

Cerebral Palsy Society of New Zealand Incorporated

BUSINESS STRATEGY - 2021



A young man with a prosthetic arm is smiling and holding a small brown horse. The background is a blurred outdoor setting with trees and a fence.

Executive Summary

The Cerebral Palsy Society was established 70 years ago. Cerebral Palsy (CP) 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 CP is often complex, involving many clinicians and multiple services. It is estimated around 7,000 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. The Cerebral Palsy Society (CPS), unlike most not-for-profits, is in the fortunate position to be financially secure. However, the revenue-building strategies the CPS has used to arrive in this position are currently under scrutiny, as is decision-making around cuts to the GET programme system of voucher distribution.

Additionally, a significant restructure of the team in mid-2020, saw a number of staff members leave the organisation. These decisions were made in the backdrop of the COVID-19 pandemic last year and have been openly questioned by some of CPS's members. Furthermore, the restructure also resulted in some reputational damage, which still needs to be carefully managed, as there have been issues aired publicly by a number of members.

As a result of these issues, the membership voted in an almost entirely new Board in October 2020.

The new Board bring increased diversity and are highly motivated to take on all the challenges the CPS will face to begin a new era. Their aim is to stabilise the organisation. However, there is a need for them to build governance skills alongside developing and overseeing a new strategic direction for the CPS.

This is being achieved by undertaking a strategic review, a financial investigation, and a review of all support offered to members with an evidence-based approach applied to what is needed. Once complete, the aim will be to extend support to all people in New Zealand affected by cerebral palsy.

This strategy provides a roadmap for the CPS to ensure organisational and financial sustainability.

Strategic Objectives

1

Ensuring future organisational and financial sustainability

2

Delivering a valued, national service to our members

3

Awareness and advocacy

4







Driving research into CP

Creating an identity for the Cerebral Palsy Society

The **strategy on a page** table on the following page aims to build on the plan and incorporate discussions with the Board at a workshop held in April 2021.

This strategy on a page has been developed to explain the CPS's work to external stakeholders including: members, donors and potential corporate and funding partners. The society's values and strategic priorities have been consolidated.

New principles/values are outlined in the table below.

Principles/Values		
 BOLD	 RELEVANT	 INCLUSIVE
We are bold and brave, and we are known as innovators in our sector	We offer services that are wanted and needed by our members	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	 RESPECTFUL	 EMPOWER
We are open and accountable both to our members and external stakeholders	We are respectful in all our interactions	We work to build connection, a sense of belonging, and to enable freedom of choice and participation in society



Strategy on a page

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

STRATEGIC PRIORITIES

Delivering national leadership

We work to create a strong recognisable brand that people know and trust

We focus on developing the appropriate structures, policies and sustainable income streams to ensure the longevity of CPS

We undertake effective governance

We develop and implement strategies to increase resilience, build capacity and plan for the future

We seek to identify and mitigate risk

Delivering valued national support to our members

We deliver valued support that meets the needs of members

We help our members navigate the challenges of a CP diagnosis.

We offer both emotional and practical support to our members

We collaborate and partner with other organisations

Providing a voice for people living with CP

We provide a voice for people living with CP to break down barriers and get the best treatment possible

We raise awareness of CP to ensure New Zealanders have a greater understanding of the condition and know where to go for help

We work with the government and key agencies to address the needs of those living with CP

Providing information and education

We will provide high-level information and education about CP to our members

We will work to increase the understanding of CP for all New Zealanders

We will use a health literacy lens to ensure the information we provide meets the needs of everyone who may need to access it

We provide information/ education and raise awareness of CP



Strategic Objective 1

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

- Review the ability to alter the Trust Deed to address the Board structure and membership to allow for at least two independent directors. Particularly, independent directors with the required skills. Independent directors also bring the advantage of an external perspective to the Board table.
- Formalise sub-committees - the Board is currently establishing subcommittees that will be in place for: finance and risk, HR, investment, and communications. There is scope to second external independent expertise when needed.
- Create a Board induction programme to provide awareness of wider aspects of the organisation. Position descriptions should be in place for all Board members clearly outlining responsibilities and expectations.
- Communicate to members around the strategy, direction and skillset required to be on the Board in order to strengthen succession planning.
- Allocate and carry out administrative and compliance duties - Board work plans, interests register, delegations policy, rotation policy reviews, review and update of all policies and awareness of gaps.

- Compile a risk register - all risk should be captured in a risk register covering: operational, financial, reputational and health and safety risks and their mitigations. See separate risk plan for the CPS.
- Undertake tikanga Māori and wider cultural training for all Board and staff members.

BRAND

There is a strong mandate from the Board to rebrand the CPS. This will be part of communicating a new strategic direction and will form a component of increasing inclusivity. A brand review will bring a stronger identity and clear brand voice.

Brand values will be identified and discussed in a separate comprehensive communications strategy.

SUPPORT AND SERVICES

See section 2.

STAFFING

Recommendations

- All roles should have clear position descriptions in place and KPIs and performance documentation for consistency and clarity at annual performance reviews.
- A senior communications manager should be appointed to deliver the communications strategy and run all aspects of the communications function, including digital cohesion, crisis and issues management, proactively engage in positive media, run awareness activities, and coordinate the advocacy strategy.

- Kaiwhakatere (Navigators) should be employed to provide personalised support to members (see service section). These would be member-facing staff who can provide navigation through all support available.
- Review the need to have voluntary roles in the office. Volunteer roles should only be established with Position Descriptions in place. These should not be remunerated roles and not be established with payment 'in kind'.

STAKEHOLDER ENGAGEMENT

Detailed stakeholder mapping will be undertaken as part of a separate communications strategy. This will outline all key stakeholders and the way the CPS should engage with them.

IMPACT AND REPORTING

All services put in place need to have measures in place to describe and communicate outputs, outcomes and impact. Appropriate reporting should be in place for different audiences. This would include Board, Government, funders, clients, public and media.

REVENUE

With the current financial structure in place, at the present time, it is unnecessary to develop fundraising streams for the CPS.

While there is no immediate need to fundraise, the model for revenue generation should be reviewed, as there will be good engagement and awareness opportunity to come from this. Several income strategies should be explored to ascertain the most viable opportunities.

Recommendations

- A case for support will be developed as part of a detailed, separate communications strategy.

BUSINESS SUPPORT

Support from businesses will offer opportunities to develop sustainable income for the CPS and a valuable method of engagement to raise awareness of the CP community's issues and of CPS.

Many businesses now realise they need to increase their Corporate Social Responsibility (CSR) activities. CPS is an appealing prospect strengthened by being a national organisation.

When considering a partnership, it is important to understand the values of potential business supporters alongside their business objectives, to ensure they pose no reputational risk. Both brands must be valued and respected.

Recommendations:

- The CPS has an opportunity to create a powerful educational offering that could be implemented with businesses as part of their diversity and inclusion initiatives.

MANAGING THE CPS'S CUSTOMER RELATIONSHIP MANAGEMENT (CRM) SYSTEM

A CRM system is a vital tool to record the CPS's stakeholders. The CPS currently utilises Presspoint which is not fit-for-purpose.

Recommendations:

- A detailed review will be undertaken to understand if the current CRM system is fit for purpose and what data needs to be captured, both around members and people that donate to the CPS.

OUTPUTS, OUTCOMES AND IMPACT

Many of the CPS's support offerings will be new. All offerings to members provide an opportunity to capture data, survey and gain understanding of members' needs and wants. To also ensure there is value in the impact of this work, measurement and reporting of the benefits needs to begin.

Outlined below are some examples of outputs, outcomes and impact measures that could be reported on once the service is more established, with data collection underway and surveys being undertaken.

OUTPUTS	OUTCOMES	IMPACT
<ul style="list-style-type: none"> • Member numbers • Number of members in the database that have newly defined datasets in place • Ethnicity of families assisted • Capture of all member calls, emails and online interactions • Healthcare professional interactions • Practical assistance provided – e.g. financial assistance offered for which area of need and the rationale for this provision • People with CP have someone to help them navigate the health system and any additional services they may require • Number of member meetings held, types of meetings • Number of education groups held • Digital data, numbers in closed Facebook groups • Numbers visiting the website, which sections / pages • Participation and voice at the table on all strands of Cerebral Palsy Clinical Network action on key items • Advocacy meetings 	<ul style="list-style-type: none"> • There is a full understanding of the composition of CP membership and their needs • The CPS expands its membership to more fully represent those living with CP in New Zealand • The various segments of the CP community have service offerings and feel heard and supported. e.g. Adolescents and Young Adults (AYA) have a CP community and ways to connect • People having more comprehensive information and feel supported in everyday life situations • The CP community know the organisation is advocating for them on their key issues and has their back • The CP community feels proud of their connections with the organisation and participate and communicate positively • People with CP and their families understand what to expect with each life stage • CP community segments know and respect that each journey is different • Members are proud of their Board representatives and support the new organisation 	<p>After interacting with the CPS, people with CP and family/whanau members will have a better understanding of their life stages journey and know what to expect, which can help alleviate anxiety and feeling overwhelmed. Impact measures could include:</p> <ul style="list-style-type: none"> • % of people with CP reporting they feel more informed about their condition • % of people with CP and their family/whanau understand more about their care and treatment options • % of people with CP feel less isolated and part of a supportive community • % of people with CP feel less anxious • % of people with CP feel safer and more confident in their daily life • % of people with CP feel more equipped to deal with the transition to employment • % of 0-2 year olds with CP have accessed xxx at an earlier stage, leading to improved outcomes • % of caregivers feel better informed and better able to support someone living with CP • % of families have had their financial burden eased • Reduced impact of living with CP

Strategic Objective 2

Delivering valued national support to our members

SUPPORT FOR MEMBERS

The CPS offers support to over 1,500 members. It is estimated that there are over 18,000 people living with CP in New Zealand, although this figure may be inaccurate as only around 68% of people are listed on the CP Register.

Regardless, there is significant opportunity for CPS to increase its membership and ensure support is provided to members across the entire country.

Support is currently offered in the form of vouchers, grants, information and coffee mornings. The needs of members are diverse due to the different age ranges, where they are at in their CP journey, and their different GMFCS levels (ranging from one to five).

Every single person's experience of living with CP is different.

VOUCHERS

CPS currently offers support in the form of vouchers via the GET Programme. Programmes they fund include a voucher system for members – known as the GET initiatives.

These include:

getOutThere – part fund public transport fares.

getPhysical – vouchers to gyms, physio sessions, yoga classes, osteopathy and rehab clinics.

getThis&That – this programme allows members to purchase small items that are needed to help manage the effects of living with their CP.

getUpAgain – This programme helps give access to and finance three to six counselling sessions.



getStructured – The Get Structured programme locks in good legal structures around a person with Cerebral Palsy. Parents will be financially assisted to set up a legal framework for a member with Cerebral Palsy.

getOnYourTrike – This programme encourages children to keep up with exercise, friends and have independence on a trike. Custom built trikes suitable for children with cerebral palsy between the ages of 3-14 years old.

Prior to the review in 2020, CPS members could apply to access up to \$1,500 worth of vouchers per year that were spread across three payment periods. With the review in 2020, members were allowed to access only one programme of their choice valued at \$350 per member. Between February 2021 and June 2021 members have been able to apply for \$300 worth of vouchers across multiple programmes, valid through to the end of June 2021. The system is being reviewed by the Board.

Typically, it is the adult members who more regularly access the vouchers. There is a desire amongst the Board to better understand the needs of members when reviewing the voucher system.

Recommendations:

Research into CP's membership

- A member deep dive project should be undertaken to understand the needs of all members. This would involve both online surveys and interviews with the current membership.
- The research undertaken would ascertain:
 - What age, stage or type of level of CP each member has
What is the split between adult, AYA and children members
 - Their geographical location
What services they have already accessed
What services they would like to see the society offer
 - What the support of the CPS has meant to members over the years members need from the society and how the CPS can better assist

Kaiwhakatere (Navigators)

- Skilled support workers or Kaiwhakatere (Navigators) should be employed to offer personalised support to members and help them access the best services for them.
- The Kaiwhakatere would have a nursing, allied health professional, or behavioural science background. Youth workers could also be considered to work specifically with adolescents and young adults (AYA).
- The Kaiwhakatere would be available to provide personalised support to members either in person or on the phone, as a trusted source of information and guidance. They would meet with members directly as required to provide emotional support and listen to any issues they may be experiencing.
- They would refer them on to other external services that would be able to help. This could include counselling, government funding that is available, independent living services, exercise programmes (please see the full list of potential options below).
- A range of agreements should be in place with different suppliers (some of these will already exist from the voucher systems. Offered services could include:
 - Youth coaching
 - Counselling
 - Exercise programmes
 - Cognitive education programmes
 - Intensive Therapy
 - Legal services
 - Life skills – driving, supported independent living, self-defence, budgeting
 - Equipment and services
 - Occupational Therapy

Increasing membership nationally

- Roadshows could be held across the country to showcase the work of the CPS and the benefits of becoming a member.
- These could be held to attract members from across the entire country. Services could then be expanded into each region as necessary.
- At the moment getOnYourTrike is offered primarily in the Auckland region, with trikes being stored at Head Office. There is significant opportunity for this programme to be extended across the country and this could be one of the offerings highlighted at the roadshows. This is also an attractive programme for corporates to support.

GRANTS

Individual grants of up to \$1,500 are offered to assist people living with Cerebral Palsy to obtain items or services that mitigate the effects of living with Cerebral Palsy. Grants should aid a person's independence and / or quality of life, or in the case of a child also that of the parents / family. Members can apply for a grant every two years and individual grants are only offered for items or services the Government does not fund.

Academic grants are offered to the value of \$2,500. These are for CP members who are studying a bachelor degree or higher and have passed a successful year at this level.

Monthly organisational grants are available to organisations that have the purpose of assisting people with Cerebral Palsy. They must be listed with the companies office or charities commission.

At the moment, only a limited number of members are applying for these grants, with sometimes only one application per month.

Recommendations:

- Grants process to be reviewed.

EVENTS

In addition to the voucher system, CPS also hold monthly coffee groups across the North and South Island. These are largely attended by older members and provide opportunities to engage with parents and younger members (including teenagers and young adults) that should be explored.

CPS previously had an MSD funded programme called Youth Alliance, focusing on youth advocacy. The Youth Alliance was a leadership group that met to discuss issues relating to young adults living with CP.

This programme was managed by a young person with CP who held the MSD funding. This funding ended at the end of June for the programme.

A key priority for CPS is ensuring that MSD Accreditation is received for the society to enable them to access MSD funding.

Recommendations:

- An analysis of the current coffee mornings should be undertaken to see if they are well-attended and valued by members. Different group activities could be established to bring together different groups of people affected by CP to share experiences and connect with one another. Individual offerings should be considered for different groups e.g. adolescents and young adults (AYA), parents of children with CP, people in their 30s and 40s, older groups.
- Activities could include:
 - Camps for AYA
 - Gaming nights for AYA
 - Leadership programmes for AYA
 - Retreats for carers/parents
 - Exercise/activity classes
 - Sports programmes



Strategic Objective

3

Awareness and advocacy

“CP turbocharged is incredibly positive and has a whole lot of traits that are wonderful”

AWARENESS

Increased awareness of Cerebral Palsy will largely come from increased advocacy activities and general communications. There is also the opportunity to increase awareness of the condition and the organisation with the general public. This includes dispelling any incorrect assumptions by the public about CP.

Two key opportunities include marking an awareness day and publicising the 70th birthday of the CPS.

There appear to be different dates marked internationally for Cerebral Palsy awareness activities. The United States Cerebral Palsy groups largely focus their activities in March, while a number of organisations, including in Australia, tend to tie their activities to World Cerebral Palsy Day which is in October.

Recommendations

- The CPS should undertake an awareness campaign to mark World CP Day on October 6, 2021. This should include both proactive media and social media activity, alongside events that members can attend. Awareness activity could include promoting awareness of the condition, what it means to live with CP, or wider issues that include the need for positive change in healthcare, education and employability as they affect the CP community.
- 70th anniversary events could be held to mark this milestone. These could be virtual or physical and provide a way of getting members together. A special 70th anniversary newsletter could be distributed to highlight the key achievements of the CPS over the years.
- The historic timeline on the website should also be updated to list key achievements. There should be an additional focus placed on key milestones, key statistics and clear communications of what is planned for the CPS in the future. This messaging will also provide a way to communicate with members about the new strategic direction of the organisation.

ADVOCACY

Advocacy is an important tool for the CPS to affect change. Advocacy initiatives should deliver evidence-based recommendations to decision makers, relevant stakeholders and those who influence them.

Advocacy for the CPS will also bring much needed awareness and visibility to the organisation. It will also highlight the needs of people living with CP (and their families) and create changes to improve their lives. Effective advocacy will be attractive to members, who will see the CPS actively representing and affecting change for some of their biggest challenges.

Advocacy work is already being undertaken by several Board members on an ad-hoc basis. The CPS is now in a place to commit to undertake strategic advocacy and provide a powerful voice for people living with CP in New Zealand. The CPS could highlight the needs of its members and work alongside other groups such as the Neurological Alliance to affect change.

Advocacy through storytelling, experience data and research is powerful. It will lead to wider understanding and the improvement in knowledge, attitudes and the changes required. With awareness of the impacts of CP, there is a greater likelihood of better outcomes and experiences.

Using an evidence-based approach means gathering relevant information, analysing it, and then packaging it in a form that can be actioned. This approach is not a one-off action. An evidence-based approach come from utilising research that is already available to the CPS through the Cerebral Palsy Clinical Network. Data from the Cerebral Palsy register may also be explored to understand what is known about the challenges of daily life with CP.

THE CEREBRAL PALSY CLINICAL NETWORK

There have been a number of work streams identified by the Cerebral Palsy Clinical Network (CPCN) since the inaugural meeting in November 2019. It is unclear from publicly available information how many of these are now underway and their progress.

The work streams involve:

- Developing and promoting best practice guidelines and resources for paediatric health professionals, early diagnosis and intervention, particularly for under 2yrs of age.
- Ensuring the voices of children and young people with CP and their families/whanau are heard and responded to.
- Ensuring improved transition from paediatrics into adult health services, supporting and using data from the Cerebral Palsy Register.
- Promoting support and understanding amongst all DHBs and Ministries around key aspects of specific treatments such as Selective Dorsal Rhizotomy (SDR) & Intensive Therapy.
- Enhancing communication across the sector (including primary healthcare) of national and international research and concepts.

- Promoting active participation in all aspects of life for people with CP
- Developing a five year strategic plan for Cerebral Palsy Health Services

The fact that the CPCN is in place signals the Ministry of Health's acknowledgment of need in this area.

Advocacy can be either undertaken at an individual level or a national level, to benefit the majority of the CP community. There are currently some great individual advocacy initiatives being undertaken, most notably with the valuable GET Structured programme.

A strategic cohesive approach now needs to be in place. This will clearly identify objectives, milestones and use identified internal - and potentially external – spokespeople.

A communications plan alongside the advocacy strategy will be essential.

Recommendations:

- A two-page summary of each of the seven strands of work being undertaken by the Cerebral Palsy Network should be completed. This will help ascertain what areas can be more fully worked through and activated.
- Ensure the CPS has representation on all relevant workstreams of the network will be important with the appropriate reporting mechanisms in place.
- A credible expert, or advisory group of experts, who will act from time to time as a spokesperson or spokespeople on key advocacy issues should be established.
- Several CP Advisory Boards (CPAB) should also be put in place. These could include an AYA Advisory Board, a Parents Advisory Board and an Adult Advisory Board.
- Statements could be prepared on certain advocacy topics e.g. employability.
- A clear need exists in advocacy on the benefits of intensive therapies. The PwC report could potentially be used as an advocacy vehicle.
- An advocacy impact report should be compiled on why the advocacy CP is undertaking is important to highlight numbers affected and why it matters. This could provide an important tool for briefing/reporting to the government.
- Key messaging should be created alongside a 'state of the nation' report/ white paper such as burden of disease report or cost of CP study. This should include key messaging and key advocacy requests, ideally with outlined solution.

PARLIAMENTARY EVENT

- A parliamentary event would provide a high profile way to officially launch the CPS advocacy initiatives. It would bring key CP leaders and supporters together. This could potentially be either a breakfast, lunch or dinner hosted by, for instance, the Minister of Health.
- Attendees should include:
 - Politicians – relevant MPs, Health Select Committee, Ministry of Health and Education key people
 - People living with CP (specific ambassadors from the regions)
 - All significant supporters
 - CP GM and Board



- If the event was held as a breakfast it could be followed by a one day roundtable workshop with lead politicians and those from the disability sector.

PARTNERING

Grouping with other like-minded organisations and key individuals increases influence on key decision-makers.

Researching and mapping out other similar services to see where the CPS's service intersects with other service providers is vital. Mapping out stakeholders will show how to leverage relationships with suppliers and where there are opportunities to build funding partnerships.

For any advocacy partnerships, key success factors include:

- Being clear that you have the same goals and objectives.
- Agreed processes/ways for working together.
- Clear, agreed messages and the ways to communicate these.
- Ensuring everyone has clear roles and responsibilities and the expectations around these.
- Clearly identifying spokespeople at the outset.
- Preparing and using a stakeholder matrix to identify other organisations with an interest in Cerebral Palsy in particular, and related disability in general, will be important.

Suggested advocacy themes

Treatment/clinical

- Align closely with the clinical network and the seven streams they are focusing on. One of these is the benefits of intensive therapies.
- Targeted therapy offering for over fives and into adulthood.

- Early intervention advocacy role.
- Evaluate whether there are enough people personally affected by CP as part of the clinical network.

Equity

- Increased Maori and Pasifika work focus.
- Remove geographical barriers currently being experienced by members.
- Youth leadership.
- AYA voice.
- Opportunities to grow the organisation's presence nationally to improve equitable access to services, such as specialist care.

Disability

- Changing the perception of disability in NZ.
- Creating leadership opportunities for adults to contribute/share knowledge with others, e.g. life skills, driving, living independently, pregnancy.
- Support offered by the Government is often ineffective e.g. won't undertake significant modifications of homes. CPS needs to work with agencies to affect change in this area.
- Employability and employment opportunities. Working with third parties for work/internship opportunities for potential employment.
- When children with Cerebral Palsy reach the age of five they effectively 'disappear' off the system.

Strategic Objective 4

Providing information and education

INFORMATION

The CPS currently provide a range of information about Cerebral Palsy on their website. However, there is significant scope for improvement.

Information should be specifically developed by the CPS for the different stages and ages of people living with CP, which is relevant to New Zealanders. A health literacy approach should also be adopted to ensure that information is provided for people of varying literacy levels. This would range from videos, infographics and fact sheets through to detailed information booklets and resources.

Recommendations:

Updating the CPS website and digital platforms:

- The website provides a vital information hub for people living with CP. It needs to be updated to ensure a more simple navigation and that it takes members directly to the specific information they are looking for. Information could be segmented with general information, and information specifically for young adults and for children.
- Other information that should be on the website includes:
 - Current and relevant research into CP, updated regularly, alongside different treatment options
 - The support/funding that is available
 - The advocacy CP is undertaking and how members can get involved
 - Links to other helpful information sources e.g. international CP organisations
 - The different life-stages and levels of CP
- The CPS's Facebook page and Instagram page are currently underutilised. They are valuable channels to get information out to members and engage them in a variety of different campaigns.
- Detailed information on how to achieve this will be outlined in a separate communications strategy.



Information for life stages

- The CPS should produce detailed information, including downloadable factsheets and booklets. This should be specific for different life stages, for example information for parents, adolescents and young adults and general information. It could be housed both on the website, and in clinical settings, e.g at Starship and in schools.
- Information for parents could include
 - Children's books about CP
 - Early childhood interventions
 - Therapies available
 - A guide for parents
 - Parent insights
 - The work of the clinical network
- Additional information for AYA is important, at present there is very limited information offered to this age group who have important and specific needs. Information could include:
 - The rights of young people
 - Living independently
 - Learning how to drive
 - What to expect at puberty
 - Self defence
 - Online dating
 - Sexual health
 - What to expect in childbirth
- In addition to physically getting together, closed Facebook groups and Zoom groups could provide a way for different groups to come together and discuss issues. These forums would be particularly attractive for AYA.

Storytelling

- Highlighting the stories of people living with CP and their different experiences is vital to create a community with members and share valuable knowledge.
- People living with CP, and parents and carers, could be interviewed in a series of short films to share their experiences, knowledge and challenges. These films would be hosted on the website and social media.
- Different Board members and CPS staff should also be featured.

Health literacy

- Health literacy refers to the level to which individuals have the capacity to obtain, process, and understand the basic health information needed to make appropriate health decisions. Part of this is ensuring that people are given information in understandable terms and manageable chunks. It is important that this information uses lots of diagrams, pictures and labels.
- A detailed health literacy project for the CPS should be undertaken. This will be informed by the member survey around need. New Zealand specific layers of information could be developed about CP for all literacy levels. This could range from videos to children's books to fact sheets and detailed information books on different topics. These could also be translated into different languages if there is the need to do so.

Research

- The CPS has an in-house researcher who works closely with the clinical network and undertakes a research project 'Cerebral Palsy Through the Lifespan' This work aims to bridge the gap between the paediatric system and adulthood with an emphasis on everyday experiences.
- It should be investigated whether the researchers' role could be broadened to encompass wider research topics e.g. quality of life, CP in adults, or whether there is appetite to fund further research projects.
- The CPS website has good information on recent research advances for CP. More information on the research that the CPS's in-house researcher is undertaking should be shared alongside New Zealand-specific research.

EDUCATION

Educating members and their families/whanau alongside the wider public, including schools and workplaces, should be a key priority for the CPS. Alongside awareness activity, greater understanding of the condition will improve experiences for people living with CP.

Recommendations:

Webinars

- Educational offerings could also be offered to members. A range of educational experts could be brought in to offer educational sessions to members e.g. around life skills, treatments etc. These could be offered as online webinars.

Classroom education sessions

- Kaiwhatare (Navigators) could visit schools that have children attending with CP to educate the children and bring a greater understanding of CP. They could answer any questions that the children have and facilitate conversations with them.

Online training modules

- Online training modules could also be offered to different groups e.g. parents, adolescents and young adults (AYA), alongside more general sessions. These could focus on the topics outlined in the information session, giving practical examples of how to implement information.

At a later stage, training modules could also be developed for workplaces and teachers in schools. These could be paid for by these institutions and focus on CP education and best-practice on how to accommodate an employee or child with CP in the classroom.



Summary

The Cerebral Palsy Society is committed to providing a quality service to its members and is in a financially secure position. Therefore fundraising is not the primary focus.

The restructure in 2020 has had a significant impact on members. Advocacy should be a strong focus alongside offering people living with CP and their families much needed support.

The new Board is committed to positive change for the society, and is in a good position to define a good governance structure and ensure its Board members are adequately equipped to deliver on strategic priorities.

There is an appetite to ensure support for members remains current and fit for purpose; with the recommendations outlined in this report the first steps to take in order to further deliver on the organisation's vision and purpose.