



# Australian & NZ Cerebral Palsy *Strategy*

**Images provided through community consultation will be added here and throughout the document**

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### Lead organisations



Cerebral Palsy Alliance is an international pioneer in research into cerebral palsy, and is a leading not for profit organisation committed to providing world-class services for people living with a broad range of disability and their families.

<https://www.cerebralpalsy.org.au/>

*Freedom and Choice*



The Cerebral Palsy Society of New Zealand's aims to enhance the lives and well-being of people with cerebral palsy in New Zealand, by empowering them to make their own choices. Through its membership, the Society offers practical every day programmes and awards grants for people with cerebral palsy, to enable access to items of service that assist in promoting independence and quality of life.

<http://www.cerebralpalsy.org.nz/>



Ability First Australia is one of Australia's largest, national, not for profit organisations, and is a strategic alliance of Australia's leading organisations

<https://abilityfirstaustralia.org.au/>



Cerebral Palsy Australia is the national peak body of organisations that work with people with cerebral palsy and people with similar disabilities and their carers.

<https://cpaustralia.com.au/>



The Australasian Academy of Cerebral Palsy and Developmental Medicine is a multidisciplinary professional academy that provides scientific education for health professionals, and promotes research and high quality clinical care standards for people with cerebral palsy and developmental conditions.

<https://ausacpdm.org.au/>

Members of the lead organisations have generously donated their time and expertise to this project, particularly those listed in Appendix A

### Steering committee

Nadia Badawi (Cerebral Palsy Alliance)  
Michael Bink (Ability First Australia)  
Shannon Clough (Consumer Representative)  
Jennifer Fitzgerald (Ability First Australia)  
Amy Hogan (Cerebral Palsy Society)  
Ingrid Honan (Cerebral Palsy Alliance)

Sarah Love (AusACPDM)  
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Iona Novak (Cerebral Palsy Alliance)  
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Andrew Rowely (Ability First Australia)  
Gilli Sinclair (Cerebral Palsy Society)  
Shirley Wong (Consumer Representative)

### Stakeholder Organisations

To ensure an extensive consultation process, representatives from key stakeholder organisations were invited to participate in the development of the Strategy and a survey was constructed to elicit feedback. The organisations and individuals involved in the development of the strategy are listed in Appendix D.

### Endorsing organisations and individuals

A list of organisations and individuals endorsing the strategy are listed in Appendix E.

The structure of the Australia and New Zealand Cerebral Palsy Strategy has been based on the format of the National Allergy Strategy.

The Strategic Action Plan is not an exhaustive list, but rather aims to provide a guide for the implementation objectives

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## 1.0 Mission, Vision, Goals, Subdomains and Guiding Principals

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### 1.1 Mission

The mission of the Australia and New Zealand Cerebral Palsy Strategy is to improve the health, participation and quality of life of individuals with Cerebral Palsy, through excellence in research, enhanced community knowledge, and provision of optimal healthcare and disability support. This will help achieve an inclusive and accessible society.

### 1.2 Vision

Our ultimate vision is a world without cerebral palsy. In the meantime, our vision is that every person with cerebral palsy has a positive quality of life, with the opportunity to fully extend themselves and live a meaningful life.

### 1.3 Goals

Quality of life is seen as an over-arching goal of this strategy document and is thus considered a necessary component of each goal outlined below and a benchmark with which to measure success. Quality of life for the purposes of this strategy includes all individual, community and societal factors that contribute to an individual's overall quality of life.

#### ***Inclusion and Engagement***

To promote accessible inclusion, engagement and participation in all aspects of life, from an individual level to community and societal levels for individuals with cerebral palsy.

#### ***Health Outcomes***

To improve health outcomes across the life-span for individuals with cerebral palsy to minimise morbidity and ensure life expectancy is in line with the broader population.

#### ***Intervention and Disability Support***

To provide effective and timely, evidence based treatments and supports to ensure optimal outcomes for individuals with cerebral palsy and their families.

#### ***Cure and Prevention***

To prevent future incidence of cerebral palsy and reduce the primary neuro-pathology for those currently living with cerebral palsy, with the goal of finding a cure.

### 1.4 Sub-domains under which goals will be addressed

**Support:** Person centred, high-quality formal and informal supports will enable individuals to exercise their right to choice and control and assist them to achieve their functional goals such as employment, education, communication, accommodation, and self-care.

**Advocacy:** To address social injustices experienced by those with cerebral palsy and to continue to make significant advances in all goal domains, community and policy advocacy will form a large component necessary to achieve the goals of this strategy.

**Research:** Research is necessary to inform all goal domains and ensure continued development, progress and reform. Maximising international connectedness will further facilitate this.

**Knowledge translation:** Increasing knowledge translation at multiple levels of society including for direct consumers, support networks, health professionals and the broader

community will lead to increased sense of empowerment and competency, and foster an understanding, accessible and accepting society.

### 1.5 Important Terminology

**People with cerebral palsy** – Anyone with a diagnosis of cerebral palsy, regardless of whether they are accessing supports or services for their disability.

**Clients** – Individuals with cerebral palsy, or families/carers of people with cerebral palsy, who are accessing supports or services.

**Support network** – All informal and formal supports for the individual with cerebral palsy, including but not limited to friends, family, colleagues, health professionals, therapists, and any other individuals involved in the care, assistance, or service provision for the individual with cerebral palsy.

**Community** – The broader network, geographical area and social structure in which the individual with cerebral palsy lives.

*The order of goals and subdomains is not intended to be hierarchical in nature, but reflect equally important areas of need in the field of cerebral palsy*

## 2.0 Background

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### 2.1 Definition and Impact

'Cerebral palsy' describes a cluster of permanent physical disabilities affecting an individual's movement and/or posture. It is caused by non-progressive damage to the developing brain typically during the antenatal or perinatal period. Although the primary neuropathology of cerebral palsy is non-progressive in nature, the clinical presentation can change throughout the life-span, impacting aspects of body movement, muscle control/coordination and posture and balance. People with cerebral palsy are also more likely to experience associated problems including chronic pain, epilepsy, intellectual impairment, vision impairment, hearing impairment, sleep disorders, behavioural difficulties, feeding difficulties and communication difficulties at significantly higher rates than the general population.

### 2.2 Presentation and Classification

The presentation of cerebral palsy is unique to each individual and varies by type and severity. The Gross Motor Classification of Function System- Extended and Revised (GMFCS-E&R) is a system used to understand the severity of cerebral palsy. This system has severity levels from 1 (minimal functional motor impairment) to 5 (significant functional motor impairment) and uses the individual's movements including sitting and walking, with and without mobility aids, to provide clinicians and families with a clear description of the person's functional motor abilities. Cerebral palsy is also classified according to both the degree of impact on various limbs and the predominant type of muscle or movement impairment. Quadriplegia occurs when all four limbs are affected by cerebral palsy, with core muscles such as mouth, face and trunk often also impacted. Diplegia occurs when both legs are impacted more severely than the arms, and hemiplegia (unilateral cerebral palsy) occurs when one side of the body is impacted. Types of muscle or movement impairments include spasticity (occurring in over 80-90% of all cerebral palsy cases); dyskinesia (occurring in 5-15% of all cerebral palsy cases); Ataxia (occurring in less than 5% of all cerebral palsy cases).

### 2.3 Risk Factors

A number of risk factors are associated with increased risk of cerebral palsy antenatally, perinatally, and postnatally including prematurity, low birth weight, bacterial and viral infections, oxygen deprivation, severe jaundice and trauma; however, the direct casual pathway leading to the brain injury is often unknown. In Australia, The Australian Cerebral Palsy Register report (2013) identified that when compared to the general population, infants with cerebral palsy are more likely to be male, premature, have low birth weight for gestational age and from a multiple birth. Specifically, 41% of infants with cerebral palsy were born prematurely and/or had low birth weight for gestational age, compared to 8.2% and 6.4% of the general Australian population, respectively.

### 2.4 Burden

Cerebral palsy is the most common physical disability in childhood. Internationally, some 17 million people are estimated to have cerebral palsy. In Australia, 1 in 500 children are diagnosed with cerebral palsy, and approximately 34,000 people currently live with the condition; a number which is expected to increase to 47,601 by 2050. The cost of caring for people with cerebral palsy within Australia is estimated at \$43,431 per person per year, with the estimated total expenditure cost of cerebral palsy in Australia \$1.47 billion per year. When including the value of lost wellbeing, this cost increases to over \$115,000 per person per annum, and a national annual cost of \$3.87 billion. Individuals with cerebral palsy and their families bear 43% of these financial costs directly; the Federal Government bears around 33% (mainly through taxation

revenues forgone and welfare payments); state governments bear under 1%, employers 5% and the rest of society approximately 19%. If burden of disease and loss of wellbeing is included, individuals with cerebral palsy bear 76% of these costs personally.

Although a range of research activities are currently underway in both in prevention and treatment, and a range of evidence based services are available, a targeted national strategy is necessary to identify areas of need, optimise resource efficiency, promote knowledge transfer and increase viable funding options. As demonstrated, creating such strategy has considerable potential for benefit at an individual, societal and economic level.

### **3.0 International Conventions and Australian Legislation**

Whilst this strategy identifies domains for continued work for cerebral palsy in Australia and New Zealand, it is important to acknowledge structures already in place internationally and nationally which support the rights of people with cerebral palsy. Through this, it will be possible to understand how the domains outlined in this strategy enact and advance existing conventions and legislation.

#### ***3.1 Rights of Persons with Disability***

The United Nations Convention on the Rights of Persons with disability was established in December 2006 and ratified in Australia in 2008.

The purpose of the convention “is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” (Convention on the Rights of Persons with Disabilities and Optional Protocol). This is achieved through the convention detailing the rights of individuals with disability and providing a framework through which countries can protect the rights of individuals with disability and dispel practices that constitute discrimination. The primary principles of the convention focus around: respect for individual dignity; autonomy; independence and decision making; removing discrimination; participation and social inclusion; respect and acceptance of diversity; equal opportunity (including that between males and females); accessibility; and respect for the evolving ability of children with disability.

The primary principles of the Convention on the Rights of Persons with Disability are legislated in Australia via the Disability Discrimination Act 1992; the most recent amendment of which occurred in June 2015. This Act stipulates that it is against the law to discriminate on the basis of disability in Australia in the areas of employment, education, accommodation, sport, access to premises, provision of goods, services or facilities, purchasing of land, activities of clubs and associations, and in the Administration of Commonwealth Government laws and programs (eg voting facilities).

Despite the ratification of the convention and enactment of legislation against discrimination on the basis of disability in Australia, a report by the National People with Disabilities and Carer Council in 2009, ‘Shut Out: the Experience of People with Disabilities and their Families in Australia’ highlighted ongoing concerns for people with disability in Australia particularly with regard to employment, supports and services, access, education, social inclusion and community participation. As such,

the National Disability Strategy 2010-2020 was developed to help advocate for disability related issues in the public policy arena, to guide government in both mainstream and disability-specific areas of policy making, to improve access to services for people with disability, and to promote inclusion of people with disability. The National Disability Strategy encompasses the following key policy areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing.

The international classification of functioning, disability and health (ICF), established by the World Health Organisation and endorsed by all Member States in 2001, provides a uniformed framework for conceptualising 'health' and 'disability' internationally. The ICF focuses on functioning and impact, which goes beyond traditional medical models of specific diagnoses, and instead looks at how a range of abilities, impairments and limitations interact with environmental, contextual and personal factors, and all contribute to an individual's functioning.

In line with the ICF focus on function and person centeredness, and to further protect the rights of Persons with Disability, the funding model for disability In Australia has undergone recent reform with the enactment of the National Disability Insurance Scheme Act 2013 and subsequent establishment of the National Disability Insurance Agency (NDIA), implemented nationally from the 1<sup>st</sup> of July 2016. This Act has established a new way of providing individualised funding support for people aged 0-65 with a disability, their families and their careers. Funding packages are provided based on the level of reasonable and necessary support an individual requires to lead an average life, which includes achieving goals such as independence, community involvement, employment and overall wellbeing. Unlike previous disability funding models, the NDIS enables the individual with disability to exercise choice and autonomy over their own support and goal achievement, and aims to provide a consistent approach to disability and service provision nationally. The National Disability Insurance Act also acknowledges the important potential for early intervention in moderating future disability and this is thus provided for under the Act.

Despite a number of positive actions undertaken to implement the key principles of the Convention on the Rights of People with Disability, a review at the Committee on the Rights of Persons with Disabilities 10th Session (September 2013) raised a number of significant ongoing concerns around the treatment of people with disability in Australia. Areas of particular concern raised included rates of employment, over representation of people with disability in the criminal justice system, vulnerability of Aboriginal people with disability, high rates of violence, abuse and exploitation of women with disability, the existence of institutionalised accomodation services, a lack of unifom legislation prohibiting sterilisation and other medical intervention without informed consent for people with a disability, a lack of knowledge around effecitveness of education policies for children with disability, and general concerns around the lack of choice for people with disability.

### ***3.2 Rights of the Child***

In addition to rights surrounding disability, children with cerebral palsy's rights are also protected under the Convention on the Rights of the Child. The United Nations Convention on the Rights of the Child was established in 1989 and ratified in Australia in December 1990. The Convention aims to protect and promote a child's right to not just survive free from hunger, want, abuse and neglect, but their right to thrive, learn, grow, reach their full potential and to have their voices heard. The convention is founded on the guiding principles of non-discrimination, the best interests of the child, the right to life, survival and development and the right to participate. These are

considered underpinning requirements necessary to realise the rights covered by the convention. Within this context, rights can be summarised under three categories: rights to survive and develop; rights to protection, and rights to participate. It outlines that children are not the property of a parent nor objects of care, but more highlights children as individual human beings, with their own rights and responsibilities appropriate to their age and development, existing as members of a family and a community. It expressly recognises parents' paramount role in the raising of children, and the importance of adapting parenting and disciplining styles to address issues of rights relative to age and development. Specific environmental factors, resources, skills and contributions necessary to achieve the rights for all children internationally are incorporated.

Although the Convention on the Rights of the Child was ratified in Australia in 1990, Australia is yet to develop a national Act expressly protecting the rights of the child. All states have implemented measures protecting the rights of the child and some rights of the child are innately protected under other national legislation such as the Disability Discrimination Act, Family Law Act, The Education and Care Services National Law Act 2010 and the Australian Education Act. Furthermore, in 2009 a "National Framework for Protecting Australian Children 2009-2020" was developed along with a "National Early Childhood Development Strategy", in 2010 "the National Plan to Reduce Violence Against Women and their Children 2010-2022" was developed and in 2015 the "Disability Standards for Education 2005" were reviewed which further support specific rights of children. Nevertheless, a lack of national legislation specifically pertaining to the rights of the child has resulted in fragmentation of state based systems and inconsistencies with regards to the degree to which rights are enforced and upheld.

#### **4.0 New Zealand Policy and Legislation**

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The New Zealand disability policies are complex and often contradictory. Multiple agencies are involved and each has their own requirements and expectations of how the policies should be executed and enacted. Fundamentally however, New Zealand and its successive governments has been an active contributor in the promotion of the rights of individuals with disabilities and their families.

The first Minister of Disability Affairs was appointed in 1999 specifically to oversee the Government's support of individuals with disabilities within society such as advocating for specific programmes and ensuring the entitlements that are already in place are accessible to as many people as possible. In 2008, New Zealand became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Subsequently, New Zealand is required to report on our progress in ratifying the key tenants of the CRPD.

In 2000, New Zealand launched the New Zealand Disability Strategy which is a government framework which aims to remove the barriers for disabled people to fully participate in society. For example, the key objectives include fostering leadership amongst the disabled youth, promote respect for disability amongst the general public, provide access to education and opportunities for employment and to collect relevant and specialized information on disability to enable effective advocacy. The government is responsible for regularly reporting on its progress in implementing the original strategy objective and the subsequent policy amendments.

In principle if not entirely in practice, New Zealand disability policies adhere to the social model of disability, which stipulates that society needs to be adapted around disabled individuals rather than individuals having to adapt to a society that is

inherently problematic to them in terms of access and acceptance. In recent years, there have been a number of advocacy movements to promote this in a very tangible way. For example, in 2009, the government introduced Individualised Funding, which states that the person with disabilities should be able to select their care givers by having control of their funding package. In 2013, several challenges were made to the long-standing policy that parents could not be paid for their care of severely disabled adult children. New Zealand is also ratifying several obligations to make major cities such as Auckland and Christchurch reach a baseline of accessible transport and universal design. As of 2016, the Department Of Conservation (DOC) has also agreed to make a minimum number of walkways accessible to wheelchairs.

As previously stated, New Zealand's disability policies are not without problems and contradictions, however we are active in our attempts at both practical and political aspirations for the rights of people with disabilities.

## **5.0 A Case for Change**

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**This section will likely be significantly shaped by community consultation once common priorities have been identified.**

Cerebral palsy is the most common physical disability in childhood. Children grow up to become adults. Individuals with cerebral palsy make up some of the most vulnerable individuals in society. To date however, a united voice advocating with and for individuals with cerebral palsy in Australia and New Zealand has been lacking. Now is the time for change.

Despite the frequent incidence of cerebral palsy, support services and research remains under-funded. Furthermore, the complexity of needs associated with cerebral palsy means that there is a great financial burden for individuals, families and society. As such, a framework outlining goals and priority objectives is necessary. This framework, informed by consumers as well as leading practitioners, researchers and service providers across the country, will allow a targeted approach, foster collaborative efforts, increase efficiency of expenditure and assist with advocacy.

With the National roll-out of the National Disability Insurance Scheme in Australia upon us, the timing is imminent. This framework will help ensure we continue to develop and offer the best available evidence based treatments, services and supports. Addressing the areas of priority outlined in this document will also better enable us, to guide the National Disability Insurance Agency and consumers about supports and services that are reasonable and necessary in order to live an ordinary life.

Having achieved major inroads thus far, such as reducing the potential detection age from approximately 2 years to 12 weeks of age, developing neuroprotective techniques resulting in a significant reduction in the incidence of cerebral palsy, developing national registers, developing and implementing a surveillance clinic for children with cerebral palsy (CP Check-Up™), and establishing a global network for prevention and cure (IMPACT for Cerebral Palsy), we are excited about what the future holds and what we can achieve with the framework of this strategy.

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## 5.2 Strategic Action Plan

### GOAL 1: Inclusion and Engagement

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**To promote active, accessible inclusion, engagement and participation in all aspects of life, from an individual level to a community and societal level for individuals with cerebral palsy.**

*Inclusion, engagement and participation has been demonstrated to have a range of positive impacts on a number of life areas.*

*Deepening our understanding of the personal and environmental factors necessary to achieve a truly inclusive society and active participation, will make it possible to develop initiatives to foster these attributes and eliminate barriers.*

*Understanding life experiences and how these shape personal attributes such as motivation and self-determination will enable us to fully understand the long-term impacts of barriers on shaping an individual and their perspective.*

*Promoting community building by educating and advocating for the benefits of engagement and active participation at all levels, from the individual level to the community and policy level is crucial in order to promote inclusion.*

*Ensure community structures and systems such as health, education and aged care systems, facilitate the inclusion of individuals with cerebral palsy*

#### **Priority Objectives**

- To understand the mechanisms of benefit associated with greater participation.
- To identify determinants of greater participation.
- To develop initiatives to promote and foster participation.
- To provide outstanding support to assist people to participate to their fullest potential.
- To determine skills necessary to achieve a desired participation outcome, and create effective strategies to develop these skills.
- To provide services which encourage multilevel participation.
- To promote a sense of motivation, self-efficacy and ownership over one's own participation.
- To better understand the role of social and support frameworks in shaping engagement and thus quality of life.
- To examine the role of learnt behaviour and past experience on participation.
- To examine the role of personal characteristics on participation.
- To understand and address barriers (such as access and quality when available) to participation in:
  - Education
  - Employment
  - Physical activity
  - Leisure
  - Social inclusion/peers
  - Meaningful relationships
  - Community

- Preventative health
- To understand the role of technology in participation.
- To develop tools to accurately measure participation.
- To educate individuals with cerebral palsy and their family/carers on the benefits of participation.
- To develop resources to inform people with cerebral palsy and their families of participation opportunities available in their community.
- To understand and address the relationship between Cerebral Palsy and poverty.
- To advocate for the acceptance and inclusion of individuals with cerebral palsy in activities and community.
- To advocate policy makers for the rights of individuals with cerebral palsy to participate in all aspects of community.
- To examine differences in engagement and quality of life of individuals with cerebral palsy internationally and identify the strengths and weaknesses of policies or social structures.
- To determine what policies are needed to improve quality of life for families caring for Australians with cerebral palsy.
- To influence government and policy makers to protect and support the rights of individuals with cerebral palsy, to help reduce negative societal influences on engagement and inclusion.

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## 5.3 Strategic Action Plan

### GOAL 2: Health Outcomes

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**To improve health outcomes across the life-span for individuals with cerebral palsy to bring them in line with population averages.**

*Recognising the diverse range of health related needs across the life span of individuals with cerebral palsy is the first step necessary to improve health related outcomes.*

*Accessible and appropriate health services are required in order to help bridge the gap between health outcomes for individuals with cerebral palsy the broader population.*

*Developing a sense of competency amongst practitioners and allied health professionals in meeting the health related needs of individuals with cerebral palsy will increase the accessibility and quality of health services.*

*Understanding the impact of health on overall functioning, participation and quality of life will assist in advocating for the rights of individuals with cerebral palsy to have their health related needs met.*

*Promoting the role of general preventative and sexual health care for individuals with cerebral palsy, family members, practitioners, therapists, support workers, and the broader community, whilst supporting the individual's right to freedom of choice, is necessary.*

*Improving access to general health services and educating physicians so that individuals with cerebral palsy can have their health related needs reviewed, managed and co-ordinated by a single professional.*

#### **Priority Objectives**

- To determine the best early intervention approaches for preventing and minimizing impairments associated with cerebral palsy.
- To determine the most effective methods to manage secondary difficulties associated with cerebral palsy, such as pain and poor sleep, to reduce the impact on functioning.
- To understand the complex individual and societal mechanisms resulting in poor general health outcomes across the life span for people with cerebral palsy.
- To effect change to reduce the gap between general health outcomes for people with cerebral palsy and typically developing people.
- To understand determinants of mental health and well-being for people with cerebral palsy.
- To strive to promote the development of personal attributes associated with a positive well-being and thus quality of life, such as self-esteem, self-concept and self-efficacy.
- To take steps to re-dress causes of poorer mental health and well-being for people with cerebral palsy.
- To improve the process of transitioning between service sectors (e.g. paediatric to adult health systems, or disability to aged care funding systems)
- To understand the patterns of utilisation of health services by people with cerebral palsy.
- To identify the barriers for people with cerebral palsy in utilising preventative health services.

- To address inequalities in access to preventative health services.
- To influence societal change in the way in which people with cerebral palsy are viewed in relation to their general health needs.
- To address stigmas and inform people with cerebral palsy, partners, carers and practitioners about sexual health needs.
- To increase the sense of competency of health practitioners in meeting the health related needs of people with cerebral palsy.

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## 5.4 Strategic Action Plan

### GOAL 3: Intervention and Disability Support

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**To provide effective, individual, goal-based intervention and disability support to help individuals optimise their potential and achieve their goals.**

*Continuously refining and implementing best available early detection methods will allow for the provision of early intervention and support, in an attempt to reduce the severity of symptoms associated with cerebral palsy.*

*Adopting a person-centred, integrated approach to intervention and disability support will provide the best possible outcomes for people with cerebral palsy. Evaluation of efficacy of interventions and disability supports should be considered in the context of functional goals. Multi-disciplinary and innovative approaches utilising advances in technology should be explored.*

*An integrated approach to research and service provision will allow for ongoing development and evaluation of best available evidence based interventions and supports.*

*Translation of research, equipping health providers and individuals with cerebral palsy alike with the skills, knowledge and competency to provide or select appropriate intervention options, is paramount.*

#### **Priority Objectives**

- To develop evidence based treatments, compensatory strategies and support services effective in improving the functional ability and/or quality of life of people with cerebral palsy.
- To establish appropriate tools with which to evaluate efficacy of interventions and supports.
- To develop support frameworks to optimise quality of life for both people with cerebral palsy and their families.
- To consider the pros and cons of all support services, interventions, therapies and procedures on quality of life.
- To examine the long-term outcomes of interventions and supports.
- To determine the optimal intensity of interventions and supports.
- To offer timely, high quality, evidence based access to interventions and supports.
- To research the role of technological advances in intervention and provision of support for people with cerebral palsy to improve quality of life.
- To collaborate with commercial business to identify opportunities for making technology more accessible and viable to assist with intervention and supports.
- To establish and promote support structures to meet all the needs of individuals with cerebral palsy, not just physical needs.
- To understand the role of parents and siblings in providing therapy and support.
- To understand the impact of different forms of treatment, therapy and support on parents and siblings of people with cerebral palsy.
- To develop support frameworks to optimise quality of life for both people with cerebral palsy and their families.

- To understand interventions and supports in the context of the environment in which they are delivered.
- To investigate the most effective methods of educating parents to help improve their child's independence and function.
- To disseminate knowledge regarding efficacy of available treatments and supports to help guide people with cerebral palsy and their parents/carers to make informed decisions.
- To disseminate knowledge regarding efficacy of available interventions and supports to help guide funding bodies to make informed decisions about expected costs associated with meeting the treatment and support needs of individuals with cerebral palsy.
- To advocate for the provision of evidence based interventions, services and supports.
- To investigate the therapeutic potential for alternative therapies and support mechanisms to address factors associated with cerebral palsy.
- To provide unbiased advice to inform regulatory decisions around the integrity of intervention options.
- To address the gap between the intervention and supports that people with CP and their families need, and what they actually receive.
- To reduce time gaps between when technology or supports are discovered/created, and when they become financially and physically available for individuals with cerebral palsy.
- To develop an efficient service model so that maximal services reach people with CP and their families.
- To advise regulatory bodies and individuals with CP with regards to changes to policy areas and likely ramifications.
- To empower individuals with cerebral palsy and their families to advocate for their rights to intervention and support.
- To foster competency and ownership of professionals to treat and support individuals with cerebral palsy with complex needs.

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## 5.5 Strategic Action Plan

### GOAL 4: Cure and Prevention

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**To prevent future incidence of cerebral palsy and reduce the primary neuropathology of those currently living with cerebral palsy, with the goal of finding a cure.**

*Better understanding of the casual pathways of cerebral palsy is the first step necessary to developing effective preventative and/or curative strategies. This will enable and enhance investigations into new neuro-protective and neuro-regenerative techniques, such as stem cells, which may hold the potential to provide therapeutic or curative outcomes for individuals with cerebral palsy.*

*Furthermore, examining trends of cerebral palsy nationally and internationally, particularly in relation to antenatal and perinatal health policy and resources, will provide insight regarding aetiologies and efficacy of therapeutic techniques or care related initiatives.*

*Identifying and advocating for viable funding options to continue to make leading medical advances and to reduce the incidence and severity of cerebral palsy will be crucial to continue this work.*

#### **Priority Objectives**

- To map population level incidence data nationally and internationally.
- To better understand the relationship between genomics and cerebral palsy.
- To identify causes of cerebral palsy.
- To identify potential neuro-protective techniques to reduce the frequency of cerebral palsy.
- To identify potential neuro-regenerative techniques to reduce the severity of cerebral palsy.
- To conduct rigorous randomised control trials to ensure quality and consistency of evidence.
- To translate advances of best practice in the prevention and severity reduction of cerebral palsy into mainstream practice
- To advocate for practitioners to have access to and remain abreast of best available evidence.
- To provide expert guidance to policy makers around the appropriateness and efficacy of policy initiatives in preventing and reducing the impacts of cerebral palsy.
- To understand policy and practices implemented internationally and how these influence incidence and severity of cerebral palsy.
- Advocate for the importance of preventative and curative research through traditional and non-traditional funding sources.
- To remain abreast of new discoveries and flexible within a dynamic and fast moving space.
- To investigate advances in research and clinical practice for other conditions and examine any implication/relevance for the field of cerebral palsy.
- To collaborate with individuals with cerebral palsy and their families to integrate their perspectives and priorities in all we do.

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## **6.0 A Plan to Measure Success**

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**This section will be shaped by priorities identified through community consultation**

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## **7.0 Concluding Remarks**

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**These will be shaped based on priorities identified through community consultation**

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