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20 March 2023

Address to:
SA Royal Commission into Early Childhood Education and Care
By email: RoyalCommissionECEC@sa.gov.au

Dear SA Royal Commission Secretariat,

I am pleased to provide the attached submission as part of my appearance as a witness at the SA Royal Commission.

Should you require any clarification or further information, please contact Fiona Roche, Head of Government Relations, at the Institute on [Redacted]

Your sincerely,

[Redacted Signature]

Professor Andrew Whitehouse

SUBMISSION TO SUPPORT THE APPEARANCE OF PROFESSOR ANDREW WHITEHOUSE AT THE SA ROYAL COMMISSION INTO EARLY CHILDHOOD EDUCATION AND CARE (ECEC)

20 March 2023

About

Professor Andrew Whitehouse leads one of Australia's leading autism research centres, which is based at the Telethon Kids Institute. The Institute was founded 32 years ago by Professor Fiona Stanley. Under the leadership of the current Executive Director, Professor Jonathan Carapetis, the Institute is one of Australia's largest medical research institutes with a dedicated and diverse team of more than 1200 staff and students. Headquartered in WA, the Institute prides itself on the translation of research into impact to improve the lives and wellbeing of children and young people in WA, Australia and around the world.

The Institute has an office in South Australia, on North Terrace in Adelaide. The South Australian office accommodates two key research teams – our Early Years System Evidence Team and the Indigenous Genomics Team.

At the Telethon Kids Institute, Prof Whitehouse lead CliniKids, a national centre of autism excellence. CliniKids is a nationally unique model that integrates cutting-edge research into every-day clinical services. CliniKids was founded to reduce the time it takes to translate research evidence into clinical practice. It is currently estimated that research advances take a minimum of 20 years to be implemented into clinical practice. The CliniKids model seeks to dramatically reduce this time by integrating cutting edge research within high quality clinical services, enabling a swift two-way flow of information to ensure that the Autism community is receiving the very best support possible.

CliniKids supports the complex needs of children (and families) with early developmental delay and/or autism through early intervention and diagnostic services backed by leading and innovative research. With more than 50 researchers and clinicians working side-by-side, CliniKids achieves these aims through three interwoven streams.

First, CliniKids is an international leader in autism research. Further information about research achievements are detailed above, and include leading the creation of national clinical guidelines, and the development of new therapies to support autistic children and their families.

Second, CliniKids is a registered NDIS provider, and provides high-quality therapies and supports to autistic children and their families across a range of disciplines, including Clinical Psychology, Occupational Therapy, and Clinical Psychology. In 2021, CliniKids had more than 2000 clinical appointments across multiple sites. Research activities are embedded within clinical activities, which facilitates new research ideas, and decreases the time from research discovery to implementation within clinical practice.

Third, CliniKids is an Australian leader in training clinicians on high-quality therapy for autistic children. CliniKids uses its international network to become trainers on evidenced-based therapies, and then seeks to provide this training service to the Australian clinical community. CliniKids maintains an active training calendar throughout the year, including remote training.

The Inklings Model

One area that CliniKids has pioneered and is highly relevant to the work of the Royal Commission is the evidence-based Inklings therapy, which provides a major opportunity for South Australia.

What is Inklings?

Inklings is an early childhood program based on the iBASIS-VIPP therapy for babies aged 6-18 months showing early social communication delays, and thus at increased likelihood of autism spectrum disorder.

The parent support program is uses short videos of the parent with their baby to help parents better understand their baby's thoughts and feelings, the different ways that babies communicate, the importance of interaction and of following their baby's focus of interest.

What does the research say?

In a study published in *JAMA Pediatrics*,¹ an international research team led by Prof Andrew Whitehouse in collaboration with the Child and Adolescent Health Service (WA), La Trobe University, The University of Manchester and the University of South Australia, found the world's first evidence that a pre-emptive therapy in infancy could lead to such a significant improvement in children's development that they then fell below the threshold for a clinical autism diagnosis.

The four-year randomised clinical trial enrolled babies aged 9-14 months to investigate the impacts of iBASIS-VIPP. All babies had shown early signs of autism, such as reduced eye contact, imitation, or social smiling.

Over a period of five months, half received iBASIS-VIPP, while a control group received normal community therapy. Eighty-nine children completed an assessment at the start of the study, at the end of the therapy period, and when they were 3 years of age.

The study found that, at age 3 years, children who received iBASIS-VIPP:

- Had fewer social communication difficulties characteristic of autism.
- Were two-thirds less likely to meet diagnostic criteria for autism at age 3 years compared to the control group.
- Had an increase in parent-reported expressive and receptive vocabulary.
- The intervention also resulted in increased parental sensitivity to their baby's unique communication. \

Economic evaluation indicated a saving of \$3.08 for every \$1 invested in Inklings therapy.² Cost savings were modelled for the NDIS system only, and do not include savings to other systems (e.g., Education, Health etc.).

This study replicated closely the positive findings of a previous clinical trial,³ making Inklings ready for wide-scale community implementation.

¹ Whitehouse AJO, et al. Effect of preemptive intervention on developmental outcomes among infants showing early signs of autism. *JAMA Pediatr.* 2021;175(11):e213298.

² Segal, L.Whitehouse AJO. Estimated Therapy costs and downstream cost consequences of the iBASIS-Video Interaction to Promote Positive Parenting intervention vs usual care in children displaying early behavioral signs of autism. *JAMA Network Open* in press.

³ Green J et al. Parent-mediated intervention versus no intervention for infants at high risk of autism. *Lancet Psychiatry.* 2015;2(2):133-40.

The clinical trial publications and subsequent media coverage has seen direct approaches from the National Disability Insurance Agency (NDIA) and other organisations to be directly involved in accelerating implementation of Inklings (iBASIS-VIPP intervention) in Australia and internationally.

Why is there a need for Inklings?

Autism is not typically diagnosed until three years of age at the earliest, and this diagnosis is usually the ‘trigger’ to commence therapeutic support. This ‘clinical pathway’ is not aligned with current scientific understanding of the critical window of early brain development during very early life. Therapies that commence during the first 2 years of life, when the first signs of atypical development are observed and the brain is rapidly developing, may lead to an even greater impact on developmental outcomes in later childhood - a proactive approach in helping babies now, rather than waiting for an autism diagnosis to commence intervention.

Given the prevalence of autism (2 per cent of Australians), the high representative of participants with autism in the National Disability Insurance Scheme (one-third), and the lifelong support costs associated with autism, the findings of this research have profound implications for how we structure health and disability systems to best support the needs of autistic children and their families.

The aim of Inklings is to support developmentally vulnerable babies with an evidence-based therapy, which will enable them to acquire skills that help them flourish. Inklings pre-emptive therapy provides an evidence-based and cost-effective way to build early developmental skills and family functioning that have significant downstream benefits to the Health, Disability and Child Protection systems.

How does Inklings work?

Inklings uses video-feedback as a means of helping parents recognise their baby’s communication cues and responding in a way that builds their social communication development. The program focuses on supporting parents to understand the unique abilities of their babies while providing a social environment that is adaptive and responsive to their needs. This is consistent with neurodiversity affirming principles.

Inklings is delivered at fortnightly intervals for 60-75 minute for 10 sessions by a range of allied health specialists, including speech pathologists, clinical psychologists, and child health nurses.

What’s next?

The National Disability Insurance Agency (NDIA) is in advanced discussions with the Telethon Kids Institute and the Western Australian Government to conduct an Implementation Pilot of Inklings across Western Australia.

The likely model for this implementation will be for the Western Australian state health services to support the screening of babies (using existing resourcing for child health nurses) and for the NDIA to support funding the delivery of Inklings intervention within the private sector by allied health professionals. The likely commencement data for this Implementation Pilot is Q2 2023.

Inklings holds enormous promise to change the way Australia supports children with developmental vulnerability. The program provides timely support to children earlier than previously thought possible, leading to better long-term outcomes for autistic children and their families.
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It is also critical that alternative models for delivering the Inklings program are explored. In this regard, I believe that much can be learnt from the 'Improving Access to Psychological Treatment' (IAPT) program in the UK. While this program is focused on mental health disorders, such as anxiety and depression, the challenges experienced are strikingly similar to child development services, and the successes could also be similar. The reform undertaken to this sector, and its relevant to the ECEC sector, is contained in Annexe 1.

Thank you for the opportunity to present this submission to South Australian Government.

For further information or clarification, please don't hesitate to contact me (details in cover page), and/or the Institute's Head of Government Relations on [REDACTED]

20 March 2023

ANNEXE 1 – REFORMS TO THE NATIONAL HEALTH SERVICES (NHS) IN THE UK

Like many health systems in Australia, the National Health Service (NHS) in the UK had significant challenges addressing the demand for mental health services.

After several Government reviews, the UK Department of health concluded that traditional training pathways (eg. clinical psychology, family therapy, child psychotherapy) were failing to meet the demands being placed on the NHS, and that a 'low intensity' workforce was required to provide services to people with mild to moderate depression and anxiety. The view was that a new 'low-intensity' workforce might help to reduce wait times and free specialist clinicians (e.g., clinical psychologists, psychiatrists) to work with more complex cases.

There are several key elements of the IAPT program. The first was the two levels of therapists, described above, that is one for children with complex cases and one for children with mild to moderate severity.

The key innovation here was the training of a 'low intensity' workforce of professionals traditionally not included in the mental health system (eg. community workers), who completed training on a select number of evidence-based therapies known to be effective for mild/moderate data collection. The second was high quality training on evidence-based therapies.

The IAPT is considered a major population health success. In the 10 years (2008-2017), it has trained a further 7,000 therapists, and over 580,000 people were seen in IAPT clinic. Critically, the data collection indicated very positive results on patients. Over 50% of people recovered after their initial block of therapy, and 66% of people showed reliable improvements. Economic analyses have indicated substantial reductions in healthcare utilisations and costs.

The experience of implementing the IAPT model is highly instructive to the current challenges faced by the South Australia. The SA child development sector also seeking to address health issues where early intervention is critical (i.e., developmental delays), but is experiencing significant work force shortages and substantial wait times for children and families. Traditional training pathways (i.e., speech pathology, occupational therapy, physiotherapy, psychology) are also not meeting the demands placed on the system.

The Institute believes that the SA Government has the key ingredients to explore implementing a similar system in SA. First, an evidence-based therapy for children with developmental delay, Inklings (as outlined above) has been tested in two randomised controlled trials, and found to be efficacious and highly cost effective in reducing developmental problems and increasing skills in infants (aged 6-18 months) showing developmental delay

Second, SA could seek to develop a 'low intensity' work force, which could be used to provide support to children with milder developmental delays. Potential professionals who could make up this cohort include those **professionals within the ECEC sector**. With training, these professionals could be trained to deliver Inklings within ECEC settings, ensuring prompt access to an evidence-based therapy with the local community.

The Telethon Kids Institute would welcome the opportunity to discuss this model and Inklings in more detail.