1996 Birth Year Report Summary

Welcome to this summary of the Queensland Cerebral Palsy Register (QCPR) 1996 birth year report that was officially launched on 5th August 2010 by the Honourable Paul Lucas, Deputy Premier and Minister for Health. It is the first report of the QCPR and is based on data from children who were born with cerebral palsy in 1996. This particular birth year was chosen because it met the criteria for reporting set down by the Australian Cerebral Palsy Register (ACPR). It can also be compared with reports from other states for that birth year as well as the ACPR report for all Australian children with cerebral palsy, which was published in February 2010. It is the first of many reports that in the future will include birth years in addition to 1996, and will detail the best available information about the population of people with cerebral palsy in Queensland.

Rate of cerebral palsy

The overall rate of cerebral palsy in Queensland for the 1996 birth year was **1.8 per thousand live births**. This is just below the published Australian rate of 1.9 per thousand live births but is the second highest published rate of cerebral palsy from any register in Australia for this birth year.

Distribution of motor type

Almost 80% of all people with cerebral palsy had spastic motor type. Twenty-nine percent had left or right spastic hemiplegia, 36% had spastic diplegia, 13% spastic quadriplegia and 1% spastic triplegia. Five percent of all children had ataxic cerebral palsy and 2% dyskinetic cerebral palsy, which includes athetosis and dystonia. The distribution of motor type reported here is comparable to that reported in the Australian Cerebral Palsy Register, where 86% of people had spastic motor type, 6% had ataxic cerebral palsy and 6% dyskinetic cerebral palsy.

Functional abilities at age five

Using the Gross Motor Function Classification System (GMFCS), thirty-one percent of children born in 1996 had a gross motor function level of GMFCS I. This means that they were able to walk independently indoors and outdoors as well as climb stairs without needing to hold on to a person or support structure (such as a railing).

Fourteen percent of children were GMFCS II, which means that they could walk independently on all surfaces but needed to hold a railing when using stairs and were probably unable to run or jump.

Seventeen percent of children were GMFCS III, which means they either walked using sticks or crutches or perhaps used a wheelchair for rough surfaces and long distances.

Nine percent of children were GMFCS IV. This means they probably used a wheelchair for mobility or at best walked short distances with a walker and probably needed adult supervision and assistance to turn around on uneven surfaces.

GMFCS I	*31%*
GMFCS II	*14%*
GMFCS III	*17%*
GMFCS IV	*9%*
GMFCS V	*20%*

Twenty percent of children were GMFCS V, which means they were not able to sit independently without assistance from modified seating or another person.

The Queensland distribution for gross motor function in 1996 is reasonably similar to the ACPR report for all children in Australia. There, 32% of children were GMFCS I, 27% GMFCS II, 12% GMFCS III, 14% GMFCS IV and 15% were GMFCS V.

Full descriptions of each classification level and other age groups can be accessed through our website at http://www.qcpr.org.au.

Individual characteristics

Fifty-five percent of children with cerebral palsy were male and 2% had one or more parents who identified as having aboriginal origin. **These distributions are roughly in line with the ACPR report** where 56% of children in Australia with cerebral palsy were male and 3% had one or more parents who identified as having aboriginal origin.

Birth details

Almost half of all children with cerebral palsy were admitted to a neonatal intensive care unit (NICU). While 46% of people were born around term, the rate of cerebral palsy for children **born before 28 weeks gestation was 30 times higher** than that for children born at term.

Similarly, 44% of children with cerebral palsy had a birth weight of between 2.5 kg and 4 kg. However, the rate of cerebral palsy for children with a **birth weight of less than 1.5 kg was 30 times higher** than that for children born weighing between 2.5 kg and 4 kg.

Eighty-five percent of all children with cerebral palsy were singletons. While only 5% were born as a twin, their rate of cerebral palsy was almost four times that for singletons.

The rate of cerebral palsy for children born to mothers who had no previous children (1.9 per thousand live births) was marginally higher than the rate for children born to mothers who had between one and four previous children (1.6 per thousand live births). For those born to mothers who had five or more previous children, the rate of cerebral palsy was even higher (2.3 per thousand live births).

The rate of cerebral palsy for children born to mothers aged less than 35 years at the time of delivery was slightly lower than the 1.8 average at 1.5 per thousand live births. The rate for mothers aged 35 years or older was slightly higher at 2.35 per thousand live births.

Other impairments

Thirty percent of children with cerebral palsy had no visual impairment and 49% were able to see with a visual impairment recorded. Twelve percent of children with cerebral palsy born in Queensland during 1996 were recorded as functionally blind which is more than twice the overall Australian rate reported in the ACPR.

Eighty-one percent of children with cerebral palsy had no hearing impairment and 7% had some impairment recorded. Two percent of children with cerebral palsy reported bilateral deafness. These distributions are generally consistent with those reported by the ACPR.

Thirty-three percent of children with cerebral palsy had no or probably no intellectual impairment. Forty-five percent of children with cerebral palsy had some intellectual impairment recorded with a further 13% having probably some impairment. These figures suggest slightly higher rates of intellectual impairment for this group of children than that reported by the ACPR. There, 32% of children with cerebral palsy had some intellectual impairment recorded and more than half had no impairment.

Fifty-two percent of children with cerebral palsy had no epilepsy. Thirty-two percent had persistent epilepsy at five years of age and 5% had seizures that had resolved by their fifth birthday. This distribution is reasonably similar to that reported by the ACPR for all children in Australia with cerebral palsy where 31% had persistent epilepsy at five years of age.

Future directions

It is our intention to publish multiple birth years as soon as possible. It is likely that the 2011 report from the QCPR will include 1996, 1997 and 1998 birth years. If possible, we will include more birth years with the possible inclusion of 1999 and 2000.

Conclusions

Most characteristics of the 1996 birth year population of people with cerebral palsy in Queensland are similar to characteristics for the entire population of children with cerebral palsy born in Australia reported by the ACPR.

It is important not to draw conclusions about other birth years from this report. Future reports will give us a measure of variability for Queensland as well as indications of trends over time. At present, we conclude only that the **1996 birth year cohort for Queensland might have a higher rate of people with spastic quadriplegia, intellectual impairment and/or functional blindness**.

Cerebral Palsy Register Queensland

Piecing together the facts