Research in Autism Spectrum Disorders 71 (2020) 101496

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

Early detection for better outcomes: Universal developmental surveillance for autism across health and early childhood education settings

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ARTICLE INFO

Number of completed reviews is 2

Keywords:
Autism spectrum disorder
Early detection
Early identification
Early childhood education
Screening
Developmental surveillance
Universal
Community-based

ABSTRACT

Access to appropriate early intervention is dependent on timely and accurate identification of children who display early signs of developmental challenges, yet up to 22 % of Australian children have developmental issues that are undetected prior to school. Developmental surveillance using the Social Attention Communication Surveillance- Revised (SACS-R) and the Parents Evaluation of Developmental Status (PEDS) tools was implemented prospectively with a large, diverse sample in community-health and early education settings. Outcomes were investigated to compare the discriminative validity and agreement of the SACS-R and PEDS tools in the early identification of children with Autism Spectrum Disorder (ASD). Results indicate there is a significant difference in the sensitivity and rates of agreement between PEDS and SACS-R in the early identification of ASD across both settings, with SACS-R accurately identifying substantially more children with ASD. Development of policy within health and education sectors that supports implementation of robust, universal developmental surveillance can potentially improve outcomes for children at higher likelihood for ASD.

1. Introduction

The Australian Early Developmental Census (AEDC) indicates that one in five Australian children (22 %) are developmentally vulnerable in one or more developmental domains (Australian Early Development Census, 2018), while a recent longitudinal study reports that about 85 % of children with Autism Spectrum Disorder (ASD) have difficulty establishing social and emotional connections at school (Berkovits, Eisenhower, & Blacher, 2017). Efforts to provide supports to children who are experiencing developmental delays and optimise performance at school are hindered when up to three quarters of developmentally vulnerable children do not have their challenges identified, and they do not receive any early intervention or supports prior to starting school (Goldfeld, O'Connor, Sayers, Moore, & Oberklaid, 2012).

There is increasing evidence that early detection and intervention can significantly enhance long term outcomes for children with ASD and related conditions (Dawson et al., 2010). Quality early intervention provided for young children whose neurologic connections are being established has shown promising results (Rogers et al., 2019; Zwaigenbaum et al., 2015). There is strong evidence of the effectiveness of early intervention in promoting developmental outcomes in the early years, and reducing family and society

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https://doi.org/10.1016/j.rasd.2019.101496
Received 26 August 2019; Received in revised form 25 November 2019; Accepted 1 December 2019

cost savings over a person's lifetime (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Knapp, Romeo, & Beecham, 2009). Children who receive intensive, early intervention are more likely to communicate verbally (Whitehouse et al., 2019) and receive more inclusive educational placements (Charman & Baron-Cohen, 2006; Clark, Barbaro, & Dissanayake, 2017). When compared with children diagnosed at 3–5 years of age, children who received an earlier diagnosis of ASD, have been found to have improved cognitive performance and required less ongoing intervention during primary school (Clark et al., 2017). Early identification may also enable parents to be better informed about genetic implications for younger siblings, be better able to identify early signs themselves (Zwaigenbaum et al., 2009), and reduce family stress levels by providing early access to supports (Charman, 2003). Given the potential for improved long term outcomes, it is argued that every child with a developmental profile indicating possible ASD or developmental delay should be offered quality early intervention, regardless of whether or not they meet specific diagnostic criteria (Eapen, 2016). This is supported in the eligibility guidelines for early intervention through Australia's new National Disability Insurance Scheme (NDIS, 2019a, 2019b). Early identification has also become more urgent now that this scheme is mandated to provide early intervention to all eligible children but inequities in identification and access to the scheme have been identified (Carey, Malbon, Reeders, Kavanagh, & Llewellyn, 2017).

It has been established that a diagnosis of prevalent development disorders, including ASD, can reliably be made when a child is 18–24 months old (Barbaro & Dissanayake, 2017; Lord et al., 2006; Webb & Jones, 2009), with a recent study suggesting diagnostic stability for children identified at 14 months (Pierce et al., 2019). ASD can be detected as young as 12 months of age, though children are typically not diagnosed until after 3 years (Barbaro & Dissanayake, 2010, 2013; Chakrabarti & Fombonne, 2005; Veness et al., 2012). The median age of identification of ASD in Australia and globally is 4–6 years (Bent, Dissanayake, & Barbaro, 2015). Socioeconomic barriers to early detection of developmental challenges in young children have been found in health systems worldwide, with children from disadvantaged backgrounds having particularly limited access to comprehensive primary healthcare (Eapen et al., 2017). In Australia, only about 50 % of 1-year-olds, and 35 % of children between 1–4 years of age, access maternal child health nursing services (Garg et al., 2018). A recent report from the United States Centers for Disease Control and Prevention (CDC) indicates that fewer than half of children with ASD in a large representative sample of 8-year-olds received their diagnosis by age 4. Concerns about development were noted in health records of 85 % of children later diagnosed with autism before 3 years, though only 42 % received comprehensive evaluation (Baio et al., 2018). The CDC suggests that without routine screening, only about 30 % of children with developmental concerns are identified before their first year of school (Baio et al., 2018). This 2- to 3.5-year delay in identification is substantial and indicates a large gap in the current system of community screening and identification of developmental challenges, and a clear need for further research and innovation to improve practice across a wide variety of clinical and community settings.

The terms screening and surveillance or monitoring in relation to children's development are often used interchangeably, though may have different definitions in different practice contexts. 'Screening is not intended to be diagnostic, rather involves the use of specific tests or tools to identify children in the population who are likely to have a certain condition and who would benefit from more comprehensive evaluation. A universal approach to developmental surveillance involves a combination of opportunistic clinical observations, use of standardized screening tools, and consideration of parental concerns. The task of developmental screening and surveillance has traditionally been the responsibility of a range of primary care providers in the health system including general practitioners, child health nurses, and paediatricians (Oberklaid, Baird, Blair, Melhuish, & Hall, 2013). The Australian government recommends ongoing, developmental surveillance during health checks at 6, 12, 18 months and 2, 3, and 4 years of age (The Royal Australian College of General Practitioners, 2018). Health practitioners are advised to use the Parents Evaluation of Developmental Status (PEDS), which is a population level screening tool designed for children 0–8 years of age and consists of 10 open-ended questions to elicit parents' perceptions of their child's development (Glascoe, 2013a, 2013b). A pathway of referral for ASD assessment using PEDS has been defined where three or more concerns are noted about: 1) *behavior, 2) motor, 3) receptive language and/or 4) social-emotional development* at 0–35 months, or concerns noted about 5) *school, 6) social-emotional and 7) expressive/receptive language* at 3–5 years. This recommended pathway to identification using the PEDS will be referred to as PEDS (Path ASD) in the current study (Centre for Community Child Health, 2014).

1.1. Current practice in screening and surveillance for ASD

Two primary models for early detection of ASD that have been proposed, implemented and studied for efficacy. The two-stage model, as described by Glascoe, Macias, Wegner, and Robertshaw (2007), involves Level 1 universal screening using a broadband developmental surveillance questionnaire (i.e. PEDS), which can be *followed up by* an ASD specific screening questionnaire that has been designed to differentiate children with ASD from those with other disabilities (Level 2 screening) if concerns are raised during the Level 1 screening. The second model of detection involves comprehensive universal surveillance with the *concurrent administration* of an autism-specific surveillance tool and a broadband developmental screening tool.

The universal model involves systematic, population level, developmental surveillance in which an autism-specific screening tool is administered to **all children** at specified ages, in addition to routine developmental monitoring (Johnson & Myers, 2007). It is argued that this universal approach may improve rates of early identification of ASD in a timely manner due to a "one-step" approach, thus enabling earlier access to targeted intervention supports (Pierce, Courchesne, & Bacon, 2016). The universal approach could therefore facilitate educational, social, and economic benefits over the long term (Oberklaid et al., 2013) and is recommended as best practice by the American Academy of Pediatrics (AAP; Dreyer, 2016). Critics of the universal screening methodology express concerns that health professionals are unlikely to have the time and/or resources to administer an ASD-specific screening tool in primary care settings (Sand et al., 2005; Silverstein, Grossman, Koepsell, & Rivara, 2003). However, the Royal Australian College of

General Practitioners (RACGP) and the AAP recommend a system of universal developmental surveillance, including specific screening of all children for autism at 18 and 24 months to facilitate early detection of developmental challenges and timely referral to early intervention (Duby & Johnson, 2009; The Royal Australian College of General Practitioners, 2018). Despite these recommendations, rates of developmental surveillance and screening in the health system remain low, with a recent large scale study estimating only 30 % of children receive any screening by a health professional (Hirai, Kogan, Kandasamy, Reuland, & Bethell, 2018); thus, processes for implementing effective developmental surveillance for ASD in the community warrant further study.

Eapen, Črnčec, Woolfenden, and Blackmore (2014) compared the two-stage model with the comprehensive screening approach by comparing the scores of PEDS and Modified Checklist for Autism in Toddlers (M-CHAT; (Robins, Fein, & Barton, 1999) and also studied the PEDS as a possible Level 1 screening instrument for ASD. It was found that use of PEDS alone without an autism-specific screening tool may be approximately 25 % less sensitive in accurately identifying children requiring specialized ASD assessment than a comprehensive approach. The M-CHAT, which is the most commonly used population screening tool for ASD, has been found to have low positive predictive value (PPV) when used without a follow-up interview (Kleinman et al., 2008; Pandey et al., 2008; Robins, 2008; Sánchez-García, Galindo-Villardón, Nieto-Librero, Martín-Rodero, & Robins, 2019), with a recent meta-analysis finding a pooled PPV of 6 % for M-CHAT when used in community-based settings (Yuen, Penner, Carter, Szatmari, & Ungar, 2018). While the M-CHAT may be useful in identifying children who need further assessments in clinical settings, it is not recommended for use as a universal screening tool in children aged 18-months or younger, or in community-based samples to rule out ASD (Yuen et al., 2018), with an over-referral rate of 73 % (Eaves, Wingert, & Ho, 2006). There has been significant uptake of the PEDS in both primary care and early childhood education settings in Australia and wide implementation of the M-CHAT across settings internationally. Recent findings of poor sensitivity and specificity for identifying ASD are of particular concern in the context of policy related to the early identification of children with developmental challenges. Pinto-Martin et al. (2008) reported that PEDS was not as effective as a Level 1 screening tool for ASD in toddlers aged 18–30 months, with a reported specificity of 75 % and sensitivity of only 27 % for identifying ASD. In their comparison of the PEDS and M-CHAT, Pinto-Martin et al. (2008) found that almost three quarters of children who were identified as “at risk” of ASD using the M-CHAT were not identified using the PEDS, concluding that the PEDS and M-CHAT address different areas of developmental concern and that the PEDS does not adequately address concerns about play and social interaction, which are key early markers for ASD (Barbaro & Dissanayake, 2013). It has also been reported that over-referral to ASD assessment clinics (up to 80 %) has been identified using PEDS in isolation (Glascoe et al., 2007). Agreement between M-CHAT and PEDS results for children who received a diagnosis of ASD was found to be poor, raising questions about the clinical utility of the PEDS and M-CHAT as population screening tools (Wiggins, Piazza, & Robins, 2014); 19 of 22 children (86 %) identified with a high likelihood of ASD using M-CHAT did not meet diagnostic criteria for ASD, and 13 out of 22 (59 %) children received a false positive score on the combination of items related to ASD on the PEDS (PEDS Path ASD; Wiggins et al., 2014). Therefore although the AAP, among other authorities, recommend that all 2-year-olds undergo screening for ASD, the most widely used tools do not have sufficiently robust psychometric properties for use across the general population.

1.2. Evidence-based methods for prospective, early detection of ASD

To address this gap, the Social Attention and Communication Surveillance (SACS) tool was developed and validated in a large-scale prospective, community-based sample (Barbaro & Dissanayake, 2010; Barbaro, Ridgway, & Dissanayake, 2011). The tool has been revised based on analyses of early behavioral markers for ASD; the current version is known as SACS-R (Barbaro & Dissanayake, 2013). The SACS-R is a Level 1, autism-specific, developmental surveillance tool that involves training primary health-care professionals (e.g., “well-baby” / Maternal and Child Health – MCH – nurses) on the early signs of autism during a half-day workshop. There are a series of checklists covered at 12-, 18-and 24- months of age that outline key behavioural and developmental markers for social attention and communication behaviours, as described in Barbaro and Dissanayake (2010, 2013). A pre-school version of the tool for children aged 3–5 years has also been developed. The SACS-R is designed to be administered as a part of a universal developmental surveillance program, rather than a single point-in-time screening approach, by primary health-care professionals during routine infant and child health checks, to accurately identify children who demonstrate a pattern of behavior indicative of ASD, thus requiring referral to assessment and early intervention supports. It has been demonstrated that MCH nurses, working in the public health system, can effectively and accurately identify children with early signs of ASD in regular 12–24 month visits using SACS (Barbaro & Dissanayake, 2010, 2013, 2016; Barbaro et al., 2011).The SACS was found to have an overall PPV of 81 % between 12–24 months-of-age. The estimated sensitivity of the SACS is 83 % and specificity is 99.8 %. In comparison to other large-scale, community-based, screening studies for ASD, the use of the SACS did not result in a large number of false positives, with no typically developing children being identified (i.e., all children had ASD or another developmental condition such as developmental/language delay (Barbaro & Dissanayake, 2010). The very high PPV in the SACS contrasts that of the M-CHAT (PPV 6 %; Yuen et al., 2018). The training of nurses on the early signs of ASD was found to have contributed to their ability to accurately identify children at high likelihood of ASD in the general population from as early as 12 months (Barbaro & Dissanayake, 2010). Developmental surveillance for ASD using the SACS-R has been translated into a free, downloadable digital application called ASDetect (Barbaro et al., 2018) and is now available worldwide on Apple and Google platforms. Given the high sensitivity, specificity and PPV established for the SACS in primary healthcare (MCH) settings, evaluation of its potential application as a universal developmental surveillance tool for autism in early childhood education settings would be valuable.

Early childhood education professionals (ECEPs) have an important role in the ongoing monitoring of child development as attendance at community health appointments decreases while engagement with early childhood education (ECE) increases around 24 months of age (Moore & Grove, 2008). A comparison of interrater reliability between ECEPs and MCH nurses in the administration

and scoring of SACS-R was found to be very high ($k = 0.909$; Mozolic-Staunton, Donelly, Yoxall, & Barbaro, 2017). Training ECEPs in the use of a sensitive and specific developmental surveillance tool, designed to assess key developmental behaviors across time, is likely to increase the chances of accurately detecting developmental challenges including ASD in young children.

1.3. Application of evidence in practice across health and education settings in early detection

The SACS and PEDS (Path ASD) are both intended to identify early behavioural signs of ASD in young children in community-based settings. Comparison and analysis of the discriminative power of the tools when applied as part of community-based, universal developmental surveillance in two different settings will contribute to our understanding of the effectiveness of each approach and will inform policy and practice guidelines for a range of health and early childhood professionals. The current study directly compares SACS-R and PEDS (Path ASD) data collected from both community-health settings and ECE settings to determine if the two developmental surveillance methods are similar or different in predicting which children are likely to have a developmental profile suggestive of ASD, triggering referral for comprehensive assessment and early intervention supports. The extent to which SACS-R and PEDS (Path ASD) agree on which children are showing early behavioral signs of ASD when implemented in health and education settings was examined. It was hypothesised that the SACS-R has a significantly higher PPV that the PEDS (Path ASD) when employed for the purpose of universal developmental surveillance by a range of professionals in health and education contexts that are widely accessed by young children.

2. Method

2.1. Design

Two separate prospective cohort studies implemented developmental surveillance using SACS-R and PEDS with children in the general population who were attending either a routine visit at an MCH centre or were enrolled at a participating early childhood education and care centre. Professionals in each of these environments are commonly engaged with aspects of child development for large numbers of children in the Australian population but from very different disciplinary backgrounds, health and education. Comprehensive developmental follow-up assessment was offered for children who were identified with behavioral markers for ASD at a convenient time for parents and a soon as possible after being referred by their early childhood teacher or MCH nurse, typically within 2 months. The first study, was an ongoing prospective cohort study, called the *SACS* project, being undertaken in MCH centres in Melbourne, Victoria (2013–2018). The second study, *Right Kids, Right Time, Right Services* project was conducted in early childhood education centres across New South Wales and southeast Queensland (2014–2016) and aimed investigate the efficacy of routine use of SACS-R in early childhood education settings, given the promising results of application of the tool in primary health settings (Barbaro & Dissanayake, 2010; Barbaro et al., 2011; Clark, Vinen, Barbaro, & Dissanayake, 2018). Retrospective analyses of results of developmental surveillance using SACS-R and PEDS conducted during these two cohort studies was undertaken to determine the rate of agreement between SACS-R and PEDS (Path ASD) in predicting early signs of ASD in young children when implemented universally across primary health and ECE settings. The discriminant validity of SACS-R and PEDS (Path ASD) in detecting which children met diagnostic criteria for ASD on follow-up assessment was also investigated. Characteristics of the SACS-R and PEDS screening tools are summarised in Table 1. Ethical approval was obtained from Southern Cross University and LaTrobe University Human Research Ethics Committees.

2.2. Participants and recruitment

There were three groups of participants in each setting in this study:

1 Professionals (ECEPs and MCH nurses)
2 Children in the general population aged 12–36 months visiting an MCH clinic and children 12 months- 4 years enrolled in a participating early childhood education center
3 A subset of children identified with a “high likelihood” of ASD

2.3. Procedure

2.3.1. Group 1: professionals (MCH nurses and ECEPs)

In community health settings, 125 MCH nurses from health centres in 8 local government areas in Victoria (VIC), Australia were trained to monitor children’s development for the early signs of autism using skilled observations during their routine ‘well child’ checks at 12, 18, 24 and 42 months in a large prospective cohort study ($N = 13{,}489$ children). Participants were recruited to a follow-up study of the original SACS study and a detailed description of recruitment and sampling has been published in Barbaro and Dissanayake (2010), Barbaro et al. (2011). In early childhood education centres, staff and families from 20 childcare centres in Queensland (QLD) and New South Wales (NSW) were recruited via invitation to centre directors. Participants include ECEPs working in long day-care centres ($N = 60$) with children ages 12 months-4 years, children attending childcare centres aged between 12 months and 4 years ($N = 633$) and their parents.

Professionals from both groups received professional development training on the early signs of ASD with video examples of

Table 1
Characteristics of SACS-R and PEDS developmental screening tools.

Characteristic	PEDS (Path ASD)	SACS-R
Screening approach	Parental report- level 1	Professional observations- level 1
Format	10 questions covering 9 developmental concerns, 1 page Response options: no/yes/ a little	Separate checklist for each of ages 12, 18, 24 and 3–5 years with 11–22 items, covering key developmental, behavioural indicators specific to autism related to social attention and communication skills
Example of item	Do you have any concerns about how your child behaves?	Get a teddy bear, show it to the child and say "This is teddy". Then put the bear across the room (out of reach where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face?
Response options	No/yes/ a little	Typical/ Atypical
Ages	0–8 years	12, 18, 24 months and 3–5 years
Time to screen	5 min of parent time 1 − 2 min for provider/staff to score	5 − 10 min of provider time 1 − 2 min for provider/staff to score
Scoring summary	Yields overall pass/fail sore: Path A: 2 significant concerns (refer for evaluation); Path B: 1 significant concern (administer formal skill-based screen); Path C: non-predictive concerns- monitor and follow-up. Path D- Parental difficulties communicating (seek interpreter or foreign language version); Path E: No concerns (re-administer at next checkpoint) Path ASD: 3 or more concerns about learning behaviour, fine or gross motor, receptive language, or social-emotional at 0–35 months; or at 3–5 years about school, social-emotional, expressive or receptive language.	Yields overall pass/fail score: If answered 'Atypical' on 3 or more key items, refer for ASD specific comprehensive developmental assessment
Sensitivity	0.74-0.79 (moderate) *global developmental concerns; not reported for Path ASD	0.83 (high)
Specificity	0.70-0.80 (moderate) *global developmental concerns; not reported for Path ASD	0.99 (high)
Positive Predictive Value	Not reported for Path ASD	0.81 (high)
Negative Predictive Value	Not reported for Path ASD	Not reported for SACS-R

Note. Adapted from Barbaro and Dissanayake (2010), 2013); Centre for Community Child Health (2014); Glascoe (2013b).

typical vs. atypical behavior, closely matching the methodology as detailed in Barbaro et al. (2011) and Barbaro and Dissanayake (2010). After consenting to participate and completing the training workshop, educators and nurses implemented the SACS-R, using the checklist that corresponded to the age of the children being screened. Both groups of professionals invited caregivers to complete the PEDS. The PEDS tool was being implemented as standard practice in these settings. Participating professionals were asked to return completed SACS-R and PEDS forms to the research team at each study site. Children identified with a high likelihood for ASD using either the SACS-R or PEDS tools were referred for further developmental assessment by registered paediatric health professionals. Informed consent from parents was also obtained before any referrals were made for further assessment.

2.3.2. Group 2: children

Parents or caregivers of children attending childcare centres in QLD or NSW or visiting their MCH nurse in Victoria were given information about the study and invited to consent to participate in the study. The professionals were provided with guidelines and specific strategies (Kellett, 2011) for engaging with very young children to ensure that the children themselves were content and willing to participate during all stages of the research.

2.3.3. Group 3: children with a "high likelihood" of ASD

Criteria for referral to follow-up assessment was defined as three or more key items marked *Atypical* on SACS-R or where three or more concerns were noted in accordance with guidelines for PEDS (Path ASD; Centre for Community Child Health, 2014). Children identified with high likelihood of ASD in the early childhood education centres by key items on either the SACS or PEDS (Path ASD) were referred to Southern Cross University Health and Wellbeing Clinic, Gold Coast for a range of comprehensive gold-standard developmental and diagnostic assessments, as detailed below. Children who were identified with high likelihood of ASD by MCH nurses were referred to the Olga Tennison Autism research Centre, Melbourne to also undergo a similar gold-standard assessment. Outcomes of assessment were provided in a written report and discussed with families. Relevant referrals to medical professionals and early intervention services were provided.

The following assessments and a demographic questionnaire were administered by accredited allied health professionals with experience in autism diagnosis for any child identified as having high likelihood of ASD by either the SACS or PEDS who attended follow-up assessment:

1) **The Bayley Scales of Infant Development (BSID)- Third Edition** (Bayley, 2005) measures cognitive, language social-emotional,

fine and gross motor development, adaptive behaviour and provides an index score of the child's overall development for children aged 1–42 months (QLD/NSW site). OR **Mullen Scales of Early Learning** (MSEL; Mullen, 1995), which also measures non-verbal (fine and gross motor, visual reception) and verbal (receptive and expressive language) ability, in children birth to 68 months (VIC site).

2) **The Autism Diagnostic Observation Schedule, 2nd Edition** (ADOS 2; Lord et al., 2012) to assist in the diagnostic assessment of autism. The ADOS-2 is an observational assessment of communication, social interactions, play and imagination. Diagnostic classification is made by using cut-off scores to determine if the child meets criterion for Autistic Disorder, Autism Spectrum Disorder or is non-autistic. The ADOS-2 is considered the gold standard for assessment of ASD when combined with clinical judgement (both sites).
3) **The Autism Diagnostic Interview-Revised** (ADI-R) is a parent interview conducted by trained clinicians to detect the presence and severity of symptoms of autism in early childhood (Lord, Rutter, & Le Couteur, 1994). The sensitivity and specificity has been found to be lower for children below a developmental level of 18 months, thus was used only to supplement clinical judgment and other developmental assessment tools such as the ADOS in the VIC site only which included more children in younger age groups (Zwaigenbaum et al., 2009).
4) **Modified Checklist for Autism in Infants and Toddlers** (M-CHAT; Robins, Fein, & Barton, 2009). This is a 23 item yes-no parent report screening instrument for ASD. High likelihood of ASD is defined by any three items failed or two critical items failed (both sites).

2.4. Data analysis

Based on outcomes of follow-up assessment conducted by experienced clinicians, children were classified as ASD if they met criteria for diagnosis based on ADOS-2 and/or ADI-R and clinical judgement. Composite scores on BSID or MSEL were used to determine which children were showing signs of developmental and/or language delay versus ASD. Agreement statistics were calculated for the combined sample of children who were referred for a comprehensive follow-up assessment. A comparison of agreement between SACS-R and PEDS (Path ASD) on whether or not a child was demonstrating key behavioral markers for ASD was conducted across both health and ECE settings. As SACS-R and PEDS (Path ASD) were both designed to identify the early signs of ASD, they should ideally have similar, good-to-excellent, psychometric properties for identifying children with high likelihood of ASD, when implemented as universal developmental surveillance. Cohen's Kappa is commonly used to provide a measure of proportionate observed agreement between two methods that are employed to assess the same phenomena (McHugh, 2012). Proportionate observed agreement between results of SACS-R and PEDS (Path ASD) was collated across age groups and settings to ensure sufficient sample to achieve a valid kappa coefficient (Gwet, 2016).

Discriminant validity is the ability of a tool to correctly identify individuals as belonging or not belonging to a particular group (in this case, children in need, or not in need, of further assessment for ASD). The accuracy of a tool being able to discriminate between those children who are later confirmed to have ASD and those who do not is particularly important for screening in community-based settings. If a child is incorrectly classified during the screening process, valuable time for assessment and intervention can be wasted (Norris & Lecavalier, 2010). To determine the discriminative validity of the SACS-R and PEDS (Path ASD) to accurately identify children with ASD prospectively in both health and education settings, the sensitivity, specificity, likelihood ratios and positive and negative predictive values for each tool were estimated. A Bayesian approach to evaluating developmental surveillance as described by Kallner (2018) was applied in this study by examining results of discriminative validity. Bayes theorem purports that the chance a condition is present is determined by the prevalence of a condition multiplied by the weight of the evidence for or against the condition (likelihood ratio). This approach involves determining whether the surveillance process increases or decreases the probability that a child screened in an MCH or ECE setting will: 1) meet the criteria for an ASD assessment referral; 2) have the need for further assessment ruled out; or 3) require additional information. Camp (2009) recommends a predictive value of 60 % for positive screening results as the minimum acceptable level for deciding to refer for follow-up assessment and outlines guidelines for interpreting the power of likelihood ratios.

Evaluation of a screening tool in community-based practice should be guided primarily by knowledge of the likely prevalence of the condition in the population being screened (Camp, 2009). The reported prevalence of ASD ranges quite substantially from 1:59 (CDC, 2018) in North America to 1:90 in the UK (Brugha et al., 2012) and is currently cited as 1:150 in Australia (Australian Institute of Health & Welfare, 2017). A conservative estimated prevalence of 1 % has been cited in much of the recent literature and thus was utilised to calculate PPV and NPV in the current study (Sánchez-García et al., 2019). The Bayesian approach, when applied in community-based practice, is recommended to consider the influence of a low prevalence rate of ASD in the general population and imperfect nature of reference standard of autism tools (Camp, 2009). Frequencies and percentages were calculated to analyse the number of true positives, where children identified as having high likelihood of ASD by SACS and PEDS (Path ASD) were found to meet diagnostic criteria for ASD based on follow-up evaluation using the battery of standardised assessments listed above, particularly the ADOS-2, ADI-R and clinical judgment. Instances of missing surveillance results are also considered, as evidence of the consistency of implementation of universal developmental surveillance in these community settings. Of the 246 children who attended a developmental assessment due to concerns raised during developmental surveillance in MCH, 72 (29.3 %) were missing PEDS forms at all ages. There were no children for whom SACS was missing from all age points. Of the 29.3 % of children for whom PEDS was not returned in this study, 1 % were presumed to have ASD and were treated as false negative. The remaining children who participated in screening and not assessed were classified as true negatives. Consistency is essential for the success of any surveillance program. The data set from the MCH community health group has been collected over several years and is significantly larger, thus

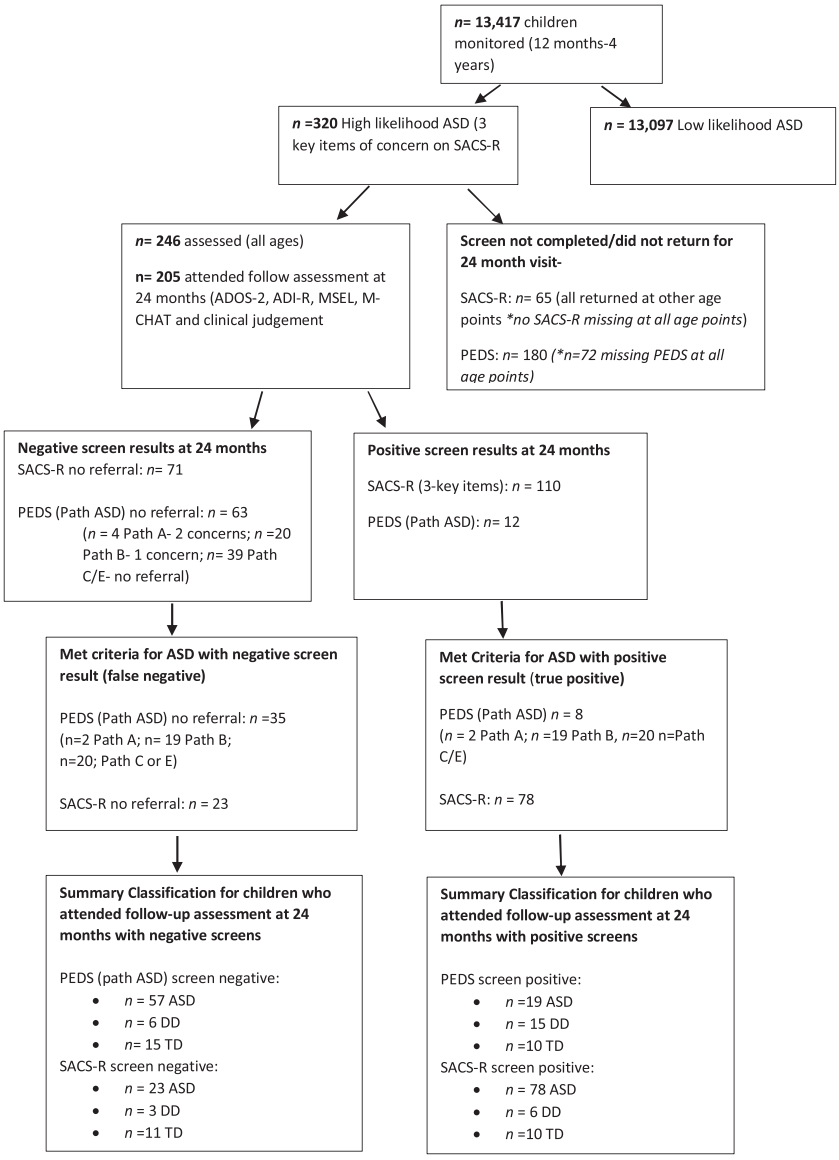

Fig. 1. Flow chart of children screened in MCH settings, with outcomes of screening and follow-up assessments at 24 months of age.

agreement between surveillance and diagnostic evaluation is reported separately for each of the age groups (12, 18, 24 months). The early childhood education project was designed as a follow-up study to apply results from the larger study which established the psychometric properties of SACS-R in MCH setting into ECEC settings. The time and costs involved in replication such a large data set in ECEC settings was prohibitive and outweighed the benefits: thus, data from both settings was combined to enable sufficient power to analyse the psychometrics of the SACS-R across both settings. As the PEDS is considered standard practice across both MCH and ECEC settings, data for analysis of PEDS used in the context of screening for children later confirmed to have high likelihood of ASD was available, enabling comparisons in this study.

3. Results

There were 14,113 children monitored across MCH and ECE settings at key points (12, 18, 24 and 36–42 months). Comprehensive follow-up assessments were completed for 264 children who met criteria for referral on either SACS or PEDS (Path ASD) during developmental surveillance conducted in the community at one or more age points. Of those assessed, 182 children were found to meet criteria for an ASD diagnosis upon follow-up assessment. Figs. 1 and 2 provide a flow chart detailing the rates of screening tools administered, follow-up visits attended and outcomes of developmental assessment for MCH and ECEC settings (Bossuyt et al., 2015). The developmental level of children who attended follow-up assessment was ascertained using composite scores on MSEL or BSID as shown in Table 2 with the criteria for developmental delay defined as > 2 SD below the mean.

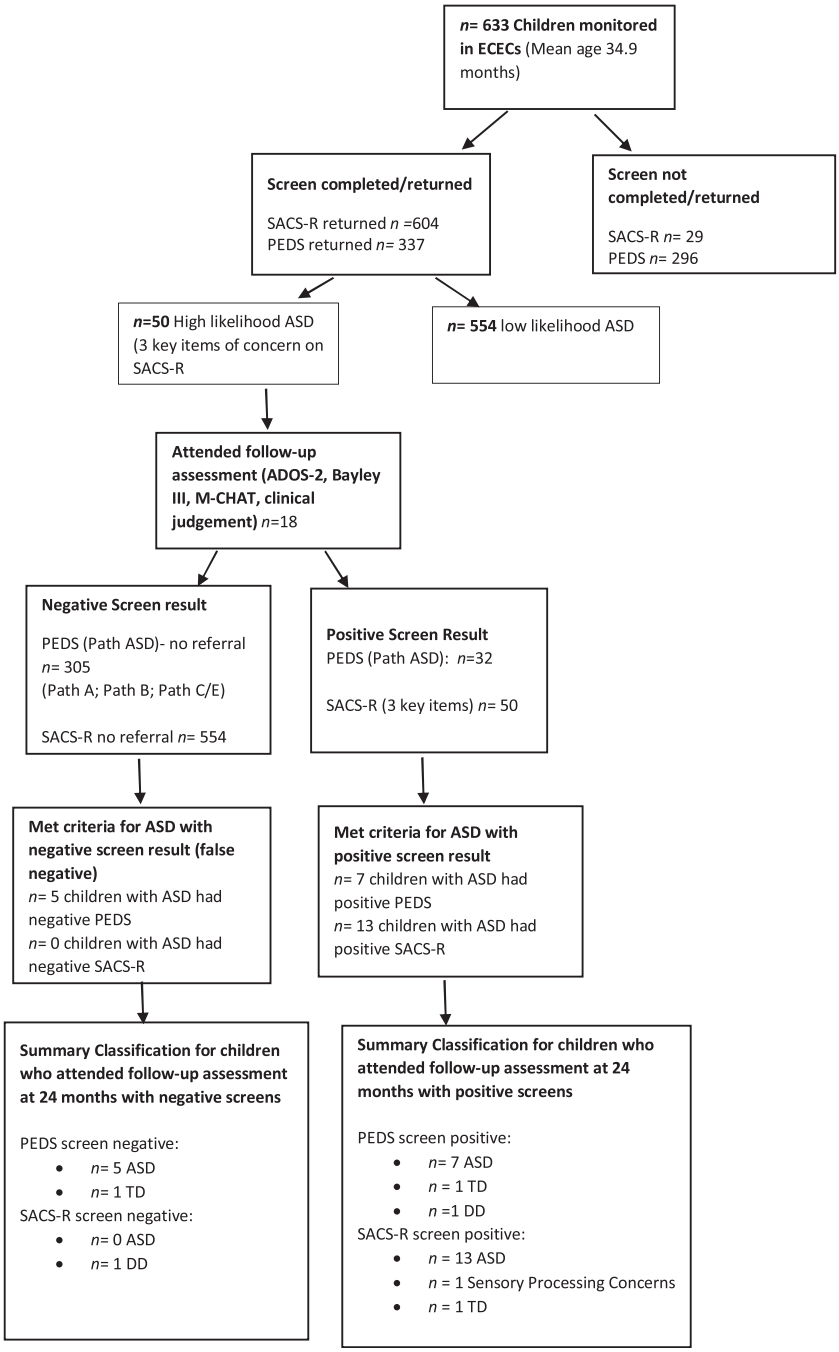

Fig. 2. Flow chart of sample of children screened in ECEC settings, with outcomes of screening and follow-up assessments.

Frequencies of referral rates on SACS and PEDS developmental surveillance at MCH visits or in ECE centres for children who attended a follow-up evaluation and had both tools completed (n = 217) were used to calculate Cohen's K. The degree of agreement between SACS and PEDS (Path ASD) regarding whether or not a child met criteria for referral to specialist ASD assessment across age groups and settings (ECE and MCH) is detailed in Table 3. Slight agreement between SACS and PEDS (Path ASD) on whether a child was showing key early behavioral markers for ASD was found (Landis & Koch, 1977) at 54.84 %; k = 0.161, 95 % CI (0.81 to 0.241, $p < .0005$).

4. Discriminative power

The rates of true positive, false positive and estimates of true and false negatives were analysed to determine sensitivity and

Table 2
Developmental level of children who attended follow-up assessment as indicated by Early Learning Composite Scores on MSEL (MCH setting) or cognitive composite score on BSID (ECEC setting).

Setting	Age (n = number of children assessed)	Mean (SD)	Percent of children with developmental delay
MCH	12 months (n = 20)	84.65 (12.48)	n = 4 (15 %)
MCH	18 months (n = 79)	72.84 (15.60)	n = 40 (50.6 %)
MCH	24 months (n = 180)	74.12 (19.68)	n = 92 (51.1 %)
MCH	3–5 years (n = 100)	79.37 (25.39)	n = 43 (43 %)
ECEC	34.9 months (mean; n = 18)	107.88 (16.48)	n = 2 (11 %) [a]

Note. MSEL Early Learning Composite Score and BSID Cognitive composite score (Mean 100; SD 15).
[a] BSID was unable to be completed due to behavioral and attention difficulties for n = 2 children, who were presumed to be have delayed development based on clinical judgement.

specificity of SACS and PEDS (Path ASD) across age groups and settings, as outlined in Tables 4 and 5. In an effort to report comprehensive psychometrics, true and false negatives were estimated, as children with negative SACS-R were not evaluated. Confirmatory evaluations are prohibitive in very large samples and it is likely that the number of truly negative cases will greatly outnumber those cases that will later be identified as false negative (Beighley, Matson, Rieske, Konst, & Tureck, 2014; Sánchez-García et al., 2019).

Discriminative validity analyses for the two tools are presented in Table 6. Likelihood ratios were calculated from sensitivity and specificity.

Estimation of Sensitivity of PEDS (Path A; 2 predictive concerns) is 0.06 and PEDS (Path B; 1 predictive concern) is 0.20, while specificity was found to be 0.99 for both pathways with predictive concerns in this sample.

5. Missing data

At the 12-, 18-, and 24-month check, 77/246 (30.2 %) children who attended a follow-up assessment due to concerns about development were missing a PEDS checklist. However, only two of 246 children were missing SACS at 12, 18 and 24 months, and SACS forms for both were received at the 42-month MCH check. There were 80 children for whom PEDS was missing at 12 months. Among the children with missing PEDS data at 12 months, 62 (77.5 %) received a diagnosis of ASD or possible ASD at 24 months. Of the 105 children who received a diagnosis of ASD or possible ASD at 24-month follow-up assessment, only four were missing SACS (3.8 %).

6. Discussion

While social, attention and communication challenges can be reliably detected in children from 12 to 18 months of age, many children who are exhibiting early behavioral signs of autism are not identified early to facilitate timely access to early intervention supports, prior to entering primary school. This study examined outcomes of SACS and PEDS developmental surveillance tools when implemented prospectively in MCH and ECE settings with a large sample of children. In practice, the PEDS is currently being used as the primary method to detect young children who may have a developmental condition, including ASD, in public health and some ECE settings. Although the PEDS has an ASD specific referral pathway, it was demonstrated that the SACS-R, completed by either a trained health practitioner or early childhood educator, was more effective than PEDS in accurately detecting children with early signs of ASD, who required further assessment and early intervention supports. While the PPV of both tools is high and are above the recommended threshold for developmental screening tools (Camp, 2009; SACS-R: 83 %; PEDS: 88 %), the sensitivity of SACS-R (82 %) compared with PEDS (Path ASD) at 6.7 % means that children who screen positive on SACS-R are much more likely to have ASD than those who are identified with ASD referral pathway using PEDS.

Children who demonstrate key early behavioural signs of ASD require referral to professionals with specialist training in diagnosis and intervention for ASD. These clinicians are often in short supply and long waiting lists are common. Early Intervention supports are funded through the NDIS in Australia, which has strict eligibility criteria requiring documented evidence of disability (NDIS, 2019a, 2019b). It is therefore critical that all early childhood professionals working in a range of settings (primary healthcare, childcare, schools) are trained to accurately identify children who may need to be referred for ASD evaluations. Current practice in many health and some education settings relies on PEDS, completed by parents. The finding that PEDS (Path ASD) and SACS agree on whether or not a child meets criteria for a referral in just over a third of cases (39.74 %) where developmental concerns were raised by caregivers, indicates that the two methods are not detecting early signs of ASD with the same level of accuracy. This is consistent with previous findings that PEDS (Path ASD) is not equivalent to using an autism specific screening tool (Eapen et al., 2014; Wiggins et al., 2014).

In both MCH and ECE settings, the probability that a child who has a developmental profile suggestive of ASD will be identified using SACS is markedly higher than the ASD referral pathway on PEDS. Furthermore, SACS, when implemented across age groups and settings, demonstrates a much better balance between sensitivity (82 %) and specificity (99.75 %), replicating results of prior studies (Barbaro & Dissanayake, 2010; Barbaro et al., 2011). While the PEDS has high specificity (99 %), its sensitivity is well below recommended standards for screening tools (6.7 %) indicating the PEDS (Path ASD) is likely to detect children who exhibit severe

Table 3
Agreement between PEDS and SACS screen results at key age points in MCH and ECE settings.

	Age 12 months (MCH)	Age 18 months (MCH)	Age 24 months (MCH)	Early Childhood Education (mean age 34.9 months)	Total
Both SACS and PEDS (Path ASD) agree positive	$n = 0$	$n = 8$	$n = 10$	$n = 8$	$n = 26$
Both SACS and PEDS (Path ASD) agree negative	$n = 40$	$n = 32$	$n = 21$	$n = 0$	$n = 93$
Only SACS positive	$n = 17$	$n = 33$	$n = 35$	$n = 9$	$n = 94$
Only PEDS positive	$n = 0$	$n = 2$	n = 1	$n = 1$	$n = 4$
Proportionate Observed Agreement					54.8 % of agreement Cohen's k: 0.16 indicating Slight Agreement (Landis & Koch, 1977)

Note. Only 3 PEDS forms were collected at the 3 year old age point, thus this age group was excluded from analysis of agreement.

Table 4
Comparison between SACS results and reference standard.

Reference Standard (ASD as indicated by ADOS-2+ clinical judgement) across health and early childhood education settings				
SACS Results		ASD	Non- ASD	Total
	SACS Positive	176 True Positive	35 False Positive	211
	SACS Negative	39 False Negative	13,863 True Negative	13,902
	Total	215	13,898	14,113

Note. False negative calculated as number of children screened negative on SACS-R, attended assessment and were found to meet criteria for ASD diagnosis. True Negative presumes that all children who did not attend follow-up assessment did not have ASD.

Table 5
Comparison between PEDS (Path ASD) results and reference standard.

Reference Standard (ASD as indicated by ADOS-2+ clinical judgement) across health and early childhood education settings				
PEDS Results		ASD	Non- ASD	Total
	PEDS (Path ASD)	24 True Positive	3 False Positive	27
	PEDS (other)	120 False Negative	13,966 True Negative	14,086
	Total	144	13,969	14,113

Note. False negative calculated as number of children screened negative on PEDS (PATH ASD), attended assessment and were found to meet criteria for ASD diagnosis (n = 79) + 1 % of children missing PEDS, presumed to have ASD (n = 40.62). True negative was calculated by estimating that 1 % of children for whom PEDS forms were missing (29 % in this sample) would have ASD, based on prevalence rate of ASD in the population, thus True Negative= (Total Sample-TP, FP, FN) x 0.29 × .01.

Table 6
Results of Discriminative validity analysis for SACS-R and PEDS (Path ASD).

Tool	Population	Children screened (n)	Likely ASD (n)	Study Prev	Sensitivity	Specificity	LR+	LR-	Predictive Values	
									PPV	1-NPV
SACS	Prospective MCH and ECE	14,113	211	0.0149	0.82	0.99	325	0.18	0.83	0.01
PEDS (Path ASD)	Prospective MCH and ECE	14,113- (29 % missing = 10,020)	101	0.0102	0.067	0.99	776	0.83	0.88	0.01

Note. Tool, method used for developmental surveillance; Population, surveillance data gathered prospectively in MCH or ECEC settings; Likely ASD, number of children meeting criteria for ASD diagnosis on gold standard assessment; study prevalence, number of children with likely ASD on follow-up/total number screened; LR+, positive likelihood ratio, sensitivity/1-specificity); LR-, negative likelihood ratio, (1-sensivitiy)/specificity; Predictive values, posterior probability; PPV, positive predictive value = the percentage of those positive on the screen who were verified by follow-up assessment as high likelihood of ASD.

symptoms of ASD and miss those with more subtle early signs of ASD. It is recommended that children with 2 or more predictive concerns (Path A) on PEDS be referred for follow-up developmental evaluation (Glascoe, 2013a). In this sample the sensitivity of PEDS (Path A) was only 6.14 %, while the sensitivity of one predictive concern (path B) was 20 %, meaning that only a small proportion of children with ASD could potentially be identified if autism-specific screening or assessment were to be conducted during follow-up in a two-step model. Results of this study demonstrate that reliance on PEDS alone to predict which children would benefit from ASD assessment is not as effective as the SACS-R in either early childhood education or child health settings.

The SACS has consistently demonstrated psychometric properties which are above recommended standards (Barbaro & Dissanayake, 2010). Sensitivity (accurate cases of ASD identified) should be 70–80%, while specificity (accurate cases of non-ASD identified), should be 80 % or above; furthermore, sensitivity should be maximized in order to miss the fewest possible cases of ASD (Glascoe, 2005). The use of the SACS-R is likely to improve predictive power in a population developmental surveillance program as demonstrated in this study where n = 94/217 (43 %) of children who were found to have a high likelihood of ASD were identified by SACS-R, but not PEDS.

More than three quarters of 2-year-olds identified with developmental concerns warranting early intervention had PEDS forms missing; sole reliance on carers completing and returning PEDS forms is therefore problematic, as it increases the likelihood of a child being missed in a universal developmental surveillance system at key age points. Given the variability in attendance at MCH visits and increasing participation in early childhood education services in Australia (Moore & Grove, 2008), it is prudent to equip all early childhood professionals, working in health and education, with effective tools to monitor the development of young children in their communities.

The outcomes of the practical application of SACS and PEDS across health and early childhood education systems in different regions of Australia support published international guidelines recommending a universal system of developmental screening and

surveillance using an autism-specific, validated tool at key age points in early childhood or whenever a parent or provider concern is expressed (American Academy of Pediatrics, 2017). A 2016 review of the AAP guidelines for screening and surveillance concluded that the evidence of effectiveness of currently available tools for identification of ASD in the general population was insufficient and recommended further large scale studies (Siu et al., 2016) As PEDS is currently one of the widely used tools to identify children in the general population who have developmental delays, including ASD, the limitations in sensitivity for identification of ASD across the 3 referral pathways designed to trigger level 2 screening (Path A, B and ASD), as well as the challenges of relying on parents to complete and return screening tools found in this study suggest that careful consideration of application of the tool for this purpose should be undertaken by professionals and policymakers. Evidence of tools with excellent sensitivity and predictive value such as the SACS-R may lead to the revision of screening guidelines in those countries where screening is currently not supported. Tracking specific, early behavioral markers of ASD at key age points during universal developmental surveillance using SACS-R in community-based settings, frequented by young children and families, may be more effective in the early detection of ASD. This study adds to the growing body of evidence that SACS-R is an effective method of universal developmental surveillance that can be used in a range of community settings to make effective and timely referrals to interventions, promoting improved developmental outcomes for children.

7. Limitations

While SACS-R and PEDS results from a large sample of children were analysed in the current study, limitations of comparing data across two different studies are important to note. The number of participants in the early childhood education and care settings is substantially smaller than that of the MCH study, which was a seminal project conducted over several years. The involvement of ECEPs in the process of systematic early detection using SACS, for which efficacy has been established in primary health settings, is intended to promote the application of this research into practice in communities across Australia, particularly in jurisdictions where participation in MCH monitoring is sporadic or not available but participation in ECE settings is more common. As this was a community-based study, the clinicians conducting the follow-up assessments were not blinded to screening results. All available information from screening tools, caregiver report, clinical observations and standardised assessments were used to determine whether or not a child met the criteria for a diagnosis of ASD.

An additional limitation is that it was not feasible to follow-up the entire sample of children who underwent surveillance as not all children identified by developmental surveillance attended follow-up assessments. Children with negative SACS-R and PEDS scores were not assessed. Therefore sensitivity, specificity and predictive values were estimated based on prevalence rates and may increase with greater compliance at follow-up.

8. Further research

Future studies examining enablers and barriers to implementing systematic, universal developmental surveillance using an evidence-based tool such as SACS-R in both early childhood education and health settings are warranted. Recent reforms in the health and disability services sector are likely to impact the referral pathways and resources available for families with young children who are experiencing developmental challenges. Closely monitoring the perspective of key stakeholders including families, educators, primary health practitioners, therapists and policy makers will be essential in optimising outcomes for children for whom there are developmental concerns.

9. Implications

The SACS-R serves as validated method of screening for key social, attention and communication skills at multiple time points during a child's development. It is an effective tool for universal developmental surveillance programs conducted in both primary health and early childhood education settings and is more effective in accurately identifying which children would most benefit from specialised assessment and early intervention than reliance on the parent questionnaire, PEDS alone. It is prudent to build capacity for evidence-based developmental surveillance methods among professionals who regularly work with young children and families across the health and education systems. The idea of universal surveillance, while a worthy policy recommendation, has encountered challenges in practice including barriers to access for children most at risk due to socio-economic and environmental factors, lack of reliable and valid tools for developmental surveillance and the considerable developmental variability in young children (Oberklaid, 2014; Pinto-Martin & Levy, 2004). This study provides real world evidence that some of these challenges associated with accurate and timely early identification of children at "high likelihood" for ASD can be addressed with the use of SACS-R as part of routine developmental surveillance across both health and early childhood education settings.

CRediT authorship contribution statement

Beth Mozolic-Staunton: Conceptualization, Formal analysis, Investigation, Writing - original draft, Project administration. **Michelle Donelly:** Conceptualization, Writing - review & editing, Supervision. **Jacqui Yoxall:** Formal analysis, Supervision, Writing - review & editing. **Josephine Barbaro:** Conceptualization, Methodology, Investigation, Resources, Funding acquisition, Writing - review & editing, Supervision.

Declaration of Competing Interest

All authors declare that they have no conflicts of interest.

Acknowledgments

The authors acknowledge the contribution of MCH nurses and ECEPs who are working to improve processes for developmental surveillance and support children experiencing developmental delays and their families. Funding from the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program, to support the training of MCH nurses and ECEPs who participated in this study is gratefully acknowledged.

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