Birth years 1996 to 2000, the story so far...

Welcome to the November 2011 update of the Queensland Cerebral Palsy Register (QCPR). Last year the QCPR reached enough registrants to provide a report on the characteristics of children with cerebral palsy born in 1996 [1]. Since that time, we have continued to collect more data for people with cerebral palsy in other birth years. We now have enough registrants to provide a preliminary summary of the characteristics of children born between 1996 and 2000, and to present this along with Queensland data from the 1996 birth year and Australian Cerebral Palsy Register (ACPR) data published for the 1993 to 2003 birth years [2].

It is important to remember that data reported below for the QCPR 1996-2000 birth years represents a preliminary analysis due to the incompleteness of current enrolment. At this time, 356 children with cerebral palsy who were born in Queensland during 1996-2000 have enrolled with the QCPR. This represents 70% of the total estimated number of children with cerebral palsy born in this period. The QCPR 1996 and ACPR 1993-2003 birth year groups have higher enrolment percentages and so provide more conclusive data.

Motor type and motor distribution

The type of cerebral palsy can be classified according to motor type and motor distribution:

Motor type refers to the different types of tonal changes:

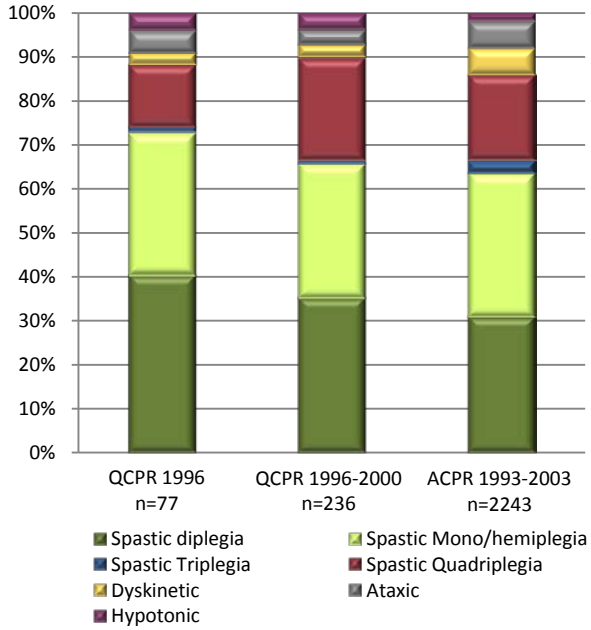
- *Spasticity* - tight muscle tone
- *Dyskinesia* - fluctuating muscle tone
- *Ataxia* - low muscle tone and poor coordination
- *Hypotonia* – low muscle tone with increased reflexes

Motor distribution refers to which limbs are involved:

- *Hemiplegia* – impacts one side of the body
- *Diplegia* – impacts legs more than arms
- *Triplegia* – impacts both legs and one arm
- *Quadriplegia* – impacts both legs and both arms

Across all three groups, 86-90% of children with cerebral palsy present with a spastic motor type. The numbers for dyskinesia (including dystonia and athetosis), are small at approximately 5% in each group. Each group also reported approximately 5% of children with an ataxic motor type and 3% with hypotonia.

Motor type and distribution of children in the QCPR 1996, QCPR 1996-2000 and ACPR 1993-2003 groups



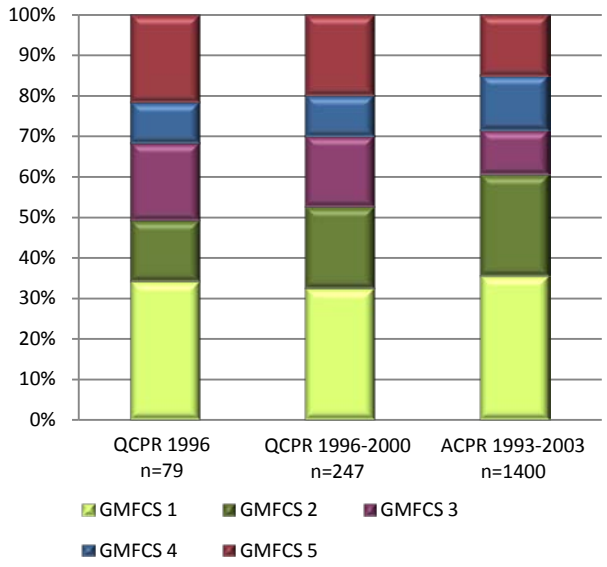
Gross motor function

The five-level Gross Motor Function Classification System (GMFCS) classifies general abilities and limitations in gross motor function for particular age groups. The broad definitions below are quoted from Palisano et al (2007) [3].

- **I** Walks without limitations
- **II** Walks with limitations
- **III** Walks using a hand-held mobility device
- **IV** Self-mobility with limitations; may use powered mobility
- **V** Transported in a manual wheelchair

To date, distribution of GMFCS levels appears similar across the three groups. Approximately 70% of children present with a GMFCS of I-III indicating the ability to walk, and approximately 30% with a GMFCS of IV-V, indicating a predominant use of wheeled mobility. Statistical comparisons will be possible when higher enrolment levels for the QCPR 1996-2000 are reached.

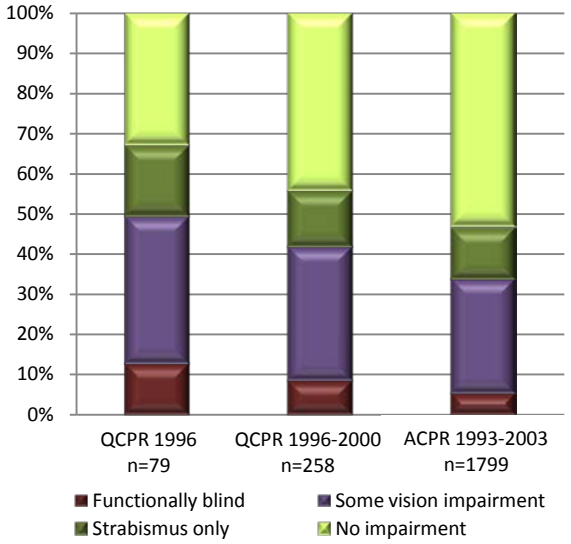
GMFCS levels of children with cerebral palsy in the QCPR 1996, QCPR 1996-2000 and ACPR 1993-2003 groups



Vision

From the 70% of children enrolled so far from the 5-year QCPR 1996-2000 group, data suggests that 33% of children have some degree of visual impairment, with the remaining majority having no vision impairment (40%) and a small number experiencing strabismus (14%). This pattern appears closer to that reported for the larger 10-year ACPR 1993-2003 group than the smaller 1-year QCPR 1996 group. Again, closer analysis will be possible when higher enrolment levels for the QCPR 1996-2000 group are reached.

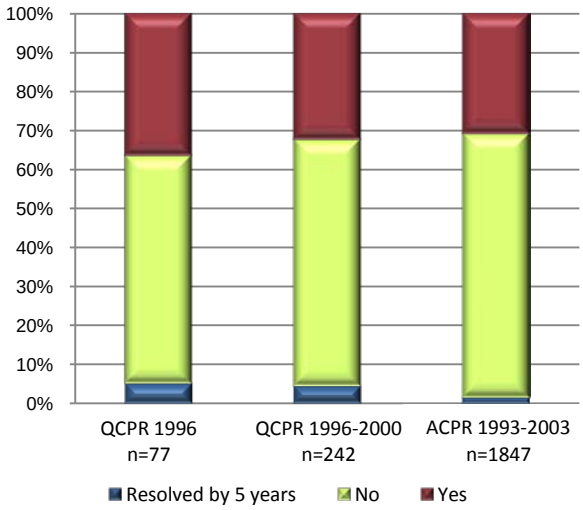
Vision status of children with cerebral palsy in the QCPR 1996, QCPR 1996-2000 and ACPR 1993-2003 groups



Epilepsy

So far, in the QCPR 1996-2000 group, parents have reported that 32% of children have epilepsy and just under 5% had their epilepsy resolved by their fifth birthday.

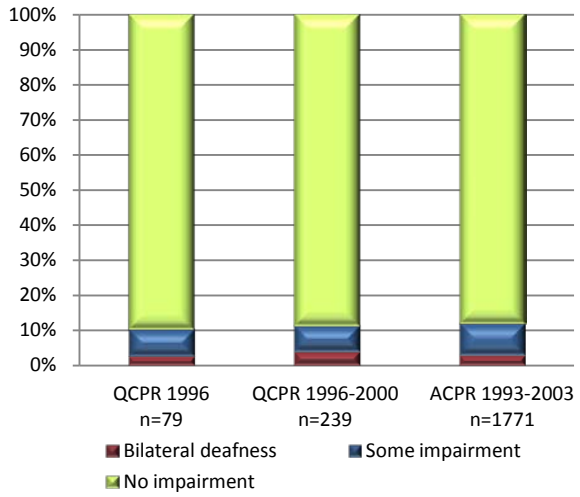
Epilepsy status of children with cerebral palsy in the QCPR 1996, QCPR 1996-2000 and ACPR 1993-2003 groups



Hearing

Across all three groups, it appears that almost 90% of children with cerebral palsy have no hearing impairment, with approximately 3% presenting with bilateral deafness.

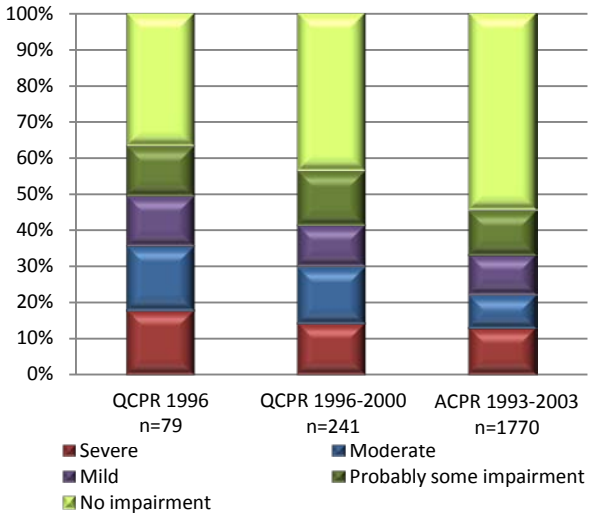
Hearing status of children with cerebral palsy in the QCPR 1996, QCPR 1996-2000 and ACPR 1993-2003 groups



Intellectual status

In the QCPR 1996-2000 group, 43% of parents reported that their child has no intellectual impairment. Of those children with suspected impairment, parents reported that approximately half have probably some or mild impairment (27%) and half have moderate or severe impairment (30%). Closer analysis will be possible with higher enrolment levels of the QCPR group.

Intellectual status of children with cerebral palsy for the QCPR 1996, QCPR 1996-2000, and ACPR 1993-2003 groups



Future plan

The QCPR would like to thank the individuals and families who have contributed their information to the quest for better understanding and outcomes for people with cerebral palsy. Please help us spread the word to others with cerebral palsy and their families: to enrol with the QCPR so that we can achieve our next milestone - a 10-year group report!

References

1. QCPR Group (2010) Queensland 1996 Birth Year Report.
2. ACPR Group (2009) Report of the Australian Cerebral Palsy Register, Birth Years 1993-2003.
3. Palisano R et al (2007) GMFCS – E & R: Gross Motor Function Classification System Expanded and Revised.