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Diagnostic delay in children with neurodevelopmental conditions attending a publicly funded developmental assessment service: findings from the Sydney Child Neurodevelopment Research Registry

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ABSTRACT

Objectives Early developmental assessment is crucial for effective support and intervention. This study examined factors that contribute to (a) older child age when caregivers first became concerned about their child's development and (b) older child age at the point of entry into developmental and diagnostic assessment. We also quantified how factors contributed to risk of children not receiving an assessment by 5 years and considered the acceptability of electronic data capture for families.

Design This cross-sectional study collected information about caregiver developmental concerns, family history and child characteristics.

Setting Children and families entered a large, publicly funded hospital-based paediatric developmental assessment service.

Participants Consecutively enrolled children (N=916) aged 6 months to 17 years with neurodevelopmental concerns and their caregivers.

Main outcomes and measures A developmental history questionnaire completed by caregivers.

Results The average age that caregivers identified developmental concerns was 3.0 years of age but the average age of a receiving a developmental assessment was 6.6 years. Only 46.4% of children received a diagnostic assessment by 5 years of age, even though 88.0% of caregivers were concerned about their child's development by that age. Parental age, relationship status, education level, prior use of support services and being from a culturally and linguistically diverse background contributed to age at identification of concern, age at diagnostic assessment and the likelihood of receiving a diagnostic assessment by 5 years. Electronic data capture had high acceptability, with 88.2% of caregivers reporting a preference for electronic completion of questionnaires.

Conclusions The study shows a substantial delay in diagnostic assessments that leaves most vulnerable children without an assessment by school age and highlights contributors to delays. These delays highlight the complexity of delivering early intervention and support

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ These data were collected on children attending a large, publicly funded, hospital-based developmental assessment service and provide information on vulnerable families seeking support for broad developmental needs.

⇒ The large research registry of children entered publicly funded assessment services. This unique registry provides many vulnerable and disadvantaged populations access to ongoing research and clinical trials.

⇒ Our findings provide additional information on how child and family factors contribute to diagnostic delays, beyond that typically gathered in population-level data sets. They highlight the potential to use targeted personalised approaches to support those most in need.

⇒ The data collected on the entire sample did not contain consistent detailed information on caregiver or child characteristics, such as caregiver stress or diagnostic symptom severity. Information regarding age of first concern was retrospectively reported by caregivers.

⇒ This clinically integrated research registry is now operational in many developmental assessment services in Sydney, with the aim to track outcomes over time to overcome limitations of cross-sectional designs and to track developmental outcomes across different populations.

policies that rely on swift and appropriate developmental assessment to vulnerable families.

INTRODUCTION

Recent years have seen an increase in the prevalence of childhood neurodevelopmental conditions.[1] Behavioural and developmental problems are among the most

frequent health concerns seen in children,[2] with approximately 1 in 10 children meeting diagnostic criteria for a neurodevelopmental condition.[3 4] There is increasing awareness of the importance of early diagnosis leading to appropriate supports and intervention for children displaying developmental delays.[5 6] For example, children who receive a diagnosis and interventions before 3 years of age may show enhanced outcomes in comparison to children who receive a later diagnosis.[7–9] When needed, there is also increasing awareness of the need to obtain an adequate developmental assessment before school entry so that education, family and child supports can be put in place to optimise outcomes.[10] However, this increased awareness is often coupled with a complex and administratively burdensome funding landscape that can serve to increase delays in accessing support.[11] For example, in Australia, funding agencies necessitate that certain steps are taken prior to provision of support, with early identification, functional assessment, case management and diagnostic assessment all being facilitators to accessing funding and early supports. Delays to accessing assessments, therefore, have a direct result on impacting the range of funding and support services needed for children and their families. When considering research examining the age at which children are likely to receive a neurodevelopmental condition diagnosis, studies typically report either population-level data obtained from national administrative databases or detailed patient-level data collected from children participating in research studies, research networks or private assessment clinics. A recent population-based cohort study in the USA reported that the incidence and timing of neurodevelopmental condition diagnoses varied by insurance type, with diagnoses made earlier for privately insured children, relative to publicly insured children.[12] Furthermore, a collation of published studies that reported child age at autism diagnosis suggested that across 35 studies, 5 years, or 60 months, was the average age.[13] The general lack of detailed patient-level information in these population studies makes it difficult to assess family and patient factors that contribute to delays in diagnostic assessments.

In contrast, studies tracking patient-level data within clinics typically use small sample sizes, research networks or private clinical services. These studies have reported mixed results to suggest that child gender[14–16] and symptom severity,[17] parental education,[18] marital status[19] and a culturally and linguistically diverse (CALD) background[20–22] may be associated with assessment and diagnosis delays (see also Daniels and Mandell for a review[23]). These mixed findings are largely specific to autism specialist assessment clinics. There has been limited research examining diagnostic delays in publicly funded services. Its critical any public health strategy considers the unique needs of this population and their services to address both mental and physical health of society. Such services are accessed by the most vulnerable families, whose children often have more complex presentations with multiple diagnoses[24 25] and limited alternative assessment and support options. Thus, it is critical to examine predictors of diagnostic delays in patients attending publicly funded assessment services, where children are likely to have multiple concerns, and families have limited access to supports. Such knowledge can advance both policy and intervention practices to improve outcomes.

In addition to examining factors that contribute to diagnostic delay in publicly funded assessment services, embedding research in these services provides the opportunity to engage families in more efficient service delivery. For example, using electronic data capture to automate the collection of clinical and survey-based information from children and families can provide clinicians with immediate access to patient results and facilitate research that can identify broad needs of children and families. This approach also enables the establishment of large-scale research registries containing information on large cohorts of children and families who typically would not present to research clinics.[26] Moreover, pilot work conducted by our team has found that electronic data capture is highly acceptable for families attending publicly funded developmental assessment services, with over 85% of attending families preferring electronic methods to paper-based completion methods.[27] Given this, embedding research in diagnostic assessment services has the potential for wide-ranging benefits, for children and families, clinical practice and research.

Against this background, our team has established a research registry integrated into standard clinical practice so that evidence-based practices can inform system improvements for public developmental assessment services. This study used data from one of the largest publicly funded tertiary diagnostic assessment services in Australia to examine factors leading to assessment delays. This study aimed to:

1. Identify the average age that caregivers identify developmental concerns in their children and the time between first concern and entry to the developmental assessment service.
2. Test the role of child (gender) and caregiver factors (age, level of education, CALD status, parental relationship status, previous use of support services) to determine their influence on the age when first concern was identified and age at the developmental and diagnostic assessment.
3. Determine the degree to which the above variables also influence the likelihood of receiving an assessment by the age of 5 years.

In addition, we investigated the acceptability of electronic data capture for families attending a publicly funded developmental assessment service, to determine whether this cohort demonstrated a preference for providing information electronically as opposed to on paper-based forms.

METHODS

Participants and setting

Participants were 916 children aged between 6 months and 17 years (M=78.66 months, SD=44.37, median=63.00 months), who attended the Child Development Unit (CDU) at the Children's Hospital Westmead, Sydney, Australia between 2019 and 2022 and consented to clinically integrated research in partnership with the Clinic for Autism and Neurodevelopmental Research at the University of Sydney. The CDU is part of the publicly funded Sydney Children's Hospital Network, which provides developmental and diagnostic assessment services to children. Any child who lives within defined geographical regions and/or who is an existing hospital patient is eligible for assessment. Given these criteria, a large proportion of referrals are children from CALD backgrounds. Children are referred for assessment of complex neurodevelopmental difficulties including autism, intellectual disability, global developmental delay, speech/language delays and other difficulties with adaptive and/or cognitive functioning.

While attending the CDU, children receive a multidisciplinary assessment. Following assessment, a diagnosis is made, and families receive feedback and recommendations. On average, about 75% of children receive an autism-related diagnosis and over 50% receive more than one diagnosis. All families participated in this study using opt-out consent procedures. In total, 26 families (2.8% of the cohort) opted out.

Measures

The Parent Carer Questionnaire (PCQ) is a six-page questionnaire, developed by the CDU to collect clinically relevant information on children and families before their appointment. Completed by the primary caregiver of the child being assessed, it collects demographic information, family history and child developmental history. A copy of the PCQ questions included in this study is found in online supplemental information. For this study, sociodemographic characteristics for caregivers (age at assessment, level of education, country of birth, primary language spoken at home, parental relationship status, previous use of support services) and children (age when concern was first identified, age at assessment, gender) were extracted. Data pertaining to questionnaire modality preference of respondents (ie, did they prefer to complete the questionnaire electronically or on paper) was also extracted. Previous use of support services referred to use of services by the caregiver and family broadly, and was not specific to services used by the child receiving an assessment. Variables pertaining to CALD status, parental relationship status and previous use of support services were recoded for ease of description and analysis (see online supplemental information).

When describing the sample and conducting analyses pertaining to age at diagnostic assessment, the full cohort of 916 cases was used. When considering factors associated with age at identification of first concern, we did not include responses where age of concern was during the mother's pregnancy or at birth (N=43), or where data pertaining to the age at which concerns were first identified were missing (N=82). For those 43 children where age of concern was reported during the mother's pregnancy or at birth, 19 (44.2%) had physical or medical complications reported at birth or shortly after birth, 18 (41.9%) received a diagnosis of a genetic condition or chromosomal abnormality, 4 (9.3%) had reports of a premature birth resulting in complications and 2 (4.7%) had reports of prenatal complications identified in utero. A cohort of 791 children was used to examine factors related to the child's age at identification of first concern. Not all participants were included in subsequent analyses due to missing data for some responses (see online supplemental table 1 for missing data summary).

Procedures

One month prior to assessment, families were sent a transdiagnostic questionnaire protocol, recommended by researchers, clinicians and community members nationally, for use in children with neurodevelopmental and mental health conditions.[26] This protocol included the PCQ and was sent electronically via the Research Enterprise Data Capture platform, an online data collection system endorsed by the University of Sydney. Families received an email reminder to complete the protocol 1 week prior to their appointment, and those who did not do so before their appointment completed it on the day of assessment as per the process described in Patel et al.[27]

Patient and public involvement

We did not consult with children, families or the broader community in relation to the questions or outcomes of this research. It is a goal of the research registry to involve children and families in the design, implementation and evaluation of future research studies. The results of this study will be disseminated through various developmental assessment services.

Statistical analysis

Statistical analyses were performed with IBM SPSS Statistics for Windows, V.27.[28] Shapiro-Wilk tests indicated that some variables (caregiver age, child age at identification of first concern, child age at assessment) were nonnormally distributed ($p<0.05$, see online supplemental table 2); therefore, all analyses were conducted using bootstrapping (2000 resamples).

To evaluate the relationship between sociodemographic variables and both child's age at identification of first concern and child's age at diagnostic assessment, we identified the following variables of interest: caregiver age, level of education, CALD status, parental relationship status, previous use of support services and child gender. Independent samples t tests, one-way Analyses of variance (ANOVAs) and Pearson's correlations were conducted to determine relationships between variables of interest and age at identification of concern or diagnostic assessment.
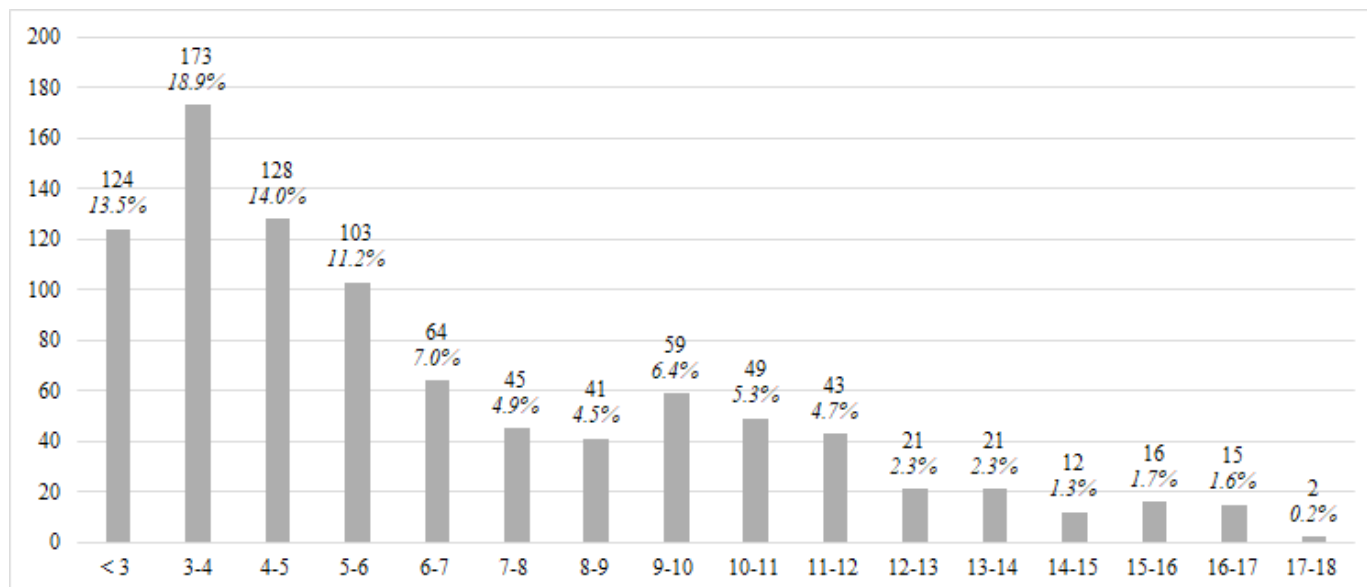
Figure 1 Frequency of diagnostic assessments by age.

Based on these relationships, we performed standard multiple regressions to determine whether these factors contributed to variability in (a) age at identification of first concern or (b) age at diagnostic assessment. We then used a binomial logistic regression to ascertain effects of key sociodemographic factors on the likelihood that children would receive a diagnostic assessment by 5 years of age.

RESULTS

Aim 1—age at identification of developmental concerns and age at diagnostic assessment

On average, children were 36.49 months old (SD=27.71) when concerns were identified by caregivers and 78.66 months old (SD=44.37) at the time of diagnostic assessment. Only 13.5% of children received a diagnostic assessment by 3 years of age (see figure 1). By 5 years of age, 46.4% of children had received a diagnostic assessment. In contrast, developmental concerns had been identified in 72.2% of children by 3 years of age, and in 88.0% of children by 5 years of age. table 1 displays characteristics for caregivers and children. On average, mothers were 37.30 years old (SD=6.41) at the time of their child's diagnostic assessment and fathers were 40.30 years old (SD=7.23).

Aim 2—factors related to age at first concern and age at diagnostic assessment

Table 2 displays the results of analyses conducted to examine differences in child's age at identification of first concern and child's age at diagnostic assessment as a function of sociodemographic characteristics. For child's age at identification of first concern, there were differences as a function of parental level of education, parental CALD status, parental relationship status and previous use of support services. Caregiver age was

positively associated with child's age at identification of first concern, for both mother's (r=0.359, p<0.001) and father's (r=0.392, p<0.001) age. With respect to child's age at diagnostic assessment, there were statistically significant differences as a function of parental level of education, parental CALD status, parental relationship status and previous use of support services. Caregiver age was positively associated with child's age at diagnostic assessment, for both mother's (r=0.519, p<0.001) and father's (r=0.451, p<0.001) age. Child factors (gender) were not related to age at first concern or age at diagnostic assessment.

Multiple linear regression analyses

Parental age, level of education, CALD status, relationship status and previous use of support services were entered into regression models to determine contribution to variability in child age at identification of first concern and diagnostic assessment. Due to heteroscedastcity, weighted least squares regressions were conducted. All other assumptions for linear regressions were met. Given the smaller sample in regressions due to unequal sample sizes across variables, we examined sociodemographic characteristics for cases removed versus included in each regression. There were some differences (see online supplemental tables 3 and 4); however, the pattern of results remained the same when comparative analyses were conducted using only cases included in subsequent regressions.

Table 3 summarises the regression models examining the contribution of caregiver factors to child's age at identification of first concern and age at diagnostic assessment. Considering predictors of child's age at identification of first concern, the full model accounted for 50.4% of variance, F(8, 685)=89.10, p<0.001. Parental age, mother's level of education, mother's CALD status, parental

Table 1 Sociodemographic characteristics caregivers and children

Caregiver characteristics	No. (%)
Mother's highest level of education (n=879)	
Primary or secondary schooling	203 (23.1%)
Vocational training	255 (29.0%)
Bachelor's degree	241 (27.4%)
Postgraduate degree	180 (20.5%)
Father's highest level of education (n=827)	
Primary or secondary schooling	234 (28.3%)
Vocational training	244 (29.5%)
Bachelor's degree	191 (23.1%)
Postgraduate degree	158 (19.1%)
Mother's CALD status (n=882)	
CALD	412 (46.7%)
Non-CALD	470 (53.3%)
Father's CALD status (n=836)	
CALD	415 (49.6%)
Non-CALD	421 (50.4%)
Parental relationship status (n=862)	
Together	647 (75.1%)
Separated	215 (24.9%)
Previous use of support services (n=916)	
Yes	525 (57.3%)
No	391 (42.7%)
Caregiver who completed the questionnaire (n=863)	
Biological mother	610 (70.7%)
Biological father	61 (7.1%)
Both biological parents together	161 (18.7%)
Other	31 (3.6%)
Child characteristics	No. (%)
Gender (n=907)	
Male	645 (71.1%)
Female	262 (28.9%)

N is varied across variables due to missing data across responses. See Supplementary Table 1 for missing data summary.
CALD, culturally and linguistically diverse.

relationship status and prior use of support services were statistically significant predictors; $p < 0.05$.

With respect to predictors of child's age at diagnostic assessment, the full model accounted for 35.2% of variance, $F_{(8, 769)} = 53.85$, $p < 0.001$. Parental age, mother's level of education, mother's CALD status, parental relationship status and previous use of support services were statistically significant predictors; $p < 0.05$.

Aim 3—factors associated with a higher likelihood of diagnostic assessment by 5 years

Of the 778 children included in the binomial logistic regression, 379 (48.7%) received a diagnostic assessment by 5 years of age. The regression model was statistically significant, $\chi^2(8)=196.39$, $p<0.001$. Five predictor variables were statistically significant ($p<0.05$): parental age, mothers' CALD status, parental relationship status and previous use of support services. Increasing parental age was associated with a decreased likelihood of receiving a diagnostic assessment by 5 years of age. In contrast, the odds of receiving a diagnostic assessment by 5 years of age were: 1.93 times greater when mothers were from a CALD background; 1.83 times greater when parents were together as opposed to separated and 1.91 times greater when families had previously engaged with services. Table 4 summarises the full model.

Acceptability of electronic data capture

In total, 845 families (92.2% of total sample) provided information related to questionnaire modality preference. The vast majority of these families (745, 88.2%) reported a preference for completing and submitting the questionnaire online compared with via post. Of the 100 respondents who reported a preference for completing questionnaires on paper, a larger proportion reported school or vocational levels of education (61.3% paper preference; 49.9% electronic preference, $\chi(3) = 19.65$, $p<0.01$)), compared with bachelors or postgraduate levels of education. Mothers ($t(814) = 2.81$, $p=0.005$) were younger in the paper preference group, and younger mothers generally had lower levels of education ($p=0.001$). No other significant differences were found between the two groups on father's age, CALD status, parental relationship status or prior use of services (all p values >0.075).

DISCUSSION

In a large publicly funded developmental assessment service and integrated research registry, developmental concerns were identified by caregivers at 3 years of age, but children did not receive an assessment until they were over 6 years of age. Only 13.5% of children received a diagnostic assessment by 3 years, the age at which early support services for neurodevelopmental conditions are recommended. Less than 50% of children received an assessment by 5 years of age, the age at which children should receive support plans to attend school. We then examined predictors of age at identification of concern and subsequent assessment. Results showed that being from a family with older, separated parents, lower levels of maternal education, being of a non-CALD background and no prior use of support services, all predicted an older age at which concerns were first identified by

Table 2 Sociodemographic characteristics stratified by age at identification of first concern and age at diagnostic assessment

	Age at identification of first concern (months)	P value*	Age at diagnostic assessment (months)	P value*
Child gender				
Male	35.91 (26.23)	0.389	77.49 (43.35)	0.184
Female	37.93 (31.11)		81.80 (46.46)	
Mother's highest level of education				
Primary or secondary schooling	37.99 (28.07)	0.034	86.98 (47.24)	0.001
Vocational training	39.62 (31.39)		80.84 (43.86)	
Bachelor's degree	33.99 (23.46)		75.49 (42.55)	
Postgraduate degree	33.48 (25.73)		70.31 (42.12)	
Father's highest level of education				
Primary or secondary schooling	39.50 (30.13)	0.014	86.94 (44.92)	<0.001
Vocational training	38.72 (32.44)		80.31 (46.57)	
Bachelor's degree	33.03 (23.45)		68.88 (39.60)	
Postgraduate degree	31.54 (21.48)		69.48 (41.25)	
Mother's CALD status				
CALD	31.80 (21.29)	<0.001	65.31 (35.92)	<0.001
Non-CALD	41.12 (32.00)		89.99 (47.48)	
Father's CALD status				
CALD	31.37 (21.61)	<0.001	66.51 (37.96)	<0.001
Non-CALD	41.52 (32.57)		88.72 (47.24)	
Parental relationship status				
Together	34.47 (26.29)	0.002	74.33 (42.89)	<0.001
Separated	42.47 (30.96)		91.68 (46.31)	
Previous use of support services				
Yes	30.75 (22.39)	<0.001	73.01 (41.08)	<0.001
No	44.75 (32.23)		86.17 (47.47)	

Data are presented as Mean (SD).
*P value for independent samples t-tests or ANOVAs between sociodemographic factors and age at identification of first concern/age at diagnostic assessment.
CALD, culturally and linguistically diverse.

parents as well as the age at which a diagnostic assessment was received.

Along with age, parental relationship status emerged as a significant predictor of both the age at which developmental concerns were identified and the age at developmental assessment. Separated parents identified developmental concerns in their child 8 months later, and their children were 17.4 months older on average when they received a developmental assessment. Their children were 1.8 times as likely to not receive an assessment by 5 years of age. While contributing factors are likely complex, relationship discord, stress and financial strain may inhibit caregivers from successfully navigating services required to receive a referral and appointment at a diagnostic assessment service.[19 29 30]

Mother's CALD status predicted the age which developmental concerns were identified, the age at assessment as well as the likelihood that a diagnostic assessment would be received by 5 years of age. Counter to recent findings,[31] we found that mothers from CALD backgrounds identified concerns in their children 9.3 months earlier than mothers from non-CALD backgrounds, and their children were 24.7 months younger when presenting for assessment. Additionally, children were 1.9 times more likely to receive a diagnostic assessment by 5 years of age when mothers were from a CALD background, relative to a non-CALD background. These findings do converge with prior linkage data, where children from a CALD background receiving autism-specific funding were diagnosed 5 months earlier than children from a non-CALD background,[20] suggesting that the relationship between CALD status and age of assessment is multifaceted. Considering our cohort specifically, an explanation may lie in the spread of education level across groups. Less than one-third of parents from non-CALD backgrounds reported university levels of education, while nearly two-thirds of parents from CALD backgrounds reported university levels of education. It is plausible that non-CALD parents

Table 3 Standard multiple regression model with key sociodemographic characteristics entered as predictors of child's age at identification of first concern

	B	SE B	β	BCa 95% CI	
				LL	UL
Age at identification of first concern					
Constant	−1.07	5.72		−16.11	19.37
Mother's age	1.14	0.22	0.38**	0.82	1.40
Father's age	0.34	0.23	0.22*	0.03	0.38
Mother's level of education	−4.24	1.54	−0.41**	−4.98	−3.49
Father's level of education	−0.26	1.17	−0.03	−3.30	1.53
Mother's CALD status	4.51	2.18	0.12*	−1.44	9.77
Father's CALD status	−4.47	2.58	−0.10	−8.71	−0.96
Parental relationship status	−5.00	2.13	−0.07*	−9.30	−0.84
Previous use of support services	−7.26	1.40	−0.16**	−10.37	−3.51
Age at diagnostic assessment					
Constant	−38.14	8.77		−55.36	−20.91
Mother's age	2.85	0.29	0.40**	2.28	3.42
Father's age	1.06	0.25	0.17**	0.56	1.55
Mother's level of education	−2.89	1.43	−0.07*	−5.69	−0.09
Father's level of education	−1.59	1.47	−0.04	−4.47	1.29
Mother's CALD status	−13.17	3.87	−0.15**	−20.76	−5.58
Father's CALD status	−5.32	3.78	−0.06	−12.73	2.09
Parental relationship status	−9.64	3.29	−0.09**	−16.09	−3.19
Previous use of support services	−9.64	2.54	−0.11**	−14.63	−4.65

R^2_{adj} = 0.50 for age at identification of first concern and 0.35 for age at diagnostic assessment. *p<0.05; **p<0.01.
BCa 95% CI, bias-corrected and accelerated 95% CI; CALD, culturally and linguistically diverse; LL, lower limit; SE B, SE error of the coefficient; UL, upper limit.

with higher levels of education may be more likely to access private service pathways, whereas those from CALD backgrounds may rely on publicly funded, culturally and linguistically supported assessment services. These findings warrant further research on the moderating role of education level as well as the contribution of additional factors such as income and employment, on the relationship between CALD background and age at identification of concerns and assessment.

An additional sociodemographic characteristic that emerged as a predictor for age at identification of concern, age at diagnostic assessment and the likelihood that a diagnostic assessment would be received by 5 years of age was previous use of support services. Parents identified concerns in their children 14 months earlier when they reported prior use of support services. Children also received a diagnostic assessment 13.2 months earlier and were 1.9 times more likely to receive a diagnostic assessment by 5 years when caregivers reported use of prior support services. This finding was regardless of whether caregivers engaged with services for themselves or other family members. This may reflect increased awareness of developmental concerns, for instance, if caregivers had previously used support services for older children.[32] It may also reflect an increased understanding of how to

navigate healthcare systems, which might facilitate timelier diagnoses.

Of interest, mother's level of education predicted the age at which concerns were first identified and the age at which children received an assessment. Mothers with a bachelor's or postgraduate level of education identified concerns in their children 6.1 months earlier on average, relative to mothers with vocational levels of education. Similarly, children received a diagnostic assessment approximately 16.7 months earlier when mothers had a postgraduate level of education, relative to mothers who had primary or secondary school levels of education. This aligns with prior findings[18 33] and highlights the importance of focusing on parental education as a modifiable risk factor when considering contributors to diagnostic delays. Maternal education in particular is acknowledged as the single best predictor of child health status and development outcomes,[34–36] and lower education is closely associated with limited health literacy.[37] Given this, there is a need to better understand the sources of health information parents are seeking to improve access to accurate information and subsequently improve health literacy and engagement with services.[38 39] Moreover, given the large gap between age at identification of concern and age at assessment, future research should

Table 4 Logistic regression predicting likelihood of receiving a diagnostic assessment by 5 years of age based on key sociodemographic characteristics

	B	SE B	OR	95% CI for OR	
				LL	UL
Constant	4.26	0.61	70.89**		
Mother's age	−0.11	0.02	0.89**	0.86	0.93
Father's age	−0.05	0.02	0.95**	0.92	0.99
Mother's level of education	0.01	0.10	1.01	0.84	1.22
Father's level of education	0.16	0.10	1.17	0.97	1.42
Mother's CALD status	0.66	0.25	1.93**	1.18	3.15
Father's CALD status	0.20	0.25	1.23	0.76	1.99
Parental relationship status	0.61	0.22	1.83**	1.18	2.83
Previous use of support services	0.65	0.17	1.91**	1.38	2.66

N=778, p<0.001. Prior engagement with services is coded as prior service use compared with no prior service use. CALD status is coded as CALD compared with non-CALD. Parental relationship status is coded as parents together compared with parents separated. *P<0.05; **p<0.01.
CALD, culturally and linguistically diverse; LL, lower limit; OR, odds ratio; SE B, SE error of the coefficient; UL, upper limit.

focus on education-based interventions and support for primary healthcare providers that may reduce diagnostic delays.

In total, 88.2% of caregivers reported that they preferred completing questionnaires online as opposed to paper. This finding provides further support[27] for the overall feasibility and acceptability of electronic data capture in this cohort. In the smaller group of families that preferred paper-based methods of collection, mothers' level of education and caregiver's age were significantly lower. Past studies have reported that older age (eg, >60 years) is associated with greater preference for paper-based methods.[40] Given our sample was principally comprised of parents of young children, some families with lower levels of education (and potentially fewer financial resources and familiarity with technology) may need to be further supported in electronic data collection methods. Future research is required to understand the needs of this group for using electronic data capture.

Findings from this study also demonstrate the potential of collecting harmonised, transdiagnostic information to develop a large, diverse research registry of children attending developmental services. As recommended by Boulton *et al*,[26] establishing a large-scale data collection network has potential to inform research, practice, policy and improve outcomes for children and families with neurodevelopmental conditions. This clinically integrated registry captured over 97% of children attending a publicly funded developmental assessment service. The aim of this registry is to provide an opportunity for clinical services to engage in more opportunities for evidence-based research practices and to provide research opportunities for best practice research and support for some of the most disadvantaged communities in Australia. This study represents the first example of this large-scale data collection and showcases the benefits of this approach for identifying the needs of children and families. Furthermore, while many research registries are comprised of self-selected samples, with participants typically from less disadvantaged backgrounds, the data presented here were collected on families from diverse backgrounds attending publicly funded services, with a large proportion of CALD and vulnerable families. Such research registries that are integrated with clinical services may go some way towards bridging the gap between the needs of vulnerable populations and conducting research that can respond to these needs. This is the first of several developmental assessment services to take part in this registry, and future studies are planned to report outcomes for different clinics, communities and regions across Australia.

Strengths and limitations

To our knowledge, this is the first study to evaluate contributors to diagnostic delays for children and families presenting to a publicly funded developmental assessment service. While prior research has largely focused on the assessment of single neurodevelopmental conditions, such as autism, our large, diverse sample contained many vulnerable families accessing publicly funded services for broad developmental needs. While we acknowledge that these services are not likely representative of all children with neurodevelopmental conditions, public services often see the most vulnerable and those from CALD backgrounds. We believe the focus on this underrepresented population is a strength of this study, but findings may not generalise to private services.

Some limitations should be acknowledged. The child and family characteristics measured did not capture detailed information on caregiver or child characteristics, such as caregiver stress or diagnostic symptom severity. Further research is also required to understand the relationship between age at assessment, developmental delays, milestones achieved and other child-related factors. In this study, we examined variables that contained the least missing data. Past research has shown a relationship between domains of developmental delay, milestone attainment and age at assessment,[41] and this is an area for future research. Furthermore, we note that information regarding age of first concern was retrospectively reported by caregivers. Prospective research designs from birth may overcome such limitations but would be logistically challenging to implement.

Conclusion

This study shows a considerable delay between identifying developmental concerns and receiving a

diagnostic assessment in a large cohort of children attending a publicly funded diagnostic assessment service. Our findings point to sociodemographic characteristics that raise risk of delayed diagnoses, signifying the importance of putting systematic and accessible supports in place for vulnerable families. This may facilitate faster access to services and increased opportunities for earlier diagnosis and intervention. Given the high prevalence of neurodevelopmental conditions and the importance of early intervention and support to drive optimal outcomes, it is critical that health services, researchers and policy makers work together to enact system-level changes, so all children in need can receive timely and appropriate supports.

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