WESTERN AUSTRALIAN REGISTER OF DEVELOPMENTAL ANOMALIES - CEREBRAL PALSY

WARDA-CP

FIELD NAMES, DESCRIPTIONS AND VALUES

INCLUDES
Birth year 1980 onwards
Cases born and/or living in WA at age 5 years
Cases under 5 years are unconfirmed

Variables held on CARES
August 2024

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Field Name: **cpnum**
Description: Unique identifier for WARDA-CP

Field Size: 4

Field Name: **stateborn**
Description: State/territory of birth

Field Size: 4

Possible values:
0 = Northern Territory
2 = NSW / ACT
3 = Victoria
4 = Queensland
5 = South Australia
6 = Western Australia
7 = Tasmania
8 = Overseas

Data Type: Derived

Field Name: **sex**
Description: Biological sex of case

Field Size: 1

Possible values:
M = Male
F = Female
Null = Unknown

Field Name: **bdob**
Description: Date of birth of case

Field Size: dd/mm/yyyy

Field Name: **bindig**
Description: Indigenous status of individual with CP

Field Size: 1

Values:

Indigenous
1 = Aboriginal but not Torres Strait Islander origin
2 = Torres Strait Islander but not Aboriginal origin
3 = Aboriginal and Torres Strait Islander origin

Non-indigenous
4 = Neither Aboriginal nor Torres Strait Islander origin

Null = Unknown / missing data

Notes: National Health Data Dictionary (p33)
Definition: A person of Aboriginal or Torres Strait Islander descent is one who identifies as such and is accepted as such by the community in which he or she lives. Three components are descent, self-identification and community acceptance.

Obtained from Hospital Morbidity Data, whereas mother's indigenous status (mindig) is obtained from Midwives data or record review (webPAS).

Field Name: **pcodebirth**
Description: Postcode for mother's usual address at time of delivery

Field Size: 4

Possible values: All WA postcodes
9990 = NT
9992 = NSW, ACT
9993 = Victoria
9994 = Queensland
9995 = SA
9996 = WA (postcode unknown)
9997 = Tasmania
9998 = Overseas

Field Name: **mdob**
Description: Mother's date of birth

Field Size: dd/mm/yyyy

Field Name: **mindig**
Description: Indigenous status of mother

Field Size: 1

Values: Indigenous
1 = Aboriginal but not Torres Strait Islander origin
2 = Torres Strait Islander but not Aboriginal origin
3 = Aboriginal and Torres Strait Islander origin

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Field Name: **cptypepredom1**
Description: Predominant CP type using classical terminology

Possible values: 1 Hemiplegia
2 Diplegia
3 Quadriplegia
4 Ataxia
5 Dyskinesia
6 Hypotonic CP

Data Type: Derived

Field Name: **cptypepredom2**
Description: Predominant CP type using classical terminology (finer categories)

Possible values
1 Right hemiplegia
2 Left hemiplegia
3 Diplegia
4 Triplegia
5 Quadriplegia
6 Ataxia
7 Athetosis
8 Dystonia
9 Hypotonic CP

Data Type: Derived

Field Name: **cpsev**
Description: Severity of CP at 5 years (historical classification)

Field Size: 1

Possible values:
1 = Minimal (motor signs present without functional impairment)
2 = Mild (symptoms result in some functional impairment)
3 = Moderate (between mild and severe, eg, ambulant with walking frame)
4 = Severe (little purposeful voluntary action though function may be acquired, IQ permitting

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Field Name: **gmf**
Description: *cpsev* regrouped into equivalent GMFCS levels:

Minimal/Mild = I-II
Moderate = III
Severe = IV-V

Data Type: Derived

Notes: Corrects difference between *cpsev* which codes motor severity of worst affected limb and GMFCS level which codes lower limb function.

See Appendix B for description of GMFCS levels

Field Name: **synd**
Description: Presence of syndrome or condition that co-exists with motor disability, or syndrome having a motor component that meets the definition of CP

Field Size: 1

Possible values:
0 = No syndrome (all other syndrome fields null)
1 = Syndrome that includes motor disorder (App B* in reference below)
2 = Syndrome that produces secondary motor disorder (App C* in reference below)
3 = Syndrome possibly related to CP
4 = Syndrome unrelated to CP
8 = Syndrome suspected, not identified

Notes: *See Appendix S1 in Smithers-Sheedy et al, What constitutes cerebral palsy in the 21st century? Devel Med Child Neurol 2014; 56:323-32.

Field Name: **syndcodesys**
Description: Coding system used to code co-existing syndrome

Field Size: 1

Possible values: 1 = OMIM (Online Mendelian Inheritance in Man)
2 = ICD10 (WHO International Classification of Diseases 2007)
8 = Syndrome suspected, not identified
Null if synd = 0

Field Name: **syndcode**
Description: OMIM or ICD10 code for co-existing syndrome or condition

Field Size: 6

Possible values: OMIM or ICD10 code
Null if synd = 0

Field Name: **syndtext**
Description: Text description of co-existing syndrome or condition

Field Size: 255

Field Name: **pnncause**
Description: Definite postneonatal cause of CP (after 28 days and before fifth birthday)

Field Size: 1

Possible values: 0 = Pre/perinatal cause
1 = Definite postneonatal cause occurring before age 2yrs
(includes neonatal injury in an undisputedly normal infant *)
2 = Definite postneonatal cause occurring at >=2yrs but < 5yrs

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Field Name: **kncause**
Description: Single cause of CP where known with certainty (ie, no doubt is expressed by any member of the medical team)

Field Size: 2

Values: **Pre/perinatal causes**
02 = Intrauterine CMV
03 = Other TORCH infection
08 = Other definite pre-/perinatal cause

Postneonatal causes
Infection:
21 = Dehydration due to gastroenteritis
22 = Other bacterial infection
23 = Other viral infection
28 = Infection nos

Cerebrovascular accident:
31 = Associated with surgery
32 = Associated with cardiac complications (not during/post surgery)
38 = Spontaneous / other CVA

Head injury
41 = MVA – Passenger in vehicle
42 = MVA – Pedestrian
43 = MVA – Unknown if passenger or pedestrian
44 = Non-accidental
45 = Fall
48 = Other head injury / nos

Other causal events:
51 = Near drowning
52 = Apparent life-threatening event (includes near-SIDS)
53 = Post-immunisation
54 = Post-seizure
55 = Peri-operative hypoxia
58 = Other postneonatal event

Neonatal causes
Note: Events occurring in the neonatal period are likely to be associated with the intrauterine environment and therefore coded as Pre-/Perinatal cause (**pnncause** = 0), with the exception of neonatal injury in an undisputedly normal infant (code **pnncause** = 1).

Notes: Coded only if known conclusively to be the sole and immediate cause of the CP, never for possible or contributing causes.

Field Name: **intellect**
Description: Intellectual ability (IQ or DQ)

Field Size: 1

Possible values:
0 = Normal / borderline (IQ/DQ >= 70 or so described)
2 = Mild impairment (IQ/DQ 50-69 or so described)
3 = Moderate impairment (IQ/DQ 35-49 or so described)
4 = Severe impairment (IQ/DQ < 35 or so described)
5 = Probably intellectually disabled (IQ/DQ < 70), severity uncertain
6 = Probably no impairment, or only borderline
Null = Unknown / missing data

Field Name: **iqgrp1**
Description: Intellectual ability grouped as
ID (IQ < 70)
No ID (IQ >= 70)

Field Name: **iqgrp2**
Description: Intellectual ability grouped by severity ranges:
Normal/borderline (IQ/DQ >= 70 or so described)
Mild ID (IQ/DQ 50-69 or so described)
Moderate ID (IQ/DQ 35-49 or so described)
Severe ID (IQ/DQ < 35 or so described)
Unknown

Field Name: **epilepsy**
Description: Epilepsy at 5 years defined as two or more afebrile seizures before age 5, not including neonatal seizures.

Field Size: 1

Possible values:
0 = None
1 = Resolved by age 5 years (seizure-free for two or more years without AEDs)
2 = Epilepsy
Null = Unknown / missing data

Field Name: **vision**
Description: Severity of visual impairment

Field Size: 1

Possible values: 0 = No impairment
2 = Some visual impairment (wears glasses)
3 = Functionally blind
Null = Unknown / missing data

Field Name: **strabismus**
Description: Presence of strabismus

Field Size: 1

Values: 0 = No strabismus
1 = Strabismus (includes surgically corrected)
Null = Unknown / missing data

Field Name: **hearing**
Description: Severity of hearing impairment

Field Size: 1

Possible values: 0 = No impairment
2 = Some impairment (includes conductive loss at 5y)
3 = Bilateral deafness
Null = Unknown / missing data

Field Name: **speech**
Description: Severity of speech delay / impairment

Field Size: 1

Possible values: 0 = No impairment
2 = Some impairment
3 = Non-verbal
Null = Unknown / missing data

Field Name: **dscore**
Description: Disability score as an estimate of overall disability.
Scores from 1 to 12:
Mild = 1-4
Moderate = 5-8
Severe = 9-12

Data Type: Derived from **cptype1, cpsev, epilepsy, intellect, vision, hearing**

See Appendix C

Field Name: **dod**
Description: Date of death of case

Field Size: dd/mm/yyyy

Possible values: Null = Case alive

Field Name:	**agedeath**
Description:	Age at death (months)
Field Size:	3

Field Name:	**deathcause1**
Description:	Primary cause of death
Field Size:	4
Possible values:	4-digit ICD10 alpha-numeric code 8888 = Not applicable (case alive) 9999 = Died, cause unknown
Notes:	See http://apps.who.int/classifications/apps/icd/icd10online/

Appendix A

Classification of Cerebral Palsy for the Australian Cerebral Palsy Register

Love S, Gibson N, Gubbay A, Blair E, Watson L

Cerebral palsy (CP) is a term that refers to a number of different movement disorders which, for the purposes of the Australian Cerebral Palsy Register (ACPR), are grouped into the following categories:

- Spastic CP is the most common type, occurring as the predominant CP type in about 80% of cases in Western Australia. It is characterised by increased muscle tone and is further classified according to the limb distribution of the hypertonia:

    - Spastic monoplegia, though rare, is the involvement of one limb only.
    - Spastic hemiplegia is the involvement of only one side of the body, usually more pronounced in the upper limb. Very minimal signs may also be present on the contralateral side.
    - Spastic diplegia means the lower limbs are more affected than the upper limbs. A significant difference in the amount of spasticity (at least 1 point difference as measured by the Modified Ashworth Scale) between the right and left lower limbs is referred to as asymmetric diplegia.
    - Spastic triplegia has been accepted as a separate category by the ACPR and is used to describe involvement of all four limbs but with the relative sparing of one upper limb, and spasticity in the other upper limb being greater than or equal to that in the lower limbs.
    - Spastic quadriplegia means that the upper limbs are equally or more affected than the lower limbs, regardless of any difference in the amount of spasticity between the right and left sides.

    In all types of spastic CP truncal tone will vary, and bulbar signs may or may not be present.

- Dyskinetic cerebral palsy has two forms:

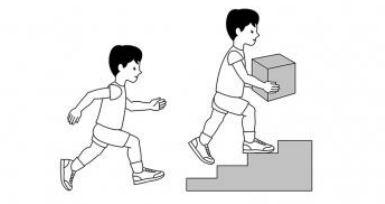
    - Athetoid cerebral palsy is characterised by increased activity with involuntary, unpredictable movements that may be present even at rest. Muscle tone tends to be decreased.

    - Dystonic cerebral palsy is characterised by reduced activity with fluctuating muscle tone, increased at times, depending on posture, mood and effort.

- Ataxic cerebral palsy is characterised by unsteady, wobbling movements or tremor, and problems with balance.

These motor disorders may occur singly or in combination. The presence of other conditions, such as impaired hearing or vision, epilepsy, intellectual disability or speech delay/impairment should be recorded separately and do not have a bearing on the classification of CP type.

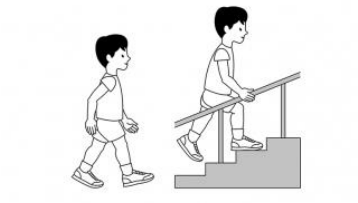
Gross Motor Function Classification System E&R between 6th and 12th birthday



GMFCS Level I

Walks without limitations

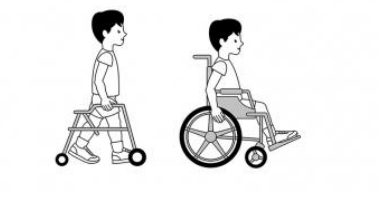
Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



GMFCS Level II

Walks with limitations

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



GMFCS Level III

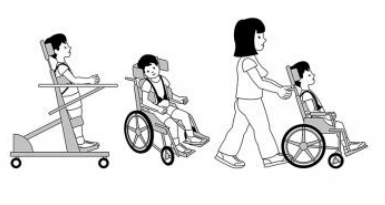
Walks using a hand-held mobility device

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

GMFCS Level IV

Self-mobility with limitations; may use powered mobility

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Transported in a manual wheelchair

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Appendix C

Disability score

In order to assess the combined impact on survival of several co-existing disabilities, an overall disability score was derived by summing the score assigned to each disability as follows:

Category of movement disorder:

Hemiplegia = 1, Diplegia = 2, Other = 3

Severity of movement disorder:

Minimal = 0, Mild = 1, Moderate = 2, Severe=3

Severity of cognitive deficit:

IQ 50-69 = 1, IQ 35-49 = 2, IQ<35 = 3

Other impairments:

Blind = 1, Bilateral deafness = 1; Current epilepsy = 1

Thus the maximum possible disability score is 12 and the minimum is 1 (minimal hemiplegia without other impairment). The most frequently occurring score was 4 (17.2%).

This scoring system entails assumptions, for example, that the disability conferred by being blind is equal to the disability conferred by increasing one category in IQ deficit or severity of movement disorder. However it has the advantage of simplicity and reflects therapists' perceptions of overall disability.

References

1. Blair E, Wallman A. Changing rates of severity of cerebral palsy and implications for practice. *Action Packed* 2000, 5(3): 18-20
2. Blair E. Life expectancy among people with cerebral palsy in Western Australia [letter]. *Developmental Medicine and Child Neurology* 2001; 43: 79