Dyson Consulting Group

Cerebral Palsy Strategy - Sector and Community Consultation Project

Final Report

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Prepared for:

The Australia and New Zealand Cerebral Palsy Strategy Working Group

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- Scope Australia who converted the Strategy documents to easy English and plain English

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1. Glossary of Terms

DCG	Dyson Consulting Group
The draft Strategy	The draft Strategy Australia and New Zealand Cerebral Palsy Strategy
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
the Act	*National Disability Insurance Scheme Act* (2013)
NDA	National Disability Agreement (NDA
CALD	Culturally and Linguistically Diverse
ATSI	Aboriginal and Torres Strait Islander
AAC	Alternative and Augmentative Communication
Survey respondent	A person or organisation who completed the online survey
Submission questions respondent	A person or organisation who completed the online submission questions
Open submission respondent	A person or organisation who made an open format submission
Consultation group member	A person who participated in a consultation group (on line or face-to-face)
Key informant	A person who participated in a key informant interview

2. Executive summary

A working group of organisations and consumer representatives commissioned a comprehensive consultation regarding the draft Australia and New Zealand Cerebral Palsy Strategy. This report presents the findings from these consultations and potential approaches for further development of the strategy.

Methods

Consultations were conducted using a mixed methods approach that minimised participation barriers for people with cerebral palsy and their families and supporters.

Results

There were 139 responses to the draft Strategy, with 87% of all responses received via the online channels of a web-based survey and online submissions. Consultation groups and interviews were also conducted with key informants.

People living with cerebral palsy, self-reported highly variable satisfaction (mean ratings using a 0 – 10 rating scale) with quality of life across different domains, for example:

- A high degree of satisfaction with where the person lived (7.76)
- A low degree of satisfaction with the general public's understanding of cerebral palsy and disability (3.33)

Qualitative information from online submissions, consultation groups and key informant interviews focussed on the importance of inclusion and of social and economic participation.

Responses to the strategy vision and mission were variable. While the concepts of 'a world without cerebral palsy' and 'prevention and cure' prompted comments and concerns via each of the consultation methods, survey respondents also expressed support for the vision. When asked *'How likely would you/your organisation be to publicly support the following vision statement…'* survey respondents working in the sector gave a mean rating of 85.6 (0 -100 scale).

Discussion

The draft Strategy seeks to provide a framework for engaging with government and supporting evidence-based practice and contemporary approaches that are informed by the preferences of people living with cerebral palsy and their families and supporters

In an environment moving away from condition specific and towards a person centred model of planning, funding and delivering programs and supports there remains a need for cerebral palsy specific strategy, particularly due to:

- the barriers experienced by many people as a result of challenges in communication
- the number of Australians living with cerebral palsy
- the need for support across the lifespan
- the potential influence on the NDIS if opportunities for social and economic participation are not fully taken up

The current goals of the draft Strategy are aligned to various segments of the sectors delivering support to people living with cerebral palsy: community and social supports, health services, disability supports and research. To facilitate engagement with government the strategy goals could also be aligned to portfolio responsibilities of government, such as employment, education, disability supports or health services.

3. Introduction

A working group of organisations and consumer representatives developed a draft Australia and New Zealand Cerebral Palsy Strategy. This working group engaged Dyson Consulting Group *'to conduct a comprehensive consultation process regarding the Australia and New Zealand Cerebral Palsy Strategy'* and to *'seek genuine feedback in order to create a document that accurately represents the needs, opinions and priorities of people with cerebral palsy, their families and people working in the field'*.

(Project briefing document).

3.1 Draft Strategy

The disability sector in Australia is changing rapidly. The shift from block funded supports delivered through a charitable model, to supports that are based on individuals' needs and preferences and delivered under insurance principles, requires support providers and sector organisations to adapt to a new operating environment. This includes increased sector co-operation and a more co-ordinated approach to working with government. A key driver of this move to cross sector co-operation is to deliver greater co-ordination, particularly ensuring research contributes to evidence-based practice and enabling findings to translate into more effective approaches and interventions. The move to cross sector co-ordination also has a strong focus on addressing gaps between disability and related sectors such as health, community services and education.

The Australia and New Zealand Cerebral Palsy Strategy (the draft Strategy) provides a framework for sector organisations to ensure a co-ordinated approach to engaging with government in a range of policy areas and to ensure that these activities are informed by the preferences of people living with cerebral palsy and their families and supporters. Such an approach enables the draft Strategy to be consistent with one of the principles of contemporary practice: *'nothing about us without us.'*

The draft Strategy has five key objectives:

- *'To outline current practices and highlight domains for further improvement in the field of Cerebral Palsy*
- *To provide a practical, unified advocacy tool based on research, clinical and social objectives taken from the field of Cerebral Palsy*
- *To summarise common goals for organisations across Australia and New Zealand, in order to foster collaborative networks*
- *To guide inter-departmental policy makers, particularly in the areas of healthcare, disability, education and aged care, on issues around quality, access and continuity of services and supports*
- *To provide a means to measure and assess progress over time'*

(Project briefing document)

The draft Strategy vision, mission and goals support the achievement of these objectives. The draft Strategy's mission is to *'improve the health, participation and quality of life of individuals with Cerebral Palsy.'* The vision is comprised of two elements, an ultimate vision of *'a world without cerebral palsy'* and a vision that *'every person with cerebral palsy has a positive quality of life, with the opportunity to fully extend themselves and live a meaningful life'*.

The strategic action plan includes four goals:

- Inclusion and engagement
- Health outcomes
- Intervention and disability support
- Cure and prevention

Each of these goals includes several priority objectives. Copies of each of the four versions of the strategy are provided in Appendix 1.

4. Project deliverables

The project was conducted in three stages:

- Stage 1 Consultative evaluation of draft Strategy (including seeking endorsement for the draft Strategy)
- Stage 2 Analysis of findings
- Stage 3 Reporting

The deliverables for the project are a draft report (completed) and this final report.

5. Methods

Consultations were used to investigate the degree of alignment between stakeholders' priorities and the draft Strategy's vision and mission, the goals, priority objectives and measurability. The findings from the consultations were also used to identify areas of potential refinement of the draft Strategy. A mixed method approach comprised of the following was used:

- An online survey
- Online submissions
- Face-to-face consultation groups
- Telephone consultation groups
- Interviews with key informants

A mixed-method approach was used to enable an inclusive process that minimised participation barriers and catered for the varying needs and levels of engagement of different stakeholder groups. Online and phone consultations were the primary methods of consultation as these methods reduced or eliminated the participation barriers of:

- Requiring people to attend a forum at a specific place and time
- Needing to arrange formal support to attend such forums

Existing communication channels (including mailing lists and social media) were used to publicise the consultation options to stakeholders. Printed flyers were also displayed in services where people living with cerebral palsy access support.

The working group also developed a website for the draft Strategy https://cerebralpalsystrategy.com.au /. This website:

- Provided a central place for information about the draft Strategy
- Hosted copies of the draft Strategy available for download, including plain English and Easy English versions
- Hosted information about community consultation sessions
- Hosted the online survey
- Enabled submissions (in a range of formats) regarding the draft Strategy

5.1 Online survey

An online survey was developed in consultation with the Strategy working group and was made available on Australia and New Zealand Cerebral Palsy Strategy website, https://cerebralpalsystrategy.com.au. The survey was created using Survey Monkey.

The survey used skip logic, branching to a different set of questions depending on whether the respondent identified as a person living with cerebral palsy; a family member or supporter of someone with cerebral palsy; or someone who works in the sector, including people working in agencies that provide support for people living with cerebral palsy, people working in advocacy organisations and researchers.

For each stakeholder type, questions were designed to be relevant to issues for that stakeholder group. A copy of the survey is contained in Appendix 2.

5.2 Submissions

The option for stakeholder submissions was included to provide an opportunity for the further identification of ideas and issues not included in the draft Strategy. Stakeholders had a choice of:

- Making an open submission in a range of file formats (including free text responses, Word documents, PDF files, photos, images of drawings, links to short video posted on a third-party site)
- Completing free text responses to a series of questions regarding the draft Strategy and describing views regarding:
    - The mission of the draft Strategy
    - The vision of the draft Strategy
    - The overarching goal of improved quality of life
    - Whether the key goals cover all of the areas relevant to them
    - Whether the wording of the goals is appropriate and easy to understand

- The prioritisation of goals

A copy of the submission questions is contained in Appendix 3.

5.3 Consultation groups

A face-to-face group consultation was conducted with adults living with cerebral palsy who also have an intellectual disability. Six people participated in this group consultation at Scope, Glenroy (Victoria). Each participant attended with a support worker who was familiar with their preferred communication style. Prior to the group consultation, participants were provided with Easy English and plain English copies of the draft Strategy and were shown how to access the draft Strategy from the website www.cerebralpalsystrategy.org.au. The group consultation took the form of a facilitated discussion regarding four key issues:

1. Identifying personal priorities, what people said they needed to live a good life
2. Nominating where these priorities fit into the draft Strategy
3. Describing indicators that the vision has been achieved
4. Identifying measures of success for the draft Strategy

A group consultation was conducted via teleconference with five young people aged 15 – 22 years. A teleconference format was used to enable people in different regions to participate in a group consultation with people of similar age. The group consultation took the form of a facilitated discussion regarding the four key issues noted above. Participants were provided with copies of the draft Strategy prior to the group consultation and were logged on to a web portal where they could view a PowerPoint presentation and a copy of the draft strategy during the session.

Commentary regarding the consultation groups conducted

Because of the barriers to participation noted above, online engagement was the most common method for individuals and families to provide feedback regarding the draft Strategy.

Initially two consultation groups were planned and advertised, one in Glenroy (Victoria) with the families of young children (aged up to 6 years) living with CP and one group in Regents Park (South Australia) with the parents of school aged children and adolescents (aged 7 – 18) living with CP. These groups were not conducted due to insufficient responses. A consultation group with the families of young children (aged up to 6 years) living with CP was also offered in Sydney. This group was also not conducted due to insufficient responses.

No further consultation groups were arranged once the responses to the draft Strategy reached saturation point; that is no new themes or significant information were emerging. Responses from consultation groups quickly reached saturation point. This was not surprising given the aspirational nature of any strategy and the extent to which Australians have engaged in discussing disability since the Productivity Commission report on Disability Care and Support (2011).

It is also noteworthy that neither the project nor the consultation groups were intended to engage with a representative sample of people living with cerebral palsy or their families and supporters. Such consultation is a much larger exercise and may have a more operational focus. The differences in responses to the different questions (rather than any differences between different groups of respondents) provide the most valuable insights.

Details of consultation group questions are contained in Appendix 4.

5.4 Interviews with key informants

Interviews were conducted with selected key informants. The Australia and New Zealand Cerebral Palsy Strategy Working Group nominated key informants who were identified as being able to provide particular perspectives or insights. Interviews were conducted to a semi-structured format with The Australia and New Zealand Cerebral Palsy Strategy Working Group providing feedback on the questions posed by DCG. Interviews were conducted via phone or teleconference at a pre-arranged time that was convenient for the interviewee. Face-to-face interviews were conducted in a mutually agreed and accessible location, such as at a local library, where this was more appropriate to the interviewee's preferred communication style.

Key informants

- First Peoples Disability Network – Indigenous Australians perspective
- Department of Health, Northern Territory - Rural and Remote perspective
- Ex-NDIS board member – government insights and NDIA perspective
- Lived experience consultant and skilled advocate – lived experience perspective
- Cerebral Palsy Alliance board member – structure and positioning of the draft Strategy

Details of interview questions are contained in Appendix 5. Where appropriate, interview questions were adapted for each interview to enable the best utilisation of key informants' expertise.

6. Findings

Findings from each of the consultation methods were analysed to identify key issues and themes in relation to:

- The vision and mission
- The prioritisation of goals
- The appropriateness of goals, including:
    - Missing goals (if any) and priority objectives under each goal
    - Responses regarding risks and barriers to achieving each goal
    - Opportunities and facilitators for achieving each goal
    - Objections or concerns regarding strategy goals, or the wording of these goals
- Success measures for the final draft Strategy

These findings are presented in relation to both the lived experience of survey respondents as well as the feedback gained from all consultation methods.

6.1 Respondents and response options

A total of 139 people provided responses regarding the draft Strategy. The online survey was the most commonly used method for providing feedback about the draft Strategy:

- 98 people (70.5%) competed the online survey
- 16 people (11.5%) responded to the online submission questions
- 8 people (5.8%) or organisations uploaded a submission document
- 11 people (7.9%) participated in a group consultation
- 6 people (4.3%) participated in a key informant interview

Table 6-1 Total responses: all consultation methods

Consultation method	Number of responses	%
Online survey	98	70.5%
Online submission questions	16	11.5%
Individual or organisation submission document	8	5.8%
Group consultation	11	7.9%
Key informant interview	6	4.3%
Total	139	

6.1.1 Online consultations – stakeholder group

All survey and submission question respondents were asked to provide information regarding:

- The stakeholder group with which they identified. People who identified as belonging to more than one group (such as a person living with cerebral palsy who also works in the sector) were able to complete more than one survey
- Their location (state or territory)

Information about the stakeholders who participated in an online consultation is summarised in **Table 6-2**. More detailed information about the location of survey respondents is detailed in Appendix 6.

Table 6-2 Online consultation –responses and respondents (summary)

Type of stakeholder	Number of respondents					
	Survey		Submission questions		Open submissions	
	N	%	N	%	N	%
The family member or supporter of a person living with cerebral palsy	40	40.8%	3	18.8%	1	12.5%
A person living with cerebral palsy	18	18.4%	3	18.8%	2	25%
A person who works for a support provider	16	16.3%	4	25%	0	%
A person who works in health	15	15.3%	2	12.5%	0	%
A researcher	6	6.1%	2	12.5%	3	37.5%

Type of stakeholder	Number of respondents					
	Survey		Submission questions		Open submissions	
	N	%	N	%	N	%
A person who works for another sector organisation (including advocacy, NDIA and peak agencies)	3	3.1%	0	0%	2	25%
Did not answer	0	0%	2	12.5%	0	%
Total	98	100%	16	100%	8	100%

Online consultation options were the response options most commonly used by the families of children and young people. Most people answering the survey were people living with cerebral palsy (n = 18, 20%) or a family member/carer/supporter (n =40,40%).

In relation to the online survey and submission respondents:

- Twenty three (16.5%) respondents identified as being a person living with cerebral palsy. Of this group 15 (65.2 %) were aged under 40 years
- Forty-four (31.6%) respondents identified as being the family member or supporter of a person living with cerebral palsy
- The majority (n = 30, 75%) of survey respondents who identified as family members/carers/supporters for a person living with cerebral palsy responded in relation to a person living with cerebral palsy who is under 18 years of age.

6.1.2 Survey respondents

6.1.2.1 Survey respondents – person living with cerebral palsy

Survey respondents who identified as being a person living with cerebral palsy or a family member or supporter were asked about the age and the need for assistance with mobility, communication or self-care of the person living with cerebral palsy (**Table 6-3**).

Table 6-3 Online survey – age of person with cerebral palsy

Age of person living with cerebral palsy	Number of people			
	Person living with CP responding		Family member or supporters responding	
	N	%	N	%
0 - 12 years	3	16.7%	19	47.5%
13 - 17 years	1	5.6%	11	27.5%
18 - 24 years	1	5.6%	5	12.5%
25 - 40 years	10	55.6%	3	7.5%
41 - 55 years	1	5.6%	1	2.5%
56 - 70 years	1	5.6%	1	2.5%
71+	1	5.6%	0	0%
Total	18	100%	40	100%

Fourteen survey respondents (77.7%) who identified as a person living with cerebral palsy indicated they always or sometimes needed assistance with mobility, communication or self-care. Thirty-three survey respondents (82.5%) who identified as a family member or supporter of a person living with cerebral palsy indicated the person for whom they provided support always or sometimes needed assistance with mobility, communication or self-care.

Table 6-4 Online survey – need for assistance

Need for assistance with mobility, communication or self-care	Number of respondents	
	Person living with CP responding	Family member or supporter responding
Always	5	19
Sometimes	9	14
Never	3	3
Did not answer	1	4
Total	18	40

6.1.2.2 Survey respondents – participation in vocational activities and education

Survey respondents living with cerebral palsy were asked about their participation in vocational activities and education. Family members and supporters were also asked about their own participation in these activities. Ten (56%) respondents with cerebral palsy and 20 (50%) of family members/supporters were working, studying or volunteering (Table 6-5).

Table 6-5 Online survey - vocational and educational participation

	Number of respondents	
Participation in vocational or educational activities	Person living with CP	Family member or supporters
Working, studying or volunteering	10	20
Looking for work, study or volunteering opportunities	3	4
None of the above	4	12
Did not answer	1	4
Total	18	40

6.1.2.3 Survey respondents – living situation

Survey respondents lived in a variety of situations. Eleven survey respondents (61%) who are living with cerebral palsy reported living with family members, five lived alone (27.7%) and one (5.5%) lived with people who are not members of their family. These survey respondents were also asked to use an 11-point Likert scale (0 - 10) to rate their satisfaction with where and with whom they live.

These respondents reported a mean satisfaction with where they lived of 7.8 and a mean satisfaction of 7.6 in relation to with whom they lived. There were insufficient survey responses to conduct an analysis of the relationship between housing or living situation and satisfaction with that situation.

Table 6-6 Online survey – living situation (person with cerebral palsy)

Living situation: Person living with CP	Number of respondents
I live alone	5
I live with my parents and/ or brothers/sister	5
I live with my spouse and/ or children	4
I live with other family members	1
I live with other people who are not my family	1
I live with my parents and/ or brothers/sisters AND I live with other family members	1
Did not answer	1
Total	18

The family members and supporters of people living with cerebral palsy were asked separately about their living situation. More than half (n = 22, 55%) of these family members and supporters lived with the person that they support and wanted to maintain this living arrangement. Two (11%) of these family members and supporters wanted to live apart from the person that they support. However, it should be noted that as stated previously, most family member/supporter respondents supported someone with cerebral palsy aged 18 years or younger and therefore this profile of responses is unsurprising.

Table 6-7 Online survey – living situation (family or supporter)

Living situation of family or supporter	Number of respondents
I live with the person I support and we want to keep living together	22
I live with people other than the person I support	11
I live with the person I support but we want to live apart	2
I live alone	1
Did not answer	4
Total	40

6.1.2.4 Survey respondents - people working in the sector

Survey respondents working in the sector were those respondents who had self-nominated as having one of the following roles:

- A volunteer
- A person who works for a support provider
- A person who works in health
- A person who works for another sector organisation (including advocacy, NDIA and peak agencies)
- A researcher

These survey respondents were asked:

> *'How does your role contribute to supporting people living with CP and their families to have a good life?'*

A total of 36 survey respondents answered this question. Responses were reviewed to identify common themes of:

- Fundraising – 3 (8.3%) survey respondents both for research funds and funding for awareness and inclusion
- Direct delivery of supports and interventions – 20 (55.5%) respondents including:
    - Respondents who reported having a particular qualification - occupational therapist, speech pathologist, physiotherapist
    - Respondents who nominated their role as having a particular focus or purpose - improve daily function, physical health and wellbeing, custom wheelchair seating, communication and swallowing difficulties, psychological interventions, counselling and family support, sleep services
- Managing or co-ordinating supports – 8 (22.2%) respondents – including information and referral services, advocacy and advice
- Conducting research - 5 (13.8%) respondents, including research regarding:
    - Causal pathways and opportunities for prevention
    - Understanding the lived experience of people with cerebral palsy
    - Evaluating the effectiveness of interventions and programs

Further information regarding survey respondents who are people working in the sector is summarised in Table 6-8 and in Appendix 6.

6.1.3 *Online submission respondents*

Online submissions were received from 24 respondents. Sixteen people (66.7%) answered the online submission questions and eight people (33.3%) made an open submission. Responses to the online submission questions were received from similar numbers of:

- People living with cerebral palsy – 3 responses (18.8%)
- Family members or supporters of people living with cerebral palsy – 3 responses (18.75%)
- People who work for a support provider – 4 responses (25%)
- People who work in health - 2 responses (12.5%)
- Researchers - 2 responses (12.5%)

Two of the responses to online submission questions did not include this information.

Responses to the open submissions were received from:

- People living with cerebral palsy – 2 responses (25%)
- Family members or supporters of people living with cerebral palsy – 1 response (12.5%)
- People who work for a sector organisation - 2 responses (25%)
- Researchers - 3 responses (37.5%)

6.2 Respondents' lived experience (satisfaction with quality of life)

6.2.1 *Introduction*

A central element of mission of the draft Strategy is *'to improve the health, participation and quality of life of individuals with Cerebral Palsy.'*

The draft Strategy vision is also focussed on ensuring that *'every person with cerebral palsy has a positive quality of life, with the opportunity to fully extend themselves and live a meaningful life…'*

With the focus of the vision and mission on quality of life, it is important to understand people with cerebral palsy's current level of satisfaction (or dissatisfaction) with the areas of life for which the draft Strategy has proposed goals. The four domains for the goals of the draft Strategy are:

- Inclusion and Engagement
- Health Outcomes
- Intervention and Disability Support
- Cure and Prevention

Although satisfaction is a subjective evaluation relative to one's expectations, measuring a level of satisfaction with different areas of life can also indicate the aspects of a strategy that respondents may view as being more relevant to their own lives.

Survey respondents who identified as a person living with cerebral palsy or a family member or supporter were asked to rate their satisfaction with several areas of their daily lives using an 11-point Likert scale (0 - 10) as per the example (Table 6-8).

Table 6-8 Example – rating scale

For example: *'How satisfied are you with:'*

	Completely dissatisfied			Neutral					Completely Satisfied		
	0										10
Your opportunities to study, work, or volunteer, if you choose?	0	1	2	3	4	5	6	7	8	9	10
Your opportunities to have a social life?	0	1	2	3	4	5	6	7	8	9	10

6.2.2 People with cerebral palsy - satisfaction with quality of life (self-report)

For people living with cerebral palsy, self-reported satisfaction with quality of life varied greatly across different domains, for example (Table 6-9):

- A high degree of satisfaction with where the person lived (7.76)
- A low degree of satisfaction with the general public's understanding of cerebral palsy and disability (3.33)

For people living with cerebral palsy, self-reported satisfaction was lowest in relation to:

- NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of cerebral palsy
- The general public's understanding of cerebral palsy and disability
- Satisfaction with your access to appropriate therapy services
- Satisfaction with doctors' understanding of cerebral palsy and disability
- Satisfaction with support workers' understanding of cerebral palsy and disability
- Satisfaction with feeling part of your community.

Table 6-9 Online survey – satisfaction (person with cerebral palsy)

Lived experience	Mean rating (0 - 10)
Satisfaction with where you live	7.76
Satisfaction with who you live with	7.56
Satisfaction with the supports and assistance you receive with daily activities	7.38
Satisfaction with your access to appropriate health services	7.27
Satisfaction with your access to public and private transport	7.06
Satisfaction with how safe you feel	6.81
Satisfaction with your choice and control over the disability supports and assistance you receive	6.69
Satisfaction with your opportunities to have a social life	6.60
Satisfaction with therapists' understanding of CP and disability	6.38
Satisfaction with your opportunities to study, work, or volunteer, if you choose	6.13
Satisfaction with the accessibility of places you go or would like to go	6.13
Satisfaction with support workers understanding of CP and disability	5.81
Satisfaction with feeling part of your community	5.69
Satisfaction with your access to appropriate therapy services	5.69
Satisfaction with doctors understanding of CP and disability	5.13
Satisfaction with NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of CP	4.60
Satisfaction with the general public's understanding of CP and disability	3.33

6.2.3 People with cerebral palsy - satisfaction with quality of life (family and supporters report)

For some people with cerebral palsy it can be difficult to measure their satisfaction with quality of life due to their age (for example, with very young children) or due to their impairments. Although family and supporters cannot always speak accurately about another person's satisfaction with quality of life,[i] it is relevant to consider their views:

- So that the experiences of these people with cerebral palsy are represented as well as possible

- Because the wellbeing of family and supporters can be affected by providing unpaid support
- Because family and supporters may publicly speak for or against a national strategy

Survey respondents who identified as being the family member or supporter of a person living with cerebral palsy were asked to rate their own satisfaction with the person with cerebral palsy's quality of life in a range of life areas. With the exception of living arrangement, these family members and supporters were generally less satisfied with the quality of life of the person with cerebral palsy than were respondents with cerebral palsy. This may reflect that:

- Family members and supporters' responses were in relation to people with more severe cerebral palsy
- Family members and supporters were the parents of children and young people with cerebral palsy, whereas responses from people living with cerebral palsy were from adolescents and adults
- Family members' and supporters' ratings of satisfaction were informed by their own lived experience and this is different from the lived experience of people living with cerebral palsy.

Table 6-10 Online survey – satisfaction (family member/supporter)

Lived experience	Mean rating (0 - 10)
Satisfaction with who they live with	9.25
Satisfaction with where they live	8.56
Satisfaction with their access to appropriate health services	7.17
Satisfaction with support workers understanding of CP and disability	6.63
Satisfaction with how safe they feel	6.51
Satisfaction with their access to public and private transport	5.83
Satisfaction with their opportunities to study, work, or volunteer, if they choose	5.72
Satisfaction with their feeling part of the community	5.72
Satisfaction with their access to appropriate therapy services	5.64

Lived experience	Mean rating (0 - 10)
Satisfaction with their choice and control over the disability supports and assistance they receive	5.56
Satisfaction with their opportunities to have a social life	5.33
Satisfaction with the accessibility of places they go or would like to go	5.06

It should be noted that the ratings of family members and supporters cannot be directly compared with the ratings of people with cerebral palsy as each group was asked to rate their satisfaction with different aspects of quality of life. In addition, it should be noted that ratings of satisfaction and priorities may be different for people living with more severe cerebral palsy, or with other characteristics such as living in a remote community or having English as an additional language.

The two areas with the least satisfaction concord with the self-report of people living with cerebral palsy:

- NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of CP
- The general public's understanding of CP and disability

6.2.4 Family members and supporters - satisfaction with own quality of life

Survey respondents who identified as being the family member or supporter of a person living with cerebral palsy were also asked to rate their satisfaction with *their own* quality of life in a range of life areas. Carers play a vital role in ensuring quality of life for people living with cerebral palsy and there is strong evidence that carers have some of the lowest satisfaction with quality of life of any group in Australian society.[ii]

Family members' and supporters' dissatisfaction with areas of their own lives is consistent with the Australian Centre for Quality of Life's research regarding the quality of life of carers.[iii] Family members and supporters who responded to the survey reported being the least satisfied with:

- The general public's understanding of cerebral palsy and disability (3.28)
- Opportunities to have a social life (4.39)
- NDIA Planners/ECEI Partners knowledge/ understanding of cerebral palsy (4.66)

Table 6-11 Online survey – own satisfaction (family member/supporter)

Lived experience	Mean rating (0 - 10)
Satisfaction with therapists understanding of CP and disability	7.61
Satisfaction with Doctors understanding of CP and disability	6.11
Satisfaction with Support workers understanding of CP and disability	6.09
Satisfaction with your opportunities to study, work, or volunteer, if you choose	5.31
Satisfaction with your feeling part of the community	5.29
Satisfaction with NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of CP	5.09
Satisfaction with NDIA Planners/ECEI Partners knowledge/ understanding of CP	4.66
Satisfaction with your opportunities to have a social life	4.39
Satisfaction with the general public's understanding of CP and disability	3.28

6.3 Responses regarding the vision and mission

6.3.1 *Submission responses*

Respondents who completed the submission form were specifically asked about the mission and the vision and any changes or additions that should be considered. A small number of submission form respondents (n = 5, 20.8%) answered these questions.

While one submission form respondent noted that the mission was *'an excellent statement that represents people living with cerebral palsy'* some respondents noted that there is '*inherent tension here between understanding the day-to-day experience of living with cerebral palsy and…the clinical factors often associated with cerebral palsy.*'

Equally a small number of submission form respondents (n = 4, 16.7%) recorded their views on the proposed vision statement. These disparate views included the need for:

- Educating and researching the wider community about cerebral palsy and other disabilities
- Staff/carer training on specific needs, such as communication
- Developing people to their full capacity

None of the open submissions explicitly discussed the vision and mission. However, six open submissions discussed some key elements of the vision, particularly:

- Participation and quality of life (the mission)
- opportunities to extend themselves and to live a meaningful life (the vision)

These elements were identified in relation to participation in chosen life roles (such as friend, student, worker) and equitable access to opportunities (particularly education and employment).

6.3.2 Survey responses

Forty (40.8%) survey respondents identified as being a person who works for a support provider, a person who works for another sector organisation (including advocacy and peak agencies) or a researcher **Table 6-2**. These respondents were asked:

- *'How likely would you/your organisation be to publicly support the following vision statement…'*
- *'How likely would you/your organisation be to publicly support the following mission statement…'*

Table 6-12 Online survey results – support for strategy vision and mission

How likely would you/your organisation be to publicly support…?	Mean rating (0 - 100)
… the following vision statement: *'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.'*	85.60
… the following mission statement: *'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.'*	91.63

These survey respondents were also invited to write free text comments, recommend changes or improvements in relation to the vision and the mission. Nine of the 12 (75%) respondents who made a comment regarding the vision, expressed concern regarding the ultimate vision of *'a world without cerebral palsy'*, particularly how this would be viewed by people living with cerebral palsy and their families. One respondent noted *'I do not feel this can be achieved - given the various causes there will likely always be some degree of people diagnosed with CP'*. One respondent noted the importance of considering families and carers in the vision *'as they have a huge impact on the ability for a meaningful life'*.

6.3.3 Key informant interview responses

Interviewees had mixed responses to the vision and mission. While all interviewees were supportive of the mission *'to improve the health, participation and quality of life of individuals with cerebral palsy'* five of the six interviewees also expressed concern regarding the first part of the vision *'a world without cerebral palsy'*. One interviewee noted *'I support research but what does this say to people with CP?* Another interviewee commented *'CP is a small part of who I am; why would I want to get rid of that?'*

Interviewees noted the mission could also include:

- Empowerment – to '*help the person move beyond their disability and to have control over their own life and to have an ordinary life.*'
- The perspective of indigenous people – *'it's important to understand quality of life for indigenous people is inextricably linked to connections with family and country''*
- Acknowledgement of the lived experience of first people in Australia and New Zealand – *'where is the perception of Maori people?'*

6.3.4 Consultation group responses

Consultation group participants were asked:

- to identify *'things you need to live a good life…[these] might be where you live and who you live with, relationships and friendships or being involved in the activities that matter to you.'*
- *'To think of the three most important things.'*

These responses were then considered in relation to the current vision and mission. Consultation group participants identified 12 things they needed to live a good life. Of these, nine (75%) were related to key determinants of quality of life - relationships and social connection or participation in chosen life roles and activities. The remaining three (25%) were related to disability supports (2) and healthcare (1) (Table 6-12).

Table 6-13 Map of priority areas for living a good life

Element of vision & mission	Priority for living a good life
Relationships and social connection	• Family • Social opportunities & friends • Being listened to & understood, communication access • Accessible places • Feeing safe
Life roles and activities	• Accessible holidays & recreation e.g. swimming camps • Inclusive education • More independence in chosen activities e.g. cooking & reading • Employment opportunities & supports

Element of vision & mission	Priority for living a good life
Optimal disability support	• More support e.g. respite • More skilled support staff
Optimal health care	• Better health services e.g. GPs

6.4 Responses regarding draft Strategy goals

The draft Strategy includes an overarching goal of quality of life as well as goals in four key domains:

- 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 cerebral palsy
- Health outcomes - to improve health outcomes across the life-span for individuals with cerebral palsy to bring them in line with population averages
- Intervention and disability support - to provide effective, individual, goal-based intervention and disability support to help individuals optimise their potential and achieve their goals
- Cure and prevention - 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

All respondents were able to provide free text responses to these goals. Specific questions in relation to these strategy goals were asked of:

- Respondents who completed submission questions
- Survey respondents who identified as being a person who works for a support provider, a person who works for another sector organisation (including advocacy and peak agencies) or a researcher
- Key informants in interviews

6.4.1 Overarching goal – quality of life

6.4.1.1 Submission responses

Respondents who completed the submission form were asked their views on improved quality of life as an overarching goal for the draft Strategy as well as any specific changes or additions that should be considered. A small number of respondents (n = 4, 16.7%) submitted an answer to this question. While one respondent noted the overarching goal was '*fine'* another commented that *'quality of life is hard to measure'*. These respondents described additional areas that could be covered under key goals:

- Support to excel in whatever they would like to do in their life
- Adult personal care rooms in community areas such as shopping plazas
- Safer public transport
- Allied health professionals experienced in working with adults with cerebral palsy
- Access to effective intervention and supports

In relation to whether the wording of the goals was appropriate and easy to understand, one respondent noted that the draft Strategy is *'quite jargony'* and could be converted to easy English. Another respondent noted that in the overall language and format of the document some terms, such as equality, were very abstract.

Four (50%) of the open format submissions referred to issues that affected quality of life for people living with cerebral palsy, particularly challenges in making social connections and barriers to participation in valued activities and roles:

- One respondent noted the importance of finding '*a supportive network of likeminded people (such as other parents of CP children) or a support network of friends, family or the wider community'*

- Another respondent noted the effect of speech on their social connections *'Speech is impaired which is the biggest drawback (not many friends)'*
- One respondent highlighted *'Equity of opportunity for education is a big issue needing addressing,'* including accommodations and access to technology in exams
- One respondent reported improved quality of life following surgery and allied health services to improve physical function, particularly mobility
- Two respondents noted the importance of work in their lives, one noting they had not been able to find part time work and one family member noting 'I *have not been able to return to full time work since my son's diagnosis, given the number of medical appointments we have on a weekly and monthly basis'*

6.4.2 Inclusion and Engagement

Interviewees, survey respondents and submission form respondents were asked their views on the goal for inclusion and engagement and whether any changes or additions should be considered.

6.4.2.1 Submission responses

There is a conceptual link between social inclusion and subjective wellbeing or quality of life. The submission from one sector organisation notes that personal wellbeing is related to four out of five of the social inclusion domains (with political participation being the fifth, not included, domain):

- Social Participation
- Social Relationships
- Service Access
- Economic/ Materials

Another submission noted that the goal for inclusion and engagement (and the goal for intervention and disability support) should *'Endeavour to reflect* *the interplay of individual, community and societal factors that impact quality of life'*. One submission noted that in relation to the goal of inclusion and engagement it was important to *'acknowledge the importance of engaging people with complex disability'* particularly as there may be additional time, effort and cost required in supporting people with cerebral palsy and complex disability.

6.4.2.2 Survey responses

Survey respondents responded positively to the goal – inclusion and engagement. Survey responses to this goal centred around two key themes:

- Being part of a community, including satisfaction with:
    - Opportunities to have a social life
    - The accessibility of places you go or would like to go
    - Feeling part of your community
    - The general public's understanding of cerebral palsy and disability
- Making a contribution, including satisfaction with:
    - Opportunities to study, work, or volunteer, if you choose
    - Access to public and private transport
    - How safe you feel

The importance of inclusion and engagement was also reflected in the comments of survey respondents who are people living with cerebral palsy:

> *'Cerebral palsy doesn't necessarily mean "I can't do this" 'I think it is important for persons without disability to understand the potential benefits of social inclusion of persons with a disability.'*

> *'Sometimes I felt that I was discriminated against when looking for appropriate roles matching my skillset.'*

One respondent commented on the importance of *'low interest home loans and affordable housing for people with disabilities, who are single, and who are only able to work part-time.'*

One respondent commented on the importance of *'education for schools regarding opportunities for children with disabilities to participate in and compete in the appropriate level of sport.'*

Family members and supporters also highlighted the challenges they experience in inclusion and engagement. One respondent noted:

> *[My caring responsibilities mean] 'limited salary or super for me and this impacts on what I can offer the rest of the children in my family.'*

Survey respondents who identified as being a person who works for a support provider, a person who works for another sector organisation (including advocacy and peak agencies) or a researcher were also asked to rate their support for the goal for inclusion and engagement.

Table 6-14 Online survey – support for goal, inclusion and engagement

How likely would you/your organisation be to publicly support the following goal statement?	Mean rating (0 - 100)
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.'	92.18

6.4.2.3 Interview responses

All key informants identified that some features of the typical presentation of cerebral palsy (particularly effects on movement and speech and effects on communication) affected inclusion and engagement for people living with cerebral palsy. '…*people form their first impressions before they have even spoken with me.'*

Two interviewees noted that this was particularly the case for indigenous Australians. *'Others may make assumptions about the reasons for indigenous people experiencing challenges with spoken language and this affect the person with CP's social interaction, especially outside of their community.'*

6.4.2.4 Consultation group responses

In both consultation groups most (75%) of the factors which participants identified as being *'things you need to live a good life'* were related to inclusion and engagement. These responses are described in **Table 6-13**, section 4.3.4.

6.4.3 Health Outcomes

6.4.3.1 Submission responses

Respondents who completed the submission form were asked their views on the goal for health outcomes and whether any changes or additions should be considered.

One submission noted the importance of acknowledging *'the effects of complex disability for people with cerebral palsy'*. Another submission noted the importance of research that can translate into clinical practice, translating research in pain management for people living with cerebral palsy into clinical practice. One submission form respondent noted a need for national medical guidelines such as *'the use of Magnesium sulphate for pre-term babies'.*

6.4.3.2 Survey responses

Survey respondents made fewer comments regarding the goal for health outcomes. This included satisfaction with:

- Access to appropriate health services
- Therapists' understanding of cerebral palsy and disability
- Access to appropriate therapy services
- Doctors' understanding of cerebral palsy and disability

In considering health outcomes, and interventions for health outcomes, we have adopted the World Health Organization's model of function[iv] and the conceptualisation of health as a state of physical, mental and social wellbeing. Accordingly, therapy services may be viewed as a health service and/or a specific intervention to reduce the effects of impairment and/or increase activity and participation.

There was variable satisfaction with these domains. People living with cerebral palsy rated satisfaction with access to appropriate health services as 7.27 (mean) and family members and supporters rated the same domain as 7.17 (mean); only a marginal difference. However, their rating for satisfaction with access to appropriate therapy services was 5.69 for people living with cerebral palsy and 5.64 for family members and supporters. For people living with cerebral palsy satisfaction with their doctors' understanding of cerebral palsy and disability was 5.13.

In relation to health outcomes, survey responses centred on:

- The inaccessibility of some health services, such as dental services, or challenges accessing therapists with a knowledge of alternative and augmentative communication (AAC)
- Continuity of provider and service access arrangements – *'the physio that has been looking after him for 15 years is no longer allowed to see him at school'*
- The focus of expertise in cerebral palsy – *'the outdated concept that CP is a childhood disability with all expertise situated in children's hospitals…The adult healthcare system is more oriented toward spinal cord injuries or degenerative conditions which are so different*

Survey respondents who identified as being a person who works for a support provider, a person who works for another sector organisation (including advocacy and peak agencies) or a researcher were also asked to rate their support for the goal for health outcomes.

Table 6-15 Online survey – support for goal, health outcomes

How likely would you/your organisation be to publicly support the following goal statement?	Mean rating (0 - 100)
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.'	85.08

6.4.3.3 Interview responses

Interviewees were also asked their views on the goal for health outcomes.

One interviewee noted that health services were often not accessible for people living in regional and remote communities. Another interviewee noted that access was not only an issue in relation to the location of services and that communication access (inaccessibility) remained a significant barrier to accessing health services.

6.4.3.4 Consultation group responses

One consultation group participant's response to the activity -identifying '*things you need to live a good life'* is related to health outcomes. One participant noted the importance of accessing quality health services, particularly general practitioners.

6.4.4 Intervention and Disability Support

6.4.4.1 Submission responses

Submission form respondents were asked their views on the goal for intervention and disability support and whether any changes or additions should be considered.

None of the submission form respondents made comments in relation to the goal for intervention and disability support. However, seven (87.5%) of the open submissions discussed intervention and disability support. These responses were in two themes:

- Access to treatments and interventions such as *'personalised exercise programs'*, faster access to aids and equipment (particularly for children), multidisciplinary pain management, medical procedures (including surgery and intramuscular botulinum toxin-A injections), programs for older people living with cerebral palsy
- Improving providers' capabilities in delivering services to people living with cerebral palsy, particularly the capabilities of general practitioners

6.4.4.2 Survey responses

Several of the domains of lived experience in the survey are related to intervention and disability support. People living with cerebral palsy reported variable levels of satisfaction with these domains (mean ratings 0 – 10), being:

- Supports and assistance with daily activities (7.38)
- Choice and control over disability supports and assistance received (6.69)
- Support workers' understanding of cerebral palsy and disability (5.81)
- NDIA Planners/Early Childhood Early Intervention Partners' knowledge and understanding of cerebral palsy (4.60)

Family members and supporters reported a lower level of satisfaction with choice and control over disability supports and assistance received (5.56) and a slightly higher level of satisfaction with:

- Support workers' understanding of cerebral palsy and disability (6.09)
- NDIA Planners/Early Childhood Early Intervention Partners' knowledge and understanding of cerebral palsy (4.66)

Several survey respondents noted the importance of knowing how to interact with people who are non-verbal and people with cerebral palsy and described the effect of limitations in these skills on their experience in accessing intervention and disability support:

> *'I would like people to stop talking about me in front of me. People seem to think that because I can't speak that I can't hear. That's not true.'*
>
> *'Why is communication given such low priority when it is the core of revealing the person behind the disability. No one can substitute for an individual's "voice" yet access to communication support and training of communication partners for people with severe movement disorder are given little or no support, particularly in regional areas of Australia.'*

Several survey respondents suggested greater investment in programs such as exercise programs, assistive technology and support with intimate relationships. *'Sexual opportunities are dismissed by most services. It HAS to be bought up, not just talked about but included as an option.*'

Some survey respondents stressed the importance of *'a real focus on the over 18s'*, including concerns regarding condition specific entitlements such as some benefits for people who are blind or vision impaired. *'As a community people living with CP or supporting those living with CP… we need to learn from and copy the vision impaired community and to band together and lobby for more services, opportunities and community understanding of CP'.*

One respondent noted a need for *'more support and options for those who may fall through the cracks because they have less severe physical or medical limitations'.'*

The role of funders and program administrators was also recognised as important in achieving the draft Strategy goals. *'NDIS consultants should have more knowledge and understanding of the day to day and long-term needs.*'

Survey respondents who identified as being a person who works for a support provider, a person who works for another sector organisation (including advocacy and peak agencies) or a researcher we also asked to rate their support for the goal for intervention and disability support.

Table 6-16 Online survey– support for goal, intervention & disability support

How likely would you/your organisation be to publicly support the following goal statement?	Mean rating (0 - 100)
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.'	88.60

6.4.4.3 Interview responses

One interviewee noted the role of disability supports in facilitating choice and control. *'Support agencies become over protective of people and this hinders the opportunity to grow and to experience part of life. Learning from risks and mistakes is part of growing up. We are not babies we are adults.*'

One interviewee noted that the different conceptualisation of disability in some indigenous communities can act as a barrier to accessing intervention and disability support. *'... the conceptualisation of what we call disability is not the same in traditional communities where differences may be accepted as part of the fabric of the community.'* It was also noted that current support systems are not always responsive to the needs of indigenous people, particularly understanding life roles. *'Connection to culture and country is central to planning and support to attend events on country'*.

6.4.4.4 Consultation group responses

Consultation group participants identified that access to supports that met their needs (including respite/ short term accommodation and assistance) and access to skilled support staff were both important to '*things you need to live a good life'*. In both consultation groups participants described these supports as enablers for participation in preferred activities and chosen life roles. See **Table 6-13**, section 6.4.3.

6.4.5 Cure and Prevention

6.4.5.1 Submission responses

Respondents who completed the submission form were asked their views on the goal for cure and prevention and whether any changes or additions should be considered.

One submission respondent reported research was important in discovering '…*what causes cerebral palsy, how can we better treat CP, the potential preventative in medical treatment and finally one day a cure.*'

None of the open submissions recorded a view on the goal for cure and prevention.

6.4.5.2 Survey responses

One survey respondent noted *'There seems to be so much emphasis on therapy. This obviously needs to continue because it's helping people with CP live their lives on a daily basis however, if we REALLY want to improve the lives of people with CP, find out how to cure them.'*

Survey respondents who identified as being a person who works for a support provider, a person who works for another sector organisation (including advocacy and peak agencies) or a researcher we also asked to rate their support for the goal for cure and prevention.

Table 6-17 Online survey – support for goal, cure and prevention

How likely would you/your organisation be to publicly support the following goal statement	Mean rating (0 - 100)
Cure and Prevention: '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.'	81.98

6.4.5.3 Interview responses

One key informant interview noted *'the term cure is particularly problematic. I question whether a cure is realistic within the timeframe of the Strategy. The term cure is offensive to people with disability and has the potential to be quite damaging across the sector more broadly.*'

Another key informant (interviewee) noted that the goal in relation to cure and prevention was part of a medical model of disability. *'I am happy as I am as a person. As long as I get the support I need I'm fine. CP is more of a problem for other people, not for me.*'

6.4.5.4 Consultation group responses

Participants in consultation groups spoke of the importance of quality of life over a focus on cure and prevention. Several participants commented that *'you can't cure CP'* and *'you can't cure us'*.

6.5 Prioritisation of strategy goals

6.5.1 Submission responses

Respondents who completed an online submission form were also asked to prioritise the goals of the draft Strategy from 1 (highest priority) to 4 (lowest priority).

These ratings indicated:

- A clear consensus on the priority of some goals - 80% of respondents rated cure and prevention as 4th priority
- Differing opinions on the priority of other goals - 40% of respondents rated inclusion and engagement as 1st priority and 40% of respondents rated health outcomes as 1st priority

Table 6-18 Online submission – prioritisation of strategy goals

Goal	Priority 1	Priority 2	Priority 3	Priority 4
Inclusion and engagement	40%	40%	0%	20%
Health outcomes	40%	20%	40%	0%
Intervention and disability support	20%	40%	40%	0%
Cure and prevention	0%	0%	20%	80%

Submission form responses were reviewed to identify questions or priority objectives that respondents indicated should be included in the draft Strategy.

Three submission form responses nominated such priority objectives:

- Intervention and support – specifically support to access employment and housing
- Intervention and support – specifically in relation to communication
- Inclusion and engagement – specifically the accessibility of the built environment
- Health outcomes – accessing medical services, particularly increasing the skills of general practitioners

Four open submissions identified accessing medical services as a priority. Three open submissions identified support to access employment or education as a priority.

Consultation group responses

Consultation group participants nominated similar priority objectives, drawn from their lived experience. As part of the consultation group activities participants mapped these priority areas and objectives to the goals of the draft Strategy.

These ratings are summarised in **Table 6-19**.

Table 6-19 Map of priority areas and strategy goals

Goal	Priority objectives
Inclusion and engagement	• Family
	• Social opportunities & friends
	• Being listened to & understood, communication access
	• More independence in chosen activities e.g. cooking & reading
	• Employment opportunities & supports
	• Inclusive education
	• Accessible places
	• Feeing safe
	• Accessible holidays & recreation e.g. swimming camps
Intervention & disability support	• More support e.g. respite • More skilled support staff
Health outcomes	• Better health services e.g. GPs

6.6 Measurement of progress towards meeting the goals of the Strategy

Submission responses

Respondents who completed the submission form were asked about the most appropriate ways to measure progress towards these goals and priority objectives. Three submission form respondents and one open submission respondent provided a response to this question, with two respondents describing possible measures:

- Interviewing people and their families, carers, medical practitioners and staff who work and care for people with cerebral palsy to review how the draft Strategy has progressed over a certain amount of time
- Introducing specific measures:
    - An increase in the number of accessible spaces in any particular area/town
    - The establishment of new/stronger legislation towards accessibility

  - The utilisation and uptake of services
  - The number of people with cerebral palsy who are employed
  - The alignment of services or research priorities with the draft Strategy

Interview responses

Two interviewees identified potential measures of progress towards meeting the goals of the draft Strategy.

One interviewee noted that measures of quality of life should include qualitative data including, *'stories of people's experience and measuring the size and capacity of people's support networks'*.

One interviewee noted that measures could focus on goal attainment. '...they *need to be linked to the individual. What's relevant for one person may not be relevant for another'*.

Consultation group responses

Participants in the consultation groups were asked about indications of a successful strategy by asking the question 'We will know the vision and mission are being achieved when...' These participants were also asked about potential measures for success.

These participants identified success measures that were grounded in their lived experience and that focussed on areas they identified as being important: inclusion and engagement and intervention and disability supports.

These success measures are summarised in Table 6-20.

Table 6-20 Success measures – consultation group participants

Strategy area	Success indicator	Measure
Inclusion and engagement	• Employment - Having a paid job that is meaningful, interesting and what I want	• the number of people who want to work and who have a job
	• when cerebral palsy doesn't have a social stigma	
	• when people ask my opinion and they make changes based on my opinion	
	• when I am in the city with my friends, going shopping and seeing an Ed Sheeran concert	• the number of accessible shops and other places
	• when people understand what I am communicating	• the number of shops that are communication friendly
	• when I have a steady relationship	
	• when I can share positive experiences with other young people	• the number of people who can communicate with me
	• when I can go on a holiday with my friends	• the number of accessible aeroplanes
Intervention and disability supports	• when people want to work with me	• the number of services I can access
	• when I have permanent support staff	• the number of support workers who can work with me
	• when the staff at the swimming pool can help me	• the number of staff at the pool who can support me

7. Discussion

In this section the rationale for a condition specific strategy is discussed as well as possible approaches to the vision, mission & strategy goals and a possible approach to further development of the strategy. These possible approaches and rationale are based on the findings from the consultations described in this report.

7.1 Rationale for a cerebral palsy specific strategy

Over the past decade, government and programs of supports in the disability sector have moved from condition specific organisations and programs to an approach based on the needs of each individual. The recent consolidation of funding to sector advocacy organisations is one example of this and the NDIS takes this approach in relation to determining eligibility for scheme participation and making decisions regarding individual participants plans. In this environment it is important to be able to clearly articulate why a strategy focussed on a particular condition is needed. Responses from key informant interviews have noted several factors that support a condition specific strategy in relation to cerebral palsy:

- Cerebral palsy is a relatively common condition.
- The size of the population of people living with cerebral palsy is such that improvements in the social and economic participation of people living with cerebral palsy have the potential to positively affect the viability of lifetime care schemes, specifically the NDIS.
- People living with cerebral palsy will typically access supports throughout the course of their life. This long-term timeframe means that actions (or a lack of actions) to support social and economic participation also have the potential to positively or negatively influence scheme viability of the NDIS
- The presentation of cerebral palsy typically affects interactions in daily life. Challenges in speech and communication as well as in movement

often result in higher barriers to participation than are experienced by people who have similar support needs but who do not experience challenges in speech and communication. This situation results in significant lost opportunities for individuals and families as well as for society and the economy.

- Many people living with cerebral palsy do not have an intellectual disability. At the same time technology is rapidly changing how people live, work, travel & communicate. Barriers to social and economic participation are more readily able to be removed through the use of technology such as remote access to workplace computers and alternative communication technology. A failure to address these barriers is likely to result in lost potential for economic participation over a very long time frame.

7.2 Vision & mission

The vision and mission received mostly positive responses.

> *'…we need to have a closer look towards finding more information about what causes cerebral palsy, how can we better treat CP, the potential preventative in medical treatment and finally one day a cure.'*
>
> *'I love the first part of the vision, a world without CP.'*

However, a minority of respondents expressed strong opposition to the vision statement, '*Our ultimate vision is a world without cerebral palsy'*.

Twelve survey respondents (12.2 %) made free text comments expressing concern about this part of the vision. Three survey respondents said the likelihood of them endorsing the vision statement was less than 25%. Concerns regarding this part of the vision statement were also raised in both of the consultation groups and by five of the six interviewees.

Their comments provide some insight on this sentiment:

‘Whilst finding a cure sounds great I feel this statement may be negative towards some people currently living with CP as they may not feel they need to be cured but rather supported to reach their potential.’

I cannot support the idea that human beings should all be “perfect”.

‘The ultimate vision can be perceived as discriminatory towards those living with cerebral palsy currently.’

‘Due to the range of causes of CP I see the concept of a world without it to be unrealistic, it's not a disease we can eradicate for example and that this jars with me… gives the general population the impression that this is something that will eventually go away.’

‘I don't like the "world without cerebral palsy" section as I do not feel this can be achieved - given the various causes there will likely always be some degree of people diagnosed with CP and I feel that a lot of them chose to own and take pride in their diagnosis when they are ready to do so. I strongly agree with the rest of the statement!’

‘I also have issue with 'a world without CP' within the disability community wanting to eradicate disability may be seen as eugenic (even though I know this is not the intent of the statement). It would seem more progressive to remove the barriers associated with CP, or reduce the impact of CP than to aim to eradicate it. Perhaps borrowing more from the social model of disability would be a good idea for this statement - however I am aware the draft Strategy addresses cure and prevention research, so I understand why the aim is to not have CP in the world might be considered.

Although only a minority of respondents expressed these view, the views were strongly held. It is possible that this part of the vision, the concept of a cure and a world without cerebral palsy, might cause controversy and act to undermine support for the draft Strategy. Responses to the strategy goal of cure and prevention are discussed in section 6.2.4.

Possible approach: use a co-design approach to redraft the vision statement, rebalancing the focus of the vision on quality of life for people living with cerebral palsy and the ultimate vision of *'a world without cerebral palsy'*.

7.3 Strategy goals

7.3.1 Inclusion and engagement

The findings from all consultation methods consistently focussed on the importance of social inclusion and participation in valued life roles for people living with cerebral palsy, particularly:

- Enhancing employment and volunteering opportunities for adults with disability
- Increasing participation in political, art and cultural activities
- Improving the accessibility (including communication accessibility) of Government and government agencies, places and transport
- Activities to change community attitudes

Respondents also noted that social inclusion support underpins achieving the overarching goal of quality of life. In the submission from one sector organisation it was also noted that social inclusion needs to:

- Address the importance of engaging people with complex disability
- Recognise the additional time, effort and costs involved in supporting people with cerebral palsy and complex disability

Intervention and disability support are enablers of inclusion and engagement that can act to support participation in chosen activities and life roles and can act as enablers in people's full participation and inclusion in a civil society.

This participation and inclusion is fundamental to achieving the overall strategy goal of quality of life.

7.3.2 Intervention and disability support

Respondents in a range of consultation forums indicated that the goal of intervention and disability support was important to them, particularly as an enabler of individuals optimising their potential and achieving their goals. As described in section 5.4.4.2, survey respondents rated moderate to low levels of satisfaction with life domains related to intervention and disability support, particularly:

- Support workers' understanding of cerebral palsy and disability.
- NDIA Planners/Early Childhood Early Intervention Partners' knowledge and understanding of cerebral palsy

Comments made in the submissions, are consistent with these survey responses.

One submission noted the importance of reflecting *'the interplay of individual, community and societal factors that impact quality of life alongside the clinical factors associated with cerebral palsy.'* This was particularly in relation to the goals of Inclusion and Engagement and Intervention and Disability Support.

7.3.3 Health outcomes

Like intervention and disability support, access to health services (and achieving health outcomes) is an enabler of inclusion and engagement. Positive health outcomes support participation in chosen activities and life roles and in doing so can act to support the achievement of the overall strategy goal of quality of life.

Satisfaction with access to therapy services and primary health services (GPs) were among the lowest rated elements of the survey. These results can inform the further development of the draft Strategy action plan; particularly as many health services that people living with cerebral palsy access are *'mainstream'* services separate to allied health services and supports that may be accessed under the NDIS.

The barriers to accessing healthcare for people with disability are well documented. Lack of access to routine and preventative healthcare such as dental services or health screening services can result in poorer health outcomes and services. A lack of staff skills in using alternative and augmentative communication can act as a barrier to people accessing such services. The public health system in Australia is part of a large health sector offering a broad range of services. Innovative approaches to building the capability of the health sector in delivering services to people with disability, particularly people who experience barriers to communication access, have the potential to improve both access to health services and health outcomes. Opportunities for a co-ordinated approach across the disability sector have to potential to deliver more significant improvements in the accessibility of health services and thus improved health outcomes.

7.3.4 Cure and prevention

Although well supported overall, with 81% of survey respondents reporting their likely support for the goal, there were disparate views regarding the appropriateness of the goal – cure and prevention.

The different and strongly held views in relation to the goal of cure and prevention may have the potential to overshadow the draft Strategy as a whole. While some respondents indicated their support for this goal, others were strongly opposed to such a goal being included in the draft Strategy.

These strongly held views cannot be taken as representative of all stakeholders. This is particularly the case for people living with cerebral palsy and their family and supporters. While, some family members and supporters were highly supportive of a goal focussed on cure and prevention, some adults living with cerebral palsy claimed this was a part of their identity and placed a higher priority on inclusion, engagement and quality of life.

Having such different views is not unique to this strategy. Achieving consensus on the other goals of the draft Strategy may provide a foundation for endorsement of the draft Strategy as a whole.

Possible approach: use a co-design approach to redraft the goal statement for cure and prevention, rebalancing the focus of the goal on early interventions and preventative strategies with the ultimate goal of *'finding a cure'*. Refer also possible approach in section 6.1.

7.4 Further development of the draft Strategy

The findings presented in section 6 can inform further development of the draft Strategy. The discussion in this section has been informed by the following considerations regarding approaches to strategy development:

- The overarching goal of a strategy provides a mechanism for describing measures of success, addressing the *question 'What does success look like?'*
- The structure of a strategy provides a framework for engaging with key stakeholders (including government, a sector or industry and consumers), addressing the question *'What needs to be done to achieve success'*
- An effective strategy will clearly articulate how its overarching goal will be achieved and will use a structure that enables government to engage with the draft Strategy. In particular, the structure will enable government to take a co-ordinated approach and will enable different parts of government to respond to a relevant part of the Strategy, such as goals in relation to health services, tertiary education or housing.
- The draft Strategy includes proposed solutions to the issues identified as well as describing the sector's commitment to delivering some of these solutions.

One key informant noted that, *‘A messy structure makes it hard to talk to government and can enable buck passing’*.

The National Disability Agreement (NDA) provides a potential structure for the draft Strategy, with outcomes in relation to:

- People with disability achieving economic participation and social inclusion
- People with disability enjoying choice, wellbeing and the opportunity to live as independently as possible
- Families and carers being well supported

The roles of the Commonwealth and of State and Territory Governments are also described in the NDA. Harmonising the priority objectives with the roles of government and with major policy areas can enable different areas of government to engage with the components of the draft Strategy that are aligned with their areas of responsibility, such as accessible health services or employment programs.

The timeframe for the current National Disability Strategy is 2010-2020. There is an opportunity to align the timeframe of the Cerebral Palsy Strategy with the next (post 2020) National Disability Strategy.

One respondent noted that, *‘This draft Strategy could be better aligned with the policy framework and functions of government so goals or action can be addressed to the right jurisdiction, department or policy area; such as the health interface, transport, education, housing or communities (inclusion & engagement). The NDIS will be much more interested in working with the draft Strategy where it articulates the different responsibilities of different areas of government.*’

Another key consideration is the condition specific nature of the draft Strategy. Governments at Commonwealth and State/territory level are moving away from condition specific policies and program to supports that respond to individual needs. The move from programs such as Helping

Children With Autism (HCWA) to Early Childhood Early Intervention under the NDIS is an example of this shift. This change does not mean that there is no longer place for condition specific strategies and programs but that the rationale for such a strategy needs to be clearly articulated.

In the case of the Australia and NZ Cerebral Palsy Strategy, several key informants have articulated the rationale for a strategy in a way that is aligned with government policy and programs.

One key informant noted the implications for the sustainability of the NDIS. *'We need a strategy because the incidence of CP is lower but there is a much higher cost over a longer timeframe. This goes to issue of making the scheme viable.'*

Another key informant noted that for many people with cerebral palsy there were particular features that increased barriers to economic participation and social inclusion beyond those experienced by people with other health conditions, such as degenerative neurological conditions or spinal cord injury. *'We are very visible. You can't really hide CP and so people form their first impressions before they have even spoken with me. People underestimate me. Because I have difficulties with physical impairment and communication people think I also have a cognitive impairment so this affects how they interact with me.'*

Possible approach: consider alignment of the strategy goals with areas of government responsibility, particularly:

- *Health* – with a focus on the education of health sector providers esp. primary care providers and general practitioners in cerebral palsy and providing services to people who use alternative or augmented communication
- *Education* – with a focus on building the capacity of schools and education institutions and on enabling access to inclusive education for students with cerebral palsy

- *Employment* – with a particular focus on capitalising on the opportunities that new technologies can provide in creating new employment opportunities and in building the disability confidence and capability of employers in employing people with cerebral palsy, particularly addressing employer awareness and attitudes.
- *Human services* – including disability supports and the NDIS, with a particular focus on education regarding cerebral palsy and building the capability of staff at the NDIS and frontline staff at other agencies (Centrelink etc.)

Consider the timeframe for the draft Strategy and potential benefits of alignment with the timeframe for the next National Disability Agreement.

8. Achieving endorsement of the draft Strategy

As part of the survey and submission forms respondents were asked whether they would like the opportunity to endorse the final version of the draft Strategy. A total of 24 respondents indicated they would like the opportunity to endorse a final version, being:

- 16 survey respondents
- 3 respondents who completed a submission form
- 5 respondents who completed an open submission

A list of respondents willing to review the draft Strategy has been provided under separate cover.

9. Conclusion

Thank you for the opportunity to present this report. I look forward to discussing this with you at your convenience.

Maree Dyson

Sally. Canobi

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10. Appendix 1 – Draft Australia and New Zealand Cerebral Palsy Strategy

The strategy has four versions:

- Full draft
- Strategy summary
- Easy English
- Plain Language

Australian & NZ
Cerebral Palsy
Strategy

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

Contents

Acknowledgments

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/

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 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 it's 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/

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

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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

Foreword

1.0 Mission, Vision, Goals, Subdomains and Guiding Principals

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

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 1st 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

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

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^{TM}), 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.

5.2 Strategic Action Plan

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 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.

5.3 Strategic Action Plan
GOAL 2: Health Outcomes

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.

5.4 Strategic Action Plan
GOAL 3: Intervention and Disability Support

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.

5.5 Strategic Action Plan
GOAL 4: Cure and Prevention

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 makes 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 or new discovers 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.

6.0 A Plan to Measure Success

This section will be shaped by priorities identified through community consultation

7.0 Concluding Remarks

These will be shaped based on priorities identified through community consultation

Australian & NZ
Cerebral Palsy
Strategy

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:

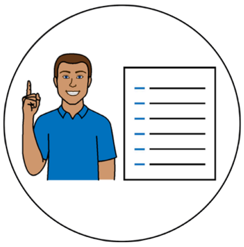
- Reduction in incidence of CP in Australian to 1 in 600 births
- Reduction in severity of CP, as measured by GMFCS level
- Increased expenditure proportionally on CP related research
- Integration between health and disability sectors to better meet needs
- Increased availability of evidence based interventions/therapies 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.

Australian & NZ Cerebral Palsy Strategy

Our Goals for Cerebral Palsy

Easy English



Hard Words

This book has some hard words.

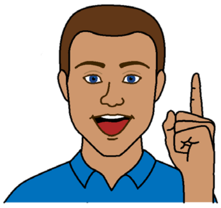
The first time we write a hard word

- the word is in **blue**

- we will write what the hard word means.

About this book

We want to write about our **goals** for **cerebral palsy**.



Goals are things that you want to happen.

Cerebral palsy is a disability that makes it hard to move your muscles.

We call it CP.

We have thought of some goals.

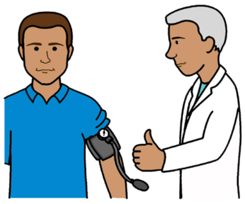
We want to hear what you think of them.

We want to hear from

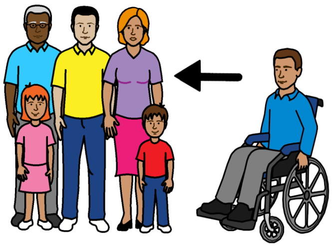
- people with CP
- their families
- people who work in this area.

What we want to do

We want people with CP to



- have better health

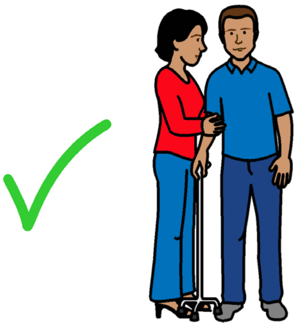


- join in with their community

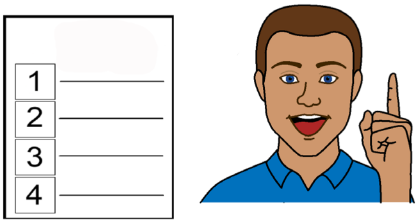
- have a good life.

We can do this if we

- do work to learn about CP
- teach the community about CP



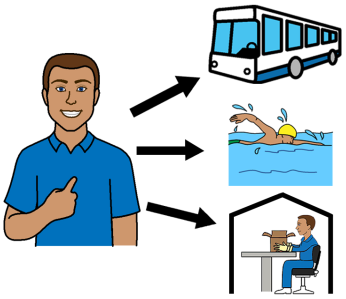
- give good healthcare
- give good disability support.



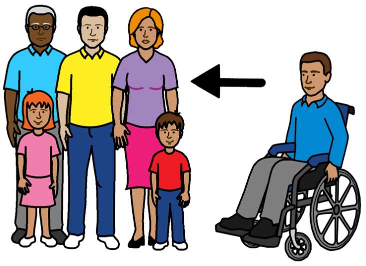
Goals

We have 4 goals for people with CP.

1. Join in with the community.



We want people with CP to do things they want in life.

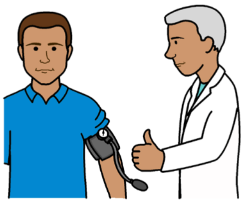


We can help this happen if we

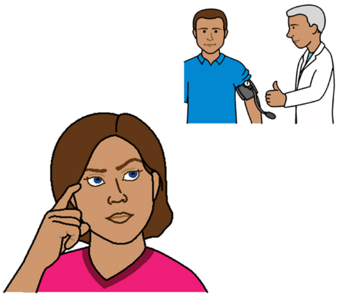
- help people join in with the community
- make sure people with CP have the right to join in with their community
- make ways for people with CP and their families to join in

- find out if things that happened in the past make it hard to join in now.

2. Better Health.

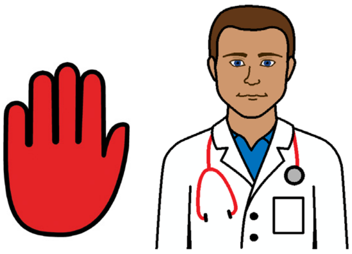


We want people with CP to have better health.

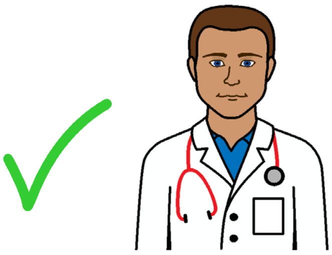


We can help this happen if we

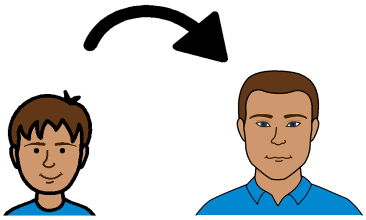
- change the way people think about CP and health



- find out what makes it hard for people with CP to go to the
  - doctor
  - hospital

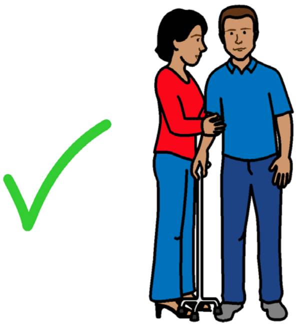


- help doctors and nurses work better with people with CP



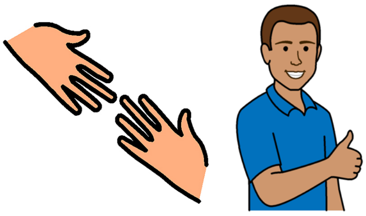
- help people with CP when they change service. For example, from child services to adult services.

3. Support for people with CP.

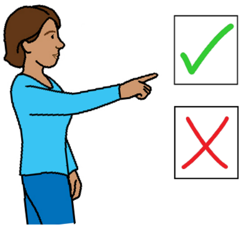


We want people with CP to get good therapy and support.

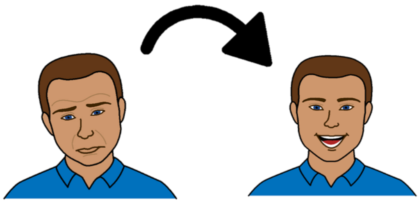
We can help this happen if we



- make therapy and support to help people with CP and their families have a better life



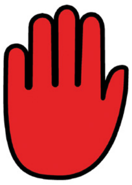
- say if different therapy and support is good or bad



- find out how different support changes things for people with CP and their families

- tell people with CP and their families about different therapies and supports.

4. Stop CP from happening and make it better for the people who have it.

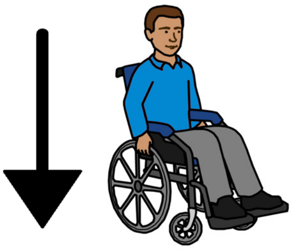


We want to stop more people from having CP.

We want to find a cure for CP.

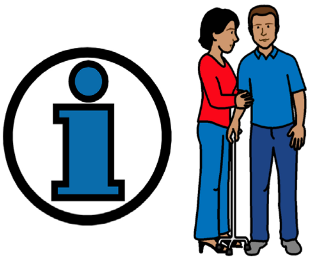
We can help this happen if we

- listen to people with CP and their families and do what they say



- find out if health care can make fewer people get CP

- make sure health care workers have the best information they can get



- use the best information in our health care.

What you think

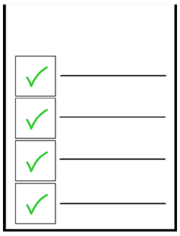
We want to know what you think about

Cerebral Palsy
ALLIANCE

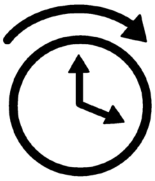
Our Goals for Cerebral Palsy

Easy English

- what we have said in this book



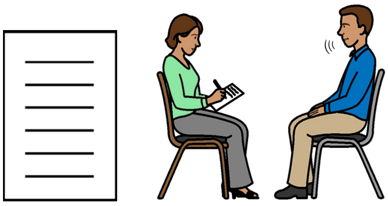
- how we will know if our goals work



- when we should check if our goals work.

How to give feedback

1. Go to www.cerebralpalsystrategy.com.au.



2. Give your feedback or book a meeting.

You can ask your family and friends for help to give your feedback.

Notes

ability first AUSTRALIA

Cerebral Palsy ALLIANCE

Cerebral Palsy AUSTRALIA

Freedom and Choice
Cerebral Palsy Society

AusACPDM
Australasian Academy of Cerebral Palsy and Developmental Medicine

Scope's Communication and Inclusion Resource Centre
wrote the Easy English in October, 2017. www.scopeaust.org.au
To see the original contact Cerebral Palsy Alliance.

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Change picture © 2011. www.changepeople.co.uk

Australian & NZ Cerebral Palsy Strategy

Plain language version - October 2017

Purpose of this consultation paper

This is a consultation paper about the Australia and New Zealand Cerebral Palsy Strategy.

We have written a draft strategy with input from a working group.

The draft strategy outlines:
- goals and priorities to better meet the needs of people with cerebral palsy (CP)
- ways we can work together to achieve common goals
- ways we can influence government policy, systems, society and practice.

We want feedback from:
- people with cerebral palsy
- family members
- professionals who work in the field
- key decision-makers, for example, politicians and the NDIA.

We want to hear your feedback about our strategy and any other issues you want us to address.

The strategy

Our vision is for people with CP to live a meaningful life.

Our mission is to improve the quality of life, health and participation of people with CP through quality research, communications, healthcare and support.

Goal 1 – Inclusion and engagement

To ensure people with CP are able to participate in all aspects of life. For example, we aim to:

- provide services that enable participation at all levels
- advocate for the rights of people with CP to participate in the community
- develop resources about community activities that might interest people with CP and their families
- research how learned behaviour and past experience affects participation.

Goal 2 – Health outcomes

To improve health outcomes for people with CP. For example, we aim to:

- improve the way society views the health needs of people with CP
- research the barriers faced by people with CP when accessing preventative health services
- improve the way health practitioners address the needs of people with CP
- improve transitions between service sectors (paediatric to adult health systems, or disability to aged care funding systems).

Goal 3 – Intervention and disability support

To provide effective, timely, evidence-based treatments and supports to people with CP and their families. For example, we aim to:

- develop a range of supports to improve quality of life for people with CP and their families
- provide evidence-based advice to key stakeholders to help shape quality intervention options
- learn about the impact of different forms of treatment, therapy and support on parents and siblings of people with CP
- communicate treatments and supports to people with CP and their families so they can make informed decisions.

Goal 4 – Cure and prevention

To reduce the frequency and severity of CP and find a cure. For example, we aim to:

- work with people with CP and their families to ensure their opinions shape our direction
- identify ways to reduce the frequency of CP
- identify ways to reduce the severity of CP
- ensure best-practice techniques are used in mainstream health services.

Measuring success

Our goals need to be measurable. We want your feedback about how we can measure outcomes for each goal. For example, reduce the incidence of CP in Australia to 1 in 600 births by 2020 date.

Strategy Review

We want your feedback about when this strategy should be reviewed in future.

More information

You can find out more about our strategy and ways to provide feedback by:

- visiting cerebralpalsystrategy.com.au
- contacting Ingrid Honan at ihonan@cerebralpalsy.org.au

Scope's Communication and Inclusion Resource Centre wrote the plain language version.
October 2017 www.scopeaust.org.au To see the original contact Cerebral Palsy Alliance.

11. Appendix 2 – Survey questions

What is this about?

We have developed a draft Cerebral Palsy Strategy for Australia and New Zealand. A strategy is a plan to help reach a goal. Having one strategy for cerebral palsy is the best way to help government and funders to understand what can help people with cerebral palsy to live a good life.

You can use this survey to tell us what you think about the draft Strategy. You can also use the survey to tell us what is important for us to know about living with cerebral palsy.

You can ask someone to help you do the survey if you want.

About you

NB: all respondents complete these first three questions

1. I am: (radio buttons)
    - A person living with cerebral palsy (links to part A)
    - The family member or supporter of a person living with cerebral palsy (links to part B)
    - A volunteer (links to part C)
    - A person who works for a support provider (links to part C)
    - A person who works in health (links to C)
    - A person who works for another sector organisation (including advocacy, NDIA and peak agencies) (links to part C)
    - A researcher (links to part C)
2. I am:
    - 0-12
    - 13 - 18
    - 18-24
    - 25 – 40
    - 41-55
    - 55-70
    - 71+

3. I live in:

- Australia Post code _______
- New Zealand – North Island
- New Zealand – South Island
- Outside Australia & New Zealand

Segmented questions (depending on the answer to the question 1)

Part A: Questions for Person with CP

1. Do you need assistance with mobility, communication or self-care:
   - Always
   - Sometimes
   - Never
2. Tell us about your living situation (please tick all boxes that apply to you):
   - I live alone
   - I live with my parents and/ or brothers/sister
   - I live with my spouse and/ or children
   - I live with other family members
   - Other people who are not my family

3. Are you:
   - Working, studying or volunteering
   - Looking for work, study or volunteering opportunities
   - None of these

4. How satisfied are you with:

	Completely dissatisfied					Neutral				Completely Satisfied	
	0	1	2	3	4	5	6	7	8	9	10
Where you live?	o	o	o	o	o	o	o	o	o	o	o
Who you live with?	o	o	o	o	o	o	o	o	o	o	o

Feeling part of your community?	o	o	o	o	o	o	o	o	o	o	o
How safe you feel?	o	o	o	o	o	o	o	o	o	o	o
Your opportunities to study, work, or volunteer, if you choose?	o	o	o	o	o	o	o	o	o	o	o
Your opportunities to have a social life?	o	o	o	o	o	o	o	o	o	o	o
The supports and assistance you receive with daily activities?	o	o	o	o	o	o	o	o	o	o	o
Your choice and control over the disability supports and assistance you receive?	o	o	o	o	o	o	o	o	o	o	o
Your access to appropriate health services?	o	o	o	o	o	o	o	o	o	o	o
Your access to appropriate therapies?	o	o	o	o	o	o	o	o	o	o	o
Your access to public and private transport?	o	o	o	o	o	o	o	o	o	o	o
The accessibility of places you go or would like to go?	o	o	o	o	o	o	o	o	o	o	o
The general public's understanding of CP	o	o	o	o	o	o	o	o	o	o	o

and disability?											
Doctors understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o
Therapists understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o
NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of CP?	o	o	o	o	o	o	o	o	o	o	o
Support workers understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o

5. Keeping up to date

Would you like to receive a final version of the document or be included in updates about the draft Strategy

Yes ☐ No ☐ (radio buttons)

If yes,

- Name <text box here>
- email address. <text box here>

6. Endorsing the Strategy

Would like the opportunity to endorse the final version of the draft Strategy? (note, if you endorse the draft Strategy your name will be listed in the endorsement section of the draft Strategy)

Yes ☐ No ☐

If yes,

- Name <text box here>

- email address. <text box here>

Thank you for completing this survey. If you want to provide more information you can also make an online submission at xxxxx <insert link to website here>.

Part B: Questions for family member/ supporter

1. Do does the person with cerebral palsy who you support need assistance with mobility, communication or self-care:
   - Always
   - Sometimes
   - Never
2. Tell us about your living situation:
   - I live alone
   - I live with the person I support but we want to live apart
   - I live with the person I support and we want to keep living together
   - I live with people other than the person I support
3. Are you: (radio buttons)
   - Working, studying or volunteering
   - Looking for work, studying or volunteering
   - None of these
4. For the person you support, how satisfied are you with:

	Completely dissatisfied				Neutral					Completely Satisfied	
	0	1	2	3	4	5	6	7	8	9	10
Where they live?	o	o	o	o	o	o	o	o	o	o	o
Who they live with?	o	o	o	o	o	o	o	o	o	o	o
Their opportunities to study, work, or volunteer, if they choose?	o	o	o	o	o	o	o	o	o	o	o
Their opportunities	o	o	o	o	o	o	o	o	o	o	o

to have a social life?											
Their access to public and private transport?	o	o	o	o	o	o	o	o	o	o	o
The accessibility of places they go or would like to go?	o	o	o	o	o	o	o	o	o	o	o
How safe they feel?	o	o	o	o	o	o	o	o	o	o	o
Their feeling part of the community	o	o	o	o	o	o	o	o	o	o	o
Their choice and control over the disability supports and assistance they receive?	o	o	o	o	o	o	o	o	o	o	o
Their access to appropriate health services?	o	o	o	o	o	o	o	o	o	o	o
Their access to appropriate therapy services?	o	o	o	o	o	o	o	o	o	o	o
NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of CP?	o	o	o	o	o	o	o	o	o	o	o
Support workers understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o

5. How satisfied are you with:

	Completely dissatisfied	Neutral	Completely Satisfied

	0	1	2	3	4	5	6	7	8	9	10
Your opportunities to study, work, or volunteer, if you choose?	o	o	o	o	o	o	o	o	o	o	o
Your opportunities to have a social life?	o	o	o	o	o	o	o	o	o	o	o
Your feeling part of the community	o	o	o	o	o	o	o	o	o	o	o
The general public's understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o
Doctors understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o
Therapists understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o
NDIA Planners/ECEI Partners knowledge/ understanding of CP?	o	o	o	o	o	o	o	o	o	o	o
Support workers understanding of CP and disability?	o	o	o	o	o	o	o	o	o	o	o

6. Keeping up to date

Would you like to receive a final version of the document or be included in updates about the draft Strategy?

Yes ☐ No ☐

If yes,

- Name <text box here>
- email address. <text box here>

7. Endorsing the draft Strategy

Would like the opportunity to endorse the final version of the draft Strategy? (note, if you endorse the draft Strategy your name will be listed in the endorsement section of the draft Strategy)

Yes ☐ No ☐

If yes,

- Name <text box here>
- email address. <text box here>

Thank you for completing this survey. If you want to provide more information you can also make an online submission at xxxxx <insert link to website here>.

Part C: Questions for people working for a support provider, working for another sector organisation and researchers

1. How does your role contribute to supporting people living with CP and their families to have a good life?
   <Free text response>

2. How likely would you/your organisation be to publicly support the following vision statement:

‘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.’

Scale: 0 – 10

Extremely unlikely					Neutral					Highly likely
0	1	2	3	4	5	6	7	8	9	10

You can write comments, recommended changes or improvements here

<Free text response.'

3. How likely would you/your organisation be to publicly support the following mission statement:

'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.'

Scale: 0 – 10

Extremely unlikely				Neutral						Highly likely
0	1	2	3	4	5	6	7	8	9	10

You can write comments, recommended changes or improvements here

<Free text response>

4. How likely would you/your organisation be to publicly support the following goal statements:

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.'

Scale: 0 – 10

Extremely unlikely				Neutral						Highly likely
0	1	2	3	4	5	6	7	8	9	10

You can write comments, recommended changes or improvements here

<Free text response>

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.'

Scale: 0 – 10

Extremely unlikely					Neutral					Highly likely
0	1	2	3	4	5	6	7	8	9	10

You can write comments, recommended changes or improvements here

<Free text response>

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.'

Scale: 0 – 10

Extremely unlikely					Neutral					Highly likely
0	1	2	3	4	5	6	7	8	9	10

You can write comments, recommended changes or improvements here

<Free text response>

Cure and Prevention

'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.'

Scale: 0 – 10

Extremely unlikely					Neutral					Highly likely
0	1	2	3	4	5	6	7	8	9	10

You can write comments, recommended changes or improvements here

<Free text response>

5. Consent to use quotes

Do you consent to your responses to this survey being used in the final survey? We would not say who made the quote.

Yes ☐ No ☐

6. Keeping up to date

Would you like to receive a final version of the document or be included in updates about the draft Strategy?

Yes ☐ No ☐

If yes,

- Name <text box here>
- email address. <text box here>

7. Endorsing the draft Strategy

Would like the opportunity to endorse the final version of the draft Strategy? (note, if you endorse the draft Strategy your name will be listed in the endorsement section of the draft Strategy)

Yes ☐ No ☐

If yes,

- Name <text box here>
- email address. <text box here>

Thank you for completing this survey. If you want to provide more information you can also make an online submission at xxxxx <insert link to website here>.

12. Appendix 3 – Submission questions

1. I am:
   - A person living with cerebral palsy
   - The family member or supporter of a person living with cerebral palsy
   - A volunteer
   - A person who works for a support provider
   - A person who works in health
   - A person who works for another sector organisation (including advocacy and peak agencies)
   - A researcher
2. I am: (radio buttons)
   - 0-12
   - 13 - 18
   - 18-24
   - 25 – 40
   - 41-55
   - 55-70
   - 71+
3. I live in: (radio buttons)
   - Australia Post code ________
   - New Zealand – North Island
   - New Zealand – South Island
   - Outside Australia & New Zealand

4. Mission Statement

“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.”

What is your view of the proposed mission statement? Please tell us about any specific changes or additions that should be considered?

Comment box <Free text response>

5. Vision Statement

"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."

What is your view of the proposed vision statement? Please tell us about any specific changes or additions that should be considered?

Comment box <Free text response>

6. 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.

What is your view of improved Quality of Life as an overarching goal? Please tell us about any specific changes or additions that should be considered?

Comment box <Free text response>

7. Key goals

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."

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 CP and their families."

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.”

Do the key goals cover the area’s most relevant to you? Please tell us about any changes or additions that should be considered.

Comment box <Free text response>

Is the wording of the goals appropriate and easy to understand? Please tell us about any improvements you think are needed?

Comment box <Free text response>

8. *Prioritising Key Goals*

Please number the goals below in the order you think they should appear in the document. (set response boxes to only accept characters 1 – 4)

☐ Inclusion and Engagement

☐ Health Outcomes

☐ Intervention and Disability Support

☐ Cure and Prevention

9. *Measuring success*

What are the priority objectives for the goals? Please tell us about any changes or additions that should be considered? Examples of objectives include:

1. A reduction in severity of CP
2. Increased family-based interventions
3. Increased funding for parent and family wellbeing
4. More accessible services available for people based regionally/rurally

Comment box <Free text response>

What are the most appropriate ways to measure progress towards these goals? Examples of measuring progress include:

5. The number of people accessing services
6. Increased funding to the sector
7. Improved quality of life of people with cerebral palsy
8. Changes in people's attitude

Comment box <Free text response>

10. General feedback

Is the overall language and format of the document appropriate? Are there any specific changes or additions that should be considered?

Comment box <Free text response>

Do you have any other comments in relation to the draft Strategy?

Comment box <Free text response>

Final questions for all respondents

11. Consent to use quotes

Do you consent to your responses to this survey being used in the final survey? We would not say who made the quote.

Yes ☐ No ☐ (radio buttons)

12. Keeping up to date

Would you like to receive a final version of the document or be included in updates about the draft Strategy

Yes ☐ No ☐

If yes,

- Name <text box here>

- email address. <text box here>

13. Endorsing the draft Strategy

Would like the opportunity to endorse the final version of the draft Strategy? (note, if you endorse the draft Strategy your name will be listed in the endorsement section of the draft Strategy)

Yes ☐ No ☐

If yes,

- Name <text box here>
- email address. <text box here>

Thank you for completing this submission form. If you want to provide more information you can also submit a document <insert link to webpage here>, send us a photo <insert link to mailto button here>, or a video <insert link to webpage here>.

We will include a range of images in the draft Strategy. We may not be able to include all images that people send us.

13. Appendix 4 – Consultation group questions

Living a good life –

- We would like you to work in small groups
- We would like you to think about what you need to live a good life.
- Try to think of the three most important things.
- You can record these on the sheets we have or you can get supporter to do this.
- Prompt if needed - things you need to live a good life might be where you live and who you live with, relationships and friendships or being involved in the activities that matter to you.

Links to the draft Strategy –

- Thinking about what you need to live a good life, we'd like you to tell us where the three things that you identify fit into the Strategy.

Priorities –

- What are your top three ideas
- Where do they fit into the draft Strategy?

Measuring success –

- Looking again at the vision and mission from earlier today. How will we know if the vision and mission are being achieved?
- What does success look like?

14. Appendix 5 – Key informant interviews – interview questions

Introduction

My name is ______________________from Dyson Consulting Group. Is this still a good time to talk?

About this project

A draft Australia and New Zealand Cerebral Palsy Strategy has been developed by strategy partners and consumer representatives. Dyson Consulting Group has been engaged 'to conduct a comprehensive consultation process regarding the Australia and New Zealand Cerebral Palsy Strategy' and to 'seek genuine feedback in order to create a document that accurately represents the needs, opinions and priorities of people with cerebral palsy'.

As part of this consultation we are seeking interviews with key informants such as yourself, in relation to the draft Strategy and regarding the findings emerging from the online and face-to-face consultations conducted to date.

Interview questions

1. *Using respondent experiences to inform strategy development*

Participants were asked about their satisfaction with:

- their participation in work study and volunteering
- their satisfaction with opportunities to participate in community and society
- the capacity of the service and support sectors
- choice and control over supports

What aspects of this experience (if any) are unique to people living with CP? Do you see a need for programs or policies specific to CP in this space?

2. *Responses to the vision & mission of the draft Strategy*

The phrase 'a world without cerebral palsy' is part of the current vision statement. How do you see this phrase this resonating with people living with CP and their families/ supporters? (note one respondent gave a score of 20/100 citing the goal to eliminate CP as unrealistic and preferring a focus on achieving a more inclusive community).

3. *Responses to the goals of the draft Strategy*

The goals of the draft Strategy are:

- Inclusion and Engagement
- Health outcomes
- Intervention and Disability Support
- Cure and Prevention

In relation to these goals what (if anything) is needed that is specific to people living with CP?

4. *Endorsing the draft Strategy*

What is needed for individuals and organisations to be willing to publicly endorse the draft Strategy? (25% of people who submitted submission questions and 4% of survey respondent were willing or likely to publically endorse the draft Strategy).

5. *Other comments*

Do you have any other comments or issues you wanted to raise that we have not already covered today?

Conclusion

Thank you for your time. We appreciate your insights and your contribution to this project. I'll remind you that your responses are confidential. We may quote you in our final report but will not identify who made the quote

Thank you – if you need to contact me my details are ____________

15. Appendix 6 – Survey Respondents (demographic data)

Number of survey respondents by stakeholder category and location/postcode

Stakeholder type	Location/Postcode								
	NZ	NSW & ACT	VIC	QLD	SA	WA	TAS	Unknown	Total
A person living with cerebral palsy	1	4	6	1		4	1	1	18
The family member or supporter of a person living with cerebral palsy		10	17	1	2	9	1		40
A person who works for a support provider		13	1			2			16
A person who works for another sector organisation (including advocacy, NDIA and peak agencies)		1				2			3
A person who works in health	1	8	2			3	1		15
A researcher		5	1						6
Total	2	41	27	2	2	20	3	1	98

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16. References

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[i] Cummins, R. (2002). "Proxy responding for subjective well-being: a review." International Review of Research in Mental Retardation **25**: 183-207.

[ii] Cummins, R., C. Hughes, et al. (2007). The wellbeing of Australians - carer health and wellbeing. Melbourne, Australian Centre on Quality of Life: Deakin University.

[iii] ibid

[iv] (2001). ICF: international classification of functioning, disability and health (short version). World Health Organization Geneva.