



15TH NATIONAL
RURAL HEALTH
CONFERENCE
Better together!

24-27 MARCH 2019
Hotel Grand Chancellor
Hobart, Tasmania



NATIONAL RURAL
HEALTH
ALLIANCE LTD

State-wide implementation of the Social Attention and Communication Surveillance-Revised (SACS-R)

Ali Morse, Tony Barnett, Lyndsay Quarmby

Centre for Rural Health, University of Tasmania

Abstract

Through the early identification of Autism Spectrum Disorder (ASD), access to early intervention services is possible and better outcomes achieved. This study investigated the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) by the Child Health and Parenting Service (CHaPS) nurses to identify children at “high likelihood” for ASD. The SACS-R is a developmental surveillance tool that has been used by the CHaPS in rural and urban areas of Tasmania since 2016 as part of children’s routine health checks. Over 100 nurses were trained and undertook surveillance with ~ 6000 children, aged 12-24 months. This practice change was evaluated with the parent and their child at the centre of the process through the use of an innovative methodology, Design Thinking (DT). DT utilises a collaborative approach 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. A mixed-method approach was selected to investigate these key stakeholders’ experiences of the implementation of the SACS-R, including questionnaires administered through surveys and follow up in-depth interviews. This paper reports on the research methodology and procedures. It was anticipated that DT would enable greater understanding of the implementation of the SACS-R. I conclude that DT is a robust and effective approach that supports the investigation of unique perspectives. A DT framework captured stakeholder experiences of the implementation process of the SACS-R and therefore can inform the roll out across other Australian jurisdictions and health service settings.

Introduction

Autism Spectrum Disorder (ASD) affects between 1-2% of the population (Thomas, Hovinga, Rai, & Lee, 2017; Lyall et al., 2016; Elsabbagh et al., 2012). It is a complex, neurodevelopmental condition with lifelong impacts, characterised by deficits in social attention and communication skills and the presence of repetitive, restricted, sensory or stereotyped behaviours and interests (Barbaro & Dissanayake, 2016).

Ensuring that children receive confirmation of an ASD diagnosis as early as possible is dependent on early identification. Early ASD identification enables access to support and intervention, thus children’s developmental outcomes can be maximised (Schreibman et al., 2015). Undiagnosed and

delayed diagnoses of ASD place an unnecessary psychosocial and economic burden on families and communities (Wannenburg & van Niekerk, 2018). Therefore, it is of great benefit that the condition is identified as early as possible in order to begin intervention and support and avoid needless delays. There are a number of factors that account for delays in early diagnosis, but it is predominantly due to delay in referrals for diagnostic evaluation (Ozonoff et al., 2018).

Tasmanian health care organisations, such as the Child Health and Parenting Service (CHaPS), Autism Specific Early Learning & Care Centre (ASELCC), St Giles, Early Childhood Intervention Service (ECIS) and Tasmanian Autism Diagnostic Service (TADS) have always done an exceptional job in providing services to children. These organisations are involved in the surveillance, assessment, monitoring, and support of young children's development across a number of domains (cognitive, physical [growth and medical], social, emotional, behaviour, and nutrition).

Barbaro and Dissanayake (2010) created a novel and effective surveillance tool called Social Attention and Communication Surveillance (SACS), which successfully identifies children at "high likelihood" of ASD between 12 and 24 months. This study examines the implementation of the SACS-Revised (SACS-R), which is a revision of the original SACS (Barbaro and Dissanayake, 2013). The SACS-R enables the assessment of different key developmental milestones depending on the presenting age of the child. It supports early identification and intervention. The SACS-R has recently been adopted by the Tasmanian CHaPS.

The Tasmanian CHaPS began almost 100 years ago. This state government-funded service provides free universal screening for children from birth to four years old. The SACS-R is a new initiative that has recently been incorporated into the routine clinical service of the CHaPS nurses. When a child is identified at "high likelihood" of ASD, the CHaPS nurse makes a referral for further assessment, specifically for the administration of the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) and the Autism Diagnostic Interview-Revised (ADI-R).

This presentation focuses on the methodology used to explore the enablers and barriers of the state-wide implementation of the SACS-R early childhood autism surveillance program into the public health system. The methodology supports the evaluation of the implementation process by integrating the perspectives of key stakeholders.

The current study draws on implementation science (IS) processes and a Design Thinking (DT) framework. Collectively, IS and DT rest on the idea that a deep exploration and understanding of practice change can lead to improved outcomes.

Implementation science

Implementation science (IS) incorporates the study of the influences on healthcare and the behaviour of professionals within organisations, and the organisations themselves. IS also examines the process of implementing evidence-based programs, practices or policies (EBPs) into health care settings. According to Eccles and Mittman (2006) "implementation research is the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care." However, it takes somewhere between fifteen and twenty years for research to be converted into EBPs that are suitable for broader use (Dearing & Kee, 2012). Therefore, IS strives to minimise the length of time between new research findings and their utilisation in health care settings. It can be used to help bridge the knowledge-practice gap by detecting the barriers and enablers of integration of the research into the real world (Grol and Wensing, 2013). A question central to IS is

“how can we best ensure that EBPs, such as early identification of ASD, are delivered effectively within clinical service delivery?”

Design thinking

Integral to the introduction of a health service innovation is the selection and application of the appropriate evaluation methodology. Design thinking (DT) is an engineering methodology that depends on co-operation between multidisciplinary teams to improve and assess innovative ideas (Martin et al., 2017). DT is a customer-focused framework. It prioritises and applies resources to meet the needs of the customer or end-user over the needs of the organisation (Brown, 2008). A DT approach can be applied in the context of health innovation, where the patient (or parent of the patient) is the customer and the support agency (e.g., CHaPS, or St Giles) is the organisation.

The underlying principles of DT are human-centered research, collective and diverse teamwork and rapid prototyping, which involves incorporation of the insights of the end-user. Thus, DT is a bottom-up initiative that fosters new approaches to complex and persistent healthcare problems (Roberts, Fisher, Trowbridge & Bent, 2016). These features make it suitable to inform the planning, implementation and evaluation of the SACS-R into the routine clinical practice of CHaPS.

In this study, the CHaPS nurses’ experience of the process from the initial training, administration of the surveillance tool, consideration of how the experience was for the parent to the referral process to St Giles for further assessment is explored. Utilisation of DT enables accumulation of evidence that provides research findings that informs the change process, sustainability of service delivery and health outcomes of the end-user.

Roberts and colleagues suggest that the concept of DT could potentially enable health systems to innovate in ways that cut across organisational, political, geographical and sectorial boundaries (Roberts et al., 2016). Fundamental to the DT framework is deep empathy for the end-user in order to prioritise their needs and concerns.

Methods and approach

A mixed-methods research approach was selected to explore the use of DT in a health service setting. Quantitative and qualitative methods were used. The researchers created survey questions based on a well-established instrument: the Measurement Instrument for Determinants of Innovations (MIDI: Fleuren, 2014) and developed an interview schedule to achieve a good understanding of the end-users’ and key stakeholders experience of the implementation process. At the time of writing, data has been collected from the CHaPS staff via interviews and surveys.

Participants and setting

This presentation is taken from a larger study (see table below) that is comprised of three participant groups—primary stakeholders (parents), internal stakeholders (three groups, two of whom are included in this presentation and described below) and external stakeholders (agencies that directly or indirectly support children with ASD). The table below summarises the progress with data collection from each group: Finished = **F**; data collection has begun, but is yet to be completed (Commenced = **C**); and yet to be collected (Not Started = **NS**).

Participant group	How data collected	Stage of data collection
Primary stakeholders		
Parents	Questionnaire (online survey) and interview	C At the time of writing: 10 CSQs submitted 3 interviews conducted
Internal stakeholders		
CHaPS nurses	Questionnaire (47 items) and interview	F 83 MIDI 37 interviews
NUMs, CNE, ADoNs, DoN	Questionnaire (10 items) and interview	F 9 MIDI 5 interviews
St Giles DAT, ASELCC	Interview	C 10 conducted 3 remaining
External stakeholders		
AAP, ECIS, Autism Tasmania, Members of Parliament, allied health professionals, representatives from health and educational associations	Interview	NS

Internal stakeholder participants (CHaPS nurses and managerial staff) were eligible to participate if they were aged 18 years and over, English speaking, and had experience with, or knowledge of developmental assessment and/or ASD surveillance or undertook work with people suspected of having ASD. Participants were recruited from The Department of Health & Human Services (DHHS)/Tasmanian Health Service (THS) CHaPS, Tasmania, Australia.

The CHaPS deliver services across the state, with the THS dividing their CHaPS clinics into three major regions (North, North-West, and South). In the North, 23 CHaPS clinics operate, with 14 in the North-West and 28 in the South. This study sourced data from all 65 clinics. Ethics approval for the study was obtained from the Human Research Ethics Committee, University of Tasmania.

Data collection

A convenient sampling method was used for recruitment. The MIDI questionnaire served to investigate three specific components: implementation of the SACS-R surveillance tool (Group 1—eight items), clinical use of the SACS-R (Group 1—26 items) and the CHaPS organisation itself (Group 1: 13 items; Group 2: 10 items).

The research team developed a semi-structured interview guide with prompts. The content of each question was aimed at eliciting from each participant an exploration of the enablers and barriers around the state-wide implementation of the SACS-R early childhood surveillance program into the CHaPS. The interview questions enabled participants' to express their thoughts about the implementation process, including experience of the surveillance tool, perceptions regarding the parent experience, on-referral to St Giles, and technical aspects of the process.

CHaPS staff who completed the MIDI questionnaire were also invited to be interviewed, either by phone, face-to-face, or via social media platforms with one of the researchers. All of the interviews were conducted by A.M. from March to May 2018, either face-to-face at the participant's place of work or over the phone. The average time for nurse interviews was 13 minutes and for the manager interviews, 21 minutes. Participant recruitment ceased when informed consent sheets no longer arrived in A.M.'s computer inbox. The interviews were audiotaped and transcribed by A.M.

Data analysis

Survey data

The data collected from the MIDI questionnaire was entered into Microsoft Excel Spreadsheet. An independent researcher (T.B.) verified the entered data. A comma separated values (csv) file was generated, which was imported into an SPSS 25 program. Frequency distribution and descriptive analysis was initially conducted and stacked histograms were generated.

Interview data

The transcripts were coded and data was analysed using thematic analysis techniques (Higginbottom, 2015; Braun & Clarke, 2012; Liamputtong, 2009; Braun & Clarke 2006). The researcher who conducted all the interviews firstly deepened her familiarity with the data through replaying the audio-recordings, reviewing her notes made during the interviews, transcribing the interviews and then re-reading the transcripts. An initial sorting exercise was conducted to identify reoccurring ideas (simple content analysis). Themes were then generated to understand some of the enablers and barriers to successful implementation of the SACS-R across the service.

Results

Overall, the implementation of the SACS-R was successful. The findings from the questionnaire data revealed that irrespective of the setting (clinic compared with C U @ Home), nurse participants expressed satisfaction with the instrument.

The findings from the interview data indicated that nurses' experience varied. Some nurses had been involved with the SACS-R administration for two or more years, following the July 2016 training, while others had only been doing the assessments for a couple of months. Regardless of length of time in the field and level of SACS-R involvement, the data suggests that the surveillance tool was well regarded and welcomed by nurses. The tool offered reassurance to the nurse and the parent, irrespective of whether the child's presentation was typical or atypical. If the child was assessed as presenting as typical, the nurse was able to indicate what had been observed to support that observation. Likewise, if the child presented as atypical, the nurse could state that they had not observed a particular response on a minimum of three key items and it was now important that a referral was made to St Giles DAT to investigate this further.

Since the project commenced, the CHaPS have undertaken a large number of SACS-R assessments state-wide. A number of children have been assessed 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 ASD, ie 1-2% of the population (Elsabbagh et al., 2012).

Discussion

At the core of a DT structure is listening to the end-user, thus when a practice change is introduced, input from the end-user is essential. The methodological approach of this study served to integrate the perspectives of the stakeholders to identify the enablers and barriers associated with state-wide implementation of the SACS-R. Since July 2016, CHaPS nurses have been incorporating the SACS-R into the routine child health checks and assessing ~ 6000 children's social attention and communication behaviours. This also represents ~ 6000 parents who have participated in their child's health checks.

This research was not without its challenges. There were issues associated with instrument selection, i.e. needing to locate both a questionnaire framework and interview schedule structure that would align with a DT approach. Preparation of a complex ethics application and establishment of instruments for three stakeholder groups was time consuming. The planned timing for data collection from each of the stakeholder groups was delayed by unavoidable external factors. One of the main challenges with utilising a DT approach is ensuring recruitment of sufficient participants to enable that deeper thorough understanding of the stakeholders' perspectives.

Challenges aside, DT provides a richness of data that enables the researcher to access the complexity of the nurses' experience of the process. Moreover, the researcher comes to a deeper understanding of their experience of the process and a strong grasp on the enablers and barriers, something that quantitative research alone is unable to provide.

Key learnings from the mixed-method approach, within a DT framework, were that overall, enablers and barriers were readily identified via the quantitative and qualitative data gathered from service staff. It was clear that the CHaPS use of the SACS-R increased their confidence in not just detecting children at "high likelihood" of ASD between 12-24 months but moreover, in referring to St Giles for further assessment and subsequent early intervention. It is widely agreed that a gap exists between science and implementation of EBPs into the public health system (Atkins et al., 2016; Hooker & Taft, 2016; Ketelaar et al., 2008). However, because the utilisation of a DT approach facilitates insights into the thoughts, feelings and experiences of the end-user at the time of implementation, any potential lengthy delays can be identified, understood and addressed. The collective information from stakeholders serves to identify enablers and barriers in the current implementation process. As a result, recommendations can be proffered that support the needs of the end-user and inform future implementation roll outs.

In September, 2018 it was announced that the Victorian maternal and child health (MCH) nurses would be provided with a \$1.1 million training package to enable them to identify young children at "high likelihood" of ASD. La Trobe University's Olga Tennison Autism Research Centre are training all MCH nurses in the administration of the SACS to use at their 12, 18 and 24 month consults. A Training Needs Analysis was conducted with the entire MCH workforce, parents and autistic people, to inform the training delivery. As a result of the analysis, there are pre-training online learning modules; face-to-face (F2F) training on the SACS; and online modules that accompany the SACS F2F training. All MCH nurses and MCH students, ~ 2000 people in total, will be trained, commencing May, 2019.

If a child is identified as having a diagnosis of ASD they are referred back to their GP and/or paediatrician, to the National Disability Insurance Association, allied health professionals and the Child and Adolescent Mental Health Services team.

Recommendations

This initial stage of the evaluation indicates that DT is a very appropriate framework to engage the end user, evaluate the practice change and enable greater understanding from a research perspective about the experience of the implementation of the SACS-R in Tasmania. Consequently, the end-users' participation has contributed extensively to the broader research findings that can now be used to inform improved roll out across other Australian health service settings.

Acknowledgements

This project is supported by the Cooperative Research Centre for Living with Autism (Autism CRC).

Disclosures

The authors have no conflict of interest to declare. A.M. is supported by the Autism CRC with a three year PhD scholarship.

References

- Atkins, M., Rusch, D., Mehta, T. & Lakind, D. (2016). Future Directions for Dissemination and Implementation Science: Aligning Ecological Theory and Public Health to Close the Research to Practice Gap. *Journal of Clinical Child & Adolescent Psychology*, 45(2), 215-226. DOI: 10.1080/15374416.2015.1050724 <https://doi.org/10.1080/15374416.2015.1050724>
- Barbaro, J. & Dissanayake, C. (2010). Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: The social attention and communication study. *Journal of Developmental & Behavioral Pediatrics*, 31, 376-385.
- Barbaro, J. & Dissanayake, C. (2013) Early markers of autism spectrum disorders in infants and toddlers prospectively identified in the social attention and communication study. *Autism* 17, 64-86.
- Barbaro, J. & Dissanayake, C. (2016). Diagnostic stability of autism spectrum disorder in toddlers prospectively identified in a community-based setting: Behavioural characteristics and predictors of change over time. *Autism*. doi:10.1177/1362361316654084
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Braun, V. & Clarke, V. (2012). Thematic Analysis. In: Cooper, H. (ed) *APA Handbook of Research Methods in Psychology, Vol 2: Research Designs: Quantitative, qualitative, neuropsychological, and biological* (57-71). Washington, DC, US: American Psychological Association. doi:10.1037/13620-0004
- Brown, T. (2008). Design thinking. *Harvard Business Review*, 86 (5), 84-92.
- Dearing, J. W. & Kee, K. F. (2012). Chapter (Historical Roots of Dissemination and Implementation Science) in a book (Dissemination and Implementation Research in Health: Translating Science to Practice). 10.1093/acprof:oso/9780199751877.003.0003
- Eccles, M. & Mittman, B. (2006). Editorial: Welcome to Implementation Science. *Implementation Science*, 1 (1). doi:10.1186/1748-5908-1-1
- Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcin, C., ... Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Res*, 5 (3), 160-179. doi:10.1002/aur.239

- Fleuren, M., Paulussen, T., Dommelen, P., & Buuren, van S. (2014). Towards a measurement instrument for determinants of innovations. *International Journal for Quality in Health Care*, 26 (5), 501–510.
- Grol, R. & Wensing, M. (2013). Implementation of change in healthcare: A complex problem. In: Grol, R., Wensing, M., Eccles M, et al. (Eds), *Improving Patient Care: The Implementation of Change in Health Care* (2nd ed., pp. 3-17). UK: Wiley Blackwell.
- Higginbottom, G. (2015). Data Management, Analysis and Interpretation. In: Higginbottom, G. & Liamputtong, P. (Eds.), *Participatory Qualitative Research Methodologies in Health* (59-79). London, UK: Sage.
- Hooker, L. & Taft, A. (2016). Using theory to design, implement and evaluate sustained nurse domestic violence screening and supportive care. *Journal of Research in Nursing*, 21 (5–6), 432-442.
- Ketelaar, M., Russell, D., & Gorter, J. (2008). The Challenge of Moving Evidence-Based Measures into Clinical Practice: Lessons in Knowledge Translation, Physical & Occupational Therapy In Pediatrics, 28 (2), 191-206. doi:10.1080/01942630802192610
- Liamputtong, P. (2009). *Qualitative Research Methods* (3rd ed). Victoria, Australia: Oxford University Press.
- Lyall, K., Croen, L., Daniels, J., Fallin, M. D., Ladd-Acosta, C., Lee, B. K., ... Newschaffer, C. (2016). The Changing Epidemiology of Autism Spectrum Disorders. *Annu Rev Public Health*. doi:10.1146/annurev-publhealth-031816-044318
- Martin, L., Porter, A., Pelligrini, V., Schnatz, P., Jiang, X., Kleinstreuer, N., Hall, J., Verbiest, S., Olmstead, J., Fair, R., Falorni, A., Persani, L., Rajkovic, A., Mehta, K., and Nelson, L. (2017). A design thinking approach to primary ovarian insufficiency. *Panminerva Medica*, 59(1), 15-31. Online version at <http://www.minervamedica.it>
- Ozonoff, S., Young, G., Brian, J., Charman, T., Shephard, E., Solish, A., & Zwaigenbaum, L. (2018). Diagnosis of Autism Spectrum Disorder After Age 5 in Children Evaluated Longitudinally Since Infancy. *Journal of the American Academy of Child & Adolescent Psychiatry* 57 (11), 849-857.
- Roberts, J. P., Fisher, T. R., Trowbridge, M. J., & Bent, C. (2016). A design thinking framework for healthcare management and innovation. *Healthcare: the journal of delivery science and innovation*, 4 (1), 11-14. doi:10.1016/j.hjdsi.2015.12.002
- Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., ... Halladay, A. (2015). Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. *J Autism Dev Disord*, 45(8), 2411-2428. doi:10.1007/s10803-015-2407-8
- Thomas, S., Hovinga, M. E., Rai, D., & Lee, B. K. (2017). Brief Report: Prevalence of Co-occurring Epilepsy and Autism Spectrum Disorder: The U.S. National Survey of Children's Health 2011-2012. *J Autism Dev Disord*, 47 (1), 224-229. doi:10.1007/s10803-016-2938-7
- Wannenburg N. & van Niekerk R. (2018). Early diagnosis and intervention for autism spectrum disorder in Africa: insights from a case study. *African Health Sciences* 18(1), 137-146. <https://dx.doi.org/10.4314/ahs.v18i1.18>

Presenter

Ali Morse is a clinical psychologist with an active interest in neurodevelopmental conditions. She has completed two theses: 'Deliberate Self-Harm in Rural and Urban Adolescents' (Bachelor of Science: Honours) and 'Couples Coping with Breast or Gynaecological Cancers' (Masters of Clinical Psychology). In 2008, Ali was awarded a Primary Health Care Honours Scholarship. In 2009, she was selected as 'Best Presenter' (Sixth Annual Statewide Symposium of Primary Health Care Research, Evaluation and Development Program). In 2011, she received The Jim Bacon Memorial Foundation Scholarship for the Care and Treatment of Cancer. Prior to becoming a psychologist, Ali was a teacher for over twenty years. She worked as a college psychologist for five years and moved into private practice. Ali particularly enjoys working with people of all ages with autism spectrum disorder (ASD). It is the work with the families that she values the most, and she finds it very rewarding. In November 2016, Ali was awarded a PhD scholarship and commenced her candidature with the Centre for Rural Health under the supervision of Associate Professor Tony Barnett and Dr Lyndsay Quarmby on Developmental Surveillance of ASD in Tasmania and specifically around the implementation of the Social Attention and Communication Surveillance-Revised (SACS-R) program.