



Therapy for infants showing early signs for autism

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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.

autismcrc.com.au

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'.

1. Study aims

The aim of the Clinical Trial, *Therapy for infants showing early signs of autism*, was to test the efficacy of a manualised early intervention program called iBASIS-VIPP in a sample of community-referred infants. These infants were identified as showing early signs of autism and aged between 9 – 14 months of age and were followed to between the ages of 15 and 21 months.

We hypothesised that 6-months of fortnightly iBASIS-VIPP therapy sessions would:

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

2. Findings

- 95% of families who were enrolled participated in all parts of the study to outcome (103 in total).
- There was no significant change in early autism behaviours as measured using AOSI and assessed verbal and non-verbal skills among infants in the iBASIS-VIPP therapy group compared to those who accessed usual services.
- Caregivers in the iBASIS-VIPP therapy group reported that their child had improved communication and language skills, compared to caregivers of infants accessing usual services.
- Specifically, caregivers of toddlers who received the six months of early iBASIS-VIPP therapy reported that their child understood an average of 37 more words, and spoke an average of 15 more words, than those who received usual services.
- As most children were not using words at the start of the therapy period, these parent-reported language gains are an important improvement.

3. Limitations

- Is it realistic to expect a substantive impact on emerging 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?

- Does an intervention-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.

4. 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 an autism diagnosis. 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, Maternal Child Health nurses and Child Development Services 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.

5. 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



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