

The cost of cerebral palsy in Australia in 2018

Report prepared for Cerebral Palsy Australia, Cerebral Palsy Alliance, and The Australasian Academy of Cerebral Palsy and Developmental Medicine

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Glossary

Acronym	Full name
AAC	augmentative and alternative communication
ABODS	Australian Burden of Disease Study
ABS	Australian Bureau of Statistics
ACPR	Australian Cerebral Palsy Register
AGPSCC	Australian General Practice Statistics and Classification Centre
AIHW	Australian Institute of Health and Welfare
AWE	average weekly earnings
BEACH	Bettering the Evaluation and Care of Health
BFMF	Bimanual Fine Motor Function Classification System
BTOS	broad type of service
CFCS	Communication Function Classification System
DALY	disability adjusted life year
DES	Disability Employment Service
DSP	Disability Support Pension
DSS	Department of Social Services
EDACS	Eating and Drinking Ability Classification System
FCCS	Functional Communication Classification System
GMFCS	Gross Motor Function Classification System
GP	general practitioner
MACS	Manual Ability Classification System
MBS	Medicare Benefits Schedule
MRI	magnetic resonance imaging
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PBS	Pharmaceutical Benefits Scheme
SDAC	Survey of Disability, Ageing and Carers
SWS	Supported Wage System
WHO	World Health Organization
VSL(Y)	value of a statistical life (year)
VSS	Viking Speech Scale
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death

Foreword

In Australia, there are around 40,000 people living with cerebral palsy. This report by Deloitte Access Economics highlights the significant economic impact of the condition to Australia. It also demonstrates that a stronger focus on reducing the severity of this condition, or reducing its prevalence, would make a material difference for our economy and in the day-to-day lives of people with cerebral palsy and their families.

The introduction of the National Disability Insurance Scheme has made significant inroads into ensuring that people with cerebral palsy are receiving the right supports, and have more control over their life choices, but there is still much to be done for the Scheme to deliver on its promise to participants with cerebral palsy. In particular, for the Scheme to achieve its full potential, a deeper understanding of cerebral palsy and its unique impacts is required in policy and practice.

In 2018, a coalition of national cerebral palsy focused organisations, service providers, researchers, as well as people with cerebral palsy, started working together to develop Australia and New Zealand's first Cerebral Palsy Strategy with the overarching mission of improving the quality of life, health and inclusion for people with cerebral palsy through various initiatives.

As part of the Strategy, we felt it was important to understand the economic cost of cerebral palsy in Australia, and to build the case for how implementing the Strategy can reduce these costs.

The Deloitte Access Economics report on 'The cost of cerebral palsy in Australia in 2018' demonstrates the significant economic impact of cerebral palsy and underscores the need for greater investment in key priority areas such as healthcare, disability support, research and community awareness.

We believe increased, early investment in these areas is imperative, and will not only make a fundamental difference to individuals living with cerebral palsy, but will ultimately benefit the wider community socially and economically by minimising the impact of cerebral palsy and maximising the participation of people with cerebral palsy.

This report by Deloitte Access Economics helps us to understand where strategic investments can be made by policy makers to deliver profound improvements in the lives of Australians with cerebral palsy. These investments would create a step-change improvement in the social and economic participation of people with cerebral palsy, significantly reducing the overall economic cost of the condition.

Early intervention

- Making an investment in the early years of each child with cerebral palsy means that the level of impairment can be lessened (e.g. assessed functional impairment (based on Gross Motor Function Classification System) downgraded), with whole of life cost reduced significantly. Opportunities exist in relation to early diagnosis, and by accelerating the uptake of innovations in specialised disability and health services.
- Early onset of aging – clearly, as with any older Australians, investment in appropriate aged care support is fundamental. By better responding to the well documented early onset of aging experienced by many people with cerebral palsy, increased social and economic participation will be achieved throughout their life.

Improving access to health services

- Improved primary health interventions, and better-informed acute health services, will lead to substantially improved health outcomes for people with cerebral palsy. Interactions with the health system will reduce over time, and quality of life will be significantly enhanced, with a flow on to improved economic and social participation.

Prevention, cures

- Much exciting research has been initiated to identify the causes of cerebral palsy and reduce the number of people born with the condition. Some opportunities are also beginning to open up in relation to potential

cures based on certain causes. Boosting funding for this research would provide a real opportunity and fundamental change to the proportion of people born with this condition.

Accessibility

- Implicit in this report's analysis of the economic impact of cerebral palsy are the limiting factors of poor physical and communication access on the social and economic participation of people with cerebral palsy. Further investment in addressing these barriers is fundamental to reducing the economic impact of this condition.

Employment

- This report identifies productivity losses as a major factor contributing to the economic cost of cerebral palsy, particularly with regards to a reduction in workforce participation. Therefore, investing in the capacity of people with cerebral palsy, and addressing some of the unique barriers they face in finding work, provides a strategic opportunity to boost their economic and social participation.

Ultimately, by embracing the opportunities outlined above, the economic impact of cerebral palsy can be significantly reduced. This will be achieved off the back of improvements in the economic participation of people with cerebral palsy, together with lower health and support costs through the lifespan.

This report is an important part of our collaborative engagement with government, organisations and individuals to deliver the outcomes of the Australian and New Zealand Cerebral Palsy Strategy. It should be read as a companion piece to the Strategy.



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On behalf of the Australian and New Zealand Cerebral Palsy Strategy Collaboration

For more information and to access the Australian and New Zealand Cerebral Palsy Strategy:
www.cerebralpalsystrategy.com.au



Executive summary

Key findings

- There were estimated to be approximately 35,500 people living with cerebral palsy in Australia, or 0.14% of the population in 2018.
- Recent falls in the birth prevalence of cerebral palsy mean that this rate could reduce to 0.11% by 2060, if the recent falls in birth prevalence are maintained.
- The total cost of cerebral palsy in Australia in 2018 was \$5.17 billion, or \$145,642 per person with cerebral palsy in 2018.
- The total financial cost of cerebral palsy in Australia was estimated to be \$3.03 billion in 2018. Significant costs include lost productivity (\$1.29 billion), costs of disability support services (\$1.12 billion) and efficiency losses (\$553.59 million).
- The total cost of lost wellbeing on each person with cerebral palsy was \$2.15 billion, or \$60,458 per person with cerebral palsy in 2018.

Background

Cerebral palsy describes a group of disorders of movement and posture arising from non-progressive injury or maldevelopment of the developing brain in a baby or infant. Cerebral palsy is associated with a range of perinatal factors including congenital infections, preterm birth, intrauterine growth restriction, birth asphyxia and multiple pregnancy. In a small proportion of cases cerebral palsy is caused by illnesses or accidents in infancy.

As cerebral palsy is an umbrella term for a group of disorders, the experience of cerebral palsy is different for each person. Some people with cerebral palsy can walk with very few limitations, while others may require the use of a wheelchair for mobility. Some people may solely have a motor or posture disorder; however, many people will also have associated impairments of sensation, cognition, communication, vision, behaviour or seizures. There is no cure for cerebral palsy, it is a lifelong condition.

Prevalence

In this report, prevalence was estimated by combining historical data on incidence and mortality, with the number of live births in each year. In Australia, the best source of the incidence ("birth prevalence") of cerebral palsy is the Australia Cerebral Palsy Register, which draws together data from cerebral palsy registers from each state and territory. Up until the early 2000s, the incidence of cerebral palsy had remained relatively stable at 2.0-2.5/1,000 live births. Recent results from the Australian Cerebral Palsy Register show a decreasing trend in the incidence of cerebral palsy, to 1.9/1,000 live births (2007-09) to 1.4/1,000 live births (2010-2012).

Survival rates for people with cerebral palsy have improved significantly over the twentieth century, and most children with cerebral palsy now have an almost normal life expectancy, noting that the mortality rate for those aged under one year are significantly higher than for the general population. However, mortality rates for people with severe cerebral palsy are approximately 20 times higher than for those with mild cerebral palsy.

In 2018, there are estimated to be 35,522 Australians with cerebral palsy. Of this, approximately 60% are independently ambulant (Gross Motor Function Classification System (GMFCS) I-II)). The remaining 40% of people range from those who can walk with an assistive device (e.g. walking frame), through to those who require the use of a wheelchair for mobility (GMFCS III-V).

Costs of cerebral palsy

The total financial costs associated with cerebral palsy were estimated to be \$3.03 billion in 2018, which equates to \$85,184 per person with cerebral palsy. In addition to these, the lost wellbeing from cerebral palsy, calculated using disability adjusted life years (DALYs) and monetised using the value of a statistical life year

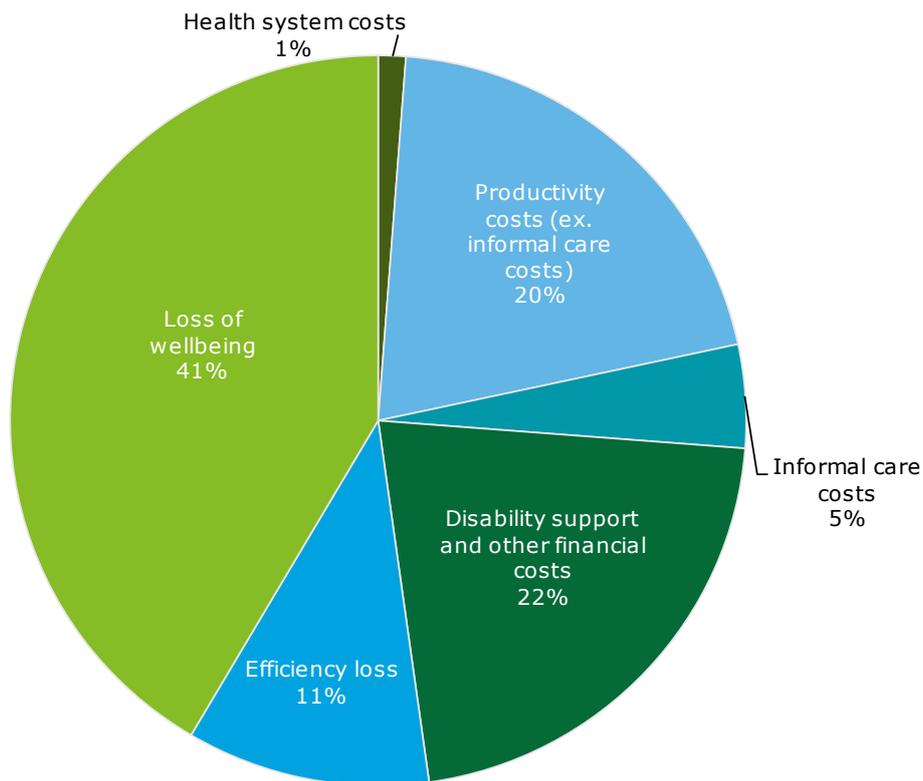
(VSLY), was \$2.15 billion in 2018, or \$60,458 per person with cerebral palsy. This equates to a total cost for cerebral palsy of \$5.17 billion in 2018. These proportions of total costs are shown in Chart i.

Productivity losses are the largest component of financial costs (\$1.29 billion), which includes short-term absences from work (“absenteeism”), reduced productivity while at work (“presenteeism”), reduced employment rates due to lower workforce participation, premature mortality, the opportunity cost of informal care provided by friends and family members, and other administrative overheads borne by employers.

The costs of disability support and service are also significant (National Disability Insurance Scheme (NDIS) being 18.5% of total costs and non-NDIS support costs being 3.1% of total costs). Disability support costs include items such as wheelchairs and other mobility devices, as well as multi-disciplinary services (e.g. physiotherapy, speech pathology), and the costs of managing other associated impairments. NDIS support is not typically provided to people with cerebral palsy in GMFCS I-II.¹

The lost wellbeing, a monetary value of the healthy life lost due to disability and premature death, represents 41.5% of costs.² While the experience of cerebral palsy is very different between individuals, across the entire prevalent cohort the weighted average disability weight has been calculated to be 0.23, which is roughly equivalent to the disability weight for moderately severe Parkinson’s disease. These costs associated with cerebral palsy are summarised in Table i.

Chart i Proportion of costs for cerebral palsy in 2018



Source: Deloitte Access Economics calculations

¹ Eligibility for the NDIS considers factors other than motor severity. Thus, a number of people with cerebral palsy in GMFCS level I – II may qualify, however this number is considered small enough to have minimal impact on calculations.

² The burden of disease methodology is non-financial, where life and health can be measured in terms of DALYs. Disability weights are assigned to various health states, where zero represents a year of perfect health and one represents death.

Table i Costs of cerebral palsy in 2018, per person and as a proportion

Age	Total cost (\$m)	Per person (\$)	Proportion (%)
Health system costs	62.42	1,757	1.2
Hospital costs	28.66	807	0.6
Out-of-hospital health costs	33.76	950	0.7
Productivity costs	1,293.63	36,417	25.0
Absenteeism	133.59	3,761	2.6
Presenteeism	315.59	8,884	6.1
Reduced employment rates	479.46	13,497	9.3
Premature mortality	128.57	3,619	2.5
Other productivity costs	0.06	2	0.0
Informal care costs	236.36	6,654	4.6
Disability support and other financial costs	1,669.88	47,009	32.3
NDIS	956.35	26,922	18.5
Non-NDIS (including aged care)	159.10	4,479	3.1
Efficiency losses	553.59	15,584	10.7
Funeral costs brought forward	0.85	24	0.0
Total financial costs	3,025.93	85,184	58.5
Loss of wellbeing (non-financial)	2,147.62	60,458	41.5
Total costs	5,173.56	145,642	100.0

Source: Deloitte Access Economics calculations. Note: totals may not add due to rounding.

Projections to 2060

The most recently reported incidence of 1.4/1,000 live births represents a significant decline from average levels of 2.0-2.5 that were experienced over the second half of the twentieth century. If these levels hold, by 2060 there will be approximately 46,000 people with cerebral palsy. Due to population growth, this represents a fall in the extrapolated prevalence rate from 0.14% in 2018, to 0.11% in 2060. Under this scenario, by 2060 the costs of cerebral are estimated to be \$6.81 billion (in 2018 dollars). Sensitivity testing identified the extrapolated prevalence rate and total cost under a "best case scenario" in 2060. If the incidence in 2018 was to fall to 1.0/1,000 live births, and this rate held to 2060, there would be an estimated 40,883 thousand people with cerebral palsy in 2060, and the total cost would be \$5.95 billion.

Deloitte Access Economics

1 Introduction

Deloitte Access Economics quantified the economic burden of cerebral palsy in Australia in 2018.

This 2019 report builds on Access Economics' previous work for Cerebral Palsy Australia in 2008, which estimated the cost of Cerebral Palsy in Australia in 2007. This report quantifies the 2018 cost of cerebral palsy in Australia with updated methodology, inputs and parameters.

This report has been structured in the following manner:

- **Chapter 2** discusses the approach taken to estimate the economic costs of cerebral palsy.
- **Chapter 3** presents extrapolated prevalence estimates for cerebral palsy in Australia in 2018.
- **Chapter 4** estimates the costs of cerebral palsy to the health system by type of cost, and by payer.
- **Chapter 5** discusses the productivity costs due to cerebral palsy.
- **Chapter 6** outlines disability support costs and other financial costs that arise from cerebral palsy.
- **Chapter 7** estimates the wellbeing loss due to cerebral palsy.
- **Chapter 8** summarises the total costs of cerebral palsy.

1.1 What is cerebral palsy?

Cerebral palsy refers to a group of movement and posture disorders arising from non-progressive disturbances to the developing brain (Rosenbaum et al. 2007). While there has been debate on the most appropriate definition for cerebral palsy, the Australian Cerebral Palsy Register (ACPR) has adopted the approach used by the Surveillance of Cerebral Palsy in Europe³ (ACPR Report 2018, 2018). This allows the use of any definition that is consistent with the five key elements as per publications by Bax (1964), Rosenbaum et al. (2007), Mutch et al. (1992) and Bax et al. (2005). By this definition, cerebral palsy is:

- an umbrella term for a group of disorders;
- a condition that is permanent but not unchanging;
- involves a disorder of movement and/or posture and of motor function;
- due to a non-progressive interference, lesion, or abnormality; and
- the interference, lesion, or abnormality originates in the immature brain.

The definition used in this report include these five key elements in line with the 2008 report produced by Access Economics. Here cerebral palsy is defined:

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.

1.2 Diagnosis of cerebral palsy

Diagnosis of cerebral palsy typically occurs between the ages of 12 and 24 months (Novak et al., 2017). However, recent advances have enabled experts to be able to identify infants at high risk of cerebral palsy at earlier ages. It is now possible for infants with newborn detectable risks (those that are born preterm, infants with neonatal encephalopathy, birth defects and infants admitted to a neonatal intensive care unit) to undergo early assessment as to determine their risk of cerebral palsy. The most accurate

³ The Surveillance of Cerebral Palsy in Europe is a study of cerebral palsy across six different European Union Countries.

measures of assessment are a combination of neuroimaging (via MRI) and as well as the General Movements Assessment (Novak et al., 2017). When used together these tests detect cerebral palsy with very high levels of accuracy.

There are two possible diagnostic pathways described based on age. This is because some tests like the General Movements assessment can only be used under 20 weeks corrected age, and about 50% of children with cerebral palsy do not have a "typical" clinical history of risk factors for cerebral palsy. It is suggested that any infant over the age of 5 months who has past the age for General Movements assessment should undergo testing for cerebral palsy if they have any of the following:

- an inability to sit independently by age 9 months;
- hand function asymmetry; or
- an inability to take weight through the heel and forefoot of the feet.

Magnetic resonance imaging (MRI) can establish well-defined lesions on the brain, although it may be unable to detect some lesions because of rapid growth or myelination. Further assessment to confirm a positive MRI scan or where motor function abnormalities persist despite an initial normal finding can include the Hammersmith Infant Neurological Examination as well as the Developmental Assessment of Young Children.

1.3 Types of cerebral palsy

Although the classification of cerebral palsy motor types can be complex and has been subject to debate among experts, traditional classification of cerebral palsy is based on the predominant motor type and the bodily distribution of motor impairment, accompanied by a description of associated impairments.

1.3.1 Types of cerebral palsy

The motor types of cerebral palsy are spasticity, dyskinesia, ataxia and hypotonia. A proportion of people with cerebral palsy also have a mixed presentation.

Spasticity

Spastic cerebral palsy is the most common motor type, comprising 85-91% of all cerebral palsy cases (ACPR Report 2018, 2018). Spasticity presents as a stiffness or tightness of muscles, with areas of the body affected having increased deep tendon reflexes, tremors, weakness and a characteristic gait patterns, often including toe walking (Kriger, 2006). In some cases, movement can become very difficult or even impossible. Spastic CP can be further described by the parts of the body impacted:

- **Hemiplegia** is the involvement of only one side of the body. The upper limb is usually more affected than the lower limb making fine motor activities and daily living activities particularly difficult.
- **Diplegia** describes the involvement of the lower limbs to a greater extent than the upper limbs.
- **Quadriplegia** describes the involvement of all four limbs, with arms equally or more affected than legs as well as the trunk.

Dyskinesia

Dyskinesia is reported for around for 4-7% of all cerebral palsy cases (Novak et al., 2017). This motor type includes both dystonic and athetoid forms of CP and is often found in conjunction with spasticity. Dystonia is categorised by involuntary movements, which are particularly present when the person attempts to move. Where the involuntary movements are slow and continuous, this is known as athetosis.

Ataxia and hypotonia

Both ataxia and hypotonia are frequently present alongside other motor types but are the least common sole/predominant motor types of cerebral palsy. Ataxia accounts for 4-6% of all cases and is characterised by problems with balance and depth perception, an unsteady wide-based gait, and poor coordination particularly when attempting fine motor activities (Novak et al., 2017). Hypotonia, particularly truncal hypotonia, is often found in persons with cerebral palsy, but isolated hypotonia

(diminished muscle tone without other signs of motor impairment that cannot be explained by cognitive impairment) accounts for only 1-2% of all cases.

1.3.2 Functional severity classifications of cerebral palsy

There are several methods for classifying the severity or functional limitations experienced by individuals with cerebral palsy. Examples are shown below, in Table 1.1. Other examples not included in Table 1.1. include the Viking Speech Scale (VSS), the Functional Communication Classification System (FCCS) and the Bimanual Fine Motor Function Classification System (BFMF)

The Gross Motor Function Classification System (GMFCS) in particular, has been widely adopted. In this report GMFCS levels have been grouped as I and II (I - II), and III, IV and V (III - V) to disaggregate costs and for the presentation of extrapolated prevalence estimates and costs.

Table 1.1 Examples of functional classifications of cerebral palsy

	Level I	Level II	Level III	Level IV	Level V
GMFCS*	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.	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.	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.	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.	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.
MACS	Handles objects easily and successfully	Handles most objects, but with somewhat reduced quality and/or speed of achievement	Handles objects with difficulty; needs help to prepare and/or modify activities	Handles a limited selection of easily managed objects in adapted situations	Does not handle objects and has severely limited ability to perform even simple actions
CFCS	Effective sender and receiver with unfamiliar and familiar partners	Effective but slower-paced sender and/or receiver with unfamiliar and familiar partners	Effective sender and receiver with familiar partners	Sometimes effective sender and receiver with familiar partners	Seldom effective sender and receiver even with familiar partners
EDACS	Eats and drinks safely and efficiently	Eats and drinks safely, but with some limitations to efficiency	Eats and drinks with some limitations to safety; there may be limitations to efficiency	Eats and drinks with significant limitations to safety	Unable to eat or drink safely – tube feeding may be considered to provide nutrition

Source: Palisano et al. (1997), Compagnone et al. (2014) *We have used the exact GMFCS definitional wording noting that many with cerebral palsy may no longer be children.

1.4 Risk factors

In discussing the risk factors for cerebral palsy, it is important to note that a risk factor is something that increases the chance that a child will develop cerebral palsy; however, this does not imply causation.

The causal pathways to cerebral palsy are complex and for the majority ($\approx 80\%$) of people, the exact cause or pathway that led to their cerebral palsy will remain unknown (Novak et al., 2017). For most ($\approx 95\%$) people, the brain injury or maldevelopment that led to their cerebral palsy occurred in the pre/perinatal period. There are many known biological pre/perinatal risk factors for cerebral palsy such as preterm birth, low birth weight, multiple birth, bacterial and viral intrauterine infections, intrauterine growth restriction, congenital anomalies, genetic variants, antepartum haemorrhages, perinatal stroke and kernicterus (Korzeniewski et al., 2018; Novak et al., 2017; MacLennan et al., 2015). Additionally, there are a number of known pre/perinatal environmental risk factors, for example low socioeconomic status, that are also important due to their potential to impact the health of both mother and developing baby (Korzeniewski et al., 2018; Woolfenden et al., 2019).

In high income countries like Australia, only a small proportion ($<5\%$) of cerebral palsy cases are caused by an injury, insult or illness in the post-neonatal period (after 28 days and prior to 2 years of age). Blair et al. (2016) identified that the distribution of post-neonatal causes of cerebral palsy have changed over the past 30 years with improved infection control and increased awareness of the need to protect infants from head injuries. Examples of these improvements include government supported vaccination programs, initiatives concerning the safety of infants around pools, playgrounds and vehicles.

1.5 Associated impairments

In addition to motor function limitations, many people with cerebral palsy will have other associated impairments. Associated impairments may impact the quality of life of the person and place additional strain on the family and the healthcare system. More severe limitations of motor function increase the risk of associated impairments including those listed below (Cerebral Palsy Alliance, 2018).

- **Intellectual impairment** - the person may experience difficulty understanding and interpreting the information that they receive. Potential impacts of this may include difficulty with attention span, learning, decision-making and problem solving. Intellectual impairment may result in the person experiencing other comorbidities such as anxiety, behavioural challenges and sleep disturbances. Generally, the greater the level of a person's physical impairment, the more likely it is that they will have an intellectual disability. However, there are people who have a profound level of physical impairment, who do not have an intellectual disability. Conversely, there can be others with a mild physical impairment who have an intellectual disability. Current data suggests that approximately 50% of people with CP will have some level of intellectual impairment.
- **Speech impairment** - can include articulation, fluency and voice disorders. People with CP can also experience language disorders i.e. difficulties in understanding or expressing language. Approximately 60% of people with CP will have speech impairment including almost 25% who will rely solely on non-verbal communication strategies.
- **Visual impairment** - can range from mild to functional blindness and may involve strabismus.⁴ Problems with eyesight may also be associated with behavioural issues, frustration or anxiety. Individuals with more severe forms of cerebral palsy are more likely than others to experience high myopia, absence of binocular fusion, and/or dyskinetic strabismus.
- **Hearing loss** - can range from mild impairment to bilateral deafness. Hearing loss can be caused by similar risk factors associated with cerebral palsy, such as infections, oxygen restriction to the brain and low birth weight. Approximately 10% of people with cerebral palsy will have some level of hearing impairment.
- **Epilepsy** - is a disorder of brain function that takes the form of recurring convulsive or non-convulsive seizures. Some types of epilepsy are as a direct result of the damage to the brain whereas others are not directly related. Epilepsy can present a significant barrier to a child's development and will often need prescribed medication to reduce its frequency and severity. Seizures can affect speech, intellectual functioning and physical functioning. Medication is the most effective intervention for epilepsy and the child's doctor, or therapist, may also recommend modifications to the student's school supports and equipment. Some medications have side effects which cause

⁴ Sometimes called "crossed eyes" in young children, this condition is the lack of coordination between the eyes, such as one or both eyes turning in, out, up or down.

drowsiness or irritability. Both epilepsy and the related medication can affect a person’s behaviour and attention span.

Other associated impairments include learning difficulties, pain, sleep issues, behavioural and emotional issues, spinal and hip abnormalities, saliva control issues and continence and constipation (Cerebral Palsy Alliance, 2018).

Table 1.2 Associated impairments of cerebral palsy

Impairment	Proportion of cerebral palsy population with impairment (2016, %)	Proportion of cerebral palsy population with impairment (2018, %)
Epilepsy	29	29
Intellectual	60*	46
Speech	61	63
Vision	34	35
Hearing	11	11

Source: ACPR Report 2016, and ACPR Report 2018. *includes “unconfirmed” impairment

1.6 Treatment and interventions

Cerebral palsy is a life-long condition with no cure. There are no specific treatments that can remediate the brain damage responsible for the complex clinical–functional dysfunctions typical of cerebral palsy. There are, however, many interventions that can be provided that are aimed at improving a person’s functional capabilities and quality of life. As with many disabilities, early diagnosis and intervention can improve outcomes and assist children in overcoming developmental disabilities (Kriger, 2006).

In recent years, there have been rapid increases in cerebral palsy rehabilitation and care delivery due to greater knowledge about effective treatments, and the progressive integration and accessibility of high-tech aids such as robots, assistive technology, adaptive equipment, virtual reality, exoskeletons, telemedicine and e-health (Novak et al., 2013). Assistive technology-based programs have been effective in promoting independence of children with cerebral palsy (Stasolla et al., 2018). Table 1.3 outlines types of therapy and treatment available for people with cerebral palsy.

Table 1.3 Interventions for cerebral palsy

Broad focus of intervention	Type of therapy and/or treatment
Rehabilitative interventions	<ul style="list-style-type: none"> ▪ Bimanual therapy ▪ Constraint-induced movement therapy ▪ Goal-directed training ▪ Occupational therapy ▪ Home programs for improving motor activity performance and/or self-care ▪ Robotic rehabilitation (for arm and leg training) ▪ Virtual reality rehabilitation
Spasticity management	<ul style="list-style-type: none"> ▪ Baclofen (oral format or intrathecal baclofen) ▪ Botulinum toxin ▪ Diazepam ▪ Selective dorsal rhizotomy ▪ Orthopaedic surgery ▪ Single-event multilevel surgery ▪ Hip surveillance for maintaining hip joint integrity ▪ Orthoses and casting
Other movement disorders management: dystonia	<ul style="list-style-type: none"> ▪ Anticholinergic medications (e.g., trihexiphenidyl) ▪ Tetrabenazine ▪ Benzodiazepines (e.g., diazepam) ▪ Baclofen ▪ Deep brain stimulation
Cognitive behaviour and social skills intervention	<ul style="list-style-type: none"> ▪ Behaviour therapy and coaching ▪ Cognitive behaviour therapy ▪ Communication training (alternative and augmentative communication) ▪ Parent training counselling
Comorbidities interventions	<ul style="list-style-type: none"> ▪ Management of epilepsy (antiepileptic medicines, vagus nerve stimulation) ▪ Nutritional management ▪ Reflux management ▪ Dysphagia management ▪ Fundoplication, ▪ Percutaneous endoscopic gastrostomy/jejunostomy ▪ Pain management ▪ Bone health management (bisphosphonate medication, vitamin D) ▪ Management of bladder dysfunction (urinary retention and incontinence) and bowel dysfunction (constipation and soiling) ▪ Management of respiratory complications ▪ Management of visual and hearing impairment
Environmental interventions	<ul style="list-style-type: none"> ▪ Assistive technology and assistive devices (eg, wheelchairs, robotics, and communication devices), ▪ Environmental control systems ▪ Home automation systems

Source: Trabacca et al. (2016)

1.7 Coordinated management

As discussed in Access Economics' (2007) report on the economic cost of cerebral palsy in 2007, cerebral palsy is a life-long condition and usually the weakness, stiffness or unwanted movements remain throughout the person's life. While cerebral palsy cannot be cured, treatment can improve a person's capabilities, allowing them to enjoy near-normal adult lives if their disabilities are properly managed. In general, the earlier treatment begins, the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them (Kriger, 2006).

There is no standard therapy that works for every individual with cerebral palsy. Health care professionals use tests and evaluation scales to determine a child's level of disability, and then make decisions about the types of treatments and the best timing and strategy for interventions. Once the diagnosis is made, and the type of cerebral palsy is determined, a team of health care professionals will work with a person

and his or her carers to identify specific impairments and needs, and then develop an appropriate plan to tackle the core disabilities that affect the person's quality of life.

A coordinated cerebral palsy management plan will combine the services of various health professionals as described below. In many instances, an intervention plan will involve the expertise of more than one health care professional.

- **Physicians:** This can include a paediatrician, paediatric neurologist, rehabilitation paediatrician/specialist who is trained to help developmentally disabled children. One of these individuals often acts as the leader of the treatment team, integrates the professional advice of all team members into a treatment plan and ensures the plan is implemented.

Physicians will consider the role of various medications in the management of the individual's movement disorder (e.g., spasticity or dystonia), and other associated conditions (e.g., seizures, pain, gastro-oesophageal reflux).

- **Physiotherapists:** Physiotherapists may design specific programs aimed at attaining and improving the functioning of muscles, mobility, and preventing deformities such as contractures from occurring. They may provide exercises and activities to work toward two important goals: preventing weakening or deterioration in the muscles that are not being used, and keeping muscles from becoming fixed in a rigid, abnormal position (contracture). Physiotherapists also help people work on their other motor and participation goals.
- **Occupational therapists:** design treatment programs focus on optimising upper body function, improving posture, and making the most of a person's abilities. They work to assist individuals to participate and gain skills in daily activities such as dressing, eating, toileting, playing, going to and engaging in school or work, and taking part in recreation and leisure activities.
- **Speech therapists:** (also known as speech-language therapists or speech-language pathologists) observe, diagnose, and treat the communication disorders associated with cerebral palsy. Their programs focus on teaching children how to overcome specific communication difficulties and / or prescribing communication systems known as augmentative and alternative communication (AAC) systems. These can range from low/light technology systems such as signing or use of alphabet charts to high technology systems or devices, such as speech generating devices (Kriger, 2006).

Speech therapists may also work with children with cerebral palsy who have difficulty eating and drinking, to assess their swallowing ability and make recommendations regarding diet or oral feeding modifications. In severe cases where swallowing problems are causing malnutrition, a doctor may recommend tube feeding, in which a tube delivers food and nutrients down the throat and into the stomach, or gastrostomy, in which a surgical opening allows a tube to be placed directly into the stomach (Taylor, 2001). Individuals with swallowing difficulties are also at risk for breathing food or fluid into the lungs, recurrent lung infections, and progressive lung disease. The individuals most at risk for these problems are those with spastic quadriplegia.

- **Surgeons:** Orthopaedic surgery is designed to lengthen contracted muscles, balance joint forces, transfer motor power, fuse unstable joints, correct bone deformity to improve biomechanical alignment, reduce joint subluxation and dislocation to improve joint congruency, diminish painful spasticity, and maintain, restore, or stabilise spinal deformity (Koman et al, 2004). Surgery is often recommended when spasticity and stiffness are severe enough to make walking and moving about difficult or painful. For many people with cerebral palsy, improving the appearance of how they walk – their gait – is also important. A more upright gait with smoother transitions and foot placements is the primary goal for many children and young adults (Taylor, 2001).
- **Social workers:** Help individuals and their families locate community services, resources and programs. They may also be involved in supporting coordinated care advocating for resources to support the individual and family.
- **Psychologists:** Help individuals and their families cope with the special stresses and demands of cerebral palsy. In some cases, psychologists may also oversee therapy to modify unhelpful or destructive behaviours.
- **Educators:** Play an especially important role when intellectual or learning disabilities present a challenge to education.

- **Pharmacists:** Provide a review of past and current pharmacological interventions, as well as education of the person regarding appropriate use of pharmacological interventions.
- **Orthotists:** Prescribe and manufacture braces and other orthotic devices to compensate for muscle imbalance, improve posture and walking and increase independent mobility.
- **Equipment specialists:** Physiotherapists, occupational therapists, orthotists and engineers may be involved in prescribing and/or designing mechanical aids such as wheelchairs, rolling walkers, standing frames, specialist seating and other equipment for individuals who require support for mobility or posture.

2 Estimating the costs of cerebral palsy

This section describes the approach taken to estimate the costs of cerebral palsy in Australia, and outlines some of the key economic terms, how costs are borne by members of society, and some of the underlying methodology presented throughout the following chapters.

Specific methodologies for each of the costs associated with cerebral palsy are outlined further in the chapter where they are discussed. The costs of cerebral palsy in Australia were estimated for the year 2018, categorised into broad types of costs as outlined below.

- **Financial costs to the Australian health system** include the costs of running hospitals, general practitioners (GPs) and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals and of over-the-counter medications, allied health services, research and other financial costs (such as health administration).
- **Productivity costs** include reduced workforce participation, more days absent from work, reduced productivity at work, loss of future earnings due to premature mortality, and the value of informal care (lost income of carers).
- **Disability support costs and other financial costs** are comprised of the cost of disability support services, such as the NDIS, efficiency losses⁵, or reduced economic efficiency, associated with the need to raise additional taxation to fund provision of government services and the brought forward funeral costs due to premature mortality.
- **Wellbeing costs** arise from the pain, suffering and premature death that result from cerebral palsy, measured in terms of the years of life (or healthy life) lost using the wellbeing loss methodology.

Different costs of disease are borne by different individuals or sectors of society. Understanding how the costs are shared helps to make informed decisions regarding interventions. While people with cerebral palsy are most severely affected by the condition, other family members and society also face costs as a result of the condition.

From the employer's perspective, depending on the impact of cerebral palsy, work loss or absenteeism will lead to costs such as higher wages (that is, accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring and retraining due to premature mortality.

Australian governments typically bear costs associated with the health system and other services such as disability programs (noting there are also out of pocket expenditures and other payers), although in reality taxpayers (society) pay for these services through taxes. The analysis in this report shows the first-round impacts on government and employers. No second round or longer-term dynamic impacts are modelled (i.e. changes in wages or labour market outcomes associated with the economic burden of cerebral palsy).

Any future costs ascribed to Australians with cerebral palsy in 2018 were estimated in net present value terms to reflect the value of utility today rather than in the future. Taking inflation, risk and positive time preference into consideration, a real discount rate of 3% is traditionally used in discounting healthy life and is used in discounting other cost streams in this report, for consistency.

⁵ Commonly referred to as a deadweight loss

3 Epidemiology of cerebral palsy

This chapter discusses the incidence and mortality from cerebral palsy, estimates the extrapolated prevalence of cerebral palsy in 2018, and projects the extrapolated prevalence of cerebral palsy to 2060.

Key findings

- The most recent results (2010-2012) from the Australian Cerebral Palsy Register show that the incidence of cerebral palsy has fallen significantly to 1.4/1,000 live births, down from an average of 2.00-2.50/1,000 live births over the past two decades. Mortality rates have remained relatively stable.
- In 2018, there are estimated to be 35,522 people in Australia living with cerebral palsy. Of these:
 - 58% are GMFCS Level I - II
 - 42% are GMFCS Level III - V
- In 2018, it was estimated that cerebral palsy will be the primary cause in 116 deaths.
- If the current incidence and mortality rates remain constant, it was estimated that 46,790 people will have cerebral palsy in 2060. This represents a prevalence rate of 0.11%, down from 0.14%.

Cerebral palsy is the most common physical disability in childhood (Rosenbaum et al., 2007). In Australia, cerebral palsy registers collect data on the incidence of cerebral palsy, however there are no population level data collected on the prevalence of cerebral palsy.⁶ As such, for this report the estimate of extrapolated prevalence of cerebral palsy was built using the bottom up approach with incidence rates (to calculate the number of new entrants to the prevalent cohort) and mortality rates (to calculate the number of exits from the prevalent cohort).

3.1 Incidence rates

The best source on the incidence of cerebral palsy in Australia is the ACPR, which is a collection of birth registers from each state and territory. The ACPR was established in 2008 as a research database to facilitate the study of the distribution, frequency and severity of cerebral palsy; the causes and determinants of cerebral palsy; the effectiveness of prevention strategies; and to help plan and evaluate services.

As discussed above, the ACPR has adopted the definitional approach used by Surveillance of Cerebral Palsy in Europe Group. This approach accepts any definition of cerebral palsy that includes the following five key elements common to the definitions published by Bax (1964), Rosenbaum et al. (2007) and Mutch et al. (1992) that cerebral palsy:

- is an umbrella term for a group of disorders;
- is a condition that is permanent but not unchanging;
- involves a disorder of movement and/or posture and of motor function;
- is caused by a non-progressive interference, lesion, or abnormality; and
- the interference, lesion, or abnormality originates in the immature brain.

In Australia these inclusion criteria for cerebral palsy must be met at five years of age to be included in the cerebral palsy registers. The APCR data currently reports data from 1993 onwards. Whilst all state

⁶ The ABS National Health Survey does not identify cerebral palsy as a separate condition.

and territory cerebral palsy registers contribute data to the ACPR, three long-standing registers from South Australia, Victoria and Western Australia are considered to provide a complete record of all cases of cerebral palsy, and so these registers have been used to estimate incidence (more commonly referred to as 'birth prevalence' in cerebral palsy epidemiology, as an unknown number of children die before their cerebral palsy is recognised).

Up until the early 2000s, the incidence of cerebral palsy had remained relatively stable at 2.00-2.50/1,000 live births. However, recent results from the ACPR show a decreasing trend in the incidence of cerebral palsy, to 1.90/1,000 live births from the 2007-09 birth cohort, and then 1.40/1,000 live births from the 2010-2012 birth cohort.

To estimate extrapolated prevalence, the year 1918 was chosen as the first year to model from. Using 1918 as the first year ensures that everyone who was born with cerebral palsy in the past 100 years has been captured in the estimate, as most people born in or before 1918 who have cerebral palsy are unlikely to be alive today.

1918 to 1944

For this period, a conservative estimate of 1.98/1,000 live births was used in the calculations, based on the lower bound historical trend reported and the simple average of the historical data from registers in Western Australia, South Australia and Victoria. As most people born in 1918 who have cerebral palsy are unlikely to be alive today, the impact of this estimated incidence rate has a smaller effect on the estimated extrapolated prevalence in 2018, compared to more accurate estimates from the ACPR for more recent births.

1944 to 1992

For this period, an incidence rate of 2.25/1,000 live births was used. This is the midpoint between 2.00 and 2.50, which is the general consensus on the incidence of cerebral palsy over this period (Blair & Watson, 2006). This rate had remained relatively stable for 60 years (Reddihough & Collins, 2003) and was therefore held steady until 1992.

1993 onwards

Data provided to the ACPR by the three long-standing registers from South Australia (established in 1998), Victoria (1980) and Western Australia (1979) have been used. These jurisdictions have complete ascertainment for birth years 1993-2012 and are believed to have registered all eligible children in their respective jurisdictions. For this reason, data from these cerebral palsy registers were selected for calculations pertaining to rates of cerebral palsy. Data from the remaining jurisdictions were not yet fully ascertained for all birth years 1993-2012 at the time of writing and were therefore not included in calculations.

Table 3.1 shows the incidence rates used in the calculations for estimating the 2018 extrapolated prevalence. Data on live births in each period were sourced from the Australian Bureau of Statistics (ABS) Australian Historical Population Statistics (2014) and ABS Population projections 2012 to 2101 (2013).

Table 3.1 Summary of incidence rates used in extrapolated prevalence estimates

	1918-45	1945-92	1993-94	1995-97	1998-00	2001-03	2004-06	2007-09	2010 +
Incidence rate	1.98	2.25	2.10	2.20	2.30	2.10	2.10	1.90	1.40 ⁷

Source: ACPR Report 2016 (2016), ACPR Report 2018 (2018), Blair et al. (2001), Reddihough and Collins (2003).

Although cerebral palsy is found across all socioeconomic groups, there is a clear association between cerebral palsy and socioeconomic status. This correlation is partly due to low birthweight being associated with low socioeconomic status and cerebral palsy being strongly associated with low birthweight. However, even within the normal birthweight ranges, rates of cerebral palsy are 2.42 per 1,000 live births for those in the lowest socioeconomic groups compared to 1.29 per 1,000 for the most affluent groups (ACPR, 2013).

3.2 Mortality rates

By the mid-twentieth century, it is reported that survival rates of people with cerebral palsy had improved considerably (Emond et al., 1989). As highlighted in the 2008 report by Access Economics, improvements in survival rates can be attributed to changes in various medical and social factors, such as improved intensive care procedures, the use of antibiotics, greater integration into the community, and a better responsiveness to the rights of people with disabilities (Cerebral Palsy Australia, 2005).

Children with cerebral palsy now have an almost normal life expectancy, with mortality due to cerebral palsy being very low (Trabacca et al., 2016). Despite the overall low mortality rate, a larger proportion of people born with cerebral palsy do not survive into childhood when compared to those born without the condition, especially when severe motor disability is comorbid with another disability.

However, while there have been significant improvements over the first half of the twentieth century, recent Australian based studies have been able to show little to no improvements in survival rates since that time. One reason mortality rates have shown little to no improvement, is improved neonatal care enabling the survival of infants with increasingly severe disabilities that would have otherwise not survived birth (Blair, 2001). These infants, due to their severe disabilities, have higher mortality rates later in childhood and later in life, when compared to those with lower severities of disability. It is suggested that the survival of more people born with severe levels of cerebral palsy is offsetting the improved mortality rates for those with milder forms of cerebral palsy.

Hutton (2006) measured the survival rates of children with severe cerebral palsy. This study estimated that children with cerebral palsy had only a 50% chance of surviving to 13 years and a 25% probability of surviving to 30 years. Hutton's (2006) analysis into life expectancy in severe cerebral palsy classified four types of functional disability: cognitive, motor, vision and hearing. It was found that severe disability in any of these categories lead to significantly lower survival prognosis in comparison to those not severely disabled. A significant indicator of the child's likely prognosis was the ability to operate their wheelchair manually, with those children who were unable to, having significantly higher mortality rates.

Looking at recent studies using Australian based registry data, a number of observations are noted. Reid et al. (2012) was a study of 3,507 individuals with cerebral palsy, which recorded 418 deaths of individuals born with cerebral palsy in Victoria, Australia between 1970 and 2004. This study found that:

- Mortality was highest in children aged under 15 years but decreased to twice the population rate in the 35- to 40-year age group.
- Respiratory causes were the most common direct causes of death.
- The strongest independent predictor of mortality was no independent ambulation, with additional predictors being severe intellectual impairment, epilepsy, deafness and term birth.

It is noted that similar predictors were found by Blair et al. (2001) where it was observed that mortality of people with cerebral palsy is highest for those who have severe physical impairments impeding

⁷ The rate of 1.4 per 1,000 live births is from the APCR Report 2018 (2010 – 2012 data) and held constant for projections out to 2060.

mobility and feeding in combination with intellectual disability. Blair et al. (2001) and Reid et al. (2012) note that there has been no improvement in survival over the periods observed in their studies.

The results of Reid et al. (2012) showed that there was no statistically significant change in mortality rates over the past several decade. However, the mortality rate of cerebral palsy does differ significantly by age.

- The mortality rate from cerebral palsy in the first year of life is highest, at 0.83%.
- Between the ages of 1 and 40 years old, the mortality rate of cerebral palsy is estimated to be 0.58%.
- No data were available on mortality rates from cerebral palsy over 40 years of age. As such, for this age group, the general population mortality rate for those over the age of 40 years of 0.68% from the Australian Bureau of Statistics (ABS) (2017) was used.

While these rates were used to calculate the extrapolated prevalence of cerebral palsy, it is important to note that not all people with cerebral palsy die because of their condition. The relative risk of mortality for people with cerebral palsy in 2018 was calculated by netting mortality rates for people with cerebral palsy and the mortality rates for the general population. This provides the additional risk of death in different age brackets due to cerebral palsy. Using this relative risk of mortality, **it has been estimated that 116 people died specifically due to cerebral palsy in 2018**. However, in total there were estimated to be 258 people with cerebral palsy who died in 2018. This number is higher than the number of deaths due to cerebral palsy, as a person with cerebral palsy can die from some other factor unrelated to their condition.

3.3 Extrapolated prevalence of cerebral palsy in 2018

To calculate extrapolated prevalence, the bottom-up approach was used. This uses historical incidence rates (as above) to calculate the number of new entrants to the prevalent cohort and historical mortality rates (as above) to calculate the number of exits from the prevalent cohort each year from 1918. Using the historical incidence and mortality data for people with cerebral palsy, the sum of this becomes the extrapolated prevalence for 2018.

In 2018, the extrapolated prevalence of cerebral palsy was estimated to be 35,522 people.

Table 3.2 shows the estimated number of people with cerebral palsy in each age-gender group.

Table 3.2 Extrapolated prevalence of cerebral palsy in 2018, by age and gender

Age	Males	Females	Total
0-4	1,191	1,133	2,324
5-9	1,166	1,108	2,274
10-14	1,112	1,055	2,167
15-19	1,088	1,040	2,128
20-24	1,218	1,169	2,387
25-29	1,313	1,291	2,603
30-34	1,342	1,332	2,674
35-39	1,254	1,248	2,501
40-44	1,150	1,161	2,311
45-49	1,194	1,219	2,413
50-54	1,078	1,104	2,182
55-59	1,069	1,106	2,175
60-64	945	987	1,931
65-69	821	861	1,681
70-74	689	730	1,418
75-79	462	512	974
80-84	299	372	671
85+	265	442	707
Total	17,655	17,867	35,522

Source: Deloitte Access Economics calculations. Note: totals may not add due to rounding.

As can be seen in Table 3.2, the extrapolated prevalence of cerebral palsy was estimated to be highest in the 30-34 age category for males and females, which is consistent with underlying population demographics. As a percentage of the total population, the **extrapolated prevalence rate of cerebral palsy was estimated to be 0.14%**.

The 2007 report by Access Economics estimated the prevalence of cerebral palsy in 2007 to be 33,797, which was projected to increase to 37,874 in 2018. For the current report, the estimated extrapolated prevalence for 2018 was 35,522. Compared to the estimate made in 2007 for 2018, the prevalence of cerebral palsy has decreased by approximately two thousand people. This change was due to:

- **Lower incidence rates:** The most recent incidence rates have shown that after a long period of stable incidence at around 2-2.5 per 1000 live births, the rate of cerebral palsy per 1,000 live births has declined. The decline has seen rates fall to around 1.9 cases per 1,000 live births from 2007-2009, and 1.4 cases per 1,000 live births from 2010-2012. This recent decline has been reflected in recent Australian studies such as Galea et al. (2018).
- **Fewer births:** recent data from the ABS have shown a slowdown in the rate of increases in live births, compared to projections that were used in the 2007 calculations.

The 2018 estimates also relied on more recent data from Reid et al. (2012), compared to the 2007 estimates which used data from Blair et al. (2001). These data from Reid et al. (2012) show a slightly improved mortality rate (0.582% for ages 1-40, compared to 0.596% used in the 2008 report, from the Blair paper). However, this improvement in mortality rates (which has the effect of increasing the prevalence) was not sufficient to reverse the effect of the lower incidence rates.

3.4 Extrapolated prevalence of cerebral palsy by GMFCS levels

The extrapolated prevalence of cerebral palsy in 2018 was estimated for each of the GMFCS levels. As explained in Section 1.3.2, this system is commonly used to classify the severity of mobility restrictions from lowest (Level I) to highest (Level V).

Estimating the extrapolated prevalence of each GMFCS level was undertaken using the same method as per the overall extrapolated prevalence estimates, with severity-specific estimates for incidence and mortality used. Consistent with the overall approach, incidence rates for each severity level were varied historically, with mortality rates for each severity level held constant.

3.4.1 Incidence rates

The ACPR data provides historical estimates of incidence rates for two groups: GMFCS I – II and GMFCS III – V, for both Victoria and Western Australia. These registers are seen to be the most complete and accurate for capturing incidence rates for different GMFCS levels at this time. These data provide incidence estimates for three-year periods over 1995 to 2012.

As data on incidence by severity is only available from 1995 onwards, the incidence used in calculating overall prevalence in Section 3.3 was used for the years prior to 1995. Data published on characteristics of the sample used by Blair et al. (2001) on severity of motor impairment was used to weight and estimate overall incidence, to incidence by GMFCS level for pre-1995.

To calculate the number of people born with cerebral palsy at different GMFCS levels from 1995 onwards, the incidence by severity (GMFCS I-II and GMFCS III-V) provided by the ACPR was weighted by the populations of Victoria and Western Australia. The two levels of severity by motor impairment provided by ACPR were then categorised to each of the GMFCS levels based on the proportions of levels of severity published in the ACPR report (2016).

3.4.2 Mortality rates

As with the calculations to estimate overall extrapolated prevalence for 2018, specific mortality rates were applied to each of the five GMFCS levels. Unpublished mortality rate data were provided⁸ on the cohort of 3,507 people in the study undertaken by Reid et al. (2012). These mortality rates were based on three levels of motor impairment: mild, moderate and severe. These three levels of severity by motor impairment were categorised to each GMFCS level based on published methodology (Reid et al., 2012), with GMFCS I and II considered mild, GMFCS III considered moderate, and GMFCS IV and V considered severe. Mortality rates at each level of severity were held constant over the period of analysis.⁹

3.4.3 Results

Applying the GMFCS specific incident and mortality rates discussed above from 1918 to 2018, the extrapolated prevalence in 2018 for each grouped GMFCS level are:

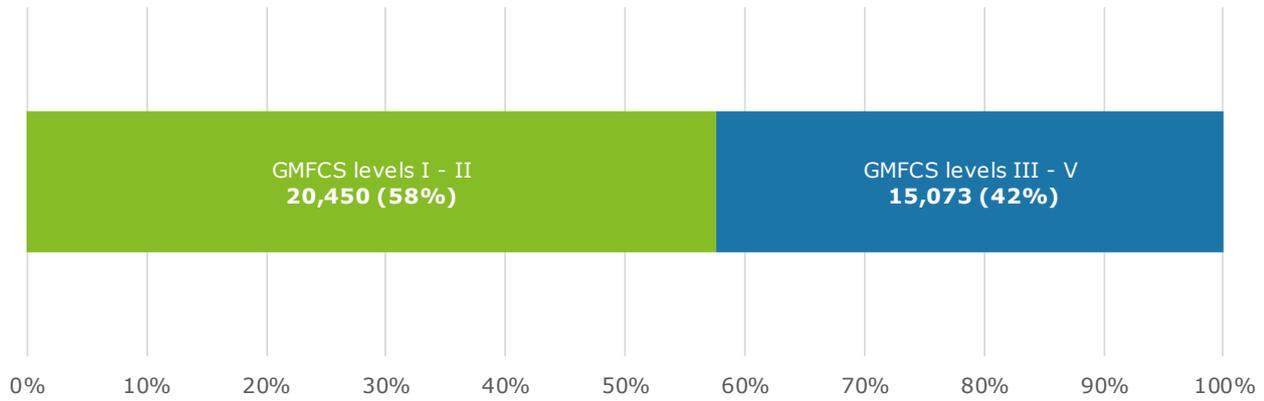
- **20,450** people in GMFCS level I – II
- **15,073** people in GMFCS level III – V.

Over half (58%) of all people with cerebral palsy in 2018 are in grouped GMFCS levels I – II, meaning over half of those with cerebral palsy are able to walk indoors and outdoors with a railing, and at least a minimal ability to run or jump (Cerebral Palsy Alliance, 2018). However, this group may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces (specifically those in GMFCS level II). Physical assistance may also be used to walk by people in GMFCS level II, such as a handheld mobility device or use of a wheeled mobility device over long distance. The distribution of extrapolated prevalence by grouped severity is shown below in Chart 3.1.

⁸ Personal communication with Dr Sue Reid, 02 October 2018.

⁹ Reid et al. (2012) found no improvements in mortality rate overtime, however international examples have shown a mixed picture, with some improvements in mortality for severe cases recorded, albeit with limited statistical significance (Strauss et al., 2007).

Chart 3.1 Extrapolated prevalence of cerebral palsy in 2018, by grouped GMFCS level (I-II, and III-V)



Source: Deloitte Access Economics calculations.

4 Health system costs

This chapter outlines the total health system costs due to cerebral palsy, including expenditure in hospitals, out of hospital medical treatment, and on pharmaceuticals.

Health system costs are the financial costs associated with the health care of people living with cerebral palsy. These costs comprise the costs of treatment in hospitals; consultations and treatment in out-of-hospital settings (such as primary and community care) and medications subsidised through the Pharmaceutical Benefits Scheme (PBS).

Key findings

- Total health system costs due to cerebral palsy were estimated to be \$62.42 million in 2018, or \$1,757 per person with cerebral palsy.
- The largest cost was hospitals, at \$28.66 million or 45.9% of all costs to the health system.
- Governments bore approximately 69% of health system costs, while individuals and families bore just over 17% of total health system costs.

4.1 Total health system costs

Health system cost for cerebral palsy can be difficult to quantify due to lack of data available and inconsistencies in reporting of various health costs to different types of diseases. With data on cerebral palsy specific health care being limited, a bottom-up approach was taken to estimate total health system costs due to cerebral palsy in 2018, using evidence from the Bettering the Evaluation and Care of Health (BEACH) dataset, hospital separation statistics and health system expenditure on disease and injury from the Australian Institute of Health and Welfare (AIHW), and information from the PBS on the most common medicines prescribed to people with cerebral palsy.

Table 4.1 shows the **total health system costs in 2018 of \$62.42 million, and costs per person with cerebral palsy of \$1,757**, broken down by category of health expenditure. The largest component of health system costs is treatment in hospitals, at 45.9% of total health expenditure, reflective of the high cost of providing hospital services.

Health system costs in Australia are financed through a split of public funds (federal and state and territory governments) and private funds (out-of-pocket and private health insurance). Funding is administered through a number of different programs and jurisdictions. This includes the Commonwealth's Medicare Benefits Schedule (MBS), which provides full or partial rebates under a fee-for-service model, and the National Health Reform Agreement, which provides activity-based funding for free treatment in public hospitals. There is also a substantial component of private funding which includes private health insurance and out-of-pocket costs.

The different bearers of funding for the health system costs have been estimated for cerebral palsy based on healthcare expenditure data from the AIHW (2018). The total cost of health care for cerebral palsy in 2018 was paid for by:

- the Federal Government **\$25.78 million, or 41%**;
- state and territory governments **\$17.10 million, or 27%**;¹⁰
- individuals and families **\$10.30 million or 17%**; and
- private health insurance and other funding **\$9.24 million or 15%**.

¹⁰ Discrepancies in proportions of government expenditure exist due to rounding.

Table 4.1 Total health system expenditure, 2018

Category	Total cost (\$m)	Per person (\$)	Proportion (%)
Total hospital	28.66	807	45.9
Hospital inpatients	24.51	690	39.3
Hospital outpatients	4.15	117	6.7
Unallocated	14.07	396	22.5
Research	10.10	284	16.2
Allied health	7.72	217	12.4
GP visits	0.87	25	1.4
Specialists	0.80	22	1.3
Medications	0.14	4	0.2
Imaging	0.05	1	0.1
Pathology	0.02	0	0.0
Total	62.42	1,757	100.0

Source: Deloitte Access Economics calculations. Note: totals may not add due to rounding.

Chart 4.1 Health system costs of cerebral palsy in 2018, by component (% of total)

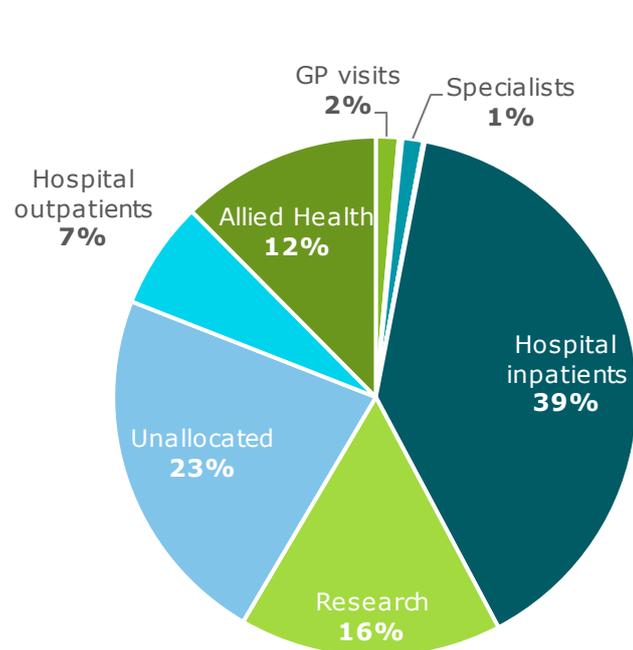
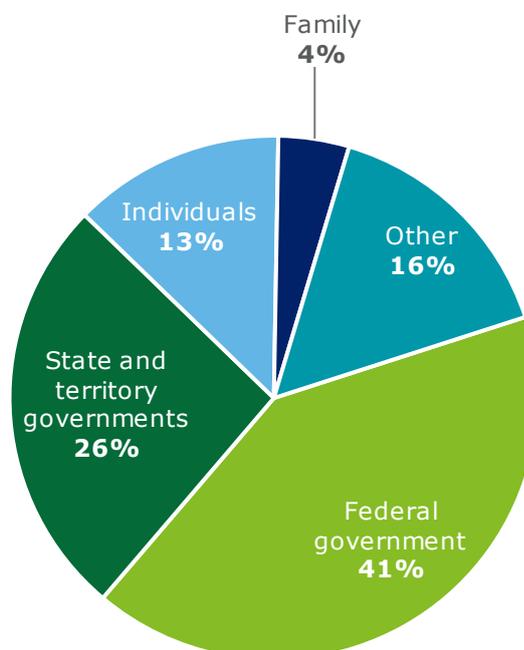


Chart 4.2 Health system costs of cerebral palsy in 2018, by bearer (% of total)



Source: Deloitte Access Economics calculations.

The AIHW recently estimated that cerebral palsy cost the Australian health system approximately \$31.9 million in 2015-16 (AIHW, 2019), using both top-down and bottom-up approaches to estimate costs.¹¹ The AIHW estimates are around 50% lower than those presented here, which is attributed to methodological differences in calculating and assigning costs to one disease or condition. Furthermore, the AIHW has excluded research costs and unallocated costs, which have been included in total overall health system costs in this report. This therefore excludes a large proportion of spending (approximately 39%) related to the healthcare industry and results in Deloitte Access Economics' estimates being considerably larger.

Similar to the approach in this report, the AIHW uses a range of techniques and data sources to allocate health expenditure. The AIHW has also relied on the 2007 BEACH dataset to estimate out-of-hospital service costs and as a result, similar estimates of costs for most out-of-hospital services have been made by the AIHW. While the BEACH survey data were considered full and robust in 2007, it is noted that treatment practice in the primary and allied health sectors has evolved in the 11 years since it was published. As such, greater and more recent insight into treatments and costs for people living with cerebral palsy by primary care and allied health providers is strongly recommended going forward. Such a survey could be included as an extension of the ABS Australian Health Survey and would provide further insight for health services research purposes.

4.1.1 Health system costs by GMFCS level

While the total health system cost per individual with cerebral palsy are estimated to be \$1,757, costs are unlikely to be consistent across different levels of severity of cerebral palsy. Most data sources used in calculating the overall health system costs, including the BEACH dataset and AIHW hospital statistics, do not differentiate between different types and severities of cerebral palsy.

As discussed in Section 1.6, the different therapies and interventions that can be undertaken for those with cerebral palsy are various and can be dependent on the level of severity and associated conditions. An Australian study – Pareezer et al. (2012) – considered 155 Australian children with cerebral palsy who had varying GMFCS levels over a six-month period, and investigated their interaction with medical and allied health care. This study found a strong positive correlation between GMFCS level and costs.

The study found that there is an increasing average cost of allied health therapy per child according to their functional severity (GMFCS level). It also found that medical costs follow a similar stepwise pattern; however, there is a higher medical cost per child associated with regular medications, therapy and provision of orthoses for GMFCS I compared to other levels. Overall, when excluding the costs of aids and modifications, children at GMFCS V had the greatest average cost per child.¹²

Applying the results from this study to the total health care costs calculated above and weighting to extrapolated prevalence by grouped GMFCS levels calculated in Section 3.4, the average healthcare costs per person by grouped GMFCS levels has been estimated. The estimates of average costs per person by grouped GMFCS levels presented in this chapter should be treated with caution. The relatively small sample size (155) and period of study (6-months) may not provide an entirely accurate representation of overall health costs. Further, the Pareezer study was of children, who may incur a higher per person level of health expenses, compared to the average costs for all people with cerebral palsy.

Table 4.2 shows the results of applying health care costs by grouped GMFCS levels from the study by Pareezer et al. (2012) to the overall health care costs that were calculated in Section 4.1. As would be expected, healthcare costs for GMFCS levels III – V are higher than GMFCS levels I – II at an average of \$2,432 per person. GMFCS levels I – II are 48% lower, at \$1,260 per person.

¹¹ A top down approach provides the total costs of a program element (e.g. hospital costs) due to a condition. A bottom up approach involves estimating the number of cases incurring each cost item and multiplying the number of cases by the average cost of each item. Both bottom-up and top-down approaches were used in estimating the cost of cerebral palsy in this report.

¹² It is important to note that the Pareezer study included a wider range of costs than are included in Chapter 4. This is because many of the costs in the Pareezer study are captured in Chapter 6.

Table 4.2 Healthcare costs per person, by GMFCS level

GMFCS Level	\$ per person
I - II	1,260
III - V	2,432
All (average per person)	1,757

Source: Deloitte Access Economics, using Pareezer et al. (2012)

4.2 Hospital costs

At 45.9% of all health system costs (39.3% for admitted in-patients, and 6.7% for outpatients), treatment of cerebral palsy related conditions in hospitals accounts for the largest proportion of total health system costs. This reflects the high and growing costs of treatment in hospitals in Australia, and the types of interventions, therapies and treatments that are provided in hospitals for people with cerebral palsy.

As there is no cure and no standard therapy or treatment that works for all patients with cerebral palsy, hospital treatment may be undertaken for a variety of reasons. Treatment may include interventions for muscle, bone and joint difficulties, and surgical procedures may be undertaken by an orthopaedic surgeon to correct joint deformities and lengthen muscles. Rehabilitation specialists may also intervene in the management of some of the conditions associated with cerebral palsy, such as spasticity, musculoskeletal issues and growth. These treatments and interventions are often undertaken in children's hospitals or through specialist physical rehabilitation (outpatient) clinics of major public hospitals.¹³

A recent Australian study, by Meehan et al. (2016) linked the Victorian cerebral palsy register to the state's hospital admissions database. The study identified that in the seven years between 2007 and 2014, 80% of the cerebral palsy cohort had at least one admission into a public hospital. It noted that cerebral palsy admissions were more costly and more likely to be elective than the general population. Increased severity and complexity of cerebral palsy were associated with having more admissions and the admissions being attributable to respiratory illness. Although it is noted that hospitalisation for respiratory illness is more likely in those with cerebral palsy, data from this study was unable to be extrapolated out to provide estimates of the cost of hospital treatment for those with cerebral palsy. Alternative datasets were therefore sourced to estimate these costs.

To estimate the number of inpatient hospital separations in Australia due to cerebral palsy and the associated cost, separation statistics by principal diagnosis (ICD-10-AM) from the AIHW (2019) were used. The latest data available at the time of publication includes separations for the principal diagnosis of cerebral palsy (G80) for the 2017-18 financial year. It should be noted that these statistics are for admission of the principal diagnosis only. This means these data do not capture secondary diagnosis of cerebral palsy or for any admission into hospital of a person with cerebral palsy for an issue unrelated to cerebral palsy. These data are therefore appropriate for modelling the cost to treat cerebral palsy in hospitals, as it does not include hospital separations unrelated to the diagnosis of cerebral palsy. Adjusting the 2017-18 separation statistics to reflect extrapolated prevalence in the calendar year of 2018, it was estimated that there **were 3,457 inpatient hospital separations for the primary diagnosis of cerebral palsy in 2018.**¹⁴

To estimate the cost of treatment related to cerebral palsy for inpatients at hospital, the average cost per 'diseases of the nervous system' separation in Australian hospitals for 2018 was sourced from the AIHW's

¹³ The Cerebral Palsy Alliance <https://research.cerebralpalsy.org.au/what-is-cerebral-palsy/interventions/>

¹⁴ The 2018 estimate of hospital separations for the principal diagnosis of cerebral palsy has used a different dataset to Access Economics' 2007 report on the economic cost of cerebral palsy. Due to changes in coding since 2005-06, and availability of data, the ICD-10 separation statistics from the AIHW have been used. The decline in separations estimated from 2007 to 2018 is reflective of this change and improvement in coding, and potentially a small real reduction in actual separations over time.

Admitted Patient Care publication (2019). The AIHW do not publish the average separation costs for cerebral palsy (G80 in the ICD-10-AM), however it is noted that previous publications of the average cost per separation of cerebral palsy is in line with the average cost of the broader nervous system group. Therefore, the average cost for the inpatient episode of a disease of the nervous system was used and inflated to \$7,090. Applying this to the estimated number of separations for 2018, the **total cost of treatment as inpatients at hospital for cerebral palsy in 2018 was estimated to be \$24.51 million.**

To calculate the costs of outpatient hospital services for 2018, data from the AIHW on healthcare expenditure for 'other nervous system disorders' (which includes cerebral palsy) were adjusted for the proportion of expenditure on cerebral palsy, and adjusted for health price inflation to 2018 (Australian Institute of Health and Welfare, 2013a). **This estimated the cost of treatment for outpatient hospital services for cerebral palsy in 2018 to be \$4.15 million.**

The total expenditure on hospitals for the treatment of cerebral palsy in 2018 was therefore estimated to be \$28.66 million, or \$807 per person.

4.3 Out-of-hospital health costs

Out-of-hospital costs are the costs related to the direct management and treatment of cerebral palsy, outside of the hospital setting. This includes primary care such as GPs; specialist care consultations and treatment; pathology and diagnostic imaging; allied health; and for the purposes of reporting in this study, includes other non-hospital-based costs such as research into cerebral palsy.

Out-of-hospital health costs contribute a relatively small proportion of the overall costs associated with health care for those living with cerebral palsy (compared to in-hospital costs). This is partly due to the low cost of delivering services in the primary care and community setting as opposed to in-hospital care. For example, the average cost to visit a GP for someone with cerebral palsy in 2018 was estimated to be \$43,¹⁵ compared to the high average cost of treatment in a hospital (\$6,107). Therefore, while there are many more touchpoints in the primary care setting for those living with cerebral palsy, compared to the hospital setting – with GP encounters occurring at 9 times the rate of hospital separations due to cerebral palsy in 2018 – the overall cost to the health system is far less.

Whilst out-of-hospital costs make up a small proportion of overall health expenditure, for families and individuals living with cerebral palsy it is their main area of expenditure on healthcare. Out-of-pocket costs for families and individuals provide a large source of the funding for out-of-hospital health costs, particularly for specialist care and allied health (when not provided through the NDIS or other disability programs).

The BEACH dataset (Australian General Practice Statistics and Classification Centre (AGPSCC), 2007) provides the most comprehensive and precise statistics on the management of cerebral palsy in general practice. The BEACH study, which collected 18 years' worth of primary care and general practice data, holds records of almost 1.8 million general practice to patient encounters. Data linkages between indications and patient management are unique to BEACH, making it an information source critical for analysing primary care treatment and to undertake research in health delivery.

The BEACH dataset remains the best and most complete record of costs and treatment in the primary care setting – and is also still relied upon by the AIHW to estimate costs. However as discussed above, it is recommended that a new survey is undertaken in future, to provide a more up-to-date and accurate analysis of out-of-hospital costs for people with cerebral palsy. In lieu of a more recent dataset, the BEACH data are the preferred source of data, as opposed to collating numerous estimates of different aspects of primary health care expenditure. Collating various datasets and estimates of different aspects can result in studies using different classifications and approaches to estimate costs. This inconsistency in

¹⁵ Calculated with consideration to average bulk billing rates and average out-of-pocket costs as per Broad Type of Service (BTOS) Medicare Data 2018.

approach can mean that costs are missed (in which case, the estimates are too low), or double counted (in which case, the estimates are too high).

The BEACH dataset specific to cerebral palsy holds encounters of 151 people with cerebral palsy and details of the interactions with a GP over a seven-year period. From this dataset, we can derive the treatment path following the visit; such as specialist referral, prescription, pathology and diagnostic imaging request or allied health referral.

Using the bottom-up approach, the BEACH dataset along with a number of other sources, costs for general practice, specialist care, pathology and diagnostic imaging, medications, allied health and other costs were estimated for people with cerebral palsy in 2018.

4.3.1 General practice

The BEACH data provides information on 151 encounters with a GP for people with cerebral palsy as the main reason over a seven-year period. As the total BEACH sample-size was 91,805 visits in 2007 for all conditions, and Australians made 102.8 million visits to a GP in that year, applying the population to sample size relativity to surveyed cerebral palsy visits results in a total estimate for all of Australia of 24,155 encounters for cerebral palsy in 2007. After adjustments for the growth in general practice visits between 2007 and 2018¹⁶, it was estimated that there were 31,760 encounters with a GP for cerebral palsy in 2018. This translates into 0.89 general practice *additional* encounters for each of the estimated 35,502 people living with cerebral palsy in Australia in 2018, on top of encounters that would have occurred in the absence of cerebral palsy.

The BEACH dataset also identifies that an average of 1.06 other (non-cerebral palsy related) problems were treated or consulted on during each consultation. This indicates that approximately half of the cost of each encounter is to treat other conditions, and therefore cannot be attributed to cerebral palsy. While people with cerebral palsy often had non-cerebral palsy related issues for which they required treatment at the same visit, no participants in the study identified that treatment was required for more than one cerebral palsy related problem in the one encounter. Treating multiple issues often necessitates multiple visits to a GP. However, based on the findings from the BEACH dataset, costs per visit are considered to be synonymous with costs per person.

The BEACH report does not provide data on the length of consultations, which have a significant impact on the cost of primary care under the fee-for-service model. The BEACH dataset does, however, provide data on the therapy undertaken, further treatment and medication requested, referred or prescribed. Using these data, the proportions of encounters in general practice that were considered a standard Level B consultation and longer Level C consultation can be derived.

To calculate the cost of a standard (level B) GP consultation, the 2018 MBS rebate (\$37.05) was added to the weighted average out-of-pocket payment for GP visits, across patients who are bulk-billed, and patients who are not bulk-billed. This was estimated to be \$43 per visit.

The number and added costs of longer consultations – where GPs specified that they have provided ‘at least one other (clinical) treatment’ – were modelled as MBS level C consultations. Providing ‘at least on other (clinical) treatment’ is where the GP provided advice, education and counselling, and the treatments and medications necessary to ameliorate it.

Using these data, it was estimated that 29% of total consultations with a GP for people with cerebral palsy are a longer consultation. This compares to the national average of 17% of all consultations being for longer level C consultations. The cost of a longer consultation was modelled as per the approach for shorter consultations, which resulted in an estimated cost of \$81 per visit.

As we have estimated the proportion of all consultations that would have been longer consultations, the difference between the average cost for a shorter consultation and average cost for longer consultation

¹⁶ Medicare statistics on growth in total GP visits from the Department of Health were used to adjust from 2007 to 2018.

was added to the total cost of GP encounters. This represents an incremental cost of \$39¹⁷ for the 29% of consultations that were longer than a standard level B consultation.

Further costs for general practice were derived from the BEACH dataset including procedures provided by GPs. These were calculated to be 3% of all GP encounters for people with cerebral palsy in 2018. Procedures performed by GPs in these visits include minor procedures such as injections and wound dressing. A cost proxy (MBS item 880¹⁸) was used to estimate the extra cost for procedural treatment by GPs. Taking the bulk-billing rebate and the latest bulk-billing rate data into account, an average cost of \$54 per procedural consultation was calculated.

For the 31,760 encounters with a GP in 2018, **a total of \$0.87 million was spent on treating cerebral palsy in general practice.** This was made up of \$0.67 million for standard (level B) consultations, \$0.18 million for a longer (Level C) consultations, and \$0.03 million for procedural treatments in the clinic.

It should be noted that in calculating the cost of general practice visits, bulk-billing rates have been taken into account, however the bulk-billing incentive and other general practice-based incentives have not. The bulk-billing incentive provides a small addition to the rebate for practitioners who bulk-bill patients who hold a Commonwealth concession card. This incremental rebate is between \$6.30 and \$9.50 per consultation. No data were found to estimate the number of people with cerebral palsy who hold an eligible concession card; however, it is likely that many people would qualify for a Commonwealth concession card such as a pensioner concession card through various pathways including eligibility of the Disability Support Pension (DSP). For this reason, general practice costs for people with cerebral palsy, and the cost to the federal government are conservative estimates.

4.3.2 Specialist care

To calculate the cost of specialist care for people with cerebral palsy in 2018, the BEACH dataset was used to estimate the number of referrals to a specialist for care by a GP. The dataset identified that 19% of encounters with a GP resulted in a referral to a specialist, with a majority being for neurologists and paediatricians.

To calculate the weighted average cost of treatment by a specialist following a referral from a GP, the 2018 recommended MBS fee, the latest bulk-billing rate data and average out-of-pocket costs for non-bulk-billed consultations for specialist attendances was used to calculate an average of \$130 per standard specialist consultation.¹⁹

The BEACH dataset provides insight into the type of referrals requested by GPs. These most common referrals captured in the data were neurologists, paediatricians, orthopaedic surgeons, plastic surgeons and ophthalmologists. While the BEACH dataset provides information as to the type of specialist referral, it does not capture any subsequent or ongoing specialist treatment or consultations. For this reason, the cost of specialist care may be underestimated.

Using the weighted average costs of consultations by a specialist, **the total estimated cost for specialist treatment in 2018 was \$0.80 million.**

4.3.3 Allied health

Interventions and therapies for people with cerebral palsy may include a number of services provided by allied health professionals. Therapy provided by practitioners such as speech pathologists, physiotherapists and occupational therapists may include providing intervention for communication skills, or encouragement of a person's day-to-day movement skills such as sitting, walking, playing, dressing and toileting.

¹⁷ Totals may not add due to rounding.

¹⁸ MBS item 880: Case Conference by Consultant Physicians in Geriatric/Rehabilitation Medicine.

¹⁹ Sources: Annual Medicare Statistics 2018 <http://www.health.gov.au/internet/main/publishing.nsf/Content/Annual-Medicare-Statistics>; AIHW Patients' out-of-pocket spending on Medicare services, 2016–17 <https://www.myhealthycommunities.gov.au/our-reports/out-of-pocket-spending/august-2018>

Data on the extent and benefits of allied health services for people with cerebral palsy are limited and conflicting (Anttila et al., 2008). Modelling the costs of allied health for people with cerebral palsy is therefore more complex than other areas of the health system. This is due to the many types of allied health treatments available for various types of interventions. Furthermore, allied health can be provided in the community or outpatient setting of a hospital – fully funded by federal and state / territory governments; referred to treatment by a GP which relies on small rebates through the MBS or private health insurance; or sought privately with funding borne entirely by families and individuals.

It is also noted that the National Disability Insurance Scheme (NDIS), as discussed in Section 6.2, provides funding for allied health services for related therapies of people living with disability. Thus, the inclusion of allied health care costs that are attributed to health system expenditure should be viewed in addition to the allied health care costs that are attributed to the NDIS, and other disability support services. Given the relatively small amount of allied health care attributed to health system expenditure, the majority of allied health care expenditure sits outside of the health system for people with cerebral palsy.

Due to the lack of survey data available on the use of private allied health services for people with cerebral palsy, allied health services have been costed by using the best estimates available through these data held on healthcare expenditure by the AIHW.

Using data from the AIHW's health system expenditure on disease and injury (2013a); the proportions of health expenditure on allied health were derived by applying similar proportions relative to the total as those for 'other nervous system disorders', which includes cerebral palsy. Adjusting for health inflation to 2018, the estimated costs of allied health services for people with cerebral palsy was \$7.7 million. This equates to \$217 per person living with cerebral palsy in 2018, or 12.1% of the total spent on health care.

4.3.4 Pathology and diagnostic imaging

The BEACH data provide information on tests ordered by GPs in the treatment of patients with cerebral palsy. 4% and 1% of encounters resulted in the requesting of pathology tests and diagnostic imaging, respectively.

It should be noted that these proportions, and the estimated costs derived below are likely to be conservative. This is due to the likelihood of specialists requesting both pathology and diagnostic imaging, which is not captured in the BEACH dataset. Furthermore, it is likely that during the period of diagnosis of cerebral palsy during childhood, patients would undergo a much higher proportion of testing.²⁰ Many of these costs may be captured in the costing of hospital treatment; however, there is likely to be a proportion of diagnosis testing that is undertaken outside of the hospital setting and therefore not fully captured in this model.

To estimate the costs of pathology for those with cerebral palsy in 2018, a proxy MBS item was used. Based on the dataset and categorisation of types of pathology requested, the MBS item 66500 – '*Quantitation in serum, plasma, urine or other body fluid (except amniotic fluid), by any method except reagent tablet or reagent – 1 test*' was used. Using the 2018 recommended MBS fee (which is also the bulk-billing rebate), the average out-of-pocket cost for pathology, and the latest bulk-billing rate data, a weighted average of \$13 for pathology was calculated.

Using the same method for diagnostic imaging, where the only imaging test ordered in the sample was for an ultrasound scan of the head (MBS item 55028) a weighted average of \$217 for diagnostic imaging was calculated. **In total, 1,472 pathology and diagnostic imaging tests were ordered for cerebral palsy, at an estimated cost of \$0.06 million in 2018.**

4.3.5 Other out-of-hospital costs

A number of other costs are included in health system costs, outside of hospital costs. While these costs do not necessarily contribute directly to the care of cerebral palsy related conditions, they do form part of

²⁰ For example, see the discussion in Section 4.1.1.

the expenditure on cerebral palsy health care and in the case of expenditure on research, aim to help prevent, treat and cure cerebral palsy.

Research expenditure on cerebral palsy in Australia has grown considerably in recent years. Increased investments in health and medical research through federal government grants and programs (such as the Medical Research Future Fund), and from philanthropic donations have contributed to this growth. With 58% of the most effective cerebral palsy treatments discovered in the past 10 years (CPA Research Foundation, 2018), and many largescale local and international research projects currently underway, research expenditure on cerebral palsy now accounts for around 16% of all healthcare expenditure for cerebral palsy.

Research expenditure was estimated to be \$10.1 million for 2018. This estimate was calculated from publicly available data from the National Health and Medical Research Council, projected out to 2018 based on the compound annual growth rate of expenditure on medical research for cerebral palsy. This was combined with funding administered by the Research Foundation of Cerebral Palsy Alliance, which was established in 2005 to fund research to find a prevention and cure for cerebral palsy. The Research Foundation is funded primarily through charitable means.

Other costs to the health system include unallocated costs, which account for a large part of overall health expenditure. The latest estimates from the AIHW estimate unallocated costs to be 30% of total health care expenditure (Australian Institute of Health and Welfare, 2013b). Adjusting to reflect expenditure in the health system on cerebral palsy, it was estimated that in 2018, **\$14.1 million, or 22% of all health system costs, was spent on unallocated costs.** Unallocated costs include costs on items and services such as ambulances, administration, community and public health programs.

4.4 Pharmaceuticals

People with cerebral palsy are likely to take a number of prescribed medications to assist in the management of certain symptoms or conditions related to cerebral palsy. For example, medication can be prescribed to assist with movement issues, intervention for epilepsy to minimise the number of seizures, and medication to treat pain and sleep disorders. These medications may be administered orally, injected or delivered through surgically implanted pumps (such as Baclofen).

As discussed above, the BEACH dataset offers insight into treatment, referrals and diagnostic and pathology requests provided to individuals with cerebral palsy who had an encounter with their GP over a period of seven years. This dataset was used to derive the costs of pharmaceuticals for people with cerebral palsy in 2018.

This treatment includes GPs' recommending over-the-counter medication, GP-supplied and prescription only medicines. It should be noted that individuals are likely to independently purchase over-the-counter medicines, and other practitioners such as specialists are likely to also prescribe medication. These medicines have not been included in the modelling due to limitations of data.

The BEACH data have captured a number of prescriptions for people with cerebral palsy throughout the study, which are not necessarily prescribed as a direct result of the cerebral palsy. For example, there were two incidents of the influenza virus vaccine prescribed and administered. There is no certainty that this vaccine was prescribed to the patient due to cerebral palsy. As such, to ensure that a conservative estimate was calculated several prescriptions have been removed from the modelling.

It should also be noted that the list of prescribed medication captured over the study period is not exhaustive. Many guidelines for interventions and therapies recommended for those with cerebral palsy highlight several medications that may help with certain symptoms, which have not been captured in these data. For example, many children with cerebral palsy benefit from botulinum toxin type-A injections into muscles affected by spasticity. This has not been captured in the BEACH data.

With the likelihood of medication being prescribed by other practitioners, or purchased over the counter, and the BEACH dataset appearing to not have captured all the likely medications prescribed to someone

with cerebral palsy, the costs of pharmaceuticals for people with cerebral palsy is likely to be conservative.

The most commonly prescribed medications for people who were treated by a GP for cerebral palsy includes diazepam and baclofen to relieve muscle spasms and spasticity. Other prescriptions include the hormone medroxyprogesterone and amitriptyline used to treat nerve pain. There were also several other medications that were prescribed but not prescription-only medications. This include vitamin B12 and paracetamol which are commonly recommended as supplements and painkillers respectively for people with cerebral palsy. From these data, **it was estimated that 7,362 prescriptions were provided in 2018. This represents a cost of \$0.15 million**, which is split between funding by the federal government, and individual out-of-pocket costs.

5 Productivity costs

This chapter outlines the total productivity costs due to cerebral palsy, including reduced workforce participation, reduced productivity at work, loss of future earnings due to premature mortality, and the opportunity cost of informal care.

Key findings

- Productivity losses are the largest contribution to the economic cost of cerebral palsy in 2018, at \$1.29 billion, or \$36,417 per person with cerebral palsy.
- The largest contribution to productivity costs is the reduction in workforce participation, at \$479.46 million, or 37.1% of all productivity costs.
- Other productivity costs include:
 - Reduced productivity while at work (“presenteeism”) at 24.4% of all productivity costs.
 - Short-term absences from work (“absenteeism”) at 10.3% of all productivity costs.
 - The opportunity cost of informal care at 18.1% of all productivity costs.
- The largest bearer of productivity costs losses are individuals, at 33.7% through forgone income.

5.1 Total productivity costs

The varied nature of cerebral palsy means that its impact on productivity can be different for each person with the condition. Relative to Australians without cerebral palsy, some Australians with cerebral palsy will be in paid employment with no significant reduction in productivity, while others will be employed at a lower level of productivity and/or more days absent, and some will not be employed at all. Further, the increased mortality risk from cerebral palsy means that some people will die prematurely, which represents lost productivity in future years. For the carers of people with cerebral palsy, the care they provide represents an opportunity cost in terms of the income they would have received in the absence of their caring responsibilities.

The total cost from the loss in productivity due to cerebral palsy in 2018 was estimated to be \$1.29 billion. Of this, the largest component comes from reduced employment rates, at \$497.46 million, and reduced productivity while at work (“presenteeism”) at \$315.59 million. Table 5.1 and Chart 5.1 shows the proportions of each of these productivity costs. Chart 5.2 shows how these costs are shared among individuals, carers (typically family members of people with cerebral palsy), employers and the government. Approximately 34% was incurred by individuals in reduced income or forgone wages, 24% by employers through a reduction in production and added administration costs, 30% by the government in the form of lost taxes, and 12% for families through the unpaid care they provide to people with cerebral palsy

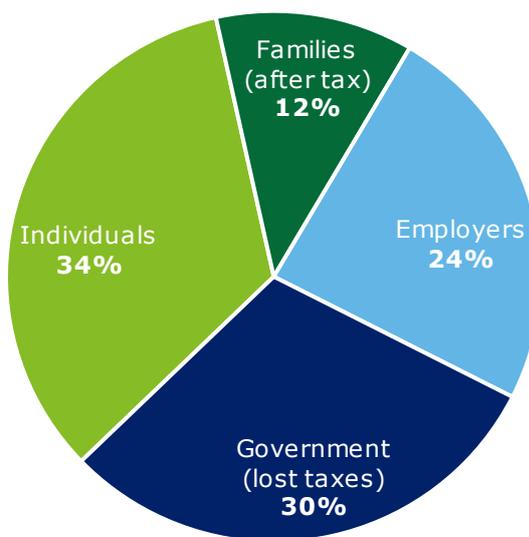
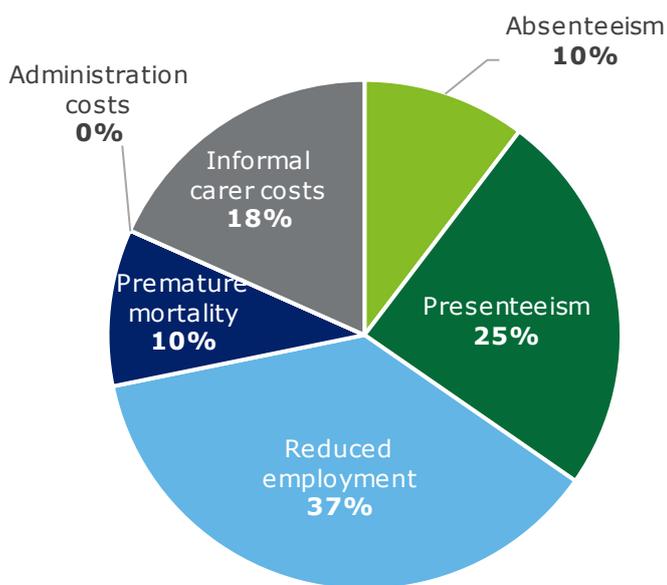
Table 5.1 Productivity costs of cerebral palsy, 2018

Category	Total cost (\$m)	Per person (\$)	Proportion (%)
Absenteeism	133.59	3,761	10.3
Presenteeism	315.59	8,884	24.4
Reduced employment	479.46	13,497	37.1
Premature mortality	128.57	3,619	9.9
Administration costs	0.06	2	0.0
Informal carer costs	236.36	6,654	18.3
Total	1,293.63	36,417	100.0

Source: Deloitte Access Economics calculations. Note: totals may not add due to rounding.

Chart 5.1 Total productivity costs of cerebral palsy in 2018, by component (% of total)

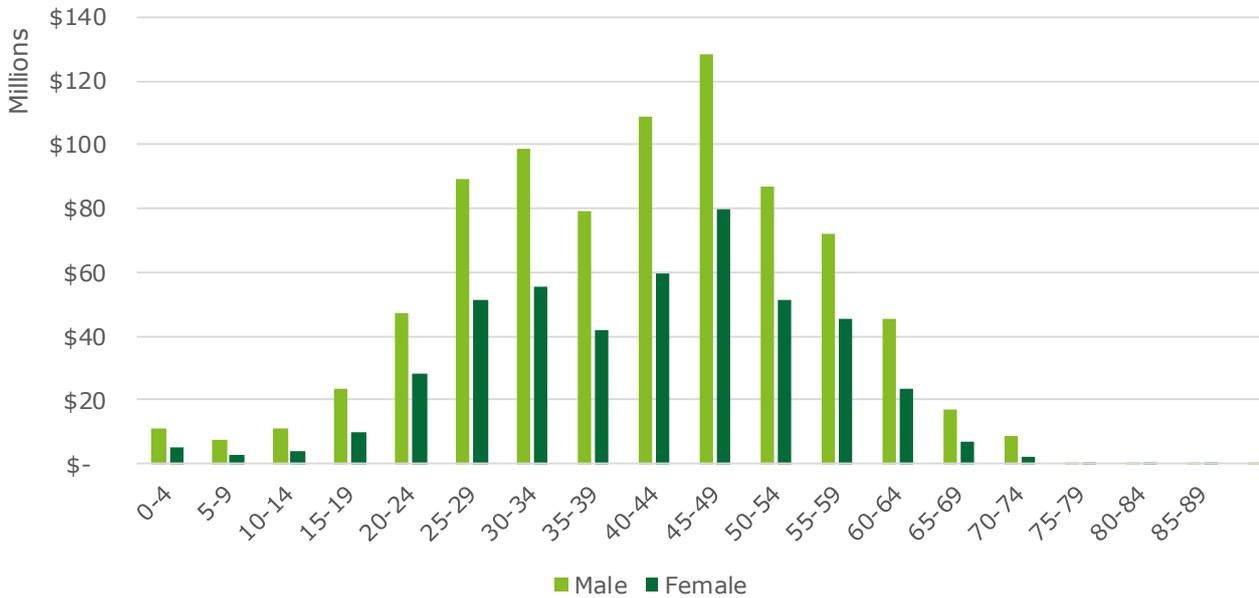
Chart 5.2 Total productivity costs of cerebral palsy in 2018, by bearer (% of total)



Source: Deloitte Access Economics calculations.

Chart 5.3 shows these costs by age and gender. Differences in total costs by age and gender group are relatively large, in part because of the pay gap (average weekly earnings, AWE) that exists between males and females. The methods for calculating each of these costs are explained in the remaining sections of this chapter.

Chart 5.3 Total productivity costs, by age and gender



Source: Deloitte Access Economics calculations.

5.2 Absenteeism

Absenteeism refers to short-term absences from work due to cerebral palsy. This may include days off to visit health professionals, for hospital admissions, or days at home when people with cerebral palsy are not well enough to work due to their condition. Absenteeism is measured by estimating the number of workdays that have been missed throughout the year, for people with cerebral palsy who are in paid employment and was estimated using the friction method. This approach estimates production losses for the time required to restore production to levels before the absenteeism occurs.

Employers often choose to make up lost production through overtime or employment of another employee that attracts a premium on the ordinary wage. The overtime premium represents lost employer profits, but also indicates how much an employer is willing to pay to maintain the same level of production. Thus, if overtime employment is not used, the overtime premium also represents lost employer profits due to lost production. For this study it was assumed that the overtime rate is 40%, based on data from Safe Work Australia (2015).

Historical data for total absenteeism (including annual and sick leave) were available for 98 people with cerebral palsy, who averaged 35.8 days away from work per year due to their condition. These data were sourced from various cerebral palsy Australia member organisations.²¹ More recent data, albeit from a smaller sample, was provided by member organisations for the purpose of this study and displayed lower average absenteeism rates than the historical data. For this reason, an assumption of 20 days of absenteeism was modelled to estimate productivity losses in 2018. Average employment rates and AWE for people with cerebral palsy were also used in the calculation and are based on ABS data for the general population by age and gender (ABS, 2018).

Based on these parameters and the AWE for each age-gender group, **it was estimated that in 2018, the total cost of absenteeism due to cerebral palsy was \$133.59 million.** This includes an \$89.66 million cost for the employer through lost output, and \$14.94 million in lost income for those with cerebral palsy who are absent from work. This loss to individuals represents the forgone income from being absent from work, due to the condition. The remaining absenteeism costs are attributed to lost household productivity, for those with cerebral palsy who do not work.

²¹ These data were provided to Access Economics for the 2008 report estimating the cost of cerebral palsy for 2007.

5.3 Presenteeism

Presenteeism refers to reduced productivity while at work due to a condition, which imposes a financial burden on employers. The impairments from cerebral palsy may reduce productivity, for example through reduced mobility and chronic pain, or through other impairments such as reduced intellectual capacity or impaired vision.

To estimate presenteeism, data were sourced from the Department of Social Services (DSS), who manages the Supported Wage System (SWS) program. Under the SWS, employers pay a productivity-based wage for people with disability that matches their independently assessed productivity rate. For example, if a person employed through the SWS is assessed as having a productivity level of 70% compared to co-workers performing the same duties, the worker and the employer can agree to ongoing employment at a pay rate of 70% of the normal rate. This reduction in income can be used as a proxy to represent the reduced productivity of the individual.

Current data from DSS for SWS productivity levels were available for 148 people with cerebral palsy, who, following independent assessment averaged a productivity level of 51.5%. This represents a loss of productivity (or presenteeism) of approximately 48.5%. Based on these data from the SWS of those with cerebral palsy, **it was estimated that the cost of presenteeism due to cerebral palsy in 2018 was \$315.59 million.**

5.4 Reduced workforce participation

Reduced workforce participation is the difference between the participation rate in the workforce of the general population and those with cerebral palsy. Studies have indicated that people with cerebral palsy have difficulty in obtaining competitive employment (Törnborn et al., 2014) and that people with cerebral palsy participate in the workforce at a much lower rate than the general population.

There are government and community programs in place that provide supported employment for people with disability, such as the SWS and Disability Employment Service (DES) providers, which can assist those with cerebral palsy to train in specific job skills, and to find a suitable job to fit their skills. Programs such as these, help bridge the difference between the workforce participation rate of the general population and of those with a disability; however, for cerebral palsy a significant gap still remains.

These gaps in employment between those with cerebral palsy and that of individuals without cerebral palsy may be attributed to physical impairment and intellectual capacity (Kruse et al, 2009). An international study has also linked cerebral palsy with greater levels of physical fatigue when compared to the general population, which contributes to an imbalance between work capability and the workload required to participate in the workforce (Jahnsen et al., 2003). A strong link between the age of those with cerebral palsy and a decreasing rate of workforce participation (when compared to the general population's decreasing rate of workforce participation) has also been seen (Törnborn et al., 2014). Employment rates have been found to be specifically low in adults with cerebral palsy and intellectual impairment, bilateral cerebral palsy, and in adults with GMFCS levels IV and V (Benner et al 2017).

Rates of employment for those with cerebral palsy vary by each study, as do their location, time and age of sample. The following recent studies have estimated the reduction in employment rates in a context similar to the Australian context:

- Benner et al. (2017) estimated a 46.4% reduction in employment rates. This study was undertaken in the Netherlands of a sample of 65 people over a 14-year period. The study found that employment rates for those with cerebral palsy remained steady over time.
- Michelson et al (2005) estimated a 64.6% reduction in employment rates. This study was undertaken in Denmark of a sample of 819 participants aged between 21 – 35 years born between 1965 and 1978 in the Danish Cerebral Palsy Registry
- Van der Dussen et al. (2001) estimated a 50.7% reduction in employment rates. This study was undertaken in the Netherlands of a sample of 80 people aged between 21 - 31 years.

A number of other international studies have highlighted the low rates of employment due to cerebral palsy; however, these studies did not include a control group.

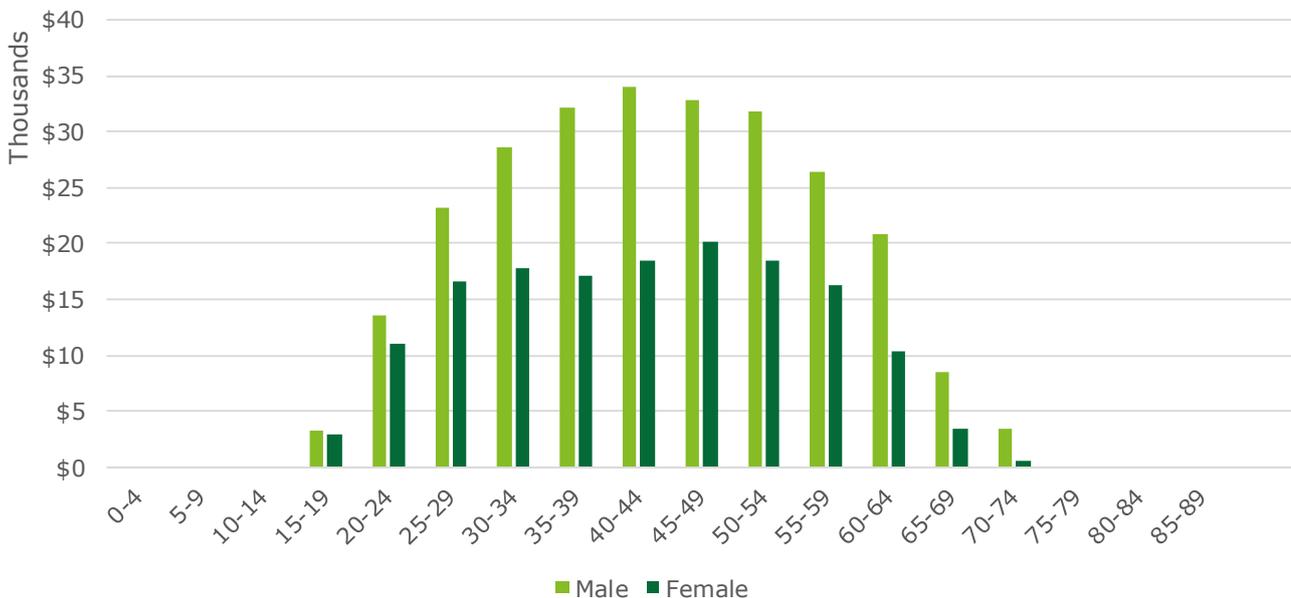
- 22.9% of those with cerebral palsy were employed in a sample of 279 over the age of 18 in Taiwan (Huang et al., 2013).
- 23.0% of those with cerebral palsy were employed in a sample of 95 over the age of 18 in Israel (Mesterman et al., 2010).

For this report, the findings from the ABS Survey of Disability, Ageing and Carers (SDAC) (2015) were used to estimate the employment rate for people with cerebral palsy in Australia compared to the general population. The SDAC includes information on 28 people with cerebral palsy who are of working age (15-64 years old).²² Among this cohort, 28.6% are employed, which compares to the general population employment rate of 71%. Thus, this indicates that the employment rate gap due to cerebral palsy in Australia is 42.4%, after adjusting for the employment rate in the general population.

While these findings from the SDAC rely on a relatively small sample size, they are broadly consistent with the findings from Michelson et al (2006), which had a much larger sample size. The participation rates in the Michelson study were also similar with the age-specific population rate in Australia. Thus, the SDAC findings have been used due to the relatively recent date of survey (2015), and as they are specific to Australia. After applying the reduced productivity against AWE data (ABS) for each age-gender group, **the estimated loss due to reduced workforce participation was estimated to be \$479.46 million in 2018.**

These costs are broken down by age and gender, as shown in Chart 5.4. The gap evident between the average cost of reduced workforce participation of males and females is due to the pay gap that currently exists between males and females. This means that for all males who are not participating in the workforce due to cerebral palsy, the forgone average income in 2018 is larger than that of females.

Chart 5.4 Reduced workforce participation cost per person, by age and gender



Source: Deloitte Access Economics calculations.

²² Distribution of the SDAC data sample is assumed normal, however due to the small sample size, it is possible that the relative standard error is high.

5.5 Premature mortality

Premature mortality refers to deaths due to a condition that are in addition to the deaths in the general population. As outlined in Chapter 3, it was estimated that cerebral palsy will be the primary cause of 116 deaths in 2018. To estimate the lost productivity from premature mortality, these deaths were applied against the estimated lifetime earnings for each age-gender group, and the probability of being employed in each age-gender group. Discounted to present values, **the total cost of premature mortality for 2018 was estimated at \$128.57 million.**

5.6 Administration costs

Administration costs are the productivity-related costs associated with the additional search and hiring costs for replacement workers due to premature mortality. For the productivity costs of cerebral palsy, this does not account for a large proportion of total productivity costs. This is in part due to the overall reduced workforce participation for those with cerebral palsy, with it being a lifelong rather than episodic condition.

The estimated number of people with cerebral palsy who die prematurely (by age and gender) is multiplied by their chance of being employed and the cost of the search and hiring for a new employee is brought forward from when it would otherwise have been expected to occur in the absence of cerebral palsy.²³ Consistent with Deloitte Access Economics' standard approach, the search and hiring cost was estimated as 26 weeks at AWE and the three-year bring forward reflects average staff turnover rates in Australia. **Productivity-related administration costs from cerebral palsy were estimated to be \$0.06 million in 2018.**

5.7 Informal carer costs

Carers are those who provide care to others in need of assistance or support. An informal carer provides this service without formal payment and does so outside of the formal care sector. An informal carer will typically be a family member or friend of the person receiving care. Carers may take time off work to accompany people with cerebral palsy to medical appointments, stay with them in hospital, or care for them at home. In the case of informal carers for those with cerebral palsy, caregiving may be needed for daily physical tasks such as changing clothes, getting in and out of bed and preparing food.

It is likely that informal carers are receiving income support through the Carer Payment and / or Carer Allowance; however, they may be forgoing paid work in the workforce. Informal carers instead undertake many of the unpaid tasks that the person with cerebral palsy would do if they did not have cerebral palsy and were able to do these tasks for themselves. Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence.

While informal carers are not in paid employment for providing this care, informal care is not free in an economic sense. Time spent caring involves forfeiting time that could have been spent on paid work. As such, informal care can be valued as the opportunity cost associated with the loss of economic resources (labour). To estimate the dollar value of informal care, the opportunity cost method measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time which cannot be spent in the paid workforce.²⁴

²³ This is brought forward three years to account for normal staff turnover rates.

²⁴ It is also possible to use the replacement cost method (which measures the cost of 'buying' an equivalent amount of care from the formal sector if the informal care was not supplied), and the self-valuation method (which measures how much carers themselves feel they should be paid for undertaking their responsibilities). However, these options were not explored further in this report.

To determine the amount of, and costs associated with informal care given by carers of people with cerebral palsy, available epidemiological data together with the ABS SDAC (ABS, 2015), were used to estimate the total number of hours of care provided to people with cerebral palsy in 2018.²⁵

Applying the SDAC data to the population with cerebral palsy, there were estimated to be around 18,060 carers who cared for people with cerebral palsy as their main condition. These are both primary²⁶ and non-primary carers. It is important to avoid the inclusion of informal care that would have been provided in the absence of the condition. This care that would have otherwise been given is based on the percentage of informal care given to the general population. The SDAC estimates this at 2.9% for the general population.

Based on the SDAC data, 50.8% of people with cerebral palsy are estimated to have an informal carer (specifically where cerebral palsy is the main condition, not secondary). Adjusting for informal care given to the general population, 47.9% or 17,032 of people with cerebral palsy are estimated to receive informal care due to their condition.

Assuming that the split between primary and non-primary carers is the same as for the population as a whole, there were an estimated 1,570 primary and 15,462 non-primary carers in 2018 for people with cerebral palsy. Based on the demographic characteristics of carers from the SDAC data, of these carers 889 and 8,754, respectively, are estimated to be employed in the workforce.

The SDAC provides the average number of hours of care provided by the primary carer of those with cerebral palsy. Of the primary carers, 11.5% provided less than 20 hours of care per week on average, 12.0% provided between 20 and 40 hours and 65.0% provided more than 40 hours (with the remaining 11.5% not stating the number of care hours provided).

Using these data, it has been conservatively calculated that there was a weighted average of 44.4 hours of informal care per week provided by primary carers for people with cerebral palsy. For non-primary carers, an estimate of 5 hours per week was made, in line with previous studies.²⁷

With these approximations of the number of primary and non-primary carers in 2018 for people with cerebral palsy, and the hours of care provided, **it has been estimated that the total opportunity costs of informal care was approximately \$236.36 million.** Most of these costs (65%) are incurred by the care providers on families (through lost income), and the remaining 35% are incurred by the Government through lost taxation revenue.

²⁵ The SDAC data sample was assumed to have a normal distribution, however due to the small sample size, it is possible that the relative standard error is high.

²⁶ A "primary carer" is defined by the ABS as "a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care)".

²⁷ Based on previous Deloitte Access Economics reports undertaken for Carers Australia; including *The economic value of informal care in Australia in 2015*.

6 Disability support and other financial costs

This chapter covers disability support costs and the other financial costs due to cerebral palsy. These costs include the costs for the NDIS and other disability services, and efficiency losses.

Key findings

- Total disability support and other financial costs are \$1.67 billion, or \$47,099 per person with cerebral palsy in 2018.
- Funding for cerebral palsy in the NDIS was \$956.35 million in 2018.
- Non-NDIS funding for support and care was \$155.06 million in 2018.
- Total efficiency losses due to cerebral palsy are \$553.59 million in 2018.

6.1 Total disability support and other financial costs

Disability support costs and other financial costs are a large component of total costs due to cerebral palsy. The largest element of this for 2018 was the cost of the National Disability Insurance Scheme (NDIS) (\$956.35 million, or 57%), efficiency losses (\$553.29 million, or 33%), and other non-NDIS disability support and care (\$155.06 million, or 9%) for people with cerebral palsy.

The NDIS provides funding packages to individuals with disabilities for all “necessary and reasonable goods and services”, however is typically only available to those people in GMFCS III-V categories (National Disability Insurance Agency, 2019) For people in category I-II, similar services – albeit of less intensity – are available through a number of disability services across Australia. Smaller costs are attributed to aged care services, and the increased risk of mortality means that funeral costs are “brought forward” from when they would otherwise have occurred.

Other financial costs also include efficiency costs on the Australian economy, commonly known as deadweight losses but referred to as efficiency loss in this report. This is due to the impact cerebral palsy has on taxation revenue, and from the efficiency losses of welfare payments and other financial transfers. The total of all these costs are shown below in Table 6.1.

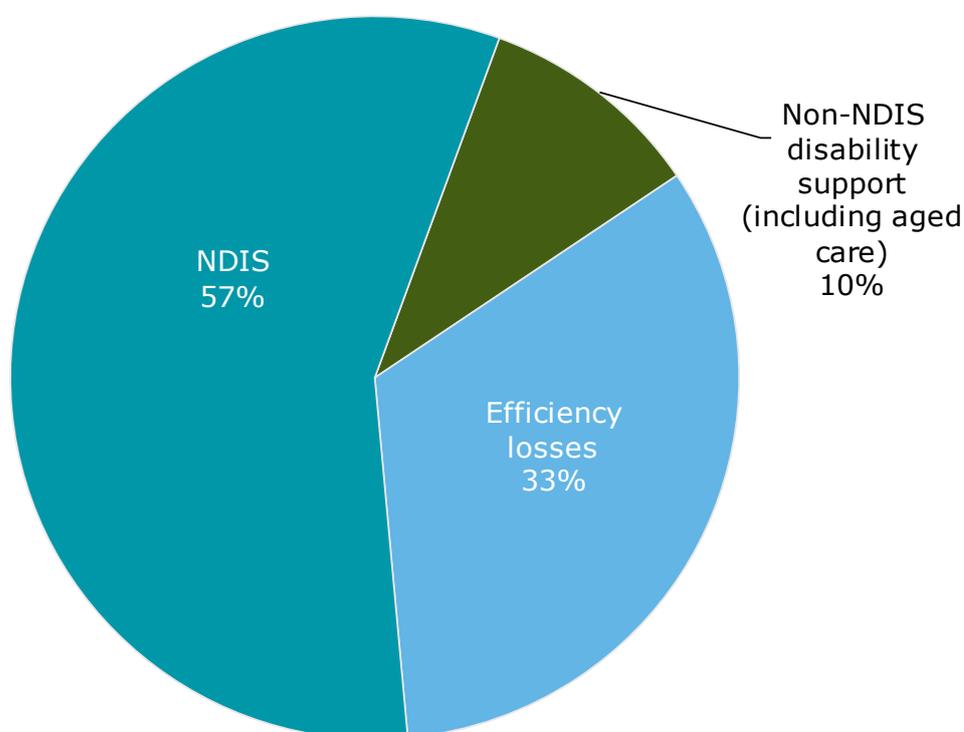
The total cost of disability support and other financial costs in 2018 due to cerebral palsy in was estimated to be \$1.67 billion. Table 6.1 and Chart 6.1 shows the totals and proportions of each component of the total disability support and other financial costs.

Table 6.1 Total disability support and other financial costs

Category	Total cost (\$m)	Per person (\$)	Proportion (%)
Cost of disability support	1,111.41	31,288	66.6
NDIS	956.35	26,922	57.3
Non-NDIS support and care (excl. aged care)	155.06	4,365	9.3
Other costs	558.47	15,722	33.4
Aged care	4.04	114	0.2
Funeral costs brought forward	0.85	24	0.1
Efficiency losses	553.59	15,584	33.2
Total	1,669.88	47,009	100.0

Source: Deloitte Access Economics calculations. Note: totals may not add due to rounding.

Chart 6.1 Total disability support and other financial costs of cerebral palsy in 2018, by component (%)



Source: Deloitte Access Economics calculations. Note: funeral costs brought forward has been rounded to 0% and therefore has been excluded from the chart.

6.2 Costs of NDIS services

Prior to the staged roll out of the National Disability Insurance Scheme (NDIS), which commenced in 2016, disability services were provided by state and territory governments through block funding to service providers. Since then, the NDIS has introduced a national scheme,²⁸ which provides funding to individuals based on their need. Using data from the National Disability Insurance Agency (NDIA), the cost to government for participants of the NDIS with cerebral palsy in 2018 has been estimated. As the

²⁸ On 12 December 2017 the Prime Minister of Australia and Premier of Western Australia (WA) announced a new Bilateral Agreement for Transition to the National Disability Insurance Scheme (NDIS) in WA. WA is the last jurisdiction to sign on to the national scheme.

NDIS has not fully rolled out across Australia, and not everyone with cerebral palsy is eligible for the NDIS, some assumptions for other financial costs have been made to capture those who are either not yet receiving assistance through the NDIS or do not qualify for the NDIS. These are detailed in Section 6.3.

6.2.1 About the NDIS

The NDIS was established in response to a 2011 Productivity Commission report that found disability services were “underfunded, unfair, fragmented and inefficient”. The scheme is a universal and uncapped program, with funding based on the needs of the individual. Prior to the NDIS there were a large number of government funded service providers (such as non-for-profit organisations), which ran services and provided support for people with disabilities. These services included accommodation support, community support, therapy, community access, respite and employment services. The services were block funded and were not necessarily flexible or universal in their delivery or provision.

The NDIA is the agency tasked with the implementation and administration of the NDIS. Commencing in 2016, after three years of trials, the scheme is due to be fully rolled out across Australia by June 2020. As at 30 June 2018, the NDIS was supporting 183,965 participants, including children in the Early Childhood Early Intervention (ECEI) gateway. By the end of the rollout, it is anticipated there will be 475,000 NDIS participants out of 4.3 million Australians living with disability (Productivity Commission, 2017).

Under the NDIS, participants can exercise choice and control by purchasing their supports directly from providers. This means funding of disability supports will no longer take place through block funding for providers, but rather through individualised support funding for participants. Individuals can use their funding to purchase a wide range of services from different providers in the market.

The NDIS does not provide income support or income replacement to those who are unable to work; rather, the NDIS provides additional funding to meet the special needs of a person with disability, such as to buy a wheelchair or to have assistance at home. Income support for those who are unable to work because of disability remains the responsibility of DSS and the Department of Human Services, through Centrelink. The NDIS does not cover the cost of services where other government schemes are in place, such as medical and other clinical services, where public hospitals and Medicare cover the costs of treatment (with the exception of allied health therapy, where the therapy is needed due to the disability).

Funding and packages for participants in the NDIS are divided into two parts – fixed supports and flexible supports:

- **Fixed supports** are for supports such as equipment, home modifications and certain types of early childhood intervention and therapy services. Generally speaking, “fixed supports” are those services deemed necessary to ensure participants’ goals or desired outcomes can be met, or those which require certain skills or qualifications from the provider. For example, if a certain amount is allocated for a new power wheelchair, it will need to be spent on a new power wheelchair.
- **Flexible supports** include funding for recreational, community access and home-based support activities. They are funded in more general terms, enabling participants to switch funding from one item to another, depending on their personal needs from week to week.

6.2.2 The cost of the NDIS for cerebral palsy in 2018

Qualifying as a participant in the NDIS requires meeting certain criteria. The NDIA lists a number of conditions that are likely to meet the disability requirements, based on Section 24 of the *NDIS Act 2013*. This includes cerebral palsy, diagnosed and assessed as severe (e.g. assessed as Level III, IV or V on the GMFCS). Due to the current requirements for eligibility in the NDIS, not everyone with cerebral palsy received support through the NDIS in 2018. Further to this, not all regions across Australia had transitioned from legacy services²⁹ to the NDIS and not everyone will choose to receive support through

²⁹ At the time of modelling costs, the regions that have not yet transitioned to the NDIS are: Caboolture/Strathpine & Maroochydore in QLD; Goulburn, Mallee and Outer Gippsland in Vic; 50-64 year olds in TAS; and Great Southern, Central North Metro, Midwest-Gascoyne & South East Metro in WA.

the NDIS. The costs associated with care for people with cerebral palsy not captured by the NDIS are estimated in Section 6.3. Data on funding and the number of people with cerebral palsy using the NDIS were sourced from a data request to the NDIA. An average funding package for cerebral palsy is the second highest for any disability funded through the NDIS (National Disability Insurance Agency, 2018). Data from the NDIA show that the average annualised plan for people with cerebral palsy was \$72,161, with the 20th percentile package at \$19,862 and the 80th percentile \$234,609.

A package for participants with cerebral palsy may include the provision of many fixed and flexible goods and services. The NDIS will fund “reasonable and necessary supports” for a person with cerebral palsy to lead a meaningful life and increase their independence and ability to participate in the community. This may include but is not limited to the following:

- formal care and assistance, such as assistance in daily personal activities;
- home and vehicle modification design and construction;
- mobility equipment;
- workplace help to allow a participant to successfully get or keep employment in the open or supported labour market;
- therapeutic supports including behaviour support and other allied health therapy; and
- help with household tasks to allow the participant to maintain their home environment.

Data from the NDIA indicate that there were over 13,000 people with cerebral palsy on the NDIS in 2018. Combining the number of participants with the average package for those with cerebral palsy, as provided by the NDIA, **the estimated costs of services provided to people with cerebral palsy through the NDIS in 2018 was \$956.35 million.** It should be noted that these costs for 2018 were not all met by the NDIS, as some participants transitioned to the NDIS during the year. It has been assumed that for these individuals, they were receiving a similar level of services at similar costs prior to transitioning to the NDIS. These are likely to have been funded through a mix of state and territory funding, and private out of pocket costs. However, for the purposes of this report the source of this funding is attributed entirely to government.

6.3 The cost of non-NDIS support and care

Other financial costs for those who are not participating in the NDIS may include the costs of aids and equipment and costs of formal care. A person with cerebral palsy in 2018 who was not a participant in the NDIS may be so for one or more of the following reasons:

- They are living in a geography where the NDIS has not yet rolled out (such as South-East Metro WA).
- They did not qualify for the NDIS (because they do not meet the eligibility criteria).
- They choose to not apply / enrol in the NDIS (for unknown or personal reasons).

The NDIA states that someone who is assessed as level III – V on the GMFCS is likely to qualify for the NDIS. It has therefore been assumed that those in levels I and II on the GMFCS did not qualify for the NDIS. Individuals who are assessed as levels I and II on the GMFCS but have associated impairments such as speech, hearing, intellectual and visual impairments may still qualify for the NDIS. However, as noted in Section 7.2, this does not typically occur, as the prevalence of associated impairments is significantly lower at lower GMFCS levels. The following sections analyse non-NDIS disability support and care costs, for GMFCS I-II, and for GMFCS III-V.

The total cost for non-NDIS disability support and care was estimated to be \$155.06 million.

This cost for non-NDIS disability support and care is broken down and detailed in the following sections.

6.3.1 GMFCS I-II

Prevalence calculations, as discussed in Section 3.3, note that 58% of people with cerebral palsy in 2018 are in GMFCS levels I and II. Therefore, there were up to 20,450 people in 2018 with cerebral palsy that may not have qualified for the NDIS as they do not meet the typical eligibility requirements, as outlined in Section 24 of the *NDIS Act 2013*. For the people with cerebral palsy who do not qualify for the NDIS, are in a geography where the NDIS was not yet rolled out, or have chosen to not access the NDIS, many are

still likely to be receiving services and support through other means. This can be through informal care (discussed in Section 5.7), through private out-of-pocket costs (personally funding goods and services), or through existing service providers funded through alternate methods (such as charities that rely on alternative sources of funding).³⁰

People with cerebral palsy in GMFCS I-II incur costs in two broad categories: formal care, and the costs of aids, equipment, and home modifications. These two categories, and the cost estimates are discussed below.

Formal care

Based on the latest SDAC data (2015), it was estimated that 61% of people with cerebral palsy with GMFCS levels I-II receive some form of formal assistance, which equates to 12,394 people in 2018. This formal assistance was likely provided by services in the community. Østensjø et al. (2003) found that the amount of assistance received increased with each GMFCS level. For people in level I, they needed minimal to moderate physical help for activities such as car and bathtub transfers, grooming, bathing, dressing and toilet tasks. Children in level II needed moderate help to perform these activities. Children in level II also needed occasional assistance when eating, and for bladder and bowel management, whereas children in level I performed these activities independently.

An analysis of SDAC data indicates that the level of formal care received for people in GMFCS level I to II is typically limited to once a week or less.³¹ Reflecting the results from SDAC and the literature discussed above, an approximation of two hours per week was used when modelling the costs of care for those in GMFCS level I to II. The value of formal care has been costed by applying an hourly cost of care for social and community services in 2018.³² Using these data it was estimated that the **total cost formal care received for people in GMFCS level I and II was \$67.26 million**. This cost is likely to be funded by private out-of-pocket costs, state and territory programs or through community organisations with other means of funding. For the purpose of this report, and because these funding sources cannot be disaggregated, the source of this funding is attributed entirely to government.

Aids, equipment and home modifications

Aids, equipment and home modifications are items such as mobility aids, assistive technology and modifications to the home, which assist in helping someone with cerebral palsy lead a meaningful life and increase their independence and ability to participate in the community. The number of aids, equipment and home modifications needed for those with cerebral palsy varies significantly based on the severity, particularly of severity in GMFCS level.

The 2015 SDAC data indicates that those with no to mild levels of motor impairment (GMFCS I – II) require very few aids and equipment in comparison to those with moderate to profound motor impairment (GMFCS III–V). The most common aids used for those with no to mild levels of motor impairment were orthoses/orthotics and mobility aids, such as crutches and walking sticks.

To estimate the cost of aids, equipment and modifications for those in GMFCS level I and II, the SDAC (2015) data provided proportions of those in GMFCS level I and II that had self-reported the use of aids, equipment and modifications. The items used and costed were foot orthoses/orthotics, mobility aids (being crutches and walking sticks) and aids for showering/bathing.

³⁰ Information from a range of disability service providers was obtained. However, the aggregate expenditure that was reported for funding cerebral palsy support services appears to be incomplete, and as such was not included in the analysis.

³¹ SDAC data does not provide the number of hours of formal care received, rather the frequency of formal care. For people with no mobility, mild mobility and moderate mobility restrictions, SDAC data showed that people typically received formal care once a week or less. As such, two hours per week was used selected to model the costs of formal care.

³² An hourly rate of \$34.79 is used for 2018. This is based on the 2018 minimum wage for social and community services employees (full and part-time at the mid point of level 4, pay point 3) for carers under the Social, Community, Home Care and Disability Services Industry Award 2010 (Fair Work Ombudsman, 2018).

The cost of these items were weighted based on their proportions of use by the cohort, average costs and useful life. For example, with 28% of people in GMFCS level I – II using a foot orthosis, at a cost of \$600 each and with the useful life of 1 year,³³ a weighted average cost of \$170 was calculated for this item. The weighted average cost for all aids, equipment and modifications and the proportions of people who used each item were applied to the number of people estimated to be in GMFCS level I – II.³⁴ **The total cost of aids, equipment and modifications for this cohort in 2018 was estimated to be \$3.63 million.**

6.3.2 GMFCS III-V

Further to those who are in GMFCS level I and II, there are also an estimated 1,200 people in the remaining GMFCS levels (III – V) that receive formal support and funding through non-NDIS programs. This calculation is based on SDAC data that 75% of people with cerebral palsy, and with severe and profound levels of mobility impairment, are receiving some type of formal care.³⁵ For the remaining 25% of people in this category, it is assumed that they receive no formal care as their care needs are fully met through informal care providers (e.g. family members).

Formal care recipients

The 75% of people receiving formal support and funding through non-NDIS programs represents 1,200 people with cerebral palsy in GMFCS III-V. These people are either not eligible for the NDIS due to their geographic location or are funded through alternative methods. The cost of care for these people has been estimated to be equal to the cost of an NDIS package. **The total cost of this cohort who receive formal care but were not funded through the NDIS in 2018 was estimated to be \$83.53 million.** It should be noted that as this uses the average NDIS package cost, this estimate includes the cost of aids, equipment, modifications and other support services for this cohort.

No formal care received

For the group that receives no formal care, this is likely because their care needs are fully met through informal care providers. This care has been costed in Section 5.7. However, this group still incurs costs for aids, equipment, and home modifications. The aids, modifications and equipment used for those with moderate to profound motor impairment were far more common and diverse than for those in GMFCS I – II, and included aids to dress, assist with incontinence, meal preparation, eating, seating, and mobility devices such as electric wheelchairs and walking frames.

The same method to calculate the cost of aids, equipment and modifications for those in GMFCS levels I - II was used for GMFCS level III – V. This was based on SDAC (2015) data which reported the number of people who used various aids, equipment and modifications. The aids, equipment and modifications that were weighted and costed for this cohort were items to assist with dressing, eating, incontinence, meal preparation, showering/bathing, toileting, moving around; and items including crutches, electric wheelchairs, scooters, walking frames and walking sticks.³⁶ Using the same method as per the GMFCS I-II group, **the costs of aids, equipment and home modifications was estimated to be \$0.63 million in 2018.** It should be noted that the cost of aids and equipment for most people with cerebral palsy who are in GMFCS level III – V are captured through NDIS (and “formal care”) costs above.

Bourke-Taylor et al. (2014) reports that the equipment needs of young Australian children with severe cerebral palsy are extensive and out-of-pocket-costs to families may be large (noting that this study was conducted prior to the roll-out of the NDIS). This study of Australian families caring for young people with

³³ The cost of \$600 is used for foot orthosis. This is based on the starting price as described by Cerebral Palsy Alliance (2018). A useful life of 2 years was used based on information by Better Health Victoria (2018).

³⁴ Websites used to cost each of the aids and equipment reported were www.chemistwarehouse.com.au, www.store.independenceaustralia.com, www.cerebralpalsy.org.au, www.wheelchairaustralia.com.au, www.mobilityhq.com.au, www.disabilityshop.com.au

³⁵ The remaining 25% are likely to have their care needs fully met through informal care.

³⁶ Websites used to cost each of the aids and equipment reported were www.chemistwarehouse.com.au, www.store.independenceaustralia.com, www.cerebralpalsy.org.au, www.wheelchairaustralia.com.au, www.mobilityhq.com.au, www.disabilityshop.com.au

cerebral palsy and complex needs (mostly with children categorised in GMFCS levels IV-V) found that most families required multiple items for their child to sit, stand, mobilise, communicate, for self-care and medical needs. Out-of-pocket costs were found to be significant, with significant variation between subjects in the study. For example, 25 families reported out of pocket costs on mobility devices, which varied from \$80 to \$24,100. This wide range of out of pocket costs is likely due to the different state and territory based programs that were in operation at the time of the study. Waiting lists to receive aids and modifications may have driven families to entirely fund aids or modifications themselves, or families may not have qualified for services or funding based on certain criteria.

This report is limited in capturing these potential out-of-pocket costs for aids and equipment, however, since the introduction of the NDIS, it is likely that many families who would have otherwise faced out-of-pocket costs no longer do so.

6.4 Aged care funding

Care and funding from the aged care sector represents support and care more closely aligned to that of disability services such as the NDIS. Funding for aged care services in Australia can be for Commonwealth Home Support Program (entry-level care), Home Care Packages (more complex coordinated care) or for residential aged care homes.

Estimating the number of people in the aged care system as a result of cerebral palsy has been based on 2015 SDAC data. Approximately, 12% of people with cerebral palsy who are aged 65 years and over, with profound mobility impairments (GMFCS V) and 1% of people with cerebral palsy and severe mobility impairments (GMFCS IV) are in a residential aged care facility (not another form of supported accommodation).³⁷

It is important to adjust this proportion for the number of people who would have otherwise been in residential aged care if it were not for their cerebral palsy. Subtracting the population-weighted proportion of SDAC respondents who reside in a residential aged care facility, approximately 10% of people with cerebral palsy and profound mobility impairments (GMFCS V) are in a residential aged care facility, and no one in any other category is in an aged care setting due to their cerebral palsy. This represents an additional 43 people in 2018 who receive aged care services due to their cerebral palsy. Using aged care expenditure from 'other nervous system disorders' (Australian Institute of Health and Welfare, 2013a) of which cerebral palsy is a part of, **expenditure specific to cerebral palsy in the aged care system for 2018 has been estimated at \$4.04 million.**

6.5 Funeral costs brought forward

The additional cost of funerals borne by family and friends of people with cerebral palsy was based on the number of deaths associated with cerebral palsy. While everyone will die eventually, and thus incur funeral expenses, the additional cost imposed by cerebral palsy is the brought forward funeral cost adjusted for the likelihood of dying anyway. The Australian Securities and Investment Commission (2017) reports that average funeral costs likely range between \$4,000 and \$15,000 in Australia. Taking the midpoint value and inflating to 2018 prices (\$10,134), **the discounted value of funeral costs associated with premature deaths was \$0.85 million**, or \$7,306 per death associated with cerebral palsy.

6.6 Efficiency losses

The act of taxation and redistribution is known as a "transfer", as resources are transferred from one entity to another. These transfers create distortions and inefficiencies in the economy, which are known as efficiency losses. These losses arise as imposing taxes on a market reduces the efficiency of resource allocation within that market because it changes the price of those goods or services being taxed. For example, an increase in income tax rates will increase the relative price of work compared to leisure and

³⁷ SDAC data does not identify any people with lower severity levels who are receiving aged care services.

therefore create a disincentive to work at the margin. Similarly, businesses may be discouraged from operating in Australia if company tax rates were too high.

Transfer costs are important when adopting a whole-of-government approach to policy formulation and budgeting. Publicly funding costs means the government must effectively increase tax revenue to achieve a budget neutral position. Alternatively, if all cerebral palsy (and its consequences) could be avoided, the government would not need to raise as much tax revenue or could spend the tax revenue on more efficient and productive services.

To estimate the efficiency loss due to lost taxation revenue (given an assumption of no change in spending), taxes were assumed to be maintained by taxing either individuals or companies more as necessary (to replace the lost tax from either stream). Each tax in the economy imposes various burdens on the efficiency of society. Analysis by KPMG (2010) and Cao et al. (2015) report the marginal burden of various government taxes (both state governments and the Federal Government). These are:

- income tax has been estimated to impose a burden of \$0.25 for every \$1 raised;
- company tax has been estimated to impose a burden of \$0.50 for every \$1 raised;
- goods and services tax has been estimated to impose a burden of \$0.19 for every \$1 raised;
- state taxes were estimated to impose a burden of \$0.45 for every \$1 raised based on the respective shares of revenue raised through major state taxes including gambling, insurance, motor vehicle taxes, payroll tax and stamp duties (KPMG, 2010; ABS, 2016d).

It is important to consider state taxes because states contribute to funding of health services, and to the funding of the NDIS (just under half of NDIS funding is provided by state and territory governments). Based on the 2017-18 budget papers (Commonwealth of Australia, 2017), approximately 70% of health expenditure is paid for by state taxes, while the remaining 30% is paid for by transfers from Commonwealth.

Thus, the relevant burden imposed by taxation to pay for state health expenditure is allocated to both income taxes, and the weighted state taxes. Weighted by the revenue raised:

- reduced income for individuals results in a 23.7% efficiency loss;
- reduced income for employers' results in a 50.8% efficiency loss;
- welfare payments, health and other government expenditure (e.g. the NDIS) results in a 29.5% efficiency loss; and
- state health expenditure results in a 45.0% efficiency loss.

In order to estimate the efficiency loss, it is necessary to estimate the value of welfare payments paid due to cerebral palsy, the reduction in income tax that is paid to government, and the value of other government expenditure due to cerebral palsy (for health costs and disability support services). Of these, the following components have previously been estimated in this report:

- Chapter 4: federal, state and territory government funding for health care services to people with cerebral palsy was estimated to be **\$42.88 million in 2018**
- Chapter 5: cerebral palsy decreases the tax paid by individuals and their employers through absenteeism, presenteeism, reduced workforce participation, and premature mortality. The value of this lost tax, that needs to be replaced from sources, was **\$119.11 million**.
- Chapter 6: government funding for the NDIS and non-NDIS disability services was estimated to be **\$1,116.30 million in 2018**.

The welfare payments due to cerebral palsy are explored in Section 6.6.1, with the total efficiency losses arising from the total transfers presented in Section 6.6.2.

6.6.1 Welfare payments

Welfare payments are transfer payments representing a shift of resources from one economic entity to another. The value of welfare (or income support) payments was calculated in order to estimate the efficiency loss. These welfare payments are calculated below through a number of datasets. It should be

noted that these payments are not themselves economic costs but rather a financial transfer from taxpayers to the income support recipients. The real resource cost of these transfer payments is only the associated efficiency loss.

Welfare payments to people with cerebral palsy

The main source of income support for people with cerebral palsy aged less than 65 years is the Disability Support Pension (DSP). People aged 65 years and older are eligible for the Age Pension, however, following Deloitte Access Economics' standard methodology, this section only considers people aged less than 65 who are receiving the DSP.

DSP is an income support payment for people who are unable to work for 15 hours or more per week at or above the relevant minimum wage, independent of a Program of Support, due to permanent physical, intellectual or psychiatric impairment. A DSP claimant must be aged 16 years or over and under the age pension age at date of claim. However, once a person is receiving the DSP, they will continue to do so beyond the age pension age (Department of Human Services, 2018).

A special data request was submitted to DSS to obtain information on the number of people who received the DSP as a result of cerebral palsy. Based on advice from DSS³⁸ and the fact that these data provided may not be an overall count of DSP recipients with cerebral palsy, these data were not used. As an alternative, data from SDAC were used to approximate how many people with cerebral palsy in 2018 were not in the labour force, not under the age of 16 or over the age of 65 and assumed to therefore be on the DSP.

A total of 17,761 people with cerebral palsy are therefore estimated to be on the DSP in 2018. However, it is likely that some of these people would have received DSP payments even in the absence of cerebral palsy, which must be netted out to estimate the additional welfare payments due to cerebral palsy. A University of Melbourne study (Tseng & Wilkins, 2003) estimates that the 'reliance' of the general population (aged 15-64 years) on income support is 13.2%.

According to the DSS annual report, as of June 2017, there were 758,911 people in Australia who were listed to have received the DSP, at a total cost of \$16.25 billion over 2016-17, or \$21,412 per person. This amount was adjusted to 2018 using CPI, which results in a per person cost of \$22,531. Using these inputs, it was estimated that **approximately \$347.35 million will be paid in DSP payments to people with cerebral palsy in 2018.**

Welfare payments to people caring for someone with cerebral palsy

There are two main income support measures available to primary carers:

- **Carer Payment** is a means-tested income support payment payable to people who cannot work full time because they provide home-based care to an adult or child who has a severe and long-term disability or health condition, or the equivalent amount of care to a number of less disabled people.³⁹
- **Carer Allowance** is a non-means tested income supplement for people who provide daily care to a person with a long-term disability or health condition.

Information on income support for carers of people with cerebral palsy was requested from DSS. These data are based on recipients caring for a person with cerebral palsy as the primary medical condition. Over 14,000 people are recorded as receiving welfare payments due to the care they provide someone with cerebral palsy. Using this information and applying the average carer payment and carer allowance to each respective cohort, it was estimated that **\$120.65 million was paid in welfare payments to people caring for someone with cerebral palsy in 2018.**

³⁸ Data obtained from DSS only included those DSP recipients who have undertaken a "Job Capacity Assessment", therefore it was advised that data received may not be an overall count of DSP recipients with 'Cerebral Palsy'.

³⁹ The person with cerebral palsy must also be in receipt of an income support payment.

Other welfare payments

Other welfare payments such as Newstart (unemployment benefits) and the sickness allowance have not been modelled due to the limitations of DSS data. These costs are assumed small and have negligible impacts on the overall cost of cerebral palsy.

6.6.2 Total efficiency losses

Table 6.2 shows the total resulting efficiency losses associated with cerebral palsy in Australia in 2018. All rates of efficiency loss include a 0.8% administrative loss which covers expenses of administering taxation (Australian Taxation Office, 2017). **The total efficiency losses associated with cerebral palsy was estimated to be \$553.59 million in Australia in 2018.**

Table 6.2 Efficiency loss due to cerebral palsy

Cost component	Rate of efficiency loss (%)	Efficiency loss (\$m)
Welfare payments	29.5	138.17
DSP	29.5	102.51
Carer pension	29.5	35.67
Lost consumer taxes	23.7	51.01
Lost company taxes	50.8	48.74
Lost carer taxes	23.7	19.35
Commonwealth health system expenditure	29.5	7.61
State/territory health system expenditure	45.0	6.46
Other government expenditure	29.5	282.23
Total	-	553.59

Source: Deloitte Access Economics calculations. Note: totals may not add due to rounding.

7 Wellbeing loss

This chapter adopts the 'wellbeing loss' methodology to quantify the impact of cerebral palsy on wellbeing. The approach measures pain, suffering and premature mortality in terms of disability adjusted life years.

Key findings

- The disability weight for cerebral palsy in Australia was calculated to be 0.23.
- The total wellbeing loss for cerebral palsy in 2018 was estimated to be \$2.15 billion, or \$60,458 per person with cerebral palsy.
- Overall, people with cerebral palsy experienced:
 - 8,061 years of healthy life lost due to disability (YLD), or 0.23 YLDs per person with cerebral palsy.
 - 6,099 years of life lost due to premature death (YLL), or 0.17 YLLs per person with cerebral palsy.
 - 14,160 disability adjusted life years (DALYs) overall, or around 0.40 DALYs per person with cerebral palsy.

7.1 Valuing life and health

The burden of disease (referred to as "wellbeing loss" in this report) methodology was developed by the World Health Organization (WHO) and is a comprehensive measure of mortality and disability from conditions for populations around the world. The wellbeing loss methodology is a non-financial approach, where life and health can be measured in terms of disability adjusted life years (DALYs). Disability weights are assigned to various health states, where zero represents a year of perfect health and one represents death. Other health states are given a weight between zero and one to reflect the quality of life that is lost due to a particular condition. For example, a disability weight of 0.2 is interpreted as a 20% loss in the quality of life relative to perfect health for the duration of the condition.

The wellbeing loss as measured in DALYs can be converted into a dollar figure using an estimate of the value of a statistical life (VSL). The VSL is an estimate of the value society places on an anonymous life. To overcome issues in relation to placing a dollar value on a human life, a non-financial approach to valuing human life is used.

As DALYs are enumerated in years of life rather than in whole lives it is necessary to calculate the value of a statistical life year (VSLY). In this report, a VSLY of \$197,482 was used. This is based on guidance published by the Office of Best Practice Regulation in the Department of Prime Minister and Cabinet (2014) and updated for inflation using the Consumer Price Index.

7.2 Estimating wellbeing loss due to cerebral palsy

Current practice, as used by the most recent Australian Burden of Disease Study (ABODS) (2016) and the most recent Global Burden of Disease Study (2013), is to assign disability weights based on the symptoms of cerebral palsy, rather than a single disability weight for the condition. This is because cerebral palsy is the umbrella term for a range of disorders, with the disability experienced by each person with cerebral palsy being different due to the differing functional limitations and associated impairments for each person.

For this report, a disability weight for cerebral palsy was estimated using permutations of functional limitations and associated impairments. Due to the varying levels of severities and associated impairments, seventy-five disability weights were calculated for different permutations. This provided individual disability weights to each GMFCS level (I to V) and five associated impairments: intellectual,

epilepsy, speech, hearing and vision. Each of the associated impairments had a disability weight assigned based on the level of associated impairment being no impairment, mild impairment and severe impairment. The calculation of only one permutation of impairment per GMFCS level (rather than multiple) means that disability weights may be considered conservative, as people with cerebral palsy sometimes have multiple associated impairments. However, given the information available, it was not possible to include multiple impairments in the modelling. It is important to note that the multiplicative approach to combining disability weights means that each additional impairment has a smaller effect than if it was considered on its own.

Using Delacy and Reid (2016), a study into the distribution of impairments among people with cerebral palsy, data were used to estimate the distribution of impairments by severity for the prevalence of cerebral palsy in 2018. The study, using state and territory data from the ACPR found that the proportions of persons with cerebral palsy with each associated impairment increased with increasing GMFCS levels.

The ABODS (2016) provides disability weights of mobility impairments for GMFCS levels I – II (mild), III (moderate), and IV – V (severe). These disability weights were 0.01, 0.061 and 0.402 for mild, moderate and severe respectively. Consistent with the ABODS approach, these three weights were mapped to the five GMFCS levels.

The ABODS also provides disability weights for the impairments of intellectual, epilepsy, speech, hearing and vision. For the purpose of this report, each disability weight for levels of impairment were averaged and assigned to “mild” or “severe” severities (when more than two severities were presented). These disability weights are shown in Table 7.1.

Table 7.1 Disability weights for each impairment.

Impairment	None	Mild	Severe
Intellectual	0	0.071	0.180
Epilepsy	0	0.263	0.552
Speech	0	0.051	0.051
Hearing	0	0.018	0.209
Vision	0	0.017	0.191

Source: ABODS (2016)

The disability weights for each GMFCS level and for “none”, “mild”, and “severe” levels of severity for the five associated impairments were then combined to establish seventy-five individual disability weights. Consistent with the standard approach for assigning multiple disability weights to a single person, multiplicative disability weights were calculated (Vos et al., 2012).⁴⁰ These are necessary, as multiple disability weights for a single person are not additive.⁴¹

Permutations have been limited to one additional impairment – so, for example, cerebral palsy with severe motor impairment plus both intellectual impairment and epilepsy was not mapped; rather only one additional impairment such as moderate motor impairment plus hearing impairment was mapped. Because of this, the overall disability weight is a conservative estimate; however, the multiplicative method of calculating multiple impairment means that each additional impairment would provide a

⁴⁰ To calculate multiplicative disability weights, the formula $1 - [(1 - DW1) \times (1 - DW2)]$ was used (where DW is the disability weight for each individual condition)

⁴¹ If disability weights are additive, for some people this may mean that the sum total of their medical conditions would result in their total disability weight being greater than 1. As a disability weight of 1 represents death, the multiplicative weights serve to limit the aggregate weight to less than 1.

diminishing marginal additional weighting, and as such may not have a large overall increase in the combined disability weight.

Using the proportions of people with cerebral palsy in each of the seventy-five permutations of motor impairment and associated impairments from Delacy and Reid (2016), **an overall disability weight for cerebral palsy based on the 2018 extrapolated prevalence was calculated to be 0.23.**

With these same data, it was also possible to calculate disability weights to show a relative weighting of cerebral palsy by different severities of motor impairment. This was calculated by using the same method as above. This shows that for those with cerebral palsy and severe motor impairment (GMFCS levels IV – V), the overall disability weight is far greater than for those with cerebral palsy and a mild motor impairment (GMFCS levels I – II). Table 7.2 below shows these individual relative disability weights for cerebral palsy.

The much larger disability weight for cerebral palsy with severe motor impairment (0.46), compared to cerebral palsy with mild motor impairment (0.05) is partly due to the increased likelihood of having an associated impairment and the relative severity of the associated impairment, as well as the greater burden of a high level of gross motor function disability. For the sake of comparison, cerebral palsy with mild motor impairment has a similar disability weight to that of moderate foetal alcohol syndrome (0.06), and cerebral palsy with severe motor impairment has a similar disability weight to that of metastatic cancer or tumour (0.45), as calculated by ABODS (2016).

Table 7.2 Calculated disability weights for severities of motor impairment plus associated impairments

Cerebral Palsy	Mild (GMFCS I – II) plus associated impairments	Moderate (GMFCS III) plus associated impairments	Severe (GMFCS IV - V) plus associated impairments
Disability weight ⁴²	0.05	0.11	0.46

Source: Deloitte Access Economics calculations.

7.2.1 Years of healthy life lost due to disability

Years of healthy life lost due to disability (YLDs) are calculated by using the disability weight estimated above and multiplied by the number of people with cerebral palsy estimated in Section 3. **Total YLDs for cerebral palsy in 2018 was therefore estimated to be 8,061, or 0.23 per person with cerebral palsy.**

7.2.2 Years of life lost due to premature death

Years of life lost due to premature death (YLLs) are based on the number of deaths associated with cerebral palsy (Section 3.2), and the years of expected remaining life at the age of death from standard life tables published by the (AIHW, 2016). **Total YLLs for cerebral palsy in 2018 were estimated to be 6,099, or 0.17 per person with cerebral palsy.**⁴³

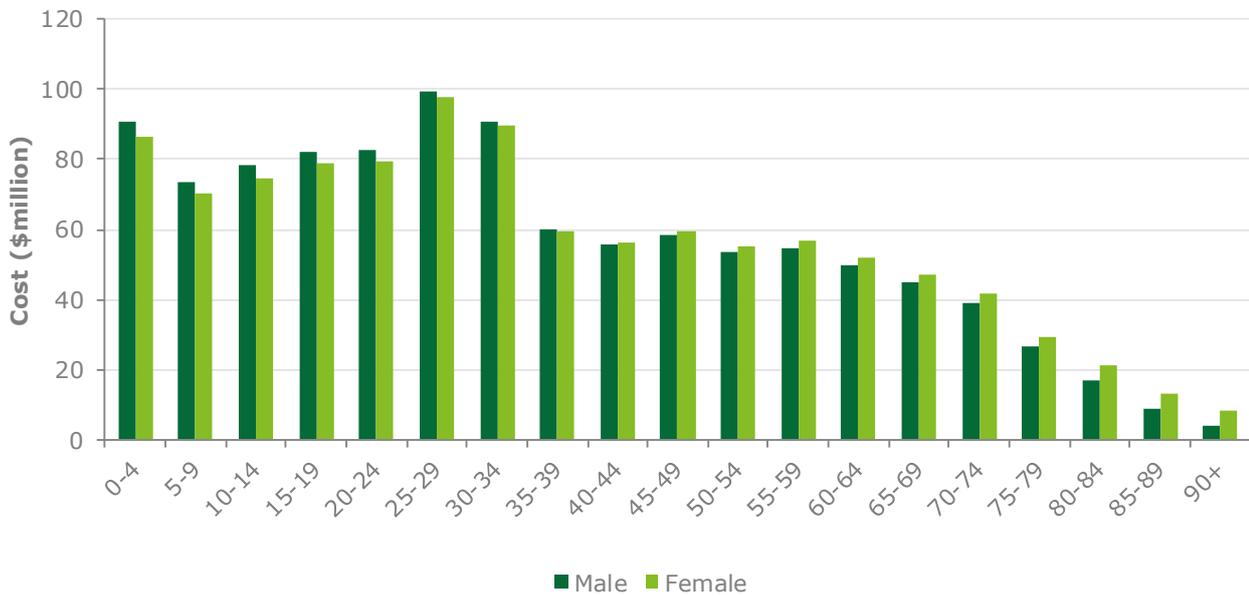
7.2.3 Total wellbeing loss

The DALYs are calculated by summing YLLs and YLDs. Total DALYs for 2018 are therefore estimated to be 14,160, or 0.40 per person with cerebral palsy. Applying the 2018 VSLY to the calculated DALYs, the total wellbeing loss was calculated to be \$2.15 billion in 2018. This translates into a wellbeing loss of \$60,458 per person with cerebral palsy. Chart 7.1 shows the total wellbeing loss by age and gender for 2018.

⁴² Disability weight for each severity of motor impairment includes the associated impairments and their prevalence.

⁴³ Consistent with the methods used in the ABODS, the YLLs due to cerebral palsy are not discounted. However, when converted to dollar terms using the VSLY, a 3% discount rate is used.

Chart 7.1 Total wellbeing loss from cerebral palsy



Source: Deloitte Access Economics calculations.

As can be seen, the wellbeing loss does not differ significantly by gender, as disability weights and the VSLY are not gender specific. The wellbeing loss is higher in the younger population, which reflects the higher prevalence in these age groups, as well as the lack of data on mortality in older age groups.⁴⁴

Compared to the results from the 2008 report, the wellbeing loss from cerebral palsy has decreased. This is driven by two methodological differences:

- The current best practice approach for estimating the disability weight for cerebral palsy is to build it up for each permutation of functional severity and associated impairments. This is different to the approach that was used at the time the 2008 report was undertaken, which used a higher disability weight.
- In 2008, the Office of Best Practice Regulation had not published guidance on the VSLY that should be used in valuing lost wellbeing. The VSLY used in the 2008 report was approximately 50% higher than the VSLY that, which increased the wellbeing loss from cerebral palsy.

⁴⁴ As mortality data in older age groups were not available, it was assumed that the mortality rate in these age groups matched the general population.

8 Cost summary and projections

This chapter summarises the total costs from cerebral palsy, and projects the extrapolated prevalence and costs of cerebral in 2060 under different scenarios.

8.1 Summary of costs

In 2018, it was estimated that cerebral palsy costs \$3.03 billion in financial costs, and a further \$2.15 billion in lost wellbeing. The total costs per person with cerebral palsy in 2018 were estimated to be \$145,642.

The largest component of costs is the lost wellbeing, at 41.5% of the total. This reflects the significant reduction in wellbeing experienced by people with cerebral palsy due to motor function limitation, and associated impairments. The next largest cost was for disability support services (21.6%), which includes both NDIS and non-NDIS costs and forms part of other financial costs. Significant costs also arise from lost productivity; due to the effect that cerebral palsy has on increasing the number of absences from work, reducing productivity while at work, and reducing employment participation rates.

The breakdown by type of cost is shown in Chart 8.1, and the breakdown by the bearer of the cost is shown in Chart 8.2. As can be seen, the largest cost burden is experienced by individuals, with large costs also borne by the federal government.

Chart 8.1 Total costs of cerebral palsy in 2018, by component (% of total)

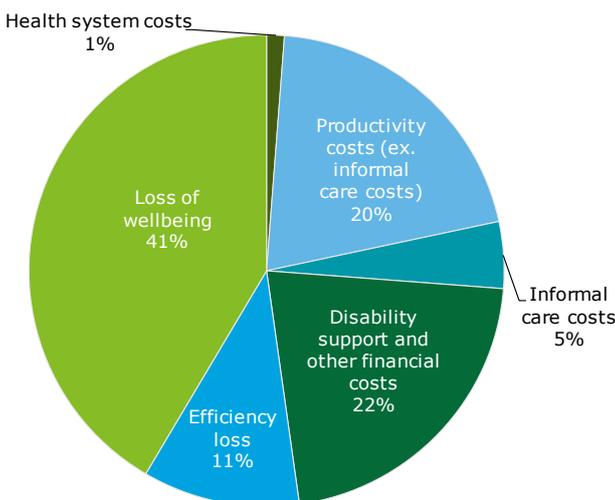
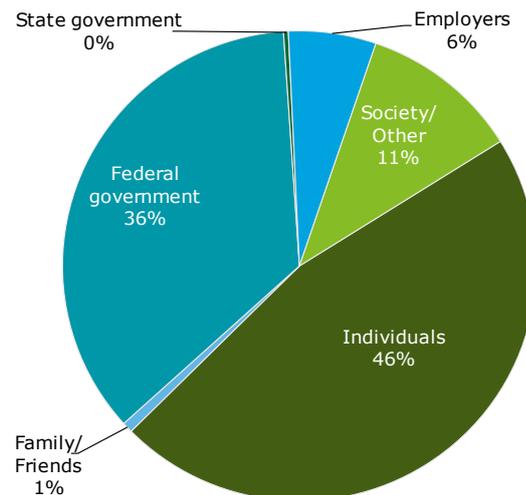


Chart 8.2 Total costs of cerebral palsy in 2018, by bearer (% of total)



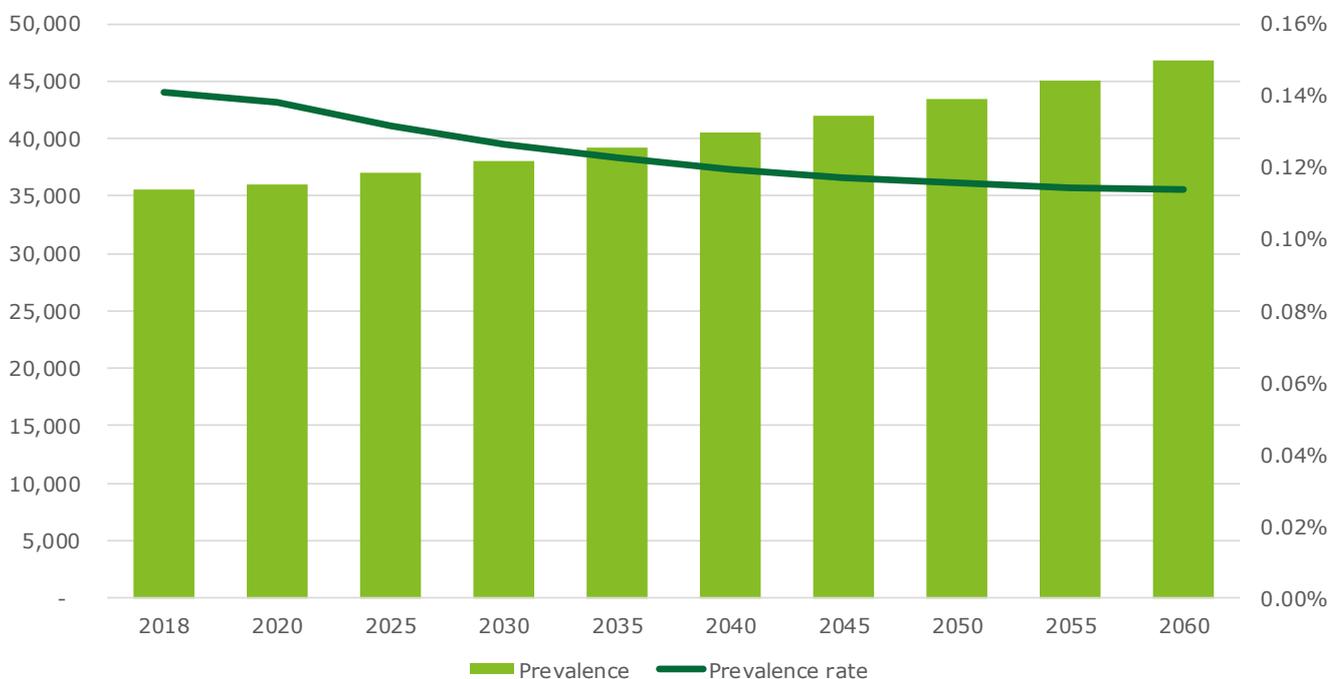
Source: Deloitte Access Economics calculations.

8.2 Extrapolated prevalence and costs of cerebral palsy in 2060

As discussed in Chapter 3, the birth prevalence of cerebral palsy has recently fallen to 1.4/1,000 live births, which is a decrease from previous levels of 1.9-2.1/1,000 live births. To analyse the effect that changes in the birth prevalence rate have on extrapolated prevalence and therefore on cost, the extrapolated prevalence and costs from cerebral palsy were projected to 2060 under different hypothetical scenarios for the birth prevalence rate.⁴⁵

For the baseline projections, the extrapolated prevalence of cerebral palsy over the period 2018-2060 was projected by applying the extrapolated incidence and mortality rates for 2018 against live birth projections (Series B) from the ABS (2013) out to 2060. The results of this analysis are shown in Chart 8.3.

Chart 8.3 Extrapolated prevalence of cerebral palsy (left) and extrapolated prevalence rate (right), 2018 to 2060



Source: Deloitte Access Economics calculations.

As shown in Chart 8.3, over this period the number of Australians with cerebral palsy is projected to increase from 35,522 in 2018 to 46,790 in 2060. However, this increase is driven by increases in the number of live births, as over this same period the prevalence rate of cerebral palsy is projected to decrease from its current level of 0.14%, to 0.11% in 2060.

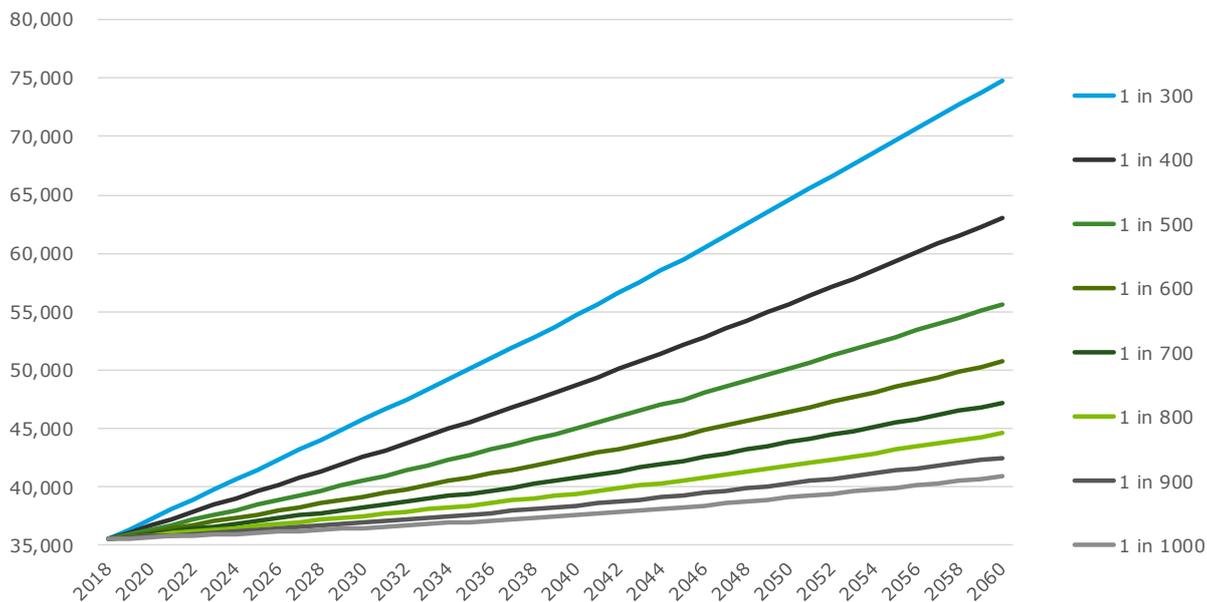
While incidence and mortality rates were held constant for estimating the extrapolated prevalence to 2060, recent evidence suggests that there may be a downward trend in the incidence of cerebral palsy. As such, alternative extrapolated prevalence projections were undertaken at different incidence rates⁴⁶, and are shown in Chart 8.4. The results in the chart were calculated by applying different estimated incidence rates from 2018 and holding these rates constant over 2018-2060. The rates were varied from 1 in 1,000 live births (a best-case scenario), through to 1 in 300 live births (a worst-case scenario), to

⁴⁵ As birth prevalence refers to the incidence of cerebral palsy in a particular year, it can take many years for a change in the birth prevalence to result in a material change to prevalence. As such, 2060 was chosen to allow sufficient time for a change in birth prevalence to result in a material change to prevalence.

⁴⁶ Mortality rates were held constant, reflecting that mortality rates have remained stable for a long period of time.

identify the impact that changes in the birth prevalence would have on extrapolated prevalence in 2060. The baseline projection (1.4/1,000 live births, shown in the chart as 1 in 700 live births), is included in the chart for context.

Chart 8.4 Extrapolated prevalence of cerebral palsy, 2018 to 2060, sensitivity analysis



Source: Deloitte Access Economics calculations.

The results in Chart 8.4 highlight the significant differences in extrapolated prevalence under different scenarios. The worst-case scenario – an increase in incidence to 1 in 300 live births – results in extrapolated prevalence of cerebral palsy increasing to almost 75,000 by 2060. The best-case scenario – a further decrease in incidence to 1 in 1,000 live births – results in 41,000 cases of cerebral palsy by 2060. This best-case scenario means there would be approximately 6,000 fewer cases of cerebral palsy in 2060, compared to the baseline projection at current incidence rates of 1.4/1,000 live births.

Projections of extrapolated prevalence at each GMFCS level were beyond the scope of analysis for this report. However, it is to be noted that recent studies have identified a decline in severity of disability among children with cerebral palsy (Galea et al., 2018), with the percentage of children with moderate to severe disability decreasing across Australian states between 1995 and 2009. If these trends continue, this would imply that by 2060 the proportion of people with severe cerebral palsy would have decreased from their current levels and the proportion of people with mild cerebral palsy increasing from their current levels.

To estimate the costs in 2060 under each scenario, the costs per person in 2018 were applied to extrapolated prevalence projections in each scenario. These are shown in Table 8.1.

Table 8.1 Extrapolated prevalence and cost projections under different scenarios

Scenario	Extrapolated prevalence, 2060		Costs, 2060 (\$b)		
	Count	Rate (%)	Financial	Wellbeing	Total
1 in 300	74,847	0.18	6.38	4.53	10.90
1 in 400	63,034	0.15	5.37	3.81	9.18
1 in 500	55,650	0.14	4.74	3.36	8.10
1 in 600	50,728	0.12	4.32	3.07	7.39
1 in 700⁴⁷	47,212	0.11	4.02	2.85	6.88
1 in 800	44,575	0.11	3.80	2.69	6.49
1 in 900	42,524	0.10	3.62	2.57	6.19
1 in 1,000	40,883	0.10	3.48	2.47	5.95

Source: Deloitte Access Economics calculations.

As shown in Table 8.1, the cost of cerebral palsy is projected to increase to \$6.81 billion in 2060, an increase from its current level in 2018 of \$1.64 billion. However, under a best-case scenario, where birth prevalence falls further to 1.0/1,000 live births, the cost in 2060 (in 2018 dollars) is projected to be \$5.95 billion, or \$860.28 million less than what baseline levels would be.

⁴⁷ 1 in 714 is the current incidence rate of 1.4/1000 live births and produces similar results to 1 in 700.

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