Western Australian Register of Developmental Anomalies 1980-2011

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REPORT OF THE WESTERN AUSTRALIAN REGISTER OF DEVELOPMENTAL ANOMALIES

1980-2011

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December 2012

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Number 19

WESTERN AUSTRALIAN REGISTER OF DEVELOPMENTAL ANOMALIES

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FOREWORD

I am grateful to Professor Bower and the staff of the Western Australian Register of Developmental Anomalies for the opportunity of providing a foreword to this annual report. The Register seeks widespread support from various clinical subspecialties to help ensure its activities remain clinically relevant and that the quality of the data within the Register is maintained at the highest level. Over the last 15 years, I have had the pleasure of providing subspecialty support to the Register in the field of Inborn Errors of Metabolism and have seen first-hand the true value of functional and relevant data for research and patient care. Despite the recent and significant transition to a new and regulated environment for the operations of the Register, the staff of WARDA never lost focus on the importance of providing timely and accurate information. This has ensured the important activities of the Register remain relevant to clinicians and researchers, and appropriate for the many families touched by the activities of the Register.

In my own subspecialty field, we are currently seeing a dramatic and significant change in the technology used to screen newborns and children for Inborn Errors of Metabolism. In the 20 years I have been working in this field, we have progressed from a few dozen recognised metabolic disorders, often detected by basic urine chromatography techniques, to a rapidly expanding spectrum of disorders potentially detectable by new techniques like bloodspot and urine tandem mass spectrometry. These new techniques enable faster screening of newborns and children for an expanding range of inherited metabolic defects. And yet, the next decade will no doubt see further expansion as the next wave of genetic sequencing technologies are applied to Inborn Errors of Metabolism, introducing new paradigms to a field that has largely relied on testing for specific biochemical markers for almost 50 years. This will create new challenges in how best to classify these new entities and their underlying genetic mechanisms, as we move from simple descriptions of phenotype to a better understanding of genotype. This will create challenges for the Register and undoubtedly impact on the nosology for many of the inherited malformations; how best to incorporate new genetic understandings into existing systems of disease description and classification and still remain clinically relevant.

With change comes challenge and the next decade is going to be exciting for the Register and its staff. The information collected by the Register will remain an important and valued resource for determining disease risk and outcomes and in planning of clinical service. Professor Bower and her staff are to be congratulated for again providing us with comprehensive annual data on developmental anomalies in Western Australia.

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SUMMARY

- On 7th January 2011, the *Health (Western Australian Register of Developmental Anomalies) Regulations 2010* were gazetted, bringing together the former WA Birth Defects Registry and WA Cerebral Palsy Register and making notification of birth defects and cerebral palsy mandatory.
- 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 2011) 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 1359 cases of birth defects were notified relating to births and terminations of pregnancy in 2011, a proportion of 4.2%. This is expected to increase as birth defects continue to be diagnosed up to the age of six years in children born in 2011 (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 regions compared with metropolitan regions (Table 3). Of note, however, neural tube defects were more common in the Midwest (2.2 per 1000) and the Goldfields (1.6 per 1000) over period 2000-2011, compared with 1.4 per 1000 or less in the other regions (Table 4).
  - In 2011, musculo-skeletal defects (14.1 per 1000 births), cardiovascular defects (9.0 per 1000 births) and urogenital defects (9.0 per 1000 births) were the most common categories of birth defects (Table 5).
  - Rates of neural tube defects (births plus terminations of pregnancy) were 1.2 per 1000 births. It is too soon to be confident of an effect of mandatory fortification of flour with folic acid (begun in September 2009) on neural tube defects. Very few infants (0.2 per 1000 in 2010) are now liveborn with a neural tube defect (Figure 1).
  - 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 has remained around 1 per 1000 for many years, although it was 0.6 per 1000 in 2011 (Figure 2).
  - Birth defects are a major cause of death. For 2011 births, a birth defect was present in 8.2% of stillbirths and 50% of neonatal deaths (Table 6). Terminations of pregnancy for fetal anomaly occurred at a rate of 6.6 per 1000 births in 2011.
  - The major sources of notification to the Registry are hospitals and private practitioners, Department of Health databases (midwives' and hospital morbidity systems) 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 3793 cases of cerebral palsy (CP) on the Register from birth-year 1956 onwards. Of these 435 (11.5%) are due to causes occurring after the first month of life and 660 (17.4%) 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: birth defects in infants conceived following assisted reproductive technologies; epidemiology of cleft lip and palate; reliability of cerebral palsy description; cerebral palsy in offspring of women with heavy alcohol use in pregnancy; and an international forum to determine what constitutes cerebral palsy.

INTRODUCTION

After several decades as successful voluntary notification registers, the WA Birth Defects Registry and the WA Cerebral Palsy Register have combined and are now known as the Western Australian Register of Developmental Anomalies (WARDA). The name change brings the two registers together and better reflects the conditions collected - although some anomalies are diagnosed before birth, not all anomalies are obvious at birth and many may not be diagnosed until several years after birth.

WARDA is now a statutory register, as the *Health (Western Australian Register of Developmental Anomalies) Regulations 2010* came into effect on January 7, 2011. The decision to become statutory was reached by consensus, after consultation with health professionals, consumers and the community, and brings the Register in line with other important health information collections in WA, such as the WA Midwives' Notification of Birth System and the WA Cancer Registry.

As a statutory register, it is now 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**.**

For the purposes of the Regulations, a developmental anomaly is defined 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 2012 for births occurring between 1 January 1980 and 31 December 2011. Data on children not born in WA but resident in the State are not included in this report. They are, however, recorded on the Registry for such purposes as evaluation of treatment and planning of facilities for children with birth defects in WA.

cerebral palsy as recorded at the age of five years. 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. Table 8 and Figure 3 in this Report cover cerebral palsy data to the 2007 birth-year cohort, while the remaining figures and tables for cerebral palsy include only data up to 2006 birth-year and are unchanged from last year's Report.

A summary of the Register's activities over the past year is also provided.

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 2005, who are now all over six years of age, 6.0% had a birth defect (Table 1). All children born from 2006 onwards are not yet six, and hence the percentage with birth defects in these later years of birth will increase as birth defects continue to be diagnosed in children up to six years of age.

Table 1
Birth Defects in Western Australia, 1980 - 2011

Year	Total births in WA	Cases of birth defects notified	WA births with defects %
1980	20825	978	4.7
1981	22240	1043	4.7
1982	22400	1066	4.8
1983	23082	1166	5.1
1984	22989	1180	5.1
1985	23402	1158	4.9
1986	23961	1214	5.1
1987	24242	1251	5.2
1988	25191	1298	5.2
1989	25582	1395	5.5
1990	26039	1470	5.6
1991	25058	1460	5.8
1992	25358	1568	6.2
1993	25370	1569	6.2
1994	25450	1610	6.3
1995	25448	1635	6.4
1996	25586	1733	6.8
1997	25257	1758	7.0
1998	25668	1662	6.5
1999	25743	1727	6.7
2000	25229	1721	6.8
2001	24932	1648	6.6
2002	24782	1564	6.3
2003	24681	1467	5.9
2004	25530	1508	5.9
2005	26984	1628	6.0
2006	28665	1701	5.9
2007	30077	1611	5.4
2008	30674	1635	5.3
2009	31219	1661	5.3
2010	31265	1475	4.7
2011	32175	1359	4.2

Demographic information

Race, sex and plurality (Table 2)

Birth defects are generally more common in multiple births and male infants. There is a lower prevalence of birth defects reported in Aboriginal children prior to 2005. This is thought to be due in part to under-ascertainment of cases of birth defects in Aboriginal children in these earlier years.

Table 2

Birth Defects in Western Australia births by Aboriginality, sex and plurality, 1980 - 2011

(Percentages are for total Western Australia births in each category)

Year of Birth	Aboriginality		Sex		Plurality	
	Non-Aboriginal		Male		Single	
	Aboriginal		Female		Multiple	
			Indeterminate			
			Unknown			
	No	%	No	%	No	%
1980-89	11178	(5.0)	6938	(5.8)	11437	(5.0)
	571	(4.6)	4766	(4.2)	312	(5.6)
			8			
			37			
1990-94	7276	(6.1)	4440	(6.8)	7408	(6.0)
	401	(5.4)	3198	(5.2)	269	(7.9)
			2			
			37			
1995-99	8098	(6.7)	4837	(7.4)	8231	(6.7)
	417	(5.5)	3642	(5.9)	284	(7.5)
			3			
			33			
2000-04	7455	(6.5)	4537	(7.1)	7613	(6.3)
	457	(5.7)	3313	(5.4)	299	(7.3)
			4			
			58			
2005-09	7793	(5.6)	4728	(6.3)	7949	(5.5)
	475	(5.4)	3460	(4.8)	319	(7.3)
			2			
			78			
2010	1424	(4.8)	838	(5.3)	1422	(4.7)
	59	(3.5)	621	(3.8)	61	(7.2)
			0			
			24			
2011	1326	(4.4)	666	(4.3)	1299	(4.2)
	43	(2.5)	684	(4.4)	70	(7.8)
			0			
			19			

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 - 2011

(Proportions are per 100); No=Number, Prop=Proportion

Health Region (WA Dept of Health)	**1980-89** No Prop	**90-94** No Prop	**95-99** No Prop	**00-04** No Prop	**05-09** No Prop	**2010** No Prop	**2011** No Prop
North Metro	4590	3165	3519	3292	3476	618	641
	5.3	6.6	7.2	6.7	5.9	5.0	5.0
South Metro	3909	2601	2975	2855	2917	537	491
	5.4	6.3	6.9	6.6	5.5	4.6	4.0
Kimberley	214	163	177	190	173	17	17
	3.9	5.5	5.6	5.6	5.0	2.5	2.6
Pilbara Gascoyne	469	247	229	222	206	40	28
	3.7	4.4	4.8	5.3	4.9	4.7	3.2
Midwest Murchison	416	245	256	214	204	39	21
	4.4	4.6	5.7	5.7	4.4	4.1	2.2
Wheatbelt	663	335	330	270	249	51	30
	4.8	5.4	6.0	5.6	5.1	5.5	3.3
Goldfields SE Coastal	408	268	305	269	216	39	23
	4.2	4.8	5.4	5.5	4.3	4.1	2.5
Great Southern	369	186	216	157	152	32	24
	4.6	4.9	5.7	4.5	4.1	4.4	3.2
Southwest	694	454	485	412	564	82	62
	4.5	5.7	5.8	4.9	5.7	3.9	3.0

Individual birth defects by Health Region (Table 4)

This is a new table in the Report, showing the proportion of births with some major birth defects for the twelve-year period 2000-2011, in each of the Health Regions of WA. 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 (2.2 per 1000) and the Goldfields (1.6 per 1000) over this period, compared with 1.4 per 1000 or less in the other regions.

Table 4

Numbers and Proportions of Cases of Some Major Birth Defects by Health Region, 2000 – 2011 (No=Number, Prop=Proportion per 1000)

Diagnostic Category (British Paediatric Association Code)	North Metro	South Metro	Kimberley	Pilbara	Mid West	Wheat belt	Gold fields	Great Southern	South West
	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop	No Prop
Neural Tube Defects (74000 - 74209)	163 1.2	167 1.4	11 1.3	11 1.1	23 2.2	16 1.4	19 1.6	12 1.4	30 1.3
Congenital Hydrocephalus (74230 - 74239)	96 0.7	90 0.8	6 0.7	8 0.8	5 0.5	6 0.5	7 0.6	11 1.3	18 0.8
Cleft Palate only (74900 - 74909)	153 1.1	115 1.0	7 0.9	4 0.4	11 1.1	12 1.0	17 1.5	8 0.9	21 0.9
Cleft Lip +/- Cleft Palate (74910 - 74929)	134 1.0	146 1.2	18 2.2	11 1.1	15 1.5	20 1.7	8 0.7	14 1.6	26 1.2
Oesophageal Atresia/Stenosis (75030 - 75038)	54 0.4	49 0.4	2 0.2	4 0.4	3 0.3	2 0.2	8 0.7	0 0.0	14 0.6
Anorectal Stenosis/Atresia (75121 - 75125)	83 0.6	63 0.5	2 0.2	7 0.7	4 0.4	2 0.2	8 0.7	5 0.6	18 0.8
Hypospadias (75260, 75263 - 75269)	461 3.5	413 3.5	17 2.1	26 2.6	25 2.4	34 3.0	37 3.2	20 2.3	73 3.2
Renal Agenesis (75300 - 75301)	55 0.4	64 0.5	0 0.0	6 0.6	3 0.3	8 0.7	6 0.5	8 0.9	14 0.6
Diaphragmatic Hernia (75661)	47 0.4	42 0.4	4 0.5	2 0.2	2 0.2	4 0.3	3 0.3	4 0.5	10 0.4
Exomphalos (75670)	59 0.4	54 0.5	3 0.4	2 0.2	6 0.6	6 0.5	6 0.5	4 0.5	6 0.3
Gastroschisis (75671)	39 0.3	53 0.4	2 0.2	2 0.2	3 0.3	4 0.3	8 0.7	3 0.3	7 0.3
Transposition of Great Vessels (74510 - 74519)	62 0.5	47 0.4	8 1.0	4 0.4	5 0.5	7 0.6	7 0.6	6 0.7	4 0.2
Hypoplastic Left Heart Syndrome (74670)	27 0.2	25 0.2	1 0.1	3 0.3	4 0.4	0 0.0	1 0.1	0 0.0	3 0.1
Down Syndrome (75800 - 75809)	401 3.0	313 2.6	19 2.3	22 2.2	31 3.0	23 2.0	21 1.8	27 3.1	66 2.9

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. 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 have what are classified as minor malformations. 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).

Table 5 shows the number and proportion per 1000 total births of the major 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 are:

- There has been a fall in **neural tube defects** in total since 1995, 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 (including voluntarily fortification of some foods with folic acid and, since September 2009, mandatory fortification of wheat flour for bread-making). It is too soon to be able to detect with confidence any additional effect due to mandatory fortification. 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. .
- 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 increase in **hypospadias** seen up to 2000-2004, when 3.8 per 1000 births were affected, has not been sustained. Rates in 2010 and 2011 were 2.7 and 2.1 per 1000, respectively.
- An increase in **diaphragmatic hernia** was seen in 2011 (to 0.6 per 1000 births) compared with previous years (0.3 – 0.5 per 1000).
- The gradual rise in **chromosomal defects** since 1980 is a result of the increasing numbers of pregnancies in women over 35 years of age, and may also be related to the increased use of first trimester screening. There has been little change, however, in the rate of **Down syndrome** in liveborn infants (Figure 2).

Table 5

Numbers and Proportions of Cases of Birth Defects by Year of Birth and Diagnosis, 1980 - 2011

(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 No	80-89 Prop	90-94 No	90-94 Prop	95-99 No	95-99 Prop	00-04 No	00-04 Prop	05-09 No	05-09 Prop	2010 No	2010 Prop	2011 No	2011 Prop
NERVOUS SYSTEM DEFECTS (74000 - 74299)	991	4.2	594	4.7	593	4.6	626	5.0	678	4.6	98	3.1	100	3.1
Neural Tube Defects (74000 - 74209)	445	1.9	251	2.0	202	1.6	182	1.5	199	1.3	36	1.2	39	1.2
Anencephalus (74000 - 74029)	203	0.9	110	0.9	90	0.7	79	0.6	84	0.6	12		12	
Spina Bifida (74100 - 74199)	201	0.9	114	0.9	96	0.8	88	0.7	89	0.6	20	0.6	19	0.6
Encephalocoele (74200 - 74209)	41	0.2	27	0.2	16	0.1	15	0.1	26	0.2	4		8	
Microcephaly (74210)	125	0.5	73	0.6	73	0.6	73	0.6	56	0.4	9		5	
Congenital Hydrocephalus (excludes those with NTD) (74230 - 74239)	157	0.7	110	0.9	122	1.0	86	0.7	115	0.8	20	0.6	26	0.8
Congenital Deafness (74287)	159	0.7	101	0.8	109	0.9	153	1.2	157	1.1	16	0.5	12	
CONGENITAL ANOMALIES OF EYE (74300 - 74399)	255	1.1	176	1.4	172	1.3	160	1.3	119	0.8	19	0.6	2	
Anophthalmia (74300 - 74309)	13		4		10		6		5		0		0	
Microphthalmia (74310 - 74319)	40	0.2	24	0.2	31	0.2	21	0.2	14	0.1	4		0	
Congenital Cataract and Lens Anomalies (743300 - 74339)	57	0.2	53	0.4	49	0.4	34	0.3	27	0.2	5		0	
CONGENITAL ANOMALIES OF EAR, FACE AND NECK (74400 - 74499)	596	2.5	457	3.6	564	4.4	584	4.7	575	3.9	62	2.0	53	1.6
Anotia, Microtia (74400 - 74401, 74421)	46	0.2	34	0.3	40	0.3	29	0.2	30	0.2	3		3	

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No	80-89 Prop	90-94 No	90-94 Prop	95-99 No	95-99 Prop	00-04 No	00-04 Prop	05-09 No	05-09 Prop	2010 No	2010 Prop	2011 No	2011 Prop
Branchial Remnants (74440 - 74448)	121	0.5	75	0.6	79	0.6	67	0.5	70	0.5	5		4	
CARDIOVASCULAR DEFECTS (74500 - 74799)	1905	8.1	1502	11.8	1589	12.4	1550	12.4	1622	11.0	307	9.8	288	9.0
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
Tetralogy of Fallot (74520)	72	0.3	58	0.5	40	0.3	38	0.3	39	0.3	13		10	
Ventricular Septal Defect (74540 - 74549)	964	4.1	829	6.5	902	7.1	864	6.9	876	5.9	172	5.5	161	5.0
Atrial Septal Defect (74551 - 74559)	309	1.3	232	1.8	259	2.0	220	1.8	261	1.8	52	1.7	40	1.2
Hypoplastic Left Heart Syndrome (74670)	44	0.2	32	0.3	20	0.2	20	0.2	32	0.2	7		5	
Patent Ductus Arteriosus (74700)	288	1.2	212	1.7	237	1.9	195	1.6	268	1.8	51	1.6	42	1.3
Coarctation of Aorta (74710 - 74719)	117	0.5	76	0.6	64	0.5	81	0.6	75	0.5	13		9	
RESPIRATORY SYSTEM DEFECTS (74800 - 74899)	198	0.8	98	0.8	148	1.2	143	1.1	155	1.1	31	1.0	29	0.9
Choanal Atresia (74800 - 74809)	36	0.2	17	0.1	17	0.1	18	0.1	10		2		1	
GASTRO-INTESTINAL DEFECTS (74900 - 75199)	1465	6.3	805	6.3	859	6.7	779	6.2	860	5.8	153	4.9	113	3.5
Cleft Palate only (74900 - 74909)	197	0.8	131	1.0	151	1.2	154	1.2	148	1.0	25	0.8	22	0.7
Cleft Lip only (74910 - 74919)	112	0.5	58	0.5	59	0.5	76	0.6	80	0.5	12		8	
Cleft Lip and Palate (74920 - 74929)	198	0.8	70	0.5	99	0.8	91	0.7	92	0.6	14	0.4	20	0.6
Tracheo-Oesophageal Fistula, Oesophageal Atresia/Stenosis (75030 - 75038)	75	0.3	34	0.3	41	0.3	50	0.4	69	0.5	6		14	0.4

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No	80-89 Prop	90-94 No	90-94 Prop	95-99 No	95-99 Prop	00-04 No	00-04 Prop	05-09 No	05-09 Prop	2010 No	2010 Prop	2011 No	2011 Prop
Pyloric Stenosis (75051 - 75058)	470	2.0	237	1.9	224	1.8	145	1.2	194	1.3	37	1.2	3	
Stenosis/Atresia Small Intestine (75110 - 75119)	63	0.3	33	0.3	35	0.3	39	0.3	36	0.2	12		8	
Stenosis/Atresia Anus (75123 - 75125)	119	0.5	86	0.7	71	0.6	86	0.7	77	0.5	21	0.7	8	
Hirschprung's Disease (75130 - 75133)	38	0.2	32	0.3	21	0.2	17	0.1	35	0.2	10		5	
URO-GENITAL DEFECTS (75200 - 75399)	3279	14.0	2335	18.3	2511	19.7	2277	18.2	2341	15.9	394	12.6	289	9.0
Undescended Testis (treated) (75250 - 75254, 75257)	1546	6.6	851	6.7	739	5.8	649	5.2	547	3.7	73	2.3	42	1.3
Hypospadias (75260, 75263 - 75269)	664	2.8	444	3.5	459	3.6	470	3.8	487	3.3	85	2.7	68	2.1
Renal Agenesis or Dysgenesis (75300 - 75306)	109	0.5	76	0.6	100	0.8	122	1.0	121	0.8	25	0.8	22	0.7
Cystic Kidney Disease (75310 - 75319)	81	0.3	91	0.7	96	0.8	125	1.0	121	0.8	25	0.8	31	1.0
Obstructive Defects Renal Pelvis (75320 - 75329)	154	0.7	198	1.6	287	2.2	294	2.3	622	4.2	134	4.3	85	2.6
Vesico-Ureteric Reflux (75344)	486	2.1	501	3.9	650	5.1	434	3.5	274	1.9	39	1.2	23	0.7
Other Anomalies of Ureter (75340 - 75343, 75345 - 75349)	135	0.6	147	1.2	187	1.5	133	1.1	175	1.2	37	1.2	38	1.2
MUSCULO-SKELETAL DEFECTS (75400 - 75699)	3352	14.3	1900	14.9	2239	17.5	1967	15.7	2099	14.2	442	14.1	513	15.9
Developmental Dysplasia of Hip (75430 - 75434, 75439)	1500	6.4	773	6.1	935	7.3	716	5.7	813	5.5	208	6.7	307	9.5
Talipes (75450, 75454-75456,75473)	508	2.2	267	2.1	251	2.0	300	2.4	303	2.1	55	1.8	44	1.4
Polydactyly (75500 - 75509)	236	1.0	135	1.1	158	1.2	142	1.1	166	1.1	37	1.2	29	0.9
Syndactyly (75510 - 75519)	158	0.7	71	0.6	81	0.6	73	0.6	107	0.7	18	0.6	10	

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No	80-89 Prop	90-94 No	90-94 Prop	95-99 No	95-99 Prop	00-04 No	00-04 Prop	05-09 No	05-09 Prop	2010 No	2010 Prop	2011 No	2011 Prop
Reduction Deformities Upper and/or Lower Limbs (75520 - 75549)	158	0.7	115	0.9	159	1.2	146	1.2	149	1.0	22	0.7	22	0.7
Craniosynostosis (75600, 75601)	105	0.4	83	0.7	75	0.6	58	0.5	78	0.5	9		5	
Diaphragmatic Hernia (75661)	71	0.3	42	0.3	59	0.5	43	0.3	48	0.3	8		20	0.6
Exomphalos (75670)	58	0.2	47	0.4	39	0.3	59	0.5	60	0.4	11		18	0.6
Gastroschisis (75671)	37	0.2	32	0.3	52	0.4	38	0.3	61	0.4	10		13	
CONGENITAL ANOMALIES OF INTEGUMENT (75700 - 75799)	714	3.1	518	4.1	717	5.6	645	5.2	416	2.8	48	1.5	37	1.1
Birth Marks, Naevus (75738)	409	1.7	283	2.2	437	3.4	413	3.3	234	1.6	23	0.7	17	0.5
CHROMOSOME DEFECTS (75800 - 75899)	557	2.4	459	3.6	556	4.4	683	5.5	834	5.6	186	5.9	170	5.3
Down Syndrome (75800 - 75809)	315	1.3	219	1.7	251	2.0	331	2.6	409	2.8	100	3.2	89	2.8
Trisomy 13 (75810 - 75819)	22	0.1	18	0.1	22	0.2	40	0.3	48	0.3	6		7	
Trisomy 18 (75820 - 75829)	40	0.2	48	0.4	64	0.5	91	0.7	121	0.8	26	0.8	24	0.7
Turner Syndrome (75860 - 75861, 75869)	29	0.1	35	0.3	44	0.3	63	0.5	59	0.4	14	0.4	21	0.7
OTHER														
Congenital Hypothyroidism (24390 - 24399)	49	0.2	54	0.4	40	0.3	64	0.5	69	0.5	7		13	
Congenital Adrenal Hyperplasia (25520 - 25529)	15	0.1	9		16	0.1	15	0.1	12		2		0	
Disorders of Amino Acid Transport and Metabolism (27000 - 27099)	38	0.2	26	0.2	35	0.3	25	0.2	43	0.3	2		6	

Table 5 (continued)

Diagnostic Category (British Paediatric Association Code)	80-89 No	80-89 Prop	90-94 No	90-94 Prop	95-99 No	95-99 Prop	00-04 No	00-04 Prop	05-09 No	05-09 Prop	2010 No	2010 Prop	2011 No	2011 Prop
Phenylketonuria (27010)	13		7		7		10		14	0.1	1		1	
Disorders of Carbohydrate Transport and Metabolism (27100 - 27199)	21	0.1	13		7		8		4		5		3	
Cystic Fibrosis (27700)	76	0.3	44	0.3	28	0.2	53	0.4	65	0.4	11		13	
G6PD Deficiency (28220)	44	0.2	22	0.2	44	0.3	30	0.2	16	0.1	2		2	
Thalassemias (28240 - 28249)	5		6		6		3		5		0		1	
Haemophilia (28600 - 28620)	19	0.1	4		19	0.1	23	0.2	12		2		0	
Muscular Dystrophies and Myopathies (35900 - 35999)	70	0.3	22	0.2	30	0.2	14	0.1	20	0.1	2		0	
Fetal Alcohol Syndrome (75992)	36	0.2	23	0.2	26	0.2	74	0.6	54	0.4	3		0	
Congenital Rubella Syndrome (77100)	24	0.1	7		2		2		0		0		0	
Non-Immune Fetal Hydrops (77800)	64	0.3	85	0.7	89	0.7	92	0.7	138	0.9	23	0.7	24	0.7

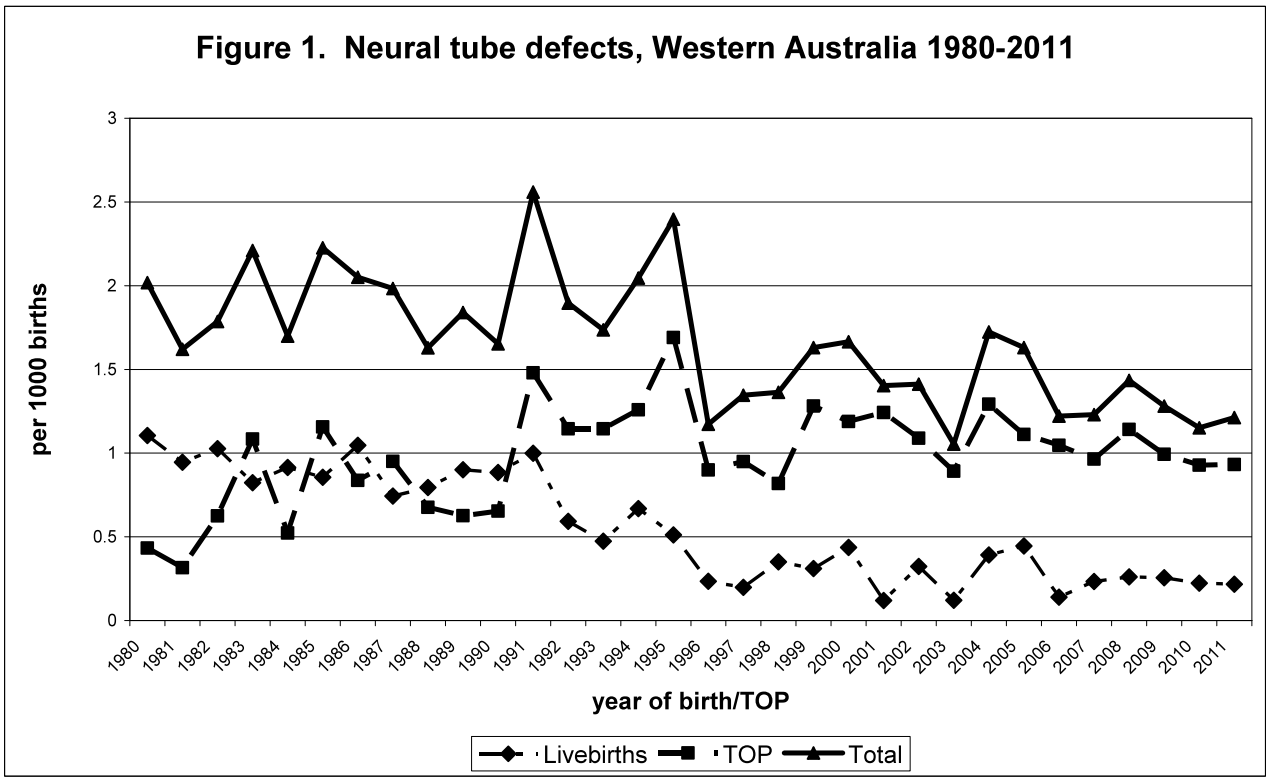


Figure 1. Neural tube defects, Western Australia 1980-2011
per 1000 births
year of birth/TOP
Livebirths
TOP
Total

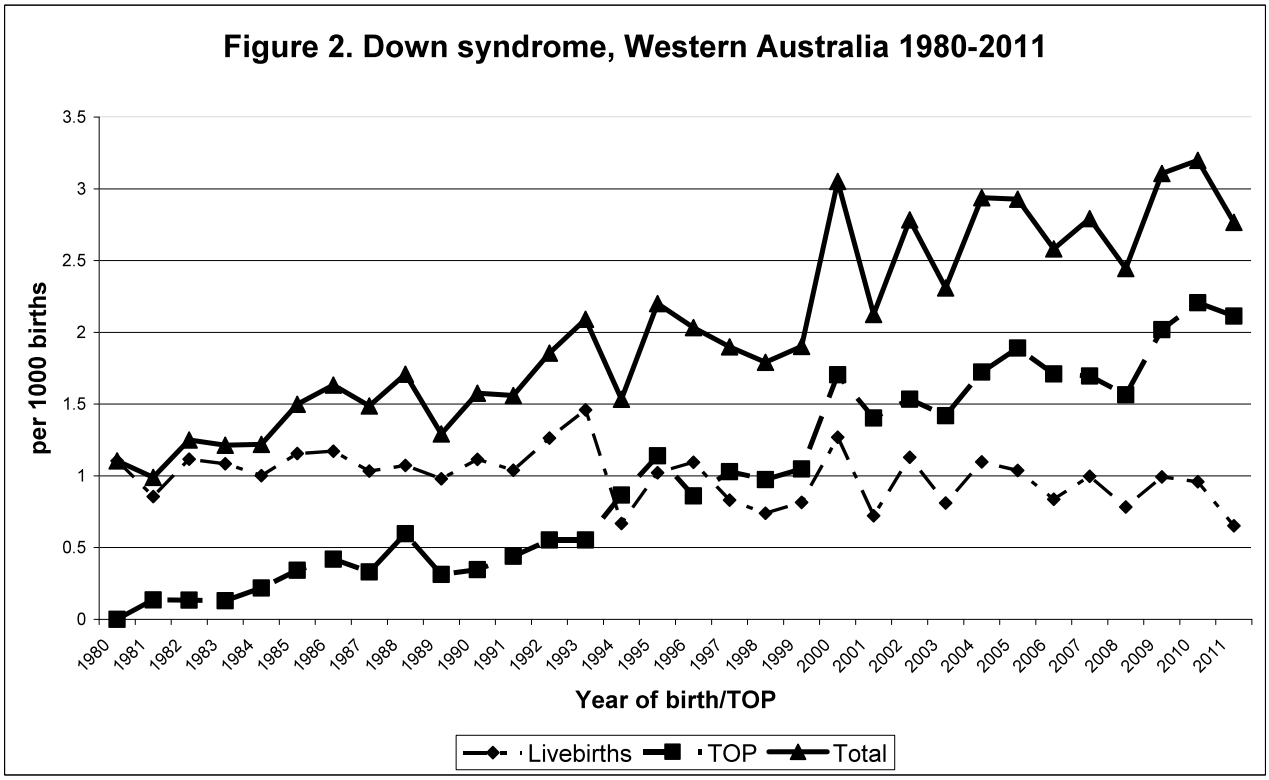


Figure 2. Down syndrome, Western Australia 1980-2011
per 1000 births
Year of birth/TOP
Livebirths
TOP
Total

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% - 50% of neonatal deaths and 11% - 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.

Table 6
Deaths with Birth Defects 1980 - 2011

Year of Birth	Stillbirths (% is of all stillbirths)		Neonatal deaths (% is of all neonatal deaths)		Postneonatal deaths (% is of all post-neonatal deaths)		Terminations of Pregnancy for fetal abnormality
	No.	%	No.	%	No.	%	No.
1980-89	251	13.5	513	39.7	213	27.5	402
1990-94	139	15.5	189	40.3	92	28.2	471
1995-99	134	14.8	145	39.1	82	38.9	635
2000-04	98	10.9	91	30.3	52	31.9	821
2005-09	106	10.0	100	30.4	62	31.5	1010
2010	18	8.3	22	32.8	6	11.3	226
2011	22	8.2	19	50.0	6*	30.0	228

* 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
MIDWIVES' FORMS	3334	1611	1422	1358	1470	288	390
HOSPITAL MORBIDITY	1440	1249	1924	2087	2067	255	0*
PAEDIATRIC HOSPITALS EXCL SPECIAL DEPTS	5510	2965	2037	1376	1237	189	191
PAEDIATRIC HOSPITALS SPECIAL DEPARTMENTS	2145	1889	1895	1546	1553	354	329
OBSTETRIC HOSPITALS EXCL SPECIAL DEPTS	1773	1055	1002	854	739	161	195
OBSTETRIC HOSPITALS SPECIAL DEPARTMENTS	328	408	596	672	838	205	222
OTHER HOSPITALS	423	56	46	89	57	9	6
CYTOGENETIC SERVICES	399	398	528	647	846	146	160
PATHOLOGY SERVICES	804	563	647	740	861	196	202
GENETICS SERVICES	1937	1499	1631	1564	1299	196	160
PRIVATE PRACTITIONERS	4983	3154	3621	3242	2879	588	590
CHILD & COMMUNITY HEALTH NURSES & DOCTORS	1201	421	252	86	39	5	1
RURAL PAEDIATRIC SERVICE	286	356	272	180	108	8	4
OTHER	618	59	61	368	449	1	0
REGISTER CHECK	765	256	193	129	211	29	25
TOTAL	25946	15939	16127	14938	14653	2630	2475

* Hospital morbidity data for 2011 births not yet available

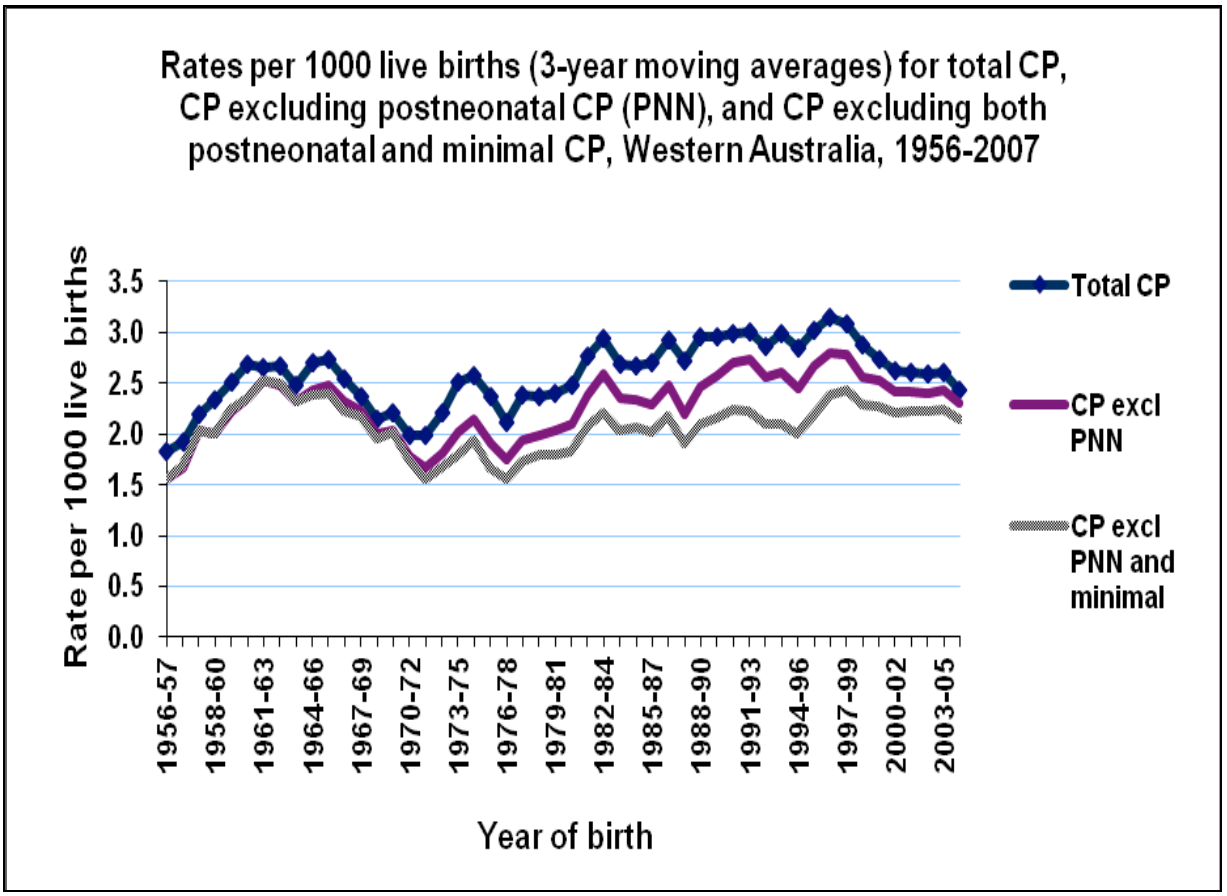
CEREBRAL PALSY DATA

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 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.

Figure 3.



CP = cerebral palsy; PNN = post-neonatal

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	328	2.64	*2.35 - 3.93*	302	2.43	*2.16 - 2.70*	273	2.20
2005-07	206	2.42	*2.09 - 2.75*	195	2.29	*1.97 - 2.61*	131	1.54

1 Excludes cases born outside WA

2 Postneonatally acquired cerebral palsy

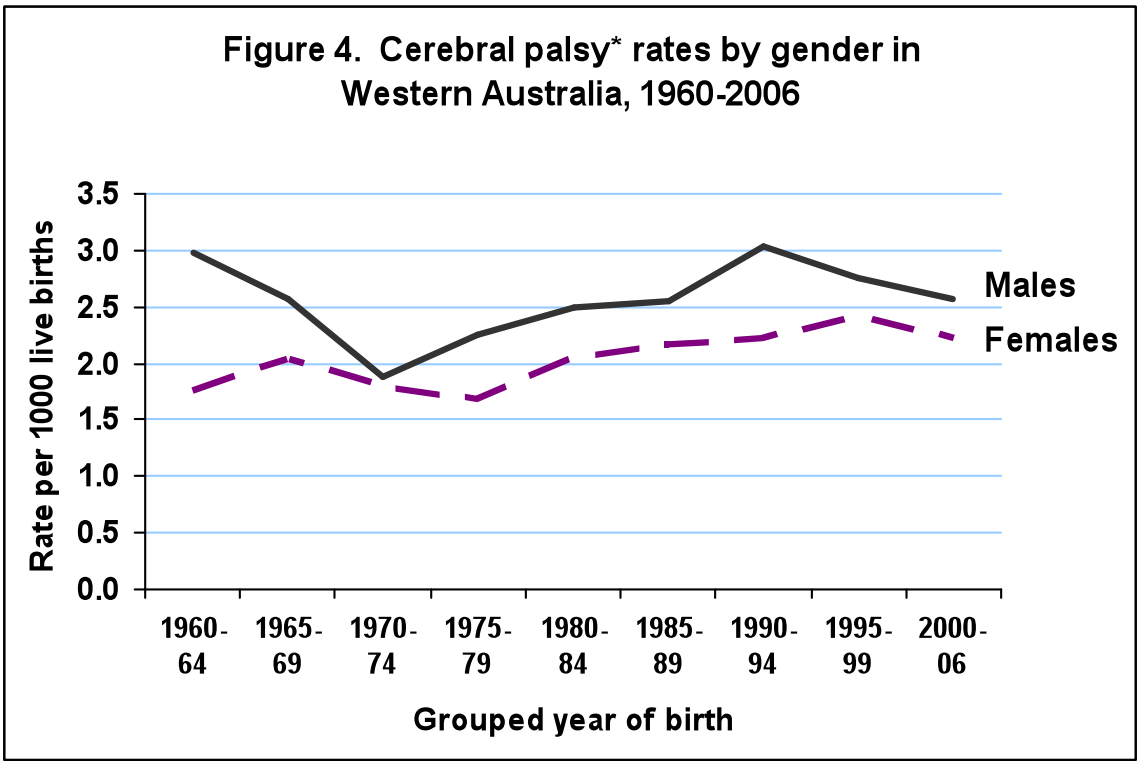
As the data for cerebral palsy for 2007 are preliminary and known to be incomplete, Table 9 and Figures 4 to 7 have not been updated to include 2007 births and hence are exactly the same as those included in last year's Annual Report.

Table 9

Cerebral palsy[1] rates and proportions by severity of motor impairment, Western Australia, 1980-2006

Year of Birth		CP Severity				All CP
		Minimal	Mild	Moderate	Severe	
1980-84	**CP**	32	75	78	67	**252**
	Rate/1000 LB	0.29	0.68	0.71	0.61	**2.28**
	95% CI	*0.19 - 0.39*	*0.52 - 0.83*	*0.55 - 0.86*	*0.46 - 0.75*	***2.0 - 2.56***
	% of all CP	12.7	29.8	31.0	26.6	**100.0**
1985-89	**CP**	37	99	77	73	**286**
	Rate/1000 LB	0.31	0.82	0.63	0.60	**2.36**
	95% CI	*0.21 - 0.4*	*0.66 - 0.98*	*0.49 - 0.78*	*0.46 - 0.74*	***2.08 - 2.63***
	% of all CP	12.9	34.6	26.9	25.5	**100.0**
1990-94	**CP**	58	97	81	96	**333**
	Rate/1000 LB	0.46	0.77	0.64	0.76	**2.64**
	95% CI	*0.34 - 0.58*	*0.61 - 0.92*	*0.5 - 0.78*	*0.61 - 0.91*	***2.35 - 2.92***
	% of all CP	17.4	29.1	24.3	28.8	**100.0**
1995-99	**CP**	51	118	85	74	**328**
	Rate/1000 LB	0.40	0.93	0.67	0.58	**2.58**
	95% CI	*0.29 - 0.51*	*0.76 - 1.1*	*0.53 - 0.81*	*0.45 - 0.72*	***2.3 - 2.86***
	% of all CP	15.5	36.0	25.9	22.6	**100.0**
2000-06	**CP**	35	163	110	120	**430**
	Rate/1000 LB	0.20	0.91	0.61	0.67	**2.40**
	95% CI	*0.13 - 0.26*	*0.77 - 1.05*	*0.5 - 0.73*	*0.55 - 0.79*	***2.17 - 2.62***
	% of all CP	8.1	37.9	25.6	27.9	**100.0**
1980-2006	**CP**	**213**	**552**	**431**	**430**	**1629**
	% of all CP	**13.1**	**33.9**	**26.5**	**26.4**	**100.0**

[1] CP - excludes cases born outside WA and those due to postneonatal causes
[2] 95% confidence interval
Note: There is one case with unknown severity in 1990-94 and two in 2000-06



*Excludes cerebral palsy due to postneonatal causes

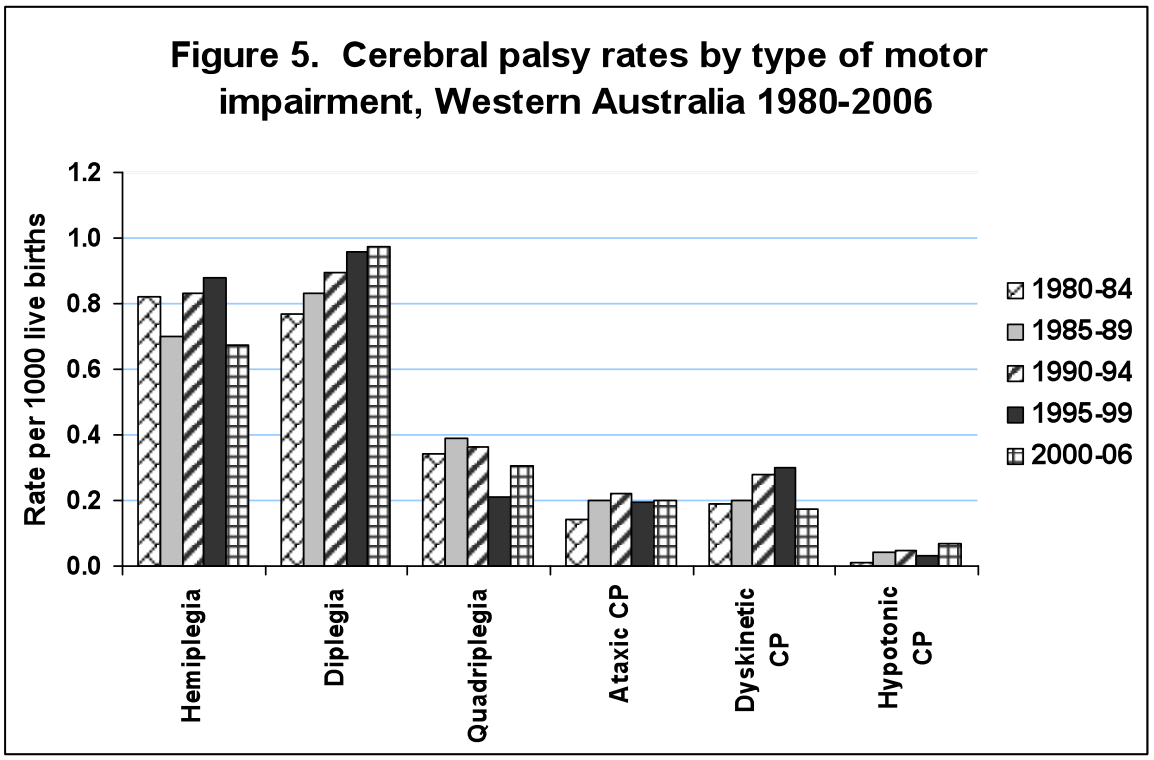


Figure 6. CP type as proportion of all CP, 1980-2006 combined

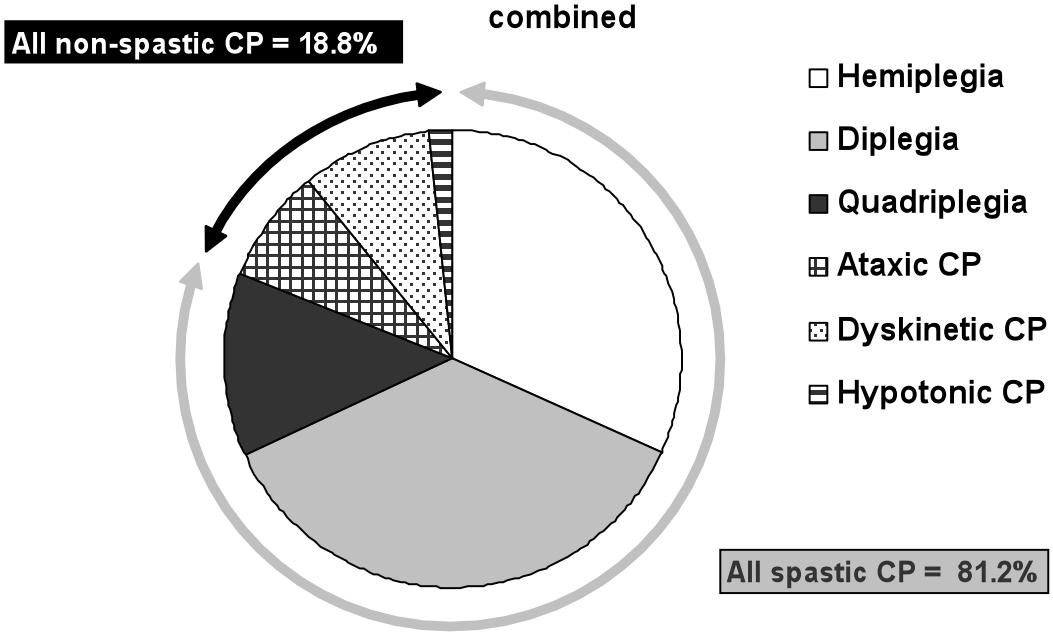
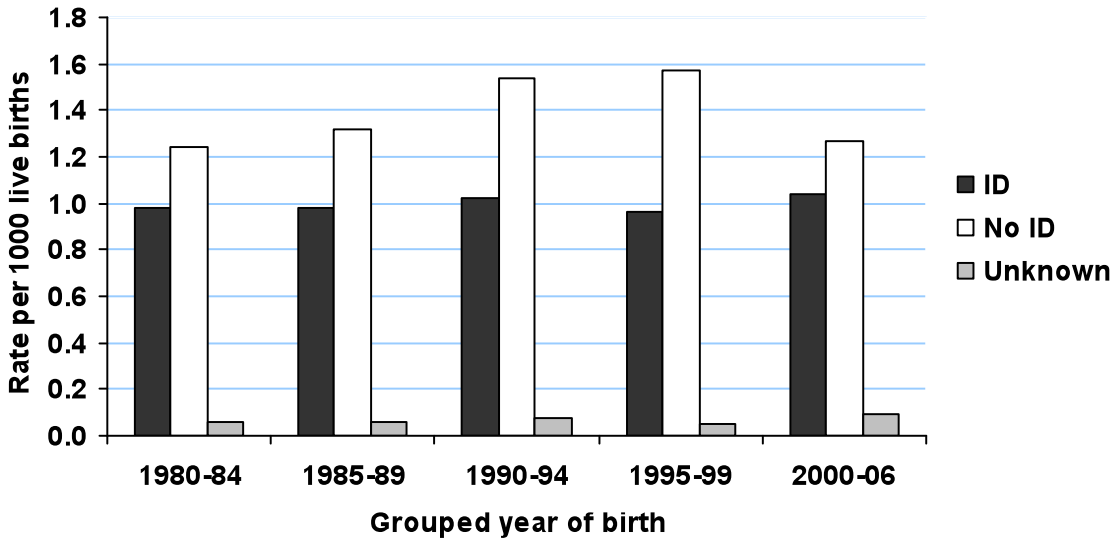


Figure 7. Cerebral palsy by presence or absence of intellectual disability (IQ <70), WA 1980-2006



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 forwarded to the Department of Health WA Human Research Ethics Committee for approval.

2. Information on developmental anomalies

Over the past year, 40 requests for information or data on developmental anomalies have been received. Eight of these requests were from the state or federal Departments of Health, 25 were from health professionals and institutions in WA, Australia or overseas, 5 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. Presentations

In the past year, over 20 presentations were made at state, national and international meetings.

4. International Clearinghouse for Birth Defect Surveillance and Research

Data based on 2009 births were provided to the International Clearinghouse for inclusion in the 2012 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. The second ACPR Report to birth year 2006 is now in preparation for publication in 2013. The ACPR took a leading role in the planning of the 4th International CP Conference 2012 in Pisa which included the 2nd World CP Registers Day, a forum for the discussion of issues arising from the collection, pooling and analysis of CP data.

6. Cerebral Palsy Community Forums

Following the creation of WARDA and the introduction of statutory notification of birth defects and CP from the beginning of 2011, a CP Community Forum led by the Community Participation Unit was held in November 2011 for families, individuals with CP and health professionals with an interest in CP. Its purpose was to explain the new legislation and how it came about and to invite their feedback. We also wanted to address issues specific to CP data collection, particularly the need to update information about CP and associated disabilities at the age of 5 years in order to report it at a consistent and meaningful age. As therapists are best placed to provide this information but are not covered by the legislation, we asked for their views on how this could best be achieved. The Forum was well attended and brought together a group of people with an interest in CP, many with

an ongoing willingness to contribute their experience and views for the benefit of CP research.

A second CP Community Forum was held in Broome in March 2012 for parents and health professionals in the northwest who were unable to come to the earlier Forum in Perth. Again led by the Community Participation Unit, it attracted wide participation and raised issues specific to regional WA, especially the infrequency and lack of continuity of therapy and medical services. WARDA information materials were unknown to them and were seen in some ways to be less relevant to their circumstances.

We especially appreciated the participation of Clare Masolin from the CP Advisory Committee and Beth Stein from the WARDA Community Reference Group who presented on behalf of WARDA, bringing a personal element to the Forums that greatly contributed to their success.

7. Research Activities

7.1 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 will compare distributions of antecedents of growth restriction between the different outcome groups in an effort to identify distal causal factors that may be more amenable to prevention.

7.2 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.

7.3 Heavy maternal alcohol consumption and cerebral palsy in the offspring

This record linkage study investigated the association between heavy maternal alcohol consumption, determined by a maternal alcohol-related diagnostic code recorded in WA health data sets from 1983 to 2007, and an outcome of cerebral palsy (CP) acquired pre-, peri- or postneonatally in offspring, as identified from the WARDA. Findings showed elevated odds of pre/perinatally acquired CP for children of non-Aboriginal mothers with an alcohol-related diagnosis recorded during pregnancy and for Aboriginal children when an alcohol-related diagnosis was recorded up to 12 months before the mother's pregnancy. Increased odds of postneonatally acquired CP following any alcohol-related diagnosis were found for non-Aboriginal children. These results suggest that heavy maternal alcohol consumption is a direct cause of pre/perinatally acquired CP, and an indirect cause of postneonatally acquired CP, in non-Aboriginal children. The lack of an association for Aboriginal children may be due to under ascertainment of alcohol-use disorders during pregnancy and other aetiological pathways. This work was conducted by Dr Colleen O'Leary and a paper has been published (O'Leary C et al. Developmental Medicine and Child Neurology. 2012;54(3):224-230).

7.4 What constitutes Cerebral Palsy?

An international collaboration to harmonise inclusion/exclusion criteria for CP registers commenced at the 1st World Congress of Registers at the ICPC 2009 in Sydney. Work has progressed in the years since, co-ordinated by the ACPR, with the collation of lists of syndromes identified in children with CP held by different registers in Australia, Europe and the US. Extensive discussions by email and teleconference have ensued about which should be included as CP, and to develop policies where possible. It is anticipated that this work will eventually be published as an update of the much-referenced Badawi et al paper of 1998, "What constitutes cerebral palsy?".

7.5 Assisted reproductive technologies (ART) and birth defects

This data linkage study estimated the prevalence of major birth defects diagnosed by 6 years of age for pregnancies conceived by ART 1994-2002 in WA, compared with all other births in WA. There were 2,911 ART births and 210,997 non-ART births over the study period. Higher order multiples and Aboriginal births were excluded.

A major birth defect was diagnosed in 8.7% of ART and 5.4% of non-ART singletons (adjusted odds ratio [aOR] 1.53, 95% confidence interval [CI] 1.30-1.79), as well as 7.1% of assisted ART twins and 5.9% of non-ART twins of unlike sex (aOR 1.08, 95% CI 0.77-1.51). The prevalence of birth defects in ART singletons and twins decreased markedly over the study period. (Hansen M et al. Obstet Gynecol. 2012;120(4):852-63).

7.6 Occurrence of facial clefts in WA 1980-2009

A research study examining the epidemiology of cleft lip and palate since 1980 in Western Australia is being undertaken by Jane Bell, a PhD student from Sydney. Around 1 in 830 children were born with a cleft lip with or without a cleft palate and 1 in 1000 children were born with a cleft palate. Clefts involving the lip were mainly

diagnosed before birth or at birth. The rate of diagnosis before birth for babies with a cleft lip has increased dramatically since the 1980s. However, children with a cleft palate only are often not diagnosed until later (especially those with a sub-mucous cleft or bifid uvula). Like other states in Australia and the rest of the world, clefts involving the lip are more common in males, and clefts involving the palate only are more common among females. Most babies (about 70%) with a cleft of the lip are not diagnosed with another anomaly, but around 60% of babies with a cleft palate only also are born with another anomaly. The next stage of the research involves record linkage to hospital and education data to compare the educational achievement and hospitalisations of children with clefts, with children without clefts. Jane has met with members of CleftPals to discuss her research and gave a presentation at their Annual General Meeting in May.

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