2018 Australian Cerebral Palsy Register Report Summary



What is the Australian Cerebral Palsy Register?

Cerebral palsy (CP) describes a group of disorders that affect body movement, muscle control, muscle coordination, muscle tone, reflex, posture and balance. Some people with CP also have other problems including epilepsy and/or difficulties with their speech, vision, hearing and intellect. These disorders are caused by an injury or problem with the developing brain. The Australian Cerebral Palsy Register is a research database that was established in 2008. It contains information about children and adults with cerebral palsy. Clinical information is provided by each of the state and territory CP registers to the Australian Cerebral Palsy Register every three years. This information (which does not include names of individual people) is used by researchers for many purposes:

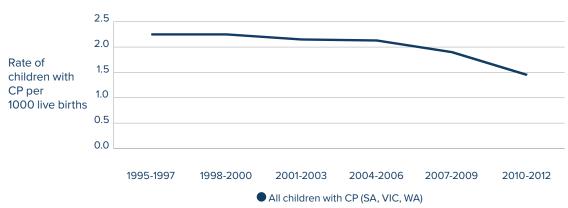
- to help service providers plan services for adults and children living with CP
- to evaluate the outcomes of new prevention strategies
- · to know how many people are living with CP
- · to understand the severity of disability and
- · to identify causes of CP.

Main findings, children born 1995-2012:

For 94% of the group, the injury that caused their CP occurred during pregnancy and/or around the time of birth. Amongst this group rates of CP declined by one-third:

- CP declined mostly amongst children born extremely early (20-27 weeks) and those born at term (37+ weeks)
- CP amongst twin born children declined
- · more children with CP were able to walk

In a smaller group of children (6%) their CP was caused by a brain injury that happened more than 28 days after birth and before 2 years of age (for example, due to stroke, infection, or an accident). Amongst this group the rate of CP declined. There were proportionally more Aboriginal and Torres Strait Islander children in this group. These children had more severe disability than other children with CP.



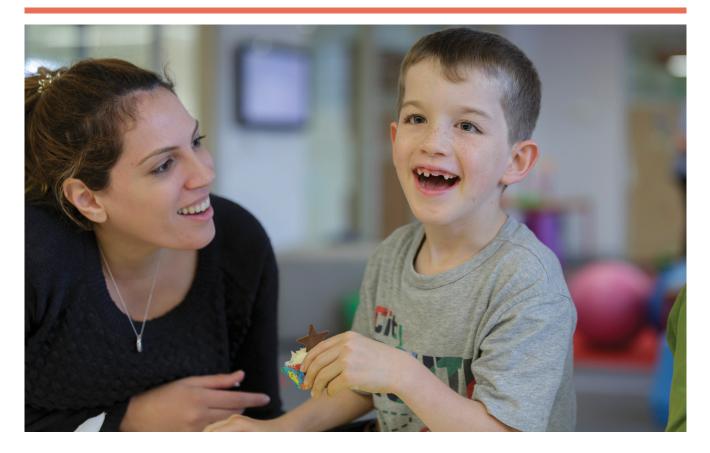
The decline in rates of CP reported here likely reflects advances in research and practice in all areas including:

- the health and care of pregnant women and their babies, particularly high risk pregnancies
- · neonatal intensive care and
- the impact of public health initiatives for healthy pregnancies and to prevent accidents.

Amidst this good news, it was also noted that at least a quarter of children with CP included in this report still had severe motor difficulties and used a wheelchair for mobility.

"This report tells us that we are on track, but there is still much to do and we must continue to invest in research" Professor Nadia Badawi AM

Currently in Australia it is estimated that there are more than 37,000 people living with CP.



The Australian Cerebral Palsy Register exists as the result of collaborative partnerships between all Australian state and territory CP registers and the organisations which support each register. The contributing registers and their organisations are as follows:

Cerebral Palsy Register	Custodian Organisation		Year the register commenced	Contact details
Australian Capital Territory/ New South Wales CP Registers	Cerebral Palsy Alliance Research Institute	Cerebral Palsy ALLIANCE RESEARCH INSTITUTE	2005	cpregister@cerebralpalsy.org.au
Northern Territory CP Register	Centre for Disease Control	NORTHERN TERRITORY GOVERNMENT	2008	natasha.murray@nt.gov.au
Queensland CP Register	CPL- Choice, Passion, Life and Queensland Health	choice • passion • life	2006	cpregister@cplqld.org.au
South Australian CP Register	Women's and Children's Health Network	Government of South Australia SA Health Hospital	1998	cpregister@sa.gov.au
Tasmanian CP Register	St Giles	Sigiles	2008	society@stgiles.org.au
Victorian CP Register	Murdoch Childrens Research Institute @ Royal Children's Hospital, Melbourne	murdoch children's research institute	1986	vic.cpregister@rch.org.au
Western Australian Register of Developmental Anomalies - CP	Department of Health WA	Western Australian Register of Developmental Anomalies	1977	linda.watson@health.wa.gov.au

A full copy of the Australian Cerebral Palsy Register Report is available at: https://www.cpregister.com

