AutismCRC

Therapy for infants showing early signs for autism

FINAL REPORT

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Copies of this report can be downloaded from the Autism CRC website **autismcrc.com.au**.

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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1. Introduction

1.1 Background

In Australia, the average age for an autism diagnosis is 4-years of age (Bent et al., 2015). Yet it is possible to observe, screen, and assess for emerging signs of autism before a child turns two. The earlier diagnosis of autism in childhood is a key goal of the Autism CRC's Early Years Program. There is significant work being undertaken towards this aim; namely through the study Autism CRC study, *Developmental surveillance for autism*, which sought to identify infants showing early signs for autism from 12-months of age and facilitate adopting a behavioural surveillance protocol by community-based primary health-care providers. With this behavioural surveillance work already underway within the Autism CRC, a strategic need was identified for a parallel stream of research to develop and evaluate therapies that can be accessed very early in life by infants identified as showing early signs of autism. The screening tool (SACS-R 12-month checklist) is a resource already adapted for use by community health care workers in Victoria. Building on this existing program of early identification, there was an opportunity to extend this work, to identify children who may benefit from early intervention support. Pre-emptive intervention (i.e., prior to a diagnosis) has the potential to support early developmental skills acquisition for infants showing behavioural features associated with autism, such as the level of eye contact, development of social gestures and a child's response to their name.

In January 2015, members of this study team published the results of a pilot randomised-controlled trial of a very early parent-mediated intervention for infants at increased likelihood of autism (due to having a sibling diagnosed with autism), called iBASIS-VIPP (Green et al., 2015, Lancet Psychiatry). Fifty-four infants aged 8-10 months were enrolled in the trial. Half the infants were assigned to the iBASIS-VIPP group through a randomisation process. Infants, with their caregivers, received ten therapy sessions over five months.

The key results of this trial were promising. The assessments conducted with the children immediately post-therapy (when the average infant age was 14-months) indicated that iBASIS-VIPP significantly improved caregiver interaction with infants. Further, there was some improvement in infant social behaviours and engaqement, and a change in specific behaviours as measured using the Autism Observation Scale for Infants (AOSI). On the basis of these results, we saw a need and opportunity to determine if these promising results might extend to a larger sample of community-referred infants with early signs of autism. As such, we aimed to follow-up this pilot study with a full-scale randomised controlled trial of iBASIS-VIPP.

1.2 Aims

The aim of the Clinical Trial, *Therapy for infants showing early signs of autism*, was to test the efficacy of the iBASIS-VIPP intervention on a larger scale than the pilot study and in a sample of community-referred infants (rather than infants at high likelihood of autism due to having an older sibling with a diagnosis).

Based on the findings of the pilot study, we hypothesised that 6-months of fortnightly iBASIS-VIPP therapy sessions would:

a) improve parent-child interaction quality
b) improve infant developmental and language skills
c) improve development of specific behaviours, as measured using the Autism Observation Scale for Infants (AOSI).

2. Research design and method

2.1 Method

To establish a full-scale randomised controlled clinical trial, two teams of researchers came together across institutions in Victoria (La Trobe University, Melbourne) and Western Australia (The University of Western Australia/Telethon Kids Institute, Perth). The University of Western Australia had secured competitive funding in 2016 to commence the trial. Support from the Autism CRC and La Trobe University's UD Research Focus Area enabled the establishment of a second site at La Trobe University, Melbourne. The establishment of this second site was crucial to ensuring we were able to enrol enough infants (and caregivers) to rigorously evaluate the outcomes of the intervention. Early autism surveillance activities were already underway in Victoria with the CRC *Project 1.005RC*. If iBASIS-VIPP was shown to be an effective intervention, the trial would also demonstrate the practicalities of how a therapy might be integrated with community surveillance and state-based differences in referral practices.

Our study was intended to be an extension (rather than a replication) of the pilot trial for iBASIS-VIPP. We aimed to extend the pilot trial in two key ways: (1) to recruit a larger number of families

(target 120 infants across two trial sites, compared to 54 infants in the pilot study), and (2) to enrol infants within the community showing early signs of autism using the surveillance tool (rather than limiting the study to infants with a sibling with a diagnosis of autism). While approximately 20% of infants with an older diagnosed sibling are likely to receive a future diagnosis of autism (Oznonoff S. et al, 2011) infant siblings do not make up the majority of children who eventually receive a diagnosis of autism. As such, we cannot assume that the results from samples of infant siblings will translate to community-referred infants (Sacrey L. et al, 2017). A broader community sample, with diverse clinical profiles, is more likely to be representative of the population of infants and caregivers that will ultimately receive a pre-emptive intervention such as iBASIS-VIPP, if found to be effective.

To identify infants in the community showing early behavioural signs associated with autism, the trial partnered with community health-care services at both sites: the Victorian Maternal and Child Health Service (MCH) in Melbourne, and the WA Child Development Service (CDS) in Perth. The trial closely approximated a 'real-world' pathway from early identification through developmental surveillance, to referral for early intervention without the need to await a confirmed diagnosis.

The study used a single-blind (i.e., assessor), randomised controlled trial (RCT) design. Infants were eligible for the study if, at the time of enrolment, they were aged between 9-14 months and showing at least three early behavioural signs associated with autism based on the Social Attention and Communication Study-Revised (SACS-R) 12-month checklist.

SACS-R 12-month checklist:

The SACS-R was used to screen infants for behavioural signs associated with autism. When administered by Maternal and Child Health nurses, the SACS-R tool has a high positive predictive value of >70% at 12 months for a later autism diagnosis (Barbaro et al, 2018; Mozolic Staunton et al, 2020). For eligibility into our study, infants were showing delays or atypical development (as reported by their primary caregivers) of at least three of the following five behaviours:

- eye contact
- social gestures
- pointing to objects to share attention
- imitation
- response to name

2.2 iBASIS-VIPP Therapy

iBASIS-VIPP is a manualised intervention comprising 10 fortnightly sessions with a trained therapist. During each session, therapists use video feedback to focus the caregiver's attention on their infant's unique communication bids. Therapists help parents to identify and understand their infant's communication cues and then respond in a way that promotes back-and-forth interactions. The focus is on everyday ways of communicating with a baby, such as through talking and interacting face-to-face, or reading a book; activities that occur within the home environment.

This therapy adopts a 'low intensity' approach to intervention, involving only 1-2 hours of contact with a therapist per fortnight over a 5-6-month period. Between sessions, caregivers are provided with ‘homework’ tasks to practice implementing strategies discussed in the face-to-face therapist sessions. The intervention uses video-guided feedback as the basis for helping caregivers identify, understand, and learn new strategies for responding to their infants. By watching themselves interact with their infant on video with a therapist present, parents are given the opportunity to reflect on both their infant’s behaviours and their own responses to these behaviours; hence, the VIPP within the protocol name, short for Video Interaction for Promoting Positive Parenting.

The trial intervention involved up to 10 individual sessions (one introductory, six-core, and up to three booster sessions) delivered in the family home by a trained clinician (here, either a speech and language therapist or a psychologist).

A fidelity tool and ongoing supervision with a trained clinician accompanied the iBASIS-VIPP intervention to ensure the delivery by therapists was maintained to a high standard.

2.3 Procedure

The clinical trial team worked successfully with the key community child services within each state. In Perth, the state-based Child Development Service (CDS) is a referral-based provider supporting the needs of children with developmental delay or difficulty. A clinician based within the CDS was seconded to work on the trial. This clinician screened all potentially eligible families (using the SACS-R 12-month checklist) referred to the CDS over the trial recruitment period. Families that were eligible and where parents provided verbal consent to participate had their details passed to the Study Coordinator located at Telethon Kids Institute who liaised with the families to schedule their first assessment appointment.

In Victoria, all babies and infants are monitored through a scheduled program by a Maternal Child Health (MCH) nurse. Nurses from a diverse selection of municipal council areas were engaged

and trained on the SACS-R checklist. The screening was incorporated into regular appointments and nurses could directly refer infants who met eligibility to a study team member at La Trobe University. The study team member then contacted families to screen for eligibility a final time via telephone using the SACS-R 12-month checklist. Eligible families were then formally invited into the study and an initial assessment appointment scheduled. Figure 1 outlines the study procedure pathway at each site.

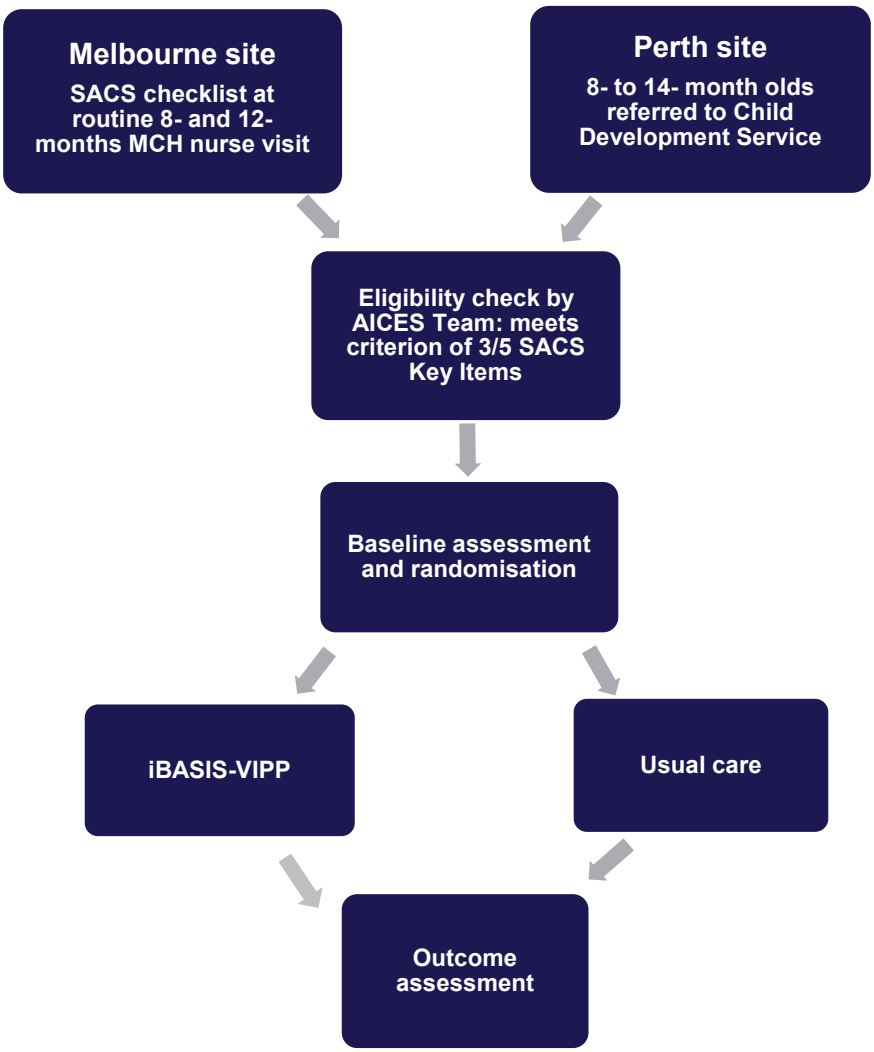
Randomisation to a treatment arm (iBASIS-VIPP or usual care; also referred to as Treatment as Usual in technical, scientific reports) was conducted for each family after their first (baseline) assessment session. Randomisation of families in the study was conducted by the Study Coordinator (located at the Telethon Kids Institute, Perth). The allocation of families to a treatment arm was by random assignment (based on a computer algorithm) using a minimization method. The minimization method was designed to address potential imbalance across the two group by controlling for:

- trial site (Melbourne/Perth)
- child age (9-11 months, 31 days; 12 months – 14 months, 31 days)
- child gender (male, female)
- SACS-R score (i.e., 3, 4 or 5 behaviours).

Families assigned to the iBASIS-VIPP group were contacted shortly after randomisation by a study therapist to commence their 10 allocated sessions of iBASIS-VIPP. Families in the usual care group were notified and informed that the team would be in contact in ~6 months' time to schedule their follow-up assessment. The usual care group involved families accessing any services that were on offer to them in the community (without study trial interference). Families in both groups were asked to keep a diary of their contact with health professionals between the baseline assessment session and their follow-up assessment session.

Six months following their baseline assessment – and once families in the iBASIS-VIPP group had completed the intervention protocol – all infants were invited back for their outcome assessment. These were conducted by a research assistant who was blind to the treatment group allocation (i.e., they did not know whether families had received the iBASIS-VIPP intervention or usual care). The baseline and the endpoint assessment (post-intervention) measured the same range of caregiver and infant outcomes (as presented in Table 3).

Figure 1: *Clinical trial procedure*



The trial procedure from referral and intake/eligibility screening through to baseline assessment and randomisation to the outcome assessment conducted immediately post-intervention.

2.4 Participants

2.4.1 Eligibility

Inclusion criteria for the trial:

- infants aged 9 – 14 months and 31 days (corrected for prematurity)
- infants displaying difficulties in the development of at least three of five key behaviours on the SACS-R (eye contact, social gestures, pointing, imitation, response to name)
- primary caregiver speaks sufficient English to participate fully in therapy sessions

Exclusion criteria:

- infants born very pre-term, before 32 weeks
- any diagnosed condition known to affect infant neurological and developmental abilities
- families not intending to remain living in the local area for trial duration.

Infants receiving community therapy were not excluded.

2.4.2 Enrolment

In total, 171 infants were assessed for eligibility across the two sites. Of these, 104 families met eligibility requirements, consented to participate in the trial and were randomised to either iBASIS-VIPP therapy or usual care. Of these participants, 51 were assigned to therapy and 53 were assigned to usual care (Table 2). After randomisation, the study team was made aware that one family did not meet the English language requirements to participate fully in the trial. As such, this family were withdrawn from the trial, leaving 50 families assigned to iBASIS-VIPP and 53 to usual care.

Table 2: *Our participants - Infant and parent/caregiver profile*

Infant characteristics	**iBASIS-VIPP**	**Usual care**
Sex - Boys - Girls	 38 (79%) 12 (24%)	 32 (60%) 21 (40%)
Older siblings on the autism spectrum	10 (20%)	10 (19%)
Chronological age (months)	12.40 (1.93)	12.38 (2.02)
Age adjusted for prematurity (months)	12.12 (1.98)	12.31 (2.00)
Family characteristics		
Annual household income >AUD$50,000	40 (95%)	44 (88%)
Mother completed university degree	33 (66%)	29 (55%)
Infant living with both biological parents	49 (98%)	52 (98%)

2.5 Measures and Analysis

At the baseline and outcome assessments, research assistants administered a range of observational assessments, blind to the family's treatment group allocation. Caregivers were also provided with questionnaires to complete about their infant's development and themselves.

- Primary outcome measure:

The Autism Observation Scale for Infants (AOSI; Bryson, S. et al, 2007) is an observational measure of early behavioural signs associated with autism spectrum disorder, including response to name, social reciprocity, and imitation. This semi-structured play-based child assessment is administered by a research assistant and designed to detect early signs of autism.

Higher AOSI Total Scores indicate a greater likelihood of a later autism diagnosis. We hypothesised that we would see reduced *AOSI Total Scores* among infants in the iBASIS-VIPP group compared to those receiving usual care.

- Secondary outcome measures:

Our secondary measures were included to help us explain why the intervention might or might not have made a significant difference to the infants' emerging signs of autism. To address the question of whether the therapy might improve infant developmental and language skills, we used the Mullen Scales of Early Learning (MSEL; Mullen, E.,1995), Vineland Adaptive Behaviour Scales (VABS; Sparrow, S. et al, 2005)6) and MacArthur-Bates Communicative Development Inventories (MCDI; Fenson, L. (1993). These are all standardised assessments of developmental/cognitive ability, adaptive behaviour, and communication and language, respectively.

The Manchester Assessment of Caregiver Infant Interaction (MACI; Wan M. et al (2017)) is a coding scheme for caregiver-infant interaction behaviour shown to differentiate, among infants with a family history of autism, those who did and did not subsequently receive a diagnosis. This measure corresponds with the research question of whether the intervention will improve parent-caregiver interaction quality.

We expected to see higher *VABS social* and *communication* and *MSEL* and *MCDI language* scores among infants in the iBASIS-VIPP group compared to those in the usual care group. Further, we expected caregivers in the iBASIS-VIPP group to be rated on the MACI as *less directive* than those in the usual care group, and that their infants would be rated as *more attentive* (see table 4 for measure summary).

Our primary outcome analysis was via an 'Intention-to-Treat' method, conducted by our trial Statistician. We had determined that a sample of 70 participants would provide >80% power to detect a 5-point difference between groups on ***AOSI Total Score*** at a significance level of α=.05. Given the estimates of effect size from our pilot trial, and this calculation, we were sufficiently powered to achieve the aims of the trial with our sample of >100 infants across the two trial sites. We considered change scores from baseline to outcome, on our secondary measures. We also recorded additional contact with health professionals received by infants in each group over the trial participation period, comparing this across the iBASIS-VIPP and usual care groups to facilitate interpretation of our main trial findings.

Table 3: *Primary and secondary study measures*

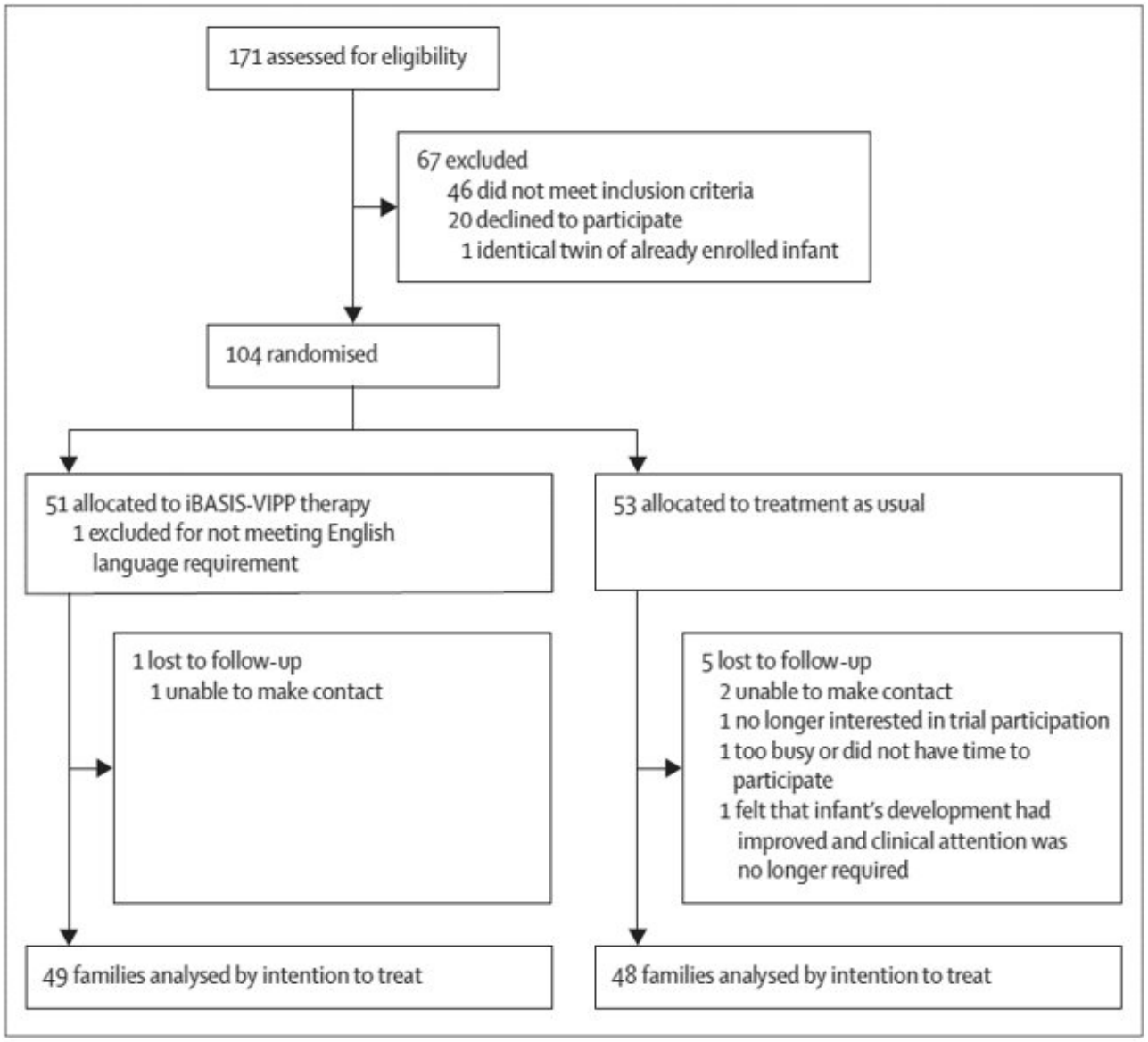
Measure	Examines	Format	Primary outcome	Secondary outcome
Autism Observation Scale for Infants	Autism behaviours	Direct assessment	✓	
The Mullen Scales of Early Learning	Infant non-verbal and verbal developmental skills	Direct assessment		✓
Vineland Adaptive Behaviour Scales	Infant adaptive behaviour skills	Parent-report questionnaire		✓
MacArthur-Bates Communicative Development Inventories	Infant receptive and expressive language knowledge and gesture use skills	Parent-report questionnaire		✓
The Manchester Assessment of Caregiver Infant Interaction	Parent-child interaction	Ratings from video footage of free-play interaction		✓

3. Findings

Overall, the retention of enrolled families in the trial was very high. Ninety-five per cent (95%) of participants who were randomised remained in the study and attended the immediate outcome assessment six months after their baseline assessment. Only a small number of participants were

lost: 1 from the iBASIS-VIPP therapy group and 5 from the usual services group (see table 5 for reasons: Whitehouse A. et al, 2019).

Table 4: *Study participants from enrolment through to the final follow-up*



Similar numbers of infants had difficulties with 3, 4, or all 5 of 5 key behaviours on the SACS-R eligibility screening measure. All infants and caregivers in the iBASIS-VIPP group attended the minimum number of therapy sessions for inclusion in the trial analyses. It is also worth noting that during the trial, a higher percentage of infants in the usual care group received a community-based intervention compared with those in the iBASIS-VIPP group. The Perth site had the most significant difference between groups for receipt of community-based therapy (1 out of 32 in the iBASIS-VIPP group also received community-based therapy, compared with 30 out of 32 in the usual care group).

The results of the trial were varied. Our primary outcome measure, the AOSI (a measure of behaviours associated with autism), presented no notable differences between the treatment groups in the change of scores from baseline to outcome assessment. In other words, iBASIS-VIPP did not lead to more change in early autism behaviours over the 6-month treatment period than we observed for infants receiving usual care.

The iBASIS-VIPP group also did not make more gains in their developmental and language skills compared to those in the usual care group on measures administered by trained research assistants. The MACI coding from the caregiver/child videos showed our parents in the iBASIS-VIPP group were not less directive than those in the usual care group, and that infants were not more attentive. These first results appear to show that the therapy did not enhance caregiver-child reciprocal communication as predicted (see table 6).

Table 5: *Findings against the hypothesis at immediate outcome assessments*

	Hypothesised	Findings
Autism Observation Scale for Infants	+	o
Parent-child interaction quality	+	o
Assessed infant skills:	+	
• ***Communication and language***	+	o
• ***Developmental abilities***	+	+

+ Positive therapeutic affect o Null effect

In summary, we found no significant differences between the two infant groups, iBASIS-VIPP and TAU, on:

- development of specific behaviours, as measured using the AOSI;
- parent sensitive responsiveness or non-directiveness ratings, or infant attentiveness to parent;
- infant developmental/language skills from direct assessment by trained research assistants.

However, we did find a significant between-group difference on caregiver-reported communication and language skills.

> **Parents in the iBASIS-VIPP group reported that their child understood an average of 37 more words, and spoke an average of 15 more words, than those who did not receive the therapy.**

Parents in the iBASIS-VIPP group also reported an increase in adaptive communication skills on the VABS for their infants, compared to parents whose infants received usual services.

There are a number of possible reasons to explain this pattern of findings. The absence of beneficial effect of iBASIS-VIPP on the caregiver-child interaction may be due to the large number of families in the usual care group who received a community-based therapy during their participation in the trial. Further investigation of this possibility did show some similarities between iBASIS-VIPP and other accessed therapies. It may also be that the clinical setting for the filming of the caregiver-child interaction, or the small window of caregiver/infant interaction that was filmed (6 minutes), did not capture the real-world dynamics of social communication. The MACI, which we used for coding parent-child interaction, may not have been sensitive enough to identify any nuanced changes in the interaction between caregiver and child, for this particular intervention and over this relatively short (6-month) follow-up period.

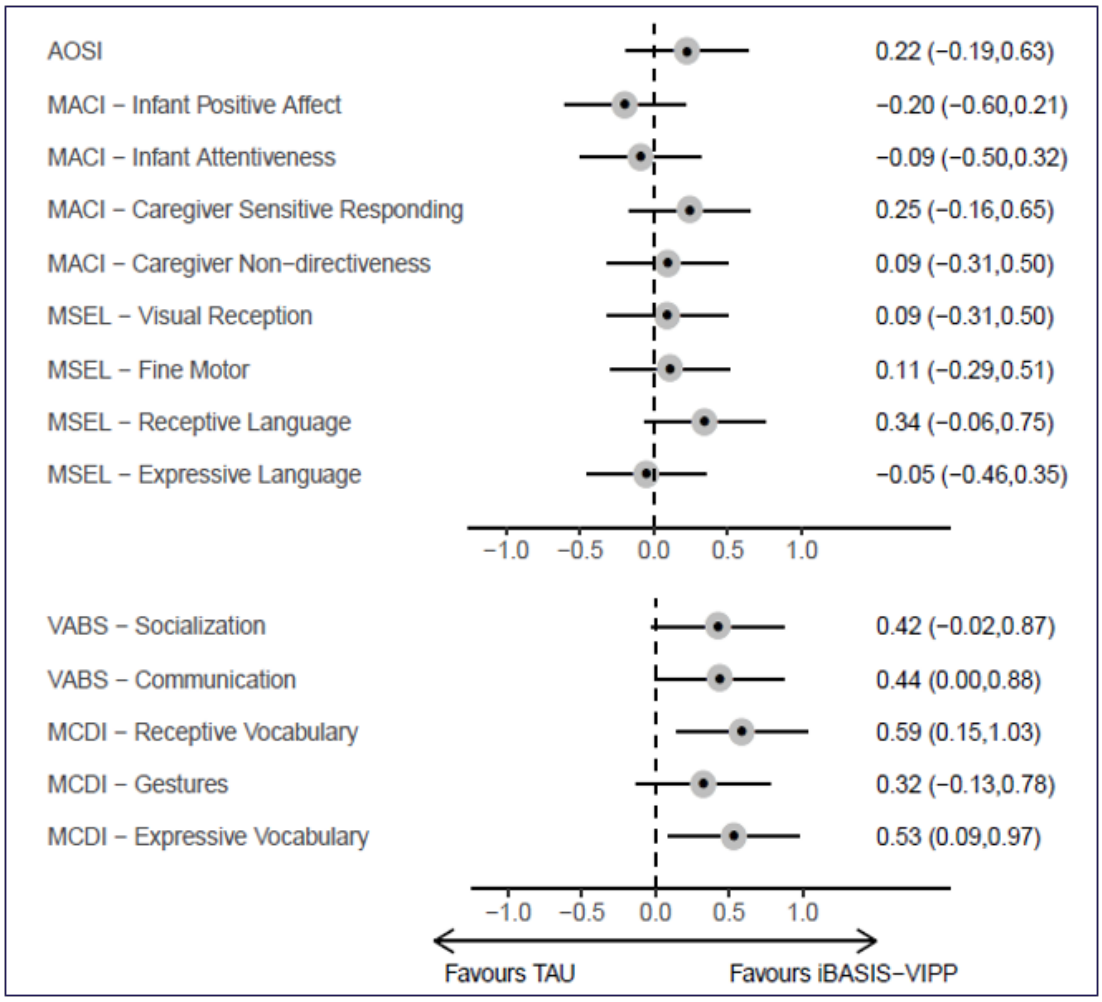
By contrast, the parent-report measures on which we did see a beneficial effect of iBASIS-VIPP, were in line with specific child skills that would theoretically have been supported through the intervention activities. These are also concrete skills that might have been more easily observed and reported to us by parents (compared to other more abstract and global measures). Further, parent-report measures benefit from a parents' opportunity to observe their infant regularly and in different contexts (compared to our other one-off, often short, assessments conducted in an unfamiliar setting with unfamiliar research assistants).

A forest plot (see table 7) provides a succinct overview of the therapy effectiveness according to each assessment conducted with participants and questionnaire that parents completed. The vertical broken line in the middle (null line) represents the point of no 'treatment effect' (no differences between the groups). For each measure, we show the 'point estimate' of the effect and whiskers that indicate 'confidence' in this point estimate. Where point estimates are toward the right of the null line, this suggests possible benefit of the iBASIS-VIPP therapy compared to usual services. However, the whiskers indicate the range of true positions for the point estimate – and

where these overlap with the null line, it is possible that the *true* point estimate could be on the other side of the line. That is, we cannot be *confident* that the point estimate is where it should be.

Overall, Figure 7 indicates confidence lines for the point estimates of most measures overlap with the null line, reflecting our interpretation of no particular benefit of the iBASIS-VIPP intervention. However, we do see movement to the right of the null line, with whisker lines not overlapping – and therefore representing confidence that the point-estimate is indeed truly to the right – for caregiver-reported (MCDI) receptive and expressive infant vocabulary and for (VABS) communication (where the whiskers just do not overlap the null). Hence, as reported above, our study suggests the iBASIS-VIPP brought significant improvements for infants' communication and language skills, compared to usual services, and as reported by parents.

Table 7: *Forest plot showing the effect size across the different trial measures*



4. Limitations

Our experience of conducting this study, and the results reported here, have led us to reflect on the following arising questions.

Firstly, is it realistic to expect a substantive impact on autism behaviours from a low-intensity, parent-mediated intervention that is delivered before an infant receives a diagnosis of autism? Given that, a) we cannot predict autism with certainty by a child's first birthday, and b) pre-emptive intervention shows only modest effects, what is the appropriate balance of informing caregivers that their infant is showing early signs for autism, and inviting them into an early intervention trial or service, but without unduly raising concerns or increasing stress?

Secondly, does a treatment-related effect specific to *parent-report* measures of child communication/language skill (not also detected in our direct assessments) reflect a) change in parental sensitivity and/or knowledge about the service they have received, or b) a genuine but subtle improvement in child skills that are not captured during direct testing? It may also be that this distinction doesn't really matter.

5. Implications for research and practice

The key directions for future research are discussed above, including our planned follow-up of this cohort to age 3-years when we will be able to determine which children have and have not gone on to obtain a diagnosis of autism. We will also be able to see whether there have been accumulated or sustained benefits of participating in iBASIS-VIPP intervention in early life, for children and their parents/caregivers. Meanwhile, MCH nurses and CDS professionals who we have upskilled in use of the SACS-R screening tool for this project will continue to support families in local communities in Melbourne and Perth through their knowledge on the early signs of autism.

6. Key recommendations

1. Future pre-emptive intervention studies should include measures for qualitative data collection to incorporate parents' experience of participating in a large-scale intervention trial. It would be valuable to know, for example; a) parent's experience of participating in the trial, b) whether their participation may influence or change how they view their child's development at the end of the study.

2. Future research should also measure change in the quality of life of infants and parents throughout their participation in any research study that is lengthy and has a therapy component.

3. Further follow-up of infants in the shorter term is warranted, beyond the immediate outcome appointment 6 months into the trial. This is something we have conducted with the current cohort, to child age 3-years when we can identify which children have and have not received an autism diagnosis, beyond the specific project work funded here. We anticipate results from our longer-term follow-up will be available and published during 2021. In addition, continued follow-up of the infants into childhood, to assess any longer-term differences between the iBASIS-VIPP group and usual care, will be of great value.

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Our values

Inclusion

Working together with those with the lived experience of autism in all we do

Innovation

New solutions for long term challenges

Independence

Guided by evidence based research, integrity and peer review

Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone

Australian Government
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