

Register

Queensland 1996 Birth Year Report

acknowledgements

Information and data collated in this first report of the Queensland Cerebral Palsy Register (QCPR) is a culmination of the joint efforts of many people and the support of many services.

Firstly, we acknowledge each person with cerebral palsy and his/her family who have generously supported this project and been committed to sharing their information. Without the groundswell of client participation that has occurred, the QCPR would not be a reality. We hope that this report honours this significant contribution and trust by people with cerebral palsy and their families.

We acknowledge the Cerebral Palsy League, the Queensland-based organisation that originally championed the cause for a register and set about finding like-minded service partners and funding sources required to establish and run the QCPR. The Cerebral Palsy League is the host of the register, providing day-to-day support for office infrastructure, information technology and management of register functions and its steering committee.

The register would not have been possible without the generous financial support of Queensland Health. Funding support was announced in 2004, following tremendous support by the then Health Minister, Hon. Wendy Edmond and the founders of the Queensland Cerebral Palsy Health Service. Today, continuing operation of the register is still attributable to recurrent funding provided by Queensland Health.

Completeness of register data is dependent on the support and referrals from staff of many service agencies across Queensland. The QCPR is especially grateful to the Cerebral Palsy League, Queensland Health, the Mater Health Services, the Department of Education and Training, and the Department of Communities (Disability and Community Care Services). These departments and agencies have contributed support through membership on the QCPR Steering Committee, disseminated information to families and provided advice in the preparation of this report. Research representatives from the University of Queensland, the Queensland Cerebral Palsy and Rehabilitation Research Centre and the Cerebral Palsy League have also contributed as steering committee members, providing ongoing advice on how client information is collected and analysed.

Individuals maintaining other client registers have also helped enormously in the design and development of the QCPR. This input assisted us to navigate the development of the database and operational processes and ensured a streamlined implementation of the register.



table of contents

Acknowledgements.....	2
Foreword from the Minister.....	4
Foreword from the Chair.....	5
Executive Summary.....	6
Cerebral Palsy.....	8
Queensland Cerebral Palsy Register.....	9
Motor Type and Distribution	
Motor Type and Distribution.....	12
Gestational Age and Spastic Motor Type.....	13
Gross Motor Function.....	14
Spastic Motor Type and Distribution and Gross Motor Function.....	15
Birth Details	
Maternal Age at Delivery.....	16
Previous Births to Mother.....	17
Plurality.....	18
Birth Weight.....	19
Gestational Age.....	21
Gestational Age by Birth Weight.....	22
Neonatal Intensive Care Unit Admission.....	23
Demographics	
Gender.....	24
Indigenous Status.....	25
Birth Origin.....	26
Vision	
Vision.....	27
Vision and Gross Motor Function.....	28
Vision, Motor Type and Distribution.....	29
Hearing	
Hearing.....	30
Hearing and Gross Motor Function.....	31
Hearing, Motor Type and Distribution.....	32
Intellectual Status	
Intellectual Status.....	33
Intellectual Status of Children with Cerebral Palsy by Spastic Motor Type.....	34
Epilepsy	
Epilepsy.....	35
Epilepsy Status and Motor Type.....	36
Epilepsy Status and Gross Motor Function.....	37
References.....	38
AppendixA.....	39
Contributors.....	40

Foreword from the minister

I commend this Queensland Cerebral Palsy Register report to every Queenslander. It provides a contemporary vision of cerebral palsy in this state. Cerebral palsy is the most common cause of disability in childhood and an estimated 100-120 babies born each year in Queensland will be affected by cerebral palsy. Queensland is Australia's fastest growing state and as such requires a plan and vision to deliver the services that a modern population expects, so all Queenslanders can benefit from the lifestyle that we are famous for. This report is an excellent resource for that future planning.



This first report outlines the population size and important characteristics of people with cerebral palsy in Queensland who were born in 1996. It provides information on known cerebral palsy risk factors including low birth weight and multiple births as well as accompanying disabilities. Cerebral palsy risk is greatly increased for babies with birth weight less than 1500g (10-12% risk) and for multiple births (with a seven fold increased risk for twins and 17 fold increased risk for triplets compared with single birth).

It is important to recognise that cerebral palsy affects each person differently, therefore people with cerebral palsy have varying individual needs.

Over the next few years, the Queensland Cerebral Palsy Register will provide information about other birth years, showing trends over time that will be essential for proper planning as the population of Queensland continues to grow.

The Register will also help clinicians better evaluate the outcomes of interventions and offer valuable health research into therapy interventions and other treatments.

The Register is linked to the National Cerebral Palsy Register which will provide a more complete picture of cerebral palsy across Australia. This partnership will also allow us to compare the characteristics of people with cerebral palsy in Queensland with those in other states in Australia.

The Cerebral Palsy League of Queensland should be commended on its fine work and the Queensland Government looks forward to continuing the partnership that it has with the organisation - together providing a healthier future for Queenslanders with cerebral palsy.

A handwritten signature in black ink, appearing to be 'Paul Lucas'.

Hon. Paul Lucas MP
Deputy Premier
Minister for Health



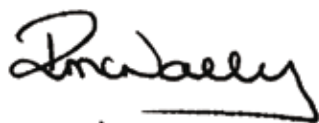
Foreword from the Chair

The Cerebral Palsy League of Queensland (CPL) has been proud to support the development of the Queensland Cerebral Palsy Register. Every 18 hours a child is born with cerebral palsy somewhere in Australia so it is vitally important that we better understand this condition. Currently there is no cure or pre-birth test, but through initiatives such as the Queensland Cerebral Palsy Register we can begin to work more effectively with researchers to find better ways forward and most importantly work with health practitioners to effectively plan and deliver the support people with cerebral palsy need.



Reports from the Queensland Cerebral Palsy Register will enable the CPL to improve the design of services for the future and better match our staff numbers and skills to where clients are located and in most need of support. CPL will also be able to better assess and quantify the gap in services being provided and work with the Government and community to close that gap.

I am proud to see the Queensland Cerebral Palsy Register produce the first of many anticipated reports that will help us to create a community that actively seeks and supports the contributions of people with cerebral palsy.

A handwritten signature in black ink, appearing to read 'Rowena McNally'.

Rowena McNally

Chairperson

Cerebral Palsy League Board of Directors

executive summary

The Queensland Cerebral Palsy Register was established in 2005 to collect data on the population characteristics of people with cerebral palsy in Queensland. The information we gather will be used to investigate the causes of cerebral palsy, find ways to prevent and manage cerebral palsy and help to plan services.

This first report details the distribution, classification, severity and known risk factors for people in Queensland with cerebral palsy who were born in 1996. It is primarily intended to provide an initial snapshot of the population of cerebral palsy in Queensland for service providers and consumer groups in the hope that better informed service planning, service provision and self advocacy will lead to improved lives for people with cerebral palsy.

The vast majority of information has been provided directly by the parents and/or guardians of children with cerebral palsy after being introduced to the cerebral palsy register by their treating clinicians. Completing records and confirming consent was undertaken actively by the registry staff.

How common was cerebral palsy in Queensland among those born in 1996?

In total, 87 people with cerebral palsy have been registered for this birth year. These children were either born in Queensland or received services in Queensland in the neonatal period. Over 10% of the total group did not live in Queensland at the time of birth, however only 5% were born outside of Queensland. The total number of babies born in Queensland in 1996 was 47,987 giving a crude prevalence of cerebral palsy of 1.8 per thousand live births.

What was the spread of motor type and motor distribution in Queensland among those born in 1996?

For these children, the motor type and distribution spread is similar to that published by the Australian Cerebral Palsy Register. Seventy-eight percent of Queensland children with cerebral palsy born in 1996 had spastic motor type. This consisted of 29% with hemiplegia, 36% with diplegia, 1% with triplegia and 13% with quadriplegia. Ataxic cerebral palsy accounted for 5% of children with cerebral palsy, dyskinesia or low tone 7% and 11% had no entry for this field. Missing

data is a combination of registrations which were lost to follow-up before information could be collected but after the diagnosis of cerebral palsy was made, and individual missing fields from otherwise completed registrations. Some children died or moved away from Australia before information could be completed and others were not contactable even after receiving a registration. These cases were retained primarily for the overall rate of cerebral palsy and we expect that as we report on younger and younger age groups the rate of missing data will decrease.

What are the effects of cerebral palsy?

Seventy-eight percent of all children on the register born in 1996 have spastic cerebral palsy. Spasticity makes movement and coordination difficult because of an increase in muscle tone and heightened response to voluntary movements. Over 28% of Queensland children with cerebral palsy born in 1996 could not walk functionally or could not walk at all. However 45% were able to walk with little or no restrictions.

Children with cerebral palsy were likely to have other impairments in addition to their motor disability. Forty-five percent of children had some vision impairment and 11% were functionally blind. The Australian Cerebral Palsy Register reported that 5.3% of people with cerebral palsy were functionally blind which suggests that for the 1996 birth year, Queensland had a higher rate of people with cerebral palsy who were blind. While this may be true it is important to resist the temptation of drawing conclusions about other birth years. Future reports will give a better indication about the rate of blindness in the Queensland population of children with cerebral palsy. It is also worth noting that 30% of children with cerebral palsy had no vision impairment at all and a further 16% had strabismus only.

Only 2% of children with cerebral palsy were bilaterally deaf while 81% had no hearing impairment. Thirty-two percent of children with cerebral palsy were diagnosed with epilepsy at five years of age and 52% reported never having had any seizures. More than 30% of children were reported to have typical intellectual abilities and approximately 50% had some level of intellectual impairment with 32% classified in the moderate or severe impairment range.

Identified risk factors

The Australian Cerebral Palsy Register Report published earlier in 2010 identified four risk factors in the development of cerebral palsy.

1. Male

The Australian Cerebral Palsy Register reported that 56.4% of all children with cerebral palsy in Australia were male. In Queensland during 1996, 55% of all children with cerebral palsy were male.

2. Preterm birth

The Australian Cerebral Palsy Register reported that 42% of all children with cerebral palsy were born before 37 weeks completed gestation. In Queensland during 1996, 38% of all children with cerebral palsy were born preterm. Children who were born before 27 weeks completed gestation had slightly more than 30 times the rate of cerebral palsy compared to children who were born between 37 and 41 weeks of completed gestation.

3. Low birth weight

Being born with a low birth weight can result from early birth or a slow rate of growth. The Australian Cerebral Palsy Register reported that 43% of all children with cerebral palsy were born weighing less than 2500g. In Queensland during 1996, 36% of all children with cerebral palsy were born with a birth weight of less than 2500g. Again, children who were born with a birth weight of less than 1500g had approximately 30 times the rate of cerebral palsy compared to children who were born weighing between 2500 and 4000g.

4. Multiple births

The Australian Cerebral Palsy Register reported that 11% of children with cerebral palsy were from a multiple birth. In Queensland during 1996, 6% of all children born were from a multiple birth. Children born as one of twins had four times the rate of cerebral palsy than those born as singletons. Children born as part of triplets or higher plurality births had 26 times the rate of cerebral palsy than those born as singletons.

Overall the picture presented of people with cerebral palsy in Queensland who were born during 1996 is consistent with data

from the rest of Australia. While there are some differences, such as the rate of bilateral blindness, it is important to seek confirmation that the 1996 birth year is representative of Queensland before searching for possible explanations of differences. It is expected that the next report of the Queensland Cerebral Palsy Register will include several birth years and test the representative nature of data presented in this first report. Nevertheless, this first picture of the population with cerebral palsy in Queensland is an achievement and a foreshadowing of even greater things to come.

cerebral palsy

Cerebral palsy is the most common physical disability in childhood. Historically the rate of cerebral palsy has been reported as between 2 and 2.5 people per thousand live births in the developed world ^[5, 7].

definition of cerebral palsy

The definition of cerebral palsy the QCPR uses is the same definition used by the Australian Cerebral Palsy Register and all other state and territory cerebral palsy registers.

Cerebral palsy:

1. Is an umbrella term for a group of disorders
2. Is a condition that is permanent but not unchanging
3. Involves a disorder of movement and/or posture and of motor function
4. Is due to a non-progressive interference, lesion, or abnormality, and
5. The interference, lesion, or abnormality originates in the immature brain ^[1].

This definition is supported by experts within all Australian registers as the most valid and useful definition of cerebral palsy available. It includes key elements from published definitions by Bax ^[2], Mutch ^[3] and Rosenbaum ^[6].

The use of a consistent definition allows data from across all Australian registers to be pooled to create the single largest collection of data from people with cerebral palsy from contiguous jurisdictions in the world. The significance of this data source cannot be underestimated; it can be used to explore the causes of cerebral palsy and methods of prevention and amelioration once the injury has been sustained.

classification of cerebral palsy

A person's presentation of cerebral palsy has traditionally been described according to two categories: motor type and motor distribution.

- Motor type refers to the type of movement disorder a

person has, for example: spasticity, dyskinesia and hypotonia.

- Motor distribution refers to which limbs are involved, for example, involvement of one arm and leg on the same side of the body is termed hemiplegia.

These descriptions remain very important ways of understanding the presentation of cerebral palsy so they are included in all reports of the Queensland and Australian Cerebral Palsy Registers.

Recent advancements have seen the development of additional methods to describe other aspects of a person's presentation of cerebral palsy. The Gross Motor Function Classification System (GMFCS) is one of these advancements and categorises the level of gross motor function or limitations achieved by children with cerebral palsy, for example the ability to sit or walk, or the need to use a walker or wheelchair. Research has shown that there are strong relationships between a child's GMFCS level and many aspects of development and function ^[4]. The usefulness of this classification system has seen it become routinely reported by cerebral palsy registers, researchers and by clinicians during service planning and evaluation for children with cerebral palsy. In line with this practice, this report will utilise it in relevant comparisons.

Aside from these three main classification systems, the individual presentations and experiences of people with cerebral palsy are also impacted by varying abilities related to vision, hearing, speech or language, intellectual status, as well as the presence of epilepsy. As each of these is common across different groups of people with cerebral palsy, this report will detail the extent they are present in the population of children with cerebral palsy born in 1996.

queensland cerebral palsy register

The purpose of the QCPR is to collect, analyse and present information that provides a picture of people with cerebral palsy in Queensland.

This information is useful for:

- Describing the types and severity of cerebral palsy experienced by people in Queensland
- Researching the causes and impacts of cerebral palsy for clients, families, service providers and funders

The register is a stand-alone service, separate from all service, research and funding organisations. It represents people with cerebral palsy living throughout Queensland regardless of the organisations they may be associated.

aims of the qcpr

These are to:

1. Describe the number of people with cerebral palsy in Queensland, their functional abilities and general geographical distribution.
2. Provide a useful collection of data that will assist service funders and service providers in designing systems that improve the lives of people with cerebral palsy in Queensland.
3. Provide a database of information useful for research into the causes of cerebral palsy and future prevention.
4. Provide a database of information useful for research into interventions that will improve the function, participation and quality of life for people with cerebral palsy.

australian cerebral palsy register

The Australian Cerebral Palsy Register is a collaboration between all Australian state and territory cerebral palsy registers, including the QCPR. The Australian register provides a central collection point for information about people with cerebral palsy from across Australia. This data is de-identified to protect the privacy of individuals with cerebral palsy. The amalgamation of data on a national scale dramatically increases the sensitivity of research into the causes and effects of cerebral palsy in Australia.

methods of the qcpr

Ascertainment

Ascertainment is a multi-stage process that includes:

- *Identifying* people with cerebral palsy
- *Contacting* each person (or their guardian) to gain consent for including them on the register
- *Collecting* the information from the person (or their guardian) about the characteristics of their cerebral palsy
- *Entering* this information in the register database
- *Confirming* the accuracy of information if required

The QCPR identifies the vast majority of people with cerebral palsy in Queensland through referrals from their service providers. A small minority of people are identified through community awareness initiatives such as publications, news stories and advertising.

To be included on the register, individuals can submit their contact information and a description of their presentation of cerebral palsy using four different methods:

- *Online* – clients (or their guardians) can register directly via the QCPR website www.qcpr.org.au.
- *Mail* – clients (or their guardians) can mail a QCPR referral card or questionnaire to the register office. Forms are available from service providers or they can be downloaded from the QCPR website.
- *Telephone* – clients (or their guardians) can telephone the register office and staff will collect information over the phone.
- *Email* – clients (or their guardians) can email their information in a message to register staff. If a QCPR questionnaire has been completed, this can also be sent to the office via email.

As well as submitting information by one or more of these methods, clients also need to submit a signed consent form before their details can be incorporated into register analyses and reports. This form records up to four different consents:

- *Collecting and entering QCPR data*
Agreeing to information about their contact details and description of cerebral palsy being uploaded to the QCPR. This information is used by register staff to report on the characteristics of cerebral palsy for people in Queensland and to contact the person if required.
- *Confirming QCPR data*
Agreeing for register staff to contact a service provider, nominated by the client (or his/her guardian), to verify information about the person's characteristics of cerebral palsy. This may involve a nominated practitioner reviewing the person's QCPR registration information. This process is used to make sure that information held on the QCPR is consistent across Queensland.
- *Transferring data to the Australian Cerebral Palsy Register*
Agreeing to information about their type of cerebral palsy being uploaded onto the Australian register. Personal identifying information is not transferred. Uploaded information is used in describing the Australian population of people with cerebral palsy.
- *Research*
Identifying they wish to be sent information about opportunities to participate in research into the causes, nature and effects of cerebral palsy. All research supported by the QCPR is approved by the QCPR steering committee and a National Health and Medical Research Council approved Australian ethics committee (currently the Cerebral Palsy League of Queensland Ethics Committee). This consent indicates a willingness to be contacted for relevant research only. Individuals must provide specific consent to each researcher prior to participation in any given research. Participation is confidential and not disclosed to or recorded by the QCPR.

The overall procedure for QCPR and Australian Cerebral Palsy Register ascertainment was reviewed and approved by the National Health and Medical Research Council, compliant with the Cerebral Palsy League Ethics Committee on behalf of

the QCPR (approval # CPLQ 2008/09-1013). Ethics approval for data porting from individual service providers to the QCPR is being sought at present. Consent has so far been received from the Royal Children's Hospital and Health Service District Ethics Committee (approval # RCH & HSD Ethics 2008/113) and the Cerebral Palsy League of Queensland Ethics Committee (approval # CPLQ 2008/09-1013).

Cohort

Information included in this report is from people born in 1996 who have a diagnosis of cerebral palsy who were:

- Born during 1996 in Queensland, whether or not they still live in Queensland, or
- Born outside of Queensland, but who now live in Queensland and/or receive Queensland services

The 1996 birth year was used in this first report for two reasons. Firstly, it met the two requirements for inclusion and reporting in the Australian Cerebral Palsy Register report, which are a prevalence of cerebral palsy greater than 1.5 per thousand live births and greater than 80% completed fields in most categories. Secondly, the 1996 birth year is within the scope of the Australian Cerebral Palsy Register report and as a result, increases our understanding of the population characteristics of cerebral palsy in Australia.

Extrapolation of findings

This is the first report of the new Queensland Cerebral Palsy Register and presents only data from children born in 1996 for analysis (see section Future Directions below). Therefore, it is important to understand that:

- The findings in this report may not reflect characteristics of people with cerebral palsy born in other birth years.
- The data is insufficient to assess trends over time in Queensland.
- Data in this report cannot be directly compared to reports from other registers that reflect multiple birth years and trends over time.

Denominator data

Where the rate of cerebral palsy per thousand live births is

given in tables or graphs the denominator value for live births is reported according to population statistics published by the Queensland Perinatal Data Collection ^[6]. Our data is grouped according to the parameters of that data for accuracy. For example, in "Age of mother", the denominator has been taken from the Queensland Perinatal Data Collection reference groupings of:

1. Less than 20 years
2. 20 - 34 years
3. 35 years or more
4. Age of mother not stated

Future directions

The 1996 birth year was chosen for this first report for three reasons. The first reason was that when the available data was first reviewed it seemed possible that enough registrations had occurred in this birth year to meet the eligibility criteria for publication of data in the Australian Cerebral Palsy Register. The second reason was that most of this birth year were still involved in children's services and as a result were likely to be contactable to verify information. Thirdly, the 1996 birth year fell inside the age range for the first Australian Cerebral Palsy Register Report that was published in February 2010.

It is our intention to publish multiple birth years as soon as possible. It is likely that the 2011 report from the QCPR will include 1996, 1997 and 1998 birth years. If possible, we will include more birth years with the possible inclusion of 1996 to 2000.

Publication of multiple birth years will give a range for prevalence of cerebral palsy in Queensland as well as the possibility of viewing trends over time. Data will be more robust with larger numbers and a measure of variability. This should allow direct comparisons with data from other cerebral palsy registers and the Australian Cerebral Palsy Register.

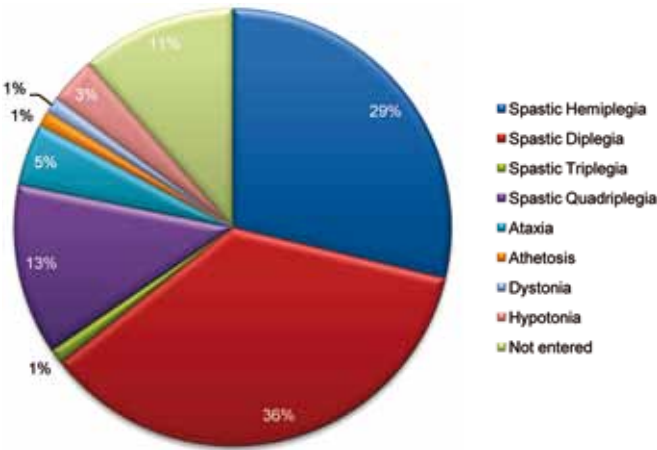
motor type and distribution

motor type and distribution

Table 1: Number of children with cerebral palsy born in 1996 by predominant motor type and motor distribution

Spastic Hemiplegia	Spastic Diplegia	Spastic Triplegia	Spastic Quadriplegia	Ataxia	Athetosis	Dystonia	Hypotonia	Not entered	Total
25	31	1	11	4	1	1	3	10	87

Figure 1: Percentage of children with cerebral palsy born in 1996 by motor type and motor distribution

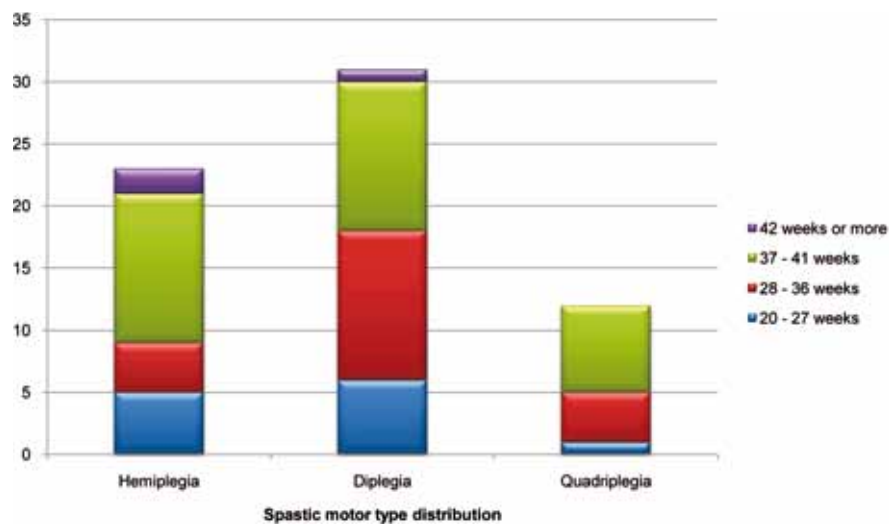


gestational age and spastic motor type

Table 2: Number of children with cerebral palsy born in 1996 by spastic motor type and gestational age

	Hemiplegia	Diplegia	Quadriplegia	Not entered/not spastic	Total
20 - 27 weeks	5	6	1	1	13
28 - 36 weeks	4	12	4	0	20
37 - 41 weeks	12	12	7	9	40
42 or more weeks	2	1	0	1	4
Not entered	2	0	0	8	10
Total	25	31	12	19	87

Figure 2: Number of children with cerebral palsy born in 1996 by spastic motor type and gestational age

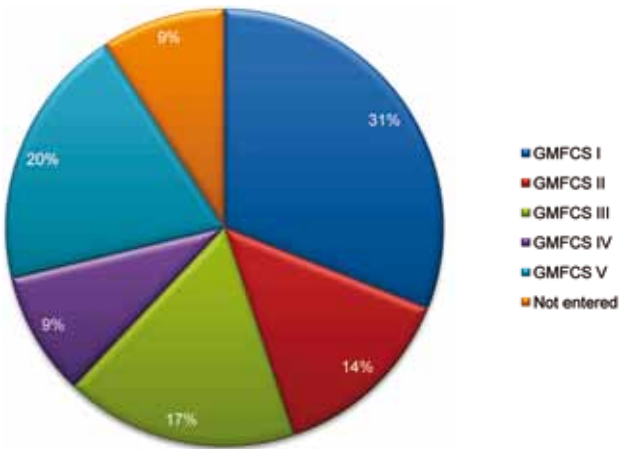


gross motor function

Table 3: Number of children with cerebral palsy born in 1996 by Gross Motor Function Classification System (GMFCS) level

GMFCS	I	II	III	IV	V	Not entered	Total
Number	27	12	15	8	17	8	87

Figure 3: Percentage of children with cerebral palsy born in 1996 by Gross Motor Function Classification System (GMFCS) level

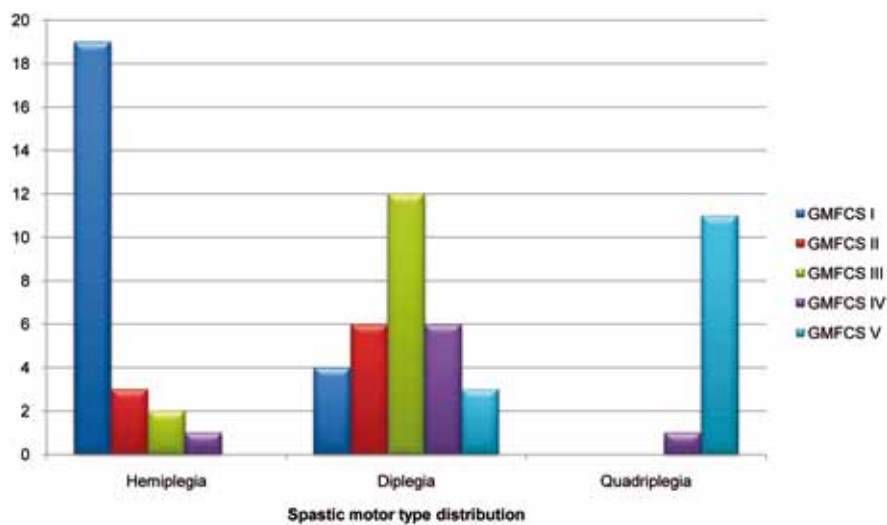


spastic motor type and distribution and gross motor function

Table 4: Number of children with cerebral palsy born in 1996 by spastic motor type and distribution, and Gross Motor Function Classification System (GMFCS) level

GMFCS	Hemiplegia	Diplegia	Quadriplegia	Not entered/ not spastic	Total
GMFCS I	19	4	0	4	28
GMFCS II	3	6	0	3	14
GMFCS III	2	12	0	1	18
GMFCS IV	1	6	1	0	12
GMFCS V	0	3	11	3	22
Not entered	0	0	0	8	8
Total	25	31	12	19	87

Figure 4: Number of children with cerebral palsy born in 1996 by spastic motor type and distribution, and Gross Motor Function Classification System (GMFCS) level



birth details

maternal age at delivery

Table 5: Maternal age at delivery for children with cerebral palsy born in 1996 and calculated rate of cerebral palsy (CP) per thousand live births (LB) in Queensland

Age of mother	All QLD children	All QLD %	Children with CP	Children with CP %	CP cases/LB in Qld
Less than 20 years	3205	6.78%	4	4.60%	1.25
20 - 34 years	38138	80.63%	56	64.37%	1.47
35 years or more	5959	12.60%	14	16.09%	2.35
Not entered			13		
Total			87		

Figure 5a: Percentage of children with cerebral palsy born in 1996 by maternal age at delivery

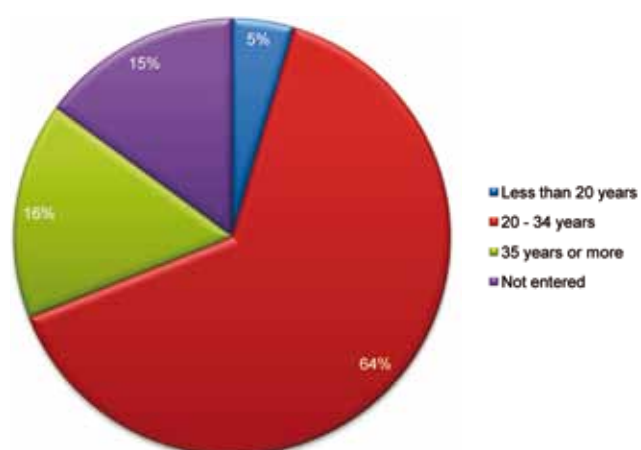
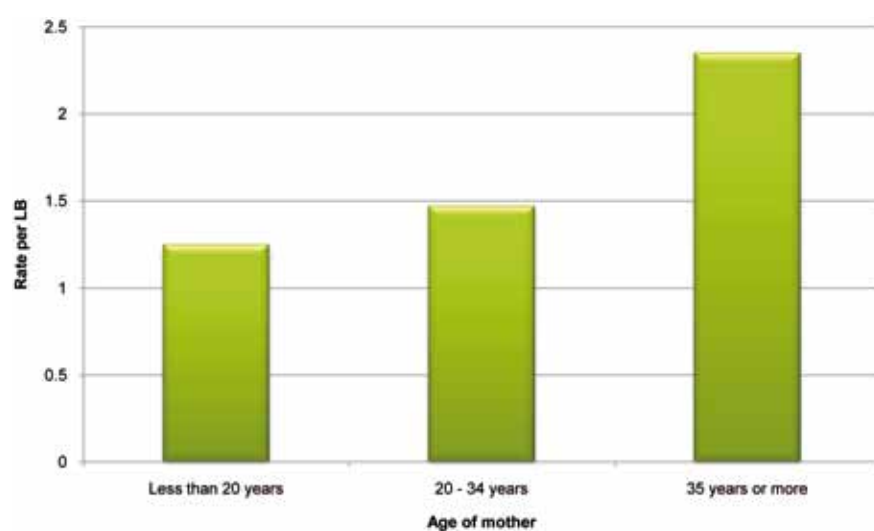


Figure 5b: Maternal age at delivery by rate of cerebral palsy per thousand live births (LB) in Queensland in 1996



previous births to mother

Table 6a: Number of previous births to mother of children with cerebral palsy born in 1996

Previous children	0	1	2	3	4	5 or more	Not entered	Total
Cerebral palsy	35	23	13	3	0	2	11	87

Figure 6a: Number of children with cerebral palsy born in 1996 by number of previous births to mother

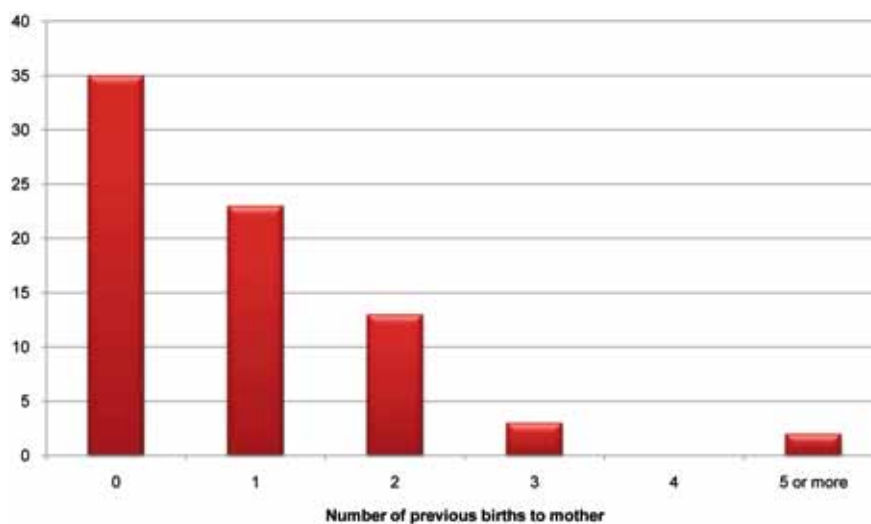
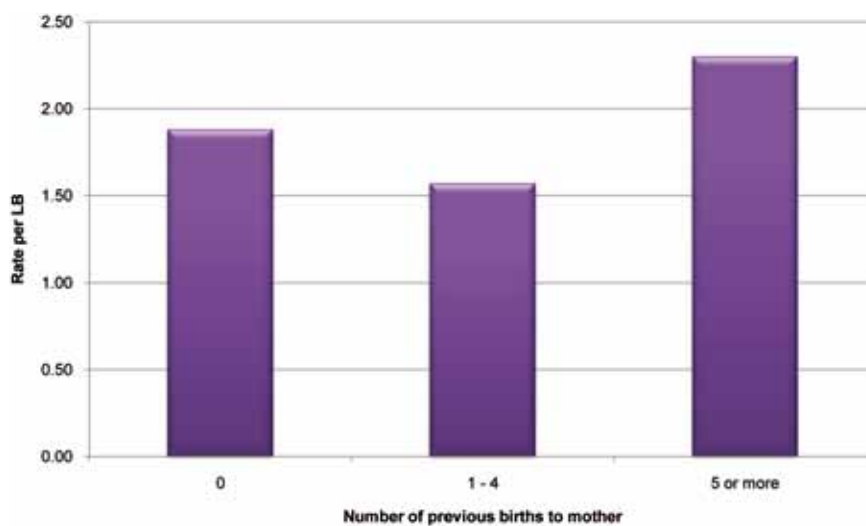


Table 6b: Number of children with cerebral palsy and all Qld-born children of birth year 1996 by number of previous births to mother

Previous births to mother	0	1 - 4	5 or more	Not entered	Total
CP	35	39	2	11	87
All QLD	18612	24814	867	9	44302

Figure 6b: Rate of cerebral palsy per thousand live births (LB) in Queensland in 1996 by number of previous births to mother



plurality

Table 7: Number and rate per thousand live births of children with cerebral palsy born in 1996 and total born in Queensland by plurality

	Singleton	Twins	Other multiples	Not entered	Total
CP children	74	4	1	8	87
CP per LB	85%	5%	1%	9%	100%
All QLD children	46645	633	24	0	47302
QLD per LB	99%	1%	0%	0%	100%

Figure 7a: Percentage of children with cerebral palsy born in 1996 and total born in Queensland by plurality

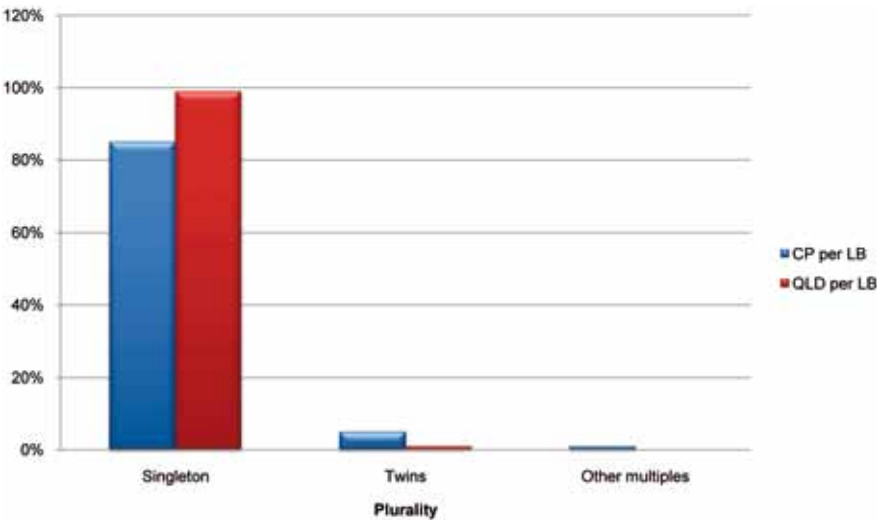
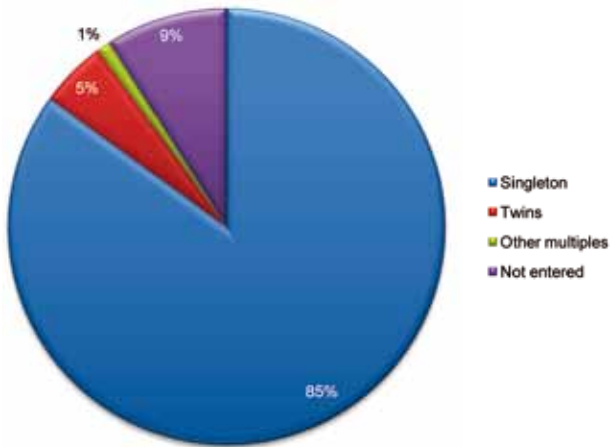


Figure 7b: Percentage of children with cerebral palsy born in 1996 by plurality



birth weight

Table 8: Birth weight for children with cerebral palsy born in 1996 by number and rate per 1000 live births (LB) in Queensland

	Below 1500g	1500g - 2499g	2500g - 3999g	Above 3999g	Not entered	Total
CP children	22	10	38	6	11	87
All QLD	733	2439	39052	5720	3	47947
CP cases per LB	30.01	4.10	0.97	1.05		

Figure 8a: Percentage of children with cerebral palsy born in 1996 by birth weight

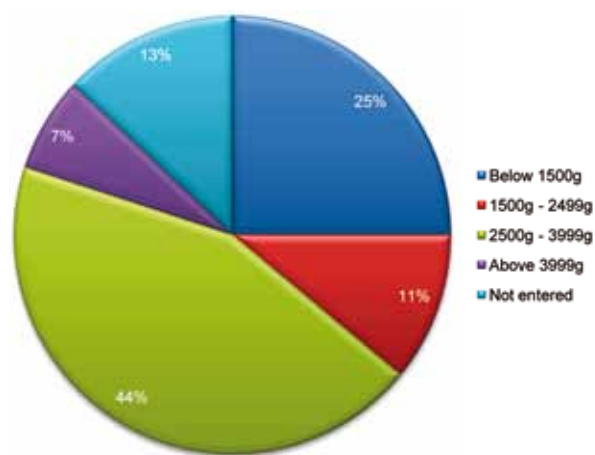
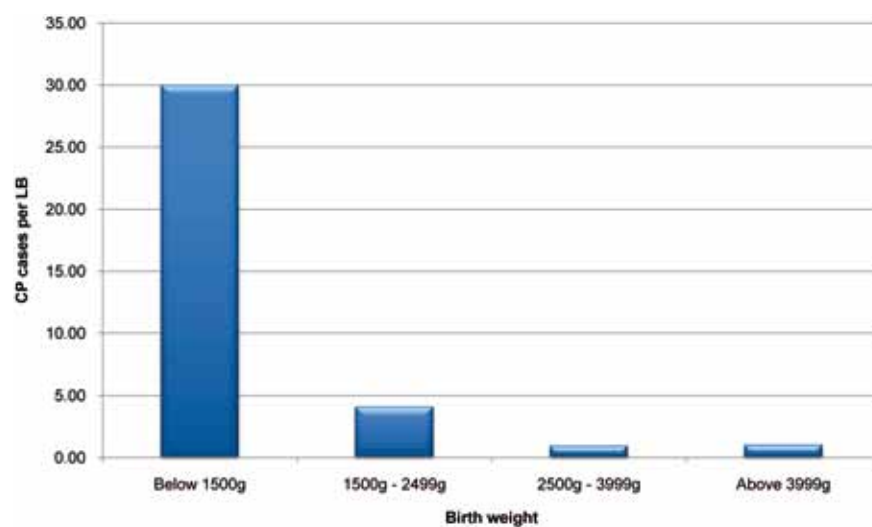


Figure 8b: Birth weight for children with cerebral palsy born in 1996 by rate per 1000 live births (LB) in Queensland

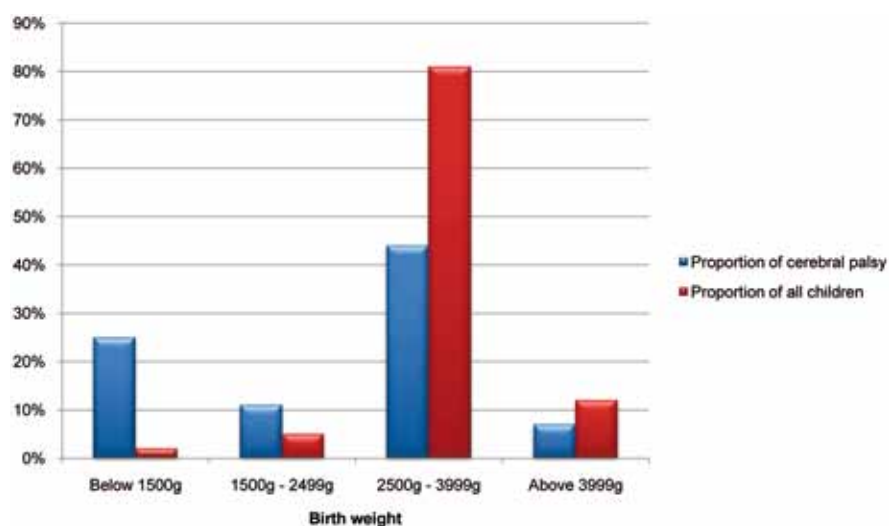


birth weight (cont.)

Table 9: Birth weight for all children born in Queensland in 1996 and children with cerebral palsy

	Below 1500g	1500g - 2499g	2500g - 3999g	Above 3999g	Not stated	Total
CP children	22	10	38	6	11	87
All Qld	733	2439	39052	5720	3	47947
Proportion of all children	25%	11%	44%	7%		
Proportion of cerebral palsy	2%	5%	81%	12%		

Figure 9: Birth weight by proportion of all children born in Queensland in 1996 and children with cerebral palsy



gestational age

Table 10: Number and rate of children with cerebral palsy born in 1996 and in all Queensland by gestational age

	20 - 27 weeks	28 - 30 weeks	31 - 32 weeks	33 - 34 weeks	35 - 36 weeks	28 - 36 weeks	37 - 39 weeks	40 - 41 weeks	37 - 41 weeks	42 or more weeks	Not stated	Total
All QLD	427					3354			43094	1110	2	47987
CP	13	12	2	5	1	20	12	28	40	4	10	87
Rate per LB	30.44					5.96			0.93	3.60		

Figure 10a: Percentage of children with cerebral palsy born in 1996 by gestational age

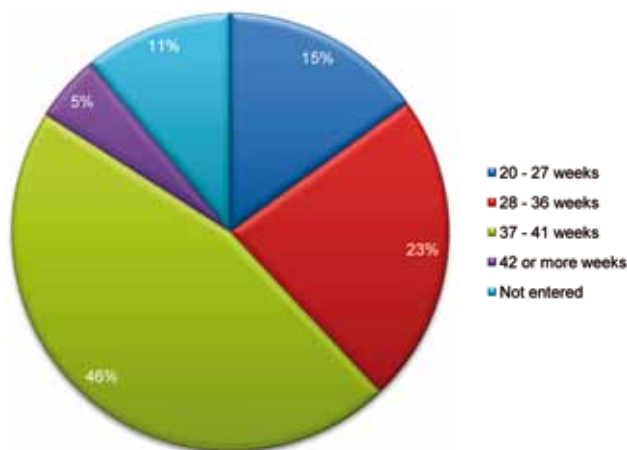
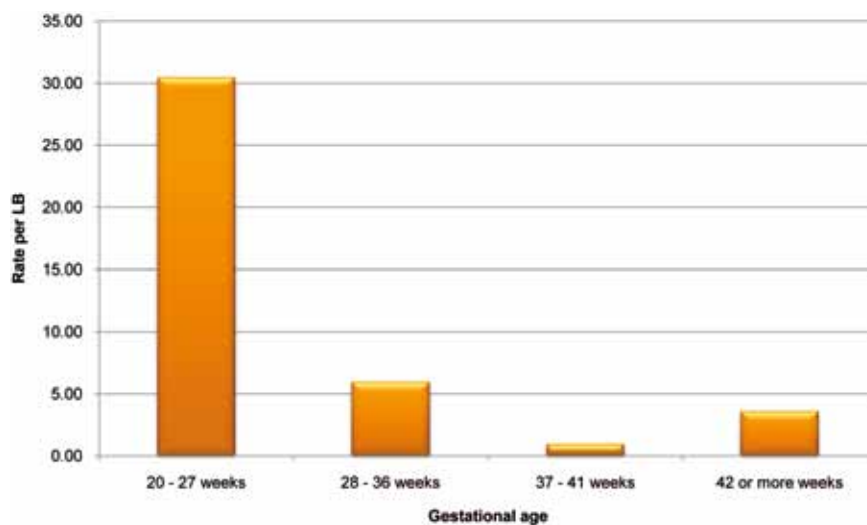


Figure 10b: Gestational age of children with cerebral palsy who were born in 1996 by rate per 1000 live births (LB)

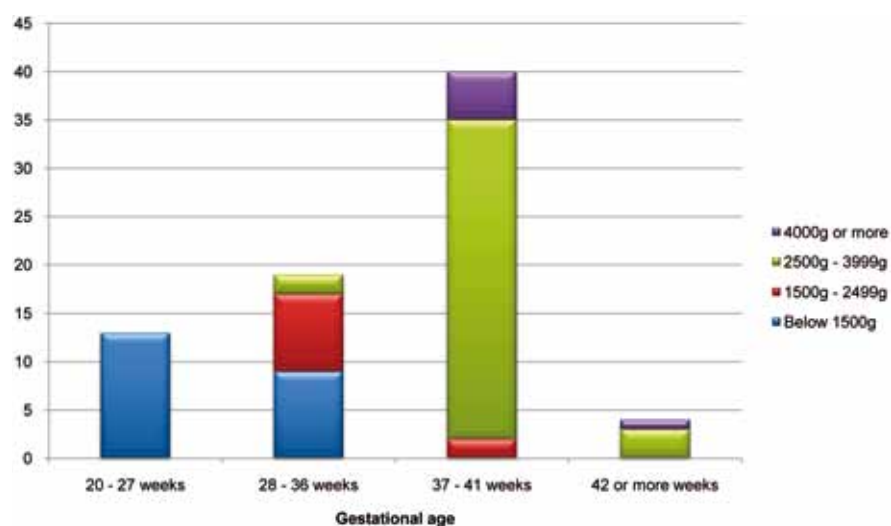


gestational age by birth weight

Table 11: Number of children with cerebral palsy born in 1996 by gestational age and birth weight

	20 - 27 weeks	28 - 36 weeks	37 - 41 weeks	42 or more weeks	Not stated	Total
Below 1500g	13	9	0	0	0	22
1500g - 2499g	0	8	2	0	0	10
2500g - 3999g	0	2	33	3	0	38
4000g or more	0	0	5	1	0	6
Not entered	0	1	0	0	10	11
Total	13	20	40	4	10	87

Figure 11: Number of children with cerebral palsy born in 1996 by gestational age and birth weight



neonatal intensive care unit admission

Table 12: Number of children with cerebral palsy who were born in 1996 and admitted to a Neonatal Intensive Care Unit (NICU)

NICU admissions	No NICU admission	Not entered	Total
39	37	11	87

Figure 12a: Percentage of children with cerebral palsy admitted to a Neonatal Intensive Care Unit (NICU)

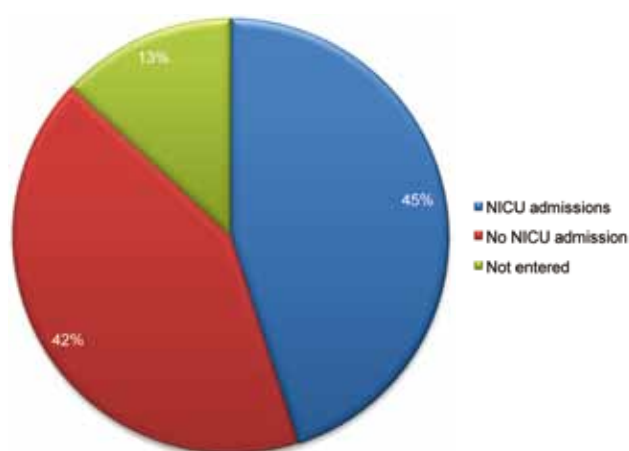
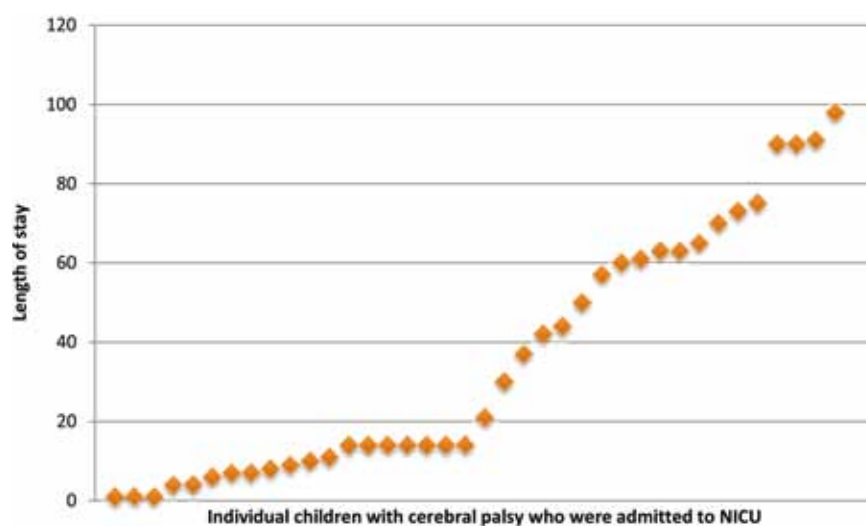


Figure 12b: Length of stay for each individual child with cerebral palsy who was born in 1996 and admitted to a Neonatal Intensive Care Unit (NICU)



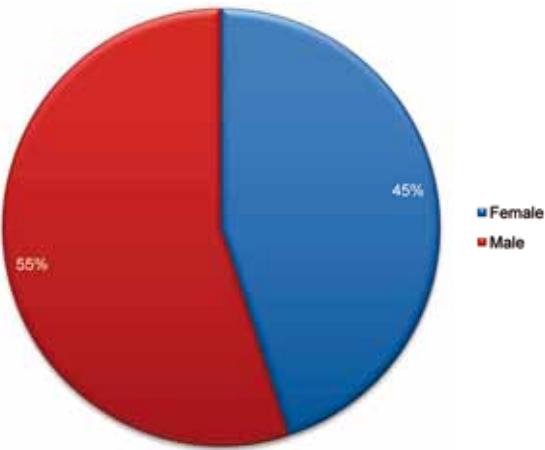
demographics

gender

Table 13: Number and rate of children born with cerebral palsy and number of all children born in Queensland by gender for birth year 1996

	Female	Male	M:F ratio	Not stated	Total
Children with cerebral palsy	39	48	1.23	0	87
All QLD	22214	23225	1.05		45439
Rate of CP gender per LB	0.78	1.18			

Figure 13: Percentage of children born in birth year 1996 with cerebral palsy by gender

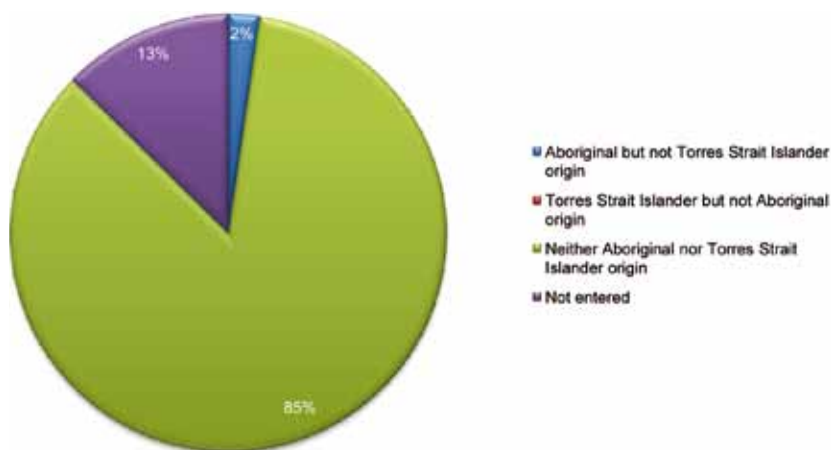


indigenous status

Table 14: Number of children with cerebral palsy born in 1996 by indigenous status

Aboriginal but not Torres Strait Islander origin	Torres Strait Islander but not Aboriginal origin	Neither Aboriginal nor Torres Strait Islander origin	Not entered	Total
2	0	74	11	87

Figure 14: Percentage of children with cerebral palsy born in 1996 by indigenous status

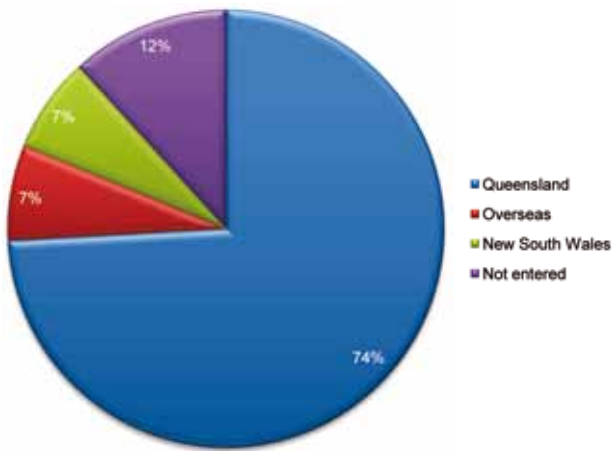


birth origin

Table 15: Number of children with cerebral palsy born in 1996 by place of residence at time of birth

QLD	OSEAS	NSW	Not entered	Total
63	6	6	10	87

Figure 15: Percentage of children with cerebral palsy born in 1996 by place of residence at time of birth



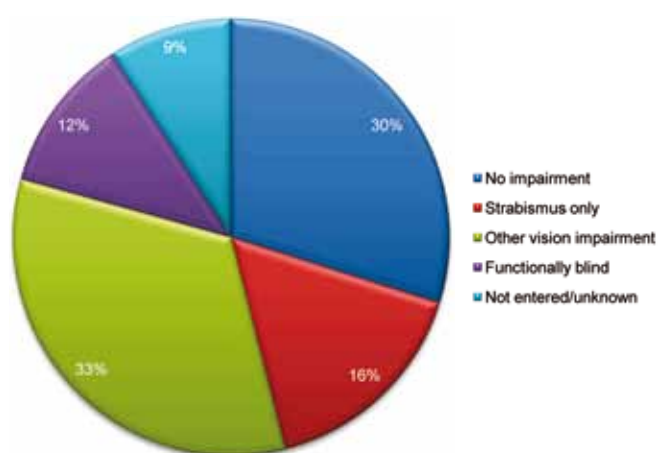
Vision

Vision

Table 16: Number of children with cerebral palsy who were born in 1996 by vision status

No impairment	Strabismus only	Other vision impairment	Functionally blind	Not entered/ unknown	Total
26	14	29	10	8	87

Figure 16: Percentage of children with cerebral palsy born in 1996 by vision status

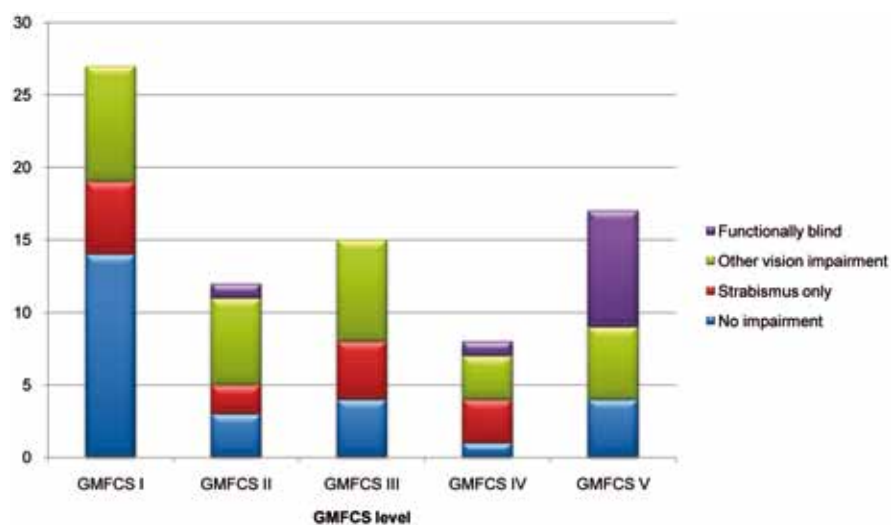


Vision and gross motor function

Table 17: Number of children with cerebral palsy born in 1996 by vision status and Gross Motor Function Classification System (GMFCS) level

	No impairment	Strabismus only	Other vision impairment	Functionally blind	Not entered	Total
GMFCS I	14	5	8	0	0	27
GMFCS II	3	2	6	1	0	12
GMFCS III	4	4	7	0	0	15
GMFCS IV	1	3	3	1	0	8
GMFCS V	4	0	5	8	0	17
Not entered	0	0	0	0	8	8
Total	26	14	29	10	8	87

Figure 17: Number of children with cerebral palsy born in 1996 by Gross Motor Function Classification System (GMFCS) level and vision status

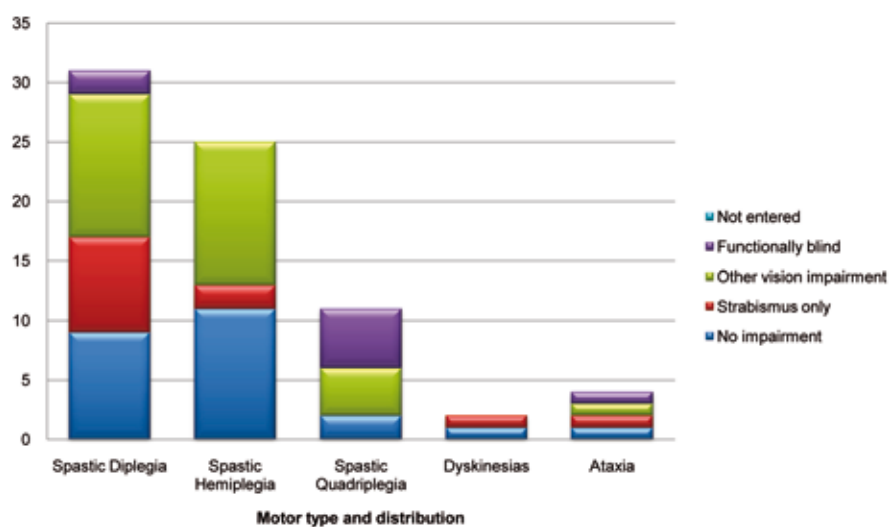


vision, motor type and distribution

Table 18: Number of children with cerebral palsy born in 1996 by vision status, and motor type and distribution

	No impairment	Strabismus only	Other vision impairment	Functionally blind	Not entered	Total
Spastic Diplegia	9	8	12	2	0	31
Spastic Hemiplegia	11	2	12	0	0	25
Spastic Quadriplegia	2	0	4	5	0	11
Dyskinesias	1	1	0	0	0	2
Ataxia	1	1	1	1	0	4
Not entered	2	2	0	2	8	14
Total	26	14	29	10	8	87

Figure 18: Number of children with cerebral palsy born in 1996 by vision status, and motor type and distribution



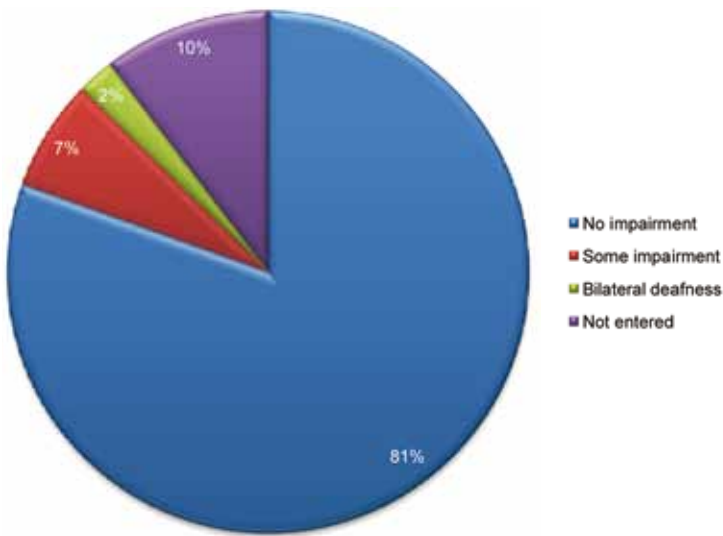
hearing

hearing

Table 19: Number of children with cerebral palsy born in 1996 by hearing status

No impairment	Some impairment	Bilateral deafness	Not entered	Total
70	6	2	9	87

Figure 19: Percentage of children with cerebral palsy born in 1996 by hearing status

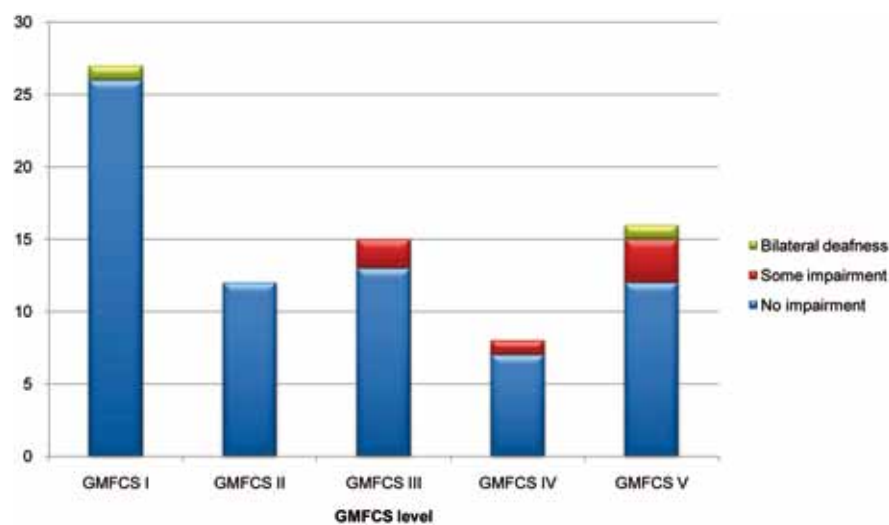


hearing and gross motor function

Table 20: Number of children with cerebral palsy born in 1996 by hearing status and Gross Motor Function Classification System (GMFCS) level

	No impairment	Some impairment	Bilateral deafness	Not entered	Total
GMFCS I	26	0	1	0	27
GMFCS II	12	0	0	0	12
GMFCS III	13	2	0	0	15
GMFCS IV	7	1	0	0	8
GMFCS V	12	3	1	1	17
Not entered	0	0	0	8	8
Total	70	6	2	9	87

Figure 20: Number of children with cerebral palsy born in 1996 by Gross Motor Function Classification System (GMFCS) level and hearing status

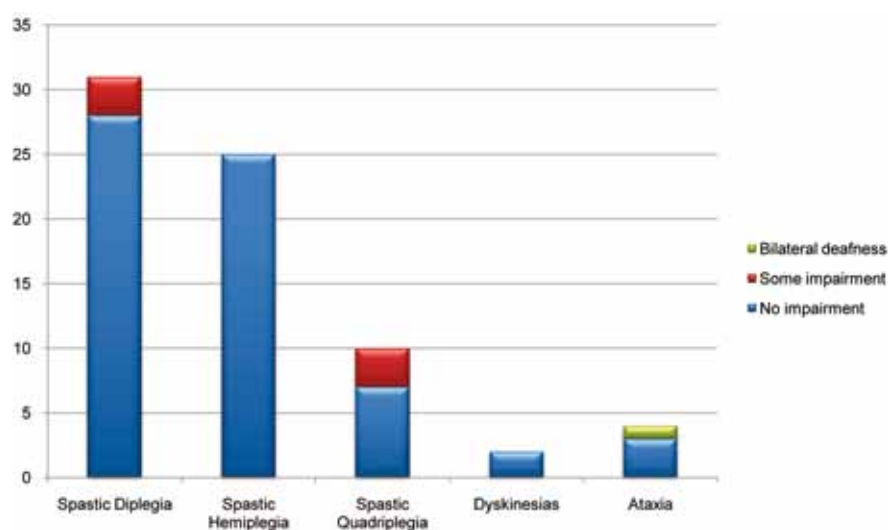


hearing, motor type and distribution

Table 21: Number of children with cerebral palsy born in 1996 by hearing status, and motor type and distribution

	No impairment	Some impairment	Bilateral deafness	Not entered	Total
Spastic Diplegia	28	3	0	0	31
Spastic Hemiplegia	25	0	0	0	25
Spastic Quadriplegia	7	3	0	1	11
Dyskinesias	2	0	0	0	2
Ataxia	3	0	1	0	4
Not entered	5	0	1	8	14
Total	70	6	2	9	87

Figure 21: Number of children with cerebral palsy born in 1996 by hearing status, and motor type and distribution



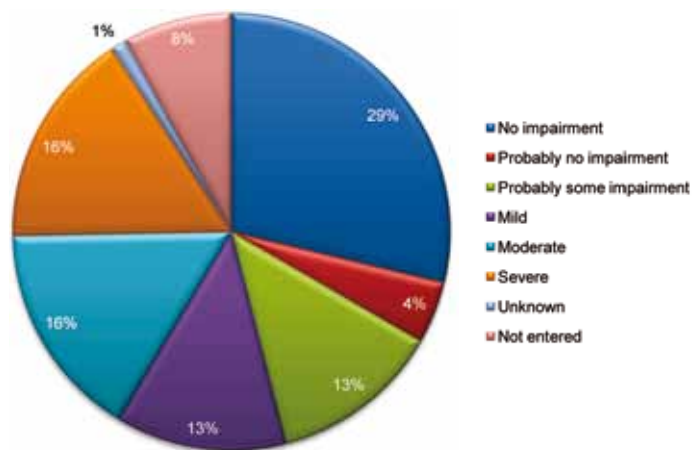
intellectual status

intellectual status

Table 22: Number of children with cerebral palsy born in 1996 by intellectual status

Intellectual impairment status	No impairment	Probably no impairment	Probably some impairment	Mild	Moderate	Severe	Unknown	Not entered	Total
Number	25	4	11	11	14	14	1	7	87

Figure 22: Percentage of children with cerebral palsy born in 1996 by intellectual status

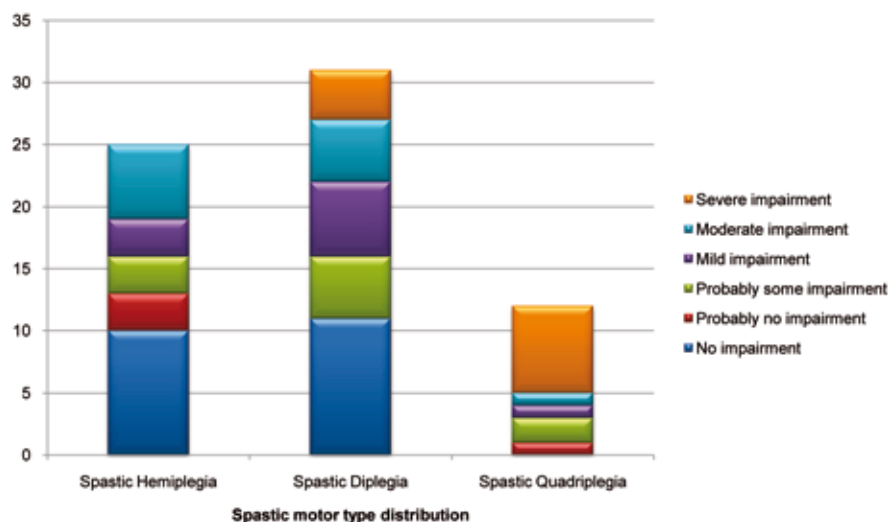


intellectual status of children with cerebral palsy by spastic motor type

Table 23: Number of children born in 1996 by intellectual status and spastic motor type

Intellectual impairment status	No impairment	Probably no impairment	Probably some impairment	Mild	Moderate	Severe	Unknown	Not entered	Total
Spastic Hemiplegia	10	3	3	3	6	0	0	0	25
Spastic Diplegia	11	0	5	6	5	4	0	0	31
Spastic Quadriplegia	0	1	2	1	1	7	0	0	12
Not entered/ not spastic	4	0	1	1	2	3	1	7	19
Total	25	4	11	11	14	14	1	7	87

Figure 23: Number of children born in 1996 by with spastic motor type and intellectual status



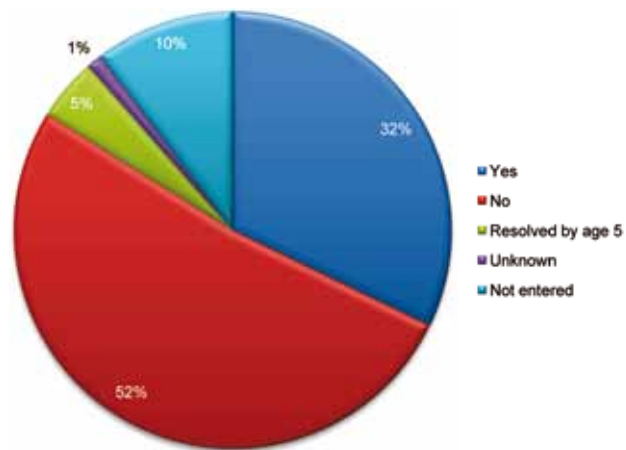
epilepsy

epilepsy

Table 24: Number of children with cerebral palsy born in 1996 by epilepsy status

Epilepsy	Yes	No	Resolved by 5 years	Unknown	Not entered	Total
Number	28	45	4	1	9	87

Figure 24: Percentage of children with cerebral palsy born in 1996 by epilepsy status

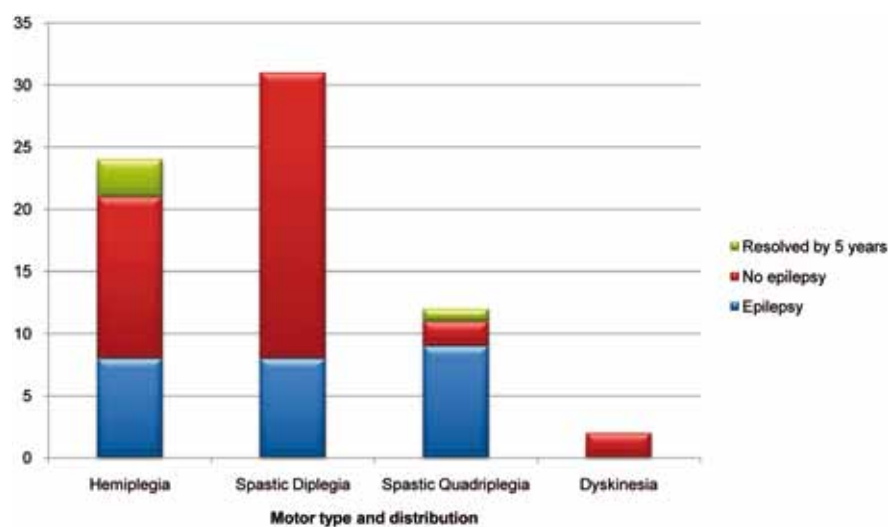


epilepsy status and motor type

Table 25: Number of children with cerebral palsy born in 1996 by epilepsy status, and motor type and distribution

	Epilepsy	No epilepsy	Resolved by 5 years	Not entered	Total
Hemiplegia	8	13	3	1	25
Spastic Diplegia	8	23	0	0	31
Spastic Quadriplegia	9	2	1	0	12
Dyskinesia	0	2	0	0	2
Not entered/ not spastic	3	5	0	9	17
Total	28	45	4	10	87

Figure 25: Number of children with cerebral palsy born in 1996 by motor type and distribution, and epilepsy status

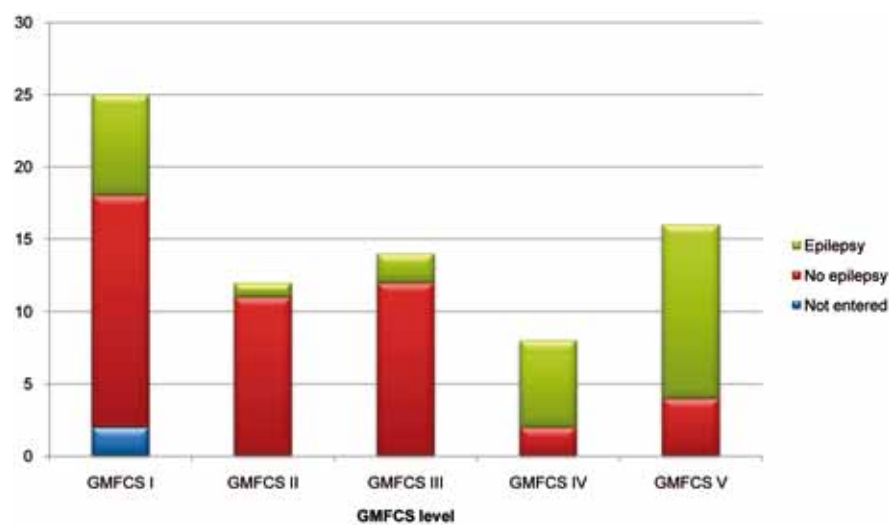


epilepsy status and gross motor function

Table 26: Number of children with cerebral palsy born in 1996 by epilepsy status and Gross Motor Function Classification System (GMFCS) level

GMFCS	Epilepsy	No epilepsy	Resolved by 5 years	Not entered	Total
GMFCS I	7	16	2	2	27
GMFCS II	1	11	0	0	12
GMFCS III	2	12	1	0	15
GMFCS IV	6	2	0	0	8
GMFCS V	12	4	1	0	17
Unknown	0	0	0	8	8
Total	28	45	4	10	87

Figure 26: Number of children with cerebral palsy born in 1996 by Gross Motor Function Classification System (GMFCS) level and epilepsy status



references

1. ACPR Group, *Report of the Australian Cerebral Palsy Register, Birth Years 1993-2003*, Dec 2009.
2. Bax M, Flodmark O, Tydeman C. Definition and classification of cerebral palsy. From syndrome toward disease. *Developmental Medicine and Child Neurology Supplement* 2007; **109**:39-41.
3. Mutch L, Alberman E, Hagberg B, Kodama K, Perat M. Cerebral palsy epidemiology: where are we now and where are we going? *Developmental Medicine and Child Neurology* 1992; **34**(6): 547-51.
4. Palisano R, Rosenbaum P, Walter S, Russel D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology* 1997; **39**:214-23.
5. Queensland Department of Health, *Perinatal Statistics* 1996. 2000.
6. Reddiough E, Collins K. The epidemiology and causes of cerebral palsy. *Australian Journal of Physiotherapy* 2003; **49**(1):7-12.
7. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. *A report: the definition and classification of cerebral palsy April 2006*. *Developmental Medicine and Child Neurology Supplement* 2007; **109**: 8-14.
8. Stanley F, Blair E, Alberman E. How common are the cerebral palsies? In *Cerebral Palsies: Epidemiology and Causal Pathways*. London: MacKeith Press, **2000**:22-29.

appendix a

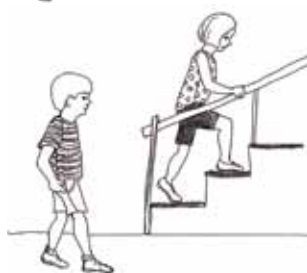
gross motor function system for children aged 4-6 years

- illustrations and descriptors



GMFCS Level I

Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.



GMFCS Level II

Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.



GMFCS Level III

Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with an assistive mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.



GMFCS Level IV

Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.



GMFCS Level V

Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.

contributors

Queensland Cerebral Palsy Register Staff

Mr Michael deLacy	QCPR Manager
Ms Christalla Louca	QCPR Administration Officer

Queensland Cerebral Palsy Register Steering Committee

A/Professor Roslyn Boyd	Scientific Director - Qld Cerebral Palsy and Rehabilitation Research Centre <i>The University of Queensland and Royal Children's Hospital</i>
A/Professor Peter Gray	Deputy Director - Department of Neonatology <i>The University of Queensland and Mater Mother's Hospital</i>
Dr Stacey Hassall	A/Manager - Evidence, Reporting and Performance <i>Department of Communities (Disability and Community Care Services)</i>
Ms Liz Hinder	Senior Advisor - Occupational Therapy <i>Department of Education and Training</i>
Dr Leanne Johnston	Principal Advisor - Research and Ethics <i>Cerebral Palsy League</i>
Ms Megan Kentish	Director - Queensland Cerebral Palsy Health Service <i>Royal Children's Hospital Brisbane</i>
Dr Lynne McKinlay	Director - Department of Paediatric Rehabilitation <i>Royal Children's Hospital Brisbane</i>
Mr Peter Mewett (Chair)	General Manager - Services <i>Cerebral Palsy League</i>
Mr John Rynn	Representative - State Client Consultative Committee <i>Cerebral Palsy League</i>

