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EARLY DETECTION OF AUTISM

How reliable are the early signs of autism?

Dr Josephine Barbaro from La Trobe University and Jaidyn Sullivan using the ASDetect app.

Eleven years ago, Dr Josephine Barbaro from La Trobe University's Olga Tennison Autism Research Centre (OTARC) began to develop a method for reliably detecting early signs of autism. The Social Attention and Communication Study (SACS) comprises a set of social-communication behaviours monitored in children aged between 12-24 months by Maternal and Child Health (MCH) nurses trained in its use. Almost 350 nurses have now monitored over 35,000 Victorian children.

In both my original SACS study (2006-08) and the second study SACS-R (ongoing since 2013), 81% of children who were identified as having a high likelihood of autism by the nurses, did in fact have autism. The SACS with 84% sensitivity and 81% positive predictive value, outperforms the next best tool, the Modified Checklist for Autism in Toddlers (MCHAT), which has a positive predictive value of 1-11% when used in community samples.

Early detection of autism is crucial, because it enables early intervention, which we now know significantly improves children's lifelong outcomes, quality of life, and family functioning.

As the average age of autism diagnosis in Australia is between four and six years, the critical opportunity for early intervention is often lost. With the multiple demands on doctors these days, parents with concerns about their young children are commonly told to 'wait and see' how their child develops.

There is still a widespread perception that autism can't be reliably diagnosed in children under the age of three, but as the robust results from our SACS studies show, we can detect early signs of autism in toddlers as young as 12 months of age. Early detection then allows earlier diagnosis by doctors and paediatricians.

Our challenge has been to find the best way to get the message about early detection to those in a position to act on it: parents, GPs and paediatricians. Our first step in

Jaidyn, Toni, Steve and Jorja Sullivan.

addressing this challenge has been transforming the solid evidence base of SACS into an accessible form – which is why we developed a mobile application, called ASDetect.

ASDetect gives parents something tangible to take to their doctor which is based on evidence, rather than 'Dr Google.' However, it is not meant to replace a formal diagnosis. Rather, it comprises a series of video-led assessment questions that guide parents through key social-communication milestones. A clear context for the behaviours that are being assessed is provided by videos of children both with and without autism. ASDetect returns an instant result of 'high' or 'low' likelihood of autism and a detailed results report that parents can take to their GP or paediatrician. It's intended to empower parents to seek answers to their concerns about their child's development.

One family that can attest to the benefits of early detection and early intervention is the Sullivan family. Before they were referred to OTARC, Jaidyn's parents Toni and Steve knew nothing about autism. "We were devastated when we heard the word," Steve said.

Their son Jaidyn was first diagnosed aged 18 months and is now 11 years old. His mother Toni said "I mean the intervention is just critical, because when they're little they learn and absorb and take on so much." Steve added "I think it also gave us more patience."

As well as empowering parents, we see great potential for ASDetect in creating widespread awareness of early social-communication milestones like a child making eye contact, pointing or responding when their name is called. A recent user survey showed that hundreds of families had sought professional support following a 'high-likelihood' result, and a subset (43%) of children had received a subsequent diagnosis. We're heartened by the warm reception ASDetect has had so far – with more than 12,000 installations since its launch in February 2016. But we also know we've got a long way still to go in spreading the word. All the evidence we have demonstrates that our method is very accurate in detecting early signs of autism, so we'd encourage doctors to familiarise themselves with the latest research in early detection and also to heed parents' concerns about their child's development.

As a way of bringing together two key groups of parents and health professionals, we're now planning for a version of ASDetect for doctors and other health professionals (ASDetectPRO) to allow the tracking of multiple children over time in a clinical setting and to facilitate a collaborative approach to detect autism in young children.

ASDetect is free and available to download for both Android and Apple devices.

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The complete academic papers by Dr Josephine Barbaro and Professor Cheryl Dissanayake discussing the first SACS program were published in 2010 and 2013 and are available on PubMed, or you can email us at ask@asdetect.org for a copy. The results of the second SACS program are currently being collected.

Dr Josephine Barbaro is a Research Fellow at the Olga Tennison Autism Research Centre, La Trobe University, and co-founder of Australia's first 'Early Assessment Clinic' for autism. Dr Barbaro's research interests are in the early identification and diagnosis of autism in infants and toddlers, and family health and wellbeing following a diagnosis. Dr Barbaro is President of the Menzies Memorial Scholars Association, and has won numerous awards for her research, including the International Society for Autism Research Clinical Dissertation Award and Nancy Millis Best PhD Award (LTU) in 2012, the Autism CRC Best Research Translation Award in 2015, and the Research and Development Project of the Year (Victorian and National iAwards) and Google Impact Challenge finalist for ASDetect in 2016.