



Cerebral Palsy Society of New Zealand Incorporated



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# Executive summary

Thanks to the inexhaustible enthusiasm of its pioneer volunteers, the Cerebral Palsy Society of New Zealand is now in its 72nd year of operation.

Cerebral Palsy is the most common cause of physical disability in childhood, affecting upwards of 1 in 500 children born in New Zealand each year. Caring for a child with Cerebral Palsy is often complex, involving many clinicians and multiple services. It is estimated around 10,000 New Zealanders currently live with Cerebral Palsy, although exact figures are not clear.

Organisational sustainability is a key focus for all not-for-profit organisations. Since undertaking a strategic review, the Cerebral Palsy Society has made significant headway over the last 18 months in actioning strategic priorities and building on our strong values-driven team culture and solid reputation. Processes are ongoing to ensure our services are relevant to our members' needs.

Both the Board and the General Manager have worked hard to implement several workstreams identified as strategic priorities (outlined in this document). There has been substantial work undertaken to build on the Cerebral Palsy Society's reputation, and an emerging culture of cohesion has been created.

Advocacy Answers New Zealand was engaged to facilitate a workshop for the Board and General Manager to review the current priorities and identify future organisational strategic priorities. Prior to the workshop participants were asked to undertake a SWOT (Strengths, Weaknesses, Opportunities, and Threats) exercise.

Several ambitious goals were identified to take the organisation to the next stage of growth. Implementing these will be integral to effectively supporting Cerebral Palsy Society members and changing the landscape positively for inclusiveness and participation.



# Cerebral Palsy Society strategic objectives









# Our values

#### BOLD

We are bold and brave, and we are known as innovators in our sector

#### RELEVANT

We offer services that are wanted and needed by our members

#### INCLUSIVE

We value the diverse community we are part of and work with integrity alongside all people – supportive of their gender, sexual orientation, ethnicities, and cultures

#### TRANSPARENT

We are open and accountable to both our members and external stakeholders

#### RESPECTFUL

We are respectful in all our interactions

#### **EMPOWER**

We work to build connection, a sense of belonging, and to enable freedom of choice and participation in society



# Our roadmap

#### VISION

Empowering people living with Cerebral Palsy

#### **OUR PURPOSE**

Collaborating with our people to ensure they are seen, heard, and live awesome lives

#### **OUR MISSION**

Enabling people with Cerebral Palsy to maximise their potential





# Strategy

# Strategic Priorities

### Delivering national leadership

#### Branding and Communications:

- Updating the Cerebral Palsy Society's communications strategy – including brand considerations, marketing, storytelling opportunities, digital and social media campaigns. A strong focus will be on the Cerebral Palsy Society's external communications and building a brand presence.
- Implementation of a new Cerebral Palsy Society website.
- Review and update of the Cerebral Palsy Society's brand with a focus on integrating the new Te Reo term for Cerebral Palsy "Hōkai Nukurangi" into the Cerebral Palsy Society's brand and story.
- Establishment of more social media campaigns to raise awareness of the impacts of Cerebral Palsy.

#### Funding:

- Developing a fundraising strategy encompassing the plan for trusts and grants, community fundraising, corporate partnerships, donor development and evolution of Be Green & Be Seen.
- Defining fundraising KPIs (Key Performance Indicators) as part of the strategy.
- Establishment of a trusts and grants process.
- Establishing corporate partnerships.
- Consideration of a social enterprise model to advise councils/businesses with the aim of improving accessibility of their facilities.

#### Staffing:

• Filling organisational skills gaps in relation to strategic goals.

#### Research:

• Considering what research the Cerebral Palsy Society could potentially fund.

#### Collaboration:

• Continuing to strengthen relationships with the New Zealand Cerebral Palsy Register and the Clinical Network, in order to build accurate statistics regarding the prevalence of Cerebral Palsy in New Zealand, and the impacts for those living with the condition.



### Delivering valued national support to our members

#### Understanding our membership:

- Completing the membership deep dive and gaining an understanding of member demographics and requirements in order to better represent their advocacy and service needs.
- Setting targets for how the Cerebral Palsy Society builds and supports its membership nationally to ensure it is representing the needs of all those who would benefit from its support. Ensuring the needs of all those living with Cerebral Palsy are represented and all voices heard.
- Measuring the Return on Investment (ROI) of the Cerebral Palsy Society's interventions for each member. A better understanding of the impact of the Cerebral Palsy Society's work.

#### Services:

- Undertaking preliminary research into camps for children with Cerebral Palsy.
- Review of resourcing for the getProgramme funding via the eCard system to understand uptake and resources required.
- Fully auditing the current service offering to determine impact.
- Identifying what workstreams may need to be stopped, and future workstreams and services.
- Reviewing what services international organisations are offering.
- Considering how to build connections with members outside of Auckland.

### Providing a voice for people living with Cerebral Palsy

#### Advocacy:

- Completing an advocacy strategy – this will encompass raising awareness of early diagnosis, the prevalence of Cerebral Palsy, its impact and effects, access and participation issues.
- Engagement with Government agencies – Te Whatu Ora, Te Aka Whai Ora, Whaikaha, Ministry of Health, Ministry of Education, Ministry of Social Development etc.
- Employing a senior advocacy resource.
- Advocating for the establishment of Centres of Excellence for four regions.

#### Media

- Developing a story bank of lived experience.
- Developing relationships with journalists (as part of communications plan).

#### Stakeholders:

 Undertaking stakeholder mapping to identify key stakeholders that the Cerebral Palsy Society needs to engage with.

### Providing information and education

- Investigation of collaboration opportunities.
- Investigating the information provided on the My CP Guide.
- Reviewing best-practice for international organisations.
- Undertaking a health literacy review of the Cerebral Palsy Society's current information to understand the gaps.





Delivering a valued, national service to our members

# Recommendations

#### Members

- Defining the membership recruitment process, who the Cerebral Palsy Society is targeting and why.
- There is a need to define the organisational strategy (and appetite) for attracting new members. This will include a decision of who the Cerebral Palsy Society serves and whether the organisation represents all those living with Cerebral Palsy, or only its members.
- Reviewing the funding of the getProgrammes in accordance with the membership growth strategy (i.e., with a greater number of members can the current level of funding be sustained).

- Reviewing the survey being undertaken as part of the Deep Dive Programme to understand member wants/needs and geographic location. At the time of writing there were 120 responses with the survey still being open.
- Undertaking a full review of all of the Cerebral Palsy Society's services to understand their uptake, effectiveness and the resourcing required to deliver these effectively. This should consider the regional spread of all services. This should be undertaken before launching any new initiatives that require extra resource.



Outputs	Outcomes	Impact
Review and update the Cerebral Palsy Society's brand.	Integration into the Cerebral Palsy Society's brand and story of the new Te Reo term for Cerebral Palsy, "Hōkai Nukurangi".	A stronger, culturally inclusive external brand presence and recognition. Percentage of website and social media interactions increased.
Review of staffing requirements.	Operational staffing levels are resourced sufficiently to deliver on current and future Cerebral Palsy Society initiatives.	Organisational strategic goals and Key Performance Indicators are delivered successfully.
Creation of a tool to measure the impact of the Cerebral Palsy Society's services and supports, resources required to deliver these services and supports.	The ability to measure Return on Investment of the Cerebral Palsy Society's services, supports and interventions.	Services and supports offered will be focused on, and driven by, outcomes and the impact on the lives of those living with Cerebral Palsy. Increased percentage of members feel that the Cerebral Palsy Society's services and supports helped them.
Establishment of a membership recruitment process and Key Performance Indicators.	Clear agreed membership growth deliverables.	Effective delivery of the Cerebral Palsy Society's vision of "empowering people living with Cerebral Palsy". Percentage of active members living with Cerebral Palsy increased.
Review of all Cerebral Palsy Society services and programmes.	Delivering services and programmes that are "fit for purpose".	Effective delivery of the Cerebral Palsy Society's vision of "Enabling people with Cerebral Palsy to maximise their potential". Increased percentage of members participating in Cerebral Palsy Society programmes report positive impact on their lives.
Develop regular member feedback tool.	Access to qualitative and quantitative data around the effectiveness of the Cerebral Palsy Society's services.	Improved member satisfaction and outcomes with "fit for purpose services". Increased percentage of active members living with Cerebral Palsy are satisfied with the services offered and had positive outcomes.





Awareness and advocacy

# Recommendations

#### Advocacy

Determining the scope of the Cerebral Palsy Society's advocacy remit. This will include the appetite for individual member advocacy alongside wider systemic advocacy. Extra resources will need to be allocated to provide in-depth member advocacy, additional to the support the new Member Support and Programme Coordinators are providing.

- Focusing on developing relationships with politicians and government agencies and all relevant stakeholders to implement the advocacy strategy well ahead of the next election cycle (early next year).
- Rather than employing an internal resource, it could be beneficial to consider engaging government relations expertise externally with specialist contacts.

#### Branding

• Considering all aspects and elements of communications (as part of the communications strategy) and deciding what needs to be a priority. It will be important to roll communications initiatives out in a staged process.

#### Information and education

The Cerebral Palsy Society currently provides a range of information about Cerebral Palsy on its website and in its welcome packs. However, there is scope for improvement.

Information should be specifically developed for the different stages and ages of people living with Cerebral Palsy, taking into account the varying health literacy levels. This would range from videos, infographics, fact sheets and detailed information booklets and resources.



Outputs	Outcomes	Impact
Updating the Cerebral Palsy Society's Communications Strategy.	Communications Strategy meets branding guidelines and includes storytelling opportunities and digital and social media campaigns, a story bank of lived experiences, strong relationships with journalists.	A stronger external brand presence and brand recognition, the first port of call for anything Cerebral Palsy-related, communication priorities identified. Percentage of referrals and enquiries to the Cerebral Palsy Society increased.
Review of the current Cerebral Palsy Society <u>website</u> .	Implementation of a new Cerebral Palsy Society website.	A more user-friendly and efficient website. Percentage of positive website user experience increased.
Establish more social media campaigns.	Strategically planned social media campaigns.	Increased awareness of the impacts of living with Cerebral Palsy in New Zealand and being the first port of call for anything Cerebral Palsy-related. Increased number of referrals and enquiries to the Cerebral Palsy Society as a first port of call for anything Cerebral Palsy-related.
Collaboration.	Strengthened relationships with the New Zealand Cerebral Palsy Register and New Zealand Cerebral Palsy Clinical Network.	An evidence-base reflecting the impacts and outcomes for those living with Cerebral Palsy, which can support the Cerebral Palsy Society's strategic advocacy goals.
Completion of the membership deep dive.	A clear understanding of our membership demographics and requirements.	Data reflecting the numbers and demographics of those living with Cerebral Palsy. The Cerebral Palsy Society is able to better represent and advocate for members and ensure equitable support for all those living with Cerebral Palsy.

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Outputs	Outcomes	Impact
Development of an Advocacy Strategy and Advocacy Goals.	An Advocacy Strategy which encompasses raising awareness, early diagnosis, the prevalence of Cerebral Palsy, its impact and effects, access and participation issues, engagement with government agencies, staffing resources required, establishment of Centres of Excellence.	An advocacy strategy which provides for clear advocacy goals and Key Performance Indicators which align with the needs highlighted by members.
Complete a stakeholder mapping exercise.	Identification of key stakeholders that the Cerebral Palsy Society needs to engage with (corporates, other service providers, government agencies, politicians etc).	The Cerebral Palsy Society engages and partners with organisations that support the Society's goals.
Review of the information provided in the My CP Guide, best-practice for international organisations and health literacy offered by the Cerebral Palsy Society.	Understanding of the gaps in information and literacy opportunities offered by the Cerebral Palsy Society currently.	Members have access to the most current information relating to Cerebral Palsy (treatments and supports available). Percentage of members living with Cerebral Palsy and their whānau/family understand more about their care and treatment options available.
Determine the scope of the Cerebral Palsy Society's advocacy remit.	Identify the need for individual advocacy alongside wider systemic advocacy and the resources required to deliver individual advocacy/navigator support.	Effective delivery of the Cerebral Palsy Society's purpose "Collaborating with our people to ensure they are seen, heard and live awesome lives". Successfully bringing about systemic changes which improves the outcomes for those living with Cerebral Palsy.





Ensuring future organisational and financial sustainability

# Governance

Significant trust is placed in not-for-profits, meaning that it is essential to have good governance. Additionally, being a not-for-profit entity means there are significant levels of public scrutiny into the operations of organisations. There are numerous mandatory and default legal duties and obligations which are imperative to adhere to.

# Recommendations

#### Governance

 All risks should be captured in a risk register covering operational, financial, reputational, staffing and health and safety risks. Risks should be graded and prioritised. Key risks should be reviewed at each Board meeting to ensure the mitigation for each risk is being implemented. New initiatives, if adopted (such as the camp) need to be fully assessed with risks recorded and managed.

- Creating a Board induction, training process and programme.
- Updating the Board skills matrix and ensure all Board members complete this to identify any skill gaps on the Board.
- Ensuring Board position descriptions are in place for all Board members with a separate job description in place for the chair to outline expectations of these roles, prior to the next Annual General Meeting.
- Appointing a second external director as allowed in the Cerebral Palsy Society's Trust Deed at the 2023 Annual General Meeting. Holding the space in the Annual General Meeting voting process for this to happen.
- Putting in place governance training for the Board from the Institute of Directors and other external providers.
- Reviewing the General Manager/ Board reporting process.
- Establishing Key Performance Indicators and a performance review process for the General Manager.

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#### Staffing

• Review organisational Human Resource capacity to understand staffing gaps which may impact delivery of current and future initiatives.

#### Funding

- Reviewing the amount of interest drawn down from investments and whether this could potentially be increased to support the Cerebral Palsy Society's service. This would support the funding of new priorities. The current team is not large and is stretched across a number of areas.
- Considering developing an endowment fund.
- Developing a detailed case for support to capture the importance of the Cerebral Palsy Society's work, it's impact and why people should support it.

- Developing a community fundraising microsite that is promoted to encourage members of the wider Cerebral Palsy Society community to organise their own fundraising initiatives as a way to 'give back' to the Society.
- Developing regular feedback loops (via survey) with members to collect qualitative and quantitative data around the effectiveness of the Cerebral Palsy Society's service.





Impact

Outcomes

# Outputs

Develop a fundraising strategy, define fundraising Key Performance Indicators and consideration of a social enterprise model.	A strategy that encompasses the plans and processes for trusts and grants, community fundraising, corporate partnerships, donor development and the evolution of Be Green & Be Seen. Secure revenue streams which sufficiently supports operational requirements in line with organisational strategic goals. A social enterprise model proposal aimed at improving accessibility of councils and businesses facilities.	A fundraising strategy that reduces the reliance on the Cerebral Palsy Society's investments for the funding of new initiatives and priorities.
Establishment of an organisational risk register.	All operational, financial, reputational, staffing and health and safety risks are recorded and mitigation actions taken.	All identified organisational risks are effectively managed and mitigated.
Establishment of a Board skills matrix.	All Board skills gaps are identified. Appointment of a second external director as allowed in the Cerebral Palsy Society's Trust Deed.	The Cerebral Palsy Society Executive Board has sufficient representation across all critical skills areas (Finance, Human Resources, Advocacy) to ensure effective governance.
Establishment of Board position descriptions.	All Board members have specific position descriptions which outline clear expectations of each role.	All Board members have a clear understanding of the expectations of their role.
Further development of a Board induction and training programme.	All Board members contribute effectively to their roles on the Board.	Upon joining the Cerebral Palsy Society Board, all Board members have completed induction and training to ensure effective and compliant governance.
Review of the General Manager Board reporting process.	The Board receives the critical information required for effective strategic decision-making.	The Cerebral Palsy Society Executive Board receives concise, accurate reporting which enables effective, impactful governance.

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Outputs	Outcomes	Impact
Establishment of Key Performance Indicators, a Performance Review and regular review meeting process for the General Manager.	Clear agreed deliverables, regular progress reporting.	Regular, effective and efficient monthly progress on agreed strategic goals between management and governance.
Review of funding drawn from investments to support operational requirements.	Financial support for resources required to deliver agreed new priorities and services.	Funding toward resources required is sufficient to deliver on agreed priorities and services.
Investigate development of an endowment fund for the Cerebral Palsy Society.	Effective funds management.	Increased and sustainable revenue streams meet the resourcing required to deliver on agreed priorities and services.
Develop a community fundraising microsite.	Increased member driven fundraising initiatives.	Increased and sustainable revenue derived from community and member driven fundraising initiatives.







Driving research into Cerebral Palsy

The field of Cerebral Palsy research is an exciting one. New studies and developments are constantly evolving. We are learning how Cerebral Palsy develops, how it affects individuals and what health and wellbeing looks like. Cerebral Palsy is an umbrella term for a wide variety of conditions and life experiences. Recently, researchers and clinicians have developed a greater understanding of the different levels and types of Cerebral Palsy, and the needs of families and individuals.



### Outputs

Review of the Australian and NZ Cerebral Palsy Strategy 2020 document.

### Outcomes

The Cerebral Palsy Society Executive Board is able to make informed decisions relating to research opportunities to be funded.

### Impact

Cerebral Palsy research is undertaken which aims to improve the lives of those living with Cerebral Palsy.







The Cerebral Palsy Society is committed to providing a high quality service which aligns with its vision, purpose and mission to both current and future members. Advocacy, member support and sustainability are key focus areas for the Board and management as they work through delivering on the strategic priorities outlined in this report.



## Hōkai Nukurangi

- to achieve what is important to you.

www.cerebralpalsy.org.nz