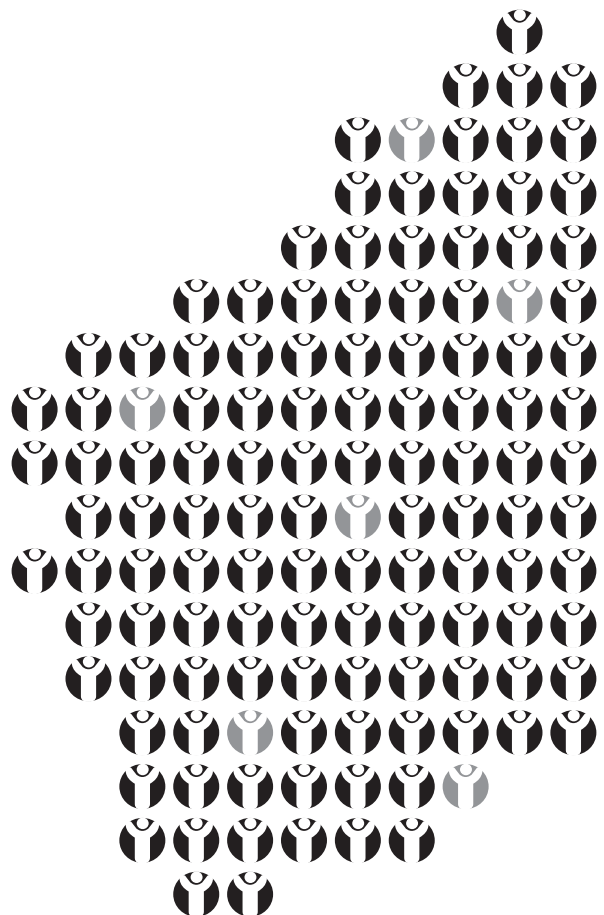


Western Australian Register of Developmental Anomalies 1980-2012

FEBRUARY 2014



**REPORT OF THE
WESTERN AUSTRALIAN REGISTER
OF DEVELOPMENTAL ANOMALIES**

1980-2012

February 2014

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REPORT OF THE
WESTERN AUSTRALIAN REGISTER OF DEVELOPMENTAL ANOMALIES

1980 - 2012

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February 2014

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WESTERN AUSTRALIAN REGISTER OF DEVELOPMENTAL ANOMALIES

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We gratefully acknowledge the support and collaboration of our colleagues at Princess Margaret Hospital, King Edward Memorial Hospital and the Telethon Institute for Child Health Research.

Our thanks to the specialist advisors to the Register and to the members of our Advisory Committees and Consumer Reference Group, for their guidance and support.

FOREWORD

I am delighted to contribute the foreword to the Annual Western Australian Register of Developmental Anomalies (WARDA) Report 2013.

The strong advocacy and commitment of all who have been involved with WARDA, developing, maintaining and then combining the Birth Defects and Cerebral Palsy Registers has to be applauded.

The success in lobbying and gaining legislative support to maximize completeness has been remarkable. The effectiveness of the Register for research, policy and clinical relevance indicates a resource vital for the future.

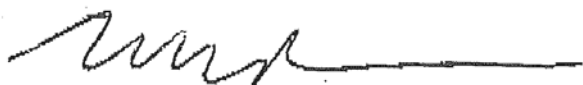
The increasing complexity of genetic and environmental interactions is challenging to all and further complicated by fiscal constraints in research, clinical management and prevention.

Data needed in lobbying for political advocacy and the development of resources reside within this Register. Nationalisation of the data base can only enhance this process.

Clinician awareness of the legislative requirements for mandatory reporting is not universal and as a clinician I understand the frustration involved in completing surveys that appear almost daily by email. This Register's notification system however is an easier form of data collection and a valuable tool, ultimately assisting in clinical management and developing efficient, affordable support services.

As the Register will capture information on a diverse spectrum of anomalies and disabilities the simplicity of notification and time efficiency in submitting data will encourage compliance. The merging or linking of data systems to assist this purpose will reflect society's need to contain escalating health costs.

Fiona Stanley, Carol Bower and the Register's enthusiastic supporters are to be congratulated on their leadership and foresight in developing the Register, now a powerful contribution to our health care system.



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SUMMARY

- The Western Australian Register of Developmental Anomalies (WARDA) (*Health (Western Australian Register of Developmental Anomalies) Regulations 2010*) monitors information based on the statutory notification of developmental anomalies in Western Australia.
- For the purposes of the Register, a developmental anomaly is defined as: cerebral palsy; or a structural or functional abnormality that is present at conception or occurs before the end of pregnancy and is diagnosed by six years of age.
- This Report provides information separately on birth defects (notified to the Register for births and terminations occurring between 1 January 1980 and 31 December 2012) and cerebral palsy in children born 1980-2007.
- For **birth defects**, the numerator data comprise anomalies occurring in livebirths and stillbirths in WA and in pregnancies terminated because of fetal abnormalities. Birth defects diagnosed prenatally and in children up to six years of age are included. The denominator data are all births in WA.
 - A total of 1520 cases of birth defects were notified relating to births and terminations of pregnancy in 2012, a proportion of 4.5%. This is expected to increase as birth defects continue to be diagnosed up to the age of six years in children born in 2012 (Table 1).
 - Birth defects were generally more common in male infants and multiple pregnancies and were reported slightly less frequently in Aboriginal compared with non-Aboriginal infants (Table 2).
 - Birth defects were also generally less frequently reported for rural compared with metropolitan regions (Table 3). Over the period 2001-2012, neural tube defects were more common in the Midwest (2.0 per 1000), Goldfields (1.7 per 1000) and Wheatbelt (1.5 per 1000), compared with 1.4 per 1000 or less elsewhere (Table 4).
 - In 2012, musculo-skeletal (17.6 per 1000 births) and urogenital defects (10.0 per 1000) were the most common categories of birth defects (Table 5).
 - In 2012, neural tube defects (births plus terminations of pregnancy) were 1.1 per 1000, the lowest level since the Register began in 1980 (Figure 1). This is likely due to mandatory fortification of flour with folic acid - continued monitoring is required.
 - Chromosomal anomalies generally have been increasing since 1980. The total rate for Down syndrome (births plus terminations) and the rate for terminations alone have steadily increased over time. The rate of Down syndrome in liveborn infants was below 1 per 1000 in 2011 and 2012 (Figure 2).
 - Birth defects are a major cause of death. For 2012 births, a birth defect was present in 8.1% of stillbirths and 27.7% of neonatal deaths (Table 6). Terminations of pregnancy for fetal anomaly occurred at a rate of 6.6 per 1000 births in 2012.
 - The major sources of notification are hospitals, private practitioners and investigative and treatment centres (Table 7).

- For **cerebral palsy**, the numerator data include all individuals identified as having cerebral palsy born in WA from 1956 onwards. Denominators are all live births in WA or, in some analyses, neonatal survivors.
 - There are currently 3924 cases of cerebral palsy (CP) on the Register from birth-year 1956 onwards. Of these 538 (13.7%) are due to postneonatal causes (occurring after the first month of life) and 700 (17.8%) were not born in WA.
 - CP rates have been consistently higher in males than in females (Figure 4).
 - There has been little change in CP rates by severity over time. A concerning increase in severe CP in the 1990-94 year group did not persist in subsequent years. For all WA-born cases born 1980-2006 combined, minimal and mild CP accounted for almost half (13% and 34% respectively), with moderate and severe CP being equally represented at just over a quarter each (26.5%) (Figure 5).
 - Different types of CP can occur singly or in combinations, and rates are presented by the predominant type. Spastic CP is the most commonly occurring type, accounting for more than 80% of all CP, though in widely varying distributions and severities. The remainder of cases are predominantly non-spastic: ataxic (8%), dyskinetic (9%) or hypotonic (2%) (Figure 6).
 - CP is accompanied by intellectual disability (IQ less than 70) in approximately 40% of cases, and this has not changed over time (Figure 7).

- Research using Register data is reported: This includes studies of oesophageal atresia, late-diagnosed developmental dysplasia of the hip, prenatal alcohol exposure and birth defects and CP, and antecedents of CP and perinatal death in term and late preterm singletons.

INTRODUCTION

As WARDA is a statutory register (*Health (Western Australian Register of Developmental Anomalies) Regulations 2010*), it is mandatory for developmental anomalies to be reported. The medical practitioner making the diagnosis or caring for the patient diagnosed and/or the chief executive officer of a hospital in which the diagnosis of a developmental anomaly is made are responsible for making the notification. This is required within six months of the diagnosis. Under the regulations, there are provisions to impose a fine for non-compliance with the regulations.

A developmental anomaly is defined in the Regulations as:

- a. cerebral palsy; or
- b. a structural or functional anomaly, which is present at conception or occurs before the end of pregnancy and is diagnosed during pregnancy, or after stillbirth or termination of pregnancy, or after live birth, but before 6 years of age (referred to as “birth defects” in this report)

WARDA has a commitment to obtain high quality, complete, and population-based information on birth defects and cerebral palsy for WA, and to use this information:

- a. to monitor the number of cases of developmental anomaly in Western Australia;
- b. to plan, monitor and evaluate services for the prevention and alleviation of developmental anomalies and the care of persons with a developmental anomaly in Western Australia;
- c. to compile and publish general or statistical information relating to developmental anomalies; and
- d. to carry out research into the causes of developmental anomalies and the effectiveness of prevention, screening and treatment services.

This report provides routine statistics on notifications of:

- **birth defects** received by 31 August 2013 for births occurring between 1 January 1980 and 31 December 2012.
- **cerebral palsy** as recorded at the age of five years, for births 1956-2008.

Data on children not born in WA but resident in the State are not included in this report. They are, however, recorded on the Register for such purposes as evaluation of treatment and planning of facilities for children with developmental anomalies in WA.

BIRTH DEFECTS DATA

Routine statistics

The numerator data in this report comprise birth defects occurring in livebirths and stillbirths in WA and in pregnancies terminated because of fetal malformation. Birth defects diagnosed in children up to six years of age are included. The denominator data in this Report are derived from information provided by the Department of Health and include only livebirths and stillbirths of 20 weeks' gestation or more.

Amongst children born in 2006, who are now all over six years of age, 6.3% had a birth defect (Table 1). As children born from 2007 onwards are not yet six, the percentage with birth defects in more recent years of birth will increase.

Table 1
Birth Defects in Western Australia, 1980 - 2012

Year of birth	Total births in WA	Cases of birth defects notified	WA births with defects %
1980	20825	977	4.7
1981	22240	1043	4.7
1982	22400	1065	4.8
1983	23082	1166	5.1
1984	22989	1179	5.1
1985	23402	1159	5.0
1986	23961	1214	5.1
1987	24242	1250	5.2
1988	25191	1298	5.2
1989	25582	1395	5.5
1990	26039	1468	5.6
1991	25058	1461	5.8
1992	25358	1569	6.2
1993	25370	1571	6.2
1994	25450	1610	6.3
1995	25448	1635	6.4
1996	25586	1734	6.8
1997	25257	1761	7.0
1998	25668	1665	6.5
1999	25743	1736	6.7
2000	25229	1726	6.8
2001	24932	1660	6.7
2002	24782	1577	6.4
2003	24681	1484	6.0
2004	25530	1565	6.1
2005	26984	1714	6.4
2006	28665	1807	6.3
2007	30077	1757	5.8
2008	30674	1760	5.7
2009	31219	1805	5.8
2010	31265	1703	5.4
2011	32191	1715	5.3
2012	33862	1520	4.5

Demographic information
Race, sex and plurality (Table 2)

Birth defects are generally more common in multiple births and male infants. There is generally a lower prevalence of birth defects reported in Aboriginal children prior to 2005.

Table 2
Birth Defects in Western Australia births by
Aboriginality, Sex and Plurality, 1980 - 2012
 (Percentages are for total Western Australian births in each category)

Year of Birth	Aboriginality		Sex		Plurality	
	Non-Aboriginal	Aboriginal	Male	Female	Single	Multiple
	No	%	No	%	No	%
1980-89	11176	(5.0)	6937	(5.8)	11434	(5.0)
	570	(4.6)	4764	(4.2)	312	(5.6)
1990-94	7278	(6.1)	4441	(6.8)	7410	(6.0)
	401	(5.4)	3199	(5.2)	269	(7.9)
1995-99	8113	(6.8)	4846	(7.4)	8245	(6.7)
	418	(5.5)	3649	(5.9)	286	(7.6)
2000-04	7549	(6.6)	4592	(7.2)	7714	(6.4)
	463	(5.7)	3358	(5.4)	298	(7.3)
2005-09	8338	(6.0)	5051	(6.7)	8504	(5.9)
	505	(5.8)	3712	(5.1)	339	(7.8)
2010	1622	(5.5)	985	(6.2)	1639	(5.4)
	81	(4.8)	694	(4.2)	64	(7.6)
2011	1650	(5.4)	889	(5.4)	1629	(5.2)
	65	(3.7)	805	(5.2)	86	(9.5)
2012	1471	(4.6)	772	(4.4)	1461	(4.4)
	49	(3.0)	724	(4.4)	59	(6.3)

Area of residence (Table 3)

Table 3 shows that the proportion of births with a birth defect has increased gradually over time in all regions. Proportions tend to be higher in the two metropolitan regions than in the rural regions. This may be due to under-ascertainment from rural regions rather than a real difference.

Table 3
Numbers and Proportions of Cases of Birth Defects by Year of Birth
and Health Region, 1980 - 2012

No=Number, Prop=Proportion per 100

Health Region (WA Dept of Health)	1980-89	90-94	95-99	00-04	05-09	2010	2011	2012
	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop
North Metro	4587 5.3	3166 6.6	3527 7.2	3335 6.8	3736 6.3	710 5.7	792 6.2	650 4.8
South Metro	3909 5.4	2600 6.3	2977 6.9	2885 6.7	3107 5.9	603 5.2	624 5.1	579 4.5
Kimberley	213 3.9	163 5.5	177 5.6	193 5.7	185 5.3	26 3.8	24 3.7	24 3.4
Pilbara Gascoyne	469 3.7	247 4.4	230 4.8	226 5.4	225 5.4	53 6.2	33 3.8	33 3.7
Midwest Murchison	416 4.4	245 4.6	257 5.7	219 5.9	220 4.8	49 5.1	30 3.2	27 3.0
Wheatbelt	663 4.8	335 5.4	331 6.0	273 5.7	274 5.6	61 6.5	40 4.3	51 5.3
Goldfields SE Coastal	408 4.2	269 4.8	305 5.4	272 5.6	230 4.6	43 4.5	31 3.4	30 3.1
Great Southern	369 4.6	185 4.9	217 5.7	160 4.6	165 4.5	39 5.3	28 3.6	28 3.9
Southwest	695 4.5	454 5.7	486 5.8	418 5.0	619 6.2	96 4.6	89 4.3	72 3.3

Individual birth defects by Health Region 2001-2012 (Table 4)

The proportions per 1000 births for these major birth defects are generally similar across regions. However, neural tube defects are more common in the Midwest (2.0 per 1000), Wheatbelt (1.5 per 1000) and the Goldfields (1.7 per 1000), compared with other regions.

Table 4
Numbers and Proportions of Cases of Some Major Birth Defects by Health Region, 2001 – 2012 (No=Number, Prop=Proportion per 1000)

Diagnostic Category (British Paediatric Association Code)	North Metro No Prop	South Metro No Prop	Kimber ley No Prop	Pilbara No Prop	Mid West No Prop	Wheat belt No Prop	Gold fields No Prop	Great Southern No Prop	South West No Prop
Neural Tube Defects (74000 - 74209)	160 1.2	168 1.4	10 1.2	14 1.4	21 2.0	17 1.5	20 1.7	12 1.4	33 1.4
Congenital Hydrocephalus (74230 - 74239)	97 0.7	93 0.8	7 0.9	9 0.9	8 0.8	8 0.7	6 0.5	11 1.3	17 0.7
Cleft Palate only (74900 - 74909)	158 1.2	125 1.0	7 0.9	4 0.4	10 1.0	13 1.1	17 1.5	7 0.8	27 1.2
Cleft Lip +/- Cleft Palate (74910 - 74929)	136 1.0	152 1.2	18 2.2	10 1.0	16 1.5	19 1.7	6 0.5	13 1.5	25 1.1
Oesophageal Atresia/Stenosis (75030 - 75038)	50 0.4	49 0.4	2 0.2	4 0.4	3 0.3	2 0.2	7 0.6	0 0.0	14 0.6
Anorectal Stenosis/Atresia (75121 - 75125)	81 0.6	70 0.6	2 0.2	5 0.5	3 0.3	2 0.2	8 0.7	5 0.6	18 0.8
Hypospadias (75260, 75263 - 75269)	463 3.4	429 3.5	20 2.4	28 2.8	26 2.5	37 3.2	38 3.3	19 2.2	73 3.2
Renal Agenesis (75300 - 75301)	61 0.4	69 0.6	0 0.0	4 0.4	4 0.4	9 0.8	6 0.5	10 1.2	16 0.7
Total Limb Reduction Defects (75520 - 75529)	109 0.8	91 0.7	6 0.7	7 0.7	8 0.8	11 1.0	9 0.8	5 0.6	20 0.9
Diaphragmatic Hernia (75661)	46 0.3	41 0.3	4 0.5	2 0.2	2 0.2	2 0.2	2 0.2	3 0.3	11 0.5
Exomphalos (75670)	61 0.4	51 0.4	3 0.4	2 0.2	6 0.6	6 0.5	3 0.3	4 0.5	6 0.3
Gastroschisis (75671)	41 0.3	56 0.5	2 0.2	2 0.2	3 0.3	4 0.3	8 0.7	3 0.3	8 0.3
Transposition of Great Vessels (74510 - 74519)	64 0.5	50 0.4	8 1.0	5 0.5	6 0.6	7 0.6	8 0.7	6 0.7	3 0.1
Hypoplastic Left Heart Syndrome (74670)	28 0.2	25 0.2	1 0.1	2 0.2	4 0.4	1 0.1	1 0.1	0 0.0	3 0.1
Down Syndrome (75800 - 75809)	404 2.9	331 2.7	20 2.4	25 2.5	28 2.7	28 2.4	21 1.8	30 3.5	65 2.8
Anotia/Microtia (74400-74401)	28 0.2	20 0.2	2 0.2	2 0.2	1 0.1	2 0.2	2 0.2	2 0.2	6 0.3

Diagnostic information

The definition of a birth defect used by the Register is: *a structural or functional anomaly, which is present at conception or occurs before the end of pregnancy and is diagnosed during pregnancy, or after stillbirth or termination of pregnancy, or after live birth, but before 6 years of age.* This includes structural (eg spina bifida), chromosomal (eg Down syndrome) and metabolic (eg phenylketonuria) defects. Each individual defect (up to a maximum of 10 defects per case) is coded according to the 5-digit British Paediatric Association ICD-9 system. Syndrome diagnoses are coded along with the major individual defects seen in that infant (eg Down syndrome, VSD and duodenal atresia occurring in one child are all coded).

Most minor malformations are excluded unless they are disfiguring or require treatment. Of all cases registered, about 90% have at least one major malformation (with or without a minor malformation); the remainder having what are classified as minor malformations. A list of exclusions is provided on the WARDA website, as well as lists (numeric and alphabetic) of the standard codes and text used by WARDA for birth defects and their major/minor classification.

Table 5 shows the number and proportion per 1000 total births of the main categories of defects, as well as the more common or important defects individually, by year of birth. Since about a quarter of the cases registered have more than one defect, the total number of defects exceeds the total number of cases. Not all individual birth defects are reported in Table 5, but information on any birth defect is available on request.

Figures 1 and 2 show livebirths, terminations and total cases with neural tube defects and Down syndrome respectively.

Some trends of note:

- There has been a fall in **neural tube defects** in total since 1995, from around 2 per 1000 to 1.1 per 1000 in 2012, and in **anencephaly** and **spina bifida** when considered separately. This is believed to be due to increased maternal intake of periconceptional folate, as folic acid supplements and food fortification (voluntary fortification for some foods from 1996 and, since September 2009, mandatory fortification of wheat flour for bread-making). Most cases of neural tube defects are detected prenatally and the pregnancy terminated (Figure 1), highlighting the importance of including terminations when monitoring trends in neural tube defects.
- There has been a marked increase in **developmental dysplasia of the hip** in 2011 and 2012 - 10.1 and 11.3 per 1000 births respectively, compared with 5.5 – 7.3 per 1000 in previous years. Possible reasons for this increase are being sought.
- The apparent fall in prevalence of **undescended testes** is partly due to the fact that this birth defect is usually registered at the time surgery is undertaken, usually around 1-2 years of age. However, there has been a lower rate since 2005.
- The gradual rise in **chromosomal defects** since 1980, a result of increasing maternal age and possibly also the increased use of first trimester screening, appears to have peaked at 6.4 per 100 births for all chromosomal defects and 3.2 per 1000 for **Down syndrome**. The rate of Down syndrome in liveborn infants fell below 1 per 1000 in 2011 and 2012 (Figure 2).

Table 5**Numbers and Proportions of Cases of Birth Defects by Year of Birth and Diagnosis, 1980 - 2012**(Proportions are per 1000 births and are only calculated if number of cases is greater than 13)
No=Number, Prop=Proportion

Diagnostic Category (British Paediatric Association Code)	80-89	90-94	95-99	00-04	05-09	2010	2011	2012
	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop
NERVOUS SYSTEM DEFECTS	995	595	598	646	731	112	133	123
(74000 - 74299)	4.3	4.7	4.7	5.2	5.0	3.6	4.1	3.6
Neural Tube Defects	445	251	203	182	201	36	46	36
(74000 - 74209)	1.9	2.0	1.6	1.5	1.4	1.2	1.4	1.1
Anencephalus	203	110	90	79	85	12	16	16
(74000 - 74029)	0.9	0.9	0.7	0.6	0.6		0.5	0.5
Spina Bifida	201	114	96	88	90	20	21	16
(74100 - 74199)	0.9	0.9	0.8	0.7	0.6	0.6	0.7	0.5
Encephalocoele	41	27	17	15	26	4	9	4
(74200 - 74209)	0.2	0.2	0.1	0.1	0.2			
Microcephaly	127	73	74	75	66	11	7	6
(74210)	0.5	0.6	0.6	0.6	0.4			
Congenital Hydrocephalus	159	110	122	87	118	20	27	24
(excludes those with NTD)	0.7	0.9	1.0	0.7	0.8	0.6	0.8	0.7
(74230 - 74239)								
Congenital Deafness	160	101	112	165	179	27	27	38
(74287)	0.7	0.8	0.9	1.3	1.2	0.9	0.8	1.1
CONGENITAL ANOMALIES OF EYE	258	176	171	168	130	24	7	16
(74300 - 74399)	1.1	1.4	1.3	1.3	0.9	0.8		0.5
Anophthalmia	13	4	10	6	5	0	0	2
(74300 - 74309)								
Microphthalmia	42	24	31	22	15	4	0	6
(74310 - 74319)	0.2	0.2	0.2	0.2	0.1			
Congenital Cataract and	57	53	49	35	29	6	1	1
Lens Anomalies	0.2	0.4	0.4	0.3	0.2			
(743300 - 74339)								
CONGENITAL ANOMALIES OF EAR, FACE AND NECK (74400 - 74499)	588	457	563	598	639	84	64	64
(74400 - 74401, 74421)	2.5	3.6	4.4	4.8	4.3	2.7	2.0	1.9
Anotia, Microtia	45	34	40	29	32	3	3	4
(74400 - 74401, 74421)	0.2	0.3	0.3	0.2	0.2			
Branchial Remnants	122	76	79	68	84	9	4	7
(74440 - 74448)	0.5	0.6	0.6	0.5	0.6			

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No Prop	90-94 No Prop	95-99 No Prop	00-04 No Prop	05-09 No Prop	2010 No Prop	2011 No Prop	2012 No Prop
CARDIOVASCULAR DEFECTS	1904	1503	1588	1554	1658	318	315	247
(74500 - 74799)	8.1	11.8	12.4	12.4	11.2	10.2	9.8	7.3
Transposition of Great Vessels (74510 - 74519)	97 0.4	50 0.4	63 0.5	64 0.5	67 0.5	7	14 0.4	16 0.5
Tetralogy of Fallot (74520)	71 0.3	58 0.5	40 0.3	38 0.3	39 0.3	13	10	8
Ventricular Septal Defect (74540 - 74549)	965 4.1	829 6.5	903 7.1	866 6.9	882 6.0	176 5.6	173 5.4	135 4.0
Atrial Septal Defect (74551 - 74559)	309 1.3	231 1.8	259 2.0	222 1.8	267 1.8	53 1.7	45 1.4	48 1.4
Hypoplastic Left Heart Syndrome (74670)	44 0.2	31 0.2	20 0.2	20 0.2	32 0.2	8	5	6
Patent Ductus Arteriosus (74700)	288 1.2	212 1.7	236 1.8	193 1.5	272 1.8	51 1.6	48 1.5	43 1.3
Coarctation of Aorta (74710 - 74719)	117 0.5	76 0.6	64 0.5	81 0.6	76 0.5	14 0.4	9	4
RESPIRATORY SYSTEM DEFECTS	198	97	147	146	159	31	37	30
(74800 - 74899)	0.8	0.8	1.2	1.2	1.1	1.0	1.1	0.9
Choanal Atresia (74800 - 74809)	35 0.1	16 0.1	17 0.1	19 0.2	12	2	1	2
GASTRO-INTESTINAL DEFECTS	1467	808	861	784	900	168	161	127
(74900 - 75199)	6.3	6.3	6.7	6.3	6.1	5.4	5.0	3.8
Cleft Palate only (74900 - 74909)	199 0.9	131 1.0	151 1.2	157 1.3	168 1.1	30 1.0	24 0.7	26 0.8
Cleft Lip only (74910 - 74919)	114 0.5	58 0.5	59 0.5	76 0.6	81 0.5	12	10	17 0.5
Cleft Lip and Palate (74920 - 74929)	196 0.8	70 0.5	99 0.8	91 0.7	92 0.6	14 0.4	20 0.6	15 0.4
Tracheo-Oesophageal Fistula, Oesophageal Atresia/Stenosis (75030 - 75038)	75 0.3	34 0.3	40 0.3	50 0.4	70 0.5	6	14 0.4	7
Pyloric Stenosis (75051 - 75058)	470 2.0	237 1.9	224 1.8	145 1.2	196 1.3	41 1.3	36 1.1	2
Stenosis/Atresia Small Intestine (75110 - 75119)	63 0.3	33 0.3	36 0.3	39 0.3	36 0.2	12	8	8
Stenosis/Atresia Anus (75123 - 75125)	118 0.5	86 0.7	71 0.6	86 0.7	77 0.5	21 0.7	10	16 0.5
Hirschprung's Disease (75130 - 75133)	38 0.2	33 0.3	21 0.2	17 0.1	36 0.2	11	5	7

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No Prop	90-94 No Prop	95-99 No Prop	00-04 No Prop	05-09 No Prop	2010 No Prop	2011 No Prop	2012 No Prop
URO-GENITAL DEFECTS	3280	2337	2517	2297	2553	495	436	340
(75200 - 75399)	14.0	18.4	19.7	18.4	17.3	15.8	13.5	10.0
Undescended Testis (treated)	1546	852	740	656	618	116	92	66
(75250 - 75254, 75257)	6.6	6.7	5.8	5.2	4.2	3.7	2.9	1.9
Hypospadias	664	444	461	474	511	104	84	75
(75260, 75263 - 75269)	2.8	3.5	3.6	3.8	3.5	3.3	2.6	2.2
Renal Agenesis or Dysgenesis	111	77	99	122	124	28	28	24
(75300 - 75306)	0.5	0.6	0.8	1.0	0.8	0.9	0.9	0.7
Cystic Kidney Disease	82	90	97	126	125	25	37	26
(75310 - 75319)	0.4	0.7	0.8	1.0	0.8	0.8	1.1	0.8
Obstructive Defects Renal Pelvis	154	204	289	297	650	149	129	93
(75320 - 75329)	0.7	1.6	2.3	2.4	4.4	4.8	4.0	2.7
Vesico-Ureteric Reflux	490	503	653	440	320	43	33	38
(75344)	2.1	4.0	5.1	3.5	2.2	1.4	1.0	1.1
Other Anomalies of Ureter	137	151	190	134	193	41	46	29
(75340 - 75343, 75345 - 75349)	0.6	1.2	1.5	1.1	1.3	1.3	1.4	0.9
MUSCULO-SKELETAL DEFECTS	3350	1900	2245	1990	2168	477	569	597
(75400 - 75699)	14.3	14.9	17.6	15.9	14.7	15.3	17.7	17.6
Developmental Dysplasia of Hip	1499	773	936	716	816	213	325	382
(75430 - 75434, 75439)	6.4	6.1	7.3	5.7	5.5	6.8	10.1	11.3
Talipes	511	269	252	301	305	55	48	42
(75450, 75454-75456, 75473)	2.2	2.1	2.0	2.4	2.1	1.8	1.5	1.2
Polydactyly	237	135	158	143	175	43	38	23
(75500 - 75509)	1.0	1.1	1.2	1.1	1.2	1.4	1.2	0.7
Syndactyly	157	72	80	74	108	18	11	12
(75510 - 75519)	0.7	0.6	0.6	0.6	0.7	0.6		
Reduction Deformities	168	116	161	150	159	23	25	27
Upper and/or Lower Limbs	0.7	0.9	1.3	1.2	1.1	0.7	0.8	0.8
(75520 - 75549)								
Craniosynostosis	105	84	76	60	81	14	12	11
(75600, 75601)	0.4	0.7	0.6	0.5	0.5	0.4		
Diaphragmatic Hernia	71	43	59	43	48	8	20	6
(75661)	0.3	0.3	0.5	0.3	0.3		0.6	
Exomphalos	58	48	40	57	60	12	18	5
(75670)	0.2	0.4	0.3	0.5	0.4		0.6	
Gastroschisis	37	32	52	38	61	10	13	13
(75671)	0.2	0.3	0.4	0.3	0.4			

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No Prop	90-94 No Prop	95-99 No Prop	00-04 No Prop	05-09 No Prop	2010 No Prop	2011 No Prop	2012 No Prop
CONGENITAL ANOMALIES OF INTEGUMENT (75700 - 75799)	714	520	720	668	514	70	64	35
	3.1	4.1	5.6	5.3	3.5	2.2	2.0	1.0
Birth Marks, Naevus (75738)	410	283	439	433	315	37	33	19
	1.8	2.2	3.4	3.5	2.1	1.2	1.0	0.6
CHROMOSOME DEFECTS (75800 - 75899)	556	457	558	692	866	201	193	184
	2.4	3.6	4.4	5.5	5.9	6.4	6.0	5.4
Down Syndrome (75800 - 75809)	316	219	251	332	412	101	93	97
	1.4	1.7	2.0	2.7	2.8	3.2	2.9	2.9
Trisomy 13 (75810 - 75819)	22	18	22	40	48	6	9	8
	0.1	0.1	0.2	0.3	0.3			
Trisomy 18 (75820 - 75829)	40	47	64	91	121	27	25	27
	0.2	0.4	0.5	0.7	0.8	0.9	0.8	0.8
Turner Syndrome (75860 - 75861, 75869)	29	34	44	63	59	13	23	13
	0.1	0.3	0.3	0.5	0.4		0.7	
OTHER								
Congenital Hypothyroidism (24390 - 24399)	49	54	40	65	69	7	23	23
	0.2	0.4	0.3	0.5	0.5		0.7	0.7
Adrenogenital Syndrome (25520 - 25529)	15	9	16	15	14	2	0	3
	0.1		0.1	0.1	0.1			
Disorders of Amino Acid Transport and Metabolism (27000 - 27099)	38	26	35	26	44	2	8	8
	0.2	0.2	0.3	0.2	0.3			
Phenylketonuria (27010)	13	7	7	10	13	1	1	2
Disorders of Carbohydrate Transport and Metabolism (27100 - 27199)	20	13	7	8	4	5	4	2
	0.1							
Cystic Fibrosis (27700)	76	44	28	54	66	12	13	9
	0.3	0.3	0.2	0.4	0.4			
G6PD Deficiency (28220)	44	22	44	30	17	3	4	0
	0.2	0.2	0.3	0.2	0.1			
Thalassaemias (28240 - 28249)	5	6	6	3	5	0	1	0
Haemophilia (28600 - 28620)	19	4	19	23	12	3	0	0
	0.1		0.1	0.2				
Muscular Dystrophies/ Myopathies (35900 - 35999)	70	22	30	14	27	3	1	3
	0.3	0.2	0.2	0.1	0.2			
Fetal Alcohol Syndrome/FASD (75992)	36	24	26	75	63	5	3	4
	0.2	0.2	0.2	0.6	0.4			
Congenital Rubella Syndrome (77100)	24	7	2	2	0	0	0	0
	0.1							

Figure 1. Neural tube defects, Western Australia 1980-2012

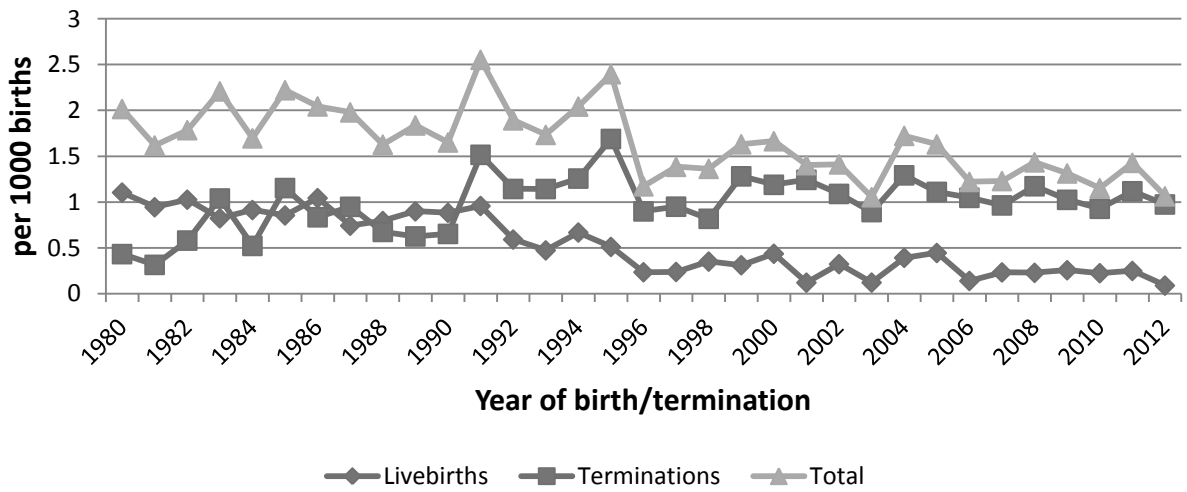
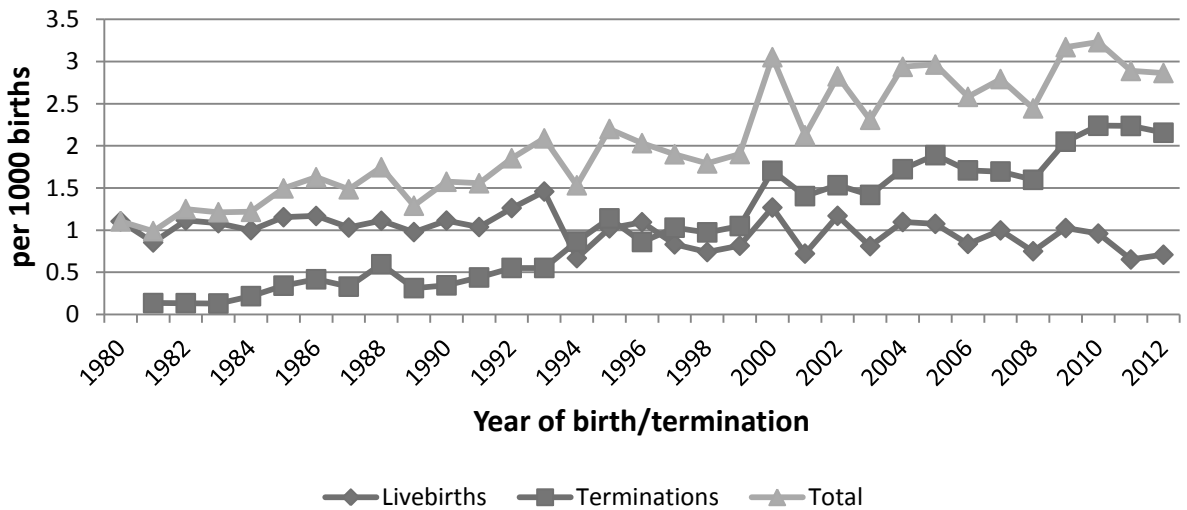


Figure 2. Down syndrome, Western Australia 1980-2012



Deaths

Table 6 shows the number (and percentage) of stillbirths, neonatal and post-neonatal deaths known to have a birth defect. Terminations of pregnancy are those which occurred following prenatal diagnosis of a fetal abnormality. Between 8% and 15% of stillbirths have a reported birth defect, as do 30% - 40% of neonatal deaths and 13% - 39% of post-neonatal deaths.

Terminations of pregnancy for fetal abnormality have increased from 1.6 per 1000 births in 1980-1989 to 7.1 per 1000 in 2011 and 6.6 per 1000 in 2012.

Table 6
Deaths with Birth Defects 1980 - 2012

Year of Birth	Stillbirths (% is of all stillbirths)		Neonatal Deaths (% is of all neonatal deaths)		Postneonatal Deaths (% is of all postneonatal)		Terminations of Pregnancy for Fetal Anomaly
	No	%	No	%	No	%	No
1980-89	254	13.7	513	39.7	213	27.5	399
1990-94	139	15.5	188	40.1	92	28.2	472
1995-99	133	14.7	145	39.1	82	38.9	634
2000-04	96	10.7	91	30.3	52	31.9	821
2005-09	106	10.0	100	30.4	62	31.5	1012
2010	18	8.3	23	34.3	7	13.2	229
2011	26	9.6	19	30.6	7	26.9	241
2012	19	8.1	13	27.7	8*	21.1	223

* Complete data on all post-neonatal deaths not yet available

Notifications

Table 7 documents the number of notifications of birth defects received from different sources by year of birth of the child. Most sources provide very consistent levels of notification.

Table 7
Numbers of Notifications by Source and Year of Birth of Cases Notified, 1980 - 2011

Notifiers	1980-89	90-94	95-99	00-04	05-09	2010	2011	2012
HOSPITAL MORBIDITY	1438	1248	1929	2163	2489	408	291	106
PAEDIATRIC HOSPITALS EXCL SPECIAL DEPTS	5509	2965	2037	1377	1239	189	193	189
PAEDIATRIC HOSPITALS SPECIAL DEPARTMENTS	2143	1888	1896	1546	1562	358	351	397
OBSTETRIC HOSPITALS EXCL SPECIAL DEPTS	1772	1055	1001	854	739	161	199	163
OBSTETRIC HOSPITALS SPECIAL DEPARTMENTS	327	409	596	672	840	211	226	206
OTHER HOSPITALS	423	56	46	89	60	11	10	10
CYTOGENETIC SERVICES	399	399	527	648	858	155	170	166
PATHOLOGY SERVICES	814	565	649	738	861	198	203	162
GENETICS SERVICES	1939	1501	1642	1626	1523	277	275	242
PRIVATE PRACTITIONERS	4985	3155	3624	3245	2980	617	686	639
CHILD & COMMUNITY HEALTH NURSES & DOCTORS	1200	421	252	86	39	5	1	5
RURAL PAEDIATRIC SERVICE	285	359	274	186	117	13	7	3
OTHER	617	60	61	368	449	1	0	0
REGISTER CHECK	765	259	194	130	222	34	57	24
TOTAL	25948	15951	16149	15086	15451	2928	306	2415

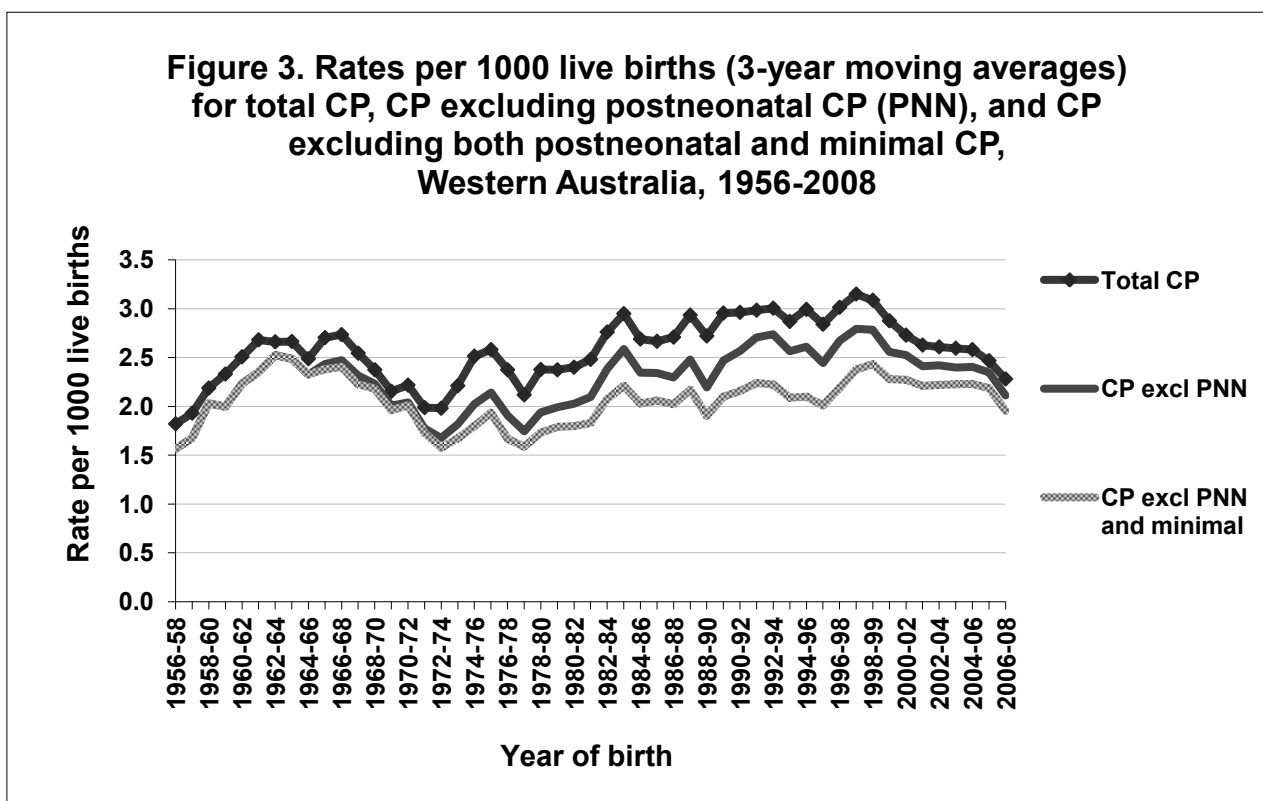
CEREBRAL PALSY DATA

Unlike other developmental anomalies that can be well described at the time they are recognised, the physical expression of cerebral palsy tends to change over time. Signs and symptoms can sometimes resolve altogether, or a syndrome in its early stages can be mistaken for cerebral palsy. For these reasons, information for all cerebral palsy cases is updated at the age of five years in order to confirm and report data at a meaningful and consistent age. There is therefore always a five-year delay in reporting cerebral palsy data.

Routine statistics

The numerator data include all individuals identified as having cerebral palsy born in WA from 1956 onwards. Cases born outside WA are included on the Register in order to estimate numbers of people requiring services but are excluded from data reported here. Cases due to causes occurring after the first month of life, such as head injury, stroke or meningitis, are also included on the Register but usually analysed separately.

Overall rates of cerebral palsy (CP) have shown little variation over time (Figure 3; Table 8). Increases from the early 1970s accompanied the introduction of neonatal intensive care, which resulted in greater survival of preterm infants who later developed CP. Continued improvements in neonatal intensive care may be responsible for reduction in rates seen from the late 1990s and sustained into the 2000s. The lower rate in 2007 and 2008 is likely to be related to under-ascertainment of cases due to the unavailability of two previously included sources of data – the Hospital Morbidity Data System and The Centre for Cerebral Palsy.



CP=cerebral palsy; PNN=postneonatal

Table 8
Cerebral palsy (CP) birth prevalence rates per 1000 live births (LB) in
Western Australia, 1956-2007

Year of birth	Total CP ¹	Rate/1000 LB	95% Confidence Interval	CP ¹ excl PNN ²	Rate/1000 LB	95% Confidence Interval	CP ¹ excl PNN ² and minimal severity	Rate/1000 LB
1956-59	125	1.85	1.52 - 2.17	108	1.60	1.29 - 1.90	108	1.60
1960-64	222	2.61	2.27 - 2.95	202	2.38	2.05 - 2.70	202	2.38
1965-69	231	2.52	2.20 - 2.85	211	2.31	1.99 - 2.62	206	2.25
1970-74	226	2.08	1.81 - 2.35	200	1.84	1.58 - 2.09	192	1.77
1975-79	247	2.40	2.10 - 2.70	202	1.96	1.69 - 2.23	183	1.78
1980-84	297	2.69	2.38 - 2.99	252	2.28	2.0 - 2.56	219	1.98
1985-89	334	2.75	2.46 - 3.05	285	2.35	2.08 - 2.63	248	2.04
1990-94	375	2.97	2.67 - 3.27	333	2.64	2.35 - 2.92	274	2.17
1995-99	378	2.97	2.68 - 3.27	329	2.59	2.31 - 2.87	277	2.18
2000-04	338	2.72	2.43-3.01	312	2.51	2.23 - 2.79	281	2.26
2005-08	276	2.39	2.11 - 2.67	257	2.22	1.95 - 2.5	240	2.08

1 Excludes cases born outside WA; 2 Postneonatally acquired cerebral palsy

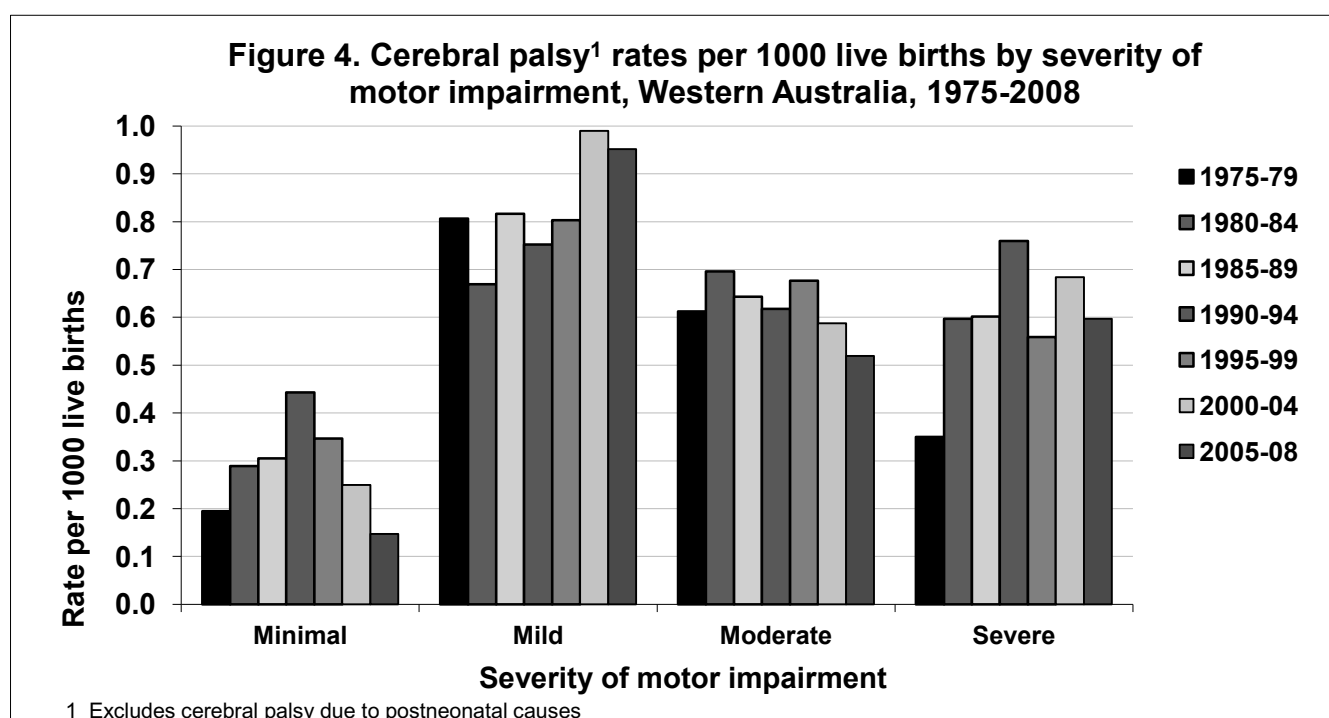
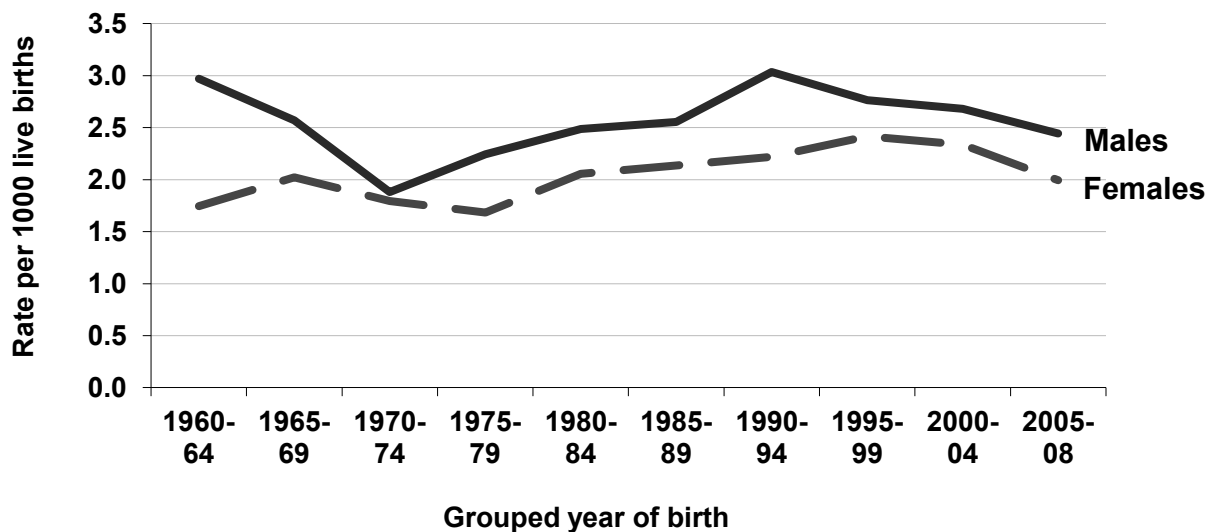


Figure 5. Cerebral palsy* rates by gender in Western Australia, 1960-2008



*Excludes cerebral palsy due to postneonatal causes

Figure 6. Cerebral palsy rates by type of motor impairment, Western Australia 1980-2006

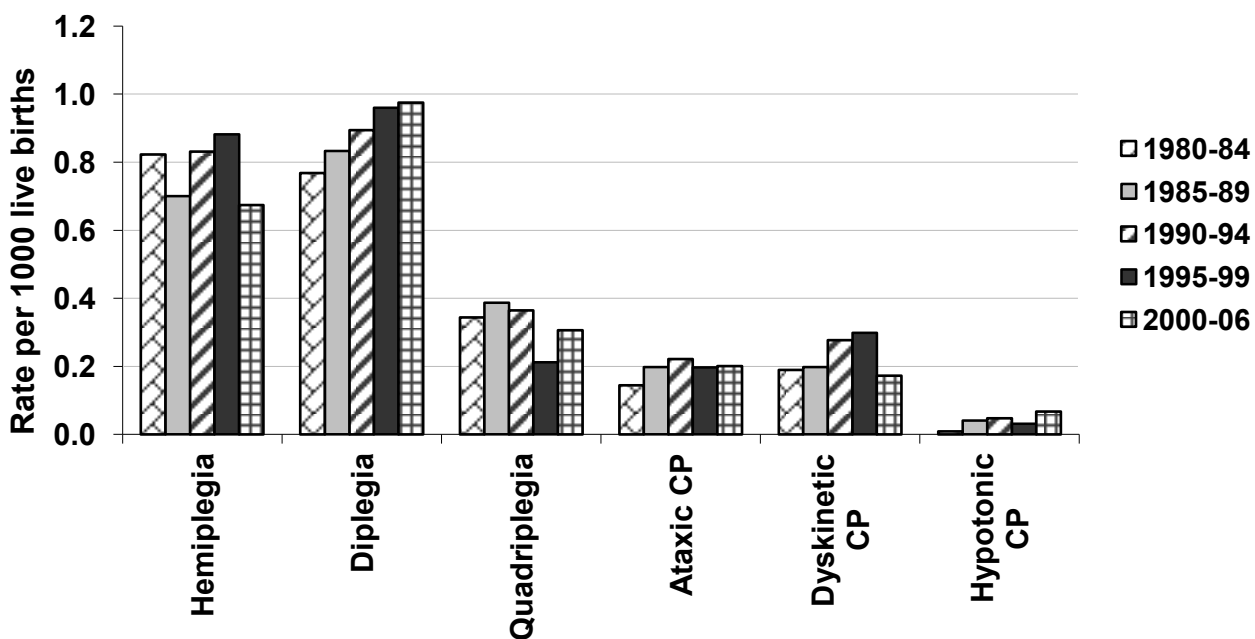


Figure 7. CP type as proportion of all CP, 1980-2006 combined

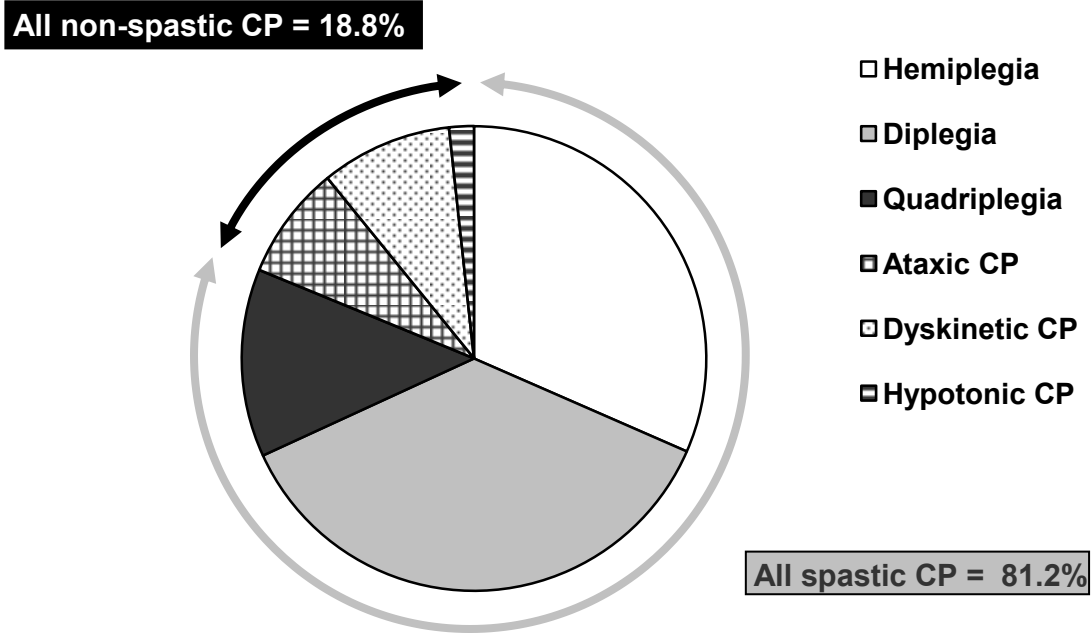
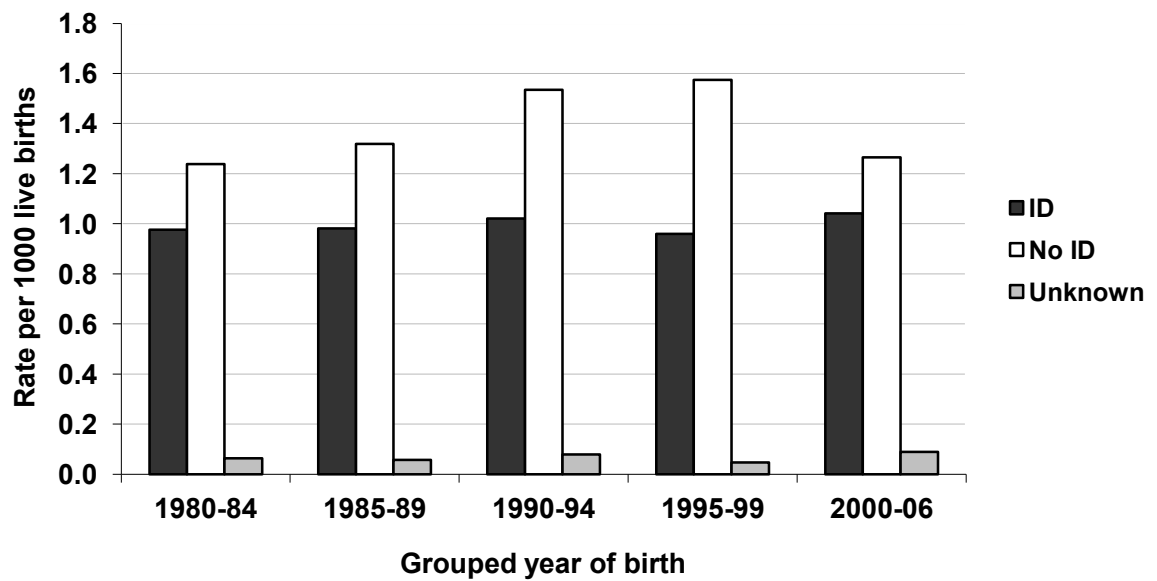


Figure 8. Cerebral palsy by presence or absence of intellectual disability (IQ <70), WA 1980-2006



REGISTER ACTIVITIES

1. Provision of data

The Register is a comprehensive source of information on birth defects and cerebral palsy in WA for use in all relevant areas of health service provision, policy development, research and evaluation. Provision of data from the Register may take two forms: (1) unnamed tabulated information similar to that contained in this report; and (2) identified or de-identified unit data for specific research projects. Requests for the latter must be submitted in writing to the Register in the first instance, and then to the Department of Health WA Human Research Ethics Committee for approval.

2. Information on developmental anomalies

Over the past year, 41 (26 BD; 15 CP) requests for information or data on developmental anomalies have been received. Two of these requests were from the state or federal Departments of Health, 32 were from health professionals and institutions in WA, Australia or overseas, 7 were from the general public, the media or students and there were two parliamentary questions. Two thirds required a considerable amount of computing, analysis and discussion, and responses to most of the remainder involved provision and/or interpretation of published data

3. Website

The WARDA website has been improved over the last year to make information more accessible and relevant to the public, health professionals and prospective researchers. In collaboration with the Consumer Reference Group we have created sections to include Family Stories and Plain Language Research Summaries and have included links to other relevant sites. The website can be easily accessed on:

http://www.kemh.health.wa.gov.au/services/register_developmental_anomalies.htm

4. International Clearinghouse for Birth Defect Surveillance and Research

Data based on 2010 births were provided to the International Clearinghouse for inclusion in the 2013 Annual Report of the Clearinghouse.

5. The Australian Cerebral Palsy Register (ACPR)

This national collaboration was spearheaded by the WA cerebral palsy team in 2002 when only three State registers were in existence, covering 45% of the Australian live born population. This progressed to 100% coverage by 2007 with all States and Territories contributing to the first pooling of data in 2008. The first ACPR Report covering birth years 1993-2003 was published in 2009. The ACPR continues to thrive with CP data collections well established in all States and Territories. Now administered by the CP Alliance NSW, State representatives meet annually to discuss data and research matters, and a second ACPR Report to birth year 2006 was published in 2013. The ACPR took a leading role in planning the Fourth International CP Conference 2012 in Pisa which included the Second World CP Registers Day, a forum for the discussion of issues arising from the collection, pooling and analysis of CP data.

6. Register-based Research

6.1 Research arising from the case-control study of cerebral palsy in term and preterm infants in Western Australia, 1980-1995

Asso/Prof Eve Blair and Sarah McIntyre, a Research Fellow at the CP Alliance in Sydney and PhD candidate are continuing to analyse this very rich data set in collaboration with Karin Nelson at the National Institutes of Health in the USA. Sarah is investigating term singletons in the study, comparing cases with and

without newborn hypoxic ischaemic encephalopathy (HIE). In her current work she has added singleton births born at 35-36 weeks, linking birth defects data from WARDA to enable a comparison of the proportion of cases in each of three CP groups (those with HIE, those with neurological abnormality not diagnosed as HIE and those without neonatal neurological abnormality) in which birth defects were present but not recognised neonatally, with a view to creating more aetiologically homogeneous groups. A second paper which will also utilise these new birth defects data deals with the different distributions of four major risk factors (sentinel events, intrauterine inflammation, growth restriction and birth defects) between the three CP groups above and three perinatal death groups (intrapartum stillbirths and neonatal deaths with and without HIE). A third paper compares distributions of antecedents of growth restriction between the different outcome groups to identify distal causal factors that may be more amenable to prevention (McIntyre et al. Antecedents of cerebral palsy and perinatal death in term and late preterm singletons. *Obstet Gynecol* 2013; 122:869-77).

6.2 Achieving reliability in the description of cerebral palsy

A collaboration of researchers from the Telethon Institute for Child Health Research and Princess Margaret Hospital (PMH) has produced, in consultation with clinicians, a standardised form to record the clinical features of CP. This innovative diagrammatic CP Description Form maximises agreement between observers by bypassing the use of poorly-defined terminology typically used to describe CP. It incorporates the Australian Spasticity Assessment Scale (ASAS) devised by our PMH collaborators, Sarah Love and Noula Gibson, to measure spasticity limb by limb, also utilising the Gross Motor Function Classification System and Manual Ability Classification System as validated measurement tools to record functional severity of CP, with a similar oro-motor function scale to be included in future. A program to train clinicians to use the ASAS and the CP Description Form continues within WA and nationally, assisted by grants from PMH Foundation, the CP Alliance and PLAN Australia. An annual clinical meeting is held which involves a motor assessment being carried out on a child with CP to demonstrate the use of the form and stimulate discussion about how we describe the signs and symptoms of CP. This is attended by a range of clinicians and has proven effective in improving inter-observer agreement between clinicians from different disciplines. The CP Description Form has generated interest in other countries, and it is currently being used in some centres in the USA.

6.3 International collaboration to standardise criteria for inclusion of cases on a cerebral palsy register

Cerebral palsy is a clinical description rather than a diagnosis and encompasses a wide range of disorders of movement and posture resulting from a non-progressive lesion in the developing brain. CP can co-occur with other recognised conditions and syndromes which may be unrelated to the CP, share a common cause with the CP or be the cause of the CP by producing a secondary motor impairment. As an ever-increasing number of syndromes are found to have genetic causes, the rate of CP could artificially decline if such cases are no longer included on CP Registers. Additionally, age limit and minimum age of survival criteria can reduce comparability of data between registers. At the 2009 World Congress of CP Registers in Sydney, an international collaboration was set up to establish a consensus regarding what should be included on a CP Register. Ongoing discussions since then have culminated in a 2013 publication which sets down consensus criteria aimed at minimising inconsistencies both within registers over time and amongst registers throughout the world (Smithers-Sheedy et al. What constitutes cerebral palsy in the twenty-first century? *Dev Med Child Neurol* 2013; DOI:10.1111/dmcn.12262).

6.4 Oesophageal atresia and tracheo-oesophageal fistula in Western Australia: prevalence, trends and associated anomalies

The aims of this study were to: examine the prevalence and trends of oesophageal atresia (OA) and/or trachea-oesophageal fistula (TOF) in WA; determine the proportion of cases with isolated and associated anomalies; and explore the impact of time of diagnosis. The study population comprised records of all infants born in WA, 1980-2009 and registered with OA and/or TOF on the WARDA. OA±TOF and TOF alone affect, on average, 1 in every 2,927 births in WA, with a total prevalence of 3.00 (n = 228) and 0.42 (n = 32) per 10,000 births, respectively. The prevalence of OA and TOF alone did not vary significantly or show a trend across the three decades: 1980-1989, 1990-1999 and 2000-2009. In contrast, the proportion and trend in the prevalence of OA+TOF increased, on average, by 2.0% per year from 2.23 (95% CI 1.66-2.92) in 1980-1989 to 3.48 per 10,000 births (95% CI 2.82-4.26) in 2000-2009. However, when cases were subdivided in isolated and associated anomalies, only the associated OA+TOF group demonstrated a significant increase. Among OA±TOF cases, 34 (32%) were diagnosed at postmortem only. Cases with OA without TOF exhibited associated anomalies in as many as 80% of cases, while a lower frequency was observed in cases with OA+TOF (64%) and TOF alone (47%). This research was conducted by Emanuele Leoncini, Natasha Nassar and Carol Bower. A paper has been submitted.

6.5 Acute lower respiratory infections and birth defects

Acute lower respiratory infections (ALRI) are leading causes of hospitalisation in children but the association between birth defects and ALRI hospitalisation is unknown. For this population-based cohort study of 245,249 singleton births in WA (1996-2005), hospitalisation data were linked to the WARDA. Overall, 9% of non-Aboriginal children and 37% of Aboriginal children with birth defects had at least one ALRI admission before age 2 years. Both Aboriginal and non-Aboriginal children with birth defects had twice the rate of hospitalisation for an ALRI compared with children with no birth defects. Rates of ALRI hospitalisation varied by type of defect but were increased for all major birth defects categories, the highest rate being for children with Down syndrome. The rate of ALRI hospitalisation was 3 times greater in children with multiple birth defects than those with isolated defects. This research was conducted by Khadra Jama-Alol, Hannah Moore, Peter Jacoby, Carol Bower and Deborah Lehmann. A paper has been submitted for publication.

6.6 Consumer collaboration in achieving statutory notification to WARDA

A paper has been published (*Bower C, McKenzie A, Watson L, Charles A. Journal of Registry Management 2013;40:9-13*) describing how consumers were key to achieving statutory notification to the WARDA. Two facilitated workshops were held for consumer and community members of groups representing birth defects, cerebral palsy and disability and the Western Australian Health Consumers' Council. Parent groups and the Health Consumers' Council were unanimous in their support for statutory notification, with three conditions: that comprehensive and open information be provided to consumer groups and the community; that consumers have input into the development of statutory notification; and that an opt-out clause be included. Following the workshops, a Consumer Reference Group was established. They decided on the name for the new register (Western Australian Register of Developmental Anomalies), developed an opt-out clause and reviewed drafts of the regulations for statutory notification. The regulations came into effect in January 2011. Consumers developed a leaflet about the WARDA, which is available on the website and a hard copy can be obtained through the WARDA office.

6.7 Prenatal alcohol exposure and birth defects using data linkage

In this study, health records of maternal alcohol-related conditions were record-linked with records of births and birth defects in offspring to estimate risk of birth defects in a total population. The exposed population was records of births 1983-2007 linked to records of women with an alcohol-related diagnosis during pregnancy in hospital, mental health and drug and alcohol services databases in Western Australia. The comparison population was records of births linked to a random sample of women who did not have a record of an alcohol-related diagnosis on those databases in the same years, frequency matched on maternal age, year of birth and Aboriginality. Birth defects identified by Hoyme et al (Pediatrics. 2005;115:39-47) as alcohol-related (ARBD- alcohol-related birth defect) were investigated.

There was a significant association between maternal alcohol-related diagnoses recorded during pregnancy and any ARBD (OR 3.14; CI 2.49-3.96). The strongest associations were with microcephaly, hydronephrosis and ventricular septal defect. Most population attributable fractions for individual ARBD were less than 3%. These are the first population-based estimates of the proportion of individual birth defects attributable to prenatal alcohol exposure. An alcohol-related diagnosis recorded during pregnancy represents heavy prenatal alcohol exposure. There is likely to be unrecorded alcohol exposure in the comparison cohort, so associations with birth defects may be underestimated. Alcohol appears to account for a small proportion of birth defects and hence attributing birth defects to alcohol exposure in the clinical setting is likely to be difficult. A paper based on this research has been published (O'Leary CM et al. Birth Defects Research Part A: Clinical and Molecular Teratology. 2013;97(7):497-504).

6.8 Late-diagnosed developmental dysplasia of the hip

Cases of developmental dysplasia of the hip (DDH) were identified from the WA Register of Developmental Anomalies and additional demographic data for each case were obtained by record linkage to the Hospital Morbidity and Midwives Notification Systems. An equal number of control records were selected from the Midwives Notification System matched by month and year of birth. Late diagnosed cases were defined by an age at diagnosis greater than 3 months. 4317 cases of DDH without any other birth defects (isolated DDH) were identified amongst WA births 1980-2010; of which 389 were diagnosed after 3 months of age. The incidence of isolated DDH was 5.45 per 1000 live births. The incidence of late diagnosed DDH was 0.49 per 1000 live births. The proportion of cases diagnosed late was significantly higher during the 1980's than in either of the following decades, thought to be due to the gradual introduction of hip ultrasound during the 1980s, allowing earlier diagnosis of DDH. The incidence of late diagnosed DDH from 1990 -2010 was 0.24 per 1000 live births. There was a trend from 1990 - 2010 for an increasing incidence of late diagnosed DDH of 2.8% per year (IRR 1.028; CI 0.998- 1.058; P = 0.067). There was a similar sized reduction in the incidence of early diagnosed DDH in the same period, of 2.2% per year (IRR 0.978; CI 0.963 - 0.994; P=0.007). Compared with controls, late-diagnosed DDH was more common in infants who were female, breech presentation, born at 42 weeks gestation or greater, and born with an assisted vaginal delivery or Caesarean section. Risk factors for late diagnosed DDH compared to early diagnosed DDH were a birth weight less than 2500g (OR 2.73 (CI 1.27 - 5.87), P<0.05) and hospital discharge within 4 days (OR 1.52 (CI 1.04 - 2.22), P<0.05). Breech presentation was protective against late diagnosis compared to early diagnosis (OR 0.37 (CI 0.22 - 0.62), P<0.001). This research was undertaken by Dr Nic Frost and Mr Colin Whitewood, Department of Paediatric Orthopaedics, Princess Margaret Hospital, and Emanuele Leoncini and a paper has been submitted for publication.

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