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**TASMANIA**

Implementation of developmental surveillance for autism using the Social  
Attention and Communication Surveillance-Revised (SACS-R) assessment  
tool for young children in Tasmania, Australia

By

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Centre for Rural Health

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## Declaration of Originality

I, Alison Jane Morse, am the author of the thesis titled *Implementation of developmental surveillance for autism using the Social Attention and Communication Surveillance-Revised (SACS-R) assessment tool for young children in Tasmania, Australia*, submitted for the degree of Doctor of Philosophy. I declare that the material is original, and to the best of my knowledge and belief, contains no material previously published or written by another person, except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright. The thesis contains no material which has been accepted for a degree or diploma by the University or any other institution.

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## **Statement of Ethical Conduct**

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University. The research conducted as part of this thesis was approved by the Tasmanian Health and Medical Human Research Ethics Committee (reference H0016974) and extends on an existing project (H0016006).

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## List of Presentations

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## Glossary of terms and definition of key concepts

AAP <sub>1</sub>	Autism Advisory Panel
AAP <sub>2</sub>	American Academy of Paediatrics
ABS	Australian Bureau of Statistics
ADI-R	Autism Diagnostic-Interview-Revised
ADoN	Assistant Director of Nursing
ADOS-2	Autism Diagnostic Observation Schedule, Second Edition
AHPRA	Australian Health Practitioner Regulation Agency
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
APS	Australian Psychological Society
ASELCC	Autism Specific Early Learning & Care Centre
ASD	Autism Spectrum Disorder (autism) is a heterogeneous, neurodevelopmental condition with numerous origins, sub-types and developmental courses
ASfAR	Australasian Society for Autism Research
Atypical	The social behaviour for the child's age is not as expected, that is, the behaviour is less frequent, inconsistent, or absent
Autism CRC	Autism Cooperative Research Centre
CALD	Culturally and Linguistically Diverse
CFC	Child and Family Centre
CHaPS	Child Health and Parenting Service
CNE	Clinical Nurse Educator
COM	CHaPS Operational Meeting
CSQ-8	Client Satisfaction Questionnaire–8 items
DALY	Disability-Adjusted Life Years
DAT	Developmental Assessment Team

DHHS	Department of Health and Human Services
DoH	Department of Health
DoN	Director of Nursing
DSM	Diagnostic and Statistical Manual of Mental Disorders
DT	Design Thinking
EBP	Evidence-Based Practice
EC	Early Childhood
e-CHaPS	CHaPS electronic health records where children’s health data is stored under their Tasmanian Health Client Index (THCI) reference number
ECEI	Early Childhood Early Intervention
ECIS	Early Childhood Intervention Service
EI	Early Intervention
EPR	Education Performance and Review
GMDS	Griffiths Mental Development Scales
GP	General Practitioner
HCWA	Helping Children With Autism
High likelihood	Strong possibility of autism
Low likelihood	Little possibility of autism
MCH	Maternal and Child Health
MDT	Multidisciplinary Team  A multidisciplinary team consists of a group of medical and allied-health professionals (e.g., paediatrician, psychologist, speech & language pathologist, and occupational therapist) who collaboratively meet the needs of an individual through assessment, diagnosis, and intervention management
MIDI	Measurement Instrument for Determinants of Innovations
MSEL	Mullen Scales of Early Learning
National Guideline	Refers to the <i>National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia</i> , developed and



published by The Cooperative Research Centre for Living with Autism (Autism CRC) in October, 2018

NDIS	National Disability Insurance Scheme
Neurodiversity	A term used to describe autism as a condition due to variations in the human brain, as opposed to a disorder that needs to be cured
NUM	Nurse Unit Manager
OT	Occupational Therapist
PHR	Public Health Record
PEDS	Parents' Evaluation of Developmental Status
RACGP	Royal Australian College of General Practitioners
SACS	Social Attention and Communication Surveillance
SACS-R	Social Attention and Communication Surveillance-Revised
Screening	Involves the use of standardised tools to identify and refine recognised risk. Screening often occurs at one point in time and tends to rely heavily on parent report
SLP	Speech & Language Pathologist
Surveillance	An ongoing process where trained professionals perform skilled observations and collect data of children's behaviour during the provision of health care
THCI	Tasmanian Health Client Index
THS	Tasmanian Health Service
Typical	The social behaviour for the child's age is as expected
UTAS	University of Tasmania

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## Abstract

Autism spectrum disorder (autism) is a neurodevelopmental condition that affects how a person experiences the world and relates to others. The prevalence of autism ranges between 1-3% of population. Through the early identification of children with autism, access to Early Intervention (EI) services may be possible and improved outcomes achieved. Tasmanian children were not being identified as early as possible, which meant they were at increased risk of avoidable developmental delays and prolonged access to intervention services. Early detection includes screening and surveillance then, if warranted, follow up diagnostic assessment, ideally conducted by a multi-disciplinary team.

The Social Attention and Communication Surveillance-Revised (SACS-R) is an autism-specific surveillance tool that detects autism and other developmental delays. It is designed to assist health care professionals to identify behaviours in young children (11-30 months of age) that are indicative of “high likelihood” of autism. The SACS-R tool was introduced into the Tasmanian Health Service (THS) in 2016 as part of a program to improve early identification of autism in this state.

The intended outcome of any innovation is positive change. However, there are often significant gaps between research and practice that result in delays to the implementation of change in practice settings. Introduction of the SACS-R tool in Tasmania required a significant service change involving the Child Health and Parenting Service (CHaPS) nurses (a statewide child assessment and support service), the St Giles Developmental Assessment Team (DAT) and other medical, educational, community and allied health stakeholders.

The aim of this study was to explore the enablers and barriers to the successful statewide implementation of the SACS-R early childhood surveillance program. Implementation Science (IS) principles underpin this study. IS seeks to understand and narrow the gap between the discovery of new knowledge and its application in health care settings. Added to this, a Design Thinking (DT) approach was used to place the end-users at the centre of the research, in this case, the parents and the children undergoing early autism surveillance.

A mixed methods research design was used. Parents, CHaPS nurses and management staff, policy groups, allied health professionals, educators, and doctors (paediatricians, GPs and psychiatrists) were recruited to the study. Data was collected through online questionnaires and surveys (n=113) and semi-structured interviews with participants (n=91). The interviews were audio-recorded, transcribed, and thematically analysed. Quantitative data was analysed using SPSS software.

Following initial analysis, quantitative and qualitative data sets were converged to identify similarities, divergences and new understandings identified by stakeholder groups. By integrating the findings, the enablers and barriers across personal, practice and policy levels were identified and understanding of the complexities of the whole process emerged. Integration also revealed the implications for successful adoption of the SACS-R into routine clinical practice within the public health system.

The key finding is that the SACS-R process was successfully introduced by the CHaPS, including the addition of an 18-month assessment, which meant that young Tasmanian children could be identified as high likelihood for autism, diagnosed, and in theory, able to be supported through access to intervention much earlier than previously possible. Two key enablers were: 1) integration of the tool into the children's appointments with the CHaPS nurses and 2) children being able to access EI services post this initial visit. Two major barriers included 1) a lack of services and 2) insufficient funding. In addition, the use of a pragmatic mixed methodology alongside a DT approach proved to enable a more nuanced understanding of the barriers and enablers from the perspectives of those involved.

Further findings indicate that the nurses had greater confidence in the developmental assessment of young children and in identifying and referring those at high likelihood of autism for diagnostic assessment. Following training, the assessment was embedded into routine practice with relative ease. However, concerns associated with inconsistent language use, lengthy wait times, and lack of services for children with autism and/or other developmental delays were identified by stakeholder groups. There was a need for ongoing refreshers, education and support for nurses and other key stakeholders.

The study shows that additional pathways need to be established to better support children and parents to access timely services, following referral and post-diagnosis, including EI. Identifying and upskilling other professionals in the delivery of the SACS-R would be highly beneficial, along with more adequate staffing. Further research is needed to enable the problem of long wait times for assessment and diagnosis to be effectively addressed.

This study is unique in Australia. It is the first to address the depth of experiences of a broad range of stakeholders across various contexts. While this research is specific to Tasmania, the findings have relevance to other health service jurisdictions. This study will benefit health practitioners, policy makers and the autism community; those who are committed to addressing early neurodevelopmental concerns for the benefit of lifelong positive outcomes.

# Chapter 1: Introduction

This chapter introduces the study, Implementation of developmental surveillance for autism using the Social Attention and Communication Surveillance-Revised (SACS-R) assessment tool for young children in Tasmania, Australia and provides background and context to the research problem, questions, and study design. It also explains the journey that led the author to explore this research topic.

Autism is a heterogeneous condition with numerous origins, sub-types and developmental courses (Masi et al. 2017). Almost 80 years ago, in 1943, Kanner provided the first description of early infantile autism and described his observations of 11 children's development and behaviour (Harris 2018). The children (8 males and 3 females) displayed an "inability to relate themselves" in a typical way from "the beginning of life", difficulties with social interaction, a lack of communication, insistence on sameness, restricted interests, repetitive behaviours, such as hand flapping, body rocking, and spinning, and "autistic aloneness" (Kanner 1943, p. 242). It took another three decades before the possible role of genetic factors in autism was considered (Rutter 2000).

Rimland (1964; 1971) designed the *Diagnostic Checklist for Behavior-Disturbed Children* (Forms E-1 & E-2) which was the first measure for assessing the symptoms of autism. From the mid-1960s onwards, the term autism was used to describe the polar opposite of what it had meant up until that time (Evans 2013), with the term shifting from being applied to individuals who overly fantasised and retreated from reality, a hallmark feature of schizophrenia, to those who did not fantasise at all but in fact failed to develop social relationships (Rutter 1972). Rutter (1972) noted that the disorder can commence up to approximately 30 months of age, but not after that time.

In 1977, the first-ever genetic study of autism was conducted with 21 same-sexed twin pairs (11 monozygotic [MZ: identical] and 10 dizygotic [DZ: non-identical] sets), where at least one twin had infantile autism (Folstein & Rutter 1977). The authors concluded two main findings: there was a significant difference in MZ-DZ concordance which indicated a strong genetic influence; and concordance within the MZ pairs revealed a wide range of deficits, cognitively and socially, which suggested that there may be various presentations within the same condition (Folstein & Rutter 1977). The work of Folstein and Rutter (1977) prompted a range of twin studies and genetic-family studies through the 1980s and 1990s that further investigated and confirmed the role of genetics in autism (Rutter 2000).

Rutter (1978) updated the definition of childhood autism to include four criteria that needed to be observed in the child prior to the age of five: onset prior to 30 months, impaired social and language abilities beyond general developmental level, and insistence on sameness evidenced by restricted interests and repetitive behaviours (Rutter 1978). Rutter's definition was included in the third edition of the American Psychiatric Association's

(1980) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III). This version of the DSM also saw infantile autism reclassified under its own category of Pervasive Developmental Disorders, where previously autism had been subsumed under the category of mental retardation (Volkmar, Cicchetti, Bregman, et al. 1992). The American *National Society for Autistic Children* (1978) proposed sensory sensitivities to the environment be included in DSM-III and although this feature was referred to, it took over three decades for hypo- and hyper-sensitivities to the environment to be included in DSM-5 (Rosen, Lord & Volkmar 2021).

The revised edition of DSM-III was DSM-III-R (1987), which provided further changes to the diagnosis of autism. First, it broadened the diagnostic concept of autism with a change from the term “infantile disorder” to “autistic disorder” to encapsulate the condition as a spectrum and thus supporting a developmental approach across the lifespan (Rosen, Lord & Volkmar 2021). Second, the 16 criteria were structured into three categories, referred to as the triad of impairments: impairments in reciprocal social interaction; impairments in communication; and restricted interests/resistance to change and repetitive movements (Volkmar, Cicchetti, Bregman, et al. 1992). Third, an additional, subclinical threshold category was created, pervasive developmental disorder not otherwise specified (PDDNOS), to allow for developmental change and developmental level and to enable greater flexibility in the diagnosis (Volkmar, Cicchetti, Cohen, et al. 1992). The DSM-IV (1994) saw the removal of fragile X syndrome as one of the sub-categories of autism. Fragile X syndrome is one of the most common inherited causes of mental retardation and whilst it can be associated with features of autism it is a genetic condition (Crawford, Acuña & Sherman 2001). DSM-IV-TR (2000) then included five disorders under one umbrella category of Pervasive Developmental Disorders (PDD): autistic disorder, Childhood Disintegrative Disorder (CDD), Asperger’s disorder, Rett syndrome, and PDD not otherwise specified (NOS), also referred to as atypical autism (Rubenstein et al. 2017).

In May 2013, with the release of the fifth edition of the DSM (DSM-5: 2013), the autistic landscape underwent a further major global change. For the first time, autism was now considered as a single diagnostic dimension. The DSM-5 presented a revision of the diagnostic criteria for autism, including removal of “Language Disorder” as a separate criterion and reducing the triad of impairments to two: social communication, and restricted, repetitive behaviours (London 2018). Four previously separate disorders (autistic disorder [autism], Asperger’s disorder, CDD, and PDD-NOS) were now all encompassed under the one category of Autism Spectrum Disorder (ASD or preferably ‘autism’). Rett syndrome was removed from DSM-5 as although its presentation mimics that of autism and it is associated with autism, research findings identified that it is a genetic disorder (Young et al. 2008).

During the past eight years or so, since the establishment of autism as a neurodevelopmental condition, the Australian autistic community, along with its associated

agencies and medical, allied health and therapeutic professionals, has experienced several substantial developments. In March 2013, prior to the unveiling of the DSM-5, came the establishment of the world's first national, cooperative research effort focused on autism, the Cooperative Research Centre for Living with Autism, referred to as the Autism, CRC. The launch of the National Disability Insurance Scheme (NDIS) followed in July 2013. The NDIS enabled Australians with a range of disabilities, including autism, to be financially supported through a model that aims to give them more choice and control as well as more appropriate types of support. Tasmania was the first Australian state to fully roll out the Scheme over six years, commencing on 1 July, 2013 and achieving full implementation by 1 January, 2019. At the time of writing, in Tasmania, the NDIS provides funding support to approximately 10,500 people between birth and 64 years of age. Coinciding with this, in 2014 the Autism Advisory Panel (AAP<sub>1</sub>) was established by the then Minister for Human Services in Tasmania, The Honorable Jacquie Petrusma MP. The role of the AAP<sub>1</sub> was to represent the autism community and address their support needs across the lifespan. Amongst many of the AAP<sub>1</sub> recommendations was that Tasmania take up early surveillance for autism through the utilisation of the SACS-R and therefore, early identification of the condition.

Currently, autism is at the centre of interest of the neurodiversity rights movement. This movement is opposed to autism being considered a disorder to be cured or eliminated (Baron-Cohen 2017). Rather, the neurodiversity rights approach, positions autism as an outcome due to variations in the human brain; that is, a neurodiverse way of processing the world rather than a neurological disorder. Neurodiversity, in this context, requires understanding and acceptance from neurotypical people. It is this thinking that encourages the use of the term 'autism' in preference to Autism Spectrum Disorder or ASD, and which I use throughout this thesis. Removing the word 'disorder' from the condition, and use of the word autism on its own, is also thought to be less stigmatising (Baron-Cohen, Scott, et al. 2009), an issue that is of great importance to the autistic community.

This thesis closely examines one innovative process that was introduced into the Tasmanian Health Service (THS) system in line with these developments, to prospectively identify infants and toddlers at high likelihood of developing autism early, the SACS-R. The language that the developers, Dr Barbaro and her research team, use to describe children's assessment outcomes has changed over the course of this project to reflect greater sensitivity to the autistic community. At the commencement of this study, the term "at risk" for autism was used to indicate that a child had an atypical SACS-R assessment, that is, they had an atypical result on three or more key items on the SACS-R. As time has progressed, the term "high likelihood" replaced "at risk". I have also adopted the most current term, that is, at high likelihood, to achieve consistency and to avoid confusion throughout the thesis.

The implementation process involves early identification of autism through the administration of the SACS-R assessment tool by the Child Health and Parenting Service (CHaPS) nursing staff. The CHaPS nurses are registered nurses with additional training in child and family health. They provide support and information to parents on a range of topics including child development.

## **1.1 Rationale and significance of the research**

Of the neurodevelopmental conditions that a child could possibly be diagnosed with (e.g. intellectual disability, communication disorder, attention-deficit/hyperactivity disorder [ADHD], specific learning disorder, motor disorder), autism has a particularly significant profile locally, nationally, and globally. This is perhaps due to its prevalence. Worldwide estimates indicate that every year, hundreds of thousands of parents are told that their child has autism (Treffert 2011). Currently, more children are diagnosed with autism than with cystic fibrosis, AIDS, and cancer combined (Rogers, Dawson & Vismara 2012). However, its profile may also be due to the complexity and variations of presentations, the impacts on wellbeing and quality of life, the economic burdens, and the complicated and disjointed diagnosis and treatment pathways (diagnosis, intervention, support, and therapeutic resources) that accompany the condition (Baxter et al. 2015; Elder, Brasher & Alexander 2016; Hsiao 2016; Morris 2014; Rahm et al. 2015; Robertson 2010; Rubenstein et al. 2018; Thomas et al. 2017; Ward, Sullivan & Gilmore 2016; Zwaigenbaum, Bauman, Choueiri, et al. 2015).

Tasmania is a rural island state of Australia with growing autism prevalence. The annual birth rate of Tasmania is approximately 5,500 babies. Based on the number of children who were monitored with the SACS-R during the research project, it can be estimated that the CHaPS nurses assessed around 76% of infants at least once. Between 1-2% of those children will go on to receive a diagnosis of autism (Elsabbagh et al. 2012; Lyall et al. 2016; Thomas et al. 2017). Australian prevalence data reflects increased numbers of diagnoses in recent years, with 2015 statistics specifying 1 in 150 people has autism, with 83% of those aged under 25 (AIHW 2017; Bent, Dissanayake & Barbaro 2015).

The burden of disease of autism was first considered in the Global Burden of Disease Study 2010 (GBD 2010), which estimated global prevalence at one in 132 individuals, which equated to 52 million people with autism and 7.7 million Disability-Adjusted Life Years (DALYs) worldwide (Baxter, Brugha, Erskine, Scheurer, Vos, and Scott, 2015). Burden of disease is the calculation of the influence of a particular health issue by assessing various factors (e.g., economic impact, morbidity, premature mortality, and disability) and then quantifying the variables using DALYs. The burden of autism begins in the early years and continues across a lifetime. Thus, as autism is an unremitting condition, inherent within the lifelong diagnosis are significant consequences. Many individuals with an autism diagnosis require support from infancy to EI, including involvement from health and educational



agencies, vocational skill development and employment support services. Timely access to these types of interventions leads to improved long-term functioning (Colombi 2017; Schreibman et al. 2015).

It is common to find that children with autism have a high incidence of comorbid conditions (Rubenstein et al. 2018) including: other neurodevelopmental disorders, e.g., ADHD (Septier et al. 2019); mental health issues, e.g., anxiety disorders (Teh et al. 2017) and depression (Ozsivadjian, Hibberd & Hollocks 2014); and health disorders, e.g., epilepsy (Mazarati, Lewis & Pittman 2017). Given the complexity of autism presentations, parents of children with an autism diagnosis often experience accompanying emotions of stress (Farmer & Reupert 2013), grief (Fernandez-Alcantara et al. 2016), depression (Gatzoyia et al. 2014) and feelings of loneliness and isolation (Ludlow, Skelly & Rohleder 2012).

It is well documented that there exists significant financial impact for parents from services (medical, therapy and intervention agencies), educational supports and from the time caregivers spend out of the work force (Dillenburger et al. 2015; Horlin et al. 2014; Lavelle et al. 2014).

Children who display behavioural indicators that they may be at high likelihood of autism need swift access to an early assessment process and diagnostic conclusion (Becerra-Culqui et al. 2018). The later a diagnosis of autism is made, the longer that children, their parents, and their teachers have to wait before there is access to appropriate support, intervention, resources, and education (Howlin & Asgharian 1999). Long waiting times to diagnosis, including total time taken from referral to assessment to diagnosis, is the main variable responsible for delays in prompt diagnosis (McKenzie et al. 2015). Furthermore, families on waitlists for follow-up intervention services experience challenges in their family quality of life (Jones, Bremer & Lloyd 2017). Education and awareness are critical for medical and allied-health professionals to heed parental concerns, identify developmental delays early and initiate referrals so that families can benefit from clinical and therapeutic advances in early intervention (Becerra-Culqui et al. 2018).

## **1.2 Early diagnosis**

Early diagnosis is important as it leads to more positive outcomes for the child's overall functioning. Research points towards EI as one of the key factors for prognosis, with recent evidence indicating that younger children are more receptive to intervention than children who begin therapy at a later age (Virues-Ortega, Rodríguez & Yu 2013; Zwaigenbaum, Bauman, Fein, et al. 2015). Therefore, early diagnosis is critical for timely access to services (Woolfenden et al. 2016); EI for improving the child's prognosis (Virues-Ortega, Rodríguez & Yu 2013); developmental outcomes and quality of life (Schreibman et al. 2015); and for reducing the financial impact endured by families and society (Dunlap & Filipek 2020). Lifelong improvements result therefore from the minimisation of delay in various skills, particularly social communication skills, optimised development, and

improved parental well-being from lowered stress from untreated autism (Zwaigenbaum, Bauman, Stone, et al. 2015).

The neurodevelopmental condition of autism and late diagnosis is a real-world concern. Autism is most commonly identified in children from 0-14 years (AIHW 2017). Recent research has enabled autism diagnoses to be accurately made during the second year of life (Barbaro & Dissanayake 2017; Steiner et al. 2012). In Australia, the average age for an autism diagnosis is between 4 years, 1 month in children under the age of 7 (Bent, Dissanayake & Barbaro 2015), 6 years in children aged up to 12 years (May & Williams 2018). In New South Wales, the average age of diagnosis was 5 years (Gibbs et al. 2019).

Providing surveillance opportunities as part of children's routine health checks enables earlier diagnosis, either an autism diagnosis and/or comorbid diagnoses or another diagnosis. In October, 2018, *A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia* was developed and published by The Cooperative Research Centre for Living with Autism (Autism CRC). The *National Guidelines* recommend and support the early and ongoing surveillance of children. The American Academy of Paediatrics (AAP<sub>2</sub>) recommends regular developmental surveillance and screening to detect the early emerging symptoms of autism (Johnson & Myers 2007). For example, the Brief Infant Toddler Social Emotional Assessment (BITSEA), a 42-item screener, is used to identify social-emotional/behavioural problems and delays/deficits in social-emotional competence in children 11-48 months old, with 19 items describing behaviours consistent with autism (Giserman Kiss et al. 2017).

Unfortunately, the identification, diagnosis and intervention journey of families is frequently a disjointed process that can have negative impacts on children and families (Boshoff et al. 2019; Crane et al. 2016; Ho et al. 2014; Moh & Magiati 2012; Wiggins, Baio & Rice 2006). Given this context, it is understandable that early identification of autism is considered by the autism community to be an Australian public health priority. It is critical that any unnecessary delays with regard to assessment and diagnosis are avoided.

Potential opportunities exist to improve the early identification, intervention, and administration of therapy in a variety of settings: medical, paediatric, allied health, childcare and schools in which children are involved. However, these environments are currently underutilised.

### **1.3 Studying the SACS-R rollout**

Barbaro and Dissanayake (2010) developed a surveillance tool, the Social Attention and Communication Study (SACS), which successfully identifies children at risk of autism between 12 and 24 months of age (Barbaro & Dissanayake 2010). The SACS was revised in 2012, with improved psychometric properties (SACS-R) (Barbaro & Dissanayake 2013). The SACS-R is a surveillance tool that enables the assessment of different key developmental milestones depending on the presenting age of the child to support early identification and

intervention. The SACS-R tool and the SACS-R program fulfil the recommendations of both the AAP<sub>2</sub> and the Australian *National Guidelines*.

In parts of Australia, internationally (South Korea, Japan, Bangladesh, Poland, Nepal, and China) and across Tasmania, the SACS-R is used to assess 12-24 month old children's social attention and communication skills. In Tasmania, prior to the use of the SACS-R, one of the ways that developmental progress was assessed in infants was through the Parents' Evaluation of Developmental Status (PEDS). Parents completed the PEDS, a standardised questionnaire which indicates parental concerns regarding development, prior to attendance at their child's CHaPS health check appointment. A comparison of the surveillance (SACS-R and the Parents Evaluation of Developmental Status [PEDS]) and screening tools (Modified Checklist for Autism in Toddlers [M-CHAT]) that are utilised in Australia, concluded the SACS-R to be the more effective assessment tool (Mozolic-Staunton et al. 2020).

The work of this dissertation builds on a larger study lead by Professor Cheryl Dissanayake that investigates the effectiveness of the SACS-R program. The Tasmanian CHaPS and the Victorian Maternal and Child Health Service (MCH) nurses were trained by Dr Josephine Barbaro, the creator of the SACS-R tool, to prospectively identify infants and toddlers who are at high likelihood of developing autism. Tasmanian and Victorian nurses, 101 CHaPS and 126 MCH, respectively, attended workshops. The nurses were trained in social-communicative development (typical and atypical presentations), early behavioural indicators of autism, the use of the SACS-R checklists (Appendix A), how to raise concerns with parents, the referral pathway, and the use of *Salesforce*. *Salesforce* is a secure electronic database which the nurses used to enter children's assessment data. Following training, the nurses were able to undertake surveillance with 11-30 month old children who attended the CHaPS and MCH sites for health checks.

The SACS-R training was presented to CHaPS staff in July, 2016. Nurses were required to use three checklists: one for each of the targeted age cohorts: 12, 18 and 24-months old. Each checklist is comprised of a specific number of items and a window for administration. The 12-month assessment includes 11 behavioural items that can be administered between 11 to 15 months. The 18-month assessment has 14 items that can be administered between 16 to 21 months. The 24-month assessment contains 15 items that can be administered between 22 to 35 months. To further explain the behavioural items on the checklists, the CHaPS staff also watched videos that demonstrated what a 'typical' and 'atypical' behaviour looks like. Atypical behaviours are those that are not what would be expected, given the presenting age of the child. There are five key items on each checklist. The three checklists all have the first three key items in common: pointing, eye contact and waving 'bye-bye'. The 12-month checklist then has imitation and response to name as its final two key items and both the 18 and 24-month have social communication (showing) and pretend play as their final two key items.

This is the first time that the SACS-R has been administered across a complete Australian state, Tasmania, having only been partially implemented in Victoria, New South Wales, and Queensland. In Tasmania, if a child's behaviour indicated atypical behavioural presentation on three of the five key items for their age, they were referred through to the St Giles DAT for further assessment utilising the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) and the Autism Diagnostic Interview-Revised (ADI-R). The SACS-R process is depicted in Figure 1-1 below.

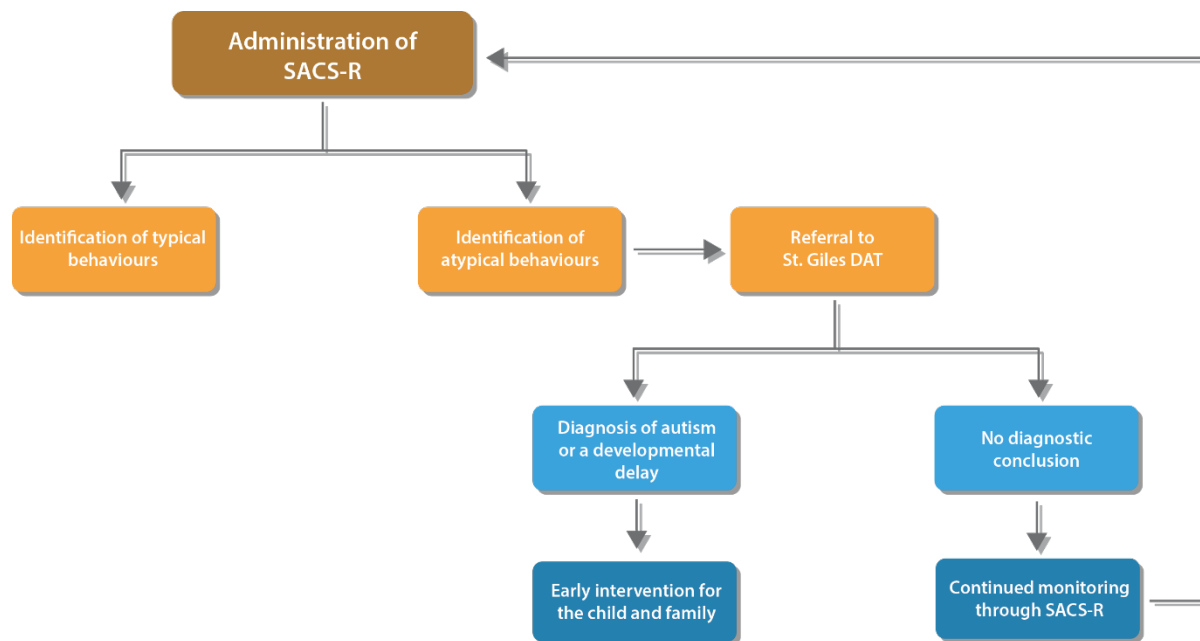


Figure 1-1. Flowchart of the administration of the SACS-R to young children in this study

The SACS-R tool can be an effective intervention to address multiple EI problems, however, its ongoing use and its effectiveness is dependent upon its successful implementation at the population level. It is necessary to identify the barriers that may inhibit the use of the SACS-R as well as enablers for its successful implementation, so that a lasting, positive change of practice within the public health service can be achieved.

It is not the focus of this study to evaluate the success of SACS-R tool. That work is being covered in the larger project and the report is pending. This study contributes to delivering the project's medium-term outcomes (see program logic model, p 44). That is, the understanding of the enablers and barriers to successful implementation; parental support; CHaPS nurses' skill development; and parental community connection.

Integral to the introduction of a health service innovation is the selection and application of the appropriate evaluation methodology. This thesis is informed by implementation science (IS) processes, that is, the influences on healthcare and the

implementation of evidence-based practices (EBPs) and draws on a design thinking (DT) approach (Roberts et al. 2016). A DT approach rests on the idea that successful application of an efficient innovation method holds the patient's experience at the front and centre of the process. It enables researchers to understand the key issues in order to create, improve or extend existing procedures with regard to tool design and service delivery. This is the first study that pairs autism surveillance and the assessment process with the use of a DT approach. The findings and learnings from this project will be useful not only in Tasmania, but to other jurisdictions and settings in Australia, and globally.

### **1.3.1 Autism CRC and AAP<sub>1</sub>**

The Autism CRC is the world's first national, cooperative research effort focused on autism across the life-span. The Australian Federal Government has allocated eight years of funding to the organisation, which also receives cash and in-kind support from Autism CRC participants. The research aims of the organisation include improving the accuracy of diagnosis to facilitate early intervention; to optimise educational environments throughout Australia so as to provide students with autism with the most appropriate opportunities to develop socially, behaviourally and academically, and to provide teachers and health professionals of young people with autism with the most effective strategies to manage complex behaviours; and to identify the ongoing needs of adults with autism (Autism CRC 2020). The current research is supported by a three-year scholarship provided by the Autism CRC.

The feasibility of the current study was due to the inception of the AAP<sub>1</sub>. During the AAP<sub>1</sub>'s four-year tenure, the participants were comprised of various members including a range of consumer representatives (e.g., people with autism and parents of children with autism), members of support and advocacy organisations, allied health professionals, researchers, educators, and government representatives. The Autism CRC made the recommendation to the AAP<sub>1</sub> that Tasmania would be suitable for a statewide rollout of the SACS-R to increase early autism surveillance and hence, early diagnosis and access to intervention services in a timely way.

### **1.3.2 Background of author**

A love of children and families underpins much of what I have done in my career. At the age of 22, I completed a Bachelor of Education (1989) and was a teacher for over two decades. Teaching brought to my attention the different neurodevelopmental conditions that can be identified in children. Moreover, the various impact that these conditions can have on the individual across numerous aspects of their functioning: social, emotional, behavioural, sensory, academic, and their capacity to participate in additional activities, e.g., sports carnivals. These conditions may also impact their family, from challenges with school attendance, administration of medications, "meltdowns", and completing homework. From time to time, a parent would request that I complete a questionnaire, which had usually

been provided by a psychologist. I often wondered that if a lifelong condition is being investigated, why is it only gaining attention now? These experiences led me to become very interested in the area of neurodevelopmental concerns for many of my teaching years.

In 2005, when my youngest child started Kindergarten, I decided to return to UTAS to study psychology. I completed my Graduate Diploma in Science, followed in 2009 by a Bachelor of Science with Honours.

It was during my Masters studies when I was fortunate to be assigned to the newly-opened, Autism Specific Early Learning Care Centre (ASELCC) in Burnie. ASELCC is a purpose-built day care for young children (either with traits of autism or an autism diagnosis) where they can access EI and learning. I experienced involvement in a multi-disciplinary team conducting assessments with children under the age of five and providing parents with support.

Following graduation from UTAS with a Masters in Clinical Psychology (2013), I went on to complete my endorsement to become a Clinical Psychologist. I worked for five years at St Virgil's College (Grades 3 to 10) as their College Psychologist and two days per week in private practice. During my first year in private practice, I worked with a team of well-regarded psychologists, who specialised in the area of assessment, diagnosis, and treatment of autism. This set me again on a pathway similar to the work I had been doing at ASELCC that involved young clients requiring autism assessment or who already had an autism diagnosis and were needing intervention. The next few years saw me meet and support a wide range of people of all ages, from the very young to older adults, to provide autism identification, assessment, diagnosis, and intervention.

In July 2016, an Autism CRC email communication advertised a PhD research project: 'Developmental Surveillance of Autism in Tasmania'. I was motivated to apply for the project for several reasons. First, I had been working clinically in the neurodevelopmental space for almost a decade and was very interested in the research that surrounded the topic of autism. Second, my psychology qualifications and experience along with my earlier professional background in teaching indicated that I would be a suitable candidate. Third, I had a desire to conduct further research in an area in which I was very passionate. Finally, I am a proud Tasmanian, having lived here all my life and raised a family in this state. Undertaking this research project has enabled me to demonstrate that with hard work and dedication, following your passion and applying your skills can result in a positive legacy, both personally and professionally. In addition, this research has provided an opportunity for Tasmania to showcase this leading-edge body of work from our island state which will positively influence improved outcomes for individuals diagnosed with autism and developmental delays now and into the future.

Through my experience as a clinical psychologist and my work within the autism field which involves assessment of children with neurodevelopmental concerns, I already have a

good understanding of the experience of parents in the autistic community. I have demonstrated that I have the skills and capacity to show empathy and knowledge not just about the condition itself, but also from a parent perspective. During past experiences I have been given feedback that my interpersonal aspects of communication effectively demonstrate empathy and understanding.

#### **1.4 The research questions and study aims**

The overarching research question of this study is: What are the enablers and barriers to a successful statewide implementation of the SACS-R into the public health system, so that infants at high likelihood of autism and developmental delays are identified in a timely way? The supplementary research question is: What information does the SACS-R data provide regarding the value of the specific 18-month assessment, only administered in the South of Tasmania? It was hypothesised that 1-2% of children who go through the SACS-R assessment process will be diagnosed with autism, and that data gathered from stakeholders will highlight the enablers and barriers to successful implementation of the SACS-R into the Tasmanian public health service.

The overall aim of this study was to explore the enablers and barriers to the successful statewide implementation of the SACS-R early childhood surveillance program. By integrating the core perspectives of key stakeholders, the barriers and enablers can be identified, understood and addressed in order to facilitate successful adoption of the SACS-R into routine clinical practice. The study draws on insights from a wide range of people (parents, CHaPS nurses, CHaPS management, St Giles Developmental Assessment Team [DAT], Autism Specific Early Learning & Care Centre [ASELCC], the AAP<sup>1</sup>, Early Childhood Intervention Service [ECIS], Autism Tasmania, members of Parliament, allied health professionals, and members of key health and educational associations) involved in the process of surveillance, assessment, diagnosis, support, and policy regarding autism in Tasmania. Their understandings are provided through the collection of quantitative and qualitative data.

A secondary research goal is to determine if the 18-month assessment is worthwhile and to investigate if there is evidence to support the benefit of its administration, alongside the 12 and 24-month assessments.

#### **1.5 Summary of research design, methods and procedures**

A mixed methods concurrent dominant status design was used, in which qualitative and quantitative data were collected in parallel, analysed separately and then merged (Creswell & Clark 2017) to compare and discuss similarities and differences of both quantitative (numeric) and qualitative (narrative) data. Several sources of data were gathered at the same time in the study. The SACS-R *Salesforce* data was collected by the CHaPS nurses for the larger study as well as to inform the current study. Survey data (from

the *Client Satisfaction Questionnaire* [CSQ-8] and *Measurement Instrument for Determinants of Innovations* [MIDI]) were used to measure the relationship between the factors (e.g., parent satisfaction; CHaPS views on the implementation of the SACS-R surveillance tool, clinical use of the SACS-R, organisation of the Tasmanian CHaPS, and the implementation process). Stakeholder perspectives regarding the SACS-R surveillance program were elicited using interviews.

My approach to evaluating this practice change was to place the parent and their child at the centre of the process, in line with DT principles. DT also informed the decision to invite key stakeholder groups to engage in the study and speak freely about their experience of the SACS-R, including the surveillance process, and further assessment at St Giles Child Health & Disability Support Services (either Hobart or Launceston) – in the context of understanding the best outcomes for parents and children. A DT approach utilises collaboration to aid understanding, development, and evaluation of the needs of the stakeholders and their responses regarding the implementation of the SACS-R project. Parents, nurses, service managers, assessment teams, support agencies, allied health professionals and representatives from health and educational associations were recruited to participate in this research.

## **1.6 Thesis structure**

Following this opening introductory chapter, the Literature Review (Chapter 2) is where the scholarship on the topic and framework for this study is described. Methodology, Design and Methods (Chapter 3) are explained under sub-headings of mixed methods study design, ethical considerations, project schedule, design thinking, sampling method, participants, inclusion and exclusion criteria, procedures, SACS-R, data collection, data management and storage, and data analysis. The Results chapter (Chapter 4) addresses the major research question by way of the study findings. Details of the analyses of the quantitative and qualitative data are presented. The chapter concludes with the integration of the findings, identifying the areas of agreement, divergence, and expansion. The key findings and secondary findings are interpreted in the Discussion chapter (Chapter 5). Overall conclusions are presented in Chapter 6. This final chapter also reiterates the purpose and design of the research, outlines the significance and the limitations of the study, and makes recommendations for further practice, policy, and research.



## Chapter 2: Literature Review

This chapter presents and evaluates literature relevant to autism, its early detection, and successful interventions. The problem under investigation are the barriers and enablers to the early identification and diagnosis of autism through the use of the SACS-R tool. The chapter is organised in relation to the key components comprising the research question, which are autism, public health surveillance, implementation science (IS), theories of change in health care, and Design Thinking (DT).

### 2.1 Search strategy

To ensure that the maximum number of relevant studies in the above fields were captured, a comprehensive electronic search was conducted on nine scientific literature databases (Google Scholar, CINAHL, PubMed/MEDLINE [National Library of Medicine, Bethesda, MD], PROQUEST, Health and Medical Complete, SCOPUS, OVID, Web of Science and PsycINFO). These databases were systematically searched for journal articles and reviews published from 2000 to 2020. The search terms used for the initial scoping for this literature review is listed in Table 2-1 below.

**Table 2-1. Search terms utilised**

Area	Search terms
Population	Infants, children
Condition	Autism spectrum disorder
Concepts and theories	Design thinking, implementation science, change theory, public health system, surveillance, screening, health innovation
Outcomes	Early diagnosis, early intervention, improved outcomes, access to health services

The literature review was limited to the following inclusion criteria: peer-reviewed, research studies published in the English language which included participants from key stakeholder groups (parents, nurses and organisations that assess young children's development). The literature was searched in a systematic way and the same search process was replicated across all databases.

### 2.1.1 Selection of articles

The initial search result yielded 132,998 articles. The search was a consolidation of these five search terms (autism [49,100], public health surveillance [49,400], change theory in health care [17,800], design thinking [498], and implementation science [16,200]). Of these, 110,498 articles were available after duplicates were removed and when screened using title and abstract. A total of 22,500 studies were reviewed for title, abstract, relevant content, and snowballing of reference lists. The articles were filtered by applying different combinations of the search terms and using Boolean operator “OR”. Following this process, the final number of articles retrieved was 2,465. These articles were reviewed for relevance and then data extraction commenced. Figure 2-1 below shows the PRISMA flow diagram (Page et al. 2020) for the literature search and articles selection process.

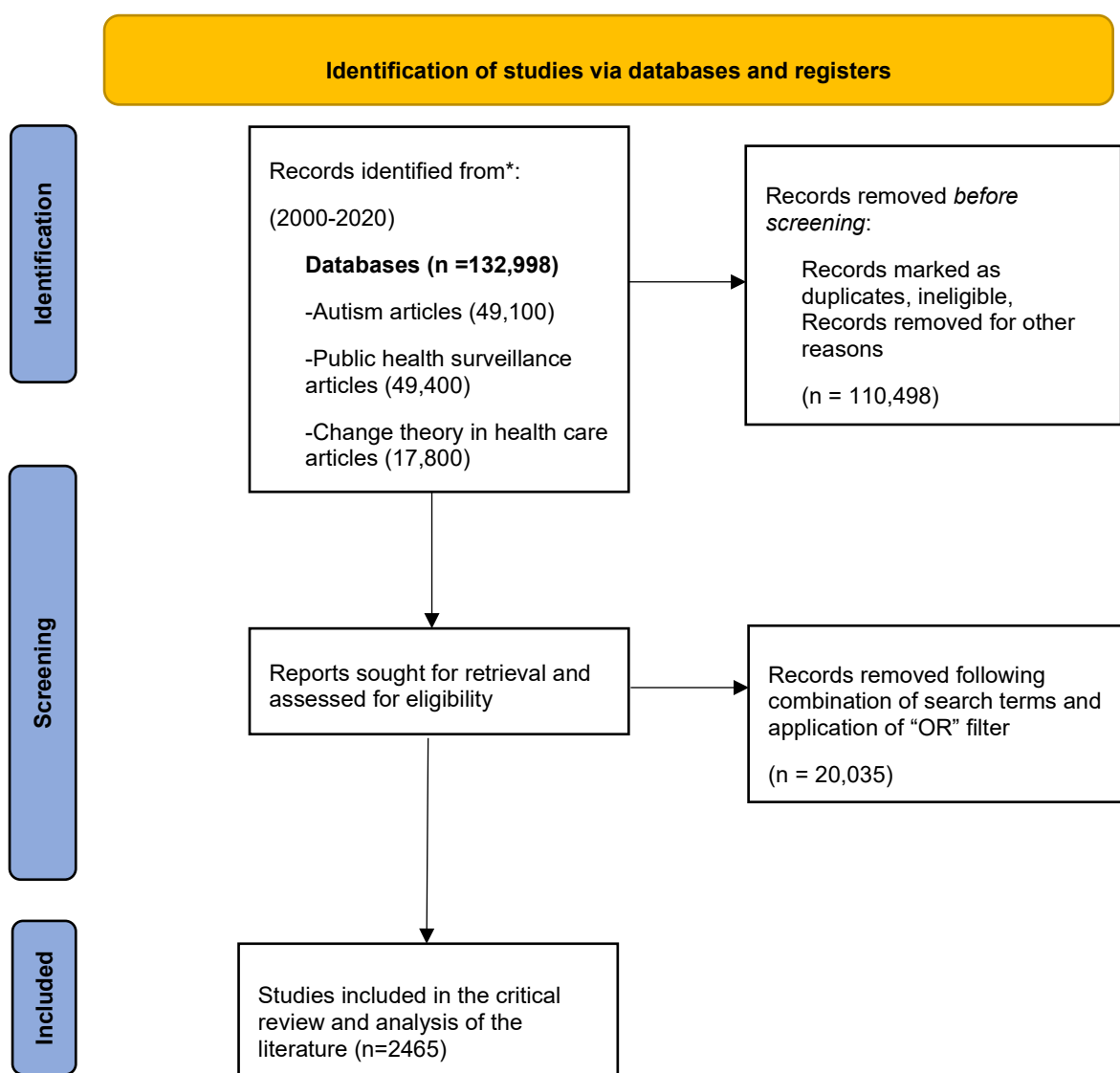


Figure 2-1. PRISMA flow diagram for literature search and article selection process

## 2.2 Autism

Autism as a singular classification is a new inclusion in the fifth edition of the *Diagnostic and Statistical Manual* (DSM-5) (American Psychiatric Association 2013). Autism is a complex, lifelong, neurodevelopmental condition with symptoms generally emerging in early childhood that comprise a range of challenges with social attention and communication, adjusting to unexpected change, cognitive empathy, repetitive behaviour, and narrow interests (Baron-Cohen 2017). The condition affects a person's daily functioning and impacts how they experience the world and relate to others.

The behavioural traits of autism are usually present prior to the age of three, however, there is great variance in young children's attainment of developmental milestones, which calls for the need to ensure that every child's progress is monitored so that any concerns can be discussed as they arise. Many children first come to clinical attention for autism when they reach school age or even later in life as challenges may not be clear until social demands exceed limited abilities to respond to social situations (American Psychiatric Association 2013; Hyman, Levy & Myers 2020; Lobar 2016; Volkmar & McPartland 2014).

The developmental challenges and symptoms of autism can vary greatly between individuals, in both nature and severity, but also in the same individual over time, alongside problems with mental and physical health (American Psychiatric Association 2013; Colombi 2017; Keenan et al. 2010; Whitehouse et al. 2017). Moreover, people with autism often experience ongoing stress as they navigate a challenging world, and thus, autism can be seen as a fluctuating disorder, with functioning varying significantly across the lifespan.

Rogge and Janssen (2019) investigated the types of costs related to autism across eight countries, including Australia, from the perspectives of the individual, family, and society. They sorted the costs into six areas: medical and healthcare services; therapeutic; education; lost productivity for adults with autism; informal care and lost productivity for caregivers; and accommodation, respite care, and out-of-pocket expenses (Rogge & Janssen 2019). Their findings were that autism brings with it a significant economic burden for individuals and families. Costs for families who have a child with autism are greater than costs for families with a neurotypical child. Furthermore, the more severe the condition, the greater the cost. The cost associated with education, early intervention, care, and individual and parental productivity loss are among the greatest costs across the lifetime (Rogge & Janssen 2019).

### 2.2.1 Autism research history

Autism was a term first coined in 1911 by Swiss psychiatrist Eugen Bleuler (Shailesh et al. 2016). He originally used the word 'autism' to describe the aloof and withdrawn presentation of some children that he had observed (Evans 2013). Bleuler noted the behaviours seemed similar to adults who had 'schizophrenia', a term he also coined, and

this application of the word continued until the 1950s (Evans 2013). Between the years 1911 and 2013 the concept of autism has undergone a radical transformation (Wolff 2004). Since Bleuler's influence, there has been an extensive volume of papers that have established the progression in understanding autism. There are, nevertheless, four landmark papers that have made a distinct and highly significant research contribution to the autism field.

The first paper includes the earliest explanation of the syndrome of 'infantile autism' by Kanner, a child psychiatrist (Kanner 1943). He linked the absence of parental connection to the occurrence of autism, which in turn led to an exploration of "refrigerator mothers". In 1977 the first autism twin study was published, the second of the landmark papers, which identified the influence of genetics (Folstein & Rutter 1977). This research was pivotal not just because of its neurobiological significance, but because it also meant that the idea that parents were responsible for autism ("refrigerator mothers") could now be abandoned. In the third key paper, Baron-Cohen and colleagues (1985) investigated the cognitive ability of children with autism to attribute beliefs to others - applying the 'theory of mind' - through the administration of the false-belief task. The fourth ground-breaking paper involved the detection of six mutations in the MeCP2 gene as responsible for Rett syndrome (Wan et al. 1999). As a result, the syndrome was no longer included as part of a neurodevelopmental category of autism, as it had been, and was excluded from the DSM-5.

Autism as a concept is now about a century old, and generally, people's understanding of the condition is predominantly still disorder-focused (Baron-Cohen 2017). Researchers, along with many adults with the condition, are questioning the appropriateness of autism continuing to be categorised as a disorder and proposing a move towards understanding autism through a strengths-based and neurodiversity lens (Baron-Cohen 2017; Cage, Di Monaco & Newell 2018; Robertson 2010; Zolyomi & Tennis 2017). As a result, the term 'neurodiversity' is gathering impetus and it is increasingly being used to describe brain differences instead of deficits, unique identity, and individual differences in people with autism (Kapp et al. 2013). Zolyomi and Tennis (2017) report that the past two decades has seen a shift in the way autism is viewed and they suggest that there is now a reduced emphasis on deficits and a greater emphasis on neurological differences.

Underpinning this approach is the evidence that people with autism can have incredible cognitive strengths, e.g., attention to detail, creative thinking and problem solving, technical abilities, and memory for detail (Baron-Cohen, Ashwin, et al. 2009; Baron-Cohen 2017; Best et al. 2015; de Schipper et al. 2016). There is a push for adults with autism to drive this change. Cage and colleagues (2018, p. 1379) argue that if enduring stereotypes are to be broken and autism stigma is to be reduced, then "autistic adults themselves must be a key source of information for improving non-autistic individuals' attitudes". Nevertheless, parents of individuals who have more severe presentations of autism have expressed a converse view: that a neurodiverse approach could minimise the challenges for those most impaired (Happé & Frith 2020; Lord et al. 2018).

### 2.2.2 Prevalence

Between 1-2% of the population is affected by autism (Elsabbagh et al. 2012; Lyall et al. 2016; Thomas et al. 2017). Autism is generally identified in younger people, with 83% of the people with a diagnosis aged under 25 (Australian Bureau of Statistics [ABS], 2016). Current findings demonstrate that incidence and prevalence estimates of autism and disorders related to the condition have significantly increased over the past three decades (Elsabbagh et al. 2012). In recent years, the number of people with autism in Australia has seen a considerable rise. In 2009 it was estimated that about 64,400 people had autism (ABS, 2012). Since 2009, there are an estimated 115,400 people diagnosed with autism, an increase of 79% (ABS, 2012). Estimates by the Centers for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDMM) Network indicated that in 2014, overall prevalence of autism for children in the United States aged eight years was one in 59 children (Baio et al. 2018). In 2015, according to the Australian Bureau of Statistics Survey of Disability, Ageing and Carers, 164,000 people were estimated to have autism. This number equates to approximately 1 in 150 people.

In 2009, 2012 and 2015, autism was most prevalent in school-aged children. Prevalence of autism, according to diagnoses calculated, increased across all age cohorts between 2009 and 2015 as shown in Figure 2-2. However, the 5-14 age group experienced the greatest increase during those seven years (Australian Institute of Health and Welfare 2017).

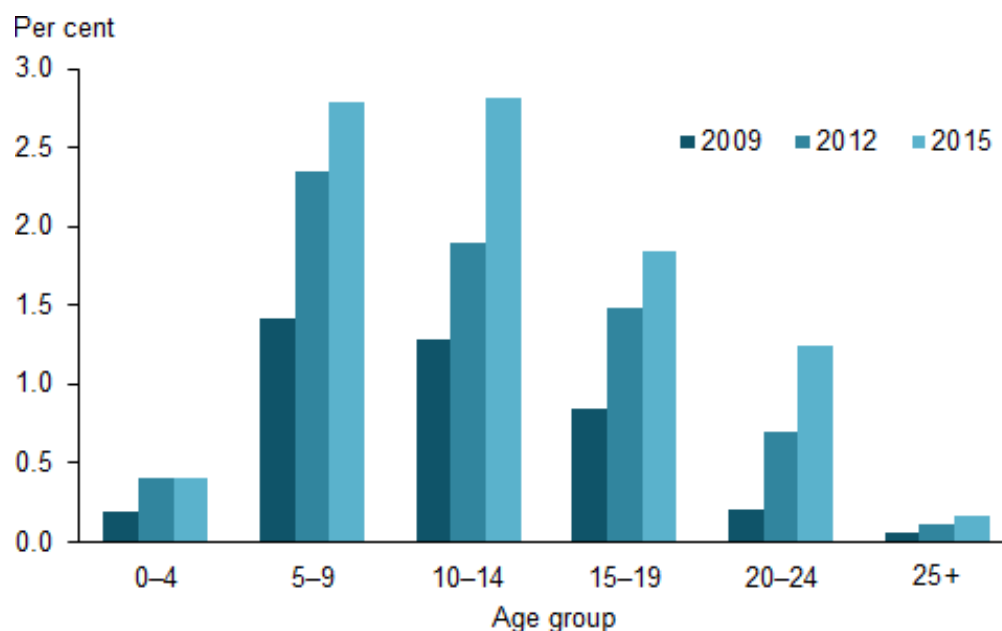


Figure 2-2. Prevalence of autism, by age group, 2009, 2012 and 2015 (Australian Institute of Health and Welfare 2017)

The increasing prevalence of autism is an important health concern and behind a major push towards early diagnosis, given the significant role it plays in families accessing early

intervention and support (Bent, Barbaro & Dissanayake 2020; Keehn et al. 2020; Zwaigenbaum, Bauman, Choueiri, et al. 2015).

Whilst it is not entirely clear why autism prevalence is increasing, numerous researchers have proposed a number of explanations that may have contributed to the marked rise, including changes in diagnostic criteria and categories with the revision of the DSM from one to the next, leading to the expansion of the diagnostic concept of autism between the late 1980s and 1990s (Baker 2002; Johnson & Myers 2007). These changes also recognised autism as occurring on a spectrum. It is highly likely that heightened awareness of the condition amongst parents and the lay and professional communities has led to knowledge growth regarding early-emerging symptoms (Wing & Potter 2002) and therefore led to increased reporting (Giserman Kiss et al. 2017). The findings of a Denmark study suggest that changes in reporting practices account for 60% of the increase in the prevalence of autism (Hansen, Schendel & Parner 2015). In addition, there is an increased sensitivity to milder cases being identified (Lyall et al. 2016). It is also likely that recommendations for regular developmental surveillance and screening introduced by the AAP<sub>2</sub> have also contributed to the increasing rates of autism diagnosis (Johnson & Myers 2007).

Differences in the methods across autism studies has also been touted as an explanation for increased prevalence rates (Isaksen et al. 2013). Isaksen and colleagues (2013) found wide variation in reported autism prevalence rates and attributed this to differences in the methods used to study prevalence, specifically, different sampling procedures and ways of applying statistical methods and differences in the diagnostic tools used to identify children which ranged from screening measures to ‘gold standard instruments’. Similarly, Hossain and co-authors (2017) investigated autism prevalence across eight South Asian countries to understand the size of the issue. They concluded that due to methodological differences in the research, that is, application of different diagnostic criteria and use of different assessment tools, it was challenging to compare prevalence rates across countries.

There has been some suggestion that there may be an actual increase in incidences of autism, but evidence does not strongly support that hypothesis (Fombonne 2003) and some uncertainty remains (Rutter 2006). Some researchers state, however, that it cannot be ruled out (DeCourcy & Ringgenberg 2019). Gernsbacher and colleagues (2005) explain the reasons for the autism “upsurge”, include changes to the diagnostic criteria, increased awareness of the condition, and improved access to funding. The research suggests that it is highly likely that there is not just one explanation as to why autism prevalence has increased dramatically over recent decades, but rather a combination of multiple factors.

The higher prevalence of autism in males compared with females has long been well-known (Baio et al. 2018; Carter et al. 2007; Ehlers & Gillberg 1993; Lai et al. 2015). However, some literature indicates that females are underrepresented in autism prevalence statistics,

particularly those without cognitive impairment (Constantino & Charman 2012; Matheis et al. 2019). This may be due to a wide range of reasons including that the clinical presentation of autism is not homogenous across genders. Research suggests that females are potentially under-identified as they present differently to males and therefore there is a need for greater investigation of the female phenotype (Rubenstein et al. 2018; Van Wijngaarden-Cremers et al. 2014). Research has identified that a gender bias exists in that ratio sample sizes are skewed, with females underrepresented in research studies (Constantino & Charman 2012; Kirkovski, Enticott & Fitzgerald 2013; Tillmann et al. 2018). In addition, females experience greater time lags to diagnosis and subsequent access to intervention and services (Fulton, Paynter & Trembath 2017; Rosenberg et al. 2011).

Irrespective of the contributing causes of a growing autism population, there are several key flow on effects and outcomes. There is increasing pressure on healthcare systems (Tariq et al. 2018) and the need for organisations to find ways to support the rising number of children diagnosed with autism (Magán-Maganto et al. 2017). There is also greater development and increasing availability of support services and funding sources (Gelbar, Smith & Reichow 2014; Otero et al. 2017; Stephens et al. 2016) to match demand.

### **2.2.3 Early concerns identified by parents**

It is widely accepted that parents are often the first to identify behavioural deviations in their children that are indicative of autism and report their concerns (Garrido et al. 2018; Hedley et al. 2016; Horovitz, Matson & Sipes 2011; Howlin & Asgharian 1999; Osterling & Dawson 1994; Ozonoff et al. 2009; Zuckerman, Lindly & Sinche 2015). This is of significance because research indicates that parental concerns have been found to be predictive of a later autism diagnosis (Ozonoff et al. 2009; Pasco et al. 2019; Sacrey et al. 2015). Experience is beneficial: parents of children who already have an older child with autism have many more concerns about subsequent child development at 12-months of age than parents of children who do not go on to receive an autism diagnosis (Herlihy et al. 2015; Ozonoff et al. 2009). It has also been found that some caregivers were not knowledgeable about the early behavioural indicators of autism and therefore diagnosis and accessing appropriate support was delayed (Anwar et al. 2018; De Giacomo & Fombonne 1998; Werner et al. 2000).

The diagnostic process can be divided into three stages: pre-diagnostic, diagnostic and post-diagnostic (Wong, Yu, Keyes, & McGrew, 2017). It is in the pre-diagnostic stage where parents have often observed some developmental concerns and/or atypical behaviour in their children and simultaneously they can feel uncertainty, confusion, and despair as they await the diagnostic process (Wiggins, Daio & Rice, 2006). Even when a child has already received a positive autism screen, having a child with social, behavioural and/or emotional symptoms without a diagnosis and experiencing a low level of social support are sources of parental stress which impact family functioning (Voliovitch et al. 2021).

Prior to diagnostic outcome, Voliovitch and co-authors (2021) measured stress in underserved, low SES parents of children identified at high likelihood of autism. It was found that parental factors, such as coping strategies, social support, and worry, are associated with parental stress before the determination of an autism assessment.

Accordingly, when parents share concerns there is a need for health care professionals to respond appropriately (Ryan & Salisbury 2012). It is not uncommon for parental concerns to be met with inaccurate reassurance or minimised by well-meaning friends and family members. It is suggested that concerns should not just be met with comforting words, but rather they need to validate what is being said and a professional needs to administer an autism screening tool (Ozonoff et al. 2009). It is important that parents feel confident to share observations with relevant health professionals who can then assist them (Caronna, Augustyn & Zuckerman 2007). The literature indicates that parents feel a level of frustration as sometimes their concerns are dismissed by paediatricians (Boshoff et al. 2018; Bultas & Pohlman 2014; Carbone et al. 2010; Freuler et al. 2014; Sperry et al. 1999).

GPs are often the front-line professionals who parents turn to for advice when they have concerns about their children (Bent, Barbaro & Dissanayake 2020; Crane et al. 2016; Young et al. 2007). As emphasised by Young and colleagues (2007), it is critical that GPs are aware of the behavioural markers of autism that would signify that the child's presentation necessitates further exploration. However, GPs report they have insufficient time and/or a limited knowledge, or a lack of confidence, in identifying the early signs, assessing and/or managing the care of a child at high likelihood of autism (MacLeod & Perepa 2020; McCormack et al. 2020; Unigwe et al. 2017). The need for GPs to receive formal autism-specific training has been highlighted in numerous studies, and by GPs themselves (Coughlan et al. 2020). Consequently, GPs often refer patients on to other health professionals (typically a paediatrician and/or members of a multidisciplinary team) to determine if assessing for autism would be prudent (Tonge & Brereton 2011).

Earlier research has recommended that if GPs are to be helpful in the process of identifying autism, there needs to be greater emphasis on the condition during the training of medical students (Shah 2001). Havercamp and colleagues (2016) implemented autism training for medical students. The students reported increased awareness, skills, and confidence in caring for patients with autism. Zuckerman and colleagues (2014) in their study of Latino children in Oregon, found that this was of importance because many families were unfamiliar with autism, and interpreted autism behavioural markers as a result of family issues. They suggested that "doctors should regularly review the early signs of autism with parents" and "should screen for autism at routine visits" (Zuckerman et al. 2014, p. 18), the latter of which the AAP<sub>2</sub> had previously recommended in 2006.

Paediatricians also play an important role in supporting parents in early identification of developmental delays, management of the condition, and assisting parents



in accessing early intervention for their child (Myers & Johnson 2007; Posar & Visconti 2020). Yet in a Brazilian study, Ribeiro and colleagues (2017) found that over half the mothers interviewed had negative experiences with their paediatrician. Many of them had their initial concerns dismissed, so were reluctant to raise their concerns a second time (Ribeiro et al. 2017). Parents attributed these interactions as a key factor in delaying their child's autism diagnosis. Boshoff and colleagues investigated parent perceptions during the diagnostic process and found that they felt unsupported by others during their child's diagnostic journey (Boshoff et al. 2019). They suggest that health professionals need to be more attuned to the parent experience.

#### **2.2.4 Delays in the process**

Worldwide, the referral pathway to assessment and diagnosis is fraught with delays (Crane et al. 2016). The literature indicates that families report consistent challenges and delays from the time of first concerns to diagnosis (Brogan & Knussen 2003; Howlin & Asgharian 1999). This time lag to diagnosis seems to have remained relatively unchanged over the past two decades. Estimates of the time between parents raising their first concerns to when they discuss these with a professional and eventually receive a diagnosis are between two and four and a half years (Crane et al. 2016; Kalkbrenner et al. 2011; Siklos & Kerns 2007). A large UK study of 1047 parents found that on average it took 3.5 years from the time a parent first shared their concerns with a health professional to their child receiving an autism diagnosis (Crane et al. 2016). According to a survey conducted by Howlin and Moore (1997), the pre-diagnostic stage can last approximately four years. More recently it has been found that although there still remains a time lag between first concerns and an autism diagnosis, the average time in Minnesota is now about two years (Myers et al. 2019). Gibbs and colleagues (2019) refer to this time between a parent first consulting a health professional and a child receiving a diagnosis as "professional gap". The extended time it takes being referred for assessment, to undergoing assessment, to receiving a diagnostic outcome has been referred to as an 'autism diagnosis crisis' (Rutherford et al. 2018).

Ideally, when first concerns are raised, parents should be able to access a diagnostic pathway that enables consultation with an appropriate professional. A large Japanese study of 1513 caregivers of children with autism investigated the factors that contribute to time lag between first concerns to selecting and accessing autism services (Fujiwara, Okuyama & Funahashi 2011). A number of risk factors were identified, including the younger the age of the child when parents' first concerns were raised, living with younger siblings, interaction difficulties, not attending school, uncertainty of parents regarding whom they should access, and longer commute and waiting times (Fujiwara, Okuyama & Funahashi 2011).

There is no established Australian standard relating to wait times between referral and assessment. The literature shows that the United Kingdom (UK) recommended wait time from referral to diagnosis in the National Autism Plan for Children (NAP-C) is 119 days

(Le Couteur 2003). Rutherford and colleagues set out to reduce wait times in Scotland through a health service improvement program which involved changes to practice across an entire service and included the development of a single pathway (Rutherford et al. 2018). Significant reductions in wait times were reported: from referral to first appointment wait times went from 14.2 to 10.4 weeks and from referral to diagnostic outcome wait times more than halved, moving from 270 to 122.5 days (Rutherford et al. 2018).

### **2.2.5 Assessment and diagnosis**

Early identification, assessment and diagnosis of autism, and access to EI, is an Australian public health priority. Identifying early signs of developmental delay as quickly as possible in a child's behaviour results in earlier access to EI programs, which can benefit their long-term outcomes (Vivanti et al. 2014). Substantial progress has been made in the early detection and intervention for young children (Swineford 2017). Nevertheless, many practitioners find the identification, assessment, and diagnosis of autism in young children to be challenging and complex (Ward, Sullivan & Gilmore 2016).

There are many barriers to early assessment, diagnosis, and intervention in autism and these have been widely discussed in the literature. Significant variability and inconsistency have been noted across Australian states and territories with regard to the provision of autism diagnoses. One of the major drivers underpinning the development of the Australian guidelines for assessment and diagnosis of autism was to ensure that there is a minimum national standard for diagnostic assessment (Whitehouse et al. 2018).

Elder and co-authors (2016) found a range of causal factors associated with children not being diagnosed early, including a lack of parent and professional education, insufficient professionals available to diagnose, lack of screening, professionals not listening to parents' concerns, and parental fear of social stigma.

Delays to diagnosis occurred for some families due to professionals adopting a 'wait and see' approach (Bent, Barbaro & Dissanayake 2020; Elder, Brasher & Alexander 2016). Gibbs and colleagues (2019) found various reasons for delays in the diagnostic pathway, including milder cases not identified or sub-clinical threshold presentations in very young children; comorbidity; or complex presentations. Farooq and Ahmed (2020) identified a number of cultural and societal barriers that inhibit early diagnosis in Pakistan. They found that parent's lack knowledge about autism, system issues, and family factors, including stigma about receiving a diagnosis, denial and financial constraints were all barriers to children being diagnosed early. Social stigma is a significant barrier to early assessment, diagnosis, and intervention. Stigma can generate feelings of inferiority and produce barriers to opportunities for individuals with autism (Hurley-Hanson, Giannantonio & Griffiths 2020). Link and Phelan (2006) suggest that fear of social stigma discourages some parents from seeking an autism diagnosis or accessing intervention for their child (Link & Phelan 2006). However, it has been suggested that this position may have altered in

recent years as research continues to advance and individuals access early intervention (Dunlap & Filipek 2020).

The challenges that parents experience during the diagnostic process can be reduced by incorporating measures that are cognisant of the parental perspective. An early diagnosis that is accurate, for example, ameliorates maternal stress related to the condition (Pozo & Sarriá 2014). The findings from many studies highlight two important factors that can greatly influence parental experiences along the diagnostic journey. First, the interpersonal behaviour of the professional and second, having open communication between the parent and the professional. Brogan and Knussen (2003) explored the determinants associated with Scottish parental satisfaction with the autism diagnostic process. It was found that the behaviour of professionals was a highly influential factor on the parental experience. Parents expressed that being listened to about their concerns, feeling respected in relation to their knowledge of their child, having the chance to ask questions, and being provided with written information were all important factors in the diagnostic experience and these contributed to greater parent satisfaction (Brogan & Knussen 2003). Osborne and Reed (2008) investigated parents' experiences of communication with professionals during the process of obtaining an autism diagnosis for their child. They found that the communication between parents and professionals in England was an important aspect regarding the level of stress parents experienced during the diagnostic process. They highlighted the need for improved interpersonal skills from professionals (Osborne & Reed 2008). More recently, Stanford and colleagues (2020) investigated the positive experiences of mothers of children with autism with professionals. They found that mothers appreciated professionals who were personable, clear in their communication style, and were able to interact with them in a relatable way, with understanding and empathy (Stanford, Totsika & Hastings 2020). Recommendations to improve the interactions between the service provider and parent, included a warm communication style regarding diagnosis, what the future holds and service provisions, along with the use of clear, layperson language, particularly for those parents who come from different cultural and linguistic backgrounds (Boshoff et al. 2019).

In Australia, children diagnosed with autism generally go on to receive a high level of quality care from their GP for their condition (Churrua et al. 2019). Whilst GPs in Australia are not responsible for the diagnosis of autism, they play a pivotal role in coordinating care for their patients' condition (Tonge & Brereton 2011; Whitehouse et al. 2018). Nevertheless, a recent review found that in five studies (Canada, United States, Turkey, the UK, and Oman) conducted between 2012 and 2018 some GPs reported significant challenges in managing care for children with autism (Coughlan et al. 2020). The GPs themselves noted that various obstacles included a lack of experience, knowledge, and training, and are constrained by time (Coughlan et al. 2020). Overall, findings from research by Coughlan and colleagues (2020) indicated that there was a wide variation in the capacity of GPs to organise intervention. They reported misunderstandings of the clinical features of autism and a lack of confidence to provide the necessary patient care.

The diagnostic stage can be an emotive time, involving a range of feelings from relief and hope to shock and confusion (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Mulligan, MacCulloch, Good, & Nicholas, 2012). Given the emotional and distressful time for parents their emotional health and wellbeing requires extra consideration and support (Hsiao 2016; Rabba, Dissanayake & Barbaro 2019). For some parents, when their child receives an autism diagnosis it brings understanding to their child's behaviour and a sense of relief – they now know what it is, that they are not alone, and that support and intervention are available (Brian et al. 2018; Crais et al. 2020; Siegel 2008). Some parents express relief that their concerns have been confirmed and that a diagnosis will enable entry to intervention (Barton et al. 2010). However, Poslawsky, Naber, Van Daalen, and Van Engeland (2014) found that whilst most parents are accepting and adapt well to their child's autism diagnosis, parental responses can vary according to autism severity and parent's nationality. Research points to the importance of addressing parental support and adjustment during the period of autism assessment and following diagnosis (Keenan et al. 2010; Siklos & Kerns 2007). Stress can be mitigated by improving communication about autism: either by addressing a lack of knowledge or an overload of information (Samadi, McConkey & Kelly, 2012).

Diagnosis research has indicated that children with autism can be accurately and reliably identified as early as 14-24 months of age (Barbaro & Dissanayake 2016; Daniels et al. 2014; Guthrie et al. 2013; Landa et al. 2013; Lord et al. 2006; Pierce et al. 2019; Steiner et al. 2012; Zwaigenbaum, Bauman, Choueiri, et al. 2015). Despite these findings, autism is frequently diagnosed after the age of three (Baio et al. 2018; Bent, Dissanayake & Barbaro 2015), typically when children enter a childcare or school environment (Gibbs et al. 2019; Shattuck et al. 2009) and particularly for those with average or above average intelligence (Yirmiya & Charman 2010). According to two recent Australian studies, the average age for an autism diagnosis is 4 years, 1 month in children under the age of 7 (Bent, Dissanayake & Barbaro 2015) and 6 years in children aged up to 12 years (May & Williams 2018). In Gibbs and colleagues' research conducted in New South Wales they found that the average age of diagnosis was 5 years (Gibbs et al. 2019). These Australian statistics indicate that a large percentage of children who eventually go on to receive an autism diagnosis are preparing to commence school without a diagnosis and we can assume they have not received any EI prior to this time.

Diagnosis typically requires a multi-disciplinary approach, involving a number of key professionals, normally a paediatrician, psychologist, occupational therapist, and speech & language pathologist. For this stage to proceed as smoothly and quickly as possible, it is essential to have good collaboration within the team alongside strong communication skills with the parents (Campbell et al. 2020). With the release of the *National Guidelines* (2018), a decision was made to permit diagnosis where possible with an appropriately qualified single clinician to minimise costs to families and reduce the burden of assessment on the child (Whitehouse et al. 2018). Following diagnosis by a clinician, the diagnostician's role then usually involves providing a report with therapy recommendations. Sometimes

completion of paperwork is also involved, otherwise this may be completed by the client's GP or paediatrician, which may activate government funding for support, depending on the child's level of severity and adaptive functioning.

### **2.2.6 Early intervention**

At the post-diagnosis stage, current literature confirms that an autism diagnosis can still be a time of stress, uncertainty, and confusion for parents (Keenan et al. 2010; Rabba, Dissanayake & Barbaro 2019). Planning for support and education needs is critical to ensure that the child has access to appropriate services, such as behavioural interventions, social and home support, alongside a plan to address academic challenges (Keenan et al. 2010). This stage is about the parents making sense of autism through information from a wide variety of sources, such as professionals, peers, social media, and books (Mansell & Morris, 2004; Mulligan, MacCulloch, Good, & Nicholas, 2012).

It is well documented that implementation of evidence-based practices (EBPs) through EI services are important in maximising positive outcomes and reducing negative impacts for children with autism (e.g., Barbaro et al. 2021; Gabbay-Dizdar et al. 2021; Hume, Bellini & Pratt, 2005; Keen, Paynter, Simpson, Sulek & Trembath, 2017; Rogers et al. 2021; Teager, Fox & Stafford, 2019; Zwaigenbaum et al. 2015). Evidence for this can be found in randomised control trials (RCTs) (e.g., Pickles et al. 2016; Rogers et al. 2012; Rogers et al. 2019; Shire et al. 2017), meta-analysis studies and systematic reviews (e.g., Hampton & Kaiser, 2016; Lane, Lieberman-Betz, & Gast, 2016; Sandbank et al. 2020; Tiede & Walton, 2019).

EI maximises children's developmental outcomes (Schreibman et al. 2015), thus, early diagnosis is important as it is the starting point for access to intervention services. When EI is focussed on specific areas of challenge, it enables improved neural development along a more typical trajectory, that lessens the entrenchment of the disability (Bradshaw et al. 2015; Dawson et al. 2010). Moreover, if commenced prior to the age of three years old, interventions enable better outcomes (verbally, cognitively, and socially) and may even prevent the unfolding of symptoms (Clark et al. 2018; Colombi 2017; Dawson 2008). For this reason alone, the literature confirms that children should be diagnosed as early as reliably possible.

Due to progress in autism research, children are being successfully identified at a much younger age (Hanley et al. 2021; Mozolic-Staunton, Donnelly, Yoxall, & Barbaro, 2020; Whitehouse et al. 2021). The introduction of developmental surveillance into parts of Australia by way of the SACS has paved the way for early identification of autism by child health nurses (Barbaro, Ridgway & Dissanayake, 2011). The current study saw the implementation of the SACS-R into Tasmania from 2016. Early detection has meant a considerable increase in the need for EI services (Landa, 2018; Reichow, Hume, Barton, & Boyd, 2018; Zhou, 2018). With rapid growth in the demand for nonpharmacological

interventions comes the need for clinicians to decide what are the most efficacious interventions to implement.

EIs are typically divided into two broad approaches: behavioural and educational (Sandbank et al. 2020). They can then be further sub-divided into seven types: behavioural (e.g., Applied Behaviour analysis [ABA], Picture Exchange Communication System [PECS], and Pivotal Response Treatment [PRT]); developmental (e.g., Paediatric Autism Communication Therapy [PACT]); naturalistic developmental and behavioural intervention (NDBI, e.g., Early Start Denver Model [ESDM]); Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH); sensory-based (e.g., sensory diets); animal-assisted (i.e. an animal is present for therapy); and technology-based (e.g., apps; computer-assisted instruction). The review of Sandbank and colleagues (2020) reported on the research evidence regarding summary effects of autism symptoms, which measured 15 outcome categories (i.e. core features of the condition, e.g., circumscribed interests or a related outcome, e.g., motor outcomes) in 6,240 children under 8 years of age. It was found that when effect size estimation was restricted to RCT study designs, only two of the seven types of intervention (developmental and NDBI) had evidence of significant positive effects. However, when effect size estimation was restricted to RCT study designs and to outcomes that held no possibility of an over- or underestimate of the size of the effect (i.e. detection bias), not one type of intervention revealed any significant effects on any of the outcome categories measured.

In a recent Australian report, clinical interventions were classified into nine categories, which included the seven outlined above plus cognitive behaviour therapy (CBT e.g., *Cool Kids*) and 'other' interventions, i.e. interventions that do not fit within these categories (Whitehouse et al 2020). Whitehouse and colleagues conducted a review of the evidence from the past 10 years from over 111 interventions across the nine categories designed for children aged 0-12 years. The research evidence included 58 systematic reviews, over 41,000 participants, and covered nearly 1800 scholarly articles. The findings offer evidence of the effects of the nine categories of intervention across various child and family outcomes. It was found that there was minimal and/or inconsistent evidence that child characteristics (i.e. age, core autism features, cognition, communication skills), or intervention delivery factors (i.e. different settings [e.g., therapy room or child's home], different formats [one-to-one or group], or via different methods [e.g., face-to-face or telehealth]), influenced the effects of interventions. On a range of child and family outcomes, there was evidence for positive effects for five interventions (CBT, behavioural, developmental, NDBIs, and technology-based interventions). There is good evidence that a child's social communication abilities can be improved through three types of intervention (behavioural, developmental, and NDBI). At the individual practice-level the evidence was variable. For some interventions the evidence was weak, with TEACCH and some sensory-based interventions (e.g., sensory diet) offering no good evidence that they provide positive intervention effects. For other sensory-based interventions, there were positive

intervention effects reported for specific interventions (e.g., music therapy) but these were limited to select child and family outcomes (e.g., communication). For TEACCH and animal-assisted interventions there was a mix of inconsistent and null intervention effects. For the 'other' intervention practices, social skills training was the only intervention that provided evidence for a positive effect on child outcomes.

It is often presumed that the more intervention hours that children receive, the greater the therapeutic outcomes. Yet the evidence from Whitehouse and colleagues (2020) was inconsistent regarding the influence that the number of intervention hours had on outcomes. Where parents/caregivers participated in the intervention with the child, there was again, no consistent evidence. However, in some cases there was a greater effect on child outcomes when compared to interventions solely delivered by a clinician. Parent/caregiver-mediated and peer-mediated interventions both had a positive effect on a range of child and family outcomes. This information can serve to inform clinical decisions relating to provision of suitable interventions to support Tasmanian children and their families so that there is improvement in social communication skills, reduction in symptom severity, enhanced child development, parental stress is minimised and parental wellbeing is enhanced (Fuentes et al. 2021).

Diagnostic delay is not the only source of parental distress, it also impacts parents when they are generally seeking guidance relating to the selection of therapeutic support and services post-diagnosis (Mazurek et al. 2019; Sritharan & Koola 2019). At this stage families face further delays when selecting and accessing autism services. Bent and colleagues (2020) indicate that although a diagnosis potentially enables a young child entry into support services, the challenge of securing and navigating services is a considerable obstacle to ongoing therapeutic support (Bent, Barbaro & Dissanayake 2020).

Research indicates that parents are dissatisfied with the diagnostic process owing generally to a lack of autism services (Crane et al. 2016; Ho et al. 2014). Even when services are available, they can be expensive and this can influence the choice of interventions a parent can select (Valentine et al. 2011), unless they have been successful in gaining National Disability Insurance Scheme (NDIS) support. However, even if NDIS funding has been secured there is often still an issue with finding suitable clinicians to provide appropriate therapies. Unfortunately for those families who live in rural and remote areas of Australia there are clear limitations in regard to access and availability of services (Prior et al. 2011). Research by Crais and colleagues (2020) provides a mixed view on parent experiences of the diagnostic journey. Whilst many parents expressed similar concerns to those set out in the literature above, some parents reported positive experiences: having their concerns heard, being well supported by experienced professionals, their children receiving accurate and timely diagnoses, and being able to access to services (Crais et al. 2020).

### 2.3. Determinants of parental stress

Throughout the autism literature on assessment, diagnosis, management and intervention, a key theme is the widespread incidence of parental stress and the various determinants. As the previous discussion demonstrates, the journey for parents in the autism community is marked by various opportunities at which stress might be exacerbated or mitigated: levels of knowledge and experience, delays in the diagnostic process, coping strategies, social support, responses from professionals, timely diagnosis, culture, and stigma. Overall, research studies support the finding that parents of children with autism, experience greater levels of stress than parents of children without autism (Baker-Ericzén, Brookman-Frazee & Stahmer 2005; Bonis 2016; Dykens et al. 2014; Ilias et al. 2018; McStay et al. 2013; Padden & James 2017; Voliovitch et al. 2021). False-positive screen results can also be a source of unwarranted stress, anxiety, and stigma for parents. By contrast, false-negative screen results can lead to delays in intervention and consequently impede a child's developmental trajectory (Marlow, Servili & Tomlinson 2019).

It is important that parental stress due to unrecognised and/or yet to be diagnosed autism be reduced and that any unnecessary delays regarding the process of assessment and diagnosis are avoided (Zwaigenbaum, Bauman, Choueiri, et al. 2015).

Moh and Magiati (2012) investigated the variables that contribute to parental stress and satisfaction during the experience of the diagnostic process (Moh & Magiati 2012). In particular, they considered the length of the process and associated delays, the number of professionals involved, the relationship between parents and professionals, and the helpfulness of information provided following diagnosis. They found that parents with higher education who earned a higher income, that is, had a higher socioeconomic status (SES), had atypical behaviours identified earlier than parents with lower SES. This finding has been consistently echoed in numerous studies (Fountain, King & Bearman 2011; Harstad et al. 2013; Mazurek et al. 2014; Zuckerman et al. 2018). Conversely, in the study conducted by Fujiwara and colleagues, they found that there was no association between the SES of the parents, the child's gender, and impairment severity for time lag between first parental concerns about their child's symptoms and accessing diagnostic and/or treatment services (Fujiwara, Okuyama & Funahashi 2011).

Nonetheless, financial strain is a key contributor to parental stress. An autism diagnosis has consequences that extend across the lifespan, including considerable support costs, initially for the child's family, but then ongoing costs for the individual, their community and government (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). Overall, the research indicates that when a family has a child with autism, the financial costs are significant and ongoing across a lifetime. Buescher and colleagues (2014) assessed the annual costs for individuals with autism, with or without an intellectual disability, in the United Kingdom (UK) and the United States of America (USA). The results revealed that the cost of supporting an individual with autism with comorbid intellectual disability for their



lifetime was \$2.4 million (US) and £1.5 million (UK). The cost of supporting an individual with autism without intellectual disability was \$1.4 million in the USA compared with £0.92 million in the UK (Buescher et al. 2014). More recent findings by Callander and Lindsay (2018) identified the areas of greatest expense for children with autism were educational services and parental productivity loss, and for adults with autism, accommodation (residential care or supported living) and individual productivity loss (Callander & Lindsay 2018).

Furthermore, medical expenses were greater for adults with autism than for children (Callander & Lindsay 2018). For parents, particularly mothers of a child with a disability, employment decisions are considerably influenced by the burden of caregiving demands (Morris 2014), with many parents of children with an autism diagnosis not participating in paid labour until after their child has completed primary school (Callander & Lindsay, 2018). Roddy and O'Neill (2019) found that in Ireland, the average yearly cost per child for families was €28,464.89, which included private specific autism services, lost income, and informal care. By contrast, annual societal costs of childhood autism, which included health, social and educational resources was €14,192. Further, autism severity is significantly linked with greater costs to families, but not societal health expenses (Roddy & O'Neill 2019). Cidav and colleagues (2013) found that costs often increase as people age due to a need for more restrictive and more expensive services. However, those children who access EI therapies are more likely to reduce long term costs, as they experience less symptoms, have fewer health care costs, engage in mainstream education and thus have greater employment opportunities (Dunlap & Filipek 2020).

Given the social, emotional, and financial determinants of parental stress, it is understandable for the need to mitigate this with various types of support. The literature indicates that social support has been found to be useful for parents of neurotypical children (Halstead, Griffith & Hastings 2018). Active problem solving has been identified as a helpful coping behaviour for parents of children with autism, serving to moderate and reduce stress (Dabrowska & Pisula 2010; Dunn et al. 2001; Sivberg 2002). Feinberg and colleagues (2014) offer problem-solving education (PSE) as a relatively new intervention to support mothers after their child receives a diagnosis of autism (Feinberg et al. 2014). PSE is a brief cognitive behavioural therapy that can be delivered effectively by early intervention staff.

A recent study found that the quality of the co-parenting relationship of parents of a child with autism affects the level of parental stress experienced. In relationships where the co-parenting relationship was of a higher quality, lower levels of parental stress were reported (Hill-Chapman, Herzog & Maduro 2013). The research of Moh and Magiati (2012) together with the work of Hill-Chapman and colleagues (2013), indicates that parents from lower SES are perhaps an important target group for specific teaching about child development and early signs of "at risk" behaviours that are indicators of autism (Moh & Magiati 2012). Bonis suggests that the creation of parent interventions to support decision-

making regarding service provision could assist parents in the management of their child's challenging behaviours and as a result, lower parental stress (Bonis 2016).

## **2.4 Public health surveillance**

The word surveillance has its roots in the French, 'surveiller' meaning to watch over and is defined as "the careful watching of someone" (Collins English Dictionary). Public health surveillance is more specifically defined as:

*The ongoing, systematic collection, analysis, and interpretation of health-related data with the a priori purpose of preventing or controlling disease or injury, or of identifying unusual events of public health importance, followed by the dissemination and use of information for public health action. (Lee & Thacker 2011)*

### **2.4.1 Screening and developmental surveillance**

Baron-Cohen and colleagues (1992) were the pioneers of autism screening using the Checklist for Autism in Toddlers (CHAT) and were responsible for the first efforts associated with detecting autism in children 18 months old. It is not uncommon for the terms 'screening' and 'surveillance' to be used interchangeably. However, screening and surveillance are two different processes and therefore it is important to clarify the terms. Surveillance is an ongoing "process of recognising children who may be at risk of developmental delays" whereas screening involves "the use of standardised tools to identify and refine that recognised risk" (Bright Futures Steering Committee 2006). Screening often occurs at one point in time and tends to rely heavily on parent report. In contrast, developmental surveillance involves a cumulative process carried out over time by skilled health care professionals to identify children who may have developmental problems (Bright Futures Steering Committee 2006). Children are monitored at several time points where the professional administering the assessment uses their clinical observation to determine whether the child's behaviour indicates the presence of any type of delay.

Developmental surveillance is a tool that enables early identification of autism to occur and, in addition, facilitates improved access to services (Woolfenden, et al. 2016). In Australia, it is recommended that developmental surveillance occurs regularly at children's health checks (The Royal Australian College of General Practitioners, 2018). The federal Department of Health Services (DHS) has implemented a developmental surveillance programme, Australia-wide, utilising the Parents' Evaluation of Developmental Status (PEDS). The PEDS is a standardised tool that can be found in every infant's personal health record (PHR), colloquially referred to as "the blue book". The PEDS is used as a prompting tool to catch any parental concerns at the 6, 12, 18-months and 2, 3, and 4 years of age at routine child checks and identify any potential developmental vulnerability (Woolfenden, Eapen, Williams, et al. 2014).

The AAP<sub>2</sub> recommends that developmental surveillance is part of every visit and endorses universal (level 1) autism-specific screening to be conducted at 9, 18, and 30-months of age (Bright Futures Steering Committee 2006; Johnson & Myers 2007). A systematic review conducted by Stewart and Lee (2017) found that between 1992 and 2015, across 28 studies, 18 different autism screening instruments had been used in low- to middle-income settings with wide ranges of sensitivities and specificities (Stewart & Lee, 2017). The Modified Checklist for Autism in Toddlers (M-CHAT) was compared with a number of autism-defining instruments, and it was found that among very preterm infants (<28 weeks of gestation) the diagnostic accuracy of the tool was poor (Gray, 2017). Both the sensitivity (52%) and the PPV (20%) were low with a high false positive rate. Consequently, the M-CHAT Revised with Follow-up (R/F) has since superseded the M-CHAT for use with children aged 16-30 months.

In their own research, the developers of the SACS-R surveillance tool found it to be the most effective method for early identification of autism to date, with an estimated prevalence of autism of 1 in 57 children, and with no typically developing children identified as high likelihood of autism (Barbaro & Dissanayake, 2013). Moreover, the SACS-R is found to be a psychometrically superior developmental surveillance tool to the PEDS (Mozolic-Staunton et al. 2020). The SACS has been validated to have strong psychometric properties (Barbaro & Dissanayake, 2010), including positive predictive value (PPV) of 81%, sensitivity of 83% and specificity of 99.8%. To increase the psychometric properties, the SACS underwent revision utilising behaviours that are the best predictors of an autism diagnosis (Barbaro & Dissanayake, 2013).

In 2020, developmental surveillance using the SACS-R was rolled out in two settings (community health and early education) in Australia (Mozolic-Staunton et al. 2020). The findings by Mozolic-Staunton et al. (2020) indicated similar findings to the SACS with a PPV of 84%; Negative Predictive Value (NPV) of 99%; sensitivity of 82%; and specificity of 99%. These results are greater than other commonly used screening tools for autism, for example, the Modified Checklist for Autism in Toddlers (M-CHAT). According to Yuen and colleagues, the use of the M-CHAT in community populations, has pooled sensitivity, specificity, and PPV of 83%, 51%, and 6% respectively (Yuen et al. 2018).

The use of the SACS-R has been published across numerous papers (Barbaro et al. 2020; Barbaro et al. 2021; Mozolic-Staunton, Barbaro, Yoxall, & Donnelly, 2021; Mozolic-Staunton, Donnelly, Barbaro, & Yoxall, 2015; Mozolic-Staunton, Donnelly, Yoxall, & Barbaro, 2017; Shrestha, Dissanayake, & Barbaro, 2021 [a]; Shrestha, Dissanayake, & Barbaro, 2021 [b]; Waddington et al. 2021; Whitehouse et al. 2019; Whitehouse et al. 2021) in various countries and jurisdictions, including New Zealand, Nepal, China, and Australia (Perth and Melbourne; New South Wales and Victoria; and New South Wales and Queensland).

#### **2.4.2 Public health surveillance and the role of nurses**

Nurses are well-placed to provide supportive care to parents during healthcare appointments (Bonis 2016; Inglese 2009) and the scope of their role is ever increasing (Inglese 2009). Frye (2016, p. 453) describes nurses as “the eyes and ears of the health care team and the voice for the parents, thus creating a critical connection between the parents and the health care team”. Nurses’ contemporary clinical practice frequently involves surveillance strategies to monitor children for age-appropriate developmental milestones, health indicators and early atypical signs in their development (e.g., Barbaro & Dissanayake, 2010; Gonzalez, Summers, Mueller, Hernandez, Gil-Lopez, Garcia & Lopez, 2015; Reichert, Eickmann & Lima, 2015; Yakuwa, Neill & Mello, 2018). Structured screening and ongoing surveillance in the early years as part of routine clinical practice could potentially identify initial presentations of autism, such as atypical social and communication development that occurs as early as 12 to 18-months of age (Ozonoff et al. 2008; Honda, et al. 2009; Zwaigenbaum et al. 2015; Fäldt, et al. 2018).

There is increasing interest in the role of collaboration between nurses and other healthcare professionals and as to how this affects and influences the delivery of quality care and outcomes (Engel & Prentice 2013; Green & Johnson 2015; Reeves et al. 2017; Seaton et al. 2020). Collaboration is the coming together of two or more agencies to deliver on an agreed outcome (Green et al 2015). Engel and Prentice (2013) suggest that collaborators, “come together largely because they wish to do so, rather because they are mandated to do so” (Engel & Prentice 2013, p. 433). A review by Seaton and co-authors (2020) found that in 50% of the studies, self-reports by allied health professionals identified opportunities for informal communication as an important element in successful interprofessional collaboration. The relevance of this to autism surveillance is that nurses can be active collaborators in the multi-disciplinary team, and the conduit for educating families, members of the community and their health care colleagues about the importance of early identification of autism (Dunlap & Filipek 2020). In addition, nurses and educators in childcare centres are already responsible for autism screening and surveillance in a number of countries, including Australia (in the states of Victoria, New South Wales, Queensland, and Tasmania), and are conducting these assessments successfully with improved outcomes for children and their families (Barbaro & Dissanayake 2010; Barbaro, Ridgway & Dissanayake 2011; Clark et al. 2018; Mozolic-Staunton et al. 2020). This confirms that nurses can be pivotal in the early identification stage and management of children experiencing neurodevelopmental concerns. Nurses play an important role in communication and building collaboration with other health professionals, alongside education for a wide range of parties, most importantly families.

#### **2.5 Implementation science**

Implementation Science (IS) involves taking what is known about improving outcomes in the research lab – or theoretically - and implementing that knowledge into

practice. The key objective of IS is to enable evidence to get into routine practice (Braithwaite et al. 2018). Successfully implementing Evidence Based Practices (EBPs) into practice, and understanding the challenges within the specific setting, is an important consideration in the field of IS. The IS approach can assist the current research with regard to understanding the challenges inherent in implementing a relatively new EBP, the SACS-R, into the Child Health and Parenting Service (CHaPS) in Tasmania. The Social Attention and Communication Study (SACS) was rolled out in pockets of Victoria, Australia, in 2010 (Barbaro & Dissanayake 2010) where the Maternal and Child Health (MCH) nurses (N=241) used a developmental surveillance approach to assess children aged two years and under (N=20,770) for autism. The SACS was revised in 2013 (SACS-R) (Barbaro & Dissanayake 2013) and for the first time in the world was rolled out in a statewide setting. The SACS-R data collection commenced in Tasmania in October, 2016 and ceased in March, 2018.

In the case of the SACS-R it has already taken a period of approximately six years to move from the lab into real world use. At the time of writing, it is yet to be taken up into CHaPS' standard routine practice. The timeline set out below in Figure 2-3 indicates the length of time between creation of the SACS and its implementation into the real world, for the purposes of the larger project.

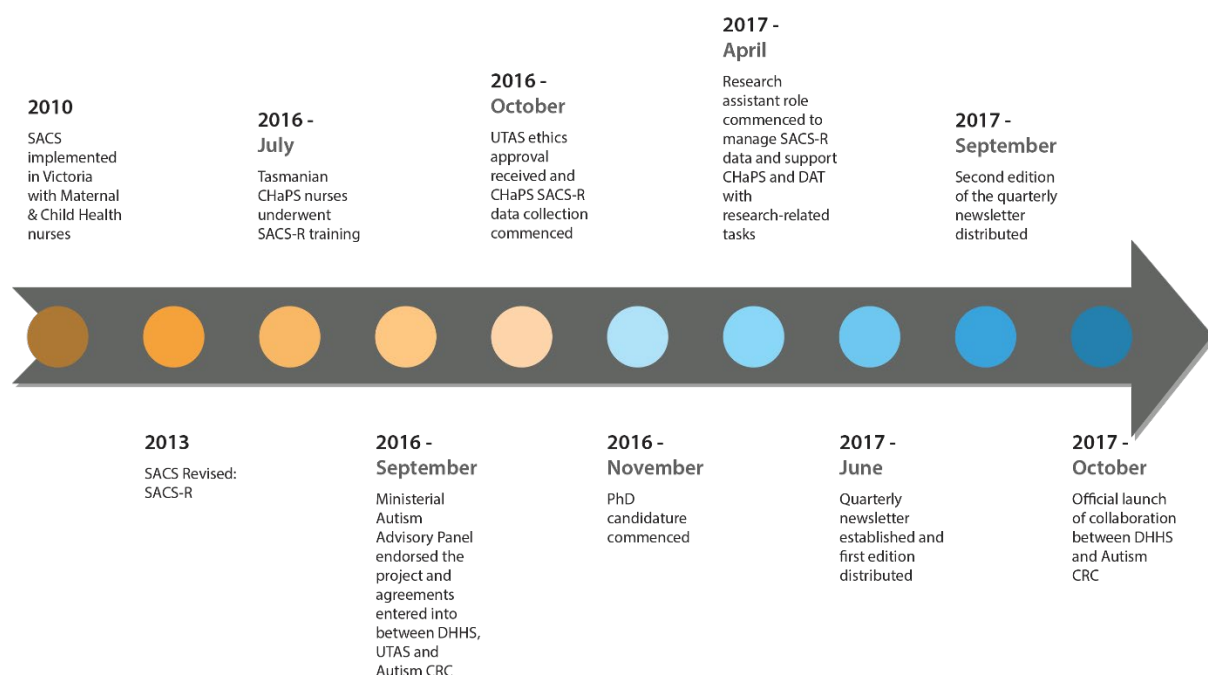


Figure 2-3. Timeline indicating the key events in the implementation process of the SACS-R into the Tasmanian CHaPS

Over the last decade or so, the IS theoretical framework has developed, by which we can better understand and minimise the length of time between new research findings and their use in public health care settings. The term first began to be utilised in the literature in approximately 2006 and referred to the regular finding that the movement from the research lab into practice was a slow process (Dearing & Kee 2012). At that time, IS was defined as:

*[T]he scientific study of methods to promote the systematic uptake of research findings and other evidence-based practice into routine practice, and, hence, to improve the quality and effectiveness of health services.*  
(Eccles & Mittman 2006, p. 1)

Since 2006 a large number of different operational definitions have appeared across IS literature, with differing terminology and concepts that at times appear to be used interchangeably (Manalili & Santana 2020; Nilsen 2015). When authors from various fields refer to the implementation of research findings into practice, they may use terms such as implementation research, dissemination, research utilisation, diffusion of innovation, action research, knowledge transfer, participatory research and translation (McKibbon et al. 2010).

Grol and Wensing (2013) indicate that the use of IS terms often differs between various parts of the world and the different fields involved, which can lead to misunderstanding. According to McKibbon and colleagues (2010), while ‘implementation science’ is preferred in Europe and in the USA, ‘knowledge transfer’ is a common term used in Canada. The term ‘knowledge mobilisation’ is also used, to refer to the transfer of scientific evidence specifically into health care practice and implementation science is the study of this knowledge mobilisation (McKibbon et al. 2010). McKibbon and colleagues offer the overarching term ‘knowledge translation’ (KT) to refer to the field of implementation of research findings into practice. They state that:

*Regardless of what term is used, the concept generally encompasses the processes aimed at converting scientific knowledge to socially beneficial actions, often through behavior change of various stakeholders and actions of decision and policy makers.* (McKibbon et al. 2013, p. 2)

Their research led to the identification of 100 terms used in published journals during 2006 to refer to KT.

IS is often used interchangeably with the terms ‘dissemination science’ and ‘translational science’ (TS) and it seems that TS and IS are almost synonymous terms. IS, according to Dearing and Kee (2012) is the study of what happens *following* the adoption of dissemination science, especially in organisational settings. By contrast, TS can exist on a continuum and bridges the sometimes unmanageable gaps that can occur between basic science and applied science, necessitating something in between to translate knowledge into application (Dearing & Kee 2012).

Graham and colleagues propose that there is much confusion and misunderstanding around the IS terms and concepts and consider that the confusion may be one of the driving variables in the lack of speed regarding the implementation of EBPs (Graham et al. 2006). In recent years, numerous researchers, e.g., McKibbon and Rabin and colleagues, have contributed to attempts to establish agreement on key principles, terms, and definitions of fundamental concepts in the IS domain. A finding common to their research was the need for consensus, consistency, and a reduction in the number of terms and concepts used to

avoid contradictions in terminology and enhance communication across different fields (McKibbin et al. 2010; Rabin & Brownson 2017; Rabin et al. 2008; Rabin et al. 2012). However, the common factor to all IS research is the emphasis on moving knowledge into action (Graham et al. 2006).

IS has two components: research and practice. Handley and colleagues (2016, p. 1) define the research component of IS similarly to how it was defined by Eccles and Mittman (above) as: “[T]he systematic study of how to design and evaluate a set of activities to facilitate successful uptake of an evidence-based health intervention”. The practice component applies to this research: it involves the identification, selection, and use of those evidence-based strategies in real-world practice settings (Handley, Gorukanti & Cattamanchi 2016; Weisz, Ng & Bearman 2013).

### **2.5.1 Research-to-practice gap**

Despite the developments in implementation science theory, it takes somewhere between fifteen and twenty years for research to be converted into EBPs that are suitable for public use (Dearing & Kee 2012). Traditionally, the idea of a ‘pipeline’ model was often applied to explain the uptake of research into practice. However, some researchers viewed this concept as far too simplistic as it portrays the process as linear, rather than long-term and iterative, and conceals the complex nature of the research–practice route (Braithwaite et al. 2018; Greenhalgh & Papoutsis 2018). Green and colleagues (2014) suggest that the outcome of the pipeline model addresses research quality but lacks consideration of the applicability of the research to the use and end-users of it. It is proposed that in order for evidence-based public health research and practice to effectively impact policy a greater focus on knowledge utilisation is required (Green et al. 2014).

The funnel analogy (Green, 2009) as depicted in Figure 2-4 below, illustrates the prolonged process of translating research to practice in public health. At each stage of dissemination, research can be lost due to leakage and clogs in the pipeline, e.g., unsubmitted or unpublished research, poor storage of information and consequently access is impacted, and delays in moving research into systematic reviews (Green et al. 2009).

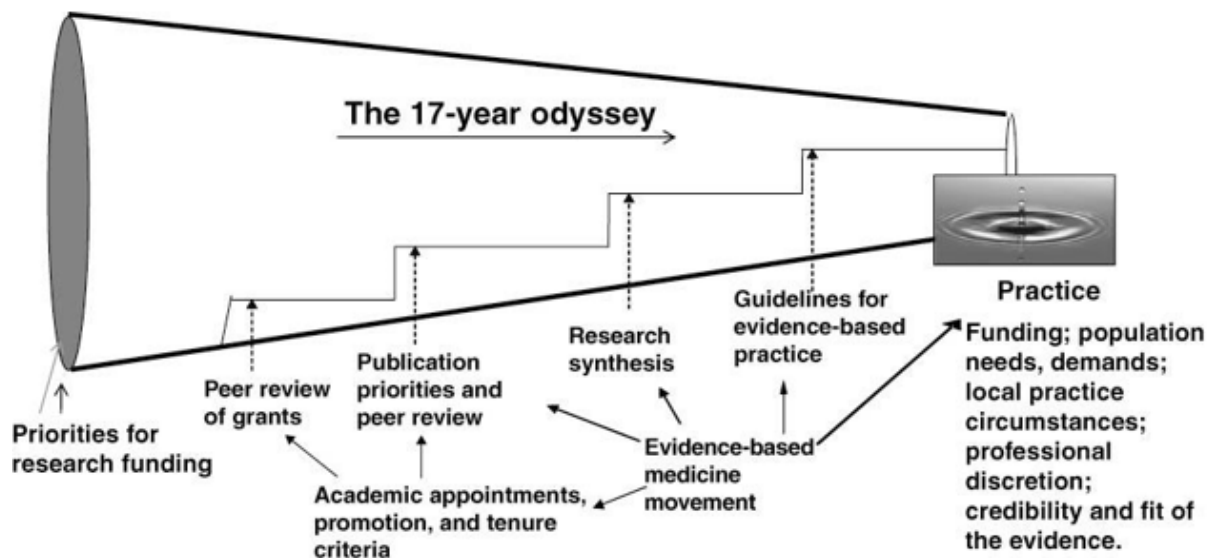


Figure 2-4. A conceptual framework to summarise the process of the creation and translation of information from research-to-practice (Green et al., 2009).

The funnel framework (Green et al 2009) offers a way to understand the progress of information to translation to practice through a combination of theories (diffusion, translation, implementation, dissemination, and application). In addition, this view allows for the implementation and utilisation process to consider the perspectives of end-users. Thus, Green and colleagues propose a rethink around the application of evidence-based practice in health (EBPH) principles to address the research-to-practice gap. They recommend that researchers make their starting point practice-based evidence, rather than scientific evidence (Green et al. 2014).

Consideration and inclusion of these influences enables the researcher to place knowledge use and the end-user at the centre of the research and practice focus (Bauer & Kirchner 2020). As a result, there is potential to impact the research-to-practice gap at the micro (individual/group) and meso (organisational/system) levels (Turner et al. 2016). Moreover, the likelihood of successful implementation of the health care innovation can be further enhanced regarding uptake and spread.

## 2.5.2 Aims and objectives of IS research in health

IS research detects the barriers and enablers of integration of research into the real world (Grol & Wensing 2013). IS considers the barriers that are encountered when generalising research findings into various fields, including health, which Hooker and Taft (2016) refer to as 'translational blocks' to the uptake of EBPs into care and service agencies. Thus, a central question of IS research is: What can be done to best ensure that EBPs are delivered effectively in practice? (Hooker & Taft 2016).



There are several methods for applying IS research. Graham et al. (2006) designed an 'action cycle' to describe the steps involved in knowledge application, which includes an assessment of barriers. Ideally this assessment does not just detect the barriers, but also identifies the enablers or supports that can be utilised to achieve successful implementation and sustainable change (Graham et al. 2006). Once the issues that influence the uptake of the knowledge are identified - such as, the knowledge itself, the agency taking on the new knowledge, or the environment in which the knowledge is to be utilised (Graham & Logan 2004; McCormack et al. 2002) - these barriers can be identified. Once pinpointed, they can be at least moderated using intervention strategies or ideally, fully addressed.

Green et al. (2014) suggest that the key problem with the smooth transition of scientific information into any practice environment lies in the way that people think about diffusion theory and dissemination research. If the thinking is that scientific evidence will just automatically effect human behaviour, the process is unsound from the start. Hence, they suggest that there would be a greater chance of influencing policy, professional practice, and public responses if the focus shifts from making practice more science-based to making science more practice-based.

Green and colleagues (2014) reviewed the array of considerations required when applying evidence-based practice in public health (EBPH) when encountering different cultures and various ways of practicing within a diversity of populations. They recommend that public health research agendas should be firstly seeking to engage the community and practitioners to assess their needs, assets, and circumstances, via program planning frameworks and the utilisation of local assessment and surveillance data. This view aligns with the current research.

Much research has been dedicated to the translation of research into health care practice and the identification of the various enablers and barriers around adoption and implementation success. Factors that have been recognised as barriers to adoption and implementation of EBPs included failure of partnership leaders to involve community stakeholders; financial constraints; lack of effective communication; ever-changing timetables; high partner turnover and decision makers' own experiential knowledge mitigating the direct effect of research findings on decision making (Breslau, 2015; Elliott & Popay, 2000). In line with these findings, Rahm et al, (2015) found that the potential barriers to implementation of Screening, Brief Intervention, and Referral to Treatment (SBIRT) were lack of consistent communication, doctors having limited time, and absence of agreement on where the intervention sits in terms of priority.

Conversely, the literature also provides consideration of the many variables and challenges that are critical to the successful adoption and implementation of EBPs (Burke et al. 2015; Chan, Oldenburg & Viswanath 2015; Northridge & Metcalf 2016). For example, effective rolling out of EBPs requires local stakeholders in the early stages of the decision-making process, and the use of coaches to enable strategic thinking regarding the

translation of EBP into practice settings (Breslau, 2015). Elliott and Popay (2000) found that research can influence policy change by facilitating conversations about policy between policy makers, health service providers and the end-users. Ongoing discussions between the researchers and the research consumers increases the use of research-based evidence in policy. Sufficient resources and ongoing, positive, clear communication at numerous organisational levels are also important factors for effective implementation to occur (Kerr, Shields, Quarmby, Roberts, & Imms, 2016).

Green and colleagues (2014) emphasised that the intended outcome of any health intervention is behaviour change, therefore, subjective measures (e.g., increased exercise and a healthier diet), may be more significant than objective measures (e.g., blood pressure results and cholesterol levels). At the heart of IS, the emphasis is also on behaviour change of the individuals but also the social context in which the evidence-based clinical innovation occurs (Woolf et al. 2015). This is achieved in two ways: first, via the identification of the enablers and barriers to uptake across various levels of setting (that is, individuals receiving the treatment, providers, organisations, and other key stakeholders) and second, through the development and application of implementation strategies that overcome the identified barriers and improve the enablers to increase the uptake of the innovation (Bauer & Kirchner 2020).

The research that eventually makes it into practice has often gone through a filtering process that selects which research that produces evidence-based clinical interventions. This one-way filtering does not always serve public health interventions well as several variables (social-psychological processes, cultural contexts, and socioeconomic conditions of public health practice) have not been factored into the decision-making process (Green et al. 2014). This indicates a need to work bi-directionally, that is, from research to evidence-based practices and in reverse from practice-based evidence to better-informed, and more relevant practices and policies (Green et al. 2014).

Glasgow and colleagues (2003) along with Glasgow and Emmons (2007) and Green and colleagues (2009) have identified numerous barriers to dissemination of evidence-based interventions in health, including characteristics of the intervention being disseminated; the situation or context of the intended target audience; the limitations of the research reporting on the intervention (such as sampling limitations, failure to evaluate costs and external validity), and barriers as a result of the interaction of the barriers (Glasgow & Emmons 2007; Glasgow, Lichtenstein & Marcus 2003; Green et al. 2009).

### **2.5.3 Theories of implementation science**

There are numerous models and theoretical frameworks that inform IS yet there is no single theory that wholly explains the research-to-practice gap (Green et al. 2014). Notwithstanding, a number of theories (Diffusion Theory, Early Theory of Imitation, Collective Behaviour Theory, and Knowledge Utilisation Theory) and frameworks (e.g., Dobbins et al. 2002; Green's [2009] utilisation-focused surveillance) have been proffered by

investigators in an attempt to steer efforts towards influencing the translation of research to public health practice and community change.

One of the most influential theories regarding public health dissemination and implementation (D&I) practices is Diffusion Theory. Diffusion is the process by which an innovation is communicated over time between members of a social group (Rogers 2003). At its core, the diffusion of an innovation is reliant on social context. Thus, the social context influences the outcome of the innovation, that is, whether the innovation is supported and accepted.

Dingfelder and Mandell (2010) investigated the successful implementation of an autism intervention through the application of Rogers' (2003) diffusion of innovation model. Rogers' theory has been used by researchers to facilitate their understanding of the dissemination and implementation of effective autism interventions. Dingfelder and Mandell (2010) stress that in order for children with autism to benefit from the best evidence-based interventions two main changes need to occur:

*Autism intervention researchers must change current practice by (a) partnering with communities to facilitate the successful adoption, implementation, and maintenance of interventions that have already been developed, and (b) developing new interventions in collaboration with these communities to ensure that the interventions meet the community's needs and capabilities, thereby increasing the likelihood of successful diffusion. (Dingfelder & Mandell 2010, p. 607)*

Rogers highlights that it is the adopter's perceptions of the attributes of an innovation that most strongly affects the rate of adoption (Rogers 2003). Lead authorities in the field of theory into practice, articulate that diffusion theory explains the natural unfolding of the dispersal of ideas and actions within social organisations. By contrast, dissemination centres around the planned effort to spread new knowledge, policies, and practices to specific audiences or the greater public (Green et al. 2009).

The findings by Davis and Howden-Chapman (1996) add to the current knowledge around the influence of research findings on health reform, but also emphasise the importance of collaboration with stakeholders, that is, researchers, policy-makers, policy analysts, managers, politicians, and relevant lay people. Working with a vulnerable population, that is, children with additional needs, brings with it unique challenges for the families and the clinicians involved. Post-diagnosis, parents are frequently inundated with various different suggested interventions, many of which are unavailable at this time in our state, therefore, there is a need to produce research that has been conducted in local, practice-based settings, in collaboration with relevant stakeholders and representatives of the proposed end-users of the research products. Flexibility is required around how this is done, whilst still remaining true to the interventions. Davis and Howden-Chapman (1996), Funk et al (2005) and Green et al (2014) all have particular implications for the current autism research project and there are some key learnings held within their collective

findings. That is, there is a need to work bi-directionally; to reframe the way health policy issues are viewed; and for partnerships with policy-makers to be established in the early stages of the process which can augment the implementation process later.

There is a saying in health care circles that the only constant in health care organisations is change (Nilsen et al. 2020). Change within the health service is driven by several factors, including customer expectations, technology advances, and increased access to information via digital media (Caulliraux & Meiriño 2015). Promoting and facilitating change in health care delivery is a key responsibility of the public health service. One of their roles is to deliver resources to ensure that people's overall health is well supported. Being able to successfully translate research into practice in the public health service can be challenging yet it is essential to the quality of the implementation of innovations (Bradley et al. 2004).

When an organisation is seeking to implement change and the desired outcome is that the change is sustainable, there are some key areas that need to be considered. Schell and colleagues (2013) investigated the capacity of public health programs, that is, any public health action, for example, direct services and policy development, to be sustainable (Schell et al. 2013). They define sustainability capacity as the presence of structures and processes that allow a program to maximise resources to successfully implement and maintain evidence-based policies and activities. Schell and co-authors (2013) identified nine domains of public health programs' capacity for sustainability: political support, funding stability, partnerships, organisational capacity, program evaluation, program adaptation, communications, public health impacts, and strategic planning. From these domains, they developed a sustainability framework that focuses on capacity, and this is presented below in Figure 2-5.

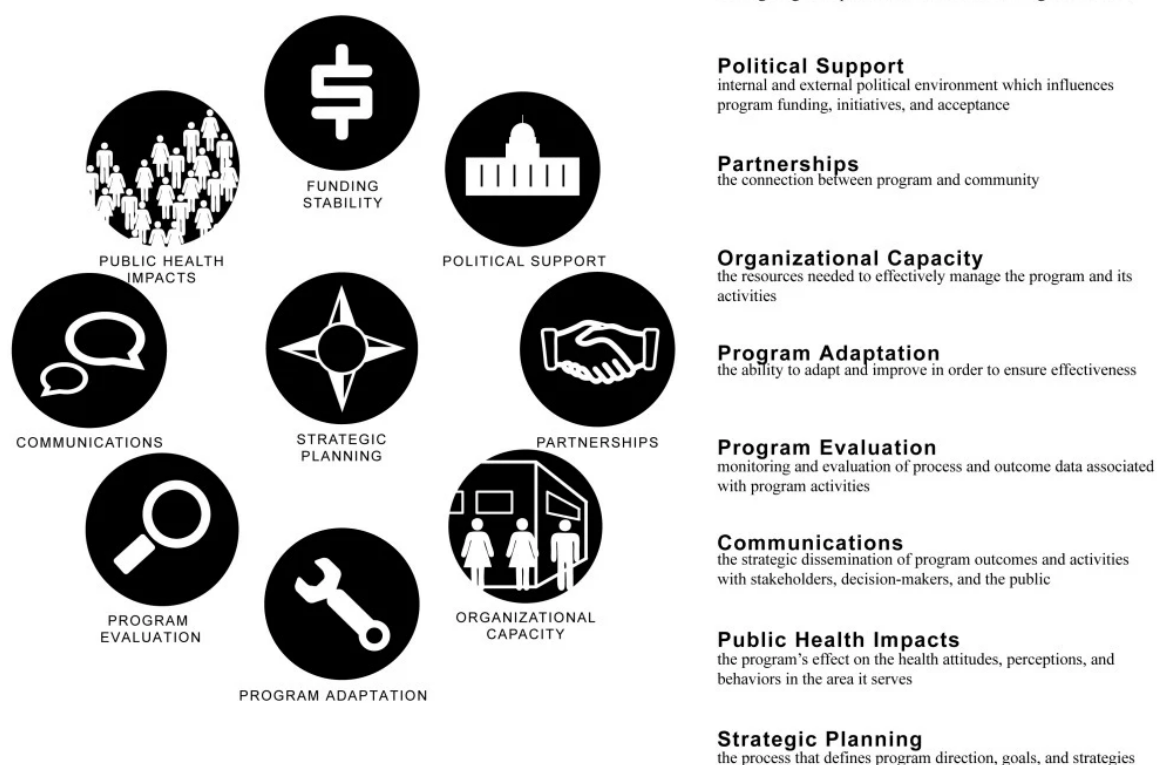


Figure 2-5. Sustainability framework and definitions (Schell et al., 2013)

According to the authors, these nine domains are fundamental to the success of public health programs and are worthy of consideration by researchers and stakeholders when planning and implementing such programs (Schell et al. 2013). They acknowledge that it is important to recognise that sometimes innovation managers do not have control over some of the aspects that influence the sustainability of the innovation, e.g., external political support for their program (Schell et al. 2013).

There are numerous change management models available that can assist with introducing and navigating change in helpful ways in order to achieve acceptance by those who will be affected by the change implementation. In the current research, Lewin's three-stage model of organisational change (1951) underpins our understanding and approach toward the change management of the implementation of the SACS-R into the CHaPS. Lewin's change theory (1951) is a widely held theory in the field of organisational change. Since the 1980s, Lewin's model has been criticised for being too simplistic and outdated (Burnes 2004c; Kanter 2003). Nevertheless, it continues to have application today. Burnes (2004) reappraised Lewin's work and concluded that the model remains relevant in the contemporary world, whether in organisations or society at large (Burnes 2004b).

Lewin's model of change is well-established within the nursing field (Abd el-shafy et al. 2019; Kassean & Jagoo 2005; McGarry, Cashin & Fowler 2012; Parsons 2000; Sutherland

2013) and offers a model of the change process in human systems (Schein 1996). The theory centres on two types of forces: driving forces and resistant or restraining forces. Driving forces push in a direction that causes the change to occur or that facilitate the change because they push a person in a desired direction, whereas restraining forces counter the driving force and hinder the change because they push a person away from a desired direction (Udod & Wagner 2018). Effective change is captured within Lewin's three-stage model of change of 'Unfreezing', 'Moving' and 'Refreezing' (Burnes 2004a; Schein 1996). Before change can occur, Lewin suggests, the organisation needs to be prepped for change and the current situation needs to be broken down, that is, "unfrozen".

This initial stage involves transition of employees by getting them on board through communicating the necessity for change and ensuring that everyone understands why the change is required and the advantages that will ensue. According to Lewin's model, the second step involves making the "change." This phase is where the stakeholders begin to familiarise themselves with the idea that the status quo is going to be different. Movement is the shift of behaviour toward a new and more beneficial pattern (Craven, Hirnle & Henshaw 2019). Enablers and barriers are identified, analysed, and summarised and all the necessary changes and improvements are proposed. It is particularly crucial in this step to keep the communication lines open and reassure and encourage the relevant people. Adjustments are made across time until the change delivers the required outcomes.

The final step of Lewin's model involves the "refreeze" phase where the changes, improvements and new processes are transferred and transformed into the relevant organisation(s). To ensure the momentum is maintained and a sense of cohesion is generated within the organisation's culture provide the necessary training and support to staff so that the process continues to progress correctly. Provide regular opportunities for staff check-ups to confirm that the changes are being utilised and staff are clear on the new procedures and processes that have been implemented. It is important that the hard work and successes are recognised and celebrated. This is particularly helpful to the restraining forces so that they can find closure. It also assists them in having positive perceptions about any potential future changes that they will also be successful. Lewin posited that effective change could not take place unless there was a "felt need" by all those concerned (Lewin 1947).

Researchers advise that the implementation should be rolled out steadily with a flexible approach and that the change implementers have 'buy-in' to ensure a smooth transition of information, fidelity to the innovation (Franks & Bory 2017) and lessen the risk of potential resistance (Jabbour et al. 2018; Kasari et al. 2010; Spetz, Burgess & Phibbs 2012; Sutherland 2013).

Handley and colleagues (2016) suggest that an effective strategy for implementing IS is a methodical assessment of the fundamental enablers and barriers. They describe a three-phase approach with each phase comprised of a number of steps to guide IS and planning

research: preintervention planning; designing the intervention strategy; and evaluating the implementation strategy. In addition to these phases and their particular steps, Handley and colleagues (2016, pp. 1-2) propose that IS research should follow three key principles in order to close the research–practice gap.

1. “behaviour change is inherent to the translation of evidence into practice, policy, and public health improvements.”
2. It is imperative to have “engagement with a range of individuals and stakeholder organisations in order to achieve effective translation and sustained improvement in implementation outcomes.”
3. “Implementation science research benefits from flexibility and often non-linear approaches in order to fit within real-world situations”.

#### **2.5.4 Implementation science and service innovation**

Employing IS principles, such as Handley’s above, is what enables effective implementation of an innovation. How do we define an innovation in health? It is considered that Schumpeter was the first to define the notion of innovation in 1934 as a unique blend of new and existing knowledge separate from interventions (Witell et al. 2016). The term is used to recognise a new intervention that is yet to be successfully introduced (Schumpeter & Backhaus 2003). Schumpeter’s foundational work was added to by Toivonen and Tuominen. The aforesaid authors presented their definition of service innovation as:

*A new service or such a renewal of an existing service which is put into practice and which provides benefit to the organization that has developed it; the benefit usually derives from the added value that the renewal provides the customers. In addition, to be an innovation the renewal must be new not only to its developer, but in a broader context, and it must involve some element that can be repeated in new situations, i.e., it must show some generalisable feature(s). (Toivonen & Tuominen 2009, p. 893)*

It is possible that at any stage of the innovation process (dissemination, adoption, implementation, and continuation) that the change that is being sought may not happen due to the impact of numerous determinants. There are four major categories of innovation determinants included in the theoretical framework along with the four stages in the innovation process as set out in Figure 2-6 below.

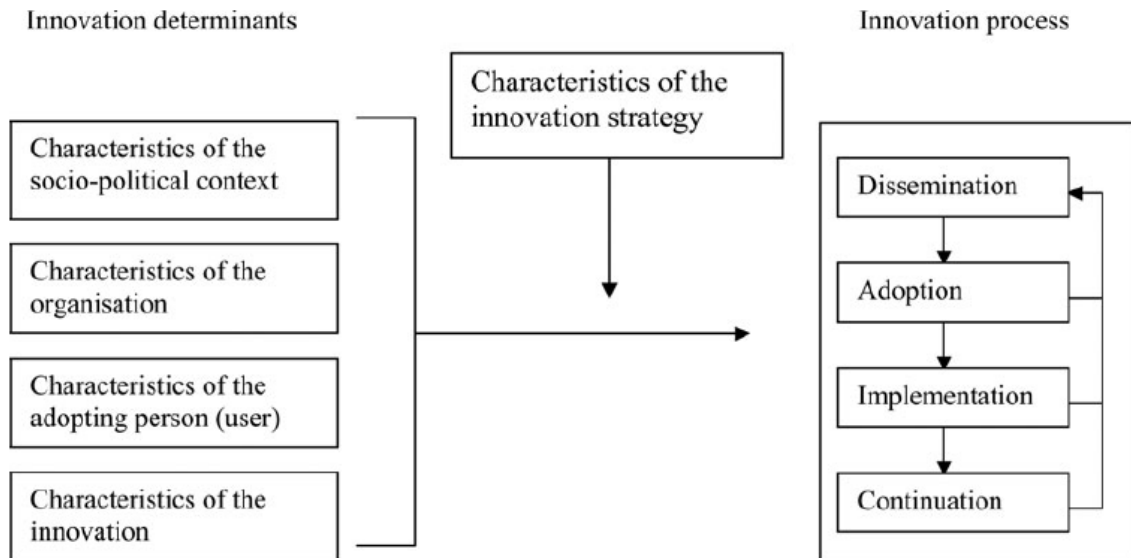


Figure 2-6. Framework of the main stages in the innovation process and related categories of determinants (Fleuren, Wiefferink & Paulussen 2004).

According to Fleuren and colleagues (2004), it is important to conduct a determinant analysis to provide the best chance for an innovation to be successfully implemented and for change to occur. They propose that a systematic strategy is required which involves the inclusion of three elements (Fleuren, Wiefferink & Paulussen 2004). First, the innovation must pay attention to the relevant determinants to the innovation process. Second, the selected methods and strategies underpinned by theory must be appropriate for influencing the relevant determinants of the innovation process.

## 2.6 Design thinking

Design Thinking (DT), also referred to as human-centered design (HCD) (Brown 2008) is a customer-focussed framework that offers an alternative, structured approach to solving “wicked problems” (Rittel & Webber 1973). In its application in healthcare research, there are three DT methods or principles: HCD prioritises the development of empathy for end-users; radical collaboration in multidisciplinary teams to generate ideas; and rapid prototyping of solutions and ongoing testing, which involves incorporation of the insights of the end-user (Ferreira et al. 2015; Kim, Myers & Allen 2017; Roberts et al. 2016).

Whilst most researchers separate the DT process into three phases or stages, some apply four stages as in the “double diamond” model (‘discover’, ‘define’, ‘develop’ and ‘deliver’) (Caulliriaux et al. 2020; Ferreira et al. 2015) and even five steps (empathise, define, ideate, prototype, and test) (Roddy & Polfuss 2020). The phases are variously referred to in different ways. Roberts and colleagues (2016) discuss the phases using the terms ‘analytical’, ‘synthesis’, and ‘rapid iterative prototyping and testing’. Others refer to them as



‘inspiration’ or ‘understanding’, ‘ideation’ and ‘implementation’ (Vechakul, Shrimali & Sandhu 2015). I herein use the former for consistency.

The analytic phase, considered the most important (Eckman, Gorski & Mehta 2016; Hendricks et al. 2018), involves the researcher empathising with the people most affected and most knowledgeable about that which needs changing. This is in order to understand their needs and identify any challenges and opportunities (Brown 2008; Brown & Wyatt 2010; Roberts et al. 2016; Vechakul, Shrimali & Sandhu 2015). “The first and most critical design thinking method, empathy, prompts teams to focus on developing a deep and diverse understanding of the explicit and latent needs, desires and values of a particular user group” (Roberts et al. 2016). A synthesis phase follows where the researcher uses stakeholders’ ideas to generate different methods for obtaining more effective outcomes (Brown 2008; Brown & Wyatt 2010; Vechakul, Shrimali & Sandhu 2015). Collaboration with a diverse range of stakeholders, along with embracing divergent thinking, is an important component of this phase (Brown 2008; Brown & Wyatt 2010). Numerous ideas are then tested quickly to expose any aspects of the concepts or proposed solutions that may have been missed before choosing the best option for fine-tuning (Roberts et al. 2016). The DT process concludes with a phase of further reflection and iteration by the researcher that re-emphasises empathy.

The study design was selected because its framework places the study participants at its centre. Empathy was built into the interview questions and the prompts when the research team were creating them. The interview questions were designed not just to build rapport with the participants but to also understand the family’s concerns. Whilst parents were directly communicating with the researcher about their child, empathy was applied when interviewing the participants. Empathy was conveyed through active listening and affirming statements and reflecting these back to participants to check understanding. The participants’ responses (located in the transcripts) provide good evidence that the researcher was empathic in her interviewing style and responses. Through parents answering the interview questions and telling their family’s story, the researcher was able to immerse herself in the parent’s experience and demonstrate empathy and understanding through her familiarity with the experience gained from working in private practice.

The principles of DT have successfully been applied to health care innovation and challenges (Eckman, Gorski & Mehta 2016). The approach has the potential to increase effectiveness and acceptance of health care innovations through active engagement with stakeholders in the design process and rapidly iterating innovation prototypes to provide the best possible chance for success (Altman, Huang & Breland 2018). DT has also been effective in other areas, including education (Fabri 2016; Jamal, Kircher & Donaldson 2021), the food industry (Ashman, Patterson & Kozinets 2021) and sport (Joachim et al. 2021).

Although DT has been used in various health care settings, the approach has never been applied to autism surveillance. By applying DT to this investigation of an autism intervention, it allows a strong focus on key stakeholders, particularly the parents. The use

of DT enables the researcher to gather evidence or data that informs the intervention in relation to the change process itself (what the problem actually is, redesigning, and making modifications); sustainability of service delivery; and improving health outcomes of the end-user (Carmel-Gilfilen & Portillo 2016; Eckman, Gorski & Mehta 2016; Yeager et al. 2016)

Researchers suggest that public health challenges could potentially be solved through the use of DT, by enabling health systems to innovate in ways that cut across boundaries (individual, community, organisational, political, geographical and sectorial) (Brown 2008; Roberts et al. 2016). The word 'design' in DT refers to understanding, that is, understanding the actual needs of the stakeholders (Ferreira et al. 2015): "Design, guided by personal narratives, offers a myriad of opportunities to inspire the healthcare experience" (Carmel-Gilfilen & Portillo 2016, p. 131). If stakeholder experiences are well understood, the results will be very helpful in informing the innovation and overall stakeholder experience can be improved (Kim, Myers & Allen 2017). Therefore, DT can be used to structure and create change that improves the patient experience, in health care innovation and delivery and therefore it can essentially be a way to close the gap between research and practice.

## **2.7 Study framework**

A program logic model offers a visual representation of the underlying theory and the reasoning that guides the program (Shakman & Rodriguez 2015). Logic models are frequently used in healthcare to provide a structured way to support planning, promotion, implementation, and evaluation (Ball et al. 2017; Clapham et al. 2017; Harris et al. 2015) and show the relationship between resources (Rehfuess et al. 2018). The inputs (resources), the outputs (the activities or services delivered to the end-user), participation, and outcomes (the changes that occur for the end-user as a result of the outputs) for this study are displayed in the model, and it further articulates their use, the relationships between them, and how they connect in order to achieve the purpose of this study. The logic model identifies the assumptions and external factors and uses evidence to connect the outputs and the outcomes.

The enablers and barriers to the successful implementation of the SACS-R into the Tasmanian CHaPS is of central interest in this study. The aim of this study was to identify these in order to expedite improved life-long outcomes for children with autism and developmental delays. The elements of successful implementation of the SACS-R and their relationship to one another are presented in a program logic model in Figure 2-7 below (Australian Institute of Family Studies 2021).

To revisit: Autism is the neurodevelopmental condition that is at the centre of this study. Young children with autism benefit from early identification and diagnosis so they can access intervention and achieve improved outcomes. The Social Attention and Communication Surveillance-Revised (SACS-R) is a reliable, autism specific early developmental surveillance tool that can be used by health care professionals to identify

behaviours in children between 11-30 months of age that may indicate high likelihood of autism. The problem is that many children are not identified until they reach a child-care or school setting and as a result do not access EI when it can be most effective.

A DT approach is used in this study to place the end-user at the centre of the research. Alongside DT, implementation science (IS) principles are employed to identify enablers that may support and barriers that may inhibit the implementation of the SACS-R. I use IS because it seeks to narrow the gap between the discovery of new knowledge and its application in health care settings. IS is a change theory that focuses on understanding and developing the process of the innovation (Handley, Gorukanti & Cattamanchi 2016). Lewin's change theory was selected as it successfully encapsulates effective change, has been widely used in organisational change, and has deep roots in the nursing field.

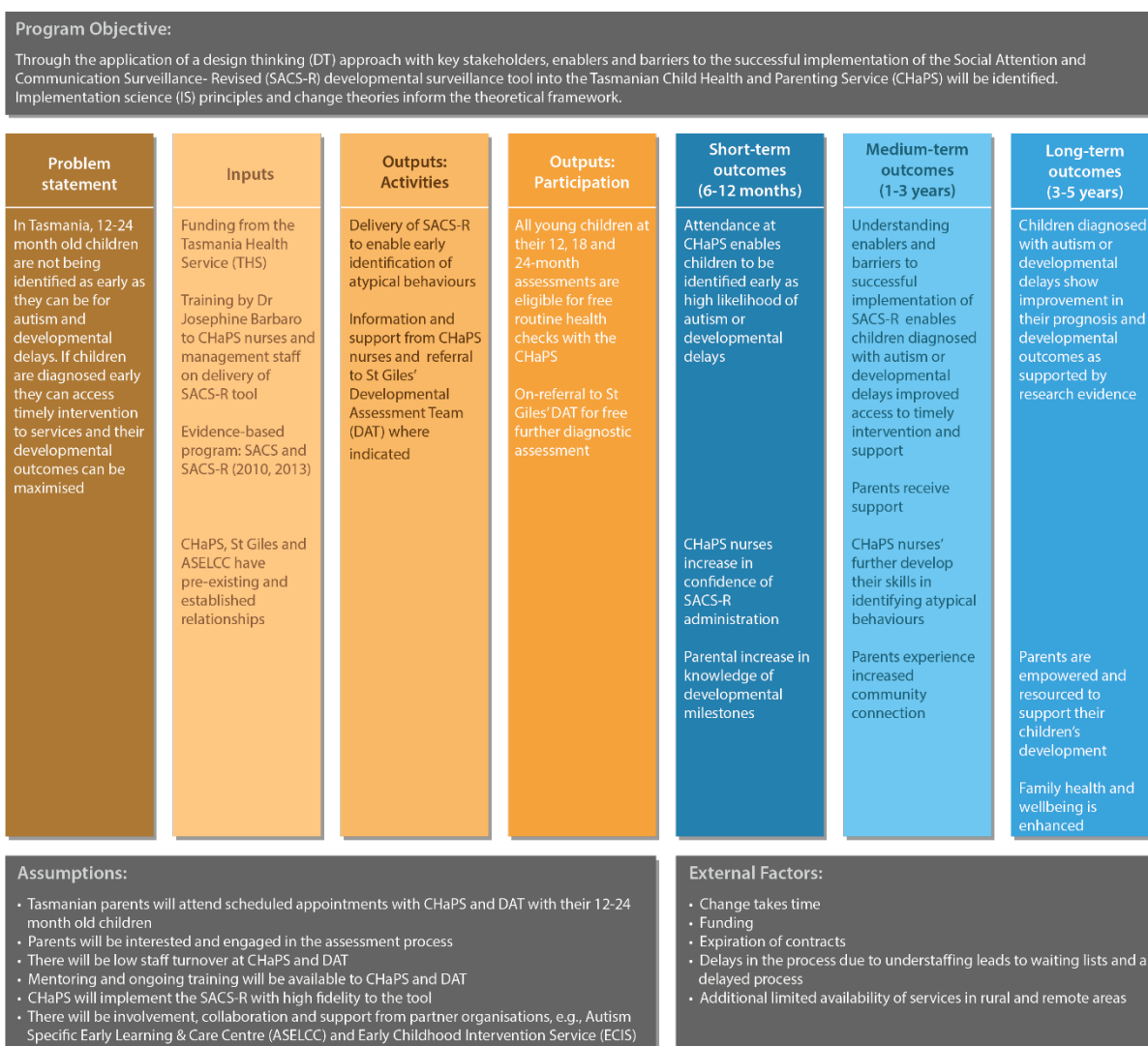


Figure 2-7. Program logic model displaying the elements of successful implementation of the SACS-R

This chapter involved a systematic search strategy using robust search terms. This process led to the development of a strong literature review based on key concepts that frame this study. The main concepts and theories discussed were: autism, developmental

surveillance, implementation science (IS) principles (including change theory), DT, enablers and barriers to successful implementation, and EI. These elements are presented in a program logic framework, depicted above in Figure 2-7, which provides a pragmatic approach to describing the thesis in a succinct way.

## Chapter 3: Methodology

This chapter discusses the methodological approach used and consists of the study design, a discussion of the mixed methods approach, and a description of the Tasmanian setting. The sampling method, characteristics of the participants, inclusion and exclusion criteria, and recruitment and procedure are all outlined in this chapter. The instruments used and the procedures relating to the data (management, storage, and analysis) are also described.

### 3.1 Study aim and design

The purpose of this study is to identify the enablers and barriers to successful statewide implementation of the SACS-R early childhood surveillance program into the health system. This program enables infants at high likelihood of autism to be identified in a timely way so they can access early intervention (EI). To answer the main research question “What are the enablers and barriers to a successful statewide implementation of the SACS-R into the public health system, so that infants at high likelihood of autism and developmental delays are identified early?”, this study draws on Implementation Science processes and a Design Thinking approach. It utilises a mixed method, concurrent study design in which quantitative and qualitative data were collected and analysed separately, then results converged.

The rationale for using a mixed methods research approach is its usefulness in the health service domain where collaboration between various stakeholders benefits not just the professionals, but most importantly the end-user. Moreover, a mixed methods research approach is effective in answering the investigative focus of the thesis from a stakeholder perspective and understanding the results. The quantitative methods include SACS-R *Salesforce* data, a questionnaire, and a survey. *Salesforce* is an electronic database used by the CHaPS nurses to enter the children’s SACS-R assessment data, controlled, and regulated by La Trobe University, Olga Tennison Autism Research Centre (OTARC), a dedicated autism research centre. OTARC obtained HREC approval for *Salesforce* data collection and the Tasmanian data contributes to the current thesis. The qualitative method involved follow-up interviews with three broad stakeholder groups: primary, internal, and external stakeholders. A detailed overview of the methodology and methods follows.

### 3.2 Mixed methods methodology

In mixed methods, the researcher collects, analyses, and integrates quantitative and qualitative data and their results, organises these procedures into specific mixed methods designs and frames these procedures within theory and philosophy (Creswell & Clark 2017). The research design was a concurrent, quan + QUAL, mixed methods design. The quan + QUAL notation indicates that the two methods occur concurrently, that is, the two strands of data collection were implemented at the same time (Morse 1991, 2003). The quantitative

and qualitative data were unequal in that there was greater emphasis placed on the qualitative data and this is denoted using capital letters (Creswell & Clark 2017). An online questionnaire for Tasmanian referred parents and a paper and pen survey for CHaPS staff were used. Semi-structured interviews were conducted with a range of stakeholders, including parents, CHaPS, St Giles and ASELCC staff, medical and allied health professionals.

A mixed methods approach has several key strengths. First, by gathering both quantitative and qualitative data, they collectively contribute to a sound understanding of the results (Creswell, Feters & Ivankova 2004). Using a mixed methods approach helps answer questions that cannot be answered by quantitative and qualitative approaches alone (Creswell & Clark 2017). For example, it helps us understand whether the views of the primary and internal (groups 1 and 2) stakeholders in their interviews along with their responses on the CSQ and MIDI converge or diverge. A second strength of mixed methods research is the rich accounts of participants' lives by allowing their words to be directly heard alongside the contribution of generalisability and statistical reliability (Borkan 2004). The third strength is that quantitative and qualitative data can both be utilised in a single study and full advantage can be taken of the strengths and the weaknesses minimised in both approaches (Johnson & Onwuegbuzie 2004).

The benefits of mixed methods research specifically for health care include opportunities to measure and investigate the experience of key health stakeholders (Carayon et al. 2015; Hussain & Tait 2015; Krutter et al. 2020). Carayon and colleagues in their systematic review of mixed methods research located 58 studies that explored human factors and ergonomics research in health care published between 2002 and 2013. The majority of those studies utilised the convergent parallel study design where quantitative and qualitative data are collected during a similar time-frame. The most common combined data collection methods were survey and interview. The authors were keen for human factors and ergonomics (HFE) researchers involved in complex healthcare quality problems to expand their use of mixed methods research as combining quantitative and qualitative data results in rich interpretations and conclusions (Carayon et al. 2015). Hussain and Tait (2015) conducted an Australian study investigating the perceptions of parents of children with developmental disabilities regarding information needs and service provision. This mixed methods study involved a survey and face-to-face in-depth interviews. The interviews produced information-rich data that significantly contributed to a comprehensive understanding of the information needs and service provision for parents, e.g., enhancing communication between health service providers and families (Hussain & Tait 2015). Krutter and colleagues (2020) investigated caregiver burden in dementia care from the perspectives of GPs, homecare nurses and family caregivers in rural Austria by way of questionnaires and in-depth semi-structured interviews. Their perspectives were compared and it was found that all three groups viewed psychological burden as the greatest type of burden experienced by caregivers. The selected mixed methods approach presented insights to the understanding of the various domains of dementia care provision (Krutter et al. 2020).

It is also appealing that the study will incorporate the voices of the participants alongside the validity and precision of the statistical analysis, to ensure the findings are applicable to other settings. Finally, mixed methods enables mapping of stakeholders' experience together with their lived experience of the success of the rollout of the SACS-R across Tasmania (Sale, Lohfeld & Brazil 2002).

There are many types of mixed methods research designs that researchers can choose from to address their research questions. Numerous classification systems or typologies have been produced in an effort to recognise all the various forms of mixed methods research designs available, (e.g., Creswell et al. 2011; Guest 2013; Johnson & Onwuegbuzie 2004; Leech & Onwuegbuzie 2009; Tashakkori & Creswell 2007; Teddlie & Tashakkori 2009). Various classification systems and typologies were investigated further to determine which approach would be the most appropriate for the current study. The typologies of Teddlie and Tashakkori (2009) and Leech and Onwuegbuzie (2009) are both widely used and were given consideration for best fit in relation to the current mixed methods research design. Teddlie and Tashakkori (2009) propose a rationale for typologies in the mixed methods field. They detail five reasons for their inclusion: typologies are tools that help researchers select their study design; they establish a common language (e.g., notations, abbreviations) for the field; they help to provide the field with an organisational structure; they help legitimise the field because they provide examples of research designs that are clearly distinct from either QUAN or QUAL designs; and are useful pedagogical tools to assist with pedagogical challenges (Teddlie & Tashakkori 2009). Leech and Onwuegbuzie (2009) suggest a three-dimensional typology: (a) level of mixing (partially or fully mixed), (b) time orientation (concurrent or sequential), and (c) emphasis of approaches (equal status or dominant status). The resulting typology is an eight-design framework as displayed in Figure 3-1. For this thesis, the typology created by Leech and Onwuegbuzie (2009) is most appropriate and will be utilised.

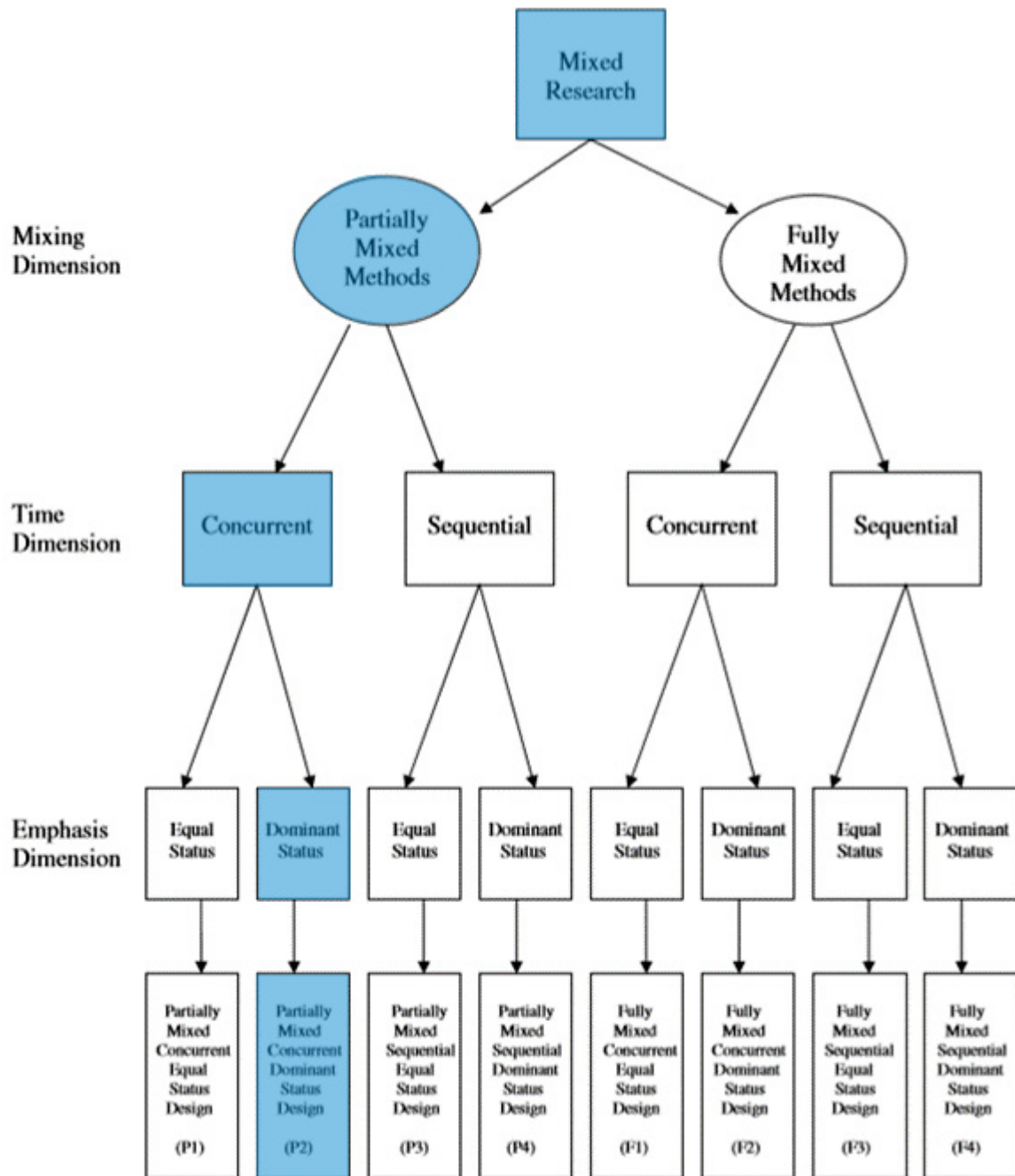


Figure 3-1. Typology of mixed methods research (Leech & Onwuegbuzie, 2009)

More specifically, this study uses a partially mixed concurrent dominant status design (P2). P2 means that the two forms of data are conducted concurrently in their entirety prior to being mixed at the data interpretation stage (Leech & Onwuegbuzie 2009). This method is similar to a convergent parallel mixed methods design where the two forms of data are collected at about the same time and the researcher then integrates the information in the interpretation of the overall results (Creswell 2014).



Creswell and Plano Clark advise researchers that when planning mixed methods research, they must consider the philosophical foundations or assumptions in their study (Creswell & Clark 2017). The philosophical approach that is selected is often referred to as a worldview, that is, the way in which one views the world (Halcomb & Hickman 2015). In the context of mixed methods research, there are four worldviews each comprising a different set of assumptions: postpositivist, constructivist, transformative, and pragmatist. Postpositivism is typically used with quantitative approaches, whereas constructivism is frequently used with qualitative approaches (Creswell & Clark 2017). The transformative approach is appropriate for research that contributes to social justice and the pursuit of human rights (Mertens, Holmes & Harris 2009). In order for the researcher to have a suitable approach to frame their research, the worldviews can be combined or used separately (Creswell 2008).

Pragmatism was chosen as the appropriate foundation for the current study as it focuses on inquiry into real-world practice, which is both objective and subjective; finds solutions to research problems (“what works”) (Creswell & Clark 2017); and “opens the door to multiple methods and different forms of data collection and analysis” (Creswell 2014, p. 11). It assists with the combination of quantitative and qualitative methods (Barbour 2013) and can be readily applied to concurrent or parallel studies such as this one where data collection comes from a range of sources (*Salesforce* consultations, questionnaires, surveys, and interviews).

The research literature offers a number of studies demonstrating that pragmatism is well-aligned with DT principles (Dalsgaard 2014; Johansson-Sköldberg, Woodilla & Çetinkaya 2013; Lindgaard & Wesselius 2017). For example, Lindgaard & Wesselius (2017) state a DT approach strives to solve complex problems and benefits from being anchored by pragmatism philosophy as it provides guidance for discussing key issues in DT. According to Dalsgaard (2014), application of the pragmatist worldview can inform DT in four ways:

1. Different issues in DT can be developed through investigation of how they have been addressed in pragmatism, e.g., pragmatism offers information on reoccurring themes and the place of experiments;
2. Pragmatism offers a conceptual framework that can lead researchers to think about the interrelatedness of DT issues, e.g., investigating and understanding the relationships between the experiments, materials, tools, and techniques used in design;
3. This new information may enhance the current approaches taken to design challenges and inspire the uptake of new approaches; and
4. Pragmatist models have already been utilised successfully in areas that involve people, in the practical arts (Brown 2017) and education (Sharma, Devi & Kumari 2018) and thus may lead to novel perspectives for DT (Dalsgaard 2014).

### 3.3 Relationship of methods to IS and DT

Hooker and Taft (2016) suggest that we need to ensure that Evidence Based Practices (EBPs), in this case the early identification of atypical behaviour in young children using the SACS-R tool, are delivered effectively in practice (Hooker & Taft 2016). The process can be safeguarded by the use of IS. Handley (Handley, Gorukanti & Cattamanchi 2016), Green (Green et al. 2014), and Fleuren (Fleuren, Wiefferink & Paulussen 2004; Fleuren et al. 2014) have all contributed to the IS field and their work has application to the current research. All three researchers and their co-authors have relevance in the evaluation of the implementation process. However, in isolation, individual frameworks are not sufficient to answer the research question, therefore a combination of IS principles has been utilised.

With each innovation it is important to recognise the relevant determinants of innovation so that the innovation strategy can be systematically designed to take into consideration the impact of those determinants so that the intended change can be effectively achieved (Fleuren, Wiefferink & Paulussen 2004). The research by Fleuren and colleagues (2004) led to the identification of 50 determinants of innovations and the development of a measurement instrument called the MIDI. It is used to measure the factors that may impact the implementation stage. It can be utilised both pre- and post-implementation of an innovation to progress researchers' knowledge. Follow-up research steered the number of determinants to be condensed to 29 (Fleuren et al. 2014). In this current study, a MIDI survey was completed by two of the three internal stakeholder groups (the CHaPS nurses and the CHaPS managers).

Complementing the P2 (partially mixed concurrent dominant status design) mixed methods design is the DT approach, which is particularly relevant as the process is "deeply human" and it offers a framework to understand the needs of the customer or end-user, prioritising and applying resources to meet their needs over those of any organisations involved (Brown 2008). It is an iterative process that aims to understand, develop, and evaluate the needs of the stakeholders and their responses regarding a change to services. DT enables the generation of new ideas and practices to find solutions to complex problems, redefining the way they are interpreted, and consequently, how they are solved (Caulliaux, Proença & Cardoso 2013). It is a bottom-up initiative that is thought to foster new approaches to persistent healthcare problems (Roberts, Fisher, Trowbridge & Bent, 2016). These features make it suitable to inform the planning, implementation, and evaluation of a program like the SACS-R into the routine clinical practice of CHaPS. By utilising a systematic process, the opportunity for success is enhanced (Roberts et al. 2016). In this study, it informs the evaluation component.

There are many unique strengths of a DT approach that support the chosen methodology of this project.

1. The DT process is an efficient way to evaluate a health innovation due to its human-centred framework that prioritises deep empathy for the desires, needs and challenges of the end-user (Ferreira et al. 2015; Kim, Myers & Allen 2017; Roberts et al. 2016). In turn, this enables an improved exploration and understanding of the research phenomena and the perspectives of the stakeholders in order to gain a comprehensive understanding of their experience (Roberts et al. 2016). Evaluating an innovation using a DT approach guides the researcher toward the end-user in order to ascertain the effect of the innovation. Practical solutions may be driven by emotional experiences (Brown & Wyatt 2010), so through engagement in the interview process, stakeholders' responses inform the researcher of the support required.
2. DT offers a high level of engagement for end users and healthcare providers which may give rise to greater acceptance and effectiveness of health care interventions (Altman, Huang & Breland 2018).
3. DT has the potential for the creation of human being-centred relevant solutions (Ferreira et al. 2015) as a result of the research.

At the heart of this research is the quest to understand the specific needs and experiences of the end users of autism services: the child, the parent, the family. Informed by DT, key stakeholders are the focus of this enquiry and the source of information about early identification of developmental delays, diagnosis and necessary supports and intervention for young children. Solutions regarding the implementation process are generated based on the data collected from these contributors, in the expectation that it will result in suitable, sustainable health system outcomes for children and their families.

DT was selected to assist in bridging the research gap between what we know to be effective practice and the time taken to implement policy and change to permit that new practice to occur within organisations. As EI is not a one-size-fits-all solution to a developmental diagnosis, a DT approach can help ascertain what it is that is needed for families in the process.

### **3.4 Participants**

The studied population contained parents, CHaPS nurses, Nurse Unit Managers (NUMs), a Clinical Nurse Educator (CNE), Assistant Directors of Nursing (ADoNs), Director of Nursing (DoN), the DATs, the ASELCC, the AAP<sub>1</sub>, Early Childhood Intervention Service (ECIS), Autism Tasmania, members of Parliament, allied health professionals, and members of key health and educational associations. The participants were organised according to stakeholder categories: primary, internal, and external as shown in Figure 3-2.

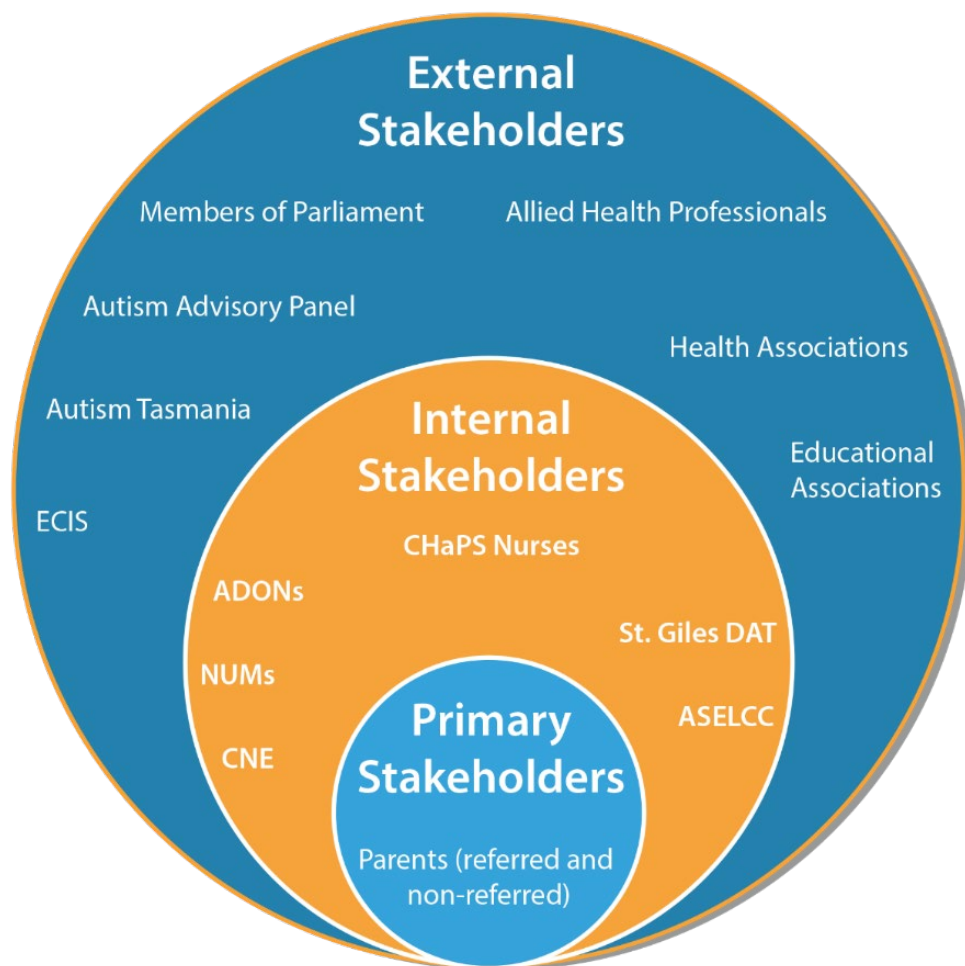


Figure 3-2. The three stakeholder categories

### 3.5 Setting

Australia is comprised of six states and two territories. Tasmania is the smallest of the states and is Australia's only island state. In September 2020, the ABS data showed that Tasmania had a population of 541,100 people (Australian Bureau of Statistics 2021). The state's population of children and youths aged between 0 and 17 years is 12,646 people. From 2005 to 2017, the population of this age bracket has reduced by 3.9%. Since 2008 the birth rate has decreased by 11.9%.

Tasmanian is divided into three main health regions: North, North-West, and South as shown in Figure 3-3 below.



*Figure 3-3. The three health regions of Tasmania*

Within these three main regions there are four major city centres: Hobart, which is the capital city of Tasmania and located in the South of the state; Launceston, located in the North; and Burnie and Devonport located in the North-West. Tasmanian children and youths 0-19 years are distributed as 50.8% in the Southern region, 27.6% in the North, and 21.7% in the North-West (Office of the Commissioner for Children and Young People 2018). In 2015, approximately 48 per cent of mothers were from the lowest SES areas, compared to 20.5 per cent nationally (Australian Institute of Health and Welfare 2020).

Tasmania's health care is organised under two systems: public and private. The Tasmanian Health Service (THS) provides public health services to Tasmanians which include hospital care, oral health, and mental health services. The THS also offers free, community-based health services for children (birth to five years of age) and their families through the CHaPS (Department of Health and Human Services 2021). The CHaPS have centres located throughout the state with a base in each of the three main regions as shown below in Figure 3-4.



Figure 3-4. Locations of Tasmanian CHaPS centres

## 3.6 Population and sample

### 3.6.1 Primary Stakeholders (Parents)

Of the 5,500 Tasmanian births per year, many of these children go to their CHaPS nurse and as the research indicates 1-2% of these children are likely to be referred for an autism assessment. The primary stakeholders included parents whose child had been assessed with the SACS-R tool as part of a routine health check appointment with Child and Health Parenting Service (CHaPS) nurses within the Tasmanian Health Service (THS).

The parents were further categorised into two groups. The first group were the 'non-referred' parents, who are parents of children who have been assessed with the SACS-R as part of their routine CHaPS universal health check, and who were found to have no

identifiable difficulties warranting further assessment. The second group were considered as 'referred' parents, which included parents of children who were flagged as high likelihood after being assessed with the SACS-R and who were subsequently referred on to the DAT for developmental assessment. These children either:

- a) did not receive an ASD diagnosis or any other diagnosis;
- b) did receive a diagnosis of ASD; or
- c) did not receive a diagnosis of ASD but did receive another diagnosis. The parents of the children in categories (b) and (c) were invited to be interviewed about their experiences of the SACS-R and the St Giles assessment to gather insights into their experience of the SACS-R assessment and referral pathway.

A non-referred parent is the parent of a child who demonstrated typical behaviours on the SACS-R and who therefore did not receive on-referral to St Giles. A referred parent is the parent of a child who showed sufficient atypical responses during the SACS-R assessment to warrant a referral to St Giles for further assessment.

### **3.6.2 Internal Stakeholders**

#### **i. Internal stakeholders (groups 1 and 2)**

Group 1 includes the CHaPS nurses. Group 2 is the managerial staff, that is, the Nurse Unit Managers (NUMs: responsible for the CHaPS nurses and oversee the SACS-R process), the Clinical Nurse Educator (CNE: responsible for managing the professional development of the CHaPS nurses), the Assistant Directors of Nursing (ADoNs), the Director of Nursing (DoN: provides overall, statewide leadership, along with the support of the ADoNs, to the CHaPS teams, the NUMs and the CNE).

At birth, the CHaPS provide all parents with a personal health record (PHR) for their child – a 'blue book'. The blue book contains parenting information and has provision for records of the baby's development and vaccination history. All families can attend the CHaPS for their child's milestone checks (2, 4, and 8 weeks; 6, 12 and 24-months; and 4 years of age) to monitor growth and development. The nurses are the people administering the SACS-R so they are directly involved in the surveillance of the children with their parents. The majority of nurses conduct their day-to-day work at the CHaPS clinics, while other nurses are involved in the *C U @ Home* Program. This program is offered to 15-19 year old, first-time parents. In the *C U @ Home* Program, a CHaPS nurse will visit the parent's home on a regular basis from the antenatal period, up until the child turns two. Statewide, at the 12 and 24-month checks, the nurses administer the SACS-R assessment. In the South, this assessment is also administered at the 18-month routine health check.

#### **ii. ASELCC and St Giles (group 3)**

Children who receive an atypical result on the SACS-R assessment are referred to the St Giles Developmental Assessment Team (DAT) for further assessment. The ADOS-2 and the ADI-R are the assessments provided and where necessary supplementary assessments are

also utilised, e.g., Griffiths Mental Development Scales (GMDS). The GMDS provides an overall measure of a child's development and individual profile of strengths and weaknesses across five domains in children aged two to eight years. The DATs also provide support to the parents of the children referred to the service. St Giles has two locations within Tasmania, one in Hobart and one in Launceston. The Launceston DAT travel to the North-West to provide these assessments to children at the St Giles-operated ASELCC, in Burnie. In line with current practice of the St Giles diagnostic services, home assessments or assessments at a local child and family centre are negotiable if families are unable to come to a centre.

ASELCC is a purpose-built long day care setting for children up to six years of age who either have traits of autism or an autism diagnosis. ASELCC offers 20 places and the children can access EI services and early childhood education. There is a multi-disciplinary team of childcare workers and specialist staff, e.g., Speech & Language Pathologist, Occupational Therapist, Child Psychologist, who provide a tailored early learning program and specific support that targets the learning and development needs of each enrolled child and their families (Department of Families Housing Community Services and Indigenous Affairs 2012).

### **3.6.3 External stakeholders**

Although this group of stakeholders is quite diverse and come from a range of professions, all members are connected (either directly or indirectly) to children and families within the health and/or educational space with regard to autism. This group is comprised of the AAP<sub>1</sub>, Early Childhood Intervention Service (ECIS), Autism Tasmania, members of Parliament, allied health professionals, and representatives from health and educational associations.

The AAP<sub>1</sub> provides input to the development of long-term autism strategies that meet the needs of Tasmanians across their lifespan. The ECIS support children (birth to school entry age) with a disability or developmental delay, providing education, therapy, counselling, assistance and support to access services (e.g., kindergarten and childcare). ECIS are familiar with the SACS-R tool and the process; they work with the children who have been administered the SACS-R and have a diagnosis.

Autism Tasmania help parents and carers of young children with autism as part of the Commonwealth Government's Helping Children With Autism (HCWA) initiative and now the Early Childhood Early Intervention (ECEI). Members of Parliament are responsible for representing the communities' perspectives on important issues. Thus, ascertaining their views on the rollout of the SACS-R program is important information to access. Allied health professionals work directly with children who have received an autism diagnosis and therefore would have views about surveillance and diagnostics. Members of health and



education associations have direct involvement in managing, treating, or teaching people with autism.

### 3.7 Sampling method

A convenience sampling method was employed for recruitment of all stakeholder groups. Interview participants were selected using this non-probability type of sampling approach. Whilst this recruitment method offered an opt-in opportunity, it concurrently hinders generalisation of the findings across the broader stakeholder group. The population and sample are summarised in Table 3-1 below.

**Table 3-1. Summary of statewide distribution of participants, their characteristics and justification for recruitment**

Group	Characteristics
<b>Primary stakeholders</b>	
Parents (n=130-160)	Statewide sample (3 regions: North, North-West, South); Male and female; Age range (15 years – 60 years). 15 years is the age eligibility criteria for young parent program (C U @ home); Parent/guardian of a child <3years old; Includes parents whose child was not referred for diagnostic assessment (non-referred group) and parents whose child was referred for developmental assessment (referred group).
<b>Internal stakeholders</b>	
Child Health and Parenting Service (CHaPS) nurses (N=101)	Female and male adults Age range 21-75 years; statewide sample.
Nurse Unit Managers (NUMs) (n=9)	Male and female adults; Managers of the CHaPS nurses; At least one representative from the North; North-West and South.
Clinical Nurse Educator (CNE) (n=1)	1 statewide female, over 21 years
Director of Nursing (DoN) + 2 Assistant Directors of Nursing (ADoNs) (n=3)	Male and female adults (>21 years); Experienced child health nurses; 3 in total statewide.
St Giles Developmental Assessment Team (DAT) (N=6)	Male and female adults; 4 North/North-West and 2 South; Each team is made up of several allied health professionals, e.g., psychologist, speech pathologist and/or occupational therapist.
Autism Specific Early Learning & Care Centre (ASELCC) (n=6)	Burnie (ASELCC only operates out of the North-West); 20-member team comprised of specially trained educators, teachers, speech pathologists, an occupational therapist, a social worker and a psychologist. Male and female Aged over 18 years
<b>External stakeholders</b>	
Autism Advisory Panel (AAP <sub>1</sub> ) (n=1)	The Chair or nominated representative; these people have professional (and sometimes personal) experience in the area

	of ASD. Panel members are from the Department of Health and Human Services, St Giles, Department of Education, service provider, families, and the National Disability Insurance Agency. Female; aged over 21 years
Early Childhood Intervention Service (ECIS) (n=6)	Range of professionals, e.g., teachers, educational advisor, visiting allied health professionals (e.g., occupational therapist, physiotherapist, psychologist, speech pathologist), who work with the children; Minimum of one representative per region (North, South, North-West). Male and female; aged over 18 years
Autism Tasmania (n=4)	CEO and ASD consultants; Through their statewide team they provide education, support and practical help to people on the autism spectrum. Male and female Aged over 18 years
Members of Parliament (n=3)	Elected by the Tasmanian people to represent their views and create legislation Male and female Aged over 21 years
Allied health professionals (n=10)	Psychologists, occupational therapists and speech pathologists from public and private practices; Statewide sample (3 regions: North, North-West, South). Male and Female Aged over 21 years
Health and educational associations (n=10)	Representatives (e.g., AMA); Statewide sample (3 regions: North, North-West, South). Male and female Aged over 21 years

The sample size calculation for all stakeholder groups was as follows:

- i. Primary stakeholders - The recruitment was planned using a convenience sample of a minimum of 100 parents (non-referred and referred), all of whom were invited to complete an online questionnaire. The primary stakeholders comprise two sub-groups of participants– non-referred and referred parents. Given that there are approximately 6,000 infants born per year in Tasmania (CHaPS: Direction, Design and Plan consultation paper, 2016) and the 1-2% prevalence rates for autism, it was anticipated that between 60-120 children from the SACS-R cohort would go on to receive a diagnosis of autism. The researchers estimated that possibly half of those, i.e., 30 to 60 parents, would be willing to participate in an interview. Between 30 and 60 interviewees would be sufficient to generate data to support some generalised conclusions about the parent experience.
- ii. Internal Stakeholders - Every CHaPS nurse in the state who had been trained in the SACS-R was to be invited to complete a survey when they attended one of their CHaPS Operational Meeting (COM) Days. These COM Days are professional development days that are held monthly throughout the state in the three regions

(North, North-West and South). We estimated that at least 20% would be willing to participate in the follow-up interview. All the NUMs, the CNE, the ADoNs and the DoN also attend these professional development days. The DATs and ASELCC are professional groups made up of people who have regular, direct involvement with children and families in their daily work and their core business is to provide assessment and/or assistance.

- iii. External stakeholders – The researchers were hopeful that they would secure representation from all key subgroups (AAP<sub>1</sub>, ECIS, Autism Tasmania, members of Parliament, allied health professionals, and health and educational associations).

With regard to numbers for the qualitative data collection (interviews), Guest and colleagues concluded that for research with a reasonably homogeneous group of participants, “a sample of six interviews may [be] sufficient to enable development of meaningful themes and useful interpretations” (Guest, Bunce & Johnson 2006, p. 78). Nevertheless, when the research “aim is to understand common perceptions and experiences..., twelve interviews should suffice” (Guest, Bunce & Johnson 2006, p. 79). We aimed for at least 12, and for data saturation. Saturation is reached when ongoing data collection does not contribute significant understanding to the issue being examined (Bernard & Bernard 2013) and when additional coding is no longer practical (Guest, Bunce & Johnson 2006). In this study, saturation of the interview data was achieved when the story content was being replicated and no new information was being presented. Although it was apparent that this point had been reached before completion of the interviews, data collection continued until all participants who had consented to participation had been interviewed.

According to Saunders et al. (2017) there are four separate approaches to the methodological principle of saturation. The fourth model is the data saturation approach which relies on the idea of “informational redundancy”. That is, the researcher recognises saturation early in the process by sensing that the interview information indicates that ongoing data collection is superfluous. Saunders and colleagues state that the decision to cease data collection can therefore occur before coding and thematic development commences.

### 3.7.1 Inclusion and exclusion criteria

The inclusion and exclusion criteria for the participants of this study are outlined below in Table 3-2.

**Table 3-2. Inclusion and exclusion criteria**

Primary Stakeholders	<ul style="list-style-type: none"> <li>• Parents/guardians of children who have undergone the SACS-R assessment parents referred to St Giles</li> <li>• Exclusion criteria: Non-English-speaking parents who were unable to communicate using the English language</li> </ul>
Internal Stakeholders	<ul style="list-style-type: none"> <li>• All of the CHaPS nurses in Tasmania, the NUMs, the CNE, the ADoNs, and the DoN</li> </ul>

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	<ul style="list-style-type: none"> <li>• The members of the St Giles DATs</li> <li>• Representatives from the ASELCC</li> <li>• Exclusion criteria: People who do not have experience with, or knowledge of developmental assessment or do not work with people suspected of having ASD</li> </ul>
External Stakeholders	<ul style="list-style-type: none"> <li>• Representatives from each of the external stakeholder subgroups were invited to participate in an interview</li> <li>• Exclusion criteria: People who have little knowledge or experience regarding ASD or are not involved in ASD surveillance.</li> </ul>

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### 3.8 Recruitment and procedures

After filtering participants through screening, based on inclusion and exclusion criteria, the following procedure was involved:

#### i. Primary stakeholders

As the lead researcher I had access to all the parents contact information whose child had undergone the SACS-R health check and provided their verbal consent to participate in the current study. To preserve confidentiality, I was the only person who made email contact with each parent that met the inclusion criteria of the study. Included in the email correspondence were the information sheet (Appendix B), consent form (Appendix C) and flyer.

Securing parent participation and their views regarding their experience of the SACS-R process was critical. CHaPS clinics and St Giles offices were the two entry points for parent recruitment. When parents came to the CHaPS clinics for their child's routine health check, paper copies of the information sheet, consent form, and the flyer inviting parent participation in the study, were available. Referred parents attending St Giles for their child's developmental assessment could also consent to participation in an interview. There was a poster displayed for parents to read, inviting their participation in the current research. St Giles staff received some completed consent forms and scanned them through to the researcher.

When I contacted the parents or vice versa it was ascertained if the parent had already completed the CSQ-8 (Appendix D) via the provided link (supplied in both the information sheet and the flyer) and submitted it. If they had not done this yet, the researcher forwarded the link to them embedded in a text message or via email so it could be completed prior to interview. A date and time for the interview was arranged and decisions made about how and where the interview would occur. The interview could be conducted by phone, Skype, Face Time or face-to-face, in the family home or at a mutually agreeable place, e.g., the parent's workplace or an office location in the Hobart CBD.

Completed consent forms were returned to me prior to interview or alternatively on the day of interview. Before commencing the interview, the parent was put at ease by being asked to describe a typical day in the life of their child. I had the parent's signed written

consent form in front of me; the preamble was read aloud; then the audiotape was turned on at the place where the parent gave their verbal consent. The interview followed the questions set out in the semi-structured interview schedule (Appendix E) along with a five-point Likert scale to determine the level of satisfaction the parent experienced during the SACS-R process.

Interviews were audiotaped and transcribed verbatim. Voice quality was good and the audio-recorder was provided by the research team. Phone interviews were typically conducted at an office location in the Hobart CBD in a quiet room. Parents were sent their transcript for editing with a two-week opportunity to respond and make changes if required.

## ii. Internal stakeholders

The CHaPS nurses (group 1), the NUMs, the CNE and the ADoNs (group 2) were informed by the DoN (and on behalf of the research team) via email, that at their next COMs Day they would be invited to complete a survey (Appendices F and G). The information sheets formed part of that email communication.

At the COM Day, the researcher introduced the nursing staff to the MIDI survey. Time was allocated for completion of the survey. On completion, surveys were dropped in a labelled box (*Completed Implementation Surveys*) and doing so, implied consent. Interest in interview participation was given via the staff member taking a copy of the relevant consent form, signing it and dropping it into a second labelled box (*Interviews*). Participating in an interview (Appendices H and I) and the use of a five-point Likert scale, would enable CHaPS nurses to share their experience, understanding and perspectives regarding the training, administration of the SACS-R tool, and on-referring to the St Giles DAT, alongside managers' experiences which involved participation in the training and overseeing the SACS-R process.

Within the next two weeks, I contacted each participant who had indicated interest in a follow-up interview and organised a date, time, and place for the interview to occur. They were given options regarding the platform they would like to use to respond to the interview questions: email, phone, face-to-face, Skype, or Face Time.

The DATs and ASELCC (group 3) staff were invited to participate in an interview via an emailed letter of introduction, with the information sheet and consent form sent as attachments. They communicated their interest in being interviewed by return email. Participants were then offered options around how they might like to respond to the interview questions, either by reply email, over the phone, in a face-to-face interview, over Skype, or Face Time. The potential for follow-up communication was mentioned, as per the information sheet.

Interviews were arranged and took place at the professionals' place of work or by phone if that was deemed more convenient by the participant. Prior to interview, the interviewer made clear arrangements with the participant regarding the time of the

interview and an estimate of how long it might take. The phone interviews were conducted in an office location in Hobart in a quiet room.

A semi-structured interview schedule (Appendix J) was used. At the time of interview, I had the participant's signed written consent form in front of me; the preamble was read aloud; then the audiotape was turned on at the place where the participant gave their verbal consent. Interviews were audiotaped and transcribed verbatim. Voice quality was good and the audio-recorder was provided by the research team. Phone interviews were typically conducted at an office location in Hobart in a quiet room. CHaPS, ASELCC and St Giles staff were sent their transcript for editing with a two-week opportunity to respond and make changes if required.

### iii. External stakeholders

This group was identified through accessing websites and utilising information that is publicly and freely available. The AAP<sub>1</sub> was directly contacted through the Chair. ECIS was contacted via email. Autism Tasmania was contacted by phone and email. Members of Parliament were contacted via phone and email. Allied health professionals were contacted through the *Tas Medicare Local* website. Representatives from health (Australian Psychological Society and the Royal Australian College of General Practitioners) and educational (Department of Education, Independent Schools and Catholic Education) associations were contacted by phone and email.

All external stakeholder agencies who responded to my initial communication were sent a follow-up personalised email to officially invite them to participate in an interview. An information sheet and consent form were sent as email attachments. A date and time for the interview was arranged and decisions made about how and where the interview would occur. The potential for follow-up communication was mentioned, as per the information sheet.

At the time of interview, I had the participant's signed written consent form in front of me; the preamble was read aloud; then the audiotape was turned on at the place where the participant gave their verbal consent. A semi-structured interview schedule (Appendix K) was used. Interviews were audiotaped and transcribed verbatim. Voice quality was good and the audio-recorder was provided by the research team. Phone interviews were typically conducted at an office location in Hobart in a quiet room. Participants were sent their transcript for editing with a two-week opportunity to respond and make changes if required. The ECIS participants were given a four-week time frame to return their transcript, which was in line with the request from the Department of Education, Education Performance and Review (EPR).

## **3.9 Storage of data and transcription process**

On completion of all interviews, the audio files were stored onto a secure, password protected University of Tasmania laptop, accessible only by me. The audio tapes were

listened to multiple times to facilitate the transcription process and reduce errors and improve reliability. The transcript was then sent to the participant for editing to achieve external reliability. Participants had an option to use track changes (procedural steps were supplied) to enable them to do any editing.

### **3.10 Instruments**

The instruments used for this project facilitated data collection, measurement of key findings, analysis, and thematic development of stakeholder perspectives in order to integrate their views to answer the research aim. This ensured that the most robust and relevant data was gathered, and the instruments facilitated understanding of the participants' perspectives, particularly for the parents. This section describes the selection of instruments for stakeholder participation. The quantitative data collection encompassed a parent online questionnaire and a CHaPS survey, one for the nurses and one for the managers.

The qualitative data collection involved stakeholder semi-structured interviews conducted by me. In line with trustworthiness guidelines (Elo 2014), all five interview schedules were 'tested' with the supervision team through a series of role plays. The team took turns being the interviewer or the respondent and tweaked questions as appropriate until a final interview schedule for each stakeholder group was agreed upon. The aim of the interviews was to add to the knowledge that had been initially gleaned in quantitative data collection, and further understand the experience of the key stakeholders regarding autism surveillance, a diagnostic pathway and EI. Each stakeholder group had a different interview template which focused on broad areas of questioning so that the participants had scope to reflect, consider and enter into a conversation style interview.

#### **3.10.1 Interview schedules**

The interview questions for the three stakeholder groups (primary, internal, and external) were developed by the research team and framed as semi-structured interviews. There were five interview schedules in total: the parents, CHaPS nurses, CHaPS management, ASELCC and St Giles, and external stakeholders. The main questions were directed to achieving the research aim as well as the theoretical underpinnings of the study, that is, a DT approach. The questions for each group were designed to discover the participants' thoughts about their experience of the SACS-R process. Each topic had several questions and at least one prompt to facilitate the interview process. In addition, a Likert scale was used alongside the interview schedule for the primary stakeholders and internal stakeholders' group 1 and 2.

##### **3.10.1.1 Primary stakeholders**

The second instrument for the primary stakeholders, the interview, was used only with the referred parents. The intention was to ascertain the parents' thoughts about their experience with the CHaPS nurse and the SACS-R assessment and the referral process to St

Giles. There were three overarching topics (the parents' experience with their child's assessment at CHaPS; the parents' experience with their child's St Giles' assessment; and the parents' satisfaction with what is going to happen in the future for them and their child). The Likert scale was used to facilitate some of the parents' responses to the interview questions.

### **3.10.1.2 Internal stakeholders**

The internal stakeholder participants are comprised of three groups – the CHaPS nurses (group 1), CHaPS management (group 2) and staff from ASELCC and St Giles (group 3). Each group had their own dedicated semi-structured interview. The interview was the second instrument for groups 1 and 2 but the only data collection instrument for group 3. The nurses' questions covered four main topics: the nurses' experience with using the SACS-R; their insights into what the SACS-R process was like for the parents; their experience with making referrals to St Giles' assessment; and the technical aspects of the process. The managers' questions covered a range of topics, including their thoughts about the SACS-R process, the role of the nurses, the piloting of the 18-month surveillance assessment, their views on the parents' experience, collaboration with project partners, technical aspects, and the next steps. The questions for ASELCC and St Giles staff covered five areas: the rollout of the SACS-R, the referral process, the experience of the parents, their thoughts around taking the SACS-R forward, and any tips for the implementation team if they were to conduct the rollout again.

The Likert scale was used once with the nurses and once with the managers. It captured the CHaPS nurses' views on how successful they thought they had been in implementing change into their practice routine. The managers were asked a similar question, about how successful they thought that the CHaPS nurses had been in trying out change in practice and integrating new practice into routine.

### **3.10.1.3 External stakeholders**

The intention of the interview was to gain an understanding of stakeholder views on three main topics: the needs of parents and their children who have autism; their knowledge of autism and their involvement in the field; and the statewide rollout of the SACS-R program.

## **3.10.2 Client Satisfaction Questionnaire**

The Client Satisfaction Questionnaire (Attkisson & Greenfield 2004) (CSQ-8) is a brief, standardised measure developed by Attkisson & Greenfield (2004). It is a standardised measure used to assess end-user's general satisfaction across varied health and human services. The instrument has demonstrated strong psychometric properties (Attkisson & Greenfield 2004; Kelly et al. 2018) across a range of settings and with different populations (Roberts, Attkisson & Mendias 1984). It has very good internal reliability (Cronbach's alphas .83-.93), high construct validity (correlations .6-.8) between it and other instruments



that measure satisfaction (Attkisson & Greenfield 2004), and high concurrent validity with the Treatment Perceptions Questionnaire (TPQ) (Kelly et al. 2018). The CSQ-8 has previously been used in Australia across various health settings (Gethin et al. 2016; Kelly et al. 2018; Tsai et al. 2016; Winter et al. 2016). It has eight questions on a four-point Likert scale and the maximum score is 32. An optional comment box is included. The CSQ-8 was used to assess parent satisfaction (non-referred and referred parents) following administration of the SACS-R assessment by the CHaPS nurse and before being interviewed (referred parents).

### **3.10.3 Measurement Instrument for Determinants of Innovation**

The Measurement Instrument for Determinants of Innovations (MIDI) (Fleuren et al. 2014) contains 47 items, 43 closed questions (based on a five-point Likert scale) and 4 open questions (2 questions on enablers; 2 questions on barriers). A Likert scoring method enables the translation of qualitative insights into quantitative data that can be analysed and used to further inform the researcher. The MIDI is a self-administered paper-based survey instrument designed to measure the determinants of an innovation that may affect or support the implementation of an innovation. Fleuren and co-authors (2004) conducted a systematic literature review and a Delphi study to investigate the conditions and factors that enhance or hinder change and successful implementation of innovations into health care organisations. Following analysis of 57 studies, the aforesaid authors created a framework to categorise factors, termed determinants, that impact the innovation process. These determinants were drawn from the Delphi study and from various theories and models devised and published by leading researchers in the field between 1990–2000 and divided into four sub-scales:

1. Determinants related to the socio-political context, e.g., the degree to which the patient is aware of the health benefits of the innovation and the extent to which the innovation fits into existing rules, regulations, and legislation;
2. Determinants related to the organisation, e.g., the decision-making process and procedures and staff turnover;
3. Determinants related to the person adopting the innovation, e.g., support received from management and the confidence to perform the behaviour needed to implement the innovation; and
4. Determinants related to the innovation, e.g., the extent to which the innovation is appealing to use and frequency of use of the innovation (Fleuren, Wiefferink & Paulussen 2004).

At this point in time, the instrument has not been validated, nonetheless, the results from the literature review of implementation studies in health organisations and the Delphi study (Fleuren, Wiefferink & Paulussen 2004) indicate that the determinants are good (Rijbroek, Strating & Huijsman 2017). A search of the literature indicates that the MIDI has not previously been used in Australia, however, it has been extensively used across Europe (Deenik et al. 2019; Kolkman et al. 2020; van Dam et al. 2020).

Three of the four aforementioned subscales were used to investigate 'Implementation of the SACS-R surveillance tool' (8 items); 'Clinical use of the SACS-R' (24 items); and 'Organisation of the Tasmanian CHaPS' (11 items). The MIDI survey for group 1 contained 47 items: 43 Likert scale response questions, four open-ended questions [two enabler and two barrier questions], and one No/Yes response. The MIDI survey for group 2 required them to answer ten items: 8 Likert scale response questions and 2 open-ended questions (one enabler and one barrier questions). The three aspects that were explored with group 1 were: 'Implementation of the SACS-R surveillance tool'; 'Clinical use of the SACS-R'; and 'Organisation of the Tasmanian CHaPS'. Group 2 responded to the 'Organisation of the Tasmanian CHaPS' aspect in their MIDI survey.

Members of the research team (AM, TB and LQ) applied the generic framework of the MIDI to formulate questions to investigate the impact of determinants on the implementation of the SACS-R. Statements contained within the four categories of MIDI items (the characteristics of the socio-political context; the organisation; the adopting person of the innovation [the user]; and the innovation) were modified or removed to explicitly explore the SACS-R and to ensure that the statements were appropriate to the target group. For example, an item under the 'Characteristics of the adopting person', MIDI item 13 refers to 'social support' and describes this characteristic as "Support experienced or expected by the user from important social referents relating to the use of the innovation (for example from colleagues, other professionals they work with, heads of department or management)." In the reworked MIDI survey, the CHaPS nurses were asked about the support received from management and the confidence to perform the behaviour needed to implement the innovation. More specifically, if they could rely on adequate assistance from their colleagues when they need to use the SACS-R (item 18) and if overall they think that the CHaPS nurses in their organisation, including themselves, can effectively support the implementation of the SACS-R as part of routine clinical practice (item 20).

### **3.11 Ethics approval and research governance**

Ethics approval was obtained from the University of Tasmania Human Research Ethics Committee (HREC #H0016974). The ethics approval was subject to a number of amendments as outlined in the project timeline (Section 3.15). It was also necessary to obtain additional organisational approval from CHaPS, St Giles, and the Department of Education (DoE) in order to interview staff. Approval was obtained from the CHaPS Nursing Director, Early Years (letter dated 12 October, 2017), the General Manager of ASELCC and St Giles (letter dated 31 October, 2017), and the Acting Director of the EPR (letter dated 13 December, 2019).

The study adhered to the principles of ethical conduct according to the World Medical Association Declaration of Helsinki (version, 2008) alongside the guidelines set out in the National Statement on Ethical Conduct in Human Research 2007 (updated 2018).

The National Statement on Ethical Conduct in Human Research 2007 (updated 2018) clearly states that the design, review and conduct of research must reflect the values of research merit and integrity, justice, beneficence, and respect. The following paragraphs summarise the key principles.

*Research merit and integrity:*

The aim of this principle is to achieve the expected outputs based on the aims of the research project via an extensive review of the current and previous literature. It ensures that respect of the participants is maintained throughout the mechanics of research process under supervision and mentorship of leaders in the field; and using resources for facilitation. This study was conducted by researchers that are qualified and competent in autism assessment, diagnosis and intervention. The supervisory team is highly experienced and qualified to guide the research area. All questionnaires, surveys and interview schedules were appropriate for the current study.

*Justice:*

It implies fairness in the recruitment process, free from disadvantaged participation in research to prevent corruption in the conduct of research. Throughout this study all participants (study participants and research participants) were treated justly in interactions and the expectations were fair and equal.

*Beneficence:*

This element encompasses that a participant understands the possible risk, harms, discomfort, or benefit associated in research participation. This is made possible through developing research project/protocol with work instructions that minimises the risk of serious adverse event. Beneficence is active in several ways throughout the study, including consideration of any risks of harm to participants or researchers and the potential benefits of research to participants and to the wider community.

*Respect:*

Respect is at the core of the *National Statement* and includes respect for privacy and confidentiality. Regarding privacy, the confidentiality and anonymity of participants is protected by the de-identification of interviews and in the dissemination of research results. The issue of data identification was addressed thoroughly in the HREC ethics application.

The research team considered potential ethical issues that could arise for the stakeholders and the researchers. The consent procedures were approved by the University of Tasmania HREC. Clear information sheets were provided and signed informed consent was required. All participants provided signed, informed consent to participate in the study. Assurance of confidentiality was given, double-checking with the participant prior to

interview that they are still happy to participate, safety measures (when visiting parents in their home), and an opportunity to withdraw data following the interview process.

To foster a positive and safe working environment, safety measures for both myself as the interviewer and the family were established, focussing on privacy of the family and safety of the researcher. One element of the research project involved the recruitment of parents in order to conduct face-to-face or phone semi-structured interviews. Parents were encouraged to talk about their involvement in the SACS-R assessment process. While not explicitly part of the interview, there was the potential that the discussion may touch on parenting practices and sensitive issues. The following safeguards were in existence and could be readily activated if there were any concerns: both myself and one of the supervisors are Clinical Psychologists and have extensive experience in child and family psychology and autism. As such, both had the necessary skills to manage any issues that might arise; if a participant were to become distressed at any time throughout the interview, the interview would have been discontinued and I would have ensured adequate supports were available to the participant either through the Clinical Psychologists on the research team or their existing supports.

I provided copies of my *Working With Children Check* card (Registration No. 515829026) to St Giles and sign their confidentiality form. If meeting with a family at a location away from the CHaPS or St Giles, there were a number of strategies employed to mitigate risk: use of a UTAS vehicle; always carrying a charged mobile phone, with emergency numbers already set on the device; asking participants to restrain animals prior to the visit; ensuring that the address of the location was forwarded to the researcher's supervisors prior to attending the interview; and at the end of the interview, I rang to check in with one of the supervisors.

### **3.12 Rigor and trustworthiness of the study and credibility of the findings**

In terms of research validity, there are many terms to describe the evaluation process: rigor, validity, reliability, and trustworthiness (Koch & Harrington 1998). The term "trustworthiness" was coined by Lincoln and Guba, and they used it to refer to the fact that the research findings are "worth paying attention to" (Lincoln & Guba 1985). However, researchers often find it challenging to agree on how to assess the validity or trustworthiness of research studies (Holloway & Galvin 2016). Nonetheless, researchers are required to guide the reader from the analysis to the results of their research.

Elo and colleagues (2014, p. 8) disagree with Holloway and Galvin, stating that: "The trustworthiness of data collection can be verified by providing precise details of the sampling method and participants' descriptions". Elo and colleagues (2014) developed a checklist for researchers so that they can improve the trustworthiness of content analysis studies across the three phases of preparation, organisation, and reporting. The preparation phase involves data collection method, sampling strategy, and selecting the unit of analysis; the organisation phase comprises categorisation and abstraction, interpretation, and

representativeness; and the reporting phase includes reporting results and reporting the analysis. The Elo and co-authors (2014) checklist was utilised to ensure the current research was trustworthy, and is detailed below in Table 3-3.

**Table 3-3. Trustworthiness checklist for the current study**

Phase	Questions checked	Evidence by relevant section in thesis
Preparation (data collection)	Collection of most suitable data for content analysis?	2.2 Autism 2.6 Design Thinking 3.2 Mixed Methods
	Best method to answer research question?	3.1 Study aim and design
	Interview questions designed appropriately?	3.10 Instruments
	Self-awareness of own skills?	1.2.2 Background of author
	Pre-testing data collection?	3.10 Instruments
Preparation (sampling)	Best sampling methods?	3.6 Sampling Method
	Best informants?	3.4 Participants
	Selection criteria?	3.7 Inclusion and exclusion criteria
	Appropriate sample?	3.6 Sampling method
	Well-saturated data?	3.6 Sampling method
Preparation (analysis)	Best unit of analysis?	3.13 Data analysis
	Too narrow/too broad?	3.13.3 Thematic analysis
Organisation (categorisation and abstraction)	How are concepts created?	3.13.1 SACS-R Salesforce data 3.13.2 CSQ-8 and MIDI survey 3.13.3 Thematic analysis
	Too many concepts? Overlaps?	3.13 Data analysis
Organisation (Interpretation)	What is the degree of interpretation in the analysis?	3.13.4 Merging the data
	How does data accurately represent the information provided?	3.13 Data analysis
Organisation (representativeness)	How do I check trustworthiness in the analysis process?	3.13 Data analysis
	How do I check representativeness of the data as a whole?	3.13.4 Merging the data
Reporting (results)	Systematic and logical?	4. Results
	Connections between results and data?	4.1 SACS-R Salesforce data 4.2 Questionnaire and survey data 4.3 Narrative Data
	Clear and understandable concepts?	4.4 Integration of findings
	Transferability evaluation possible?	4.1 SACS-R Salesforce data 4.2 Questionnaire and survey data 4.3 Narrative Data
	Systematic use of quotes?	4.3 Narrative Data
	How well do categories cover the data? Similarities and differences?	4.4 Integration of findings
	Scientific language used to convey results?	4. Results
Reporting (analysis of results)	Full description of analysis process	4. Results 4.4 Integration of findings
	Content analysis based on criteria?	5. Discussion

The rigor of the current study design was the fact that there were multiple views and they provided both quantitative and qualitative data.

My role as researcher was to draw on my skills and knowledge, but to also conduct the research with rigor and ensure trustworthiness. The researcher was independent from the stakeholder group participants and the provision of services, that is, the CHaPS nurses who administered the SACS-R and the St Giles allied health professionals who conducted the ADOS-2 and ADI-R assessments and provided clinical outcomes. Stakeholders from the various organisations operated out of separate buildings in different locations and were unaware of the names of other participants from other organisations who had consented to participate in the study.

### 3.13 Data management and storage

As the CSQ-8 was online the participants were coded according to the order in which they submitted their questionnaire, that is, C1 represents CSQ, first participant. For the MIDI survey, the respondents were coded by identifier number (the order in which the surveys were collected) and region, e.g., 11N signifies participant 11, from the North. The interviewees were coded by region, stakeholder group, identifier number, and mode of interview, e.g., NWRP3f indicates North-West, referred parent, participant three, face-to-face. The codes for the CSQ-8 and the MIDI were methodically applied and checked and double-checked for accuracy. The coding system data identification is set out below in Table 3-4.

*Table 3-4. Guide to participant coding*

Data collection tool	Region	Stakeholder group	Mode of interview
<b>C</b> - CSQ-8 <b>M</b> - MIDI	<b>N</b> - North <b>NW</b> – North-West <b>S</b> - South	<b>RP</b> – referred parent <b>N</b> - nurse <b>M</b> – CHaPS management <b>A</b> - ASELCC <b>SG</b> – St Giles <b>E</b> – External	<b>f</b> – face-to-face <b>p</b> - phone

In line with the National Statement of Ethical Conduct and the Australian Code for the Responsible Conduct of Research guidelines for data management and storage, all electronic data collected as part of this project was transferred and stored in a restricted access, secured Centre for Rural Health’s shared drive. Paper-based documentation (forms, templates, flyers, and participant data) and audiotapes were stored in a locked filing cabinet in a secured Centre for Rural Health office building at The University of Tasmania and were only accessible by me and the supervision team.

### 3.14 Data analysis

This section of the thesis describes the analysis of the two types of data, quantitative and qualitative, including descriptive statistics and thematic analysis. The numeric data was collated and summarised. The contents of the semi-structured interview transcripts were

transcribed. An account of the analysis approaches utilised by the researcher are described below.

### **3.14.1 SACS-R *Salesforce* data**

The data from children's SACS-R assessments was entered directly into the *Salesforce* database system by the CHaPS nurses (as described in Chapter 1). The data was cleaned by the Research Officer (N.S.): Early Identification and Diagnosis from the OTARC. Relevant data was subsequently extracted and analysed using *Statistical Package for the Social Sciences* (SPSS), version 24.0. Descriptive statistics were conducted on the number of children monitored with the SACS-R, the number of consultations, percentages of males and females across the data collection period by region, and descriptors by sex, age, and region. Correlations were run to investigate whether there was a statistical difference across all three regions between the numbers of males and females that presented at each of the time points for assessment.

### **3.14.2 CSQ-8 and MIDI survey**

The numeric data was entered into EXCEL spreadsheets by the researcher. There were two data sets: the CSQ-8 responses from the primary stakeholder group and the MIDI responses from group 1 and 2 of the internal stakeholders. The steps in the data entry were verified by the primary supervisor (TB). Relevant data was subsequently extracted and the results of each instrument of data collection were analysed using SPSS version 24.0. The method of data analyses and application of statistical tests were confirmed by the primary supervisor (TB). Descriptive statistics were generated on items of both data sets and a *t*-test conducted to compare mean scores on responses to the MIDI for the two internal stakeholder groups (CHaPS nurses and managers) and Levene's test of equality of variances applied. The descriptive statistics and Levene's test were run separately by the researcher and the primary supervisor (TB) to validate the accuracy of the results.

### **3.14.3 Thematic analysis**

The interview data was analysed using reflexive thematic analysis techniques (Braun & Clarke 2019; Braun, Clarke & Hayfield 2019). There have been major shifts in the application of thematic analysis since the publication of Braun and Clarke's 2006 paper (Braun & Clarke 2006). Facilitation of the most effectual reflexive thematic analysis encompasses the researcher placing themselves at the centre of the approach, taking the responsibility for knowledge production. Principally, quality reflexive thematic analysis involves "the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process" (Braun & Clarke 2019, p. 594). Coding commences the theme development process, which results from accurate interpretations and reflexive coding of the data. Themes, generated by this coding process, offer "stories" about the data, derived from "the intersection of the researcher's theoretical

assumptions, their analytic resources and skill, and the data themselves” (Braun & Clarke 2019, p. 594).

Following transcription, in order to increase familiarity with the participants’ experiences, each transcript was read whilst simultaneously listening to the corresponding audio-recording. Initial coding involved identifying prevalent elements in the interviews by the way of concepts, issues, patterns, observations, reflections, and experiences. Through a process of reflection and discussion with supervisors, the codes were categorised into major semantic themes and subthemes, acknowledging patterns of “shared meaning” connected by a central concept (Braun & Clarke 2019). Those major themes and subthemes were then further synthesised and reaffirmed via an ongoing collaborative process involving discussion and revision of transcripts between myself and supervisors, until no new themes or sub-themes were generated. The themes and sub-themes were then verified by the primary and secondary supervisor (TB and PM) in light of the original transcripts and confirmed through further collaboration and reflection (Braun & Clarke 2019) and compiled into a thematic coding book, an example of which is provided (Appendix L).

#### **3.14.4 Integration of the data**

The mixed methods analysis encompassed both quantitative and qualitative analysis of the data. A concurrent dominant status design brings the two data strands together in order for them to be compared and combined (Creswell & Clark 2017). In this study, the quantitative data sets (SACS-R *Salesforce* data, CSQ-8 and MIDI surveys) and the qualitative data sets (five semi-structured interviews) were analysed separately as described above in 3.13.3 and then the two data strands were merged, starting with the parents and moving through each stakeholder group’s data to combine the data. The data sources were all designed to gain a better understanding of the research problem and to gain insights into the SACS-R process from stakeholder perspectives. The qualitative aspect provided depth and nuance to the main research question: “What are the enablers and barriers to a successful statewide implementation of the SACS-R into the public health system, so that infants at high likelihood of autism and developmental delays are identified early?”

#### **3.15 Project timeline**

This project commenced in November 2016 through to May 2021. Following is the flowchart as set out in Figure 3-5 and the data collection table displayed in Table 3-5 that represents different phases and processes that led to completion of this project.



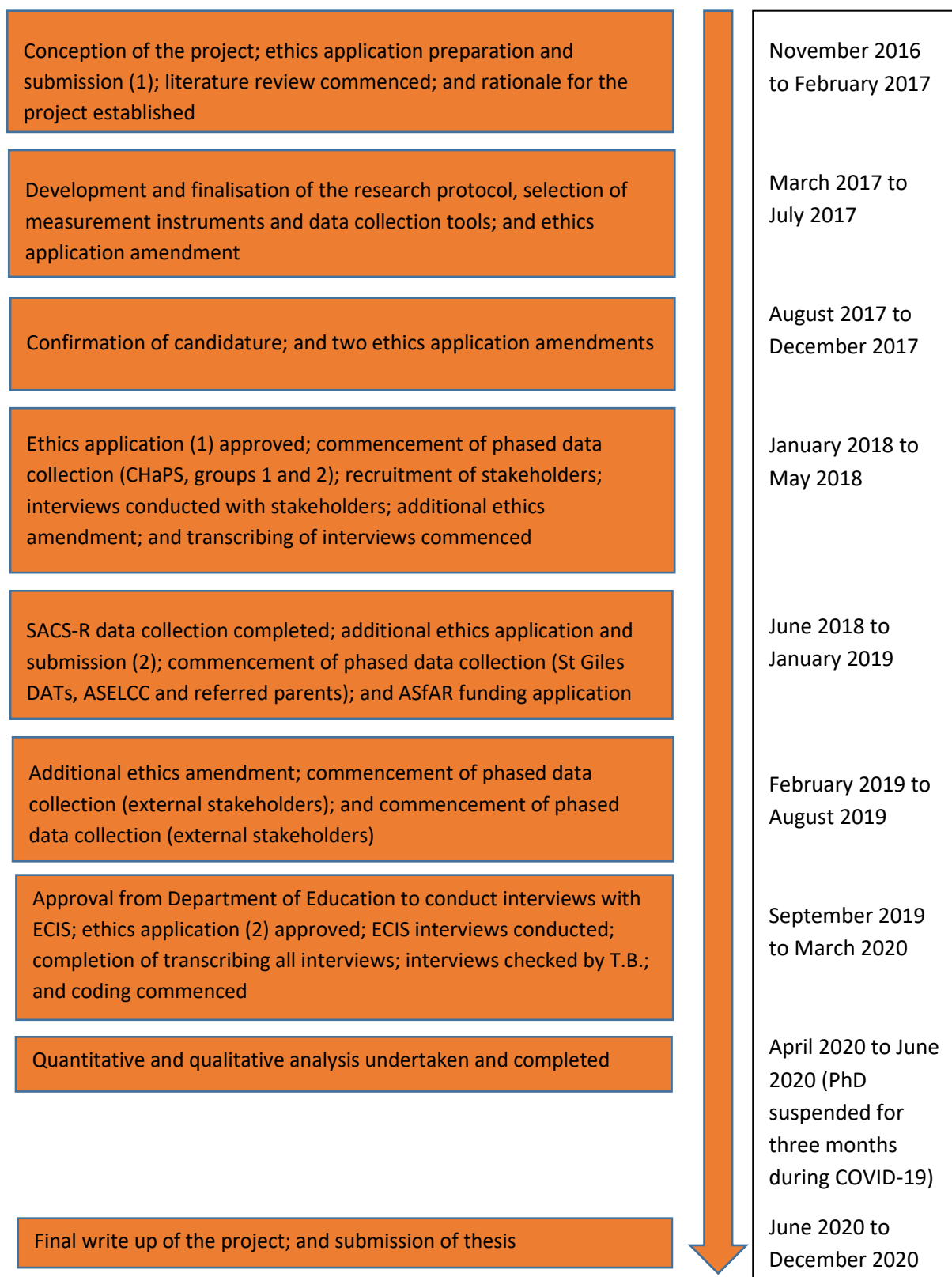


Figure 3-5. Project timeline of the thesis

**Table 3-5. Statewide data collection commencement and completion dates**

<b>Stakeholder group</b>	<b>Data collection period: Start and finish dates statewide</b>
CHaPS groups 1 and 2	March 26 <sup>th</sup> , 2018 to May 16 <sup>th</sup> , 2018 (approx. 2 months)
ASELCC	November 13 <sup>th</sup> , 2018 to May 8 <sup>th</sup> , 2019 (approx. 6 months)
St Giles DATs	November 19 <sup>th</sup> , 2018 to November 28 <sup>th</sup> , 2018 (approx. 1 week)
Referred parents	December 5 <sup>th</sup> , 2018 to September 9 <sup>th</sup> , 2019 (approx. 9 months)
External stakeholders	August 6 <sup>th</sup> , 2019 to May 27 <sup>th</sup> , 2020 (approx. 9+ months)

This chapter included a presentation of the methodology, design, and methods of this thesis. The aim of this research is to identify the enablers and barriers to successful statewide implementation of the SACS-R early childhood surveillance program into the public health system so that Tasmanian infants at high likelihood of developmental delays are identified in a timely way to trigger access to EI. It is also important to determine if the SACS-R 18-month assessment is worthwhile. To inform these two aspects of the study, a mixed methods methodology was selected which included quantitative data from *Salesforce*, *CSQs* and *MIDIs* and qualitative data derived from stakeholder interviews that were undertaken with a DT approach. A DT approach enables the researcher to understand and respond with empathy to the information that the stakeholders provide in terms of their experience of the service change. In addition, DT enables evaluation of stakeholder needs and assists in the production of novel ideas to solve “wicked” problems and to improve routine practice. These methods, which were further informed by Lewin’s change theory and IS principles, were combined to provide a full and rich picture of stakeholders’ experiences of the SACS-R process and referral pathway.

The next chapter presents the findings from the data collection outlined in this and preceding chapters. The quantitative and qualitative results of stakeholder questionnaires, surveys and interviews are presented. These results collectively led the reader to an integration of the findings and the foundational components of the summary framework (see program logic model, p 44) for a CHaPS health service change.

## Chapter 4: Results

The methodological underpinnings for this research have been set out in the previous chapter. This study used a mix of methods including quantitative (questionnaires and surveys) and qualitative data (interviews) collected from parents, CHaPS staff, St Giles, ASELCC and external stakeholders on the SACS-R process. All these data sources were then converged to address the research aim and better understand stakeholders' experiences.

Chapter 4 commences with a summary of the details of participation rates across the state of Tasmania. The quantitative results and the qualitative research findings related to the primary, internal, and external stakeholders' experiences of the implementation of the SACS-R program are then presented. The numeric data results are presented first. These are set out by instruments along with their corresponding descriptive statistics. The findings from the narrative data follow, that is, the qualitative information obtained through interviews and are presented stakeholder group by stakeholder group. The results and findings speak to the project aim: to understand the implementation process from the stakeholders' perspectives regarding the parent and child experience. I conclude the chapter by converging the main findings across the stakeholder groups, identifying the various points at which the data confirmed, contrasted, and expanded the findings.

### 4.1 SACS-R *Salesforce* data

#### 4.1.1 Number of children monitored with the SACS-R

To commence this section, a sense of the volume of the data is provided, through the number of children who were assessed at their SACS-R appointments and referral numbers through to St Giles for further assessment. There were 6,001 Tasmanian children monitored with the SACS-R across all centres between 31 October, 2016 (when ethics approval was granted for the larger study) and 23 March, 2018.

*Salesforce* data was entered into eCHaPS (the electronic health records where children's data is stored) during the 17-month period. The number of children (N=6,001) represents their very first entry into *Salesforce* at their first consultation with the CHaPS nurse at the 12, 18 or 24-month assessment. In the South, assessments were conducted at three time points: 12, 18 and 24-months compared with the North and North-West, where they only had the 12- and 24-month assessments as part of their routine visits. Historically, the 18-month routine health check existed statewide, but it was removed. It was reinstated in the South by the government when the SACS-R assessment was introduced, as part of the research project to provide a comparison between the three regions. Overall, in the North there were 1,648 children monitored, in the North-West, 1,247 and in the South, 3,106. Table 4-1 below shows males' and females' first presentation for their SACS-R assessment. It is evident that the 12-month SACS-R assessment had the largest attendance across all regions and all age-cohorts.

**Table 4-1. Salesforce cohort of children by sex and region (N=6,001)**

Region	12-month n (%)	18-month n (%)	24-month n (%)	Total n (%)
<b>North (N)</b>	1,094	45	509	1,648
• Males	583 (53.3)	25 (55.6)	263 (51.7)	871 (52.9)
• Females	511 (46.7)	20 (44.4)	246 (48.3)	777 (47.1)
<b>North-West (N)</b>	723	56	468	1,247
• Males	362 (50.1)	33 (58.9)	267 (57.1)	662 (53.1)
• Females	361 (49.9)	23 (41.1)	201 (42.9)	585 (46.9)
<b>South (N)</b>	1,740	351	1,015	3,106
• Males	858 (49.3)	177 (50.4)	524 (51.6)	1,559 (50.2)
• Females	882 (50.7)	174 (49.6)	491 (48.4)	1,547 (49.8)
<b>Tasmanian total (N)</b>	3,557	452	1,992	6,001
• Males	1,803 (50.7)	235 (52.0)	1,054 (52.9)	3,092 (51.5)
• Females	1,754 (49.3)	217 (48.0)	938 (47.1)	2,909 (48.5)

Statewide, there were 3,092 males and 2,909 females who presented for SACS-R assessment as shown in Table 4-1 above. Pearson chi-square tests were run for all three regions and sex at 12, 18 and 24-month assessments. It was found that there was no statistical difference ( $p>0.05$ ) between the number of males and females that presented for assessment in the North, the North-West and the South ( $p = 0.10$ ). In addition, no statistical difference was found between the number of males and females that presented for assessment at each of the three time points across all regions: 12-month assessment ( $p=0.11$ ); 18-month assessment ( $p=0.44$ ); and 24-month assessment ( $p=0.44$ ).

There were 3,557 children entered into the study at the 12-month assessment (1,803 males and 1,754 females); 452 children (235 males and 217 females) entered into the study at the 18-month check; and 1,992 children (1,054 males and 938 females) entered into the study at the 24-month check, as depicted above in Table 4-1.

#### **4.1.2 Number of children monitored, referred and assessed during the research period**

Figure 4-1 below depicts the number of Tasmanian children monitored, referred, and assessed during the research period. Of the 6,001 (12-24-month-old) children monitored with the SACS-R tool, 190 (3.16%) were found to be at high likelihood of autism. Of those 190 children, 143 were assessed at St Giles which resulted in 86 children (60%) being diagnosed with autism and 57 children (40%) receiving a diagnosis of developmental delay or language delay.

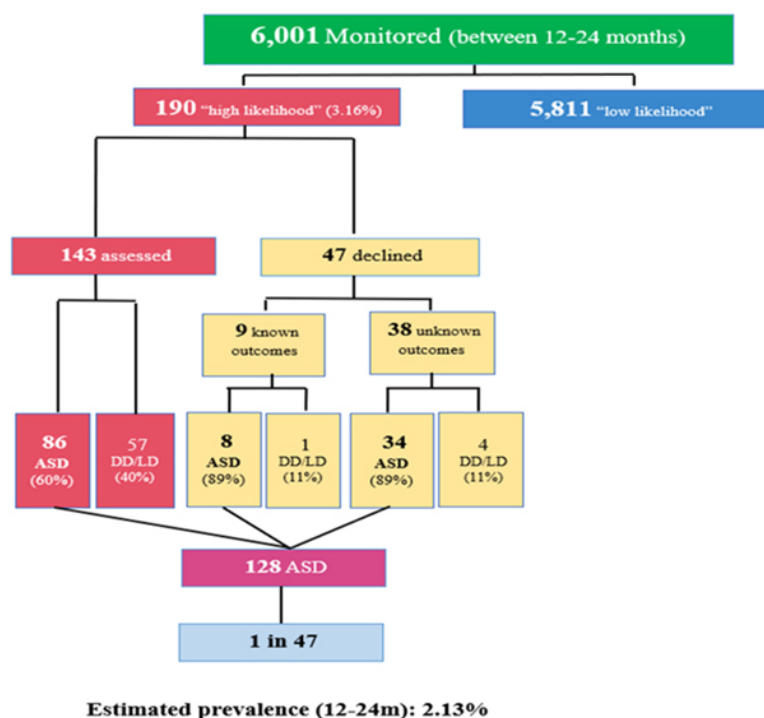


Figure 4-1. Consort figure of children monitored, referred and assessed in Tasmania (Dissanayake et al., Unpublished – Under embargo).

#### 4.2.3 Children identified as high likelihood for autism by region and age

The children's social behaviours were assessed with the SACS-R developmental surveillance tool. The overall outcome for each child was either high likelihood or low likelihood for autism, as displayed in Table 4-2 below. A child's behaviour was considered 'atypical' on an item if their social behaviour for their age was not as expected. That is, if the behaviours were less frequent, inconsistent, or absent. If a child's assessment showed three atypical results on any of the five key SACS-R items, they were deemed at high likelihood for autism. This is based on previous research looking at the most predictive behaviours for autism (Barbaro & Dissanayake 2013).

Overall, there were 29 children at high likelihood who only had one consultation. There was variation in the number of consultations for children. Some children had three consultations (n=21), 44 children had two consultations, and one child had four consultations (they were seen twice for their 12-month assessment). The statewide prevalence of high likelihood results at first consultation was 3.2% with 190 children identified. Break down by regional area reveals that there were 42 children monitored in the North (2.5%), 76 in the North-West (6.1%) and 72 in the South (2.3%) as outlined in Table 4-2 below.

**Table 4-2. Salesforce cohort of children who were identified as high likelihood for autism by region and age (N=6,001)**

Region	12-month n (%)	18-month n (%)	24-month n (%)	Total n (%)
<b>North (N)</b>	1,094	45	509	1,648
• High likelihood result	23 (2.1)	3 (6.7)	16 (3.1)	42 (2.5)
<b>North-West (N)</b>	723	56	468	1,247
• High likelihood result	36 (5.0)	9 (16.1)	31 (6.6)	76 (6.1)
<b>South (N)</b>	1,740	351	1,015	3,106
• High likelihood result	36 (2.1)	16 (4.6)	20 (2.0)	72 (2.3)
<b>Tasmanian total (N)</b>	3,557	452	1,992	6,001
• High likelihood result	95 (2.7)	28 (6.2)	67 (3.4)	190 (3.2)

At the 12, 18 and 24-month assessments, 95 children (2.7%), 28 children (6.2%) and 67 children (3.4%) were flagged at high likelihood, respectively, as shown in Table 4.2 above. At the 12-month assessment in the North, 23 children were identified as high likelihood at their first consultation, 36 in the North-West and 36 in the South. Of the children entered at 12-months (3,557 children), 1,519 children have records of attending a follow up assessment at 18- or 24-months. Of the 1,519 children who were seen for follow up appointments, 95 children were identified as high likelihood for autism (2.7%), 61 children at their first consultation at 12 months, 14 children at their 18-month consultation, and 20 children at their 24-month consultation. At the 18-month assessment in the North, 3 children were identified as high likelihood at their first consultation, 9 in the North-West and 16 in the South. At the 24-month assessment in the North, 16 children were identified as high likelihood at their first consultation, 31 in the North-West and 20 in the South.

There were 452 children who entered into the study at 18 months of age (that is, had their first assessment at this time) as shown in Table 4-2 above. Of these 452 children, 249 of them were monitored by the nurses once and 203 children were monitored at their 18- and 24-month assessments. Of those 203 children, 28 had an outcome of high likelihood for autism (6.2%).

There were differences in when a child was first identified as high likelihood for autism. Of the 66 children who were entered into the cohort at their 12-month assessment and were seen for at least one follow-up appointment, 32 were identified as high likelihood at 12 months. Of those 32 children, 13 remained at high likelihood at their 18 or 24-month follow up consultation. Fourteen children were picked up at their 18-month consultation after being assessed as low likelihood at their 12-month consultation and then at their 18-month consultation their assessment changed to high likelihood. Of those 14 children, with

regard to their 24-month assessment, nine did not have an assessment entry so we do not know their 24-month assessment outcome. Four of the 14 now presented as low likelihood and one remained with a high likelihood result. Twenty were identified at their 24-month assessment after previously being assessed as having a low likelihood result. These results are displayed in Figure 4-2 and support the importance of ongoing monitoring.

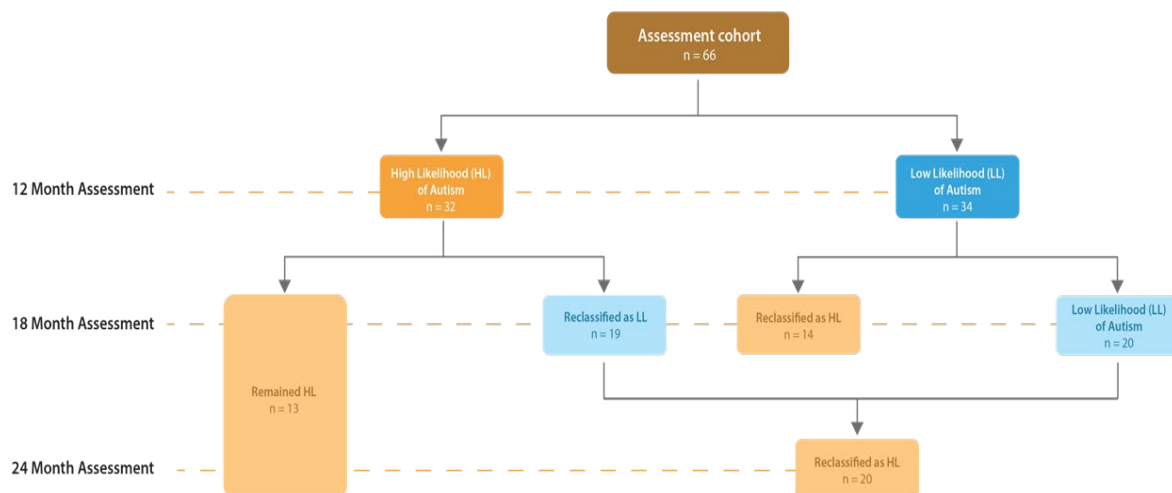


Figure 4-2. Flowchart diagram of the 66 children entered into the cohort at their 12-month assessment and seen for at least one follow-up appointment

Ten children received “double” assessments where the same SACS-R age-assessment was administered to a child twice. For three of these children, they received a low likelihood result on one administration of the assessment and a high likelihood result on another administration. For two of the children this happened at their 12-month assessment and for the third child it occurred at their 24-month assessment. From the data it cannot be determined the order in which the results occurred. None of the children lived in the South so the 18-month assessment was not a prescribed health check. For the two 12-month assessments, neither returned for an 18-month assessment, however, both attended their 24-month assessment and received a low likelihood result. For the child who received two 24-month assessments, that child had previously received a low likelihood result on their 12-month SACS-R.

For the remaining seven “double” assessments the children received the same result twice. Six of these were two high likelihood results and one of them was two low likelihood results. Five of the double high likelihood outcomes occurred at 12-month assessments and one occurred at the 24-month assessment. There was one double low likelihood result at the 12-month assessment.

Across the three regions there were 15 children, five from each region, whose 12-month assessment outcome was low likelihood, and all of these children did not have an

entry in *Salesforce* for their 18-month health check. For all 15 children, their 24-month assessment result was high likelihood. Ten of the 15 children were in the North and North-West so did not have a set opportunity for the 18-month assessment.

There were another eight children who presented as high likelihood' at their 12-month assessment, did not have an entry for their 18-month assessment and continued with a high likelihood result at their 24-month assessment. Five of those children were from the North or North-West regions where the 18-month check is not routinely offered and the remaining three were from the South where the 18-month check is a pre-determined check.

There were a couple of one-off anomalies. Thirteen children attended all three assessments. Of these, only one child consistently received a high likelihood outcome at every time point. One child was assessed on four occasions – twice at 12-months, with both results being high likelihood, once at 18-months with a low likelihood outcome, and then again at 24-months and identified as high likelihood.

During the 17-month data collection period (31 October, 2016 - 23 March, 2018) the highest number of children monitored with the SACS-R (562) across the state occurred in March 2017 (9.4%). For both the North (175) and the North-West (104), these were their largest numbers of children monitored for the entire period. The total number of children monitored statewide during the data collection period are arranged from the month of commencement to the month of completion. The relatively slow start to the program data entry can be seen in Table 4-3 below.

**Table 4-3. Number of children monitored and percentages across the data collection period (N=6,001)**

Month and year	North (n)	North-West (n)	South (n)	N (%)
Oct 2016	0	6	1	7 (.01)
Nov 2016	39	58	27	124 (2.1)
Dec 2016	61	34	27	122 (2.0)
Jan 2017	70	52	158	280 (4.7)
Feb 2017	59	81	178	318 (5.3)
Mar 2017	175	104	283	562 (9.4)
Apr 2017	48	47	178	273 (4.5)
May 2017	98	92	343	533 (8.9)
Jun 2017	114	78	237	429 (7.1)
Jul 2017	150	94	223	467 (7.8)
Aug 2017	133	90	222	445 (7.4)
Sep 2017	147	99	212	458 (7.6)
Oct 2017	117	83	165	365 (6.1)
Nov 2017	97	78	246	421 (7.0)
Dec 2017	93	35	129	257 (4.3)
Jan 2018	98	62	189	349 (5.8)
Feb 2018	83	67	151	301 (5.0)
Mar 2018	66	87	137	290 (4.8)

#### **4.1.4 Number of children monitored with the SACS-R for 12-month assessment**

The highest number of children monitored with the SACS-R for 12-month assessments across all regions was in the South (n=1,740) and the lowest number was in the



North-West (n=723). The highest number of children monitored in a single month for 12-month assessments during the data collection period was in May, 2017 in the South (n=163). The lowest number of children monitored in one month, apart from October, 2016, was in December, 2016 in the South (n=7). This information is set out in Table 4-4 below.

**Table 4-4. The number of 12-month assessments conducted monthly in each region (n=3557)**

Year/region	12-month assessments/month											
2016	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep
North	0	24	36	-	-	-	-	-	-	-	-	-
North-West	1	28	20	-	-	-	-	-	-	-	-	-
South	0	12	7	-	-	-	-	-	-	-	-	-
2017	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
North	38	37	102	33	60	82	106	89	102	72	71	63
North-West	25	48	48	19	49	50	56	54	67	47	44	27
South	78	91	154	94	163	119	129	127	130	94	134	81
2018	Jan	Feb	Mar	-	-	-	-	-	-	-	-	-
North	73	60	46	-	-	-	-	-	-	-	-	-
North-West	39	41	60	-	-	-	-	-	-	-	-	-
South	134	99	94	-	-	-	-	-	-	-	-	-

#### 4.1.5 Number of children monitored with the SACS-R for 18-month assessment

The highest number of children monitored using 18-month assessments across all regions was in the South (n=351) and the lowest number was in the North (n=45). The highest number of children monitored in one month using 18-month assessments was in May, 2017 in the South (n=57). The lowest number of children monitored in one month, apart from October, 2016, was zero and this number occurred in November, 2016 in the South, December, 2016 in the North-West and July, 2017 in the North-West. The highest number of children monitored using 18-month assessments was in the South (n=57) and the lowest number, apart from October, 2016, was again in the South and North-West (n=0). This information is displayed below in Table 4-5.

**Table 4-5. The number of 18-month assessments conducted monthly in each region (n=452)**

Year/region	18-month assessments/month											
2016	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep
North	0	2	5	-	-	-	-	-	-	-	-	-
North-West	0	5	0	-	-	-	-	-	-	-	-	-
South	0	0	1	-	-	-	-	-	-	-	-	-
2017	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
North	4	2	6	1	1	2	3	2	2	5	1	3
North-West	1	4	5	3	3	5	0	7	2	5	4	2
South	11	19	32	25	57	36	25	24	20	20	21	11
2018	Jan	Feb	Mar	-	-	-	-	-	-	-	-	-
North	1	3	2	-	-	-	-	-	-	-	-	-
North-West	2	5	3	-	-	-	-	-	-	-	-	-
South	15	21	13	-	-	-	-	-	-	-	-	-

#### 4.1.6 Number of children monitored with the SACS-R for 24-month assessment

The highest number of children monitored using 24-month assessments across all regions was in the South (n=1,015) and the lowest number was in the North-West (n=468). The highest number of children monitored in one month for 24-month assessments was in May, 2017 in the South (n=123). The lowest number of children monitored in one month, apart from October, 2016, was in December, 2017 in the North-West (n=6). This information is set out in Table 4-6 below.

**Table 4-6. The number of 24-month assessments conducted monthly in each region (n=1,992)**

Year/region	24-month assessments/month											
<b>2016</b>	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep
North	0	13	20	-	-	-	-	-	-	-	-	-
North-West	5	25	14	-	-	-	-	-	-	-	-	-
South	1	15	19	-	-	-	-	-	-	-	-	-
<b>2017</b>	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
North	28	20	67	14	37	30	41	42	43	40	25	27
North-West	26	29	51	25	40	23	38	29	30	31	30	6
South	69	68	97	59	123	82	69	71	62	51	91	37
<b>2018</b>	Jan	Feb	Mar	-	-	-	-	-	-	-	-	-
North	24	20	18	-	-	-	-	-	-	-	-	-
North-West	21	21	24	-	-	-	-	-	-	-	-	-
South	40	31	30	-	-	-	-	-	-	-	-	-

The highest number of children monitored for all three age-based assessments, that is, 12-month (n=163), 18-month (n=57) and 24-month (n=123), all occurred in May, 2017 and were all in the Southern region.

#### 4.1.7 Number of consultations

Statewide between 31 October, 2016 and 23 March, 2018 there were 6,001 children who presented at one or more appointments at a CHaPS nurse clinic. During that same period, the number of children monitored translates to the administration of 7,161 consultations. The total number of consultations for each region are set out in Table 4-7 below. For all consultations across the three regions, the highest number of consultations was conducted in the South (n=3,815) and the lowest number in the North-West (n=1,435). In all three regions, across all age cohorts, more males (51.8%) attended consultations than females (48.2%) as set out in Table 4-7 below.

**Table 4-7. Consultations by region, for each age assessment and sex (N=7,161)**

Region	12-month n (%)	18-month n (%)	24-month n (%)	Total n (%)
<b>North (N)</b>	1,115	71	725	1,911
Males	591 (53.0)	43 (60.6)	385 (53.1)	1,019 (53.3)
Females	524 (47.0)	28 (39.4)	340 (46.9)	892 (46.7)
<b>North-West (N)</b>	732	70	633	1,435
Males	368 (48.0)	41 (58.6)	358 (56.6)	767 (53.4)
Females	364 (54.5)	29 (41.4)	275 (43.4)	668 (46.6)
<b>South (N)</b>	1,754	707	1,354	3,815
Males	861 (49.1)	365 (51.6)	697 (51.5)	1,923 (50.4)
Females	893 (50.9)	342 (48.4)	657 (48.5)	1,892 (49.6)
<b>Tasmanian total (N)</b>	3,601	848	2,712	7,161
Males	1,820 (50.5)	449 (52.9)	1,440 (53.1)	3,709 (51.8)
Females	1,781 (49.5)	399 (47.1)	1,272 (46.9)	3,452 (48.2)

The centres within each region ranged in consultation volume. The top three volume centres in the North were Kings Meadows (n=498), Riverside (n=251) and Mowbray (n=178); in the North-West were Devonport (n=294), Ulverstone (n=242) and Burnie (n=186); and in the South were Kingston (n=524), Glenorchy (n=290) and Tagarilia (n=245), with Kingston being the centre that conducted the most consultations, statewide. The lowest three volume centres in the North were Swansea (n=4), Bridport (n=5) and Flinders Island (n=5); in the North-West were Zeehan (n=3), The Parenting Centre (n=3) and Latrobe (n=6); and in the South were Nubeena (n=1), Ptunarra (n=3) and Triabunna (n=3), with Nubeena being the centre that conducted the least consultations, statewide. Many of the centres with particularly low consultation numbers have shorter hours of operation, with some centres only open for one day per week.

Statewide, the greatest number of consultations, across all three age cohorts, occurred in May, 2017 (31.1%) followed by March, 2017 (28.8%). Data collection commenced on 31 October, 2016 which meant that the month of October only included one day. There were 0.3% of all consultations conducted on the first day of formal data collection.

In the North there was a peak in consultations in March, 2017 (35.8%), followed by October, 2017 (25.6%), then July, 2017 (24.5%). In October, 2016 there were zero consultations conducted across all age cohorts. The North-West had a peak in consultations in March, 2017 (26.4%), very closely followed by August 2017 (26.2%). In October, 2016 there were 1.2% consultations across the 12-month and 24-month assessments. In the North-West, 1.2% of the assessments occurred at 12 and 24-month assessments which translated to five assessments administered. In the South there was a peak in consultations in May, 2017 followed by November, 2017. In October, 2016 there was only one 24-month assessment completed accounting for 0.1% consultations across the data collection period.

In November, 2016 there were zero 18-month consultations and in December, 2016 there were a very low number of consultations.

There are clear data fluctuations in the number of consultations across the 17 months of data collection, as can be seen in Figure 4-3 below. In all three regions, but particularly in the South, the months of March, May and November, 2017 indicate busy times for the CHaPS centres. A number of hypotheses can be made to explain these results, including older siblings returning to school that freed parents up to take their baby along for assessment.

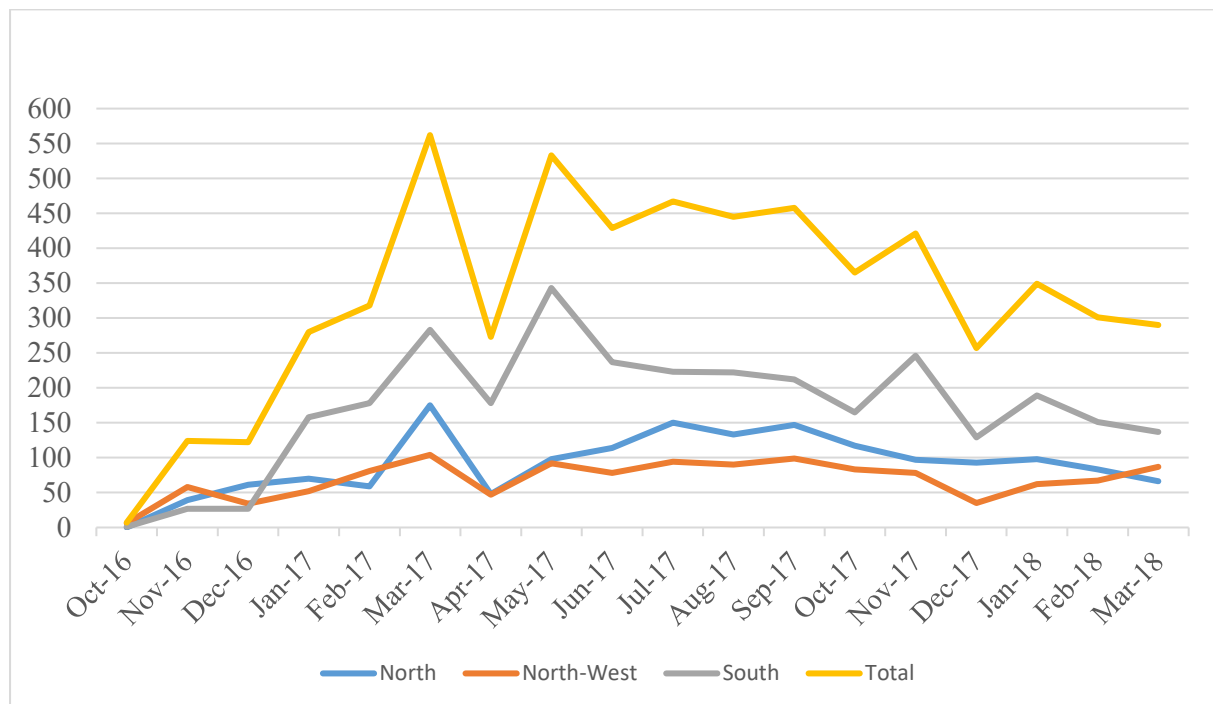


Figure 4-3. Frequency of monthly distribution of all consultations (N=7,161)

There were several troughs that could reflect parents returning to work, school holidays so older siblings are at home and it may be burdensome to take all of your children along to the CHaPS assessment. There is a dip in the number of consultations in December, 2017. December is typically a busy time of the year with people shopping and prepping for Christmas. Also, the centres would have been closed for an extended period. Consultations were lower but steady from June through to October 2017. This could be accounted for by new babies being born in September and cooler months which keep people at home.

In summary, the *Salesforce* data indicated that the initial meeting with the CHaPS nurse enabled identification of children at high likelihood of autism. Additional children were identified as high likelihood at follow-up appointments despite being assessed previously as low likelihood. Some children were assessed more than once on the same-age assessment. The *Salesforce* data strongly suggests that ongoing assessment allows children's developmental changes to be monitored.

## 4.2 Questionnaire and survey data

The survey data for the stakeholder groups includes the findings from the parent responses to the CSQ-8 and groups 1 and 2 of the internal stakeholder's responses (CHaPS nurses and CHaPS management) to the MIDI survey. Following the presentation of this information for each stakeholder group, the generated descriptive statistics for each measurement tool is presented.

### 4.2.1 Participation rates

Participation rates for the questionnaire (CSQ-8) and the surveys (MIDI) were comprised of the primary stakeholder group (non-referred and referred parents) and groups 1 and 2 of the internal stakeholder group (CHaPS nurses and CHaPS managerial staff). The participation rates are broken down by geographical region and then further divided into data collection method (questionnaire and surveys) across the primary and relevant internal stakeholder groups. The participation rate aim for this cohort was between approximately 224-244 participants. Table 4-8 below presents the quantitative data targeted participation rates by stakeholder group, their tasks, and the percentage of participation. All regions were represented.

**Table 4-8. Quantitative data stakeholder participation rates**

Stakeholder group and target numbers	Task	Total Participation n (%)
Primary: 130-160 parents <ul style="list-style-type: none"><li>• Non-referred 100</li><li>• Referred 30-60</li></ul>	All parents invited to complete the CSQ-8	21/6001 (0.35%)
Internal: group 1 <ul style="list-style-type: none"><li>• 101 CHaPS nurses</li></ul>	All CHaPS nurses invited to complete the MIDI (47 items)	83/101 (82%)
Internal: group 2 <ul style="list-style-type: none"><li>• 9 NUMs</li><li>• 1 CNE</li><li>• 2 ADoNs</li><li>• 1 DoN</li></ul>	All 13 people invited to complete the MIDI (10 items)	9/13 (69%)

The survey sample included 21 parents (referred and non-referred) who completed the CSQ-8 online and 92 CHaPS staff (83 nurses and 9 managerial staff) who completed the MIDI survey, 47 items and 10 items, respectively. There was no drop-out with questionnaire or survey completion.

### 4.2.2 Response rates

The term 'response rate' refers to the number of people who respond to a questionnaire or a survey divided by the total potential number of respondents (Phillips, Reddy & Durning 2016). With regard to the primary stakeholder group and the internal stakeholder CHaPS managerial staff (group 2), the response rates for the numeric data were much lower than anticipated. A total of 21 CSQ-8 online questionnaires were submitted by

the parents (non-referred and referred). This indicates that less than 1% of the parents took up the offer to participate in the questionnaire (n=21). Thus, these two groups were under-represented in the CSQ-8 and the MIDI survey results.

The CHaPS managerial staff (group 2) were under-represented in both the MIDI survey (n=9) and the interview procedure (n=5). There were a number of recruitment difficulties faced by the research team, which resulted in low participation rates across all three geographical regions of the state for the parent questionnaire and the internal stakeholders', group 2 survey.

#### 4.2.3 Primary stakeholders' response to the CSQ-8

All of the 6,001 parents who attended their CHaPS health check with their child between October 2016 and March 2019, were invited to complete the Client Satisfaction Questionnaire (CSQ-8). From the total number of parents, whose child underwent a SACS-R assessment, 3.12% had children who were referred on to St Giles for further assessment (n=187). Of the 187 referred parents, 5% consented to an interview about their experience (n=11). All interviewees informed the researcher that they had also completed the CSQ-8. Hence, it can be surmised that 10 of the online CSQ-8 respondents were non-referred parents.

Regarding the scoring and interpretation of the questionnaire, the CSQ-8 involves unweighted summation of the item's direction-corrected response values of 1 to 4 to compute the total scale score (Attkisson & Greenfield 2004). A participant's total score can fall anywhere between eight and 32. The higher the participant's overall score is indicative of greater satisfaction with the service they have received. In the current sample, the collective scores ranged from the lowest possible score of eight to the highest possible score of 32. The CSQ-8 items are set out below in Table 4-9 along with the descriptive statistics.

**Table 4-9. CSQ-8 items and descriptive statistics (N=21)**

Item number and question	Range	Mean (SD)	Mode	Median
1. How would you rate the quality of services provided to your child?	3	3.28 (0.90)	4	4
2. Did you get the kind of service you wanted for your child?	3	3.00 (1.14)	4	3
3. To what extent have the services met your child's needs?	3	2.95 (0.92)	3	3
4. If a friend's child were in need of similar help, would you recommend our services to him/her?	3	3.19 (0.98)	4	3
5. How satisfied are you with the amount of help your child has received?	3	2.95 (1.07)	4	3
6. Have the services you received helped your child to deal more effectively with his/her problems?	3	3.10 (1.07)	4	3
7. In an overall, general sense, how satisfied are you with the service your child received?	3	3.14 (1.06)	4	3
8. If you were to seek help again for your child, would you come back to our service?	3	3.28 (1.05)	4	4
<b>Total score (out of 32)</b>	<b>8-32</b>	<b>24.76 (7.20)</b>	<b>29</b>	<b>28</b>

For this sample, the scale demonstrated good internal consistency (Cronbach's Alpha 0.96) of responses to the items.

Of the 21 participants, 11 provided additional comments. Overall, the CSQ-8 revealed positive ratings about the assessment process conducted by the CHaPS nurse. Of the 21 questionnaire responses, four were quite negative, with three parents providing reasons in the comments section of the instrument, one of which had mixed feelings about the process:

*We think our child has been a false negative on the initial SACS-R assessment. The follow-ups at St Giles have been not timely, have taken a lot of our time as we have had to rearrange work commitments, and thus far, have been inconclusive. However, the quality of the professional attention from St Giles has always been excellent. I'm really wondering whether the screening tests are poor (C10).*

The remaining 17 responses showed that the parents were very satisfied with the SACS-R assessment process and the referral pathway. Of the 17 respondents, eight provided additional comments. For example:

*The diagnosis my daughter received through this study has been life changing so thank you. So happy to be able to access supports early for her. It's making a huge difference (C6).*

*Due to CHAPS noticing delays, I attended my paediatrician to discuss concerns, she did a blood test and a very rare chromosomal abnormality was found, we now know more about my child's condition and interventions to pursue (C9).*

*I came to health nurse for a weigh and measure, SACS-R assessment was incidental. Very happy to have assessment, it would have picked up my elder child's delays earlier (C12).*

*I am very grateful and overwhelmed with all the support provided for my son with autism. The support has made a huge impact in making each day a bit easier...for [child's name] and also myself...has already come so far since being diagnosed and we are so grateful (C13).*

#### **4.2.4 Internal stakeholders' response to the MIDI**

The internal stakeholder group is made up of three sub-groups: CHaPS nurses (group 1), CHaPS management (group 2) and ASELCC and St Giles DAT (group 3). Survey data was only collected from two of the three internal stakeholder groups, groups 1 and 2. These two groups were invited to complete the MIDI survey and a total of 92 CHaPS staff (83 nurses and nine managerial staff) completed the survey.

The CHaPS nurses completed 83 MIDI's which contained 47 items. Question 39 was a No/Yes response (asking about any changes going on that influenced the implementation of

the SACS-R) thus was not included in the analysis. Of the 83 participants in group 1, 31 participants replied 'yes', 49 replied 'no', and three left the question unanswered. It took approximately 10-15 minutes for the nurses to complete the survey.

The findings from the CHaPS nurses' surveys revealed that the nurses were satisfied with the SACS-R. In group 1, 19 nurses were from the North (22.9%), 49 were from the South (59%) and 15 were from the North-West (18.1%). For nurses, the higher the score, the more satisfied they were with the 'Implementation of the SACS-R surveillance tool' (eight items), the 'Clinical use of the SACS-R' (24 items), and the 'Organisation of the Tasmanian CHaPS' (10 items). Question 4 was reverse scored. The highest possible individual score on the MIDI survey for nurses was 215.

The CHaPS managerial staff completed 9 MIDIIs which contained 10 items. It took approximately five minutes for the managerial staff to complete the survey. The findings from the CHaPS managerial surveys revealed that overall, the managers expressed satisfaction with the SACS-R, as shown in Table 4-10 below.

**Table 4-10. Mean score and standard deviation of MIDI Likert scale**

Item number and question	Response (n)	Mean (SD)
<b><u>Implementation of the SACS-R surveillance tool</u></b>	83	4.47 (0.55)
1. The SACS-R clearly describes the behaviours you are looking to elicit from the child		
2. The SACS-R is based on factually correct knowledge on child development	83	4.45 (0.57)
3. The SACS-R provides all the information I need to monitor a child's social attention and communication skills	83	3.96 (0.83)
4. The SACS-R is too complex for me to use	83	4.50 (0.63)
5. The SACS-R is a good match for how I am used to working	83	4.22 (0.70)
6. The outcomes of using the SACS-R are clear to me	83	4.23 (0.65)
7. The SACS-R is relevant for the population I work with	83	4.58 (0.54)
8. I think parents are comfortable with the SACS-R	83	4.12 (0.59)
<b><u>Clinical use of the SACS-R</u></b>	83	4.32 (0.54)
9. The SACS-R helps me detect atypical behaviour in children		
10. The SACS-R helps me to better understand children's social attention and communication	83	4.41 (0.59)
11. The SACS-R helps me in my conversations with parents	83	4.11 (0.73)
12. I expect that using the SACS-R will detect atypical social attention and communication behaviour in young children	83	4.22 (0.56)
13. I expect that using the SACS-R will identify infants and toddlers at risk of Autism Spectrum Disorder	83	4.28 (0.67)
14. Using the SACS-R will support toddlers and children to access support earlier	83	4.52 (0.70)
15. I perceive it as my responsibility as a professional to use the SACS-R in my clinical practice	83	4.58 (0.54)
16. Parents are generally be satisfied when I use the SACS-R	83	4.10 (0.69)
17. Parents are generally cooperative when I use the SACS-R	83	4.24 (0.60)
18. I can rely on adequate assistance from my colleagues when I need to use the SACS-R	83	4.30 (0.73)



19. I can rely on adequate assistance from the SACS-R research team when I need to use the SACS-R	83	4.19 (0.76)
20. Overall, I think that the CHaPS nurses in my organisation, including myself, can effectively support the implementation of the SACS-R as part of routine clinical practice	83	4.40 (0.62)
21. In my opinion, the proportion of colleagues in my organisation who regularly use the SACS-R is	81	4.57 (0.52)
22. My colleagues expect me to use the SACS-R	83	4.60 (0.56)
23. Management expects me to use the SACS-R	83	4.78 (0.50)
24. It is my responsibility to ensure that I use the SACS-R	82	4.79 (0.41)
25. I expect my colleagues to use the SACS-R	83	4.71 (0.51)
26. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of your colleagues?	76	4.11 (0.89)
27. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of management?	79	4.30 (0.82)
28. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of the SACS-R research team?	80	4.51 (0.57)
29. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of parents?	78	4.04 (0.75)
30. I am confident in my ability to implement the items from the SACS-R	83	4.33 (0.70)
31. I have enough knowledge to use the SACS-R as intended	83	4.30 (0.64)
32. I am well aware and informed about the content of the SACS-R	82	4.28 (0.59)
<b>Organisation of the Tasmanian CHaPS</b>	89	3.71 (0.79)
33. There is a clear process in place for upskilling new or returning staff in the use of the SACS-R		
34. There is adequate staffing available in our organisation to use the SACS-R as intended	91	3.80 (0.90)
35. There are enough financial resources available to implement the SACS-R	90	3.47 (0.91)
36. There is enough time available to include the administration of the SACS-R items in my day-to-day work	91	3.79 (0.98)
37. There are enough resources (equipment, materials, space) provided by my organisation to enable me to use the SACS-R	82	3.50 (1.11)
38. There are people designated to coordinate the process of implementation of the SACS-R.	81	3.64 (0.84)
40. It is easy for me to find information in my organisation about using the SACS-R	92	3.85 (0.77)
41. I have been provided with regular feedback about progress with the implementation of the SACS-R	92	3.84 (0.80)
42. Overall, I think that the healthcare professionals within my organisation, including myself, can effectively support the implementation of the SACS-R	92	4.35 (0.52)
43. The items listed in the SACS-R fit in well with the intentions of Universal health checks	92	4.47 (0.52)
Overall average (item 4 reverse scored)	4.10 (0.95)	-

Three subscales of the MIDI were evaluated using mean estimates of the Likert scale responses. The first subscale 'Implementation of the SACS-R surveillance tool' had a mean score of 4.32 that indicated that nurses mostly agreed with all eight items, that is, a strongly favourable response to the tool. The mean scores for the second and third subscales: 'Clinical use of the SACS-R' and 'Organisation of the Tasmanian CHaPS', were 4.38 and 3.85, respectively. Overall, the three mean scores were high and indicated that nurses were in high agreement with the items on those domains. The 'Clinical use of the SACS-R' aspect

had the highest mean score. However, the questions on subscale three had a slightly lower mean score as compared to the other two subscales. One of the key reasons for this could be that the 'Organisation of the Tasmanian CHaPS' subscale was the only subscale that was responded to by both the CHaPS nurses and managers. The nurses (n=83) answered all of the items on the organisation subscale and the managers (n=9) answered eight (questions 33-36 and 40-43 of the MIDI survey group 1).

The null hypothesis is that there is no difference between the responses of group 1 (nurses) and group 2 (managers) on the eight shared items. To test the null hypothesis, a *t*-test was conducted to compare the mean scores and assess if there was a difference between nurses' and managers' responses. The *t*-test results supported the null hypothesis, thus, the result was not significant ( $t=1.79$ , 90,  $p=0.082$ ).

Levene's test of equality of variances was conducted to further confirm the reliability of the *t*-test. The outcome of the Levene's test was found to be not significant ( $F=0.41$ ,  $p=0.523$ ) and equal variance was therefore assumed. The non-significant finding of Levene's test determined that the null hypothesis was supported and thus, it is further confirmed the responses of group 1 (nurses) and group 2 (managers) had no variance for the items relating to the 'Organisation of the Tasmanian CHaPS'.

#### **4.2.4.1 Open-ended questions**

The group 1 participants responded to the following questions on enablers and barriers:

- Barriers that you think may affect your use of the SACS-R within your role;
- Strategies that you think may assist in helping you overcome any identified barriers, i.e., enablers;
- Barriers that you think may impact the use of the SACS-R within your organisation; and
- Strategies that you think may assist in helping your organisation overcome any identified barriers, i.e., enablers.

The group 2 participants responded to the following questions on enablers and barriers:

- Barriers that you think may impact the use of the SACS-R within your organisation; and
- Strategies that you think may assist in helping your organisation overcome any identified barriers, i.e., enablers

Overall, responses to the MIDI revealed that the CHaPS staff (groups 1 and 2) felt positively about the SACS-R process. CHaPS nurse participants stated:

*The structure of SACS is really useful and parents respond very well to it (11N30). Staff have been very positive about the process (15N34).*

*No barriers -it is easy to implement into practice (19N38).*

*Love the structure, which helps in the conversation with parents (36S).*

The main enablers raised by the CHaPS nurses were the extension of appointment times and the hour time slot which enabled children to get comfortable with the room and the nurse. However, others suggested that as time went on and staff became confident with the tool and could keep up with the workload, it was now time to shorten appointment times. The SACS-R helps nurses to build a relationship with the child and the parent and provides opportunities to discuss parents' observations and /or concerns. They stated that it was great to have someone to contact who could respond to enquiries in a timely manner.

The clear referral pathway to assessment, alongside thorough feedback to nurses on children's assessment outcomes, and the provision of SACS-R updates, support, and training (which were seen as crucial and participants acknowledged that these aspects are being done well), were all included as main enablers to the successful implementation of the SACS-R tool into Tasmania. Suggestions were made about technology (e.g., extending the use of the electronic platform), setting up e-CHaPS to incorporate the SACS-R assessments and associated information (e.g., referral forms) on the intranet site; reducing appointments to 45 minutes instead of an hour as most children are typical and do not require a referral (this would also help to alleviate wait lists).

The main barriers raised by CHaPS nurses included staffing shortages, large caseloads, technology challenges, funding issues, a need for appropriate tools to conduct the assessments, and time constraints in busy centres where younger babies needing to take priority over SACS assessments. Staff expressed needing more time to complete documentation and do referrals. Some required support from more experienced colleagues. Characteristics of children and parents could be challenging, e.g., children's presentations (e.g., uncooperative, tired) and personalities (e.g., shy or slow-to-warm up) and parents interfering in the assessment process or not being ready to hear outcomes, so they could be resistant, defensive, or in denial.

Moreover, there were two major concerns. First, the waitlists and lengthy delays to assessment at St Giles. Second, that even though the 18-month assessment was a pre-determined check in the South, some CHaPS nurses reported they were told to:

*Prioritise the universal health assessments as per management directive (26S);*

*Inability to send out 18-month reminders due to staff shortages (18S); and*

*We've been told we shouldn't send reminders either via SMS or post for the 18-month check (14S).*

The CHaPS nurses viewed the 18-month check as "vital". They stated that it needs to be reinstated and routinely conducted statewide and for those assessments to be made a compulsory part of the CHaPS nurses' work.

Many nurses commented that all staff need refreshers, ongoing education, and training (regarding consistency of understanding eye contact, showing, pretend play), along with orientation for new staff. Other suggestion to address barriers included adding the SACS into the Public Health Record and providing a place for the result of each assessment; creating a link between e-CHaPS and SACS-R for ease of use; making clinic spaces warm and inviting; providing a flowchart of the SACS-R process to parents; and increasing awareness of the SDACS-R through advertising.

Of the 9 CHaPS managers, barriers identified were staffing challenges (busy centres and insufficient staff, with new babies waiting because of the SACS-R); feelings of uncertainty about the referral pathway once the project ends: wanting a central contact person and access to information; delays between referral to St Giles and children receiving assessments; resources and funding costs; assisting new practitioners to utilise the SACS-R.

### **4.3 Narrative data – stakeholder interviews**

The qualitative data provides insights into the enablers and barriers to successful implementation of the SACS-R. The interview participants for this project included all but one of the sub-groups under the key stakeholder groups. The primary stakeholder group for this part of the study is group 2, the referred parents. They were invited to be interviewed by way of supplementary questions regarding their SACS-R and St Giles experience. All three of the internal stakeholder groups (CHaPS nurses, CHaPS managerial staff and Autism Specific Early Learning and Care Centre [ASELCC] and St Giles Developmental Assessment Team (DAT) were invited to further interview. The complete external stakeholder cohort were all invited to further interview.

All interviews were conducted either face-to-face or via mobile phone. In terms of location, the interviews were predominantly held over the phone. A few parents took up the offer to have the interview conducted in their home.

The interview sample consisted of 11 referred parents; 42 CHaPS staff (37 nurses and five managerial staff); six St Giles and six ASELCC staff members; and 26 various external stakeholders working within the public and private sectors in Tasmania. There was no drop-out with the interview process. Duration of interviews were as follows: parents - between 8 and 26 minutes; group 1 - between 6 and 38 minutes; group 2 – between 12 and 25 minutes; group 3 - between 11 and 85 minutes; and external stakeholders – between 9 and 49 minutes.

Given the extensive interview data collected and the word limit of the thesis, a collection of additional quotations was created for each stakeholder group. This was done to ensure that the nuances of stakeholders' responses had been captured. A sample of these additional quotations are contained in the appendices (Appendix M).

The stakeholder interviews provided in-depth, subjective data about their perspectives and experiences of the implementation process. Stakeholders were able to

respond to a variety of topics depending on their role and experience, including the SACS-R assessment process, interaction with staff in other organisations, the referral pathway, feedback sessions, reviews, the public health service system, funding, access to EI and necessary education and supports. For each stakeholder group, all regions were represented. Table 4-11 below provides further detail of the interview participants.

**Table 4-11. Interview participants and participation rates by stakeholder group**

Stakeholder groups		n
<b>Primary:</b>	group 2 - referred parents	11
<b>Internal:</b>	group 1 - CHaPS nurses	37
	group 2 - CHaPS management	5
	group 3 – ASELCC and St Giles DATs	12
<b>External:</b>	AAPs, ECIS, Autism Tasmania, Members of Parliament, allied health professionals, representatives from health and educational associations (e.g., AMA, APS, RACGP)	26

Since the project commenced, the CHaPS have undertaken a large number of SACS-R assessments statewide. A number of children have been assessed and reviewed more than once as part of their routine care. Referrals of children to St Giles for further assessment have been at levels that accord with global estimates of prevalence rates for autism, i.e., 1-2% of the population (Elsabbagh et al. 2012).

The analysis of the interview data for each of the stakeholder groups generated major themes. These themes are presented diagrammatically at the beginning of each relevant narrative section.

### **4.3.1 Primary stakeholders – referred parents**

From a regional perspective, the greatest interview response came from the Southern region, with 81.8% of the referred parents who completed the interview process residing in the South. For the North and the North-West of the state, the same interview result was obtained. There were nine referred parents from Southern Tasmania, and of these four attended a face-to-face interview and five opted for a phone interview. There was one referred parent from Northern Tasmania, and one from the North-West. Both participants had phone interviews. Of the four face-to-face interviews, two were conducted in the family home, one in the workplace and one at a mutually agreeable meeting place, an office location in the Hobart CBD.

Reflexive thematic analysis (Braun & Clarke 2019) of the parent interview data generated four themes: surveillance and referral process; organisational features and system issues; support resources and intervention services; and funding. The findings from parent interviews are presented according to these four themes. A summary of the primary stakeholder major themes and sub-themes is displayed in Figure 4-4 below. This section concludes with a general feedback summary of the parent experience.

# Primary Stakeholders – Referred Parents

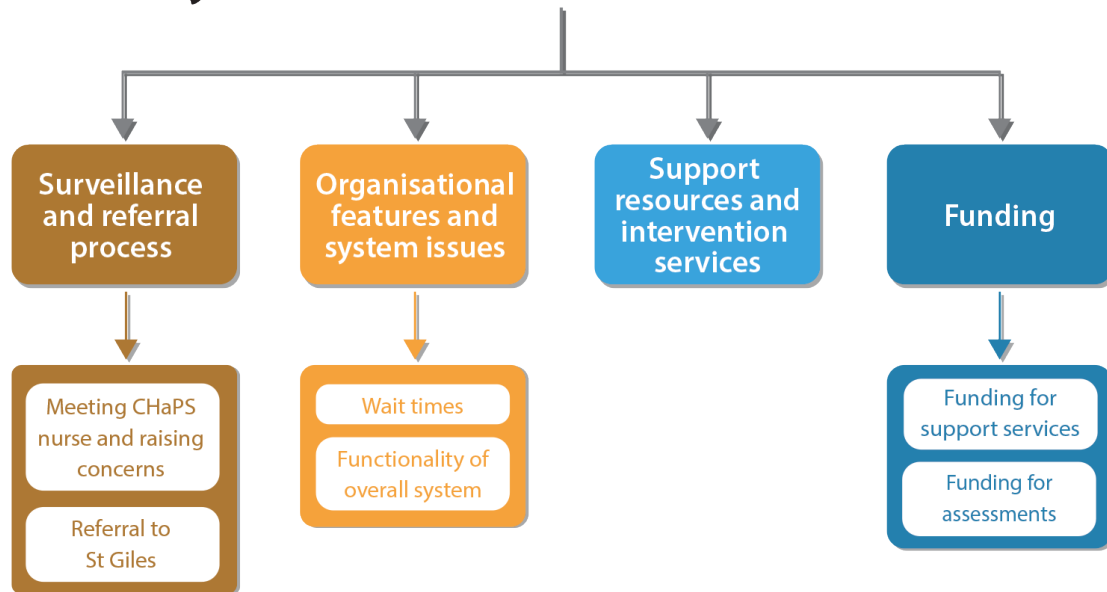


Figure 4-4. Summary of primary stakeholder major themes and sub-themes

Overall, during the parent interviews, they articulated that they were able to engage with the nurse in understanding their child’s development. The positive role and influence of the CHaPS nurses was highlighted, and they were described as “*supportive*” (SRP5p), “*helpful*” (NWRP1p) and “*knowledgeable*” (SRP3f). Overall, the eleven parents reported positive experiences with the CHaPS nurses and the St Giles DAT. The SACS-R was generally viewed as a worthwhile assessment tool that enabled early identification of atypical behaviours and enabled early access to services.

## Surveillance and referral process

This theme encompasses parents’ experiences and understanding of the surveillance process with the CHaPS nurses, their reactions to the outcomes of the surveillance tool, and their St Giles referral. The opening question I put to the primary stakeholders was an invitation to “...talk me through the process from the very beginning...let’s start with your meeting with the CHaPS nurse and move through to your child’s assessment at St Giles.”

### ***Meeting the CHaPS nurse and raising concerns***

Regarding the surveillance process, I asked parents: “Do you feel you understood what the nurse was assessing and why?” Parents spoke about receiving feedback from the CHaPS nurse after she had used the surveillance tool with their child. One parent expressed that they “didn’t really understand at the time that much” (SRP6p), however, the majority of the parents replied “yes” they did understand. Some parents attributed this to previous experience.

*I did, but I do have a background due to the fact my older son had already – didn't go through that – didn't go through the SACS, but I've already been through the autism diagnostic process with him (SRP7p).*

All parents mentioned they used this meeting to talk about concerns about their child's behaviour: either the CHaPS nurse noticed something about their child, or parents shared their concerns with the CHaPS nurse. Some parents had already raised these with their partner, a family member, a friend, or their GP. For some parents the CHaPS nurse was the first person to alert them to the fact that some of their child's developmental milestones had not been met or that they had a language delay (that is, difficulty with understanding and/or using spoken language). For example, when one parent took their child along to their 24-month CHaPS check she discovered her initial concerns were more significant than she thought.

*I thought it was the fact he was non-verbal, but when they told me he had interaction problems and social engagement, I didn't even realise that because I have nothing to compare it to, he's my only child (SRP5p).*

Other parents were informed that their child was not tracking a pointing finger with their eyes or not providing typical eye contact when they spoke. A parent of an 18 month old appreciated the CHaPS nurse noticing her child's atypical eye contact and lack of initiation of joint attention.

*It was really good. [T]he lady, she was really helpful. She noticed that, you know, [participant's daughter], doesn't provide eye contact when she talks and she doesn't – when most children get really excited and come and show you, like, "Oh my God, look at this." But she doesn't do that, she kind of hides away and just, like, "Ooh, right, this is only for me to look at, [...]" she picked up a few things that I didn't even notice (NWRP1p).*

Some parents expressed surprise that their child was not demonstrating certain behaviours.

For example, a mother of a 12 month old stated:

*So my child was [...] quite obviously not able to [...] child health nurse was pointing to something and getting him to follow it, [...] follow the pointing with his eyes and he was not interested in doing it. I was surprised that he'd failed, I was happy to be referred because I thought, well, if they want to assess him, well, that's fine, it's good to find these things out (SRP2f).*

Some parents were unsure if their child's behaviour was typically developing and having the opportunity to check with the CHaPS nurse provided assurance or confirmation. The CHaPS nurse was able to confirm with some parents that their child was not engaging with them as expected or was not responding to their name. For example, when SRP6p attended the CHaPS 18-month assessment with her daughter she learnt that:

*She wasn't like saying – she hadn't really said any words at all and she just didn't really respond to her name or like respond to many noises or play in a typical way, I suppose, so only just – and then when we went to the nurse, I guess, it became a little bit more apparent.”*

Parents shared various concerns with the CHaPS nurse, such as detecting a regression in skills. One parent noted a loss of speech where the child had been talking well for their age but within a couple of months ceased talking altogether.

*[Child's name] was talking full sentences by the age of 12 months [...] at the age of 14 months, he stopped talking completely and went mute up until he was two years old. So it was our health nurse that originally supported us in his loss of speech and referred us on to St Giles (SRP4f).*

Other parents had an older child or children with an autism diagnosis. They were aware that if you already have a child with autism then the probability of subsequent children having the condition is higher than for parents without a child with autism.

*Being that she had a sibling already diagnosed. So I made an appointment with our CHaPS nurse who I [...] had a really good relationship with. [W]e went along and she did the questionnaire [...] she didn't have as many concerns as what I had, but based on family history, was happy to on-refer us [...] I was happy with that process (SRP9f).*

Some parents made reference to their child's behavioural performance on a checklist item or the assessment as “passing” or “failing”. For example:

*It was quite obvious that he'd failed that. [...] she'd made a couple of attempts and he wasn't interested in doing it [...] And so I have to say I was pretty surprised that he'd failed because I've seen my child as very sociable and not at all interested in pointing [...] I was a bit perplexed that he had failed it because that was not on my radar (SRP2f).*

Overall, the parents were ‘very satisfied’, with the majority of parents endorsing on the Likert scale either ‘very satisfied’ or ‘quite satisfied’ and unprompted, followed with a reason for their number selection.

*I was really happy with how she picked up on things before even I noticed anything (NWRP1p).*

Even despite frustration with the process (e.g., SRP2f, page 95: surprised by the referral), they still were ‘quite satisfied’ with the service. Conversely, SRP9p expressed being ‘quite dissatisfied’:

*I didn't want to have to fight for something that I knew was there [...] I just didn't know where to go after that (SRP9f).*



### ***Being referred on to St Giles***

Statewide, parents received unexpected and expected diagnoses for their children. For example, in the North-West:

*I was actually really kind of shocked because at the time I didn't have any concerns of her having autism. I had more concerns with my son and I thought she was just kind of copying some of his traits. I was really, really impressed with how (name of St Giles employee) sat me down and she talked me through everything and I was watching (another St Giles employee) interacting with [participant's daughter's name] and they were both really, really helpful (NWRP1p).*

Parent reactions and responses to assessment feedback was mixed. A negative autism assessment outcome - that is, no autism diagnosis - evoked various responses. Participant SRP3f, for example, was grateful for the referral and to be given peace of mind and participant SRP7p felt reassured:

*I guess we were pleased with hearing about his development. He didn't receive a diagnosis of autism and I guess we [...] weren't bothered either way, I suppose, but we were glad to know that he was doing well socially and pleased to hear that he's developing well. Apart from his gross motor, he is developing as he should.*

By comparison, participant SRP9f was surprised and upset at their child not receiving a diagnosis:

*We anticipated a fairly smooth diagnostic process. [Participant's child's name] had quite distinct flags and so when we went for the assessment and then didn't get a diagnosis at all and that she hadn't met any of the criteria, I was quite surprised.*

Parents whose children received a positive assessment outcome - that is, a diagnosis of autism – expressed they were impressed with how knowledgeable the St Giles DAT were.

*I was fascinated how much they knew [...] I found it quite surprising just by two hours they could find so much out about what his issues were [...] he won't interact with people that he's warm to, [...] that was a bit effective to me as well [...] she was able to answer all the questions I had and she was able to give me so much information (SRP5p).*

Parents mentioned the manner in which the developmental assessment team approached the diagnostic process.

*He has had one assessment a year since he was one [...] he finally got his diagnosis this year when he turned three. So one year we did have two assessments and I was very pleased with that. They took their time, they didn't rush into a diagnosis, so that was great (SRP8p).*

The parents also valued the interpersonal skills of the St Giles team. They spoke about how pleased they were with the way staff interacted with them.

*You can have this letter and apply for HCWA [...] all the tools that St Giles are giving me are very helpful to help him with his future (NRP1p).*

With regard to the diagnostic outcomes of the referred children, a summary of these is provided in Appendix N.

The parents were asked if they felt confident regarding the next steps for their child and whether the recommendations were clear to them. Overall, the majority of the parents expressed that a diagnosis helped them feel confident about the next steps for their child and they shared positive comments. For example:

*Yes, definitely. On the report there were about eight recommendations and they were all mapped out, super-clear, I knew who to call and what [...] I just simply called all of them (NRP1p).*

Some parents already had their children engaged in therapies, whilst others experienced an uncertain time and felt unsure about what lie ahead.

*I knew that we would face an uphill battle from that point forward to actually get a diagnosis [...] once you've done one assessment getting a team of medical professionals and therapists to agree that it was wrong, it takes time [...] and [participant's child's name] is a girl and so I knew that the battle was on, basically (SRP9f).*

## **Organisational features and system issues**

This theme, organisational features and system issues, comprises two main sub-themes: responses to the wait times and the functionality of the overall system.

### ***Wait times***

There were varied responses from parents to the direct question regarding the time frame from their CHaPS appointment to their first appointment at St Giles for the more in-depth assessment. Some parents were contacted by St Giles within a few weeks to a few months (SRP9f) of being referred by the CHaPS nurse.

*I was very, very happy with that time (NRP1p).*

Other parents waited for much longer, some nearly 12 months, to be contacted. Participants attributed this to a busy system. There were parents who waited closer to two years.

*He was referred at 14 months and he was seen by St Giles about a month ago, so he's nearly three. So it did take quite a while to get through for that assessment. She indicated that it could be a year, so we were expecting that, but it ended up being quite a bit longer (SRP4f).*

Waiting times were challenging for some parents and they talked about how this made them feel. One parent, who had her five-year-old child also going through a similar process at the same time as her toddler, said: “There was stress, definitely” (NRP1p). Another parent described feeling unimportant.

*It adds uncertainty, that you kind of think, well, that we're not valued, I think, because especially because it's a research study that you feel not valued (SRP2f).*

Another parent felt like she was in limbo, with no idea who would be in touch or when.

*I guess just a bit unsure. Like because I was just sort of waiting, I didn't really know how long it would take or like when they were going to get back to me (SRP6p).*

Other parents were less concerned about the waiting time for various reasons, including not remembering about it: “Because I didn't have any issues, basically I forgot. I was, like, oh, they could call” (SRP3f). Some parents were kept busy with additional concerns and interventions during the waiting time.

*We also were an outpatient through the Royal Hobart Hospital and he was referred to a speech therapist and a dietician there and, while he was under their care, he also saw a neurologist (SRP4f).*

Likewise, for participant SRP5p:

*There was so much going on at the time and that was before I realised he had a real issue, as well. Like I thought it was just a non-verbal issue and because people say, oh, you know, he'll talk eventually, so I wasn't concerned as much at that stage until I found out how severe it actually was.*

Another group of parents felt more at ease during the waiting time as they conveyed a readiness to accept that their child may have autism. They perceived their child to be young and if identified as such, they would engage in the process of support and EI.

*We weren't too bothered by it just due to he is still quite young so we didn't feel like there was any urgency in getting a diagnosis or not, or no diagnosis, but, yeah, we weren't worried about it, no (SRP7p).*

Prior to attending their SACS-R assessment there were many parents who were already actively receiving support from various professional organisations. They continued to access that support during the wait time as well. Some families came to the CHaPS following consultation with an external professional who was aware of the SACS-R program. They had suggested to parents to engage with their CHaPS nurse.

*We were sent to CHaPS on recommendation of ECIS following concerns from them that [participant's child's name], potentially had social communication challenges (SRP9f).*

### **Functionality of the overall system**

The system as a whole for referred parents was not without its criticisms. Some parents were critical of the way the system is currently functioning.

*There was a lot of delays. So whether that just means the project hasn't been managed well, or whether it's just the demand has outstripped supply, I don't know, but I think that the process of moving people through it has not been very smooth. We were supposed to get yearly assessments and now that he's two, [...] he won't (SRP2f).*

Parents raised issues about the difficulties they had experienced with the process, including absence of reminder texts, not providing follow up communication and not providing time frames regarding the wait list for assessment.

In contrast, there were also many positive comments made by parents relating to their awareness of how the process went.

*I think it's great that the child health nurses are becoming more aware of – and it would have been really helpful for us to have that assessment for our older son when he was a bit younger, when we were less knowledgeable about autism and sensory processing challenges and things like that. So I think it's a really great initiative and, yeah, it's been really helpful for a lot of families (SRP7p).*

### **Support resources and intervention services**

This theme refers to parent experiences of early childhood resources and EI services available to children who have a diagnosed condition (e.g., autism, language delay, developmental delay). Support services can be provided through the public health system, private organisations, or a combination of both.

Some parents were able to access services in a timely manner. Participant SRP1p stated that:

*Because we got in so early it means that we've had access to services when she was little which gives a better outcome for schooling.*

Participant SRP5p reported a similar experience.

*I'm getting as much therapy for him as possible and that's thanks to them being able to assess him really quickly [...] and I've been able to do a lot in that time.*

The comment was also made that even though St Giles made a number of intervention and support recommendations on the report, in Tasmania these are not specific services and availability of any service is limited.

*Some of the services and that that they recommend aren't really available down here, so it's a generalised service. There's just not as many services down here in Tasmania for the under five (SRP1p).*

In addition, some parents reported that particular clinicians were difficult to access and availability of senior therapists was very limited (SRP1p).

## **Funding**

This final theme covers two broad funding areas. First, it highlights parents' experiences relating to receipt of/or utilisation of funding provided for support and intervention. Second, the experiences related to the funding provided to the Tasmanian Health Service (THS) and the Department of Health (DoH) from the State Government to implement the SACS-R assessments. Follow-up assessments with the St Giles DAT were funded by the Autism CRC.

### ***Funding for support services***

Parents expressed uncertainty around funding for services and the transition from *Helping Children With Autism* (HCWA) and *Better Start for Children with Disability* (Better Start) to the NDIS.

*At the moment it is all up in the air with the NDIS funding and who is going to get what at the end of the financial year. So we've gone through the process of going to ECEI at the moment and we start a five week wait to be seen by them (SRP4f).*

Whereas other parents felt assured about their child's funding package: For example:

*I was able to get the HCWA funding very quickly (SRP5p).*

### ***Funding for assessments***

Funding provided to the THS and DHHS for SACS-R surveillance and St Giles assessments was considered by a number of parents to be inadequate for the goals of the project. For example:

*And the impression I got, too, was that either the funding was not sufficient for the volume of clients that they had, or that perhaps the resources that were needed for each client were greater than had been expected (SRP2f).*

#### **4.3.2 Internal stakeholders – group 1: CHaPS nurses**

There was a statewide invitation made to all CHaPS nurses to participate in an interview about their experience, understanding and perspectives regarding their work in administering the SACS-R to young children. Of the 101 CHaPS nurses statewide, 37 consented to participate in an interview. Nurses either worked out of the CHaPS clinic or were part of the *C U @ Home* Program. Two nurses shared their personal experience of having children with autism.

Across the state, there were 17 nurses from Southern Tasmania, and of these, six had face-to-face interviews and 11 opted for a phone interview. From Northern Tasmania, twelve nurses participated. Seven had face-to-face interviews and five chose a phone interview. There were eight participants from the North-West. Six of these nurses requested a face-to-face interview and two had phone interviews. All of the 19 face-to-face interviews were conducted at the nurses' place of work. The phone interviews were all held in a noise-free room in an office location in the Hobart CBD.

Reflexive thematic analysis (Braun & Clarke 2019) of the internal stakeholder, group 1, CHaPS nurses' data, generated four themes: impacts on professional practice; working with parents; system issues; and the rollout of the SACS-R. The findings from the nurse interviews are presented according to these four themes. A summary of the internal stakeholder (group 1) major themes and sub-themes is displayed in Figure 4-5 below.

## Internal Stakeholders – Group 1: CHaPS Nurses

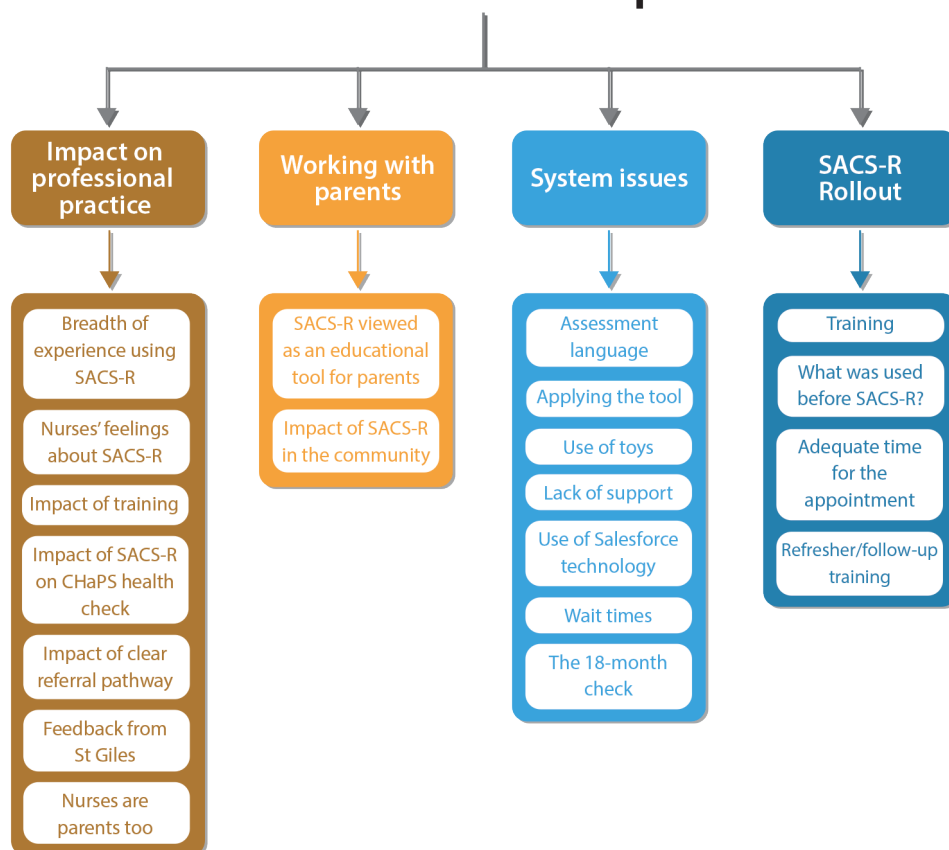


Figure 4-5. Summary of internal stakeholder (group 1) major themes and sub-themes

### Impact on professional practice

This theme refers to the various impacts that the SACS-R tool had on the CHaPS nurses' professional practice. Included here are nurses' descriptions of their experience using the tool, their feelings about it and the way they felt it impacted on their professional child development assessment. The nurses considered the impacts of the training, the impacts of the SACS-R on the routine health checks and how the SACS-R fits in with other currently used assessment measures. They also shared their views on the impact of the referral pathway. It was clear that the communication and feedback that the nurses received from St Giles was appreciated. This theme concludes with a personal look into the lives of nurses with children who have autism.

Regardless of the setting where the SACS-R tool was used, the length of time in the field, the level of SACS-R involvement, or having a lived experience of autism, the surveillance tool was very well regarded and welcomed by nurses.

Nurses reported that the use of the SACS-R led to an increased confidence in their overall clinical practice.

*I've found it's really helped my practice in identifying [...] some of the social attention and communication issues and also isolated whether or not they're related to more social sides of things or whether it's more of a communication issue (N14p).*

### **Breadth of experience using the SACS-R tool**

I commenced each interview with an invitation to nurses to “tell me about your experience using the SACS-R.” There was a wide range of experience with administering the SACS-R tool. At the time of interview, some nurses had been involved with the SACS-R rollout for two or more years, following the July 2016 training, while others had only been providing assessments for a couple of months. The opportunity to use the tool was related to the numbers of hours that nurses were working in their role. Some worked part-time, some full time, others doing relief work and moving between a number of clinics and a couple were new practitioners. A few nurses had recently returned from leave (maternity or holidays).

Experience using the SACS-R varied across participants. Some nurses were afforded limited opportunity to gain experience with administering the tool and completing referrals to St Giles, for example:

*My experience is actually quite limited, [...] SACS actually came in when I was on maternity leave. I wasn't always great at accessing [...] the online portal. I don't have any experience with that [the referral process to St Giles] because I didn't identify any atypical behaviours (S7f).*

Other participants had become quite familiar with the tool and the referral process.

*I've had a really good experience using the SACS-R in the clinic. So we've been using it for, what, two years now, almost, [...]. And then being able to give them somewhere to go, as well, and say, okay, well, this is where you're going to be referred (N14p).*

Location of service delivery also influenced the participants' experience in terms of contact with the tool. From a *C U @ Home* nurse perspective:

*I work for the C U @ Home program, so I don't actually have a lot of volume, numbers-wise. Generally speaking, I will only do like the 12-month SACS one (NW1f).*

By comparison, some of the nurses in the clinics were inundated with appointments.

*I was actually overloaded with about...with the number of referrals that were coming in, especially from ECIS where the children were just within the parameters of the two-year check (NW6f).*

### **How the nurses felt about the SACS-R tool**

The general response about the SACS-R tool was overwhelmingly positive, for example:



*I think we need to continue with it, forever. [I]t really has made a massive difference to our 12-month old and 2-year-old screens. Massive difference [to] me! My families. All of the nurses. All of us. It's awesome. Best thing we've been given. I say that to my parents all the time and they agree. And they're like, "Oh wow, yeah, I can see what you mean (NW5f).*

The CHaPS nurses spend a large proportion of their weekly work hours interacting face-to-face with parents and their children to assess the child's development. Nurses pointed out that being allocated the task of administering the SACS-R provided validity, additional structure, normalisation, and formalisation to the work they were already doing.

*I really liked the formalisation of what we already were sometimes doing. I felt like we were already doing a lot of the parts of SACS in the assessments, [...] we were given some more education around that and a pathway to follow so we weren't just sort of referring blindly on to a GP or come back in a few weeks and we'll see how things are going. It was much clearer for families with clear information to give them (S7f).*

### ***The impact of the training***

The introductory training sessions were seen by the CHaPS nurses as providing valuable information about how early indicators of autism may present in very young children's behaviour.

*When we did the initial study days [...] I found it really interesting finding out more about the subtle signs of autism in little babies and children (S14p).*

The training increased the nurses' confidence, awareness and detection of atypical behaviours that may indicate the need for referral instead of waiting.

*Being aware that we can detect this issue in younger babies, rather than waiting, [...] it used to be that you couldn't diagnose anything until they were three or four which we know then it's far too late. It's nice to have that knowledge to know that, you know, maybe it can be picked up in a 12 month old (S2p).*

The nurses raised concerns about ensuring that new CHaPS staff and staff returning from leave would be able to access the training. Included in the training were adjunct resources. Nurses appreciated these, as both additional sources for learning and the means by which to connect this new knowledge to prior.

*There were several different ways, you actually saw it with those videos, you got richer information and it goes hand in hand with our training anyway of developmental stuff, so it all just meshed together, you could see (N8f).*

Many nurses mentioned that following completion of the training they noticed an increase in their skills and a growth in their confidence. This was also due to the introduction of the tool into their routine health checks.

*The SACS has actually changed my world, as a child health nurse. [I]t has given me extra tools and skills to be able to identify where, you know, children are not [...] developing socially as we would expect them to (NW4f).*

### **Impact of the SACS-R on the CHaPS health check**

Nurses described their ability to weave the SACS-R items into their appointments.

*I'm automatically getting some good eye contact from this child. I'm seeing a social smile. The child's responding to their name. I point at something to see whether they're following my point, and then I can point out the window, and then I'm noticing that the child's bringing toys over to the parents (S14p).*

The SACS-R tool was considered a valuable addition to the CHaPS nurses' resource kit. They could now measure the behaviours rather than go by instinct.

*To be able to have a reason for that vague feeling that something wasn't quite right. [T]o be able to say, right, well, there's not enough eye contact or [...] the body language is lacking or the verbal skills aren't there [...] the listing of what would be expected and typical at that age and to be able to compare the child in the room to what you would hope for and expect from a normal child, a typically-developing child (S17p).*

Participants recognised that there was a level of resistance to the practice change.

*I think there's always a resistance when there's change being implemented. Initially, there may have been a little bit of resistance because people were just unsure of how it would change their practice and perhaps add to their workload or the time...the length of the appointments and that sort of thing. [A]s we all got more familiar with the SACS assessments and more comfortable with how we performed them and our knowledge just around recognising the different social and communications skills in children and babies, then I think we all got on board a bit better and just embraced it [...] perhaps it's improving all the time (S14p).*

Several participants felt more strongly about their colleagues' opposition to the change. They were concerned about the lack of enthusiasm they perceived from some colleagues.

*I found out that some of the areas of child health were not completing it because of the demands of the tool and the referral system, and this really disappointed me and at one stage I was very upset about the needs of children, especially in the North-West as we have lower health outcomes (NW6f).*

The nurses were asked: “How do you see the SACS-R fitting into the other screening and surveillance measures you currently use?” By and large they reported that the SACS-R is “fitting in quite nicely” (S11p) and “fits in easily” (S5f). Participants commented that the SACS-R is a useful accompaniment to the work they already undertake, and it is appropriate that CHaPS administer this assessment.

*It completely complements what we're doing and just sits completely up alongside of what we're trying to achieve in our job (N13p).*

*It fits in perfectly. Surprised that we weren't doing it before, really. I mean, it fits totally in our square (S13p).*

Moreover, the inclusion of the SACS-R into the role of the nurses enriches the service that CHaPS is able to offer.

*It's fitting in really well because social development is something that parents ask about and are worried about so it's nice to be able to offer I guess like a holistic service. Yes, so looking at their growth and development and we're also looking now at their social attention and their communication, so really good (S15p).*

### ***Impact of a clear referral pathway***

The SACS-R tool provided nurses with both a monitoring framework and a formal referral pathway. They expressed that the tool increased their professional confidence in making decisions whether to refer or not to St Giles for further assessment.

*I found it quite valuable because [...] social communication and autism concerns is something that can quite commonly come up in a child health visit so to be able to action those concerns and screen and refer or not refer, [...] really great for autonomous practice and offering our families what they're looking for (S15p).*

If a child presented atypical behaviour on three of the five key items for their age it was clear to the nurse that they needed to make a referral.

*She was deemed “at risk” by the SACS and yes, she was placed after her assessment that she was highly likely to have ASD (N6f).*

Prior to the SACS-R, if the nurse was unsure about a child’s presentation, they would invite parents to come back in six months or more to take another look at their child.

*There was no way five years ago that I would have referred that child straight away. I would have said, yes a bit slow in developing communications, I probably would have sat on her [and advised to] “come back at eighteen months” (N6f).*

The inclusion of the SACS-R into the CHaPS routine health checks now enables nurses to refer on with the assurance of follow-up and further assessment.

*A lot of these children we probably had suspicions of, that something was going on, but never really had any concrete kind of evidence to prompt that next step. Whereas now, you know being able to have a clear line of the next step being available is really good (N1f).*

*It's given a [...] linear approach to be able to refer to St Giles [...] and it gives an avenue for feedback for the parents too (N9f).*

The CHaPS nurses were unanimous in their praise of the referral process and pathway to St Giles DAT for further assessment.

*Being able to identify children that need some help and intervention, but also a pathway to send those people, whether they've actually got autism or whether they've got developmental delays or anything like that, it's a pathway that's quite clear and to have those available resources [...] it's just fantastic (NW1f).*

When asked about the process and pathway, a similar response - “straightforward” - was echoed by many of the nurses.

*It's very easy, very straightforward. [A]nd it's great to have that pathway. We never used to. I mean, back then we had nothing, so to have that pathway with St Giles is fantastic (S4f).*

### **Feedback from St Giles**

The nurses valued the feedback they received from St Giles. They were appreciative of the way communication was managed between the CHaPS and the St Giles DAT.

*We always get our reports back and I love to read them...they're so in-depth. And then the girls will send me back emails if they haven't had time to contact the child's parents in a certain time and I think that's so good (NW5f).*

*You were kept in the loop which was really nice [...] that just meant when the parents came in with the children again you were aware of where they were at (N12p).*

### **Nurses are parents too**

There were a couple of nurses with lived experience of being a parent of a child with autism. They provided further personal insights from the perspectives of both parent and nurse involved in the SACS-R process. A nurse with a child on the spectrum compared the current process against her previous experiences with her own child. She described going to her CHaPS nurse with concerns about her child and being sent to speech therapy. Her child's pathway to receiving an autism diagnosis was a difficult one.

*I went through the experience [...] with my Child Health Nurse and the processes of referral, which weren't very good way back when he [...]*

*started the process of diagnosis at two. So my experience using the SACS referral, because of the funding available for assessment through St Giles, I think it's been a lot easier process. So you actually can refer straight to St Giles rather than refer back to the GP with a suspicion...of autism (S11p).*

This experience was matched by another nurse whose child was not diagnosed until late adolescence. Now that she has been trained in the application of the SACS-R assessment she stated that her son “would have passed it with flying colours.” That experience has raised concerns for her about some of her current clients who did not flag on the key items of the SACS-R assessment. The nurse would like to keep an eye on their development.

*I sort of put something in their notes to flag it to remind me to watch them at their next appointment. I'm very keen to follow-up and see where those kids actually end up. I suppose that's actually come from my own experience of my own son who's got a diagnosis of autism, [...] he flew under the radar for a very long time. He's only just got his diagnosis in January at the age of 15 and a half, even though I've been chasing that diagnosis since the age of about four (S13p).*

The nurses indicated that they were very keen for the new process, that is, SACS-R administration and referral, to continue after the project concludes.

*I think it's great. I hope it just becomes part of normal routine check because I think it's fantastic and I've been showing all the medical students. [...] and I always show them that ASDetect because I think that's also a really great thing to hop onto that website and they have gone, "Oh, my God, that's amazing" (S18p).*

### **Working with the parents**

This theme encapsulates CHaPS nurses' views of how the tool impacted on their work directly with parents, and their insights into how the tool impacts on parental involvement. Also presented under this theme are the CHaPS nurses' observations of the educational implications for parents and the broader community that might result from use of the SACS-R tool.

Overall, the CHaPS nurses expressed that the SACS-R tool provided an effective platform to open a conversation with the parents around their child's social and emotional development.

*It's a really lovely way of parents engaging with us in understanding their child's development and for parents that have been concerned, we can either reassure them that there isn't a concern or we can identify that what they have seen themselves and they're expressing concern about is a great thing that they've identified (NW4f).*

The nurses reported that the inclusion of the SACS-R during the child health checks led to greater parent involvement than the nurses had previously experienced with parents.

Moreover, following the health check, the parents are able to continue monitoring their child's development at home.

*Having the SACS-R is really good, particularly going through it with the parent and I think it also helps them be involved in their child's care and in the assessment themselves. Just being able to have a conversation with parents (S1p).*

Nurses were able to refer parents back to the checklist and indicate the core social interaction behaviours that their child was displaying in a typical or atypical manner.

*I think it's so incredibly simple to actually say [...] to parents that these are the main things, this is what we're looking for and it's something that parents can look at [...] and recognise quite easily, [...] it's nice to have something for the parents to actually see. A lot of parents, having been given that opportunity to have a look at what their child's doing, I think they appreciate it (S4f).*

Nurses reported that if parents have any concerns about their child's development, they have easy access to the CHaPS nurses where the SACS-R can be administered. The results of the SACS-R assessment provided clarity: either reassurance to the parents or an obvious referral pathway.

*I]t's easy to get an appointment with the child health nurse, [...] without having to go through elaborate hoops of seeing paediatricians or trying to access the developmental assessment team, [...] they've been able to get a clear answer just using the screening tool, either there are concerns or there aren't and being able to provide the parents with why it is a concern or it isn't (S15p).*

Most of the nurses referred to the positive interactions that they experienced with parents. Furthermore, they spoke about the parents' receptiveness (NW2f), willingness to participate, and eagerness to understand their child's social development, irrespective of the outcome.

*It's very easy for them to understand what we're doing and if you explain [...] then they sort of have a few lightbulb moments and think, "Oh yeah." And quite often they'll say, "Yeah, well I did sort of think that something wasn't quite right" (NW5f).*

*If there has been concerns, they really are glad to know about it sooner, than later (NW2f).*

Other nurses felt that the SACS-R experience was a positive one for parents, but only when their child was developing typically. When atypical development was identified, some parents responded with disbelief, confusion, or reservation.

*For the parents of typically-developing children, I found it very positive and able to point out some of those things that the child does that were early communication skills [...] for some parents it was a bit confronting having that discussion about things not going normally [...] could be quite a difficult discussion, and not all parents would follow through necessarily with St Giles either (S17p).*

### **SACS-R viewed as an educational tool for parents**

As the nurses continued to use the SACS-R they could see that it offered a chance to use the assessment tool for parent education.

*[I can explain] this is what I'm looking at, this is the milestone, and these are the milestones they've done [...] The education for parents is massive (NW3p).*

*So being able to say we're actually looking for the communication, not just the ability to make the pointer finger, we're actually looking at the action, the communication action that goes with that finger (N6f).*

*The SACS gives us a really gentle way to explain to a parent who may not be concerned that maybe they should start looking at those things (S18p).*

Sometimes children do not perform as expected on one or two of the key items and therefore are not eligible for on-referral. Nurses can reassure parents about the result and also offer reassessment to the parents if they have any concerns.

### **Impact of the SACS-R in the community**

The nurses considered that the use of the SACS-R has had flow on effects out into the wider community, particularly in terms of education and increasing autism awareness.

*It's current. People are talking about it, people are wondering, [...] I think they like to know that their child has had a level of assessment around that (S7f).*

CHaPS nurses made some recommendations as to how to augment the education of parents, relevant organisations and the wider community about autism and early indicators, for example:

*It would be really great to be able to see some money being put in by government or being put in by an NGO to put advertising on the TV to look at these things because that's a really important part of community development and getting an understanding of peoples' expectations of their child (NW6f).*

### **System issues**

This theme encompasses the workings of the SACS-R process at a structural level, including the language that the nurses used when speaking with the parents. Of particular

interest here is the training and management issues faced by the CHaPS nurses. Whilst administering the SACS-R assessment, the nurses encountered a number of challenges that highlighted a mismatch between the training they received and the real-life application of the tool. They experienced some difficulties with utilising the necessary technology for data entry and referral. There were concerns about the wait times for assessment at St Giles for their referred families. Nurses identified clear regional differences across the state regarding inconsistency of the SACS-R 18-month assessment. There were suggestions about the SACS-R assessment being included in the next printing of the Public Health Record (PHR).

### ***Assessment language***

During training, the CHaPS nurses were given instructions on how to present the SACS-R tool to the parents. They were specifically told not to use the word “autism” when speaking to parents about the assessment or their children’s results. At times, this instruction made it difficult for the nurses to talk about the tool. They described feeling constrained by this directive as it impacted on their approach to appointments.

*I have explained it that it's not a measure of autism, that it's just a measure of how they were socialising and how they were socially communicating and then if we notice something that was different, we would be sending them on for testing (S5f).*

Although the instruction was clear that the CHaPS nurses were not to mention “autism”, the nurses sometimes found themselves in a quandary because there were parents who directly asked if the assessment was a test for autism.

*We've got this SACS checklist [...] It's all about social and communication stuff," and she just looked at me with a smile and she goes, "Is that autism?" So, as much as we don't come out and say we're screening for potential autism, the families who have concerns know what we're doing and so I don't hide that fact (S10p).*

Without being able to mention ‘autism’ some CHaPS nurses were unclear how to explain why they were referring on for further assessment, for example:

*It's not my job to go ahead and say um, we, we're specifically looking for things such as autism, um but, yeah that's probably been the only hurdle I've come across and I'm not always feeling very confident in how to word why I need to refer based on the screening that we're doing (N15p).*

Some nurses have taken steps to prepare an answer to the “Are you checking for autism?” question, should it arise, for example:

*I have explained it that it's not a measure of autism, that it's just a measure of how they were socialising and how they were socially communicating and then if we notice something that was different, we would be sending them on for testing (S5f).*



Other nurses chose to ignore the instruction and to use the term 'autism' openly.

*I find it very hard not to mention the word "autism." I know I'm not meant to, but they often say, "Do you think that?" So I find that really hard sometimes, but I just say, "Look, maybe. But that's why we're going that one step further because the girls that do the next assessment are amazing and they'll pick up anything that they think is amiss." So they're sort of happy with that (NW5f).*

One of the features of the SACS-R that nurses particularly liked was the fact that the checklist is unambiguous: "Quite clear cut in terms of yes, no, pass, fail" (NW1f). Some nurses referred to children "passing" or "failing" their SACS-R assessment (S13p). Nurses expressed that some children did not pass items: "Didn't participate and probably almost didn't pass" (S7f) or "failed" three or more of the five key items on the assessment and therefore required on-referral to St Giles.

*After about an hour, he did grin, so we thought we had a pass, but obviously we didn't (NW2f).*

Other nurses were mindful of what they had been taught in the training and avoided the use of words like "pass" or "fail".

*It's not a pass or a fail, it's identifying what's working well, what isn't working as well, and how can we support your child. We're not getting a tick or a pass or a fail or anything like that, it's about identifying are there any areas that the child's struggling that we can give them extra support in (NW4f).*

### **Applying the tool**

Nurses were also taught during the training that they must specifically observe the child demonstrating the itemised behaviours. However, they reported some confusion about how to implement this instruction.

*It says that if you can't elicit this from the child, get parental report that they do do it [...] that's the area where there's...can be the greatest ambiguity because a lot of parents might report that their child does it, but maybe it's not really with purpose (S1p).*

Some of the nurses referred to challenges with this requirement with parents reporting on their child's behaviour as opposed to the nurse witnessing the behaviour directly in the room.

*New or younger nurses may be swayed by the parents, so if they have a concern the parent can sort of, oh bub waves all the time or bub does this and that, and then the nurse may think, "Oh okay, perhaps I'm overreacting," so they might doubt themselves, so if they're inexperienced that could also be a concern that could sway the data (S9f).*

Many nurses described challenges with eliciting some key item behaviours from children, due to either non-participation or perhaps being asleep. They stated that the child's parent would often respond that their child could do it at other times, and nurses sometimes felt pressured to tick the checklist to indicate that the child could demonstrate a particular behaviour even though they had not witnessed it themselves during the appointment (N1f).

Several nurses were keen for the SACS-R assessment itself to be included in the next update of the Public Health Record (PHR). This would serve as record of completion but also further involve parents in seeking CHaPS assessments (N9f).

*What I would like is SACS to be included in our PHR [...] in the blue book. Just have a little section. [J]ust a tick a box on the page to just say...SACS-R, typical, atypical, just so that we know it's been done (N6f).*

### **Use of toys**

Utilising available toys to elicit behaviours from the children was shown in the training. When the nurses began administering the SACS-R assessments, some expressed that they needed additional toys to the ones already in the clinics. CHaPS management, in the name of equality and consistency, introduced kits to every clinic in the three geographical regions to aid nurses in carrying out their role. The CHaPS nurses' responses to the distribution of these resources fell into one of three categories. Some nurses were thankful for the assistance derived from having the toys ("I think having the toys is quite good" [N12p]), whilst others were critical of the quality of the toy kits.

*The equipment we were given was a little bit sort of thrown together at the last minute, so it wasn't very satisfactory. Some of the items we were given weren't very suitable for small children, like very small teaspoons (S17p).*

Some nurses questioned the utility of the toy kits (N8f), whilst others expressed that the children were not familiar with the toys they were presented with and felt that this lack of recognition affected the children's behavioural response (S7f). There were suggestions made about increasing resources to assist with eliciting behaviours from children (S12p) and improving the selection of toys (N4f). One nurse mentioned her experience as a parent taking her one-year-old son along to his health check.

*My 12 month old had no idea what to do with a cup and just looked at the nurse like, "I'm not thirsty" and didn't participate and probably almost didn't pass. [D]idn't do the imaginative play with the nurse in that situation [...] he wasn't playing with those sorts of toys at home. [...] that was a little barrier for him. I've got two boys. Cars, trucks, you know, train sets (S7f).*

### ***Lack of support***

Some participants felt that they did not receive adequate support in their new work from management.

*I was actually overloaded with the number of referrals that were coming in, especially from ECIS where the children were just within the parameters of the two year check. There didn't seem to be any acknowledgement of the managerial area of CHaPS that this would occur (NW6f).*

There was also mention of professionals who were not complimentary of the SACS-R or encouraging of the assessment process.

*She had had a 12-months SACS done [...] and that practitioner had referred her to St Giles and also to the paediatrician. Mum had attended the paediatrician before she got to see St Giles and the paediatrician goes, "Oh, that SACS stuff, that's just all meant to frighten parents," and I was horrified. I'm thinking, wow, we're supposed to refer to paediatricians, but they're sort of shutting it down and being actually quite critical about it (NW4f).*

### ***Use of Salesforce technology***

Following every SACS-R administration during a 12, 18 or 24-month health check, the CHaPS nurses were required to enter the SACS-R data into the online platform called *Salesforce*. If the outcome of the SACS-R assessment indicated that the child needed to be referred to St Giles for further assessment, then the nurse was also required to complete a referral to the DAT and fax it through to intake at St Giles. Some nurses found the computer interface clear and easy to use (S15p). Others, whilst they did not personally experience any technological problems, were required to support colleagues with computer issues (S6f). Some other nurses needed time and practice to become familiar with the software. Eventually they became confident with the process (NW8p). There were nurses who faced various challenges with e-CHaPS, logging on (S3p), finding their initial link (S4f) and locating passwords (NW7f).

*We have a lot of problems with e-CHaPS...it would be really great if, in the future, then it is actually linked to the e-CHaPS check, instead of having to go back to another...to go in through another database" (NW6f).*

Besides the technical difficulties that every nurse faced with not being able to access the *Salesforce* portal via Internet Explorer and needing to switch to Google Chrome, there were other additional challenges. A number of nurses had difficulties with *Salesforce* data entries and the DAT referral forms. Issues with technology seemed to be greater for those who worked as relief nurses.

### **Wait times**

After a nurse submitted a referral to the DAT they were usually contacted by someone from the St Giles intake team to confirm that the referral had been received. Following assessment, a member of the DAT would contact the referring nurse to share the outcome of the assessment.

Many nurses raised concerns about the wait times between families being referred to St Giles for further assessment and the actual occurrence of the assessment with the DAT.

*Initially, we were told that families would be seen within sort of about six to eight weeks for assessment. It's really about four or five months. Perhaps, that's because we're in a rural area and it takes a longer...obviously there's a lot more planning to come down and that sort of thing (NW8p).*

Wait times were not just a challenge in the North-West.

*Unfortunately, because the assessment waitlist has blown out down here in the South, I mean it's a six month wait for assessment (S11p).*

### **The 18-month check**

Across the state of Tasmania there was a major regional difference regarding the 18-month check. This health check was only prescribed for rollout in the South of Tasmania. Consequently, those families in the North and North-West not only did not receive a general check for their child at that age but they also missed out on the 18-month SACS-R assessment.

The Southern CHaPS nurses welcomed the opportunity to administer the 18-month check to families.

*Prior to the SACS coming in we didn't do an 18-month check. We did a 12-month and then a two-year and as we know, ASD sort of becomes more apparent towards that 18 month mark and around that 18 month mark. So for me, I was quite excited to have that back. So I think the 12, 18 and two-year is quite valuable (S11p).*

Even in the South of the state, where the 18-month check was approved, some nurses emphasised that the service was still unable to fulfil the community need for that check and assessment.

*I haven't been able to do as many 18-month SACS screenings as I would've liked. So it would've been good to have capacity in our calendars to see some more 18 month olds. So when we had a 12 month that wasn't necessarily atypical, but we did want to see them again, you know then we'd be able to possibly squeeze them in but just for seeing them on like a population level it just wasn't possible (S15p).*

The nurses considered that conducting SACS-R assessments at 18 months of age was a critical time to assess children's development.

*I think it's fantastic, and I would like the 18-month to be reintroduced. That's such an important milestone for kids. Someone who is little bit late at 12 months, you don't worry too much, but if they've certainly not got it at 18 months, you've lost it if you're not seeing them till two (S4f).*

Participants highlighted the positive potential of the 18-month SACS-R assessment.

*Be interesting to see if we pick up more children if there are those children that aren't at risk at 12 months but then go on to be at risk at 18 months. And if it's more likely to pick them up at 18 months than at 2...because the earlier we get them the better (N6f).*

Statewide, whether it was set out as their region's brief or not, the nurses were clear in their wish for 18-month checks to be part of CHaPS' core business across the state, in all regions (e.g., S8f and S14p).

### **The rollout of the SACS-R**

This final theme focuses on the practical elements and workings of the rollout of the SACS-R tool into the CHaPs nurses' clinical practice. Included in this theme are four sub-areas of discussion by the participants. First, the training that all 101 CHaPS staff attended across the state. Second, the participants responded to whether the SACS-R fits in with other measures that they are currently using in their clinical work. Third, management initially did not allocate any additional time for the health checks as previous research indicated that the assessment can be done quickly as part of the routine check. However, nurse feedback led to management allotting an increase in time for all SACS-R appointments. Finally, the nurses identified their need for further support options in the form of follow-up training and refreshers.

The majority of the nurses were effusive in their comments about the overall rollout of the SACS-R, for example:

*Increasing our awareness as practitioners what the early signs are [...] of autism in young children and also that importance of early intervention. So getting the referral pathways through, the DAT referrals through to St Giles [...] the general rollout [...] all of that worked really well as well, like with the initial study days so that we were aware of how to perform the assessments in the clinical setting. [T]he documenting. I think that the whole platform for that was working quite well (S14p).*

However, some nurses required additional guidance and support.

*A while ago I did ask for someone to come in and sit in with me with a 12-month check because it's still my concern of how to actually utilise that*

*tool. [T]he documentation part, [...] that's the worst part, is just being able to complete the detailed data once something's been identified (NW6f).*

A Likert scale was utilised as a conversation prompt to further investigate the experiences of the CHaPS nurses. They were directly asked how successful they thought the CHaPS nurses had been in trying out change in practice and integrating the new practice into routines. With the exception of one nurse, all CHaPS nurses either endorsed 'very successful' or 'quite successful'.

*Definitely five [...] it's a really good tool. We love it [...] it's easy to build in. Once you get good at it, you can build it into your practice really, really easily, it's really not that hard, [...] the people actually doing it, we really like it (S18p).*

### **Training**

Nurses were asked specifically to comment on how the training and the support they received assisted with the rollout of the SACS-R. The majority of the nurses thought that the training was interesting and enjoyable, and the support provided suited their needs in order to roll the SACS-R out effectively (S15p; NW2f). However, some nurses felt differently about the training and their responses were mixed.

*It needs to be consistent eye contact and consistent response to name and that the fact that a child does it some of the time is still not [...] typical development. [F]or me that was a big, big learning [...] point for me, because purely just looking at the [...] cheat sheet, that [...] doesn't really hint you towards that and [...] as a beginning practitioner, I probably didn't realise that I should be looking for a little bit more than that (S1p).*

*I didn't feel that the initial training was at all. I was a bit bamboozled by that, it was sort of too fast for me (S5f).*

Despite the interest in the SACS-R training, and its popularity, some nurses revealed that the timing of the training period was not ideal. The training coincided with the introduction of new technology and a big change in management with a new director starting (NW6f).

*We were just in a big learning curve with e-CHaPS, using a new tool, using a new computer system (NW7f).*

### **What was used prior to SACS-R?**

The PEDS (Parents' Evaluation of Developmental Status) is a pre-existing screening tool that is completed by parents before or during their CHaPS appointment. It is a questionnaire comprised of 10-items that addresses parental concerns about their child's development, health, and wellbeing. Nurses' comments about the PEDS and how the SACS-R fits in with it

were wide-ranging. Some nurses were not in favour of the ongoing use of PEDS now that they had the SACS-R and did not like it from a parent perspective either.

*I think PEDS is totally useless. It's a terrible tool. I just do it because we have to do it and half the time the parents don't fill it out before they come in, [...] as I'm asking the questions in the PEDS, I'm also asking the question in the SACS [...] that's how I use PEDS. [I]t wouldn't worry me if PEDS was completely out of the book (N11p).*

Many nurses preferred the SACS-R over the PEDS as the PEDS requires additional work from the nurses.

*What we use as well, the PEDS [...] got to really unpick, whereas this doesn't, you don't have to unpick it. It's all there in front of you [...] whilst PEDS gets the parents to tell you if they've got any concerns, and certainly it addresses physical side of concerns as well, this is a bit more detailed (S11p).*

Other participants felt that the SACS-R works nicely alongside the PEDS.

*We talk about how we do the physical health, then we do the social communication health. We get them to do their PEDS, we talk about food and sleep. It's just part of it. It's not something separate [...] we can actually ask some of the questions that are PEDS. We can ask a few of the SACS bits with the PEDS (N6f).*

Although the PEDS and the SACS-R can be used in a combined approach, some nurses considered the SACS-R a superior tool as it provides different and additional information to the assessment.

*It definitely complements the PEDS because they're asking about behaviours and does your child get on with well with others and that kind of thing, so that does tie in [...] it really enhances and heightens that [...] it's another step up from PEDS. I would hate to practice without this now, actually, because it's just so, so much better (NW4f).*

### **Adequate time for the appointment**

The overall consensus from the nurses was that allocation of an hour for appointments was enough time, given that the most common presentation was that of a typically developing child.

*And we've allocated an hour to do it, for example for the 12-month one, to do our child health assessment and the SACS and I think in the early stages we probably needed that hour, most of us, but I think from talking to other nurses, I think forty-five minutes is plenty to actually conduct the assessment and do the Salesforce data (S13p).*

But, if a family needs more time or there is a referral or referrals to do, the time allocated to do the SACS-R assessment *and* referral was considered inadequate.

*When we haven't seen a child for a long time, then that impedes on the workload [...] the appointments were usually about a half hour period. They have been extended to an hour. But sometimes the hour is not enough for the documentation to occur (NW6f).*

*I've had to do any referrals at the end of the day, like, there's not enough time if there is a concern you need to refer on (S3p).*

### **Refresher/follow-up training**

Many CHaPS nurses suggested that post the initial training, and after having opportunities to put the tool into practice, they would have appreciated follow-up training and refreshers (S17p; NW2f; S11p; S1p; S10p; S7f; NW6f; N14p).

*So having initial training and then maybe just another SACS contact, three to six months down the road, just to make sure you are doing it correctly and to fine-tune your practice would probably be helpful (S15p).*

More specifically, participants were interested in further explanations regarding the differences in the types of pointing; how to get the children to display the key item behaviours; additional examples of imitation behaviour; how to identify atypical eye contact; and the particular terms used.

*And just a little bit of clarification, [...] like the pointing, what does that mean? Is it the gesturing, depending on how they do it socially, or is it the pointing? So just to clarify that (N14p).*

*There's eye contact and then there's no eye contact, but in between there's the abnormal eye contact, so just reminding and clarifying some of those things, yeah, to help us to do best practice (S17p).*

It was also suggested that it would have been helpful to have had a repeat of the entire training presentation “about three months later” (NW6f). Nurses were actively seeking more information around a number of situations that had arisen once they had had the chance to use the SACS-R tool in practice. Opportunities to cover these issues in follow-up training were welcomed by the nurses, for example:

*Different ways to explain it to parents, so that the parents know that that's what we're going to be doing before they come in (S3p).*

*Just that little bit of extra training and the confidence in those conversations you could have with families (S7f).*



### **4.3.3 Internal stakeholders – group 2: CHaPS management**

Statewide, CHaPS management comprises 13 staff, some of whom are also clinicians and therefore were involved in the assessment and referral process too. Five staff members consented to participate in an interview, with each of the three regions represented. Three had face-to-face interviews and two elected to participate via a phone interview. The face-to-face interviews were conducted at the participants' place of work. The phone interviews were held in a noise-free room either from a CHaPS' workplace (to the participants' workplace) or from an office location in Hobart.

Reflexive thematic analysis (Braun & Clarke 2019) of the internal stakeholder, group 2, CHaPS managerial staff data generated four themes particular to management: their views on impacts on professional practice; managers' views on parent responses and attendance; system issues; and the rollout of the SACS-R. The findings from the management interviews are presented according to these four themes. A summary of the internal stakeholder (group 2) major themes and sub-themes is displayed in Figure 4-6 below.

## Internal Stakeholders – Group 2: CHaPS Managerial Staff

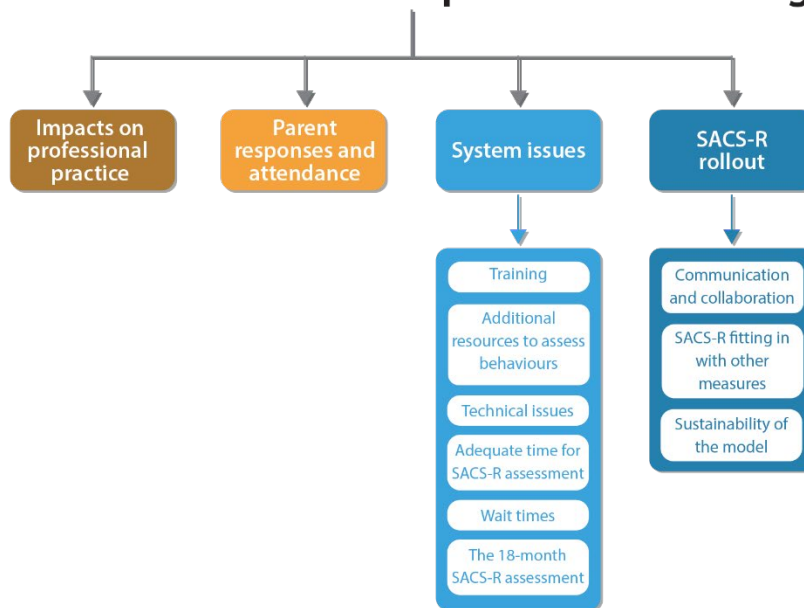


Figure 4-6. Summary of internal stakeholder (group 2) major themes and sub-themes

### Managers' views on impacts on professional practice

This theme explores the perceptions of the CHaPS managerial staff regarding the impact that the SACS-R tool and referral pathway had on the professional practice of the CHaPS nurses. Included under this theme are the managers' views of the tool as part of the nurses' role; their insights into the nurses' use of it; and its effectiveness in the hands of the nurses as a surveillance tool to identify children who require further developmental assessment. Management staff also shared their views on how the parents responded to the program, issues with the system, and the overall success of the rollout.

Each of the interviews commenced with an invitation to managers to share their "thoughts and ideas about the SACS-R and the role and the responsibilities of the CHaPS nurse." Their responses unanimously supported the SACS-R tool as a value adding resource to the nurses' role (S16p; N3f; N10f; NW9f).

*The nurses picked it up really well. And I think the reason for that is, that it is actually very relevant to the practice [...] they use it quite easily in practice (N2f).*

The managers thought the training was well-delivered and it enabled staff to identify atypical behaviours more effectively than prior to the training.

*Having done that training [...] it really made you look a lot closer at what was going on with little ones and being able to pick that up a lot better than I did before. Just even subtle signs where it made that big difference really for finding social attention and communication issues (S16p).*

Following staff training, the managers were aware that the SACS-R tool enhanced the nurses' day-to-day assessment work.

*It just really quantifies some of those vague questions that we've had, [...] but it quantifies it really neatly and then gives you a pathway too, okay, this is at risk, this isn't at risk (N10f).*

They also noted that it gave the nurses greater confidence in referring.

*It's actually given them a skilled approach to identify what concerns they had previously. This is what I have heard them say. They would look, see a child and know that there is something not quite right and sort of wait and bring them back. So I think it's given them confidence to refer [...] you can just refer with confidence knowing that they don't meet a threshold and so there's something going on (N2f).*

However, the nurses varied in their ability and the time it took to become confident with incorporating the new tool and speaking with parents about atypical behaviours.

*There are some staff who have got quite a lot of awareness and knowledge around social and communication skills and how to have those conversations in a partnership sort of way with parents, and some who weren't quite at the same skill level (NW9p).*

The Clinical Nurse Educator was cited as a staff member who played an important role in supporting colleagues who were either absent from the training or who required additional review of the training.

*Our clinical nurse educator and the people that have come to sit in clinics with nurses have helped with that. [S]he could catch up people who missed or who couldn't be at a presentation or people who struggled to grasp it (N3f).*

There were concerns identified with people in leadership roles being a potential barrier to successful implementation into routine CHaPS practice.

*There are some people in the nursing leadership group who aren't sold on it for some reason, I don't know why. The resistance is from the South, [...] you can't always get everybody on board to implement some things. But I'm quite sure it would have support from the Director of Nursing. I think it will get a lot of acceptance in the North and North-West (N2f).*

### **Managers' views on parent responses and attendance**

This theme includes the experiences of managerial staff with parents and information they have gleaned during supervision with nurses about parents and how they viewed the process. Included here are management's ideas around why parents do or do not schedule appointments with the CHaPS nurses and how we might increase participation at the two-year-old health checks.

Generally, the managerial staff shared that the SACS-R tool provided a forum for staff to engage with parents about their child's behaviour (N3f; NW9p; N10f).

*It's a nice way to engage with parents a bit more about what their children are doing, if they're parents that are reluctant to do that, because you're doing something with them and they might start to talk more about that (N2f).*

Some staff members stated that the parents' experience of the SACS-R assessment was reliant on the skill of the CHaPS nurse and the way they presented the tool.

*It probably depends a lot on the clinician and how they delivered the program, [...] it's up to the nurse to describe what's going on [...] that it's a good thing and talk about the study. I feel like it's always about understanding and being included, and I think that if they've got that knowledge of what the study is about then most parents would be really happy. Parents are actually really interested and can go away and think about it and look at their own child and see these things (S16p).*

Participant NW9p shared that she had directly been asked by some parents if the SACS-R was a test for autism.

*A couple of parents have [...] asked me, "Was that a test for autism?" And so we've had the explanation then in words that are appropriate for the parents, [...] it's a screening tool and it's just an opportunity to talk about any concerns that they or the health professional may have about their child's social and communication skills.*

The feedback that has been received by managerial staff from parents, either directly or indirectly, has been of a positive nature.

*I've had feedback from parents and it's generally positive. Certainly, ones that have been picked up and sent on have come back and been really, really happy that that's been captured, if that's the word I should use, and the clinicians generally, overall, from the stories they've told about other parents, that it's been, yeah, pretty good (S16p).*

During the interview, managerial staff were asked for their thoughts on what encourages and/or discourages parents from taking their children along to the CHaPS to undergo assessment. The range of responses was quite varied, from parents' attendance or non-attendance being considered unrelated to the SACS-R ("I would think it's nothing to do with the SACS" [N10f]) to attendance being because parents knew what the assessment was for and scheduled an appointment for that purpose.

*Most parents that came, had heard about it in some form and knew that there was something going on with their child and it kind of got them that help that they needed (S16p).*

There were also some parents who thought that the CHaPS nurses were diagnosing autism at the health checks.

*I know that there's a lot of parents out in the general community were saying to come in because we can diagnose autism. So, I mean, I know that's a little bit of a miscommunication, but I think that it's generally been pretty well taken up by parents (S16p).*

Several other factors were attributed to impacting attendance, including characteristics of the nurse and/or the parent, appointment availability, or stigma. Some staff stated that one of the reasons could be relational.

*The quality of that relationship is often key to how parents perceive coming along. The kind of reception they get when they ring to make an appointment is really important [...] sometimes peoples' past experience can be positive or negative (NW9p).*

For attendance to increase, availability of appointments is an important consideration for CHaPS.

*Whether we're able to offer them a timely appointment. How flexible we are with the times we can offer appointments to fit in with family needs (NW9p).*

Another reason that was suggested is that some parents may be reluctant to engage due to their own thought processes.

*There's some parents are very sensitive to anything that could be perceived as criticism. And some people have denial about if there's an issue, they actually don't, they're not ready for you to say this is an issue (N3f).*

A final variable that that may influence attendance is the stigma associated with autism.

*There's such a stigma around social attention and communication and autism, that I suppose there might have been thoughts from a few parents that, if they go, we'll diagnose them or something. But, I could see that there would be some parents that would be in denial, and if they go to CHaPS that suddenly they'll have this child with autism [...] I could see that a lot of parents could be put off by that (S16p).*

The staff viewed the SACS-R process as educational for parents regarding the tool and the referral pathway.

*Education, I guess, with parents, to let them know that it's actually a really good thing to have this program where they can get that help early on, that early detection and get that early help (S16p).*

There was a dichotomy between how staff perceptions of community awareness of the SACS-R.

*I'd be surprised if the community is aware of it at all (N10f).*

*I think it's been fairly well accepted by the clinicians now and I think also by the community (NW9p).*

It is apparent from the data that the 12-month check is well attended by families. However, it is clear that there is a drop off in participation for the 24-month assessment. During interview, staff were asked for any suggestions about how we might increase participation in the 2-year-old health checks. Diverse responses were given, including administration issues; meeting the needs of families; staffing constraints (NW9p); parents returning to work; raising community awareness; and aspects of hardship, e.g., difficulties with transport.

*There's a whole big range of things that are not just necessarily related to use, so it's about us sending reminders, us having more probably continuity of care so if clients saw the one nurse, that one nurse might be able to get them to come back, better than when they've seen a few. If we had a bit more engagement in that time, maybe doing some more work with childcare centres. I would think the child and family centres would have more engagement at two than maybe other centres (N3f).*

## **System issues**

This theme covers the mechanisms underpinning the SACS-R process at an operational level, including the training, assessment administration and technology problems faced by management directly or by their staff. Participants noted challenges involved with making referral to St Giles DAT and to other agencies. Staffing was identified as a concern with regard to flexibility, availability and inequities across the state. Management liked how there had been some movement with the time originally allocated for SACS-R assessments. Wait times to meet with St Giles for further assessment was an issue along with delays in timely feedback. Management staff considered that the SACS-R 18-month assessment was important, and they were very supportive of its administration statewide.

### ***Training***

The training was rolled out to all the CHaPS managers, along with the nurses, during a one-day presentation in each of the three Tasmanian regions of. Overall, the managerial staff participants described the training as interesting and engaging, for example:

*Certainly you could go out into the field after having that training [...] was a real eye opener (S16p).*

The length of time required for the training was recognised as a problem. Some participants mentioned the challenge of the entire CHaPS staff receiving the same training at the same

time in order for consistency of learning and application of the new material was challenging.

*If you talk North, North-West, we've got about sixty nurses, so to get them together, to all hear the same presentation is pretty tricky, there'll always be someone on annual leave, someone on sick leave as well as the people who get distracted at the actual presentation, so actually trying to get that across your whole workforce is quite difficult (N3f).*

One manager suggested presenting the training in discrete chunks to allow space for nurses to go and apply their new knowledge, come back together to evaluate early implementation and ask follow-up questions.

*I think the training was good, but rolled out in a bit of a hurry [...] for most of us as adult learners we want to be told...tell them why, show them how, let them try and then come back and review it, to do that quality cycle stuff in a very simplistic way. I think a lot of the staff would have benefited from an opportunity to be given some information, had an opportunity to practice, and then come back and just review how they're feeling in a fairly short timeframe, before the implementation (NW9p).*

Participants commented that having some time to practice during and after the training would have been beneficial to staff confidence in applying the tool.

*The training was rolled out and then suddenly we were all doing it and so hadn't had an opportunity, really, to process and practice in a way that wasn't with clients. Probably individual learning, probably people needed a bit more time, [...] we did the best we could, but if we were doing it again, it would be good to have a bit more of a gentle rollout than the 'here's the information, now go and do it,' sort of approach (NW9p).*

On the other hand, some managers identified that there were opportunities to practice administering assessments with children prior to the ethics application being approved and data collection into *Salesforce* commencing.

*Training was some months before it actually began to be live, that we could actually record it through Salesforce and the research program. [T]hat did give people time to practice before it went on to that (N10f).*

Conversely, it was noted that assessments were administrated during this time was undertaken with no established pathway yet in place.

*That could have been a little bit awkward because [...] parents could be aware that you were doing something, but you didn't really have a pathway at the time to send them on (N10f).*

From a management perspective, the training was well received, for example:

*The training was great. I think that it was really well rolled out (S16p).*

It was acknowledged that there will typically be some staff members who take a little longer to grasp new training.

*You're always going to have people who struggle a bit but, as far as it goes, I think that it was really quite well done (S16p).*

The role of the Clinical Nurse Educator was named as an important support to the nurses following the training.

*She could catch up people who missed or who couldn't be at a presentation or people who struggled to grasp it (N3f).*

It was suggested that the training could potentially be integrated into the nursing degree course content: "Incorporated into the training at university as well in the post-grad" (N10f) as long as some improvements were made: "Edit the training video a bit better" (N10f).

The managerial staff observed that the nurses could have benefitted from additional training geared towards raising concerns with parents.

*Some people [...] needed a bit more training around how to have those conversations in a way that's meaningful and how to deal more effectively perhaps with parents who are not considering or are in denial about any actual communications skills that their child might need some help with (NW9p).*

#### ***Use of additional resources to assess behaviours during the SACS-R assessment***

There were concerns raised by nurses regarding some challenges with getting children to perform the required itemised behaviours. Management responded by providing kits to all CHaPS centres.

*We brought some toys to do the assessment so that people could feel like it was standardised, so that might have been useful to have that as a resource all the way because some people really like the detail and they feel really like they have to get it exactly right (N2f).*

Another view is that staff should not have to depend on prescribed tools to elicit behaviours.

*I think some people are very reliant on...like we have a tea set, you don't actually need the little tea set, you could use anything, but some people are more reliant on having that tool, and especially in the beginning of the learning (N3f).*



### **Technical issues**

Management reported that staff experienced difficulties with the technical side of the process.

*The feedback I've had from some of the staff is that there are times when the technology wasn't their friend and didn't work as planned (NW9p).*

Interviewees from all three regions mentioned challenges with *Salesforce*.

*Using Salesforce was a little bit tricky for some people who are not so up-to-date with technology [...] a lot of the nurses struggled to do it, and to remember to do it [...] there was a lot of [...] missed data [...] and some nurses needed a little bit of extra help with that. Basically, it was just the technical part of using Salesforce that was the biggest thing, I think, with rolling it out (S16p).*

Nevertheless, the majority of the *Salesforce* issues were addressed in-house through collaboration and with management requesting that nurses establish a routine of doing their e-CHaPS first and then the *Salesforce* data entry. Technology difficulties with the St Giles website and forms were also raised.

*The big one is the St Giles' forms were a bit of an issue [...] their website has been a problem frequently and the referral forms, [...] which they have tried to work on, [...] to refer a child you have to go to the website and then you can do an electronic referral, which wasn't working for a while and then they had an editable electronic form which, again, wasn't working. You couldn't use it [...] you couldn't download it (N10f).*

Completing referrals to St Giles was tricky for some staff.

*Learning to do the referrals probably was technical for some people. I think there was a fair few phone calls to say "How do I do this?" or "This hasn't worked (N3f).*

### **Adequate time for SACS-R assessment**

Originally, nurses were not allocated additional time for SACS-R appointments. Staff feedback to management was that more time was needed, especially if there was a referral to complete. Managerial staff responded by instigating one hour health check appointments to be scheduled.

*The appointment time extensions [...] was a great idea, [...] to start with, people were trying to work out Salesforce and needing that extra bit of time and if somebody needed a referral it's good to have that little bit of extra time (S16p).*

It was suggested that a review of this time change prior to implementation may have been judicious.

*Probably would've been better to have asked and done a bit of a survey and made a bit of an informed decision about whether extra time really was needed. I think we sort of responded to that in a good way to support the nurses so they could have extra time (N2f).*

The extra time was required initially, but perhaps as staff became more proficient and confident with the assessment process and referral completion, the longer appointment time was not needed.

*There were some nurses saying it's a bit of a waste of time now to have an hour for a 12-month check, when a lot of children, you can do it quite easily, they don't meet the criteria, so there's no referral. So I think that was probably done a bit quickly. But probably better to allow the extra time for the people who were struggling a bit, so the anxiety was lower and it was more accepted (N2f).*

### **Wait times**

It was clear from management comments that initially the assessment process was timely with prompt pick up of referrals by the DAT and report feedback to families and the referring nurse.

*The amount of times that I had done referrals, getting reports and feedback from St Giles has been fantastic, really. It's just knowing what's going on with somebody and it's always been quite timely (S16p).*

As the project continued, unfortunately with the increasing demand on the St Giles service, assessment and reports slowed.

*The main issue, I think, for us as clinicians and for parents has been the now quite lengthy delay between the referral, the assessment and getting the report back from St Giles. We've had occasions where we've had to ring St Giles a number of times and to ask, "Has the assessment been done?" And even when the assessment has been done, there's been quite a lag between the assessment being reported to have been completed and us getting a copy of the report (NW9p).*

The CHaPS staff are not only responsible for SACS-R referrals to St Giles but also to other agencies, depending on the presentation of each child. Nurses are expected to on-refer for additional concerns unrelated to the SACS-R assessment, e.g., if a child presents with a motor delay it would be appropriate to refer them to ECIS.

*There's been a bit of confusion, [...] as to where best to refer to and the SACS process obviously is St Giles for further assessment. Because of other issues that have been identified at child health assessments, sometimes referrals are also made to the*

*Parenting Centre, the Child Development Unit, ECIS and so on, and we work very closely with those services (NW9p).*

Concerns were raised that when multiples referrals are appropriate which should happen first? Or perhaps they should all be sent to the various agencies at the same time? Or would it be best to wait and see the outcome of the St Giles assessment?

*The impact of that determines, particularly, say, for the Child Development Unit, do we keep the child on our wait list pending the outcome of the St Giles referral, or do we offer the parents an appointment? So, from that point of view, it's been a little difficult to manage the dual referrals [...] as the project has rolled out and more and more demand for SACS assessments has been happening (NW9p).*

### ***The 18-month SACS-R assessment***

The managerial staff were asked directly about their thoughts around the piloting of the 18-month surveillance. There was resounding statewide support for this assessment.

*I think any opportunity we can get to interact with parents and I think 18 months is often pivotal in terms of speech and development for little ones. So 12 months to two years is a long time in the life and development of a little child of a family. I would be supportive of that (S16p).*

*I would imagine that the data would show us that it was well worth it and then we would adopt it everywhere. I think it's a good idea to pilot [...] because 18-months isn't in our general assessments anymore. So, it's a good idea to pilot it and make sure that it's worthwhile, but I feel quite sure that it would be (N3f).*

Only the CHaPS nurses in the South of the state were directed to administer the 18-month SACS-R assessment. Participants noted that due to inadequate staffing in the North and North-West it would have been impossible to offer it in these two regions even if funding allowed. Additional staff would be required for statewide adoption of 18-month assessment to go ahead. It was also acknowledged that there would need to be some information upgrade on typical behavioural expectations if staff in the North of the state were to administer the 18-month assessment.

*Our nurses tend to be very skilled in the age groups that we do assessments around. So there's probably a bit of a knowledge deficit between one and two because we don't actually see children very often in that timespan, so it's hard to keep your practice up to say "this is what we're expecting, this is what you can expect your child to do" (N3f).*

## **The rollout of the SACS-R**

This theme concentrates on the day-to-day features and workings of the rollout of the SACS-R tool into the CHaPS. Included under this theme is the communication between CHaPS and St Giles and the collaboration with other partners in the project; how the SACS-R fitted in with other screening and surveillance tools that the CHaPS currently utilise; challenges with taking the SACS-R assessments and the referral process into the future; and suggestions for improvement.

Managerial staff were affirming in their comments about the overall rollout of the SACS-R (NW9p; S16p), for example:

*It's gone really well. I think nurses are enthusiastic about it (N3f).*

Using the Likert scale as a conversation prompt, managers were asked how successful they thought the process has been with the CHaPS nurses trying out change in practice and integrating the new practice into routines. All managerial staff endorsed either 'very successful' or 'quite successful'.

*I would say very successful...five (N2f).*

*As of today, it'll be a five. It hasn't always been a five. I think that it was a bit of a slow start with a few nurses, but I would be happy to say today that it's a five. It's been very successful and, yeah, nice one (S16p).*

### **Communication and collaboration with project partners**

Participants made many positive comments about the relationship and communication between themselves and the referring agency (N10f; N2f; S16p). CHaPS received regular feedback from St Giles regarding the appropriateness of referrals. Interestingly, when the referral system was not operating as intended, both parties felt comfortable picking up the phone to do the referral verbally and this further strengthened relationships.

*We've had very good feedback about the accuracy of the assessment and all of that, so I think that's good for their esteem even for our professional reputation. I'm pretty sure that we're St. Giles' highest referral source for children with any kind of developmental delay [...] this has only enhanced that. So we've always had fairly good communication (N3f).*

Whilst the North and South participants' comments aligned with both regions reporting very good lines of communication, the experience in the North-West differed somewhat.

*We've often had to take the initiative to ring and then ring again. We were emailing initially, but we were finding we weren't getting a timely response, so we've now taken to phoning contacts within St Giles. At times we've been told, "Oh, yes, the assessment's been done," or "No, it's another three or four weeks until that child's likely to be seen." "It won't be long now until the report comes." And so we've had to ring again after*

*another month, after their proposed definite time and we just don't have the report. [I]n the last probably six months we've found we've been having to initiate those conversations on a regular basis (NW9p).*

Besides CHaPS and St Giles, other project partners include UTAS and health service departments. Participants' comments varied, with some reporting good and positive communication.

*Really well I think, because we've had several presentations. [H]ow to do the testing and the education [...] how to make the referral and use that actual electronic process and we've had people come and sit with nurses and help them through that when they've struggled. So that's pretty full on from us, like we don't normally always get that level of follow-up when we introduce something, especially not from external providers (N3f).*

Others viewed the relationship with UTAS differently.

*I think the communication with the Uni has been very positive. I think that's a good relationship probably to build on in the future even more. Could be a bit more closer relationship between CHaPS and the Uni (N2f).*

### ***SACS-R fitting in with other measures***

The managerial staff were asked: "How do you see the SACS-R fitting into the other screening and surveillance measures you currently use?" As a group they were agreed that the SACS-R "fits really well. Absolutely value adding, yes, definitely" (N2f) and "I think it fits well in what we do and it's probably the best place to have it" (N10f). Additional responses highlighted how its use increases staff confidence and it supports and connects the tools that are already in use to assess a child's development (N3f).

*I think they fit in quite well with our other tools. It's a little bit different, I guess, because it's not something we sit and just tick off. Like our PEDS, we tend to sit and do those with parents and they circle things. Whereas with SACS, [...] it's more like working to the interview. But I think that as far as a tool, it's excellent and having those sheets of paper and bits and pieces to work off in the start, it's really helpful to see what we're expecting kids to be doing. A lot of it sort of goes hand in hand with your eye contact and attachment [...] it's all stuff that you can do all at once (S16p).*

### ***Sustainability of the model***

All participants viewed the ability to continue with the administration of the SACS-R assessments and the referral pathway to St Giles as an integral part of the service that CHaPS must continue to offer to the community to ensure the early identification of developmental delays. Nonetheless, several management considerations and challenges were cited, including staff resistance (referred to above) and government funding (S16p; N10f; NW9f), especially if 18-month assessments were to be included statewide.

*It's probably a funding, managerial kind of one [...] especially if we wanted to add in the 18-month, [...] that's not a current check we do. How long do we allocate [...] the number of babies [...] the number of hours the nurse needs [...] all of the checks per baby plus the people that have complexities, plus the travel, plus the education. [Y]ou're probably talking half an hour and if there's six and a half thousand babies born a year, then that has an impact on...so would we drop something off, would we ask the government to fund us for more FTE, that kind of thing, it's at that level (N3f).*

Managers expressed interest in an evaluation of the actual time required to administer the assessment to each age cohort, along with referral where necessary. The thinking was that an audit would enable an informed approach from the beginning, provide realistic appointment time duration and eliminate wasted time.

Data records were also hailed as a challenge moving forward.

*Trying to work out how we're going to data this stuff once it's all finished. I think that's the biggest thing for me. As far as the implementing it and continuing with your nurses [...] using it in their practice, I think that's really quite well-established. How we're going to record this data now, [...] I'm not really sure how it's going to go and how it's going to look. This is kind of what we've been doing for a couple of years now. And it works so well and we've picked up so much and it's just really made a difference (S16p).*

Comments were made about the incorporation of the SACS-R into the electronic records. This would incur further costs that would require additional funding.

*So getting that changed, that will be a cost change to it. Would have to go back to the vendor and get a section put on. Otherwise, we would have to print paper and then scan it in, which is also a cost, although I don't know if it's cheaper, but it's a lot more staff time (N10f).*

In addition to the challenge of how the data will be recorded is consideration of how families will be referred on for further assessment in the future.

*The two things I think are, internal, is how do we record it and external would be how do we refer it, what referral pathway is going to be the thing (N10f).*

Managerial staff are keen to see the outcome of this research so planning for the future can commence with the knowledge and approval of the wider community.

*Once we've got the evidence that it is best practice and supported by the research, then I think there'll be a high degree of acceptance (NW9p).*

The future holds some uncertainty for management regarding length of assessment time, staffing, the recording of the data and the referral pathway following the end of this research project.

*Obviously Salesforce won't exist, so we need to record it ourselves in some way and then, yeah, the referral, [...] some kind of pathway needs to work out, like, which is the best way to do it in each region, I guess. But that'll be the hitch, I guess, that recording of it and the referral pathway. We've set up a big expectation, [...] with the public and with ourselves on how well that worked (N10f).*

#### **4.3.4 Internal stakeholders - group 3: ASELCC and St Giles DATs**

This group of stakeholders is comprised of two agencies: Autism Specific Early Learning & Care Centre (ASELCC) and St Giles Developmental Assessment Team (DAT). The interview provided ASELCC staff an opportunity to share their experience and perspectives about working with a wide range of young children. Some of the children are involved in the ASELCC service without a diagnosis but they require intervention and further monitoring. They may have autism-like symptoms and are awaiting assessment by CHaPS or they have had their assessment with CHaPS and been referred to St Giles DAT and in the meantime attend the ASELCC. There are also children there who have undergone the SACS-R assessment and subsequent referral and assessment to the St Giles DAT and have a diagnosis. From a St Giles DAT staff perspective, the interview enabled them a chance to share their experience and understanding of receiving referrals from CHaPS for further assessment of young children with high likelihood of autism.

Twelve participants consented to participate in an interview, six from ASELCC and six from St Giles DAT (three from the South and three from the North). All six of the DAT interviews were conducted face-to-face at the participants' place of work. Three of the ASELCC interviews were held over the phone in a noise-free room in an office location in the Hobart CBD to the participants' workplace or car phone ("hands-free"). The other three ASELCC interviews were completed face-to-face at the participants' workplaces.

Reflexive thematic analysis (Braun & Clarke 2019) of the internal stakeholder, group 3, ASELCC and St Giles DAT staff generated five themes specific to their two organisations: impacts on professional practice; parents' experiences; system issues; the rollout of the SACS-R; and the sustainability of the model. The findings from the ASELCC and DAT interviews are presented under those five themes. A summary of the internal stakeholder (group 3) major themes and sub-themes is displayed in Figure 4-7 below.

## Internal Stakeholders – Group 3: ASELCC and St Giles DATs

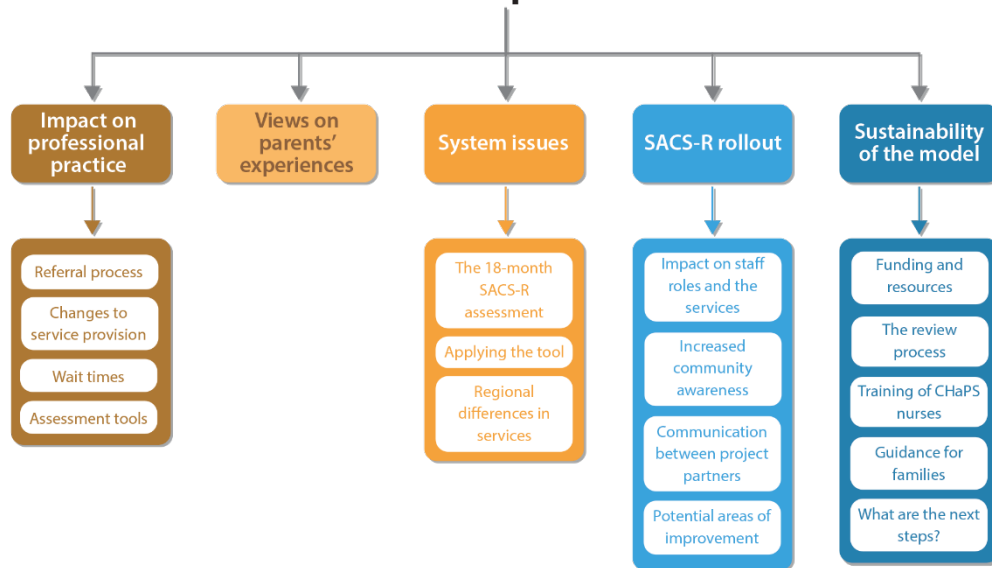


Figure 4-7. Summary of internal stakeholder (group 3) major themes and sub-themes

### Impact on professional practice

This theme encapsulates the effect that the SACS-R implementation had on the roles of ASELCC and St Giles DAT staff. Contained in this section are staff experiences of the referral process and their comments pertaining to how the quality of the CHaPS referrals impacted their work. As a result of the SACS-R surveillance, it was necessary to make changes to the services that both these organisations provided. The topic of wait lists was discussed and how they affect all parties involved – the child, the parents, and the staff of the two agencies. There was also discourse in relation to assessment training and the pros and cons of ancillary assessment tools.

#### *Referral process*

Participants were directly asked about their experiences of the referral process by CHaPS nurses to St Giles DAT. The question was interpreted and answered in a variety of ways. Some participants replied in terms of changes to their workload.

*It has saved me some assessments, so that's been good. It definitely helps us to have somebody doing that screen beforehand and identifying children at possible risk and then we obviously do further assessments, like I do the ADOSes here (NWA1f).*

Some highlighted a lack of flexibility with regard to increasing staff because there was no surplus funding to access.

*The amount of work and the amount of referrals that were coming and the amount of increasing waitlists as we saw more and more referrals coming*



*through without the capacity to upscale our service delivery because we didn't have any additional funding (NWA5p).*

Others stated the SACS-R increased their knowledge and skill set as well as that of the nurses and parents.

*We've increased the knowledge of our CHaPS nurses and of families as well. We've seen an increase, probably, in CHaPS referrals for even older kids because they've picked up on things so it's been across the board. I know it's meant to be a autism screener, but it's picked up lots of language delay and global developmental delay that from a clinical perspective we're very happy to be picking up at 12 months, 24 months because those kids need speech support, they need occupational therapy, whatever it might be. The improvements in those children because the ones we have been able to review we have noticed improvements because they've been - just mum and dad are more aware and they've been able to access services and seek some more support (NSG1f).*

There was praise for the CHaPS nurses, and participants saw that they were providing additional, new referral support for families.

*Involving the CHaPS nurses has been really good and, given parents, I suppose, a gentler way in because I think CHaPS nurses usually have good relationships with families, where often when people see paed's, it's often very rushed and people say your kid might have autism and then suddenly you've got a referral and it's all a bit like what's going on? Where I think the CHaPS nurses have alleviated some of that (NSG1f).*

As receivers of the referrals, participants welcomed the new process.

*The referral process was really simple and delightful when the timeframes were better, [...] you've just seen your CHaPS nurse [...] a month ago, this is the assessment, this is the process that's going to happen (NWA5p).*

It was expressed that there was variability between the CHaPS referrers.

*Some of the CHaPS nurses are more consistent than others. Some are very good referrers. Some, we don't hear from very much, so I'm not sure whether they're just not seeing the children or perhaps it might be to do with the way that they administer the SACS. With individual SACS nurses there might be just perhaps more training required or just maybe they will refer more often once they're more experienced. But they've had a fair bit of time with it (NWA2f).*

Participants stated that the quality of the referrals received from the CHaPS nurses were mixed. While some referrals contained adequate information, others had insufficient content to go ahead and contact the parent. If the referral held inadequate information or evidence, a staff member would need to contact the referring nurse to clarify and discuss the referral, creating additional work.

*Referrals varied immensely from particular CHaPS nurse to CHaPS nurse in terms of the level of information that was included in the referrals. There were some CHaPS nurses where like it was no, yes, no, yes, no, yes, no comment, no other kind of information at all. There were others who provided really lengthy comments and observations that supported the observations at the back (NWA5p).*

Some participants shared a different experience, reporting that all the referrals they had received were suitable.

*Every referral we got from the child health nurse was appropriate. I can't think of any that weren't. So that was interesting, that all the children got assessments that they needed, whether that's some kind of delay or autism (SSG1f).*

Some children may have been referred at a follow-up SACS-R assessment rather than at their initial check. This may have occurred for a variety of reasons.

*I think we may have missed some that needed to be assessed because sometimes when the child came in for review, we'd see the previous SACS where it was all marked typical or something and then maybe it was a different child health nurse or they got more education or the parents started reporting differently and then they actually got referred (SSG1f).*

It was noted that CHaPS referrals to the DAT and other services have improved over time. For example, some nurses transferred their learning about atypical development across age groups as their experience with the tool developed.

*I think CHaPS nurses were generally inexperienced of referring to us. But, with support, they're really good now. The quality of the referrals has got much better. The CHaPS nurses' understanding of what autism or developmental delay might look like, they're applying that to the older children – like at their four year old checks. So we're getting a few four year old check children come through [...] they've gone, oooh, there's still something going on there, we'll refer because they now know, they're a bit more aware of what services they can refer and we do take those older kids as well (NSG1f).*

Some staff raised concerns about over-referring of children, particularly in the North-West.

*Especially when we were starting, where kids that were typical in the SACS still got referred through because either mum or dad was super, super concerned and said, no, no, we need help, or there was a history of autism in the family and they came up as typical, but the CHaPS nurse was either pressured or felt they needed to refer anyway. So those kids we saw early on (NSG1f).*

Another suggested cause for over-referral was that nurses and parents perceived that an additional service had been created that could alleviate concerns. Rather, the SACS-R led to a second referral DAT pathway being created. There was the original referral pathway of

pre-kinder kids, who are typically aged between three and four years old and then the SACS-R referral pathway of children aged between 12 and 24 months old. Now there were two assessment pathways with assessments being conducted by the same staff members from the same existing service.

*There's been a lack of services, particularly in the North-West, so they went, "oh, awesome, there's someone going to assess, we don't have to wait". So, traditionally, TADS, who have a massive 12, 18 month waitlist, at least, are the only service that would assess autism and I think they went "SACS project, young kids, oh my God, this is amazing", and we got a lot of referrals (NSG1f).*

Participants described variable parent experiences of the referral process. Some thought the new process was beneficial for parents who were worried about their child.

*It gives parents somewhere to go. Just that early way to check symptoms they might be worried about. Then maybe more of a pathway to follow after that...getting them into the pathway earlier (NWA1f).*

For some families it was apparent that the referral process had not been explained clearly to them. The St Giles staff had become aware of this and knew that they needed to go gently when they made their initial contact with families about scheduling an assessment.

*Most of the CHaPS nurses now are quite good at saying this is because your child is having social communication difficulties. There has been a few families that have come in and we've gone, "One of the things we're looking at today is autism," and the family goes, "What are you talking about?" So those families have probably had a bit of a rougher ride because they've been blindsided by this knowledge that, "Oh, you're assessing autism." It doesn't happen very often, but they stick in your mind (NSG1f).*

An additional result of some parents not being appropriately informed about the referral, meant they came alone to the St Giles assessment for their child.

*If they knew they were coming for an autism assessment, working parents may have taken the day off work if they had realised that it was going to be something that was as significant as it was (NWA5p).*

Not only did some parents come without a significant other they also came unprepared emotionally for the feedback.

*A shock diagnosis because they didn't realise that they were coming for that purpose, and so I guess some disbelief and some upset because they were coming to an assessment kind of not entirely briefed that it was going to be an autism assessment (NWA5p).*

Cultural background was perhaps another factor that impacted parents' understanding of the day of the assessment and what it entailed.

*Sometimes those people were from non-English speaking backgrounds, so perhaps hadn't fully understood, [...] that it might be good to have a second person there or implied that this is going to be a fairly full on day, but wasn't explicitly said or was hard for people with different vulnerabilities, so even non-English speaking background or perhaps less educational level, you know, where it came as a much bigger shock when those things happened, versus, clearly for families who knew what they were coming to and [...] were having some concerns about their child, particularly those who had older children who have autism (NWA5p).*

### ***Changes to service provision***

As a direct result of the SACS-R, much younger children were referred to both ASELCC and St Giles. ASELCC will accept referrals and provide intervention for any child who is of pre-school age and displaying autistic features.

*We definitely received referrals for children who were much younger than what we'd previously been receiving because they had gone through that pathway. And a lot more children. We seemed to have quite a few of them come through at once (NWA4p).*

The St Giles age range for assessment and intervention is zero to five years of age, with the staff typically working with three and four year olds. The use of the SACS-R meant that staff were experiencing younger children coming though.

*We certainly weren't seeing children at 12 months of age, and didn't often see them at 18 months of age. So that has been a lovely opportunity for me to work with children of that age and to become more familiar with the assessment protocol of a toddler module, [...] a great opportunity to consolidate learnings in regard to all the assessment tools (SSG2f).*

Catering for those younger-aged clients required both organisations to make various service changes. One impact was the need for extra furniture and a change to facilities.

*As the number of younger children coming into the ASELCC service increased, additional cots were needed: We've got more sleepers now. The young ones do sleep a little bit (NWA3f).*

Accommodations to programs were another service adjustment required.

*Programs that we would use to address self-regulation [...] might be designed for older children, but we have found ways of modifying programs. The Alert program self-regulation is from six to eight, sort of the starting age. So we were already modifying it down to sort of four year olds for one of our rooms (NWA1f).*

Another effect of having younger children accessing services, and/or being assessed, was that staff needed to reacquaint themselves with knowledge around the behaviour of a younger cohort.

*Refreshing in our own minds what children at that age should and shouldn't be doing because obviously we're probably used to a bit of older children and then to have younger children (NWA4p).*

The SACS-R referrals generated more collaborations between professionals. Participants reported increases in case conferences for collegial support and case formulations.

*That process of having a case conference, [...] using that here with child health nurses as well has been a really good strategy. There's certainly more people talking to more people [...] even though they might not all be sitting around a table, certainly you've got emails with several cc'd in and there's a track of people replying and things, so it does seem to be more inclusive with the SACS-R, absolutely (NWA2f).*

Staff were very positive about the relationships across agencies and the collaboration between the ASELCC, ECIS, CDU, DAT, CHaPS, and the Parenting Centre (NWA2f; NWA5p). There is close communication during face-to-face meetings, over the phone and via email.

*The communication has been quite open and honest and bi-directional. So everyone has been quite reciprocal and receptive to working towards whatever it is that we're working towards, whether that be integration or early identification for supports (SSG3f).*

Prior to the SACS-R, the North and the South DATs used slightly different diagnostic approaches to assessing young children. The SACS-R rollout led to a merging of diagnostic approaches where the assessment is completed in one day, including the diagnostic discussion and feedback. This approach provided a consistent way of conducting assessments across the state. Some participants viewed this model of assessment as having distinct advantages for parents, staff, and children.

*I really liked that the parents didn't have to wait for a prolonged period of time for the different assessment components to be completed and for the reports to be written and that sort of thing before they got feedback. And it was quite neat, as well, because it was all fresh in our minds that we both saw the child in the same day, got all the information together and gave the feedback back to the family, so I liked that it was quite a smooth process (SSG1f).*

However, clear disadvantages of the merging of diagnostic approaches were also noted.

*That could be very overwhelming for both staff and families [...] there were lots of factors to consider with the young toddlers, like they would normally have a day sleep and then, impinging on that time, the children would get so tired by the end of two assessments. And the staff, [...] it was*

*quite exhausting a lot of the time to feel that pressure to get an accurate assessment done, give a full developmental assessment and then the ADOS (SSG1f).*

One participant was not in favour of the assessment model.

*The clinical process of an assessment should be the parents' journey. Quite a quick process for some families coming in that are not necessarily expecting a diagnosis and then leaving that day with a diagnosis, all within their consent, but not necessarily for their readiness to process (SSG2f).*

Due to the influx of assessments, staff anticipated that they would be required to spend an increased amount of time on writing reports. However, given the younger ages of the children being assessed, staff discovered that their reports could actually be briefer as there is less to talk about because there is less developmental history to cover. During the time of increased referrals, considerations and adjustments were made to ensure that parents were supported. For example, ASELCC and St Giles staff supported parents with completing NDIS applications.

There were some staff changes that occurred during the project which resulted in breakdowns in communication. For example, two UTAS employees who occupied key roles in communication and cross-checking of referrals left midway through the project.

*The person who was doing the bulk of the data cleaning and the person who was leading the project, both leave midway through the project, [...] that hasn't been helpful in terms of continuity [...] left a space in terms of the process of communication (NWA5p).*

### **Wait times**

In line with increased referrals, an inevitable consequence was increased wait times. Families were on long wait lists for ASELCC intervention and for assessment by the St Giles DAT. It was suggested that the projections for assessment were misjudged, and even when that became known, the government did not respond to the increased demand.

*Waitlists, that's not been ideal. Predicting the number of assessments that needed to occur, [...] vastly underestimating what was going to be required because we've now ended up with a 12 to 18 month waiting list for kids to be assessed and if we had truly estimated those things properly, we would have not been in that position. Those wait times have been consistently an issue for the last more than 12 months and that there hasn't been any move by the State Government to work to rectify that (NWA5p).*

The wait lists grew as time went along. At the beginning of the project, families could expect an assessment within weeks. At the time of writing, waiting times are about a year.

*At the start it was very quick. We'd get a referral, they'd be seen within a matter of weeks, where now it's months. So that's becoming a challenge, so there's more waiting and more uncertainty (NSG1f).*

The waitlists for enrolment to ASELCC were thought to be due to the flood of younger children.

*It did mean that we had a bit of a waitlist because obviously one of our rooms is for the much younger children and that room kind of filled up quite quickly. We started having more children in that room per day. So usually it was five children per day and I believe we went to six per day because the demand was so great for that room, but also with the waitlist (NWA4p).*

When people are waiting for long periods of time it did not just impact the referral processes, people's mood and well-being were also affected.

*I know a lot of families can get frustrated with the wait time at times because they feel like they're not moving forward without a diagnosis. Even though they are accessing support, they still don't have that answer of is it autism or isn't it (NWA6p).*

Wait times also had an affect on how busy and stressed the staff were.

*I work in the red room and that's the youngest room that we've got, and the youngest we've had is 18 months. So 17 or 18 up to three years, and our room is super busy, super busy with enrolments (NWA3f).*

*It's definitely been incredibly stressful for the team in terms of meeting expectation of all of the stakeholders in terms of the timeframes, managing waitlists, that has been really challenging (NWA5p).*

Some staff were disheartened by the number of families waiting for services.

*It is a huge backlog. It's massive - it's very stressful for us because initially we were providing those assessments in a timely manner and now we're not. So, yeah, it's not a great feeling (NSG2f).*

Staff found it hard to inform parents about the waitlist.

*Having to talk about like wait times with families is a really kind of difficult thing when you're quoting a wait time to a family that is longer than the child has been alive (NWA5p).*

Others were more pragmatic about the situation.

*The waitlist is always tricky. I'm sure more people have said a shorter waiting list is always better, but I can understand why we have it. I guess it's hard to sort of isolate the SACS project from all the other support our children have (NWA6p).*

Staff shared their views about waiting times from a parent perspective. They heard that a parent may perceive that their child's presentation may improve during the period of waiting for an appointment with St Giles. Thus, they no longer see the assessment as necessary and do not wish to pursue it.

*It became more difficult over time if we were doing an assessment that was based on a CHaPS assessment that had happened 12 months ago and they're saying we've had lots of improvement and then I don't think I really need to come for an assessment (NWA5p).*

Some staff viewed the North-West coast families as being well-catered for during the waiting period in comparison to their regional counterparts.

*On the North-West, like our children have access to a lot of other support so that I don't know if that's consistent with what is happening across the state, particularly with the ASELCC being on the coast (NWA6p).*

There was a suggestion that more flexible staffing arrangements could help to manage wait lists.

*It would be nice, at times, to have had the flexibility to increase staffing levels and then reduce them according to need, some fluidity there to maintain waiting lists. I guess, the idea of an early assessment is that you get the early assessment and early intervention, but when waiting lists grow to 12 to 15 months, you've just lost your edge, you're not achieving what you set out to achieve (SSG2f).*

### **Assessment tools**

The ADOS-2 and the ADI-R were the two approved standardised measures that the DAT were to use for assessment. Prior to the rollout of the SACS-R the ADOS-Toddler module was rarely required but now that the younger children were coming through it was utilised regularly.

*The ADOS-Toddler, we hadn't had a lot of experience in that before SACS, but now we have a lot (SSG1f).*

The staff expressed that they had not been supported in the ADOS training for the project as they would have expected or liked.

*I think it was disappointing to us that the research project didn't fund everyone to have lots of training of the ADOS, but some of that resourcing we were required to do (NWA5p).*

The St Giles DATs use the Mullen Scales of Early Learning (MSEL) as a supplementary assessment when they need to assess whether a child has a developmental delay. The MSEL is a developmental assessment used to assess language, motor, and perceptual abilities in children from birth to 68 months. The staff were not in favour of the use of the Mullens. An



alternative assessment tool that is valued by the DATs is the Griffiths Mental Development Scales (GMDS). It provides an overall measure of a child's development and individual profile of strengths and weaknesses across five domains in children aged two to eight years. Participant SSG3f, for example, completed the GMDS training and found the assessment tool very useful with SACS-referred children.

### **Views of parents' experiences**

The participants' perceptions were that for the vast majority of parents, the SACS-R experience and referral process has been positive.

*Families have had access to early assessments. So whether their child has autism or doesn't have autism, the fact that they've had access to an early, multidisciplinary assessment that can identify a child's kind of strengths or difficulties and put them on the pathway to some early intervention that has been positive (NWA5p).*

The CHaPS nurse role was identified as a critical one in the parents' journey through the process. Not only did concerned parents seek out the CHaPS nurse but the nurses were able to communicate the process and reassure the family of a referral pathway to investigate further.

*Quite a lot of families have gone to CHaPS nurses because they were worried and wanted help, so those families have been really happy that they're getting an assessment when their kid is so young. And then there's probably been some that didn't know anything was wrong, but when the CHaPS nurse explained, they went, "Oh, okay, we'll get it checked out because if you're concerned maybe something is going on." I think most families have had a relatively positive experience (NSG1f).*

Going through the SACS-R process enabled parents to garner early support.

*Being able to go to a CHaPS nurse and the CHaPS nurses having enough information to get families in contact with people who can support them I think is the most important thing, really. And I know that a lot of my families are very vulnerable and need as much extra support as possible and that's been supported through that process of getting a diagnosis and just even having the conversations about your child is showing characteristics of autism is being well done at the moment, particularly in the North-West coast (NWA6p).*

In contrast, some participants perceived the parent experience of the process from CHaPS health check to assessment as challenging.

*I think a lot of them felt quite overwhelmed and confused by it (SSG1f).*

*There are some families that - and I think that no matter who had referred them [...], would have had a challenging time of it [...] they just did not*

*even have autism on the cards. Even if the CHaPS nurse has said about autism, they've come to us still believing that, no, there's nothing going wrong. And they're probably among the most challenging ones to deal with and so we often do a lot more follow-up with them, so additional feedback or follow-up phone calls. And some families don't want to engage once they've heard that news, and some families need some time to take it in and then they're like, okay, what do we need to do now? We've had a few really disappointed families because they believe their child has autism (NSG1f).*

Some participants communicated that many parents needed clarity regarding services, that is the who, when and how they were to connect with support services. Staff could see that they needed assistance.

There were families who already had an older child with an autism diagnosis. With that child they had experienced an arduous process of waiting for an assessment, sometimes over years. Staff reported that these parents were grateful for the SACS-R process. However, they also stated that some of those parents were upset about their earlier experience.

*For those families where it's been a really positive experience compared to an older sibling, but actually that has brought up feelings of grief and frustration as well because why has it been so easy for this one and it was such a palaver for the other one, or that I'm still on a waiting list for the other one and I'm still not getting sessions for the other one (NWA5p).*

Participants reported that parents responded in different ways to receiving or not receiving a diagnosis from the DAT. Overall, receiving the diagnostic outcome was viewed as a positive experience for most families, although there were some who found it challenging. Some parents were taken aback by their child receiving a diagnosis.

*A lot of our parents go through a bit of an initial shock phase and that wanting to seek out a little bit more information, and often they do come to us in that period for more information and more reassurance and just for general support. Having those discussions with parents that we do feel like your child will more than likely get a diagnosis, it's still quite a shock and a big step forward with that label (NWA6p).*

There were other parents whose child was found to not have autism but to have another diagnosis.

*But has some other language delay or global developmental delay or the like, the experience of those families has been really positive as well because we've been able to give them an assessment that kind of put some of the documented strengths and weaknesses of their child on paper that allowed them to kind of go the next step to get supports either from ECIS or from the ECEI pathway or the like (NWA5p).*

Participants viewed the assessment day itself as demanding on the parents and the children.

*I think a vast majority of families would have found it a very big morning, the three hours of assessment, and they probably left quite exhausted. Some families would have been here four hours, maybe even five hours if they stayed on the premises for a bit of a break before we gave feedback (SSG2f).*

DAT staff shared that because the children were being picked up at a younger age by the SACS-R, it was much easier for them regarding the assessment process as the atypical behaviours were easier to recognise. In addition, they viewed that the parent response to diagnosis of a younger child was overall, more readily acceptable.

*It's probably a bit quicker and, generally speaking, families have seemed quite receptive to hearing that their child has autism and it just seems to be quite different compared to when we've given diagnoses to older children, it's much more complicated, it takes a lot more time and families, it seems a bit harder for them to come to terms with the diagnosis (NSG3f).*

Parents were faced with diagnostic outcomes during a period of time where the funding models were changing from HCWA to the ECEI/NDIS model. Historically, the DATs had assisted parents with the next steps of accessing supports and now they felt they were unable to help in the ways they had previously.

*Whereas HCWA, if you got a diagnosis you would be eligible straightaway. We don't know how much funding you'll get, you're going to have to work really hard to advocate for your child's needs. It's just created so much more angst for families and, from our point of view, it's like, okay, we've diagnosed this family's child with autism and we're sending them away to go through more administrative bureaucratic hoops (NSG2f).*

## **System issues**

This theme contains three aspects of the SACS-R process. First, ASELCC and St Giles DAT staff identified concerns regarding the removal of, yet the clinical importance of, the 18-month SACS-R assessment. Second, they also highlighted how critical it was for the tool to be administered in line with the training protocols. Third, they emphasised the positives and negatives of service differences across the state.

### ***The 18-month SACS-R assessment***

Participants were very clear in their support of the 18-month SACS-R assessment. They stated that an assessment conducted at that age was critical in identifying children at high likelihood of autism and developmental delays.

*There's so much development between 12 and 18 months [...] if you're waiting all the way till 24 months that's a big gap if their language hasn't developed. [S]tarting to walk and talk, we expect more in terms of their*

*social communication skills, using more of the eye contact, gestures should be developing and that's not always the case by 12 months, but it's not necessarily a concern at 12 months, but it would be, say, at 18. But if wait till 24 months, well, then we might have missed out on a period of time. I think it's a really crucial check for the CHaPS nurses to be doing for sure (NSG1f).*

Although referrals come through for 12 month old children to be assessed by the DAT, it is unusual for them to receive an autism diagnosis at such a young age. At 18 months, the team is able to diagnose with absolute confidence.

*That timing is crucial. With the 12-month surveillance tool we often can't necessarily diagnose children at that age, whereas at that 18-month there's a definite profile. It's a lot more robust in terms of picking up those children at risk. All the research shows that that's the time when you can more effectively diagnose a child at risk of autism and I don't understand why that 18-month check was taken out, other than it was a financial decision. But we're missing those children. They could be accessing services six months earlier, at least six months earlier (NSG2f).*

From a family perspective, participants identified that it could be comforting to parents to have their appointments six-monthly and not have to wait a long time between appointments. Staff acknowledged that it is possible that a child might not be identified as needing further assessment at the time of their 12-month check. Therefore, the 18-month assessment also provides a safety net so that children are not being missed.

*The 12-months SACSs were being done and then being able to check that again at 18 months, I think that would be good to keep going. And obviously if you get families who miss an appointment and then they just go to their next appointments, if that's the 18-month one, the serious one, yeah (NWA4p).*

### ***Applying the tool***

During the training the nurses had been told that they needed to directly observe the child displaying the key behavioural items. Participants reiterated the importance of this directive being followed so that every assessment was accurately recorded. If the instruction was not followed it had the potential outcome of children being missed. This was even more critical in regions where the 18-month SACS-R assessment was not part of the rollout. For example, if a 12-month SACS was administered and the child was entered into *Salesforce* as 'typical' and then at their 24-month assessment they were found to be 'atypical', the child's data was examined for interrogation.

*There were often qualitative comments about the child or some question marks about the administration of that SACS at 12 months. So there'll be things like Mum reported blah, blah, blah, and you kind of go, well, based on the fact that that Mum reported, then they obviously didn't do that*

*because they're writing in the comments [...]so it didn't happen in the CHaPS session, [...] if the CHaPS nurse has said that, no, they didn't do that, they would have been flagged at 12 months (NWA5p).*

It was noted that although the SACS-R is designed to be a surveillance tool for autism it has the additional value of identifying children who present in an atypical way.

*I'm actually clinically quite happy to have speech kids coming through and kids that might have a developmental delay, those kind of things, because, for me, they're just as disabling as having autism, in some cases more, if you've potentially got a severe intellectual disability versus autism without significant comorbid developmental delays. They need to be picked up. And parents are just as concerned about intellectual disability as they are about autism [...] clinically I think it's a really good tool (NSG1f).*

### **Regional differences in services**

Numerous staff commented on the service options available to families across the three distinct regions of the state of Tasmania. There are clear differences in each region and accessibility depends on where a family lives. Some participants felt that families on the North-West coast had access to more specialist services.

*I think what we probably have a little bit more of than other places that I have been to is the support in childcare centres. So we offer actually satellite programs and we offer training to childcare centres and I think that's probably an area that would be more supported with the SACS project and with the CHaPS nurses because often we're going in and saying to the childcare centres - like they'll say, "oh, we have concerns about this child" and we're saying "have you asked them if they've had their health check up, have you sent them to the child health nurse, have you supported them through that?" and they'll go, "oh, no" (NWA6p).*

The fact that the initiative was statewide was particularly beneficial for the families living in the North-West of Tasmania.

*For the North-West coast that had a particularly positive impact because previously there was no pathway directly from a child health nurse into diagnostic assessment (NWA5p).*

*I've seen direct benefits from all my families that I work with in the age group that the SACS-R supports. Particularly on the North-West coast when it is quite tricky to access people [...] being able to access diagnoses and get excellent support from the CHaPS nurses [...] they have some skills to be able to refer to the right areas (NWA6p).*

By way of contrast, other participants viewed that the families residing in the North-West were at a distinct disadvantage in comparison to the North and South of the state.

*In Tasmania we've kind of become used to, sadly, a bit of a postcode lottery and depending on where you live as to which services you might have access to (NWA5p).*

Regional staff shortages impact the North-West's ability to offer services at the same level as the North and South, and means that the established North contingent is required to also cover the North-West's assessment needs. Some accept the fact that the North-West is unable to offer the same level of services as other areas in the state, but nevertheless, they are appreciative of the collegiality that they experience.

*One of the beautiful things about working up here is that you might have services thin on the ground, but the ones that are here work well together (NWA2f).*

### **The rollout of the SACS-R**

This theme encompasses the practical elements and workings of the rollout of the SACS-R tool into the CHaPS. This section opens with a presentation of the participants' overall experience of the rollout. Then four themes are presented as follows: the impacts on staff roles and the services; how the use of the SACS-R has increased community awareness; the lines of communication between the project partners; and suggested areas for improvement to the rollout process.

Participants were generally very positive about the overall rollout of the SACS-R, and the fact that it was a statewide initiative, for example:

*I think it's been really great. It's nice to see that early intervention can happen at an early age, more so than children establishing their set routines and guidelines and parents kind of crying out for help when they're like four. And like it's never too late, but it's harder to change some of those restrictive behaviours when they're a little bit older (NWA3f).*

*It's a steady stream of referrals, it's a good referral pathway (NWA2f).*

Others, although enthusiastic, were mindful of the challenges that had been faced during the SACS-R project rollout.

*I've really enjoyed working with SACS, despite all the difficulties. I think it's an amazing project, a very good surveillance tool and I hope it gets rolled out Australia-wide (SSG1f).*

Some staff thought that a regularly updated manual would have been helpful to assist staff in navigating the changes that were made throughout the project.

*It's been a little chaotic with evolving processes and it would have been great to have had an evolving assessor's guide [...] in terms of protocols and exactly what's to happen because there were numerous changes along*

*the way that were, perhaps, communicated randomly over emails, rather than all popped into one document (SSG2f).*

Prior to the SACS-R rollout, children on the North-West coast with concerns could only go through the Child Development Unit (CDU) pathway. Establishing a single, statewide agency responsible for accepting referrals, conducting assessments, and storing all the related information was cited as a strong positive.

*The fact that we have had one organisation doing all of the assessments has worked well [...] there's been consistency in terms of the implementation of the assessment process across the state. Really have a good sense of the referral numbers and the speed with which we're getting through the referrals or not, as the case may be, and the fact that kind of all of that information is contained in one location has been useful (NWA5p).*

Some staff expressed that the rollout was not as efficient as it could have been.

*A lot of the details perhaps could have run more smoothly. That's just working out the logistics of such an enormous project in a sort of practical, real-world setting of the clinic (SSG1f).*

There were various comments about whether the CHaPS nurses embraced the rollout from the start. Nonetheless, once the nurses got through the initial implementation phase the rollout moved along successfully.

*Once we were in the throes of that kind of research project, that was relatively smooth sailing with the CHaPS nurses insomuch as there was a really established process, they knew exactly what they needed to do from the perspective of administrating the actual SACS, but also then the kind of data entry process around putting it into Salesforce and making referrals and all of those things (NWA5p).*

### ***The impacts on staff roles and the services***

ASELCC and St Giles DAT staff described how the introduction and use of the SACS-R had impacted their role and service. An increase in staff confidence was reported. Paired with increased confidence, the tool provides a new way of raising concerns with parents.

*People are now more confident about bringing up concerns regarding developmental delays and talking about it from a social communication developmental delay, rather than having to name up the word autism, so it's given them a way of introducing their concerns to the families without feeling as awkward as they might have done in the past (NSG2f).*

The DATs were flooded with referrals and they were unable to provide a timely response. The St Giles North DAT were also responsible for coverage of the North-West and responding to referrals from that region.

*It's inundated us with referrals and we didn't have enough funding and staffing and resourcing to actually provide the service that we needed to do, [...] they're still now waiting for at least eight to 12 months before they get the assessment because we don't have enough staffing to see them in an appropriate time frame. So that's had a huge impact on us in terms of stress levels, and we've had to travel across the North-West of the state because we don't have staffing in the North-West, so our role, I suppose, has expanded to the North-West, but we actually haven't been funded or resourced for that. So, yes, that puts pressure on us as well (NSG2f).*

Although the DATs have been assessing and diagnosing children for years, the SACS-R pathway meant they were sometimes the first person to speak about the possibility of autism with a child's parents.

*We had to get used to talking about autism with families up front from the beginning. They're coming in and we actually had to say, "Your child has been referred to us with social communication difficulties and children with social communication difficulties might have those difficulties for a reason, and some of those reasons might be autism, global developmental delay, language delay, and we're going to have to look at all of those today." So that conversation, initially, was quite hard for us because we'd never actually mentioned autism unless it had been raised before. So, yes, we found that a bit daunting, but now we feel comfortable in talking to parents about this (NSG2f).*

### ***The use of the SACS-R has increased community awareness***

Some participants viewed the waitlists as a factor in increasing the awareness of the SACS-R and the associated services.

*We've seen a lot of younger referrals come through and it has made parents more aware, and I think the education and the awareness that everybody is getting from having intervention at an early age is quite valuable. Never had a waiting list up until now. I think it's the awareness that's out in the community now. I think people are more aware or more accepting, as well, and know the pathways to take to either self-refer or get a referral and understand that it's okay (NWA3f).*

*The SACS-R has raised awareness beyond the nursing community and St Giles (NWA2f).*

*The general community [...]. Parents are talking and parents are saying go and see your child health nurse if you've got concerns because they have tools that can look at that. So, word of mouth has been great in that respect (NSG2f).*



### ***Communication between project partners***

The DAT were keen for some face-to-face interaction with referrers to further enhance their positive relationships.

*Just put faces to names because there's a heap of names I know of CHaPS nurses, but I wouldn't have a clue who they are if I saw them in the street. You could be great relations [...] but we don't know who the referrers are beyond names on paper. It would be great to have a day here where they come in just to meet them and things like that, so that would be amazing. The same in the North-West. I know there's a few CHaPS nurses I know of there, but I wouldn't have a clue who they actually are if I saw them so that would be nice (NSG1f).*

The communication and relationships between St Giles and the CHaPS were named as important factors in the success of the SACS-R rollout. The DAT staff and the CHaPS nurses worked closely together throughout the project. There was regular contact about assessment results and queries about whether to refer or not.

*Nurses are contacting us for information and querying their results, what they're finding, and asking questions about, well, should I refer, or should I not refer, what should I do? So they are seeking a lot more input from us and then we're learning about them and what's happening in the community (NSG2f).*

When a child presented as atypical and was referred on, DAT would communicate directly with the referring CHaPS nurse.

*We had some good communication lines happening with the child health nurses, especially initially when it was starting to rollout and [participant's colleague] and I were in charge of making those initial calls to families and we got feedback directly to child health nurses and thanked them for the referral, and to get those processes set up, and that's where we got a bit of feedback and a bit of education both ways about how things were going (SSG1f).*

Given the large number of referrals received from the CHaPS to the DATs, it has impacted St Giles' usual ability to communicate with the referring party.

*The information back to the CHaPS nurses hasn't always been as timely as they would like, to know that the referral has, A, been accepted, that, B, when the child is likely to be seen, [...] just the timeliness of us being able to respond because the level of work generally that the SACS project has put on us has meant that our systems haven't been always as tight as we would like them to be (NWA5p).*

Following assessment at St Giles, with parent permission, the DAT shared information with the referring nurse, ASELCC and ECIS staff.

*It seems pretty straightforward with the communication, like with the reports, with the file notes and that sort of thing. They're quite open for us to see, as professionals, with consent (NWA3f).*

ASELCC have always experienced good communication with St Giles and ECIS.

*They're excellent [referring to the reports completed by the DAT]. Really thorough, really good. We always seem to communicate with ECIS pretty well. We usually do anyway - before there was SACS involved (NWA1f).*

In contrast, some participants reported miscommunication and a need for increased and clearer communication between project partners.

*There's a whole bunch of misinformation around that process [...] the SACS isn't as well-embedded as it could be. So we are hearing from certain CHaPS nurses that they don't need to do the SACS assessment anymore, found that that was just part of the research project, which was not the intention and not the intention of the ongoing funding that's been provided to both the CHaPS nurses and to St Giles (NWA5p).*

St Giles staff expressed that from the outset it was not apparent to them from the information they had received from La Trobe University, DHHS and UTAS what the referral numbers were regarding essential referrals.

*It really wasn't clear in terms of whether we were supposed to see all of the children referred by the CHaPS nurses within that time period. La Trobe said, You've got 6,000 so that's all we need, whereas DHHS said, No, we want you to see every single child that's been referred throughout that period, which we actually weren't resourced to do. DHHS want us to still assess them, which we will because we've accepted the referrals (NSG2f).*

There was praise for the UTAS research assistant and the key role they played in the research project.

*The communication between [research assistant's name], the research assistant, and us was spot-on and we couldn't have survived without her. So she'll be sorely missed by us, but she was a great support and we were always communicating and making sure that no child was missed (NSG2f).*

There was concern that there was communication happening between the State Government and the researchers when the questions should have been asked of the service delivery partner, that is, St Giles.

*Information being handed back to the State Government was not always indicative of what was happening from our perspective because it was coming via other researchers (NWA5p).*

At the outset of the project, it was agreed that stakeholders from the SACS-R team and the research implementation team would meet on a regular basis. A meeting schedule was established for monthly gatherings and updates.

*In the early stages of the SACS rolling out, had really frequent statewide meetings, [...] we were meeting as a team to discuss the rollout and the systems and the processes, [...] just generally to talk about places and situations and issues and report writing and all the kinds of things that were influencing our practice. So I guess that allowed us to kind of have a state approach to managing these things (NWA5p).*

To begin with, the meetings were regular. But due to busy diaries, meetings were sometimes cancelled and/or rescheduled.

*We didn't have those implementation meetings as frequently as I think should have been happening with the other stakeholders because they certainly were happening quite frequently initially and then petered out as well, which was a problem, I think, because it meant that we weren't catching issues as they were arising (NWA5p).*

*My frustration was probably more with communication between the university. The communication was going really well to begin with. We had those stakeholder meetings [...] I don't think communication between all of the stakeholders actually worked that well after those meetings dropped off (NSG2f).*

It was suggested that if those meetings had occurred as planned, along with enabling contribution from the service delivery partner from the very beginning, some of the issues that arose could have been avoided.

*St Giles' involvement in some of the decision making came too late. We didn't get really invited into meetings about the research until really the tail end of the study, [...] there were signs early on that we were going to struggle with the numbers of referrals, with the resourcing that we had been given, [...] those things were all foreseeable had we been spoken to sooner. Forecasting and [...] risk management around how we're going to manage these things if we get more referrals [...] that kind of contingency planning was not clearly done as well as it should have been done (NWA5p).*

Participant NSG1f was hopeful that an exit plan for the project may have been covered in one of the implementation meetings.

*I know there's been implementation meetings and things going on, but I have no idea when the last one was or what was discussed or if or what the exit plan is, like I've got no idea so I just, yeah, head down, bum up, keep doing what I need to. There's no clear direction. Like it's a wider issue than just SACS (NSG1f).*

The roll out of the SACS-R led to a shared language across agencies.

*The CHaPS nurses and St Giles and ECIS and everybody that's kind of been involved having a shared language through the use of the SACS tool has been useful. So when we're talking about what the kind of early signs of autism look like that we're all on the same page and the fact that that kind of has debunked, I guess, some of the kind of myths that might have prevailed within the child health service or within ECIS around the fact that you need to be doing X, Y, and Z to be autistic and that how autism looks in little kids may be different if they're 12 months old or 18 months old or 24 months old and then compared to what they might look like when they're older (NWA5p).*

### **Areas for consideration and improvement to the rollout process**

Participants made suggestions about how the rollout of the SACS-R process could be enhanced. The role of the CHaPS nurses was considered pivotal in the success of the rollout. Nurses being provided with mentoring, ongoing training and support would be helpful in assuring consistency and uniformity in referring.

*There seems to be sometimes maybe some inconsistencies between the actual nurses, as far as the ones that are more likely to refer (NWA1f).*

The Northern St Giles DAT travels regularly to the North-West to provide assessment services to that region. It is important that the families on the North-West coast are “continuing to have the Developmental Assessment Team travel out here to do the SACS” (NWA4p). It is critical that more staff are recruited to deliver services to the North-West coast.

Several DAT staff experienced the assessment process as quite challenging. Potential improvements were highlighted, including separating out the ADOS (child) and the ADI-R (parent) assessments and administering them individually rather than at the same time. Some suggestions to the current process were made.

*Intense working with children in that age group without the parent available to the child, I felt, was not ideal. So the parent was involved in an interview with somebody else in the room at the time and I think [...] some of the children, would have benefitted from the parent being more available to them. And, also, the acoustics in the room detract from the child's ability, potentially, to respond to some of the assessment items. Also a little stressful for two staff working under those conditions, each trying to complete their own components with a level of background noise and a variation of the child's emotional regulation throughout (SSG2f).*

Some participants articulated that it would have been useful to have greater accountability within the process and for tasks to be completed as they were intended. For example:

*There'd been some problems with [...] intake into St Giles, [...] it would be helpful to have almost an auditing process [...] to make sure everything is*

*on track and to have some kind of chain of command where that could be conveyed and make sure that that's done before things snowballed. [I]f things aren't done on time and we keep taking on these children at the same pace and then it just gets out of control. Make sure things happened at the times they were supposed to be, like report writing, as well as intake (SSG1f).*

### **Sustainability of the model**

The staff considered the ongoing ability to be able to offer the SACS-R across our state as a priority for our Tasmanian families. There were a number of suggestions made about how the new system would need to change in order to be sustainable. Areas of concern and recommendations regarding planning for the future were discussed, including funding and resources; the review process conducted by the DATs; training of the CHaPS nurses; necessary guidance for families; and the next steps now that the research project has finished.

Participants mentioned various ideas that could be included in the new system to support its viability. Having a research assistant and strong and regular communication between the stakeholders from the commencement of the project were cited as important considerations.

*It would have been great to have had a research assistant onboard at the start. I think ongoing communication between all stakeholders throughout the project and not just stopping in the middle of it. And just, yeah, I suppose clearer communication between the universities and St Giles (NSG2f).*

Some staff voiced that the childcare centres can play a key role in steering families through the SACS-R process. Staff at the centres could suggest to parents that they can take their child to their CHaPS nurse for their SACS-R assessment.

*So often an easier way of going 'your child has autism' is [...] the childcare centres is if they send them back to the child health nurses and say you need to have your check up. I feel like childcare centres still don't have that information and that's not there. It's natural instinct to go, have we checked if this child's had their check up, which if that information is in the childcare centres then any child that they are seeing, any concerns with...whether autism or not, is going to the child health nurse and I just think it would be a bit of a smoother process (NWA6p).*

Providing nurses with additional resources for their reference when they are assessing children with the SACS-R was thought to be useful.

*Great to have video footage that they could keep going back to and just reminding themselves what's typical, what's not typical [...] maybe having a little manual or something that could be referred to as well, [...] pointing to share, what are we actually looking for here and actually talking about it and talking about what it means in terms of typical development, what it*

*means in terms of atypical development, what it means in terms of social communication and giving it relevance and meaning (NSG2f).*

It was suggested that it would be helpful to be able to share children's status information with relevant staff. All of the organisations involved with the families each have their own record system and they are not linked. Participants identified the value of being able to share information and the ability to track a child's assessment progress.

*If we come across a child that we [...] know that has been referred to a CHaPS nurse for a SACS assessment, because the Tasmanian Health Service are a different organisation and we're a not-for-profit organisation, we have different databases [...] we can ring up to see that a child has attended, but we don't see their outcome. We can get that information through consent forms with the parents and sharing information, which is a little bit longwinded (NWA2f).*

If staff numbers were increased statewide then SACS-R consultations could occur at all three time points in all three regions, followed by timely diagnostic assessments and the delivery of EI support services.

*Needs to be more people that can help, or that qualified help that agencies that can provide and fill the gap for that so that surveillance can occur regularly at that 12, 18 and 24 because I think if you have multiple agencies, as in serving that one family over that period, that's a good thing. There needs to be more allied health service generally, but I think that if early childhood, early intervention stuff is to work, then it really does need to be happening earlier. But, also, then the service needs to be there to address that (SSG3f).*

The SACS-R enables children to be identified at a much younger age compared to previously. But, if the waitlists are long and the assessment and intervention services are under-resourced, being identified early and then being assessed 12+ months later is of no benefit.

*We can see these kids so much younger and pick up on those things, and I think that's one of the sad parts of how understaffed it's been, how much the waitlist has now blown out because we're not seeing those children at least till they're two, and we've been seeing nearly three-year-olds and things now just because of the waitlists and things like that. So, yeah, it's quite unfortunate that's not been managed that well (NSG1f).*

Greater promotion of the CHaPS and the services they provide would be beneficial as: "there are still people that seem to get missed" (NWA1f). It is important that families are aware of the CHaPS nurses' role and schedule their child's appointments: "Making sure that families do attend those appointments" (NWA4p). Increasing the CHaPS' profile in the community was also suggested.

*Some sort of advertising that you could, if you had concerns, go to your child health nurse [...] putting it out there more, really, so people know*

*what's going on and the general public, as well as service providers (NWA1f).*

### **Funding and resources**

One of the major challenges identified with taking this initiative into the future is funding.

*Funding, funding, funding, funding. We need [...] at least twice as much funding to basically deliver in a timely way. If we had twice as much funding now, the waitlist would stay the same, it wouldn't allow us to reduce the waiting list, and the waiting list at the moment is 15 to 18 months, maybe more, which is vastly inappropriate for children of that age [...] we just need more money for diagnostic assessments generally in the state, but particularly for the early assessment (NWA5p).*

Overall, for the process to run smoothly and in a timely way from SACS-R assessment through to St Giles assessment, report and feedback, more resources are required for staffing (NSG1f).

*For staffing it needs sufficient money to be allocated, basically, for it to work, particularly as in order to get through those assessments, time had to be taken out of our other general caseload. So it needs to be funded sufficiently to get adequate staffing [...] you really need to make sure there's the staffing to cover the intake process. And all the admin that's associated with the SACS, as well. Make sure that's all adequately funded for so that it doesn't come out of the general DAT budget (SSG1f).*

The underlying reason for identifying children as early as possible and referring them on for further assessment is to ascertain if they have autism or a delay of some sort is, so they can access support services early. However, across Tasmania there has been a dearth of support services available, in the public and private sectors.

*We had hoped that the broader service would be more available, but waiting lists are well over 12 months now for therapy services for many children in a public funded system. So they have not had a continuity of care from that point of view of the assessment from after the assessment (SSG2f).*

*At the moment there is such a wait for speech, for occupational therapy, whether it's here at St Giles or if you're going further afield, to other services, there's a huge wait. So groups like the Ripples Group, I think those play groups, those kind of things, if we could see them supported (NSG1f).*

St Giles is keen to be the successful referral partner in the SACS-R process in the future. However, there are concerns around costs and funding.

*We definitely under-costed what it would require in terms of both staff time, but also administrative support time and that the true cost of the impact on St Giles wasn't really considered (NWA5p).*

### ***The review process***

The research protocol stipulated that children were to be reviewed. This was challenging for St Giles staff as they were hampered by competing pressures including insufficient staff and inadequate funding.

*The reviews were good for the younger kids, though they're time-consuming. I suppose if we can make a clear diagnosis straight up, that's great, and reviewing them is maybe not as necessary (NSG1f).*

*The review process was tricky to kind of manage in the context of we've got this massive list of new referrals, kids that haven't actually been seen, and we've got these other kids that needed review because of the research protocol (NWA5p).*

Some staff suspected that due to the staffing issues the reviews may not be part of the process in the future.

*We probably wouldn't be doing the reviews. Like if you get a diagnosis, you've got your diagnosis and you're gone (NSG1f).*

There was a suggestion to funnel 12 month old children who had been assessed but had not yet received a diagnosis, into groups where they could still be monitored. This would also alleviate the pressure for review.

*The families are still going to get support, we've still got eyes on them because if they say - well, here at St Giles we'd have all the files, notes on file, we could look at those and then we'd assess them, say, at 18 months or we might go - because there'd be hopefully an OT, a speechie in that group and other professions, they'd go, mmm, no, that kid is not autism, that kid clearly has a language delay, let's get them to speech therapy and maybe they don't need to go through the whole diagnostic criteria if you've got some agreement there at that level (NSG1f).*

Despite the workload challenges of the review process, some staff were in support of the reviews continuing.

*Having the reviews has been a positive approach as well because you can talk about where you've seen improvements, even if the child has had a diagnosis of autism and they're quite delayed, we still try to highlight where we're seeing those gains. Be able to identify what we see as those even subtle improvements, I guess, is helpful for parents to hear that and to see that the efforts they've been putting in have been making some changes (NSG3f).*



### ***Training of the CHaPS nurses***

A number of participants identified that the CHaPS nurses may require additional training to support them in embedding the assessment in their everyday practice but also to ensure they maintain a high level of skill (NSG2f).

*I think some more ongoing training of the child health nurses would have been very helpful, and specific training for individuals that might not have been understanding it as well. Feedback from perhaps management within the child health nurse, rather than just indirectly through SACS, whether that was followed up if the child health nurses were under-referring, for example, consistently making the same errors and that sort of thing would have been helpful (SSG1f).*

More specifically with regard to the nurses receiving training, was them understanding the difference and differentiating between imitation and pretend play.

*Some were possibly indicating a child could do pretend play because they had been shown what to do and thus were imitating rather than engaging in spontaneous pretend play. If they're showing a child maybe how to, you know, the teddy is drinking from the cup and then the child does it that they see that as pretend play, where it actually wasn't pretend play, it was imitative (NSG2f).*

Some participants queried whether the SACS-R assessments were administered and processed as intended.

*I did notice that there were some SACS screenings, especially early on, that were not possibly done the way that they were supposed to be done, [...] we gave some feedback to the child health nurses [...] items were marked typical and which were atypical, [...] some of the nurses would have perhaps rated the SACS items based on the parent report, rather than their own observations (SSG1f).*

### ***Guidance for families***

Many participants recognised that families need support at various points across their assessment journey from the CHaPS SACR-assessment to the post-diagnosis phase.

Prior to their CHaPS health check, it was suggested that families receive an information pack, outlining the process.

*Families who are about to do their health checks, whether there's an information pack that goes out about what happens at a health check [...] maybe including that child health nurses do this and it's something that might happen. So maybe [...] just to every child or every family, just something that says this is something that happens, and this is what it's for (NWA4p).*

Assisting parents to understand the various roles of the professionals involved can be useful.

*Having clear guidance for parents, and around who does what. When there's paediatricians involved, especially, and the parents are seeing - there's confusion with them between the roles of the different organisations they're going to see and if they've contacted one, do they need to contact another one (NWA2f).*

Participants highlighted the need to support families while they are on waitlists, including helping them to complete ECEI/NDIS documentation (NSG2f).

*So I think if you want to have a family-centred practice and be dealing with the emotional side of it with parents, it's a lot more than just quickly churning them out. You do need to give some extra support for parents and give them more information. When there was the transition from HCWA to the NDIS, I found that I was spending a lot more time with SACS clients just to make sure that they had everything documented and everything they needed for the HCWA funding before it cut out (SSG1f).*

Offering the option of receiving additional guidance post-diagnosis could be a valuable support for families.

*A follow-up meeting or a three months' later [...] to get them to that next level of support and accessing other services. At that initial meeting, they might take two things away of five, [...] two months down the track they might get another phone call and say how are you going and are you accessing this and saying, okay, well, you are accessing two of the five things, these are another three options that you could be accessing. Getting them in contact with services and providing as much support for those families as possible (NWA6p).*

### **What are the next steps?**

Now that the research project has finished, where to from here? ASELCC and St Giles staff were keen for the SACS-R process and referral pathway to continue.

*Make sure it keeps going, for starters. I think if it didn't occur, then there'd be a massive gap in - it would just be another hole in the net. We wouldn't be capturing these children as early as we would without the SACS project (NWA2f).*

As noted above, a boost in funding, resources and services were thought to be desperately needed if the process is to continue smoothly (SSG1f).

*We're not resourced sufficiently to see those children that are being referred. And then, from a Tasmanian perspective, we don't have enough intervention services, especially in the North and the North-West for families to access support and intervention. And I don't know what Tasmania or the government is going to do about that. The NDIS says that*

*services will appear because they are needed, but we know in Tasmania that we have a shortage of allied health professionals and can't maintain our allied health professionals in services already. And so, therefore, parents get funding through the ECEI pathway, but then actually can't find a service to access. So I think the main challenge is resourcing, resourcing for assessment and intervention (NSG2f).*

If St Giles was the successful partner, the SACS-R referral pathway would require its own staffing, distinct from the staff who receive referrals into the DAT pathway.

*Making sure it is completely separate from whatever is already in place because I think the SACS has sometimes impacted on DAT kids and DAT has impacted at the moment with our pre-kinder kids. We've just gone we can't do as many SACS assessments as we should be because we've got all these DAT pre-kinder kids that just have to be seen before school starts (NSG1f).*

In moving forward, addressing staffing and the management of waitlists is a priority (NSG1f).

*For St Giles it's the time, the staffing to continue seeing the young children and not having huge waiting lists because that just defeats the purpose. If they're sitting on a waitlist for six to 12 months then it's not really that early diagnosis anymore, is it? (NSG3f).*

Participant SSG2f saw great opportunity to keep improving the system.

*In Tasmania we now have a great opportunity to build on the knowledge and expertise that the service has gained and so I think that St Giles would be well-placed to build on from here in terms of the links are established and the waiting list is there and it's within the scope of what we were seeing as our business. But it depends on how NDIS, ECI funding is approached and how the State Government, yeah, approaches funding for the service. So the way ahead is to - I guess, some of the things are communication with the other stakeholders and politicians - which I imagine is happening anyway - in terms of the need and benefits for these early-aged assessments, but also the smooth pathway that we've got, there's a prime opportunity to utilise (SSG2f).*

It is not only the CHaPS nurses who administer the SACS-R. The tool is also used by St Giles staff, including the Speech & Language Pathologists and the Occupational Therapists. There is an opportunity to consider other service providers becoming SACS-R trained and for them to make referrals to the DATs.

*GPs could start using the SACS tool because often that's going to be perhaps the first point of contact [...] from my personal experience, my children's GPs aren't very tuned into the more subtle signs of autism at a young age and, yeah, if they could be trained or given some understanding in being able to use or have a contact within each practice that's able to*

*administer the SACS and kind of make the appropriate referrals, then that would be ideal (NSG3f).*

Campaigning and education about the SACS-R tool and its associated research would be beneficial to its acceptance and support in the wider health community.

*Having the purpose of it really clear. More publicisation for the services in terms of GPs and other first line providers who would be seeing children in that age bracket so they can really understand the research, that it's a tool that is very strongly predictive and it's a very useful tool, so they need to get behind it, [...] how you get all the GPs together. Better promotion of the purpose of it and why it's so important would be useful (NSG3f).*

A recommendation was made for the CHaPS to also roll out the pre-school age (36 month) SACS (NWA5p; NSG3f).

This participant group raised concerns that once the research project concludes, the nurses may go back to conducting the child health checks as they did prior to the SACS-R training. There is a push from stakeholders to maintain the SACS-R as standard practice in the CHaPS' health checks. It is important to establish ways to support the CHaPS nurses to continue to view the SACS- R as a valuable addition to their skill set and to continue to administer it in their everyday work.

*Business-as-usual includes using the SACS tool as part of your 12 and 24-month checks, but is that really happening? [I]t's a real step back if it's not [...] being supported to continue in whatever way [...] they need to make it continue. I don't know what that is in terms of leadership or funding or training or all of those things. I certainly have concerns that the structure of the research project kind of required it and I worry that when it kind of goes back to being just a tool in your toolbox, not part of your standard operating procedure, that people will only pull the SACS out when they have concerns about autism, but if you've got concerns about autism, you probably don't need the SACS tool (NWA5p).*

Participant NSG1f voiced concern that there had been no discussion around an exit plan from the research project referral pathway.

*Now the research has finished, like we're still doing the last of those under 6,000 children as a part of the project and some of the reviews for them, but we're like what are we doing with - because referrals are still coming in, which is fantastic, but what exactly are we doing with them? Are they now becoming just part of our normal intake, going on the normal waitlist, or we'd prefer to have a separate waitlist so those younger kids are getting seen. Like, we have a day a week that's just for them, versus our older pre-kinder kids that we are seeing. Yeah, but what does that look like? So we're just kind of keeping on with business-as-usual at the moment (NSG1f).*

### 4.3.5 External stakeholders

The external stakeholders included people with a range of different perspectives. Final participation numbers achieved statewide were 26 interviews with a regional split of North 3; North-West 1; and South = 22). As detailed in Table 4-12 below, the proportions of professionals varied across the group, from one participant to eleven participants in some professions/categories. However, we considered this to be an authentic picture of the external stakeholder views of the Tasmanian population who work within the field.

**Table 4-12. External stakeholder groups and participants by geographical area**

External stakeholders	Number	Region and Role
Autism Advisory Panel	1	South
Early Childhood Intervention Service	3	North and South -Principal -Teacher and -Autism consultant
Autism Tasmania	1	South
Members of Parliament	1	South
Allied health professionals	6	South -Occupational Therapist-2 -Psychologist-3 -Speech & Language Pathologist-1
Reps from health associations	11	North-West and South -Paediatrician-4 -Psychiatrist-1 -General Practitioner-3 -Statewide policy role-3 (Children's therapy and services-1 and Disability & Community Services-2)
Reps from educational associations	3	North and South -Education consultant-1 -Tasmanian Disability and Education Reform Lobby-1 -Catholic Education system-1

This group of stakeholders incorporates a diverse range of people from a variety of roles and professions. They are Members of the Autism Advisory Panel, staff from ECIS and Autism Tasmania, politicians, allied-health professionals (psychologists, occupational therapists, speech & language pathologists from the public and private sectors), and representatives from the health and educational associations. Potential participants were initially contacted by either email or phone call and invited to be interviewed. Follow-up emails with relevant attachments were forwarded to them regarding the interview process and offers of dates, times, and location to conduct the interview presented.

The interview process presented the external stakeholders with an opportunity to share their views about the SACS-R program. Twenty-six participants consented to participate in an interview. Twelve of the external stakeholder interviews were conducted face-to-face. Of those twelve, eight were held at the participants' workplace, three were

held in the Board Room at an office location in Hobart and one was held at my private practice. The remaining fourteen interviews were conducted over the phone to the participants' workplace from a noise-free room at an office location in Hobart. The interviews, on average, took approximately 20 minutes.

Reflexive thematic analysis (Braun & Clarke 2019) of the external stakeholder data generated five themes: professionals' views on impacts on professional practice; views on parents' experiences; increasing community understanding and awareness; system issues; and sustainability of the model. The findings from the external stakeholder interviews are presented under those five themes. A summary of the external stakeholder major themes and sub-themes is displayed in Figure 4-8 below. Additional quotations are contained in Appendix M.

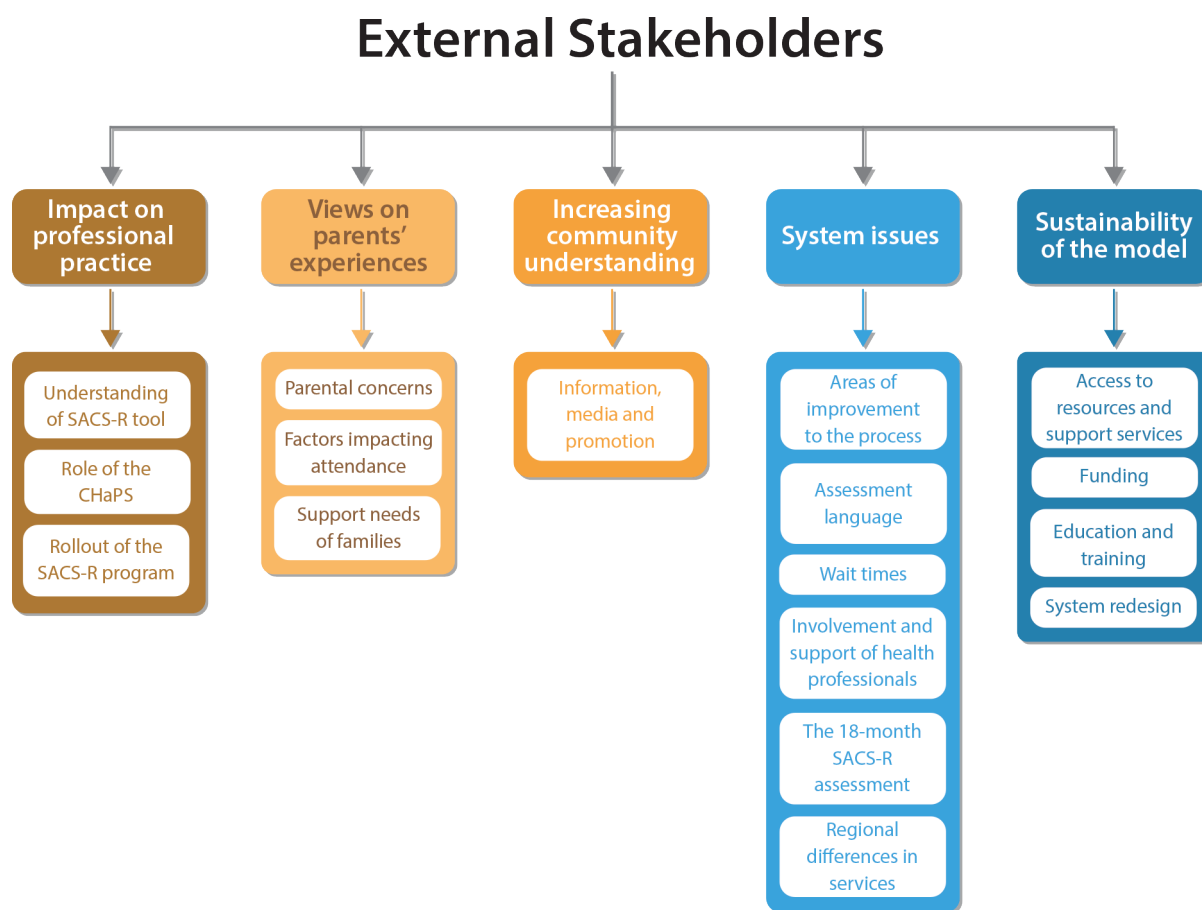


Figure 4-8. Summary of external stakeholder major themes and sub-themes

## Professionals' views on impact on professional practice

This theme refers to the impact of the SACS-R program and outcomes on the external stakeholders' professional practice. Participants in this group may work in the autism space but may not be directly involved in administering the SACS-R assessment or referring on to St Giles DAT through the SACS-R pathway but may assess for autism and diagnose or on-refer for opinion and management. Alternatively, they may be further removed from the field and have some direct bearing on decision making and policy outcomes. Included under this theme is interviewees' awareness and understanding of the SACS-R tool and their knowledge about the role of the CHaPS and the rollout of the statewide SACS-R program.

### ***Awareness and understanding of the SACS-R tool***

Participants were asked directly if they were aware of the developmental surveillance for autism in Tasmania. Responses varied considerably. There was a large proportion of professionals who did not have any knowledge of the tool or the program. Some of these people conducted research when they were contacted to participate in the study and read up on the topic prior to their interview.

*I actually know absolutely nothing about it. I mean, the first I sort of heard about it was when you sent me the information (SE8).*

There were those who were aware of the tool's existence but not overly-familiar with it; responses ranged from nil knowledge of the tool (SE2) to a minimal understanding that it is administered by the CHaPS nurses (NE1; NWE1). Nevertheless, a small number of participants knew enough about the SACS-R to provide a descriptive comment and indicate that they were in favour of it.

*The things that will really promote it and what I've seen is, one, that it's a free service and it is recommended by a range of health professionals. I think that's quite known from GPs to psychologists, to OTs, they all kind of know that that service is available and it is quite widely recommended. And because it is done from such a young age, I think that's a really good thing because they've seen them in the early stages and then as they're getting a bit older it's something that they're familiar with and it's not so scary than kind of going through to a new service (SE2).*

There were several participants who were very knowledgeable about the SACS-R tool and program and viewed it as a positive addition for Tasmanian families.

*The SACS-R was an initiative that was auspiced by the Autism Advisory Panel in terms of the rollout here in Tassie. It's a screen that is done by maternal child health nurses. It started in Victoria looking for a quick, easy screen that can be done - universal screenings, rather than targeted screenings, looking for early indicators of autism and if they meet a threshold of a certain number or a certain collection of behaviours that have been observed, then they are then referred to an individual assessment of autism. It's done at various age groups (SE1).*

Some participants indicated they were onboard with the tool and acknowledged that they are well-placed to direct parents to their CHaPS nurse for their child to undergo the SACS-R surveillance. For example:

*It's certainly something that we could refer on to [...] we've already got that relationship [...] often if anything comes from a health professional we're more likely to listen to it than our partner or something else, so I guess someone who has a different relationship to us. I wonder is it something that GPs sort of mention? (SE6).*

It was identified that the SACS-R assessment is the prompt that commences the process of identifying atypical behaviour. One participant was in the routine of referring parents to their CHaPS nurse if there were concerns.

*So in the clinic practice, I'll often have children as young as two or three that come in and the query of where do they sit, where do they fit, and often I will say, "Have you gone through the health nurse, have they done the checklist, have they done----?", and so working that through to how we can assist them in their process (SE4).*



There was a vocal group of paediatricians who knew about the tool and were unhappy with the concept of the program. They disputed the plan to implement the program into Tasmania. They were concerned that their apprehensions about the program were dismissed.

*I argued against implementing it in Tasmania with my colleagues for a number of reasons. We were involved quite late in the proposal process and were rather stunned, statewide, that it had been rolled out without really talking to any of the professional groups involved in delivery of service (SE20).*

### **Role of the CHaPS**

Overall, this stakeholder group viewed the CHaPS as an excellent source of knowledge and support.

*Parents are pretty much onboard with wanting to know has their child reached a certain height, a certain weight, sleeping issues, all the rest, you know, the very first port of call for parents and so that they're very interested in going to the nurses anyway. And so, it's an additional support that they've got there (SE4).*

In their role, the CHaPS can utilise their administration of the SACS-R to raise concerns with parents.

*It also helps, I guess, give child health nurses a structured way to talk to parents where there are red flags, where there may not have necessarily been a way to have these conversations before, and I think that's really valuable and really helpful (SE7).*

Of the interviewees who knew about the SACS-R being administered as part of children's routine health checks, they were supportive of the minimal impact on nurses' time and their workload.

*I could see when she was pulling out the little SACS task. [S]he actually did a really seamless job of putting it in as part of her assessment which was great (SE7).*

It was expressed that although the nurses could identify atypical behaviour through the administration of the SACS-R, it does not lead to the support that is needed.

*I think the CHaPS nurses are really great at being able to provide support, and they're really great at being able to find the flags, but it's what we do with that. And that worries me because just simply doing that on its own doesn't necessarily achieve better outcomes for these kids. It might flag them early, but it's the follow-up services that are critical (NE2).*

Some, whilst complimentary of the range of the CHaPS nurses' expertise, thought their energies could be channelled more broadly than autism.

*The furthering the skillset of CHaPS nurses, and I think that's fantastic. I think CHaPS nurses have huge numbers of skills and are underemployed and their scope of practice needs to increase, but I think there are perhaps services that might be better than just chasing autism (SE20).*

It was suggested by participants that after a child has been flagged (but the family is still at the pre-diagnosis stage and awaiting assessment at St Giles), CHaPS could simultaneously provide community work and assistance. In addition, families should be able to get some “light-touch support” and intervention whilst awaiting the diagnostic assessment stage.

*Yes, there is a hold up in the middle part of it [...], they're not diagnosed yet, they're not anything yet, but we know that they're flagged and they're high, and so that the community nurses providing – like, if they had the training then as well so that they're not just doing screening, but they're also doing community work with those children as well and assisting them. I mean, there's certain programs that can easily be run by child health nurses (SE4).*

### ***The rollout of the SACS-R program***

The CHaPS was seen as an appropriate organisation to administer the SACS-R assessment and attempt to gain the best coverage of families and connect with other agencies (SE16).

*Certainly the feedback is having a tool that the nurses can use with families is beneficial and then providing a referral source (SE17).*

However, parents can only become involved in the SACS-R program if they are aware of it and choose to access those services (SE21).

There was concern that those families who need CHaPS the most are sometimes those who do not access the service.

*The people least likely to attend are our most socioeconomically deprived, and the ones who are least likely to have the social supports to say, hey, I'm worried about your little one as well. So the ones who most need the CHaPS nurses, perhaps, are the ones most likely to drop out. Maybe turn up for their six week check, but not those after. We've got to get the basics right before we get the frills (SE20).*

Participant SE15 suggested that the more susceptible families in our communities require a more universal nurse home visiting program.

Some participants noted that the SACS-R assessment tool and the program rollout had made many parents and groups in the community aware of developmental assessment.

*It goes a very long way to putting it on people's radars, to help parents, especially who have been having kind of concerns or having questions, to be able to raise it with their GPs, get referrals for paediatricians. It kind of puts into words, I think, what a lot of parents might be feeling and experiencing, and I think that's a really helpful tool (SE7).*

Others reported that the SACS-R program had impacted their day-to-day work in terms of increased referrals from the CHaPS and hospitals, particularly with regard to a younger age group coming through.

*The landscape has very much changed since that has been happening with the CHaPS nurses, especially that we get a lot of referrals now to our service from a much younger cohort of children, which is really good for us because we know about early intervention. We would consider three, three and a half, a referral for a child with red flags on the spectrum to actually be a little bit on the late side now. And a lot of that is because of the SACS (SE22).*

It was noted that children are increasingly coming into ECIS via the CHaPS nurses' referrals based on the outcome of the SACS-R assessment.

*Certainly, through the CHaPS, it's been pretty seamless in terms of their surveillance referral to our service which often then will lead on to another screening tool. We might do it again, for example (SE22).*

The SACS-R program was viewed by the majority as a good fit for our state. Not only because they considered it supported families to identify concerns early but because it was a free service from CHaPS assessment to further assessment and potential diagnosis with St Giles DAT.

*Anything that helps in early detection of developmental delay and the possibility of autism being ultimately diagnosed is it just supports the research. It says the earlier that we can get involved, the sooner that we can work with that child and to change their trajectory and work with their family to build their capacity (SE11).*

Many interviewees who were optimistic about the program, were aware of the larger context and potential flow-on effects, including early detection and intervention and the identification of older siblings who did not have an earlier opportunity.

*Early detection and early diagnosis leads to EI which leads to, hopefully, a better prognosis. I'm hoping that the results show that it's actually worthwhile because the kids are getting detected earlier and the diagnosis is happening earlier (SE7).*

A number of participants recognised the pros and cons of the rollout of the SACS-R program into the THS.

*I think that it's really helpful in lowering the age. Whether or not we've got the support network worked out post-diagnosis, I'm not completely sure. [I]t's a really positive initiative in terms of the earlier we have access to early intervention, the more positive outcome for the families, but I think that beyond just the blinkered view of autism and looking at neurodevelopment across the lifespan, that we probably need something a little bit more strategic for the state and a little bit more holistic for the*

*state. But in terms of a cost effective screening intervention, I think that SACS-R is quite good (SE1).*

Where the concern lay for a number of stakeholders was what comes after the child has been flagged on the SACS-R. The argument surrounding ‘why diagnose earlier if the intervention cannot be provided?’ was echoed by many within this stakeholder group.

*The diagnosis is just a diagnosis, if we can’t do any intervention then obviously that’s not necessarily in the best interests of the child (SE18).*

Some interviewees were uneasy about the unequal investment in early identification compared with funding and/or access to intervention and therapy.

*I think anything that enhances early detection of ASD in Tassie children is always a great thing. My only concern is that it’s a lot of investment into the early detection and diagnosis, but not an equivalent amount into the intervention, therapy kind of things once the diagnosis has been made (SE13).*

Numerous participants viewed the SACS-R program as a three-part process – surveillance, assessment and intervention services.

*You can’t treat this as a standalone tool and tick it and go, look, we did it because you can cause many, many problems by doing that. What you actually need to be doing is understanding that it is a step along the pathway and you can’t just look at getting that right without getting everything else right at the same time (NE2).*

Some participants were very resistant to the SACS-R program and unsupportive of the rollout altogether. They felt strongly that parents are better off not knowing that their child has autism if there is an inability to follow through with intervention, resources, and support.

*It’s like bringing in a cancer screening program. If you then don’t have anyone to do gastroscopies and colonoscopies and surgery, it’s better not to know. For cancer it is. If you’re going to die anyway, I’d rather die not knowing than die on a waiting list. I mean, these kids aren’t going to die, but being told your kid has autism when it’s only a screening test? You know, believing you’ve got cancer on the basis of a screening test is wrong, you’ve got to be diagnosed properly (SE20).*

Some considered it “a disjointed effort at present” (SE15) and suggested there was more work to do before the program was acceptable. The paediatricians as a group in themselves were strongly opposed to the rollout of the SACS-R in Tasmania.

*Screen, positive screen for two years, finally get an assessment, a year later get your NDIS package. That’s nuts. We need support early (SE20).*

Interviewee SE15 was in favour of *observation*, providing strategies, guiding parents and professionals in EI, and assisting children with their social communication. Nonetheless,

they protested the fact that the resources needed to deal with autism diagnoses and the array of potential differential diagnoses were lacking.

*You're going to raise a hype on doing an assessment tool [...] many other factors affect social communication and those things. There is the attachment aspect as a psychologist, which are not factoring in. We are not factoring in learning developmental delays. You have not got a referral pathway set up. We're saying you're doing it backwards. You can't start your research without doing some ground foundation things. What are you going to do with the kids you diagnose? So CHaPS nurses only send to St Giles. What is the responsibility once you have made a probable diagnosis? We have not got the resources to deal with the fallout. Why do you want to do something which is going to stretch your already stretched thing? Put in early interventions, put in everything, do not put in labels (SE15).*

This participant viewed the SACS-R as a single interpretation of a child's presentation. This was perceived as a problem if an autism diagnosis is being considered at 12 months of age.

*Nobody can diagnose at 12 months. So if you think you can – we need to follow these kids after 18 years to decide who is autistic or not. And so if it is something else, it was not autism in the first place. So early diagnosis, from my perspective, is important to be able to put in the strategies to help the family cope, accept, absorb and move forward because early intervention does make a difference. Learning speech, learning everything does make a difference. So I'm saying that this thing, social communication skills if they are deficit, we have to put in the strategies to help these kids, not focus on the labels (SE15).*

If a child displays an atypical presentation on the SACS-R, participant SE18 was concerned that it becomes a fait accompli that they have autism and are only considered through an autism lens.

*One of the tricky things with the SACS-R is that obviously we're looking for a specific condition and one of the kind of recommendations that I would have around evaluation of children with neurodevelopmental concerns, or developmental problems is that we need to keep a very open mind when we first evaluate them, not to single in on, oh, well, this child screened positive for the SACS-R, they definitely need an ADOS and an ADI-R (SE18).*

It was suggested that children who flag on the SACS-R items require a global, medical assessment from a paediatrician as a priority over a DAT assessment (SE18).

### **Views on parents' experiences**

This theme covers the views of the stakeholders about how the process was for the parents. They provide insights about families and their concerns for them along their children's assessment journeys including consideration of the psychological impacts on parents. Included here are their understandings about why parents do or do not schedule appointments with the CHaPS nurses and how attendance at the health checks could be

increased. The theme concludes with consideration of the breadth of families' support needs and investigation of when might be the most beneficial time to deliver support to families.

### ***Parental concerns***

A number of participants acknowledged that parents want to be able to delight in their young children and be able to do that without categorising them.

*I have families that haven't liked having the ASD in their child flagged as early as it has been because they feel like they're battling the system from the beginning. Which is of interest to me because I know that I very much felt that way with my youngest one. We held off a diagnosis, even though we were 99% sure where it was going to land, because we wanted to be able to enjoy that 12, 18, 24 months without having to worry about the battles that we had ahead. And for some of the families that I deal with they feel like they've been dealing with this label for the entirety of their child's life and they haven't had a chance to actually always enjoy it (NE2).*

For some parents, they feel sad when they realise that their child is atypical and the revelation may lead to a shift in their aspirations.

*There is a grieving process. You thought you were just going to have your neurotypical child and I think if people know that they'll have their challenges and bits and pieces, but all of a sudden a diagnosis of autism comes along and it's, wow, my expectations for my child have completely changed (SE11).*

In contrast, other parents experience a sense of reassurance.

*The feeling is relief. Of course there's always families where that is not what they want [...] by far and wide the majority of families we work with would say, earlier the better (SE22).*

Every family and every child is different. The difficulties that each family faces are diverse.

*One of the questions I ask is "how does your child's autism impact on family life" and it's a really full-on question, you know parents often break down in tears (SE4).*

There are the day-to-day challenges that families face and then often a new set of challenges arise as parents begin to navigate the academic space for their child.

*I think the school system is a real worry for a lot of families so where the kids don't necessarily fit in or that need something else or home schooling (SE13).*

Some participants wondered if parents were aware that their child had undergone the SACS-R assessment; they were interested in whether it was intentionally conducted in a covert way.

*Do the families actually know they're doing a SACS-R? I've had families that come and say, "They did a screen, but I don't know what it was, but on the referral it says they did a SACS." So I'm just not sure if families know they're having the screen, whether that's part of the protocol that they are meant to or they just didn't hear it or didn't process it or it didn't land when they were told. [M]y hunch was I don't think they know they're doing it [...] I feel really uncomfortable about that (NE3).*

Participants indicated that telling a parent that their child may have autism is worrying to them.

*Autism causes a lot of anxiety. And a suggestion of autism causes massive, massive parental stress (SE15).*

Some participants specified that there are unnecessary emotional impacts placed on parents that may be present at various times throughout the assessment journey.

*We've got to obviously be careful that we're not doing more harm by identifying children who may be at risk and then not being able to provide them with the [supports]– the family then have some heightened anxiety about what's going on, but we're not able to provide them with any intervention, and that obviously isn't a great outcome (SE18).*

Of concern to some interviewees was that a possible autism diagnosis, or a substantiated one, may influence the way a child is parented, depending on the supports available to the family.

*We know, psychologically, that if you change your expectations of a child, their output changes to match your expectations. So if at 12 months you think your child has got possibly autism and you need to watch their language and you just accept them – if you're supported and it's like, right, [interviewee used their own name], you have to talk, you have to point, you have to share. If we have a really strong program in to support me as a parent, fine, but if I'm a poorly educated parent and I'm told my child is going to have language problems, you might stop talking to them. You might go, oh, well, he likes the iPad because he's autistic, I'll give him more time on it. It's how it changes parenting without it being a verified diagnosis and without appropriate input that concerns me (SE20).*

### **Factors impacting health check attendance**

Participants suggested a range of reasons that influence whether a parent does or does not take their child to visit the CHaPS nurse. Generally, interviewees thought that at the core of attendance or non-attendance is the motivation of the parent.

*You have a range of families who will either engage with that or not anyway, regardless of whether they're going to do a surveillance check for autism. I think, for those families, if they are concerned around that, in my experience it probably could be because they might find out something*

*they already know. If they are aware that that check is going to happen. But then families sit in two camps. A lot of families sit in that I want to know, let's do it, let's get this check done, it's kind of what I thought. Some families find it validating (SE22).*

Many interviewees mentioned that busy parents; having more than one child; and parents feeling greater confidence were all logical reasons which would impact on attendance at CHaPS health checks.

*The lack of time. It was really difficult to get an appointment, especially for a second child because I went back to work a lot earlier. Yes, so for like my second child it was actually finding a time where I could go to have my child health check without having it impact on my work, which was really difficult (SE7).*

Establishing rapport with the local CHaPS nurse was viewed as a pivotal factor in influencing parents' ongoing attendance at the health checks.

*We've got a mixed bag of nurses out there. When you talk to mums of babies about the CHaPS nurses, there is a variation in styles. And I'm friends with a number of CHaPS nurses who are brilliant, who I think would be fantastic people for mums, they're just so holistic, they've got credibility, they've got experience. There are other nurses who are bloody terrifying and you have quite educated health background parents coming in crying because the CHaPS nurse has made them feel like shit about a weight loss that, actually, when you go through a chart it isn't a weight loss. So some nurses don't have good credibility and lose patients' respect (SE20).*

Some participants suggested that parents could be concerned about the stigma that may be associated with detecting something is atypical about their child and therefore avoid going to their local CHaPS nurse.

*People might be hesitant to follow-up because they feel like they're moving into a disability space. So, it's destigmatising that (SE17).*

The majority of interviewees suggested that parents may be reluctant to attend their CHaPS health checks due to what they are experiencing emotionally, including denial and/or embarrassment (SE13, SE2, SE11).

It is not uncommon for well-meaning friends and families to tell worried parents that everything is fine, even though they do not have the professional experience to make that judgement.

*As a clinician and as a friend of a parent seeking an ASD assessment, many mothers are told by family, friends, and some professionals, that there is nothing wrong with their child, certainly not ASD. They are discouraged from seeking an assessment, or their denial is reinforced (SE13).*



Of greater concern to participants was that medical professionals will sometimes dismiss parental worries, suggesting that gender is the reason for delays.

*This is what families report to us that they would still go to a GP with a three-year-old who isn't talking and a boy, often with little boys, and this is fairly regular still, often told - don't worry, it's just because they're boys. I saw a mother the other day and she said, "What do you think?" Everyone is telling her not to worry about it [...] the GP said don't worry. In an hour, I said, "I see some what we would call red flags." She said, "Thank you, I'm not going crazy (SE22).*

Other factors that were identified that may hinder attendance, included a lack of knowledge about the free service itself and families not having capacity to get to their CHaPS centre (SE12; SE1).

*Knowing that the service is available would certainly be a first step. I know for some of our families that don't have a car, they get here by public transport and it might be they've got six other children and there's nobody to look after the children whilst they take them to the appointment. I guess there's all those logistical kind of things which can be a barrier (SE6).*

Non-attendance could be due to fear and/or a lack of understanding about autism in general (NE1). Many people are unfamiliar with what the early behavioural signs of autism are and therefore it can often go undetected (SE18). Participants also suggested that the timing of the identification of autism may seem too premature for some parents (SE8). Some parents experience worry about what may lie ahead for their child (NE2).

There was a common feeling that a general disengagement from the health service probably exists (SE1). Participants expressed that parents need to be informed that it is essential that all three checks are attended (NE2; SE19).

Interviewees generated some ideas around ways to increase participation of Tasmanian children at their health checks and subsequent SACS-R assessments. Suggestions included the use of reminder messages; families connecting with and accessing Child and Family Centres; aligning routine checks (dental, SACS-R, vaccinations); and increasing awareness through targeted publicity campaigns (SE18).

### ***Support needs of families***

Overall, it was recognised that there was a need for children, parents, and families to be supported through the assessment and diagnosis journey. Some participants proposed that wrap-around support is realistically required from the time a family is concerned and then ongoing for the family's assessment, diagnostic and post-diagnostic journey. Interviewees articulated that support needs extend more broadly than the disability-related needs of the child. Long-term, whole-family support is critical in conjunction with parent support (SE9; NE1; SE14).

*A continuum of care and support is important. To know that there is a place for their child to function and to be included in the community, if that's deliverable. That would be the ideal thing, I suppose. That's the sort of emotional support, but that would go further if they could know there are some areas in place that they can get that physical support (SE12).*

The needs of the child and the needs of the family do not exist independently. Parents often feel isolated with regard to their child's atypical development, being responsible for navigating social and sensory issues, which result in behavioural challenges.

*It's all about emotional regulation. That's their key. That's the driver that causes families so much more grief. And so they isolate themselves because they don't want to go to the park where their child is going to have a massive meltdown, they don't want to go to birthday parties or family gatherings or anything like that. So that is what I find impacts the most for families, it's just the isolation because of the difficulties of the child when they go out to those types of events. If they're just home, it drops off so, of course, they stay more in that (SE4).*

Many participants commented that parents are often juggling work and trying to access therapeutic services; they desperately need emotional support during these times of feeling overwhelmed (SE11).

Participants identified that parents require general support, but they also need specific support in order to make decisions about services for their child, that is, what services are to be accessed and in what priority order. Families need to assess the highest-need of their child and focus on securing access to those services. However, this task is impacted by the family's understanding, capacity, and financial situation to make those decisions and source suitable supports (SE13; SE2).

Interviewees spoke about what they thought to be the most appropriate time to deliver support to children and their families. They recognised that every family's timing, journey and needs are unique, so ideally what is offered needs to be flexible and able to be tailored to each family's individual needs (SE19).

*For some families it's about having behavioural management above everything else, for other families it will be having speech or OT or physio above everything else. It really is dependent on the child. [I]t's just as much about the wraparound services for the families as it is for the actual services that the child is going to have to access (NE2).*

Some participants held the idea that the family has to be ready to receive support (SE1; NE3; SE6) and suggested that it should be available to them whenever they require it. Other participants suggested that all mothers and children need support that ideally commences in the perinatal period.

*From birth. All children, irrespective of the diagnosis, should be supported through the first year of life and so that they have the positive interactions*

*too and then identify it. So it's just making sure that – probably before birth to make sure that the mother's stress is down, she doesn't drink alcohol. It is really the first 1,000 days if you want to put it in those terms (SE15).*

Participant responses in terms of 'when' support should be allocated ranged from specific periods where they considered support would be of most benefit to the family to simply, 'across the lifespan'. Some participants pinpointed the pre-diagnosis stage as a time when families need the most support (SE13) whilst others proposed that it was essential to provide support to families at the time of assessment and diagnosis (SE9; SE3, SE16) and then others stated that there are particular ages, that children and their families need the most support.

*It tends to be around the three, four-year-old mark that things really heat up as far as the emotional regulation goes, as far as the difficulties with the social development really, really stands out big time (SE4).*

Other participants considered that following diagnosis, the times of transition across the lifespan posed the greatest need for children and their families (SE1; SE14). Some interviewees advocated that family support in the post-diagnostic phase would be beneficial to enable parents to follow-up on recommendations and to access services.

*Someone going through the recommendations with them, to help navigate all of that. It's almost like a social work kind of role, I think. I think that's really lacking, and I find, especially if I'm working with newly diagnosed families, that I tend to have to fill that role. So they don't know how to navigate systems, they don't know who to talk to, they don't know who to advocate for them, they don't know about the NDIS. Even though it's all in the report, or sometimes not, but, yeah, it's hard to know what they actually need and where to start. It can be really overwhelming (SE7).*

Many participants were aware that the research evidence certainly recommends an EI approach to support (SE4; SE6; SE9; SE2).

Numerous participants communicated that families need assistance to navigate the current system. It is confusing for families and sometimes even for staff and providers (SE22; NWE1).

*It's a bloody difficult system to navigate. Even those who are staffing the system are never quite sure where to send people, how to send them, or what the best route is and so it's generally a scattergun approach that we'll just refer to everyone everywhere (SE1).*

It is important for families to look after their own mental health and wellbeing and to take a break from caring for their child. Accessing respite care provides all family members an opportunity to recharge (SE13; SE14).

## **Increasing community understanding and awareness**

This theme includes interviewees' insights into community-wide understanding of autism, and of families who have children with autism. Participants share their knowledge about what is currently being done to respond to the needs of local communities and where the gaps exist. Also covered here are stakeholders' perceptions about community information on autism and the CHaPS service. They provide some suggestions about ways to increase community understanding through promotion.

Participants conveyed that there had been recent shifts in the community's level of concern and awareness of autism.

*It certainly seems to have been an evolving and increasing area of need in terms of at least concerns about autism and raising the question about that. Even if the absolute numbers haven't necessarily gone up there's definitely more concern and more awareness in the community (SE18).*

It was acknowledged that shopping centres, supermarkets and other companies have offered invitations to the autism community to experience autism-friendly hours in a sensory sensitive environment (SE3; SE4). Despite these bids to support people on the spectrum and build community awareness, some interviewees considered current efforts to be negligible.

*I don't think enough is being done to challenge the stereotypes or combat the stigma surrounding ASD, and there is certainly no promotion of the skills and abilities of kids on the spectrum (SE13).*

Many stakeholders expressed that "a more supportive community with more opportunities" (SE21) was necessary (SE3). One participant suggested that it would be reasonable to think that schools are often a good place to start conversations and increase health awareness. Unfortunately, their experience did not back that notion.

*Our school has "Autism Awareness Week" each year – as far as I can see, this only seems to involve 'wearing something blue'. [M]y son came home from school and said he'd learnt that 'autistic people can't speak and they need to use a computer'. It would be great if they even acknowledged ASD in their school newsletter, not just in Autism Awareness Week – though I can't recall them even mentioning it then (SE13).*

### **Information, media and promotion**

A key method identified by participants to increase community understanding and awareness is to provide information to people. The use of media attention was recognised as a way to enlighten people about autism and to assist in reducing the associated stigma.

*There's a lot more media attention on the things that people with ASD can do, rather than what they can't do (SE3).*

Informing families of supports that they can access themselves can be empowering (SE17).

Participants mentioned that advertising and promotion within the community of the role of the CHaPS nurse, including the SACS-R, was important so that everyone was correctly informed about the scope of the services they provide to families (SE14; SE5).

*Everyone knows about the CHaPS. They might not necessarily think of them in terms of that assessment step or screening step. I think the perception would be, oh, I go there to have my baby weighed and so the lack of knowledge that, actually, there is actually this screening, not just from a pure health perspective, it is about developmental as well. And I don't know how well understood that would be across the board population (SE17).*

## **System issues**

This theme focuses on the major operational areas that the stakeholders identified as requiring rethinking and further development. System processes are at the centre of stakeholders' concerns, including the speed of the assessment pathway, having timely access to support services, and the need for professionals and the systems (health, education, disability) to all be working together more effectively. The creation of multidisciplinary teams (MDTs) is initially presented here and investigated further under the theme 'Sustainability of the model' (System redesign). Other topics covered under this theme are consistency of language across professions, the extensive waiting lists that exist statewide for assessment and therapies, ensuring that GPs and paediatricians are kept updated on the status of their patients' autism journey, the 18-month SACS-R assessment not being standardised across Tasmania, and different service opportunities depending on where families live.

### ***Areas for consideration and improvement to the process***

Several participants voiced that the current system already has all the pieces needed to make the autism pathway a success. Nonetheless, it is judged as not operating as successfully as it could. What was suggested was a strengthening of referral pathways, an increase in resources and for the current system to be promoted and utilised effectively and confidently by families, so that many children may never need to access disability services (SE1).

*The approach that's being put on the ground is [...] if we go through this we'll probably never go anywhere near the more formal disability system because we can get in early and give you some strategies. So I think it's really the referral pathways and the confidence of families to use the system. I think it's all there. I think all the parts are there, it's just how they are promoted and used, and then on the back of that you've got the resource issue (SE17).*

The participants acknowledged that the intention of the SACS-R program is clear, that is, to identify children early so that they can access EI (SE15). But if the services are congested

with clients who have been attending therapy for a long period of time, that impacts access for younger clients to those services.

*Needs to be a little bit of a reform that happens across Tassie, I reckon, about how we have our exit plans built into therapy for people who have been coming for a gazillion years and then to also be able to service the early intervention model in a really quick and efficient and intensive way so that we don't have them choking up the system when they're still 17 and 18 years old. They're clogged up with older clients and then that means that the young kids aren't getting any therapy which means that they'll have bigger ramifications in the longer term (SE5).*

It was suggested that the Personal Health Record (PHR), also known as the “Blue Book”, could include additional information for parents about what is covered at the CHaPS appointments and the importance of attending (SE3). Interviewees noted the importance of the CHaPS nurses receiving regular updates and training opportunities (SE13). Overall, the external stakeholders shared the ongoing concern that the current system in Tasmania does not provide enough support services and agreed that the resultant blocked system needs improving (SE13).

*If it is working and it's flagging early, then that's doing its job. But the problem is you've got a whole lot of ancillary services that need to fit off that and that's where we need to be concentrating. It can't just be doing SACS-R and nothing else because all you're doing is creating a whole lot of red flags and a whole lot of children who need support, but then you don't have any or enough support services wrapped around them and their families to provide the early intervention which is really what that's designed to do [...] if we don't actually have those services, we end up with a bottleneck which is of no use to anybody really (NE2).*

Stakeholders voiced ‘resource issues’ as a major concern that is constantly hovering over families and providers and is not showing any signs of change or improvement. Timely access to services is unobtainable due to the thin markets (SE14). In terms of service provision, there is a need for clarity. Under which system, health or disability, does the autism issue lie? If the answer is both, then greater collaboration between the two systems is necessary on a national scale. Contemporary feedback sees a major disconnect between the two (SE1). Participants voiced the value of developing relationships between mainstream health services and the partners alongside building a cohesive bridge between what is a health service and what is a disability service to support our families.

From an educational perspective, it was recommended that important information, gathered by services that children have accessed previously, be forwarded to the school to assist with allocating effective support.

*There's no follow through on the information once they come into any schooling. [H]aving that flow through of information where it actually doesn't fit just in the CHaPS area, it actually flows through into the*

*education system [...] it's really vital to have that flow on of information because if someone, say, goes to an early intervention service, that information will come through, but they may not know if someone has been somewhere else, and how do you find that out? (NE1).*

The gateway to accessing support in the academic setting is achieved as a result of assessment and a diagnostic label. To this end, if assessment and diagnosis is delayed, it is a barrier to students receiving the support they need prior to school entry.

Many interviewees were cognisant of the difficulties children with autism and their families face in the school setting. Schools are often not sufficiently resourced to support children with autism.

*These kids do need assistance in being maintained in that environment. So the number of students that are approved by the Minister of Education to be home-schooled is a great indicator of failure and the number of students that are e-schooled, [...] the number of students that are not involved in excursions because it's too much trouble, these are all the things that will attack their connection with community. So those are the things that we've got to be aware of and make sure that we do everything within our powers to keep those children engaged (SE11).*

Stakeholders commented on a desire to bring professionals together to work more collaboratively with regard to their clients (SE14). The paediatricians and allied-health professionals communicated their enthusiasm about developing MDTs, however, resourcing continues to be an underlying barrier alongside poor allocation of funds and limited long-term vision or strategic planning (SE13).

### ***Assessment language***

There were some elements around language usage that were raised by the external stakeholder group. A number of interviewees noted that the language used when talking with other stakeholders about a child's performance on the SACS-R assessment was not always helpful and sometimes it was quite ambiguous (NE3).

*I don't know how it's all framed to them and that might be based on the individual person doing the assessment. But I think the framing, we're trying to see if there's areas that might just need some further support rather than saying your child is atypical (NWE1).*

During the interviews, use of the word "disorder", as per the interview schedule when asking about Autism Spectrum Disorder, generated the following responses:

*I think the word 'disorder' in ASD is a very contentious word. For a family, that word 'disorder' in itself, I think, can do a lot of negative, it doesn't help promote awareness about what it actually is (SE22).*

*I have a problem with “ASD” in as much as how we define it. So in our language we don’t use ASD, we see that’s more of a diagnostic criteria term. So we tend to talk about the autism spectrum (SE11).*

### **Wait times**

This stakeholder group was consistent in their view that agencies and practices are full and have considerable waiting lists that prohibit timely and effective access to resources and services (SE22; SE21).

*If we’re flagging them at 18 to 24 months, but they’re not seeing anybody for another year, or another two years, that’s an issue. And then they’re going into early childhood education and school without necessarily the right supports. We’ve got ECIS, but we don’t have a huge amount outside of that, and a lot of the private practices are full or have very long waiting lists (NE2).*

There are delays across all services – assessment, therapeutic, wrap-around support, and funding.

*The feedback that I’m getting from families who once they’ve engaged in this system is the delays in assessment, delays in accessing services, delays in getting funding, NDIS challenges, so all of that is really making it tricky. And I guess this goes beyond the initial diagnosis but into actually accessing the early interventions to help support those families. That’s where it seems to be the hardest sort of challenge that we have (SE14).*

An interesting point was raised around waiting lists for services. It was suggested that wait lists may not be a true indication of the number of people actually waiting as families may have their name on multiple wait lists (SE1). There was concern that parents would not bother taking their children to their CHaPS nurse because if a problem is detected, the wait time for follow-up assessment with the DAT is lengthy (SE20; SE11). Quite a few participants referred to the enormous wait lists at TADS and the requirement to engage a paediatrician in the process which is another source of waiting (SE8; SE5; SE11; SE7).

Participant SE18, whilst acknowledging the long wait times for assessment, still concluded that even though access to services was difficult, that is not a motive not to provide autism surveillance.

*One of the potential concerns of any screening program is that there’s enough support for further evaluation once the screening has been detected to be positive and I think that’s been one of the concerns that I’ve had, that a number of my paediatric colleagues have had, is we recognise that some of the further assessment services are already relatively swamped [...] there are long wait times for formal assessments. Ideally, picking up early and providing those services early on would be fantastic and very much supported, and obviously that’s the intention, and sometimes you don’t know what the need is until you start to screen and*



*look for these things, so I think it's not necessarily a reason not to screen (SE18).*

A flow on effect of lengthy delays for services means that children with NDIS plans will not be able to utilise their funding.

*There's long, long waiting periods, [...] they have to be better met, because otherwise we're going to have a whole lot of money in peoples' plans that doesn't get spent (SE11).*

### ***Involvement and support of health professionals***

It was recognised that GPs and paediatricians wished to be kept abreast of where their patients are in their autism journey. As things stand currently, there are no formal medical linkages back to the GP or paediatrician. They are not being updated as to whether or not the child has undergone the SACS-R, the results of the assessment, and whether they have/have not been referred to St Giles (SE16; SE15). Interviewees stated that they wanted to know more about the SACS-R program itself so they can provide additional support to their patients.

*GPs will be interested to know and want to know a referral pathway because the waiting lists for lots of things are so long and so difficult. You've got a panicked parent who has all of a sudden got this tool that says, oh, gosh, my child might have autism, or be on the autism spectrum, and then they turn to the GP. If the GP doesn't know enough about it and isn't well equipped enough, they might not be able to reassure or assist to get that assessment quickly enough. GPs would want to be involved and would want to know about it (SE16).*

Some of the stakeholders were seeking specific support for themselves and their professional colleagues working in the autism area.

*I'm seeing a great system developing here to help these people. I would like to see more support for GPs, more paediatricians and more support for the psychologists specialising in this area (SE19).*

### ***The 18-month SACS-R assessment***

Overall, the external stakeholders were very supportive of the 18-month check. The 18-month surveillance was viewed as an important safeguard for families (SE20).

*If there are a few flags at 12 months, and you'd want to kind of see what had happened in those six months. That's just such a big gap and it's a big time. So much happens in between 12 and 18 months (SE7).*

One of the major benefits of the 18-month check is that early detection at that age leads to even earlier intervention.

*We had a little girl last year with a diagnosis through that process through CHaPS, came through with red flags and then came to us, she ended up*

*getting a diagnosis at 18 months. Now that's not becoming that unusual now for us to be working with families and children who are under two (SE22).*

This stakeholder group were fervently opposed to the absence of the 18-month check in both the North and North-West (SE7). For example:

*The biggest challenge is the fact that we don't have a standardised 18-month check in Tasmania. As part of the autism initiative, we actually funded putting the 18-month check in and that's time-limited. So there's a resource implication to make that continue, which is why we're quite interested to see the final sort of outcome to say, well, if there's a material difference in the age groupings, then there's more evidence to put to government to say yay or nay (SE17).*

This was highlighted as an issue with regard to inconsistency of process and services across the state.

*Lack of the 18-month check is a big hindrance for continued continuity of that service. I'd be really interested to know the drop off between 12 months and two years because I certainly think that, once you've kind of done that 12-month check, you have to wait another whole 12 months to go back [...] kind of less of a priority, and you were kind of less in a routine to do that (SE7).*

It was noted that the 18-month check was one of the recommendations laid out by the AAP<sub>1</sub>, but it was not supported by the CHaPS.

*I know that the Child Health and Parenting Service weren't always supportive of doing the 18-month check. So I think there's good support for a 12-month and 24-month. [T]here were a whole lot of recommendations made in that report [AAP<sub>1</sub>], and one was around [...] continuing 18-month checks. And I don't think that was necessarily supported by Health (SE9).*

### **Regional differences in services**

By and large this stakeholder group were concerned about the inequities that face rural and remote families, particularly the lack of services for their North-Western counterparts (SE11; SE20). Tasmania's remote regions were generally considered by participants to be more disadvantaged than the major city centres, like Hobart. Add in factors regarding transport and funds required to travel, alongside capacity of service providers, and then services tend to fall away completely for some families (NE2). However, there are clear differences within the state in terms of service response, e.g., the North-West coast have the ASELCC. Some participants perceived that the North-West contingent were receiving an appropriate level of services in comparison to the Northern and Southern regions.

*It's better than what I have seen previously in Hobart. They were referred for further intervention at the Autism Early Learning Centre which I think that was really good because that gave parents – if they've been told that*

*their child is abnormal that they're given that service and able to access that service and probably that's been pretty good up here, I think that access up here. But I don't think that it was working well when they were all referred to St Giles for assessment. Yeah, probably up the North-West I think it's probably worked a bit better (NWE1).*

Others saw it very differently:

*Epecially the North-West coast, in my experience, those guys, whilst they've got the St Giles Autism Early Childhood Centre up there, they have significant amounts of issues getting early diagnosis. And then when you do get it, it's then what access to services do you actually have if the flags are flagged (NE2).*

### **Sustainability of the model**

This final theme encompasses the two foremost challenges identified by the external stakeholder group: access to services and funding difficulties, the latter of which feeds back into the lack of resources. Participants offered their thoughts about education and training for current stakeholders and additional professionals. This theme concludes with the interviewees' critical analysis of the existing model and their determination if it is viable in its current form. Their ideas surrounding an overhaul of the SACS-R system and fresh concepts contributing to a system redesign are presented below.

#### ***Access to resources and support services***

##### ***Equity (geographically; socioeconomically)***

As outlined above in System issues: 'Regional differences in services', participants identified that there are geographical inequities within Tasmania in terms of access to resources and support services. In addition, from a health perspective the current model is also inequitable, socioeconomically.

*Unfortunately, I think people who are a bit more privileged, access help and so that further means that other children are kind of suffering more health inequities because their families can't access or can't advocate for them (NWE1).*

It was noted that inequity also exists in academic settings. In comparing the settings of primary and secondary schools, it was expressed that secondary schools typically have significantly less access to supports (e.g., speech and language pathologists) compared with primary schools (SE6). In the school environment, a child's capacity to speak and communicate socially are pivotal to their ability to develop connections with their peers.

*Probably speech and social communication [...] the most obvious barriers to them, to their education. If they can't communicate with their peers, they get isolated, they don't form friendships, they need so much explicit teaching and learning to develop those and schools are often poor, poor as in people poor, to help them with that (SE10).*

### *Mainstream schools*

The current climate in mainstream schools does not meet the disability education standards. Many children are excluded from conventional education and are offered alternatives like e-schooling and home schooling (SE21; SE9). Schools have some excellent staff members who support children and their families, unfortunately, collectively, they are generally, inadequately trained and under-resourced to be able to assist effectively (SE11; NE2).

ECIS do an incredible job of preparing mainstream schools for new students and ensuring that everyone is well-informed about the child's needs.

*There might be always a need to have some services that work to get children ready for inclusion and mainstreaming. [T]hat's going to be the biggest predictor of their overall success is to be ready for mainstream school and to be able to maintain their involvement with mainstream school all the way through because we know that high school is a great point of where there's a disconnect (SE11).*

### *Support schools*

Apart from the ASELCC in Burnie, there is no other centre in Tasmania that provides intervention services to specifically address autism from an early age. The presence of Southern Support School (SSS) in Howrah and the Autism Unit at Rose Bay High School were acknowledged as places of educational support in the Southern region. However, SSS is not autism-specific and eligible students must be on the Severe Disability Register.

*I know we've got Southern Support, but it seems like they're pretty full (SE6).*

*The Autism Unit is great, but in high school ages there's only sort of services for ten children in the South. That's not enough. There needs to be more, and, yes, more funding for supports within the schools. And looking at the whole thin market, having properly trained, or better trained support staff. I mean, with the NDIS we've got this huge increase in support workers and facilities, but not a huge increase in their skills (SE7).*

Several participants highlighted Tasmania's need to create schools to fill the niche between SSS services and mainstream classrooms (SE6; SE7; SE13). In addition, more autism-specific services, like ASELCC on the North-West coast would be welcomed in the South (SE6; SE7; SE11).

Overall, this stakeholder group acknowledged the state's challenges with service provision (NWE1). Service delivery for Tasmanian families is impeded by lack of services available.

*If you've got these flags, that's all well and good, [...] we then don't have the professionals to back up and either make the diagnosis or provide the therapies that are required for early intervention because we simply don't have the services available (NE2).*

## Resources

There is an incredible demand for services in Tasmania – assessment services, therapeutic services, specialised services, and wrap-around services for families – and they are unable to meet the need (SE13).

*It's great to be able to flag these issues and investigate them further, but you've got to have those resources in place so it can be done in a timely way, otherwise parents become disillusioned with the system and they go home and are just worried without knowing who to go or to find out more. Other supports as well as the child health nurse need to be in place and supports that are available in a timely fashion that are free or affordable for parents (SE3).*

If a child is flagged, it is critical to have assessment and follow-up services available. The availability of EI is required for a wide range of presentations, not just for those with autism. Each family and every child is unique so it would be expected that support needs will differ from individual-to-individual. To this end, it is important that supports are tailored to fit the specific needs of individuals and their respective family (SE21; SE17; SE20, SE6; SE7; SE18).

### *Lack of staff availability*

Statewide, in both the private and public sectors, there is very limited availability of practitioners to conduct assessments, provide diagnoses and deliver follow-up intervention and support (SE7; NWE1).

*We do have very limited available practitioners to actually do the assessment and the diagnosis, and that wait-time sometimes can put people off. It's the limited allied-health, in particular, professionals that are available to see these kids once they do have a diagnosis (SE2).*

Interviewees commented that there aren't just long wait lists for allied-health professionals but also for patients to access paediatricians too (NWE1; SE19; SE14).

*And I know from experience with my youngest child, I didn't get her into LGH to see a paediatrician, but we were really struggling with big bits and pieces, there was an 18 month wait because she wasn't considered the worst of the worst (NE2).*

Professionals need to be able to link families in with knowledgeable health professionals who can provide useful strategies to support the child's development and manage not just everyday practical issues but those complex issues as well (SE6). It is not just access to appropriate professionals, it is the *early* access that is needed, along with funding if also required (SE5; SE17).

*That would be probably the biggest thing, I think, for families and for practitioners is just trying to get the early help and assistance once they're flagged (SE14).*

## **Funding**

The SACS-R program is a cross-agency initiative. For the program to be successful, long-term strategic investment involving cohesive services with clearly defined roles is essential (SE1; SE4; SE10).

*Right now, the SACS-R was only funded until last year [...] and then Minister Petrusma made the election commitment of the \$100,000 per year for the next three years towards the early identification of autism, which is awesome, but, really, \$100,000 doesn't really go very far in a year when you've got so many different players involved. Minister Petrusma had quite a focus on autism and now that she has stepped aside and we have a new Minister, it will be important to keep it at a political level to keep it funded because it's not permanent funding (SE1).*

All but one interviewee named “funding”, “money for services” and/or “money for support” as *the* major challenge with taking this new health service initiative into the future. From a ministerial perspective the response to that direct question [“What do you perceive might be the major challenges with taking this new health service initiative into the future?”] was encouraging.

*Provided the evaluation is strong, I don't see funding as a challenge at all. So some people might think funding, but I would say that if the evaluation says it's necessary and of value and we've picked up X number, then I don't see that as a barrier. That's my personal opinion. But I think more broadly into the future what would be good in the evaluation is to see the increasing uptake of parents at all three stages of check and the fact that X number of children have been referred and so I don't really see any barriers, to be honest (SE12).*

## **Government**

Overall, this stakeholder group perceived that the government was responsible and accountable for ensuring the success of the SACS-R program.

*I think the responsibility of diagnosis, I believe, still sits with the state and, quite honestly, it should be resourced appropriately. The major barrier is peoples' capacity to pay for private diagnosis, and for those people we're letting those children down if the state isn't providing a timely access to diagnosis. It's very clear to me that it's the state's responsibility (SE11).*

Participant NE2 summed up the issue clearly:

*The government needs to look at this as a whole of government issue and they need to be able to look at what the research tell us about the best success in terms of early intervention and how children with autism progress. And then we need to design our services so that it is an all of government service. So if you are going through SACS-R and you do get those red flags, there is a pathway of what happens next and that it's*

*delivered in a timely fashion and that each of the different government services are talking to each other so by the time we get to a school-aged child, the school is ready - that's what ECIS does well now [...] they understand that transition [...] that child isn't subject to anything different to anybody else, they don't have to start school later, they don't have to do less days or less hours or be in a different room or a different classroom. It's about making sure that everybody is properly informed. And if you do that with kids with autism, you can do it for kids with anything else. It's just about understanding what the pathway should look like, what the best practice services are and just designing our service delivery accordingly. What we can't do is just rely on SACS-R to do the flags and go, there, look we've done it, look at this wonderful thing we've done, but we don't have the wraparound services to then go to families this is what happens next (NE2).*

Participants voiced concerns that they did not think that the government would commit financially to ongoing autism support because they would not consider the issue important enough (SE7; SE8).

*There is a lack of political will to adequately fund ASD-relevant therapeutic services in the state (SE13).*

#### **NDIS**

The largest primary disability category within the NDIS encompasses participants on the autism spectrum. Nonetheless, the available support resources do not equate to the number of participants nor their acknowledged challenges and therapeutic support needs.

*The services exist, but when you're looking at over 30% of participants in the NDIS are on the autism spectrum, and the funding has grown from – according to the Productivity Commission – will grow from 11 billion to 22 billion, I haven't seen evidence of the market of supply grow to the same extent (SE11).*

Interviewees talked about the introduction of the NDIS and how its roll out had increased the already-existing pressure on services. As a result of NDIS packages, along with recent DAT diagnostic outcomes an amass of children who are awaiting support has eventuated.

*The NDIS has also hampered a lot of people from accessing assessment services, and because a lot of places are closing their books now to people who are not with the NDIS which is excluding members of our community from being able to access these services (NE1).*

Currently there are families waiting to be accepted into the NDIS and there is a surfeit of applications which creates a holding pattern. There is also a Catch-22 in terms of assessments and plans.

*It's very hard to get in for early childhood assessments until you've got an NDIS plan, but you can't get an NDIS plan until you've got a package (SE20).*

Participants noted that the NDIS should not be regarded as a panacea for disability support (SE4) as the Scheme is absent in a number of important areas.

*NDIS isn't in education, it isn't in health, it isn't in justice, so it can't be just, well, that's the NDIS, they'll fix that. It's the whole community and what the state is still responsible for (SE11).*

*NDIS and their early intervention approach provides the opportunity, but I think the experience on the ground in Tassie is it's not working as effective, it's not working how I think the model is intended for a whole bunch of reasons, part of which is we just have an allied-health workforce shortage across the board and we're all competing. And so it's just, again, having the service sector out there that families can engage with (SE17).*

#### *Early Childhood Intervention Service cuts*

Early Childhood Intervention Service (ECIS) prepare school staff to receive new students and ensure that everyone is well-informed about new students' needs. One of the heralded beauties of ECIS is the fact that families who are in receipt of their support do not have to provide evidence of a diagnosis (SE22). Interviewees lamented the cuts to ECIS and recognised the potential threat of government decisions that could lead to the abandonment of this organisation altogether (SE5).

*The cuts to ECIS are a big problem. I mean, they're now saying they'll keep it going, but ECIS was a lovely, non-diagnosis specific way of getting extra support for kids with developmental needs, whereas a lot of the Federal funding is diagnosis specific, and that's problematic. So, I don't think our service is meeting the needs of children with developmental disability of any sort well, or autism, across the ages (SE20).*

Some participants made a plea to retain ECIS long-term. Notwithstanding, the hours that families currently receive from this organisation for EI and therapeutic support do not come close to what the evidence indicates is required to influence the child's trajectory.

*The early intervention centres that use the best practice and use the guidelines in terms of 20 hours a week of intervention, [...] you've got your ECIS, which is amazing, but it's an hour a fortnight (SE7).*

From a ministerial viewpoint, their perspective on ECIS was a very positive one.

*They do integrate well with our Child and Family Centres, which is almost like a hub model. I consider they are like a bit of a gold standard of school for students, well, young kids with disability because it's more like based on an educational model, not a health model, [...] and we're going to continue to fund ECIS, which is a good thing (SE12).*



## ***Education and training***

Interviewees expressed that there was a general need for appropriate education and training across multi-sites and to include all of the roles and integrated provision areas that support children and families along their autism journey (SE13).

*That knowledge of what is typical development and what is atypical and, yeah, what are some signs to look out for, I think that is probably pretty valuable information (SE6).*

*Helping parents and teachers or child carers to understand the reason for the behaviour, what's the reason behind the behaviour, giving the child some alternative ways of saying something, so they might want to just use a thumbs up or a symbol with a cup to the mouth sort of action or something like that if the child really wants to communicate but doesn't have the words. That's probably one that causes the most angst for the toddlers and therefore for the parents and the child carer (SE3).*

## ***Parents***

Educating parents about the importance of attending their child's regular CHaPS checks was highlighted (SE3). It was recognised by participants that parents in general need to increase their understanding of autism and the importance of securing services as soon as possible (NE2; SE21; SE3). Participants also thought that parents could benefit from understanding the important and valuable role they can contribute to the progression of their child's development (SE14; NWE1).

*How do we use parents as a support, rather than just supporting parents? Making the parent a resource, training them, give them the supports so the professionals are the supporters (SE15).*

*Parents are the best agents of change for their kids. But we owe it to them to help them understand where their kid is at and what they can do and to show them where those resources are. We only see the kid once every now and then, a parent is with them every day, so we need to give them the tools to do what they need to do. And I just think we're really letting the parents down (SE20).*

Participants stated that the government should provide educational support to parents at the point of post-diagnosis so that they are fully informed about resources (SE2).

## ***Professionals working with families***

Therapy providers reported having made changes within their organisations to address the lack of availability of clinicians. They are offering less face-to-face, one-to-one therapy, and increasing parent education so that parents can be upskilled to support their children therapeutically at home (SE5).

Participants voiced that there are not enough services or professionals who are experienced and/or confident enough in working with children with autism (SE13; SE3). Some interviewees indicated that there were challenges within the general practitioner sector that need addressing. Several participants viewed medical professionals as the gatekeepers to families accessing further support and suggested that they needed additional education.

*Lack of education of referral pathway people, so your GPs and paediatricians. I'm still finding that archaic kind of mentality in that with a couple of the paediatricians especially, that "wait and see". Come back in six months and let's review in six months, let's review in 12 months. And they're, oh, the kid's five and at school, oh, there you go. So there's that kind of really archaic, first do no harm kind of thing. So, yeah, I think that's a big barrier (SE7).*

They suggested that at a minimum, GPs should know about the SACS-R and refer families to their CHaPS nurse for assessment. In addition, GPs could be trained to administer the tool to their patients (SE22). The GP representatives expressed that they were interested in broadening their knowledge of autism and expressed that it would be beneficial to incorporate the SACS-R into their learning (SE19).

#### *School staff*

Interviewees from the medical and allied-health disciplines expressed that school staff need professional learning and autism-specific training (SE8; SE13). Participants from the education community concurred that their skills needed further support and were in favour of including medical and allied-health professionals in the school setting.

*We don't have the skills, we don't have the speech pathologist skills, we don't have the paediatrician skills, we don't have the psychologist skills. We need those allied-health professionals working alongside us. And the numbers that we deal with in a school is just huge (SE10).*

Interviewees also contributed that it is not just about children on the spectrum. Schools need to be building services so that an inclusive environment is created that enables any child to have successful access (NE2).

#### *Community*

It was suggested that providing education in the community about the CHaPS nurses' role would increase people's understanding and also increase family attendance when their child's health check was due (NE1). Even more broadly than just community awareness, national awareness was proposed as a way to educate people about autism and promote understanding.

*I wonder if that might be addressed by a sort of national campaign about helping people to understand what an Autism Spectrum Disorder is, what the implications of it are, what the strengths of it are, what the limitations of it are for people in terms of living their life (SE8).*

### ***System redesign***

Overall, participants were concerned about statewide staff shortages, inadequate service provision and insufficient government funding. A wide variety of solutions were offered to address the difficulties that the rollout of the SACS-R program has further amplified. There were several overarching policy and government challenges identified (SE18).

*From a policy perspective, meeting the National Guidelines and then reaching an across-government agreement about what that means and how you deliver that and how well the SACS-R meets that requirement. From a government perspective, always, is the funding challenge. So demonstrating the return on investment of the early intervention, and then I think governments always worry about, well, what happens when? So you achieve diagnosis, what then? And is there a service sector and actually the qualified allied-health professionals to meet the demand? (SE9).*

Other participants did not advocate that the solution to these challenges was funding. They reasoned that the relevant professionals needed enhanced deliberation and agreement on diagnoses (SE3). Some respondents promoted changes to health care parameters and equitable distribution of service access (SE20).

There were a number of participants who acknowledged that for Tasmanian people to achieve an allied-health qualification in many of the disciplines, they would be required to travel interstate. Unfortunately, after qualifying, many of them do not return to the state. It was suggested that if UTAS could offer allied-health courses that would potentially contribute to building a workforce in our state to support our families (SE9; SE11; SE17).

Other suggestions related to study at the tertiary level, involved interfacing established clinicians with newly certified professionals so they could proficiently provide services too (SE11).

Stakeholders discussed ways that could ensure that there is a workforce, particularly in more isolated regions, and that families could have access to that workforce. They made suggestions about how to address the issue.

*There might be particular geographic locations where we might need to think about placing services. So we're starting to think about the system a bit differently and not saying everyone has to come to a centre (SE17).*

Participants proposed that if children were not reaching their developmental milestones as expected, families could have access to alternative services whilst in the waiting period for assessment and/or therapy from traditional therapeutic arms (SE17; SE1).

From a medical perspective, participants were keen to further upskill medical practitioners and recommended the establishment of a statewide neurodevelopment service (SE15).

*A specialist sort of neurodevelopmental government run clinic with a range of professionals, multi-disciplinary professionals that could undertake ASD assessments in a very structured and formalised way. With no waitlist (SE8).*

It was suggested that ideally, families should be assessed in a timely manner (a minimum number of appointments over a maximum of three months) then linked in with services. Preferably, families would access support from a single organisation with all the necessary service providers located in the one establishment (SE5 p SE1; SE7; SE2).

As acknowledged by the interviewees, one of the most difficult aspects that needs addressing is the lack of staff. How to increase the workforce? What are the alternatives to the current model? (NE2, NWE1). Some participants suggested the creation of new work roles (e.g., social worker positions) to provide support to families, especially those with literacy challenges, in relation to coordinating services (NWE1).

One interviewee was hopeful that the current system *will* be successful once the contribution of the NDIS eases (SE17). Others viewed the NDIS as quite arbitrary and recognised that some families face challenges accessing the scheme.

*The NDIS has rolled out [...] I think that is working really well for some families now and not for others, and I'm thinking the ones it's not is more complex about the fact that they don't know how to get access to it, they can't read the documentation, it is huge, they don't understand it, they don't understand their rights and responsibilities and their literacy standards aren't good enough to be able to – they need so much support (SE10).*

Suggestions were made in reference to making the existing system more holistic and robust by addressing key elements of the process such as the referral pathway to assessment and wait lists (SE21).

*Over the next three years we'll need to do a bit of a focus on just the whole diagnostic space because all our services have such long waiting lists. [L]ike how do we increase resources in that area or do things differently including best practice assessment? Probably the other one for me is the referral pathway, so getting that awareness out there and actually that understanding (SE17).*

Some participants suggested outsourcing assessments in an attempt to decrease the current wait lists, for example:

*All of the services that would do assessment are totally, totally overwhelmed. [I]n the private sector that's really expensive. I think that if they actually probably looked at a model where they could outsource some of the work that the government itself can't cope with would probably help. So if you were looking at maybe having some government-funded initiatives, say if they bought five hours a week from a psychologist and*

*speechie to come in from externally to bump the service along, that would probably work (SE5).*

The ASELCC model was recognised as not just a valuable therapeutic support to families on the North-West coast, but its existence also decreased the burden of early assessment.

*I think it would work well if what's happening with the Autism Early Learning Centres is continued. I think that's really a vital part of that, rather than automatic referral to the St Giles autism assessment team straightaway, and particularly because there's not that pressure at the moment now with the accessing the HCWA funding anymore and the model changes with NDIS as well, too (NWE1).*

Participants shared that in Queensland, Occupational Therapists (OTs) are employed by the Department of Education. OTs travel out to schools and support children with autism diagnoses and their teachers. Input from allied-health professionals in schools was considered a worthwhile addition to supporting students on the spectrum. In Tasmania, there are no OTs in the public school system (SE2).

Stakeholders were interested in strengthening community relationships and finding opportunities to connect with families based on ease of accessibility regarding where they are at, not just geographically, and without the burden on families to seek services. Rather, the services would come to them and ideally provide broad coverage.

*If you've got a place where you can just go hang out and it's part of your everyday life already, I think that's going to be the beginning of increasing the health literacy and increasing the understanding (SE1).*

*If you've got a community centre with drop-in and parenting support and cooking classes and co-babysitting and something that looks really like a social event, but is actually structured and parenting support and picking up PND and picking up developmental disability, and structured play with a teacher and a quick referral to an early intervention service or maternal mental health service or housing referral, or domestic violence referral, that is bloody fantastic. That is going to make such a difference to our kids, if we can protect them by protecting their primary caregivers, we're going to do much better (SE20).*

Participants raised the potential of services becoming involved with communities and young families at the *Launch Into Learning* level.

*I think that the actual tool has a lot of implication for the childcare sector and for Launch Into Learning programs because we know that there's a massive uptake of families in both those arenas. Kids are more likely to be going to childcare or go to a Launch Into Learning program than probably anything else these days pre-four. That's where they go now. So, I think training up some of those teachers and educators (SE22).*

Childcare centres that specialise in supporting children on the autism spectrum were identified as being a cost-effective way of intervening therapeutically with a large number of children at the one time.

*A specially trained childcare centre with staff that are really responsive and know ASD [...] an ASD-friendly childcare centre, where, say if you've got 24 kids, 12 of them are on the spectrum, but the other 12 aren't so there's a lot of opportunity for peer modelling and interaction. All of the intervention can happen within their childcare day. Parents are able to be a part of that. And, yeah, they've got sort of specially trained staff...there's a great transition to school program (SE7).*

This group of stakeholders were clear in their recommendations about what they envisaged in the near future in the autism space regarding assessment, diagnosis and support. They expressed the importance of building Child and Family Centres (CFCs) to improve family accessibility and strengthen communities (SE20; SE21).

*The Child and Family Centres are really great enablers. They have got the appropriate environments in the vulnerable areas, but there should be a uniform program across the Child and Family – something like the Early Start Denver Model is fantastic, where the professionals can train the families to be the enablers. Because we will never have enough resources for the professionals to do all the work that needs to be done (SE15).*

However, the people living in rural and remote areas may be unable to engage with those services (NWE1).

Stakeholders indicated that due to the current limited access to services, families simply miss out on therapy. Collectively, their desire was to see Tasmania working on developing and implementing an MDT approach. MDTs are the solution at the heart of this stakeholder group's hopes for the future in the autism space.

*If we had a robust developmental multi-disciplinary team with good numbers of allied-health professionals, so the CHaPS nurse could say, gee, I'm a little bit worried about little Harry, please come and see my friends, the MDT. I've got a psychologist and a speechie who will be great. And they might say, look, Harry is a little bit slow with his language, here are some great things you can do to help Harry. Do these things at home and we'll see you again in six months. We're not going to put a label on you now. I think that's a win/win situation. You're supporting a parent, you're fostering better parenting, it's something that's applicable across a wide group of kids (SE20).*

#### **4.4 Integration of findings**

The final exploration of the results is via an integration of the quantitative and qualitative findings. The integration of results facilitates three main outcomes. First, the identification of enablers and barriers across personal, practice and political levels. Second,

understanding of the complexities of the whole process from first discussions to implementation, referral pathway and then early support and intervention. Finally, identification of the implications for successful adoption of the SACS-R into routine clinical practice within the public health system.

The results were converged using integration principles and practices as described by Fettes and colleagues (Fettes, Curry & Creswell 2013). The process of integration was to synthesise the stakeholder results. Results were further sorted and into thematic categories that were common across groups. This led to the generation of five major themes that originated from the parent experience and were built upon and further developed from other key stakeholders' views: meeting with the CHaPS nurse; referral to St Giles; waiting for an assessment; receiving an assessment; and the post-diagnosis phase. There were two additional themes generated, not raised by the parents, but collectively shared by the internal and external stakeholders: insights into the communication and collaboration between project partners and services; and insights into the sustainability of the current model.

#### **4.4.1 Convergence tables**

The experiences of the referred parents are the starting point for the convergence of the qualitative and quantitative data. Then the views of the other participants were summarised and incorporated, indicating where and how they agreed (confirmation), disagreed (discordance) or expanded on the results of parents' experiences (as set out in Tables 4-13 to 4-19 below). This is presented in tabular form, with the parents' results in the first column, and subsequent stakeholder results in the subsequent columns. Coloured cells denote corresponding sub-themes across stakeholder groups.

**Table 4-13. The parent pathway: parents' experiences of meeting with the CHaPS nurse (initial and subsequent appointments)**

Parents' experiences	Confirmation	Discordance	Expansion
First meeting was a good opportunity to have SACS-R screening and meet with a professional to discuss concerns	All stakeholder groups appreciated the meeting point. Opportunity to not only use tool, but facilitated engagement with parents, form relationships, intervene early	Nurses lacked time/capacity to conduct assessments, enter data or complete referrals. This varied across the state	Nurses' confidence in making referrals increased. Developed relationships with DAT
Overall, the CSQ-8 data supports that the parents had a positive experience engaging with the CHaPS nurses	CSQ-8 data revealed that parents were satisfied with the SACS-R assessment process MIDI and interview data verified nurses were satisfied with the SACS-R tool		Non-attending families at (CHaPS/DAT) still require support
	<i>Salesforce</i> data confirms that the first meeting picked up children at high likelihood. It also shows that parents returned for follow-up appointments and additional children were also identified at those points		
	<i>Salesforce</i> data indicates repeated use of the SACS-R for the same-age assessment	Some Southern nurses were directed by management not to pursue 18-month checks (internal stakeholders)	The 18-month assessment was not a pre-determined check in the North or the North-West
	<i>Salesforce</i> data shows that follow-up assessments tracked developmental changes		
	MIDI and interview data suggested that managers were satisfied with the SACS-R assessment process	The SACS-R tool was being used by other professionals, who were untrained, outside of CHaPS appointments (external stakeholders)	People in other professions, e.g., GPs, could also be trained in the administration of the SACS-R and the referral process
There was confusion around whether the SACS-R was an assessment for autism	Nurses and managers struggled with not being able to call it an 'autism assessment' and devised various inconsistent answers to parents' queries about what the SACS-R was for		Public education about autism is needed, and greater efforts to increase community awareness
	External stakeholders were concerned whether the SACS-R assessment was covertly administered		
	An assessment results in an unwanted label of autism (external stakeholders)		Importance of nurses receiving continued support in their role and having access to ongoing training
Consistency and clarity were needed with regard to the terms used, e.g., "autism" vs "social attention/communication"; "passing" or "failing" vs "typical" and "atypical"		Inconsistent language between parents and nurses. Nurses trained to use particular terms, however, there was a mismatch between their training and practice	Given the evidence regarding the ambiguity of language across stakeholder groups there is a need for monitoring and support



**Table 4-14. The parent pathway: parents' experiences of referral to St Giles**

Parents' experiences	Confirmation	Discordance	Expansion
There were parents who did not expect to be referred	The experience was challenging for some parents (internal stakeholders)	Nil identified	The SACS-R process and a clear referral pathway to St Giles for further assessment is valued
Some parents were relieved to be referred	CSQ-8 data indicated that the parents were satisfied with the referral pathway		Why even conduct the assessment if timely follow-up and services are unavailable? (external stakeholders)
There were parents who requested to be referred despite their child receiving a typical SACS-R result. These were first-time parents or parents who had an older child with a diagnosis	Parents and nurses with an older child with a diagnosis were appreciative of the current pathway  Experiences with older children had caused parental upset (internal stakeholders)		The process resulted in improved communication and collaboration between project partners and services
Other parents anticipated a referral and subsequent receipt of intervention but were not referred			Absence of pre-determined 18-month check in the North and the North-West meant limited referral opportunities

**Table 4-15. The parent pathway: parents' experiences of waiting for an assessment with St Giles DAT**

Parents' experiences	Confirmation	Discordance	Expansion
Some wait times were very long	All stakeholder groups agreed that the waiting times (for St Giles and ASELCC) were a major problem  St Giles now had two pathways but were utilising the same staff	It should be a swift service so that parents do not need to go elsewhere (external stakeholders)	During the wait, families need to have access to services  Child expectations and parenting styles can be impacted negatively during the wait (external stakeholders)
Emotional time (stress, frustration)	This was not just the case for parents. St Giles and ASELCC staff were stressed too and felt overburdened	Families in the North-West had the advantage of ASELCC services (internal and external stakeholders)	It is necessary to provide parental support regarding the stress and anxiety experienced by families  Flexible support and back up for services (St Giles) given their reported stress  There is unnecessary emotional impact placed on parents (external stakeholders)
Some parents showed a readiness for diagnosis and subsequent early intervention	The younger the child the more accepting the parents seem to be of the potential outcome (primary and internal stakeholders)		
Prior to assessment some families were already receiving professional support for their child	It is good to be able to get started with other services. Parents should not have to wait (external stakeholders)		

**Table 4-16. The parent pathway: parents' experiences of receiving an assessment with St Giles DAT**

Parents' experiences	Confirmation	Discordance	Expansion
Impressed with the knowledge, professionalism and support received at time of diagnosis			Delivery of diagnostic information and the support provided (including NDIS paperwork) were important variables in parents' acceptance of the outcome
Received a diagnosis		Concern expressed for parents who came alone to the assessment and were unprepared for the outcome (internal stakeholders)	There is wide support for early identification of autism and developmental delays (primary and internal stakeholders)
Did not receive any diagnosis		Paediatricians assumed a high rate of false positives and low rate of false negatives, which can cause unnecessary parental anxiety	
Unexpected diagnosis	Even so, parents and St Giles DAT felt overwhelmingly positive about the assessment process	Emotional time for parents. Some were uninformed and unprepared so they came to the assessment without support (internal stakeholders)	Support and guidance are needed for <i>all</i> families from the SACS-R assessment to the post diagnosis phase, not just those who receive an unexpected diagnosis

**Table 4-17. The parent pathway: parents' experiences during the post-diagnosis phase**

Parents' experiences	Confirmation	Discordance	Expansion
Reviews did not occur as planned	St Giles noted that reviews did not go ahead as proposed due to the waitlist for assessment, which was a priority over conducting reviews		The project was under-costed so reviews were not undertaken as intended due to waitlists and staff shortages
Some parents were able to get in early and access services	Every stakeholder group agreed that EI is critical		A child should not require a diagnosis to access support (internal and external stakeholders)
Recommended services had long waits lists	All stakeholder groups agreed that there was limited availability and/or delays in receiving intervention and support	There are enough services the issue is how the funding is being utilised (external stakeholders)	Regional differences exist across the state
There are no services available, unless in the private fee-paying system and even then there is limited access			Families cannot access timely and effective access to services
There is uncertainty around funding for support services, therapy and further and/or ongoing assessment	Internal and external stakeholders stressed the need for parents to have assistance to navigate the services		Tasmania is in a time of transition from <i>HCWA</i> and <i>Better Start</i> to the NDIS
Due to inadequate funding, the goals of the project (e.g., timely DAT assessments) could not be achieved	Internal stakeholders concurred that funding was insufficient for the project		Government funding was lacking and could not meet the needs of families and the goals of the project
			Supporting parents as effectively as possible regarding information about what the St Giles assessment involves and the possible outcomes

The results specific to the internal and external stakeholders regarding aspects of the SACS-R rollout that were not raised by the parents are converged in Tables 4-18 and 4-19. Their results concerning communication and collaboration between project partners and services (Table 4-18) and the sustainability of the model (Table 4-19) are summarised and incorporated, indicating where and how they agreed, disagreed, or 'expanded' on each other's experiences, rather than the parent pathway.

**Table 4-18. Internal and external stakeholders' insights into the communication and collaboration between project partners and services**

Clinical pathway	Confirmation	Discordance	Expansion
Enables monitoring of adherence to the aims of the project and ensures families are supported throughout the assessment and diagnostic journey	Internal stakeholders were supportive of regular opportunities to communicate and were disappointed when the meetings no longer occurred	St Giles DAT contacted parents regarding upcoming assessments and found that they had not been sufficiently informed about the assessment	Ongoing training of nurses; clear language used; and parents being appropriately informed about what the St Giles assessment entails, e.g., length of time; can bring a support person; there will be a diagnostic outcome
			Continue to build professional links between services to ensure success
	CHaPS nurses, St Giles and ASELCC were appreciative of the relationships established between services		Relationship development between health and disability services to enhance support to families

**Table 4-19. Internal and external stakeholders' insights into the sustainability of the current model**

Clinical pathway	Confirmation	Discordance	Expansion
Throughout the process, families are continuously in the wait-zone	Both stakeholder groups agree that for the SACS-R to make sustainable change in Tasmania it needs to be funded appropriately and resourced sufficiently to support the process	The ASELCC in the North-West is the only one in the state and is considered very successful. Should this be replicated in the North and South?	<p>The SACS-R program is a three-part process – surveillance, assessment and intervention services. Whole of service delivery needs to be addressed with clear clarification of the delays in order to move forward in an integrated way</p> <p>Inform all relevant services about what is available, i.e., the SACS-R assessment, referral pathways, ECIS</p> <p>Need a central place for collection of information that services can access to support the child and family as effectively as possible</p>

The highlights of the convergence of the qualitative and quantitative data as set out in the above seven tables include the following:

1. Across all data, there was confirmation of broad support for the administration of the SACS-R tool.
2. The findings from the various stakeholder groups were largely confirmatory, however, there were multiple points of discordance and expansion.
3. All stakeholders confirmed that the 18-month assessment was useful in identifying children with high likelihood of autism. Expanding on this finding, was that some nurses in the Southern region reported that they were directed not to pursue 18-month assessments.
4. Confusion, ambiguity, and lack of transparency regarding language use in the context of autism came through from the qualitative assessment across stakeholder groups. Expanding this finding, the SACS-R tool was found to be in use by untrained professionals, raising issues about language inconsistency, training needs, and multiple stakeholder involvement beyond the CHaPS nurses.
5. Most parents were satisfied with their child's referral to the DAT. Some children were referred even though they received a typical SACS-R result. This was due to them being a first-time parent who was seeking reassurance or a parent who had an older child with a diagnosis. Other stakeholders expanded on this finding, observing the referral pathway to be efficient and clear. Expanding further on this finding, some parents came with the expectation of referral and did not receive one.
6. Paediatricians assumed a high false-positive and low false-negative rate and concluded that these outcomes would cause unnecessary anxiety amongst parents. In reality, there was divergence in thoughts and experiences here, with the parents not showing concern for false assessment results. In contrast, parents felt relieved and grateful for the opportunity for their child to be thoroughly assessed by a multi-disciplinary team.
7. Post-diagnosis there were several areas in which the findings were confirmed across all stakeholder groups (parents, nurses, and managers) including long waiting times, lack of follow-up with reviews, and having limited public health service resources. However, there was discordance from the external stakeholders who suggested that there is enough funding across the state but due to poor governance across services it is not being utilised appropriately.
8. All stakeholders confirmed the importance of building professional links between services. These connections were viewed as essential to the successful delivery of the SACS-R program. To do this, sustainable change in Tasmania is required through ongoing funding and generation of key resources.

#### **4.4.2 Summary**

In Chapter 4 the quantitative results and qualitative findings were set out. An analysis of the *Salesforce* data using descriptive statistics and Pearson chi-square tests was provided. The key finding of the *Salesforce* data was that 6,001 children presented over the 17-month period (representative of 76% of children eligible for SACS-R assessment). The

number of children monitored, attended a total of 7,161 consultations. More males were monitored for SACS-R assessments than females and this trend was indicated across the study period for all regions. Of the 6,001 children monitored, 190 (3.14%) had a high likelihood outcome and 128 of these received an autism diagnosis. This result represents 1 in 47 children and an estimated prevalence rate (12-24 month) of 2.13%.

A mixed method approach integrated the quantitative and qualitative data, that assisted the researcher in converging the findings of the study. First, the quantitative element included the CSQ-8 questionnaire and MIDI survey data. These data sets were analysed using descriptive statistics and non-parametric tests. Second, the qualitative interviews were conducted and were analysed using thematic analysis to generate the themes and sub-themes.

The findings of the narrative data coupled with the results of the quantitative indicated that there was overlap and agreement and also discordance amongst stakeholders', with the data collectively indicating areas for support and recommendations. The key results are as follows. Parents meeting with CHaPS nurse to share any concerns about their child's development was a positive experience for both parties. The tool identified children at high likelihood of autism at 12, 18 and 24-months assessment and facilitated their referral to the DAT. The 18-month assessment proved worthwhile with additional children picked up at this assessment after having been initially assessed as low likelihood at their 12-month assessment. It was discovered that other professionals who were untrained in the administration of the SACS-R were using it in their work. Language inconsistencies across stakeholder groups was highlighted as a challenge along with nurses feeling uncomfortable about not being clear with parents about the purpose of the assessment.

It was perceived that the North and North-West were at a disadvantage compared with the Southern region in terms of the 18-month assessment and intervention. However, they do have the ASELCC which is highly regarded and a source of excellent support and many expressed that it would be helpful to replicate this organisation in other areas of the state.



## Chapter 5: Discussion

The overall aim of this thesis was to investigate the enablers and barriers to successful statewide implementation of the SACS-R early childhood surveillance program into the public health system. Of particular interest was consideration of the implementation process from the perspective of the people it most effects, that is, the children who have autism and their parents. The purpose of this chapter is to discuss the key findings in the context of the existing evidence. This chapter also highlights the biases, limitations, strengths, and problems encountered during the various phases (pre-conception, during, and post-conception) of this project.

This chapter commences with a dedicated discussion of the significance of the *Salesforce* data results. A discussion of the overarching key findings related to parents' experiences throughout the SACS-R journey follows. Those key findings are incorporated with the findings associated with the experiences of the internal and external stakeholders. Three theoretical frameworks are used to explore the extent to which the factors can be considered as enablers or barriers for successful implementation.

The SACS-R program involved the training of 101 CHaPS nurses in the administration of the SACS-R tool in order to identify 11-30 month old children who are at high likelihood of autism. Following training, the nurses were able to assess children's behaviour, record behavioural outcomes in *Salesforce* and refer children to the DAT for further assessment. This developmental surveillance approach for assessing children's social and communication behaviours was new for the CHaPS and Tasmanian families and was successfully administered to young children across the three regions of the state.

### 5.1 Implications of *Salesforce* results

The Tasmanian birth rate per month directly informs the number of children eligible for monitoring with the SACS-R. Figures from the Australian Bureau of Statistics (ABS) on the Tasmanian birth rate per month were accessed for the period between September, 2014 and March, 2017 (N=14,683) (Australian Bureau of Statistics 2021). The ABS data was investigated to ascertain if the *Salesforce* data coincided with the study's statistical analyses. The data indicates that the average number of Tasmanian births for the years 2014-2017 was 5,798 children per year. Across those four years, male births outnumbered female births every year by an average of 130 births. The annual birth rate in Tasmania has been declining slightly. This is confirmed through the ABS data report that shows the number of births recorded for years 2016, 2017 and 2018 were 5,815, 5,472 and 5,406, respectively, an average of 5,564 per year.

The ABS data (2021) indicates that the two peak times for babies being born in Tasmania in 2017 were May (n=489) and September (n=490). May 2017 was the second biggest birth month (by one birth) for the year. The September, 2017 babies would be

eligible to present to the CHaPS for their 12-month assessment in approximately September, 2018 so they fall outside the *Salesforce* data collection window.

During the 17 months of data collection, 31 October, 2016 - 23 March, 2018, 6,001 children aged between 12-24 months were assessed statewide. The approximate number of children born between October, 2014 – March, 2017 and thus eligible for assessment at 12, 18 and/or 24 months of age in the data collection period was 14,170 children. Whilst 6,001 children being assessed is to be acknowledged as a worthwhile effort by parents and CHaPS nurses, it is a conservative number of presentations given the number of children that could have potentially been assessed. It can be estimated that, the CHaPS nurses may be seeing around 76% of all new births at least once (4,236/5,564).

At every age cohort more males than females were brought along to consultations. This correlates with the birth statistics, as more males than females were born in the period leading up to and during the study period and therefore eligible for assessment during the data collection dates. In addition, there are further possible reasons why more males presented for SACS-R assessment than females. First, there is a long held view in communities that females develop language abilities at an earlier age than males (Etchell et al. 2018) and this may affect parents' enthusiasm for having their male children assessed. Second, neurodevelopmental conditions, such as autism, ADHD and intellectual disability affect more males than females and also impact language development (Etchell et al. 2018). The research indicates that males are two to four times at higher risk than females of being diagnosed with a neurodevelopmental condition (May et al. 2019), thus triggering parent action at a younger age. Finally, and more specifically, it has been well established that there is a higher prevalence of autism in males than females (Elsabbagh et al. 2012; Maenner et al. 2020; Schaafsma & Pfaff 2014; Shaw et al. 2020). As such, parents of male children are more likely to be noticing signs of concern.

The *Salesforce* statewide results showed that 3.2% of children monitored with the SACS-R displayed an atypical presentation. This percentage was a much higher rate than the literature indicates, that is 1-3%. All three regions had prevalence estimates higher than expected. On closer analysis, the higher than expected percentage rate overall for Tasmania was attributable to the North-West. Here there was particular unexpected variation, with 6.1% of the SACS-R assessments yielding an atypical result, compared with the North (2.5%) and South (2.3%) which were more in line with prevalence estimates. Although the North-West had the lowest number of consultations statewide, the region had the greatest number of atypical children monitored. One possible explanation for this statistic is that the study offered an opportunity for children to be referred on, as opposed to experiencing long wait times for previous diagnostic teams. It is highly likely that the nurses anticipated that the newly-established referral pathway provided a swift route to formal assessment for families. That is, there was a rush on of referrals under the SACS-R program.

The 18-month assessment was only a pre-determined assessment in the South. Thus, if children attended an 18-month assessment in the North or North-West it was either due to a concern from the parent and/or the CHaPS nurse. If a child is not assessed at 12 months and they live in the North or North-West of the state, they need to wait another 12 months for their 24-month assessment. From Figure 4-2 in the Results chapter, it is clear that the SACS-R assessment was picking up a large number of children at the 18-month assessment.

It is evident from the results that children benefitted from coming in for their very first consultation at 18 months old. This major finding - that the 18-month assessment was worthwhile - has implications for the retention and expansion of that age assessment into the future. If the 18-month assessment was not provided consistently across all the three regions there would be children who would not be identified and EI would not occur during the optimal age range.

Regarding the results of the 14 children above (Results chapter p 78 onwards) who were identified at their 18-month assessment as high likelihood (after being assessed as low likelihood at their 12-month assessment), it is reasonable to conclude that the nine children who did not return for their 24-month assessment did not do so because they had been referred on to the DAT for assessment. In relation to the two children who had two 12-month assessments, one 'atypical' and one 'typical', it would be considered a fair hypothesis to state that the 'atypical' result occurred first then the 'typical'. If it was the reverse scenario, that is, the 'typical' result followed by the 'atypical', then it would be reasonable to suspect that the parent would have been offered an 18-month assessment even though both children resided outside the southern region where the 18-month assessment was not pre-determined. Given that their final result was 'typical' the nurse probably recommended to return at 24-months. Attendance at SACS-R assessments is driven by parental behaviour so perhaps the parents (and the nurses) felt assured by the repeat 12-month assessment and the nurses invited them to return for their children's 24-month assessment to secure further reassurance. It can be seen from the data that in both these cases the nurses' determination was accurate. The children both attended their 24-month assessment and both received a 'typical' result.

Five of the "double" assessments where the result was 'atypical', occurred at the 12-month SACS-R and in regions where the 18-month assessment was not pre-determined. Four of those five children did not have any data entered for an 18-month assessment so it appears that the nurses may have been adhering to protocol. Nonetheless, two of those five children went on to receive an 'atypical' result at their 24-month assessment and one of the typically presenting children who was tested twice with the 12-month SACS-R, also returned an atypical result at their 24-month assessment. Had those children had the opportunity to attend a pre-determined 18-month check it is highly probable they may have been identified six months earlier and referred onto the DAT. It may also be possible that the two children had been referred to the DAT following their 12-month assessment and came back at 24 months to have a check-up and monitor progress with the SACS-R. I would assume

that this was probably the more likely scenario. However, regarding the 12 North and North-West children whose 12-month assessment outcome was 'typical' who then returned 12 months later for their 24-month assessment and were flagged as "high likelihood", they may have missed out on a potential six months of EI. More of a concern, are the five of the eight children who presented as 'atypical' at their 12-month assessment. They did not attend their 18-month assessment, presumably because they were from the North or North-West regions, and returned at 24-months and received an atypical result. There are another five children who theoretically could have been receiving timely intervention, potentially 12 months earlier. The data shows that in many North/North-West monitored children, both 'typical' and 'atypical, the nurses were happy to invite parents to bring their child back for an 18-month assessment.

Overall, the Tasmanian data recently received from OTARC revealed that of the 6,001 children who were monitored with the SACS-R, 190 were identified as atypical and referred through for further assessment at St Giles (Dissanayake et al. unpublished – under embargo). Of those 190 children, the diagnostic outcomes were as follows: 128 autism and 62 developmental delay/language delay. This is an important finding, that came as a surprise to the research team, as 100% of the children flagged on the SACS-R as high likelihood for autism were found to either have autism or some type of delay. Moreover, this indicates that the SACS-R is not only a surveillance tool that is sensitive to autism. In addition, it has capacity to identify young children who present with a number of atypical behaviours. This result is in direct contrast to what the external stakeholders anticipated. That is, high false positive results associated with SACS-R surveillance.

## **5.2 SACS-R implementation enablers and barriers**

Three main theoretical approaches are used to frame the discussion of the results related to the parent and stakeholder experiences of the dissemination and uptake of the SACS-R process that follows. These are classic theory, determinant framework, and evaluation framework (Nilsen, 2015). Green and colleagues' (2014) classic theory informs the development in thinking that has occurred over time regarding the knowledge–practice gap and its outcomes. Of particular relevance to the current study is their surveillance framework which emphasises the impact of social and community factors on the end-user along with their identification of the various factors that facilitate knowledge utilisation.

I draw on aspects of Green's utilisation-focused surveillance framework in conjunction with Fleuren's (2004) framework of determinants as post-measure to assess the impact of determinants on the SACS-R innovation. Determinant numbers are identified, as set out in Chapter 2. I also engage with the Implementation Science (IS) theoretical framework of Handley and colleagues' (2016), which comprises three phases: preintervention planning, designing the intervention strategy and evaluating the implementation strategy. Their three key principles that should be adhered to in order to

address the evidence–practice gap inform my discussion, that translation to successful sustained practice change requires:

1. behaviour change;
2. engagement with a range of individuals and stakeholder organisations; and
3. room for flexibility or non-linear approaches that fit within the real-world context.

Analysing my results using these frameworks, alongside other relevant literature on the topic, it is clear that the implementation process has been complex, containing multiple enablers and barriers, each with capacity to impede or facilitate at various points along the journey. I now discuss these in more detail.

### 5.2.1 Parent, child and nurse meeting

The enablers and barriers to a successful first meeting and the use of the SACS-R tool are summarised in Table 5-1 below.

**Table 5-1. The enablers and barriers to child and parent meeting with the CHaPS nurse and the SACS-R is administered**

Enablers	Barriers
<ul style="list-style-type: none"> <li>-Opportunity to discuss concerns; positive relationship with nurse is pivotal</li> <li>-Objective tool for identification</li> <li>-CHaPS nurses were committed to using the tool to support families</li> <li>-A clear referral pathway had been established within existing child health services</li> <li>-Supportive of appointments and EI</li> </ul>	<ul style="list-style-type: none"> <li>-Non-attendance at appointments</li> <li>-Stigma</li> <li>-Parents do not want their child labelled</li> <li>-Inconsistencies in elements of the administration of the SACS-R</li> <li>-The SACS-R training conflicted with parents' questions</li> <li>-No regular or ongoing training</li> <li>-Large proportion of stakeholders were not familiar with the SACS-R tool nor the program</li> </ul>

The stand-out finding was that parents viewed appointments with the CHaPS nurses positively. Engagement with the CHaPS nurse provided parents with a chance to discuss any concerns about their child's development and they valued the opportunity to have a professional listen to their concerns. However, evidence-based research suggests that parents often feel unheard and unsupported by health professionals during their child's health assessment journey (Elder, Brasher & Alexander 2016) and feel that their concerns are frequently minimised or dismissed (Boshoff et al. 2019; Bultas & Pohlman 2014; Carbone et al. 2010; Sperry et al. 1999).

These issues were not found in the current study. This difference may be due to the following reasons. First, the CHaPS is a well-known, well-utilised child health organisation that has serviced Tasmanian families for many years with the delivery of children's health checks and the tool was incorporated into this established, professional service. When key behaviours were in line with the child's age and appropriate development the nurse was

able to provide accurate and informed reassurance to parents. Equally, if the child's behaviour was atypical for their age, the nurse was able to indicate what those behaviours were and provide direction by referral to St Giles for further assessment. Irrespective of whether their child's presentation was typical or atypical, the meetings provided reassurance for parents as well as knowledge and support. These findings align with Fleuren and colleagues' (2004) determinants related to the socio-political context (1, 2, and 4) and to the innovation (34, 37, 38, and 39) and they influenced the success of the SACS-R process.

Second, assessments were free. At the age of 12, 18 and/or 24 months a child and their parent can meet with their local CHaPS nurse without cost for a routine health check, which included the new SACS-R assessment. Parents willingly attended appointments and cooperated in the process, without a financial burden.

The findings of the current study indicate that it was a strength of the rollout of the SACS-R program for the tool to be embedded into two already existing and strong child health services, the CHaPS and St Giles. Nurses found the tool easy to use and were able to quickly and accurately pinpoint behavioural concerns and make decisions to refer the child on to the DAT. The CHaPS and DAT staff viewed the SACS-R program as beneficial to families as they were able to see the positive results of the implementation of the innovation.

The SACS-R tool gave nurses confidence in surveillance. They had clear guidelines on how to administer the surveillance tool and accurately identified very young children who presented atypically. This finding is supported by that of Barbaro and colleagues (2011) who also found that MCH nurses, when specifically trained in the administration of the SACS paired with parents' concerns, can reliably recognise autism and other developmental delays prior to two years of age (Barbaro, Ridgway & Dissanayake 2011). Not only is the ability of nurses to refer appropriately to the DAT confidence-building for those health professionals, it also means that parents can be directed to a team who then formally diagnose their child.

The determinants related to characteristics of health professionals (24, 25, 26, 28, 29, and 30) in the framework developed by Fleuren and colleagues (2004) indicates these are important enablers. The staff were equipped with the skills, knowledge and confidence required to implement the SACS-R program efficiently and effectively. The SACS-R tasks that the nurses had been assigned were relevant to their already existing roles. Moreover, the nurses perceived that parents were cooperative and satisfied with the SACS-R program. Fleuren and colleagues' (2004) determinants related to the organisation (9, 12, 13, and 16), further support this argument. That is, the SACS-R process had been integrated into the policies of the CHaPS and the DAT by management. In addition, relationships were developed and there was interprofessional collaboration between staff members across different organisations. Finally, the staff were skilled with the necessary expertise to implement the SACS-R process.

This finding is also supported by principle 2 of Handley et al. (2016, p. 2) for successful implementation, which states: various people and organisations are involved in carrying out the assessment process and they have “credible, intimate and necessary understandings of the concerns, values, assets and activities of their communities”.

Characteristics of the organisation, such as the impact of staff turnover, is an innovation determinant that can impact the success of the process (Fleuren, Wiefferink & Paulussen 2004). In this study, regardless of whether a parent was attending an initial meeting or the third, they sought a positive relationship with the assigned nurse and valued a good relational fit. These results also align with the interaction recommendations proposed by Boshoff and colleagues (2019) who reported that parents appreciate partnerships with health professionals who offer a warm approach. A positive and supportive interaction from the nurses towards the parents is, therefore, an important aspect in the success of the SACS-R implementation, hindered by high staff turnover.

However, staff turnover in family-centred organisations can encroach on the ability for the same nurse to always be available to the same family. Thus, the ability of the CHaPS to be able to offer continuity of care to each family is not always possible. During interviews, staff shared their concerns of case overload, being understaffed and under-resourced during period of staff leave. Staff had been directed by CHaPS management to prioritise newborn babies over exiting SACS-R appointments, meaning older children risked missing out. These issues indicate a need for targeted improvements in timely delivery of care at organisational level and at state level, including adequate resources to prevent staff burn out as a result of increased case workload. Funding to resource autism across the Tasmanian state is necessary to achieve successful outputs.

Ongoing training and regular refreshers for all staff (new, current, and returning) will be important to the success of the ongoing use of the tool. This was made apparent due to the lack of fidelity to the assessment process, evident in a number of ways. For example, there were incomplete and inaccurate referrals. Also, staff going on leave or returning from leave would miss SACS-R updates. An additional concern was that nurses new to the organisation were untrained but administering the SACS-R. These findings are supported by previous studies which found that health professionals appreciated opportunities to receive ongoing training (Fernandez et al. 2010; Kerr et al. 2016; Russell et al. 2010; Trembath et al. 2019). Education and training programs (specific to SACS-R practice and implementation process) regulated by other relevant organisations through administration of case studies would assist nurses, new and continuing, to be competent and confident in delivery of the SACS-R tool. The creation of a buddy or mentoring system to support colleagues in assessing children’s behaviours and completing referrals accurately would provide additional positive support (Seaton et al. 2020).

At this early stage in the parent journey, three major inconsistencies between the SACS-R training, advice and the actual administration of the SACS-R were evident. First, the

nurses sometimes did not witness the child performing a behaviour, yet they ticked that the child was typical on that item because the parent told them that their child could do it. This response is in direct contrast to what the nurses had been taught during the training. Second, after several months of administering the SACS-R, the nurses spoke to management about their ability to elicit the itemised behaviours from the children without props. CHaPS management responded by providing each CHaPS site with toy kits to assist the nurses in getting children to produce the identified behaviour. The use of toy kits was not in line with the training which meant that the nurses were not adhering to a standardised delivery of the SACS-R. In addition, the kits were not available from the commencement of assessments and even when the kits became available, some nurses chose not to use them. Other nurses used the toys but then considered them dangerous and then either stopped using toys altogether or acquired their own toy kit.

Third, there were some untrained professionals in external organisations who were also administering the SACS-R to children; it was not only being administered by the trained CHaPS nurses. The SACS-R assessment was designed to be administered only by people who have been trained in its use by appropriate staff from La Trobe University. Nevertheless, staff outside of the CHaPS and St Giles who had not attended the SACS-R training were using the SACS-R with children.

Inconsistencies and variations such as these are barriers to successful implementation. In line with Handley's (2016) first principle: the behaviour of the assessor is not reflective of existing practice or training or policy guidelines. These inconsistencies indicate that fidelity to the training has not been achieved and as a result the success of the implementation of the innovation could be jeopardised. By not following protocol, the child's assessment record may be inaccurate and therefore it is possible that children who should be referred are missed. The importance of maintaining fidelity to an established model, assessment tool or intervention is also supported by Fernandez and colleagues (2010), Franks and Bory (2017), Kerr and colleagues (2016), Russell and colleagues (2010) and Trembath and colleagues (2019) to ensure that the delivery of EBPs is successful. This finding also resonates with Handley's (2016) third phase, the evaluation process of the implementation strategy. This phase involves appraisal of how well the intervention was implemented, that is, fidelity. In Green's (2014) framework, listed under 'application implementation', fidelity is also important.

It is apparent there was a mismatch between the training ideals of the SACS-R program and the practice environment. In order to address these, measures that have been proven to work in the health sector could be useful, such as: essential mandatory guidelines for training of staff before implementation and administration of the SACS-R tool; embedding SACS-R training in professional healthcare degree courses (medicine, education and allied health); and development of continuous quality improvement standards for quality assurance, risk management and improving end-user experience.



Another less-tangible implementation barrier was the mismatch between day-to-day language with that prescribed by the trainers. This refers to the finding that during appointments some parents directly asked the nurse if they were checking their child for autism. In the SACS-R training the nurses had been instructed to tell parents they would be assessing a number of things during the appointment, including their child's social attention and communication skills – not autism. Green's (2014) utilisation-focused surveillance framework states user's requirements for information and the formation of collaborative relationships are important for successful implementation. Avoiding referring to 'autism', posed a barrier to successful implementation of the SACS-R – because the 'user requirement for information' was missing in this encounter. Fleuren's (2004) determinants related to the characteristics of the health professionals (32 and 33) are also relevant to this finding. That is, nurses wanted to adhere to the training guidelines whilst simultaneously they felt they should be transparent with parents. Thus, the nurses were confronted with an ethical dilemma.

All stakeholder groups voiced support for the administration of the tool in CHaPS appointments because it led to the early identification of delays in young children. This finding is supported by recent literature that showed that EI can impact neural development (Colombi 2017; Pickles et al. 2016). However, the paediatricians' support was only on the proviso that the assessment did not lead parents to feel anxious or think that their child had autism.

Even though the external stakeholder group was widely supportive of EI, they expressed some resistance and uneasiness about a number of the components of the SACS-R process. First, they were concerned about potential false-positive SACS-R results and the emotional impact this would have on parents. Although research literature agrees that inaccurate results can create needless anxiety and stress on parents (Marlow, Servili & Tomlinson 2019), in this study parents and St Giles DAT did not share this concern.

Moreover, some external stakeholders were not comfortable with the fact that children as young as 12 months old could be potentially pathologised and/or were having diagnostic labels applied to them following the SACS-R and DAT assessments. In addition, they speculated that parents did not want their child labelled, due to stigma. This is a genuine concern. The literature reflects that one of the many obstacles to early assessment, diagnosis and intervention in autism is parental fear of social stigma (Elder, Brasher & Alexander 2016; Hurley-Hanson, Giannantonio & Griffiths 2020). However, again, there is some discordance here, as parents did not voice that concern. CHaPS nurses and the DAT noted that some families did not attend their scheduled SACS-R or St Giles appointments and when followed up made excuses and/or hung up on them – indicating possibly a reluctance to continue. Because those parents were not in the interview group for this study, that perspective was not heard, so it is difficult to draw definitive conclusions.

Some external stakeholders were concerned that if a child presents as atypical on the SACS-R, it becomes a *fait accompli* that they have autism, and from then on are only considered through an autism lens as the ADOS-2 and ADI-R are systematically administered. However, in reality, the SACS-R identifies atypical behaviours that indicate high likelihood of autism and/or some other delay, and the DAT is skilled in assessing and diagnosing conditions other than autism. The '*fait accompli*' assumption was not evident in this study.

These stigma-related challenges are barriers to successful implementation of the SACS-R, partly because an evidence-to-practice gap is apparent. Following Handley (2016, principle 2), because the innovation did not involve the external stakeholder group from the outset of the project, there was a lack of collaboration and engagement and some participants felt unheard or disengaged. According to Fleuren and colleagues (2004) when there is a lack of support from external stakeholders an innovation in health care will struggle to be successful.

There was a proportion of external stakeholders who were not only unfamiliar with the SACS-R tool and program, but also with recent developments in autism research. This was perhaps surprising given their professional connection with young children and families in the SACS-R age bracket. For example, some General Practitioners (GPs) were still offering parents a "wait and see" and/or "he's a boy" approach. This indicates that they were not aware of the latest research regarding the ability to detect developmental delays in young children (Coughlan et al. 2020). Paediatricians also were ill-informed about the SACS-R tool, the CHaPS training, the difference between the use of the terms screening and surveillance, the referral pathway, and the latest autism research on the stability of an autism diagnosis by the age of 18 months (Boshoff et al. 2018; Ribeiro et al. 2017). The statement was made that parents are better off not knowing that their child has autism if the diagnosis is made on the basis of a screener. As per Fleuren (2004), people who are in positions to influence the opinions of others, such as the GPs and paediatricians, can impact the success of the innovation (determinant 50). Cross-collaborative training sessions may provide a solution. These sessions could bring together all professional stakeholders in discussion forums to highlight problems in practice and address them through peer-review and sharing research evidence. SACS-R training could be offered to all stakeholders involved in the process.

### **5.2.2 Referral to St Giles**

Following the child and parent meetings with the CHaPS nurse, children who were flagged on a minimum of three of the five key items were referred on to St Giles DAT for further assessment. The enablers and barriers to a successful referral are summarised in Table 5-2 below.

**Table 5-2. The enablers and barriers to referral to St Giles DAT for further assessment**

<b>Enablers</b>	<b>Barriers</b>
-Sense of relief for some -Experience with an older sibling, where the pathway had been more difficult	-Creating cause for unnecessary concern and worry

Receiving a referral to St Giles for further assessment was a relief for some parents. This result is supported by the research of Barton and colleagues (2010) but others found that parents of children who were identified at high likelihood of autism experienced parental stress prior to an autism assessment (Crane et al. 2016; Voliovitch et al. 2021). As discussed in section 5.2.1, in addition to concerns about false-positives, external stakeholders generally, felt that parents would not feel relieved after being referred to the DAT, but rather that it would be a time of unnecessary worry. However, those concerns were unfounded in the current study, partly due to the already established pathway to early assessment with St Giles.

Some parents had an older child with an autism diagnosis, for whom the pathway to a diagnostic outcome had been long and challenging. Their current experience was different: their child had been identified at a young age as showing some atypical social attention and communication behaviours and further assessment was organised. This finding corresponds with Fleuren and colleagues' (2004) determinants related to the socio-political context (1 and 2) which influenced the success of the SACS-R process. Parents were welcoming of the next step as they were aware of the importance of early identification of developmental delays and how a formal diagnosis is the gateway to accessing funding, support, and early intervention.

### **5.2.3 Waiting time**

After being referred to St Giles DAT for further assessment, parents entered a waiting phase. This time period varied from a number of weeks to over a year. The barriers to an acceptable waiting time are summarised in Table 5-3 below.

**Table 5-3. The enablers and barriers to waiting times**

<b>Enablers</b>	<b>Barriers</b>
-Nil identified	-Timeframes were not communicated -Follow-up appointments for assessment were not timely -Services were unavailable or there were long wait lists

The implementation of the SACS-R tool would have benefitted from clear understandings about wait times, for all involved. Parents were unaware of waiting times between referral to the DAT and their child's assessment date. Nurses were unable to communicate time frames because they did not know how long the wait would be, as these had varied throughout the period. Parents, nurses, and St Giles would have benefitted from knowing the length of time from CHaPS referral to the DAT to diagnostic outcome. At the time of referral, nurses ideally should have been able to inform parents of wait times, updating these as necessary along the way. However, in reality when the referrals first started to come through to St Giles from the CHaPS, the DAT were able to meet with families within a couple of weeks of receiving the referral, alongside the pool of children involved in the already existing pathway of referrals. As the CHaPS referrals increased, longer waiting times ensued.

Waiting times for autism assessment is an ongoing, unresolved barrier to early diagnosis in Australia and internationally (Crane et al. 2016; Rutherford et al. 2018). There was conjecture from many stakeholders that St Giles were simply understaffed and consequently were unable to deliver timely follow-up assessments on this aspect of the project. Established realistic waiting periods would have been a reasonable expectation of the program, along with monitoring of the DAT wait times and updating parents as needed. Despite long wait times for diagnostic assessment, the age at diagnosis for children in the SACS-R program was far earlier than the age that recent Australian studies have reported, that is, 4 years, 1 month in children under the age of 7 (Bent, Dissanayake & Barbaro 2015).

When wait times are unavoidable, there are examples of this period being used positively, chiefly through provision of parent-led interventions (Brian et al. 2018; Brian et al. 2017; Pickles et al. 2016; Rogers et al. 2012; Rogers et al. 2014). External stakeholders were keen for families to commence with other services and/or interventions whilst their assessment dates were pending as Northern families did with the ASELCC in Burnie. Families, whilst awaiting diagnostic assessment, engage with activities run by the centre. This approach is consistent with numerous authors who support enabling intervention to start for children who display early markers of autism before a diagnosis is confirmed (Brian et al. 2018; Brian et al. 2017; Rogers et al. 2012; Rogers et al. 2014; Schreibman et al. 2015).

Unfortunately, apart from Burnie, services to offer these interventions were largely unavailable. As Handley (2016, principle 3) indicates, for new interventions to be successful, the system needs to adopt a flexible and cyclical approach that accommodates the nuances of real-world settings. A long-term view of what the SACS-R pathway would look like was lacking in this rollout. Earlier steps in the process will need to be revisited and re-evaluated in order to address this issue, especially those aspects relating to staffing and availability of services. Additional funding to train new allied health professionals to lessen the work overload and reduce the protracted waiting time period would be valuable. Another possible solution to this problem would be to establish a triage system to prioritise the children who have more complex presentations. Offering programs to families during the

waiting phase could help to alleviate a sense of ‘wasting time waiting’. There are many suitable programs for children that could be facilitated by trained CHaPS nurses (including the *Westmead Feelings Program* and ‘Social Thinking’ resources developed by Michelle Garcia Winner and her team) and parents could be introduced to the *Early Start Denver Model* (Rogers, Dawson & Vismara 2012).

#### 5.2.4 Assessment with St Giles

Following the waiting period, families were scheduled to meet with the St Giles DAT for an in-depth assessment, feedback, and diagnostic outcome. The enablers and barriers to a successful meeting with St Giles DAT are summarised in Table 5-4 below.

**Table 5-4. The enablers and barriers to assessment with St Giles DAT, receiving feedback and the assessment outcome**

Enablers	Barriers
-Positive relationships -Feedback and guidance	-Reviews did not occur as planned -Paediatricians were not supportive

Parents and DAT staff highlighted the importance of positive working relationships during this phase of the implementation pathway. The current study found that parents appreciated the way the DAT staff interacted with them in a supportive, empathic, and professional way. In addition, parents valued the knowledge, feedback and guidance provided to them by the DAT during the diagnostic stage. The results of the current study are supported by those of Stanford and colleagues (2020) who found that mothers valued professionals who engaged with them in a personable way, using clear communication and having an understanding and empathic manner (Stanford, Totsika & Hastings 2020). In contrast, Osborne and Reed (2008) found that the communication between professionals and parents during the diagnostic period was often challenging and a source of parental stress and that professionals’ interpersonal skills needed improvement (Osborne & Reed 2008). To maintain this enabler to successful implementation of the SACS-R process, the end-user experience should be monitored using measures of client satisfaction, e.g, score comparison on the CSQ-8 (Winter et al. 2016).

Another enabler of this period was that the DAT staff organised the assessment, feedback, and diagnostic outcome to typically occur within the same day which enabled all aspects of the diagnosis phase to be contained within a single appointment. The literature provides strong evidence that the assessment phase is typically a protracted process, one which takes numerous appointments, involving a number of key professionals to ensure that a multi-disciplinary approach has been utilised to reach diagnostic conclusion (Bent, Barbaro & Dissanayake 2020; Crane et al. 2016; Rutherford et al. 2018). The findings of the current study reflect the opposite: assessment, feedback and diagnosis happened within one to two appointments with all the allied health professionals available in the one setting

and the same time. Depending on several factors, e.g., complexity of the assessment, parents' emotional health, disposition of the child and/or how tired they were, parents were given the option of whether assessment, feedback and diagnostic outcome all occurred within the one day or whether it was preferable to have the components spread over two appointments. The majority of parents opted for a single appointment. Having the assessment, feedback and diagnostic process in a single session enabled a swift diagnostic outcome and the opportunity for families to access services more quickly.

One of the objectives of the SACS-R program was for the DATs to offer reviews at six-monthly intervals until the age of 2.5 years, regardless of diagnostic outcome. The original intent of the project was that if a child was referred at, e.g., 12 months of age, they would be assessed at 12 months of age and then reviewed at 18, 24 and 30 months. At the outset of the project this did occur, but as time went on and demand increased, staff were unable to meet the demand and had to prioritise new SACS-R referrals over SACS-R reviews. Hence, there was no opportunity to assess a child's progress. Now, following the completion of the research project phase, a review is only offered to families when a diagnosis of autism has not made, but the DAT suspects high likelihood of autism. These negative factors related to staff capacity (determinant 15) and time availability (determinant 47) clearly impede the innovation process (Fleuren, Wiefferink & Paulussen 2004). The lack of reviews is in direct opposition to recommendations for ongoing monitoring and assessment (Bright Futures Steering Committee 2006).

An indirect obstacle to the success of the assessment with the DAT was the lack of buy-in from the paediatricians. Paediatricians expressed that it was pointless children undergoing assessment if the next steps could not be offered to families in a timely manner, such as services like ECIS, St Giles, and various therapeutic agencies to provide support to families.

The DAT are a multi-disciplinary team of health professionals who are proficient and skilled in identifying and determining diagnoses relating to children, and not just autism. Moreover, in keeping with the autism rights movement, parents have a right to be informed about their child's health status by way of an accurate diagnosis (Baron-Cohen 2017). Whilst not supported by a large majority of the paediatricians, parents nonetheless welcomed that a diagnosis helped them feel confident about the next steps for their child.

Green's (2014) utilisation-focused surveillance framework specifies user's needs for information and the formation of collaborative relationships are important for the success of innovations. The 'user requirement for information' was upheld in these assessment interactions and thus was an enabler to successful implementation of the SACS-R program. Handley (2016, principle 2) suggests that it is critical to the project to engage the external stakeholder group in order for effective translation to be achieved. Paediatrician support for the SACS-R program is a critical hurdle to overcome, to improve the overall endorsement of

the initiative within Tasmania. While this lack of support persists, the SACS-R will struggle to be successful.

### 5.2.5 Post-assessment

After families receive feedback from the St Giles DAT and are told their children's diagnostic outcome, they enter the post-diagnosis phase. The enablers and barriers to a successful post-diagnosis phase are summarised in Table 5-5 below.

**Table 5-5. The enablers and barriers to the post-assessment phase**

Enablers	Barriers
-Nil identified	-Lack of services and funding (all stakeholder groups)

Early identification of autism is a useful guiding principle along with the gold standard for treatment which is Early Intervention (EI). There is extensive research that supports commencing evidence-based interventions as early as possible, with a range of different services, depending on the needs of the child, in order to enhance child development (AlSalehi & Alhifthy 2020; Bonis 2016; Colombi 2017; Dawson et al. 2010; Kasari et al. 2010; Landa 2018). EI is widely recognised as the best opportunity for improved prognosis and quality of life (Magán-Maganto et al. 2017; Virues-Ortega, Rodríguez & Yu 2013; Zwaigenbaum, Bauman, Choueiri, et al. 2015).

All stakeholder groups recognised that post-diagnosis, despite service recommendations outlined in the DAT reports along with parents' confidence, there is a paucity of services. Some stakeholders focussed on a lack of services and voiced that if timely follow-up and services are unavailable, why assess at all? Paediatricians, in particular, were unaware of any benefits parents might be experiencing and how early diagnosis had impacted families in a positive way. The unequivocal praise for Early Childhood Intervention Service (ECIS) could not be ignored in this project: preparing schools for new students and ensuring that everyone is well informed about their needs; and EI without a diagnosis so they can work with families when they are in the wait-zone.

Nevertheless, there were some families that were already engaged with services prior to their child's confirmed autism diagnosis. However, these were the minority. Most children, even those identified as being funded under the Early Childhood Early Intervention (ECEI) model, were either not receiving EI or could not access the range of services or the number of sessions that are required. Bent and colleagues support this finding. They found that parents outside of Tasmania also face an ongoing challenge securing therapeutic services for their children (Bent, Barbaro & Dissanayake 2020). There are not enough providers under the ECEI system, even in the private sphere, to fulfil the need and accommodate the changes from the NDIS rollout.

Two additional topics external to the parent journey are now discussed:

1. Communication and collaboration between project partners and services; and
2. Model sustainability

### 5.2.6 Service communication and collaboration

The enablers and barriers to successful communication and collaboration between project partners and services are summarised in Table 5-6 below.

**Table 5-6. The enablers and barriers to communication and collaboration between project partners and services**

Enablers	Barriers
-Communication and collaboration between relevant professionals was valued  -Positive shift in language usage and terms over the course of the project	-Parents more likely to go to their GP than the CHaPS nurses if they had concerns about their child's development  -Dichotomy in language usage and understanding of terms across disciplines

The SACS-R program was strengthened by the successful interprofessional teamwork. Staff from the CHaPS, St Giles and ASELCC sought one another out with the aim of providing further support to the families in their care, e.g., making a phone call to ascertain if a referral had been received or to clarify the observation of a behaviour or to check the progress of a report. Professional relationships were developed and further strengthened over the course of the project. Seaton and colleagues (2020) found that allied health professionals valued interprofessional collaboration and viewed it as a critical aspect in the delivery of quality care to individuals in the healthcare sector. Green's (2014) utilisation-focused surveillance framework highlights user's requirements for information and the formation of collaborative relationships are important for successful implementation. Having strong interprofessional connections, promoted successful implementation of the SACS-R – because the 'user requirement for information' was active in these interactions.

Over the course of the project there was a positive shift in language usage and terms which opened up the space for greater acceptance and understanding of autism. The phrase "at risk" for autism, for example, has been used in the literature for decades and refers to the fact that autism has a strong genetic basis (Happé & Frith 2020; Volkmar & McPartland 2014). At the outset, in the description of the project itself, "at risk" was used. As the project progressed, the phrase "high likelihood" replaced "at risk" in a move to further encourage sensitivity around the use of language when discussing individuals and/or the condition (as discussed in the Introduction chapter, p 3).

This coincides with a growing shift in the way that autism is viewed, with a greater focus on neurological difference rather than considering the condition as a deficit



(Robertson 2010; Zolyomi & Tennis 2017). Participants were inclined to refer to autism as a “condition” or as being “on the spectrum” or “neurodiversity” in preference to the use of the term “disorder” or “ASD”. A number of external stakeholders were aware that language needs to be more inclusive of difference and progress to include words like “early childhood early intervention” and “neurodiversity”. Barriers to accessing support will continue to exist until words like these become increasingly part of our vernacular and are seamlessly integrated into our discussions within the service system (Elder, Brasher & Alexander 2016; Hurley-Hanson, Giannantonio & Griffiths 2020).

Nevertheless, a lack of shared language and mutual understanding of terms across disciplines persists. Terms were used interchangeably and inaccurately. For example, when nurses sometimes referred to a “pass” or “fail” or “present” and “absent”. Both the SACS-R assessment and *Salesforce* data entry specifically uses the words ‘typical’ and ‘atypical’ when considering the child’s performance. Words like “absent” and “present” or “pass” and “fail” were not part of the qualitative descriptions to be used either on the paperwork or in conversation with parents. Yet, nurses used these words when interacting with parents and in the interviews. This inconsistent language amongst professionals creates a barrier because when across the implementation field a shared understanding of terms is needed to enhance professional relationships and progress the implementation of EBPs (Dopp et al. 2019; McKibbin et al. 2013).

The external stakeholders continued to use the word ‘screening’ interchangeably with the word ‘surveillance’. The differences between the two are important, as screening is the use of standardised tools to identify and refine recognised risk, whereas surveillance is an ongoing process of recognising children who may be at risk of developmental delays (Bright Futures Steering Committee 2006). Moreover, developmental surveillance involves an ongoing monitoring over multiple time points by specifically trained health care professionals to identify children who may have developmental problems (Bright Futures Steering Committee 2006). This has implications for the successful implementation of a ‘surveillance’ tool.

Further education and updates are needed to understand the qualitative differences between the two processes and to use the words accurately in any discourse. This is supported by research conducted by McKibbin and colleagues (2013) and Dopp and colleagues (2019) on problems that occur when translating health research into health care settings.

External stakeholders stated that when parents have concerns about their child’s development, they are more inclined to go to their GP than their local CHaPS nurse. The literature certainly supports this view with GPs commonly being the first health professional that parents go to for guidance when they have worries about their children (Bent, Barbaro & Dissanayake 2020; Crane et al. 2016; Young et al. 2007). However, the literature also supports the fact that GPs do not have enough time, knowledge and/or confidence to

provide the level of care that these patients require (MacLeod & Perepa 2020; McCormack et al. 2020; Unigwe et al. 2017). Given this, it would seem practical that GPs become more aware of and involved in the SACS-R process.

### 5.2.7 Is the model sustainable?

The enablers and barriers to successful sustainability of the model are summarised in Table 5-7 below.

**Table 5-7. The enablers and barriers to sustainability of the model**

Enablers	Barriers
-It is doable; there are enough resources and funding	-Lack of awareness of the program and/or tool -Lack of buy-in -Lack of ongoing support from government -Impact of the NDIS on availability of resources

In order for the SACS-R program to successfully continue in Tasmania over time a shared vision and a clear plan for sustainability is needed. To safeguard the program, a comprehensive understanding of the enablers and barriers to successful implementation is needed, and a strategy to address them. The results of this research will assist this aim and help in supporting families and providing access to timely intervention for young children. Factors impacting long-term sustainability will need changing, such as staffing issues, and ample resources. Second, positive behaviour change at the individual, organisational, and policy levels needs to be established in order to ensure the sustainability of the existing SACS-R model (Green et al. 2014; Handley, Gorukanti & Cattamanchi 2016; Woolf et al. 2015).

Not all stakeholders were in favour of the SACS-R program, and some of the external stakeholder participants were particularly critical of some aspects of the process. However, overall, they were of the opinion that the present model could be successful using the current resources and funding but not as it is currently done. They were in favour of the MDT approach and supporting the CFCs in our communities. Any measures that assist in bridging the evidence–practice gap and improve engagement between stakeholders (Handley 2016, principle 2; Fleuren 2004) will help to gain movement and improvement in the innovation outcomes and ensure its sustainability.

The external stakeholder group perceived that one of the greatest barriers to successful implementation was a lack of ongoing support from government. They are concerned that Tasmania has a lack of long-term strategies to support autism innovation. What has been offered they considered to be reactive and a “token donation”, rather than a committed strategic investment over time. Government buy-in, irrespective of whom is in

political power, and a long-term commitment to the autism community are critical to the success of early identification, assessment, and intervention (Green & Johnson 2015).

During the interviews, particularly with the external group stakeholders, the comments made in relation to the National Disability Insurance Scheme (NDIS) were prolific. In theory, the NDIS offers a national approach that endeavours to provide funded supports to timely EI. In reality, Tasmania has a shortage of allied-health professionals and in addition, the NDIS has created roadblocks to accessing services despite participants having funding. A two-prong approach linking policy and practice is needed.

In the current study, Lewin's model of change assists in understanding the problem and points the researcher to the need for a suitable approach to understand the stakeholders' perspectives. These insights were provided through the use of a DT approach. Lewin's model is widely used across the nursing field (Abd el-shafy et al. 2019; Kassean & Jagoo 2005; McGarry, Cashin & Fowler 2012; Parsons 2000; Sutherland 2013) and centres on two types of forces: driving forces and resistant or restraining forces as discussed previously in Chapter 2. The first step in eliciting change involves priming and preparing to unfreeze the withholding situation. In the context of this study, this step involved building communication with the stakeholders to identify enablers and barriers to the practice change, to understand why the change is required and the advantages that the SACS-R implementation process will bring to early diagnosis of autism and developmental delays.

Following communication building and establishing future objectives and outcomes, the second step of Lewin's model involves making the "change." In this step, I identified, analysed, and summarised the enablers and barriers, and processed implications and recommendations necessary for the change to occur. In the final step, in line with Lewin's model, this thesis "refreezes" the changes and improvements required for the relevant organisation(s) in the SACS-R implementation process through recommendations for practice, policy and research (refer to Chapter 6).

### **5.3 Study methodology**

There was a high participation rate from the internal stakeholder groups, particularly from the CHaPS nurses with regard to the surveys and interviews. The external stakeholder group was well represented from a number of fields (medical, allied health, education, and policy) which enabled a range of diverse views.

Utilising a mixed methods approach is an effective way to investigate a complex phenomenon as it provides the researcher opportunities to statistically measure and investigate stakeholder experiences and insights. Moreover, it facilitated the aim of the study to be achieved by affording the researcher a solid understanding of the results and findings. Johnson and Onwuegbuzie (2004) note that a mixed methods approach enables the weaknesses of a single approach to be reduced and the strengths to be maximised, with

the combination of approaches providing additional explanation and depth to the other data strand.

There was a lower than expected response from the primary stakeholder groups across the state. Whilst the initial pathways for recruitment of parents to participate in the questionnaire and the referred parent interview, secured a small number of parents, they certainly did not attract the response that the research team had anticipated. Due to the suboptimal parent recruitment, additional methods were applied in order to achieve greater parental involvement. First, the researcher conducted a mail out to all parents in the St Giles database who had attended an assessment as a result of the SACS-R referral process. This proved challenging and was also disappointing. Given this outcome, an email was also sent from St Giles' reception to those same parents, requesting their participation in the research. Regrettably, a clerical error led to a disclosure of all parents' names and their email addresses. The researcher then approached St Giles and ASELCC management about placing an ad on their *Facebook* pages. A long wait ensued, nonetheless, approval was eventually received from management to advertise through *Facebook*. An additional ethics amendment was submitted and approved. Unfortunately, the response rate from parents was not as anticipated, with low numbers being recruited. However, it was very important that they had a voice and they contributed useful insights to the research. It is possible that the parents who participated in the study may have had a relatively higher level of education to have responded to the "plain language statement".

There were additional challenges faced in relation to the ethics process. It was not a unified ethics process. In order for the Department of Education to permit the researcher to approach ECIS staff to recruit them for participation in an interview, they required many questions to be answered about the research, despite already having ethics approval. It was necessary to submit an ethics amendment to satisfy their requirements. From initial discussions with the EPR, it took almost three months from submitting the application form (*Permission to Conduct Research in Tasmanian Government Educational Settings*) on 24 September, 2019 to receiving the approval (13 December, 2019). Following approval from EPR it was then necessary to submit another ethics amendment form to the HREC (refer to Section 3.14) before the researcher could proceed with recruiting ECIS participants and conduct interviews.

The recruitment sequence was perhaps not as well thought out as it could have been. The Department of Health said they would not support CHaPS nurses handing out flyers to parents but would allow the invitation material to sit on tables in the waiting room for parents to collect of their own volition. Had there been someone occupying the role of a statewide program manager, they could have assisted with the recruitment of primary stakeholders and as a consequence, study participation from the parents may have been enhanced.

I commenced data collection with the CHaPS nurses. In retrospect, they may not have been the best stakeholder group to begin with and perhaps I should not have targeted the groups discretely. Indeed, there may have been benefits to knowledge building by interviewing participants from the range of stakeholder groups simultaneously.

The CHaPS nurses were very resistant to the use of the CSQ with parents. The nurses were concerned that the brief 8-item questionnaire would be interpreted as an opportunity for parents to assess them and their practice instead of the SACS-R tool. Deliberations about this went back and forth between the chief investigator, the Director of Nursing and me over a number of months. This concern required amendments to be made to the original ethics documentation process and as a result, the ability to commence data collection with this stakeholder group was significantly delayed.

There were changes in personnel over the course of the project, with two key team members leaving the project. One of my secondary supervisors resigned from UTAS and the project research assistant (RA) went on maternity leave. The repercussions from these two absences meant a) the regular, statewide implementation team meetings ceased, and b) it was necessary to find a replacement secondary supervisor and get them up to speed on the project. Furthermore, one aspect of the RA's role included ensuring that no child slipped through between CHaPS surveillance and the St Giles DAT assessment. The RA regularly ran checks to safeguard against children being missed and with the RA on leave, this task stopped.

### **5.3.1 Ethics sampling recruitment**

Location was a limitation in the current research. Victoria had a superior set up in comparison to Tasmania in terms of rolling out the SACS-R program. The SACS and SACS-R were both developed by Dr Barbaro who lives in Victoria and works at La Trobe University, where the OTARC is housed. The OTARC was able to approach the SACS-R program from a research point of view and were able to access participants from within their organisation. By comparison, in Tasmania, commercial services were used. Whilst this was a pragmatic approach, it meant that there were very big differences in the current project's scope of participant numbers and therefore, participant sample sizes and outcomes were impacted.

There were differences in terms of diagnostics between Tasmania and Victoria. The diagnostic assessments conducted in Tasmania occurred in a real-world setting where competing demands existed. For example, the same diagnostic team that responds to the usual referrals to St Giles for assessment was also used for the SACS-R pathway. Staff numbers were not increased to cater for this new pathway, rather their existing role and hours were now divided across the two intake paths. Additional staff were not employed to assist with the increased workload. In comparison, Victoria's SACS-R program operated under a more controlled environment that was specifically dedicated to the SACS-R referrals and follow-up diagnostic assessments.

## **5.4 Credibility of the results**

### **5.4.1 Strengths**

This study has numerous strengths across areas of study design, methodology, use of established instruments that are widely used, interpretations of synthesis of data, and member checking in regard to the transcripts. The details of these strengths are provided below.

A major strength of the current study is its methodological rigor. The trustworthiness checklist (Elo *et al.*, 2014) demonstrates the strength of the qualitative component. There were three coders involved in the reflexive analysis of the interview data. Stakeholders were provided opportunities to make amendments, deletions, or further additions to their interview transcript. This potentially eliminated interviewer bias, that may have resulted in misinterpretation or inferences about a stakeholder's intended reported perspective. Inclusion of this process also ensured further rigour to the methodological approach.

This study utilised a mixed method approach to integrate the quantitative and qualitative data. This was carried out using different data collection tools including the CSQ-8 questionnaire, MIDI surveys and interviews which enabled validation of information gained across data strands. Through a convergence approach, a deeper understanding of the complexities of the stakeholders' experience was achieved.

The current research used a convenient sampling method which is expedient, cost effective and relatively simple. For the interview data collection, overall, the external stakeholder group was well represented from all regions of the state, with paediatricians, GPs, allied health professionals, and representatives from various health and educational associations participating.

It was anticipated that Design Thinking (DT) would enable greater understanding of the implementation of the SACS-R. To my knowledge this is the first study to use DT in an Australian, statewide sample to understand the autism assessment process. It has enabled me to hear multiple stakeholder perspectives whilst simultaneously generating great consideration and empathy for the parents.

Lewin's three stage model of change was used, and it provided the opportunity for the stakeholders to successfully communicate their views. In addition, the refreezing step facilitated understanding of the diverse range of views. This enabled the evaluation of stakeholder perspectives and generation of implications and recommendations for policy, practice and research as discussed in Chapter 6.

### **5.4.2 Limitations**

There are a number of limitations to the current study that should be noted. First, the gender of the participants was uneven. All of the primary stakeholders and groups 1 and

2 of the internal stakeholders were female. With regard to the parents, male caregivers did not volunteer to participate and there was only one male stakeholder (in group 3 of the internal stakeholders) involved in the entire data collection. Second, there were some problems with the administration of the SACS-R. There was a miscommunication that led some nurses to cease entering children's SACS-R assessment outcomes into *Salesforce*. This was communicated to the primary researcher (AM) during nurses' interviews and confirmed in consultation with the Research Officer from the OTARC. This could have been prevented by maintaining resources such as having an individual to work as a conduit between all organisations and being aware of this issue early so it could have been rectified immediately. Third, the nursing group was not homogenous with respect to experience and their approach to developmental assessment. Fourth, although the interview questions were trialled with one of the participant groups (management) and changes were made in accordance with their feedback, no other participant group questions were trialled. Members of the research team met following the first set of interviews to review and discuss whether any changes to the questions were needed. At that point they agreed that they were appropriate, thus no changes were made to the interview questions throughout the research. Participants seemed to understand all of the interview questions and appeared not to experience any difficulty in providing responses. Fifth, feedback was received from primary stakeholders, however, the number of parents recruited to the interview portion of the study was small (n=11). It was considered that some parents may have low literacy levels and therefore may not have known about the study or chose not to participate and this may have affected recruitment.

Although a convenient sampling method has inherent strengths, the sample sizes recruited as a result of this approach are not representative of the population. Thus, the findings are not able to be generalised. Notwithstanding, the results of this study provide valuable insight about the latest prevalence of autism and the impact this neurodevelopmental condition has on the quality of life of individuals, their families, communities, and government agencies.

This study used Lewin's three-stage model of change. We were unable to adhere to the second step that involved keeping the communication lines open with all stakeholders. Several main challenges were encountered regarding participant recruitment and participation. The sample size of this study was constrained due to the impact of a number of significant variables, including allocated time for data collection and poor uptake of the invitation to participate in a brief questionnaire and interview.

#### **5.4.3 Sources of bias**

There was only one researcher, me, who conducted all of the 91 interviews. Consideration of researcher bias is important as another researcher with a different background and experiences may have had different insights into the data. I have had over a decade of experience working in the field and therefore will have my own biases about the

topic areas covered during interview. Adhering to the interview schedule and following coding procedures assists in reducing the potential for any personal bias in this instance.

The interviews were conducted over a long period of time, approximately two years (March, 2018-May, 2020), so early interviews may be different to later ones as the interviewer gained experience with the interview schedules and the experience of interviewing.

As the parent sample size was small, with only eleven parents participating in an interview, the findings may reflect a recall bias to under- or over-reporting of experiences, e.g., wait times between referral and assessment.

#### **5.4.4 Summary**

This chapter was the critical appraisal of the key findings that were reported in the Chapter 4 Results of the thesis. In summary, following were the highlights. First, the SACS-R program was overall successfully rolled out and implemented across Tasmania. Second, nurses' professional confidence increased as they accurately administered the tool and referring on successfully to the St Giles DAT. Third, the SACS-R was generally readily embedded into the CHaPS nurses' routine practice. The next chapter (Chapter 6) is the final chapter of the thesis. It presents a brief review of the study, together with a discussion of conclusions drawn from the findings, and the significance and limitations of the research. A number of suggestions and recommendations are then made for further policy, practice and research.



## Chapter 6: Conclusions

The purpose of this chapter is to summarise the lessons learned from the key findings. It provides a summary of recommendations focused on three areas: policy, practice, and research.

### 6.1 Overview and aim of the thesis

This study is unique in Australia as it is the first to take a close look at the experiences of range of Tasmanian stakeholders across a variety of settings about early identification, diagnosis, and intervention for autism.

The aim of this study was to explore the enablers and barriers to the successful statewide implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) early childhood surveillance program. It was based on the rationale that Tasmanian children can be diagnosed with autism and developmental delays much earlier than was previously being achieved, and that through early diagnosis, children and families can access services in a timely way and improve lifelong outcomes. The research questions asked: what are the enablers and barriers to a successful statewide implementation of the SACS-R into the public health system, so that infants at high likelihood of autism and developmental delays are identified in a timely way? And: What information does the SACS-R data provide regarding the value of the specific 18-month assessment, only administered in the South of Tasmania?

The study was conducted against a backdrop where the state had recently adopted the SACS-R as a new instrument to be used by all Child Health and Parenting Service (CHaPS) nurses in their routine developmental assessment of infants and young children. The SACS-R is a developmental surveillance tool that identifies atypical behaviours that indicate high likelihood of autism and/or developmental delay at 12-24 months old. It facilitates the referral of young children to the Developmental Assessment Team (DAT). The study aims were achieved through investigation of the perspectives of key stakeholders involved in the surveillance tool rollout, with the experiences of the parent and children as the central concern.

A concurrent mixed methods research design informed by implementation science principles and a pragmatic worldview design thinking approach was utilised, to understand the experiences and insights of key stakeholders. Methods included questionnaires, surveys, and interviews. Use of quantitative instruments facilitated the generation of information from parents who had been referred on to further services for diagnosis, as well as staff from the CHaPS, St Giles, the ASELCC, and external stakeholders. These included *Salesforce* data, an online questionnaire (CSQ-8), and a MIDI survey. The data from *Salesforce* was analysed to provide descriptive statistics of demographic information, including the number of children monitored with the SACS-R and the number of consultations attended. The CSQ-

8 provided insights into non-referred and referred parents' level of satisfaction with the SACS-R assessment administered by the CHaPS nurse. Completion of the MIDI by CHaPS staff enabled the researcher to measure the factors that served as either an enabler or a barrier to the successful implementation of the SACS-R into the Tasmanian health service.

The primary source of qualitative data was from semi-structured interviews conducted by the researcher with a range of stakeholders, including referred parents, CHaPS nurses and managers, St Giles and the ASELCC staff, educators, medical and allied health professionals. The two phases of data collection were conducted, then integrated at the final analysis. Theories and frameworks created by Green (Green et al. 2014), Fleuren (Fleuren, Wiefferink & Paulussen 2004) and Handley (Handley, Gorukanti & Cattamanchi 2016) and their respective colleagues formed the basis for the analysis of the enablers and barriers to successful implementation. The program logic model framework (see p 44) assisted in structuring the key components of the study: autism, surveillance, IS, and DT.

## **6.2 Key findings**

The key finding of this thesis is that the SACS-R process was successfully introduced by the CHaPS, including the addition of the 18-month assessment, which meant that young Tasmanian children could be identified as high likelihood for autism, diagnosed, and in theory, able to be supported through access to intervention much earlier than previously possible. Two key enablers were found: 1) integration of the tool into the children's appointments with the CHaPS and 2) children being able to access early intervention (EI) services post this initial visit. However, all stakeholder groups agreed that there were barriers to successful implementation, which included 1) a lack of services and 2) insufficient funding.

In addition, the use of a pragmatic mixed methodology alongside a DT approach proved to enable a more nuanced understanding of the barriers and enablers from the perspectives of those involved, providing additional depth to these key findings.

In the following sections, I highlight the key details of the various enablers and barriers.

### **6.2.1 Major enablers**

#### **6.2.1.1 Integration of the tool into the CHaPS nurse visits**

- Parents were provided opportunities to meet with the CHaPS nurses to share any concerns about their child's development and this was viewed as a positive experience for both parties. These appointments enabled parents to receive either confirmation that their child was developing appropriately or to be offered the opportunity of on-referral for further assessment to St Giles.
- Parents who had an older child with an autism diagnosis found this new pathway more satisfactory and fulfilling in managing their concerns and their child needs.

- The content captured in the convergence tables supported a strong response to the identified area of need, that is, identification of young children with autism and other developmental delays.

#### **6.2.1.2 Timely access to intervention services**

- The nurses felt satisfied with the SACS-R being added to the services that they offered families. Use of the SACS-R tool provided them with confidence to refer on to St Giles. Having a clear pathway available for further assessment enabled nurses to complete referrals as appropriate.
- Nurses appreciated clear and regular communication with colleagues across disciplines and organisations to advance children's outcomes.
- The CHaPS managerial staff expressed that they were very welcoming of the clear pathway for children and families.
- The ASELCC and the DATs welcomed the establishment of a new referral pathway, which was critical to the family journey to diagnosis, and appreciated opportunities to build professional relationships with colleagues in other organisations.
- The external stakeholders claim that there are sufficient resources and funding, but the problem lies in how that money is applied.
- Prior to the SACS-R some assessment tools were in use by the CHaPS nurses (e.g., PEDS), however, there were problems with the developmental assessment of young children. Specifically, the pathway to referral and assessment was unclear, convoluted and limited in its application.

### **6.2.2 Major barriers and concerns**

#### **6.2.2.1 Lack of services**

- Due to time constraints, prescribed review appointments to monitor progress post-diagnosis were not conducted. Some parents did not attend either their scheduled SACS-R appointment or their follow-up assessment with St Giles. Times of appointments were unknown.
- Nurses expressed concerns that inadequate staffing, the ability to reduce long waiting lists, access to the 18-month SACS-R assessment for all Tasmanian regions, and the sustainability of the model would not be possible without an ongoing, dedicated commitment from government.
- The DATs were concerned for families with regard to lengthy delays for assessment. As the project unfolded, the length of the waiting times increased.
- Tasmanian health services in both the public and private spheres were unable to offer the necessary follow-up support as outlined in the recommendations of their child's DAT report.

#### **6.2.2.2 Language confusion**

- Nurses and managers struggled with a lack of transparency in not being able to say to parents that the SACS-R assessment was an 'autism assessment', particularly when a parent directly asked if the test was for autism. CHaPS staff devised various answers to parents' queries about the purpose of the SACS-R. The frequently changing 'correctness' of what language to use was confusing and has the potential to undermine confidence and trust.
- External stakeholders incorrectly used terms across communications. There were some indicators that some of these stakeholders were not updated with the latest research and evidence in the field regarding stability of an autism diagnosis at 18 months of age and the importance of EI in relation to brain neuroplasticity.

#### **6.2.2.3 Inconsistent administration of the tool**

- There was a mixed response from nurses in relation to being confident in administering the tool. In the day-to-day application of the SACS-R tool, some nurses did not follow through on their responsibility of either administering the tool as trained and/or recording the data in *Salesforce*.
- The CHaPS managerial staff were concerned that there had been no follow-up training and they viewed this as potentially advantageous to nurses for their ongoing confidence and completion of accurate referrals.
- There were explicit requests for ongoing refreshers and follow-up training. It was considered most appropriate for these to occur once the nurses had had the opportunity to apply the tool in their day-to-day work and were familiar with the tool and referral procedures.
- The DATs expressed that nurses needed ongoing training to maintain their confidence in the SACS-R assessment administration and also to ensure the accuracy and reliability of their referrals.

#### **6.2.2.4 Insufficient funding**

- Stakeholders highlighted the need for adequate ongoing funding and resources to ensure continuity of CHaPS support to the children and families and the necessary follow-up intervention services.
- Lack of ongoing support and funding was identified by the ASELCC and the DATs. They were aware of the lack of services and resources post-diagnosis for families in Tasmania.

#### **6.2.2.5 Lack of awareness and support from all stakeholders**

- There was a lack of awareness of the SACS-R program and/or the tool and a lack of buy-in from the paediatricians. Some external stakeholders, particularly the paediatricians, were unsupportive of the SACS-R program. They were concerned about potential false-positive SACS-R results, emotional impacts on families, associated stigmatisation of diagnoses at such an early age, lengthy waiting times, and the availability of services.

- Paediatricians thought that early intervention was in the best interests of all children and this should happen without diagnoses and labels. They held the belief that children should not be diagnosed: 1) early and 2) when services cannot be provided. They stated that if parents had developmental concerns for their children, they would take them to their GP, not to the CHaPS nurse.

### 6.3 Implications for policy

Embedding early childhood developmental surveillance and access to timely intervention into policy is critical to ensure that individuals' potential outcomes are maximised. This research aligns with the policy priorities highlighted by local and national organisations (Autism Tasmania, Autism CRC, and Australian Autism Alliance). They advocate for the needs of people with autism and those who provide support to them.

Significantly, the stakeholders interviewed in this project highlighted the importance of networking (for people with autism, their parents and carers, and medical and allied health professionals) and developing connections with families and Child and Family Centres (CFCs) in the community. It is important that policies safeguard the agency (experience, voice, and satisfaction) of the family unit. Families need access to evidence-based practices (EBPs), interventions and services in a timely way, and dissemination of information to families, health providers and community members is vital.

Policies need to operationalise continuous quality improvement processes through use of better clinical governance models across service delivering organisations for improved care delivery to the autism community.

Additional pathways need to be established following referral and post-diagnosis. There is increasing demand for services in the more rural and remote areas of the state, and policy initiatives are needed to attract workforce to these areas.

### 6.4 Implications for practice

To improve early detection and outcomes for children and families with autism, the following implications for practice improvement are highlighted:

- Administer the SACS-R tool to *every* child aged 11-30 months old. This is in line with one of the key outcomes of the *Salesforce* data results that showed that 100% of children who were identified as high likelihood for autism using the SACS-R developmental surveillance tool received either a diagnosis of autism or some other developmental delay.
- The finding that there was a lack of buy-in from the paediatricians is currently a considerable barrier. However, there is the potential that with dialogue, education, and collaboration, that paediatricians in their vital role as providers of holistic health services for young children, may support the SACS-R as one aspect of a more wide-ranging assessment practice. It is feasible that the paediatricians may view the

process as appropriate if the DAT were to readminister the SACS-R upon referral and utilise the results alongside other measurement tools to assess children with atypical development. It is necessary to have the paediatricians' acceptance of the process as they are frequently the professional that GPs first refer to if they suspect that a young child may have autism and they may be the one to guide the multidisciplinary assessment and provide direction with access to EI.

- Involving the paediatric body is an important element of the collaborative process so that their support of the assessment process can be secured. Initiating consultation with paediatricians to discuss the assessment process and seeking their opinions and support are important elements to ensure that a comprehensive neurodevelopmental surveillance protocol is established and can be ongoing in the state of Tasmania.
- Accurately, sensitively, and clearly describe the SACS-R pathway as a pathway for early assessment of autism – using that term - being mindful of this as potentially confronting for parents.
- Acknowledge and address the stigma associated with autism by practicing in ways that increase awareness and acceptance of the condition: assist people with autism who have challenges to become people with autism who face less challenges.
- Ensure standard practice regarding thoroughness and integration is applied to the administration of the tool.
- Acknowledge that the pathway allows benefits for children with other social communication difficulties and developmental delays.
- The SACS-R tool has demonstrated capacity to be useful in detecting a wide-range of atypical development. Thus, it would be useful for the SACS-R to be included as part of a more comprehensive neurodevelopmental screening protocol.
- Address parental support and adjustment during the waiting period.
- Facilitate parent confidence, empowerment, and ability to advocate for their child.
- Acknowledge that diagnosis can bring with it possible high emotion and distress. Consequently, parents' emotional health needs to be a high priority during the three phases of the diagnostic journey.
- Allied health providers and support organisations provide parents with education, training opportunities, and guidance on navigating and accessing therapeutic and support services.
- Increase parent skills and their capacity to contribute to their child's progress and development through education and training in parent-led intervention programs, particularly while families are awaiting further assessment and/or access to services, and parenting workshops on varying topics, e.g., applying to the NDIS for funding can increase a family's sense of agency. Monitor and support parents with the completion of NDIS paperwork; informing families of the next steps and available support; and assisting them to source and access therapeutic supports and interventions for their child.

- Build in flexibility to respond to the demand of waiting lists, adjusting staffing levels accordingly.
- The creation of an autism electronic manual would be useful to CHaPS, ASELCC and St Giles staff so that there is a central place to access information. It would also include any updates, reminders, and changes to the SACS-R process to ensure consistency of administration across the three organisations. Examples of manual content would include a description and explanation around the shift in language use; latest research; and evidence-based interventions for parents to use and/or access.
- It is of clinical relevance that the Australian National Guidelines are incorporated into practices and are matched to the current assessment processes. Clarity is essential regarding assessments and reports that contribute to funding decisions with NDIS/ECEI. The functional assessments and use of recommended assessment tools required by the funding body need to be determined and applied.
- Not all children who are referred to the DAT require a full autism assessment. Thus, having the ability to select the most appropriate assessment tool would enhance the assessment process and make efficient use of assessment time.
- Establish a core storage system where information and reports can be located by schools and agencies. A central place where essential information can be found will mean that parents do not have to repeatedly supply their child's developmental history, dates of appointments and with whom, and provide evidence of assessment outcomes and copies of reports.

## 6.5 Implications for research

This research showed that DT is an approach that enabled identification and assessment of enablers and barriers of successful implementation of the SACS-R. It also provided enhanced understanding of the implementation process of the SACS-R. Stakeholders were able to generate solutions to the challenges that were recognised. A DT approach also informs the evaluation and leads to solid stakeholder buy-in.

This research used a MIDI survey to determine the enablers and barriers of successful implementation of the SACS-R process. MIDI is a widely used, but not yet validated instrument. Even though the MIDI was selected for this project, having no validation and cross-cultural adaptation is a shortcoming that could be addressed through development of projects that work towards translating MIDI to become a more rigorous validated instrument. A key finding in the use of the MIDI survey was that the results were positively skewed in all three domains and across both stakeholder groups. This finding relates back to the validation of the instrument. Therefore, it is important that the MIDI survey should be tested against an alternate gold standard tool and validated using discriminatory and reliability analysis.

The findings of the project will mean that the next phase will commence with a good understanding of what has been successfully achieved and where improvements need to be made. It is envisaged that once the barriers are addressed and the enablers are supported and strengthened, the process could be effectively rolled out to families and relevant stakeholders via a sustainable program in other states and territories across Australia.

## **6.6 Recommendations**

In view of these implications, the following specific recommendations are made:

- Long-term government investment in autism surveillance.
- Government responsibility to ensure that CHaPS are kept up to date with updated autism best-practice and education and training.
- Embed the SACS-R in accreditation processes conducted by the THS, for evaluation of service delivery through use of continuous quality improvement principles.
- Develop practice guidelines of the SACS-R tool to support consistent integration and administration.
- Ongoing education, training, and professional development for all stakeholders.
- Increased services in regional and remote areas of Tasmania.
- A strategy to ensure qualitative and quantitative research extending beyond this work is essential to improve practice and development of new or revised policies, exploring the cultural and socio-economic context to understand enablers and barriers at a deeper level through engagement with culturally and linguistically diverse (CALD) families.
- Extending ASELCC across Tasmania.
- Improve the lack of service provision along with ongoing issues relating to extensive wait times for diagnostic and therapeutic services and workforce retention through: 1) advocacy across forums including Public Health Association Australia and Autism Tasmania; and 2) State and Federal Government funding that is redistributed in areas of need: diagnostic assessment and MDTs; therapeutic services; training; and development of CFCs.

## **6.7 Summary**

In summary, this study adds significantly to our understanding of the enablers and barriers to successful implementation of the SACS-R tool. Design Thinking and Implementation Science provided a robust and effective framework by which the inclusion of unique and varied perspectives was enabled, all the while keeping the impacts on parents and children a central concern. The study captured multiple stakeholder experiences of the implementation process of the SACS-R and thus can inform the rollout across other Australian jurisdictions and health service settings.

Tasmania has an opportunity to build on the knowledge and expertise that CHaPS and the DATs have gained from this experience so far. Both organisations are well-placed to



capitalise on the work achieved with established organisational links and a firm pathway to early diagnosis and support. Although the waiting list is a persistent problem, it is within the scope of the THS and government to address the staffing issues and funding allocation. Broader factors for consideration include the ECEI/NDIS funding.

Robust, collaborative communication between key stakeholders is essential in early-age assessments. With a solid pathway already in place, and families already utilising services and having access to diagnostic outcomes, Tasmania is in a prime place of opportunity to utilise and build on the work already invested in achieving great outcomes for children with autism and their parents.

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## Appendix A - SACS-R checklists (12, 18 and 24-month assessments)

### SACS-Revised (SACS-R): 12-MONTH ASSESSMENT

#### Pointing (KEY ITEM)

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?

TYPICAL / ATYPICAL

#### Eye contact (KEY ITEM)

Has the child spontaneously made eye contact with you during the session?

If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?

TYPICAL / ATYPICAL

#### Waving 'bye-bye' (KEY ITEM)

Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child).

Does s/he wave back?

TYPICAL / ATYPICAL

#### Imitation (KEY ITEM)

Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'.

Does s/he imitate you?

TYPICAL / ATYPICAL

#### Response to name (KEY ITEM)

Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)

TYPICAL / ATYPICAL

#### Follows point

Get the child's attention and then point to an object across the room and say 'WOW, look at that!'

Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)?

TYPICAL / ATYPICAL

#### Social smiles

Has the child smiled while making eye contact with you? If not, smile at the child.

Does s/he smile back? (Do not use physical contact to elicit a smile)

TYPICAL / ATYPICAL

#### Conversational babble

Does the child babble (e.g. saying agaga, adaba, mama, dada) in a conversational like manner?

TYPICAL / ATYPICAL

#### Speaks 1-3 words

Does the child speak 1-3 recognisable words?

TYPICAL / ATYPICAL

#### Understands simple instructions

Show the child a block and place it beside him/her. Then ask, "Give me the block".

Does s/he give you the block?

TYPICAL / ATYPICAL

#### Attending to sounds

Has the child been attending to / seem interested in sounds during the session?

TYPICAL / ATYPICAL

**If answered ATYPICAL to 3 of the 5 'KEY ITEMS', child is 'AT RISK' for ASD.  
Please refer child to the SACS-R team for a comprehensive developmental assessment.**

11 items

5 key items

$\frac{3}{5}$  key items flagged  $\Rightarrow$  St Giles DAT

\* Window for administration:  
11 to 15 months + 30/1 days

## SACS-Revised (SACS-R): 18-MONTH ASSESSMENT

### Pointing (KEY ITEM)

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?

TYPICAL / ATYPICAL

### Eye contact (KEY ITEM)

Has the child spontaneously made eye contact with you during the session?

If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?

TYPICAL / ATYPICAL

### Waving 'bye-bye' (KEY ITEM)

Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child).

Does s/he wave back?

TYPICAL / ATYPICAL

### Social communication (showing) (KEY ITEM)

Does the child try to communicate with you or the parent in a SOCIAL manner? That is, has s/he held up a toy/object and "showed" it to you, WITH eye contact? (Ask parent if not observed).

TYPICAL / ATYPICAL

### Pretend play (KEY ITEM)

Give the child a toy cup and pot. Say "Can you pour a drink and drink it?"

Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy)

TYPICAL / ATYPICAL

### Imitation

Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'.

Does s/he imitate you?

TYPICAL / ATYPICAL

### Response to name

Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)

TYPICAL / ATYPICAL

### Follows point

Get the child's attention and then point to an object across the room and say 'WOW, look at that!'

Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)?

TYPICAL / ATYPICAL

### Social smile

Has the child smiled while making eye contact with you? If not, smile at the child.

Does s/he smile back? (Do not use physical contact to elicit a smile)

TYPICAL / ATYPICAL

### Uses 5-10 words

Does the child use 5-10 words?

TYPICAL / ATYPICAL

### Understands words

Does the child understand many more words than they use?

TYPICAL / ATYPICAL

### Obeys simple instructions

Show the child a block and place it beside him/her. Then ask, "Give me the block".

Does s/he give you the block?

TYPICAL / ATYPICAL

### Points to facial features

Get the child's attention. Say 'point to your eyes/nose/mouth'.

Does s/he point to his/her eyes/nose/mouth?

TYPICAL / ATYPICAL

### Loss of skills

Ask the parent if the child has lost ANY language or social skills at ANY age.

Has the child lost any skills?

TYPICAL / ATYPICAL

**If answered ATYPICAL to 3 of the 5 'KEY ITEMS', child is 'AT RISK' for ASD.**

**Please refer child to the SACS-R team for a comprehensive developmental assessment.**

*14 items                      \* window for administration:  
5 key items                16 to 21 months + 30/1 days  
3/5 key items flagged ⇒ St Giles DAT*

## SACS-Revised (SACS-R): 24-MONTH ASSESSMENT

### Pointing (KEY ITEM)

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?

TYPICAL / ATYPICAL

### Eye contact (KEY ITEM)

Has the child spontaneously made eye contact with you during the session?

If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?

TYPICAL / ATYPICAL

### Waving 'bye-bye' (KEY ITEM)

Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child).

Does s/he wave back?

TYPICAL / ATYPICAL

### Social communication (showing) (KEY ITEM)

Does the child try to communicate with you or the parent in a SOCIAL manner? That is, has s/he held up a toy/object and "showed" it to you, WITH eye contact? (Ask parent if not observed).

TYPICAL / ATYPICAL

### Pretend play (KEY ITEM)

Give the child a toy cup and pot. Say "Can you pour a drink and drink it?"

Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy)

TYPICAL / ATYPICAL

### Imitation

Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'.

Does s/he imitate you?

TYPICAL / ATYPICAL

### Response to name

Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)

TYPICAL / ATYPICAL

### Follows point

Get the child's attention and then point to an object across the room and say "WOW, look at that!"

Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)?

TYPICAL / ATYPICAL

### Social smile

Has the child smiled while making eye contact with you? If not, smile at the child.

Does s/he smile back? (Do not use physical contact to elicit a smile)

TYPICAL / ATYPICAL

### Uses 20-50 words

Does the child use 20-50 words?

TYPICAL / ATYPICAL

### 2-word utterances

Does the child use some two-word phrases (e.g., more drink)?

TYPICAL / ATYPICAL

### Follows simple commands

Show child a teddy bear and place it across the room. Then ask, "Go and get me teddy".

Does s/he give you the teddy?

TYPICAL / ATYPICAL

### Loss of skills

Ask the parent if the child has lost ANY language or social skills at ANY age.

Has the child lost any skills?

TYPICAL / ATYPICAL

### Parallel play

Does the child play near (not necessarily with) other children? (ask parent)

TYPICAL / ATYPICAL

### Interest in other children

Does the child seem interested in other children their own age? (ask parent)

TYPICAL / ATYPICAL

**If answered ATYPICAL to 3 of the 5 'KEY ITEMS', child is 'AT RISK' for ASD.**

**Please refer child to the SACS-R team for a comprehensive developmental assessment.**

*15 items*

*5 key items*

*3/5 key items flagged ⇒ St Giles DAT*

*\*window for administration:*

*22 to 35 months*



## Appendix B - Primary stakeholder information sheet



**FACULTY OF HEALTH**  
Centre for Rural Health

Locked Bag 1322  
Launceston Tasmania 7250  
T +61 3 6324 4009  
F +61 3 6324 4040

### Participant Information Sheet – Parents

Designing for success: Statewide implementation of the Social Attention and Communication Surveillance-Revised (SACS-R)

#### Invitation

You are invited to take part in a study investigating the implementation of developmental surveillance to assist in early identification of difficulties in social attention and communication behaviours in infants and toddlers, which represent important developmental milestones. The study is being conducted by Ali Morse (PhD candidate and Clinical Psychologist), Associate Professor Tony Barnett and Dr Lyndsay Quarmby. This is a collaborative study between the University of Tasmania, the Department of Health and Human Services and St Giles.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### 1. 'What is the purpose of this study?'

The Child Health and Parenting Service (CHaPS) nurses use the Social Attention and Communication Surveillance-Revised (SACS-R) assessment as part of your child's health check. Your child's social attention and communication development is being observed by the CHaPS nurse to identify whether their development is typical for age. Social attention and communication skills might include regular eye contact with people, interest in others, smiling at others, sharing interest in an object or event with others, and communicative vocalisations.

#### 2. 'Why have I been invited to participate in this study?'

If your child is 12 months or older, we would really like to hear from you about that assessment.

#### 3. 'What if I don't want to take part in this study, or if I want to withdraw later?'

Participation in this research project is voluntary. If you decide to take part and later change your mind, you are free to withdraw the information you have provided up to four weeks following participation.

#### 4. 'What does this study involve?'

This study involves:

Completion of a brief, anonymous questionnaire (*Client Satisfaction Questionnaire: CSQ-8*). This survey should take less than 5 minutes to complete. You do not have to answer any questions that you do not wish to answer. Submission of your survey implies that you consent to participate in this study.

**5. 'Will I benefit from the study?'**

Whilst there is no direct benefit from participating in this study, be assured that your participation helps us understand the implementation of the SACS-R and future health service implementation.

**6. 'What happens with the results?'**

The information gathered for the study will be used for research. The results will be published in scholarly journals, reports and presented at conferences, but no information that discloses your, or your child's, identity will be used so that all personal details will remain confidential. A summary of the results of this study will also be available on request at the conclusion of the project.

**7. 'What should I do if I want to discuss this study further before I decide?'**

If you would like to know more at any stage, please do not hesitate to contact Ali Morse, Centre for Rural Health, University of Tasmania on 03 6226 6905, [Ali.Morse@utas.edu.au](mailto:Ali.Morse@utas.edu.au) or Associate Professor Tony Barnett, Centre for Rural Health, University of Tasmania on 03 6324 4011, [Tony.Barnett@utas.edu.au](mailto:Tony.Barnett@utas.edu.au) or Dr Lyndsay Quarmby, Centre for Rural health, University of Tasmania on 03 6324 4029, [Lyndsay.quarmby@utas.edu.au](mailto:Lyndsay.quarmby@utas.edu.au)

**8. 'Who should I contact if I have concerns about the conduct of this study?'**

This study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 6254 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer, is the person nominated to receive complaints from research participants. You will need to quote ethics reference number: H0016974

**9. 'How do I participate?'**

If you wish to participate, please enter the following link into your browser

<http://surveys.utas.edu.au/index.php/822715?lang=en>

or contact one of the researchers (Ali Morse, [Ali.Morse@utas.edu.au](mailto:Ali.Morse@utas.edu.au) 03 6226 6905 or Associate Professor Tony Barnett, 03 6324 4011, [Tony.Barnett@utas.edu.au](mailto:Tony.Barnett@utas.edu.au) or Dr Lyndsay Quarmby, 03 6324 4029, [Lyndsay.quarmby@utas.edu.au](mailto:Lyndsay.quarmby@utas.edu.au)) for the link to be sent to you embedded in a text message or email.

**Thank you for taking the time to consider this study.**

**This information sheet is for you to keep.**

## Appendix C - Primary stakeholder consent form



**FACULTY OF HEALTH**  
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Launceston Tasmania 7250  
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### Participant Consent Form – Parent (referred)

Designing for success: Statewide implementation of the Social Attention and Communication Surveillance-Revised (SACS-R)

(HREC Approval Number: H0016974)

1. I agree to take part in the study named above and my consent is given voluntarily.
2. The nature, purpose and possible effects of the project so far as it affects me, have been fully explained to my satisfaction by the researcher.
3. The details of the interview process have also been explained to me, including the length of time it will take, how and where the interview will take place and how my responses will be used. I understand that:
  - I will be interviewed about my experience regarding my child's Social Attention and Communication Surveillance-Revised (SACS-R) assessment conducted by the CHaPS nurse and the St Giles' assessment process.
4. I have been given the opportunity to have a member of my family or friend present while the project was explained to me.
5. I understand that no information regarding my child's developmental history will be shared and my responses given at the time of interview will not be published so as to reveal my identity.
6. I understand that my involvement in the project will not affect my relationship with any health professionals involved in the care of my child. I also understand that I am free to withdraw the information I have provided through my participation up to four weeks following collection. My withdrawal will not effect my legal rights, my medical care or my relationship with the Tasmanian Health Service.
7. I understand that I will be given a copy of the information sheet and signed consent form. I am not giving up my legal rights by signing this consent form.
8. I understand that the project will be conducted in accordance with the latest versions of the *National Statement on Ethical Conduct in Human Research 2015* and applicable privacy laws.

9. I agree to allow the audio-recording of the interview, and am aware that the interview will be transcribed and upon request can be sent to me for approval and/or editing before my information is coded. I know that I can request a copy of my transcript. I understand that this information will be kept in secure storage on Centre for Rural Health password protected electronic files on a computer server.

Participant's name \_\_\_\_\_

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Participant's email address \_\_\_\_\_

Participant's phone number \_\_\_\_\_

**Researcher Statement**

I have explained this project and the implications of participation in it to this volunteer and believe that the consent is informed and that he/she understands the implications of participation.

Name of investigator \_\_\_\_\_

Signature of investigator \_\_\_\_\_ Date \_\_\_\_\_

## Appendix D - Client Satisfaction Questionnaire (CSQ-8)

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Client Satisfaction Questionnaire

The questions in this survey pertain specifically to the Social Attention and Communication Study-Revised (SACS-R) assessment, which was conducted by your child's CHaPS nurse at their routine child health check. Please answer all of the questions. We also welcome your comments and suggestions. Thank you very much. We appreciate your help.

[Participant Information Sheet](#)

There are 9 questions in this survey.

Load unfinished survey

Next

Exit and clear survey

horised by the Associate Director, Service Delivery & Support , IT Services

Future Students | International Students | Postgraduate Students | Current Students

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Quality of Service				
	Excellent	Good	Fair	Poor
How would you rate the quality of services provided to your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Kind of Service				
	No, definitely not	No, not really	Yes, generally	Yes, definitely
Did you get the kind of service you wanted for your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Services Met Needs				
	Almost all of my child's needs have been met	Most of my child's needs have been met	Only a few of my child's needs have been met	None of my child's needs have been met
To what extent have the services met your child's needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Service Recommendation				
	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
If a friend's child were in need of similar help, would you recommend our services to him/her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Satisfaction				
	Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied
How satisfied are you with the amount of help your child has received?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Service Effectiveness				
	Yes, they helped a great deal	Yes, they helped somewhat	No, they really didn't help	No, they seemed to make things worse
Have the services you received helped your child to deal more effectively with his/her problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall Satisfaction				
	Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
In an overall, general sense, how satisfied are you with the service your child received?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Further Support?				
	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
If you were to seek help again for your child, would you come back to our service?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please feel free to comment below.				

## Appendix E - Primary stakeholder semi-structured interview schedule

### Referred Parent Supplementary Interview Questions (V2)

Preamble:

- Hello. My name is Ali Morse.
- Firstly, thank you so much for your recent completion of the questionnaire and thank you for your additional time today for this interview.
- I am a PhD student investigating the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) into the state of Tasmania.
- I am interested in the experience of your child's assessment for social attention and communication when you attended the Child Health and Parenting Service (CHaPS) and St Giles. I'm going to be talking about the social attention and communication assessment a lot, so I'll just call it SACS from here on in – is that okay with you?
- The implementation of the SACS-R is relatively new to Tasmania. I will be asking you a number of questions to get a better understanding of the process that you and your child have gone through.
- I have already sent you the information statement and you have returned a copy of your signed consent form. Just as a reminder, if you change your mind at any time throughout the interview, we can stop the recording. You are also free to withdraw up to four weeks following your interview. Are you still happy to participate?

Overarching topic ❖ Question	Prompts
Experience with your child's assessment at CHaPS ❖ Can you talk me through your experience of your child's assessment in relation to social communication and attention as you understand it occurred at your CHaPS appointment?	Let's start with your appointment with the CHaPS nurse and move through to your child's assessment at St Giles. Did you have any concerns about your child's development prior to any of your child's CHaPS appointments? If so, did you voice those concerns: What was the response?
❖ How satisfied were you with your child's assessment of social communication and attention at the CHaPS. Did you feel you understood what the nurse was assessing and why?	Using this 5-point Likert scale ('very dissatisfied' to 'very satisfied'), would you please indicate the level of satisfaction you felt in relation to your child's SACS assessment.
❖ How long was it from the time of the CHaPS appointment where the nurse discussed referral to your first appointment with St Giles? What was this time like for you? How old was your child at the time?	Did the nurse give you an idea of how long it might take? Were you given any information about how long the waitlist for assessment might be? Did you discuss the results with your GP or any other trusted person in your life?

<p>Experience with your St Giles' assessment</p> <ul style="list-style-type: none"> <li>❖ How satisfied were you with the assessment you and your child received at St Giles?</li> <li>❖ Which St Giles location did you attend?</li> </ul>	<p>Again, using this 5-point Likert scale ('very dissatisfied' to 'very satisfied'), would you please indicate the level of satisfaction you felt.</p>
<ul style="list-style-type: none"> <li>❖ How was the feedback appointment for you?</li> </ul>	<p>What happened when your child</p> <ul style="list-style-type: none"> <li>(a) did not receive a diagnosis?</li> <li>(b) was diagnosed with ASD?</li> <li>(c) Did not receive a diagnosis of ASD but did receive another diagnosis?</li> </ul>
<p>Satisfaction with what is going to happen in the future for you and your child</p> <ul style="list-style-type: none"> <li>❖ Do you feel confident about the next steps for your child? Were the recommendations clear to you?</li> </ul>	<p>For the last time, using this 5-point Likert scale ('very dissatisfied' to 'very satisfied'), would you please indicate the level of satisfaction you feel about where to from here</p>
<p>Is there anything else that you would like to add that you did not get a chance to discuss?</p>	

## Appendix F - Internal stakeholder (group 1) MIDI survey

### SACS-R Implementation Questionnaire for the Tasmanian CHaPS nurses

**Adapted with permission from: Measurement Instrument for Determinants of Innovations (MIDI).** M.A.H. Fleuren, T.G.W.M. Paulussen, P. Van Dommelen, and S. Van Buuren. Leiden: TNO, 2014.

This is a 45-item questionnaire and the purpose is to find out what you perceive to be the **enablers** and **barriers** related to the successful implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) surveillance tool into the routine practice of your organisation.

This survey will take you approximately 10 to 15 minutes to complete.

We are seeking your opinion about how things are going for you, regarding your use of the SACS-R tool; your clinical practice; and your opinion from an organisational perspective about the implementation of the SACS-R.

**Your responses are anonymous.**

**Please circle your response to each statement.**

#### Implementation of the SACS-R surveillance tool

1. The SACS-R clearly describes the behaviours you are looking to elicit from the child

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

2. The SACS-R is based on factually correct knowledge on child development

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

3. The SACS-R provides all the information I need to monitor a child's social attention and communication skills

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

4. The SACS-R is too complex for me to use

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

5. The SACS-R is a good match for how I am used to working

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

6. The outcomes of using the SACS-R are clear to me

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

7. The SACS-R is relevant for the population I work with

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

8. I think parents are comfortable with the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

#### Clinical use of the SACS-R

9. The SACS-R helps me detect atypical behaviour in children

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

10. The SACS-R helps me to better understand children' social attention and communication

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

11. The SACS-R helps me in my conversations with parents

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

12. I expect that using the SACS-R will detect atypical social attention and communication behaviour in young children

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

13. I expect that using the SACS-R will identify infants and toddlers at risk of Autism Spectrum Disorder

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

14. Using the SACS-R will support toddlers and children to access support earlier

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

15. I perceive it as my responsibility as a professional to use the SACS-R in my clinical practice

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

16. Parents are generally be satisfied when I use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

17. Parents are generally cooperative when I use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

18. I can rely on adequate assistance from my colleagues when I need to use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

19. I can rely on adequate assistance from the SACS-R research team when I need to use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

20. Overall, I think that the CHaPS nurses in my organisation, including myself, can effectively support the implementation of the SACS-R as part of routine clinical practice

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

21. In my opinion, the proportion of colleagues in my organisation who regularly use the SACS-R is

<b>Not a single colleague</b>	<b>A minority</b>	<b>Half</b>	<b>A majority</b>	<b>All colleagues</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

22. My colleagues expect me to use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

23. Management expects me to use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

24. It is my responsibility to ensure that I use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

25. I expect my colleagues to use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

26. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of your colleagues?

<b>Very little</b>	<b>Little</b>	<b>Not a little/Not a lot</b>	<b>A lot</b>	<b>A great deal</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

27. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of management?

<b>Very little</b>	<b>Little</b>	<b>Not a little/Not a lot</b>	<b>A lot</b>	<b>A great deal</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

28. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of the SACS-R research team?

<b>Very little</b>	<b>Little</b>	<b>Not a little/Not a lot</b>	<b>A lot</b>	<b>A great deal</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

29. With regard to working in accordance with the SACS-R, to what extent do you comply with the opinions of parents?

<b>Very little</b>	<b>Little</b>	<b>Not a little/Not a lot</b>	<b>A lot</b>	<b>A great deal</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

30. I am confident in my ability to implement the items from the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

31. I have enough knowledge to use the SACS-R as intended

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

32. I am well aware and informed about the content of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Please list any **barriers** that you think may affect **your use** of the SACS-R **within your role**.

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Please make comment on any strategies that you think may assist in helping **you** overcome any identified barriers, i.e. **enablers**.

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#### **Organisation (Tasmanian CHaPS)**

33. There is a clear process in place for upskilling new or returning staff in the use of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

34. There is adequate staffing available in our organisation to use the SACS-R as intended

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

35. There are enough financial resources available to implement the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

36. There is enough time available to include the administration of the SACS-R items in my day-to-day work

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

37. There are enough resources (equipment, materials, space) provided by my organisation to enable me to use the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

38. There are people designated to coordinate the process of implementation of the SACS-R.

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

39. Are there any other changes (e.g., reorganisation, merger, cuts, staffing changes, other innovations) going on that influence the implementation of the SACS-R as part of routine clinical practice

<b>No</b>	<b>Yes</b>
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40. It is easy for me to find information in my organisation about using the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

41. I have been provided with regular feedback about progress with the implementation of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

42. Overall, I think that the healthcare professionals within my organisation, including myself, can effectively support the implementation of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

43. The items listed in the SACS-R fit in well with the intentions of Universal health checks

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Please list any **barriers** that you think may impact the use of the SACS-R within your **organisation**.

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Please make comment on any strategies that you think may assist in helping your **organisation** overcome any identified barriers, i.e. **enablers**.

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Thank you for taking the time to complete this questionnaire.



## Appendix G - Internal stakeholder (group 2) MIDI survey

### SACS-R Implementation Questionnaire for the Tasmanian Nurse Unit Managers, Clinical Nurse Educator, Assistant Directors of Nursing and Director of Nursing

**Adapted with permission from: Measurement Instrument for Determinants of Innovations (MIDI).** M.A.H. Fleuren, T.G.W.M. Paulussen, P. Van Dommelen, and S. Van Buuren. Leiden: TNO, 2014.

This is a 10-item questionnaire and the purpose is to find out what you perceive to be the **enablers** and **barriers** to the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) surveillance tool.

This survey will take you approximately 5 to 10 minutes to complete.

**Your responses are anonymous**

**Please circle your response to each statement.**

There is a clear process in place for upskilling new or returning staff in the use of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

There is adequate staffing available in our organisation to use the SACS-R as intended

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

There are enough resources (e.g., personnel, finances, equipment, materials, space) available to the staff to successfully support the implementation of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

There is enough time available for CHaPS staff to administer the SACS-R into their day-to-day work

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

It is easy for me to find information in my organisation about using the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

I have been provided with regular feedback about progress with the implementation of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Overall, I think that the healthcare professionals within my organisation, including myself, can effectively support the implementation of the SACS-R

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The items listed in the SACS-R fit in well with the intentions of Universal health checks

<b>Totally disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Totally agree</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Please list any **barriers** that you think may impact the use of the SACS-R within your **organisation**.

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Please make comment on any strategies that you think may assist in helping your **organisation** overcome any identified barriers, i.e. **enablers**.

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Thank you for taking the time to complete this questionnaire.

## Appendix H - Internal stakeholder (group 1) semi-structured interview schedule

### CHaPS Nurses Interview Questions

Preamble:

- Hello. My name is Ali Morse.
- Firstly, thank you so much for your recent completion of the questionnaire and thank you for your additional time today for this interview.
- I am a PhD student investigating the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) into the state of Tasmania.
- I am interested in your thoughts and ideas about the SACS-R, the role and responsibilities of the Child Health and Parenting Service (CHaPS) nurses and St Giles. I would like to take this opportunity for you to discuss and make comment on these topics.
- The implementation of the SACS-R program represents a new innovation to CHaPS in Tasmania and requires a collaborative approach that involves parents, nurses, managers, and policy groups. I will be asking you a number of questions to facilitate a better understanding of this statewide change, but with a major focus on the parents of the children suspected of having ASD.
- I have already sent you the information statement and you have returned a copy of your signed consent form. Just as a reminder, if you change your mind at any time throughout the interview, we can stop the recording. Are you still happy to participate?

Overarching topic ❖ Question	Prompts
SACS-R implementation enablers and barriers ❖ Can you tell me about your experience using the SACS-R?	What has worked well? Where do you think there is room for improvement? And what? How was your experience talking with parents about the results of the SACS-R? Overall, how successful do you think the CHaPS nurses have been with trying out change in practice and integrating the new practice into routines? Using this 5-point Likert scale ('not successful' to 'very successful'), would you please indicate the level of success you felt about the CHaPS nurses' implementation of change into their practice routine.
Parent response ❖ What do you think the parents' experience with the SACS-R was like?	

❖ How has your experience been with the referral process to St Giles?	As you know, the CHaPS nurses are the referrers to St Giles following SACS-R assessments.
Technical aspects ❖ What about the training and the support you received? Were they sufficient in enabling you to implement the SACS-R?	What has been your experience around making entries into <i>Salesforce</i> ? Have you felt you have had sufficient time to complete all the requirements necessary for the SACS-R completion and data entry?
❖ How do you see the SACS-R fitting into the other screening and surveillance measures you currently use?	
❖ Is there anything else that you would like to add that you did not get a chance to discuss?	

## Appendix I - Internal stakeholder (group 2) semi-structured interview schedule

### Internal Stakeholders Group 2 Supplementary Questions

Preamble:

- Hello. My name is Ali Morse.
- Firstly, thank you so much for your recent completion of the questionnaire and thank you for your additional time today for this interview.
- I am a PhD student investigating the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) into the state of Tasmania.
- I am interested in your thoughts and ideas about the SACS-R, the role and responsibilities of the Child Health and Parenting Service (CHaPS) nurses and St Giles. I would like to take this opportunity for you to discuss and make comment on these topics.
- The implementation of the SACS-R program represents a new innovation to CHaPS in Tasmania and requires a collaborative approach that involves parents, nurses, managers, and policy groups. I will be asking you a number of questions to facilitate a better understanding of this statewide change, but with a major focus on the parents of the children suspected of having ASD.
- I have already sent you the information statement and you have returned a copy of your signed consent form. Just as a reminder, if you change your mind at any time throughout the interview, we can stop the recording. Are you still happy to participate?

Overarching topic ❖ Question	Prompts
<p>Your thoughts and ideas about the SACS-R and the role and responsibilities of the CHaPS nurse</p> <ul style="list-style-type: none"> <li>❖ How do you think the rollout of the SACS-R in CHaPS has gone?</li> <li>❖ What are some of the things that worked well in the use of the SACS-R as part of routine health checks?</li> <li>❖ What are some of the things that did not go so well in the use of the SACS-R as part of routine health checks?</li> <li>❖ What are your thoughts around the piloting of the 18-month surveillance?</li> </ul>	<p>What has worked well? What are the areas for improvement? What do you think encourages and/or discourages parents in the community from taking their child along to CHaPS to undergo social attention and communication surveillance by the nurses?</p> <p>How do you suggest we increase participation of Tasmanian children when their two-year-old health check is due?</p> <p>What do you see as the implementation enablers and barriers regarding the SACS-R tool becoming part of Tasmanian routine practice?</p> <p>Overall, how successful do you think the process has been with the CHaPS nurses trying out change in practice and integrating the new practice into routines? Using this 5-point Likert scale ('not successful' to 'very successful'), would you please indicate the level of success you felt about the process of implementation of change into practice routine.</p>

<p>Parent response</p> <ul style="list-style-type: none"> <li>❖ How do you think the parents felt about the process?</li> </ul>	<p>Have you had any feedback? How was it responded to?</p>
<p>Partner collaboration</p> <ul style="list-style-type: none"> <li>❖ How do you feel the collaboration with other partners in the project has gone?</li> </ul>	<p>With St Giles? The university? Other departments in the health service?</p> <p>How would you describe the lines of communication between CHaPS and St Giles and vice versa?</p>
<p>Technical aspects</p> <ul style="list-style-type: none"> <li>❖ Can you tell me about any technical issues that arose along the way?</li> </ul>	<p>For example, <i>Salesforce</i>; pen and paper data documentation to eHealth records; CHaPS appointment times extended.</p> <p>Were there any additional issues encountered by the CHaPS? If so, how have they been resolved?</p>
<ul style="list-style-type: none"> <li>❖ How do you perceive the SACS-R fitting in with the other screening and surveillance tools?</li> </ul>	<p>Is it value adding or not?</p>
<p>The future/What next</p> <ul style="list-style-type: none"> <li>❖ What would you suggest the implementation team could do differently if commencing statewide rollout of the SACS-R again?</li> <li>❖ What do you perceive to be the major challenges with taking this new initiative into the future?</li> </ul>	<p>Would you recommend any changes to the processes relating to the surveillance tool, for example, the training in the SACS-R, the administration of the tool, forward referrals?</p>
<ul style="list-style-type: none"> <li>❖ Is there anything else that you would like to add that you did not get a chance to discuss?</li> </ul>	

## Appendix J - Internal stakeholder (group 3) semi-structured interview schedule

### St Giles DAT and ASELCC Interview

Preamble:

- Hello. My name is Ali Morse.
- Thank you so much for your time today.
- I am a PhD student interested in understanding the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) into the state of Tasmania.
- I am interested in your thoughts and ideas about the Child Health and Parenting Service (CHaPS) and the SACS-R and would like to take this opportunity for you to discuss and make comment on this topic.
- The implementation of the SACS-R program represents a change to CHaPS in Tasmania and requires a collaborative approach that involves parents, nurses, managers, and policy groups. I will be asking you a number of questions to facilitate a better understanding of this statewide change, but with a major focus on the parents' needs regarding their children suspected of having ASD.
- I have already sent you the information statement and you have returned a copy of your signed consent form. Just as a reminder, if you change your mind at any time throughout the interview, we can stop the recording. You are also free to withdraw your data from the study up to four weeks following your interview. Are you still happy to participate?

Overarching topic ❖ Question	Prompts
Rollout of SACS-R <ul style="list-style-type: none"> <li>❖ How do you perceive the rollout of the SACS-R in CHaPS has gone?</li> <li>❖ How has the communication been between your organisation and other partners? e.g. CHaPS, university, ECIS</li> <li>❖ How do you think the rollout of the SACS-R has impacted your role and service?</li> </ul>	What has worked well? What are the areas for improvement?  Do you see any advantage to pursuing the administration of the 18-month surveillance?
Referral process <ul style="list-style-type: none"> <li>❖ How did the referral process between the CHaPS nurses and St Giles Developmental Assessment Team (DAT) go?</li> <li>❖ Have you needed to make any service changes as a result of referrals of much younger children?</li> </ul>	How would you describe the lines of communication between CHaPS, St Giles DAT, ECIS and ASELCC and vice versa?  PD needs? Service innovations?

<p>Parent response</p> <ul style="list-style-type: none"> <li>❖ What do you think the parents' experience of the process was from CHaPS health check to assessment?</li> </ul>	
<p>The future/What next?</p> <ul style="list-style-type: none"> <li>❖ What do you perceive to be the major challenges with taking this new initiative into the future?</li> </ul>	<p>How can we improve the process?</p> <p>Would you recommend any changes to the processes relating to the surveillance tool?</p> <p>Service needs?</p>
<p>SACS-R Implementation team</p> <ul style="list-style-type: none"> <li>❖ What would you suggest the implementation team could do differently if commencing statewide rollout of the SACS-R again?</li> </ul>	
<ul style="list-style-type: none"> <li>❖ Is there anything else that you would like to add that you did not get a chance to discuss?</li> </ul>	



## Appendix K - External stakeholder semi-structured interview schedule

### External Group Interview

Preamble:

- Hello. My name is Ali Morse.
- Thank you so much for your time today.
- I am a PhD student investigating the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) into the state of Tasmania.
- I am interested in gaining an understanding of your views on the rollout of the SACS-R program and would like to take this opportunity for you to discuss and make comment on this topic. As you may know, the SACS-R program utilises a developmental surveillance approach to identify children at risk of ASD at three time points (12-, 18- and 24-months of age) during their routine child health checks. The implementation of the program represents a change to the Child Health and Parenting Service (CHaPS) in Tasmania and requires a collaborative approach that involves parents, nurses, managers, and policy groups. I will be asking you a number of questions to facilitate a better understanding of this statewide change, but with a major focus on the parents' needs regarding their children suspected of having ASD.
- I have already sent you the information statement and you have returned a copy of your signed consent form. Just as a reminder, if you change your mind at any time throughout the interview, we can stop the recording. You are also free to withdraw your data up to four weeks following the completion of the interview. Are you still happy to participate?

Overarching topic ❖ Question	Prompts
<p>In your work, what areas of the state do you cover? (if applicable)</p> <p>Your knowledge regarding Autism Spectrum Disorder (ASD), the Social Attention Communication Surveillance-Revised, (SACS-R), the Child Health and Parenting Service (CHaPS) and parents' needs</p> <p>❖ Could you tell me a little about your interest in, and involvement with ASD?</p>	
<p>ASD</p> <p>❖ The ASD field is often changing. How do you manage to keep abreast of what's happening?</p>	<p>What are your current sources of information regarding the latest research around assessment for ASD?</p>
<p>SACS-R</p> <p>❖ Are you aware of the developmental surveillance for ASD here in Tasmania? Can you tell me about this?</p> <p>❖ How do you think the SACS-R program has worked? Is it a good fit for our State?</p>	<p>How well does this new health service initiative meet the needs of children with ASD and their families?</p>
<p>❖ What do you think encourages and/or discourages parents in the community from</p>	

<p>taking their child to undergo surveillance for ASD by the CHaPS nurses using the SACS-R?</p> <p>❖ How do you suggest we increase participation of Tasmanian children when their two-year-old health check is due?</p>	
<p>❖ What do you perceive to be the major challenges with taking this new health service initiative into the future?</p>	
<p>Overall process</p> <p>❖ Can you tell me about any enablers or barriers that exist which might support or hinder our community's ability to deliver timely, effective assessment, diagnosis, and support to young children with ASD?</p>	
<p>Specific needs of young children with ASD in our community</p>	
<p>❖ What do you think are the main needs of an infant or toddler with ASD? What about the needs of the families/carers of the child?</p>	<p>How are these needs met through current services or does the current service meet the needs?</p> <p>How can the needs be better met?</p> <p>When do you think is the most appropriate time to deliver support to a child with ASD and their family?</p>
<p>❖ What do you see as the challenges of the current service processes? What do you see as future solutions?</p>	<p>What would you like to see to support families who have a child with ASD?</p> <p>Outline priorities that you would like the public health system, welfare, education, etc. to support over the next 3 years and provide examples of activities that may address these priorities</p>
<p>❖ Is there anything else that you would like to add that you did not get a chance to discuss?</p>	

## Appendix L - Thematic coding book example

**Theme 1: Impacts on professional practice (nature of the work/legitimacy)**

Sub-theme	Source	Code/idea and/or quote	The point is...	Cross over with another theme
Formalisation	S10p	"...normalising the assessment of social and communication skills"	Normalising – what that means/the word usage for S10p	Overlap with 2.3
	S5f	S5f: "It's what we do."		
	S7f	S7f: "...formalisation of what we already were doing"	Formalising the assessment process; a formal pathway has been established; nurses are already doing this work; it's always been unofficially part of what they do	
	S9f	"...we're already doing a health check so it's not as if we're doing anything different really."		
	S10p	"makes that part of our normal child health assessments much more acceptable and expected by parents"		
	N11p	"...a more formal kind of approach to it..."		
	S9f	"it's not an extra thing...we were already looking at it anyway, but now it's in the program"		
	S12p	"Gives the appointments more structure"		
	N13p	"Well, I just think it absolutely fits with what we're trying to do anyway, the whole thing around early intervention. I can't imagine not doing this, regardless of whether we're doing a research project or not...it will be just automatically part of what we would be doing, I hope, anyway."		
	N6f	It's just part of the check now, not something separate"		
	N7f	Provides a more clinical way of asking the things already being asked		
	S3p	An important addition to what they already use..."we always observe, but we don't have like a screening process. We would assess speech, but not really how they were engaging socially with us or their environment."		
	S12p	"I haven't felt it's any more work load because I just think it's more so just streamlining what we were probably already doing, but just maybe not really thinking as deeply about those things."		
Confidence	S7f	"I did feel more confident in my assessments..." "I probably felt quite confident shortly after the training..."		
	S13p	"...we're all much more confident in knowing what, I suppose, even knowing what autism is and how it presents at early ages and, yeah, more likely to pick it up."		

**Theme 1: Impacts on professional practice (nature of the work/legitimacy)**

Personal / professional cross over	S18p	“...sometimes think <b>would I have referred them previously at two years of age?</b> ”	Increased confidence; confident in administration; confidence to know when to/when not to <b>refer</b> (not to <b>refer</b> but keep eyes on)
	N12p	“...with all the <b>training</b> that we had, I felt a little bit nervous first up, but after doing a couple I felt quite confident with them.”	
	S2p	“More aware”	
	S13p	“Knowledge that it can be picked up in a 12 month old” “...much more aware”; “We’re all much more confident in knowing what autism is and how it presents at early ages and more likely to pick it up”	
	S14p	“Increasing our general awareness”; “I find that because of my knowledge and know-how now, it’s all at the front or foremost in my mind for a lot of the other checks that you’re doing with children at different ages and being able to have those conversations with the <b>parents</b> , as well, around early signs of autism in children, yeah, just because of the extra knowledge and know how that I have about it, too.”	
	S18p	“...more aware of the eye contact and imitation”; “...it’s improved my skills of observation”	
	N6f		
	N7f		
	N14p	“It’s made me very aware, a lot more aware of social communication in those younger kids that we probably used to sort of sit on a lot longer and sort of think, oh, well, just maybe in another year they’ll have grown and that behaviour may have changed or it may be less...we’re not sitting on them as long and we’re able to get them seen a lot earlier and assistance if they need it, as well, which is great.”	
	S14p		
	S11p		
	S13p	received diagnosis @ 15.5yrs – he would have <b>passed</b> the SACS	

**Theme 1: Impacts on professional practice (nature of the work/legitimacy)**

Training and skills	N8f	“Training was good”/ the training, paperwork, vignettes were all great	Training and skills increased and developed		
	S7f	“...extra training and the confidence in those conversations you could have with families.”			Confidence 1.2
	S14p				
Intuition vs checklist → tool box  Experience	N6f	Training especially the difference between pointing to show and share	Taught how to do the assessments and do the documentation	Individual differences in how the SACS-R will be administered	
	S5f	“...oh, look, she's just not interested in doing it today so we'll just wait till another time. So that is the difference with the CU@Home. I think in the clinic that would be more challenging, especially because you don't know the kids.”	Age of nurse; setting		
	S9f	Nurses (new, young, inexperienced, not confident) may be swayed by parents and thus a referral not done			
	NW1f	CU@H nurse so low numbers/only do 12 month SACS – 24 months SACS administered in clinic		Limited opportunity 3:1	

## Appendix M - External stakeholder additional interview transcript quotes

Theme	Quote and Participant identification
<b>Professionals' views on impacts on professional practice</b> <i>Awareness and understanding of the SACS-R tool</i>	<p>"I don't really have much experience with at all. I haven't heard parents mention it before. I haven't really heard it come up at all, so I wonder if I've been living under a rock" (SE6); "I don't know a lot about it, I will admit. I have obviously looked it up because you were going to interview me" (SE16).</p> <p>"I haven't seen it before. I don't understand too much about how it works in Tasmania. I know, from what I've seen, that it is done over three age groups and it's – is it video conference? No? It's done through video, with video involved? That's what I'd heard. So, other than that I haven't really heard how it is working in Tasmania or much about it" (SE2); "I'm aware of it, but I couldn't say that I know very much about it. I know that it happens with child health nurses" (SE3); "I did have a conversation with someone just incidentally and she was talking about one of the assessments the child health nurses can do to screen a baby or a toddler for sort of markers for autism" (NE1); "I'm aware of the SACS being undertaken by the CHaPS nurses. I don't know a lot about it except I think it relates to questions mainly around social communication issues, but I haven't actually been able to see what one looks like or what questions form it either. I guess I previously had spoken with other paediatricians about it and I kind of wasn't too sure about the – I think if there were elevated scores that a lot of those children were referred to St Giles when I was working in the South for further assessment" (NWE1); "My experience really in seeing children with suspected autism is more so being referred from the Child Health nurse, but I'm not really aware of that assessment tool specifically. I don't know much about it, I just know that that's something that they do" (SE14).</p> <p>"That's like an early check. Is that right? Yes, so that's the, I think, 12 months, 18 months and 24 months. And I think that's great, but that's pretty much the extent of my knowledge, and that's, I think, with every child, is it, through the CHaPS? I've had no evidence to suggest it's not a success. I think the earlier the better in terms of the checks" (SE12).</p> <p>"It's for professionals to do with families and I know that you have to have certain – it's an indicator of red flags, you know, is it something we should be exploring further. So it gives us a nice snapshot, some key questions to ask to try and get a bit of a feel for whether we should be concerned. And so it gives a nice stamp in time as well at the 12, 18, 24 months" (NE3); "It's for professionals to do with families and I know that you have to have certain – it's an indicator of red flags, you know, is it something we should be exploring further. So it gives us a nice snapshot, some key questions to ask to try and get a bit of a feel for whether we should be concerned. And so it gives a nice stamp in time as well at the 12, 18, 24 months" (NE3).</p> <p>"I know that the developmental surveillance tool came out of Latrobe and OTARC, and it was trialled very successfully in Victoria, when we'd heard about it, and it was about the time that the Autism Advisory Panel were looking into diagnostic services and how to make them more effective and timely for parents" (SE7).</p> <p>"How are you going to implement it at that point?" And the next thing we knew the CHaPS has agreed to do that and then they had an Autism Council deciding this and then I said, "Have you actually thought through the model that you're doing? I think Jacque Petrusma was there at that time. And then she set up that Autism Advisory Panel, but they did not put any paediatricians in there. So I actually objected. I objected and I said where's the paediatric because, come on, we are the ones who are diagnosing it. Everybody and the Autism Advisory Panel was only people with conflict of interest, okay. I mean, I felt who are funded to do their autism advisory work. Not conflict of interest, but with vested interest. Who work in the field, but there was no dissenting voice or a voice of reason or a voice of saying, 'Is there another way to do it?'" (SE15).</p>
<b>Role of the CHaPS</b>	<p>"The child health nurses are a wonderful resource [...] certainly very knowledgeable about children and their development [...] and they're really good at knowing when to investigate more, not necessarily to say, ah, there's the problem, but to say let's just check this out a bit closer" (SE3).</p> <p>"To have a statewide program where you've got health nurses trained in a fairly – it's robust, but it's not overly time-consuming for them to do, and that just then gives the heads up for the rest of the other organisations to come onboard" (SE4).</p> <p>"Using it as a screening tool at those age groups would hopefully stop children falling through the net [...] and this is less likely to have those gaps and to miss people. It may be there's been more people who are caught in the net who <i>don't</i> have autism spectrum, but I think that's worth it for not missing the other people" (SE16); "What I found quite good about the project was just the fact that we are bringing the health nurses in [...] a whole different group of people in that we hadn't necessarily had a direct relationship with. Cross working collaboratively between mainstream, universal parenting service into specialist diagnostic teams and pathways and things. I think there's probably been good relationships built on that" (SE17).</p>
<b>The rollout of the SACS-R program</b>	<p>"Looking at picking things up early is obviously the ideal" (SE18).</p> <p>"Having it rolled out with the child health nurses, [...] is a good way to try and capture most people" (SE16); "It was only picking up people who were going to their health nurses anyway and I guess I've been noticing that quite a lot of people don't use that service" (SE21).</p>

	<p>“You have to change the model of care of looking after the vulnerable and we should have home visit nurses who build a relationship with vulnerable families” (SE15).</p> <p>“It’s just identifying children at a much younger age and, as a result, because they were being picked up earlier they are also coming to our service earlier and, therefore, engaging in our programs a lot earlier” (SE21); “We just said to one of our mums this week, “Congratulations, you’ve graduated.” “He came to us through the SACS and I remember him, he was either 17 or 19 months old and I thought that was like a wow, look how early kids are getting to us because of SACS. So that was my first, like a golden moment thinking this is amazing” (NE3).</p> <p>“I think it’s a great fit for our State. I know the child health system, I have two children of my own, [...] get the checks done, it’s a free service, it’s kind of well-advocated from birth and well-promoted through the GPs [...] in terms of a fit, a surveillance tool that can be done as part of those developmental checks is a really good way to screen for, hopefully, [...] a lot of the population” (SE7); “Diagnosis either takes a very long time or is very expensive, or both [...] for many it’s just not realistic to be able to pay that” (SE3).</p> <p>“The younger we can get them, obviously, and their needs what they require, the speech, the OT, the physio, everything very early, can really, really help out as they hit kindergarten age” (SE4); “Quite a few older siblings have been identified since the rollout of the SACS-R and it’s increasing our autism literacy” (SE1).</p> <p>“It’s a fantastic process [...] if they’re going through St Giles, like there’s a bog, there’s a bog down where they actually get a diagnosis is what I’m finding. So even if there’s a query at such a young age, to get an actual diagnosis that is where I think there’s like a neck where we need more practitioners that can do the actual diagnoses because, yeah, like in the clinic we’re still seeing five, six-year-olds, seven-year-olds, eight-year-olds, they’re not level 1, they’re level 2, and they’re coming through and you go, “How come you weren’t picked up earlier?” Or just, “Oh, we’ve been waiting for so long to get an assessment.” So that’s the only drawback that I’ve found, that we just need more people doing that” (SE4).</p> <p>Some queried whether the SACS-R tool had provided an advantage in terms of increasing diagnoses: “I think probably the challenge for us, as policy makers, is how does the SACS-R tool, like how consistent is it with the direction that the National Guidelines set? The reports that I hear from St Giles [...], we have to take the report of the funded organisation undertaking a project with a little bit of scepticism, I suppose, because there is always a continuing interest in continued funding. And so we need to really carefully assess whether we would see similar outcomes with or without the tool. And as I have said, I know from our own autism diagnostic service that we have had increased amount of request for assessment, but no similar increase in actual diagnosis. And I think when I reflect back on the project report, we felt like there was a similar thing happening. So there was increased assessment, and the SACS-R tool, I think, has a higher requirement for re-assessment at certain points, so we didn’t necessarily see any higher outcome diagnosis” (SE9).</p> <p>“I don’t think it’s worked well, and I don’t think it’s a good fit. We were dismissed as saying just because you haven’t got services doesn’t mean we shouldn’t find things” (SE20).</p> <p>“Putting in the appropriate sustainable resources and not a patchy, disjointed job” (SE15).</p> <p>Moreover, participant SE20 looked to the Muir-Gray criteria and suggested that the SACS-R program did not hold up against these principles: “I really like to look at screening as an important tool and apply the classical Muir-Gray type criteria to it. It needs to be inoffensive and acceptable, applicable to a broad range of the population. It needs to be for a disease in which intervention or treatment is available in order to make a difference, and something that’s quite significant. And I think this test fell down on a number of those criteria. I know it’s a contentious point, but early intervention in autism, we don’t have a huge evidence base. I know, as a paediatrician, that early intervention helps across the board with the parent, but differentiating the EI for autism at 12 months of age versus standard EI, I think the evidence base isn’t necessarily there and in a population of our size, screening out for kids who might be ASD at 12 months when we actually have a completely overloaded service and no appropriate service delivery, I think is unethical” (SE20).</p> <p>“You’re looking at it from a research perspective to say Australia is doing research, but that’s at the cost of children and families who are going to be affected by what you’re doing” (SE15).</p> <p>“There are so many other things. You’re not actually training the CHaPS nurses, you just said use this tool and refer to us” (SE15).</p> <p>I think getting evaluated by a [...] paediatrician to think more broadly about these things – because certainly some kids who present with autistic features have some underlying medical diagnosis [...] that needs its own evaluation and assessment. . Some of them will have genetic syndromes and that might be worth identifying early to be able to give feedback to the family about the genetic risk to subsequent children, that this is obviously identifying these things early allows them to make those decisions. If you’re not seeing them until they’re three or four then they might already have another sibling or [...] two, whereas if we can pick them up early and identify those things then maybe we could give that information to the family about thinking about planning for further children in the</p>
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	family. But I fully recognise that paediatric services aren't readily available and available in a timely fashion always to families as well (SE18).
<b>Views on parents' experiences</b> <i>Parental concerns</i>	<p>"There are families that don't want labels [...] often the sort of mantra we have with families, it's just a name, it's just a label, the child won't change, but the landscape around the child will change" (SE22); "The low expectations put on children who have a label of autism and the old myths of what that looks like is still a very big barrier. People don't want that label on their kids" (NE2); "Some parents might have some sort of objection to even going down that path and even sort of thinking about their children having an Autism Spectrum Disorder" (SE8)</p> <p>"It varies with each child and their challenges vary. It's a journey that the family goes on. (SE11)</p> <p>"I remain concerned about the anxiety, particularly in our less well-educated parents who have no resources. So the parents who come in sort of teary, look, I'm here for behaviour and, by the way, the nurse thinks my kid has got autism" (SE20).</p> <p>"We are putting the burden on the families without having clarity about whether it is or not. You have a deficit, you have the strategies, you know, to help with early intervention, put in everything you can and re-assess and actually label if the clarity is there" (SE15); "This is a screening test so it's going to have a high rate of false positives and a low rate of false negatives, which means we'll have a high rate of anxiety generation (SE20); "Lots of families are having autism discussed with them very early for things then when we see them in clinic, because they can't get into services, and we don't have concerns. And I think the anxiety arising is something we need to be conscious of because we know parental anxiety in the first few years can affect bonding and can affect emotional development, and it's really important" (SE20); "We're dealing with really anxious and overwhelmed parents at the point of diagnosis or before diagnosis. But the flipside of that is it's not helping to delay it if it was inevitable, but if it doesn't end up being ASD there's a bit of a concern there that there was worries that didn't need to happen" (SE21).</p>
<b>Views on parents' experiences</b> <i>Factors impacting health check attendance</i>	<p>"Lots are busy, and there's perhaps some working parents who don't have that opportunity to fit it in in their working hours that a health nurse might be there. I think sometimes the second and third and fourth babies may not get the same routine visits to the health nurse that you might have with your first. And maybe they know a bit more and feel a lot more confident and a lot less necessary to go to your health nurse" (NE3); "By the time they hit two, everybody is a bit busier than when they're little and parents are a bit more confident in dealing with it" (NE2).</p> <p>"Having a good relationship with their CHN would encourage greater participation in the SACS-R" (SE13); "Some parents have not so positive experiences with their child health nurses. And I think that would be by far in the minority and overall they're excellent, but I think sometimes that can be a barrier as well, they said that they were given some unhelpful advice early on and were unlikely to go back there" (SE14); "In the past, they were very popular and so lots of parents would want to go and take their child from birth onwards to a CHaPS nurse and, just having discussions with parents over the years about how difficult it was to find a CHaPS nurse that actually was friendly, approachable and also treating the parents with respect, was often a challenge, and also finding a CHaPS nurse who was diagnostically very good, [...] exploring with the parents on how they're going, [...] I was having this discussion around the CHaPS nurses these days and saying who are the good ones, who are the ones that people talk about in our local area that they're on a waiting list for people to go and see compared to others that people can't get away from fast enough because they have made assumptions about a parent" (NE1).</p> <p>"There's a lot of stigma around ASD and I think quite a lot of parents are reluctant to have a label applied to their child (SE13);</p> <p>"They might not want a label for their child. They might suspect that there's a disorder, but they might just want their child to just go through the normal schooling and whatever without going down those sort of extra or special services. There's some stigma attached to having ASD" (SE3); "Parents sometimes don't want to see it, or they don't know enough about it. Autism still has, very much, a connotation it shouldn't have around what that means for children" (NE2); "I know when I worked in that field, even although you went through the whole assessment, some parents were just not wanting that diagnosis. You know, they were just like "I don't want it, I think it's stigmatising, pathologising, I don't agree with it"" (SE8).</p> <p>I think a lot of parents are in denial about the whole thing or maybe don't see a problem. So they don't think it's necessary for their child to go through that process" (SE13); "Some families can be quite embarrassed that it hasn't been picked up earlier sometimes. Even though it is quite an early service, it's still, oh, why hadn't I noticed that, and sometimes they can be in denial about some of the things that are going on" (SE2); "There can be a fair bit of denial in an autism diagnosis. Anecdotally, that seems to be fathers. So you've got to have good support structures in place where people can see the opportunities, rather than the diagnosis" (SE11).</p> <p>"Whilst there's some awareness of autism, and there's certainly a lot more of awareness of autism now, there's limited understanding of it and so that in itself can create fear. And so I guess if people, yeah, don't have the understanding and they're aware that their child may be being screened for it, they may purposely avoid it as well" (SE1); "What's some things to be looking out for and maybe what are some red flags that mean I should come along" (SE6); "Maybe not necessarily being aware of the importance of those key checks" (SE7).</p>



	<p>“It would be the fear factor of judgment, it would be the lack of being able to potentially read a document they have to sign, so they’d need to be cared through that. I think it’s the way it’s presented. Like it needs to be non-threatening and, if your child does come out with a diagnosis of autism, that that needs to be in the preamble that there are supports and there’s access out there to help not just the child, but the whole family. I think that’s critical to the whole process” (SE10).</p>
	<p>That it’s relatively early and that they might sort of have this idea that, oh, they’ll come right, or maybe they need to be a bit older” (SE8).</p>
	<p>“Parents are sometimes a bit wary of us well-meaning health and medical types problematising their child. Everybody else in the family was late to talk, I don’t really want you to look into this any further or anything like that” (SE18).</p>
	<p>“If you start to have a child that’s flagged at, let’s say 12 and 18 months, you may not want to go back for that two year one because you might be very scared of what that means for you and for your child. It may be that at two they’re starting to – if their behaviours are getting worse, you start to isolate yourself and so you’re less likely to go and seek help” (NE2).</p>
	<p>“We’ve got a generally low health literacy rate within Tasmania. I think that it’s a general avoidance of the universal screening measures in general” (SE1).</p>
	<p>“We need to have the messaging that it’s important to have your early childhood checks right through, including two” (NE2); “It’s a factor of stressing the importance for the parents with that check. Certainly, if you’re flagging issues in the other checks, then hopefully the parents will respond at the two-year check” (SE19).</p>
	<p>“Maybe a text message, email or post reminder (parents could choose when they first attend the child health nurse) could help” (SE16); “If you tied it in with the vaccination schedule and how parents are getting formal reminders if they’re late on their vaccinations and it affects childcare rebates and subsidies and those sorts of things. So whether it was some sort of automated system, [...] just awareness and publicity. Some sort of publicity campaign around it” (SE14); “I suppose if there were other things that were particularly aligned to that assessment at two years of age, whether there could be other things that were kind of thought to be really useful to be doing at two years, dental checks maybe. They could get a free dental visit at the same time [...]. It’s a great time to be assessing speech and language and communication” (SE18).</p>
	<p>“A diagnosis is only a very small part of it [...] it may be the key to the gate of funding, or it may not be [...] it doesn’t change the capacity of a family to function. Regardless of diagnosis, getting back to that early family function and setting up those dynamics, supporting the dynamics from the get-go because from what I see people can generally limp through toddlerhood and infancy and, yeah, it’s great if they can receive the early intervention so that I guess there are less functional barriers later on” (SE1).</p>
	<p>“We don’t have special needs here, we have the same needs. What they need is a family that understands and can support them and they need access to services. It’s really important for the families to understand what it means, and have a pathway, because it’s about the family being able to provide what they think is the right support for their child, and it’s going to be different for every child. And they need access to information and services that can support them to support their child” (NE2).</p>
	<p>“There’s a broader need for family support. I actually think that families need a whole lot more support than they’re given. The focus is very much on the child and the child’s diagnosis and needs, which are important. But quite often what we might see is that parents’ coping mechanisms are really challenged. They might feel some loss or grief” (SE9).</p>
<p><b>Views on parents’ experiences</b>  <i>Support needs of families</i></p>	<p>“It’s that network of support that’s going to be built in for the long haul” (NE1); “At the beginning of the investigation trail. The problem starts when a parent is worried. And it’s an incredibly challenging and difficult sort of timeframe, even before a diagnosis. So support needs to start right from the beginning” (SE14).</p>
	<p>“It’s really tough when you’ve got them on the weekend and you’ve got them undiluted for 24/7 over the weekend, whereas when they’re sending them to school or you’re sending them to therapeutic services, you actually can have time to have a break and what do you do during that time? and how do you recharge and who do you talk to when things are tough? And also being able to say things are really tough and it’s actually not a reflection on you as a parent, it’s actually saying this is a challenging situation” (NE1).</p>
	<p>“More support for parents. With our assessments, after we’ve diagnosed there’s a lot of recommendations for children, but there’s not very many recommendations for parents and the family and I think they need a lot more support” (SE13); “It’s the family who have to take the initiative to go, okay, what’s my priority, can I afford it, do I need to see a psych, an OT, a speechie. They need to decide that and I think a lot of the time they’re just initially overwhelmed by the diagnosis, let alone trying to have to figure out where do I find an OT, where do I find a speechie, how much is it going to cost, how much can be funded by Medicare or do I go on NDIS, and all of that, I think, it often gets lost” (SE2).</p>
	<p>Their main needs are certainly emotional support, but knowledge, understanding, awareness, building their capacity to be able to engage with their children.</p>
	<p>Understanding some of the delays that their child will have and being able to work to incrementally work with that child at their pace [...] at a pace that’s appropriate where you bring the family along the journey (SE11).</p>

	<p>“Each situation, to me, varies. Some parents are really well equipped and are able to cope with the various problems they’re presented with, some just curl up in a ball and hide. So each situation needs to have its own input. The support might be focused at the child, the support might be focused at a parent level. One parent might be coping better than the other” (SE19); “As early as possible, in the form that the family is ready for. It depends on the child” (NE2); “You’re going to be capturing children who may not have autism, but have other issues in that screening process, but they still need support and help to kind of reach their full potential in life. So probably early on, when the problem is first identified I think is when they should be getting supports in place, whether or not they end up with a diagnosis of autism or not” (NWE1).</p>
	<p>“Support needs to be readily available as soon as the parents have identified a need. So pre-diagnosis is when the support needs to be there. As soon as the parent is starting to think, wow, life seems to be harder than what it is for most people, where can I get that support, how can I move forward?” (SE1); “As soon as we can. As soon as they’re ready” (NE3); “They have to be ready to receive support which can certainly take time, but when they are ready, as soon as possible. Certainly for a lot of people they seem to have had got their diagnoses maybe quite late after their parents had already been questioning things for a while. So, yes, certainly we’re not always able to deliver early intervention, but certainly early, when they’re ready, would be ideal” (SE6).</p>
	<p>“Often really worn down by being the primary parent and trying to meet all of their child’s needs, especially at the point where they haven’t been diagnosed yet, and they haven’t had access to various therapies and whatnot. They’ve been trying to do it singlehandedly with their own money and their own time and trying to be resourceful” (SE13).</p>
	<p>“The earlier the better” (SE4); “We know the research is there around early intervention and being able to learn from a young age, but I guess in terms of barriers of that, often knowledge and understanding that early intervention is important can be tricky (SE6); “Best practice would be immediately, seeking an early intervention approach and I think that’s the whole point of the SACS-R approach around that early diagnosis. And what we know is that the longer children wait, the less likely they are to reach developmental goals” (SE9); “As soon as possible, really. So early intervention is kind of where the best evidence is, but getting in early, even before diagnosis, sometimes to have that support so they do have the support network and that they’re not getting a diagnosis and then all of a sudden being told you need to go and see this person and this person and this person. I’ve often found the families that I continue to see after a diagnosis, they have a lot better outcomes because you’ve been working with them that pre-diagnosis and supporting them through a diagnosis and then moving on from that” (SE2).</p>
	<p>“Assessment is a really critical time for families, and quite often where they’re left and feel most lost” (SE9).</p>
	<p>“As soon as they’re diagnosed. And possibly even before if there’s a long waiting list. And before can be not so much this is what your child needs because they’ve got autism, it’s this is what your child needs because they’re displaying these behaviours. So you’d be treating the behaviours from the start while you’re waiting for the diagnosis” (SE3).</p>
	<p>“From the assessment tool onwards. So even if the assessment tool doesn’t result in a diagnosis, I think the support has to happen right from then if you’re going to be introducing that as a possibility, and then it needs to be ongoing. And probably, depending on the issues and the problems for that particular person, and depending how well our early intervention is done for someone, but it needs to extend on to adulthood as well often and there needs to be good handovers and a little bit of integration between the adult and child system. Like, sometimes it’s sort of like, oh, they’re 18, goodbye, and then they’re left with nothing again. So, again, that interface needs to run smoothly, and it comes to resources again” (SE16).</p>
	<p>“I think at every key transition point in their lives that there does seem to be more difficulty and by taking the focus off the individual that has the diagnosis and putting it onto family function and keeping it – I guess like addressing routines in their lives and assisting their problem-solving and equipping them with the skills to problem-solve rather than being reliant on a service that is constantly changing with funding and, amidst these higher level changes, if we can be strengthening the family and their skills to cope, then I think overall, we will probably end up with a strengthened community at the end of it” (SE1); “When entering the schooling age, [...] it’s all the way through. And needs will change day to day, week to week, month to month. So having the flexibility for those parents, to have that care and the services available to them to be flexible and negotiable and to change rapidly in response the children’s changing needs” (SE14).</p>
	<p>“We have to really support the families to access these services because just telling them at the end of the session and not following up on it can be quite tricky. So whether that be you have your diagnosis and then you have a follow-up appointment where you’re going three months down the track, how are you going, do you need help, do you need some recommendations for some psychologists or OTs? Just to kind of see how they’re coping with all of that” (SE2).</p>
	<p>“I think parents are really, really confused [...] since the NDIS rollout of the Early Childhood Early Intervention [...]. So families come to us and they have no idea. They have no idea who we are compared to the NDIS, compared to St Giles” (SE22); “In terms of the process for accessing NDIS it’s sometimes longer than it should be. And also the parents who have literacy issues or difficulty accessing, getting onto the NDIS, they’re often the ones who aren’t getting any support (NWE1).</p>

	<p>“Support is really often not there or not there enough. It’s something that is really critical, Having a good support network that they can draw on whether that be other family members or friends or health professionals that can, yeah, be there for them when it is trickier, and certainly having people that can provide them with knowledge and skills to be able to help their child in the best way that they can” (SE6); “I think respite is really helpful for lots of families, but that can be extremely tricky” (SE13); “It’s very hard caring for a child with ASD and parents burning out is common, and probably I see the parents more than I see these children and I see the effects on their mental health and burnout. And I think in disadvantaged families as well, a lot of these kids end up in the foster home system and out of home care. So having really good support for families, in-home support, practical support, like people coming and helping them with housework and taking over from parenting for a bit to give them a bit of respite” (SE14).</p>
<p><b>Increasing community understanding and awareness</b>  <i>Information, media and promotion</i></p>	<p>“You see it happening in little ways, like supermarkets having a quiet hour where they turn off their piped music and they advertise this is a quieter time to come to the supermarket with your child who has sensory issues. Going to visit Santa, those sorts of things (SE3); “I know organisations are coming on-board with supermarkets that have the dimming of the lights, now the airports up in Launceston, they’ve now got the flight simulation sort of thing and more and more people and organisations are coming on-board to help those kids, which is great” (SE4).</p> <p>“Understanding in the community about children who do struggle, understanding about the kid having a meltdown in the supermarket, that kind of thing” (NWE1); “We could probably still do a bit more, and maybe just having people generally aware of things like sensory issues” (SE3); “People understanding them. Social communications supporting their communication. But, basically, it’s lack of understanding” (SE21).</p> <p>“I think information is really important, and what they can do themselves. So there’s quite a bit that families can do themselves once they’ve been given that information. So that’s where places like Autism Tas and various support groups are actually quite valuable” (SE17).</p> <p>“Just changing the perception around what that service is for families, just away from that perhaps traditional it’s around the baby’s growth and sleep and into more of a holistic service, which it is, but perhaps it could advertised as that” (SE14); “If they knew that if they had concerns about the development that that 24-month check would really help with that, but I think the parents would be more likely to probably go through to their GP than to the nurses. So I guess it’s more about a marketing kind of thing. Marketing and explaining to parents what its function was” (SE5); “Making people aware that it’s there and it’s available so I suppose it’s that promotion. Even doing the whole whichever check they go to, be it 12 months or 18 months, that you almost book the two year one in to a degree, even if the timing actually changes. It’s more about putting it on peoples’ calendars and radars, I think (SE17).</p>
<p><b>System issues</b>  <i>Areas for consideration and improvement to the process</i></p>	<p>“More support for accurate diagnosis early, with Child Health nurses and so on, [...] would be great, but we’re heading down a good road at the moment, but let’s just keep developing it and make it better” (SE19).</p> <p>“Until we actually work on our processes, then I don’t know how else we can fix what’s broken. Because we do have some amazing resources and some amazing therapists and all sorts of things, but it’s just the efficiency with which they’re being utilised is somewhat – yeah, it’s questionable” (SE1).</p> <p>“If there’s a child with a diagnosis with a neurodevelopmental problem, [...] getting timely interventions, appropriate assessments, and then appropriate supports for the need of that child is how we need to go” (SE15).</p> <p>“Maybe that Blue Book could have a little bit in it about what you could gauge from each of those particular milestone visits, the advantages [...] early intervention equals huge successes. I guess that could be the other message that that Blue Book could have for parents” (SE3).</p> <p>“It almost seems pointless to be [...] doing all of this diagnosing, detecting early on without having the services for the intervention available. It worries me that it will raise a lot of uncertainty and worry and anxiety with families who then aren’t able to receive the appropriate treatment. Great, you make the diagnosis, but then what?” (SE13).</p> <p>“[T]here’s a massive challenge in the lack of therapists’ availability. So once they do get a diagnosis and it says they need OT, speech and physio, then they’re not available. More kids have got those plans, but they haven’t been able to access therapists unless - they’re once again on a really long waitlist. So the supports all need to be there if we’re going to be diagnosing these kids early” (SE21).</p> <p>“You transition from diagnosis through to ongoing support, the diagnosis sits within the health system, whereas ECEI and NDIS sits within disability and so just even going from a patriarchal-directed system over to a self-directed system but is the person encouraged to use choice and control? That’s a massive cultural step to be taking and we’re probably not preparing our peeps, our most vulnerable peeps for that transition to the system because it’s like this huge disconnect between the two systems” (SE1).</p> <p>“The roll out of NDIS, ECEI has been fairly poor in Tasmania. Poor nationwide, to be honest, and the understanding of its purposes and intent and the early childhood partners that we have here are struggling to understand, but also because of our segmented children’s therapy services. Really understanding that it doesn’t matter where the funding is coming from, it’s the child and family that should be at the centre of it” (SE1).</p>

	<p>Gaining acceptance of the SACS-R program from the paediatricians was emphasised as an essential achievement to improving the overall process: “Paediatrician buy-in is going to be a big one. And getting some bloody services” (SE20).</p> <p>One participant advocated achieving something that currently does not exist; line of sight to the delays that are being experienced by families: “If we could follow the journey of those families that were identified through the SACS program, to the time that they took to get a funded service and to get access to an allied-health professional, for instance, I think that would tell a big story. If you add all that up, the concept of early intervention is lost” (SE11).</p> <p>“I’ve come across quite a few families that home school because it’s the only way to meet their various needs educationally, but then they miss out on other services, such as psychology and speech therapy” (SE13).</p> <p>“I do think a lot about my role as a GP working in a private practice [...] it does feel a little bit disconnected from the Child Health nurse clinics and the public service in a way and having more sort of interconnectedness, [...] even sort of things like team meetings about patients, [...] you need to have the funding for that because you can’t sell it to GPs on a voluntary basis, unfortunately. And whether it’s just shared education sessions and [...] getting to know the people in these services who are around and of allied services as well just to sort of have that sort of sense of that multi-disciplinary team rather than sort of everyone working separately and getting the odd letter between each other, but other than that it doesn’t seem like it’s very connected” (SE14).</p> <p>“Keeping your child health nurses really well-trained” (SE13).</p> <p>“There’s got to be some real action taken to develop the market” (SE11).</p> <p>“Reducing or more quickly handling the bureaucracy to reduce the delays” (SE19).</p> <p>“You’ve got to have good support structures in place where people can see the opportunities, rather than the diagnosis” (SE11).</p> <p>“The thing I’d probably like to see [...] having increased capacity for assessments to be done” (NWE1).</p> <p>“It’s the access that’s the challenge, [...] the families that I know that have been going through it have just found it very frustrating and soul destroying trying to navigate the bureaucracy, really, and the access to funding and access to appointments” (SE14).</p> <p>“The sooner we start to work with these children, the economic benefits are there to be seen. If these things are delayed it actually exacerbates their ability to enter mainstream schools. This is sort of one of the greater benefits of being able to get started, to get these children ready so that they can enter school with their peers” (SE11).</p> <p>“We need to be working together and in a multidisciplinary format using the resources we have in a more cohesive way. I’m not saying we need more funds. I believe Australia has lots of funds, they just don’t use it correctly. It’s bigger than just autism if we want to actually change the intergenerational deprivation” (SE15); “I struggle with the fact that we have no multidisciplinary diagnostic assessment service. We definitely need a better funded service” (SE13).</p>
<b>System issues</b> <i>Assessment language</i>	<p>“I do get confused when she says something like “SACS-R completed” – what’s the language she uses? – something like “the child passed.” Something like that. So I don’t know whether that means they passed and so they don’t have autism, or they passed and they are flagging for autism. The language used both myself and the autism consultant said is that meaning they display lots of indicators or not? Like we weren’t sure what it meant” (NE3).</p>
<b>System issues</b> <i>Wait times</i>	<p>“Anecdotally, we know that for families in the early intervention space, it is very complex and difficult, mainly because of the waitlists” (SE22); “There were people waiting for a very long time for the assessment and that caused a lot of anxiety. I think up to a year might be accurate” (SE21).</p> <p>“We don’t have good numbers about the specific needs, so it’s really difficult to anticipate what is coming up and what is a genuine need or do we have the same people on the different waitlists for the different services” (SE1).</p> <p>“If the word on the street is, yeah, yeah, they said that, but then you’ve got to wait to get into St Giles and it’s six months or a year, what’s the point?” (SE20); I’m not sure what St Giles’ situation is now, but they’re not very clear on what they’re funded to do. So there is quite a delay” (SE11).</p> <p>TADS: “There are waitlists, [...] and that’s frustrating for parents, it’s not helpful for children [...] there’s a wait time, and certainly for TADS to get an assessment” (SE8); “I think the waiting list now for TADS is, what, two years?” (SE5); “We know the problems with funded diagnosis is the wait periods. So the wait periods are probably up over 12 months, maybe 15 months now through TADS or through – well, I think it is only TADS now” (SE11); “Huge wait lists is the big challenge. The child needs to see a paediatrician before they can access services at TADS for a diagnosis, which means they’re waiting for a paediatrician, TADS won’t action the referral until there’s a paediatrician, and then they see the paediatrician, then they’ve got to wait for TADS and then they’ve got to go back to the paediatrician. So it’s very....there’s a lot of delays, unnecessary delays, I think. It’s a big challenge. And I guess staff shortages, like there’s just not enough labour” (SE7).</p>
<b>System issues</b> <i>Involvement and support of health professionals</i>	<p>“GPs want to be the integral part with the families and be involved with the families. And the Child Health nurses are really important too, but they’re not with that family forever. We’re their doctor in our minds forever” (SE16); “Where does the paediatrician come in? Where does the GP come in?” (SE15).</p>

	There was a sub-group of interviewees who were strongly opposed to diagnosis if access to timely support and services were unavailable: “You should only diagnose things early if you can do something about it effectively” (SE20).
<b>System issues</b> <i>The 18-months SACS-R assessment</i>	<p>“There are so many subtle variations in development at 12 to 18 months to two years that I’m thinking if I’ve been doing this for 20 years and have a lot of training in the area and sometimes you go, “I’m not sure, I need to see you again”” (SE20).</p> <p>“I certainly think the lack of the 18-month health check is a huge challenge” (SE7).</p>
<b>System issues</b> <i>Regional differences in services</i>	<p>“The North-West coast which is pretty well under-serviced at the moment” (SE11); “The North-West absolutely struggles. They have fewer services than us, they can’t get a multidisciplinary developmental assessment. A lot of their CAMHS positions and allied-health positions are unfilled because they’re a point five. Who moves to Burnie for a point five job? And there’s a very low private insurance rate so you can’t say, “I’ll work in the hospital point five, or the developmental team for point five and in private.” So the paediatricians up there are really despairing. They would have much preferred generic early intervention to be brought into place across the board than something specific for autism” (SE20).</p> <p>“We simply don’t have a timely access to the type of services that many of these families need, and the further North you go, the less services there are. The further West you go, there’s even less from there” (NE2).</p>
<b>Sustainability of the model</b> <i>Access to resources and support services</i>	<p>“Better access to paediatricians. If our Child Health nurses had more time with their patients that’d be great. GPs having time with their patients, that’d be great” (SE19).</p> <p>“There’s a lack of opportunities for those people that cannot afford to pay for a private diagnosis” (SE11).</p> <p>“There’s not enough staff [...] a lack of resourcing in terms of staff” (SE8).</p> <p>“Access to timely services. They do need good, clear information, and then clear referral pathways” (SE17).</p> <p>“That ‘what do I do next?’ isn’t clear. We know ideally what happens next, but in reality it’s a lot more difficult” (NE2).</p> <p>“So it would be great if there was more resourcing in the schools or for the home-schooling families” (SE13).</p> <p>“There’s limitations in long waiting lists for the Autism Diagnostic Services. And alternative services are often very expensive and can’t be afforded by most families” (NWE1); “It’s a biased population who goes, the worried well. The ones who need their help don’t reach there. Correct?” (SE15).</p> <p>“The supports in high school are often not the same as in junior school and certainly with Department of Education speech pathologists, there’s not very many in high schools. The majority are in junior schools. So, yeah, often - the Department of Education has said to me, well, once they’re in high school there’s not really much we can do. They’re sort of on their own. We hope that they get a good teacher or teacher’s aide, but I guess that support is really not there and it’s concerning because that’s not when support needs to be reduced because that’s the time of big transition” (SE6).</p> <p>“The main thing they need is skilled staff, skilled, allied-health professionals, or any – not even skilled, there’s like a lack of allied-health professionals, is the big one” (SE7); “There’s also a lack of private therapists in our region as well with huge waiting lists” (NWE1); “I think the ability of the Autism Diagnostic Service to do the assessment struggle. Also up here there’s a lot of problems with the Child Development Unit and they’re having trouble recruiting allied-health specialists, like psychologists to their services. So it’s a huge allied-health staffing issue” (NWE1).</p> <p>“And then the paediatric appointments - that’s probably less of a problem than the allied-health staffing issue, but it’s still a problem” (NWE1); “Paediatricians is a problem in Hobart at the moment, though. Just getting them into them from a GP point of view is very tough. We haven’t got a bad paediatrician in town, they’re fantastic, but just the waiting times are huge” (SE19); “Certainly paediatricians are very involved in that timeframe and I know just across the board it’s very hard to get a timely visit with a paediatrician” (SE14).</p> <p>“If there is something that comes up as a red flag or leads on to a diagnosis, then having those specialised services with people who are trained in autism, in particular, to be able to address areas that are trickier at that point in time” (SE6).</p> <p>“Early access to those allied-health, so physios and speech therapists and occupational therapists, and it seems to be that that’s really challenging and the funding for that seems to be really challenging to access as well” (SE14); “All the services are backlogged up with clients then the young kids aren’t getting through to be able to get the early intervention to change the outcome for their later years” (SE5); “Certainly the research across the board around early intervention for young children with disability is very strong around getting in as early as you can. If you overlay the autism diagnosis on top of that then it can only be a good thing. And then with the opportunities now with the National Disability Insurance Scheme, once that settles down, there in theory, should be this pathway of assessment, diagnosis, referral for services, early intervention and, hopefully, better outcomes” (SE17).</p> <p>“Timely access to services if needed, professionals who are skilled and empathic, play-groups, appropriately supported childcare places, opportunities to learn and practice new skills, particularly social skills, understanding and knowledgeable adults/educators, access to other children, a close relationship with care-givers, a safe and secure home environment with supportive parents who are well-equipped, knowledgeable, and</p>

	<p>supported themselves. Given the comorbidity of ASD with a range of other disorders, they also need appropriate assessment and intervention of comorbidities” (SE13).</p> <p>“A lack of services to be able to conduct the assessments. That there are a higher number of children that are coming through. And the reports are fantastic. Like they’re always so informative, it’s such a process and I don’t think you can limit that in any way, but there needs to be more people doing it” (SE21); “The challenge, as with anything, is demand. So it has created more demand on our assessment services and I don’t know if they can keep pace with the assessments that are coming through” (SE17); “You need to get a full developmental assessment as soon as concerns are raised. Regardless of your kid’s developmental disability, if it’s a language dyspraxia, if it’s a motor disability, when we pick it, we should be thoroughly assessing it and then providing support. And there shouldn’t be that delay. We need support early” (SE20); “There’s no shortage of people needing support and needing a service” (SE6); “Early detection, early intervention, supporting intensive early intervention for kids with a diagnosis of ASD. Well, actually, even if they’re not diagnosed with ASD, with language delays or cognitive delays or any flags, there should be access to early intervention” (SE7); “There are going to be a whole different range of services that are needed for different families. Some families are going to need assistance to get to appointments or to travel or to manage work or whatever. Obviously, you know the classic sort of things that we think about are speech therapy, occupational therapy, psychology and those services, but increasingly there’s recognition that there are other areas that may be of use as well. So those kind of well-recognised disciplines and relatively well evidence-based interventions obviously are the kind of top tier, but there may well be other things that are particular to this particular child that are going to be very helpful, whether that’s around their particular sensory sensitivities or their particular needs, say in the childcare environment or whatever. So there might need to be modifications or other things that they need there” (SE18).</p> <p>“That was a concern I had in 2017 I guess when I was working in the South too, that there was a large number of children who were considered – well, large maybe might be the wrong word – but in terms of then what happened and so it kind of ended up – yeah, like it’s fine to do a screening process, but also you need to have the framework for what happens afterwards” (NWE1).</p> <p>Schools: “The belief that the school system should be catering for everybody and that it doesn’t” (SE21); “I know that the Advisory Panel report did reflect on some of this. It did make some recommendations around broader education, and awareness raising across the health and education sectors at least. And more autism-friendly work places would be good. So those sorts of recommendations are touched on...those thoughts on support that go more broadly than just the disability-related needs of the child” (SE9).</p> <p>Schools: “I just don’t think schools are resourced well enough to be able to achieve that more inclusive environment” (SE11); “The work around education is really about making sure that the right adjustments are being made and, for kids with autism, it doesn’t have to be big adjustments, it’s just about making sure we’re communicating on their level” (NE2).</p>
<b>Sustainability of the model</b> <i>Funding</i>	<p>“There’s a big delay from diagnosis to going through NDIS and getting your package and that sort of thing. That side of it is very challenging and parents feel very overwhelmed” (SE14).</p> <p>“We seem to have a lot of ingredients to the recipe and not an overall method” (SE1); “Are governments committed for a long time on this, or is it just going to be a, oh, well, this is our area, we’ll do it for five years, a new government comes in, no, no, we’re not funding this” (SE4); “Funding to back it up, to keep it going, not one of those one-off things that last a few years and then there’s nothing to keep it going and support it” (SE10).</p> <p>“Some more money in there for staff [ECIS]” (SE21).</p> <p>“One of the challenges would be that the powers that be would not see it as a priority” (SE7); “The political climate in terms of where the budget is apportioned, and why that might be an area of need that needs to be prioritised. I mean, there are so many competing needs, it all sort of comes down now to government about money and we don’t have money to do that, we don’t have money to do that” (SE8).</p> <p>“NDIS has made huge, huge inroads for families. It’s very hit and miss, though. I get really surprised when a child with similar needs to another child, there might be \$30,000 difference and you sort of go what does that mean, how does that equate, and other families say, oh, we had this support person come with us and now our NDIS all the time doubled. And then there are other parents who have to fight with NDIS all the time about, but, our other kids need some of our time too so we just want some respite care for our child for a certain amount of time and they’re really fighting to get that. And they don’t seem to understand the needs as much as that, yes, the child needs all the therapies, but also the family needs additional support, and that’s where NDIS has to come on-board more” (SE4).</p> <p>“Luckily at ECIS you don’t have to have a diagnosis to be on autism programs or to be working in that intervention space around those strategies” (SE22).</p> <p>“ECIS really needs to not go. That’s the hub” (SE5)</p>
<b>Sustainability of the model</b> <i>Education and training</i>	<p>“There is insufficient training of all professions, including teachers, allied-health, paediatricians, et cetera” (SE13); “There needs to be a priority around education so that it’s not so devastating when the A word is mentioned” (SE21); “There needs to be universal training about what needs to be done. That part of it has not been done at all.</p>

	So, okay, it's all right as a research project, so let's see what the research shows, but they have to embed it in the community, which has not been done" (SE15).
<b>Sustainability of the model</b> <i>Education and training (parents)</i>	<p>"I suppose they think they're walking, they're talking, they're eating solids, job done. So, I guess helping parents to understand that there are a lot of other things to be looking for that a parent who sees the child everyday might miss" (SE3); "Even for a child who appears to be developing along the expected ways [...] it's still really important to have that professional eye on them. Maybe not in terms of talking about ASD, but in terms of if there is any delay, early intervention can help. So maybe that point of view might encourage parents to come. I guess, too, just reminding parents that it's not just the ASD check [...], their gross and motor coordination and all of that" (SE3).</p> <p>"Definitely parental support and education and information and support groups, resources for them to empower themselves to help support their child through that journey" (SE14); "Children need to have parents who've been provided education on how to structure life at home and support the social communication skills, and also providing safe and stable environments for the children and routine and looking at things like sleep hygiene and things like that. But, yeah, so the children would need to have the framework, what their family can do, and educating the family to provide I guess the therapy I think is really important, and support for parents who find that difficult too" (NWE1).</p> <p>"In terms of the government, I think they really need to, with that diagnosis phase, just really also add in that key education phase afterwards [...] even if it's just that one session after the diagnoses have happened, [...] and that's a very overwhelming moment for these parents' life that I don't think they have the ability to take in all of that information and I think that's something that kind of gets lost and it's really, really important that they understand that there's a way forward and what services can be available" (SE2).</p> <p>"We have kids that are referred where the parents or other family members firmly believe that it's not ASD because the child can make eye contact. Just even basic things like some myths or misunderstandings about ASD are a problem to begin with because then the children aren't referred" (SE3); "They think that it means their child will achieve less, which isn't true. So part of it is about myth busting what autism is" (NE2); "They also need to understand more about it and hooking in with support straight away" (SE21).</p>
<b>Sustainability of the model</b> <i>Education and training (professionals working with families)</i>	<p>"One of the ways that we're changing our service is to increase parenting education offered, evening talks to parents, [...] getting the parents prepped-up to do the treatment" (SE5).</p> <p>"If you don't have that knowledge which this surveillance check could come into, then a lot of kids are being missed. We get kids, we get families very late at three and a half because they're not going to their CHaPS nurse, they went to their GP and they got told just to wait six months. That worries me" (SE22).</p> <p>Just talking about psychologists within the psychology training program, that there were some more education of the psychologists to work with ASD so that there are more maybe clinicians out there who feel a bit more competent or more at ease with working with children with ASD because I think a lot of them aren't because it's well out of their comfort zone" (SE13); "Consistency and training for the professionals. Some sort of encouragement for professionals to work in that field, and I guess that would come with more training too, as you find out about things, you become interested in it and go, yeah, I could do that, I feel confident to do that" (SE3).</p> <p>"If something like that could be more structured with General Practice Training Tasmania, or be part of a learning module for GPs as part of their continued medical education it would be beneficial for us as well" (SE19).</p>
<b>Sustainability of the model</b> <i>Education and training (school staff)</i>	<p>"In schooling as well, there's often a bit of a lag in early education as well because they have to develop models of funding and stuff seem to make it a little bit difficult for children to get more assistance in the classroom" (NWE1).</p> <p>"I think it would be good for schools to be aware of ASD-specific strategies. I think it should probably be mandatory, actually, in terms of teaching and education" (SE8); "It's very difficult in schools to rollout the help that's needed. For us, when we're doing our assessments, we also obtain information from the teachers. We really rely on them to provide a certain amount – a certain type of information which if they are not necessarily skilled in that area or haven't observed them that can be an issue. So education for them would be really helpful as well" (SE13).</p> <p>"An inclusive aspect that allows them to deal with any child with a disability, and not just deal with our mainstream 80% so that people can actually universally access things" (NE2).</p>
<b>Sustainability of the model</b> <i>Education and training (community)</i>	<p>A number of participants highlighted that education generally regarding communication is key and there is a need for intensive support sometimes to get the social communication going: "Being able to communicate if their language is delayed. If a toddler isn't able to say I'm thirsty, I'm hungry, I'm tired, I want that toy, it's frustrating. When children are frustrated, they throw things or squeal or bite or kick or whatever it is that they do. That then gets perceived as being aggressive behaviour and parents feel they need to discipline, so I guess communication" (SE3).</p> <p>"Maybe parents are not fully aware of what CHaPS nurses actually can do. And it's not just filling in your Blue Book, it's actually having a little chat and saying how are you going?, how are you sleeping?, because the baby is not sleeping, how are you catching</p>

	up?, do you have enough support?, those kind of questions and building that good connection with parents” (NE1).
<b>Sustainability of the model</b> <i>System redesign</i>	“I think kind of the way that the intake process for us in the THS, but we’re trying to put one in place at the moment. So I think if there was more capacity for the early learning autism, suspected autism children if there was a bigger capacity there and stuff was managed there that would be really helpful to facilitate” (NWE1).
	“There may need to be a sort of tiered approach to that [...] the kind of gold standard is a multi-disciplinary assessment. We have limited access to that in Tasmania, mainly through St Giles Developmental Assessment Team, certainly using the gold standard tools, the ADOS and the ADI-R, which is obviously what the Tasmanian Autism Diagnostic Service does, but that’s usually a single practitioner assessment which has its own limitations. And so grading or deciding which children need which service and how do we do that, [...] making sure that the appropriate children go to the appropriate service so that the service utilisation is better” (SE18).
	“We need to redesign a lot of our health-based services so that they are more accessible. Having health hubs within the community where families with young children already are so that it’s not another trip to go to” (SE1).
	“Our Child and Family Centres and the integrated hub model we’ve got there, and I guess we probably need a similar model when it comes to ASD” (SE12).
	“We’ve got good evidence of knowing what to do about this if we screen positive, it’s just about having the resources available to carry out what’s required. In the current space, you could certainly make an argument that a better use of resources would be to put the funding allocated to the screening into early assessment, early intervention services rather than kind of early identification. Having said that, sometimes we need to do the screening to identify what the need is and then just need to commit to funding what’s required in terms of the evaluation process. And some of that might be funding individual people, but some of it might be training other people to be doing those assessments or revisiting and rethinking about how we provide evaluation services for people” (SE18).
	“It would be easy to say put more money into it. I think the solution needs to come from several different aspects. It’s not just getting someone to make that diagnosis in a timely way or in a non-expensive way, but it’s also having all the professionals even agree on how that diagnosis should be. We, as professionals, need to be conferring with each other and really making sure that we’re getting it right and consistent right across” (SE3).
	“We need universal healthcare. We need a much bigger allied-health sector in Tasmania, and we need it to be evenly distributed according to population” (SE20).
	“At a State level, there’s a challenge for us to provide the qualifications within the State so that we have those greater opportunities to keep those qualified people here” (SE9); “People leave the island to study and so you’ve got to encourage people to come back” (SE17); “We’ve got to get governments putting pressure on universities to offer and incentivise people to get into these courses for the next generations coming through” (SE11).
	“We’ve got to look at models of intervention which are based on training. I mean, it’s having senior practitioners working with recently qualified graduates and other workers that can implement a program for a child which isn’t all based on the day of just seeing the expert” (SE11).
	“If kids aren’t hitting their developmental milestones even while you’re waiting for a confirmation there are different interventions you can have. “While you’re waiting for a diagnosis, did you know you can access these range of programs, playgroups, all sorts of things that might assist?”” (SE17); “Integrating services better within the community and strengthening the supports within the community. Some of these kids even without diagnosis could benefit from intervention in their waiting time” (SE1).
	“Access to doctors with experience in ASD. So, for instance, quite a lot of doctors, I don’t think they feel particularly well-skilled up in ASD understanding and management, even within a general medical setting. So I think that needs to be inbuilt into the sort of medical undergraduate curriculum, as necessary” (SE8); “We want to desperately set up a neurodevelopment service, and the funding [...] we do need to set up a – which is with the paediatrician input. You can’t have just allied-health doing something in the community without an oversight. Because it is the investigations, it is making sure that the differential is there, making sure everything is appropriate in the context. We do need a tertiary level neurodevelopmental service, you know with the interested people, not somebody who is not interested, trained, capable, experienced. And it should be a statewide thing with a hub and spoke model” (SE15).
	“I would like to see that any child referred for an assessment, or family referred for an assessment, has that done within a maximum of three months through a minimum number of appointments that they need, so that it’s streamlined, it’s easy and accessible for them, and then it’s not just getting the diagnosis, but making sure that they have the capacity to link in with the services that they require at the time” (SE1); “Seamless services would be great where they could go to one place to get their services, but that’s really tricky in this model” (SE5); “Have a one-stop-shop so they’re not travelling from pillar to post to go and see five different health professionals” (SE7); “It all depends on funding. So right now we have the NDIS in place, which can make it quite tricky in terms of not having a service available that has everyone all together and funding time to meet together and if there was a service available that did have everyone under the same roof and you did have the ability to kind of have those meetings and sitting down with



	the family and everyone involved, [...] it happens sometimes, but [...] that is rare at the moment [...] there's so much evidence around multi-discipline approaches, especially with [...] kids on the spectrum [...] tap into each other and goal-set together and plan therapy [...] would be really beneficial" (SE2).
	"It's about how can we better use – if we need to use technology and telehealth, that type of stuff" (NE2); Finding ways to do that assessment and perhaps a more telehealth model might be thought about. Like we're doing a lot of telehealth at the hospital at the moment and it works fairly well. So they might be able to use a model like that, rather than face-to-face stuff. The majority of families can access that fairly easily on their mobile phones" (NWE1).
	"Social work stuff for families would probably be helpful, and then having more parent education opportunities too" (NWE1); "Having like a kind of social work coordinating role for families who are finding it hard to negotiate all of the different systems would be really helpful. And that that isn't reliant on the parents having to be able to negotiate all of that stuff to start with. So there are families that are kind of missing out who do struggle with literacy and things. So having those types of supports in place. Yeah, and I guess having - so that then they can access ECEI as well" (NWE1).
	"The research across the board around early intervention for young children with disability is very strong around getting in as early as you can. If you overlay the autism diagnosis on top of that then it can only be a good thing. And then with the opportunities now with the National Disability Insurance Scheme, once that settles down, there in theory, should be this pathway of assessment, diagnosis, referral for services, early intervention and, hopefully, better outcomes (SE17).
	"Working more holistically between the services and the priority of reducing the wait and reducing the wait going for an assessment and for the services (SE21).
	"It's really sad that the Education Department don't have any DoE OTs. And coming from Queensland, we had that and it was just something that I was used to. So we have OTs that are employed by the Department of Education that go out to schools and see these kids that have a diagnosis of ASD. So coming from that and coming here and just thinking, oh, so many kids are missing out and OTs are really great at changing environment and doing really small things to help kids in the school environment" (SE2).
	"If we can, I guess, strengthen the community with their health awareness by getting in where families already are, then that's going to be increased uptake" (SE1).
	"I love the idea of family centres [...] fantastic because you've got a million hooks to go. You've got great playgrounds for the kids, you've got child health, you've got visiting paediatricians, sometimes you've even got financial services, you've got groups" (SE20); "The CFCs are getting on-board with autism-specific playgroups, which is fabulous, and their staff are starting to attend professional learning so that they can set stuff up within the centre" (SE21). However, the people living in rural and remote areas may be unable to engage with those services "The utilisation of Child and Family Centres could be considered, but there's always the isolated families that can't even access those" (NWE1).

## **Appendix N - Parent participant (primary stakeholder) characteristics and a summary of the diagnostic outcomes of the referred children**

During the interview process parents (N=11) shared the diagnostic status of their children. Six children received a single diagnosis of autism. One child had a comorbid diagnosis of autism and global developmental delay (GDD). GDD can also be identified using the SACS-R. There are five developmental domains: language, social, emotional, cognitive, and physical. A diagnosis of GDD is given if the child is younger than five years old and is demonstrating delays in more than one of the developmental domains.

One 12-month old presented with some features of autism but was sub-clinical threshold so did not receive a diagnosis of autism. However, the mother, GP and the CHaPS nurse indicated to the parent that they will keep “eyes on” the child via administration of the SACS-R at their follow-up checks at 18- and 24-months of age. There were three children who were referred to St Giles but did not receive an autism diagnosis. One of the children attended their CHaPS SACS-R assessment very early on in the roll out of the SACS-R (SRP3f). The child’s Mum was a newly arrived migrant and she became concerned when her child did not wave at the CHaPS nurse. Waving “bye-bye” is one of the five key items on the 12, 18 and 24-months SACS-R. This was the only key item that the child did not display and thus they were not eligible for referral to St Giles. But the parent was seeking further reassurance and was keen to have her child assessed so the nurse completed a referral for an assessment at St Giles.

Another child who did not flag on three of the key items of the SACS-R but had an older sibling with autism, was referred to the DAT (SRP7p). The parent was keen for her child to be assessed through St Giles and the nurse supported that referral despite the lack of atypical evidence from the assessment. A third child who flagged on the SACS-R and also had an older sibling with autism, did not receive an autism diagnosis (SRP9f). However, they went on to receive a diagnosis with a private paediatrician. The diagnostic outcomes are displayed in the table below.

## Interview duration and diagnostic outcome of referred parents

Participant I.D.	Duration of interview (mins and secs)	Child's age in months at time of referral (r) and / or assessment (a) ~ = approximately	No autism diagnosis	Autism diagnosis	Autism diagnosis + co-morbid diagnosis
NRP1p	7:06	24r - 25a			✓
NWRP1p	9:17	18r - 19a		✓	
SRP1p	9:44	12r - 16a		✓	
SRP2f	26:10	12r	✓ but eyes on to monitor development		
SRP3f	26:04	~12r - 24a	✓		
SRP4f	7:44	14r - ~34a		✓	
SRP5p	13:52	24r - ~24 (a)		✓	
SRP6p	10:41	18r - ~30a		✓	
SRP7p	13:50	18r - ~30a	✓ but a diagnosis of gross motor delay		
SRP8p	8:30	12r - ~12a		✓	
SRP9f	17:12	~18r - ~21a	✓		

Key: N=North      NW=North-West      S = South

RP = Referred Parent

p = phone      f = face-to-face