Birth Years 1996 – 2005

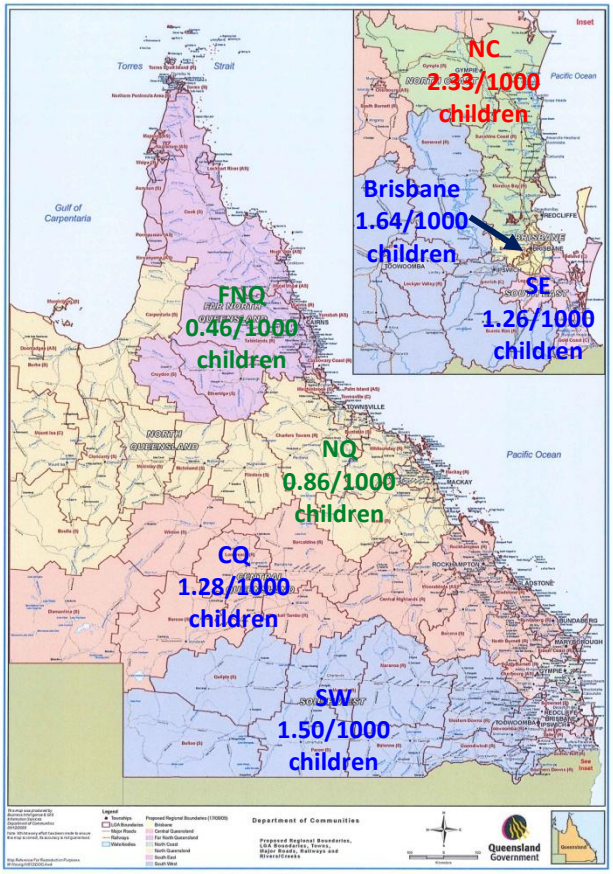
Summary Report

Welcome to the November 2013 update of the Queensland Cerebral Palsy Register (QCPR). Last year the QCPR published a report detailing the characteristics of 881 children born from 1996 to 2005. That report is available online by following the publications tab at http://www.qcpr.org.au. There are links to other publications written by the QCPR and by other researchers who have collaborated with the QCPR, along with other useful information that might be interesting.

This summary will use the data used in the latest publication and report on additional variables that registrants have asked us about through the new web site. Specifically, this summary reports on geographical distribution and general functional abilities of people with cerebral palsy (CP).

Geographical distribution of children with cerebral palsy on the QCPR

These data represent children with cerebral palsy (CP) born 1995 to 2005 in the 7 Disability Services regions as a fraction of the total children in that region counted in the Australian Bureau of Statistics census. To calculate the number of children, we summed the reported number from each postcode within each region. There were 5 postcodes that crossed regional boundaries in which case the total number of children and the number of children with cerebral palsy in that postcode were added to both regions.

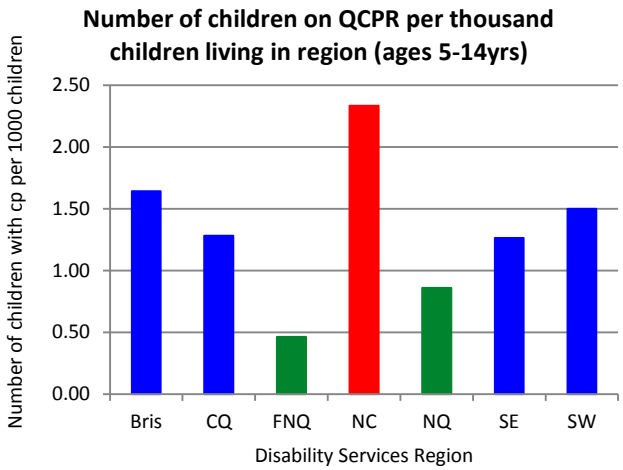


Map of DS regions with rate of CP overlaid sourced from http://www.communities.qld.gov.au/gateway/about-us/regions

The regions in blue, including Brisbane (Bris), South East (SE), South West (SW) and Central Queensland (CQ) were around the average. North Queensland (NQ) was low and Far North Queensland (FNQ) was very low. North Coast is higher than the others.

Far North Queensland had much fewer children than other regions (58% of the next smallest region and 44% of the average number of children) and the rate is possibly more susceptible to children with cerebral palsy moving away. The QCPR is undertaking a project that will determine if this is occurring but FNQ is also susceptible to other issues. It is the furthest region away from the QCPR office and there are fewer people who refer children to the QCPR. It is possible that children with cerebral palsy living in FNQ are simply not on the register.

The number of children with CP in North Queensland was low and the North Coast was high, but it is currently not known if these are natural variations between regions that will change over time or the result of one or more specific causes. Below are the same data in graphic form that more intuitively shows the variations.



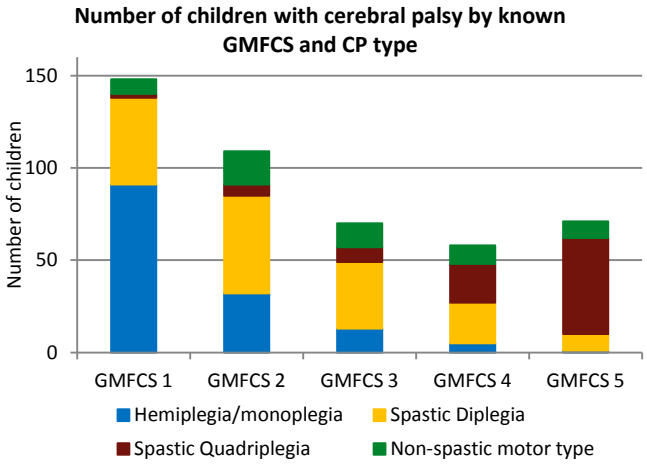
Function Vs CP type

The QCPR uses two classifications, the Gross Motor Function Classification System (GMFCS) and the CP type classification. CP type classifications are important for investigating causal pathways of cerebral palsy. Since aetiologies of different CP classifications are different, it is likely that causal pathways will be different and therefore prevention of those different pathways will be different.

It will remain important to have classification systems that distinguish and target prevention at different causal pathways but CP type classifications are poor at predicting the ability or needs of a person with CP.

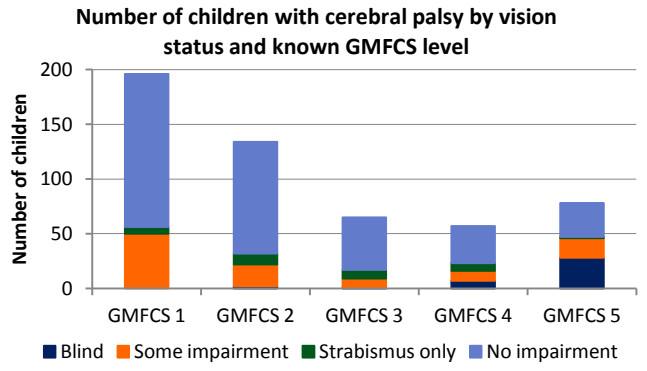
For description and prediction of motor ability we use the GMFCS. It is a simple to use, reliable scale that, at least until 16 years old, predicts how well a person with CP will be able to move around, walk or use an aid such as a frame or wheelchair.

GMFCS Vs CP type classification



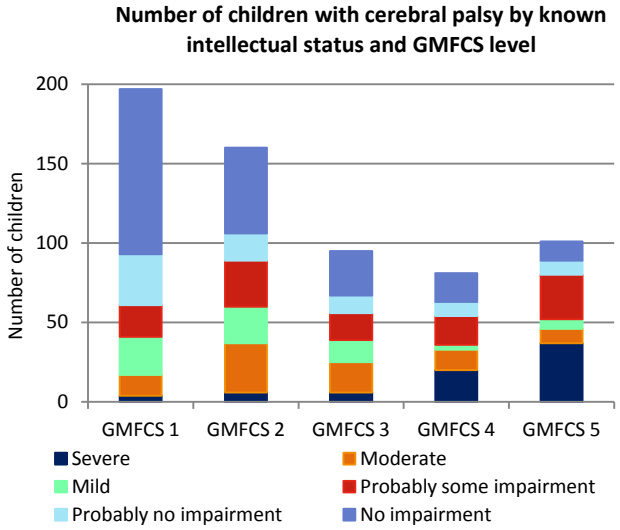
In general, children with hemiplegia/monoplegia and spastic diplegia have lower (better able) GMFCS levels but people with spastic quadriplegia have higher GMFCS levels. Non-spastic CP is evenly distributed.

GMFCS Vs Vision



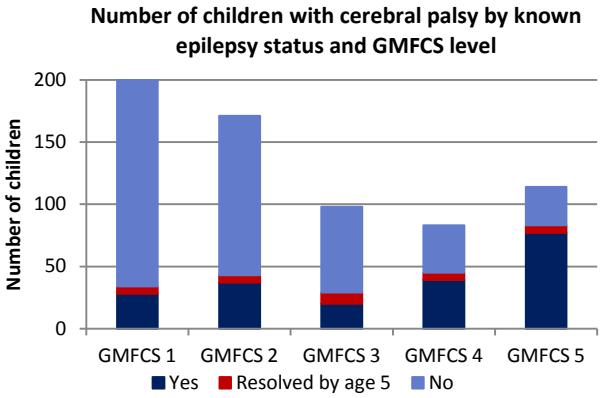
More than half of children with CP have a visual impairment of some sort and almost all children who were classified functionally blind were GMFCS level 5.

GMFCS Vs Intellectual Status



The percentage of people with some intellectual impairment increases with GMFCS level (31% GMFCS 1 to 79% GMFCS 5) and 78% of children with severe intellectual impairment are GMFCS level 4 or 5.

GMFCS Vs Epilepsy



Almost one third (30%) of all children with CP had active epilepsy at age 5 and 68% of children who were GMFCS level 5 had epilepsy at age 5.

Future plans

The QCPR are currently researching the geographical mobility of families, attempting to determine how often people move house and the reasons. We will compare them with the wider population to determine if there are specific reasons that children with cerebral palsy move houses. The first study will include people up to 20 years old.

We also plan to investigate how young adults with CP move around the community. We hope the study will help families plan for the future as their children approach adulthood.

If there are other questions you would like the QCPR to investigate, please let us know through the feedback form on our web site at http://www.qcpr.org.au.