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## **Epidemiology of gastrostomy insertion for children and adolescents with intellectual disability.**

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## **Contributors' Statement Page**

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 conceptualised 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.

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

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A/Prof Jenny Downs conceptualized and designed the study, was responsible for obtaining funding coordinated and supervised linked data collection, reviewed and revised the manuscript and was the principal investigator of the research.

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

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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 1983-2009 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 dataset. 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.

**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).

### **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 three percent of children with ID had gastrostomy insertion performed, with the highest incidence in children under three years of age.
- The two largest identified groups of ID were genetically caused syndromes and neonatal encephalopathy.
- Gastrostomy use across different social groups was equitable in the Australian setting.

# 1 INTRODUCTION

2           Around 1.5-2.0% of children born each year develop an intellectual disability (ID)[1].  
3 Compared to unaffected children, these children have more physical disability and medical  
4 comorbidities (e.g. epilepsy[2]), are up to ten times more likely to be hospitalised[3] and have a  
5 nine-fold increase in mortality[4]. Children with complex medical needs often have feeding  
6 difficulties. Consequences include poor nutrition and growth, aspiration of food and fluids into the  
7 lungs, recurrent chest infections and progressive lung disease.[5] Families and carers often find  
8 feeding routines time-consuming[6,7], compounding other high-level care demands. Gastrostomy is  
9 one management option to improve daily feeding regimens, long-term nutrition and medication  
10 administration[8]. It is used across a range of indications[9-13] but children with neurological  
11 impairments have more frequent use[6,11,12,14] including a substantial proportion who have  
12 ID[15].

13           The United Nations Convention on the Rights of Persons with Disabilities clarifies that  
14 quality health care should be provided without discrimination on the basis of disability[16].  
15 Principles guiding equitable health care delivery include consideration of availability, accessibility,  
16 acceptability, adaptability and quality, known as the 4AQ framework[17]. Children with ID are  
17 more likely to live in families of low socioeconomic status and rural residence, and have higher  
18 representation among Indigenous groups[18-23]. These factors could make them especially  
19 vulnerable to health inequalities. Given the high frequency of feeding difficulties in ID, it is  
20 important to understand the barriers and enablers that affect accessibility to this procedure.

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

27

## 28 **MATERIALS AND METHODS**

29 We conducted a retrospective birth cohort study using linked health administrative, disability and  
30 population databases available in the state of WA (2014 population: 2.5 million[24]). The study  
31 observation period was from 1 January 1983 to 31 December 2014.

32

### 33 *Study population and data sources*

34 The WA population is centralized, approximately 80% living in the greater area of its capital city  
35 Perth[25] and all pediatric gastrostomy insertions are performed at the only tertiary children's  
36 hospital. We included linked population-based health, disability and administrative data sets[26-28]  
37 in our analyses.

38 The state Midwives Notification System (MNS)[28] was used to identify all children born  
39 alive in WA between 1 January 1983 and 31 December 2009. To account for the lag between birth  
40 and identification of ID and to ensure that most of the eligible children were diagnosed, children  
41 were required to be at least 5 years of age at the time of data extraction. Thus, cases were defined as  
42 children diagnosed between 1 January 1983 and 31 December 2014 based on identification of ID  
43 from either one of the following data sources: 1) the Intellectual Disability Exploring Answers  
44 (IDEA) database[29] which collects information on children with ID from statewide disability  
45 service registration and/or school education records; or 2) the WA Register of Developmental  
46 Anomalies (WARDA)[28] which incorporates data on cases with both birth defects and cerebral  
47 palsy. Most cases were identified from IDEA (n=11,525, 98.2%) and WARDA contributed an  
48 additional 204 (1.8%) cases. For all identified cases of ID, demographic, disability and health data  
49 were extracted from the IDEA database, WARDA, MNS, the Hospital Morbidity Data Collection  
50 (HMDC), and death registrations[28,29].

51 Socioeconomic status was measured using the Index of Relative Socio-Economic Advantage  
52 and Disadvantage (IRSAD) centile ( $\leq 20\%$ , 21-40%, 41-60%, 61-80%,  $>80\%$ ) and remoteness of

53 residence was based on the Accessibility and Remoteness Index for Australia score (major cities,  
54 regional or remote). Both indicators were based on birth home address at the Census Collection  
55 District level (1996, 2001, 2006) or the Statistical Area 1 level calculated by the Australian Bureau  
56 of Statistics[30]. Aboriginality was defined as being a person of Aboriginal descent, and was coded  
57 as either Aboriginal or non-Aboriginal using a validated algorithm[31].

58 The primary outcome measure was defined as first hospitalization in children younger than 18  
59 years for gastrostomy insertion, including open gastrostomy and percutaneous endoscopic  
60 gastrostomy (PEG) placements, within the study period. For hospitalizations up to December 1987,  
61 the International Classification of Procedures in Medicine (ICPM) codes were used to identify  
62 hospitalizations during which gastrostomy insertion was performed [Open: 5-431, 5-432; PEG:  
63 N/A]. Thereafter, the International Classification of Disease, ninth revision (ICD-9-CM) (Jan 1988  
64 – Jun 1999) and the Australian Classification of Health Intervention (ACHI) (Jul 1999 – Dec 2014)  
65 codes were used [ICD-9-CM - Open 43.19; PEG 43.11, and ACHI - Open 30375-07, 90302-00;  
66 PEG 30481-00, 30482-00]. Fundoplication, a procedure that may be performed in conjunction with  
67 gastrostomy insertion, was also identified (ICPM - 5-445; ICD-9-CM - 44.66; ACHI - 30527-0(0-5)  
68 30529-00, 30529-01, 30530-00).

69

#### 70 *Covariates*

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

74

#### 75 *Categorization of etiologies of ID in children with gastrostomy*

76 ICD-9-CM and ICD-10-AM codes for all recorded hospitalizations were reviewed for individuals  
77 who had a gastrostomy insertion to identify the most likely reason (causal or associated factors) and  
78 then grouped accordingly[32].

79

80 *Statistical Analysis*

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

85 We examined how the occurrence of gastrostomy insertion changed by calendar year by  
86 investigating the annual incidence rate over time. The rate was calculated based on the number of  
87 first gastrostomy insertions performed in individuals aged younger than 18 years in each calendar  
88 year divided by the person-time at risk of receiving the procedure from the start of the relevant year  
89 until date of first gastrostomy insertion, date of death or end of the year, whichever occurred first.  
90 The incidence rate was measured in cases per 10,000 person-years. Overall age-specific rates over  
91 calendar year, as well as the rates by socioeconomic status, remoteness area and Aboriginality, were  
92 presented. Our analysis focused on periods with full data coverage for each age group given that  
93 birth cohort study methodology had a staggered start. For example, for the age group 3-5 years, the  
94 trend commenced in 1988 because data were available for children aged 3, 4 and 5 years in that  
95 year. We estimated the linear annual percentage change (APC) of incidence rate for each age group  
96 from Poisson regression models with the number of incident cases within that age group during  
97 each year as the dependent variable and the total corresponding time at risk as the offset. Robust  
98 standard errors were used to allow for overdispersion. In the subgroup analyses, difference in age-  
99 specific APCs between the two levels of each variable (Aboriginality: Aboriginal v. non-  
100 Aboriginal; socioeconomic status: most disadvantaged (1<sup>st</sup> IRSAD quintile) v. more advantaged  
101 (2<sup>nd</sup>-5<sup>th</sup> IRSAD quintile); remoteness area: regional/remote v. major cities) were estimated using an  
102 interaction term of calendar year and the subgroup variable. Adjusted effects were obtained by re-  
103 running the model using all three variables and their interaction terms.

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

107

### 108 *Ethical approvals*

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

111

## 112 **RESULTS**

113 We identified 11,729 individuals with ID. Of these, 325 children (2.8%) underwent gastrostomy  
114 insertion between 1983 and 2014. Characteristics of the study population by gastrostomy insertion  
115 status are shown in Table 1. The prevalence increased from 1.9 per 100 live births (95% confidence  
116 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  
117 the 2000-2009 birth cohort. More than half (53.5%) were male, approximately four-fifths (86.1%)  
118 non-Aboriginal, and nearly two-thirds (61.5%) lived in major cities. Gastrostomy was usually  
119 performed early in life (0-5 years: 69.8%) and the median age at admission was 3 years 4 months  
120 (interquartile range 1.6-7.9 years). New gastrostomy insertion was predominantly performed using  
121 the percutaneous endoscopic technique (84.6%), with 28.0% (n=91) also having a fundoplication.  
122 Majority of the fundoplication surgery was carried out at time of first gastrostomy insertion (50.5%,  
123 n=46), and the rest were performed either after (40.7%, n=37) or before (8.8%, n=8) gastrostomy.

124

### 125 *Incidence rate of gastrostomy insertion in intellectual disability*

126 The age-specific incidence rates of first gastrostomy insertion from 1983 to 2014 for individuals  
127 with ID are presented in Figure 1. Since 1983, rates increased among children younger than three  
128 years (APC 6.9%, 95% CI 4.4,9.4). A similar trend was observed for children aged 3-5 years (APC  
129 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

130 preadolescent children (9-11 years APC -0.1%, 95% CI -6.9,7.1; 12-14 years APC -1.1%, 95% CI -  
131 11.5,10.5) and the incidence of new cases decreased in the oldest age group (15-17 years) (APC -  
132 8.2%, 95% CI -17.6,2.4).

133

#### 134 *Subgroup analyses*

135 Age-specific incidence rates of first gastrostomy insertion by socioeconomic status, remoteness area  
136 and Aboriginality subgroups are presented in Figures 2, 3 and 4, respectively. Adjusted for  
137 Aboriginality and remoteness area at birth, there was a small increase in rate of change comparing  
138 children of families from the most disadvantaged group (1<sup>st</sup> IRSAD quintile) to those in more  
139 advantaged group (2<sup>nd</sup>-5<sup>th</sup> IRSAD quintiles) in the 0-2 years (adjusted APC difference 1.8%, 95%  
140 CI -3.8,7.7) and 3-5 years (adjusted APC difference 2.6%, 95% CI -4.7,10.5) age groups (Table 2).  
141 Similar increase was observed in the same age groups comparing individuals of families from  
142 regional/remote areas to those from major cities (0-2 years: adjusted APC difference 3.4, 95% CI -  
143 2.1,9.2; 3-5 years: adjusted APC difference 3.0, 95% CI -4.3,10.9). More pronounced difference  
144 was observed among Aboriginal children compared to their non-Aboriginal peers when the  
145 procedure was performed at 0-2 years (adjusted APC difference 12.6%, 95% CI 4.4,21.4) and 3-5  
146 years (adjusted APC difference 13.6%, 95% CI 0.8,28.0).

147

#### 148 *Causes for ID among children with gastrostomy*

149 The majority (n=10,644, 90.7%) had mild or moderate ID (Table 1). In those who underwent  
150 gastrostomy insertion the majority had severe ID (60.0%, 22.1% of all children with severe ID) and  
151 only just over a third had mild/moderate ID (36.3%, 1.1% of all children with mild/moderate ID)  
152 (Table 1). The most likely cause for ID in those who underwent gastrostomy insertion is shown in  
153 Table 3. The largest subgroup (n=110, 33.8%) were those classified with a presumed genetic cause.  
154 Among the specific causes, neonatal encephalopathy (n=48, 14.8%) accounted for a considerable  
155 proportion whilst congenital infections (n=21, 6.5%) and post-natal causes (injury, asphyxia,

156 meningitis or encephalitis) were less common (n=23, 7.1%). The youngest median age of  
157 gastrostomy insertion was observed for children with a chromosomal disorder (1.7 years, IQR 1.0-  
158 3.3 years) whereas children with injury or asphyxia underwent gastrostomy insertion later (8.1  
159 years, IQR 3.7-14.2 years). Chromosomal abnormalities, multiple congenital abnormalities and  
160 epileptic encephalopathy were more common in males who underwent gastrostomy, and  
161 prematurity, genetic syndromes, hydrocephalus and congenital infection were more common in  
162 females (p<0.001, Table 3).

163

## 164 **DISCUSSION**

165 We used linked data to investigate gastrostomy use in children with ID in WA over a 32-year period  
166 where the prevalence was 277 cases per 10,000 live births (2.8%), compared with 6.7 cases per  
167 10,000 live births in the general pediatric population[15]. The increasing prevalence of gastrostomy  
168 use may be influenced by its perceived value in reducing carer burden[6,33], enabling home- rather  
169 than hospital-based care[34,35], clinician preferences[36] and the importance of stabilizing  
170 nutritional support over the longer term. Increasing use may also reflect more proactive clinical  
171 management during the early years, in parallel with a remarkable period of social and political  
172 change that supports greater use of community- or home-based care for children with a  
173 disability[37-39] and enhanced accessibility and choice for individuals with disabilities[16,38,40].  
174 Parents and carers have a greater role in seeking solutions with clinicians to ameliorate daily  
175 challenges in their children's lives, including consideration of gastrostomy insertion to stabilize  
176 feeding difficulties.

177 We examined both socioeconomic and geographic factors that could influence accessibility to  
178 gastrostomy, as well as the influence of Aboriginality. The prevalence of ID is greater among the  
179 proportion of the population with the highest level of disadvantage [19,20,41] and we observed a  
180 small increase in gastrostomy use among the lowest socioeconomic quintile in children younger  
181 than six years, after adjusting for the effects of remoteness area and Aboriginality. This finding is

182 contrary to the usual patterns for other conditions, procedures or health services where accessibility  
183 is often limited in groups associated with low socioeconomic status[42,43].

184 Overall, we found a slightly higher incidence of gastrostomy insertion among young children  
185 whose mothers lived outside the major cities at the time of their birth. Western Australia has a vast  
186 land mass (2.3 million square kilometers) and for those in rural Australia, residential isolation can  
187 impact access to health care services[44]. However, geographic distance from the tertiary care  
188 center in Perth did not appear to reduce access to gastrostomy for children living in rural/remote  
189 locations.

190 Australian Aboriginal people have significantly poorer health including higher prevalence of  
191 illness and significantly shorter life expectancy[45]. At least one third of Aboriginal adults live in  
192 areas defined as the lowest 10% of disadvantage[45] and they experience disparities in access to  
193 health services, despite high prevalence of chronic disease[46,47]. Additionally, cultural  
194 differences, language barriers and rural or remote residences can preserve disadvantage. We also  
195 noticed that the most disadvantaged group (1<sup>st</sup> IRSAD quintile) had greater proportion of  
196 Aboriginal children (26.5% vs 8.8% in 2<sup>nd</sup>-5<sup>th</sup> IRSAD quintiles) and they were also more likely to  
197 live in rural or remote areas. Despite existing disparities, we found a higher rate of first gastrostomy  
198 insertion among Aboriginal children compared to their non-Aboriginal peers, driven by increasing  
199 numbers of young Aboriginal children undergoing the procedure between 2007 and 2011. While  
200 disadvantages often co-occur in different domains, the presence of a centralized public health  
201 system in Australia, combining centralized specialist resources, a coordinated rural pediatric service  
202 enabling case identification and follow up, and the efforts and influences of clinician champions  
203 working in rural and remote areas and targeting Indigenous communities[48] may have impacted  
204 this trend allowing for ready access by groups who typically experience poorer access to services.  
205 Many Aboriginal children are cared for by different members of the extended family at different  
206 times according to cultural practices (“kinship care”) and others will have foster carers[49,50], but  
207 our findings suggest that that reach to gastrostomy services was retained.

208 Our findings provide additional insights into the diagnoses associated with gastrostomy. The  
209 “event” likely to have caused the ID was prenatal or perinatal in origin in most children, with the  
210 two largest groups being syndromic or following neonatal encephalopathy. Males were more likely  
211 to receive a gastrostomy where their ID was associated with chromosomal abnormalities, consistent  
212 with the predominance of males with an X-linked ID[51] or in association with preterm birth where  
213 males are more commonly affected[52]. The 49 syndromic causes of ID are likely to have been  
214 heavily weighted by Rett syndrome, a severe disability affecting approximately 1/10,000 female  
215 births where gastrostomy is performed in approximately one quarter of individuals[6]. We were  
216 surprised to note that gastrostomy was necessary for some children with Fetal Alcohol Spectrum  
217 Disorder, a cause of disability which is usually milder and one that is fully preventable.

218 Strengths of this study were the longitudinal nature of the population-based data including  
219 capacity to identify children with ID. However, some children with congenital abnormalities may  
220 have had ID but could have died prior to registration and therefore would not have been identified  
221 for this study. Moreover, availability of and access to a genetic diagnosis has improved  
222 considerably over recent years and information may not have been available from HMDC or IDEA  
223 records. Thus our aetiological classification of ID was the best it could be given the information  
224 available to us. We also acknowledge that our examination of accessibility to gastrostomy is but one  
225 aspect of the delivery of equitable health care. Gastrostomy was accessible across the WA  
226 population but our data linkage methodology cannot provide insight on whether the services were  
227 culturally and socially acceptable, the extent to which protocols were adaptable to individual child  
228 and family needs, and service quality including safety profiling[17].

229

### 230 *Conclusion*

231 We have investigated the use of a procedure designed to improve the delivery of calories and  
232 nourishment in children with feeding difficulties and ameliorate the day to day care burden for  
233 families. Gastrostomy is used frequently in children with ID and no apparent accessibility barriers

234 were found in our investigation. More research in relation to long-term outcomes for both child  
235 health and carer burden could explain more clearly why more parents are choosing to accept  
236 gastrostomy as part of their child's clinical support.

237

238

### 239 **Compliance with Ethical Standards**

240

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243

244 **Conflict of Interest:** The authors declare that they have no conflict of interest.

245

246 **Ethical approval:** All procedures performed in studies involving human participants were in  
247 accordance with the ethical standards of the institutional and/or national research committee and  
248 with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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

251

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

254

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

	<b>No gastrostomy</b>	<b>Gastrostomy</b>
N	11,404	325
Year of birth	n (row %) (col %)	n (row %) (col %)
1983-1984	551 (97.5) (4.8)	14 (2.5) (4.3)
1985-1989	2,075 (98.2) (18.2)	38 (1.8) (11.7)
1990-1994	2,716 (97.2) (23.8)	78 (2.8) (24.0)
1995-1999	2,297 (97.3) (20.1)	64 (2.7) (19.7)
2000-2004	1,991 (96.6) (17.5)	70 (3.4) (21.5)
2005-2009	1,774 (96.7) (15.6)	61 (3.3) (18.8)
Sex		
Male	7,488 (97.7) (65.7)	174 (2.3) (53.5)
Female	3,916 (96.3) (34.3)	151 (3.7) (46.5)
Severity level of intellectual disability		
Mild/Moderate	10,526 (98.9) (92.3)	118 (1.1) (36.3)
Severe	686 (77.9) (6.0)	195 (22.1) (60.0)
Missing	192 (94.1) (1.7)	12 (5.9) (3.7)
Indigenous status		
Non-indigenous	9,787 (97.2) (85.8)	280 (2.8) (86.1)
Indigenous	1,617 (97.3) (14.2)	45 (2.7) (13.9)
Remoteness area		
Major cities	7,289 (97.3) (63.2)	200 (2.7) (61.5)
Regional or remote	2,994 (96.8) (26.3)	98 (3.2) (30.2)
Missing	1,201 (97.8) (10.5)	27 (2.2) (8.3)
IRSAD quintile		
1st (<=20%)	3,331 (97.6) (29.2)	83 (2.4) (25.5)
2nd (21-40%)	2,524 (97.1) (22.1)	75 (2.9) (23.1)
3rd (41-60%)	1,893 (97.2) (16.6)	55 (2.8) (16.9)
4th (61-80%)	1,425 (96.0) (12.5)	59 (4.0) (18.2)
5th (>80%)	1,035 (97.5) (9.1)	26 (2.5) (8.0)
Missing	1,196 (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)

**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.

	Socioeconomic status (1 <sup>st</sup> IRSAD quintile vs 2 <sup>nd</sup> - 5 <sup>th</sup> IRSAD quintile [baseline])		Remoteness area (regional/remote vs. major cities [baseline])		Aboriginality (Aboriginal vs. non- Aboriginal [baseline])	
	Unadjusted	Adjusted <sup>a</sup>	Unadjusted	Adjusted <sup>b</sup>	Unadjusted	Adjusted <sup>c</sup>
Age group	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (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;  $\beta$ , APC difference (%); CI, confidence interval

<sup>a</sup> adjusted for Aboriginality and remoteness, and their interaction terms with calendar time

<sup>b</sup> adjusted for socio-economic status and Aboriginality, and their interaction terms with calendar time

<sup>c</sup> adjusted for socio-economic status and remoteness, and their interaction terms with calendar time

**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	*	*
		Multiple congenital abnormalities	8 (2.5)	1.8	1.0 – 4.4	*	*
	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	*	*
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	*	*
	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	*	*
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	*	*	
Miscellaneous (n=27, 8.3%)			27 (8.3)	5.8	3.6 – 8.5	16 (59.3)	11 (40.7)

\* Data not presented for cell counts if either gender contained less than five cases.

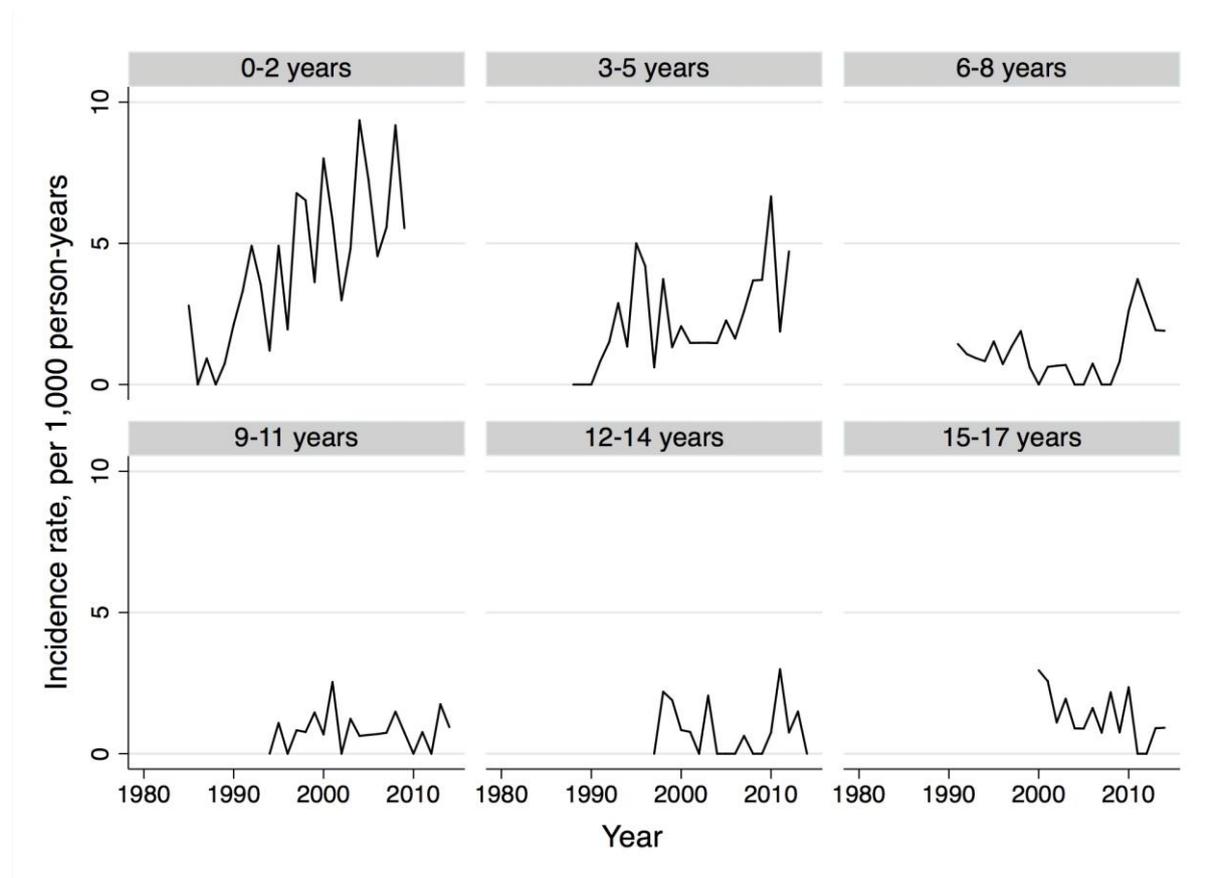
**Figure 1.** Age specific incidence rates of first gastrostomy insertion over calendar year (1983-2014) in children born alive in Western Australia between 1983 and 2009.

**Figure 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 (1<sup>st</sup> IRSAD quintile) compared with families in more advantaged groups (2<sup>nd</sup>-5<sup>th</sup> IRSAD quintiles).

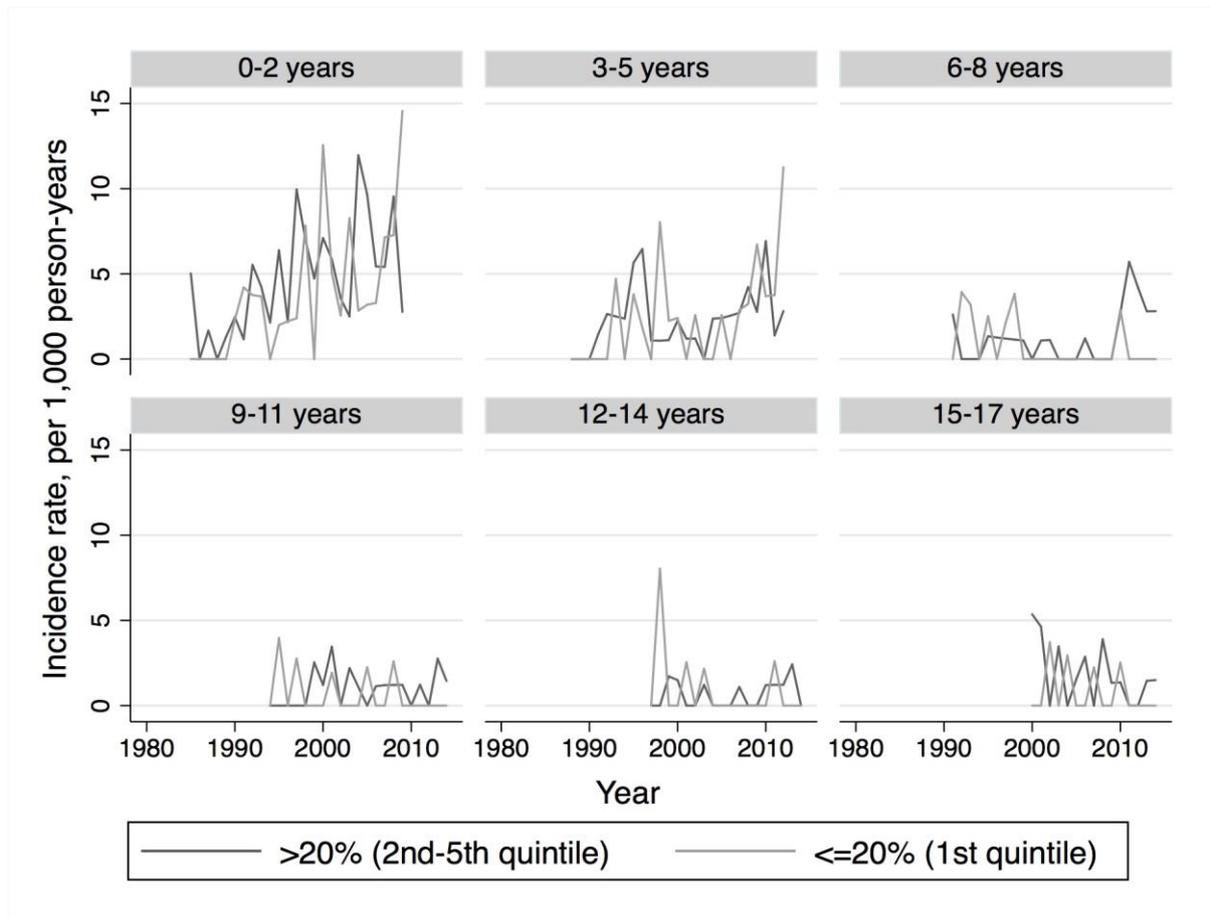
**Figure 3.** Age specific incidence rates of first gastrostomy insertion over calendar year (1983-2014) in children born alive in Western Australia between 1983 and 2009, presenting children whose families lived in regional/remote communities compared with those who lived in major cities.

**Figure 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.

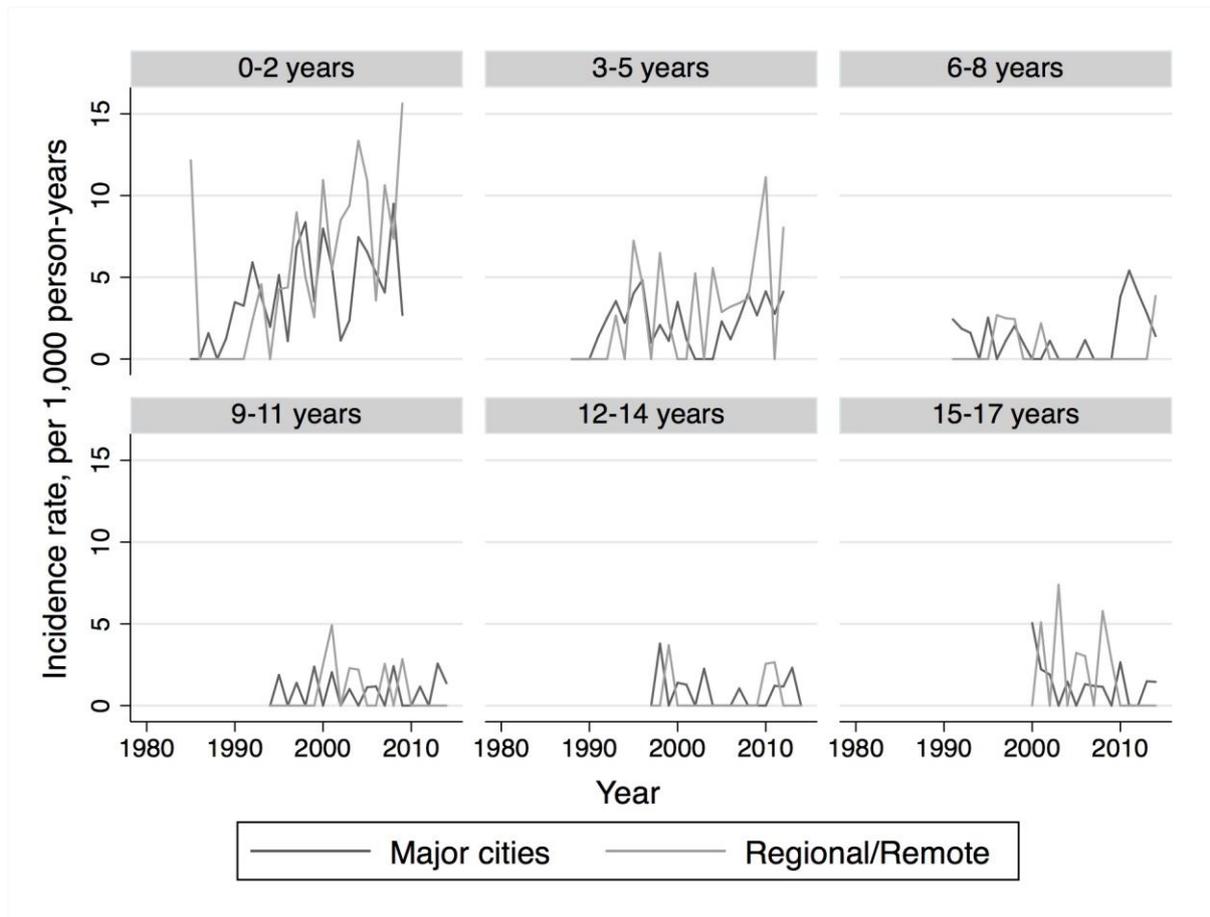
**Fig 1** Age specific incidence rates of first gastrostomy insertion over calendar year (1983-2014) in children born alive in Western Australia between 1983 and 2009



**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 (1<sup>st</sup> IRSAD quintile) compared with families in more advantaged groups (2<sup>nd</sup>-5<sup>th</sup> 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



**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

