



The Australia and New Zealand Cerebral Palsy (CP) Strategy aims to identify and outline goals for Cerebral Palsy. The document will be the first of this kind in Australia and New Zealand. The Strategy will involve research, clinical and social issues on CP. Identifying common goals and priorities will help us to better meet the needs that people with CP want met; form collaborative networks to work towards common goals; and provide a voice to influence policy, systems, society and practice across Australia and New Zealand.

To create this document we would like input from people with CP, family members and professionals in the field. So far we have written a first draft of the strategy within a working group, and we have included some key areas here for feedback. However, please do not feel limited by what is here. If you have suggestions beyond what is here, about what you feel a strategy should say/do, please feel free to include this in your feedback. The strategy will also need to measure success towards the objectives over time, so please feel free to include feedback about this. All comments and feedback is very welcome!

The general outline of the draft so far is: mission, vision, goals, background information and a case for change. Then there is a strategic action plan which is broken into four goals, with priority objectives under each goals.

Below are some excerpts from the strategy that we would particularly like to seek your feedback on.

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 CP, through excellence in research, enhanced community knowledge, and provision of optimal healthcare and disability support. This will help achieve an inclusive and accessible society.

Vision

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

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***
- ***Health Outcomes***
- ***Intervention and Disability Support***
- ***Cure and Prevention***

Priority Objectives

Within each goal, priority objectives will be listed under the broad areas of:

- ***Support***
- ***Advocacy***
- ***Research***

- **Knowledge translation**

Goal 1) Inclusion and Engagement

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 CP.

Examples of Priority Objectives:

- **Support:** To provide services which encourage multilevel participation.
- **Advocacy:** To advocate policy makers for the rights of individuals with cerebral palsy to participate in all aspects of community.
- **Research:** To examine the role of learnt behaviour and past experience on participation.
- **Knowledge Translation:** To develop resources to inform people with cerebral palsy and their families of participation opportunities available in their community.

Goal 2) 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.

Examples of Priority Objectives:

- **Support:** To improve the process of transitioning between service sectors (e.g. paediatric to adult health systems, or disability to aged care funding systems)
- **Advocacy:** To influence societal change in the way in which people with CP are viewed in relation to their general health needs.
- **Research:** To identify the barriers for people with CP in utilising preventative health services.
- **Knowledge Translation:** To increase the sense of competency of health practitioners in meeting the health related needs of people with CP.

Goal 3) Intervention and Disability Support

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

Examples of Priority Objectives:

- **Support:** To develop support frameworks to optimise quality of life for both people with CP and their families.
- **Advocacy:** To provide unbiased advice to inform regulatory decisions around the integrity of intervention options.
- **Research:** To understand the impact of different forms of treatment, therapy and support on parents and siblings of people with CP.
- **Knowledge Translation:** To disseminate knowledge regarding efficacy of available treatments and supports to help guide people with CP and their parents/carers to make informed decisions.

Goal 4) Cure and Prevention

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

Examples of Priority Objectives:

- **Support:** To collaborate with individuals with CP and their families to integrate their perspectives and priorities in all we do.
- **Advocacy:** To advocate for practitioners to have access to and remain abreast of

best available evidence.

- **Research:** To identify potential neuro-protective techniques to reduce the frequency of CP.
- **Knowledge Translation:** To translate advances of best practice in the prevention and severity reduction of CP into mainstream practice

Measurability:

This refers to how we will measure success towards these goals. Examples of measurability are outlined below. Feedback from consultation will be used to help shape measurability included in the strategy:

- Reduction in incidence of CP in Australian to 1 in 600 births
- Reduction in severity of CP, as measured by GMFCS level
- Increased expenditure proportionally on CP related research
- Integration between health and disability sectors to better meet needs
- Increased availability of evidence based interventions/therapies across the life-span
- More publically available resources for people with CP and families of people with CP
- Satisfaction with NDIA funding across the lifespan and severity level.
- Improved quality of life as measured by (?). Your feedback on what best reflects real life improvements in quality of life would be valued. E.g. increased time spent in community?

Review Period:

We hope that this strategy will continue to evolve and provide direction as new priorities arise. If you have suggestions on a recommended review period, please feel free to provide them.

