AutismCRC

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FINAL REPORT

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LA TROBE UNIVERSITY

Olga Tennison Autism Research Centre

Australian Government
Department of Industry, Science, Energy and Resources

AusIndustry
Cooperative Research Centres Program

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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.

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

The term autism spectrum disorder (ASD) is used only when discussing a diagnosis as described in the Diagnostic and Statistical Manual of Mental Disorders: DSM 5 (American Psychiatric Association, 2013). Participating children have otherwise been referred to as children on the autism spectrum. However, it is acknowledged that the language with which those on the autism spectrum is described is rapidly evolving.

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# 1. Executive summary

The importance of early recognition and diagnosis of autism is well established as this facilitates access to targeted early learning and functional supports for very young children. Despite increased knowledge on early presentations of autism in infancy and toddlerhood, children in Australia are rarely diagnosed with Autism Spectrum Disorder (ASD) prior to four years of age.

In this project, our aim was to train primary care nurses in Victoria and Tasmania on the early signs of autism at 12-, 18- and 24-months using Social Attention and Communication Surveillance – Revised (SACS-R), so that they can monitor children as part of routine child health assessments at these ages. In so doing, our overall objective was to reduce the age of diagnosis of autism at two study sites, with the implementation of SACS-R in Tasmania being a state-wide implementation.

A total of 276 nurses were successfully trained on the SACS-R with both the training and the implementation being highly evaluated across sites. In monitoring children during their routine assessments at the Victorian sites and in Tasmania, 2% and 3% of children monitored, respectively, were referred for a developmental and diagnostic assessment due to showing key early markers for autism between 12- to 24-months. While the majority of these children met criteria for a diagnosis of (83% and 60%, respectively), all remaining children who did not meet criteria for diagnosis for autism had either a developmental and/or language delay (DD/LD), with no false positive cases identified among the 19,512 children monitored. Importantly, it was found that where the 18-month check-up was not implemented in Tasmania, the referrals were less accurate, arguing for the importance of monitoring children at this key developmental age.

Universal developmental surveillance of young children by trained early childhood professionals has the potential to identify those at high likelihood of autism and other developmental conditions. On the basis of the study findings, we recommend that:

- all primary care professionals working with children between 12- to 24-months, including GPs, MCH/CHaPs nurses, and early childhood education and care workers, are trained on the SACS-R
- universal surveillance for autism using the SACS-R be implemented nationally within all services with clients between 12- to 24-months of age
- 18-month checks in the North and North-West of Tasmania be reintroduced to facilitate more accurate referral of children with early signs of autism.

Importantly, 57% of children on the autism spectrum were identified and diagnosed by 24 months of age at the Victorian site, with 78% identified and diagnosed by 36 months of age. All children referred for a diagnosis were administered a range of standardised assessments. Based on the assessments undertaken in Victoria, it was observed that the cognitive abilities of children later diagnosed with autism diverged progressively further from their chronological age over time compared to children with other developmental conditions; this finding highlights the importance of identifying children as early as possible and providing them with ready access to much needed supports to bolster their learning potential. Thus, we recommend:

- Clear referral pathways be developed for children deemed at high likelihood of autism not only to facilitate early diagnoses but also to access targeted learning supports.

# 2. Introduction

The reliance on behavioural features to diagnose autism (American Psychiatric Association, 2013) means that a firm diagnosis rarely occurs prior to 3-years of age, with the mean age of diagnosis in Australia and elsewhere being over four years (Baio et al., 2018; Bent, Barbaro & Dissanayake, 2015; May & Williams, 2018). It is usually a delay or absence of emerging language which results in children being referred and diagnosed with autism. However, much research indicates that infants and toddlers who are later diagnosed with autism show anomalous social attention and communication behaviours, even before the expected emergence of language (see review by Barbaro & Dissanayake, 2009; Zwaigenbaum et al., 2009). Delays in diagnosis leads to stress in parents as they navigate the complex pathway to a diagnosis for their child (Bent, Barbaro & Dissanayake, 2020; Crane, Chester, Goddard, Henry, & Hill, 2016; Zuckerman, Lindly, & Sinche, 2015). The early identification of children showing early signs of autism is the first step to facilitating early referral and diagnosis. Undertaking a developmental and/or behavioural assessment, administration of a screening tool, regular attendance at well-child health checks, and consulting fewer health professionals have all been associated with earlier diagnoses (Daniels & Mandell, 2014; Goin-Kochel & Myers, 2004).

Our foremost objective in the research outlined here was to promote the early identification of autistic children by community service providers so that they may receive an early diagnosis. With early identification and diagnosis, children can begin participation in intervention programs at younger ages, with evidence that the earlier the intervention is initiated, the better the developmental outcomes (Clark, Dissanayake & Barbaro, 2017; Flannagan et al., 2015; Szatmari et al., 2015; Vivanti & Dissanayake, 2016). Early identification, in enabling access to earlier diagnoses and intervention, thus has the potential to not only contribute to better developmental opportunities and long-term outcomes for individuals and their families, but also to reduced levels of family stress (Crane et al., 2016).

We are in a unique position, within many states in Australia, to provide a means of early identification for autism through existing routine assessments of infants and toddlers undertaken within primary care settings. For example, in Victoria, Maternal and Child Health (MCH) nurses monitor child health and development across 10-visits from birth to 3.5 years of age at MCH Centres. Of particular importance is the fact that some of the early social attention and communication markers useful in identifying autism are routinely monitored at these routine infant check-ups. Moreover, parental concerns about their child's development are also recorded, providing additional information about the early development of children. Our team leveraged this universal service to undertake a prospective study to identify autism in infancy and toddlerhood, prior to the establishment of the Autism CRC.

## 2.1 The Social Attention and Communication Study

The original Social Attention and Communication Study (SACS) comprised a PhD project whereby 241 MCH nurses from 184 MCH centres within 17 local government areas (LGAs) in Melbourne, Victoria, were trained to monitor the early signs of autism. A schedule of behavioural items deemed important to the early identification of autism at 12-, 18-, and 24-months was developed following an extensive literature review, as part of the PhD program of research. This study was our first to attempt to translate contemporary experimental evidence on the markers of autism in infancy (Barbaro & Dissanayake, 2009; Clifford & Dissanayake, 2008; Zwaigenbaum et al., 2007) into routine practice within a primary care setting with a community-based sample, in order to facilitate the early identification of autism, prospectively.

Between 2006 - 2008, the MCH nurses continuously monitored 22,000 children between 12- to 24-months using the three afore mentioned behaviour schedules. Those children who did not show 3 of 5 ‘key’ behaviours at either 12-, 18- or 24-months were flagged as having a ‘high likelihood’ of receiving a future diagnosis of autism and referred to the SACS team for a comprehensive developmental and behavioural assessment. The study was longitudinal, with infants who showed an absence of key behaviours at their routine assessments being followed up at 6-montly intervals until 24-months of age.

One percent of children monitored were referred by MCH nurses as meeting criteria for a high likelihood of autism, with 81% of these children who attended their developmental assessment meeting criteria for a diagnosis of autism by 2-years of age; with one exception, the remaining children (19%) had either a developmental and/or language delay (Barbaro & Dissanayake, 2010). This outcome is, perhaps, unsurprising as the three behavioural schedules (for 12-, 18- and 24-month old infants) and the nurses training on these were evaluated and extremely well received. Moreover, the MCH nurses reported positive outcomes in their work as a result of their training and participation in the SACS (Barbaro, Ridgway, & Dissanayake, 2011).

The results from the SACS indicated that primary health care professionals, such as MCH nurses, were able to correctly identify and refer infants and toddlers on the autism spectrum with a high level of accuracy as a result of their training on the early signs of autism. These findings were in stark contrast with those following use of autism screeners which are typically administered at a single point in time. As the early indicators of autism are variable during the first two years of life (Barbaro & Dissanayake, 2013; Jones, Gliga, Bedford, Charman, & Johnson, 2014; Landa, Holman, & Garrett-Mayer, 2007; Ozonoff & Iosif, 2019), the various screening approaches developed to facilitate earlier identification have had poor psychometric properties for autism, such as the Modified Checklist for Autism for Toddlers (M-CHAT; Klienman et al; Robins et al., 2014; Yuen, Penner, Carter, Szatmari, & Ungar, 2018), particularly when utilised in low-risk community-based samples. For example, the M-CHAT, designed to be utilised between 18- to 24-months, misses over 70 percent of toddlers on the autism spectrum, and incorrectly identifies over 80 percent of toddlers who have intellectual disability but are not on the spectrum (Stenberg et al., 2020). Routine surveillance increases the chances of identifying children on the autism spectrum whose social attention and communication difficulties may not be evident at a given time (Landa et al., 2007; Ozonoff, Williams, & Landa, 2005). By utilising a developmental surveillance approach (rather than a once-off screening), which entails repeated monitoring of children at regular intervals, in combination with direct behavioural observation by healthcare professionals, we demonstrated that it was possible to successfully monitor young children on the autism spectrum within a universal community health service.

The three behaviour checklists of the SACS were subsequently revised (SACS-Revised or SACS-R) following determination of which items at each age (12-, 18- and 24-months) were most predictive of an autism diagnosis at 24-months (Barbaro & Dissanayake, 2013). Moreover, upon following up the SACS sample, high diagnostic stability was established at both 4-years (Barbaro & Dissanayake, 2017) and at 7 – 9-years (Clark, Dissanayake & Barbaro, 2017) of age. Clark et al. (2017) also found that children made remarkable cognitive gains over time; while 64% of children had an IQ < 70 at 24-months, this had reduced to 46% by 4-years, and only 8% of children diagnosed early had IQ's < 70 by school age.

In another study comparing the SACS cohort diagnosed at 24-months to a comparison group diagnosed between 3- to 5-years, Clark, Vinen, Barbaro, and Dissanayake (2018) found that the gains made by children diagnosed by 24 months were significantly greater at school age than those made by the comparison group (i.e., 24% had IQ's <70 cf. 8% in the SACS group). Moreover, while 77% of children diagnosed early attended a mainstream school, only 57% of the comparison group did so; the early diagnosed group also required less ongoing support than children diagnosed later. These improved outcomes are likely to be due to earlier access to intervention, with children in the early diagnosed group having received significantly more intervention (11 months on average) than those diagnosed after 3-years. Age of access to early intervention (which was 12 months earlier on average in the early diagnosed group), rather than the amount of intervention, was strongly correlated with children's cognitive outcomes at school age, highlighting the importance of early identification and diagnosis.

## 2.2 The Social Attention and Communication Study – Revised

The study described in this report was designed as a replication of the original SACS (Barbaro & Dissanayake, 2010) using the revised items (SACS-R; Barbaro & Dissanayake, 2013), and was funded as a Strategic Project to be undertaken in Victoria and (subsequently extended to) Tasmania. It was based on the best available evidence and aimed to integrate this evidence base within standard practice within the Victorian MCH service and the Child Health and Parenting Service (CHaPS) in Tasmania.

Implementation of the SACS-R in Victoria mirrored the first study whereby children identified as having a high likelihood of autism were referred to a specialist university-based team for their developmental and behavioural assessments. However, unlike in the original study (Barbaro & Dissanayake, 2010), all children monitored by the Victorian MCH nurses until 24-months on the SACS-R were checked again for signs of autism at 42 months of age, to identify any children on the spectrum at their 42-month MCH check). Those children monitored in Tasmania were only monitored until 24-months and, unlike in Victoria, were referred to a community-based assessment clinic (St Giles Paediatric Services) for their developmental and behavioural assessments.

The study reported here models how we can utilise existing frameworks to identify early differences in development - in this case, autism. Thus, the key objective in the current study accords with one of the overarching goals of the MCH and CHaPS services, which is to promote the early detection of physical, social and emotional factors affecting young children and their families. The project has the capacity to model a new approach for early identification of autism that may be implemented across the nation.

## 2.3 Research aim

The overall aim in the SACS-R study was to prospectively identify infants who will go on to receive a diagnosis of autism within routine assessments undertaken at early childhood services in Victoria and Tasmania, following training of frontline professionals. Based on the original SACS, we predicted that implementation of SACS-R within universal developmental surveillance services in Victoria and Tasmania would yield high positive predictive values (with at least 81% in Victoria). We also expected that most or all 'false-positive' cases for autism would have either a DD/LD, condition, or disorder (e.g., genetic), thereby also benefitting from earlier identification. We also predicted that implementation of the SACS-R will result in the correct diagnosis of at least 50% of autistic children before 2-years of age and at least 70% by 3-years.

# 3 Research design and methods

The study was undertaken between 2013 - 2019. Ethics approval was sought and received from the La Trobe University and University of Tasmania Human Ethics Committees for the Victorian and Tasmanian implementations, respectively.

Implementation of the SACS-R required the training of nurses on the early signs of autism, and how to monitor children's social attention and communication skills between the ages of ~12 months to 3.5 years during their routine consultations at 12-, 18-, 24-, and 42-months in Victoria, and at 12, 18-months (where applicable) and 24-months in Tasmania. Workshops were first delivered for the 12- to 24-month checks (~half day), and then for the 42-month checks (~ 2 hours; Victoria only).

The SACS-R was designed to be implemented in the MCH and CHaPS centres as part of, rather than in addition to, children's standard 'Key Ages and Stages' visits. Our aim was to minimise burden without compromising the nurses' ability to identify children at high likelihood of autism. The methodology was developed and refined in partnership with key stakeholders (Municipal Association of Victoria and MCH nurses, MCH coordinators, policy advisors, the Child Health and Parenting Service of the Tasmanian Health Service, Tasmanian Government), and through continual improvement based on feedback.

## 3.1 Participants

### 3.1.1 Victoria

The Victorian cohort comprised 13,511 children monitored by their MCH nurse at their routine health checks at 12-, 18-, and 24-months of age across eight LGAs (Banyule, Bayside, Boroondara, Hume, Kingston, Knox, Moonee Valley, Nillumbik) in Melbourne, Victoria. The mean Socio-Economic Index for Areas (SEIFA; which is an index of 'relative socio-economic advantage and disadvantage'), for of the eight LGAs involved in the study was 1058.5, slightly higher than the mean for Metropolitan Melbourne (1027).

### 3.1.2 Tasmania

The Tasmanian cohort comprised 6,001 children monitored by their CHaPS nurse at their routine health checks at 12- and 24-months of age in the North and North-West regions, and at 12, 18-, and 24-months in the South (where the 18-month check was implemented specifically for this project). Given the whole of state implementation, the SEIFA score for the State of Tasmania is 958.5.

## 3.2 Training

Prior to implementation in Victoria and Tasmania, 126 MCH and 150 CHaPS nurses, respectively, received a face-to-face training workshop, conducted by Dr Josephine Barbaro. Each workshop comprised of between 10 to 60 nurses. This training was incorporated into the ongoing professional development programs which focus on improved identification of developmental challenges, and which are routinely attended by the nurses. The training capitalises on nurses pre-existing knowledge of early developmental milestones and enhances it through highlighting the key social-communication milestones which predict a diagnosis of autism in infants and toddlers. All content was delivered in 'lay' terms (with minimal jargon) to enhance accessibility

Nurses were trained on typical and atypical social-communicative development prior to focusing on the early and later signs of autism, as well as the particular items of interest within the child’s health record which are indicative of signs of autism across the first three years of life. The importance of the early detection of autism was emphasised, including evidence on the impact of timely intervention on children’s developmental outcomes, the effects on family stress, and the empowerment of families to make informed choices following early detection of their children.

The workshop incorporated videos to build capacity in identification of early signs of autism using the SACS-R items during routine consultations (see Appendix A for SACS-R items). The SACS-R is designed to aid nurses in their decision making by systematically guiding them to monitor key behaviours within their routine consultations. The nurses were also trained to use Salesforce which is the customer relationship management (CRM) platform used to enter the assessment data and help track monitored children throughout the study. The nurses also received clear instruction on how, and when, to raise developmental concerns with families, and referral pathways were provided dependent on location. We evaluated the SACS-R training undertaken in Victoria and Tasmania.

## 3.3 Measures

### 3.3.1 Training evaluation

The nurses who were trained on SACS-R were evaluated on the training. The Victorian nurses were also followed up and questioned on the perceived usefulness of the SACS-R for identifying and referring children with a high likelihood of autism one year following implementation (See Appendix B and C for these Evaluation Forms). Nurses rated their responses on a 5-point likert scale of ‘Strongly Agree’ to ‘Strongly Disagree.’

### 3.3.2 SACS-R implementation and child assessments

**Social Attention and Communication Surveillance-Revised** (SACS-R; Barbaro & Dissanayake, 2013; Mozolic-Staunton, Donelly, Yoxall, & Barbaro, 2020) is an observationally-based, early developmental surveillance tool with 12 to 15 early social-communication markers monitored at 12-, 18-, and 24-months of age (see Appendix A). Children were identified at ‘high likelihood’ for autism, and subsequently referred for assessment if they did not show three out of five ‘key’ social-communication markers indicative of autism (i.e., *imitation* and *response to name* at 12 months only; *eye contact, pointing*, and *use of gestures* at 12-, 18-, and 24-months; *showing* and *pretend play* at 18 and 24 months). As noted earlier, the original SACS tool had an excellent Positive Predictive Value (PPV; 81%) for identifying autism between 12- and 24-months of age, and excellent *estimated* sensitivity (84%) and specificity (99%; Barbaro & Dissanayake, 2010).

**Autism Diagnostic Observation Schedule – Second edition, Toddler module** (ADOS-2 Toddler; Luyster et al., 2009). The ADOS-2 Toddler is a semi-structured, play-based assessment developed to elicit behaviours relevant to an autism diagnosis in toddlers up to 30 months. It has excellent test-retest and inter-rater agreement (intra-class correlations ≥ .90), and excellent sensitivity and specificity cut-off scores for autism versus other developmental conditions (≥. 81; Luyster et al., 2009).

**Autism Diagnostic Interview-Revised** (ADI-R; Le Couteur, Lord, & Rutter, 2003). Administered at 24-months and older, the ADI-R is a 93-item, semi-structured diagnostic parental interview for autism, assessing communication, reciprocal social interaction, play, and restricted, repetitive, and sensory behaviours. It has excellent test-retest and inter-rater agreement (intra-class correlations ≥ .92), and excellent discriminant validity between autistic and non-autistic individuals for each of the domains (Lord, Rutter, & Le Couteur, 1994). The ADI-R Toddler Algorithm Total Scores are reported in this study (Kim & Lord, 2012).

**Mullen Scales of Early Learning (**MSEL; Mullen, 1995) This measure was administered to determine the presence of developmental and/or language delays at each age. The MSEL is a norm-referenced, standardised developmental assessment that measures verbal (expressive and receptive language) and non-verbal (fine motor and visual reception skills) abilities. It has excellent test-retest and inter-scorer reliability for children ≤ 24 months of age ($r \geq .82$). Both age-equivalence scores and developmental quotients (DQs) are reported here.

## 3.4 Procedures

### 3.4.1 Referral

Children were identified and referred by the MCH/CHaPS nurses during their routine 12- to 24-month consultations, with a follow-up at children's 42-month MCH check (Victoria only) to identify any children on the autism spectrum who were 'missed'. Children were determined as having a 'high likelihood' for autism based on not showing three of the five 'key' items when monitored. Victorian infants/toddlers were referred to the Olga Tennison Autism Research Centre (OTARC) at La Trobe University for a developmental and behavioural assessment (see standardised measures in previous section), and assessed at 6-monthly intervals by the research team in Victoria between 12- to 24-months, and thereafter at 42-months. Tasmanian infants/toddlers were referred to St Giles Paediatric Services for their assessments using the same standardised measures.

### 3.4.2 Gold-standard diagnostic assessments

Children were assessed at 12-, 18- and/or 24-months using the ADOS-2 Toddler and ADI-R at 24-months by trained clinical assessors. Final diagnostic status was determined by 24 months of age using these tools, combined with clinical judgment utilising all the information gained from formal testing (including the MSEL scales also administered at each age to ascertain developmental level), observations, developmental history, and any previous assessments by other health professionals, where applicable. Furthermore, 67% (143 of 240 children in Victoria) attended the 42-month assessment to confirm their diagnosis, using the ADOS-2 Module One or Two (Lord, Luyster, Gotham, Guthrie, 2012) and ADI-R. Only seven children changed diagnostic categories, representing 5% of the sample – five from ASD to non-ASD, and two from non-ASD to ASD. For these children, their final diagnostic status was changed and assigned to the relevant group in the current study. Where necessary, video footage of the assessment was reviewed to help with diagnostic decisions.

# 4 Findings

## 4.1 Training evaluation

The evaluation of the training by the Victoria and Tasmanian child health nurses were very similar, thus the training evaluation is presented for the Tasmanian site only. As only the Victorian nurses were evaluated following one year of implementation, these data are also provided below.

Summary data from the training evaluation by the CHaPS nurses are presented in Figure 1. As apparent from these data, the training was very well received, with 94-100% of nurses strongly endorsing each statement about the training and their implementation of the SACS-R.

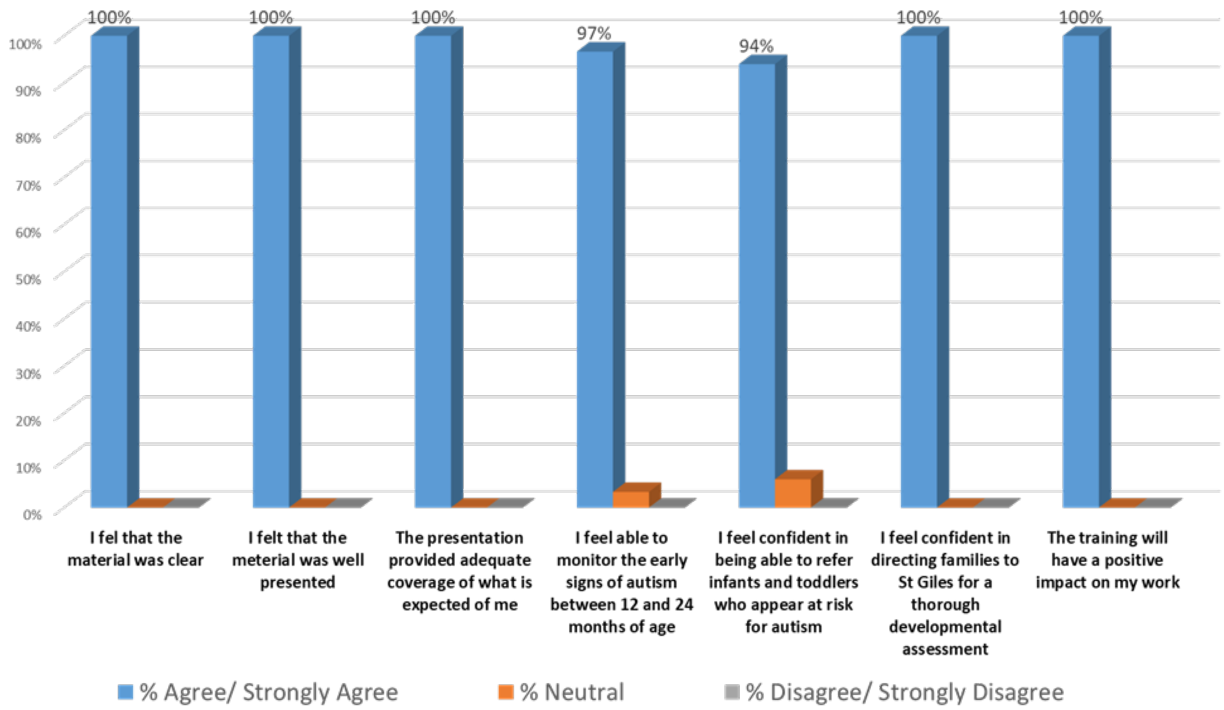


**Figure 1: Evaluation of SACS training CHaPS Nurses**

### 4.1.2 One-year post-implementation (Victoria only)

Summary data from the MCH nurses evaluation of the SACS-R training are presented in Table 1 below. The large majority of nurses reported confidence in monitoring and referring children based on the early signs of autism between 12- to 24-months of age, and also reported a positive impact of SACS-R on their work. While 60% of nurses strongly agreed that they felt confident in referring children showing early signs to a paediatrician for a developmental assessment, only 33% were strongly confident that paediatricians would be aware of early signs of autism in infancy and toddlerhood, highlighting the need for training these and other professionals.

Sixty one percent of nurses strongly agreed that additional time was added to their work only in instances where a child was showing anomalies in their development, and 87% strongly agreed that parents were comfortable with their children being monitored on the SACS-R. The evaluation data highlights the feasibility and acceptability of the SACS-R implementation within the Victorian MCH service.

**Table 1: Evaluation of SACS-R by Victorian Maternal and Child Health Nurses following one-year of implementation**

| Item | % Agree/Strongly Agree | % Neutral | % Disagree/Strongly Disagree |
|---|---|---|---|
| **The SACS has been easy to implement in my current practices** | 80 | 12 | 8 |
| **The SACS has had a positive impact on my current practice for autism monitoring** | 87 | 11 | 2 |
| **The SACS has had a positive impact on my current practice for monitoring of developmental and language delays** | 88 | 9 | 3 |
| **The SACS has added additional time to my consultations only in instances where a child is showing problems in development** | 61 | 22 | 17 |
| **The SACS has added additional time to ALL of my consultations** | 48 | 24 | 28 |
| **I have received timely advice following my queries to the SACS personnel (if applicable)** | 70 | 24 | 6 |
| **I feel confident in monitoring for signs of autism at 12 months of age** | 92 | 6 | 2 |
| **I feel confident in monitoring for signs of autism at 18 months of age** | 94 | 4 | 2 |
| **I feel confident in monitoring for signs of autism at 24 months of age** | 97 | 2 | 1 |

| Item | % Agree/Strongly Agree | % Neutral | % Disagree/Strongly Disagree |
|---|---|---|---|
| **I feel confident in referring children to the SACS team for further developmental assessment (if applicable)** | 82 | 12 | 6 |
| **I feel confident that paediatricians know what ASD looks like in infancy/toddlerhood** | 33 | 46 | 21 |
| **I feel confident in referring to paediatricians for further developmental assessment for autism** | 60 | 29 | 11 |
| **I feel confident in referring to other specialists (e.g. psychologists) for a developmental assessment for autism** | 67 | 23 | 10 |
| **Parents have been comfortable with the SACS being undertaken in their centre** | 87 | 10 | 3 |
| **Parents felt being a part of the SACS was a positive experience (for parents who have been referred to the SACS team)** | 66 | 30 | 4 |

## 4.2 SACS-R implementation

### 4.2.1 Victoria

A consort diagram of children monitored, referred and assessed in Victoria is presented in Figure 2 below. A total of 327 children of the total sample monitored were identified at 'high likelihood' for autism and referred for a developmental assessment, yielding a referral rate of 2.4% by 24-months of age. A total of 240 children (54 females) who were referred attended a follow-up assessment at the OTARC (73.4%). A total of 23 children were first seen at 12-months (2 females) for a developmental and behavioural assessment, 68 were first seen at 18-months (17 females), and 128 at 24-months (27 females). A further 21 children who were identified as at 'high-likelihood' for autism between 12 – 24 months only attended their appointment at 42 months. Thirty-four (34) families who declined attendance have known outcomes through follow-ups with parents and the MCH nurses. The remaining children (53) had their outcome determined statistically for calculation of psychometrics based on an imputation model for missing data.

The average age of parents of children assessed at OTARC was 34-years of age for mothers and 38-years of age for fathers, with 63% of mothers and 68% of the fathers having a university qualification. Most children were from an Australian background (62%), and the sole language spoken at home was English for 69% of households.

As observed in Figure 2 below, based on the developmental and behavioural assessments, 199 children (83%) were diagnosed with autism by 24-months, with the remaining 41 children having either a developmental or language delay (DD/LD).

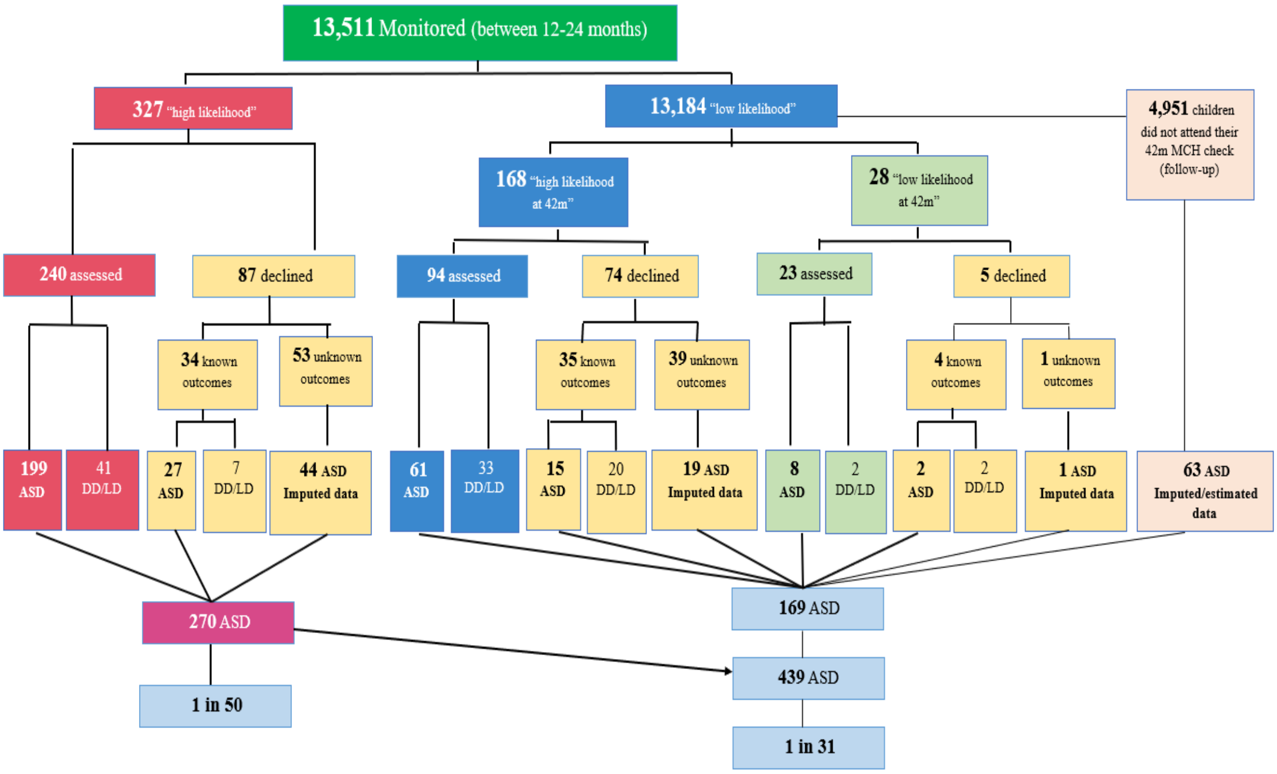


**Figure 2: Consort figure of children monitored, referred and assessed in Victoria**

Table 2 presents the Positive Predictive Value (PPV) for autism calculated at each age, ranging from 74% at 12-months to 86% at 24 months. The SACS-R had overall PPV for autism of 83%. No non-autistic children were identified at 'high likelihood' on the SACS-R.

In addition, all children with a 'low likelihood' for autism (between 12- to 24-months) continued to be monitored until 42-months by their MCH nurse. A further 168 children were referred based on having a 'high likelihood' of autism using a preschool version of the SACS (SACS-PR). Ninety-four of these children (56%) attended their assessment session, with 61 children (65%) diagnosed with autism at 42-months, and the remainder with a developmental or language delay (DD/LD). A further twenty-eight children, who had a 'low likelihood of autism at 42 months, were also referred due to parental/MCH nurse concerns; of these 8 (35%) were diagnosed with autism. There were 4951 children who did not attend their 42-month MCH consultation; it is estimated that 63 children from this sample would be on the autism spectrum (please see Barbaro et al., 2022 for further details).

The prevalence of autism in the monitored cohort in Victoria was 2.00% by 24-months of age; this rose to 3.25% when children diagnosed following their 42-month check were included.

**Table 2: Gender ratios and positive predictive values at each age of children assessed**

| | 12 months | 18 months | 24 months | 12-24 months | 42 months | 12-42 months |
|---|---|---|---|---|---|---|
| **Age identified at 'high likelihood'** | 35 | 84 | 121 | 240 | 94 | 334 |
| **Gender ratio (M : F)** | 4.83 : 1 | 3 : 1 | 3.43 : 1 | 3.44 : 1 | 4.22 : 1 | 3.63:1 |
| **Diagnosis** | | | | | | |
| **Autism** | 26 | 69 | 104 | 199 | 61 | 260 |
| **Developmental / language delay** | 9 | 15 | 17 | 41 | 33 | 74 |
| **Positive Predictive Value** | **74%** | **82%** | **86%** | **83%** | **65%** | **78%** |

### 4.2.2 Tasmania

Across Tasmania, a total of 190 children were identified at 'high likelihood' for autism, yielding a referral rate of 3.2% by 24-months of age. A total of 143 children who were referred (75%) attended the assessment at St Giles, with the remaining 47 families declining the referral for assessment. A total of 39 children were first seen at 12-months (11 female) for a developmental and behavioural assessment, 31 were first seen at 18-months (7 female), and 73 at 24-months (17 female).

The average age of parents of children assessed at St Giles was 31.7 years of age for mothers and 34.4 years of age for fathers, with 23.7% of mothers and 18.3% of the fathers having a university qualification. The majority of the sample had an Australian background (82.7%), and the sole language spoken at home was English for 92.1% of households.

As observed in Figure 3 below, 86 children were diagnosed with autism at St Giles, with the remaining 57 children having either a language or developmental delay. The SACS-R as utilised in Tasmania had a PPV for autism of 60%, ranging from 55% at 18-months to 64% at 24 months; once again, no non-autistic children were referred by nurses (see Table 3). The estimated prevalence in the cohort monitored in Tasmania was 2% at 24-months.

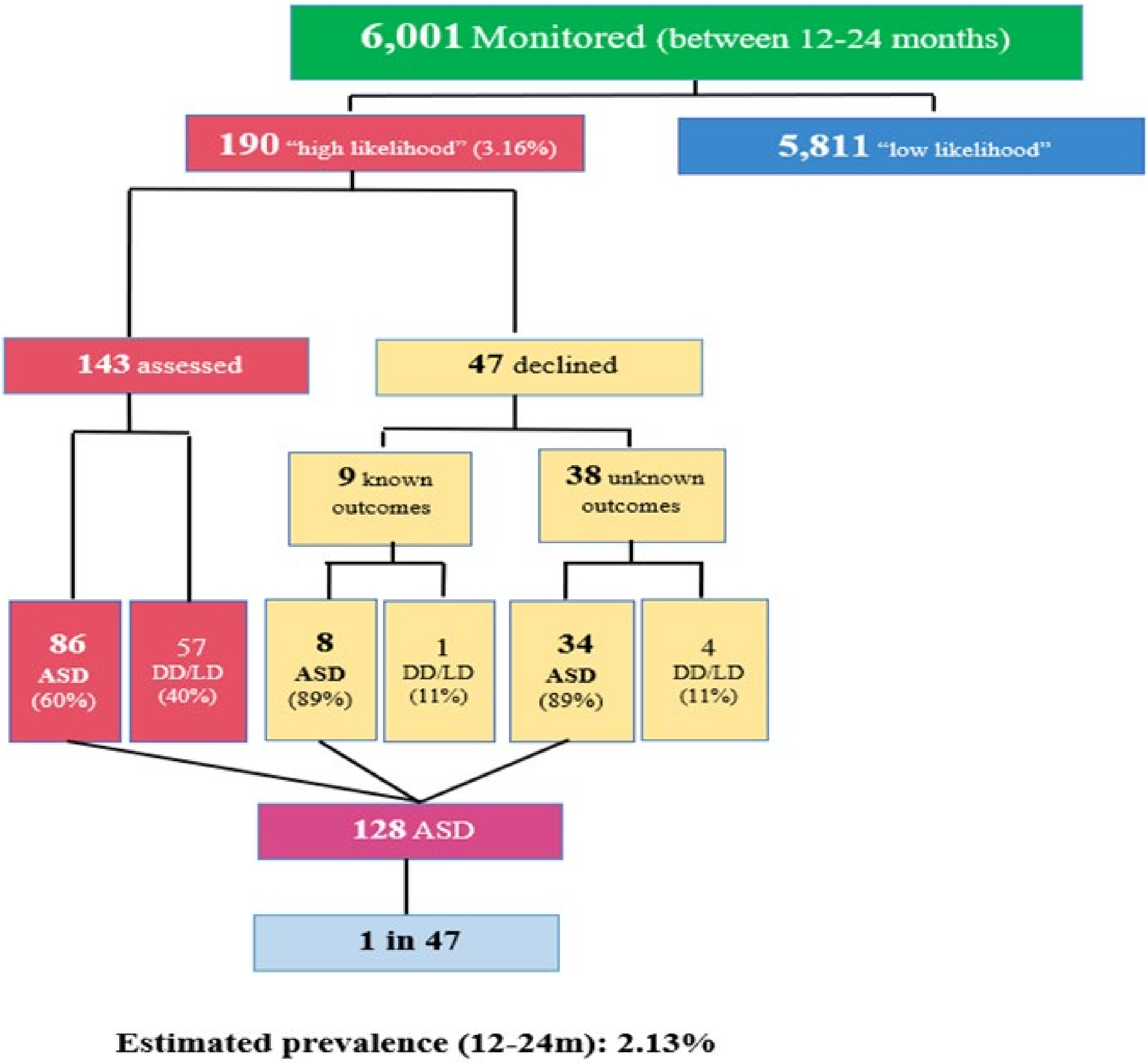


**Figure 3: Consort figure of children monitored, referred and assessed in Tasmania**

**Table 3: Gender ratios and positive predictive values at each age of children assessed**

| | 12 months | 18 months | 24 months | 12-24 months |
|---|---|---|---|---|
| **Age identified at 'high likelihood'** | **39** | 31 | 73 | 143 |
| **Gender ratio (M-F)** | 2.54 : 1 | 3.42 : 1 | 3.29 : 1 | 3.08 : 1 |
| **Diagnosis** | | | | |
| **Autism** | 22 | 17 | 47 | 86 |
| **Developmental / language delay** | 17 | 14 | 26 | 57 |
| **Positive Predictive Value** | 56% | 55% | 64% | 60% |

AutismCRC

As the health checks in the North and North-West regions were undertaken at only 12- and 24-months of age and at 12-, 18-, and 24-months in the South, the data for referral and diagnosis were examined separately for each area, and presented in Table 4. It is apparent that the referral rate was particularly high in the North-West region where 6% of monitored children were identified as having a 'high likelihood' of autism in comparison to the North and South regions that had referral rates resembling those at the Victorian site. Interestingly, the PPV for autism was highest in the South at 71% which included the 18-month check-up, with the North and North-West having more similar PPVs for autism.

**Table 4. Breakdown of child referrals and diagnoses by region**

| Regions first seen | Children entered | Total number of children 'at high likelihood' | Diagnosis of children at St Giles | | Diagnosis from the community | | Total known Diagnosis | | Unknown children |
|---|---|---|---|---|---|---|---|---|---|
| | | | ASD | DD/LD | ASD | DD/LD | ASD | DD/LD | |
| **North** | | | 34 children | | 3 children | | 37 children | | 5 |
| | 1,648 | 42 (2.54%) | 19 (56%) | 15 (44%) | 2 (67%) | 1 (33%) | 22 (58%) | 16 (42%) | |
| **North-West** | | | 54 children | | 3 children | | 57 children | | 19 |
| | 1,247 | 76 (6%) | 28 (52%) | 26 (48%) | 3 (100%) | 0 (0%) | 31 (54%) | 26 (46%) | |
| **South** | | | 55 children | | 3 children | | 58 children | | 14 |
| | 3,106 | 72 (2.31%) | 39 (71%) | 16 (29%) | 3 (100%) | 0 (0%) | 42 (72%) | 16 (28%) | |
| **Total** | | | 143 children | | 9 children | | 152 children | | 38 |
| | 6001 | 190 (3.16%) | 86 (60%) | 57 (40%) | 8 (89%) | 1 (11%) | 94 (62%) | 58 (38%) | |

## 4.3 Developmental assessments

Summary data from the behavioural and developmental assessments undertaken of children at each age in Victoria, following referral to OTARC by the community nurses for being at 'high-likelihood' of autism, are presented below.

### 4.3.1 Victoria

Tables 5 - 8 presents data on the assessments undertaken at the 12-, 18-, and 24- month checks, respectively. Those children seen between 12- to 24-months were also followed up at 42-months with these data presented in Table 9. The MSEL and the ADOS were administered at each age, with the ADI-R only administered at the 24- and 42-month assessments.

As the children diagnosed with autism were significantly younger than those with developmental or language delays when tested at 12- and 18-months, chronological age was covaried in the analyses of group differences at these ages. From data in Table 5, it is apparent that children later diagnosed with autism were already showing significantly more delay in verbal ability at 12-months, particularly in expressive language, compared to those who later received a diagnosis of DD/LD; they also had elevated scores on the ADOS-T by 12-months, meeting criteria for 'high likelihood' of autism.

**Table 5: Mean (SD) age, MSEL, and ADOS scores for children assessed following referral at the 12-month check**

| Variable | ASD (n=16) | DD/LD (n=7) | Group Differences |
|---|---|---|---|
| **Chronological age** | 14.0 (0.9) | 14.8 (0.4) | ASD < DD/LD* |
| **Non-verbal mental age** | 14.0 (2.2) | 15.1 (1.8) | NS |
| **Verbal mental age** | 10.3 (1.7) | 11.8 (0.9) | ASD < DD/LD* |
| **Overall mental age** | 12.2 (1.5) | 13.5 (1.1) | NS |
| **Visual reception DQ** | 96.1 (23.7) | 103.4 (20.9) | NS |
| **Fine motor DQ** | 110.6 (15.6) | 113.6 (7.3) | NS |
| **Receptive language DQ** | 74.3 (21.0) | 78.3 (9.0) | NS |
| **Expressive language DQ** | 79.3 (14.5) | 90.2 (8.5) | ASD < DD/LD* |
| **ADOS-2 T Calibrated Severity Score** | 5.8 (1.9) | 2.9 (0.9) | ASD > DD/LD ** |

NB: All ages are in months. ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; DQ = Developmental Quotient; ADOS-T = Autism Diagnostic Observation Schedule-Toddler Module. * $p < .05$; ** $p < .01$

By 18 months, the groups were different in verbal and overall mental age. Although both expressive and receptive language were lower, it was only the difference in receptive language that was statistically reliable. Once again, there were no significant differences in non-verbal abilities. Once again, autism signs were significantly elevated in the 18-month group later diagnosed with autism (see Table 6).

**Table 6: Mean (SD) age, MSEL, and ADOS scores for children assessed following referral at the 18-month check**

| Variable | ASD (n=63) | DD/LD (n=15) | Group Differences |
|---|---|---|---|
| **Chronological age** | 19.7 (1.3) | 20.7 (0.8) | ASD < DD/LD** |
| **Non-verbal mental age** | 16.4 (3.1) | 17.6 (3.4) | NS |
| **Verbal mental age** | 12.2 (4.3) | 16.3 (4.2) | ASD < DD/LD* |
| **Overall mental age** | 14.3 (3.1) | 16.9 (3.3) | ASD < DD/LD* |
| **Visual reception DQ** | 83.0 (20.0) | 86.5 (20.9) | NS |
| **Fine motor DQ** | 88.6 (16.9) | 87.8 (13.4) | NS |
| **Receptive language DQ** | 62.0 (25.6) | 85.5 (29.3) | ASD < DD/LD* |
| **Expressive language DQ** | 64.6 (21.6) | 74.7 (20.0) | NS |
| **ADOS-2 T Calibrated Severity Score** | 7.0 (2.2) | 3.2 (2.0) | ASD > DD/LD*** |

NB: All ages are in months. ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; DQ = Developmental Quotient; ADOS-T = Autism Diagnostic Observation Schedule-Toddler Module. * p < .05; ** p < .01; *** p < .001

By 24-months the children diagnosed with autism were showing significant delays relative to the DD/LD group on three of the four subscales of the MSEL including both expressive and receptive language (see Table 7). Both the ADOS-2 and the ADI-R were administered, showing significantly elevated scores for those children meeting criteria for a diagnosis of autism.

**Table 7: Mean (SD) age, MSEL, ADOS and ADI-R scores for children following referral at the 24-month check**

| Variable | ASD (n=154[a]) | DD/LD (n=34) | Group Differences |
|---|---|---|---|
| **Chronological age** | 27.3 (2.9) | 27.0 (2.4) | NS |
| **Non-verbal mental age** | 21.8 (5.1) | 23.3 (4.1) | NS |
| **Verbal mental age** | 17.5 (7.4) | 21.7 (6.4) | ASD < DD/LD** |
| **Overall mental age** | 19.6 (5.9) | 22.5 (4.9) | ASD < DD/LD** |
| **Visual reception DQ** | 78.9 (21.7) | 88.0 (16.6) | ASD < DD/LD** |
| **Fine motor DQ** | 84.0 (17.4) | 87.7 (14.2) | NS |
| **Receptive language DQ** | 63.1 (28.9) | 86.0 (24.9) | ASD < DD/LD*** |
| **Expressive language DQ** | 67.2 (26.7) | 76.9 (22.6) | ASD<DD/LD* |
| **ADOS-2 Calibrated Severity Score** (Toddler, M1, M2) | 7.1 (2.3) | 2.9 (1.2) | ASD > DD/LD*** |
| **ADI-R Toddler Overall Total Score** | 14.6 (6.0)[b] | 6.0 (4.3) | ASD > DD/LD*** |

NB: All ages are in months. ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; DQ = Developmental Quotient; ADOS-T = Autism Diagnostic Observation Schedule-Toddler Module; ADI-R Toddler Overall Total Score = Autism Diagnostic Interview-Revised Toddler Algorithm Overall Total. * p < .05; ** p < .01; *** p < .001

[a] one child withdrawn; data excluded; [b] missing data for four children in ASD group

By 42-months (Table 8), autistic children had significantly lower non-verbal mental age (not significantly different at earlier ages) as well as verbal mental age compared to their peers with DD/LD. Elevated autism characteristics meant that they met criteria for an autism diagnosis. All children have been seen previously at an earlier age.

**Table 8: Mean (SD) age, MSEL, ADOS and ADI-R scores for children assessed at 42-months of age (and previously seen between 12- to 24-months)**

| Variable | ASD (n=128[a]) | DD/LD (n=30) | Group Differences |
|---|---|---|---|
| **Chronological age** | 44.7 (4.2) | 44.2 (2.9) | NS |
| **Non-verbal mental age** | 35.5 (11.7) [b] | 39.9 (7.8) | ASD < DD/LD* |
| **Verbal mental age** | 33.7 (15.0) | 40.5 (9.0) | ASD < DD/LD* |
| **Overall mental age** | 34.6 (13.0) [b] | 40.2 (7.9) | ASD < DD/LD* |
| **Visual reception DQ** | 81.1 (29.5) [b] | 95.5 (20.9) | ASD < DD/LD* |
| **Fine motor DQ** | 79.7 (24.8) [c] | 87.8 (18.7) | NS |
| **Receptive language DQ** | 77.2 (35.0) | 96.0 (21.0) | ASD < DD/LD* |
| **Expressive language DQ** | 75.4 (33.9) | 89.7 (21.8) | ASD < DD/LD* |
| **ADOS-2 Calibrated Severity Score** | 6.7 (1.7) | 2.7 (1.5) | ASD > DD/LD*** |
| **ADI-R Social Interaction (A)** | 10.4 (5.6) [d] | 5.9 (4.4)[d] | ASD > DD/LD** |
| **ADI-R Communication Nonverbal (B)** | 7.6 (3.9) | 10 (-) | NS |
| **ADI-R Communication verbal (B)** | 9.5 (4.2) | 4.5 (3.8) | ASD > DD/LD*** |
| **ADI-R RRB (C)** | 5.0 (4.2) | 3.7 (2.8) | NS |
| **ADI-R Abnormality (D)** | 3.0 (0.9) | 2.3 (0.6) | ASD > DD/LD** |

NB: All ages are in months. ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; DQ = Developmental Quotient; ADOS-2 = Autism Diagnostic Observation Schedule-2nd Edition; ADI-R = Autism Diagnostic Interview-Revised Diagnostic Algorithm score; A = Qualitative abnormalities in reciprocal social interaction; B total= Qualitative abnormalities in communication, Nonverbal or Verbal; C Total=Restricted, Repetitive and Stereotyped patterns of behaviour; D Total=Abnormality of development evident at or before 36 months
* $p < .05$; ** $p < .01$; *** $p < .001$

[a]2 children too young at time of assessment; data excluded; [b] missing data for 3 children in ASD group; [c] missing data for 2 children is ASD group; [d] ADI-R n=60 (ASD n=45, DD/LD=15), children only received an ADI-R at their 42-month follow up if we were unsure of their diagnostic category; [e] ADI-R Communication Nonverbal n=13 (ASD n=12, DD/LD=1), and ADI-R Communication Verbal n=47 (ASD n=33, DD/LD=14)

Table 9 presents assessment data from those children aged 42-months who had not been seen at an earlier age. As the autistic children were, again, significantly younger, chronological age was covaried in the comparative analyses. Children diagnosed with autism had significantly lower cognitive scores and higher autism scores compared to those who did not meet diagnostic criteria for autism.

**Table 9: Mean (SD) age, MSEL, ADOS and ADI-R scores for children referred for the first time at 42-months of age**

| Variable | ASD (n=68[a]) | DD/LD (n=48) | Group Differences |
|---|---|---|---|
| **Chronological age** | 45.8 (5.8) | 48.0 (4.5) | ASD < DD/LD* |
| **Non-verbal mental age** | 40.1 (10.8) | 49.4 (8.6)[b] | ASD < DD/LD*** |
| **Verbal mental age** | 41.1 (12.0) | 48.6 (9.5) | ASD < DD/LD** |
| **Overall mental age** | 40.6 (10.8) | 49.1 (8.1)[b] | ASD < DD/LD*** |
| **Visual reception DQ** | 89.8 (24.1) | 106.8 (20.8)[b] | ASD < DD/LD*** |
| **Fine motor DQ** | 86.2 (20.5) | 100.9 (16.7) | ASD < DD/LD*** |
| **Receptive language DQ** | 86.7 (24.1) | 100.8 (18.0) | ASD < DD/LD** |
| **Expressive language DQ** | 93.8 (26.0) | 104.3 (23.2) | ASD < DD/LD* |
| **ADOS-2 T Calibrated Severity Score** | 6.78 (1.7)[c] | 3.6 (2.1) | ASD > DD/LD*** |
| **ADI-R Social Interaction (A)** | 10.6 (5.1)[d] | 5.5 (3.0)[d] | ASD > DD/LD*** |
| **ADI-R Communication Nonverbal (B)** | 9.5 (2.5)[e] | 2.5 (2.1)[e] | ASD > DD/LD* |
| **ADI-R Communication verbal (B)** | 9.9 (4.9)[e] | 5.7 (3.8)[e] | ASD > DD/LD*** |
| **ADI-R RRB (C)** | 5.3 (2.6)[d] | 2.5 (1.2)[d] | ASD > DD/LD*** |
| **ADI-R Abnormality (D)** | 2.6 (1.2)[d] | 1.8 (1.1)[d] | ASD > DD/LD** |

NB: All ages are in months. ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; DQ = Developmental Quotient; ADOS-2 = Autism Diagnostic Observation Schedule-2nd Edition; ADI-R = Autism Diagnostic Interview-Revised Diagnostic Algorithm score; A = Qualitative abnormalities in reciprocal social interaction; B total= Qualitative abnormalities in communication, Nonverbal or Verbal; C Total=Restricted, Repetitive and Stereotyped patterns of behaviour; D Total=Abnormality of development evident at or before 36 months
* $p$ < .05; ** $p$ < .01; *** $p$ < .001

[a]one child withdrawn; data excluded; [b] missing data for one child in DD/LD group; [c] missing data for one child in ASD group; [d] missing data for one child in ASD group; ADI-R n=60 (ASD n=45, DD/LD=15), children only received an ADI-R at their 42-month follow up if we were unsure of their diagnostic category; [e] ADI-R Communication Nonverbal n=8 (ASD n=6, DD/LD n=2), and Verbal n=107 (ASD n=61, DD/LD=46)

When observing the mean scores for cognition (both mental ages and DQ's) of both groups in Table 9 relative to those in Table 8, it is apparent that the means in Table 9 are consistently higher across both groups in comparison to those in Table 8, indicating that the children who were first seen at 42 months, regardless of their diagnoses, were more cognitively able than those who were followed up at 42 months having also been seen at earlier ages (between 12- and 24-months). Their ADOS and ADI-R scores, however, appear similar regardless of if they had previously been seen for an assessment or not.

# 5 Limitations

Despite the ambitious nature of the study reported here, and the positive findings from implementation of SACS-R, some limitations should be acknowledged. Foremost amongst these was the lack of an 18-month check-up in the North and North-West of Tasmania, with only the South implementing the 18-month assessment. Nonetheless, this created a natural experiment which is reflected in the findings, as discussed below. Furthermore, as the Tasmanian site only joined the study latterly, we were unable to follow-up all children monitored at 42-months, restricting calculation of the various psychometrics for the Tasmanian implementation of SACS-R.

# 6 Implications for research and practice

A key objective in undertaking this Strategic Project on *Developmental surveillance for autism* across two states was to highlight the feasibility and utility of promoting the early detection of autism in Australia. The overall aim in implementing the Social Attention and Communication Surveillance-Revised (SACS-R) within the Victorian and Tasmanian child health services was to prospectively identify infants and toddlers who will go on to receive a diagnosis of autism, and to do so at their routine assessments undertaken at these universal early childhood services, following training of frontline professionals. The results from each implementation indicates that it is feasible to implement the SACS-R and, importantly, the project results closely replicate our previous findings (Barbaro & Dissanayake, 2010; Barbaro Ridgway & Dissanayake, 2011).

## 6.1 SACS-R implementation

As with our previous research, the success of the SACS-R implementation rested squarely on the MCH/CHaPS nurses given their rich knowledge of children's developmental milestones. It was this invaluable expertise that ensured that these nurses were able to be successfully trained to implement SACS-R, and to refer accordingly with a high level of accuracy. Indeed, in keeping with our prediction, no non-autistic children were referred at either site for further assessment and diagnosis, with all children referred needing some level of assessment and further attention for their developmental challenges. Thus, there were no true false positives reported, which means that funds and time were not unnecessarily expended in incorrectly referring children who did not have developmental concerns and undertaking further assessments of them. Furthermore, the ready uptake of the training and accurate implementation are reflected in the evaluations of training and implementation reported by the nurses in Victoria and Tasmania. The positive evaluations were consistent across the two sites, and largely consistent with the evaluations of training in the original SACS (Barbaro, Ridgway & Dissanayake, 2011).

Based on the original SACS study (Barbaro & Dissanayake, 2010), we predicted that implementation of SACS-R within universal developmental surveillance services in Victoria and Tasmania would yield high positive predictive values (PPV), which was the case, particularly in Victoria (83%). We also predicted that implementation of the SACS-R will result in the correct diagnosis of at least 50% of children on the autism spectrum by 2-years of age, and at least 70% by 3-years. This was achieved, as determined based on the estimated prevalence figures of 2.00% at 24-months of age, and 3.25% at 42 months in Victoria. Indeed, based on the data from Victoria, 57% of children on the autism spectrum were identified by 24 months of age (208 children), with 78% identified by 36 months of age (283 children) exceeding our expectations.

The findings in both Victoria and Tasmania were equivalent in many ways, with the exception of more children being identified and referred in Tasmania (3% versus 2%) and a lower PPV in Tasmania (60% vs 83%) compared to Victoria, respectively. Interestingly, with regard to Tasmania, the PPV for autism was highest in the South at 71%, where the additional 18-month check was added (as available in Victoria), with the North and North-West having more similar PPVs where the child checks were only conducted at 12- and 24-months. This finding is supportive of re-introducing the 18-month checks in the North and North-West to facilitate more accurate referral of children showing early signs of autism. Eighteen months is a particularly important time developmentally (Williams, Clinton, & Canadian Paediatric Society, Early Years Task Force, 2011), both in terms of general language development as it marks the period of the vocabulary spurt (Nazzi & Bertoncini, 2003) and, further, in terms of autism as this is the age at which many children become withdrawn or lose communication and/or language skills (Thurm, Powell, Neul, Wagner, & Zwaigenbaum, 2018). Moreover, the lower PPV in Tasmania (including in the South) compared to Victoria may also be an outcome of referral to a generalist early assessment service in Tasmania (St Giles) compared to referral to an autism specialist research team in Victoria who are highly trained on the very early diagnosis of autism. The diagnosis of autism is undertaken using behavioural criteria provided by the DSM-5 (APA, 2013) and assisted by using ‘gold standard’ tools such as the ADOS and the ADI-R. Nonetheless, it is important to acknowledge that appraisal of these behaviours rely heavily on the diagnosing clinician’s experience and skill, with marked differences noted across Australian states (Taylor et al., 2016). Indeed, while feasible, the diagnosis of autism in very young children can be complex, due to marked variability in presentation and rapid development during the first years of life (Steiner, Goldsmith, Snow, & Chawarska, 2012).Thus, it would be of value to independently view and assess videotapes of the diagnoses undertaken across the two states such that a percentage of tapes of those deemed and not deemed to meet DSM-5 criteria for ASD are observed under blinded conditions to ascertain whether differences in differential diagnosis are apparent between assessment sites. Nonetheless, despite the noted differences across the two sites, the estimated prevalence of autism at 24-months of age, across both sites, was approximately 2% which is in keeping with current global estimates (Maenner et al., 2020). Importantly, the nurses received equivalent training by the same expert (JB) across both states, who endorsed the training and implementation of SACS-R to a high level in each state.

We expected that the Positive Predictive Value (PPV) of the SACS-R would be similar to the estimated rates calculated by Barbaro and Dissanayake (2010) between 12-24 months. As predicted, the PPV of the SACS-R between 12-24 months was very high (83%), similar to that of the original SACS (81%). This result should be viewed in light of popular screening tools in wide use such as the M-CHAT (Yuen, Penner, Carter, Szatmari, & Ungar, 2018), particularly when used in community-based samples utilised here where a pooled PPV of 6% was reported. Indeed, many children with intellectual disability are flagged with autism on the M-CHAT, while those children on the autism spectrum without cognitive impairments are likely to be missed (Stenberg et al., 2020). These findings, combined with an over-referral rate of 73% (Eaves, Wingert, & Ho, 2006) mean that the M-CHAT cannot be recommended for universal use. Indeed, it is because of the poor psychometric properties of the screening tools available to date that the value of universal screening and surveillance for autism have been questioned (Siu & US Preventative Services Task Force, 2016). The current findings on the SACS-R speak to the possible success of such programs when robust tools are utilised.

## 6.2 Developmental profiles

Comparison of the developmental and behavioural profiles of the Victorian children later diagnosed with autism relative to those who (were referred and assessed but) did not meet criteria for autism but rather had a DD/LD across the different ages reveals clear differences at each age, which become more marked over time. Even by 12-months of age, the children later diagnosed with autism were showing elevated behavioural traits of autism on the ADOS, and lower verbal mental ages, particularly in expressive language ability, compared to children with a DD/LD. The difference between children's chronological and mental ages became larger with increasing age, particularly in the autistic group where the difference was an average of 1.8 months at 12-months, subsequently increasing at each age, until at 42-months, the children on the spectrum's mean overall mental age was 10 months lower than their chronological age (compared to a 4 month difference at 42 months in the DD/LD group). A further finding of note is that compared to those autistic children followed up to 42-months (who had previously been seen between 12- to 24-months), those first assessed at 42-months were more cognitively able although with equivalent levels of autistic traits, which may explain why their parents did not attend the earlier assessments, and why some were only identified and referred at this age.

# 7 Key recommendations

- All primary care professionals caring for children between 12- to 24-months, including GPs, MCH/CHaPs nurses, early childhood education and care workers, are trained on the SACS-R
- The introduction of universal surveillance for autism using the SACS-R nationally within all services with clients between 12- to 24-months of age
- 18-month checks in the North and North-West of Tasmania should be reintroduced to facilitate more accurate referral of children with early signs of autism
- Develop clear referral pathways for children deemed at 'high likelihood' of autism not only to facilitate early diagnoses but also to access to targeted learning supports
- Further research involving the independent review of videotaped assessments undertaken in Victoria and Tasmania to ascertain any differences in differential diagnosis apparent between assessment sites to inform improvements in diagnostic practise.

## 7.1 Conclusions

The importance of education about the early characteristics of autism and the value of early identification and intervention cannot be underestimated. Early identification, diagnosis and intervention provides the greatest opportunity for better long-term outcomes for children (Clark, Dissanayake & Barbaro, 2017; Flannagan et al., 2015; Szatmari et al., 2015). In this study, it was possible to implement evidence-based practice within two universal community-based early childhood services, serving to prevent countless families the financial and emotional cost of traversing numerous services, usually for many years, in the hope of identifying their child's condition (Crane et al., 2016). Recognising this, the Victorian Government has already implemented the SACS-R across the state (similar to Tasmania within the context of the current study) so that, as in this study, all children are monitored for early signs of autism in their second year of life (at 12-, 18- and 24-months).

Based on the findings reported here, it is incumbent on us to now promote the prospective identification of infants and toddlers showing early signs of autism as part of the routine monitoring of child health and wellbeing, nationally. It is also important that such an undertaking be combined with the development of referral pathways for children deemed at 'high likelihood' of autism in consultation with relevant stakeholders (agencies/professionals involved in diagnosis of autism) alongside utilisation of the Australian *National Guideline for the Assessment and Diagnosis of ASD* (Whitehouse et al., 2018). This Guideline outlines a step-by-step process for conducting an assessment of autism concerns from the time of referral to the end of the diagnostic process. It is anticipated that simultaneous access to the National Disability Insurance Scheme (NDIS) for timely intervention and supports for the child and family will result in improved outcomes for all autistic individuals and families living with autism in Australia.

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# 9 Appendicies

## Appendix A - SACS-R Items

| Behavior | Age at which behaviour is monitored | | |
|---|---|---|---|
| | 12-months | 18-months | 24-months |
| Pointing | ✓ K | ✓ K | ✓ K |
| Eye contact | ✓ K | ✓ K | ✓ K |
| Waving “bye, bye” | ✓ K | ✓ K | ✓ K |
| Response to name | ✓ K | ✓ | ✓ |
| Imitation | ✓ K | ✓ | ✓ |
| Social communication (showing) | | ✓ K | ✓ K |
| Pretend play | | ✓ K | ✓ K |
| Follows point | ✓ | ✓ | ✓ |
| Social smile | ✓ | ✓ | ✓ |
| Conversational babble | ✓ | | |
| Says 1-3 clear words | ✓ | | |
| Attending to sounds | ✓ | | |
| Understands/obeys simple instructions | ✓ | ✓ | |
| Uses 5-10 words | | ✓ | |
| Understands words | | ✓ | |
| Points to facial features | | ✓ | |
| Loss of skills | | ✓ | ✓ |
| Uses 20-50 words | | | ✓ |
| 2-word utterances | | | ✓ |
| Interest in other children | | | ✓ |
| Use/understanding of language | | | ✓ |
| Parallel play | | | ✓ |

## Appendix B - Training Evaluation Form

TRAINING EVALUATION FOR THE
**SOCIAL ATTENTION AND COMMUNCIATION STUDY** (SACS)

To assist us in improving the training we have provided for you, could you please complete this evaluation form. Please circle the number which best describes your view. Thank you for your participation and useful comments.

**Evaluation**

| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| I felt that the material was clear | 1 | 2 | 3 | 4 | 5 |
| I felt that the material was well presented | 1 | 2 | 3 | 4 | 5 |
| The presentation provided adequate coverage of what is expected of me | 1 | 2 | 3 | 4 | 5 |
| I feel able to monitor the early signs of autism between 12 and 24 months of age | 1 | 2 | 3 | 4 | 5 |
| I feel confident in being able to refer infants and toddlers who appear at risk for autism | 1 | 2 | 3 | 4 | 5 |
| I feel confident in directing families to St Giles for a thorough developmental assessment | 1 | 2 | 3 | 4 | 5 |
| The training will have a positive impact on my work | 1 | 2 | 3 | 4 | 5 |

Comments

What did you like most about the training?

________________________________________

________________________________________

________________________________________

What did you like least about the training?

________________________________________

________________________________________

**Additional Comments**

________________________________________

________________________________________

________________________________________

________________________________________

*Thank you for your assistance.*

## EVALUATION OF THE SOCIAL ATTENTION AND COMMUNICATION STUDY-REVISED (SACS-R) – FOLLOW UP

To assist us in evaluating the implementation of the SACS-R, could you please complete this evaluation form. Please circle the number which best describes your view. Thank you for your continued participation in the SACS-R

### Evaluation

| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | |
|---|---|---|---|---|---|---|
| The SACS has been easy to implement into my current practice | 1 | 2 | 3 | 4 | 5 | |
| The SACS has had a positive impact on my current practice for ASD monitoring | 1 | 2 | 3 | 4 | 5 | |
| The SACS has had a positive impact on my current practice for monitoring of developmental and language delays | 1 | 2 | 3 | 4 | 5 | |
| The SACS has added additional time to my consultations only in instances where a child is showing problems in development | 1 | 2 | 3 | 4 | 5 | |
| The SACS has added additional time to ALL of my standard consultations | 1 | 2 | 3 | 4 | 5 | |
| I feel confident in monitoring for signs of ASD at 12 months of age | 1 | 2 | 3 | 4 | 5 | |
| I feel confident in monitoring for signs of ASD at 18 months of age | 1 | 2 | 3 | 4 | 5 | |
| I feel confident in monitoring for signs of ASD at 24 months of age | 1 | 2 | 3 | 4 | 5 | |
| I have received timely advise following my queries to the SACS personnel (if applicable) | 1 | 2 | 3 | 4 | 5 | N/A |
| I feel confident in referring children to the SACS team for a further developmental assessment (if applicable) | 1 | 2 | 3 | 4 | 5 | N/A |
| I feel confident that paediatricians know what ASD looks like in infancy/toddlerhood | 1 | 2 | 3 | 4 | 5 | |
| I feel confident in referring to paediatricians for a further developmental assessment for ASD | 1 | 2 | 3 | 4 | 5 | |

**Please turn over →**

## Our values

### Inclusion

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

### Innovation

New solutions for long term challenges

### Evidence

Guided by evidence-based research and peer review

### Independence

Maintaining autonomy and integrity

### Cooperation

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

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