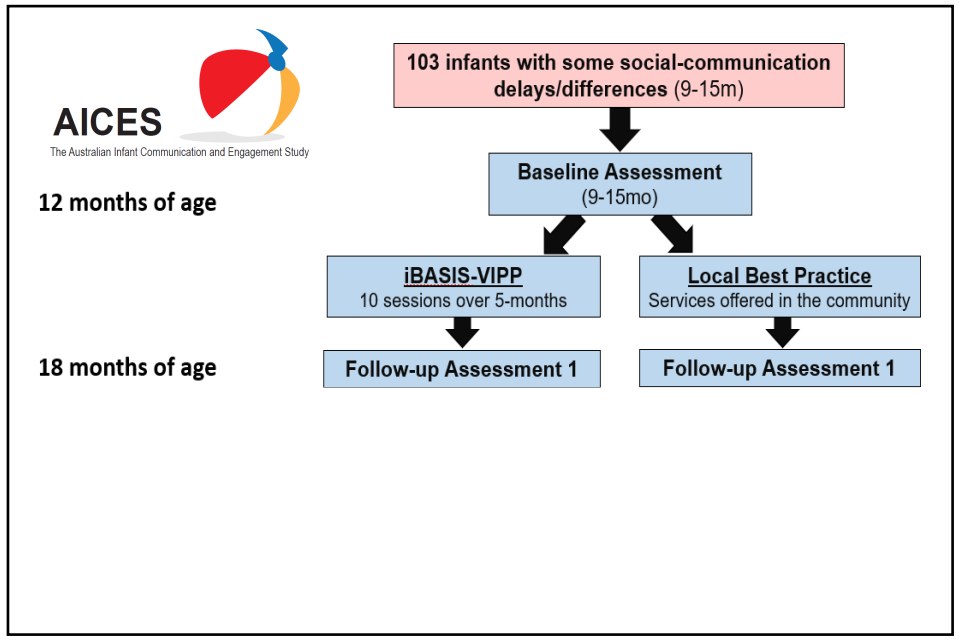
Improve infant developmental and language skills

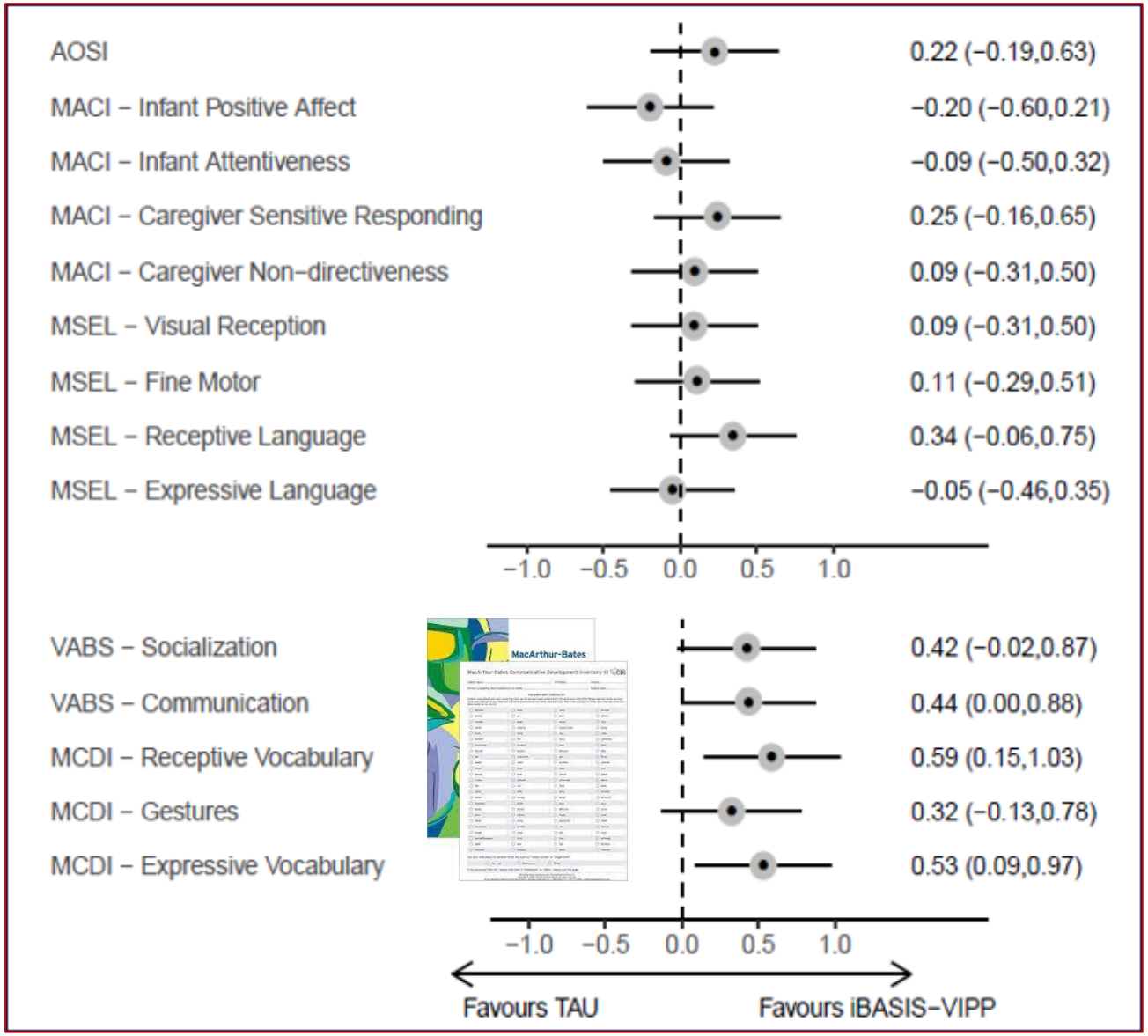
- Dev/cognitive skills (MSEL); Adaptive behaviour (VABS-II)

Reduce the extent of early autism behaviours

- Autism Observation Scale for Infants (AOSI; Bryson et al., 2007)
- Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012)

Results: Immediate Post-Intervention Outcomes





Results: Cumulative Benefits into Early Childhood

AICES
The Australian Infant Communication and Engagement Study

103 infants with some social-communication delays/differences (9-15m)

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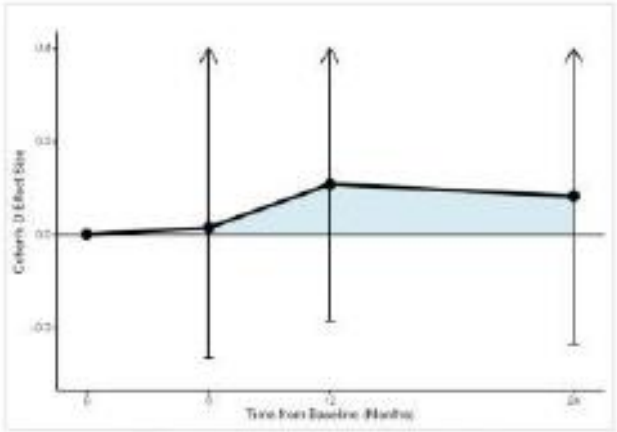
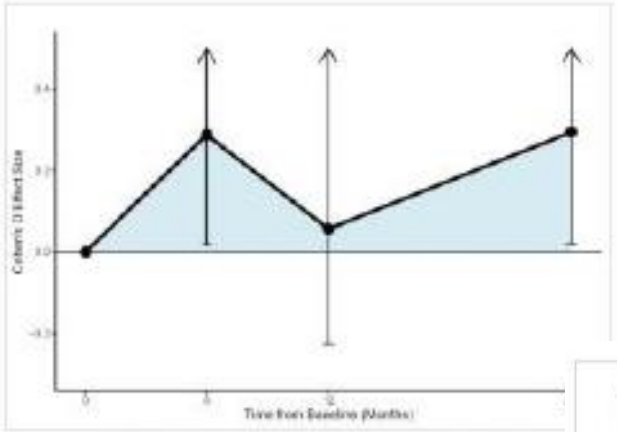
36 months of age	Follow-up Assessment 3	Follow-up Assessment 3

Results: Cumulative Benefits into Early Childhood

MSEL



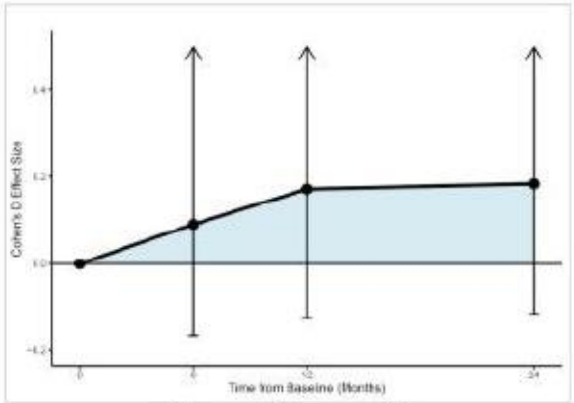
Expressive Language



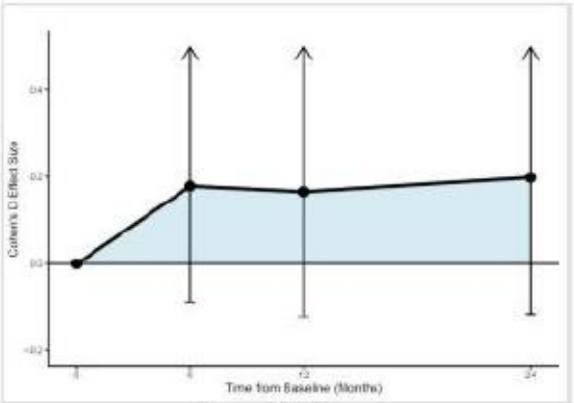
Receptive Language

Usual services set to zero; difference for iBASIS-VIPP:

- Single time-point point estimates:
- Cumulative 'Area Under the Curve' (AUC):



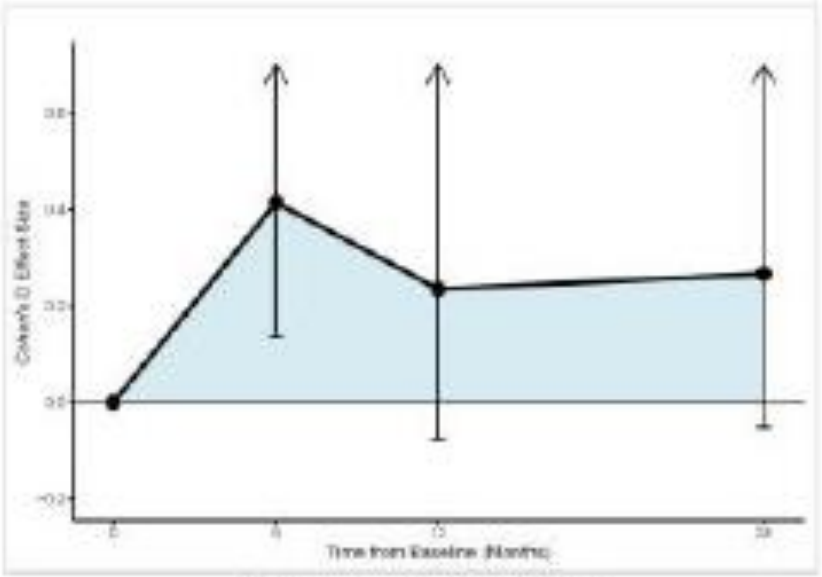
Visual Reception



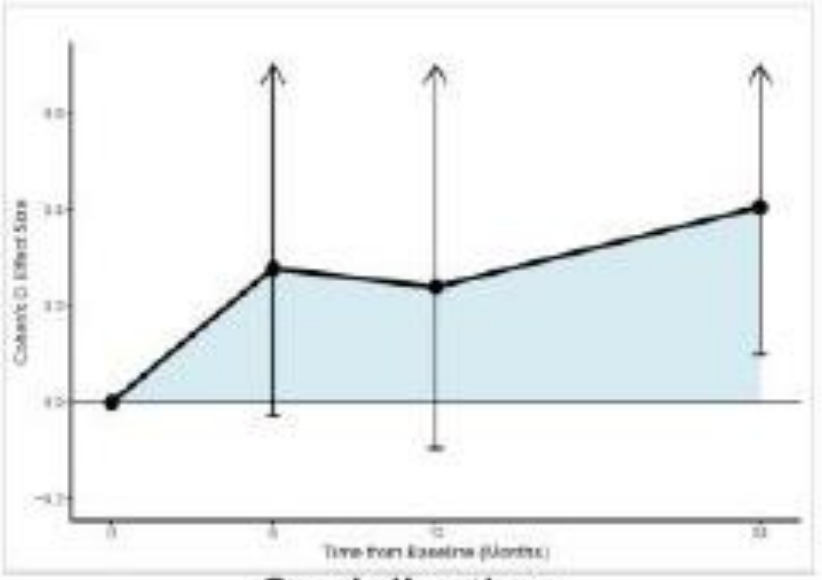
Fine Motor

Results: Cumulative Benefits into Early Childhood

VABS-2

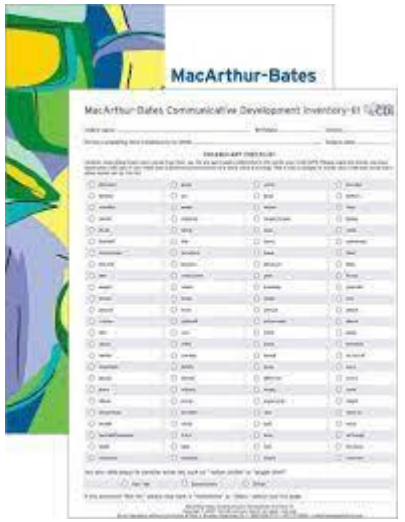


Communication

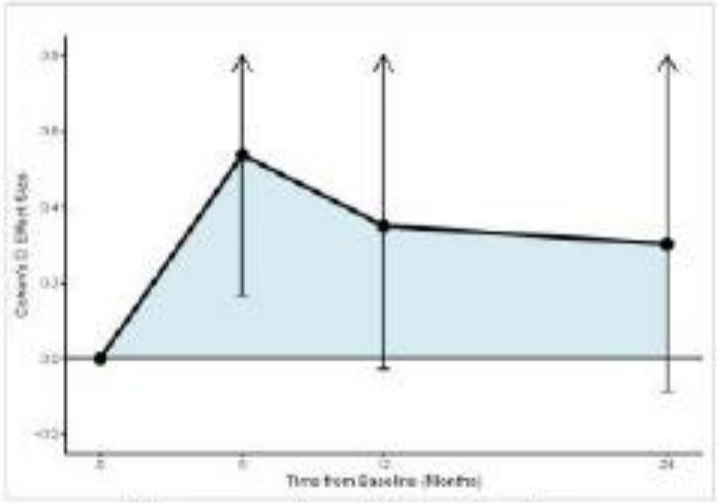


Socialization

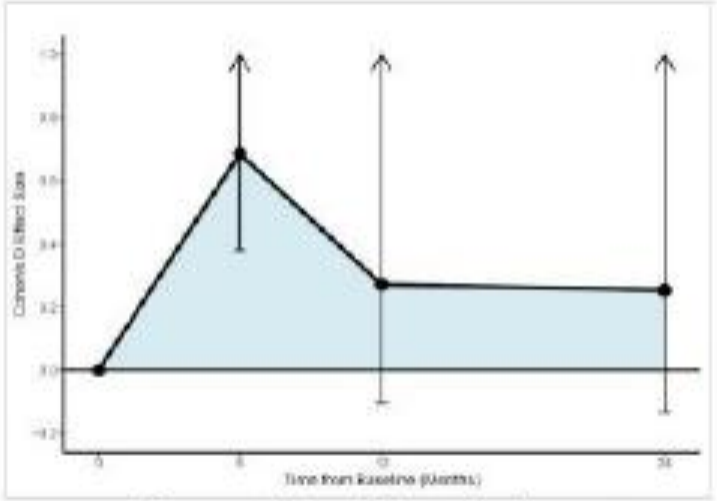
Results: Cumulative Benefits into Early Childhood



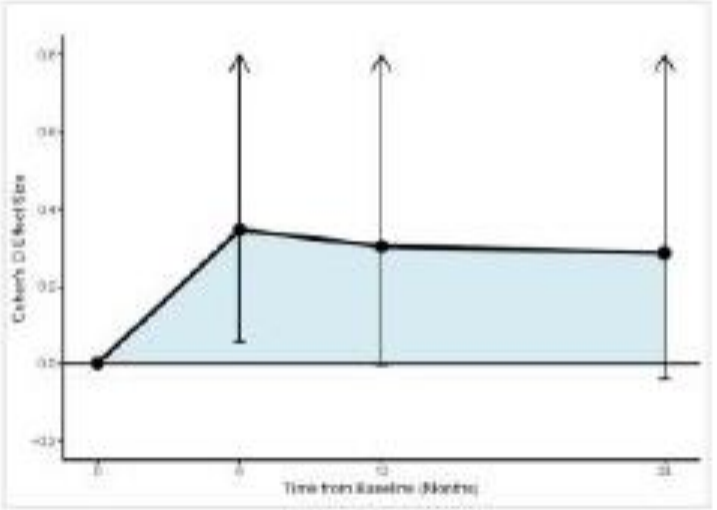
MCDI



Expressive Vocabulary



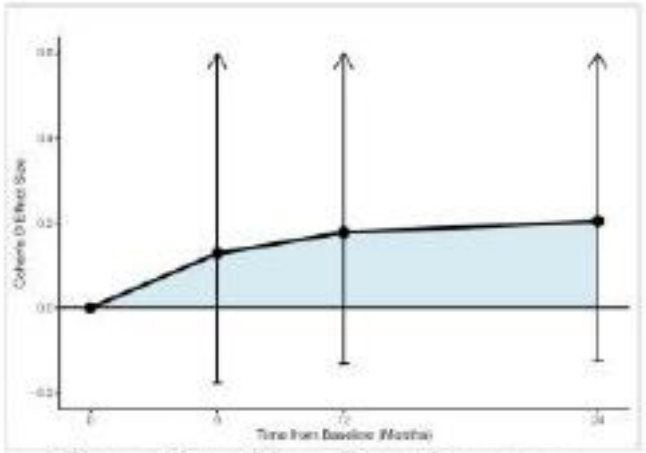
Receptive Vocabulary



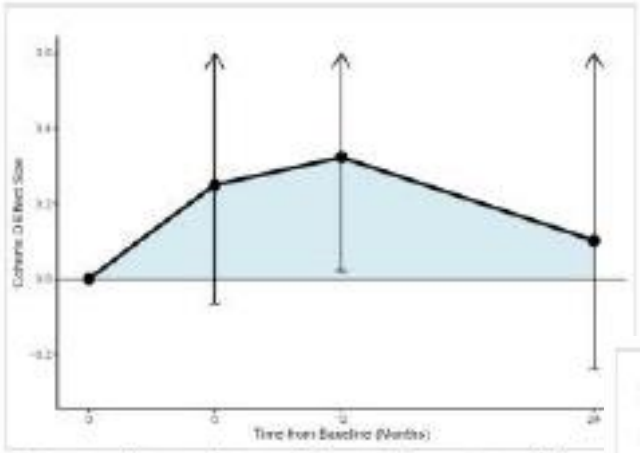
Gestures

Results: Cumulative Benefits into Early Childhood

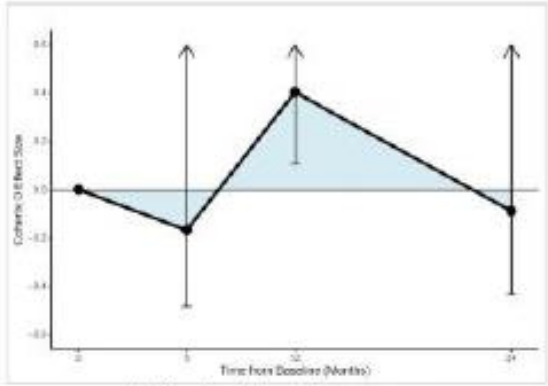
MACI



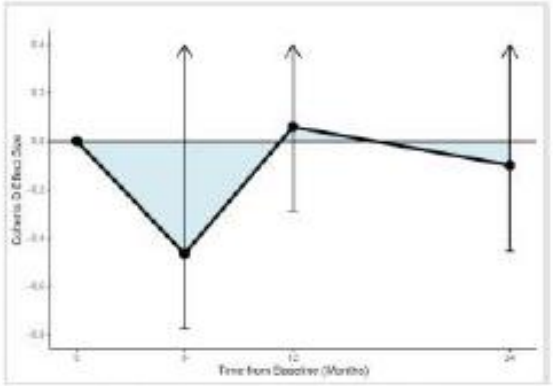
Caregiver Nondirectiveness



Caregiver Sensitive Responding



Infant attentiveness

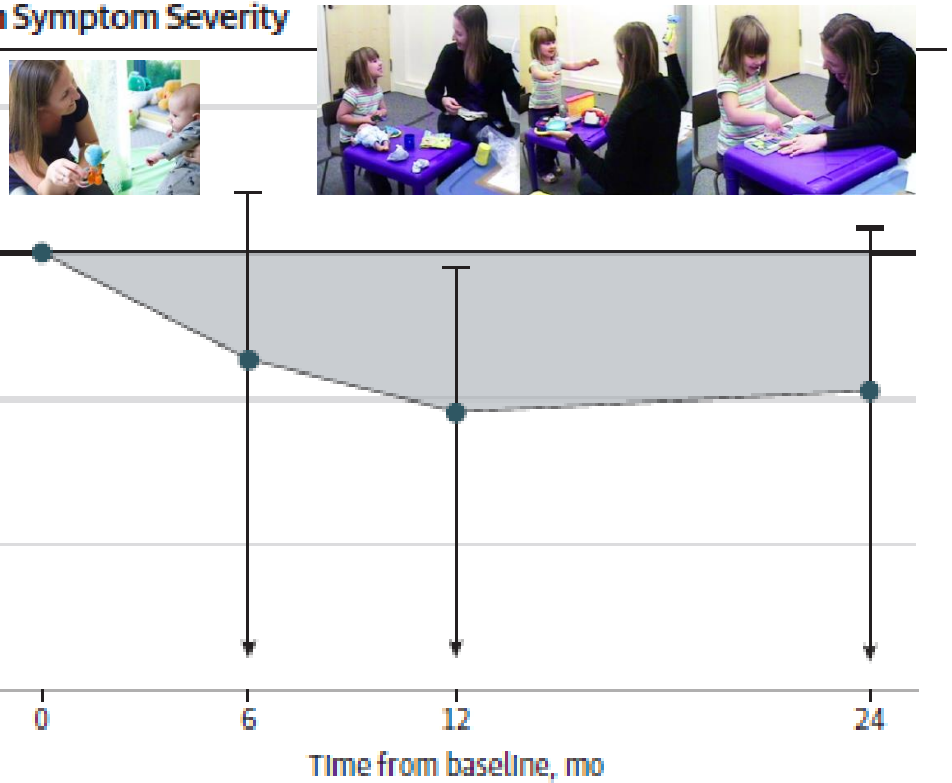


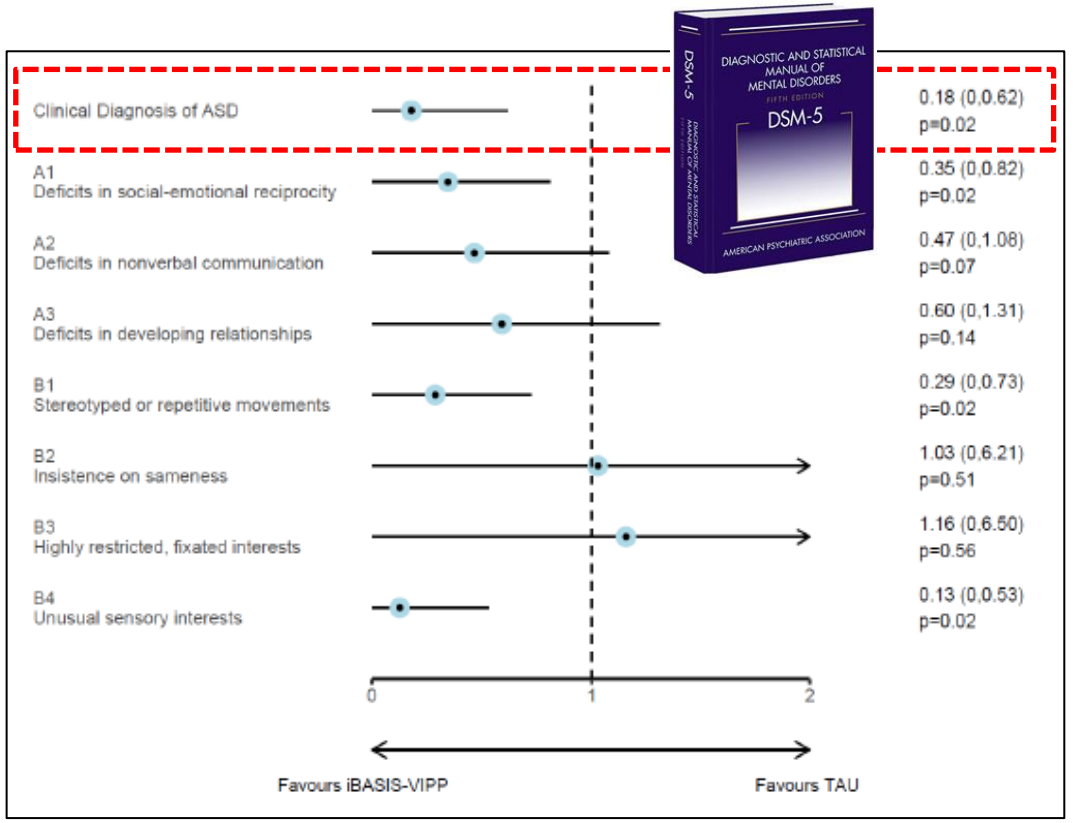
Infant Positive Affect

Results: Emerging Autism Behaviours Cumulative Impact & Diagnosis at age 3-

AICES
The Australian Infant Communication and Engagement Study

Figure 2. Treatment Effect Over Time for the Primary Outcome of Autism Symptom Severity





Summary and Impact

AICES
The Australian Infant Communication and Engagement Study

A low-intensity, parent-mediated pre-emptive intervention:

- Improved parent-reported language outcomes (already by 18 months)
- Reduced extent of autism symptoms ⟹ Reduced likelihood of diagnosis by age three years
  - Consistent with Green et al. (2017; *J Child Psychol Psychiatry*)
- No adverse effects

A landmark finding that can change how we support children and families

A positive approach, consistent with neurodiversity perspective:

- Working with each child's unique strengths and differences
- Creating an environment that helps them learn in as best for them, and empowers parents

Next Steps for AICES

AICES
The Australian Infant Communication and Engagement Study

Other focus on:

- How assessments work with local (and clinically-indicated) samples (Hudry et al., 2021, *Autism*)
- How children learn language (Smith et al., Kennedy et al., in preparation)
- How child temperament shapes development (including toward internalising/externalising problems)
- Impact of early child skills/differences on parental wellbeing (Chetcuti et al., 2021a,b, *Autism Res*; 2021, *Res Child Adol Psychopathol*)

This Topic = Testing a new way to support children with autism and their families

(Whitehouse et al., 2019, *Lancet Ch Adol Health; 2021, JAMA Ped*)

- Cost benefit? Within-trial cost-effectiveness + projected cost savings into middle childhood
- Planned 'Transition-to-School' followup (2022-2023)

Communicating and Understanding Baby Study

CUBS (aka "Baby AICES")

How can we best support infants at increased autism likelihood from birth?

Including where parents/ caregivers are autistic?

Recruiting <u>pregnant women</u> where:

- ✓ Main home language = English
- ✓ Family lives in metro Melbourne or Perth (+ no plans to relocate in 2 years)
- ✓ Carrying a single baby (not twins+)

And infant is at increased likelihood of autism in one of two ways:

1) **Immediate family member** (Full sibling, biological mother/father) has Autism, ADHD, Intellectual Disability/Global Developmental Delay; or
2) **Extended family member** (half sibling, biological aunt/uncle/grandparent) has Autism (only)

cubs@latrobe.edu.au

Recruitment closes mid 2022; families can self-refer

Technology-Supported Early Identification & Diagnosis

JVCKENWOOD Corp. *'Gazefinder'*

Two aligned studies testing ~2-minute eye-tracking assessment:

1) **AICES subgroup → Early identification pilot:**
   - Feasibility and acceptability (Chetcuti et al., under review)
   - Potential utility for early identification and diagnosis (in preparation)

2) **Clinical device trial → Diagnostic classification accuracy:**
   - N=200 2- to 4-year-olds with & without ASD
   - Accuracy of algorithm based on gaze data to differentiate groups
   - Therapeutic Goods Administration (TGA) submission; for potential use as a diagnostic aide
   - Opportunity for usability test:

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Stefanie Dimov

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Maryam Boutrus

Abby Chee Alena Clark

Matthew Cooper

Megan Harrap Lisa Matys

Murray Maybery Sarah Pillar

Daniel Pope Kandice Varcin

University of South Australia

Leonie Segal

University of Manchester, UK

Jonathan Green

Carol Taylor Ming Wai Wan

Evelina Children's Hospital, UK

Vicky Slonims

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Evelina London

CELEBRATING 25 YEARS University of South Australia

Government of Western Australia Department of Health

AutismCRC