Australian & NZ Cerebral Palsy Strategy

2020

Contributing Authors

Australian and New Zealand Cerebral Palsy Strategy Collaboration

A collaboration consisting of representatives from cerebral palsy organisations and consumer representatives from Australia and New Zealand.

Lead organisations

Ability First Australia is a not-for-profit strategic alliance between 14 of Australia's leading disability service providers, with member organisations in all states and territories. Our members have a long and trusted history, having supported people with disability for between 50 and 85 years.
https://abilityfirstaustralia.org.au

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

Cerebral Palsy Australia is the national peak body of organisations that work with people with cerebral palsy as well as 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

The Cerebral Palsy Society of New Zealand 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 everyday programs 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

Working Group

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Acknowledgements

Expert Panel

An Expert Panel of professionals and key influencers in the field of cerebral palsy provided additional consultation throughout development and drafting of The Strategy. These individuals were invaluable in providing a breadth of stakeholder perspectives.

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Groups/organisations represented by the Expert Panel

- CP Quest
- NHMRC Clinical Centre of Research Excellence the Australasian Cerebral Palsy Clinical Trials Network
- Centre of Research Excellence in Cerebral Palsy
- Cerebral Palsy Alliance
- Cerebral Palsy Education Centre
- Cerebral Palsy Support Network
- Kids Rehab WA
- Victorian Paediatric Rehabilitation Service
- New Zealand Cerebral Palsy Register
- Australian Cerebral Palsy Register
- New South Wales and Australian Capital Territory Cerebral Palsy Register
- Northern Territory Cerebral Palsy Register
- Queensland Cerebral Palsy Register
- South Australian Cerebral Palsy Register
- Tasmanian Cerebral Palsy Register
- Victorian Cerebral Palsy Register
- Western Australian Register of Developmental Anomalies – Cerebral Palsy

Community Consultation

The Strategy Collaboration would like to thank all members of the cerebral palsy community who contributed their valuable input through participating in community consultation. Special thanks to Shannon Clough and Shirley Wong who contributed countless hours representing the cerebral palsy community as part of the Strategy Collaboration. We would also like to thank Chrissie Cowan (Kāpō Māori Aotearoa Inc. New Zealand), June Riemer (First Peoples Disability Network Australia) and all those who contributed quotations and photos to be featured in The Strategy.

Please note, quotes included in the Strategy were obtained through community consultation and are therefore not necessarily reflective of the opinions of the individuals featured in photos.

Executive Summary

Aim and Objective of The Strategy

Our vision is a society where every person with cerebral palsy, and their family, have a positive quality of life and are supported and empowered to have control over their own life choices. Our vision is also to prevent cerebral palsy, minimise its impact, improve outcomes and promote change that fosters inclusion.

The mission of the Australian and New Zealand Cerebral Palsy Strategy is to improve the health, function, participation and quality of life of individuals with cerebral palsy and their families, through advocating for the provision of optimal healthcare and disability support, excellence in research and enhanced community knowledge. This will help achieve a more inclusive and accessible society.

Cerebral palsy is the most common physical disability in childhood and people with cerebral palsy experience significant barriers in everyday life. Complex and lifelong physical, medical, educational and social needs associated with cerebral palsy remain unmet. Furthermore, relative to the condition's prevalence, cerebral palsy remains under-recognised both at a societal level and within the political arena.

This lack of recognition has significant negative implications for people with cerebral palsy and their families. Some people with cerebral palsy are not being provided the supports and opportunities necessary to develop and thrive. Multiple and cumulative lost opportunities can limit an individual's ability to reach their full potential. The long-term, complex nature of cerebral palsy means that cumulative lost opportunities experienced across the life span can lead to reduced economic participation in adulthood, greater need for supports, reduced independence and poorer quality of life, all of which correlate with poorer individual, societal and economic outcomes.

As such, a targeted Australian and New Zealand Cerebral Palsy Strategy is necessary to:

- Document priorities identified by people with cerebral palsy, their families and professionals in the field of cerebral palsy, to establish targets for change;
- Inform key decision makers of unmet needs in the field of cerebral palsy;
- Optimise the efficient use of resources through building collaborative networks that act on identified priority areas;
- Increase viable and sustainable funding avenues through clear articulation of objectives determined by stakeholders; and
- Advocate for the needs of people with cerebral palsy and their families.

Achieving the priorities identified in The Strategy has considerable potential for benefit at an individual, societal and economic level.

Methodology

Comprehensive, independent community consultation was undertaken in order to create a document that

Image supplied courtesy of Cerebral Palsy Alliance

accurately represents the needs, opinions and priorities of people with cerebral palsy, their families and professionals working in the field. Consultation used a mixed methods approach including focus groups, webinar, an online survey about life satisfaction, an online questionnaire about specific content of a draft version of The Strategy, online open submissions where people could upload text, images or video, and telephone interviews.

139 people with cerebral palsy, family members, supporters and professionals working in the field completed the independent community consultation.

The Strategy was also presented at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference in Auckland 2018 where professionals provided feedback. Furthermore, an Expert Panel of 25 experts in the field (including people with cerebral palsy, family members and professionals) helped shape The Strategy.

Structure

Quality of life is an over-arching goal of The Strategy and is considered a necessary component of each goal outlined below as well as a benchmark with which to measure success. Quality of life for the purposes of The Strategy is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [1].

The Strategy is comprised of four goal areas. Goals are structured to be person-centred and designed to encompass concepts of functioning, disability and contextual factors outlined by the International Classification of Functioning, Disability and Health (ICF) framework [2]. The goals of The Strategy are:

Inclusion and Engagement
To promote inclusion and active participation in all aspects of life, from an individual level to a community and societal level, for people with cerebral palsy and their families.

Health and Well-being
To improve health and well-being outcomes across the life span for people with cerebral palsy, to minimise impairment, maximise function 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 people with cerebral palsy and their families.

Prevention and Cures
To continue to reduce and ultimately prevent the future occurrence of cerebral palsy, and reduce the impact and severity of the damage to the brain for those born with and living with cerebral palsy, with the goal of finding cures. For the purpose of The Strategy we define 'cures' as highly effective treatment/s for cerebral palsy that convey significant improvements in function and/or reduction of symptoms.

Image supplied courtesy of St Giles, Tasmania

Under each goal are a range of short-term, medium-term and long-term priority objectives (outlined in the full strategy). Priority objectives are specific areas of unmet need and fall broadly within the sub-domains of support, advocacy, research, and knowledge translation.

The Strategy will undergo a five-yearly review to ensure accountability, measure progress, and allow for priority objectives to be updated in line with changing needs, so that it remains current and relevant.

Success Indicators

Success indicators are measurable and achievable outcomes for the current Strategy term. Success indicators will be used to benchmark progress towards achieving the priority objectives. In addition to goal-specific success indicators, The Strategy specifies a number of foundational success indicators which were identified as being necessary in order to achieve The Strategy mission and vision. Success indicators are not an exhaustive list, rather they aim to provide a guide for the implementation of priority objectives. A summary of success indicators is included below, with full details provided in the body of The Strategy.

Strategy Success Indicators

FOUNDATIONAL SUCCESS INDICATORS

1. Inclusion of cerebral palsy related variables in nationally collected data.
2. Better utilisation of National Disability Insurance Agency (NDIA), Individualised Funding (IF)/Enhanced Individualised Funding (EIF) and Disability Support System Transformation data to inform efficient use of funding for cerebral palsy.
3. Collection of common cerebral palsy related data elements across service providers and researchers funded by federal government agencies.
4. Continuity and long-term funding for State and National Cerebral Palsy Registers.
5. Inclusion of participation, quality of life and economic evaluation in all intervention and support research.
6. Increase in the proportion of allocated research funding in line with the rate of occurrence and functional impact of cerebral palsy relative to other conditions.
7. Inclusion of people with cerebral palsy, Aboriginal and Torres Strait Islander people and Māori peoples, and/or their families in co-designing all research and initiatives directly related to the field.

GOAL – INCLUSION AND ENGAGEMENT

1. Develop a suite of valid and reliable quality of life, engagement and participation measurement tools.
2. A measurable increase in the proportion of people with cerebral palsy achieving self-directed participation life goals.
3. A measurable increase in the number of adults with cerebral palsy that are gainfully employed above the minimum wage.
4. Inclusion of mobility and complex communication needs of people with cerebral palsy in built environment and transport accessibility legislation.
5. A 500% increase in the number of communication accessible spaces (hospitals, government buildings, local shops etc.) for people with cerebral palsy and their families, both in urban and rural areas.
6. Increase in community understanding of cerebral palsy and how to communicate with people with complex communication needs.
7. Increase in representation of people with cerebral palsy in print and screen media.

GOAL – HEALTH AND WELL-BEING

1. Increase in the number of Category 1 funded research projects examining, addressing and/or translating research targeting improved health and well-being outcomes for people with cerebral palsy, from antenatal to adulthood.
2. A measurable increase in the proportion of infants at risk, children, youth and people with cerebral palsy accessing preventative health screening/intervention.
3. Increase in funding and access to targeted active surveillance and treatment of health and well-being-related needs associated with cerebral palsy across the life span.
4. Inclusion of evidence-based content about cerebral palsy in nationally accredited training degrees and ongoing professional development programs.

GOAL – INTERVENTION AND DISABILITY SUPPORT

1. A significant reduction in the time gap between diagnosis of “at risk” of cerebral palsy and the provision of first intervention.

2. Establishment of a recognised working relationship between The Strategy Collaboration/Expert Panel and NDIA, IF/EIF and Disability Support System Transformation to inform, and advocate for, necessary interventions and disability supports for people with cerebral palsy.

3. A proportional increase in the number of interventions and disability supports available for people who do not currently have equitable access for example those people living outside major cities, socially and economically disadvantaged peoples, and people of culturally and linguistically diverse backgrounds.

4. Increase in the number of services, supports and interventions available to Aboriginal and Torres Strait Islander people and Māori peoples that reflect their cultural beliefs and practices.

5. Obtain data documenting the breakdown of national funding allocated for services, supports, and interventions both by severity level and across the life span to inform, help refine and advocate for necessary and optimal funding provisions for people with cerebral palsy.

6. A more streamlined approach to state and national education, so that people with cerebral palsy receive the same level of support for all national exams (NAPLAN and HSC, SATs, National Certificate Educational Achievement (NCEA) Part I, II and III) as has been provided throughout their schooling, without additional application processes.

GOAL – PREVENTION AND CURES

1. Greater levels of funding committed to understanding the causes of cerebral palsy and identifying new preventative, curative and ameliorating strategies aimed at reducing the impact of cerebral palsy.

2. Implementation of best practice strategies for preventing cerebral palsy in at least 80% of major public hospitals across Australia and New Zealand.

3. Earlier diagnosis of children with cerebral palsy before 12-months of age (from 52% to 70% diagnosed before 12-months).

4. Reduction in the severity of cerebral palsy (from 1 in 3 children unable to 1 in 4 children unable to walk).

CONCLUSION

The Australian and New Zealand Cerebral Palsy Strategy reflects a united voice informed by people with cerebral palsy, their families, professionals and researchers across Australia and New Zealand. Immediate action is necessary and warranted to address the priority areas identified within The Strategy. This will not only benefit people with cerebral palsy their families and supporters, but is expected to lead to improved economic and social outcomes for Australia and New Zealand.

Contact Details

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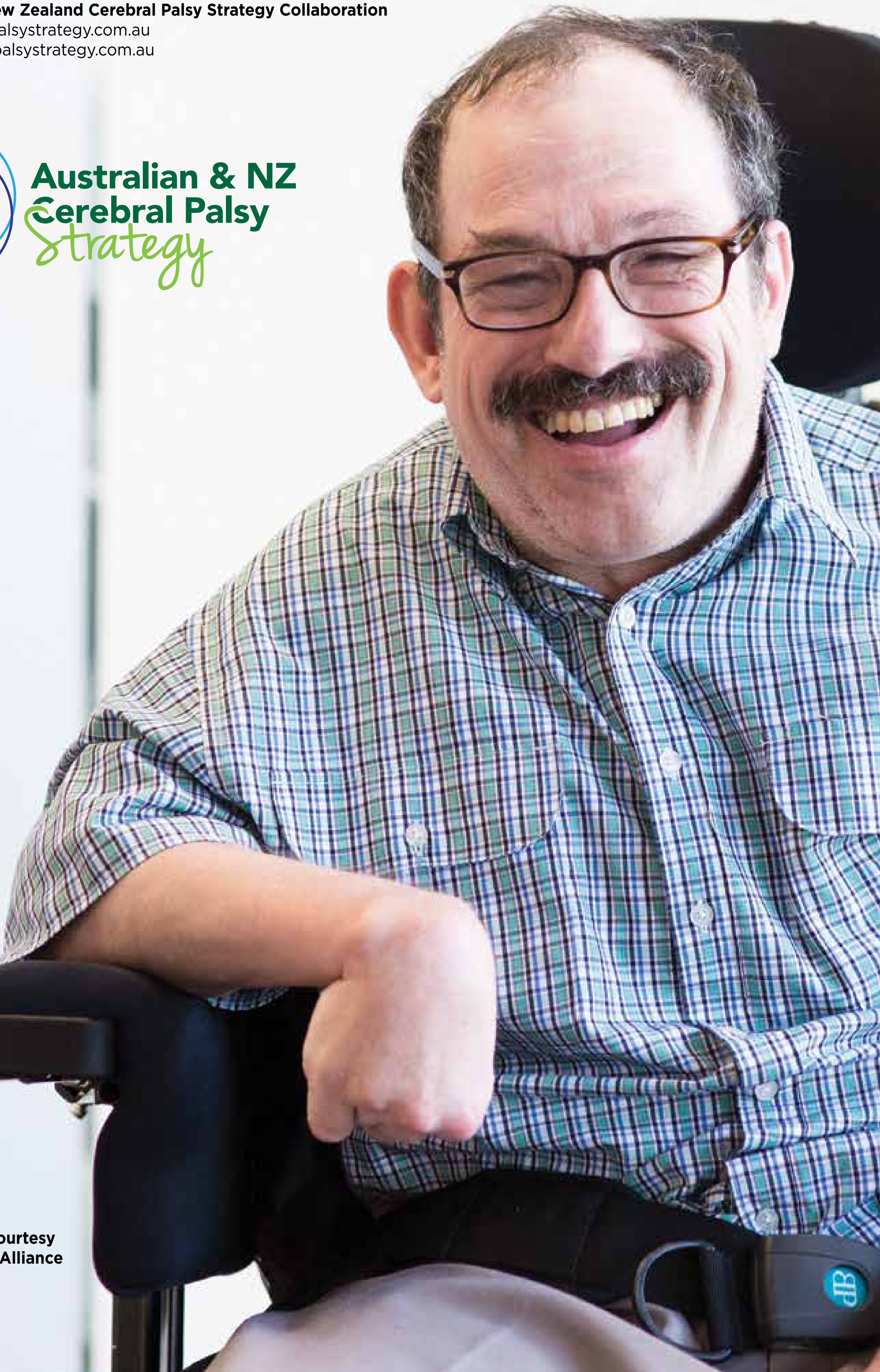

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Australasian Academy of Cerebral Palsy and Developmental Medicine

Cerebral Palsy Society
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