ABSTRACT

Objectives To report on knowledge translation strategies and outcomes from the implementation of the early detection guidelines for cerebral palsy (CP) in a state-wide tertiary early intervention (EI) service and investigate the impact of social determinants on clinical services.

Design Retrospective longitudinal cohort study.

Setting The Western Australia tertiary paediatric EI service.

Participants EI clinicians, consumers and children using the EI service.

Outcome measures Knowledge translation strategies including consumer perspectives, clinician training and Communities of Practice (CoP) guided implementation. We measured changes in referral number and age, delivery of early detection and intervention following the implementation of the guidelines. Exposure to adverse childhood experiences (ACEs), appointment non-attendance (DNA) rates, remoteness and socioeconomic quintiles were used to measure social determinants of health using negative binomial (Incidence Rate Ratios, IRR) and logistic regression (Odds Ratios, ORs).

Results Ten consumers participated in Focus Groups, 100 clinicians were trained and 22 clinicians established a monthly CoP. Referrals increased fourfold to 511 children. Corrected gestational age at referral decreased from a median of 16.1 to 5.1 months (p<0.001) and at first appointment from 18.8 to 6.8 months (p<0.001). Children living in social disadvantage had the highest DNA risk (quintile 1 vs 5: IRR 2.2, 95%CI 1.1 to 4.6, p=0.037). Children exposed to ACEs had higher odds of living in social disadvantage (quintile 1 vs 5, OR=3.8, 95%CI 1.4 to 10.0, p=0.007). No significant association was found between remoteness and DNA rate or ACE score.

Conclusions Implementation strategies reduced referral age and improved the delivery of early detection assessments. Further investigation of the association between social disadvantage, DNA risk and ACE score is required in the development of a state-wide early detection network.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ First report on the implementation of Integrated Knowledge To Action strategies used to implement the clinical guidelines for the early detection of cerebral palsy in a state-wide early intervention service and the impact of social determinants of health on service engagement.

⇒ Access to accurate, comprehensive longitudinal clinical service data.

⇒ Adverse childhood experience scores were recorded retrospectively, and a higher proportion of missing scores in early study phases limited the analysis to phases B and C; results should be interpreted with caution.

⇒ Consumer perspective informed design but not service evaluation.

⇒ The age of diagnosis was not routinely recorded, so age of referral was used as a proxy for access to early detection and early intervention services.

INTRODUCTION

Cerebral palsy (CP) is the most common childhood physical disability, with a prevalence of 1.4 cases per 1000 live births reported in the literature.12 CP is an umbrella term for a heterogeneous group of posture and movement disorders “causing activity limitation, … attributed to non-progressive disturbances that occurred in the developing fetal or infant brain …” (Rosenbaum et al., p. 9).

Historically, referral for the diagnosis of CP has occurred between 8 and 16 months of age,4-6 with diagnosis delayed until 19 months of age.1 However, international guidelines for the early detection of CP provide recommendations for earlier detection.2 This represents a clinical practice change from a ‘wait-and-see’ approach to one which informs a provisional diagnosis of ‘high-risk’ CP before
The early detection guidelines (henceforth ‘the guidelines’) describe two clinical pathways. Pathway one is for infants with ‘newborn detectable risks’, for whom referral by 5 months corrected gestational age (CGA) is recommended to enable very early detection by the classification of brain MRI using the MRI Classification System, General Movement Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE). Pathway two is for infants with ‘infant detectable risks’ which may not become evident until after 5 months CGA, for whom the guidelines recommend using MRI, HINE and the Alberta Infant Motor Scale to detect high risk of CP.

Referral as soon as newborn or infant detectable risks are recognised facilitates early identification and early referral for intervention. Early, CP-specific interventions focus on optimising developmental outcomes by capitalising on heightened dependent neural plasticity and caregiver support. Yet, in 2019 te Velde et al. reported only 21% of Australian infants received a diagnosis of CP before 6 months of age, signalling the need for knowledge translation strategies to support the implementation of the guidelines into clinical practice. The Integrated Knowledge to Action (IKTA) framework was used to translate the clinical guidelines into practice.

To date, the guidelines have been implemented in services for high-risk infants after discharge from neonatal intensive care units or a targeted diagnostic clinic. However, this is the first report on the use of IKTA strategies to implement the guidelines, the first implementation of the guidelines within an existing state-wide early intervention service for children with a wide variety of complex conditions and the first investigation of the sociodemographic influences on access to early detection and early intervention services.

Perth Children’s Hospital (PCH) is the sole tertiary paediatric hospital in Western Australia and provides an EI service for children at risk of CP from an area of 2527013 km². Western Australia has a range of population densities, climatic and socioeconomic conditions, with some families living in areas of relatively high social disadvantage. The social gradient of health described by Marmot and Bell means Western Australian children living in areas of social disadvantage are more likely to have poorer health and developmental outcomes across the lifespan, more likely to have a disability and more severe CP. Children in areas of social disadvantage use less early childhood services and are more vulnerable to adverse childhood experiences (ACEs) with a higher impact on children with neurodisability.

The second objective was to determine any association between social determinants of health, ACEs and access to the service. We hypothesised that investigation of whether children who live in conditions of relative social disadvantage attend less EI service appointments and have higher exposure to adversity would provide information to improve access to services.

**METHODS**

**Study design and data sources**

This was a retrospective cohort study implemented using the IKTA framework (see figure 1) and reported using the Standards for Reporting Implementation Studies (StaRI) checklist. The service commenced in July 2015 and a phased approach to service development and implementation took place over 5 years. Three 18-month implementation phases were used to measure the changes over time and compared with the 12-month preimplementation phase. The phases were preimplementation: 1 July 2014 to 30 June 2015, phase A: 1 July 2015 to 31 December 2016, phase B: 1 January 2017 to 30 June 2018 and phase C: 1 July 2018 to 31 December 2019. Each implementation phase focused on a different aspect of the Action Cycle of the IKTA.

During phase A, the ‘at-risk’ CP service model was developed and adapted to the PCH EI service context. The results of consultation with consumers from our Consumer Advisory Group and EI Focus Groups...
(unpublished data), referrers and clinicians informed a revised early intervention service model and expansion of the clinical service to include early detection of children at risk of CP. During phase B, the barriers to knowledge use were assessed and clinicians were trained in the recommended early detection assessment tools and interventions. Phase C focused on the selection and implementation of assessments and interventions for the right children at the right time in accordance with the guidelines. Data collection processes and quality were improved, and data were used to monitor and evaluate implementation of the service.

Data were obtained from the Paediatric Rehabilitation Information System (PRIS), a purpose-built web-based clinical database used by EI clinicians to collect and review data used for standard clinical care.

Ethics approval
Ethical approval was granted by the Human Ethics Committee for the Child and Adolescent Health Services of Western Australia (RGS4288) and Curtin University (HRE2021-012).

Public/patient involvement
Members of our Consumer Reference Group (CRG), who have lived experience or are parents of children with disability, approved the study design and evaluation plan. Parents of children with CP who had attended the EI service informed the design and implementation of the ‘at-risk’ CP service. The CRG has continuing involvement in service evaluation, communication and interpretation of findings to guide future development.

Setting
The study took place within the state-wide tertiary paediatric EI service of Western Australia. Before implementation of the guidelines, approximately 50 infants per year with complex medical or surgical histories at risk of neurodevelopmental delay were referred to the EI service. Families were seen in a multidisciplinary clinic for diagnosis and received allied health early intervention before referral to community disability service providers by 2 years of age.

Some children at very high risk of CP (eg, those with severe hypoxic ischaemic encephalopathy) were referred to this original EI service. However, most children at risk of CP were monitored by other PCH specialties and referred to the Entry Clinic of the PCH Cerebral Palsy Mobility Service (CPMS) for diagnosis and spasticity management, hip surveillance or orthopaedic intervention.

Characteristics
The ‘at-risk’ CP service is embedded within the PCH EI service and modelled on a collaborative clinical research framework, with links to national and international clinical research networks.37 EI services are provided by an early childhood team of medical specialists, allied health clinicians, nurses, a clinical coordinator, clinical researchers and administration staff. The multidisciplinary team provide diagnostic assessments, referral to clinical research trials and access to interim early intervention services, whilst facilitating timely referral to tertiary specialist services and National Disability Insurance Scheme funded community-based therapy. Children with CP or ‘at risk’ are invited to participate in early intervention clinical trials.

Participants
There were three groups of participants in this study. The first were parents of children referred to the EI service who were invited to participate in focus groups. The second were clinician referrers and those who work with infants and children at risk of CP in Western Australia, who were targeted for education and training during the implementation of the guidelines. Although the primary focus was on training PCH EI clinicians, enrolment was offered to all clinicians whenever possible.

The third group of participants were all children referred to the PCH EI service between 1 July 2015 and 31 December 2019 for CP detection under 4 years of age. Children referred to the CPMS Entry Clinic between 1 July 2014 and 30 June 2015 were allocated to the preimplementation phase, and children referred between 1 July 2015 and 31 December 2019 were allocated to one of the three 18-month implementation phases.

Children in participant group 3 were excluded if they were not referred for diagnosis of CP or were older than 4 years of age at referral, as those children are referred elsewhere for service coordination. Children who lived in regional and remote areas were excluded from research trials due to the travel required for participation. There were no exclusions for participant groups 1 or 2.

Outcome measures
During phases B and C, the reduction in barriers to knowledge use was measured by the number of clinicians trained in use of the early detection tools, of children referred to research trials, of clinicians involved in the GMA Community of Practice (CoP) and frequency of meetings. Data processes, quality and use for clinical audits were reviewed to measure service monitoring and evaluation.

The clinical implementation measures used retrospective data from PRIS to identify the number of children referred for early CP detection, CGA at date of referral and first appointment. The date of referral was used in this study to measure access to early detection and intervention as children are seen soon after referral and a separate date of diagnosis was not routinely recorded. Children who attended appointments were allocated to either assessment pathway 1 or 2 described in the guidelines to measure changes in the proportion and timing of MRI, GMA and HINE assessments. Children were allocated to a CP diagnosis category (CP, not CP or unclear), and those with a diagnosis of CP to a severity category using the Gross Motor Function Classification Scale—Expanded and Revised (GMFCS-ER).38
An ACE checklist, adapted for use in the Australian paediatric clinical context by Wickramasinghe et al. (online supplemental appendix 1), was used to retrospectively record children’s exposure to ACEs. All children in phase C were given an ACE score, as were children with a diagnosis of CP in phases A, B and the preimplementation phase.

All children offered appointments were allocated to both an Australian Bureau of Statistics (ABS) Socio Economic Index of Relative Social Advantage and Disadvantage (SEIFA) quintile and an Accessibility Remote-Economic Index of Australia Remoteness Area, based on each child’s usual residential address. DNA rates were calculated by dividing the number of EI appointments attended by the number offered.

Statistical methods

Count data are reported for primary implementation IKTA strategies. For clinical implementation variables, frequencies and proportions are reported for categorical variables, with differences between study phases assessed using $\chi^2$ tests or Fisher’s exact test when expected cell counts are <5. For continuous variables, medians and IQRs are reported due to the skewed distributions, with differences between phases assessed using non-parametric tests. To compare SEIFA quintiles, a proportions test was used comparing the study participants with ABS Western Australia population data.

Associations between SEIFA quintile and Remoteness Area with DNA rate and ACE scores were investigated using negative binomial (DNA count data) as the data were overinflated, and logistic regression (ACE score yes/no). Data from phases B and C were used in the logistic regression model due to large volumes of missing ACE data in the other phases. Multivariable models were considered; however, only one predictor remained significant so only univariable models are presented.

All missing data are reported. Statistical significance level was set at $p<0.05$. All analysis was performed using Stata 16.1.

RESULTS

Implementation process

During phase A, 10 consumers were engaged in Focus Groups to understand their perspectives of early detection and intervention. Feedback was used to adapt development of the service model to the local context (unpublished data). Early detection clinics were increased from 1 to 4 per week with additional medical, allied health, nursing, coordination and administration staff. Research and knowledge translation were supported by an Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN) Post-Doctoral Fellowship. During phases B and C, 100 clinicians were trained in early detection assessments and interventions and four clinicians became HINE Train the Trainers. Clinical researchers were embedded in the early intervention service; 132 children were identified as eligible for at least one of six research trials and 64 (48.5%) of eligible children were enrolled in a trial.

During phase C, a CoP for GMA clinicians with 22 members was established and continues to meet monthly to maintain quality, professional development and a consultancy service for clinicians around Western Australia. Quality improvement projects were formed within two clinical working groups to develop family resources, increase family engagement, develop standardised reporting formats and measure intervention outcomes. Fourteen clinical audits have been undertaken by clinician–researchers, and the research investigating the early development of speech and language in infants with CP and motor impairment is ongoing.

Clinical outcomes

Five hundred and eleven children were referred under 4 years of age for CP detection; 54% were male, 58% were born at term and eight children died during the study period. There was no significant difference in SEIFA quintile ($p=0.111$) or remoteness category ($p=0.510$) across the phases (table 1). Four hundred and ninety-four children attended EI service appointments.

Pathway one: children referred under 5 months CGA

During each implementation phase, an increasing proportion of children had an MRI performed and less children were missing MRIs ($p<0.001$). More children had GMA results available during the combined implementation phases A, B and C (60.8%, n=127) compared with the preimplementation phase (16.7%, n=1) ($p=0.041$). No children on pathway 1 had HINE assessments during the preimplementation phase; this increased to 5.7% (n=2) in phase A, 19.7% (n=13) in phase B and 38.9% (n=42) in phase C (table 1).

There was a significant change in the proportion of children with a confirmed CP diagnosis in each phase, which increased during phase A before reducing in each phase to 33.4% in phase C ($p=0.004$). The number of children who received a diagnosis of CP during phase A was 23, increasing to 24 in phase B and 36 in phase C.

Pathway two: children referred over 5 months CGA

A higher proportion of children had MRI results available in each study phase ($p<0.001$). No children on this pathway had HINE assessments in the preimplementation phase or phase A, 5.2% (n=4) had a HINE in phase B and 9.2% (n=8) in phase C. There was a decrease in the number of children with missing HINE assessments, reducing from 79.2% (n=57) in phase A to 74% (n=57) in phase B, to 60.9% (n=53) in phase C (table 1).

The proportion of children diagnosed with CP during each phase followed a similar trend to pathway 1. During phases A, B and C, the number of children who received a diagnosis of CP were 36, 33 and 31, respectively. However, 46% (n=17) of children in phase A, 76.5% (n=26) in phase B and 64.5% (n=20) of children in phase C who received a CP diagnosis were not referred until after...
Table 1  Cohort demographics, sociodemographic variables, early detection assessments and CP diagnosis category

|                          | Total n (%) | Preimplementation n (%) | Phase A n (%) | Phase B n (%) | Phase C n (%) | P value all phases | Combined phases A, B, C P value | Preimplementation vs combined phases A, B, C P value |
|--------------------------|-------------|-------------------------|---------------|---------------|---------------|--------------------|--------------------------------|---------------------------------|
| Children referred to EI service under 4 years old | 511 (100.0) | 49 (9.6) | 113 (22.1) | 152 (29.7) | 197 (38.6) | 462 (90.4) | | |
| Gender                   |             |                         |               |               |               |                    |                                |                                  |
| Female                   | 233 (45.6)  | 22 (44.9) | 48 (42.5) | 70 (46.1) | 93 (47.2) | p=0.880            | 211 (45.7) | p=0.918                          |
| Male                     | 278 (54.4)  | 27 (55.1) | 65 (57.5) | 82 (53.9) | 104 (52.8) | 251 (54.3) |                                |                                  |
| Gestational age at birth |             |                         |               |               |               |                    |                                |                                  |
| Preterm (<37 weeks)      | 211 (41.3)  | 17 (34.7) | 42 (37.2) | 56 (36.8) | 96 (48.7) | p=0.161*           | 194 (42.0) | p=0.574*                          |
| Term (37 to <42 weeks)   | 296 (57.9)  | 32 (65.3) | 70 (61.9) | 95 (62.5) | 99 (50.3) | 264 (57.1) |                                |                                  |
| Post-term (42 weeks)     | 4 (0.8)     | 0 (0.0) | 1 (0.9) | 1 (0.7) | 2 (1.0) | 4 (0.9) |                                |                                  |
| Deceased during study period |           |                         |               |               |               |                    |                                |                                  |
| No                       | 503 (98.4)  | 49 (100.0) | 111 (98.2) | 149 (98.0) | 194 (98.5) | 454 (98.3) | p=0.999*                  | 454 (98.3) | p=0.999*                          |
| Yes                      | 8 (1.6)     | 0 (0.0) | 2 (1.8) | 3 (2.0) | 3 (1.5) | 8 (1.7) |                                |                                  |
| Children not deceased    | 503 (98.4)  | 49 (9.7) | 111 (21.7) | 149 (29.2) | 194 (38.0) | 454 (90.3) |                                |                                  |
| SEIFA quintile           |             |                         |               |               |               |                    |                                |                                  |
| Quintile 1 (low)         | 91 (18.1)   | 8 (16.3) | 31 (27.9) | 26 (17.4) | 26 (13.4) | p=0.111            | 83 (18.3) | p=0.276                          |
| Quintile 2               | 109 (21.7)  | 11 (22.4) | 21 (18.9) | 35 (23.5) | 42 (21.6) | 98 (21.6) |                                |                                  |
| Quintile 3               | 124 (24.7)  | 7 (14.3) | 24 (21.6) | 32 (21.5) | 61 (31.4) | 117 (25.8) |                                |                                  |
| Quintile 4               | 100 (19.9)  | 12 (24.5) | 18 (16.2) | 34 (22.8) | 36 (18.6) | 88 (19.4) |                                |                                  |
| Quintile 5 (high)        | 72 (14.3)   | 11 (22.4) | 16 (14.4) | 19 (12.8) | 26 (13.4) | 61 (13.4) |                                |                                  |
| Missing                  | 7 (1.4)     | 0 (0.0) | 1 (0.9) | 3 (2.0) | 3 (1.5) | 7 (1.5) |                                |                                  |
| Remoteness category      |             |                         |               |               |               |                    |                                |                                  |
| Major city               | 397 (78.9)  | 42 (85.7) | 81 (73.0) | 117 (78.5) | 157 (80.9) | 355 (78.2) | p=0.558*                  | 355 (78.2) | p=0.585*                          |
| Regional                 | 72 (14.3)   | 5 (10.2) | 22 (19.8) | 22 (14.8) | 23 (11.9) | 67 (14.8) |                                |                                  |
| Remote                   | 34 (6.8)    | 2 (4.1) | 8 (7.2) | 10 (6.7) | 14 (7.2) | 32 (7.0) |                                |                                  |
| Children who attended    | 494 (96.7)  | 49 (9.9) | 107 (21.7) | 143 (28.9) | 195 (39.5) | 445 (90.1) |                                |                                  |
| ACE risk category        |             |                         |               |               |               |                    |                                |                                  |
| No (score=0)             | 205 (41.5)  | 1 (2.0) | 18 (16.8) | 76 (53.1) | 110 (56.4) | p<0.001*           | 204 (45.8) | p<0.001*                          |
| Yes (score 1 to 6)       | 146 (29.6)  | 11 (22.5) | 30 (28.0) | 38 (26.6) | 67 (34.4) | 135 (30.3) |                                |                                  |
| Not reported             | 143 (28.9)  | 37 (75.5) | 59 (55.1) | 29 (20.3) | 18 (9.2) | 106 (23.8) |                                |                                  |
| Pathway 1—referred ≤5 months† | 215 (43.5) | 6 (2.8) | 35 (16.3) | 66 (30.7) | 108 (50.2) | 209 (97.2) |                                |                                  |
| MRI                      |             |                         |               |               |               |                    |                                |                                  |
| MRI ≤5 months            | 163 (75.8)  | 2 (33.3) | 16 (45.7) | 52 (78.8) | 93 (86.1) | p<0.001*           | 161 (77.0) | p=0.034*                          |
| MRI >5 months            | 15 (7.0)    | 1 (6.7) | 2 (5.7) | 5 (7.9) | 7 (6.8) | 14 (16.7) |                                |                                  |
| No MRI recorded          | 37 (17.2)   | 3 (60.0) | 17 (48.6) | 9 (13.6) | 8 (7.4) | 34 (16.3) |                                |                                  |

Continued
| GMA† | Total | Preimplementation | Phase A | Phase B | Phase C | P value all phases | Combined phases A, B, C | P value Preimplementation vs combined phases A, B, C |
|------|-------|-------------------|---------|---------|---------|-------------------|------------------------|--------------------------|
| Wring or fidgety age | 128 (69.5) | 1 (16.7) | 20 (57.1) | 37 (61.6) | 70 (64.8) | p=0.105* | 127 (60.8) | p=0.041* |
| No GMA | 87 (40.5) | 5 (83.3) | 15 (42.9) | 29 (43.9) | 38 (35.2) |
| HINE | | | | | | | | |
| HINE ≤5 months | 57 (26.5) | 0 (0.0) | 2 (5.7) | 13 (19.7) | 42 (38.9) | p<0.001* | 57 (27.3) | p=0.103* |
| HINE >5 months | 44 (20.5) | 0 (0.0) | 7 (20.0) | 10 (15.2) | 27 (25.0) | |
| No HINE recorded | 114 (53.0) | 6 (100.0) | 15 (74.3) | 43 (65.2) | 39 (36.1) | |
| CP diagnosis category | | | | | | | | |
| No | 127 (59.1) | 2 (33.4) | 12 (34.3) | 41 (62.1) | 72 (66.7) | p=0.004* | 125 (59.8) | p=0.248* |
| Yes | 87 (40.5) | 4 (66.6) | 23 (65.7) | 24 (36.4) | 36 (33.4) | |
| Unclear | 1 (0.5) | 0 (0.0) | 0 (0.0) | 1 (1.5) | 0 (0.0) | |
| Pathway 2—referred >5 months | 279 (56.5) | 43 (15.4) | 72 (25.8) | 77 (27.6) | 87 (31.2) | 236 (84.6) |
| MRI | | | | | | | | |
| MRI ≤5 months | 24 (8.6) | 0 (0.0) | 2 (2.8) | 11 (14.3) | 11 (12.6) | p<0.001* | 24 (10.2) | p<0.001 |
| MRI >5 months | 126 (45.2) | 2 (4.7) | 24 (33.3) | 41 (53.2) | 59 (67.8) | |
| No MRI recorded | 129 (46.2) | 41 (95.3) | 46 (63.9) | 25 (32.5) | 17 (19.5) | 88 (37.3) |
| HINE | | | | | | | | |
| HINE >5 months | 12 (4.3) | 0 (0.0) | 0 (0.0) | 4 (5.2) | 8 (9.2) | p=0.010* | 12 (5.1) | p=0.101* |
| Missing and referred ≤2 years old§ | 194 (69.5) | 27 (62.7) | 57 (79.2) | 57 (74.0) | 53 (60.9) | 167 (70.8) |
| Not eligible; referred >2 years old | 73 (26.2) | 16 (37.2) | 15 (20.8) | 16 (20.8) | 26 (29.9) | 27 (24.2) |
| CP diagnosis category | | | | | | | | |
| No | 153 (54.8) | 18 (41.9) | 36 (50.0) | 44 (57.1) | 55 (63.2) | p=0.102* | 135 (57.2) | p=0.171* |
| Yes | 125 (44.8) | 25 (58.1) | 36 (50.0) | 33 (42.9) | 31 (35.6) | |
| Unclear | 1 (0.4) | 0 (0.0) | 0 (0.0) | 1 (1.2) | |

*Fisher’s exact.
†All ages in months are corrected gestational age.
‡Three children had first GMA >5 months.
§HINE assessment ceiling age.
ACE, adverse childhood experience; CGA, corrected gestational age; CP, cerebral palsy; EI, early intervention; GMA, General Movement Assessment; HINE, Hammersmith Infant Neurological Examination; SEIFA, Socio Economic Indices for Areas.
12 months CGA. The diagnosis of CP was unclear in only two (0.4%) children; one was lost to follow-up and one moved interstate before the confirmation of a CP diagnosis could be made.

One hundred and ninety-four (91.5%) children with a confirmed diagnosis of CP had a GMFCS-ER level recorded. Distribution of GMFCS-ER level did not change significantly across the implementation periods (p=0.963) and reflects distribution on the Australian CP Register.43

Median CGA at referral decreased in each successive implementation phase (p<0.001), starting from 16.1 months (IQR 10.1–26.2) in the preimplementation phase, reducing to 10.4 months (IQR 3.1–17.9) in phase A, 7.1 months (IQR 1.1–15.9) in phase B and 5.1 months (IQR 0.4–14.5) in phase C (figure 2). No children were referred before term equivalent age in the preimplementation phase, compared with 10 in phase A, 19 in phase B and 30 in phase C. The earliest age of referral was 45 days preterm (n=1) during phase B.

Median CGA at first attended appointment decreased significantly in each implementation phase from 18.8 months (IQR 15.4–31.3) in the preimplementation phase to 6.8 months (IQR 2.7–18.8) in phase C (p=0.001). When analysed by discipline, the median CGA for first medical appointments reduced from 20.8 months (IQR 15.5–32.9) in the preimplementation phase to 7.8 months (IQR 4.1–18.4) in phase C (p=0.001). Median CGA for first allied health appointments reduced sharply in phase A to 3.8 months (IQR 1.4–7.8) before stabilising at 5.1 (IQR 2.1–11.2) months in subsequent phases (online supplemental table).

**Sociodemographic variables**

A higher proportion of children referred to the PCH EI service resides in ABS quintiles of relative disadvantage compared with the Western Australian population (figure 3); 18% of the EI population resides in quintile 1 (relative social disadvantage) compared with 13% of the wider population. In contrast, only 15% of the EI population resides in quintile 5 compared with 21% of the Western Australian population.

The DNA rate for children in the lowest (most disadvantaged) SEIFA quintile was 2.2 times higher than that for children in the highest quintile (p=0.037, 95% CI 1.1 to 4.6), and children in quintiles 2 and 3 had DNA rates two times higher (table 2).

Children in quintile 1 had 3.8 times higher odds than children in quintile 5 of having an ACE score of 1 to 6 (p=0.007, 95% CI 1.4 to 10.0). Children in quintiles 2 to 4 also had higher odds of having an ACE score greater than 0; however, this did not reach statistical significance (table 2).

Children living in remote and regional Western Australia did not have significantly higher DNA rates compared with children living in the major city of Perth and did not have significantly higher odds of an ACE score greater than 0 (table 2).

**DISCUSSION**

This study shows phased implementation of the early detection guidelines in an existing state-wide tertiary EI service reduced the age of referral for infants at risk of...
and improved the access to early diagnosis and early intervention services. The age of referral dropped from 16.1 months before implementation of the guidelines to 5.1 months, lower than the 8- to 16-month range previously reported.4–6 Services in Australia17 19 and North America which have implemented the guidelines found similar effects in high-risk infant follow-up clinics14 or networks.16 Implementation within a state-wide EI service enabled the rapid translation of the guidelines to clinical practice, informed by the consumer perspective, and in a separate review after implementation parents reported high levels of satisfaction with the new EI service. The PCH EI service now includes a comprehensive early detection service for children at risk of CP, with targeted early intervention and access to clinical trials.

Access to timely early detection assessments and early intervention improved during the study. A higher proportion of children were referred on pathway 1 under 5 months CGA, attended their first appointment earlier and received the standardised early detection assessments as recommended by the guidelines. Installation of a new MRI in the referring neonatal unit during study phase A facilitated access to term equivalent age MRIs and a significant increase in the clinical use of MRIs; by phase C over 80% of children had MRI results available. 65% children had GMAs recorded in phase C; however, there are still some babies referred on pathway 1 who are missing GMAs. The lack of an interoperable and integrated electronic medical record contributes to this gap by reducing access to GMAs performed in referring neonatal units, resulting in missing information and potential assessment duplication. Although not all children received early detection assessments on time, all children requiring tertiary intervention were referred to allied health before transfer to appropriate community services. The median age at the first allied health appointment reduced to 5.1 months CGA, and 63% of children on pathway 1 had their first EI appointment with allied health in phase C. Te Velde et al19 also found some babies were referred for CP-specific early intervention before the early diagnosis

### Table 2  Impact of sociodemographic factors on appointment non-attendance and adverse childhood experiences: univariable negative binomial and logistic regression models

| Predictors  | Children | Appointments offered | Appointments not attended | DNA rate (per 100 appointments) | Univariable model |
|-------------|----------|-----------------------|---------------------------|---------------------------------|-------------------|
| SEIFA quintile |          |                       |                           |                                 |                   |
| Quintile 1 (low) | 91 (18.3) | 889 (14.4)            | 73 (18.4)                 | 8.2                             | 2.2 (1.1 to 4.6)†  |
| Quintile 2    | 109 (22.0)| 1226 (19.8)           | 101 (25.4)                | 8.2                             | 2.1 (1.0 to 4.3)†  |
| Quintile 3    | 124 (25.0)| 1897 (30.7)           | 140 (35.3)                | 7.4                             | 2.0 (1.0 to 3.9)†  |
| Quintile 4    | 100 (20.2)| 1181 (19.1)           | 52 (13.1)                 | 4.4                             | 1.3 (0.6 to 2.7)  |
| Quintile 5 (high) | 72 (14.5)| 991 (16.0)            | 31 (7.8)                  | 3.1                             | 1.0               |
| Remoteness    |          |                       |                           |                                 |                   |
| Major city    | 397 (78.9)| 5720 (91.5)           | 360 (89.8)                | 6.3                             | 1.0               |
| Regional      | 72 (14.3)| 405 (6.5)             | 32 (8.0)                  | 7.9                             | 1.1 (0.6 to 1.9)  |
| Remote        | 34 (6.8)| 123 (2.0)             | 9 (2.2)                   | 8.8                             | 1.2 (0.5 to 2.9)  |

| Predictors  | Children | No ACE score | ACE score | Univariable model |
|-------------|----------|--------------|-----------|-------------------|
| SEIFA quintile |         |              |           |                   |
| Quintile 1 (low) | 43 (15.0)| 19 (10.3)    | 24 (23.5) | 3.8 (1.4 to 10.0)† |
| Quintile 2    | 68 (23.8)| 44 (23.9)    | 24 (23.5) | 1.6 (0.6 to 4.0)  |
| Quintile 3    | 81 (28.3)| 54 (29.4)    | 27 (26.5) | 1.5 (0.6 to 3.6)  |
| Quintile 4    | 58 (20.3)| 40 (21.7)    | 18 (17.7) | 1.4 (0.5 to 3.5)  |
| Quintile 5 (high) | 36 (12.6)| 29 (14.8)    | 9 (8.8)   | 1.0               |
| Remoteness    |          |              |           |                   |
| Major city    | 234 (80.4)| 150 (80.7)  | 84 (80.0) | 1.0               |
| Regional      | 37 (12.7)| 23 (12.4)    | 14 (13.4) | 1.1 (0.5 to 2.3)  |
| Remote        | 20 (6.9)| 13 (7.0)     | 7 (6.7)   | 1.0 (0.4 to 2.5)  |

† p<0.05.

DNA, did not attend; IRR, incidence rate ratio; OR, Odds Ratio; SEIFA, Socio Economic Index for Areas.
clinic appointment. Earlier access to EI services meets parents’ needs for early, timely diagnostic information and access to interventions,44 including those promoting family function,45 in alignment with both the early detection7 and early intervention13 guidelines. Early detection also enables clinicians to exclude a diagnosis of CP and therefore remove the potential stress of a CP diagnosis for the families of children with a neurodisability that is not CP, and to redirect intervention efforts appropriately.

The number of children diagnosed with CP in each 18-month implementation phase approximates the Australian CP prevalence rate of 1.2 per 1000 live births46 per annum. However, the reported prevalence of CP in Western Australia is 1.5 per 1000 live births per year,46 and while more than half of the children diagnosed with CP were referred before 5 months CGA by phase C, there are still some children with infant or newborn detectable risks not being referred by 12 months CGA. Although the feasibility of confirming a CP diagnosis well before 12 months CGA has been demonstrated,14 16 17 19 47 some barriers to early referral4–6 remain which need to be comprehensively assessed and addressed in Western Australia.

Detection of the remaining children at risk of CP in Western Australia will require implementation of a state-wide education network for primary, secondary and tertiary health and disability providers to identify emerging signs of risk and facilitate earlier referrals, especially for children with infant detectable risks such as upper limb asymmetry. Network development commenced during this study; clinicians from around the state were invited to early detection training, supported through the GMA CoP, and clinical outreach services were initiated. Successful implementation of population screening of infants at fidgety age using GMA,48 facilitated by machine learning algorithms to automate scoring49 is under investigation50 to provide an accessible, sustainable method of identifying all infants at risk early.31 In addition to accurate identification of risk, success will require a system for secure transfer of results, clinical validation, good communication with parents and clear pathways to fast track referral to specialised early intervention services.

Providing equitable state-wide EI services to a jurisdiction as large and diverse as Western Australia is challenging when more children referred to the PCH EI service live in conditions of relative social disadvantage compared with the Western Australian population. Although we did not find a significant association between remoteness and risk of DNA, this may be because existing supports for regional and remote families are effective. Supports include funding for travel and accommodation, access to telehealth and care coordination. All staff are trained to deliver culturally safe care, which includes routine use of Aboriginal Liaison and Koorliny Moort52 services, and interpreters for culturally and linguistically diverse families. We did find children living in lower SEIFA quintiles were at risk of higher DNA rates and had higher odds of being exposed to ACEs, reinforcing existing evidence that children living in social disadvantage use less health services32 33 and are at higher risk of ACEs.27 34 Assessment of the social determinants of health that impact each family’s capacity to engage and care coordination roles are already embedded in the EI service to improve access and adherence to health care.53–58 While these are the first steps to tailoring care and providing appropriate referrals,39–61 children living in social disadvantage are more vulnerable to existing structural health system inequities such as siloed care and poor transitions between health and disability services, and some children are still falling through the gaps. A combination of health system changes, consumer-informed care coordination roles which work in partnership with families and build capacity to navigate complex service pathways, and programmes like ENVISAGE45 which empower parents of children with neurodisability will contribute to improving engagement and outcomes. The Access to Care Framework,34 which outlines patient and provider influences on access and engagement, could be used to guide future research and reduce complexity at system, organisational and service levels. Qualitative research enabling the consumer perspective of barriers and facilitators to referral and engagement will be important for development and implementation of a state-wide early detection network to improve equitable accessible EI services.

Some study limitations must be noted. Referral date was used as a proxy for access to the EI service; both median CGA at referral and first-attended appointment reduced during the study period. We do not report diagnosis date as communication of diagnostic and prognostic information, provided in the context of the therapeutic relationship with each family to facilitate understanding and acceptance, varied and reduced data accuracy. Using referral date potentially limits both comparisons to papers that report the date of CP diagnosis and confirmation that earlier access in this study resulted in earlier diagnosis. Many children had additional diagnoses to their primary diagnosis of CP; however, accurate reporting was not supported by systematic recording. Family perspectives informed service development but not the implementation process, nevertheless a separate postimplementation consumer review was positive. ACE scores were reported retrospectively. To minimise bias, inaccurate or missing data, the multidisciplinary team triangulated the data at weekly clinical review meetings. Occasionally families relocate from regional and remote postcodes to the metropolitan area for the birth of a high-risk baby, potentially impacting the accuracy of SEIFA and remoteness data for a small number of children.

CONCLUSION

The use of the IKTA framework, informed by consumer perspectives, enabled the rapid translation of the guidelines for early detection of CP to clinical practice and resulted in a comprehensive EI service providing targeted early intervention and access to clinical trials. Further investigation and action on the impacts of social inequity on service
engagement will be important in the development of a state-wide early detection network. The aim of the network will be to ensure all infants at risk of CP in Western Australia and their families have access to the right care in the right place at the right time, and that each child reaches their individual developmental potential.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

Ethics approval This study involves human participants and was approved by the Human Ethics Committee for the Child and Adolescent Health Services of Western Australia (REG428) and Curtin University (HREC2021-012). A waiver of consent was sought and approved as part of the ethics approval process for this study as the project met the requirements in the NHMRC National Statement on Ethical Conduct on Human Research 2007 (Updated 2018) of negligible risk.

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