AutismCRC

A multistate trial of an early surveillance program for autism within General Practices in Australia

EXECUTIVE SUMMARY

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Autism CRC

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.

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.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

Executive summary

Introduction

The early detection of developmental conditions such as autism is vital to ensure children can access appropriate and timely evidence-based supports and services. However, many children are not able to access such early supports due to delays in identification. For example, the mean age of diagnosis for Autism Spectrum Disorder (ASD; hereafter, autism) in Australia is 49 months (Bent et al., 2015), despite the ability to detect and diagnose autism from 18- to 24-months (Barbaro & Dissanayake, 2009). The delay in identification of these children requires addressing urgently (Eapen, 2016).

Accordingly, this study aimed to develop a protocol for the accurate early detection of developmental differences including autism in Australia, by synergising and building on existing State and Federal programs. It was proposed that general practitioners (GPs), through their opportunistic contacts with young children, such as the 18-month vaccination or visits for other reasons, could engage parents/caregivers in the developmental monitoring of their toddlers, to identify the early signs of developmental differences such as autism.

The overall objective of the project was to develop and evaluate an approach to early autism detection within a developmental surveillance framework in children aged 18 to 24 months, using opportunistic GP clinic visits in the primary care setting (Barbaro et al., 2021). This project aimed to examine whether, compared to usual practice (surveillance as usual; SaU), an autism surveillance protocol (ASP) pathway would be associated with:

- improved uptake and completion of developmental and autism surveillance;
- increased accuracy in identifying children at ‘high likelihood’ of an autism diagnosis and related conditions, such as developmental and/or language delay.

Secondary outcomes to be investigated included whether the ASP pathway would increase parental/caregiver engagement, health literacy, and satisfaction in accordance with the National Guideline for the Assessment and Diagnosis of Autism in Australia (National Guideline) and increase GP awareness and utilisation of developmental and autism surveillance tools and resources.

The second part of the study comprised of a qualitative component, which was used to ascertain parental/caregiver participation and experience in the program. The study also captured stakeholders' (including parents/caregivers and health professionals) perspectives of the barriers and enablers influencing the implementation of the National Guideline.

Method

Within each state (NSW and Victoria), approximately 30 GP clinic 'clusters' were recruited. Children (n=122) aged approximately 18- to 24-months attending participating GP clinics were recruited as part of each cluster. A 'universal developmental surveillance' approach to recruitment was implemented, such that any child between the eligible ages attending an appointment at the clinic for any reason, including for an immunisation, can be recruited to the study.

For the qualitative component of the study, six parents/caregivers of participating children from each site and 12 participating GPs and/or clinic practice nurses (PNs) were recruited from each state with the aim to recruit equally from each study pathway. The study was split into three phases.

Phase 1

GPs and PNs received training on the study procedure and use of the study iPad and weblink, and, for those in the ASP group, the study screening tools and resources.

ASP Pathway

Parents/caregivers who were interested in participating in the study completed the following developmental surveillance instruments: 'Learn The Signs Act Early' (LTSAE); Parents' Evaluation of Developmental Status (PEDS); Quantitative Checklist for Autism in Toddlers-10 item (Q-CHAT-10); and Ages and Stages Questionnaire: Social-Emotional (ASQ:SE). The GP/PN completed the Social Attention and Communication Surveillance-Online (SACS Online) tool with the child during the appointment. An embedded algorithm in the online study platforms scored the responses in the parent/caregiver and clinician tools to identify children who had developmental differences and/or 'high likelihood' of an autism diagnosis.

SaU Pathway

GPs and PNs used a standard template to log the methods and tools used by the GP to assess children's likelihood of an autism diagnosis.

Phase 2

Parents/caregivers of children in both the ASP and SaU pathways who were identified as having a 'high likelihood' of an autism diagnosis by their GP between 18- and 24-months of age were invited by the research team to complete a developmental assessment when the child was aged approximately 24-months. Additionally, a randomly selected 10% of screen negatives from both pathways were also invited to complete this same assessment. The following tools were used as part of the assessment: Autism Diagnostic Observation Schedule-Second Edition (ADOS-2); Autism Diagnostic Interview-Revised (ADI-R); Mullen Scales of Early Learning (MSEL); Vineland Adaptive Behavior Scales, third edition (VABS-3); Sensory Experiences Questionnaire - short form (SEQ). Parents/caregivers also completed a more detailed general and demographic questionnaire in addition to the abovementioned assessments.

Phase 3

Parents/caregivers of all children recruited to both the ASP and SaU pathways of the study completed the preschool version of the Social Responsiveness Scale, Second Edition when their child was approximately 30 months of age. Parents/caregivers of children identified with developmental differences from both arms also completed a semi-structured questionnaire to evaluate the uptake of recommendations, experience of assessment/service use, supports and services received, and parental satisfaction with the health and disability services.

Phase 3a

The worldwide 2019 novel coronavirus (COVID-19) pandemic led to the introduction of stay-at-home 'lockdown' public health orders in Victoria on 24 March 2020 and NSW on 31 March 2020. This led to a significant decrease in the number of people attending face-to-face general practice appointments in both states, but particularly in Victoria due to the longer duration of the lockdowns. Thus, the number of children recruited to the study was greatly reduced. Due to the impacts of the COVID-19 pandemic on the study, from January 2021 the study team placed greater focus on the qualitative component of the study, with analysis of quantitative data already collected conducted, where possible.

GPs and PNs who participated in the study and parents/caregivers of children recruited to the study were invited to participate in a semi-structured interview. The interviews aimed to understand the feasibility of conducting a developmental surveillance program within the general practice setting; understanding the associated challenges, enablers, and solutions to the process of conducting childhood developmental surveillance; and pathways to early supports and services when a developmental difference is identified.

Summary of findings

This study provided initial evidence for the feasibility and acceptability of the digital screening checks for early identification of developmental differences including early signs of autism. Through the ASP pathway, a greater number of children were identified who had developmental differences and went on to receive a diagnosis of autism in comparison to the SaU pathway. The results of the 'gold standard' assessment of screen negatives and the outcomes of the SRS-2 at 30 months of age indicated that the majority of 'low likelihood' children in the ASP pathway were correctly classified, and thus that the ASP pathway is accurate. Psychometric calculations for the ASP pathway were determined, indicating that the ASP pathway has high sensitivity (100%), specificity (80%), positive predictive value (90.9%), and negative predictive value (100%). It also highlighted the need for developmental surveillance, as opposed to single point in time developmental screening, to ensure all children with developmental differences and/or conditions are identified.

The consensus from the qualitative study with parents/caregivers and GPs was that the tools in the ASP pathway were simple and easy to complete, and as a result they were able to access timely identification and diagnosis for their children where required. The study also highlighted the need for structural changes within general practice, such as further training of service providers and awareness of the community, the importance of child developmental checks and ongoing monitoring in the critical toddler years. Specifically, the need for sufficient time for GPs to complete developmental checks, and a Medicare item for this, was raised by both GPs and parents/caregivers.

The findings from this study suggest that parents/caregivers encounter multiple barriers to accessing early identification of developmental differences including autism, due to long waiting times and major delays in getting their child assessed, with further wait for NDIS support to access early supports and services. This is particularly evident for parents/caregivers from culturally and linguistically diverse backgrounds, who experience added waiting time due to lack of appropriate service providers available in the community.

Strengths and limitations

Some of the findings in relation to barriers and enablers may be related to local issues and the circumstances over the study duration caused by the COVID-19 pandemic. However, the findings sit within the broad international literature on the use of screening tools by health professionals and thus the findings from this study appear to be transferable to other similar settings. Despite the careful planning by the study team, the severe and ongoing impacts of the COVID-19 pandemic on both general practices and families had a devastating impact on the study. Given the challenges experienced by the community, and in particular families with young children during the extensive lockdowns, it is not unexpected that reduced participation would also stem from the parent/caregiver side. We maintained the quality of the study through an awareness of reflexivity and efforts to achieve a high level of interpretive rigour/trustworthiness.

Implications for research and practice

Significant learnings were gained in terms of conducting and adapting a large scale RCT during a pandemic, which, given the ongoing lockdowns due to COVID-19 both in Australia and worldwide, would prove useful for future research. Practical considerations include projects being designed to enable participants to complete questionnaires and other measures remotely or on their own devices when required and ensuring studies can be pivoted to accommodate lockdowns, with such measures built into the study where possible. Alternatively, other methods such as approaching parents/caregivers prior to attending an appointment or ‘opt-out’ recruitment should be considered.

Key recommendations

- **Increase awareness** and importance of developmental screening and surveillance via education and training about signs of autism (across the lifespan and for all genders), implementing National Guideline recommendations for the autism diagnostic process and effective support mechanism for individuals on the autism spectrum and their families.

- **Wider dissemination of early autism training for GPs** (i.e., SACS-R) and general child development training (i.e., RACGP modules developed for GPs and PNs), along with wider implementation of the National Guideline.

- The Medical Services Advisory committee should include an **MBS item** allowing GPs to book appointments specifically for developmental screening/surveillance.

- Parents/caregivers should be given access to questionnaires **prior to attending** the clinic for the appointment, to ensure sufficient time to complete the questionnaires and enable GPs to have timely access to the results.

- Develop **resources for parents/caregivers** including culturally and linguistically diverse (CALD) communities to inform and educate families on the importance of early developmental monitoring.

- There is a need to **increase the number and capacity of professionals** (including cultural and linguistic diversity) available in the community to undertake autism assessments through the roll out of autism diagnostic training for multidisciplinary child health professionals.

- NDIS process to **include provision for GPs to provide ongoing care, support, and appropriate referrals** to children and parent/caregivers.

Conclusion

This study found that it is feasible for GPs to engage parents/caregiver in developmental monitoring of children with the use of a standardised autism surveillance pathway. The results indicated that both GPs and parents/caregivers were interested in the use of the ASP pathway tested in this study and that this pathway was successful in identifying children who were on the autism spectrum and/or had other developmental conditions. The fulfilment of the recommendations reported here would be of benefit to the implementation of an effective and national program for developmental surveillance of Australian toddlers for the early signs of autism and other developmental conditions.

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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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