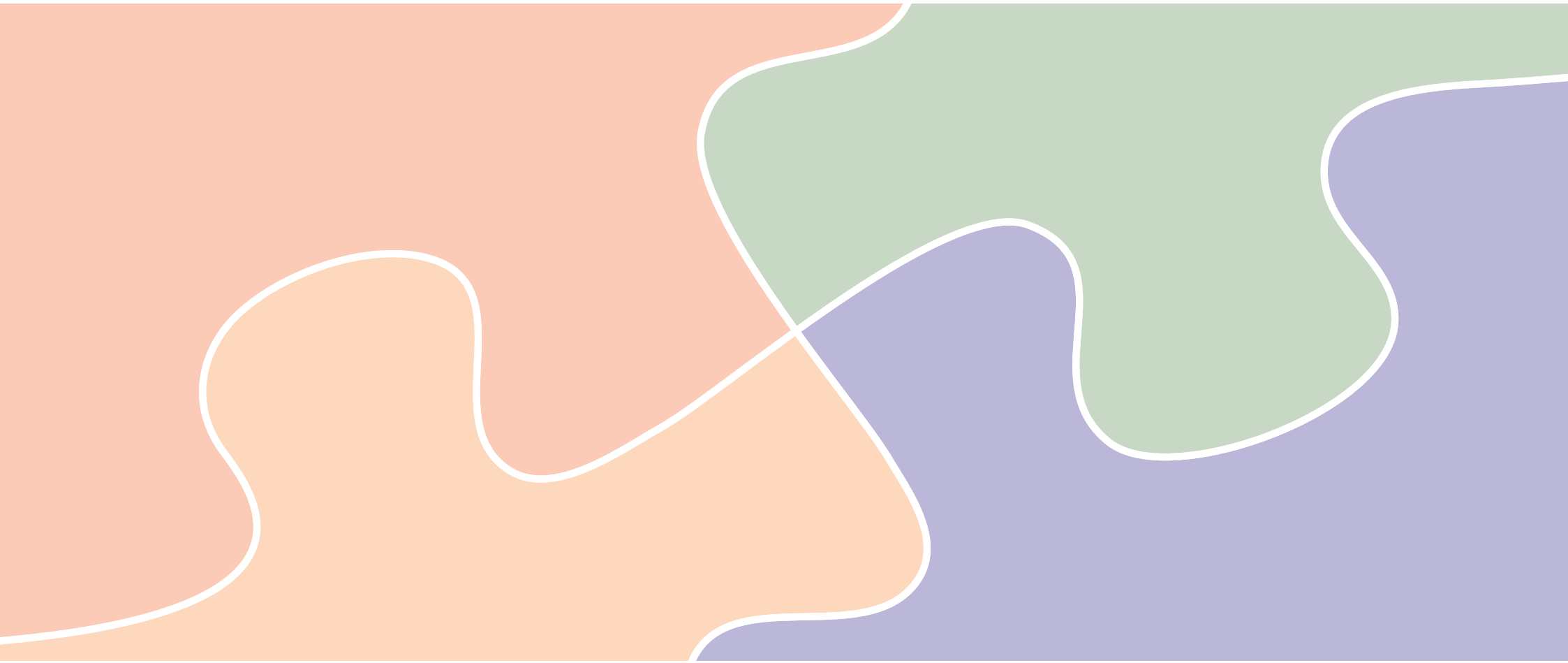

# CP Register Queensland

## Report: 1995–2008 Birth Years

# Acknowledgements

Information and data collected in this report of the Queensland Cerebral Palsy Register (QCPR) continues to be a culmination of the joint efforts of many people and the support of many services.

We are forever grateful to each person with cerebral palsy and his/her family who have generously supported this project and been committed to sharing their information. Without the ground swell of participation that has occurred, the QCPR would not be a reality. We hope that this report continues to honour the significant contribution in trust by people with cerebral palsy and their families.

We acknowledge CPL – Choice, Passion, Life, the Queensland-based organisation that originally championed the cause of the registered in Queensland. The CPL remains the host of the register, providing day-to-day support office infrastructure, information technology and support for our steering committee.

The QCPR would not have been possible without the generous financial support of the Queensland government. Funding support was announced in 2004 through Queensland Health and continuing operation of the register is still attributable to recurring funding provided by the Department of Communities, Child Safety and Disability Services.

Completing records of the QCPR data is dependent on the support and referrals from staff of many service agencies across Queensland. The QCPR is especially grateful to CPL, Queensland Health, Mater Health Services, the Department of Education and Training, and the Department of Communities, Child Safety and Disability Services. These departments and agencies have contributed support to 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 CPL have also contributed steering committee members, providing ongoing advice on how client information is collected and analysed.

Historically most referrals originated from CPL services and the Queensland Cerebral Palsy Health Service (QCPHS), through the RCH. We would particularly like to acknowledge the commitment of the administration staff whose tireless efforts have been critical in obtaining referrals from the QCPHS.

Finally we would like to acknowledge the collegiate support of the Australian Cerebral Palsy Register members who are a never-ending source of inspiration and expertise.

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Recommended citation:
QCPR, Report of the Queensland Cerebral Palsy Register: 1995 – 2008 Birth Years, December 2014

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# Foreword

On behalf of CPL – Choice, Passion, Life, I am proud to host the Queensland Cerebral Palsy Register (QCPR), with the work it has achieved to date and the publication of this latest report.

Since its inception in 2005, the QCPR has published three reports describing previously unknown and unavailable information about people with cerebral palsy in Queensland. The first report in 2010 presented diagnostic, birth and demographic data about people born in 1996. It was supplemented in 2012 with a report covering ten birth years, 1996 to 2005. This third report extends into older and younger birth years by presenting population-level descriptions for people born in the years 1995 to 2008.

Each year, an estimated 100-120 babies born in Queensland will be diagnosed with cerebral palsy – the most common cause of childhood physical disability. The data presented here is an invaluable resource for policy-makers, service providers, planners, researchers and designers of treatment interventions. The QCPR also collaborates with the Australian Cerebral Palsy Register (ACPR) to further understand and measure the causes and effects of cerebral palsy, Australia-wide.

The need for population level statistics will help service providers and policy makers build capacity to satisfy the needs of service recipients in preparation for the National Disability Insurance Scheme (NDIS). People and families with cerebral palsy who receive disability support services will benefit by the availability of authoritative information presented in this report.

As a final note, I look forward to continued collaboration with the Queensland Government in continuing to fund and operate the cerebral palsy register. Currently, this invaluable and important support is provided by the Department of Communities, Child Safety and Disability Services, and previously by Queensland Health.

I commend to you the *Report of the Queensland Cerebral Palsy Register: 1995-2008 Birth Years*.

Angela Tillmanns
Chief Executive Officer
CPL

# 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 is used to investigate the causes of cerebral palsy, find ways to prevent cerebral palsy, continually improve practice and interventions, and help to plan services.

This third report adds 4 birth years to previous reports, which is a significant increase over the previous report that covered 10 birth years, published just two years ago. It details distribution, classification, severity and known risk factors for people in Queensland with cerebral palsy who were born from 1 January 1995 to 31 December 2008. Where possible the numbers of people in each category are presented by birth years, which allows the reader to estimate year-to-year variation in the characteristics of people with cerebral palsy in Queensland. It is expected that this data will be used by service providers and consumer groups to better inform their decision-making.

The vast majority of the information is still being provided directly by parents and/or guardians of children with cerebral palsy after being introduced to the register by their service providers and clinicians. In the period since the previous report there has been a steady flow of referrals from the Queensland Cerebral Palsy Health Service which, along with the maintenance of referrals from CPL, has increased the total ascertainment of registrants to more than 2300 overall. The full process of ascertainment is described on page 7. Completing records and confirming consent was undertaken actively by the registry staff.

*How common was cerebral palsy in Queensland among those born between 1995 and 2008?*
In total, 1252 people with cerebral palsy have been registered for the birth years 1995 to 2008. Of these, 1074 were born in Queensland or admitted to a Queensland hospital in the neonatal period. If all 1252 people are included, the crude prevalence of cerebral palsy in Queensland is 1.7 per thousand live births. This is the method that was used in previous reports.

Using only those people who were born in Queensland or were treated in a Queensland hospital during the neonatal period the prevalence of people with cerebral palsy on the register in Queensland is 1.5 per thousand live births.

*What was the spread of motor type and motor distribution in Queensland among those born 1995 - 2008?*
Spastic motor type accounts for 87% of all people with cerebral palsy on the register born between 1995 and 2008. This consisted of 31% spastic hemiplegia or monoplegia, 35% spastic diplegia, and 21% spastic triplegia or quadriplegia. Additionally, 3% had ataxia, 6% had dyskinesia (more with dystonia than athetosis) and 4% were classified as having hypotonia.

Missing data is a combination of registrations 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 people 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.

*What are the effects of cerebral palsy?*
Of all people with cerebral palsy on the register born between 1995 and 2008, the vast majority (87%) have spastic motor type. Spasticity makes movement and coordination difficult due to an increase in muscle tone and heightened response to movements. Further, 31% of the cohort with cerebral palsy born between 1995 and 2008 could not walk functionally or could not walk at all and classified as Gross Motor Function Classification System (GMFCS) level IV or GMFCS level V. Nevertheless, 56% of the cohort were able to independently

walk and managed stairs or rough surfaces with a rail by the age of five years and classified as GMFCS level I or GMFCS level II.

People with cerebral palsy were likely to have other impairments in addition to their motor disability.

There were 53% of the cohort with some visual impairment and 5% who were functionally blind. Almost all people who were functionally blind were either GMFCS level IV or GMFCS level V and 71% had spastic quadriplegia. With the exception of spastic quadriplegia and hypotonia, between 50% and 60% of people with all motor type classifications have no visual impairment.

Approximately half of the cohort had no, or probably no, intellectual impairment, and 25% had a moderate to severe intellectual impairment. The higher the child's GMFCS level, the more likely it was they had an intellectual impairment. For those people with GMFCS level I, 30% had some level of intellectual impairment. Of people classified as GMFCS level V, 80% had some level of intellectual impairment.

At age five, 31% of the cohort born between 1995 and 2008 had epilepsy. The higher the child's GMFCS level, the more likely it was they had epilepsy at age five. For people with GMFCS level I, 13% had epilepsy at age five. For those people with GMFCS level V, 72% had epilepsy. Of all people with spastic triplegia or quadriplegia, 60% also had epilepsy at age five.

Twelve percent of the cohort born in Queensland between 1995 and 2008 were recorded as having some hearing impairment and 3% were bilaterally deaf (including those who are now able to hear with cochlear implants).

**Identified risk factors**

This analysis of the data held on the QCPR identified the following factors that were associated with increased rates of cerebral palsy.

1. *Male*
   In Queensland, 56% of the cohort born between 1995 and 2008 were male.

2. *Preterm birth*
   In Queensland, 48% of the cohort had a gestational age at delivery of less than 37 completed weeks. There was 33 times the rate of cerebral palsy in people born prior to 28 weeks completed gestation compared with those people born 37- 41 weeks completed gestation.

3. *Low birth weight*
   Being born with a low birth weight can result from premature birth or a slow rate of intrauterine growth. In Queensland between 1995 and 2008, 46% of the cohort were born with a birth weight under 2500 grams. The rate of cerebral palsy for people born smaller than 1500 grams was 36 times higher than for those people born 3500-4499 grams.

4. *Multiple births*
   In Queensland, 3% of people born between 1995 and 2008 were the product of a multiple birth. People born one of twins were 9 times more likely to have cerebral palsy than singletons and people born as triplets or higher plurality were 32 times more likely to have cerebral palsy than singletons.

5. *Indigenous status*
   Seven percent of the cohort (1995-2008) were born to mothers who identified as Aboriginal or both Aboriginal and Torres Strait Islander. Only 4.6% of all people born in Queensland in the same period were born to mothers who identified as Aboriginal or both Aboriginal and Torres Strait Islander.

# Cerebral palsy

Cerebral palsy is the most common physical disability in childhood. Historically the rate of cerebral palsy has been reported as between two and 2.5 people per thousand live births in the developed world [2, 8].

**Definition of cerebral palsy**

The definition of cerebral palsy used by the QCPR is the same definition used by the Australian Cerebral Palsy Register (ACPR) and all other Australian State and Territory Cerebral Palsy Registers.

Cerebral palsy:

1. Is an umbrella term from the 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 most valid and useful definition of cerebral palsy available. It includes key elements from published definitions by Bax [2], Mutch [3], and Rosenbaum [7].

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 in contiguous jurisdictions in the world [new]. The significance of this data source cannot be underestimated; it will 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 cerebral palsy has traditionally been described according to motor type and motor distribution:

*Motor type* refers to the type of movement disorder a person has, for example: spasticity, dyskinesia or hypotonia.
*Distribution* refers to which limbs are involved.

Combining both motor type and distribution allows the following classifications: Spastic cerebral palsy involves very high muscle tone causing stiff or jerky movements. Spasticity can be distributed predominantly on one side of the body (hemiplegia); affecting the legs more than the arms (diplegia); affecting both legs and particularly one arm (triplegia); or affecting both arms and legs with the arms more affected or equally effected than the legs (quadriplegia). Dyskinetic cerebral palsy is where muscle tone fluctuates for changes causing difficulty with control and coordination of movements. This category includes both athetosis and dystonia. Ataxic cerebral palsy has low muscle tone and poor coordination causing a shaking type movement or tremors. Hypertonic cerebral palsy requires low muscle tone in the presence of increased stretch reflexes.

These descriptions remain very important to understanding the nature of cerebral palsy since by definition cerebral palsy is a group of different disorders with different presentations that have different findings on brain imaging [5]. It is likely that different presentations have different causal pathways and it is therefore likely that they will be susceptible to different methods of prevention. Additionally, the understanding of how brain injury affects function is improving [6] and therefore the different presentations of cerebral palsy will possibly require different methods of intervention.

Recent advancements have seen the development of additional methods to describe aspects of a person's presentation of cerebral palsy. The Gross Motor Function Classification System (GMFCS) categorises the level of gross motor function achieved by people with cerebral palsy, for example the ability to sit and 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 in clinical and scientific endeavour. In light of this practice, the current report will utilise it in relevant comparisons.

Aside from these two 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 in people with cerebral palsy, this report will detail the extent they are present in the population of people with cerebral palsy born 1995 – 2008.

# Queensland cerebral palsy register

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

This information is useful for:

- Describing the population of people who have cerebral palsy in Queensland, including regional groupings, abilities and birth histories.
- Researching the courses and impacts of cerebral palsy from registrants, families, service providers and funders.

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

**Aims of the QCPR**

The aims of the QCPR are to:

- Describe the number of people with cerebral palsy in Queensland, their functional abilities and general geographical distribution.
- Provide a useful collection of data that will assist service funders and service providers in designing systems to improve the lives of people with cerebral palsy in Queensland.
- Provide a useful collection of data that will inform people with cerebral palsy and their families about the scope of cerebral palsy in Queensland.
- Provide a database of information useful for research into the causes of cerebral palsy, future prevention and intervention strategies.
- Collaborate with other CP registers in Australia so as to provide the best possible source of information about cerebral palsy in Australia.

**Australian cerebral palsy register**

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

**Methods of the QCPR**

Ascertainment is a multistage 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 not collected at the time of referral (e.g. home postcode at time of birth)
- *Entering* this information into 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 service providers, particularly CPL and the Queensland Cerebral Palsy Health Service (QCPHS). The small minority of people identified through community awareness initiatives such as publications, news stories, advertising and the website.

To be included on the register, individuals can submit their contact information with or without the remaining dataset using four different methods:

- *Online* – registrants (or their Guardian) can register directly via the QCPR website http://www.qcpr.org.au, and follow the link to the database.
- *Mail* – registrants (or their Guardian) can mail the QCPR referral card or questionnaire to the register office. These forms are available from service providers or they can be downloaded from the QCPR website.
- *Telephone* – registrants (or their Guardian) can telephone the register

office and staff will collect information directly.

- *Email* – registrants (or their Guardian) can email the information in a message to register staff. If the QCPR questionnaire has been completed, this can also be sent to the office by email.

As well as submitting information by one or more of these methods, clients also need to submit a signed consent form so the details can be incorporated into register analyses and reports. If not submitted at initial contact, the consent form can be downloaded from the QCPR website or staff will follow up with each registrant individually.

The consent form records up to 4 different consents:

- *Collecting and entering QCPR data*
  Agreeing to their contact details and other information being uploaded onto the QCPR. This information is used by register staff to report on the characteristics of people with cerebral palsy in Queensland and contact the person (or their Guardian) to collect or update individual data and to send information summaries for their use.

- *Transferring data to the Australian Cerebral Palsy Register*
  Agreeing to their individual characteristic information being uploaded to the Australian register. Personally identifying information is not transferred. Uploaded information is used in describing the population of people with cerebral palsy in Australia.

- *Research*
  Identifying whether they wish to be sent information about opportunities to participate in research into the causes, nature and efficacy of interventions for persons with 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. 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 however participation is confidential and not disclosed to, or recorded by the QCPR.

- *Confirming QCPR data*
  Agreeing for register staff to contact the service provider, nominated by the registrants (or their Guardian), to verify information about the person's clinical details or birth history. This may involve a nominated practitioner reviewing the person's QCPR registration information. This process is used to ensure that information held on the QCPR is consistent across Queensland.

The overall procedure for the QCPR was reviewed and approved by a National Health and Medical Research Council compliant ethics committee (approval # CPLQ 200809-1013). Ethics approval for data porting from specific service providers to the QCPR has so far been received from the Royal Children's Hospital and Health Service District Ethics Committee (ref # RCH & HSD Ethics 2008/113), the Cerebral Palsy League Ethics Committee (ref # CPLQ 2008/09–1013) and Mater Health Services Human Research Ethics Committee (ref # 1642E).

From 29 November 2014 the Royal Children's Hospital and Health Service District and Mater Children's Hospital will amalgamate to form a single organisation called the Lady Cilento Children's Hospital (LCCH). The QCPR has received no formal advice from the LCCH ethics committee, however informal advice suggests that the contact details and branding of information and consent forms will need to be updated once that information is available and that no other administrative actions will be necessary for the QCPR to continue receiving information with the same ethical clearance as previously granted.

**Cohort**

Information included in this report is from people born from 1 January 1995 to 31 December 2008 with a diagnosis of cerebral palsy at five years of age and who were born in Queensland, whether or not they still live in Queensland, or

born outside Queensland but who now live in Queensland or receive services in Queensland.

**Denominator data**

Where the rate of cerebral palsy per thousand live births (LBS) is given in tables or graphs, the denominator value for live births is reported according to population statistics published electronically by the Queensland Health Statistics Unit at http://www.health.qld.gov.au/hsu/peri.asp. Statistics from each year from 1998 are published separately. Data for gender, gestational age, birth weight and indigenous status of the yearly Queensland population were extracted and used for comparison of proportions between the population of people who subsequently registered on QCPR and the whole population of births or for the calculation of rates of cerebral palsy within specific categories.

# Important notes for interpreting tables and graphs

In general, tables include all data that is held on the register from people who do not have a known post-neonatal cause, including unknown values. Graphs and figures are used to represent specific information included in the tables and depending on the information intended to convey they either include unknown values or not. In general, graphs with only one dependent value, will be bar graphs and will include unknown values. Graphs with two dependent values usually do not have unknown values included because there are three different sets of unknown values (value 1 is unknown, value 2 is unknown, or both values are unknown). Including these different unknown values in a single graph makes it difficult to understand and does not add significantly to the information that the graph is intended to convey. Where possible abbreviations such as GMFCS are used in the titles of graphs and tables, but only if the full text has previously been used and the intended abbreviation has been displayed.

**Notes applying to all tables**

The totals in tables are calculated by adding all the known values and appear in the tables before the unknown values. The number of people will therefore equal the total as displayed in the table as well as the unknown values displayed directly after the total.

With the exception of "unknown values" all percentages are calculated by the number divided by the total of known values [n/ (all people-unknown)]. As a result, percentages of known values will add up to 100% +/- rounding errors. The symbol "^" will be displayed on the bottom of the table to indicate this.

Percentages of unknown are calculated by the number of unknown divided by the number of people [n/total+unknown]. The symbol "*" will be displayed at the bottom of the table to indicate this.

Unless stated in the title, all tables exclude data from those with known post-neonatal causes. The symbol "Pn" is displayed below the table to indicate this.

**Notes applying to all graphs**

For bar graphs, where the vertical axis represents a number of people, the labels on top of each bar will be percentage of known. The symbol "^" will be displayed at the bottom of the graph to indicate this. There will be no label on the unknown bar to indicate the percentage of all people however the number of people in this bar can be read along the vertical axis as usual and the percentage of total people can be read in the table directly above the graph. The data is always available but it is not displayed so that the percentages of known values add up to 100%.

For bar graphs, where the vertical axis represents a percentage of people, the labels on top of each bar along the horizontal axis will be number of people.

Where there are two dependent variables, such as graphs that have stacked columns, data are excluded where one or both of the values are missing. The symbol "u" will be displayed underneath the graph to indicate this.

Graphs that display a rate per thousand live births (LBS) use published data from the Queensland Health Statistics Centre to calculate the rate for all Queensland births as well as the denominator values for rates of people with cerebral palsy. The specific publications used were the yearly Queensland Perinatal Statistics published online yearly from 1998 at http://www.health.qld.gov.au/hsu/peri.asp and the symbol "q" will be displayed below the graph to indicate this. These figures show rates of cerebral palsy in various categories for the 11 years from 1998 to 2008.

**Summary**

| | |
|---|---|
| ^ | Percentage of known values only |
| * | Percentage of all values including known and unknown |
| Pn | Excludes data from those with a known post-neonatal cause |
| q | Uses published data from the Perinatal Data Statistics Unit |
| u | Excludes data where one or both values are missing |

# General Classification

## Motor type and distribution

Table 1: Number of people with cerebral palsy by predominant motor type and distribution

`

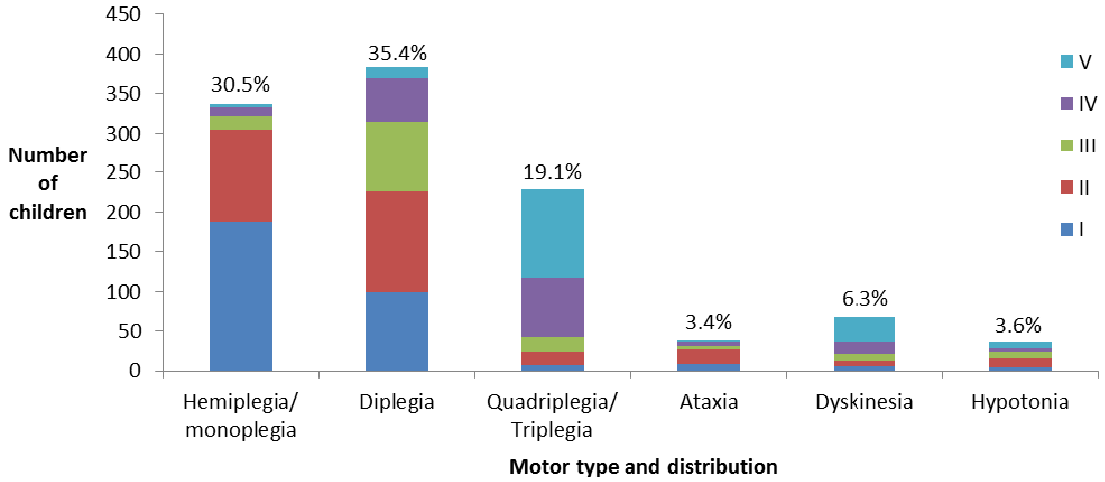
| Motor type and distribution | 1995 n % | 1996 n % | 1997 n % | 1998 n % | 1999 n % | 2000 n % | 2001 n % | 2002 n % | 2003 n % | 2004 n % | 2005 n % | 2006 n % | 2007 n % | 2008 n % | Total n % |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Spasticity | | | | | | | | | | | | | | | |
| - Hemiplegia/ monoplegia | 24 | 30 | 19 | 19 | 26 | 24 | 20 | 31 | 20 | 21 | 34 | 25 | 23 | 33 | 349 |
| | 36.9% | 30.9% | 21.8% | 28.4% | 31.7% | 28.6% | 30.8% | 38.3% | 25.6% | 23.3% | 38.6% | 32.1% | 25.8% | 37.5% | 30.6% |
| - Diplegia | 16 | 37 | 36 | 27 | 29 | 29 | 19 | 29 | 24 | 31 | 28 | 29 | 37 | 34 | 405 |
| | 24.6% | 38.1% | 41.4% | 40.3% | 35.4% | 34.5% | 29.2% | 35.8% | 30.8% | 34.4% | 31.8% | 37.2% | 41.6% | 38.6% | 35.6% |
| - Quadriplegia/ Triplegia | 15 | 18 | 15 | 18 | 19 | 14 | 13 | 16 | 23 | 21 | 18 | 19 | 18 | 11 | 238 |
| | 23.1% | 18.6% | 17.2% | 26.9% | 23.2% | 16.7% | 20.0% | 19.8% | 29.5% | 23.3% | 20.5% | 24.4% | 20.2% | 12.5% | 20.9% |
| Ataxia | 2 | 7 | 4 | 1 | 2 | 6 | 2 | 1 | 5 | 3 | 2 | 0 | 1 | 3 | 39 |
| | 3.1% | 7.2% | 4.6% | 1.5% | 2.4% | 7.1% | 3.1% | 1.2% | 6.4% | 3.3% | 2.3% | 0.0% | 1.1% | 3.4% | 3.4% |
| Dyskinesia | | | | | | | | | | | | | | | |
| - Mainly athetosis | 5 | 1 | 0 | 0 | 3 | 2 | 4 | 0 | 0 | 3 | 2 | 0 | 3 | 2 | 25 |
| | 7.7% | 1.0% | 0.0% | 0.0% | 3.7% | 2.4% | 6.2% | 0.0% | 0.0% | 3.3% | 2.3% | 0.0% | 3.4% | 2.3% | 2.2% |
| - Mainly dystonia | 2 | 1 | 7 | 2 | 1 | 4 | 3 | 3 | 2 | 7 | 1 | 2 | 4 | 3 | 42 |
| | 3.1% | 1.0% | 8.0% | 3.0% | 1.2% | 4.8% | 4.6% | 3.7% | 2.6% | 7.8% | 1.1% | 2.6% | 4.5% | 3.4% | 3.7% |
| Hypotonia | 1 | 3 | 6 | 0 | 2 | 5 | 4 | 1 | 4 | 4 | 3 | 3 | 3 | 2 | 41 |
| | 1.5% | 3.1% | 6.9% | 0.0% | 2.4% | 6.0% | 6.2% | 1.2% | 5.1% | 4.4% | 3.4% | 3.8% | 3.4% | 2.3% | 3.6% |
| Total | 65 | 97 | 87 | 67 | 82 | 84 | 65 | 81 | 78 | 90 | 88 | 78 | 89 | 88 | 1139 |
| Unknown | 10 | 6 | 4 | 9 | 5 | 8 | 7 | 7 | 7 | 13 | 12 | 4 | 13 | 8 | 113 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**The Motor type and distribution with the highest incidence was spastic diplegia followed by spastic hemiplegia.**

**Eighty-five percent of the entire cohort had spastic motor type.**

Figure 1: Number of people with cerebral palsy, born 1995-2008, by predominant motor type and distribution and by GMFCS level




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

**GMFCS level V was most frequently represented in the spastic quadriplegia subtype (65%) and the dyskinesia subtype (17%).**

**GMFCS level I most frequently represented in the spastic hemiplegia (60%) and diplegia subtypes (32%).**

# Gross Motor Function Classification System (GMFCS)

Table 2: Number of people with cerebral palsy by GMFCS level

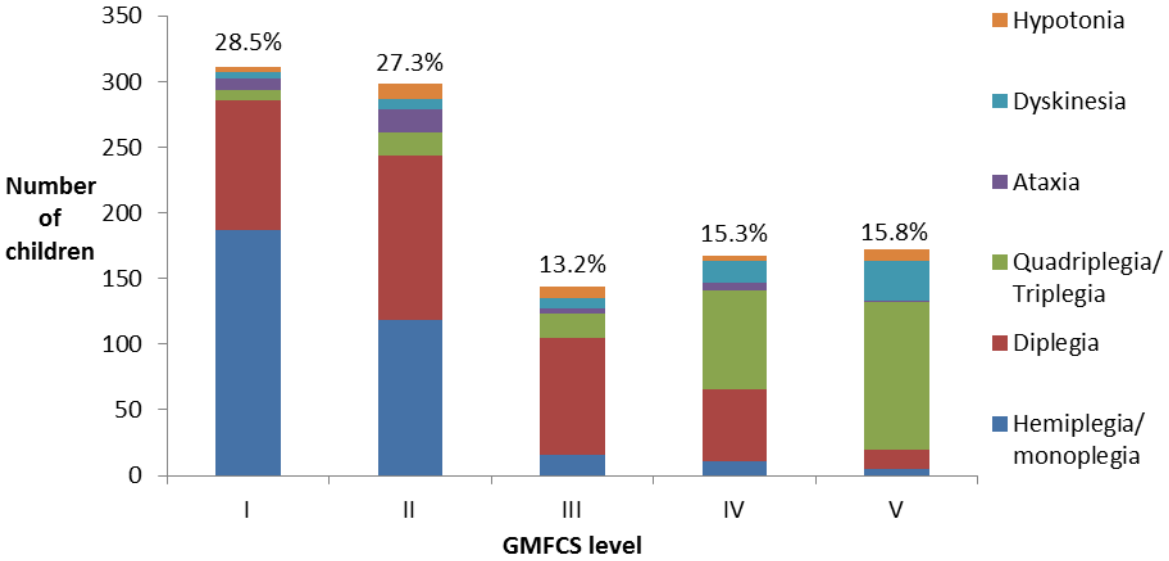
| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| GMFCS | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| I | 19 | 32 | 18 | 25 | 21 | 23 | 12 | 21 | 21 | 31 | 30 | 21 | 29 | 28 | 331 |
| | 27.5% | 32.7% | 22.5% | 35.7% | 25.9% | 28.8% | 19.4% | 26.6% | 26.3% | 35.6% | 33.7% | 25.9% | 29.3% | 29.8% | 28.8% |
| II | 16 | 20 | 24 | 15 | 18 | 23 | 16 | 25 | 26 | 23 | 21 | 24 | 29 | 27 | 307 |
| | 23.2% | 20.4% | 30.0% | 21.4% | 22.2% | 28.8% | 25.8% | 31.6% | 32.5% | 26.4% | 23.6% | 29.6% | 29.3% | 28.7% | 26.7% |
| III | 12 | 15 | 19 | 6 | 13 | 10 | 8 | 13 | 4 | 7 | 14 | 7 | 11 | 16 | 155 |
| | 17.4% | 15.3% | 23.8% | 8.6% | 16.0% | 12.5% | 12.9% | 16.5% | 5.0% | 8.0% | 15.7% | 8.6% | 11.1% | 17.0% | 13.5% |
| IV | 10 | 11 | 5 | 14 | 15 | 12 | 16 | 12 | 14 | 5 | 15 | 15 | 18 | 15 | 177 |
| | 14.5% | 11.2% | 6.3% | 20.0% | 18.5% | 15.0% | 25.8% | 15.2% | 17.5% | 5.7% | 16.9% | 18.5% | 18.2% | 16.0% | 15.4% |
| V | 12 | 20 | 14 | 10 | 14 | 12 | 10 | 8 | 15 | 21 | 9 | 14 | 12 | 8 | 179 |
| | 17.4% | 20.4% | 17.5% | 14.3% | 17.3% | 15.0% | 16.1% | 10.1% | 18.8% | 24.1% | 10.1% | 17.3% | 12.1% | 8.5% | 15.6% |
| Total | 69 | 98 | 80 | 70 | 81 | 80 | 62 | 79 | 80 | 87 | 89 | 81 | 99 | 94 | 1149 |
| Unknown | 6 | 5 | 11 | 6 | 6 | 12 | 10 | 9 | 5 | 16 | 11 | 1 | 3 | 2 | 103 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**GMFCS level I (28.8% and GMFCS level II (26.7%) were the most frequent classifications.**

**GMFCS level III (13.5%) was the least frequent classification.**

Figure 2: Number of people with cerebral palsy, born 1995-2008, by GMFCS level and motor type and distribution




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

**Spastic hemiplegia or diplegia subtypes accounted for more than 90% of GMFCS level I, more than 80% of GMFCS level II and more than 70% of GMFCS level III.**

**Spastic quadriplegia and dyskinesia accounted for more than 80% of GMFCS level V and more than 50% of GMFCS level IV.**

# Birth details

## Maternal age at delivery

Table 3: Number and percentage of people with cerebral palsy by maternal age group at delivery

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Maternal age | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| ≤19 yrs | 3 | 5 | 3 | 4 | 4 | 3 | 2 | 2 | 5 | 3 | 2 | 4 | 2 | 4 | 46 |
| | 4.8% | 6.3% | 4.8% | 7.0% | 6.8% | 5.0% | 3.7% | 3.4% | 7.5% | 4.2% | 2.6% | 6.0% | 2.5% | 4.9% | 4.9% |
| 20-24 yrs | 9 | 16 | 11 | 4 | 9 | 11 | 11 | 11 | 9 | 12 | 12 | 15 | 11 | 7 | 148 |
| | 14.5% | 20.0% | 17.5% | 7.0% | 15.3% | 18.3% | 20.4% | 18.6% | 13.4% | 16.9% | 15.4% | 22.4% | 13.8% | 8.5% | 15.8% |
| 25-29 yrs | 24 | 21 | 24 | 26 | 20 | 17 | 15 | 20 | 16 | 17 | 29 | 15 | 19 | 22 | 285 |
| | 38.7% | 26.3% | 38.1% | 45.6% | 33.9% | 28.3% | 27.8% | 33.9% | 23.9% | 23.9% | 37.2% | 22.4% | 23.8% | 26.8% | 30.4% |
| 30-34 yrs | 15 | 25 | 20 | 13 | 19 | 21 | 16 | 16 | 25 | 25 | 22 | 20 | 26 | 24 | 287 |
| | 24.2% | 31.3% | 31.7% | 22.8% | 32.2% | 35.0% | 29.6% | 27.1% | 37.3% | 35.2% | 28.2% | 29.9% | 32.5% | 29.3% | 30.6% |
| 35-39 yrs | 11 | 12 | 5 | 8 | 5 | 8 | 10 | 8 | 9 | 11 | 11 | 13 | 13 | 23 | 147 |
| | 17.7% | 15.0% | 7.9% | 14.0% | 8.5% | 13.3% | 18.5% | 13.6% | 13.4% | 15.5% | 14.1% | 19.4% | 16.3% | 28.0% | 15.7% |
| ≥40 yrs | 0 | 1 | 0 | 2 | 2 | 0 | 0 | 2 | 3 | 3 | 2 | 0 | 9 | 2 | 26 |
| | 0.0% | 1.3% | 0.0% | 3.5% | 3.4% | 0.0% | 0.0% | 3.4% | 4.5% | 4.2% | 2.6% | 0.0% | 11.3% | 2.4% | 2.8% |
| Total | 62 | 80 | 63 | 57 | 59 | 60 | 54 | 59 | 67 | 71 | 78 | 67 | 80 | 82 | 939 |
| Unknown | 13 | 23 | 28 | 19 | 28 | 32 | 18 | 29 | 18 | 32 | 22 | 15 | 22 | 14 | 313 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**More than 60% of all people with CP were born to mothers aged between 20 and 35 years.**

**Almost 20% of people with CP were born to mothers 40 years and older.**

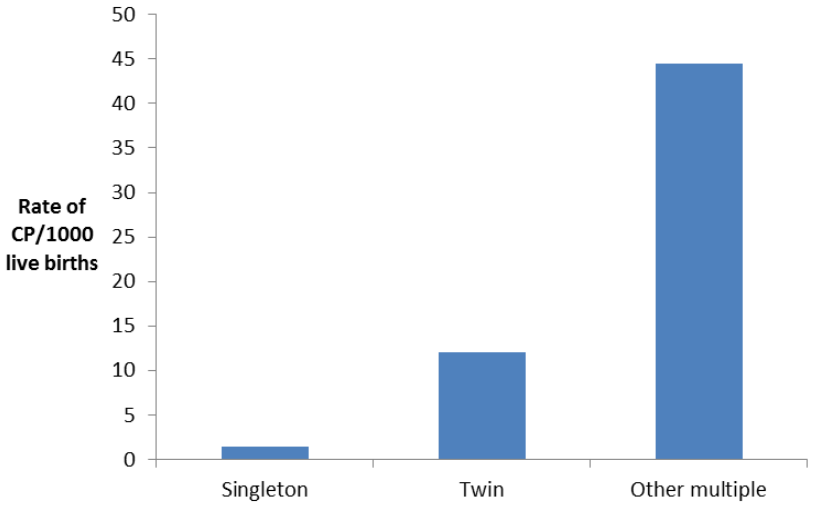
## Plurality

Table 4: Number and percentage of people with cerebral palsy by birth plurality

| Plurality | 1995 n % | 1996 n % | 1997 n % | 1998 n % | 1999 n % | 2000 n % | 2001 n % | 2002 n % | 2003 n % | 2004 n % | 2005 n % | 2006 n % | 2007 n % | 2008 n % | Total n % |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Singleton | 55 | 92 | 71 | 61 | 69 | 69 | 54 | 65 | 66 | 80 | 79 | 71 | 82 | 75 | 989 |
| | 85.9% | 94.8% | 89.9% | 85.9% | 88.5% | 89.6% | 84.4% | 80.2% | 85.7% | 87.9% | 84.0% | 87.7% | 89.1% | 82.4% | 87.0% |
| Twins | 9 | 4 | 7 | 10 | 7 | 7 | 10 | 12 | 10 | 10 | 15 | 10 | 8 | 14 | 133 |
| | 14.1% | 4.1% | 8.9% | 14.1% | 9.0% | 9.1% | 15.6% | 14.8% | 13.0% | 11.0% | 16.0% | 12.3% | 8.7% | 15.4% | 11.7% |
| Triplets | 0 | 1 | 1 | 0 | 0 | 1 | 0 | 3 | 0 | 1 | 0 | 0 | 2 | 2 | 11 |
| | 0.0% | 1.0% | 1.3% | 0.0% | 0.0% | 1.3% | 0.0% | 3.7% | 0.0% | 1.1% | 0.0% | 0.0% | 2.2% | 2.2% | 1.0% |
| Higher order multiple | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 4 |
| | 0.0% | 0.0% | 0.0% | 0.0% | 2.6% | 0.0% | 0.0% | 1.2% | 1.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.4% |
| Total | 64 | 97 | 79 | 71 | 78 | 77 | 64 | 81 | 77 | 91 | 94 | 81 | 92 | 91 | 1137 |
| Unknown | 11 | 6 | 12 | 5 | 9 | 15 | 8 | 7 | 8 | 12 | 6 | 1 | 10 | 5 | 115 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

Figure 3: Rate of people with cerebral palsy, born 1995-2008, per thousand live births (LB) by plurality




**Most people with CP are singletons (87%) and almost 12% are twins.**

**The rate of CP was almost 9 times higher for twins than singletons and 30 times higher for higher order multiples.**

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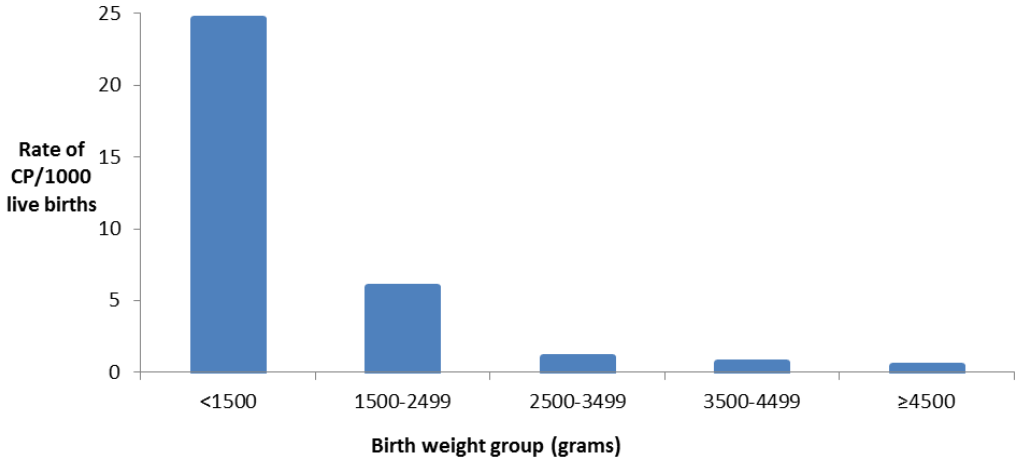
## Birth weight

Table 5: Number and percentage of people with cerebral palsy by birth weight in grams

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Birth weight | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| <1500 | 10 | 23 | 25 | 19 | 24 | 22 | 10 | 26 | 17 | 28 | 21 | 14 | 21 | 22 | 282 |
| | 17.2% | 24.2% | 32.1% | 27.1% | 32.4% | 28.6% | 15.6% | 32.9% | 23.0% | 30.8% | 23.1% | 17.9% | 23.9% | 25.6% | 25.6% |
| 1500-2499 | 15 | 14 | 14 | 15 | 9 | 14 | 16 | 16 | 14 | 14 | 23 | 14 | 25 | 25 | 228 |
| | 25.9% | 14.7% | 17.9% | 21.4% | 12.2% | 18.2% | 25.0% | 20.3% | 18.9% | 15.4% | 25.3% | 17.9% | 28.4% | 29.1% | 20.7% |
| 2500-3499 | 16 | 38 | 29 | 24 | 24 | 25 | 23 | 28 | 29 | 31 | 24 | 34 | 28 | 20 | 373 |
| | 27.6% | 40.0% | 37.2% | 34.3% | 32.4% | 32.5% | 35.9% | 35.4% | 39.2% | 34.1% | 26.4% | 43.6% | 31.8% | 23.3% | 33.8% |
| 3500-4499 | 16 | 20 | 9 | 12 | 17 | 16 | 14 | 9 | 14 | 16 | 23 | 16 | 13 | 18 | 213 |
| | 27.6% | 21.1% | 11.5% | 17.1% | 23.0% | 20.8% | 21.9% | 11.4% | 18.9% | 17.6% | 25.3% | 20.5% | 14.8% | 20.9% | 19.3% |
| ≥4500 | 1 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 2 | 0 | 0 | 1 | 1 | 7 |
| | 1.7% | 0.0% | 1.3% | 0.0% | 0.0% | 0.0% | 1.6% | 0.0% | 0.0% | 2.2% | 0.0% | 0.0% | 1.1% | 1.2% | 0.6% |
| Total | 58 | 95 | 78 | 70 | 74 | 77 | 64 | 79 | 74 | 91 | 91 | 78 | 88 | 86 | 1103 |
| Unknown | 17 | 8 | 13 | 6 | 13 | 15 | 8 | 9 | 11 | 12 | 9 | 4 | 14 | 10 | 149 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

Figure 4a: Rate of people with cerebral palsy, born 1995-2008, per thousand live births (LB) by birth weight




**More than half of people with CP are born 2500g – 4499g.**

**The rate of CP is 36 times higher in babies born less than 1500g than in babies born 3500g-4499g and 13 times higher in babies born 1500g-2499g.**

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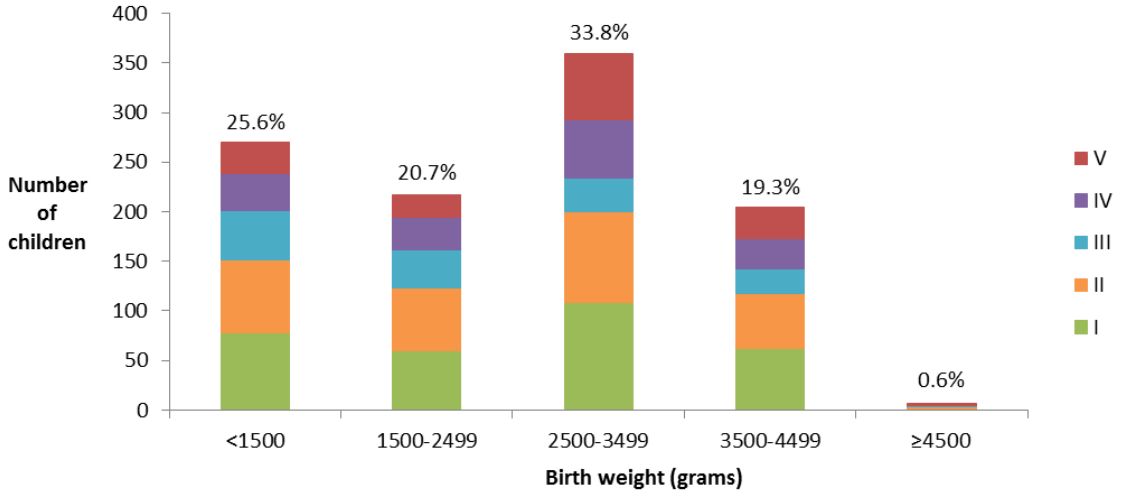
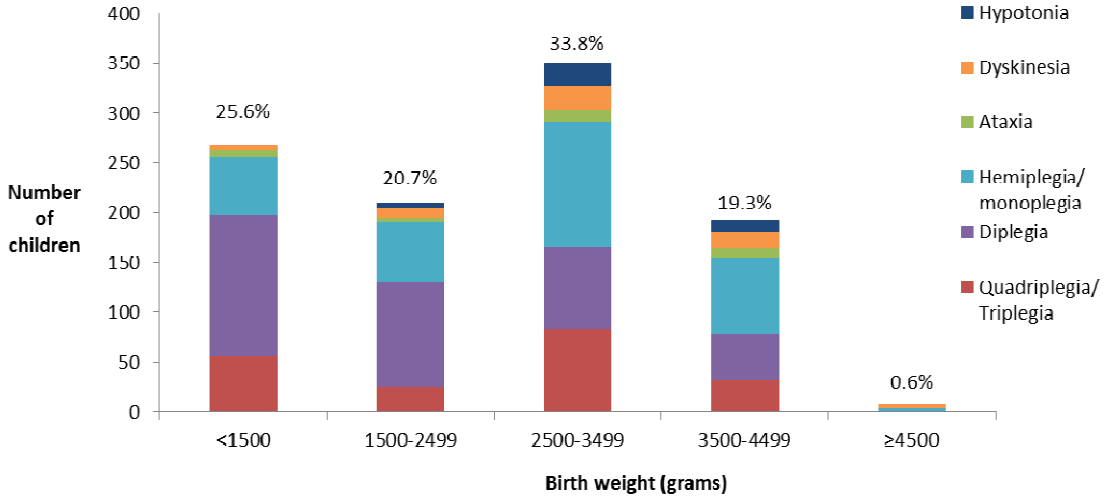
Figure 4b: Number of people with cerebral palsy, born 1995-2008, by birth weight and GMFCS level




**There is little change in the frequencies of GMFCS level across gestational age bands.**

**Spastic diplegia has higher frequencies in smaller birth weights while hemiplegia and hypotonia are higher in the larger birth weights.**

Figure 4c: Number of people with cerebral palsy, born 1995-2008, by birth weight and motor type and distribution




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

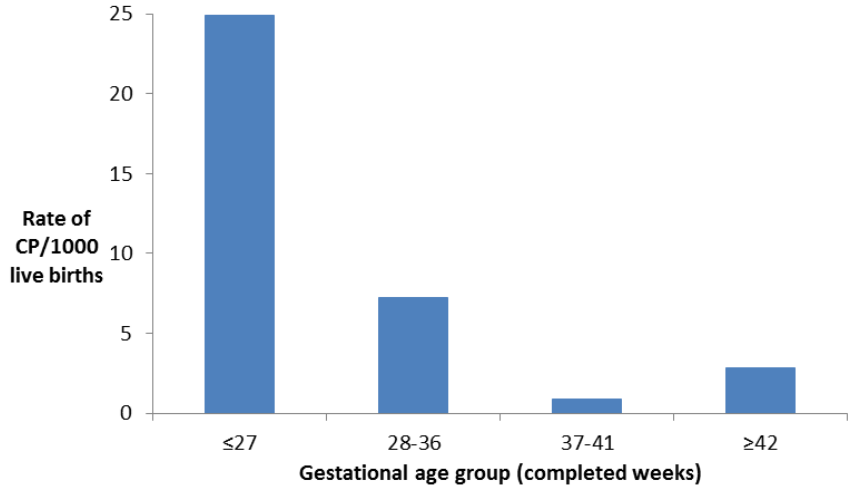
## Gestational age

Table 6: Number and percentage of people with cerebral palsy by gestational age in completed weeks at delivery

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Gestational age | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| ≤27 | 4 | 13 | 15 | 14 | 10 | 9 | 7 | 15 | 7 | 17 | 15 | 8 | 7 | 11 | 152 |
| | 6.5% | 13.4% | 17.9% | 20.0% | 12.8% | 11.4% | 10.4% | 18.3% | 9.0% | 18.7% | 16.3% | 10.0% | 7.5% | 11.8% | 13.3% |
| 28-36 | 22 | 28 | 27 | 19 | 25 | 34 | 20 | 30 | 26 | 27 | 24 | 26 | 45 | 39 | 392 |
| | 35.5% | 28.9% | 32.1% | 27.1% | 32.1% | 43.0% | 29.9% | 36.6% | 33.3% | 29.7% | 26.1% | 32.5% | 48.4% | 41.9% | 34.2% |
| 37-41 | 36 | 55 | 37 | 36 | 42 | 32 | 39 | 37 | 45 | 45 | 51 | 45 | 38 | 40 | 578 |
| | 58.1% | 56.7% | 44.0% | 51.4% | 53.8% | 40.5% | 58.2% | 45.1% | 57.7% | 49.5% | 55.4% | 56.3% | 40.9% | 43.0% | 50.4% |
| ≥42 | 0 | 1 | 5 | 1 | 1 | 4 | 1 | 0 | 0 | 2 | 2 | 1 | 3 | 3 | 24 |
| | 0.0% | 1.0% | 6.0% | 1.4% | 1.3% | 5.1% | 1.5% | 0.0% | 0.0% | 2.2% | 2.2% | 1.3% | 3.2% | 3.2% | 2.1% |
| Total | 62 | 97 | 84 | 70 | 78 | 79 | 67 | 82 | 78 | 91 | 92 | 80 | 93 | 93 | 1146 |
| Unknown | 13 | 6 | 7 | 6 | 9 | 13 | 5 | 6 | 7 | 12 | 8 | 2 | 9 | 3 | 106 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

Figure 5a: Rate of people with cerebral palsy, born 1995-2008, by gestational age

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**More than 50% of people with CP are born term (37-41 weeks).**

**The rate of CP for people born earlier than or equal to 27 completed weeks was almost 29 times higher than those people born 37-41 weeks and the rate was 8 times for people born 28-36 weeks.**

Figure 5b: Number of people with cerebral palsy, born 1995-2008, by gestational age and GMFCS level

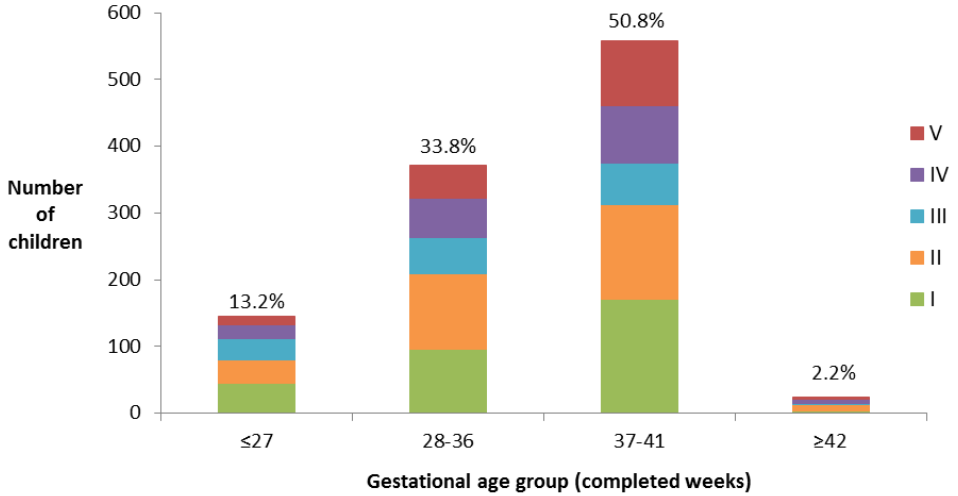
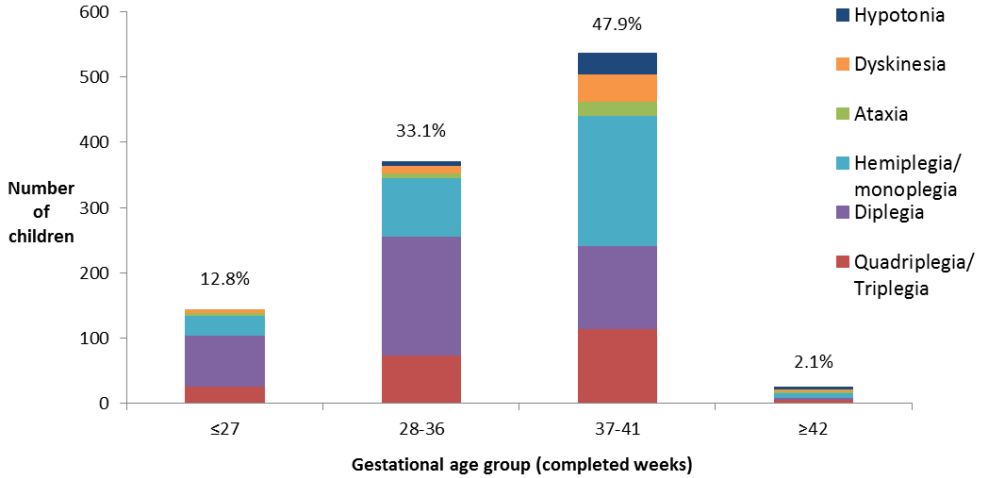



Figure 5c: Number of people with cerebral palsy, born 1995-2008, by gestational age and motor type and distribution




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

**There are small changes in the proportions of gestational ages present across the GMFCS levels with GMFCS level III slightly over represented and GMFCS V slightly under represented in those born earlier than 28 weeks completed gestation.**

**There are higher proportions of hemiplegia in term and later gestational ages and larger proportions of diplegia in those born earlier than 37 weeks.**

## Admission to more than routine care

Table 7: Number and percentage of people with cerebral palsy by type of neonatal care

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Type of care | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| NICU only | 4 | 23 | 15 | 13 | 16 | 17 | 11 | 15 | 12 | 18 | 16 | 8 | 10 | 5 | 183 |
| | 6.6% | 24.7% | 19.7% | 19.4% | 20.8% | 21.8% | 17.5% | 19.2% | 15.8% | 20.7% | 17.8% | 9.9% | 11.1% | 5.6% | 16.5% |
| NICU and SCN | 24 | 23 | 30 | 19 | 28 | 34 | 23 | 36 | 23 | 26 | 29 | 29 | 47 | 37 | 408 |
| | 39.3% | 24.7% | 39.5% | 28.4% | 36.4% | 43.6% | 36.5% | 46.2% | 30.3% | 29.9% | 32.2% | 35.8% | 52.2% | 41.1% | 36.9% |
| SCN only | 10 | 12 | 12 | 13 | 8 | 8 | 8 | 8 | 8 | 13 | 10 | 18 | 13 | 16 | 157 |
| | 16.4% | 12.9% | 15.8% | 19.4% | 10.4% | 10.3% | 12.7% | 10.3% | 10.5% | 14.9% | 11.1% | 22.2% | 14.4% | 17.8% | 14.2% |
| Routine care only | 23 | 35 | 19 | 22 | 25 | 19 | 21 | 19 | 33 | 30 | 35 | 26 | 20 | 32 | 359 |
| | 37.7% | 37.6% | 25.0% | 32.8% | 32.5% | 24.4% | 33.3% | 24.4% | 43.4% | 34.5% | 38.9% | 32.1% | 22.2% | 35.6% | 32.4% |
| Total | 61 | 93 | 76 | 67 | 77 | 78 | 63 | 78 | 76 | 87 | 90 | 81 | 90 | 90 | 1107 |
| Unknown | 14 | 10 | 15 | 9 | 10 | 14 | 9 | 10 | 9 | 16 | 10 | 1 | 12 | 6 | 145 |

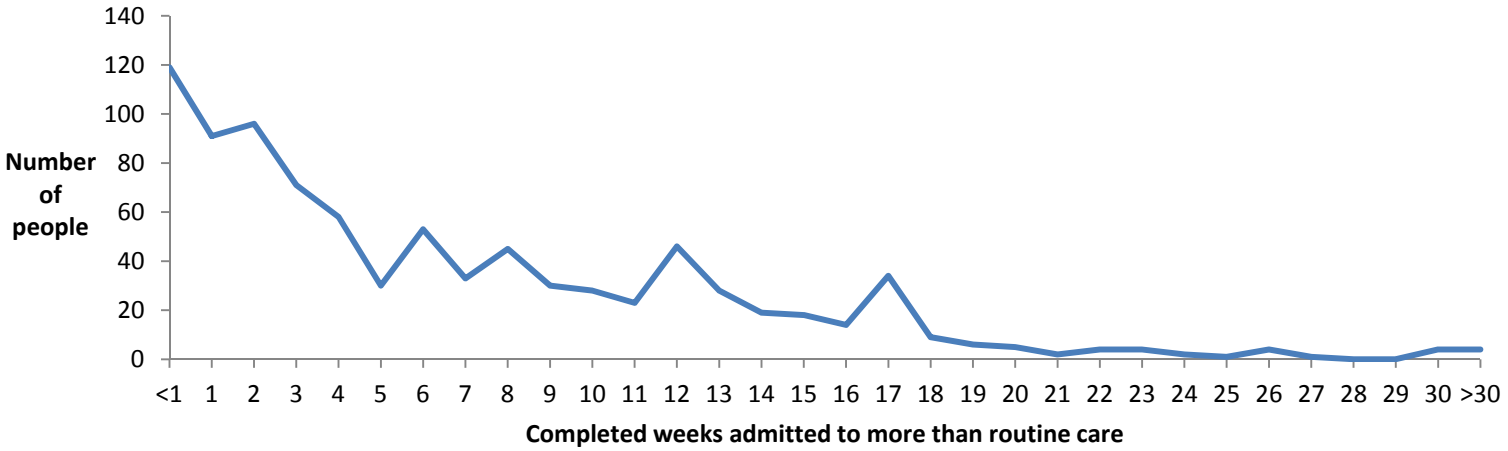
^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

NICU: Neonatal intensive care unit
SCN: Special care nursery

**Almost one third of people with CP receive routine neonatal care.**

**Two thirds of the people in this cohort are admitted to more than routine care for more than 25 hours and half of those people are admitted to both a special care nursery and a neonatal intensive care unit.**

Figure 6: Number of people with cerebral palsy, born 1995-2008, who were admitted to more than routine neonatal care for greater than 24 hours by length of stay (completed weeks)




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**Of those admitted to more than routine care for more than 24 hours, 13% stayed less than one week and 35% stayed less than 4 weeks.**

**One percent of people in our cohort stayed longer than 6 months in more than routine care.**

# Demographics

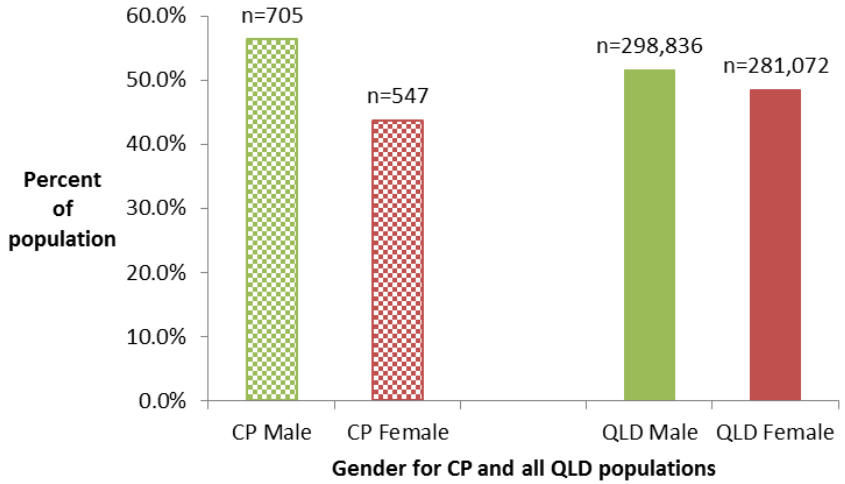
## Gender

Table 8: Number and percentage of people with cerebral palsy by gender

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Gender | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| CP Male | 44 | 54 | 46 | 45 | 45 | 54 | 39 | 52 | 44 | 68 | 59 | 39 | 62 | 54 | 705 |
| | 58.7% | 52.4% | 50.5% | 59.2% | 51.7% | 58.7% | 54.2% | 59.1% | 51.8% | 66.0% | 59.0% | 47.6% | 60.8% | 56.3% | 56.3% |
| CP Female | 31 | 49 | 45 | 31 | 42 | 38 | 33 | 36 | 41 | 35 | 41 | 43 | 40 | 42 | 547 |
| | 41.3% | 47.6% | 49.5% | 40.8% | 48.3% | 41.3% | 45.8% | 40.9% | 48.2% | 34.0% | 41.0% | 52.4% | 39.2% | 43.8% | 43.7% |
| Total | 75 | 103 | 91 | 76 | 87 | 92 | 72 | 88 | 85 | 103 | 100 | 82 | 102 | 96 | 1252 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

Figure 6: Percent of people with cerebral palsy, born 1995-2008, and percent of all people in QLD, born 1998-2008, by gender




**Male gender is an increased risk for CP with 56.3% of the cohort being male.**

**In the whole Queensland population born 1998-2008, male gender is 51.5%.**

q Uses published data from Perinatal Data Statistics

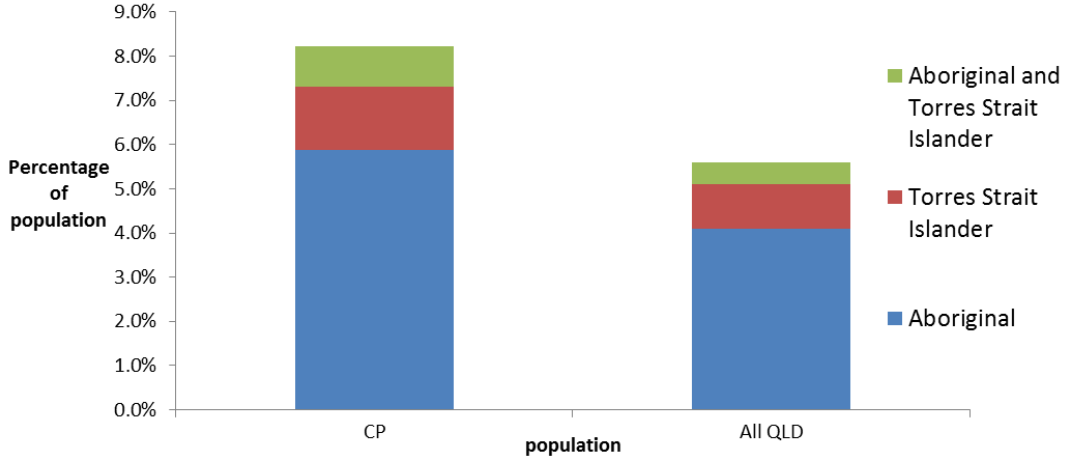
## Indigenous status

Table 9: Number and percentage of people with cerebral palsy by indigenous status

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Indigenous | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Aboriginal | 4 | 5 | 5 | 3 | 2 | 3 | 2 | 5 | 4 | 5 | 7 | 4 | 5 | 5 | 59 |
| | 6.3% | 5.6% | 7.1% | 5.3% | 3.1% | 4.7% | 3.6% | 7.7% | 6.1% | 7.4% | 8.8% | 5.2% | 5.7% | 5.6% | 5.9% |
| Aboriginal and Torres | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 2 | 2 | 2 | 0 | 2 | 0 | 0 | 11 |
| Strait Islander | 0.0% | 0.0% | 0.0% | 1.8% | 0.0% | 1.6% | 1.8% | 3.1% | 3.0% | 2.9% | 0.0% | 2.6% | 0.0% | 0.0% | 1.1% |
| Torres Strait Islander | 0 | 0 | 3 | 1 | 0 | 0 | 0 | 1 | 0 | 3 | 0 | 0 | 0 | 1 | 9 |
| | 0.0% | 0.0% | 4.3% | 1.8% | 0.0% | 0.0% | 0.0% | 1.5% | 0.0% | 4.4% | 0.0% | 0.0% | 0.0% | 1.1% | 0.9% |
| Non-Indigenous | 59 | 84 | 62 | 52 | 63 | 60 | 53 | 57 | 60 | 58 | 73 | 71 | 82 | 83 | 917 |
| | 93.7% | 94.4% | 88.6% | 91.2% | 96.9% | 93.8% | 94.6% | 87.7% | 90.9% | 85.3% | 91.3% | 92.2% | 94.3% | 93.3% | 92.1% |
| Total | 63 | 89 | 70 | 57 | 65 | 64 | 56 | 65 | 66 | 68 | 80 | 77 | 87 | 89 | 996 |
| Unknown | 12 | 14 | 21 | 19 | 22 | 28 | 16 | 23 | 19 | 35 | 20 | 5 | 15 | 7 | 256 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

Figure 7: Percentage of people with cerebral palsy and all people born in Queensland by indigenous status (1998 – 2008)




q Comparison with Queensland Perinatal Statistics

**Almost 8% of people in the cohort were Aboriginal, Torres Strait Islander or both.**

**In the birth years 1998-2008 the rate of CP in people identified as Aboriginal (2.5/1000LBS) was almost twice as high as the rate for people who were non-indigenous (1.3/1000LBS).**

# Associated impairments

## Vision status

Table 10: Number of people with cerebral palsy by vision status

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Vision status | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Functionally | 2 | 10 | 3 | 3 | 6 | 4 | 3 | 2 | 3 | 4 | 2 | 3 | 4 | 1 | 50 |
| blind | 3.0% | 10.4% | 3.9% | 4.3% | 7.6% | 5.1% | 4.8% | 2.6% | 4.2% | 5.1% | 2.3% | 3.8% | 4.3% | 1.1% | 4.5% |
| Some | 30 | 38 | 34 | 22 | 31 | 28 | 25 | 20 | 26 | 23 | 26 | 35 | 29 | 28 | 395 |
| impairment | 45.5% | 39.6% | 44.2% | 31.4% | 39.2% | 35.9% | 40.3% | 26.3% | 36.6% | 29.5% | 30.2% | 44.3% | 31.5% | 31.5% | 35.9% |
| No impairment | 29 | 34 | 32 | 33 | 32 | 37 | 30 | 45 | 33 | 47 | 45 | 26 | 45 | 44 | 512 |
| | 43.9% | 35.4% | 41.6% | 47.1% | 40.5% | 47.4% | 48.4% | 59.2% | 46.5% | 60.3% | 52.3% | 32.9% | 48.9% | 49.4% | 46.6% |
| Strabismus only | 5 | 14 | 8 | 12 | 10 | 9 | 4 | 9 | 9 | 4 | 13 | 15 | 14 | 16 | 142 |
| | 7.6% | 14.6% | 10.4% | 17.1% | 12.7% | 11.5% | 6.5% | 11.8% | 12.7% | 5.1% | 15.1% | 19.0% | 15.2% | 18.0% | 12.9% |
| Total | 66 | 96 | 77 | 70 | 79 | 78 | 62 | 76 | 71 | 78 | 86 | 79 | 92 | 89 | 1099 |
| Unknown | 9 | 7 | 14 | 6 | 8 | 14 | 10 | 12 | 14 | 25 | 14 | 3 | 10 | 7 | 153 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**Forty-seven percent of people had no vision impairment.**

**Thirty-six percent of people had some vision impairment. The frequencies were spread over all categories of GMFCS and subtypes with slightly higher proportions in GMFCS levels IV-V.**

**Almost 5% of people were functionally blind and they were mostly in GMFCS levels IV-V as well as spastic quadriplegia subtype.**

Figure 8a: Number of people with cerebral palsy, born 1995-2008, by GMFCS level and vision status

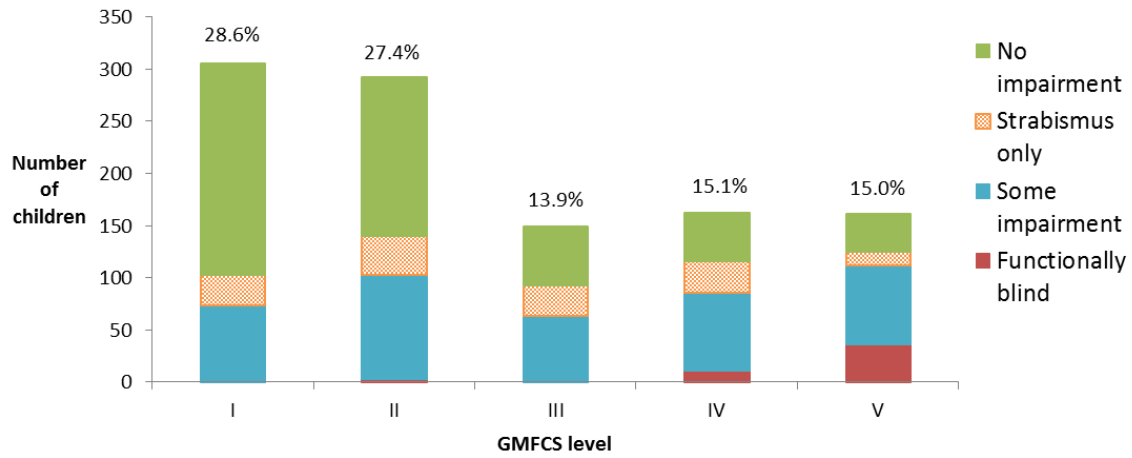
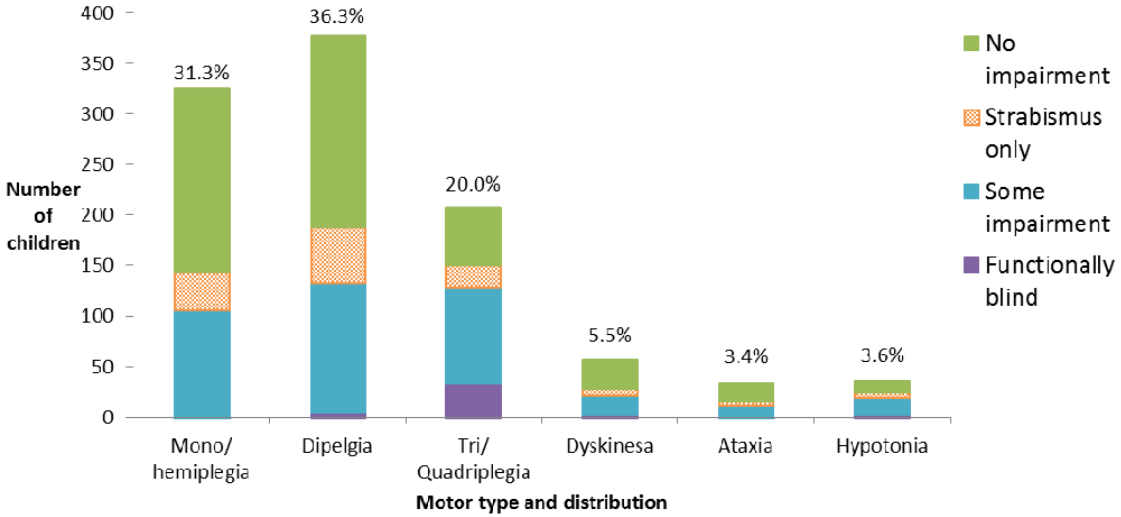



Figure 8b: Number of people with cerebral palsy, born 1995-2008, by motor type and distribution and vision status




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

## Hearing status

Table 11: Number and percentage of people with cerebral palsy by hearing status

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Hearing status | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Bilateral | 0 | 2 | 3 | 2 | 2 | 3 | 2 | 1 | 4 | 1 | 3 | 1 | 2 | 3 | 29 |
| deafness | 0.0% | 2.1% | 3.9% | 2.9% | 2.6% | 3.9% | 3.2% | 1.3% | 5.6% | 1.3% | 3.6% | 1.3% | 2.2% | 3.4% | 2.7% |
| Some | 5 | 7 | 8 | 4 | 9 | 8 | 8 | 7 | 4 | 14 | 5 | 6 | 5 | 7 | 97 |
| impairment | 7.7% | 7.3% | 10.4% | 5.8% | 11.7% | 10.4% | 12.9% | 9.1% | 5.6% | 17.9% | 6.0% | 7.5% | 5.4% | 8.0% | 8.9% |
| No impairment | 60 | 87 | 66 | 63 | 66 | 66 | 52 | 69 | 63 | 63 | 76 | 73 | 85 | 78 | 967 |
| | 92.3% | 90.6% | 85.7% | 91.3% | 85.7% | 85.7% | 83.9% | 89.6% | 88.7% | 80.8% | 90.5% | 91.3% | 92.4% | 88.6% | 88.5% |
| Total | 65 | 96 | 77 | 69 | 77 | 77 | 62 | 77 | 71 | 78 | 84 | 80 | 92 | 88 | 1093 |
| Unknown | 10 | 7 | 14 | 7 | 10 | 15 | 10 | 11 | 14 | 25 | 16 | 2 | 10 | 8 | 159 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**Almost 89% of all people with CP in our cohort had no hearing impairment.**

**Only 3% were bilaterally deaf but any association with GMFCS level or motor type and distribution is small.**

Figure 9a: Number of people with cerebral palsy, born 1995-2008, by GMFCS level and hearing status

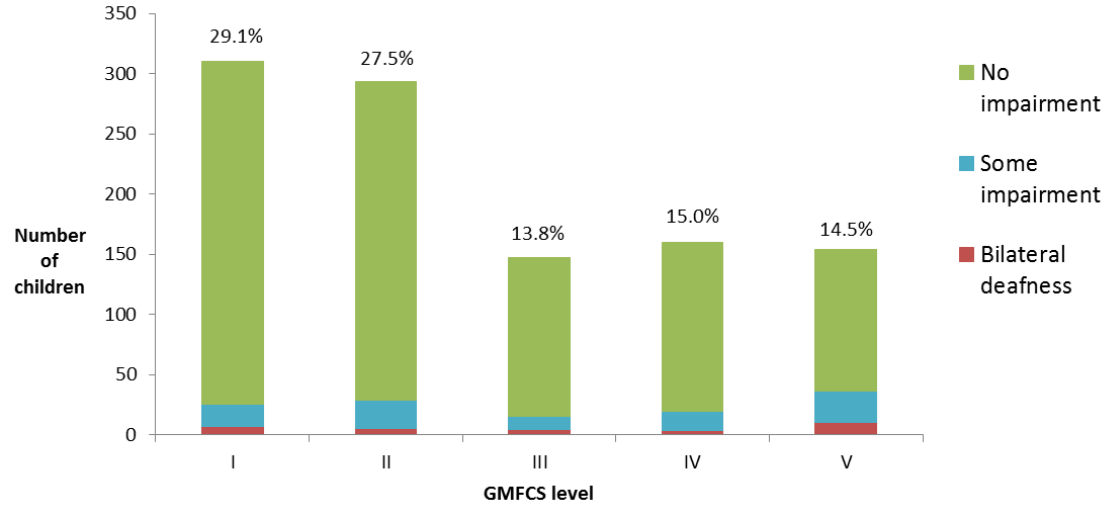
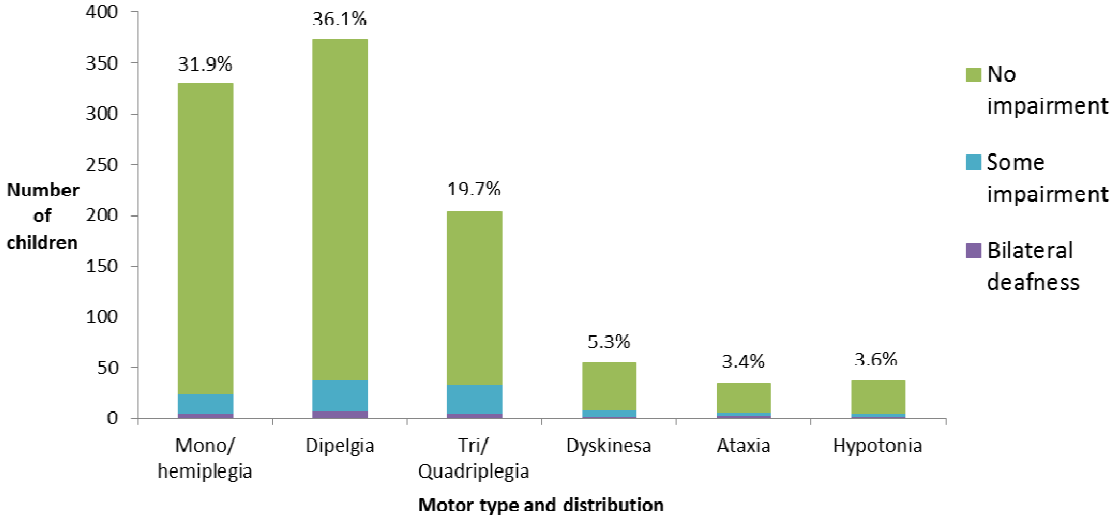



Figure 9b: Number of people with cerebral palsy, born 1995-2008, by motor type and distribution and hearing status




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

## Intellectual status

Table 12: Number and percentage of people with cerebral palsy by intellectual status

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Intellectual status | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Severe impairment | 11 | 17 | 11 | 11 | 15 | 8 | 5 | 5 | 4 | 5 | 9 | 11 | 8 | 4 | 124 |
| | 16.9% | 17.5% | 14.3% | 15.9% | 19.0% | 10.5% | 8.3% | 6.6% | 5.8% | 6.5% | 11.5% | 13.9% | 9.0% | 4.6% | 11.5% |
| Moderate impairment | 11 | 16 | 9 | 15 | 16 | 12 | 5 | 4 | 10 | 9 | 8 | 4 | 9 | 12 | 140 |
| | 16.9% | 16.5% | 11.7% | 21.7% | 20.3% | 15.8% | 8.3% | 5.3% | 14.5% | 11.7% | 10.3% | 5.1% | 10.1% | 13.8% | 13.0% |
| Mild impairment | 8 | 17 | 14 | 9 | 3 | 6 | 10 | 7 | 12 | 5 | 5 | 7 | 7 | 8 | 118 |
| | 12.3% | 17.5% | 18.2% | 13.0% | 3.8% | 7.9% | 16.7% | 9.2% | 17.4% | 6.5% | 6.4% | 8.9% | 7.9% | 9.2% | 10.9% |
| Probably some impairment | 8 | 14 | 13 | 7 | 9 | 22 | 16 | 11 | 14 | 16 | 11 | 16 | 10 | 7 | 174 |
| | 12.3% | 14.4% | 16.9% | 10.1% | 11.4% | 28.9% | 26.7% | 14.5% | 20.3% | 20.8% | 14.1% | 20.3% | 11.2% | 8.0% | 16.1% |
| Probably no impairment | 7 | 5 | 4 | 5 | 9 | 4 | 8 | 11 | 10 | 18 | 13 | 8 | 10 | 12 | 124 |
| | 10.8% | 5.2% | 5.2% | 7.2% | 11.4% | 5.3% | 13.3% | 14.5% | 14.5% | 23.4% | 16.7% | 10.1% | 11.2% | 13.8% | 11.5% |
| No impairment | 20 | 28 | 26 | 22 | 27 | 24 | 16 | 38 | 19 | 24 | 32 | 33 | 45 | 44 | 398 |
| | 30.8% | 28.9% | 33.8% | 31.9% | 34.2% | 31.6% | 26.7% | 50.0% | 27.5% | 31.2% | 41.0% | 41.8% | 50.6% | 50.6% | 36.9% |
| Total | 65 | 97 | 77 | 69 | 79 | 76 | 60 | 76 | 69 | 77 | 78 | 79 | 89 | 87 | 1078 |
| Unknown | 10 | 6 | 14 | 7 | 8 | 16 | 12 | 12 | 16 | 26 | 22 | 3 | 13 | 9 | 174 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**Approximately half of all people with CP in our cohort had no intellectual impairment.**

**Severe impairment increased with increasing GMFCS level and was highest in the spastic quadriplegia and dyskinesia subtypes.**

Figure 10a: Number of people with cerebral palsy by GMFCS level and intellectual status

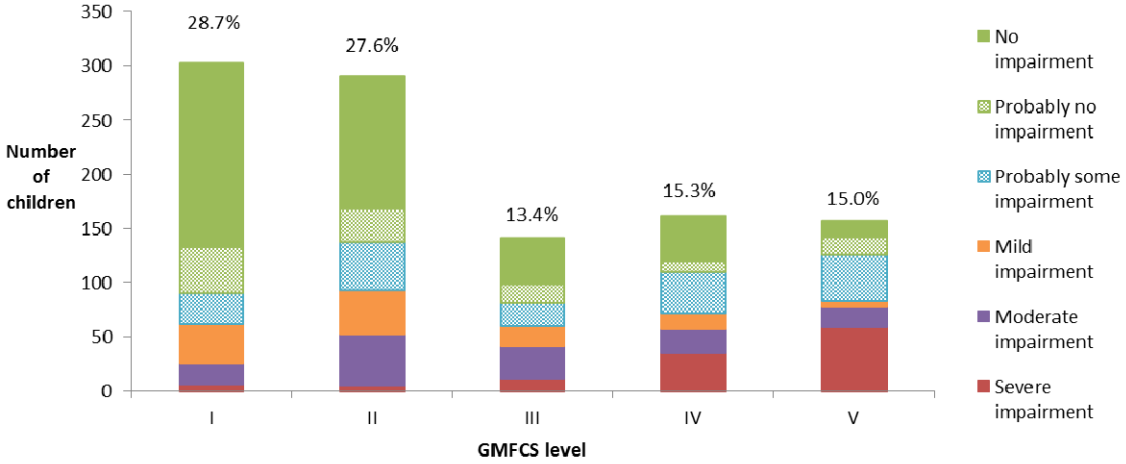
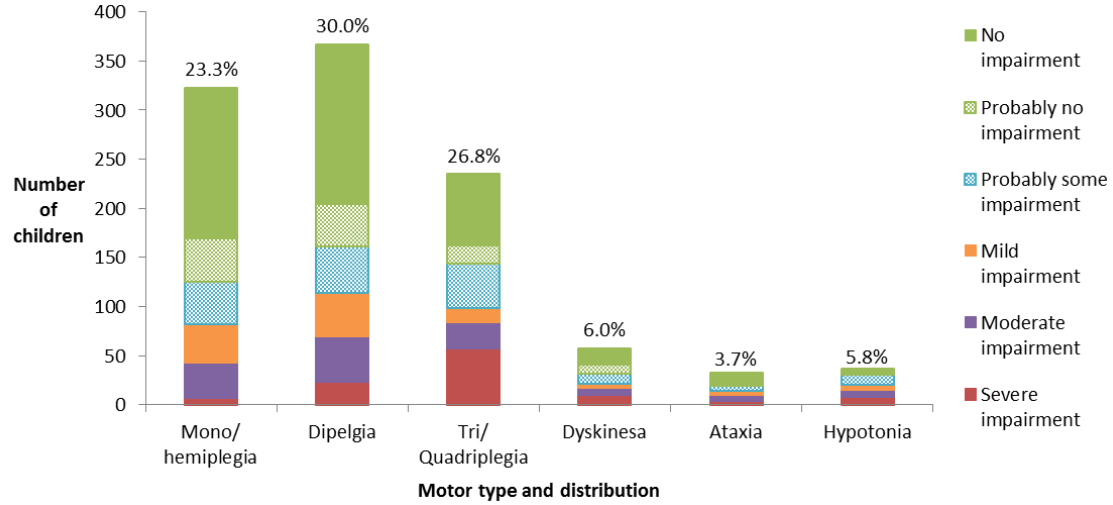



Figure 10b: Number of people with cerebral palsy by motor type and distribution and intellectual status




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

## Speech status

Table 13: Number and percentage of people with cerebral palsy by speech status

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Speech status | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Non-verbal | 16 | 26 | 13 | 18 | 20 | 17 | 16 | 18 | 17 | 22 | 13 | 18 | 25 | 18 | 257 |
| | 24.2% | 27.1% | 16.5% | 26.5% | 24.7% | 22.1% | 25.0% | 22.8% | 23.3% | 27.8% | 15.9% | 22.0% | 26.9% | 20.2% | 23.2% |
| Some | 26 | 30 | 33 | 26 | 26 | 21 | 28 | 26 | 30 | 33 | 29 | 33 | 27 | 31 | 399 |
| impairment | 39.4% | 31.3% | 41.8% | 38.2% | 32.1% | 27.3% | 43.8% | 32.9% | 41.1% | 41.8% | 35.4% | 40.2% | 29.0% | 34.8% | 36.0% |
| No impairment | 24 | 40 | 33 | 24 | 35 | 39 | 20 | 35 | 26 | 24 | 40 | 31 | 41 | 40 | 452 |
| | 36.4% | 41.7% | 41.8% | 35.3% | 43.2% | 50.6% | 31.3% | 44.3% | 35.6% | 30.4% | 48.8% | 37.8% | 44.1% | 44.9% | 40.8% |
| Total | 66 | 96 | 79 | 68 | 81 | 77 | 64 | 79 | 73 | 79 | 82 | 82 | 93 | 89 | 1108 |
| Unknown | 9 | 7 | 12 | 8 | 6 | 15 | 8 | 9 | 12 | 24 | 18 | 0 | 9 | 7 | 144 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**Nearly 60% of people with CP had some speech impairment making it the most frequent impairment measured by the QCPR.**

**Twenty-three percent of people with CP did not use speech communication and this increased with increasing GMFCS level.**

**Half of people in dyskinesia and hypotonia subtypes were non-verbal along with 61.1% of people with spastic quadriplegia.**

Figure 11a: Number of people with cerebral palsy, born 1995-2008, by GMFCS level and speech status

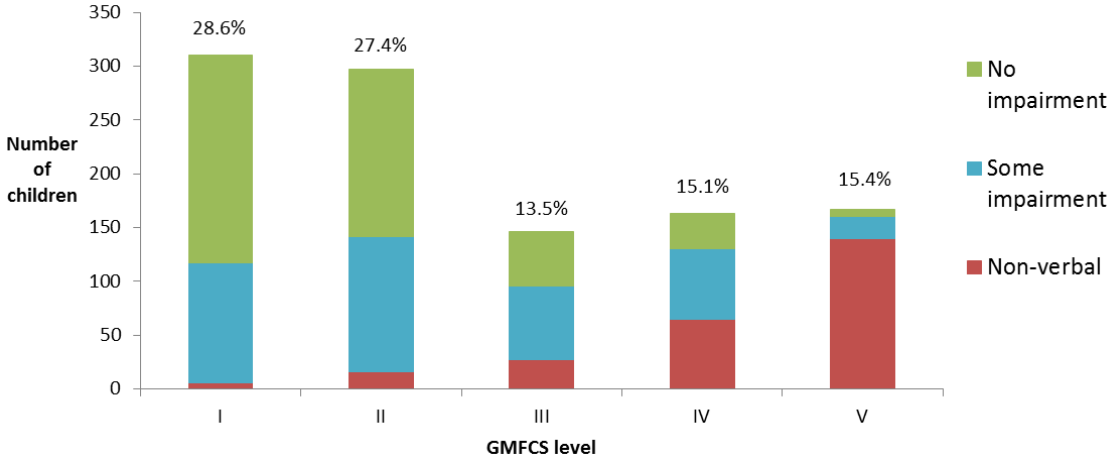
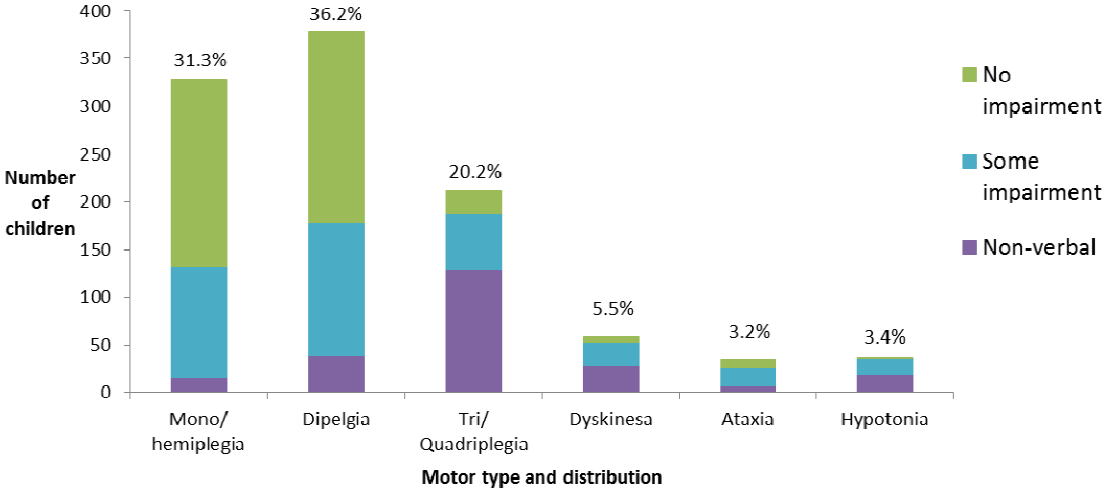



Figure 11b: Number of people with cerebral palsy, born 1995-2008, by motor type and distribution and speech status




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

## Epilepsy status

Table 14: Number and percentage of people with cerebral palsy by epilepsy status

| | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 1995-2008 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Epilepsy status | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Yes | 32 | 37 | 22 | 24 | 29 | 30 | 23 | 14 | 23 | 19 | 23 | 25 | 21 | 18 | 340 |
| | 47.8% | 38.5% | 27.8% | 34.8% | 36.3% | 38.5% | 37.1% | 18.2% | 31.9% | 22.6% | 26.4% | 31.3% | 22.8% | 20.2% | 30.6% |
| Resolved by | 1 | 5 | 5 | 2 | 3 | 7 | 1 | 5 | 2 | 5 | 1 | 2 | 2 | 4 | 45 |
| age 5 | 1.5% | 5.2% | 6.3% | 2.9% | 3.8% | 9.0% | 1.6% | 6.5% | 2.8% | 6.0% | 1.1% | 2.5% | 2.2% | 4.5% | 4.0% |
| No | 34 | 54 | 52 | 43 | 48 | 41 | 38 | 58 | 47 | 60 | 63 | 53 | 69 | 67 | 727 |
| | 50.7% | 56.3% | 65.8% | 62.3% | 60.0% | 52.6% | 61.3% | 75.3% | 65.3% | 71.4% | 72.4% | 66.3% | 75.0% | 75.3% | 65.4% |
| Total | 67 | 96 | 79 | 69 | 80 | 78 | 62 | 77 | 72 | 84 | 87 | 80 | 92 | 89 | 1112 |
| Unknown | 8 | 7 | 12 | 7 | 7 | 14 | 10 | 11 | 13 | 19 | 13 | 2 | 10 | 7 | 140 |

^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause

**Nearly 30% of people with CP had epilepsy at 5 years old, including 4% who had seizures previously but they had resolved.**

**The proportion of people with epilepsy increases from 13% in GMFCS level I to 72% in GMFCS level V.**

**Sixty percent of people with spastic quadriplegia subtype had epilepsy at 5 years.**

Figure 12a: Number of people with cerebral palsy, born 1995-2008, by GMFCS level and epilepsy status

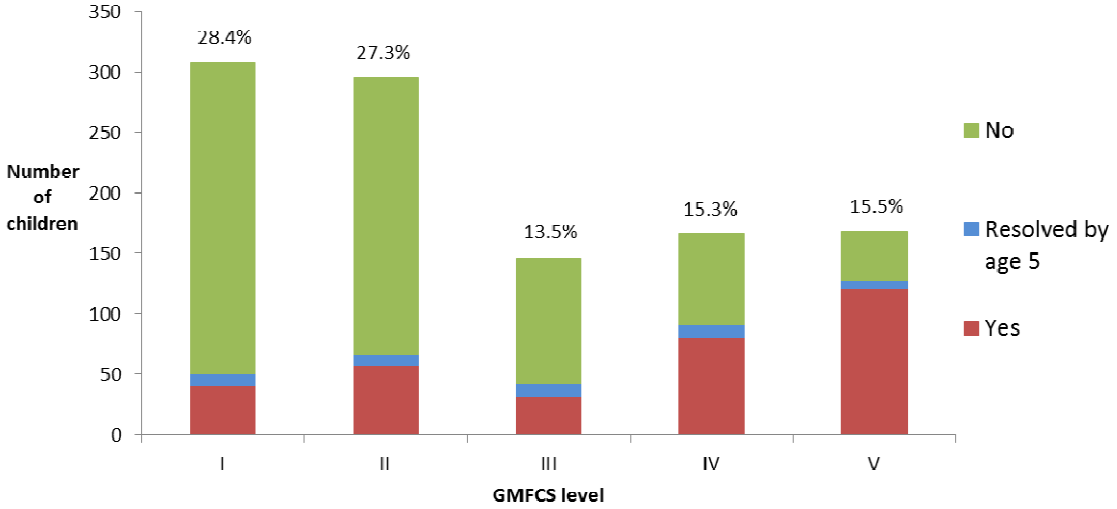
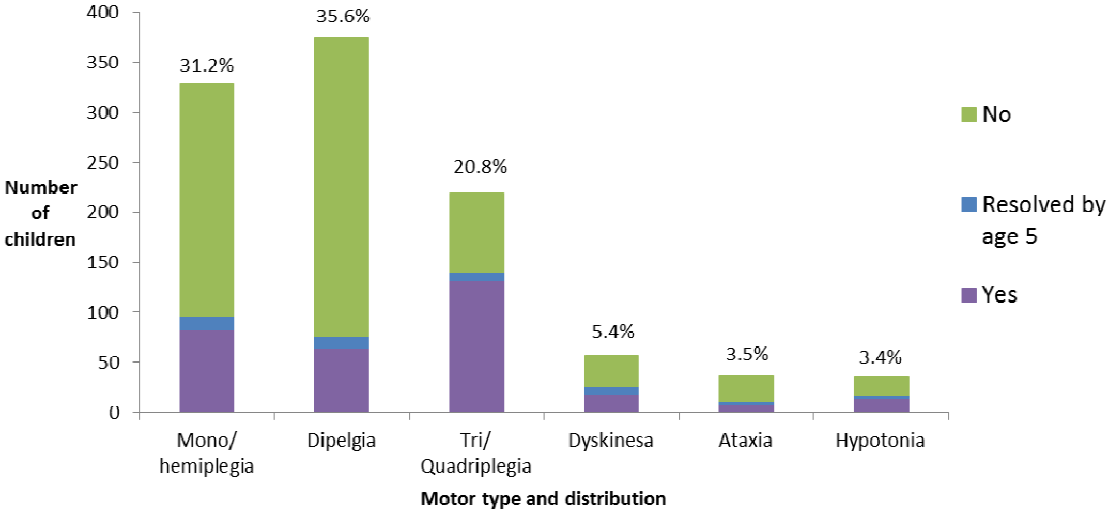



Figure 12b: Number of people with cerebral palsy, born 1995-2008, by motor type and distribution and epilepsy status




^ Percentage of known values only; Pn Excludes data from those with a known post-neonatal cause; u Excludes data where one or both values are missing

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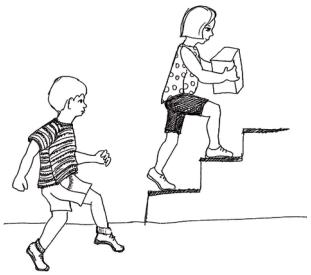
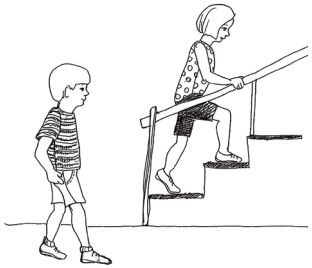
# Appendix a

## Gross motor function system for children aged 4–6 years – illustrations and descriptors



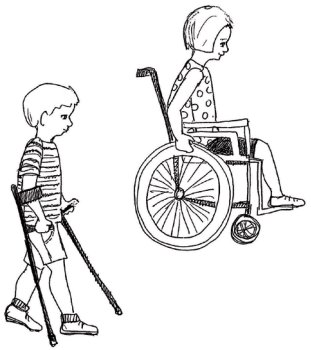
### GMFCS Level I

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.



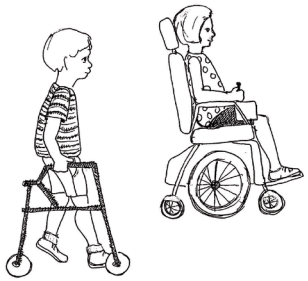
### GMFCS Level II

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.



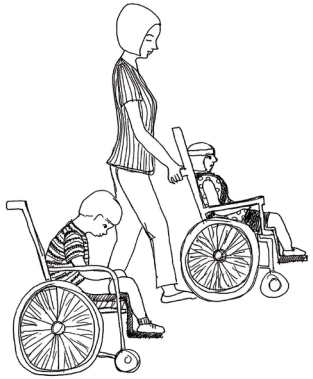
### GMFCS Level III

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.

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| Ms Christalla Louca | QCPR Administration Officer |

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