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ORIGINAL ARTICLE

Epidemiology of gastrostomy insertion for children and adolescents with intellectual disability

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Abstract

The largest group of recipients of pediatric gastrostomy have neurological impairment with intellectual disability (ID). This study investigated trends in first gastrostomy insertion according to markers of disadvantage and ID etiology. Linked administrative and health data collected over a 32-year study period (1983–2014) for children with ID born between 1983 and 2009 in Western Australia were examined. The annual incidence rate change over calendar year was calculated for all children and according to socioeconomic status, geographical remoteness, and Aboriginality. The most likely causes of ID were identified using available diagnosis codes in the linked data set. Of 11,729 children with ID, 325 (2.8%) received a first gastrostomy within the study period. The incidence rate was highest in the 0–2 age group and there was an increasing incidence trend with calendar time for each age group under 6 years of age. This rate change was greatest in children from the lowest socioeconomic status quintile, who lived in regional/remote areas or who were Aboriginal. The two largest identified groups of ID were genetically caused syndromes (15.1%) and neonatal encephalopathy (14.8%).

Conclusion: Gastrostomy is increasingly used in multiple neurological conditions associated with ID, with no apparent accessibility barriers in terms of socioeconomic status, remoteness, or Aboriginality.

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What is Known:
- *The use of gastrostomy insertion in pediatrics is increasing and the most common recipients during childhood have neurological impairment, most of whom also have intellectual disability (ID).*

What is New:
- *Nearly 3% of children with ID had gastrostomy insertion performed, with the highest incidence in children under 3 years of age.*
- *Gastrostomy use across different social groups was equitable in the Australian setting.*

Keywords Gastrostomy · Intellectual disability · Epidemiology · Accessibility · Incidence

Abbreviations

ACHI	Australian Classification of Health Intervention
APC	Annual Percentage Change
CI	Confidence Interval
HMDC	Hospital Morbidity Data Collection
ICD	International Classification of Disease
ICPM	International Classification of Procedures in Medicine
ID	Intellectual disability
IDEA	Intellectual Disability Exploring Answers
IRSAD	Index of Relative Socio-Economic Advantage and Disadvantage
MNS	Midwives Notification System
PEG	Percutaneous Endoscopic Gastrostomy
WA	Western Australia
WARDA	Western Australian Register for Developmental Anomalies

Introduction

Around 1.5–2.0% of children born each year develop an intellectual disability (ID) [10]. Compared to unaffected children, these children have more physical disability and medical comorbidities (e.g., epilepsy [39]), are up to ten times more likely to be hospitalized [9], and have a ninefold increase in mortality [11]. Children with complex medical needs often have feeding difficulties. Consequences include poor nutrition and growth, aspiration of food and fluids into the lungs, recurrent chest infections, and progressive lung disease [42]. Families and carers often find feeding routines time-consuming [20, 33], compounding other high-level care demands. Gastrostomy is one management option to improve daily feeding regimens, long-term nutrition, and medication administration [40]. It is used across a range of indications [3, 14, 17, 29, 37] but children with neurological impairments have more frequent use [17, 20, 29, 47] including a substantial proportion who have ID [25].

The United Nations Convention on the Rights of Persons with Disabilities clarifies that quality health care should be provided without discrimination on the basis of disability [45]. Principles guiding equitable health care delivery include consideration of availability, accessibility, acceptability, adaptability, and quality, known as the 4AQ framework [15]. Children with ID are more likely to live in families of low socioeconomic status and rural residence, and have higher representation among indigenous groups [8, 18, 30, 43, 44, 50]. These factors could make them especially vulnerable to health inequalities. Given the high frequency of feeding difficulties in ID, it is important to understand the barriers and enablers that affect accessibility to this procedure.

Understanding the diagnostic characteristics of children with ID who receive gastrostomy will provide a platform from which to evaluate patient care and outcomes. Accordingly, this study aimed to describe the incidence of gastrostomy insertion within a population of children and adolescents with ID in Western Australia (WA) over a 32-year period using linked data, investigate factors influencing gastrostomy use, and identify etiological groupings of ID for individuals receiving gastrostomy.

Materials and methods

We conducted a retrospective birth cohort study using linked health administrative, disability, and population databases available in the state of WA (2014 population: 2.5 million [2]). The study observation period was from 1 January 1983 to 31 December 2014.

Study population and data sources

The WA population is centralized, approximately 80% living in the greater area of its capital city Perth [1], and all pediatric gastrostomy insertions are performed at the only tertiary children's hospital. We included linked population-based health, disability, and administrative data sets [26, 27, 31] in our analyses.

The state Midwives Notification System (MNS) [31] was used to identify all children born alive in WA between 1 January 1983 and 31 December 2009. To account for the lag between birth and identification of ID and to ensure that most of the eligible children were diagnosed, children were required to be at least 5 years of age at the time of data extraction. Thus, cases were defined as children diagnosed between 1 January 1983 and 31 December 2014 based on identification of ID from either one of the

following data sources: (1) the Intellectual Disability Exploring Answers (IDEA) database [36] which collects information on children with ID from statewide disability service registration and/or school education records or (2) the WA Register of Developmental Anomalies (WARDA) [31] which incorporates data on cases with both birth defects and cerebral palsy. Most cases were identified from IDEA ($n = 11{,}525$; 98.2%) and WARDA contributed an additional 204 (1.8%) cases. For all identified cases of ID, demographic, disability, and health data were extracted from the IDEA database, WARDA, MNS, the Hospital Morbidity Data Collection (HMDC), and death registrations [31, 36].

Socioeconomic status was measured using the Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) centile (≤ 20%, 21–40%, 41–60%, 61–80%, > 80%), and remoteness of residence was based on the Accessibility and Remoteness Index for Australia score (major cities, regional, or remote). Both indicators were based on birth home address at the Census Collection District level (1996, 2001, 2006) or the Statistical Area 1 level calculated by the Australian Bureau of Statistics [5]. Aboriginality was defined as being a person of Aboriginal descent, and was coded as either Aboriginal or non-Aboriginal using a validated algorithm [16].

The primary outcome measure was defined as first hospitalization in children younger than 18 years for gastrostomy insertion, including open gastrostomy and percutaneous endoscopic gastrostomy (PEG) placements, within the study period. For hospitalizations up to December 1987, the International Classification of Procedures in Medicine (ICPM) codes were used to identify hospitalizations during which gastrostomy insertion was performed (open 5–431, 5–432; PEG N/A). Thereafter, the International Classification of Disease, ninth revision (ICD-9-CM) (January 1988–June 1999) and the Australian Classification of Health Intervention (ACHI) (July 1999–December 2014) codes were used (ICD-9-CM—open 43.19; PEG 43.11, and ACHI—open 30,375–07, 90,302–00; PEG 30481–00, 30,482–00). Fundoplication, a procedure that may be performed in conjunction with gastrostomy insertion, was also identified (ICPM—5-445; ICD-9-CM—44.66; ACHI—30,527-0(0–5) 30529–00, 30,529–01, 30,530–00).

Covariates

Age at admission for first gastrostomy insertion was categorized into six groups: 0–2 years, 3–5 years, 6–8 years, 9–11 years, 12–14 years, and 15–17 years. Birth year was grouped by 5-year period intervals after 1984: 1983–1984, 1985–1989, 1990–1994, 1995–1999, 2000–2004, and 2005–2009.

Categorization of etiologies of ID in children with gastrostomy

ICD-9-CM and ICD-10-AM codes for all recorded hospitalizations were reviewed for individuals who had a gastrostomy insertion to identify the most likely reason (causal or associated factors) and then grouped accordingly [49].

Statistical analysis

Prevalence of gastrostomy insertion in children with ID by birth year group was calculated by dividing the number of children in the specific birth year interval who received a gastrostomy insertion before 18 years of age by the number of live births within the birth period and was reported as cases per 100 live births.

We examined how the occurrence of gastrostomy insertion changed by calendar year by investigating the annual incidence rate over time. The rate was calculated based on the number of first gastrostomy insertions performed in individuals aged younger than 18 years in each calendar year divided by the person-time at risk of receiving the procedure from the start of the relevant year until date of first gastrostomy insertion, date of death or end of the year, whichever occurred first. The incidence rate was measured in cases per 10,000 person-years. Overall age-specific rates over calendar year, as well as the rates by socioeconomic status, remoteness area, and Aboriginality, were presented. Our analysis focused on periods with full data coverage for each age group given that birth cohort study methodology had a staggered start. For example, for the age group 3–5 years, the trend commenced in 1988 because data were available for children aged 3, 4, and 5 years in that year. We estimated the linear annual percentage change (APC) of incidence rate for each age group from Poisson regression models with the number of incident cases within that age group during each year as the dependent variable and the total corresponding time at risk as the offset. Robust standard errors were used to allow for overdispersion. In the subgroup analyses, difference in age-specific APCs between the two levels of each variable (Aboriginality: Aboriginal vs. non-Aboriginal; socioeconomic status: most disadvantaged (first IRSAD quintile) vs. more advantaged (second to fifth IRSAD quintile); remoteness area: regional/remote vs. major cities) were estimated using an interaction term of calendar year and the subgroup variable. Adjusted effects were obtained by re-running the model using all three variables and their interaction terms.

The median and interquartile range of age of first gastrostomy insertion for each diagnostic group were described. The association between diagnostic group and sex was examined using Pearson's chi-squared test of independence.

Table 1 Characteristics of 11,729 children with intellectual disability born in WA (1983–2009), by gastrostomy status

	No gastrostomy	Gastrostomy
N	11,404	325
	n (row %) (col %)	*n* (row %) (col %)
Year of birth		
1983–1984	551 (97.5) (4.8)	14 (2.5) (4.3)
1985–1989	2075 (98.2) (18.2)	38 (1.8) (11.7)
1990–1994	2716 (97.2) (23.8)	78 (2.8) (24.0)
1995–1999	2297 (97.3) (20.1)	64 (2.7) (19.7)
2000–2004	1991 (96.6) (17.5)	70 (3.4) (21.5)
2005–2009	1774 (96.7) (15.6)	61 (3.3) (18.8)
Sex		
Male	7488 (97.7) (65.7)	174 (2.3) (53.5)
Female	3916 (96.3) (34.3)	151 (3.7) (46.5)
Indigenous status		
Non-indigenous	9787 (97.2) (85.8)	280 (2.8) (86.1)
Indigenous	1617 (97.3) (14.2)	45 (2.7) (13.9)
Remoteness area		
Major cities	7289 (97.3) (63.2)	200 (2.7) (61.5)
Regional or remote	2994 (96.8) (26.3)	98 (3.2) (30.2)
Missing	1201 (97.8) (10.5)	27 (2.2) (8.3)
IRSAD quintile		
First (≤ 20%)	3331 (97.6) (29.2)	83 (2.4) (25.5)
Second (21–40%)	2524 (97.1) (22.1)	75 (2.9) (23.1)
Third (41–60%)	1893 (97.2) (16.6)	55 (2.8) (16.9)
Fourth (61–80%)	1425 (96.0) (12.5)	59 (4.0) (18.2)
Fifth (> 80%)	1035 (97.5) (9.1)	26 (2.5) (8.0)
Missing	1196 (97.8) (10.5)	27 (2.2) (8.3)
Age at admission (years), median (IQR)		*3.4 (1.6, 7.9)*
Age at admission (years)		
0–2		149 (45.8)
3–5		78 (24.0)
6–8		32 (9.8)
9–11		24 (7.4)
12–14		20 (6.2)
15–17		22 (6.8)
Year of procedure		
1983–1999		122 (37.5)
2000–2009		143 (44.0)
2010–2014		60 (18.5)

Ethical approvals

Ethical approval was obtained from the Department of Health WA (#2016/32) and the Western Australian Aboriginal Health Ethics Committee (747).

Results

We identified 11,729 individuals with ID. Of these, 325 children (2.8%) underwent gastrostomy insertion between 1983 and 2014. Characteristics of the study population by gastrostomy insertion status are shown in Table 1. The prevalence increased from 1.9 per 100 live births (95% confidence interval [CI] 1.5, 2.5) among those born in 1983–1989 to 3.4 per 100 live births (95% CI 2.8, 4.0) in the 2000–2009 birth cohort. More than half (53.5%) were male, approximately four fifths (86.1%) non-Aboriginal, and nearly two thirds (61.5%) lived in major cities. Gastrostomy was usually performed early in life (0–5 years: 69.8%) and the median age at admission was 3 years 4 months (interquartile range 1.6–7.9 years). New gastrostomy insertion was predominantly performed using the percutaneous endoscopic technique (84.6%), with 28.0% (n = 91) also having a fundoplication. Majority of the fundoplication surgery was carried out at time of first gastrostomy insertion (50.5%, n = 46), and the rest were performed either after (40.7%, n = 37) or before (8.8%, n = 8) gastrostomy.

Incidence rate of gastrostomy insertion in intellectual disability

The age-specific incidence rates of first gastrostomy insertion from 1983 to 2014 for individuals with ID are presented in Fig. 1. Since 1983, rates increased among children younger than 3 years (APC 6.9%, 95% CI 4.4, 9.4). A similar trend was observed for children aged 3–5 years (APC 4.6%, 95% CI 1.1, 8.2) and 6–8 years (APC 3.9%, 95% CI − 2.7, 11.0). The trend was flat among preadolescent children (9–11 years APC − 0.1%, 95% CI − 6.9, 7.1; 12–14 years APC − 1.1%, 95% CI − 11.5, 10.5) and the incidence of new cases decreased in the oldest age group (15–17 years) (APC − 8.2%, 95% CI − 17.6, 2.4).

Subgroup analyses

Age-specific incidence rates of first gastrostomy insertion by socioeconomic status, remoteness area, and Aboriginality subgroups are presented in Figs. 2, 3, and 4, respectively. Adjusted for Aboriginality and remoteness area at birth, there was a small increase in rate of change comparing children of families from the most disadvantaged group (first IRSAD quintile) to those in more advantaged group (second to fifth IRSAD quintiles) in the 0–2 years (adjusted APC difference 1.8%, 95% CI − 3.8, 7.7) and 3–5 years (adjusted APC difference 2.6%, 95% CI − 4.7, 10.5) age groups (Table 2). Similar increase was observed in the same age groups comparing individuals of families from regional/remote areas to those from major cities (0–2 years: adjusted APC difference 3.4, 95% CI − 2.1, 9.2; 3–5 years: adjusted APC difference 3.0, 95% CI − 4.3, 10.9). More pronounced difference was observed among Aboriginal children compared to their non-Aboriginal peers when the procedure was performed at 0–2 years (adjusted APC difference 12.6%, 95% CI 4.4, 21.4) and 3–5 years (adjusted APC difference 13.6%, 95% CI 0.8, 28.0).

Causes for ID among children with gastrostomy

The most likely cause for ID in those who underwent gastrostomy insertion is shown in Table 3. The largest subgroup (n = 110, 33.8%) were those classified with a presumed

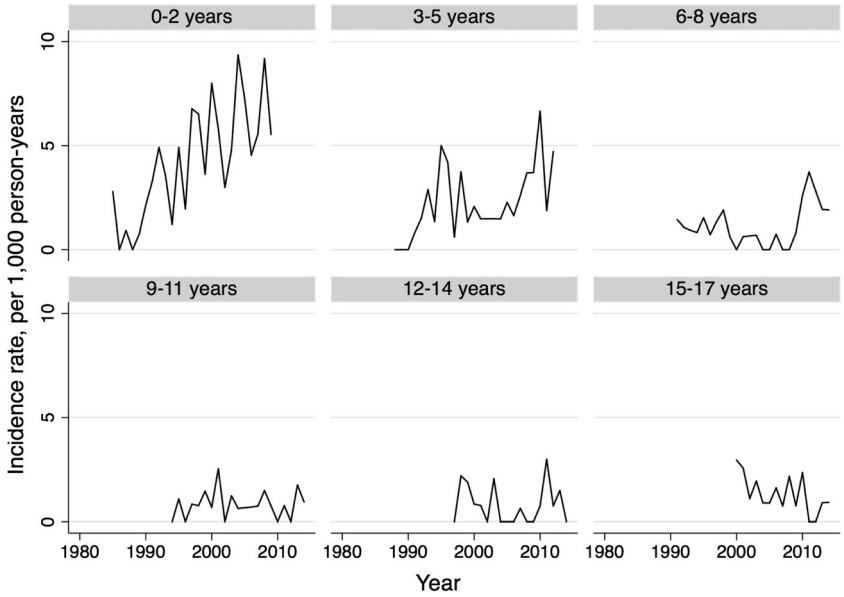

Fig. 1 Age-specific incidence rates of first gastrostomy insertion over calendar year (1983–2014) in children born alive in Western Australia between 1983 and 2009

genetic cause. Among the specific causes, neonatal encephalopathy ($n = 48$, 14.8%) accounted for a considerable proportion while congenital infections ($n = 21$, 6.5%) and post-natal causes (injury, asphyxia, meningitis, or encephalitis) were less common ($n = 23$, 7.1%). The youngest median age of gastrostomy insertion was observed for children with a chromosomal disorder (1.7 years, IQR 1.0–3.3 years), whereas children with injury or asphyxia underwent gastrostomy insertion later (8.1 years, IQR 3.7–14.2 years). Chromosomal abnormalities, multiple congenital abnormalities, and epileptic encephalopathy were more common in males who underwent gastrostomy, and prematurity, genetic syndromes, hydrocephalus, and congenital infection were more common in females ($p < 0.001$; Table 3).

Discussion

We used linked data to investigate gastrostomy use in children with ID in WA over a 32-year period where the prevalence was 277 cases per 10,000 live births (2.8%), compared with 6.7 cases per 10,000 live births in the general pediatric population [25]. The increasing prevalence of gastrostomy use may be influenced by its perceived value in reducing carer burden [7, 20], enabling home- rather than hospital-based care [28, 41], clinician preferences [22], and the importance of stabilizing nutritional support over the longer term. Increasing use may also reflect more proactive clinical management during the early years, in parallel with a remarkable period of social and political change that supports greater use of community-

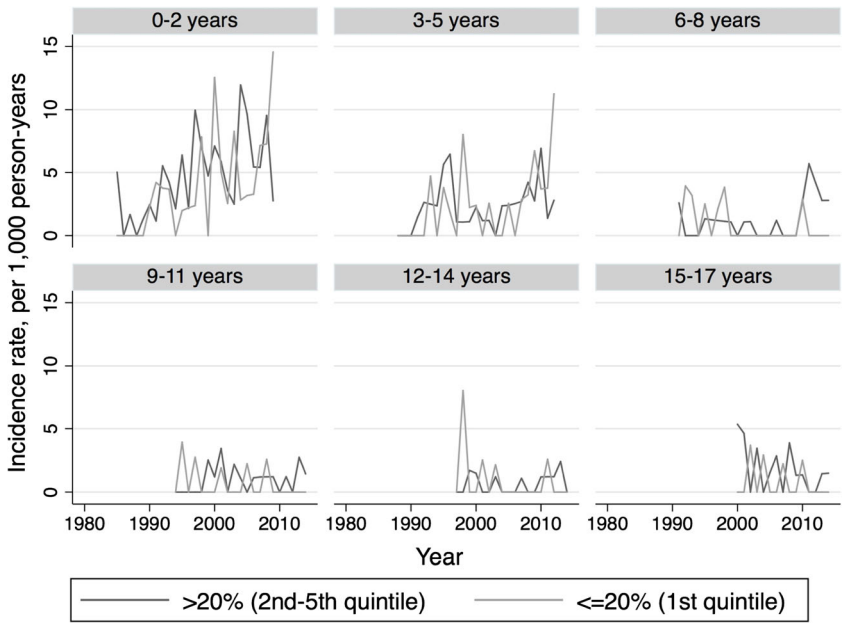

Fig. 2 Age-specific incidence rates of first gastrostomy insertion over calendar year (1983–2014) in children born alive in Western Australia between 1983 and 2009, presenting children whose families were in the most disadvantaged group (first IRSAD quintile) compared with families in more advantaged groups (second to fifth IRSAD quintiles)

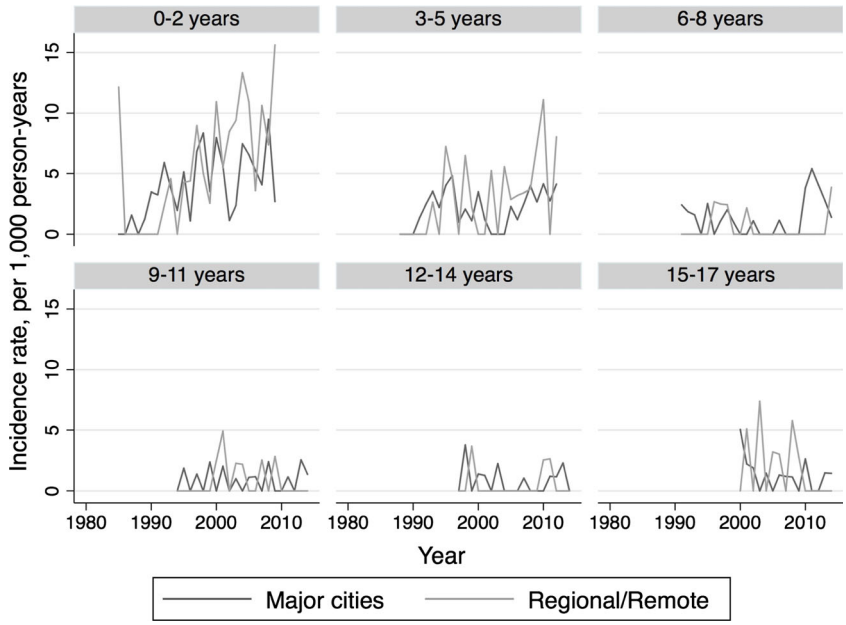

Fig. 3 Age-specific incidence rates of first gastrostomy insertion over calendar year (1983–2014) in children born alive in Western Australia between 1983 and 2009, presenting children whose families lived in regional/remote communities compared with those who lived in major cities

or home-based care for children with a disability [21, 34, 35] and enhanced accessibility and choice for individuals with disabilities [34, 45, 46]. Parents and carers have a greater role in seeking solutions with clinicians to ameliorate daily challenges in their children's lives, including consideration of gastrostomy insertion to stabilize feeding difficulties.

We examined both socioeconomic and geographic factors that could influence accessibility to gastrostomy, as well as the influence of Aboriginality. The prevalence of ID is greater among the proportion of the population with the highest level of disadvantage [10, 18, 30], and we observed a small increase in gastrostomy use among the lowest socioeconomic quintile in children younger than 6 years, after adjusting for the effects of remoteness area and Aboriginality. This finding is contrary to the usual patterns for other conditions, procedures, or health services where accessibility is often limited in groups associated with low socioeconomic status [12, 48].

Overall, we found a slightly higher incidence of gastrostomy insertion among young children whose mothers lived outside the major cities at the time of their birth. Western Australia has a vast land mass (2.3 million km^2) and for those in rural Australia, residential isolation can impact access to health care services [23]. However, geographic distance from the tertiary care center in Perth did not appear to reduce access to gastrostomy for children living in rural/remote locations.

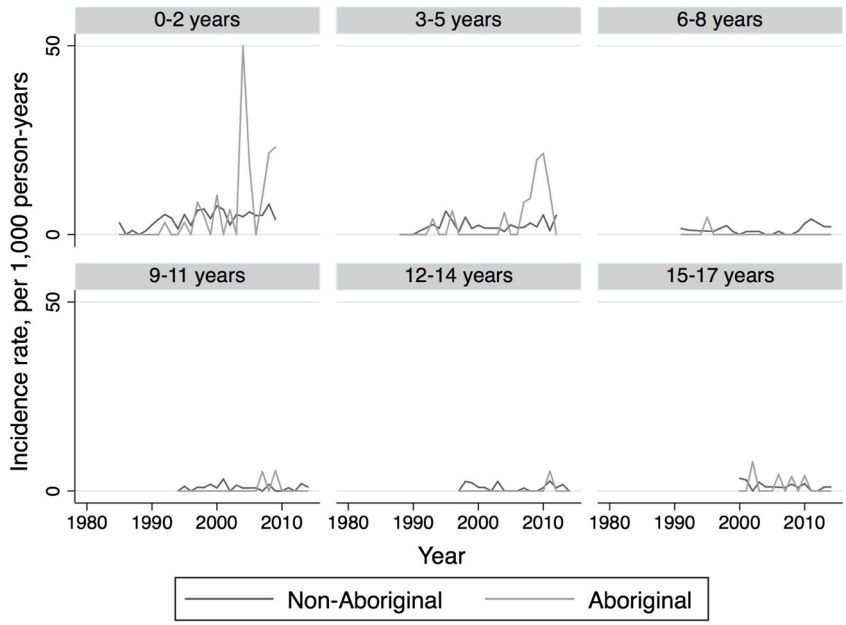

Fig. 4 Age-specific incidence rates of first gastrostomy insertion over calendar year (1983–2014) in children born alive in Western Australia between 1983 and 2009, presenting children who were Aboriginal compared with those who were non-Aboriginal

Table 2 Subgroup analysis of annual percentage change of age-specific incidence rates of first gastrostomy insertion over calendar year, by socioeconomic status, remoteness area, and Aboriginality

Age group	Socioeconomic status (first IRSAD quintile vs. second to fifth IRSAD quintile [baseline])		Remoteness area (regional/remote vs. major cities [baseline])		Aboriginality (Aboriginal vs. non-Aboriginal [baseline])	
	Unadjusted β (95% CI)	Adjusted[a] β (95% CI)	Unadjusted β (95% CI)	Adjusted[b] β (95% CI)	Unadjusted β (95% CI)	Adjusted[c] β (95% CI)
0–2 years	3.9 (− 1.8, 10.0)	1.8 (− 3.8, 7.7)	5.1 (0.4, 10.9)	3.4 (− 2.1, 9.2)	15.5 (7.4, 24.1)	12.6 (4.4, 21.4)
3–5 years	4.8 (− 3.3, 13.6)	2.6 (− 4.7, 10.5)	5.2 (− 2.4, 13.4)	3.0 (− 4.3, 10.9)	15.1 (1.9, 29.9)	13.6 (0.8, 28.0)

IRSAD The Index of Relative Socio-Economic Advantage and Disadvantage, β APC difference (%), CI confidence interval

[a] Adjusted for Aboriginality and remoteness, and their interaction terms with calendar time

[b] Adjusted for socio-economic status and Aboriginality, and their interaction terms with calendar time

[c] Adjusted for socio-economic status and remoteness, and their interaction terms with calendar time

Australian Aboriginal people have significantly poorer health including higher prevalence of illness and significantly shorter life expectancy [6]. At least one third of Aboriginal adults live in areas defined as the lowest 10% of disadvantage [6] and they experience disparities in access to health services, despite high prevalence of chronic disease [4, 38]. Additionally, cultural differences, language barriers, and rural or remote residences can preserve disadvantage. We also noticed that the most disadvantaged group (first IRSAD quintile) had greater proportion of Aboriginal children (26.5 vs. 8.8% in second to fifth IRSAD quintiles), and they were also more likely to live in rural or remote areas. Despite existing disparities, we found a higher rate of first gastrostomy insertion among Aboriginal children compared to their non-Aboriginal peers, driven by increasing numbers of young Aboriginal children undergoing the procedure between 2007 and 2011. While disadvantages often co-occur in different domains, the presence of a centralized public health system in Australia, combining centralized specialist resources, a coordinated rural pediatric service enabling case identification and follow-up, and the efforts and influences of clinician champions working in rural and remote areas and targeting indigenous communities [13] may have impacted this trend allowing for ready access by groups who typically experience poorer access to services. Many Aboriginal children are cared for by different members of the extended family at different times according to cultural practices ("kinship care") and others will have foster carers [32, 51], but our findings suggest that that reach to gastrostomy services was retained. These findings illustrate the importance of care coordination and health leadership to achieve better care delivery to disadvantaged groups of children, and provide the much needed evidence to inform policy makers locally as well as globally.

Our access to both hospital and disability population data sets is unique and enabled description of etiological groupings that illustrate clinical diversity in those children who underwent gastrostomy. The "event" likely to have caused the ID was prenatal or perinatal in origin in most children, with the two largest groups being syndromic or following neonatal encephalopathy. Males were more likely to receive a gastrostomy where their ID was associated with chromosomal abnormalities, consistent with the predominance of males with an X-linked ID [24] or in association with preterm birth where males are more commonly affected [19]. The 49 syndromic causes of ID are likely to have been heavily weighted by Rett syndrome, a severe disability affecting approximately 1/10,000 female births where gastrostomy is performed in approximately one quarter of individuals [20]. We were surprised to note that gastrostomy was necessary for some children with Fetal Alcohol Spectrum Disorder, a cause of disability which is usually milder and one that is fully preventable.

Table 3 Etiologies of intellectual disability in children who underwent gastrostomy insertion ($n = 325$)

			N (%)	Age first gastrostomy (years)		Sex, *n* (row %)	
				Median	IQR	Male	Female
Prenatal ($n = 184$, 56.6%)	Genetic ($n = 110$, 33.8%)	Genetic syndromes/mitochondrial	49 (15.1)	2.5	1.1–8.2	17 (34.7)	32 (65.3)
		Metabolic disorders	25 (7.7)	3.1	1.6–4.2	15 (60.0)	10 (40.0)
		Chromosomal	19 (5.8)	1.7	1.0–3.3	14 (73.7)	5 (26.3)
		Neuronal migration disorder	17 (5.2)	3.5	1.3–6.0	9 (52.9)	8 (47.1)
	Birth defects ($n = 43$, 13.2%)	Structured cerebral defect	15 (4.6)	3.2	1.6–6.0	6 (40.0)	9 (60.0)
		Microcephaly	11 (3.4)	9.0	2.5–12.6	6 (54.6)	5 (45.4)
		Hydrocephalus	9 (2.8)	9.0	2.6–9.7	[a]	[a]
		Multiple congenital abnormalities	8 (2.5)	1.8	1.0–4.4	[a]	[a]
	Teratogenic ($n = 31$, 9.5%)	Congenital infection	21 (6.5)	4.5	2.0–8.7	7 (33.3)	14 (66.7)
		Fetal Alcohol Spectrum Disorder	10 (3.1)	1.8	0.5–2.7	[a]	[a]
Perinatal ($n = 91$, 28.0%)	Intrauterine/intrapartum ($n = 67$, 20.6%)	Neonatal encephalopathy	48 (14.8)	4.4	1.8–8.6	32 (66.7)	16 (33.3)
		Prematurity	19 (5.8)	2.0	0.6–8.7	[a]	[a]
	Neonatal ($n = 24$, 7.4%)	Epileptic encephalopathy	18 (5.5)	2.9	2.5–6.4	12 (66.7)	6 (33.3)
		Neonatal/other unspecified	6 (1.8)	3.2	2.8–5.6	[a]	[a]
Post-neonatal ($n = 23$, 7.1%)		Injury or asphyxia	15 (4.6)	8.1	3.7–14.2	6 (40.0)	9 (60.0)
		Meningitis/encephalitis	8 (2.5)	4.8	2.3–12.4	[a]	[a]
Miscellaneous ($n = 27$, 8.3%)			27 (8.3)	5.8	3.6–8.5	16 (59.3)	11 (40.7)

[a] Data not presented for cell counts if either gender contained less than five cases

Strengths of this study were the longitudinal nature of the population-based data including capacity to identify children with ID. However, some children with congenital abnormalities may have had ID but could have died prior to registration and therefore would not have been identified for this study. Moreover, availability of and access to a genetic diagnosis has improved considerably over recent years and information may not have been available from HMDC or IDEA records. Thus, our etiological classification of ID was the best it could be given the information available to us. We also acknowledge that our examination of accessibility to gastrostomy is but one aspect of the delivery of equitable health care. Gastrostomy was accessible across the WA population but our data linkage methodology cannot provide insight on whether the services were culturally and socially acceptable, the extent to which protocols were adaptable to individual child and family needs, and service quality including safety profiling [15].

Conclusion

We have investigated the use of a procedure designed to improve the delivery of calories and nourishment in children with feeding difficulties and ameliorate the day-to-day care burden for families. Gastrostomy is used frequently in children with ID and no apparent accessibility barriers were found in our investigation. More research in relation to long-term outcomes for both child health and carer burden could explain more clearly why more parents are choosing to accept gastrostomy as part of their child's clinical support.

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Authors' Contributions Dr. Wong conceptualized and designed the study, was responsible for obtaining funding, performed the linked data analysis, participated in the initial writing of the manuscript, and reviewed and revised the manuscript.

A/Prof. Leonard conceptualized and designed the study, was responsible for obtaining funding, coded the indications for gastrostomy according to hospitalization data, and reviewed and revised the manuscript.

Mr. Pearson provided interpretation for the analysis of Aboriginality data and critically reviewed and revised the manuscript with reference to Aboriginality.

Dr. Glasson drafted the initial manuscript and reviewed and revised the manuscript from conceptualization to completion.

Prof. Forbes conceptualized and designed the study, was responsible for obtaining funding, reviewed and revised the manuscript, and critically reviewed the manuscript for important intellectual content regarding aspects of gastroenterology.

Dr. Ravikumara conceptualized and designed the study, was responsible for obtaining funding, reviewed and revised the manuscript, and critically reviewed the manuscript for important intellectual content regarding aspects of gastroenterology.

A/Prof. Jacoby conceptualized and designed the study, was responsible for obtaining funding, provided specialist statistical support, and reviewed and revised the manuscript.

Ms. Bourke collected data for the study and critically reviewed the manuscript for important intellectual content regarding aspects of intellectual disability.

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All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval was obtained from the Department of Health WA (#2016/32) and the Western Australian Aboriginal Health Ethics Committee (747).

Informed consent Informed consent was not obtained from individual participants included in the study due to the nature of the anonymized data linkage data.

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