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ORIGINAL ARTICLE

A Preliminary Trial of an Early Surveillance Program for Autism and Developmental Delays within General Practices

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Abstract

There are inequities in engagement with established early childhood developmental surveillance programs, eclipsing disadvantaged families. The current study sought to address this by dovetailing developmental surveillance with immunization visits and other opportunistic contacts with children at general practices). While 53 General Practices were recruited, significant COVID-19 disruptions resulted in only 81 children being screened (both parent-administered and GP completed). Of the 81 children, 11 screened positive and all of them along with 5% of screen negatives (i.e. 4 children) received clinician-administered reference-standard assessment for autism and developmental delay (DD) using Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview Schedule –Revised (ADI-R), and Mullen Scales of Early Learning (MSEL). All children found by reference-standard assessment to have probable autism and/or DD had screened positive during the screening process, and 90.9% of children who screened positive were found by reference-standard assessment to have probable DD or autism. The findings provide early evidence for the feasibility and usefulness of parent completed and GP administered developmental measures during opportunistic contacts with GPs as a promising method to facilitate early identification of DD or autism.

Highlights

- There are inequities in engagement with established early childhood developmental surveillance programs, eclipsing disadvantaged families and as a result, children are missing out on early identification and early supports for developmental disabilities.
- We believe that the approach used here in terms of using opportunistic contacts (including vaccination visits) to engage parents and GPs in monitoring their children's development will offer an equitable way of achieving near-universal coverage for developmental checks in the preschool period.
- We expect the readership to be interested in this novel model as our finding of feasibility and usefulness of the program in early identification of developmental needs utilising the primary care visit offers promise for scaled up implementation leveraging the opportunistic contact with children and families during vaccination and other routine health contacts including in resource constrained environments.

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Keywords Developmental Screening · Developmental assessment · Autism spectrum disorder · Developmental disability · General medical practice · Early identification

Well-baby checks incorporating critical preventive health programs are routinely conducted from birth through to preschool. In Australia, this is articulated in policies such as the Primary Health Care 10-year plan (2022–2032) that highlighted the importance of developmental checks (Australian Government Department of Health, 2022) and the 2020 Mental Health Inquiry Report (Productivity Commission, 2020) that also called for regular developmental (including social and emotional) checks during early childhood. However, research with culturally diverse populations in Australia has revealed significant barriers in parental engagement for completion of developmental checks, with the odds of non-attendance at Well Child Visits higher for mothers born overseas, household annual income lower than AUD$25,001, and living in a socioeconomically disadvantaged neighbourhood (Ayer et al., 2020; Woolfenden et al., 2016). Thus, an *inverse care law* has been found such that those children with developmental delays particularly from socioeconomically disadvantaged and culturally and linguistically diverse backgrounds, were least likely to access health promotion programs such as routine developmental checks (Eapen et al., 2017). Further, it has been shown that developmental screening has the potential to decrease the inequity by identifying and referring children with developmental needs from minority or traditionally underserved backgrounds (Wallis et al., 2021).

At the start of primary school, 20% of Australian children are found to have developmental delays with the rate increasing to 30% for children from priority populations such as Indigenous Australians (Australian Early Development Census, 2018). There has been a rise in the pediatric consultations for developmental and behavioural disabilities with autism spectrum disorder (39–56%), attention deficit hyperactivity isorder (47–55%) and intellectual Disability (18–36%) accounting for most first consultations (Hiscock et al., 2017; Palfrey et al., 2005). The presence of undiagnosed and unsupported conditions have life-long and intergenerational impact (Woolfenden et al., 2019) with poor academic outcomes (Brinkman et al., 2013; O'Connor et al., 2020) and a greater risk of juvenile justice involvement, adult disability, and morbidity (Moore et al., 2017). While early supports provided in the preschool years yield the best outcomes and return on investment (Dodge, 2018; Shonkoff, 2017; Webster-Stratton et al., 2001), most children are identified too late (Sheldrick et al., 2011), thereby missing opportunities for early supports. In this regard, it has been shown that early supports provided to families to facilitate attunement and communication with their infants and toddlers resulted in increased communication abilities and less need for intensive support ongoing (Whitehouse et al., 2021). Similarly results from a systematic review observed that children who were at risk of cerebral palsy receiving early childhood intervention showed improvement in cognitive outcomes across preschool years (Spittle et al., 2015).

Despite established universal early childhood health services that include developmental surveillance programs, there is inequity in access and engagement with these programs, particularly for families from disadvantaged backgrounds who struggle to understand and navigate the health system (Garg et al., 2017). One way of addressing the current inequity is to dovetail such programs with immunization visits and other opportunistic contacts when children attend primary care providers for any health service needs. In Australia, due to the well-baby checks being implemented through the Child and Family Health Nurse services as part of the state health system, General Practitioners operating under the Federal health system have not been traditionally involved in the developmental screening program. The current study aimed to change this by engaging parents of 18- to 24-month-old children attending general practice clinics. The results described in this paper were not part of a randomized controlled study but the participants were drawn from a cluster-randomised control study with two arms: the Autism Surveillance Pathway (ASP) or the Surveillance as Usual (SaU) pathway (Barbaro et al., 2021). The aim was to report on preliminary data regarding the feasibility and usefulness of a developmental surveillance program dovetailed with immunization and other opportunistic visits.

Materials and Methods

Participants

A total of 53 general practices across Sydney, New South Wales (NSW) (n = 30) and Melbourne, Victoria (n = 23) were recruited. The significant COVID-19 lockdowns experienced in Victoria in 2020–2021 limited clinic (n = 23) and child (n = 41) recruitment, with no opportunity for follow-up; hence, this paper will report only on NSW data with 81 children and their parents/caregivers recruited during opportunistic visits during November 2019–April 2021. Of these, 56 (69%) children were in the ASP group, with the remaining 25 children in the SaU pathway. Parents/caregivers in both groups completed electronic versions of the participant information/consent form and a brief demographic questionnaire. Regardless of the purpose of the GP visit (immunization or for other health service needs), those in the ASP pathway received parent and GP completed screening measures (see below). The SaU pathway comprised of the GP recording any developmental screening and assessment completed during the consultation using a standardised template and whether any developmental differences were identified during the visit. The current analysis focuses on 15 children from the ASP pathway who underwent a reference-standard autism diagnostic assessment. SaU participants were not included as the GPs in the SaU pathway did not complete any developmental screening or assessments for the children nor did they identify any children as having developmental concerns that would have warranted a reference-standard assessment. As per the study protocol (Barbaro et al., 2021), the participants of the reference-standard assessment included 11 children who screened positive and four who screened negative (comprising a randomly selected 5% of screen negatives).

Procedure

The procedure for recruitment and assessment is described in the study protocol (Barbaro et al., 2021), although recruitment was much lower than originally anticipated due to the impacts of COVID-19. In brief, the ASP pathway involved parent/caregiver completion of online screening assessments on a mobile device whilst waiting for their child's GP appointment. These included a brief demographic questionnaire and the following screening tools: Learn The Signs Act Early (Centre for Disease Control and Prevention, 2020), a developmental checklist covering social/emotional, language/communication, cognitive, and movement/physical development; the Parents' Evaluation of Developmental Status (PEDS; Glascoe, 2013), a general developmental screening tool; and the Quantitative Checklist for Autism in Toddlers-10 item (Allison et al., 2012), an autism-specific screening tool. During the appointment, the GPs completed an online version of the Social Attention and Communication Surveillance-Revised (Barbaro et al., 2022) tool, which allows trained professionals to identify children at high likelihood of autism through monitoring social-communication behaviors. Parents of children who were positive for concerns on any of the four screening tools were administered a secondary assessment, the Ages and Stages Questionnaire-Social Emotional Scale (ASQ:SE, Squires et al., 2002), with parents having the option to complete this in the clinic after their child's appointment or at home. Children were invited by the research team to complete a reference-standard developmental assessment if they: 1) screened positive using the SACS-R and/or the LTSAE (regardless of the results from the other tools); 2) screened positive using the Q-CHAT-10 and/or PEDS *and* the ASQ:SE (with a negative result for SACS-R and LTSAE); or 3) were a randomly selected 5% of screen negatives (in order to estimate any false negatives). When children were $\geq$ 24 months of age, families attended the reference standard assessment conducted by members of the research team. The researchers conducting these assessments were blind to the group status (i.e. which of the above three screening scenarios led the child to be included in the reference-standard assessment) and the child's screening results (i.e. screen positive or negative).

The reference-standard assessments conducted by a research reliable assessor were: the Mullen Scales of Early Learning (Mullen, 1995), a standardized measure with subscales of fine motor, visual reception, receptive language and expressive language; the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al., 2012b) or ADOS-Toddler module (ADOS-T; Lord et al., 2012a), a standardized observational assessment for autism; and the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) conducted with parents. These assessments were used to determine probable diagnoses for autism and developmental delay (DD) (i.e. delay in any developmental domain including motor, speech and language, cognition, self-help skills etc.). Parents also completed a detailed child and family demographic questionnaire, with all giving written informed consent.

Total scores for each screening tool were calculated, screening algorithms were run, and children were identified as screening positive or negative for autism or DD. The reference-standard assessment was used to yield a research-based probable diagnostic outcome. Percentages of the sample with various results from each of the

screening and reference-standard assessment processes were calculated. Note that statistics for sensitivity and specificity were not able to be reliably calculated due to the very small sample size.

The study had approval from UNSW Research Ethics Committee HC190143 and also had clinical trial registration with ANZCTR (ACTRN12619001200178).

Results

Sample Characteristics

The focus sample was comprised of 15 children (male: n = 10, female: n = 5; mean age = 20.2 months, SD = 3.4 months). All but one of the children (93.3%) had been born in Australia. Two-thirds (66.7%) of families identified as Australian, 40.0% as Vietnamese, and 30.3% identified with another group, including Aboriginal Australian, Asian, South American, or European, with respondents able to nominate more than one group. Forty percent of parents'/caregivers' highest educational attainment was a university qualification, with 33.3% having completed a non-university tertiary qualification. All but one child (93.3%) lived with both parents in the same house. Annual household income ranged from < AUD$35,000 to > AUD$175,000, with the mean of AUD$68,000 compared to the average national house hold income of AUD$121,108.

Screening Assessment

There was variability in completion of the screening tools, including in the percentage of children that screened positive according to each measure. Due to the COVID-19 restrictions it was not always feasible to follow up on incomplete forms but since all children completed LTSAE/SACS-R, anyone screening positive on those measures were included in reference standard assessment. Those who screened positive on SACS-R, PEDS, LTSAE or QCHAT-10 received ASQ:SE, and 84.6% screened positive on this secondary measure. All the 11 children who were classified as screening positive in phase 1 in the ASP pathway as well as a randomly selected 5% of screen negatives (four children) received reference-standard assessment.

Figure 1 shows how each child was identified as screening positive for features of autism or DD (n = 11; 73.3%) through the screening process (see protocol paper for detail; (Barbaro et al., 2021). There were eight children (72.7%) who screened positive on the Q-CHAT-10, with three of these children also positive on the SACS-R.

All children found by the reference-standard assessment to have probable autism or DD screened positive for concerns during phase 1. Of the four children screening negative in phase 1, none were found to have indications of autism or DD by reference-standard assessment. False positives appeared at a low rate when using the

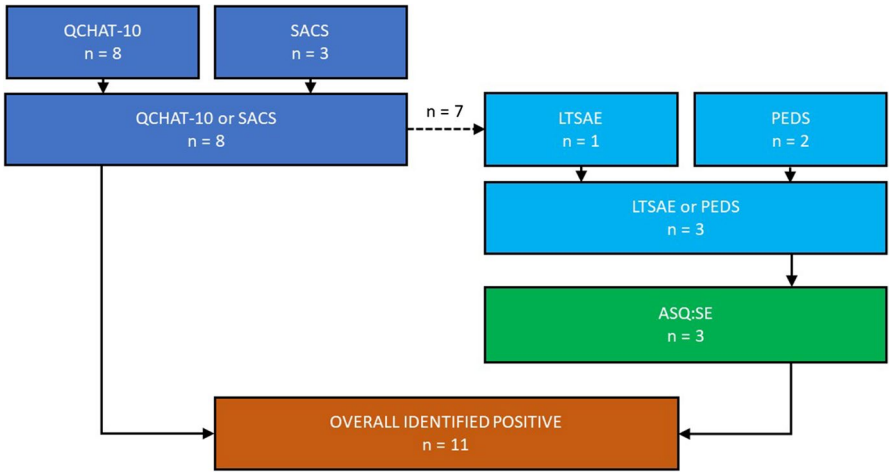

Fig. 1 The way in which a total of 11 children came to a screen positive result. Starting with 81 children who underwent the screening assessment, children were determined as having a high likelihood for autism if they: **a** were identified as high likelihood for autism by either the Q-CHAT-10 or the SACS-R Online assessment (regardless of the outcome of the other tools); or **b** were identified as having developmental delays by LTSAE and/or PEDS and ASQ:SE (but were found not at high likelihood for autism by Q-CHAT-10 and SACS-R Online). Part **a** with numbers screening positive is shown in the dark blue section; part **b** is light blue and then green, showing the two-step process

screening process to detect autism or DD, as 90.9% of children screening positive were found by the reference-standard assessment to have indications of likely autism or DD. Further, 54.6% of the children who were positive in the screening process were found to have a likelihood of autism, as per reference standard assessment.

It was also noted that the combination of just the Q-CHAT-10 and LTSAE assessment tools, which together identified 10 children as screening positive, had a similar crossover with the results of reference-standard assessment. All of the children found in the reference-standard assessment to have autism or DD screened positive on the Q-CHAT-10 and LTSAE and vice versa. Further, 60.0% of the children screening positive by these two measures were later found to have probable autism on reference-standard assessment.

Discussion

The aim of the current study was to examine the potential utility of a screening process by which children who may be autistic or have other (motor, speech and language, cognitive etc.) developmental delays (DD) could be identified early. The screening process described here showed promise in identifying those amongst the sample who had probable autism or DD, with high percentages of crossover between children identified in the screening process and in the reference-standard assessment process.

The children identified in this study through the screening process used were able to have their needs identified when they were approximately 24 months old,

thereby providing opportunities for the GPs to make referrals for early supports and services utilizing the plasticity of the developing brain that offers the best trajectory outcomes. There is significant need for accurate early screening for autism and DD to be made universally available and accessible. We have previously identified that groups with the highest rates of developmental delays are the groups least likely to seek assistance (Eapen et al 2017). Establishing a means of developmental screening in primary care as a fully-funded government initiative is a strategic mechanism to address the current inequity in access to early identification of developmental disabilities including autism, and allow targeted supports commensurate with needs (Diaz et al., 2023). Within this context, it should be noted that many parents and GPs identified a preference for a dedicated appointment for child developmental assessment when concerns are identified during screening using opportunistic contacts such as immunization or other health service visits. Utilizing the tools from the current study, further steps have been taken to develop the robustness of early developmental screening in Australia. The SACS-R (Barbaro et al., 2022) is used universally within the Victorian Maternal and Child Health system, as well as in early childhood education in NSW and Queensland (Mozolic-Staunton et al., 2020). Further, a digital Watch Me Grow-Electronic platform has been developed in NSW that incorporates LTSAE and Q-CHAT-10 with automated scoring, transmitting results and recommendations to the parents and to health professionals for immediate use (Kohlhoff et al., 2022). The system also sends automated reminders to take the developmental checks using LTSAE at the next recommended age and stage, thereby facilitating ongoing developmental monitoring until starting school (Eapen et al., 2022). This is consistent with the finding from another study that has found that conjoint screening and monitoring is more effective for identifying developmental disabilities such as autism (Barger et al., 2022).

Clearly, this study has been carried out with significant limitations due to COVID-19 lockdowns restricting recruitment, which meant the sample undergoing developmental screening (n = 81) and the sample receiving reference-standard assessment (n = 15) were small relative to the expected sample size. This has limited the ability to conduct statistical analysis to determine the reliability and validity of the screening method and the tools used here. Despite this, it was possible to demonstrate the utility of screening for quickly identifying children who would benefit from additional assessment and access to supports and services. This is encouraging, as early identification using opportunistic health contacts could overcome some of the barriers in uptake of developmental checks identified in earlier studies. This is particularly critical for children from culturally and linguistically diverse` and socioeconomically disadvantaged background as it has the potential for children screened positive to be linked up with early supports and services that would make a real difference for those children who would not have otherwise engaged with the services.

In conclusion, this study was able to provide early indications that family GP-based screening has the potential to result in early and accurate detection of children in need of further assessment and early supports/services for autism or DD. This process was built on engaging parents in a quick screening process conducted in collaboration with family GPs, and empowering parents to monitor their children's development

using simple screening tools at recommended ages. It is anticipated that larger studies will follow to confirm these findings and to determine whether any cultural adaptations are needed especially for specific ethnic or cultural groups.

Key messages

1. Autistic children and children with developmental disabilities: It is important for the support needs to be recognized early so that the right support can be put in place as soon as possible.
2. Professionals: Identifying Autistic children and children with developmental disabilities during early childhood visits with general practitioners is possible, and allows for better outcomes through earlier supports and services.
3. Policy makers: Programs for universal screening of autism and developmental disability are feasible and have the potential to accurately identify children who will benefit from further assessment and supports early in life, when there is potential to deliver improved lifelong outcomes for children and their families.

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Availability of Data and Materials Data will be available by contacting the corresponding author.

Compliance with Ethical Standards

Conflict of Interest The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Ethical Approval It was reviewed and performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments, with approval from Human Research Ethics Committee, University of New South Wales Sydney HC190143 Research Ethics Committee.

Informed Consent Written informed consent to participate in this study was provided by the participants' parent or caregiver.

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