



# 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 continues to honour 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 support for our steering committee.

The register would not have been possible without the generous financial support of Queensland Health. Funding support was announced in 2004 and continuing operation of the register is still attributable to recurrent funding provided by Queensland Health.

Completing records 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.

Historically, most referrals came from CPL services. While that contribution remains, over the past 18 months, referrals of new registrants from the Queensland Cerebral Palsy Health Service (QCPHS), based mainly at RCH, has increased dramatically. We would like to acknowledge the support of management and clinicians in QCPHS that was instrumental in establishing the processes for this increase. We would particularly like to acknowledge the commitment of the clerical staff whose tireless efforts have been critical in every single referral from 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. They have indirectly contributed to this report in too many ways to detail and it remains an honour to work with them.

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# foreword from the Chair

On behalf of the Queensland Cerebral Palsy Register Steering Committee, I commend this second report from the Register to you.

The Queensland Cerebral Palsy Register only commenced in 2005 and is still in its infancy compared to some other State's registers. The Register's first report was released in 2010, one year ahead of schedule and provided data on a single birth year, 1996.

At that time, we forecast that the Register's 2012 report would provide data across three to five birth years. In this context it is a significant achievement that this second report provides data across a ten-year cohort of birth years.

Great credit goes to the Register's team of Michael deLacy and Christalla Louca and to the many individuals and organisations who have lent their support in making this unexpected result a reality. The Steering Committee wishes to particularly acknowledge the support of the Queensland State Government, through Queensland Health, for its funding support of the Register and to the Cerebral Palsy League, which hosts the Register, for contributing its practice expertise and business support and infrastructure.

Cerebral palsy is the most common cause of physical disability in childhood and it is anticipated 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 broad range of services that a modern population expects. We believe that the Register's second report is an excellent resource for that future planning.

The Queensland Cerebral Palsy Register is also linked to the Australian Cerebral Palsy Register, which aims to provide a more complete picture of the characteristics of cerebral palsy across Australia to better inform our understanding of potential causes and thus prevention of cerebral palsy, while at the same time, informing policy and practice development to reduce its impact on the lives of those Australians affected by cerebral palsy.

Peter Mewett

Chair

Queensland Cerebral Palsy Register Steering Committee

A list of all members of the Queensland Cerebral Palsy Register Steering Committee can be found at the conclusion of this report.



## 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 cerebral palsy, continually improve practice and interventions, and help to plan services.

This second report details distribution, classification, severity and known risk factors for people in Queensland with cerebral palsy who were born from 1 January 1996 to 31 December 2005. Where possible the numbers of children in each category are divided by birth years which allows the reader to estimate year-to-year variation in the characteristics of people with cerebral palsy in Queensland for the first time. It is expected that this data will be used by service providers, service funders 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 dramatic increase in referrals from the Queensland Cerebral Palsy Health Service which, along with the maintenance of referrals from the Cerebral Palsy League, has increased the total ascertainment of registrants to over 2000 in all birth years. The full process of ascertainment is described on page 8. Completing records and confirming consent was undertaken actively by the registry staff.

How common was cerebral palsy in Queensland among those born between 1996 and 2005?

In total, 881 people with cerebral palsy have been registered for the birth years 1996 to 2005. Of these, 702 were born in Queensland and 801 were admitted to a Queensland hospital in the neonatal period. If all 881 people are included, the crude prevalence of cerebral palsy in Queensland is 1.8 per thousand live births. This is the method that was used in the previous report detailing our 1996 birth year report.

Using only those children who were born in Queensland or were treated in a Queensland hospital during the neonatal period the prevalence of children with cerebral palsy on the register in Queensland is 1.6 per thousand live births.

What was the spread of motor type and motor distribution in Queensland among those born between 1996 to 2005?

Spastic motor type presentation accounts for 87% of all children with cerebral palsy on the register born between 1996 and 2005. This consisted of 30% spastic hemiplegia or monoplegia, 36% spastic diplegia, 2% spastic triplegia and 20% spastic quadriplegia. Additionally, 4% had ataxia, 6% had dyskinesia (more with dystonia than athetosis) and 3% were classified as having hypotonia.

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

#### What are the effects of cerebral palsy?

Of all children with cerebral palsy on the register born between 1996 and 2005, 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, 28% of children with cerebral palsy born between 1996 and 2005 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, 55% of children with cerebral palsy 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.

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

There were 54% with some *visual impairment* and 6% who were functionally blind. Almost all children who were functionally blind were either GMFCS level IV or GMFCS level V and 67% had spastic quadriplegia. With the exception of spastic quadriplegia, between 50% and 60% of children with all motor type classifications have no visual impairment.

There were 39.3% of children with cerebral palsy who had no or probably no *intellectual impairment*, while 31% had a moderate to severe intellectual impairment. The higher the child's GMFCS level, the more likely it was they had no, or probably no, intellectual impairment. For those children with GMFCS level I, 36% had some level of intellectual impairment. Of children classified as GMFCS level V, 88% had some level of intellectual impairment.

At age five, 30% of children with cerebral palsy born between 1996 and 2005 had epilepsy. The higher the child's GMFCS level, the more likely it was they had *epilepsy* at age five. For children with GMFCS level I, 14% had epilepsy at age 5. For those children with GMFCS level V, 67% had epilepsy. Of all children with spastic triplegia or quadriplegia, 59% also had epilepsy at age 5.

Thirteen percent of all children with cerebral palsy born in Queensland between 1996 and 2005 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, 57% of children with cerebral palsy born between 1996 and 2005, were male.

#### 2. Preterm birth

In Queensland, 49% of children with cerebral palsy born between 1996 and 2005 had a gestational age at delivery less than 37 completed weeks. There was 33 times the rate of cerebral palsy in children born prior to 28 weeks completed gestation compared with those children born between 37 and 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 1996 and 2005, 46% of all children with cerebral palsy and were born with a birth weight under 2500 grams. The rate of cerebral palsy for children born smaller than 1500 grams was 32 times higher than for those children born larger than 2500 grams.

#### 4. Multiple births

In Queensland, 6% of children born between 1996 and 2005, were the product of a multiple birth. Children born one of twins were 8 times more likely to have cerebral palsy than singletons and children born as triplets or higher plurality were 30.1 times more likely to have cerebral palsy than singletons.

#### 5. Indigenous status

Six percent of children with cerebral palsy (1997-2005) were born to mothers who identified as Aboriginal or both Aboriginal and Torres Strait Islander. Only 4.6% of all children 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 2 and 2.5 people per thousand live births in the developed world <sup>[2, 9]</sup>.

#### 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 Australian 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
- Involves a disorder of movement and/or posture and of motor function
- Is due to a non-progressive interference, lesion, or abnormality, and
- The interference, lesion, or abnormality originates in the immature brain <sup>[1]</sup>.

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  $^{[8]}$ .

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 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 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.
- Distribution refers to which limbs are involved.
   Combining both motor type and distribution allows the following

classifications:

Spastic cerebral palsy involves very tight 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 affected than the legs (quadriplegia). Dyskinetic cerebral palsy is where muscle tone fluctuates or changes causing difficulty with control and co-ordination of movements. This category includes both athetosis and dystonia. Ataxic cerebral palsy has low muscle tone and poor co-ordination causing a shaking type movement or tremors. Hypotonic cerebral palsy requires low muscle tone in the presence of increased stretch reflexes.

These descriptions remain very important to understanding cerebral palsy. Cerebral palsy is by definition a group of different disorders with different presentations that have different findings on brain imaging <sup>[6]</sup>. It is likely that different presentations have different causal pathways and it is therefore likely they will be susceptible to different methods of prevention. Additionally, our understanding of how brain injury affects function is still improving <sup>[7]</sup> 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 children 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 <sup>[4]</sup>. The usefulness of this classification system has seen it become routinely reported in clinical and scientific endeavour. In line with 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 children with cerebral palsy born 1996 - 2005.

# 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 population of people who have cerebral palsy in Queensland, including regional grouping, abilities and birth histories.
- Researching the causes and impacts of cerebral palsy for clients, families, service providers and funders.

The register is a standalone 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

These 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 and future prevention.
- Collaborate with other CP registers in Australia to provide the best possible source of information about cerebral palsy in Australia.

#### 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. The amalgamation of data on a national scale dra-

matically increases the sensitivity of research into the causes and effects of cerebral palsy in Australia.

#### methods of the 9CPR

#### 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 not collected at the time of referral (e.g. home postcode at time of birth)
- 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 the service providers, particularly the Cerebral Palsy League (CPL) and the Queensland Cerebral Palsy Health Service (QCPHS). 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 with or without the remaining dataset using four different methods:

- Online clients (or their guardians) can register directly via the QCPR website www.qcpr.org.au, and follow the link to the database.
- Mail clients (or their guardians) 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 clients (or their guardians) can telephone the register office and staff will collect information over the phone.
- Email clients (or their guardians) can e-mail the information in a message to register staff. If the QCPR questionnaire has been completed, this can also be sent to the office via e-mail.

As well as submitting information by one or more of these methods, clients also need to submit a signed consent form before 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 to the QCPR. This information is used by register staff to report on the characteristics of people with cerebral

palsy in Queensland and to 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 characteristics information being
   uploaded to 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 whether 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 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 client (or their Guardian), to verify information about the person's clinical details and birth history. This may involve a nominated practitioner reviewing the persons QCPR registration information. This process is used to ensure that information held on the QCPR is consistent across Queensland.

The overall procedure for QCPR was reviewed and approved by a National Health and Medical Research Council compliant ethics committee behalf of the QCPR (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 Health Service District Ethics Committee (ref # RCH & HSD Ethics 2008/113), the Cerebral Palsy League of Queensland Ethics Committee (ref # CPLQ 2008/09-1013) and the Mater Health Services Human Research Ethics Committee (ref# 1642E).

#### Cohort

Information included in this report is from people born from 1 January 1996 to 31 December 2005 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.

It includes 120 children (14%) who were not born in Queensland. Exactly half (60 children) of the total number were born in New South Wales and almost one third (39 children) were born overseas. Eleven were born in Victoria, two in South Australia, three in Tasmania and five in Western Australia. The report also includes children born in Queensland but living in New South Wales, Victoria and Tasmania but not in South Australia or Western Australia.

#### **Denominator data**

Where the rate of cerebral palsy per thousand live births (LB) is given in tables or graphs, the denominator value for live births is reported according to population statistics published by the Queensland Health Statistics Centre <sup>[5]</sup>. Our data is grouped according to the parameters of the data for comparison. 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

# important notes for interpreting tables and graphs

In general, tables include all data that is held on the register from children 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. Including these different unknown values in a single graph makes it very 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 as presented in this paragraph.

#### 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 children 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 children-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 children [n/total+unknown]. The symbol "\*" will be displayed at the bottom of the table to indicate this.

Unless directly stated in the title, all tables include data from birth years 1996 – 2005. The symbol "b" is displayed below the table to indicate this. Nearly all tables include data from these birth years.

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 children, the labels on top of each bar will be percentage of known. The symbol "A" 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 children however the number of children in this bar can be read along the vertical axis as usual and the percentage of total children can be read in the table directly above the graph. The data is always available but it is not displayed on the graph because the percentages would not add up to 100% if it was and this would be confusing and also unrelated to the information the graph is intended to convey.

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

Unless stated in the title, all graphs include data from birth years 1996 – 2005. The symbol "b" will be displayed below the graph to indicate this. Several graphs do not include all birth years.

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 (LB) 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 children with cerebral palsy. The specific publication used is referenced <sup>[5]</sup> and the symbol "q" will be displayed below the graph to indicate this.

#### 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
- Excludes data where one or both values are missing
- b Data from all 10 birth years included (1996 2005)

# motor type and distribution

## motor type and distribution

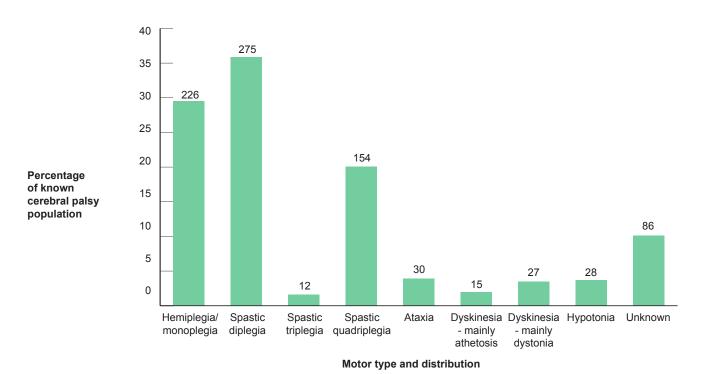
Table 1: Number of children with cerebral palsy by predominant motor type and distribution.

|                                |        |        |         |        |        | В             | irth year | /s      |        |         |         |               |               |
|--------------------------------|--------|--------|---------|--------|--------|---------------|-----------|---------|--------|---------|---------|---------------|---------------|
| Motor                          | 1996   | 1997   | 1998    | 1999   | 2000   | 1996-<br>2000 | 2001      | 2002    | 2003   | 2004    | 2005    | 2001-<br>2005 | 1996-<br>2005 |
| type and distribution          | n      | n      | n       | n      | n      | n             | n         | n       | n      | n       | n       | n             | n             |
|                                | (%)^   | (%)^   | (%)^    | (%)^   | (%)^   | (%)^          | (%)^      | (%)^    | (%)^   | (%)^    | (%)^    | (%)^          | (%)^          |
| Spasticity                     |        |        |         |        |        |               |           |         |        |         |         |               |               |
| <ul> <li>Hemiplegia/</li></ul> | 27     | 22     | 22      | 25     | 23     | 119           | 16        | 23      | 20     | 16      | 32      | 107           | 226           |
| monoplegia                     | (29.7) | (25.3) | (32.4)  | (30.5) | (27.4) | (28.9)        | (24.2)    | (34.3)  | (26.7) | (21.3)  | (44.4)  | (30.1)        | (29.5)        |
| - Diplegia                     | 34     | 35     | 28      | 31     | 28     | 156           | 19        | 27      | 26     | 27      | 20      | 119           | 275           |
|                                | (37.4) | (40.2) | (41.2)  | (37.8) | (33.3) | (37.9)        | (28.8)    | (40.3)  | (34.7) | (36.0)  | (27.8)  | (33.5)        | (35.9)        |
| - Triplegia                    | 1      | 0      | 1       | 1      | 2      | 5             | 1         | 1       | 1      | 3       | 1       | 7             | 12            |
|                                | (1.1)  | (0.0)  | (1.5)   | (1.2)  | (2.4)  | (1.2)         | (1.5)     | (1.5)   | (1.3)  | (4.0)   | (1.4)   | (2.0)         | (1.6)         |
| - Quadriplegia                 | 16     | 14     | 14      | 17     | 14     | 75            | 17        | 13      | 19     | 15      | 15      | 79            | 154           |
|                                | (17.6) | (16.1) | (20.6)  | (20.7) | (16.7) | (18.2)        | (25.8)    | (19.4)  | (25.3) | (20.0)  | (20.8)  | (22.3)        | (20.1)        |
| Ataxia                         | 8      | 4      | 1       | 2      | 5      | 20            | 2         | 1       | 4      | 3       | 0       | 10            | 30            |
|                                | (8.8)  | (4.6)  | (1.5)   | (2.4)  | (6.0)  | (4.9)         | (3.0)     | (1.5)   | (5.3)  | (4.0)   | (0.0)   | (2.8)         | (3.9)         |
| Dyskinesia                     |        |        |         |        |        |               |           |         |        |         |         |               |               |
| <ul> <li>Mainly</li></ul>      | 1      | 0      | 0       | 3      | 2      | 6             | 4         | 0       | 1      | 3       | 1       | 9             | 15            |
| athetosis                      | (1.1)  | (0.0)  | (0.0)   | (3.7)  | (2.4)  | (1.5)         | (6.1)     | (0.0)   | (1.3)  | (4.0)   | (1.4)   | (2.5)         | (2.0)         |
| - Mainly                       | 1      | 7      | 1       | 1      | 5      | 15            | 3         | 1       | 1      | 5       | 2       | 12            | 27            |
| dystonia                       | (1.1)  | (8.0)  | (1.5)   | (1.2)  | (6.0)  | (3.6)         | (4.5)     | (1.5)   | (1.3)  | (6.7)   | (2.8)   | (3.4)         | (3.5)         |
| Hypotonia                      | 3      | 5      | 1       | 2      | 5      | 16            | 4         | 1       | 3      | 3       | 1       | 12            | 28            |
|                                | (3.3)  | (5.7)  | (1.5)   | (2.4)  | (6.0)  | (3.9)         | (6.1)     | (1.5)   | (4.0)  | (4.0)   | (1.4)   | (3.4)         | (3.7)         |
| Total                          | 91     | 87     | 68      | 82     | 84     | 412           | 66        | 67      | 75     | 75      | 72      | 355           | 767           |
| Unknown                        | 8      | 4      | 9       | 3      | 9      | 33            | 9         | 11      | 7      | 17      | 9       | 53            | 86            |
|                                | (8.1)* | (4.4)* | (11.7)* | (3.5)* | (9.7)* | (7.4)*        | (12.0)*   | (14.1)* | (8.5)* | (18.5)* | (11.1)* | (13.0)*       | (10.1)*       |

<sup>^ \*</sup> Pn see page 10

## motor type and distribution cont.

Figure 1: Percentage and number of children with cerebral palsy by predominant motor type and distribution.



^ \* b Pn see page 10

The majority of children with cerebral palsy (87.3%) have a predominantly spastic motor type. Spastic diplegia has the highest incidence of any motor type and distribution classification.

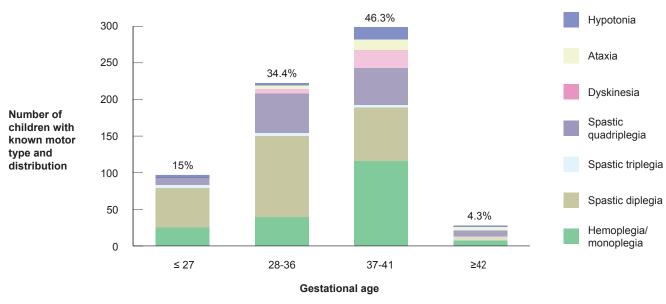
## motor type and distribution and gestational age

Table 2: Number of children with cerebral palsy by predominant motor type and distribution and gestational age (in completed weeks).

|                         |              |               | Gestatio      | onal Age    |        |               |
|-------------------------|--------------|---------------|---------------|-------------|--------|---------------|
| Motor type              | ≤27          | 28-36         | 37-41         | ≥42         | Total  | Unknown       |
|                         | n            | n             | n             | n           | n      | n             |
|                         | (%)          | (%)           | (%)           | (%)         | (%)    | (%)           |
| Spastic                 |              |               |               |             |        |               |
| - Hemiplegia/monoplegia | 25           | 39            | 116           | 7           | 187    | 35            |
|                         | (3.9)        | (6.0)         | (17.9)        | (1.1)       | (28.9) | (4.4)         |
| - Diplegia              | 54           | 111           | 75            | 6           | 246    | 27            |
|                         | (8.3)        | (17.1)        | (11.6)        | (0.9)       | (38.0) | (3.4)         |
| - Triplegia             | 4            | 4             | 3             | 0           | 11     | 1             |
|                         | (0.6)        | (0.6)         | (0.5)         | (0.0)       | (1.7)  | (0.1)         |
| - Quadriplegia          | 10           | 54            | 51            | 8           | 123    | 31            |
|                         | (1.5)        | (8.3)         | (7.9)         | (1.2)       | (19.0) | (3.9)         |
| Ataxia                  | 0            | 6             | 24            | 1           | 31     | 11            |
|                         | (0.0)        | (0.9)         | (3.7)         | (0.2)       | (4.8)  | (1.4)         |
| Dyskinesia              | 4            | 5             | 15            | 4           | 28     | 2             |
|                         | (0.6)        | (0.8)         | (2.3)         | (0.6)       | (4.3)  | (0.3)         |
| Hypotonia               | 0            | 3             | 17            | 2           | 22     | 6             |
|                         | (0.0)        | (0.5)         | (2.6)         | (0.3)       | (3.4)  | (0.8)         |
| Total                   | 97<br>(15.0) | 222<br>(34.3) | 301<br>(46.5) | 28<br>(4.3) | 648    |               |
| Unknown                 | 4<br>(0.5)   | 12<br>(1.5)   | 12<br>(1.5)   | 0<br>(0.0)  |        | 141<br>(17.9) |

<sup>^ \*</sup> Pn see page 10

Figure 2: Number of children with cerebral palsy (birth years 1996-2005) by predominant motor type and distribution and gestational age (in completed weeks), excluding cases with one or both values unknown.



<sup>^ \*</sup> Pn see page 10

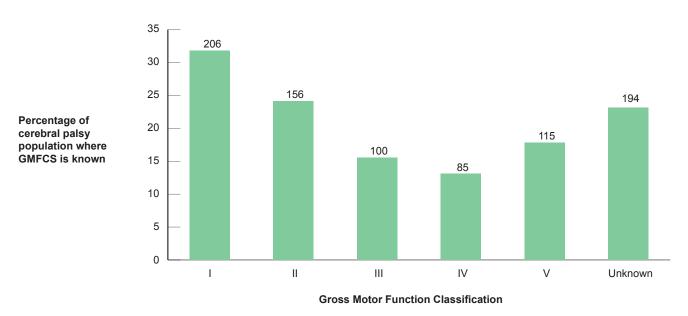
## gross motor function

Table 3: Number of children with cerebral palsy by GMFCS level.

|         |              |              |              |              |              | В             | irth year    | /s           |              |              |              |               |               |
|---------|--------------|--------------|--------------|--------------|--------------|---------------|--------------|--------------|--------------|--------------|--------------|---------------|---------------|
|         | 1996         | 1997         | 1998         | 1999         | 2000         | 1996-<br>2000 | 2001         | 2002         | 2003         | 2004         | 2005         | 2001-<br>2005 | 1996-<br>2005 |
| GMFCS   | n<br>(%)     | n<br>(%)     | n<br>(%)     | n<br>(%)     | n<br>(%)     | n<br>(%)      | n<br>(%)     | n<br>(%)     | n<br>(%)     | n<br>(%)     | n<br>(%)     | n<br>(%)      | n<br>(%)      |
| I       | 30<br>(33.0) | 18<br>(23.4) | 25<br>(36.8) | 22<br>(28.2) | 26<br>(33.3) | 122<br>(31.1) | 12<br>(26.7) | 19<br>(30.6) | 17<br>(30.4) | 21<br>(42.0) | 15<br>(35.7) | 84<br>(32.9)  | 206<br>(31.8) |
| II      | 17<br>(18.7) | 26<br>(33.8) | 15<br>(22.1) | 16<br>(20.5) | 21<br>(26.9) | 97<br>(24.7)  | 9 (20.0)     | 17<br>(27.4) | 14<br>(25.0) | 9<br>(18.0)  | 10<br>(23.8) | 59<br>(23.1)  | 156<br>(24.1) |
| III     | 15<br>(16.5) | 17<br>(22.1) | 7<br>(10.3)  | 12<br>(15.4) | 8<br>(10.3)  | 62<br>(15.8)  | 9 (20.0)     | 12<br>(19.4) | 5<br>(8.9)   | 4<br>(8.0)   | 8<br>(19.0)  | 38<br>(14.9)  | 100<br>(15.5) |
| IV      | 10<br>(11.0) | 4<br>(5.2)   | 13<br>(19.1) | 14<br>(17.9) | 11<br>(14.1) | 56<br>(14.3)  | 6<br>(13.3)  | 7<br>(11.3)  | 8<br>(14.3)  | 4<br>(8.0)   | 4<br>(9.5)   | 29<br>(11.4)  | 85<br>(13.1)  |
| V       | 19<br>(20.9) | 12<br>(15.6) | 8<br>(11.8)  | 14<br>(17.9) | 12<br>(15.4) | 70<br>(17.9)  | 9 (20.0)     | 7<br>(11.3)  | 12<br>(21.4) | 12<br>(24.0) | 5<br>(11.9)  | 45<br>(17.6)  | 115<br>(17.8) |
| Total   | 91           | 77           | 68           | 78           | 78           | 392           | 45           | 62           | 56           | 50           | 42           | 255           | 647           |
| Unknown | 7<br>(7.1)   | 14<br>(15.4) | 7<br>(9.3)   | 7<br>(8.2)   | 14<br>(15.2) | 49<br>(11.1)  | 29<br>(39.2) | 15<br>(19.5) | 22<br>(28.2) | 40<br>(44.4) | 39<br>(48.1) | 145<br>(36.3) | 194<br>(23.1) |

<sup>^ \*</sup> Pn see page 10

Figure 3: Percentage<sup>^</sup> of children with cerebral palsy by GMFCS level.



<sup>^ \*</sup> a b Pn see page 10

Slightly more than half (55%) of children with cerebral palsy at age five were classified as GMFCS level I or II. They were able to independently walk and manage rough surfaces and stairs with a rail. Approximately 28% were classified at levels GMFCS IV or V at age five. This group use a wheelchair for functional mobility all or most of the time.

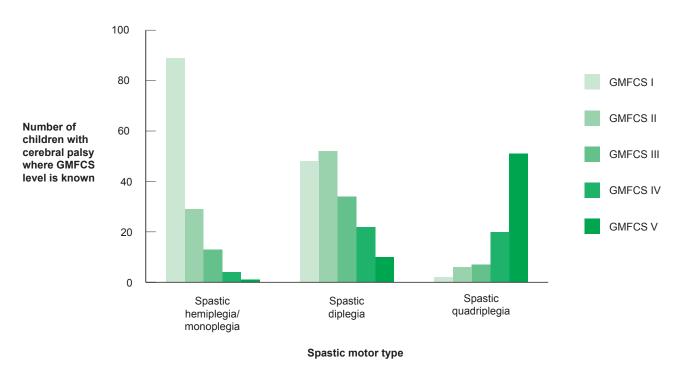
## motor type and distribution and gross motor function

Table 4: Number of children with cerebral palsy by predominant motor type and distribution and GMFCS level.

|                         |               | Gro           | oss Motor Fun | ction Classifica | ation System I | evel  |               |
|-------------------------|---------------|---------------|---------------|------------------|----------------|-------|---------------|
| Motor type              | I             | II            | III           | IV               | V              | Total | Unknown       |
| Spastic                 |               |               |               |                  |                |       |               |
| - Hemiplegia/monoplegia | 89<br>(19.8)  | 29<br>(6.4)   | 13<br>(2.9)   | 4<br>(0.9)       | 1<br>(0.2)     | 136   | 86<br>(10.0)  |
| - Diplegia              | 49<br>(10.9)  | 52<br>(11.6)  | 34<br>(7.6)   | 22<br>(4.9)      | 10<br>(2.2)    | 167   | 106<br>(12.3) |
| - Triplegia             | 0<br>(0.0)    | 2<br>(0.4)    | 0<br>(0.0)    | 1<br>(0.2)       | 1<br>(0.2)     | 4     | 8<br>(0.9)    |
| - Quadriplegia          | 2<br>(0.4)    | 6<br>1.3)     | 7<br>(1.6)    | 20<br>(4.4)      | 51<br>(11.3)   | 86    | 68<br>(7.9)   |
| Ataxia                  | 2<br>(0.4)    | 6<br>(1.3)    | 7<br>(1.6)    | 6<br>(1.3)       | 6<br>(1.3)     | 27    | 22<br>(2.6)   |
| Dyskinesia              | 4<br>(0.9)    | 8<br>(1.8)    | 3<br>(0.7)    | 1<br>(0.2)       | 1<br>(0.2)     | 17    | 13<br>(1.5)   |
| Hypotonia               | 2<br>(0.4)    | 4<br>(0.9)    | 2<br>(0.4)    | 3<br>(0.7)       | 2<br>(0.4)     | 13    | 15<br>(1.7)   |
| Total                   | 148<br>(32.9) | 107<br>(23.8) | 66<br>(14.7)  | 57<br>(12.7)     | 72<br>(16.0)   | 450   |               |
| Unknown                 | 7<br>(0.8)    | 4<br>(0.5)    | 2<br>(0.2)    | 1<br>(0.1)       | 3<br>(0.3)     |       |               |

<sup>\*,</sup> a, b, Pn, see page 10

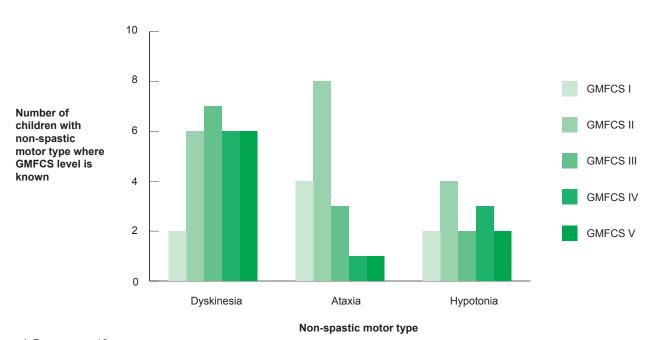
Figure 4a: Number of children with cerebral palsy by spastic motor type and distribution and GMFCS level.



a \* b Pn see page 10

## motor type and distribution and gross motor function cont.

Figure 4b: Number of children with cerebral palsy by non-spastic motor type and GMFCS level.



u b Pn see page 10

# birth details

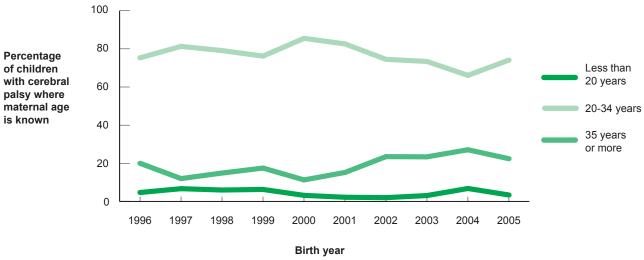
## maternal age at delivery

Table 5a: Number and percentage of children with cerebral palsy by maternal age group at delivery, excluding cases with known post-neonatal causes.

|          |            |            |            |            |            | В             | irth year | /s         |            |            |            |               |               |
|----------|------------|------------|------------|------------|------------|---------------|-----------|------------|------------|------------|------------|---------------|---------------|
|          | 1996       | 1997       | 1998       | 1999       | 2000       | 1996-<br>2000 | 2001      | 2002       | 2003       | 2004       | 2005       | 2001-<br>2005 | 1996-<br>2005 |
| Maternal | n          | n          | n          | n          | n          | n             | n         | n          | n          | n          | n          | n             | n             |
| age      | (%)^       | (%)^       | (%)^       | (%)^       | (%)^       | (%)^          | (%)^      | (%)^       | (%)^       | (%)^       | (%)^       | (%)^          | (%)^          |
| <20      | 4<br>(4.7) | 5<br>(6.7) | 4<br>(6.0) | 4<br>(6.3) | 2<br>(3.2) | 19<br>(5.4)   | 1 (2.2)   | 1<br>(2.0) | 2<br>(3.1) | 4<br>(6.8) | 2<br>(3.4) | 10<br>(3.6)   | 29<br>(4.6)   |
| 20-24    | 16         | 12         | 8          | 9          | 12         | 57            | 8         | 6          | 8          | 11         | 5          | 38            | 95            |
|          | (18.8)     | (16.0)     | (11.9)     | (14.3)     | (19.4)     | (16.2)        | (17.4)    | (11.8)     | (12.5)     | (18.6)     | (8.6)      | (13.7)        | (15.1)        |
| 25-29    | 21         | 22         | 27         | 19         | 18         | 107           | 13        | 18         | 17         | 6          | 17         | 71            | 178           |
|          | (24.7)     | (29.3)     | (40.3)     | (30.2)     | (29.0)     | (30.4)        | (28.3)    | (35.3)     | (26.6)     | (10.2)     | (29.3)     | (25.5)        | (28.3)        |
| 30-34    | 27         | 27         | 18         | 20         | 23         | 115           | 17        | 14         | 22         | 22         | 21         | 96            | 211           |
|          | (31.8)     | (36.0)     | (26.9)     | (31.7)     | (37.1)     | (32.7)        | (37)      | (27.5)     | (34.4)     | (37.3)     | (36.2)     | (34.5)        | (33.5)        |
| 35-39    | 14         | 9          | 8          | 9          | 7          | 47            | 7         | 10         | 11         | 13         | 9          | 50            | 97            |
|          | (16.5)     | (12.0)     | (11.9)     | (14.3)     | (11.3)     | (13.4)        | (15.2)    | (19.6)     | (17.2)     | (22.0)     | (15.5)     | (18.0)        | (15.4)        |
| 40+      | 3<br>(3.5) | 0 (0.0)    | 2<br>(3.0) | 2<br>(3.2) | 0<br>(0.0) | 7<br>(2.0)    | 0 (0.0)   | 2<br>(3.9) | 4<br>(6.3) | 3<br>(5.1) | 4<br>(6.9) | 13<br>(4.7)   | 20<br>(3.2)   |
| Total    | 102        | 91         | 79         | 85         | 94         | 352           | 75        | 82         | 83         | 91         | 84         | 278           | 630           |
| Unknown  | 17         | 16         | 12         | 22         | 32         | 99            | 29        | 31         | 19         | 32         | 26         | 137           | 236           |
|          | (16.7)*    | (17.6)*    | (15.2)*    | (25.9)*    | (34.0)*    | (12.3)*       | (38.7)*   | (37.8)*    | (22.9)*    | (35.2)*    | (31.0)*    | (19.8)*       | (15.8)*       |

<sup>^ \*</sup> Pn see page 10

Figure 5a: Percentage of children with cerebral palsy by known maternal age group at delivery.



b Pn see page 10

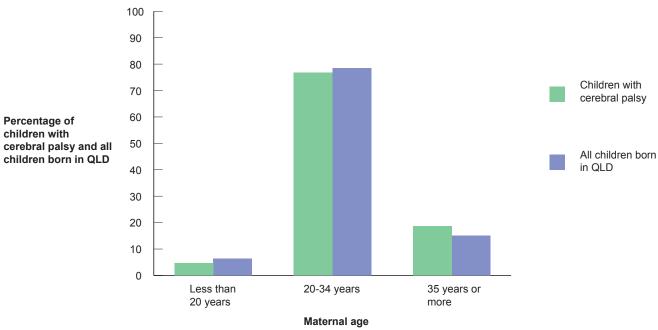
### maternal age at delivery cont.

Table 5b: Percentage of children with cerebral palsy and all children born in Queensland by maternal age group at delivery.

|                 |        |        |        |        |        | В             | irth year | /s     |        |        |        |               |               |
|-----------------|--------|--------|--------|--------|--------|---------------|-----------|--------|--------|--------|--------|---------------|---------------|
|                 | 1996   | 1997   | 1998   | 1999   | 2000   | 1996-<br>2000 | 2001      | 2002   | 2003   | 2004   | 2005   | 2001-<br>2005 | 1996-<br>2005 |
| Gestational age | %CP^   | %CP^   | %CP^   | %CP^   | %CP^   | %CP^          | %CP^      | %CP^   | %CP^   | %CP^   | %CP^   | %CP^          | %CP^          |
|                 | (%QLD) | (%QLD) | (%QLD) | (%QLD) | (%QLD) | (%QLD)        | (%QLD)    | (%QLD) | (%QLD) | (%QLD) | (%QLD) | (%QLD)        | (%QLD)        |
| <20             | 4.7    | 6.7    | 6.0    | 6.3    | 3.2    | 5.4           | 2.2       | 2.0    | 3.1    | 6.8    | 3.4    | 3.6           | 4.6           |
|                 | (6.8)  | (6.8)  | (6.5)  | (6.6)  | (6.6)  | (6.7)         | (6.5)     | (6.3)  | (6.2)  | (6.0)  | (5.6)  | (6.1)         | (6.4)         |
| 20-34           | 75.3   | 81.3   | 79.1   | 76.2   | 85.5   | 79.3          | 82.6      | 74.5   | 73.4   | 66.1   | 74.1   | 73.7          | 76.8          |
|                 | (80.6) | (79.8) | (79.8) | (79.3) | (78.6) | (79.6)        | (78.3)    | (78.2) | (77.4) | (77.0) | (76.5) | (77.5)        | (78.5)        |
| 35+             | 20.1   | 12.0   | 14.9   | 17.5   | 11.3   | 15.3          | 15.2      | 23.5   | 23.4   | 27.1   | 22.4   | 22.7          | 18.6          |
|                 | (12.6) | (13.4) | (13.7) | (14.1) | (14.8) | (13.7)        | (15.2)    | (15.4) | (16.4) | (17.0) | (17.9) | (16.4)        | (15.1)        |

<sup>^</sup> Pn see page 10

Figure 5b: Percentage of children with cerebral palsy compared to all children born in QLD by maternal age group at delivery.



<sup>^</sup> b Pn see page 10

Over 75% of children with cerebral palsy were born to mothers older than 19 and younger than 35 years. Approximately 5% were born to mothers younger than 20 years. Almost 20% of children were born to mothers older than 34 years, which is slightly higher than the percentage of all children born in Queensland to mothers older than 34 years [5].

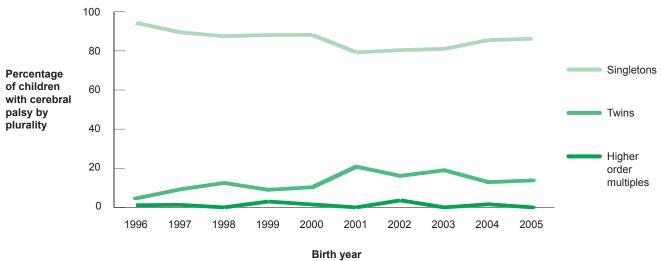
## plurality

Table 6: Number and percentage of children with cerebral palsy by birth plurality.

|                       |               |               |               |               |               | В             | irth year     | /s            |               |               |               |                |                |
|-----------------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|----------------|----------------|
|                       | 1996          | 1997          | 1998          | 1999          | 2000          | 1996-<br>2000 | 2001          | 2002          | 2003          | 2004          | 2005          | 2001-<br>2005  | 1996-<br>2005  |
| Plurality             | n<br>(%)^      | n<br>(%)^      |
| Singleton             | 82<br>(94.3)  | 68<br>(89.5)  | 56<br>(87.5)  | 59<br>(88.1)  | 60<br>(88.2)  | 325<br>(89.8) | 38<br>(79.2)  | 45<br>(80.4)  | 51<br>(81.0)  | 53<br>(85.5)  | 50<br>(86.2)  | 237<br>(82.6)  | 562<br>(86.6)  |
| Twins                 | 4<br>(4.6)    | 7<br>(9.2)    | 8<br>(12.5)   | 6<br>(9.0)    | 7<br>(10.3)   | 32<br>(8.8)   | 10<br>(20.8)  | 9<br>(16.1)   | 12<br>(19.0)  | 8<br>(12.9)   | 8<br>(13.8)   | 47<br>(16.4)   | 79<br>(12.2)   |
| Triplets              | 1<br>(1.1)    | 1<br>(1.3)    | 0<br>(0.0)    | 0<br>(0.0)    | 1<br>(1.5)    | 3 (0.8)       | 0 (0.0)       | 1<br>(1.8)    | 0<br>(0.0)    | 1<br>(1.6)    | 0 (0.0)       | 2 (0.7)        | 5<br>(0.8)     |
| Higher order multiple | 0<br>(0.0)    | 0 (0.0)       | 0 (0.0)       | 2<br>(3.0)    | 0 (0.0)       | 2 (0.6)       | 0 (0.0)       | 1<br>(1.8)    | 0 (0.0)       | 0 (0.0)       | 0 (0.0)       | 1 (0.3)        | 3<br>(0.5)     |
| Total                 | 87            | 76            | 64            | 67            | 68            | 362           | 48            | 56            | 63            | 62            | 58            | 287            | 649            |
| Unknown               | 12<br>(12.1)* | 15<br>(16.5)* | 11<br>(14.7)* | 15<br>(18.3)* | 23<br>(25.3)* | 76<br>(17.4)* | 27<br>(36.0)* | 22<br>(28.2)* | 15<br>(19.2)* | 28<br>(31.1)* | 23<br>(28.4)* | 115<br>(28.6)* | 191<br>(22.7)* |

<sup>^ \*</sup> b Pn see page 10

Figure 6: Percentage of children with cerebral palsy by plurality.



b Pn see page 10

Approximately 86% of children with cerebral palsy were singletons and nearly 13% had a twin. Approximately 1% were one of triplets or higher order multiples.

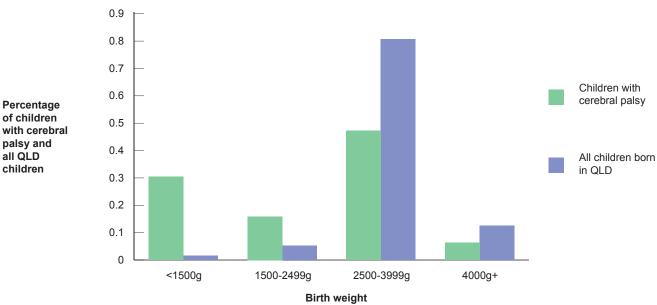
### birth weight

Table 7: Number (and percentage) of children with cerebral palsy (birth years 1996-2005) by birth weight in grams, excluding cases with known post-neonatal causes.

|               |            |            |         |            |         | В             | irth year | 's      |         |            |            |               |               |
|---------------|------------|------------|---------|------------|---------|---------------|-----------|---------|---------|------------|------------|---------------|---------------|
|               | 1996       | 1997       | 1998    | 1999       | 2000    | 1996-<br>2000 | 2001      | 2002    | 2003    | 2004       | 2005       | 2001-<br>2005 | 1996-<br>2005 |
| Birth weight  | n          | n          | n       | n          | n       | n             | n         | n       | n       | n          | n          | n             | n             |
|               | (%)^       | (%)^       | (%)^    | (%)^       | (%)^    | (%)^          | (%)^      | (%)^    | (%)^    | (%)^       | (%)^       | (%)^          | (%)^          |
| <1500         | 22         | 21         | 18      | 23         | 22      | 106           | 13        | 18      | 15      | 20         | 12         | 78            | 184           |
|               | (26.2)     | (29.6)     | (29.5)  | (35.4)     | (33.3)  | (30.5)        | (30.2)    | (32.1)  | (26.8)  | (33.9)     | (21.8)     | (29.0)        | (29.9)        |
| 1500 - 2499   | 12         | 12         | 11      | 9          | 11      | 55            | 12        | 14      | 12      | 12         | 15         | 65            | 120           |
|               | (14.3)     | (16.9)     | (18.0)  | (13.8)     | (16.7)  | (15.9)        | (27.9)    | (25.0)  | (21.4)  | (20.3)     | (27.3)     | (24.2)        | (19.5)        |
| 2500 - 3499   | 33         | 26         | 20      | 17         | 20      | 116           | 14        | 17      | 20      | 17         | 13         | 81            | 197           |
|               | (39.3)     | (36.6)     | (32.8)  | (26.2)     | (30.3)  | (33.4)        | (32.6)    | (30.4)  | (35.7)  | (28.8)     | (23.6)     | (30.1)        | (32.0)        |
| 3500 - 4499   | 17         | 11         | 12      | 16         | 13      | 69            | 4         | 7       | 9       | 9          | 15         | 44            | 113           |
|               | (20.2)     | (15.5)     | (19.7)  | (24.6)     | (19.7)  | (19.9)        | (9.3)     | (12.5)  | (16.1)  | (15.3)     | (27.3)     | (16.4)        | (18.3)        |
| 4500 and over | 0<br>(0.0) | 1<br>(1.4) | 0 (0.0) | 0<br>(0.0) | 0 (0.0) | 1<br>(0.3)    | 0 (0.0)   | 0 (0.0) | 0 (0.0) | 1<br>(1.7) | 0<br>(0.0) | 1<br>(0.4)    | 2 (0.3)       |
| Total         | 84         | 71         | 61      | 65         | 66      | 347           | 43        | 56      | 56      | 59         | 55         | 269           | 616           |
| Unknown       | 15         | 20         | 15      | 20         | 26      | 96            | 31        | 23      | 22      | 31         | 26         | 133           | 229           |
|               | (15.2)*    | (22.0)*    | (19.7)* | (23.5)*    | (28.3)* | (21.7)*       | (41.9)*   | (29.1)* | (28.2)* | (34.4)*    | (32.1)*    | (33.1)*       | (27.1)*       |

<sup>^ \*</sup> Pn see page 10

Figure 7a: Percentage of children with born cerebral palsy compared to all children born in QLD (1996-2000) by birth weight in grams.

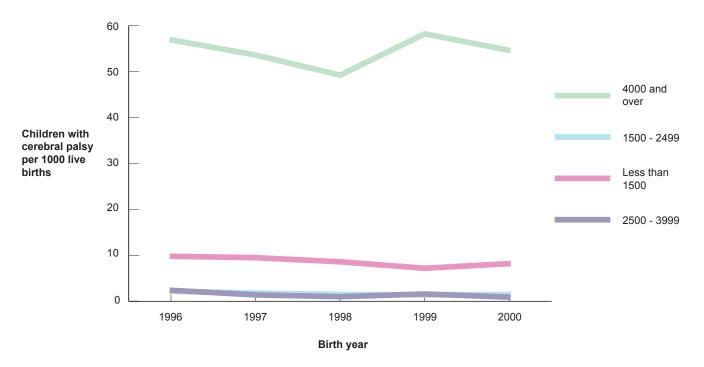


Pn see page 10

There was a higher proportion of children born weighing under 2500g than there was for all Queensland children in this birth period [5]. Similarly, 30% of children were born weighing under 1500g compared to the all Queensland children value of 1.6%.

## birth weight cont.

Figure 7b: Rate of children with cerebral palsy (1996-2000) per thousand live births (LB) by birth weight in grams.



Pn q u see page 10

The Queensland rate of cerebral palsy for those born weighing under 1500g was 54.5 per thousand live births. Children born with a birth weight under 1500g were 32 times more likely to have cerebral palsy than those born weighing between 2500g and 4000g.

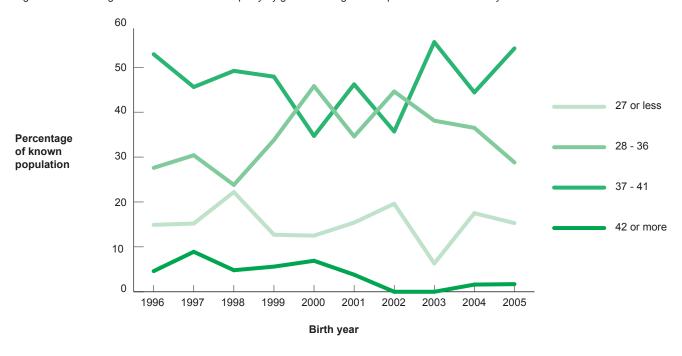
## gestational age

Table 8: Number (and percentage) of children with cerebral palsy by gestational age.

|                 |         |         |         |         |         | Е             | Birth year | /s      |         |         |         |               |               |
|-----------------|---------|---------|---------|---------|---------|---------------|------------|---------|---------|---------|---------|---------------|---------------|
|                 | 1996    | 1997    | 1998    | 1999    | 2000    | 1996-<br>2000 | 2001       | 2002    | 2003    | 2004    | 2005    | 2001-<br>2005 | 1996-<br>2005 |
| Number of weeks | n       | n       | n       | n       | n       | n             | n          | n       | n       | n       | n       | n             | n             |
|                 | (%)^    | (%)^    | (%)^    | (%)^    | (%)^    | (%)^          | (%)^       | (%)^    | (%)^    | (%)^    | (%)^    | (%)^          | (%)^          |
| ≤ 27            | 13      | 12      | 14      | 9       | 9       | 57            | 8          | 11      | 4       | 11      | 9       | 43            | 100           |
|                 | (14.9)  | (15.2)  | (22.2)  | (12.7)  | (12.5)  | (15.3)        | (15.4)     | (19.6)  | (6.3)   | (17.5)  | (15.3)  | (14.7)        | (15.0)        |
| 28 - 36         | 24      | 24      | 15      | 24      | 33      | 120           | 18         | 25      | 24      | 23      | 17      | 107           | 227           |
|                 | (27.6)  | (30.4)  | (23.8)  | (33.8)  | (45.8)  | (32.3)        | (34.6)     | (44.6)  | (38.1)  | (36.5)  | (28.8)  | (36.5)        | (34.1)        |
| 37 - 41         | 46      | 36      | 31      | 34      | 25      | 172           | 24         | 20      | 35      | 28      | 32      | 139           | 311           |
|                 | (52.9)  | (45.6)  | (49.2)  | (47.9)  | (34.7)  | (46.2)        | (46.2)     | (35.7)  | (55.6)  | (44.4)  | (54.2)  | (47.4)        | (46.8)        |
| ≥ 42            | 4       | 7       | 3       | 4       | 5       | 23            | 2          | 0       | 0       | 1       | 1       | 4             | 27            |
|                 | (4.6)   | (8.9)   | (4.8)   | (5.6)   | (6.9)   | (6.2)         | (3.8)      | (0.0)   | (0.0)   | (1.6)   | (1.7)   | (1.4)         | (4.1)         |
| Total           | 87      | 79      | 63      | 71      | 72      | 372           | 52         | 56      | 63      | 63      | 59      | 293           | 665           |
| Unknown         | 12      | 12      | 12      | 14      | 20      | 70            | 22         | 23      | 15      | 27      | 22      | 109           | 179           |
|                 | (12.1)* | (13.2)* | (16.0)* | (16.5)* | (21.7)* | (15.8)*       | (29.7)*    | (29.1)* | (19.2)* | (30.0)* | (27.2)* | (27.1)*       | (21.2)*       |

<sup>^ \*</sup> Pn see page 10

Figure 8a: Percentage of children with cerebral palsy by gestational age in completed weeks at delivery.

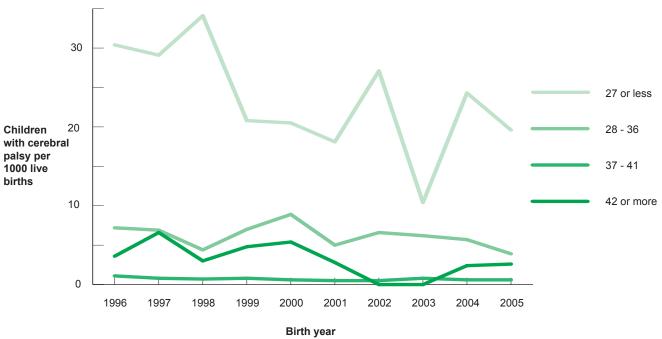


Pn q u see page 10

Almost half of children with cerebral palsy were born prior to 37 weeks completed gestation, with approximately 15% born prior to 28 weeks.

## gestational age cont.

Figure 8b: Rates of cerebral palsy per 1000 live births (LB) by gestational age.



Pn see page 10

The rate of cerebral palsy for children born before 28 weeks completed gestation was 23.5 per thousand live births. This rate is 33.6 times higher than that for children born between 37 and 41 completed weeks gestation.

The rate of cerebral palsy for children born between 28 and 37 weeks completed gestation was 8.9 times higher than the rate for children born at term.

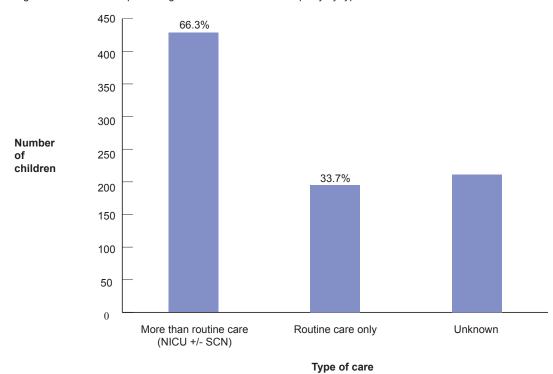
## admission to more than routine care

Table 9: Number and percentage of children with cerebral palsy by type of neonatal care.

|                               |        |        |        |        |        | В             | irth year | /s     |        |        |        |               |               |
|-------------------------------|--------|--------|--------|--------|--------|---------------|-----------|--------|--------|--------|--------|---------------|---------------|
|                               | 1996   | 1997   | 1998   | 1999   | 2000   | 1996-<br>2000 | 2001      | 2002   | 2003   | 2004   | 2005   | 2001-<br>2005 | 1996-<br>2005 |
| Type of care                  | n      | n      | n      | n      | n      | n             | n         | n      | n      | n      | n      | n             | n             |
|                               | (%)^   | (%)^   | (%)^   | (%)^   | (%)^   | (%)^          | (%)^      | (%)^   | (%)^   | (%)^   | (%)^   | (%)^          | (%)^          |
| NICU <sup>1</sup> only        | 21     | 14     | 16     | 19     | 22     | 92            | 18        | 18     | 14     | 19     | 20     | 89            | 181           |
|                               | (25.0) | (20.0) | (25.0) | (27.1) | (33.8) | (26.1)        | (39.1)    | (34.6) | (23.3) | (32.2) | (37.7) | (33.0)        | (29.1)        |
| NICU <sup>1</sup> and Special | 20     | 25     | 19     | 22     | 26     | 112           | 13        | 19     | 14     | 16     | 8      | 70            | 182           |
| Care                          | (23.8) | (35.7) | (29.7) | (31.4) | (40.0) | (31.7)        | (28.3)    | (36.5) | (23.3) | (27.1) | (15.1) | (25.9)        | (29.2)        |
| Special Care only             | 12     | 9      | 10     | 7      | 7      | 45            | 3         | 6      | 4      | 1      | 6      | 20            | 65            |
|                               | (14.3) | (12.9) | (15.6) | (10.0) | (10.8) | (12.7)        | (6.5)     | (11.5) | (6.7)  | (1.7)  | (11.3) | (7.4)         | (10.4)        |
| Routine care only             | 31     | 22     | 19     | 22     | 10     | 104           | 12        | 9      | 28     | 23     | 19     | 91            | 195           |
|                               | (36.9) | (31.4) | (29.7) | (31.4) | (15.4) | (29.5)        | (26.1)    | (17.3) | (46.7) | (39.0) | (35.8) | (33.7)        | (31.3)        |
| Total                         | 84     | 70     | 64     | 70     | 65     | 353           | 46        | 52     | 60     | 59     | 53     | 270           | 623           |
|                               | (0.0)  | (0.0)  | (0.0)  | (0.0)  | (0.0)  | (0.0)         | (0.0)     | (0.0)  | (0.0)  | (0.0)  | (0.0)  | (0.0)         | (0.0)         |
| Unknown                       | 14     | 20     | 12     | 13     | 25     | 84            | 28        | 24     | 17     | 31     | 27     | 127           | 211           |
|                               | (14.3) | (22.2) | (15.8) | (15.7) | (27.8) | (19.2)        | (37.8)    | (31.6) | (22.1) | (34.4) | (33.8) | (32.0)        | (25.3)        |

<sup>&</sup>lt;sup>1</sup> Neonatal Intensive Care Unit

Figure 9a: Number and percentage of children with cerebral palsy by type of neonatal care.



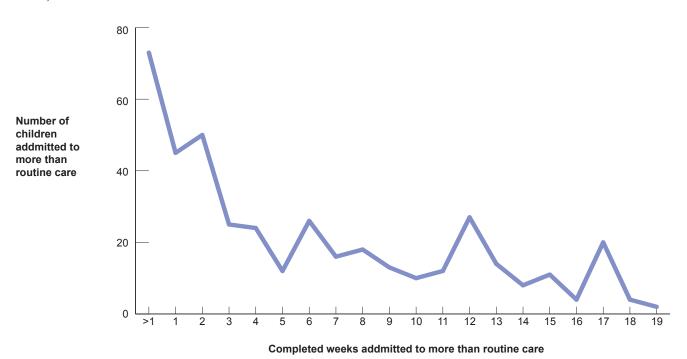
^ b Pn see page 10

Where the level of neonatal care is known, 33% received routine care only and 67% spent more than 24 hours in a neonatal intensive care unit or special care nursery.

<sup>^ \*</sup> Pn

## admission to more than routine care cont.

Figure 9b: Number of children with cerebral palsy who were admitted to NICU or SCN for more than 24 hours by length of stay (completed weeks).



b Pn see page 10

Of the 428 children with cerebral palsy admitted to more than routine care, 19 were admitted for 24 hours or less and then discharged back to routine care. Over 70 spent more than one day but less than 7 full days in more than routine care.

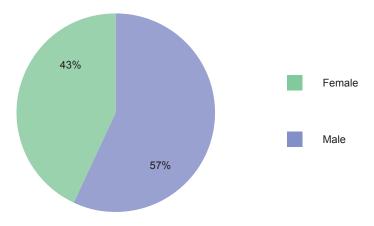
# demographics

## gender

Table 10: Number and percentage of children with cerebral palsy by gender.

|         | Birth year/s |        |        |        |        |               |        |        |        |        |        |               |               |
|---------|--------------|--------|--------|--------|--------|---------------|--------|--------|--------|--------|--------|---------------|---------------|
|         | 1996         | 1997   | 1998   | 1999   | 2000   | 1996-<br>2000 | 2001   | 2002   | 2003   | 2004   | 2005   | 2001-<br>2005 | 1996-<br>2005 |
| Gender  | n            | n      | n      | n      | n      | n             | n      | n      | n      | n      | n      | n             | n             |
|         | (%)          | (%)    | (%)    | (%)    | (%)    | (%)           | (%)    | (%)    | (%)    | (%)    | (%)    | (%)^          | (%)^          |
| Male    | 50           | 49     | 43     | 48     | 54     | 244           | 38     | 43     | 44     | 60     | 47     | 232           | 476           |
|         | (51.0)       | (53.8) | (57.3) | (56.5) | (58.7) | (55.3)        | (51.4) | (55.8) | (57.1) | (67.4) | (58.8) | (58.4)        | (56.8)        |
| Female  | 48           | 42     | 32     | 37     | 38     | 197           | 36     | 34     | 33     | 29     | 33     | 165           | 362           |
|         | (49.0)       | (46.2) | (42.7) | (43.5) | (41.3) | (44.7)        | (48.6) | (44.2) | (42.9) | (32.6) | (41.3) | (41.6)        | (43.2)        |
| Total n | 98           | 91     | 75     | 85     | 94     | 441           | 75     | 82     | 82     | 90     | 83     | 397           | 862           |

Figure 10: Percentage of children with cerebral palsy by gender.



b Pn see page 10

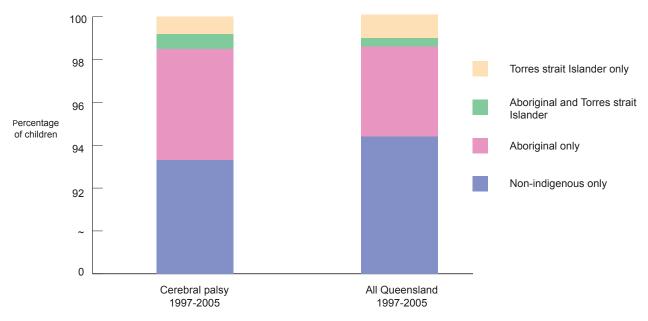
#### indigenous status

Table 11: Number and percentage of children with cerebral palsy by indigenous status.

|   |               |               |               |               |               | В             | irth year     | /s            |               |               |               |                |                |
|---|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|----------------|----------------|
|   | 1996          | 1997          | 1998          | 1999          | 2000          | 1996-<br>2000 | 2001          | 2002          | 2003          | 2004          | 2005          | 2001-<br>2005  | 1996-<br>2005  |
|   | n             | n             | n             | n             | n             | n             | n             | n             | n             | n             | n             | n              | n              |
| Indigenous status                           | (%)^          | (%)^          | (%)^          | (%)^          | (%)^          | (%)           | (%)^          | (%)^          | (%)^          | (%)^          | (%)^          | (%)^           | (%)^           |
| Aboriginal                                  | 4<br>(4.5)    | 4<br>(5.6)    | 5<br>(7.9)    | 3<br>(4.3)    | 2<br>(3.2)    | 18<br>(5.1)   | 3<br>(6.7)    | 2<br>(3.8)    | 4<br>(6.7)    | 4<br>(7.7)    | 1<br>(1.9)    | 14<br>(5.4)    | 32<br>(5.2)    |
| Aboriginal and<br>Torres Strait<br>Islander | 0<br>(0.0)    | 0 (0.0)       | 1<br>(1.6)    | 0 (0.0)       | 2<br>(3.2)    | 3 (0.8)       | 0 (0.0)       | 1<br>(1.9)    | 0 (0.0)       | 0 (0.0)       | 0 (0.0)       | 1 (0.4)        | 4<br>(0.7)     |
| Torres Strait<br>Islander                   | 0 (0.0)       | 2<br>(2.8)    | 0<br>(0.0)    | 0 (0.0)       | 0<br>(0.0)    | 2 (0.6)       | 0 (0.0)       | 1<br>(1.9)    | 0 (0.0)       | 2<br>(3.8)    | 0 (0.0)       | 3<br>(1.1)     | 5(0.8)         |
| Non Indigenous                              | 84<br>(95.5)  | 66<br>(91.7)  | 57<br>(90.5)  | 66<br>(95.7)  | 58<br>(93.5)  | 331<br>(93.5) | 42<br>(93.3)  | 48<br>(92.3)  | 56<br>(93.3)  | 46<br>(88.5)  | 51<br>(98.1)  | 243<br>(93.1)  | 574<br>(93.3)  |
| Total                                       | 88            | 72            | 63            | 69            | 62            | 354           | 45            | 52            | 60            | 52            | 52            | 261            | 615            |
| Unknown                                     | 14<br>(13.7)* | 19<br>(20.9)* | 16<br>(20.3)* | 17<br>(19.8)* | 32<br>(34.0)* | 98<br>(21.7)* | 30<br>(40.0)* | 30<br>(36.6)* | 22<br>(26.8)* | 38<br>(42.2)* | 31<br>(37.3)* | 151<br>(36.7)* | 249<br>(28.8)* |

<sup>^ \*</sup> b Pn see page 10

Figure 11: Percentage of children with cerebral palsy and all Queensland births by indigenous status (1997 - 2005).



<sup>^</sup> Pn see page 10

An overwhelming majority (93%) of children with cerebral palsy were non-indigenous. Between 1997 and 2005, 6.2% of children with cerebral palsy were born to mothers who identified as having Aboriginal or both Aboriginal and Torres Strait Islander origin. Fewer than 1% of children with cerebral palsy were born to mothers whose indigenous status was Torres straight Islander only.

## Vision

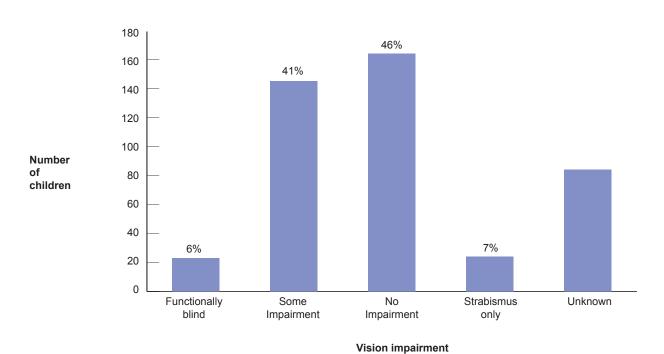
#### Vision

Table 12: Number of children with cerebral palsy by vision status.

|                                 |          |            |             |            |            | В             | irth year | /s         |            |            |            |               |               |
|---------------------------------|----------|------------|-------------|------------|------------|---------------|-----------|------------|------------|------------|------------|---------------|---------------|
|                                 | 1996     | 1997       | 1998        | 1999       | 2000       | 1996-<br>2000 | 2001      | 2002       | 2003       | 2004       | 2005       | 2001-<br>2005 | 1996-<br>2005 |
| Vision status                   | n        | n          | n           | n          | n          | n             | n         | n          | n          | n          | n          | n             | n             |
|                                 | (%)^     | (%)^       | (%)^        | (%)^       | (%)^       | (%)           | (%)^      | (%)^       | (%)^       | (%)^       | (%)^       | (%)^          | (%)^          |
| Functionally blind              | 9        | 3          | 3           | 5          | 3          | 23            | 2         | 4          | 4          | 3          | 1          | 14            | 37            |
|                                 | (12.0)   | (4.1)      | (4.6)       | (6.8)      | (4.3)      | (6.5)         | (4.1)     | (7.5)      | (7.4)      | (5.7)      | (2.1)      | (5.5)         | (6.0)         |
| Some impairment (wears glasses) | 33       | 32         | 24          | 29         | 27         | 145           | 19        | 10         | 18         | 11         | 12         | 70            | 215           |
|                                 | (44.0)   | (43.8)     | (36.9)      | (39.2)     | (39.1)     | (40.7)        | (38.8)    | (18.9)     | (33.3)     | (20.8)     | (25.5)     | (27.3)        | (35.1)        |
| No impairment                   | 33       | 34         | 30          | 33         | 34         | 164           | 28        | 37         | 28         | 38         | 33         | 164           | 328           |
|                                 | (44.0)   | (46.6)     | (46.2)      | (44.6)     | (49.3)     | (46.1)        | (57.1)    | (69.8)     | (51.9)     | (71.7)     | (70.2)     | (64.1)        | (53.6)        |
| Strabismus only                 | 0<br>(0) | 4<br>(5.5) | 8<br>(12.3) | 7<br>(9.5) | 5<br>(7.2) | 24<br>(6.7)   | 0 (0.0)   | 2<br>(3.8) | 4<br>(7.4) | 1<br>(1.9) | 1<br>(2.1) | 8<br>(3.1)    | 32<br>(5.2)   |
| Total                           | 75       | 73         | 65          | 74         | 69         | 356           | 49        | 53         | 54         | 53         | 47         | 256           | 612           |
| Unknown                         | 23       | 18         | 10          | 10         | 23         | 84            | 25        | 24         | 24         | 37         | 34         | 144           | 228           |
|                                 | (23.5)*  | (19.8)*    | (13.3)*     | (11.9)*    | (25.0)*    | (19.1)*       | (33.8)*   | (31.2)*    | (30.8)*    | (41.1)*    | (42.0)*    | (36.0)*       | (27.1)*       |

<sup>^ \*</sup> b Pn

Figure 12a: Number and percentage of children with cerebral palsy by vision status.

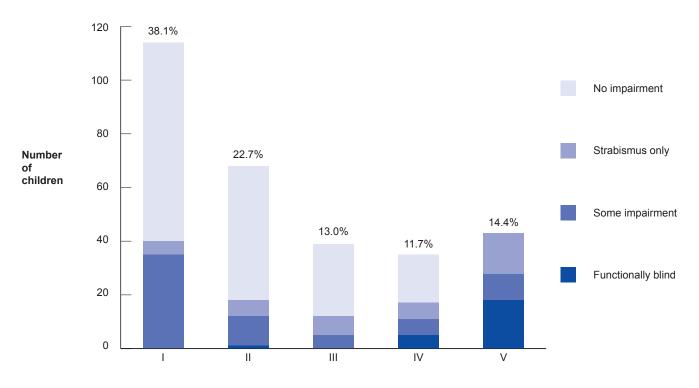


^ b Pn see page 10

More than half (53.9%) of children with cerebral palsy have some type of visual impairment.

## Vision and gross motor function

Figure 12b: Number of children with cerebral palsy by vision status and GMFCS level.



**Gross Motor Function Classification System level** 

^ b Pn see page 10

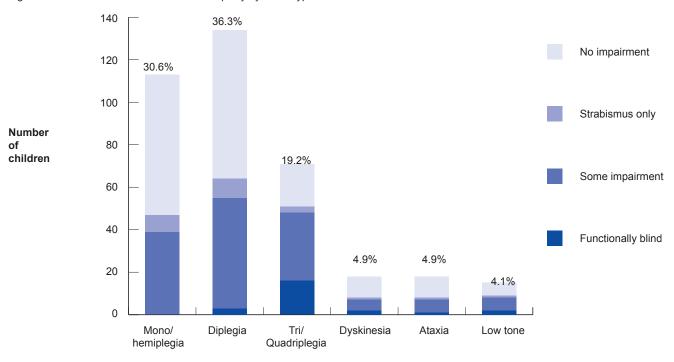
Almost all children who were functinally blind were classified GMFCS level IV or V.

Almost 70% of children with cerebral palsy GMFCS levels I, II and III had no visual impairment.

Almost 50% of children at GMFCS IV had no visual impairment, while only 35% of children with cerebral palsy at GMFCS level V had no visual impairment.

## Vision, motor type and distribution

Figure 12c: Number of children with cerebral palsy by motor type and distribution.



Motor type and distribution

^ b Pn see page 10

Most (67%) children with cerebral palsy who were functionally blind had spastic quadriplegia.

Most (50% - 60%) children with other motor type classifications, had no visual impairment at all.

# hearing

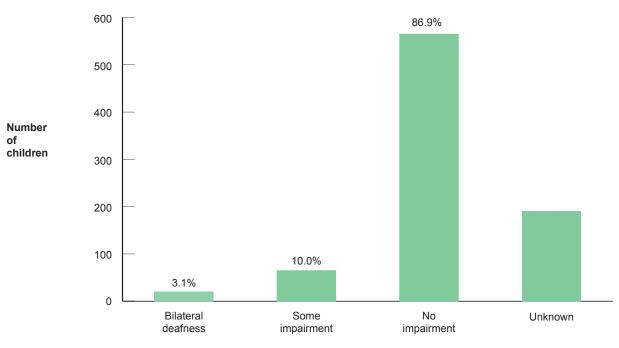
### hearing

Table 13: Number of children with cerebral palsy by hearing status.

|  |         |         |         |         |         | В             | irth year | /s      |         |         |         |               |               |
|--|---------|---------|---------|---------|---------|---------------|-----------|---------|---------|---------|---------|---------------|---------------|
|  | 1996    | 1997    | 1998    | 1999    | 2000    | 1996-<br>2000 | 2001      | 2002    | 2003    | 2004    | 2005    | 2001-<br>2005 | 1996-<br>2005 |
|  | n       | n       | n       | n       | n       | n             | n         | n       | n       | n       | n       | n             | n             |
|  | (0/ \A  | (%)^    | (%)^    | (%)^    | (%)^    | (%)^          | (%)^      | (%)^    | (%)^    | (%)^    | (%)^    | (%)^          | (%)^          |
| Hearing status                                     | (%)^    | (70)    | (70)    | (70)    | (70)    | (70)          | (70)      | (70)    | (70)    | (70)    | (70)    | (70)          | (70)          |
| Bilateral deafness                                 | 1       | 3       | 1       | 2       | 3       | 10            | 2         | 1       | 4       | 2       | 1       | 10            | 20            |
|  | (1.1)   | (3.9)   | (1.5)   | (2.7)   | (4.2)   | (2.7)         | (4.1)     | (1.8)   | (6.8)   | (3.6)   | (1.9)   | (3.7)         | (3.1)         |
| Some impairment (includes conductive hearing loss) | 7       | 7       | 4       | 8       | 9       | 35            | 7         | 3       | 3       | 12      | 5       | 30            | 65            |
|  | (8.0)   | (9.2)   | (6.1)   | (10.7)  | (12.5)  | (9.3)         | (14.3)    | (5.3)   | (5.1)   | (21.4)  | (9.6)   | (11.0)        | (10.0)        |
| No impairment                                      | 80      | 66      | 61      | 65      | 60      | 332           | 40        | 53      | 52      | 42      | 46      | 233           | 565           |
|  | (90.9)  | (86.8)  | (92.4)  | (86.7)  | (83.3)  | (88.1)        | (81.6)    | (93.0)  | (88.1)  | (75.0)  | (88.5)  | (85.3)        | (86.9)        |
| Total  | 88      | 76      | 66      | 75      | 72      | 377           | 49        | 57      | 59      | 56      | 52      | 273           | 650           |
|  | (0.0)   | (0.0)   | (0.0)   | (0.0)   | (0.0)   | (0.0)         | (0.0)     | (0.0)   | (0.0)   | (0.0)   | (0.0)   | (0.0)         | (0.0)         |
| Unknown  | 3       | 2       | 1       | 2       | 8       | 64            | 3         | 4       | 2       | 6       | 3       | 127           | 191           |
|  | (10.2)* | (16.5)* | (12.0)* | (11.8)* | (21.7)* | (14.5)*       | (33.8)*   | (26.0)* | (24.4)* | (37.8)* | (35.8)* | (31.8)*       | (22.7)*       |

<sup>^ \*</sup> b Pn see page 10

Figure 13a: Number of children with cerebral palsy by hearing status.



**Hearing status** 

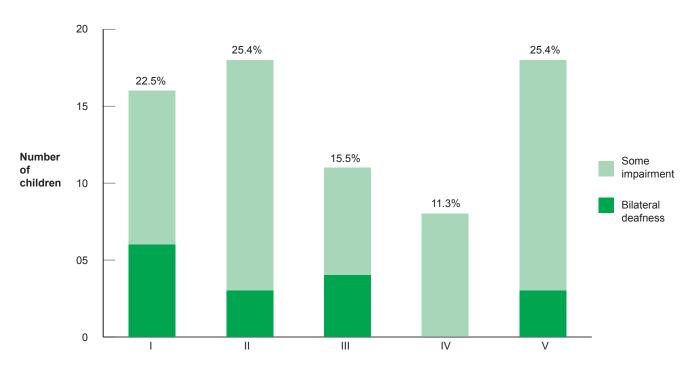
Almost 87% of children with cerebral palsy had no recorded hearing impairment.

There were 3.1% recorded as being bilaterally deaf (including those who now hear with cochlear implants).

<sup>^</sup> b Pn see page 10

## hearing and gross motor function

Figure 13b: Number of children with cerebral palsy who have a hearing impairment by type of hearing impairment and GMFCS level.

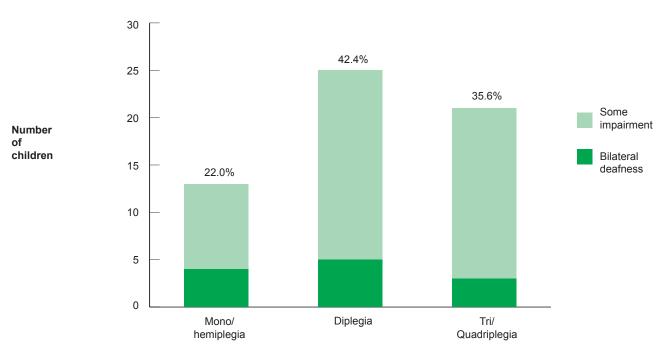


**Gross Motor Function Classification System level** 

b Pn see page 10

## hearing and spasfic mofor type

Figure 13c: Number of children with cerebral palsy who have a hearing impairment by type of hearing impairment and spastic motor type.



Spastic Motor type and distribution

b Pn see page 10

# intellectual status

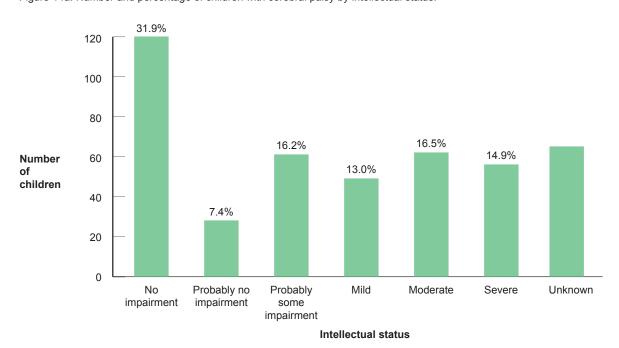
## intellectual status

Table 14: Number and percentage of children with cerebral palsy by intellectual status.

|                          |              |              |             |            |             | В             | irth year   | /s          |            |            |         |               |               |
|--------------------------|--------------|--------------|-------------|------------|-------------|---------------|-------------|-------------|------------|------------|---------|---------------|---------------|
|                          | 1996         | 1997         | 1998        | 1999       | 2000        | 1996-<br>2000 | 2001        | 2002        | 2003       | 2004       | 2005    | 2001-<br>2005 | 1996-<br>2005 |
| Intellectual status      | n            | n            | n           | n          | n           | n             | n           | n           | n          | n          | n       | n             | n             |
|                          | (%)^         | (%)^         | (%)^        | (%)^       | (%)^        | (%)^          | (%)^        | (%)^        | (%)^       | (%)^       | (%)^    | (%)^          | (%)^          |
| Severe                   | 16           | 10           | 9           | 14         | 7           | 56            | 2           | 2           | 4          | 4          | 3       | 15            | 71            |
|                          | (18.0)       | (13.5)       | (13.6)      | (18.2)     | (10.0)      | (14.9)        | (4.7)       | (3.6)       | (6.9)      | (7.8)      | (6.8)   | (6.0)         | (11.3)        |
| Moderate                 | 14           | 10           | 14          | 15         | 9           | 62            | 2           | 3           | 7          | 5          | 2       | 19            | 81            |
|                          | (15.7)       | (13.5)       | (21.2)      | (19.5)     | (12.9)      | (16.5)        | (4.7)       | (5.5)       | (12.1)     | (9.8)      | (4.5)   | (7.6)         | (12.9)        |
| Mild                     | 16<br>(18.0) | 13<br>(17.6) | 9<br>(13.6) | 4<br>(5.2) | 7<br>(10.0) | 49<br>(13.0)  | 7<br>(16.3) | 6<br>(10.9) | 5<br>(8.6) | 2<br>(3.9) | 0 (0.0) | 20<br>(8.0)   | 69<br>(11.0)  |
| Probably some impairment | 11           | 12           | 8           | 11         | 19          | 61            | 12          | 7           | 11         | 9          | 7       | 46            | 107           |
|                          | (12.4)       | (16.2)       | (12.1)      | (14.3)     | (27.1)      | (16.2)        | (27.9)      | (12.7)      | (19.0)     | (17.6)     | (15.9)  | (18.3)        | (17.1)        |
| Probably no impairment   | 5            | 4            | 6           | 8          | 5           | 28            | 9           | 9           | 12         | 14         | 9       | 53            | 81            |
|                          | (5.6)        | (5.4)        | (9.1)       | (10.4)     | (7.1)       | (7.4)         | (20.9)      | (16.4)      | (20.7)     | (27.5)     | (20.5)  | (21.1)        | (12.9)        |
| No impairment            | 27           | 25           | 20          | 25         | 23          | 120           | 11          | 28          | 19         | 17         | 23      | 98            | 218           |
|                          | (30.3)       | (33.8)       | (30.3)      | (32.5)     | (32.9)      | (31.9)        | (25.6)      | (50.9)      | (32.8)     | (33.3)     | (52.3)  | (39.0)        | (34.8)        |
| Total                    | 89           | 74           | 66          | 77         | 70          | 376           | 43          | 55          | 58         | 51         | 44      | 251           | 627           |
| Unknown                  | 9            | 15           | 9           | 8          | 22          | 65            | 31          | 22          | 20         | 39         | 37      | 149           | 214           |
|                          | (9.2)*       | (18.7)*      | (12.0)*     | (9.4)*     | (23.9)*     | (14.7)        | (41.9)*     | (28.6)*     | (25.6)*    | (43.3)*    | (45.7)* | (37.3)*       | (25.4)*       |

<sup>^ \*</sup> Pn

Figure 14a: Number and percentage of children with cerebral palsy by intellectual status.

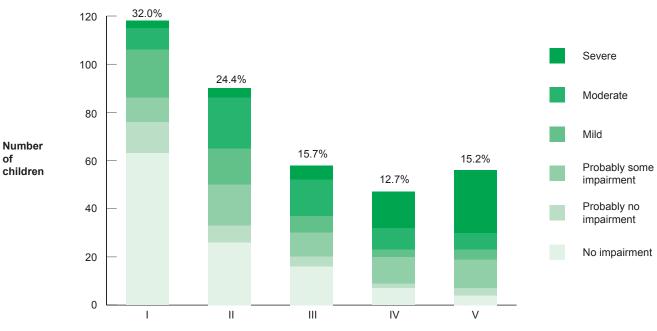


^ b Pn see page 10

Of the children with cerebral palsy and known intellectual status, 39.3% were reported as having no or probably no intellectual impairment and 31.4% as having moderate to severe intellectual impairment.

## intellectual status and gross motor function

Figure 14b: Number of children with cerebral palsy by intellectual status and GMFCS level.



**Gross Motor Function Classification** 

b Pn see page 10

Most (64.4%) children at GMFCS I had no or probably no intellectual impairment.

Approximately 35% of children with cerebral palsy at GMFCS level II or III had no or probably no intellectual impairment.

At GMFCS IV (19.1%) and at GMFCS V (12.5%) fewer children were reported as having no or probably no intellectual impairment.

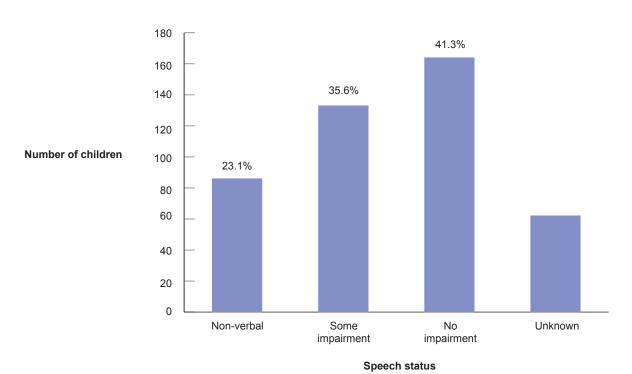
# **SPEECH**speech status

Table 15a: Number and percentage of children with cerebral palsy by speech status.

|                 |               |               |               |              |               | В             | irth year     | /s            |               |               |               |                |                |
|-----------------|---------------|---------------|---------------|--------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|----------------|----------------|
|                 | 1996          | 1997          | 1998          | 1999         | 2000          | 1996-<br>2000 | 2001          | 2002          | 2003          | 2004          | 2005          | 2001-<br>2005  | 1996-<br>2005  |
|                 | n             | n             | n             | n            | n             | n             | n             | n             | n             | n             | n             | n              | n              |
| Speech          | (%)^          | (%)^          | (%)^          | (%)^         | (%)^          | (%)^          | (%)^          | (%)^          | (%)^          | (%)^          | (%)^          | (%)^           | (%)^           |
| Non-verbal      | 24<br>(27.3)  | 13<br>(16.7)  | 15<br>(27.8)  | 19<br>(24.1) | 15<br>(20.3)  | 86<br>(23.1)  | 10<br>(20.8)  | 14<br>(21.0)  | 15<br>(23.4)  | 15<br>(28.8)  | 7<br>(14.0)   | 61<br>(21.7)   | 147<br>(22.5)  |
| Some impairment | 27<br>(29.5)  | 32<br>(41.0)  | 26<br>(46.3)  | 27<br>(34.2) | 21<br>(30.4)  | 133<br>(35.6) | 26<br>(52.1)  | 24<br>(38.7)  | 24<br>(37.5)  | 21<br>(40.4)  | 21<br>(42.0)  | 116<br>(41.7)  | 249<br>(38.2)  |
| No impairment   | 38<br>(43.2)  | 33<br>(42.3)  | 26<br>(25.9)  | 33<br>(41.8) | 34<br>(49.3)  | 164<br>(41.3) | 13<br>(27.1)  | 25<br>(40.3)  | 29<br>(39.1)  | 17<br>(30.8)  | 22<br>(44.0)  | 106<br>(36.6)  | 270<br>(39.3)  |
| Total n known   | 89            | 78            | 67            | 79           | 70            | 383           | 49            | 63            | 68            | 53            | 50            | 283            | 666            |
| Unknown         | 10<br>(21.4)* | 13<br>(12.4)* | 10<br>(14.3)* | 6<br>(4.8)*  | 23<br>(17.9)* | 62<br>(14.6)* | 26<br>(32.4)* | 15<br>(15.1)* | 14<br>(15.8)* | 39<br>(38.1)* | 31<br>(35.9)* | 125<br>(27.7)* | 187<br>(20.8)* |

<sup>^ \*</sup> Pn see page 10

Figure 15a: Number and percentage of children with cerebral palsy (birth years 1996-2000) by speech status.



<sup>^</sup> Pn see page 10

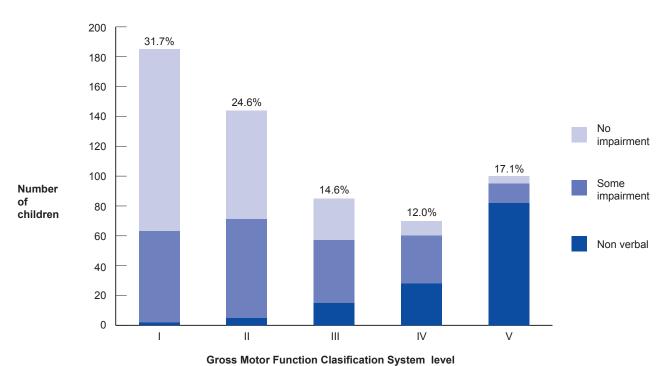
## speech and gross motor function

Table 15b: Number of children with cerebral palsy (birth years 1996-2000)# by speech status and GMFCS level.

|                 |     |    |     | GMFCS | )  |       |         |
|-----------------|-----|----|-----|-------|----|-------|---------|
| Speech status   | 1   | II | III | IV    | V  | Total | Unknown |
| Non-verbal      | 2   | 5  | 15  | 28    | 82 | 132   | 15      |
| Some impairment | 61  | 66 | 42  | 32    | 13 | 214   | 35      |
| No impairment   | 122 | 73 | 28  | 10    | 5  | 238   | 32      |

Pn see page 10

Figure 15b: Number and percentage of children with cerebral palsy (birth years 1996-2000) by speech status and GMFCS level.



<sup>^</sup> Pn see page 10

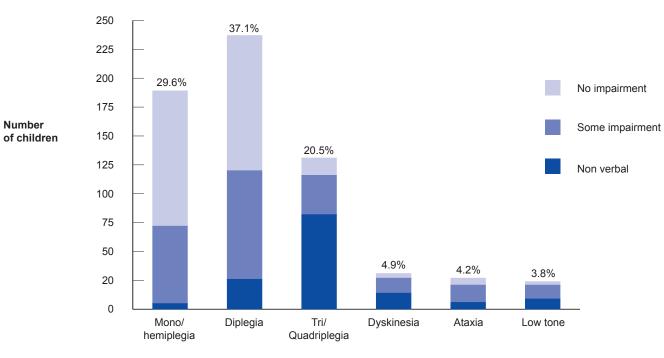
## speech and motor type and distribution

Table 15c: Number of children with cerebral palsy (birth years 1996-2000)\* by speech status and Gross Motor Function Classification (GM-FCS)level.

|                 |                     | Motor type and distribution |                      |            |        |          |       |         |  |  |  |  |  |
|-----------------|---------------------|-----------------------------|----------------------|------------|--------|----------|-------|---------|--|--|--|--|--|
| Speech status   | Mono/<br>hemiplegia | Diplegia                    | Tri/<br>quadriplegia | Dyskinesia | Ataxia | Low tone | Total | Unknown |  |  |  |  |  |
| Non-verbal      | 5                   | 26                          | 82                   | 14         | 6      | 9        | 142   | 5       |  |  |  |  |  |
| Some impairment | 67                  | 94                          | 34                   | 13         | 15     | 12       | 235   | 14      |  |  |  |  |  |
| No impairment   | 117                 | 117                         | 15                   | 4          | 6      | 3        | 262   | 8       |  |  |  |  |  |

Pn

Figure 15c: Number of children with cerebral palsy (birth years 1996-2000) by epilepsy status and motor type and distribution.



Motor type and distribution

<sup>^</sup> Pn see page 10

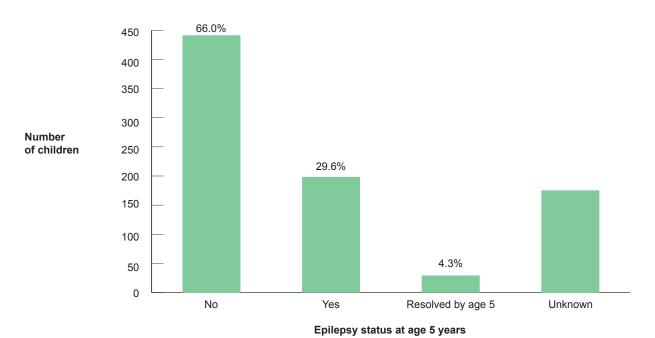
# epilepsy epilepsy

Table 16: Number and percentage of children with cerebral palsy by epilepsy status.

|                   |            |            |            |            |            | В             | irth year | /s         |            |            |            |               |               |
|-------------------|------------|------------|------------|------------|------------|---------------|-----------|------------|------------|------------|------------|---------------|---------------|
|                   | 1996       | 1997       | 1998       | 1999       | 2000       | 1996-<br>2000 | 2001      | 2002       | 2003       | 2004       | 2005       | 2001-<br>2005 | 1996-<br>2005 |
| Epilepsy status   | n          | n          | n          | n          | n          | n             | n         | n          | n          | n          | n          | n             | n             |
|                   | (%)^       | (%)^       | (%)^       | (%)^       | (%)^       | (%)^          | (%)^      | (%)^       | (%)^       | (%)^       | (%)^       | (%)^          | (%)^          |
| Yes               | 32         | 21         | 22         | 29         | 26         | 130           | 14        | 10         | 17         | 14         | 13         | 68            | 198           |
|                   | (36.4)     | (26.9)     | (33.3)     | (37.7)     | (36.6)     | (34.2)        | (30.4)    | (17.2)     | (26.6)     | (23.0)     | (22.0)     | (23.6)        | (29.6)        |
| Resolved by age 5 | 4<br>(4.5) | 5<br>(6.4) | 3<br>(4.5) | 3<br>(3.9) | 6<br>(8.5) | 21<br>(5.5)   | 0 (0.0)   | 3<br>(5.2) | 1<br>(1.6) | 3<br>(4.9) | 1<br>(1.7) | 8<br>(2.8)    | 29<br>(4.3)   |
| No                | 52         | 52         | 41         | 45         | 39         | 229           | 32        | 45         | 46         | 44         | 45         | 212           | 441           |
|                   | (59.1)     | (66.7)     | (62.1)     | (58.4)     | (54.9)     | (60.3)        | (69.6)    | (77.6)     | (71.9)     | (72.1)     | (76.3)     | (73.6)        | (66.0)        |
| Total             | 88         | 78         | 66         | 77         | 71         | 380           | 46        | 58         | 64         | 61         | 59         | 288           | 668           |
| Unknown           | 10         | 13         | 10         | 8          | 21         | 62            | 28        | 20         | 14         | 29         | 22         | 113           | 175           |
|                   | (10.2)*    | (14.3)*    | (13.2)*    | (9.4)*     | (22.8)*    | (14.0)*       | (37.8)*   | (25.6)*    | (17.9)*    | (32.2)*    | (27.2)*    | (28.2)*       | (20.8)*       |

<sup>^ \*</sup> Pn see page 10

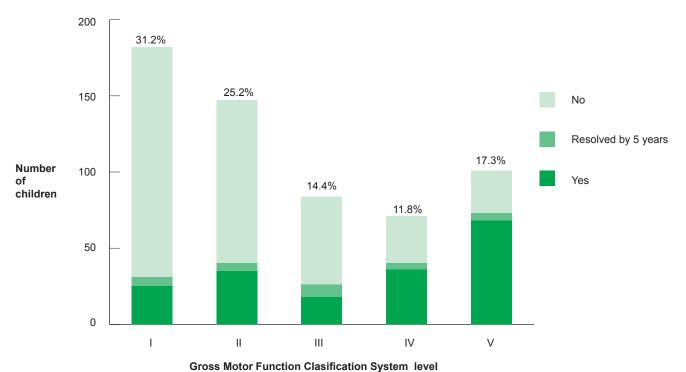
Figure 16a: Number and percentage of children with cerebral palsy by epilepsy status.



^ b Pn see page 10

## epilepsy and gross motor function

Figure 16b: Number of children with cerebral palsy by epilepsy status and GMFCS level.

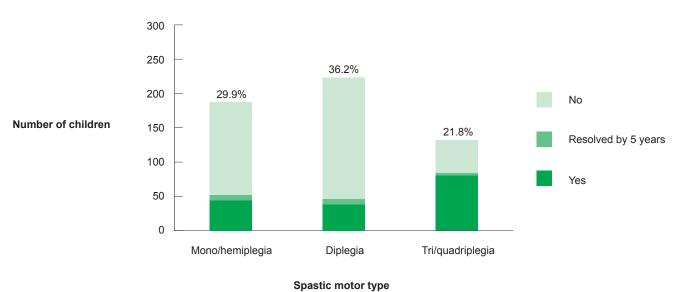


^ b Pn see page 10

For children at GMFCS I, 13.7% had active epilepsy at age five. For children at GMFCS V, 67.3% had active epilepsy at age five.

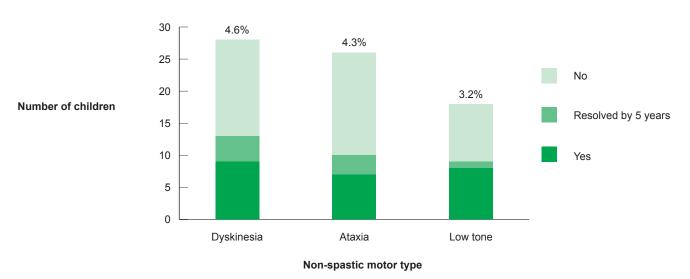
## epilepsy and motor type and distribution

Figure 16c: Number of children with cerebral palsy by epilepsy status and spastic motor type and distribution.



b Pn see page 10

Figure 16d: Number of children with cerebral palsy by epilepsy status and non-spastic motor type.



b Pn see page 10

With the exception of spastic quadriplegia, all motor type and distribution classifications had fewer than 50% of children with epilepsy at age five.

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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.



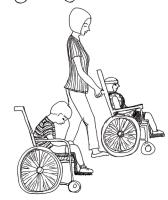
#### **GMFCS Level III**

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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