



Developmental surveillance for autism

Prospective identification of autism in infants and
toddlers: Social Attention and Communication
Surveillance

EXECUTIVE SUMMARY

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The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

Copies of this report can be downloaded from the Autism CRC website autismcrc.com.au.

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

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

Executive summary

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

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

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

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

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

Importantly, 57% of children on the autism spectrum were identified and diagnosed by 24 months of age at the Victorian site, with 78% identified and diagnosed by 36 months of age. All children

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

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

Our values



Inclusion

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



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

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



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